

2008

Dementia in Europe Yearbook 2008



with a focus on social support, socio-economic cost,
psycho-social interventions and prevention

Including the Alzheimer Europe Annual Report 2007



This project has received financial support from the European Commission. Neither the European Commission nor any person acting on its behalf is responsible for any use that might be made of the following information.

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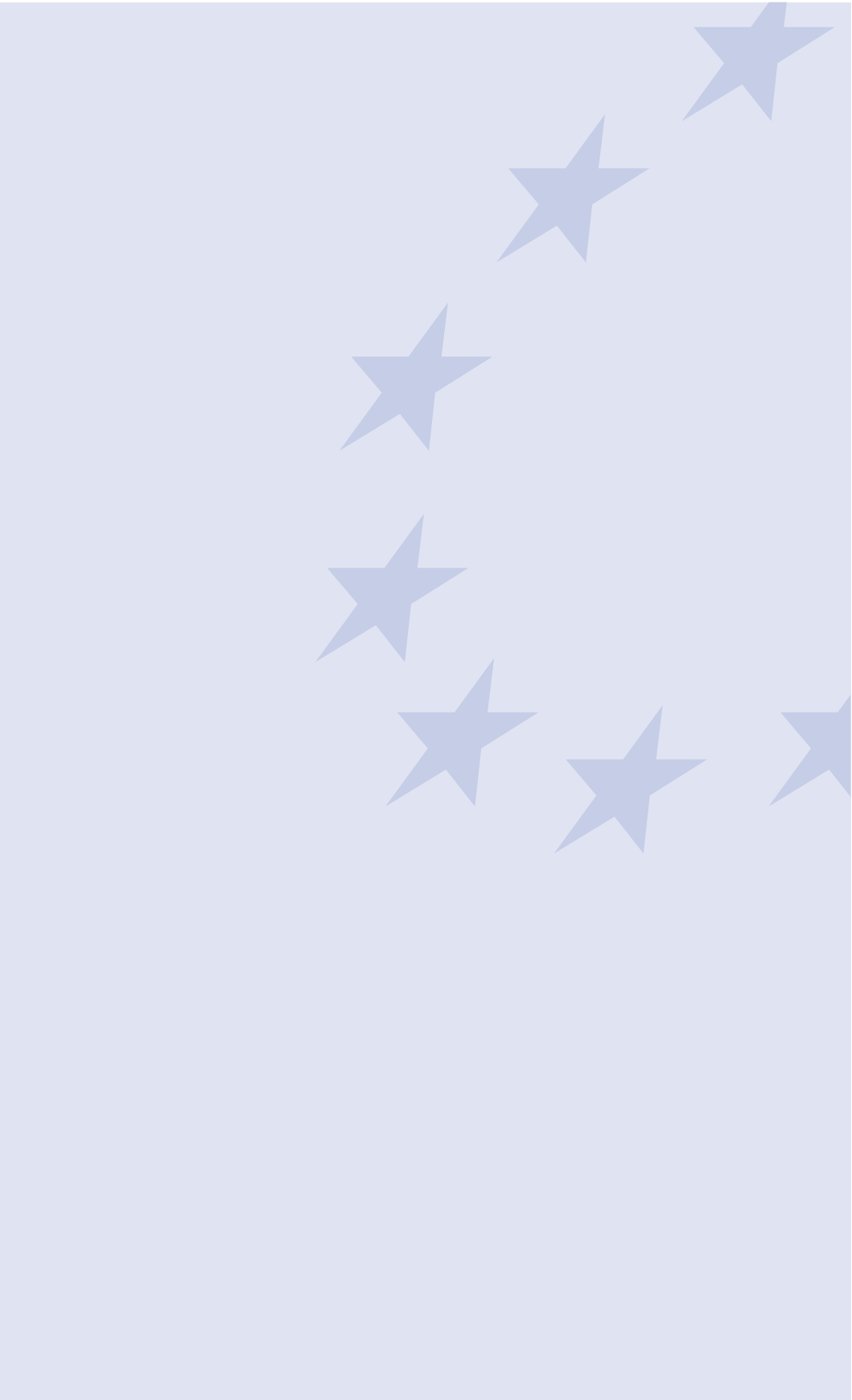
Alzheimer Europe gratefully acknowledges the co-financing it has received from Fondation M@déric Alzheimer for the coordination of the EuroCoDe project and for the work packages on social support systems, the socio-economic cost of dementia and psychosocial interventions.

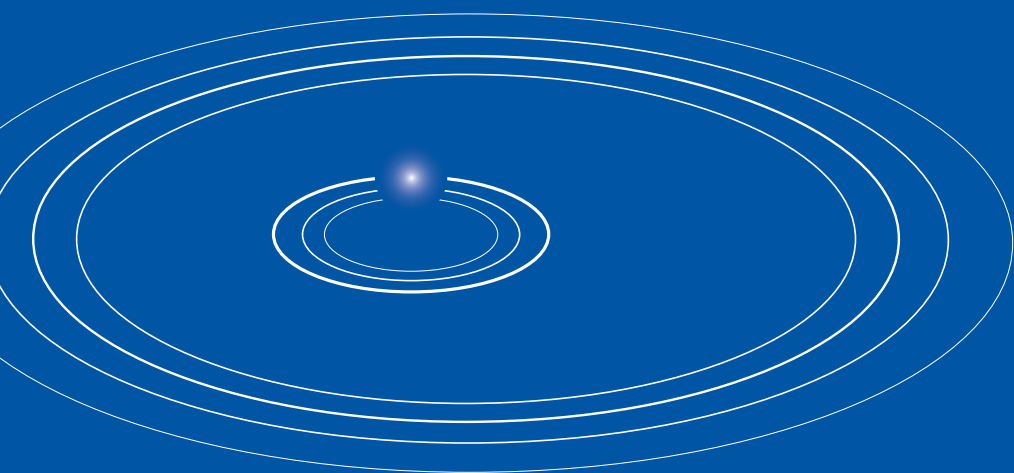


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Forewords

1.1 *Androulla Vassiliou, European Commissioner for Health*



I am delighted to be able to introduce this edition of the Dementia in Europe Yearbook published by Alzheimer Europe. Alzheimer's disease and other dementias, including all neurodegenerative diseases, are major points of attention in the European Union public health information and prevention policies, and as the European Commissioner responsible for public health, these are issues that I feel very strongly about. I would also like to take this opportunity to highlight some recent achievements and actions in this field, many achieved with the invaluable cooperation of Alzheimer Europe.

The White Paper COM(2007) 630 "Together for Health: A Strategic Approach for the EU 2008-2013" of 23 October 2007, develops the EU Health Strategy and has explicitly identified and addressed the important need for a better understanding of neurodegenerative diseases such as Alzheimer's disease and other dementias. The Commission maintains its priority to achieve the necessary recognition that is in proportion to the magnitude of the problem and costs faced by society, by using the facilities provided by the Health Programme 2008-2013 as much as possible. The current situation for EU-level monitoring of neurodegenerative diseases, such as Alzheimer's disease, is still unsatisfactory because competent authorities at national level have only just begun to consider this a main priority.

The European Ministerial Conference "Fight against Alzheimer's disease and related disorders," held on 30-31 October 2008 under the French Presidency of the Council, was the first opportunity to discuss the conclusions submitted to the Health Council in December 2008. These conclusions are an excellent starting point for a long-term action addressing the importance of the problem. Such action would focus on strategies for preventing Alzheimer's and related disorders, non-medical strategies, adaptation, skills of professional and voluntary caregivers, links with rare diseases, and the need for a collaborative approach between Member States and the Commission in the field of research.

The European Commission has also proposed to link a part of the future work on Alzheimer's disease to the European Pact for Mental health and Well-being, established on 13 June 2008; a Council Recommendation in 2009 will support this proposal. It should, however, be clear that Alzheimer's disease is a neurodegenerative disease for which the mental health aspect is only one dimension of the problem, and further actions in other fields will also be necessary in the future.

Alzheimer's disease remains under-diagnosed in the EU. According to the available epidemiological data, only half of the patients suffering from the disease are currently identified. There are several reasons for this under-diagnosis, in particular

the fact that many doctors are not yet convinced of the benefits of a medical approach to Alzheimer's disease or its therapeutic treatment. This under-diagnosis is chiefly observed in elderly patients, but it also concerns younger subjects. When the diagnosis is eventually made, it is typically late and at the stage of confirmed dementia.

In order to further our understanding of neurodegeneration, brain research and, in particular, research on Alzheimer's and neurodegenerative diseases have received continuous support since the establishment of the early Framework Programmes; the 5th Framework Programme (1998–2002) invested about €20m in research on Alzheimer's disease, mainly through the key action on “The ageing population and their disabilities.” The 6th Framework Programme (2002–2006), dedicated a further €250m to brain and neuroscience research, of which about €40m has been invested in supporting translational research programmes on Alzheimer's disease, which are currently underway. Moreover, in order to tackle research fragmentation and to support cooperation and coordination in this field, an ERA-NET (European Research Area), specifically dedicated to national public or other bodies responsible for financing or managing research activities on neurodegenerative diseases (including Alzheimer's disease), has received funding. Furthermore, the 7th Framework Programme (2007–2013) emphasises collaborative research with a specific sub-activity on “Research on the brain and related diseases, human development, and ageing.” It is expected that the 7th Framework Programme will offer a broad range of possibilities needed to address Alzheimer's disease research as a priority at the EU level.

In 2005, a new network supported by funding from the Public Health Programme was created by Alzheimer Europe to implement the important EuroCoDe initiative (European Collaboration on Dementia). The various guidelines and indicators will be developed by specific working groups comprising representatives from the majority of Member States. Data on the prevalence on Alzheimer's disease and other dementias are now available across the EU, and are included in the ECHI (European Community Health Indicators), thanks to the valuable and essential work of Alzheimer Europe. As proven by the previous editions of the Dementia Yearbook in 2006 and 2007, the ‘Dementia Yearbook 2008’ provides a comprehensive and complete overview of the present situation of Alzheimer's disease and other dementias in the EU.

The European Commission is well aware that Alzheimer Europe is and has been the main network monitoring dementia cases in the EU. As a non-profit organisation, I am happy and proud to say that Alzheimer Europe is extensively supported by funding from the Public Health Programme, thus supporting their task of aiming to improve the care and treatment of Alzheimer patients. I know very well that the EuroCoDe Project led by Alzheimer Europe is a great health action success and the Commission will be proud to continue the collaboration with Alzheimer Europe within the framework of the Health Programme 2008–2013.

I hope that this 2008 edition will further reinforce common practices in the different areas and stages of the disease and ultimately contribute towards improving our knowledge and treatment of dementia, thus improving the lives of Alzheimer patients in Europe.

I would like to thank Alzheimer Europe for all their valuable work, and for publishing this yearbook, and I wish them success in all their future actions.

Androulla Vassiliou

1.2 Françoise Grossetête, Member of the European Parliament and Chairperson of the European Alzheimer's Alliance



It gives me great pleasure to introduce the third edition of Alzheimer Europe's "Dementia in Europe Yearbook". The previous editions provided interesting comparisons regarding the numbers of people affected, the availability of anti-dementia drugs, the provision of home care and the social support systems in the 27 Member States of the European Union, as well as in Iceland, Norway, Switzerland and Turkey. This latest edition completes the picture with information on the socio-economic impact of the disease, possible preventative approaches and recommendations on how to improve the social support of people with dementia and their carers.

Developed within the framework of the European Commission funded project "European Collaboration on Dementia – EuroCoDe", the yearbooks have proved valuable tools for policy makers to compare the state of dementia care in their country to other European countries and I am convinced that this type of exchange of good practices can contribute to an improvement in the lives of the 6.1 million people with dementia across the European Union.

Concrete steps need to be taken now involving policy makers, researchers, professionals, patients and their carers. It is encouraging to see that some countries have already embarked on ambitious national Alzheimer or dementia plans and I am particularly proud that this year, the 3rd Alzheimer's Plan was launched in France and President Sarkozy pledged €1.6 billion to accomplish the Plan's objectives.

As the Chairperson of the European Alzheimer's Alliance, I was delighted that the Plan also included a clear commitment to make dementia a European priority. Together with my colleagues John Bowis (United Kingdom), Katalin Levai (Hungary), Jan Tadeusz Masiel (Poland) and Antonis Trakatellis (Greece), I launched a Written Declaration in the European Parliament calling for concerted action on a European level in the field of Alzheimer's disease with increased research funding, better support for people with dementia and their carers, as well as recognition for the role of Alzheimer associations.

In the European Parliament, we have of course always paid close attention to the demographic changes in our societies and the specific needs of people with dementia and their carers. As Rapporteur for the establishment of the Innovative Medicines Initiative (IMI), I was proud that my colleagues supported the initiative's aim to increase the investment of the European Union in research, with effective

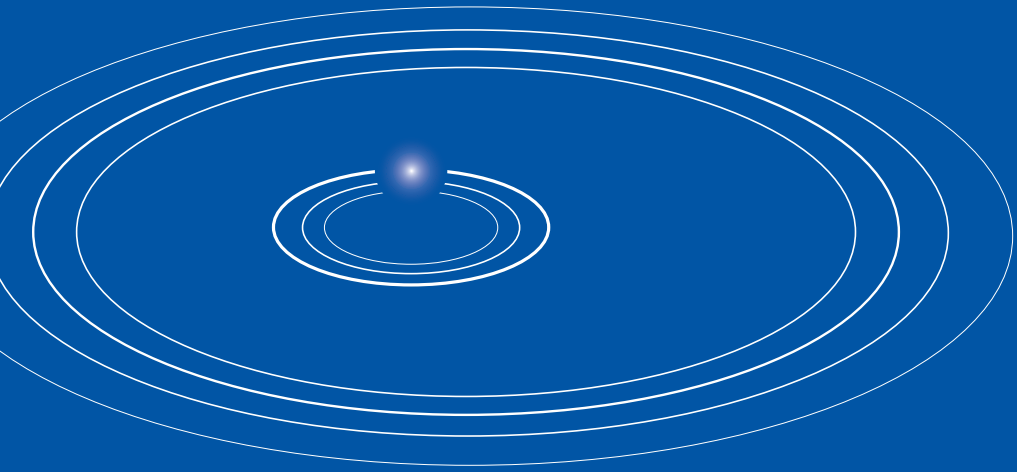
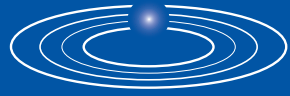
resources having been dedicated to research into the causes, diagnosis and treatment of Alzheimer's disease.

Other European Parliament reports have addressed the demographic challenges in Europe, the need for solidarity between generations, the improvement of mental health and the enhancement of the quality of life of older people with the use of new information and communication technologies. The renewed social agenda will also be an opportunity to address the needs of people with dementia and their carers.

I am hopeful that under the French Presidency of the European Union, these different initiatives will be combined in order to develop a comprehensive action plan for our fight against Alzheimer's disease and other forms of dementia.

As Chairperson of the European Alzheimer's Alliance, I will give my full support to increased co-operation between Member States in this field. I am sure that the many findings contained in this third Dementia in Europe Yearbook will provide important guidance to policy makers and I look forward to continuing the excellent collaboration with Alzheimer Europe on these issues.

Françoise Grossetête



Introduction



The European Collaboration on Dementia, our three-year project funded by the European Commission, is drawing to a close and it gives me great pleasure to introduce our third “Dementia in Europe Yearbook” with the findings of four of the six working groups set up within the framework of our project.

The working group led by Dianne Gove from Alzheimer Europe carried out an extensive survey on the varying social support provided to people with dementia and their carers by national governments and found huge variations as regards access to services and treatment between the different European countries covered in the study. Nevertheless, the multidisciplinary group was able to develop key recommendations on how to improve the social support for people with dementia and their carers, with the development of national Alzheimer plans, the respect of the dignity and rights of people with dementia and equality of access to social support being among the key recommendations.

The working group led by Anders Wimo from the Karolinska Institute carried out a thorough analysis of socio-economic studies in the dementia field across Europe. Their estimate of the cost of dementia in the European Union amounts to €130 billion with €57.3 billion in direct costs and €72.7 billion in informal care costs borne by families and carers. These figures clearly demonstrate that the care of people with dementia presents a great challenge for all European societies, a challenge that will only increase in future due to the ageing of the European populations.

Myrra Vernooij-Dassen from the Nijmegen Alzheimer Centre and her working group carried out an overview of guidelines and recommendations on psychosocial interventions in dementia. Unlike for pharmacological treatments, there are fewer existing guidelines and the working group was only able to identify five countries with such guidelines with a further three countries having developed reports or consensus papers. Nevertheless, the group managed to develop a set of 17 key recommendations, as well as 15 quality indicators for psychosocial care which will undoubtedly be a valuable tool for anyone interested in this field.

Finally, Lutz Frölich from the Central Institute for Mental Health in Mannheim and his working group analysed studies on the possible prevention of Alzheimer's disease. While biological factors, such as age, gender and genetics, will of course remain outside the scope of any possible prevention strategy, the group found increasing evidence of the role of cardiovascular, behavioural, environmental and nutritional risk factors. The recommendations of this working group should be taken to heart by individuals to lower their respective risks, but equally by policy makers to develop comprehensive prevention strategies.

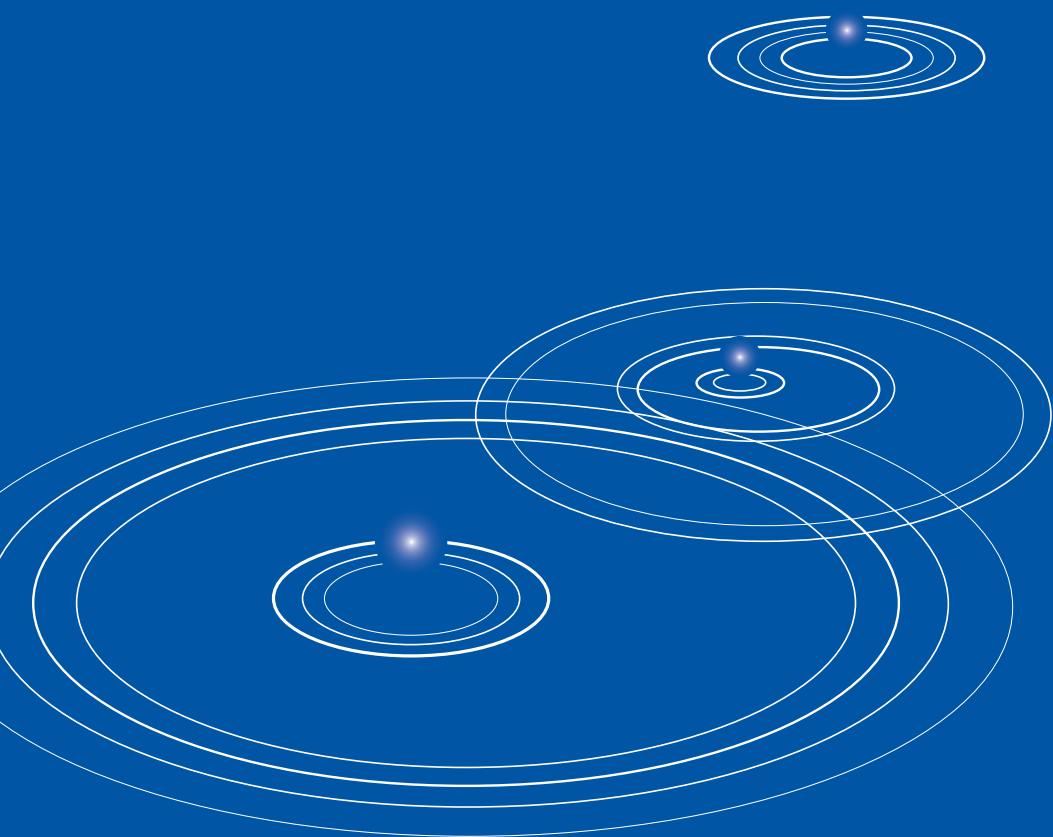
Our thanks go to the four leaders of the working groups, as well as all the other experts who took an active part in the development of the different recommenda-

tions that we have included in this Yearbook. This project would not have been possible without their contributions or the financial support by the European Commission under its public health programme. Finally, we would like to thank Fondation Médéric Alzheimer for the financial support they gave for the coordination of the project, as well as their scientific input into our work on psycho-social interventions, the socio-economic cost of dementia and the social support of people with dementia and their carers.

As with previous editions of our Yearbook, we hope that this edition will make for interesting reading for policy makers, researchers and everyone interested in dementia. We were particularly delighted to have President Sarkozy single out our project at the recent French Presidency Conference on Alzheimer's disease in Paris on 31 October and praise it as a concrete action and project which resulted in rich data on how to improve the care and support of people with dementia across the European Union. We hope that this Yearbook will live up to those expectations.

Jean Georges
Executive Director
Alzheimer Europe





*Recommendations and examples
of good practice in the provision
of social support to people with
dementia and carers*

3.1 Introduction

There are many different forms of dementia of which Alzheimer's disease is the most common. Dementia is not actually a disease but rather a set of symptoms (or a syndrome in medical terms). It involves progressive damage to the brain and causes a gradual deterioration of people's functional capacity as well as changes in their roles, responsibilities and social relations. All these changes and losses affect the person's identity and sense of self. Dementia affects other people too i.e. relatives and others in the person's social network. As the disease progresses, effects become increasingly evident and the person with dementia becomes more dependent on other people for help and support.

There are currently over 6 million people with dementia in the European Union¹ and it is predicted that this number will double in the next 20 years² along with the ageing of the population. There are also millions of carers, often elderly people with limited resources, who care for people with dementia at home to the best of their ability with varying levels of support from the State. In some countries, support from the State for people with dementia and carers (e.g. in the form of services, allowances and care structures) is quite well developed whereas in others, it is virtually inexistent. Alzheimer Europe has carried out a survey in the framework of the 3-year EC-funded "EuroCoDe" project to investigate the kind of social support³ available to people with dementia and carers in Europe and to write recommendations to policymakers on the basis of its findings.

The EuroCoDe survey was carried out in 2007 with the help of its national member associations and a few external experts. Individual national reports⁴ were produced as well as a comparative document⁵ of the overall findings. These findings reflected the general availability of services and support at that time; they were not a measure of the number of individual services or the quality of such services. Nevertheless, respondents provided additional information about problems linked to the provision of such services e.g. barriers to access, overall availability, how services are funded and the extent to which available services are suited to the specific needs of people with dementia.

It should be noted that the responses to the survey reflected the views of representatives of Alzheimer associations and in some cases external experts who were nevertheless linked to the associations. As such, it could be argued that these were subjective views but on the other hand, the Alzheimer associations and associated experts are ideally placed to understand the kind of support that people with dementia and carers need and to consider these needs in the light of the available services.

1 Alzheimer Europe (2006), *Dementia in Europe Yearbook 2006*, Alzheimer Europe

2 Ferri et al. (2005), Global prevalence of dementia: a Delphi consensus study, *the Lancet*, vol. 366, 2112-2117

3 Please refer to Section 6 for a brief glossary containing definitions of social support and carers and for a list of the members of the working group.

4 Alzheimer Europe (2007), *Dementia in Europe Yearbook 2007*, Alzheimer Europe

5 Alzheimer Europe (2008), *Comparative report on the level of social support provided to people with dementia and their carers in Europe*, Alzheimer Europe

We recognise that policy makers in Europe are at various stages in the development of good quality social support to people with dementia and carers. These recommendations should be understood as representing an optimal situation which policy makers should aim to achieve.

This document contains an executive summary of the recommendations to improve the provision of social support to people with dementia and carers. This is followed by a more complete presentation of the important issues which we feel should be considered when providing such support and finally a collection of examples of good practice.

3.2 Executive summary

Overriding goals and principles

1. Governments should set up national action plans for dementia care and set aside the necessary funds to implement them.
2. Governments should ensure that people with dementia and carers have equal access to the social support (i.e. support, care, services and facilities) they need.
3. Measures should be taken to improve the quality of social support, remove barriers to accessing it and ensure a sufficient supply of services in all geographical areas.
4. Governments should take measures to facilitate independent living and the social integration of people with dementia.
5. Governments should promote the early diagnosis of dementia.
6. In addition to advance statements for medical treatment, governments should create possibilities for people to express in advance their wishes concerning their future care and social support, and to appoint a trustworthy person to speak on their behalf.
7. Governments should develop campaigns and measures to combat the stigmatisation and abuse of people with dementia.

Respecting the rights and dignity of people with dementia

8. Services and support to people with dementia should be provided in such a way as to maintain or enhance their autonomy and dignity, whilst at the same time balancing this with the need to ensure their safety.
9. The needs, wishes, rights, protection and individuality of each person with dementia should be at the centre of any social support provided.
10. People with dementia should be consulted and informed about any social support they receive and every effort should be made to obtain their consent.
11. Governments should ensure that regulations relating to the provision of social support to people with dementia are enforced.
12. People with dementia should not be subjected to restrictive or coercive measures. Instead, alternative means of ensuring safety or providing care should be developed.

State funding and organisation of social support

13. The organisation and financing of healthcare and social support should be coordinated in such a way as to ensure a seamless provision of care, support and services to people with dementia and effective coordination between healthcare and social care systems and providers.

14. In order to ensure a sufficient number of trained healthcare professionals and providers of good quality social support to people with dementia, governments should invest in training and provide incentives to attract professionals to this domain.
15. Measures should be taken to limit the potential financial burden of dementia on carers and people with dementia. This might include compensation for loss of income, assistance with costs incurred, protection of pension fund contributions and tax deductions for costs linked to care etc.
16. People with limited resources should be given the financial assistance necessary to access the social support they need but access should not be limited solely to people on a low income.
17. Alzheimer Associations, NGOs, charitable organisations and volunteer networks should be provided with appropriate support from the State for the services they provide.

Ensuring equal access to social support

18. People with dementia should have access to appropriate and good quality social support if and when needed, irrespective of the type or stage of dementia, the specific diagnosis, geographical location, living situation, age or any other means of discrimination.
19. The specific needs and living situation of certain groups of people with dementia should be recognised and appropriate support provided e.g. those with alcohol dependency or learning disabilities, living alone or in rural areas, on a low income and/or from minority groups etc.
20. People with dementia should have access to a general information service to direct them towards available social support, assistance to help them apply for it and an advocate to inform them of their rights and ensure that their rights are respected.
21. In each community, there should be a “dementia contact person” who is available to answer questions about the disease and the kinds of services available.

General issues surrounding the provision of social support

22. A rehabilitative approach to social support for people with dementia should be developed and provided on a multidisciplinary basis in collaboration with people with dementia and carers (please refer to section 3.2 of this report for further details).
23. Every person with dementia should have a dementia care coordinator, regular assessment of his/her needs and appropriate case management.
24. Social support should be provided when needed and not solely when the person with dementia has reached a specific level of general disability.

25. Carers should be entitled to a separate assessment of their needs, resources and willingness to provide care.
26. Dementia should be a component part of doctors' undergraduate training.
27. Continuous training in dementia care should be provided to all stakeholders and at every level of service provision from decision making to practice.
28. Care and service providers should have access to medical expertise whenever needed, irrespective of where care is provided.
29. A combined preventive and curative approach should be adopted when appropriate.

Issues related to the provision of home care/outpatient services and support

30. Social support should be provided if and when required, taking into account the wishes and usual daily routine of the person with dementia and the possible need for care at any time of the day or night.
31. People with dementia should have access to information, counselling, psycho-education, appropriate psychological support, different kinds of therapies and meaningful activities, and training in coping with activities of daily living.
32. Carers should have access to information, counselling, psychoeducation, appropriate psychological support and training, as well as bereavement counselling.
33. Children and adolescents should have access to specially adapted support.
34. A wide range of services, which respond to the specific needs of the person with dementia, should be available including, for example, assistance with personal care and hygiene, housework, mobility, eating and drinking, taking medication, shopping, laundry, transport and home maintenance.
35. The importance of social contact, exercise and mental stimulation to help maintain existing capacity should be recognised and appropriate support provided.
36. Day care and occasional night care in centres should be available for people with dementia. Staff in such centres should be suitably trained in dementia care.
37. People with dementia should have access to affordable assisted technology and home adaptations suited to their particular needs and capacities.
38. Carers should have regular access to affordable respite during the day, in the evening, at night and for varying periods of time.
39. A replacement carer (or an allowance to pay for a replacement carer) should be provided during this period in the home or in a centre. Attempts should be made to ensure that this causes the least disturbance possible to the person with dementia.

Residential and palliative care

40. Flexibility in the provision of short or long-term residential care should be encouraged in order to respect autonomy, maximise independent living and respond to changing needs and temporary or crisis situations. Emergency wards of hospitals are not suitable places for such care.
41. Measures should be taken to ensure that every person with dementia has access to affordable and good quality long-term residential care when needed. If this is not possible, appropriate temporary measures should be found.
42. Semi-residential and alternative forms of residential care should be developed which maximise the potential for independent living.
43. Palliative care services at home, in centres and provided by mobile palliative care teams should be available to people with dementia when needed. Access should not be restricted to those who also have a diagnosis of cancer.
44. Recommendations on issues specifically related to end-of-life and palliative care can be found in Alzheimer Europe's "guidelines on the good end-of-life care of people with dementia" (2008).

3.3 General Recommendations

3.3.1 Ethical, legal and financial issues

3.3.1.1 Dignity, autonomy and social inclusion

First and foremost, people with dementia are friends, relatives, neighbours and fellow members of society. The fact that they have a specific medical condition is secondary. They have an inherent dignity, value and personhood which remains with them throughout the whole course of the disease and should be respected at all times. The gradual loss of capacity makes it difficult for people with dementia to maintain their place and active participation in society i.e. in the private sphere, within the community and in the workplace. Carers may also experience social exclusion based on the effects of dementia on their loved ones. However, maintaining social contact and remaining active helps preserve autonomy and physical and mental well-being for longer, minimise the need for assistance and prevent social isolation and depression. The real barriers to social inclusion and equal citizenship are often discriminatory attitudes and procedures, as well as a lack of understanding. These are issues which can be addressed. There is therefore an urgent need to raise awareness of dementia and take measures to combat stigmatisation, negative stereotyping, discrimination and indifference.

When providing social support and services to people with dementia, it is important to respect their right to self-determination: This means ensuring that their wishes are taken into consideration and their consent obtained. As dementia progresses, it becomes increasingly difficult to obtain fully informed consent from people with dementia. However, it is always possible to involve them in the decision-making process to some extent, keeping them informed, asking and/or finding out from others about their preferences and taking into account previously expressed wishes.

Recommendations on dignity, autonomy and social inclusion

1. Services and support to people with dementia should be provided in such a way as to maintain or enhance their autonomy and dignity.
2. In addition to advance statements for medical treatment, governments should promote possibilities for people to express their wishes concerning care and social support, and to designate in advance a trustworthy person to speak on their behalf, whilst they still have sufficient capacity to do so.
3. People with dementia should be informed of these possibilities when the diagnosis is disclosed in case they have not already made such arrangements and still have sufficient capacity to do so.
4. Consent should be sought from the person with dementia. As standard consent procedures are likely to be unsuitable in many cases, alternative and novel approaches should be sought.

5. Difficulties communicating wishes or understanding should not be mistaken for implicit consent or indifference.
6. As some forms of support may also have consequences (e.g. financial, practical or time-wise) for carers and/or be provided in the carer's home, their wishes and rights should also be considered and as far as possible respected.
7. Consent issues should be handled very carefully in order to avoid abuse and/or measures which are disproportionate to the need.
8. Whilst respecting the privacy of people with dementia, people providing services should be vigilant for signs of possible difficulty, abuse or neglect experienced by people with dementia, and report this to their supervisors.
9. The person with dementia and his/her needs should be at the centre of any support provided. In addition, his/her wishes and individuality should always be taken into consideration.
10. Measures should be taken to promote the early diagnosis of dementia.
11. Campaigns to combat stigma should be developed.

3.3.1.2 Living at home, safety issues and preventing abuse

Ensuring that people with dementia can remain in their own homes for as long as they wish to do so (and insofar as it is possible for them) is becoming a priority for many governments as they gradually realise the positive effect that this can have on people's physical and mental health and well-being, as well as the fact that it is usually less expensive for the state. Nevertheless, people with dementia must also have the option of affordable and suitable residential care. Enabling people to continue living at home requires careful attention to obtaining the right balance between autonomy and safety, to the rights and needs of carers who are directly concerned by this choice and to the risk of possible isolation.

As the needs of the person with dementia change, the home may become ill-adapted to their needs and render the task of caring more difficult. Fortunately, assisted technology and adaptations to the home can be a tremendous help and may even delay the need for residential care.

People with dementia are at increased risk of different forms of abuse (e.g. verbal, physical, financial and psychological abuse as well as neglect) due to their progressive loss of capacity, communication difficulties and increasing dependence on others. Abuse can occur in any setting but may be more difficult to detect in the home setting and for people with dementia living alone.

Recommendations on living at home, safety issues and preventing abuse

1. Measures should be taken to ensure that people with dementia are able to continue living in their homes for as long as they wish and it would be reasonably possible for them to do so.

2. Measures should be taken to ensure that couples can carry on living together if they wish to do so e.g. by increased home care services or establishments which accept couples. This should not be limited to married couples.
3. The right balance between safety and autonomy must be ascertained by means of an ongoing evaluation process covering autonomy and safety issues.
4. The importance of maintaining social networks should be recognised and measures taken to try to prevent social isolation.
5. Transport for practical and social purposes should be provided or subsidised. This should extend to carers accompanying a person with dementia.
6. People in the early stage of dementia should be provided with individualised training in managing everyday tasks and developing coping strategies in order to enhance their autonomy and protect them from accidents and abuse.
7. The specific needs of people with dementia living alone, especially with regard to safety issues, should be considered.
8. The development of affordable assisted technology, adapted to the needs of people with dementia, and access to affordable home adaptations should be encouraged as a means to promote autonomy and safety.
9. Suitably adapted tele-monitoring systems should be completely funded by the state in the case of people with dementia living alone.
10. Measures should be taken to ensure that ethical issues linked to the use of assisted technology are always taken into consideration and that assisted technology is suited to the needs of each individual user.
11. Semi-residential or alternative forms of residential care should be developed which maximise the potential for independent living e.g. sheltered housing, group home living arrangements and boarding.
12. Restrictive or coercive measures should not be used and instead alternative means of ensuring safety or providing care adopted.

3.3.1.3 The planning, funding and organisation of services and support

The planning, funding and organisation of relevant care and support for people with dementia is often insufficient and inappropriate but is becoming a priority for many governments as the number of people with dementia steadily increases. Some have even made dementia care a political priority and set up action plans and policies with the appropriate funding to address a variety of issues linked to support, services, facilities and research. The way that social support is organised is also of utmost importance. People with dementia need affordable social support and services which were designed with their specific needs in mind and which are adapted to their individual situation and condition.

A few countries have long-term care insurances or allowances which are specifically designed to address the needs of people who have long-term care needs e.g. based on disabilities, old age or chronic conditions such as dementia. There are of course other ways to fund and organise social support to people with dementia. Whichever system is in use, it must be clear who, or which, authority is responsible for each type of support. The obligation to provide social support to elderly, disabled or vulnerable adults is often laid down in law and sometimes delegated to local municipalities. However, in practice, many people with dementia do not receive the support they need as laws are not enforced, funds for support are lacking and/or there is poor coordination between the different government authorities and levels.

*Recommendations on the planning, funding and
organisation of services and support*

1. In order to meet the need for dementia care, which is set to increase dramatically in the next few decades, governments should set up national action plans for dementia care and set aside the necessary funds to implement them.
2. The organisation and financing of healthcare and social care should be better coordinated so as to ensure a seamless provision of care, support and services to people with dementia.
3. Measures should be taken to ensure effective coordination between healthcare and social care systems and providers.
4. Governments should ensure that regulations and laws relating to people's rights to assessment and/or appropriate care are respected and enforced.
5. Appropriate measures should be taken to ensure that municipalities and other authorities provide the support and services that are needed.
6. Services should be provided which respond to the specific needs of people with dementia and not those of another group e.g. the elderly or the disabled, irrespective of how the services are funded (i.e. according to age or disability).
7. It should be made clear which regulations governing access to support and services apply to people with dementia. If this is linked to the elderly, disabled or other groups, as it is in some countries, the criteria governing access should be sufficiently wide as to include people with dementia.
8. The important role of Alzheimer Associations, NGOs, charitable organisations and volunteer organisations in providing services and support to people with dementia and carers should be recognised.
9. Such organisations of recognised value should be provided with the appropriate funding from the State to continue their activities.
10. Governments should encourage donations to such organisations e.g. by granting tax deductions for donations.

11. Efforts should be made to provide stable funding for various forms of support.
12. There should be a special time schedule or network for medical services for people with dementia and their carers because people with dementia have difficulty waiting for hours to see a general practitioner and the carer has little time as he/she often provides care on a full-time basis.
13. Measures should be taken to reduce delays in obtaining an appointment with a specialist.

3.3.1.4 Financial support to people with dementia and carers

Having dementia, or caring for a person with dementia, can lead to a loss of income (for example, through loss of paid employment and consequently of pension fund contributions), as well as additional costs (as services and support are seldom fully reimbursed or covered by the state, and may require out-of-pocket payments). Moreover, the valuable work provided by carers is often taken for granted by the state and their needs overlooked. As it may become increasingly difficult for people with dementia (and in many cases carers) to get out and socialise, it is important that they have access to affordable transport and a means of contact with the outside world.

Recommendations on financial support to people with dementia and carers

1. In recognition of the additional costs incurred when caring for a person with dementia, carers should receive a care allowance.
2. Measures should be taken to protect the state pension rights of people who give up paid employment or reduce their hours in order to care for a person with dementia.
3. People diagnosed with dementia who have to give up paid employment should be entitled to an allowance to compensate for the loss of income and measures to protect their pension rights.
4. People with dementia should be entitled to tax deductions on the grounds of their incapacity and for employing a person to provide home care services.
5. People with dementia who receive funding to pay for services should be allowed to select relatives and close friends as providers of those services.
6. People with dementia should be exempt from paying television and radio licences and be eligible for special reductions on the cost of public transport.

3.3.2 General framework for care and support

3.3.2.1 The need for a flexible approach

People with dementia and their carers⁶ have a right to lead their lives as normally as possible. It is important that they maintain control over their lives for as long as possible. The life situations of people with dementia and their carers are varied and the needs and wishes of people with dementia and their carers are always individual, as is the need for different kinds of services. Needs and life situations

⁶ The term “carers” is used here to refer to partners, relatives and close friends who live with the person with dementia or are closely involved in their care (on an informal basis). However, it should be noted that many people with dementia live alone and/or have no carers.

change as the disease progresses and this is why people with dementia and their carers need support and services on a continuous basis. People with dementia need timely diagnosis, accurate and appropriate information and sufficient counselling after the diagnosis has been made, adequate and ongoing support, individual assistance and different types of care like home care, day care and institutional care geared towards maintaining functional capacity. A flexible approach to social support, services and care is therefore essential.

In order to offer high-quality services and ensure a flexible provision of services, it is very important to evaluate thoroughly and regularly each individual's needs, functional capacity and life-situation. This should be completed by a regular and systematic follow-up.

The views of people with dementia are always important when designing, developing, providing and evaluating services and care. It is therefore essential to find a way to ascertain the individual needs of people with dementia. Official service models are often rather traditional and rigid and they do not sufficiently take into account the individual and changing needs of people with dementia and their carers. This leads to a situation in which support is not given in the right way at the right time. As a person's situation or the situation in a family can change quite rapidly and there may be crisis situations at home, the service system should be able to react to these changes in a timely and immediate fashion.

To meet these varying needs, flexibility and possibilities for choice are essential. Individually tailored care and service packages are therefore needed because standard and general solutions are not effective. Flexibility in services and care can only be achieved by listening to people with dementia and their carers' opinions, wishes and needs, assessing the situation thoroughly and having enough information about their overall situation. Flexibility may also be linked to the timing or location of a service. Indeed, a flexible approach is particularly important in rural areas where services are often scarce.

Recommendations on the need for a flexible approach

1. People with dementia should have the possibility of choice and access to individually tailored care and service packages.
2. The system of service provision should be sufficiently flexible to allow for immediate assistance whenever the person's life-situation changes or in times of crisis.
3. The views of people with dementia should always be taken into account when designing, developing, providing and evaluating services and care.
4. The individual needs, functional capacity and life-situation of the person with dementia should be thoroughly and regularly evaluated, and a regular and systematic follow-up carried out.

5. The individuality of the person with dementia should also be respected. This might include his/her sense of priorities, values, cultural and religious beliefs and practices, personal history and idiosyncrasies.
6. In order to access such information, people providing services should take the time to communicate with people with dementia, talk to carers and consult any available written documents such as advance directives or statements of values.

3.3.2.2 The rehabilitative approach

In addition to flexibility of services, a rehabilitative approach is also very important. The main aim of the rehabilitative approach is to support the functional capacity of the person with dementia and the quality of life and sense of control of both the person with dementia and his/her carer. A rehabilitative approach in services and care is aimed at supporting individual resources, autonomy and self-determination, and self-efficacy in the daily life of the person with dementia and his or her carer. In this way, possibilities for the person with dementia to take part in meaningful activities are enhanced and supported. The availability of choice contributes towards self-determination.

The rehabilitative approach in dementia care can be seen as reflecting the basic idea of the ICF (International Classification of Functioning, Disability and Health, WHO 2001 ⁷) in which disability is described as a dynamic interaction between health conditions (e.g. diseases, disorders) and contextual factors (personal and environmental factors). Environmental factors include the physical, social and attitudinal environment and the environment can either support or hinder a person's functioning, participation and activities.

Dementia affects all areas of a person's functional capacity (physical, psychological, cognitive and social). The way that dementia progresses and its effects on a person's life are always individual. Functional capacity is affected by many factors such as the type and severity of dementia, other diseases, medication, personality and the physical and psychosocial environment. It is possible to support people's capacities and resources by means of a rehabilitative approach of which the holistic assessment of functional capacity is a cornerstone.

Respecting human rights and individuality, supporting autonomy and self-determination, recognising lost and remaining skills and supporting functional capacity are basic values within a rehabilitative approach, which can be achieved by listening to the person with dementia, trying to understand his/her situation, wishes and needs and involving him or her and his or her carer in planning and evaluating the care provided. In addition, the evaluation of functional capacity, which is a basic element of the rehabilitative approach, and all this information helps in the setting of clear and individual aims for the rehabilitative approach.

Positive results have been obtained using different methods of the rehabilitative approach e.g. the multi-factorial support system in which both the person with dementia and his or her family carer are supported. The rehabilitative approach should be a key principle in day care services, short-term care and long-term care.

3.3.2.2.1 The rehabilitative approach throughout the whole care chain

Improved early diagnosis calls for the use of all possible means to maintain both the quality of life and functional capacity of people with dementia. It gives them the possibility to continue to lead a fairly normal life and to spend many good years at home. A rehabilitative approach to services and care can be seen as an essential means of empowering both people with dementia and their carers.

As the situation is constantly changing along with the progression of the disease, setting realistic aims and choosing individual and appropriate means of support are key factors in the rehabilitative approach. The main aim is not necessarily to improve functional capacity but rather to maintain it and to create real possibilities to use it to its full extent. The general aims of rehabilitation differ at different stages of the disease. In the early stage, it is important to support a person's independency, normal activities and usual way of life, to support functional capacity, to maintain meaningful roles and functions and to find appropriate compensatory strategies for those capacities that are already affected by the disease. In the middle stage, it is important to support remaining abilities and resources, and to create possibilities for success and a sense of achievement in order to support a person's identity. In the advanced stage, it is essential to provide support for mental and physical capacities as well as for the ability to interact. Environmental factors should also be taken into account in order to create a pleasant environment and prevent disorientation ⁸.

3.3.2.2.2 Assessment of the functional capacity and life situation of the person with dementia

When evaluating functional capacity within the rehabilitative approach, it is essential to look at the person with dementia in a holistic way i.e. as an individual with an individual life history, values, preferences, wishes and needs as well as being a part of his or her environment and society. The evaluation of functional capacity should include interviewing both the person with dementia and his or her carer, using validated measurements and tests and observing how the person with dementia is coping with daily activities. The evaluation should be carried out regularly and whenever there are obvious changes in the person's situation. It is important not only to look at the individual but also the environment. The environmental factors can either support or restrict the functional capacity of the person with dementia.

3.3.2.2.3 An unbroken continuum in services and care

The continuum in rehabilitative services is important because the situation of each person with dementia changes as the disease progresses. Whilst people with dementia and their carers need clear information, support for adaptation (adaptation

⁸ Additional information on rehabilitation and rehabilitative approach can be found in the following article: Pirttilä T, Heimonen S, Granö S. (2007). The essential role of rehabilitation in dementia care. *Gerontologia* 21(4):320-328. This article is published in Finnish and a translation can be found in the EuroCoDe database.

training courses) and counselling at the beginning of the disease in order to be able to lead as full a life as possible, these needs gradually change. Social support should be provided on a continual, ongoing basis, from detection of the first symptoms to the end of the disease. People with dementia and their carers should know at all times where to turn for information, support and counselling.

3.3.2.2.4 The knowledge and skills of social and health care personnel

Using a rehabilitative approach provides resources and also supports functional capacities both individually and effectively. However, this places many demands on the social and health care personnel. It necessitates the collection of information from a variety of sources about the person's preferences and wishes, his or her personality and life-course, the disease and its stage and the person's functional capacity in order to provide help and support in the best possible way. This enables personnel to create opportunities for people with dementia to use their resources and capacities in their everyday lives. However, personnel must be trained in using a rehabilitative approach in their work and educated in dementia care.

Activities and activity programming are essential elements of rehabilitative care. Through individually selected activities the person with dementia is encouraged and supported to use his/her physical, cognitive, emotional and social resources to the full extent, which improves and maintains his/her functional capacity. The activities should be meaningful for the individual in question and they should provide a sense of usefulness, pleasure, success and efficacy. Choosing the right kind of activities is achieved with the help of a comprehensive assessment of the person's individual needs and resources.

Recommendations on the rehabilitative approach

1. The rehabilitative approach should be individually and holistically planned and provided, and should be developed and provided on a multidisciplinary basis with the co-operation of carers, and on the basis of information about the life history and current situation of the person with dementia and his/her needs and wishes.
2. An effective information system should be developed to ensure that such information is readily available to the relevant personnel and that confidentiality is respected.
3. A rehabilitative approach should be systematic, timely and flexibly provided. The type and stage of dementia, as well as the personality, life situation, life-style and individual habits of the person with dementia, should be taken into account.
4. An individual plan for rehabilitation is needed, in which the aims, means and responsibilities are clearly defined. This plan should be drawn up by a multi-disciplinary team of professionals together with the person with dementia and his/her carer and it should be evaluated regularly and systematically.

5. In order to support and/or help to maintain quality of life and functional capacity, appropriate and timely support, services and care are needed at the different stages of the disease. Services should be provided on a continuous and seamless basis based on a thorough and holistic needs assessment and on an evaluation of functional capacity.
6. The functional capacity of the person with dementia should be assessed thoroughly and in a systematic way.
7. The rehabilitative approach should be a key principle in day care and in different forms of institutional care.
8. Personnel should be trained in using a rehabilitative approach in their work and educated in dementia care.

3.3.3 Suitability, accessibility and barriers to obtaining support, services and care

The surveys carried out on behalf of Alzheimer Europe into the availability of social support throughout Europe revealed that whilst services and various forms of support exist, this is not always suitable and/or equally accessible to all people with dementia and carers in specific countries. In some cases, the barriers are based on eligibility criteria, in some cases on a lack of availability of services and sometimes on a combination of the two.

In some countries, people diagnosed with one of the less common forms of dementia cannot access services because only certain forms of dementia are officially recognised. Where services do exist, people with less common forms of dementia such as fronto-temporal dementia, variant Creutzfeldt-Jakob disease or alcohol-related dementia may find that the services do not correspond to their specific needs. Younger people with dementia and those who also have learning disabilities such as Down's syndrome may feel out of place in day care centres for people with dementia who are mostly older.

It is important to take into consideration the specific needs of certain groups of people with dementia e.g. those who live alone or who have limited financial resources. However, such criteria are sometimes used to limit access to services and support for other groups of people with dementia. Similarly, the fact that a person with dementia lives with other people should not lead to an assumption that the latter will provide the care he/she needs (although there is a legal obligation in some countries for certain relatives to support dependent parents).

Accessing appropriate support is particularly problematic when the services available are or were originally intended for a different group of people e.g. the elderly or people with disabilities. For example, services which were designed for people with disabilities are often heavily orientated towards physical needs. In such cases, the typical symptoms of dementia make it difficult for people to use some of the

services that are available e.g. meals on wheels, certain home monitoring systems and day care where no transport is provided. As the difficulties that they encounter are not always obvious or even visible, their real needs may go unmet.

Standard services are not always appropriate for people from certain ethnic or other minority groups. Consequently, people from such groups may be excluded or exclude themselves. Failure to develop appropriate services which respond to the needs of various minority groups and respect their cultural differences (e.g. linked to language, dietary requirements etc.) represents a form of discrimination.

*Recommendations on suitability, accessibility and barriers
to obtaining social support*

Different types of dementia and disability status

1. Services should be developed which take into account the specific needs of people with different types of dementia e.g. with fluctuating capacity, different levels of mobility and more pronounced alteration of mood. Examples of such services might include day care for people with Down's syndrome or for people with early onset dementia or support groups for people with fronto-temporal dementia etc.
2. Diagnoses of specific forms of dementia should not be used to exclude certain people with dementia from the services and support they need.
3. If access to services and support is dependent on official recognition of a disability, then all forms of non-reversible dementia should be accepted as contributing towards the required level of disability.
4. Eligibility criteria based on disability or care needs should take into account the specific nature of dementia and consequently avoid bias towards physical disability or needs. The physical needs of people with dementia should nevertheless be recognised and appropriate support provided e.g. prevention and treatment of decubitus ulcers and incontinence and assistance with mobility, eating and drinking.
5. People with dementia should not have to wait until a specific level of general disability or global need has been reached before being considered eligible for any services.

Addressing specific needs

6. Specific assessment with appropriate case management should be provided to people with dementia, taking into account any specific needs e.g. of younger people with dementia, people with dementia who live alone etc. Support and services provided should be individually tailored to those needs.
7. Measures should be taken to provide people with dementia and carers from ethnic minorities with services and support that respect their cultural traditions, language and dietary restrictions. There may also be less obvious minority

groups within the general population of specific countries with special needs and expectations.

8. People with limited resources should be given the financial assistance necessary to access the services and support they need but services should not be limited solely to people on a low income.

Rural areas and isolated or close-knit communities

9. Appropriate forms of support, effective co-ordination and additional transport should be provided in rural or isolated areas.
10. Novel approaches should be developed if necessary which take into consideration the particular needs and situation of people living in such areas.
11. Measures should be taken to ensure a sufficient number of qualified service providers in rural and isolated areas.
12. A special effort should be made to combat stigma in close-knit communities.

Availability of suitable structures and appropriately trained staff

13. Measures should be taken to ensure that there is a sufficient number of services, care networks and care structures along with trained staff in all areas. Where this is not the case, compensatory measures should be taken such as mobile care teams, organised transport and more flexible care arrangements.
14. Institutions for long-term care are needed with staff who are trained in caring for people with different types of dementia whose needs may be different.
15. Continuous training in dementia is needed for all stakeholders and at every level of service provision from decision making to practice.
16. Dementia should be a component part of doctors' undergraduate training.
17. Information should be provided to general practitioners about the burden of caring on carers and how this may affect their quality of life.
18. Other non-medical staff, as well as volunteers, should, as a minimum, have a basic understanding of what dementia is and how to communicate with people with dementia. They should be encouraged to take part in such training and rewarded for doing so e.g. in terms of a bonus or a higher status.

3.4 Specific services and support for people with dementia and carers

3.4.1 Outpatient services and self-help

Dementia affects cognitive functions such as memory, logical reasoning and abstract thought which not only affect the ability to carry out certain everyday tasks such as shopping, cooking, and cleaning, but also lead to self neglect and contribute towards accidents. It can also cause difficulties which, on the surface, may seem to be purely physical e.g. difficulties with mobility, manipulating objects, visual perception, swallowing and incontinence, but actually are also influenced by cognitive difficulties. The combined cognitive and physical problems make it difficult for people with dementia to live independently and make them increasingly dependent on other people for assistance. To complicate matters, certain behavioural and psychological symptoms, such as aggression, depression and wandering, can render the task of providing care more difficult and may have serious consequences e.g. abuse.

However, people with dementia do not all experience the same symptoms in the same order or to the same extent. Their needs and capacities are very individual, hence the need for a wide range of services and a flexible system as mentioned in section 3.2.1 above. Finally, in order to preserve the mental and physical health and wellbeing of carers, their needs must also be recognised and appropriate support provided.

Recommendations on outpatient services and self-help

General issues

1. Services should be available which are suited to the specific needs of people with dementia. This may involve creating new services and/or adapting existing services.
2. A dementia care coordinator (or “care manager”) should be appointed for every person with dementia.
3. Personnel providing home care services should be encouraged to involve people with dementia in daily activities and care to the extent that this is possible so as to help preserve their remaining capacities.
4. When providing services, the importance of social interaction for people with dementia should be recognised.
5. A survey should be carried out involving people with dementia and carers in order to determine the kinds of services and support needed.

Information, self-help organisations and volunteers

6. There should be a general information service to orientate people towards the services and support which are available to them in connection with their condition.
7. In each community, there should be a “dementia contact person” who is available to answer questions about the disease and the kinds of services available.
8. Assistance should be provided to people with dementia who have difficulty understanding or carrying out the procedure for applying for support.
9. People with dementia should have access to an advocate who can inform them about their rights and, if necessary, speak on their behalf about matters relating to their rights not being respected.
10. Special attention should be paid to the information needs of people with dementia living alone.
11. The important role that volunteers, neighbours and people from the local community play in the provision of services and support should be recognised and promoted.
12. Volunteers, neighbours and people from the local community providing services and support to people with dementia should be provided with training and, if necessary, some form of official identification. This should also be the case for people who have been appointed in advance by the person with dementia to make decisions on his/her behalf.

Different types of care in the home

Personal assistance and home help

13. Supervision/assistance for taking medication should be provided if needed, not just for medication linked to the treatment of dementia but also for other comorbid conditions.
14. Assistance with personal care should be provided if and when needed i.e. at various times of the day and as far as possible in accordance with the person's usual routine.
15. A combined preventive and curative approach to skin care and incontinence should be provided including both medical and non-medical aspects of such care and the provision of appropriate and sufficient continence pads or equipment.
16. Measures to assist with eating or drinking and/or the provision of meals should be adapted to the specific needs of people with dementia.
17. Assistance with housework, mobility, shopping, laundry and transport should be provided as well as ad hoc assistance with small-scale home maintenance jobs.

Night care

18. A home-based night care service should be available to people living alone in need of care or supervision at night.
19. Mobile night care services should also be available.
20. Carers looking after a person with dementia in need of night-time care should be entitled to a replacement carer on a regular basis.

Palliative care

21. People with dementia in need of palliative care should be able to receive palliative care services and support at home.
22. Whilst the decision of where to receive palliative care should be based on the needs and wishes of the person with dementia, the views of carers should also be considered.
23. A palliative care coordinator/advisor should be appointed for every person with dementia receiving palliative care. His/her task would be to coordinate the various service providers and be available to carers for advice at any time.

Counselling/therapy ⁹ and support for people with dementia

24. People with dementia should have access to individual or group counselling/therapy, psychoeducation and support throughout the whole course of the disease provided that it is beneficial to them.
25. As the disease progresses and verbal skills deteriorate other approaches to enhance psychological and emotional well-being should be made available to people with dementia ¹⁰.

Counselling, therapy, support and training for carers

26. Carers should have access to counselling/therapy, on an individual or group basis, and psychoeducation depending on their needs.
27. Bereavement counselling should be available to carers.
28. Carers should have access to training aimed at helping them cope with specific tasks related to caring but also to cope with the emotional and physical effects of caring.
29. When providing counselling, therapy or training for carers, the need to find suitable arrangements for the care of the person with dementia should also be considered as otherwise carers may be unable to take advantage of the services being offered.
30. Free advice from experts should be available by phone, preferably round the clock e.g. 24 hour telephone helpline or an out-of-hours number for emergencies.
31. Information, support groups and individual counselling/therapy if necessary should be made available to children and adolescents living in families with a person with dementia. A different approach may be needed for each group.

⁹ The word counselling is used here to refer to psychological counselling and not to the provision of information or advice.

¹⁰ A complete set of guidelines on psychosocial interventions were produced in the framework of the EuroCoDe project by Vernooij-Dassen et al. and can be obtained from Alzheimer Europe.

32. In cases where a child or adolescent has become the carer of his/her parent or relative appropriate professional support should be provided and care taken to minimise further upheaval.

Holidays and social and leisure activities

33. The importance of social contact, meaningful activities and physical exercise for the well-being of people with dementia and the preservation of their remaining capacities should be recognised and form an integral part of care packages whether at home, in day care centres or in residential care settings.
34. Opportunities for people with dementia and carers to socialise together should be encouraged e.g. Alzheimer cafés and excursions.
35. Measures should be taken to enable people with dementia and carers to have a holiday from time to time either together or separately.
36. Alzheimer associations, working in collaboration with carers and volunteers, who organize holidays for people with dementia (with or without carers) should be financially supported by the State.

3.4.2 Semi-residential care and respite for carers

At some stage, people with dementia who are living at home may either need or benefit from specific additional care, which cannot be obtained in the home environment. In this case, the care can only be provided on a semi-residential basis e.g. day care or night care. The demand for this type of care varies because each person's needs and situation are different. For example, one person might wish to attend a day care centre for social interaction or perhaps to take part in activities designed to stimulate cognitive abilities, whereas another might attend as he or she cannot be left alone for long periods of time for safety reasons or due to specific needs.

Sometimes day or night care also serves as a means of respite for carers, as well as cover for the usual carer who may be temporarily absent. Carers cannot be expected to care for people with dementia 24 hours a day 7 days a week without a break. Respite provides them with a much needed rest which is not only essential for their mental and physical well-being, but can also help them to cope with caring for longer. However, for this to be effective, they must have the reassurance that the person with dementia is safe and is being provided with quality care.

Recommendations on semi-residential care and respite for carers

Day care

1. Appropriate day care should be provided to people with dementia. This should be provided in an environment which has been designed or adapted with the needs of people with dementia in mind.
2. Day care centres should be run by staff who have been trained in dementia care.

3. Access to medical staff (either on-site or who can be called in) should be available in all day care centres for people with dementia.
4. For many people, especially those living alone, the transport service may have to be combined or coordinated with personal assistance e.g. helping the person out of bed, to get washed and to get dressed.
5. For people with dementia who do not live alone, transport times should be co-ordinated with carers as they may have other obligations e.g. linked to school hours if they have children and/or working hours if in paid employment.

Night care

6. Night care should be available to people with dementia who cannot be cared for at night at home and who, occasionally or regularly, need care or supervision at night.
7. Additional places for night care should be available for emergency situations e.g. where a carer is unexpectedly unable to provide care at night.
8. Wherever possible, night care should be provided in small-scale units rather than on large wards so as to minimise confusion and distress in the person with dementia.

Respite for carers

9. Carers should be entitled to respite on a regular basis if and when required and also in the form of a minimum number of weeks per year.
10. A replacement carer or an allowance to pay for a replacement carer should be provided during this period.
11. Flexible respite care services should be provided which take into consideration the carer's needs and the well-being of the person with dementia.
12. When organising respite care, measures should be taken to minimise the possibility of causing distress to the person with dementia.
13. Respite care services in the home should be developed.

3.4.3 Residential care

Good quality, affordable residential care facilities for people with dementia are lacking in most countries. Consequently, access to such care is often limited to people with dementia who fulfil specific criteria, such as having limited financial resources, living alone or being in urgent need of some form of residential care. However, there are many more people who would benefit from such care and who should have equal access to it. Residential care should not be considered as a last resort, or just for people with very advanced dementia. On the contrary, it can also be a way to promote the autonomy of people with dementia at an earlier stage of the disease.

Recommendations on residential care

Short-term residential care

1. Short-term residential care facilities should be available to cater for the temporary need for professional round-the-clock care of people with dementia.
2. Establishments accepting people for short-term residential care should have suitably qualified and trained personnel to take care of people with dementia. Emergency wards of hospitals are not at all suitable.
3. Such care should be available if and when needed. The assessment of need should not focus entirely on the condition of the person with dementia but should also take into account the needs and situation of carers.
4. Care should be taken to avoid moving the person with dementia around too often as this could be disturbing and lead to confusion, disorientation, stress and/or a further deterioration of his/her condition.
5. As an alternative to short-term residential care, in the case of a lack of available places, alternative forms of care should be developed e.g. temporary live-in carers, boarding.

Long-term residential care

6. Measures should be taken to ensure that every person with dementia has access to affordable and good quality long-term residential care when needed.
7. Waiting lists should be reduced and temporary solutions found if necessary.
8. Suitable long-term care facilities should be set up which have been designed with the needs of people with dementia in mind.
9. Creative solutions to long-term care should be investigated particularly for sparsely populated areas e.g. boarding, live-in carers, small-scale facilities etc.
10. Measures should be taken to ensure that people with dementia on a low income also have access to long-term residential care. On the other hand, places should not be restricted solely to people on a low income, with the most severe level of disability and/or living alone.
11. Long-term residential care should be offered when it would be beneficial to the person with dementia without waiting until his/her condition deteriorates to such an extent that it becomes an absolute necessity.
12. Professional carers should be adequately trained in dementia care.
13. Non-medical care staff employed in such establishments should also have at least a basic understanding of dementia and of how to communicate with people with dementia.

3.4.4 Palliative care

In its guidelines on good end-of-life care for people with dementia, Alzheimer Europe clearly states its opinion that palliative care is the best option for people with end-stage dementia. However, residential palliative care facilities which accept people with dementia are lacking in Europe¹¹ and palliative care services at home are not always available or adequate. It should also be noted that palliative care is an approach and a philosophy which can be adopted much earlier on in the course of the disease and not limited to the very last stage of life.

Recommendations on palliative care

1. End-stage dementia should be recognised as a terminal condition which may necessitate palliative care.
2. People with dementia should be entitled to residential palliative care when their condition necessitates it.
3. A diagnosis of dementia and/or lack of oncological diagnosis should not serve as a means to exclude a person with dementia from a place in a residential palliative care establishment.

¹¹ National reports of the European Association for Palliative Care (<http://www.eapcnet.org/Policy/CountriesReport.htm>) and the Alzheimer Europe's comparative report on social support to people with dementia and carers produced in the framework of the EuroCoDe project.

3.5 Examples of good practice

3.5.1 Respecting dignity and autonomy

3.5.1.1 Respecting freedom of movement (Norway)

Staff at the “Blidensol” residential home in Norway have developed a procedure designed to respect individual freedom of movement whilst at the same time taking measures to promote safety. People with dementia with sufficient capacity can, with the head of the unit, sign a written agreement which outlines the conditions for going out alone. Then, whenever they go out, they tell staff when they will be back. If they are not back by the agreed time, steps are taken to find them. First, staff call them on their mobile phone; if unsuccessful, they then go out to look for them. If they do not find them, they contact relatives. Finally, as a last resort, they contact the police.

3.5.1.2 Respecting individuality and different rhythms of life (France, Germany)

A small residential care centre in the Beaujolais region of France offers individualised, tailored activities at night which take into account people’s wishes and different rhythms of life e.g. making cakes with a former baker, watching films with a film enthusiast etc. This is reported to have resulted in calmer nights with less anxiety and a reduction in the use of sleeping tablets.

There are also some nursing homes in Germany which offer a similar service which they call the night café.

3.5.1.3 Assistance with paperwork and administrative formalities (Luxembourg)

Under the long-term care insurance in Luxembourg, people are entitled to “support” for up to 14 hours per week. One of the services which falls into this category is help with official paperwork. This is particularly important for people with dementia who do not yet have a power of attorney or some form of guardianship.

3.5.1.4 Protecting the rights of people with dementia still in paid employment (England, Scotland)

In the United Kingdom, the Disability Discrimination Act 1995 prevents discrimination on the grounds of disability. Employers have a duty to make reasonable adjustments to a job or workplace (e.g. delegating responsibilities or changing the nature of the person’s tasks) if they are aware of a person’s disability and to grant special leave for rehabilitation, assessment or treatment.

3.5.1.5 Proxy decision making and representation in the domain of welfare (Scotland)

It is possible in Scotland for a person to choose, in advance of incapacity, a welfare power of attorney who can make decisions about care and treatment on his/her behalf when he/she is no longer able to do so.

3.5.2 Social inclusion and psychosocial support

3.5.2.1 Social contact and holidays for people with dementia and carers (Luxembourg, Germany)

The supervision service that is available in Luxembourg and Germany under the long-term care insurance also provides a means to break the isolation of people with dementia who live alone and monitor their general well-being and needs. In Luxembourg, excursions and social activities fall into the category “support” and can be refunded under the long-term care insurance.

3.5.2.2 Alzheimer Cafés (Netherlands)

Alzheimer Cafés, based on a concept devised by Bère Miesen in the Netherlands, have been set up in a number of countries in Europe. The Alzheimer Café is an informal meeting place where people with dementia and carers can get together, socialise, exchange experiences, learn how to cope with the disease better and benefit from support and advice from professionals. It is a kind of “protected environment” where they can relax without fear of criticism from outsiders or of people noticing the symptoms of dementia as everyone is in a similar situation.

3.5.2.3 Outings for couples (France)

An Alzheimer Association in Mulhouse (France) organises days out for couples where one of the partners has dementia. Once a month, a day care facility with a professional carer is made available to them. Meals are provided and a trip to a nearby town is organised. This enables the couples to get out of the house, socialise and share their experiences but it also serves as a very gradual introduction to day care.

3.5.3 Living at home: safety issues and preventing abuse

3.5.3.1 Maintenance in the home and supervision (Malta, Luxembourg, Germany)

Using faulty household appliances or trying to take care of small maintenance jobs around the home can be dangerous for people with dementia and even lead to accidents. In Luxembourg there is a service, covered by the long-term care insurance, which ensures the maintenance of household equipment for dependent people who can no longer manage such tasks themselves. Similarly, in Malta, the Maltese Department for the Elderly organises a handyman service offering a range of 70 different repair jobs.

However, faulty appliances and poor home maintenance are not the only source of danger. Memory loss, confusion and loss of capacity can all lead to the need for extra supervision. This is possible in Luxembourg and Germany through the long-term care insurance system but often the amount of supervision provided is nevertheless insufficient.

3.5.3.2 Tele-alarm monitoring systems (Denmark, Malta)

Tele-alarm systems, which can be used by people with dementia, are available in several countries. In Denmark, they are provided free of charge by municipalities. It is important to ensure that the system can be easily used by people with dementia. In Malta, a system has been designed which the Malta Alzheimer Society considers suitable for people with dementia.

3.5.3.3 Keeping a friendly watch on elderly people (Malta)

In 1982, a charitable organisation in Malta (Caritas) set up a “good neighbour scheme”. It involves every elderly person being visited, assessed and invited to take part in this free service. If the elderly person wishes, volunteers will motivate neighbours who then keep a friendly and regular watch on the elderly person. Some neighbours provide actual assistance whereas others simply alert the relevant authorities to the possible need for services.

Furthermore, specially trained personnel delivering “meals on wheels” inquire whether the person needs anything and keep an eye on the home environment. They are expected to report anything unusual to the service organisers. Whilst the privacy of the service user must be protected, this may help detect cases of abuse, neglect or simply the need for additional services.

3.5.3.4 Alternative living arrangements (Germany)

In Germany, “Wohngemeinschaften” (living communities) are now being set up for people with dementia. In the past, this kind of living arrangement was mainly for students. Living in a Wohngemeinschaft involves 6 to 8 people sharing an apartment or house. Each person has his/her own room and shares common facilities. If support and services are needed, they can be provided in the form of home care whereby certain needs (e.g. for cleaning, helping prepare food etc.) can be pooled but individual needs are nevertheless also met. There is no permanent live-in carer but round-the-clock care can be coordinated if needed. Carers are expected to play an active role in the daily lives of the inhabitants as the Wohngemeinschaft is considered as the actual home of the inhabitants and not as residential care. Costs can be partly refunded under the long-term care insurance.

3.5.4 Support for people from minority groups and those living in rural areas

3.5.4.1 Support for people with dementia and carers from ethnic minorities (Germany, Scotland, Switzerland)

Increased mobility within Europe has resulted in many people growing old in countries which are not their own. This is a trend which is likely to continue. However, specific support for people with dementia and carers from ethnic minorities and/or who are expatriates is scarce and patchy.

In Germany, some organisations have developed guidelines on how to provide care in a way which respects the cultural background of particular groups of people. Others have actively tried to reach the Turkish and Muslim communities. As ethnic minorities often live in specific localities rather than being uniformly distributed throughout a particular country, measures are often locally based and sometimes led by Church organisations and community groups.

Alzheimer Scotland publishes information in several languages but also offers a specific Polish and Ukrainian information and advice service in one particular area of Scotland.

In Switzerland, there are two nursing homes for specific groups of people with dementia – one for people with dementia from Latin countries and the other for Jewish people with dementia.

3.5.4.2 Support for lesbian, gay, bisexual and transgender carers (England)

Caring for someone with dementia is a challenging task that often leads to isolation and stress. Being lesbian, gay, bisexual or transgender (LGBT for short) can sometimes make finding support even harder. The LGBT Carers group was set up by the Alzheimer's Society in 1998. It now has a telephone support service operated by gay men and lesbian women, a downloadable newsletter and an "inclusion toolkit" which contains information about the group, its services, advice on choosing residential care and information on legal issues. The Group's volunteers are also increasingly being used to advise service providers on ways in which to achieve diversity and inclusion within their own situations.

3.5.4.3 Novel approaches to service provision in rural areas (Finland, Norway, Scotland)

Rural and isolated areas often lack the structures which are necessary to provide much needed services. Novel approaches are therefore needed such as the memory clinic bus which tours around Lapland offering memory testing and counselling services.

Assistance or supervision taking medication is lacking in a few countries and is not uniformly provided in many. In Norway, however, assistance taking medication is considered more satisfactory in rural areas than in towns with people sometimes receiving two visits and a telephone call per day to ensure that they take their tablets.

There are day care centres in the rural areas of Scotland but many find it difficult to survive financially. Other difficulties include a lack of appropriate venues, a shortage of appropriate people to provide the service and the population being thinly dispersed over a large area. This requires creative options, such as Alzheimer Scotland's day care that is provided in the sitting rooms of bed and breakfast accommodation when there is a sufficient number of people requiring this service within a manageable geographical area.

3.5.5 Measure to ensure respite for carers

3.5.5.1 Respite care in the home (Belgium, Germany)

In parts of Belgium, there is a service which involves substitute carers staying in a person's home from 7 to 14 days in order to provide respite for carers. The role of the substitute carer is not only to provide care but also to spend time evaluating the remaining capacities of the person with dementia and recording notable events and strategies adopted. This information is then passed on to the carer on his/her return and the substitute carer might also suggest intervention strategies adapted to the individual home situation.

In some parts of Germany, networks of trained and supervised volunteers have been set up to provide social support in the homes of people with dementia at the request of carers. Such support might, for example, involve providing company and conversation or taking the person for walks etc. The service also provides support and/or respite to carers. The volunteers receive a small payment for any costs they may have incurred but this is below the level of normal wages.

3.5.5.2 Home-based respite care at night (Belgium, France)

In the Antwerp region of Belgium, there is a mobile night care at home service. Professional carers, managed by a coordinator, provide support, comfort and care two or three times a week between 21.30 and 06.30 to people with chronic illnesses, Alzheimer's disease or at the end of life. This is financed by the Flemish government of Belgium.

A home care service provider based in Dunkirk (France) specialises in providing brief interventions at night of no longer than 30 minutes which complement other services and support those already in place. The service is extremely flexible. Visits can be organised on a fixed and regular basis, as required or whenever there is an emergency. Most visits are to help people to go to sleep, to get up, to get ready and just to check that all is well.

3.5.5.3 Financing or providing a substitute carer (Germany, Norway)

In Germany, people with dementia are entitled to EUR 1,432 per year under the long-term care insurance to pay for a replacement professional or informal carer (not a close relative) whilst their usual carer is absent or on holiday. According to the Deutsche Alzheimer Gesellschaft, this only covers about two weeks' substitute care but is nevertheless a measure which can help carers organise a short break. In Norway, under the Social Services Act, carers in need of respite are entitled to a two-week break during which time the person with dementia is temporarily taken into residential care.

3.5.6 Specific services and support to people with dementia and carers

3.5.6.1 Personal care (Scotland)

In Scotland, free personal care is provided to people over the age of 65 who have been assessed as needing it. People with dementia under the age of 65 would still be entitled to such support but it would be means tested.

3.5.6.2 Joint psychological support for people with dementia and carers (France)

Joint psychological support for carers and people with dementia, provided at home by psychologists, has proven beneficial in the Isère region of France. The organisers claim that it has resulted in a reduction in the level of anxiety, conflict and tension between people with dementia and carers which in turn improves both quality of life and the care relationship.

3.5.6.3 Memory Centre (with additional advisory function) (Romania)

Most elderly people from Romania have, as adults, lived under a communist dictatorship. They are therefore not accustomed to the idea of having rights and of ways to access those rights. This is why the Memory Centre, which is based in Bucharest, was not only designed for the purpose of diagnosing dementia, but also to provide guidance for patients and their families on how to access their rights. At the Memory Centre, carers and people with dementia benefit from information, emotional support and guidance to help them find their way through the legislative maze currently existing in Romania. In addition, carers can obtain free advice and counselling on different problems linked to caring for a person with Alzheimer's disease.

3.5.6.4 Educational programme for carers (Germany)

An educational programme, called the "Circle of Care" ("Hilfe beim Helfen"), has been developed in Germany to exchange experiences among carers and to provide information about the disease, living with people with dementia, legal matters and respite for carers etc. The programme is offered in the form of seven two-hour sessions. Information for referents and handouts for the participants are available on a CD-ROM. The costs are reimbursed by the German long-term care insurance. Similar programmes exist in other countries.

3.5.6.5 Stress management and relaxation workshops (France)

In the Haute-Savoie region of France, stress management workshops have been organised to help carers understand, recognise and control stress. Participants also have the opportunity to meet and exchange experiences with other carers. This is followed by a relaxation session including exercises on concentration and breathing. The workshop ends on a social note, with participants and instructors sharing a meal together.

3.5.6.6 Combined crisis intervention unit/winter garden (France)

The clinical gerontological department of a hospital in Saint-Etienne (France) has created a winter garden for people with dementia who have been admitted due to a crisis situation. The garden, with its fountain and plants, has a calming effect on patients and helps reduce anxiety and tension. Carers also benefit from the calm environment. The garden serves as a kind of transitory place between hospital and home, and provides an ideal environment for professionals to resolve the crisis situation and to find out with carers what might have triggered the crisis.

3.5.6.7 Support for the dying (Luxembourg, Germany)

The association Omega 90, which is financed by the Luxembourg Ministry of Family, is made up of several organisations including, amongst others, the Red Cross and Caritas. It has a helpline operated by professionals and provides training to the volunteers who visit dying people and their families in hospital and at home. In order to ensure that volunteers are appropriately trained, the German Alzheimer Association (Alzheimer Gesellschaft) and the German Hospice Association (Hospiz Gesellschaft) recently joined forces in order to provide dementia-specific training for hospice volunteers.

3.6 Glossary

Social support:

The term “social support” should be understood as referring to resources and/or services which are provided to carers and people with dementia to help them cope with the consequences of the disease on their daily lives. This could include psychological, social, physical and financial support, as well as various types of care such as palliative care, nursing care and respite care, and care facilities such as nursing homes and day care centres. The term is also used to refer to nursing care insofar as it relates to dementia e.g. dealing with bedsores, incontinence or taking tablets. We realise that the definition of social support may differ considerably from one country to the next but it is the definition which was used in the EuroCoDe survey upon which the recommendations in this document are based.

Carer

The term “carer” is used to refer to informal carers e.g. relatives and friends who take care of a person with dementia. Care is usually provided on a voluntary basis without payment although some carers might not feel that they actually had any choice in becoming a carer and some might receive some form of payment from the State for the care they provide. The term does not refer to professional carers such as doctors, nurses, social workers and home care workers etc.

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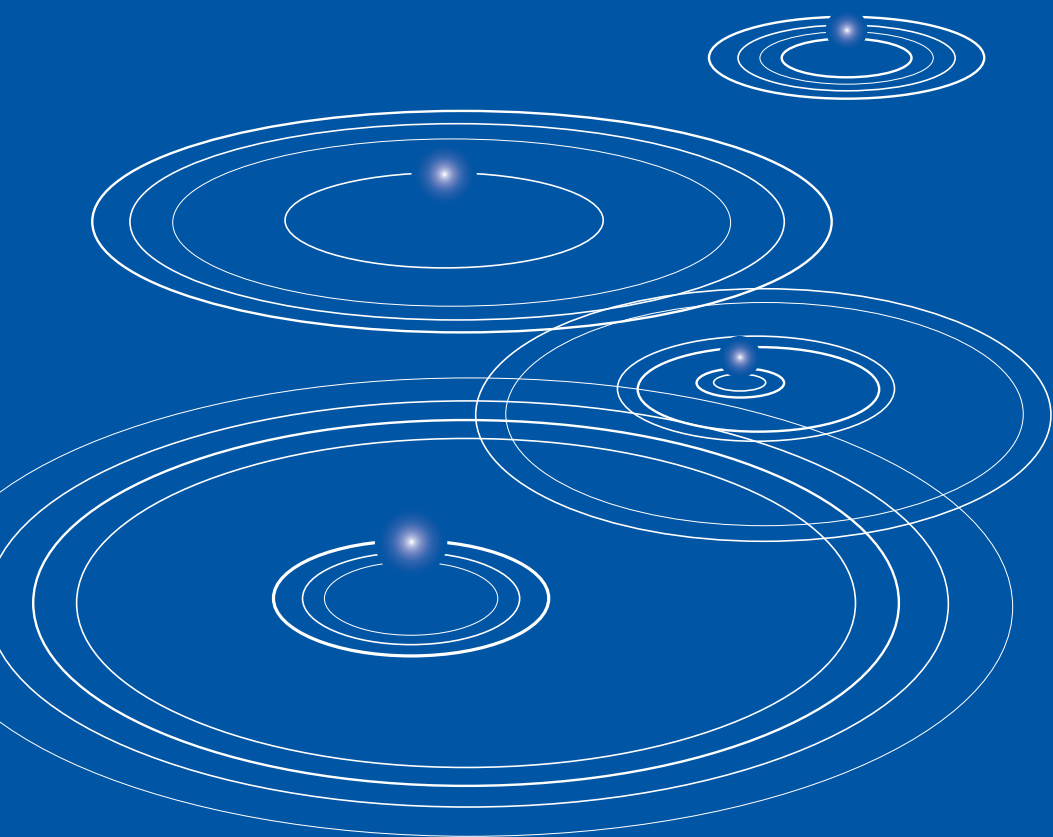
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*The socio-economic
impact of dementia*

4.1 Introduction

Dementia disorders are chronic, progressive, long-lasting and, so far, incurable. Despite the direct effects on the patients and their next of kin, this pattern (which dementia disorders have in common with other disorders such as mental illness, rheumatoid disorders, diabetes etc.) also has an enormous impact on the medical and social sectors (1). The combination of expensive care, the high prevalence (about 6 million people today suffer from dementia in the EU), the heavy impact of informal care do indeed stress the basic questions in health economic analysis (2, 3).

The aim of this section is to highlight some basic concepts in health economics and to make an inventory and comparative report of existing studies describing the socio-economic impact of dementia. The main focus is on the cost of illness and to some extent also on the burden of illness in terms of DALYs (disability adjusted life years).

In order to describe the cost of the illness of a disease or group of diseases with a chronic progressive long-lasting course, some basic points need to be discussed:

- The health economical context
- Perspective/viewpoint
- Costing taxonomy
- The top-down vs bottom-up approach
- Gross costs (total costs) vs net costs (incremental costs)
- Prevalence or incidence-based approach
- The contribution of informal care
- Different care patterns in Europe

The results will also have some policy implications:

- Describe the variation in utilisation of dementia care resources in the EU
- Impact of informal care

4.2 The Health Economical Context (Welfare Theory) – Provision and utilisation of health services – the economic questions

By Hannu Valtonen, University of Kuopio (Finland)

4.2.1 Need, supply, demand and utilisation

For each individual, the utilisation of health services seems to be quite unproblematic - we go to the doctor when we feel ill. If the illness turns out to be of a more severe kind, the doctor sends us to hospital, and finally, when the illness has been cured, we get out of the hospital. The same applies for various social support services (home help for the elderly, community services etc.). However, even as individuals, we may ask ourselves 'is this really so severe that I have to go to see a doctor? Is this worth a visit?' When we look at the whole health and social care system, then the determination of utilisation is not simple, and it is not just based on health needs or social support needs. In economics, we study the determination through the concepts of need, demand and supply of health services, that together determine the amount of services used in a given country in any given year.

By demand of social and health services we mean the amount of services people are willing to use at given prices. The 'prices' here refer not only to the user charges, but to all the trouble and effort needed (travelling, time etc.) to obtain the services. The supply of services is defined respectively, it is the amount of services the suppliers (social service providers, doctors, health care institutions) would be willing to produce in given circumstances. The determination of the supply of health services varies from one country to another, depending on the national policies concerning the organisation of the health and social service sectors (production; private or public basis; and financing, taxes, insurance, public and private) and the economic potential of the country (the availability of both manpower and monetary resources).

The actual quantity of services is determined by both demand and supply, and both of these forces may have an independent effect on the utilisation of services. For example, if in some region, some new service institutions are built, this new capacity may increase the amount of services used even if the needs of the population are unchanged.

The need for health services seems in every day language quite unproblematic: Health status is a state or condition of an individual, either a subjective feeling about health and illness or, more objectively, something that is determined by a doctor. The need for health services can also be understood narrowly (the person is diagnosed with some illness) or widely (in terms of physical and social functional capacity). Quite a large proportion of individual health problems can be solved without actual professional health services.

In the case of social services, the definition of the need is more complicated: first, in many cases the need is not an individual phenomenon, but it concerns a family, a group of people, or even a neighbourhood. In the case of an elderly couple, where the husband has dementia, the wife and maybe also the children taking care of their parents may also need social support. Secondly, need is often defined in every day speech or maybe even in research in terms of the support system (e.g. the need for ‘income support’ or a ‘maintenance grant’; services or income transfers) when the actual problem is linked to their welfare (need in this sense) and changes in people’s lives (e.g. poverty) caused for example by poor education, unemployment etc. The basis for the need and the services potentially provided by the service system do not have a one-to-one equivalence. The elderly couple may need sympathy, information, encouragement, someone to talk to, social contacts but the service system may provide ‘home help’ (formally, a home help worker is expected to do the cleaning and shopping and a home nurse to take care of medication and measure blood pressure etc., and both of them may informally act as a social contact). When evaluating the performance of the service system, the needs from the elderly couple’s point of view should be more important than the needs seen from the service provider’s point of view. A third special feature in the social services is, that as in the case of health needs, quite a lot of social functional problems can be solved or the individuals and their families can be supported without the intervention of professional social services. In the case of social problems of the family, the informal care and support are very important. There are also cases, where it is not necessary to make a difference between health needs and social needs.

Short definitions for these concepts are:

- *need of social services* - individual physical and social functioning, and social capacity of a group related to the ability to benefit from social services and informal support
- *need of health services* - morbidity, health status, ability to benefit from health services
- *demand of health and social services* - the amount of health services people are willing to use determined by the health needs and other factors affecting demand
- *supply of health and social services* - the amount of health services that the organisations providing services would be willing to supply for the people, the amount and organisation of the service supply depends on national policies and on the economic potential of the country
- *use of health and social services* - the amount of health services people are actually consuming, determined by demand and supply.

The demand for health and social services is influenced by factors other than the need for these services. These factors include gender, income, socio-economic status and education (for certain needs, the utilisation of services differs between income groups and educational groups, or various cultural factors; with some needs and depending on income, the utilisation of services varies across population groups with different cultural backgrounds). There may be many different ‘other factors’, and it is not possible to generate an exhaustive list of them.

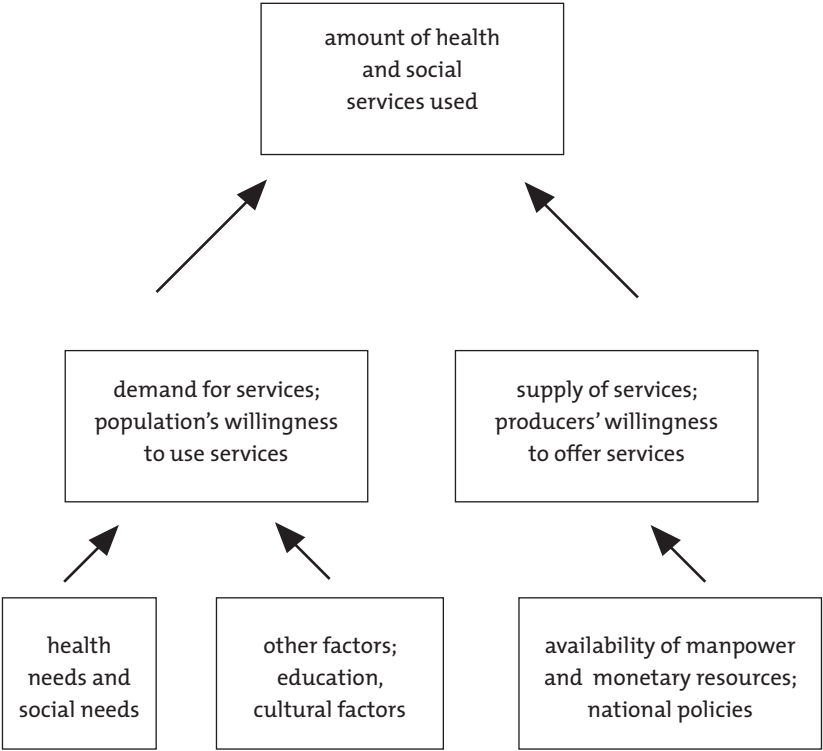


Figure 1. The determination of the utilisation of health and social services

The socio-economic impact of any health or social problem is linked to the determination of health and social service utilisation: When a person is ill or has a social problem, his or her welfare (and in fact that of the whole society) is affected because of the illness (morbidity, mortality, problems in physical and social functional capacity) or lack of social support, cure and care. These negative effects can be reduced by appropriate interventions. In other words, if the provision of services is insufficient, people pay the costs in terms of welfare losses. The various health and

social care interventions require some resources that could have been used in another way to improve the welfare of the population (i.e. the use of health and social care resources have consequences on other areas).

4.2.2 The need and demand for social and health services

The term ‘need’ means different things in different contexts. In health economics, we use this term in both the objective and subjective sense (4). We may talk about subjectively felt ‘perceived need’ when individuals feel that now they have to go doctor or they feel that they need some kind of social support. A person is also said to have a need for health services, when a doctor after making a diagnosis states that the person in question has a disease that can be treated with some health services i.e. the person can benefit from health services, and the term need refers to ‘capacity to benefit’ from the services. The term ‘objective’ refers always to someone (a doctor, nurse, social worker, health care and social care professional etc.) evaluating the need from outside. A person may have subjective need for health and social services, when according to his own evaluation (e.g. perceived health in surveys; perceived capacity to cope with everyday life) his health is weak, and he could benefit from the services. The objective and subjective definitions of need are different perspectives of a person’s mental, physical and social functional capacity. They are not competing views of the need for services, and we cannot say that either of them is wrong.

Need can be measured both at individual and at population level. At individual level e.g. perceived health is a valid subjective measure of health status. Objective measures that are often used, are e.g. the presence of long-term illnesses or a professional evaluation of a person’s health status. At population level, morbidity figures, for example, express the health status of one population (like Estonia) compared to another population (e.g. Finland).

For our purposes, it is important to remember that ‘need’ can also be defined as ‘capacity to benefit’, because this definition leads us to consider how well the health and social services are organised - is all the ‘capacity to benefit’ met?

Need for health and social services leads to a demand for these services. People are willing to use various services, either because they feel that they need them, or that they are sick, have problems in everyday life, or service provider experts have told them that they should use certain services.

But, there are also other things that may have an effect on demand (reflecting people’s willingness to use various services). One of them is quite obviously income - if people have to pay all the costs of the health services they are using, those on a low income can use fewer services than richer people, even if their need for services is the same. We may reasonably assume that if the prices people are paying from

their own pockets increase, the demand for the services will decrease. If the price of any service increases, it is less likely that people will be able to afford it. Other factors that have a similar effect to that of price are time costs - if a person has to spend a lot of time travelling to the service facilities, it may affect service use in the same way as prices do.

Furthermore, it is known that there are also some other factors that affect demand in addition to need and income, and time costs. It seems that in all countries, with the same need, people with higher education are willing to use more health services than people with lower education. There are also other things that may affect demand, such as sex, age, all sorts of cultural differences etc. Men and women, and people of different ages, may use the services very differently.

4.2.3 Supply of social and health services

In figure 1, we have the determination of the utilisation of health and social services. The demand alone cannot determine the amount of services used in a given year, i.e. the people may be willing to consume more services than what will actually be used. In the determination of the utilisation, we need also the concepts of supply: someone must produce the services, there must be a capacity to provide health services. The institutions and people providing the services are willing to produce a certain amount of services depending on the capacity, availability of beds, personnel, facilities, technology etc. If the population is willing to use more services than what is available, then willingness to use does not translate into utilisation.

We can empirically measure supply by various health care capacity measures, numbers of different groups of personnel, available beds and numbers of primary care doctors etc.

4.2.4 Utilisation of health and social services

This is why (please see diagram), the utilisation of services is a result of two different societal forces: demand and supply. In welfare service provision, social and health care, supply has a relatively larger impact (there is relatively more power on the supply side than on the demand side) on service utilisation than in many other service or commodity markets. This is due to the agency relationship: The supplier of health services (doctor, health care professional) and to some extent also suppliers of social services usually know more about the various welfare problems and about necessary interventions (illnesses, treatments and their potential effectiveness) than the customer, client or patient does, and consequently the supplier has to act as an agent for the former. The supplier has also more power in the interaction due to his/her position as professional expert. Because of the information asymmetry and the professional position, relatively more power is concentrated in the supply side of the services. Sometimes it can be said that these services are

‘supply-led’ services indicating that supply organisation determines the utilisation of the services.

The whole socio-economic impact of any social or health problem has its origin in the determination of the needs, the utilisation of the services and the structure of the service system built to respond to the social and health needs of the population.

The socio-economic impact of dementia and Alzheimer’s disease can be defined as being comprised of these two components:

- 1) Deterioration of health and social welfare losses due to the illness, and
- 2) the resources devoted to diminishing and preventing those welfare losses.

The components are measured in different units because welfare losses (anxiety, pain, suffering, stress and death of individuals and their families) cannot and should not be measured in monetary terms, whereas the value of resources used in health and social care are to a large extent easily measurable in monetary terms ¹².

All welfare losses due to dementia cannot be compensated, removed or prevented, but the progress of the illness might be changed, and the coping of the individuals and their families can be improved. The aim of the impact estimation should thus be

- 1) to estimate the scale of the problem (welfare losses, preventable welfare losses)
- 2) to estimate how much and in what kind of structures resources (formal and informal) are allocated to dementia care,

and after 1) and 2) are known

- 3) to evaluate, make recommendations, and have a public discussion about how the amounts and organisation of the resources could be reorganised in order to use the resources in diminishing the welfare losses as much as possible and reasonably compared to other welfare needs of the population.

¹² If indirect costs (production losses) are to be included in the costs, they should be kept separate from real resource costs.

4.3 Health economic aspects of dementia

By Anders Wimo, Karolinska Institute (Sweden), Linus Jönsson and Anders Gustavsson, I3 Innovus (Europe)

4.3.1 The viewpoint

A health economic analysis can be presented from different perspectives. A societal perspective is recommended by most economists. It includes all relevant costs (direct medical and non-medical costs within the health and social sectors and indirect costs due to production losses and costs of informal care) and outcomes (5). However, the analysis can also be done from a specific payer's point of view such as a municipality, a county council, an insurance company, a caregiver or a patient (the latter correspond to "out-of-pocket costs"). Depending on the perspective chosen, the results of the analysis are different. Crucial in any health economic analysis is transparency regarding the viewpoint.

4.3.2 Costing taxonomy

There are different ways to define costs. It is common to present costs as direct costs and indirect costs (although this is under debate). Direct costs are derived from "resources used" such as costs in the formal health care and social service systems (e.g. hospital care, nursing home care, medication, home aids etc.) while indirect costs reflect "lost resources", such as loss of production due to morbidity and mortality. Direct costs can be divided into direct medical costs (within the medical sector such as hospital care, visits to physicians) and non-medical direct costs, such as costs of long-term institutional care, social services etc. The classification, quantification and costing of unpaid informal care is complex and controversial (2, 6, 7). The costing process consists of two phases; firstly, resource utilisation is measured in physical units (such as days in nursing home, hours of home support) and secondly, resource utilisation is expressed in terms of cost, mostly by a multiplication of unit costs (e.g. a cost of nursing home care at USD 200/day) and physical units of resource utilisation). A comprehensive and validated instrument in dementia is the Resource Utilization in Dementia instrument (RUD)(8).

4.3.3 Cost of illness approaches

Cost of illness (COI) studies are descriptive and cannot be used in priority discussions. However, COI-studies show how costs are distributed among different sectors and payers in the formal and informal care systems and they can also be used to follow costs over time.

In a COI study it must be clarified how the cost calculations were carried out and which cost categories are included.

It is important to differentiate between costs for patients with a disease (sometimes referred as gross costs) and costs specifically due to a disease (net costs). All costs of a person with dementia are not caused by the dementia disorder. Other conditions may contribute, such as diabetes, arthritis, cardiac disorders and for those who live in an institutional setting a part of the costs refer to needs for any person such as food and accommodation (so called hotel costs).

There are also two ways to collect data. With a top-down approach, the sources are often registered data of total costs of all kinds of care on e.g. a national level and then costs are distributed to special disorders. With a bottom-up approach, a representative sample of patients with a specific disorder, such as dementia, is carefully examined with a focus on resource utilisation and costs. In a next step, these costs are extrapolated to e.g. a nation's total population by a multiplication of the cost per person by the prevalence. These two methods are often combined due to insufficiencies of data with just one of the approaches.

Cost of illness can also be described in terms of a prevalence or incidence-based approach. The prevalence approach estimates the total costs for all persons with a disease during a specified period of time (usually a year), whilst with the incidence approach, costs are estimated from the beginning of a disease and onwards during the whole course of the disease.

Costs can also be presented vs different states of dementia. The most frequent used “vehicle of costs” is the Mini Mental State Examination (9). It is also possible to use other “vehicles”, such as ADL-capacity in terms of Katz’ index of ADL (10) and CDR (Clinical Dementia Rating scale (11)) .

4.3.4 Burden of dementia

There are some effects of disorders that are difficult to estimate in terms of costs, such as intangible costs (e.g. pain, psychosocial problems, problems in social functioning and activities of daily living). Such costs are in general not included in cost of illness estimates because of the problems expressing the effects in terms of costs, even if the intangible costs are significant for many diseases (12). As a proxy of the intangible costs, the burden can be expressed in terms of disability adjusted life years (DALYs) (13) or lost quality-adjusted life-years (QALYs). Burden figures do not provide any information on how costs are distributed amongst different “payers” and give no information on how big a proportion of the total resources are used up by a particular disorder. DALYs has been criticised because it favours productivity and because gender differences are not sufficiently incorporated (14, 15).

Furthermore, the use of QALYs is somewhat controversial, particularly regarding the elderly (16). One advantage with QALYs is that comparisons with other disorders are possible. However, this may disadvantage chronic, incurable, progressive disorders when these are compared with e.g. curative surgical treatment or cataract or hip replacement surgery, where the incremental effects are substantial. Due to the natural characteristics of dementia and many other mental conditions, many patients have difficulties providing the necessary information for the calculations e.g. for QALYs, so the use of proxies is unavoidable. Furthermore, if the proxy is a family member, the answers may partly reflect the situation and interests of the proxy. Another approach, HYE Healthy Years Equivalents (HYE) (17) are also controversial (18) and require a great number of health scenarios for the analysis (19).

WHO presents global estimates of the burden of disease in terms of DALYs, and with all the possible disadvantages in mind, DALYs have been extracted here for Europe (20). As a comparison, we have used DALYs of diabetes.

4.4 The impact of informal care

By David McDaid, London School of Economics (United Kingdom)

It is important to recognise that there are both rewards and difficulties associated with caregiving; yet often, the positive aspects may be overlooked. This desire and willingness of family members to provide care can mean that policy makers and other stakeholders are tempted to treat informal care as a ‘free resource’. However, it can entail significant economic costs for individuals and society. Economic analysis is primarily concerned with the opportunity costs of caring; i.e. what would have been done had an individual not been caring.

Caring for someone with dementia can sometimes be, literally, a 24-hour-a-day activity. While the availability of family carers may reduce the need for professional support, carers will incur a loss of time (and hence a cost) which they could have used for work, or to pursue leisure activities. Individuals may become isolated from their social network of family and friends as the disease progresses and caregiving becomes a full-time occupation (21). Evidence of high levels of distress and depression among carers of people with dementia can be seen in many studies of service users and in community surveys (22-26). They may also incur additional out-of-pocket expenses to support a relative financially. There can also be adverse impacts on their physical health, e.g. as a result of the strains of helping an individual to cope with essential activities of daily living.

Inclusion of the full costs of caring can thus be very important in a comprehensive economic analysis and could make a difference when decision makers have to determine whether it is cost-effective to introduce specific services or programmes to support family caregivers or provide other interventions. It also provides an indication of the costs that may fall on statutory services in future if there is a shortage of such carers due to the ageing of the population in most European countries.

However, because of methodological difficulties in estimating informal care costs, and often too narrow a focus solely on the health care system alone, the cost to family carers has often been ignored within economic analyses. In particular, identifying the best alternative use of time is not always easy, particularly if a family carer already has been responsible, to some extent, for an individual - e.g. a spousal carer already undertaking a range of activities that benefit the whole household. This has led to a considerable variation in estimates of the cost of caring with estimates for Alzheimer’s disease and other forms of dementia ranging from 36 to 85 per cent of total costs in one review (27).

Improving our understanding firstly of what is known about its actual impacts on caregivers in different settings and contexts across Europe is a key element of our literature review. A second issue is to look at the different ways in which the con-

tributions of informal caregivers can be measured and the valuations attached to such contributions. Again variations in methods used can lead to substantially different estimates in the costs of care emerging. In undertaking this work it is important to recognise that work assessing the economic value of informal caring has not been restricted to dementia alone; estimates can for instance be found for other mental disorders as well as for physical diseases (28, 29). Our literature review also looks at the transferability and relevance of measurement and valuation methods used for carers of people living with other health problems.

Over 3,000 papers meeting our inclusion criteria were initially identified, including more than 2,687 (reduced to 2,016 after limits applied) in Medline alone. Final inclusion figures are still being processed with some work on databases to be completed, with some data still needing to be entered into Access database. (See Next Steps). Few additional papers were found in Econlit for instance – in total 192 papers were initially identified – this was filtered down to 79 papers the majority of which were identified through Medline. Overall more than one third of papers focus on Alzheimer's disease and other dementias.

Some preliminary results are reviewed here. Our initial analysis also indicates that the evidence base on both the costs of informal care for Alzheimer's disease and other dementias as well as the inclusion of informal care in estimates of costs in other areas is increasing with recent estimates identified across a number of European countries e.g. (30-33) as well as being a component of costs in some evaluations of drug and non-drug interventions e.g. (34-38). In addition, the literature on informal care costs from other parts of the world also continue to increase e.g. (39). There are also a number of studies which have sought to project the long-term costs of Alzheimer's disease and other forms of dementia across Europe and elsewhere – to varying extents these have sought to incorporate the costs of informal care (40).

Another approach is to look at the extent to which end-of-life transfer of assets compensates individuals for informal care activities (41). There have also been some developments in the way in which caregiving activities are measured and in particular not only to more accurately identify time spent caring, but also to better identify subjective and objective burden (42) as well as 'process utility' or immediate rewards from the caregiving experience (43). One continuing limitation generally appears to be a lack of information from the context of central and Eastern Europe, although one small exploratory study of the costs of informal care for dementia in Turkey can be identified (44).

4.5 The cost of illness and burden of dementia in Europe

By Anders Wimo, Karolinska Institute (Sweden), Linus Jönsson and Anders Gustavsson, I3 Innovus (Europe)

A literature review was conducted for papers reporting data on costs of care for patients with diagnosed dementia or possible/probable Alzheimer’s disease.

Two approaches were used, the first includes bottom-up data, the second includes top-down cost-of-illness studies or similar.

The advantage with the bottom-up approach is that it allows stratification on disease severity and different cost types. This analysis is based on Jönsson-Wimo (in press). For European specific studies, Medline, EMBASE and Current Contents were searched for the following terms (in any field):

(Dementia OR Alzheimer*) AND (Cost OR Economic) AND (Europe* OR Austria OR Belgium OR Cyprus OR Czech Republic OR Denmark OR Estonia OR Finland OR France OR Germany OR Greece OR Hungary OR Ireland OR Italy OR Latvia OR Lithuania OR Luxembourg OR Malta OR Netherlands OR Norway OR Poland OR Portugal OR Slovakia OR Slovenia OR Spain OR Sweden OR Switzerland OR United Kingdom)

As part of the Swedish council on technology assessment in health care’s (SBU) dementia project(45), a general search was conducted in PubMed/Medline, Ingenta, Cochrane Library, NHSEED/THA, HEED, PsycINFO, ERIC, Societal services abstracts and Sociological abstracts. The search terms (MESH/Subheadings when appropriate) were dementia/Alzheimer’s disease/Alzheimer disease combined with costs, economics. This search also resulted in papers with both a top-down and bottom-up approach.

More than 500 references were identified in the first rounds. Many irrelevant papers could be removed by title reading. The abstracts of the remaining papers were then reviewed manually.

The cost of illness and burden of dementia are here presented in three ways:

- for EU 27,
- for EU27 + candidate countries (Croatia, Former Yugoslav republic of Macedonia and Turkey) + countries in the European Economic Area (Norway, Iceland, Liechtenstein) + Switzerland,
- for the whole of Europe.

The prevalence figures, which are used for the cost of illness estimates, are based on metaanalysis by Eurodem (46) combined with population statistics from UN.

In 2005, it was estimated that there were about 6.2 million people with dementia in EU27 (Table 1).

Table 1. Prevalence of Alzheimer’s disease and other forms of dementia in Europe in 2005 (in millions).

	Prevalence
EU 27	6.17
EU27+ candidate countries , EEA countries and Switzerland	6.63
Europe	8.45

Fourteen papers were finally selected as eligible for the European cost model (Table 2).

The key criterium was that direct costs and informal care costs could be identified.

For countries where no cost of illness figures were available, imputation was used. Four care patterns were identified and used for the imputation representing the relation between formal care (direct costs) and informal care in Northern (mainly formal care), Western (mix between formal and informal care), Southern (mainly informal care) and Eastern Europe (mainly informal care) (based on UN’s region classification of Europe). The imputation figures were also adjusted for differences in GDP per person between countries.

Table 2. Papers included in the European cost model.

Country/region	Region	Source
Denmark	Northern	(47)
Ireland	Northern	(48)
Scandinavia	Northern	(31)
Sweden	Northern	(49)
UK	Northern	(50)
Belgium	Western	(32)
France	Western	(51)
Germany	Western	(52)
Netherlands	Western	(53)
Italy	Southern	(54, 55)
Spain	Southern	(56)
Turkey	Southern	(44)
Hungary	Eastern	Gulacsi et al. (forthcoming Eurocode report)

The total cost of illness of dementia disorders in EU27 in 2005 was estimated at € 130 billion (table 3), of which 56% were costs of informal care. The corresponding costs for a wider EU sphere was €136 billion and €141 billion for the whole of Europe.

Table 3. Cost of illness in Europe (€ billion) in 2005 for Alzheimer’s disease and other forms of dementia.

	Direct costs	Informal care	Total costs
EU 27	57.3	72.7	130.0
EU27 + candidate countries , EEA countries and Switzerland	60.9	74.8	135.7
Europe (including Turkey)	63.3	77.7	141.0

The costs per people with dementia was about € 21,000 per year (table 4), while it was somewhat lower for the wider EU sphere and for the whole of Europe.

Table 4. Annual cost per person with dementia in Europe (€) in 2005 for Alzheimer's disease and other forms of dementia.

	Direct costs	Informal care	Total costs
EU 27	9,272	11,773	21,045
EU27 + candidate countries, EEA countries and Switzerland	9,186	11,280	20,466
Europe (including Turkey)	7,485	9,194	16,679

When the burden of dementia disorders in terms of DALYs is compared to diabetes, the burden figures are higher for dementia (Table 5).

Table 5. Burden in terms of DALYs in Europe for Alzheimer's disease and other forms of dementia and diabetes.

	DALYS x 1000		DALYS per 100,000 persons	
	AD and other forms of dementia	Diabetes	AD and other forms of dementia	Diabetes
EU 27	2,799	1,973	350	247
EU27 + candidate countries, EEA countries and Switzerland	2,227	1,452	398	260
Europe	2,799	1,973	350	247

4.6 Regional Patterns

4.6.1 Northern Europe: The societal costs of dementia in Sweden

By Anders Wimo, Karolinska Institute (Sweden), Linus Jönsson and Anders Gustavsson, I3 Innovus (Europe)

In a report from the National Board of Health and Welfare in Sweden, the number of people with dementia and the societal costs of dementia were estimated for 2005 (49). This report is an update of a previous report regarding 2000 (57). It was estimated that the number of people with dementia had increased from 133,000 to 142,200 between 2000 and 2005. The societal costs included costs of institutional care, social services at home, day care, medical care at home, hospital care, visits to physicians and other types of medical staff, emergency care, drugs, and informal care. Due to a decrease in the number of institutional beds, the number of institutionalised people with dementia had decreased from 75,000 (56% of the people with dementia in 2000) to 64,500 (45% of the people with dementia in 2005). Different methods were partly used for the cost of illness estimates but if the same costing approach was used for both years, the total societal costs had increased from SEK 49.6 billion to SEK 50.1 billion (€ 5.3 and 5.4 billion respectively) but since the number of people with dementia was larger, the costs per person with dementia had decreased from SEK 373,000 in 2000 to SEK 352,000 in 2005 (about € 40,000 and 38,000 respectively). The municipalities had by far the greatest economic burden. The net costs were estimated to be about 75% of the societal gross costs. There was a close relationship between the severity of cognitive decline, from SEK 64,000 (€6,900) with no cognitive decline) to SEK 420,000 (€45,000) for severe cognitive decline. The costs of informal care was estimated with a conservative approach in the base option, but depending on costing and a quantification approach to informal care in the sensitivity analysis, the proportion of the costs of informal care varied from about 10% to 50% of the societal costs. The main reason for the decrease in the societal costs per person with dementia was the decrease in the number of institutionalised people with dementia. The societal costs of dementia were also compared to Swedish cost of illness studies regarding other diseases. The societal costs of dementia were the highest but close to the costs of dementia were costs of psychiatric disorders (excluding dementia) and rheumatic disorders, indicating that economic burden of chronic long-lasting disorders. The costs of these disorders were higher than the costs of cancer, diabetes and cardiovascular disorders.

4.6.2 Western Europe: Economic environment of Alzheimer's disease in France

By Paul-Ariel Kenigsberg, Fondation Médéric Alzheimer (France)

The French health and social care environments of Alzheimer's disease have evolved considerably during the 2003-2008 period. Caregiver associations took an active part in this evolution.

From 2003 to 2007, Fondation Médéric Alzheimer surveys (58-60) show a 35% increase in the number of services for diagnostic and therapeutic follow-up (memory clinics: from 213 in 2003 to 353 in 2007; day hospitals: from 95 to 165; other services: from 164 to 125); a 30% increase in the number of services for gerontological information and coordination (from 538 to 867); a three-fold increase in the number of day care centres (from 33 to 107); a 30% increase of support activities (other than day care centres) for people with the disease; a 7-fold increase in services organising activities directed towards caregivers (from 282 to 1,946 services) and a 13-fold increase in activities offered (from 427 to 5,965 activities). Between 2005 and 2007, surveys show an increase of 84% of common activities for people with the disease and family caregivers (from 690 to 1,272 activities), offered by 60% more services (from 434 to 693 services). Although the total number of nursing homes remained stable between 2003 and 2008, the proportion of homes admitting people with dementia increased from 54% to 69% (from 5,710 to 6,827), but more of them with limitations (from 56% to 69%), concerning aggressive or disruptive behaviours and the risk of wandering away.

Reimbursed health care expenditure for people diagnosed with Alzheimer's disease and other forms of dementia, recognised as a chronic illness, are 100% covered by the national health insurance system. Health insurance also supports partial reimbursement of families' expenditure on respite care. However, some goods or services are not reimbursed by the health insurance system, like private psychological care or incontinence pads, the cost of which has to be covered by families. In institutional care, expenditure on room and board is mainly covered by families. According to a recent Senate report (61), people unable to afford a monthly payment of at least €1,500 cannot access institutional care. About 80% of people in institutional care have revenues lower than the price charged by the institution. About 24% of people living in long-term care institutions receive a social allowance for room and board (*aide sociale à l'hébergement*) of about €1,500 per month, which can be recovered by the State from the estate of the deceased person (62).

In October 2004, Alzheimer's disease and other forms of dementia were officially classified as a specific chronic illness (ALD 15), distinct from psychiatric disorders. In December 2006, only 198,319 people were registered under ALD 15 in France (63), which means that only one quarter of the estimated 850,000 people with the dis-

ease had administrative recognition of their diagnosis. In 2004, the reimbursed expenses for community-dwelling people registered under ALD 15 amounted to €8,453/patient/year, of which dementia-specific costs came to €5,943/patient/year, representing physician visits (€363/patient/year), drugs (€1,236), biological examinations (€83), hospital care (€4,586), nursing care (€1,148), physical therapy (€331), transportation (€173), medical devices (€427), other expenses (€107).

Compared to other chronic diseases, Alzheimer's disease and other forms of dementia (ALD 15) costs to French health insurance are similar to those of malignant tumors (€5,722/patient/year) and much higher than costs of coronary disease (4,764 €/patient/year), diabetes (€4,265/patient/year) or severe arterial hypertension (€3,815 /patient/year)(64).

Social services for the dependent elderly are co-financed by families, health insurance, pension institutions, local governments (*conseils généraux*) and communities, national public funds now being provided through the *Caisse nationale de solidarité pour l'autonomie (CNSA)*, a new financing institution created in 2004, in charge of financial compensation for the dependent elderly and the handicapped. A new risk management section of the social security system, specifically dedicated to the risk of autonomy loss, will manage compensation systems for dependence and handicap, regardless of age (65).

Individual public allowance for autonomy (*APA-Allocation personnalisée pour l'autonomie*), a financial compensation for the elderly dependent aged 60 and above, set up in January 2002, partially funds human aid, assistive technology and specific housing installations for dependent people. The average autonomy allowance granted was €493/month for people in domiciliary care and €574/month for those in an institution (66).

The total costs for people with dementia, including direct and indirect costs, estimated in a 2005 Parliament report, were €17,472 for people living at home and €26,671 for people living in an institution. Families supported 55% of overall costs, health insurance 26% and local councils 19% (67).

A new plan for Alzheimer's disease and other forms of dementia, with a total budget of € 1.6 billion over the 2008-2012 period, was announced by President Sarkozy on 1 February 2008 (Plan "Alzheimer et maladies apparentées 2008-2012" ; www.elysee.fr). It is based on the results of the national expert committee, led by Professor Joël Ménard, which issued recommendations in November 2007 (68).

Financial resources for the new Alzheimer plan will be drawn from expected savings by national health insurance. Parliament has approved an increase of co-payment (*franchises médicales*) by most people covered by national health insurance in France, through a lower reimbursement of drugs (€0.50 per box), paramedical

interventions (€0.50 per procedure) and patient transportation (€2 per trip), with a maximum of €50/patient/year. Patients on a low income and pregnant women will be exempt from this scheme. Savings in reimbursements for national health insurance are expected to reach €850 million annually, the financial product being allocated to fund plans for Alzheimer's disease, cancer care and palliative care. Resources allocated to the Alzheimer plan, starting with €300 million in 2008, are planned to reach €500 million in 2012.

For the most part, medico-social expenses of the new plan (*€1.24 billion over 5 years*) are financed jointly by the national health insurance and the *Caisse nationale de solidarité pour l'autonomie (CNSA)*, healthcare expenses (*€226 million over 5 years*) by national health insurance and research expenses (*€201 million over 5 years*) by the State.

The new 2008-2012 Alzheimer plan has 11 objectives: to provide increased support to caregivers, strengthen coordination between all intervening parties, allow people with the disease to choose support at home, improve access to diagnosis and optimise the care pathway, improve institutional admission for a better quality of life of people with Alzheimer's disease, value skills and develop education for professionals, promote research, organise an epidemiological follow-up, organise public information and raise awareness, promote an ethical reflexion and approach, make Alzheimer's disease a European priority.

4.6.3 Southern Europe: Economic environment of Alzheimer's disease in Mediterranean countries

By Paul-Ariel Kenigsberg, Fondation Médéric-Alzheimer (France)

In Greece and Turkey, access to diagnosis and care for people with dementia appears to be hampered by cultural barriers. In Turkey, a population-based study of people without dementia, aged 70 years and older, living in an urban area of Istanbul, showed that the concept of dementia was not generally considered as a medical problem by the elderly Turkish population, regardless of age and education (69). Another Turkish study showed that the impact of informal care is very high. (44).

Greece only moved toward a national healthcare system in the 1980s. In 2001 in rural populations, healthcare was served to a large extent by physicians without formal training in general practice and a low level of knowledge in relation to Alzheimer's disease. People with frontotemporal lobar degeneration are diagnosed later in the disease in Greece and Turkey than in the United States, presumably because their behavioural symptoms are not easily detected by the medical system in these countries, highlighting the need to create culturally appropriate indices of the behavioural symptoms (70). Psychiatrists of the Aristotle University of Thessaloniki have challenged the appropriateness of neuropsychological assessment with exist-

ing instruments to Greek psychogeriatric patients, as validation studies in Greece revealed certain difficulties both for the Mini-Mental State Examination (MMSE) and the Cambridge Cognitive Evaluation for the Elderly, probably due to cultural differences, functional illiteracy of the Greek elderly, restricted access to news over past decades, coexistence of mood disorders and low levels of cooperation with the examiner (71).

In Italy, organisational factors, such as scanner availability and waiting lists, play an important role in the prescription of imaging examinations in patients with cognitive impairment, with a rather low perceived added value for the diagnosis of Alzheimer's disease among Alzheimer's centres in Northern Italy in 2003 (72). The total cost of brain disorders in Italy has been estimated to be €40.8 billion in 2008 (3% of the gross national product), of which €8.6 billion for dementia (21% of the total) (73). In 1997, the first Italian study on primary data estimated annual non-medical costs per person with Alzheimer's disease to be LIT 13,388,000/year (€6,914 for 2008), and informal unpaid care to be LIT 72,877,000 (€ 37,637 for 2008) (54).

In Spain, specific cultural contexts in Hispanic culture, with the importance of family key values, have been shown to influence dementia caregiving in relation to burden and depressive symptoms (74). Most people with dementia in Spain live at home with their families, women being the major contributors to informal care (75). Current change in the family structure is transforming the care of people with dementia through new cohabitation arrangements and rotation practices between family members, a mechanism related to the rejection of long-term care institutions (76). Willingness to pay of the general population for alternative policies directed towards people with Alzheimer's disease has been estimated to be €4/hour per person for home care, €0.43/hour for day centres and €0.42 /hour for medium or long stay centres (77).

Direct health care costs of Alzheimer's disease represented 2.4% of the total public health expenditure in the Canary Islands in 2006. Across all severity levels, total annual cost was estimated to be €10 billion for Alzheimer's disease patients older than 65 in Spain. The average annual cost per person with Alzheimer's disease was €28,198. The most important categories of costs were for informal care and drugs. Costs increased with cognitive impairment with an average annual cost of €14,956 for mild, €25,562 for moderate and € 41,669 for severe stages (30, 78). An economic modelling study estimated in 2006 that community-based people with Alzheimer's disease under standard care were spending 6 months in a non-dependent state and incurred average total costs of €24,700 per person over 2 years (35). In a population setting, costs of vascular dementia in people aged 65 and above have been estimated to be €11,039 per person per semester, compared to € 8,086 per semester for Alzheimer's disease (33).

About 34% of people with Alzheimer's disease were treated by specific drugs in 2004 in Spain. Overall consumption of these drugs has increased from 0.026 to 3.235 defined daily dose per 1,000 inhabitants per day (DHD) between 1996 and 2004. Overall costs of the DHD dispensed in 2004 reached about € 6 million. As total treatment cost increased ninety-fold in current €, daily treatment cost decreased by about 30% during this period (79).

4.6.4 Eastern Europe: Burden of illness of dementia in Hungary

By Laszlo Gulacsi, Katalin Ersek, Krisztian Karpati, Corvinus University of Budapest, Health Economics and Technology Assessment Research Centre (Hungary)

In Hungary, as in other countries in the Central-East European region, the burden of dementia shows the most similar upward trend. Along with the demographic changes, the number of people with dementia in each old-aged age-group has increased remarkably. The proportion of the 65+ population has increased from 14.40% up to 15.7% from 1996 to 2005 according to WHO HFA data (80).

In 2008, a cross-sectional study of 88 consecutive dementia patients and their care givers from three GP practices and one outpatient setting - as well as of 66 patients from six elderly homes - was conducted involving physicians and nurses; performing the Resource Utilization in Dementia (RUD), Mini Mental State (MMSE), and health related quality of life European Quality of Life 5 Dimension (EQ-5D) questionnaires.

Using the results of previously conducted surveys from 1998-1999 (81) and 2005 (82), we established the proportion of patients with dementia divided into age-groups. We estimated these figures using the results from surveys involving 103, 99 and 407 patients from physician offices. In these studies diagnosis and severity of dementia were linked to MMSE scores, in the moderate, mild and severe dementia categories. Linka et al. used the usual classification (0-18, 19-24 and 25-30 scores), the other study divided the patients into groups made by 0-19, 20-26 and 27-30 scores. Based on the data of 1998-99, we established the proportion of the patients with dementia for the examined population and then extrapolated it to the population groups of the appropriate years' population. These resulted in the following: for 2001 (based on Linka et al. study) we estimated a figure of 86,783 (17.7% of the 65-69 age-group) and 239,401 (38.7% for the 75+ population). From the Leel-Őssy survey our estimation resulted in 286,144 patients (27.9%), 351,605 patients (45.3%) and a further 120,027 patients (42.9%) from the 60-69, 70-79 and 80+ age-groups, respectively.

The study of Leel-Őssy et al. expanded the survey to 222 people with dementia living in elderly homes. Based on an examination of mental impairment, we estimat-

ed the proportion of the people with dementia in elderly homes in the age-group of 59, the 60-69, 70-79, 80-89 and 90+ age-groups as follows: 33.3%, 20.9%, 39.1%, 46.4%, 62.5% and 38.6%.

According to the Ministry of Social Affairs and Labour, in 2007 there were approximately 6800 people with dementia living in elderly homes. In the statistics at 2005, about 7,000 people with Alzheimer's disease (AD) are reported (Hungarian Central Statistical Office).

In our cross sectional survey 62.5% of the patients were diagnosed with AD. The total direct cost for each patient was €551/month (30 days) (sd. 2,622), while the indirect cost per patient amounted to €52 (sd. 187). The average monthly direct costs for the 65-75, the 75-85 and the 85+ age-groups are the following: €160 (for MMSE groups '0-18' is €223, '19-24' is €89), €283 (for MMSE '0-18' is €399, '19-24' is €144, '25-30' is €52) and €419 (for MMSE '0-18' is €565, '19-24' is €257), respectively.

Examining the EQ-5D values there is a notable difference among MMSE categories (and age-groups). The average EQ-5D values for severe dementia (MMSE '0-18') is 0.300, for mild dementia ('19-24') it is 0.535. Compared to the general Hungarian population (in brackets) in the 55-65, 65-75, 75-85 and 85+ population the average EQ-5D values are: 0.276 (0.765), 0.530 (0.756), 0.424 (0.634) furthermore 0.220 (0.629).

4.7 Conclusions

The care of dementia presents a great challenge for the EU. Dementia disorders are highly prevalent, extremely costly and cause a great burden for both patients and caregivers. In a situation where the financial resources in the health care and social security systems are put under a great deal of stress and with an increasing number of people with dementia, it is important to discuss how to improve care and the cost-effectiveness of care. The relation between the progression of the disease and formal and informal care is complex. How these factors interact depends on the organisation of care and since the care patterns vary across EU, it is fundamental to discuss each country's local prerequisites for dementia care.

The health economic database of dementia is still small, although expanding and the methodological problems are obvious. The number of studies into economic burden is restricted to a few European countries and particularly the situation in Eastern Europe need to be highlighted more. There are several established research networks in the EU, e.g. this EuroCoDe project via Alzheimer Europe and EADC (European Alzheimer Disease Consortium), European Association of Geriatric Psychiatry, European Federation of Neurological Sciences, but there is a great need for even better collaboration and also for the stable funding of research including health economic research on the socio-economic impact of dementia. The national initiatives taken in Sweden, France and Germany as well as the EU initiative highlighted at the presidency conference in Paris on 30-31 October 2008 can indeed be regarded as a good start.

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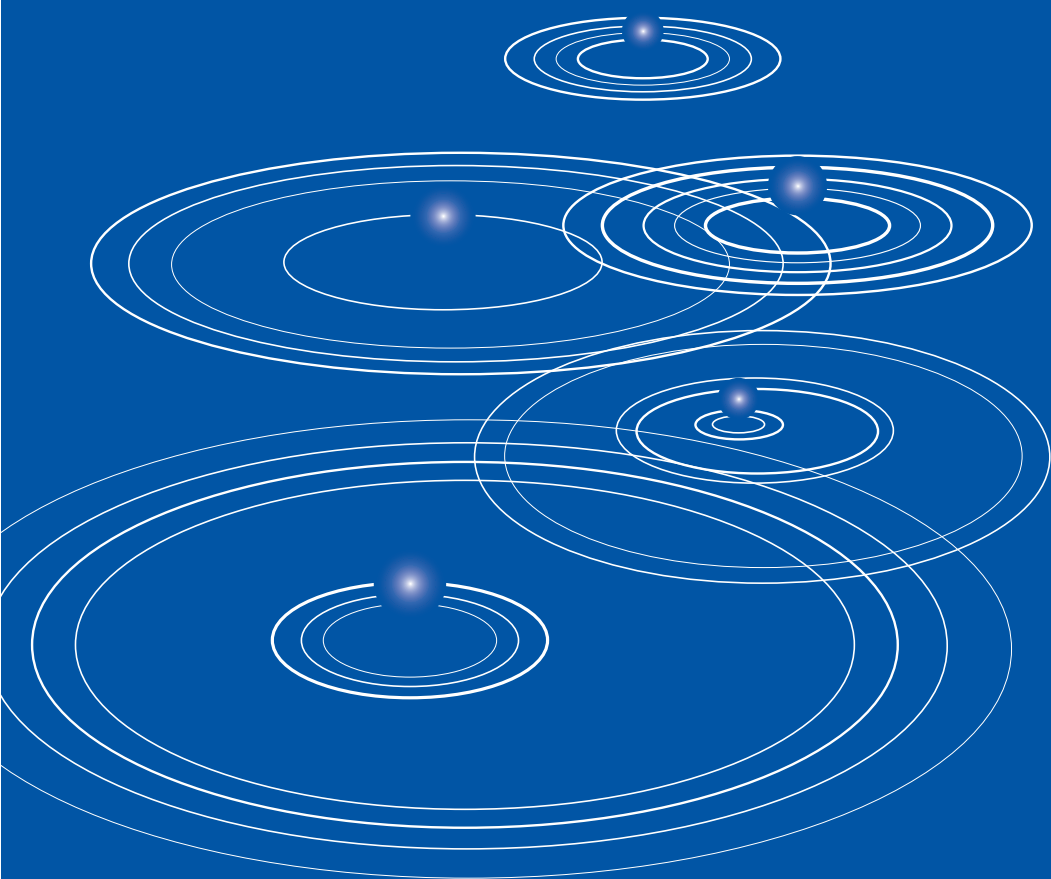
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*European guidelines
on psychosocial
interventions*

5.1 Introduction

While pharmacological treatments undergo strict double-blind placebo-controlled studies, the same is very often not the case for the various non-pharmacological or psychosocial interventions used with people with dementia and their carers. Therefore, the aim of this project is to identify the evidence and consensus based recommendations for psychosocial interventions in dementia care in order to develop a set of potential quality indicators. This reliable set of quality indicators could be used as an instrument to improve the quality of psychosocial care in dementia in Europe.

5.2 Development of the quality indicators

A quality indicator is “a measurable element of practice performance, for which there is evidence available or consensus that it is capable of assessing improvement in the quality, and hence change in the quality of care provided” (Lawrence and Olesen, 1997). A quality indicator measures the quality of the performance of professional practice (Grol et al, 2005).

The aspects of practice can be expressed most simply as a numerator (describing actual performance in target group) and a denominator (describing target group in absolute numbers).

In this way, the quality of care can be described explicitly as a percentage between 0 and 100 (Grol et al, 2005).

Example:

$$\frac{\text{Number of people with dementia that are assessed for depression (numerator)}}{\text{Total number of people with dementia (denominator)}} \times 100\%$$

Quality indicators can refer to structures, processes or outcomes of provided care. Structural indicators focus on organizational aspects of service provision, process indicators focus on the actual care delivered to and negotiated with patients, outcome indicators focus on the ultimate goal of the care given (Grol et al, 2005).

Examples of the different types of quality indicators:

- **Structure:** Percentage of dementia care services that are using a validated instrument to assess depression in people with dementia.
- **Process:** Percentage of people with dementia that are assessed for depression at dementia care service.
- **Outcome:** Percentage of people with dementia diagnosed with depression who receive treatment

5.3 Methods

The work group members agreed that the potential set of quality indicators should be applicable to the range of psychosocial problems and interventions. This general level is new and there is no format which can be followed. There is a need for such a general focus since systematic reviews indicated that no specific intervention is superior.

Rather than developing quality indicators for a specific category of professionals, the set is meant for use by all stakeholders. It should be potentially helpful for a specific patient. It can be used by professional and non-professional carers.

Considering this as a starting point the quality indicators should cover:

1. patients and carers' needs
2. potential interventions
3. how to identify needs for care and to make action plans acceptable for all those involved

Considering the scope and available time for this project the best method to develop a set of potential quality indicators is a method which is objective, not time consuming and uses available knowledge. The quality indicators are therefore derived from evidence-based guidelines by an iterated consensus rating procedure. This procedure combines evidence with expert opinion (Campbell et al, 2002, 2003, Grol et al, 2005).

It starts with selecting core recommendations from evidence-based guidelines. Then, an expert panel is used to reach consensus about the most useful recommendations. Finally, the set of potential quality indicators is constructed based on the key recommendations.

The building blocks of the quality indicators are:

- 1) a review of reviews on the effects of psychosocial interventions
- 2) an inventory on recommendations for psychosocial interventions included in dementia guidelines across Europe
- 3) consensus on key recommendations by European dementia experts.

5.4 *Building blocks of quality indicators*

5.4.1 Review of reviews

To gather available evidence on the effect and effectiveness of psychosocial interventions a literature search was carried out to identify reviews on the subject.

5.4.1.1 Search strategy

We searched for reviews in Pubmed and the Cochrane library using the following terms:

Dementia (MESH) AND psychosocial OR non-pharmacological OR intervention;
limits: review.

Reviews found using this strategy were used as a source for new references of reviews on the subject. The articles found were presented at the work group members and they agreed to only select systematic reviews and reviews that were available in the Cochrane library and not written before 1999. Also, they were asked to add any missing reviews they knew of, meeting the selection criteria.

5.4.1.2 Results

The strategy described above resulted in the selection of 17 reviews (appendix 1). Because some work group members were at that moment involved in writing a systematic review that would meet the search criteria, preliminary results were included. Also, there seemed to be a lack of reviews focussing specifically on the use of psychosocial interventions in institutional care. Therefore, a review of the literature on this subject, especially aiming at the communication between patients and nursing staff was carried out.

5.5 Inventory of guidelines on psychosocial interventions across Europe

5.5.1 Search for guidelines

To start the inventory the Interdem network was used to gather information on available guidelines on psychosocial interventions in dementia across Europe. Contacts in the following countries were sent an email with a request to gather guidelines on the subject: the UK, Spain, the Netherlands, Belgium, France, Germany, Ireland, Italy, Portugal, Switzerland, Greece, Poland, Sweden, Austria, Denmark and Finland.

No information was received from contacts in Greece, Poland and Austria. The information received from the other contacts was put together in a table (appendix 2) and is discussed hereafter.

5.5.2 Results

5.5.2.1 Countries for which no documents/guidelines were available

In **Finland**, there are guidelines on the diagnosis and pharmacotherapy of Alzheimer's disease that were published in May 2006 but no documents on psychosocial approaches are available.

In **Belgium**, no national guidelines are available but documents/guidelines on the subject from Germany and the Netherlands are used in dementia care.

In **Denmark**, the Ministry of Social Affairs published a literature review of the documented effects of caring-methods for people with dementia. The conclusion was that the various psychosocial interventions do appear to have a positive effect on people with dementia and on the different problems that often occur along with the disease. But there is no solid documentation on the effect of the methods.

In **Sweden**, two expert groups were working on the development of guidelines which should have been published in Autumn 2008. Recommendations are done, including psychosocial interventions.

5.5.2.2 Countries with papers/reports on psychosocial interventions available

In **France**, two consensus papers exist; one was published in 2008 by HAS which underlined that only reality orientation had some robust evidence of effectiveness and that in general the evidence level of psychosocial interventions is very low. Another national report concerning psychosocial interventions was published in 2005 (OPEPS) for the Ministry of Health. Conclusions were similar to the HAS report.

In **Switzerland**, a consensus paper on diagnostics and therapy of Alzheimer's disease was published (2003) by the "Forum Alzheimer Suisse". The only important information on psychosocial interventions was the recommendation to first use non-pharmacological interventions in the "treatment" of behavioural symptoms and only, if unsuccessful, to try pharmacological strategies.

In **Ireland**, an "Action plan for dementia" (1999) exists, developed by the National Council on Ageing and Older People. The plan is a reflection of the views of health care professionals and policymakers working in the area of dementia and should serve as a model of best practice for the provision and planning of services to meet the individual needs of people with dementia and their carers. Some attention is given to psychosocial interventions but no specific recommendations about their use are done.

5.5.2.3 Guidelines on psychosocial interventions available

In **Italy**, different types of guidelines/documents on dementia are available: guidelines governing relationships between the Italian Alzheimer's Societies and pharmaceutical companies, general guidelines coordinated by medical doctors, and guidelines for the treatment of Alzheimer's disease (2005). The last one is an evidence-based review article by a committee of experts from the Italian Association of Psychogeriatrics in which several psychosocial interventions are discussed.

In **Germany**, the most important and recent (May 2006) guideline on psychosocial interventions was developed by the Kuratorium Deutsche Altershilfe and the Institut für Pflegewissenschaft der Universität Witten/Herdecke for the German Ministry of Health. These guidelines only focus on institutional care. The German society for psychiatry, psychotherapy and neurology developed guidelines for the treatment of dementia. Besides pharmacological treatment, it also recommends the use of different psychosocial interventions for different stages of dementia. Other German guidelines/documents on dementia treatment which give attention to psychosocial approaches focus on day care facilities, the use of restraints, and general practitioners.

In the **Netherlands**, guidelines on dementia treatment and/or care are available for medical doctors, and nursing staff. The guidelines for geriatricians mainly focus on diagnosis and pharmacological treatment and only list psychosocial interventions in the appendix. The guideline developed for general practitioners pays more attention to the psychosocial environment of dementia patients but recommendations are carefully described. For nursing staff there is a handbook on the use of Snoezelen in institutional care, developed by the Netherlands Institute for Health Services Research. This institute also developed a guideline for the support of apathetic or depressed dementia patients, which is entirely focused on a psychosocial approach by nursing staff. The Dutch society for Nursing Home Physicians developed guidelines for the management of problem behaviours in nursing home pa-

tients. It mentions pharmacological as well as psychosocial approaches for treating and monitoring problem behaviours in nursing home patients.

Furthermore, a consensus paper on the cooperation between general practitioners and professional caregivers was developed for diagnostics and support for dementia patients and their informal caregivers. It stresses the importance of emotion-oriented care.

In the **United Kingdom**, the two most important national clinical guidelines on dementia are developed by SIGN (2006) (for Scotland) and for England & Wales, the guidelines produced jointly by NICE & SCIE (2006), covering both health and social care. Both guidelines contain chapters on psychosocial interventions and give recommendations based on systematic literature searches. Several other guidelines/documents which mention the importance of the psychosocial environment and/or use of psychosocial interventions besides pharmacological treatment are available for general practitioners, social care workers and the local government.

In **Spain**, several guidelines are also available. The guidelines of the Spanish Society of Familiar and Community Medicine (1999), the Spanish Multidisciplinary Group for the Coordinated Attention of a Patient with Dementia (2002), and the Working Group for Alzheimer's Disease and Other Dementias of Late Life (2001) provide recommendations on the use of psychosocial interventions in dementia care and treatment. Other guidelines/documents mention some psychosocial aspects of dementia treatment and/or care but do not give recommendations on the use of specific psychosocial interventions.

5.5.2.3.1 Quality of the guidelines

To assess the quality of the guidelines, the work group used the AGREE-instrument (AGREE collaboration) to rate them. The guidelines that were most recently developed and which paid broad attention to psychosocial interventions were chosen for this procedure. Ratings were solely based on the sections about psychosocial interventions. Other sections in the guidelines were not considered during the rating procedure, except for the more general parts about the development of the guideline. The scores do not therefore reflect the quality of any of the guidelines as a whole.

5.5.2.3.2 Results

A total of 9 guidelines from 5 countries were rated with the AGREE-instrument. The Italian guideline and SIGN guideline were rated by all work group members during a meeting in Brussels. The other 7 guidelines were rated by at least two people. In some cases two work group members (NICE, Rahmenempfehlungen) in the other cases by one work group member and a dementia expert known by a work group member, who was able to rate the guideline in its original language (Spanish or Dutch).

Results were calculated according to the instructions given in the AGREE-document and scores by domain are presented in table 1. Higher percentages reflect better quality.

Table 1. Appraisal of chapters about psychosocial interventions in European dementia guidelines. AGREE domain scores.

Guideline	Domain score (%)					
	Scope and purposes	Stakeholder involvement	Rigour of development	Clarity and presentation	Applicability	Editorial independence
SIGN	65	32	79	56	46	72
Italian guidelines	57	36	45	42	6	33
NICE	89	88	90	88	89	100
Rahmenempfehlungen	89	71	79	67	28	58
Spanish multidisc. group	78	46	38	71	17	8
CBO	78	46	40	13	0	58
NIVEL	83	83	52	63	22	50
LESA	44	46	19	46	28	42
NHG	39	50	43	67	17	42

It can be concluded that quality varies not only between guidelines but also within guidelines. The NICE guidelines have the highest scores for all domains and therefore have the best overall quality of all guidelines that were rated.

5.5.3 Consensus on key recommendations by European dementia experts

5.5.3.1 Procedure step by step

5.5.3.1.1 Agreement on composition and selection of expert panels in each country

The work group decided out of convenience to have only expert panels in countries where an Interdem member could be contacted. Also, at the Alzheimer Europe conference in Estoril (Portugal, 2007) people involved in dementia care were invited to take part in the consensus procedure. It was agreed by the work group members that it was important to approach at least the opinion leaders in each country involved. An expert in dementia care was defined as someone who is involved in dementia care, like researchers, carers, or clinicians.

To guarantee the objectivity of the procedure and avoid time consuming face-to-face panel discussions in different countries led by different people, the experts rated the recommendations by means of a questionnaire.

5.5.3.1.2 Selection of core recommendations by the work group

All evidence-based recommendations on psychosocial interventions found in the European guidelines on dementia through the inventory of guidelines were gathered. These recommendations were then discussed by the work group members during a face-to-face meeting. A recommendation was included for the postal rounds when it was agreed by work group members that it was important for psychosocial care in dementia. It was ensured that selected recommendations did not overlap with the area of other Eurocode work packages.

5.5.3.1.3 First postal round

During the first round of questionnaires experts were asked to rate each recommendation twice, based on the questions (appendix 3):

- 1) Would applying this recommendation to dementia care contribute to the improvement of its quality?
- 2) How much priority should this recommendation be given in dementia care in your country?

Experts were also asked to list their personal top 5 recommendations for each category, starting with the recommendation they found most useful for improving the quality of dementia care. Experts were also permitted to add or adjust the recommendations presented.

5.5.3.1.4 Second postal round

All recommendations included in the first round were also included in the second postal round. Recommendations that were adjusted or added by the experts during the first round were also included in the second questionnaire.

Experts were then asked to rate all recommendations based on the question (appendix 4):

- Considering the way in which dementia care will be organised in your country in the next 5 years, how feasible is implementation of this recommendation within 5 years in (parts of) your country?

The added and adjusted recommendations were also rated for their contribution to improve the quality of care.

5.5.3.2 Results

5.5.3.2.1 Selection of core recommendations by work group

Of all available evidence-based recommendations in European guidelines on dementia a total of 104 were selected by the work group members for their relevance to psychosocial care in dementia. These recommendations were then divided into 8 categories and a questionnaire was constructed for the first postal round.

The recommendations were derived from the following guidelines:

- Dementia: Supporting People with Dementia and their Carers - NICE-SCIE (UK)
- Management of patients with dementia: A national clinical guideline - SIGN (UK)
- Rahmenempfehlungen zum Umgang mit herausforderndem Verhalten bei Menschen mit Demenz in der stationären Altenhilfe - Kuratorium Deutsche Altershilfe + das Institut für Pflegewissenschaft der Universität Witten/Herdecke (Germany)
- Diagnostiek en medicamenteuze behandeling van dementie (diagnosis and pharmacological treatment in dementia - CBO (Netherlands)
- Richtlijnen voor verzorgenden (depressie en apathie) (Guidelines for health aides) - NIVEL (Netherlands)
- NHG standaard dementie (Dutch college general practitioners)

5.5.3.2.2 Expert panel and postal rounds

About 80 questionnaires were handed out to dementia experts attending the Alzheimer Europe Conference in Estoril in May 2007. They were asked to fill in the questionnaire and sent it back to the work group in the envelope provided. Furthermore, an email request was sent to Alzheimer centre coordinators in as many European countries as possible in September 2007. They were also asked to fill in the questionnaire and send it back to the work group by email or regular mail. By these means nineteen questionnaires were filled in and received back by the work group.

Additionally, about 60 questionnaires were sent by regular mail to Interdem contacts in different European countries. The contacts were asked to fill in a questionnaire and/or hand it out to colleagues. Thirty of these questionnaires were filled in and sent back.

A total of 49 questionnaires were sent back from May 2007 until December 2007. These were filled in by dementia experts from 13 different European countries: Belgium (4), Denmark (1), Finland (6), France (5), Germany (2), Greece (1), Italy (8), the Netherlands (9), Poland (2), Slovakia (1), Spain (4), Turkey (1), and the UK (5).

The work group decided to change the second postal round into an email round because of time considerations. The 49 experts that had filled in a questionnaire during the first round were therefore sent an email request in May 2008 to also fill in the second questionnaire, which was attached to the email. Unfortunately, not all of the 49 experts could be reached by email because email addresses were no longer in use.

Therefore, only 38 of the 49 experts were sent a request and 14 questionnaires were filled in and returned by email between May and July 2008. These 14 questionnaires came from experts from 9 different countries: Belgium (2), Denmark (1), Finland (2), France (2), Italy (1), the Netherlands (2), Poland (1), Turkey (1), and the UK (2).

5.5.3.2.3 Constructing the potential set of quality indicators

In order to construct a reliable set of potential quality indicators, it is important that the set of key recommendations they are based on score high on average for usefulness for improving quality of dementia care. Also, there should not be much variation in scores for a single recommendation because disagreements between experts can lead to problems when implementing the quality indicators into practice because of lack of consensus. (Grol et al, 2005, RAND/UCLA handbook).

The construction of the potential set of quality indicators was divided over two work group meetings. During the first meeting (May 2008) the results of the first questionnaire round were discussed. These results showed that average scores for usefulness as well as priority were high for all of the 104 recommendations (table 2). Medians ranged between 5-9 and therefore it could be concluded that experts agreed that almost all of the 104 recommendations are important for improving quality of dementia care. Because statistic results did not differentiate enough, the work group decided that the set of key recommendations would be based on the results of the top 5 listings of the 49 experts.

Table 2. Overall results of the first and second expert questionnaire rounds

	Overall			Median frequency (# recommendations with median)									
	N range	Mean	Median range	4	4.5	5	6	6.5	7	7.5	8	8.5	9
Useful	47-49	7.65 SD: 0.64	5-9	0	0	1	3	1	14	0	65	1	19
Priority	47-49	7.29 SD: 0.68	5-9	0	0	1	7	0	27	0	61	0	8
Implement	13-14	6.09 SD: 0.71	4-8	4	1	3	29	13	46	3	5	0	0

The overall ranking of recommendations in the top 5 listings was calculated as follows per category:

For each number-one ranking by an expert, a recommendation was awarded 5 points, for each number-two ranking, a recommendation was awarded 4 points and so on.

In this way, an overall top 5 per category was calculated. For categories with less than 10 recommendations (2 categories), only the top 3 recommendations were included. One category existed of only two recommendations which were ranked equally important by the experts and were therefore both included. Finally, a total of 33 recommendations ranked top 5 or top 3 overall in their category were discussed during the first work group meeting. Recommendations were joined together wherever

possible, recommendations that overlapped with others were excluded and recommendations were rephrased if this was thought necessary. This resulted in a final set of 17 key recommendations (appendix 3).

During the second and final meeting (October 2008) the work group constructed the potential set of quality indicators based on the 17 key recommendations and results of the second questionnaire round. Expert ratings for feasibility of implementations indicated that not all of the 17 key recommendations were considered equally implementable (table 2). Key recommendations that scored a median of 6 or lower (5 recommendations) were not turned into a quality indicator unless the work group agreed that it covered a basic principle of psychosocial care in dementia and therefore was essential for improving its quality.

At the end of this meeting 15 quality indicators were constructed (appendix 4).

This potential set consisted of:

- 11 quality indicators for people with dementia
- 3 quality indicators for informal carers of people with dementia
- 1 quality indicator for formal carers of people with dementia

All quality indicators are process indicators and therefore focus on the actual care delivered to and negotiated with people with dementia and their caregivers at any health care service providing dementia care.

5.6 Conclusion

The aim of this project was to identify the evidence and consensus-based recommendations for psychosocial interventions in dementia care in order to develop a set of potential quality indicators.

During the course of this project the work group gathered evidence by conducting a review of reviews and an inventory of European guidelines on psychosocial interventions.

The main conclusions of the review are that interventions directed at both the person with dementia and the informal carer are the most effective ones, especially when these interventions are multi-component, address personal needs for care, and help to reframe dysfunctional perceptions into more effective ones. The inventory of dementia guidelines across Europe revealed that attention to the use of psychosocial interventions in dementia is growing in several European countries. However, only in 5 countries recommendations for psychosocial interventions have been found in dementia guidelines.

All psychosocial recommendations found through the inventory of European guidelines were gathered and rated for usefulness in improving quality of dementia care. The opinion of 49 European dementia experts from 13 different European countries was used for a consensus set of key recommendations for psychosocial care in dementia. Finally, the work group constructed a set of 15 reliable, potential quality indicators based on these key recommendations. This set of quality indicators provides policy makers and health care professionals an useful instrument to implement evidence-based recommendations and improve quality of psychosocial care for people with dementia and their carers in European countries.

All of the quality indicators developed here focus on the process of the care delivered to people with dementia and their caregivers. Ideally, quality of care is measured by the outcome of the care given. Unfortunately, there is no clear consensus on which outcome measures could be used best in psychosocial intervention research. The Interdem group therefore reached a European consensus on outcome measures to be used in psychosocial intervention research (Moniz-Cook et al, 2008). The recommended outcome measures should be used by researchers in order to improve the comparability of results of psychosocial intervention studies in Europe. In the end this will result in better scientific evidence for the effectiveness of psychosocial interventions and the improvement of the psychosocial care given to people with dementia and their caregivers.

5.7 References

Campbell SM, Braspenning J, Hutchinson A, and Marshall M. *Research methods used in developing and applying quality indicators in primary care*. Qual Saf Health Care 2002;11:358-364

Cambell SM, Braspenning J, Hutchinson A, and Marshall MN. *Research methods used in developing and applying quality indicators in primary care*. BMJ 2003;326:816-819

Collaboration AGREE. *Appraisal of Guidelines for Research and Evaluation (AGREE) instrument* [<http://www.agreecollaboration.org>]

Grol R, Wensing M, Eccles M. *Improving Patient Care: The Implementation of Change in Clinical Practice*. Oxford: Elsevier, 2005.

Lawrence M and Olesen F. *Indicators of quality in health care*. Eur J Gen Pract 1997; 3:103-108

Moniz-Cook E, Vernooij-Dassen M, Woods R, Verhey F, Chattat R, De Vugt M, Mountain G, O'Connell M, Harrison J, Vasse E, Dröes RM, Orrell M; INTERDEM group. *A European consensus on outcome measures for psychosocial intervention research in dementia care*. Aging Ment Health. 2008;12(1):14-29.

Fitch K, Bernstein SJ, Aguilar MS, Burnand B, LaCalle JR, Lazaro P, van het Loo M, McDonnell J, Vader J, Kahan JP. *The RAND/UCLA Appropriateness Method User's Manual*. Downloaded 29-10-2008 from www.rand.org

5.8 Appendix 1 - References and conclusions/recommendations of the 17 selected reviews

Brodaty H, Green A, Koschera A. *Meta-Analysis of Psychosocial Interventions for Caregivers of People with Dementia*. JAGS 51:657–664, 2003

Programmes that involve the patients and their families and are more intensive and modified to caregivers' needs may be more successful. Caregiver interventions can have effects on delaying nursing home admission, which for many is desirable. Unsuccessful interventions are short educational programmes (beyond enhancement of knowledge); support groups alone, single interviews, and brief interventions or courses that were not supplemented with long-term contact do not work.

Chung JCC, Lai CKY. *Snoezelen for dementia (Review)*. Cochrane Database Syst Rev. 2002;(4):CD003152

Owing to the limited data obtained from the two included randomised controlled trials (RCT), it is not feasible to draw a conclusion in this review about the efficacy of Snoezelen. Although the pooled results of the two studies did not demonstrate a significant result in favour of Snoezelen, they independently demonstrated significant results in favour of Snoezelen. Regarding the short-term effects, Kragt 1997's subjects presented significantly fewer behavioural problems (e.g. apathy, restlessness) during the Snoezelen sessions than the control sessions. Baker 2001's subjects were more responsive to their surrounding environments immediately after the sessions.

From the practice perspective, snoezelen programmes demonstrate positive immediate outcomes in reducing maladaptive behaviours and promoting positive behaviours, suggesting that it should be considered as part of the general dementia care programme.

Clare L, Woods RT, Moniz Cook ED, Orrell M, Spector A. *Cognitive rehabilitation and cognitive training for early-stage Alzheimer's disease and vascular dementia (Review)*. Cochrane Database Syst Rev. 2003;(4):CD003260.

The present findings do not provide strong support for the use of cognitive training interventions for people with early-stage AD or vascular dementia, although these findings must be viewed with caution due to the limited number of RCTs available and to the methodological limitations identified, and further well-designed trials would help to provide more definitive evidence.

Due to a complete absence of RCTs evaluating an individualised cognitive rehabilitation approach, it is not possible at present to draw conclusions about the efficacy of individualised cognitive rehabilitation interventions for people with early-stage dementia, and further research is required in this area.

Cooke DD, McNally MCN, Mulligan KT, Harrison MJG, Newman SP. *Psychosocial interventions for caregivers of people with dementia: a systematic review*. *Aging & Mental Health* 2001; 5(2): 120–135

The studies reviewed here do show that it is possible to produce consistent improvements in caregivers' knowledge of the care recipients' illness, but knowledge appears unrelated to psychological and social outcomes. The findings of the review suggest that the inclusion of social components in interventions or a combination of social and cognitive components appears to be relatively effective in improving psychological well-being.

Forbes D, Morgan DG, Bangma J, Peacock S, Adamson J. *Light Therapy for Managing Sleep, Behaviour, and Mood Disturbances in Dementia (Review)* Cochrane Database of Systematic Reviews 2004, Issue 2. Art. No.: CD003946.

There is insufficient evidence of the efficacy of light therapy in managing sleep, behaviour, cognition or mood disturbances associated with dementia. Available studies are of poor quality.

Heyn P, Abreu BC, Ottenbacher KJ. *The Effects of Exercise Training on Elderly Persons With Cognitive Impairment and Dementia: A Meta-Analysis*. *Arch Phys Med Rehabil* 2004 Vol 85

Exercise training increases fitness, physical function, cognitive function, and positive behaviour in people with dementia and related cognitive impairments. Exercise was associated with statistically significant positive treatment effects in older patients with dementia and cognitive impairments. The meta-analysis results suggest a medium to large treatment effect for health-related physical fitness components, and an overall medium treatment effect for combined physical, cognitive, functional, and behavioural outcomes. The results provide preliminary evidence for the effectiveness of exercise treatments for persons with dementia and related cognitive impairments.

Lee H, Cameron M. *Respite care for people with dementia and their carers*. *Cochrane Database Syst Rev*. 2004;(2):CD004396

Results from three randomized controlled trials provided no evidence of any benefit of respite care for people with dementia or for their caregivers for any outcome including rates of institutionalization and caregiver burden. However, a host of methodological problems in available trials were identified. Further methodologically sound research is needed before any firm conclusions can be drawn. No meaningful conclusions for practice can be drawn from the available evidence.

Livingston G, Johnston K, Katona C, Lyketsos CG. *Systematic review of psychological approaches to the management of neuropsychiatric symptoms of dementia*. *Am J Psychiatry*. 2005 Nov;162(11):1996–2021.

Behavioural management techniques centered on individual patients' behaviour are generally successful for reduction of neuropsychiatric symptoms, and the effects of these inter-

ventions last for months, despite qualitative disparity. Psychoeducation intended to change caregivers' behaviour is effective, especially if it is provided in individual rather than group settings, and improvements in neuropsychiatric symptoms associated with these interventions are sustained for months. We therefore recommend these types of interventions. Music therapy and Snoezelen, and possibly some types of sensory stimulation, are useful treatments for neuropsychiatric symptoms during the session but have no longer-term effects. The cost or complexity of Snoezelen for such small benefit may be a barrier to its use. Specific types of staff education lead to reductions in behavioural symptoms and use of restraints and to improved affective states. Staff education is, however, heterogeneous, although instruction for staff in communication skills and enhancement of staff members' knowledge about dementia may improve many outcomes related to neuropsychiatric symptoms. Teaching staff to use dementia-specific psychological therapies for which there is limited evidence of efficacy may not improve these outcomes.

Little evidence is available on the effectiveness of reminiscence therapy, but more positive evidence exists for cognitive stimulation therapy. Training for caregivers in behavioural management techniques had inconsistent outcomes but merits further study. The evidence for therapeutic activities is very mixed, and the study findings for these interventions are contradictory and inconclusive. Specialized dementia units were not consistently beneficial, but changing the environment visually and unlocking doors successfully reduced wandering in institutions. These promising interventions merit more study.

There is no convincing evidence that simulated presence interventions or reduced stimulation units are efficacious for neuropsychiatric symptoms. Reality orientation therapy, validation therapy, "admiral" nurses, and Montessori activities had no effect on neuropsychiatric symptoms.

Neal M, Barton Wright P. *Validation therapy for dementia*. Cochrane Database of Systematic Reviews 2003, Issue 3. Art.No.: CD001394.

There is insufficient evidence from randomized trials to allow any conclusion about the efficacy of validation therapy for people with dementia or cognitive impairment.

Pusey H, Richards D. *A systematic review of the effectiveness of psychosocial interventions for carers of people with dementia*. Aging & Mental Health 2001; 5(2): 107–119

The overall methodological quality of the studies was poor, particularly with regard to sample size, and methods of random allocation. Individualized interventions that utilized problem solving and behaviour management demonstrated the best evidence of effectiveness. This approach is also closest to the effective model of psychosocial interventions currently in use with other severe and enduring illnesses.

Price JD, Hermans DG, Grimley Evans J. *Subjective barriers to prevent wandering of cognitively impaired people*. *Cochrane Database Syst Rev*. 2000;(4):CD001932

There is no evidence so far that subjective barriers reduce wandering, and the possibility of harm (particularly psychological distress) cannot be excluded. If used, then subjective barriers should form part of a diverse approach to problem wandering, which may include the identification and definition of the problem in the individual, preventative activities such as exercise classes or occupational therapies, and improved communication between carer and wanderer.

Sörensen S, Pinquart M, Duberstein P. *How Effective Are Interventions With Care-givers? An Updated Meta-Analysis*. *The Gerontologist*. 2002; 42(3): 356–372

Interventions are, on average, successful in alleviating burden and depression, increasing general subjective well-being, and increasing caregiving ability/knowledge. The majority of these effects persist after an average of 7 months postintervention. Providing psychoeducational interventions, psychotherapy, and a combination of several of these interventions, as is done in multicomponent approaches, is most effective for improving caregiver well-being in the short term.

Teri L, McKenzie G, LaFazia D. *Psychosocial Treatment of Depression in Older Adults with Dementia*. *Clin Psychol Sci Prac* 12: 303–316, 2005

Using multiple techniques, including behavioural skill training, communication, social engagement, and sensory and environmental stimulation in a variety of settings, including long-term care and private homes, 7 of the 11 treatments demonstrated clear improvements in depression. In 6 studies, these improvements were maintained beyond the active treatment period. Commonalities across these programmes included assessment strategies, individualisation of strategies, providing treatment in a one-on-one format, using multiple treatment components in a coordinated programmatic approach, and focusing on teaching caregivers to deliver treatments to the persons with dementia. Much of what caregivers were taught involved problem-solving disease difficulties and facilitating increased pleasant social interaction.

Thorgrimsen L, Spector A, Wiles A, Orrell M. *Aroma therapy for dementia*. *Cochrane Database Syst Rev*. 2003;(3):CD003150

Aroma therapy showed benefit on measures of agitation and neuropsychiatric symptoms for people with dementia in the only trial that contributed data to this review, but there were several methodological difficulties with this study. More well designed large-scale RCTs are needed before conclusions can be drawn on the effectiveness of aroma therapy. Additionally, several issues need to be addressed, such as whether different aroma therapy interventions are comparable and the possibility that outcomes may vary for different types of dementia.

Verkaik R, van Weert JCM, Francke AL. *The effects of psychosocial methods on depressed, aggressive and apathetic behaviours of people with dementia: a systematic review.* Int J Geriatr Psychiatry 2005; 20: 301–314.

There is some evidence that Multi Sensory Stimulation/Snoezelen in a Multi Sensory Room reduces apathy in people in the later phases of dementia. There is scientific evidence, although limited, that Behaviour Therapy–Pleasant Events and Behaviour Therapy–Problem Solving reduce depression in people with probable Alzheimer’s disease who are living at home with their primary caregiver.

There is also limited evidence that Psychomotor Therapy Groups reduce aggression in a specific group of nursing home residents diagnosed with probable Alzheimer’s disease. The evidence comes from a maximum of two high quality RCTs that arrive at the same positive results.

Although the evidence for the effectiveness of some psychosocial methods is stronger than for others, overall the evidence remains quite modest and further research needs to be carried out.

Vink AC, Birks JS, Bruinsma MS, Scholten RJS. *Music therapy for people with dementia (Review).* Cochrane Database Syst Rev. 2004;(3):CD003477

The methodological quality and the reporting of the included studies were too poor to draw any useful conclusions. Despite five studies claiming a favourable effect of music therapy in reducing problems in the behavioural, social, emotional, and cognitive domains we cannot endorse these claims owing to the poor quality of the studies.

Woods B, Spector A, Jones C, Orrell M, Davies S. *Reminiscence therapy for dementia (Review).* Cochrane Database Syst Rev. 2005 Apr 18;(2):CD001120

The evidence-base for the effectiveness of reminiscence therapy (RT) continues to rest largely on descriptive and observational studies, with the few RCTs available being small, of relatively low quality and with some variation in outcome, perhaps related to the diverse forms of RT used. It is too early to provide any indication of the effectiveness of reminiscence therapy in comparison with other psychosocial interventions, such as validation therapy or music therapy. However, given its popularity with staff and participants, there is no reason not to continue with its further development and evaluation. The need for training, support and supervision for staff carrying out this work is emphasised in much of the RT literature.

5.9 Appendix 2 - Table. Guidelines/papers on dementia that give

Country	Title	Users	
France	Alzheimer's disease and related conditions - Diagnosis and treatment (HAS) (2008)	Professionals in dementia care for clinical practice	
	RAPPORT sur la maladie d'Alzheimer et les maladies apparentées (OPEPS) (2005)	Health care policy makers	
Switzerland	Diagnostik und Therapie der Alzheimer Krankheit: Ein Konsensus für die Schweiz	Medical specialists and general practitioners	
Ireland	An action plan for dementia (1999)	Professionals in dementia care + policy makers	
Italy	Guidelines for the treatment of Alzheimer's disease from the Italian association of psychogeriatrics (2005)	Clinical specialist (neurologists, geriatricians, psychiatrists)	
Germany	Rahmenempfehlungen zum Umgang mit herausforderndem Verhalten bei Menschen mit Demenz (2006)	Formal caregivers in institutional care	
	Handlungsempfehlung zu Fixierung und freiheitsbeschränkenden Maßnahmen Demenzkranker (2001)	Professionals in dementia care	
	Behandlungsleitlinie Demenz (2000)	Psychiatrist, psychotherapists, neurologists	
	BDA Manuale-Demenz (1999)	General practitioners	
	Zur Betreuung Demenzkranker in Tagespflegeeinrichtungen	Professionals in dementia care	
Netherlands	Diagnostiek en medicamenteuze behandeling van dementie (CBO) (2005)	Geriatricians, professionals	
	Landelijke Eerstelijns Samenwerkings Afspraak Dementie (LESA) (2005)	General practitioners and professional caregivers	
	Richtlijnen voor verzorgenden (depressie en apathie) (2004)	Formal caregivers	
	NHG-standaard dementie (2003)	General practitioners	
	Dementie (gezondheidsraad) (2002)	Policy makers	
	Richtlijn probleemgedrag (2002)	Nursing home physicians	

attention to psychosocial interventions available across Europe

Developers	Policy driven/evidence-based
Haute Autorité de Santé	Evidence-based and expert consensus
Medical experts	Policy-driven consensus
Alzheimer Forum Schweiz: doctors, med. Specialists	Evidence-based consensus
National Council on Ageing and Older People	Policy-driven
Experts from the Italian Association of Psychogeriatrics	Evidence-based
Kuratorium Deutsche Altershilfe + das Institut für Pflegewissenschaft der Universität Witten/Herdecke	Policy-driven Experts
Deutsche Expertengruppe Dementenbetreuung (professionals dementia care)	Expert-opinion consensus
German society for psychiatry, psychotherapy, and neurology	Evidence-based and expert consensus
German society for general practitioners	Clear and rapid information sheet for use in practice based on experts opinions/experiences.
Deutsche Expertengruppe Dementenbetreuung (formal caregivers daycare)	Expert opinion-consensus
Geriatricians, professionals	Evidence-based
General practitioners, professionals, professional caregivers	Evidence-based and consensus
Netherlands institute for health services research (NIVEL)	Evidence-based
General practitioners, professionals	Evidence-based
Health council of the Netherlands	Policy-driven
Dutch Society of Nursing home physicians (NVVA)	Evidence-based and consensus

UK	Management of patients with dementia: A national clinical guideline (2006)	Health care professionals	
	Dementia: Supporting People with Dementia and their Carers (2006)	Practitioners and service commissioners	
	Knowledge set for dementia (2006)	Social care workers	
	Everybody's business. Integrated mental health services for older adults: a service development guide (2005)	Health and social care practitioners, guide for developing/improving mental health services	
	Care Homes for Older People, National Minimal Standards (2002)	Care homes	
	Guidelines for the management of agitation in dementia (2001)	Clinicians	
	Modern standards and service models for older people (2001)	National Health Service, (local) government, people working with older people	
	Guidelines for the primary care management of dementia (1998)	General practitioners	
Spain	Guideline for dementia. Concepts, criteria and references for dementia patient assessment (2003)	Neurologist	
	Attention coordinated for dementia patient (2002)	Health and social care practitioners	
	Comprehensive care for dementia (2002)	Health care practitioners.	
	Guide of quality criteria in social and sociosanitary centres: for elderly people in nursing homes (2002)	Health and social care practitioners working in social centres and residents	
	Coordinated Attention of the Patient with Dementia (2001)	Health and social care practitioners	
	Dementia Spanish consensus (2000)	Psychiatrist	
	Dementia. Guideline (1999)	GPs	

Scottish Intercollegiate Guidelines Network (SIGN)	Evidence-based
Multidisciplinary team of health and social care professionals, a person with dementia, carers, and guideline methodologists (NICE-SCIE)	Evidence-based
Skills for Care (employment interests, service users and carers and union and professional associations in social care)	National Vocational Qualifications (NVQs) based on National Occupational Standards
Department of Health	Policy-driven
Department of Health	Policy-driven
Specialist old age psychiatrists, geriatricians, psychologists, general practitioners, and social scientists involved in the care of people with dementia in the UK and Ireland	Evidence-based
National service framework for older people: Department of Health	Policy-driven
North of England evidence based guidelines development project	Evidence-based
Neurology Study Group on Behavior and Dementia	Policy-driven
Spanish Multidisciplinary Group for the Co-ordinated Attention of a Patient with Dementia	Policy-driven
Public Sanitary System of Andalucía	Policy-driven
Authors: Jose A. De-Santiago and J. Zurro	Policy-driven
Working Group for Alzheimer's Disease and Other Dementias of Late Life	Policy-driven
Spanish Society of Psychiatry	Policy-driven
Spanish Society of Familiar and Communitary Medicine	Policy-driven

5.10 Appendix 3 - Set of 17 key recommendations

General

1. Treatment of dementia always involves at all stages emphasising the unique qualities of the individual with dementia and recognising the patient's personal and social needs.

The combination of different types of support, each tailored to the person and the situation is preferable to offering one type of support or a standard care package.

2. Healthcare professionals should be aware that many people with dementia can understand their diagnosis, receive information and be involved in decision making.

Psychosocial interventions for comorbid depression and/or anxiety

3. A care plan for people with dementia, including those with comorbid depression should be drawn up on the basis of the life history, social and family circumstances, and preferences (such as diet, sexuality and religion) of the person with dementia. Activities should be adjusted to ensure that they are achievable with the limitations the patient has.
4. Assess and monitor people with dementia for depressions and/or anxiety.
5. Non pharmacological interventions should be considered in decreasing comorbid agitation, depression and/or anxiety and should be tailored to the person's preferences, skills and abilities. Monitor response and adapt the care plan as needed.

Behaviour that challenges

6. People with dementia who develop non-cognitive symptoms that cause them significant distress or who develop challenging behaviour should be offered an assessment at an early opportunity to establish the factors likely to generate, aggravate or improve such behaviour. The assessment should include the person's physical health and behavioural and functional analysis conducted by professionals with specific skills, in conjunction with carers and care workers. The assessment should lead to an individually tailored care plan and the coordination of care should be documented and reviewed regularly. The frequency of the review should be agreed by the carers and staff involved and documented.
7. People with dementia and challenging behaviour should be treated with acceptance and respect during a psychiatric crisis involving delusions, panic attacks, hallucinations and aggressive behaviour. The feelings that cause the behaviour and distract the patient should be identified. Confirmation of delusions should be avoided. De-escalation strategies should be used in the handling of aggressive behaviour. Restraint should be avoided and only used as a last resort.

Pain relief

8. If there are unexplained changes in behaviour or signs of distress, assess for undetected pain, using an observational pain assessment tool if helpful.
9. In severe dementia, treat pain both pharmacologically and non-pharmacologically. Consider the person's history and preferences when choosing non-pharmacological therapies.

Support for carers

10. Respite or short-break services should be available and include, for example, day care, day and night sitting, adult placement and short-term and/or overnight residential care.
11. Assess and monitor carers of people with dementia for anxiety and/or depression, especially in cases of problematic behaviour. Social workers/nurses should anticipate and intervene, especially when caregivers experience symptoms of depression, to prevent overburdening.
12. Care plans for carers should include tailored interventions such as individual or group psycho-education and training courses about dementia, services and benefits, and dementia-care problem solving. The general practitioner and/or other professionals should inform the family and caregivers of the local situation.

Management and coordination of care

13. Care managers/coordinators should ensure that there is coordinated delivery of health and social care services, including a combined care plan, agreed by health and social services, that takes into account the changing needs of the person with dementia and the carers. A case manager, one or two assigned people who would maintain regular contact with the patient and the main caregiver should be involved in aiding patients with dementia and their caregivers.
14. Care plans should address the activities of daily living (ADL) that maximise independent activity, enhance function, adapt and develop skills, and minimise the need for support.

Staff training

15. Health and social care managers should ensure that all staff working with older people in the health, social care and voluntary sectors have access to dementia-care training (skill development) that is consistent with their roles and responsibilities. This should include comprehensive training on interventions that are effective for people with dementia.
16. Staff should show a validating, respectful attitude in working and communicating with people with dementia.

Principles of care

17. Identify specific needs, including those arising from:

- sensory impairment
- communication difficulties
- ill health

5.11 Appendix 4 - Set of 15 potential quality indicators for psychosocial care in dementia

5.11.1 Quality indicators for people with dementia

Recommendation	Numerator	Denominator
A care plan for people with dementia, should be drawn up on the basis of the life history, social and family circumstances, and preferences (such as diet, sexuality and religion) of the person with dementia.	Number of people with dementia with registration of a care plan, including: Life history, social and family circumstances, preferences (diet, sexuality, religion).	Total number of people with dementia at service
Treatment of dementia always involves at all stages emphasising the unique qualities of the individual with dementia and recognising the patients' personal and social needs. The combination of different types of support, each tailored to the person and the situation is preferable over offering one type of support or a standard care package.	A. Number of people with dementia with registration of personal and social needs in care plan and/or medical record B. Number of people with dementia with registration of a personalized shared care plan between the informal carer and care professional	A. Total number of people with dementia at service B. Total number of dementia patients that are offered support at service
Identify specific needs, including those arising from: sensory impairment communication difficulties ill health	Number of people with dementia who receive a periodical needs assessment including: sensory impairment communication difficulties ill health	Total number of people with dementia at service
Care plans should address the activities of daily living (ADL) that maximise independent activity, enhance function, adapt and develop skills, and minimise need for support.	Number of people with dementia whose care plan includes both ADL and recreational, social, leisure and structured day activities.	Number of people with dementia at service

Activities should include recreational, social, leisure and structured day activities should be adjusted to ensure that they are achievable with the limitations the patient has.		
Healthcare professionals should be aware that many people with dementia can understand their diagnosis, receive information and be involved in decision making.	Number of people with dementia who have registered that diagnosis is discussed and that they were asked whether they wanted to hear explicit diagnosis and prognosis	Total number of people with dementia at service
Assess and monitor people with dementia for depressions and/or anxiety.	Number of people with dementia that are assessed periodically for depression and/or anxiety	Total number of people with dementia at service
People with dementia who develop non-cognitive symptoms that cause them significant distress or who develop challenging behaviour should be offered an assessment at an early opportunity to establish the factors likely to generate, aggravate or improve such behaviour. The assessment should include the person's physical health and behavioural and functional analysis conducted by professionals with specific skills, in conjunction with carers and care workers. The assessment should lead to an individually tailored care plan and the coordination of care should be documented and reviewed regularly. The frequency of the review	Number of people with dementia who show non-cognitive symptoms that cause them significant distress or who develop challenging behaviour that have a tailored care plan based on an assessment conducted by professionals including: • physical health • depression • undetected pain or discomfort • side effects of medication • individual biography, including beliefs, spiritual and cultural identity • psychosocial factors • physical environmental factors	Total number of people with dementia who show non-cognitive symptoms that cause them significant distress or who develop challenging behaviour at service

should be agreed by the carers and staff involved and documented.	specific behavioural and functional analysis. The frequency of review of the care plan is agreed on by the informal carers and staff involved and documented in the notes.	
Psychosocial interventions should be considered and should be tailored to the person's preferences, skills, and abilities. Monitors response and adapt the care plan as needed.	A. Number of people with dementia whose care plan says that they receive psychosocial interventions, tailored to the person's preferences, skills, and abilities. B. Number of people with dementia for whom a psychosocial intervention was instituted for behavioural problems before pharmacological treatment was started	A. Total number of people with dementia at service B. Total number of people with dementia at service, receiving pharmacological interventions for behavioural problems.
Care managers/coordinators should ensure that there is coordinated delivery of health and social care services, including a combined care plan, agreed by health and social services, that takes into account the changing needs of the person with dementia and the carers. A case manager, one or two assigned people who would maintain regular contact with the patient and the main caregiver should be involved in aiding patients with dementia and their caregivers.	Number of people with dementia who have an assigned professional who maintains regular contact with the patient and the main caregiver and ensures coordinated delivery of health and social care services	Number of people with dementia at service

5.11.2 Quality indicators for informal carers of people with dementia

Recommendation	Numerator	Denominator
Respite or short-break services should be available and include, for example, day-care, day and night sitting, adult placement and short-term and/or overnight residential care.	Number of carers of people with dementia for whom it is registered that respite or short-break care is offered to them	Total number of carers of people with dementia at service
Assess and monitor carers of people with dementia for anxiety and/or depression.	Number of carers of people with dementia that are periodically assessed for anxiety and/or depression	Total number of carers of people with dementia at service
Care plans for carers should include interventions tailored to carers' needs and preferences such as individual or group psycho-education and training courses about dementia, services and benefits, and dementia-care problem solving. The general practitioner and/or other professionals should inform the family and caregivers of the local situation.	Number of carers of people with dementia who are offered psychosocial interventions, tailored to their needs and preferences	Total number of carers of people with dementia

5.11.3 Quality indicators for formal carers of people with dementia

Recommendation	Numerator	Denominator
Health and social care managers should ensure that all staff working with older people in the health, social care and voluntary sectors have access to dementia-care training (skill development) that is consistent	Number of staff at care service/facility that receive specific dementia-care training at a regular basis, at least once a year	Number of staff at care service/facility

with their roles and responsibilities. This should include comprehensive training on interventions that are effective for people with dementia.		
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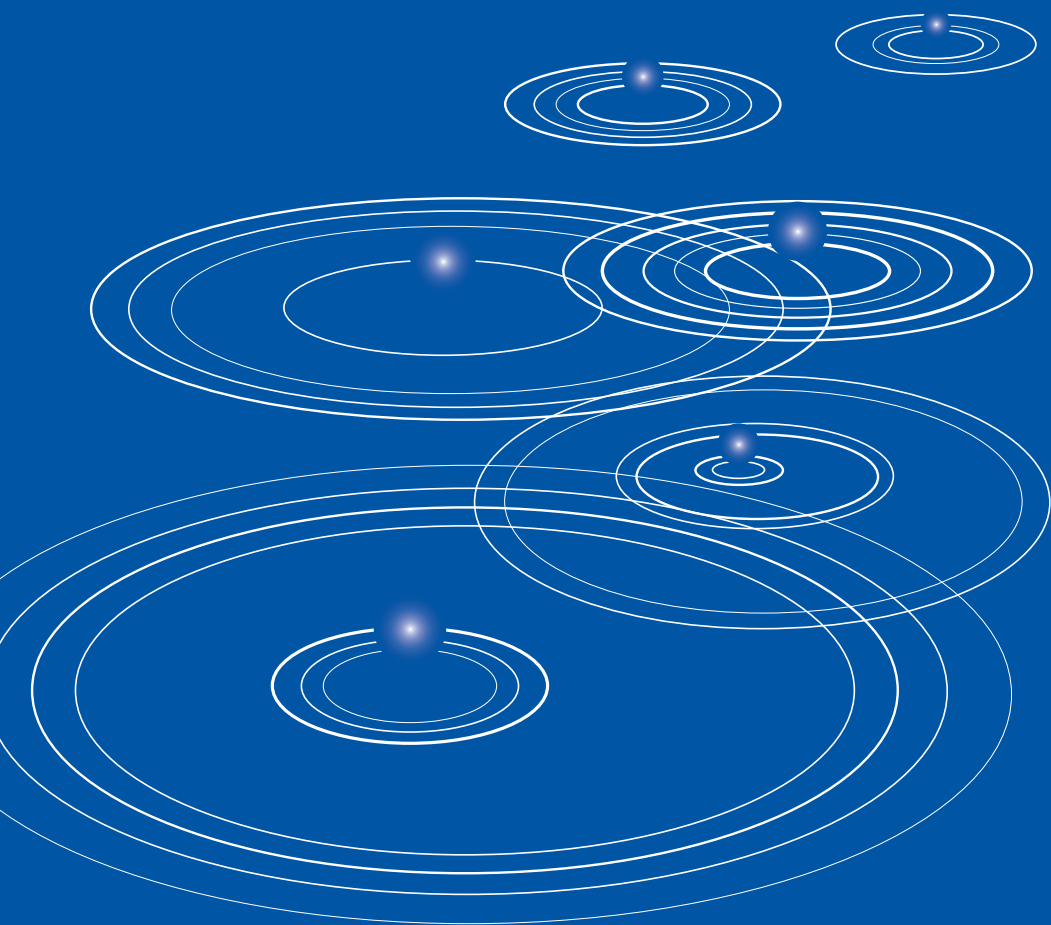
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*Risk factors
and prevention*

6.1 Introduction

Dementia is a complex condition. There is no single straightforward cause, and no way of definitely preventing it. No curative treatment is yet available. Thus extensive efforts for development of effective measures for prevention or risk management of this condition are needed. Identification of individuals at increased risk of dementia is a first precondition. Many factors influence an individual's risk of developing dementia. Some of these, such as age or genetics, cannot be changed. Nevertheless there are several factors related to lifestyle, such as physical activity, smoking, alcohol drinking or nutrition, as well as (cardio)vascular factors, which all modify the risk of dementia. These factors can be influenced by interventions, which in turn might delay the burden of dementia in a public health perspective. The aim of this project is to develop an inventory of recommendations for a healthy lifestyle to prevent dementia. A systematic review will form the basis of a description of risk factors of dementia.

6.2 *What are risk factors?*

A health-related risk factor is a statistical measure that describes our chances of something negative happening to us. The presence of 'risk factors' is associated with an increased chance that the disease will develop at all or will develop earlier. Risk factors are characteristics of a person (e.g. blood group) or environmental conditions (e.g. sunlight) which appear to have some relationship to the development of a disease. Other examples include exposures to a substance, family background or work history. Risks are measured by analysing large numbers of people, not individuals, so what is true for a large population may not be true for an individual.

Delaying the onset of Alzheimer's disease (AD) by 5 years would decrease its prevalence by 50%.

6.3 Cardiovascular risk factors

Recent epidemiological evidence suggests an association between AD and vascular risk factors such as arterial hypertension, diabetes mellitus, general atherosclerosis and arterial fibrillation. Control of vascular risk factors could prevent the development of dementia. Future dementia can be significantly predicted by high age (ffl47 years), low education (<10 years), hypertension, hypercholesterinemia and obesity.

There is an association of type 2 diabetes mellitus, hypertension, dyslipidaemia and obesity with dementia. Risk of dementia was generally largest in studies that measured these risk factors at midlife (compared to late life) and had a long follow-up time. At midlife, the population attributable risk of dementia among these cardiovascular risk factors was highest for hypertension. Later in life diabetes appears to convey the highest risk of dementia.

6.3.1 Hypertension

Hypertension has received a lot of attention because it may represent a common and potentially modifiable risk factor not only for cardiovascular and cerebrovascular disorders but also for AD. Long-term population-based follow-up studies have shown that high blood pressure (BP), especially at midlife, is associated with an increased AD risk later in life. Whether low BP accelerates the AD process after onset of the illness is still a matter of debate. Longstanding hypertension may lead to various changes in cerebral arteries and alters the autoregulation of blood flow to the brain. Under these conditions, episodes of hypotension may lead to hypoperfusion and ischemia in vulnerable brain areas. These brain changes may further impair cognition. Some observational studies indicated that antihypertensive medication, especially long-term treatment, may reduce the risk of dementia, including AD. As results are contradictory, more information especially about possible effects of treatment of hypertension at midlife is needed.

6.3.2 Cholesterol

High serum total cholesterol (TC) values at midlife increases the risk of late-life AD. Midlife TC has also been related to AD-type brain changes in autopsy studies. The role of high cholesterol later in life and closer to dementia onset is less clear, as some studies indicate either no association or an inverse association of hypercholesterolemia with subsequent AD development. Recent data suggest a bidirectional relationship between TC and dementia; high TC is a risk factor for subsequent AD 20 years later, but decreasing TC after midlife may reflect ongoing disease processes and may represent a risk marker for late-life dementia. Little information is currently available regarding other cholesterol types (LDL, HDL, triglycerides). The brain is the most cholesterol rich organ in the body, and disturbances in brain cholesterol metabolism have been linked with all the main neuropathological changes in AD.

Some experimental studies have shown that statins may reduce β -amyloid production in vitro and in vivo. The currently available epidemiological and clinical data on statins and AD give a rather mixed picture.

6.3.3 Diabetes mellitus and metabolic syndrome

Diabetes has been associated with an increased risk of AD in several cohort studies, while others have found no association. In elderly, the true prevalence of diabetes mellitus (DM) is over 30%, and more than half of them are asymptomatic and undiagnosed. In addition, more than 30% have impaired glucose tolerance, which makes more than half of elderly people affected with hyperglycemia. The potential biological mechanisms underlying the diabetes-AD association are many. Diabetes is associated with changes in cerebral microvessels and blood brain barrier (BBB). Some studies have indicated that higher insulin levels are associated with the risk of dementia/AD. Besides indicators of diabetes and metabolic syndrome, inflammatory markers e.g. high CRP levels have also been suggested as risk factors for cognitive decline and AD. There seems to be an association between HbA_{1c} level, (which is a marker of glucose control) and risk of developing mild cognitive impairment (MCI) or dementia in postmenopausal osteoporotic women primarily without diabetes. These findings support the hypothesis that glucose dysregulation is a predictor for cognitive impairment.

6.3.4 Overweight and Obesity

The National Institutes of Health (NIH) define overweight in terms of the body mass index (BMI). The BMI is a person's weight in kilograms (kg) divided by their height in metres (m) squared. Overweight is a BMI of 27.3% or more for women and 27.8% or more for men, while obesity is defined as a BMI of 30 and above, according to the NIH. The prevalence of overweight and obesity is more than 50% among adults in Europe and the United States. Obesity is increasing across the world, with severe consequences on cardiovascular health, but its association with the risk of AD has so far been less extensively studied. Weight loss seems to occur during the pre-clinical phases of dementia, and recent follow-up studies have suggested that low body mass index (BMI) could actually be an early sign of dementia. There is increasing evidence from long-term population-based studies that high BMI at midlife, or at late-life 9-18 years prior to dementia is associated with an increased AD risk. The prevention of overweight and obesity, even at greater ages, might be important for the prevention of dementia. Only a few studies have investigated the association between fat intake and the risk of dementia. It has been reported that high saturated fat and cholesterol intakes might be risk factors for Alzheimer disease, particularly among individuals carrying the apolipoprotein E ϵ 4 allele. Several studies have shown an association between higher intake of total calories and fats in elderly individuals without dementia and higher risk of Alzheimer's disease, particularly in carriers of the APOE ϵ 4 allele. Central obesity in midlife increases the risk

of dementia independent of diabetes and cardiovascular comorbidities. Fifty per cent of adults have central obesity; therefore, mechanisms linking central obesity to dementia need to be unveiled. There seems to be a J-shaped relationship between BMI and dementia, such as being overweight and being underweight increase the risk of dementia in late life.

In a Finnish study on obesity at midlife (BMI 30 kg/m^2) was associated with the risk of dementia and AD even after adjusting for possible confounding factors like sociodemographic status. Midlife obesity, high total cholesterol level, and high systolic blood pressure were all significant risk factors for dementia.

Obesity at midlife is associated with an increased risk of dementia and AD later in life. The role of weight reduction for the prevention of dementia needs to be further investigated.

6.4 Environmental/nutritional

6.4.1 Alcohol drinking

Cognitive impairment is frequently observed in heavy drinkers and visuomotor capacity, memory or abstract thinking is affected in those individuals. Excessive alcohol consumption can lead to alcohol-related brain damage and severe loss of short-term memory, and is responsible for alcoholic dementia, also named Korsakoff's syndrome. This disease is associated with the lack of vitamin B₁, frequently associated with malnutrition in heavy drinkers. It is assumed that light to moderate alcohol consumption may lower the risk of cognitive decline and dementia. The health benefit may be mediated by a protective effect against vascular disease, as moderate alcohol consumption lowers the risk of stroke as well as subclinical infarcts and white matter disease on brain imaging. Binge drinking in midlife is associated with an increased risk of dementia. There is evidence that risk of dementia increased with rising alcohol consumption for those people who carried the ApoE ϵ 4 allele. One possible explanation could be that individuals with the ϵ 4 allele have less effective neural repair mechanisms and thus would be more susceptible to the deleterious effects of alcohol. On the other hand, resveratrol, a polyphenol may partly be responsible for the beneficial effects of wine, especially of red wine. It has complex physiological effects via gene modulation: antioxidative, cytoprotective and anti-inflammatory. The impact of alcohol consumption on the incidence of MCI and its progression to dementia has been studied recently. Patients with MCI who were moderate drinkers, i.e. those who consumed less than 1 drink/day (approximately 15g of alcohol), had a lower rate of progression to dementia than abstainers.

There seems to be a J-shaped association between alcohol intake and a variety of adverse health outcomes, including coronary heart disease, diabetes, hypertension, congestive heart failure, stroke, dementia, Raynaud's phenomenon, and all-cause mortality. Light to moderate alcohol consumption (up to 1 drink daily for women and 1 or 2 drinks daily for men) is associated with cardioprotective benefits, whereas increasingly excessive consumption results in proportional worsening of outcomes. Other studies have shown that a history of heavy drinking or alcohol abuse might be associated with an increased occurrence of dementia and Alzheimer's disease.

There is insufficient evidence to promote alcohol to nondrinkers as a means of reducing dementia risk. As there is still debate whether the positive effects of moderate alcohol consumption are due to methodological artefacts, e.g. the fact that people who do not drink at all are more ill in general. Abstinent people might have deliberately stopped alcohol consumption due to severe chronic illness like past alcohol addiction.

6.4.2 Smoking

The interaction between smoking and dementia is complex. Smoking is a clear risk factor for cardiovascular disease and stroke. In prospective population-based cohort studies like the Rotterdam study, smoking was a risk factor for AD. Overall in this study, smoking doubled AD (relative risk 2.3). The risk was much higher in individuals without an APOE $\epsilon 4$ allele. A recent collaborative population-based study in Europe confirmed that smoking is associated with higher rates of cognitive decline in elderly subjects without dementia; higher cigarette-year consumption was correlated with a significantly higher rate of decline. Older family and case-control studies have found that smoking has a protective effect against developing Alzheimer's disease. In contrast, others have argued that the results reported by case-control studies were a consequence of survival bias rather than a true protective effect of smoking. Thus, any lower rates of Alzheimer's disease among smokers may have little or nothing to do with any protective quality of smoking. Interestingly, findings from several studies have shown that there is an increased risk of dementia and Alzheimer's disease associated with smoking in those without an APOE $\epsilon 4$ allele.

6.4.3 Mediterranean diet

Adherence to a so-called "Mediterranean diet", i.e. a diet containing more fish than (red) meat, more vegetables and fruit than carbohydrates and moderate amounts of wine, (MeDi) may affect not only risk for Alzheimer's disease (AD) but also subsequent disease course: Higher adherence to the MeDi is associated with lower mortality in AD. The gradual reduction in mortality risk for higher adherence to this diet suggests a possible dose-response effect.

6.4.4 W-3 fatty acids and fish intake

Elderly people who eat seafood or fish at least once a week are at lower risk of developing dementia. Daily consumption of fruit and vegetables was associated with a decreased risk of all cause dementia. Weekly consumption of fish seems to be associated with a reduced risk of all cause dementia but only among ApoE epsilon 4 non-carriers. Regular use of omega-3 rich oils seems to be associated with a decreased risk of borderline significance for all cause dementia. Regular consumption of omega-6 rich oils not compensated by consumption of omega-3 rich oils or fish seems to be associated with an increased risk of dementia among ApoE epsilon 4 non-carriers. Frequent consumption of fruit and vegetables, fish, and omega-3 rich oils may decrease the risk of dementia and Alzheimer's disease, especially among APOE $\epsilon 4$ non-carriers.

Although consumption of lean fried fish doesn't seem to have a protective effect, consumption of fatty fish more than twice per week is associated with a reduction in risk of dementia by 28% in comparison to those who eat fish less than once per month. This effect seems to be selective to those without the $\epsilon 4$ allele.

However, until data from randomised trials become available for analysis, there is no good evidence to support the use of dietary or supplemental omega 3 polyunsaturated fatty acids (PUFA) for the prevention of cognitive impairment or dementia.

6.4.5 Homocystein, Folate (Folic Acid) and Vitamin B12

Plasma total homocysteine has emerged as a major vascular risk factor. Homocysteine is a sulfur amino acid in the blood whose metabolism is closely related to that of the vitamins folate, B6, and B12. Too much of it can damage blood vessels and it has also been linked with dementia. Folate and other B vitamins, including vitamins B6 and B12 help process and lower levels of homocysteine. Fortified cereals, green leafy vegetables, orange juice, yeast extract and liver are all good sources of folate. There is evidence that having too little folate may contribute to the cognitive impairment of some older people's brains. This may result in reversible damage or possible increase in the risk of AD and vascular dementia. Low levels of folate and vitamin B12 might be related to an increased risk of Alzheimer's disease. The results from a prospective, observational study indicated that an increased plasma total homocysteine level is an independent risk factor for the development of dementia and AD. But there is no evidence currently that folate or vitamin B12 deficiency is associated with the neuropathologic hallmarks of AD. It is not yet known whether increasing your intake of folate either through diet or by taking supplements will reduce the risk of developing dementia.

6.4.6 Antioxidants/Vitamin C and E

One hypothesis that accounts for both the heterogeneous nature of AD and the fact that ageing is the most obvious risk factor is that free radicals are involved. The probability of this involvement is supported by the fact that neurons are extremely sensitive to attacks by destructive free radicals. Free radicals are a by-product that occurs when the body uses oxygen. They are harmful and can cause damage inside the cells of the body. Environmental factors such as cigarette smoke or pollution can increase the level of free radicals in the body. Antioxidants are the body's defence system against free radicals, as they mop up these destructive molecules. The danger from free radical damage increases with age. Some researchers think that the destructive effect of free radicals may be one of the causes of brain cell death in Alzheimer's disease. This has led to interest in whether increasing antioxidant intake through diet or vitamin supplements could provide any protection against Alzheimer's disease. It seems that patients taking vitamin E supplement might have a slower progression of AD than patients taking placebo. In studies, neither supplemental dietary nor total intake of carotens and vitamin C and E was associated with a decreased risk of AD. In the Honolulu-Asia Aging Study (HAAS), men had been followed for research purposes for more than 30 years. It showed that midlife dietary intake of beta-carotene, flavonoids, and vitamin E and C was not related to the incidence of dementia and its subtypes in late life. Others have investigated

the association between the intake of antioxidants from food and the risk of AD. The results from a population-based cohort study with a mean follow-up period of six years suggested that high intake of vitamin C and vitamin E from food might be associated with a lower incidence of Alzheimer's disease. They found that those who had the highest intake of vitamin E had a 43% lower risk of developing Alzheimer's disease compared with the people who had the lowest intake. There was a slight association between high intake of vitamin C and risk of Alzheimer's disease. The results from the Chicago Health and Aging project showed that those with the highest intake of vitamin E from food, but not from vitamin supplements, had a 70% lower risk of developing Alzheimer's disease. This reduced risk was only found in those people who did not have the ApoE ϵ 4 gene. Vitamin C did not seem to offer any protection.

6.5 *Biological risk factors (non modifiable)*

6.5.1 Ageing

Age is the most important known risk factor for AD. The risk of developing the disease doubles every five years over age 65. Dementia may occur at any age, although rarely below the age of 60. Although age is the most significant risk factor that we know about, dementia is not an inevitable part of ageing.

6.5.2 Family history of dementia

Some genetic risk factors have been identified so far, but only a small proportion of AD cases can be explained by specific gene mutations. The risk of dementia and AD has been shown to be increased among people with a family history of dementia, but contradictory results exist as well. Life table analyses have shown a cumulative risk of dementia to first-degree relatives of AD cases of approximately 50% by age 90, while relatives of purported control subjects had a much lower cumulative risk. Studies of AD among twin pairs over age 70 provide the strongest support for genetic causation. Monozygotic twin pairs show higher concordance rates for AD than dizygotic twin pairs

6.5.3 Genetic factors

Genes may be related to disease in two ways: through autosomal-dominant mutations, in themselves sufficient to cause the disease alternatively, gene variations (polymorphisms) may indirectly increase disease risk without being sufficient in themselves to cause the disorder. This latter group are referred to as susceptibility genes. Familial AD refers to small numbers of cases (at least 5% of all cases), in which there is a clear pattern of autosomal dominant inheritance. Such clear patterns usually are associated with an age of onset before 60 years of age. The disease usually starts in the 40s and 50s. These mutations have principally concerned early onset AD, and only explain a small proportion (less than 1%) of total cases. Some susceptibility genes are also currently being studied, of which polymorphisms of the apolipoprotein E gene have received the most attention, with earliest clinical reports suggesting it to be present in about 90% of late onset cases (which occur predominantly after 60 years old and do not have an apparent autosomal dominant mode of inheritance). Meta-analysis of recent epidemiological studies has shown that while ApoE $\epsilon 4$ is more common in all forms of AD than in controls, it is specifically related to the late onset rather than the early onset variant. ApoE $\epsilon 4$ is thus seen to be mostly strongly associated with late onset familial cases of AD. Having one copy of the ApoE $\epsilon 4$ gene increases a person's risk of developing AD by up to four times. Someone with two copies of ApoE $\epsilon 4$, one from each parent, has a 10 times greater risk and earlier age of onset than individuals who inherited one $\epsilon 4$ allele, but only about 2% of the population have two copies of $\epsilon 4$. The most common form of the gene is $\epsilon 3$. About 60% of the population have two copies of ApoE

$\epsilon 3$ and are at average risk, which means that about half will develop the disease by their late 80s. About one in six people has at least one copy of ApoE $\epsilon 2$. This form of the gene delays the onset and decreases the risk of AD. The lowest risk is for people who have two copies of ApoE $\epsilon 2$. It is important to recognise that this gene affects risk and is not a predictor of whether someone will develop AD. Although ApoE $\epsilon 4$ increases the risk of developing the disease it does not make it certain. Many people who develop AD do not have an ApoE $\epsilon 4$ gene, and some with the $\epsilon 4$ type do not develop the disease. It is now recognised that ApoE is not the 'cause' of AD, but rather an important link in a biological chain of events, AD itself appearing less like a single disease process and more the result of the failure of diverse neuronal compensatory and repair mechanisms to deal with multiple ageing-related aggressions. An interactive effect with ApoE in AD has now been demonstrated in relation to a number of other risk factors so that the ApoE $\epsilon 4$ carriers might be more vulnerable to various adverse environmental factors e.g. physical inactivity, saturated fat intake, alcohol drinking, diabetes, high BP and low B12/folate.

6.5.4 Gender

It has been suggested that the prevalence of AD is higher in women than in men. It is not clear whether this difference is due to biology, to the fact that women tend to live longer or to their behaviour. On the other hand, studies from provide evidence against a sex difference in the risk of AD. Vascular dementia is more common in men than women across all age groups. This may be because risk factors for vascular dementia, such as high blood pressure and heart disease, are more common in men. Overall, 66% of people with dementia are female. However, the proportion varies with age group: women account for only 37% of people with dementia between 65 and 69, but 79% of people with dementia aged 90 and above.

6.6 Behavioural factors

Regular and high intensity leisure time physical activities (e.g. dancing, walking) seem to reduce dementia risk. In a population-based study, leisure-time physical activity at midlife at least twice a week was associated with a reduced risk of dementia and AD.

A prospective cohort-study in the USA found that incidence rate of dementia was 13 per 1000 persons-year for participants who exercised 3+ times/week compared with 19.7 per 1000 persons-year for those who exercised fewer than 3 times/week. Risk reduction associated with exercise was greater in those with lower performance levels/ poorer physical functioning at baseline. Data from the Canadian Study of Health and Aging have associated regular physical activity (defined by a simple “yes/no” question) with a reduced risk of AD. The CAIDE study showed that regular leisure time physical activity at midlife may protect against dementia and AD later in life. The risk reduction was 50% for dementia and 60% for AD. Associations between increased activity and decreased risk seem to be more pronounced among the APOE 4 carriers. Regular physical activity may reduce the risk or delay the onset of dementia and AD, especially among genetically susceptible individuals. Social and mental activities have also been suggested to protect against AD. Generally, an active lifestyle may increase cognitive reserve capacity, reduce stress and thus protect against development or expression of dementia.

6.6.1 Cognitive activity/education

A higher level of education appears to reduce the risk for dementia. More frequent participation in cognitive activity is associated with reduced incidence of dementia. A cognitively inactive person seems to be more likely to develop AD than a cognitively active person. Frequent cognitive activity was also associated with reduced incidence of mild cognitive impairment and less rapid decline in cognitive function.

There even appears to be a dose-response relationship of education, each additional year of formal education further delays the time of accelerated cognitive decline.

6.6.2 Psychosocial activities

Living alone, having no close social ties, not participating in social and leisure activities and never having married seems to increase dementia risk. Recent studies have found that Alzheimer’s disease in particular is negatively associated with diversity of activities and intensity of intellectual activities and positively associated with psychosocial inactivity, unproductive working style, living with a dominant spouse and physical inactivity. A potential protective effect of the psychosocial network on dementia can be demonstrated in several studies. Multivariate analyses suggest an independent effect, especially of sports and cultural activities, and of the number of confidants. There seems to be a decreased risk for dementia for high challenge at work, high control possibilities at work, and high social demands at work.

Subjects with high leisure activity seem to have less risk of developing dementia. Reading, visiting friends or relatives, going to movies or restaurants, and walking for pleasure or going for an excursion seem to be most strongly associated with a reduced risk of incident dementia. In the Bronx Aging Study, leisure activities, reading, playing board games, playing musical instruments, and dancing were associated with a reduced risk of dementia.

A population-based study of Swedish twins suggests that greater complexity of work, and particularly complex work with people, may reduce the risk of AD. Several studies of the relationship between the psychosocial network or activity level and dementia have focused only on a short time span before the onset of clinical dementia.

These results point to a possible independent protection against dementia from social relationships and from physical and intellectual activities in midlife, possibly also in later life.

6.6.3 Depression

Cohort studies have yielded inconsistent results, with some indicating a statistically significant increased risk for AD with history of depression. Meta-analytic evaluation of depression and risk for AD concluded an elevated risk for dementia in people previously diagnosed with depression. History of depression, and particularly an early onset, but not presence of depressive symptoms increased the risk for AD. Interval between diagnoses of depression and AD was positively related to increased risk of developing AD, suggesting that rather than a prodrome, depression may be a risk factor for AD. To date, no evidence exists to answer the question whether early detection and successful treatment of depression in the elderly (or perhaps in younger people) reduce the risk for subsequent AD. Therefore, no clear guidelines can be given.

6.6.4 Stress

Measures of work-related stress (job dissatisfaction and high job demands) seem not to be associated with dementia risk many years later. Greater reactivity to stress seems to predict higher risk of dementia controlling for age, education, sex, occupational status, alcohol use, and smoking status. Looking at monozygote twins, co-twin control analyses also showed that dementia probands were more likely to report high reactivity to stress than their co-twins who did not have dementia. Overall, indicators of stress due to environment were not associated with dementia, whereas the individual characteristic of reactivity to stress predicted dementia risk. Distress proneness was also associated with more rapid cognitive decline. Whether psychotherapy that could lead to more stress tolerance could decrease risk in vulnerable individuals is not known.

6.7 Recommendations

From these risk and protective factors some recommendations regarding lifestyle and health behaviour appear plausible:

To do:

- Have good social ties with a number of confidants
- Have many diverse (= physical, mental and social) leisure activities.
- Have physical activity (three times a week or more, like walking, gardening, sports...)
- Eat a Mediterranean diet
- Eat fruit and vegetables regularly
- Eat fatty fish at least once a week
- Do cognitive training whilst still healthy
- Have challenging work and cognitive activity

To Avoid:

- heavy drinking, as well as binge drinking or alcohol abuse and addiction
- being overweight
- central obesity
- hypercholesterinamia
- saturated fat intake (try to reduce it)
- getting type 2 diabetes
- high blood pressure in mid life
- smoking
- depression (try to prevent it)
- working with pesticides

6.8 Intervention studies – rational and challenges

However, even if such recommendations appear plausible and substantiated by the epidemiological data, randomised controlled intervention trials (RCTs) are the gold standard and are required to prove the effect of an intervention aiming at these risk factors. The multifactorial and heterogeneous character of AD allows multiple prevention approaches, but its long preclinical phase makes prevention trials challenging. As many persons are affected, relatively small effects of an integrative intervention on common risk factors may have a huge impact on public health. Intervention studies integrating several different approaches have not been done for AD so far, and disappointing results of previous trials with single agents in elderly or already cognitively impaired persons (e.g. the Women Health Initiative Study with estrogen, NSAID trial, vitamin E in mild cognitive impairment (MCI) trial) point out some key issues:

- timing – starting earlier may lead to better effects;
- target group – a healthy, too young population will require very long follow-up times;
- large sample sizes and considerable financial resources;
- appropriate outcome measures - cognitive impairment may be better than ‘conversion’ to dementia.

Ethical issues need also to be carefully considered, since placebo-controlled trials for high BP or cholesterol are not possible because such treatments are known to protect against cardio/cerebrovascular diseases (e.g. Syst-Eur). These issues and need for preventive trials were also highlighted in the recent Guidelines for AD and other dementias by the European Medicines Agency (EMA) (<http://www.emea.europa.eu>).

Carefully designed and monitored RCTs are thus needed to clarify to what extent intervention will delay cognitive impairment among people with an increased dementia risk. These data will have a great scientific value and will be needed for health education and community planning.

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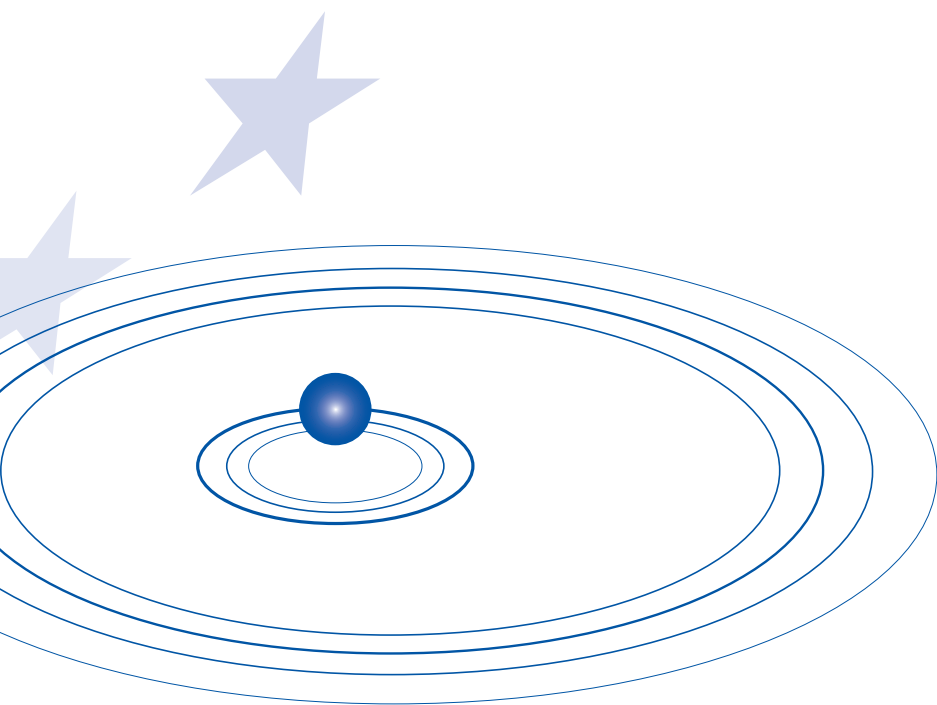
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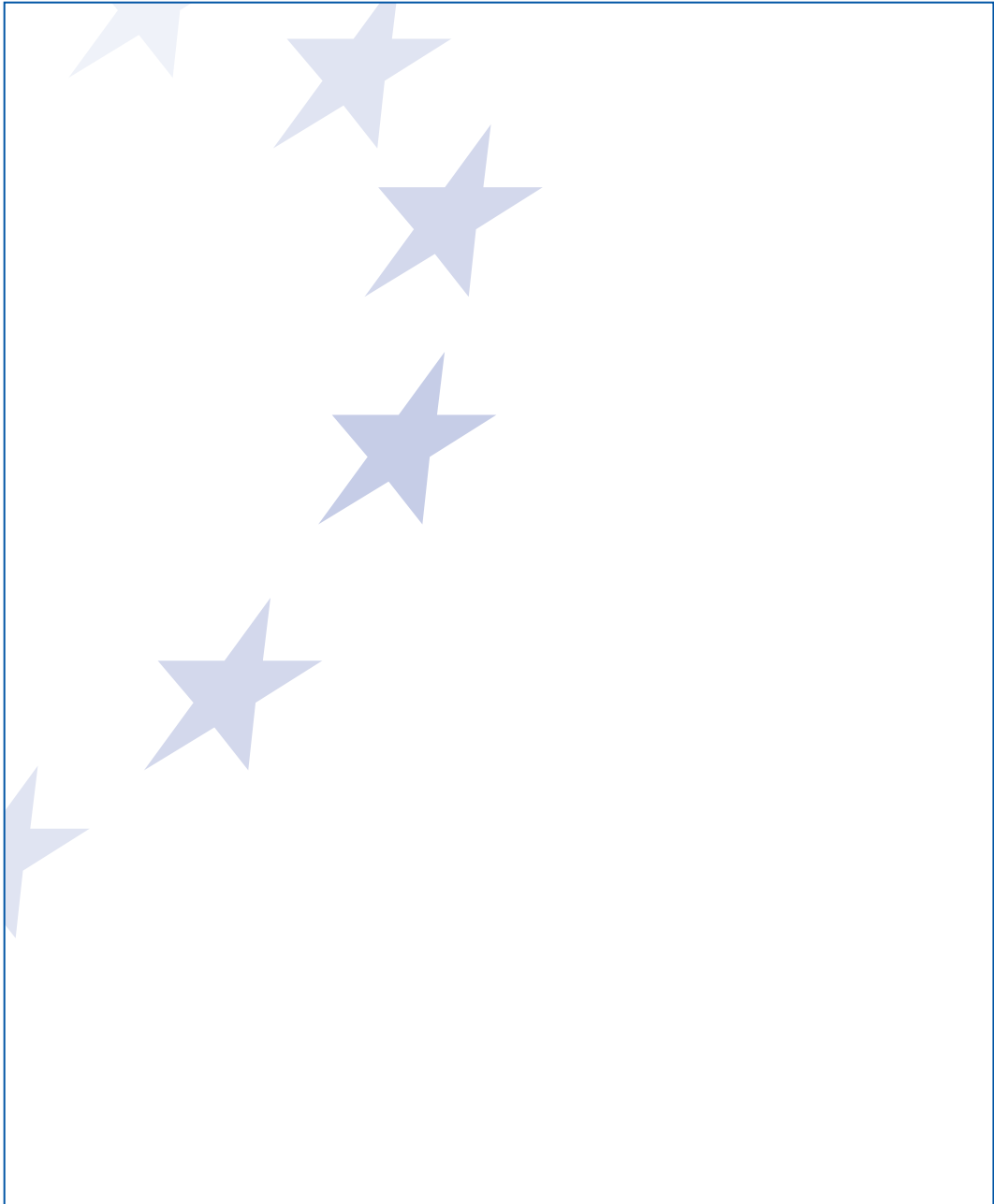
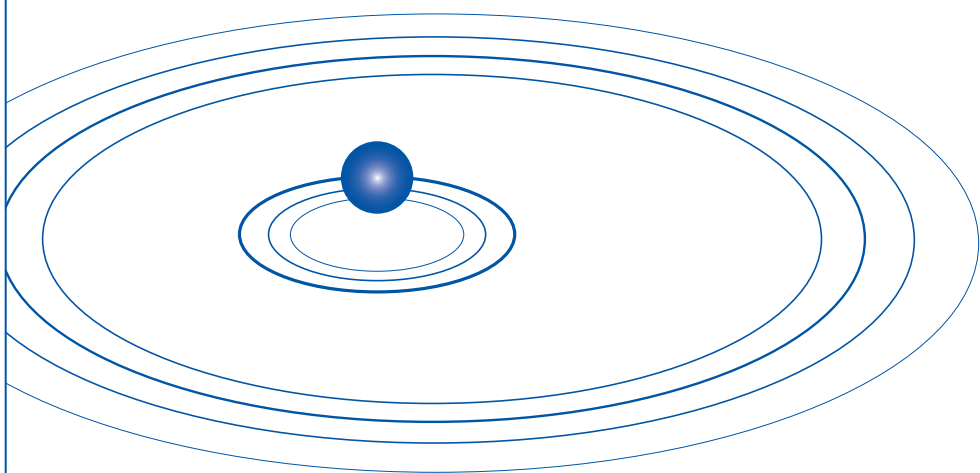


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Annual Report 2007

1.1 Preface



Alzheimer Europe adopted the Paris Declaration of the political priorities of the European Alzheimer movement at its Annual General Meeting in 2006. Little did we know then what an influence the document would have for the work of our organisation and what an impetus it would give to our campaign to make dementia a European priority.

The Declaration truly became a rallying point for our member organisations and it provided policy makers with an overview of the main challenges faced by people with dementia and their carers. We were delighted to see the creation of the European Alzheimer's Alliance in 2007, chaired with dedication, enthusiasm and energy by Ms. Françoise Grossetête, MEP from France and by the end of the year we were able

to count on the support of 30 Members of the European Parliament from different countries and different political backgrounds. Our cause truly transcends the traditional political and national borders.

We were also able to organise a week-long exhibition in the European Parliament and the turnout of Members of the European Parliament and representatives of other European institutions was very encouraging.

At our lunch debate in the European Parliament in November 2007, we received the clearest signal yet from all three main European institutions (European Commission, European Parliament and Council of Ministers) that our campaign to make dementia a European priority was making progress. We were delighted that Vladimir Spidla, European Commissioner for Employment, Social Affairs and Equal Opportunities gave a very warm welcome to our work. He highlighted the importance of using the open method of coordination to exchange best practices in this field and to include the impact of Alzheimer's disease in future policies for the elderly and health care planning.

Françoise Grossetête promised the backing of the European Parliament and announced that she would collaborate with her colleagues in order to dedicate a Written Declaration to the fight against Alzheimer's disease. Finally, the representative of the French Permanent Representation announced at the meeting that the French Presidency of the European Union would make dementia one of its priorities during the second half of 2008. These are important short-term goals to work towards.

As Chairperson of Alzheimer Europe, I am of course encouraged by this growing commitment to our cause by policy makers on a European level, but equally on a national level. The close collaboration between Alzheimer Europe and its national organisations was essential for the continued success of our campaign.

Apart from this political focus, Alzheimer Europe was also able to progress considerably on two further key projects, our Commission financed “European Collaboration on dementia – EuroCoDe” project and end-of-life care of people with dementia.

As in 2006, we were able to bring together researchers from different countries and different specialities as part of our EuroCoDe project. In 2007, the first results of the survey on social support systems was included in the second Dementia in Europe Yearbook and the other working groups of the project were equally productive in such different subjects as the prevalence, prevention, diagnosis, treatment and the psycho-social management of dementia, as well as the socio-economic impact of the disease. I am confident that the project will deliver even more interesting results for policy makers and researchers by the end of 2008.

End-of-life constituted another key priority for the organisation and we were able to bring together experts in the field from our organisations, as well as independent researchers. In 2007, the expert group met twice and Alzheimer Europe carried out an extensive literature search on this important subject with a view to producing recommendations to promote good quality end-of-life care.

I continue to be proud of the many achievements of Alzheimer Europe in 2007 and look forward with confidence to the coming years. I am grateful to the commitment of our small, but highly dedicated staff without whom it would not have been possible to look back on such a successful year.

Similarly, I would like to thank all our supporters and I would like to single out in particular the European Commission for the support of our EuroCoDe project, as well as our Luxembourg organisation for the secondment of our Executive Director and the use of our rent free offices in Luxembourg. I am particularly pleased that we were able to further increase the number of companies who supported us in 2007 and my thanks go to all of them: Janssen-Cilag, Pfizer, Lundbeck, GlaxoSmithKline, GE Healthcare, Novartis, Lilly, PhRMA, Wyeth, Numico and Merck Sharp & Dohme.

Maurice O’Connell
Chairperson

1.2 Executive Summary

In 2007, Alzheimer Europe:

- Continued to gather support for its Paris Declaration of the political priorities of the European Alzheimer movement and by the end of 2007 had collected signatures of 139 European and national policy makers, 48 organisations and 714 individuals,
- Created the European Alzheimer's Alliance chaired by Françoise Grossetête, MEP and supported by 30 Members of the European Parliament at the end of 2007,
- Organised a week-long exhibition on Alzheimer's disease in the European Parliament from 17 to 21 September 2007,
- Presented the second "Dementia in Europe Yearbook" focusing on the social support systems for people with dementia in 31 European countries at a lunch debate in the European Parliament on 6 November 2007 at which Vladimir Spidla, European Commissioner for Employment, Social Affairs and Equal Opportunities participated,
- Continued its participation at the meetings of the Management Board of the European Medicines Agency and its Working Party with Patient and Consumer Organisations,
- Attended the quarterly meetings of the NGOs affiliated to the Council of Europe,
- Organised a meeting with the government affairs of its national organisations to develop a European public affairs strategy,
- Welcomed Alzheimer Bulgaria as a provisional member of the organisation and continued to liaise with Alzheimer associations in Estonia, Hungary, Lithuania and Slovenia,
- Revisited its communication strategy and improved the information exchange with its national member organisations with monthly updates and quarterly e-mail newsletters,
- Saw its website continue to attract over 55,000 visitors every month,
- Organised, in collaboration with Alzheimer Portugal, a successful annual conference in Estoril attended by over 300 participants, as well as over 80 speakers from 25 different countries,
- Started updating the national reports on the legal rights of people with dementia in the Member States of the European Union,
- Responded to various European policy initiatives including the regulation on advance therapies, the Pharmaceutical Forum consultations on quality criteria and its diabetes information tool,
- Submitted its response to the consultation of the European Commission on information to patients,

- Joined the “Alliance for MRI”,
- Endorsed the policy statement of the European Patients’ Forum on animal research,
- Adopted a positive position on the use of supernumerary embryos in stem cell research,
- Called on governments to ratify the Hague Convention for the International Protection of Adults,
- Developed close working relations with the European Association of Geriatric Psychiatry, the European Alzheimer’s Disease Consortium and the Interdem network,
- Continued as an active member of the European Patients’ Forum,
- Set up an expert group on end-of-life care of people with dementia and carried out an extensive literature search on the subject,
- Carried out an extensive survey on the level of support available for people with dementia and their carers in 31 European countries,
- Coordinated the Commission funded project “European Collaboration on Dementia – EuroCoDe” resulting in 2007 in
 - o a comparative report on social support systems,
 - o an overview of guidelines on the diagnosis and treatment of dementia and
 - o an inventory of national guidelines on psycho-social interventions,
 - o a draft report on the socio-economic impact of dementia,
 - o a report on the current understanding of the risk and protective factors in dementia and
 - o an overview of European prevalence studies,

1.3 Our strategic objectives

The strategic plan of Alzheimer Europe provides a clear mission statement for the activities of the organisation and defines this mission as changing perceptions, policy and practice in order to improve the access by people with dementia and their carers to treatment options and care services.

The strategic plan furthermore defines six key objectives for the organisation: representing the interests of people with dementia and their carers, involving and supporting national Alzheimer associations, improving the information exchange between Alzheimer Europe, its members and European structures, promoting best practice through the development of comparative surveys, developing policy statements and developing strategic partnerships.

1.3.1 Making dementia a European priority and representing the interests of people with dementia and their carers

In 2006, Alzheimer Europe adopted the “Paris Declaration on the political priorities of the Alzheimer movement in Europe”. The document is a call for action to policy makers and was the main tool for Alzheimer Europe in 2007 to lobby European and national policy makers.

In 2007, Alzheimer Europe made great progress in representing the interests of people with dementia and their carers and in strengthening its contacts with different European institutions.

The Paris Declaration continued to gather support and at the end of 2007, 139 European and national policy makers, 48 organisations and 714 individuals has signed the Declaration. The campaign to European policy makers was coordinated with the national member organisations from the respective countries.

A special section on the Dementia in Europe website was dedicated to the Paris Declaration and its supporters.

The European Alzheimer’s Alliance was formally created in 2007 and its Bureau was established in July 2007 with Françoise Grossetête (France) as Chairperson and Brian Crowley (Ireland), Jolanta Dickute (Lithuania) and Joseph Muscat (Malta) as Vice-Chairpersons. The Alliance met on 4 September 2007 in Strasbourg and a second meeting took place in November 2007 together with a lunch debate which Alzheimer Europe organised on that occasion. By the end of 2007, some 30 Members of the European Parliament had given their support to the Alliance.

Alzheimer Europe also organised a week-long exhibition in the European Parliament from 17 to 21 September. During the launch of the exhibition on 18 September, Astrid Lulling, MEP said: “We are confronted with a veritable dementia epidemic,

with the numbers of people with Alzheimer's disease and other forms of dementia, expected to double or treble by 2050. As European policy makers, we support the urgent call of Alzheimer Europe to give dementia a higher priority on the European health and social agenda. We owe it to the 6.1. million Europeans living with Alzheimer's disease or another form of dementia, as well as their families to act now."

Françoise Grossetête, MEP (France), chairperson of the newly created European Alzheimer's Alliance continued: "Every 24 seconds a new case of dementia arises in Europe. We need increased research funding to understand the causes of Alzheimer's disease and to identify new and better ways of treating and preventing such diseases. If we were able to delay the onset of the disease by only 5 years, we would be able to significantly reduce the numbers of people with dementia and to ensure a better and longer quality of life of our citizens. I intend to dedicate a written declaration to Alzheimer's disease and already call on my colleagues in the European Parliament to give it their full support. I am delighted to see the initiatives currently undertaken by President Sarkozy in France to increase the funding for Alzheimer's disease. I will liaise very closely with my colleagues in France to ensure that dementia finds its rightful place in the plans of the French Presidency of the European Union in the second half of 2008."

During a lunch debate organised by Alzheimer Europe on 6 November 2007, representatives of different European institutions gave a clear signal that the fight against Alzheimer's disease and other forms of dementia would feature prominently in the plans of the European institutions in 2008.

Welcoming the launch of Alzheimer Europe's second "Dementia in Europe Yearbook" dedicated to a presentation of the social support provided by governments to people with Alzheimer's disease in different European countries, Vladimir Spidla, European Commissioner for Employment, Social Affairs and Equal Opportunities congratulated Alzheimer Europe on emphasising the social impact of Alzheimer's disease and other forms of dementia on people diagnosed, as well as on their families and carers. He stressed the need for improved training of medical and care professionals, as well as of family carers in order to improve the care and support of people with dementia. In particular, he highlighted the importance of using the open method of coordination to exchange best practices in this field and to include the impact of Alzheimer's disease in future policies for the elderly and health care planning.

Alzheimer Europe also continued to participate in the meetings of the Management Board of the European Medicines Agency as well as the Working Party with Patient and Consumer Organisations.

With the exception of the May meeting, which coincided with an Alzheimer Europe Board meeting, representatives of the organisation attended all the quarterly meetings of the NGOs affiliated to the Council of Europe.

1.3.2 Involving and supporting national Alzheimer associations

In order to better involve national organisations in its campaign, Alzheimer Europe organised a meeting with public affairs and government affairs representatives of its national member organisations. The meeting served to provide the national delegates with in-depth information on the functioning of the European institutions and to involve them in the development of a European public affairs strategy.

Similarly, Alzheimer Europe actively involved its member organisations in the definition of its various policy statements.

In 2007, Alzheimer Europe also continued to liaise with Alzheimer associations in Estonia, Hungary, Lithuania and Slovenia which are currently not members of the organisation. At the Annual General Meeting, a second organisation from Bulgaria was accepted as a provisional member.

1.3.3 Improving the information exchange between AE, its members and European structures

In 2007, Alzheimer Europe revisited its communication strategy and improved the information it provides to its national member organisations on relevant scientific breakthroughs and on interesting policy developments. The organisation continued sending out monthly updates on its activities, as well as quarterly e-mail newsletters.

The Alzheimer Europe website continues to be a useful source of information for people interested in finding out more about Alzheimer Europe and the care and treatment of people with dementia. As in 2006, the number of visitors remained high with, on average, over 50,000 persons visiting the Alzheimer Europe website every month.

Month	Visitors 2007	Visitors 2006
January	52,697	35,545
February	45,806	39,671
March	53,640	66,306
April	45,759	82,362
May	57,415	81,633
June	66,606	49,577
July	75,573	53,859
August	67,719	33,449
September	49,676	45,370
October	50,433	40,821
November	47,373	44,779
December	57,401	46,601
TOTAL	670,098	619,973
Average	55,841	51,664

The Estoril Conference from 9 to 12 May constituted an ideal opportunity to disseminate the political priorities of Alzheimer Europe contained in the Paris Declaration. The three-day conference was attended by close to 300 delegates from all across Europe.

Over 80 speakers from 25 different countries shared their knowledge and experience in dementia care, awareness raising and political advocacy.

Entitled “The sound of silence”, the conference was a reminder about the social exclusion which may still result from a diagnosis of dementia and the stigma attached to the disease in various European countries. The conference therefore made an impassioned call to policy makers to give a voice and listen to people with dementia and their carers.

At the closing ceremony of the conference, invited policy makers gave their backing to the Paris Declaration of Alzheimer Europe which was signed by Jose Nunes Liberato, the Chief of Staff of the President of the Portuguese Republic, Carlos Coelho, MEP, Joao Semedo, Member of the Portuguese Parliament, Jorge Coelho, Member of the State Council and Antonio Capucho, Mayor of Caiscais.

1.3.4 Promoting best practice through the development of comparative surveys

In 2007, Alzheimer Europe continued with its survey on the support available for people with dementia and their carers from the different national governments in the European countries covered by the membership of the organisation. This “social Lawnet” constituted a major priority for the organisation. The results of this study also formed an integral part of the organisation’s contribution to the EuroCoDe project.

Alzheimer Europe also continued the work commenced with its Lawnet projects and started updating some of the national reports on the legal rights of people with dementia and their carers.

1.3.5 Developing policy statements

Alzheimer Europe continued to be active on a number of different policy issues.

The organisation continued to respond to various European policy initiatives such as the regulation on advance therapies, the Pharmaceutical Forum consultations on quality criteria for health-related information and its Diabetes Information Tool.

In June, Alzheimer Europe submitted its response to the consultation of the European Commission on information to patients. In its contribution, the organisation highlighted the role that patient organisations in general and Alzheimer associations in particular can and should play in providing high quality information to patients and to people with dementia and their carers. The organisation also reiterated its opposition to direct to consumer advertising of medicines to the general public, but stressed that individual patients wanting to access information on medicines from the pharmaceutical industry should have a right to do so.

Within the context of the Portuguese Presidency Roundtable on Health Strategies in Europe, Alzheimer Europe sent a contribution highlighting the importance of including Alzheimer's disease and other forms of dementia into a European strategy and called upon the European Commission to devise a Dementia Plan and to create a High Level Group on Dementia.

Also, Alzheimer Europe joined the "Alliance for MRI" and called upon European institutions to exclude MRI technologies from the scope of the Physical Agents Directive.

With regard to animal research, Alzheimer Europe endorsed the policy statement of the European Patients' Forum which called for increased investment into alternatives to the use of animals in research while at the same time recognising the need of their continued use in medical research under strict conditions.

Alzheimer Europe also supported a call initiated by the European Federation of Unpaid Parents and Carers to call on European institutions to carry out a study on non-remunerated work (including that of carers).

But the organisation did not limit itself to policy issues covered by the European institutions. Thus Alzheimer Europe also gave its backing to the Hague Convention for the International Protection of Adults and called on European countries to ratify this legal framework for the mutual recognition of guardianship measures.

Finally, after a thorough consultation of its member organisations, Alzheimer Europe adopted a positive position on the use of supernumerary embryos in stem cell research.

1.3.6 Developing strategic partnerships

The development of strategic partnerships continued in 2007. Thanks to the EuroCoDe project, it was possible for Alzheimer Europe to develop closer ties with organisations such as the European Association of Geriatric Psychiatry, the European Alzheimer's Disease Consortium and the Interdem network.

As in previous years, Alzheimer Europe continued as an active member of the European Patients' Forum and its Executive Director served on the Executive of the organisation.

Alzheimer Europe also collaborated with the "Alliance for Health and the Future" in the publication of a report on the intergenerational aspects of dementia entitled: "Dementia in your family" which resulted from a workshop attended by representatives of the two organisations.

1.4 Alzheimer Europe Projects

1.4.1 End-of-life care

End-of-life care was identified as a major challenge by all member associations when Alzheimer Europe first developed its previous business plan. Unfortunately, apart from dedicating a workshop to the issue at the AE conference in Paris, little progress was achieved in this area. For this reason, it was proposed to make end-of-life issues a central preoccupation for the organisation in 2007.

As with previous business plan programmes, a working group was set up comprised of representatives of interested Alzheimer associations and other specialists with relevant expertise in the area. This working group met twice in 2007 and advised the Information Officer in developing a report on end-of-life care.

1.4.2 Social Lawnet

A thorough analysis of the social support provided by governments and other authorities was carried out in 2007. Alzheimer Europe gathered information on relevant legislation about the financing and organisation of care of people with dementia.

A survey revealed the level of support available for people with dementia and their carers to access care services (home care, day care, residential care, respite care) but also the direct support received by carers (care allowances and other benefits). Another aspect that was looked at was labour legislation (paid leave or time off to care, consideration of years cared for pension purposes) of relevance to carers of people with dementia.

This allowed a comparison of the situation of people with dementia and their carers in the different European countries and the identification of good practices best suited for the specific needs of people with dementia and their carers.

The information was included in the 2007 Year Book, with comparative information included in the European section, as well as more detailed information in the sections covering the different European countries.

EU Commissioner Vladimir Spidla, the European Parliament Social Affairs Committee Chair Jan Andersson and Portuguese Social Affairs Minister and President of the Council of Ministers José António Vieira da Silva contributed forewords to the 2007 Yearbook.

1.4.3 European Collaboration on Dementia

2007 constituted an important year for the Commission funded project “European Collaboration on Dementia – EuroCoDe”.

The project brings together a wide range of actors and centres such as:

- Alzheimer’s Disease International, European Alzheimer’s Disease Consortium, European Association of Geriatric Psychiatry, European Federation of Neurological Societies, Interdem, International Association of Gerontology – European Region and North Sea Dementia Research Group in the Steering Committee of the project,
- University of Stirling and the Alzheimer associations of Finland, Germany, Portugal and Romania in the work package on social support systems,
- Cochrane Dementia and Cognitive Improvement Group at the University of Oxford, University Medical Centre of Amsterdam, National Institute of Psychiatry (Budapest), the Heinrich-Heine Universität and the University La Sapienza of Rome in the work package on diagnosis and treatment,
- University Medical Centre St. Radboud, University of Hull, University of Wales (Bangor), Hôpital Broca and Fundación Intrás in the work package on psycho-social interventions,
- European Alzheimer’s Disease Consortium at the University Hospital of Toulouse, Technische Universität München, Wrocław Medical University and Karolinska Institutet in the work package on prevalence,
- Karolinska Institutet, London School of Economics, Corvinus University (Budapest), European Health Economics and University of Kuopio in the work package on the socio-economic cost of dementia,
- Central Institute for Mental Health – Mannheim, University of Maastricht, Alzheimer Scotland – Action on Dementia, University of Debrecen and Karolinska Institutet in the work package on prevention and risk factors.

In 2007, the project resulted in:

- A comparative report on the level of social support provided to people with dementia and their carers in Europe
- An overview of International, European and national guidelines on the diagnosis and treatment of dementia
- An inventory of national guidelines on psycho-social interventions and European indicators on such interventions
- An overview of European prevalence studies
- A draft report on the socio-economic impact of dementia

- A report on the current understanding of the risk and protective factors in dementia.

Alzheimer Europe also developed a web interface which will allow the interactive development of a guideline database and the comparison of different guidelines.

1.5 Annex 1: Meetings attended by AE representatives

Date	Place	Meeting
11 January	Brussels, Belgium	Meeting with European Federation of Unpaid Parents and Carers at Home (FEFAF)
15 January	Brussels, Belgium	Meeting with PhRMA
15 January	Brussels, Belgium	Meeting with Fondation Roi Baudouin
23 January	Brussels, Belgium	European Parliament Launch of Cervical Cancer Week
24 January	Brussels, Belgium	Centre for New Europe lunch on information to patients
25-26 January	Basel, Switzerland	EGAN/Roche workshop on clinical trials registries
29 January	Brussels, Belgium	Executive meeting of European Patients' Forum
30-31 January	Strasbourg, France	Council of Europe NGO meeting
1-2 February	Vienna, Austria	Lundbeck symposium
12 February	Brussels, Belgium	EFPIA think tank with patient organisations
15 February	London, UK	Training session for patient organisations involved in EMEA activities
16 February	London, UK	EMA Working Group with Patient Organisations
22 February	Lisbon, Portugal	Meeting with Alzheimer Portugal
25 February	Brussels, Belgium	AE Board
26 February	Brussels, Belgium	EuroCoDe – Meeting of Working Groups
2 March	Luxembourg, Luxembourg	Meeting with Alzheimer's Disease International
7-8 March	London, UK	EMA Management Board
8 March	Brussels, Belgium	European Parliament seminar "1957-2007: Women who built Europe"
8 March	London, UK	Meeting with GE Healthcare

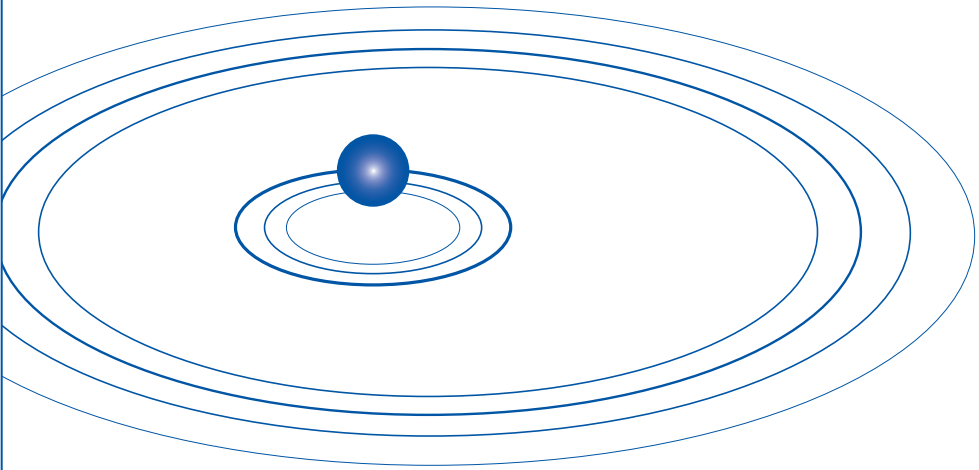
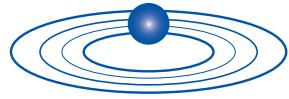
19-20 March	Brussels, Belgium	European Voice Conference: "Healthcare 2007 – Diagnosing our Future"
20 March	Brussels, Belgium	Executive meeting of European Patients' Forum
20-21 March	Brussels, Belgium	European Patients' Forum Conference: "The empowered patient"
20 March	Brussels, Belgium	Meeting with PhRMA
22 March	London, UK	Workshop on Eurogenguide project
23 March	Luxembourg, Luxembourg	Meeting with Luxembourg Association of Neurologists
26 March	Göttingen, Germany	Meeting with European Alzheimer's Disease Consortium
26 March	Göttingen, Germany	Meeting with European Association of Geriatric Psychiatry
26 March	Göttingen, Germany	Meeting with German Competence Network Dementia
3-4 April	Brussels, Belgium	Working group of European Patients' Forum
11 April	Brussels, Belgium	Meeting with conference organisers for 2009 AE Conference
16 April	Brussels, Belgium	Meeting with Marie Panayotopoulos, MEP (Greece)
18 April	Strasbourg, France	Council of Europe NGO meeting
20 April	Paris, France	GlaxoSmithKline meeting on APOE and genetic testing in Alzheimer's disease
2 May	Brussels, Belgium	CHES Meeting on information to patients
8 May	Estoril, Portugal	Steering Committee Meeting of European Collaboration on Dementia
9 May	Estoril, Portugal	Alzheimer Europe Board meeting
9 May	Estoril, Portugal	Alzheimer Europe Annual General Meeting
9-11 May	Estoril, Portugal	17th Alzheimer Europe Conference

10 May	Estoril, Portugal	Meeting with Wyeth Europe
10 May	Estoril, Portugal	Meeting with Numico
11 May	Estoril, Portugal	Meeting with GlaxoSmith-Kline
14 May	Brussels, Belgium	European Parliament meeting on counterfeit medicines
15 May	Brussels, Belgium	Meeting with Bernadette Bourzai, MEP
15-16 May	New York, USA	Pfizer meeting on health outcomes for future Alzheimer treatments
23 May	Brussels, Belgium	European Commission stakeholders meeting "Healthy Democracy"
25 May	Copenhagen, Denmark	Meeting with Lundbeck
31 May-1 June	London, United Kingdom	EMA Working Party with Patient and Consumer Organisations
1 June	Brussels, Belgium	EFPIA conference on "Medicines research, driving Europe's health"
5 June	Luxembourg, Luxembourg	Meeting with Ligue Alzheimer, Belgium
5 June	Brussels, Belgium	EPF Meeting on Information to patients
6 June	Brussels, Belgium	Meeting with Nathalie Griesbeck, MEP
7 June	London, United Kingdom	EMA Management Board
7 June	Brussels, Belgium	European Men's Health Forum
8 June	Brussels, Belgium	Executive of the European Patients' Forum
9-10 June	Brussels, Belgium	General Assembly of the European Patients' Forum
12 June	Brussels, Belgium	European Parliament debate on the relationship between patient organisations and the pharmaceutical industry
12 June	Brussels, Belgium	Launch of European Parliament Carers' Interest Group
13 June	Brussels, Belgium	Meeting with European Society of Radiology

14 June	Brussels, Belgium	European Parliament meeting on Citizens' mobility
19 June	Luxembourg, Luxembourg	European Commission Task Force on Chronic Conditions
26 June	Strasbourg, France	Council of Europe NGO meeting
7 July	Brussels, Belgium	Alzheimer Café
12-15 July	Milwaukee, USA	Alzheimer's University of Alzheimer's Disease International
18 July	Brussels, Belgium	Meeting with Françoise Grossetête, MEP
24 July	Luxembourg, Luxembourg	Meeting with Ligue Alzheimer
15 August	Luxembourg, Luxembourg	Meeting with GlaxoSmith-Kline
27 August	Brussels, Belgium	Meeting with Myriad Pharmaceuticals
27 August	Brussels, Belgium	Meeting with Pfizer
5 September	Strasbourg, France	Launch of European Alzheimer's Alliance
10 September	Brussels, Belgium	EFPIA think tank
12 September	Libramont, Belgium	Participation in press conference of Ligue Alzheimer
12 September	Brussels, Belgium	Executive of European Patients' Forum
13 September	Brussels, Belgium	Joint meeting of European Patients' Forum and Standing Committee of European Doctors
17-21 September	Brussels, Belgium	European Parliament Exhibition "Making dementia a European priority"
17 September	Brussels, Belgium	Alzheimer Europe Board Meeting
18 September	Brussels, Belgium	Meeting with Alzheimer Europe Sponsors
19 September	Brussels, Belgium	Meeting with Pfizer
21 September	London, United Kingdom	EMA Working Party with Patient and Consumer Organisations
25 September	Pau, France	20th anniversary meeting of Béarn Alzheimer

2 October	Brussels, Belgium	Meeting with Lilly
10 October	Brussels, Belgium	Meeting with Eurocarers
10 October	Brussels, Belgium	“Rendez-vous des européens” on information to patients
10-13 October	Caracas, Venezuela	Annual Conference of Alzheimer’s Disease International
16 October	Luxembourg, Luxembourg	Meeting with Lilly
17 October	Paris, France	Symposium on “Alzheimer’s disease, towards a public private partnership”
3 November	Brussels, Belgium	Alzheimer Europe Palliative Care Expert Meeting
6 November	Brussels, Belgium	Alzheimer Europe Public Affairs Meeting
6 November	Brussels, Belgium	AE European Parliament Lunch
6 November	Brussels, Belgium	“Alzheimer’s and driving” conference
8-10 November	Budapest, Hungary	Vascular Dementia Conference
9 November	Brussels, Belgium	EFPIA workshop on “Working with the media”
11 November	Brussels, Belgium	Alzheimer Europe Board
12 November	Brussels, Belgium	EUROCODE – Working Groups
22 November	Brussels, Belgium	Forum on nutrition in care homes and home care
24-25 November	Amsterdam, Netherlands	European Multiple Sclerosis Platform Conference
26-28 November	Brussels, Belgium	Autumn Conference of European Patients’ Forum
28 November	Luxembourg, Luxembourg	Meeting with Lundbeck
28 November	Brussels, Belgium	Meeting with Katalin Levai, MEP
29 November	Brussels, Belgium	EPPOSI conference “Shaping the future of healthcare in Europe – How?”
3-4 December	Strasbourg, France	Meeting on “Predictivity, genetic testing and insurance” of the Steering committee for Bioethics of the Council of Europe

3 December	Brussels, Belgium	Meeting with Dorette Corbey, MEP
4 December	Brussels, Belgium	European Homecare Conference
6 December	Brussels, Belgium	Life Science Circle Meeting
7 December	London, United Kingdom	EMA Working Party with Patient Organisations
10 December	Brussels, Belgium	Meeting with Parliament Magazine
13 December	London, United Kingdom	EMA Management Board
20 December	Strasbourg	Council of Europe NGO meeting



Financial Report

2.1 Report of the independent auditor



ALZHEIMER EUROPE **Association sans but lucratif**

Report of the réviseur d'entreprises
and
annual accounts as at December 31, 2007

To the Board of Directors
ALZHEIMER EUROPE
Association sans but lucratif

LUXEMBOURG

REPORT OF THE REVISEUR D'ENTREPRISES

Report on the annual accounts

We have audited the accompanying annual accounts of **ALZHEIMER EUROPE**, which comprise the balance sheet as at December 31, 2007 and the profit and loss account for the year then ended.

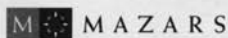
Board of directors' responsibility for the annual accounts

The board of directors is responsible for the preparation and fair presentation of these annual accounts in accordance with Luxembourg legal and regulatory requirements relating to the preparation of the annual accounts. This responsibility includes: designing, implementing and maintaining internal control relevant to the preparation and fair presentation of annual accounts that are free from material misstatement, whether due to fraud or error; selecting and applying appropriate accounting policies; and making accounting estimates that are reasonable in the circumstances.

Responsibility of the réviseur d'entreprises

Our responsibility is to express an opinion on these annual accounts based on our audit. We conducted our audit in accordance with International Standards on Auditing as adopted by the Institut des réviseurs d'entreprises. Those standards require that we comply with ethical requirements and plan and perform the audit to obtain reasonable assurance whether the annual accounts are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the annual accounts. The procedures selected depend on the judgement of the réviseur d'entreprises, including the assessment of the risks of material misstatement of the annual accounts, whether due to fraud or error. In making those risk assessments, the réviseur d'entreprises considers internal control relevant to the entity's preparation and fair presentation of the annual accounts in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control.



An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates made by the board of directors, as well as evaluating the overall presentation of the annual accounts.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Opinion

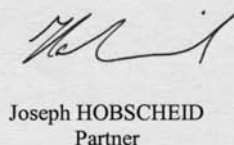
In our opinion, the annual accounts give a true and fair view of the financial position of **ALZHEIMER EUROPE** as of December 31, 2007, and of the results of its operations for the year then ended in accordance with the Luxembourg legal and regulatory requirements relating to the preparation of the annual accounts.

Luxembourg, May 21, 2008

For MAZARS, Réviseurs d'entreprises



Philippe SLENDZAK
Partner



Joseph HOBSCHEID
Partner

Appendix:

- balance sheet as of December 31, 2007
- profit and loss account for the year ended December 31, 2007

2.2 Balance sheet as of December 31, 2007

ALZHEIMER EUROPE

Balance sheet as of December 31, 2007

	<u>2007</u>	<u>2006</u>
	<u>EUR</u>	<u>EUR</u>
ASSETS		
Current assets		
Debtor EU Commission - Eurocode	59.480	-
Other debtors	37.314	10.229
Advance payments - Eurocode partners	27.199	51.254
Cash at bank and on deposit	<u>159.103</u>	<u>141.014</u>
	283.096	202.498
Accruals	472	354
Total Assets	<u><u>283.568</u></u>	<u><u>202.852</u></u>
LIABILITIES		
Capital and reserves		
Results brought forward	90.170	73.446
Result of the year	<u>16.588</u>	<u>16.724</u>
	106.758	90.170
Creditors		
Payments received on account - EU Commission - Eurocode	-	19.644
Payments received on account - Other	86.672	45.557
Trade creditors	5.752	15.660
Creditors - Eurocode partners	77.436	21.248
Other liabilities	<u>6.950</u>	<u>10.573</u>
	176.810	112.682
Total Liabilities	<u><u>283.568</u></u>	<u><u>202.852</u></u>

2.3 Profit and loss account – Year ended December 31, 2007

ALZHEIMER EUROPE

Profit and loss account Year ended December 31, 2007

	<u>2007</u> <u>EUR</u>	<u>2006</u> <u>EUR</u>
Other operating income		
Sponsorship	266.964	183.176
Sponsorship received on account	-74.972	-45.557
EU Subsidy	84.481	78.631
Co-financing in kind	89.409	92.342
Membership fees	47.125	41.250
Donations	531	57
Publication sales and royalties	4.253	7.059
Internet services	3.120	5.815
Project participation	16.436	24.325
Other operating income	12.598	6.120
Alzheimer Europe Conference	43.640	58.597
Eurocode Partner Income	303.036	265.452
External charges		
External experts	-138.356	-125.525
Publication and information material	-37.309	-29.629
Travel expenses	-22.554	-27.091
Communication costs	-32.411	-19.473
Accommodation expenses	-38.109	-28.773
Office rent and associated costs	-24.962	-22.291
Office stationary and related costs	-1.976	-2.470
Leasing	-16.051	-8.362
Membership fees	-1.670	-750
Other costs	-2.007	-6.941
Irrecoverable debt	-1.000	-
Alzheimer Europe Conference	-37.349	-53.558
Eurocode Partner expenses	-303.036	-265.452
Staff costs		
Wages and salaries	-97.907	-85.491
Social security costs	-27.424	-23.324
Interest receivable and similar income	3.420	974
Interest payable and similar charges	-1.332	-2.387
	<u>16.588</u>	<u>16.724</u>

2.4 Annex 1: Acknowledgements

2.4.1 Support from organisations and foundations

Alzheimer Europe is grateful to Association Luxembourg Alzheimer and the Luxembourg Ministry for Family for the secondment of the Executive Director of Alzheimer Europe and the office space they make available to the organisation free of charge.

Alzheimer Europe gratefully acknowledges the generous contribution of Fondation Médéric Alzheimer to the EuroCoDe project and the support of Mazars who carried out the audit of the organisation's financial accounts free of charge.

2.4.2 Support from corporate sponsors

In 2007, Alzheimer Europe had an audited income of €875,012. Sponsorship by the pharmaceutical industry and other corporate sponsors amounted to €221,407 or 25.31%.

The following table lists sponsorship and donations received by individual companies, as well as other payments, such as speakers' fees, honoraria and support for travel and subsistence costs. The global support received from individual companies is also presented in terms of percentages of the overall income of the organisation in line with the policy of the European Medicines Agency on transparency requirements for accredited patients' organisations.

Company	Sponsorship and donations	Honoraria and travel support	TOTAL (2007)	% of AE income (2007)	TOTAL (2006)	% of AE income (2006)
Janssen-Cilag	€40,000		€40,000	4.57%	€40,000	5.24%
Pfizer	€35,000	€4,620	€39,620	4.53%	€36,361	4.76%
Lundbeck	€30,000	€4,985	€34,985	4.00%	€42,224	5.53%
GlaxoSmithKline	€25,000	€2,107	€27,107	3.10%	€26,300	3.44%
Novartis	€20,000		€20,000	2.29%	€16,723	2.19%
Lilly	€10,000		€10,000	1.14%		
PhRMA	€10,000		€10,000	1.14%		
Wyeth	€8,300		€8,300	0.95%		
Merck Sharp & Dohme	€5,000		€5,000	0.57%	€7,891	1.03%
Roche		€881	€881	0.10%	€319	0.04%
EFPIA		€64	€64	0.00%	€744	0.10%
APIFARMA					€1,529	0.20%
Drug Information Association					€158	0.02%
Sub-total: Support by the pharmaceutical industry			€195,957	22.40%	€172,249	22.55%
GE Healthcare	€20,000	€450	€20,450	2.34%	€927	0.12%
Numico	€5,000		€5,000	0.57%	€10,000	1.31%
Sub-total: Support by other corporate sponsors			€25,450	2.91%	€10,927	1.43%
Total: Support by corporate sponsors			€221,407	25.31%	€183,176	23.98%

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The Dementia in Europe Yearbook 2008 presents the results of four of the six working groups involved in the EC-funded European Collaboration on Dementia (EuroCoDe) project, as well as Alzheimer Europe's Annual Report for 2007. The book provides a summary of the work carried out in the fields of social support, the socio-economic impact of dementia, psychosocial interventions and risk factors and prevention by researchers and experts from all over Europe.

