

Dementia in Europe Yearbook 2007



Including the Alzheimer Europe Annual Report 2006

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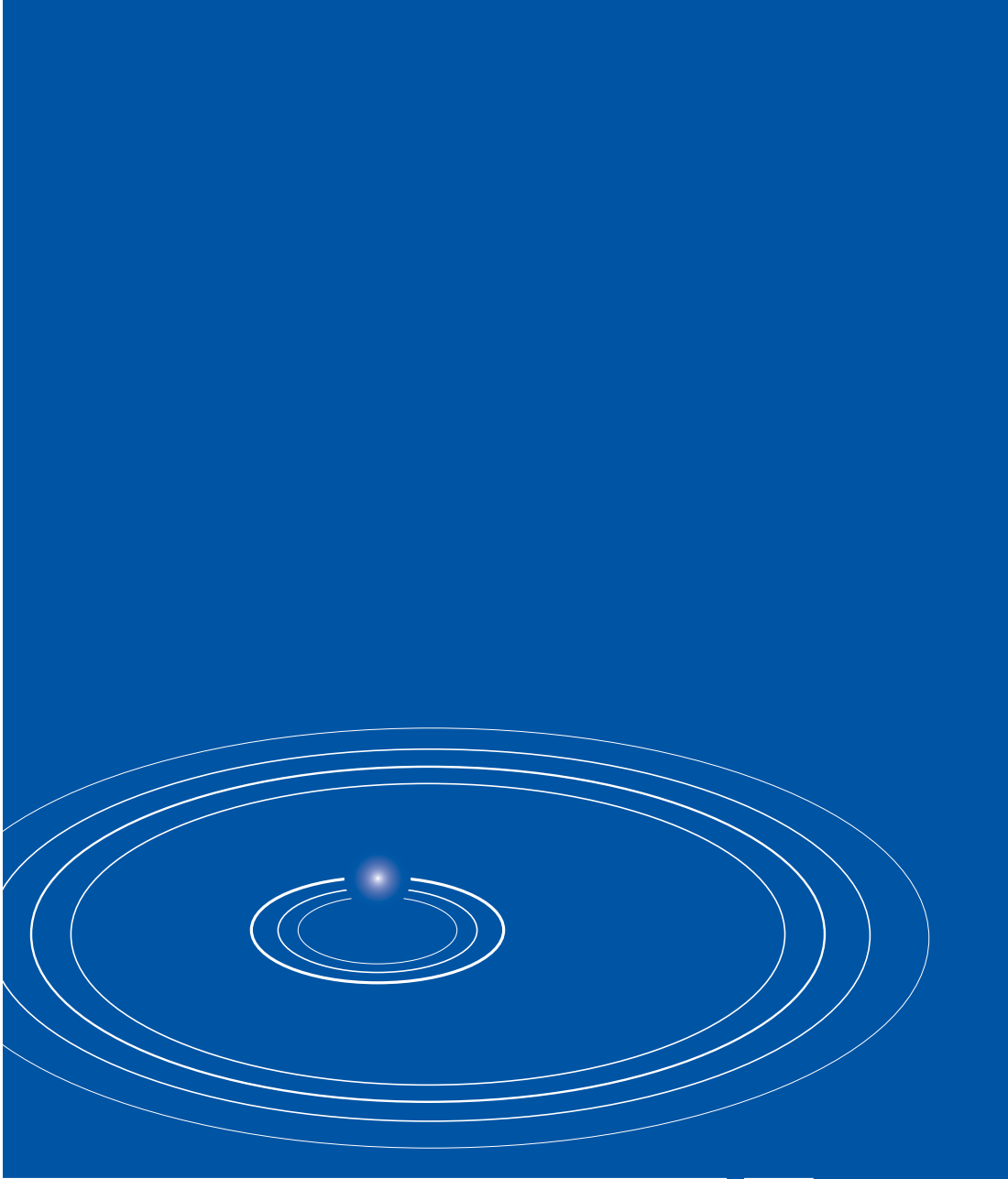
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Forewords



1.1 Vladimír Špidla, European Commissioner for Employment, Social Affairs and Equal Opportunities



Dementia is an issue which most of us - politicians as well as the broader public - feel uncomfortable about. Unlike many other differences between people, it is a form of diversity which hardly anyone wishes to celebrate. And it must be said that this discomfort vis-à-vis dementia cannot be considered a mere prejudice or lack of understanding. After all, it is indeed difficult to stay unaffected by the perspective of the erosion of our cognitive capacities which are so fundamental to our notion of the human self.

Yet (as a major recent debate on a different topic has emphasised) we need to face such uncomfortable truths which have a society-wide or even global impact. They cannot be wished away, and responsible individuals as well as responsible societies must draw the necessary consequences from them. Member States of the European Union are among those which aim to constitute such responsible societies. As such, they cannot overlook the problem of dementia - because it involves human suffering; because it concerns important aspects of the way in which our societies are organised; and, finally, because it is growing and set to grow further in the decades to come.

In 2005, the European Commission published a Green Paper which opened a Europe-wide debate on demographic change. In this Green Paper as well as in debates and documents which followed, the Commission stressed the need to appreciate the positive aspects of population ageing, i.e. longer life expectancies, and discussed policies which could increase the participation of older workers in economic life. I am convinced it is indeed vital to recognise the valuable contribution which many older people can still make, both in the economic sphere and outside it in a broader social context, and to counter ageist stereotypes and prejudices. Ageing does not automatically equal illness, frailty or dementia. It should be recognised that the majority of today's elderly are healthy and active. However, it is also clear that within the rapidly growing numbers of elderly people, there will be a sizable minority of those who will be ill and frail. And unless there is a spectacular medical breakthrough, the number of persons suffering from dementia will also continue to increase.

In the current debate on population ageing, more and more people recognise that what we are facing is not a simplistic issue. It is not just about delaying retirement - it concerns a conscious re-structuring of our societies, of our health care and social services, our workplaces and job markets, of our streets and public spaces, and of our systems of general education and specialised training. A larger population of very old persons, a minority of which will probably suffer from dementia, will have

different needs than in the past. Already, the emphasis is shifting from purely material aspects of well-being to those of human rights and human dignity, of highest achievable autonomy coupled with social interaction, with survival as a social being. This development is highly relevant for the issue of dementia because all people, including those with a cognitive deficit, have human rights; all should have their human dignity respected; and all have emotional needs which should be met by other human beings.

There is a lot that needs to be done. Member States, particularly those which are lagging behind in this respect, should reform, replace or complement large residential institutions by promoting the development of individualised social services in the community or at least close to it. The issue of ill-treatment of the elderly, in particular those who are suffering from dementia or otherwise frail and vulnerable, needs to be addressed through policies aiming at prevention rather than repression. It also appears useful to encourage the development of social gerontology as well as of specialised geriatric medicine, and to support research in these areas. Fortunately, in all these respects, there are models of good practices in Europe which can be drawn upon. And although most of what can and must be done falls within the jurisdiction of the Member States rather than the European institutions, I am convinced that the European Commission will continue to support progress in this area through its financial instruments as well as through the Open Method of Coordination on social inclusion, social protection and long-term care, which is particularly relevant to dementia sufferers.

People who suffer from dementia should not be forgotten. They need our empathy and help as fellow beings, but they also need thoughtful, sensitive and forward-looking public policies on local, national and European level. As politicians, we cannot afford to overlook the uncomfortable truths.

Vladimír Špidla

1.2 José António Vieira da Silva, Minister for Labour and Social Solidarity (Portuguese Presidency of the European Union)



As Portuguese Minister for Labour and Social Solidarity, I am honoured and privileged to have been asked to introduce the second Dementia in Europe Yearbook. The yearbook has already become an essential reference for all concerned with Alzheimer's disease and other forms of dementia and amongst other issues it covers the latest European policy and good-practice developments in this sphere.

There can be no doubt that the yearbook makes a truly remarkable contribution to raising the social and cultural profile of Alzheimer Europe's political priorities in the European Union, as embodied in the 2006 Paris Declaration. It is bound to enhance the culture of support and innovative policy-making, dovetailing actively with the essential contributions being made by Alzheimer's associations.

All of these efforts aimed at raising society's awareness about the special needs of people suffering from Alzheimer's and other forms of dementia, as well as at changing psychological and cultural attitudes, deserve our constant appreciation and encouragement at a time when values and interests are being transformed at an ever increasing pace.

Such praiseworthy efforts are taking place within the dynamic and innovative framework of the European Year of Equal Opportunities for All. Its aim is to create a fairer society that fosters more innovative political commitments, in which our communities will be refreshingly intellectually receptive to our fellow citizens who suffer from Alzheimer's disease or other forms of dementia.

Given this context, one of the priorities of the Portuguese Government is to take up political action on issues relating to the quality of life and autonomy of such sufferers and their families. The government has made an unshakable commitment to protecting their rights and ensuring their involvement in society. The policy measures implemented include the National Long Term Care Network. This network is the result of an active partnership between the Ministry of Health and the Ministry for Labour and Social Solidarity, aimed at providing for ongoing health care and social assistance for all citizens suffering from any degree of dependence, be it temporary or permanent.

The innovative introduction of ongoing or long-term care has meant reorganising the way in which the health and social security services respond to the health and social assistance needs of the elderly and dependent, and it has resulted in the need for decisions to be taken about the level of care to be provided, depending on the specific requirements of those who need it. This means that care begins the moment a patient is discharged from hospital and is pursued in the home, in order to ensure that treatment is continuous and that individuals make a functional recovery and are reintegrated into society. This approach is achieved via health-centre-based home-care teams working with local social security services and cooperating with private social welfare institutions and charities.

As such, I am convinced that the determined and sustainable policies that have been developed will enable Alzheimer's sufferers and their families to have the fullest confidence in the innovative responses created by the health and social security systems.

I would like to reiterate the honour and privilege I mentioned at the beginning of this introduction, and I offer my best wishes for the success for this second edition of the Dementia in Europe Yearbook.

José António Vieira da Silva

1.3 Jan Andersson, Chairman of the Committee for Employment and Social Affairs of the European Parliament



As the Chairperson of the European Parliament Committee on Employment and Social Affairs, I am therefore pleased to welcome this second edition of the “Dementia in Europe Yearbook” by Alzheimer Europe. The organisation is right in calling attention to the social impact of a disease like Alzheimer’s disease, but equally of other forms of dementia which affect over 6.1 million citizens in the European Union.

In the absence of a cure for Alzheimer’s disease, it is clear that patients as well as their carers do not only need medical attention, but also social support. I am therefore delighted that the European Commission provided funding for the “EuroCoDe – European Collaboration on Dementia” project of Alzheimer Europe and that one of the six work packages of the project looked into the social support provided by national governments in the Member States.

It is clear from the findings that social support of people with dementia and their carers varies considerably from one country to another. While some countries may have a wide range of services available to most patients, in others there is a scarcity of adequate and/or affordable support services, such as home help, day care, respite care and of course also residential care.

The same is true as regards the support provided by governments, be it as care allowances or other entitlements such as tax refunds or direct payments to pay for services, for employing a person to provide home care services or for necessary home adaptations and this Alzheimer Europe publication reveals striking differences between countries.

I hope that this publication will enable European and national politicians to identify good practices in the social support provided to people with dementia and their carers. In my opinion, it is clear that one model can never be used throughout Europe, but we can all learn from experiences and examples in other countries.

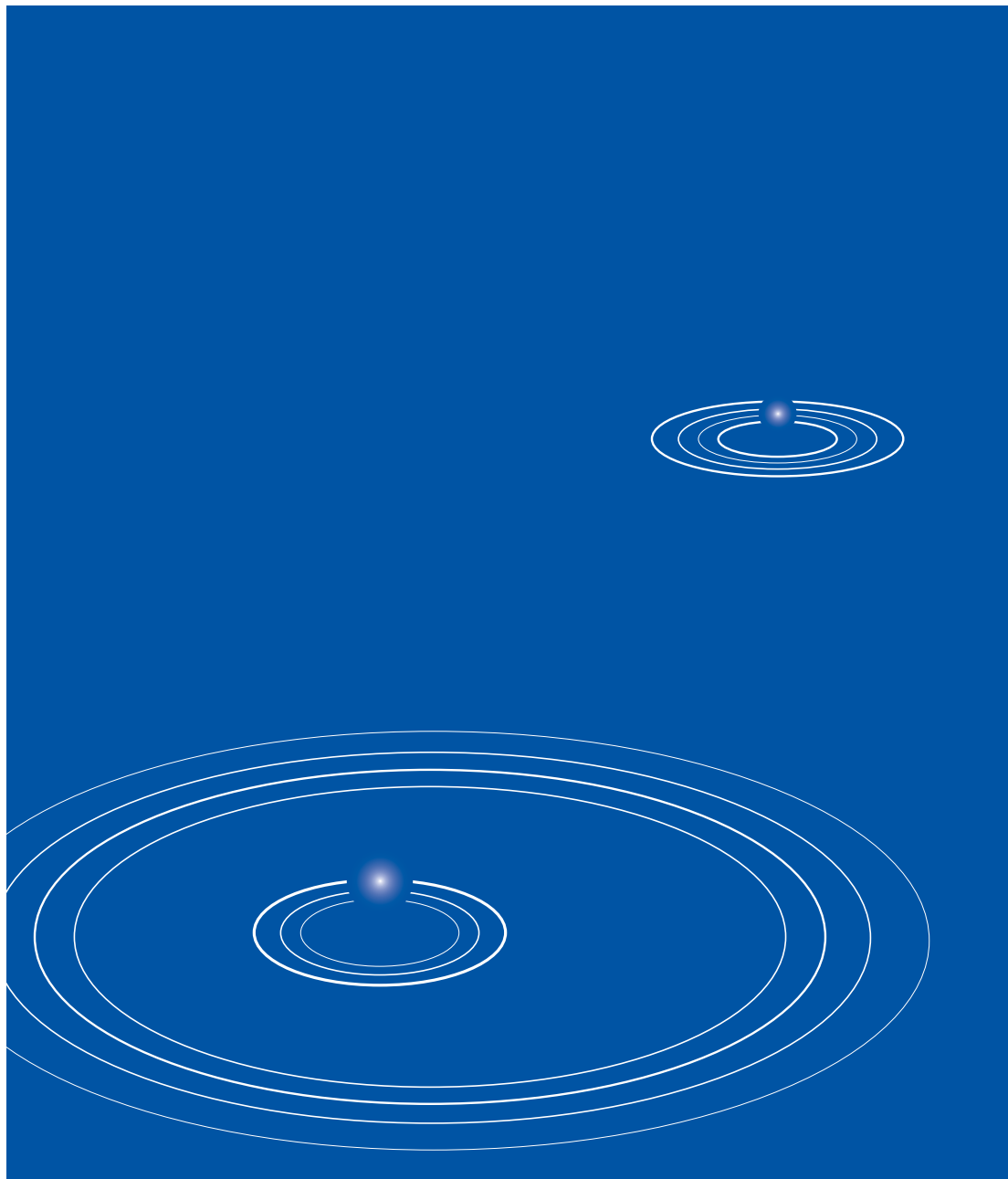
With the ageing of all European populations, we will be facing more cases every year and it is estimated that the number of people with dementia will double in Western Europe and treble in Eastern Europe. The dementia epidemic will pose serious challenges to the health and social budgets in all Member States.

This publication highlights some of the solutions provided by Member States to alleviate the burden on families and I am looking forward to the discussions and new ideas this report will generate.

I am happy to give my wholehearted support to this initiative aimed at improving the quality of life of people with dementia and their carers. We owe it to the 6.1 million citizens directly affected by this disease, as well as their families.

Jan Andersson





Introduction



It gives me great pleasure to present the second edition of the “Dementia in Europe Yearbook” which Alzheimer Europe produced in the framework of its “European Collaboration on Dementia - EuroCoDe” project.

The highly successful first edition focused on providing an overview of the numbers of people living with dementia in the European Union and the availability and reimbursement of Alzheimer medicines in 31 European countries.

In this edition, we highlight the findings of the work package on social support systems of our EuroCoDe project. Social support of people with dementia and their carers is an essential part of the management of the disease and our survey amongst our national member organisations revealed the huge discrepancies that exist across Europe when it comes to the services that exist and the support provided by governments for people with dementia and their carers.

The ultimate aim of this work package of the EuroCoDe project is to identify good practices in the social support provided by governments and to draft recommendations on how social support could be improved. Work on this will continue next year.

Even at this stage though, it is possible to already draw some very early conclusions on the findings of our project.

- There are huge differences in the provision of services for people with dementia between the different European countries studied in our project and even sometimes within countries.
- Similarly, the level of support by governments varies considerably between European countries.
- The organisation of social support is often fragmented. Various government departments (health, social affairs and employment) are in charge of different aspects of social support and in some countries, social support is furthermore organised on a national, regional and local level.
- A multitude of service providers co-exist. Services can be run by the public, private and/or voluntary sector and very often quality indicators for the care of people with dementia are missing.
- Few specialised services exist which cater for the specific needs of people with dementia and their carers. Rather than being able to call on dementia-specific services, people with dementia and their carers therefore often have to rely on more general services primarily dedicated to elderly people or disabled people.
- A considerable number of services were reported as being in a difficult financial situation due to the lack of secure and long term funding arrangements.

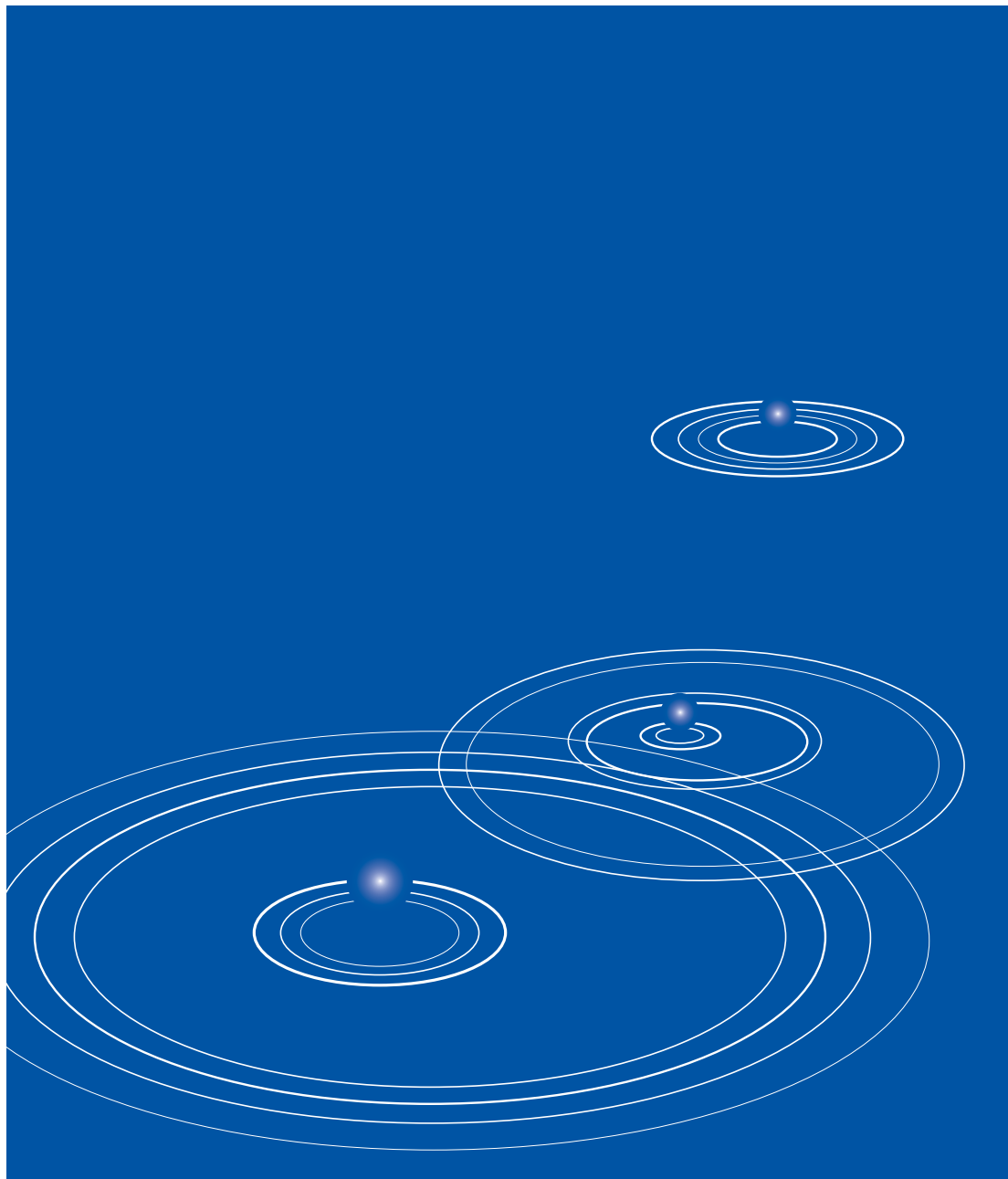
On behalf of Alzheimer Europe, I would like to thank Dianne Gove as the project coordinator of this work package who prepared most of the reports of the different European countries on the basis of the questionnaires which were returned by our member organisations and other experts in the field. Thanks to her work and the contributions of the other members of the working group (Letitia Dobranici, Hans-Jürgen Freter, Sirkkaliisa Heimonen, Sabine Henry, Louise McCabe, Federico Palermi and Maria do Rosario Zincke dos Reis), we were able to bring together a wealth of information on how the social support of people with dementia and their carers is organised in Europe.

We hope that this Yearbook will generate the same level of interest as the first edition and that it will contribute to a better understanding of the existing social support systems for people with dementia and their carers across Europe.

In particular, we hope that policy makers will pay close attention to interesting models of social support described for some countries and attempt to remedy the situation in those countries where service provision and support is particularly patchy or inadequate.

Jean Georges
Executive Director
Alzheimer Europe





*Social support
systems in Europe –
“A European Survey”*

3.1.1 Introduction

Between January 2006 and October 2007, as part of its work on the three-year “EuroCoDe” (European Collaboration on Dementia) project, Alzheimer Europe carried out a survey into the level of social support provided to people with dementia and their carers in the member states of the European Union, as well as in Switzerland, Norway and Iceland. This was just one part of the overall project which also involves the development of consensual prevalence rates, guidelines on diagnosis and treatment, guidelines on non-pharmacological treatments, recommendations on risk factors and prevention strategies and an analysis of the socio-economic cost of Alzheimer’s disease.

3.1.2 Methodology

3.1.2.1 The working group and national experts

The survey on social support systems in Europe was organised and carried out by members of a working group headed by Alzheimer Europe consisting of the following members:

- Dianne Gove from Alzheimer Europe
- Federico Palermi from the Fondation Médéric Alzheimer
- Hans-Jürgen Freter from the Deutsche Alzheimer Gesellschaft in Germany
- Letitia Dobrancici from Societatea Alzheimer, the Romanian Alzheimer Association
- Louise McCabe from Stirling University in Scotland (representing Alzheimer Scotland)
- Maria Do Rosarió Dos Reis Zincke from APFADA, the Portuguese Alzheimer Association
- Sabine Henry from La Ligue Alzheimer in Belgium
- Sirkkaliisa Heimonen from the Ikäinstituutti, Age Institute (representing Alzheimer Keskusliitto, Finland)

The actual information contained in the following country reports was mainly provided by Alzheimer Europe’s member associations. For some countries, it was provided by external experts. Their names and organisations can be found in the footnote on the first page of each country report.

3.1.2.2 The questionnaire

The working group drafted, piloted and refined the questionnaire together on the basis of regular email contact, three working group meetings and one steering committee meeting. The questionnaire, which was written in English and divided into two parts, was completed by one person in each of the countries covered. However, in many cases, that person worked in collaboration with other experts in the relevant domains.

Responses were received in English, French, German and Spanish. The information received was then transferred into a national report, circulated amongst the working group and refined over a period of seven months with the help of the person who had completed the questionnaire.

3.1.3 The country reports

3.1.3.1 Terminology

In this study, we have used the term social support to refer to resources and/or services to help carers and people with dementia cope with the practical and social consequences of the disease on their daily lives. This could include psychological, social, physical and financial support, various types of care such as palliative care, nursing care and respite care, and employment-related support for carers. Nursing care is included only insofar as it relates to dementia e.g. dealing with bedsores, incontinence or taking tablets. We realise that this definition of social support may differ considerably from one country to the next but have nevertheless included this wide range of support for all countries covered by the Eurocode survey.

The term “carer” has been used to refer to informal caregivers e.g. relatives and friends who take care of the person with dementia. In some countries, non-married couples and same sex partners are entitled to the same rights as married couples (e.g. for special leave), but in many cases, this is not specified and possibly not the case. Informal caring is usually done on a voluntary basis without payment although some carers might not feel that they actually had any choice in becoming a carer and some might receive some form of payment from the state for the care they provide. The term does not refer to professional carers such as doctors, nurses, social workers and home care workers etc.

3.1.3.2 Structure and content of the country reports

The country reports are divided into two sections.

Part 1 of each national report covers the organisation and funding of social support for people with dementia, and the legislative framework surrounding the provision of social support. It also contains information from the Alzheimer associations or experts on barriers to the social support provided e.g. based on age, disability, place of residence or type of disease etc. and whether the social support available was, in their opinion, adequate and suited to the specific needs of people with dementia and their carers.

Part 2 covers the actual availability of specific forms of support i.e. specific services, benefits and legal entitlement to leave etc. It contains information about the existence of such support, who pays for it and whether there are alternative sources of support (other than from the state) e.g. from voluntary associations, religious groups and NGOs.

The working group decided not to include comparative tables summarising which services were available in which countries as they felt that this could be misleading and open to misinterpretation. There were two main reasons for this: 1. the availability of certain services, such as day care centres, is sometimes extremely limited (e.g. only a couple of centres in the whole country) and 2. sometimes, services are available but there are barriers to access, such as disability status, geographical distance, the existence of family carers or high costs, which means that only a fraction of people with dementia can benefit from them. For example, they felt that stating that day care centres exist in a particular country, when in fact there are only two in the whole country, would be misleading. Similarly, the existence of particular support is of no use if people cannot access it for various reasons.

We asked respondents whether, in their opinion, specific services were sufficient. This enabled them to provide a more complete picture of the actual level of support available to people with dementia. However, it should be borne in mind that such information is based on their subjective experience and work with family carers, as well as their familiarity with the provision and level of social support within their country. Many respondents provided additional information where they felt that it was important to do so, e.g. if long-term residential care exists but staff are not trained to deal with people with dementia, if specific services are totally financed by service users or if services do not correspond to the needs of people with dementia, such as delivering meals but not ensuring that people with dementia are able to eat them.

3.1.4 Limitations to the national reports

Although national Alzheimer associations are ideally placed to know about the existence of support for people with dementia and carers, they cannot guarantee to have covered every single service available. A controlled nation-wide study involving the quantification of all existing services was beyond the scope of this project.

Moreover, the national Alzheimer associations and external experts were keen to point out the following limitations.

- In some countries, the organisation and financing of social support differs from one state or county to the next. In such cases, respondents have tried to give a general overview of the availability of support, in some cases including examples of services available in specific states or counties.
- Services are sometimes project based, which means that their existence may be limited, that they are not widely available and that they may end when funding is withdrawn or runs out.
- Some services are only offered at local level. In countries where local councils are responsible for the provision of services, there may be huge differences in actual availability across the whole country.

- Some of the smaller Alzheimer organisations with limited funds and personnel were unable to access the necessary expertise, particularly in the field of law and employment.

3.1.5 The next step

The next stage of the project is to compare the results obtained from the survey in order to determine the extent to which social support in Europe is suited to the needs of people with dementia and their carers.

On reading through the various country reports it is already clear that social support for people with dementia varies greatly from one country to the next. In some countries, considerable effort is made to enable people with dementia to continue living in their own homes whereas in others, for people who can no longer manage to live within the community, the only option is to move into an institution. It also becomes clear that certain services such as palliative care, advice on continence, companionship and social activities, sitting services and the use of tele-alarm monitoring systems are, with a few exceptions, insufficient.

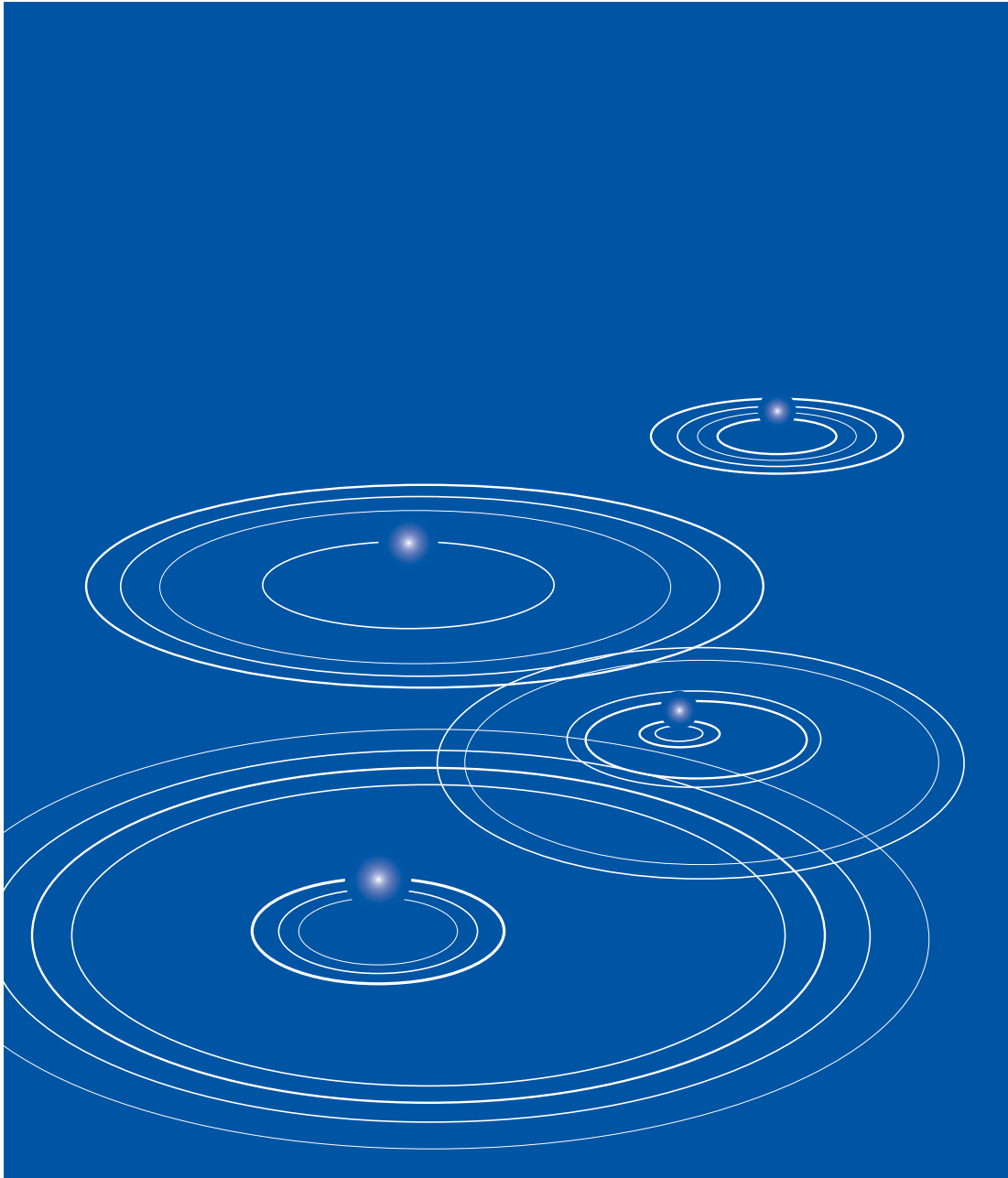
Recommendations on how to improve social support, along with examples of good practice, will be finalised next year and the results should be available from Alzheimer Europe in December 2008.

3.1.6 1.1.5 Acknowledgements

Alzheimer Europe would like to thank the members of the working group, Alzheimer associations and external experts for all the work they put into writing these reports. If readers have any questions or comments about the information on social support in specific countries, they are welcome to contact Alzheimer Europe (info@alzheimer-europe.org) which will forward any questions or comments to the relevant Alzheimer association or external expert.

Finally, Alzheimer Europe would like to express its gratitude to the European Commission and the Fondation M@déric Alzheimer for financially supporting this project.





*Social support
systems in Europe –
“National results”*

4.1 Austria ¹

4.1.1 Organisation and financing of social support to people with dementia and carers

4.1.1.1 Background information on the social/healthcare system in Austria

The Republic of Austria is composed of nine federal states known as Länder. The Länder are divided into political districts which are further divided into local communities. The Parliament has two chambers: the Lower House of Parliament (the Nationalrat) and the Upper House (the Bundesrat). These two chambers and the Federal Ministry of Health and Women are primarily responsible for legislation in the domain of health.

Obligatory health and accident insurance was introduced in 1887/1888 and now covers 97.6% of the population. However, long-term care is financed through general taxation.

(Source: Hofmarcher and Rack, 2006)

4.1.1.2 The organisation of social support for people with dementia and carers

The Federal Ministry for Social and Consumer Protection (Bundesministerium für Soziales und Konsumentenschutz - BMSK) and the regional states are responsible for the organisation of social support to people with dementia/dependent elderly people. In regional areas, due to inadequate structures, there is some overlap between the health care and social welfare systems. The State, the private sector, the voluntary sector and NGOs all provide services.

The long-term care allowance (Pflegegeld) is granted to people whose disability necessitates a permanent need for personal care (at least 6 months). There are seven levels of disability and private physicians are responsible for deciding on eligibility and the level of disability. Level 1 is the lowest level and intended for people whose disability necessitates between 50 and 74 hours of care per month, whereas levels V to VII, are for people who require 180 hours of care or more. This benefit is intended to enable people to stay at home for as long as possible and to promote self determination and family support.

4.1.1.3 The overall funding of social support for people with dementia and carers

In Austria the principle of subsidiarity (Subsidiaritätsprinzip) is applied which means that financial responsibility for care follows a set order: 1st the family, 2nd the commune, 3rd the “Land” (provincial state) and 4th the state. Please refer to the sub-section on the legal framework surrounding the provision of social support for details of the extent of the family responsibility to provide maintenance.

¹ The information in this report on social support for people with dementia and their carers in Austria was provided by Antonia Croy and Roswitha Bartsch from the Austrian Alzheimer Association (Alzheimer Angehörige Austria).

The long-term care allowance is financed through general taxation, not through social insurance contributions. It is not means tested and is tax free. The amount that service users have to pay for services not covered by the long-term care allowance is based on their available financial means (Eigenleistung). This is, however, dependent on income and assets, including those of close relatives. According to Blaha (2006), the conditions for calculating people's available financial means are still governed by regional state legislation despite efforts to harmonise these laws in the last 10 years.

People who have been judged eligible for the long-term care allowance are paid a cash benefit on a monthly basis independent of their income and assets or the reason why they need care. This is exempt from tax and can be spent in any way that the recipient sees fit e.g. to pay for services or to pay an informal carer. The allowance is paid directly to the person in need of care or to his/her legal representative/guardian. Although the hours of care are the same for Levels 5, 6 and 7, the conditions for entitlement are different. In 2006, the levels of the allowance were as follows:

- Level 1: €148.30 for care needs of more than 50 hours
- Level 2: €273.40 for care needs of more than 75 hours
- Level 3: €421.80 for care needs of more than 120 hours
- Level 4: €632.70 for care needs of more than 160 hours
- Level 5: €859.30 for care needs of more than 180 hours
- Level 6: €1171.70 for care needs of more than 180 hours
- Level 7: €1562.10 for care needs of more than 180 hours

(Source: Verband Steirischer Alten-Pflege und Betreuungsheime, 2006)

The State does not really support Alzheimer associations, but local authorities do provide a certain amount of support.

4.1.1.4 The legal framework surrounding the provision of social support

4.1.1.4.1 *The Constitution*

Social rights are not mentioned in the Austrian Constitution which dates back to 1857. However, the European Convention on Human Rights was ratified by Austria in 1958 and this has the same status as the Constitution (BVG 1964 BGBl Nr.59).

Paragraph 15a of the Constitution (B- VG) covers general measures taken by the State and the provincial states with regard to long-term care needs and an agreement regarding the overall aims and principles of long-term care throughout the whole of Austria (BGBl. Nr.866/1993, entered into force on 1 January 1994).

4.1.1.4.2 Laws

The Federal Long-Term Care Allowance Act and the Provincial Long-Term Care Allowance Act (BPGG, came into force on 1 July 1993) introduced a flat rate payment system for expenditure on long-term care. This made long-term care allowances uniform throughout Austria and introduced a legally enforceable entitlement provided that there is a need for care which will presumably last for at least 6 months (Hofmarcher and Rack, 2006).

The Federal Law on Guardianship of Disabled People came into force on 1 July 1984. It gives guardians the power to assist mentally disabled people in every area of life where they cannot manage without risk of endangering themselves. The amendment to this law (SWÄG of 1 July 2007) contains measures to reduce the intervention of guardians and extend the powers of family carers.

Patientenanwaltschaft: Since 1990, patient advocates/representatives have been independent and free from any kind of pressure from individuals, groups or institutions. Their role is to provide information about patients' rights and services and help sort out disputes but they have no power to legally enforce decisions or to legally represent people.

The Federal Law on the Protection of Personal Freedom during a Stay in a Home or other Care Institution (Heimaufenthaltsgesetz – HeimAufG) - came into force on 1 July 2005. The Care Home Contract Law (HVerG, came into force on 1 July 2004), which is an integral part of the Law on Consumer Protection (§27b-27i), sets the conditions for care home contracts.

The basis for support for disabled people goes back to §23 of the “Bundesbehindertengesetzes” of 1990 (formerly known as the Nationalfondsgesetz). There has been a support fund since June 2001, although payments for home transformations were even made prior to this date. Since 1.1.2004, the support fund has also granted payments to family carers when, as a result of illness, holiday, further training or other important reasons, they have been prevented from providing care and in cases of social hardship (limited income) BGBl Nr.71/2003.

Austria is made up of 9 federal states and some laws differ from one federal state to the next. According to Austrian civil law, married couples are legally responsible for each other's maintenance. They can fulfill this obligation by means of payment or the provision of services. In Vienna, only married couples are responsible for each other but in almost all the other federal states, children are obliged to provide maintenance for their parents. In Vorarlberg, even grandchildren may be held responsible for the maintenance of their grandparents.

According to social assistance laws in most provinces, children may, in certain circumstances, be obliged to contribute towards the costs of community care and resi-

dential care for their parents. Numerous decisions have been made by the Supreme Federal Court with regard to the conditions upon which the provisional authorities can demand that relatives contribute towards the cost of care.

Other relevant laws include the Amendment to the Law on Social Rights which is part of the ASVG (the general social insurance law) and the Amendment to the Law on Social Rights of 2005 (BGB1 Nr.132/2005).

4.1.1.4.3 Current reforms

With regard to ongoing reforms, the Amendment to the Law on Social Rights of 2007 is expected to lead to an improvement in the social protection of informal carers. This is likely to result in improved conditions for care at home in accordance with a government programme covering a new way of organising care (24 hour care and financing). (Source: www.bmsk.gv.at, Pflagetelefon: 0800 201622)

A pilot project, which started in October 2006 and ended in September 2007, provided elderly people in need of care and their carers with a cost free advice/check of about 1.5 hours. This was carried out by qualified care personnel in each person's usual care environment i.e. the home. Their willingness to have such a check and the usefulness of it were assessed.

4.1.1.5 The suitability of social support for people with dementia and carers

4.1.1.5.1 Adequacy and accessibility in general

There are no limits governing access to support on the grounds of age or type of dementia. On the other hand, insufficient attention is paid to the specific needs of people with dementia, although this is gradually improving.

4.1.1.5.2 People living in rural areas

In rural areas, there is a lack of support both quantitatively and qualitatively.

4.1.1.5.3 People with different types of dementia and younger people with dementia

There is no specific support for people with different types of dementia or for younger people with dementia.

4.1.1.5.4 People from ethnic minorities

There is no support that is specifically designed to meet the needs of people with dementia and their carers from ethnic minorities in Austria.

4.1.2 Services and support for people with dementia and their carers

4.1.2.1 Types of care

4.1.2.1.1 Day care

Day care in day care centres exists in Austria but this service is insufficient. Moreover, it is means tested so service users have to pay some or all of the cost themselves.

4.1.2.1.2 Respite care

Respite care in the home is available but must be completely paid for by service users.

Short-term and long-term respite care is available and means tested. Consequently, it must be either partly or fully paid for by service users. Some NGOs also offer short-term and long-term respite care.

The Austrian Alzheimer Association considers all types of respite care services and long-term residential care available in Austria for people with dementia insufficient in terms of quality and quantity.

4.1.2.1.3 Long-term residential care

Long-term residential care (e.g. in nursing homes or old people's homes) is financed from public subsidies and is also means tested. Prices can vary from about EUR 1,100 to EUR 3,600 per month. Up to 80% of a person's pension may be used to pay for residential care (with 20% being considered as “pocket money”). The long-term care allowance may also be used towards the cost of care in such homes (Grilz-Wolf et al., 2003). A person's personal savings (e.g. in a savings account) may be taken immediately and used to contribute towards the cost of residential care. If a person has property, the state can take some or all of the proceeds of the sale after the person's death in order to pay for the residential care that he/she has received. The recuperation by the state of savings and proceeds from the sale of property only happens if the person received public subsidies.

Residential homes are run by non-profit organisations, public providers and commercial providers and there are considerable regional differences in terms of quality and quantity.

4.1.2.1.4 Palliative care

Palliative care at home is available. For most people, it is free but there are differences in how providers are financed from one regional state to the next.

There are also palliative care centres but service users may have to contribute partly or completely towards the cost of this service. Financing is different in each regional

state but in general, there is a reduction in price after 14 days. This is not particularly good for service providers.

The above-mentioned palliative care services are also provided by NGOs and the Church. Volunteers provide palliative care but just at home. Nevertheless, the Austrian Alzheimer Association considers the provision of palliative care services insufficient.

4.1.2.1.5 *Monitoring in the home via alarm systems*

It is possible for people to have a tele-alarm system in their homes but they must pay for it themselves. NGOs provide some support for this service which is considered sufficient.

4.1.2.2 *Personal assistance and home help*

4.1.2.2.1 *Personal assistance*

The following services are available:

1. Assistance with personal hygiene
2. Assistance dealing with incontinence
3. Supervision/assistance taking medication
4. Assistance eating and drinking
5. Assistance with mobility e.g. lifting, moving and walking
6. Assistance with skin care e.g. hydration and pressure sores
7. Companionship/social activities
8. Occupational therapy/ergotherapy
9. Assistive devices
10. Home adaptation/transformation

The first two services are considered by the Alzheimer Association as being sufficient on the whole. Both are also provided by NGOs. The rest of the services are considered sufficient with the exception of companionship/social activities and occupational therapy. The latter is sufficient in cities but not in rural areas. NGOs also provide assistance taking medication and with skin care, as well as assistance with mobility and companionship/social activities (which are also provided by volunteers). Church organisations provide companionship and social activities too.

With regard to the financing of these services, all are means tested and service users pay part or all of the cost depending on their available resources. The State may pay all the cost of assistive devices. Home adaptation/transformation are financed through a grant from the State which is means tested.

4.1.2.2.2 Home help

Assistance with housework (e.g. dusting, cleaning and tidying) is available. It is means tested and also provided by NGOs. The Austrian Alzheimer Association considers this service sufficient.

Help is provided with the preparation of meals and a meals-on-wheels service exists. Whereas the former is partly funded by the State and partly by service users, the latter is completely funded by service users, although it is possible that financial support for this is occasionally provided in some regions. NGOs also provide these services which are considered sufficient by the Austrian Alzheimer Association.

Shopping, transportation and laundry services are available. They are partly funded by the State and partly by service users, but users may have to pay the full cost of assistance with shopping. Fortunately, this is also provided by NGOs and volunteers. Assistance with shopping and laundry is considered sufficient. This is not the case for assistance with transportation.

4.1.2.3 Psychosocial support and training for people with dementia and carers

4.1.2.3.1 General information

There are two services in Austria responsible for providing general information on access to services. Both are completely funded by the State. The first is the “Pflegetelefon”, a kind of care services helpline, which is free and available throughout the whole of Austria; the second is “Sozial Ruf Wien” which covers Vienna. These services are considered sufficient.

4.1.2.3.2 Counselling and holidays

Counselling services for people with dementia and for carers are insufficient. Those for people with dementia are based on private initiatives and are not funded by the State at all. Some are provided by NGOs and volunteers. For carers, the situation is slightly different. In addition to private initiatives which are not funded by the State and services provided by NGOs and volunteers, counselling is also provided through helpline services such as the Pflegetelefon and the Sozialruf (mentioned above) and through the Internet. These services are completely financed by the State.

Services designed to enable people with dementia to have a holiday are based on private initiatives and are insufficient. Some are organised by NGOs and volunteers. The State sometimes contributes towards the cost.

For carers, the situation is much the same except for the fact that the Federal Social Office may contribute towards this through its support fund. Money from this fund for people with disabilities is granted on the basis of §22 of the Law on Disability, §21a BPGG. A pilot project to provide relief to carers started on 1 February 2007 and will run until 31 January 2008. Since 1 September 2006, a pilot project of the KOBV (Association of War Victims and Disabled People) has been running to give family carers a holiday.

A pilot project to provide initial counselling to people with dementia and carers is being carried out by NGOs with the support of the Federal Ministry. It started in October 2006 and will end in 2007.

4.1.2.3.3 Training

Training for carers is insufficient. It is provided solely by NGOs and volunteers. Service users have to pay for it completely themselves.

4.1.2.4 Work/tax related support for people with dementia

There are no legal provisions to protect the rights of people who have been diagnosed with dementia who are still in paid employment.

A tax allowance is granted to people with dementia who do not receive a care allowance (§35 EStG) and in the case of exceptional costs which exceed the amount of the care allowance (§34 EStG). There are no tax allowances for employing someone to provide home care services. Tax refunds, grants and other incentives for necessary home adaptations are means tested. The Federal Office for Social Affairs may coordinate with other providers.

As mentioned earlier, the long-term care allowance can be used to pay for services directly.

Everyone who receives a care allowance is exempt from paying the basic charge for a telephone. Exemption from paying television and radio licences is means tested. This is covered by the law FGO §47 Abs.1.

4.1.2.5 Work/tax related support for carers and carer allowances

Carers are not entitled to paid time off work or flexible working hours to help them care for someone with dementia. They may, however, take unpaid time off work for up to 6 months to care for someone who is dying. Carers are not entitled to any tax benefits or payments from the State for the care services they provide.

Carers may take out a voluntary additional insurance to cover them against losses to their pension fund resulting from stopping work to care for someone. However, according to the Amendment to the Social Law, which came into force on 1.7.2007, family carers are entitled to favourable/reduced pension fund contributions.

A reform of the Social Law of 2007 is currently being assessed. This would involve halving the contribution of insured people in order to promote further insurance contributions towards a pension fund for people who care for a close relative for a maximum of 48 months at Care Level 4 (there are 7 levels) and would cover the whole contribution from Care Level 5 onwards.

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4.2 Belgium²

4.2.1 Organisation and financing of social support to people with dementia and carers

4.2.1.1 Background information on the social/healthcare system in Belgium

The Belgian health care system is based on a Bismarckian model with 99% of the population paying obligatory social insurance contributions. It is estimated that 60% of people with Alzheimer's disease are cared for at home and 40% in institutions. Belgium is made up of 3 regions and available support, prices and regulations vary considerably from one region to the next. Most of the information in this report is based on the Walloon region and cannot therefore be considered truly representative of the whole of Belgium.

4.2.1.2 The organisation of social support for people with dementia and carers

The Ministry of Public Health is responsible for social support to people with dementia on a federal, regional and community level. There is a federal minister, regional ministers and communal ministers i.e. 11 ministers in charge of this issue.

However, in the Flemish region there is a long-term care insurance (LTCI) whereas in Wallonia there is not. The LTCI is obligatory in Flanders and optional in Brussels. It costs EUR 25 per year and entitles people at home to a payment of EUR 90 per month and people living in an institution to a payment of EUR 125 per month provided that they fulfil the necessary criteria for payment. (Declercq and Van Audenhove, 2004). The LTCI covers extra non-medical expenses once a person has reached a certain level of dependency in terms of home care or is in a nursing home. From January 2008, the payment will rise to EUR 118 for home care and EUR 125 for people living in nursing homes (De Lepeleire, 2007).

There is no specific system for people with dementia. They are covered by the general social security system.

4.2.1.3 The overall funding of social support for people with dementia and carers

The Belgian social security system covers illness, maternity, invalidity, old age, unemployment, work-related illnesses and family allowances. It also covers the cost of diagnosing dementia. There are no special measures specifically designed for people with dementia.

The system operates on the basis of obligatory contributions from employers and employees. The National Organisation for Social Security distributes the money amongst the different branches.

² The information in this report on social support for people with dementia and their carers in Belgium was provided by Sabine Henry and Sylvie Loneux from la Ligue Nationale Alzheimer Liga and Dr. Michel Ylief.

Treatment by anticholinesterase inhibitors and Memantine is refunded subject to the fulfillment of certain criteria set by the INAMI. Bi-therapy is not permitted. Hospitalisation is covered by the social security system.

The State partly contributes toward the cost of:

- accommodation in care and rest homes depending on the degree of dependency of the person concerned.
- home care depending on the level of dependency of the person concerned and on his/her revenue.

Activities and services are offered freely by the Ligue Nationale Alzheimer Liga to people with dementia and their carers. The State provides subsidies, material aid and employment incentives to Alzheimer associations.

4.2.1.4 The legal framework surrounding the provision of social support

According to the **Belgian Constitution** (article 23):

Everyone has the right to live a life in accordance with human dignity. These rights include: (...) 2) the right to social security, to protection of his/her health and to social, medical and legal assistance (unofficial translation).

Law of 7 January 2002 (art. 2) on public centres for social action (M.B. 05.08.1976, p.9876; err. : M.B. 26.11.1976, p.15027)

Law of 27 February 1987 relating to allowances for handicapped people (M.B. 01.04.87; erratum: M.B. 06.08.87)

- Royal decree of 6 July 1987 relating to the allowance for the replacement of revenue and the integration allowance.
- Royal decree of 5 March 1990 relating to the allowance for elderly people
- Royal decree of 22 May 2003 relating to the procedure for the handling of documents for the allowances granted to handicapped people.
- Royal decree of 17 July 2006 implementing article 4, §2, of the Law of 27 February 1987 relating to the allowances for handicapped people.
- Ministerial order of 30 July 1987 fixing the categories and the guide for the evaluation of the degree of autonomy in connection with the test for the right to the integration allowance.

Law relating to the obligatory health care insurance and coordinated benefits of 14 July 1994

Law of 24 February 2003 concerning the modernisation of the management of social security

Law of 5 June 2002 relating to the maximum amount to be charged by the health care insurance and articles 40 to 46 of the Law Programme of 30 December 2005, edition 2, relating to the obligatory health care insurance and payments.

Law of 22 August 2002 relating to patients' rights

4.2.1.4.1 In the Walloon region:

Decree of 5 June 1997 relating to rest homes, service homes and day care centres for elderly people resulting in the creation of the Wallonia Council for the Third Age, modified by the Decree of 6 February 2003.

Governmental order for the Walloon region of 22/05/2003 covering short-term stays in the Walloon region.

Governmental order for the Walloon region of 16 July 1998 governing the title of "aide familiale"

4.2.1.4.2 In the Flemish region

There are numerous laws and decrees for the Flemish speaking part of Belgium but unfortunately this information was not available in English.

There are currently no reforms underway.

4.2.1.5 The suitability of social support for people with dementia and carers

4.2.1.5.1 Adequacy and accessibility in general

Since 1982, Belgium has adapted its health and social welfare systems in order to ensure a continuity of care to people with dementia and dependent people. However, reforms are still necessary. Moreover, available support and conditions governing access to such support are not well known.

Certain care and rest homes accept people with dementia. Amongst these, certain care and rest homes have units specifically for "disorientated people". However, available places are limited and there are long waiting lists. There are no home care services and assistance adapted to the specific needs of people with dementia. There are, however, a few pilot projects and private initiatives.

4.2.1.5.2 People living in rural areas

Assistance in rural areas is more difficult to access than in towns.

4.2.1.5.3 People with different types of dementia

There is no support targeted at people with different kinds of dementia.

4.2.1.5.4 People from ethnic minorities

There are no specific services or support for people with dementia and their carers from ethnic minorities.

4.2.1.5.5 Younger people with dementia

In the Flemish-speaking part of Belgium, there are support groups for people with dementia under the age of 65. Otherwise, there are no specific services for this subgroup.

4.2.2 Services and support for people with dementia and their carers

4.2.2.1 Types of care

4.2.2.1.1 Day care

There are general day care centres (centres d'accueil) and nursing day care centres (centres de soins de jour) in Belgium which are both partly funded by the State. Users have to pay between EUR 15 and EUR 20 per day. The State pays a fixed price of EUR 5 for nursing care in a general day care centre and EUR 28 for nursing care in a nursing day care centre. Although most have room for new clients, there are not enough centres. Moreover, they are not sufficiently used for two main reasons:

1. Transport of people with dementia to and from the centres is not always provided.
2. Centres are often located too far away from the home of the person with dementia

4.2.2.1.2 Respite care

Respite care at home exists and is partly funded by the State.

Night care is also available in centres in the Walloon region for people with dementia or people who are disorientated. It was originally a three-year project, which started in 2003 and was jointly managed by the Ligue Alzheimer ASBL and the Walloon region. Now, places are available for evening or night care in 3 institutions in Wallonia.

Short-term residential respite care exists but is insufficient. Since 2003, 117 rest/care homes (maisons de repos et soins known as MRSs) in the Walloon region have been authorised to have beds for short stays. These beds will gradually become available. Certain health insurance companies also offer their clients the possibility of short stays (either in an MRS of their choice or in pre-determined homes). Since 2005, places in short-term residential care have also been available in the Flemish and German-speaking communities. Service users have to pay about EUR 33 per day and the institutions also receive a fixed amount and regional subsidies from the State.

4.2.2.1.3 Long-term residential care

Long-term residential respite care is also available. There are no institutions just for people with dementia but some MRSs accept people with dementia. Some have a special wing just for “disorientated people.” However, most of these establish-

ments have long waiting lists for people with dementia. In 2004, the average cost of long-term residential care in Belgium was EUR 12,264 p.a. (EUR 20,000 with charges included), to be paid by service users. The rest home or care home receives a further annual fixed payment from the state amounting to EUR 30 to EUR 45 per day depending on the level of dependence of its residents (as measured on the Katz scale).

4.2.2.1.4 Palliative care

Palliative care has been available in Belgium since the 1990s and is partly funded by the State. In 1991, limited funds were made available for palliative care at home and in centres. This was used to develop services but the number of services available remains insufficient and little known about. Very few people with dementia receive palliative care.

4.2.2.1.5 Monitoring in the home via alarm systems

Tele-alarm systems exist. Their price varies from one commune to the next, but they cost on average EUR 25 per month. It is possible to apply to health insurance companies for financial assistance.

4.2.2.2 Personal assistance and home help

Home care services (including personal assistance and home help) are not specifically designed for people with dementia but there is nevertheless a variety of services available. Paramedical services are provided by nurses, physiotherapists and speech therapists who are paid by the health care insurances for the services they provide according to the duration and type of disease. They are registered with the INAMI. This is a service which coordinates the provision of home care and home help and organises necessary assistance on the basis of an assessment of needs. This service is free.

4.2.2.2.1 Personal assistance

Non-medical assistance with personal hygiene is provided by family and sanitary assistants (“aides familiales et sanitaires”). In the Walloon region, the “aides familiales” are registered. Some services are completely financed by the State, others only partly, but the service user’s contribution is adapted to his/her income (usually between EUR 0.87 and EUR 7.81 per hour). This service is considered satisfactory.

There is no specific service providing assistance with eating and drinking but assistance can be negotiated with the coordination service for home help. The price is calculated according to each person’s income and the State may contribute towards the cost.

Assistance with mobility is available and partly funded by the State but it is insufficient. It is provided in the framework of services provided by family and sanitary assistants but the assistance is not specifically for people with dementia.

Companionship/social activities are also provided within this framework subject to negotiation with the coordination services. In addition, there are Alzheimer cafés. The aim of these cafés is to have a place where people with dementia, their carers and people interested in dementia can get together, exchange information and give each other support.

Ergotherapy is available and partly funded by the State but it is insufficient as it is not yet well developed and consequently, not many people know about it.

Home adaptations are partly funded by the State.

There are no services providing assistance with incontinence, skin care or assistive devices.

4.2.2.2.2 Home help

Family and sanitary assistants and/or home help assistants provide assistance with housework. This service is partly funded by the State. Assistance with shopping, laundry and transport services are also available and partly funded by the State. All these services are considered sufficient. Transport services are not only provided by the State but also by health insurance companies and volunteers. Home help assistants who are registered in the Walloon region receive a fixed payment of EUR 5,21 per hour.

Meals-on-wheels are provided by the Centre Public d'Action Sociale (the cost is adapted to each person's income) or by caterers (the cost varies). Alternatively, family and sanitary assistants may help with the preparation of meals.

Additional services (e.g. hairdressing and chiropody) are available. The price varies.

4.2.2.3 Psychosocial support and training for people with dementia and carers

4.2.2.3.1 Information and counselling

La Ligue Alzheimer provides information about dementia and available support. It receives subsidies from the State but also has revenue from private donations, services and profits from sales. It functions on the basis of volunteers but in keeping with the development of the association, it now also has professional support.

Counselling for people with dementia is provided in the context of the Alzheimer cafés. The number of these cafés in Wallonia and Brussels is steadily increasing. The aim of the cafés is to inform people about the medical and psychosocial aspects of dementia in an informal manner. The cafés also help break social isolation and encourage social interaction. Meetings start with an informal discussion which is followed by a presentation of a pre-determined theme. Then there is a question and answer session. The cafés are partly financed by the State and will be evenly distributed throughout Belgium in the not too distant future. In the Flemish part of Belgium there are “dementia expertise centres”.

The Ligue Alzheimer has a 24 hour telephone helpline (0800/15 225) which is a confidential service operated by former carers and professionals. Operators are non-judgemental, available and empathetic and try to respond to enquiries in the best possible way.

At the request of families or other interested parties, the Ligue Alzheimer organises individual or family meetings. This type of meeting provides a more personal approach to understanding the problems encountered and to better understand the life of the person with dementia and the social and family context. Fears and expectations can be addressed more effectively as visual contact often facilitates communication.

Support groups for informal carers and professional carers are often organised by The Ligue Alzheimer. They are partly funded by the State and will soon be available throughout the whole country. These meetings usually focus on a particular theme which is selected in advance. They tend to be informal and the group facilitators encourage an exchange of ideas and tips designed to help carers and professionals to help themselves and each other to manage the difficulties they encounter in their daily lives with the person with dementia.

“Community care centres” exist in the Flemish part of Belgium, which provide a meeting place for people over 55 and those in need of home care. The idea is to provide information, prevent isolation and make professional care more accessible (Declercq and Van Audenhove, 2004).

4.2.2.3.2 Holidays

There are no services to provide holidays for people with dementia but holidays for carers are privately organised and are partly subsidized by the State.

4.2.2.3.3 Training

Carers may benefit from training through the “Cercle de Soins” which is in constant development in Brussels and the rest of Belgium, and will soon be available throughout the whole of the country. It is partly financed by the State. This training programme is made up of 6 modules spread over 1 year. The aim of the training is to provide support to carers looking after a person with dementia with a particular emphasis on maintaining the person with dementia at home for as long as possible. The Ligue Alzheimer also organises conferences, destined for the general public, on dementia, its consequences and available support.

4.2.2.4 Work/tax related support for people with dementia

4.2.2.4.1 Allowances for people with dementia

Dementia is not an officially recognised pathology in Belgium but people with dementia can benefit from allowances for handicapped people. There are three such allowances.

4.2.2.4.1.1 Allowance for the replacement of revenue

The allowance for the replacement of revenue is granted to handicapped people between 21 and 65 years of age whose physical and mental state has reduced their earning capacity by a third or less than what a person could earn in a particular profession in the general employment market. The maximum amounts received per annum (depending on which category a person is in) are as follows:

- Category A: €5,261.63
- Category B: €7,892.45
- Category C: €10,523.26

(Direction Générale Personnes Handicapées, 2007)

4.2.2.4.1.2 Integration allowance

The integration allowance is granted to handicapped people between 21 and 65 years of age who, due to their reduced autonomy, incur extra costs. Requests for this allowance must be addressed to the mayor of the commune where the person is on the population register or on the register of foreign residents. The maximum amounts received per annum (depending on which category a person is in) are as follows:

- Category I: €1,006.06
- Category II: €3,407.81
- Category III: €5,445.26
- Category IV: €7,933.06
- Category V: €8,999.56

(Direction Générale Personnes Handicapées, 2007)

4.2.2.4.1.3 Allowance for elderly people

The allowance for elderly people is granted to handicapped people aged 65 or over who have extra costs due to their reduced autonomy.

The maximum amounts received per annum (depending on which category a person is in) are as follows:

- Category I: €854.61
- Category II: €3,262.24
- Category III: €3,966.36
- Category IV: €4,670.27
- Category V: €5,736.77

(Direction Générale Personnes Handicapées, 2007)

These three allowances are calculated on the basis of the revenue of the handicapped person as well as that of his/her partner. Certain reductions are nevertheless applied with regard to these revenues. To qualify for these allowances, a person must be aged between 21 and 65 (for the first two allowances) or 65 or over for the allowance for elderly people, be resident in Belgium and actually be living in Belgium. He/she must also have one of the nationalities mentioned in the law.

4.2.2.4.2 Other benefits or protective measures

There are no legal measures to protect the rights of people with dementia who are still in paid employment. People with dementia are not entitled to tax refunds, benefits or direct payments to pay for services, for employing a person to provide home care services or for necessary home adaptations.

The Law of 27 February 1987 relating to allowances for handicapped people grants reductions on telephone charges, gas and electricity bills, and public transport as well as free radio and television licences for handicapped people with sufficient points on the dependency scale.

4.2.2.5 Work/tax related support for carers and carer allowances

4.2.2.5.1 Leave granted to carers

4.2.2.5.1.1 Leave to care for a seriously ill person

There are two forms of leave designed to help people care for a sick or dying person. The first is the “congé pour maladie grave d’un proche”. This allows people to completely or partly give up their paid work to assist or care for a member of their household or family up to the second-degree who is suffering from a serious illness for a certain period of time. Serious illnesses include those illnesses or medical interventions which are considered by the doctor in charge of the patient as necessitating any form of social, family, mental or moral assistance for the patient’s convalescence. There are two possibilities:

- A part-time or full-time employee can totally suspend his/her work for up to 12 months per patient.
- A person working full-time or at least $\frac{3}{4}$ time can reduce his/her working hours by $\frac{1}{5}$ or $\frac{1}{2}$ during a period of 24 months per patient.

In both cases, each period of leave taken must be of at least 1 month and no more than 3 months. Employees must request such leave 7 days in advance of the requested starting date. The relevant royal decrees are of 10/08/1998, 07/05/1999, 12/08/1991 and 10/06/2002.

The allowances granted for such leave are as follows (index linked as of 1 October 2006):

Table 1: Allowances granted for leave to take care of a seriously ill person

Type of leave/reduction of hours	Allowance granted
Complete leave for full-time workers	EUR 684.94
Complete leave for part-time workers	EUR 684.94 paid on a pro rata basis
For a reduction of 50% of working hours	EUR 342.46 (if under 50 years old) EUR 580.90 (if over 50 years old)
For a reduction of 20% of working hours	EUR 116.18 (if under 50 years old) EUR 232.36 (if over 50 years old)

Source: Service Public Fédéral, Emploi, Travail et Concertation Sociale (2007)

4.2.2.5.1.2 Palliative care leave

The second form of leave is “congé pour soins palliatifs”. This allows people to partly or completely give up their work for a specific period of time in order to provide palliative care to a person who has an incurable illness. This person does not necessarily have to be a member of the family. Palliative care is considered as including any form of assistance (medical, social, administrative or psychological) and care given to a person with an incurable illness who is in the terminal phase of that illness. The relevant royal decrees are of 02/01/1991, 07/05/1999, 12/08/1991 and 10/06/2002. There are two possibilities:

- A part-time or full-time employee can totally suspend his/her work for one month per patient. This can be extended once by a further one month's leave.
- A person working full-time or at least $\frac{3}{4}$ time can reduce his/her working hours by $\frac{1}{5}$ or $\frac{1}{2}$ for a period of one month per patient.

The period of leave may commence on the first day of the week following the week in which the employer receives a medical certificate from the employee. This medical certificate must have been provided by the doctor of the person in need of palliative care and must state that the employee has agreed to provide such care. The identity of the person in need of palliative care must not be revealed.

The allowance for palliative care leave is exactly the same as that for leave to care for a seriously ill person. Please refer to the table above for details.

4.2.2.5.2 Other benefits

Carers are not otherwise entitled to flexible working hours, free or subsidised pension contributions from the State or any form of payment for the care they provide.

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4.3 Bulgaria³

4.3.1 Organisation and financing of social support to people with dementia and carers

4.3.1.1 Background information on the social/healthcare system in Bulgaria

Until 1990, Bulgaria had a Communist government. This was replaced in 1991 by a multiparty parliamentary democracy, governed by a single chamber with a president as head of State. Prior to 1991, Bulgaria had a Semashko kind of health care system (a centralised, tax-based system). Although it became clear that certain elements of this system were problematic, it was not until 1997, when the health care system seemed to be in danger of collapsing, that measures were taken to rationalise the system and improve the effectiveness of health care provision. Social health insurance was introduced at the end of the 1990's but out-of-pocket payments remain a problem for people on a lower income (Koulaksazov et al., 2003).

4.3.1.2 The organisation of social support for people with dementia and carers

Specific support for people with dementia and their carers is not available in Bulgaria. However, people with mental disorders can attend social houses which are financed and supported by the State. Unfortunately, the conditions in these social houses are often poor.

The current European trend is to encourage people with dementia to remain with their families but the appropriate services and support are not available due to a lack of regulations and of practical and financial support for carers.

Social support is organised by the Ministry of Labour and Social Policy and by the Agency for Social Support. This is general social support which people with dementia can benefit from but to do so, they have to have the necessary health certification as without this, they are not eligible for social support. The house doctor in coordination with a specialist doctor prepares a set of documents for a special Commission (Териториална експертна лекарска комисия (ТЕЛК) – Territorial Expert Medical Commission), which certifies the level of disability and the Municipality supplies the social support according to the Regulations of the Agency for Social Support.

The Ministry of Labour and Social Policy does not accept responsibility for people with dementia. Although it is responsible for the homes for people with dementia, the administration of this Ministry, which has direct responsibility for these homes, tries to transfer responsibility to the Ministry of Health (which only covers medical treatment) on the grounds that the people in these homes are ill.

As a result of pressure from the European Union and with the help of financial support, some projects are now underway. Unfortunately, they are too generalised and are dedicated to people with mental disabilities. They do not cater for the needs

³ The information in this report on social support for people with dementia and their carers in Bulgaria was provided by Mrs. Zvezdelina Trifonova from the Bulgarian Alzheimer Society (Compassion Alzheimer Bulgaria).

of people with dementia. Compassion Alzheimer Bulgaria recently submitted a project proposal entitled “deinstitutionalisation through the provision of community-based services for risk groups” but this was classified as not relevant or important for Bulgaria and therefore rejected.

Cooperation between the State and the private sector, voluntary associations and NGOs is progressing very slowly. Currently, support for people with dementia is insufficient and constructive cooperation between the State and the above mentioned parties, which is necessary to resolve this problem, is clearly lacking. In fact, the Ministry of Labour and Social Policy avoids a constructive dialogue and cooperation with Alzheimer Bulgaria.

4.3.1.3 The overall funding of social support for people with dementia and carers

Social houses are 100% funded by the State through general taxation. There are places for about 800 people in Bulgaria and the cost is about EUR 100 per person per month. This is paid by the State. Service users do not pay anything.

Social services (i.e. the provision of food and home cleaning) are only partly financed by the State in that the State pays 20% of the cost and the person with dementia or his/her family pay the remaining 80 %.

Social houses and social services are supposed to be funded through general taxation.

4.3.1.4 The legal framework surrounding the provision of social support

There is no specific law covering support for people with dementia or their carers. People with dementia are covered by legislation for people with disabilities who need some kind of social support.

The Law on Social Support – 19.05.1998г (ЗАКОН за социално подпомагане-19.05.1998 г) deals with social support in general. The Regulation of 5.11.1998 covering the application of the Law on Social Support (ПРАВИЛНИК за прилагане на Закона за социално подпомагане Приет с ПМС № 243 от 5.11.1998 г) is also relevant.

The problems of people with dementia are covered by the Decree N: 4 – from 16.03.1999 on the Requirements and Supply of Social Services (НАРЕДБА № 4 от 16.03.1999 г. за условията и реда за извършване на социални услуги). This is a common regulation relating to the kinds of services provided, minimum standards and the control of these services.

4.3.1.5 The suitability of social support for people with dementia and carers

4.3.1.5.1 Adequacy and accessibility in general

None of the existing social services are specifically designed for people with dementia. Only general services are available which cater for general needs, not those that are specifically related to dementia.

The provision of social services throughout Bulgaria is insufficient. Consequently, people with dementia have difficulty accessing them.

The State does not provide sufficient funds to ensure adequate services in social houses. For this reason, social houses are frequently situated in isolated, rural areas where it is difficult to find qualified staff.

4.3.1.5.2 People living in rural areas

As stated above, social houses are often situated in rural areas rather than in larger towns.

4.3.1.5.3 People with different types of dementia

There are no services that are aimed at people with specific types of dementia.

4.3.1.5.4 People from ethnic minorities

There are no services that are aimed at people with dementia or carers from ethnic minorities.

4.3.1.5.5 Younger people with dementia

Access to most social services is based on disability rather than age, but home help and the meals service are both for the elderly so younger people with dementia would presumably be excluded.

4.3.2 Services and support for people with dementia and their carers

4.3.2.1 Types of care

4.3.2.1.1 Day care

There are no day care centres in Bulgaria. There are, however, day care centres for young disabled people but they are not suitable for people with dementia.

4.3.2.1.2 Respite care

Respite care in the home and short-term respite care services do not exist.

4.3.2.1.3 Long-term residential care

However, long-term residential respite care (in social houses) does. This is completely funded by the State which pays EUR 100 to EUR 120 on average per person. Staff in such care centres are usually inadequately trained. Most of the people who benefit

from such care are there because they are not cared for by relatives. Many have no diagnosis. The Bulgarian Alzheimer Association considers this service insufficient and plans to organise training for staff in these establishments.

4.3.2.1.4 Palliative care

There are no palliative care centres or provisions for palliative care at home in Bulgaria.

4.3.2.1.5 Monitoring in the home via alarm systems

There are no tele-alarm systems whereby a person can signal for assistance in case of emergency.

4.3.2.2 Personal assistance and home help

4.3.2.2.1 Personal assistance

Private companies provide assistance with personal hygiene, eating and drinking, as well as supervision taking medication. These services are not specifically designed for people with dementia and are financed totally by the service users.

The following services are not available:

1. Assistance with mobility e.g. lifting, moving and walking
2. Assistance dealing with incontinence
3. Assistance with skin care e.g. hydration, preventing and dealing with bedsores
4. Companionship and social activities
5. Occupational therapy/ergotherapy
6. Assistive devices
7. Home adaptation/transformation

4.3.2.2.2 Home help

Assistance with housework (e.g. cleaning the home) and with the preparation of food (or delivery of meals to the home) is a social service provided to the elderly. The State only contributes 20% towards the cost of this service. The remainder must be paid by service users (or by their carers). Shopping, transportation and laundry services do not exist.

The Bulgarian Alzheimer Association considers that the existing social services covering personal assistance and home help are insufficient.

4.3.2.3 Psychosocial support and training for people with dementia and carers

A general information service to direct people towards the services they need does not exist. However, there is a general clinical psychologist in every main hospital who can provide such information. He/she would be partly paid by the State and partly by the service user. The Bulgarian Alzheimer Association provides more spe-

cialised information through publications and its telephone help-line. The Association tries to make use of existing information channels i.e. the Administration of Social Houses, doctors, specialists in the field, State institutions, people with dementia themselves and their carers.

There are no counselling services or support groups for people with dementia or their carers. Similarly, there are no services which organise holidays for people with dementia or their carers, or which provide substitute carers to enable the latter to organise their own holidays or time off caring.

4.3.2.4 Work/tax related support for people with dementia

There is no legislation relating to the rights of people with dementia in paid employment e.g. to protect their job security and social rights.

People with dementia who receive a pension are entitled to a supplement to purchase services on the basis of disability provided that they have the necessary health certification. The actual amount received depends on their level of disability. They are not entitled to tax refunds or other financial incentives for employing a person to provide home care services or to pay for necessary home adaptations.

People with dementia are entitled to reductions for telephone and transport services but do not benefit from subsidised or free television or radio licences.

4.3.2.5 Work/tax related support for carers and carer allowances

Carers are not entitled to any paid time off work or flexible working hours in order to organise more effectively the care of a person with dementia. They can, if they wish, try to negotiate with their employer unpaid time off work but this is not covered by any specific legislation.

Carers do not receive any direct or indirect payments from the State for caring and they are not entitled to any tax benefits/incentives for the care they provide.

The State does not pay or contribute towards the State pension scheme when a carer gives up paid employment in order to care for a person with dementia.

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Unless otherwise stated, the information in this report was provided by Ms Zvezdelina Trifonova and the Bulgarian Alzheimer Society (Compassion Alzheimer Bulgaria) in May 2007

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Law on Social Support (in English): http://www.bcnl.org/doc_en.php?DID=309

4.4 Cyprus

Alzheimer Europe was unable to obtain information on the social support provided to people with dementia and their carers in Cyprus.

4.5 Czech Republic⁴

4.5.1 Organisation and financing of social support to people with dementia and carers

4.5.1.1 Background information on the social/healthcare system in the Czech Republic

On 31 December 1992, Czechoslovakia was peacefully dissolved and became two new countries, the Czech Republic and Slovakia. In January 1993, the Czech Republic adopted a new constitution and became a parliamentary democracy. With regard to healthcare, there was a transition following the Velvet Revolution from a national health system, in which healthcare was free, to an insurance-based system involving obligatory contributions to state health insurers. There has also been a transition away from policies and practices designed to segregate people with disabilities and dependent seniors from the rest of the so-called normal population (Holmerová, 2004).

4.5.1.2 The organisation of social support for people with dementia and carers

The Law 108 2006 (please see section below on the legal framework surrounding the provision of social support) provides the legal framework for the provision of social care. However, this legislation is new and has completely changed the provision of social care in the Czech Republic. The Law on Social Services came into force in January 2007. Therefore, it is difficult to evaluate the new system.

The Ministry of Labour and Social Affairs is responsible for coordination in the field of social care, decrees and recommendations etc. People who need care (including people with dementia) have the right to have an assessment and to a care allowance (if they are assessed as being in the 1st to 4th category). The allowance amounts to CZK 2,000, 4,000, 8,000 or 11,000 per month. It can be used to purchase social services but does not cover the complete cost. Social services are registered and there is a system of quality control including quality standards for care and standards for the qualifications of staff.

Providers of social care include the State, regional authorities, municipalities, NGOs and the private sector. Nowadays most providers are public but it is estimated that with the new legislation, the share of private social care providers will increase.

Long-term care is provided in both social and health care institutions.

4.5.1.3 The overall funding of social support for people with dementia and carers

Depending on the outcome of the assessment a care allowance may be paid to people who need care. Long-term care is still divided between the health and social care sectors. Long-term care hospitals and psychiatric hospitals are funded by the general health care insurance. Some social services (and residential homes) are co-funded by the State and regional authorities.

⁴ The information in this report on social support for people with dementia and their carers in the Czech Republic was provided by Iva Holmerová, M.D., Ph.D. from the Czech Alzheimer Society.

Alzheimer Associations may apply for grants from the Ministry of Health, the Ministry of Labour and Social Affairs and the regional authorities etc.

4.5.1.4 The legal framework surrounding the provision of social support

There is no legal definition of long-term care in the Czech Republic. However, Act No 108 2006 on Social Care (Zákon o sociální péči) is relevant as it covers care standards, quality control, care allowances and the right to assessment. It came into force on 1 January 2007 but it is still in the process of being implemented. The Decree Vyhláška 505 is also of relevance. It addresses practical issues covered by the law e.g. standards etc.

The Governmental Committee on Seniors has decided to deal with long-term care and to submit a proposal to the government.

4.5.1.5 The suitability of social support for people with dementia and carers

4.5.1.5.1 Adequacy and accessibility in general

The Czech Alzheimer Society provides a database (www.gerontologie.cz) with relevant information on care. However, care services for people with dementia are neither adequate nor accessible to all those who need them. They respond to specific needs in a very limited way (depending on each institution and municipality etc.). However, some residential homes are setting up new departments that better respect the specific needs of people with dementia. Hospitals, on the other hand, have no specialised services for dementia and often people with dementia are restrained in acute hospital care settings.

4.5.1.5.2 People living in rural areas

In some parts of the country, especially in rural areas, there are no relevant social services. However, this should change with the new law.

4.5.1.5.3 People with different types of dementia

There are no specialised services for people with different kinds of dementia.

4.5.1.5.4 People from ethnic minorities

There is no support specifically designed to meet the needs of people with dementia and carers from ethnic minorities.

4.5.1.5.5 Younger people with dementia

There are no specific services for younger people with dementia. They are usually treated by neurologists.

4.5.2 Services and support for people with dementia and their carers

4.5.2.1 Types of care

4.5.2.1.1 Day care

A limited number of day care centres exist in the Czech Republic but this may change when the new legislation is implemented. Day care is partly funded through the care allowance and partly through the budget for each day care centre. Some day care centres benefit from support from the Church, NGOs and volunteers.

4.5.2.1.2 Respite care

The Czech Alzheimer Society organises respite care at home (granny sitting). This is partly financed through grants with users and their families also contributing towards costs. The new law on social services (please see previous section) defines respite services but this kind of service has not been greatly developed. It is not considered sufficient.

Residential short-term respite care is available but insufficient. This may change with the new legislation. Long-term residential respite care exists and is partly funded by the State. Residential care is well developed but long-term care (health and social care) is insufficient.

4.5.2.1.3 Palliative care

Services providing palliative care at home exist but are insufficient. The general health care insurance and other resources co-fund hospices but there is no specialised palliative care for people with dementia. There is only one small department for palliative care for people with dementia. Hospices focus mainly on people with oncological diagnoses.

4.5.2.1.4 Monitoring in the home via alarm systems

Telephone alarm systems exist but are rarely sufficient. They are funded by various means.

4.5.2.2 Personal assistance and home help

4.5.2.2.1 Personal assistance

The following services exist but are considered insufficient:

1. assistance with personal hygiene.
2. assistance with eating and drinking (not the preparation of food).
3. assistance dealing with incontinence and/or skin care (available if classed as part of home care)

Service users must contribute towards the cost of the above-mentioned services. Some services are organised and financed by municipalities. However, only some municipalities provide such services. If eligible for a care allowance, this can be used to contribute towards the cost of these services.

Services offering companionship and social activities are insufficient. They are funded in different ways. Some are provided by municipalities but this is rare. There are also some voluntary services.

Ergotherapy/occupational therapy, home adaptations and assistive devices are insufficient. These services are usually funded by municipalities.

4.5.2.2.2 Home nursing care

When provided by home care nursing agencies on the basis of a doctor's prescription, assistance with mobility is funded by the general health care insurance. When provided by home help agencies, it is funded through the care allowance.

Assistance/supervision taking medication is sometimes provided by home care nursing agencies. In such cases, the service is funded through the general health care insurance.

4.5.2.2.3 Home help

The following services exist but are insufficient:

1. Assistance with housework
2. Help with the preparation of meals (including meals-on-wheels)
3. Transportation service

Assistance with shopping is available and tends to be sufficient in areas where home help services are provided. Where laundry services exist they are usually sufficient.

4.5.2.3 Psychosocial support and training for people with dementia and carers

A general information system exists which provides information on access to services but it is insufficient.

Counselling services are available for people with dementia (most run by the Czech Alzheimer Society) but holiday services are not. For carers, counselling services, holidays (in order to have a break from caring) and training are available. All these services are considered insufficient by the Czech Alzheimer Society.

Counselling services are funded by the Czech Alzheimer Society. The other services are rare but are mostly organised and funded by municipalities or NGOs.

4.5.2.4 Work/tax related support for people with dementia

People with dementia are not entitled to protective measures if in paid employment, to tax refunds/benefits on the basis of incapacity or to tax refunds/incentives for employing a person to provide home care services. However, the Law 108 2006 (which came into force on 1 January 2007) entitles them to a care allowance. They receive this allowance personally and are free to decide who will provide the care they need. They could, for example, pay a family carer to provide the assistance they need. They can also use the allowance to pay for any kind of service but must be able to show that it was used for care purposes.

Grants for home adaptation exist, not only for people with dementia but also for people with incapacity, but they are rare. Various reductions exist for disabled people (e.g. for television licences and transport) but the system is chaotic. People who are entitled to special privileges on the basis of severe disability receive a “special privilege card”. This is issued by municipalities with extended powers.

4.5.2.5 Work/tax related support for carers and carer allowances

There is no work/tax related support for carers. They do not, for example, have the possibility of taking paid or unpaid time off work to care for a person with dementia or to have flexible working hours to help them fit caring into their work routine.

However, the Act on Sickness Insurance (Zákon 54 o nemocenském pojištění zaměstnanců. 1956) grants an allowance to men or women who cannot work because they have to care for a sick relative living in the same household. The allowance (which amounts to 69% of the average wage) is provided in the first nine days of the sickness and is granted only once for each diagnosis.

The State does not contribute towards pension contributions for people who give up paid employment in order to provide care, and carers are not entitled to payments or tax benefits/incentives from the State for the care they provide.

4.5.3 Bibliography

Unless otherwise stated, information provided by Iva Holmerová, M.D., Ph.D (the Czech Alzheimer Society) in July 2007.

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4.6 Denmark⁵

4.6.1 Organisation and financing of social support to people with dementia and carers

4.6.1.1 Background information on the social/healthcare system in Denmark

Denmark has a national health service which aims to ensure that all citizens have equal access to healthcare services. This includes free home nursing. A local government reform came into force on 1 January 2007. The Consolidation Act on Social Services was part of this reform.

4.6.1.2 The organisation of social support for people with dementia and carers

Social support to people with dementia and carers is the responsibility of the Ministry of Social Affairs. The Ministry of the Interior and Health is responsible for healthcare. According to §83 of the Consolidation Act on Social Services, the municipal council shall offer personal care and assistance as well as assistance or support for necessary practical work in the home to people who are unable to carry out these activities “due to temporary or permanent impairment of physical or mental functions or special social problems.” The actual services to be provided in accordance with the Consolidation Act on Social Services are determined by the municipal council which can also pay for services from the private sector.

When arranging for the care and attendance of a person with a diagnosis of dementia, the municipal council must as far as possible respect his/her wishes for future care, attendance and housing as expressed in a “care testament” (§83.4).

The provision of services is determined by the municipal council on a case by case basis subject to an assessment of needs. The aim of the assistance provided is partly to maintain physical or mental skills and partly to remedy the most serious consequences of impaired physical or mental functions or special social problems. Service users are entitled to a choice of different providers for the services to which they have been assessed as being entitled. They can also choose between public and private service providers.

4.6.1.3 The overall funding of social support for people with dementia and carers

Social support for people with dementia and carers is financed through general taxation.

The State does not directly support Alzheimer associations but associations can apply for endorsement from Tips- og Lotto (surplus from gambling) which is granted on the basis of the funds that the organisation has raised itself.

⁵ The information in this report on social support for people with dementia and their carers in Denmark was provided by Merete Jensen from the Danish Alzheimer Association

Paragraph 18 of the Consolidation Act on Social Services states that the municipal council must cooperate with voluntary social organisations and associations and that each year it must allocate funds to support voluntary social work.

4.6.1.4 The legal framework surrounding the provision of social support

The Consolidation Act on Social Services of 18 January 2007 is relevant to the provision of social support to people with dementia and their carers.

There is no legal obligation to have a specific policy for dementia care in Denmark. However, chapter 25 of the Consolidation Act on Social Services demands quality standards and action plans for all kinds of services rendered.

According to §82 (1) of this act, municipal councils must provide assistance to people with substantial mental impairment who are unable to attend to their own interests even if they are unable to consent to it but such assistance cannot be administered by means of physical coercion.

4.6.1.5 The suitability of social support for people with dementia and carers

4.6.1.5.1 Adequacy and accessibility in general

Adequate information on people's rights and possibilities with regard to services and support is still lacking.

4.6.1.5.2 People from ethnic minorities

The State partly finances support for people with dementia and carers from ethnic minorities but such support is scarce. It is sometimes also provided by NGOs, volunteers and the Church.

4.6.1.5.3 Younger people with dementia

Some services are only accessible to younger people with dementia (i.e. under the age of 67). On the other hand, day care facilities for younger people with dementia are lacking.

Paragraphs 96 and 97 of the Consolidation Act on Social Services provide special provisions for people under 67 with substantial and permanent impairment of physical or mental function with an activity level requiring particular support.

4.6.2 Services and support for people with dementia and their carers

4.6.2.1 Types of care

4.6.2.1.1 Day care

Day care centres exist and are completely funded by the State but they are not for younger people with dementia. Day care is also provided by private organisations.

4.6.2.1.2 Respite care

The municipal council is obliged to offer substitute or respite care services to spouses, parents or other close relatives caring for a person with impaired physical or mental function (Consolidation Act on Social Services, §84, 1)

Respite care services at home, as well as short-term and long-term residential respite care, exist and are completely funded by the State. Private organisations also offer sitting services but the availability of respite care at home in case of acute need is often problematic.

4.6.2.1.3 Long-term residential care

The cost of long-term residential care is divided into the cost of housing and the cost of care. The latter is essentially free. With regard to the cost of housing, the person pays a rent and is considered a tenant. Prices vary quite a lot. A bill has been passed which limits the waiting time for a place in residential care to 2 months but this will not come into force until 2009. Meanwhile, there is a shortage of places.

4.6.2.1.4 Palliative care

Palliative care at home is provided in the form of home care nursing which is completely funded by the State. Similarly, there is a growing number of hospices and palliative care units in hospitals. Nevertheless, palliative care is only partly developed in Denmark and is therefore insufficient.

4.6.2.1.5 Monitoring in the home via alarm systems

Tele-alarm systems are completely funded by the State but the municipalities have different levels of service.

4.6.2.2 Personal assistance and home help

4.6.2.2.1 Personal assistance

The following services exist and are completely funded by the State but availability varies from one municipality to the next:

1. Assistance with personal hygiene
2. Supervision/assistance taking medication
3. Assistance eating and drinking (not the preparation of food)
4. Assistance with mobility e.g. lifting, moving and walking
5. Assistance with incontinence
6. Assistance with skin care
7. Occupational therapy/ergotherapy
8. Assistive devices

Companionship/social activities are also available and partly funded by the State but not for younger people with dementia. With regard to supervision/assistance taking medication (mentioned above), this is covered within the legal framework regulating the provision of services but in practice, it is unclear whether this service is widely available. Information was not available on home adaptations/transformations.

4.6.2.2.2 Home help

The following services exist and are completely funded by the State but availability varies from one municipality to the next:

1. Assistance with housework e.g. cleaning, dusting and tidying
2. Help with the preparation of meals (including meals on wheels)
3. Assistance with shopping

Transportation services and laundry services are also available but are only partly funded by the State. According to the Danish Alzheimer Association, transportation services for mentally disabled people are not very effective.

4.6.2.3 Psychosocial support and training for people with dementia and carers

A general information service exists covering access to services. Counselling for people with dementia and carers is also available. These services are partly funded by the State but are insufficient as they do not meet current demand. However, many private organisations, NGOs and volunteers also offer these services.

Concerning holidays for people with dementia, there are only scattered offers based on private initiatives from NGOs, volunteers and the Church for which people with dementia must contribute towards the cost. The only holidays for carers are those which are made possible through the provision of respite care (which is completely funded by the State).

The State completely finances training for carers. This is insufficient but it has improved considerably in the last few years.

4.6.2.4 Work/tax related support for people with dementia

The rights of people who have been diagnosed with dementia and who are still in paid employment are partly covered by legislation relating to the rights of people who are ill or disabled.

People under 67 years of age with substantial and permanent physical or mental impairments and with an activity level requiring particular support are entitled to a subsidy towards the cost of engaging assistant carers, supervisors and attendants. This is paid directly to the person in need of care (known as the recipient) provided that he/she can handle the organisation of such assistance. A person un-

der 67 whose freedom of movement is impeded due to substantial and permanent physical or mental impairment is entitled to 15 hours of attendance (which continues after the age of 67). He/she can designate a person to act as attendant who is then employed by the municipal council (if accepted by the latter). People with close connections to the recipient are not usually accepted for this job. Alternatively, the municipal council may decide to make a cash payment to the recipient in order to hire an attendant him/herself. Additional expenses incurred by the recipient for the attendant's transportation and other associated costs can be claimed from the municipal council. This cannot exceed DKK 663 per year. Further details can be found in §§96 and 97 of the Consolidation Act on Social Services.

There are no tax refunds, benefits, payments or reductions for people with dementia. However, elderly people are entitled to reduced fares on public transport at certain times of the day e.g. not during rush hours.

4.6.2.5 Work/tax related support for carers and carer allowances

4.6.2.5.1 Paid leave to care for a person with dementia

According to chapter 22 of the Consolidation Act on Social Services carers are entitled to up to 6 months' leave to care for a close relative/person who is handicapped or suffering from a serious disease. During these months (which can be divided into two periods of 3 months), the carer is actually employed by the municipal council. He/she signs a contract and receives a fixed salary (currently DKK 16,556 per month with a small deduction for a pension scheme contribution).

Chapter 23 of the Consolidation Act on Social Services deals with the care of terminal patients who wish to die at home and for whom hospital treatment has been assumed to be futile on medical grounds and therefore not necessary. The terminally ill person must agree to the establishment of a "constant care relationship" whereby a close relative/person provides care. An employer paying a salary to an employee during his/her absence from work in connection with caring for a closely connected person, thereby ensuring that the employee suffers no loss of earnings, is entitled to receive the amount otherwise payable to the employee by way of the constant care allowance. The constant care allowance amounts to 1.5 times the amount of sickness benefit that the carer would have been entitled to had he/she been ill. In other cases, (e.g. when the carer is not in paid employment), the carer may claim a constant care allowance of DKK 11,609 per month him/herself but not in addition to other welfare benefits. Where there are joint carers, the allowance can be divided between them according to the percentage of care that each provides. The constant care allowance ends 14 days after the death of the terminally ill person. Temporary admission to hospital does not affect the constant care allowance but the impossibility to continue care at home does.

4.6.2.5.2 Unpaid leave to care for a person with dementia

Arrangements for unpaid time off work to care for people with dementia are dependent on agreements with employers and collective labour market agreements (which may vary depending on the sector of professional activity).

4.6.2.5.3 Other provisions

Carers are not entitled to flexible working hours or free/subsidised pension contributions from the State. The only benefit they receive from the State is that linked to paid leave (which cannot exceed 6 months) or the constant care allowance for care of a terminally ill person.

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Unless otherwise stated, information provided by Merete Jensen (Danish Alzheimer Society) in July 2007

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4.7 Estonia⁶

4.7.1 Organisation and financing of social support to people with dementia and carers

4.7.1.1 Background information

There is as yet no specific action plan for the organisation of the welfare of people with dementia in Estonia. However, the Ministry of Social Affairs recently ordered the Estonian Gerontology and Geriatrics Association to research into the care needs of people with dementia. This research, which was finalised in March 2007, was carried out in cooperation with the Estonian Association of Alzheimer's Disease. The research report has been presented to the Ministry of Social Affairs, which will, on the basis of this report, take measures to develop and fund services for people with dementia and their carers. National welfare service standards are also being drawn up by the Ministry.

4.7.1.2 The organisation of social support for people with dementia and carers

The highest authority, with regard to social support and its legal framework of organisation as well as the existence of regulations, is the Estonian Ministry of Social Affairs. As social welfare and health care are both under the jurisdiction of the Ministry of Social Affairs, the relationship/interaction between the two is intensive.

The general welfare of people with dementia is organised by the local government which is best acquainted with local life. The local government can decide whether to provide services itself or to purchase them from private or public organisations. The local government is only under the obligation to organise/provide care for childless elderly people living alone. It does not intervene if the person has "legal subsistence" (i.e. children or even grandchildren who are obliged to provide or arrange care for the parent or grandparent).

In order to be eligible for services, people have to have their needs assessed. Elderly people may be offered a geriatric assessment. Geriatric assessments were introduced in 2004. They consist of a single assessment to determine clients' needs and to provide them with suitable services covering health care, nursing care and welfare services. The geriatric assessment team is composed of a physician, a nurse and a social worker. An international standardised tool is used for the assessment. Services are then provided on the basis of each person's needs and financial situation. Elderly people with dementia can use all the services provided to the elderly for as long as they are able to do so and/or as long as the local government is able to provide such services. If the person cannot cope with these regular services, he/she is usually put in a nursing home. Services for people in need of assistance are mainly provided in special social welfare homes.

⁶ The information in this report on social support for people with dementia and their carers in Estonia was provided by Eve Võrk from the Estonian Association of Alzheimer's Disease.

4.7.1.3 The overall funding of social support for people with dementia and carers

Funding for social welfare comes from local government budgets, the State budget and various other sources. The State budget provides local governments with funds for social welfare mainly via the Estonian Health Insurance Fund⁷ but the local governments may also have to use their own budgets to finance services. However, there are over 200 municipalities in Estonia and some of them are very small. Consequently, those which do not have the necessary funds to offer a full range of services sometimes group together and provide services jointly (Ministry of Social Affairs, 2005). Voluntary organisations, churches, foundations, commercial associations and non-profit organisations can all provide social services.

There is some financial disagreement linked to the provision of services. For example, when long-term or short-term nursing care is provided in a medical care institution it is funded by the Estonian Health Insurance Fund (EHIF), but when similar nursing care is provided in a welfare institution it is not funded by the Health Insurance Fund and must, on the contrary, be completely funded by the service users themselves. This problem has been acknowledged and solutions to it are actively being sought.

Providers of social services may charge users or their families for their services. According to the Family Law of 1994, spouses are legally obliged to provide maintenance for each other. Similarly, children and kinsfolk are legally obliged to take care of their elderly relatives. However, if they are unable to do so or if an elderly person does not have any relatives, the government must assume responsibility for his/her care.

The State does not support the Estonian Association of Alzheimer’s Disease and the latter has not asked for any support from the State. The association does not have paid staff so all its activities are based on the work of volunteers. The Estonian Association of Alzheimer’s Disease comprises specialists from different fields (neurologists, psychiatrists and social workers), who are actively involved in their field and are specialised in diagnosing dementia, therapy and the welfare of people with dementia.

There are no self-help organisations in Estonia.

4.7.1.4 The legal framework surrounding the provision of social support

Dementia is not mentioned in any national acts.

The Constitution of the Republic of Estonia (28 June 1992) contains statements about the family’s duty to care for its members who are in need and the State’s duty to support services provided by volunteers and the local government:

⁷ In 2001, the EHIF was created and replaced the existing Central Sickness Fund. It covers 94% of the population and is responsible for contracting health care providers, paying for health services and refunding medication costs amongst other things. In 2003, the EHIF started to cover expenses for long-term care, nursing care and some home care (Hit Summary, 2004).

- §27 The family has a duty to care for its needy members.
- §28 The State shall promote voluntary and local government welfare services.

The Local Government Organisation Act (2 June 1993) §6 defines the competence and tasks of local governments in organising local life. One of the functions of a local government is to organise, in the rural municipality or city, social assistance and services as well as welfare services for the elderly.

The Family Law Act (12 October 1994) defines family members' mutual obligation of maintenance and custody, and the provision of care. The relevant paragraphs and chapters are:

- § 21 Duty of maintenance of spouse
- § 22 Duty of maintenance after divorce
- § 64 Duty of child who has become an adult to maintain parent
- § 66 Duty of grandchild to maintain grandparent
- § 68 Maintenance of step-parent and foster parent
- § 69 Support for other family members
- Chapter 11 Guardianship
- Chapter 12 Curatorship

The Social Welfare Act (8 February 1995) establishes the organisational, economic and legal grounds for social welfare and regulates relationships evolving in social welfare. The principles and purposes of social welfare are: "the observation of human rights, the responsibility of persons for their own and their family members' ability to cope, the obligation to provide assistance if the potential for a person or family to cope is insufficient and the promotion of the ability of persons and families to cope [§3 (1)]."

The welfare of the elderly is discussed in §27 of this law which states:

In order to assist the elderly to cope in surroundings familiar to them and to have a life of equal value with other persons, rural municipality governments and city governments shall:

- establish opportunities for cheaper alimentation (food);
- ensure the accessibility of information concerning services provided and establish opportunities for the use of social services;
- ensure opportunities for interaction and hobbies;
- ensure the security and independence of the elderly living in social welfare institutions, respect for their private life and the opportunity to participate in decision-making pertaining to their physical and social environment and future.

All laws mentioned above form part of a framework for the organisation and provision of services. Welfare services for the elderly/people with dementia have not yet been validated by any governmental service standards. Standards for services have been validated in Tallinn and the State is in the process of creating them for use at national level. It is likely that national welfare standards will come into force in 2009.

4.7.1.5 The suitability of social support for people with dementia and carers

4.7.1.5.1 Adequacy and accessibility in general

The services provided to people with dementia and their carers are not adequate and accessible. The ability of local governments to organise and provide services is very different. Small governments and rural areas are less developed than bigger cities. In cities, the organisation and accessibility of services is better. In the last couple of years, diagnosing dementia has improved a lot, but the development of services has not improved as quickly.

Services specially targeted at people with dementia respond to their needs. Other more general services to which they may be entitled (e.g. home care) do not necessarily meet their actual needs.

4.7.1.5.2 People living in rural areas

As stated above, the ability of local governments in rural areas to provide services is often not as good as that in larger towns.

4.7.1.5.3 People with different types of dementia

National statistics on the diagnosis of dementia are collected separately for Alzheimer’s disease and for vascular dementia but only for out-patient admission. In the case of mental and behavioural disorders related to the use of psychoactive substances, statistics for dementia are recorded separately for out-patient admission. Other forms of dementia are not recorded separately in statistics. They are all classified as general dementia. There are no services specifically designed for people with different types of dementia.

4.7.1.5.4 People from ethnic minorities

Data is not collected on ethnic origin and there are no services specifically designed for people with dementia or their carers from ethnic minorities.

4.7.1.5.5 Younger people with dementia

Precise data on the age of people with different forms of dementia is not available as in statistics based on age, dementia falls under section Foo-F-99 which includes all mental and behavioural disorders. Age-based statistics are available for people presenting primarily with Alzheimer’s disease (G30) but not for other forms of dementia. The national social welfare service providers collect data on diagnoses but not according to gender, nationality and age.

People with dementia under the age of 63 (who are not yet entitled to a pension) may be considered as disabled. If they wish to apply for disability status and are of working age, their capacity to work must be evaluated by an expert team and a rehabilitation plan drawn up. The evaluation team is selected nationally but they are entitled to choose from among different service providers a team that is conveniently located and appropriate to their needs.

There are no services that are specifically designed for younger people with dementia.

4.7.2 Services and support for people with dementia and their carers

4.7.2.1 Types of care

4.7.2.1.1 Day care

Day care is insufficient because day care services for people with dementia are only available in two major cities, namely Tallinn and Tartu and in special sections for people with dementia in three Estonian nursing homes (in Merivälja, Iru and Koeru).

The service is organised by local governments, which also cover the major part of the expenses. The person with dementia has to pay for meals, medicine, care and nursing supplies (diapers etc.) as well as for transportation costs (if this is arranged).

Day care is generally organised by the institutions that are administered by the local government, but one NGO in Tallinn also provides this service.

4.7.2.1.2 Respite care

Respite care in the home is not available. However, there are short-term and long-term residential respite care services. These services are organised and funded by local governments. Several NGOs also provide residential respite care. The local government funds respite care for people who do not have legal sustenance (i.e. a child or grandchild who is legally obliged to provide for them). Those who do, must cover the cost of respite care themselves.

4.7.2.1.3 Long-term care

Services for people with dementia are provided in some specialised units created near welfare institutions. This may take the form of day care (e.g. day care in a social centre or near a day centre for the elderly or in a social accommodation unit as a separate department) or long-term residential care in an adjusted unit in a nursing home/retirement home. However, the majority of people with dementia are still cared for in general rather than specialised nursing or service homes.

The service user and his/her legal subsistence must pay for a place in the nursing home if they are able to do so. If they are unable to do so, the local government may pay part or all of the cost.

The State does not cover the cost of nursing. However, this may be partly or fully covered by the local government, which evaluates the economic situation of the person in need of the service and of his/her legal subsistence i.e. to determine whether or not the person and his/her family have enough resources to cover the nursing costs. The local government may take between 85% and 100% of the person's pension to cover the cost of nursing. Sometimes, the person is left with part of his/her pension for personal use.

The cost of long-term residential care varies considerably (EEK 5,000 to 15,000 per month). It depends on where the home is located, what kind of services it offers, whether nursing products are needed (e.g. incontinence pads) and whether the person needs extensive supervision. Nursing homes in towns are usually more expensive than those in rural areas.

4.7.2.1.4 Palliative care

There are no palliative care services for people with dementia in Estonia.

4.7.2.1.5 Monitoring in the home via alarm systems

Services providing a tele-alarm system do not exist.

4.7.2.2 Personal assistance and home help

4.7.2.2.1 Personal assistance

The following services are not provided at home to people with dementia in Estonia:

1. Assistance with personal hygiene
2. Assistance/supervision taking medication
3. Assistance eating and drinking
4. Assistance with mobility e.g. lifting, moving and walking
5. Assistance with skin care (please see below for information regarding pressure sores)
6. Companionship/social activities
7. Occupational therapy/ergotherapy

People with dementia, who live at home and have a need for the above-mentioned services, but do not have relatives to take care of them, are accommodated in nursing homes. In nursing homes for long-term care, these services are provided (except for occupational therapy/ergotherapy). Home maintenance services are not offered

to people with dementia who have carers/family as all kinds of care must be covered by the carers/family. If the family has the available resources, it can purchase services from private entrepreneurs.

The treatment of pressure sores is a service offered by home nurses, appointed by general practitioners (GPs). This service (nursing, treatment of bedsores and other nursing procedures) is financed by the Health Insurance Fund and is free of charge for the service user. The service is more widely available in cities and larger towns. In rural areas, there may be some problem with the availability of the service but the State has done a lot of work in order to improve availability and the service is improving every year.

Assistance dealing with incontinence is provided by NGOs. The State covers 40% of the cost and service users must pay the remaining 60%. This service is considered insufficient.

Assistive devices are usually provided by NGOs and private companies. They are partly funded by the State and partly by those needing them. However, there are not enough assistive devices available. If the devices provided by the State are all in use and a person cannot or does not want to be put on a waiting list, he/she has the right to obtain the devices at his/her own expense i.e. without financial support from the State.

Home adaptations are organised by local governments. People may be entitled to cost free home adaptations or may have to partly or completely fund them themselves. The price charged for the service depends on the service user's economic status and on the existence of legal subsistence. The service is provided by the local government, which also contracts NGOs and self-employed entrepreneurs and business organisations.

4.7.2.2.2 Home help

Assistance with housework is provided by local governments, NGOs and business organisations. Providing this service is part of the commitment of local governments under the Local Government Organisation Act. They can also purchase this service, in which case, the service providers selected are usually NGOs.

If provided by a local government this service can be either cost free/provided in kind or partly or completely funded by the user, depending on his/her level of income and on whether he/she has "legal subsistence". If provided by NGOs and business organisations, the service is completely funded by the service user. In this case, the cost depends on the market conditions.

Help with the preparation of meals (including meals-on-wheels), assistance with shopping, laundry services and transportation services are organised by local gov-

ernments. Depending on a person's level of income and available means of support, the service is either completely or partly funded by the service user. The service is organised by local governments and it can be provided by the institutions of the local governments or by NGOs. These services are considered insufficient by the Estonian Association of Alzheimer's Disease. Transportation and laundry services are not uniformly available throughout the country and are more common in cities.

4.7.2.3 Psychosocial support and training for people with dementia and carers

There is no general information service to inform the public about the availability of services. Information about different services is provided by local government social workers. There is no Internet service for information or for counselling either and no telephone help-line.

Members of the Estonian Association of Alzheimer's Disease and the Estonian Association of Gerontology and Geriatrics provide some counselling on a voluntary basis. They and some educational centres for health and social care workers also provide training for carers and in welfare institutions if a need is expressed but not on a regular basis as it is project-based. Apart from this, carers do not have any access to training.

There are no services providing holidays to people with dementia or their carers.

4.7.2.4 Work/tax related support for people with dementia

There are no protective measures for people with dementia who are still in paid employment. People with dementia are not entitled to tax refunds or benefits on the basis of personal incapacity or for employing someone to provide home care services. Similarly, they are not entitled to direct payments to pay for services or to reduced prices for television licences, radio licences and public transport. However, a person with dementia is entitled to make use of all benefits based on old age (for elderly people with dementia) or based on disability (for people with dementia of working age).

For example, although there are no state reductions on televisions and phones, various telephone companies offer cheaper package deals for senior citizens in order to gain clients.

Similarly, the Law on Public Transport (adopted on 26.10.2000) allows local governments to validate bargain prices on parish and city transport lines (§5) and defines target-groups for state-wide benefits which public transport service providers are obliged to offer cost free or at a reduced price e.g. free inner-state transportation (on railways, highways and waterways) for severely disabled adults as well as reductions of up to 50% on inner city public transport for disabled people (§29).

In addition to the benefits mentioned above, local governments can grant extra benefits to the elderly and to families with a large number of children according to §5 of the same law. The transportation service providers can also make additional reductions and such reductions are indeed being made. If public transport providers make reductions themselves, the State does not cover the costs.

Tax refunds for home adaptations are available but are not based on a diagnosis of dementia. The terms and procedures for giving grants are determined by local governments. They are dependent on people's economic status and the existence or absence of legal subsistence. As for other forms of social welfare, home adaptations are covered by the following laws: the Family Law Act, The Local Government Organisation Act and The Social Welfare Act.

4.7.2.5 Work/tax related support for carers and carer allowances

Carers are not entitled to paid or unpaid time off work in order to care for a person with dementia but they are entitled to flexible working hours.

The State does not subsidise pension fund contributions for carers who give up work in order to care for a person with dementia.

Carers do not receive tax benefits/incentives for the care that they provide. However, according to the Social Welfare Act they are entitled to a payment if the person with dementia has been diagnosed with a high level of disability. The local government defines the terms and procedures for the granting of this payment but may decide not to grant it to carers with a high income.

According to §23 of the Social Welfare Act of 1995 (supplementary social benefits paid from local government budget), carers have a right to apply for carer subsidies from the local government. §23 states:

- Rural municipality governments and city governments may grant and pay supplementary social benefits from a local government budget subject to certain conditions and procedures established by the local government council.
- Rural municipality governments and city governments may grant and pay the caregiver's allowance to caregivers and guardians (with active legal capacity) of people over 18 years of age according to the terms and orders established by the local government council.

Carers receiving this allowance are expected to support the person in everyday activities and provide care services at home.

Otherwise, there are no special grants/subsidies for the carers of elderly people with dementia.

4.7.3 Bibliography

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- The Social Welfare Act (8 February 1995)
- The Constitution of the Republic of Estonia (28 June 1992)
- The Local Government Organisation Act (2 June 1993)

4.8 Finland⁸

4.8.1 The organisation and financing of social support for people with dementia and carers

4.8.1.1 The organisation of social support for people with dementia and carers

According to the Social Welfare Act (710/1982) social support is organised in the following way: The Ministry of Social Affairs and Health is responsible for general planning, guidance and supervision concerning social welfare and the Provincial State offices are responsible for planning, guidance and supervision concerning social welfare within each province. The Ministry of Social Affairs and Health has a programme and guidelines for the regional development of social protection. The ministry formulates guidelines and recommendations concerning social protection. The Ministry of Social Affairs and Health draws up legislation and guides its implementation. It prepares targets for social welfare and health care and an action programme for each four-year electoral term that is adopted by the government in office. The programme includes a decision on resources that is examined each year in connection with the state budget.

Finland's municipalities are in charge of the tax-based funding of social welfare and health services for all their inhabitants. The organisation of social services and the provision of income support are arranged by each of Finland's 431 municipalities (social services include elderly care services). Municipalities take care of the planning and implementation of social welfare. Municipalities organise social services for their residents, provide social assistance to people living in the municipality, pay social allowances to their residents, organise guidance and counselling on social welfare benefits and other forms of social security and their use, provide information on social welfare and other forms of social security and organise training, research and experimental and development activities concerning social welfare and other forms of social security.

The municipalities may provide services themselves or arrange them in cooperation with neighbouring municipal authorities. A municipality may also contract services from another municipality or from a private service provider. The state supports this local organisation of services through allocations of state subsidies. The composition of services is not defined in precise detail by law, which means that services may differ from one municipality to another. Nevertheless, it is stated in law that certain basic services must be available in all municipalities. The public sector plays a central role in the development of social protection. Social and health care services, provided privately or by associations, supplement those organised by municipalities and offer an alternative to them.

The main policy aim is that as many older people as possible should be able to live independent lives in their own homes, and in a familiar social and living environment. Living at home is supported by rapid access to professional social welfare and

⁸ The information in this report on social support for people with dementia and their carers in Finland was provided by Sirpa Granö from the Alzheimer Society of Finland.

health care services. Residential services and different forms of institutional care are provided to people who can no longer manage to live at home. In order to carry out this policy, each municipality is expected to have an up-to-date policy strategy concerning care for older people that safeguards their social rights. The strategy should include a service development programme, the starting points of which are to ensure a good quality of life for older people, their self-determination and independence, regardless of their functional capacity. Services should start from the client and cooperation with relatives and between service providers and the client's family should function smoothly.

4.8.1.2 The overall funding of social support for people with dementia and carers

Services and support are funded through general taxation. A fee for service basis is used in the private sector.

4.8.1.3 The legal framework surrounding the provision of social support

Perustuslaki (731/11.6.1999 – came into force on 1.3.2000) - The Constitution safeguards economic, social and educational basic rights for all people living in Finland. The state and the municipal authorities guarantee that these basic rights are respected. Services and income protection are guided by legislation: all residents in Finland are by law guaranteed access to social welfare (social services, benefits and income support). The aim of the social welfare system is to provide high quality and sufficient services to all members of the population. In the Constitution it is stated, that those who cannot obtain the means necessary for a life of dignity have the right to receive indispensable subsistence and care. The public authorities shall guarantee for everyone adequate social, health and medical services.

The improvement of clients' status in social welfare is provided by the Act 'Laki sosiaalihuollon asiakkaan asemasta ja oikeuksista' (812/22.9.2000 – came into force on 1.1.2001) - Act on the Status and Rights of Social Welfare Clients (unofficial translation). This Act lays down the key legal principles concerning the participation, treatment and legal protection of social welfare clients. The purpose of the Act is to promote client-orientated services, the confidentiality of client-service provider relationships and the client's right to quality social welfare and good treatment.

'Hallintolaki (434/2003- came into force on 1.4.2004) - Administrative Procedure Act'. The aim of this Act is to achieve and promote good administration and access to justice in administrative matters. This Act contains provisions on the fundamental principles of good administration and on the procedure applicable in administrative matters. When for example applying for social benefits, this Act defines how a decision should be made and communicated to the client and how clients can appeal against a decision. In the Act it is defined how authorities should guide clients in the application process and in completing an application, and how they should provide clients with a written decision including the reasons for the decision.

'Potilaslaki (785/1992 – came into force on 1.3.1993) - Act on the Status and Rights of Patients'. This Act shall apply to the status and rights of patients in health care and medical care. In this Act, patients' rights to good care and treatment are defined as well as principles concerning access to care and the right to have necessary information. In March 2005 a change in this law came into force (containing new provisions) the aim of which was to improve clients' access to care in a reasonable period of time as well as their right to have an individualised plan for examinations, care and medical rehabilitation.

'Sosiaalihuoltolaki (710/1982 – came into force on 1.1.1984) - Social Welfare Act'. This Act defines certain services as follows: 'social welfare' means social services, social assistance, social allowance and related measures intended to promote and maintain the social security and functional ability of the individual, the family and the community. In this law social services and benefits are defined. The municipalities are responsible for organising these services for their inhabitants. A change in this Act came into force quite recently (1.3.2006) and it introduced the right to have a quick access to service evaluation within a reasonable period of time for people over 80 years of age or those who are receiving special care allowances on the basis of the National Pensions Act.

'Laki sosiaali- ja terveydenhuollon asiakasmaksuista' (734/1992 – came into force on 1.1.1993) unofficial translation: Act on client fees in social- and health-care & 'Asetus sosiaali- ja terveydenhuollon asiakasmaksuista' (912/1992 – came into force on 1.1.1993) Unofficial translation: Decree on client fees in social and health-care'. Both this law and the decree define how payments for social services, such as home care, but also for short-term care and long-term care in institutions, are determined. For example, fees for long-term institutional care are determined on the basis of the client's income. They may be set at up to a maximum of 80% of the client's net income. The fees are the same for both social and health care institutions. Clients in long-term institutional care are left with no more than 20% of their net income after fees, at least EUR 80 a month. There is an annual ceiling for public healthcare service fees.

'Laki vammaisuuden perusteella järjestettävistä palveluista ja tukitoimista' (380/1987 – came into force 1.1.1988) & 'Asetus vammaisuuden perusteella järjestettävistä palveluista ja tukitoimista' (759/1987 – came into force on 1.1.1988) – unofficial translation: Act and decree on services and support for disabled persons. In this law and decree, certain kinds of services are defined, such as transportation services and home modifications. A disabled person's right to counselling and adaptation training are also defined. This is a secondary act compared to the Social Welfare Act.

'Kansaneläkelaki (347/1956 – came into force on 1.1.1957) - National Pensions Act ja Kansaneläkeasetus (594/7.12.1956 – came into force on 1.1.1957) - National Pensions

Decree'. In this Act and Decree, details of the pensioners' care allowance are defined. The pensioners' care allowance is intended to make it possible for pensioners (i.e. people who receive a pension) with an illness or disability to live at home, as well as to promote home care and to reimburse such pensioners for extra costs incurred as a result of illness or disability. It can be paid to people aged 65 or over or to people under 65 who are receiving a full disability pension, rehabilitation subsidy, individual early retirement pension, special assistance for immigrants, or earnings-related old-age pension paid to the under 65s as a follow-up to a disability pension. The care allowance is granted if the pensioner's functional ability has diminished to such an extent that his/her capacity to look after him/herself and to handle ordinary everyday activities without assistance has deteriorated on account of the illness or injury. Depending on the degree of assistance or supervision needed, and on the amount of extra costs incurred, the pensioners' care allowance is paid according to the lower, higher or special payment category. The care allowance is tax free.

'Sairausvakuutuslaki (1224/21.12.2004 – came into force on 1.1.2005) – unofficial translation: Health Insurance Act'. In this Act, there are definitions for drug reimbursement as well as for the reimbursement of travel costs that are caused by examinations and the treatment of a disease as well as reimbursement for expenses for private care. The sickness insurance reimburses a portion of the cost of prescribed medicines. Reimbursements are usually granted at the pharmacy on the production of a 'Kela card', which is issued by the Social Insurance Institution.

'Omaishoidon laki (937/2.12.2005 – came into force on 1.1.2006) Family Carers Act'. The aim of this Act is to promote informal care by providing sufficient social and health care services and continuity in care and by supporting the work of informal carers. This Act defines allowances and services to which family carers, who look after older person, for example, are entitled. The municipality and the person providing care draw up a care agreement that includes a plan for care and services. In 2006, the minimum caregivers allowance was EUR 300 per month. There is no upper limit on the allowance, which is taxable. The caregiver who has made an agreement with the municipality is entitled to employment pension accrual, on the condition that he or she is not already on a pension. The municipality also covers the caregiver's accident insurance. People receiving a caregivers allowance are entitled to two free days a month during a period when the nature of the care they have provided has been very demanding. During this statutory free time, the municipality is responsible for providing care to the elderly person.

'Tieliikennelaki (267/ 3.4.1989 – came into force on 1.4.1982) - Road Traffic Act'. In this Act, it is stated that there is a special parking permit for conveying disabled people.

In the Act and Decree on taxation 'Tuloverolaki (30.12.1992/1535- came into force on 6.5.1993) – unofficial translation: Income Tax Act' and 'Tuloveroasetus

(30.12.1992/1551- came into force on 6.5.1993) – unofficial translation: Income Tax Decree', there are definitions of tax deductions on the grounds of invalidity e.g. handicap caused by disease. In the Act, there is also a definition of the reduction of tax solvency (that can be caused by high medical expenses).

'Laki toimeentulotuesta (1412/30.12.1997 – came into force on 1.3.1998) – Act on Social Assistance'. Social assistance is "last resort" financial assistance under social welfare, the purpose of which is to ensure a person's or family's basic living costs (e.g. for an apartment, health care, day care for children when needed) and help them to cope independently. Social assistance is used to ensure that the person or family has at least the minimal living standard necessary for a life of human dignity.

'Eläkkeensaajien asumistukilaki (591/28.7.1978 – came into force on 1.1.1980).' The pensioners' housing allowance can be granted to people over 65 on a low-income by the Social Insurance Institution.

4.8.1.4 The suitability of social support for people with dementia and carers

4.8.1.4.1 Adequacy and accessibility in general

There are problems in both adequacy and accessibility of services: the services vary from one municipality to the next. For example there are evident deficits in adequacy and accessibility of adaptation training and day care aimed especially at people with dementia. There are deficits in home care and rehabilitative services.

Recognising and responding to the specific needs of people with dementia is not so well developed. Services are not very flexible and specific needs are not recognised or adequately met.

Finland's Slot Machine Association (RAY) raises funds through gaming operations to support Finnish health and welfare organisations. For this purpose RAY, which is an association, has the exclusive right in Finland to operate slot machines and casino table games, as well as to run a casino. Under the terms of the Slot Machine Funding Assistance Act RAY can grant assistance to incorporated, non-profit societies and foundation for the purpose of promoting health and social welfare.

The Alzheimer Society and most of its local chapters receive funding from RAY for their projects. In addition to this, many municipalities co-operate with local associations.

4.8.1.4.2 People living in rural areas

Many innovative measures are needed with long distances if services are to be provided in rural areas. In Lapland, for example, is used a memory clinic bus is used with memory testing and counselling services.

4.8.1.4.3 People with different types of dementia

Some local associations provide information separately to people with Lewy body dementia, Alzheimer’s disease and vascular dementia.

4.8.1.4.4 People from ethnic minorities

There is limited support for people with dementia and their carers from ethnic minorities. For example, in the Alzheimer Association in Helsinki there is a counselling service for people who speak Russian and throughout Finland, there is written information in Russian on memory disorders and dementia. This is funded by RAY (the Slot Machine Association). However, this is insufficient.

4.8.1.4.5 Younger people with dementia

There are certain subgroups whose specific needs are not yet well known: The specific needs of younger people with dementia and their family carers, as well as people living alone, are not very well catered for.

However, people with dementia under 65 years of age have slightly better possibilities to get rehabilitation services than older people.

4.8.2 Services and support for people with dementia and their carers**4.8.2.1 Types of care****4.8.2.1.1 Day care**

According to a study carried out by the Alzheimer Society into the quality and availability of services for people with dementia (Tervonen, 2005), there are clear deficits in the provision of day care services in Finland. According to this study, 36 % of municipalities stated that they did not have day care for people with dementia. Another problem is that even if there is day care in municipalities, it does not necessarily take into account the special needs of people with dementia. This means that day care is not provided on a rehabilitative basis. Day care is partly funded by the State (the municipality) and partly by service users. The latter pay a maximum of EUR 12 per day.

Some Alzheimer or dementia associations provide day care and the municipality purchases places for people with dementia in these day care centres. In some associations, there are currently projects to develop a rehabilitative approach to day care with financial support from the Slot Machine Association (RAY). The associations work in close collaboration with the municipalities and the aim is to implement this service as a part of the official services available.

4.8.2.1.2 Respite care**4.8.2.1.2.1 Respite care at home**

Respite care at home exists but the availability of this service is rather restricted (at least in some smaller, rural municipalities). This kind of service is mainly offered

by private service providers and some NGOs (e.g. the Red Cross). The State does not finance respite care at home at all, so service users have to pay for it themselves.

Some projects have been developed by Alzheimer and dementia associations in order to provide sitting services but the aim of these projects was to support the functional capacity of a person with dementia by means of rehabilitative activities, as well as by giving informal carers some free time.

4.8.2.1.2.2 Short-term residential respite care

The municipalities are responsible for organising residential care, but short-term care for people with dementia should be rehabilitative and individually planned etc., and this is currently not the case. The main aim of respite care is to support the provision of home care and if short-term care is not rehabilitative, the patient's condition and/or functional capacity could deteriorate during the care period. This, in turn, could further affect the family carer's situation and the continued provision of home care.

Short-term residential respite care is partly financed by the State and partly by the service user who may be asked to pay up to EUR 26 per day. Private service providers also offer residential respite care and short-term care services.

4.8.2.1.3 Long-term residential care

Long-term residential respite care is available but it tends to be offered to people who are in a very bad condition rather than to those who need it. Fees for long-term residential care are determined on the basis of the service user's income (up to a maximum of 80% of his/her net income). This means that people in long-term residential care may be left with just 20% of their monthly income although there is a minimum of EUR 80 per month. The fees are the same for both social and health care institutions.

Private service providers also offer long-term residential respite care.

4.8.2.1.4 Palliative care

Palliative care at home is available but this varies from one municipality to the next. It is partly funded by the State and partly by service users. Continual care is charged on a monthly basis. The amount to be paid by the service user depends on the amount of care needed, his/her monthly income and the size of his/her family.

The inpatient wards of municipal health centres and home nursing services are jointly responsible for the end-of-life care of people with cancer. There are also private service providers and private hospitals which offer palliative care at home to those who can afford it.

Palliative care in an actual centre is available and is partly financed by the State. Service users contribute towards costs in the same way as they would for full-time residential respite care i.e. up to 80% of their income.

4.8.2.1.5 Monitoring in the home via alarm systems

Municipalities provide a tele-alarm service to those who have been assessed as needing it. People living alone and/or who need a security system are given preference. Service users have to contribute towards the cost of the service. They are usually charged a monthly payment on the basis of their income.

There is a strong interest in tele-alarm systems in the private sector. Systems are being developed and it is already possible to purchase this service from private service providers.

4.8.2.2 Personal assistance and home help

4.8.2.2.1 Personal assistance

4.8.2.2.1.1 General personal assistance

Assistance with personal hygiene is available and partly funded by the State. It is part of the support services for home care. People's needs are first evaluated and then a service and care plan is drawn up which specifies which services they should receive. Private service providers also offer assistance with personal hygiene.

Supervision/assistance taking medication is classed as a home nursing service and is partly funded by the State. It can also be obtained from private service providers. Many people with dementia experience problems taking medication, especially those who live alone.

Assistance with eating and drinking is available but this service is currently insufficient. Whilst a meals-on-wheels service exists and is partly funded by the State, people who need assistance to actually eat their food and drink have to rely mainly on private service providers and help from their informal carers.

Assistance with mobility (e.g. lifting, moving and walking) is insufficient. Whilst the service exists and is partly funded by the State, many people do not have enough opportunities to get out as there are not enough assistants. There are, however, volunteers.

With regard to incontinence, municipal health centres give disposable equipment to people with some serious diseases (e.g. diabetes, cancer and fistula patients) free of charge and also lend them the devices they need for their care. People with dementia with severe incontinence are entitled to free incontinence pads. To receive these devices or pads, clients need to obtain a cover note from their health centre doctor. It is also possible to purchase disposable incontinence pads from private sector suppliers.

Assistance with skin care is classed as home care/nursing or assistance with personal hygiene and is partly funded by the State. It can also be purchased from private service providers.

4.8.2.2.1.2 Companionship, social activities and occupational therapy

Companionship and social activities are not funded or provided by the State other than in the context of day care. If classed as an actual service in a day care centre, it can be partly funded by the State but service users must also contribute towards the cost. In addition to traditional service centres (the term “service centres” includes apartments and services which inhabitants can choose to buy such as cleaning, meals and washing clothes) and day care centres, municipalities, associations and parishes run activity clubs, study groups, neighbourhood clubs and village or community meeting points.

Occupational therapy is mainly aimed at people who need rehabilitation. In such cases, it is entirely funded by the State. However, people with dementia are not usually considered eligible which means that they would have to pay for it themselves.

4.8.2.2.1.3 Assistive devices and home adaptations

The provision of assistive devices is mainly the responsibility of municipal health centres. Older people can borrow the assistive devices they need, such as walkers, from their health centres free of charge to help them in the home or in other situations where they need to be more mobile. The rehabilitation units of the hospital districts provide more expensive devices, such as electric wheelchairs and special beds.

Support is given to older people in the form of home improvements and the provision of service housing. Home improvements usually consist of modifications to toilets and bathrooms, the removal of door frames, the widening of doorways and the installation of various kinds of support. Help with renovation work is provided in the context of legislation on services for people with disabilities and through government loans for basic renovations and repairs, and grants. Severely disabled people are reimbursed by the municipality for the cost of home conversions and for assistive devices and equipment installed in the home.

Home adaptation costs are covered if the alterations are essential to the client in order to be able to manage independently and if they are linked to overcoming the impediments of disability or sickness. Conversion work usually involves alterations to kitchens and bathrooms, widening doors, removing door frames and constructing ramps. Compensation is also provided for planning home conversions and for the removal of obstacles from the immediate surroundings of a client’s home.

4.8.2.2.2 Home help

Home help is available but it does not always take into consideration the special needs of people with dementia. The range of services provided is rather restricted at the moment and inflexible. In fact, many municipalities no longer provide assistance with housework (e.g. cleaning, dusting and tidying). When available, it is partly funded by the State and partly by service users. However, there are private companies which provide assistance with housework and there are tax refunds for the purchase of private assistance with housework. For this reason, people are increasingly making use of these services.

Help with the preparation of meals can be provided by home help workers. They can prepare meals for more than one day when they visit their clients. Meals can also be delivered to people's homes or provided at sheltered homes and day care centres. These services are partly funded by the State and partly by service users. It is also possible to purchase this kind of service privately.

Assistance with shopping is available and partly funded by the State. This service is fairly restricted but many shops and markets have an Internet ordering and delivery service.

Transport services are available for older people who have trouble getting around and who cannot use public transport. Transport is organised mainly by taxi, but special service transport lines with mini buses (which often include an assistant) and other forms of group transport are increasingly being used especially in big cities. Clients are charged the same fare as for public transport. As a general rule, transport services should be available, but people with dementia have difficulties obtaining this kind of service. For people in day care, transportation is arranged by group taxis and some day-care centres have their own transportation service. The State partly contributes towards the cost of this service.

It is possible to purchase assistance with laundry from private service providers. The State may contribute towards the cost of this service if provided as part of home care. Service users would also have to contribute towards the cost of the service.

4.8.2.3 Psychosocial support and training for people with dementia and carers

In some communities, local associations provide information about the various kinds of services available. They may be partly funded by the State.

4.8.2.3.1 Counselling for people with dementia and carers

Counselling services for people with dementia exist. According to a study into the availability and quality of services for people with dementia (Tervonen 2005), 40 % of municipalities described the availability of counselling services as good. Many Alzheimer and dementia associations develop counselling services in memory centre projects. A large number of municipalities have set up memory centres as part of primary health care centres or memory nurses work in health centres.

Such counselling services are completely funded by the State. A person with dementia and/or a carer could, for example, have a meeting with a memory nurse at a health centre free of charge. Alzheimer and dementia associations also run support groups and provide individual counselling for people with dementia and carers.

4.8.2.3.2 Holidays for people with dementia and carers

Holidays for people with dementia are available but this service is insufficient. There are in fact only a few possibilities which are offered by Finnish slot machine associations.

Carers who receive a caregivers allowance are entitled to two free days a month. This must be taken after a period of time when the care that they were providing was very demanding. During this statutory free time, the municipality is responsible for caring for the elderly person and for partly financing this care. The carer must also contribute towards the cost of the stand-in carer. Private service providers also offer substitute carers.

4.8.2.3.3 Training for carers

Training is available for carers but this is mainly the responsibility of Alzheimer and dementia associations and other associations. The State does not provide any funds for the training of carers.

4.8.2.4 Work/tax related support for people with dementia

There are no measures to specifically protect the rights of people diagnosed with dementia who are still in paid employment.

People with dementia are entitled to tax refunds/benefits on the basis of their personal incapacity. This is covered by the Income Tax Act and the Income Tax Decree which came into force on 6 May 1993. The decree contains details of tax deductions on the basis of invalidity e.g. handicap caused by disease. In the act, there is a definition for the reduction of tax solvency caused by high medical expenses.

It is also possible to have a tax deduction for employing somebody to do the housework e.g. cleaning, shopping or other basic activities of daily living. This is covered by the Income Tax Act 1535/30.12.1992.

In some areas, there have been pilot projects to give direct payments to people with dementia in order to enable them to pay for services themselves.

The Act and Decree on Services and Support for Disabled People (*Laki vammaisuuden perusteella järjestettävistä palveluista ja tukitoimista (380/1987)* and *Asetus vammaisuuden perusteella järjestettävistä palveluista ja tukitoimista (759/1987)*), which came into force on 1.1.1988, define certain kinds of services, such as transportation and home modifications. They also define a disabled person's right to counselling and adaptation training.

There are no reductions on TV licences, radio licenses and or public transport for people with dementia. However, everyone over 65 years old is entitled to reduced prices on public transport.

4.8.2.5 Work/tax related support for carers and carer allowances

4.8.2.5.1 Time off work and flexible working

Carers are not entitled to paid time off work to care for someone with dementia. They may, however, be able to justify an occasional absence (without pay) for unavoidable family reasons.

Under the Working Hours Act, an employer and employee can come to an agreement over flexible working hours within set limits, setting the start and end of the working day. With flexible working hours, the daily working hours can be shortened or lengthened by not more than 3 hours.

4.8.2.5.2 Benefits and allowances

The Family Carers Act (1.1.2006) aims to promote informal care by providing sufficient social and health care services, and continuity in care and by supporting informal carers in their work. This Act defines the allowance and services that are granted to family carers looking after an older person, for example.

Relatives (e.g. spouses, partners or children) looking after an older person are entitled to an allowance for this from the municipality. The municipality may also arrange various social and health care services to back up this care. A care agreement is drawn up by the municipality and the person providing care which includes a plan for the provision of care and services.

In 2006, the minimum caregivers' allowance was EUR 300 a month. There is no upper limit on this allowance which is taxable. In order to benefit from the caregivers allowance, carers must apply to the municipality. The allowance is not always granted as it depends on the financial resources of each municipality.

Carers are not entitled to tax benefits for the care they provide. However, carers who have made an agreement with the municipality are entitled to employment pension accrual, provided that they are not already on a pension. The person who leaves his/her job does not lose her pension because of being at home as a caregiver. The municipality also covers the caregiver's accident insurance.

4.8.3 Bibliography

Unless otherwise stated, information provided by Sirpa Granö of the Alzheimer's Society of Finland in June 2007.

Tervonen (2005), Dementiabarometri 2005. Alzheimer-keskusliiton julkaisusarja 1/2005

Useful websites:

- Website of Ministry of Social Affairs and Health: www.stm.fi
- Website of Alzheimer Society of Finland (in Finnish): www.alzheimer.fi
- Website of the Association of Caregiving Relatives and Friends (also contains some information in English): www.omaishoitajat.com

4.9 France⁹

4.9.1 Organisation and financing of social support to people with dementia and carers

4.9.1.1 The organisation of social support for people with dementia and carers

4.9.1.1.1 State level

Since the new government took office in May 2007, social protection has been split between two Ministries and a Secretary of State:

- The Ministry of Health, Youth and Sports
- The Ministry of Labour, Social Relations and Solidarity
- The Secretary of State for Solidarity

Three central State services ensure the coordination and planning of the social protection policy:

- the General Direction of Health (*Direction Générale de la Santé*), pilot of health policy
- the Direction of Hospitals and Healthcare Organisation (*Direction de l'Hospitalisation et de l'Organisation des Soins*), coordinator of the organisation and funding of hospitals and healthcare
- the General Direction of Social Action (*Direction Générale de l'Action Sociale*), coordinator of the social policy, including dependence and dementia care

Regional and local State services for Health and Social Affairs (*Directions Régionales et départementales des Affaires Sanitaires et Sociales*) implement national policies, and define and coordinate action at their levels. Regional Hospital Agencies (*Agences Régionales de l'Hospitalisation*) are in charge of the regional policy for healthcare institutions.

The new government is currently reviewing a new scheme to merge health and social care at a regional level.

4.9.1.1.2 Local level

Local governments at the departmental level (*Conseil Général*) enact legal departmental schemes for the elderly and act as trustees for long-term care institutions. They operate “departmental offices for impaired persons” (*Maisons départementales du handicap*), offering at local government level a single office for information, counselling and access to legal benefits for the impaired. It is foreseen that this will be extended to the elderly.

Communities (*Communes*) coordinate, organise and fund social action in their territory through the local Social Centres (*Centre Communal d'Action Sociale*).

⁹ The information in this report on social support for people with dementia and their carers in France was provided by the Fondation Médéric Alzheimer.

4.9.1.1.3 Government policy for people with dementia

Two national plans for people with dementia were implemented in 2001 and 2004, the aims of which were to:

- recognise dementia as a health priority
- adapt services to respond better to the needs of people with dementia and their carers
- facilitate early diagnosis and care
- improve home care
- adapt care homes to take specificities of dementia care into account
- develop professional education
- consider people with early onset dementia
- develop studies and clinical research

In 2004, Alzheimer's disease was recognised as an "affection de longue durée", as a consequence of which all healthcare expenditure is financed by the health insurance.

In 2007, dementia was declared a "great national cause". A large public awareness campaign has been funded by the State and the new government has announced a third Alzheimer plan (currently under construction) to be implemented in January 2008.

4.9.1.2 The overall funding of social support for people with dementia and carers

Funding is split between local governments (*Conseils généraux*), the national office of solidarity for autonomy (CNSA), the health insurance, the state, mutual and private insurances, pension institutions, communities and users. There is no specific funding for dementia care. Financial compensation for people with dementia is awarded under the general procedures concerning the dependent elderly.

4.9.1.2.1 Health care

Healthcare expenditure (medical or nursing visits and procedures, medicines, biological examinations, physical therapy, medical devices and transportation to hospital) are financed by the national health insurance (77% of expenditure), the state (1.4%), mutual insurance (7.4%), private insurance companies (3.2%), pension institutions (2.4%) and households (8.6%) (*DREES, comptes nationaux de la santé en 2006, sept 2007*).

4.9.1.2.2 Social care for the dependent elderly

Social care personnel costs, including housing, are mainly financed by the health insurance (40%), local governments (*conseils généraux*: 18%), the national office of solidarity for autonomy (CNSA: 10%) and users (33%). Personnel costs account

for 85% of long-term-care costs (*Centre d'analyse stratégique, 2007*). Other social support may be provided at the local level by communities.

Elderly dependent people are entitled to public monetary benefits, either at home or in an institution. People must be at least 60 years old. Their level of dependence is assessed using a national scale (*AGGIR - acronym for Autonomie, Gérontologie, Groupe Iso Ressource*)

- Group GIR 1 comprises elderly people confined to a bed or armchair, with severely altered mental functions, needing essential and continuous presence of caregivers.
- Group GIR 2 concerns elderly people confined to a bed or armchair, with intellectual functions not totally altered, in need of care for most activities of daily living. This group also comprises ageing people with altered mental functions but still able to move.
- Group GIR 3 comprises elderly people with preserved mental autonomy, partially able to move, but needing assistance every day and several times a day for body care.
- Group GIR 4 concerns elderly people unable by themselves to stand up, lie down or sit, but who are able to move around their place when standing, sometimes requiring help for toilet and to get dressed. This group also concerns people with no locomotion problems but requiring help for body activities and meals.
- Group GIR 5 concerns elderly people only needing specific assistance for toilet, meal preparation and cleaning.
- Group GIR 6 concerns elderly people who have not lost their autonomy for essential activities of daily living.

The public allowance for autonomy APA (*allocation personnalisée d'autonomie*), set up in January 2002, allows partial funding for human assistance, technical assistance and specific housing installations for dependent people. It is granted only to people over 60 years old, belonging to groups GIR 1 to GIR 4, after individual medical and social assessment. Autonomy allowance tariffs are fixed by the Ministry of Labour, Social relations and Solidarity for both home assistance and institutional care. Allowance allocation is managed by local governments (*Conseil Généraux*). The allowance is granted upon first application for 76% of people asking for home assistance and 90% of people seeking institutional care.

A total of 1,008,000 people were benefiting from a public autonomy allowance in December 2006, of whom 60% were living at home and 40% in institutions. For dependent people living at home, 3% were assessed in GIR 1, 19% in GIR 2, 22% in GIR 3 and 56% in GIR 4. For dependent persons living in institutions, 15% were assessed in GIR 1, 43% in GIR 2, 17% in GIR 3 and 25% in GIR 4.

Maximum monthly allowances allocated to people belonging to the first 4 groups were respectively €1,189 (GIR 1); €1,019 (GIR 2); €764 (GIR 3); €509 (GIR 4) (September 2007 figures). The average allowance granted by local governments in 2006 was 26% below the national maximum amount set by the Ministry.

The average monthly allowance for dependent people living at home was €490, rising with the level of dependence: €972 (GIR 1); €769 (GIR 2); €575 (GIR 3); €356 (GIR 4). Average monthly allowance for dependent people living in institutions was €406 (€484 for combined GIR 1 and 2; €299 for combined GIR 3 and 4).

Although there is no means testing for a dependent person to be entitled to the autonomy allowance (in accordance with equity principles), there is a co-payment based on the dependent person's income (because of shrinking government finances). An assistance plan is proposed to the dependent person, mentioning the level of co-payment. The costs of individual assistance plans use reference costs based on local government tariffs.

For dependent people living at home there is no co-payment when the dependent person's income is lower than €658 per month (which is the case for 28% of dependent people living at home). There is a progressive co-payment up to a monthly income of €2,622 then a 90% co-payment above this threshold.

For dependent elderly people living at home, local governments paid in 2006 approximately 84% of individual assistance programmes (average cost €410 per month), with 16% co-payment from the dependent people.

For elderly people living at home (dependent or not), an additional allowance of €255 per month restricted by means testing can be obtained for those with an annual income of less than €7,635 for a single person and €13,374 for a household. Local government coverage for home help (household chores) does not exceed 60% of costs, users' out-of-pocket expenses varying from council to council.

For dependent elderly people living in institutions, local governments covered only 68% of the dependence tariff (average €402 per month; €478 in GIR 1 or 2; €293 in GIR 3 or 4).

4.9.1.3 The legal framework surrounding the provision of social support

The French legal framework for long-term care is subdivided into three sets of legal measures:

- The organisation and financing of social care
- The organisation and financing of health care
- The legal protection of sick people

4.9.1.3.1 Major legal measures relative to social care

- Law of 20 July 2001, concerning financial support for the elderly with loss of autonomy, creating a new personalised autonomy allowance (*APA-allocation personnalisée pour l'autonomie*) (cf. 11.2).
- Law of 2 January 2002, reforming social care, which involved an in-depth modification of the legal framework of institutions and services, providing flexibility and consistency to the system and defining the specificities and boundaries of the social care sector versus the health care sector.
- Law of 30 June 2004, concerning solidarity for the autonomy of elderly and impaired persons, creating the national office of solidarity for autonomy (*CNSA, Caisse nationale de solidarité pour l'autonomie*), to ensure solvency and secure long-term financing and territorial equity for long-term care.
- Law of 11 February 2005, concerning equality of rights and chances, involvement and citizenship of impaired persons, recognising the dependence of the elderly as a form of impairment.
- Decree of 19 December 2005, creating the “departmental office for impaired persons” (*Maison départementale du handicap*), offering at the local government level a single office for information, counselling and access to legal benefits for the impaired and the elderly.
- Decree of 8 March 2007 creating the national agency for assessment and quality of social care institutions.

4.9.1.3.2 Major legal measures relative to health care

- Law of 9 June 1999, providing legal access to and the development of palliative care.
- Law of 4 March 2002, concerning patients' rights and the modernisation of the health care system, which introduces healthcare networks to coordinate professionals at health territory levels.
- Law of public health of 9 August 2004, defining national health objectives and indicators for major diseases, including dementia.
- Decree of 4 October 2004, recognising dementia as a chronic disease (*affection de longue durée*), which allows 100% coverage of medical costs by the national health insurance.

4.9.1.3.3 Major legal measures relative to sick persons

- Law of 4 March 2002, concerning patients' rights and the modernisation of the health care system, which recognises :
 - legal protection for healthcare system users (information, consent, medical files)
 - legal value of health care proxy (*personne de confiance*)
 - compensation related to medical responsibility

- Law of 22 April 2005, concerning patients' rights and end-of-life, which :
 - condemns “unreasonable obstinacy” in the pursuit of treatment or care
 - requires a collegial procedure in case of restriction or withdrawal of treatment
 - reinforces the role of the health care proxy through the collegial procedure
 - recognises the legal value of advance directives
- Law of 5 March 2007, reforming mechanisms for the legal protection of vulnerable adults, which :
 - creates a power of attorney for future protection (health and property issues)
 - reaffirms the principles of necessity, subsidiary and proportionality
 - reinforces a person's rights (protection of home, assets...)
 - simplifies and harmonises the three mechanisms for the legal protection of vulnerable adults (guardian, curator, trustee)
- Law of 18 January 2005 introducing a programme for social cohesion, promoting domiciliary labour.
- Law of 9 June 1999, providing legal access to and development of palliative care, allowing legal leave to support a family member in the last stage of a terminal illness. This measure has been replaced by another one (family solidarity leave) within the pension law of 22 August 2003.
- Law of 22 August 2003 reforming pensions, creating a family solidarity leave, allowing the carer to support a relative suffering from a life-threatening disease. This leave cannot exceed six months.
- Decree of 18 April 2007, concerning leave to support a member of the family with severe impairment or loss of autonomy, allowing the carer to take unpaid time off work for caring without losing his/her position. This leave cannot exceed 1 year over a lifetime employment period.

4.9.1.4 The suitability of social support for people with dementia and carers

4.9.1.4.1 Adequacy and accessibility in general

Services within the social domain (i.e. home help, information, coordination and respite care) have been developed since the 1960s with a strong general emphasis on gerontology (older people with no specific pathology/disability). Consequently, specific skills for the evaluation and a more targeted response to the needs of people with dementia are not yet systematically part of the training of professional carers. Although some specific training courses are now being developed, they are still not systematically included in the initial state training of professionals in the social domain.

Medical or more “pathology related” services (e.g. day hospitals and psychosocial support for carers) are mainly provided by or in relation with the memory centres, which have developed a specific competence in dementia in the last ten years.

However, they evolved mainly out of geriatric or neurological centres and have less emphasis on group port and psychological support to people with dementia etc. (i.e. no “psychiatric” or “mental health” culture). Developments in this area have therefore been slower.

The services provided by nursing homes for elderly dependent people (respite care, long term care and day care centres) are still very much orientated towards general gerontology, although psychologists and some of the other professionals involved are increasingly developing skills that are more targeted at people with dementia. There is no big framework or unified structuring of the basic skills needed which would include an emphasis on dementia specific topics but efforts are currently being made. Evidence of this can be seen in the emergence of special care units and in the awareness of the management within these units that there is a need for specific training in dementia for the staff working there. But there are still no unified in-training programmes. There are no specific services for people with dementia and their carers from ethnic minorities.

4.9.2 Services and support for people with dementia and their carers

4.9.2.1 Types of care

4.9.2.1.1 Day care

Day care centres exist. In the 2007 national survey of the Fondation M@déric Alzheimer (FMA), 740 day care centres offering a total of 5,297 places specifically for people with dementia were identified. Some of these places are offered within larger groups of older dependent people who are not cognitively impaired, whereas some are specifically for groups of people with dementia. Some local Alzheimer associations have set up day care centres of their own.

Day care is partly financed by the state and partly by service users. The amount of the state allowance for dependent people (the “APA”) depends on income. The maximum amount of APA is €1,200 per month for the level “most dependent GIR 1” if the person’s income is less than €670 a month. The state charges the full cost if the person has a higher income. The personal contribution goes from 10 to 90% if the income is €2,700 or above).

4.9.2.1.2 Respite care

Respite care in the person with dementia’s own home is not available. Residential respite care (during the day or at night) is theoretically available. In practice, the supplementary cost of residential respite care exceeds the monthly average amount of APA. Night care services (where a person stays only for a limited time) are developing slowly. To-date, there are only about 50 out of the 5,000 home care services available via the APA. Some are developing services specifically targeted at people with dementia. The service is funded through the APA.

Short-term residential respite care (not more than 3 days) is available but is not considered sufficient for two main reasons. Firstly, the average amount of APA covers the general expenses for day care and home help services but not, in practice, other services. Secondly, the offer is still far behind the macro-demand. It is estimated that there are about 50 structures offering such services specifically for people with dementia, and some 100 to 200 others offering the services to elderly people in general. This type of offer comes out of home care services, day care centres or nursing homes (the latter offering mostly non dementia-specific respite care).

Long-term respite care (for 10 days or more to allow the carer to have a break) is available and is partly funded by the state and partly by service users (on the same basis as for day care).

4.9.2.1.3 Long-term residential care

Long-term residential care is available. Out-of-pocket expenses for long-term housing in an institution amount to about €1,500 per month. Part of this is financed by the dependent person's income (average net pension in 2004: €1,503 per month for men and €938 per month for women). Public social assistance for housing (*aide sociale à l'hébergement*, provided by the State or local governments) is offered to people who cannot afford to pay the full cost of long-term care housing. This assistance is not free and is recovered by the public authorities from the deceased person's estate. 24% of people in residential home care receive public social assistance for long-term care housing.

4.9.2.1.4 Palliative care

There are services offering palliative care at home which are partly funded by the state. Hospital and mobile palliative care teams, as well as a huge network of volunteer palliative care associations, have developed in the last ten years, but the approach is general and the professionals and volunteers rarely have the necessary dementia-specific skills. The National Health Authority is currently running a project to develop a framework for palliative care in dementia within the next few years.

Less than ten home care services are now offering a specific palliative care approach for people with dementia living at home. This might develop in the future due to competition amongst service providers and the need to develop specific market profiles for services provided in people's own homes.

Almost every local hospital now has a palliative care unit or a mobile team in its network. But even in these units and teams, dementia is not well known. Pain management and support to carers is quite good, but other aspects of support to the person with dementia (such as non verbal communication and measures to enhance quality of life) are less developed. Palliative care in centres/hospitals is partly funded by the state and partly by service users. Pain management is financed by the health insurance and the other forms of care are often delegated to volunteers.

4.9.2.1.5 Monitoring in the home via alarm systems

Tele-alarm systems are available and can be partly reimbursed through the APA, but in practice there is very little demand for this.

4.9.2.2 Personal assistance and home help

4.9.2.2.1 Personal assistance

Most home help services propose a combination of assistance with personal hygiene and home help. In practice, they also supervise the taking of medication although this should actually be done by nursing services. A survey carried out by Fondation Médéric Alzheimer in 2005 revealed that (all conditions combined), 76,000 people received assistance/supervision taking medication from community nursing services.

The home help services provide assistance with eating and drinking and with mobility i.e. lifting, moving and walking.

Assistance dealing with incontinence is available but this is mainly in the form of continence pads which are reimbursed by the APA. Education or training to help prevent or manage incontinence is not available. The community nursing services provide assistance dealing with pressure sores.

Companionship and social activities are provided by associations, as part of home help services and by some professionals even though most have no specific training in dementia.

Assistive devices are available on the same basis as the tele-alarm systems mentioned in the previous sub-section.

The above-mentioned personal assistance services are partly funded by the state through the APA and partly by services users. Please refer to the section on the funding of social support for more information.

Some local coordinations have a network which includes an ergotherapist and a preventive home visit as part of their preventative strategy. Most have no ergotherapist and home visits are only made to people who have recently had an operation and were hospitalised, in which case the ergotherapist of the hospital would make the visit. Unlike the above-mentioned services, ergotherapy is completely funded by the state.

Home adaptations/transformations, like ergotherapy, are not systematically available and they can be expensive. When available, they are partly funded by the state and partly by service users.

4.9.2.2.2 Home help

The following services are available and are partly financed by the state through the APA:

1. Assistance with housework e.g. cleaning, dusting and tidying
2. Help with the preparation of meals (including meals-on-wheels)
3. Assistance with shopping
4. Transportation service
5. Assistance with laundry

Preparation as well as help with eating is mainly provided by the home care services. Education or training by professionals on how to encourage eating in dementia is rare. Concerning shopping, home help services sometimes have social assistants who go shopping but this offer is not systematic. Transportation is a big problem as only 30% of days care centres have a transportation service. Assistance with laundry is mostly provided by home care services within the APA package.

4.9.2.3 Psychosocial support and training for people with dementia and carers

Five years ago, information and coordination centres for the elderly were set up but they were not specifically for people with dementia. Five years ago, information and coordination centres for the elderly were set up but they were not specifically for people with dementia. The authorities intend to stick to general centres as well as promoting the building up of general gerontological care networks for the elderly. Some have nevertheless developed networks just for dementia. According to a survey carried out by FMA in 2007, there are now 15 networks specifically for people with dementia out of 867. These information and coordination networks are completely funded by the state. Alzheimer associations also provide information about dementia, mainly to carers.

4.9.2.3.1 Counselling for people with dementia and carers

Counselling for people with dementia is very scarce. FMA's 2007 survey revealed that 242 organisations offered support groups for people with dementia. 11 of these were Alzheimer associations; most were day care centres or memory clinics. Individual psychological support for carers is offered by two thirds of memory clinics as well as at day care centres, by Alzheimer associations and by gerontological information services. Altogether, the FMA survey recorded 736 organisations offering individual psychological support and 550 organisations offering support groups for carers. Counselling for carers and people with dementia is partly funded by the state and partly by service users.

4.9.2.3.2 Holidays for people with dementia and carers

According to the FMA 2007 survey, only 52 organisations offered holidays for people with dementia on their own, of which 11 were Alzheimer associations. A further 19

offered weekend breaks. 47 offered holidays for people with dementia and carers together, and 25 offered weekend breaks for both. In some cases, the state contributes towards the cost of such holidays but sometimes service users have to cover the full cost.

4.9.2.3.3 Training for carers

Training is provided by several organisations (e.g. memory centres, Alzheimer associations, information services and day care centres). Training courses tend to be heterogeneous and do not always reflect the latest developments which have been proven effective.

4.9.2.4 Work/tax related support for people with dementia

People with dementia are entitled to benefits on the basis of their incapacity and do not have to pay tax for the employment of a person to provide care at home. They may be entitled to benefits or grants for home adaptations and to certain reductions on radio and television licences and on public transport.

4.9.2.5 Work/tax related support for carers and carer allowances

4.9.2.5.1 Time off work and flexible working

4.9.2.5.1.1 Unpaid leave to care for a terminally ill person

The Law of 22 August 2003 reforming pensions introduced a family solidarity leave. Article L. 225-15 states that any employee who has a relative or person living in his/her home suffering from a terminal illness can benefit from family solidarity leave according to the conditions defined by decree. Leave can be taken for three months with the possibility of extending this for a further three months maximum. Employees should apply by registered mail with recorded delivery to their employer two weeks before the required start of leave requesting family solidarity leave. The request should be accompanied by a medical certificate in which it is stated that the terminally ill person does indeed have a terminal illness. In case of emergency, confirmed by a doctor, the leave can start as soon as the employer receives the letter.

Leave ends at the end of this period or if the terminally ill person dies before this time, three days after his/her death. The employee should try to inform the employer of his/her return to work three days in advance.

4.9.2.5.1.2 Unpaid leave to care for a person with severe impairment or loss of autonomy

The Decree of 18 April 2007, concerning leave to support a member of the family with severe impairment or loss of autonomy allows an employee to take unpaid time off work to care without losing his/her job. This leave is for 3 months and can be renewed. It cannot, however, exceed 1 year of the employee's lifetime period of employment.

The application must be made two months in advance of the required starting date of leave. This can be shorted to 2 weeks in case of emergency or 1 month for each successive renewal. The application must contain proof of the relationship to the person in need of assistance as well as evidence of the seriousness of the handicap or loss of autonomy.

People taking unpaid leave of this kind can also apply for subsidised pension contributions.

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4.10 Germany ¹⁰

4.10.1 Organisation and financing of social support to people with dementia and carers

4.10.1.1 Background information on the social/healthcare system in Germany

Long-Term-Care Insurance (“Pflegeversicherung”), hereafter referred to as LTCI, is a relatively new branch of the German social insurance system. It came into effect on 1.1.1995 for home care and on 1.7.1996 for long-term institutional care. There was an important amendment in 2001 (PfLEG). All members of the statutory Health Care Insurance (HCI) are automatically covered by the LTCI. It is designed for all who need care because of disabilities or chronic diseases, independent of age. About 2 million people are entitled to it. 85% of them are over 60 and most of them need care because of dementia.

The German system is characterised by a division between health care insurance (which covers medical cure, diagnosis, treatment, medical care such as injections and the care of people who are bed-ridden) and long-term care insurance (which covers long-term home and residential care). The two systems sometimes enter into conflict with each trying to reduce its costs.

4.10.1.2 The organisation of social support for people with dementia and carers

The Bundesministerium für Familie, Senioren, Frauen und Jugend (Federal Ministry for Family Affairs, Senior Citizens, Women and Youth) and the Bundesministerium für Gesundheit (Federal Ministry for Health) are responsible for the legal framework of social support to people with dementia. Actual social support services are commercial or organised by traditional non-profit organisations (Wohlfahrtsverbände) like “the Red Cross”, Diakonie, Caritas and others, which operate on a nation-wide basis. Some services are communal. Some of the projects of the Deutsche Alzheimer Gesellschaft (e.g. telephone help-line; production of information materials) are funded by the Federal Ministry of Senior Citizens etc. Other projects are funded by the Health Care Insurance. This is also the case for regional Alzheimer Associations.

Access to benefits under the LTCI is not determined by a specific diagnosis but by the level of care needed and benefits are given to the person who needs them, not the carer. The person in need of care can choose between private care and professional care, including care at home, day care at a centre and nursing home care. He/she can also decide whether to receive cash benefits which can be used to pay for services, even from relatives, or benefits in kind (i.e. non cash benefits) from professional service providers (known as “Sachleistung”). A combination of the two is also possible.

To be eligible, the person in need of care must be evaluated by the medical service of the statutory HCI (MDK) at home. The person’s current capacities are assessed by means of medical examinations, ADL codes and guidelines for the assessment

¹⁰ The information in this report on social support for people with dementia and their carers in Germany was provided by Hans-Jürgen Freter from the Deutsche Alzheimer Gesellschaft.

process. Moreover, there must be a substantial need for care for at least 6 months in the following areas: personal hygiene, eating and preparing food, mobility (e.g. getting in and out of bed) and housekeeping.

There are three levels/categories of care (known as Pflegestufen):

- Level I (erheblich pflegebedürftig): considerable care needs - 90 minutes, including at least 45 minutes of basic care.
- Level II (schwerpflegebedürftig): severe care needs – 3 hours, including at least 2 hours of basic care.
- Level III (schwerstpflegebedürftig): extreme care needs – 5 hours, also at night, including at least 4 hours of basic care.
- In addition, there is fourth level, known as “special hardship” for which 7 hours of care are needed.

4.10.1.3 The overall funding of social support for people with dementia and carers

HCI and LTCI are obligatory for everybody, except those who are self-employed. Everybody has to pay a certain amount of their income (up to a limit). For the LTCI, employees pay 1.7% of their gross income and there is an income limit of €3,200. This amount is taken directly from their wages by the employer and transferred to the LTCI fund. Social welfare is financed by taxes and is means tested. Costs for long-term care (except medical care) are only partly covered by the LTCI (according to SGB XI). It is allowance based and not intended to fully cover costs. “Hotel costs” in nursing homes (costs for apartment and meals) are not covered. In addition, home care (provided by families) is where possible given priority over institutional care. Cash and in-kind benefits for care at home and in a nursing home are as follows:

Table 1: cash payments and in-kind benefits under the LTCI

	Cash payments for home care	Professional services at home	Nursing home care
Level I	€205	€384	€1,023
Level II	€410	€921	€1,279
Level III	€665	€1,432	€1,432
Special hardship		€1,918	€1,688

4.10.1.4 The legal framework surrounding the provision of social support

The most important acts and laws surrounding the provision of social support in Germany can be found in the volumes of the Sozialgesetzbuch (the “Social Code”), hereafter referred to as SGB:

- Sozialgesetzbuch (SGB) Fünftes Buch (V). Gesetzliche Krankenversicherung (SGB V) from 20.12.1988, last amendment 22.12.2006 (Statutory Health Care Insurance) (HCI)
- Sozialgesetzbuch (SGB) Neuntes Buch (IX). Rehabilitation und Teilhabe behinderter Menschen (SGB IX) from 19.6.2001, last amendment 2.12.2006. (Law on rehabilitation and participation of people with personal incapacity)
- Sozialgesetzbuch (SGB) Elftes Buch (XI): Soziale Pflegeversicherung (SGB XI) from 26.5.1994, last amendment 5.12.2006 (Long-term Care Insurance) (LTCI)
- Sozialgesetzbuch (SGB) Zwölftes Buch (XII): Sozialhilfe (SGB XII) from 27.12.2003 (Social assistance, welfare)

Important general reforms are underway, namely:

- the Health Care Insurance (reform underway since April 2007). It includes better rights for “geriatric rehabilitation”. The consequences for people with dementia are as yet unclear.
- the Long-Term Care Insurance (probably for 2008)

4.10.1.5 The suitability of social support for people with dementia and carers

4.10.1.5.1 Adequacy and accessibility in general

The LTCI is primarily orientated towards somatic health problems. The system is not geared towards the needs of people with geronto-psychiatric diseases. It does not meet the special needs of people with Alzheimer’s disease i.e. supervision, motivation, activation, instruction/support. Many services and many nursing-homes do not respond to the needs of people with dementia even though a high percentage of their clients are people with dementia. Furthermore, there is a lack of information about existing services and how to get money or services from the LTCI.

4.10.1.5.2 People living in rural areas

There are deficits in rural areas.

4.10.1.5.3 People from ethnic minorities

There are only a few provisions for people with dementia and carers from ethnic minorities. Most are for Turkish people. In Berlin, for example, the “AWO Landesverband” offers information days in Turkish and publishes the 10 warning signals for Alzheimer’s disease in Turkish. There are also special outpatient services in the Berlin region specifically for Turkish people but they are not greatly used as they are not known about. The organisation also tries to reach Muslims through the mosques. Other organisations providing assistance to immigrants have developed

guidelines on how to care for elderly immigrants in a way that respects their cultural background. Further details can be found in *Alzheimer Info, Ausgabe 2/06* published by the Deutsche Alzheimer Gesellschaft e.V.

4.10.1.5.4 Younger people with dementia and people with different types of dementia

For people with early-onset dementia it is difficult to find suitable services because most services are designed for people over 65 years of age. It is the same for people with fronto-temporal dementia.

4.10.2 Services and support for people with dementia and their carers

4.10.2.1 Types of care

4.10.2.1.1 Day care

Day care centres exist but there are not enough and only some of them are suitable for people with dementia. Moreover, there are big regional differences and day care is expensive (€50 to €100 per day). The cost of day care is covered by the LTCI (§ 41 SGB XI) but only at the level of “Pflegegeld” for which there are three levels: I: €205, II: €410 and III: €665. Some of the costs may also be covered by Social Assistance.

“Night care” is mentioned together with day care in § 41 SGB XI: the patient lives at home and spends some hours at night in a special centre. However, this service does not exist in Germany.

4.10.2.1.2 Respite care

Sitting services have to be paid out of pocket or using “Pflegegeld” from the LTCI. Those who choose money from the LTCI (“Pflegegeld”) can use it to pay for respite care in the home. There are commercial services (“Pflegen Daheim”) which provide care for 24 hours a day in the home, but they are expensive (about €100/day). There are also voluntary services which visit people at home for a few hours once or twice a week.

Short-term residential respite care for people with dementia exists but there are not enough places and those that are available are often inadequate. It is partly funded by the State through the LTCI (§ 42 SGB XI on short-term care) and partly by service users. People are entitled to up to 4 weeks per year (this is called “Kurzzeitpflege”) for which costs of up to €1,432 per year are refunded. Short-term residential care costs about €100 per day.

There are about 8,000 long-term care institutions in Germany. Very few offer specialised care for people with dementia although some have special units for people with dementia and some offer special care throughout the day. The conscientiousness and qualifications of the personnel have improved over the last years.

Nevertheless, most long-term care units do not provide the necessary care. This is often due to staff shortages. Long-term residential care is funded by a combination of the LTCL, the service user and if necessary, social assistance. The LTCL pays, according to the different care-levels (“Pflegestufen”), I: €1,023, II: €1,279 or III: €1,432. This only covers a part of the costs which are between €1,800 and €3,200 per month. There are big regional differences.

4.10.2.1.3 Palliative care

There are only a few services in Germany offering palliative care in the home. Traditionally, they are specially designed for patients suffering from cancer. The Deutsche Alzheimer Gesellschaft and Hospiz Gesellschaft have together developed a curriculum for hospice volunteers. Palliative care in the home is partly funded by the State and partly by service users (according to § 39a of the HCl - SGB V). The reform of the HCl proclaims a right for patients to palliative care but this has not yet been put into practice.

Palliative care in palliative care centres or units is not normally available (unless the person with dementia also suffers from a somatic disease). One reason for this is that with dementia (unlike with cancer), it is difficult to define what actually constitutes the end of life. Consequently, the HCl does not pay at all.

4.10.2.1.4 Monitoring in the home via alarm systems

There are different organisations which provide monitoring/tele-alarm systems in the home but some people with dementia are not able to understand and use such services. The State does not provide funding for this kind of service as tele-alarm systems are not included in the official catalogue of assistive devices (the “Hilfsmittelkatalog”). Service users have to pay for it themselves and it usually costs about €20 per month.

4.10.2.1.5 General supervision and additional care

In 2002, the SGB XI was amended (Pflegeleistungs-Ergänzungsgesetz, § 45 a,b,c SGB XI) thereby making it possible for people with dementia to obtain additional benefits subject to the fulfillment of certain conditions. According to §45a, people with dementia, a cognitive handicap and mental diseases who have care requirements of level I, II or III, who are living at home (not in a nursing home) and who find themselves restricted in their daily lives (due to cognitive problems and inability to plan and structure the day, resulting in dangerous situations) are entitled to general supervision and additional care services.

According to §45b SGB XI, an additional amount of €460 per year can be used for:

- Day and night care
- Short-term care
- Outpatient care (but not for basic care and housekeeping)
- Easily accessible forms of support (“niedrig-schwellige Betreuungsangebote”) like groups for patients (“Betreuungsgruppen”) and visiting services by trained volunteers.

4.10.2.2 Personal assistance and home help

4.10.2.2.1 Personal assistance

4.10.2.2.1.1 Assistance with personal hygiene

Outpatient services which provide assistance with personal hygiene (e.g. bathing, washing hair, cutting nails, shaving etc) are available throughout the whole of Germany. Unfortunately, the people providing these services are often not qualified to work with people with dementia and very often, people with dementia are not given the time they need. Assistance with personal hygiene is partly funded by the State through the LTCI and partly by service users. The LTCI only covers part of what people with dementia really need. It does not pay for the actual time needed.

4.10.2.2.1.2 Supervision/assistance taking medication, eating and drinking and with mobility

Supervision/assistance taking medication is completely funded by the HCI and this is considered sufficient.

Assistance eating and drinking is partly funded through the LTCI but people with dementia are often not given the time they need.

Assistance with mobility (e.g. lifting, moving and walking) is available under the LTCI but only in the context of care. This means that walking for recreational or social purposes, for example, would not be covered by the LTCI.

4.10.2.2.1.3 Assistance dealing with incontinence and skin care

Services exist to provide assistance dealing with incontinence but there is often not enough knowledge about incontinence and promoting continence. The HCI pays for continence pads. The changing of incontinence pads etc. is part of the services financed by the LTCI. Assistance with skin care is available and partly funded through the LTCI.

4.10.2.2.1.4 Companionship/social activities and occupational therapy

Companionship/social activities are funded up to maximum of €460 through the LTCI (§ 45). There are groups of volunteers who are trained to help people with dementia, groups for people with dementia run by volunteers (known as Betreuungsgruppen) and visiting services, but these are not available throughout the whole country.

Occupational therapy/ergotherapy is funded through the HCI. Unfortunately, therapists often lack the necessary knowledge of how to deal with people with dementia. To be eligible for this service, it is necessary to have a doctor’s prescription (as is the case for physiotherapy).

4.10.2.2.1.5 Assistive devices and home transformation/adaptation

Assistive devices are available but this service is often insufficient. Devices are partly funded by the State and partly by those who need them. The HCI pays for continence pads, wheelchairs and other items listed in the “Hilfsmittelkatalog” (the catalogue of assistive devices). A doctor’s prescription is necessary.

Under the LTCI (§ 40 SGB XI), home transformations/adaptations can be refunded up to a limit of €2,557 per year. Service users must pay the rest themselves. This service is probably insufficient as many people do not know about it.

4.10.2.2.2 Home help

4.10.2.2.2.1 Assistance with housework

Assistance with housework is covered by the LTCI provided that the potential service user has been classed as being in need of care according to the criteria of the LTCI i.e. that he/she needs assistance with eating and drinking, personal hygiene and mobility. The LTCI only covers part of the cost.

4.10.2.2.2.2 Assistance with the preparation of meals (including meals-on-wheels)

Assistance with the preparation of meals and with eating is available on an outpatient basis but there is often not enough time. This is funded by the LTCI.

Some private firms and organisations like the Red Cross also deliver food to the home but do not help service users to eat it. People with dementia often do not know what to do with it. This service has to be paid for privately.

4.10.2.2.2.3 Assistance with shopping and laundry

The LTCI partly funds assistance with shopping and laundry services (both of which are classed as part of housework known as “hauswirtschaftliche Verrichtungen”) but as with assistance with housework only if the potential service user is in need of care according to the terms of the LTCI. Commercial laundry services can be found all over Germany.

4.10.2.2.2.4 Transportation service

Transportation to hospital or to the doctor’s for those who are ill is funded by the HCI (according to SGB V - Krankentransport). Special transportation services exist for those who are recognised as handicapped (according to SGB IX - Schwerbehinderung). These services are financed by the local communities (SGB IX). The Deutsche Alzheimer Gesellschaft considers this service insufficient, especially in rural areas.

4.10.2.3 Psychosocial support and training for people with dementia and carers

There are different information services which are funded by the State or NGOs. For example, there are 103 Alzheimer Associations and many counselling services for families, carers or older people which also do counselling in cases of dementia. However, there are not enough and those providing this kind of service are often not qualified to deal with people with dementia.

4.10.2.3.1 Counselling for people with dementia and carers

Counselling for people with dementia exists but is insufficient. It is partly funded by the LTCl. There are support groups (“Betreuungsgruppen”) but individual counselling and group therapy for people with dementia are not normally available.

Alzheimer organisations, other organisations and small local self-help groups offer counselling and support groups for carers. Groups are sometimes funded by the HCl (funding of “self help groups”) or the communities.

4.10.2.3.2 Holidays for people with dementia and carers

There are some possibilities for holidays for people with dementia and their carers, some with volunteers but this is not sufficient. Most are organised by Alzheimer associations and are partly funded by the LTCl (“Verhinderungspflege”).

Under the LTCl (§ 39 SGB XI - “Verhinderungspflege”), people with dementia are entitled to €1,432 per year to pay for a substitute carer, if the normal carer is not available because of illness, vacation etc. With this money another informal or professional carer (but not a close relative) can be paid. According to the Deutsche Alzheimer Gesellschaft, this amount of money only covers costs for about 2 weeks.

4.10.2.3.3 Training for carers

The HCl provides training for carers (“Pflegekurse”) which mostly concentrates on somatic care. Two years ago, the Deutsche Alzheimer Gesellschaft (in cooperation with Janssen-Cilag) set up a special programme for carers of people with dementia (“Hilfe beim Helfen” CD-ROM). It benefits from collaboration with one Health Care Organisation (Barmer Ersatzkasse) which funds the costs. Carers can benefit from up to €460 worth of training per year under the LTCl (§45 SGB XI). Most of these courses are organised by local Alzheimer Organisations. They get the money (up to €460 per participant) directly from the Health Care Organisation.

4.10.2.4 Work/tax related support for people with dementia

People with dementia are not entitled to any particular protection if in paid employment solely on the basis of a diagnosis of dementia. However, if it becomes clear that they have some form of personal incapacity (“Schwerbehinderung”), then they are covered by the law SGB IX which gives them better job security and more days’ paid leave.

The law SGB IX and the Law on Income (“Einkommenssteuergesetz”) entitle people with dementia to tax benefits on the grounds of their personal incapacity. The Law on Income also entitles them to tax refunds/incentives for employing a person to provide home care services. This falls into the category of special hardship (“besondere Belastungen”).

As mentioned in previous sections, people with dementia may be entitled to cash payments under the LTCI (SGB XI) which they can use to pay for services. This is based on their incapacity and the resulting needs rather than on their diagnosis of dementia. They may also be eligible for financial assistance to pay for home transformations under the LTCI.

People with dementia are legally entitled (SGB IX) to reductions on television and radio licences as well as reductions on public transport but only on the basis of their incapacity (not because they have dementia). From a degree of incapacity of 50 upwards and a walking incapacity local public transportation is free.

4.10.2.5 Work/tax related support for carers and carer allowances

Carers are not legally entitled to paid or unpaid time off work to care for someone with dementia or to flexible working hours (although they may be able to make a private arrangement with their employers).

According to § 44 of the Law SGB XI, people who provide at least 14 hours’ care per week and who work no more than 30 hours per week are entitled to subsidised pension fund contributions from the State. For example, if a carer reduces his/her working hours from 40 to 20 per week, the LTCI pays for 20 hours into the pension fund.

Although carers are not entitled to payment for the care they provide, they are entitled to a deduction of €946 on their income provided that the person with dementia does not receive money from the LTCI. This is covered by the Law on Income (“Einkommenssteuergesetz”).

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4.11 Greece¹¹

4.11.1 Organisation and financing of social support to people with dementia and carers

4.11.1.1 Background information on the social/healthcare system in Greece

The Greek health care system is a mixture of the Bismarck model and the Beveridge model in that it functions mainly on the basis of social insurance contributions and State funding. A national health service was introduced in 1983. This was later divided into 17 administrations of health regions, each with a director and an administrative board. A national social care system was established in 1988 (Sissouras et al., 2002, Liarigovinou, 2005).

4.11.1.2 The organisation of social support for people with dementia and carers

The Ministry of Health and Social Solidarity is responsible for social support to people with dementia/dependent elderly people. It achieves this through the provision of psychological support for people with dementia and their carers, by providing financial support, including medication and a benefit for people with severe dementia and through cognitive rehabilitation programmes for people with dementia. Needs must be first assessed by a medical committee. Support may be provided in kind or by means of payments or tax exemptions (European Commission, 2006).

Some local authorities provide home care services but such services are not provided uniformly throughout the country. This is further complicated by a lack of available information on entitlement and availability of services. The majority of older people continue to live at home either with their families or alone. Families play a key role in providing care, especially in rural areas. (Alzheimer Europe, 2006).

However, in the last two decades the State has taken measures to increase community care services for older people so that they can remain in their own homes for as long as possible thereby enabling them to maintain their independence and enhance their quality of life. These measures include the creation of open care community centres for older people (KAPIs) and the help at home programme (Alzheimer Europe, 2006).

The State supports Alzheimer associations by providing financial support. However, such support is limited.

4.11.1.3 The overall funding of social support for people with dementia and carers

The Ministry of Health and Social Solidarity is responsible for the financing of the National Health Service. It is also responsible for health and social services for the disabled and for elderly people (Goffin et al. 2007). Social support for people with dementia is funded through the obligatory health insurance. The insurance contribution is

¹¹ The information in this report on social support for people with dementia and their carers in Greece was provided by Mrs Fotini Kounti from the Greek Association of Alzheimer's Disease and Related Disorders.

2.55% of the salary of employees with an additional 5.1% contribution from the employer. For pensioners, 4% of their pension is deducted for the insurance contribution (European Commission, 2005).

The Greek Orthodox Church provides a range of services for the elderly, particularly those on a low income and who live alone. These services are all completely free of charge (Sissouras et al., 2002).

4.11.1.4 The legal framework surrounding the provision of social support

It is stated in the Constitution and in Civil Law that the family is responsible for the care of dependent relatives of all ages but also that the State will care for the health of citizens and will adopt special measures for the protection of young people, the elderly and invalids, as well as providing assistance to the needy. Consequently, if a family is unable to care for a dependent relative, the dependent person is taken care of by the Social Security system.

Law N.1397/1983 covers the provision of full health coverage to all citizens and is therefore linked to the creation of the National Health Service. Law N. 2889/2001 led to the division of the NHS into 17 regional health authorities. Law N.3329/2005 transformed them into 17 Administrations of Health Regions (Liarigovinou, 2005).

The transfer of responsibility for the management and operation of KAPIs to local authorities occurred as a result of article 68 of Law N.1416/84.

The relevant law concerning the help at home for the elderly programme is Law N.2082/92.

The setting up/administration of institutes and legal entities which provide social care services on behalf of the Greek Orthodox Church is regulated by Law 590/1977 (Sissouras et al., 2002).

4.11.1.5 The suitability of social support for people with dementia and carers

4.11.1.5.1 Adequacy and accessibility in general

Social support and services are mainly adequate and accessible. However, they are not linked to rural areas and there are limited services for people with severe dementia. They respond to the psychological and cognitive needs of people with dementia, through rehabilitation programmes (although not in all parts of the country), but not to their financial and practical needs. Host houses and hospitals are needed as well as services providing cognitive and rehabilitation programmes throughout the whole country.

4.11.1.5.2 People from ethnic minorities

Services are accessible to people with dementia and carers from ethnic minorities.

4.11.1.5.3 Adequacy and accessibility in general

There are no services that are specifically designed for younger people with dementia.

4.11.2 Services and support for people with dementia and their carers

4.11.2.1 Types of care

4.11.2.1.1 Day care

In general, day care services are available for people in the early stages of dementia but not for people with severe dementia. They are partly funded by the State or NGOs. Amongst the different kinds of day care services available, there are KAPI centres, Help at Home services, Day Protection Centres for the Elderly and centres run by Alzheimer associations, NGOs and the Church.

4.11.2.1.1.1 KAPI

“Centres for the open protection of the elderly” (known as KAPI) aim to provide the necessary support to enable elderly people (in relatively good health) to live independently in their own homes for as long as possible. Most offer the following services:

- Preventive medical services
- Physiotherapy programmes
- Ergotherapy programmes
- Health education
- Recreational activities (Daniilidou et al. 2005)

4.11.2.1.1.2 Help at Home

Many KAPI centres collaborate with the Help at Home project which offers a range of services to elderly people who are unable to manage on their own, i.e. social services (counselling and information) health care services and family assistance (with housework, personal care and eating as well as befriending) (Daniilidou et al. 2005).

4.11.2.1.1.3 Day Protection Centres for the Elderly

There are also Day Protection Centres for the Elderly which operate during normal working hours and are usually linked to KAPI centres and work in cooperation with bodies responsible for the provision of social services and Health Units. These small units are specifically for elderly people with social problems who have chronic or temporary physical or mental health problems, who are unable to care for themselves and who have limited financial resources (Sissouras et al., 2002).

4.11.2.1.1.4 Day care centres run by Alzheimer associations

The Greek Alzheimer and Associated Disorders Association has eight day centres (three in Athens, three in Thessaloniki, one in Volos and one in Chania on the island of Crete). The services offered at these day care centres include discussion groups, seminars for caregivers and professionals, memory training for patients presenting with early-stage disease, music therapy (for patients at all stages), speech therapy, physiotherapy, cognitive rehabilitation, psychotherapy and mental exercises.

4.11.2.1.2 Respite care

Care Home Units offer respite care and are partly funded by the State but are not available throughout the whole of Greece. In many areas, neighbours, friends and volunteers also offer sitting services (Mestheneos et al., 2004). Respite care during the day and at night is limited. Some NGOs and the Church also provide respite care in the home. Short-term residential respite care also exists and is partly funded by the State. Again, it is not available throughout the whole country.

4.11.2.1.3 Long-term residential care

Long-term residential care for the elderly is provided in old people's homes and nursing homes for the chronically ill and is mainly funded by the State. Places are usually given to people on a low income who have to contribute towards the cost unless they have no financial means, in which case, it is free of charge. Most of the nursing homes are in the big cities. In addition, there are homes called “houses of serenity” which are run by the Church and there are homes run by private organisations (Sissouras et al., 2002). However, according to Lamura (2003), less than 1% of people over 65 years of age lives in residential homes.

4.11.2.1.4 Palliative care

There are no services providing palliative care at home or in palliative care centres for people with dementia.

4.11.2.1.5 Monitoring in the home via alarm systems

In Greece, there is a private 24-hour tele-alarm system linked to family, neighbours, the police or the ambulance service (Mestheneos et al., 2004).

4.11.2.2 Personal assistance and home help

According to the Greek Association of Alzheimer's Disease and Related Disorders, there are limited services funded by the State providing personal assistance and home help for people with dementia in Greece.

Transport is only provided for people attending day care centres and this is partly funded by the State. Some NGOs also run transport services.

However, as mentioned earlier, certain services, such as shopping, laundry and cleaning, are provided to dependent elderly people on a low income through the Help at Home programme. Community care services, when available, are free at the point of use (Mestheneos et al., 2004).

4.11.2.3 Psychosocial support and training for people with dementia and carers

Some NGOs and volunteers organise counselling services for people with dementia which are partly funded by the State. People with dementia do not pay anything.

Counselling for carers is provided in day centres funded by the State and the European Community. Carers do not have to pay anything. NGOs also provide this service but it is not available everywhere in Greece.

There are no provisions for holidays for carers and/or people with dementia but training is available for carers in some parts of the country and this is partly funded by the State. NGOs, such as the Greek Red Cross and the Greek Alzheimer and Associated Disorders Association, also provide training for carers, as well as cognitive rehabilitation and psychotherapy for people with dementia.

4.11.2.4 Work/tax related support for people with dementia

People with dementia are not entitled to any tax benefits on the grounds of personal incapacity or for employing someone to provide home care. They are not entitled to grants for home adaptations or reduced costs for television and radio licences or public transport. Public insurance does not offer benefits to people who need assistance from a third party.

Insurance organisations offer a benefit to people who need assistance from a third person. This amounts to 50% of the basic pension. Certain conditions must be fulfilled in order to be eligible (MISSOC, 2006).

4.11.2.5 Work/tax related support for carers and carer allowances

Carers are not entitled to any direct benefits or allowances for the services and care they provide. However, they may be able to claim income tax relief for supporting a dependent elderly relative (Mestheneos et al., 2004).

Carers are not entitled to paid time off work or flexible working hours. However, labour legislation allows for carers employed in the public sector to take up to 6 days' unpaid leave to fulfill their caring obligations (Mestheneos et al., 2004).

Spouses of people with a severe invalidity (more than 65%) can claim an old-age pension with favourable conditions but they must have been married for at least 10 years (European Commission, 2006). Apart from this, there are no special provisions for carers with regard to their pension fund contributions.

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4.12 Hungary¹²

4.12.1 Organisation and financing of social support to people with dementia and carers

4.12.1.1 The organisation of social support for people with dementia and carers

Alzheimer Europe was unable to obtain information on the social support provided to people with dementia and their carers in Hungary.

The Hungarian Ministry of Social Welfare and Labour, the Ministry of Health, local governments in the country and the “Service of Charity of the Roman Catholic Church” are all responsible for social support to people with dementia/dependent elderly people. In Dementia Centres, social workers provide social and legal assistance to families caring for people with dementia. They are also responsible for diagnosing dementia. Unfortunately, there are only 84 such facilities in Hungary and waiting lists are long (from 2-4 months). General practitioners who first come into contact with people with memory problems tend to see this as a natural part of ageing, so many people with dementia do not get help from dementia centres in time.

The health care and social systems are both involved in the provision of long-term institutional care. The State also cooperates with the private sector in the sense that the State provides financial support to each person receiving care in a State/private institution. Co-operation between the State and NGOs is only formal. It is limited to certain public events and does not cover social services.

Home help is one of the basic mandatory social services provided by local authorities to care for people, usually older persons, who are unable to care for themselves. Long-term home care is available from local authorities but only for a very limited number of people with dementia. Of the 24-hour daily care necessary, a maximum 2-hour service is offered against payment. Generally speaking, the carers who provide this service are not trained for the task and are unwilling to stay with the person with dementia alone. Thus, in about 99% of cases, long-term home care is provided by family carers. There are no day care facilities, and respite homes and long-term care institutions are very limited in number.

If a person with dementia has no spouse, his/her children are obliged to care for him/her. Children of the person with dementia often have to give up their jobs in order to do so due to a lack of financial resources to pay for private care and as there is no adequate social support available (i.e. no day care and limited home care services). Chances of returning to the labour market afterwards are very slim. In the absence of social support from the State, carers have to bear the burden alone and many end up mentally and physically exhausted with financial difficulties. To make matters worse, there is still a great deal of stigma attached to dementia in Hungary.

¹² The information in this report on social support for people with dementia and their carers in Hungary was provided by Eva Himmer from the Hungarian Alzheimer Society.

4.12.1.2 The overall funding of social support for people with dementia and carers

Private institutions are virtually inaccessible due to high costs. State, supported home-care is limited to the provision of meals (in many towns and villages) at a low cost. People with dementia and their family carers are not entitled to home care benefits because dementia is not regarded as a “disability” under existing Hungarian law. Financial resources are very limited at local government level. Therefore, applications made by carers of people with dementia are mostly refused because they are not disabled. Owing to the high cost of Alzheimer medications the majority of people with dementia cannot afford to buy them. Only 50% of the cost is covered by the Social Security. The Hungarian Alzheimer Society is lobbying to change this to 90% (or 70% minimum) as the cost of Alzheimer drugs is very high compared to the average income of Hungarian citizens.

There is no regular State financial support of Alzheimer associations. However, once a year the Hungarian Alzheimer Society is entitled to apply for State grants, as are all other Hungarian NGOs. The available funding (should the application be successful) is very low, particularly when compared with other NGOs. Dementia is not currently regarded as a health care priority in Hungary.

4.12.1.3 The legal framework surrounding the provision of social support

As under current Hungarian law, people with dementia are not regarded as “disabled”, they are not entitled to any of the financial or social benefits which are granted to other disabled people. The Hungarian Alzheimer Society is lobbying together with the Hungarian MEPs to bring about positive changes in view of the new UN Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities. It hopes that this will result in dementia being put on the Disability Act’s list which determines entitlement to regular financial support and for families to finance external carers. Hopefully, this Act will make possible the creation of day care or even temporary institutional care. On 21 September, the Hungarian Alzheimer Society established a dialogue with the Hungarian Social and Labour Ministry to this end. People with autism were recently added to the list after a period of hard lobbying.

The main general legislation of relevance to the provision of social support amongst other things to people with dementia and carers is as follows:

- Law of 1997 on Health
- Act II on Social Welfare of 1993 which mentions separately the organisation of day-care and nursing homes for people with dementia (but day-care facilities for people with dementia are not actually available in Hungary).
- The 2007 Act on the Budget of the Republic of Hungary provides higher monthly normative State funding (approximately 30% more) for nursing homes (either State or private) for people with dementia than that for other homes for the elderly.

Although the law provides for the State funding of normative day-care fees, day-care facilities are not available because local authorities do not set up day-care centres on the basis of these low fees. The normative fees do not cover the full cost of weekly day care stipulated by law.

The drafting of a new Social Act is in progress, which will hopefully take into consideration the changed requirements and the role and responsibility of the State and local governments. A uniform caring system will hopefully be created in 2007.

4.12.1.4 The suitability of social support for people with dementia and carers

4.12.1.4.1 Adequacy and accessibility in general

According to the Hungarian Alzheimer Society, available services do not respond to the needs of either people with dementia or the family carers.

4.12.1.4.2 People from ethnic minorities

There are no special provisions for people with dementia and carers from ethnic minorities. They are entitled to the same support as that given to other citizens.

4.12.2 Services and support for people with dementia and their carers

4.12.2.1 Types of care

4.12.2.1.1 Day care

There are no day-care facilities for people with dementia in Hungary.

4.12.2.1.2 Respite care

Respite care in the home is not available from the State. A limited number of private service providers offer this service but at a high cost.

Short-term residential respite care is available but only privately and at a high cost. In exceptional circumstances, respite care can be provided subject to payment in the long-term care wards of hospitals.

4.12.2.1.3 Long-term residential care

State/local government owned nursing homes accept a very limited number of people with dementia for which there are waiting lists ranging from 3 to 7 years. By law, 80% of the person's pension is taken to pay for this service. In the majority of cases however, this amount is not sufficient to cover the monthly fee for institutional care. Consequently, families must pay extra monthly fees.

There are only a few privately owned nursing homes. Entrance costs (i.e. a down payment) render them inaccessible to most Hungarians. Entrance costs are between HUF 3 million (EUR 12,000) and HUF 5 million (EUR 20,000). Excluding the entrance costs, the monthly fee for care is HUF 150,000 (EUR 600) to 180,000 (EUR 720) net. The average pension in Hungary is HUF 65,000 (EUR 260).

The “Service of Charity of the Roman Catholic Church” also provides long-term care services in seven care units (for approximately 200 people).

4.12.2.1.4 Palliative care

Palliative care at home is not available. It is available in palliative care centres and partly funded by the State but it is only accessible to people with cancer.

4.12.2.1.5 Monitoring in the home via alarm systems

Special tele-alarm systems are not available in Hungary for people with dementia. Some local governments operate such systems for the elderly but they are not suitable for people with dementia.

4.12.2.2 Personal assistance and home help

4.12.2.2.1 Personal assistance

It is possible to obtain assistance with personal hygiene and assistance with eating and drinking from social workers who are employed by the local governments. But service users must pay the full cost of these services. Assistive devices are also available but the State does not contribute anything towards the cost. The following services are not available in Hungary:

- Supervision taking mediation
- Assistance with mobility
- Assistance dealing with incontinence
- Assistance dealing with skin care
- Companionship/social activities
- Home adaptation/transformation
- Occupational therapy/ergotherapy

4.12.2.2.2 Home help

Meals are one of the basic social services provided by local authorities, ensuring at least one hot meal a day for people in need of social assistance who are unable to provide this for themselves or whose carers are permanently or temporarily unable to do so. Local authorities must also provide meals for people who are unable to organise their own meals in any other way because of their age or state of health (Act III of 1993, Section 62). Due to financial limitations, many local authorities are unable to provide this service even though it is stipulated by law that they should do so.

Assistance with shopping, housework, transport and laundry is not available. Due to financial limitations and despite legal provisions, many local authorities are unable to provide this service.

4.12.2.3 Psychosocial support and training for people with dementia and carers

The Hungarian Alzheimer Society operates a help-line and provides free personal consultations on request to family carers throughout the year. Information is also available on its website, in publications, books and through awareness campaigns etc.

Counselling is not available for people with dementia but the Hungarian Alzheimer Society provides regular counselling to carers, free of charge, in Budapest and elsewhere if required. There are no provisions for holidays either for people with dementia or carers.

The Hungarian Alzheimer Society provides training for carers whenever funding is available.

4.12.2.4 Work/tax related support for people with dementia

There are no protective measures for people with dementia who are still in paid employment. In fact, a person who has been diagnosed with dementia is often dismissed from his/her job. People with dementia are not entitled to tax refunds or benefits on the basis of incapacity as in Hungary, dementia is not considered a disability. They are not entitled to tax refunds or incentives for employing a person to provide home care services, to directive payments to pay for such services, to financial assistance with home adaptations or to reduced prices/cost free television and radio licences or public transport. However, all Hungarian citizens over the age of 65 are entitled to free land transport within the country. A diagnosis of dementia does not in itself entitle a person to any benefits or reductions.

4.12.2.5 Work/tax related support for carers and carer allowances

Carers are not entitled to paid time off work or flexible working hours to enable them to care for someone with dementia. Those who take unpaid time off work to care for a relative may easily lose their jobs and would not be entitled to any benefits.

If carers are entitled to care benefits, the period of time spent caring is taken into account when calculating the pension. However, it is rare for people caring for someone with dementia to be entitled to care benefits.

4.12.3. Bibliography

Unless otherwise stated, information provided by Eva Himmer (the Hungarian Alzheimer Society) in September 2007.

4.13 Iceland¹³

4.13.1 Organisation and financing of social support to people with dementia and carers

4.13.1.1 The organisation of social support for people with dementia and carers

According to legislation on communal social services, each commune is responsible to enable those in need of support to continue living at their own homes for as long as possible, in case of social problems. Support for people with dementia and their carers is based on this principle: to help people live in their own homes for as long as it is reasonable to do so. Direct services to private homes are mainly of two kinds, i.e. homecare, supplied and financed by the state, and home services, supplied and partly financed by the commune, and partly financed by the recipients of the services. The main difference is that while homecare relies on medical needs, and includes assistance in the handling of medicine, home services mainly address social needs, such as running a home. Far too little money, however, is allocated to these services, which is evident, for example, from the low salaries and the subsequent continued lack of staff. Thus people often do not receive the services that they are entitled to by law. An effort is being made to provide daycare for those who in need in specialised daycare centres, with 12 to 20 residents in each centre. They have been highly praised. Reports show that carers generally appreciate the day care centres and find care homes and hospitals to be lacking in spirit and comparison. The day care centres are mostly funded by the state (Public Insurance) with day fees, but communes and carers also share the costs.

Recently, a certain change of attitude has occurred with regard to services for people with dementia. Day care centres have been growing in number at an increased rate recently, and plans have been made for many new care homes.

The Ministry/organisation responsible for social support to people with dementia/dependent elderly people is *Félagsmálaráðuneytið*.

In Iceland, a substantial portion of what in other countries counts as social services belongs to the Ministry of Health, e.g. the Public Insurance offices which handle all financial support and grants offered in social circumstances, due to ill health, as well as handling payments of the state's share in medicine and care. The new government has pledged to transfer all matters concerning financial support and insurances to the Ministry of Social Services. These changes are currently underway.

The state and communes are responsible for running nearly all social and medical services in Iceland. However, due to a rather strong tradition, independent associations run care homes and day care homes for the elderly, and now day care centres for people with dementia. Private enterprise also exists in the domain of health care and is increasing. The main rule concerning these private service providers is that once permission has been granted for a privately run care home or day care centre,

¹³ The information in this report on social support for people with dementia and their carers in Iceland was provided by Helgi Johann Hauksson from the Icelandic Alzheimer Association (FAAS).

the state will grant the association or private enterprise comparable funding to what it grants its own institutions in the same domain. Authorisations and/or contracts about the state's share also include clauses on reliability. The grant depends on the quality of the services provided and user fees not exceeding a certain amount.

4.13.1.2 The overall funding of social support for people with dementia and carers

Public social support is mostly funded through general taxation. There are exceptions to this rule in that all taxpayers, for example, are obliged to pay a fixed sum to the Management Fund of Elders, which is supposed to directly support the construction of services for the elderly.

FAAS is the only organisation in Iceland that focuses on dementia. Direct state support to FAAS has been negligible. FAAS receives no regular public funding and all attempts to apply for such have been refused. However, FAAS receives an annual grant from parliament, for which the association has to re-apply each year. The grant is insubstantial and totally inadequate compared to the extent of the problem of dementia or the association's activities.

4.13.1.3 The legal framework surrounding the provision of social support

No legislation has been made in Iceland concerning people with dementia in general or Alzheimer patients in particular, but social service legislation, public insurance legislation and legislation on matters concerning the elderly all touch upon services needed by and available to people with dementia. Such legislation relies on constitutional clauses on human rights, which again rely on the European convention on Human Rights, which has been signed by Iceland.

The four laws which most directly concern people with dementia are:

Lög um málefni aldraðra (125/1999 came into force on 11 January 2000) Law on Matters Concerning the Elderly.

Lög um almannatryggingar (117/1993 came into force on 1 January 1994) Law on Public Insurance. This legislation was republished in 2007 with various changes and clauses made and added since, as Law no. 100/2007, valid since 30 May 2007 – A recently elected government has declared that the law on public insurances will be thoroughly re-examined. The President of the State Public Insurance offices, Karl Steinar Guðnason, who is responsible for the application of this legislation, has described the current law as “rags so often stitched and patched, that they barely hold.”

Lög um félagslega aðstoð (118/1993 came into force on 1 January 1994) Law on Social Support. Republished in 2007 as Law no. 99/2007, on 11 May 2007, without a complete overhaul, valid since 30 May 2007.

Lög um félagsþjónustu sveitarfélaga (40/1991 came in force 17 April 1991) Law on communal social support.

4.13.1.3.1 Reforms underway

A new government was formed in spring 2007 consisting of a coalition between the Independence Party (conservatives) and the Alliance (social democrats). As elections approached, issues concerning the elderly and people with dementia were quite broadly covered and discussed, along with issues concerning the disabled. Many promises of reform were made in these domains. They are reflected in the government’s policy statement and its declarations about a total reform in the support systems for the elderly, sick and disabled. The work has formally begun, but it is as yet too soon to say where it will lead.

It is worth mentioning, however, that the new minister of social services has the support and trust of associations of patients, disabled people and the elderly, and has been known for a long time for her concern about these groups and their issues. She is familiar with issues linked to dementia.

4.13.1.4 The suitability of social support for people with dementia and carers

4.13.1.4.1 Adequacy and accessibility in general

Law and regulations do not differentiate services on the basis of particular diseases or ailments, but aim to provide services for each person according to his or her needs. The LSH Dementia Reception at Landakot, Reykjavík, plays a vital role in prioritising patients and allocating them places and services. The main criterion is an evaluation carried out by a team of doctors, psychiatrists, nurses and social workers. The outcome of a the RAI evaluation is decisive with regard to assigned care and nursing. However, the services offered are scarce, specialists and specially trained staff are lacking, as well as staff in general, which has led to long waiting lists and some services which should be provided not being available at all.

Politicians and administrations tend to emphasise the creation of general rather than specialised services. In Iceland, in recent years, nursing places for the elderly have increased in number, but do not respond to the specific needs of people with dementia. Home services and home care are provided, but staff are neither prepared nor taught about the specific needs of people with dementia or their carers. Furthermore, staff are not allocated solely for services to people with dementia. Providing people with dementia with special services, other than those that their general health situation demands, is still merely a matter of discussion.

General services are rather good, but specialised services, other than day training centres and nursing places, are virtually non-existent.

4.13.1.4.2 People living in rural areas

In the urban area in and around Reykjavík services for people with dementia have grown much faster than in rural areas. There are, for example, no specialised day training centres for people with dementia outside the Reykjavík area, nor any clinics specialised in analysing dementia (dementia receptions), and residential respite care is only offered in the capital city. Many smaller municipalities show great determination to assist people with dementia and their carers more thoroughly than they do today, and in many places people with dementia have access to the same facilities as other elderly people. That is, however, far from sufficient, and FAAS puts great emphasis on the importance of strengthening specialised services for people with dementia and their carers in the countryside. Day training centres are their top priority, as they have, in their experience, been central in increasing awareness and an understanding about dementia.

4.13.1.4.3 People with different types of dementia

No distinction is made with regard to services based on different types of dementia. Services are merely provided on the basis of each person's situation and needs at any given time.

4.13.1.4.4 People from ethnic minorities

There are no services specifically for people with dementia and their carers from ethnic minorities.

4.13.1.4.5 Younger people with dementia

Legislation covering services for the elderly, i.e. people aged 67 and over, which grants rights and access to various services, including nursing homes, does not include patients under the age of 67. The government has declared that this will be rectified.

FAAS, the day training centres and other parties have started support groups and given them financial support. These include a support group for younger people with dementia, run in association with a day training centre which provides younger patients with special care. Apart from this, younger people with dementia do not receive any particular support as such.

4.13.2 Services and support for people with dementia and their carers

4.13.2.1 Types of care

4.13.2.1.1 Day care

Day-care centres have had good results in Iceland and this has been widely noticed. Even if rural areas are still lagging behind and demand has not been satisfied in the Reykjavík area either, day care places have increased in number in recent years, and the state seems to have a clear policy of going further in that direction.

The state pays the major part or up to 90% of the costs of running day-care centres, but service users and carers have to pay the rest.

FAAS, the Icelandic Red Cross, the volunteer organisation Sjúkþjálfing and the Society of Senior Citizens joined forces in a common initiative to open Iceland's first day-care centre in 1986. Currently FAAS runs two more day-care centres, and work is underway to establish even more. Other day-care centres are owned and run by municipalities. The state provides all the centres with a fixed amount for each person, regardless of which party runs the day-care centres, as long as all permits have been obtained and other demands fulfilled.

4.13.2.1.2 Respite care

A service to provide respite care at home does not exist. However, FAAS tries to give its members as much support as possible, through experienced members helping newer ones.

Short-term residential respite care is available and completely funded by the state but there are constant complaints that it is far from sufficient in number and that it is far from satisfying needs and demand. Actually, only 2 beds are set aside for respite care, for 3000 patients, but individual institutes do their utmost to meet the more severe needs as they arise.

FAAS is currently working on a facility specifically intended for residential respite care in the same building as the association's day care services. It is ready and will open once the Ministry of Health has pledged to support it.

4.13.2.1.3 Long-term residential care

Long-term residential care is completely funded by the state but there is actually none available. Individual institutions do their utmost to meet the most severe needs as they arise.

4.13.2.1.4 Palliative care

There are no services providing palliative care at home. Palliative care at a centre is only offered at one institute, situated in the area surrounding Reykjavík. It serves that area quite well but does nothing to cater for the needs of rural areas. The service provided is first-class and highly praised, but insufficient. It is completely funded by the state.

4.13.2.1.5 Monitoring in the home via alarm systems

Tele-alarm systems can be purchased privately from the private sector. The state does not provide any funding for this service.

4.13.2.2 Personal assistance and home help

4.13.2.2.1 Personal assistance

4.13.2.2.1.1 Home nursing

“Home nursing” takes care of the patient’s day-to-day hygienic needs, assistance taking medication and assistance dealing with incontinence, if such support is deemed necessary. When there is enough staff offering these services, they are satisfactory but as with many other home nursing projects, there is often a lack of staff which might indicate that salaries in this field should be higher. Visits to assist taking medicine often drop from twice a day to once a day or from 3 times a week to 1 or 2 times a week etc.

4.13.2.2.1.2 Home assistance

Assistance with eating and drinking (not with the preparation of food) would be categorised as “home assistance” and as such should be available but it is often lacking due to staff shortages and lack of time. When available, it is partly funded by the state and partly by service users. As mentioned earlier, a distinction is made between “home nursing” and “home care” whereby home nursing is fully funded by the state and home care is partly funded by municipalities, and partly by the service user, depending on his/her income.

There are no services providing assistance with skin care, occupational therapy, home adaptations and mobility e.g. lifting, moving and walking. There are also no services providing companionship and/or social activities although experienced members of FAAS try to help others as much as possible.

4.13.2.2.1.3 Assistive devices

There is a distinct lack of clarity concerning people’s rights to assistive devices and state support for their purchase or rental. The state’s share of the cost ranges from negligible to complete cover. Changes to official policy are constantly being made with regard to the amount and extent of state support, the price of each piece of equipment, and each distinct disease or disability. The state does not support the purchase or rental of assistive devices for people with dementia in specific, but people with dementia can make use of some of the general services from the State Insurance Offices’ Assistive Device Center, on the basis of general regulations about support.

4.13.2.2.2 Home help

The following services are available:

1. Assistance with housework e.g. cleaning, dusting and tidying
2. Assistance with the preparation of meals (including meals on wheels)
3. Assistance with transportation
4. Assistance with laundry

Assistance with shopping is not available.

People pay a fixed and reasonable amount for assistance with housework and the preparation of meals. However, too little time tends to be spent on housework and people cannot get help preparing all the meals they need, usually just assistance with one meal per day and not at weekends. Assistance with laundry is scarce and partly funded by the state. It is considered expensive for service users.

If an official evaluation has detected that a person needs driving to certain places for important purposes, a service is provided a few times per month for which the service user pays a small fixed fee. The remainder of the cost is borne by the state. However, the rules governing eligibility are narrow and not very useful for people with dementia.

4.13.2.3 Psychosocial support and training for people with dementia and carers

The following services are not available in Iceland:

1. General information services about available services
2. Holidays for people with dementia and/or carers
3. Counselling for carers
4. Training for carers

Counselling for people with dementia is available but is not sufficient. FAAS runs some support groups for which it covers most of the cost. Some funding is provided by the state but this is constantly being reduced.

4.13.2.4 Work/tax related support for people with dementia

In Iceland, there are no measures to protect people with a diagnosis of dementia who are still in paid employment. They are not entitled to tax benefits or allowances on the basis of incapacity or to employ a person to provide home care. Similarly, they are not entitled to direct payments to pay for services, grants for home adaptations or reductions on radio and television licences or on public transport.

4.13.2.5 Work/tax related support for carers and carer allowances

People caring for a person with dementia are not entitled to paid or unpaid leave or to flexible working hours. They are not entitled to subsidised pension contributions. They are, however, entitled to receive a direct payment from the State if they are under 67 years old and have an especially burdensome task of caring for a relative. They must prove that they had a job or income for some time before and that they lost it as a result of having to care for the relative. This is covered by the Law on Public Insurance (Lög um almannatryggingar - 117/1993) which came into force on 1 January 1994.

4.13.3 Bibliography

Unless otherwise stated, information provided by Helgi Johann Hauksson from Alzheimer Iceland (FAAS) in September 2007.

4.14 Ireland¹⁴

4.14.1 Organisation and financing of social support to people with dementia and carers

4.14.1.1 Background information on the social/healthcare system in Ireland

The Government’s 2001 Health Strategy: *Quality and Fairness: A Health System for You* broadly accepted The Action Plan for Dementia (O’Shea & O’Reilly, 1999) and committed to its implementation over a seven-year period. Today, despite some improvements, many of its recommendations have yet to be implemented. The Alzheimer Society of Ireland (ASI) is currently lobbying government with their Dementia Manifesto which is supported by research entitled ‘Implementing Policy for Dementia Care in Ireland’. They are calling for dementia to be made a National Health Priority and for the full and accelerated implementation of the Action Plan.

4.14.1.2 The organisation of social support for people with dementia and carers

The Health Services Executive (HSE) is the state body organised regionally that is charged with providing Public Health Services in the Community or ‘Community Care Services’ under various Health Acts. These services may also be provided by voluntary NGOs in conjunction with or on behalf of the HSE. Community care services may include public health nursing, home help services, day care and respite care, physiotherapy, occupational therapy and chiropody. The HSE is also responsible for managing Nursing Home Subvention payments. The HSE also provide ‘Home Care Packages’, they are made available according to service availability in an area and the aim is to assist older people living at home. Extra funding for these packages was made available in 2006 and 2007. However, the HSE is still working on standardising the approach to this service on a nationwide basis and so availability and level of service differs around the country.

Medical cards are given to those over 70 or who pass a means test. Medical card holders are generally automatically entitled to these services free of charge. Non medical card holders may also be entitled to services depending on their individual circumstances. Entitlement to community care services is not clear cut and there is a wide variation in the level of services available in different parts of the country resulting in huge variations and inequalities in service provision. The rules about which community care service must be provided differ in accordance with the differing services. In some cases the HSE is obliged to provide a service and in others they are not, one of the reasons for this is that the health services provided by the HSE reflects the specific population in the area.

One of the unique elements of the Irish social care provision system is the role played by NGOs - in many cases it is the NGO who is the main provider of the service with financial support from the state.

¹⁴ The information in this report on social support for people with dementia and their carers in Ireland was provided by Samantha Taylor from the Alzheimer Society of Ireland.

When care in the community is no longer possible, the person may enter long term residential care – again there are a number of ways in which state support is provided to the person and his/her family as well as a number of different service providers operating in this area. The latter includes direct provision by the state, provision by the NGO sector but with financial support from the state and private provision. The system is extremely complex and again there are major geographical inequities in the provisions by the state.

The Department of Social and Family Affairs is responsible for the issuing of financial supports. There are a range of supports that can be made available. In general a person must pass a means test or income assessment or have paid enough Pay Related Social Insurance (PRSI) to avail of these supports. Some of these supports include Carers Allowance, Carers Benefit, Respite Care Grant, Pre-Retirement Allowance, Household Benefit Allowance, Living Alone Allowance.

The Department of Community, Rural and Gaeltacht Affairs operates Community Support for Older People in the form of grants which can be used to improve social support and security for older people in their own homes by providing grants for security locks on doors and windows, security lighting, smoke alarms etc. In addition, people may apply to their local authority when looking for support with accommodation or housing and for grants to help them make home adaptations to suit their needs due to an illness or accident.

The Department of Health & Children, Minister for Health and Minister of State with special responsibilities for Older People are responsible for the social support of people with dementia. The Department of Social and Family Affairs, and Minister for Social and Family Affairs as well as the Department of Community, Rural and Gaeltacht Affairs and the Minister for Community Rural and Gaeltacht Affairs, also influence services and support for people with dementia.

The Department of Health through the Health Services Executive (HSE) provides health services such as Home Care Packages and other HSE services such as Nursing Home Subvention. The Department of Social Welfare operates payments such as the Carers Allowance and Pensions. The Department of Community, Rural and Gaeltacht Affairs is the department responsible for areas such as rural transport initiatives, alarms for the elderly and they have a number funding opportunities for regional health related projects which NGO's etc can apply for. They also manage Lottery grants.

The HSE provides funding to ASI to provided Home Care and Day Care supports to people with dementia, their family and carers. In addition, The Citizens Information Board, formally Comhairle, provided funding to the Alzheimer Society of Ireland to set up the Advocacy Pilot Project in North Dublin.

4.14.1.3 The overall funding of social support for people with dementia and carers

State support and services are funded through general taxation and a 2% health levy which working people automatically pay. Many services are means tested and this restricts availability to families who do not meet the means test criteria. People aged 70 and over are entitled to a medical card which gives automatic access to health care services without a means test.

The Health Service Executive provides funding to ASI to provide dementia specific day care centres and home care services. Currently the funding does not meet the full cost of these services and ASI fundraises to meet the balance.

Other Departments also have funding streams available for research or specific projects which can be applied to by self-help organisations. For many of these projects, the funding will meet a percentage of the cost and the organisation must raise the balance to meet the full cost.

4.14.1.4 The legal framework surrounding the provision of social support

The key Acts influencing care for people with dementia in Ireland are:

- The Social Welfare Consolidation Act 2005,
- The Social Welfare Act 2006.
- Health Acts – 1947 to 2004 (these outline the legislative framework for Health and personal social services)
- Health (Nursing Homes) (Amendment) Act, 2007
- The Disability Act 2006 (this creates the legislative framework for a needs assessment to be carried out on the person with the disability)

The legislative approach to social service provision for older people with a disability has been one of ‘enabling’ the institutions of the state to provide care rather than placing an ‘obligation’ on them. There is very little emphasis in the Irish legislation on a ‘rights based approach’ to service provision.

The Department of Health and Children published draft National Standards for Residential Care Settings for Older People in 2007. The interim Health Information and Quality Authority currently has two working groups devising standards, The National Quality Standards for Residential Care Settings for Older People and Dementia Specific Standards for Specialist Care Units/Alzheimer Units. The aim of the groups is to finalise the Standards in 2007.

The Government is currently drafting legislation to deal with capacity issues in vulnerable adults. The proposed legislation will impact directly on people with dementia in that it is moving away from the adversarial approach towards a guardianship approach along with outlining clear rules regarding when a person has

competence. This new legislation will positively impact on the lives of people with dementia and their families.

4.14.1.5 The suitability of social support for people with dementia and carers

4.14.1.5.1 Adequacy and accessibility in general

While there have been improvements in the provision of care, much remains to be done. Many of the key recommendations outlined in the Action Plan for Dementia (1999) have yet to be implemented.

Some improvements have been made in enhanced training and education for staff, increased at-home respite care, additional specialised dementia units and more old age psychiatry consultants. However, progress has been slow on implementing the Action Plan for Dementia. The ASI is calling for dementia to be made a National Health Priority as they do not feel that the available services respond adequately to the specific needs of people with dementia.

Current diagnostic and assessment services are wholly inadequate. Therefore, by the time a diagnosis is confirmed, the person's dementia has significantly progressed and early intervention strategies missed. There is a lack of services for people in the early stages of their dementia.

As already indicated, there are many regional and geographic variations in service provision and access to services in many cases solely relate to where you live and are not at all based on the person's needs. This is true of both direct state service provision and NGO provision.

Those people who have access to services experience many limitations to the services – there is very little flexibility and more often than not, they are not comprehensive in meeting the person's needs. Twilight, evening and weekend services in terms of home care and day care are totally inadequate. Dementia specific training for those working in the caring field is often lacking. As a result, there is often premature admission to acute or long term care, which in turn places huge unnecessary burden on these health care systems.

A research paper "Perceptions of Stigma in Dementia, An Exploratory Study" outlines key recommendations for policy, service planning and information provision/education. One of the main recommendations of this research is that greater levels of resources are needed to augment the availability, accessibility and usefulness of person-centred dementia specific services that support the abilities of people with dementia. The appointment of core community based case managers throughout the country is highlighted as a priority for service planning and provision.

The reports mentioned are available on www.alzheimer.ie

4.14.1.5.2 People from ethnic minorities

There is no specific support available for people with dementia and their carers from ethnic minorities.

4.14.1.5.3 Younger people with dementia

The ASI has highlighted a range of areas where services are inadequate or inaccessible. A recent report on younger people with dementia found that the impact of age restrictions on many services for people with dementia and the complete lack of services dedicated to the specific needs of younger people with dementia are a serious concern.

4.14.2 Services and support for people with dementia and their carers**4.14.2.1 Types of care****4.14.2.1.1 Day care**

Day care is available but is not sufficient. More dementia specific day care centres are needed as well as better transport to access the service. The Alzheimer’s Society of Ireland (ASI) does provide some dementia-specific day care centres. Day care is funded partly by the state and partly by service users. There is a need to increase links with home care services to prepare people better for day care.

4.14.2.1.2 Respite care

Respite care is available but this is not sufficient. Waiting lists occur and there are geographic disparities related to funding and to the recruitment of carers. Respite care is partly funded by the state and partly by service users. NGOs provide separate in-house respite which is part funded by the state.

1-2 weeks per year residential respite is provided for most people with dementia and this is completely funded by the state. ASI provides one respite centre nationwide which is partly funded by the State and partly through service users and other forms of fundraising.

Long term respite care is provided at a sufficient level. It is partly funded by the state and partly by service users.

4.14.2.1.3 Long-term residential care

In Ireland there is a mix of public and private long-term residential care. There are adequate levels of private services but inadequate levels of public services and a need for more dementia specific options. Full-time long term residential care is financed by the State. Means testing is applied and personal property included in the calculation of available means. There are no out-of-pocket payments.

4.14.2.1.4 Palliative care

End of life services are rarely provided for or planned for people with dementia. The current palliative care model operated in Ireland does not actively include people with dementia.

4.14.2.1.5 Monitoring in the home via alarm systems

Tele-care systems are available and are generally sufficient.

4.14.2.2 Personal assistance and home help

4.14.2.2.1 Personal assistance

Fully state-funded support is available for:

1. Personal Hygiene
2. Assistance taking medication
3. Incontinence
4. Skin care
5. Assistive devices

Partly state-funded support is available for

1. Assistance eating and drinking
2. Assistance with mobility
3. Social activities
4. Home adaptation

None of the services are provided at a level that the Alzheimer's Society of Ireland (ASI) considers to be sufficient. Services which provide support such as help with personal hygiene and incontinence are provided through public health or registered nurses and these services are thus limited. Occupational therapy services which would help with skin care and home adaptation are poorly resourced and staffed. The ASI provides some home care services and day care which begin to address the lack of support for people with dementia particularly addressing social needs. Assistive devices are available for those with a medical card but availability is limited.

4.14.2.2.2 Home help

Again some services are fully state-funded while others are part funded by the state and part by service users.

Fully funded services include:

1. Assistance with housework
2. Laundry services

Partly funded services include:

1. Meals on wheels
2. Assistance with shopping
3. Transportation

None of these services are provided at a level that the Alzheimer’s Society of Ireland considers to be sufficient.

4.14.2.3 Psychosocial support and training for people with dementia and carers

Information on support and services is provided by the government in Ireland but this tends to be done by different agencies. There is no one-stop-shop for service users and people with dementia to get information and advice. The ASI provides a Helpline and information services which is funded by fundraising.

There are no formal counselling services for people with dementia or their carers although ASI provides opportunities for peer-support. An annual respite care grant is available for carers to enable them to take a break but there are no services offering holidays for people with dementia. There is no training provided for carers of people with dementia by the state but ASI and other NGOs may provide some training.

4.14.2.4 Work/tax related support for people with dementia

A person who is deemed unfit to work and has met the required PRSI (Pay Related Social Insurance) conditions and is under age 66, may claim for Illness Benefit.

The Invalidity Pension is a long term, PRSI contribution based payment for people over 60. They must satisfy both medical and social insurance conditions and be deemed permanently incapable of work because of illness or incapacity.

A Disability Allowance is available to people who do not meet the PRSI conditions, are under 66 years of age and have an injury, illness or disease which causes them to be ‘substantially restricted’ in doing work. A person must pass a means test to qualify.

This is covered by The Social Welfare Consolidation Act 2005 and The Social Welfare Act 2006.

Direct payments or the equivalent are available in some cases. The Health Services Executive (HSE) will provide money to a person to buy in home help or home care where this is not available directly through the HSE. There are maximum limits and qualifying conditions attached.

There are a number of other ways for a person with dementia to get assistance with home adaptations. This depends on whether the person is an owner occupier or living in social housing. For owner occupiers there are schemes available to meet up to 90% of the cost of the adaptations. For people in social housing the total cost will be met up to a maximum of €20,320. Everyone must apply to their local authority and an Occupational Therapist must then assess the individual situation. The rules for this assistance can change depending on where a person lives and the local authority that is applicable to that person. Due to a large number of applications currently some local authorities have suspended the scheme.

People over 70 automatically qualify for a free travel pass and for the household benefit package which includes a television licence as well as electricity, gas and telephone allowances. There is also a separate fuel scheme.

If a person is under 70, then there are restrictions, mostly means testing which apply to these benefits. If a person qualifies for Disability Allowance or Invalidity Pension then they will get a Free Travel Pass. They may also qualify for the Household Benefit Package if they meet certain other conditions, for example living alone. This is covered by the Social Welfare Consolidation Act 2005 and The Social Welfare Act 2006.

4.14.2.5 Work/tax related support for carers and carer allowances

An employed person taking care of an incapacitated individual is entitled to an allowance known as IT47. This is an allowance that can be claimed if a person, his/her spouse or a relative is incapacitated for a tax year by reason of physical or mental infirmity and they employ a person to take care of the incapacitated individual. This is covered by The Taxes Consolidation Act 1997 and subsequent Annual Finance Acts.

Carers are not entitled to paid time off work for caring but can take unpaid time off. They can leave work on an unpaid basis for a minimum of 13 weeks and a maximum of 104 weeks to look after someone in need of fulltime care. They will not be paid but their job must be kept open while they are on this leave.

People who have paid enough PRSI contributions may be able to apply for Carers Benefit which is a payment for those caring full time which is available for 2 years. This is covered by the Carer's Leave Act 2001. If people are on Carer's Leave and/or in receipt of Carers Benefit, then while they are on this leave or in receipt of this payment they will be credited with PRSI contributions (for a maximum period of 2 years), which protects their future social welfare payments such as the state

pension (contributory). Other tax benefits available to carers include: Home Carers Tax Credit, Claim for Dependent Relative Tax Credit, Health Expenses and Medical Expenses Relief. These are covered by the following laws: The Carer’s Leave Act 2001, The Social Welfare Consolidation Act 2005 and The Social Welfare Act 2006.

4.14.3 Bibliography

Unless otherwise stated, information provided by Samantha Taylor (Alzheimer Association of Ireland) between April and August 2007.

For copies of documents, full reference and/or further information, please see:

<http://www.alzheimer.ie>

<http://www.welfare.ie>

<http://www.revenue.ie>

4.15 Italy¹⁵

4.15.1 Organisation and financing of social support to people with dementia and carers

4.15.1.1 Background information on the social/healthcare system in Italy

In 1978, the National Health System was set up in Italy. In the same year, Local Health Authorities (USL) were created which were controlled by the municipalities. However, it was not until 2000 that a legal framework and financial basis for a national development of social services was established.

There is still a strong emphasis on support from the family. Care of the elderly is traditionally considered as a kind of “social duty” by the family, especially the women on whom the main burden of care falls. According to Auser (2001), “it is generally accepted as normal and legitimate that the community and institutions should become involved in caring for elderly family members only after the family resources – often interpreted in a very extended sense (up to the third degree of kinship) have run out (in Polverini et al. 2004).

Demand for home care services has nevertheless increased significantly but supply has been fairly limited. The percentage of over 65 year-olds using home care services in Italy is very low (i.e. 1% of the population) compared to other countries e.g. 5.5% in the United Kingdom, 6.5% in Germany and almost 10% in Scandinavia (Minguzzi in Polverini et al. 2004). Moreover, there have been considerable differences in the development and distribution of home care services, particularly between the north and south of the country. There are also differences between the populations. For example in the north, elderly people tend to live in better conditions; on the islands, such as Sicily and Sardinia, there is a higher percentage of chronic diseases and disability (Nesti et al. 2003). Services tend to be fragmented and public expenditure on health services is fairly low.

4.15.1.2 The organisation of social support for people with dementia and carers

Each ‘regione’ (totalling 20) in Italy is autonomous in organising overall social services, and there exist wide levels of difference between one region and another. In some (e.g. Emilia Romagna, Toscana, Lombardia and Veneto), some type of social support is contemplated and organised, but in others dementia care is confined to day centres or private organisations. Carers are very much left to their own devices in many regions, although things seem to be gradually improving.

The Ministry of Health and the Ministry of Social Services are responsible for social support for people with dementia/elderly dependent people. Each Region has its autonomous authority responsible for such matters. There is some overlap and a certain degree of conflict between the two Ministries. There is also some degree of interaction between the State, the private sector and voluntary associations/NGOs.

¹⁵ The information in this report on social support for people with dementia and their carers in Italy was provided by Marie V. Gianelli from Scuola provinciale per le Professioni Sociali Bolzano (Bozen) and Andrea Fabbo (MD).

4.15.1.3 The overall funding of social support for people with dementia and carers

Support for people with dementia and carers is mainly funded through general taxation, and an additional fee for each service.

In Italy, citizens must purchase a ticket in order to have access to services within the National Health Service. People who are over 65 years old and those suffering from an officially recognised chronic and disabling disease do not have to pay.

The Law 328/2000 on the Establishment of an Integrated System of Social Services and Interventions gave local governments the authorisation to make various kinds of economic transfers (known as vouchers) which can be used by elderly people to purchase services. However, only about 10% of municipalities issue such vouchers. Care allowances, on the other hand, are more widely used but they are nevertheless more common in the north of the country than in the south (Scarpa, 2006).

The regions have legislative powers over health and welfare but home care services are financed entirely by local councils. Such services are generally rendered to people on low incomes. Elderly people may have to contribute towards costs using their pensions, vouchers and care payments. Those with extremely limited financial resources may be exempt from making these partial payments. According to Dogliotti et al. (1999), there is a die-hard cultural misconception in Italy that care is not considered as a right to be claimed by each and every citizen, but rather as a concession from above, similar to some sort of ‘charity’ (in Polverini et al., 2004, p.57).

According to Nesti et al. (2003), national surveys have revealed that 15% of families caring for an elderly relative employ informal carers on a private basis for more than 20 hours per week. These carers are often immigrants and the amount paid per month ranges from approximately EUR 500 in the South to EUR 800 in the North (Salvini, 2006). In some cases, families use the vouchers that they are given for services to contribute towards the cost of private care.

4.15.1.4 The legal framework surrounding the provision of social support

Reform of the National Health System began in 1992 with the Health Care Decree no. 502/1992, followed by the “Objective: Ageing Persons” project (the National Plan for Welfare), Law no. 328/2000 relating to the creation of an integrated care and social services system and finally the Guidance and Coordination related to Health and Social Integration Act of 2001.

The objective of the National Plan for Elderly People was to better coordinate medical and social services so as to ensure their integration within the home care services system. Related services are intended to promote the well-being of elderly people and to help them to maintain their autonomy.

Every person in Italy, with insufficient financial resources, irrespective of age, can ask for “alimony” from his/her family. According to articles 433, 438 and 443 of the Civil Code, relatives can fulfil this obligation either by paying money every month or by accepting and supporting the person in their own home (Polverini et al., 2004).

4.15.1.5 The suitability of social support for people with dementia and carers

4.15.1.5.1 Adequacy and accessibility in general

Health services (assessment and diagnosis, especially within the national CRONOS project, which was concluded two years ago) are adequate and accessible, although limited in some rural areas and for different types of dementia. Generally speaking, the same cannot be said for social support and psycho-social interventions.

The attitude is ‘top-down’, not ‘bottom-up’, so not much importance is given either to the assessment or the satisfaction of specific needs. Families often sacrifice a great deal of time and effort in order to meet their relatives’ needs.

4.15.1.5.2 People from ethnic minorities and younger people with dementia

There is no specific support for people from ethnic minorities and for younger people with dementia.

4.15.2 Services and support for people with dementia and their carers

4.15.2.1 Types of care

4.15.2.1.1 Day care

Day care exists but is insufficient. It is partly funded by the state and partly by service users.

4.15.2.1.2 Respite care

Respite care in the home is available but only private services are considered sufficient. In some regions e.g. in Emilia, the municipalities contribute towards this service. Short-term and long-term respite care is not generally available.

4.15.2.1.3 Long-term residential care

There is no national regulation but tentative guidelines are being drafted at regional level.

4.15.2.1.4 Palliative care

Palliative care at home is mainly funded by service users. There are no palliative care centres for people with dementia.

4.15.2.1.5 Monitoring in the home via alarm systems

Private companies offer home tele-alarm systems but people must pay for this themselves. Generally speaking, this service is insufficient. In the Emilia Romagna region, this will be introduced in the next few months.

4.15.2.2 Personal assistance and home help

4.15.2.2.1 Personal assistance

The following services are available:

- Assistance with personal hygiene (partly funded by service users) – insufficient
- Occupational therapy/ergotherapy – insufficient
- Assistive devices – perhaps in some regions
- Home transformations – only on a private basis

The following services are not available:

- Assistance taking medication
- Assistance with eating and drinking
- Assistance with lifting and moving
- Assistance with incontinence
- Assistance with skin care
- Companionship/social activities

4.15.2.2.2 Home help

In some regions, there are plans to provide assistance with housework. The following services do not exist:

- Help with the preparation of meals
- Assistance with shopping
- Transportation service
- Laundry service

4.15.2.3 Psychosocial support and training for people with dementia and carers

There is a general information service providing information about the availability of services but it is only sufficient in a few regions. Counselling services exist for people with dementia but this is not considered sufficient. Holidays for elderly and disabled people are available but not specifically for people with dementia. Training for carers is available in some regions e.g. Emilia.

4.15.2.4 Work/tax related support for people with dementia

There are no legal provisions to protect people diagnosed with dementia who are still in paid employment. They are not entitled to tax refunds or benefits on the basis of their incapacity or for employing someone to provide home care services. People with dementia are not entitled to any reductions for television or radio licences or on public transport.

They may, however, be entitled to direct payments to pay for care. This takes the form of a cheque called ‘assegno di cura’. In some regions, it is possible to apply for home adaptations e.g. in Emilia where there is a CAD (Centro Adattamento

Ambientale e Domestico). They may also be entitled to an allowance, called the “indennità di accompagnamento” but this is paid directly to their carer (please see below).

4.15.2.5 Work/tax related support for carers and carer allowances

4.15.2.5.1 Paid leave

Article 33 of Law 5.2.1992 n.104 deals with paid time off work for people who have a relative with a severe handicap (e.g. a person with dementia who has been officially declared an “invalid” under the “Invalidity Law”). The spouse or relative (up to third degree i.e. brother-in-law, father-in-law etc.) is entitled to up to 3 days’ leave per month. This leave is fully paid by the INPS (the national social security agency) or another social security agency. It is not necessary to live under the same roof as the severely handicapped person. The leave is taken on a daily basis and can be continuous or staggered. However, it cannot be accumulated from one month to the next. Furthermore, under this law the relative can request to be transferred, when feasible, to another place of work (of his/her company), which is closer to the disabled relative, but cannot be transferred without his/her consent.

4.15.2.5.2 Unpaid leave

Article 4 of Law 8.3.2000 n.53 deals with long-term unpaid leave for people with serious family problems e.g. whereby a member of the family is dependent and unable to manage activities of daily living. It is granted to the spouse or relatives up to the third degree. Up to 2 years’ unpaid leave can be taken in a staggered manner. At the end of the stipulated period of time, the worker has the right to return to his/her job. He/she also has the right to return earlier if not otherwise stipulated by her/his company.

4.15.2.5.3 Carers allowance

In accordance with Law 11.2.1980 n.18, the “indennità di accompagnamento” is granted to people who have been officially declared as being “invalid” i.e. they are unable to accomplish activities of daily living. In order to qualify, the person must first make an application to be declared an invalid in accordance with the “Invalidity Law”. The allowance was Euro 450.78 in 2006. It is not means tested and is paid to the carer. S/he may also be eligible to purchase a car without having to pay VAT.

4.15.3 Bibliography

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4.16 Latvia¹⁶

4.16.1 Organisation and financing of social support to people with dementia and carers

4.16.1.1 Background information on the social/healthcare system in France

After a long period of Soviet occupation, Latvia regained its independence on 21 August 1991 and elected the Saeima (Latvia's parliament) in 1993. Since regaining independence, the healthcare system has been reformed several times. Latvia is administratively divided into 26 districts, with an additional 7 cities (with separate status) and 483 municipalities (pagasts) (Karaskevica et al., 2001).

4.16.1.2 The organisation of social support for people with dementia and carers

The Ministry of Welfare of the Republic of Latvia, the Ministry of Health of the Republic of Latvia and the local communities of the regions of Latvia are responsible for social support to people with dementia.

Generally, support for people with dementia is provided by the state – by social care institutions (e.g. old people's homes, etc.) and by hospitals, and in other ways - by support provided by communities (e.g. day centres, half way houses, etc.). A third kind of social assistance is provided by NGOs, the church and volunteer organisations. In this way, the state provides support in social care centres and mental health care hospitals and the local communities provide out-patient care through day centres and half-way houses etc. The communities provide financial support for NGO care services. However, there is no specialised assistance for people with dementia and their carers. There is only one day centre in Latvia (in Riga) that provides general support for people with dementia and their carers. Services from voluntary associations have not yet been developed in this specific field and there are as yet no self-help organisations for people with Alzheimer's disease or other forms of dementia.

4.16.1.3 The overall funding of social support for people with dementia and carers

Support for people with dementia (e.g. Alzheimer's disease) is provided through general taxation. Support is provided in old people's home and during stays in specific departments as well as at mental health care hospitals. During their stay there, the hospital provides social care. Over 25% (approximately) of people with dementia stay in hospital for over a year just to receive social support, not for treatment.

People with dementia who are considered disabled (and who have a specific degree of disability as assessed by a specialist) are entitled to home care services funded by the state provided that their relatives cannot provide the necessary assistance.

¹⁶ The information in this report on social support to people with dementia and carers in Latvia was provided by Docent Māris Taube, MD from the Public Health Agency.

4.16.1.4 The legal framework surrounding the provision of social support

The main relevant laws are as follows:

- The Law of Social Assistance and Social Services (accepted by Saeima i.e. the Parliament on 25.11.2004). This covers general social assistance and social service aspects for people with disabilities and mental health problems, not specifically social assistance for people with dementia (Alzheimer diagnosis).
- The Law of Communities (accepted by Saeima on 19.05.1994 including lots of changes – the last ones on 18.03.2005). This Law contains general regulations for both kinds of communities (local and regional), economic background, competence and collaboration with other institutions.
- The Law of Medical and Social Security of Disabled Persons (accepted by Saeima on 01.01.1993).

The above-mentioned laws cover general social assistance and social service issues for people with disabilities and mental health problems. They do not specifically refer to social assistance for people with dementia.

Draft guidelines “Improvement of mental health 2007 – 2017 for inhabitants of Latvia” have recently been produced. They were initially based on the work of specialists of the Mental Health State Agency and the Ministry of Health, but now the work is being continued by the Public Health Agency. The draft guidelines, as a draft document, are currently being discussed by all the competent institutions. They include developments in all aspects of mental health including the care of people with different kinds of dementia.

There are also now draft “Guidelines on the policy to reduce disability and its consequences 2005-2015” which include different kinds of support for people with mental health problems (including Alzheimer’s disease and other forms of dementia).

4.16.1.5 The suitability of social support for people with dementia and carers

4.16.1.5.1 Adequacy and accessibility in general

Specific services for people with dementia (including those diagnosed with Alzheimer’s disease) should be developed, paying attention to out-patient care (e.g. community care). In hospitals there are general departments for elderly people - geriatric departments in general hospitals and in psychiatric clinics for people with dementia, where these people can receive support and help. Thus, the support system of social services for people with dementia is currently based solely on an institutional approach, rather than on out-patient care and services. In Latvia, there is only one community social day centre “Ozolaine” (in Riga) which provides support for people with dementia and their carers, ensuring a range of services such as social and health services, legal services, ergotherapy, physiotherapy, movement therapy, support groups, counselling and different cultural activities. The number of such centres should be increased to ensure accessibility and the possibility to receive adequate support.

Community care (or out-patient care) for people with dementia has only just started to develop in recent years and it should be promoted in order to shorten their stay and reduce the need for social care in state-run general hospitals (known as “profile state hospitals”), as well as to develop a support system for their carers.

4.16.1.5.2 People from ethnic minorities

There is sufficient support for people from ethnic minorities (mainly Russian speaking). The population of Latvia is not very multinational and almost all ethnic minorities speak/understand Latvian, Russian or English.

4.16.2 Services and support for people with dementia and their carers

4.16.2.1 Types of care

4.16.2.1.1 Day care

Day care centres are completely financed by the State. However, few provide support for people with mental health problems and there is only one day centre “Ozolaine” which provides services designed for people with dementia. “Ozolaine” is supported by the regional community and is located in a district of Riga.

Support for elderly people who live on their own as well as for mentally handicapped people is provided by the Riga Samaritan Union, St John Help, “Saulessvece”, as well as some public organisations but the support is not specially designed for people with dementia.

4.16.2.1.2 Respite care

There are no services for respite care in the home that are specifically designed for people with dementia.

Short-term and long-term residential respite care is available and completely funded by the State. This is nevertheless considered insufficient as it is provided in the geriatric departments of general hospitals, in old people’s homes or in mental hospitals but not within the community care system. Draft guidelines on the improvement of people’s mental health are being produced that will eventually affect the provision of social support to people with different mental health problems (including people with dementia), including measures to promote mental health such as the creation of day centres, halfway houses and other forms of support.

NGOs, volunteers and the Church do not provide short-term residential respite care that is specifically for people with dementia. They do, however, accept people with dementia in their establishments and try to cope with individual cases.

4.16.2.1.3 Palliative care

Different kinds of palliative care at home (i.e. services and support) are available, which are partly financed by the State, but are not specifically for people with dementia. Therefore, such services are not considered sufficient.

Palliative care is also available and completely funded by the state at the Latvian Oncology Centre, in specific departments of general hospitals and in old people's homes but not in the form of community care and support. Services have not yet been developed to deal with the specific problems of people with dementia. Services provided by NGOs, volunteers and the Church are not specifically for people with dementia either.

Palliative care is covered in the draft guidelines for the improvement of mental health (mentioned earlier).

4.16.2.1.4 Monitoring in the home via alarm systems

A tele-alarm system exists and is partly funded by the State but it is not targeted at people with dementia. A special kind of tele-alarm system specifically for people with dementia is being developed by the Riga City Council in collaboration with the Riga Samaritan Union.

4.16.2.2 Personal assistance and home help**4.16.2.2.1 Personal assistance**

The following services are available but are not specifically designed for people with dementia. With the exception of assistance with eating and drinking, which is partly financed by service users, they are all completely financed by the State:

1. Assistance with personal hygiene
2. Assistance with eating and drinking
3. Assistance with mobility lifting and moving: provided by state centres and local communities
4. Assistance with incontinence: since 2007 people with incontinence (including people with dementia) have been entitled to purchase necessary equipment for incontinence at 50% of the price thanks to the public organisation Inco Centre in collaboration with NGOs. Also, consultations with specialists are now free of charge.
5. Assistance with skin care: available at hospitals, rehabilitation centres and old people's homes
6. Occupational therapy/ergotherapy: subject to the fulfillment of conditions
7. Assistive devices: developed and provided by state institutions (Centre for Technical Assistance)
8. Home adaptations

Assistance/supervision taking medical and companionship/social activities are not available.

With regard to occupational therapy/ergotherapy, general services are provided by public organisations and day centres with the exception of the day centre “Ozolaine” in Riga which provides a service specifically designed for people with dementia. A trend has been started to develop such services in the home environment. Access to occupational therapy/ergotherapy, is dependent on disability status and a functional assessment carried out by a professional ergotherapist.

4.16.2.2.1 NGOs, volunteers and the Church

There is no information available about services for personal assistance provided by NGOs, volunteers or the Church that are specifically aimed at people with dementia. However, NGOs are very active and work closely with the patient union and Inco Centre to provide services for people suffering from incontinence. Also, public organisations such as “Gaismas stars” and church volunteers (e.g. St John Help “Saulesvece” and the Diacony Centre) provide general occupational therapy but again not specifically for people with dementia. A general service providing assistance with eating and drinking for old people is provided by Riga Samaritan Union and some church volunteers (not by state institutions) but is not specifically for people with dementia.

4.16.2.2.2 Home help

The following services are available in Latvia but, with the exception of assistance with housework, must be partly financed by service users.

1. Assistance with housework
2. Help with the preparation of meals (incl. meals-on-wheels)
3. Assistance with shopping
4. Assistance with laundry
5. Assistance with transport

The above-mentioned services are not specifically designed for people with dementia. They are provided by local communities in collaboration with the Riga Samaritan Union, the Diacony Centre and regional volunteer organisations of disabled people and their relatives. Specific home help services for people with dementia, to be provided at state level, are mentioned in the draft guidelines on mental health promotion.

4.16.2.3 Psychosocial support and training for people with dementia and carers

Information on support groups is provided by the public organisation “Sustento” but this is not specifically for people with dementia. “Sustento” is a local organisation for people with special needs (including those with mental health problems) and it is a

member organisation of the European Disability Forum (EDF) which unites 23 NGOs from different European countries. Information about general services is also provided by local communities (by social services institutions). The only day centre for people with dementia “Ozolaine” (in Riga) also provides information about access to services.

Counselling is completely financed by the state. However, it is insufficient as there is only one day centre for people for dementia (“Ozolaine” which is supported by Riga City Council) that provides counselling for people with dementia as well as for their carers. The counselling provided covers different domains e.g. psychological, health care, legal issues, employment, recreation possibilities and housing issues. Counselling services for people with mental health problems and their carers (not specifically for people with dementia) are also provided by “Sustento”, “Gaismas stars” (within the ESF financed projects), “Dzirksts” (support groups) and St. John Help “Saullessvece” (church). Specific services and counselling for people with dementia are mentioned in the guidelines of mental health promotion and will eventually be provided by the state throughout the whole country.

Holidays for people with dementia and carers are available uniquely through the “Ozolaine” day centre and they are completely financed by the State. The need for this kind of service should be included in the guidelines on mental health promotion.

Training for carers is provided by the day care centre for people with dementia “Ozolaine” (Riga) as well as individually by doctors, nurses at hospitals and social workers at social service institutions but not sufficiently for carers of people with dementia. It is organised as group training covering different aspects of care and is completely funded by the state. This kind of training (including courses, seminars and workshops) for the carers of people with dementia is mentioned in the draft guidelines of mental health promotion and will therefore soon be provided by the state throughout the whole country.

4.16.2.4 Work/tax related support for people with dementia

4.16.2.4.1 Employment protection

State employment legislation policy covers employee security and health, but regulations do not specifically refer to people diagnosed with dementia in paid employment. The Ministry of Welfare and institutions such as the State Work Inspectorate and the National Tripartite Council are responsible for these issues. The relevant laws are as follows:

1. The Law of Social Assistance and Social Services (accepted by Saeima i.e. the Parliament, on 25. 11.2004)
2. The Law of Work (accepted by Saeima on 06.01.2001; last changes on 21.09.2006)

3. The Law of Work Protection (accepted by Saeima on 01.01.2002.; last changes on 16.12. 2004)
4. The Law of State Work Inspection (accepted by Saeima on 01.01.2002.; last changes on 07.10. 2004)

4.16.2.4.2 Allowances and benefits

If the person with dementia is considered disabled (according to a specific degree of disability assessed by specialists), he/she may receive a disability benefit as well as cost free or reduced price technical mobility devices and transport, tax refunds and special credit facilities for special accommodation adapted to their specific needs, different kinds of insurance and possibilities to access professional rehabilitation services. This is covered by the following laws:

- The Law of Medical and social security of disabled persons (accepted by Saeima on 01.01.1993)
- The Law of Social Assistance and Social Services (accepted by Saeima on 25.11. 2004)
- The Law on Tax Income (accepted by Saeima on 11.05. 1993)
- The law of Communities (accepted by Saeima on 19.05.1994 with numerous amendments up to 18.03.2005)

Tax refunds/incentives to employ a person to provide home care services are being considered by certain communities.

4.16.2.5 Work/tax related support for carers and carer allowances

There are no provisions to enable carers to combine paid employment with caring such as flexible hours or paid or unpaid leave. They do not benefit from subsidised pension contributions, payment for the care they provide or tax benefits.

4.16.3 Bibliography

Unless otherwise stated, information provided by Docent Māris Taube, MD from the Public Health Agency in August 2007

Karaskevica, J. et al. (2001), Health care systems in transition, European Observatory on Health Care Systems, WHO: <http://www.euro.who.int/document/e72467.pdf>

Useful links:

- 1) www.lm.gov.lv (Ministry of Welfare of Latvia Republic)
- 2) www.vm.gov.lv (Ministry of Health of Latvia Republic)
- 3) www.sustento.lv (local public organisation of people with specific needs)
- 4) www.spf.lv (Administration of social services)
- 5) www.likumi.lv (Latvia and Europe legislation)
- 6) www.rehab.lv (internet site on rehabilitation issues)
- 7) www.koledzarrc.lv (home page of Social integration centre)
- 8) www.lps.lv (Association of Communities, Latvia)

4.17 Lithuania¹⁷

4.17.1 Organisation and financing of social support to people with dementia and carers

4.17.1.1 Background information on the social/healthcare system in Lithuania

In the late 18th century, Lithuania became part of the Russian Empire. After the First World War, it became an independent state but was absorbed into the USSR after the Second World War. Between 1918 and 1940, Lithuania began to develop a health care system based on the Bismarck model. However, after the country's absorption into the USSR, health care was reorganised according to the Semashko system. In March 1990, Lithuania declared its independence from the USSR and undertook a series of reforms of the health care system (Cerniauskas, G. and Murauskiene, L. 2000). Nowadays, the Ministry of Health is responsible for the general supervision of the entire health care system but social care is the responsibility of the Ministry of Social Security and Labour. In the last few years, new legislation has been passed on the integration of disabled people and on the provision of social services.

4.17.1.2 The organisation of social support for people with dementia and carers

The Ministry of Social Security and Labour is responsible for drawing up and implementing state social services programmes and projects. County governors implement the state social services policy in their respective counties. Municipalities are in charge of ensuring the provision of social services to their residents by planning and organising social services and controlling the quality of social services of general interest and social attendance. They are also responsible for carrying out needs assessments, determining people's ability to pay for services and making the appropriate charges. Finally, there is a Social Services Monitoring Department which assesses, monitors and controls the quality of social services. There is some degree of overlap between the health care and the social welfare sectors and a considerable need for coordination with regard to decisions and processes.

Public authorities can contract any type of service provider. However, it is fairly common for the public authorities to fund the services that they themselves provide (rather than those provided by others, even in preference to county-owned facilities). Consequently, private facilities are often limited to addressing the needs of families that are able to pay significant amounts for the services they offer. Voluntary associations/NGOs tend to play a minor role in the provision of services due to their limited capacity and experience.

There are two main kinds of social support: social services of general interest and special social services. Social services of general interest include: information, counselling, mediation and representation, social and cultural services, organisation of transportation, organisation of catering, provision of necessary clothes and footwear as well as other services. Special social services are granted in cases where the general services are insufficient. They include social attendance (complex

¹⁷ The information in this report on social support for people with dementia and their carers in Lithuania was provided by Liuba Murauskiene from “MTVC” (“Training, Research and Development Center”, <http://www.mtvc.lt>)

assistance not requiring permanent attendance by specialists including assistance at home and temporary lodging) and social care (day care, short-term care and long-term care).

Municipalities may in specific cases decide to replace the above mentioned services by “money for care” (cash payments). This is the most common form of social support. In addition, people with limited financial resources may also benefit from social insurance sick leave benefits, as well as disability and old-age pensions. The main recipients of social services are disabled adults, severely disabled adults and elderly people.

The State supports patients’ organisations through the tendering of projects proposed by NGOs. Such procedures are handled by the Disabled Affairs Department under the Ministry of Social Security and Labour and by the Ministry of Health. Unfortunately, support is often provided on an annual basis and linked to the budgetary cycle of the ministries which leads to a lack of sustainability. Furthermore, only limited resources are available and these are linked to specific activities. Funds are not granted for permanent staff wages. Umbrella organisations have tended to receive such funding in the past but small organisations also compete for the same funds. There are no accurate estimations as to the final allocation of such funds.

4.17.1.3 The overall funding of social support for people with dementia and carers

Social services are funded through general taxation and in many cases there are co-payments.

Some social services are financed through the municipal budget whereas for the provision of social care for severely disabled people, there are special targeted subsidies from the State budget. The municipality decides on the co-payment for social services by carrying out an assessment of income (for social attendance) or a means assessment including income and property (in the case of long-term social care). In some cases, percentages (e.g. 20%, 50% or 80%) of income are set as minimum limits and maximum ceilings for co-payments but 100% payments are possible in some cases.

Cash benefits are mostly funded through the state social insurance scheme. Certain allowances (mostly related to poverty) are paid through general taxation. The obligatory health insurance fund is a source of reimbursement for certain costs (e.g. linked to incontinence). Moreover, the services of a social worker, who is also a member of a community mental health care team, are included in the primary care capitation fee calculation.

The Decree of the Minister of Social Security and Labour and the Minister of Health, which came into force on 01.07.2005, approved the rules for the reimbursement of

the costs of special permanent care and attendance, vehicle acquisition and adjustment and transportation. Children, disabled adults and elderly dependent people may be entitled to such reimbursements. The amendment of this decree, which came into force on 1 January 2007, included dementia. A score of 0-10 on the Mini-Mental State Examination (MMSE) was taken as an indicator for special permanent care and an MMSE score of 11-20 as an indicator for special permanent attendance (assistance).

4.17.1.4 The legal framework surrounding the provision of social support

The Ministry of Social Security and Labour elaborated and recently adopted a long list of legal documents in the field of social support. However, the actual implementation of the new approaches is of increasing concern.

4.17.1.5 The suitability of social support for people with dementia and carers

4.17.1.5.1 Adequacy and accessibility in general

The adequacy and accessibility of services for disabled people (including people with severe dementia), elderly sick people, other people with diagnosed diseases and (minimally) carers is limited. People living in rural and deprived areas have difficulties accessing adequate services. One of the reasons for this is that local budgets are somewhat limited and this is the main source of funding for social services.

In short, care is predominantly targeted at disabled people and social support is mostly linked to the incapacity to work. Therefore, assistance targeted at people with certain diagnoses is practically inexistent. The only exception to this is severe dementia which last year was officially recognised by general practitioners as a special need.

On the other hand, the level of support to be provided is established through the needs assessment procedure. So the actual support given to people with dementia at local level could significantly vary from one municipality to the next (depending on local resources, professional capacity, infrastructure, political priorities and attitudes).

4.17.1.5.2 People living in rural areas

As stated above, people with dementia and carers living in rural areas often have difficulty accessing adequate services.

4.17.1.5.3 People from ethnic minorities

There is no social support or services specifically targeted at people with dementia and their carers from ethnic minorities.

4.17.2 Services and support for people with dementia and their carers

4.17.2.1 Types of care

4.17.2.1.1 Day care

There are day care centres in Lithuania but with regard to mental health, the day care centres are mostly targeted at providing care for children. NGOs have played an important role in initiating and establishing a network of day care centres for mentally disabled children. According to official statistics, 1,700 volunteers worked in day care centres in 2006.

Day care centres with activities for adults (including those with dementia) are being piloted. For example, such a centre was recently created in Vilnius with financial support from the European Social Fund. According to official statistics, 14,400 elderly people attended day-care centres for the elderly in 2006. 6,000 disabled adults (of which almost 50 percent were of retirement age) received care in the relevant day-care centres. Day care is partly funded by the State. Funding from public sources is supplemented by co-payments (the amount of which is calculated on the basis of an income assessment).

4.17.2.1.2 Respite care

Respite care in the home exists but there is insufficient information about it. The regulatory framework for short-term residential respite care has been established but there is no information available as to the actual availability of this service.

4.17.2.1.3 Long-term residential care

Long-term residential respite care exists. It is partly funded by the State/municipal budgets and partly by service users. Means testing is applied which covers both income and assets. Up to 80% of a person's income can be taken into account. Property may be included when the person's income is insufficient (European Commission, 2006). This service is considered insufficient. At the beginning of 2007, there were 520 people with dementia out of 5,302 residents and a further 455 people on the waiting lists for social care facilities for the mentally disabled. This situation must be considered in the context of a lack of alternative support.

4.17.2.1.4 Palliative care

Palliative care at home is not available. However, health care institutions intend to introduce such a service. The prices and rules for payment for palliative care services to be covered by the Statutory Health Insurance Fund should soon be adopted. Whilst, the planned palliative care at home service is not directly targeted at people with dementia, those with a co-diagnosis might eventually benefit from these planned measures. In general, terminally ill patients are admitted to different healthcare institutions, but the largest number is admitted into nursing and

long-term hospitals (European Association for Palliative Care, 2005). However, palliative care for people with dementia at palliative care centres is not available.

4.17.2.1.5 Monitoring in the home via alarm systems

Tele-alarm systems are not available from the State or from NGOs, volunteers or the Church.

4.17.2.2 Personal assistance and home help

Under the new Law on Social Services, a distinction is made between social attendance at a person's home whereby home helpers provide services for up to 4 hours per day and social care at a dependent person's home whereby various specialists provide guardianship services for more than 4 hours per day (European Commission, 2006). Social attendance and social care are two types of special social services.

4.17.2.2.1 Personal assistance

4.17.2.2.1.1 Assistance with daily activities, incontinence and skin care

The following services are available and completely funded by the State:

1. Assistance with personal hygiene
2. Assistance eating and drinking (not with the preparation of food)
3. Assistance with mobility e.g. lifting, moving and walking
4. Assistance/supervision taking medication
5. Assistance dealing with incontinence

The first three services are funded through the municipal budget. These services are provided by municipal or contracted institutions/organisations but due to a lack of resources and capacity, they are often of limited scope. Priority is given to severely disabled people who live alone. The actual package of services provided is determined on the basis of an assessment of needs.

Assistance/supervision taking medication is also provided by municipal or contracted institutions/organisations and, as mentioned above, is often of limited scope with priority being given to severely disabled people who live alone. However, the actual assistance or supervision can only be provided by a licensed nurse and the costs are integrated into the primary health care capitation fee (which is the same mechanism used for financing integrated care).

Assistance dealing with incontinence is completely financed by the State Health Insurance Fund, but this is insufficient as physicians can only prescribe a limited number of incontinence pads. No assistance dealing with skin care (e.g. hydration and pressure sores) is available. Assistive devices are not available either.

4.17.2.2.1.2 Companionship, occupational therapy and home adaptations

Companionship/social activities are sometimes provided by patients' organisations on a project basis. NGOs obtain limited financial support from the State for this. They therefore have to rely on donations to support these activities.

There are occupational therapy rooms in the majority of community health centres. However, the activities provided are more club-like than therapy orientated and very few people with dementia take part in such activities. Some of the costs are covered as an integrated component of the payment for community mental health teamwork (under the capitation fee). Other costs are paid through targeted NGO projects.

Home adaptations/transformations are available and completely funded by the State. However, this is only for disabled people with limited mobility. There is a list of relevant disorders and the vast majority are clearly of a somatic nature. Home adaptations for people with mental disorders are virtually inexistent (except in the case of children). If and when financed by the State, various proportions of the cost are borne by the State and municipal budgets (depending on each individual case).

4.17.2.2.2 Home help

The following home help services are provided by municipal or other contracted institutions/organisations:

1. Assistance with housework
2. Help with the preparation of meals (including meals on wheels)
3. Assistance with shopping
4. Transportation
5. Assistance with laundry

Due to a lack of resources and capacity, the home help services mentioned above are of limited scope and priority is given to severely disabled people living alone. The actual assistance provided is dependent on a needs assessment.

According to official statistics, 7,900 people including 3,700 elderly people, 3,400 disabled elderly people and 700 disabled people of working age received home help in 2006. Most of them live in cities. 800 people (predominantly from rural areas) received financial compensation instead of support in kind. Home help is partly funded by State/municipal budgets and partly by service users subject to an assessment of their available income. In some cases, 100% public funding is possible.

4.17.2.3 Psychosocial support and training for people with dementia and carers

There is a general information service providing information about the availability of services to the public. It is completely funded by the State but according to Alzheimer associations, this is not sufficient for people with dementia and their carers.

Counselling for people with dementia, holidays for people with dementia and counselling for carers are available but of limited scope as there are very few NGOs providing such services. Those which do are partly funded by the State although less support for counselling carers is available than for counselling people with dementia. Patient organisations also receive some support from donors such as pharmaceutical companies.

There are no special provisions to enable carers to have a holiday e.g. payments or a substitute carer. Similarly, training for carers is not available.

4.17.2.4 Work/tax related support for people with dementia

There are no protective measures for people who have been diagnosed with dementia who are still in paid employment. They are not entitled to any tax refunds or benefits on the basis of their incapacity, to pay for someone to provide home care services or for necessary home adaptations.

People with severe dementia who need support with personal care and home help (from carers) are granted a cash payment. If they are living in a long-term social care facility, extra money is transferred from public funds to the social care facility on their behalf.

There are no reductions on television or radio licences or on public transport for people with dementia. However, old-age pensioners are entitled to numerous reductions on public transport, for newspaper/magazine subscriptions, telephone, Internet and visits to museums etc. (but not for TV and radio because they are mostly free of charge).

4.17.2.5 Work/tax related support for carers and carer allowances

Under the Law on Sickness and Maternity Social Insurance (IX-110/12.21.2000), a carer is entitled to take temporary paid care leave in order to take care of a member of his/her family. This leave is paid for by the employer and the social insurance fund.

Up to 30 days' unpaid time off work for caring is granted to employees to take care (on their own) of a disabled person in need of permanent nursing care. Employees can also request unpaid leave for a period of time recommended by the health institution to care for a sick relative. The two forms of unpaid leave are covered by the Labour Code.

An agreement can be made at any time between the employee and the employer concerning flexible working hours and a work schedule fixed. This is also covered by the Labour Code.

Carers are not entitled to tax benefits/incentives for the care they provide or to subsidised pension contributions. However, since 2006 carers of people with dementia can receive a monthly allowance from the municipal budget. This is regulated by the Government By-law on Approval of 2003/2012 National Social Integration Programme for Disabled and the respective regulation related to the special care/attendance needs recognition.

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4.18 Luxembourg¹⁸

4.18.1 Organisation and financing of social support to people with dementia and carers

4.18.1.1 Background information on the social/healthcare system in Luxembourg

In 1991, a Consultative Commission was set up to look into the possibility of creating a dependency insurance scheme. Users, carers and voluntary as well as private organisations were all invited to participate in the consultation which eventually led to the introduction of a long-term care insurance (LTCI) in 1999, known in Luxembourg as the “assurance dépendance” or “Plegeversicherung”. This was part of the government’s dual policy to support elderly and disabled people in their own homes for as long as possible whilst at the same time developing user-oriented care strategies.

Between 1998 and 2003, 17,933 requests for assistance were registered by the Ministry of Social Security. Of these, 83.2% were from people over 70 and of the accepted applications, 62.6% were from people in need of home care (Ferring and Weber, 2005).

4.18.1.2 The organisation of social support for people with dementia and carers

4.18.1.2.1 The long-term care insurance

Luxembourg’s long-term care insurance (LTCI) came into force in January 1999. It covers the long-term care needs for people who need considerable and regular assistance from another person for essential acts of daily living (ADLs). These acts include:

- personal hygiene: washing, oral hygiene, care of skin, hair and nails, and going to the toilet;
- nutrition: preparation of food adapted to the person’s needs and assistance eating it.
- mobility: assistance moving, comfortable positioning in a bed or chair, getting dressed and undressed, moving about within the home, sitting up, getting up and down stairs, going out and returning home.

Assistance includes carrying out all or part of the above-mentioned tasks on behalf of the person, or supervising/supporting the person so as to enable him/her to carry out the task autonomously. Once deemed eligible for services on the basis of required assistance with essential ADLs, a wider range of services is available. The LTCI also applies to people with dependency in residential care but in this report we will concentrate on provisions for people with dementia still living at home.

The minimum requirement for essential ADLs is at least 3 ½ hours per week for at least 6 months. A person’s needs are evaluated by the “Cellule d’évaluation et

¹⁸ The information in this report on social support for people with dementia and their carers in Luxembourg was taken mainly from the Law of 19 June 1998 on the Long-term Care Insurance and the websites of Hëllef Doheem, the Ministry of Social Security and Association Luxembourg Alzheimer.

d'orientation" (CEO) which then draws up a care plan on the basis of those evaluated needs. The CEO is a multidisciplinary team under the authority of the Ministry of Social Security. The final decision concerning entitlement to services and the amount of services to be provided is taken by the Union of Sickness Funds ("Union des caisses de maladie") based on information about the assessment carried out by the CEO. The Union of Sickness Funds is responsible for:

- the individual classification of dependency, as well as the attribution, reduction and suppression of the different benefits and services;
- the payment of nursing services, the elaboration of nursing contracts and the negotiation of the monetary value of nursing services;
- negotiation with service providers concerning the provision of nursing aids (Ferring and Weber, 2005).

4.18.1.2.2 Services in kind and direct payments

Care can be provided by informal carers (including relatives and partners) or by professionals. However, the CEO can modify the care plan (and in particular the amount of care provided by informal carers) if it feels that this would be in the best interests of the person with the care needs.

Assistance with essential ADLs cannot exceed 24 ½ hours per week or 38 ½ in exceptional cases (approved by the CEO). Services are provided "in kind" by professional carers. The limit of 24 ½ hours per week or 38 ½ for services (provided in kind) can be increased by 2 ½ and 4 hours respectively for household tasks (e.g. shopping, laundry, housework and the maintenance of essential equipment) if this is considered necessary by the CEO.

These services can be replaced by an allowance to purchase services from non-professional carers such as family and friends. However, this cannot exceed 7 hours per week. If a person has been assessed as being entitled to more than 7 hours' care per week, an additional payment can be made for half of the extra hours' care between 7 and 14 hours per week. For example, a person, who has been evaluated as needing 11 hours' care per week, could receive a payment for 9 hours (i.e. 7 hours plus half of the extra 4 hours). If a person needs more than 14 hours' care per week, the care must be provided completely by professional carers. Payments are tax free and transferred to a bank account every month.

In addition to services provided by informal carers and the established help networks, there are about 23 associations, registered with the Ministry of Family Affairs, which operate on a voluntary basis.

4.18.1.3 The overall funding of social support for people with dementia and carers

The LTCl is financed by people (whether they are Luxembourg residents or simply commuters from the surrounding countries) who contribute to the Luxembourg healthcare insurance. For the monthly contribution, each person pays 1.4% of his/her total gross income (less a quarter of the minimum social salary). For Luxembourg residents, investments, rental and other sources of income are also included in the calculation of annual contributions. The State also contributes towards the LTCl which is, in addition, partly financed by a tax on energy.

The price per hour of service (provided by professional carers) is EUR 52.44. Cash payments for informal carers (of half the amount paid to professionals) are granted up to a maximum of EUR 262.50 per month.

The payment of professional carers is weighted according to the qualifications of the carer. For example, a nursing aid has a coefficient of 1, a qualified nurse 1.3 and professionals such as psychologists and physiotherapists a higher coefficient. Unqualified domestic aids have a coefficient of 0.7 (Ferring and Weber, 2005).

People who need support but do not qualify for the LTCl as they need less than the minimum 3 ½ hours per week can still obtain services but must pay for them. They may be entitled to financial assistance towards the cost of the services but this is means tested (Ferring and Weber, 2005).

4.18.1.4 The legal framework surrounding the provision of social support

The Law of 19 June 1998 (“assurance dépendance”) led to the introduction of the obligatory long-term care insurance on 1 January 1999.

Loi du 23 décembre 2005 modifiant différentes dispositions du Code des assurances sociales en matière d’assurance dépendance. This law deals with the modification of certain measures in the code of social insurance with regard to the long-term care insurance.

The Law of 28 August 1998 on Hospital Establishments grants patients suffering from an incurable and terminal illness the right to a dignified death by avoiding “acharnement thérapeutique¹⁹” and maintaining as far as possible the quality of life. It is stipulated that the doctor must assist the dying person right to the end and act in such a manner as to permit the patient to maintain his/her dignity. It is the doctor’s duty to provide palliative care in order to help alleviate physical and psychological suffering. In addition, he/she must also provide the relatives of the patient with adequate assistance to relieve their suffering. Finally, as the patient approaches death, he/she has the right to be permanently accompanied by at least one person of his/her choice in conditions which permit his/her dignity to be respected.

¹⁹ This means the relentless pursuit of treatment even when there is no hope of recovery, cure or improvement.

The Grand Ducal Decree of 5 November 1999 covers the financing of home adaptations.

4.18.1.5 The suitability of social support for people with dementia and carers

Information on the suitability of social support for people with dementia and their carers was unfortunately unavailable. This was also the case for services and support for people living in rural areas, people with different types of dementia, younger people with dementia and people from ethnic minorities.

4.18.2 Services and support for people with dementia and their carers

4.18.2.1 Types of care

4.18.2.1.1 Day care

The Association Luxembourg Alzheimer has 6 specialised day care centres for people with dementia in the following towns: Luxembourg (Bonnevoie and Dommeldange), Esch-sur-Alzette, Dahl, Berchem and Rumelange. The LTCI covers specialised day care. The CEO decides how many days per week of day care a person is entitled to under the LTCI. In rare cases, people with dementia are authorised to attend a day care centre 7 days a week. For this reason, the centre at Bonnevoie is open 7 days a week and there is another centre in the north of Luxembourg which opens on a Sunday if there is sufficient demand. The LTCI covers part of the cost of day care and the person attending the centre must pay EUR 21.53 per day in addition.

Hëllef Doheem has 7 psycho-geriatric day care centres.

4.18.2.1.2 Respite care

Respite care at home is available in Luxembourg. This consists of a qualified person spending the day at the home of the person needing the service. Some also engage in activities designed to stimulate memory and improve mobility.

In Howald, a suburb of Luxembourg, there is a psycho-geriatric care home (Foyer Hesper Kopp) which provides night time care so as to give informal carers a break. It is run by Hëllef Doheem.

Every year, the person in need of care receives twice the amount of his/her LTCI allowance which can be used to finance a stand-in person for three weeks' respite care. The three weeks do not have to be used all at once.

There are a number of establishments in Luxembourg offering long-term residential care. The nursing homes in Differdange, Echternach and Vianden have units for people with dementia. In January 2004, there were 49 institutions (34 integrated centres for the elderly and 15 nursing homes) with a capacity of 4,562 beds (Ferring and Weber, 2005).

4.18.2.1.3 Palliative care

Specialised palliative care teams provide global care to the person in need of palliative care and to his/her family. These teams operate a helpline and home visits 24 hours a day, 7 days a week throughout the whole of Luxembourg. Support can also be provided to families following the death of their loved ones.

“Omega 90” is an organisation which is financed by the Ministry of the Family and also through private donations. It is made up of several organisations (including Amiperas, Caritas, Croix-Rouge, Fondation Luxembourgeoise contre le Cancer, Hëllef Doheem and Doheem Versuergt) and has a helpline run by professionals. It also organises and trains volunteers who visit the dying and their families in hospitals and at home in order to provide company and support.

4.18.2.1.4 Monitoring in the home via alarm systems

The organisation “Hëllef Doheem” organises a 24 hour tele-alarm system known as “Secher Doheem”. This service is provided by means of a simple device which is linked to the person’s telephone combined with a bracelet or necklace which emits a signal. People with a monthly income exceeding EUR 1,581 must pay EUR 36.18 per month for the service plus EUR 94.12 for the installation. People with less than EUR 1,581 per month may be entitled to financial assistance from the commune in which they reside but the amount paid varies from one commune to the next (Service Télé-Alarm, 2007).

4.18.2.2 Personal assistance and home help**4.18.2.2.1 Personal assistance**

The following services are available in Luxembourg and covered by the LTCI:

1. Assistance with personal hygiene (including brushing teeth, skin care, hair care, nail care and going to the toilet)
2. Assistance with mobility
3. Assistance with eating and drinking (including cutting up and mixing food)

4.18.2.2.2 Home help

The following services are available in Luxembourg and covered by the LTCI:

1. Assistance with housework
2. Assistance with shopping
3. Assistance with laundry
4. Assistance maintaining essential household equipment in order

The two biggest providers of home help services and personal assistance are Hëllef Doheem and HELP.

A meals-on-wheels service is operated throughout the whole country by various communes, cities and the Red Cross.

The CEO can authorise products that are necessary for assistance and care. For example, dependent people who are incontinent are entitled to a monthly payment of EUR 95.72 to pay for or contribute towards the cost of continence pads. This amount is index linked.

4.18.2.2.2.1 Home adaptations and assistive technology

Home adaptations may be authorised by the CEO if considered necessary to allow a person to maintain or increase his/her autonomy with regard to personal hygiene, the preparation of meals and mobility both in and out of the home. The amount paid is fixed by decree. In June 2007, the limit was EUR 26,000 (Ministry of Social Security, 2007). Unfortunately, the procedure for obtaining approval for a grant for home adaptation is quite lengthy. It can take up to two years.

It is also possible to obtain financial aid for extra costs incurred as a result of moving into accommodation that is more suited to a person's degree of dependency. The maximum amount granted is EUR 300 per month and not more than EUR 26,000 in total.

Assistive devices may be authorised by the CEO to allow a person to maintain or increase his/her autonomy with regard to personal hygiene, nutrition and the preparation of meals, mobility both in and out of the home, getting dressed, domestic tasks, shopping and both verbal and written communication. In addition, assistive devices may be authorised for needs linked to security and the prevention and relief of pain. Assistive devices are usually provided on loan but if this is not possible, a grant may be provided so that the person can purchase the necessary equipment. The grant from the LTCI will not exceed EUR 26,000.

It is not necessary to need a minimum of 3 ½ hours' care per week for essential ADLs to be eligible for a technical aid or a home adaptation. The need must, however, be justified and approved by the CEO. Both home adaptations and assistive devices may also be authorised to help carers ensure the provision of assistance and care.

4.18.2.2.2.2 Support services

A range of services, described as "support" are available under the LTCI. They include:

- Surveillance of the dependent person at home
- Helping the dependent person with administrative tasks e.g. official paperwork
- Excursions/social activities
- Individual or group support

The LTCl covers a maximum of 14 hours of support services per week.

4.18.2.2.3 Advisory services

Under the LTCl, advisory services are available but for a limited period of time. They include:

- Advice on essential ADLs
- Advice on the use of assistive technology
- Advice to carers and relatives

4.18.2.3 Psychosocial support and training for people with dementia and carers

The Association Alzheimer Luxembourg (ALA) has a round the clock telephone helpline. Hëllef Doheem also has a helpline providing information on its services, the long-term care insurance and potential measures to be taken to enable people to continue living at home (Ferring and Weber, 2005).

ALA organises self-help groups for carers. Sometimes, carers can come with the person with dementia who is looked after whilst they attend the meeting. These support groups are free of charge but carers are invited to make a voluntary contribution if they so wish. There has not been sufficient demand for support groups for people with dementia.

There are no organised holidays for people with dementia and/or carers with the LTCl system. However, as mentioned in the section on respite care, people with dementia receive an extra allowance to enable them to arrange for stand-in carer for up to three weeks per year and to give the informal carer a break.

Training sessions for informal carers are regularly organised and provided by ALA. Most courses are offered in Luxembourgish, but also in French if there is sufficient demand. These courses cost EUR 25 for 10 sessions.

4.18.2.4 Work/tax related support for people with dementia

Information on work/tax related support for people with dementia was unfortunately unavailable.

4.18.2.5 Work/tax related support for carers and carer allowances

On the basis of a declaration made by the dependent person, the LTCl pays the social contributions of the carer to the State pension (provided that he/she does not have a private pension). This payment covers the contribution of the employer and that of the insured person. The actual amount is calculated on the basis of the minimum monthly salary of an unskilled worker.

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4.19 Malta²⁰

4.19.1 Organisation and financing of social support to people with dementia and carers

4.19.1.1 Background information on the social/healthcare system in Malta

As Malta is so small (316 km² with a population of 400,000), all policies are promulgated and passed by the national government. There are consequently no formal regional or district tiers of health care.

Nevertheless, there are 68 local councils. They do not have any policy making power but many have an elected person who is responsible for monitoring the provision and quality of services for the elderly.

In Malta the Civil Code clearly places the responsibility of caring for a spouse or parent with family members. According to the Maltese Civil Code (Book first of persons, art. 2), a married person who is in need of help with daily living can rely on maintenance from his/her spouse provided that they still live together. Maintenance is defined in article 19, paragraph 1 as including food, clothing, health and habitation. Children are bound to maintain their parents or other ascendants who are indigent. However, neither of the spouses can claim maintenance from their children if such maintenance could be provided by the other spouse (art. 5.3). No one is legally obliged to care for unmarried people or widows with no children. The State would be responsible for their care.

There is little interaction between state, private and voluntary providers but Forum Malta in Europe works to strengthen the interface between government and NGO's.

4.19.1.2 The organisation of social support for people with dementia and carers

In 1987, the Government set up a Department for the Care of the Elderly which is responsible for taking care of the special needs of the elderly. The aim, in providing these services, is to enable elderly people and those with special needs to remain living within the community for as long as possible. Community services for the elderly and for people with special needs are heavily subsidised by the State. People receiving such services pay a nominal fee based on their income (Ministry of Health, 2002).

Services are not targeted specifically for people with dementia and they are slow to respond especially in times of crisis. Entry into a long stay government home may take months to arrange.

As mentioned above, social support, when provided, is organised through the Department for the Elderly and Community Care. Social Workers are responsible for conducting assessments for people in state hospitals or in the community.

²⁰ The information in this report on social support for people with dementia and their carers in Malta was provided by Dr Charles Scerri and Dr Stephen Abela from the Malta Dementia Society.

Requests for the homecare help service must be accompanied by a medical report. This is sent to the Department for the Elderly and Community Services, which then arranges for a social worker to visit the applicant in their home in order to assess their needs. The number of hours granted is dependent on each person's needs.

There is a Ministry for Social Policy but this is more to do with families and children, disability affairs and addictive behaviour.

4.19.1.3 The overall funding of social support for people with dementia and carers

Health care and services are funded through general taxation. The health care system is publicly financed through general taxation and is free at the point of delivery although users may have to make out-of-pocket payments. Private healthcare is fairly common (Ministry of Health, 2002). National (social) insurance serves to fund pensions.

The government may also provide support for people with dementia through specific grants. Over the last two years, the Malta Dementia Society obtained a grant to attend Alzheimer Europe conference in Paris. They also obtained two other grants through a national charity event known as iStrina which takes place at the end of the year. The grants were for specific projects: the first for information leaflets and the second for a national helpline.

4.19.1.4 The legal framework surrounding the provision of social support

The main legislation that governs home care in Malta is the Social Security Act (Cap. 318). This law deals with the provision of benefits, assistances and pensions to the poor, sick, elderly and the unemployed. A Carer's Pension is payable to "all unmarried or widowed persons who are taking care, on their own of a parent who is bed-ridden or confined to a wheel-chair". A legal notice entitled State Financed Services Rate Regulations (L.N. 259 of 2004) determines the amount that an elderly person residing in state financed homes shall contribute to Government for his/her care and upkeep. Care is classified as Level 1 care, where residential care with only minimal basic care is provided and Level 2 care where the residential service provided includes such level of care that goes beyond minimal basic care as certified by the Interdisciplinary Assessment Team within the Elderly and Community Services Department.

Relevant laws include the Social Security Act, Chapter 318 and the Mental Health Act, Chapter 262.

A white paper has been drafted which will regulate the work of NGOs and can be found at:

http://msp.gov.mt/documents/ngo/strengthening_voluntary_sector.pdf

4.19.1.5 The suitability of social support for people with dementia and carers**4.19.1.5.1 Adequacy and accessibility in general**

There is no problem with accessibility although many services need to be up-graded. Services in the community such as day care, respite care and community psychiatric nurses are scarce.

4.19.1.5.2 People living in rural areas

Since Malta is a small country, there are no difficulties with accessibility to services and support for people living in rural areas.

4.19.1.5.3 People with different types of dementia

There are associations for people with conditions that are at a higher risk of developing dementia e.g. Huntington’s disease or Down’s syndrome.

4.19.1.5.4 People from ethnic minorities

There are no special provisions for people with dementia and carers from minority ethnic groups.

4.19.1.5.5 Younger people with dementia

There are no specific services targeted at younger people with dementia. However, they would be able to access the regular services that are available in general.

4.19.2 Services and support for people with dementia and their carers**4.19.2.1 Types of care****4.19.2.1.1 Day care**

There are 13 day centres mainly for people who are over 60 years of age. Priority is given to elderly people living alone, those who are not involved in social activities and those who could be at risk spending long hours on their own. The centres, which are open 5 days a week, offer physical education, social and creative activities and sometimes educational talks on relevant issues e.g. health, home safety and welfare services. Intergenerational activities are encouraged and outdoor activities are organised twice monthly. People attending day centres are required to pay a nominal fee (ranging from Lm 1 to Lm 2.5 a month depending on how many times they attend the centre) with an additional 50 cent charge being made for couples.

Although it is the responsibility of the national government to provide day-care centres, it is often on the initiative of local councils which in many cases also provide and furnish the actual building.

A new day centre is starting which will have 20 places for 3 times a week specifically for people with dementia. This is funded by the state. This centre, known as the Paul Cuschieri Activity Centre, was officially opened in July 2007 and is located

within the grounds of St. Vincent de Paul Residence (a long-term institution). Staff members have received training on person-centred dementia care.

4.19.2.1.2 Respite care

Respite care is mainly provided at Zammit Clapp Hospital, a specialised geriatrics assessment and rehabilitation hospital and at St. Vincent de Paul Residence, a residential complex. Both these units are state-run and free. However, places are limited and an application has to be submitted beforehand. Respite can also be organised in residential homes run on a profit making basis, as well as in church-run residential homes.

There are not enough respite care services even though there is an ever increasing demand. Night services are non-existent and sitting services do not exist.

Respite beds are available at one hospital for 2 weeks and at one long-stay residence for 6 weeks. This service is provided by the government for free but it is never enough. Respite can also be organised in private homes (at the service user's own expense).

4.19.2.1.3 Long-term residential care

In Malta, long term care is provided by the state and can also be church-run or private. The choice depends on the ability and preference to pay for these costs through self-funding.

If the person does not have the financial resources to pay for their own care, then the only option is to apply for long-term care from the state. The government has two types of facilities. The Government Community Homes (totalling 7 small community homes with approximately 620 places) are intended for physically independent elderly people requiring sheltered accommodation. For those who enter into such schemes, 60% of their total income is levied by the government. Those who have more nursing needs are admitted to the St. Vincent de Paul Residence, a long stay facility of approximately 1000 beds. This residence provides a mixture of nursing/long-stay beds in around 27 wards. For these residents, 80% of their total income is levied by the government.

For those who can afford and prefer to fund their own care, church homes or private homes are an alternative. There are about 10 church homes each housing between 50 and 200 elderly residents. Church homes charge smaller fees (around Lm 10 – Lm 15) but in view of their popularity, the number of places is limited and waiting lists for an available place are longer. Church homes provide care for both independent and dependent residents.

Private homes cost more than church homes and charges depend on the individual home and on care needs. Prices can range from Lm 15 for basic care to Lm 30 for highly dependent clients. There has been a lot of interest in this area. Consequently,

several new private homes have been established to meet the increasing demands. There are usually enough places available in the private homes.

4.19.2.1.4 Palliative care

The Malta Hospice Movement offers a comprehensive range of services to terminally ill people, most of whom are elderly. This is partly funded by the state and includes home care, day therapy, spiritual support, night and day nursing in the home, respite care, assistance with bathing and hairdressing. However, this is solely for terminally ill patients with cancer or motor neurone disease, not for people with dementia.

4.19.2.1.5 Monitoring in the home via alarm systems

There is a tele-alarm system, known as TELECARE, which is run by the government and the local telephone operator “MALTACOM”. The telecare service is partly funded by the state and is designed to enable subscribers to call for help when needed. It gives older people, those with special needs and also their friends and relatives a feeling of security and encourages subscribers to carry on living in their own homes. The service is available to elderly couples/people living alone aged 80 and over, people over 70 suffering from a chronic illness, people of any age living alone who are afflicted by a life threatening illness and people who are afflicted by a life threatening illness whose carers would benefit from the service. In case of emergency, the elderly person just needs to press a button on the unit itself or on a pendant worn round the neck and a call is made to the Control Centre which has full medical details as well as the contact details of the person, the doctor and two relatives, friends or neighbours who have a key. The service costs Lm 1 per month for single people and Lm 1.16 for two people living together. The Malta Dementia Society considers this a good service.

Assistive devices are not well developed yet. MALTACOM has a system of telephone linked alarms for gas leaks, smoke, flooding, theft, etc. There is a subsidised rental fee but it is highly subsidised by MALTACOM as the company’s commitment to social responsibility.

The Independent Living Advice Centre is an organisation run by volunteers which promotes the use of technical aids to enable frail and elderly people with disabilities to manage daily activities and retain their independence.

There is a procedure for people to obtain financial support to adapt a bathroom or to fix a stair lift. People with disability, including people with dementia, are eligible.

4.19.2.2 Personal assistance and home help

4.19.2.2.1 Personal assistance

A community nursing service is provided which is a good service and reaches all those who need it. This is completely funded by the state. This community nursing services provide a range of nursing services including skin care.

Supervision of medicine is also available from community nurses who may visit patients for short courses of drug administration if required such as injections or pessaries. This is completely funded by the state.

Assistance with mobility is provided by community nurses but this service is not sufficient. Domiciliary visits by a physiotherapist can be organised for assessment and short courses of therapy. This is completely funded by the state.

An incontinence service is available to people over 60 years of age or younger people with special needs. Incontinence pads/diapers are heavily subsidised in order to permit people with this problem to continue living in the community. Nevertheless, there is a charge which ranges from 7 cents to 11 cents each.

4.19.2.2.2 Home help

The homecare help service provides non nursing care, personal assistance and help with light domestic work to older people i.e. over 60. The services are adapted to each person's individual needs. People over the age of 85 are given priority. Other criteria include having special needs and the ability to live a relatively independent life in one's own home if given assistance, being terminally ill or living alone with no formal or informal family support network. There is a nominal fee of Lm 1 per week for a single person and Lm 1.50 in the case of more than one person benefiting from the service. The preparation of meals incurs an additional charge of 50 cents for a single person and 75 cents for more than one person. This service includes housework, preparation of meals and assistance with shopping.

The Malta Dementia society reports that this is a highly abused service and is now being limited to 4 hours/ week.

Transportation services are only available to and from hospitals and out-patient clinics.

Meals-on-wheels are provided 7 days a week by the Maltese Cross Corps (a non-governmental organisation) and the Catholic Action Movement in collaboration with the Department for the Elderly and Community Services. People over 60 years of age and people with disability, who are unable to prepare their own meals, can benefit from this service. Each meal costs 95 cents (approx. EUR 2.2). When delivering the meals, the specially trained staff ask whether the elderly person needs anything and keep an eye on the person's home environment. They are expected to report anything unusual to the organisers of the service.

4.19.2.3 Psychosocial support and training for people with dementia and carers

There is a general information centre for community services provided by the department of the elderly.

At Zammit Clapp Hospital (Geriatrics Unit of 60 beds and Day Hospital) there is a memory clinic. New patients and carers are enrolled on a “memory class” which provides group therapy for patients while carers attend for caregiving skills.

In addition, the social work unit provides psychological counselling, guidance and assistance to certain categories of elderly people including those with dementia and those living alone with a high level of dependency. The unit “deals with social casework, provides advocacy for clients, facilitates self-help management and develops action plans, performs crisis intervention work, provides assessments for residential homes, home care help service and assessments of Carer’s Pension for the Department of Social Security, and liaises with the geriatric, general and rehabilitation hospitals, the Health Department, police, Local Councils and other community organisations.” A medical report is necessary to benefit from this service. Once approved, either the social worker visits the person in their own home or the person has a meeting with the social worker at the offices of the Department.

There are some training opportunities for carers of people with dementia. These include the memory classes at Zammit Clapp Hospital and regular talks and video presentations to caregivers organised by The Malta Dementia Society. This is a free service.

There is no provision for people with dementia and/or their carers to take a holiday.

4.19.2.4 Work/tax related support for people with dementia

People with dementia are not entitled to protective measures if in paid employment. There are some early retirement schemes which may entitle them to tax refunds and benefits on the basis of personal incapacity. People with dementia are not entitled to direct payments to pay for services or for tax refunds or incentives for employing someone to provide home care services.

People with dementia in Malta are entitled to financial reimbursement for home adaptations following assessment by occupational therapy or social work departments. This is governed by the Social Security Act.

There are no entitlements for reduced cost television or radio licences or public transport on the grounds of dementia. However, a card, called the Kartanzjan card, is issued automatically to every person upon his or her sixtieth birthday. It must simply be collected at the local council office. This card entitles its holder to obtain certain rebates and concessions e.g. free football ground tickets, reductions on bus

fares, reductions on the Gozo ferries and other establishments, reductions on certain Air Malta flights, and telephone rebates. A second version of the Kartanzjan is issued upon the person's seventy-fifth birthday which grants additional benefits (Government of Malta, 2007).

4.19.2.5 Work/tax related support for carers and carer allowances

Carers are entitled to take unpaid time off work for caring but not paid leave. Carers can apply for this responsibility leave, granted on a yearly basis, to take care of a dependent relative. They can also apply for flexible working in the form of reduced hours.

Carers are not entitled to free or subsidised pension contributions. They can, however, receive payment from the state for caring in the form of the Carer's Pension. This is granted to an unmarried relative who all by him/herself and on a full-time basis cares for a dependent person living in the same residence. The applicant must not have capital resources exceeding Lm 6,000 (EUR 13,976). The weekly amount paid is Lm 35.82 (EUR 83.51). Additional bonuses of Lm 1.34 (EUR 3.12) per week and Lm 58 (EUR 135.10) per six months are also paid (Government of Malta, 2007).

Carers are not entitled to any other tax incentives or benefits.

4.19.3 Bibliography

Unless otherwise stated, information provided by Dr Stephen Abela and Dr Charles Scerri (Malta Dementia Society) between April and September 2007

The website of the Government of Malta can be found at: <http://www.gov.mt/index.asp?l=2>

4.20 Netherlands²¹

4.20.1 Organisation and financing of social support to people with dementia and carers

4.20.1.1 Background information on the social/healthcare system in the Netherlands

In the Netherlands, over 10% of the population has a chronic somatic illness and over 16% have a long-term psychological disorder. It became clear towards the end of the 1980s that extra attention needed to be paid to the needs of people with chronic disorders. There was a gradual move towards community-based care and a shift in focus from the illness to the person with the illness. Current measures are intended to help people live independently in their own environments for as long as possible (Ministry of Health, Welfare and Sport, 2007a).

As of January 2006, a new insurance system for curative healthcare came into force in the Netherlands. Under the new Health Insurance Act (*Zorgverzekeringswet*), all residents of the Netherlands are obliged to take out a health insurance.

Another important recent change is the Social Support Act (*Wet maatschappelijke ondersteuning, WMO*), which came into force in the Netherlands on 1 January 2007. The WMO covers the care and support of people with prolonged illness, invalidity or age-related diseases.

4.20.1.2 The organisation of social support for people with dementia and carers

The new health insurance comprises a standard package of essential healthcare. The package provides essential curative care tested against the criteria of demonstrable efficacy, cost effectiveness and the need for collective financing.

Under the new Social Support Act (WMO), municipalities are responsible for providing social support to those in need regardless of the level of support they may have from friends, family or acquaintances. The Ministry of Health, Welfare and Sport (MHWS) defines the framework within which municipalities can develop policies in keeping with the composition and demands of their inhabitants (MHWS, 2007b).

The municipalities are legally obliged to provide care services to the elderly and disabled (MHWS, 2007a). People in need of care can apply to a special municipal agency for care services. If assessed as needing domestic care, personal care, nursing, supportive guidance, activity guidance or temporary residential care, the agency decides which services and how much of each service the person is entitled to. The person can then decide whether to have the services in kind, a cash payment or a combination of the two. The cash payment is known as a personal budget or “*pgb*”. Since 2007, amounts up to EUR 2,500 need not be accounted for whereas amounts over EUR 2,500 per year must be used to pay people or agencies to provide care. Relatives can be paid provided that a contract is made.

²¹ The information in this report on social support for people with dementia and their carers in the Netherlands was provided by Marco Blom from the Dutch Alzheimer Association.

The municipalities are responsible for the provision of assistance with housework, as well as for aids, mobility and wellbeing. They can also offer a personal budget. This means that people may end up with two different personal budgets (MHWS, 2007c).

People with dementia and their carers do not make much use of the personal budget. They prefer to seek assistance from the service providers.

4.20.1.3 The overall funding of social support for people with dementia and carers

Before 2006, there were two types of health insurances: compulsory and voluntary. Employees, people entitled to a social benefit and self-employed people with incomes up to a certain level were compulsorily insured under the Social Health Insurance Act (Ziekenfondswet). People on a higher income could choose to either take out a private health insurance or to go through life uninsured.

The new system is a private health insurance with social conditions. The system is operated by private health insurance companies and the insurers are obliged to accept every resident in their area of activity. A system of risk equalisation enables the acceptance obligation and prevents direct or indirect risk selection.

The insured pay a nominal premium to the health insurer. Everyone with the same policy pays the same insurance premium which is currently approximately EUR 1,100 p.a. (Hoogervorst, 2007). The remainder of the cost is paid by the insured through income-related contributions. Employers contribute by making a compulsory payment towards the income-related insurance contribution of their employees.

In the Netherlands, everyone who pays health insurance premiums is now entitled to a rebate of up to EUR 255 if no claim is made during the preceding year. This scheme, known as the 'no-claim rebate rule', was introduced in 2005. Those who do incur health costs, but less than EUR 255, will receive a reduced rebate equal to the difference between the actual costs and the maximum rebate amount. Those whose healthcare costs exceed EUR 255 will receive nothing. At the end of 2005, almost four million Dutch policyholders received a full or partial rebate.

The costs of GP consultations are not included in the calculation for rebate entitlement. The no-claim rebate rule applies only to the standard insurance cover, and not to any supplementary policies. Moreover, the rule does not apply to people under the age of 18 (since they do not pay premiums).

The personal budget mentioned in the previous sub-section is not dependent on income but the co-payment for it is.

4.20.1.4 The legal framework surrounding the provision of social support

As stated above, social support to people with dementia and carers is provided in the framework of the new Health Insurance Act (Zorgverzekeringswet) which

came into force on 1 January 2006 and the Social Support Act (Wet maatschappelijke ondersteuning), known as the WMO, which came into force on 1 January 2007. The WMO encompasses three other laws, namely, the Services for the Disabled Act (WVG), the Social Welfare Act and some parts of the Exceptional Medical Expenses Act (AWBZ) (MHWS, 2007b).

4.20.1.5 The suitability of social support for people with dementia and carers

4.20.1.5.1 Adequacy and accessibility in general

There is a large national programme currently running which is targeted at improving the quality and quantity of care provided. This National Dementia Programme aims to stimulate the regions to create better, more and different care arrangements. At the moment, services are inadequate and availability is poor due to huge regional differences in care arrangements and the existence of waiting lists for certain services such as nursing homes, small-scale housing and day care.

4.20.1.5.2 People living in rural areas

People living in rural areas do not have particular problems accessing services although transportation is sometimes problematic. However, it is important to note that the greying of the population is particularly noticeable in rural areas, so this may result in a shortage of services.

4.20.1.5.3 People with different types of dementia

In the Dutch system, there is no differentiation between types of dementia. Social support is provided for all types of dementia although it is possible that people with fronto-temporal dementia may be considered unsuitable for small-scale housing.

4.20.1.5.4 People from ethnic minorities

There is a whole range of services targeted at people with dementia and carers from ethnic minorities but they are not used much and funding varies.

4.20.1.5.5 Younger people with dementia

There are specialised nursing homes, day-care programmes, group-based interventions and mental health services specifically for younger people with dementia. There are no other differences in the provision of care for this group.

4.20.2 Services and support for people with dementia and their carers

4.20.2.1 Types of care

4.20.2.1.1 Day care

Day care exists and is completely funded by the State but it is insufficient. Potential service users must fulfil certain criteria in order to be eligible for day care.

4.20.2.1.2 Respite care

Respite care in the home is available but insufficient. It is partly funded by local municipalities and partly by service users. This service is also provided by volunteers and Alzheimer associations.

Short and long-term residential respite care is available but is insufficient. In the future, more long-term residential respite care will be needed. Short-term respite care is partly funded by the State and partly by service users, whereas long-term respite care is completely funded by the State.

4.20.2.1.3 Long-term residential care

Most long-term residential care is financed by the so-called Algemene Wet Bijzondere Ziektekosten. This is a non-means-tested social insurance programme financed by premiums. In most of the institutional settings, residence and care are integral parts of the services provided. The government has started a process to separate residence from care and intends to separate the costs for care and rent, or residence, in institutional settings. Furthermore, care recipients will be allowed to organise housing on a private basis (e.g. to rent it from a real estate company) and to receive care on a separate basis from another party (van Waarde, 2007).

4.20.2.1.4 Palliative care

Palliative care at home is available and sufficient. It is partly funded by the State and partly by service users. Palliative care in a centre is completely funded by the State but this service is considered insufficient.

4.20.2.1.5 Monitoring in the home via alarm systems

Tele-alarm systems exist and are partly funded by the State (by municipalities). This service is not considered sufficient.

4.20.2.2 Personal assistance and home help

4.20.2.2.1 Personal assistance

The following services are available and partly funded by the State (the municipalities). They are considered insufficient:

- Assistance with personal hygiene
- Supervision/assistance taking medication
- Assistance with eating and drinking (not the preparation of food)
- Assistance with mobility e.g. lifting, moving and walking

Assistance with incontinence is covered by the health care insurance. It is completely funded by the State. Assistance with skin care, on the other hand, must be completely funded by service users. Neither of these services is considered sufficient.

Municipalities partly fund companionship/social activities and occupational therapy but these services are insufficient.

Assistive devices and home adaptations are available but are insufficient. Home adaptations are partly financed by the State but service users must pay for assistive devices themselves. The State does not contribute towards the costs.

4.20.2.2.2 Home help

The following services are partly funded by the State but they are considered insufficient.

- Assistance with housework
- Assistance with the preparation of meals (including meals-on-wheels)
- Transportation

Assistance with shopping and laundry is also available but insufficient. Service users must pay the full cost for these services.

4.20.2.3 Psychosocial support and training for people with dementia and carers

Numerous organisations provide general information on the availability of services. They are not funded by the State. People with a personal budget have set up their own organisation to protect their interests. It is called Per Saldo. It provides legal support, a telephone helpline, information, meetings and courses, as well as an electronic marketplace for people seeking services and service providers (MHWS, 2007c).

Counselling services are available for people with dementia and carers but the services for people with dementia are only available in a few places. When available, counselling is partly funded by the State.

Holidays for people with dementia are sometimes organised by voluntary organisations and Alzheimer Nederland. However, service users have to cover the full cost themselves. There are no provisions to enable carers to have a holiday e.g. substitute carers.

Training is available for carers. It is partly funded by the State and partly by the service users.

The above-mentioned services are considered insufficient.

4.20.2.4 Work/tax related support for carers and carer allowances

4.20.2.4.1 Paid leave

Employees can take paid time off work to sort out emergency situations such as a death in the family, a burst water pipe or to care for a sick relative. The leave should be reasonable and in keeping with the emergency situation. However, if a person's partner (with whom he or she lives) suddenly becomes ill and needs instant care, the first day off can count as emergency leave but subsequent days cannot. They count as a different kind of leave (Ministry of Social Affairs and Employment, 2007).

Ten days' leave can be taken per year to care for a sick child, partner or parent if it is necessary that the employee provides such care. In such cases, the employer must pay at least 70% of the employee's wage. The employer receives compensation for this (Pijl, 2003).

Employees do not have legal right to time off work to care for a dying person but employers may agree to grant such leave. It can be granted to people who are close to the dying person even if the latter is in an institution. The leave consists of at least one third of the employee's working hours. The leave can be from one to six months but can be extended to a maximum of 18 months. During this time, the employee receives a payment with a maximum of € 490.54 a month paid from public funds (Pijl, 2003).

4.20.2.4.2 Unpaid leave

Long-term compassionate leave can be taken by employees who need to take care of a seriously ill child, parent or partner whose life is at serious risk. For a maximum of twelve weeks per year, the employee can take up to half of his/her working hours as compassionate leave. These hours are not paid but the remaining working hours are. They can be spread out over a period of up to 18 weeks subject to agreement with the employer. A request for long-term compassionate leave must be made in writing at least 2 weeks before the requested start of leave. With regard to payment, certain collective labour agreements or other agreements with employers may result in part payment of the hours taken as compassionate leave (Ministry of Social Affairs and Employment, 2007).

4.20.2.4.3 Flexible working

The Working Hours (Adjustment) Act 2000 (wet aanpassing arbeidsduur) gives employees the right to increase or decrease their working hours. This right applies to employees in the public and private sector who have been employed by a particular company for at least one year. The request, which can be made once every two years, must be made 4 months in advance and must contain details of the starting date for the change, the magnitude of the adaptation of working time and how the working hours would be divided over the week (International Labour Organisation, 2002).

4.20.2.4.4 Tax rebates

People who are caring for an elderly dependent parent, brother or sister (who lives in the same household) are entitled to a tax rebate for expenses incurred if these expenses exceed 11.2% of their income (National Alliance for Caregivers, 2003).

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4.21 Norway²²

4.21.1 Organisation and financing of social support to people with dementia and carers

4.21.1.1 Background information on the social/healthcare system in Norway

Norway has been a constitutional state since 1842 and a sovereign state since 1905 when it dissolved its union with Sweden. Its health care system is based on equal access to all citizens irrespective of their social status, income and location. An important step in achieving this was the introduction of the National Insurance Scheme in 1967 (Johnsen, 2006).

4.21.1.2 The organisation of social support for people with dementia and carers

The Ministry of Health and Care Services and the Ministry of Labour and Social Inclusion are the governmental offices responsible for social support for people with dementia and carers. There is some overlap between the social/welfare and health-care systems. In 2006, the government issued Report nr 25 (2005-2015) to the Storting – Care plan 2015. Dementia was one of the elements in focus in this strategy and the Ministry of Health and Care Services will introduce the plan in October 2007.

The private sector and some NGOs sell services to the State. In addition, unpaid volunteers also provide services and assistance. Interaction between the State and the voluntary sector is under consideration at the moment as the State wishes to increase this interaction.

The Norwegian Alzheimer Association has for many years received financial support for its dementia help-line. This year, it also received NOK 1 million as a consequence of Report nr 25. Local authorities often co-operate with the local dementia associations in organising support groups or training for carers.

4.21.1.3 The overall funding of social support for people with dementia and carers

Services are financed through general taxation but in some cases, service users have to also pay a fee. The State provides block grants to fund services that are provided by the municipalities. Sometimes, these grants are “earmarked” for certain groups and purposes, such as to provide services for the elderly or to enable people with mental disabilities to carry on living in their own homes (Helsetilsynet, 2006). Municipalities have the right to levy taxes on the population to help finance their activities (Johnsen, 2006).

4.21.1.4 The legal framework surrounding the provision of social support

The following laws are relevant to the provision of social support to people with dementia and their carers.

²² The information in this report on social support for people with dementia and their carers in Norway was provided by Maija Juva from the Norwegian Alzheimer Association.

- Lov av 19.11.82, nr 66 om helsetjenesten i kommunene (Act on Health Service in Municipalities). This Act regulates the municipal health services. The purpose of the Act is: to promote health and prevent illness and injury; to diagnose and treat illness and injury; to provide medical habilitation and rehabilitation; to provide care; to give medical help in case of accidents or other acute situations. Everyone is entitled to necessary health care within the municipality in which he or she lives in or where he or she is temporarily staying.
- Sosialtjenesteloven av 13.12.91 (Social Services Act). The purpose of this Act is: 1) to promote economic and social security, improve the standard of living for people in financial difficulties, contribute to increased equality and prevent social problems; 2) to contribute to each individual being able to live and reside independently and to have an active and meaningful life together with other people.
- Pasientrettighetsloven av 02.07.99 (Act on the Rights of Patients). The purpose of this Act is to make sure that all people have equal access to health services of good quality. A new chapter in this Act, chapter 4 A. Health services to patients without capacity to consent who resist health services will come into force on 01.01.2008. The purpose of this new chapter is to be able to give necessary health-care in order to prevent damage and limit the use of restraint. Providing health-care to people who resist has to be done with respect for the physical and mental integrity of the individual and, as far as possible, in agreement with the patient’s self-determination.

Reforms are underway. For example, there is the Dementia Care Plan 2015 mentioned above which will come into force later in the year and there are also planned changes to the Law on Patients’ Rights.

4.21.1.5 The suitability of social support for people with dementia and carers

4.21.1.5.1 Adequacy and accessibility in general

Services are not adequate in the whole country. They vary from one municipality to the next depending on local priorities. The State does not direct the local municipalities one way or the other. It may make suggestions but it is the local authorities that decide.

There is a huge gap between the specific needs of people with dementia and the availability of services.

4.21.1.5.2 People living in rural areas

People living in the countryside have fewer possibilities than those living in densely populated areas. The size of a Norwegian municipality varies from 1,500 to 500,000 inhabitants and there are big differences in the ability of the each municipality to organise satisfactory care for people with dementia.

4.21.1.5.3 People with different types of dementia

There is little support to people with different types of dementia. The same kind of support is usually offered to everyone with a diagnosis of dementia. There are only a few exceptions.

4.21.1.5.4 People from ethnic minorities

There is only support for one ethnic minority, the Sami people. This support was initiated by the Norwegian Alzheimer association. After a project period of three years there are now local dementia associations and a dementia help-line for the Sami population. There is also a brochure and a DVD in the Sami language.

4.21.1.5.5 Younger people with dementia

Some larger municipalities have day-care facilities which are particularly suited to the needs of younger people with dementia but most younger people with dementia do not receive social support that is specifically designed for them.

4.21.2 Services and support for people with dementia and their carers

4.21.2.1 Types of care

4.21.2.1.1 Day care

Day care in day care centres exists but only 4% of people with dementia living at home benefit from it. It is partly funded by the State.

4.21.2.1.2 Respite care

Respite care at home is completely funded by the State but it is not available all over the country. Some NGOs and volunteers also provide this service. Short-term and long-term residential respite care is also available and funded by the State but it is insufficient (particularly long-term residential respite care for people with dementia).

4.21.2.1.3 Long-term residential care

75% of the monthly pension of the service user is taken to cover the costs of long-term residential care. In addition, 85% of additional means (e.g. interest from shares or bank savings) goes to the residential care institution. This cannot, however, exceed the real cost of such care. Means testing is applied but personal property is not included in the calculation of available means.

4.21.2.1.4 Palliative care

Palliative care at home is completely funded by the State but is insufficient. People with dementia are, in principle, entitled to this service on the same basis as other patients but in practice most of them have to move to nursing homes in order to get adequate care. Some NGOs also provide this service. There are no palliative care centres/hospices just for people with dementia. Those that exist are for people with cancer and are completely funded by the State.

4.21.2.1.5 Monitoring in the home via alarm systems

Tele-alarm systems exist but are insufficient. The local authorities evaluate whether a person needs a tele-alarm system or not. Economic issues may influence this evaluation. It is also possible for service users to finance the tele-alarm system completely themselves.

4.21.2.2 Personal assistance and home help

4.21.2.2.1 Personal assistance

The following services are provided free of charge if the local authorities agree that the person needs them. Unfortunately, this decision is often influenced by the financial situation and overall priorities of the municipalities.

1. Assistance with personal hygiene
2. Assistance/supervision taking medication
3. Assistance with eating and drinking
4. Assistance with mobility (lifting, moving and walking)
5. Assistance with incontinence
6. Assistance with skin care
7. Ergotherapy
8. Assistive devices

Assistance with personal hygiene is available throughout the whole country but the amount of assistance each individual receives is often insufficient. There are great variations depending on the local authorities. Many private companies offer such services which means that people with a good financial situation also have the option of paying privately for assistance with personal hygiene.

Assistance/supervision taking medication is insufficient in towns but in rural areas/the countryside it is considered sufficient. People in isolated regions taking medication may receive a visit from a nurse twice a day and a telephone call in the middle of the day to remind them to take their medicine.

Assistance with eating and drinking is supposed to be provided but in many places, meals are just delivered to the door and no assistance is provided. Volunteers sometimes provide assistance with eating and drinking.

Assistance with mobility (lifting, moving and walking) is insufficient. Often, it does not correspond to people's needs. For example, many people are not helped out of bed at times that suit them, they may be placed in a chair for the whole day and put to bed far too early in the day. Lots of people do not get taken out at all.

Incontinence pads are available on the same basis as medicines. People must obtain a prescription from a doctor which they then take to a chemist's. They have to contribute towards the cost of the pads but once they have reached the limit of NOK 1,600 that year (for medicines, visits to the doctor and incontinence pads), the pads are free of charge for the rest of the year. Concerning assistance with incontinence, in many cases the pads are often not changed sufficiently often.

Services providing assistance with skin care are insufficient and there is a shortage of ergotherapy in most areas of the country.

There is some confusion surrounding the provision of assistive devices. In many cases neither the municipalities, which should be providing these devices, nor the patients know which devices they are entitled to. Dementia associations help by giving information to carers so that they can request the appropriate devices from the relevant authorities.

Finally, companionship/social activities and home transformations are available but only partly financed by the State. Both are insufficient. NGOs, volunteers and the Church all offer some degree of social support in the form of home visits and gatherings at centres for the elderly or at churches. Nevertheless, there are still many lonely people with dementia.

4.21.2.2.2 Home help

The following services are all available and partly funded by the State:

1. Assistance with housework
2. Help with the preparation of meals (including meals-on-wheels)
3. Assistance with shopping
4. Assistance with transport
5. Assistance with laundry

The last three are considered insufficient. In some places, NGOs offer a meals-on-wheels service. Many municipalities have stopped providing assistance with shopping and advise people to arrange for shops to deliver their groceries instead. Nevertheless, in many places, volunteers provide assistance with shopping. Transportation services vary from one municipality to the next but some NGOs have a transport service to bring people with dementia to their organised activities.

4.21.2.3 Psychosocial support and training for people with dementia and carers

The municipalities should inform people about all the services that are available but often they do not give adequate information. Specialists responsible for diagnoses also inform people about available services. Dementia associations provide information via the dementia help-line and meetings which are open to everyone.

Some dementia associations have support groups for people with dementia and also for carers which are partly funded by the State. Service users do not pay anything for this service. Another NGO, the Church City Mission, also provides counselling for carers. Nevertheless, counselling services for people with dementia and carers are considered insufficient.

Holidays for people with dementia are sometimes available but this is insufficient and not funded by the State at all. However, people with dementia may be entitled to a two-week stay in a nursing home (completely funded by the State) so that the carer can have a holiday. In some cases, this is regularly repeated in that the person with dementia spends two weeks at home and two weeks in an institution. Carers are entitled to these breaks/holidays under the Social Services Act, but in practice local authorities decide whether or not carers get a break.

Training for carers is available but insufficient. Local dementia associations often organise training courses and implement them together with local authorities. Such courses are partly funded by the State and partly by service users. At the moment, this is insufficient. However, the government recently started a three-year project to increase training for carers, which is being run in collaboration with the Norwegian Alzheimer Association.

4.21.2.4 Work/tax related support for people with dementia

People with dementia, like people with other illnesses, cannot be sacked simply on the grounds that they are ill. However, if they cannot manage to do their job properly and the employer cannot find other more suitable tasks, they can be made redundant on the grounds of illness. This is covered by the Health Insurance and Pension Act (unofficial translation) (Lov om folketrygd of 28.02.1997).

People with dementia, who can prove that they have extra expenses because of their illness, are entitled to a small monthly payment (*grunnstønad*). People with dementia who employ someone to provide private help at home are entitled to another payment known as the *hjelpstønad*. These payments are available in accordance with the provisions of the Health Insurance and Pension Act. This act also covers home adaptations which are mostly financed by the State or by municipalities.

People with dementia in receipt of a disability pension are entitled to half price fares on public transport services. If they have difficulty using public transport, they may be entitled to a certain number of taxi rides per year at a reduced price. This is dependent on local authorities.

4.21.2.5 Work/tax related support for carers and carer allowances

Carers are not entitled to paid or unpaid time off work or flexible working hours in order to help them organise care giving. They are not entitled to tax refunds/incentives for the care they provide or State subsidised pension contributions.

However, under the Social Services Act, carers may receive direct payments from the municipalities for caring. The number of hours they are paid for is decided by the local authorities and does not usually cover the actual hours spent caring.

4.21.3 Bibliography

Unless otherwise stated, information provided by Maija Juva (Norwegian Alzheimer Society) between May and September 2007.

Johnsen, J. R. (2006), Health Systems in Transition,
<http://www.euro.who.int/Document/E88821.pdf>

Norwegian Board of Health Supervision (2006), Norwegian Health and Social Services,
<http://www.helsetilsynet.no>

Useful links:

<http://www.nasjonalforeningen.no/demens>

<http://www.shdir.no> (also English section)

<http://www.aldringoghelse.no>

4.22 Poland²³

4.22.1 Organisation and financing of social support to people with dementia and carers

4.22.1.1 Background information on the social/healthcare system in Poland

During the period of independence (between 1918 and 1939), a limited Bismarckian social health insurance system was introduced, covering about 7% of the population. In 1945, a Ministry of Health was created and the State took over responsibility for health care.

In the 1980s, there was a series of health reforms aimed at decentralisation. Integrated healthcare management units, known as ZOZ (Zespół Opieki Zdrowotnej) that had been created in the 1970s were given greater power.

However, the general health insurance act of 1997 (enforced on 1 January 1999) brought back an insurance-budgetary model of health care funding whereby the State budget was no longer responsible for funding health services. Unfortunately, there were considerable regional differences in service provision and even different prices for the same service. These and other problems with the system led to the Law on General Insurance in the National Health Fund (enforced on 1 April 2003) which established the National Health Fund. The branches of the National Health Fund are responsible for providing health services to insured people. In 2004, the National Health Fund was officially declared not in accordance with the Constitution.

There is currently very little State provision of community care services. NGOs play an important role but services are still scarce. According to Kuszewski et al. (2005), there has been a parliamentary debate about a possible role for mutual insurances for health and social care, which would include separate long-term care insurance for the elderly. Source: Ministry of Health (2007) and WHO (2005).

4.22.1.2 The organisation of social support for people with dementia and carers

There is no system of social support specifically designed for people with dementia and their carers. However, people who are ailing or need social support, because they live alone or are dependent, are entitled to receive paid (or partly paid) home help and support organised by local governments.

There are special services for the elderly but none specifically for people with dementia. The Ministry of Labour and Social Policy is responsible for social support to people with dementia/dependent elderly people. The Ministry of Health is responsible for medical services only.

²³ The information in this report on social support for people with dementia and their carers in Poland was provided by Mirka Wojciechowska from the Polish Alzheimer Association.

NGOs are involved in various activities aimed at providing services for people with dementia and their carers. The Ministry of Health may (or may not) co-finance certain activities and tasks of NGOs, but it is up to NGOs to fight for a better quality of life for people with dementia in Poland. The private sector provides some services, e.g. nursing homes, but they are not specially designed for people with dementia.

Support from the State (mainly the Ministry of Health) is inadequate and sporadic. The amount of money that organisations apply for from the government to finance their activities, which could help people with dementia and their families cope with the disease, is much greater than what they actually receive and the amount is decreasing every year, while the number of NGOs seeking financial support is increasing. For example, to cover the costs of the awareness activities and campaigns of the Polish Alzheimer Association, it has to look for other sponsors, as the government refuses to fund such activities. Since 2004, financial support from the Ministry of Health has been provided every year but very late in the year, so the resources that are eventually granted cover a period of just 4 or 6 months. Self-help organisations also apply to local government for financial support and, as in the above situation, the money only covers 8 to 9 months. In both cases, organisations must compete for financial support.

4.22.1.3 The overall funding of social support for people with dementia and carers

Social support for people with dementia and carers is funded through general taxation and an obligatory health insurance. In addition, people are asked to contribute towards the cost of any services they receive.

4.22.1.4 The legal framework surrounding the provision of social support

Certain articles of the Polish Constitution of 2 April 1997, covering economic, social and cultural freedoms and rights, could be of relevance to the provision of social support to people with dementia. For example:

Article 67

- A citizen shall have the right to social security whenever incapacitated for work by reason of sickness or invalidity as well as having attained retirement age. The scope and forms of social security shall be specified by statute.

Article 68

- Everyone shall have the right to have his/her health protected.
- Equal access to health care services, financed from public funds, shall be ensured by public authorities to citizens, irrespective of their material situation. The conditions for, and scope of, the provision of services shall be established by statute.

- Public authorities shall ensure special health care to children, pregnant women, handicapped people and persons of advanced age.

(<http://www.sejm.gov.pl/prawo/konst/angielski/kon1.htm>)

Other relevant legislation includes:

- The Social Welfare Act of 12 March 2004 (Ustawa nr 64 z dnia 12 marca 2004 o pomocy społecznej)
- The Psychiatric Act (Ustawa o ochronie zdrowia psychicznego z 1994 r. - Dziennik Ustaw nr 111, poz 535 wraz z późniejszymi zmianami)

The Polish Alzheimer Society is not aware of any reforms underway which might eventually affect the level of support provided to people with dementia and their carers. It does not feel that people with dementia and their carers are the focus of the current government or MPs.

4.22.1.5 The suitability of social support for people with dementia and carers

4.22.1.5.1 Adequacy and accessibility in general

Social support for people with dementia and carers is neither adequate nor accessible. In fact, it is not generally available at all. The situation is very difficult especially in rural areas. Larger towns, where Alzheimer associations have been set up and are active, help people with dementia and their carers make use of the existing services available to the general public. The problem is that although general care services should be available to everybody in need, they are actually only accessible to low-income families.

Unfortunately, the available services do not meet the needs of people with dementia. Home helpers responsible for providing care at home are rarely qualified or properly trained to understand the needs of people with dementia. Family carers who are members of the Polish Alzheimer Association are often responsible for training the professional carers themselves.

4.22.1.5.2 People living in rural areas

As stated above, the provision of social support is especially difficult in rural areas. Services such as assistance with personal hygiene, day care centres and counselling for people with dementia are particularly difficult to find.

4.22.1.5.3 People with different types of dementia

As there are no services specifically designed for people with dementia in general, there are none for specific types of dementia either.

4.22.1.5.4 People from ethnic minorities

There are no specific services for people with dementia and carers from ethnic minorities.

4.22.1.5.5 Younger people with dementia

Age does not seem to be important as if a person has been diagnosed with Alzheimer's disease, he/she has the same rights to use available services, especially if he/she has been granted the status of dependent person. However, there are no services specifically designed for younger people with dementia.

4.22.2 Services and support for people with dementia and their carers

4.22.2.1 Types of care

4.22.2.1.1 Day care

Day care is partly funded by the State and partly by service users.

However, very few cities have day-care centres. Some are run by NGOs, others by local governments. The latter are quite rare. In Warsaw, for example, there is only one such facility yet it is estimated that at least 11,000 people in Warsaw have dementia, with only 15% having been diagnosed. The Polish Alzheimer Association considers the provision of day care totally insufficient.

A few Alzheimer associations (e.g. in Lodz, Poznan, Lublin, Torun and Olsztyn) have managed to set up day-care centres but there is always a threat that the local government will suddenly withdraw financial backing for such services.

The Church also provides day-care services e.g. in Plock, but the quality of the service is questionable and without logistic support from NGOs there is a risk, according to the Polish Alzheimer Association, of doing more harm than good to people with dementia who are usually treated like children.

4.22.2.1.2 Respite care

Sitting services are generally available during the day but professional carers are not sufficiently trained and the service is only available for families on a low income. Moreover, it is not specifically designed for people with dementia. There is no night time respite service in Poland.

The State may contribute towards the cost of this service and service users may also have to pay a fee for this service. This is based on the income of the whole family in a particular household.

Short-term residential respite care exists but is insufficient. Existing long-term residential homes seldom want to admit people with dementia, simply because they are afraid of not being able to cope with various problems. It is not profitable for them to allow people to stay for short periods. Generally, such institutions do not want patients to stay for less than a month. The State contributes towards the cost of short-term and long-term respite care and service users must also pay a fee.

4.22.2.1.3 Long-term residential care

Although there are very few long-term residential homes solely for people with dementia, there are numerous homes for the elderly and frail. On average, 30% of the people admitted to such homes have dementia. Many have no prior diagnosis. Long-term residential care is partly funded by the state and partly by service users when the person using the service, or members of his/her family, cannot cover the full cost i.e. when their income is too low. The cost of long-term care varies. A few years ago long-term care homes charged 70% of a person's pension, however much the pension was, but nowadays, each home calculates the costs and expects the users to cover them. The local government is only responsible for covering the remaining costs in the case of very poor people.

4.22.2.1.4 Palliative care

Palliative care is only available for people with cancer.

4.22.2.1.5 Monitoring in the home via alarm systems

Monitoring in the home via alarm systems is insufficient. It is provided solely by private agencies and is not specifically designed to be used by people with dementia.

4.22.2.2 Personal assistance and home help

4.22.2.2.1 Personal assistance

Assistance with personal hygiene is available, especially in big towns, but insufficient. Rural areas are usually neglected. As with other services, it is not designed specifically for people with dementia. Another problem is that only people on a low income are entitled to this service. If provided, it is partly financed by the State and partly by the service user.

Assistance with mobility e.g. lifting, moving and walking and social companionship/activities form part of the social support services that are generally available but they are not specifically designed for the needs of people with dementia. Therefore, they are insufficient. These services are partly financed by the State and partly by service users.

Social community nurses from outpatient clinics in a patient's place of residence may, if available, visit the patient and instruct the family carer on how to deal with pressure sores. The family carer may then ask the nurse again if he/she can't cope. This is totally insufficient. Service users with a high income/pension have to pay the full cost of the service. The state partly or in some cases almost fully pays for the service for people on a low income/pension. Alzheimer associations also provide training to carers on how to deal with such problems and where to find help. The Polish Alzheimer Association arranges for nurses to visit people with dementia at home.

Some NGOs provide nursing services to people with dementia in their own homes, but this is scarce. Moreover, it is costly to NGOs and financial support from the State is difficult to obtain for this service.

Disabled people who adapt their homes are entitled to refunds from the government. This only covers part of the cost.

The following services are not available:

1. Supervision/assistance taking medication
2. Assistance eating and drinking
3. Assistance dealing with incontinence
4. Occupation therapy/ergotherapy (unless available through day care centre)
5. Assistive devices/assisted technology

However, people with dementia are entitled to 60 incontinence pads at half price provided that they obtain a prescription for them from a general practitioner.

4.22.2.2.2 Home help

A few home help services are available and partly funded by the State. They include:

1. Assistance with housework
2. Help with the preparation of meals (incl. meals-on-wheels)
3. Assistance with shopping

However, as these services are not specifically designed for people with dementia and only available to people on a low income, they are insufficient.

There is no laundry service and no special means of transport for people with dementia. Carers who order a normal taxi may be entitled to some discount if they can prove that the patient is disabled.

4.22.2.3 Psychosocial support and training for people with dementia and carers

There is no general service to provide information about access to services in general. The Polish Alzheimer Association has a telephone helpline.

Counselling services for people with dementia and for carers are solely provided by Alzheimer Associations. For this reason, counselling services only exist in towns where there is an Alzheimer Association and there is a lack of such services in small towns and rural areas. This is insufficient. The Alzheimer Associations do not receive any funds from the State for counselling people with dementia. Counselling for carers is partly funded by the State.

Holiday services, specially designed for people with dementia, are only available if and when an Alzheimer Association can run them. The Polish Alzheimer Association has been running such forms of respite for more than 10 years, but it is getting more and more difficult, especially when no financial support is provided by the State. The State may contribute towards the cost but many carers are still unable to afford such holidays (two weeks may cost as much as their monthly salary/pension). There are no provisions for carers to have a holiday e.g. by providing a respite carer so that the carer can have a break.

The Polish Alzheimer Association and local Alzheimer’s organisations are the sole providers of training for family carers and this is considered insufficient. The State does not, as a rule, contribute towards the cost of this training, unless the Alzheimer associations are lucky enough to receive some funds from the Ministry of Health or from the local government for educational projects.

4.22.2.4 Work/tax related support for people with dementia

There are no protective measures for people with dementia in paid employment. They are not entitled to tax refunds for employing people to provide home care services and they are not entitled to direct payments to pay for services. However, a person with dementia, like any other disabled or elderly person (i.e. over 75 years of age), is entitled to a care benefit of 150 zloty (EUR 35) per month.

People with dementia, like disabled people, are entitled to tax refunds/benefits due to their incapacity and also for home adaptations. This is based on tax legislation.

People with dementia who have been granted the status of disability of the first category (i.e. they are unable to live independently) are entitled to certain reductions e.g. on television and radio licences. Public transport (buses, trams, the underground and some trains) can be used free of charge by people with dementia and their carers. This is covered by tax law, the Acts Monitor, nr.14 of 2004, article 176 (ORDYNACJA PODATKOWA, DZIENNIK USTAW nr 14 z 2004, pozycja 176).

4.22.2.5 Work/tax related support for carers and carer allowances

According to the Labour Code (KODEKS PRACY), every spouse or child caring for a sick adult is entitled to 14 days’ paid time off work per year. There are no legal provisions granting a right to unpaid time off work or flexible working hours.

The State takes over responsibility for the payment of pension contributions but only partly so that a carer can retire earlier to look after a person with dementia or any other sickness. However, each year spent caring, before one’s legal date of retirement, is calculated as if it were 7 months and not 12 months. The relevant law is the Labour Code (KODEKS PRACY).

Carers are not entitled to direct or indirect payment from the State for caring. They are not entitled to tax benefits/incentives for the care they provide either.

4.22.3 Bibliography

Unless otherwise stated, information provided by Mirka Wojciechowska (Polish Alzheimer Society) between April and September 2007

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Ministry of Health official website (2007): <http://www.mz.gov.pl/wwwmzold/index?mr=mo&ms=&ml=en&mi=535&mx=o&mt=&my=464&ma=5166> – accessed on 11 April 2007

4.23 Portugal²⁴

4.23.1 Organisation and financing of social support to people with dementia and carers

4.23.1.1 Background information on the social/healthcare system in Portugal

Portugal has been a constitutional democratic republic since 1974 when the Salazar-Caetano regime, which had lasted 48 years, was overthrown. After the revolution of 1974, considerable changes took place in the organisation of health care services. In 1976, the citizen’s right to health was incorporated into the Portuguese constitution. This was followed in 1979 by the establishment of the National Health Service which was to be universal, comprehensive and free of charge (Bentes et al. 2004).

4.23.1.2 The organisation of social support for people with dementia and carers

There is no specific state department in charge of social support for people with dementia and carers. Although the situation of these people was the subject of a study conducted by the Social Security Department, no serious measures were taken or services created to respond to the requirements identified in this study.

APFADA, the Portuguese Alzheimer Association, is currently the leading organisation in providing aid to its target population, even though new players, mainly in the private sector, are arriving on the scene and creating new services.

The Ministry of Work and Social Solidarity, through the Assistant Secretary of State, has the jurisdiction in matters related to the rehabilitation and integration of elderly people or people with disability. The Ministry of Health, through the Assistant Secretary of State, is also responsible for the development and coordination of health care programmes for elderly and dependent people.

Recently, the Ministry of Health and the Ministry of Work and Social Solidarity created the grounds for the establishment of a National Integrated Continued Care Network (Rede Nacional de Cuidados Continuados Integrados). This network will gather as partners a variety of different institutions, private companies and state services (hospitals, health centres, etc) with the goal of providing quality health services of continued and palliative care.

The Ministry of Work and Social Solidarity, through the Social Security and SNRIPD (National Secretary for Rehabilitation and Integration of People with Disability), has been funding APFADA’s Day Care Centre, In-Home care and other services. With the institution of the National Integrated Continued Care Network, several new players from the private sector and non profit organisations will be establishing partnerships with state departments.

²⁴ The information in this report on social support for people with dementia and their carers in Portugal was provided by Rui Barros de Abreu on behalf of the Portuguese Alzheimer Association (APFADA).

4.23.1.3 The overall funding of social support for people with dementia and carers

Support for people with dementia and their carers is funded by general taxation, SNS (the National Health Service) service fees and service co-partnership.

4.23.1.4 The legal framework surrounding the provision of social support

The following table contains information from the Constitution of the Republic of Portugal and various Portuguese laws which are relevant to the provision of social support to people with dementia and carers.

4.23.1.4.1.1 The Constitution of the Republic of Portugal

Part I: Fundamental rights and duties Title III, Economic, social and cultural rights and duties Chapter II, Social rights and duties Article 63, Social security and solidarity	3. The social security system provides protection for citizens in sickness or old age or when disabled, widowed, orphaned or unemployed, and in all other situations in which the means of subsistence or the capacity to work have been lost or impaired.
Title III, Economic, social and cultural rights and duties Chapter II, Social rights and duties Article 64, Health	1. Everyone has the right to have his or her health safeguarded and the duty to defend and foster it. 2. The right to the safeguarding of health shall be met by: b. The creation of economic, social, cultural and environmental conditions that guarantee, specifically, the protection of children, the young and the old; the systematic improvement of living and working conditions; the promotion of physical fitness and sports in schools and among the people; the development of health education for the people and practices of healthy living.
Title III, Economic, social and cultural rights and duties Chapter II, Social rights and duties Article 67, Family	2. The State has the duty of protecting the family, in particular by: b. Promoting the establishment of, and guaranteeing access to, a national network of day-care centres and other social facilities for family support, and a policy for the aged;

<p>Title III, Economic, social and cultural rights and duties</p> <p>Chapter II, Social rights and duties</p> <p>Article 72, The Elderly</p>	<p>1. Old people have the right to economic security and to conditions of housing and of family and community life that respect their personal autonomy and prevent or surmount their isolation and marginal position in society.</p> <p>2. The policy for the old shall also include economic, social and cultural measures that aimed at providing old people with opportunities for self-fulfilment through active participation in the life of the community.</p>
<p>Part II: Organisation of the economy</p> <p>Title I, General principles</p> <p>Article 81, Primary duties of the State</p>	<p>In economic and social matters the primary duties of the State are:</p> <p>a. To promote an increase in the social and economic well-being and quality of life of the people, in particular of those most underprivileged, in the context of a strategy of sustainable development;</p>

4.23.1.4.1.2 ACTS (from the government):

<p>-Decreto-lei nº 123/97 de 22.05</p> <p>Torna obrigatória a adopção de um conjunto de normas técnicas básicas de eliminação de barreiras arquitectónicas</p>	<p>Decree about the access to public buildings, and on the streets to people with incapacity.</p>
<p>-Despacho Conjunto nº 18</p> <p>891/2006 de 06.06</p> <p>Definição de procedimentos das Entidades prescriptoras e financiadoras de ajudas técnicas</p>	<p>Dispatch regarding funds to assistive devices for people with incapacity.</p>
<p>-Despacho Conjunto MS/MESS, de 01.07.1994</p> <p>Despacho Conjunto MS/MSSS, de 04.07.1996 (DR n.º 204, II Série, de 03.09.1996)</p>	<p>Joint Acts by Health and Social Security and Work ministries creating and regulating the Integrated Support Programme for Elderly People.</p>

<p>-Despacho Conjunto MS/MSSS, de 24.07.1997 (DR n.º 192, II Série, de 21.08.1997)</p> <p>-Despacho Conjunto MS/MTS n.º 407/98, de 15.05.1998 (DR n.º 138, II Série, de 18.06.1998)</p> <p>Criação e regulamentação do Programa de Apoio Integrado a Idosos</p>	
<p>- Decreto-Lei Nº64/2007</p> <p>Define o regime jurídico de instalação, funcionamento e fiscalização dos estabelecimentos de apoio social geridos por entidades privadas</p>	<p>Decree that defines the rules for the creation, running and inspection of social support settings.</p>
<p>- Despacho Normativo n.º 62/99, de 12.11</p> <p>Aprova as normas que regulam as condições de implantação e funcionamento de Serviços de Apoio Domiciliário</p>	<p>Dispatch from the government ruling the home care service.</p>
<p>- Despacho Nº4250/2007, de 23.03.2007</p> <p>Determinações sobre a participação do Estado nos medicamentos para o tratamento da doença de Alzheimer.</p>	<p>Ministerial dispatch about the NHS support/co-partnership of Specific Alzheimer Disease medication.</p>
<p>- Decreto-Lei nº 100/2006, 06.06</p> <p>Cria a Rede Nacional de Cuidados Continuados Integrados.</p>	<p>Decree from the government establishing the National Integrated Continued Care Network. This law improves services like intermediate care, long-term care and rehab care.</p>

- Decreto-Lei n.º 265/99, de 14 de Julho

Altera o Decreto-Lei n.º 329/93, de 25 de Setembro, que estabelece o regime de protecção na velhice e na invalidez dos beneficiários do regime geral de segurança social. Confere aos idosos dependentes, entre eles os que apresentem “quadros de demência grave” um complemento de pensão.

Decree that rules the General Regime of Social Security. Grants an additional financial support for people with Dementia in latter stages.

4.23.1.5 The suitability of social support for people with dementia and carers

4.23.1.5.1 Adequacy and accessibility in general

There is still a lack of information on health services, community services and general information about dementia and its consequences. This fact is obstructing early stage diagnosis and intervention.

Most of the services that support people with dementia are destined for elderly people and do not have the physical structure or human resources to provide quality care. These services are managed by non-profit organisations, partly funded by the State and difficult to access, especially the long-term care facilities and nursing homes.

Most of the services only provide assistance to people at specific stages in the dementia process, and people often experience discontinued care.

4.23.1.5.2 People living in rural areas

Unfortunately there are no specific services for people with dementia living in rural areas, but they are supported by services for the elderly (Aged People Services) which are run by non-profit organisations or the Church.

4.23.1.5.3 People with different types of dementia

Support provided in Portugal does not take into account different kinds of dementia.

4.23.1.5.4 People from ethnic minorities

There are no services that are specifically for people with dementia and carers from ethnic minorities.

4.23.1.5.5 Younger people with dementia

The services for the elderly that are available do not respond to the needs of early stage or younger people with dementia.

4.23.2 Services and support for people with dementia and their carers

4.23.2.1 Types of care

4.23.2.1.1 Day care

Day care centres exist. They are partly funded by the State, partly by service users. The average cost of a Day Care Centre is €23 per day and families have to pay 40% of their total income, up to that maximum. If that 40% is not enough to pay for the service, the State will then pay the rest. When day care is private, the service is totally paid by the service user.

4.23.2.1.2 Respite care

Respite care at home is available but this is very much on a small scale and is provided by voluntary or non-profit organisations. When the service is part of the agreement between the In-Home Care provider and the service user, it is partly paid by the user and partly by the State.

Very few short-term respite services exist i.e. not more than 5. Those that do are partly funded by the State and partly by service users. For private short-term respite, service users must pay the total cost themselves.

There are no long-term respite care services in Portugal.

4.23.2.1.3 Long-term residential care

With regard to long-term residential care, it was estimated by the social security service in 2004 that 30% of clients in certified nursing homes had some form of dementia. This estimate did not take into account non-profit or non-certified organisations. Private companies charge clients about EUR 50 per day. If managed by non-profit organisations, they are funded by the State and the client. In such cases, means testing is applied and clients have to contribute 70-85% of the family income up to a certain maximum which in 2007 is about EUR 26 per day.

4.23.2.1.4 Palliative care

Palliative care services, either at home or in a palliative care centre, are not available.

4.23.2.1.5 Monitoring systems

A tele-alarm system is available and is sufficient. It is partly funded by the State and partly by service users. However, it is not used by people with dementia as up until very recently, the available systems were unsuitable and expensive.

A few months ago APFADA established an agreement for a GPS device called “Localiser Find Me”. People with dementia can now buy this for 50% of its market value which means that it would cost them €250. Existing devices were too complicated to use, very expensive (around €1500) and limited (they could only be used inside the house or in care settings).

4.23.2.2 Personal assistance and home help

4.23.2.2.1 Personal assistance

The following services are available and are partly funded by the State:

1. Assistance with personal hygiene
2. Assistance with eating and drinking
3. Assistance with mobility e.g. lifting, moving and walking

The Portuguese Alzheimer Society considers these services sufficient. They can also be obtained from private companies but in that case, service users must pay the total cost.

Assistance/supervision taking medication, dealing with incontinence and/or skin care is also available and provided by private companies and Community health centres. Palliative care providers offer assistance with skin care, but palliative care services do not respond to current demand or are too expensive. It is possible to ask the Social Security for financial support for technical aids, incontinence products, medication or a private nursing home, but each case is analysed individually. Although assistive devices are available, they are not generally used by people with dementia.

Companionship and social activities are provided by volunteers. This is not sufficient.

Occupational therapy/ergotherapy is available. It is partly funded by the State, partly by service users and is not sufficient.

There are a few schemes operated by town councils that adapt people’s homes in accordance with their needs. This is completely funded by the State but is insufficient.

4.23.2.2.2 Home help

Assistance with housework and with shopping is only provided by private companies and must be completely financed by service users. It is therefore insufficient.

Help with the preparation of meals (including meals-on-wheels) is available. This service is partly financed by the State and partly by service users. If the service is provided by private companies, then service users must pay the full cost themselves. On the whole, this service is considered to be sufficient.

Transportation is provided by fire departments and private companies. The State may partly or fully contribute towards the costs of the service but some users have to pay for it completely themselves. This service is not considered sufficient.

Laundry services exist and they are considered sufficient. The State may contribute partly towards the cost of this kind of service.

4.23.2.3 Psychosocial support and training for people with dementia and carers

APFADA provides information on services that are available for people with dementia and carers. There are no other organisations providing this service and it is therefore considered insufficient.

Other services provided by APFADA include:

1. Counselling for people with dementia
2. Counselling for carers
3. Holidays for people with dementia
4. Holidays for carers (or replacement carers to enable carers to have a break)
5. Training for carers

These services are considered insufficient. Moreover, APFADA does not receive financial assistance from the State for the provision of these services. The holidays for carers can only be provided to a small group of people with funding from a few private companies. With regard to the training of carers, APFADA has recently signed an agreement with an insurance company that will support financially the increase of training for carers.

4.23.2.4 Work/tax related support for people with dementia

There is no legal protection for people with dementia who are still in paid employment. People with dementia are not entitled to tax refunds on the grounds of their incapacity or for employing someone to provide home care services for them. There are no grants for home adaptations, no reduced rates on television licences or public transport and no entitlement to direct payment to pay for services. There are general arrangements for people with disabilities.

However, people with dementia, who are in need of constant attendance by another person, are entitled to a payment from the State. This is covered by: Decreto-lei n° 265/99, de 14 de Julho; Decreto-lei n° 309-A/2000, de 30 de Novembro and Portaria n°1357-A/2006, de 30 de Novembro. If eligible for this allowance, they receive a regular payment of between €79.68 and €159.35 per month in addition to their pension. If they do not have any income or a pension, the State adds €34.39 to the pension of their husband or wife.

4.23.2.5 Work/tax related support for carers and carer allowances

Carers are not entitled to time off work for caring (either paid or unpaid), flexible working hours, tax benefits or pension contributions for the services they provide.

4.23.3 Bibliography

Unless otherwise stated, information provided by Rui Barros de Abreu (on behalf of APFADA, the Portuguese Alzheimer Society) in April 2007

Bentes, M. et al. (2004)), Health Care Systems in Transition: Portugal, <http://www.euro.who.int/document/e82937.pdf> WHO, European Observatory on Health Care Systems

4.24 Romania²⁵

4.24.1 Organisation and financing of social support to people with dementia and carers

4.24.1.1 Background information on the social/healthcare system in Romania

In 1989, there was a revolution in Romania which brought the Communist government to an end and set up a Republic led by a President and governed by a two-chamber parliament. The Semashko health system (a centralised, tax-based system) which had been in place from 1949 to 1989 was gradually transformed into a decentralised and pluralistic social health insurance system based on a contractual relationship between the health insurance funds and service providers. Romania and its health care system are in a period of transition. Equity remains a problem, expenditure on health care pro capita remains fairly low and social care is limited but recent changes in legislation²⁶ are likely to have an impact on the provision of social care (Vladescu, C. et al. 2002).

4.24.1.2 The organisation of social support for people with dementia and carers

The Ministry of Labour, Social and Family Solidarity is responsible for social support to people with dementia/dependent elderly people. Since entering the European Union, several projects have been started which involve collaboration between the State and NGOs which apply to be partners for structural funds with the intention of developing day care centres and memory clinics.

A new law (Law 448) has been passed which regulates the rights and obligations of handicapped people in order to promote their social inclusion and integration. The methodological norms for Law 448 are not yet available.

Alzheimer Associations receive support from the State for set periods of time, usually several years. This support, which tends to be provided by the local authorities, consists of designated places for day care centres where the cost of utilities (e.g. water and electricity consumption) is borne by the local authorities. Therefore, the Alzheimer Society has not had to pay for utilities or rent.

4.24.1.3 The overall funding of social support for people with dementia and carers

Services and benefits provided by the State are funded through an obligatory health insurance and general taxation.

Employees and employers each pay 7% to the insurance fund. Pensioners also pay 7% but the handicapped have free access to health insurance. Unfortunately, there have been problems collecting health insurance contributions (Vladescu et al., 2002).

²⁵ The information in this report on social support for people with dementia and their carers in Romania was provided by Letitia Dobranici from the Romanian Alzheimer Association.

²⁶ Please refer to the section on the legal framework surrounding the provision of social support.

Taxes are still an important source of funding, representing 21.6% of healthcare financing in 1999.

4.24.1.4 The legal framework surrounding the provision of social support

There are two main laws of relevance to the provision of social support in Romania. The recently adopted Law 448, regulating the rights and obligations of handicapped people, led to the repeal of 4 other laws but as the methodological norms for this law have not yet been issued, the situation is somewhat unclear and the potential impact of the law is temporarily limited.

Any use of the term “the elderly” should be understood as referring to people who have reached the legal age of retirement. In July 2006, the standard age for retirement was 57 years and 10 months for women and 62 years and 10 months for men. This is gradually changing and by 2015, it will be 60 and 65 years respectively.

4.24.1.4.1 Laws

Number/reference	Date	Title/description
Law 487	8/8/2002	Law on Mental Health and Protection of People with Mental Disorders
Law 448	6/12/2006	This law regulates the rights and obligations of handicapped people in order to promote their social inclusion and integration.

4.24.1.4.2 Decrees and regulations

Number/reference	Date	Title/description
Order MSF 726	24/10/2002	Criteria for establishing the degree of handicap for adults and application of the measures of special protection
H.G. 1764	28/12/2005	Updating of the social allocation for blind adults and of the monthly fee granted to adults with a severe handicap other than blind people
Order of Ministry of Public Works 649	25/4/2001	Approval of the norms concerning the adaptation of civilian buildings and urban space for the special requirements of handicapped people

Number/reference	Date	Title/description
Order SSPH 79	29/7/2002	Approval of average monthly cost for maintenance of handicapped people in institutions of special protection
H.G. 329	4/4/2003	Approval of rules, organisational framework, and functioning of institutions for the special protection of handicapped people
Order MSF and MMSS 491/180	3/6/2003	Approval of the grid for the medical and social evaluation of people admitted into assistance institutions for medical and social services
H.G. 729	21/7/2005	Establishes the amount of money allocated for daily food provided by public institutions of public assistance
Order ANPH 205	16/8/2005	Approval of minimal standards of quality for residential centres for adult handicapped people (day care centres and sheltered housing)
O.G. 30	31/1/2004	Modification of OUG 170/1999 regarding the gratuity of medical assistance, drugs and prostheses for some categories of people with special needs
Order MTCT, MS and MMSSF 216/189/3469	1/7/2005	Approval of methodology and norms regarding the gratuity of transportation by metro and quantum for this gratuity for severely handicapped people and for their personal assistants
H.G. 1175	14/10/2005	Approval of the national strategy concerning the protection, integration and social inclusion of severely handicapped people in Romania from 2006 – 2013
Order ANPH 367	30/11/2005	Approval of criteria for the selection of projects in the field of protection, integration and social inclusion of the handicapped
Order ANPH 363	7/12/2005	Approval of the National Plan regarding the training of personnel from the system of protection of handicapped people in 2006-2008 and the framework for training and specific training of the personnel involved in the protection and care of handicapped adults

Number/reference	Date	Title/description
H.G. 427	7/5/2001	Approval of the methodological norms regarding the conditions for hiring personal assistants, and the rights and obligations of personal assistants of handicapped people
H.G. 197	1/3/2006	Approval of the programmes of national interest in the field of protection of the rights of handicapped people and in the field of social assistance of the elderly, the homeless and victims of family violence, as well as the financing for these programmes
Order ANPH 175	12/12/2006	Approval of minimal standards of quality for homecare social services for handicapped adults

4.24.1.5 The suitability of social support for people with dementia and carers

4.24.1.5.1 Adequacy and accessibility in general

There is a significant problem concerning adequacy and accessibility of services. First of all, there are very few services that are specifically designed for people with dementia. People with dementia can benefit from services designed either for handicapped people or elderly people but in a limited way (e.g. a person cannot attend a day care centre if cognitively impaired and he/she is not admitted into hospital due to a lack of personnel trained in dealing with dementia issues). There are few hospital wards able to provide specific care for people with dementia and a family member is required to provide care while his/her relative is hospitalised. Social assistance is very poorly represented.

4.24.1.5.2 People living in rural areas

There are many rural areas where a family doctor is not available, so for minor investigations or a simple medical consultation, the person has to go to the nearest hospital or polyclinic which in some cases is about a hundred kilometres away.

4.24.1.5.3 People with different types of dementia

People with different types of dementia have different rights. At this moment in time, only Alzheimer’s disease is recognised as a handicap by the commissions assessing handicap for adults. This means that people with other types of dementia cannot be granted the severe disability degree which would entitle them to support and services.

4.24.1.5.4 People from ethnic minorities

There is no specific support for people with dementia and their carers from ethnic minorities.

4.24.1.5.5 Younger people with dementia

Access to services and support from the State is dependent on eligibility for the severe handicap category and not on age. Consequently, younger people with dementia can access services (provided that they have Alzheimer's disease and not another form of dementia) but these services are not necessarily adapted to the specific needs of younger people with dementia.

4.24.2 Services and support for people with dementia and their carers

4.24.2.1 Types of care

4.24.2.1.1 Day care

There are very few day care centres for people with dementia in Romania. A few were opened by the Romanian Alzheimer Society under the PHARE LIEN programme in Nehoiu, Galati, Bucharest and Timisoara but since the local authorities stopped supporting these projects, only the one in Timisoara is still functional. In the past, the State provided the premises and covered expenses for utilities.

There have been several project proposals from local authorities (town halls) to open day care centres but sometimes premises that are initially proposed for day care centres end up being used for other purposes, especially if alternative usage is likely to generate a profit. There is a growing number of project proposals and it remains to be seen in the coming months or years if any of these will be for people with dementia.

There are reports of two further day care centres, partly funded by Dutch organisations and partly by the local council in Bistrita Nasaud County.

There are several day care centres in the country which benefit from the support of the Church but they are for elderly people with social problems and not specifically for people with dementia. Some NGOs have developed day care centre projects but without the support of local authorities (i.e. for premises and utilities), they are unlikely to last for more than a couple of years.

4.24.2.1.2 Respite care

There are no organised services covering respite care at home. However, in rural areas, there have been isolated cases of carers asking their relatives to come and look after the person with dementia for a couple of weeks so that they can have a break or go on holiday.

Sometimes, when carers are no longer able to cope, they try to arrange for the person with dementia to be admitted into a psychiatric ward for several days. This is possible if they know a doctor who is understanding and willing to admit the person with dementia for a short time. Private homes exist which accept people

with dementia for short periods of time. This usually costs between EUR 600 and EUR 1,400 per month.

4.24.2.1.3 Long-term residential care

Long-term residential care services funded by the State are not specifically designed for people with dementia. Means testing is applied and there may be out-of-pocket payments but property is not included in the calculation of available means.

There are long waiting lists for available places (sometimes over a year) and no social assistants to carry out accurate assessments. To make matters worse, there is a tremendous amount of bureaucracy surrounding applications for places in these institutions. As it is not possible to obtain assistance with the paperwork, this makes the whole process very difficult for carers and virtually impossible for people with dementia.

Private long-term residential homes also exist but they are not specifically designed for people with dementia either.

4.24.2.1.4 Palliative care

Several discrete attempts have been made by NGOs to provide palliative care at home. The Casa Sperantei from Brasov is a good example although it does not just provide this service for people with dementia. Apart from these limited attempts to provide palliative care, there are no palliative care services either at home or in centres.

4.24.2.1.5 Monitoring in the home via alarm systems

There are no tele-alarm systems whereby a person can signal for assistance in case of emergency.

4.24.2.2 Personal assistance and home help

4.24.2.2.1 Personal assistance

People who qualify for the severe handicap degree issued by the territorial commissions responsible for assessing adult handicap are entitled to the following services, for which they must nevertheless contribute towards the costs:

1. Assistance with personal hygiene
2. Supervision/assistance taking medication
3. Assistance with eating and drinking
4. Assistance with mobility (e.g. lifting, moving and walking)
5. Assistance with incontinence
6. Assistance with skin care

Services exist linked to companionship and assistance maintaining social activities but the costs must be covered totally by the service users. There are no services for occupational therapy/ergotherapy, assistive devices and home adaptation/transformation.

4.24.2.2.2 Home help

Assistance with housework, shopping and laundry services exist but must be totally funded by the service users. There are no transportation services. Help with the delivery of meals is available and is usually provided by NGOs and the Church. However, it is not specifically aimed at people with dementia as it is intended for people with a poor social and economic status. The NGOs are not directly involved in the preparation of meals but they transport food from restaurants and canteens, as well as food packages or food products, to people with dementia from poor families. This service does not function on a regular basis as it is dependent on the availability of funds i.e. from fund-raising activities or from local authorities. The Church also transports food to old people, some of whom have dementia.

4.24.2.3 Psychosocial support and training for people with dementia and carers

There is no general information service designed to inform people about available services in Romania.

Limited psychosocial support exists for people with dementia and their carers. For example, individual counselling for people with dementia may be offered by psychiatrists but only if they are specifically involved in the field of dementia. Psychiatrists are paid for a maximum of 14 consultations per day and cannot make a separate charge for counselling. Consequently, counselling is only offered by those who are willing to do it freely.

For carers, there are support groups organised by the Alzheimer Society in Bucharest. A token fee is requested from carers attending these groups. The rest of the costs are covered by the Romanian Alzheimer Association.

Training is available for carers. This is partly funded by the State and partly by the carers themselves.

There are no holiday services for people with dementia e.g. either alone, with carers or with personal assistants. Similarly, there are no provisions to enable carers to take a holiday e.g. payment or a substitute carer.

4.24.2.4 Work/tax related support for people with dementia

There are no specific provisions to protect people with dementia who are in paid employment e.g. from unfair dismissal or deterioration of their future social rights.

People with dementia are entitled to tax refunds and/or benefits due to their incapacity, direct payments from the State to pay for services (if eligible) and tax refunds/incentives for employing a person to provide home care services. They are not entitled to tax refunds, grants or other incentives for home transformations.

According to Law 488 of 2006, people with dementia are entitled to reductions on their television and radio licences and to free public transport. A person with dementia who owns his/her own house does not have to pay tax on it.

4.24.2.4.1 Work/tax related support for carers and carer allowances

Carers are not entitled to paid or unpaid time off work or flexibility in their working hours in order to care for a person with dementia. The State does not provide free or subsidised pension contributions to people who give up paid employment as a result of care giving.

Carers do not benefit from tax benefits or incentives for the care they provide. However, in accordance with Law 448 of 2006 and Law 487 of 2002, carers of people with dementia with the severe disability degree receive payments from the State towards the cost of caring. The National Authority for Handicapped People grants an allowance of EUR 100 per month and the local authorities, (the town councils) grant an allowance of EUR 20 per month. This is paid in the middle of each month (the handicapped person receives a separate coupon as proof that the money has been received).

4.24.3 Bibliography

Unless otherwise stated, information provided by Letitia Dobranici (Romania Alzheimer Society) between March and September 2007

Vladescu, C. et al. (2002), Health Care Systems in Transition, Romania, <http://www.observatory.dk>

4.25 *Slovak Republic*

Alzheimer Europe was unable to obtain information on the social support provided to people with dementia and their carers in the Slovak Republic.

4.26 Slovenia

Alzheimer Europe was unable to obtain information on the social support provided to people with dementia and their carers in Slovenia.

4.27 Spain²⁷

4.27.1 Organisation and financing of social support to people with dementia and carers

4.27.1.1 Background information on the social/healthcare system in Spain

Juan Carlos I became the Head of State in 1975 following the death of the dictator Franco. In 1978, a new constitution was passed which led to the establishment of a Parliamentary Monarchy and a new territorial organisation of the State. 1978 also saw the creation of the National Health Institute and in 1986 health care financing was transformed from an insurance-based system to one that is mainly based on taxation. The National Health Service does not cover social and community care (Rico, et al. 2002).

4.27.1.2 The organisation of social support for people with dementia and carers

The Ministry of Employment and Social Affairs (M.T.A.S.) is responsible for social support to people with dementia/dependent elderly people. However, the actual organisation of social support is regulated by each autonomous community and its respective town councils. Services are generally provided by local authorities and the private sector (mostly non-profit organisations).

The State finances projects carried out by associations and NGOs. Unfortunately, support for Alzheimer associations is sometimes insufficient and irregular which means that projects sometimes have to be discontinued.

The health care and social welfare systems are independent. They are under the authority of different Ministries and have different sources of funding. There is no interaction between the two.

4.27.1.3 The overall funding of social support for people with dementia and carers

Home social services are financed jointly by the Ministry of Employment and Social Affairs, the regional ministries of Social Welfare and the town councils. Rico et al. (2002) estimated the percentage of financing for social care as being 20% central State funding (i.e. taxation), 30% regional funding and 20% local funding. In addition to government provided services, voluntary associations and non-profit associations such as the Red Cross also provide social home care services (Carrillo, 2005).

Home-based care services that are publicly provided or arranged are means tested. They are free for people who are on the minimum pension. People who have an income twice as high as the minimum pension must pay for the services whereas those on an intermediary income must pay a certain amount which is calculated on the basis of their income. In Catalonia, the overall family resources are taken into account when calculating how much the service user must contribute. In this

²⁷ The information in this report on social support for people with dementia and their carers in Spain was provided by Ms Ines Quiroga on behalf of the Fundación Alzheimer España.

community, the service user can sign an acknowledgement of debt in which he/she agrees to make a future payment as part of an inheritance (Comas-Herrera et al. 2003).

4.27.1.4 The legal framework surrounding the provision of social support

It is stated in the Constitution of 1978 that elderly people are entitled to social support:

Article 50: To citizens in old age, the public authorities shall guarantee economic sufficiency through adequate and periodically updated pensions. Likewise, and independently of the family obligations, they shall promote their welfare through a system of social services which shall take care of their specific problems of health, housing, culture, and leisure.

However, there is no actual law covering the provision of social services at state level. Each of the 17 communities has its own laws. For example, the law for the Community of Madrid is: Law 11/2003 on Social Services of the Community of Madrid of 27 March. Decrees and regulations are determined by the autonomous communities and town councils. Consequently, citizens do not have a legally established right to social services.

A law reform is currently underway to promote the personal autonomy of dependent people i.e. Law 39/ 2006 of 14 December promoting the Personal Autonomy of Dependent People.

4.27.1.5 The suitability of social support for people with dementia and carers

4.27.1.5.1 Adequacy and accessibility in general

According to the Fundación Alzheimer España, social services and benefits are insufficient and do not respond to the specific needs of people with dementia.

4.27.1.5.2 People from ethnic minorities

There are no services specifically for people with dementia and their carers from ethnic minorities.

4.27.2 Services and support for people with dementia and their carers

4.27.2.1 Types of care

4.27.2.1.1 Day care

Day care centres exist but are insufficient. They are partly funded by the State and partly by service users. The provision of this service is means tested and can, in certain cases, cost about 25% of a person’s pension (Comas-Herrera et al. 2003). Volunteers and NGOs also provide day care services.

4.27.2.1.2 Respite care

Respite care in the home as well as short-term and long-term residential respite care services exist but are insufficient. Services users have to contribute towards the cost. Volunteers and NGOs also provide respite care services.

4.27.2.1.3 Palliative care

Palliative care services in the home as well as in centres exist but are insufficient. Palliative care at home is part of the health care system and is completely financed by the State. The cost of palliative care in centres is either shared by the State and service users or completely covered by the State.

4.27.2.1.4 Monitoring in the home via alarm systems

Tele-assistance and tele-alarm services are offered in at least 10 of the autonomous communities (Imsero in Larizgoitia Jauregi, 2004). This is insufficient. The autonomous communities that do have such systems are sometimes partly subsidised by the State, but sometimes service users have to pay the full cost of the service.

4.27.2.2 Personal assistance and home help

4.27.2.2.1 Personal assistance

The following services exist but are insufficient. They are all either partly or completely financed by service users. In certain cases, the State contributes towards the cost.

1. Assistance with personal hygiene
2. Supervision taking medication
3. Assistance with mobility e.g. lifting, moving and walking
4. Assistance with skin care e.g. hydration, preventing and dealing with bed sores
5. Companionship and social activities
6. Occupational therapy/ergotherapy
7. Assistive devices
8. Assistance dealing with incontinence
9. Assistance with eating and drinking (not with the preparation of food)
10. Home adaptation/transformation

The first two services are also provided by volunteers and NGOs. Those numbered 3 to 7 are also provided by NGOs. Home adaptation/transformation is extremely insufficient. However, in Andalusia, Castilla-Leon and Valencia, a service exists which consists of helping to adapt the home to the needs of a dependent person (Imsero in Larizgoitia Jauregi, 2004).

4.27.2.2.2 Home help

As with personal assistance, home help services exist but are insufficient. They are also either partly or completely financed by service users, with the State contributing towards costs in certain cases. The available services include the following:

1. Assistance with housework
2. Help with the preparation of meals (including meals-on-wheels)
3. Assistance with shopping
4. Transportation
5. Laundry

The first three services are also provided by NGOs. A meals-on-wheels service is only available in the cities of Malaga and Cordoba (Andalusia) and in the city of Lerida (in Catalonia)(Imserso in Larizgoitia Jauregi, 2004).

4.27.2.3 Psychosocial support and training for people with dementia and carers

Psychosocial support and training for people with dementia A general information service covering access to services is available and is funded completely by the State. NGOs also provide general information services. Counselling, support groups and holiday services for people with dementia and carers exist. Such services for people with dementia are either partly or totally funded by the State, whereas those for carers are only partly funded by the State. NGOs also provide these services. Some NGOs provide training for carers which is either partly or totally funded by the State.

4.27.2.4 Work/tax related support for people with dementia

People with dementia in paid employment are entitled to an incapacity pension if they have to give up their job due to dementia. They are also entitled to tax refunds/benefits based on their incapacity. However, they are not entitled to tax refunds/incentives for employing a person to provide home care services, tax refunds/incentives for home adaptations or direct payments to purchase services. People with dementia benefit from reduced fares on public transport.

4.27.2.5 Work/tax related support for carers and carer allowances

Carers are entitled to paid and unpaid time off work for caring. Flexible working hours are not sufficiently used as a solution to help carers organise their caregiving tasks. They do not benefit from free or subsidised pension contributions from the State.

Carers are entitled to tax relief for caring for a person with dementia provided that they first obtain a certificate of disability (certificado de minusvalía) for the latter. According to Comas-Herrera (2003), this tax relief is quite small in absolute terms and is for heads of families who pay user charges for privately purchased care for an older person with dependency.

4.27.3 Bibliography

Unless otherwise stated, the information in this report was provided by Ms Ines Quiroga on behalf of the Fundación Alzheimer España in March 2007.

Carrillo, E. (2005), WHHO International Compendium of Home Health Care:

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Spanish Constitution of 1978 (with amendments up to 27 August 1992):

http://expired.oefre.unibe.ch/law/icl/sp00000_.html

4.28 Sweden²⁸

4.28.1 Organisation and financing of social support to people with dementia and carers

4.28.1.1 Background information on the social/healthcare system in Sweden

In 1992, the Swedish government implemented the Community Care Reform (known as the Ädelreform) which involved the decentralisation of responsibility and resources for the care of the elderly from regional to local governments.

Half of the municipalities, 144 of 290, in the country have now taken over responsibility for health and medical care in everyday life. In the other municipalities, the county councils are responsible.

4.28.1.2 The organisation of social support for people with dementia and carers

The Ministry of Health and Social Affairs in Sweden is responsible for general planning, guidance and supervision aimed at older people. The overall policy is designed to ensure that people have the possibility to live independently and safely in their own homes as long as they wish with support and home-care if needed. These targets are established by the Swedish Government and Parliament.

In Sweden, the welfare of the elderly is divided between three levels of government:

- at national level: the Parliament/Government (responsible for establishing policy aims and directives by means of legislation and economic guiding measures)
- at regional level: the county councils (responsible for the provision of medical and health care)
- at local level: the municipalities (responsible for meeting the social services and housing needs of the elderly).

The municipalities are responsible for organising services and home care for their inhabitants. They can provide services themselves or they can purchase them from private providers but they must keep track of the care that they are providing and of the care provided by private companies. Support from voluntary organisations is limited.

The municipalities are independently responsible for providing social and home care. Social legislation provides a legal framework which gives the municipalities freedom to develop the law according to local conditions and political decisions. They can therefore interpret their obligations differently. Many municipalities have developed their own informal guidelines on service provision with the result that in some areas, for example, elderly people who only need help with cleaning are no longer eligible for home-help. Some have introduced means testing for some services.

²⁸ The information in this report on social support for people with dementia and their carers in Sweden was provided by Lennart Garney from the Demensförbundet.

The provision of services is based on an assessment of the person's housing, services and care needs. This is usually carried out by a municipal care manager, or as is often the case for elderly people, by an interdisciplinary care planning team.

4.28.1.3 The overall funding of social support for people with dementia and carers

Social support for people with dementia and carers is funded through general taxation and individual service fees. The State provides funding to Alzheimer associations on the basis of the number of local associations and the number of members. Support is also given for telephone advisory services etc.

The fees charged for home help are determined by the amount of help needed and a person's income. Nevertheless, people receiving home care only pay a fraction of the actual cost. Also, since 1 July 2002, there has been a maximum fee for elderly people resident in the municipalities.

4.28.1.4 The legal framework surrounding the provision of social support

The care of older people, which includes the care of people with dementia, is regulated by three laws. Each law regulates in a different way what the public sector can expect in relation to the individual and what kind of rights the individual has.

The laws are as follows:

- The Law of Health and Medical Services (HSL) 1982:763;
- The New Social Service Legislation (SOL) SFS 2001:453 (which came into force on 1 January 2002);
- The Law of Support and Service to Certain Persons with Handicap (LSS) 1994 which is a law of rights and carefully specifies the obligations of municipalities and county councils as well as individual rights.

Only younger people, under 65 years, with dementia have a right to receive help from a personal assistant instead of home care.

§29 of the Law of Health and Medical Services HSL and chapter 3, §5 of the New Social Legislation Sol, states that home care services should be organised in consultation with the people and relatives who are asking for a special kind of assistance. A decision made in accordance with the social law can be appealed if the decision is wholly or partially against the person's wishes.

There are no law reforms currently underway.

4.28.1.5 The suitability of social support for people with dementia and carers

4.28.1.5.1 Adequacy and accessibility in general

Since an increasing number of people with dementia remain at home in their usual environment for an increasingly long period of time during the course of the disease, specially developed care and support measures are needed that target them and their close relatives. In a number of municipalities, there are clear plans and strategies for how the municipalities can provide individual adapted care for people with dementia. In many other areas, both knowledge regarding the needs of people with dementia and their relatives and the activities and resources offered to meet these needs are insufficient.

In 2002, the Government decided to set up a working group to compile available knowledge about the situation of people with dementia and their relatives. Its objective was to try to provide a comprehensive overview of the current situation. The group has presented a national view of how dementia care has evolved in Sweden in recent years and the areas that it is important to prioritise and develop in the next few years. This report, entitled “På väg mot en god demensvård” (On the way towards good dementia care), was published by the Ministry of Health and Social Affairs in 2003. This report has led to a number of different projects in the Municipalities and County Councils.

There are no national facts about users’ satisfaction but many local studies have been carried out which show that people are generally satisfied with home care. General satisfaction is, however, a blunt measure for services and care. The failings become much clearer when specific questions are asked. Another problem is that many people cannot answer the questions because of their disease. Often the questionnaire or interview is answered by a relative even though users’ and relatives’ opinions about care often differ. In 2003, the Swedish Dementia Association (Demensförbundet) published an extensive study on the situation of caregivers.

In studies where users have been asked how important a certain fact is, the answer has very often been that having the same member of staff is important for their safety. A common experience is that staff are in a hurry. There is no time to talk and be together socially. Questions which are given the highest evaluation are those concerning treatment and accessibility. It is also important to be aware of the needs of people with dementia and their relatives and to understand the experience and needs of people with dementia in particular. In some communities, specially organised home-care for people with dementia has been started.

Support for people with dementia in their own homes varies greatly from one community to the next. In the inquiry into dementia in 2002, 9% of the communities said that they had specially arranged home care for people with dementia. In certain cases, there is specific planning and a strategy on how the communities should treat and give individually designed care to people with dementia. Elsewhere, knowledge about people with dementia and their relatives is insufficient.

However, a great deal of education/training for staff working with people with dementia has been organised. Awareness of the importance for staff who provide care and support to persons with dementia to have the requisite knowledge has increased. They have to know how to behave towards people with dementia, how to stimulate them, what attitude to have when handling challenging behaviour and how to make the most of a person's remaining capacity.

4.28.1.5.2 *People from ethnic minorities*

Some support is available for people with dementia and carers from ethnic minorities but this is insufficient. When available, it is partly funded by the State and partly by service users.

4.28.2 Services and support for people with dementia and their carers

4.28.2.1 Types of care

4.28.2.1.1 *Day care*

According to the The New Social Service Legislation (SOL), municipalities should support people caring for dependent relatives. An important means of support for people with dementia, to enable them to live at home, is day care which can provide stimulation and ensure the safety of people with dementia, as well as providing relief for the relatives. However, day care is not compulsory. Day care centres which exist are partly funded by the State and partly by service users. They are considered insufficient.

4.28.2.1.2 *Respite care*

There are no services providing respite care at home. Short-term and long-term residential respite care exists but this is insufficient. Both types of respite care are partly funded by the State and partly by service users.

4.28.2.1.3 *Palliative care*

Palliative care at home and in palliative care centres is available and partly funded by the State. The home service is considered insufficient but palliative care in centres is considered sufficient.

4.28.2.1.4 *Monitoring in the home via alarm systems*

Tele-alarm systems are available and are partly funded by the State. However, this service is considered insufficient.

4.28.2.2 Personal assistance and home help

4.28.2.2.1 Personal assistance

The following services are available. They are partly funded by the State and partly by service users:

1. Assistance with personal hygiene
2. Supervision/assistance taking medication
3. Assistance eating and drinking (not with the preparation of food)
4. Assistance with mobility e.g. lifting, moving and walking
5. Assistance with skin care
6. Companionship/social activities
7. Occupational therapy/ergotherapy
8. Assistive devices (provided by the municipalities)
9. Home adaptations/transformations

The first two services are almost sufficient. The rest are considered insufficient.

Assistance dealing with incontinence is also available and is completely funded by the State but it is nevertheless considered insufficient.

4.28.2.2.2 Home help

A range of services are available to help people in the home. They include:

1. Assistance with housework
2. Delivery of readymade meals
3. Assistance with shopping
4. Transportation service
5. Assistance with laundry

The above-mentioned services are all partly funded by the State and partly by service users. On the whole, they are not considered sufficient. Assistance with shopping is considered insufficient in some areas.

4.28.2.3 Psychosocial support and training for people with dementia and carers

The availability of general information services (covering access to services) varies throughout the country but those that do exist are completely funded by the State.

Counselling services for people with dementia are partly funded by the State and partly by service users. Carers must pay the complete cost of counselling services themselves. In both cases, the services are considered insufficient.

There are no specific provisions for people with dementia and/or carers to have holidays. Training courses are available for carers but the State does contribute at all towards the costs so carers have to pay the full cost themselves. This is not considered sufficient.

4.28.2.4 Work/tax related support for people with dementia

There are no protective measures for people diagnosed with dementia who are still in paid employment. They are not entitled to tax refunds on the basis of personal incapacity or for employing someone to provide home care services, they do not receive direct payments to pay for care and they are not entitled to tax refunds, grants or incentives for necessary home adaptations.

People with dementia are, however, entitled to reductions on public transport fares. This is covered by the Law of 1997:736 (Lag om färdtjänst).

4.28.2.5 Work/tax related support for carers and carer allowances

Carers are not entitled to paid or unpaid time off work or flexible hours on the grounds of their caregiving duties. They do not receive free or subsidised pension contributions for the care that they provide or any kind of payment from the State or tax benefits/incentives.

4.28.3 Bibliography

Unless otherwise stated, information provided by Lennart Garney (Demensförbundet) in June 2007

4.29 Switzerland²⁹

4.29.1 Organisation and financing of social support to people with dementia and carers

4.29.1.1 Background information on the social/healthcare system in Switzerland

The first Swiss health insurance act was passed by the Federal Government in 1911. This obliged insurers to register with the Federal Social Insurance Office. The insurances were individually contracted (i.e. not employer based) and the funds were not allowed to make a profit. Individual cantons could decide whether the insurance was obligatory but by 1990, nearly 98% of the population had purchased such an insurance.

The revised Health Insurance Law of 1994 significantly changed the system and made health insurance obligatory for all residents in Switzerland. Insurance companies are obliged to accept all applications for insurance cover and the insured are allowed to change insurer once or twice a year (Civitas, 2002).

4.29.1.2 The organisation of social support for people with dementia and carers

Financial support is mainly organised at federal level. Support is also organised by the cantons and the communes but organisation differs from one canton to the other. There are no special provisions for people with dementia.

The Federal Department of Home Affairs (especially the Federal Social Insurance Office and the Federal Office of Public Health) of the Swiss Confederation is responsible for creating the legal framework and organising support to people with dementia and their carers at federal level. Various organisations at cantonal level are also involved. Private initiatives and voluntary associations are quite important as the State does not cover everything.

Organisations which provide support to the elderly and to sick people receive grants from the Federal Social Insurance Office. The Swiss Alzheimer Association benefits from State support. It receives a subsidy (of a fixed amount) and money for the services it provides e.g. the helpline and respite care at home (also for its branches). Other associations like Pro Senectute also receive subsidies.

4.29.1.3 The overall funding of social support for people with dementia and carers

Support for people with dementia and carers is financed by different sources: social insurances for old age and incapacity, obligatory health insurance, income taxes and of course the private income and fortune of the people concerned.

Social insurances (Old Age and Survivors insurance and Incapacity insurance) cover the costs for the “vital minimum” for all residents in Switzerland. They are financed by obligatory payroll deduction (under the AHVG and IVG laws – please see below).

²⁹ The information in this report on social support for people with dementia and their carers in Switzerland was provided by Marianne Wolfensberger from the Association Alzheimer Suisse.

The obligatory health insurance contributions (premiums) are set according to age, gender and rates applied in each region of the country (costs vary from one region to another and health politics are largely the responsibility of the cantons). They are not linked to earnings or income. Each person is insured individually. People whose contributions represent 8 to 10% of their income may be entitled to means-tested tax-based subsidies from the State and the cantons. The cantons have the power to define the criteria for the granting of such subsidies.

The obligatory health insurance covers part of the cost of home care (provided by the home care organisation Spitex) or residential care (based on prices that are determined by the cantons). Patients/service users must pay an annual franchise and make a further contribution towards costs. The remainder of the cost is covered by the cantons. People may opt for a higher franchise in order to reduce their health insurance premium.

People who have difficulty coping with daily life activities may apply for an incapacity allocation from the State. Private insurance offers the possibility to take out a special insurance for this kind of costs.

4.29.1.4 The legal framework surrounding the provision of social support

The main legislation of relevance to the provision of support to people with dementia and their carers is as follows:

- Bundesverfassung (Constitution SR 101;18.4.99, which came into force on 1.1.2000) Art. 41: social support and care for all people is guaranteed by the Confederation and the Cantons.
- Bundesgesetz über die Alters- und Hinterlassenenversicherung AHVG (Federal law on old age and survivors insurance) (SR 831.10; 20.12.46 which came into force on 1.1.49, with various revisions). This assures a minimum income for elderly people including complementary financial support if needed (Bundesgesetz über Ergänzungsleistungen zur Alters-, Hinterlassenen- und Invalidenversicherung ELG, SR 831.3). Art. 43bis covers an allocation for incapacity - "eine Hilflosen-schädigung".
- Bundesgesetz über die Invalidenversicherung IVG (Federal law on incapacity insurance) (SR 831.20; 19.6.59 which came into force on 15.10.59, with various revisions). This assures a pension and other financial help in case of incapacity. It also foresees an allocation for people with an incapacity who have not yet reached the age of retirement.
- Bundesgesetz über die berufliche Alters-, Hinterlassenen- und Invalidenvorsorge (Federal law on professional insurance for old age, survivors and invalids) (SR 831.40, 25.6.1982, which came into force on 1.1.85) including various important revisions. It introduced an obligatory insurance for employees (payroll deduction). This assures an old-age pension and an invalidity pension.

- Bundesgesetz über die Krankenversicherung (Federal law on health insurance) (SR 832.10; 18.3.94, which came into force on 1.1.96). It concerns the basic obligatory insurance which covers the cost of medical treatment, drugs and care (also partly long-term care).

The laws are completed by a series of regulations, such as the Krankenpflege-Leistungsverordnung (KLV) RS 832.112.3, which determines the nature of the care acts, organisation of care in institutions and home care services. However, there are also many cantonal laws and regulations because in Switzerland health care is a cantonal matter (i.e. there are 26 different legislations).

With regard to legislative reforms, a revision of health insurance is planned, particularly regarding long-term care. It is proposed that the insurance should only pay part of the cost. According to the law in force, dating back to 1994, all costs should be paid by the obligatory insurance but, due to the increase in costs, lower tariffs have been applied to calculate the part of the insurance. The new law aims to fix the part of total costs to be covered by the obligatory insurance. The remaining costs will have to be paid by the patients and the cantons.

4.29.1.5 The suitability of social support for people with dementia and carers

4.29.1.5.1 Adequacy and accessibility in general

Obtaining the necessary information requires a lot of personal effort. The Swiss Alzheimer Association with 20 branches in the Cantons and some other organisations (e.g. Pro Senectute) offer information and some services.

Homecare provided by Spitex (an organisation specialising in homecare services) is very well developed, also in rural areas.

There are not enough day and night care centres (a study carried out by Swiss Alzheimer Association stated that only 12% of needs are covered by the existing 124 centres). Financial support is insufficient.

More and more residential care settings are introducing specific dementia units but there are not enough to cover needs.

The services that the Swiss Alzheimer Association (and some other organisations) offers respond to the specific needs of people with dementia and their carers.

4.29.1.5.2 People living in rural areas

As stated above, Spitex offers homecare services in rural areas as well as in agglomerations but day and night care centres are scarce and the few that exist are mostly located in larger agglomerations. Transportation services provided by the Red Cross and volunteers are not well developed in rural areas.

4.29.1.5.3 People from ethnic minorities

A special nursing home for people with dementia from Latin countries was set up in Zurich 2 years ago and there is also a Jewish nursing home near Zurich.

4.29.1.5.4 Younger people with dementia

The Swiss Alzheimer Association offers support groups for carers (and children) of younger people with dementia and is planning to organise holiday weeks for younger people with dementia (with/without their carers).

4.29.2 Services and support for people with dementia and their carers

4.29.2.1 Types of care

4.29.2.1.1 Day care

Day care centres exist but they are insufficient as they only cover about 12% of actual demand. Fairly often they are operated by nursing homes. Some are partly subsidised by the Cantons or communes but there are also centres which do not receive any funding from the State. Some centres also offer night-time care.

4.29.2.1.2 Respite care

Some branches of Alzheimer Switzerland offer private respite care at home on a one-to-one basis. This service is possible by the hour and also for whole days and nights. It is financed by the family and so far some subsidies have been received from the State. The respite carers receive a small remuneration.

Nursing homes offer short-term stays to relieve carers (as long as the bed is not occupied by a long-term resident...). These can be partly funded by the State and partly by service users.

4.29.2.1.3 Long-term residential care

Long-term residential care is funded by service users and the health insurance. Service users pay for hotel costs, which means the actual cost of accommodation and the health insurance covers care costs but only up to a maximum of FR 80 per day. There may also be additional out-of-pocket expenses such as materials for care, various services and small personal expenses. The state/canton/commune may pay the amount that is not covered by the health insurance if the service user does not have sufficient resources. The price for long-term residential care is the same for all residents. It is not means tested.

4.29.2.1.4 Palliative care

Palliative care services at home and in centres are mostly available. They are funded by the State, the health insurance and the patients themselves. Some NGOs, volunteers and churches also offer such services. According to the European Association for Palliative Care (2005), there are some hospices that are funded privately. The

Swiss homecare association (Spitex) states that it provides support to the dying and their families (Spitex, 2007).

4.29.2.1.5 Monitoring in the home via alarm systems

A tele-alarm system is available but people must pay for it themselves. The State does not contribute towards the cost.

4.29.2.2 Personal assistance and home help

4.29.2.2.1 Personal assistance

The following services are available in Switzerland:

1. Assistance with personal hygiene
2. Supervision/assistance taking medication
3. Assistance eating and drinking
4. Assistance with mobility e.g. lifting, moving and walking
5. Assistance with incontinence
6. Assistance with skin care
7. Companionship/social activities
8. Occupation therapy/ergotherapy
9. Assistive devices
10. Home adaptation/transformation

The first four services are provided by Spitex (the homecare services organisation) and are considered sufficient. Spitex may also provide assistance with incontinence and skin care. These services are partly funded by the State and partly by the obligatory health insurance. Patients must pay the remainder themselves. Volunteers also provide assistance with personal hygiene and mobility and it is possible that other associations offer assistance with eating and drinking. Spitex is limited in the time that it can spend on assistance with mobility.

The Swiss Alzheimer Association and some volunteers provide companionship and social activities. This is insufficient. Service users must pay for these services completely.

Occupational therapy/ergotherapy is mainly provided in day care centres/homes. Spitex also provides this service in peoples' homes. The service is partly financed by the health insurance if the person has a medical prescription and partly by the person him/herself.

Assistive devices are available and some are funded by the health insurance or incapacity insurance but many people do not know about them.

Home adaptations are partly funded by the State and partly by the person who needs them. It is possible to obtain funding from an incapacity insurance.

4.29.2.2.2 Home help

Certain services are available but are not funded by the health insurance. Consequently, service users have to pay for them themselves. This includes assistance with housework (can be provided by Spitex), help with the preparation of meals including meals-on-wheels (provided by the Swiss Red Cross and Pro Senectute), assistance with shopping (provided by volunteers), transportation (provided by the Swiss Red Cross and volunteers but not well developed in rural areas) and laundry services (provided by Spitex).

4.29.2.3 Psychosocial support and training for people with dementia and carers

The State does not have a service to inform the public of the availability of various services but it does finance the helpline of the Swiss Alzheimer Association and certain other organisations which provide information about services. NGOs and volunteers are also involved in providing this service. However, these services need to be developed further.

Counselling services for people with dementia are being set up in different places but, at the moment, they are insufficient. Those that exist are partly funded by the State and partly by service users. NGOs receive financial support from the State for these services in the form of grants. Counselling services for carers are sufficient and partly financed by the State (e.g. in the form of grants to NGOs) but carers also have to partly pay for counselling themselves. However, the Swiss Alzheimer Association and the organisation Pro Senectute both offer counselling services for carers.

Services to enable people with dementia to take holidays are under construction and being extended. There are currently eight branches of the Swiss Alzheimer Association and some Pro Senectute organisations offering this kind of service. They are partly funded by the State (the Federal Social Insurance Office to be precise) in order to cover the costs of the assisting volunteers. Service users (people with dementia and carers) must pay their own hotel costs. There are also nursing homes that offer holiday stays for people with dementia. Costs are paid by the service users.

There are currently no official services designed to give carers a holiday (i.e. a substitute carer or holiday money). When a carer is unable to take care of the person with dementia because of his/her own health problems, the person with dementia can be taken into a hospital or a nursing home. The sick carer is entitled to the necessary treatment and drugs through the health insurance. Short stays in spas or similar centres for relaxation on medical prescription are very rare. Private insurance arrangements may offer cover for a substitute carer.

As the State does not contribute towards the cost of training, carers must pay for it themselves. The Swiss Alzheimer Association and a few other organisations such as memory clinics, Pro Senctute and the Swiss Red Cross may occasionally organise training for carers.

4.29.2.4 Work/tax related support for people with dementia

The Employment Law in the Code of Obligations contains limited provisions to protect people against dismissal on the grounds of illness. It does not specifically mention dementia. However, there are some regulations for blocking periods (“Sperrfristen”) in case of illness during which time a person cannot be dismissed.

The Federal Law on Old Age and Survivors Insurance (AHVG) and the Federal Law on Incapacity Insurance (IVG) contain provisions for an incapacity allocation.

A tax deduction for costs incurred due to an illness is granted on the basis of federal and cantonal laws. There is no tax refund for employing someone to provide home care services.

People with dementia are entitled to financial assistance to make home adaptations. This is covered by the Law on Incapacity Insurance (IVG) and the Decree on the provision of Means of Assistance through the Invalidity Insurance of 29.11.1976.

4.29.2.5 Work/tax related support for carers and carer allowances

Carers do not have any legal right to paid or unpaid time off work for caring. However, the law (the Employment Law in the Code of Obligations, Art. 329) has been extended by jurisprudence. It is therefore possible to have paid time off work to care for a terminally ill person but otherwise people are dependent on the goodwill of their employer.

Art 36 of the Employment Law of 13/3/1964 states that employers have to take family responsibilities (including the care of a sick relative) into account when fixing working hours. Employees do not have a legal right to flexible working hours but a lot of companies in Switzerland offer flexible working hours to all their staff.

The State does not offer free or subsidised pension contributions to carers. The AHV-contribution is deducted from the income. Carers who have a paid activity pay the normal contribution. Carers who do not have a professional paid activity do not pay contributions but at the end, they have less credit. In accordance with the Federal Law on Old Age and Survivors Insurance (AHVG), carers who cannot work and thus pay their contributions to the State pension fund are entitled to some kind of compensation. This may take the form of credits towards their pension (AHV-Betreuungsgutschriften) or in some cantons, a direct payment.

4.29.3 Bibliography

Unless otherwise stated, information provided by Marianne Wolfensberger (the Swiss Alzheimer Society) in September 2007.

Website containing texts of relevant laws in French and German:

http://www.admin.ch/ch/f/rs/831_10/index.html

European Association for Palliative Care (2005), Report on palliative care in Switzerland:

<http://www.eapcnet.org/download/forPolicy/Switzerland.pdf>

Pro Senectute (an organisation for seniors): <http://www.pro-senectute.ch/f/index.cfm>

Spitex (2007), website of the Swiss homecare association: <http://www.spitex.ch>

The Swiss Healthcare System 2002: <http://www.civitas.org.uk/pdf/Switzerland.pdf>

Federal Office of Public Health: <http://www.bag.admin.ch>

4.30 Turkey

Alzheimer Europe was unable to obtain information on the social support provided to people with dementia and their carers in Turkey.

4.31 *United Kingdom - England, Wales and Northern Ireland*³⁰

4.31.1 **Organisation and financing of social support to people with dementia and carers**

4.31.1.1 **Background information on the social/healthcare system in England, Wales and Northern Ireland**

Prior to 1948, healthcare was a luxury that not everyone could afford. Workers on a low wage had access to free doctors but everyone else had to pay. For those who could not pay, there was the Royal Free Hospital which initially relied on consultants giving their services free of charge and money from legacies, donations, subscriptions and fund-raising events. There were also other charitable and voluntary hospitals. Elderly people who could not care for themselves sometimes ended up in work houses, later known as Public Assistance Institutions.

In 1942, the Beveridge Report recommended a universal and comprehensive service covering all people and all needs. The National Health Service (NHS) was formed and started to function in 1948. Although initially intended to provide free health care, within 3 years it was necessary to charge a small contribution from service users. (Source: NHS, 2007 and Lowe, 2002)

4.31.1.2 **The organisation of social support for people with dementia and carers**

4.31.1.2.1 ***Responsibility and overall coordination***

The Department of Health is responsible for social support to people with dementia. The National Health Service Act 1977 requires NHS bodies and local authorities to co-operate with one another in order to secure and advance the health and welfare of people of England and Wales.

Ideally, health and social care teams should work together at a local level and nationally, but this is often not the case. There are mechanisms to support joint working for example – power to pool budgets, jointly commission services and create Care Trusts – which are a type of NHS body introduced in 2002 to provide better-integrated health and social care. The idea behind care trusts is that by combining both NHS responsibilities and local authority health responsibilities under a single management, care trusts can increase continuity of care and simplify administration.

S.A.P. (Single Assessment Process) is a standardised holistic assessment framework across health and social care which ensures that duplication is minimised and an individual receives timely and proportionate assistance appropriate to their risks and needs. The Single Assessment Process aims to put individuals at the centre of their own assessment and subsequent personalised care planning. Originally brought in for older people, it is increasingly being used as the framework for other adult groups.

³⁰ The information in this report on social support for people with dementia and their carers in England, Wales and Northern Ireland was provided by Clive Evers from the Alzheimer's Society.

Joint Commissioning is key to providing effective social care for adults and children. It is the process by which social services and health authorities decide how to spend their money to get the best possible services for local people.

4.31.1.2.2 Organisation of health services and social care

Many people with dementia and their families have multiple needs, which can be identified, assessed and addressed by more than one agency or sector. In particular people with dementia may receive support from both or either of the health and social care systems. An added complication is that the support and care needed by people with dementia and their families could be delivered by government, private or voluntary organisations. However, most support and care is not provided through structured organisations but by individuals, whether unpaid family members, other unpaid caregivers or – increasingly by individuals employed under direct payment or individual budget arrangements.

4.31.1.2.2.1 Health services

In the UK the lead specialty that has evolved to diagnose and treat people with dementia is old age psychiatry. However, even within the UK, diagnosis and treatment might also be carried out by a geriatrician (e.g. if there is concomitant acute physical illness requiring admission to a general hospital), a neurologist (e.g. where the person is relatively young) or a GP (where the GP has a particular skill or interest in the area).

It is UK policy that all areas should have a specialist old age psychiatry service and data held by the Royal College of Psychiatrists’ faculty of old age psychiatry suggest that is now the case. The traditional model of old age psychiatric service delivery combines first assessment either at home following a GP request for a consultant domiciliary visit or more rarely in an out-patient clinic. Follow-up may then be by further consultant home visits, out-patient attendance or Community psychiatric nurses (CPNs).

4.31.1.2.2.2 Social care services

Many of the needs of older people with dementia stem from deterioration in their health and are usually met appropriately by health care services. Other needs are better met by social services, but the boundaries between the two are sometimes hard to draw and potentially have implications for access and level of care, and for the balance of funding.

Social services can organise care at home as well as long term and short term residential care. A significant change in the service portfolio for older people over recent years has been the development of ‘extra care housing’ as an alternative to long-term care and as a community focus for intermediate care schemes’ (SSI 2003 p.7). Earlier manifestations of these services were called ‘very sheltered housing’ and ‘housing and care’ schemes. Retirement communities can come within this

category (e.g. see Croucher et al 2003 on Hartrigg Oaks in York). Most extra care housing is provided by the social rented sector (local authorities or registered social landlords). Extra care housing still only provides a small proportion of accommodation for people with dementia.

4.31.1.2.3 Interaction between the State and voluntary associations/NGOs

The Voluntary Sector Compact is the agreement between government and the voluntary and community sector to improve their relationship for mutual advantage and community gain.

Whilst there are many government departments that offer funding to voluntary organisations, the main department for Alzheimer's disease and dementia is the Department of Health. There is a special programme of funding called Department of Health Section 64 funding to enable charities to develop services and resources. The following website gives more details: <http://www.governmentfunding.org.uk/>

4.31.1.3 The overall funding of social support for people with dementia and carers

How support is funded depends on whether the services required are to be provided by the National Health Service (NHS) or social services.

4.31.1.3.1 NHS

The NHS is largely free at the point of delivery and is funded out of centrally collected general taxation. However, set charges apply to most adults for prescriptions, optician services and dentistry.

4.31.1.3.2 Social care

Services provided or arranged through social services departments of local authorities are funded from central and local taxation and are subject to user charges (personal care is means tested in England, Wales and Northern Ireland).

If care is provided via social services all or some of the cost can be passed on to the person receiving the services depending on their financial position. A nationally applicable means test takes account of an individual user's income and assets.

4.31.1.3.3 Home care

Most local authorities charge for home care and will ask anyone with savings over a certain limit to pay all of their home care costs. Each local authority can decide its own charges for home care. Variation in charges therefore exists between different local authorities, although charges must be 'reasonable' and anyone who feels that they are excessive has a right to complain.

4.31.1.3.4 Nursing home care

If a person has been assessed as fulfilling continuing NHS health care criteria (where the primary need is a health need), the NHS will pay for all of their care. Anyone living in a nursing home should automatically have been assessed for continuing NHS care.

If a person in a nursing home has not been assessed as eligible for continuing NHS care, they will be entitled to financial assistance with the cost of their nursing care. This is known as the registered nursing care contribution. The amount that the NHS will contribute towards a person’s nursing care is determined by an assessment of the level of nursing care needed. This places the level of need in one of three bands (high, medium or low), with each band corresponding to a level of funding.

4.31.1.3.5 Residential care

People living in residential care homes have usually not been assessed for continuing NHS health care and services provided would be means tested.

4.31.1.4 The legal framework surrounding the provision of social support

The following acts (presented in chronological order) are relevant to the provision of social support.

National Health Act 1946 (came into power 1948):

Due to the National Health Act, free and comprehensive health services are provided.

National Assistance Act 1948 (came into power 1948):

The National Assistance Act creates a duty for local authorities to provide accommodation for persons aged 18 or over who by reason of age, illness, disability or any other circumstances are in need of care and attention which is not otherwise available to them and for the local authority to charge that person for accommodation, following a financial assessment (section 21).

Local authorities may also make arrangements for promoting the welfare of persons who are over 18 and blind, deaf, or dumb or suffer from any mental disorder or who are substantially and permanently disabled (section 29).

The Chronically Sick and Disabled Persons Act 1970:

The Chronically Sick and Disabled Persons Act creates a duty for local authorities to inform themselves of the number of persons to whom they have to provide assistance and existence of welfare services in their area. They are also required to inform people who use those services of any other service that may be relevant to them.

Under section 2 of this act local authorities are also required to make arrangements to provide assistance to anyone who falls under section 29 of the National Assistance Act 1948 – including amongst other things meals, equipment, transport to reach any services provided under section 29 and practical assistance for the person in their home.

Guidance published in 2002 under section 2 of this Act introduced Fair Access to Care Services (LAC(2002)13). This introduced a national framework for councils to use when setting their eligibility criteria. The framework is based on risks that arise from needs associated with various forms of disability, impairment and difficulty, and will help councils to promote the independence of those seeking their help. The guidance prioritises the risks faced by individuals into four bands - critical, substantial, moderate and low - and requires councils to adopt these bands in determining their criteria. The risks within the framework relate to both immediate and longer-term risks. The guidance stated that in setting their eligibility criteria councils should take account of the resources locally allocated and available to adult social care. Many councils now only provide services to those in the substantial and critical bands.

The National Health Service Act 1977:

The National Health Service Act sets out the services that should be provided by the NHS, for example hospital accommodation, medical, dental, nursing and ambulance services and any other services for the diagnosis and treatment of illness. It also gives local authorities the power to provide some services, including day centres and home help and laundry services (it is a duty of the local authority to provide the latter two services to people who are unwell or disabled).

When requested to do so by a disabled person, his/her authorised representative or someone who provides care for him/her, a local authority shall decide whether the needs of the person call for the provision by the authority of any services under section 2 of the 1970 Act.

Also, it gives the local authority a duty to take into account the abilities of a person's carer to carry on caring when it is assessing the needs of an individual.

The Mental Health Act 1983:

This act covers the care and treatment of mentally disordered people. It gives the criteria for compulsory detention in hospital.

The Disabled Persons Act 1986:

This Act strengthened the provision surrounding the meeting of various needs of disabled people in respect of the Chronically Sick and Disabled Persons Act 1970.

National Health Service and Community Care Act 1990:

This act was brought in to promote community care. Each local authority should prepare and publish a plan for the provision of community services in their area and keep this under review. The local authority should consult any health authority, housing authority (if relevant) and relevant voluntary organisations within their boundaries when developing this plan. The responsibility places a duty on authorities to assess people for social care and provide the support they require (section 47(1)). The act established the familiar procedures of ‘care management’ (social services) or ‘care programme approach’ (NHS) which the statutory departments now operate to. A mixed economy of care is promoted with the independent, private and voluntary sectors being encouraged to provide resources.

Carers (recognition and services) Act 1995:

A carer may request that the local authority carry out an assessment of their ability to carry on providing care, before assessing an individual under section 47(1) of the National Health Service and Community Care Act 1990.

Community Care (Direct Payments) Act 1996:

If a local social services or social work department has a direct payments scheme, people can, if they prefer, ask to be given the money to pay for the care services themselves.

The Carers and Disabled Children Act 2000 (came into force in April 2001):

The Carers and Disabled Children Act gave carers the right to an assessment of their own needs to help them to continue to care, irrespective of whether the person they are caring for has had their own needs assessment. The assessment is available to any carer who provides or is intending to provide regular and substantial care. There is no definition of ‘regular and substantial care’; this is decided by social services.

Care Standards Act 2000:

The Care Standards Act established a regulatory framework for social care. It established the independent National Care Standards Commission (NCSC) (now Commission for Social Care Inspection) which regulated and inspects social care providers and the Commission for Health Improvement (CHI) (now the Healthcare Commission) which assesses and reviews the performance. It also introduced national minimum standards for care homes and domiciliary care providers.

Health and Social Care Act 2001:

This Act makes provisions for local authorities to make 'direct payments' in lieu of direct provision of services to individuals assessed as requiring care.

Health and Social Care (Community Health and Standards) Act 2003:

This Act abolished the NCSC and CHI and created the Commission for Social Care Inspection and the Commission for Healthcare Audit and Inspection (the Healthcare Commission). The majority of the NCSC's functions transferred to CSCI, with the exception of those functions relating to the provision of independent healthcare, which transferred to the CHAI. All of the CHI's functions transferred to the CHAI.

The National Health Service Act 2006, The National Health Service (Wales) Act 2006 and The National Health Service (Consequential Provisions) Act 2006:

The many amendments to the legislative foundation of the NHS – the NHS Act 1977 – leave the law very complex and inaccessible. To remedy the risk of misunderstanding and errors in relation to the law, Ministers agreed in 2002 that the Law Commission should undertake the law reform exercise of consolidation. Most health legislation made since 1977 has therefore been summarised within three Acts of Parliament. They received Royal Assent on 8 November 2006 and came into effect on 1 March 2007 (subject to a few exceptions). The consolidation is primarily one of the structure and operation of the NHS. It will include most, but not all, of the health legislation since 1977. Therefore, the NHS Act 1977 and much of the subsequent legislation has been repealed and replaced.

The Acts affected by consolidation are as follows:

Health and Social Care (Community Health Standards) Act 2003; National Health Service Reform and Health Care Professions Act 2002; Health and Social Care Act 2001; Health Act 1999; National Health Service (Private Finance) Act 1997; National Health Service (Primary Care) Act 1997; National Health Service (Residual Liabilities) Act 1996; Health Authorities Act 1995; National Health Service and Community Care Act 1990; Health and Medicines Act 1988; Hospital Complaints Procedures Act 1985; Health and Social Security Act 1984; Health Services and Public Health Act 1968; and Ministry of Health Act 1919.

4.31.1.5 The suitability of social support for people with dementia and carers

4.31.1.5.1 Adequacy and accessibility in general

There is no shortage of evidence from various parts of the UK that mental health remains one of most common unmet needs of older people (e.g. Department of Health 2001, Holmes et al 1995; Social Services Inspectorate 1997; MRC-CFAS 1999). Recognition of dementia among health and social care staff is poor and while GP

knowledge of dementia is growing, there are still problems in this area resulting in delays in getting a diagnosis and referral to specialist services.

When the Audit Commission followed up their 2000 report on mental health services for older people, *Forget Me Not*, they still found many areas in England without specialist teams for older people with mental health problems, and many teams did not have all the recommended core professions represented. Respite care was hard to access, day hospital services were not available in more than half the areas surveyed, and only a third of the areas had jointly agreed assessment and care management procedures. Almost a quarter of all areas studied had no clear service goals or plans. The physical environments in which respite and hospital services were provided were unsuitable for older people with mental health problems in over a third of the areas, and specialist settings – where available – had ‘consistently good quality physical environments’ in only half the areas.

Many services for people with dementia are provided by generalist services, which often have insufficient training in the specific needs of people with dementia.

4.31.1.5.2 *People living in rural areas*

In general, there is a higher prevalence of dementia in rural and coastal local authorities, and a lower prevalence in urban and metropolitan authorities.

This regional variation will have an impact upon the adequacy of local funding to meet the health and social care needs of people with dementia. Apart from the higher proportion of people with dementia, rural authorities with their dispersed populations may face increased costs and logistical difficulties in providing home-based care in the community (Dementia UK report, 2007).

Transport can be a difficulty for people with dementia and carers living in rural areas without access to private transport and where public transport is infrequent or difficult to use. This can mean that services are less easily accessed if transport is not provided. The NICE dementia clinical guidelines recommend that transport should be provided for carers to enable them to access services such as respite care.

4.31.1.5.3 *People with different types of dementia*

Early diagnosis and assessment of dementia is essential as only then can people with dementia and their carers access the services, information and drug treatments that they may need. The subtype diagnosis should be established. The NICE dementia clinical guidelines state that a diagnosis of subtype of dementia is required and recommend structural imaging (MRI or CT scanning) to help establish the type of dementia. However, there are barriers to using this equipment.

In a National Audit Office report (2007) census, 26 per cent of Community Mental Health Teams used MRI scans regularly, while 66 per cent used CT scans regularly. Average waits were 10 weeks for MRI scans and seven weeks for CT. Half of CMHTs

were waiting more than two months for an MRI scan and a quarter waited more than 2 months for CT. Some memory services pay acute trusts for scans whilst others have in-house facilities, which may affect their use of scanning.

4.31.1.5.4 People from ethnic minorities

Recognition of the mental health needs of older people from Black and minority ethnic groups may be lower than in the white population (Lloyd 1993, but see Oduoye and Shah 1999). Adamson (2001) found limited knowledge of dementia among families of South Asian and African/Caribbean descent, which could cause difficulties in the planning of community-based services. Gaining a better understanding of the mental health needs of minority ethnic communities has been stated as a policy aim in Wales and England (Welsh Assembly Government 2003, Social Services Inspectorate 2003).

Support for ethnic minorities is available but insufficient. It is funded by a combination of the State, the service users and charities.

4.31.1.5.5 Younger people with dementia

There is also a shortage of specialist services for younger people with dementia – leaving no option for them than services set up for older people, which may not meet their needs.

4.31.2 Services and support for people with dementia and their carers

4.31.2.1 Types of care

4.31.2.1.1 Day care

Day care centres exist. They are partly funded by the State and partly by the service users.

4.31.2.1.2 Respite care

Respite care in the home is available. It is means tested (Social Services Department). It can also be purchased privately. Short-term and long-term residential respite care services are also available.

Recent surveys have found that day care and respite care provision is not always adequate:

- In a web forum survey of service users and unpaid carers, over half (51 per cent) of respondents felt the amount of day care provided to them was too little. For 17% of respondents no respite care was available at all when requested (National Audit Office report, 2007).
- A survey of Community Mental Health Teams (CMHTs) for older people (a key mechanism for delivering services to people with dementia at a local level) showed that some cannot provide or cannot fund services such as day care and

respite care. More than a fifth said that funding was a barrier to providing day care and respite care.

- When CMHTs were asked if they would be able to provide day care at the level required locally, responses were: Yes – 74.4%; No (not available) – 3.3%; No (is available but not funding for it) – 19.2% (National Audit Office report, 2007).
- When CMHTs were asked if they would be able to provide respite care at the level required locally, responses were: Yes – 66.6%; No (not available) – 6.2%; No (is available but not funding for it) – 23.2% (National Audit Office report, 2007).

Given that family carers play a vital role, day care and respite services may make the difference between a person with dementia being able to live at home or having to enter a care home (National Audit Office report, 2007).

4.31.2.1.3 Long-term residential care

Long-term residential care is available for people who meet the criteria. It is partly funded by local authorities on the basis of a financial assessment which takes into account both income (including state or private pensions) and capital (savings, investment and the value of a person’s home). If the person with dementia has over a certain amount of capital (up to £21,500 in England and up to £22,000 in Wales), he/she will be expected to refund the whole cost. The value of a home is usually counted as capital but in some cases it is not e.g. if a husband, wife, partner, relative over 60 or incapacitated person under 60 still lives in the home. Income in the person’s own name may also be counted but there are a few exceptions and the Local Authority has to allow the resident to retain a personal expenses allowance of £20.45 per week for his/her own use.

4.31.2.1.4 Palliative care

Palliative care, either at home or in a palliative care centre, is not generally available but there are a few exceptions. For instance, there are isolated examples of services for palliative care at home, some of which provide a good service. Although there is no comprehensive service for people with dementia, there are Palliative Care Teams for older people. If provided at all, palliative care is partly funded by the State and partly by the service users. There are also hospices, which are funded by charitable donations, but they do not usually offer palliative care to people with dementia.

4.31.2.1.5 Monitoring in the home via alarm systems

Tele-alarm systems are available which are partly funded by the State. The Church, Age Concern England and the Red Cross also provide tele-alarm services.

4.31.2.2 Personal assistance and home help

4.31.2.2.1 Personal assistance

The following services are available:

1. Assistance with personal hygiene
2. Supervision/assistance taking medication
3. Assistance eating and drinking (not preparation of food)
4. Assistance with mobility e.g. lifting, moving and walking
5. Companionship/social activities.
6. Occupational therapy
7. Assistive devices
8. Home adaptation/transformation
9. Assistance dealing with incontinence
10. Assistance with skin care

The first eight services are partly funded by the State, partly by service users. Assistance with skin care and incontinence is totally funded by the State.

Some services are provided by NGOs and volunteers. For example, DIAL UK and the Disability Living Foundation provide assistance with mobility and there are a few associations which provide advice and training related to continence.

The Alzheimer's Society does not consider any of the above services to be sufficient. For example, people with dementia and carers have frequently reported problems with assistance in eating and drinking in hospitals. People with dementia need help to eat and drink, for example having food cut up and being reminded to take fluids. The Alzheimer's Society regularly receives reports of people losing significant amounts of weight during stays in hospital because they have not been adequately nourished. The causes of this include lack of time, skill and understanding, and poor choices of food. This also makes people with dementia more susceptible to hospital-acquired infections and can delay recovery.

It also regularly receives reports on its helpline of people with dementia in hospitals being found soaked in urine and of long delays before the issue is remedied. In some instances carers report having to change someone's clothes themselves or clean them up, without assistance. There are a number of reasons why people with dementia could become incontinent. These include forgetting to go, mistaking other things for the toilet and not knowing where the toilet is. These reasons can be easily remedied with practical considerations and appropriate training for staff, but can be a problem in hospitals if no one takes responsibility for this.

4.31.2.2.2 Home help

The following home help services are available:

1. Assistance with housework e.g. cleaning and dusting
2. Help with the preparation of meals (incl. meals-on-wheels)
3. Transportation
4. Laundry

They are all partly financed by the State. The Alzheimer’s Society and Age Concern England are both charities which provide a transportation service. There are no services available to help people with dementia with their shopping.

Home care support services are not sufficient. National Audit Office report (2007) found that access to and quality of home care could be improved. In practice there are a very small percentage of older people receiving intensive home care packages and these focus on those with the greatest need. Surveys have shown that two thirds of local authorities were only supporting people with severe or critical needs. It has been predicted that based on current trends, nobody with lower level needs will receive support by 2009 (Local Government Association, 2006).

Access to care services must be widened to allow people with lower level needs to receive support. The report Dementia UK (2007) makes the following recommendation:

People with dementia need improved home care support packages, including low-level support to retain their independence and dignity.

Stated national policy focuses on early identification and intervention. However, local authorities across the country have been skewing access to home care support towards people with the highest levels of need. It is now very difficult for people not classed as having substantial or critical levels of need to access services. As the population ages and the number of people with dementia increases, this situation will worsen. People with dementia can stay at home for longer with their families if the right support is put in place.

- The number and extent of home care packages must be increased.
- Home help services such as help with cleaning, shopping, DIY and gardening must be brought back.
- The opportunities for people with dementia and carers to access direct payment and individual budgets must be increased.

4.31.2.3 Psychosocial support and training for people with dementia and carers
NGOs and charities such as the Alzheimer's Society provide general information about access to services. This is partly financed by the State.

Counselling services are available for people with dementia and for carers, but there are very few for people with dementia and those for carers are insufficient. They are partly funded by the State and partly by charities.

Holiday services for people with dementia are available but insufficient. They are partly financed by the State and partly by the service users. Vitalise is a national disability charity which provides holidays for people with dementia. It works with volunteers so as to also enable carers to have a break from caring. In general, carers wishing to take a holiday have limited possibilities for respite care.

Services providing training for carers are funded by the State, the service users and charities, but they are insufficient. The Alzheimer's Society also provides some training for carers.

4.31.2.4 Work/tax related support for people with dementia

4.31.2.4.1 Protective measures

The Disability Discrimination Act (DDA) of 1995 protects people with dementia who are still in paid employment. Some of the core concepts of the DDA are that disabled people must not be treated less favourably than non-disabled people, some of their duties should be allocated to another person and that they should be granted leave for rehabilitation, assessment or treatment.

4.31.2.4.2 Tax benefits

People who are severely mentally impaired (i.e. they have a severe impairment of intelligence and social functioning which appears to be permanent) are entitled to council tax reductions. This is covered by the Local Government Finance Act 1992. They are not, however, entitled to tax benefits for employing a person to provide them with home care services.

4.31.2.4.3 Allowances and grants

The Disability Living Allowance (DLA) grants a tax-free benefit for children and adults up to the age of 64 who need help with personal care or have walking difficulties because they are physically or mentally disabled. The rules for DLA can be found in sections 71-76 of the Social Security Contributions & Benefits Act 1992, and The Social Security (Disability Living Allowance) Regulations 1991.

The Attendance Allowance (AA) is a tax-free benefit for people aged 65 or over who need help with personal care because they are physically or mentally disabled. The rules for AA are in sections 64-67 of the Social Security Contributions & Benefits Act 1992, and the Social Security (Attendance Allowance) Regulations 1991.

Whilst not entitled to reductions or benefits for TV, radio or transport on the grounds of dementia, people with dementia over the age of 65 are, like other people of the same age, entitled to reductions on television licences and to free transport.

Under the Health and Social Care Act 2001, local councils are obliged to offer the option of direct payments in place of services currently received for anyone who has been assessed as needing help from social services.

People with dementia can apply to the local authorities for a Disabled Facilities Grant to adapt their homes. This is means tested and at the discretion of the local authorities.

4.31.2.5 Work/tax related support for carers and carer allowances

4.31.2.5.1 Time off work and flexible working

Paid compassionate leave is available, but is at the discretion of the employer, and is not specifically for the needs of carers. However, if time off is needed to cope with personal circumstances which do not fall under emergencies involving a dependant (see below) a carer may have a right to time off as compassionate leave under their contract of employment.

Employees (working under a contract of employment) have the right to take a reasonable amount of unpaid time off work to deal with unexpected or sudden emergencies involving a dependant. A dependant is defined as a husband, wife, child or parent, anyone living in a household as a member of the family, or anyone who reasonably relies on an individual for assistance. Dependency leave is usually unpaid but some employers have policies which allow paid leave to be taken.

Both of the above-mentioned possibilities are covered by the Employment Relations Act 1999.

The current flexible working law (Employment Act 2002) is to be extended from April 2007 to give carers of adults the right to request flexible working (under the Work and Families Act 2006). The law currently enables parents with a child under 6 or a disabled child under 18 to make a request for flexible working, and places a duty on employers to consider such request seriously and only reject them for good business reasons.

4.31.2.5.2 Benefits and payments

The Home Responsibilities Protection (HRP) serves to protect the basic State Retirement Pension position of carers in the UK. If an individual receives Income Support and does not need to register for work, because they are caring for someone who is sick or disabled, they will receive HRP automatically. If an individual is regularly spending at least 35 hours a week looking after someone who is receiving Attendance Allowance, Disability Living Allowance at the middle or highest rate for per-

sonal care, or Constant Attendance Allowance, they can apply for HRP. If an individual gets Carers Allowance they will get national insurance credits and will not usually need HRP.

Carer's Allowance and income support. Carers can claim the Carer's Allowance if they are aged 16 or over and spend at least 35 hours a week caring for a person getting Attendance Allowance, or Disability Living Allowance (at the middle or highest rate for personal care), or Constant Attendance Allowance. They may be able to claim income support if aged 16 to 59 and caring for someone who is sick or elderly. If also entitled to Carer's Allowance, carers may be able to get an extra amount included in Income Support. This is called a carer premium.

The Carer's Allowance is covered by the Social Security Contributions and Benefits Act 1992 and The Regulatory Reform (Carer's Allowance) Order 2002. Income support is covered by the Social Security Contributions and Benefits Act 1992, the Social Security Administration Act 1992, and the Social Security Act 1998.

Carers may receive a 25% council tax discount if they provide care for at least 35 hours a week and live with the person they care for, are not the partner or parent of the person being cared for, and care for someone who receives either the highest rate of the care component of DLA (Disability Living Allowance) or the higher rate of attendance allowance or constant attendance allowance. This is covered by the Local Government Finance Act 1992 and The Council Tax (Additional Payments for Discount Disregards Regulations) 1992.

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4.32 *United Kingdom - Scotland*³¹

4.32.1 **Organisation and financing of social support to people with dementia and carers**

4.32.1.1 **Background information on the social/healthcare system in Scotland**

As part of the process of devolution, the UK Parliament based at Westminster (in England) transferred certain powers to three bodies – the Scottish Parliament, the National Assembly for Wales and the Northern Ireland Assembly.

In 1998, the Scotland Act passed into law. This led to elections in May 1999 for the first Scottish Parliament for almost 300 years. The Scottish Parliament does not have a second chamber (equivalent to the House of Lords). It has 129 members who are elected for a fixed four-year term.

1 July 1999 marked the transfer of powers on devolved matters from the Secretary of State for Scotland to the Scottish Executive. Devolved matters are those that are not included on the list of reserved matters for which the UK Parliament retains responsibility. Health is classed as a devolved matter and as such the Scottish Parliament can pass its own laws in this domain.

The Scottish Executive is made up of the Scottish Ministers. It is the administrative arm of government in Scotland and is responsible for health services. More precisely, it determines national objectives for health services and provides a clear statutory and financial framework for NHSScotland (Scottish Executive and Scotland Office, 2007).

4.32.1.2 **The organisation of social support for people with dementia and carers**

The statutory sector (local authorities and National Health Service) works together in the planning and commissioning of services from a variety of providers, with local authorities taking the lead. The statutory sector agencies are accountable to the Minister for Health and Community Care. Service provision is shared among the statutory sector, the informal sector, the voluntary sector and the private sector:

- Statutory sector – local authorities are direct providers of social care service. However, since the National Health Service & Community Care Act 1990 they have been expected to be facilitators of care and to maximise the use of private, voluntary and informal sector provision.
- Informal care – the huge contribution to care provision that is made by informal carers is now being recognised as a crucial component of social care provision.
- Voluntary sector – this sector is one of the largest providers of community care services in Scotland. Alzheimer Scotland is contracted by the local authority to provide services to people with dementia in most local authority areas in Scotland.

³¹ The information in this report on social support for people with dementia and their carers in Scotland was provided by Kate Fearnley from Alzheimer Scotland.

- Private sector – the private sector provision in community care tends to be mainly within the elderly care home sector.
- The regulation and inspection of care services has been carried out by the Scottish Commission for Regulation of Care since 2002, which is a non departmental public body. Prior to this the regulation of care services was carried out by the registration and inspection units in the 32 local authorities and 12 health boards.

The Minister for Health and Community Care has overall responsibility for health and social care policy in Scotland. The Scottish Executive Health Department is responsible for both the National Health Service for Scotland and for the development and implementation of health and social care policy.

Joint working between the National Health Service and local authorities has been the policy direction since the late 1990s. This was introduced by the ‘Modernising Community Care’ Action Plan (Scottish Office 1998). A Joint Future Group was established in 1999 to encourage joint working. Initiatives include single assessments of clients with information shared between health and social care services and the joint resourcing of services.

Alzheimer Scotland and other voluntary sector organisations receive state funding for developing and providing specific services. The funds they receive from the local authority are generally for services such as day care and home care for a specific number of clients. Central government provides some core funding for voluntary sector organisations, and also some funding for specific activities such as information campaigns, training for staff or specific projects of national relevance. Funding is generally time limited and gaining ongoing funding for services is problematic. Most organisations run on time limited funding from a number of sources and have to continually seek new funding from a variety of organisations e.g. charity trusts, national lottery etc.

4.32.1.3 The overall funding of social support for people with dementia and carers

Community care services commissioned or provided by the local authority are funded primarily through Grant Aided Expenditure from the Scottish Executive. This comes from general taxation.

4.32.1.4 The legal framework surrounding the provision of social support

The following laws are relevant to the provision of social support to people with dementia and their carers:

- Social Work (Scotland) Act 1968 – placed the organisation and provision of welfare services for ‘persons in need’ with local authority social work departments. This act introduced local authority responsibility to promote social welfare, and forms the basis of community care regulations.

- National Health Service & Community Care Act 1990 – policy aim of shifting the balance of care from hospitals and institutions to community based settings. It reduced direct central government expenditure on residential care and placed a duty on local authorities to assess the need for community care services. It applied to the elderly, disabled and those with mental/physical health problems.
- Carers (Recognition & Services) Act 1995 – allowed carers to request an assessment of their needs when the person being cared for is being assessed or re-assessed. The Community Care & Health (Scotland) Act 2002 extended this to allow carers to have their needs assessed independently.
- Direct Payments Act 1996 – gave local authorities the power (but not the duty) to provide payments to those assessed as requiring community care services to enable them to directly purchase their own services. Community Care & Health (Scotland) Act 2002 made it a duty for local authorities to offer direct payments to all people with community care needs from June 2003.
- Adults with Incapacity (Scotland) Act 2002 – provided new safeguards to protect the interests of people with dementia and new ways for people to make their own choices about who will handle their affairs if they cannot do so themselves.
- Regulation of Care Act 2001 – overhauled the registration and inspection of care services and the social services workforce. Established the Scottish Care Commission for the Regulation of Care and gave government ministers the power to produce care standards for services.
- Community Care and Health (Scotland) Act 2002 – introduced free personal care for people over 65 and the regulation of charging for home care services. It included measures to enable greater joint working between NHS and local authorities. It also gave local authorities a duty to identify as well as inform carers of their right to a needs assessment, independent of the person being cared for.

There are also numerous relevant decrees and regulations but there are simply too many to list here.

4.32.1.5 The suitability of social support for people with dementia and carers

4.32.1.5.1 Adequacy and accessibility in general

Scotland needs a better level of funding for dementia care. It also needs better strategic planning to ensure there is an equal level of service provision across the country. At present the care on offer is dependent on where a person lives. Alzheimer Scotland recently asked all local authorities if they provided overnight care to people with dementia and more than half cannot provide it as part of a package of care. Research carried out by Alzheimer Scotland in 2004 identified:

- 27% of people with dementia and their carers received a short break in a year
- 10% of people with dementia received home care
- 11% of people with dementia received day care

People with dementia use a range of services but there is a lack of specialist services for people with dementia. Indeed, Alzheimer Scotland has found that some local authorities are moving towards funding larger generic services rather than specialist services, as these are less costly to run. There is a need for health and social care staff to be more aware of the illness and positive approaches to communication and care.

4.32.1.5.2 *People living in rural areas*

There are day care centres in rural areas but many find it difficult to survive financially. Difficulties in providing services in the rural areas of Scotland include lack of appropriate venues, a shortage of appropriate people to provide the service and the population being thinly dispersed over a large area. This requires creative options, such as Alzheimer Scotland's day care that is provided in the sitting rooms of bed and breakfast accommodation when there is a sufficient number of people requiring this service within a manageable geographically area.

4.32.1.5.3 *People with different types of dementia*

There is a lack of provision of long-term respite care for people with alcohol-related dementia.

4.32.1.5.4 *People from ethnic minorities*

There are some initiatives directed towards people from ethnic minorities. These initiatives are area specific and are unlikely to meet the needs of everyone. Alzheimer Scotland runs a Polish and Ukrainian Service that offers information and advice to Eastern European older people. However, this service only covers a limited geographical area in Scotland. The Scottish Executive runs a grant scheme for voluntary organisations to help ethnic minority groups access mainstream services. Grants are for time limited periods and only a small amount of applying organisations actually receive funding. Alzheimer Scotland provides information in a number of languages. Statutory organisations also provide information in different languages and interpreters when required. These initiatives are sometimes partly or fully funded by the State. Some are fully funded by the service users. Some services are provided on a voluntary basis by churches and community groups in response to the local population profile.

4.32.1.5.5 *Younger people with dementia*

There is a lack of provision of respite/short breaks, long-term respite care services and appropriate day care for younger people with dementia.

4.32.2 Services and support for people with dementia and their carers

4.32.2.1 Types of care

4.32.2.1.1 Day care

Day care centres exist but the level of care available is not sufficient and waiting lists are common. The availability of day care is dependent on location. Town day centres tend to be oversubscribed and rural centres struggle to survive financially. The level of funding available for specialist day care is often not sufficient to cover full costs and there can be a need for fundraising. Day care suffers from an old fashioned image. There is a need for more person-centred care and more imaginative care. There is also a need for services that meet the needs of younger people with dementia. Research carried out by Alzheimer Scotland revealed that only 11% of people with dementia receive day care (2004).

Day care in day care centres may be partly or fully financed by the State but some carers have to pay the full cost. This depends on their financial situation.

Voluntary sector organisations (NGOs) are often the providers of day care services, usually funded by block contracts and spot purchase from local authorities. Small community-based organisations such as churches and community centres also run day care in some areas, on a similar basis.

4.32.2.1.2 Respite care

Respite care services in the home exist but the level of respite care at home available is not sufficient. There are waiting lists and the eligibility criteria are too restrictive. Also, respite care at home is mainly for people with high support needs and there is not enough staff to provide services. Alzheimer Scotland recently carried out a survey of all Scottish local authorities and found that more than half do not provide overnight care as part of a care package.

Short-term respite care services are available but the level of provision is not sufficient. It is very often not seen as a planned package of care. There is a lack of choice and also appropriate provision for younger people with dementia. Alzheimer Scotland's research identified that only 27% of people with dementia and their carers received a short break in a year (2004).

Long-term respite care services are not considered sufficient. There is a lack of provision for people with high support needs, alcohol-related dementia and younger people with dementia. Available services are difficult to access and there is limited choice.

The different kinds of respite care may be partly or completely financed by the State. This depends on the individual circumstances of the services users who may have

to partly or fully pay for respite care themselves. Short-term respite care provided by the National Health Service is free at the point of delivery. However, most short-term respite is provided in nursing homes.

4.32.2.1.3 Long-term residential care

According to the report “The Dementia Epidemic” (Alzheimer Scotland, 2007), about 40% of residents in long-term residential care have some form of dementia. For people on low incomes and few savings the cost of full-time residential care is met by the state i.e. local government. However, for people with modest savings and income they pay for their accommodation/hotel costs. This means tested and personal property is included in the calculation. In Scotland personal and nursing care is free to the service user because it is paid for by local government.

4.32.2.1.4 Palliative care

Palliative care at home is not sufficient for people with dementia. Service provision is very patchy and non-existent in some areas. Dementia is not widely recognised as an illness that requires palliative care.

If provided as a medical service, it is free at the point of delivery. Otherwise, financial support from the State for this service depends on individual circumstances.

Palliative care provided at centres exists but is insufficient. There are tight eligibility criteria and people with dementia are only likely to qualify if other medical problems, such as cancer, become a priority. The State completely funds palliative care if it is in a hospital setting. There are also hospices which provide end-of-life care, mostly for people with cancer and younger people. They rely on fundraising for their income.

4.32.2.1.5 Monitoring in the home via alarm systems

This type of alarm systems is widely used by local authorities and housing associations for vulnerable groups including the elderly. Depending on individual circumstances, the State contributes partly or fully to the cost of this service. The use of other types of equipment in aiding care is dependent on the extent to which the local authority has invested in the technology.

4.32.2.2 Personal assistance and home help

4.32.2.2.1 Free personal assistance/care

Free personal care is defined as “the means of care which relates to the day-to-day physical tasks and needs of the person cared for and to mental processes related to these tasks”. It is provided cost free to people over the age of 65 years. People with dementia under the age of 65 are not entitled to free personal care and would be subject to means testing. Medical care is free at the point of delivery. This could apply to assistance dealing with incontinence and skin care.

Available services include:

1. Assistance with personal hygiene – There are often waiting lists to receive assistance with personal hygiene. Home carers have a short time allocated to each person and do not have enough time to do everything. There is a lack of staff for evening care.
2. Supervision/assistance taking medication – There has been a lack of clarity in guidance and some local authorities do not consider supervision/assistance taking medication as free personal care. Consequently, they do not provide it.
3. Assistance eating and drinking – As home carers are often limited for each visit and are rushed, there is a lack of assistance with eating and drinking in the evening in many areas. Please see section on “home help” for other services linked to meals.
4. Assistance with mobility e.g. lifting, walking and moving – There is an issue about people getting this type of service at times of the day when it would best suit them rather than fitting into the care providers’ schedule. There is a lack of staff for evening cover.
5. Assistance dealing with incontinence – An assessment would be carried out by a health care worker and incontinence pads provided. Ongoing day-to-day support would then be provided by home care workers as part of personal care. The amount of time home care staff have is an issue and evening care is a problem. Medical care is free at the point of delivery.
6. Assistance with skin care – This could be provided by a district nurse or home care worker. Home care staff are often overstretched and this would not be a priority.

4.32.2.2.2 Other services which do not fall into the “free personal care” category

The provision of companionship services and social activities is patchy and it can be difficult to get funding as these services are not seen as a priority. There are not enough activities suited to younger people with dementia. Financial support from the State for these services is dependent on individual circumstances and is means tested. Some community based organisations such as churches and community centres provide these services, but this varies widely from area to area.

The level of service provision for occupational therapy/ergotherapy is not sufficient and is non-existent in some areas. There are waiting lists and people can wait a long time to access this service. It is, however, part of the National Health Service and is free at the point of delivery.

Assistive devices are not being used to their full potential and it can be very slow for people to get access. There are often waiting lists due to annual budget limitations. Individuals may have to contribute dependent on circumstances.

Support for home adaptation/transformation would depend on whether the person lived in public or private housing. Grants are available for people in private housing who meet the criteria. Support also depends on individual financial circumstances. A local authority or housing association landlord may undertake work or offer a move to more appropriate housing.

4.32.2.2.3 Home help

Assistance with housework is available but subject to means testing. There are issues with waiting lists and the amount of time care workers have allocated to each client. Services provided will also vary between local authorities. It may be provided on a voluntary basis by churches and community groups but again provision varies between locations.

Assistance with the preparation of meals for those over 65 is provided as part of free personal care. However, there has been a lack of clarity in guidance and a few local authorities still do not see this service as free personal care. There are also issues with waiting lists and the amount of time care workers have allocated to each client. For people under 65, there is means testing for assistance with the preparation of meals. The delivery of meals is not covered by free personal care. Means testing is applied and most people make a contribution to meal delivery. Assistance with the delivery of meals is also provided on a voluntary basis by churches and community groups but this varies between locations.

Assistance with shopping is available and means tested. There are issues with waiting lists and the amount of time care workers have allocated to each client. It is also provided on a voluntary basis by churches and community groups but provision varies between locations.

Hospitals and local authorities run transportation to and from their services for those with mobility problems. Day centres usually provide transport to and from the day centre. Financing of various transportation services depends on how each system operates. It is also provided on a voluntary basis by churches and community groups but provision varies between locations. With regard to public transport and parking, everyone over the age of 60 is entitled to free bus travel and the “blue badge scheme” entitles people to free parking. A diagnosis of dementia does not, however, provide automatic entitlement to a blue badge.

A laundry service may also be provided as part of a care package from the local authority but it is means tested.

4.32.2.3 Psychosocial support and training for people with dementia and carers

4.32.2.3.1 General information

There is a general information service (covering access to services available in Scotland) which is completely funded by the State but it is not sufficient and people do

not receive a consistent level of service. Alzheimer Scotland provides an information service and a 24 hour free phone telephone helpline. However, people with a new diagnosis of dementia may not be made aware of its existence at the time of diagnosis. Alzheimer Scotland does not charge people with dementia or carers for the provision of information. Its information and helpline service is not funded by the State but by fundraising. There is no charge for information provided by the National Health Service. There are also other sources of information that are dependent on initiatives in particular areas.

4.32.2.3.2 Counselling

Counselling services for people with dementia exist but there is not an adequate level of service. For carers, counselling services are not sufficient and provision varies between locations. Counselling is funded by the State and through fundraising.

Alzheimer Scotland provides counselling for people with dementia in some areas through its services and branches. However, service provision is restricted by funding. In some areas counselling or support groups are organised by health professionals such as community psychiatric nurses. Overall, access to this type of support is very patchy but service users are not charged for this service. Alzheimer Scotland also provides counselling for carers but coverage is limited by funding. It is also provided on a voluntary basis by churches and community groups with provision varying between locations.

4.32.2.3.3 Holidays

The provision of holiday services for people with dementia is unlikely to meet demand. A carer can ask the social work department to assess the needs of the person with dementia, which includes the need for a holiday or respite care. If they assess the person with dementia as needing a holiday they have a legal duty to provide one under Section 2 of the Chronically Sick and Disabled Persons Act. If the social work department assess the person with dementia as needing respite care they should provide it, but they are not legally obliged to do so. In both cases, they charge for this according to the person's income.

Holidays for people with dementia and for carers are provided on a voluntary basis by churches and community groups, but provision varies between locations. Some Alzheimer Scotland services and branches have organised holidays for small groups of carers and people with dementia.

Holidays for carers may be facilitated by providing respite/short breaks for people with dementia. Other services are dependent on initiatives by local authorities or voluntary organisations. However, services are not sufficient to meet the number of carers who would benefit from receiving a holiday.

4.32.2.3.4 Training

Training for carers is available but the level of service is neither sufficient nor consistent. Alzheimer Scotland provides a carer training programme and also runs information days aimed at carers. Its carer training services have also been purchased by local authorities. Training costs may be partly or fully funded by the State. It is therefore necessary to rely on fundraising.

4.32.2.4 Work/tax related support for people with dementia**4.32.2.4.1 Protective measures**

People with dementia come under the Disability Discrimination Act 1995 which prevents discrimination on the grounds of their disability. Employers have a duty to make reasonable adjustments to a job or workplace if they are aware of the person's disability. However, it is likely that most people would have given up their employment before they received a diagnosis of dementia.

4.32.2.4.2 Tax benefits

People with dementia are not entitled to a tax refund or incentive for employing a person to provide home care services.

4.32.2.4.3 Allowances and benefits

If the person with dementia needs care or supervision, they may qualify for Attendance Allowance (over 65) or Disability Living Allowance (under 65). Attendance Allowance is covered by the Social Security Act 1975, whereas Disability Living Allowance is covered by the Disability Living Allowance & Disability Working Allowance Act 1991.

These two benefits do not depend on the person's income. They are paid at different rates according to the person's needs. Disability Living Allowance has two components (care needs and mobility needs) whereas Attendance Allowance has only one. Also, the Incapacity Benefit can be paid to someone of working age who is not able to work because of illness or disability and has paid enough National Insurance contributions. If not, he or she can still claim Income Support.

If assessed as requiring community care services and the person wishes to purchase their own services, the local authority has a duty to offer direct payments. This is covered by the Community Care & Health (Scotland) Act 2002.

There are a number of benefits that people with dementia will qualify for as a result of their age rather than the diagnosis of dementia. These benefits are covered by various Acts of Parliament. They include:

- Free TV licences for everyone over 75 years
- Free/concessionary travel across Scotland for everyone over the age of 60, which means that the majority of people with dementia are covered. However, the rules on disabled entitlement do not automatically entitle younger people with dementia.

- Winter fuel allowance for everyone over 60 years (£200 per annum)

Local authority social work departments operate grants for home adaptations for people with a disability. There are also a number of Care and Repair Schemes for elderly and disabled people. However, their coverage is not uniform across the country. The relevant law is the Housing (Scotland) Act 1987

4.32.2.5 Work/tax related support for carers and carer allowances

4.32.2.5.1 Time off work and flexible working

Carers are not entitled to paid time off work for caring. However, there is a statutory right to time off for dependents, but this is unpaid. This was introduced with the Employment Relations Act 1999. In addition, employees are entitled to take a reasonable amount of time off if they have worked for their employer for at least one year and there is an emergency relating to the person they care for. This can include a breakdown in care arrangements, the person being cared for falls ill or there is a need to make longer-term arrangements for care. Any additional entitlement would be at the discretion of the employer.

Flexibility for carers of people with dementia is at the discretion of the employer. The Employment Act 2002 gives working parents of disabled children under 18 years the right to request flexible working arrangements. However, this does not apply to people caring for older people. The Carers (Equal Opportunities) Act 2004 places a duty on local authorities to consider carers' outside interests, including work, when carrying out an assessment.

4.32.2.5.2 Benefits and payments

'Home Responsibilities Protection' applies to a carer who has been looking after someone long term and does not have sufficient qualifying years for the basic state pension. This was introduced with the Social Security Pensions (Home Responsibilities and Miscellaneous Amendments) 1978. Carers do not qualify for this automatically. They must either be in receipt of Income Support or caring for someone regularly for over 35 hours a week who is in receipt of Attendance Allowance or Disability Living Allowance.

Carers may be eligible for Carers Allowance if they care for someone at least 35 hours per week and that person is in receipt of Attendance Allowance or Disability Living Allowance. The Carers Allowance (originally Invalid Carers Allowance) was introduced with the Social Security Act 1975. A carer will not receive carers allowance if they earn more than £84 per week (after deductions). The amount of Carers Allowance is also reduced by a number of other benefits including the state pension. The highest amount of carers allowance is £46.95 per week.

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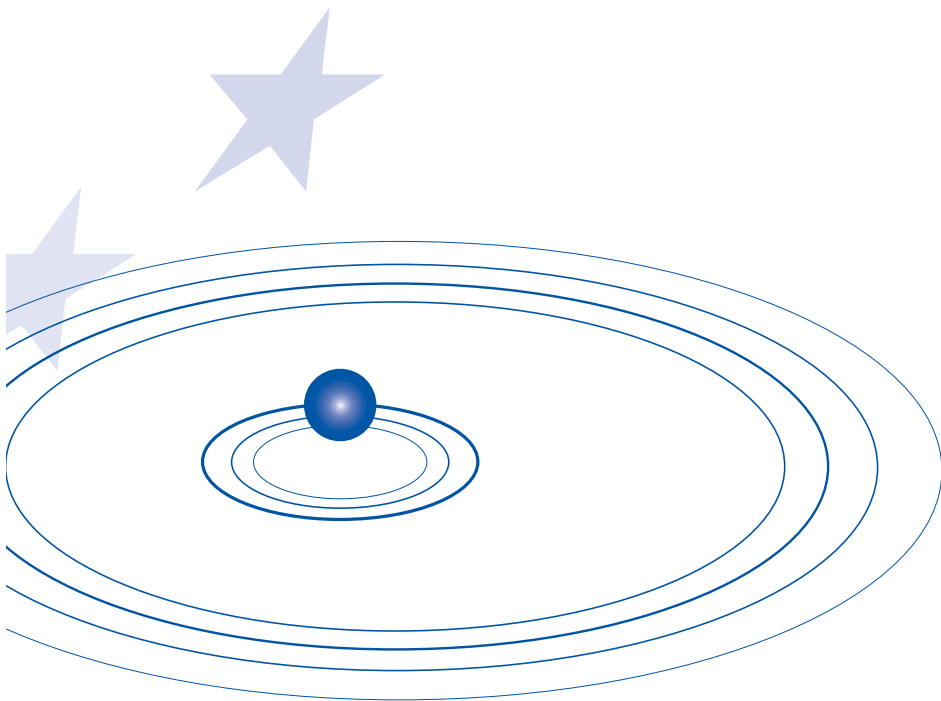
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***Alzheimer Europe
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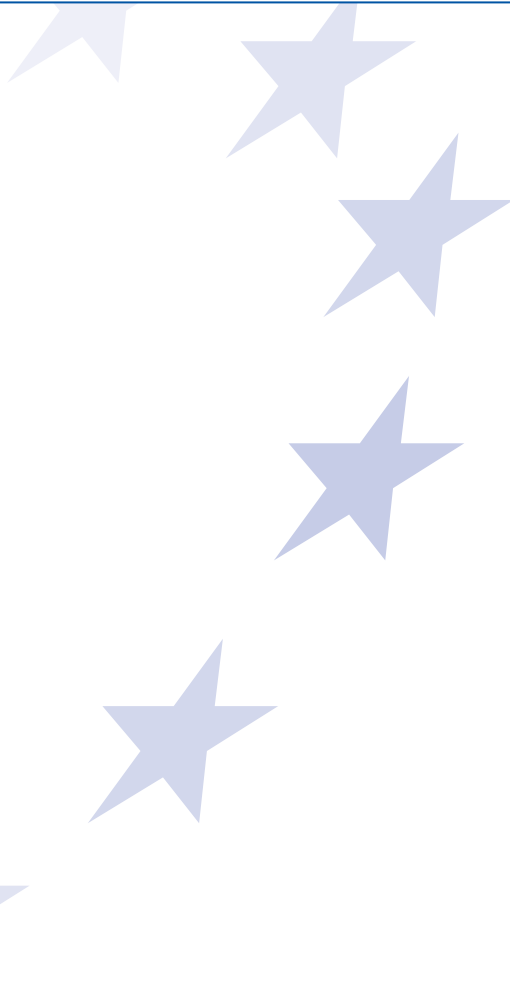
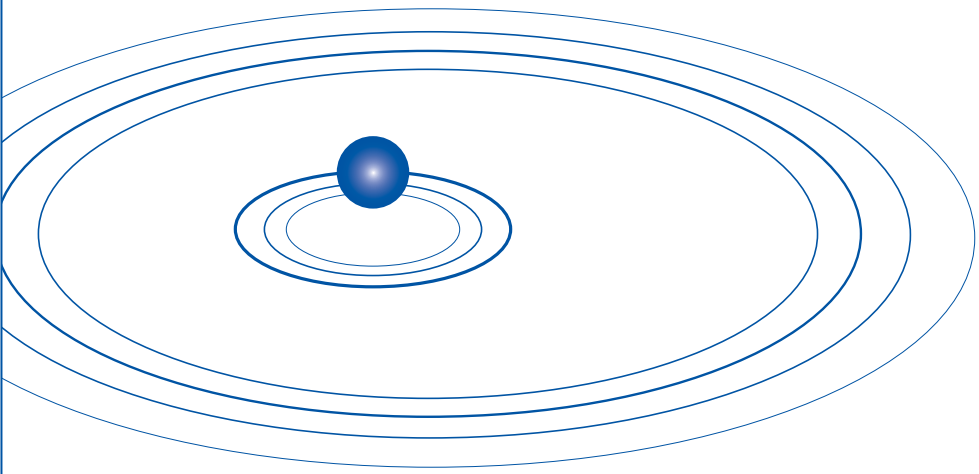


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Annual Report 2006

1. Preface



1906 was the year that Alois Alzheimer first described the symptoms of a disease that ultimately came to bear his name and Alzheimer associations across Europe used the commemoration of the centenary of this discovery to make an inventory of the achievements over the preceding 100 years.

Alzheimer Europe dedicated its 16th Annual Conference to providing an overview of some significant scientific breakthroughs with regard to the causes, genetics, diagnosis and treatment of dementia. Equally important though, we looked at the development of care services, the growing role of Alzheimer associations and the improvements in our understanding of the impact and experience of dementia.

For me as the chairperson of Alzheimer Europe, 2006 also provided the perfect opportunity to assess the state of development of our own organisation and the contributions it has made over the past years.

As you will see from this Annual Report, 2006 was indeed a very productive year for the organisation. Financially, it was the best year to date with an income of €763,798 which represents more than a doubling of our income compared to 2005 (€362,543). A major portion of this increase can of course be explained by our successful project application under the Commission public health programme and the acceptance of our project “EuroCoDe – European Collaboration on Dementia”.

This European project featured of course very prominently in our activities and thanks to the project, we were able to publish the very first edition of our “Dementia in Europe Yearbook”. The 2006 edition provided an estimate of the number of people with dementia in 31 European countries, as well as a clear overview of the very different national systems for the reimbursement of anti-dementia and the provision of home care.

This publication was very warmly welcomed by Commissioner Kyprianou and by Members of the European Parliament when we launched the Yearbook officially on 7 November 2006. We were delighted to hear that the Commission had high expectations from this project and that they would consider the development of a Commission Communication on Alzheimer’s disease and other forms of dementia after the successful completion of our project in 2008. What a significant medium-term objective to work towards and what great encouragement for all our partners involved in the project!

Alzheimer Europe also passed a significant milestone towards a greater recognition of dementia by policy makers. At our Annual General Meeting in Paris, our member

organisations unanimously adopted a veritable call for action to European and national policy makers to make dementia a European public health priority and we were delighted to hear Philippe Bas, French Minister for Social Affairs and the Elderly give the full support of the French government to the priorities outlined in our Paris Declaration. This Declaration has in the meantime been signed by over 100 policy makers clearly showing that Alzheimer Europe and its member organisations have the possibility and means to reach out and convince policy makers of the significant impact of dementia on all European societies and public health policies.

In any normal year, these two significant achievements would be enough to make any European organisation proud. But Alzheimer Europe was active in many other areas and I would just like to single out our Carers' Survey which we conducted in partnership with Lundbeck, our new publication on advance directives and our concerted action to defend the access of people with dementia to anti-dementia drugs threatened by the recommendations of the National Institute for Health and Clinical Excellence in the United Kingdom as other examples of the breadth of actions undertaken by our organisation.

As Chairperson of the organisation, I am truly proud of these achievements and look forward with full confidence to the continued growth of Alzheimer Europe. Of course, none of this would have been possible without the vision and commitment of our dedicated staff, our Executive Director, Jean Georges, our EU Public Affairs Officer, Annette Dumas, our Information Officer, Dianne Gove and our Communication Officer, Sandrine Lavallé and I would like to take this opportunity to give them my heartfelt thanks.

Similarly, the best people with the best ideas can only do as much as the financial situation allows and without the continued support of our sponsors and the identification of new ones, our achievements would be a lot less remarkable. I would therefore like to thank all the supporters of Alzheimer Europe who shared my confidence in the organisation and agreed to support our activities.

In particular, I would like to single out the European Commission and its support of our EuroCoDe project, as well as our Luxembourg member organisation for seconding our Executive Director and providing rent free offices to the organisation. My thanks also go to Lundbeck, Janssen-Cilag, Pfizer, GlaxoSmithKline, Novartis, Fondation Médéric Alzheimer, Numico and Merck Sharp & Dohme.

Maurice O'Connell
Chairperson

2. Executive Summary

In 2006, Alzheimer Europe:

- Successfully increased its public affairs role and appointed an EU public affairs officer who had regular contacts with representatives of the different European institutions,
- Adopted the Paris Declaration on the political priorities of the European Alzheimer movement which provided the start of a campaign towards European and national policy makers to make dementia a European public health priority,
- Received the support of Philippe Bas, French Minister for Social Affairs and the Elderly for the political priorities contained in the Paris Declaration as well as individual endorsements of over 100 European national policy makers,
- Collaborated on various working groups set up by the European Commission, such as the Task Force on Major and Chronic Conditions, the Working Party on Morbidity and Mortality and the Working Group on Relative Effectiveness of the Pharmaceutical Forum,
- Contributed to the Commission consultation on its Transparency Initiative and adopted a position paper on “information to patients” for the discussions of the Pharmaceutical Forum,
- Organised a well attended lunch-debate on Alzheimer’s disease in the European Parliament on 7 November,
- Launched its first “Dementia in Europe Yearbook” with information on the prevalence of dementia, the reimbursement of anti-dementia drugs and the home care systems in 31 European countries,
- Progressed with the development of its Parliamentary Friends of Alzheimer Europe and garnered the support of 17 Members of the European Parliament for this initiative,
- Launched a new website (www.dementia-in-europe.eu) dedicated to the presentation of the Paris Declaration and the information of the Dementia in Europe Yearbook,
- Was accredited by the European Medicines Agency as a patient organisation complying with the agency’s strict rules on transparency, democracy and legitimacy,
- Continued its collaboration with the European Medicines Agency through its membership on the EMEA Management Board and the Working Group with Patient Organisations,
- Attended the quarterly meetings of NGO’s with consultative status at the Council of Europe,
- Involved its national member organisations in the different activities of the association,

- Continued the implementation of its communication strategy and published a quarterly newsletter with information on scientific breakthroughs, relevant European developments and the activities of the organisations and its members,
- Further developed its website which attracted close to 620,000 visitors (compared to 240,000 in 2005),
- Organised the well attended 16th Alzheimer Europe Conference in Paris from 29 June to 1 July,
- Carried out a survey on the reimbursement systems of anti-dementia drugs in 31 European countries and developed a further survey on the social support provided by governments to people with dementia and their carers,
- Reviewed some of the information on the legal protection of people with dementia obtained in its earlier Lawnet project,
- Developed a draft position on stem cell research and carried out a consultation of its members on this subject,
- Adopted a position on the disclosure of a diagnosis of dementia,
- Coordinated a response to the NICE recommendations backed by over 100 associations and individuals calling on NICE to revise its recommendations and allow patients at all stages of the illness to have access to drug treatments,
- Developed a closer collaboration with and attended the conferences of the European Association of Geriatric Psychiatry and the European Federation of Neurological Societies,
- Continued its active involvement in the European Patients' Forum and saw its Executive Director elected as the Vice-Chairperson of the organisation,
- Successfully completed the contract negotiations with the European Commission for its project "EuroCoDe – European Collaboration on Dementia" bringing together 34 centres and organisations from across Europe and organised two meetings of the different working groups of the project, as well as a meeting of the steering committee,
- Coordinated the activities of the EuroCoDe project with the different working groups carrying out an extensive literature search and an analysis of existing guidelines in the areas of social support systems, diagnosis and treatment, psychosocial interventions, prevalence, the socio-economic cost of dementia and prevention and risk factors,
- Partnered with Lundbeck for the development of a survey on carers' needs which was conducted by the AE member organisations in France, Germany, Poland, Scotland and Spain which revealed the impact of dementia on carers, the lack of information provided at the time of diagnosis, the scarcity of care services and the significant financial contributions of carers to the care of people with dementia,

- Collaborated in the Task Force of the European Federation of Neurological Societies for the revision of its guidelines on the management of dementia and ensured that the need for early referral of diagnosed patients and their carers to Alzheimer associations was included in the revised guidelines,
- Published a detailed report on the findings of its project on advance directives which included a report on the literature review, on overview of the legal status of advance directives in some European countries and the organisation's position on the use of advance directives by people with dementia,
- Developed a guide for people with dementia and their carers at the onset of the disease entitled "After diagnosis – what next?" which was translated into Greek and Italian and published in Greek,
- Finalised its review of the home care systems in Europe and included national reports on the organisation of home care in 31 European countries in the Dementia in Europe Yearbook and the new website of the organisation (www.dementia-in-europe.eu),
- Saw the publication of the third edition of its German Care Manual and the second edition of the Portuguese version,
- Increased its membership by welcoming the Maltese and Bulgarian organisations as full and provisional members respectively,
- Diversified its funding sources and enlarged the circle of sponsors of the organisation,
- Developed a new concept for Alzheimer Europe conferences.

3. Our strategic objectives

The new strategic plan of Alzheimer Europe provides a clear mission statement for the activities of the organisation and defines this mission as changing perceptions, policy and practice in order to improve the access by people with dementia and their carers to treatment options and care services.

The strategic plan furthermore defines six key objectives for the organisation: representing the interests of people with dementia and their carers, involving and supporting national Alzheimer associations, improving the information exchange between Alzheimer Europe, its members and European structures, promoting best practice through the development of comparative surveys, developing policy statements and developing strategic partnerships.

3.1. Representing the interests of people with dementia and their carers

Alzheimer Europe strengthened its contacts with the European institutions through the appointment of Annette Dumas, as the EU public affairs officer who was given the task of maintaining regular contact with members of the European Parliament and the European Commission.

3.1.1. European Commission

As the project leader of “EuroCoDe – European Collaboration on Dementia “, Alzheimer Europe became a member of the European Commission Task Force on Major and Chronic conditions and the Working Party on Morbidity and Mortality. Jean Georges also represented the European Patients’ Forum in a working group on relative effectiveness set up by the European Commission in the framework of the European Pharmaceutical Forum.

Alzheimer Europe also contributed directly to a number of consultations organised by the European Commission. In September, the organisation gave its support to the Transparency Initiative of Commissioner Kallas and welcomed the proposal to introduce strict criteria on transparency and legitimacy for European organisations lobbying the different European institutions. In September, Alzheimer Europe also contributed to the discussions on “information to patients” within the Pharmaceutical Forum set up by the European Commission.

3.1.2. European Parliament

On 7 November 2006 on the occasion of the centenary of Alois Alzheimer’s discovery, Alzheimer Europe organised a lunch-debate in the European Parliament in Brussels. The event, which was hosted by Astrid Lulling, MEP (Luxembourg), was very well attended with over 20 participants from different European institutions, including Georgina Georgiou from the Cabinet of Commissioner Markos Kyprianou,

12 Members of the European Parliament and a further 6 assistants of other MEPs who were unable to attend the meeting themselves.

At the meeting, Alzheimer Europe presented the first edition of its “Dementia in Europe Yearbook” which contains information on the prevalence of dementia in Europe, the reimbursement of anti-dementia drugs and the provision of home care in 31 European countries (27 EU Member States and Iceland, Norway, Switzerland and Turkey).

Alzheimer Europe also progressed with the development of its group of Parliamentary Friends of the organisation and in 2006, this initiative received the support of 17 Members of the European Parliament: Henrik Lax, Riitta Myller and Kyösti Virrankoski (Finland), Angelika Niebler, Thomas Ulmer and Anja Weisgerber (Germany), Brian Crowley and Kathy Sinnott (Ireland), Alessandro Battilocchio (Italy), Astrid Lulling (Luxembourg), Joseph Muscat (Malta), Jan Tadeusz Masiel (Poland), Miroslav Mikolasik (Slovakia), Charlotte Cederschiöld (Sweden), Corien Wortmann-Kool (the Netherlands) John Bowis and Catherine Stihler (the United Kingdom).

3.1.3. European Medicines Evaluations Agency

Alzheimer Europe continued its collaboration in the activities of the European Medicines Agency (EMA) through the membership of its Executive Director in the EMA Management Board and his involvement in the Working Group with Patient and Consumer Organisations.

The working group continued its focus on improving patient involvement in such areas as the provision of information on medicines to patients as well as pharmacovigilance and the reporting of adverse drug reactions.

On 3 February 2006, Alzheimer Europe was informed by the EMA services that the organisation complies with the strict criteria of democracy, representation, transparency and legitimacy required of patient organisations and Alzheimer Europe was thus accepted as one of the first organisations to be accredited by EMA to be involved in EMA activities.

3.1.4. Council of Europe

Besides the institutions of the European Union, Alzheimer Europe also continued its collaboration with the Council of Europe. As an organisation with consultative status, Alzheimer Europe took part in the quarterly meetings of NGOs affiliated to the Council of Europe and participated in the meetings of organisations with an interest in health.

3.2. Involving and supporting national Alzheimer associations

National member organisations were involved in all the projects of the organisation. The development of a new strategic plan and priorities for 2007 was achieved after full consultation with Alzheimer Europe's members. Similarly, the home care and reimbursement reports would have been impossible to complete without the active participation of AE members.

Alzheimer Europe also responded to the review of NICE's recommendations for the treatment of Alzheimer's disease, a position which was backed by all member organisations.

The Alzheimer Europe conference was well attended by members and the very good attendance at the Annual General Meeting and positive feedback obtained gave an indication of the high level of satisfaction of the current direction of the organisation. The centenary event in the European Parliament was also attended by a number of AE members who had the opportunity to meet with MEPs from their own country.

3.3. Improving the information exchange between AE, its members and European structures

In line with its communication strategy adopted in 2004, Alzheimer Europe continued to gather information on scientific developments and published them in a quarterly e-mail newsletter together with information on its activities and those of its member organisations, as well as on relevant European developments.

3.3.1. Alzheimer Europe Website

The Alzheimer Europe website continues to be a useful source of information for people interested in finding out more about Alzheimer Europe and the care and treatment of people with dementia. Between 2005 and 2006, the number of visitors more than doubled with over 50,000 persons visiting the Alzheimer Europe website every month.

Month	Visitors 2006	Visitors 2005
January	35,545	13,208
February	39,671	15,681
March	66,306	17,391
April	82,362	15,835
May	81,633	13,540
June	49,577	16,543
July	53,859	21,357
August	33,449	15,469
September	45,370	22,298
October	40,821	27,095
November	44,779	31,623
December	46,601	29,221
TOTAL	619,973	239,261
Average	51,664	19,938

Alzheimer Europe regularly updated its website with information on its latest activities, the projects of its member organisations, research findings and the latest European developments.

On 7 November 2006, Alzheimer Europe launched a new website (www.dementia-in-europe.eu) which is dedicated to the Paris Declaration on the political priorities of the European Alzheimer movement. The website provides information on the prevalence of dementia and an overview of the reimbursement systems and the provision of home care in 31 European countries. Furthermore, the website provides a list of the various policy makers who gave their support to the Alzheimer Europe campaign to make dementia a European public health priority.

3.3.2. 16th Annual Conference in Paris, France

Alzheimer Europe organised its 16th Annual Conference in Paris from 29 June to 1 July. As in previous years, the conference was an ideal opportunity for representatives of Alzheimer associations to meet and exchange information and experience. The conference which was organised under the auspices of the President of the French Republic was attended by some 400 delegates from a wide range of European countries and with different professional backgrounds.

The conference was also the setting for the organisation adopting its Paris Declaration on the political priorities of the European Alzheimer movement which outlines a clear call for action to European and national policy makers to make Alzheimer's disease a European public health priority.

3.4. Promoting best practice through the development of comparative surveys

In order to support its members' lobbying activities to improve the access of people with dementia and their carers to a high level of care services and treatment options, Alzheimer Europe included a work package on social support systems in its European project "European Collaboration on Dementia". The project will aim at analysing the support provided by governments to people with dementia and their carers with a view of identifying best practices in this field.

As a first step, Alzheimer Europe carried out a survey of the reimbursement systems for the existing anti-dementia drugs which was published in the Dementia in Europe Yearbook.

Furthermore, the more general survey on social support systems was developed by the European project working group and was piloted amongst some of Alzheimer Europe's member organisations.

Finally, Alzheimer Europe also started a review of the work it carried out under its Lawnet project which looked at the legal protection of people with dementia in the then 15 Member States of the European Union. Efforts were undertaken to identify pertinent laws from the new Member States of the European Union.

3.5. Developing policy statements

In 2006, Alzheimer Europe contributed to the European discussions on "information to patients" and the European Commission Transparency Initiative. Both positions were adopted by the Alzheimer Europe Board.

A draft position on stem cell research was approved by the Board to be sent out for full consultation to member organisations, but the adoption of a final position was postponed till 2007 to allow for further consultation within and with national member organisations.

A position on the disclosure of a diagnosis was adopted by the Board at its November meeting.

On 13 February 2006, Alzheimer Europe called on the National Institute of Health and Clinical Excellence (NICE) to revise its preliminary recommendations for the treatment of Alzheimer's disease and allow patients at all stages of the illness to have access to drug treatments. Backed by over 100 associations and experts in the dementia field from 35 countries, Alzheimer Europe questioned the discriminatory nature of the NICE recommendations which effectively disbarred English and Welsh people with Alzheimer's disease from treatment options available under the national health systems of other European countries.

3.6. Developing strategic partnerships

Alzheimer Europe was able to involve other European networks in its various activities and in particular the EuroCoDe project. The involvement of Alzheimer Europe in the task force of the European Federation of Neurological Societies (EFNS) for the review of its guidelines also shows the greater recognition of Alzheimer Europe and the interest of European medical and scientific organisations to work more closely with the association. Alzheimer Europe also participated in the 2006 conferences of the European Federation of Neurological Societies (EFNS) and the European Association of Geriatric Psychiatry (EAGP).

Alzheimer Europe also continued its collaboration with other European patient and carer organisations through its active membership in the European Patients' Forum (EPF). In 2006, Jean Georges, Executive Director of Alzheimer Europe was re-elected to the Executive Committee of the European Patients' Forum and appointed as its Vice-President.

4. *Alzheimer Europe Projects*

4.1. **European Collaboration on Dementia**

In 2005, Alzheimer Europe was informed by the European Commission that its project “European Collaboration on Dementia” had been accepted for funding under the Public Health Programme. The project aims on the one hand at setting up a European network of all the actors involved in dementia research, treatment and care in Europe and on the other hand at developing consensual guidelines on diagnosis and treatment, psychosocial interventions, prevalence rates, risk factors and prevention, the socio-economic impact of dementia and social support systems.

The working groups of the different work package leaders met twice in 2006 and the work package leaders gave an overview of their work plan and methodology to the members of the steering committee who met in June in the framework of the Alzheimer Europe conference.

All working groups concentrated on identifying existing guidelines in their respective fields and carried out an extensive search and analysis of the available literature.

In the framework of its project, Alzheimer Europe published its first “Dementia in Europe Yearbook” with information on the prevalence of dementia, the reimbursement systems for anti-dementia drugs and the home care support systems in 31 European countries. Alzheimer Europe was delighted that this new publication was prefaced by EU Commissioner Kyprianou, the Chair of the EP Committee for Public Health Florenz and Finnish Minister for Social Services Hyssälä who was the acting President of the European Council of Health Ministers.

The project brings together a wide range of actors and centres such as:

- Alzheimer’s Disease International, European Alzheimer’s Disease Consortium, European Association of Geriatric Psychiatry, European Federation of Neurological Societies, Interdem, International Association of Gerontology – European Region and North Sea Dementia Research Group in the Steering Committee of the project,
- University of Stirling and the Alzheimer associations of Finland, Germany, Portugal and Romania in the work package on social support systems,
- Cochrane Dementia and Cognitive Improvement Group at the University of Oxford, University Medical Centre of Amsterdam, National Institute of Psychiatry (Budapest), the Heinrich-Heine Universität and the University La Sapienza of Rome in the work package on diagnosis and treatment,

- University Medical Centre St. Radboud, University of Hull, University of Wales (Bangor), Hôpital Broca and Fundación Intrás in the work package on psychosocial interventions,
- European Alzheimer's Disease Consortium at the University Hospital of Toulouse, Technische Universität München, Wrocław Medical University and Karolinska Institutet in the work package on prevalence,
- Karolinska Institutet, London School of Economics, Corvinus University (Budapest), European Health Economics and University of Kuopio in the work package on the socio-economic cost of dementia,
- Central Institute for Mental Health – Mannheim, University of Maastricht, Alzheimer Scotland – Action on Dementia, University of Debrecen and Karolinska Institutet in the work package on prevention and risk factors.

4.2. Alzheimer Europe Campaign “Make dementia a European public health priority”

At its Annual Meeting in Paris on 29 June, Alzheimer Europe and its member organisations unanimously adopted the Paris Declaration on the political priorities of the European Alzheimer movement.

This declaration asks European and national policy makers to:

- Make Alzheimer's disease a public health priority by developing national and European action programmes on Alzheimer's disease and by increasing the funding of research into the causes, prevention and treatment of Alzheimer's disease and other dementias,
- Promote the early diagnosis of the disease by developing awareness campaigns on Alzheimer's disease and making dementia a compulsory part of medical training,
- Improve the quality of life of people with dementia and their carers through the development of support and respite services and increased financial support for these services,
- Promote the autonomy and dignity of people with dementia through systematic information of people diagnosed, the recognition of advance directives and improvements to existing guardianship systems.

At the end of the three day conference in Paris, Maurice O'Connell, chairperson of Alzheimer Europe and Arlette Meyrieux, chairperson of the French Alzheimer's association signed the declaration on behalf of the delegates and formally presented it to Philippe Bas, Minister for Social Welfare, the Elderly, the Disabled and the Family. In his response, the Minister gave the full support of the French government to the outlined priorities and thanked Alzheimer associations for their important contribution to the ongoing discussions in France and throughout Europe.

Alzheimer Europe proceeded to present the Declaration to European policy makers at a meeting in the European Parliament on 7 November and developed a new website dedicated to the Declaration. By the end of 2006, over 100 policy makers had given their support to the political priorities outlined by Alzheimer Europe.

4.3. European Carers' Survey

In 2005, Alzheimer Europe in collaboration with Lundbeck co-ordinated a survey on carers' needs with its member organisations in France, Germany, Poland, Scotland and Spain. The field work was carried out in December 2005 and January 2007 and each participating organisation reached its target of 200 returned questionnaires.

A report with the findings was presented at the Alzheimer Europe conference and was launched formally on the occasion of World Alzheimer's Day on 21 September.

The findings revealed that half of carers spend at least 10 hours per day looking after their loved one. Half felt that they had received inadequate information at diagnosis: four out of five wanted more information on help and support services – only two out of five were informed about the existence of an Alzheimer association – and half wanted more information on drug treatments,

Perhaps most concerning was the fact that more than half of carers do not have access to services such as home care, day care, or residential/nursing care and when these services are available, many carers have to pay themselves.

Ultimately, the survey showed that only 17% of carers considered that the level of care for the elderly in their country is good.

4.4. Finalisation of business plan programmes

The previous business plan of Alzheimer Europe covered the period of 2003-2006 and set the following objectives for the organisation:

- Ensuring that people with dementia and their carers are referred to Alzheimer associations at the time of diagnosis,
- Promoting the autonomy of people with dementia through the recognition of advance directives,
- Improving the support and counselling of carers of people with dementia at the onset of the disease,
- Promoting quality of care at home.

4.4.1. Alzheimer associations

In 2006, Alzheimer Europe developed an extensive position on the disclosure of diagnosis in which it presented its views on the need for people diagnosed to be informed of their diagnosis, the importance of early referral to Alzheimer associations and advice on the communication of the diagnosis and the information needs of people with dementia and their carers.

The same year, the European Federation of Neurological Societies published its new guidelines for the diagnosis and management of dementia. Referral of newly diagnosed patients and their carers to Alzheimer associations was included as a good practice point in these guidelines, which responded clearly to the business plan priority of Alzheimer Europe to ensure such a referral.

4.4.2. Advance directives

The position on advance directives which Alzheimer Europe adopted in 2005 was included in the “Dementia in Europe Yearbook” which was sent to European policy makers and other European organisations active in the field of dementia.

Furthermore, Alzheimer Europe published a full report with background information on the use of advance directives by people with dementia resulting from a literature search and a survey of the legal status of such advance directives.

4.4.3. Support of people with dementia and their carers at the onset of the disease

Alzheimer Europe developed a guide for people with dementia and their carers to respond to the immediate questions they may have after hearing a diagnosis of Alzheimer’s or another form of dementia.

This guide was approved at the Annual General Meeting in Paris and welcomed as an important tool to provide better information for both people with dementia and their carers at the start of their patient journey.

In 2006, the guide entitled “After diagnosis – What next?” was translated into Italian and Greek and the Greek edition of the Guide was also published in 2006.

4.4.4. Quality of care at home

Alzheimer Europe finalised its survey of the home care systems in a number of European countries. The report was circulated for final corrections to all of Alzheimer Europe’s member organisations in 2006 and approved by the Alzheimer Europe Board. The national reports were included in the “Dementia in Europe Yearbook” and included on the new website of Alzheimer Europe (www.dementia-in-europe.eu).

5. Other activities

5.1. Alzheimer Europe Publications

Apart from the Dementia in Europe Yearbook, the report on advance directives and the report on the Carers' survey mentioned above, Alzheimer Europe was glad to see the Greek Alzheimer's association translate and publish the AE Guide "After diagnosis – what next?".

2006 also saw the publication of the third edition of the Alzheimer Europe Care Manual in German and the second edition of the Care Manual in Portuguese.

Finally, Annette Dumas and Sabine Henry contributed an article on "Alzheimer's disease: towards a European approach. Who is taking up the challenge" to *Actus Gériatrie*.

5.2. Membership development

Alzheimer Europe continued to network informally with Alzheimer associations in a number of European countries which are not currently members of the organisation. The contacts with the Maltese and Bulgarian associations were particularly useful in that they resulted in both member organisations participating in AE activities and being accepted as full and provisional member respectively.

Contacts with the Slovenian Alzheimer's organisation have also progressed and the organisation expressed an interest in becoming a member of the organisation.

5.3. Fundraising

Alzheimer Europe was able to enlarge its circle of corporate sponsors in 2006 by receiving funding from GlaxoSmithKline, Merck Sharp & Dohme and Novartis. Also, the organisation was able to attract non-pharmaceutical funding from Fondation Médéric Alzheimer and Numico.

In 2006, the Alzheimer Europe Board also adopted a new sponsorship policy to be implemented in 2007 and the following years.

5.4. Conference concept

A new conference concept was prepared and discussed with the Board. This document which clarifies the responsibilities of the host organisation and Alzheimer Europe was approved by the Annual General Meeting in Paris and the Board adopted new Conference Guidelines at its meeting in November 2006. The new guidelines will ensure a greater collaboration between Alzheimer Europe and the host organi-

sation, as well as due compensation for the services provided by Alzheimer Europe for the organisation of the annual conferences. The new concept will be applicable from the 2009 Alzheimer Europe conference onwards.

6. Annex 1: Meetings attended by AE representatives

Date	Place	Meeting
11 January	London, UK	EMA Committee of Orphan Medicinal Products
12 January	Brussels, Belgium	Meeting with Novartis
21 January	London, UK	Annual General Meeting of European Patients' Forum
25 January	Brussels, Belgium	EFPIA Think Tank
31 January	Basel, Switzerland	Meeting with Novartis
1 February	Basel, Switzerland	Novartis workshop on collaboration between pharmaceutical companies and patient advocates
2-3 February	Brussels, Belgium	EUCOMED Conference: "Enhancing efficiency and quality of life – the case of homecare"
7-8 February	Brussels, Belgium	EPF Recruitment Interviews
15 February	London, UK	EMA Working Group with Patient Organisations
16 February	Brussels, Belgium	Meeting with Merck Sharp & Dohme
16 February	Brussels, Belgium	Meeting with Pfizer
25-26 February	Luxembourg, Luxembourg	EUROCODE – Meeting of Working Groups
7 March	Paris, France	DIA EuroMeeting
7 March	Brussels, Belgium	EP lunch-debate on priorities for European health research
8 March	Brussels, Belgium	Launch of the Women's Health report in European Parliament
9 March	London, UK	EMA Management Board
18-19 March	Lisbon, Portugal	Lundbeck Symposium "Overcoming everyday challenges in Alzheimer's disease"
20 March	London, UK	Meeting with GE Healthcare
21 March	Brussels, Belgium	EGE Conference on the ethical aspects of nanomedicine

21 March	Brussels, Belgium	Meeting with DG Research of the European Commission
21 March	Brussels, Belgium	AMIGO Society Roundtable on "Information to patients"
22 March	Brussels, Belgium	EPF Executive
22 March	Brussels, Belgium	EFPIA Think Tank
28 March	Brussels, Belgium	CHES conference on 7th research framework programme
31 March	Brussels, Belgium	EC Conference on the economic and budgetary impact of ageing
4 April	Brussels, Belgium	Commission workshop on lessons learnt from FP6
4-5 April	Paris, France	Meeting with France Alzheimer
10 April	Luxembourg, Luxembourg	Meeting with Lundbeck
11 April	Strasbourg, France	Council of Europe NGO Meeting
26 April	London, UK	EPF Executive
27 April	London, UK	Carer Survey Meeting
7 May	London, UK	EuroGenGuide Meeting
11 May	Brussels, Belgium	EP hearing on advance therapies
11 May	Brussels, Belgium	EFPIA Think Tank
12 May	Brussels, Belgium	Meeting with Merck Sharp & Dohme
15 May	London, UK	Meeting with International Longevity Centre
15 May	London, UK	GSK Health Advisory Board
16 May	Brussels, Belgium	Meeting with Parliamentary Assistants of Linda McAvan, MEP (UK), Anneli Jäätteenmaki, MEP (Finland) and Astrid Lulling, MEP (Luxembourg)
17 May	Brussels, Belgium	Meeting with Pfizer
17 May	Brussels, Belgium	Meeting with Roche
18 May	Brussels, Belgium	Meeting with Novartis
20-21 May	Brussels, Belgium	Alzheimer Europe Board

23 May	Lisbon, Portugal	Meeting with Portuguese Alzheimer's Association
24 May	Lisbon, Portugal	APIFARMA Patient Convention
26-28 May	Rome, Italy	Annual General Meeting of European Disability Forum
6 June	Luxembourg, Luxembourg	Task Force on Major and Chronic Conditions
7 June	Luxembourg, Luxembourg	Working Party on Morbidity and Mortality
8 June	London, UK	EMA Management Board
8 June	Brussels, Belgium	Meeting with Pfizer
9 June	Brussels, Belgium	Meeting with Plejaden
20 June	Vienna, Austria	Symposium on "Intergenerational aspects of dementia" at the European Social Services Conference
22 June	Brussels, Belgium	Annual General Meeting of the European Patients' Forum
28 June	Paris, France	AE-Pfizer Seminar on media and communication skills
29 June	Paris, France	Alzheimer Europe Board
29 June	Paris, France	Alzheimer Europe Annual General Meeting
29 June- 1 July	Paris, France	16th Alzheimer Europe conference
2 July	Paris, France	EUROCODE – Steering Committee
4 July	Brussels, Belgium	EPF Executive
4 July	Brussels, Belgium	CHES Round Table on information to patients
12 July	Brussels, Belgium	Meeting with Peter Liese, MEP (Germany)
18-19 July	Madrid, Spain	Novartis Seminar at ICAD Conference
8 August	Luxembourg, Luxembourg	Meeting with Numico
29 August	Brussels, Belgium	Meeting with Corien Wortmann-Kool, MEP (Netherlands)
2-5 September	Glasgow, UK	EFNS Conference

7 September	Brussels, Belgium	Meeting with Finnish Alzheimer's Association
8 September	Brussels, Belgium	EPF Executive
13 September	Brussels, Belgium	Commission Conference on Long Term Care
14 September	Brussels, Belgium	Meeting with the Parliamentary Assistant of Ria Oomen-Ruijten, MEP (Netherlands)
15 September	London, UK	EMA Working Group with Patient Organisations
19 September	Brussels, Belgium	MSD Lunch on Alzheimer's disease in European Parliament
20 September	Brussels, Belgium	Friends of Europe Lunch on Information to Patients
20 September	Brussels, Belgium	Belgian Brain Council Conference on reimbursement of anti-dementia drugs
21 September	Brussels, Belgium	EFPIA Think Tank
22-23 September	Cologne, Germany	Conference of the European Association of Geriatric Psychiatry
27 September	London, UK	Meeting with Novartis
28 September	London, UK	EMA Management Board
30 September	Brussels, Belgium	EPF Executive
1 October	Brussels, Belgium	EPF Executive
4 October	Luxembourg, Luxembourg	Meeting with GlaxoSmith-Kline
10 October	Brussels, Belgium	The Centre Meeting on Health Tourism
11 October	Brussels, Belgium	Working Group on relative effectiveness of the Pharmaceutical Forum
12-13 October	Berlin, Germany	ADI Conference
16 October	Brussels, Belgium	Meeting with Joseph Muscat, MEP (Malta)
19 October	Luxembourg, Luxembourg	Meeting with GE Healthcare
20 October	Brussels, Belgium	GSK Seminar on transparency of industry/patient organisations relationships

20 October	Brussels, Belgium	Meeting with the Parliamentary Assistants of Roselyne Bachelot, MEP (France) and Jan Tadeusz Masiel, MEP (Poland)
30 October	Brussels, Belgium	EPF Policy Working Group
5 November	Brussels, Belgium	Alzheimer Europe Board
6 November	Brussels, Belgium	EUROCODE – Working Groups
6 November	Brussels, Belgium	AE Public Affairs Meeting
7 November	Brussels, Belgium	AE-GSK Workshop
7 November	Brussels, Belgium	AE Lunch-debate on Alzheimer's disease in European Parliament
7 November	Brussels, Belgium	AE-Numico Workshop
14 November	Brussels, Belgium	Meeting with GE Healthcare
15 November	Brussels, Belgium	EPF Recruitment Interviews
18 November	Sligo, Ireland	Annual Conference of Alzheimer Society of Ireland
21 November 2006	Brussels, Belgium	EPF/EFPIA Conference on "Strengthening Patient Organisations"
22 November	Brussels, Belgium	EFPIA Seminar on the use of animals in research
23 November	Brussels, Belgium	Meeting with Jan Tadeusz Masiel, MEP (Poland)
27 November	Brussels, Belgium	Meeting with Parliamentary Assistant of Astrid Lulling, MEP (Luxembourg)
28 November	Brussels, Belgium	Meeting with Miroslav Mikolasik, MEP (Slovakia)
30 November	Brussels, Belgium	Weber Shandwick Meeting on German Presidency
4 December	Brussels, Belgium	EFPIA Think Tank
5 December	Brussels, Belgium	EPF Executive
6 December	Brussels, Belgium	Meeting with Charlotte Cederschiold, MEP (Sweden)
8 December	London, UK	EMA Working Group with Patient Organisations
11 December 2006	Paris, France	Meeting with Medical Mobile

13 December	Luxembourg, Luxembourg	Task Force on Major and Chronic Diseases
15 December	Brussels, Belgium	Meeting with Merck Sharp & Dohme
20 December	Brussels, Belgium	Meeting with Janssen-Cilag

7. Annex 2: Balance sheet as of December 31, 2006

	2006 (Euro)	2005 (Euro)
ASSETS		
Current assets		
Debtors	10,229	40,141
Subsidies due (EC)	10,363	
Cash at bank and on deposit	141,014	100,616
	<hr/>	<hr/>
	161,606	140,757
Accruals	354	120
	<hr/>	<hr/>
	161,960	140,877
LIABILITIES		
Capital and reserves		
Results brought forward	73,445	83,745
Result of the year	16,724	10,300
	<hr/>	<hr/>
	90,169	73,445
Creditors		
Payments received on account	45,557	30,000
Trade creditors	15,660	20,172
Other liabilities	10,573	17,260
	<hr/>	<hr/>
	71,790	67,432
Accruals		
	<hr/>	<hr/>
	161,960	140,877

8. Annex 3: Profit and loss account – Year ended December 31, 2006

	2006 (Euro)	2005 (Euro)
Support and revenue		
Subsidies from the EC	233,270	
Other operating income		
Co-financing in kind	203,155	114,885
Corporate sponsorship	183,176	165,415
Sponsorship received on account	45,557	
AE Conference	58,597	10,000
Membership fees	41,250	40,000
Other sponsorship/Subsidies	24,325	6,391
Publication sales and royalties	7,059	12,012
Other operating revenue	6,120	4,834
Internet services	5,815	5,925
Donations	57	1,500
External charges		
External experts	- 335,668	- 119,591
AE Conference	- 53,558	
Travel & Accommodation	- 93,586	- 60,170
Publication and Information material	- 29,629	- 19,859
Other costs	- 24,307	- 574
Office rent and associated costs	- 22,291	- 22,887
Communication costs	- 19,473	- 17,828
Equipment & Leasing	- 8,363	- 13,248
Office stationery and related costs	- 2,692	- 1,810
Membership fees	- 750	- 700
Irrecoverable debt		- 937
Staff costs		
Wages and salaries	- 85,491	- 88,670
Social security costs	- 23,324	- 24,322
Interest receivable and similar income	974	581
Interest payable and similar charges	- 2,387	- 1,247
	<hr/>	
	16,724	-10,300

9. Annex 4: Acknowledgements

9.1. Platinum donors and sponsors (Donations and sponsorship from €50,000)

Alzheimer Europe is grateful to Association Luxembourg Alzheimer and the Luxembourg Ministry for Family for the secondment of the Executive Director of Alzheimer Europe and the office space they make available to the organisation free of charge.

9.2. Gold donors and sponsors (Donations and sponsorship between €20,000 and €49,999)

Alzheimer Europe is grateful to GlaxoSmithKline, Janssen-Cilag, Lundbeck and Pfizer which generously agreed to support the activities Alzheimer Europe carried out in the framework of its business plan in 2006.

Furthermore, Alzheimer gratefully acknowledges the support it has received from Lundbeck for the organisation of a carers' survey in France, Germany, Poland, Scotland and Spain and from GlaxoSmithKline for the support of delegates to the AE conference in Paris and a workshop on the company's research activities in the Alzheimer's field.

9.3. Silver donors and sponsors (Donations and sponsorship between €5,000 and €19,999)

Alzheimer Europe gratefully acknowledges the support of Numico for its contribution to the European Parliament event of Alzheimer Europe and for the organisation of a workshop on the company's research activities in the Alzheimer's field.

Alzheimer Europe is grateful for the generous contribution of Fondation Médéric Alzheimer to the Eurocode project of Alzheimer Europe.

Alzheimer Europe is grateful to Novartis and Merck Sharp & Dohme for their support to the activities of Alzheimer Europe.

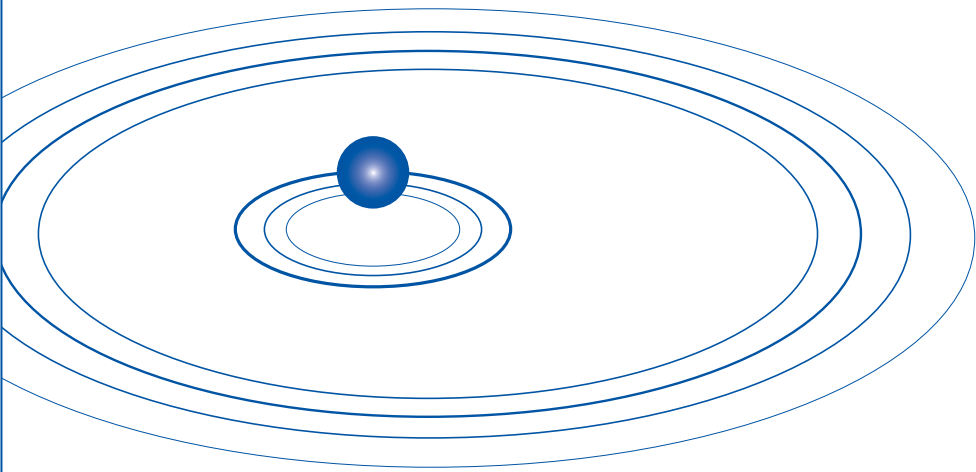
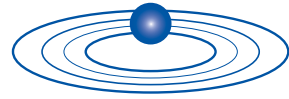
9.4. Bronze donors and sponsors (Donations and sponsorship between €1,000 and €4,999)

Alzheimer Europe is grateful to Mazars for having carried out the audit of the 2006 financial accounts of the organisation free of charge.

9.5. Support from corporate sponsors

In 2006, Alzheimer Europe had an audited income of €763,798. Sponsorship by the pharmaceutical industry and other corporate sponsors amounted to €183,176 or 23.98%. The following table lists sponsorship and donations received by individual companies, as well as other payments, such as speakers' fees, honoraria and support for travel or subsistence costs. The global support received from individual companies is also presented in terms of percentages of the overall income of the organisation in line with the policy of the European Medicines Agency with regard to the transparency requirements for patients' organisations.

Company	Sponsorship and donations	Other payments	TOTAL	% of AE income
Lundbeck	€30,000	€12,224	€42,224	5.53%
Janssen-Cilag	€40,000		€40,000	5.24%
Pfizer	€35,000	€1,361	€36,361	4.76%
GlaxoSmithKline	€25,000	€1,300	€26,300	3.44%
Novartis	€15,000	€1,723	€16,723	2.19%
Merck Sharp & Dohme	€7,891		€7,891	1.03%
APIFARMA		€1,529	€1,529	0.20%
EFPIA		€744	€744	0.10%
Roche		€319	€319	0.04%
Drug Information Association		€158	€158	0.02%
Sub-total: Support by the pharmaceutical industry			€172,249	22.55%
Numico	€10,000		€10,000	1.31%
GE Healthcare		€927	€927	0.12%
Sub-total: Support by other corporate sponsors			€10,927	1.43%
Total: Support by corporate sponsors			€183,176	23.98%



Financial Report

1. Report of the independent auditor



To the Board of Directors
ALZHEIMER EUROPE A.s.b.l.

LUXEMBOURG

REPORT OF THE REVISEUR D'ENTREPRISES

Report on the annual accounts

We have audited the accompanying annual accounts of **ALZHEIMER EUROPE A.s.b.l.**, which comprise the balance sheet as at December 31, 2006 and the profit and loss account for the year then ended, and a summary of significant accounting policies and other explanatory notes.

Board of directors' responsibility for the annual accounts

The board of directors is responsible for the preparation and fair presentation of these annual accounts in accordance with Luxembourg legal and regulatory requirements relating to the preparation of the annual accounts. This responsibility include : designing, implementing and maintaining internal control relevant to the preparation and fair presentation of annual accounts that are free from material misstatement, whether due to fraud or error ; selecting and applying appropriate accounting policies and making accounting estimates that are reasonable in the circumstances.

Responsibility of the réviseur d'entreprises

Our responsibility is to express an opinion on these annual accounts based on our audit. We conducted our audit in accordance with International Standards on Auditing as adopted by the Institut des Réviseurs d'Entreprises. Those standards require that we comply with ethical requirements and plan and perform the audit to obtain reasonable assurance whether the annual accounts are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the annual accounts. The procedures selected depend on the judgement of the réviseur d'entreprises, including the assessment of the risks of material misstatement of the annual accounts, whether due to fraud or error. In making those risk assessments, the réviseur d'entreprises considers internal control relevant to the entity's preparation and fair presentation of the annual accounts in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control.

An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates made by the board of directors, as well as evaluating the overall presentation of the annual accounts. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.


Opinion

In our opinion, the annual accounts give a true and fair view of the financial position of **ALZHEIMER EUROPE A.s.b.l.** as of December 31, 2006 and of the results of its operations for the year then ended in accordance with the Luxembourg legal and regulatory requirements relating to the preparation of the annual accounts.

Luxembourg, May 3, 2007

For MAZARS, Réviseurs d'entreprises


Philippe SLENDZAK
Partner


Joseph HOBSCHIED
Partner

Appendix:

- balance sheet as of December 31, 2006
- profit and loss account for the year ended December 31, 2006

2. Balance sheet as of December 31, 2006

ALZHEIMER EUROPE A.s.b.l.

Balance sheet as of December 31, 2006

	<u>2006</u>	<u>2005</u>
	EUR	EUR
ASSETS		
Current assets		
Debtor EU Commission - Eurocode	31.611	-
Other debtors	10.229	40.141
Advance payments - Eurocode partners	51.254	-
Cash at bank and on deposit	<u>141.014</u>	<u>100.616</u>
	234.108	140.757
Accruals	354	120
	<u>234.462</u>	<u>140.877</u>
Total Assets	<u>234.462</u>	<u>140.877</u>
LIABILITIES		
Capital and reserves		
Results brought forward	73.446	83.745
Result of the year	<u>16.724</u>	<u>-10.300</u>
	90.170	73.445
Creditors		
Payments received on account - EU Commission - Eurocode	51.254	-
Payments received on account - Other	45.557	30.000
Trade creditors	15.660	20.172
Creditors - Eurocode partners	21.248	-
Other liabilities	<u>10.573</u>	<u>17.260</u>
	144.292	67.432
Total Liabilities	<u>234.462</u>	<u>140.877</u>

3. Profit and loss account – Year ended December 31, 2006

ALZHEIMER EUROPE A.s.b.l.

Profit and loss account
Year ended December 31, 2006

	<u>2006</u>	<u>2005</u>
	EUR	EUR
Other operating income		
Sponsorship	183.176	165.415
Sponsorship received on account	-45.557	-
EU Subsidy	78.631	-
Co-financing in kind	92.342	114.885
Membership fees	41.250	40.000
Donations	57	1.500
Publication sales and royalties	7.059	12.012
Internet services	5.815	5.925
Project participation	24.325	6.391
Other operating income	6.120	4.834
Alzheimer Europe Conference	58.597	10.000
Eurocode Partner Income	265.452	-
External charges		
External experts	-125.525	-119.591
Publication and information material	-29.629	-19.859
Travel expenses	-27.091	-28.773
Communication costs	-19.473	-17.828
Accommodation expenses	-28.773	-31.397
Office rent and associated costs	-22.291	-22.887
Office stationary and related costs	-2.470	-1.810
Leasing	-8.362	-13.248
Membership fees	-750	-700
Other costs	-6.941	-574
Irrecoverable debt	-	-937
Alzheimer Europe Conference	-53.558	-
Eurocode Partner expenses	-265.452	-
Staff costs		
Wages and salaries	-85.491	-88.670
Social security costs	-23.324	-24.322
Interest receivable and similar income	974	581
Interest payable and similar charges	-2.387	-1.247
	<u>16.724</u>	<u>-10.300</u>

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