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Dementia Care in 9 OECD Countries: A Comparative Analysis

Pierre Moïse,

Michael Schwarzinger,

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SUMMARY

1. Dementia and its most common manifestation, Alzheimer's disease, is a complex disorder that afflicts primarily the elderly, affecting an estimated 10 million people in OECD member countries. The complexity of the disease makes treating dementia extremely difficult, involving a wide variety of social and health care interventions. Typically, these two aspects of dementia care are examined separately. This paper adopts a conceptual model that examines both types of interventions and how they interact along the dementia care continuum.

2. There are no effective health care treatments for stopping dementia, which is why the social care aspect plays an important role in treating the disease, with family members an integral part of this process. This paper shows that programs designed to help alleviate the burden of family members caring for a relative with dementia can have positive health benefits to both patient and family. In particular, the use of group-living, where dementia patients are housed with other patients to provide temporary relief, is shown to be more effective than other forms of 'respite' care.

3. Standard and reliable outcome measures are needed to better determine which interventions are effective. This paper shows that, while no clear consensus on a particular measure exists, researchers are closing in on a reliable set of measures for evaluating the various aspects of dementia health: cognition, activities of daily living and behaviour.

4. This paper provides a comparative analysis of dementia care in 9 countries, with a particular focus on Alzheimer's disease. The purpose is to provide health policymakers with a better understanding of the variations in approaches to treating dementia that exist among OECD countries to help them better formulate health policies for treating dementia.

RESUME

5. La démence et la maladie d'Alzheimer, sa manifestation la plus courante, sont des troubles complexes qui touchent principalement les personnes âgées. D'après les estimations, elles concernent quelque 10 millions d'individus dans les pays de l'OCDE. La complexité de ces pathologies rend extrêmement difficile toute méthode de soins et nécessite une prise en charge à la fois sociale et médicale. Le plus souvent, ces deux aspects de la prise en charge de la démence sont examinés séparément. La logique conceptuelle adoptée dans le présent document en propose une analyse globale et étudie leur interaction tout au long du continuum de soins.

6. Il n'existe aucun traitement efficace permettant d'arrêter la progression de la démence ; c'est la raison pour laquelle l'entourage familial joue un rôle fondamental dans sa prise en charge, dont il fait partie intégrante. Le présent document montre que les programmes visant à alléger le fardeau des personnes s'occupant d'un proche atteint de démence peuvent avoir des effets positifs sur la santé du patient comme de sa famille. En particulier, les unités de vie, dans lesquelles sont hébergées des personnes atteintes de démence, et qui visent à soulager temporairement la famille de ces patients, se sont révélées plus efficaces que d'autres formes de « placement temporaire ».

7. Il importe de disposer de mesures normalisées et fiables, afin de mieux apprécier l'efficacité des diverses initiatives. Selon le document, malgré l'absence de consensus, les chercheurs utilisent un ensemble d'outils pour évaluer l'état de démence en fonction de trois critères : les facultés cognitives, l'aptitude à accomplir les activités de la vie quotidienne et le comportement.

8. Ce document compare la prise en charge des malades atteints de démence dans neuf pays, en s'intéressant plus particulièrement à la maladie d'Alzheimer. Il a pour objectif de permettre aux responsables des politiques de la santé de mieux comprendre les diverses approches retenues par les pays de l'OCDE, afin de les aider à élaborer des politiques efficaces en la matière.

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1. INTRODUCTION

9. Dementia is both a chronic and progressively debilitating disease. In recent years it has become a major policy issue in OECD countries, with a significant proportion of the older population suffering from the disease, many requiring long-term support and care. The economic and social implications are substantial for patients, their caregivers and for health and social care systems, and will increase along with the ageing of populations in OECD countries. In this paper, we concentrate on dementia in older persons (aged 65 years and older), with a particular focus on Alzheimer's Disease where data permit.

10. The purpose of this paper is to assist countries in formulating policies to manage dementia in their country by providing policy-relevant comparisons across OECD countries.[1] Five main study questions will be addressed:

- What is the burden of dementia in the participating countries, including the prevalence, mortality, disability and the resulting care needs?
- Are there variations in how dementia is treated across the continuum of care, including diagnosis, acute care, primary care, community care, and long-term care? What is the balance between health and formal social care? What is the level of informal care giving, and the support provided to carers?
- What are the reasons for any differences in the care approaches, particularly in relation to the impact of policies and economic incentives? Are there differences in terms of access and utilisation of services between different groups in the community?
- What is the effect of differing care approaches on outcomes for patients and caregivers, and on costs for both formal and informal care?
- What are the implications for health and social care systems?

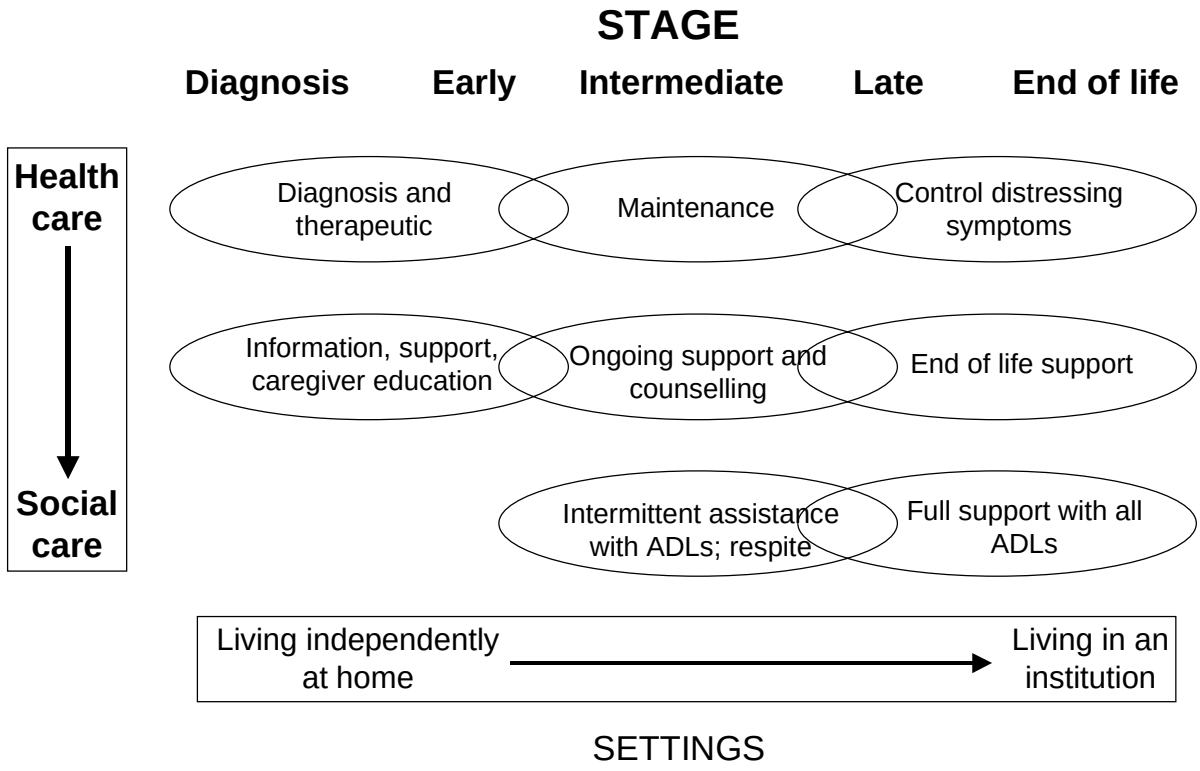
1.1 Conceptual model and scope

11. Care provided to dementia patients is varied and comes from a wide range of sources. It is provided by a range of people and services, including those within the family, publicly provided services, and privately purchased services. These services may include health care, social care, housing, income support, and legal advice. The primary focus of this paper will be on health care and social care.

12. Within health and social care relevant to dementia patients, there is quite a degree of complexity due to the presence of multiple services, settings and caregivers. The interactions between these components and how they fit into the continuum of care are illustrated in Figure 1.1.

1. OECD countries' health care systems vary considerably. People not familiar with these difference can refer to two OECD studies comparing these health care systems study (OECD, 1992; OECD, 1994).

Figure 1.1: Care continuum for dementia patients



Note: ADLs = Activities of Daily Living. A description is given in footnote 3.

13. The main stages that occur with the progression of dementia are indicated at the top of the figure. The distinction between each of these stages is not precise, and individual patients will move along this continuum at different rates. The first stage identified is the diagnosis stage, which marks the initial entry into the care system (dementia is a difficult disease to detect, meaning there can be a substantial number of individuals who enter the care system in later stages along the continuum – see Section 4.2.1.). This stage will be marked by a number of diagnostic tests and assessments, and provision of information and support in relation to the diagnosis. The second stage identified is termed the early stage, when symptoms tend to be relatively mild with only a fairly minimal impact on activities of daily life. The intermediate stage is marked by an increasing dependence on the help of others. The late stage is when the person is unable to look after themselves without continuous assistance from others. The final stage indicated here is the end of life stage, where palliative care becomes necessary.

14. One of the main problems faced will be defining the boundary between health and social care, or indeed whether such a boundary should be delineated. The organisational boundary between health and social care varies between countries. In some countries there is little segregation of the two broad types of care for dementia patients, but in other countries this is not the case. The funding, organisation and delivery of health care can be very separate from that for social care, which can have implications for the care of dementia patients. Due to this variation in the boundary between health and social care, and also because there is no real reason to separate the care into two distinct groups for the purposes of our discussion here, we have indicated the continuum of health to social care running from the top to the bottom of Figure 1.1, with no boundary between the two. The services indicated at the top of the diagram tend to be those that are usually thought of as ‘health care’, while those at the bottom are usually thought of as ‘social care’.

15. The content of the ovals in Figure 1.1 seek to summarise the main services provided for dementia patients. These ovals are purposely overlapping as, again, there is no clear distinction between each phase of care across the continuum.

- *Diagnosis and therapeutic*: largely deals with diagnostic tests and assessments, drug therapy aimed at delaying progression of the disease, rehabilitation and behavioural therapies.

- *Maintenance*: the focus is now moving to maintenance of functions, such as drug treatment to minimise common co-morbidities associated with dementia (*e.g.*, depression).

- *Control distressing symptoms*: here the aim has progressed to minimising and coping with the distressing symptoms of dementia, such as aggressive behaviour.

- *Information, support, caregiver education*: focuses on the patient and caregiver's need for support and information in the early stages, as well as providing the caregiver with specific education and training to prepare for the next stages of the condition.

- *Ongoing support and counselling*: during this stage, the focus of support and counselling will be shifting to the caregiver, though specific needs for support and reassurance will still be appropriate for the patient.

- *End of life support and counselling*: in relation to 'palliative care'.[2]

- *Intermittent assistance with Activities of Daily Living (ADLs) or Instrumental Activities of Daily Living (IADLs),*[3] *respite care*: activities of daily living include personal care such as bathing, dressing, using the toilet, and eating. At this stage, patients are likely to be able to undertake some (or part) of these activities independently. Also, respite care aimed at providing a break from caring responsibilities for the caregiver, is included here.

- *Full support with all ADLs and IADLs*: the patient is fully dependent on others in order to undertake these activities.

16. The final section of the figure indicates that there is also a continuum in 'settings'. In the early stages of the condition, the patient is likely to be living independently at home, while by the end it is most likely that the patient will be living in an institution (though there are exceptions to this). This continuum in settings also has an impact on the role of the caregiver. Initially they are likely to have some role in supporting the patient, and this role is likely to increase while the patient is still living at home. A marked change in their role will occur at the time the patient is admitted to an institution.

1.2 Structure of the report

17. Following the Introduction, the Background section provides a brief description of dementia. One of the aims of this report is to ascertain the burden dementia places on OECD societies, this section fulfils

2. Care received by patients in the terminal phase of their illness. The goal of palliative care is to provide comfort and minimise pain when medical intervention is no longer a viable option.

3. Activities of Daily Living (ADLs; daily activities) and Instrumental Activities of Daily Living (IADLs; activities that allow a person to live independently) are common classifications used in relation to assistance provided to individuals with functional limitations. Examples of ADLs include bathing, dressing, toiletting and eating. Examples of IADLs include cooking, housecleaning, shopping, managing money.

that aim by providing an epidemiological background for dementia and Alzheimer's disease providing a picture of resulting care needs.

18. Section 3 of the report outlines the important policy issues underlying dementia that most concern policymakers. Policies and programs regarding dementia and Alzheimer's disease are more likely to be encompassed under general policies and programs regarding the disabled, elderly and mental health. The purpose of this section is not to define and compare dementia-specific policies, but rather to set out broad objectives which can be used for formulating dementia policies.

19. The conceptual model explained in Section 1.1. provides the framework for the analysis of health and social care related to dementia in Section 4. Where they exist, dementia-specific health and social care programs are examined and the experiences of participating countries compared. The purpose is to identify those programs, dementia-specific or not, that work best in providing care for dementia patients and their caregivers.

20. In Section 5 outcomes are discussed. Since at present dementia is an incurable disease, the focus is on outcomes that slow the progression of the disease. A special facet of dementia and Alzheimer's disease is the role that caregivers play and how this affects their health, consequently, this section also contains discussion on outcomes of caregivers.

21. The economic aspects of dementia are discussed in Section 6.

22. The final section provides discussion around some of the major issues identified in the main body of the report and provides some conclusions regarding the comparisons of various policies for treating dementia. A specific focus of the discussion will be the future burden dementia will place on society since it is expected to increase significantly as the elderly populations of OECD countries increase and grow older.

2. BACKGROUND AND EPIDEMIOLOGY

23. Dementia is an acquired syndrome of decline in memory and other cognitive functions sufficient to affect daily life in an alert patient (American Psychiatric Association, 2000). It is a common condition among the elderly, affecting an estimated 6.4% of all persons aged 65 years and older, based on a major study of prevalence of dementia undertaken in eight European countries (Lobo, *et al.*, 2000).[4] Alzheimer's disease (AD), the most common form of dementia, accounts for about three quarters of dementing disorders in North America and Europe, and about half in Asia, although the prevalence of AD in Asia increases to 61% when only recent studies are taken into account (Fratiglioni, De Ronchi *et al.* 1999). This discrepancy in dementia subtypes across world regions is likely an artefact related to the pathologic overlap of AD with vascular dementia.

24. Difficulties in establishing a precise diagnosis of AD and in distinguishing AD from vascular dementia limit considerably the comparability across countries of the epidemiology of AD. Moreover, the natural history of AD occurs mainly outside the health care system, at least in the mildest stages of dementia. Consequently information from national health care administrative databases that can be useful in comparing incidence or mortality rates across countries for other ageing-related diseases are either nonexistent regarding prevalence or incidence or unreliable regarding mortality (a discussion of the more technical elements of dementia and AD is included in an Annex).

25. Despite these difficulties, epidemiological data on prevalence and mortality of dementia are important to help establish the burden this disease places on societies. This section presents the latest epidemiological estimates available for each country in this study. In three countries, *i.e.* Australia, Canada, England and Wales, we were able to obtain prevalence data at the national level. For the remaining six countries we used regional data based on epidemiological studies that are not necessarily representative of the corresponding national population. Several prevalence estimates were available for each country, which contrast with the paucity of incidence estimates available. Mortality rates from national administrative databases are analyzed qualitatively to encompass the recognition of AD as an underlying cause of death over time and across countries.

2.1 Medical background

26. Clinical symptoms of AD typically begin late in life, generally after age 60, with subtle short-term memory problems. Patients may have difficulty finding words, planning meals, managing finances or medications, using a telephone and driving without getting lost. Many capacities may initially remain intact, including the performance of self-care activities of daily living (eating, bathing, grooming) and social skills. Changes in behaviour and mood may occur at an early stage with personality alterations, irritability, anxiety or depression (Small, Rabins *et al.* 1997).

27. In more severe stages, the disease impairs the ability to recall information acquired early in life (*e.g.*, names of relatives). Other cognitive functions (language, orientation and judgement) worsen continuously to the point of interfering with the ability of the person to function independently. Delusions,

4. The study included cohorts in Denmark, Finland, France, Italy, the Netherlands, Spain, Sweden and the United Kingdom.

hallucinations, aggression and wandering often develop in middle and late stages. Patients may also fail to recognise their relatives. These changes in behaviour are the most troubling to caregivers and frequently lead to family distress and nursing home placement.

28. In the period just prior to death, patients are mute, exhausted, bedridden and incontinent. Death occurs on average ten years after the first symptoms of memory loss, with a range of 3 to 20 years (Larson, Kukull *et al.* 1992; Small, Rabins *et al.* 1997).

29. A definite diagnosis of AD is ultimately based on histological evidence in the brain at autopsy, but the presence and severity of clinical symptoms of AD *de vivo* may be related to the occurrence of cerebrovascular lesions (Snowdon, Greiner *et al.* 1997; Kalaria 2000; Kudo, Imaizumi *et al.* 2000; Petrovitch, White *et al.* 2000).

30. The risk factors for AD have been set out in Small, Rabins *et al.* 1997. The primary risk factors are age and family history. Some studies report that by the age of 90 years, almost 50% of persons with a first-degree relative with AD develop the disease themselves. The aliproprotein E genotype is associated with the common, late onset form of AD, although this is also found in unaffected elderly persons and not found in many patients with AD. Some forms of late-onset AD have also been linked to chromosome 12, and there may be additional but as-yet unidentified genetic susceptibility. Other possible risk factors include a previous head injury, female sex and lower education level.

2.2 Prevalence of AD and dementia (the need for care)

31. Prevalence of AD and dementia are important indicators of the present need for health and social care. Comparisons of the supply of health and social care, costs and health outcomes require adjustments on the national burden of dementia, or at least an understanding of differences in variations across countries. A proper accounting of the burden of AD and dementia would include incidence data, however, inconsistency and lack of available data on incidence make cross-country comparisons almost impossible. Therefore, only data on prevalence are used here to describe the burden of AD and dementia.[5]

Prevalence of dementia

32. Dementia prevalence data were available for each country participating in the study, but with considerable variation. Where applicable, one study was selected per country based on three criteria: 1) recent epidemiological study; 2) inclusion of mild cases; 3) gender and age-specific figures. Methodological issues surrounding selected studies are outlined in the Annex.

33. As shown in Table 2.1, prevalence of dementia is very low at younger ages and similar for both genders (less than 3% in the age group 65-70). Prevalence of dementia increases almost exponentially with age regardless of gender (nearly doubling every 5 years), but the increase is much more rapid for females for whom prevalence is much greater for the oldest age. Dementia prevalence estimates, however, are strikingly different across countries. For example, dementia prevalence in both France and Germany for females aged 90 and older was estimated to be greater than 50%, whereas in Spain the corresponding estimate was slightly less than 30%. These trends are supported by prevalence figures estimated by Fratiglioni, *et al.* (1999) in a review of dementia published studies on dementia prevalence and incidence.

5. The decision to rely on prevalence data only was taken following a meeting of experts participating in the study in November 2002.

Table 2.1: Prevalence of dementia per 100 persons by age and sex in 9 OECD countries

	Males						Females					
	65 - 69	70 - 74	75 - 79	80 - 84	85 - 89	90+	65 - 69	70 - 74	75 - 79	80 - 84	85 - 89	90+
Australia	0.8	2.0	3.2	5.8	16.4		0.3	1.3	3.1	7.4	23.9	
Canada		4.5	8.2	15.1	22.6	30.4		4.6	9.1	17.4	28.1	41.1
England and Wales	2.2		8.0		18.0		1.8		10.3		26.0	
France			7.7	12.5	22.9	27.0			5.7	16.6	29.9	52.8
Germany												
Japan	3.8						3.8					
Spain	1.0	1.2	2.0	4.3	9.3	15.4	0.4	2.9	2.4	8.9	14.8	28.1
Sweden	3.4		7.7		21.9		2.5		9.6		26.1	
United States	1.6	2.9	7.2	15.5	23.5	29.9	1.3	3.6	7.7	15.1	28.4	42.2

Notes

1. Data for Australia and Japan are based on an Epi survey which did not rely on DSM-III-R.
2. Data for Canada is for Ontario only.

Sources

Australia: AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers confidentialised record file;
Canada: hospital discharge (CIHI) and physician services (OHIP) databases 1999;
England and Wales: Medical Research Council Cognitive Function and Aging Study 1992; France: **?** Aquitaine 1998;

34. We cannot dismiss the fact that differences in dementia prevalence may be due to methodological differences in the underlying studies, despite our attempts to reduce these differences. There is no current means of disentangling true differences in dementia prevalence across countries from methodological differences since methodology is still not reproducible from one study to another. In the Annex, sensitivity analysis was carried out to provide several figures per country. Nevertheless, with the support of other studies these data provide a broad outline of four major characteristics of dementia prevalence: (1) the presence of dementia is very low among the younger elderly (roughly 65 to 75 years), (2) the prevalence of dementia increases exponentially with age, especially for those aged 80 years and older, (3) dementia is much more prevalent among women, especially for the oldest age groups (90 years and older), and (4) there are differences in dementia prevalence across countries, especially for the oldest age groups, although some of this variation is likely due to methodological differences in the various studies.

Prevalence of Alzheimer's Disease

35. AD prevalence data were provided by three countries, France, Spain and the US In other countries, previous epidemiological studies did not provide AD prevalence data because it was not clinically assessed (Australia) or experts preferred to rely on pooled data (England and Wales, Japan, Sweden). Missing data were replaced by AD proportions found in pooled data from European studies in these five countries (Lobo, Launer *et al.* 2000). Accordingly, in the age-groups 65-69, 70-74, 75-79, 80-84, 85-89 and 90+, the AD proportion of all dementia cases was assumed to be 38%, 52%, 32%, 57%, 69%, 80% in males and 70%, 74%, 72%, 67%, 70%, 77% in females. These assumed AD proportions by gender- and age-groups were similar to those of countries providing raw data, except in the older French population (raw proportions higher than assumed proportions) and the older female Spanish population (proportions less than assumed proportions).

Table 2.2: Prevalence of Alzheimer's disease by age and sex in 9 OECD countries

	Males						Females					
	65 - 69	70 - 74	75 - 79	80 - 84	85 - 89	90+	65 - 69	70 - 74	75 - 79	80 - 84	85 - 89	90+
Australia	0.4	1.1	1.7	3.1	8.7		0.2	0.9	2.2	5.3	17.0	
Canada		2.4	4.3	8.0	12.0	16.1		3.3	6.5	12.4	20.0	21.8
England and Wales	1.2		4.2		9.5		1.3		7.3		18.4	
France			4.1	6.6	12.1	14.3			4.0	11.8	21.2	28.0
Germany												
Japan	2.1						2.1					
Spain			0.4	2.1	5.9	12.8	0.4	1.4	1.6	7.9	9.0	15.3
Sweden	1.8		4.1		11.6		1.8		6.8		18.5	
United States	0.4	1.6	4.1	9.4	15.6	21.4	0.9	2.8	4.7	11.0	20.8	31.1

Notes

1. Data for Australia and Japan are based on an Epi survey which did not rely on DSM-III-R.
2. Data for Australia, Canada, England and Wales, Germany, Japan and Sweden are calculated based on assumed prevalence of AD within dementia.

Sources

36. Given the assumptions in the preceding paragraph, the pattern of prevalence for AD across age groups, gender and country is similar to that for dementia. As shown in Table 2.2, prevalence of AD was very low at younger ages (less than 2% in the age group 65-70) but increased almost exponentially with age and female gender at older ages (up to 46% in French females above 90 years).

37. Since AD prevalence was calculated as a fixed proportion per age group and gender for all countries, differences across countries by age and gender reflect the same differences as those estimated for total dementia prevalence. Given the fact methodological differences can probably account for some, if not most, of the cross-country differences in dementia prevalence, it may be safe to assume there are no significant differences between countries in the prevalence of dementia and Alzheimer's disease by age and gender. Small differences across countries should not affect the analysis in this report, since the purpose of estimating prevalence rates is to establish a general pattern of the burden of dementia.

Prevalence of moderate to severe AD

38. The progressively debilitating nature of Alzheimer's disease means that the need for care is gradual, building up from the initial stages when the disease is first diagnosed to when care is needed most during the later stages. Consequently, prevalence of AD by stage would provide a better reflection of the burden AD places on societies. Data for all stages would be preferable, but if these are not available then prevalence of moderate to severe AD, when the need for care is strongest, would be preferred.

39. Only three countries provided raw data on the prevalence of dementia or AD by severity (Australia, Canada, France). Consequently, the prevalence of moderate to severe AD by age and gender was estimated for all countries following the approach proposed in the Swedish country report, which is based on two assumptions. First, studies have shown that the distribution of severity in dementia and AD are similar, with differences of less than 5% (Fratiglioni, Forsell *et al.* 1994). Therefore, it was assumed that the distribution of severity in AD was the same as that for overall dementia, allowing us to focus the discussion on AD. Second, previous studies have shown that the proportion of moderate to severe dementia cases increased with age and female gender (Fratiglioni, Forsell *et al.* 1994; von Strauss, Viitanen *et al.* 1999) (see also the French report). Accordingly, in age-groups 65-74, 75-84, over 85, we assumed the

following proportions of moderate to severe AD cases, as defined by a Mini-Mental Status score below 18 or a Clinical Dementia Rating above 1: 50%, 60%, 70%, in males and, 50%, 70%, 90% in females. Under these assumptions, Table 1.3 indicates that prevalence of moderate to severe AD cases could be as high as 24% in females and 14% in males older than 85 years.

Table 2.3: Prevalence of moderate to severe Alzheimer's disease by age and sex in 9 OECD countries

	Males						Females					
	65 - 69	70 - 74	75 - 79	80 - 84	85 - 89	90+	65 - 69	70 - 74	75 - 79	80 - 84	85 - 89	90+
Australia	0.4	1.4	3.1	6.7	21.4		0.4	1.4	3.1	6.7	21.4	
Canada		1.2	2.6	4.8	8.4	11.3		1.6	4.5	8.6	18.0	19.6
England and Wales	0.6		2.5		6.7		0.6		5.1		16.6	
France			1.5	7.4	9.5				2.3	7.5	19.6	
Japan	1.1						1.1					
Spain			0.2	1.3	4.1	9.0				5.5	8.1	13.8
Sweden	0.9		2.4		8.1		0.9		4.8		16.7	
United States	0.2	0.8	2.5	5.6	10.9	15.0	0.5	1.4	3.3	7.7	18.7	28.0

Notes

1. Data for Australia and Japan are based on an Epi survey which did not rely on DSM-III-R
2. Data for Canada, England and Wales, Germany, Japan and Sweden are calculated based on assumed prevalence of Alzheimer's disease within dementia.
3. Data for Canada, England and Wales, Japan, Spain, Sweden and United States are calculated based on assumed prevalence of moderate to severe Alzheimer's disease within Alzheimer's disease.

Sources

40. We were able to test our modelling approach using raw data from the three countries providing information on the prevalence of dementia or AD by severity. Similar figures were observed in Canada and France between raw and modelled prevalence of moderate to severe AD, and they were comparable to those published in the rare studies on the topic (Boersma, Eefsting *et al.* 1998; Hy and Keller 2000). However, raw data in Australia were much higher than those computed, in particular for males (3 to 5 times higher). The discrepancy found in Australia could be due to different methodologies in the assessment of dementia severity, since it relied on the report of disability by a household representative or staff member in the 1998 Australian Disability, Ageing and Carers survey (almost all dementia cases were reported as severe or profound) whereas inother countries assessment relied on a clinical assessment by means of a standardized instrument (Mini-Mental Status score or Clinical Dementia Rating).

2.3 Mortality rates of AD

41. Cognitive impairment and disability are the most recognized problems associated with AD, but AD is increasingly being recognized as an underlying cause of death (Aguero-Torres, Fratiglioni *et al.* 1999; Baldereschi, Di Carlo *et al.* 1999; Witthaus, Ott *et al.* 1999; Jagger, Andersen *et al.* 2000; Helmer, Joly *et al.* 2001; Wolfson, Wolfson *et al.* 2001; Dodge, Shen *et al.* 2003). In the most recent publication, Dodge *et al.* showed that AD could reduce life expectancy by 50% in males and 40% in females at age 70 with a remaining but decreasing effect on mortality up to the age of 90 (Dodge, Shen *et al.* 2003). However, AD as the underlying or contributory cause of death on death certificates as recorded in administrative databases appears to be understated (Ewbank 1999; Ostbye, Hill *et al.* 1999). While it is

important to recognize the mortality aspect of AD, analyses of AD mortality based on death certificates must be approached with caution.

42. Six countries (Australia, England and Wales, France, Germany, Sweden, and the United States) provided administrative data of mortality rates of AD as an underlying cause over time, whereas data were limited to 1999 in Japan and Spain. Table 2.4 shows time series of mortality rates of AD per 100 000 inhabitants aged 65 and over and standardized on age from the underlying cause on death certificates in England and Wales, Sweden, and United States. As shown in Table 6, the analysis of time series of mortality rates is hampered by the change of coding instrument over time, *i.e.* a transition from the International Classification of Diseases ICD-9 to the ICD-10 from 1993 to 1999 in the various countries had a dramatic impact on mortality rates of AD in the following year, *e.g.*, divided by 3 in Sweden or 2 in England and Wales. However, the analysis of time series within periods without change in coding instrument showed two different patterns: rates of mortality atrributed to AD increased continuously in the United States over time, in particular in women, whereas rates of mortality attributed to AD remained at the same level in Australia, England and Wales, France, Germany, and Sweden.

Table 2.4: Time series of mortality rates of AD per 100,000 inhabitants aged 65 and over and standardized on European population from underlying cause on death certificates in Australia, England and Wales, France, Sweden and United States

	Australia		England and Wales		France		Germany		Sweden		United States	
Year	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
1990	--	--	108	107	81	87	22	21	74	100	61	59
1991	--	--	110	123	80	85	--	--	78	102	62	61
1992	--	--	109	112	73	82	--	--	75	103	63	63
1993	--	--	**55**	**65**	78	87	--	--	74	99	71	72
1994	--	--	**55**	**66**	79	86	--	--	69	97	77	81
1995	--	--	**64**	**73**	75	86	35	33	78	101	84	90
1996	--	--	**59**	**71**	74	84	--	--	75	97	84	95
1997	**53**	**64**	**55**	**69**	73	85	--	--	**23**	**27**	86	102
1998	**51**	**60**	**53**	**70**	86	99	--	--	**22**	**26**	86	106
1999	**51**	**59**	**53**	**72**	84	103	--	--	**25**	**37**	**87**	**108**
2000	**43**	**62**	**46**	**63**	**--**	**--**	**29**	**27**	**31**	**36**	--	--

Bold figures are related to ICD-10 (Australia:1997; England and Wales:1993; France:2000; Germany:1998; Sweden:1997; and United States:1999)

43. Table 2.5 shows mortality rates of AD and dementia per 100 000 inhabitants from the underlying cause on death certificates of the latest year available in Australia, England and Wales, France, Germany, Spain, Sweden, and United States. As expected, mortality rates of AD and dementia were higher in the oldest groups and in females in all countries. If we take into account the decrease of 2 to 3 times in mortality rates of AD that will follow the introduction of ICD-10 instrument in France and Spain, mortality rates of AD were much higher in Australia, England and Wales and the United States than in France, Germany, Spain, and Sweden. These discrepancies were found in mortality rates of AD after standardization on the European population aged 65 and over, but also in the crude population aged 85 and over. The low recognition of AD as an underlying cause of death in the latter group may be even higher in France and Germany where AD accounts for more than 75% of all dementia related deaths, although it is lower than 35% in Spain and Sweden. Overall, mortality rates showed a variable recognition of AD as an underlying cause of death between countries, but with higher rates in the oldest, and in females, in all countries.

Table 2.5: Mortality rates of AD and dementia per 100 000 inhabitants from underlying cause on death certificates in the latest year available according to International Classification of Diseases instrument and country

ICD instrument	ICD-10										ICD-9			
Country (year)	Australia (2000)		England and Wales (2000)		Germany (2000)		Sweden (2000)		United States (1999)		France (1999)		Spain (1999)	
	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
	Standardized European population aged 65 and over													
Mortality rate of AD	43	62	46	63	29	27	31	36	87	108	84	103	59	71
Mortality rate of dementia	110	141	71	92	37	35	174	193	143	176	100	115	189	216
Proportion of AD in mortality rate of dementia	39%	44%	65%	68%	76%	77%	18%	19%	61%	61%	84%	90%	31%	33%
	Population aged 85 and over													
Mortality rate of AD	217	417	266	377	109	110	150	161	467	654	443	596	221	286
Mortality rate of dementia	641	982	414	578	164	167	1088	1307	815	1150	525	673	1002	1265
Proportion of AD in mortality rate of dementia	34%	42%	64%	65%	66%	66%	14%	12%	57%	57%	84%	89%	22%	23%

Box 2.1: Future burden of dementia and Alzheimer's disease

It is generally accepted that ageing OECD populations will increase the prevalence of ageing-related diseases, in particular dementia and Alzheimer's (AD). Furthermore, improvements in health and social care will prolong survival further increasing the pool of people suffering from dementia and Alzheimer's disease.

We estimated separate projections of the number of people with dementia and those with moderate to severe Alzheimer's disease, by age and gender for 2010 (the tables are included in the technical appendix):

- Dramatic increases in the projected prevalence rates for dementia in 2010 for the population aged 75 and over. Even larger increases in prevalence for people with moderate to severe AD.
- Stable or decreasing dementia prevalence rates for the younger elderly (65 – 74 years) in all countries for which data were available. A similar pattern exists for the prevalence of moderate to severe AD in this age group.

2.4 The burden of dementia and Alzheimer's disease

44. Lack of reliable data at the national level make cross-country comparisons of the epidemiology of AD a difficult exercise. However, the purpose of this section is to establish a picture of the burden that dementia and AD places on OECD countries' health and social care systems. This does not require establishing epidemiologically robust estimates. Rather, what is needed is a broad-brush painting of the dementia burden, particularly those people who are most susceptible to suffering from the disease. This information can thus be used in helping to target dementia policies most efficiently.

45. Persons aged 75 and older are much more affected by dementia and AD then the younger elderly, with prevalence increasing rapidly with age. At the oldest age groups, females are much more affected by dementia and AD than are males. Not surprisingly, the same pattern holds for moderate to severe AD, and for mortality due to dementia or AD. Significant budget constraints may force some governments to consider targeting dementia policies at persons aged 75 and older, with particular attention to very elderly women. This may become particularly necessary when the post-war baby boom cohorts reach the age where susceptibility to dementia and Alzheimer's is significant.

3. POLICY ISSUES AND APPROACHES

46. Dementia is a relatively new area of policy focus compared to many other of the diseases and conditions which impose a large burden on society. Few OECD countries have specific policies for the condition. Policy for this condition is frequently encompassed in wider policies and statements. In addition, discussions of policy issues are relatively rare in the research literature. In this section, we outline the main policy issues and formulate a set of key policy-related questions to be addressed in the study

3.1 Policy issues

47. Underlying the policy issues is a core set of policy principles commonly raised as appropriate in the formulation of dementia policies (Box 3.1). The first two in particular – to remain at home as long as possible and to support caregivers – appear to be universally accepted as desirable policy principles in the countries participating in this study.

Box 3.1: Common policy principles in relation to dementia

- Remain at home as long as possible- delay institutionalisation
- Support carers in order to achieve this
- Patients need as much control over their care as possible, but recognise limitations due to cognitive impairment (*e.g.,* in relation to having the capacity to make informed choices)
- Co-ordination of services at local level where possible
- Institutional care, when required, should be as home-like as possible
- Equate service provision with need
- Early diagnosis should be encouraged

Source: Marshall 1999, Riggs 2001.

Need for services

48. A primary requirement for all countries in relation to dementia policy is to determine, as much as possible, what are the needs for services for dementia at the population level. It has been acknowledged that there is a lack of this type of information available for policy makers (Marshall 1999). A key indicator of the need for services is the prevalence of dementia in the population. Further, patients with more advanced forms of the condition are likely to have greater needs for services compared to other patients. Information on the prevalence of dementia is provided in the preceding Chapter.

49. A more difficult question to answer is what will the need for services for this group be in the future. This will depend on a number of assumptions, including population ageing, availability of informal caregivers, and changes in options for prevention and treatment. Nevertheless, there appears to be general

agreement that due to population ageing alone, there is likely to be an increased need for dementia services into the future.

50. Another indicator of the need for services is the current utilisation of services. However, this may mask the fact that there may be unmet needs for services due to lack of capacity or appropriate services. Utilisation information can nevertheless provide further insight into the types and intensity of service needs for dementia patients, which is vital given the complex needs of this patient group.

51. A related policy issue is to determine under what circumstances these services should be provided. For example, should eligibility for services be based on assessment of limitations in ADLs or IADLs, or some other criteria such as ability to pay (Newcomer *et al.* 2001)? This issue will be explored to some degree in this paper.[6]

Costs of services

52. As well as the need for services for dementia patients, the costs associated with these services is also of vital policy importance. Given the complex need for services that particularly accompanies the more advanced forms of the condition, it is important to know what the associated costs are. This includes costs associated with health or social care systems (direct costs), as well as costs that exist outside these systems (indirect costs). For this condition, indirect costs associated with informal caregiving, such as lost earnings and production, can be significant (Newcomer, Fox and Harrington 2001). In Section 6 the costs associated with dementia are calculated for a number of countries for whom this information was available.

53. It is also of policy interest to ascertain the likely costs that would be associated with alternative models of service provision. For example, do certain modes of support for caregivers enable admission to institutional-based care to be delayed in a way that reduces total costs? Where available, information on costs associated with particular models of care in the different countries is examined, along with any research studies that have compared the costs of a set of alternative care models.

Caregiver's role and needs

54. Perhaps the most important feature of dementia care that distinguishes it from non-mental illnesses is the role of 'informal' caregivers in providing care to people with dementia and their own needs in helping them fulfil this role. A close family member, such as a spouse or child, most often provides this informal care. The importance of the informal caregivers' role in dementia care has increased because of the general shift to community-based care. The role of informal caregivers is an essential element of this shift, and is discussed further in this section. The role of informal caregivers in dementia care is also explored in Section 4.

55. The caregiver's role in dementia care can be particularly challenging due to the characteristics of the condition. These patients often remain physically well, despite losing their cognitive ability. It is likely that eventually the patient will not recognise the caregiver, may be aggressive, and will often 'wander' away from home. All of these behaviours can be very stressful and emotionally difficult for the caregiver. It is possible that the caregiver's health may suffer due to their demanding role with depression recognised as a particular risk (Ory *et al.* 2000).

56. Caregivers require support in order to undertake this role. This includes information, training and counselling. They are likely to require assistance from formal care services, especially as they may be

6. This issue is dealt with in greater detail in another OECD study, the Long-Term Care Study which is due to be completed in the second half of 2004.

elderly themselves. Respite care is therefore necessary to provide a break from their caregiving role, particularly as functioning declines. The flexibility, regularity and quality of respite care are as much a policy issue as for other types of care such as community-based care and institutional care. In Section 5 we provide some information on the benefits to informal caregivers of some interventions.

57. An important policy issue is the availability of caregivers, firstly in terms of current availability, but also in the longer-term. To some degree, the policy shift to community-based care relies on the availability of informal caregivers as a substitute for formal care provided in institutions (Riggs 2001). Can we assume that they will be available in the future to take on this role? To what degree are current levels of caregiver availability reliant on spouses and children not being part of the workforce? These aspects are likely to change in the future as the labour force changes, particularly with increasing numbers of women in the workforce (Stone 2000).

58. Other demographic changes are also likely to impact on the availability of caregivers in the future. Decreasing fertility rates means that fewer children of dementia patients are likely to be available as potential caregivers. This combined with the fact that families are now more likely to live further away from parents further reduces the likely availability of caregivers. Box 4.1 summarizes the issue of the future availability of informal caregivers.

59. A final issue here is in relation to costs. There are societal costs associated with supporting the caregiver role, including information and support, costs associated with respite care, and in some cases an allowance is paid directly to the caregiver. Certainly there is also the cost of any formal health and social care provided to the patient who remains in the community. An often used rationale to justify these costs is that the amount of support provided in the community will at least be budget neutral, or even result in savings. But the validity of this assumption has been questioned (Newcomer, Fox and Harrington 2001), particularly in the light of the principles that are the basis for encouraging non-institutional care: improving quality of life or increasing choice. There has been a trend to supporting increasingly more severe cases in the community, which is also likely to increase the associated costs.

Co-ordination of care issues

60. As stated earlier, dementia care is based on a complex set of services involving many sectors. These services come from a wide range of providers, in many different settings. Given this complexity, it is important to ask whether these services are well co-ordinated. This is an issue that has often been raised, with many concluding that co-ordination between services has room for improvement (for example, Marshall 1999, Advisory Panel on Alzheimer's Disease 1996).

61. In countries that have marked divisions between health care and social care, this is an obvious area for potential problems in co-ordination. Patients may have a good chance of accessing different parts of the health system, but may not be adequately introduced to the social care system at the appropriate time. Health professionals may not understand the social care system well, so may not be in a position to guide patients and their family to the appropriate person(s) in relation to particular needs. Similarly, social care professionals may not be in a position to advise when and how best to access the health care system when particular health issues arise with dementia patients. Even within each of these there may be co-ordination problems, for example in the use of primary health care, mental health care and acute health care (Howe 1997).

62. These issues are largely about how the system is co-ordinated from the patient and their family's perspective. One way of improving co-ordination that has been suggested is for each patient to have a person assigned as their co-ordinator. A suggested potential person to undertake this role is the primary care physician due to the fact that they are likely to be one of the first points of contact with the 'system'

(Cohen, Pringle and LeDuc 2001). Another approach often taken in health/social care systems is to ensure that there is a point of contact for information and referral, such as through a phone-based information line.

63. Another facet of co-ordination is at the policy and planning level. It is often the case that responsibility for dementia is given to one particular government ministry, such as to the ministry responsible for ageing. But it is clear that there are issues that are important to more than one part of government, such as health, housing, and social support for example. The co-ordination between areas of government has been suggested as another area where improvement could be made, through structural changes or other means as appropriate (Marshall 1999).

64. A problem with having a complex web of services for dementia patients is the potential for cost-shifting [‘the process of using excess revenues from one set of services or patients to subsidise other services or patient groups’ (Getzen, 1997)]. Where there are multiple sources of funding, there is an incentive to maximise funding from each source, which may not always be an efficient approach. An example of this relates to the boundary between acute care and long-term institutional care. If the source of funding for these differs, there is an incentive for each to try and ensure that maximum use is made of the other where possible.

65. A final important issue is whether or not dementia-specific policies and services should be adopted, or whether dementia care should be integrated under more general policies and programs (Marshall 1999). Most countries in our study appear to have at least some specific dementia focus at the policy level, though there is variation in how far this is taken, with only some implementing specific dementia policies.

66. There is also variation in the degree to which the settings of services used by dementia patients are dementia-specific (for example specialised or segregated units in residential care settings), compared to integration into more general services. It has been argued that the needs of dementia patients are unique, and thus require specialised care. This approach has also been argued to be necessary for the welfare of other patients, due to the aggressive nature of some dementia patients (Tinker, McCreadie and Salvage 1994). However, the counter argument is that this leads to segregation from society more generally, which may be detrimental to the patient’s quality of life (Stone 2001).

Access and equity across care continuum

67. As identified in Box 3.1, one of the principles commonly applied to dementia care (including residential and non-residential care) is that service provision should be based on need. But it is not straight-forward to determine how that need will be assessed. A frequent starting point is to undertake some type of assessment of functional ability, such as ability to undertake ADLs or IADLs. However, the degree to which other factors should be accounted for, such as availability of family support and ability to pay for private services, is not so clear.

68. The issue of equity across the care continuum involves more than just accessing the system. While access to the system is a first concern, it is also important to examine equity in terms of the amount and type of services utilised, the quality of these services, and the outcomes of these services. The extent to which information on dementia will be available in these areas is not clear, with an initial literature review revealing only a small number of studies (for example Doyle 2001, Montgomery & Williams 2001).

69. One approach to assessing equity in service provision is to compare the experience of different groups of patients. This can include people from different ethnic groups, geographical areas, or financial situations (Advisory Panel on Alzheimer’s Disease 1996). Again, there appears to be only a small number

of studies published on this topic. However, there does appear to be some evidence of differential access to people from various ethnic groups (LoGiudice *et al.* 2001, Stephenson 2001).

70. A final policy issue is whether dementia patients are disadvantaged in relation to other patients. Does the nature of the condition result in inequitable treatment compared to other patient groups in accessing all parts of the continuum of care? Are there particular difficulties faced by this patient group, and is sufficient funding provided to ensure this patient group receives their 'fair share' of resources. Also, in health systems which are placing increased emphasis on consumer choice, what implications will that have for patients with decreased cognitive function who are not likely to be in a position to make appropriate choices (Advisory Panel on Alzheimer's Disease 1996).

Financing of services

71. How best to finance the care of dementia patients is of vital interest to policymakers. This includes the source of financing, which influences the balance between public provision of services and private responsibilities. The role of insurance in meeting the financial costs of care is also important, as is the level of government involved in the financing of services. These are issues that are more relevant to a an aggregate view of health and social care systems, but wherever warranted dementia-specific issues are discussed in this paper.

Quality of care

72. The quality of care, both formal and informal, provided to dementia patients has many important policy aspects. Firstly however, we need to know whether there are recognised standards of care for dementia (for example in the US: Knopman *et al.* 2001, Doody *et al.* 2001). And if so, what can policy makers do to ensure that the quality of care is of an acceptable standard, for example through facilitating the formation of guidelines, or through regulations and monitoring.

73. Quality of care can be broken into three components: quality of the inputs (such as the workforce), quality of the service provision itself, and quality of the outcomes of the service (The Academy for Health Services Research and Health Policy 2002). The first of these, the quality of the workforce, has been raised as an important aspect of quality of care for dementia patients (Riggs 2001, Stone 2001). In particular, staff shortages and lack of specific training in relation to dementia are highlighted. Further, it is important to consider the quality of care that is being provided by informal caregivers, particularly as the care needs of the patient progressively becomes more demanding. This issue is touched upon in the Health and Social Care section.

74. In terms of the quality of the provision of care, there are many aspects that are raised in the literature. These include the potential importance of early diagnosis to ensure that drug treatment and other interventions can be provided when appropriate, and support and education for the patient and family can begin. Other relevant aspects of quality of care provision include maintaining the dignity of the patient, use of alternatives to physical and chemical restraints where possible, and use of 'new' approaches to care, special care units, and new types of home/community-based care and assisted living.

Outcomes of dementia care

75. The third dimension of quality, quality of outcomes, is discussed in Section 5. In that section, we include the issues of outcomes for patients (which is related to quality of care), as well as outcomes for caregivers. In this paper an 'outcome' is considered to be the change in the dementia patient that is at least partly attributed to an intervention. This is related to the more specific notion of 'health outcome' which considers the change in health status due to a health intervention (Hurst 2002). For dementia patients it is

often more appropriate to extend this and examine functional status, reflected in measures such as 'quality of life' and 'disability'.

76. As well as looking at the outcomes for patients, it is also vital to examine the outcomes for informal caregivers. As mentioned in the discussion on the caregiver, caring for a person with dementia can be very demanding, which may have negative aspects for the caregiver including an impact on health. It is recognised that caregiving can also be a very positive experience, particularly if appropriate support is available to undertake this role.

Move to community-based services

77. There has been a substantial change in policy focus over the last few decades to favour care of people with long-term needs in the community, rather than in institutions.[7] This change has included both the discharge of patients from long-term care institutions (for example individuals in psychiatric institutions) as well as a shift in service delivery from that dominated by institutional care, to a larger proportion being based outside of institutions (Gibson *et al.* 2001). This trend has certainly occurred in aged care generally, which has extended to those with dementia as well (Marshall 1999).

78. This shift was largely justified based on two arguments. First, care outside an institution is likely to result in a higher quality of life for the patient, at least until the severity of the condition meant that this was no longer viable. Second, it was argued that this shift would reduce public sector expenditure on institutional care, and therefore less expenditure would be needed to support the same individual in the community.

79. Care outside an institution is usually provided in the patient's home, or in a home-like group home. This care largely relies on a mix of formal and informal care (usually family caregivers), in contrast to care in an institution which relies on formal care from the staff of the institution.

80. The balance between institutional and home-based care for dementia patients is of interest to this study. Related to this, questions such as at what stage of progression of the condition are patients usually admitted to an institution, and is there a 'right' balance between community-based and institutional-based care are also examined.

81. There are a number of implications of this shift to community care. For the patient and family, it is generally seen as positive in terms of quality of life for the patient. However, informal caregivers need adequate support to be able to undertake this role. As the condition progresses, there is likely to be an increased burden on the caregiver and family, as well as a decrease in safety for the patient, and it is generally expected that admission to an institution will be required at some point. Issues in relation to the role of informal caregivers have been discussed in the earlier section on *Caregiver's role and needs.*

82. There are of course also implications for the health and social care systems resulting from this shift to community-based care. There will be a need to establish and/or expand the services available in the community. It is not always straightforward to change the setting in which services are provided. There may be a need to provide specialised equipment, safety issues to deal with, and increased costs associated with the need to travel to each patient. The shift to community-based care and delay in admission to an institution is also likely to result in an increase in severity of cases in institutional care, with resulting implications for staffing and other resources.

7. A couple of OECD studies have recognized the policy aim of "ageing in place" where possible as an accepted goal in OECD countries for long-term care (OECD 1996; OECD 2003).

83. Finally, there are also wider implications for society with this increased use of community-based care. There are workforce issues involved, as the increased reliance on informal caregivers may result in interruptions to employment for some caregivers. There is also a likely increase in need for some other types of community support infrastructure, such as support for the caregiver, increased need for help at home when these tasks are not taken up by family members, and differing needs for housing and transport services.

Role of different 'stakeholders'

84. There are many stakeholders involved in dementia care. The central of these is of course the patient and caregiver. The role of the caregiver has been discussed in the earlier section on *Caregiver's role and needs*. Other stakeholders include the government, private sector health and social care providers, advocacy groups, non-government organisations, and volunteer groups. The various roles of these groups differ across countries, however, there are a number of common issues that arise.

85. The government's role in dementia care is a vital one for policy. Potential roles in the service domain include funding, regulation, setting of standards, planning and in some cases provision. Notably in relation to the first two of these, governments have a significant range of choices to make in terms of their involvement. Just as the government role in providing health care differs across countries, so it does as well in the provision of broader services for dementia patients.

86. The balance between self-provision of services, and community support for these services, is a decision that needs to be made. To what level should individuals or their families be expected to provide for themselves in relation to these services, and what support can they expect from other sectors of the community, including financial assistance. Public policy will not only determine the government's role, but will also influence the role played by other stakeholders. For example, incentives may be established through subsidies or tax advantages to support caregiving.

87. An issue that appears often in policy documents and in literature from advocacy groups is the issue of community knowledge of dementia (for example Marshall 1999). General knowledge about dementia is much lower than for some other diseases and conditions that impact on health and functional capacity. Aspects of this include recognition of initial symptoms, the need to seek health advice early, and support that is available to dementia patients and their families. A mechanism for providing information and referral to dementia patients and caregivers is therefore essential. Advocacy groups or non-government organisations can perform this role: if they do not, the responsibility falls on government.

4. HEALTH AND SOCIAL CARE

88. This Section provides a discussion of the health and social care aspects of caring for dementia patients, using as a framework the inter-relationships between the stages of dementia, care and setting depicted in Figure 1.1.

89. The main aspect to consider from Figure 1.1 is that the care continuum for dementia should be a seamless process. We have already seen in Section 2 that there is no clear delineation in the progression of dementia. However, the type of care required and the setting within which it is provided depends on the severity of the disease. Health and social care for dementia should move through the various stages of the disease as a seamless process, as needs for both types of care eveolve. In reality, for a number of reasons, the provision of health and social care is not as seamless as it should be.

90. Dementia health care is typified by diagnosis, management aimed at slowing the progression of the disease's symptoms (there is currently no treatment that can halt the disease) and providing care as these symptoms gradually worsen. Most of the discussion of health care will focus on the first two types of health care, diagnosis and management of the disease. Caring for persons afflicted with Alzheimer's disease skirts the boundary between health and social care, illustrated by the box on the left-hand side of Figure 1.1. Social care is defined in this report as 'assistance with the normal activities of daily life, including personal functioning and domestic maintenance provided on a continuing basis to older people and/or a reduced degree of independence in instrumental activities of daily living (IADL), for people with Alzheimer's Disease (AD) or other forms of dementia.' Specific activities of social care involve personal care, home help services, and supervision/surveillance provided daily by informal and formal caregivers. It is the assistance with 'daily activities' that is important in defining social care.[8]

91. For ease of presentation, this section is structured to follow the various stages of the progression of dementia, from diagnosis to end of life. In order to capture some sense of the seamlessness of the progression, there are four sub-sections, one for each inter-stage, *i.e.* (1) diagnosis – early, (2) early – intermediate, (3) intermediate – late, and (4) late – end of life. In virtually every case, the particular intervention being examined extends across more than one stage, which is represented in the diagrams by the ovals which cover a range of roughly three separate stages.

4.1 STAGE: Diagnosis - Early

Detection

92. Dementia is not an easy disease to diagnose. The initial symptoms of subtle short-term memory problems that increase gradually over time mean it can easily go undetected for years before becoming apparent (Larson, Kukull and Katzman 1992). Even in the intermediate stages of the disease, when the

8. Several factors limit the comparisons in this section: (1) it was almost impossible to distinguish between social care for people with generic disability and dementia; (2) where information on social care for dementia was available, age and severity were extremely difficult to obtain; (3) many data provided were based on regional surveys and may not be representative of the country, (4) considerable variation in the information provided limited cross-country comparability. Much of the information provided by participating experts was supplemented with published material in the public domain.

signs of dementia are more easily recognizable, many patients remain undiagnosed (Boustani M, *et al.*, 2002; Olafsdóttir M, Skoog I and Marcusson J, 2000). The result is that many persons with dementia are not receiving required care.

93. An accurate diagnosis of dementia during the early stages of the disease is desirable. Early detection may confer a number of benefits to both the diagnosed person and his/her family, such as: making possible timely referral for dementia-related education, caregiver counselling, and social services or support (Feed *et al.*, 1999); providing a diagnosis when it can still be understood by the patient who can provide some input on care alternatives (Fearnley, McClennan and Weaks, 1998); and deciding early on who will take care of the person with dementia. However, despite the benefits of early diagnosis, the number of undiagnosed cases of dementia suggests efforts should first be concentrated on improving the accuracy of diagnoses during the intermediate stages of the disease (a description of the methods used to diagnose dementia is included in the Annex).

94. The odds of an accurate diagnosis are increased if social and health care professionals who come into frequent contact with the elderly are aware of the signs of dementia. General practitioners have regular contact with their patients, making them the first line of defence against the disease.[9] Therefore, it is important that GPs, especially those with sizeable proportions of elderly patients in their practices, receive basic training in detecting dementia, learn how to treat it in its early stages and recognize where and when to refer patients to appropriate specialists.[10]

95. There are several possibilities which may explain why many cases of dementia go undetected: since current treatments are perceived to be ineffective, many GPs may not see the interest in detecting dementia until the problems become severe; in many countries GPs may not be authorized to initiate the prescribing of anticholinesterases; GPs may simply not see enough patients with dementia to be aware of the signs; a significant amount of training is required for clinical examination and psychometric testing to be effective, which may not be cost-effective for GPs except those with sizeable rosters of elderly patients.

96. Despite the difficulties in diagnosing Alzheimer's disease at an early stage of development, many countries have in place health care strategies that stress the importance of early detection. These strategies rely upon a set of well-established guidelines for diagnosing Alzheimer's disease (see Annex II, on Epidemiology). For example, in the United Kingdom, the National Service Framework (NSF) for Older People recognizes explicitly the importance of the early recognition of dementia. Standard 7 of the NSF provides guidelines on how to diagnose dementia that include patient history, assessment of cognitive impairment and physical examination. In general, strategies that target Alzheimer's disease, whether at a national level such as in France, Spain or the United Kingdom, or at a sub-national level such as in Ontario (Canada), Sweden or the United States, stress the importance of the early detection of Alzheimer's disease to help patients and their families prepare for the burden of caring that lies ahead.

97. Hopes have been raised about the potential of screening programs using genetic testing. However, these tests, which rely on the presence of the apolipoprotein E genotype, are only able to tell if an individual is susceptible to acquiring dementia in the future; the presence of this genotype does not indicate that a person will develop AD, only that the person is at high risk of developing the disease. As a result, these tests are the subject of intense study to determine their efficacy and how they can be used for

9. This applies more to persons living independently than to those living in institutions because the latter are more likely to already suffer from Alzheimer's, they are generally older and many have been admitted into institutions because they are already suffering from the disease.

10. We attempted to collect data on ambulatory care, including numbers of consultations for dementia by physician specialty, but these data were generally unavailable.

potential screening programs. This uncertainty means that screening programs based on detecting the presence of this genotype have not been recommended (see Annex II for more details).

Drug treatment

98. Medication shows the most promise for the medical treatment of dementia, however, due to the biological complexity of the disease, therapeutic management of dementia is very limited. Though most interventions rely on drug therapy, these provide only symptomatic relief (Mayeux and Sano 1999).[11] Currently, the only drugs approved for treating AD act by inhibiting acetylcholinesterase, a neurotransmitter which correlates with the impairment of memory. Anticholinesterases are only used in the early stages of the disease since it is only effective in patients with mild to moderate AD. This promising class of drugs does not act upon the disease itself, it only slows the progression of the symptoms. The use of these drugs in treating other aspects of dementia, such as mild cognitive impairment, severe dementia and vascular dementia, are an important focus of current clinical trials (see the Annex on research for more details).

99. Tacrine was the first of these drugs approved for the treatment of dementia (Table 4.1). Due to the frequency of adverse effects (Mayeux and Sano 1999), the large dosage required and the need for constant surveillance (Country report France, 2003), tacrine is rarely prescribed today. Indeed, tacrine is no longer approved for use in treating AD in Australia, where it is not included in the Pharmaceutical Benefits Scheme of approved drugs, nor in Japan and Sweden, where it was taken off the market. Tacrine has never been approved for use in Canada nor by the NHS in the United Kingdom.

Table 4.1: Approval dates for the use of anticholinesterases

	Tacrine	Donepezil	Rivastigmine	Galantamine	MMSE score
	Date Approved	Date Approved	Date Approved	Date Approved	
Australia*	1995	1998	2000	2001	10 - 26
Canada (Ontario)	Never approved	1997	2000	2001	10 - 26
France*	1994	1997	1998	2000	10 - 26
Germany		1997	1999		
Japan	Never approved	1999		2001	
Spain			1999		
Sweden	1995	1997	1998	2000	
United Kingdom**	Never approved	2001	2001	2001	12 - 26
United States	1993	1996	2000	2001	

Note: The names of these drugs refer to their non-brand names as they appear in the ATC Index (2000): tacrine (N06DA01), donepezil (N06DA02), rivastigmine (N06DA03) and galantamine (N06DA04).
* Refers to dates drugs were approved for marketing. Australia - tacrine has never been listed on the Australian Pharmaceutical Benefits Schedule (PBS); donepezil, rivastigmine and galantamine were listed on the Australian PBS in 2001. France - tacrine and donepezil were approved for reimbursement in March 1998; rivastigmine was approved for reimbursement in September 1999, 4 months after it was approved for use; galantamine was approved for reimbursement in 2001.
** Donepezil, rivastigmine and galantamine were licensed for use earlier than 2001. These drugs were approved by the National Institute of Clinical Excellence (NICE) in 2001.

11. There are some forms of dementia that are curable through drug treatment, but they are scarce and subject to initial testing when dementia is suspected.

100. Tacrine has since been replaced by a group of three drugs with fewer adverse side-affects: donepezil, rivastigmine and galantamine. Of the three, donepezil has been around the longest (Table 4.1) and is the most widely prescribed because of its once-a-day regimen and reasonable tolerability (Mayeux and Sano 1999). For example, in Ontario at least two-thirds of prescriptions filled for dementia patients were for donepezil. In France, it was estimated that 60% of AD patients who were prescribed drugs were given donepezil. However, donepezil is effective for only some AD patients and its efficacy remains limited for anywhere from a few months to up to 2 years (NIA, 2000).

101. Rivastigmine and galantamine have been approved for treating AD only within the last few years (Table 4.1). These two drugs appear to be prescribed less than donepezil, perhaps because of their more recent availability. The latest anticholinesterase to be tested in clinical trials, memantine, acts against the effects of glutamate in stimulating the N-methyl-D-aspartate receptor, which has been implicated in the pathogenesis of AD. It has brought positive results for treating moderate-to-severe cases of AD (Reisberg B, *et al.* 2003) and is now available in Germany, Great Britain, Sweden and Spain, with clinical trials underway in a number of other countries.

102. Data on utilisation of anticholinesterases by Defined Daily Dosages (DDDs) per 1 000 population per day were available for only 3 countries, Australia, Sweden and the United Kingdom (Table 4.2). As expected, utilisation has been increasing in all three countries. There is significant variation in utilisation across the three countries. Utilisation is greatest in Sweden where anticholinesterases use exceeded 1 DDD per 1 000 population per day in 2000, as compared to 0.073 DDDs per 1 000 population per day in 2000 (increasing to 0.165 in 2001) in the United Kingdom and only 0.021 DDDs per 1 000 population per day in 1999 in Australia. The figure for Australia is based on the use of Donepezil only, but it is still lower than utilization in the United Kingdom where in 1999 use of Donepezil was 0.04s DDD per 1 000 population per day.

Table 4.2: Anticholinesterases - DDD/1000 population/ day

Country	1997	1998	1999	2000	2001
Australia		0.013	0.021	0.00	
Sweden	0.170	0.520	0.850	1.200	1.570
United Kingdom		0.029	0.048	0.073	0.165

Source: *Australian Statistics on Medicines 1999-2000*, Commonwealth Department of Health and Ageing (Australia); Country reports (Great Britain and Sweden).

103. There are some drugs recommended for treating noncognitive symptoms of AD. There is strong evidence from clinical trials that antipsychotics are effective in treating agitation or psychosis in patients with dementia (Doody, *et al.*, 2001). Selective serotonin-reuptake inhibitors (SSRI) have proven to be effective in treating depression (Mayeux and Sano, 1999), but potential side effects should guide the choice of which SSRI is prescribed (Doody, *et al.*, 2001). Behavioural symptoms were reduced in some patients given anticholinesterases in clinical trials, but since behavioural symptoms weren't measured endpoints these drugs cannot be recommended for treatment of behavioural symptoms in AD (Mayeux and Sano, 1999).

Guidelines

104. Given the uncertainty underlying drug treatment for dementia, medical guidelines play an important role in helping determine treatment choices. Guidelines are generally similar across countries, recommending anticholinesterases be used only in patients with mild to moderate forms of AD (except memantamine which is being recommended for use in moderate-severe cases). There are, however, slight

differences in how guidelines define the boundary between moderate and severe AD for the purpose of recommendations for drug therapy.

105. The most commonly used tool to assess cognitive impairment, one that is used by most medical guidelines recommending drug treatment for AD, is the Mini-Mental State Examination (MMSE). The MMSE is a series of questions and mental tests, with a scoring range of 0 - 30. People with AD generally score 26 points or less, with a score of less than 10 historically interpreted as being indicative of severe cognitive impairment (Folstein MF, Folstein SE, McHugh PR, 1975). Based on these scores and the lack of effectiveness of anticholinesterases in treating severe forms of AD, a typical guideline would recommend use for patients scoring 10 points or more, but not for persons scoring less than 10 points, which would be considered severe AD, nor for persons scoring more than 26 points, which would indicate no symptomatic AD present.

106. Guidelines on the use of anticholinesterases for treating AD tend to differ more in where they define the boundary between moderate and severe AD, then on the boundary between mild AD and no AD. On the one hand, some guidelines consider a person to have severe AD if they score 10 points or less on the MMSE scale. This is the case with the PBS in Australia, the Ontario Drug Benefit Plan (Canada) and in France. On the other hand, some guidelines consider a score of less than 12 points as indicative of severe AD. This is the recommendation of NICE (National Institute of Clinical Excellence) in the United Kingdom. In addition to a lack of uniformity in boundaries for the MMSE for guidelines, the presence of other tests of cognitive impairment add to the complexity of defining boundaries on the severity scale for Alzheimer's disease.

107. The impact of guidelines on physicians' prescribing patterns for AD is unclear. They are likely to have been instrumental in influencing physicians to stop prescribing tacrine in favour of donepezil. It is too early to tell what influence guidelines will have on the use of other anticholinesterases. The uncertainty surrounding where the boundary between moderate and severe AD lies may also have an impact on prescribing patterns. Certainly, if NICE (National Institute of Clinical Excellence) used a score of 10 as its definition of the lower boundary for moderate AD then UK physicians would have prescribed more anticholinesterases (assuming the upper boundary does not change).

Awareness of dementia

108. The probability of detecting dementia can be enhanced through increased awareness of the disease by family and friends, the people with the most contact with a person at risk of acquiring dementia. Educational campaigns about dementia are an effective means of making the public aware of the risk factors and signs of dementia. They also fill a need for support and information in the early stages of the disease and help prepare the patient and family for the disease's subsequent stages. The campaigns are an integral tool in the dementia strategies of most governments in the countries in our study. Alzheimer's associations acting as non-governmental organisations (NGOs) representing dementia patients also play an important role in educating the public about dementia. In many cases their advocacy role on behalf of dementia sufferers and their families have pushed governments to make dementia a top priority (details concerning the various strategies in place for combating dementia are included in Annex I, including a table on the various NGOs operating in the countries in our study).

4.2 STAGE: Early - Intermediate

Memory clinics

109. As the disease progresses past the early to the intermediate stage, treatment moves from slowing the progression of the disease to limiting the co-morbidities associated with dementia, such as depression. Presently, there are few effective medical options for treating dementia at this stage.

110. A treatment option that is available for patients in the intermediate stage of the disease is the memory clinic. Memory clinics have existed since the 1980s (Bayer, Pathy and Twining, 1987). There does not appear to be any precise definition of what constitutes a memory clinic, but generally, a memory clinic combines clinical work and research. The clinical work tends to be multi-disciplinary, involving clinicians and social care professionals. The research aspect of memory clinics tends to focus on the evaluation of anti-dementia agents, although some do research on non-drug related care.

111. In one form or another, memory clinics are operated in all the countries participating in our study. It is difficult to obtain an exact number of such facilities, probably owing to the varied nature of their functions. There appears to be little effort to create a national network of memory clinics; information from the various country reports suggests memory clinics seem to develop as local initiatives, most being linked to university hospitals. The National Institute of Aging in the United States funds twenty-nine Alzheimer's Disease Centers whose common goal is to promote research on AD. These clinics are linked to a National Alzheimer Coordinating Center, which facilitates data sharing, and multicentre studies. Additional linkages, in particular for large drug studies, are also in place. In addition, each centre has its own area of research expertise, ranging from medical care treatments to caregiving and coping (Country report US, 2003).

112. In the UK and the US, primary care physicians often refer patients to memory clinics when they are available. In the UK, this probably reflects recommendations from NICE (National Institute of Clinical Excellence) and the NSF (National Service Framework) for Older People which recommend memory clinics, while in the US this is especially true of patients who self-refer. The poor prognosis for anybody afflicted with AD is likely a deciding factor in referring a patient to a memory clinic. Nevertheless, most patients do not live near memory clinics and are therefore more likely to be referred to a specialist for treatment.

Informal care

113. The responsibilities of informal caregivers begin to increase noticeably as dementia progresses from the early to the intermediate stage of the disease. During this phase the focus of support and counselling will begin to shift to the caregiver, though specific needs for support and reassurance will still be appropriate for the patient.

114. Informal care givers also have at their disposal education and training programs to help them provide proper care for dementia patients. Many of these programs are provided through Alzheimer's disease organisations in much the same way as they provide information to the public in general, this is an important source for dementia-specific programs in several countries. Governments are also active in providing needed support to informal caregivers. Some of these programs are listed in Table 4.3.

Table 4.3: Education and Training for Informal Caregivers

Country	Dementia specific	Comments
AUS	Yes	The Carer Education and Workforce Training Project is a short-term programme, which provides coordinated national education and training courses for carers and respite workers caring for people with dementia and aggressive behaviours. Dementia Education and Support Program provides education, support and information services to people with dementia and their carers, including a National Freecall Dementia Helpline.
CAN (Ontario)		
DEU	No	According to Social Law (Sozialgesetzbuch, SGB) XI, participation in educational programmes is free of charge.
ESP		
FRA	Yes	Available in a few AD organizations (*e.g.*, Southern Alzheimer-Paris France Association, France Alzheimer)
GBR		
JPN		
SWE	No	Program is available in most municipalities. It is composed of small groups to encourage mutual support for one another. This program has been expanded over last 3 years.
USA	No	Information is provided on specific diseases and dementias and assistance in learning how to provide hands-on care, generally by private organizations.

Source: Country reports

115. Most dementia patients are still living at home at this stage, although some may move into institutional care. For those patients still living at home, informal caregivers bear the main caring responsibility. For example, it has been estimated in Sweden that the ratio of time spent on care for ADL and IADL by informal caregivers vs. formal caregivers is roughly 4:1 (Table 4.4). This ratio is likely to be higher in countries such as Japan and Spain with strong traditions of extended families, though variations across countries in social support systems may also be a contributing factor.

Table 4.4: Status of Informal Caregivers for the Elderly Living at Home

	Percentage of caregivers who are …				
Country	**Family members**	**Female**	**Spouses***	**Adult children***	**Amount of time spent on care by informal caregiver**
AUS	75% (living in the same household)	72% ('98)[1)]	43%[a)]	26%[b)]	
CAN	92.3%	75%	52.6%	37.8%	
DEU		73%[2)]	28%	22%	45.5 hours per week (dementia care)
ESP		45%[c)]			
FRA		99%[d)]	18%	53%	
GBR					78%
JPN		85%[3)]	36%	52%[e)]	
SWE		62%	91% for male patients; 72% for female patients		80% (ADL, IADL)
USA		75%[5)]	25%[6)]	42%[6)]	67% (including non-dementia) [7)]

***Notes*:**
a) For individuals aged 70 and over requiring care, 72% of caregivers are spouses (Commonwealth of Australia, 2001).
b) For individuals aged 60 and over requiring care, 40% are adult children (Commonwealth of Australia, 2001).
c) As a percent of co-residents spouse caregivers (Schneider, et. al., 1999).
d) Refers to the percentage of females employed in the context of family services.
e) 11% for people aged 60-69; 69% for people aged 80 and over (Commonwealth of Australia, 2001).
***Sources*:**
1) (Jenson and Jacobzone, 2000), *2)* (Ostner, 1998), *3)* (Jacobzone, 1999), *4)* (Schneider, *et al.*, 1999), *5)* (Super, 2002), *6)* (Shirey and Summer, 2000), *7)* (Stone, 2000).
CAN (Smale and Dupuis, 2002).
GBR (Wenger, Burholt and Scott, 1998).
SWE (Wimo, *et al.*, 2002).

116. Family members are the likeliest providers of informal care. Most primary informal caregivers are women. The preponderance of women as caregivers means they are most likely to suffer many of the ills that accompany informal caregiving such as health problems, strained relationships with family and others and a less positive outlook. To a varying degree, adult children or spouses play an important role in informal caregiving. For example, in Japan the responsibility of providing care to frail elderly parents primarily rests with middle-aged adult children, usually daughters-in-law or daughters (Ogawa & Ermisch, 1996). The situation in Sweden, where females are more likely than males to be informal caregivers likely reflects the situation in other countries, although the number may vary. While the characteristics of informal caregivers are well known, what is less clear is the amount of time informal caregivers spend on caring for dementia patients.

117. The burden informal caregivers face has increased with the general shift from institution to community-based care. This is particularly the case for for carers of elderly individuals with dementia, for whom the care required is greater – and requires more continued watchfulness – than for individuals with general disabilities. This shift towards a greater reliance on home-based care is due in part to the recognition by governments that most patients who require care with ADLs and IADLs wish to remain at home for as long as possible, but also because many governments have relied on informal caregiving as a relatively inexpensive means of relieving spending pressures in their health care systems [recent observation of a drop in co-residence among the elderly in Japan and Spain (OECD 2002) may indicate a slowing down of this shift]. Thus, while most countries state they value the vital role informal caregivers play in the care of dementia, the lack of dementia-specific support programs for informal caregivers belies this claim.

118. One of the consequences of providing care for a family member or spouse with dementia is the depletion of personal and social resources. Financial support programs for informal caregivers can help ease some of the financial difficulties families face when caring for a family member with AD. These programs are outlined in Table 4.5. There are two types of financial support available to informal caregivers: tax credits and direct financial support. Canada, Spain and the United States offer tax relief for informal caregivers; in Canada it is a fixed amount of 400 (CDN) per year, whereas in the US the tax relief is equivalent to 30% of expenses incurred in the caring of a disabled adult. Australia, France and Sweden offer direct cash payments to persons who care for a dependent adult. In addition to the cash payment, Australia also offers financial assistance for home modifications. None of these programs are dementia-specific.

Table 4.5: Financial support programs for informal caregivers

Country	Means testing	Tax credit	Comments
AUS	Yes	No	Carer Payment is available to full time caregiver. No overlapped benefit is allowed.
	No	No	Carer Allowance is available to those with heavy caring responsibility. Dual benefit is allowed.
	Yes	No	Financial assistance with home modifications are available with variance from region to region.
CAN	No	Yes	Caregiver Tax Credit: income-restriced refundable tax credit reduces federal income tax by a minimum of (CDN)400 a year for individuals residing with and providing in-home care for an infirm dependent relative over 65.
(Ontario)	No	No	A sales tax exemption for respite care has the effect of reducing the costs to care-givers by approximately 15%.*
DEU	No. Eligibility is based on the patient's need for assistance with ADLs		Benefits are provided by long-term care insurance. Long-term care expenses for up to 4 weeks per calendar year up to 205, 410, 665 euros per year, depending upon the care level. For people with dementia, additional 460 euros are provided according to the LTC Suplementary Act. Informal carers who provide care in the home for at least 14 hours weekly are entitled to a contribution to their pension insurance up to 358 Euros per month. Contributions are ranked by the amount of care provided.
ESP	Yes	Yes	Tax relief is available to families who look after an elderly person.
FRA	Yes (Income affects the amount)	No	Remuneration is provided as part of the Personalized allowance for atonomy (L'Allocation Personnalisee d'autonomie). Informal caregiver (spouses are excluded) may receive this directly or indirectly through service agencies.
GBR		No	The Carer's Allowance, which is specifically for carers who are over working age or unable to work because of caring duties, is not income related although it does have an earnings limit. Cash payments are funded by Benefits Agency.
JPN	See comments		Long-term care insurance
SWE	No. Eligibility is based on the nursing load.	No	Available in 65% of municipalities, varies by municipality. Working age caregiver is paid as much as that of a formal home-helper. Retired caregiver is paid much less. Current trend is away from remunerating caregivers to provision of an increased range of supportive services.
USA	Yes	No	Cash payment or vouchers for services or supplies are available in some states.
	Yes	Yes	Tax credit, which is 30% of the care-involved expenses, is available in the event that the caregiver must pay caring expenses in order to work or look for work.

Source: Country reports except * (Jenson and Jacobzone, 2000).

119. In Germany and Japan, national long-term care insurance is available to provide support for informal caregivers. The German system offers financial compensation for expenses incurred by family caregivers depending on the level of care, including an additional 460 euros per year for people with

dementia (Long-term Care Supplementary Act). The Japanese national long-term care insurance system does not offer direct financial assistance, instead it provides professional services directly for the disabled elderly. In both cases these are non-dementia specific programs.

120. Governments are faced with a dilemma if the financial support provided to informal caregivers is roughly equivalent to the cost of providing professional care. Employment friendly policies aimed at keeping potential informal caregivers employed in the wider labour market could necessitate the subsitution of professional care services. From the patient's point of view, the use of professional services may not be optimal since it may be the combination of help with ADLs provided by a family member or spouse that is most desired.

121. However, social reliance on family care can lead to no professional services being available, due to lack of reliable demand. This is one reason Japan had decided not to reimburse family carers through its newly-introduced long-term care insurance scheme.

122. In addition to the loss or reduction of finances, the loss of pension contributions can weigh heavily on the decision to exit the workforce, whether on a part-time or full-time basis, to care for a family member with dementia. The option of having time spent providing care for a dependent adult credited as a contributory period towards the caregiver's pension may provide a compelling incentive for temporarily leaving the workforce to provide care. Presently 'caring credits' are available in Canada, Germany and the UK.[12]

123. The use of respite services bridges the gap between total reliance on professional care at home and involvement by family and spouses in the care of dementia. Table 4.6 depicts some of the respite care programs in place. Respite care is the provision of appropriate and temporary care or supervision of functionally impaired persons to enable the care giver to maintain his/her provision of assistance to the person. In the present case this would apply to providing that assistance to persons with dementia, although with respect to financial support, there are no dementia-specific programs in place (although Australia appears to be moving towards providing a dementia-specific respite care program).

12. This is the subject of an working paper "The Effects Of Partial Careers On Pension Entitlements", Monika Queisser & Edward Whitehouse (OECD Social, Employment and Migration Working Papers [forthcoming].)

Table 4.6: Respite and group-living care programs

Country	Means testing	Home	Home and institution	Institution
AUS	Yes (both)	Residential Respite : short-term care in residential aged care facilities.	Carer Respite Centre : with a network of day care centres it provides services at day care centre or at home. The centre acts as a single contact point for respite services.	
CAN (Ontario)	Yes			
DEU	Yes	Day-centres*		In Germany there is - in particular in the big cities - a lack of respite services which are mostly associated with nursing homes. Due to progressive decreasing duration of hospital stay this situation probably will get even worse.
ESP	Yes		Expert centres*	Assisted living: Approximately 175,000 places available.
FRA	Yes		Respite hospitalisataion program*	Group-living/cantou: a person is in charge of a dozen residents with cognitive dependency. Features vary depending on institution.
GBR	Yes	Day Care respite is funded by SS, Local Authority (LA), or Voluntary Organizations(VO). Sitter services are funded by SS, VO, or private.		Respite Admissions to hospitals, nursing homes, or residential homes. These are funded by National Health Service (NHS), Social Services (SS).
JPN	NA			Group-living for the elderly with dementia. About 2,200 centres with 1,000 to be added by 2004. This is the preference of many families eleigible for LTC insurance
SWE	Yes	Short-term (1-2 weeks): provides break for personal & medical reasons. Respite care at home is available in 87% of municipalities. Extended over the last few years.	Regular shift model: 2 weeks at home and 3 weeks at care center or vice & versa	Group-living: small group home for 6 – 8 people. Residents have their own room, but share communal areas and have access to service and care provided by resident staff around the clock.
USA	Varies across states	Available in most states. Service delivery and funding differ across states. It is the most prevalent service being provided by states, and is generally in great demand.		

Source: Country reports, except * (Colvez A, et. al., 2002)

124. Respite care is provided at home, in a residential institution, or in some cases a combination of these two residential categories. Colvez *et al.* (2002) analysed 20 different types of respite care programs in eight European countries, classifying them under five different categories of alternative methods of respite care which we have regrouped under the three types of residential categories for which respite care is offered (Table 4.7).

Table 4.7 Respite and group-living care programs by residential category

Home	**Home and residential institution**	**Residential institution**
Home social-services: in addition to social services, may include medical services related to dementia care	*Expert centres*: run by medical services, providing both medical and social care to patient at home or in a residential facility	*Group-living/cantou*: caregiving is based on lodging of patients in specialised housing which groups them around a common living area.
Day centres: daily relief provided to informal care giver	*Respite hospitalisation care*: patient is temporarily hospitalised and when returned home or institutionalised solutions for a better caring program are studied	

Note: See Table 1 of Colvez *et al.* (2002) for more details.
Source: Colvez *et al.*, 2002.

125. Generally, respite care is available in most countries to patients living at home or in residential institutions. On the one hand, this may be limited to respite care restricted to a specific residential category whether it is for patients living at home, such as Residential Respite in Australia or Day Care Respite in Great Britain, or for patients living in residential institutions such as respite care associated with nursing home in Germany or with Group-living/cantous in France. Hybrid respite programs like the expert centres in Spain or Australia's Respite Care program offer patients and their care givers more flexibility in the care setting, be it at home or in an institution.

126. Assisted-living, which includes group-living and cantou, has gained in importance in recent years as a means of respite care.[13] Sweden in particular has embraced the group-living concept as a successful housing arrangement for people with dementia. Although there are no dementia-specific group-living facilities, 15 000 of the 17 000 available beds are occupied by dementia patients. In fact, group-living has been so successful that group-living facilities are now being integrated into other assisted-living facilities (Wimo, *et al.*, 1995; Annerstedt, 1997).

127. As the prevalence of dementia increases in the future, the pressure for governments to rely on informal caregivers will increase. However, the increased demand for informal caregivers may be accompanied by a decrease in supply (See Text Box 4.1). This will limit the scope for using informal care givers as a substitute for professional home care services, as well as increase the pressure to admit dementia patients into long-term care institutions or provide long-term care in acute care hospitals. This problem may be somewhat mitigated if the recent experience in Sweden, where informal caregivers upped their contributions in response to reductions in formal care services (Johansson, *et al.*, 2003), is an indication of future responses to excess demand for formal care services. In any event, the flexibility of

13. Assisted-living can be considered as institutional long-term care if only patient residency is taken into account. Colvez *et al.* (2002) treated group-living/cantou as respite care in the sense of providing support to informal caregivers who would, however, cease to co-habit with the patient. The essential element of assisted-living is that it groups together individuals with cognitive impairment whereas long-term care facilities tend not to distinguish patients with cognitive impairments from other patients.

governments to use informal care givers as a means of reducing health care spending will be greatly diminished.

Box 4.1: Future availability of informal caregivers

There are several reasons to suspect that the availability of informal caregivers will decline in the future. Below are some trends which, if they continue will contribute to reducing the availability of informal caregivers:

Ageing populations: will mean an increase in the number of very elderly people, who are less able to provide informal care for their spouses than younger people. The overall effects of ageing are, however, ambiguous. Some projections from the United Kingdom indicate a *growing* supply of care in the next 20 years due to an increase in older spouse carers offsetting the decline in younger family members (Pickcard, *et al.*, 2000). It is not known whether similar projections have been found for other countries.

- Increase in labour market participation among women (Stone, 2000): the availability of daughters to provide informal care will decrease due to competing demands from work and child rearing as their participation in the formal labour market increases.
- Smaller family sizes: reduced birth-rates and changes in family structure due to divorce, separation and single person households will contribute to smaller families. The decline of the extended family, in particular in countries where this is more prevalent, will also contribute to reducing the availability of informal caregivers.
- Geographic distance between elderly parents and their children: as more children move further away from their parents' homes, the pool of individuals able to care for aging parents will diminish.
- Changing norms about care giving for parents: will contribute to declining numbers of informal caregivers if Jansson *et al.*'s (1997) study in Sweden, where a growing proportion of adult children were not willing to care for their frail parents in the family home, reflects evolving tendencies in other countries.

4.3 STAGE: Intermediate - Late

128. Once dementia has progressed beyond the intermediate stage, worsening symptoms and other emerging difficulties such as wandering render the role of the caregiver particularly difficult. At this stage formal and institutional care takes over the role of primary caregiver. Also at this stage, the social care aspect is now the dominant feature of dementia care, with health care relegated to the control of distressing symptoms (antipsychotic drugs are often subscribed by doctors, but these have not proved to be very effective). Patients in the intermediate to late stages of dementia require full support with ADLs, requiring more professional care giving and, almost inevitably, admission to a long-term care institution.

129. At this point it may be useful to clarify the concept of long-term care.[14] For the purpose of this study it is defined as 'health and social care given on a continuing basis to older/individuals with chronic impairments and/or a reduced degree of independence in activities of daily living.' The concept of long-term care is broader than the medical model associated with more acute care, and has been described as primarily low-tech, although perhaps more complicated as the severity of illness in long-term care has tended to increase in recent years (Stone 2000).

130. Paraprofessionals, certified nursing assistants, home health aides, home care workers and personal care workers are the primary providers of formal social care for dementia patients and are overwhelmingly female (Stone, 2000). Most of them, with the exception of nursing background staff, have no formal qualifications and low remuneration.

14. The issue of long-term care is dealt with in greater detail in another OECD study, the Long-Term Care Study which is due to be completed early 2004.

131. Most countries are experiencing staff shortages in long-term care facilities. Both Australia and France reported a shortage of qualified nurses. Germany traditionally has fewer nursing staff in nursing homes than other European countries and the situation may be worsening as staff-to-resident ratios have fallen recently. The Bureau of Labour Statistics in the United States estimates that personal and home care assistance will be one of the fastest growing occupation categories, however, the available pool of labour may fall short of demand because of the difficult work and low pay.

Formal non-institutional care (community care)

132. Community care is the bridge between care provided mainly by family members, where the patient is still living at home, and long-term care where care is provided by professional carers where the patient is living full-time in a long-term care institution. The fundamental difference between long-term institutional care and community care is that under the latter, formal care-giving services support non-institutional residence. Older people with dementia may stay at home or in temporary care facilities for a short period of time in community care whereas institutional care is usually regarded as a permanent residence. Furthermore, community care is different from informal care at home in that various formal care-giving systems are involved in the caring process, which can be provided with or without the involvement of informal caregivers. Community care services are not meant to provide temporary relief to informal caregivers, instead they are full-time professional care services provided to the patient when the burden placed on the informal care giver is no longer tenable.

133. Governments have recognized both the need and importance of community care for people with dementia for a number of reasons:

1) Most expect demographic and social changes that might impact on the informal network of social care (see Box 4.1);

2) the well-being of elderly people who are ill is partly dependent on the well-being of their caregivers, consequently there is a need to decrease the burden on informal caregivers;

3) the shift from institutional to community care entails a decrease in public expenditure, assuming that care provided in the community is less expensive than care provided in an institution; and

4) this shift was accompanied with the belief that care outside an institution is likely to result in a higher quality of life for the patient.

134. In most participating countries, various community-based social care programs have been developed. However, the extent and level of service programs vary from country to country. Table 4.8 shows features of community home help services for the elderly.

Table 4.8 Community care (home-help services)

Country	Help ADL	Nursing Help (non ADL)	Means Tested	Dementia-specific	Comments
AUS	Yes	Yes	Yes		Home and Community Care Programme (HACC) is open to everyone who needs care. Services may be charged. Eligibility for both Community Aged Care Packages (CACPs) and Extended Aged Care at Home (EACH) Programme is assessed by an Aged Care Assessment Team.
CAN (Ontario)	Yes	Yes	Yes		In Ontario Community Care Access Centres (CCACs) determine eligibility for, and buy on behalf of consumers highest quality best priced visiting professional and homemaker services.
DEU			No	Yes	Long-term Care Supplementary Act support home care for people with dementia.
ESP					Systematic ADL and nursing help services are being developed
FRA					
GBR	Yes	Yes	Yes	Yes	Care from a registered nurse is always provided free by the NHS, regardless of setting.
JPN	Yes	Yes	See comments (far right column)		Covered through Long-term care insurance. Services are provided depending on patient need.
SWE	Yes			Yes	Eligibility varies among municipalities.
USA	Yes				Medicaid-eligible people can get services. For home health care, doctor's certification is needed.

Source: Country reports

135. Similar to programmes for informal caregivers, most countries do not provide dementia-specific home help services. Germany, Sweden and the United Kingdom have introduced dementia-specific home care services programs. In January 2002, as part of the Long-Term Care Supplementary Act, benefits from long-term care insurance for people with dementia and in significant need of care were increased in Germany. Day care for people with dementia has been available in Sweden since the early 1990s. Since the Social Services Act stipulates that the responsibility of providing social services and personal care falls upon the municipalities, day care services for dementia vary by region. Not surprisingly, day care has a positive effect on the well-being of patients and informal care givers alike. In fact, Wimo, *et al.*, (1990) and (1993) concluded that the benefits of day care might be even greater for the informal caregivers/spouses.

136. Most community services for older people with dementia are delivered within the general long-term care systems of each country. The Social Services Act in Sweden and long-term care insurance in Germany and Japan provide these services. In Australia, the Home and Community Care Programme, started in 1985, covers these services and has been enhanced in subsequent years by the introduction of

Community Aged Care Packages in the 1990s. The Australian government's commitment towards a greater emphasis on community care has continued in 2003 with an informal review of the community care system, with the goal of developing a comprehensive model for the national provision of community care services. A formal system of community care is not yet in place in Spain, but a system of home-help services is being developed.

137. It is difficult to pinpoint exactly what factors determine the use of community care. In a Canadian study, Morgan *et al.* (2002) identified barriers to the use of formal services by rural families caring for a relative with dementia. These barriers include: lack of privacy, erroneous beliefs and attitudes, lack of awareness, problems in acceptability and accessibility of services, and difficulties in service delivery (*e.g.*, patients' refusal to help). Home care staff observed that in many cases caregivers refused to accept any help until they had reached a crisis situation, which often involved a breakdown in the caregiver's health.

138. Once the decision has been reached that care support services are required, eligibility is determined through a needs assessment test. Who determines eligibility varies from country to country. To qualify for a place in a special home in Sweden, elderly people must be tested in terms of their care needs by municipal authorities. In Germany (Medizinischer Dienst der Krankenkassen), Japan (Long-Care Insurance) and the United States (Medicaid), eligibility is assessed by a health insurer. In Japan, eligibility is assessed using an 85-item assessment tool to establish the level of impairment (0-5 levels), in Germany a medical services team assesses the level of assistance required for ADLs while in the U.S., eligibility depends on the specific state's functional eligibility requirements. In the United Kingdom, the assessment of care needs is initiated by whichever health or social care professional first comes into contact with the patient, whereas in both Australia, through Aged Care Assessment Teams (ACATs), and France, a medico-social team assesses eligibility.

Formal institutional care

139. The late stages of dementia require continuous care, rendering it almost impossible to provide adequate care at home. Dementia patients in the late stage of the disease almost always require continuous care and thus are admitted to a long-term care facility where such care is possible. However, there is no strict definition of what constitutes a long-term care facility, other than the fact that persons admitted are resident full-time. For example, in Sweden nursing homes, homes for the aged and group living are all classified as "special housing (Särskilt boende)" units. In all the Scandinavian countries some places in nursing homes are used for short-term care (Szehebely, 1999). Hence, in physical terms there are difficulties in identifying a building, a ward or a room as "a nursing home bed."

140. The two main determinants of admission to a long-term care institution for dementia patients are the severity of dementia and caregiver-related factors. Dementia severity has been identified as a key predictor of institutionalisation in many studies (Juva *et al.*, 1997; Fratiglioni et at., 1994; Severson *et al.*, 1994). A longitudinal study conducted in the United Kingdom (Cohen & Pushkar, 1999) supported this by noting that the group moving directly into long-term care tended to have lower MMSE scores, with more deterioration on the Global Deterioration Index at the beginning of the study. A Canadian longitudinal study (Hebert *et al.*, 2001) also identified severity of disability due to dementia as one of the key risk factors for institutionalisation. Caregiver-related factors are the other strong predictor of institutionalisation (*e.g.*, Brodaty *et al.*, 1993; Cohen *et al.*, 1993). The study by Hebert *et al.* (2001) identified such caregiver-related risk factors for institutionalisation as age over 60, not being first-degree-kin and poor health of the caregiver.

Table 4.9 Long-term care facilities

Country	Admission eligibility	No. of Beds	No. of residents with Dementia	Comments
AUS	People with a high level of disability and care needs, assessed by ACATs, may be admitted.	143,000	Number of beds: 151,000; Number of residents with probable dementia: 46,000	Funding is provided by the Federal Government according to the Resident Classification Scale (RCS). It is estimated that about 40 % of all people with dementia are thought to be currently receiving care in federally subsidised aged care homes (Australian Institute of Health and Welfare, 2001) Dementia is not considered as a specific condition in admission.
CAN	In Ontario, Community Care Access Centres (CCACs) determine eligibility for, and authorize all admissions to, all long-term care facilities.			CCACs, instated by the Ontario Ministry of Health, are governed by independent, incorporated non-profit boards of directors. The boards are accountable, through service agreements, to the Ministry of Health.
ESP	The most critical factor to be considered in admission is the existence of a caregiver among the patient's relatives who can look after the patient.	3,328 homes	NA	Varying levels of medical care are provided. Of 3,328 homes, 43.93% are privately-owned, and 22.86% are publicly-owned.
FRA		247,000 places in long-term care centres (2000).	NA	Defined as: medicalised institution where medical care is provided. It may be chosen as the last resort. Seldom a deliberate choice for the elderly.
DEU		8,900 nursing homes (About 621,000 long-term institutional care places) (2000)	About 60% of the total residents (about 50,000)	Short-term, part-time (day or night), or full-time institutional care is available. In the case of full-time institutional care, care costs up to a total sum of 1,432 euros per month is provided. Long-term care expenses are covered by long-term care insurance, which is compulsory.
GBR	Means tested	NA	NA	As of 2000 nursing care is available for free under the National Health Services to everyone in a care home who needs it.
JPN	People aged 65 and older needing nursing care, who are insured by LTCI may be admitted.	NA	NA	Nursing care is provided by local government or private licensed providers. Dementia is one of 15 age-related diseases.
SWE	Those elderly who are in very extensive need of care and attention.	29,000	23,000	In some municipalities, special dementia care units have been integrated within nursing home facilities. There is an emergence of small homelike units with all the medical and technical resources of a nursing home.
USA		1,965,000	About 50% (in 1996, 19.2% of nursing homes had special care units, 65.6% of which are for patients with dementia).	In 1999, more than half of Medicaid funding was spent on institutional care. Ownership: Government - 6.7%; Private for-profit - 64.8%; Private non-profit - 28.6%. Expenditure: $111 billion in 2002 (28% Private; 38% Medicaid; 30% Medicare; 4% Other sources)

141. Patient's level of care need was cited most often as the main determinant of admission to a long-term care facility (Table 4.9), despite the fact absence of an informal caregiver(s) is one of the major predictors of earlier institutionalisation of people with dementia. One exception is Spain where absence of an informal caregiver was cited as the critical factor for admission to a long-term care facility. However, for patients in the late stages of dementia, even in the presence of an informal caregiver, level of care need is likely the most important criterion that needs to be assessed since the burden of care at home is probably too great. Unfortunately for late-stage dementia sufferers, admission eligibility tends to be based on the amount of care services required with no specification as to type of disease, meaning dementia patients are assessed the same along with patients with other physical and mental disabilities. Faced with a shortage of eligible places in almost all countries in the study, late-stage dementia patients, especially those with aggressive behaviours, have greater difficulty in finding places in long-term care facilities since facilities will tend to pick the least burdensome patients from those eligible for admission.

142. In practice, with the possible exception of France, cream skimming of patients eligible for admission to a long-term care facility was not cited as a problem. In France, a diagnosis of Alzheimer's disease was reported to be a factor for a non-specialised institution to refuse admission. With less than ten specialised psycho-geriatric institutions in the country, such adverse selectivity can pose problems in securing necessary care and relieving informal carers. Recognizing the problem dementia sufferers face in gaining admission to long-term care facilities, the Australian government introduced the Residential Classification Scale (RCS) in 1997 to provide greater incentives for long-term care facilities to admit dementia patients. Funding under the RCS increases as the severity of dementia increases, making it easier for late-stage dementia sufferers to gain admission to long-term care facilities. Since the introduction of the RCS, average funding for residents with dementia has increased 124%.

143. Once dementia patients are admitted into a long-term care facility, they are generally treated the same as other patients although in Japan and Spain dementia patients tend to be isolated. Recognizing the special needs of dementia patients, long-term care facilities are increasingly singling dementia patients out for special care. Provision of special care to dementia sufferers may also have beneficial outcomes for non-demented residents (Tinker A, 1994). Special care units for dementia patients have been developed, or are in the process of being developed, in Great Britain, Germany (Demenzstationen), Sweden and the United States. Specific details on the composition of the units are not available but there is likely to be considerable variation. Whether or not isolating dementia patients from other residents enhances their well-being is subject to debate. However, the aim of these special units is not to isolate dementia patients, but to maximize the well-being of patients with dementia, facilitate their care and minimise the burden to personnel.

144. Germany is the one country where dementia-specific long-term care institutions exist. As well as significant efforts to develop assisted-living units within and outside of nursing homes as alternatives to classical nursing homes, special care nursing homes have been built which cover the whole spectrum of dementia care and provide an adequate environment for people with dementia.

145. In the absence of dementia-specific long-term care institutions or special units, some types of long-term care provision are better able than others to cope with the demanding care that dementia patients require. The composition of 'high-level care' institutions vary across countries, but generally in addition to accommodation they provide nursing and personal care and are therefore better able to meet the special needs of late-stage dementia patients – even if the services are not tailored specifically to dementia but more generally to all patients requiring greater levels of care than normal long-term care residents. For example, 'nursing homes' in Australia deliver high-level care. There are also some aged care homes in Australia that specialise in low-level care but which offer the full continuum of care allowing residents to stay in one location even as the type of care they need increases. However, in most countries, psychiatric facilities or hospitals provide this type of care.

146. In general, with a few exceptions in Germany, dementia-specific long-term care institutions do not appear to exist in the countries participating in this study. This is not optimal for meeting the care needs of dementia patients. However, the existence of specialised dementia units within long-term care institutions and high-level care homes demonstrates that there is a recognized need to provide additional care for late-stage dementia patients. This may lead to the future development of dementia-specific long-term care institutions.

4.4 STAGE: Late – End of Life

147. The final stage in the progression of any terminal illness is death. The progressive, degenerative nature of AD can make the road leading up to this point a long and difficult journey for both patient, family and friends. At this stage medical treatment marginally prolongs life and is related to treating the complications of the disease such as pneumonia.

Palliative care

148. Palliative care is care received by patients in the terminal phase of their illness. The goal of palliative care is to provide comfort and minimise pain knowing that medical intervention is no longer a viable option. The intention of palliative care is not to hasten death but to improve the quality of life for the patient. Palliative care also includes support for the patient's family to help them cope with the illness and their bereavement afterwards.

149. The use of palliative care for end-stage dementia patients does not appear to be widespread.[15] The reasons for this situation are difficult to fathom since end-stage dementia shares many of the same characteristics as other terminal illnesses, such as cancer, for which palliative care is widespread. What is more, hospices and specialist palliative care services are not likely to have the expert skills necessary for dealing with the special problems associated with dementia. In the UK, a recent report highlights the issue of palliative care for mental health with specific recommendations for dementia (Addington-Hall J, 2000). Other studies, such as the *Development of Guidelines for Palliative Care in Residential Aged Care* in Australia may include specific issues relevant to dementia. Hopefully more research and development into palliative care for dementia will be forthcoming.

4.5 Issues to consider

150. At present there is no cure for dementia and Alzheimer's disease. Anticholinesterases offer the most promise so more clinical trials on these drugs should continue. Research funding should be encouraged to test these drugs for non-cognitive problems such as depression and to continue work on other forms of dementia and mild cognitive impairment, as well as for more severe forms of dementia. These drugs have been proven to be effective against placebo or non-treatment so the next step in clinical trials should be to directly compare these drugs.

151. Financial support for informal caregivers offers a means by which carers can care for a demented person without the prospect of a precipitous drop in finances. But other considerations need to be taken into account. On the one hand, these supports offer disincentives to older female workers, who are most likely to be providing informal care to an individual with dementia, to remain in the workforce. Whether or not this is desirable, financial support alone may not be enough to ensure informal care is provided. For

15. This was not identified as a priority area at the November 2002 experts meeting. The evidence of a lack of palliative care specific to dementia is based on the direct responses of a few of the experts participating in the study, a cursory review of the relevant literature and the many non-responses from the experts to the question of whether a discussion of palliative care was warranted.

example, informal caregivers may feel the loss of pension contributions outweighs the financial support and thus opt to remain in the workforce. This could lead to more costly community care or admission into a long-term care facility.

152. There are several effective choices for respite care, with group-living appearing to be the most popular and gaining in popularity. The reasons for the popularity are not entirely clear, but more studies comparing different modes of respite care, such as Colvez *et al.* (2002), are needed to provide the evidence base to support the growing consensus that group-living is the most effective means of respite care for dementia caregivers (see Table 4.7).

153. When home-based care is no longer tenable, admission to a long-term care facility is the next step. At present there are two main patient characteristics that determine admission for a person with dementia: severity of the disease and the availability of an informal caregiver. Both characteristics should be considered and the special requirements of dementia patients should not hinder admission.

154. What the future holds in terms of the supply of carers for persons afflicted with dementia is a particularly important issue. Most signs point to a diminishing pool of informal caregivers to choose from which could put strains on other caring modes for dementia patients. For example, this could lead to long-term care facilities in earlier stages of the disease or a greater use of formal home-based care. However, current lower remuneration and difficult working conditions may have the same effects on the supply of formal carers, exacerbating the problem further.

155. Finally, a number of proponents espouse the view that the special problems of dementia patients warrant special treatment. As a result dementia-specific programs are beginning to take root. In many cases the evidence for the effectiveness of dementia-specific programs is lacking or at least ambiguous. Competing resources for caring for other diseases means that careful consideration of the evidence is necessary before embarking on these types of programs. Better co-ordinated services, for both dementia care specifically and mental health in general, should help to facilitate this task.

5. OUTCOMES

156. Health outcomes have been described as "those changes in health status strictly attributable to the activities of the health system" (Hurst 2002). This definition of health outcomes has particular relevance for dementia, for it encompasses not only the view of health outcomes as being the result of health care interventions, but also takes account of the social care aspect of dementia care. It also extends beyond dementia patients since caring for a family member with dementia can negatively impact on the caregiver's health.

157. A detailed assessment of the efficacy of each of the interventions examined in the previous section is beyond the scope of this study. The purpose of this section is to provide some rationale for why some interventions are favoured more than others, the rationale being interventions with favourable outcomes.[16] It relies on the research literature to provide the required information, making use of meta-analyses of published studies wherever these existed. This task is easier for health care interventions, since the field can easily be narrowed down to the use of cholinesterase inhibitors, the only widely accepted medical treatment for dementia. The plethora of research studies on social care of dementia in recent years, the penury of syntheses of findings and the lack of established social measures such as quality of life relative to health-related measures makes assessing the efficacy of social care more difficult.

5.1 Care receivers

158. Presently, dementia is poorly assessed by the usual health outcome indicators. Biological and imaging markers are lacking, and most importantly, survival rates are complicated by the age specific prevalence of dementia (the oldest are at increased risk for dementia), and from the lack of accuracy in estimating the time of dementia onset. This is not surprising since the only known effective health care interventions for dementia are aimed at slowing the progression of the symptoms of the disease, not the disease itself. Therefore, measures of cognitive decline and functional disability are important outcome measures for dementia.

159. The multiple aspects of dementia, progressive and irreversible decline in cognition, activities of daily living (ADL) and behaviour, make it a difficult disease to quantify in a single health outcome measure. Therefore, there are a number of outcome measures that have been developed for dementia and Alzheimer's disease. Since it is the loss of cognition that most characterizes dementia, the most commonly used health outcome measures tend to be those used to assess this aspect of the disease. These include the Mini-Mental State Examination (MMSE) and the Alzheimer's Disease Assessment Scale-cognitive subscale (ADAS-cog). The Clinical Dementia Rating (CDR) scale is another tool that measures several aspects of dementia, providing a global measure of dementia health outcomes.

16. There are numerous reasons why some interventions get favoured over others, which do not always conform to the evidence-base.

Table 5.1: Features of outcome measures that make them suitable for use in clinical trials on clinical practice

Aspect	Outcome measure	Features of an "ideal" assessment scale			Ideally suited for assessing given aspects in		
		Valid	Reliable	Adequate assessment of aspect in question	Clinical trials	Clinical practice	Regulatory purposes
Cognition	ADAS-cog	X	X	X	X		X
	MMSE	X	X	X	X	X	
	DAD	X	X	X	X		X
ADL	ADCS/ADL	X	X	X	X		X
	PDS	X	X	X			X
	GAS	X	X	X		X	
Behaviour	NPI	X	X	X	X	X	X
Global Function	CIBIC-plus	X	X	X	X	X	X
	CDR	X	X	X	X	X	X
	GBS	X	X	X	X		X

Adopted from Winblad *et al.* (2001)
Acronyms for outcome measures: ADAS-cog (Alzheimer's Disease Assessment Scale-cognitive subscale); MMSE (Mini-Mental State Examination); DAD (Disability Assessment for Dementia); PDS (Progressive Deterioration Scale); GAS (Goal Attainment Scaling); NPI (Neuropsychiatric Inventory); CIBIC-plus (Clinician's Interview-Based Impression of Change); CDR (Clinical Dementia Rating); GBS (Gottfries-Brånes-Steen)

160. In a recent review, a group of 10 physicians from Australia, Canada, France, Japan, Sweden, the United Kingdom and the United States reviewed current criteria used for measuring success in treating Alzheimer's disease (Winblad *et al.*, 2001). Though the purpose of the review was to assess outcome measures for use in clinical trials of pharmaceuticals for treating Alzheimer's disease, the study provides a useful reference for the various instruments available. Table 5.1, reproduced from the study, summarizes the various outcome measures available and their suitability for use in clinical trials. All the measures in question were deemed valid, reliable and able to provide an adequate assessment of the aspect in question, which, depending on the instrument was cognition, activities of daily living (ADL), behaviour or global function. Where they differed was with respect to their suitability for assessment in one of three areas, clinical trials, clinical practice and regulatory purposes. For the purposes of this section, our interest lies with the first two areas.

161. As noted above, both ADAS-cog and MMSE are commonly used measures of cognitive function. Although both measures are used for assessing results of clinical trials, ADAS-cog is considered a more sensitive measure of cognition, assessing a range of functions including memory, language, orientation and praxis and is probably a superior research tool. The complexity of ADAS-cog is a disadvantage in clinical practice, which makes the easier to use MMSE more suitable for use by practicing physicians (Tariot 2001).

162. Regarding ADL, Winblad *et al.* conclude that the Disability Assessment for Dementia (DAD) scale and the Alzheimer Disease Cooperative Study ADL score (ADCS/ADL) were ideally suited for clinical trials but not for clinical practice, for which Goal Attainment Scaling (GAS) was ideally suited. However, given the difficulties in comparing patient responses regarding their goals, GAS is likely not a suitable outcome measurement tool for an international comparison study.

163. Due to the variability in behavioural aspects, finding a suitable measurement tool is difficult. The authors felt the Neuropsychiatric Inventory (NPI) was ideally suited for assessment of behaviour in both clinical trials and practice. The added advantage of the NPI is that it can be used to assess the amount of caregiver stress, an important outcome for dementia care as will be seen below.

164. Finally, two measurement tools of global function were rated suitable for both clinical trials and practice. The Clinician's Interview-Based Impression of Change – plus caregiver input (CIBIC-plus) asks whether the patient has improved, stayed the same or worsened in terms of behaviour, general psychopathology, cognition and ADL. However, there is potential bias based on the value assessments of the evaluating physician (Winblad, *et al.*, 2001), which may make it less suitable than the Clinical Dementia Rating (CDR) scale. The CDR scale assesses the patient's abilities to function in memory, orientation, judgement, ADL, hobbies and interests, and ability to live in the community, based on information gleamed from both the patient and a reliable informant. The advantage of the CDR over CIBIC-plus in an international study is that it has been standardized for multicentre use (Morris, *et al.*, 1997).

165. Perhaps the easiest health outcomes indicator to measure is time from diagnosis to long-term institutional care or nursing home placement (NHP). It is an important measure since it represents a major milestone in the progression of dementia. The date of admission to a long-term care facility should be easily retrievable from administrative data bases or during follow-up in clinical trials, lends itself to survival analysis and is easy to measure (Knopman *et al.*, 1999). Some difficulties in using time to NHP do arise. Measuring the starting point would be difficult since diagnosis of dementia can be unreliable. Due to the uncertainty regarding time elapsed from the first signs of cognitive decline to definite diagnosis of dementia, studies using time to NHP as an outcome measure ideally are based on incident cases of dementia (Sweden country report). For international comparisons, time to NHP may not be appropriate since it assumes there are no differences across countries regarding their long-term care institutions. Nevertheless, time to NHP appears to be closely related to the progression of dementia and should be considered a valid outcome measure (Knopman *et al.*, 1999).

166. Studies have shown there are a multitude of characteristics predictive of length of time from diagnosis of dementia to nursing home placement. Not unexpectedly, severity of dementia at baseline is predictive of a shorter length of time to nursing home placement (Yaffe *et al.*, 2002; Heyman *et al.*, 1997; Hogan *et al.*, 1994; Fratiglioni *et al.*, 1994). Other characteristics that have been shown to predict a shorter length of time to NHP include increased age, unmarried (even stronger for unmarried men) and male (Yaffe *et al.*, 2002; Heyman *et al.*, 1997; Hogan *et al.*, 1994). However, these characteristics may not be as strong predictors of dementia severity. In a study of 341 patients from a clinical trial of selegiline and tocopherol, Knopman *et al.* (1999) show that patients admitted to a nursing home had no difference in two patient characteristics, gender and age, from those patients not admitted to a nursing home at baseline, but who had more severe cases of dementia.

167. One explanatory variable Knopman *et al.* did not include in their study was a measure of caregiver well-being. This is important because there are studies that demonstrate that health care interventions aimed at caregivers may result in lengthening the time to NHP. In two separate studies, comprehensive support and counselling services for spouse-caregivers had a demonstrable effect on reducing time to NHP (Mittelman *et al.*, 1996; Mittelman *et al.*, 1993).

168. In the study by Knopman *et al.* (1999), they found that after a two-year period, 33% of patients enrolled in a drug trial, all classified as stage 2 dementia on the CDR scale, were institutionalized. Their results also show that a greater proportion of patients whose CDR staging of dementia deteriorated to stage 3 were institutionalized than those who remained at stage 2. Heyman *et al.* show that the overall median time from enrolment in the study to the first event, NHP or death, was 3.1 years, but was significantly less for unmarried men (2.1 years) than for married men or women.

169. Where time to NHP is not available, placement in a nursing home itself may be considered as a suitable health outcome for dementia. There are many studies that show NHP to be associated with dementia. An early study in Sweden found that 55% of subjects with dementia were institutionalized

compared with only 3% of non-demented patients (Fratiglioni, *et al.* 1994). Of 553 patients admitted to a Canadian dementia clinic and followed for five years, 79% of patients with probable AD were institutionalised (Hogan, *et al.*, 1994).

170. Perhaps due to long duration, where survival of ten years is not uncommon, and poor prognosis, where treatment is aimed at slowing the progression of the disease, most studies on dementia and AD do not use mortality as an outcome measure. From an epidemiological point of view, dementia and Alzheimer's disease are similar to cancer in that the duration of the disease can be lengthy and is terminal (much less so for cancer), a profile which should lend itself to using survival as an outcome measure for dementia. Yet survival as well is not a commonly used outcome measure for evaluating interventions for dementia and AD.

Results

171. A sufficient evidence-base has been developed concerning the use of cholinesterase inhibitors that most countries have in place guidelines regarding their use. The outcome measure most used for recommending the use of these drugs is the MMSE measure of cognition (Table 4.1), but this is likely due to its greater ease of use in clinical practice than some of the other measures of cognition (Table 5.1). A survey of a review article on best-practices for managing dementia (Doody RS, *et al.*, 2001) shows that the outcome measures used most often for evaluating clinical trials of cholinesterases inhibitors are ADAS-cog (cognition – used in 10 of 16 identified trials) and CIBIC-plus (global functioning – used in 8 of 16 identified trials). MMSE was used in 5 trials but as a secondary measure of cognition to ADAS-cog in 4 of these trials.

172. Based on evidence from clinical trials, outcome measures of cognition, behaviour and global functioning demonstrate that cholinesterase inhibitors are better than placebo, but no head-to-head comparisons have yet been made (Doody RS, *et al.*, 2001). Memantine, another cholinesterase inhibitor, has been shown to be effective in moderate-to-severe AD using CIBIC-plus and ADCS/ADL as the primary outcome measures (Reisberg B, *et al.*, 2003). Although survival was not measured in these trials, cholinesterase inhibitors delayed progression of symptoms by about 3 to 6 months compared to placebo which may increase survival if the end point death is also delayed.

173. Doody *et al.* also reviewed some non-pharmacological interventions for dementia care. They found that educational programs had no effects on disease severity, although some programs did delay placement in a nursing home. Alzheimer's special care units in long-term institutional care units were demonstrated to have some success in reducing patient behavioural disturbances, but the strength of the results were limited by a lack of randomized controlled clinical trials.

5.2 Impact on informal caregivers

174. The demands of caring for someone afflicted with dementia can be stressful. In general, informal caregivers are less healthy than non-caregivers (Ory *et al.*, 2000; Ory *et al.*, 1999; Grafström, Nordberg and Winblad, 1993; Grafström, *et al.* 1992). In fact, there is evidence to suggest that caring for a person with a cognition-impaired disability, such as dementia, may be more burdensome on the caregiver than caring for a person with a physical disability (Schofield, 1998; Light, Liederhe and Lebowitz, 1994; Morris, Morris and Britton, 1988).

175. Understandably, the situation of caregivers for persons suffering from dementia is portrayed in a negative tone. This characterisation, however, belies what many caregivers may feel; that caring for an afflicted loved one, while an unexpected task, is seen more as an accepted responsibility that they wish to be an integral part of, rather than an unwelcome burden. A good example of this ambiguity is seen when

family members are confronted with the decision to admit a family member suffering from dementia into a long-term care facility. Arguably, this may be one of the most stressful decisions a person is required to take, despite the significant reduction in the burden of care. The reduction in a caregiver's welfare due to the unexpected and stress inducing responsibility of caring for a loved one afflicted with dementia may be offset by the positive experience of being an integral part of the patient's care.

176. It is well established that caring for a family member with dementia places a significant psychiatric burden on the caregiver. Researchers generally rely on three tools to help them assess the psychiatric burden caregivers carry: standardized self-report measures, structured diagnostic interviews and indicators of psychotropic drug use (Ory, *et al.*, 2000).

177. Studies have shown that the most common psychiatric morbidities appear to be anxiety and depression (Dunkin & Anderson-Hanley, 1998; Schulz *et al.*, 1995). In both Canada and the United States, it is estimated that about half of caregivers suffer from some form of depression (Small, *et al.*, 1997; Schulz, *et al.*, 1995; Schulz and O'Brien, 1994; Gallagher, Lovett and Zeiss, 1989). Colvez, *et al.* (2002) found that 78% of spouses and 47% of children caregivers in 7 countries (Belgium, Denmark, *France*, *Germany*, *Spain* and *Sweden*) suffered from depression.

178. Beyond the psychological impact of providing care for a family member with dementia, what is less known is that there is a significant negative physical impact as well, though the results are not as clear (Ory, *et al.*, 2000; Grafström, *et al.*, 1992). Studies reporting on the physical well-being of caregivers measure four basic types of outcomes: self-rated global health; the presence of chronic conditions, illnesses, physical symptoms, and disabilities; health-related behaviours, medication use, and health services utilisation; and physiological indices (Ory *et al.*, 2000).

179. Caregivers generally assess themselves as being in poorer health than persons with no immediate family member suffering from dementia (Ory, *et al.*, 2000). Also, when compared to relatives of persons institutionalized for dementia, dementia caregivers may have poorer health (Grafström, Nordberg and Winblad, 1993; Grafström, *et al.*, 1992).

180. Most of the main determinants of negative health outcomes for caregivers closely resemble those for general negative health outcomes (Ory *et al.*, 2000), namely female gender, spousal relationship and socio-economic status (Colvez *et al.*, 2002, Ory *et al.*, 2000). However, there are two additional risk factors for negative health outcomes that are unique to caregivers. It has been shown that cognitive impairment and patient behavioural problems are linked to caregiver physical and mental health (Ory, *et al.* 2000). Other characteristics such as the availability of support systems, caregiver's perception of the patient's symptoms and caregiver's attitude and behaviour towards the patient are known to affect the caregivers' level of stress (Donaldson, Burns, 1999).

181. Cognitive impairment is commonly associated with dementia, but persons with dementia also suffer from significant behavioural disturbances such as aggression and resisting help with care. For caregivers, these behavioural problems create mental problems of their own, including anger, grief and resentment (DeKosky and Orgogozo, 2001).

182. In addition to the psychiatric and physical burdens, there exist several other aspects of caregiver burden which can be measured when evaluating outcomes; Winblad et. Al (2001) list several of these, including: how demanding the patient is, stress of the caregiver, embarrassment, anger, dependence, loss of control, and the limitation of life hopes and aspirations.

183. Time spent by the caregiver caring for the patient is an outcome that is often used. Examples of scales that measure caregiver time include the Caregiver Activities Time Survey, the Caregiver Activity

Survey, the Resource Utilisation in Dementia (RUD) scale or the Caregiver Time Questionnaire (Winblad, Wimo and Almkvist, 2000). There also exist specific caregiver burden scales such as the Screen for Caregiver Burden, designed to identify distressing caregiver experiences (Vitaliano, *et al.*, 1991) or the Zarit Burden Interview Scale (Zarit, Reever and Bach-Peterson). The Zarit Burden Interview Scale (ZBIS) in particular appears to be a widely used instrument. The ZBIS measures the impact that caring for a person with disabilities has on the caregiver's emotional, social, physical and financial well-being; it can be considered as the caregiver counterpart to global function measures for dementia patients such as CIBIC-plus or CDR, though it is not a dementia-specific tool.

Results

184. In their literature review on best practices for the management of dementia, Doody *et al.* (2001) examined several interventions for their impact on caregivers as well as dementia patients. Educational programs provided modest improvements in disease knowledge and confidence among caregivers, but when combined with support and or counselling caregivers experienced reductions in depression, tension, anger, fatigue and confusion.

185. Sörensen, Pinquart and Duberstein did a meta-analysis on the effectiveness of interventions for family caregivers (Sörensen, Pinquart and Duberstein, 2002), though their review was not limited to dementia. Not surprisingly, they found that respite/daycare was more effective in reducing caregiver burden than psychoeducation and supportive interventions (counselling). Both respite/day care and psychoeducation demonstrated positive benefits in reducing caregiver depression and improving well-being. These effects were irrespective of the disease care receivers were suffering, so the authors tested separately whether caring for someone with dementia influenced the effects. The results of these tests show that the positive effects of interventions were lower for caregivers of dementia patients; this may reflect the greater burden of caring for demented individuals more than the effectiveness of these interventions for dementia caregivers.

186. In their study of programmes providing support to both the patient and the informal caregiver, Colvez, *et al.* (2002) compared the effects of five different respite care programs on Alzheimer patients' informal caregivers' health status and work burden. Self-administered questionnaires were given to caregivers to assess health, using the Nottingham Health Profile, and work burden using the ZBIS. Group-living/cantou was the only intervention shown to be effective in improving caregivers' health status in all four dimensions studied (energy, social isolation, emotional reactions and sleep). With respect to work burden, their results unambiguously show that group-living/cantou is the most effective means of reducing care burden (this was not due to the fact that patients were no longer living at home; group-living/cantou was superior even when compared with other institutionalised care means).

5.3 Quality of life

187. Increasingly, quality of life is being recognized as an important focus of health outcomes for dementia and Alzheimer's disease (Winblad, Wimo and Almkvist, 2000). There is however a significant debate about how to measure such a personal and subjective state in patients who may not be able to properly assess how they feel without the use of proxies. This does not pose a problem for quality of life measures for caregivers.

188. There exist few dementia-specific scales that assess quality of life, in many cases generic measures pertaining to no specific illness are used (Winblad, Wimo and Almkvist, 2000). Recent years have seen the introduction of several dementia-specific measures of quality of life. The Dementia Quality of Life (DqoL) measure is one such example (Brod, *et al.*, 1999). The DqoL does not rely on a proxy interview and shows evidence of being reliable and valid, the limitation with the DqoL is that it can only

be used for patients with mild to moderate dementia, patients in the later stages of the disease are likely not able to answer questions of their own states properly (Brod, *et al.*, 1999). There are at least three other instruments available for measuring dementia-specific quality of life: QOL-AD (Jonsson, *et al.*, 2000; Logsdon, *et al.*, 2002), QOLAS (Jonsson, *et al.*, 2000; Selai and Trimble, 1999) and a recent measure developed by the London School of Hygiene and Tropical Medicine (Banerjee, *et al.*, 2003).

5.4 Best outcomes

189. The number of studies on dementia care is growing rapidly, but the research is so disparate that it is difficult to see a critical mass for recommending particular interventions developing at this stage. One area that would greatly enhance the applicability of research for policymakers would be the development of a consensus on the best outcome measures. This is particularly true for studies on the effectiveness of interventions for family caregivers. The wide variety of psychiatric and health problems associated with caring for a person makes it a difficult task, but not an impossible one. One example is the increasing use of the ZBIS in studies measuring carer burden points to an emerging consensus in this aspect, one that would be enhanced through the validation of this instrument for dementia studies. Another is the popularity of CIBIC-plus and ADAS-cog as outcome measures in clinical trials for anticholinesterases.

190. Apart from anticholinesterases for treating cognitive impairment in dementia, clear evidence of the effectiveness of other interventions is patchy. There is some evidence that suggests special care units for dementia patients in long-term care institutions are effective, but more evidence from random control trials are needed. For informal caregivers, education alone seems to have some positive benefits, but the best results appear to be when education is combined with counselling. If more studies like the one by Colvez *et al.* (2002) demonstrating the effectiveness of group-living for improving caregivers' health emerge then a true evidence base will exist to justify the popularity of these types of arrangements.

6. THE ECONOMIC IMPACT OF DEMENTIA

191. Thus far we have examined the impact of dementia and AD in terms of the burden of health and the resources that are required to provide health and social care. In this section we turn to the economic consequences of the impact these diseases impose on OECD societies.

6.1 Cost-of-illness studies

192. Cost-of-illness studies describe the economic burden of a given illness by estimating the value of all goods and services consumed in order to prevent, diagnose, treat, and otherwise cope with the illness for a given period. Cost-of-AD/dementia studies are scarce in most OECD countries. This section is limited to cost-of-AD studies since these were the most comparable. Where these studies exist they tend to incorporate different cost components (*e.g.*, inclusion valuations of the opportunity costs of informal care) and follow different methodologies. Thus caution should be taken when interpreting the results.

193. Costs are typically classified into direct, indirect, and intangible costs. Direct costs generally refer to changes in resource use attributable to the intervention, either medical costs or non-medical costs such as informal caregiving or transportation consumed in the provision of an intervention. Indirect costs refer to productivity losses related to an illness such as reduction in hours of employment or withdrawal from the workforce for an informal caregiver. Intangible costs refer to the intrinsic value of health as measured by contingent valuation.

194. Estimates of the cost-of-illness may be generated in two ways, the 'top down' and the 'bottom up' approaches. In the 'top down' approach, total expenditures are estimated and then disaggregated by illnesses, whereas in the 'bottom up' approach the cost items of different goods and services used for treating a given illness are identified, measured and valued to estimate the total cost of that illness.

195. Finally, cost-of-illness studies generally represent the costs of all persons who have the illness in a given period of time, regardless of when they were diagnosed. These prevalence-based costs are useful for predicting the impact of illness on public and private expenditures. In this paper we focus on studies using a 'bottom up' approach that allows cost estimates per AD case. In particular it avoids the problem of relating total expenditures to an uncertain number of AD cases per country (see Section 2).

196. A crucial point to consider when evaluating the costs of AD is from whose perspective are the costs being considered. Table 1 provides the costs of AD considered from three alternative perspectives: society, patients and their families, and public or private insurers (third-party payers). The study perspective is a critical determinant of which resources to identify and measure in AD. For example, third-party payers are generally not concerned with the costs of informal caregiving, but from society's point of view, informal caregiving accounts for most of the costs of AD, at least in the earlier stages. We focus in this section is on studies with a societal perspective that encompass all costs.

Table 6.1: Costs of Alzheimer's disease under alternative perspectives

Type of cost	Cost element	Perspective		
		Societal	**Patients and family**	**Public or private insurer (third-party payer)**
Direct medical	Medical care	All medical care costs	Out-of-pocket expenses*	Covered payments
	- Units	All units	Those paid out-of-pocket	Those covered
	- Price	Opportunity costs	Amount paid out-of-pocket	Amount paid and administration cost
Direct non-medical	Patient time cost for intervention	Cost of all time used	--**	None
	Marketed caregiving	All costs	Out-of-pocket expenses	Covered payments
Indirect	Unmarketed, informal caregiving	All costs	Opportunity cost to caregivers	None
	Transportation and other non-medical services	All costs	All costs	None
	Sick leave, disability, other transfer payments	Administration costs	Amount received	Amount paid by insurer and own administration

Adapted from Gold M. *et al.* (1996)
* Out-of-pocket expenses may differ greatly from one country to another.
** AD patients are generally over age 65 and therefore likely to not be working.

197. The cost elements to be estimated follow once the proper perspective is chosen. In order to properly assess the costs of AD it is important to understand how these cost elements may be affected by underlying characteristics. Specific examples for AD include: (1) are the cases taken from data culled from administrative records, which as has already been demonstrated can lead to underestimating the true presence of AD; (2) how were the cases diagnosed, by clinical diagnosis or by a diagnosis based on an algorithm, such as a score on a cognitive screening test; (3) if the diagnoses were determined on the basis of a screening test, which one was used, in the latter two cases, different methods of diagnosis can lead to different measures of the underlying presence of AD. Other aspects that can affect the estimated costs of AD include the costing exercise employed, should charges be calculated (probably not if the aim is to measure costs from society's perspective) or direct costs and whether costs are taken from formal records or information taken from recall of expenditures. Finally, the location from which medical and related services are received determines the source and availability of information on cost of these services.

Costs of AD by disease severity

198. One would expect the severity of AD to have an impact on costs, so several studies calculate the costs associated with AD by disease severity. Tables 2, 3, 4 and 5 provide data on the costs of AD by cognitive decline as measured by the Mini-Mental State Examination for France, Spain and the United States.

199. It seems intuitive to expect direct costs to increase with disease severity and this does appear to be the case in most studies (Rice *et al.* 1993; Ernst *et al.* 1997; Hux *et al.* 1998; Fagnani *et al.* 1999; Boada *et al.* 1999), but it is not so straightforward that this should also occur for indirect costs. As the disease worsens from moderate to severe AD the informal caregiver may increase their paid working hours if the

person they were caring for is admitted to a long-term care institution, this will have the effect of lowering calculated indirect costs; how indirect costs are calculated will determine the magnitude of the effect. However, the estimated impact of AD severity on indirect costs is mixed. Using data from the Canadian Study of Health and Aging, Hux *et al.* (1998) estimated indirect costs, measured as unpaid care and supervision time, to be lowest for severe AD (Table 6.5). Boada *et al.* (1999) estimated the indirect costs associated with lost working hours declined continuously with AD severity, but total indirect costs increased (Table 6.4). Indirect costs as calculated by Fagnani *et al.* (1999) and Rice *et al.* (1993) increased with disease severity (Table 6.2 and 6.3 respectively).

200. Indirect costs for other diseases in most cost-of-illness studies tend to be significantly larger than the direct costs due to the large value of foregone income. However, one would not expect this for an ageing-related disease like AD for which most individuals stricken with the disease were likely not part of the workforce. Fagnani *et al.* estimated indirect costs to be lower than direct costs (Table 6.2), while Hux *et al.* found indirect costs were lower for moderate and severe AD but not for mild AD (Table 6.5). Boada *et al.* on the other hand found indirect costs to be greater than direct costs irregardless of severity (Table 6.4). Finally, Rice *et al.* found indirect costs to be greater than direct costs when estimated for community-based care, but less when estimated for institutional care (Table 6.3).

Table 6.2: Gross costs of Alzheimer's disease (AD) in France by level of severity (2000), U.S.D (% of total costs)

Cost per AD case	**Cognitive deterioration**							
	Mild		**Moderate**				**Severe**	
	(MMSE > 20)		**(MMSE 16 – 20)**		**(MMSE 11 – 15)**		**(MMSE ≤ 10)**	
Direct medical								
Medical resources	1 969	(19)	3 023	(17)	3 831	(15)	4 871	(15)
Nursing home	5 428	(52)	5 785	(33)	6 166	(24)	7 514	(23)
Direct non-medical								
Marketed caregiving	2 664	(26)	4 227	(24)	6 773	(27)	9 229	(28)
Subtotal	***10 062***	***(97)***	***13 035***	***(75)***	***16 770***	***(66)***	***21 615***	***(65)***
Indirect								
Unmarketed, informal caregiving	360	(3)	4 365	(25)	8 462	(35)	11 553	(35)
Total	**10 422**	**(100)**	**17 400**	**(100)**	**15 233**	**(100)**	**33 169**	**(100)**

Note: MMSE – Mini Mental State Examination
Source: Adapted from Fagnani F., *et al.* (1999)

Table 6.3: Gross costs of Alzheimer's disease (AD) in the United States by level of severity and location of care, in U.S. Dollars (2000)

Cost per AD case	Community-based care		Institutional care	
	Mild to moderate	Severe	Mild to moderate	Severe
Formal costs	10 040	21 446	45 885	55 963
Informal costs	42 076	47 942	3 822	7 546
Total	52 117	69 388	49 707	63 510

Source: Adapted from Rice *et al.* (1993).

Table 6.4: Gross costs of Alzheimer's disease (AD) in Spain by level of severity (2000), U.S.D (% of total costs)

Cost per AD case	Cognitive deterioration							
	Mild		Moderate		Severe			
	(MMSE > 18)		(MMSE 12 – 18)		(MMSE < 12)		Average	
Direct medical								
Visits	632	(4)	621	(3)	619	(2)	624	(3)
Hospitalisation	295	(2)	224	(1)	598	(2)	372	(2)
Medication	567	(4)	644	(3)	672	(3)	628	(3)
Examinations	367	(3)	356	(2)	270	(1)	331	(2)
Health materials	87	(1)	73	(<0)	399	(2)	186	(1)
Direct non-medical								
Home care	338	(2)	1 634	(9)	2 049	(8)	1 341	(7)
Day centre	287	(2)	394	(2)	862	(3)	514	(3)
Transport	113	(1)	220	(1)	374	(1)	708	(4)
Subtotal	***2 688***	***(18)***	***4 170***	***(22)***	***5 847***	***(23)***	***4 235***	***(22)***
Indirect								
Lost working hours	515	(4)	485	(3)	276	(1)	425	(2)
Main caregiver	9 653	(66)	11 351	(61)	14 229	(56)	11 744	(60)
Auxiliary caregivers	1 732	(12)	2 713	(14)	4 924	(19)	3 123	(16)
Subtotal	***11 900***	***(82)***	***14 550***	***(78)***	***19 430***	***(77)***	***15 293***	***(78)***
Total	**14 589**	**(100)**	**18 721**	**(100)**	**25 277**	**(100)**	**19 529**	**(100)**

Note: MMSE – Mini Mental State Examination
Source: Adapted from Boada *et al.* (1999)

Table 6.5: Gross costs of Alzheimer's disease (AD) in Canada by level of severity (2000), U.S.D (% of total costs)

Cost per AD case	Cognitive deterioration							
	Mild		Mild to Moderate		Moderate		Severe	
	(MMSE 21 - 26)		(MMSE 15 – 20)		(MMSE 10 – 14)		(MMSE < 10)	
Direct medical								
Medication, physician fees	257	(2)	262	(1)	296	(1)	352	(1)
Nursing home	0	(0)	5 525	(30)	18 569	(63)	35 199	(84)
Direct non-medical								
Community services	2 243	(21)	2 632	(14)	1 395	(5)	646	(2)
Subtotal	***2 500***	***(23)***	***8 418***	***(46)***	***20 260***	***(69)***	***36 198***	***(87)***
Indirect								
Unpaid direct care time	6 430	(60)	8 012	(44)	6 116	(21)	3 986	(10)
Unpaid net supervision time	1 816	(17)	1 823	(10)	2 871	(10)	1 651	(4)
Subtotal	***8 246***	***(77)***	***9 835***	***(54)***	***8 987***	***(31)***	***5 637***	***(13)***
Total	**10 746**	**(100)**	**18 253**	**(100)**	**29 247**	**(100)**	**41 385**	**(100)**

Note: MMSE – Mini Mental State Examination
Source: Hux, *et al.* (1998)

Comparison of cost of Alzheimer's disease studies between countries

201. To date, most cost-of-illness studies related to dementia or AD refer to the United States. We selected the most referenced of these studies (Rice *et al.* 1993; Ernst and Hay 1994), although they are now dated. We were able compare national cost-of-illness information from Canada, France, Spain, Sweden and the United States that used the 'bottom-up' approach based on epidemiological data.[17]

202. Table 6.6 provides data on the costs per AD case for Canada, France, Spain, Sweden and the United States with costs broken down into direct medical (including nursing homes), direct non-medical and indirect costs converted to year 2000 U.S.D. Total annual costs per AD patient were highest in the United States and lowest in Spain (the data from Rice, *et al.* (1993) were excluded since these were divided between community-based care and institutional care). Direct and indirect medical costs were also highest in the U.S. Indirect costs in Canada, France and Sweden were significantly lower but this may reflect the recent transfer of indirect costs to direct non-medical costs in Sweden, the use of the minimum wage in the province of Ontario (as opposed to the average industrial wage) to reflect the value of unpaid time in Canada, and probable underestimation for France.

203. Direct costs were mainly driven by the costs associated with nursing homes (about one quarter of total annual costs). The reason why indirect costs in Spain are so high, 76% of total costs, is not readily apparent. Perhaps indirect costs include costs associated with nursing home. Detailed analysis of cost items proved to be difficult because long-term care covers different matters in these countries, the relative price of items may be not reproducible between countries, the time frame is different between studies, and the process of dementia care may have changed over time. Moreover, cost-of-AD studies are difficult to

17. Australia and Japan provided cost-of-illness estimates using a 'top-down' approach, whereas information on informal care was lacking in UK study (McNamee *et al.* 2001; Comas-Herrera *et al.* 2003)

compare *ex post* when variables that do influence the costs are not provided, *e.g.*, AD proportions by severity level or socio-economic level of the community surveyed.[18]

Table 6.6: Bottom-up cost-of-illness studies of Alzheimer's disease in Canada, France, Spain, Sweden and the United States, in 2000 U.S.D Purchasing Power Parity

Cost per AD case	Country (year of study)									
	Canada (1991)		France (1993)		Spain (1998)		Sweden (2000)		USA (1994)	
Direct medical										
Excl. nursing home	305	(1)	3 677	(16)	2 144	(11)	1 469	(4)	3 647	(8)
Nursing home	19 373	(67)	6 378	(27)	0	(0)	9 011	(26)	9 571	(22)
Total direct medical	*19 677*	*(68)*	*10 055*	*(43)*	*2 144*	*(11)*	*10 480*	*(30)*	*13 218*	*(30)*
Direct non-medical	*1 500*	*(5)*	*6 286*	*(27)*	*2 565*	*(13)*	*19 065*	*(55)*	*4 659*	*(11)*
Indirect	*7 690*	*(27)*	*7 200*	*(31)*	*15 294*	*(76)*	*4 990*	*(15)*	*26 424*	*(60)*
Total	**28 868**	**(100)**	**23 542**	**(100)**	**19 529**	**(100)**	**34 365**	**(100)**	**44 301**	**(100)**

Source: Canada – Hux, *et al.* (1998); France – Fagnani, *et al.* (1999); Spain – Boada, *et al.* (1999); Sweden – Wimo and Jonsson (2001); US – Ernst and hay (1994).

6.2 Cost-effectiveness analysis of cholinesterase inhibitors

204. Cost-effectiveness analysis of an intervention compares the added current and future costs of producing one additional unit of health output to a reference strategy (Gold *et al.* 1996). Cost-effectiveness analysis of cholinergic augmentation therapy for mild to moderate AD (*i.e.*, donepezil, rivastigmine and galantamine) adds the difficulties of cost-of-AD studies to those of economic evaluation of health outcomes in AD and current uncertainty regarding duration of effect. The following provides the main results of these cost-effectiveness analyses, summarizes the debates that surrounded the launch of these drugs based on economic evaluations, where performed, and relate those to drug expenditures.

205. Cost-effectiveness analysis of cholinesterase inhibitors is generally built on Markov models describing the natural history of AD. Some drawbacks in cost-effectiveness analysis conducted to date were summarized in a recent review of NICE (National Institute of Clinical Excellence) (Clegg *et al.* 2001). First, for several reasons the economic valuation of health outcomes in AD is currently limited: interviews of patients and caregivers have proved to be difficult (Neumann *et al.* 1999a); there is no agreed methodology to integrate positive externalities to caregivers from drug treatment of AD (Ernst and Hay 1997); clinical trials relied on the measurement of cognitive decline, which is not correlated to health-related quality-of-life outcomes of interest to compute Quality-Adjusted Life Years; the measure of cognitive decline may be insensitive to medication-related changes (Clegg *et al.* 2001). Second, clinical trials of cholinesterase inhibitors were generally limited to 24 weeks. With a time horizon of 24 weeks in most cost-effectiveness studies, *e.g.*, donepezil would be cost-effective with a 68% chance (given a willingness-to-pay for a QALY of 50 000 U.S.D) (Claxton *et al.* 2001). Extending information on efficacy of cholinesterase inhibitors beyond 24 weeks would drastically reduce the uncertainty surrounding decision analysis models. Whereas information was not available when decision makers had to decide on the launch of cholinesterase inhibitors, a recent Swedish cost-effectiveness study with a time horizon of one year showed that donepezil is still cost-effective for mild to moderate AD (Wimo *et al.* 2003).

18. The country report for Canada showed differences in medical resource consumption related to socio-economic status of the patient's community.

Table 6.7: Cost-effectiveness analysis (CEA) of cholinesterase inhibitors (AChEI - donepezil or rivastigmine) with link to decision making

Country	CEA performed	Main conclusions	Reference
Australia	No	--	--
Canada	Yes	Cost-effective	O'Brien, *et al.* (1999)
England and Wales	Yes	Caution	Clegg, *et al.* (2001)
France	No	--	--
Germany	No	--	--
Japan	Yes	Cost-effective	Ikeda, *et al.* (2002)
Spain	No	--	--
Sweden	Yes	Cost-effective	Jonsson, *et al.* (1999)
United States	Yes	Cost-effective	Neumann, *et al.* (1999b)

206. Our interest here is in the use of cost-effectiveness analysis to inform decision makers. As shown in Table 6.7, cost-effectiveness analyses or their review were conducted in five of the nine countries (Canada, England and Wales, Japan, Sweden, and the United States) participating in the study. However, they have had little or no influence on the decision to launch cholinesterase inhibitors. Furthermore, even in countries where no CEA were performed anticholinesterases were still launched. In countries requiring cost-effectiveness analysis of new drugs for formulary inclusion and/or reimbursement decisions (Australia, Canada (Ontario), England and Wales, and some large managed care organizations in The United States), the use of cost-effectiveness of cholinesterase inhibitors may be limited by the potential shift in cost burdens between sectors. For instance, the delay in institutionalization, the most expensive component of health care for AD, is likely to increase informal caregiver burden, whereas from society's point of view this short delay may not produce significant savings.

6.3 Cholinesterase inhibitors' expenditures

207. Data on expenditures on cholinesterase inhibitors were available for Australia, England and Wales, Germany, Japan, and Sweden. Table 7 shows expenditures on these drugs over time when related to the population aged 65 and over. In all countries, expenditures on cholinesterase inhibitors increased dramatically over time in conjunction with successive launches of cholinesterase inhibitors (donepezil, rivastigmine, and then galantamine), awareness of these drugs, and the importance of the market of antidementia drugs. Although cholinesterase inhibitors became available at similar times in all countries, there is dramatic variation in use of these drugs per individual aged 65 and over. Drug expenditures per capita in England and Wales in particular appear to be much less than in the other countries, but cholinesterase inhibitors were not generally available free on the NHS until 2001. Since then there has been an enormous increase in use of these drugs and the gap in expenditures between England and Wales and the other countries in Table 6.8 has likely narrowed significantly.

Table 6.8: Cholinesterase inhibitors' expenditure per 1 000 persons aged 65 and over in Australia, England and Wales, Germany, Japan and Sweden (in U.S.D PPP)

Year	Australia		England and Wales		Germany		Japan		Sweden	
	USD	Rate of increase	USD	Rate of increase	USD	Rate of increase	USD	Rate of increase	USD	Rate of increase
1997			124						1 576	
1998			357	187%					4 735	200%
1999			589	65%	3 160		524		7 722	63%
2000	2 298		1 037	76%	4 870	54%	2 479	373%	10 338	34%
2001	3 523	53%	2 047	97%			4 033	63%	12 851	24%

Note: Expenditure per 1000 persons aged 65 and over was calculated by dividing the total expenditure on Cholinesterase inhibitors (ATC code N06DA) by the population aged 65 and over and multiplying by 1000
Expenditure data for Germany are based on prescriptions within general health insurance
Source: Country responses to the OECD Dementia Case study questionnaire; OECD (2002)

Box 6.1: Future costs of Alzheimer's disease

What will be the future monetary costs to OECD countries if the future burden of Alzheimer's disease will increase? Using data from cost-of-illness studies (Table 6.6) and AD prevalence rates (Tables A.4 and A.5 in the appendix) we estimated total costs for Alzheimer's disease in Spain, Sweden and U.S. for the year 2010.

The figures presented here are for total costs only. Costs were calculated by applying the estimated AD prevalence rates for 2000 (Table A.4) and 2010 (Table A.5) to the cost per AD case figures in Table 6.6 (2000). The first line shows total costs for 2000 and the second line shows total costs for 2010.

	Spain	Sweden	USA
(1)	4 958	4 262	134 206
(2)	6 325	4 843	157 680

According to our estimates, in 2010 the economic burden of dementia will have increased by 28% in Spain, 14% in Sweden and 17% in the United States when compared to 2000.

6.4 Costs of Alzheimer's disease

208. Comparison of the economic burden of AD across countries has limited application at present. Nevertheless, cost-of-illness studies can shed some light on the economic burden of AD. Not surprisingly, medical costs unambiguously rise with the severity of the disease. There is mixed evidence on the cost of informal care which points to the need for a more standard methodology for measuring this aspect of AD care. However, this may not be a priority since the main cost element of informal care, lost income, may not have as much relevance as for other conditions, since a significant proportion of AD informal carers may be retired.

209. In most cases where cost-effectiveness analyses of anticholinesterases were performed they were demonstrated to be cost-effective. However, cost-effectiveness analyses have had little influence on the decision to launch these drugs, for which expenditure has been increasing steadily since their general acceptance in the late 1990s. International comparative economic analyses of AD would benefit greatly from a study comparing prices of anticholinesterases and the health insurance environment to complement information on consumption and expenditure.

210. Increases in the number of persons suffering from AD in the future alone will lead to increases in spending on caring for the disease, but the magnitude of the increases will depend on many factors. Unforeseen advances in medical technology is perhaps the most unpredictable, and potentially largest, factor that will determine future costs of dementia care.

7. CONCLUSION

7.1 What are the service needs of dementia care receivers?

211. Dementia and Alzheimer's disease policy should begin by targeting the population most vulnerable to the disease, the older elderly population. The circumstances that dictate availability of Alzheimer's disease and dementia care services depend to a great extent on the staging of the disease, the intensity of required services gradually increasing along with the disease's progression. With approximately 70% of persons with Alzheimer's disease aged 75 and over suffering from moderate to severe AD, service needs for this segment of the population are particularly acute. This group may have different needs from the younger elderly, for example they are more likely to have multiple comorbidities or to be living alone, so dementia policy should take particular heed of their circumstances.

212. Detecting dementia in its early stages is difficult but important, as attested by the number of governments that stress the importance of early detection in their dementia strategies. Early detection cannot halt the disease as is the case with many cancers if detected early, but it can help prepare patients and their families for the difficult road that lies ahead. Families need as much time as possible to make the important decisions they will face such as who will provide most of the care. Screening is not a viable option for detecting dementia so general practitioners, especially those with significant proportions of elderly in their practice, can play an important role in detecting the disease early. GPs should be encouraged to learn more about how to recognize the first signs of dementia, the appropriate tools to confirm a suspected diagnosis, and to which specialist medical and social services the patient should be referred.

213. Education is also important for the carers of people with dementia. In the early stages education will be important if the patient is to participate in the decision process, since he/she may not be able to understand the problem in the later stages of dementia. Education when combined with counselling has also been shown to be particularly effective in reducing physical and psychological problems among caregivers.

214. The use of anticholinesterases for slowing cognitive decline indicate cost-effectiveness in the early and moderate stages of dementia. Results of the use of memantine for treating moderate to severe dementia are promising and more research into the use of anticholinesterases for treating the later stages, as well as for behavioural problems, should be encouraged.

215. Allowing dementia patients to live in the community for as long as possible is a universally desirable policy principle espoused by policymakers. Knowing the circumstances under which dementia patients require admittance to a long-term care institution is important for informing policy. Demented persons and their families will not face this decision of entering a long-term care facility until the latter stages of the disease, at which point two main factors play a decisive role. The first of these is the severity of the disease: there will come a point where the patient will need constant surveillance due to problems such as wandering and behavioural problems that are extremely taxing for carers, such that care can no longer be provided at home. The second of these is the availability of a family caregiver. Many people with moderate to severe dementia can remain at home for an extended period of time if there is someone there able to care for them.

216. Dementia care is provided by a wide variety of sources, so an obvious issue to explore is how these services are co-ordinated. This is an issue that we did not delve into in any great detail and it is not an easy one to resolve. It is not difficult to get everyone to agree that co-ordination of dementia services is a good idea, but the numerous players involved in the provision of services (including physicians, nurses, home care workers and long-term residential care administrators – together with the different government departments and health and long-term care insurers involved in the funding and planning) complicate the task of agreeing to who shall do the co-ordination. This is an issue well worth studying on its own.

217. The co-ordination of services is also complicated by whether social care associated with dementia should be specifically tailored to the disease or not. On this question the jury is still out. There is little evidence at present to demonstrate that dementia-specific services are effective. The penury of dementia-specific social care services may be a tacit acknowledgement of this fact. Nevertheless, it does appear that the special needs of dementia patients requires dementia-specific social care. More evidence is clearly needed on the positive effects of dementia-specific services on dementia patients – as well as the impact on other patients in long-term care institutions (in the case of special dementia units).

7.2 How best to support dementia caregivers?

218. A second policy principle that is also universally accepted is the need to provide adequate support to carers of individuals with dementia. In the early stages of the disease this will not be a major concern. As dementia progresses family members will be increasingly called upon to provide social care. For many carers this will entail a reduction of hours in the paid workforce. Some governments provide financial support to informal caregivers to help offset some of their lost income, but other considerations need to be taken into account. Foregoing pension contributions can be an additional cost to reducing paid working hours, one which may be too expensive for some carers, especially those that are nearing retirement. Providing pension credits in lieu of missed contributions for carers can help reduce this cost. A sensible financial support package would include both tax and pension credits for carers.

219. Respite care is an option that can allow people with dementia to remain in the community without carers unduly sacrificing income. There are many forms of respite care that are effective but the popularity of group-living and the results of at least one comparative study against other respite care modes (Colvez, *et al.*, 2002) support the expansion of this type of respite care.

7.3 What are the outcomes of dementia interventions?

220. Few interventions for dementia have unambiguously demonstrated positive outcomes, but for many this is perhaps a matter of a proper evidence base being built. Anticholinesterases for slowing cognitive decline are probably the interventions that have been demonstrated the most effectiveness. Certainly group-living shows great promise for supporting caregivers. Dementia special care units in long-term care institutions have been demonstrated in some studies to be effective, as has education combined with counselling, but more evidence is required before stronger recommendations regarding their use can be considered.

221. Improvements in health outcome measures for dementia, especially regarding a consensus on the best measures, would help considerably in establishing the most effective interventions. ADAS-cog and MMSE for measuring cognition, CIBIC-plus and CDR for global function appear to be the best instruments for measuring outcomes in dementia patients. It is difficult to arrive at any kind of consensus for outcome measures for carers of dementia patients. The ZBIS which measures carer burden is widely accepted but it is not dementia-specific. The recent development of dementia-specific quality of life measures is welcome.

7.4 What does the future hold for dementia?

222. Ageing OECD populations will provide particular challenges to health and social care systems. The dual phenomena of growing populations of elderly persons, those most susceptible to dementia, and increased longevity are likely to lead to an increase in the number of people with dementia. This will require additional resources, and well-trained staff to provide the necessary health and social care.

223. What will be the additional cost to society of these additional resources? The answer is not entirely clear. Based on current trends the range of spending increases for dementia care are anywhere from 0 to 28% in net present value terms. Certainly unforeseen advances in medical technology have the potential to push the costs of dementia care into the high range, but several studies suggest that projected spending levels on health care for the elderly may not be as large as suspected (Moïse and Jacobzone, 2003). Better methods at estimating total costs for dementia care are required to properly assess the future cost burden.

224. Will there be adequate resources to meet the needs of a larger dementia population? The answer will depend greatly on the availability of informal caregivers. Current wisdom points to an undersupply of informal caregivers in the future for a number of reasons. This will put further strain on other resources since the flexibility of relying on informal caregivers will be lessened.

ANNEX 1. DEMENTIA PROGRAMS

225. The most influential bodies in the field of dementia advocacy, research, policy and planning are governments, mainly through health and social welfare ministries and associated institutes, such as the National Institute on Aging in the US, and non-governmental organisations (NGOs). This working paper has compared the various policies and interventions of 9 OECD countries for treating dementia and Alzheimer's disease. However, the main body of the report does not attempt to detail all of the strategies used by these countries for dealing with dementia. This annex presents some of the main dementia strategies and programs in place.

226. OECD governments are the most important stakeholders in setting the dementia policy agenda, so this appendix outlines some of the most important programs and policies in place. In addition to governments, NGOs provide significant contributions, especially in an advocacy role. This section includes a table with information on the more prominent NGOs in the 9 countries participating in this study (Table A.1). This table is not an exhaustive list of all organisations advocating on behalf of dementia and AD.

INTERNATIONAL

227. The two main bodies operating at the international level are Alzheimer's Disease International and Alzheimer Europe. These NGOs, like all the NGOs listed in Table A.1 are non-profit organisations. They act as an umbrella organisation for the many Alzheimer's disease NGOs.

AUSTRALIA

228. "The formulation and delivery of dementia policy involves the intersection of a range of Federal, State and Territory government programmes as well as non-government organisations, communities and individuals" (Australia country report). At the national level, dementia programs fall primarily within the scope of aged-related programs.

229. The main dementia program of national scope is the *Dementia Education and Support Programme* (DESP). The Federal Government provides annual funding to the Alzheimer's Association Australia to support the DESP. The program offers several services to help those with dementia and their carers, these include: a 24 hour telephone Dementia Helpline which provides information and referral services, educational services, facilitation of support groups, and provision of short term counselling services. The measure also provides for ongoing dementia assessment by Aged Care Assessment Teams.

230. The Federal Government also provides funding to the Alzheimer's Association Australia for dementia-related projects through the National Respite Carers Program (NRCP). The NRCP operates three projects aimed primarily at carers of people with dementia: the *National Dementia Behaviour Advisory Service* provides an around the clock, free telephone advisory service to dementia carers and respite workers; the *Early Stage Dementia Support and Respite Project* provides respite for dementia cares mainly in rural and remote areas; and the *Carer and Education Workforce Training Project* provides education and training for carers and respite workers caring for people with dementia. All three projects are delivered through the Alzheimer's associations, the latter in conjunction with carers association.

- The Federal Government provides the primary funding for two long-term programs for caregivers operated by State and Territorial Governments: Psychogeriatric Care Units (PGUs) and Dementia Support for Assessment (DSA). The primary role of PGUs is to provide support and training for residential care staff involved with caring for people with dementia. The DSA provides funding to Aged Care Assessment Teams in rural and remote areas to facilitate their capacity to employ specialist staff or buy expertise from

CANADA

231. **Ontario**: In 1996 the provincial government launched *Ontario's Strategy for Alzheimer Disease and Related Dementias*. The project began with a three-year period of stakeholder consultations, which resulted in the release of a draft action plan in 1999 and a commitment by the provincial government to invest CAD 68.4-million over a five-year period. The project plan outlines ten points of focus: 1) long-term care (LTC) facility staff education and training specific to the treatment of dementia; 2) development of a standardized physician training program based on practice outcomes related to dementia; 3) instatement of a public education coordinator at each of the thirty-nine Alzheimer societies to increase public awareness and education; 4) implementation of new design standards in long-term care facilities to ensure appropriate, safe environments; 5) expanding respite services for caregivers; 6) increased research on caregiver needs to ascertain and document the key community services required by caregivers; 7) development of provincial policy in support of advance directives on care choices; 8) funded hiring of psychogeriatric consulting resources to support LTC facility staff; 9) development of local referral protocols between LTC facilities, community care access centres (CCAC's), local Alzheimer societies, and specialized geriatric services to coordinate specialized diagnosis and support; and 10) the initiation of intergenerational volunteer programs in LTC facilities and community services.

FRANCE

232. In September 2000, the "Ministre de l'Emploi et de la Solidarité" (Minister for Employment and Solidarity) and the "Secrétaire d'Etat à la Santé et à l'Action sociale" (Secretary of State for Health and Social Action) released the *Rapport Girard*, a report on the situation of Alzheimer's disease in France. The report was based on interviews with various players in the health and social care sectors, providing an account of the current situation of Alzheimer's disease and its future. The report concludes with a formulation of 12 proposals for action.

233. In October 2001, the French Government presented an action plan for persons suffering from Alzheimer's disease and related disorders, based on the proposals for action put forth by the *Rapport Giard*. The program revolves around six objectives: 1) identify the first symptoms and the appropriate next step for the patient, 2) provide the means for access to quality diagnosis, 3) preserve the dignity of the patient, 4) provide support and information to patients and their families, 5) improve the quality of aged care living facilities, and 6) support studies and clinical research.

GERMANY

234. At the national level, the Ministry of Health (Bundesministerium für Gesundheit und Soziale Sicherung, BMGS) and the Ministry of Family, Seniors, Women, and Youth (Bundesministerium für Familie, Senioren, Frauen und Jugend, BMFSFJ) support novel strategies of dementia care including group care, day centres, special care units, trained home visiting helpers, alternative living arrangements, group living (cantous), and music therapy. The maximum duration of these projects is 3 years.

235. The BMFSFJ is planning an action programme to improve dementia care on a national level. Within the framework of this programme, the Ministry is co-operating with the national Alzheimer's

Association (Deutsche Alzheimer Gesellschaft) to meet two of its objectives, to enhance the use of available information and stimulate the integration of services for people with dementia. Started in November 2001, a telephone hotline is available for patients, caregivers, and professionals which provides information on disease, diagnosis, treatment, legal issues and local services, as well as individual counselling.

236. At the regional level (federal states, Bundesländer), the various Ministries for Social Affairs provide partial support for dementia self-help initiatives, caregiver counselling, and dementia group care (Betreuungsgruppen). The BMFSFJ has launched the programme "Future Structures of Help for the Elderly" (Altenhilfestrukturen der Zukunft) which supports 8 local projects until April 2003. These projects include training and support of dementia home helpers, improvement of dementia-specific knowledge of care professionals, evaluation of group living in a rural area, integration of services supporting caregivers in terms of case management, evaluation of milieu therapy in nursing homes, and music therapy for patients with dementia in nursing homes and hospices.

JAPAN

237. Japanese Psychogeriatric Society (www.rounen.org)

SWEDEN

238. Specific campaigns about dementia centres (*e.g.*, memory clinics) are rare but information about them is included in general information and campaigns about dementia. However, in 1994, the National Corporation of Swedish Pharmacies (*Apoteksbolaget*) ran "Dementia Year" – a campaign highlighting different aspects of dementia.

239. The two Swedish patient/caregiver organisations (*Demensförbundet* and *Alzheimerföreningen*) also run various campaigns about dementia. On World Alzheimer's Day, for example, a wide range of information activities take place both locally and nationally.

UNITED KINGDOM

240. The Government is giving mental health for older people priority. The main document of reference concerning dementia care in the UK is the National Service Framework (NSF) for Older People,[19] which was published by the Department of Health in March 2001 and which completes the 2000 NHS Plan.[20]

241. The NSF for Older People has been developed with the advice of an External Reference Group, chaired jointly by Pr Ian Philp, Professor of Health Care for Elderly People, University of Sheffield, now the National Director for Older People's Services, and Ms Denise Platt, Chief Inspector, Social Services Inspectorate. The External Reference Group brought together older people and their carers, health and social services professional staff, NHS and social services managers and partner agencies.

242. The NSF for Older People sets out for the first time clear standards for the care of older people in all settings across health and social services with a particular focus with mental health problems associated with older age. Implementation in England started in 2001. In Wales, the Welsh Assembly Government is still considering whether all of NSF provisions for Older People will apply in Wales. It cannot be adopted in Wales without some refinement and it will be considered alongside the Older Person's Strategy. The

19. http://www.doh.gov.uk/nsf/olderpeople.htm

20. http://www.doh.gov.uk/nhsplan/nhsplan.htm

standard relating to mental health would be taken forward by the team who are implementing the NSF for Adult Mental Health services in Wales.

243. "Standard 7: Mental Health in Older People" refers to dementia directly. Standard 7 is designed to ensure that the right services are there to meet the needs of older people with mental health problems (and people of all age with dementia) whether they live at home, in residential care or are being cared for in hospital.

244. NSF Standard 7 aims to promote good mental health in older people and to treat and support those with dementia and depression. It sets out to make sure that older people have access to integrated NHS and local authority mental health services that provide effective diagnosis, treatment and support, for them and their carers.

245. The Priorities and Planning Framework (PPF) for 2003-06 requires that services to meet the needs of people with dementia and depression are given a high priority. By April 2004 Protocols must be in place across all health and social care systems in order to provide integrated services for the care and management of older people with mental health problems.

246. This encourages local initiatives. For example, under a new Dementia Services Collaborative within a partnership across the North East, Yorkshire and North Lincolnshire, as of 2002, General Practitioners and staff from community health services, hospitals and social services will join forces with the voluntary and independent sector to make it easier for people with dementia to get help. There will be up to 30 local teams to:

- increase early diagnosis of dementia;
- make it easier for older people with dementia to get information about services and the help that is available;
- make it easier for people to get the care they need; and
- make dementia care services more focused on the needs of the patients.

247. There is also an aim in the UK to provide high-quality evidence-based care. Thus the Department of Health is supporting research into dementia through national and regional programs of research. Examples include a project supported by the NHS Research and Development Health Technology Assessment Program on "Measurement of health related quality of life in people with dementia: the development of a new instrument responsive to change and an evaluation of current methodology". Regionally supported projects include a randomised single blind controlled trial evaluating an evidence based psychological therapy package for dementia, being carried out by University College London Medical School. The AD2000 trial is being led by the Clinical Trials Unit at the University of Birmingham into costs and benefits of Aricept for dementia. The Department also provides the support costs for research undertaken in the NHS funded by charities and research councils. In addition, in 2003 the Secretary of State for Health announced that as part of the eighth wave of its work, the National Institute for Clinical Excellence (NICE) will be producing guidelines on dementia care, including the use of anti-psychotic drugs.[21]

21. The National Institute for Clinical Excellence was set up as a Special Health Authority for England and Wales on 1 April 1999. It is part of the National Health Service (NHS), and its role is to provide patients, health professionals and the public with authoritative, robust and reliable guidance on current "best

UNITED STATES

Alzheimer's Disease Centres

248. Twenty-nine Alzheimer's Disease Centers (ADCs) are currently funded by the National Institute on Aging. The common goal of the centres is to promote research on Alzheimer's disease through established research networks that facilitate collaboration among AD researchers and promote the sharing of ideas, data and research results. A goal of the ADC centres is to apply the results of funded research to improve the diagnosis and treatment of Alzheimer patients. The program's long-term goals are to cure and prevent Alzheimer's disease.

249. Each centre funded by the NIA has its own area of scientific emphasis. Research endeavours range from basic biology and mechanisms of AD to caregiving and coping issues. Scientists from a broad range of disciplines are involved, not only in research efforts but also in the training of new AD researchers and clinicians. Many of the centres have affiliated clinical facilities for diagnosis and treatment. Many offer clinical, diagnostic, treatment, and research opportunities in rural, underserved and minority communities. A number of sites focus on basic science research issues that may eventually translate into better tests for the early detection of dementia. However, no clinical or population based screening for dementia is currently being coordinated and implemented across the various ADCs (personal communication).

250. The costs of diagnosis and treatment at the different AD centres is variable. Centres may accept Medicare, private reimbursement and Medicaid payment. Reimbursement rates by public and private insurance programs do not appear to be different for these centres, although receipt of care may depend on whether a given centre accepts the level of reimbursement offered by the patient's insurer. Opportunities exist at many of the centres for volunteers to participate in drug research studies, support groups, and other structured research programs not typically encountered in non-ADC treatment facilities. Email addresses and contact information for all ADCs can be accessed over the internet at the web address for the National Alzheimer's Disease Centres Program Directory at the National Institute on Aging: http://www.alzheimers.org/pubs/adcdir.html.

251. The research centre at the University of Washington in Seattle functions as the National Alzheimer's Coordinating Centre (NACC). This site maintains a Minimum Data SET (MDS) of research information collected at all ADC sites, and coordinates access and use of the data by participating research teams. Researchers at the NACC oversee issues of data cleaning and quality control, foster collaborative research among ADCs, and provide statistical and epidemiological support to the individual centres regarding use of the NACC database. The National Alzheimer's Coordinating Centre can be accessed at the following web address: http://www.alz.washington.edu.

252. In addition to the National Family Caregiver Support Program, in 1994 the Administration on Aging started the Alzheimer's Demonstration Grant to States program. Starting with a handful of states, 33 states are now involved with all 50 states expected to participate eventually. The current federal budget is U.S.D 15 million. Funding is through competitive, renewable three-year demonstration grants. Initial funding to awardees is primarily federal, with state funding increasing to a 45% match by the third year. The intent is for the state to take over funding (or other funding be found) when federal funds cease. This program's mandate, also, is to reach the underserved. Currently 1 000 professional providers in 150 communities are involved, serving 3 673 clients. The majority are minority persons, and residents of rural

practice". The guidance covers both individual health technologies (including medicines, medical devices, diagnostic techniques, and procedures) and the clinical management of specific conditions.

areas (Montgomery, 2002). Thus there is good evidence that the Alzheimer's Disease Demonstration Grant to States program, while still comparatively new, is meeting its objective.

253. Individual states also offer caregiver support programs. A survey of 25 states (and the findings may hold for the rest) found that such programs may be funded through general revenue funds, or through home and community-based care programs that serve both the care recipient and the family caregiver. Respite care is offered in most of these states, but eligibility requirements, service delivery, and funding differ across states. Additional services are also offered, comparable to those mandated under the National Family Caregiver Support Program, but also including support groups. Some states offer families cash or vouchers to purchase the services or supplies most appropriate to each family's needs (Coleman, 2000).

254. Finally, nongovernmental agencies, such as the Alzheimer Association, not only advocate on behalf of persons with dementia and their caregivers, but also sponsor research on Alzheimer's disease and dementing disorders, provide information, and facilitate support groups. National and state programs tend to be targeted to persons of lower income, minority status, or those living in areas where there is restricted access to services. Persons reached by organizations such as the Alzheimer Association are more likely to have more education and income, and to belong to the majority population. Overall, however, the extent to which caregivers know about and use the services available, and the impact that such use has, is unclear. Given the size of the caregiver group (which is undoubtedly larger than the number of persons with dementia), the funds available may not be adequate.

Table A. 1: Selected national non-Governmental Organisations (NGOs) concerned with dementia and Alzheimer's disease

Country	Organisation	Purpose	Internet address
Australia	Alzheimer's Association Australia Carers Australia	Peak body providing support and advocacy for the 500,000 Australians living with dementia National voice of family members who provide care and support for persons with a disability, mental illness, chronic condition or who are frail aged	www.alzheimers.org.au www.carers.asn.au
Canada	Société Alzheimer Society Canada & (Alzheimer Society of Ontario)	The three levels of the Society -- national, provincial and local -- work together to form a nationwide network of services to help Canadians affected by Alzheimer Disease	www.alzheimer.ca www.alzheimerontario.org
France	France Alzheimer et Maladies Apparentées	The principal objectives of the organisation are to inform and support family members of persons afflicted with dementia, inform public opinion and government, promote research and train volunteers and health professionals.	www.francealzheimer.com
Germany	Deutsche Alzheimer Gesellschaft	The organisation's goals are to: promote an understanding of Alzheimer's disease and other dementias in the general population; take an active part in health and socio-political activities; improve the ability of afflicted persons to cope with the disease and of relatives to provide independent help; provide relief for carers through emotional support and local assistance; co-operate with the regional Alzheimer societies; provide possibilities to support scientific research of dementia and dementia care; and develop and test new methods of care	www.deutsche-alzheimer.de
Japan	Alzheimer's Association Japan	Is an organization concerned with people with dementia including Alzheimer's disease and their family caregivers. The Association's members include family caregivers, doctors, nurses, social workers, care workers and volunteers.	http://www.alzheimer.or.jp/
Spain	Fundación Alzheimer España	The FAE favours a multidisciplinary approach for providing support to Alzheimer's Disease patients and their families. Helped found Alzheimer Europe along with AD organisations in the Netherlands, Belgium and Ireland. It's primary priorities are: Information, education, advice	www.alzheimer.rediris.es

Table A. 1: Selected national non-Governmental Organisations (NGOs) concerned with dementia and Alzheimer's disease

Country	Organisation	Purpose	Internet address
		and support, and advocacy on behalf of AD patients.	
	Confederación Española de Familiares de Enfermos de Alzheimer y otras Demencias	The CEAFA represents 116 associations in Spain. It's goal is to improve the quality of life of the more than 50,000 families of patients with AD in Spain.	www.ceafa.org
Sweden	Demensförbundet	Protects the interests of those stricken with dementia as well as their relatives. Has 12,000 members and 110 local organisations.	www.demensforbundet.se
	Alzheimerföreningen		www.alzheimerforeningen.nu
United Kingdom	Alzheimer's Society	The Society provides helplines and support for carers, runs quality day and home care, funds medical and scientific research and gives financial help to families in need. It campaigns for improved health and social services and greater public understanding of all aspects of dementia. The Society has branch centres in England, Wales and Northern Ireland.	www.alzheimers.org.uk
	Alzheimer Scotland	Alzheimer Scotland is the national and local voice of and for people with dementia and their carers in Scotland. It helps people with dementia, their carers and families. Members include carers, relatives, people with dementia, professionals, groups and organisations.	www.alzscot.org
	Dementia Voice	Works to promote service development and best practice in dementia care.	www.dementia-voice.org.uk
United States	Alzheimer's Association	The Association is a national network of 81 chapters and more than 220 local points of service. It ranks as the top private funder of research into the causes, treatments, and prevention of Alzheimer's disease. The Association is a strong advocate on behalf of, and provides education and support for people diagnosed with the condition, their	www.alz.org

Table A. 1: Selected national non-Governmental Organisations (NGOs) concerned with dementia and Alzheimer's disease

Country	Organisation	Purpose	Internet address
		families, and caregivers.	
International	Alzheimer's Disease International	Alzheimer's Disease International is the umbrella organisation of Alzheimer associations around the world, which offer support and information to people with dementia and their caregivers.	www.alz.co.uk
Europe	Alzheimer Europe	Alzheimer Europe's aim is to raise awareness of all forms of dementia through coordination and cooperation between Alzheimer and related disorders organisations in Europe, as well as organising support to the sufferers of the disease and their carers	www.alzheimer-europe.org

ANNEX 2. MEDICAL AND EPIDEMIOLOGICAL BACKGROUND

255. Dementia is one of the most common diseases among the elderly. Alzheimer's disease (AD) is the predominant cause of dementia. AD results in a progressive and irreversible decline in cognition, functioning and behaviour. As the occurrence of AD increases exponentially with age, AD increases extensively the burden of disease in the elderly, particularly the very old, in terms of disability and mortality. Moreover AD can have a tremendous impact on the families of AD patients.

I. MEDICAL BACKGROUND

Definition, symptoms and pathogenesis

256. Dementia is an acquired syndrome of decline in memory and other cognitive functions sufficient to affect daily life in an alert patient (Diagnostic and Statistical Manual of Mental Disorders, version IV). Alzheimer's disease (AD) is the most common form of dementia, accounting on its own for 74.5% of all dementia cases in North America, 61.4% in Europe and 46.5% in Asia (Fratiglioni, L., D. De Ronchi, *et al.* (1999).

257. Clinical symptoms of AD typically begin late in life, generally after age 60, with subtle short-term memory problems. Patients may have difficulty finding words, planning meals, managing finances or medications, using a telephone and driving without getting lost. Many capacities may initially remain intact, including the performance of self-care activities of daily living (eating, bathing, grooming) and social skills. Changes in behaviour and mood may occur at an early stage with personality alterations, irritability, anxiety or depression.

258. In more severe stages, the disease impairs the ability to recall information acquired early in life (*e.g.*, names of relatives). Other cognitive functions (language, orientation and judgement) worsen continuously to the point of interfering with the ability of the person to function independently. Delusions, hallucinations, aggression and wandering often develop in middle and late stages. Patients may also fail to recognise their relatives. These changes in behaviour are the most troubling to caregivers and frequently lead to family distress and nursing home placement.

259. In the period just prior to death, patients are mute, exhausted, bedridden and incontinent. Death occurs on average ten years after the first symptoms of memory loss, with a range of 3 to 20 years (Larson, Kukull *et al.* 1992; Small, Rabins *et al.* 1997).

260. A diagnosis of AD involves several factors (Ritchie and Touchon 1992):

- A definite diagnosis of AD is based on histologic evidence in the brain: dense plaques containing the β-amyloid peptide and elements of degenerating neurons, *i.e.* neurofibrillary tangles composed of abnormally phosphorylated tau protein and loss of neurons and neuronal connections. The pathology in AD is confined to the central nervous system. The underlying mechanisms of these post-mortem findings are not yet well understood.

- The loss of neurons and neuronal connections in the cholinergic system is correlated with the impairment of memory. In particular, the cholinergic system is strongly involved in dementia with Lewy bodies, *i.e.* a new nosological entity that could occur in up to 25% of AD cases (Small, Rabins *et al.* 1997), and may be a good candidate for cholinergic augmentation therapy (see paragraph I.3 below). However, dementia with Lewy bodies has few specific clinical features (Hohl, Tiraboschi *et al.* 2000; Walker, Ayre *et al.* 2000).
- The presence and severity of clinical symptoms of AD may be related to the occurrence of stroke, in particular in the oldest ages at high risk for both AD and stroke. In a post-mortem cohort study, the individuals with histologic evidence of AD were more likely to be demented in the presence of stroke (85% of 27 patients with stroke vs. 57% of 37 patients without, respectively) (Snowdon 1997).

261. Prior stroke also places an individual at increased risk for vascular dementia, the second most common form of dementia after AD. Difficulty in distinguishing vascular dementia from AD can limit the comparability of epidemiological studies of AD, though the onset of vascular dementia may be abrupt, distinguishing these cases from the more gradual onset of AD.

262. Vascular dementia is not a single disease but several types of syndromes with vascular disease at its origin. The two most common mechanisms of vascular dementia are multiple cortical infarcts and a single strategic infarct. In the former case, known as multiinfarct dementia, the cumulative effects of several infarcts eventually lead to cognitive decline through damaged neural nets. In the latter case a single strategic infarct is sufficient to cause cognitive decline. Cases of vascular dementia can be further classified as cortical, subcortical or a mixture of AD and vascular dementia.

263. Another condition often associated with AD is mild cognitive impairment (MCI), in fact, MCI is often used to refer to the stage of cognitive decline prior to attaining AD. MCI is difficult to detect since quite often the symptoms of declining cognition are not easily distinguishable from normal cognitive decline among health individuals. Memory loss is the most common symptom. Less common symptoms include language disturbance, attentional deficit and deterioration in visuospatial skills.

I.2 Risk factors of late-onset AD

264. Apart from age as a risk factor, which will be analysed in the epidemiological section below, apolipoprotein E genotype is the primary risk factor identified for late-onset AD (Small, Rabins *et al.* 1997). Other possible risk factors include very old women with postmenopausal oestrogen deficiency, men with previous head injury resulting in loss of consciousness, adult onset diabetes mellitus and lower education level. However, the causes of late-onset AD remain largely unknown. These risk factors are analysed below:

- Apolipoprotein E (apoE) genotype

  a) Even if genetic dissection of late-onset AD is problematic, the apoE-ε4 allele on chromosome 19 has been shown to act as a dose-dependent age-of-onset risk factor among stable populations (Schellenberg 1995; Myers, Schaefer *et al.* 1996). The association may be affected by ethnicity and/or racial origin (*i.e.* Caucasian Americans with apoE-ε4 allele were at greater risk of AD (relative risk (RR)=2.5 (95% confidence interval (CI), 1.1 to 6.4) than African Americans or Hispanics with no significant risk) (Tang, Stern *et al.* 1998).

  b) However, the apoE-ε4 allele is neither necessary nor sufficient to cause AD. At least 35 to 50% of patients with AD do not carry an apoE-ε4 allele and 50% to 75% of apoE-ε4 heterozygous, who account for 88% of apoE-ε4 carriers, will not develop AD (1995). Thus

'genetic testing' for AD is not recommended for predictive screening in asymptomatic persons nor as a diagnosis marker in demented patients (1995).

c) The role of apoE-ε4 allele in AD pathogenesis is not clear. The association of apoE-ε4 allele with vascular dementia and stroke (Myers, Schaefer *et al.* 1996) suggested a possible interaction between apoE-ε4 and atherosclerosis in the aetiology of AD (Hofman, Ott *et al.* 1997). However, the apoE-ε4 seems to increase the risk of AD independently of its effect on dyslipidemia and atherosclerosis (Prince, Lovestone *et al.* 2000).

- Females

a) Age-specific incidence rates among men and women show inconsistent results. A general higher incidence of AD in women was found in Sweden (Fratiglioni, Viitanen *et al.* 1997), The Netherlands (Ott, Breteler *et al.* 1998) and France (Letenneur, Commenges *et al.* 1994; Letenneur, Gilleron *et al.* 1999), but the gender pattern was inconsistent over age in this latter study.

b) However, in a recent pooled analysis of EURODEM data, age-specific incidence rates were similar in men and women until age of 85 and showed a higher incidence rate in women compared to men after 85 years (Andersen, Launer *et al.* 1999). Two American cohort studies did not find gender difference in age-specific incidence, but did find an inconsistent gender pattern at higher ages (Bachman, Wolf *et al.* 1993; Rocca, Cha *et al.* 1998).

c) Taking into account the higher life expectancy of women and a higher dementia risk at very old ages, the lifetime risk for 65-year-old woman to develop AD at the age of 95 years was twice as high as for men (22% and 9% respectively) (Andersen, Launer *et al.* 1999). Therefore, the difference in life expectancy between men and women might be the main factor for gender prevalence patterns.

- Postmenopausal estrogens deficiency

a) A review of 10 randomised controlled trials (Haskell, Richardson *et al.* 1997) and a recent additional trial (Mulnard, Cotman *et al.* 2000) were not conclusive on the beneficial impact of oestrogen replacement therapy, which is still under current research.

- Adult onset diabetes mellitus

a) The association found between adult onset diabetes mellitus and AD in the population-based historical cohort study in Rochester, Minnesota, (Leibson, Rocca *et al.* 1997) was recently confirmed in the Rotterdam cohort study (RR=1.9 (95% CI, 1.2 to 3.1). (Ott, Stolk *et al.* 1999)

b) The association could be causal, *i.e.* insulin resistance syndrome, independent of the apoE genotype (Kuusisto, Koivisto *et al.* 1997), and insulin dependence (Ott, Stolk *et al.* 1999) increase the risk. Or the association could result from shared risk factors, *e.g.*, common histological features may be found.(Lorenzo, Razzaboni *et al.* 1994)

- Previous head injury with loss of consciousness in men

a) In a meta-analysis of seven case-control studies, an association between head injury with loss of consciousness and AD was supported for males only (Mortimer, van Duijn *et al.* 1991).

This finding has also been found in more recent case-control studies (odds ratio between 1.6 (95% CI, 0.8 to 3.4)(van Duijn, Tanja *et al.* 1992), 2.1 (95% CI, 1.1 to 3.8)(O'Meara, Kukull *et al.* 1997) and 4.0 (95% CI, 2.9 to 5.5)(Guo, Cupples *et al.* 2000)). Furthermore, a previous head injury without loss of consciousness was also found to be a milder risk factor (OR=2.0 (95% CI, 1.5 to 2.7).(Guo, Cupples *et al.* 2000)

b) However, neither the "1935-1984 Omstel County Minnesota traumatic brain injury cohort" nor the Rotterdam cohort study demonstrated an association between head injury in men and AD (relative risk for men=1.4 (95% CI, 0.8 to 2.3) and 0.8 (95% CI, 0.4 to 1.9) respectively).(Mehta, Ott *et al.* 1999; Nemetz, Leibson *et al.* 1999) Moreover the assumption that head injury reduces the time to onset of AD was not supported in the two studies.

- Lower educational level (and in some studies lower occupation status)

a) A lower educational level was consistently associated with late onset AD in prevalence studies(Fratiglioni, Grut *et al.* 1991; Ott, Breteler *et al.* 1995) and in some cohort studies.(Stern, Gurland *et al.* 1994; Evans, Hebert *et al.* 1997; Launer, Andersen *et al.* 1999; Letenneur, Gilleron *et al.* 1999)

b) However this risk factor was not found in other cohort studies.(Beard, Kokmen *et al.* 1992; Cobb, Wolf *et al.* 1995)

c) When two possible biases in cohort studies, both related to the level of education were controlled for, *i.e.* loss to follow-up and the use of cognitive screening tests, the association still remained.(Geerlings, Schmand *et al.* 1999)

d) The etiologic relationship between a lower educational level and late-onset AD is currently not clear. Rather than the 'brain reserve' hypothesis, the association may be explained by a higher rate of stroke in this population due to increased cardiovascular risk factors (see above).(Del Ser, Hachinski *et al.* 1999) However, some cardiovascular risk factors have been dismissed, *e.g.*, smoking.(Leibovici, Ritchie *et al.* 1999; Wang, Fratiglioni *et al.* 1999)

- Level of social support

a) A poor social network increased the risk of developing AD (*e.g.*, never-married persons were twice as likely to develop AD than married individuals or cohabitants in the French cohort PAQUID (RR=2.3, $p<0.02$) (Helmer C, Neurology 1999). This result was also found in single individuals or persons without close social ties compared with married people living together (Fratiglioni L, Lancet 2000).

I.3 Diagnosis, treatment and prevention

Diagnosis

265. Diagnosis is often delayed (5 years on average after the first symptoms of memory loss) because of the insidious nature of AD.(Larson, Kukull *et al.* 1992)

- In 90% of cases, the diagnosis of AD can be made on the basis of the informant interview and clinical assessment, including neurological and mental status evaluation.(Small, Rabins *et al.*

1997) According to the NINCDS-ADRDA[22] criteria set, diagnosis of probable AD must include an impairment in memory and at least one other cognitive function (*e.g.*, language or perception), a progressive worsening of memory and at least one other cognitive function, no disturbance in consciousness, onset of AD between 40 and 90 years of age and the absence of another brain disorder or systemic disease that might cause dementia.(McKhann, Drachman *et al.* 1984)

- If a diagnosis remains unclear, a repeated assessment in 6 months is indicated to check for progressive decline.(Small, Rabins *et al.* 1997)

- An assessment with recourse to high technology is preferred to identify common treatable comorbidities and uncommon treatable causes of dementia.(Small, Rabins *et al.* 1997) Current research is attempting to discover possible diagnosis markers for AD.(Kahle, Jakowec *et al.* 2000; Killiany, Gomez-Isla *et al.* 2000). The recent availability of cholinergic augmentation therapy has increased incentives towards diagnosis.

- Magnetic resonance imaging (MRI) has received increasing interest for AD diagnosis (Killiany RJ, Ann Neurol 2000; Petersen RC, Neurology 2000) and is recommended instead of CT Scan, which lacks specificity. Moreover, brain perfusion scintigraphy (*e.g.*, with 99mTc-HMPAO) could also contribute to differential diagnosis of dementia, isolating dementia with Lewy bodies (Donnemiller E, Eur J Nucl Med 1997).

- The definite diagnosis of AD is based on autopsy.(McKhann, Drachman *et al.* 1984)

266. One of the most widely accepted diagnostic criteria for AD was published in 1984 by the NINCDS-ADRDA (see annex).(McKhann, Drachman *et al.* 1984) The criteria are mostly taken up in the latest version of the Diagnostic and Statistical Manual of Mental Disorders (DSM IV, 1994) of the American Psychiatric Association, commonly used in the U.S. and Canada. The DSM IV is also linked to the latest version of the International Classification of Diseases (ICD 10, 1992) of WHO, commonly used in Europe. In the past, lack of consensus on these classification systems may have led to different diagnostic conclusions and thus different prevalence estimates (see Epidemiology section below).

267. These standardised diagnosis criteria are consistently implemented by standardised instruments, *e.g.*, the Cambridge Mental Disorders of the Elderly Examination (CAMDEX) administrated by health professionals is related to both ICS10 and DSM IV.

22. National Institute of Neurological and Communicative Disorders and Stroke - Alzheimer's Disease and Related Disorders Association.

Table A.2. Criteria for the diagnosis of Alzheimer's disease

Diagnosis	Criteria
Probable AD	All of the following must be present: - Dementia established by examination and documented by objective testing - Impairment in memory and at least one other cognitive function (*e.g.*, language or perception) - Progressive worsening of memory and at least one other cognitive function - No disturbance in consciousness - Onset between 40 and 90 years of age -Absence of another brain disorder or systemic disease that might cause dementia In addition, the diagnosis may be supported by one or more of the following: - Loss of motor skills - Diminished independence in activities of daily living and altered patterns of behaviour - Family history of similar disorder - Laboratory results consistent with the diagnosis (*e.g.*, cerebral atrophy on CT Scan)
Possible AD	Fulfilment of the above criteria with variation in the onset of symptoms or manifestations or in clinical course; or a single, but gradually progressive, cognitive impairment without an identifiable cause Another brain disorder or systemic disease that is sufficient to produce dementia, but is not considered to be the underlying cause of the dementia in the patient
Definite AD	Fulfilment of the above clinical criteria and histological evidence of AD based on examination of brain tissue obtained at biopsy or autopsy

Adapted from McKhann *et al.*, 1984

Medical management

268. Current treatments provide only symptomatic relief (Mayeux and Sano 1999)

- Cholinergic augmentation therapy (anticholinesterases) to compensate the loss of acetylcholine, *i.e.* a neurotransmitter which correlates with the impairment of memory. Two sets of drugs are available

  – Tacrine(1993) is the first to have been discovered. Nowadays it is rarely prescribed because of the frequency of adverse effects (up to 55%).
  – Donepezil(1996) and Rivastigmine(1999)

    Donepezil is one of the most widely used drugs because of its once-a-day regimen and reasonable tolerability.(Mayeux and Sano 1999) However, its efficacy remains low and limited to mild and moderate AD. (Donepezil provides significant improvements in cognition in 15% of patients over 24 weeks of follow-up) and its cost-effectiveness depends highly on how long it will be efficacious (uncertain at present), the stage of disease and the setting of the patient (community or nursing home).(Neumann, Hermann *et al.* 1999) Savings would be achieved in mild AD patients who live initially in the community if the drug effect persists for 24 months. In the same favourable scenario, no savings were found for moderate AD patients with a cost-effectiveness ratio around 50 000 U.S.D/QALY.

- Treatment of behavioural manifestations of AD:
  - Depression (selective serotonin-reuptake inhibitors, SSRI),
  - Delusions (antipsychotics),
  - Agitation, anxiety (antipsychotics, and benzodiazepine)
  - Sleep disturbance (melatonin under clinical trials).

269. The next generation of treatment under current randomised trials is focused on delaying the onset of AD and slowing the progression of the disease. These include limiting oxidative stress (vitamin E, selegiline)(Mayeux and Sano 1999), inflammation (nonsteroidal anti-inflammatories) (Stewart, Kawas *et al.* 1997; Mackenzie 2000), postmenopausal oestrogen deficiency (Mayeux and Sano 1999) and the formation, accumulation or cytotoxic effects of β-amyloid peptide(Naslund, Haroutunian *et al.* 2000)). In particular, an experimental vaccine directed against β-amyloid peptide was shown to be an effective treatment in mice (Barbour R, Nature 1999). Human clinical trials should begin in 2000.

270. Preventing the reoccurrence of a new stroke is the main method of managing vascular dementia. This is done primarily by treating the underlying disease, such as hypertension, with drugs, including antiplatelet agents. As with AD, as the disease progresses, patients with vascular dementia will require increased help with ADLs, which eventually is likely to lead to placement in a long-term care institution. Vascular dementia is the target of several recent clinical trials for anticholinesterases, including memantine (Orgogozo, *et al.*, 2002; Wilcock, Mobius and Stoffler, 2002), galantamine (Erkinjuntti, *et al.*, 2002) and donepezil (Wilkinson, *et al.*, 2003; Black, *et al.*, 2003). In each of these trials there was a demonstrable effect on ADAS-cog scores, although in the case of memantine this was due to worsening of the placebo group. These drugs appear to be less effective on improving global assessments or ADLs.

271. There is presently no effective treatment for MCI. Since MCI is often a precursor condition to AD, interventions used in the early stages of AD may be potentially beneficial for patients with MCI. Anticholinesterases seem to be the main focus of clinical trials for treating MCI (Jones, 2003; Jelic and Windblad, 2003).

Prevention

272. Public health attempts at risk factor reduction are non-specific of AD, *e.g.*, reduction of risk factor for stroke, lifestyle modification to limit adult onset diabetes mellitus, and head injury prevention. The advantages of postmenopausal oestrogen replacement therapy are more broadly discussed (decreased risk of osteoporosis and cardiovascular disease but increased risk of breast cancer). Similarly, the potential advantages of nonsteroidal anti-inflammatory drugs in the prevention of AD should be discussed in the light of their side effects in the elderly population, *e.g.*, peptic ulcers and impaired kidney function.

I.4 Health and Social Outcomes

Health outcomes

273. AD increases extensively both functional disability and mortality among the elderly:

- <u>Functional disability</u>

  In a community-based cohort study, 32% of people aged 75 or older at baseline, plus an additional 14% within 3 years after baseline, had a functional dependence defined by the need for assistance in one or more of 6 basic activities of daily living. At baseline, dementia was the major cause of functional dependence (OR=5.9 (95% CI, 4.1 to 8.5) ranking before stroke (OR=2.9 (95% CI, 1.9 to 4.3), hip

fracture (OR=2.7 (95% CI, 1.9 to 3.8) and heart disease (OR=1.4 (95% CI, 1.0 to 1.9). Moreover half of the functional dependence developed within 3 years was attributable to dementia. Stroke and heart disease did not emerge as significant determinants of functional dependence at follow-up. The results were the same when standardising for institutionalisation.(Aguero-Torres, Fratiglioni *et al.* 1998)

- Mortality

  In the same community-based study, the relative risk of death for AD patients was increased (RR=2.0 (95% CI, 1.5 to 2.7), particularly in older women.(Aguero-Torres, Fratiglioni *et al.* 1999) Moreover around 165 000 excess deaths in the US, *i.e.* 7.1% of all deaths, were attributable to AD in 1995 (Ewbank 1999). AD was the third leading cause of death in the US and appeared to be clearly understated by the underlying or contributory cause on death certificates, *i.e.* understated by a factor 5. The 'malignancy of dementia' was confirmed recently in an Italian cohort study of people aged 65 to 84 years where dementia and institutionalisation were found to have the highest mortality risk ratios over two years of follow-up (3.6 (95% CI, 2.6 to 5.1) and 4.2 (6 (95% CI, 2.2 to 7.9) respectively) ranking before cancer, heart failure or diabetes (Baldereschi, Di Carlo *et al.* 1999).

- Quality of life indicators

274. At present AD is poorly assessed by usual health outcome indicators. Biological and imaging markers are lacking. Moreover, survival rates are complicated by the age specific prevalence of AD, *i.e.* the oldest are at increased risk for AD, but also from the lack of accuracy in the time of AD onset. Thus AD related health outcomes rely upon various subjective scales.

- Patient scales are used for cognitive screening (*e.g.*, Mini Mental Status Examination (MMSE), AD for assessing cognitive impairments (*e.g.*, Alzheimer's Disease Assessment Scale-cognitive (ADAS-c) recommended by the FDA for drug submission), behavioural changes (*e.g.*, Alzheimer's Disease Assessment Scale-non-cognitive (ADAS-nc) and quality of life.
- Clinician scales are used for assessing AD severity (*e.g.*, Clinical Dementia Rating scale, or the Global Deterioration Scale), and AD functional and behavioural impairments (*e.g.*, Clinician Interviewed-Based Impression of Change scale (CIBI) or Clinical Global Impression of Change (CGIC).
- However, the importance placed on these subjective scales should be accompanied by a rigorous assessment of their psychometric properties: validity (*i.e.* it measures what it is intended to measure), reliability (*i.e.* the same score is given by repeated measurements in stable patients) and responsiveness (*i.e.* capacity to detect changes) in each AD population of OECD countries. There is a need to further evaluate these tools and standardising them for the purpose of international comparisons.[23]

23. For example, the Resident Assessment Instrument (RAI), recently adapted to different long-term care settings might provide a useful instrument: 1) RAI includes the Minimum Data Set (MDS) which covers a wide range of functional domains and disease diagnoses, 2) MDS items can also be used to measure the quality of care (for instance Quality Indicators assess the use of physical restraint), 3) RAI is a standardised, validated (with inter-observer reliability) and international tool (the interRAI network includes 19 countries most of them OECD countries), 4) RAI is based on the individual patient level and avoids facility-level comparisons which may be meaningless as long-term facilities' case-mix varies enormously across countries, 5) RAI, initially developed to assess nursing home residents, is nowadays used for assessing other long-term care settings with identical items when it makes sense (RAI-Home Care is validated and RAI "family" with RAI-Mental Health, RAI-Acute Care, RAI-Post-acute Care is under current validation), For instance, RAI provided useful cross-national information about physical restraint use and anti-psychotic prescriptions in nursing home cares after adjusting on case-mix (Carpenter, I., Bernabei R. *et al.* 2000).

Social outcomes

275. Dementia-related disability generates strong social pressures on informal and formal care systems. Dementia is a major factor for functional disability, whereas other chronic conditions lead more frequently to death. AD has a major impact on family caregivers, particularly at later stages of AD. Indeed AD care-giving is consistently associated with increased psychiatric morbidity, (*i.e.* depression and anxiety), physical morbidity (*i.e.* poorer self-rated health status, less physical activity and rest) and increased medication use. However, the increase in physical symptoms, illnesses or disabilities is still being discussed. It has been shown that AD is a factor for psychiatric and physical morbidity among caregivers, even once other socio-economic determinants have been controlled for (*e.g.*, female gender, lower income, high stress or personality disorders) (Schulz 2000).

276. Compared to care-giving for non demented persons, care-giving for demented persons requires greater amounts of care (40+ hours of care: 6.1% vs. 12.0% and constant care: 10.9% vs. 16.1%). This may have an impact in terms of working activity (6.6% vs. 13.4%), early retirement (2.8% vs. 5.9%), giving up leisure (40.9% vs. 55%), having less time for other family members (38.1% vs. 52%), perceiving that other family members were not doing their fair share of care-giving (74.1% vs. 59.4%) and greater family conflict over care-giving (Ory, Hoffman *et al.* 1999).

277. From a social standpoint, AD may generate significant direct and indirect costs. The indirect cost due to productivity lost by unpaid caregivers and family caregivers accounted for 60% of the estimated costs to society (annual cost of U.S.D 34 000 per patient in 1991) (Ernst and Hay 1994). Indeed, 7 out of 10 AD patients are living in the community and 75% of home care is provided by close relatives. In the National Survey on Family Care-Giving in the U.S. (1996), up to 5 million households were estimated to provide care for 2 millions AD patients in 1995 (Ory, Hoffman *et al.* 1999).

278. The availability of informal care-giving is challenged by recent social trends. In addition, in 1999 AD patients accounted for the majority of patients in long-term care facilities, up to 90% in nursing homes in several OECD countries. In addition to the changes in perception of AD, nursing homes may finally be insidiously specialised in AD disease.

279. The main medical challenge from a policy perspective is to delay the onset of Alzheimer disease and slow its progression in order to delay entry in a nursing home. Any additional time gained before entry in a nursing home can therefore be considered as a desirable social outcome. This may call for enhanced family support. This has been shown in studies to delay entry in a nursing home (Mittelman, Ferris *et al.* 1996).

II EPIDEMIOLOGICAL BACKGROUND

II.1 Trends in prevalence and incidence

Trends in prevalence

280. A recent review (Fratiglioni, De Ronchi *et al.* 1999) provides information on trends in prevalence:

- In all countries, prevalence of dementia taken from 36 studies increased almost exponentially with age, up to the most advanced ages. When data were pooled by continent, *i.e.* North America, Europe and Asia, prevalence showed very similar figures up to 85 years (very low under the age of 60 years; 0.5% in the age group 60-64 years; 1.5% in the age group 65-69; 3% in the age group 70-74; 6% in the age group 75-79; 12% in the age group 80-84). A greater variation in prevalence was observed over 85

years probably due to a smaller sample size in the oldest European studies (the prevalence of dementia varied between 42.3% in Europe and 68.3% in Asian Americans in the age group 95 years and more). However, the trend in prevalence in recent European studies tends to provide support to the higher figures.

- AD was the leading cause of dementia in all countries. AD accounted for 74.5% of all dementia cases in North America, 61.4% in Europe and 46.5% in Asia. The higher prevalence of vascular dementia in Asia, *i.e.* 38.1% of prevalent dementia cases to be compared to 27.6% in Europe and 10% in North America, decreased when recent Asian studies were pooled.

281. This is consistent with previous reports: the prevalence of moderate to severe AD was shown to increase exponentially with age in a meta-analysis of 4 epidemiological studies conducted between 1985 and 1989 (doubling every 4.2 years after 60 years of age: 0.2% in the age group 60-64 years; 0.4% in the age group 65-69; 0.9% in the age group 70-74; 2.1% in the age group 75-79; 4.7% in the age group 80-84; 10.8% in the age group 85-89; 21.0 in the age group 90-94) (Ritchie, Kildea *et al.* 1992).

282. Differences in prevalence between Western countries seem to reflect methodological rather than real differences. Indeed, methodological differences accounted for 76% of excess variation in prevalence rates of AD among 15 studies published between 1984 and 1993 (Corrada, Brookmeyer *et al.* 1995).

1. Variation in diagnosis criteria and procedure. Prevalence rates of AD increase with the inclusion of mild cases of dementia (73% of the studies) (Corrada, Brookmeyer *et al.* 1995). Various sets of dementia diagnostic criteria have also had an effect on prevalence rates by subtype of dementia (Erkinjuntti, Ostbye *et al.* 1997). As real diagnosis markers were lacking in 1994, CT scans (53% of the studies) and the Hachinski Ischemic Score (67% of the studies) underestimated the prevalence of AD (Corrada, Brookmeyer *et al.* 1995).
2. Other methodological settings. The type of sample (random sample (57%) vs. population based surveys), the type of community (urban (67%), mixed urban/rural (20%) vs. rural) significantly increased AD prevalence rates. The inclusion of institutionalised patients (67%) had no effect (Corrada, Brookmeyer *et al.* 1995).
3. AD duration. Prevalence is determined both by incidence and disease duration. The influence of health care system and/or general health conditions on AD survival may vary between developed countries but is difficult to assess.

Limitations in the comparability of prevalence data for dementia and AD across countries

283. Several factors limit the comparability across countries of prevalence estimates for dementia. Firstly, criteria for the diagnosis of dementia differ substantially from one epidemiological study to another. Erkinjuntti *et al.* (1997) estimated that the prevalence of dementia could vary in the same sample from 3% based on the International Classification of Diseases (ICD 10, 1992) to 17% based on the Diagnostic and Statistical Manual of Mental Disorders (DSM IIIR, 1987) Secondly, epidemiological studies vary in the neuro-psychological screening tests used in the population and in identification of those screened positive (Corrada, Brookmeyer *et al.* 1995). Thirdly, mild cases of dementia, which account for the majority of dementia cases, were included in about three quarters of epidemiological studies. Comparison of studies that included mild cases with those that do not is meaningless.(Corrada, Brookmeyer *et al.* 1995) Fourthly, the inclusion of institutionalized patients or of minority populations, *e.g.*, in the U.S., could influence epidemiological estimates.(Corrada, Brookmeyer *et al.* 1995) Fifthly, the increasing awareness of early AD diagnosis' benefits in relation to a possible medication may improve dementia diagnosis in recent epidemiological studies. Sixthly, prevalence estimates may be higher in longitudinal studies when compared to cross-sectional studies because the diagnosis benefits from the record of the evolution of the subject's cognitive performances over time. Finally, prevalence estimates are

inaccurate: while dementia is rare below age 75 it is a frequent condition above this age, but, with rare exception, sample sizes tend to be quite small in these age groups.(Fratiglioni, Viitanen *et al.* 1992; Polvikoski, Sulkava *et al.* 2001)

Trends in incidence

284. The review discussed above (Fratiglioni, De Ronchi *et al.* 1999) also provides recent information on trends in incidence:

- The incidence of dementia taken from 15 studies increased with age from 0.8 to 4.0 per 1 000 person years in those aged 60 to 64 years to 49.8 to 135.7 per 1 000 person years for the population older than 95 years. However, it is still unclear if the incidence of dementia in very old ages continues to increase or reaches a plateau.
- AD was the most common cause of dementia in 14 studies. AD accounted for 70.6% of all incident dementia cases in North America, 58.9% in Europe and 47.8% in Asia. It is likely that both AD and vascular dementia occur simultaneously in the development of dementia, which can be attributed to one or other subtype depending on the diagnostic criteria set.

285. These findings are consistent with a previous meta-analysis.(Jorm and Jolley 1998).

286. The lower incidence rates of dementia in North America are probably due to methodological differences, in particular to the exclusion of mild cases (Fratiglioni, De Ronchi *et al.* 1999).

287. Incidence studies typically build on prevalence studies. In addition to cross-country methodological limitations common in studies that estimate prevalence rates, incidence studies encounter two additional limitations. Firstly, the number of new dementia cases per year is very low and makes incidence estimates more uncertain. Secondly, clinical assessment of mild dementia cases is difficult and could explain discrepancies found in previous meta-analyses.(Jorm and Jolley 1998; Fratiglioni, Launer *et al.* 2000) Finally, fewer longitudinal incidence studies are undertaken than cross-sectional prevalence studies because of the costs of follow-up. In consequence, dementia incidence data were not provided by some countries.

Projections in the number of AD patients

288. There is currently no evidence for a change in levels of incidence (Rocca, Cha *et al.* 1998). However, the prevalence of AD is increasing due to several factors, including demographic changes, increased longevity for the overall population and increased longevity for AD patients themselves. For example, Brookmeyer Gray *et al.* (1998) found that the prevalence of Alzheimer Disease in the U.S. would increase 4-fold over the next 50 years from 2.32 millions in 1997 to 8.64 millions in 2047. This increase is primarily due to demographic changes. Hypothetical interventions delaying the onset of AD by 1 year or 5 years (*i.e.* 10% or 50% reduction in incidence risk respectively) would reduce the expected prevalence of AD in 2047 by 770 000 or 4.0 million respectively.

289. In the Global Burden of Disease study (Murray *et al.*, 1997), dementia in established market economies accounted for 437 000 years of life lost (200 000 in men, 230 000 in women) and 2.43 million years lived with disability (924 000 in men, 1.51 million in women) in 1990. Dementia (excluding cerebrovascular disease) accounted for 2.4% of the total DALYs (Disability Adjusted Life Years). This made dementia the eighth highest cause of disease burden in the overall population. In 2020, 5.56 million DALYs were expected to be lost due to dementia, which would still remain the eighth highest cause of disease burden, representing 3.5% of the total DALYs.

Estimated prevalence rates

290. As noted in Section 2.2, data on prevalence rates for dementia and moderate to severe AD were estimated for all 9 countries participating in the study. Some of the assumptions used in calculating these data are reported in the main report. What follows are additional notes to what has been provided in the main body of the report. The studies used to estimate prevalence are included in Table 2.

291. Prevalence is determined by both incidence and disease duration. If we are to consider that true differences exist in dementia prevalence across countries, *e.g.*, because different risk factors for dementia may vary across countries or because the dementia case fatality rate could vary across health and social care systems, then we should rely on national or even regional figures. On the other hand, if we are to believe that the natural history of dementia from disease onset to death is universal, then we could use pooled prevalence data from OECD country-specific studies.

292. These considerations were taken into account in Table 3, where four sets of gender- and age-specific prevalence figures are applied to the census data of each country for the year 2000: 1) the country-specific prevalence; 2) the pooled data from 11 European studies with 2346 identified cases of mild to severe dementia; (Lobo, Launer *et al.* 2000) 3) the lowest, and 4) the highest figures from data provided by each country by gender- and age-group. Table 4 provides country projections for the year 2010, assuming no change in temporal trends in gender- and age-specific prevalence figures. In all OECD countries, the ageing of the population results in dramatic increases in the projected number of dementia cases in 2010, in particular in the population 75 years of age and older.

293. Similar to the approach for calculating the prevalence of dementia, Table 5 provides four sets of gender- and age-specific prevalence figures for moderate to severe AD that are applied to census data of each country for year 2000: 1) the country-specific prevalence; 2) the pooled data from 11 European studies; (Lobo, Launer *et al.* 2000) 3) the lowest, and 4) the highest figures from data provided by each country by gender and age-group. Table 6 provides the numbers per country projected to the year 2010, assuming no change in temporal trends in gender- and age-specific prevalence figures.

Table A.3. Prevalence study and methodological issues

Region and year	Diagnostic criteria	Screening test	Population	Sample Size	Comments	No. of prevalence studies
AUS, '98	AD or dementia reported by household rep. or staff member	No	Disability, Ageing and Carers Survey	15 715 houshld.	(1); no clinical assessment	1
CAN, '91	DSM-III-R	MMSE	Canadian Study of Health and Aging	10 263	(1); (2); (3)	2
ENG & WALES, '92	DSM-III-R	MMSE	Regions chosen to capture the main variations in urban-rural differences, socioecon. levels & rates of chronic dis.; no heterogen. found between sites	5 222	(2); (3)	1
FRA, '98	DSM-III-R	MMSE	Gironde and Dordogne provinces	3 777	(2); (3)	1
DEU, '97	DSM-III-R	MMSE	Liepzig municipality	1 265	(2); (3); age 75+ only	5
JPN, '98	DSM-IVand ICD-10	Question. & HDS-R	Nagasaki prefecture	3 965	(2); no brain imaging	13
ESP, '99	DSM-III-R	MMSE	Zaragoza municipality	7 546	(2)	2
SWE, '90 & '98	DSM-III-R	MMSE	Kungsholmen parish of Stockholm	2 368	(2); age 75+ only	1
USA, '99	DSM-III-R	MMSE	Cache County, Utah	5 092	(2); additional proxy interviews	18

Note: All studies included mild cases; (1) Survey(s) national in scope; (2) Epidemiological surveys; (3) Institutionalisation included. DSM – Diagnostic and Statistical Manual of Mental Disorders; ICD – International Classification of Diseases; MMSE – Mini-Mental State Examination; HDS-R – Hasegawa's dementia scale (highly correlated with MMSE)

Table A.4. 2000 - Predicted number of people with dementia by age and gender

			Rates used				
Country	Sex	Age group	Country-specific	Eurodem	Lowest	Highest	Population
Australia	Male	65-74	8 207	13 287	5 933	20 127	599 576
		75+	25 209	35 554	16 910	60 912	402 019
	Female	65-74	5 187	13 318	5 187	20 588	655 112
		75+	59 771	76 967	47 857	129 842	627 662
Canada	Male	65-74	19 421	22 411	10 041	34 313	1 022 148
		75+	95 286	61 922	30 431	105 631	675 532
	Female	65-74	31 333	23 316	9 058	36 353	1 160 495
		75+	210 822	143 677	91 197	243 262	1 114 128
England and Wales	Male	65-74	51 057	51 023	22 840	77 907	2 320 779
		75+	160 526	147 066	71 411	251 080	1 622 354
	Female	65-74	47 459	54 003	21 018	83 705	2 666 209
		75+	423 236	377 547	242 707	638 560	2 823 565
France	Male	65-74	N/A	51 104	22 864	77 891	2 320 304
		75+	186 415	136 239	68 121	235 017	1 490 987
	Female	65-74	N/A	58 299	22 700	90 228	2 872 342
		75+	511 853	365 018	235 551	625 158	2 729 015
Germany	Male	65-74	N/A	74 542	33 494	115 185	3 431 262
		75+	204 163	153 215	76 715	266 554	1 702 455
	Female	65-74	N/A	85 297	33 188	132 333	4 216 584
		75+	706 976	525 585	334 669	905 151	4 094 001
Japan	Male	65-74	135 613	130 307	58 521	201 035	5 988 664
		75+	297 349	279 861	136 943	480 073	3 081 631
	Female	65-74	96 652	136 700	52 872	216 164	6 937 406
		75+	693 566	706 346	444 265	1 195 073	5 606 668
Spain	Male	65-74	19 037	38 272	17 143	58 554	1 744 267
		75+	46 145	95 526	46 145	163 406	1 070 771
	Female	65-74	33 658	42 279	16 416	66 032	2 109 368
		75+	155 041	225 333	140 705	380 786	1 821 034
Sweden	Male	65-74	11 906	7 874	3 514	11 906	354 681
		75+	32 771	28 580	14 045	48 767	308 501
	Female	65-74	10 140	8 283	3 231	12 746	404 877
		75+	69 215	63 541	40 551	107 181	483 782
United States	Male	65-74	184 744	184 744	82 539	280 331	8 350 826
		75+	807 851	558 246	271 106	950 221	6 115 394
	Female	65-74	242 534	202 807	79 011	313 345	9 968 495
		75+	1 794 291	1 365 344	871 563	2 304 795	10 399 095

Table A.5. 2010 - Predicted number of people with dementia by age and gender

Country	Sex	Age group	Rates used: Country-specific	Eurodem	Lowest	Highest	Population
Australia	Male	65-74	9 811	16 144	7 281	25 245	752 041
		75+	33 238	45 347	22 414	77 378	481 837
	Female	65-74	5 941	15 465	5 941	24 983	808 078
		75+	76 884	95 969	61 417	161 399	722 639
Canada	Male	65-74	N/A	26 220	11 822	40 960	1 220 160
		75+	130 373	85 584	43 307	145 073	886 686
	Female	65-74	N/A	26 196	10 071	42 217	1 364 318
		75+	281 530	194 529	127 115	328 654	1 385 115
England and Wales	Male	65-74	56 264	55 394	24 913	85 852	2 557 451
		75+	184 723	171 437	86 248	292 040	1 795 815
	Female	65-74	50 481	55 344	21 358	88 137	2 835 997
		75+	464 072	422 324	276 999	713 409	2 972 930
France	Male	65-74	N/A	49 398	22 109	75 385	2 245 667
		75+	236 691	174 306	85 885	298 077	1 865 860
	Female	65-74	N/A	53 448	20 799	82 890	2 640 773
		75+	635 181	453 475	292 760	763 404	3 334 244
Germany	Male	65-74	N/A	97 234	43 286	145 843	4 344 542
		75+	283 828	215 907	101 402	367 974	2 446 226
	Female	65-74	N/A	103 152	40 366	157 060	4 968 309
		75+	808 983	595 194	381 023	1 003 884	4 488 214
Japan	Male	65-74	155 841	149 708	67 188	230 462	6 865 254
		75+	460 807	443 545	212 744	750 937	4 878 356
	Female	65-74	109 164	154 395	59 729	243 983	7 828 280
		75+	1 019 335	1 029 729	657 712	1 735 278	7 817 411
Spain	Male	65-74	17 598	35 120	15 784	54 305	1 617 695
		75+	62 332	126 841	62 332	216 418	1 364 857
	Female	65-74	30 049	38 038	14 718	60 078	1 927 261
		75+	213 920	303 379	193 789	510 825	2 300 052
Sweden	Male	65-74	15 452	9 798	4 431	15 452	460 311
		75+	36 764	31 776	16 473	54 163	319 948
	Female	65-74	12 194	9 230	3 537	15 014	486 864
		75+	76 515	71 579	47 257	121 094	494 104
United States	Male	65-74	209 423	209 423	94 532	328 323	9 780 473
		75+	952 794	650 485	328 799	1 106 908	6 738 131
	Female	65-74	262 785	218 562	83 936	353 331	11 431 622
		75+	2 134 283	1 614 953	1 058 857	2 726 004	11 370 884

Table A.6. 2000 - Predicted number of people with moderate to severe AD by age and gender

Country	Sex	Age group	Rates used: Country-specific	Eurodem	Lowest	Highest	Population
Australia	Male	65-74	1 943	3 078	1 869	4 452	599 576
		75+	9 423	12 147	5 706	22 636	402 019
	Female	65-74	1 903	4 871	1 903	7 657	655 112
		75+	34 931	43 264	24 815	81 907	627 662
Canada	Male	65-74	4 271	5 163	3 124	7 546	1 022 148
		75+	33 488	21 979	10 879	40 190	675 532
	Female	65-74	11 282	8 523	3 322	13 504	1 160 495
		75+	121 844	82 317	47 823	156 370	1 114 128
England and Wales	Male	65-74	11 245	11 771	7 129	17 159	2 320 779
		75+	54 011	51 532	25 026	94 785	1 622 354
	Female	65-74	17 096	19 747	7 711	31 120	2 666 209
		75+	242 779	218 079	127 859	414 332	2 823 565
France	Male	65-74	N/A	11 800	7 151	17 172	2 320 304
		75+	82 531	48 736	24 713	89 956	1 490 987
	Female	65-74	N/A	21 320	8 329	33 552	2 872 342
		75+	353 673	213 016	124 782	405 527	2 729 015
Germany	Male	65-74	N/A	17 093	10 305	25 204	3 431 262
		75+	75 832	54 418	27 655	101 599	1 702 455
	Female	65-74	N/A	31 189	12 176	49 192	4 216 584
		75+	421 198	304 164	176 401	578 083	4 094 001
Japan	Male	65-74	31 277	29 904	18 040	44 028	5 988 664
		75+	108 759	98 529	48 303	182 001	3 081 631
	Female	65-74	35 307	49 929	19 379	80 146	6 937 406
		75+	397 229	401 325	231 818	761 042	5 606 668
Spain	Male	65-74	N/A	8 820	5 338	12 882	1 744 267
		75+	16 030	33 127	16 030	61 168	1 070 771
	Female	65-74	N/A	15 453	6 021	24 524	2 109 368
		75+	84 433	127 373	73 209	241 568	1 821 034
Sweden	Male	65-74	2 636	1 825	1 110	2 636	354 681
		75+	11 735	10 183	5 009	18 652	308 501
	Female	65-74	3 655	3 030	1 186	4 744	404 877
		75+	39 692	36 414	21 266	69 069	483 782
United States	Male	65-74	39 196	42 751	25 953	61 952	8 350 826
		75+	322 620	196 319	95 305	359 597	6 115 394
	Female	65-74	91 509	74 174	28 992	116 545	9 968 495
		75+	1 037 173	784 097	457 686	1 489 330	10 399 095

Table A.7. 2010 - Predicted number of people with moderate to severe AD by age and gender

			Rates used				
Country	Sex	Age group	Country-specific	Eurodem	Lowest	Highest	Population
Australia	Male	65-74	2 289	3 679	2 208	5 489	752 041
		75+	13 027	16 315	8 049	29 853	481 837
	Female	65-74	2 175	5 641	2 175	9 236	808 078
		75+	45 566	54 848	32 148	103 744	722 639
Canada	Male	65-74	5 043	5 979	3 589	8 910	1 220 160
		75+	47 972	31 633	16 233	56 801	886 686
	Female	65-74	13 231	9 557	3 688	15 613	1 364 318
		75+	165 772	113 557	67 352	215 780	1 385 115
England and Wales	Male	65-74	12 292	12 683	7 637	18 756	2 557 451
		75+	65 414	62 786	31 885	113 796	1 795 815
	Female	65-74	18 148	20 206	7 825	32 647	2 835 997
		75+	269 841	247 255	147 008	470 030	2 972 930
France	Male	65-74	N/A	11 399	6 905	16 608	2 245 667
		75+	105 087	62 368	30 625	114 604	1 865 860
	Female	65-74	N/A	19 544	7 631	30 814	2 640 773
		75+	437 783	261 260	153 957	494 934	3 334 244
Germany	Male	65-74	N/A	22 629	13 796	32 437	4 344 542
		75+	100 462	73 171	33 695	135 968	2 446 226
	Female	65-74	N/A	37 758	14 822	58 536	4 968 309
		75+	475 281	340 746	199 621	644 665	4 488 214
Japan	Male	65-74	35 981	34 395	20 766	50 533	6 865 254
		75+	166 493	154 641	73 776	282 318	4 878 356
	Female	65-74	39 879	56 394	21 893	90 468	7 828 280
		75+	589 627	590 569	345 102	1 120 795	7 817 411
Spain	Male	65-74	N/A	8 050	4 852	11 878	1 617 695
		75+	22 217	45 245	22 217	82 893	1 364 857
	Female	65-74	N/A	13 894	5 395	22 278	1 927 261
		75+	116 439	173 631	101 542	329 023	2 300 052
Sweden	Male	65-74	3 344	2 223	1 329	3 344	460 311
		75+	14 070	12 039	6 338	21 624	319 948
	Female	65-74	4 377	3 366	1 295	5 546	486 864
		75+	44 958	42 083	25 131	79 944	494 104
United States	Male	65-74	42 565	47 665	28 571	71 282	9 780 473
		75+	387 818	239 999	122 417	433 820	6 738 131
	Female	65-74	98 601	79 724	30 731	130 616	11 431 622
		75+	1 259 210	944 194	561 483	1 793 656	11 370 884

GLOSSARY

Country abbreviations

AUS - Australia
CAN - Canada
DEU - Germany
FRA - France
ESP - Spain
GBR - Great Britain
JPN - Japan
SWE - Sweden
USA - United States of America

Activities of Daily Living (ADL): items that specify daily activities necessary for a person to care of oneself such as dressing, bathing, eating, toileting, getting in and out of bed/chair.

Alzheimer's disease (AD): a neurodegenerative disease that eventually results in the irreversible loss of neurons, particularly in the cortex and hippocampus, that gradually leads to memory loss, behaviour and personality changes, and a decline in cognitive ability.

Alzheimer's Disease Assessment Scale-cognitive subscale (ADAS-cog): a sensitive psychometric measure used in clinical trials for assessing the effectiveness of treatment on multiple cognitive outcomes.

Anticholinesterases (cholinesterases inhibitors): drugs for treating dementia by inhibiting acetylcholinesterase, a neurotransmitter which correlates with memory impairment.

Apolipoprotein E genotype (APOE): the APOE gene directs the manufacture of ApoE protein, of which excess amounts are associated with plaques in the brains of people with AD. This fact has led research into developing screening tests to detect the presence of APOE as a predictor of possible AD.

Assisted living: provides services to meet residents' individualized scheduled needs, based on the residents' assessments and service plans and their unscheduled needs as they arise. Assisted living has different meanings depending on the country. For example, in the U.S. it refers to a special type of institutional setting and in the United Kingdom Extra Care broadly equates to assisted living.

Attributable Risk: Additional risk of disease in the exposed group over that in the unexposed group. If lung cancer occurs in 1 of 10 000 non-smokers every year (made up numbers) and in 100 of 10 000 smokers, the attributable risk of smoking is 99 of 10 000. Attributable risk = Incidence in those exposed minus incidence in those not exposed.

Cantou: see Group-living

Case Fatality Rate: The rate of death from a disease in patients with that disease. For example, 1000 males in Charleston, SC are infected with HIV. During 1998, 10 HIV-infected males in Charleston, SC died for a case fatality rate of 10/1000 or 1%.

Clinical Dementia Rating (CDR): a global measure of patient's abilities to function in six areas – memory, orientation, judgement, ADL, hobbies and interests, and ability to live in the community.

Clinician's Interview-Based Impression of Change – plus caregiver input (CIBIC-plus): a global measure of patient's behaviour, general psychopathology, cognition and ADL.

Community-based care: supportive services provided to persons with disabilities outside of institutional settings, where services are provided around a person's living circumstances and involves short stays in temporary care facilities.

Cost-effectiveness analysis: an analytic tool in which costs and effects of a program and at least one alternative are calculated and presented in a ratio of incremental cost to incremental effect. Effects are health outcomes, such as cases of a disease prevented, years of life gained, or quality-adjusted life years, rather than monetary measures as in cost-benefit analysis.

Cost-of-illness study: an analysis of the total global costs associated with the prevention, diagnosis and treatment of a specific disease.

Defined Daily Dose (DDD): unit of measurement of pharmaceutical consumption defined as the assumed average maintenance dose per day for a drug used on its main indication in adults.

Dementia: an acquired syndrome of decline in memory and other cognitive functions sufficient to affect daily life in an alert patient. The most common form of dementia is Alzheimer's disease.

Direct costs: are the monetary costs of health care resources, (*e.g.*, tests, drugs, supplies, health care personnel, and medical facilities) consumed in the provision of an intervention or in dealing with the side effects or other current and future consequences linked to it.

Early-onset Alzheimer's disease: occurs in people younger than 65

Formal care: care services supplied by any organisation, in either the public or private sector, as opposed to care provided by family or friends. Includes care provided in institutions like nursing homes, as well as care provided to older persons living at home by either professionally trained care assistants, such as nurses, or untrained care assistants.

Group-living: centres where caregiving is based on the lodging of patients in specialised housing which groups around a common living area. Life is organised around domestic activities led by a registered nurse or housekeeper. There is no medical service attached to this structure.

Incidence Rate: Number of new cases of a disease in a specified period / average population at risk (*i.e.* prevalent cases excluded) during that period. Rate is usually expressed as per 100 000.
Indirect costs: productivity gains or losses related to illness or death; in cost-of-illness studies it is usually measured in terms of lost wages.

Informal care(giver): unpaid care provided to a person afflicted with dementia. Informal caregivers are usually an immediate family member such as children or spouse. To be considered informal, the provision of care cannot be paid for as if purchased as a service, but the informal caregiver may receive income transfers conditioned on his/her provision of informal care and possibly, in practice, some informal payments from the person receiving care.

Instrumental Activities of Daily Living (IADL): items that specify activities necessary to live independently in the community such as shopping, specific housework chores, preparing meals and handling personal finances

International Classification of Diseases (ICD-9; ICD-10): ninth and tenth revisions of the World Health Organisation's disease classification system.

Late onset dementia: occurs in people 65 years or older

Long-term care (LTC): individuals need long-term when dependent for an extended period of time, in this study due to dementia, which limits their ability to carry out basic self-care or personal tasks that must be performed every day, defined as ADLs or IADLs.

Long-term care institutions: are places where care and accommodation is provided as a package by the same legal entity (public agency, non-profit or private company). Residents may or may not be charged separately for care services and accommodation. The decisive criteria for being considered an institution is that care and accommodation is provided to users by the same legal entity.

Markov models: a type of mathematical model containing a finite number of mutually exclusive and exhaustive health states, having time periods of uniform length, and in which the probability of movement from one state to another depends on the current state and remains constant over time.

Memory Clinic: a memory clinic is a centre providing specialist services for persons with dementia, often combining clinical work and research. The clinical work tends to be multi-disciplinary, involving clinicians and social care professionals.

Mild Cognitive Impairment (MCI): is a specific type of memory loss; people with this disorder have sharp thinking and reasoning skills, but their short-term memory declines. Typically, people with the disorder have the most trouble remembering recently acquired information and knowledge, while their recall of long ago events may remain intact.

Mini-Mental State Examination (MMSE): a clinical screening instrument used to measure patient's cognition in 5 areas – orientation, attention, immediate and short-term recall, language and the ability to follow simple verbal and written commands.

Mortality Rate: Total number of deaths / total number of people per unit of time.
Outcomes: changes in health status strictly attributable to the activities of health or social care systems.

Palliative care: care received by patients in the terminal phase of their illness. The goal of palliative care is to provide comfort and minimise pain when medical intervention is no longer a viable option.

Prevalence Rate: Number of people with a disease at a given point (period) / population at risk at a particular point (period). Rate is usually expressed as per 100 000. Prevalence = Incidence X duration
Quality-Adjusted Life Years (QALY): takes into account both quantity and the quality of life generated by healthcare interventions. It is the arithmetic product of life expectancy and a measure of the quality of the remaining life-years. QALY weights are measured on a scale of 0 (death) to 1 (a year of perfect health).

Respite care: care offered to provide temporary relief to informal caregivers; can take the form of increased support in the home or regular attendance at a day centre.

Standardized Mortality Rate: Mortality rate adjusted for a confounding variable such as age.
Vascular dementia: results either from extensive narrowing and blockage of the arteries that supply blood to the brain or from strokes caused by an interruption of blood flow to the brain. The initial onset of symptoms usually is abrupt, but sometimes the disease progresses slowly, making it difficult to distinguish it from Alzheimer's disease. It's common for vascular dementia to cause problems with thinking, language, walking, bladder control and vision.

Zarit Burden Interview Scale (ZBIS): an interview-based measure of caregiver burden that examines the impact of the care receiver's disabilities on the caregiver's emotional, social, physical and financial well-being.

Glossary of Terms

(Adapted from (Gold, Siegel *et al.* 1996))

Contingent valuation: A method of placing a monetary value on a good or service that is not available in the marketplace by determining, contingent on it being available in the marketplace, the maximum amount that people would be willing to pay for it (buying price) and/or the minimum amount that people would be willing to accept to part with it (selling price).

Cost-effectiveness analysis: An analytic tool in which costs and effects of a program and at least one alternative are calculated and presented in a ratio of incremental cost to incremental effect. Effects are health outcomes, such as cases of a disease prevented, years of life gained, or quality-adjusted life years, rather than monetary measures as in cost-benefit analysis.

Cost-of-illness study: An analysis of the total costs due to prevent, diagnose, treat, and cope with a specific disease.

Direct medical costs: The value of health care resources, (*e.g.*, tests, drugs, supplies, health care personnel, and medical facilities) consumed in the provision of an intervention or in dealing with the side effects or other current and future consequences linked to it.

Direct non-medical costs: The costs of non-medical goods, services, and other resources, such as caregiving or transportation, consumed in the provision of an intervention or in dealing with the side effects or other current and future consequences linked to it.

Indirect costs: A term used in economics to refer to productivity gains or losses related to illness or death; in accounting is it used to describe overhead or fixed costs of production.

Markov models: A type of mathematical model containing a finite number of mutually exclusive and exhaustive health states, having time periods of uniform length, and in which the probability of movement from one state to another depends on the current state and remains constant over time.

Opportunity cost: The value of time or any other ‘input’ in its highest value use. The benefits lost because the next-best alternative was not selected.

Perspective: The viewpoint from which a cost-effectiveness analysis is conducted.

Relative price: A comparison of the price of one product or service to the price of another comparable product or service.

Transfer cost: Also known as transfer payment. A payment made to an individual (usually a government body) that does not perform any service in return. Examples are social security payments and unemployment compensation.

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