Dementia in Europe Yearbook 2013

Alzheimer Europe

with a focus on national policies relating to the care and support of people with dementia and their carers, as well as the prevalence of dementia

including the Alzheimer Europe Annual Report 2012

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Table of contents

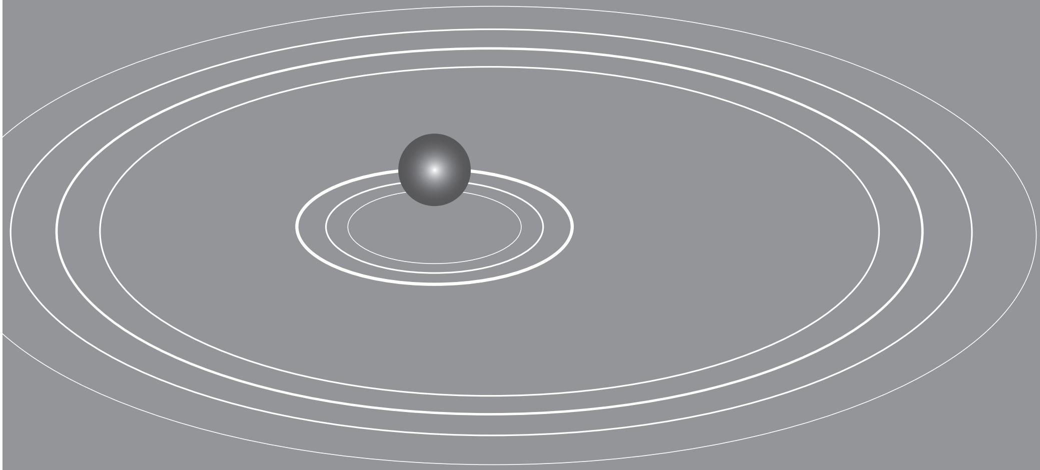
Introduction **6**

National Reports **8**
- 1 *Austria* 9
- 2 *Belgium* 15
- 3 *Bulgaria* 23
- 4 *Croatia* 30
- 5 *Cyprus* 34
- 6 *Czech Republic* 36
- 7 *Denmark* 41
- 8 *Estonia* 48
- 9 *Finland* 49
- 10 *France* 58
- 11 *Germany* 69
- 12 *Greece* 75
- 13 *Hungary* 79
- 14 *Iceland* 80
- 15 *Ireland* 82
- 16 *Italy* 91
- 17 *Jersey* 95
- 18 *Latvia* 99
- 19 *Lithuania* 100
- 20 *Luxembourg* 107
- 21 *Malta* 115
- 22 *Netherlands* 123
- 23 *Norway* 132
- 24 *Poland* 138
- 25 *Portugal* 140
- 26 *Romania* 145
- 27 *Slovakia* 152
- 28 *Slovenia* 154
- 29 *Spain* 158
- 30 *Sweden* 159
- 31 *Switzerland* 168
- 32 *Turkey* 174
- 33 *United Kingdom (England, Wales and Northern Ireland)* 178
- 34 *United Kingdom (Scotland)* 187

Acknowledgements **202**

Appendix 1:
The prevalence of dementia in Europe **206**

Appendix 2 **210**



Introduction

It gives me great pleasure to present the Dementia in Europe Yearbook 2013. In addition to the Annual Report of Alzheimer Europe for 2012, it contains our work on national policies relating to the care and support of people with dementia and their carers, as well as details of the prevalence of dementia in the 28 member states of the European Union (currently 8.7 million) and Switzerland, Norway, Iceland, Jersey and Turkey (currently just over 0.5 million). Details of the prevalence of dementia in each country can be found in relevant sections of the report as well as an overview in Appendix 1, along with an explanation about the basis for these calculations.

The report provides information about the situation in 34 countries regarding national policies focusing on the provision of care, the training of healthcare professionals and social care staff, and support at home, in the community and in nursing homes. As many countries do not yet have a national dementia plan, we asked experts to provide us not only with details of provisions in such plans but also details of any other relevant policy provisions (e.g. guidelines, laws and regulations). Information on national policies was unfortunately not available in some countries due to the lack of a relevant expert or Alzheimer association. For these countries, we have nevertheless included details of prevalence and for some, the support offered by the national Alzheimer association.

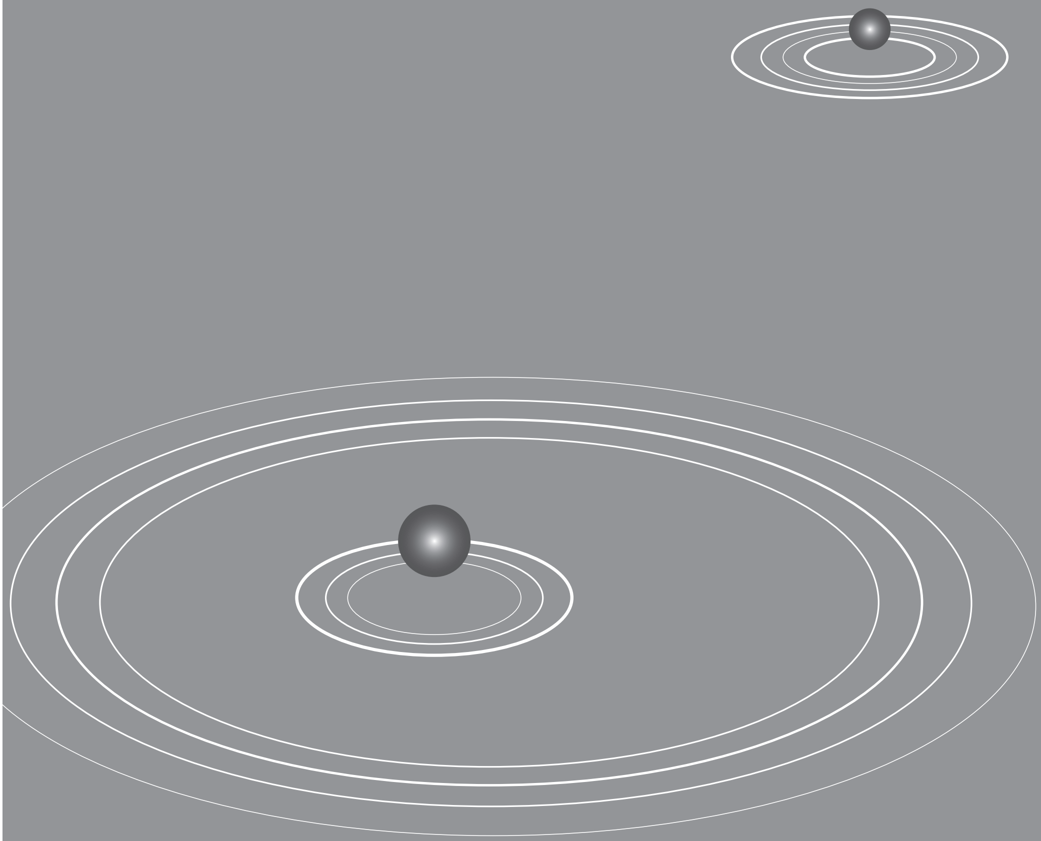
This report represents a kind of snapshot of provisions for the care and support of people with dementia and carers up to November 2013. Some countries, such as Scotland, and Luxembourg, have introduced new national dementia strategies and others have made significant progress with draft plans (e.g. in Portugal, the Czech Republic, Bulgaria, Slovenia and Ireland). As countries develop new national dementia strategies and monitor the progress of existing strategies, it may be helpful to compare provisions in other countries.

Alongside national provisions, national Alzheimer associations provide a great deal of support to people with dementia and their carers. Wherever possible, we have prepared details of the services and support they offer and a comparative table can be found in Appendix 2. The level and type of support provided is obviously dependent on their resources, structure and goals, combined with the kind of support already provided by the state and other organisations. Consequently, when comparing the data, it is important to bear this in mind. Tables comparing the involvement of healthcare professionals in dementia care and support, and where people with dementia receive care can also be found in Appendix 2

Most of the reports were written by or with the assistance of Alzheimer Europe's member associations to whom we are immensely grateful. Some external experts also helped compile the reports. The names of all those who made it possible to produce this report are acknowledged at the end of each country report. I would also like to thank our staff, Dianne Gove, Alex Teligadas and Annette Dumas, for compiling the various reports and Katherine Ellis for preparing the comparative tables.

It is hoped that this information will enable readers to gain an impression of how different countries have addressed these common issues and perhaps learn from and adapt where necessary the various solutions which have been attempted.

Jean Georges
Executive Director
Alzheimer Europe



National Reports

1 Austria

1.1 Background information

1.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Austria in 2012 as being 145,431. This represents 1.73% of the total population of 8,428,915. The number of people with dementia as a percentage of the population is somewhat higher than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter. However, according to Alzheimer Austria, 50-60% of people with dementia are probably not diagnosed.

Age group	Men with dementia	Women with dementia	Total
30 – 59	2,934	1,646	4,580
60 – 64	448	2,156	240,058
65 – 69	3,818	3,320	240,977
70 – 74	5,566	7,946	214,673
75 – 79	8,347	12,143	168,129
80 – 84	11,462	21,123	140,260
85 – 89	8,976	28,403	108,635
90 – 94	3,743	18,630	45,703
95+	643	4,126	9,097
Total	**45,938**	**99,494**	**145,431**

1.1.2 Where people with dementia receive care and support

The following table shows the type of accommodation in which people with dementia in Austria are living (e.g. at home, in various types of residential care and/or in hospitals or psychiatric institutions).

Place of residence	YES or NO	Estimated number/Additional information
At home (alone)	Yes	Low
At home (with relatives or close friends)	Yes	60-80% of people with dementia
At home (with other people with dementia)	Yes	Some people with dementia live in a “betreute Wohn-gemeinschaft”
In general/non-specialised residential homes	Yes	
In specialised residential homes for people with dementia	Yes	
In general/non-specialised nursing homes	Yes	
In specialised nursing homes for people with dementia	Yes	
In hospitals, special wards or medical units	No	
In psychiatric establishments	Yes	Very low

It is estimated that 60-80% of people with dementia live at home, most of them with female carers/family members (i.e. partners, daughters, daughters-in-law, sons and friends). People with dementia only stay in hospitals, special wards or medical units for medical treatment. They do not live there. A "betreute Wohngemeinschaft" is a place where a small group of people with dementia live together and any support or care needed is either purchased privately or supplied by the state on the basis of each individual's assessed need and his/her right to receive such support or care according to the principle of subsidiarity (please see below). A "betreute Wohngemeinschaft" is considered as a private home and not a nursing home. Most can be found in Vienna.

Approximately two thirds of residents in nursing homes have dementia (Wancata et al., 2001). No precise data is available as to the proportion of residents in general/non-specialised residential homes who have dementia or concerning the type of nursing homes in which two thirds of the residents have dementia.

The ratio of staff to residents in homes for older people and care homes depends on the level of care needed by the residents and also differs from one region to the next. The following table provides an overview of the different ratios of staff to residents in three different areas according to the level of care needed (expressed as categories ranging from 0 to 7). In addition to these ratios, the proportion of staff with different levels of specialisation/training is also specified and varies from one region to the next.

Care level	Steiermark region	Oberösterreich region	Vienna region
0		1: 24	1: 20
1	1: 12	1: 12	1: 20
2	1: 6	1: 7.5	1: 7
3	1: 3.7	1: 4	1: 2
4	1: 2.6	1: 2.5	1: 1.75
5	1: 2.5	1: 2	1: 1.5
6	1: 2.3	1: 1.5	1: 1.25
7	1: 2	1: 1.5	1: 1

Source: Tupy (2011)

1.2 The organisation of care and support for people with dementia

1.2.1 The overall organisation of care and support

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 older people. In regional areas, due to inadequate structures, there is some overlap between the healthcare 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.

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.

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 that 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.

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 (BGB1. Nr.866/1993, entered into force on 1 January 1994).

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. In rural areas, there is a lack of support both quantitatively and qualitatively. There is no specific support for people with different types of dementia or for younger people with dementia. Similarly, there is no support that is specifically designed to meet the needs of people with dementia and their carers from ethnic minorities in Austria.

1.2.2 How specific aspects of care and support are addressed

The provision of care and support to people with dementia in residential and home care is covered in some national policies. There is government legislation, for example, covering:

- Standards of care and support,
- Controlling and monitoring care and support,
- Continuity of care and support,
- Staffing levels,
- Funding and control bodies,
- Complaint procedures (the Nursing Home Law, "Bewohnervertretung"/representation of residents and the Guardianship Law),
- Promoting well-being and autonomy (the Nursing Home Law, Guardianship Law and Care Allowance Law),
- Involving people with dementia in decisions about care and support (the Guardianship Law).

1.3 Training

1.3.1 Which social and healthcare professionals provide care and support

The following social and healthcare professionals are involved in the provision of care and support to people with dementia in residential care or living at home.

Social or healthcare professional	Involved in the provision of care and support to people with dementia in residential care or at home
Nursing staff	Yes
Auxiliary staff	Yes
Allied health professionals	Yes, if organised privately
Specialists (e.g. psychiatrists, gerontologists, neurologists)*	No
General practitioners*	No
Other	Yes (validation therapists if privately organised; also voluntary visiting services)

* Only if they are linked to the provision and organisation of care and support (i.e. not with regard to their role to provide medical treatment).

1.3.2 The type of training that social and healthcare professionals receive

With regard to nursing staff, knowledge about dementia is included in the special training of psychiatric nurses. This is covered in the Law on Health and Nursing Care (Law: "Gesundheits- und Krankenpflegegesetz). Auxiliary staff (who provide general assistance, usually with no medical or nursing training) are state recognised but there are different levels of training (i.e. varying from ten weeks to one year and provided by official or private schools). Social sector professionals, such as social workers, are educated to degree or Masters (BA or MA) level at state recognised "Fachhochschulen" (which are equivalent to universities). Allied health professionals (e.g. language therapists, physiotherapists, dieticians, podiatrists) have specific training which leads to a state recognised qualification.

1.3.3 How the training of social and healthcare professionals is addressed

The training of social and healthcare professionals in the residential or home care, which covers or includes dementia, is addressed in some national policies.

According to the "Gesundheits- und Krankenpflegegesetz", health and nursing care education must include basic/elementary knowledge about dementia. In some social services, specialised nurses and carers for older people (Altenpfleger) provide specialised knowledge about dementia to home help staff and visiting services (e.g. people who sit with the person with dementia and talk but do not carry out any care tasks).

Certain groups of social and healthcare professionals such as psychologists, psychiatrists, psychotherapists and validation therapists receive training in the behavioural and psychological symptoms of dementia. This is covered in national guidelines.

Certain groups of social and healthcare professionals who are responsible for providing palliative or end-of-life care to people with dementia have guidelines and professional codes.

Case managers and care managers receive training in the assessment of capacity.

1.4 Support for informal carers

Some forms of support for informal carers are addressed in national policies.

1.4.1 Respite

Carers who are caring for a person with level 3 care needs are entitled to three weeks per year respite from caring, which is financially covered by the Federal Social Office (the "Bundessozialamt").

1.4.2 Training

There is no national policy covering the training of informal carers.

1.4.3 Consultation/involvement in care decisions

Carers who are the legal representatives of a person with dementia are consulted and involved in care decisions in accordance with guardianship legislation.

1.4.4 Counselling/support

There is no national policy covering counselling/support for informal carers.

1.4.5 Other

As of 1 January 2014, people caring for a person with needs defined as care level 3 will be entitled to three months' break from work ("Pflegekarenz") or three months' part-time work ("Pflegeteilzeit"). For the three-month break, carers will receive a payment based on their last wage but up to maximum of EUR 1,400 per month. For the part-time work, carers will be able to reduce their working time by a minimum of ten hours per week and the payment they receive will be calculated on the basis of their reduced income. These two measures are designed to make it easier for carers to combine work and care responsibilities during difficult periods without fearing losing their jobs. However, the request for a carers' break must be approved by each person's employer.

Support for carers is also provided by private organisations such as the carers organisations ("Interessensvertretung pflegender Angehöriger), Alzheimer Austria; MAS-Alzheimerhilfe, Bad Ischl, the Red Cross and Caritas. The communities and regions also provide support through projects.

1.5 National Alzheimer Association

Alzheimer Austria provides the following services and support

Helpline	
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	✓
Care coordination/Case management	
Home help (cleaning, cooking, shopping)	
Home care (personal hygiene, medication)	
Incontinence help	

Assistive technologies / ICT solutions	
Tele Alarm	
Adaptations to the home	
Meals on wheels	
Counselling	✓
Support groups for people with dementia	✓
Alzheimer cafes	✓
Respite care at home (Sitting service etc)	
Holidays for carers	✓
Training for carers	✓
Support groups for carers	✓
Day care	
Residential/Nursing home care	
Palliative care	

1.6 References

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1.7 Acknowledgements

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2 Belgium

2.1 Background information

Belgium is a Federal State, composed of 3 regions and 3 communities: the Flemish community, the Walloon community and a small German-speaking community. The responsibilities for healthcare and support to older people are shared among the three authorities. Laws, regulations and decrees fall to each respective authority.

2.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Belgium in 2012 as being 191,281.This represents 1.77% of the total population of 10,787,788. The number of people with dementia as a percentage of the population is somewhat higher than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	3,591	2,001	5,593
60 – 64	650	3,009	3,658
65 – 69	4,497	3,754	8,251
70 – 74	6,353	8,894	15,247
75 – 79	12,057	17,420	29,477
80 – 84	17,066	30,863	47,929
85 – 89	12,668	35,393	48,061
90 – 94	5,317	21,681	26,998
95+	772	5,294	6,067
Total	**62,972**	**128,309**	**191,281**

It has not been possible for Ligue Alzheimer-Alzheimer Liga (LINAL) to make a distinction between the people diagnosed with Alzheimer's disease and those with other types of dementia. As the specific examinations and evaluations needed to make a diagnosis are not always offered to the person with dementia symptoms, it is very difficult to evaluate the number of people who have not been diagnosed with dementia but still have the disease (Ylieff et al., 2006).

Nevertheless, LINAL estimates that some 185,000 people have dementia in Belgium (9% of the people aged 65 and over). In Brussels, LINAL estimates the number of people with dementia to be 13,684. It seems there are 98.53 people with dementia per square kilometre in Brussels, again according to LINAL (rtbf, 2013).

In 2010, in Flanders, it was estimated that 100,000 people had dementia. About 2,000 of them were people below 65 years of age (Vandeurzen, 2010).

In their book, Ylieff et. al. (2006) refer to the latest epidemiological study that was carried out in Belgium in 1994. This study shows that 9% of the population aged 65 and over had dementia.

In Flanders, the figures are the following (Vandeurzen, 2010):

- Over 10% of people over 65 have dementia,
- Over 20% of people over 80 have dementia,
- More than 40% of people over 90 have dementia.

2.1.2 Where people with dementia receive care and support

The following table provides estimates of the number of people with dementia living at home, in various types of residential care and in hospitals or psychiatric institutions.

Place of residence	YES or NO	Estimated number/Additional information
At home (alone)	Yes	There is no specific breakdown for each proposal. By deduction from the King Baudouin Foundation report, 55% of people with Alzheimer's disease live at home. (KCE, 2009) In Flanders, 70% of people with dementia live at home. Family members or people in the neighbourhood give care to these people. The majority of caregivers are over 50 and are women (Vandeurzen, undated).
At home (with relatives or close friends)	Yes	
At home (with other people with dementia)	Yes	
In general/non-specialised residential homes	Yes	45% of people with Alzheimer's disease live in an institution (KCE, 2009).
In specialised residential homes for people with dementia	Yes	
In general/non-specialised nursing homes	Yes	
In specialised nursing homes for people with dementia	Yes	
In hospitals, special wards or medical units	No	Hospitalisation is for a limited period of time and cannot be considered as a residential place (Van Audenhove et al., 2009).
In psychiatric establishments	Yes	Figures are unknown

There are no official data as to the percentage of residents who have dementia in general/non-specialised residential homes or in general/non-specialised nursing homes.

In **general, non-specialised residential homes in** Belgium, staff norms for 30 beds vary between 4.5 to10 full time nursing staff (nurses and auxiliary nurses). Also, one nursing staff member must be present night and day for 75 beds (Van Audenhove et al., 2009).

In the Walloon community, nurses and auxiliary nurses must permanently be in a position to respond to calls from the residents and do day and night watches. In addition, at least one nurse or auxiliary nurse must be present night and day for a capacity of up to 60 beds, 2 for a capacity of between 60 to 129 beds, 3 for a capacity of between 130 and 199 beds and 4 for a capacity of over 199 beds in residential and nursing homes as well as in short stay residences (Wallex, undated).

In **general/non-specialised nursing homes**, 5 full time nurses (including one chief nurse) must be available for a capacity of 30 beds, 5 full time auxiliary nurses and one full time allied health professional (occupational therapist, physiotherapist, speech therapist) (Van Audenhove et al., 2009).

In the Walloon community, in 2008, there were 196 beds in **specialised residential homes** accredited by the Region, 985 beds not accredited by the Wallonia Region and 304 non-accredited beds in the Brussels region (Van Audenhove et al., 2009).

The government in Wallonia has produced specific norms for the admission and care of disoriented people in specialised units (Walloon government decision of 15 October 2009 relative to the enforcement of the decree of 30 April 2009, relative to the accommodation of elderly people) (Wallex, 2009).

2.2 The organisation of care and support for people with dementia

In line with initiatives organised by political parties, associations or independent actors, the care of people with dementia is organised as follows (non-exhaustive list):

Extra-muros:

- home care and support,
- coordination services,
- integrated home care,
- family and older people support services,
- nursing care,
- family support services,
- home care,
- tele-assistance,
- home help, meals on wheels,
- mental health services,
- psycho-social interventions,
- telephone helplines,
- family associations,
- volunteers,
- memory clinics accredited by the national health insurance (INAMI-RIZIV).

Inta-muros:

- day centres,
- day care centres,
- night care centres,
- short-term care centres,
- serviced residential homes,
- rest homes,
- rest and care homes,
- care centres for disoriented people,
- small-scale standardised residences.

At Federal level:

- INAMI -RIZIV finances memory clinics. (http://www.inami.fgov.be/care/fr/revalidatie/convention/hospitals-memory/)
- INAMI- RIZIV finances the training of the dementia referent.
- INAMI -RIZIV finances 'Protocole 3' (this protocole was signed between the Federal Government, the Communities and the Regions. It foresees the provision of dedicated finances to study alternative care and support for old vulnerable people). The conditions under which the INAMI-RIZIV may agree conventions is spelt out by the Royal Decree of 02 July 2009.

In Belgium, the provision of care and support is addressed in some national policies:

At regional level:

In Wallonia, the Alzheimer Plan has 13 objectives around 3 axes that will help to improve the provision of care and support to people with dementia and their carers.

- Axis 1: ensure a better understanding and management of dementia and a pertinent management of dementia at a community level.
- Axis 2: improve the quality of life of people with dementia and their carers during the different stages of the disease.
- Axis 3: gain a better understanding of the disease and set up an action plan.

In Flanders, the Flemish Dementia Plan 2010-2014 also addresses the provision of care and support (Vandeurzen, 2010). This plan focuses on a limited number of goals:

- Change the way society conceptualises dementia and communicates about the disease. Negative phrasing like 'a tsunami of dementia' can result in 'excess disability', in unnecessary harm.
- Promotion of healthy living, healthy ageing.
- Support of the autonomy of people with dementia and their social network.
- Special focus on young people with dementia and other specific groups.
- Innovation through science and research.
- Towards a dementia-friendly Flanders.

At the time of producing this publication, the Brussels Region was still working on an Alzheimer Plan.

2.3 Training

2.3.1 Which social and healthcare professionals provide care and support

Different healthcare professionals work in different settings: nurses work in institutions and old people's homes; auxiliary nurses work in institutions; auxiliary family helps provide home- support; allied professionals such as language therapists, physiotherapists, dieticians, podiatrists work in institutions and provide support at the person's home; specialists such as psychiatrists, gerontologists and neurologists provide ambulatory care; while general practitioners work in their private practice or at the person's home. Other people, like volunteers provide support in institutions and at home.

2.3.2 The type of training that social and healthcare professionals receive

The training for various competences is addressed by different bodies: the Federal Public Health Service and the INAMI-RIZIV, the Federation of Home Services or the public social services centres (CPAS - Centres Publics d'Action Sociale), the French Community social promotion training, independent training centres, Alzheimer Liga in Flanders, Ligue Alzheimer asbl in Wallonia and Brussels, Expertise Centre Dementia Flanders.

Nurses have to follow an A1 and A2 training so they can work in institutions and people's homes while auxiliary nurses need to have followed higher secondary studies to be able to work in institutions.

(A1 nurses can work in all areas of nursing care while A2 nurses scope of activity is more reduced. They cannot work in intensive care, emergencies, for instance).

In the Walloon region, healthcare professionals must follow a 1 to 2 day continuous training on a yearly basis, depending on their role and qualifications. This training is general and not specific to dementia. Nevertheless, it is possible to choose specific training modules related to dementia. A testimony / acknowledgement of participation is given for the majority of the trainings.

The majority of the trainings in Wallonia are accredited by an 'attestation de participation' (paper that officially recognises that the person has participated in the training) except for one training: the exception is the training at Federal level, of the 'dementia-referent' that leads to a certification. This enables a nursing home to benefit from the financing of a part-time position for the staff members that have completed this certification.

2.3.3 How the training of social and healthcare professionals is addressed

At Federal level, training to become a dementia reference person lasts 60 hours and is accredited by the Federal Public Health Service and the INAMI for the staff in nursing homes. This training may lead to the financing of a part-time job in a nursing home if the professional has a basic training matching clear criteria and if 25 people with dementia are living in a nursing home.

At Regional level, the regions have formally spelled out the obligation to put in place a continuous training for health and social care professionals (Decree of 30 April 2009 relative to the accreditation of home care and support coordination centres with a view to obtaining subsidies – Moniteur Belge of 15/06/2009 or the Walloon community decision towards the execution of Decree of 30 April 2009 relative to the admission and care of older people). This training is general and not specific to dementia.

The French Community gives an accreditation to the 'ACCORDé' training for professionals who work at people with dementia's homes and nursing homes.

Wallonia has an Alzheimer Plan. Objective 10 of the plan is to 'develop a specific dementia training for professionals'.

In Flanders, Alzheimer Liga provides training to its core members and volunteers (caregivers, relatives).

The "Expertisecentrum Dementie Vlaanderen" (Expertise Centre Dementia Flanders and the 9 regional centres for dementia focus primarily on professional trainings (for instance professionals working in residential care). They also deploy initiatives to reach relatives and informal carers.

In Flanders, other actors, such as mutual insurance associations and universities, also offer training (through symposia, workshops or other initiatives) for nursing staff, auxiliary staff, or social sector professionals.

The Flemish Alzheimer Plan 2010-2014 includes training for dementia referents and for dementia consultants in order to (Vandeurzen, 2010):

- Improve and speed up diagnosis,
- Encourage research,
- Eliminate stigma,
- Ensure more autonomy for the people with dementia and carers,
- Provide tailored residential care: in cooperation with the home care and in accordance with the residential decree, offer people with dementia differentiated day-care, stays, night-care and small-scale housing,
- Ensure early care planning is more timely and examines the extent to which medical-technical support meets patient needs,
- Specific attention given to young people with dementia and "forgotten groups': immigrants, the poor, people with disabilities, with Down's syndrome,
- Innovation through science and research,
- Dementia-friendly Flanders: this encompasses teamwork with other authorities and actors on the ground, including: people with dementia, their carers and their associations and organisations.

The courses for social and healthcare professionals are taught by the Dementia Expertise Centre in Flanders and are commissioned by the Flemish government for health, family and welfare.

The Flemish Alzheimer's Association also provides training to its volunteers and carers.

At the time of printing this book, the Brussels Region was developing an Alzheimer Plan.

2.4 Support for informal carers

At regional level, in Wallonia, the Alzheimer Plan specifically supports carers under Axis 2: improve the quality of life of people with dementia and their carers during the different stages of the disease.

In particular, Objective 3 will seek to ensure the provision of quality information for the people with dementia and their carers and Objective 4 will seek to support informal carers and family members as prime actors in the support of people with dementia.

In addition, the following groups provide support to the carers:

- Family associations,
- Sickness funds,

- NGOs and political groups,
- Ligue Alzheimer ASBL (Alzheimer Cafés, Information sessions, free phone help line, annual conference, Alzheimer Café Day),
- Flemish Alzheimer's Association: family groups for carers and relatives for (young) people with dementia (peer support groups), conferences, free-phone helpline training, World Alzheimer’s Day. The Flanders region is working towards dementia-friendly communities. This region has engaged in team work with authorities and various stakeholders on the ground (people with dementia, their carers, Alzheimer and carers associations).

Ligue Alzheimer in Wallonia created and promoted the concept of dementia-friendly cities “Ville Amie Démence” or “ViADem” (http://www.ville-amie-demence.be/)

In Flanders, the King Baudouin Foundation, the Association for cities and municipalities, and other organisations (such as the Flemish Alzheimer’s Association and the Expertise Centre Dementia Flanders) support dementia-friendly projects.

The organisation also provides trainings (including ‘dementia referent’ trainings), organises meetings where people can talk and exchange experiences and conferences all over Wallonia and Brussels.

2.5 National Alzheimer Association

The National Alzheimer Association of Belgium provides the following services and support

Helpline	✓
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	
Care coordination/Case management	
Home help (cleaning, cooking, shopping)	
Home care (personal hygiene, medication)	
Incontinence help	
Assistive technologies / ICT solutions	
Tele Alarm	
Adaptations to the home	
Meals on wheels	
Counselling	✓
Support groups for people with dementia	
Alzheimer cafes	✓
Respite care at home (sitting service etc)	
Holidays for carers	
Training for informal carers	✓
Support groups for informal carers (peer groups)	✓
Day care	
Residential/Nursing home care	
Palliative care	

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2.7 Acknowledgements

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3 Bulgaria

3.1 Background information

3.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Bulgaria in 2012 as being 109,893. This represents 1.49% of the total population of 7,397,873. The number of people with dementia as a percentage of the population is somewhat lower than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	2,527	1,435	3,962
60 – 64	465	2,507	2,972
65 – 69	3,316	3,334	6,650
70 – 74	4,315	7,293	11,608
75 – 79	7,687	12,889	20,575
80 – 84	10,315	19,551	29,866
85 – 89	6,560	16,778	23,338
90 – 94	2,381	7,364	9,744
95+	284	892	1,177
Total	**37,851**	**72,042**	**109,893**

The number of people effectively diagnosed with dementia is likely to be lower than the above estimate. Again, no official statistical data regarding these numbers are available.

The estimated percentage of residents who have dementia in general/non-specialised residential homes is: 1% in public homes, 10% in private homes. This includes both diagnosed and undiagnosed cases.

In April 2013, the National Health Insurance Agency started to reimburse the costs for Alzheimer's disease medications. In cooperation with the hospitals that diagnose the disease and prescribe medicines, the Alzheimer Bulgaria Association (ABA) has started gathering data. By the end of 2013, it should be possible to have more informed data on the number of people diagnosed with dementia and to make an estimate on the number of people with dementia in Bulgaria.

Until 2006, there were no epidemiological studies in the country. The first study in the country was carried out in 2006-2007 in the Varna region by Assoc. Prof. Ivan Dimitrov, MD. Ph.D. (Dimitrov et al., 2012).

In specialised residential homes, there is 1 nursing staff worker per 20 residents. In general residential homes, there is an estimated 1 nursing staff worker per 30 residents.

In specialised residential homes, there is 1 auxiliary staff worker per 20 residents. In general residential homes, there is an estimated 1 auxiliary staff worker per 25 residents. Depending on the availability of project funds, for home care-the government offers "personal and social assistants" who do not have the qualifications to care for people with dementia.

The ratio of staff to residents in general/non-specialised residential homes is estimated to be 1 nursing staff worker for every 30 residents (including residents who do not have dementia) and 1 nursing staff worker and 1 auxiliary staff worker for every 20 residents in specialised residential homes for people with dementia.

3.1.2 Where people with dementia receive care and support

Place of residence	YES or NO	Estimated number/Additional information
At home (alone)	Yes	An estimate was not possible.
At home (with relatives or close friends)	Yes	There are no official data or statistics. ABA estimates that 98.17% – 98.37% of people with dementia live at home. This includes both diagnosed and undiagnosed cases.
At home (with other people with dementia)	–	There are no official statistics and an estimate was not possible.
In general/non-specialised residential homes	Yes	There are no official statistics. ABA estimates that 5,648 people live in non-specialised public homes for the elderly. Approximately 1% of them have dementia. The association also estimates that some 3,400 people live in non-specialised privately-owned homes for the elderly. Approximately 10% of them have dementia. These percentages include both diagnosed and undiagnosed cases.
In specialised residential homes for people with dementia	Yes	There are no official statistics. ABA estimates that 1% of people with dementia live in specialised residential homes (836 people dispatched over 14 public homes). This only includes diagnosed cases.
In general/non-specialised nursing homes	No	There are no nursing homes in Bulgaria.
In specialised nursing homes for people with dementia	No	There are no nursing homes in Bulgaria.
In hospitals, special wards or medical units	No	These services are not available in Bulgaria.
In psychiatric establishments	Yes	There are no official statistics. ABA estimates that between 0.1% – 0.3% people with dementia are in psychiatric establishments.
Other: residential homes for people with psychiatric disorders	Yes	The organisation estimates that about 0.03% of people with dementia live in public residential homes for people with psychiatric disorders (1,049 people, with about 3% of them having dementia). This includes both diagnosed and undiagnosed cases.

* Note: estimates for the percentage of people with dementia who are housed in private non-specialised residential homes are not based on any statistical data due to lack of any public control over private residential homes.

The Regulation Act on the application of the Social Assistance Act gives a definition of a home for old people with dementia: it is a specialised institution providing a range of services to people with dementia, as established by protocol from a medical consultation commission and/or an expert decision of a territorial/national expert medical commission.

In specialised institutions for old people, including those with dementia, an obligatory evaluation of the needs of every institutionalised disabled person should be made, his/her need of support should be determined, including his/her capability of living in society. An important part of this process consists of including people with dementia as much as possible in the decision-making process concerning the type of care which will be chosen. According to Bulgarian legislation, social services are provided only after exhausting the possibilities offered by community services.

As of May 2013, there are 161 specialised institutions for old people in Bulgaria, with an overall capacity of 11,207 places, which include: 14 homes for older people with dementia with a capacity of 825 places, from which 799 places are occupied; 27 homes for older people with mental retardation with a capacity of 2,207 places; 13 homes for old people with mental disorders with a capacity of 1,049 places; 22 homes for older people with physical disabilities with a capacity of 1,345 places; 4 homes for older people with sensory disorders with a capacity of 133 places; 81 homes for older people with a capacity of 5,648 places. Those placed in homes for older people with dementia account for about 7% of the entire number of people placed in specialised institutions. Being diagnosed with the respective disorder and thus corresponding to the profile of the institution is a pre-requisite.

3.2 Overall organisation of care and support for people with dementia

3.2.1 The overall organisation of care and support

The transition from traditional Bulgarian institutionalised care, to services offered in the community and family environment, mostly consists of increasing the range of services such as day care centres, centres for social rehabilitation and integration, protected housing, and development of the model for providing services in a home environment (personal assistant, social assistant, home assistant, and home social patronage). The efforts of the government in recent years have been directed towards the development of innovative intra-sector services for these people so as to satisfy their social and health service needs.

For the provision of social services within an institution, even for a short period of time, the efforts of the government are geared towards providing more community-based services adjusted to the specific needs of these people. The community social services are of a preventive nature and increase the social inclusion opportunities for people with dementia. The social services system has expanded considerably over the past few years as a result of the reforms directed towards improvement of planning, deinstitutionalisation and the provision of more services in community and family environments.

The policy environment

- Project for a National Strategy for Long-term Care

  In Bulgaria, a project for a National Strategy for Long-term Care is currently being developed. The main goal of this strategy is to create conditions for an independent and worthwhile life for elderly and disabled people by improving access to social services and the quality of these services, expanding the service network in the country, de-institutionalising, as well as encouraging interaction between health services and social services. The strategy outcome should ensure a holistic support for families that take care of disabled and older people. Once the strategy is accepted, an Action Plan will be drawn up, which will include specific projects in the field of long-term care. One of the projects will be geared towards the de-institutionalisation of people from the homes for older people with dementia. The plan will incorporate all necessary measures, amount and sources of financing, including EU Structural funds.

State institutions actively cooperate with non-governmental organisations in designing new approaches for the care of disabled people, including people with dementia, and in providing appropriate conditions for their full inclusion in the life of the community.

- National dementia plan

  The government is currently working on a national dementia plan. The Ministry of Health is talking mostly about people with disabilities instead of people with dementia. ABA wants to establish special programmes for people with dementia which are not covered by the programmes for Personal assistant, Social assistant and Home assistant.

The Ministry of Labour and Social Affairs is preparing a national strategy for long-term care. ABA is also working on the same strategy together with the Ministry of Labour and Social Affairs. ABA's proposal is to establish special programmes for people with dementia. At the same time, coordination is needed for the two documents that will be prepared by the two Ministries.

Supporting legal provisions

1. **Law on Integration of Disabled People (LIDP) and Regulations on the implementation of the Law on Integration of Disabled People.**

The law and regulations are based on the constitutional proposition that disabled people are placed under special protection of the state and society. It is based on the principles of prohibition and prevention of all forms of discrimination due to disabilities.

The Law on Integration of Disabled People (LIDP) clarifies the specific needs as well as the need to employ an individualised approach when choosing an equitable measure.

The Bulgarian legislator has created the necessary mechanisms for guaranteeing the fulfilment of disabled people's right to independence and social integration. Equally, the law forbids manifestations of direct or indirect discrimination towards disabled people.

An essential component of the Law is the evaluation of the disability and the possibility for integration. The disability evaluation is performed by means of a medical expertise as well as a social assessment.

2. **Socio-economic protection**

Part of the national budget is used for investments, rehabilitation and the social integration of disabled people.

The social integration monthly allowance seeks to improve the social status of disabled people. The size of the allowance is calculated as a percentage of the guaranteed minimum income (GMI). The amount of the social integration monthly allowance changes whenever the amount of the GMI changes.

The social integration monthly allowance covers the additional costs for transport services, information and telecommunication services, training, spa and rehabilitation services.

It is calculated on the basis of individual needs, type of disability and disability level or the level of the inability for social adaptation.

The monthly allowance and aid granted by LIDP are free from taxes and fees.

3. Implementation of the Convention on the Rights of Persons with Disabilities

On 26.01.2012 Bulgaria approved a Law on the Ratification of the United Nations Convention on the Rights of Persons with Disabilities. This law provides for additional scope in the areas of protection and discrimination on the basis of 'disability' in all spheres of public life.

An expert group was then set up to prepare a two-year action plan to implement the Law. The plan consists of three phases which respectively encompass the setting up of an expert group for coordinating the execution of the plan, developing concepts for changes and actions pertaining to the ratification of the supplementary protocol (Phase 1); approving changes in the Bulgarian legislation and introducing a coordinating mechanism as well as a mechanism for monitoring the Convention's implementation (Phase 2); increasing the capacity of the structures responsible for implementing the Convention, as well as popularising the Convention among the public (Phase 3).

3.3 Training

3.3.1 Which social and healthcare professionals provide care and support

The following social and healthcare professionals are involved in the provision of care and support to people with dementia in residential care or living at home.

Social or healthcare professional	Involved in the provision of care and support for people with dementia in residential care or at home
Nursing staff	Yes
Auxiliary staff	Yes
Allied health professionals	No
Specialists (e.g. psychiatrists, gerontologists, neurologists)*	No. There are no gerontologists in Bulgaria as a medical profession. There are no medical specialists on the pay-roll in residential homes. Their help is requested on a case-by-case basis. Neurologists determine the diagnosis. After that, care is provided by families and psychiatrists if necessary.
General practitioners*	No
Other:	Yes (certified carers: manager/coordinator, social worker, employment therapist, medical specialist, and psychologist*.)

* In homes for older people with dementia and Family-Type Boarding Centres (FTBC), predetermined specialist posts necessary for the functioning of the social service include manager/coordinator, social worker, employment therapist, medical specialist, and psychologist.

With regard to the specialists who take care of people in specialised institutions and community social services, the standards and criteria for servicing personnel are described in the current legislation.

There are specific specialist posts for each type of service necessary for the functioning of the social service and ensuring the quality of care. Depending on the judgment of the social service manager and/or coordinator, other specialists can also be provided in accordance with the specific needs of the consumers and the social services. The number of medical specialists and 'sanitars' (health officers without any specialised education) in specialised institutions depends on the number of patients who need 24-hour uninterrupted care.

Staff should be prepared to perform the basic principles of the social service in their everyday work: individual support for every patient/resident; acceptance of individual uniqueness and differences; creating a feeling of security and comfort in the home; support in developing the self-sufficiency of patients/residents; participation of patients/residents in communal life to the extent of their needs, interests and resources.

So as to achieve the goals and improve the quality of service-provision, a team of external specialists can be employed part-time, including a psychologist, a social worker, a clinical social worker, a speech therapist, a rehabilitator and others who can contribute their expertise depending on the needs of the person concerned.

3.4 National Alzheimer Association

The Alzheimer Bulgaria Association provides the following services and support:

Helpline	✓
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	✓
Care coordination/Case management	
Home help (cleaning, cooking, shopping)	
Home care (personal hygiene, medication)	
Incontinence help	
Assistive technologies / ICT solutions	
Tele Alarm	
Adaptations to the home	
Meals on wheels	
Counselling	
Support groups for people with dementia	
Alzheimer cafes	
Respite care at home (Sitting service etc)	
Holidays for carers	
Training for carers	
Support groups for carers	✓
Day care	
Residential/Nursing home care	
Palliative care	

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Lazar Lazarov, Deputy – Ministry of Labour and Social Policy

4 *Croatia*

4.1 Background information

4.1.1 Prevalence of dementia

Croatia has no official register of people with dementia. Although Croatia is considered as one of the countries with the oldest populations in Europe, some recent publications state that the prevalence of dementia in Croatia is approximately 80,000 (Mimica and Presečki, 2010a and 2010b).

Alzheimer Europe estimates the number of people with dementia in Croatia in 2012 as being 67,076. This represents 1.53% of the total population of 4,387,376 people. The number of people with dementia as a percentage of the population is comparable to the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	1,484	842	2,326
60 – 64	272	1,348	1,620
65 – 69	1,699	1,645	3,344
70 – 74	2,586	4,381	6,967
75 – 79	4,724	8,381	13,106
80 – 84	5,493	12,420	17,913
85 – 89	2,995	11,280	14,275
90 – 94	922	5,466	6,389
95+	218	918	1,136
Total	**20,394**	**46,682**	**67,076**

4.1.2 Where people with dementia receive care and support

The following table provides estimates from Alzheimer Croatia of the number of people living at home, in various types of residential care and in hospitals or psychiatric institutions.

Place of residence	YES or NO	Estimated number/Additional information
At home (alone)	Yes	5%, all non-diagnosed cases
At home (with relatives or close friends)	Yes	60%, refers mainly to Slavonia and Dalmatia regions.
At home (with other people with dementia)	No	
In general/non-specialised residential homes	Yes	Less than 20%
In specialised residential homes for people with dementia	Yes	Not possible to quantify. There are very few residential homes for people with dementia.
In general/non-specialised nursing homes	Yes	15%
In specialised nursing homes for people with dementia	Yes	Not possible to quantify. There are very few nursing homes for people with dementia.

Place of residence	YES or NO	Estimated number/Additional information
In hospitals, special wards or medical units	No	
In psychiatric establishments	Yes	Not possible to quantify. *See also below.

* The following hospitals operate psychogeriatric wards in Croatia:

- University Psychiatric Hospital Vrapče (99 bed capacity) and Psychiatric Hospital Sv. Ivan (49 beds), both in Zagreb;
- Psychiatric Hospital in Popovača (50 beds), close to Zagreb;
- Psychiatric Hospital in Lopača (90 beds), close to Rijeka.
- Psychiatric Hospitals on island Rab (43 beds) and island Ugljan (126 beds).

These institutions operate both "acute" and "chronic" psychiatric beds, according to patients' needs. The acute beds are for short stays and are associated with higher costs per day. The chronic beds, intended for longer term care, are much cheaper to operate. In spite of the much higher cost of psychogeriatric beds, the Croatian Health Insurance Fund pays the same price per bed for people with dementia and for chronically ill psychiatric patients. This economic constraint is hampering the development of psychogeriatric wards in the entire country.

In general/non-specialised residential homes, approximately 20% of residents have dementia, including undiagnosed cases. In general/non-specialised nursing homes, some 20-30% of residents have dementia, including undiagnosed cases. These percentages are based on Alzheimer Croatia estimates.

The following ratios of staff to residents are for immobilised and partially mobile patients in general/non-specialised residential and nursing homes:

- One specialised nurse for every 100 residents,
- Six nurses for every 50 residents,
- Ten caregivers for every 50 residents,
- One physiotherapist for every 50 residents,
- One social worker for every 100 residents,
- One occupational therapist for every 100 residents.

There are no specialised public residential or nursing homes for people with dementia in Croatia.

4.2 The organisation of care and support for people with dementia

Croatia does not have a national dementia plan or any special provision of care and support for people with dementia.

People who depend on another person for help (e.g. people with advanced stages of diabetes or who are immobilised after severe trauma, CVI, etc.) may apply for support from a social care centre. This is provided at a cost of approximately EUR 30-70 per month, depending on their economic status.

The majority of people with dementia are cared for by their immediate families, especially in the Slavonia and Dalmatia regions. In the central and western regions, people with advanced dementia may be admitted to public nursing homes (non-specialised for dementia) and a few private residential homes.

The public homes have significant shortages of both capacity and staff. Immobilised people with dementia have been admitted to these homes since 2007, but the number of beds is very limited.

During the past few years, new day centres in the capital Zagreb have opened as public residential/non-specialised homes or as health centres. People with dementia with severe psychiatric symptoms and behaviour disorders are admitted to psychogeriatric wards in the larger Croatian psychiatric hospitals.

4.3 Training

There is no official programme for training healthcare professionals to work with people with dementia. There is also no special training for nursing staff, auxiliary staff or allied health professionals that work with people with dementia in residential or home care.

Physicians who have completed a four-year specialisation in internal medicine may also complete a further two-year geriatric specialisation.

There are currently ten psychiatrists working in psychogeriatric wards around the country. They have varying clinical experience in working with patients with dementia but no formal education. There is also a very small number of neurologists who work with and diagnose people with dementia, but this is purely an individual choice - they do not have any formal geriatric medical education.

4.4 Support for informal carers

There is no official support for informal carers. However, carers can get some support through Alzheimer Croatia. This support relies on GPs, neurologists and psychiatrists who voluntarily provide their services to the association. Carers can also receive support from social workers, who provide information about the availability of non-specialised nursing or residential homes.

4.5 National Alzheimer Association

Alzheimer Croatia provides the following services and support:

Helpline	✓
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	✓
Care coordination/Case management	
Home help (cleaning, cooking, shopping)	
Home care (personal hygiene, medication)	
Incontinence help	
Assistive technologies / ICT solutions	

Tele Alarm	
Adaptations to the home	
Meals on wheels	
Counselling	✓
Support groups for people with dementia	✓
Alzheimer cafes	✓
Respite care at home (Sitting service etc.)	
Holidays for carers	
Training for carers	✓
Support groups for carers	✓
Day care	
Residential/Nursing home care	
Palliative care	

Alzheimer Croatia has been helping people with dementia, their families and carers since 1999. The association aims to raise dementia awareness, eliminate stigma and widely disseminate the existence of support services that are available for people with dementia. In addition to the above-mentioned services, Alzheimer Croatia has also organised various lectures and participated in many meetings, conferences and congresses dealing with Alzheimer's disease and other forms of dementia.

In 2012, Alzheimer Croatia organised the 6th Croatian Congress on Alzheimer's disease in Primošten, one of the biggest Alzheimer's disease conferences ever to be held in Croatia. During the past eight years, the association has also organised events to commemorate World Alzheimer's Day on the most popular squares in the centre of the capital Zagreb. (Mimica et al., 2012).

Alzheimer Croatia's work is also recognised internationally: the association is a full member of Alzheimer's Disease International (ADI) since 2006 and of Alzheimer Europe since 2012.

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5 *Cyprus*

5.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Cyprus in 2012 as being 11,250. This represents 1.07% of the total population of 1,047,311. The number of people with dementia as a percentage of the population is lower than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	385	203	588
60 – 64	54	252	307
65 – 69	383	331	714
70 – 74	525	704	1,229
75 – 79	804	1,074	1,877
80 – 84	1,076	1,665	2,741
85 – 89	758	1,561	2,318
90 – 94	294	885	1,180
95+	53	243	296
Total	**4,333**	**6,917**	**11,250**

5.2 National Alzheimer Association

The Cyprus Alzheimer Association provides the following services and support:

Helpline	✓
Information activities (newsletters, publications)	✓
Website	
Awareness campaigns	✓
Legal advice	✓
Care coordination/Case management	✓
Home help (cleaning, cooking, shopping)	✓
Home care (personal hygiene, medication)	✓
Incontinence help	✓
Assistive technologies / ICT solutions	
Tele Alarm	
Adaptations to the home	
Meals on wheels	✓
Counselling	✓
Support groups for people with dementia	✓
Alzheimer cafes	
Respite care at home (Sitting service etc.)	✓
Holidays for carers	
Training for carers	

Support groups for carers	✓
Day care	✓
Residential/Nursing home care	
Palliative care	

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Antigoni Diakou, President of the Cyprus Alzheimer Association

Irene Georgiou, Assistant Director of Clinic/Department of Mental Health Services, Representative of the Mental Health Services to the Committee

Yiannis Kalakoutas, Director of Mental Health Services, President of the Alzheimer Multidisciplinary Committee

6 *Czech Republic*

6.1 Background information

6.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in the Czech Republic in 2012 as being 143,309. This represents 1.36% of the total population of 10,565,678. The number of people with dementia as a percentage of the population is somewhat lower than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	3,763	2,055	5,818
60 – 64	713	3,576	4,289
65 – 69	4,747	4,417	9,164
70 – 74	5,091	8,087	13,178
75 – 79	8,436	14,278	22,714
80 – 84	11,846	25,164	37,009
85 – 89	7,753	25,617	33,370
90 – 94	2,855	12,600	15,455
95+	328	1,984	2,312
Total	**45,532**	**97,778**	**143,309**

It is estimated that the majority of people with dementia have not been diagnosed.

6.1.2 Where people with dementia receive care and support

The following table provides estimates by the Czech Alzheimer Society of the number of people with dementia living at home, in various types of residential care and in hospitals or psychiatric institutions.

Place of residence	YES or NO	Estimated number/Additional information
At home (total)	Yes	100,000
At home (with relatives or close friends)	Yes	Not available
At home (with other people with dementia)	Yes	Not available
In homes for seniors	Yes	25,000
In homes with "special regime" including dementia	Yes	10,000
In specialised nursing homes for people with dementia	No	–
In special hospital wards or units: – Long-term care hospitals – Psychogeriatric departments – Post-acute and aftercare hospitals	Yes	7,000 total, of which: 3,000 2,000 2,000

In total, an estimated 42,000 people with dementia are currently in various types of social care, long-term care and post-acute care institutions.

An estimated 68% of residents in general/non-specialised residential homes have dementia. This is based on a Czech Alzheimer Society survey of eight such establishments.

There is no information available about the ratio of staff to residents in social care institutions.

32,000 people with dementia were treated in outpatient care facilities in 2011 (UZIS - Czech Institute of Health Information and Statistics, 2012).

8,493 people with dementia diagnoses were hospitalised in 2011, including all hospitals, "nursing homes" and psychiatric units (UZIS - Czech Institute of Health Information and Statistics, 2012).

6.2 The organisation of care and support for people with dementia

There are three levels of government: the parliament, the regions and the municipalities.

The parliament enacts legislation and the 14 Czech regions are responsible for registering healthcare and social care providers. Both public and private providers receive funding from the general health insurance system. This funding is based on tenders: the Ministry of Health organises tenders for hospitals and other types of in-patient care, while the regions organise tenders for other care providers. Czech municipalities do not play a role in health and social care provision.

There is a draft Czech Alzheimer plan for 2014–2017 but it is not official. As a result, there are very few specific provisions for the care and support of people with dementia.

However, people with dementia and their family caregivers can use social services, even without a formal dementia diagnosis. They can get personal assistance, home respite care, consulting and day care centre or residential home services for elderly and specialised residential homes. There is a care allowance, which, to some extent, promotes the acceptance of people with a greater need of help to the social facility. This allowance is automatically paid to the social facility that provides care.

All social services, irrespective of the founder (city, county, religious, NGO, private), may apply for a grant. Grants are given on a regional basis as a redistribution of state resources. Grants can only be obtained by social services that are registered with the regional government. Clients of these services must co-pay to use the service, up to a limit defined by law.

People with dementia have full access to healthcare. In theory, GPs are meant to act as gatekeepers but their recommendations are not always needed or sought. It is possible to see a specialist without prior referral and people with dementia can be treated by neurologists, psychiatrists and geriatricians.

Within the healthcare system, there are currently long-term care hospitals or departments, and in psychogeriatric departments that provide long-stays of "healthcare type".

In the social care system there are two types of homes for seniors, namely those for people with severe disabilities and homes with a “special regime” for people with chronic health conditions including dementia. Despite the fact that the health status of these people is often very complex, healthcare issues – according to the Social Services Act – are not part of the formal system of quality control in these institutions.

People with special needs may move into a residential home or a home with special regime. Residents at these homes have to pay for their accommodation and “mandatory” services that include food and assistance with activities of daily living. These two items will generally consume their entire care allowance and up to 85% of their pension. Healthcare, drug co-payments and other services are paid for separately by residents. Municipalities are responsible for hiring and paying staff that includes care workers, social workers and others. Some homes also employ medical staff such as nurses or physiotherapists, but this is not required by law.

There are very few private care homes and the quality of their services is very often questionable.

The system of long-term care provision in the Czech Republic is very fragmented and thus difficult to describe as a whole. The main problem is the separation and discontinuity of healthcare and social care services. Social care services do not consider the complex health needs of residents, while healthcare services do not reflect the fact that some health conditions are long-term and patients with these conditions need continuous healthcare and long-term care and support. This problem will likely persist even after legislative changes that are currently being envisaged.

6.3 Training

6.3.1 Which social and healthcare professionals provide care and support

The following social and healthcare professionals are involved in the provision of care and support to people with dementia in residential care. However, in some cases there are currently very few such professionals.

Social or healthcare professional	Involved in the provision of care and support to people with dementia in residential care
Nursing staff	Yes
Auxiliary staff	Yes
Allied health professionals	Yes
Specialists (e.g. psychiatrists, gerontologists, neurologists)*	No
General practitioners*	No
Other	Yes (Physiotherapists, occupational therapists)

* Only if they are linked to the provision and organisation of care and support (i.e. not with regard to their role to provide medical treatment).

6.3.2 The type of training that social and healthcare professionals receive

There is currently no official dementia-specific training for nursing staff, auxiliary staff or allied health professionals that work in residential or home care. However, there are some educational programmes accredited by the Ministry of Social Affairs.

6.3.3 How the training of social and healthcare professionals is addressed

There is currently no official dementia-specific training for social and healthcare professionals.

The Ministry of Education, Youth and Sports is responsible for setting standards for educating and training physicians towards their first degrees. University medical studies consist of six years of study.

The Ministry complies with European Directive 36/2005/EC, which sets conditions for obtaining and recognising medical degrees and specialised postgraduate training for physicians and non-physician health professionals.

Medical school graduates must complete an accredited training programme in a selected medical specialty and pass a state licensing exam in order to be allowed to work independently as physicians. Similarly, nurses must complete an accredited Bachelor's degree programme and may also obtain specialisations (Bryndová L., et al., 2009).

6.4 Support for informal carers

There is no official support for informal carers in the Czech Republic. They have access to personal assistance, home respite care and similar services, but in reality these services are rare or non-existent.

6.5 National Alzheimer Association

The Czech Alzheimer Association offers the following services and support.

Helpline	✓
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	
Care coordination/Case management	
Home help (cleaning, cooking, shopping)	
Home care (personal hygiene, medication)	
Incontinence help	
Assistive technologies / ICT solutions	
Tele Alarm	
Adaptations to the home	
Meals on wheels	
Counselling	✓
Support groups for people with dementia	✓
Alzheimer cafes	
Respite care at home (Sitting service etc)	✓
Holidays for carers	
Training for carers	
Support groups for carers	✓
Day care	
Residential/Nursing home care	
Palliative care	

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6.7 Acknowledgements

Martina Mátlová, Executive Vice President, Česká alzheimerovská společnost (Czech Alzheimer's Society)

7 Denmark

7.1 Background information

7.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Denmark in 2012 as being 85,562. This represents 1.53% of the total population of 5,592,738. The number of people with dementia as a percentage of the population is quite similar to the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	1,805	1,004	2,809
60 - 64	361	1,652	2,014
65 – 69	2,928	2,367	5,295
70 – 74	3,635	4,765	8,401
75 – 79	5,201	6,940	12,141
80 – 84	6,970	11,349	18,319
85 – 89	5,441	13,709	19,150
90 – 94	2,756	10,554	13,310
95+	618	3,506	4,124
Total	**29,715**	**55,847**	**85,562**

The number of people with dementia in Denmark is not known exactly. Denmark has a register, where each person has a unique number. The number, called the "personnumber", is needed for a lot of things (e.g. to consult a general practitioner). Every time a person goes to hospital for treatment or tests, the final diagnosis has to be registered. However, the only way to gain access to the register is to be involved in a scientific project. In 2003, a scientific study based on the register found that around two thirds of the estimated number of people with dementia had been diagnosed.

Although it is not currently possible to provide more precise data, we do know that only a proportion of those diagnosed with dementia have been through a proper investigation to establish the diagnosis.

7.1.2 Where people with dementia receive care and support

The following table provides estimates of the number of people with dementia living at home, in various types of residential care and in hospitals or psychiatric institutions.

Place of residence	YES or NO	Estimated number/Additional information
At home (alone)	Yes	Not known
At home (with relatives or close friends)	Yes	
At home (with other people with dementia)	Yes	
In general/non-specialised residential homes	Yes*	

Place of residence	YES or NO	Estimated number/Additional information
In specialised residential homes for people with dementia	*	
In general/non-specialised nursing homes	*	
In specialised nursing homes for people with dementia	*	
In hospitals, special wards or medical units	No	
In psychiatric establishments	Yes	

* In Denmark, no distinction is made between residential homes and nursing homes.

The percentage of residents in nursing homes who have dementia is not known but it is estimated to be around 85%. This figure seems to have been increasing over the years.

The ratio of staff to residents in nursing homes is about 0.75 (i.e. 1:1.3), sometimes slightly higher (e.g. if the percentage of people with dementia in a particular home is higher than usual).

7.2 The organisation of care and support for people with dementia

7.2.1 The overall organisation of care and support

Denmark has three levels of government:

1. The parliament and the ministries who make the overall laws.
2. Five regions with responsibility for running the hospitals and for general practitioners, who are private but have an agreement with the regions on how to work. They are paid by the regions.
3. 98 local municipalities which are responsible for homecare, care homes, home nursing and rehabilitation.

If a person needs to go into a care home, they move into their own flat in a complex called a "care centre". They then have to pay their own rent and also for food, medicine, washing and electricity. If they are in need, they can be reimbursed for some of the rent. The municipalities are responsible for, and pay for, the staff (e.g. nurses, social and health assistants and helpers). The need to go into a care home is assessed by the authorities in the person's local municipality.

The municipalities offer three different levels of care. People who live at home can receive:

1. Homecare in the form of a fixed number of hours per week/day. For example, this might include help getting washed and dressed, help getting in and out of bed and help with medicine.
2. "24-hour care" in their own home, which means that they can receive help several times during the day and it is also possible to receive visits at night.
3. If this kind of care isn't sufficient, a person can move into a flat in a "care centre". The centre offers 24-hour care by trained staff.

Some care centres have a smaller part of the centre with flats for people with severe dementia, but they are becoming fewer as most of those who need a placement in a care centre have dementia.

Care homes (i.e. in the care centres) are the only kind of institutionalised care available unless a person needs psychiatric care, in which case they would have to go to a specialised psychiatric nursing home.

There are very few private care homes.

7.2.2 How specific aspects of care and support are addressed

Provisions relating to the care and support of people with dementia are covered in some national policies.

Standards of care and support

All of the five regions in Denmark have now implemented "a case management protocol" which stipulates which action should be taken, starting from the patient's first meeting with the doctor up to interaction with the municipalities. This protocol emphasises the importance of a proper diagnosis and stipulates how support should be provided to patients and carers through the disease.

In care homes/residential homes there are rules about what should be included in the patient's record.

Controlling and monitoring care and support

Every other year, or yearly if necessary, the Danish Health and Medicines Authority inspects the care centre in order to ensure that the rules are followed.

Continuity of care and support

Issues related to the continuity of care and support are addressed in the above-mentioned "case management protocol".

Interdisciplinary cooperation and coordination

Issues related to Interdisciplinary cooperation and coordination are addressed in the above mentioned "case management protocol".

Needs assessments (e.g. ensuring that it is timely, fair and appropriate)

In order to obtain home care or a flat in a care centre, a person must apply to the authorities in the municipalities. The application is assessed by a social worker or a "dementia coordinator". There are general rules about how to obtain financial and other support from the municipalities. If the person does not choose a specific care centre, they should not have to wait more than two months to have a flat in a care centre offered to them.

Staffing levels

There are no specific regulations on staffing levels, except that there has to be enough staff to meet the needs of the people who live in the care centre. Similarly, there are no specifications from the government concerning the kinds of qualifications that staff ought to have. The politicians at the level of the municipalities are responsible for ensuring adequate staffing levels.

Research into care and support

Research into care and support is carried out, mainly in the form of projects. The costs are covered by grants from the government based on individual applications or private funds. A certain amount of money is set aside every year to this kind of research in the national financial budget. It may, for example, be allocated to research into "old age problems" and people with an interest in dementia can apply for it.

Funding and control bodies

There are minimum standards for how big the flat in a care centre must be. As staff members very often have to help the person with dementia in the bathroom, there are also minimum requirements for the size of the bathroom. Every flat has to be equipped with a kitchen/kitchenette. The municipalities are responsible for this and have to make sure that the flats meet these requirements.

The standard of the flats and of the care provided is controlled by The Danish Health and Medicines Authority.

Complaint procedures

There is a complaints procedure whereby complaints about decisions made by the municipalities can be lodged in the first instance to the municipality itself. If the decision is upheld, the municipality has to send the complaint on to an independent body, which makes the final decision.

Respecting individuality and cultural diversity

People with dementia who have rented a flat in a care centre can decide which furniture and decorations they would like to bring with them. However, there are certain limitations as the flat is also the workplace of the staff and the bed is provided by the care centre, as it has to be a special bed. This specific issue is covered by legislation on the Protection of the Workforce (Arbejdsmiljøloven). Special eating habits are respected. This is covered by the rules of individual care centres.

Involving people with dementia in decisions about care and support

No one in Denmark can be treated or cared for without informed consent, or through the use of force. If the person with dementia does not have the capacity to make a particular decision, a close relative can decide on his/her behalf. Under certain circumstances, the use of force is possible. It must be absolutely necessary and the prior authorisation from the authorities in the municipality must have been obtained. This does not apply to medical treatment. It is covered by Act No. 81 on Social Services of 4 February 2011,

7.3 Training

7.3.1 Which social and healthcare professionals provide care and support

The following social and healthcare professionals are involved in the provision of care and support to people with dementia in residential care or living at home.

Social or healthcare professional	Involved in the provision of care and support to people with dementia in residential care or at home
Nursing staff	Yes (also auxiliary nurses called "social and health assistants")
Auxiliary staff	Yes (e.g. social and health helpers and people with no training at all, especially during holiday periods, as well as cooks and cleaners etc.)
Allied health professionals	Yes (see below)
Specialists (e.g. psychiatrists, gerontologists, neurologists)*	No
General practitioners*	Yes (in some areas to educate staff)
Other	Yes (dementia coordinators)

* Only if they are linked to the provision and organisation of care and support (i.e. not with regard to their role to provide medical treatment).

Trained nurses have a three-year Bachelor's degree, usually with a special interest in elderly care, but are not necessarily trained in geriatric nursing. Only 4.7% of staff members in residential care are trained nurses. Nurses with special training in dementia are employed by the municipalities to supervise home care and to help families to cope with care. They also work as consultants in care centres (residential care). These nurses are often called "Dementiacoordinators" (*see more below) as they help people with dementia and their carers to obtain coordinated support.

There are also auxiliary nurses, who are called "social and health assistants". They must first train to become a "social-and health helper" (see below for details) before they can become a social and health assistant. The additional training to become an assistant consists of 1 year bedside and 8 months' theoretical education. Around 32% of staff have this education. The education is not a Bachelor's degree but at the end of the course students obtain an authorisation to work independently. Those who wish to study further can go on to study for a Bachelor's degree in nursing.

There are different kinds of auxiliary staff who are involved in providing care for people with dementia in residential and home care. "Social and health helpers" have 14 months of education: 6 months at a school and 8 months' "bedside" learning. These helpers account for about 62% of staff. There are also quite a lot of people with no training at all, especially during vacation periods, as well as kitchen personnel and cleaners etc.

With regard to allied health professionals, some care centres employ physiotherapists, occupational therapists (in charge of activities etc.), social education workers, and dieticians.

Dementia coordinators/consultants have no specific education. Some are nurses by profession whereas others have knowledge about dementia at an administrative level.

As an experiment, general practitioners have been employed in five different municipalities to educate staff and to be GPs for the people living in in the care centre.

7.3.2 The type of training that social and healthcare professionals receive

Training in/knowledge about dementia is not part of the compulsory curriculum for nurses but relevant courses can be selected. For auxiliary staff, there is the training for social and health helpers which from 2013 onwards also includes information about dementia.

7.3.3 How the training of social and healthcare professionals is addressed

The training of social and healthcare professionals is addressed in national policies. From 2013 onwards, the curriculum for social and health helpers must include one week of training about dementia.

7.4 Support for informal carers

7.4.1 Respite

The municipalities are obliged to offer possibilities either for the person with dementia to go into a care home for a short period of time or to provide someone to go into the person's home to look after him or her while the daily carer does other things. However, the amount of respite that the municipalities have to offer is not stipulated. It is assessed individually, based on each person and each situation. It can thus vary from one municipality to another.

7.4.2 Training

According to the "case management protocol", there is a joint obligation for the memory clinic and the local authorities to offer basic education for carers. Basic education comprises some knowledge about dementia-related diseases such as symptoms of cognitive decline, medical treatment, how to understand the symptoms, legal matters and where to get help. Not all municipalities and localities have memory clinics but they are all connected to one specific memory clinic. The memory clinics are operated by the regions.

7.4.3 Consultation/involvement in care decisions

Carers are involved in care decisions only if the person with dementia can no longer make informed decisions. In such cases, carers are entitled to make decisions on behalf of the person with dementia. An assessment of capacity must be carried out each time that a decision needs to be made and in case of incapacity, this must be noted in the person's medical file. However, in cases where the use of force is being considered, a legally-appointed decision maker must be consulted in accordance with Act no. 81 on Social Services.

7.4.4 Counselling/support

All of the 98 municipalities have employed dementia nurses, dementia coordinators or dementia consultants. Whatever they are called, their main task is to educate, counsel and support carers. They also go into care centres to counsel the staff in difficult cases.

7.4.5 Case management (insofar as this relates to care)

Please see above

7.5 National Alzheimer Association

The Danish Alzheimer Association (Alzheimerforeningen) provides the following services and support.

Helpline	✓
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	
Care coordination/Case management	
Home help (cleaning, cooking, shopping)	
Home care (personal hygiene, medication)	
Incontinence help	
Assistive technologies / ICT solutions	
Tele Alarm	
Adaptations to the home	
Meals on wheels	
Counselling	✓
Support groups for people with dementia	✓
Alzheimer cafes	✓
Respite care at home (Sitting service etc)	
Holidays for carers	✓
Training for carers	✓
Support groups for carers	✓
Day care	
Residential/Nursing home care	
Palliative care	

7.6 Acknowledgements

Anne Arndal, Chairperson, Alzheimerforeningen (Danish Alzheimer Society)

8 Estonia

8.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Estonia in 2012 as being 21,720. This represents 1.62% of the total population of 1,339,762. The number of people with dementia as a percentage of the population is slightly higher than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	417	256	673
60 – 64	65	405	470
65 – 69	446	531	977
70 – 74	679	1,457	2,136
75 – 79	1,133	2,587	3,721
80 – 84	1,419	4,112	5,532
85 – 89	912	4,161	5,073
90 – 94	312	2,145	2,457
95+	85	597	681
Total	**5,469**	**16,252**	**21,720**

9 *Finland*

9.1 Background information

9.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Finland in 2012 as being 92,232. This represents 1.71% of the total population of 5,402,627. The number of people with dementia as a percentage of the population is somewhat higher than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	1,717	944	2,661
60 – 64	395	1,855	2,250
65 – 69	2,748	2,321	5,069
70 – 74	3,270	4,664	7,935
75 – 79	5,431	8,062	13,493
80 – 84	7,572	14,557	22,129
85 – 89	5,459	16,956	22,414
90 – 94	2,272	10,866	13,139
95+	421	2,721	3,141
Total	**29,287**	**62,945**	**92,232**

9.1.2 Where people with dementia receive care and support

The following table provides estimates of the number of people with dementia living at home, in various types of residential care and in hospitals or psychiatric institutions.

Place of residence	YES or NO	Estimated number/ Additional information
At home (alone)	Yes	Estimated 25–40% (incl. non-diagnosed cases)
At home (with relatives or close friends)	Yes	Estimated 20–30% (incl. the non-diagnosed cases)
At home (with other people with dementia)	Possibly	Not known but undoubtedly very rare
In general/non-specialised residential homes	Yes	8.7% based on health care statistics(*)
In specialised residential homes for people with dementia	Yes	Included in the above statistics
In general/non-specialised nursing homes	Yes	6.1% based on health care statistics(*)
In specialised nursing homes for people with dementia	Yes	Included in the above statistics
In hospitals, special wards or medical units	Yes	6.4% based on health care statistics(*)
In psychiatric establishments	No	People with a memory illness do not live in psychiatric establishments but there may be rare and usually temporary exceptions.

* Data from National Institute for Health and Welfare 2009. The statistics show living arrangements of the 36,000 people with a memory illness diagnoses in hospitals, residential care and home care.

Thus majority of the estimated 130,000 people with memory illnesses are not included in this data either because they live at home or because their memory illnesses is not the primary reason for residency or care.

According to statistics from the National Institute for Health and Welfare (2009), 12.5% of residents in general/non-specialised residential homes (i.e. where staff are only available during the day) have dementia compared to 39.6% of residents in residential homes with staff available throughout the day and night.

Of all the people living in long-term care (residential homes and nursing homes combined), 80-85% have a memory illness. In nursing homes, this may be even 90% (source not known). As people with mild cognitive impairment might be included in these figures, a more cautious figure would be 46.3% (National Institute for Health and Welfare, 2009).

The National Framework for High-Quality Services for Older People (Ministry of Social Affairs and Health, 2008) requires that the ratio of staff to residents should be at least between 1: 2 and 1:1.67 and preferably between 1:1.43 and 1:1.25 – depending on the residents and their (medical) needs.

It is not mandatory to follow the framework. During the preparation of the new "Act on Supporting the Functional Capacity of the Older Population and on Social and Health Services for Older Persons" (from 1 July 2013), there was debate about whether or not to include regulations for a sufficient staff-ratio and it was eventually left out. The law states that every establishment must have an adequate staff-ratio that correlates with the number of residents and their ability to function, and ensures the quality of services provided. If these requirements are not fulfilled by the end of 2014, adjustments to the law will be made.

9.2 The organisation of care and support for people with dementia

9.2.1 The overall organisation of care and support

Informal carers provide a great deal of care for people with dementia but society holds the biggest and ultimate responsibility for caregiving and rehabilitation. Living at home as long as possible is an aim, but often people with a memory illness move to a long-term care establishment in the moderate or severe stages of the disease at the latest. This is commonly preceded by periods of short-term care, often in "intervals" (for example in two-week periods). The aim is to provide care facilities that are "homely", but the reality is that still too many people end up in a hospital bed in the late stages of the disease.

The need to move into assisted living or institutional care is determined by municipal social services based on their own, the doctor's and the person's own / closed-one's assessments. The wellbeing of the informal caregiver is usually the main focus and often defines the point at which the person with a memory illness moves into long-term care.

The need for broad range of rehabilitation services is stated in professional guidelines and national development programmes, but resources are still too scarce.

Every person's right to an evaluation of their need for services is specified in the Act on Supporting the Functional Capacity of the Older Population and on Social and Health Services for Older Persons (from 1 July 2013). Expert recommendations and guidelines (for example the Current Care Guidelines) state that every person with a memory illness is entitled to an up-to-date care and rehabilitation plan.

The care and rehabilitation of people with memory illnesses is organised by various service providers, including municipalities and federations of municipalities (public social and health care including home care, care homes and rehabilitation) implemented with government support, hospital districts (information and guidance about rehabilitation) and Kela (an independent social security institution offering rehabilitation). In addition, Finland has a wide range of social welfare and healthcare organisations, providing services both free of charge and for a fee.

The cost of the services varies depending on the need for attendance, but society supports care and rehabilitation and only a fraction of the cost is borne by the person with a memory illness or his/her family. There are municipal and privately owned care homes but both are financially supported by the municipality. The variety of services is even wider if purchased directly from private service providers and/or using service vouchers, which many municipalities grant for social and health services.

The cost of long-term care depends on the facilities and the services provided. The cost of assisted living consists of the rent and every additional service the resident uses/needs. Institutional care is more expensive but usually includes every possible service including food, medicine and round-the-clock care.

9.2.2 How specific aspects of care and support are addressed

Care and support of people with dementia are addressed in national policies as follows:

Standards of care and support

The National Framework for High-Quality Services for Older People (2008) defines the values and ethical principles guiding the provision of services for older people. It also outlines strategies for boosting quality and effectiveness in three dimensions: (1) promoting health and welfare and developing the service structure, (2) staffing levels and staff skills and management, and (3) old-age living and care environments. Following the framework is not mandatory.

The Finnish Medical Association, Duodecim, develops and updates Current Care Guidelines which are national, evidence-based clinical practice guidelines in support of health care decision making and for the benefit of the patient. The Guideline for Memory diseases was published in 2006 and updated in 2010. It covers the standards of diagnostics and care for people with memory diseases.

Controlling and monitoring care and support

According to the National Memory Programme the local authorities and joint authorities will be responsible for procuring 24-hour care for the patients in a manner that ensures that the rights of people with dementia are guaranteed and that the chosen service providers have sufficient know-how for the treatment of people with dementia.

The National Framework for High-Quality Services for Older People instructs that The National Institute for Health and Welfare provides indicators for monitoring and comparing promotion of health and welfare, service needs, service structures and finances.

Continuity of care and support

The service system in Finland is based on units offering different levels of care and support. In this model the patient has to change location when her/his needs of care and support change. These problems in the continuity of care have been identified in the National Memory Programme and the local authorities are urged to avoid unnecessarily moving residents.

One of the objectives in The National Memory Programme is to reduce the amount of residential care and to increase the availability of treatment alternatives based on housing and personalised services.

Interdisciplinary cooperation and coordination

The efficient clinical pathways, which combine social welfare, primary health care, specialist medical care and rehabilitation services in a seamless bundle, are one target in the Memory Programme and the local authorities are urged to create them.

Needs assessments (e.g. ensuring that it is timely, fair and appropriate)

The case worker coordinating care and support is mentioned in The National Memory Programme as a key factor of cost-effective support that meets the needs of the person with a memory illness and his/her family.

The recently approved Act on Supporting the Functional Capacity of the Older Population and on Social and Health Services for Older Persons" (from 1 July 2013) states that local authorities are responsible for assessing the need for services to support wellbeing, health, functioning and autonomy of each older citizen when s/he demands it.

Facilitating access to care and support

The National Memory Programme states primary health care providers responsible for both treatment and follow-up of the people with cognitive disorders. It highlights the importance of the case management as a means of ensuring that patients and their families have access to as much information as possible about the services available from the public sector, the private sector and the third sector.

In addition to the primary health care providers, the occupational health care providers (which provide services to the working population) are responsible to detecting memory illnesses and referring patients to further examinations and care.

Staffing levels

The National Framework for High-Quality Services for Older People gives recommendations about staffing levels in home care and in 24-hour care. It states that the strategic guidelines of the staff should be incorporated into the local old-age strategies and integrated into the personnel strategies.

Research into care and support

The National Memory Programme identifies The National Institute for Health and Welfare, universities and other research organisations as responsible for producing information about services used by people with memory illness, the quality of those services, the effectiveness and quality of clinical pathways as well as costs. Information about best practices and the current situation is also needed to support the development work carried out by local authorities and joint authorities.

Funding and control bodies

The following table provides details of the responsibilities of the social welfare and health care system in Finland (gathered and published by Ministry of Social Affairs and Health).

Guidance	Licences and monitoring	Provision
Ministry of Social Affairs and Health • Prepares legislation and guides its implementation • Directs and guides the development of social welfare and health care services, and social welfare and health care policy • Defines social welfare and health care policy guidelines, prepares key reforms and guides their implementation and coordination • Is responsible for links with political decision-making	**Regional State Administrative Agencies** Guide and monitor municipal and private social welfare and health care services and evaluate the availability and quality of basic services provided by municipalities. They grant licences to private service providers in the region. **National Supervisory Authority for Welfare and Health Valvira** Guides, monitors and manages the administration of licences for the social welfare and healthcare sector, alcohol administration and environmental health and protection.	**Municipalities, private service providers and organisations** Municipalities are responsible for organising social welfare and health care. They can provide basic social welfare and health care services alone, or form joint municipal authorities with other municipalities. Municipalities may also purchase social welfare and health care services from other municipalities, organisations or private service providers. Hospital districts organise specialised medical care. Some specialised medical care services are organised on the basis of special responsibility areas of university hospitals.

In addition to the above, the work of the third sector (the Memory Society and its 43 associations) is mainly funded by Finland's Slot Machine Association (RAY).

Communication skills with patients

One of the four main targets of the National Memory Programme is to make the public and professionals' attitudes towards memory disorders and people with the disorders more positive. It is hoped that this change in attitudes will improve interaction and communication with the people with memory disorders.

Complaint procedures

The Act on Supporting the Functional Capacity of the Older Population and on Social and Health Services for Older Persons" (from 1 July 2013) instructs each residential care unit and home care unit to monitor its' own work in relation to the quality of services, safety and overall functioning. The older people and their relatives have the right to appeal to patients' and social ombudsmen if they have complaints about the services (based on the Act on the Status and Rights of Patients and The Act on the Status and Rights of Social Welfare Clients). When the complaints cannot be solved within the unit, it is possible to appeal to a supervisory body.

Promoting well-being and autonomy

Rehabilitation services are mentioned in the Memory Programme as tools to increase the quality of life and optimise the functional capacity of the people with dementia living in home or in residential care. Rehabilitation needs to be seen as a goal-oriented form of care and a specialist branch of medicine in its own right.

The National Memory Programme recognises the high-quality living aids and information technology as means to promote the safe, full and active life of people with dementia.

Respecting individuality and cultural diversity

The National Memory Programme identifies the need for personalised palliative care plans and clear documentation to support them.

Finland has two national languages (Finnish and Swedish), and citizens are entitled to use both of them.

The laws and frameworks highlight the importance of offering adequate services of a high quality. The issues of individuality and cultural diversity arise from this idea, but are not clearly stated in the documents.

Involving people with dementia in decisions about care and support

At local level municipalities are required to maintain council of the elderly which keep track of the services for elderly citizen in general level.

The National Memory Programme emphasizes the rights of people with dementia. Involvement to their own care and support is not mentioned as itself but should be incorporated to the set of rights.

Other

Attitudes towards people with memory disorders are given a significant importance in the Finnish National Memory Programme. What is needed is an attitude check to allow people with cognitive problems and dementia to be included in society on equal terms with others, to lead a full and active life and to have timely access to the support, treatment and care that they need to enable rehabilitation.

9.3 Training

9.3.1 Which social and healthcare professionals provide care and support

The following social and healthcare professionals are involved in the provision of care and support to people with dementia in residential care or living at home.

Social or healthcare professional	Involved in the provision of care and support to people with dementia in residential care or at home
Nursing staff	Yes
Auxiliary staff	Yes
Allied health professionals	Yes
Specialists (e.g. psychiatrists, gerontologists, neurologists)*	No
General practitioners*	No

* Only if they are linked to the provision and organisation of care and support (i.e. not with regard to their role to provide medical treatment).

Nurses (with a Bachelor's degree) and licenced practical nurses (auxiliary nurses) (with a vocational degree) work in both residential and home care. They work independently but medical care is under the authority of doctors. Nurses may administer medical treatment and procedures, whereas practical nurses help with daily living, like hygiene and monitoring clients' condition. Practical nurses may also have a licence to administer medicine. These professions and their rights are regulated by law and supervised by Valvira, the National Supervisory Authority for Welfare and Health (which operates under the Ministry of Social Affairs and Health).

Auxiliary staff work in both residential care and in home care, preparing and delivering meals, cleaning, helping with simple acts of daily living etc. They usually have no medical or care training.

Physiotherapists (with a Bachelor's degree) and occupational therapists (with a Bachelor's degree) work both in the residential and home care setting, but not in every establishment. The people in home care can be referred to see speech and language therapists (with a Master's degree), dieticians (with a Master's degree) and podiatrists (with a vocational degree). Majority of the people in the home care does not use these services.

Professionals who have a Bachelor of Social Services or a Bachelor of Elderly Care work irregularly in residential care. They may have a licence to administer medicine, if properly trained.

9.3.2 The type of training that social and healthcare professionals receive

Basic information about dementia is a small or moderate part of the training of nurses and part of elderly care studies. Auxiliary staffs' theoretical and practical training includes modules in dementia and dementia care. For social sector professionals and for allied health professionals (e.g. language therapists, physiotherapists, dieticians, podiatrists), basic information about dementia might be a small or moderate part of their training, if they specialise in the care of older people. There is a range of courses in the context of continuing education for memory nurses.

9.3.3 How the training of social and healthcare professionals is addressed

The National Memory Programme sets goals with regard to the training of social and healthcare professionals. It states that education authorities and organisations should pay particular attention to ensuring that basic, further and supplementary social welfare and health care training includes enough elements aimed at promoting brain health, detecting memory disorders in their early stages, treating and rehabilitating patients, providing palliative and end-of-life care and supporting people with dementia and their families.

We do not currently have systematic criteria for the training of professionals in all levels of education in dementia care in Finland. According to the National Memory Programme, national targets should be agreed for the skills that professionals (such as nurses and coordinators) working with individuals with memory disorders and dementia must have.

9.4 Support for informal carers

Support for informal carers is addressed in national policies.

9.4.1 Respite

The Act on Support for Informal Care has been in effect since 2006 In Finland. Based on the Act, carers, who have made an agreement on support for informal care with municipalities, are entitled to at least three days of leave during the months, in which the carer is bound to providing around-the-clock care.

9.4.2 Training

Based on the Act on Support for Informal Care, when a carer and municipality make an signed agreement on support for informal care, a care and service plan must be attached to this contract. Necessary services for the care receiver, care allowance and leave for the carer, and services that support informal care such as training should always be defined in a care and service plan.

9.4.3 Consultation/involvement in care decisions

Based on the Act on the Status and Rights of Patients if a patient because of mental disturbance or mental retardation or for other reason cannot decide on the treatment given to him/her, the legal representative or a family member or other close person of the patient has to be heard before making an important decision concerning treatment to assess what kind of treatment would be in accordance with the patient's will.

9.4.4 Counselling/support

Based on the Social Welfare Act and the new Act on Care Services for the Elderly, municipalities are obligated to organize guidance and counselling on social welfare benefits and other forms of social security and their use.

9.4.5 Case management (insofar as this relates to care)

Based on the Social Welfare Act and the new Act on Care Services for the Elderly, municipalities are obligated to organize guidance and counselling on social welfare benefits and other forms of social security and their use.

9.4.6 Other

There is a working group preparing a national developmental plan for informal care, which was set up by the Ministry of Social Affairs and Health and will run until the end of 2013.

Information could be added here about what the Finnish Association does, in addition to national policies, to support carers and people with dementia.

9.5 National Alzheimer Association

The Alzheimer Society of Finland (Muistiliitto) provides the following services and support.

Helpline	✓
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	✓
Care coordination/Case management	
Home help (cleaning, cooking, shopping)	
Home care (personal hygiene, medication)	
Incontinence help	
Assistive technologies / ICT solutions	
Tele Alarm	
Adaptations to the home	
Meals on wheels	
Counselling	✓
Support groups for people with dementia	✓
Alzheimer cafes	✓
Respite care at home (Sitting service etc)	✓
Holidays for carers	✓
Training for carers	✓
Support groups for carers	✓
Day care	✓
Residential/Nursing home care	✓
Palliative care	

9.6 References

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9.7 Acknowledgements

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10 France

10.1 Background information

10.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in France in 2012 as being 1,174,956. This represents 1.85% of the total population of 63,457,777. The number of people with dementia as a percentage of the population is somewhat higher than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	19,740	11,368	31,108
60 – 64	3,869	18,585	22,454
65 – 69	25,951	21,861	47,811
70 – 74	33,783	47,147	80,930
75 – 79	64,953	94,912	159,865
80 – 84	98,525	178,698	277,224
85 – 89	82,948	228,798	311,746
90 – 94	39,487	152,321	191,808
95+	6,587	45,424	52,010
Total	**375,843**	**799,113**	**1,174,956**

Out of an estimated 850,000 people who had dementia in France in 2004, 50% had not been diagnosed (OPEPS, 2005).

10.1.2 Where people with dementia receive care and support

The following table provides estimates of the number of people with dementia living at home, in various types of residential care and in hospitals or psychiatric institutions.

Place of residence	YES or NO	Estimated number/Additional information
At home (alone)	Yes	60% of all people with dementia live at home (alone, with relatives or close friends or with other people with dementia). This includes non-diagnosed cases (OPEPS, 2005).
At home (with relatives or close friends)	Yes	
At home (with other people with dementia)	Yes	
In general/non-specialised residential homes	Yes	40% of all people with dementia live in residential care (USLD, EHPAD, maisons de retraite, logements-foyers, petites unités de vie, centres d'hébergement temporaires) (OPEPS, 2005).
In specialised residential homes for people with dementia	Yes	
In general/non-specialised nursing homes	Yes	

Place of residence	YES or NO	Estimated number/Additional information
In specialised nursing homes for people with dementia	Yes	
In hospitals, special wards or medical units	Yes	
In psychiatric establishments	No	

Definitions:

USLD (Unité de Soins Longue Durée): these are long-term care units in a hospital for people for whom the state requires, in principle, constant medical surveillance. To be admitted to a USLD, the person must show important signs of loss of autonomy/incapacity to wash, get up, get dressed and eat on their own) and require continuous medical and technical care.

Current capacity is 32,000 beds. The mean average stay in a USLD is of a year and a half.

EHPAD (Etablissement d'Hébergement pour Personnes Agées Dépendantes): they are nursing homes for dependent old people. They can be public, private or not-for profit. There are currently 6,850 EPHAD in France, offering over 500,000 places. They provide medical attendance 24 hours a day,

Maison de retraite: this is a residential home that becomes an old person's place of living. The residents benefit from a private space (bedroom) and collective amenities (food, cleaning, laundry…).

Foyer-logement: this is an intermediary solution between a person's usual place of living and a residence for older people. Foyers logements are non-medical residential buildings where autonomous elderly people can live in a secure environment. These people may also benefit from occasional support if needed (external home service such as cleaning support, meals on wheels).

Foyers logements usually propose small (furnished or unfurnished) apartments for private use and areas dedicated to social interaction and access to common service areas such as laundry, restaurant andmeeting rooms.

Petites unites de vie: these units cater for people who neither wish to live on their own nor wish to live in large communities like residential homes. There are small residential places that do not exceed 25 people. They are located in a familiar social environment. The residents have a private space but participate in the community (cooking, gardening…). This allows the residents to live independently and retain their autonomy for as long as possible. These units are managed by a house-keeper.

A thousand of such structures exists in France, some organising medical care.

Centres d'hébergement temporaire: Various solutions exist for people who cannot live on their own for a limited period of time either because their state of health does not allow them to do so or because of the absence of a family member who regularly looks after them. These structures can also allow a smooth transition before entering another structure.

Foundation Médéric Alzheimer's inventory has identified 10,000 structures, spanning all types of residence. EHPAD and USLD remain the main accommodation structures for people with loss of autonomy, including those with Alzheimer's disease and other forms of dementia. 71% of them (7000 establishments) offer accommodation and/or care to people with dementia. Most of them are general/non-specialised (Fontaine et al., 2012).

Residential establishments that accommodate most of the people with dementia are EHPAD and USLD. The majority of them are general/non-specialised in that they offer accommodation and care to a wide range of people. But, for 91% and 95% of them, this includes people with dementia.

People with dementia may be cared for in different ways:

- In specialised establishments for people with dementia, but there are very few (179).
- In establishments that include specialised units for people with dementia.
- In general/non specialised establishments, and this is the majority.

According to Fontaine et al. (2012), 50% of residents in establishments experience moderate or severe cognitive impairment. The percentage is low in residential homes (logements-foyers: 17%, maisons de retraite: 32%, petites unités de vie: 41%), but it is high in residential care: it stands at 63% in USLD (medical units in hospital), and 50% in EHPAD (nursing homes).

Admission modalities for people with dementia, some structures can be totally dedicated to this population but are very few (179 in total), other structures can offer one or several specialised units while other structures do not have any specialised units at all. The latter represent the majority of the available structures.

Percentage of structures that accept people with dementia at entry point are the following: among the 10,000 structures that have been identified, 7,000 (71%) have declared to accept people with dementia at entry point, EHPAD and USLD remain the main providers: 91% and 95% of them respectively accept people with dementia at entry point.

The percentage of people with cognitive disorders among the residents is 63% in USLD, 50% in EHPAD, 41% in 'Petites Unités de Vie', 32% in residential homes, 17% in foyer logements.

The ratio of staff to residents in EHPAD is 1:1.75 (KPMG, 2012).

10.2 The organisation of care and support for people with dementia

- Care support in general

  In France, medical care for people with dementia is reimbursed at 100%. But medical care represents only 10% of the total cost of Alzheimer's disease. For the remaining 90%, people with dementia, like every old people suffering from dependency, may get an allowance called APA (Allocation Personnalisée d'Autonomie = personalised autonomy allowance). This allowance is allocated by each department / district. The allocated amount is related to the person's own resources and level of dependency.

  When people with dementia live at home, this allowance covers costs related to the employment of auxiliary staff, home improvements, incontinence products, day care centres. When they live in an establishment, it covers the cost of residential care (EHPAD, USLD, residential homes).

In France, the provision of care and support is especially covered by the professional good practice recommendations published by the ANESM (Agence Nationale de l'Evaluation et de la qualité des établissements et Services Sociaux et Médico-Sociaux = national agency for the evaluation and quality of social establishments and services as well as social-medical services) and by the HAS (Haute Autorité de Santé – French Health Authority).

- Home care

In December 2011, the HAS published a recommendation on the disclosure of diagnosis and the support of people with dementia. A specialist (neurologist, geriatrician or psychiatrist) has to disclose the diagnosis during a long and dedicated consultation. The specialist has to inform the general practitioner by sending the consultation's minutes. This coordination between the GP and the specialist is a guarantee of continuity of care and support.

Controlling and monitoring of care and support is multidisciplinary, coordinated by the GP, in cooperation with a neurologist, geriatrician or psychiatrist. The GP has to propose a care and support plan in collaboration with the patient and his family. The GP has to ensure that the plan is implemented in collaboration with the specialist who made the initial diagnosis, and different coordination structures.

This care and support plan includes:

- in the recognition of the disease as a long-term disease ("ALD 15") for the full reimbursement (100%) of medical care,
- pharmacological and non-pharmacological treatments,
- comorbidity treatment,
- nutritional monitoring,
- information about associations,
- information about respite structures,
- information about social services,
- advice for adapting home,
- needs assessments,
- monitoring by the GP,
- monitoring by a psychologist or psychiatrist.

Then, the GP has to complete a thorough consultation at the patient's home in order to:

- talk about the diagnosis and check the understanding of the patient and his family,
- complete a medical, psychosocial and environmental assessment: falls, weight, conflicts, sleep,
- assess needs of the patient and the carer,
- inform the patient about the available structures and financial aids,
- anticipate the future and take necessary decisions,
- identify suffering and caregiver burnout.

(Haute Autorité de Santé (2011)).

The INPES (Institut National de Prévention et d'Education pour la Santé = national institute for prevention and health education) published a document in May 2012 to help GPs to carry out this consultation. This is the opportunity for the patient to express his expectations and needs, and to be involved in decisions about care and support (INPES, 2012).

- Residential care

The law of 02 January 2002 imposed on the EHPAD to set up an individual care plan for each patient. In a recommendation published in 2008 by the ANESM, it was recommended to involve the patient throughout the implementation and the monitoring of the plan, in order to respect his individuality, his lifestyle, his choices, his expectations.

Furthermore, the ANESM published in February 2009 a recommendation for the support of people with dementia in residential care. This recommendation inter alia covers: life habits, washing nutrition, mobility, sleep, social life, security, dignity, well-being and autonomy. For example, it is recommended to develop a new kind of communication in order to counterbalance the difficulties of expression and participation related to the Alzheimer's disease (anesm, 2009).

Between 2001 and 2012, the ANESM published four other recommendations about the quality of life in EHPADs:
(http://www.anesm.sante.gouv.fr/spip.php?page=rubrique&id_rubrique=107).

10.3 Training

10.3.1 Which social and healthcare professionals provide care and support

The following social and healthcare professionals are involved in the provision of care and support to people with dementia in residential care or living at home in France (Fontaine et al., 2012).

Staff category	Specialities	EHPAD	USLD
Nursing staff	Nurses	99%	100%
	Auxiliary nurse	99%	99%
Auxiliary staff *	Psychomedical support	78%	41%
	Animateur	90%	92%
	Auxiliaire de vie **	42%	11%
	Auxiliary nurse gerontology	22%	24%
Allied health professionals	Psychologist	80%	81%
	Occupational therapist	30%	67%
	Dietician	23%	80%
	Physiotherapist	19%	83%
	Psychomotor therapist	15%	26%
	Speech therapist	3%	19%
	Chiropodist	3%	18%
General practitioners	Coordination doctor	85%	70%

* provides general assistance, usually with no medical or nursing training

** professional who visits a person who needs assistance in their daily activities at home or in a substitutive place

10.3.2 The type of training that social and healthcare professionals receive

Not all professionals who provide care to people with Alzheimer's disease in their home or in a structure receive training on dementia during their curriculum. It is thus within the scope of continuous professional training that they can receive specific education about dementia, the support and care that can be given to these people. Continuous professional training is provided by accredited training centres. For instance, France Alzheimer has been accredited since 1991 to provide training to professionals on Alzheimer's disease and other forms of dementia (http://www.francealzheimer.org/menu-secondaire/formation-professionnelle).

In 2011, 86% of the structures that accepted people with dementia at entry point provided their staff with some specific training to help them care for these people (Fontaine et al., 2012).

The staff members that provide home care, nurses in EHPAD, psychologists, can access short training courses (2-5 days) or longer courses (10-15 days)

In order to offer a professional qualification to the auxiliary nurses and the psycho-medico staff who are already employed in a structure dealing with people with dementia, a new qualification has been created within the Alzheimer Plan 2008-2012; gerontology care assistant (Assistant de Soins en Gérontologie). This 140-hour training does not deliver any diploma, only a EUR 90 bonus each month.

Any employee working with people with dementia can also train as an auxiliary medico-psychologist and get a state diploma. France Alzheimer provides this training which includes some 500 hours of theory including 140 hours specific to the care of a person with dementia.

Finally, the Alzheimer Plan 208-2012 has included the training of an additional 2,000 occupational therapists and psychomotor therapists. An information document directed to these professionals spells out the evaluation and the modalities of re-adaptation and care likely to be carried out in the home of a person with dementia (Haute Autorité de Santé/French Health Authority, 2010).

10.3.3 How the training of social and healthcare professionals is addressed

The training of the professionals in social and medico-social structures (such as the EHPAD) falls within a legal provision. The law regulates the structures' contribution to the continuous professional training of its staff.

The obligation is variable depending on the annual mean workforce of these structures and the possible sector agreements that have been extended by ministerial decree: from 0.05% of the staff costs for structures of less than 10 employees to 1.60% for structures with 20 employees or more.

In France, a state-run structure (Organisme Paritaire Collecteur Agréé par l'État - OPCA) collects the financial contributions each company has to pay towards the life-long training of staff and then re-distributes it to the companies who engage in the training of their staff.

The OPCA main missions are to advise the employers and the employees, enable the financing of the training deemed necessary to the delivery of the companies missions and the retention or evolution of the competences of the employees.

For the position of gerontology care assistant, there is a competency reference book, an activity reference book and a training reference book published as annexes of the 23 June 2010 decree. All training structures have the obligation to comply with these reference books. (For further details in French, see "Arrêté du 23 juin 2010 relatif à la formation préparant à la fonction d'assistant de soins en gérontologie" on www.legifrance.gouv.fr).

France Alzheimer organises specific trainings for the ASG = gerontology care assistant and AMP = auxiliary medico-psychologist.

Short trainings are proposed to the professionals who intervene in the home, in EHPAD, psychologists. There are no reference books for these trainings that the training centres have to comply to. The programme, and in particular the importance given to dementia, is dependent upon each training centre.

The diploma of medico-psychologist professional (Aide Médico-Psychologique – DEAMP) was set up by decree n° 2006-255 of 02 March 2006 and the syllabus of the training by decree of 11 April 2006. The training spans over 497 hours of theory training, 140 of these hours being specific to the support of a person with dementia. This can also be accessed at www.legifrance.gouv.fr under "Décret n° 2006-255 du 2 mars 2006 instituant le diplôme d'Etat d'aide médico-psychologique").

10.4 Support for informal carers

Through its local branches, France Alzheimer provides support to the people with dementia and their families during the course of the disease, from diagnosis to end of life.

A psychologist and a France Alzheimer volunteer who has experience in caring for a person with dementia work in a team to organise various activities. This two-person team is trained by the Association and is a main feature of the various activities proposed by France Alzheimer.

France Alzheimer Halt Relay® are organised by some local associations over half days, one to four times a month. They are animated by a trained team composed of volunteers and a psychologist. These Halt Relays are a place where the couples receive support, can talk and exchange through both joint and individual activities.

France Alzheimer Memory Cafés® welcome both the person with dementia and the carer in a public place open to all. They are orchestrated by a volunteer of a local France Alzheimer branch and a psychologist, sometimes with debates. They are genuine places where families, people with the disease and friends can share information and receive a captive ear.

Some of France Alzheimer's branches organised friendly or cultural outings are organised for the people with the disease and their families: restaurant, pick nicks, cinema, museums or castle visits.

France Alzheimer also organised speech groups (groupes de parole) that are animated by a psychologist and sometimes co-animated by a volunteer. They give the families an opportunity to meet and exchange experiences about daily problems faced when living with a person with dementia.

Individual interviews are proposed by some local branches. They are led by a psychologist specifically trained to accompany the families having to take important decisions or going through crisis situations.

10.4.1 Respite

The French Alzheimer Plan 2008-2012 has enabled the development and diversification of respite services in order to offer carers new solutions that are more flexible and better suited to their needs. Different innovative respite solutions have been experimented like holiday stays, cultural and artistic activities, and some of them like multiservice platforms (support, respite) have been tested then developed on the all territory. The number of places in day care centres has been also increased.

France Alzheimer also offers innovative respite solutions that keep the person with dementia and the carer from isolation, accompany the person with the disease and preserve the carer's health status.

Alzheimer Holiday-Respite Breaks® are organised from May to October in different touristic regions in France. They are managed by volunteers and specialists specifically trained by the association. These breaks are for France Alzheimer members. They offer the families an opportunity to relax and share experiences, while allowing them to take part in tailored cultural and play activities. Depending on the financial means of the families, France Alzheimer may cover up to half of the cost of the break.

Unlike all other activities organised by France Alzheimer, the 'Holiday-Respite Breaks'® require financial participation from the families. However, France Alzheimer dedicates huge funds to make these holiday breaks accessible to the families with reduced means. Activities proposed by France Alzheimer to couples person with dementia / spouse.

10.4.2 Training

The French Alzheimer Plan 2008-2012 has implemented a two-day training programme for carers to help them cope with the disease. In partnership with France Alzheimer, the training is free and offers to carers the knowledge they need, providing the essential tools for understanding the patient's difficulties, adapting the environment and maintaining relationships. Since 2009, more than 18,500 carers have been trained.

The trainings are given by a psychologist/volunteer team who receives a systematic 14-hour training provided by France Alzheimer. All teams receive the same training, all over the territory.

10.4.3 Consultation/involvement in care decisions

The law of 2 January 2002, imposed on nursing homes (EHPAD, USLD) to implement an individual care plan for each patient. The ANESM recommended involving the patient throughout the implementation and the monitoring of the plan, in order to respect the person's lifestyle, choices and expectations. This was an opportunity for the resident to be involved in decisions about care and support.

This law has also required to nursing homes to implement a 'social life council' including at least two residents representatives so that families be involved in decisions about the organisation of activities, support and services.

10.4.4 Counselling/support

One of the priorities of the Alzheimer Plan 2008-2012 was to organise a 'long consultation' (consultation longue) at the home of the person with dementia. This new type of consultation is carried out by the family GP in the presence of the carer. The aim is to evaluate the needs of the person with dementia, those of the family and the support put in place:

- discuss the diagnosis and check the understanding of the patient and his/her family,
- carry out a medical, psychosocial and environmental assessment: falls, weight, conflicts, sleep,
- assess needs of the patient and the carer,
- inform the patient and the carer about available structures and financial aids,
- anticipate the future and take necessary decisions,
- identify suffering and caregiver burnout.

This consultation was bilaterally agreed by the GPs and the CNAMTS with a convention that took effect on 26 September 2011 and was effectively implemented from March 2012 onwards. The GPs are paid EUR 46 for such a consultation that is fully reimbursed by the healthcare system. It can take place only once a year or more, depending on should the state or the environment of the person with dementia deteriorate. INPES issue in May 2012 a document that should guide the GPs through the consultation 'Practice Guidance. Alzheimer's disease: how to conduct a 'long visit' (Repères pour votre pratique. Maladie d'Alzheimer: réaliser une visite longue). France Alzheimer contributed to the writing of this document (HAS, 2011).

During this consultation at the patient's home, the GP may suggest that the carer goes through a dedicated and annual carer consultation (consultation annuelle des aidants). This type of consultation takes place at the GPs practice. This type of consultation seeks to assess the psychological and nutritional conditions of the carer, identify health issues related to the caring of the person with dementia, and propose solutions that are more flexible and better suited to their needs: support groups, training, and psychotherapy.

In 2012, the French Health Authority published some good practice recommendations targeted at the GPs covering the medical follow-up of the carers of people with dementia or related disorders.

In collaboration with France Alzheimer (2011), the HAS also produced a brochure to inform the carers about the availability of such a consultation. It has never been printed on paper for the GPs to distribute due to a lack of funding but can be downloaded (see references section).

On 6 October 2010, the first 'national carers day' was organised in France. This is an initiative of the previous government without any link to the Alzheimer Plan. The objective is to reach all the carers, not only those who take care of a person with dementia.

However, this initiative has tended to lose intensity over the years. One reason may be that the date chosen is too close to World Alzheimer's Day.

10.4.5 Case management (insofar as this relates to care)

The French Alzheimer Plan 2008-2012 has experimented and deployed over territory some "Centres for autonomy and integration of people with dementia" (Maisons pour l'Autonomie et l'Intégration des personnes malades d'Alzheimer - MAIA). These centres aim to create a better coordination between care, information and support structures, in order to define a personalised care pathway.

The Plan has also implemented two case managers in each centre. The case manager coordinates social and healthcare, providing the link between the teams and guaranteeing real multidisciplinary care suited to each individual's situation.

More information can be accessed on: http://www.plan-alzheimer.gouv.fr/mesure-no4.html

10.5 National Alzheimer Association

France Alzheimer offers the following services and support-

Helpline	✓
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	✓
Care coordination/Case management	
Home help (cleaning, cooking, shopping)	
Home care (personal hygiene, medication)	
Incontinence help	
Assistive technologies / ICT solutions	
Tele Alarm	
Adaptations to the home	
Meals on wheels	
Counselling	✓
Support groups for people with dementia	✓
Alzheimer cafes	✓
Respite care at home (Sitting service etc.)	✓
Holidays for carers	✓
Training for carers	✓
Support groups for carers	✓
Day care	
Residential/Nursing home care	
Palliative care	

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10.7 Acknowledgements

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11 Germany

11.1 Background information

11.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Germany in 2012 as being 1,572,104. This represents 1.92% of the total population of 81,990,837. The number of people with dementia as a percentage of the population is somewhat higher than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	28,656	15,745	44,401
60 – 64	4,740	22,149	26,889
65 – 69	37,007	30,784	67,792
70 – 74	70,514	96,980	167,494
75 – 79	113,093	156,392	269,485
80 – 84	128,627	228,221	356,848
85 – 89	93,540	285,604	379,143
90 – 94	34,516	176,903	211,419
95+	6,443	42,190	48,633
Total	**517,136**	**1,054,968**	**1,572,104**

A series of epidemiological field studies have revealed that more than 50% of people who had dementia (as identified by the research psychiatrists) did not have a diagnosis.

11.1.2 Where people with dementia receive care and support

The following table provides estimates of the number of people with dementia living at home, in various types of residential care and in hospitals or psychiatric institutions.

Place of residence	YES or NO	Estimated number/Additional information
At home (alone)	Yes	Generally it is said that two thirds of people with dementia live in private households. A small proportion (most of them with beginning dementia) is living alone.
At home (with relatives or close friends)	Yes	Most of them with carers as partners and family members, a part with help of ambulant services
At home (with other people with dementia)	Yes	During the last ten years special "Wohngemeinschaften für Menschen mit Demenz" developed (especially in Berlin and Brandenburg). See definition below.
In general/non-specialised residential homes	Yes	
In specialised residential homes for people with dementia	Yes	

Place of residence	YES or NO	Estimated number/Additional information
In general/non-specialised nursing homes	Yes	Those who do not live in private households mostly live in nursing homes (“Altenpflegeheime”). Most of them are not specialised and care for people with and without dementia. More and more nursing homes have special units for people with dementia (some are called “Hausgemeinschaften”).
In specialised nursing homes for people with dementia	Yes	
In hospitals, special wards or medical units	Yes	Only a few people with dementia live in hospitals.
In psychiatric establishments	Yes	Only a few people with dementia live in psychiatric establishments.

A „Wohngemeinschaft“ is a big (private) apartment where 8 to 12 people with dementia live together and are cared for by an ambulant service (this does not have the status of a nursing home. Further information in German can be found at: http://www.deutsche-alzheimer.de/fileadmin/alz/pdf/factsheets/FactSheet13_02.pdf. There are no official statistics but it is estimated that there are 1,000 Wohngemeinschaften for 8 to 12 people in Germany.

General/non-specialised residential homes such as “Altenheime” and, more extensively, “Seniorenresidenzen” are usually designed for a comfortable life of older people but not for care. There are no statistics but probably only a very small number of people with dementia live in such places.

With regard to general/non-specialised nursing homes, the results of epidemiological studies in “Altenpflegeheimen” suggest that two thirds of the residents have dementia (Weyerer and Bickel, 2007). Based on a probability sample of 609 long-term care institutions in Germany, a sample of 86 facilities was drawn by applying a two stage random procedure. Of the 4,481 residents assessed in 58 care facilities (mean age 82.6 years; 78% female) on average 68.6% were affected by a dementia syndrome and 56.6% by a severe dementia-syndrome Schäufele, et al., 2013). The researchers concluded that people with dementia form the major group of residents in German nursing homes”.

The ratio of staff to residents (”Personalschlüssel” – the personnel quota) differs from one federal state to the next and depends on the care-level. In Baden-Württemberg, it is:

- Nursing and care staff in relation to people with care needs. At least half of the staff have to be registered nurses (Pflegefachkräfte):
  - o Care level I: 1:3.96 to 1:3.13
  - o Care level II: 1:2.83 to 1:2.23
  - o Care level III: 1:2.08 to 1:1.65
- For the care of people with care needs, who in addition have dementia, the following ratios apply:
  - o Care level I: 1:2.38
  - o Care level II: 1:1.70
  - o Care level III: 1:1.25

11.2 The organisation of care and support for people with dementia

11.2.1 The overall organisation of care and support

In Germany, the long-term care law (Pflegeversicherungsgesetz) is applicable to people in need of care (regardless of whether they have a physical or psychiatric condition or are young or old). An assessment determines whether someone needs care based on the definition in the law. People can choose between "Pflegegeld" (money which they can use themselves) and the use of outpatient services or, if necessary, of care in a nursing home. The amount paid by care insurance, depending on the level of care (i.e. 1, 2 or 3), only covers part of the real costs.

The long-term care insurance (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 though there have been some improvements since January 2013 (especially with regard to those without a care level but with a special need for supervision who can now get services from LTCI).

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.

Nursing homes are regulated by the laws of the federal states. Their laws about "living and care in institutions" are all somewhat different. The care in nursing homes is controlled by the "medical service" of the care insurance.

In Germany there were, at end of 2011, more than 10,700 nursing homes with 723,000 residents. 54% belong to non-profit organisations like Caritas, Diakonie, the Red Cross, 40% are private and 6% belong to the municipality (Statistisches Bundesamt 2013).

There is a relatively small but growing number of 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. In Gelsenkirchen, there is a dementia service centre for migrants, which offers counselling, literature and special sport programmes. Other organisations providing assistance to immigrants have developed guidelines on how to care for older immigrants in a way that respects their cultural background. Further details can be found in Alzheimer Info 2/2006 published by the Deutsche Alzheimer Gesellschafte.V. 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.

11.2.2 How specific aspects of care and support are addressed

Several aspects of care and support are addressed in national policies.

- Expert standards exist covering different themes (e.g. nutrition, prevention of decubitus). Information in German can be obtained at:
  http://www.wiso.hs-osnabrueck.de/dnqp.html

- The Medical Service of Health Insurances (Medizinischer Dienst der Krankenkassen) and the “Heimaufsicht” (a supervisory authority for nursing homes) of federal states are responsible for the control and monitoring of care and support.
- Needs assessment is governed by the Medical Service of Health Insurances.
- Access to support is governed by the “Pflegestützpunkte“ („Pflegeberatung der Pflegekassen“ according to § 7a SGB XI (Care insurance law).
- The „Heimpersonalverordnung“ (regulation on staff in nursing homes) regulates the proportion of qualified staff in nursing homes.
- The Deutsches Zentrum für Neurodegenerative Erkrankungen (German Centre for Neurodegenerative Diseases) and universities are doing research into care and support („Versorungsforschung“).
- Funding and control bodies for care and support are partly governed by the Ministry for Research or the Ministry of Health or the Ministry for Senior Citizens.
- The acquisition of communication skills with patients is part of healthcare professionals’ training and is not regulated at national level.
- Complaint procedures are governed by the „Heimaufsicht“ of the federal states.
- The promotion of well-being and autonomy, as well as respect for individuality and cultural diversity, are covered by the “Charta der Rechte pflegebedürftiger Menschen“ (Charter for the Rights of People with Care Needs).
- People with dementia are involved in decisions about care and support via legal instruments such as advanced directives (“Betreuungsverfügung“, „Patientenverfügung”.

There are numerous regulations concerning care and support which can be found in the German care insurance law (Sozialgesetzbuch XI).

11.3 Training

11.3.1 Which social and healthcare professionals provide care and support

The following social and healthcare professionals are involved in the provision of care and support to people with dementia in residential care or living at home.

Social or healthcare professional	**Involved in the provision of care and support to people with dementia in residential care or at home**
Nursing staff	Yes. Nursing carers (Krankenpflege) and carers of older people (Altenpflege)
Auxiliary staff	Yes
Allied health professionals	Yes
Specialists (e.g. psychiatrists, gerontologists, neurologists)	Yes, insofar as they are responsible for the prescription of ergotherapy etc.
General practitioners	Yes, insofar as they are responsible for the presciption of ergotherapy etc.
Other	Yes. Social workers

11.3.2 The type of training that social and healthcare professionals receive

The official qualifications for nursing staff are usually obtained after 3 years' study. For auxiliary staff, there are different training courses, partly licensed by the federal state. These courses have different titles and their duration also differs. With regard to social sector professionals, in some universities for social work, dementia is included in training, but it is not known to what extent. The same applies to the training of allied health professionals.

The Law on Professions in the Care of Older People ("Gesetz über die Berufe in der Altenpflege") is a law at national level which defines general standards. No reference is made to dementia. The content of education itself is managed at federal state level and covers a wide range of themes. The curriculum is vast and it is therefore difficult to make general statements. However, the training of auxiliary staff is likely to include basic knowledge about dementia, care and support of people with dementia and the behavioural and psychological symptoms of dementia.

11.4 Support for informal carers

The following support for carers is addressed or covered by national policies:

11.4.1 Respite

Respite care is addressed in the context of the long-term care insurance. It entitles carers to € 1,550 per year to pay for a substitute carer ("Verhinderungspflege", § 39 SGB XI), day care (§ 41 SGB XI) between € 450 and € 1.550 per month (depending on care level) and short-term care (§ 42 SGB XI) up to € 1.550 per year. Further details in German are available from the Deutsche Alzheimer Gesellschaft (2013).

11.4.2 Training

Training is addressed in the long-term care insurance (§ 45 SGB XI), according to which carers can participate in courses concerning physical and social care.

11.4.3 Consultation/involvement in care decisions

Consultation/involvement in care decisions seems to occur but is not part of legislation.

11.4.4 Counselling/support

Counselling/support is addressed in the long.term care insurance (§ 7 SGB XI).People in need of care and their family carers are entitled to couselling, especially by "Pflegestützpunkte" (care consulting centres).

11.4.5 Case management (insofar as this relates to care)

Case management (insofar as this relates to carers) is also addressed.in the long-term care insurance (§§ 7, 92). In fact case management is poorly financed.

11.4.6 Other

The law on Family Care Time (Familienpflegezeitgesetz, 2012) covers release from work to care for somebody for a limited period of time.

The support of carers is mainly covered by the care insurance law.

11.5 National Alzheimer Association

The German Alzheimer Association provides the following services and support.

Helpline	✓
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	✓
Care coordination/Case management	
Home help (cleaning, cooking, shopping)	
Home care (personal hygiene, medication)	
Incontinence help	
Assistive technologies / ICT solutions	
Tele Alarm	
Adaptations to the home	
Meals on wheels	
Counselling	✓
Support groups for people with dementia	✓
Alzheimer cafes	✓
Respite care at home (Sitting service etc)	✓
Holidays for carers	✓
Training for carers	✓
Support groups for carers	✓
Day care	✓
Residential/Nursing home care	
Palliative care	

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Sabine Jansen, Executive Director, Deutsche Alzheimer Gesellschaft

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12 Greece

12.1 Background information

12.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Greece in 2012 as being 201,766. This represents 1.77% of the total population of 11,418,878 people. The number of people with dementia as a percentage of the population is somewhat higher than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	4,064	2,232	6,296
60 – 64	649	3,122	3,771
65 – 69	4,618	4,052	8,670
70 – 74	7,348	10,887	18,236
75 – 79	14,753	20,865	35,618
80 – 84	21,655	33,744	55,399
85 – 89	14,685	30,307	44,992
90 – 94	5,873	15,666	21,539
95+	1,747	5,499	7,246
Total	**75,392**	**126,375**	**201,766**

According to Alzheimer Hellas, approximately 50,000 people are living with dementia but have not been diagnosed.

12.1.2 Where people with dementia receive care and support

The following table provides estimates of the number of people with dementia living at home, in various types of residential care and in hospitals or psychiatric institutions.

Place of residence	YES or NO	Estimated number/Additional information
At home (alone)	Yes	20%
At home (with relatives or close friends)	Yes	50%
At home (with other people with dementia)	No	–
In general/non-specialised residential homes	Yes	10%
In specialised residential homes for people with dementia	No	–
In general/non-specialised nursing homes	Yes	10%

Place of residence	YES or NO	Estimated number/Additional information
In specialised nursing homes for people with dementia	No	–
In hospitals, special wards or medical units	No	–
In psychiatric establishments	Yes	10%
Other (please specify)	No	–

Alzheimer Hellas estimates that 70% of residents in general/non-specialised residential homes have dementia, while this percentage drops to 25% in general/non-specialised nursing homes.

The ratio of staff to residents in various establishments is shown below, based on Alzheimer Hellas estimates:

- 1:20 in general/non-specialised residential homes
- 10:1* in general/non-specialised nursing homes
- 1:5 in specialised residential homes for people with dementia
- 1:5 in specialised nursing homes for people with dementia

* The ratio of ten staff members per resident is due to inconsistent hiring policies in the Greek public sector. It is also very likely the main cause of the government's current policy to gradually close down these facilities.

12.2 The organisation of care and support for people with dementia

There is no official dementia plan or related legislation for the care and support of people with dementia.

Greece is divided into five regions that operate hospitals and are responsible for general practitioners. Hospitals are privately run enterprises that are funded by the regions. These regions encompass 98 local municipalities that are responsible for home care, care homes, home nursing and rehabilitation.

If a person needs to go into a care home, they move into a flat in a complex called a "home care centre". They have to pay their own rent and also for food, medicine, laundry and utilities. The municipalities provide staff such as nurses, social and health assistants and helpers. The need to go into a care home is assessed by local authorities.

Care homes are the only kind of institutionalised care available, unless a person needs special psychiatric care, in which case they go to a specialised nursing home. There are very few private care homes.

Alzheimer Hellas operates approximately ten day care centres in the country, some of which receive EU funding.

12.3 Training

12.3.1 Which social and healthcare professionals provide care and support

The following social and healthcare professionals are involved in the provision of care and support to people with dementia in residential care or living at home:

Social or healthcare professional	Involved in the provision of care and support to people with dementia in residential care or at home
Nursing staff	Yes
Auxiliary staff	Yes
Allied health professionals	Yes
Other	Psychologists
Specialists (e.g. psychiatrists, gerontologists, neurologists)*	Yes. The majority of specialists try to find ways to support patients with dementia at their homes.
General practitioners*	No

* Only if they are linked to the provision and organisation of care and support (i.e. not with regard to their role to provide medical treatment).

12.3.2 The type of training that social and healthcare professionals receive

There is no official training or qualification for social and healthcare professionals that deal with people with dementia. Alzheimer Hellas organises various seminars and conferences, but these are not officially recognised.

12.4 Support for informal carers

There is no official support for informal carers. Alzheimer Hellas provides some services which are described in section 15.5.

12.5 National Alzheimer Association

Alzheimer Hellas operates all over Greece, with association members providing services on a voluntary basis. The association organises conferences and seminars, including an educational teleconference programme. There are also telephone helplines and two newsletters. On a more local level, associations operate day centres, home services and caregiver support groups.

Helpline	✓
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	✓
Care coordination/Case management	✓
Home help (cleaning, cooking, shopping)	
Home care (personal hygiene, medication)	✓
Incontinence help	
Assistive technologies / ICT solutions	
Tele Alarm	
Adaptations to the home	
Meals on wheels	

Counselling	✓
Support groups for people with dementia	✓
Alzheimer cafes	✓
Respite care at home (Sitting service etc.)	
Holidays for carers	
Training for carers	✓
Support groups for carers	✓
Day care	✓
Residential/Nursing home care	
Palliative care	

12.6 Acknowledgements

Magda Tsolaki, Professor of Neurology, Aristotle University (Thessaloniki) and Chair of the Greek Federation of Alzheimer's Disease and Related Disorders.

13 Hungary

13.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Hungary in 2012 as being 148,927. This represents 1.5% of the total population of 9,949,589. The number of people with dementia as a percentage of the population is comparable to the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	3,391	1,960	5,351
60 – 64	591	3,207	3,780
65 – 69	3,932	4,223	8,156
70 – 74	5,133	9,844	14,976
75 – 79	8,005	16,175	24,180
80 – 84	10,736	25,908	36,645
85 – 89	7,693	26,620	34,313
90 – 94	3,422	14,387	17,809
95+	750	2,966	3,716
Total	**43,636**	**105,291**	**148,927**

14 Iceland

14.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Iceland in 2012 as being 3,922. This represents 1.19% of the total population of 328,290. The number of people with dementia as a percentage of the population is considerably lower than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	107	58	165
60 – 64	17	73	90
65 – 69	113	89	203
70 – 74	139	178	316
75 – 79	249	307	557
80 – 84	392	559	951
85 – 89	297	617	914
90 – 94	142	425	567
95+	31	129	160
Total	**1,487**	**2,435**	**3,922**

14.2 National Alzheimer Association

The Alzheimer Association of Iceland provides the following services and support to people with dementia and their carers.

Helpline	
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	
Care coordination/Case management	✓
Home help (cleaning, cooking, shopping)	
Home care (personal hygiene, medication)	
Incontinence help	
Assistive technologies / ICT solutions	✓
Tele Alarm	
Adaptations to the home	
Meals on wheels	
Counselling	✓
Support groups for people with dementia	
Alzheimer cafes	✓
Respite care at home (Sitting service etc.)	
Holidays for carers	

Training for carers	
Support groups for carers	
Day care	✓
Residential/Nursing home care	
Palliative care	

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15 Ireland

15.1 Background information

15.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Ireland in 2012 as being 49,470. This represents 1.08% of the total population of 4,579,498. The number of people with dementia as a percentage of the population is somewhat lower than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	1,527	851	2,378
60 – 64	225	1,009	1,234
65 – 69	1,623	1,282	2,904
70 – 74	2,098	2,687	4,785
75 – 79	3,336	4,281	7,617
80 – 84	4,328	6,906	11,233
85 – 89	3,025	7,646	10,672
90 – 94	1,440	5,312	6,752
95+	294	1,601	1,895
Total	**17,895**	**31,574**	**49,470**

In 2007, O'Shea produced estimates of the prevalence of dementia in Ireland up to 2036:

Year	Estimated number of people with dementia
2016	49,153
2021	58,044
2026	70,115
2031	85,847
2036	103,998

There is no national dataset on actual numbers of people diagnosed with dementia by GP's (Cahill et al 2012). It is therefore not known how many are likely to have dementia without having received a diagnosis.

15.1.2 Where people with dementia receive care and support

The following table provides estimates of the number of people with dementia living at home, in various types of residential care and in hospitals or psychiatric institutions.

Place of residence	YES or NO	Estimated number/Additional information
At home (alone)	Yes	26,104 (Cahill et al., 2012)
At home (with relatives or close friends)		No figures available

Place of residence	YES or NO	Estimated number/Additional information
At home (with other people with dementia)		No figures available
In general/non-specialised residential homes		
In specialised residential homes for people with dementia		
In general/non-specialised nursing homes	Yes	14,266 (Cahill et al., 2012)
In specialised nursing homes for people with dementia		(some of the people included in the above figure are in dementia specific units attached to the Health Service Executive (HSE).
In hospitals, special wards or medical units	Yes	644 (Cahill et al., 2012)
In psychiatric establishments	Yes	456 (Cahill et al., 2012)

With regard to specialised nursing homes for people with dementia, extended care units for older people and private nursing homes (that have beds allocated to people with dementia or in the few stand-alone Dementia specific Centres similar to those run by the Alzheimer Society of Ireland) are included in the 14,266 mentioned in the above table.

There are also some sheltered housing schemes in Ireland which cater for people with dementia. Figures are not available as some are operated by local communities and do not always come under health funding.

According to the Department of Health (2011), 31.4% of residents in long stay units and 4.0% of residents in limited stay units have dementia.

However, this estimate is much higher in other reports (i.e. over 60%). In one small study in Dublin 89% of people over 65 years were reported to have some form of cognitive impairment. (Flood, 2012). These estimates apply to all people with dementia, not only those who have been formally diagnosed.

With regard to the ratio of staff to residents in various establishments where people with dementia live or receive care, the Health Information and Quality Authority (HIQA) sets standards (which are supported by regulation) and inspects these establishments. One of the standards relates to staffing levels:

> *"At any point in time, the number and skill mix of staff on duty is determined and provided according to a transparently applied, nationally validated, assessment tool, to plan for and meet the needs of the residents. This is subject to regular review.*
>
> *"The staffing numbers and skill mix of qualified/unqualified staff are at all times appropriate to the assessed needs of the residents and the size, layout and purpose of the residential care setting." (Health Information and Quality Standard 23.4, 2009, p. 41)*

15.2 The organisation of care and support for people with dementia

15.2.1 The overall organisation of care and support

The overall organisation of care and support for people with dementia is regulated by the governments (i.e. policy makers through legislation and regulations and the Department of Health/Minister of Health), as well as by the Health Information & Quality Authority (HIQA) (which inspects services) and the Health Service Executive (Statutory Body) which is responsible for delivering services. Care and support are organised as follows.

The Integrated Services Directorate manages all hospital and community public health services in Ireland and has responsibility for the delivery of all health and personal social services across the country including hospital, primary, community and continuing care services. This also includes management of an overall budget of over €13bn and a statutory and voluntary sector workforce of 105,000.

The range of health and personal social services provided by the HSE and its funded agencies are managed within four Regions. Each of the HSE's four administrative areas has a Regional Health Forum, which includes representatives from the city and county councils within that area.

The HSE's 4 Regions are divided into HSE Areas. Each HSE Area has an Area Manager who is responsible for managing all of the public health services in their area of operation. HSE Areas include all Hospital Services and Local Health Office services, integrated into one seamless health service for the people living in that area.

Clinical strategies and programmes have been established to improve and standardise patient care throughout the organisation by bringing together clinical disciplines and enabling them to share innovative solutions to deliver greater benefits to every user of HSE services.

The directorate has established a number of National Clinical Programmes which are based on three main objectives, namely to improve the quality of care delivered to all users of HSE services, improve access to all services and improve cost effectiveness.

The National Clinical Programme for Older People includes people with dementia through the Model of Care for Specialist Geriatric Services.

This initiative is aimed at significantly improving access for frail older patients to specialist geriatric teams (doctors, nurses and therapists), day hospitals, specialist inpatients beds and rehabilitation beds. This will improve the quality of care received by older patients and shorten the length of hospital stay.

The Model of Care for Specialist Geriatric Services, Acute Service Provision, is Part 1 of a two part model of care. Part 1 describes the patient's journey within the acute hospital as an inpatient or outpatient in specialist clinics or ambulatory day hospital.

Part 2 of the model of care will address services for older people in general practice, primary and community care and is due for completion in 2013.

The components of acute Specialist Geriatric Services (SGS) include:

- The establishment of specialist geriatric teams
- Dedicated in-patient specialist geriatric wards
- In-patient rehabilitation facilities (both on and off the acute hospital site)
- Community outreach to nursing homes
- Ambulatory day hospital services
- Access to home supports
- Access to long-term residential care

Further information about the Model of Care and the Specialist Geriatric Services can be found at: http:www.hse.ie and www.hse.ie/eng/about/Who/clinical/natclinprog/Older-People

15.2.2 How specific aspects of care and support are addressed

A large number of relevant national policy documents/Health Service Strategies and Plans have shaped the way that services have developed over the years and on how they will develop into the future. The following are some examples of such documents. This is not an exhaustive list.

1. The Years Ahead (1988) Policy for Older People Services
2. Quality & Fairness (2001) Strategy for Health Services (10 year strategy)
3. Primary Care Strategy (2001)
4. National Health Promotion Strategy (2005)
5. Vision for Change (2006) (Government Publication) Strategic Direction for Mental Health Service in Ireland
6. Report of the Interdepartmental Working Group on Long-Term Care (2008)
7. Tackling Chronic Disease - A Policy Framework for the Management of Chronic Diseases (2008)
8. The National Women's Strategy (2007 – 2016)
9. National Men's Health Policy (2008 - 2013)
10. HSE Population Health Strategy (2008)
11. Action Plan for Health Research (2009 - 2013)
12. National Guidelines on Physical Activity for Health (2009)
13. Changing Cardiovascular Health: National Cardiovascular Health Policy (2010-2019)
14. Review of the Recommendations of Protecting Our Future: Report of the Working Group on Elder Abuse (2010)
15. Future Health – A Strategic Framework for Reform of the Health Service 2012-2015.
16. Summary of the public consultation for the Dementia Strategy (2012)

    The first stage of the process was to assemble the research and evidence upon which the strategy will be developed. This was completed in 2012 and the report of the findings "Creating Excellence in Dementia Care: a Research Review for Ireland's National Dementia Strategy (Research Review)" was published. A guide for the general public, "Future Dementia Care in Ireland: Sharing the Evidence to Mobilise

Action", was compiled to disseminate the report's findings and to give a better understanding of dementia. This is available at: www.doh.ie.

17. Programme for Government (2011-2016).
18. The National Action Plan for Social Inclusion 2007 – 2016
19. The National Housing Strategy for People with Disabilities 2011–2016
20. National Carers Strategy (2012)
21. National Positive Ageing Strategy (NPAS) (2013) Government Publication
22. National Consent Policy (HSE, 2013)

The National Carers' Strategy (2012) signals the Government's commitment to recognising and respecting carers as key care partners and to responding to their needs, across a number of policy areas. By setting out a vision to work towards, and an ambitious set of national goals and objectives to guide policy development and service delivery, the strategy seeks to ensure that carers feel valued and supported to manage their caring responsibilities with confidence and are empowered to have a life of their own outside of caring. The four national goals for carers are:

1. To recognise the value and contribution of carers and promote their inclusion in decisions relating to the person that they are caring for,
2. To support carers to manage their physical, mental and emotional health and well-being,
3. To support carers to care with confidence through the provision of adequate information, training, services and supports,
4. To empower carers to participate as fully as possible in economic and social life.

The National Positive Ageing Strategy (NPAS) (2013) Government Publication also has four goals, which are to:

1. Remove barriers to participation and provide more opportunities for the continued involvement of people as they age in all aspects of cultural, economic and social life in their communities according to their needs, preferences and capacities.
2. Support people as they age to maintain, improve or manage their physical and mental health and wellbeing.
3. Enable people to age with confidence, security and dignity in their own homes and communities for as long as possible.
4. Support and use research about people as they age to better inform policy responses to population ageing in Ireland.

The National Quality Standards for Residential Care Settings for Older People in Ireland (HIQA, 2009) contains a special section entitled "Supplementary criteria for dementia-specific residential care units for older people".

The Alzheimer Society of Ireland commissioned three external experts to write policy papers in order to generate new ideas, promote cutting-edge concepts and contribute to a much more informed debate in relation to the soon-to-be-developed National Dementia Strategy.

The first was the Expert Policy Paper Series 2012, A National Dementia Strategy for Ireland: Signposting the Possibilities: A Clinician's Perspective (Alzheimer Society of Ireland) by Henry O'Connell

The second was the Expert Policy Paper Series 2012 Integrated Care Pathways for People with Dementia. Exploring the Potential for Ireland and the forthcoming National Dementia Strategy, by Dr Kate Irving and Ms Lisa McGarrigle, School of Nursing and Human Sciences Dublin City University.

The third was the Expert Policy Paper Series 2012 Financing Dementia by Dominic Trépel PhD. (University of York).

15.3 Training

15.3.1 Which social and healthcare professionals provide care and support

The following social and healthcare professionals are involved in the provision of care and support to people with dementia in residential care or living at home.

Social or healthcare professional	Involved in the provision of care and support to people with dementia in residential care or at home
Nursing staff	Yes
Auxiliary staff	Yes
Allied health professionals	Yes (mostly in Public Units)
Specialists (e.g. psychiatrists, gerontologists, neurologists)*	Specialists are mostly Hospital based. Consultant Psychiatry for later life and teams also provide services in the community and to Residential Care on referral.
General practitioners*	General Practitioners (GP's) in some HSE facilities are contracted to provide medical cover.

* Only if they are linked to the provision and organisation of care and support (i.e. not with regard to their role to provide medical treatment).

Concerning allied health professionals, some public (i.e. State-run) nursing homes have occupational therapists and physiotherapists, and others have access to speech and language therapists, and dieticians, social workers, podiatry/chiropody and other services as necessary. Some state nursing homes also employ hairdressers and provide access to other alternative therapists.

15.3.2 The type of training that social and healthcare professionals receive

Nurses and other health and social care workers have access to a specific introduction course in dementia care which was launched in 2012 (following a training needs analysis of health and social care staff working in home care and residential care and acute hospital care) through a special national dementia project which was led by the Nursing Midwifery and Development Unit. This course is open to the multi-disciplinary team. A training manual and tapes have been produced. A "train the trainer" approach has been adopted for roll out across all services.

Nurses and other healthcare professionals can also access diploma courses in gerontology and dementia care, Masters programmes in gerontology or dementia care, Dementia Mapping and on-line courses in dementia with the different universities as part of their continuing professional development (CPD). The Nursing and Midwifery Council of Ireland also facilitates the roll out of accredited courses for nurses as part of their CPD.

Many auxiliary staff have completed FETAC (please see below) Level 5 courses which include relevant caring modules. Auxiliary staff can also access the dementia specific course on caring for people with dementia, as outlined above, with access to tapes and a handbook.

The "Further Education and Training Awards Council" (FETAC) was the statutory awarding body for further education and training in Ireland. From June 2001 until the establishment of **Quality and Qualifications Ireland** (QQI) on 6 November 2012, FETAC made awards at levels 1 to 6 on the **National Framework of Qualifications**. These awards are now made by QQI.

FETAC award holders can be assured that their awards will continue to be recognised, both at home and abroad, and will enable progression pathways through the NFQ. For further information, please see: http:www.fectac.ie.

There are many other courses (not included) that health and social care staff access in order to enhance their knowledge base and equip them with the skills and competencies to care for people with dementia such as responsive behaviours and alternative therapies etc.

The need for specialised knowledge about dementia has been raised in several national policy documents such as Creating Excellence in Dementia Care (2012), Vision for Change (2006) and in policy documents of the Alzheimer Society of Ireland etc. The Action Plan for Dementia (1999) as well as the HIQA standards (2009) mentioned the need for training in their recommendations.

Education/training has been recommended in several national reports, especially for special training for GPs in dementia care and also for other health and social care professionals, especially in the acute hospital and setting and in home care services.

15.3.3 How the training of social and healthcare professionals is addressed

In recent years there has been a much greater focus on training in dementia care as a result of recommendations from several published reports (as mentioned above). Many organisations have undertaken their own training needs analysis with staff to establish training deficits and address same. There has also been a greater investment in staff training in order to respond to the implementation of external standards and regulatory requirements all of which aim to promote higher standards of care and improved outcomes for service users. There are now more colleges and other educational centres providing courses for health and social care staff with greater choice available to all of the multi-disciplinary team members. Some third level institutions have worked on site with service providers through person centred care programmes (using reflective practice) which had very positive outcomes/experiences for both staff and service users. This includes good access to online courses.

In 2012 Genio (part funded by HSE and Atlantic Philanthropies), who work in partnership with the HSE on specific projects, rolled out a course "Endeavour for Excellence" which included a focus on dementia care.

15.4 Support for informal carers

Support for informal carers is addressed in national policy through the National Carers Strategy which applies to all carers, including the carers of people with dementia. Several National Carer organisations have advocated very successfully, to address gaps in support services for carers (see next section on the National Alzheimer Association).

Consultation/involvement in care decisions:

The HSE is currently working in partnership with several agencies (in Ireland) including the Alzheimer Society of Ireland to develop a home grown Carer Assessment tool in consultation with INTERRAI (International) which will ensure that the needs of carers are considered in relevant assessment processes. Carers' issues are also addressed in other policy documents listed in previous sections of this report.

15.5 National Alzheimer Association

The Alzheimer Society of Ireland provides the following services and support.

Information Helpline	✓
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	✓
Care coordination/Case management	✓
Home help (cleaning, cooking, shopping)	✓
Home care (personal hygiene, medication)	✓
Incontinence help (continence promotion)	✓
Assistive technologies / ICT solutions	✓
Tele Alarm	✓
Counselling	
Support groups for people with dementia	✓
Alzheimer cafes	✓
Respite care at home (Sitting service etc.)	✓
Holidays for carers	
Training for carers	✓
Support groups for carers	✓
Day care	✓
Residential/Nursing home care (respite care)	✓
Palliative care support	✓

The Alzheimer Society of Ireland also provides advocacy, policy and research, a dementia advisory service and early interventions. In addition, it supports the development of dementia friendly communities through awareness raising programme. Local branch structures within the Society support local service development initiatives and are very proactive in responding to the local needs and service demands for people with dementia and carers. The Society is also actively engaged in on-going research and in lobbying Government for improved dementia services ensuring that people with dementia receive the right service at the right time in a timely manner.

15.6 References

Cahill, S., O'Shea, E. and Pierce, M. (2012). *Creating Excellence in Dementia Care*: *A Research Review for Ireland's National Dementia Strategy, Trinity College, Dublin and the Irish Centre for Social Gerontology,*

Cahill, S., O'Shea, E. and Pierce, M. (2012). *Future Dementia Care in Ireland*, Publisher

Department of Health (2011). *Long-Stay Activity Statistics 2011*. Department of Health (see Table B7, p.20)

Health Information and Quality Authority (HIQA). (2009). *National Quality Standards for Residential Care Settings for Older People in Ireland*. HIQA

Flood, J. (2012), Mental Health: Dementia Module 173: January 2012; Forum distance learning project in association with the ICGP. *Forum*, pp. 1-4

O'Shea, E. (2007). *Implementing Policy for Dementia Care in Ireland. The Time for Action is Now*. The Alzheimer Society of Ireland.

15.7 Acknowledgements

The Alzheimer Society of Ireland

16 Italy

16.1 Background information

16.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Italy in 2012 as being 1,272,317. This represents 2.09% of the total population of 60,964,145. The number of people with dementia as a percentage of the population is somewhat higher than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

An estimated 40% of all people with dementia have not received a diagnosis. (CNR)

Age group	Men with dementia	Women with dementia	Total
30 – 59	21,529	11,830	33,359
60 – 64	3,615	17,220	20,834
65 – 69	28,402	24,503	52,905
70 – 74	43,916	61,878	105,794
75 – 79	78,872	113,943	192,815
80 – 84	107,893	195,928	303,822
85 – 89	84,671	236,950	321,621
90 – 94	38,741	153,097	191,838
95+	7,337	41,991	49,328
Total	**414,975**	**857,341**	**1,272,317**

16.1.2 Where people with dementia receive care and support

The following table provides estimates of the number of people with dementia living at home, in various types of residential care and in hospitals or psychiatric institutions:

Place of residence	YES or NO	Estimated number/Additional information
At home (alone)	Yes	Small percentage
At home (with relatives or close friends)	Yes	80%*
At home (with other people with dementia)	No	
In general/non-specialised residential homes	Yes	Small percentage with MCI
In specialised residential homes for people with dementia	No	
In general/non-specialised nursing homes	Yes	15% (CENSIS)
In specialised nursing homes for people with dementia	Yes	5%*
In hospitals, special wards or medical units	No	
In psychiatric establishments	No	

It is estimated that more than half of all residents in general/non-specialised nursing homes have dementia. Ratios of staff to residents are not available.

In June 2012, the region of Lazio enacted the local law DPC99/2012 "Assistenza territoriale residenziale a persone non autosufficienti, anche anziane." Amongst other things, this law regulates the amount of time spent by nursing home workers with each resident during a working day:

- Nurses: 36 minutes per day per resident,
- Physiotherapists: 25 minutes,
- Healthcare workers: 70 minutes,
- Other staff: 9 minutes.

This corresponds to the entire staff devoting 140 total minutes of care per day per resident.

16.2 The organisation of care and support for people with dementia

16.2.1 The overall organisation of care and support

Diagnoses for dementia are made by specialised Alzheimer evaluation units called UVA. A diagnosis is followed by a therapeutic plan that includes drug prescription and administration.

In a small minority of regions, this will also include the provision of specific care, e.g. day care, home care, etc. However, in most regions this remains the responsibility of the patient's family, which will frequently seek support from local Alzheimer associations.

16.2.2 How specific aspects of care and support are addressed

There is no national policy on the provision of care and support. However, some Italian regions have adopted guidelines and the Emilia-Romagna and Lazio regions have enacted local laws. The number of services varies with the quality of the care home; the "top end" care homes provide many more services and facilities than the average home.

16.3 Training

16.3.1 Which social and healthcare professionals provide care and support

The following social and healthcare professionals are involved in the provision of care and support to people with dementia in residential care or living at home.

Social or healthcare professional	Involved in the provision of care and support to people with dementia in residential care or at home
Nursing staff	Yes
Auxiliary staff	Yes
Allied health professionals	Yes
Specialists (e.g. psychiatrists, gerontologists, neurologists)*	No
General practitioners*	Yes
Other	Yes: geriatricians and psychologists

* Only if they are linked to the provision and organisation of care and support (i.e. not with regard to their role to provide medical treatment).

16.3.2 The type of training that social and healthcare professionals receive

The Ministry of Health authorises training courses in all medical subjects including dementia (ECM, Educazione Continua in Medicina) for all of the professions above except the auxiliaries. Training for auxiliary staff is provided by the regions.

The ECM courses are attended by health professionals on a voluntary basis and according to their needs. Attendance is not required by law and there is no central register of course attendance or completion.

16.3.3 How the training of social and healthcare professionals is addressed

There is no national training policy, as Italy does not have a National Dementia Plan.

16.4 Support for informal carers

There is no official support for informal carers. However, the "top-quality" centres provide support, usually in cooperation with local Alzheimer associations.

Section 1.5 below describes the services provided by Alzheimer Uniti Onlus.

16.5 National Alzheimer Association

The table below lists services provided by Alzheimer Uniti Onlus.

Helpline	✓
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	✓
Care coordination/Case management	✓
Home help (cleaning, cooking, shopping)	
Home care (personal hygiene, medication)	✓
Incontinence help	
Assistive technologies / ICT solutions	✓
Tele Alarm	✓
Adaptations to the home	✓
Meals on wheels	
Counselling	✓
Support groups for people with dementia	✓
Alzheimer cafes	✓
Respite care at home (Sitting service etc.)	✓
Holidays for carers	
Training for carers	✓
Support groups for carers	✓
Day care	✓
Residential/Nursing home care	✓
Palliative care	✓

16.6 References

Italian National Institute of Statistics (2011). “*Resident population - Final data: Resident population by sex, age class and citizenship - Final data*”. Accessed on 31 July 2013 at http://dati.istat.it

Italian Longitudinal Study on Aging (ILSA) study, conducted by the Consiglio Nazionale delle Ricerche (CNR), www.cnr.it

Study conducted by CENSIS, www.censis.it

16.7 Acknowledgements

Luisa Bartorelli, Geriatrician and President of Alzheimer Uniti Onlus.

17 *Jersey*

17.1 Background information

17.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Jersey in 2011 as being 1,401. This represents 1.43% of the total population of 97,857. The number of people with dementia as a percentage of the population is slightly below the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	35	20	55
60 – 64	6	25	31
65 – 69	35	30	64
70 – 74	55	72	128
75 – 79	94	118	212
80 – 84	119	194	313
85 – 89	93	222	315
90 – 94	34	163	197
95+	12	73	85
Total	**483**	**918**	**1,401**

The above figures are from 2011 as these were the most recent populations statistics available from The States of Jersey Population Census for Jersey alone i.e. not combined with Guernsey.

17.1.2 Where people with dementia receive care and support

The following table provides estimates of the number of people with dementia living at home, in various types of residential care and in hospitals or psychiatric institutions.

Place of residence	YES or NO	Estimated number/Additional information
At home (alone)	Yes	
At home (with relatives or close friends)	Yes	
At home (with other people with dementia)	Yes	
In general/non-specialised residential homes	Yes	
In specialised residential homes for people with dementia	Yes	
In general/non-specialised nursing homes	Yes	
In specialised nursing homes for people with dementia	Yes	
In hospitals, special wards or medical units	Yes	
In psychiatric establishments	No	

The exact figures for the number of people in each of the above categories and the percentage of the residents in those categories who have dementia are unknown but there is a move to make funding available to establish these numbers.

17.2 The organisation of care and support for people with dementia

In 2011, the Health and Social Services department commissioned a report by KPMG entitled 'A Proposed New System for Health and Social Services' which ultimately resulted in a proposal of the States of Jersey Council of Ministers, 'Health and Social Services: A New Way Forward', outlining significant changes to the way healthcare is administered in Jersey. This proposition was adopted by the Government in 2012 and work is now underway to implement the recommendations within it. Dementia was identified as a priority and the Health and Social Services department is currently in the process of implementing three services specifications for people with dementia, namely:

1. Mental Health Liaison Service to support people with dementia in care homes and acute settings.
2. Community Mental Health Team caring for people with dementia in the community
3. Memory Assessment Early Diagnosis Service enhancing the role of the Memory Clinic.

These specifications outline the enhancement of existing services and the provision of new services to support people with dementia.

Meanwhile, people with dementia are supported by their GPs and via the Memory Clinic by way of an allocated care co-ordinator. They are able to access other services via their care coordinator such as occupational therapists and continence advisors.

17.3 Training

17.3.1 Which social and healthcare professionals provide care and support

The following social and healthcare professionals are involved in the provision of care and support to people with dementia in residential care or living at home.

Social or healthcare professional	Involved in the provision of care and support to people with dementia in residential care or at home
Nursing staff	Yes
Auxiliary staff	Yes
Allied health professionals	Yes
Specialists (e.g. psychiatrists, gerontologists, neurologists)*	No
General practitioners*	No

* Only if they are linked to the provision and organisation of care and support (i.e. not with regard to their role to provide medical treatment).

17.3.2 The type of training that social and healthcare professionals receive

Training in what dementia is and in person centred care is available for care home and care agency staff but this is not mandatory at present.

17.3.3 How the training of social and healthcare professionals is addressed

The training of professionals is currently piecemeal but it is hoped that a fourth service specification will be drawn up to address this area which will include a professional development manager who will be responsible for all aspects of dementia training.

17.4 Support for informal carers

A specific fund has been allocated by the Health and Social Services Department to provide all forms of respite for people with dementia including residential respite and respite in the home environment.

17.5 National Alzheimer Association

The Jersey Alzheimer's Association provides the following services and support.

Helpline	✓
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	
Care coordination/Case management	
Home help (cleaning, cooking, shopping)	
Home care (personal hygiene, medication)	
Incontinence help	
Assistive technologies / ICT solutions	✓
Tele Alarm	
Adaptations to the home	
Meals on wheels	
Counselling	✓
Support groups for people with dementia	✓
Alzheimer cafes	✓
Respite care at home (Sitting service etc.)	
Holidays for carers	
Training for carers (also from St John Ambulance)	✓
Support groups for carers	✓
Day care	✓
Residential/Nursing home care	
Palliative care	

All the funds for the Jersey Alzheimer's Association come from donations and fundraising, apart from an annual grant of £14,160 from Health and Social Services Department. Running costs are budgeted to be approx. £100,000 p.a. The Associations feels that it would not be able to do what it does without the continuing generosity of the businesses and individuals. The Association also offers the following support and services:

Saturday Club

A service for people in all stages of dementia that gives carers a break, either for the day or for an hour or two. Transport and a three-course lunch are provided, along with a variety of activities. Staff members are fully trained in all aspects of person-centred dementia care and training is constantly updated. Around 15 – 20 people attend each week and the staff/client ratio is high so it is possible to provide more personalised care and activities. An open referral system is operated although guests are frequently referred by their Community Psychiatric Nurse or Social Worker.

Musical Memories

A music therapy programme specifically designed for people in all stages of dementia, their families and carers. The programme involves singing, seated exercises and playing instruments. Attendance varies from 20 to 46 including groups from care homes.

Training & Education

Workshops are organised in schools and other youth organisations to give young people an understanding of what happens when a person gets dementia and how it can affect the family unit. All students are presented with a Certificate following the session. Students from Jersey College for Girls attend the Musical Memories sessions as part of their enrichment programme. They also do a short course on Understanding Dementia. Two-hour workshops on understanding dementia are offered to professional organisations and local companies who may come into contact with people with memory problems and confusion during their daily work.

School Projects

For the past two years, students on the Alternative Curriculum and at Greenfields have been creating artwork, photographs and woodcraft to brighten up Government-run wards. The Manager of the Jersey Alzheimer's Association meets all new students at the beginning of term and talks a little about what it is like to live with dementia.

Carpenter

A volunteer professional carpenter does small carpentry jobs for people with dementia in their own homes, free of charge for those who might have financial difficulties. The Jersey Alzheimer's Association has agreed to purchase any extra materials he might need.

17.6 References

States of Jersey (2012). *Health and Social Services; a new way forward. States of Jersey.* Can be downloaded at:
http://www.statesassembly.gov.je/AssemblyPropositions/2012/P.082-2012.pdf

See also: http://www.gov.je/Government/Pages/StatesReports.aspx?ReportID=591

http://www.gov.je/SiteCollectionDocuments/Government%20and%20administration/R%20CensusReport%2020120808%20SU.pdf

Williams, R. (2012). *A proposed new system for health and social services; integrated community services: people living with dementia*, Version 2. Can be downloaded from:

http://www.gov.je/SiteCollectionDocuments/Government%20and%20administration/R%20HSSD%20OBC%20Dementia%2020120912%20MC.pdf

17.7 Acknowledgements

Kim Averty, Honorary Secretary, the Jersey Alzheimer's Association

18 Latvia

18.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Latvia in 2012 as being 35,714. This represents 1.6% of the total population of 2,234,572. The number of people with dementia as a percentage of the population is slightly above the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	718	436	1,153
60 – 64	100	622	721
65 – 69	772	945	1,717
70 – 74	1,197	2,607	3,804
75 – 79	1,860	4,309	6,170
80 – 84	2,274	7,052	9,326
85 – 89	1,341	6,721	8,062
90 – 94	495	3,234	3,729
95+	145	887	1,032
Total	**8,902**	**26,812**	**35,714**

19 Lithuania

19.1 Background information

19.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Lithuania as being 47,335. This represents 1.44% of the total population of 3,292,454. The number of people with dementia as a percentage of the population is somewhat lower than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	1,054	645	1,699
60 – 64	139	870	1,009
65 – 69	1,036	1,273	2,308
70 – 74	1,580	3,376	4,956
75 – 79	2,632	5,889	8,521
80 – 84	3,351	9,337	12,688
85 – 89	2,029	8,626	10,655
90 – 94	634	3,932	4,565
95+	113	820	933
Total	**12,567**	**34,768**	**47,335**

19.1.2 Where people with dementia receive care and support

The following table highlights where people with dementia live.

Place of residence	YES or NO	Estimated number
At home (alone)	Yes	No available data
At home (with relatives or close friends)	Yes	
At home (with other people with dementia)	Yes	
In general/non-specialised residential homes	Yes	
In specialised residential homes for people with dementia	No	
In general/non-specialised nursing homes	No	
In specialised nursing homes for people with dementia	No	
In hospitals, special wards or medical units	Yes	
In psychiatric establishments	Yes	

No data were available on the percentage of people with dementia as a percentage of the population living in such establishments.

The general number of personnel working in elderly and disabled people care homes (included people with dementia) is 5,900. In addition, there are approximately 570 social workers and 2,121 social workers' assistants.

19.1.3 The organisation of care and support for people with dementia

The Law on Social Services (dated February 20, 2006, No X-493) stipulates that the main aim of social services is to provide assistance to a person or family who, by reason of age, disability, social problems, partially or completely lacks or has lost the capability to care independently for him/herself and to participate in society.

Social services are provided to all residents in need. The need for such services is assessed according to a combination of principles of co-operation, participation, complexity, accessibility, social justice, relevance, efficiency, comprehensiveness. The provision of support is tailored to the individual's stage of dependency and capacities to compensate for this loss of independence.

Social services will be provided to an older person by creating the right conditions for the person to live at home, with the family and manage independently his/her household for as long as possible. The social services will organise the assistance combining personal healthcare and special assistance measures, thus maintaining social relationships with the family, relatives and society.

Social services shall be provided to a person with a severe disability by ensuring a safe and healthy environment, assistance respecting human dignity, and the coordination of personal healthcare, assistance, education to help compensate for the lost independency as well as ability to maintain social relationships with the family and society.

Social services are provided under the social assistance system.

People with dementia can benefit from informal or formal care at home care or short term care and long term care in social care institutions.

Social services can be provided by public or private providers. People have free choice of services provider.

Organisation of care in national policies

- Action Plan of National citizens' outcome of ageing consequences strategy

  This Plan approved by Resolution of Government January 10, No 5, 2005, includes measures to ensure social care establishments offer quality activities to the elderly; to make a proper diagnosis of chronic non-communicable diseases and to improve their treatment by increasing accessibility of services, and to encourage expansion of medical rehabilitation services for the elderly. These measures include improvement of the fate of people with dementia and Alzheimer's disease. The final implementation is scheduled in 2013.
- Integrated Help at Home Development Programme

  The main goal of this programme started in 2012 is to ensure the accessibility and expansion of social care services (including nurse care services) and integrated home support for the elderly, disabled adults and children and for family members by consulting and involving informal carers (volunteers, neighbours and other) into the process.

The Lithuanian health system's development framework 2011-2020 has increased funding to facilitate the integration of nursing and support care, palliative care and home nursing services.

- Standards of care and support

The Social Care Standards were approved by the Minister of Social Security and Labour in 2007. (Decree of the Minister of Social Security and Labour dated April 20, 2007, No A1-46). The standards cover:

- Controlling and monitoring care and support

Social care institutions are responsible for the quality of social care provided. The Department of Supervision of Social Services under the Ministry of Social Security and Labour is responsible for the assessment, control and supervision of social care, according to Licencing Rules of Social Care Establishments approved by Resolution of Government dated May 16, No 528, 2012.

- Interdisciplinary cooperation and coordination

According to the law on Social Services, the management, granting and provision of social services is based on co-operation and mutual assistance between a person, family, community, the organisations defending the interests and rights of social groups of people, social services establishments, municipal and state institutions;

- Needs assessments

Individual needs are assessed and should be provided in a timely, fair and appropriate manner according to the specific needs of the person.

- Staffing levels

Personnel working in social care establishments and providing home care is regulated by the Social Care Standards of Work Time for Workers Providing Social Care (Decree of the Minister of Social Security and Labour dated November 6, 2006, No A1-317).

- Funding and control bodies

State, municipality budgets, EU Structural Funds are the funding and control bodies for the implementation of the various programmes.

- Complaint procedures

According to the Law on Social Services dated February 20, 2006, No X-493, the Department of Supervision of Social Services under the Ministry of Social Security and Labour investigate complaints of social care establishments, common interest and social attendance services. All clients (users, carers) are informed that they have the right to appeal against decisions and to make complaints about their care. Also, user forums, councils of residents of social care establishments give them the opportunity to appeal or to raise a variety of issues with a view to influencing and improving their stay.

- Involving people with dementia in decisions about care and support

Legislation addressing the provision of care in residential care homes is regulated by the Law on Social Services dated February 20, 2006, No X-493, Social Care Standards (Decree of the Minister of Social Security and Labour No A1-46, 2007), Licensing Rules of Social Care Establishments approved by Resolution of Government dated May 16.

Social services are provided to a person (family) taking into consideration the individual interests and needs of the person (family) of this Law and continuously assessing the efficiency of the social services provided in respect of development or compensation for the person's (family's) possibilities and abilities to care for his private (family) life or to participate in society.

Services and support for people with dementia and their carers

- Help at home

  People in need of home help are regularly visited by social workers or social workers' assistants. Local municipalities estimate the need for social care. Social attendance or social care at home includes performance of housework and care by home helpers.

  Social care services include services which are provided by a team of specialists (social workers, social workers assistants, healthcare, assistants and others depends on the need) at a person's home.

  Elderly and disabled people can receive day care services at home from 2 hours till 8 hours per day up to 7 times per week, short - term care (respite care) up to 8 hours per day till one month at person's home.

  In some cases, when it is impossible to organise social services in monetary form, services may be changed into a cash allowance. This target benefit is paid for foster families, people with disability, elderly and their families in order to ensure social assistance. Cash allowance financed from the municipal budgets.

- Day care and short-term care

  Elderly and disabled people can receive day care services in day care centres from 3 hours per day up to 5 days per week in institutions.

  Short-term social care (respite care) for elderly and disabled people not less than 12 hours per day till 6 months per year or 5 days per week or termless in institution.

  Day care and short-term care is financed from the State or municipal budgets or special targeted subsidies of the state budget to municipal budgets.

- Residential care

  Residential care is provided for children and adults with disabilities and elderly people in social care homes (old age homes, specialised social care homes, social care homes for disabled people, independent living home, etc.)

  Residential care is financed from the State or municipality budgets or special targeted subsidies of the State budget to Municipality budgets.

19.2 Training

19.2.1 Which social and healthcare professionals provide care and support

The following social and healthcare professionals are involved in the provision of care and support to people with dementia in residential care or living at home.

Social or healthcare professional	Involved in the provision of care and support to people with dementia in residential care or at home
Nursing staff	Yes
Auxiliary staff	Yes
Allied health professionals	Yes

Services for people living at home, in social care establishments and others can be provided by social workers, assistants of social workers, individual care personnel, nurses, assistants, etc.

19.2.2 The type of training that social and healthcare professionals receive

According to the Social Workers and Social Workers' Assistants Qualification Law (Decree of the Minister of Social Security and Labour dated April 5, 2006, No A1-92) social workers should have trainings (16 academic hours) every year and receive a certificate. Also, Social Workers' Assistants should have trainings (16 academic hours) every year.

The 'Methodological Centres' are responsible for the preparation of specific training programmes for the social workers and their assistants. These centres are social care organisations, which provide residential care, home care or day care centres. They use their own experience or invite other professionals to prepare the programmes and provide training. The programmes must be evaluated by the Department of Supervision of Social Services under the Ministry of Social Security and Labour (the 'Department'). An Evaluation Committee with evaluate the programme before receiving approval by the director of the Department. The number of hours of the training is specified by the programme. The social workers who have followed the training will receive a certification recognised at state level.

Dementia is included in the programmes provided by the Methodological Centres. There are 206 programs for the social workers and 107 for their assistants. Themes such as care of people with dementia, changing behaviour and other themes in relation to gerontology are included in the programmes.

Nurses, doctors and other health specialists should have continuous training. Once a year, nurses must follow 60 academic hours of training, and doctors 120 hours. For specialists who work directly with older people and people with dementia or Alzheimer's disease, the Methodological Centres organise special qualification training courses. For instance, nurses are trained in psychosocial rehabilitation of people with mental health problems, older people with mental health problems, care features and similar themes.

19.2.3 How the training of social and healthcare professionals is addressed

The 'Social Workers and Social Workers' Assistants Qualification Law' of 2006 also stipulates that every social worker and their assistants should enhance their qualification with no less than 16 academic hours per year.

The 'Social Service Staff Competency Training Programme' (Decree of the Minister of Social Security and Labour dated April 28, 2012, No. A1-303) aims to enhance the quality and level of knowledge and competence of the social workers and their assistants who are working in social settings. The programme also aims to identify the need for trainings. The programme's training themes are related to the basic/elementary knowledge about dementia, care and support of people with dementia, behavioural and psychological symptoms of dementia and the assessment of capacity.

The competency of social workers, their assistants is supervised by the Department. The Department organises seminars for the qualification for social workers and their assistants.

The training of the staff working in social work area (such as social workers, social worker's assistants, for instance) is regulated as follows:

1. The competence of social workers is regulated by education restrictions. From 1 of July 2011, only people who have the acquired higher (university or non-university) education in social work or equivalent education shall be entitled to the position of a social worker.
2. The competence of social workers is periodically assessed during the certification. Certification of social workers is obligatory and ensured by the Senior Certification Commission of Social Workers and territorial certification commission.
3. In 2013-2015 The Programme of Competence trainings for the employees of social services establishments are implementing. According to it new evaluation of competence, competence development, oriented to development of organisation and strengthen forms of team are checking.
4. In 2012, the 'Integrated Help Development Programme' included support by consulting and involving informal carers (volunteers, neighbours and other) into social care process (including nurse services) process. The aim is to offer better quality social care services at home and increase the knowledge of all team workers (social and health sector).
5. Social workers are not only providers, they are often mediators towards policy makers, ministries, municipalities, NGO's and also make proposals.

The health professionals are restricted by requirements to provide healthcare services:

Specialisation	**Duration**
Healthcare Professional (Medical doctor – General Practitioner) *	Basic medical studies 3 years
Doctor therapist *	Basic medical studies 6 years + 5 years specialisation
Doctor in general medical practice *	Basic medical studies 6 years + 5 years specialisation
Neurologist *	Basic medical studies 6 years + 4 years of specialisation
Nurses responsible for general care	3,5 years (in College) 4 years (in University)
Assistant Nurse	360 h courses
Masseur	2 years (in vocational training school) or 160 h of specialisation after training as a masseur, nurse, midwife, physiotherapist and other health professional specialists
Physiotherapist	3 years (in College) 4 years (in University)
Occupational therapist	3 years (in College) 4 years (in University)

* These 4 professions are involved in care process

19.3 Support for informal carers

National policies support carers in the field of respite care, training, consultation, counselling and support, case management.

- The National social integration for disabled 2013-2019 programme defines implementation measures for people with disabilities and their families. Care givers are involved into the projects of social integration for people with disabilities: taking part in self-help groups, sociocultural activities, recreation camps activities and other special events for disabled and their families.
- A reform of the Conception of Special Needs System Reordering and the Conception on Development of Services for Disabled – independency and social abilities will be evaluated and expanded. The aim of conception is how to change cash allowances into social services.
- The National Demographic Strategy of Family Welfare Policy was implemented between 2011 and 2013. One of the target priorities was to consult caregivers facilitate return to the labour market.

  The aim of this measure is to ensure safe environment and high quality of services provided to elderly people, the disabled and children in stationary social care establishments by modernising current and establishing new institutions of stationary social services. Current support structures were refurbished and new stationary institutions of social services constructed, reconstructed and repaired as well as provided with necessary equipment and furniture. It is invested to small, cosy social care establishments, groupware living homes in the communities. All this was made possible thanks to the European Structural Funds.

19.4 References

19.5 Acknowledgements

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Agne Uogintiene, Ministry of Social Security and Labour

20 Luxembourg

20.1 Background information

20.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Luxembourg in 2012 as being 6,989. This represents 1.34% of the total population of 523,179. The number of people with dementia as a percentage of the population is somewhat lower than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	188	103	292
60 – 64	27	118	145
65 – 69	185	148	333
70 – 74	257	354	611
75 – 79	456	639	1,095
80 – 84	653	1,136	1788
85 – 89	410	1,248	1,659
90 – 94	127	733	859
95+	24	182	206
Total	**2,327**	**4,662**	**6,989**

According to Insight SantéSécu, an information publication of the Ministry of Health, dementia and cognitive impairment rank second among the main causes for dependency in Luxembourg. Dementia affects 33% of the beneficiaries of the 'dependency insurance'.

The average age of the beneficiaries of this insurance was 82.9 in 2010 and the majority of these were in nursing homes. Insight SantéSécu also gives a dementia prevalence ratio of 2.6 females to one male (Insight SantéSécu, 2013).

20.1.2 Where people with dementia receive care and support

The following table provides estimates of the number of people with dementia living at home, in various types of residential care and in hospitals or psychiatric institutions.

Place of residence	YES or NO	Estimated number/Additional information
At home (alone)	Yes	+/- 5%
At home (with relatives or close friends)	Yes	+/- 10%
At home (with other people with dementia)	Yes	+/- 2%
In general/non-specialised residential homes	Yes	No data
In specialised residential homes for people with dementia	Yes	No data
In general/non-specialised nursing homes	Yes	+/- 10%

Place of residence	YES or NO	Estimated number/Additional information
In specialised nursing homes for people with dementia	Yes	+/- 40%
In hospitals	No	
In psychiatric establishments	Yes	

The percentage of people living in general/non-specialised residential homes who have dementia is unknown. The lack of data also goes for the number of people with dementia living in general/non-specialised nursing homes.

However, according to the Ministry of Health in 2000, 46% of people receiving support under the dependency insurance lived at home and 54% in a nursing or residential home. In 2010, the figures were 45% and 55% respectively (Ministry of Health, 2013).

The ratio of staff to residents in general/non-specialised residential homes, general/non-specialised nursing homes, specialised residential homes for people with dementia and in specialised nursing homes for people with dementia is also unknown

20.2 The organisation of care and support for people with dementia

20.2.1 The overall organisation of care and support

In Luxembourg, the care of people with dementia is organised by the Parliament and the Ministries that are competent in this domain. If a person needs to go into a care home, this person is responsible for payment of the rent, food and washing. Medicine and care assistance are paid by the national dependency or care insurance schemes of Luxembourg.

Information on dementia and how to use care allowances is provided by the Alzheimer Luxembourg Association, the Parliament, Ministries, the long-term insurance body, nursing and care institutions. "Memory walks" are also opportunities to provide information.

The long-term care insurance – 'Assurance dépendance'

Long-term care insurance (the so-called 'dependency insurance') came as a response to the demographic ageing of the population and the lack of adequate support in the existing structures. Following a report on the dependence of older people in 1992, some recommendations were made: set up a global project to manage the dependency of older people, promote a flexible organisation of care around the older person, set up training in geriatrics, brainstorm on the management of psychological dependence, reform the nursing homes for older dependent people, reinforce the efficacy of home care and introduce the idea of a forum that would link up all actors on the ground.

The long-term insurance law was voted in 1998 and came into force in 1999. Dependence then became a risk covered by the Social Security of Luxembourg. The dependency insurance became the fifth pillar of the social security system; it became obligatory with the objective of protecting citizens against the danger of poverty linked to the high costs of long-term care. Access to this insurance was unconditional, i.e. not dependent upon age or place of residence.

The law has four leading principles: priority is given to home care before resorting to nursing home care; rehabilitation prior to care; support in kind before support in cash; as well as continuity in care.

Dependency is clearly defined in the 1998 law. The central concept of the definition is the need for support supplied by a third person:

- The cause of dependency must be a mental disease or a similar deficiency.
- The care need must cover activities of daily living.
- The intensity threshold of the need is 3.5 hours a week.
- The physical capacity to engage in activities of daily living as well as the psychological and mental capacity of the person must be considered with the exclusion of any other consideration.
- The care need must be for at least six months.

Having access to an independency allowance is an individual measure, based upon the support and care required. Based on the information gathered by the professional in charge of the evaluation, the necessary support and care are laid out in a care plan.

The law was modified in 2005. The modifications did not affect the fundamental aspect of the 1998 law but the concept of quality was introduced to the support and care provided. This also applies to the health professionals and informal carers. In 2008, the Committee for the quality of allowances (Commission de qualité des prestations) set up a pluri-annual work plan insisting on the improvement of the quality of the information targeted at users. The 2005 modifications also introduced greater flexibility in the access to care.

The new law provided for the setting up of a couple of new bodies (Ministère de la Sécurité Sociale, 2013):

- the Committee for the quality of allowances: its mission is to propose reference norms and standards for the quality of support and care, for technical aids and home adaptation.
- the Evaluation and Orientation body was given control over the quality of the support and care provided to the dependent person as well as control over the appropriateness of the support given to the dependent person.

Services in kind and direct payments

Services in kind can be converted into direct payments. This is limited to the support and care that allow the person to engage in activities of daily living:

- For up to seven hours of support and care to enable activities of daily living, the allowance can be converted in full.
- Between seven and fourteen hours, half of the allowance can be converted
- Over fourteen hours, no conversion is possible.
- The maximum that can be received in cash corresponds to 10.5 hours per week (Kerger, 2013).

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

The dependency insurance is financed by the State budget (35% of the spending in 2012 and 40% in 2013), part of the 'electricity tax', and the tax-payers dependency contribution (Kerger, 2013).

The contribution base is made up of the professional income, substitution income (revenus de remplacement) and patrimony.

The dependence contribution rate is currently fixed at 1.4% ((Ministère Sécurité Sociale, 2013)

Now that the dependency insurance has been in existence for 15 years, it is observed that spending increases 1.8 times more rapidly than the number of beneficiaries. In 2010, the average total annual cost was EUR 31,500. Costs related to activities of daily living remain the highest costs. They have tripled since the introduction of the dependency law. Support care activities, however, show a far sharper increase.

The financial stability of the dependency insurance is fragile: the reserve gradually diminishes. The balance will become negative in 2013. To keep a viable system, the contribution rate necessary to keep the balance between income and spending is estimated at 1.43% in 2013. It should reach 1.73% in 2013 (Insight SantéSécu, 2013).

In-kind support is paid directly to the providers. Cash support is given directly to the dependent person (Kerger, 2013).

Organisation of the long-term insurance (dependency insurance)

- The National Health Fund (Caisse Nationale de Sécurité – CNS) takes the decisions and establishes the budgets.
- The Consultative Committee gives advice on the measuring instruments that assess dependency.
- The Evaluation and Orientation body will assess dependency as well as the quality and quantity of the allowances.
- The Quality Committee sets up standards for the quality of care.

Four types of service providers match the living place of the dependent person: networks of support and care, semi-stationary centres, long-term care nursing homes and intermittent care nursing homes.

The conditions for the service-providers to be accredited are clearly spelled out: the service provider must have an accreditation from the relevant ministry and adhere to the framework convention that defines the relationship between the Caisse Nationale de Santé (CNS – National Health Fund) and the providers by signing a support and care contract.

The service providers are members of COPAS, the Confederation of care and service suppliers (Confédération des Organismes Prestataires d'Aides et de Soins) (Kerger A., 2013; Ministry of Health, 2013)

The dependency insurance stipulates that each support or care activity is granted a standard duration. This will be used to evaluate the threshold of the allocated allowances.

The need of care must cover the essential tasks of daily living. The minimum requirement is 3.5 hours per week for at least six months (Insight SantéSécu, 2013).

20.2.2 How specific aspects of care and support are organised

The provision of care and support is addressed by national policies in the area of residential and home care. This covers standards of care and support, continuity of care and support, interdisciplinary cooperation and coordination, staffing levels, the promotion of well-being and autonomy, the respect of individuality and cultural diversity, the involvement of people with dementia in decisions about care and support.

Types of care

- **Day care**

  The long-term care insurance – dependency insurance covers specialised day care.

  In the case of home care, in-kind and cash allowances can be combined so the beneficiary gets optimal care. This is referred to as mixed or combined allowances.

  The dependency insurance stipulates the following; basic life activities: 24.5 hours per week, 38.5 hours per week in exceptional situations, support activities: 14 hours per week, housework activities: 2.5 hours per week with another 1.5 hours for exceptional housework activities.

- **Palliative care**

  Palliative care in hospitals is covered by the national health insurance, under the hospital budgets. The law concerning palliative care, advance directives and end-of-life care was voted in 2009.

  Extra-muros (outside hospital) palliative care is covered by the dependency insurance. It concerns support and care in activities of daily life, support for house-keeping, an allowance for the purchase of necessary cleaning and care products. Medical and therapeutic care is covered by the national health insurance.

  Since 2004, the Ministry for the Family and Integration provides financial support for palliative care at home, on the basis of a convention (Ministry of Health, 2013).

  Today, the average cost of palliative care per beneficiary for the dependency insurance is EUR 6,207 euros. The average daily cost paid by the dependency insurance is EUR 154.96. The Ministry for the Family and Integration and the national health insurance contribute another EUR 150 and the national health insurance pays for the GPs, nursing care and physiotherapy. However, it is not always easy to say if this support is always linked to end-of-life care.

  The Hëllef Doheem Foundation and the Help network, have created specialised units for the delivery of palliative care at home:

Home adaptations

Home adaptations are covered by the dependency insurance. The first law of November 1999 laid out the modalities and limits to support home adaptations. Since 2007, the formalisation of the procedure aims at finding optimal and functional solutions for the beneficiary.

The support of the dependency insurance can only be granted with a view to maintain the individuals in their home (article 23 of the December 2006 law). Home adaptations can be supported up to EUR 26,000 (Kerger, 2013).

20.3 Training

20.3.1 Which social and healthcare professionals provide care and support

The following social and healthcare professionals are involved in the provision of care and support to people with dementia in residential care or living at home.

Social or healthcare professional	Involved in the provision of care and support to people with dementia in residential care or at home
Nursing staff	Yes
Auxiliary staff	Yes
Allied health professionals	Yes
Specialists (e.g. psychiatrists, gerontologists, neurologists)*	Yes
General practitioners*	Yes
Other	Yes (psychotherapists)

* Only if they are linked to the provision and organisation of care and support (i.e. not with regard to their role to provide medical treatment).

20.3.2 The type of training that social and healthcare professionals receive

The training of social and healthcare professionals is not covered by any healthcare or social policies. The national dementia strategy that was that was adopted in March 2013 includes a measure that will evaluate the continuous training needs of the professionals in various settings (long-term nursing homes, hospital settings) (Ministry of Health, Ministry of the Family and Integration, 2013).

20.3.3 How the training of social and healthcare professionals is addressed

The training about dementia for social and healthcare professionals is at the discretion of the establishment where these professionals work. In general, the nursing staff, auxiliary staff, social sector professionals and allied professionals such as language therapists, physiotherapists, dieticians and podiatrists do receive some training.

The training of social and healthcare professionals employed in residential or home care settings also depends on the establishments where these people work. They receive specialised knowledge about dementia, basic/elementary knowledge about dementia, training about the care and support of people with dementia as well as palliative or end-of-life care training.

The training of healthcare professionals is in the form of continuous training for the staff and other people working in the domain of care.

20.4 Support for informal carers

20.4.1 Respite

All the daily activities organised to care for a dependent person also seek to provide respite care to the informal carer.

Nuetswaach, an experimental project, carried out by the Hëllef Doheem Foundation in collaboration with the Evaluation and Orientation Body between March 2011 and February 2012, sought to provide respite care to the informal carers by organising a night watch of the dependent person (Ministry of Health, 2013).

Since then, a measure of the national dementia strategy includes the possible introduction of a new item under the dependency insurance, namely a night watch.

Another measure of the national dementia strategy is awareness-raising amongst informal carers about existing respite care support.

20.4.2 Counselling / support

With the introduction of the dependency insurance, support groups have been set up all over the territory. The Hëllef Doheem Foundation and the Help network organise support groups to help informal care for the affected family member.

A measure of the national dementia strategy is to provide information accessible to a wide public about the various forms of dementia and the existing care support. With the support of new communication technologies, this measure should reach out to the carers of people with dementia.

20.4.3 Case management

Another measure will seek to evaluate the information, orientation and counselling needs of people with dementia and their carers. A contact point would be identified to help the family to navigate the system.

20.5 Alzheimer Association

The Alzheimer Association of Luxembourg provides the following services and support:

Helpline	✓
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	✓
Care coordination/Case management	✓
Home help (cleaning, cooking, shopping)	
Home care (personal hygiene, medication)	
Incontinence help	
Assistive technologies / ICT solutions	
Tele Alarm	
Adaptations to the home	✓
Meals on wheels	
Counselling	✓
Support groups for people with dementia	✓
Alzheimer cafes	✓
Respite care at home (Sitting service etc)	
Holidays for carers	
Training for carers	✓
Support groups for carers	✓
Day care	✓
Residential/Nursing home care	✓
Palliative care	✓

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21 Malta

21.1 Background information

21.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Malta in 2012 as being 5,301. This represents 1.26% of the total population of 419,212. The number of people with dementia as a percentage of the population is somewhat lower than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	142	78	219
60 – 64	31	143	173
65 – 69	181	155	336
70 – 74	230	335	565
75 – 79	379	563	942
80 – 84	415	796	1,211
85 – 89	311	819	1,130
90 – 94	152	447	598
95+	39	88	126
Total	**1,878**	**3,423**	**5,301**

According to a recent study using EuroCoDe prevalence data (Scerri and Scerri, 2012), there were 5,198 people with dementia in 2010 (not including the under 60 age group, which, in the above table, is based on prevalence rates from the EURODEM study). This is expected to increase to 6,071 in 2015, 7,175 in 2020, 9,883 in 2030, 12,372 in 2040 and 12,955 in 2050. No data is available on the estimated number or percentage of people who have dementia but have not been diagnosed.

21.1.2 Where people with dementia receive care and support

The following table provides estimates of the number of people with dementia living at home, in various types of residential care and in hospitals or psychiatric institutions.

Place of residence	YES or NO	Estimated number/Additional information
At home (alone)	Yes	Low
At home (with relatives or close friends)	Yes	High
At home (with other people with dementia)	Yes	Very low
In general/non-specialised residential homes	Yes	High
In specialised residential homes for people with dementia	No	None exist
In general/non-specialised nursing homes	Yes	High

Place of residence	YES or NO	Estimated number/Additional information
In specialised nursing homes for people with dementia	No	None exist
In hospitals, special wards or medical units	Yes	Very low (very few units are available
In psychiatric establishments	Yes	Very low

No precise data is available concerning the percentage of residents with dementia living in general/non-specialised residential homes or general/non-specialised nursing homes. However, the number of individuals with dementia in each is considered to be significantly high.

The ratio of staff to residents in general/non-specialised residential homes and in general/non-specialised nursing homes is usually adequate for elderly residents who do not have dementia. Although there are no specialised residential homes or specialised nursing homes for people with dementia, there are units housing individuals with dementia. In these units, the ratio of staff to residents is less than 1:3, which is considered inadequate.

21.2 The organisation of care and support for people with dementia

21.2.1 The overall organisation of care and support

Most of the care for people with dementia is provided in the community by family members (Innes, Abela and Scerri, 2011).

As Malta is so small (316 km^2), all policies are promulgated and passed by the national government. There are consequently no formal regional or district tiers of healthcare. 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 that 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/widowers 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 NGOs.

In 1987, the Government set up the Department of Elderly and Community Services (within the Parliamentary Secretariat for the Elderly and Community Care) 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). Following the change in government in March of 2013, the Parliamentary Secretariat for the Elderly and Community Care was renamed as Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing under the remit of the Ministry for the Family and Social Solidarity.

Services are not targeted specifically for people with dementia and they are slow to respond especially in times of crisis. Entry to a long-stay government home may take months to arrange due to long waiting lists.

As mentioned above, social support, when provided, is organised through the Department of Elderly and Community Services. Social Workers are responsible for conducting assessments for people in state hospitals or in the community. 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.

Healthcare and services are funded through general taxation. The healthcare 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 (for example to purchase medicine that is not reimbursed under the National Health System). Private healthcare is fairly common (Ministry of Health, 2002). National (social) insurance serves to fund pensions.

There is no problem with accessibility to services and support, even for people living in rural areas, although many services need to be up-graded. Services for individuals with dementia in the community such as day care, respite care and community psychiatric nurses are scarce. There are associations for people with conditions that mean they are at a higher risk of developing dementia e.g. Huntington's disease or Down's syndrome. There are no special provisions for people with dementia and carers from minority ethnic groups.

21.2.2 How specific aspects of care and support are addressed

Although the Malta Dementia Strategy has not yet been published, sections addressing the provision of care and support are included. These should cover both residential (central and private) and home care settings. The main objectives of the strategy in this particular area include:

a. Provide training opportunities for professionals and other staff within healthcare services to help in the management and care of people with dementia.
b. Set up a liaison service that specialises in the treatment of dementia in acute general hospital. The multidisciplinary team may be based in the general hospital or visit the hospital on a regular basis.
c. Ensure that all patients with dementia have a care plan developed during their hospital stay after consultation with specialists in this field. Individual care plans will address activities of daily living that maximise independent activity, enhance function, adapt and develop skills and minimise the need for support.

d. Offer rehabilitation services to people with mild-to-moderate dementia following a stay in acute hospital if there is a need for it. This service will seek to equip the patient to return to the community. Assessment of the needs of carers will also be undertaken. People with severe dementia may need more specialised services to meet their physical, psychological and mental health needs.
e. Develop dementia specialist units within the community to assess and care for people with dementia.
f. Enhance the dementia rehabilitation programme.
g. Strengthen human resource capacity of memory classes.
h. Extend the operating hours of the Dementia Activity Centre thereby increasing flexibility for patients and carers.
i. Provide training to staff working in community day centres in order to be able to deal with behavioural and physical needs of people with dementia as well as creating an activity programme suitable for these patients.
j. Make appropriate transport services available to take patients to and from activity centres.
k. Develop a Dementia Liaison Interdisciplinary team which will serve as a point of referral and support for people with dementia and their families/carers in order for the family to gain easy access to services, according to their needs.
l. Provide additional support for the Dementia Helpline, as this serves as an important source of information and support to people with dementia and their carers.
m. Provide home support programmes: this includes both specialised home help for individuals with dementia and respite services in the community. This will require the training of a team of certified care-workers and the appointing of a dementia home-help coordinator. Different forms of respite care will become available to accommodate patients' needs.
n. Increase the number of beds dedicated to institutional community respite for people with dementia, thereby increasing availability.
o. Assist in the setting up of a voluntary service for the elderly in the community with the aim of providing companionship to individuals with dementia as well as the elderly in general, as well as providing some respite to carers.
p. Assist in the creation of a network to help individuals with dementia and their carers in having peer support. This may be achieved by boosting non-government organisations working in this field.
q. Provide financial assistance to purchase/rent new assistive technologies e.g. safety alarms, fall alerts, wandering alarms, as well as to provide continued support in other assistive technologies, e.g. telecare

Most of the care is provided in the community by family caregivers. Other support is offered by the government in the form of:

a. *Memory Clinic*: The Memory Clinic is a specialised out-patient clinic for individuals aged 60 years and above, who have symptoms such as increasing forgetfulness and/or confusion that may possibly indicate the onset of dementia. The clinic is run by a team of professionals who carry out a thorough assessment of the patient's condition, functional status and living situation. If dementia is confirmed, then further information about the condition, advice about treatment options and support services will be provided.

b. *General Geriatrics Clinic*: Many patients with a diagnosis of dementia also attend the general geriatric out-patient clinics at the Rehabilitation Hospital Karin Grech, since cognitive impairment commonly exists concurrently with other co-morbid illnesses in older people.

c. *Dementia Rehabilitation Programme*: A Dementia Rehabilitation Programme is currently being offered after the patient is assessed at the Memory Clinic. Here further assessments are carried out by the occupational therapists and speech language pathologists. Functional ability, cognitive assessments, domestic, language and swallowing assessments are carried out according to need.

d. *Memory Classes*: Memory Classes are organised at Rehabilitation Hospital Karin Grech. The classes take the form of 10 parallel sessions, one for the person with dementia and a separate information session for caregivers and relatives.

21.3 Training

21.3.1 Which social and healthcare professionals provide care and support

The following social and healthcare professionals are involved in the provision of care and support to people with dementia in residential care or living at home.

Social or healthcare professional	Involved in the provision of care and support to people with dementia in residential care or at home
Nursing staff	Yes
Auxiliary staff	Yes
Allied health professionals	Yes
Specialists (e.g. psychiatrists, gerontologists, neurologists)*	Yes (usually gerontologists)
General practitioners*	No

* Only if they are linked to the provision and organisation of care and support (i.e. not with regard to their role to provide medical treatment).

21.3.2 The type of training that social and healthcare professionals receive

Social and healthcare professionals in the residential care and home care setting receive the following training:

Nurses need to have a BSc degree in Nursing Studies issued by the University of Malta to practice the profession. Dementia training is covered in topics related to Geriatrics and Neurology. However, such training is limited and inadequate (Scerri and Scerri, 2013).

No formal training is provided to auxiliary staff and learning occurs mostly through work experience. Occasional talks on dementia management and care are organised by the Malta Dementia Society. These are open to all, including non-professionals. Informal talks are also organised by residential care/home care settings but no data is available on number of attendees and job description.

Social sector professionals as well as allied health professionals (e.g. language therapists, physiotherapists, dieticians, podiatrists) receive very limited training, if any, in dementia.

21.3.3 How the training of social and healthcare professionals is addressed

The Malta Dementia Strategy is still in its draft form and is not yet published. However, it is envisaged that it will contain a section relating to the development of the workforce in the various aspects of dementia management and care. This will include undergraduate and postgraduate training (through collaboration with the University of Malta), training of health and social care staff (also in collaboration with the Malta Dementia Society), specialisation in the context of developing a multidisciplinary team (by increasing collaboration between different categories of healthcare professionals), training of caregivers (in collaboration with the Malta Dementia Society and government-supported dementia care homes), and increase in specialised training to boost the number of medical specialists in the field of dementia.

Meanwhile, most training is provided as undergraduate programmes in the various healthcare disciplines at the University of Malta. However, coverage of dementia in programmes at undergraduate level is low, variable and most of the time fragmented. Furthermore, most training focuses on the medical model leaving out the social context of the condition. In the recent years, there has been increased interest in expanding the level of dementia training at undergraduate and postgraduate levels. Indeed, one of the objectives of the Malta Dementia Strategy is to develop, in collaboration with the University of Malta, undergraduate level study units on the medical, social, psychological and economic aspects of dementia for all health and social care students. An interdisciplinary team approach will be fostered and emphasised using appropriate teaching methodologies, starting at this level. The strategy also highlights the need for continuous professional development to update skills.

21.4 Support for informal carers

The support of carers is addressed in national policies in the following ways.

21.4.1 Respite

Respite Care is provided for a limited period of time through government-supported residential/nursing homes. Respite is also provided by the dementia activity centre during working days/hours. The national dementia plan aims to increase respite also in view of the fact that the numbers of people with dementia in Malta is expected to rise considerably in the coming years. Furthermore, due to the current decrease in the birth rate, family care and support is expected to decrease significantly.

21.4.2 Training

Most of the training for carers is provided by the Malta Dementia Society through the organisation of talks and seminars. The aim of the strategy is also to increase dementia training to caregivers in collaboration with the Malta Dementia Society.

21.4.3 Consultation/involvement in care decisions

With regard to consultation/involvement in care decisions, involvement in dementia care decisions is currently at the discretion of the specialist. The national plan aims to increase the involvement of people with dementia and caregivers/family members in decision-taking.

21.4.4 Counselling/support

Most of the Counselling/support for caregivers is currently provided by the Malta Dementia Support Group which organises activities for people with dementia and their caregivers.

21.4.5 Case management (insofar as this relates to care)

The national plan will put an emphasis on developing a care pathway specific to each and every person with dementia according to their needs. The inclusion of home care support programmes should also help in this regard.

Services relating to carer support are currently very limited and most carers are of the opinion that they are left to fend for themselves following a dementia diagnosis. The launch of the Dementia Helpline was a step in the right direction, as for the first time carers coming from the community could be advised on the best practices. However, the much needed services for individuals with dementia have yet to materialise. Psychological, palliative and end-of-life support is absent. The dementia activity centre is well attended but lacks a transport infrastructure and will certainly not cope with future demand. Monitoring of residential units housing individuals with dementia needs to be improved to reflect current best practices. Assistive technology to support caregivers at home (as clearly indicated in the national plan) should also be introduced as soon as possible.

21.5 National Alzheimer Association

The Malta Dementia Society provides the following services and support.

Helpline	✓
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	
Care coordination/Case management	
Home help (cleaning, cooking, shopping)	
Home care (personal hygiene, medication)	
Incontinence help	
Assistive technologies / ICT solutions	
Tele Alarm	
Adaptations to the home	
Meals on wheels	
Counselling	
Support groups for people with dementia	
Alzheimer cafes	✓
Respite care at home (Sitting service etc)	
Holidays for carers	
Training for carers	✓
Support groups for carers	✓
Day care	
Residential/Nursing home care	
Palliative care	

Some of the above services, which are not provided by the Malta Dementia Society, are provided for free (or against a nominal fee) by the Maltese government. These include home help, home care, incontinence help, a telecare system, meals on wheels, day care and residential/nursing home care. As of November 2013, the telecare system was improved to include a wider range of services aimed at increasing independent living.

21.6 References

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21.7 Acknowledgements

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22 Netherlands

22.1 Background information

22.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in the Netherlands in 2012 as being 245,560. This represents 1.47% of the total population of 16,714,228. The number of people with dementia as a percentage of the population is somewhat lower than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	5,637	3,127	8,765
60 – 64	1,090	4,882	5,972
65 – 69	7,882	6,242	14,125
70 – 74	9,804	12,769	22,573
75 – 79	15,665	21,448	37,112
80 – 84	20,500	35,934	56,343
85 – 89	14,765	41,265	56,030
90 – 94	6,748	28,788	35,536
95+	1,156	7,858	9,014
Total	**83,247**	**162,314**	**245,560**

22.1.2 Where people with dementia receive care and support

The following table provides estimates of the number of people with dementia living at home, in various types of residential care and in hospitals or psychiatric institutions.

Place of residence	YES or NO	Estimated number/Additional information
At home (alone)	Yes	70% (alone, with relatives or close friends, with other people with dementia)
At home (with relatives or close friends)	Yes	See above
At home (with other people with dementia)	Yes	See above
In general/non-specialised residential homes	No	
In specialised residential homes for people with dementia	Yes	30% (in specialised residential homes for people with dementia, in general/non-specialised nursing homes, in specialised nursing homes for people with dementia, in hospital, special wards or medical units, in psychiatric establishments, and others
In general/non-specialised nursing homes	Yes	See above
In specialised nursing homes for people with dementia	Yes	See above
In hospitals, special wards or medical units	Yes	See above
In psychiatric establishments	Yes	See above

22.2 The organisation of care and support for people with dementia

22.2.1 Overall organisation of care

Standards of care and support

Since July 2013 a national standard on dementia (de Zorgstandaard Dementie) was developed (http://www.alzheimer-nederland.nl/actueel/nieuws/2013/juli/zorgstandaard-dementie-en-publieksversie-gereed.aspx). These are guidelines for the provision of integrated care to people with dementia. They span the whole spectrum of disease development: from the first concerns such as forgetting things, to the terminal stage of the disease. The guidelines are broadly accepted and now implemented by the most prominent and important professionals working in dementia healthcare.

Organisation of care

- At national level: the 'Delta Plan Dementia' (http://www.alzheimer-nederland.nl/extra/deltaplan-dementie.aspx)

  In the summer of 2011, Alzheimer Nederland, VUmc Alzheimer Centre and the national umbrella organisation of medical university hospitals (NFU) took the initiative for a new national plan. In May 2013, the organisation launched the 'Delta Plan Dementia' alongside insurers, business partners and other parties. The main goal of this plan is scientific research for future patients and better care for patients today. It also takes the carers into account.

  The plan includes the setting up of a national register, for instance.

  The government donated a financial incentive of EUR 32,000,000 for this purpose.

  The name "Delta Plan" was chosen, as it reflects the increase in the number of people with dementia in a similar way to the expected flood of 1953. After the flood, a national strategy was formed to fight a possible new flood. Embankments along the coast and dikes in river areas were built and great pieces of land were reclaimed.
- At regional level: insurers stimulate regions to form networks on dementia care. Alzheimer Nederland participates in every region. At the moment there are 90 dementia regions involving different stakeholders who work together for better dementia care in their region. Alzheimer Nederland encourages the regions to use the national standard on dementia.
- At local level: Municipalities are also responsible for their citizens, providing them with good information to be able to participate in social networks for instance.

  The Social Support Act (Wet maatschappelijke ondersteuning, WMO), which came into force in the Netherlands on 1 January 2007 covers the care and support of people with prolonged illness, invalidity or age-related diseases.

  Under 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".

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.

When writing this report, the Netherlands was preparing a national transition. Governmental budgets for care were going to be decentralised to the municipalities. The budgets for day care for people with dementia are concerned by this change. This implies that municipalities must understand what people with dementia and their carers need. Alzheimer Nederland encourages municipalities to become dementia friendly. Therefore, the organisation introduced a service page on its website (www.alzheimer-nederland.nl/gemeenten). It gives information about figures, facts and leaflets about dementia.

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

Since 2006, there has been a new 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 pays a nominal premium to the health insurer. Everyone with the same policy pays the same insurance premium. 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 small rebate if no claim is made during the preceding year. This scheme, known as the 'no-claim rebate rule', was introduced in 2005. 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.

The legal framework surrounding the provision of social support

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.

Social support to people with dementia and carers is provided in the framework of this new Health Insurance Act (Zorgverzekeringswet) 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).

The suitability of social support for people with dementia and carers

- 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.

- 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.

- 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.

- 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.

- 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.

22.2.2 How specific aspects of care and support are addressed

Services and support for people with dementia and their carers

- 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.

- 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.

- 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).

- 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.

- 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.

Personal assistance and home help

- 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 healthcare 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.

- 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.

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.

22.3 Training

22.3.1 Which social and healthcare professionals provide care and support

The following social and healthcare professionals are involved in the provision of care and support to people with dementia in residential care or living at home.

Social or healthcare professional	Involved in the provision of care and support to people with dementia in residential care or at home
Nursing staff	Yes
Auxiliary staff	Yes
Allied health professionals	Yes
Specialists (e.g. psychiatrists, gerontologists, neurologists)*	Yes
General practitioners*	Yes
Other	Yes

22.4 Support for informal carers

There is no national policy regarding informal carers of patients with dementia, but there is a national policy for informal carers in general. Besides that, the local authorities are obliged by law to support informal carers in their community.

Every two years Alzheimer Nederland carries out a broad survey on the perceived impact of caring on caregivers. The results are used to identify solutions to improve the situation.

22.4.1 Respite

The local authorities are obliged by law (Vmo) to support informal carers in their community, e.g. by providing respite care.

22.4.2 Training

Training is available for carers. It is partly funded by the State and partly by the service users.

22.4.3 Counselling/support

The local authorities (municipalities) are obliged by law to support informal carers in their community, for example by giving information, respite care, advice, emotional support, practical help and financial support.

22.4.4 Work/tax related support for carers and carer allowances

- 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 a 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 monthly payment from public funds (Pijl, 2003).

- 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).

- Flexible working time

  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).

- 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).

22.5 National Alzheimer Association

Alzheimer Nederland provides the following services and support:

Helpline	✓
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	✓
Care coordination/Case management	
Home help (cleaning, cooking, shopping)	
Home care (personal hygiene, medication)	
Incontinence help	
Assistive technologies / ICT solutions	
Tele Alarm	
Adaptations to the home	
Meals on wheels	
Counselling	
Support groups for people with dementia	
Alzheimer cafes	✓
Respite care at home (Sitting service etc)	
Holidays for carers	
Training for carers*	✓
Support groups for carers	✓
Day care	
Residential/Nursing home care	
Palliative care	

* Web-based/help training for carers (Alzheimer experience is a web-based film for those who wish to become an Alzheimer assistant).

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22.7 Acknowledgements

Julie Meerveld, Manager Advocacy, Alzheimer Nederland

Anne-marie Bruijs, Employee Advocacy, Alzheimer Nederland

23 *Norway*

23.1 Background information

23.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Norway in 2012 as being 77,158. This represents 1.56% of the total population of 4,960,482. The number of people with dementia as a percentage of the population is fairly similar to the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter. It is not known how many people with dementia are not diagnosed.

Age group	Men with dementia	Women with dementia	Total
30 – 59	1,641	880	2,520
60 – 64	313	1,377	1,690
65 – 69	2,240	1,763	4,003
70 – 74	2,457	3,244	5,701
75 – 79	4,056	5,448	9,504
80 – 84	6,374	10,418	16,792
85 – 89	5,467	13,920	19,387
90 – 94	2,855	10,999	13,854
95+	529	3,177	3,706
Total	**25,932**	**51,226**	**77,158**

23.1.2 Where people with dementia receive care and support

The following table provides estimates of the number of people with dementia living at home, in various types of residential care and in hospitals or psychiatric institutions.

Place of residence	YES or NO	Estimated number/Additional information
At home (alone)	Yes	60% (Engedal and Haugen, 2005)
At home (with relatives or close friends)	Yes	
At home (with other people with dementia)	Yes	
In general/non-specialised residential homes	Yes	27,5% (of the total population in nursing homes)
In specialised residential homes for people with dementia	Yes	32,5% (of the total population in nursing homes)
In general/non-specialised nursing homes	Yes	
In specialised nursing homes for people with dementia	Yes	
In hospitals, special wards or medical units	No	
In psychiatric establishments	No	

People with dementia do not generally live in general/non-specialised residential homes. However, about 80% (i.e. 35,000 people) of residents in general/non-specialised nursing homes have dementia.

The ratio of staff to residents in general/non-specialised nursing homes and in specialised nursing homes for people with dementia not known.

23.2 The organisation of care and support for people with dementia

23.2.1 The overall organisation of care and support

Norway's healthcare 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).

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 healthcare 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 introduced the plan in October 2007.

The main service provider is the public healthcare service but the private sector and some NGOs sell services to the State as well. 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 care of people with dementia is organised by the municipalities of which there are 430.

Services are financed through general taxation but in some cases, service users have to also pay a small 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. Municipalities have the right to levy taxes on the population to help finance their activities (Johnsen, 2006).

Services are not adequate in the whole country. They tend to vary from one municipality to the next depending on local priorities.

The size of a Norwegian municipality varies from 1,500 to 500,000 inhabitants and there are big differences in the ability of each municipality to organise satisfactory care for people with 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.

For the time being, there is only support for one ethnic minority, the Sami people. This support was initiated by the Norwegian Alzheimer association. There are brochures for Sami people living with dementia and Sami carers in the three different Sami languages and structured education available for Sami carers. The Directorate of Health initiated a wide collaboration of different organisations to better information and services for other ethnic minorities.

The government is currently focusing on increasing day care services in all municipalities through earmarked grants.

In Norway, there are estimated 3,000 people with dementia under 65. 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 don't receive social support that is specifically designed for them.

23.2.2 How specific aspects of care and support are addressed

The following aspects of care and support are addressed in the National Dementia Strategy (Norwegian Ministry of Health and Care Services, 2008) and in the Act of 2 July 1999, No. 63 relating to Patients' Rights (see references section for link to these documents).

- Continuity of care and support,
- Needs assessments (e.g. ensuring that it is timely, fair and appropriate),
- Research into care and support,
- Communication skills with patients,
- Promoting well-being and autonomy,
- Respecting individuality and cultural diversity.

23.3 Training

23.3.1 Which social and healthcare professionals provide care and support

The following social and healthcare professionals are involved in the provision of care and support to people with dementia in residential care or living at home.

Social or healthcare professional	Involved in the provision of care and support to people with dementia in residential care or at home
Nursing staff	Yes
Auxiliary staff	Yes
Allied health professionals	No
Specialists (e.g. psychiatrists, gerontologists, neurologists)*	No
General practitioners*	No

* Only if they are linked to the provision and organisation of care and support (i.e. not with regard to their role to provide medical treatment).

23.3.2 The type of training that social and healthcare professionals receive

Within specialised nursing home units for people with dementia, the following levels of education/training have been recorded (Eek & Kirkevold 2011):

- 3 years of college healthcare (50%),
- 3 years of college with specialised training in dementia/ geriatrics,
- 21% of nurses have a Bachelor's degree,
- 7% of nurses have a Bachelor's degree and specialised training in dementia/ geriatrics,
- 9% have no relevant education.

23.3.3 How the training of social and healthcare professionals is addressed

The training of social and healthcare professionals is covered in national policies. The National Dementia Strategy states that various training programmes will be developed for internal use by municipal health and care, including training packages in basic dementia knowledge. Nursing homes and assisted living facilities can also receive grants for training programmes (The ABC of Dementia Care).

23.4 Support for informal carers

23.4.1 Respite

The development of respite services was identified as a long-term strategy and outcome target for 2015 in the National Dementia Plan in which it is stated, "Those who assume strenuous care tasks shall be offered extensive respite services and professional support. Well-set-up programmes and respite services can also give family caregivers a break from their daily routine" (Norwegian Ministry of Health and Care Services, 2008, p. 21).

23.4.2 Training

See section 17.3.3. and 17.3.7.

23.4.3 Consultation/involvement in care decisions

Section 4-6 of the Patients' Rights Act of 1999 covers the situation whereby an adult with legal capacity is not competent to consent. In such cases, his/her next of kin may consent to highly invasive treatment in terms of its extent or duration. The next of kin may also be consulted in order to determine what patient would have wanted. If a person has been declared legally incapacitated, his/her consent should be obtained if at all possible but if not, it is the guardian who would be asked to provide consent. In the context of this law, the next of kin is chosen by the patient and if s/he has not done so, an order of priority is applied starting with the spouse, followed by people with other relationships, including non-married partners.

23.4.4 Counselling/support

In the National Dementia Plan it was stated that during the first four years of the plan period the Government would ensure the spread of schools for family caregivers and support groups through a three-year development programme. The aim of the schools was described as being to provide knowledge about dementia disorders and offer support and guidance to families. The programme was to consist of preparing training materials, training course leaders and implementing measures. Such materials were to be used by municipal health and social services in giving professional guidance to users and their family members.

23.4.5 Case management (insofar as this relates to care)

In section 2-5 of the Patients' Rights Act of 1999, it is stated that any patient who requires long-term, coordinated health services is entitled to have an individual plan drawn up. Section 3-1 further states that the patient is entitled to participate in the implementation of his/her healthcare and that if the patient is not competent to give consent, his/her next of kin is entitled to participate with him/her. In addition, the patient's possible wish for another person to be present when healthcare is provided should be accommodated as far as possible.

23.5 National Alzheimer Association

The Norwegian Alzheimer Association (Nasjonalforeningen for folkehelsen) provides the following services and support

Helpline	✓
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	
Care coordination/Case management	
Home help (cleaning, cooking, shopping)	
Home care (personal hygiene, medication)	
Incontinence help	
Assistive technologies / ICT solutions	
Tele Alarm	
Adaptations to the home	
Meals on wheels	
Counselling	✓
Support groups for people with dementia	✓
Alzheimer cafes	✓
Respite care at home (Sitting service etc.)	
Holidays for carers	
Training for carers	✓
Support groups for carers	✓
Day care	
Residential/Nursing home care	
Palliative care	

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23.7 Acknowledgements

May-Hilde Garden, Expert Consultant in Dementia, Nasjonalforeningen for folkehelsen

Anne Kjersti Toft, Political Advisor, Nasjonalforeningen for folkehelsen

24 Poland

24.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Poland in 2012 as being 501,092. This represents 1.31% of the total population of 38,317,090. The number of people with dementia as a percentage of the population is somewhat lower than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	13,101	7,514	20,615
60 – 64	2,241	11,909	14,150
65 – 69	12,085	12,145	24,230
70 – 74	15,942	28,492	44,435
75 – 79	30,629	55,874	86,503
80 – 84	40,150	92,009	132,159
85 – 89	25,098	89,064	114,162
90 – 94	9,315	44,356	53,671
95+	1,808	9,358	11,167
Total	**150,371**	**350,721**	**501,092**

24.2 The organisation of care and support for people with dementia

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.

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 mostly they are not specially designed for people with dementia.

Support from the State (mainly the Ministry of Health) is inadequate and sporadic. It 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.

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.

24.3 National Alzheimer Association

The Alzheimer Association of Poland provides the following services and support.

Helpline	✓
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	✓
Care coordination/Case management	✓
Home help (cleaning, cooking, shopping)	
Home care (personal hygiene, medication)	
Incontinence help	
Assistive technologies / ICT solutions	
Tele Alarm	
Adaptations to the home	
Meals on wheels	
Counselling	✓
Support groups for people with dementia	
Alzheimer cafes	
Respite care at home (Sitting service etc.)	
Holidays for carers	✓
Training for carers	✓
Support groups for carers	✓
Day care	✓
Residential/Nursing home care	✓
Palliative care	

24.4 Acknowledgements

Alicja Sadowska, Alzheimer Association of Poland

25 *Portugal*

25.1 Background information

25.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Portugal in 2012 as being 182,526. This represents 1.71% of the total population of 10,699,333. The number of people with dementia as a percentage of the population is somewhat higher than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
60 – 64	597	3,004	3,601
65 – 69	4,495	4,146	8,641
70 – 74	6,793	10,241	17,034
75 – 79	12,262	18,518	30,780
80 – 84	16,583	29,983	46,566
85 – 89	11,667	29,720	41,387
90 – 94	5,249	17,800	23,048
95+	902	4,719	5,621
Total	**62,260**	**120,266**	**182,526**

An unrelated 2010 study found a prevalence rate of 2.7% among people aged 55-79 in northern Portugal (Belina Nunes, et al., 2010).

There is no information about the number of people with dementia who have not been diagnosed.

25.1.2 Where people with dementia receive care and support

An estimated 80% of people with dementia live at home, alone or with family. There is no significant information about the number of people with dementia living outside their homes.

Place of residence	YES or NO	Estimated number/Additional information
At home (alone)	Yes	Percentage unknown.
At home (with relatives or close friends)	Yes	Percentage unknown.
At home (with other people with dementia)	Yes	Percentage unknown.
In general/non-specialised residential homes	Yes	Percentage unknown.
In specialised residential homes for people with dementia	Yes	Percentage unknown.
In general/non-specialised nursing homes	Yes	Percentage unknown.
In specialised nursing homes for people with dementia	Yes	There are very few such homes in Portugal. Percentage unknown.

Place of residence	YES or NO	Estimated number/Additional information
In hospitals, special wards or medical units	Yes	Only if the person is hospitalised for another disease. Percentage unknown.
In psychiatric establishments	Yes	Only temporary hospitalisation. Percentage unknown.

The percentage of residents in general/non-specialised residential homes who have dementia is estimated at 30%. The same figure applies to those living in general/non-specialised nursing homes.

There is no information available on the ratio of staff to residents in specific types of residential or nursing homes. However, there are minimum ratios for all homes that depend on whether residents are "dependent" or "very dependent":

Staff	Dependent people	Very dependent people
Socio-cultural animator	1:40	1:40
Nurse	1:40	1:20
Auxiliary staff (day service)	1:8	1:5
Auxiliary staff (night service)	1:20	1:20

Non-profit organisations like Alzheimer Portugal can apply for separate, special agreements with the Social Security Ministry. These provide more financial support but carry requirements such as more staff and/or staff with higher qualifications. These agreements are possible because dementia is considered an "untypical" condition.

25.2 The organisation of care and support for people with dementia

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 healthcare programmes for elderly and dependent people.

Support for people with dementia and their carers, as for any citizen, is funded by general taxation, SNS (the National Health Service) service fees and service co-partnership.

There is no specific state department in charge of social support for people with dementia and carers. However, in 2006 the Ministry of Health and the Ministry of Work and Social Solidarity launched what they called "a new organisational model" to provide care to people in a dependency or lack of autonomy situation - The National Integrated Continued Care Network (Rede Nacional de Cuidados Continuados Integrados). This network gathers 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.

Most of the services that support people with dementia are destined for older people and don't 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.

In general, services only provide assistance to people at specific stages in the dementia process, and people often experience discontinued care. The services for older people that are available do not respond to the needs of early stage or younger people with dementia.

Unfortunately there are no specific services for people with dementia living in rural areas, but they are supported by services for older people (Aged People Services) which are run by non-profit organisations or the Church. There is no specific support for people with different kinds of dementia or for people with dementia and carers from ethnic minorities.

There is no specific organised care for people with dementia either, nor is their care and support addressed in national policy. Most (80%) of these people live at home, with or without home service and/or day care centre attendance.

There are very few nursing or residential homes specifically for people with dementia and these are operated by private companies or NGOs such as Alzheimer Portugal. These homes follow the same rules as any other nursing or residential home. There are some care quality certification systems in place, but institutions are not legally obliged to follow them. There are a very few state-run nursing homes, but these are very reluctant to accept people with dementia. In general, nursing homes do not have adequate resources to look after people with dementia.

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 association's Day Care Centre, In-Home care and other services are financially supported by the Ministry of Work and Social Solidarity.

25.3 Training

25.3.1 Which social and healthcare professionals provide care and support

The following table shows the type of social and healthcare professionals that provide care and support to people with dementia in residential care or living at home:

Social or healthcare professional	Involved in the provision of care and support to people with dementia in residential care or at home
Nursing staff	Yes
Auxiliary staff	Yes
Allied health professionals	Yes
Specialists (e.g. psychiatrists, gerontologists, neurologists)*	No
General practitioners*	No
Other	Social workers, occupational therapists, psychologists

* Only if they are linked to the provision and organisation of care and support (i.e. not with regard to their role to provide medical treatment).

Nurses, socio-cultural animators and auxiliary workers are the only types of staff required in a nursing or residential home working team.

25.3.2 The type of dementia training that social and healthcare professionals receive

All employers in Portugal must provide 35 hours per year of certified training to their employees. This is a general rule - there is nothing specific for health or social care professionals or for dementia.

25.3.3 How the training of social and healthcare professionals is addressed

There is no official dementia training for health or social care professionals.

Alzheimer Portugal is a certified training organisation and regularly conducts a variety of training programmes. However, there is no unique programme officially recommended.

25.4 Support for informal carers

There is no official support for informal carers in Portugal.

Alzheimer Portugal supplies information in its offices, by telephone or email, through its newsletter, website and Facebook page and with leaflets and brochures. The association provides psychological support and training for informal carers and hosts social involvement activities such as Memory Cafes.

25.5 National Alzheimer Association

The table below lists services provided by Alzheimer Portugal.

Helpline	
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	✓
Care coordination/Case management	
Home help (cleaning, cooking, shopping)	✓
Home care (personal hygiene, medication)	✓
Incontinence help	✓
Assistive technologies / ICT solutions	
Tele Alarm	
Adaptations to the home	
Meals on wheels	✓
Counselling	✓
Support groups for people with dementia	✓
Alzheimer cafes	✓
Respite care at home (Sitting service etc.)	✓
Holidays for carers	
Training for carers	✓
Support groups for carers	✓
Day care	✓
Residential/Nursing home care	✓
Palliative care	

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25.7 Acknowledgements

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Tatiana Nunes, Public Relations Officer, Alzheimer Portugal

Ana Margarida Cavaleiro, Training and Projects Officer, Alzheimer Portugal

Ana Sofia Gomes, Social worker, Alzheimer Portugal

26 Romania

26.1 Background information

26.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Romania in 2012 as being 270,304. This represents 1.26% of the total population of 21,387,517. The number of people with dementia as a percentage of the population is somewhat lower than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	7,459	4,252	11,711
60 – 64	1,145	6,095	7,241
65 – 69	7,216	7,184	14,401
70 – 74	11,215	19,206	30,421
75 – 79	19,986	34,356	54,342
80 – 84	23,960	47,881	71,841
85 – 89	14,542	41,079	55,621
90 – 94	4,415	17,304	21,719
95+	546	2,463	3,009
Total	**90,484**	**179,820**	**270,305**

26.1.2 Where people with dementia receive care and support

The Romanian Alzheimer Society did not have any data regarding the place of residence of people with dementia

26.2 The organisation of care and support for people with dementia

26.2.1 The overall organisation of care and support

The health system is a decentralised and pluralistic social health insurance system based on a contractual relationship between the health insurance funds and service providers.

The Ministry of Labour, Social and Family Solidarity is responsible for social support to people with dementia/dependent elderly people.

Services and benefits provided by the State are funded through an obligatory health insurance and general taxation.

Alzheimer's disease, vascular and Parkinson dementia are now recognised as handicaps.

In Romania, a specific legislation, distinct from anti-discrimination legislation, refers to 'handicap' and, until September 2010, 'persons with disabilities' were defined as those "lacking abilities to normally carry out daily activities due to a physical, mental or sensory impairment and requiring protective measures for rehabilitation, integration and social inclusion" (Article 2 of Romanian Act 448/2006 on the Protection and promotion of the rights of people with a handicap). This definition was amended in September

2010 by Emergency Ordinance 84/2010 to "persons whose social environment hinders completely or limits their access to equal opportunities in the life of society, requiring protective measures to support their integration and social inclusion, as the social environment is not adapted to their physical, sensory, psychological, mental and/or associated impairments" (Emergency Ordinance 84/2010 on amending Act 448/2006 on the protection and promotion of the rights of persons with a handicap), which goes beyond the definition of disability used in Chacón Navas as the emphasis is put on the duty to secure accessibility and on the intertwining of social and medical elements in disability (European Commission, 2012).The specific legislation on disability further maintains the definition of disability (handicap) in Article 5 (16), which was not amended following the September 2010 changes. Handicap is defined as "the generic term for impairments/ deficiencies, limitations in activity and restrictions in participation defined according to the International Classification of Functioning, Disability and Health adopted by the World Health Organisation, and which highlight the negative aspect of the interaction between the individual and the environment" (Article 3 (16) of Romanian Act 448/2006 on the Protection and promotion of the rights of persons with a handicap) (European Commission, 2012).

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. 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.

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.

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

26.2.2 How specific aspects of care and support are addressed

Day care

There have been several project proposals from local authorities (municipalities) to open day care centres but sometimes premises that were initially proposed for day care centres ended up being used for other purposes, especially if alternative usage was likely to generate a profit. 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.

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.

Palliative care

Several discrete attempts have been made by NGOs to provide palliative care at home. The Casa Sperantei from Brasov and Bucharest are good examples 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.

Personal assistance and home help

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.

In order to be provided with a personal assistant, a person has to obtain a grade one handicap certificate. For a person with dementia, the following procedure applies:

- Diagnosis of dementia from a specialist (psychiatrist, neurologist) and a form describing the evolution and symptoms. The specialist should demonstrate that the patient needs permanent supervision and recommend either the necessity of a personal assistant or institutionalisation in a long-term institution.
- An Expertise Commission for Persons with Handicap will examine the patient and his/her medical documents and will decide on the grade of handicap.

- The patient or the family should find a person willing to become the personal assistant. The personal assistant will be paid by the local authorities. Personal assistants must complete training programmes offered by local authorities.
- The patient's condition is periodically revised by the Commission.

Personal assistants are considered and treated like staff hired by the local authority. They are paid for 8 hours' work per day. They have to have a daily schedule and present an activity report every week. Their activity should be monitored by representatives of the Social Protection Departments, but the Romanian Alzheimer Society stresses that this is not always the case.

Home help

Assistance with housework, shopping and laundry services exists but must be totally funded by the service users. There are no transportation services. Help with the delivery of meals is available. 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.

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.

26.3 Training

The following social and healthcare professionals are involved in the provision of care and support to people with dementia in residential care or living at home.

Social or healthcare professional	Involved in the provision of care and support to people with dementia in residential care or at home
Nursing staff	No
Auxiliary staff	No
Allied health professionals	No
Specialists (e.g. psychiatrists, gerontologists, neurologists)*	No
General practitioners*	No
Other	Yes, certified carers

26.3.1 The type of training that social and healthcare professionals receive

Certified carers

There are two types of certified carers (as they appear in the Romanian Occupational Code): home carers for people who are ill and home carers for elderly people. They are certified on the basis of Government Ordinance. 129/200 and they are legally certified by the Ministry of Employment. Their training should be organised by providers who have been accredited by the National Council for the Professional Training of Adults.

In Romania, a person can become a certified carer after attending a training course. The course is open to anyone interested in obtaining such qualifications in order to find a job or those for whom this type of activity is a part of everyday life such as having an older family member in need of care. In order to be certified, home carers of elderly dependent people should follow 11 training modules over 360 hours of training (120 hours for theory and 240 for practice). More information, in Romanian, can be found on: http://developeyourself.wordpress.com/2011/11/24/curs-de-ingrijitor-batrani-la-domiciliu/. Any NGO that is accredited by the State can organise courses for carers. The State only sets the number of hours and curricula for these courses. The qualified people can then be hired by different organisations (state social departments, NGOs, private sector) or become authorised personnel in the field (i.e. they can be self-employed).

Private companies avoid having certified carers because the training period is too long and expensive. Most of the private companies work with untrained personnel; they only recommend "carers" and require a fee from the carer and from the beneficiary. Then the patient or the family illegally pays the carer. Taxes on wages are so high that only rich people can afford to hire a carer legally.

26.4 Support for informal carers

26.4.1 Respite

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.

26.4.2 Training

Training is available for carers. This is partly funded by the State and partly by the carers themselves. More information can be found on:

http://developeyourself.wordpress.com/2011/11/24/curs-de-ingrijitor-batrani-la-domiciliu/

26.4.3 Consultation/involvement in care decisions

The Romanian Alzheimer Society is not aware of any specific obligation to obtain service users' views about such services. It has found such specifications only in a guide issued by the Romanian Government in collaboration with the Ministry of Health and Social Protection and the National Institute for Preventing and Combating Social Exclusion of Persons with Handicap – "Occupational standards for personal assistants" author Dr. Verginia Cretu, 2003.

Moreover, the Romanian Alzheimer Society is not aware of any initiatives by service providers to obtain and assess the opinions of people with dementia and carers about the quality of home care services.

26.4.4 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, 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 177 per month.

26.5 National Alzheimer Association

The Alzheimer Association of Romania provides the following services and support:

Helpline	
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	
Care coordination/Case management	
Home help (cleaning, cooking, shopping)	
Home care (personal hygiene, medication)	
Incontinence help	
Assistive technologies / ICT solutions	
Tele Alarm	
Adaptations to the home	
Meals on wheels	
Counselling	✓
Support groups for people with dementia	✓
Alzheimer cafes	
Respite care at home (Sitting service etc.)	
Holidays for carers	
Training for carers	✓
Support groups for carers	✓
Day care*	✓
Residential/Nursing home care	
Palliative care	

* This service will be available very soon after the publication of this book.

26.6 References

Chopin, I. & Uyen, Do T. (2012). *Developing Anti-Discrimination Law in Europe. The 27 EU Member States, Croatia, Former Yugoslav Republic of Macedonia, Iceland, Liechtenstein, Norway and Turkey compared*. European Commission

26.7 Acknowledgements

Catalina Tudose, President of Romanian Alzheimer Society

Maria Moglan, Vice-President of Romanian Alzheimer Society

27 *Slovakia*

27.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Slovakia in 2012 as being 58,608. This represents 1.07% of the total population of 5,480,332. The number of people with dementia as a percentage of the population is considerably lower than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	1,965	1,106	3,071
60 – 64	294	1,548	1,841
65 – 69	1,761	1,826	3,588
70 – 74	2,129	3,936	6,065
75 – 79	3,227	6,421	9,648
80 – 84	4,142	10,180	14,322
85 – 89	2,927	10,056	12,982
90 – 94	1,201	4,873	6,075
95+	188	828	1,016
Total	**17,834**	**40,774**	**58,608**

27.2 National Alzheimer Association

The table below lists services provided by the Slovak Alzheimer’s Society.

Helpline	✓
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	
Care coordination/Case management	✓
Home help (cleaning, cooking, shopping)	
Home care (personal hygiene, medication)	
Incontinence help	
Assistive technologies / ICT solutions	
Tele Alarm	
Adaptations to the home	
Meals on wheels	
Counselling	✓
Support groups for people with dementia	
Alzheimer cafes	
Respite care at home (Sitting service etc.)	
Holidays for carers	
Training for carers	✓

Support groups for carers	✓
Day care	✓
Residential/Nursing home care	
Palliative care	

27.3 Acknowledgements

Darina Grniakova, Project Manager, Slovenská Alzheimerova spoločnost (Slovak Alzheimer's Society)

28 Slovenia

28.1 Background information

28.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Slovenia as 32,034 in 2012. This represents 1.57% of the total population 2,040,057. The number of people with dementia as a percentage of the population is slightly higher than the EU average, 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Spomincica (Forget Me Not), the Slovenian Alzheimer Association, estimates that 30,000 people have dementia in Slovenia and that 1% of people under 60 have dementia. It is also estimated that only 50% of the population with dementia has been diagnosed in Slovenia.

Age group	Men with dementia	Women with dementia	Total
30 – 59	744	405	1,149
60 – 64	131	600	731
65 – 69	830	729	1,559
70 – 74	1,182	1,830	3,012
75 – 79	1,961	3,396	5,357
80 – 84	2,398	5,730	8,128
85 – 89	1,490	6,102	7,593
90 – 94	494	3,251	3,745
95+	94	668	762
Total	**9,324**	**22,711**	**32,034**

28.1.2 Where people with dementia receive care and support

The following table provides estimates of the number of people with dementia living at home, in various types of residential care and in hospitals or psychiatric institutions.

Place of residence	YES or NO	Estimated number/Additional information
At home (alone)	Yes	
At home (with relatives or close friends)	Yes	
At home (with other people with dementia)	No	
In general/non-specialised residential homes		
In specialised residential homes for people with dementia	Yes	In Slovenia, there are homes for the elderly with residential and nursing units
In general/non-specialised nursing homes	Yes	It is estimated that 25% live in non-specialised nursing homes and nursing homes for people with dementia
In specialised nursing homes for people with dementia	Yes	

Place of residence	YES or NO	Estimated number/Additional information
In hospitals, special wards or medical units	Yes	Only temporarily, for treatment
In psychiatric establishments	Yes	Only temporarily, for treatment

According to Spomincica, there were some 17,386 residents living in homes for the elderly in 2011. Of those, 25% were estimated to have dementia at various stages (from early to late stage). Most of the homes for the elderly in Slovenia have departments dedicated to people with dementia.

Around 120 nursing homes shelter some 1,950 people with dementia.

In general/non-specialised residential homes, the ratio of staff to residents is 2 for 20 people.

28.2 The organisation of care and support for people with dementia

In Slovenia, nursing homes do not have dedicated dementia wards.

The auxiliary staff is well organised all over Slovenia. They provide meals on wheels for the people with dementia or can help with the cleaning.

For daily home support, the person with dementia or the carer must find a helper and pay for the related costs. Public social organisations or local communities can provide home support twice or 3 times a week. While these will pay part of the cost, a financial contribution will be requested from the carer.

Volunteers are rare and hard to find. This is a challenge: an increasing number of young people will be diagnosed with dementia in the future and their carers will be faced with the dilemma of how to take care of these people with being still at work.

28.3 Training

28.3.1 Which social and healthcare professionals provide care and support

The following social and healthcare professionals are involved in the provision of care and support to people with dementia in residential care or living at home.

Social or healthcare professional	Involved in the provision of care and support to people with dementia in residential care or at home
Nursing staff	Yes
Auxiliary staff	Yes
Allied health professionals	Yes
Specialists (e.g. psychiatrists, gerontologists, neurologists)*	No
General practitioners*	No

* Only if they are linked to the provision and organisation of care and support (i.e. not with regard to their role to provide medical treatment).

28.3.2 The type of training that social and healthcare professionals receive

Some of the education nurses and healthcare providers receive training during the education process. After completion of the formal education process, training of the healthcare staff very much depends on how the nursing homes are managed. Nursing home staff members can usually attend a number of different trainings. Training is provided and partly financially supported by the Ministry of health, the Ministry of labour and the Social Chamber. Some of the nursing homes also organise and financially support the training itself. The training is organised a few times per year and it usually lasts for two to three days. It is officially recognised.

28.3.3 How the training of social and healthcare professionals is addressed

Training of social and healthcare professionals is not addressed in any national policy. However, training will be included in the dementia strategy that different stakeholders are currently developing in Slovenia. At the time of preparing this report, a Dementia Working Group was working with the Ministry of Health of the new government to continue the work engaged under the previous government with the goal to produce a National Dementia Plan for Slovenia.

28.4 Support for informal carers

It is possible for an informal carer to become a 'Family Helper', but the governmental financial support is very low. Most families decide to look for help from another informal carer. This assistance is payable. The cost is around EUR 3 to 7 per hour and the price varies depending on how many hours the carer stays with the patient.

There are few organisations in Slovenia that provide help with patient's nursing, feeding, bathing, as well as bringing prepared meals to the patients at home. This support is 80% substituted by the government and provided by the local community care. It is controlled by Social Services organisations. The cost of this kind of care service is approximately EUR 3.43 per hour and 20 hours per week can be used by the patient. Additional cost is for bringing prepared meals to the patients at home.

The government provides daytime centres in nursing homes with different activities for patients with dementia. Also, supervised sections for dementia patients are available in nursing homes.

Spomincica provides activities for dementia patients and their relatives named "Forget me not". The programme runs over 10 year and the lectures are held by the medical doctors, specialists for dementia, as well as other healthcare workers involved in the dementia care. Its purpose is consultation and training at home.

The association has other subsidiary associations all over Slovenia. They organise and coordinate self-help groups once per month in all major Slovenian cities.

Spomincicaprovides support for dementia patients and their families in various ways:. it organises events such as "Alzheimer cafés" in open public spaces (library, café shops, bistro) for formal and informal carers. Here they can get new information about dementia and share their experiences.

28.5 National Alzheimer Association

The table below lists services provided by Spomincica:

Helpline	✓
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	✓
Care coordination/Case management	✓
Home help (cleaning, cooking, shopping)	
Home care (personal hygiene, medication)	✓
Incontinence help	✓
Assistive technologies / ICT solutions	
Tele Alarm	
Adaptations to the home	
Meals on wheels	✓
Counselling	✓
Support groups for people with dementia	✓
Alzheimer cafes	✓
Respite care at home (Sitting service etc)	
Holidays for carers	
Training for carers	✓
Support groups for carers	✓
Day care	✓
Residential/Nursing home care	✓
Palliative care	✓

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Aleš Kogoj, President, Spomincica

Stefania Lukic Zlobec, Spomincica

Mihela Spanja, Carer, Spomincica

29 Spain

29.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Spain in 2012 as being 818,347. This represents 1.75% of the total population of 46,771,596. The number of people with dementia as a percentage of the population is somewhat higher than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	17,375	9,481	26,856
60 – 64	2,402	11,656	14,057
65 – 69	18,472	16,098	34,570
70 – 74	26,083	37,211	63,294
75 – 79	50,021	72,307	122,328
80 – 84	76,543	131,888	208,431
85 – 89	56,821	140,923	197,744
90 – 94	26,993	92,135	119,128
95+	5,440	26,498	31,938
Total	**280,149**	**538,197**	**818,347**

30 Sweden

30.1 Background information

The National Dementia Strategy of the Swedish National Board of Health and Welfare (2010) is the first national guideline for care in dementia within the field. The guidelines emphasise evidence-based and evaluated treatments and methods of care for people with dementia and support for their next of kin. National guidelines for care in dementia include recommendations for both social services and healthcare. The guidelines include recommendations for diagnosis, person-centered care, pharmaceutical drugs, day care, accommodation and support to relatives.

The purpose of the National Board of Health and Welfare guidelines is that they will be a support for decision makers in municipalities, counties and regions so that they can control the healthcare and social services through open and systematic prioritisation. Some of the guidelines is aimed primarily at policy makers and business lines and is an aid to management and leadership at all levels of healthcare and social services. Other parts are mainly for unit managers, nurse practitioners and other health and social care staff.

30.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Sweden in 2012 as being 173,135. This represents 1.82% of the total population of 9,495,392. The number of people with dementia as a percentage of the population is somewhat higher than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	2,980	1,625	4,605
60 – 64	604	2,739	3,343
65 – 69	5,127	4,054	9,181
70 – 74	6,527	8,244	14,771
75 – 79	9,695	12,689	22,384
80 – 84	14,441	23,119	37,561
85 – 89	12,777	29,889	42,665
90 – 94	7,016	23,326	30,343
95+	1,312	6,971	8,283
Total	**60,479**	**112,656**	**173,135**

Statistics from the Swedish Dementia Registry (Svedem) are quite similar. Svedem estimates the number of people with dementia in Sweden in 2012 as being 160,000. The risk of developing dementia increases with age. Eight percent of those aged 65 or older and almost half of those 90 years or older have dementia. Dementia rarely affects people under 65. In Sweden, the estimated number of younger people with dementia is about 8,000 to 9,000, most of whom are aged between 60 and 65. Approximately 24,000 people each year develop some form of dementia and about the same number die of a dementia-related disease as a consequence of having dementia.

Approximately two thirds of people with dementia have been assessed and received a diagnosis of dementia. The National Board of Health and Welfare estimates that the effect of its recommendations on a basal and expanded investigation is that the number of investigations is increasing by about 7,000 inquiries annually.

30.1.2 Where people with dementia receive care and support

The following table provides estimates of the number of people with dementia living at home, in various types of residential care and in hospitals or psychiatric institutions. These figures are:

Place of residence	YES or NO	Estimated number/Additional information
At home (alone)	Yes	55% alone or with relatives
At home (with relatives or close friends)	Yes	
At home (with other people with dementia)	No	
In general/non-specialised residential homes	No	
In specialised residential homes for people with dementia	Yes	15% (diagnosed cases)
In general/non-specialised nursing homes	Yes	15% (diagnosed and undiagnosed cases)
In specialised nursing homes for people with dementia	Yes	15% (diagnosed cases)
In hospitals, special wards or medical units	No	
In psychiatric establishments	No	
Other (please specify)	No	

The National Board of Health and Welfare recommends that people with dementia should be able to remain living in their own home for as long as they can and wish, with the help of relatives, home care, day care and home healthcare.

Later in the disease course, the National Board believes that the social services should offer people with dementia a place in a small-scale residential care unit specifically designed for people with dementia. Social services should also work to ensure that the accommodation environment is personalised, home like and enriched and that the people who need to go outdoors are given the opportunity to do so.

The National Board also believes that social services should promote a psychosocial residential environment characterised by safety and availability, and where the person with dementia can enjoy meaningful activities throughout the day.

However, there are very large differences between municipalities in the organisation and staffing, as well as in the content, of the health and social care for people with dementia.

Younger people with dementia have special requirements, and specialist multidisciplinary services should be developed, allied to existing dementia services, to meet their needs for assessment, diagnosis and care. Day care and residential care for younger people with dementia is available in certain municipalities.

Information is not available on the percentage of residents in various residential care settings who have dementia or on the ratio of staff to residents in different establishments.

30.2 The organisation of care and support for people with dementia

30.2.1 The overall organisation of care and support

The public responsibility for care of the elderly in Sweden exists at three levels. At the national level, parliament and the government set out policy aims and directions by means of legislation and economic steering measures. At the regional level, it is the county councils that are responsible for health and medical care. At the local level, the municipalities are legally obliged to provide social services and to meet the housing needs of the elderly. People with dementia have the same rights as other fellow citizens. Further information can be obtained from the Swedish Association of Local Authorities and Regions (www.skl.se).

According to the Social Services Act, individuals in Sweden have the right to receive public service and help at all stages of life.

Social services in each municipality have the main responsibility for providing care for the elderly. This is their duty under the Social Services Act. The Act states that elderly people must be able to live and lead independent lives in safe conditions and have an active and meaningful existence in the company of others.

Examples of the most common services include home help for tasks such as shopping, laundry and cleaning, but also personal care, meals and emergency alarms. People may also apply to move to special housing accommodation. Municipalities are entitled to design health and social care services that are adapted to local conditions. This means that the support offered to elderly people may vary.

The Social Services Act, the Health and Medical Services Act and the Act concerning Support and Service for Persons with Certain Functional Impairments guide the municipalities' work on health and social care for elderly people. The municipalities are responsible for certain aspects of health and medical care for elderly people under the Health and Medical Services Act. Care of the elderly must focus on enabling elderly people to live in dignity and enabling them to feel a sense of well-being. This provision applies to both publicly and privately run operations. Under the Social Services Act, elderly people must be able to choose, to the extent that is possible, when and how they receive support and help in the home and other services. The municipalities are responsible for the financing, content and most of the actual delivery of care services.

The National Board of Health and Welfare is the expert and supervisory agency for social service activities.

30.2.2 How specific aspects of care and support are addressed

Care and support which is relevant to people with dementia and their carers is specifically addressed in various national policies.

The Healthcare Act (1982:763). Health services must be operated to meet the requirements for good health. This means that health services should be of a high quality and should meet patients' needs for security in care and treatment, be readily available, based on respect for patient autonomy and integrity, promote good contact between the patient and healthcare staff and meet the patients' needs for continuity and safety of healthcare.

The Social Services Act (2001:453). Society Social Services shall, in keeping with the principles of democracy and solidarity, promote economic and social security, equality of living conditions, and active participation in society. Activities should be organised on the basis of respect for people's autonomy and integrity.

Social services care for the elderly should give people the opportunity to live in dignity and should promote well-being. The Social Services Committee should strive to give older people the opportunity to live independently in a safe environment and have an active and meaningful life in community with others. The Social Services Act (2010:427) provides that the Social Services Committee should ensure that older people have access to good housing and provide easily accessible services to those who need support and help in their homes. The municipality will establish special housing for the service and care for older people who require special assistance. The older person should as far as possible, be able to choose when and how support and help in housing and other easily accessible services should be provided. Act (2010:427).

The Swedish Council on Health Technology Assessment

The Swedish Council on Health Technology Assessment is the authority that evaluates medical practices. Reports from The Swedish Council on Health Technology Assessment (SBU) represent a support for decision making within healthcare and describe the benefits, risks and costs of various treatments, tests or other measures. SBU strives to promote care consciously and systematically, basing its decisions on the best available scientific facts (evidence), which must be combined with clinical experience and each patient's own wishes. (See www.sbu.se for further information.)

The National Board of Health and Welfare recommendation on dementia care

Person-centred care is a central concept. Person-centred care means that staff in healthcare and social services treat the person with dementia as a person with experience, self-esteem and rights despite decreasing functions, strive to understand what is best for the person with dementia from his/her perspective, cherish the person's self-determination and the opportunity for staff to see the person with dementia as an active partner, confirm the person's experience of the world, strive to involve his/her social networks in healthcare and social services, and try to establish a relationship with the person with dementia.

National Healthcare Quality - National quality registers

In Sweden there are 73 national quality registers. Quality Registers allow for learning and continuous improvement, and they are a necessary ingredient of a modern healthcare system. The National Quality Directory is a system for monitoring and developing treatment results. It contains individual-level data on the problem, the actions taken and outcomes in health and social care. Once a record has been fully developed, it is possible to follow up the progress made in healthcare for all patients in the country.

National quality registers involve a decision group consisting of participants from the National Board of Health and Welfare, the Swedish Association of Local Authorities and Regions (SKL), the Swedish Society of Nursing and the Swedish Society of Medicine. “National Quality” is coordinated by the Swedish Association of Local Authorities and Regions.

There are four registers that are very useful in dementia care. These records are used by most municipalities in the country.

1. The “Swedish Dementia Registry” (Svedem) aims to improve the quality of dementia care in Sweden by collecting data to monitor changes in populations, diagnoses and treatment of dementia. The goal of the registry is to ensure an equivalent, optimised treatment of patients with dementia.
2. The “Behavioral and Psychological Symptoms of Dementia” (BPSD) is a national quality register. The registry is intended to ensure the quality of care provided to people with dementia. Prior training is available on how to practically apply the registry.
3. The “Senior Alert - National Quality” registry focuses on preventative care. People in care who are 65 years and older who are at risk of falling, developing pressure sores, becoming malnourished or suffering from dental/oral problems can be registered in Senior Alert.
4. The National Council for Palliative Care, supported by the National Board of Health, has established a national palliative quality registry. The purpose of the registry is to gradually improve the care of the dying. Activities that should be included in the registry are based on the stated goal to pursue palliative care according to the WHO definition and a defined mission to pursue palliative care.

For business managers and supervisors, the statistics extracted from the registry can be used to measure the burden of care, or for quality assurance and comparison with the rest of the country.

Care planning

In all the planning, the social and health services work together so that the needs of the person with dementia, both for social care and healthcare, are met. Health and social care planning, based on effective cooperation between the person with dementia, families and staff, can increase the possibility of individual self-determination and help ensure that health and social care is individualised.

30.3 Training

30.3.1 Which social and healthcare professionals provide care and support

The following social and healthcare professionals are involved in the provision of care and support to people with dementia in residential care or living at home.

Social or healthcare professional	Involved in the provision of care and support to people with dementia in residential care or at home
Nursing staff	Yes
Auxiliary staff	Yes
Allied health professionals	Yes

Social or healthcare professional	Involved in the provision of care and support to people with dementia in residential care or at home
Specialists (e.g. psychiatrists, gerontologists, neurologists)*	Yes
General practitioners*	Yes
Other	Care managers and unit managers

* Only if they are linked to the provision and organisation of care and support (i.e. not with regard to their role to provide medical treatment).

The nursing programme is comprised of 180 credits. Completion of course requirements leads to a degree in nursing (professional degree, Bachelor of Science in Nursing) and Medicine Bachelor of Nursing Science (Bachelor of Medical Science in Nursing). Supplementary education for older nurse would be desirable.

Auxiliary nurses can work in emergency care, clinics, home care, elderly care, psychiatry and group homes. Access to employment in any of the above professions requires the acquisition of between 1,350 - 1,500 points of health and social care courses. When targeting the care of older people, 100 points in dementia care must be acquired.

The National Board of Health and Welfare recommends multidisciplinary work. The people who participate in the multi-disciplinary work may vary over time. Often, doctors and nurses are the first professionals that people have contact with but as the need for care increases, other professionals become involved. This could include care managers, unit managers for older people, dementia nurses, nursing assistants, social workers, occupational therapists, physiotherapists and neuropsychologists.

In specialised residential homes for people with dementia, staff members are usually trained nurses and auxiliary nurses. In other care settings, it is very different. In one place, all the personnel might be qualified, whereas in another, 40% may have no training.

It is the aim of the National Board of Health and Welfare that staff should have at least nurse and auxiliary nurse education and special skills in dementia.

30.3.2 The type of training that social and healthcare professionals receive

There are many educational opportunities in dementia care. It is difficult to provide an equitable distribution across the country.

University and College education

The Doctors' Specialisation in dementia care consists of 60 credits. There is now an online Master's course in dementia care for general practitioners. The first course started in 2012. The programme presents the latest research in the field of dementia including diagnostics, disease mechanisms, palliative medicine and treatment. After graduating, doctors are awarded the title "Silvia Doctor". (See http://www.info@ki.se for further details.)

Nursing Specialisation in care of the elderly, 60 Credits. Specialist Nurse targeting elderly care is responsible for the promotion of health and prevention of disease and disease complications of the elderly. The education create opportunities for lifelong development and a dignified death. A base of the complex needs of the care and rehabilitation of older and professional experience as a nurse is a requirement. Available at 7 colleges in the country. (See www.regeringen.se/demestsjukaaldre for further details).

Nursing Science with specialisation in dementia - Silvia Nurse, 30 Credits.

It has a distinct nursing perspective on the palliative care philosophy with symptom control, communication and relationships, teamwork and support to families. After completion of the training you're provided the title "Silvia Nurse" by HM Queen Silvia at a ceremony at Silviahemmet, Stockholm. (See www.shh.se for further details.)

Specialisation in dementia care for auxiliary staff, 30 Credits.

The training is based on the palliative care philosophy. After completing the training, students receive a brooch and provided the title "Silvia Sister" by HM Queen Silvia at a ceremony at Silviahemmet, Stockholm. Today, there are 371 certified Silvia Sisters in Sweden. (See www.shh.se for further details.)

National skills training, 1-3 weeks.

This training is aimed at staff working in the care sector who are responsible for people with dementia. This could include registered nurses, unit managers, care managers, occupational therapists, physiotherapists, nurses and nursing assistants. There is a great emphasis on the latest research findings on Alzheimer's disease and other forms of dementia. (See www.kcgeriatrik.se for further details.)

Online Education

Dementia ABC was launched in 2010 in conjunction with the National Board of Health and Welfar who published national guidelines for dementia care. Through online education, the Swedish Dementia Centre helps ensure that the National Board recommendations are applied in assisted living communities and nursing homes and result in good dementia care across the country. The Swedish Dementia Centre also provides training for community health centres, care managers and homecare. Training for inpatient care and assisted living facilities is also planned. The courses are free of charge. (See www.demenscentrum.se for further details).

Migration School

The proportion of older people with a foreign background is increasing in Sweden. The goal of web training is to increase the knowledge of all interested parties and to adapt dementia care so that people who are born abroad receive the same quality of dementia care as that provided to native Swedes. A free dementia course in Farsi is now available on the web. (See www.kc.minneskliniken.sus@skane.se for further details).

30.3.3 How the training of social and healthcare professionals is addressed

The National Board of Health and Welfare Recommendation on Training.

The Healthcare and Social Services should provide educational opportunities to staff, mainly nurses and auxiliary nurses, who work in healthcare, nursing and the care of people with dementia. Such training should be long-term and combine practical training, supervision and feedback. Although there are no explicit requirements for education, the advantages of such training are described as being:

- To help increase staff knowledge and positively affect their behavior and attitude towards people with dementia.
- To decrease the number of behavioural and psychological symptoms in people with dementia and increase their welfare.
- To have a positive impact on their work (job satisfaction, experience of fatigue) and on nursing content through tutoring in combination with training.
- To achieve best results through long-term education combined with practical training, coaching and feedback.

Different employers then set different requirements. A good employer requires some nurse and auxiliary staff to have Silvia Sister Training. These staff may then become tutors and mentors for the other staff. A few care establishments require 7.5 credits in dementia. Many require that all of the employees in the unit have had at least a week's dementia training. Some employers require all their staff to undergo Dementia ABC training. Some jobs require new staff to read through Dementia ABC computer courses prior to starting work. Many people who work in dementia care would like to have clear training requirements.

30.4 The support of informal carers

The Social Services Act (2010: 427) addresses the care of older people and one of the provisions of this act is that the municipalities in Sweden must offer support to people caring for a loved one who is chronically sick, old or has disabilities. This includes providing support to people who care for a person with dementia. Home help services and other assistance provided to people with dementia may also be beneficial to carers and relatives. The range of initiatives varies from one municipality to the next. Typical examples include: daytime activities, home help services and assistance in the home, consultation and training, respite care, discussion groups, technical assistance, and meeting venues for friends and family. When friends and family members of people with dementia contact the Alzheimer's Association, Dementia Association and The National Association for Friends and Family, they can also receive advice and support, and share their experiences with people in similar situations through their local groups, which also organise lectures, workshops and excursions.

The National Board of Health and Welfare Recommendations on the Support of Carers

In the recommendations on the support of carers of the National Board of Health and Welfare (2010), it is stated that a combination of education, psychosocial support and different types of skills training has a positive impact both on families and on older people with dementia.

Recommendation for support for information carers:

- It is given in a structured form, i.e. there should be a manual or a procedure to follow,
- It is run by people, who are trained to provide support,
- It covers 8 to10 meetings over a period of 3 to 6 months,
- Meetings following urgent themes such as education about the disease, treatment, or what support social care offers,

- It provides practical training on how to handle difficult situations and changes in behaviour.
- It provides opportunities to practice between the meetings,
- It provides psychosocial support, such as emotional support, advice or help to manage stress.

30.5 National Alzheimer Association

The Alzheimer Association of Sweden provides the following services and support.

Helpline	✓
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	✓
Care coordination/Case management	✓
Home help (cleaning, cooking, shopping)	
Home care (personal hygiene, medication)	
Incontinence help	
Assistive technologies / ICT solutions	✓
Tele Alarm	
Adaptations to the home	
Meals on wheels	
Counselling	✓
Support groups for people with dementia	✓
Alzheimer cafes	✓
Respite care at home (Sitting service etc.)	
Holidays for carers	
Training for carers	✓
Support groups for carers	✓
Day care	
Residential/Nursing home care	
Palliative care	

30.6 References

The National Board of Health and Welfare (2010). *Guidelines and recommendations on dementia care*. [Socialstyrelsen (2010). Nationella riktlinjer för vård och omsorg vid demenssjukdom] Summary in English can accessed at:
http:www.socialstyrelsen.se/nationalguidelines/nationalguidelinesforcareindementia

Website of the Swedish Council on Health Technology Assessment: www.sbu.se/en

Website of the Swedish Association of Local Authorities and Regions: www.english.skl.se

30.7 Acknowledgements

Kristina Westerlund, Administrative Director, The Alzheimer Society of Sweden

31 Switzerland

31.1 Background information

31.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Switzerland in 2012 as being 133,722. This represents 1.73% of the total population of 7,733,709. The number of people with dementia as a percentage of the population is somewhat higher than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	2,699	1,507	4,205
60 – 64	462	2,122	2,583
65 – 69	3,473	2,882	6,355
70 – 74	4,560	6,317	10,876
75 – 79	7,659	10,972	18,631
80 – 84	10,710	19,127	29,838
85 – 89	8,637	22,821	31,458
90 – 94	4,819	17,245	22,064
95+	1,183	6,528	7,711
Total	**44,201**	**89,521**	**133,722**

In 2004, the Swiss Alzheimer Association carried out a survey and found that 1/3 of people with dementia had not been diagnosed (Nationale Umfrage, 2004). Today, the association estimates that approximately 50% of people with dementia have not been diagnosed. (Schweizerische Alzheimervereinigung, 2004)

31.1.2 Where people with dementia receive care and support

The following table provides estimates of the number of people with dementia living at home, in various types of residential care and in hospitals or psychiatric institutions (Schweizerische Alzheimervereinigung, 2003/2004).

Where do people with dementia live?	YES or NO	Estimated number/Additional information
At home (alone)	Yes	It is estimated that 21,000 people with dementia live at home.
At home (with relatives or close friends)	Yes	It is estimated that 45,000 people with dementia live at home with close relatives.
At home (with other people with dementia)	No	
In general/non-specialised residential homes	Yes	No estimates are available.
In specialised residential homes for people with dementia	Yes	No estimates are available
In general/non-specialised nursing homes	Yes	It is estimated that 22,500 people with dementia live in general/non-specialised nursing homes.

Where do people with dementia live?	YES or NO	Estimated number/Additional information
In specialised nursing homes for people with dementia	Yes	It is estimated that 22,500 people with dementia live in specialised nursing homes for people with dementia.
In hospitals, special wards or medical units	No	
In psychiatric establishments		Not stated

The percentage of residents who have dementia in general/non-specialised residential homes is 2%. In general/non-specialised nursing homes, about 60-65% of the residents have dementia (Bartelt, 2012).

31.2 The organisation of care and support for people with dementia

31.2.1 The overall organisation of care and support

In Switzerland, the healthcare system is complex. Tasks and responsibilities are distributed between Confederation, Cantons and Communities (communes). The Cantons play an important role in healthcare. They decide the planning of long-term care homes, or even have their own dementia strategies (Canton of Vaud, Geneva and Valais).

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 AHV and IVG laws). This is called the 1st pillar. The 2nd pillar is the Occupational Benefit Plans concerning old-age, survivors and invalidity, financed by the employers and the employees.

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 other home care organisations) or residential care (based on prices that are determined by the cantons (law ruling the financing of long term care). 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. This allocation is not linked to earnings or income.

Private insurance offers the possibility to take out a special insurance for this kind of costs.

The Swiss Federal Constitution lays down the following social provisions:

'Art. 41

1 The Confederation and the Cantons shall, as a complement to personal responsibility and private initiative, endeavour to ensure that:

   1. everyone has access to social security;
   2. everyone has access to the healthcare that they require;

(…)

2 The Confederation and Cantons shall endeavour to ensure that everyone is protected against the economic consequences of old-age, invalidity, illness, accident, unemployment, maternity, being orphaned and being widowed.

(…)

4 No direct right to state benefits may be established on the basis of these social objectives'.

A National Dementia Strategy will be elaborated by the Federal Office of Public Health and the cantonal directors of health. It will define objectives but the realisation of these objectives will be at a cantonal level.

The national Strategy is in the consultation phase in the moment. It will adopted by the Dialog Nationale Gesundheitspolitik in November 2013. More information can be found on: http://www.bag.admin.ch/themen/gesundheitspolitik/13916/index.html?lang=fr

The provision of care in addressed in national policies: the law on general health insurance includes rules for services (type and quantity) that will be covered by the insurance.

At federal level, everyone has access to the healthcare they require. And what the insurance has to pay. More information can be found on: http://www.bag.admin.ch/themen/krankenversicherung/index.html?lang=en

Each canton decides how many homes they need.

31.2.2 How specific aspects of care and support are addressed

The provision of care and support is addressed in federal law and in dementia plans of three Cantons.

There is a dementia action plan in the Canton of Vaud. The Canton of Valais has dementia recommendations while the Canton of Geneva has a report in view of the implementation of a cantonal Alzheimer Plan.

On 12 March 2012, the Swiss Council of States (upper house of the federal Parliament) approved a series of proposals which effectively call upon the government to prepare a national dementia plan.

On 21 November 2013, the 'Swiss national health policy dialogue' adopted its national dementia strategy. This strategy clearly spells out the necessity to act and proposes defined objectives. The main points are: access to information and individualised counselling, coordination of basic services for tailored access to early screening, diagnosis, treatment, support and care, specific training for care providers, financing of care and support adapted to the needs of the person. (See press release of the Swiss Alzheimer Association in French at: http://www.alz.ch/index.php/communiques-de-presse.html.)

The cantons will now have the responsibility of implementing this strategy.

31.3 Training

31.3.1 Which social and healthcare professionals provide care and support

Social or healthcare professional	Involved in the provision of care and support to people with dementia in residential care or at home
Nursing staff	Yes
Auxiliary staff	Yes
Allied health professionals	Yes
Specialists (e.g. psychiatrists, gerontologists, neurologists)	Yes
General practitioners	No

31.3.2 The type of training that social and healthcare professionals receive

Training of social and healthcare professionals in dementia in not addressed in any national policy in Switzerland. The country is currently developing a national policy where this will be addressed.

The training for the doctors is regulated on Federal level (see also http://www.fmh.ch/bildung-siwf.html). The training of other social and healthcare professionals is done at Federal and Cantonal level. OdASanté is the body in charge of the trainings of the continuous trainings of health professionals across Switzerland. The trainings lead to Federal or Confederation qualifications. More information about this organisation can be found on: http://www.odasante.ch/index.php?l=fr.

The amount of training in dementia that GPs receive in the course of their professional training to become a GP differs from one university to the next. Dementia is included in courses on psychiatry, geriatrics and internal medicine. GPs are obliged to do 80 hours of continuing education per year but not specifically in dementia.

There is no official standard for training in dementia but lot of courses are organised by employers. Alzheimer Switzerland started a training (or sensitisation) programme for the auxiliary personal in the homes.

Curaviva, the Association for Swiss homes and social institutions also provide training.

31.4 Support for informal carers

At the time of going to print, the Swiss national dementia strategy was approved and consequently, provisions relating to the support of carers (and people with dementia) are likely to change in coming months.

31.4.1 Respite

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.

31.4.2 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.

In Switzerland, there is a system of “bonifications pour tâches d’assistance “(allowances for caring activities). These allowances do not constitute cash allowances per se but represent a bonus added to a person’s individual pension account. In other words, a person who provides care for a family member’s benefits from an additional income. This is the first pillar of the AVS (http://www.ahv-iv.info/ahv/00161/00183/index.html?lang=fr).

In some cantons, the family carers receive a direct payment. This solution is also on the political agenda at Federal level.

31.5 National Alzheimer Association

The Swiss Alzheimer Association provides the following services and support.

Helpline	✓
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	✓
Care coordination/Case management	✓
Home help (cleaning, cooking, shopping)	
Home care (personal hygiene, medication)	
Incontinence help	
Assistive technologies / ICT solutions	
Tele Alarm	
Adaptations to the home	
Meals on wheels	
Counselling	✓
Support groups for people with dementia	✓

Alzheimer cafes	✓
Respite care at home (Sitting service etc.)	✓
Holidays for carers	✓
Training for carers	✓
Support groups for carers	✓
Day care	
Residential/Nursing home care	
Palliative care	

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31.7 Acknowledgements

Marianne Wolfensberger, Swiss Alzheimer Association

32 Turkey

32.1 Background information

32.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in Turkey in 2012 as being 331,512. This represents 0.44% of the total population of 74,508,771. The number of people with dementia as a percentage of the population is considerably lower than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	22,871	13,064	35,934
60 – 64	2,391	11,760	14,151
65 – 69	13,972	12,672	26,644
70 – 74	18,042	26,148	44,190
75 – 79	28,676	42,083	70,759
80 – 84	31,055	51,446	82,501
85 – 89	14,175	29,264	43,439
90 – 94	3,309	8,714	12,023
95+	436	1,435	1,871
Total	**134,927**	**196,586**	**331,512**

It is estimated that more than half of people with dementia have not received a diagnosis although it is likely that this percentage is now lower as awareness about dementia has significantly increased.

32.1.2 Where people with dementia receive care and support

The following table provides estimates of the number of people with dementia living at home, in various types of residential care and in hospitals or psychiatric institutions.

Place of residence	YES or NO	Estimated number/Additional information
At home (alone)	Yes	8%
At home (with relatives or close friends)	Yes	85%
At home (with other people with dementia)	No	
In general/non-specialised residential homes	Yes	2%
In specialised residential homes for people with dementia	No	
In general/non-specialised nursing homes	Yes	3%
In specialised nursing homes for people with dementia	Yes	1%
In hospitals, special wards or medical units	No	
In psychiatric establishments	Yes	1%

It is estimated that about 10% of residents in general/non-specialised residential homes have dementia. In Turkey residential homes do not usually accept people with dementia. However some of the elderly people staying in residential homes develop dementia. In general/non-specialised nursing homes, the number of residents who have dementia is about 50%.

The ratio of staff to residents in different types of accommodation is as follows:

- 1:8 in general/non-specialised residential homes,
- 1:5 in general/non-specialised nursing homes,
- 1:5 in specialised nursing homes for people with dementia.

32.2 The organisation of care and support for people with dementia

32.2.1 The overall organisation of care and support

The majority of people with dementia live at home with their relatives or they live in the house of their children. Care is provided mainly by the members of the family. Some families especially from the upper-middle class can employ professional caregivers in their houses but this is very limited.

A few nursing homes (both private and state-run) are also available. Day care centres are a new emerging trend. These are run by the municipalities in urban areas but there are not many of them. There are also some special care units like "decubitus ulcer treatment teams" which are supported by municipalities in a few major cities.

In the last two years, home visits by GPs have been initiated. In any case, GPs visit bedridden patients in their own house. In addition, a few state-run hospitals organise homecare teams including specialists. These teams are starting to visit bedridden patients at home.

32.2.2 How specific aspects of care and support are addressed

The State supports families financially. For example, depending on the disability scores of the patients, families receive funding or some financial benefits.

If people with dementia cannot be cared for at home, there are some state-run nursing homes and people with dementia can be transferred to these places.

Codes linked to nursing homes and residential homes are available. Also, there is a draft document with minimum standards for nursing homes.

The Alzheimer Association of Turkey is aware of a (draft) national ageing plan which includes medical and social issues linked to dementia.

32.3 Training

32.3.1 Which social and healthcare professionals provide care and support

The following social and healthcare professionals are involved in the provision of care and support to people with dementia in residential care or living at home.

Social or healthcare professional	Involved in the provision of care and support to people with dementia in nursing homes
Nursing staff	Yes
Auxiliary staff	Yes
Allied health professionals	Yes
Specialists (e.g. psychiatrists, gerontologists, neurologists)*	Yes
GPs	No

* Only if they are linked to the provision and organisation of care and support (i.e. not with regard to their role to provide medical treatment).

There are special high schools called "health occupation high schools" and graduates of these schools can work as nurses in Turkey. Also people who have graduated from normal high schools can apply for places on special graduate programmes in universities and after this education, they can work as nurses.

No special training is needed for auxiliary staff. People need to complete a 4-year special graduate programme to become language therapists and physiotherapists in Turkey.

32.3.2 The type of training that social and healthcare professionals receive

Nursing staff receive education about dementia in their primary training. They may have additional training but this is their choice. The Alzheimer Association of Turkey annually organises a training course where majority of the attendees are nurses. It does not organise a special training programme for auxiliary staff.

Social sector professionals receive education about dementia in their primary university training. No additional special training is required. Allied health professionals (e.g. language therapists, physiotherapists, dieticians, podiatrists) are not required to have special training in dementia.

32.3.3 How the training of social and healthcare professionals is addressed

The training of neurologists, psychiatrists and geriatricians includes specialised knowledge about dementia and about the behavioural and psychological symptoms of dementia. That of GPs, other specialists and nurses includes basic/elementary knowledge about dementia

All medical doctors (MD) have a 6-year formal education in Turkey. In this period they receive a special education related to dementia in their Neurology and Psychiatry rotation. After 6 years of education, MDs can apply for residency programmes where they need to pass a qualification exam. In the residency programmes for neurology and psychiatry there is a special training about dementia. It is not known if nurses and social sector professionals receive any special training about dementia.

32.4 Support for informal carers

There are no national policies addressing support for informal carers (e.g. respite care, training, consultation/involvement in care decision counselling and support).

32.5 National Alzheimer Association

The Turkish Alzheimer Association provides the following services.

Helpline	✓
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	✓
Care coordination/Case management	✓
Home help (cleaning, cooking, shopping)	
Home care (personal hygiene, medication)	✓
Incontinence help	
Assistive technologies / ICT solutions	
Tele Alarm	
Adaptations to the home	✓
Meals on wheels	
Counselling	✓
Support groups for people with dementia	✓
Alzheimer cafes	✓
Respite care at home	
Holidays for carers	✓
Training for carers	✓
Support groups for carers	✓
Day care	✓
Residential/Nursing home care	
Palliative care	

32.6 Acknowledgements

Başar Bilgiç, Member of the Executive Committee of the Turkish Alzheimer Association

33 United Kingdom (England, Wales and Northern Ireland)

33.1 Background information

33.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in United Kingdom in 2012 as being 1,037,791. This represents 1.65% of the total population of 62,798,099. The number of people with dementia as a percentage of the population is somewhat higher than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	19,842	11,351	31,192
60 – 64	3,601	16,969	20,570
65 – 69	27,972	23,320	51,293
70 – 74	37,905	50,617	88,522
75 – 79	64,125	84,973	149,098
80 – 84	90,051	143,537	233,588
85 – 89	71,704	172,183	243,887
90 – 94	37,134	129,610	166,744
95+	8,248	44,651	52,899
Total	**360,581**	**677,210**	**1,037,791**

According to the 2011 census, the population of the United Kingdom (UK) was 63,182,000; approximately 53.0 million in England, 3.1 million in Wales and 1.8 million in Northern Ireland.

According to the 2011 census, approximately 14 million people in the UK are aged over 60; 11,832,806 in England, 767,429 in Wales, and 358,010 in Northern Ireland.

Age	England	Wales	Northern Ireland
30 – 34	3,509,221	174,694	119,839
35 – 39	3,549,116	183,045	122,260
40 – 44	3,885,934	213,155	131,848
45 – 49	3,879,815	220,711	131,645
50 – 54	3,400,095	201,599	116,933
55 – 59	2,996,992	186,923	99,272
60 – 64	3,172,277	204,885	94,290
65 – 69	2,508,154	166,007	82,121
70 – 74	2,044,129	134,543	63,479
75 – 79	1,669,345	108,202	50,358
80 – 84	1,258,773	79,232	36,366
85 – 89	776,311	49,360	21,165
90 +	403,817	25,200	10,231

Alzheimer's Society made the following estimates for the number of people with dementia in 2012: 665,065 in England, 44,598 in Wales and 18,862 in Northern Ireland.

Estimates of the numbers of people with dementia are made by applying a prevalence estimate to the numbers of people in any given population. This estimate is then compared with the number of people diagnosed with dementia according to data in the National Health Service (NHS) Quality and Outcomes Framework (QOF) indicator number DEM1. The difference between these figures is the number of people we believe to be living with dementia in the UK without a diagnosis.

The estimates of prevalence rates that are used by Alzheimer's Society are those which were calculated in the Dementia UK report (Knapp and Prince, 2007). For this report, we commissioned academics to produce a report on numbers of people with dementia and cost of dementia to the UK. The process used to calculate the prevalence estimates was the Delphi consensus method which is explained in more detail in the report.

In 2012, 293,738 people in England had an official diagnosis of dementia; Alzheimer's Society estimates that this is 44.2% of the total number of people with dementia. In Wales, the figure was 17,184 or an estimated 38.5% of the total. In Northern Ireland the figure was 11,882 or an estimated 63.0% of the total.

33.1.2 Where people with dementia receive care and support

The following table provides estimates of the number of people with dementia living at home, in various types of residential care and in hospitals or psychiatric institutions.

Place of residence	YES or NO	Estimated number/Additional information
At home	Yes	Two thirds (of which one third live alone)
In a care home (type not specified)	Yes	Two thirds
In hospitals	Yes	Up to a quarter of hospital beds at any given time
In psychiatric establishments		No statistics or estimate available

In the UK, one-third of people with dementia live in a care home and two-thirds live in the community (Knapp and Prince, 2007). From the proportion that lives in the community, one-third of these live alone in their homes (Mirando-Castillo, 2010). At any one time, up to a quarter of hospital beds are occupied by people with dementia (Alzheimer's Society, 2009).

Recent research indicates that 80% or more of care home residents in the UK have dementia or significant memory problems (Alzheimer's Society, 2013). The ratio of staff to residents in various care establishments varies locally and regionally.

33.2 The organisation of care and support for people with dementia

33.2.1 The overall organisation of care and support

A wide range of health and social care services are available to people with dementia and their carers. There are many different types of health and social care services, including home care and day care as well as the services provided by doctors and nurses. The services available, and the way they are organised, vary from area to area. Some services are in short supply in some areas and many have to be paid for. Many services are arranged through the National Health Service (NHS) or through local authority social services. Some services are also provided by private businesses and voluntary organisations.

Many care services can be arranged through the local authority social services department. How services are organised, and the kinds of services offered, differs from one local authority to the next, but services often include equipment and adaptations, meals on wheels or frozen food delivery, home care, respite or short break services, day care and care in a care home. Many local authorities offer these services in partnership with other organisations. The local authority's role may include making a community care assessment (described in more detail in question 17) and helping to build a support plan. They may also undertake monitoring and reviews.

Care assistants may help with personal care, such as getting the person up, washed and dressed, helping with continence, changing bedding and emptying commodes, doing laundry, supervising meals to make sure the person eats properly, supervising taking medication, providing company and social activities, and putting the person to bed at night. A support plan should outline the needs and aspirations of the person with dementia and the services that are necessary to enable these needs to be met.

In England

The majority of health services, including emergency care, elective hospital care, and community and mental health services are now commissioned by Clinical Commissioning Groups (CCGs), of which there are 211 in England. This process is supported by NHS England. Social services are managed by local authorities, of which there are 152 in England.

In Wales

There are seven Local Health Boards (LHBs) in Wales which are responsible for planning and securing delivery of primary, community, secondary care services in their areas. There are also 3 NHS Trusts in Wales which have a specialised national remit. Social services are managed by local authorities, of which there are 22 in Wales.

In Northern Ireland

There are six Health and Social Care (HSC) Trusts in Northern Ireland. Trusts manage and administer hospitals, health centres, residential homes, day centres and other health and social care facilities and they provide a wide range of health and social care services to the community.

33.2.2 How specific aspects of care and support are addressed

Care services in the UK are regulated to ensure that they demonstrate adherence to essential standards. In England these standards are set out in the Care Quality Commission's (CQC) Essential Standards of Quality and Safety. In Wales, care services are regulated by the Care and Social Services Inspectorate Wales (CSSIW) according to minimum standards for care homes for older people, domiciliary care agencies, and nurses' agencies. In Northern Ireland, health and social care is regulated by the Regulation and Quality Improvement Authority (RQIA) according to the minimum standards.

A major barrier to people with dementia accessing the advice, information and support (emotional, practical and financial) that they need from social services, voluntary agencies and support groups is the fact that diagnosis rates are so poor.

Once a diagnosis of dementia is confirmed, their GP should arrange to see the person with dementia from time to time to assess changes and discuss any problems. He or she may refer the person with dementia to a specialist for help in assessing changes, and for advice on ways to deal with specific difficulties. The GP is also responsible for the general health of the person with dementia. The GP and a hospital specialist may jointly prescribe treatment, depending on the person's situation, where they live, and what medication they are already taking. Some services, such as community nursing, are arranged through the GP, either directly or after discussion with social services.

If a person is confused, has memory problems or has dementia and may need support, under the NHS and Community Care Act 1990 their local authority social services department should carry out a community care assessment. The 'community care assessment', also referred to as a 'care assessment' or a 'needs assessment', enables social services to find out what the person's care needs are, and to decide which services could help to meet those needs. This could be a range of services, as described in question 9.

The local authority must provide services to meet the needs of the person, if those needs are such that they fall within the eligibility criteria that have been set locally for the level of needs the local authority will meet. Services may be provided directly by the local authority or arranged through other agencies, such as health or housing departments, or voluntary or private organisations. The local authority can adopt up to four separate bands of needs, depending on their own financial resources, that reflect the severity of risk to a person's independence if these needs are not met. These are: critical, substantial, moderate and low needs. Due to financial pressures on their resources, most local authorities will only meet critical and substantial needs. This means that many people with dementia are not receiving the support that would help them to live well with their condition.

The local authority can charge for the services it arranges. However, only the person receiving the services will be financially assessed. The assessors will ask questions about the person's financial circumstances to see how much, if anything, they can contribute towards the cost of services. People on low incomes are exempt from payments. The procedures for charging for care in the person's own home and the amounts charged vary among local authorities, but government guidance sets out a broad framework for the local authority to follow. However, these charges can add up to a considerable sum of money over time. This 'dementia tax' punishes people for not developing a condition which would be covered by the NHS. Proposals for a cap on care costs in England are currently going through the legislative process, but Alzheimer's Society does not believe that these proposals go far enough.

Rather than receive services arranged by the local authority, the person with dementia or their carer may instead choose to be given a 'direct payment' from the local authority so they can arrange the services themselves. The local authority must be satisfied that the person is willing and able to manage a direct payment, either alone or with assistance.

33.3 Training

33.3.1 Which social and healthcare professionals provide care and support

The following social and healthcare professionals are involved in the provision of care and support to people with dementia in residential care or living at home.

Social or healthcare professional	Involved in the provision of care and support to people with dementia in residential care or at home
Nursing staff	Yes
Auxiliary staff	Yes
Allied health professionals	Yes
Specialists (e.g. psychiatrists, gerontologists, neurologists)*	No
General practitioners*	No

* Only if they are linked to the provision and organisation of care and support (i.e. not with regard to their role to provide medical treatment).

To work as a nurse in the NHS you must have a degree in nursing. Nursing degrees are offered in four different areas: adult, children, learning disabilities and mental health. Nurses who want to specialise in dementia care tend to follow the mental health nursing route.

No formal qualifications are necessary for some entry-level healthcare assistant roles. However, it is possible to start work as a healthcare assistant through an apprenticeship. There may be the opportunity to obtain qualifications in Healthcare Support Services or Clinical Healthcare Support, which may lead to roles with greater responsibility.

Many social care jobs will not require any qualifications to start with, depending on the level or type of job. It could be possible to enter the sector as an apprentice or to undertake a variety of qualifications, for example a level 2 Health and Social Care Diploma to be a care worker, a level 3 Health and Social Care Diploma to supervise others or a degree to become a social worker or an occupational therapist.

Health Education England (HEE) was established as a Special Health Authority in June 2012 to provide leadership for the new education and training system in England. HEE supports healthcare providers and clinicians to take greater responsibility for planning and commissioning education and training through the development of Local Education and Training Boards (LETBs), which are statutory committees of HEE.

There are no comparable organisations in Wales and Northern Ireland.

33.3.2 The type of training that social and healthcare professionals receive

Access to training in dementia care varies considerably across the caring professions. There is no mandatory dementia training for staff providing care in the home or working in residential homes. Details of the content of the training in dementia mentioned in the previous section are not known.

33.3.3 How the training of social and healthcare professionals is addressed

The training of social and healthcare professionals is addressed in national policies.

England

Objective 13 of the Living Well with Dementia: a national dementia strategy (2009) is 'An informed and effective workforce for people with dementia. Health and social care staff involved in the care of people who may have dementia to have the necessary skills to provide the best quality of care in the roles and settings where they work. To be achieved by effective basic training and continuous professional and vocational development in dementia.'

Actions that will be taken by the Department of Health to take on board the implications of the dementia strategy include:

- The Department to work with representatives of all bodies involved in professional and vocational training and continuing professional development to reach agreement on the core competencies required in dementia care.
- These bodies to consider how to adapt their curricula and requirements to include these core competencies in pre- and post-qualification and occupational training.
- Such changes also to inform any review of national health and social care standards.
- Commissioners to specify necessary dementia training for service providers.
- Improving continuing staff education in dementia.

The strategy states that the ambition is for curricula for undergraduate professional qualifications and continuing professional development for doctors, nurses, therapists, other relevant health service staff and social care staff to all contain modules on dementia care. There is currently a range of training and education providers in dementia care but no nationally recognised system of quality assurance for this training.

The Prime Minister's Challenge on Dementia (2012), commits to working with the sector to identify how best to improve early diagnosis of dementia through improvements in awareness, education and training and through potential improvements to the General Practitioner (GP) contract.

Wales

Improved training for those delivering care is one of four priority areas outlined in the National Dementia Vision for Wales (2011). In this vision, Welsh Government makes the commitment to improve training in dementia care by:

- developing training packages to be delivered to health and social care professionals and local authorities on dementia;
- creating training packages (learning resources) to support carers;
- oroviding additional training to Community Advice Listening Line staff.

Northern Ireland

"Improving Dementia Services in Northern Ireland: a regional strategy" (2011) commits the Department of Health, Social Services and Public Safety's (DHSSPS) HR Directorate, Health and Social Care Board, Public Health Agency and HSC Trusts to co-ordinating a training and development plan across primary, community and secondary care, in statutory and non-statutory sectors, to improve knowledge and skills in providing care to people with dementia. This plan will include the needs of those providing informal care to people with dementia.

33.4 Support for informal carers

The issue of support for informal carers is addressed in national policies.

England

The carers' strategy "Recognised, Valued and Supported" sets out actions to support carers for 2010-2014. Priorities include:

- supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages
- enabling those with caring responsibilities to fulfil their educational and employment potential
- personalised support both for carers and those they support, enabling them to have a family and community life
- supporting carers to remain mentally and physically well.

Wales

The Carers Strategy was last updated in 2007. Between November 2012 and February 2013, Welsh Government consulted on a refresh of the Strategy. We expect this to be launched in June 2013.

Northern Ireland

Northern Ireland's carers strategy Caring for Carers was published in 2006.

With regard to the support of carers in general, just as people with dementia should receive a community care assessment, unpaid carers over the age of 16 are entitled to an assessment of their own needs, if they are providing, or intending to provide, a substantial amount of care on a regular basis. Local authorities can provide carers with services in their own right. These are subject to charges or may be covered by direct payments in the same way as services for people with dementia. The same issues around the level of eligible need also apply to carers and limit the number of carers who receive support. Furthermore, many carers do not even have a needs assessment; carers may not be aware that they are entitled to this and local authorities do not proactively aim to identify people who are providing unpaid care.

Carers who spend more than 35 hours a week looking after someone with substantial care needs are also eligible to receive Carers Allowance.

33.5 National Alzheimer Association

The Alzheimer's Society provides the following services and support.

Helpline	✓
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	
Care coordination/Case management	✓

Home help (cleaning, cooking, shopping)	✓
Home care (personal hygiene, medication)	✓
Incontinence help	
Assistive technologies / ICT solutions	✓*
Tele Alarm	
Adaptations to the home	✓*
Meals on wheels	
Counselling	
Support groups for people with dementia	✓
Alzheimer cafes	✓
Respite care at home (Sitting service etc.)	
Holidays for carers	✓*
Training for carers	✓
Support groups for carers	✓
Day care	✓
Residential/Nursing home care	
Palliative care	

* The Alzheimer's Society sells some AT devices and home adaptation items in its shop and sometimes organises day trips for carers.

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33.7 Acknowledgements

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34 United Kingdom (Scotland)

34.1 Background information

34.1.1 Prevalence of dementia

Alzheimer Europe estimates the number of people with dementia in United Kingdom in 2012 as being 1,037,791. This represents 1.65% of the total population of 62,798,099. The number of people with dementia as a percentage of the population is somewhat higher than the EU average of 1.55%. The following table shows the estimated number of people with dementia between 30 and 59 and for every 5-year age group thereafter.

Age group	Men with dementia	Women with dementia	Total
30 – 59	19,842	11,351	31,192
60 – 64	3,601	16,969	20,570
65 – 69	27,972	23,320	51,293
70 – 74	37,905	50,617	88,522
75 – 79	64,125	84,973	149,098
80 – 84	90,051	143,537	233,588
85 – 89	71,704	172,183	243,887
90 – 94	37,134	129,610	166,744
95+	8,248	44,651	52,899
Total	**360,581**	**677,210**	**1,037,791**

Table 1: Estimated number of people with dementia in the United Kingdom

The population of Scotland currently stands at approximately 5.2 million. Alzheimer Scotland has calculated the estimated number of people with dementia in Scotland. For the 30-89 age groups, population projections for 2013 (2010 based) from the General Register Office for Scotland were used. For the 90+ age group, population projections for 2013 (2010 based) from the Government Actuary's Department were used. Two sets of prevalence rates were applied to the population projections. The first was from Alzheimer Europe's EuroCoDe study (2009) for ages 60+ and the second from a study conducted by Harvey1 (1998) for the under 60 age group. As can be seen from Table 2 below, it is estimated that there are 85,809 people with dementia in Scotland. Based on EuroCoDe prevalence rates, Alzheimer Scotland estimates that about 50% of people with dementia have not received a diagnosis.

Age group	Men with dementia	Women with dementia	Total
30 – 59	703	742	1,445
60 – 64	304	1,452	1,756
65 – 69	2,532	2,131	4,663
70 – 74	3,271	4,604	7,875
75 – 79	5,570	7,847	13,417
80 – 84	7,552	13,011	20,563
85 – 89	5,428	13,839	19,268
90 – 94	2,788	10,089	12,876
95+	634	3,312	3,946
Total	**28,782**	**57,027**	**85,809**

Table 2: Estimated number of people with dementia in Scotland

34.1.2 Where people with dementia receive care and support

The following table provides estimates of the number of people with dementia living at home, in various types of residential care and in hospitals or psychiatric institutions.

Place of residence	YES or NO	Estimated number/Additional information
At home	Yes	An estimated 60%
In a care home (type not specified)	Yes	An estimated 40%
In hospitals, special wards or medical units	Yes	
In psychiatric establishments	Yes	

A detailed breakdown regarding the number of people living at home and in residential care does not exist. As stated in the above table, there are an estimated 60% of people with dementia living at home and 40% living in care homes (including different forms of residential care and in long-term hospital care). This estimate is backed-up by the most recent care home research on dementia prevalence and cognitive problems in residents.

Approximately 90% of residents in care homes have dementia or cognitive difficulties (Lithgow et al., 2012). The number of people in care homes for older people is approximately 33,600 (ISD 2012). ISD is the statistical NHS information service.

Figures relating to the ratio of staff to residents in various care establishments are not available.

34.2 The organisation of care and support for people with dementia

34.2.1 The overall organisation of care and support

While some aspects of welfare provision are reserved matters for the UK Government, the provision of Health and Social Care is devolved to the Scottish Parliament. Most aspects of the social security system, which makes provision for a range of social security benefits, are the responsibility of the Department for Work and Pensions, a department of the UK Government. This includes a range of social security benefits, which provide financial assistance, such as state retirement pensions, disability benefits, and benefits for people of working age who are unable to work due to unemployment, caring commitments, or through illness or disability. Some aspects of social security are devolved to the Scottish Parliament.

Overall responsibility for health and social care in Scotland sits with the Scottish Government. The current 14 Scottish health boards and 32 Scottish local authorities have respective statutory responsibilities for the health and social care in Scotland.

The Scottish Government has recently introduced a bill to change the way in which health and social care is arranged in Scotland. The Public Bodies (Joint Working) (Scotland) Bill was introduced to Parliament on 28 May 2013. The Bill sets out a legal framework for the integration of adult health and social care in Scotland and is focussed on improving outcomes for people by providing consistency in the quality of services, ensuring people are not unnecessarily delayed in hospital and maintaining independence by creating integrated health and social care services that support people to stay safely at home for longer.

34.2.2 The legal framework for the organisation of care and support

Scotland has an established and complex legal framework for the provision of care and support, particularly in relation to care at home and in care homes.

Social care and support in Scotland is accessed through an assessment of needs. Under the Social Work (Scotland) Act 1968 local authorities have a general duty to promote social welfare by making available advice, guidance and assistance to "*persons in need*". The Act also creates a duty on local authorities to undertake an assessment of need for individuals who appear to have social care needs. Local Authorities manage their resources by applying eligibility criteria thresholds. Where a person has assessed eligible needs, which meet the eligibility criteria thresholds, the local authority has a statutory duty to meet those needs. Under the Chronically Sick & Disabled Persons Act 1970 local authorities have a duty to provide services that meet assessed eligible needs.

Individuals with eligible assessed needs can choose to take a direct payment in lieu of services in order to arrange their own care and support however, take up is relatively low. The Scottish Government is introducing self-directed support legislation to ensure that individuals have greater access to a range of choices about how they arrange their own care and support.

The Social Work (Scotland) Act allows local authorities to charge a person receiving care at home services and to determine their own charging policy for non-residential care services. Charges must be reasonable and practical.

Where a person has assessed needs which may best be met within a care home, local authorities have a duty to provide or secure the provision of residential accommodation under the National Assistance Act 1948.

Where a person is unable to meet the cost of care home accommodation local authorities are obliged to carry out a financial assessment of the residents ability pay. A national legal framework (National Assistance (Assessment of Resources) Regulations 1992) set out how local authorities carry out the financial assessment. The framework sets out how a person's income and capital (including land or property owned by the resident) should be treated in order to determine the contribution he/she makes towards the cost of a care home.

The Community Care and Health (Scotland) Act 2002 introduced free personal and nursing care in Scotland for people age 65 or over. The act requires that local authorities do not charge for any care and support services which can be defined as personal or nursing care.

For people receiving care at home this means local authorities cannot charge people aged 65 or over for any personal or nursing care services although they can charge for eligible non personal care services. People assessed as needing care in a care home receive a minimum contribution, from April 2013, of £166 for personal care per week and £75 for nursing care per week (if assessed as also needing nursing care), towards the non-accommodation costs of a care home place.

34.2.3 How specific aspects of care and support are addressed

Standards of care and support

The Standards of Care for Dementia in Scotland relate to everyone with a diagnosis of dementia in Scotland regardless of where they live, their age, the supports they receive or the severity of their illness. This includes younger people, people with a learning disability and people with rare types of dementia. They apply to people living in their own homes, care homes or hospitals, especially general hospitals. These standards have been developed to help people with dementia and their carers understand their rights, and how these rights can help make sure that they receive the support they need to stay well, safe and listened to.

The standards are underpinned by two main sources of information. The first is the Charter of Rights for People with Dementia and their Carers in Scotland. The second is what people with dementia and their carers, in Scotland, have identified as being important to them and what they want from services. The standards are used in conjunction with "Promoting Excellence: A framework for health and social care staff working with people with dementia and their carers".

Content, quality and monitoring of care and support

The Regulation of Care (Scotland) Act 2001 creates the legal framework for the National Standards of Care in Scotland and for the Care Inspectorate who are a regulatory body for the registration and inspection all adult, child and independent health and social care services in Scotland. The Care Inspectorate registers care services in Scotland such as care homes, day centres and services that provide care in a person's own home. The Care Inspectorate inspects care services to make sure they are providing quality care as set out in legislation and the National Care Standards. It investigates complaints and has enforcement powers it can use to make sure poor quality services improve. The National Care Standards include standards of care at home and in care homes.

With regard to possible complaints, The Social Work (Scotland) Act 1968 sets out the legal power for Scottish Ministers to require local authorities to establish complaints procedures. All local authorities operate a complaints procedure relating to its social work functions based on Scottish Government guidance issued in 1996. The complaints process has three parts:

1. an informal problem solving stage intended to resolve complaints,
2. unresolved complaints are then investigated by specially designated staff,
3. if a complaint remains unresolved, complainant can ask for an independent Complaints Review Committee to consider it.

Promoting well-being and autonomy/Respecting individuality and cultural diversity

The Equality Act 2010 provides the legal framework for promoting equality in Scotland and rest of the UK. It is intended to simplify, streamline and strengthen the law to give individuals greater protection from unfair discrimination and sets a new standard for those who provide public services to treat everyone, with dignity and respect.

The Act harmonises the current legislation to provide the UK with a new discrimination law which protects individuals from unfair treatment and promotes a fair and more equal society. The Act replaces nine main pieces of legislation covering equal pay, sex/gender discrimination, disability discrimination and employment equality.

Involving people with dementia in decisions about care and support

See the following section for details.

34.2.4 Issues relating to care and support in Scotland's National Dementia Strategies

The Scottish Government published Scotland's second, three year, National Dementia Strategy in June 2013. The strategy sets out an ambitious plan for the period 2013 to 2016 and is based key outcomes which emerged from National Dementia Dialogue events run across Scotland in partnership with Alzheimer Scotland during 2012/13. These events brought together a broad range of stakeholders, including people with dementia and carers. The key priorities identified were:

- more people with dementia living a good quality life at home for longer,
- dementia-enabled and dementia-friendly local communities, that contribute to greater awareness of dementia and reduce stigma,
- timely, accurate diagnosis of dementia,
- better post-diagnostic support for people with dementia and their families,
- more people with dementia and their families and carers being involved as equal partners in care throughout the journey of the illness,
- better respect and promotion of rights in all settings, together with improved compliance with the legal requirements in respect of treatment,
- people with dementia in hospitals or other institutional settings always being treated with dignity and respect.

Scotland's second National Dementia Strategy (2013-2016) makes 17 commitments, all of which are in some way, either directly or indirectly, linked to the care and support of people with dementia. These are:

1. To sustain and, where appropriate improve further, dementia diagnosis rates.
2. To transform the availability, consistency and quality of post-diagnostic support by delivering the new post-diagnostic HEAT target.
3. To test and evaluate a range of approaches to providing better integrated care and support on the basis of the 8 Pillars model, centred on a Dementia Practice Coordinator role.
4. Commission Alzheimer Scotland to produce an evidence based policy document outlining the contributions of AHPs to ensuring implementation of the 8-Pillar model.
5. To take further action to support safe and supportive home environments and the importance of the use of adaptations and assistive technology, in maintaining the independence and quality of life of people with dementia and their carers.
6. To take further action to support and promote best practice in advance care planning, the assessment of capacity to consent to treatment and adherence to proper procedures for making decisions for people with dementia who lack capacity.
7. To publish a report on the implementation of the Standards of Care for Dementia in Scotland to date.

8. To continue to improve staff skills and knowledge by working with National Health Service, NHS Education Scotland and Scottish Social Services Council to take forward a second Promoting Excellence training plan across the period of this Strategy.
9. To work with NHS Education Scotland, Scottish Social Services Council, NHS Health Scotland, NHS 24 and Alzheimer Scotland to develop and launch an innovative digital platform for dementia, which will help inform and empower people with dementia and their families and carers in being equal partners in care.
10. To develop and deliver a 3-year National Action Plan to improve care in acute general hospitals.
11. To set out plans for extending the work on quality of care in general hospitals to other hospitals and National Health Service settings.
12. To work with Scottish Care, Scottish Social Services Council, NHS Education Scotland and others to assess the need for, and take further action on, improving service response around care homes, care at home and adult day care services. This will include attention to staff training and support for the implementation of the post-diagnostic HEAT target and the commitment on reducing inappropriate prescribing of psychoactive medication for people diagnosed in care homes.
13. To finalise and implement a national commitment on the prescribing of psychoactive medications, as part of ensuring that such medication is used only where there is no appropriate alternative and where there is clear benefit to the person receiving the medication.
14. To take account of the expectations and experience of people with dementia and their carers in taking forward the work on outcomes for the integration of health and social care.
15. To continue to support research through funding The Scottish Dementia Clinical Research Network and supporting the work of the new Scottish Dementia Research Consortium in its objective to bring together the range of dementia research interests in Scotland and maximise the impact of and funding opportunities for research capacity here.
16. To undertake a brief piece of work focusing on the care pathway for people with dementia in these groups, through diagnosis and support, through treatment and care, taking account of the particular challenges for carers and family members with the objective of identifying what further actions are required to ensure that each of the key improvement areas – diagnosis, post-diagnostic support, care co-ordination requires modification to take account of the needs of different groups.
17. To oversee and ensure progress on the dementia agenda and in implementing this Strategy, we will carry over from the first Strategy an Implementation and Monitoring Group to co-ordinate, support and monitor progress on the other commitments outlined in this Strategy.

With reference to commitment 10, the 3-year National Action Plan sets out 10 key actions which are linked to the implementation of the Standards of Care for Dementia in Scotland in hospitals to be overseen by an expert Dementia Standards in Hospitals Implementation and Monitoring Group. The 10 Actions are:

- Identify a leadership structure within National Health Service Boards to drive and monitor improvements,

- Develop the workforce against the Promoting Excellence knowledge and skills framework,
- Plan and prepare for admission and discharge,
- Develop and embed person-centred assessment and care planning,
- Promote a rights-based and anti-discriminatory culture,
- Develop a safe and therapeutic environment,
- Use evidence-based screening and assessment tools for diagnosis,
- Work as equal partners with families, friends and carers,
- Minimise and respond appropriately to stress and distress,
- Evidence the impact of changes against patient experience and outcomes,
- To set out plans for extending the work on quality of care in general hospitals to other hospitals and NHS settings.

Scotland's National Dementia Strategy 2013/16 builds on the work of the 2010, in particular the work to improve diagnostic rates and post diagnostic support. From April 2013 the Scottish Government has guaranteed a minimum of one year's post diagnostic support, through a link worker, for people newly diagnosed with dementia including person-centred support plan. This target will be due for delivery by 2015/16. This supports sustained independence within context of strong family and community support and promotes early decision making on future care options as part of person-centred care. The post diagnostic support guarantee is based on Alzheimer Scotland's 5 Pillar Model of Post Diagnostic Support. The five pillars are:

1. help to understand the illness and manage symptoms,
2. support to stay connected to the community,
3. peer support,
4. help with future decision-making,
5. developing a personalised care plan for their future care.

The 2013/16 Strategy also includes a commitment to test Alzheimer Scotland's 8 Pillar Model of Community Support. This model sets out an integrated and comprehensive, evidence-based approach to supporting people with dementia living at home during the moderate to severe stages of the illness. Alzheimer Scotland are currently working with the Scottish Government and other key stakeholders to identify four sites to carry forward the Scottish Governments' commitment to testing the 8 Pillars Model.

Scotland's National Dementia Strategy sits within a wider policy context which aims to transform and improve health and social care services in Scotland. Other key strands of that work include:

Integration of Health and Social Care

The Scottish Government is taking forward legislation to allow for the local integration of adult and older people's health and social care services in Scotland; the need to improve the response to dementia is one of the key policy drivers for this work and health boards, local authorities and the voluntary sector are involved in this process. See references section for link to further information.

Reshaping Care for Older People/Change Fund

The Scottish Government is investing £300 million to facilitate changes in the way services are designed and care is delivered, including services for people with dementia. Health and Social Care Partnerships will set out their intentions for the future delivery of care for people with dementia and their carers in their respective planning documents and have the ability to develop plans together through joint commissioning processes.

Carers Strategies

"Caring Together: The Carers Strategy for Scotland 2010-15", which is underpinned by £98 million of investment between 2008 and 2015, recognises that carers must be seen as equal partners in the delivery of care as their support enables people with dementia to live at home and in their own communities safely, independently and with dignity.

Self-directed Support

Self-directed support is a major reform to the way in which social care and some healthcare services are delivered and gives greater choice and control to individuals, including people with dementia and their carers, to decide how the financial resources are spent, including taking a direct payment, to arrange care and support around the their lives.

Housing

A Strategy for Housing for Scotland's Older People: 2012 – 2021 emphasises the role of housing and housing-related support in 'shifting the balance of are' towards independent living in the community and reducing the use of institutional care settings.

Palliative Care

Two reports on "Living and Dying Well" (see references section for details) promote the provision of palliative and end-of-life care to all, regardless of diagnosis, and are consistent with, and highly supportive of, improvements in care for people with dementia and their families.

34.3 Training

34.3.1 Which social and healthcare professionals provide care and support

The following social and healthcare professionals are involved in the provision of care and support to people with dementia in residential care or living at home.

Social or healthcare professional	Involved in the provision of care and support to people with dementia in residential care or at home
Nursing staff	Yes
Auxiliary staff	Yes
Allied health professionals	Yes
Specialists (e.g. psychiatrists, gerontologists, neurologists)*	No
General practitioners*	Yes (GPs play a key role in referring people with dementia to the services they need)
Other	Yes (Home Support staff from statutory (local authorities), private and voluntary sector home care providers)

* Only if they are linked to the provision and organisation of care and support (i.e. not with regard to their role to provide medical treatment).

34.3.2 The type of training that social and healthcare professionals receive

In Scotland, all health and social care staff who work with people with dementia should have some training in dementia care. In accordance with Scotland's Promoting Excellence framework (see next sub-section), the content of such training should include the following:

- Specialised knowledge about dementia.
- Basic/elementary knowledge about dementia.
- Care and support of people with dementia.
- Behavioural and psychological symptoms of dementia.
- Palliative or end-of-life care of people with dementia.

The level of knowledge covered in each of the above categories is determined by the level of practice of the groups receiving the training.

The assessment of capacity is also of relevance to the type of training received by health and social care staff who work with people with dementia. The Adults with Incapacity (Scotland) Act 2000 creates the legal framework for any intervention in the property, financial or welfare matters relating to an adult with incapacity in Scotland. The act sets out fundamental principles which must be taken into account when considering any intervention. The act also defines incapacity. There is no single mechanism for the assessment of capacity, but the Scottish Government has published "Communication and Assessing Capacity: A guide for social work and healthcare staff", to support professionals in assessing the capacity of individuals who may come under protection of the Act. The Adults with Incapacity (Scotland) Act 2000: "Code of Practice For Practitioners Authorised to Carry Out Medical Treatment or Research Under Part 5 of the Act" and the British Medical Association's (BMA), "Medical treatment for adults with incapacity - guidance on ethical and medico-legal issues in Scotland", also provide guidance for medical practitioners on assessment of capacity. Understanding the legal rights and protections of people with dementia are key components of the Promoting Excellence framework and the Standard of Care for Dementia in Scotland, including understanding how the provisions of the Adults with Incapacity (Scotland) Act 2000 relate to people with dementia. Please see the references section for details of various guides linked to the assessment of capacity.

34.3.3 How the training of social and healthcare professionals is addressed

Scotland's first national dementia strategy published in June 2010 identified that training was a significant issue for health and social care staff who work with people with dementia. The 2010 strategy made a commitment to develop a framework which sets out the knowledge, skills and behaviour expected of all health and social care staff working with people with dementia. Under the auspices of the Dementia Programme Board, chaired by Alzheimer Scotland, the National Health Service (NHS) Education for Scotland and the Scottish Social Services Council and other stakeholders, including the Scottish Dementia Working Group and the National Dementia Carers Action Network, developed "Promoting Excellence: A framework for health and social services staff working with people with dementia, their families and carers" to support delivery of the aspirations and change actions outlined in the strategy.

Promoting excellence sets out four levels of practice. These are the:

1. Dementia Informed Practice Level" which sets out the baseline knowledge and skills required by all staff working in health and social care settings including a person's own home.
2. Dementia Skilled Practice Level" which sets out the knowledge and skills required by all staff that have direct and/or substantial contact with people with dementia and their families and carers.
3. Enhanced Dementia Practice Level" which sets out the knowledge and skills required by health and social services staff that have more regular and intense contact with people with dementia, provide specific interventions, and/or direct/manage care and services.
4. Expertise in Dementia Practice Level" which sets out the knowledge and skills required for health and social care staff who by virtue of their role and practice setting, play an expert specialist role in the care, treatment and support of people with dementia.

The knowledge and skills outlined at each level are constructed in an incremental way. For example, staff operating at the 'Dementia Enhanced Practice' level would also possess the knowledge and skills, attitudes and behaviours described at all preceding levels. Given the scope of the workforce across health and social services this framework does not identify specific health and social services staff roles in relation to the framework domains. Each individual staff member and their employer must take responsibility in ensuring they correctly interpret and apply the content and aspirations of the framework to their role in relation to working with people with dementia, their families and carers.

The development of the framework was informed by a number of activities including:

- Evidence, best practice guidance and literature reviews.
- Reviews of existing competency frameworks.
- Links being made with wider UK Dementia work programmes.
- Stakeholder consultation and engagement.

The Promoting Excellence framework is underpinned by values and principles that reflect what people with dementia, and their families and carers, in Scotland, have said are most important to them. The framework emphasises the rights of people with dementia and their carers and was developed alongside the development of Standards of Care for Dementia in Scotland led by the Mental Welfare Commission for Scotland. The standards the promoting excellence framework are based on The Charter of Rights for People with Dementia and their Carers in Scotland. Please see the references section for details of these documents.

The Promoting Excellence framework is intended for use by individuals, service provider and organisational level, including education and training providers. This is achieved by assisting:

- Individual members of staff to fully understand the values, knowledge, skills and behaviours expected of them in delivering excellence in dementia care, support and treatment.

- Individual staff members, alongside their managers, to identify and explore their strengths and any gaps in skills or knowledge in the role they perform and to address any development needs.
- Organisations to ensure staff have the necessary knowledge and skills to meet the needs of people with dementia, their families and carers, and to plan development activities to meet the aspirations of excellence in dementia care, support and treatment.
- Organisations to identify any staff development needs to support the delivery of the Standards of Care for Dementia in Scotland.
- Education and training providers to inform the content of the education and training they provide and shape the design and delivery of future focused vocational and professional undergraduate and post graduate education and training.
- People with dementia, their families and carers to ensure they are aware of, and can exercise their rights and entitlements to excellence in their care, support and treatment throughout the illness and in any setting.

34.4 Support for informal carers

There are several provisions relating to carers in Scotland. These are not specific to, but do include, those who care for someone with dementia.

Two key pieces of legislation make provisions for carers in Scotland:

- Social Work Scotland Act 1968 (the duties relating to carers assessment are inserted by the Community Care & Health (Scotland) Act 2002)
- The Community Care & Health (Scotland) Act 2002

The Community Care & Health (Scotland) Act 2002 creates the following rights and duties relating to carers.

- The right of carers to ask for a "carers assessment" of their needs as carers,
- A duty on local authorities to inform carers of their right to an assessment,
- A duty on local authorities to take into account carers' views when putting together a community care package,
- Rights to assessment for parent carers, and young people under 16,
- A duty on NHS Boards to produce Carer Information Strategies, detailing how they will provide information to carers, including their right to an assessment.

These rights and duties are underpinned by the key principle that local authorities, the NHS and other support agencies should recognise and treat carers as key partners in providing care. A carer's assessment should consider whether the amount of care given by a carer is given by choice, the impact of care on the health of the carer, on his/her needs, work, relationships and social life. The carer also has the right to be involved in local authority decision making relating to the care of the person s/he supports.

In 2010, the Scottish Government published Caring Together: The Carers Strategy for Scotland 2010-15. Amongst its aims, the Carers Strategy seeks to ensure that carers have the ability to combine caring responsibilities with work, social, leisure and learning opportunities and retain a life outside of caring, and to be involved in planning and shaping the services required for the service user and the support for themselves. Issues such as respite, training, consultation/involvement in care decisions, counselling/support and case management are all covered in this documents which sets out plans for delivering on the following key issues:

- Prioritising support to carers,
- Equality issues for carers,
- Carers rights,
- Carer involvement in planning, shaping and delivering services and support,
- Identification of carers,
- Carers assessments (Carer Support Plans),
- Types of support,
- Information and advice,
- Carer health and well-being,
- Short breaks (respite),
- Carer training and education,
- Housing and housing support,
- Use of assistive technology,
- Advocacy support,
- Employment and skills,
- Tackling poverty among carers: Financial Inclusion,

34.5 National Alzheimer Association

Alzheimer Scotland provides the following services and support.

Helpline	✓
Information activities (newsletters, publications)	✓
Website	✓
Awareness campaigns	✓
Legal advice	
Care coordination/Case management	✓
Home help (cleaning, cooking, shopping)	✓
Home care (personal hygiene, medication)	✓
Incontinence help	
Assistive technologies / ICT solutions	✓
Tele Alarm	
Adaptations to the home	
Meals on wheels	
Counselling	✓
Support groups for people with dementia	✓
Alzheimer cafes	✓
Respite care at home	✓
Holidays for carers	✓
Training for carers	✓
Support groups for carers	✓
Day care	✓
Residential/Nursing home care	
Palliative care	✓

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34.7 Acknowledgements

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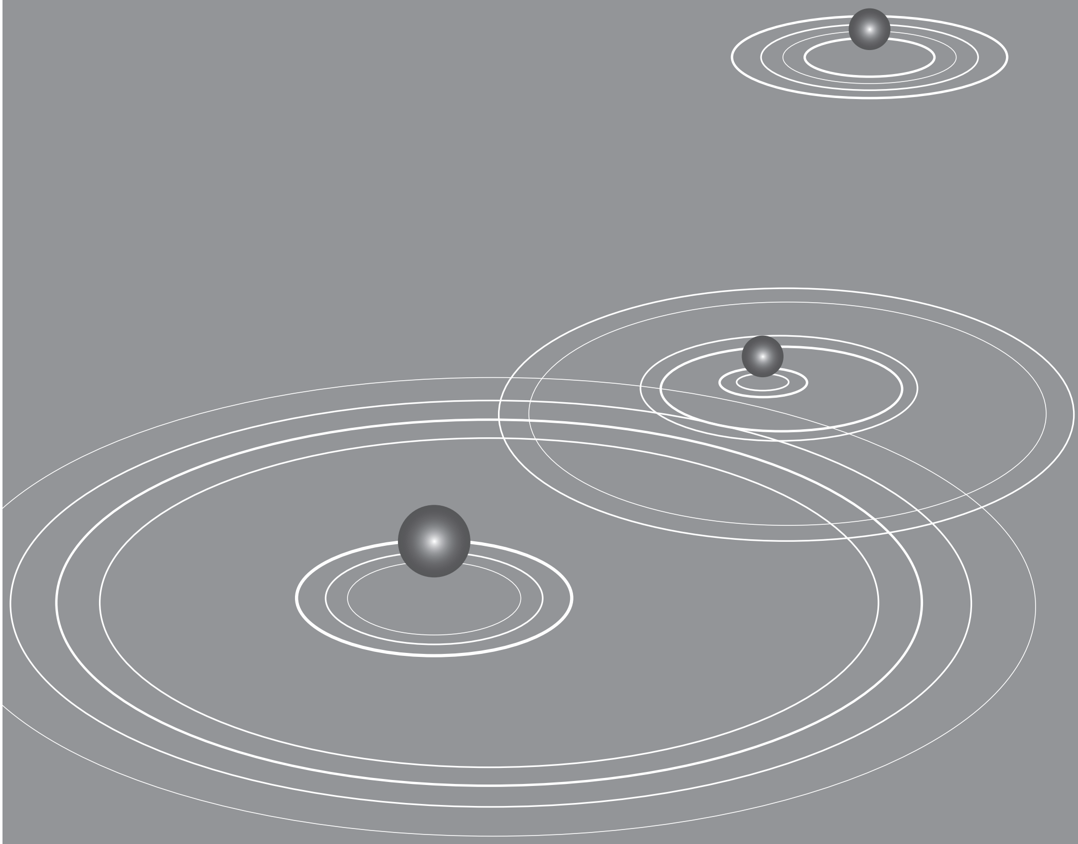

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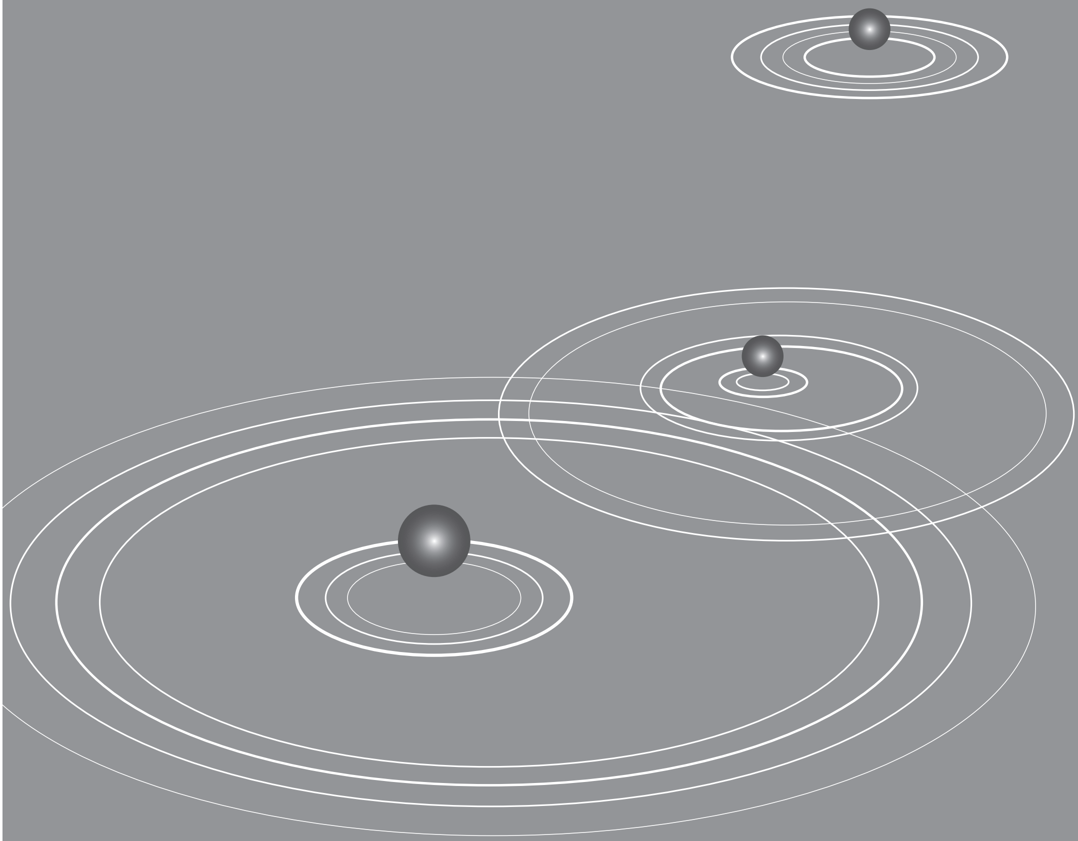

Appendix 1: The prevalence of dementia in Europe

The importance of knowing the prevalence of dementia in Europe

At a regional, national and international level, strategic planning of health and social policy is dependent on accurate estimation of the size of the challenge, and with this comes an ability to estimate the future cost of the care, support and treatment needed. At an individual level the ability of patient associations to be able to offer evidence-based knowledge to patients and caregivers is a minimal expectation. Knowledge about the numbers of people affected by dementia is therefore essential.

The following tables provide details of the prevalence of dementia within the EU-28 countries, as well as in Jersey, Iceland, Norway, Switzerland and Turkey. We have separated both sets of countries so as to have a figure for the European Union, and one for additional countries in which Alzheimer Europe has a member association.

What we mean by prevalence

When we use the term "prevalence", we are referring to the estimated proportion of individuals in a given population that have a particular condition, in this case dementia, at a specific time. This includes people who have recently developed dementia, as well as those who have already had the condition for some time (i.e. incident and prevalent cases). A prevalence rate is the total number of cases of a disease in a known population divided by the total population (New York State Department of Health, 1999). This differs from an incidence rate which measures the number of new cases of a condition divided by the number of people at risk for the condition, starting from a group of people who do not yet have it. In other words, incidence rates represent the rate at which new cases develop in the population, whereas prevalence rates provide a snapshot of the health status of a particular population at a given time (Prince, 2008). The figures we present here concern the latter.

How we calculated the prevalence figures for this report

For our calculations, we used projected population statistics from the United Nations for 2012 and two sets of prevalence rates. The resulting figures which you can see in the tables are the result of multiplying the population in given age groups (i.e. 30 to 59, followed by 5-year age groups, ending with 95+) with one of two sets of prevalence rates:

1. Prevalence rates from the EURODEM study were used to calculate the prevalence of dementia in the 30 to 59 age group. EURODEM (1991) was an EU-funded study, based in the Erasmus Medical Centre, Rotterdam. This was a collaborative study involving the analysis of 12 population-based epidemiological studies from 8 countries in relation to the prevalence of dementia. The results were published in an article by Hofman et al. (1991) and the work was updated in 2000. The studies are highly relevant today even though they were based on cohorts commenced in the 1980's, and do not include data from Eastern Europe (Alzheimer Europe, 2013).
2. Prevalence rates from the EuroCoDe study were used to calculate the prevalence of dementia in the 60 to 95+ age groups. EuroCoDe (2008) was also an EU-funded project, co-ordinated by Alzheimer Europe involving 6 work packages. Emma Reynish was the leader of the work package, whose aim was to develop prevalence rates for dementia. A total of 194 articles were identified from the literature search. 31 studies were identified as possible for inclusion in collaborative analysis and the researchers of those studies were invited to submit data. Raw data was obtained from 17 studies

> and used in the collaborative analysis of dementia prevalence rates in Europe. Reynish and her colleagues also analysed epidemiological data for prevalence rates for early onset dementia but found that this was sparse and involved studies with low numbers and wide variation in rates, perhaps due to differing study designs. They did not therefore develop new prevalence rates for younger people with dementia and this is why we are using a combination of two different sets of rates.

For full details of the prevalence rates used, please see Alzheimer Europe (2013) and Hofman et al. (1991). It is important to bear in mind that the prevalence rates used are based on studies involving diagnosed cases of dementia. As many people with dementia do not receive a diagnosis, the actual number of cases is likely to be much higher than the figures suggest.

Table 1. The Prevalence of Dementia in Europe (EU-28)

Country	Men	Women	Total	% of population
Austria	45,938	99,494	145,432	1.73
Belgium	62,972	128,309	191,281	1.77
Bulgaria	37,851	72,042	109,893	1.49
Croatia	20,394	46,682	67,076	1.53
Cyprus	4,333	6,917	11,250	1.07
Czech Republic	45,532	97,778	143,310	1.36
Denmark	29,715	55,847	85,562	1.53
Estonia	5,469	16,252	21,721	1.62
Finland	29,287	62,945	92,232	1.71
France	375,843	799,113	1,174,956	1.85
Germany	517,136	1,054,968	1,572,104	1.92
Greece	75,392	126,375	201,767	1.77
Hungary	43,636	105,291	148,927	1.50
Ireland	17,895	31,574	49,469	1.08
Italy	414,975	857,341	1,272,316	2.09
Latvia	8,902	26,812	35,714	1.60
Lithuania	12,567	34,768	47,335	1.44
Luxembourg	2,327	4,662	6,989	1.34
Malta	1,878	3,423	5,301	1.26
Netherlands	83,247	162,314	245,561	1.47
Poland	150,371	350,721	501,092	1.31
Portugal	62,260	120,266	182,526	1.71
Romania	90,484	179,820	270,304	1.26
Slovakia	17,834	40,774	58,608	1.07
Slovenia	9,324	22,711	32,035	1.57
Spain	280,149	538,197	818,346	1.75
Sweden	60,479	112,656	173,135	1.82
United Kingdom	360,581	677,210	1,037,791	1.65
Total	**2,866,771**	**5,835,262**	**8,702,033**	**average 1.55**

Table 2. The Prevalence of Dementia in Europe
Jersey, Iceland, Norway, Switzerland and Turkey

Country	Men	Women	Total	% of population
Jersey	483	918	1,401	1.43
Iceland	1,487	2,435	3,922	1.19
Norway	25,932	51,226	77,158	1.56
Switzerland	44,201	89,521	133,722	1.73
Turkey	134,927	196,586	331,513	0.44
	207,030	**340,686**	**547,716**	**average 1.29**

Table 3. The Grand Total

Countries	Men	Women	Total
EU-28 plus Jersey, Iceland, Norway, Switzerland and Turkey	3,073,801	6,175,948	9,249,649

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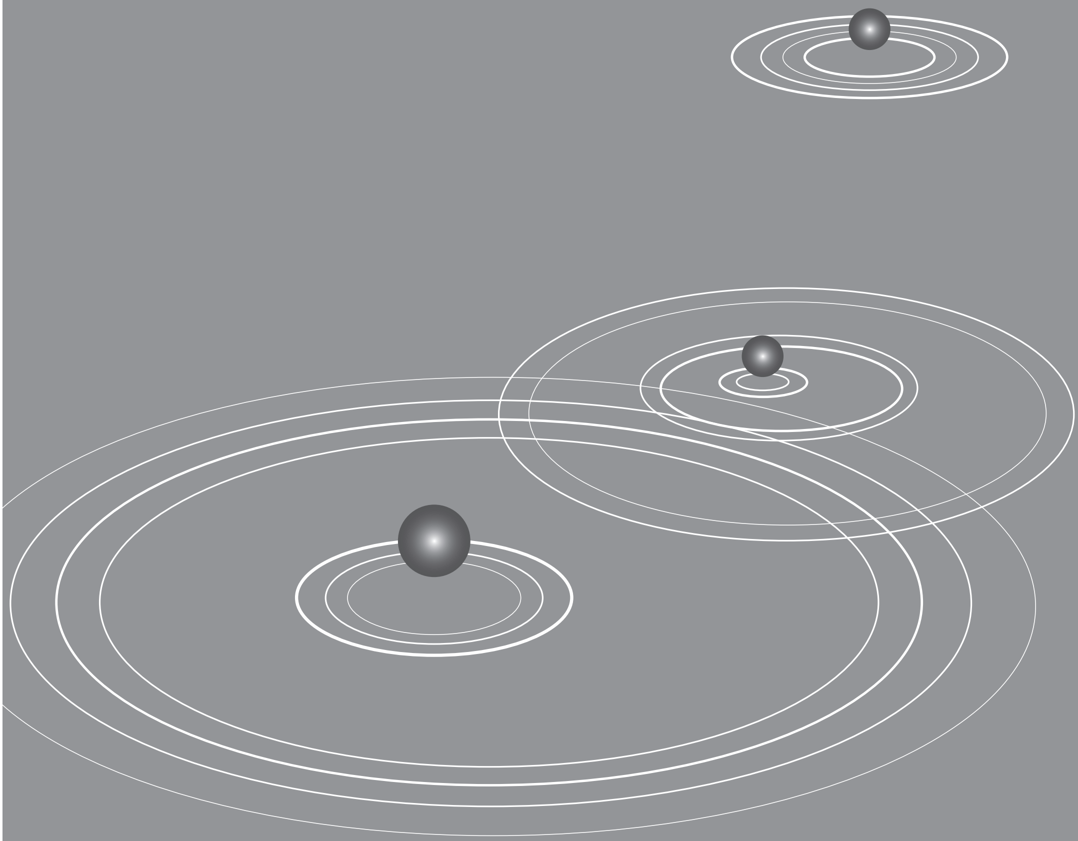


Appendix 2

Table 4: Which social and healthcare professionals provide care and support

The responses in the following table provide a general overview whereby a tick indicates that the social or healthcare professionals are involved in some way in the provision of care and support to people with dementia in residential care or at home (not medical treatment). Please check the relevant country report for full details as there may be limitations to the response given. Please also see the key at the end of this section for details of the codes used for each country.

	Nursing staff	Auxiliary staff	Allied health professionals	Specialists	General practitioners	Other
AU	✓	✓	✓			✓
BUL	✓	✓				✓
CZ	✓	✓	✓			✓
DK	✓	✓	✓		✓	✓
FIN	✓	✓	✓			
FR	✓	✓	✓	✓	✓	
GER	✓	✓	✓	✓	✓	✓
GR	✓	✓	✓	✓	✓	
IRE	✓	✓	✓	✓	✓	
IT	✓	✓	✓		✓	✓
JER	✓	✓	✓			
LITH	✓	✓	✓			
LUX	✓	✓	✓	✓	✓	✓
MAL	✓	✓	✓	✓		
NL	✓	✓	✓	✓	✓	✓
NOR	✓	✓				
POR	✓	✓	✓			✓
ROM						✓
SLV	✓	✓	✓			
SWE	✓	✓	✓	✓	✓	✓
SWI	✓	✓	✓	✓		
TUR	✓	✓	✓	✓		
UK (E.W.NI)	✓	✓	✓			
UK (SC)	✓	✓	✓		✓	✓

Table 5: Where people with dementia receive care and support

The responses in the following table provide a general overview whereby a tick indicates that people with dementia either live at home or in certain types of establishments. Please check the relevant country report for an indication of estimates of the percentage of people with dementia in each type of living arrangement. Please also see the key at the end of this section for details of the codes used for each country.

	At home (alone)	At home (with relatives or friends)	At home (with other pwd)	In general residential homes	In specialised res. homes for pwd	In general nursing homes	In specialised nursing homes for pwd	In hospitals	In psychiatric establishments	Other
AU	✓	✓	✓	✓	✓	✓	✓		✓	
BE	✓	✓	✓	✓	✓	✓	✓		✓	
BUL	✓	✓		✓	✓				✓	✓
CRO	✓	✓		✓	✓	✓	✓		✓	
CZ	✓	✓	✓	✓		✓		✓		
DK	✓	✓	✓	✓	✓	✓	✓		✓	
FIN	✓	✓		✓	✓	✓	✓	✓		
FR	✓	✓	✓	✓	✓	✓	✓	✓		
GER	✓	✓	✓	✓	✓	✓	✓	✓	✓	
GR	✓	✓		✓		✓			✓	
IRE	✓					✓		✓	✓	
IT	✓	✓		✓		✓	✓			
JER	✓	✓	✓	✓	✓	✓	✓	✓		
LITH	✓	✓	✓	✓				✓	✓	
LUX	✓	✓	✓	✓	✓	✓	✓		✓	
MAL	✓	✓	✓	✓		✓		✓	✓	
NL	✓	✓	✓		✓	✓	✓	✓	✓	
NOR	✓	✓	✓	✓	✓	✓	✓			
POR	✓	✓	✓	✓	✓	✓	✓	✓	✓	
SLV	✓	✓			✓	✓	✓	✓	✓	
SWE	✓	✓			✓	✓	✓			
SWI	✓	✓		✓	✓	✓	✓			
TUR	✓	✓		✓		✓	✓		✓	
UK (E,W,NI)	✓	✓	✓	✓	✓	✓	✓	✓		
UK (SC)	✓	✓	✓	✓	✓	✓	✓	✓	✓	

Table 6: Services and support offered by Alzheimer associations in different countries

In some cases, further information/notes have been given concerning services provided (e.g. where there are conditions, or where data is missing). For these specifications, please refer to the information contained in the national report for each country.

	Helpline	Information activities (newsletters, publications)	Website	Awareness campaigns	Legal advice	Care coordination/Case management	Home help (cleaning, cooking, shopping)	Home care (personal hygiene, medication)	Incontinence help	Assistive technologies / ICT solutions	Tele Alarm
AU		✓	✓	✓	✓						
BE	✓	✓	✓	✓							
BUL	✓	✓	✓	✓	✓						
CRO	✓	✓	✓	✓	✓						
CYP	✓	✓		✓	✓	✓	✓	✓	✓		
CZ	✓	✓	✓	✓							
DK	✓	✓	✓	✓							
FIN	✓	✓	✓	✓	✓						
FR	✓	✓	✓	✓	✓						
GER	✓	✓	✓	✓	✓						
GR	✓	✓	✓	✓	✓	✓		✓			
ICE		✓	✓	✓		✓				✓	
IRE	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
IT	✓	✓	✓	✓	✓	✓		✓		✓	✓
JER	✓	✓	✓	✓						✓	
LUX	✓	✓	✓	✓	✓	✓					
MAL	✓	✓	✓	✓							
NL	✓	✓	✓	✓	✓						
NOR	✓	✓	✓	✓							
POL	✓	✓	✓	✓	✓	✓					
POR		✓	✓	✓	✓		✓	✓	✓		
ROM		✓	✓	✓							
SLK	✓	✓	✓	✓		✓					
SLV	✓	✓	✓	✓	✓	✓		✓	✓		
SWE	✓	✓	✓	✓	✓	✓				✓	
SWI	✓	✓	✓	✓	✓	✓					
TUR	✓	✓	✓	✓	✓	✓		✓			
UK (E,W,NI)	✓	✓	✓	✓		✓	✓	✓		✓	
UK (SC)	✓	✓	✓	✓		✓	✓	✓		✓	

	Adaptations to the home	Meals on wheels	Counselling	Support groups for people with dementia	Alzheimer cafes	Respite care at home (Sitting service etc)	Holidays for carers	Training for carers	Support groups for carers	Day care	Residential/Nursing home care	Palliative care
AU			✓	✓	✓		✓	✓	✓			
BE			✓		✓			✓	✓			
BUL									✓			
CRO			✓	✓	✓			✓	✓			
CYP		✓	✓	✓		✓			✓	✓		
CZ			✓	✓		✓			✓			
DK			✓	✓	✓		✓	✓	✓			
FIN			✓	✓	✓	✓	✓	✓	✓	✓	✓	
FR			✓	✓	✓	✓	✓	✓	✓			
GER			✓	✓	✓	✓	✓	✓	✓	✓		
GR			✓	✓	✓			✓	✓	✓		
ICE			✓		✓					✓		
IRE				✓	✓	✓	✓	✓	✓	✓	✓	✓
IT	✓		✓	✓	✓	✓		✓	✓	✓	✓	✓
JER			✓	✓	✓			✓	✓	✓		
LUX	✓		✓	✓	✓			✓	✓	✓	✓	✓
MAL					✓			✓	✓			
NL					✓			✓	✓			
NOR			✓	✓	✓			✓	✓			
POL			✓				✓	✓	✓	✓	✓	
POR		✓	✓	✓	✓	✓		✓	✓	✓	✓	
ROM			✓	✓				✓	✓	✓		
SLK			✓					✓	✓	✓		
SLV		✓	✓	✓	✓			✓	✓	✓	✓	✓
SWE			✓	✓	✓			✓	✓			
SWI			✓	✓	✓	✓	✓	✓	✓			
TUR	✓		✓	✓	✓		✓	✓	✓	✓		
UK (E,W,NI)	✓			✓	✓		✓	✓	✓	✓		
UK (SC)			✓	✓	✓	✓	✓	✓	✓	✓		✓

Alzheimer Europe Annual and Financial Report 2012

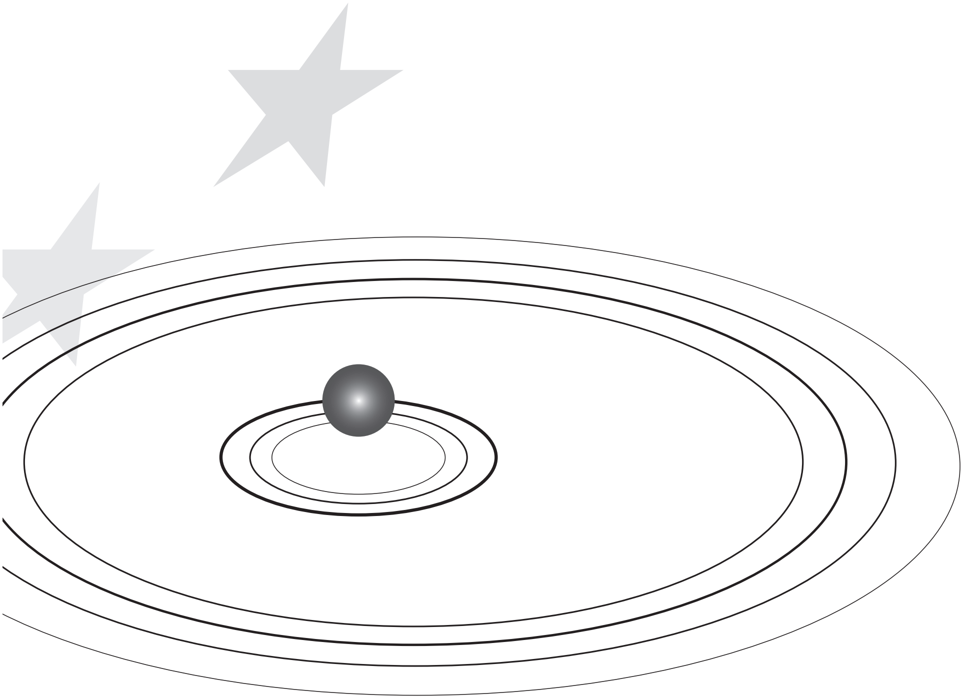
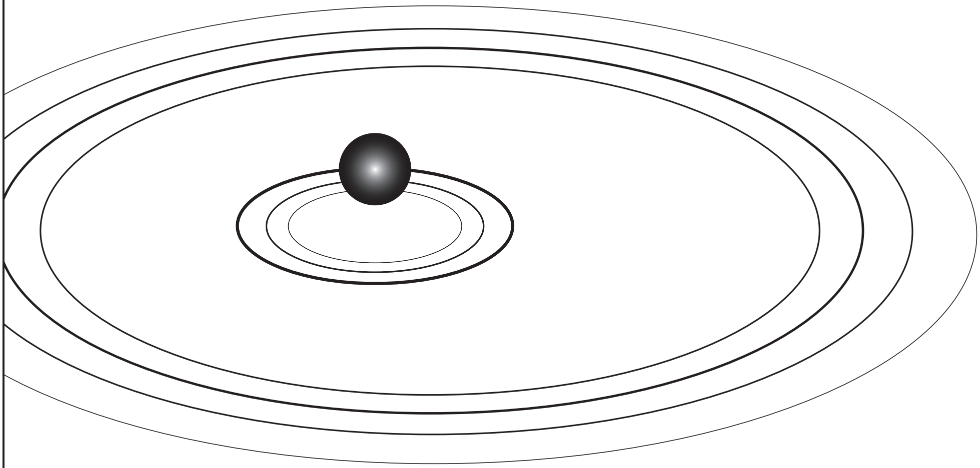


Table of contents

Annual Report 2012 **220**
1 *Preface* 221
2 *Executive Summary* 223
3 *Introduction* 225
4 *AE Core Activities* 226
    4.1 *Objective 1: Making dementia a European priority* 226
    4.2 *Objective 2: Supporting policy with facts* 227
    4.3 *Objective 3: Basing our actions on ethical principles* 229
    4.4 *Objective 4: Building a stronger organisation* 231
5 *Other activities and projects* 234
    5.1 *EU Project participation* 234
    5.2 *Other projects* 234
    5.3 *Corporate Affairs* 235
6 *Annex: Meetings attended by AE representatives* 236

Financial Report **242**
1 *Report of the Réviseur d'entreprises agréé* 243
2 *Balance sheet as of December 31, 2012* 245
3 *Profit and loss account Year ended December 31, 2012* 246
4 *Breakdown of income* 247
    4.1 *Introduction* 247
    4.2 *Funding of core activities (EUR 619,177.75)* 247
    4.3 *Funding of project activities (EUR 627,034.19)* 249
    4.4 *Overall funding* 250



Annual Report 2012

1 Preface

It gives me great pleasure to look back on my past year as Chairperson of Alzheimer Europe and I admit to a real sense of pride about our impressive list of achievements.

In line with the strategic plan which we adopted in 2011, this year's Annual report is broken down according to the activities we have undertaken in order to further our four key strategic objectives of making dementia a priority, supporting policy with facts, basing actions on ethical principles and building a stronger organisation.

I am particularly proud of the progress we have achieved in involving people with dementia in all our activities and in ensuring their voices are heard loud and clear by decision makers on a European level. When we embarked on the development of our European Working Group of People with Dementia (EWGPWD), we were unsure whether we would be able to form a multi-national group to communicate in English and I was therefore delighted that we were able to start our group with no less than eleven representatives from eleven different national Alzheimer associations.

We can count on their representative Helga Rohra, who was elected as the group's first chairperson, to actively represent their views as she sits as a member with full voting rights on the Alzheimer Europe Board. The impact of the group as a whole on our work is already significant as the group provided us with invaluable insight on how to make our Annual Conferences more dementia friendly, presented their views and shared their experiences at a lunch debate in the European Parliament and regularly contributes to our newsletter and magazine. The group has huge potential and I look forward to our continued collaboration.

The involvement of people with dementia stems from our deep-felt commitment to a rights-based approach to dementia and I am therefore happy that we have continued the development of our European Dementia Ethics Network. Over the years, we have published a series of strong positions in which we promote respect of the ethical principles of autonomy, solidarity and dignity. Last year's focus on the ethical issues linked to restrictions of freedom was a welcome addition to our work in this field.

Our campaign to make dementia a European priority continues to pay dividends as we saw the adoption of new dementia strategies in Finland and Northern Ireland in 2012 and progress towards this aim in the Czech Republic, Italy, Luxembourg and Malta. At our Annual Conference in Vienna, Rudolf Hundstorfer, the Austrian Minister of Labour, Social Affairs and Consumer Protection, committed his country's government to developing its own national strategy.

On a European level, we saw continued interest in the work of our European Alzheimer's Alliance and we currently have 66 Members from 22 EU countries and all political groups represented in the European Parliament. What a great demonstration that dementia truly does not know any geographical borders, or any political differences.

Our Annual Conferences also go from strength to strength and last year's conference in Vienna saw yet another increase in the number of participants with 518 delegates from

42 countries and over 120 speakers. Our forward looking motto of "Changing perceptions, practice and policy" resonated well with the participants who provided concrete examples of projects, activities and initiatives aimed at improving the lives of people with dementia and their carers.

It is great to see that on so many levels we have seen progress with more participants and speakers at our conference, more recipients of our newsletter, more meetings attended by AE staff, more visitors to our website, more policy makers joining our European Alzheimer's Alliance and more European projects that we have become involved in.

While this progress results in an increased workload for our organisation, I am also aware that we have not seen a corresponding increase in our staff and that these activities have been carried out by a small team of five permanent staff and two consultants. My heartfelt thanks go to our Executive Director, Jean Georges and his team comprised of Alex Teligadas, Annette Dumas, Dianne Gove, Julie Fraser, Grazia Tomasini and Gwladys Guillory. Their dedication to our common cause is truly inspirational.

I also wish to thank my Board colleagues and all the representatives of our national member organisations who have freely given of their precious time to attend meetings, provide advice and respond to requests and surveys. The accomplishments of Alzheimer Europe would not have been possible without the active participation and involvement of our members across Europe.

Finally, as always, I have to finish my introduction by thanking all the supporters and sponsors of Alzheimer Europe. The operating grant by the European Commission for a third year made it easier to carry out our core activities and the additional support to our Annual Conference in Vienna was also very welcome. The support of our Luxembourg member organisations also merits a special mention, as they seconded the Executive Director to work on behalf of Alzheimer Europe and provided us with rent free offices. In addition, we were able to count on project and conference funding from a number of foundations and corporate sponsors. The full list is included in our financial report and we are deeply grateful for their support.

I hope you will share my enthusiasm for Alzheimer Europe and its achievements when reading this Annual Report.

Heike von Lützau-Hohlbein
Chairperson

2 Executive Summary

In 2012, Alzheimer Europe

- Received an operating grant under the EU public health programme to finance its core activities,
- Signed a memorandum of understanding with ALCOVE, the European Joint Action on dementia and collaborated on ALCOVE's work packages on prevalence, behavioural and psychological symptoms, timely diagnosis and advance care planning,
- Cooperated with the Joint Programme On Neurodegenerative Diseases Research,
- Continued its collaboration with the European Medicines Agency,
- Increased membership of its European Alzheimer's Alliance to 66 Members of the European Parliament from 22 Member States and all seven political groups,
- Involved Members of the European Parliament in meetings as well as interviews for the Dementia in Europe magazine,
- Campaigned with the Alliance for MRI to ensure the use of MRI is not jeopardised by the implementation of the Electromagnetic Fields Directive,
- Contributed to the Commission's reflection process on neurodegenerative diseases and campaigned for dementia to be recognised as priorities in Horizon 2020, Health for Growth and the European Innovation Partnership on Active and Healthy Ageing,
- Monitored activities of the Council of Europe and contributed to a consultation on the use of health-related data by insurance companies,
- Carried out an inventory of national dementia strategies and policies by focusing on medical and scientific issues (research, early diagnosis, treatment and medical education),
- Produced 35 national reports describing national strategies and policies and published them in the 2012 edition of the Dementia in Europe Yearbook,
- Continued to cover scientific and policy developments in the framework of its European Dementia Observatory and included a total of 446 news articles in its monthly e-mail newsletter,
- Expanded its website and increased the number of visitors by over 53% in comparison to 2011 with total visitors of 334,542,
- Continued with the development of the European Dementia Ethics Network bringing together European experts in the field of dementia ethics and carried out an in-depth literature review on the ethical issues linked to restrictive measures,
- Published a report with its position and recommendations on the ethical issues linked to restrictive measures,
- Promoted a zero tolerance approach to the use of restraint in people with dementia,
- Officially launched the European Working Group of People with dementia with representation of 11 people with dementia from 11 different organisations who elected their own Chairperson and Vice-Chairpersons,
- Welcomed Helga Rohra as the Chairperson of the European Working Group of People with Dementia as a full member of the Alzheimer Europe Board,

- Organised meetings between members of the European Working Group of People with Dementia and Members of the European Parliament,
- Organised a successful 22nd Annual Conference in Vienna which was entitled "Changing perceptions, practice and policy" and which was attended by over 500 delegates from 42 countries and which featured over 120 speakers,
- Re-elected the members of the Board to lead the organisation from 2012 to 2014,
- Consulted and involved its member organisations in meetings and projects and organised two meetings with public affairs representatives to exchange information on dementia strategies and national advocacy efforts,
- Welcomed the Croatian and Slovenian Alzheimer's associations as new full members of the organisation,
- Continued its membership within the European Patients' Forum,
- Expanded its collaboration with AGE Platform Europe,
- Contributed to the ongoing discussions within Alzheimer's Disease International on regionalisation,
- Set up the Alzheimer Europe Foundation and appointed the three first members of the Foundation Board,
- Collaborated with the PharmaCog project by dissemination information on the project through its website and newsletter and at a lunch debate in the European Parliament,
- Partnered with the DECIDE project and developed reports on data confidentiality laws in European countries and disseminating information to the wider patient and carer community,
- Participated in meetings of the NILVAD project,
- Published a sub-analysis of its "Value of knowing" survey in the peer-reviewed International Journal of Alzheimer's disease,
- Organised three lunch debates in the European Parliament dedicated to the PharmaCog project, the place of Alzheimer's disease in the future European public health and research programmes and on living with dementia,
- Published three editions of its Dementia in Europe magazine with updates on policy developments and interviews with policy makers on a national and European level.

3 Introduction

The Strategic Plan of Alzheimer Europe sets out the four main objectives of the organisation and highlights key aims and actions to be undertaken under each objective for the period covered by the plan (2011-2015). This year's Annual Report breaks down the organisation's core activities into these four key strategic objectives and follows the structure of the 2012 Annual Work Plan which was adopted at the Annual General Meeting in Warsaw in 2011.

In addition, the report highlights the activities undertaken by Alzheimer Europe in support of EU projects it had been partnering with and presents those activities which it has been able to carry out thanks to the support of its corporate sponsors.

4 AE Core Activities

In 2012, Alzheimer Europe received the support of the European Commission. The following core activities of the organisation were funded thanks to an operating grant to Alzheimer Europe in the framework of the Public Health Programme.

4.1 Objective 1: Making dementia a European priority

4.1.1 Collaboration with EU Initiatives

In 2012, Alzheimer Europe developed closer ties with the ALCOVE project, the European Joint Action on Dementia and organised a number of face-to-face meetings with the coordinators and work package leaders. A memorandum of understanding was signed between the two organisations with ALCOVE delegating Prof. Dawn Brooker to participate in public affairs meetings organised by Alzheimer Europe and the AE Information Officer taking part in ALCOVE work package meetings on timely diagnosis and advance care planning. AE also provided data collected in the framework of the EuroCoDe project to the ALCOVE work package on prevalence. Finally, AE supported the ALCOVE work package on behavioural and psychological symptoms by surveying its member organisations on existing educational programmes for carers of people with dementia.

Alzheimer Europe actively participated in the stakeholder consultations organised by the Joint Programme on Neurodegeneration to ensure that the views of people with dementia and their carers were reflected in the Joint Programme's Strategic Research Agenda which was launched in February 2012.

Alzheimer Europe continued its collaboration with the European Medicines Agency in 2012. AE staff participated in the plenary meeting for all patient organisations accredited at the European Medicines Agency.

4.1.2 European Alzheimer's Alliance

Alzheimer Europe continued its close contacts with Members of the European Parliament. The number of MEPs who joined the European Alzheimer's Alliance grew from 58 to 66 by the end of 2012, representing 22 Member States of the European Union and all of the seven political groups in the European Parliament.

Alzheimer Europe gratefully acknowledges the support of the following Members of the European Parliament who were present or represented at the various meetings organised by Alzheimer Europe: Liam Aylward (Ireland), Heinz Becker (Austria), Frieda Brepoels (Belgium), Nessa Childers (Ireland), Brian Crowley (Ireland), Nathalie Griesbeck (France), Françoise Grossetête (France), Marian Harkin (Ireland), Sean Kelly (Ireland), Peter Liese (Germany), Astrid Lulling (Luxembourg), Linda McAvan (United Kingdom), Elisabeth Morin-Chartier (France), Alojz Peterle (Slovenia), Sirpa Pietikäinen (Finland), Marc Tarabella (Belgium), Angelika Werthmann (Austria) and Marina Yannakoudakis (United Kingdom).

A number of Alliance members also supported Alzheimer Europe's work by contributing to the organisation's Dementia in Europe magazine or by supporting national member organisations in their campaigns to make dementia a national and European priority:

This was the case of MEPs Oana Antonescu (Romania), Maria Badia i Cutchet (Spain), Milan Cabrnoch (Czech Republic), Ole Christensen (Denmark), Françoise Grossetête (France), Frédérique Ries (Belgium), Glenis Willmott (United Kingdom) and Marina Yannakoudakis (United Kingdom).

4.1.3 Jointly developing policy

In 2012, Alzheimer Europe continued its collaboration with the Alliance for MRI, a coalition of organisations, scientists and Members of the European Parliament campaigning to ensure that the implementation of the Electromagnetic Fields Directive does not jeopardise the use of MRI for the diagnosis of Alzheimer's disease and other dementias. The successful campaign resulted in the Council of Ministers first postponing the transposition deadline of the directive and ultimately excluding MRI from the scope of the directive.

AE also contributed to the Commission's reflection process on chronic diseases by asking for neurodegenerative diseases to be included and by calling for the development of national dementia strategies and greater EU collaboration in this field.

Other EU initiatives that AE followed closely were the negotiations for Horizon 2020, the new research framework programme and the European Innovation Partnership on Active and health Ageing. AE campaigned for the inclusion of dementia as priority areas in both these important EU initiatives.

Alzheimer Europe monitored the activities of the Council of Europe and contributed to a consultation on the collection and use of health-related data by insurance companies

4.2 Objective 2: Supporting policy with facts

4.2.1 Comparing national systems and identifying best practices

A significant number of EU countries have developed national dementia strategies or are in the process of doing so. However, the state of development and implementation varies greatly between countries. Alzheimer Europe therefore decided to carry out an inventory and comparison of national dementia strategies. In addition, the organisation paid close attention to more general policies in those countries which have not yet developed formal strategies.

Due to the great number of issues covered in dementia strategies, AE decided to divide this work over successive years: In 2012, it focused on the medical and scientific issues (research, early diagnosis, treatment and medical education) and in 2013, it will focus on social and care aspects.

The aim of this key priority was to develop national reports with an overview of national strategies and policies and to publish them in the 2012 edition of the Dementia in Europe Yearbook.

In collaboration with representatives of its national member organisations, Alzheimer Europe was able to carry out an extensive inventory of national strategies and policies in four key areas.

First, the organisation focused on information on existing national dementia strategies or Alzheimer plans by providing background information, as well as details on their time frame, funding, implementation and monitoring. In addition, we included data on the involvement of the national Alzheimer association and/or people with dementia in these strategies. For countries where no strategy existed, Alzheimer Europe identified information on the state of development of such strategies or on campaigns promoting the adoption of such a national strategy.

The second focus of data collection was on issues surrounding the diagnosis of dementia. Details are provided of the existence of national diagnostic guidelines or policies promoting early diagnosis. In addition, we identified which healthcare professionals are responsible for diagnosing dementia, the type and degree of training for GPs in dementia and information on the tests which are required for the diagnosis of dementia.

Thirdly, information on medical treatment was collected. We included information on the availability and reimbursement of medicines in general and of the existing four Alzheimer's treatments (donepezil, rivastigmine, galantamine and memantine) in particular. In this section, we also included information on treatment guidelines for those countries where such guidelines exist.

The fourth and final focus of the inventory was on research in the field of dementia. We aimed to identify data on exiting research programmes dedicated to the field of Alzheimer's disease and other forms of dementia. In addition, we noted whether countries were involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) or the Joint Action "ALzheimer COoperative Valuation in Europe (ALCOVE).

As countries varied greatly as to the existence of national strategies, national diagnostic or treatment guidelines or national research programmes, the reports we produced varied greatly from one country to another.

Thanks to the support of national Alzheimer associations and external experts, it was possible to produce national reports for all countries of the European Union, as well as Croatia, Jersey, Norway, Switzerland and Turkey. For the United Kingdom, separate reports were produced for England, Northern Ireland, Scotland and Wales due to the existence of separate national dementia strategies.

These reports were included in the 2012 version of the Dementia in Europe Yearbook and have also been made available on the Alzheimer Europe website.

Alzheimer Europe received additional financial support from the Alzheimer Europe Foundation for its work on national dementia strategies.

4.2.2 European Dementia Observatory

Over the past years, Alzheimer Europe has continuously improved the information it provides to its members and external stakeholders on key developments. As a long-term objective, Alzheimer Europe would like to set up a European Dementia Observatory where all relevant developments in the dementia field will be monitored and reported on.

In 2012, the monthly e-mail newsletters contained information on the latest activities of Alzheimer Europe and its member organisations and those of the European Alzheimer's Alliance, as well as information on interesting policy initiatives both on a national and European level. Alzheimer Europe also covered research developments in its monthly newsletter. Finally, Alzheimer Europe included human interest stories of people living with Alzheimer's disease or another form of dementia and provided information on new resources.

In 2012, Alzheimer Europe published 11 editions of its newsletter with one newsletter spanning the holiday period in "August-September".

A total of 446 articles were featured in 2012 (443 in 2012) in Alzheimer Europe's monthly e-mail newsletters and these articles can be broken down as follows:

Subject	Number of articles (2012)	Number of articles (2011)
Activities and projects of Alzheimer Europe	49	45
European policy developments in the field of dementia and European Alzheimer's Alliance	78	75
National policy developments	21	29
Activities and projects of AE member organisations	97	82
Scientific developments	136	145
Dementia in Society	28	37
New resources, publications and job opportunities	29	27

The information was also included on the Alzheimer Europe website which continued to receive a significant number of visitors throughout the year. Compared to 2011, the website attracted over 53% more visitors as the number of unique visitors increased from 217,471 in 2011 to 334,542 in 2012.

Month	Visitors (2012)	Visitors (2011)
January	19,762	14,953
February	21,965	16,987
March	25,706	18,215
April	26,441	15,494
May	26,533	16,107
June	28,915	17,359
July	23,327	20,426
August	23,575	15,057
September	28,504	19,921
October	41,805	22,796
November	44,645	22,653
December	33,291	17,503
Total:	**334,542**	**217,471**

4.3 Objective 3: Basing our actions on ethical principles

4.3.1 Ethical aspects of restrictions of freedom

The work on dementia ethics started in 2009 and had the aim of collecting and disseminating ethical positions and recommendations, to provide in-depth coverage of specific ethical dilemmas and to develop, where possible, consensual positions and recommendations.

Building on the work carried out in 2010 and 2011, the focus of the 2012 activities of the European Dementia Ethics Network was on developing a report on the ethical aspects of restrictions of freedom and coercive measures.

For this work, AE was able to refer to the inventory of national laws on restrictive measures which was carried out as part of the 2011 work plan of the organisation.

As with previous ethics projects, an in-depth literature review was carried out with the aim of providing an objective analysis of the literature relating to the ethical aspects of restrictions of freedom.

This literature review and analysis was conducted together with a working group comprised of the following experts:

- Dr Anna Maki-Petäjä-Leinonen, Researcher, Faculty of Law, University of Helsinki (Finland)
- Dr Antonio Burgueño Torijano, Director of the National Program to Untie the Elderly and the Person with Dementia in Spain (Spain)
- Mr Dr Brenda Frederiks, Assistant Professor Health Law, VU Medical Centre (Netherlands)
- Prof. Chris Gastmans, Professor of Medical Ethics, Centre for Biomedical Ethics and Law, Faculty of Medicine, Catholic University of Leuven (Belgium)
- Ms Dianne Gove, Information Officer, Alzheimer Europe (Luxembourg)
- Ms Eleanor Edmond, Freelance trainer and consultant in capacity legislation (Ireland)
- Dr Fabrice Gzil, Fondation Médéric Alzheimer, Research Programme Manager (France)
- Mr James McKillop, MBE, Scottish Dementia Working Group (SDWG) and Mrs Maureen McKillop, carer (Scotland, UK)
- Ms Jan Killeen, Policy Consultant, Alzheimer Scotland (UK)
- Ms Maria do Rosário Zincke dos Reis, Lawyer, Alzheimer Portugal (Portugal)
- Dr Marianna Siapera, MD, Greek Association of Alzheimer's disease and Related Disorders (Greece).

The working group met twice in 2012. At these meetings, the experts discussed the various ethical issues that were identified, aimed to provide a balanced argument of various positions regarding the ethical issues and finally, developed a consensual position on these issues.

The issues which were examined in greater detail were the following:

- Restrictions of the freedom to choose one's residence or place of stay
- Freedom to live in the least restrictive environment which pays close attention to various classes of restraint (physical restraint, chemical restraint, the use of force, coercion, environmental or psychological restraint, the use of assistive technologies)
- Freedom to act according to individual values (sexuality, relationships and living arrangements)
- Restrictions imposed on people's ability to play an active role in society (voting, making a will and driving).

The literature review and key recommendations were published in a report. At the end of the report, a few useful annexes were included. The first provided an overview of 10 key points for zero tolerance for the use of restraint in persons with dementia and the second provided a personal account from a person with dementia's views on the importance of driving. A glossary and a detailed bibliography were also included in the report.

Alzheimer Europe received additional financial support from Fondation Médéric Alzheimer and the Alzheimer Europe Foundation for its report on ethical issues linked to restrictions of freedom of people with dementia.

4.4 Objective 4: Building a stronger organisation

4.4.1 European Working Group of People with Dementia

In 2011, Alzheimer Europe adopted recommendations with regard to the involvement of people with dementia in AE's activities and in 2012, the organisation started with the development of a European Working Group of People with Dementia.

In 2012, Alzheimer Europe organised three meetings with people with dementia.

1. An exploratory meeting was held in Glasgow in April 2012 to present the aims of the group and to discuss these with interested people with dementia. This meeting also served for an exchange of views on national involvement policies and the identification of good practices. The first meeting was attended by nine people with dementia from six associations and an additional 20 representatives of associations interested in promoting the involvement of people with dementia at national level.
2. The group was officially launched during the 22nd Alzheimer Europe Conference in Vienna and the group elected its own Chairperson (Helga Rohra from Germany) and Vice-Chairpersons (Jean-Pierre Frognet from Belgium, Agnes Houston from Scotland/United Kingdom and Jan Frederik Meijer from the Netherlands). The participants at the meeting also discussed a number of ideas on how to make conferences and meetings more inclusive. The meeting was attended by 11 people with dementia from 11 different associations. An additional four people with dementia participated as speakers or delegates in the AE Conference.
3. A final meeting was organised in December and the group was presented at a lunch debate in the European Parliament. The group discussed ways of presenting themselves and appointed representatives to working groups set up by Alzheimer Europe. For some participating people with dementia and their carers, meetings were organised with Members of the European Parliament from their respective countries (Nessa Childers from Ireland, Linda McAvan from the United Kingdom, Alojz Peterle from Slovenia, Sirpa Pietikäinen from Finland, Marc Tarabella from Belgium). These meetings were attended by 10 people with dementia from 10 different countries.

4.4.2 22nd Alzheimer Europe Conference in Vienna

In 2012, Alzheimer Europe organised its 22nd Annual Conference in collaboration with Alzheimer Austria. The conference entitled "Changing perceptions, practice and policy" took place from 4 to 6 October and attracted over 500 delegates from 42 countries.

Participants represented a wide range of backgrounds within the dementia field and Alzheimer Europe was particularly glad to welcome 15 people with dementia from 12 countries. Alzheimer Europe provided bursaries to provide 11 people with dementia with transport and accommodation.

The conference featured some 120 speakers in plenary and parallel session, special symposia and workshops. The four plenary sessions focused on the changes needed to cope with the growing number of people with dementia in Europe and included a round-table discussion on "Changing policy – national strategies and European collaboration on dementia".

The Annual General Meeting of Alzheimer Europe also took place in the framework of the 22nd Alzheimer Europe Conference in Vienna. At the meeting, the members of the organisation approved the annual and financial reports, adopted the organisation's 2013 Work Plan and Budget and elected a new Board. Heike von Lützau-Hohlbein (Germany), Iva Holmerová (Czech Republic) and Maria do Rosário Zincke dos Reis (Portugal) were re-elected in their posts as Chairperson, Vice-Chairperson and Honorary Treasurer respectively and Charles Scerri (Malta) was elected as Honorary Secretary. Patrick Maugard (France), Maurice O'Connell (Ireland) Sirpa Pietikäinen (Finland), Alicja Sadowska (Poland) and Henry Simmons (United Kingdom) were all re-elected as Members of the Board and were joined by Helga Rohra, who joined the Board as a full voting member as the Chairperson of the European Working Group of People with Dementia.

4.4.3 Supporting and involving member organisations

Alzheimer Europe consistently involves its member organisations in meetings, projects and activities. A particularly successful series of meetings brought together the public affairs representatives of various national associations.

These meetings were aimed at exchanging information on national dementia strategies and policies and the campaigning and advocacy activities of Alzheimer associations. In 2012, these meetings were organised at the same time as the European Parliament lunch debates and focused on:

- The role of general practitioners in the detection and diagnosis of Alzheimer's disease,
- Care pathways from primary to secondary care,
- Diagnostic protocols,
- The reimbursement of treatments,
- GP training and support,
- Support of dementia research by national governments,
- Awareness campaigns and lobbying activities of national Alzheimer associations,
- The involvement of national organisations in the development and monitoring of dementia strategies.

15 member organisations were represented at these meetings.

4.4.4 Membership development

With the exception of Estonia, Hungary, Latvia and Lithuania, Alzheimer Europe currently counts members in all of the Member States of the European Union.

In 2012, Alzheimer Croatia and the Slovenian Alzheimer's Association were welcomed as full member organisations and the Annual General Meeting decided to continue the provisional membership of Alzheimer Bulgaria, Foundation Compassion Bulgaria and Alzheimer Uniti (Italy).

4.4.5 Strategic Partnerships

In 2012, Alzheimer Europe continued as an active member of the European Patients' Forum and participated in the EFPIA think tank meetings which bring together patient representatives and the pharmaceutical industry to discuss issues of common concern.

Alzheimer Europe also strengthened its collaboration with AGE Platform Europe, as well as the ageing, mental health and carers intergroups in the European Parliament. On the occasion of World Alzheimer's Day, Alzheimer Europe and AGE issued a joint press release calling for the development of age- and dementia-friendly environments across Europe. Alzheimer Europe also contributed to AGE's two-year WeDO project which resulted in a "European quality framework for long-term care services".

Alzheimer Europe contributed to the ongoing discussions within Alzheimer's Disease International (ADI) on regionalisation. The Chair of AE attended the ADI Conference in London to present the organisation's views.

4.4.6 Alzheimer Europe Foundation

In an effort to diversify the funding of the organisation, the Alzheimer Europe Board decided to allocate a funding surplus of EUR 120,000 at the end of 2011 for the creation of the Alzheimer Europe Foundation. The registration process for this Foundation was started in 2012 and the Alzheimer Europe Board nominated Maria de Rosário Zincke dos Reis, Heike von Lützau-Hohlbein and Iva Holmerová as the first Board members of this independent Foundation.

The aims of the foundation are as follows:

- To support networking activities of national Alzheimer's associations in the framework of Alzheimer Europe,
- To encourage the involvement of people with dementia in European conferences, meetings and projects,
- To promote European dialogue on legal and ethical issues in dementia,
- To support the exchange of information and good practices on national dementia strategies and Alzheimer's plans.

5 Other activities and projects

5.1 EU Project participation

5.1.1 PharmaCog

Alzheimer Europe continued its involvement in the PharmaCog project. PharmaCog, short for "Prediction of cognitive properties of new drug candidates for neurodegenerative diseases in early clinical development" is a project which started its work on 1 January 2010 thanks to significant funding from the Innovative Medicines Initiative.

Alzheimer Europe represents the interests of people with dementia and their carers in this consortium and helps with the dissemination of the research results to a lay audience. In 2012, the organisation updated the section of its Internet site dedicated to the PharmaCog project and, provided progress reports of the project in its newsletter and magazine.

AE was represented by Alex Teligadas at the PharmaCog General Assembly in Marseille on 16 and 17 January and the Annual Review meeting in Brussels on 11 May.

5.1.2 DECIDE

In 2012, Alzheimer Europe also continued its collaboration with the DECIDE project which is funded through the Seventh Framework Programme of the European Union (FP7). The aim of DECIDE (Diagnostic Enhancement of Confidence by an International Distributed Environment) is to design, implement, and validate a GRID-based e-Infrastructure.

Alzheimer Europe helped with the dissemination of research results to the patient and carer community, provided reports on the application of data confidentiality laws in EU countries and collaborated with Luxembourg lawyers on the wording of the legal disclaimer for users of the e-infrastructure. Alex Teligadas represented AE at the second interim review in Brussels on 2 March.

5.1.3 NILVAD

In 2012, Alzheimer Europe started its collaboration with the NILVAD project, a phase III clinical trial of the drug nilvadipine on some 500 people with mild to moderate Alzheimer's disease in nine European countries. As with other EU funded projects, Alzheimer Europe represents the views of people with dementia and their carers in the research consortium, provides advice on ethical issues and disseminates results to a wider audience.

Alzheimer Europe was represented by Alex Teligadas at the launch meeting in Dublin on 15 and 16 February and a pre-trial meeting on 1 October in Amsterdam.

5.2 Other projects

5.2.1 Value of knowing

The results of the "Value of knowing" survey which were launched at the Alzheimer's Association International Conference in Paris in 2011 continued to be used by the organisation in 2012 in its advocacy work calling for greater access to a timely diagnosis for people with dementia.

In 2012, a scientific paper with a sub-analysis of the research results was published in the peer-reviewed International Journal of Alzheimer's disease: "The impact of experience with a family member with Alzheimer's disease on views about the disease across five countries".

5.3 Corporate Affairs

5.3.1 European Parliament lunch debates

In 2012, Alzheimer Europe organised three successful lunch debates in the European Parliament which were well attended by MEPs:

- On 28 February, Elisabeth Morin-Chartier, MEP (France) replaced her colleague Françoise Grossetête, MEP (France) and hosted a lunch debate dedicated to the PharmaCog project. Dr. Elisabetta Vaudano, Principal Scientific Manager of the Innovative Medicines Initiative (IMI), presented the rationale of the European iniative in identifying bottlenecks in the drug development and ensuring the right drug gets to the right patient, at the right stage and at the right dose. Dr. Alexandra Auffret (Université de Marseille) and Jill Richardson (GlaxoSmithKline) provided an update on the project's aims and achievements to date.
- On 26 June, Liam Aylward, MEP (Ireland) hosted a lunch debate entitled "Alzheimer's disease in the new European public health and research programmes" at which European Commission representatives Jürgen Scheftlein and Philippe Cupers presented the plans of their respective Directorates-General.
- On 4 December, Sirpa Pietikäinen, MEP (Finland) hosted a lunch debated entitled "Living with dementia: learning from the experiences of people with dementia" at which three people with dementia, Nina Balackova (Czech Republic), Helga Rohra (Germany) and Daphne Wallace (United Kingdom) presented their personal experiences of living with dementia and made recommendations to attending policy makers.

5.3.2 Dementia in Europe Magazine

In 2012, Alzheimer Europe published three editions of the "Dementia in Europe Magazine". These magazines included a variety of articles on policy developments, as well as interviews with European and national policy makers including EU Commissioners John Dalli (Health and Consumers), Neelie Kroes (Digital Agenda) and Androulla Vassiliou (Education), Health Ministers Mars di Bartolomeo (Luxembourg), Maria Guzenina-Richardson (Finland), Astrid Krag (Denmark), and Edwin Poots (Northern Ireland) and JPND Executive Board member Enda Connolly.

Alzheimer Europe also included detailed information on its various projects and meetings, such as the European Parliament lunch debates and Annual Conference of the organisation. In addition, the magazine featured a section on "Living with dementia" where people with dementia and carers provided insightful accounts of their own experiences of dementia.

The magazine launched at the 22nd Alzheimer Europe Conference included a special supplement dedicated to Austria highlighting a number of interviews with Austrian policy makers and their views on the situation of people with dementia in their country.

6 Annex: Meetings attended by AE representatives

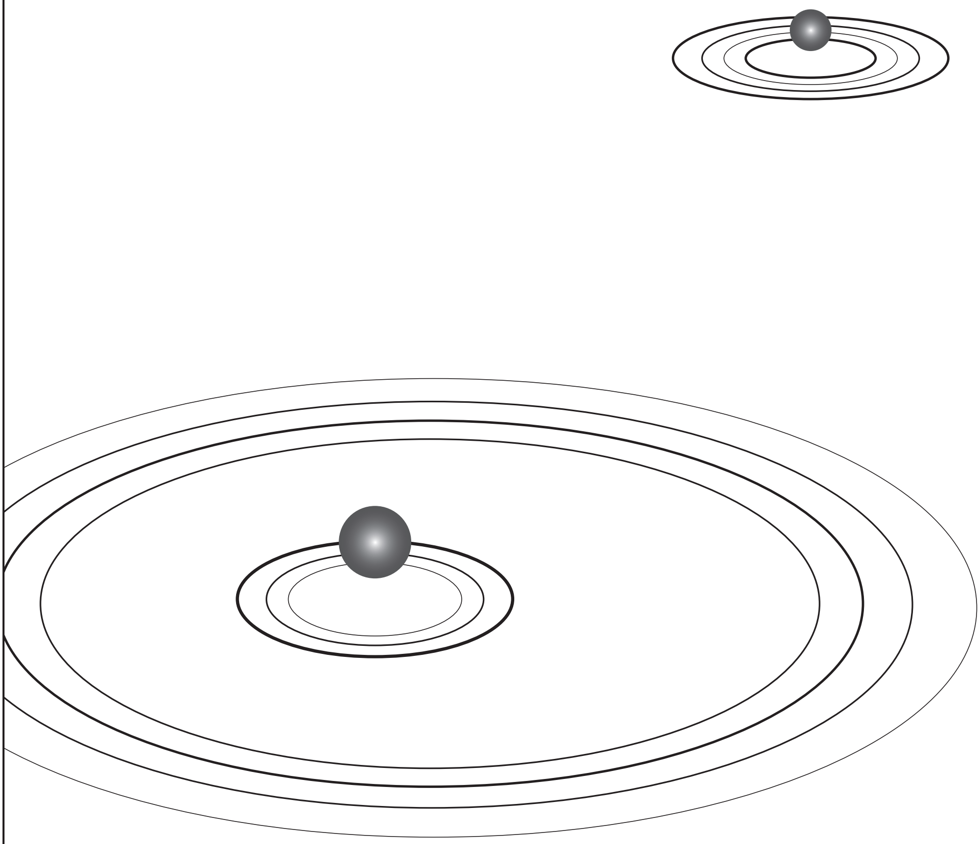
Date	Meeting	Location
5 January	Meeting with Sanofi	Brussels, Belgium
11 January	Meeting with Richard Ashworth, MEP (United Kingdom)	Brussels, Belgium
12 January	Meeting with Maria Iglesia Gomes on European Innovation Partnership on Active and Healthy Ageing	Brussels, Belgium
13-14 January	Pfizer Workshop on the "Alzheimer's Lexicon"	Miami, USA
16 January	PharmaCog General Assembly	Marseille, France
16 January	Award Ceremony of European Foundation Initiative on Dementia	Brussels, Belgium
19 January	Meeting with Fondation Roger de Spoelberch	Luxembourg, Luxembourg
20 January	Meeting with ALCOVE	Luxembourg, Luxembourg
24-25 January	Annual Conference of European Forum for Good Clinical Practice	Brussels, Belgium
25 January	Alliance for MRI	Brussels, Belgium
7 February	Launch of Strategic Research Agenda of Joint Programming Initiative (JPND)	Brussels, Belgium
7 February	Visit of MSD Clinical Trial site	Aalst, Belgium
10 February	Meeting with Health Attaché of Hungarian Permanent Representation to the EU	Brussels, Belgium
15-16 February	NILVAD launch meeting	Dublin, Ireland
22-25 February	Conference of Romanian Alzheimer's Society	Bucharest, Romania
27-28 February	AE Board Meeting	Brussels, Belgium
28 February	European Parliament lunch-debate "The PharmaCog collaboration"	Brussels, Belgium
28-29 February	AE Working Group on national dementia strategies	Brussels, Belgium
6 March	WeDo Meeting	Brussels, Belgium
7-8 March	Meetings with Alzheimer's Disease International	London, United Kingdom
8 March	Interdem Meeting	London, United Kingdom
8 March	EFPIA Think Tank Meeting	Brussels, Belgium
9 March	Meeting with Alzheimer Vaucluse	Brussels, Belgium
22-23 March	EMA Workshop on "Medicines for older people"	London, United Kingdom
26 March	Meeting with Angelika Werthmann, MEP (Austria)	Brussels, Belgium
27 March	Age Intergroup of European Parliament	Brussels, Belgium

Date	Meeting	Location
3 April	Conference on European Innovation Partnership on Active and Healthy Ageing	Brussels, Belgium
11-12 April	Meeting with ALCOVE	Paris, France
13 April	GSK Health Advisory Board	London, United Kingdom
15-17 April	European Working Group of People with Dementia	Glasgow, United Kingdom
18 April	European Patients' Forum General Assembly	Brussels, Belgium
19 April	European Patients' Forum Seminar	Brussels, Belgium
23-25 April	Global Forum on Incontinence	Copenhagen, Denmark
26-27 April	ALCOVE Workshop "Finding the right balance between autonomy and protection of the person with dementia"	Brussels, Belgium
2 May	Meeting with GE Healthcare	London, United Kingdom
3 May	Meeting with Novartis	Luxembourg, Luxembourg
4 May	Meeting with Lilly	Brussels, Belgium
4 May	European Parliament Health Committee meeting on "Health for Growth"	Brussels, Belgium
10-11 May	PharmaCog Interim Review	Brussels, Belgium
11 May	Meeting with Alzheimer Slovenia	Brussels, Belgium
16 May	Meeting with conference organiser of 22nd Alzheimer Europe Conference "Changing perceptions, practice and policy"	Vienna, Austria
24 May	Symposium "Ethique et recherche"	Toulouse, France
1 June	Meeting with GSK	Brussels, Belgium
6 June	IMPACT Consortium Meeting	Trondheim, Norway
7 June	European Parliament hearing on "the prevention of age related diseases in women"	Brussels, Belgium
7 June	Multi-Stakeholder initiative on Alzheimer's disease	Brussels, Belgium
12 June	Meeting with Health Attaché of Hungarian Permanent Representation to the EU	Brussels, Belgium
14-15 June	Working group on ethical issues linked to restrictions of freedom	Brussels, Belgium
19 June	AGE Platform seminar on "Impact of the crisis on older people"	Brussels, Belgium
19-20 June	Council of Europe symposium on "Biobanks and biomedical collections"	Strasbourg, France
21 June	Sanofi meeting with patient organisations	Paris, France

Date	Meeting	Location
22 June	Meeting with Alzheimerföreningen (Sweden)	Luxembourg, Luxembourg
25-26 June	AE Board Meeting	Brussels, Belgium
26 June	European Parliament lunch-debate "The place of Alzheimer's disease in the new European public health and research programme"	Brussels, Belgium
26 June	Corporate Round Table	Brussels, Belgium
26-27 June	AE Working Group on national dementia strategies	Brussels, Belgium
27 June	Meeting with Fondation Médéric Alzheimer	Brussels, Belgium
4 July	ALCOVE Work Package meeting on early diagnosis	Worcester, United Kingdom
4-5 July	European Innovation Partnership on Active and Healthy Ageing Meeting of the Action Group on Age Friendly Environments	Brussels, Belgium
6 July	Meeting with Nutricia	Luxembourg, Luxembourg
9 July	PharmaCog Steering Committee Meeting	Stevenage, United Kingdom
23 July	Meeting with office of Angelika Werthmann, MEP (Austria)	Brussels, Belgium
23 July	Meeting with European Parkinson's Disease Association	Brussels, Belgium
27-28 August	Meeting with Malta Dementia Society	Valletta, Malta
5 September	Meeting with SCRM Avocats	Luxembourg, Luxembourg
7 September	Meeting with conference organiser of 22nd Alzheimer Europe Conference "Changing perceptions, practice and policy"	Vienna, Austria
11 September	Meeting with office of Sirpa Pietikäinen, MEP (Finland)	Brussels, Belgium
20 September	Press conference for 22nd Alzheimer Europe Conference "Changing perceptions, practice and policy"	Vienna, Austria
28 September	EFPIA Think Tank Meeting	Brussels, Belgium
1 October	NILVAD Steering Committee Meeting	Amsterdam, Netherlands
1 October	Meeting with Ligue Alzheimer and Workshop on "Dementia friendly cities"	Brussels, Belgium
2 October	European Innovation Partnership on Active and Healthy Ageing Meeting of the Action Group on Age Friendly Cities	Brussels, Belgium

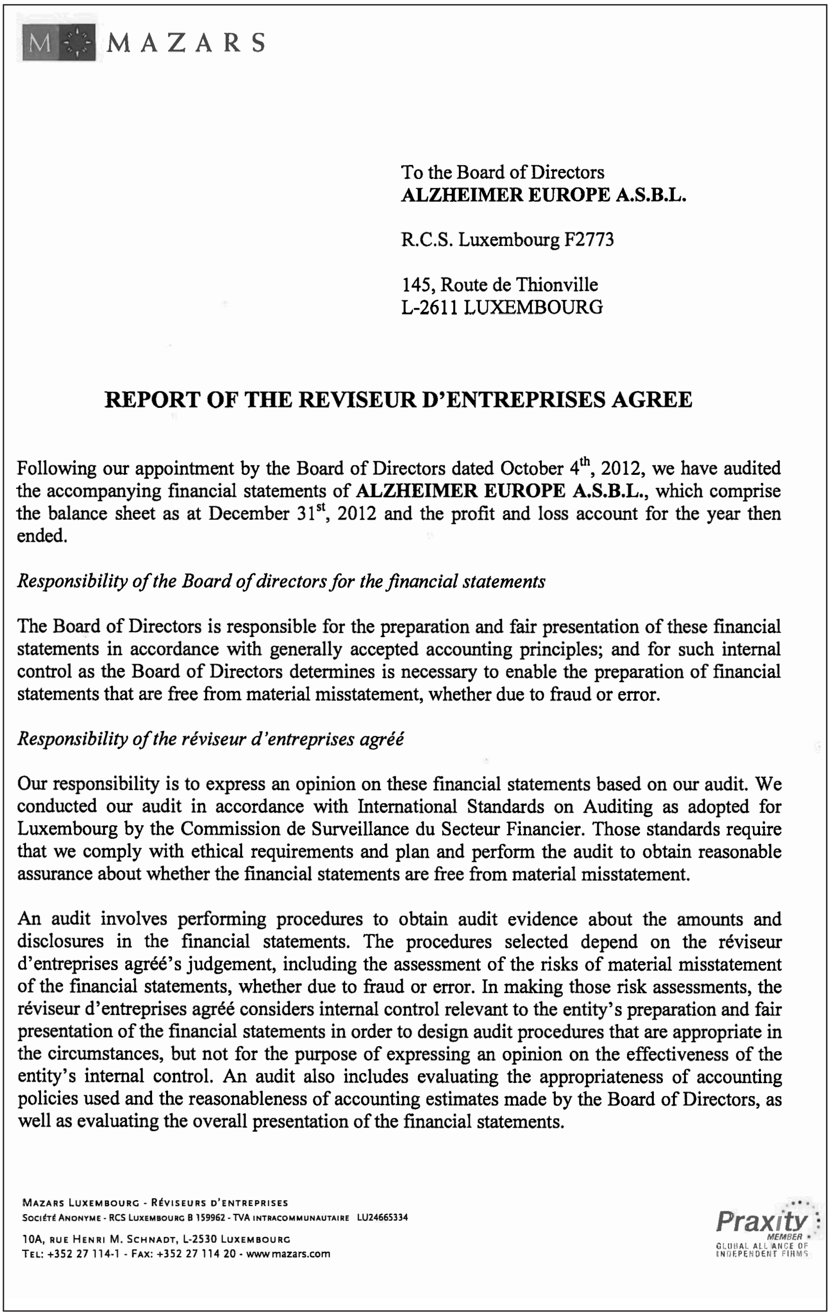
Date	Meeting	Location
3-4 October	European Working Group of People with Dementia	Vienna, Austria
4 October	AE Board Meeting	Vienna, Austria
4 October	AE Annual General Meeting	Vienna, Austria
4-6 October	22nd Alzheimer Europe Conference "Changing perceptions, practice and policy"	Vienna, Austria
5 October	Meeting with Alzheimer's Disease International	Vienna, Austria
7 October	Working group on ethical issues linked to restrictions of freedom	Vienna, Austria
12-13 October	Meeting with Cypriot Alzheimer's Association	Nicosia, Cyprus
19 October	Sanofi meeting on Alzheimer's disease	Chilly Mazarin, France
25 October	Meeting with European Society of Radiology	Brussels, Belgium
30 October	General Assembly of European Federation of Neurological Associations	Brussels, Belgium
31 October	Meeting with Novartis	London, United Kingdom
1 November	Study visit of Lilly's Erl Wood Research Centre	Erl Wood, United Kingdom
6 November	Partner Conference of European Innovation Partnership on Active and Healthy Ageing	Brussels, Belgium
8 November	Meeting with European Parkinson's Disease Association	Brussels, Belgium
13 November	Pfizer stakeholders' day on clinical trials	Brussels, Belgium
14 November	WeDo Final Conference	Brussels, Belgium
16 November	Meeting with Redburn Solutions and Invest Northern Ireland	Luxembourg, Luxembourg
19 November	25th Anniversary Celebration of Association Luxembourg Alzheimer	Luxembourg, Luxembourg
20 November	AGE thematic seminar "Creating an age-friendly EU"	Brussels, Belgium
22 November	DSIDC Autumn Conference "Ethics and Dementia Care"	Dublin, Ireland
23 November	GSK Health Advisory Board	London, United Kingdom
27 November	Health-EU Editorial Board	Luxembourg, Luxembourg
29 November	EMA training session on pharmacovigilance legislation	London, United Kingdom
30 November	EMA Working Party with Patient and Consumer Organisations	London, United Kingdom

Date	Meeting	Location
3 December	European Working Group of People with Dementia	Brussels, Belgium
3-4 December	AE Board Meeting	Brussels, Belgium
4 December	European Parliament lunch-debate "Living with dementia" and launch of Dementia in Europe Yearbook	Brussels, Belgium
7 December	Meeting with Alzheimer Slovenia	Brussels, Belgium
10 December	PharmaCog Steering Committee Meeting	Lille, France
11 December	EFPIA Think Tank Meeting	Brussels, Belgium
12 December	Meeting with Luxembourg Alzheimer's Association and Integrated BioBank of Luxembourg	Luxembourg, Luxembourg
13-15 December	ELTECA Meeting on long-term care	Prague, Czech Republic
17 December	Vodafone Accessibility Awards Ceremony	Brussels, Belgium



Financial Report

1 Report of the Réviseur d'entreprises agréé



MAZARS

To the Board of Directors
ALZHEIMER EUROPE A.S.B.L.

R.C.S. Luxembourg F2773

145, Route de Thionville
L-2611 LUXEMBOURG

REPORT OF THE REVISEUR D'ENTREPRISES AGREE

Following our appointment by the Board of Directors dated October 4th, 2012, we have audited the accompanying financial statements of **ALZHEIMER EUROPE A.S.B.L.**, which comprise the balance sheet as at December 31st, 2012 and the profit and loss account for the year then ended.

Responsibility of the Board of directors for the financial statements

The Board of Directors is responsible for the preparation and fair presentation of these financial statements in accordance with generally accepted accounting principles; and for such internal control as the Board of Directors determines is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

Responsibility of the réviseur d'entreprises agréé

Our responsibility is to express an opinion on these financial statements based on our audit. We conducted our audit in accordance with International Standards on Auditing as adopted for Luxembourg by the Commission de Surveillance du Secteur Financier. Those standards require that we comply with ethical requirements and plan and perform the audit to obtain reasonable assurance about whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the réviseur d'entreprises agréé's judgement, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the réviseur d'entreprises agréé considers internal control relevant to the entity's preparation and fair presentation of the financial statements 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 financial statements.

MAZARS LUXEMBOURG - RÉVISEURS D'ENTREPRISES
SOCIÉTÉ ANONYME - RCS LUXEMBOURG B 159962 - TVA INTRACOMMUNAUTAIRE LU24665334

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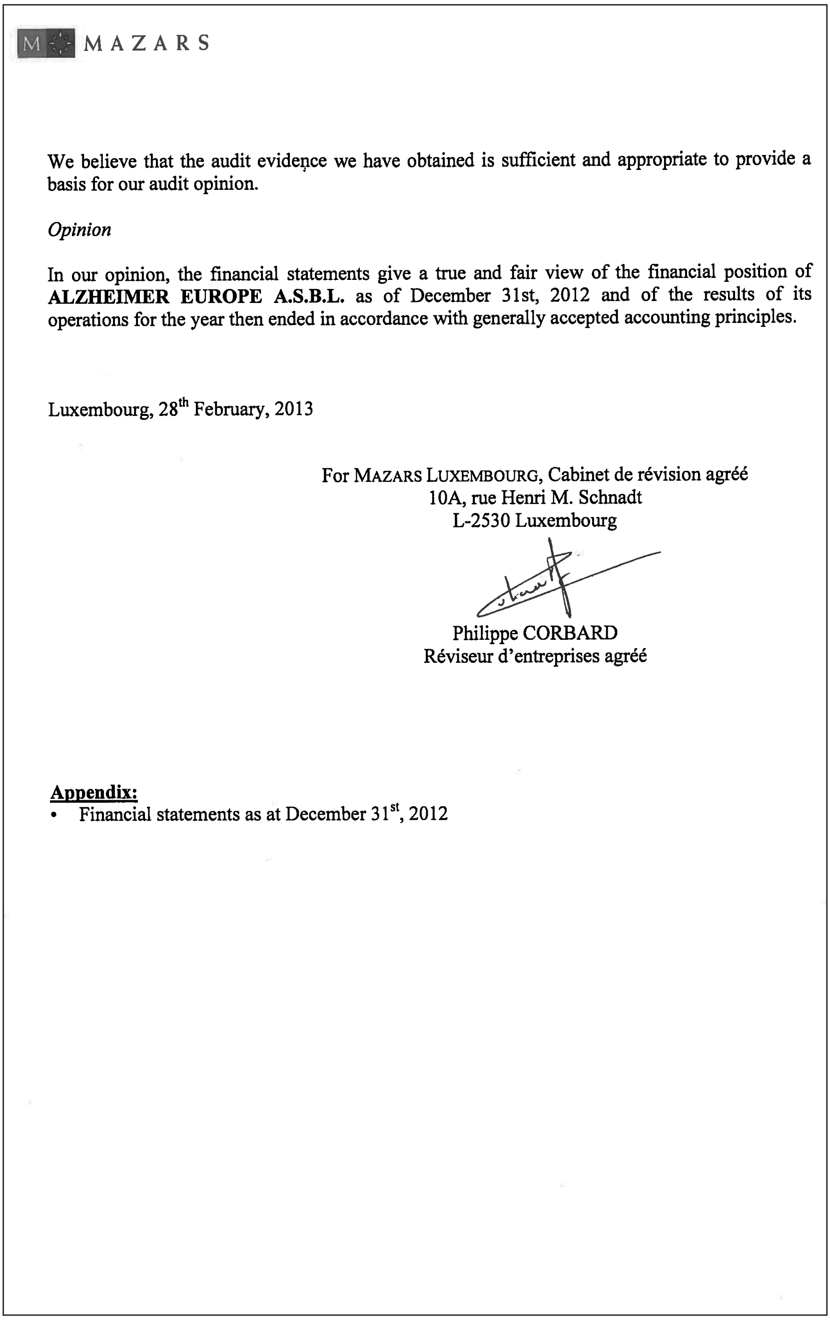
Praxity MEMBER
GLOBAL ALLIANCE OF INDEPENDENT FIRMS



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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 financial statements give a true and fair view of the financial position of **ALZHEIMER EUROPE A.S.B.L.** as of December 31st, 2012 and of the results of its operations for the year then ended in accordance with generally accepted accounting principles.

Luxembourg, 28th February, 2013

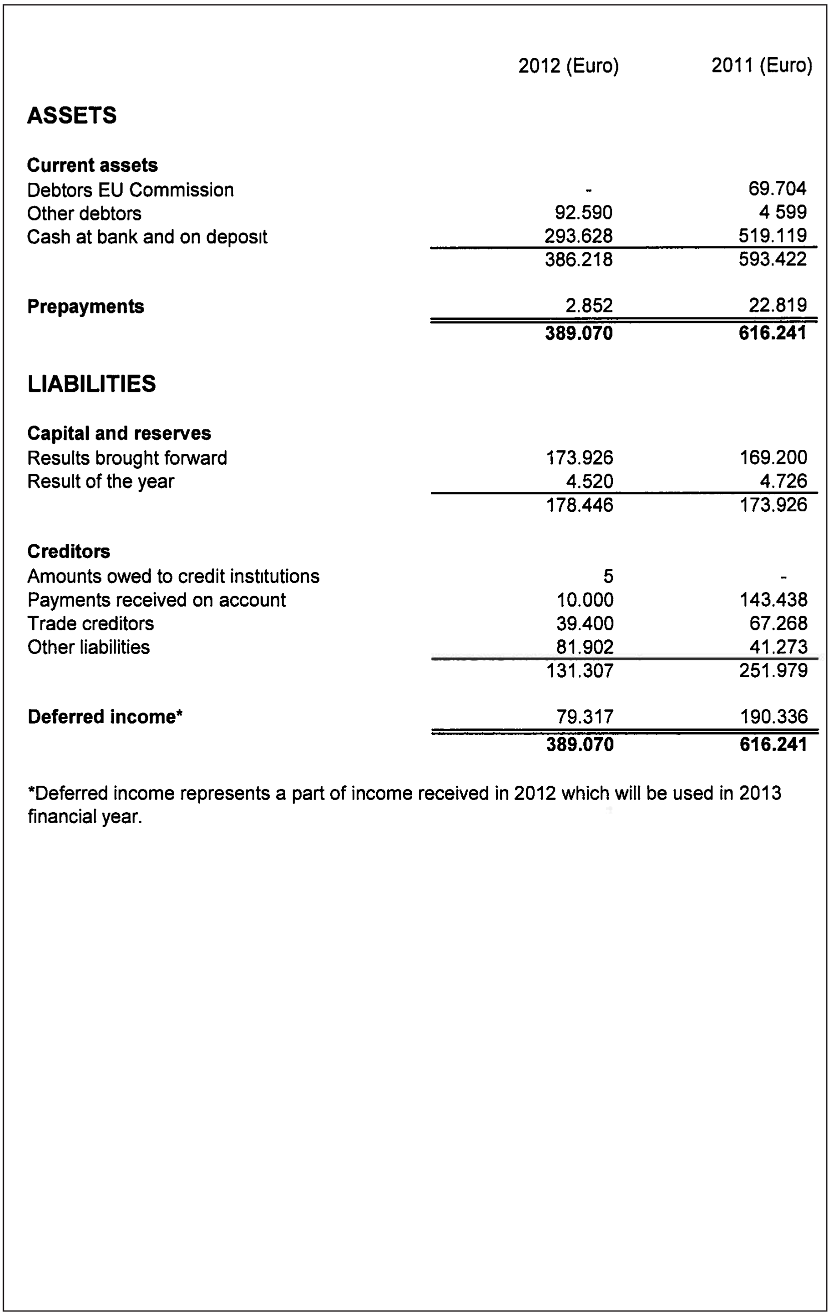
For Mazars Luxembourg, Cabinet de révision agréé
10A, rue Henri M. Schnadt
L-2530 Luxembourg

Philippe CORBARD
Réviseur d'entreprises agréé

Appendix:

- Financial statements as at December 31st, 2012

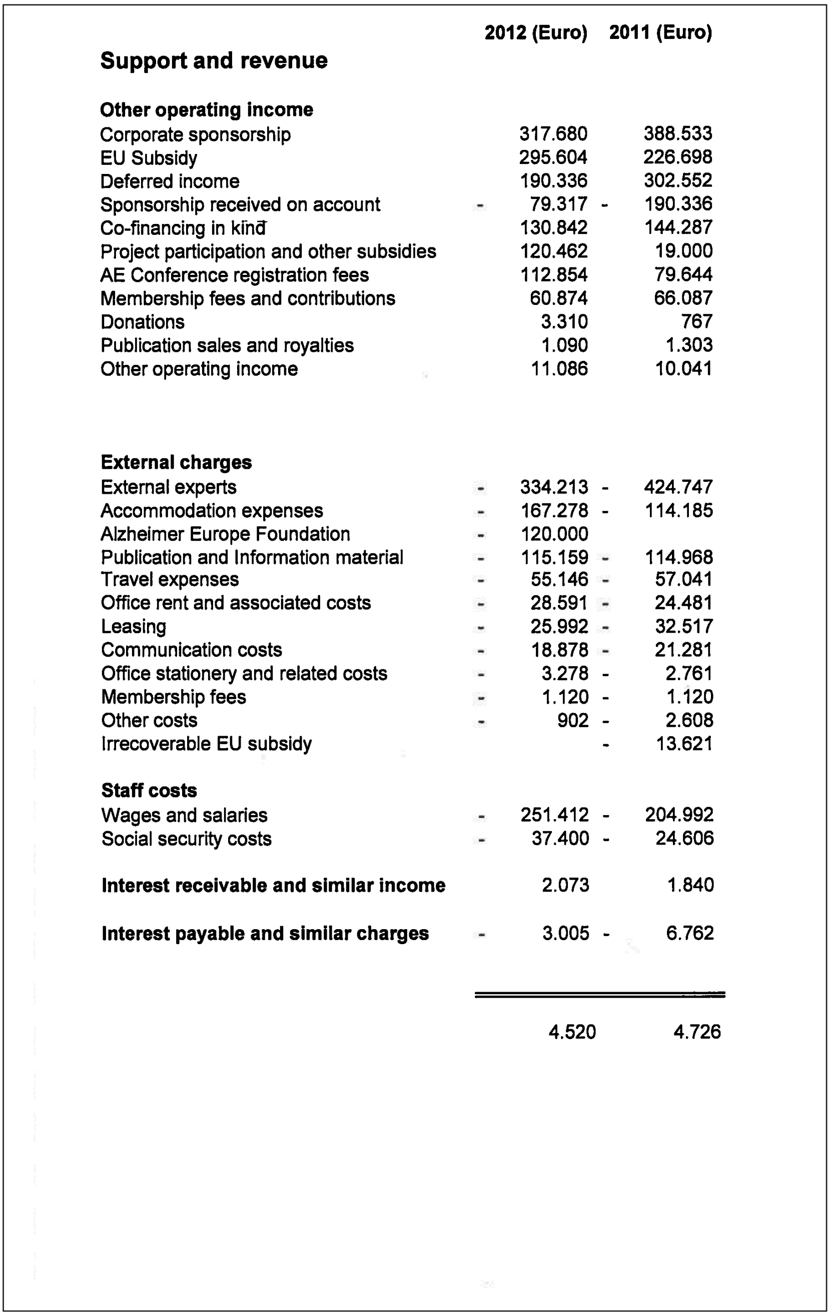
2 *Balance sheet as of December 31, 2012*



	2012 (Euro)	2011 (Euro)
ASSETS		
Current assets		
Debtors EU Commission	-	69.704
Other debtors	92.590	4 599
Cash at bank and on deposit	293.628	519.119
	386.218	593.422
Prepayments	2.852	22.819
	389.070	**616.241**
LIABILITIES		
Capital and reserves		
Results brought forward	173.926	169.200
Result of the year	4.520	4.726
	178.446	173.926
Creditors		
Amounts owed to credit institutions	5	-
Payments received on account	10.000	143.438
Trade creditors	39.400	67.268
Other liabilities	81.902	41.273
	131.307	251.979
Deferred income*	79.317	190.336
	389.070	**616.241**

*Deferred income represents a part of income received in 2012 which will be used in 2013 financial year.

3 Profit and loss account Year ended December 31, 2012



	2012 (Euro)	2011 (Euro)
Support and revenue		
Other operating income		
Corporate sponsorship	317.680	388.533
EU Subsidy	295.604	226.698
Deferred income	190.336	302.552
Sponsorship received on account	- 79.317	- 190.336
Co-financing in kind	130.842	144.287
Project participation and other subsidies	120.462	19.000
AE Conference registration fees	112.854	79.644
Membership fees and contributions	60.874	66.087
Donations	3.310	767
Publication sales and royalties	1.090	1.303
Other operating income	11.086	10.041
External charges		
External experts	- 334.213	- 424.747
Accommodation expenses	- 167.278	- 114.185
Alzheimer Europe Foundation	- 120.000	
Publication and Information material	- 115.159	- 114.968
Travel expenses	- 55.146	- 57.041
Office rent and associated costs	- 28.591	- 24.481
Leasing	- 25.992	- 32.517
Communication costs	- 18.878	- 21.281
Office stationery and related costs	- 3.278	- 2.761
Membership fees	- 1.120	- 1.120
Other costs	- 902	- 2.608
Irrecoverable EU subsidy		- 13.621
Staff costs		
Wages and salaries	- 251.412	- 204.992
Social security costs	- 37.400	- 24.606
Interest receivable and similar income	2.073	1.840
Interest payable and similar charges	- 3.005	- 6.762
	4.520	4.726

4 *Breakdown of income*

4.1 Introduction

In 2012, Alzheimer Europe had an audited income of EUR 1.246,211.94 of which EUR 619,177.75 (49.68%) were for the organisation's core activities (including the organisation's Dementia Ethics Network and EUR 627,034.19 (50.32%) were for the organisation's annual conference, corporate affairs activities and other projects.

4.2 Funding of core activities (EUR 619,177.75)

In 2012, the core funding of Alzheimer Europe was composed as follows:

- EUR 235,603.94 (38.05%) from public funding,
- EUR 149,272.10 (24.11%) from member organisations,
- EUR 141,755.83 (22.89%) from foundations and other non-profit organisations,
- EUR 70,335.64 (11.36%) from deferred income brought forward from the financial year 2011,
- EUR 7,840.37 (1.27%) from corporate sources,
- EUR 2,073.19 (0.33%) from bank interest and similar,
- EUR 1,210.62 (0.20%) from individuals,
- EUR 11,086.06 (1.79%) from other sources.

4.2.1 Public funding

In 2012, the breakdown of public funding totalling EUR 235,603.94 can be broken down as follows:

- Alzheimer Europe received EUR 190,000 as an operating grant from the European Commission, EUR 20,889 for its participation in the DECIDE project, EUR 17,725.28 for its participation in the PharmaCog project and EUR 6,989.66 for its participation in the NILVAD project.

4.2.2 Funding from member organisations

In 2012, the EUR 149,272.10funding from member organisations can be broken down as follows:

- EUR 60,874.39 in membership fees and contributions
- EUR 58,391.66 from the Luxembourg member organisation through the secondment of the AE Executive Director,
- EUR 12,000 from the Luxembourg member organisation by providing the offices of Alzheimer Europe free of rent,
- EUR 16,500 in co-financing from Board members and representatives of member organisations in time donated to the organisation (at EUR 300 per day) and
- EUR 1,506.05 from Alzheimer Scotland as support to the preparatory meeting of the European Working Group of People with Dementia in Glasgow.

4.2.3 Foundations and organisations

The EUR 141,755.83 which Alzheimer Europe received in 2012 from foundations and other non-profit organisations can be broken down as follows:

- EUR 68,260 from Alzheimer Europe Foundation which supported the organisation's Dementia in Europe Yearbook and European Dementia Ethics Network,
- EUR 39,300 in donated time by experts involved in the ethical work and comparison of national dementia strategies of Alzheimer Europe (at EUR 300 per day),
- EUR 29,195.83 as direct support from Fondation Alzheimer, Luxembourg and
- EUR 5,000 from Fondation Médéric Alzheimer which supported the European Dementia Ethics Network.

4.2.4 Deferred income

In 2012, Alzheimer Europe was able to contribute EUR 70,335.64 to its core activities which came from deferred income in 2011.

4.2.5 Corporate support

In 2012, Alzheimer Europe received EUR 7,840.37 from corporate sources as core-funding which can be broken down as follows:

- EUR 6,000 from Mazars which carried out the audit of the organisation's 2011 and 2012 accounts free of charge,
- EUR 1,650 from Newswweaver which provided an e-mail facility free of charge and
- EUR 190.37 as a donation from Mark Krueger and Associates.

4.2.6 Bank interest and similar

In 2012, Alzheimer Europe had an income of EUR 2,073.19 from bank interest and similar income.

4.2.7 Individuals

In 2012, AE received EUR 1,210.62 from individuals which can be broken down as follows:

- EUR 1,090.62 in publication sales and
- EUR 120 in donations.

4.2.8 Other income

In 2012, EUR 11,086.06 came from other sources not mentioned above.

4.3 Funding of project activities (EUR 627,034.19)

In 2012, Alzheimer Europe received EUR 627,034.19 for its various projects, including its Annual Conference in Vienna, the Alzheimer Europe Foundation and its corporate affairs activities, of which

- EUR 317,680.07 (50.66%) came from corporate sponsors
- EUR 120,000 (19.14%) from deferred income brought forward from the financial year 2011,
- EUR 112,854.12 (18.00%) from private individuals,
- EUR 62,500 (9.97%) from public sources and
- EUR 14,000 (2.23%) from foundations and other non-profit organisations.

4.3.1 Corporate support

The corporate support received by Alzheimer Europe for its activities in 2012 (EUR 317,680.08) can be broken down as follows:

- Janssen and Lilly each contributed EUR 50,000 towards AE’s corporate activities and the Annual Conference in Vienna,
- Pfizer and Novartis contributed EUR 40,000 towards AE’s corporate activities,
- GlaxoSmithKline contributed EUR 35,000 in support,
- GE Healthcare provided EUR 30,000 in support of AE’s corporate activities and the Annual Conference in Vienna,
- SCA Global Hygiene contributed EUR 20,000 towards AE’s corporate activities and the Annual Conference in Vienna,
- Nutricia contributed EUR 20,000 towards AE’s Annual Conference in Vienna,
- Lundbeck contributed EUR 10,000 towards AE’s corporate activities.

In addition, AE received EUR 879.51 in travel support from Pfizer and EUR 1,782.56 as travel support and honoraria from GlaxoSmithKline.

4.3.2 Deferred income

In 2012, Alzheimer Europe was able to dedicate EUR 120,000 for the setting up of the Alzheimer Europe Foundation. This funding came from deferred income in 2011.

4.3.3 Private individuals

In 2012, Alzheimer Europe received EUR 112,854.12 in registration fees for the Alzheimer Europe Conference in Vienna.

4.3.4 Public funding

In 2012, Alzheimer Europe received EUR 60,000 as a grant from the European Commission and EUR 2,500 from Land Niederösterreich for its Annual Conference in Vienna.

4.3.5 Foundations and non-profit organisations

In 2012, Alzheimer Europe received EUR 10,000 from the Network of European Foundations and EUR 4,000 from Fondation Roi Baudouin for its Annual Conference in Vienna.

4.4 Overall funding

The following table lists all sources of income received in 2012.

In line with the policy of the European Medicines Agency on transparency requirements for accredited patients' organisations, this is presented in total amounts as well as in terms of percentages of the overall income of the organisation.

Funding source	Funding received (2012)	As% of AE income (2012)	As% of AE income (2011)
Janssen	50,000.00	4.01%	4.03%
Lilly	50,000.00	4.01%	4.03%
Pfizer	40,897.51	3.28%	4.04%
Novartis	40,000.00	3.21%	
GlaxoSmithKline	36,782.56	2.95%	2.90%
GE Healthcare	30,000.00	2.41%	
Sanofi	20,000.00	1.60%	2.22%
Lundbeck	10,000.00	0.80%	1.61%
Bayer			11.28%
Sub-total: Pharmaceutical funding	277,680.07	22.28%	30.11%
Nutricia	20,000.00	1.60%	
SCA Global Hygiene	20,000.00	1.60%	1.21%
Mazars	6,000.00	0.48%	0.24%
Newsweaver	1,650.00	0.13%	
Mark Krueger and Associates	190.37	0.02%	
Sub-total: Other corporate sources	47,840.37	3.84%	1.45%
Total: Corporate funding	325,520.44	26.12%	31.56%
Deferred income	190,335.64	15.27%	24.38%
Total: Deferred income	190,335.64	15.27%	24.38%
European Commission	295,603.94	23.72%	18.27%
Land Niederösterreich	2,500.00	0.20%	
Total: Public funding	298,103.94	23.92%	18.27%
Association Luxembourg Alzheimer	70.391.66	5.65%	8.03%
Other member organisations	78,880.44	6.33%	7.91%
Total: Member organisations	149,272.10	11.98%	15.94%
Individuals (Conference fees, donations, registration fees)	114,064.74	9.15%	6.59%
Total: Individuals	114,064.74	9.15%	6.59%
Alzheimer Europe Foundation	68,260.00	5.48%	
Fondation Alzheimer, Luxembourg	29,195.83	2.34%	
Network of European Foundations	10,000.00	0.80%	

Funding source	Funding received (2012)	As% of AE income (2012)	As% of AE income (2011)
Fondation Médéric Alzheimer	5,000.00	0.40%	1.13%
Fondation Roi Baudouin	4,000.00	0.32%	0.40%
Other organisations (donated time)	39,300.00	3.15%	0.77%
Total: Foundations and organisations	155,755.83	12.50%	2.31%
Bank interest and similar	2,073.19	0.17%	0.15%
Total: Bank interest and similar	2,073.19	0.17%	0.15%
Other income	11,086.06	0.89%	0.81%
Total: Other income	11,086.06	0.89%	0.81%
Total Income	1,246,211.94	100.00%	100.00%

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