

Needs Assessment Report

Dementia and Older People

October 2003

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EXECUTIVE SUMMARY

INTRODUCTION

Dementia is a slowly progressive but ultimately terminal organic brain syndrome. The ageing of the “baby boomers” of the 1950s and 60s will result in a significant mass ageing in Scotland. There are currently 57,000 older people with dementia in Scotland. By 2040 there will be 104,000.

This report is aimed at planners and commissioners of care for people with dementia and their carers. It provides underpinning for implementation of the National Framework for Mental Health Services in Scotland. It highlights the importance of identifying a) the specific nature of dementia, b) the variety of needs of people with dementia and carers, and c) the implications for the whole of Scottish society. It looks for creative and imaginative service planning and delivery to be built into a joint local authority and health strategy. Above all it calls for a balance of care and a focus on the needs of people with dementia.

POLICY CONTEXT

Planning for dementia comes under the present government’s policies of developing care services. Key themes within this are modernisation, inclusion, justice for all, community based care, support of carers and partnership between agencies and service users and carers. Modernisation implies efficient and economic delivery of services. A number of key documents have been produced that elucidate this requirement. Two recent relevant Acts are Regulation of Care (Scotland) 2001 and Adults with Incapacity (Scotland) 2000.

DEFINITIONS

Dementia refers to a range of illnesses that result in global impairment of brain function. The level of disability experienced by the person with dementia depends on interaction between the disease, the individual and the environment. It has been called a bio-psycho-social syndrome. The experience of the disability and consequent needs therefore vary and require a variable response from a “full sequence” of services. Dementia is mostly associated with old age. Early onset dementia or dementia that is a result of other disease is discussed in a separate Scottish Needs Assessment Programme report noted in section 1.3. Other risk factors are as yet unclear although there is some understanding of the risk factors for vascular dementia and the genetics of Alzheimer’s disease. The majority of people with mild to moderate dementia live at home. Clear and early diagnosis is essential. Co-morbidity is common and often missed.

THE PERSON'S JOURNEY

The dementia journey is always unique. The challenge to planners is to provide a balance of services that can respond to the particular journey in a rational way. Early signs of dementia can be dismissed as a normal part of ageing. As the disease progresses people may start to lose the capacity to manage their daily lives and carers may have difficulty in understanding this loss. Public information and awareness is required so that opportunities for early diagnosis and generation of less disabling environments can be maximised. There is a great importance in establishing early and accurate diagnosis. The role of the GP is crucial in triggering diagnosis. Memory clinics could have a greater role in clinical practice. Psychiatric beds are used for both diagnostic/assessment and short stay purposes. Once the person has been diagnosed their needs should be assessed using *single shared assessments*, a corner stone of the Joint Future initiative. Part of the assessment process must include self-assessment and people involved in decision making. This implies a need for advocacy for people who are no longer able to articulate their own needs. The assessment must be inclusive and recognise the continuing role of staff with specialist knowledge and skills. Consultants in the medicine of old age should be centrally involved.

The managed clinical network proposed by the Acute Services Review is of central importance in developing the *community dementia/mental health team*. Continuity and integration are essential. As well as basic needs, the needs of people with dementia include cultural and spiritual needs, which are sometimes overlooked. A useful way to think about need is using the concept of "intervals of care". The shorter the interval needed in episodes of care for the person with dementia, the greater the need.

SERVICES

The general aim of services for people with dementia and their carers is to keep people with dementia in their own homes and communities as long as possible. This presupposes the maximisation of the person's capacity for living a full life in the community and to promote wellbeing and ability and the minimisation of physical, social and environmental constraints that disable the individual. A menu of services should be available which is imaginative and flexible. A checklist of services is provided. It is understood that no one person will use all the services all the time, and that use of one often obviates the need for another. Only where a full range of flexible and responsive services is available will it be possible to enable people to make choices in meeting individual needs. Good services imply good training of staff with clear and accurate information and standards. The goal is dementia friendly general services and specialist services in all areas of Scotland providing a full sequence of services. Services that fill the empty day in enjoyable and productive ways meet the needs of the people with dementia and their carers. A particular group which needs attention is the significant minority of people with dementia who live alone. Their needs may differ from those who live with family.

There is widespread acknowledgement that community care would collapse without carers. Carers of people with dementia alongside those they care for are amongst the most socially excluded groups in Scottish society, especially co-resident carers. Carers of people with dementia may be at greater risk of psychological ill health than other carers. However it appears that quite limited amounts of service provision are sufficient to reduce stress in some carers. Carers are most taxed by keeping the person with dementia occupied and in providing supportive supervision. Other factors such as rural issues, ethnic minority status groups, poverty and housing have a bearing on service use and value. There is a need for affordable access to small scale homely environments that use modern technology. A high

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percentage of people living in care homes and continuing NHS care have dementia. People in these settings often have extensive physical disabilities and other conditions that require high quality care from acute hospital staff. It is noted that all acute and post acute hospital services now deal with older people who are confused. Knowledgeable and sympathetic management of such patients greatly diminishes their distress and is a very rewarding part of the acute and post acute care of older patients.

QUALITY STANDARDS

The National Guidance on Standards gives a framework to which standards for dementia care should aspire. High standards rely on good training. Staff issues currently preoccupying the NHS also feature in voluntary and private sectors. Staff shortages, poor training and lack of integration are all issues. Staff need appropriate skills and competencies, skills mix within teams and good managerial support. There are five principles to produce good quality care: leadership, policy implementation, training, support services and job security.

PLANNING AND COMMISSIONING

This includes both health promotion and community planning. The goal of the dementia friendly community is not simply in relation to the built environment but also with respect to public knowledge and attitudes and access to the social, cultural and spiritual life of the community. Commissioners of services should attend to the balance of care so that a full sequence of services can be offered in any part of Scotland, based on the needs of people with dementia and their carers. The problem in most areas of Scotland is either that the full sequence is not available or, as is widely acknowledged, that service levels are insufficient to meet need. Principles of good practice must underpin planning.

POPULATIONS

Having identified what services should be provided, in consultation with people with dementia, carers and their organisations, planners and commissioners will then require to determine the mix of services required to meet need, the ways existing resources, including staff, can be developed, and what investment is required to create the balance of joint services. Population estimates can then help determine scale, distribution and location for services, on the basis that services should be accessible to those with dementia and their carers.

EVALUATION

Good evaluation must move beyond the descriptive. Evaluation must be based on meeting the needs of people with dementia and on the measured effects of services on people with dementia and their formal and informal carers. This report suggests a number of research priorities with respect to dementia. Routine monitoring in some of these areas to facilitate evaluation is suggested. The report offers a list of questions that should be posed by evaluators which offers a guide for evaluation of services. It also gives examples of the kinds of evaluation available.

ONE

INTRODUCTION

- 1.1 This report is written primarily for people whose job it is to plan and commission health and care services. It will also be of interest to those who provide services. It provides underpinning for implementation of the Mental Health Framework and ensures that the needs of this group are understood in the Government's priority for mental health services.
- 1.2 The report is based on the principle of a balance of care in which it is understood that exactly the same combination of services would be unlikely in every area of Scotland, but that provision is designed and adequate to meet the same needs in whatever way is locally appropriate. It focuses on the needs which must be met, as far as possible in or near the person's own home. It places as much emphasis on the needs of carers as of the person with dementia themselves, because the illness has a profound effect on carers as well as the person with dementia.
- 1.3 The Scottish Needs Assessment Programme (SNAP) began life as a self-help network and was incorporated within the networking functions of the Public Health Institute of Scotland (now NHS Health Scotland). The original Dementia report (first published in 1997) was part of a portfolio of needs assessment within the Mental Health Framework. Rapid and important changes in the field of dementia have prompted the production of an updated version of the Dementia Report, which is now a free-standing report within the needs assessment series. As the series already includes the SNAP Report – *Huntington's Disease, Acquired Brain Injury and Early Onset Dementia*, which was published in 2000, this report focuses on older people with dementia, although this report has much that is also relevant for younger people with dementia.
- 1.4 People with dementia have a terminal illness of the brain, which usually progresses slowly over a long period. They share a range of disabilities such as impaired memory, impaired learning, and impaired reasoning. The group of diseases under the general heading of dementia include Alzheimer's Disease, Vascular Dementia, Lewy body dementia as well as a host of others experienced by much smaller groups of people such as Pick's disease, Cadasil, and CJD. There is also a group of less progressive conditions such as alcohol related brain damage (ARBD). Except for the last of these there is much, so far inconclusive, research on the causes of these diseases. Thus preventive strategies are still in their infancy and drug treatment is, at present, limited to cholinesterase inhibitors which slow down progress in about a quarter of people with Alzheimer's disease. There are several psychological interventions with similar



rates of efficacy although they are not widely available.¹ However, much can be done to optimise ability, prevent avoidable deterioration and promote well-being.

- 1.5 The 'baby boomers' of the 1950s and 60s will be in their 70s and 80s in the 2030s, and, with lower fertility from the 1970s the overall population structure in Scotland is changing dramatically. Whilst greater longevity is also relevant, these broader demographic factors are the main reason why *"the projection for 2031 shows significant mass ageing. Between 2000 and 2031 the number of people over 65 is expected to increase from 787,000 to 1,200,000; and those over 85 from 84,000 to 150,000."*²
- 1.6 The number of people with different forms of dementia is set to continue to grow substantially, and the number of people in high-risk groups will also increase. These groups include people with a learning disability who are ageing, people with alcohol problems and people in their seventies and eighties. The prevalence is as high in one in five people who are over 85 years.
- 1.7 As the diseases progress the disabilities inevitably worsen. This ultimately affects every aspect of functioning. The presentation can be complicated by concomitant physical and psychiatric disorders in many people, as it can by the lack of skill and understanding in both the general population and the health and social services.
- 1.8 There are approximately 57,000 older people with a diagnosis of dementia in Scotland, with an estimated 40,000 having moderate to severe dementia. The number of people under 65 with these disabilities is not well established. The figure of 2,000 with Alzheimer's disease is generally accepted, but the number of people with learning disability and dementia (the highest risk group being those with Down's Syndrome) is unknown, as is the number of people with Alcohol Related Brain Damage.

TWO

POLICY CONTEXT

2.1 The development of care services in Scotland in recent years and the future of these services over the next few years can be seen within the overall context of policy directions set by the present government with a number of key themes including:

- modernisation
- best value
- partnership
- social inclusion/social justice
- policies/strategies for community care
- mental health
- carers

MODERNISATION

2.2 The government signalled its intentions for the health service in "*Designed to Care – Renewing the National Health Service in Scotland*", published in December 1997. This stated the government's wish to see a 'seamless service based on primary care', a service which would concentrate on improving health and reducing health inequalities, through a 'partnership approach', away from the competition of an internal NHS market.

2.3 '*Our National Health – A plan for action, a plan for change*' extended these themes, with more specific proposals for communication and listening to people, for improving the patient's journey, for better access, speed of response, reduced waiting times, integrated assessment, single door services and one stop clinics. The three clinical priorities for the NHS were to include developing mental health services.

2.4 For care services, "*Modernising Social Work – An Action Plan*", published by the Scottish Executive in 1998, had three main aims, which were:

- quicker and better decision making, through delegated decision making and financial responsibility
- more flexible and better quality home care services, including a shift in the balance of care towards these services
- agencies working in partnership in localities, through better operational and strategic planning, joint budgets, joint services and joint systems.

2.5 The government's modernising agenda for care services was further set out in the White Paper "*Aiming for Excellence – Modernising Social Work Services in Scotland*", leading on to the Regulation of Care (Scotland) Act 2001 establishing:

- the Scottish Commission for the Regulation of Care to register, inspect and enforce care standards in care services
- the Scottish Social Services Council to maintain a register of staff, regulate professional and vocational education, and publish codes of conduct and practice for all staff.

The definition of national care standards and the regulation of services and staff by these two new bodies will have a major influence on the development of care services for people with dementia in Scotland.

BEST VALUE

2.6 Best Value in public services is based on the principles of ownership, transparency and accountability. The key elements of Best Value have been identified as sound governance in assessing needs and managing services, performance measurement including benchmarking, continuous improvement, and three year budgeting. The fundamental issue for commissioners of services for people with dementia remains how to meet need in ways which deliver quality and maximise budgets.

PARTNERSHIP

2.7 The general theme of partnership has been promoted by the government in a range of policy areas. Both "*Designed to Care*" for the NHS and the "*Action Plan*" for care services identified the importance of partnership to the government in relation to the delivery of services. The policy of the Scottish Executive in this area has been further defined both in its response to the Report of the Joint Future Group, and its response to the report of the inquiry into community care carried out by the Health and Community Care Committee of the Scottish Parliament.

2.8 The Joint Future Group Report made a series of proposals with recommendations for joint action by local authorities and health services which were of direct relevance to the assessment for and delivery of community care services, including:

- single assessments of need using a jointly agreed assessment tool
- intensive care management for complex cases
- shared information
- joint resourcing and joint management of services (single management of staff, buildings and money).

2.9 Local Outcome Agreements between local authorities and NHS Boards are intended to define service changes, targets, and how 'pooled budgets' are to be invested. The Community Care and Health (Scotland) Act 2002 also proposes that Scottish Ministers should be given powers to intervene if there is insufficient evidence of change in local areas.

SOCIAL INCLUSION/SOCIAL JUSTICE

2.10 In 1999, the Scottish Office published a report "*Social Inclusion – opening the door to a better Scotland*", which set out the five principles of the government's approach to social inclusion: integration (partnership), prevention (focusing on young people), understanding (what works), inclusiveness (what people need), and empowerment (individuals and communities).

TWO POLICY CONTEXT

2.11 The Scottish Executive sees its response to the Royal Commission on Long Term Care and its specific proposals for free personal care, single shared assessments and additional investments as significant components of a social justice policy. They will all have an impact on care services for people with dementia and their carers. At the same time, community planning should also allow for the spiritual, social and cultural needs of those with dementia to be fully taken into account by those planning services for all groups in local communities.

POLICIES/STRATEGIES FOR COMMUNITY CARE

2.12 Whilst the transfer of responsibilities and funding from DSS to local Councils has had the intended effect of controlling expenditure, the desired shift from institutional to non-institutional care has not occurred, and the Scottish Executive is now seeking to give this renewed emphasis with additional funding following its Spending Review, and in its response to the Royal Commission, the Joint Future Report and the Report of the Scottish Parliament Health and Community Care Committee. Health and social care policy is directed toward supporting people in their own homes or in homely settings for as long as possible. Whilst promoting the crucial importance of developing intensive personal care services, the Scottish Executive has properly recognised the need to extend domestic care services in supporting people in their own homes.

2.13 The Scottish Executive has also accepted that the system of Direct Payments can help empower people and give them greater control over services, and, having extended the potential for such payments to be given to older people, is proposing in the Community Care and Health (Scotland) Act 2002 to make it a statutory duty that Councils have a Direct Payments Scheme open to all care groups.

MENTAL HEALTH

2.14 The Framework defines the policy position of the Scottish Executive and the context for the development of mental health services. The Framework requires health, social work, and housing to establish joint commissioning teams and to work together with the voluntary sector to provide complementary services. The Framework highlighted the need to involve and empower users in planning services locally and, at a national level, established the Mental Health and Wellbeing Support Group with funding to invest in change.

2.15 The Adults with Incapacity (Scotland) Act 2000 now provides arrangements for making welfare, health and financial decisions on behalf of adults who lack the capacity to take some or all decisions for themselves because of mental disorders or inability to communicate.

CARERS

2.16 In the last few years, the needs of carers have been formally recognised by the government both in the UK and in Scotland, where the National Carers' Strategy, published in November 1999, has provided a policy framework for services in relation to the provision of information and advice, assessment of needs, and the development of support services. One of the central objectives of the National Carers' Strategy in Scotland is to ensure the development of respite services, with an emphasis on a more flexible approach to meeting needs, and this should mean a significant increase in short breaks of a few hours or more, delivered in carers' own homes.

2.17 The Carers (Recognition And Services) Act gave carers their own separate rights to assessment, and the provisions of the Community Care and Health (Scotland) Act 2002 will require that local authorities take account of a carer's assessment within community care assessments.

THREE DEFINITIONS

DESCRIPTION

3.1 Dementia is a term used to refer to a variety of illnesses and conditions which result in a global impairment of brain function and a decline in intellectual functioning, personality changes and behaviour problems which disrupt independent living, skills and social relationships. Terms such as “confused elderly” and “senility” are best avoided. The former gives no indication of timescale of illness nor does it differentiate between functional psychoses, delirium and other organic brain disease. The latter implies a causal effect of age, which is inappropriate.

Table 1. Types of Dementia

CLINICAL FEATURES	CHARACTERISTICS
Alzheimer's disease	
Extensive damage to nerve cells in the brain; Laboratory tests are usually normal; Genetic cause in only a minority of cases; 60% of dementia patients have Alzheimer's disease.	Progressive worsening of memory and other intellectual functions including language, motor skills and perception; Impaired activities of daily living; Altered patterns of behaviour; Behaviour disturbance occurs frequently but is not inevitable; In final stages there can be severe problems with communication, mobility, continence and feeding.
Vascular Dementia	
Many similarities with the deficits found in Alzheimer's disease; Associated with history of stroke disease; Symptoms of frontal lobe damage appear earlier than in Alzheimer's disease; Evidence for modifying the course of vascular dementia is not yet clear; May be affected by active treatment of cardiovascular disease, cardiovascular risk factors and diabetes to reduce strokes.	Disturbances of gait, incontinence, depression and non-specific symptoms such as dizziness, nausea and headache; Symptoms of frontal lobe damage such as impaired motivation, problems with decision making and ability to react to changes in environment; Periods of relative stability and of sudden decline occur more commonly in vascular dementia than Alzheimer's disease.

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Lewy body disease	
<p>Features of Parkinson's disease, which can appear before or after the dementia begins; Most people with this illness are sensitive to anti-psychotic medication, which must be used very cautiously.</p>	<p>Tremor, rigidity and slowness of movement; Delusions and hallucinations occur frequently; fluctuation over several days is typical. Unexplained falls are common.</p>
Alcohol Related Brain Damage (ARBD)	
<p>Association of heavy alcohol intake with vascular disease and therefore increased risk of vascular dementia; Alcohol intoxication and withdrawal accompanied by Thiamine deficiency also associated with the more specific disorder - Wernicke's Korsakoff's syndrome; Thiamine replacement may help with eye and gait problems, less so with memory deficits.</p>	<p>Severe problems with memory and problems with attention are seen despite retention of language; Inertia and apathy are also common; Eye problems and gait problems; Progression of the condition may be halted or slowed with abstinence.</p>
Fronto-temporal dementia (FTD)	
<p>Disease progression usually slow. The presentation of Pick's disease is similar to that of fronto-temporal dementia.</p>	<p>Behavioural and emotional problems when memory, speech and motor abilities retained; Major problems judging the risks associated with their behaviour - may be disinhibited; Combination of memory retention and lack of social conformity is difficult for carers; Apathy, inertia and loss of speech are common.</p>
Subcortical dementias	
<p>Includes a number of illnesses such as progressive supranuclear palsy, motor neurone disease, Parkinson's disease, Huntington's disease and multiple sclerosis; Each is associated with specific neurological changes.</p>	<p>Intellectual deficits are more similar to FTD than to Alzheimer's or vascular dementia; The appearance of intellectual problems is modified by the neurological effects of the physical disease.</p>
CJD	
<p>A rare form of dementia; Rapid progression of neurological problems and deterioration over 12-18 months is typical; Younger people are more commonly seen.</p>	<p>Problems with balance, and incontinence; Speech, language and memory are also affected; A history of mood and behaviour problems usually precedes the neurological features.</p>

EFFECTS OF DEMENTIA

3.2 The level of disability associated with dementia depends not only on the severity of cognitive impairment but also on other factors, including the available social supports. Whilst the social model of disability emphasises how the external social and controllable environment should be seen as causing disability in addition to medical conditions, dementia has also been described as a bio-psychosocial syndrome,³ i.e. the result of an interaction between:

- the disease (aetiology, degree of damage to brain, presence of comorbid conditions and impairment)
- the individual (personality and previous coping style)
- the environment (physical and social – carers, income, housing, food, local community).

3.3 The nature and degree of impairment varies between people such that people progress through the condition at different rates and with different symptoms.^{4,5} This variable degree of impairment results in a variable need for care. The nature of the response, the support provided by carers and services and the ways in which the environment is modified, taking account of social, economic and cultural factors will in turn partly determine how disabling the dementia becomes.

3.4 Although the precise course of progressive dementia for an individual is not predictable, the most prominent early impairment is in memory. People with dementia also have difficulty learning new material and with abstract thinking, planning, judgement and language (e.g. aphasia) and can show disinhibited behaviour, mood disturbances and personality changes.⁶ These changes cause significant disruption to everyday living skills (e.g. cooking, shopping, eating, handling finances), work and social roles.

3.5 In addition, as dementia is largely, although not exclusively, a disorder of old age, people with dementia commonly have co-existing medical conditions and physical illnesses (e.g. arthritis and cardiovascular difficulties) and experience difficulty with activities of daily living (e.g. cooking, walking). In addition communication difficulties may obscure the presence of mental health problems, such as depression, which is under-recognised in people with dementia.

PRIMARY PREVENTION

3.6 Since dementia is largely a disorder of old age, any measures taken to reduce premature mortality can have the effect of increasing the numbers of people at risk of living with impairments; hence the concurrent emphasis on 'adding life to years'.⁷ Given the ageing of the population, the prevalence of dementia, in Scotland as elsewhere, is predicted to increase very significantly.

3.7 An increased prevalence of dementia has implications for both individuals and service provision. Since the progress of the condition cannot be reversed, although it can sometimes be slowed, there would be immense public health benefits if ways of delaying or avoiding the occurrence of dementia could be found. There has been considerable research interest in investigating possible risk factors for dementia, and a review of the evidence is given in Appendix 1.

THREE DEFINITIONS

3.8 Vascular dementia, caused by a disruption of blood supply within the brain, may be related to health behaviours, and may be preventable to an extent. The only factors known to increase susceptibility to dementia of the Alzheimer type are old age, family history (with some evidence of genetic factors in a minority of cases), educational achievements, deprivation and the presence of certain conditions (see Table 1). However, research continues to increase understanding of the mechanisms involved in the development of dementia and it seems likely that evidence of risk factors and protective factors will be available in the near future.

LIVING CIRCUMSTANCES

3.9 As can be seen in Table 2, previous estimates from two studies in Scotland,^{8,9} and one in England¹⁰ suggest that more than half of people with dementia live in private households in the community, and most of these live with others. The Scottish estimates are likely to be underestimates as those from England of people with dementia in the community focused only on those with severe cognitive impairment, and the people in the second Scottish study were only those known to services. People with mild to moderate cognitive impairment are more likely to be living in the community.

3.10 The discrepancy between the English¹¹ and Scottish^{12,13} figures may be due to a variety of factors: the Scottish data were gathered in 1994, whereas the English data were gathered in 1985-1986; institutionalisation rates may also differ between Scotland and England. There does not appear to have been more recent work in Scotland to provide a more up-to-date analysis, although the balance of residence will almost certainly have changed because of the decrease in the number of hospital beds for older people with mental health problems in the NHS, and the significant increase in the number of nursing home places.

Table 2. Percentage of people with dementia by place of residence

Place of residence	Schneider et al 1993	Gordon et al 1995	Gordon & Spicker 1997
In the community	63	55	55
Alone	13	21	25
With others	50	34	30
In institutions	36	45	45
Residential Care Homes	19	15	12
Nursing Homes	7	8	13
Hospital Settings	11	22	20

Note: See Appendix 2. for research details and methods

The figures for people at home and in various institutional settings reflect both the journey taken by people with dementia as their conditions progress, and the care pathway which many of them follow as services seek to meet their changing needs.

FOUR

THE PATIENT'S JOURNEY AND THE CARE PATHWAY

EARLY SIGNS

- 4.1 The early signs of dementia include forgetfulness, problems with words, and swings in moods. These can also of course be the sign of other diseases or life changes. The signs of dementia can also be indicators of vitamin deficiency or depression. People may dismiss these changes as insignificant, or as a normal part of the ageing process. Others may become worried and anxious about what the future has in store.

PUBLIC INFORMATION AND AWARENESS

- 4.2 In this situation people need easy access to good basic information, accessed in a wide range of professional locations or public places. Local hospitals, GP surgeries, social work offices and other places people go for information need to be staffed by people who have an awareness, and who are resourced to give out facts and advice about dementia, not only in leaflets written in English, but also in other languages, large print, cassette and video.

The 24-hour dementia Helpline (0808-808-3000) and website of Alzheimer Scotland – Action on Dementia www.alzscot.org are good sources of information. Alzheimer Scotland also has leaflets available in English, Bengali, Chinese, Hindi, Italian, Polish and Urdu. Alzheimer Scotland has also produced a guide and leaflet (both entitled *Creating dementia-friendly communities, 2001*) to encourage everyone in the community to be more aware of people with dementia and the ways in which they can be helped.

A greater awareness of dementia in the general public should lead to less disabling environments, with attention, for example to higher visibility of toilets.

Mrs J found it impossible to find the toilet in Glasgow Airport and was acutely anxious on the journey home and incontinent on arrival to her sadness and embarrassment.

AS THE CONDITION PROGRESSES

- 4.3 As Alzheimer's disease progresses or someone with vascular dementia has another small stroke, then the difficulties, emotions and behaviours associated with dementia become more pronounced. People become more forgetful about recent time and events, and about names and places. People may become more emotional, demonstrative or depressed, and express feelings and reactions more openly, including irritation and anger. People may start to lose the capacity to manage their daily lives through increasing difficulties with household appliances (cookers, microwaves, washing machines, TV), or with shopping (lists, money).

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- 4.4 Those with developing dementia and their families may well recognise that there are problems but have difficulty understanding them, talking to spouse, family or others about them, or knowing where to go for information, advice and assistance. Whilst anxiety about further change and deterioration may be high, the stigma of mental illness may inhibit people and their families from sharing and seeking help with their concerns and difficulties.

Mr S contacted the local project of Alzheimer Scotland – Action on Dementia after seeing the telephone number in the local newspaper. He was upset and frustrated as he was finding it very difficult to cope with his wife's challenging behaviour at home. She was confused in her environment, not understanding normal conversation, arguing repeatedly, not washing and forgetting how to complete everyday tasks. He had involved the GP who said that she probably had dementia, but who offered no information about the way ahead or support agencies.

The project resource worker advised Mr S to contact their GP for a referral for psychiatric assessment. This he did, but to no avail. During this time Mr S was needing a great deal of support to help him cope and he himself was also battling with health problems. The GP agreed to make the referral, but this took several weeks, as the carer had to remind the GP when he heard nothing. However, the assessment and diagnosis was eventually obtained and then services clicked into place. This was approximately four months after Mr S first contacted the Project and many months after the presentation of dementia signs was significant.

DOMICILIARY, OUT-PATIENT AND IN-PATIENT DIAGNOSIS

- 4.5 The *Report of the Expert Group on Healthcare of Older People - Adding Life to Years*¹⁴ has indicated that, "NHS Boards should ensure that there are services to provide rapid assessment of cognitive impairment, with appropriate access to modern drug treatment and follow up."
- 4.6 Whilst people with dementia and their carers would like to have an accurate and early diagnosis, there is ample evidence that general practitioners and their primary care team are not aware of a substantial percentage of people with dementia in their practices.^{15,16} This is not just an issue in the UK. A study in the Netherlands¹⁷ found that the sensitivity of the GP was related to help-seeking behaviour, with low sensitivity in patients with a low contact rate. It was also related to the use of less specific diagnostic labels by the GP (cognitive impairment), and to poor recognition of cognitive impairment in patients who visited their GP. More recent research in Western Australia¹⁸ found the general practitioners were perceived to have referred people with dementia late for community care, despite the carer having experienced difficulties for a considerable time period. Within the UK, although the more routine checks carried out on people of 75+ years may have done something in recent years to correct this situation, there are still likely to be issues in this area.

In the UK GPs have variable views and attitudes towards the benefits of early diagnosis¹⁹ and there are suggestions that their self reported approach to diagnosis and management is not consistent with recommended practice.²⁰

Mr J was told he had vascular dementia and he is very clear that he may deteriorate suddenly. Like many people with dementia he has experienced a strong creative urge and his pictures reflect his anxiety about the fragility of his cognitive competence as well as being works of art in their own right.

- 4.7 There is a growing body of research work on screening processes and tools, and the development of drug treatments is adding emphasis to the need for early accurate diagnosis. The extra time that early diagnosis can give people with dementia and carers to consider future care, financial and housing arrangements, whilst they still have the mental capacity to do so, is clearly important. Evaluative studies have shown how screening instruments used, for example, in general practice can be very useful.²¹
- 4.8 Most people with dementia who receive specialist diagnosis and assessment are seen on domiciliary visits by consultants or at outpatient clinics. At this stage Community Psychiatric Nurses (CPNs) may also be involved.
- 4.9 It has been suggested that Memory Clinics could have a greater role in clinical assessment. The second 'Leicester survey of memory clinics in the British Isles'²² concluded that:

"as memory clinics move out from academic centres into mainstream clinical services, there is potential for greater co-ordination of their activities, and the development of an agreed core data set for assessment that would be valuable in the national monitoring of new anti-dementia treatments in clinical practice."

- 4.10 Diagnostic work and assessment may also involve other hospital facilities. Most NHS Board areas have old age psychiatry assessment wards or designated beds, although there is a substantial difference between areas regarding the number of such places.
- 4.11 Of the 7,760 psychiatric beds available in NHS hospitals in Scotland at 31 March 2001, 4,007 were designated for the psychiatry of old age.²³ (Table 3) The mean length of stay in hospital for patients of 161 days reflects usage of those beds both for diagnostic/assessment/short stay purposes and also for people on a longer term basis.²⁴
- 4.12 Research in the early 90s²⁶ noted a wide range of policies regarding the concept and use of in-patient assessment, and argued that the range of provision of assessment beds had more to do with the historical balance of care than with differences in need for such services. An examination of more recent figures for the admission of older people with dementia suggests this remains the case. Table 3 illustrates significantly different rates of admission of older people to mental health beds between Scotland's NHS Board areas, and these differences are found both in relation to the rates for first admissions and all admissions, suggesting there may need to be a review of admissions policies and eligibility criteria in some areas.

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Table 3. Admissions and Readmissions of people with dementia to NHS beds

Mental illness hospitals and psychiatric units Inpatient admissions of older people with dementia ages 65 and over; Year ending 31 March 1999						
Health Board Area	First Admission	Readmissions	Other	Total	First Admission Rate per 1,000 pop 65+	All Admissions Rate per 1,000 pop 65+
Argyll & Clyde	89	207	120	416	1.3	6.3
Ayrshire & Arran	241	316	57	614	3.9	10.0
Borders	66	89		155	3.3	7.7
Dumfries & Galloway	57	46	30	133	2.1	4.9
Fife	162	182	27	371	2.9	6.7
Forth Valley	65	96	43	204	1.6	5.0
Grampian	217	255	20	492	2.8	6.5
Greater Glasgow	274	347	56	677	2.0	4.9
Highland	16	91	10	117	0.5	3.6
Lanarkshire	73	112	241	427	1.0	5.6
Lothian	259	562	163	984	2.3	8.8
Orkney	-	-	-	-	-	-
Shetland	-	-	-	-	-	-
Tayside	143	114	122	379	2.1	5.5
Western Isles	-	-	-	-	-	-
Scotland	1,665	2,420	891	4,977	2.1	6.3

Source: ISD Scotland (SMR4/SMR04) - Scottish Health Statistics 2000

SINGLE SHARED ASSESSMENTS

- 4.13 Post diagnostic services should include information and advice encouraging individuals and their families to carry out personal planning. Diagnosis should also provide a fundamental early component of any full assessment, and arrangements should be in place to enable easy access from diagnosis to full assessment, including assessment of carer needs.
- 4.14 As part of the Single Shared Assessment in the case of people with dementia, clinical assessment is necessary to determine whether symptoms/difficulties have treatable causes, e.g. diet, conditions other than dementia, or whether there is a form of dementia which can now be moderated by drug treatments. Distinguishing treatable conditions from dementia is one of the key tasks of health services regarding dementia care.
- 4.15 An assessment is necessary, not only to determine physical cause and response, but also to be able to give proper advice and information to the patients, carers and other professionals. The clinical assessment of people with dementia should also take account of other medical factors and consider the needs of the whole person.
- 4.16 The Single Shared Assessment should also consider personal, domestic, social, cultural, housing and environmental factors, to determine what elements in the

person's environment are causing disability, and to establish what supports and services would best meet the needs related to dementia, any other physical impairments, and carers.

Mrs C's family ran a Chinese restaurant and take-away in a Scottish town where they were the only Chinese family. When the family could no longer care for Mrs C at home, she was admitted to a unit where the staff had no idea about Chinese culture and expected her to use a knife and fork, wear a dress, use a toilet with a pan and eat the British food. Mrs C was plainly desperately distressed and she deteriorated very sharply.

4.17 Both the Joint Future Group and Care Development Group have considered issues related to assessment of older people, including those with dementia, within the context of joint working and the introduction of free nursing care in care homes, and free personal care. Their concern has been, not only to deal with the frustration for people and their families and the waste of resources from repetition and duplication in assessments by different professionals, but also to bring about much more consistency of practice across Scotland. The Scottish Executive Circular of Guidance on Single Shared Assessments established certain key principles (Table 4) to take the process forward, which should lead to improvement in the assessment of people with dementia and their carers.

Table 4. Single Shared Assessments

Key Principles in Single Shared Assessment	
1.	People who use services and their carers should be actively involved and enabled to participate.
2.	The type(s) of assessment should be appropriate to the person's indicated needs: <ul style="list-style-type: none">• Simple assessment• Comprehensive assessment• Specialist assessment• Self-assessment.
3.	Assessment should be undertaken by the most appropriate lead professional.
4.	The assessor should be appropriately skilled and qualified to deal with the type and level of assessment.
5.	Appropriate information should be shared by informed consent of the person or the person's representative.
6.	Single Shared Assessment must facilitate access to all community care services
7.	Other professionals and agencies must accept the results.

4.18 The Circular states (para 11) that "Agencies should review and, where necessary, develop jointly their arrangements for ensuring that people with special communication needs and people from minority ethnic groups can participate fully in the assessment of their needs", and (para 13) that, "the Single, Shared Assessment process therefore should be designed to ensure that carers' needs can be identified either in conjunction with or separately from the person being cared for."

4.19 The proposals for Single Shared Assessments have included a requirement that local health, social work and housing services agree and use an assessment tool, either CarenapD for people with dementia or a tool consistent with it .^{26,27, 28}

4.20 The adoption of a national Resource Utilisation Measure (RUM) has also been recommended, as a means to establish and monitor the dependency levels of people being assessed and using the various services available. There were major issues about how the forerunners of the RUM, i.e. SHRUGS (Scottish Hospital Resource Utilisation Groups) and SCRUGS (Scottish Care Resource Utilisation Groups) took account of dementia, and their validation within this context and these will need to be dealt with by the Resource Utilisation Measure to be introduced.

SELF ASSESSMENT AND ADVOCACY

4.21 It will be important to ensure that jargon and bureaucracy do not obscure the fundamental importance of involving people with dementia and their families in the assessment process and developing the process of self-assessment alongside other systems. Within this context the increasing recognition of the need for advocacy services has been especially relevant to people with dementia and their carers, who have particular difficulties in communicating their needs and wishes, and are amongst the most socially excluded groups in society.

All services respond to patients' needs and preferences. Patients are involved in decisions about their own care through effective two-way communication and information sharing. (Generic - Patient Focus - Standard Statement - Clinical Standards Board for Scotland, 2002).

4.22 One of the consequences of dementia is that people with the condition eventually reach a stage when they no longer have the capacity to articulate their own needs. This is when it is important for their carers, families, welfare attorneys and welfare guardians to speak on their behalf. When no one is available to speak on their behalf or when there is a conflict of interest, advocacy services are required. Although there are interesting developments in advocacy services across Scotland, they have been uneven and most are generic rather than specialist services for people with dementia. The challenges are to educate generic services to be better able to help people with dementia, and to encourage appropriate people with an interest in or relationship with the person with dementia to act on their behalf (See Advocacy and Dementia, Alzheimer Scotland Action on Dementia, 1996).

4.23 The Adults with Incapacity (Scotland) Act 2000 made provisions for safeguarding the welfare, and managing the finances and property, of people, including some older people with dementia, who lack the capacity to take some or all decisions for themselves. It provides safeguards in allowing other people to make decisions on those unable to do so for themselves.

RISK ASSESSMENT

4.24 There are risks of self-harm by the person with dementia because of their memory loss or the physical disability which may be associated with their dementia. There may be risks for those whose dementia relates to alcohol addiction, which is increasingly common. There are risks, which need to be assessed, which relate more to abuse by another person. These include financial, sexual, emotional, physical and medication.

4.25 Considering and weighing up risk will remain a difficult area of assessment, both for professionals and families. Whilst the process of risk assessment may become more formal and standardised across the country, the balance between the independence of the person with dementia and control by carers or professional will remain a difficult matter of judgment.²⁹

4.26 New technologies have the potential, as part of a plan of care, to minimize some risk. They can for example, turn a cooker off when there is too much heat or smoke. They can alert relatives or staff to an unwise exit in the middle of the night. They can also record activity, which may be useful in determining the degree of risk, or provide reassurance that the person is active. Ethical issues arise as they do with any intervention, which impinge on privacy and self-determination, but ethical practice is possible and practicable.³⁰

ORGANISATIONAL ARRANGEMENTS - REFERRAL, ASSESSMENT, TREATMENT & CARE MANAGEMENT

4.27 A Single Shared Assessment of a person who has serious memory problems or confusion should always include a medical component, and, if there is dementia, should also always include an assessment of health and social circumstances and the need for health and social care services. Easy access to holistic medical and social circumstance assessments, which will often involve many of the professional staff identified in Table 5, must be a fundamental foundation stone of any service arrangements.

4.28 ‘Joint management’ arrangements are being developed locally, which are expected to conform to a ‘joint management structure’ model or a ‘partnership body’ model with an aligned or pooled budget. Whatever model is adopted, the way that assessment and care management is arranged, coordinated and managed should effectively deliver the requirements for people with dementia and their families, which are set out in Figure 1.

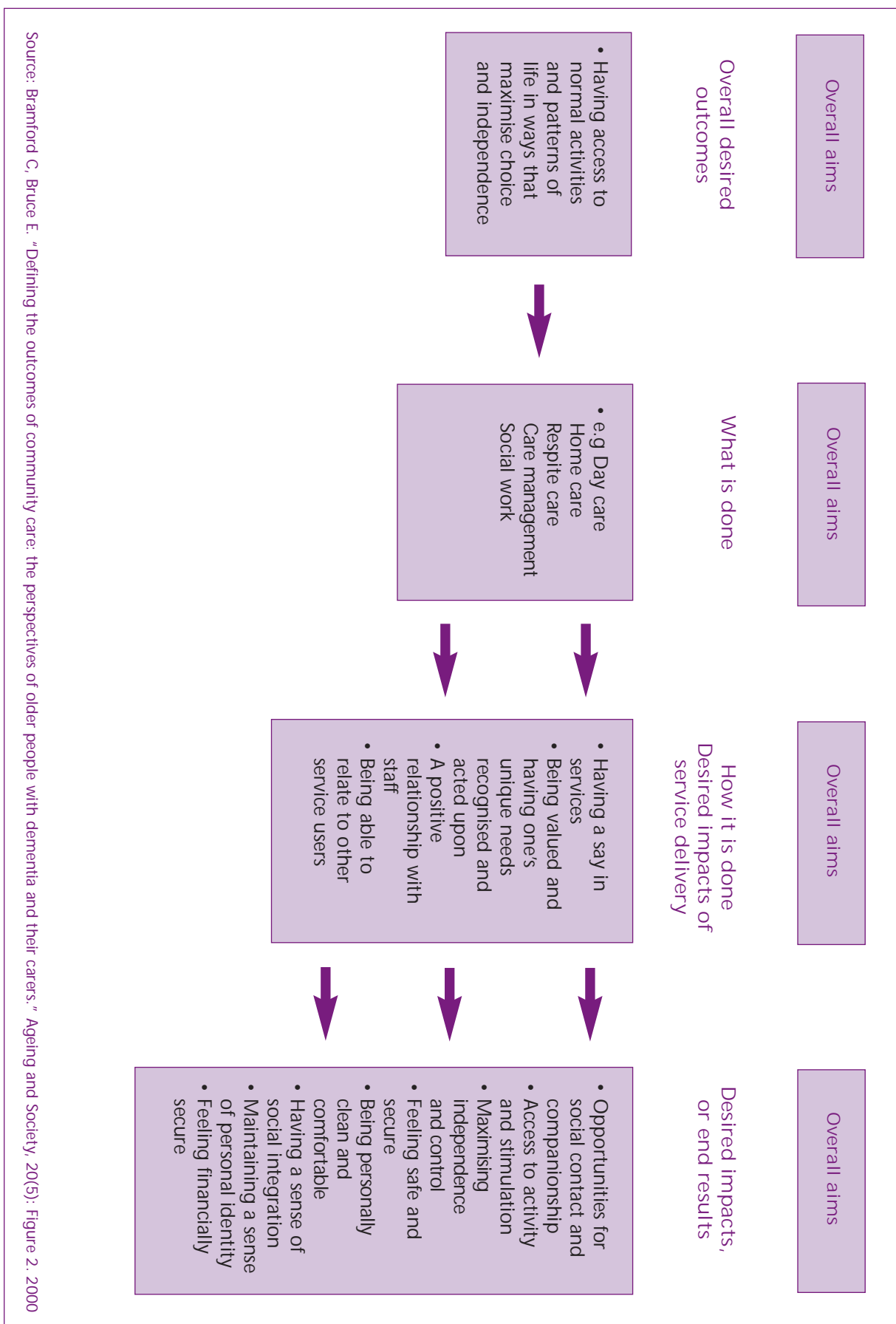
4.29 There are issues for people and their carers about how to access assessments, issues about the referral process between the professional staff, and issues about how the assessment process is managed and coordinated. Whilst the Scottish Executive, in its response to the Joint Future Report, has determined that services to older people should be ‘jointly resourced and managed’, there is no definitive view about how mental health services to older people, and specialist services for people with dementia should fit in to new forms of organisation.

Table 5. Professional Staff who may be involved in Single Shared Assessments

Assessment Staff
Consultant in Old Age Psychiatry Consultant in Old Age Medicine Social Worker Specialist Registrar Community Psychiatric Nurse General Practitioner NHS Consultants Nurse Care Providers Clinical Psychologist Occupational Therapist Physiotherapist Speech therapist Housing Officer Dietician Pharmacist

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FIGURE 1: SUMMARY OF OUTCOMES FOR OLDER PEOPLE WITH DEMENTIA



Source: Bramford C, Bruce E. "Defining the outcomes of community care: the perspectives of older people with dementia and their carers." *Ageing and Society*, 20(5): Figure 2. 2000

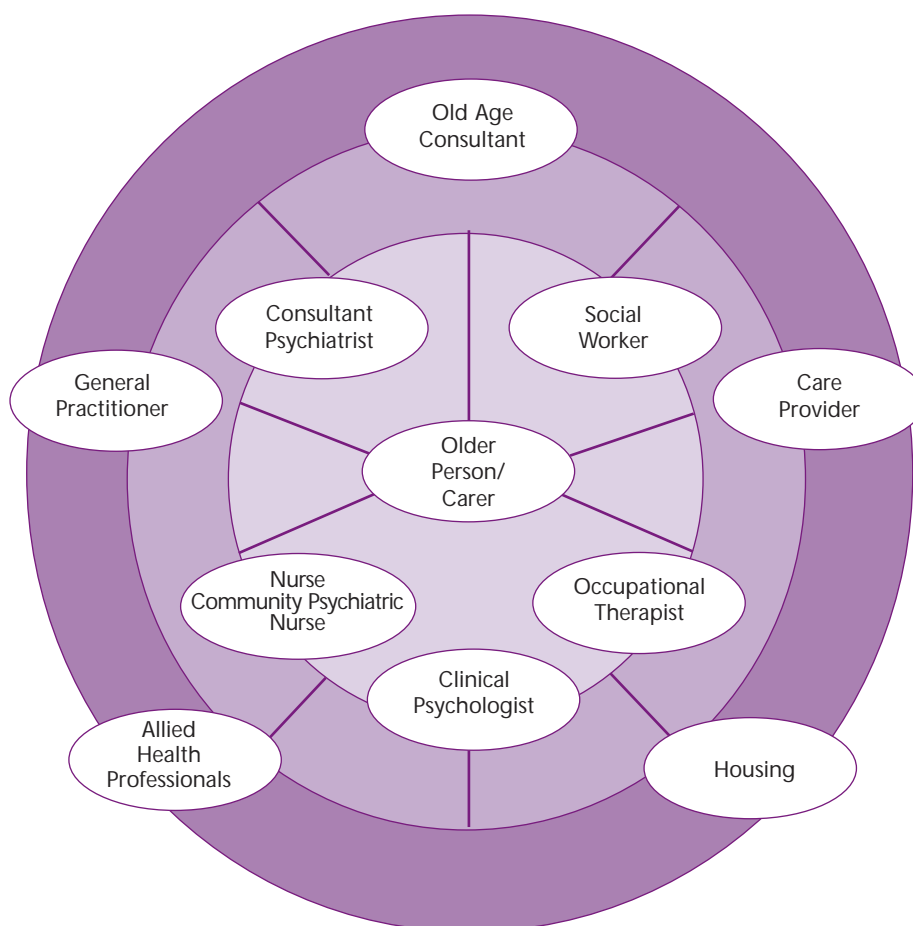
4.30 The fact that a significant proportion of people receiving specialist geriatric services have dementia, and most of those receiving psychogeriatric services have physical disabilities, reflects the fact that people need an inclusive approach. The current challenge is to find better ways to deliver such an inclusive approach in ways which still recognise the continuing role for people and places with special knowledge and skills.³¹

4.31 Older people with dementia and their carers find themselves at the centre of a complex web of professional staff. The Royal College of Psychiatrists, in a paper on the Mental Health Team,³² suggests that such teams have five core professionals:

- Psychiatrists
- Nurses (including CPNs and nurse therapists)
- Social workers
- Clinical psychologists
- Occupational Therapists.

4.32 Other professional staff, such as rehabilitation workers and physiotherapists are also identified as having a part to play in certain cases, and the GP is seen as having a key role. In relation to people with dementia this report also highlights the importance of other Consultants in the medicine of older age, and housing workers. On the basis of the need for review and reassessment, taking account of the knowledge and views of care providers is also crucial. Whilst the rate of change varies significantly in individual

Figure 2. Organisational arrangements for diagnosis, assessment, care planning



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cases, it will be appropriate to formally review the developing situation of many older people with dementia every three to four months.

- 4.33 Within this general context the concept of "managed clinical networks" proposed by the Acute Services Review (1998) has much to offer. The Review³³ saw the development of managed clinical networks as "the most important strategic issue for acute services in the NHS in Scotland" and stated that:

"The emphasis in clinical networking is on connection and partnership rather than isolation and self sufficiency, on distribution of resources rather than centralisation, and on maximising the benefits for all patients rather than a fortunate few... The term 'network' implies that care is delivered seamlessly by a chain of interconnected people and operations, and it is the relationship between these people which forms the very structure of the network and governs its operation... Erosion of unhelpful barriers between primary and secondary care is seen as an important objective... the concept of a lead clinician as having central importance."

- 4.34 Whilst the Royal College describes the composition and functions of the Mental Health Team, such teams are not in existence universally across Scotland. However, there is no doubt that the routes into assessment through GPs and primary care, through social work staff in the community and through a range of staff in acute hospitals, need to lead to an assessment which may involve all of those listed above, and the question is how closely they will work as team members.
- 4.35 It has already been determined that the 'joint future' will require the further development of team working to offer assessment and care management from:
- Hospital based Assessment and Rehabilitation Teams for Older People
 - Community Teams for Older People.
- 4.36 People with dementia and their carers, who are using the services of such teams, will at times need specialist assessment, rehabilitation and care management. There will therefore be a continuing requirement for specialist Consultants, Community Psychiatric Nurses, Social Workers, Occupational Therapists and other Allied Health Professionals, sometimes working in hospitals or the community for older people with mental health problems including dementia. There may be scope for an extension of the existing models of:
- Community Dementia Teams/Old Age Mental Health Teams.
- 4.37 Such specialists may also have a role with people who have early onset dementia, and who also have problems in accessing comprehensive, multidisciplinary assessment. Their needs and services were examined in the SNAP Report, "*Huntington's Disease, Acquired Brain Injury and Early Onset Dementia*", which was published in 2000.³⁴
- 4.38 It is clear that there have been some excellent developments in multidisciplinary team working both in hospitals and in the community in recent years. Specialist resource teams have been shown to lead to improved rates of detection.³⁵ Studies of models of intensive care management, based in community mental health teams, have also demonstrated an impact on reducing admissions to institutional care, improving the quality of life of users and carers and reducing levels of risk.³⁶ However it was also



noted that the impact of the scheme on placement outcome occurred at the end of the second year and resulted in higher levels of service receipt and thus costs.

4.39 Each specialist mental health/dementia team will be shaped by local needs, existing and reshaped resources, referral patterns and the range of service options. In the light of developments with single shared assessment and joint resourcing, attention needs to be paid to the unpredictability and variability in the needs of people with dementia, including:

- continuity when people are transferred between services
- integration with primary care
- integration with intensive care management.

4.40 Comparisons between the responses of community mental health teams to those with dementia and those with affective disorders have shown that the former may receive shorter periods of intervention, focusing on assessment/diagnosis and long term care.³⁷ There may be greater dependence on services for the person with dementia yet the person may still have more unmet needs at follow up.³⁸

4.41 Social work teams sometimes receive referrals for people with dementia who were not previously known to specialist health services. Thus it is important to be able to identify unmet health needs so that the person's GP can be alerted to these needs.³⁹ Surveys of primary care teams⁴⁰ have also shown that dementia was associated with high levels of unmet need, mainly for mainstream support and help with supervising the elderly person. Therefore whatever the criteria for referral to a specialist mental health team and whatever the aims and objectives of the team, it is important that there is effective integration with other levels of service, particularly primary care, hospital care and care management. The availability of access on a 7-day, 24-hour basis and speedy access to practical support services, especially for crisis management, will assist prevention of admission to hospital/care home and facilitate rapid discharge and rehabilitation.

THE NEEDS OF PEOPLE WITH DEMENTIA

4.42 Information about what people with dementia need help with comes from three sources: a reanalysis of OPCS data in England;⁴¹ a study in Scotland in Tayside during 1992-1994;⁴² and in 1994 in Forth Valley.⁴³ The Scottish studies made various findings, which are set out below.

Table 6. Assistance needed by people with dementia

<p>1. Mobility</p> <ul style="list-style-type: none"> • more than half of people with dementia identified by services have a problem with mobility <p>2. Domestic help</p> <ul style="list-style-type: none"> • 77% of those living in the community need help with domestic tasks <p>3. Personal Care</p> <ul style="list-style-type: none"> • 89% of people with dementia need some help with personal care including continence, 66% of these are in institutional care • over half (56%) of people in the community need help at least once a day with personal care • (62%) need help with personal care at night time <p>4. Behaviour problems</p> <ul style="list-style-type: none"> • (76%) need attention because of behaviour problems and a half of these live in hospitals or nursing homes • (57%) of people with dementia have behaviour problems which require attention at night time <p>5. Service Needs</p> <ul style="list-style-type: none"> • the majority of people with dementia living in the community, who were identified by services, need help with personal care, domestic tasks, and behaviour problems (Gordon et al., 1995) • most of those who need help, need it more than once a day.
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4.43 The list of needs in Table 6 is not comprehensive, but only highlights some of the main needs identified by past research studies. A more complete list would, for example, make reference to both cultural and spiritual needs, as well as some other specific services, such as palliative care. This list does not include very basic needs such as food, drink, shelter, warmth, bathing and going to the toilet, yet all have additional dimensions for people with dementia. There has been recent recognition of the extent of under-nutrition and dehydration of older people especially in long term care settings⁴⁴ and acute hospitals. Many of these people will have dementia and the issue for them is the difficulties around intake of food and drink, as well as availability.

Miss U was not eating in the day centre. When staff put her table under a light she began to eat her lunches without difficulty. She had been unable to see her food and unable to explain her difficulty.

4.44 Another useful way to structure thinking about needs and service responses is through Isaacs and Neville's 'intervals of care'. Using this concept Alzheimer Scotland⁴⁵ has suggested that a proportion of people with dementia can be identified against the given intervals as follows:

- independent 6%
- long interval (weekly) 11%
- short intervals (regularly during the day) 48%
- critical (constant care or supervision) 34%.

FIVE SERVICES

5.1 Health and care services are potentially involved with people with dementia and their families from the early identification of the disease until the person's death. However, in practice most people with dementia and their carers are offered services only when some crisis has occurred. The shortage in both health and social care for people with dementia has resulted in unnecessary stress for the carer and a lack of appropriate care for people with dementia.⁴⁶

DRUG TREATMENTS/PHARMACEUTICAL INTERVENTIONS

5.2 Drug treatments now feature as part of the 'patient's journey', in a way which has developed significantly since the publication of the original SNAP report, and are now an important feature of the service to people with dementia.

5.3 Three classes of drug treatment need to be considered:

- Antidepressants
- Antipsychotics
- Cholinesterase Inhibitors.

Antidepressants

5.4 There is strong evidence that antidepressant drugs are effective against anxiety and depressive symptomatology. Both anxiety and depression can impair optimal functioning in people with dementia and if concurrent depression is suspected a trial of antidepressant treatment is warranted. There is no evidence that any antidepressant is better than another in this group but it is sensible to avoid drugs with significant effects on blood pressure, those which might exacerbate bowel and bladder problems or which are cardiotoxic.

Antipsychotics

5.5 Although aspects of the use of antipsychotics in people with dementia appear controversial, an examination of all controlled trials by Schneider et al⁴⁷ demonstrates that they are clearly effective drugs. Antipsychotics are most likely to be useful for delusions, hallucinations, diurnal restlessness, irritability and aggression. They should not be regarded as the sole intervention for these problems.⁴⁸

5.6 Efforts should be made to identify modifiable causes including environment and interpersonal relationships. Many of these behavioural and psychological problems can

be self-limiting, disappearing after three to six months. Therefore, when antipsychotic drugs are used, review should be mandatory, and if the problem has disappeared a cautious reduction should be attempted.

- 5.7 There are very few drug trials which compare the effectiveness of atypical antipsychotics with conventional antipsychotics in people with dementia. A reasonable conclusion is that the former are at least as effective but have less detrimental effect on alertness and mobility. Increased caution is required when the patient has Lewy body dementia. Over 60% of such patients will be sensitive to the effects of antipsychotics and in some cases such sensitivity can be extreme. However, since delusions and hallucinations can be particularly troublesome in such patients, careful evaluation of small doses of antipsychotics is justified.

Cholinesterase Inhibitors

- 5.8 Consideration of drug treatments needs first to be considered within a broad perspective. Currently only around 20% of people who might benefit from treatment are actually referred. Conversely approximately one-third of people who are referred are unsuitable for treatment either because of physical health, severity of illness or erroneous diagnosis. Of those treated approximately 50% of people will respond positively. A positive response is characterised by short-term improvement in a mixture of intellect, daily functioning, social behaviour, psychological problems and carer stress. In addition, there is a possibility that people who respond may have a slower rate of decline of their illness with a reduction in requirement for additional care especially institutional care. Therefore, whilst it is important to acknowledge the limitations of these drug treatments, one must also recognise their effectiveness, their safety and the significant benefits to some people with dementia and their families which can result from their use.
- 5.9 The first report of benefit to patients with Alzheimer's disease from the use of a Cholinesterase Inhibitor (Tacrine) was published in 1986.⁴⁹ Results of further trials have been variable, but have tended to show a small benefit over placebo. Outcome from long-term treatment is often measured by a reduction in the need for institutional care and all studies, using models generated from the Tacrine studies, have shown a hypothetical reduction in long-term care costs.
- 5.10 Tacrine is not licensed in the UK due to toxic effects on the liver. Three other Cholinesterase Inhibitors, i.e. Donepezil, Rivastigmine and Galantamine are licensed for mild to moderate Alzheimer's disease. Published trials have generated a total database in excess of 10,000 patients. The consistent conclusion is that these drugs improve cognition over a period of up to nine months with evidence of sustained ability to undertake activities of daily living, a reduction in behavioural and psychological problems and a lessening of time required for direct carer input. One study has followed up long-term use over at least three years and shown a slower rate of decline in those treated than those who received placebo.
- 5.11 At present these drugs are approved for use for patients with diagnosed Alzheimer's disease and an MMSE score between 12 and 26. Despite national guidelines, poor referral rates and evidence of postcode prescribing have restricted the use of these drugs in the UK.

5.12 No published studies have shown factors which discriminate responders from non-responders at baseline. Emerging unpublished data suggests that there are clear differences between responders and non-responders. Older people are as likely to respond as younger people. Economic modelling shows considerable health and social care savings in the short term (6-12 months) and in overall care costs over a three-year period. Some studies also show an effect on behavioural problems amongst those with severe dementia.

5.13 More research⁵⁰ suggests that Cholinesterase Inhibitors may be useful for vascular dementia and there are reports of effectiveness in people with dementia with Lewy bodies.⁵¹ However, most evidence relates to effectiveness in Alzheimer's disease. To optimise the effective use of these drugs suitable patients are normally identified through the use of protocols covering diagnosis, severity of illness, and physical health with change in each of these being measured to indicate response to treatment.

5.14 In conclusion, therefore, although the effect of Cholinesterase Inhibitors is seldom dramatic they are the only drugs shown to improve the core features of Alzheimer's disease for some people with some evidence that benefit is maintained over three years. Even with 'modest' improvements, significant savings are likely to occur. In addition, the reduction of carer time is likely to be an important factor in reducing stress.

CONSENT TO TREATMENT - THE ADULTS WITH INCAPACITY (SCOTLAND) ACT 2000

5.15 Concerns have been expressed for many years about the legal framework for medical consents, for example about the inappropriate use of neuroleptics in nursing homes.⁵²

5.16 From July 2002, aspects of the medical treatment of people with dementia have been covered by the Adults with Incapacity (Scotland) Act. The Act already previously allowed carers and family members improved access to the finances of adults with incapacity including those with dementia. In relation to medical care, where a patient is unable to consent to treatment, a treatment plan with arrangements for review will be required. In addition, there will be scope to appoint a welfare guardian who can make decisions about the patient's care and treatment on his/her behalf after appointment through the courts, if the patient does not have a previously appointed attorney with this power. The Adults with Incapacity (Scotland) Act therefore increases the opportunity for individuals to determine aspects of their future treatment at a time when they have capacity to do so by appointing a welfare power of attorney with specific powers to make medical decisions. Doctors will also have to take into account any advance health statements that the adult has prepared, in accordance with the principle that the past and present wishes of the adult must be taken into account.

CARE PLANNING, CARE MANAGEMENT AND KEY WORKING

5.17 Formal Scottish Office Guidance in the early 1990s identified the need for care management to meet assessed need through the co-ordination of health and social care services for vulnerable people with complex needs. The Framework identified the Care Programme Approach for those with severe and enduring mental illness. More recently the Joint Future Report recommended that care management should be redefined as 'Intensive Care Management' for people with complex or frequently changing needs, and that only those with special training should carry out 'Intensive Care Management'.

- 5.18 The consistent aim throughout this period has been to improve the way in which services are arranged, and coordinated more efficiently and effectively to meet need. The apparent need for continually redefining the concept reflects the belief that care management is not working adequately in Scotland. The development of new 'jointly managed and resourced' services will focus attention again on care management as the agencies involved review their approaches to this work.
- 5.19 The general concept of care management is still of one person having the role of 'key worker' in the community, acting as the main link for the person with dementia and carers, listening to them and communicating with them, and coordinating all aspects of health and care services in response to an integrated assessment of need. This role is complemented by the role of 'key workers' in particular services, such as day centres and care homes, which have special responsibilities for communication, care and review with particular service users/residents. In relation to people with dementia and their families the concepts of care management and key working remain as important as ever. The role of key worker could usefully be much further extended for people living at home through home care services and their staff.

A survey of local authorities in Scotland looking at care management for older people and those with dementia found wide variations in policy and practice and highlighted the limited development of intensive care management.⁵³

Specialist care management for people with dementia demonstrates an impact on delaying admission to long term care and improved quality of life.⁵⁴ It appears that this type of assessment may be an effective way of establishing the feasibility of community care or that long-term care is required, and has an impact on the level of admissions.⁵⁵

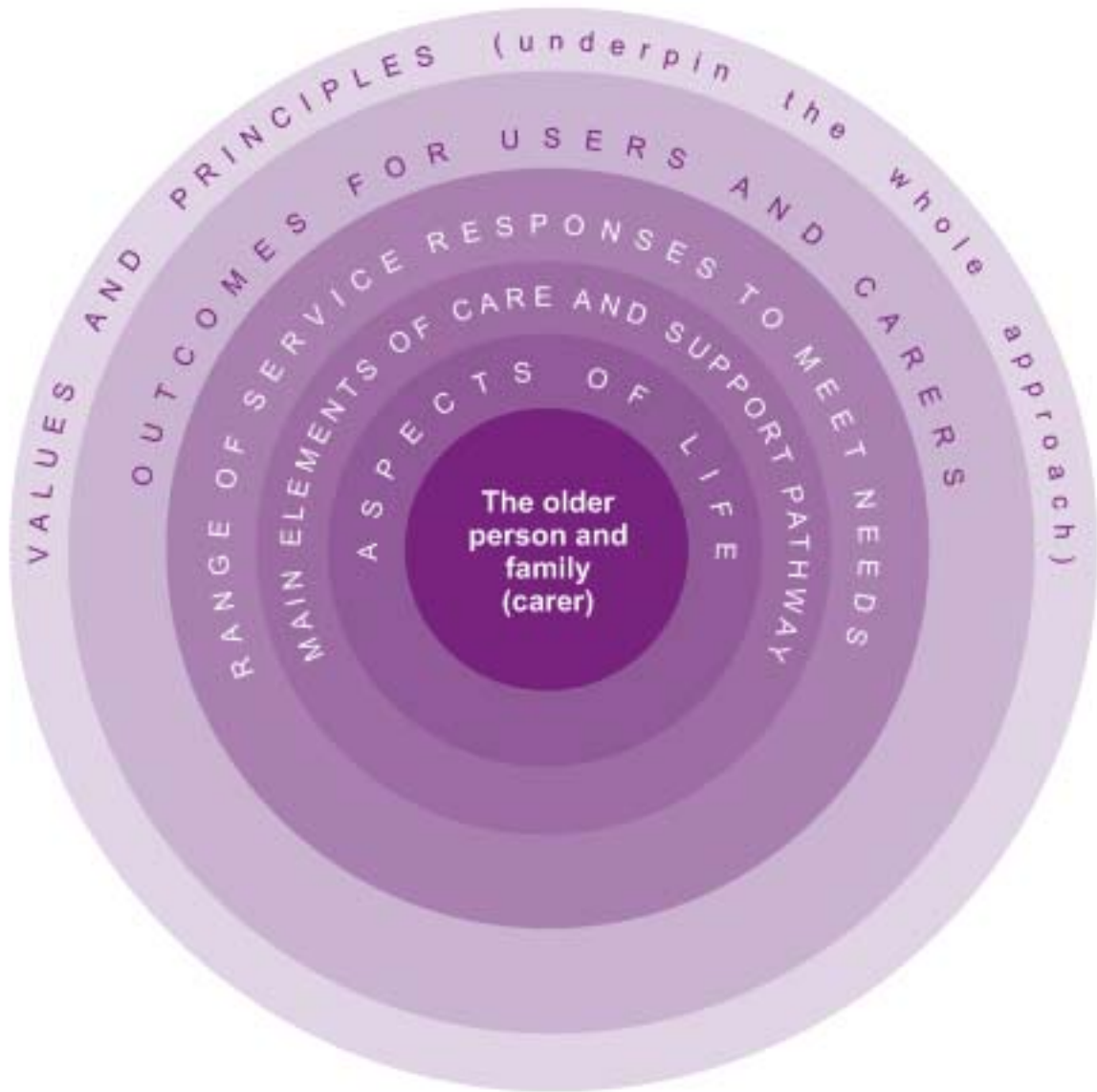
SERVICES FOR PEOPLE AT HOME

- 5.20 A wide range of services should be available to meet assessed need and support people with dementia in their own homes, and the needs of their carers.

Evidence for the efficacy of services for people living at home is emerging⁵⁶ but many studies are less than satisfactory because they fail to deal with the issues of optimal amounts of intervention and appropriate outcome measures.

Figure 3 sets out the relationship between needs, the range of service responses and outcomes (a more detailed version of this figure is included as Appendix 3). The effectiveness of services to meet needs will depend on their availability, accessibility and intensity: this results in more stable and effective packages of care, adjusted to meet the changing needs of users and carers.^{57,58}

Figure 3. Needs, Service Responses and Outcomes



KEY

- I. The older person and family (carer)
- II. Aspects of life
- III. Main elements of care and support pathway
- IV. Range of service responses to meet needs
- V. Outcomes for users and carers
- VI. Values and principles (underpin the whole approach)

FIVE SERVICES

Table 7. Health and Social Care Services for People Living at Home

<p>Information, Advice and Support legal/financial/welfare benefits advice counselling and emotional support peer support groups respite services carer education advocacy housing support</p> <p>Practical Assistance domestic help/shopping/cleaning help with managing money preparation of meals</p> <p>Personal and Nursing Care personal care (day/night) intensive home care evening care crisis response community nurse</p>	<p>dementia CPN housing support/extra care housing aids and adaptations assistive technology palliative care</p> <p>Clinical Services general practitioner services memory clinics occupational therapy pharmacy help physiotherapy speech therapy specialist consultant</p> <p>Supporting Activities rehabilitation social stimulation day opportunities/day hospitals /day centres</p>
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- 5.21 It is not being proposed that every older person with dementia will need to receive all of the above services, and indeed receiving certain of the services listed would obviate the need for provision of others in individual cases. However, it is suggested that Table 7 does provide a checklist of services which should be available locally, and that only where a full range of services is available will it be possible to enable people to make choices in meeting individual needs.
- 5.22 Similarly it is not proposed that all of these services should be offered as specialist resources for people with dementia. This would not only be impractical, especially in some rural settings, but is undesirable in services which are seeking to integrate people with dementia into broader communities. However, consideration should be given to the design and functioning of each service to ensure it can properly meet the special needs of people with dementia and their carers. The need for some separate specialist resources should also be considered in relation to each item in the service listing.
- 5.23 There is no proper baseline of information about specialist services, or of the use made by people with dementia and their families of services more generally. Although information is kept and routinely made publicly available (e.g. Scottish Executive Community Care Statistics 2000)⁵⁹ on the local scale and national distribution of services for older people, and for mental health services, obtaining data on current assessment, domiciliary care, acute hospital care, respite and long stay care services for people with dementia is difficult.
- 5.24 Figures are not routinely kept for the number of older people with dementia using services, for example home care, community nursing, day care or respite, and the number of specialist services either in community or institutional settings is very limited. It is very difficult to evaluate the national and local position in the absence of such information, and this is an area which demands greater attention.

5.25 The SHRUGS and SCRUGS data, mentioned above and collected by ISD (the Information and Statistics Division of NHS Scotland), has provided extensive, valuable information about the dependency levels of people in NHS long stay beds and in care homes, but there have been issues about the validity of the data in relation to people with dementia.

5.26 People with dementia are cared for in a variety of care settings and by numerous parts of the NHS, local authority, voluntary and private sectors. Joint provision and management of services for people with dementia has been rare while joint planning of services has developed in an irregular fashion. In addition, there is great diversity in the provision of both 'dementia-friendly' and specialist services for people with dementia across the regions of Scotland. Services are provided in a patchwork fashion, varying considerably from one area to another. This diversity reflects a range of factors including:

- differing balances between health and social care services
- differing balances between institutional and non-institutional provision
- local history, pressures and priorities
- local geography including urban and rural issues

There will be a need for both dementia friendly general services and specialist services in all areas of Scotland. The latter are definitely required for people with high levels of challenging behaviour and some people with complex needs.

5.27 Surveys in Scotland have provided an indication by carers of service provision and use by those they care for.^{60,61,62,63} Findings from these studies present an inconclusive picture, with relatively small sample sizes, in two areas of the country. The highest levels of contact reported for people with dementia by their carers was with general practitioners, the home help service and district nurses, but with significant variations between the two areas studied. Less than one in five in both areas had had contact with social workers or CPNs, or had used day care, day hospital, day sitter or meals on wheels services.

5.28 A recent study has found that *"memory clinics can complement the traditional old age psychiatry practice of home assessment visits for people with memory disorders, and lead to effective early psychosocial interventions that have long-term benefits for patients and carers."*⁶⁴

5.29 It must be emphasised that the choice of service demonstrated in these studies depends partly on their availability in the area studied ('balance of care'). The scale and balance between health and social care services provided by the range of agencies involved varies enormously from area to area. In particular parts of Scotland a significant minority of people with dementia are not known to services.^{65,66}

Service patterns are changing and mainstream services (such as home care staff and Community Psychiatric Nurses) are being provided for longer hours. There are also increasing numbers of projects such as the Govan project which visit people, as necessary, throughout the night, taking them into the centre if they need to be cared for. Evening care is provided in some care homes and increasingly day care centres are open at weekends.

FIVE SERVICES

- 5.30 Certain research findings are available which have specific implications for service development. Research on activities has considered the 'empty day' experienced by people with dementia. Day care and home care have been shown to be associated with maintenance at home. Research has suggested that people with dementia who live alone are more likely to be admitted to residential care and thus warrant special attention from social/medical services.⁶⁷ A significant minority of people with dementia live alone, and their needs will differ from those who live with family.
- 5.31 There is some evidence that people living alone, without family carers and friends, may not have a preference for privacy and solitude, but rather that they may need additional support to maintain a social network which existing patterns of care management and professional working may not facilitate.⁶⁸
- 5.32 Those people without friends and family may only be referred to community care teams when signs of cognitive deterioration become more overt, for example wandering at night or creating disturbances.⁶⁹

SERVICES FOR CARERS

- 5.33 Whilst formal care services play a major part in caring for people with dementia, most of the assistance and support they need is provided by family carers. There is widespread acknowledgement that community care would collapse without carers.^{70,71,72} The government has therefore properly identified carers a key priority group for attention, and in consequence a National Strategy for Carers in Scotland has been developed.
- 5.34 Whilst recently established national strategies have started to recognise the needs of carers and have begun to set out governmental responses, the last ten years has also seen the growth and development of carers' organisations, including Carers Scotland and the Princess Royal Trust for Carers, alongside a range of local Carers' Forums.

Mrs P lived with her mother who had dementia and who was very dependent on her. Mrs P lost her daughter in a car accident and felt unable to cope with her mother following the funeral. One night she reached the end of her tether and her mother was admitted to an acute admission ward where she was very withdrawn until she died some weeks later. Mrs P felt very guilty. She would have preferred someone to come into her house and help her care for her mother for a number of weeks until she was able to cope again. Some counselling for her bereavement would have helped too.

- 5.35 An estimated 125,000 carers in Scotland, including 35,000 carers over 65 years, look after someone for more than 20 hours per week, compared with only 10,000 cases, where local authority home helps are involved for more than 10 hours per week. This means that most of the care being provided to the 35,000 people with dementia who live at home, including the 21,000 who have moderate to severe dementia and need help with basic self care, is being given by family carers. Carers are generally women, either a daughter or spouse, although there are a significant number of male spouse carers. Any decline in availability of carers following increasing numbers of women in the workforce and other social and demographic trends⁷³ will affect the care needs of people with dementia.⁷⁴ The Royal Commission⁷⁵ took a somewhat different view. They considered that the input of carers is relatively elastic and expands to meet gaps in much the same way as gaps in the balance of care force services to extend their remit.

5.36 Carers of people with dementia, alongside those they care for, are amongst the most socially excluded groups in Scottish society, especially co-resident carers. There is ample documentation that caring is associated with mental health problems, such as depression and anxiety.^{76,77,78} The link between caring and physical ill health is less clear. The negative psychological effects of caring can be prevented (e.g. feelings of burden from caring around the clock) or treated (e.g. depression associated with witnessing declining independence in family member). Risk factors for these negative effects have been identified. Services should assess carers for these risk factors and should target resources at those groups at highest risk of negative effects.⁷⁹ Any needs assessment of people with dementia also demands a needs assessment of carers, with particular emphasis on identifying risk factors and appropriate supports.

Carers of people with dementia may be at greater risk of psychological ill health than other carers.⁸⁰ There are difficulties in measuring the benefits of services to carers in terms of the impact on carer's levels of stress. However it appears that quite limited amounts of service provision would be sufficient to reduce stress in some carers.⁸¹

5.37 Providing an augmented domiciliary care service where home support workers provided emotional support, advice and information along with practical help did not affect the psychological status of the intervention or control group but did result in the person with dementia whose carer received the innovative service living for longer in the community.⁸²

5.38 These carers have needs for information about diagnosis and prognosis, about the full range of services and about local and national voluntary organisations.⁸³ Especially for spouse carers the absence of a confiding relationship may increase carers' stress.⁸⁴

5.39 Whilst it may no longer be the case that most community-based services for people with dementia are designed to support carers rather than to 'treat' dementing illness,⁸⁵ such support services remain an essential element of dementia services. These include day services such as day hospital and day care; home support including home help and sitter services; respite both in hospital and in other residential settings; carer support groups; and medical services, including primary care.

Research on day and overnight respite⁸⁶ found that carers report that these services lack flexibility. In their sample of carers representing 3 cities, carers reported dissatisfaction that respite was generally provided in two week blocks, day care was almost always offered between mid-morning and mid-afternoon and sitter services were usually provided in set numbers of hours. These times were not viewed as being as helpful as other times such as evening and weekend hours.

5.40 While carers have expressed a preference for home-based day care and respite services,⁸⁷ at this time there is no information available as to the extent of its provision or use in Scotland. One study,⁸⁸ some years ago, found institutional respite to be most well developed in more scattered population areas and in cities.

5.41 Surveys in Tayside⁸⁹ suggested that between 25% and 40% of carers there used some form of institutional respite in the previous year. 12% of the sample used it on a regular basis. A further study⁹⁰ also found that 16% of the sample of informal carers had used non-hospital residential respite services for an average of 24 days and 11% had used hospital respite for an average of 32 days in the past year.

FIVE SERVICES

5.42 The apparent under-use of the services is problematic and may be a result of a variety of factors including: carers' ignorance about the service;⁹¹ reluctance on the part of the person with dementia to attend (e.g. day services);⁹² transportation difficulties;⁹³ and the appropriateness of the service for the carers' needs.⁹⁴

Table 8. Carers' Needs, Service Deficiencies and Service Requirements

<p>Need for:</p> <p>Additional home help support 33%</p> <p>one hour or more a day of help with housework 24%</p> <p>similar levels of help with personal care 10%</p> <p>additional help from general practitioners 27%</p> <p>day hospital services 26%</p> <p>day care and meals on wheels services 25%</p> <p>one hour a day or more of help with supervision 34%</p> <p>additional respite support 28 %</p> <p>sitter services 24%</p> <p>additional support from sheltered housing 20%</p>		Philp et al (1995)
<p>Service deficiencies:</p> <p>Concentration of care on hospital sites</p> <p>lack of adequate day and respite facilities</p> <p>lack of adequate domiciliary services</p> <p>inadequate information giving, education, and training for carers.</p>		Donaldson et al (1991)
<p>Service requirements:</p> <p>extended home help service</p> <p>transport for day care in rural areas</p> <p>sheltered housing</p> <p>flexible day and respite care</p> <p>support groups and social service support for carers</p> <p>smaller more homely homes</p> <p>a register of information</p> <p>keyworkers</p>		Donaldson et al (1991)

5.43 In addition to the listed service requirements, the study of community care plans suggested that there needed to be a general development of mainstream medical services and domiciliary support for people with dementia and their carers. The study also indicated the specific need for innovative domiciliary support services to assist carers with aspects of caring the research had discovered they find most difficult – keeping the person with dementia occupied and providing supervision.

5.44 Within this context the work of Alzheimer Scotland continues to be of great importance across the country. It has both a campaigning and service providing role, including the full range of information, advice and direct care services.

RURAL ISSUES

5.45 Service provision for people with dementia and their carers living in remote and rural areas was highlighted in the late 1990s.^{95,96} One study was carried out in the Highlands,⁹⁷ and an action research study in North Wales highlighted the need for support services for carers and people with dementia who were often isolated when living in remote rural areas of Wales.⁹⁸ The prevalence of dementia in rural areas in other countries has received more attention,⁹⁹ along with the experiences of those who care for people with dementia.^{100,101}

5.46 Recent work carried out in relation to quality of services in rural Scotland has included reference to the generic older population's views¹⁰² of health service provision in general and older peoples' services in particular.¹⁰³ However, such work does not provide information on dementia specifically nor use of health and social care services for carers and people with dementia. Local authorities may have assessed the need for services in their area for people with dementia.¹⁰⁴ This does not appear to be the norm, however, and does not tell us of services available across sectors, nor the experiences of the users of available services; carers and people with dementia. Current research at the University of Stirling will provide evidence based on interviews with users and carers in rural and remote areas of Scotland.

MINORITY ETHNIC GROUPS

5.47 There is considerable concern that services for people with dementia are underused by people from minority ethnic communities. A major difficulty in making dementia services more accessible to ethnic minority communities is that the number of people with dementia in these communities is very small and quite widely dispersed, except in some city areas. There have been few examples of services that have been effective in reaching out to older people with dementia in minority ethnic communities in Scotland, and the problems for minority ethnic older people with dementia and their families has been a neglected issue.

Mrs S's family would not consider respite care because they did not consider that proper arrangements would be made for her needs in terms of food preparation and worship. Her daughter in law had a major depression as a result of the burden of care for her mother in law and her adolescent children.

5.48 Various research studies^{105,106,107} have examined health and social care services for people from minority ethnic groups. The main issues causing concern are:

- information, communication and language
- access to services
- the sensitivity of services to culture
- experience of direct and indirect racism.

5.49 The proper responses to these issues are the same for dementia as for other health and care services, and include:

- making staff in existing services more aware of the cultures in ethnic minority communities, so that services could be better tailored to their individual needs

- working with older people's groups within ethnic minority communities to explain the illness and availability of services
- increasing the ethnic diversity of staff working in dementia services
- developing specialist 'ethnic' dementia services and projects.

POVERTY AND DEMENTIA

5.50 Poverty increases the difficulties faced by people with dementia and their carers by reducing the choices which may be available. Access to services may be made more difficult by dependence on public transport, especially for people in rural communities and housing schemes on the periphery of urban areas. There will be less income available for the increased heating and cleaning costs that are often incurred by people with dementia living in their own homes. The experience of Alzheimer Scotland's Welfare Benefits Project is that there is widespread underclaiming of welfare entitlements and that most people with dementia and their carers need a great deal of assistance to make effective claims.

HOUSING

5.51 Housing is described as the foundation of social care and is closely linked to promoting optimum physical and mental health.¹⁰⁸ Thus people with dementia are vulnerable to all the factors that affect the capacity of a person to stay in their own home or move into suitable housing at an appropriate stage.

5.52 In Scotland, housing associations have a long tradition of providing housing for older adults, but have only marginally turned their attention to people with dementia. Supported housing for people with dementia provides domestic and ordinary types of accommodation in small group settings. The aim of this kind of housing is to help people with dementia be as independent as possible, provide them with choice and offer them a home for life.¹⁰⁹

5.53 However, although there are some exceptions, housing options for people with dementia remain limited.

5.54 An increasing number of, but far from sufficient long-stay services have been developed or adapted to address the unique needs of people with dementia. For example, smaller domus-like units have been developed.¹¹⁰ Special care units within nursing and residential care homes whilst well established in the US,¹¹¹ are now developing in Scotland.¹¹²

5.55 The Confused and Demented Elderly (CADE) units in New South Wales have been an influential model in the development of small-scale care settings in Scotland. CADE units were designed for the care of people with dementia with high levels of disturbed behaviour.¹¹³ Each unit houses eight residents. The managers report that size is a therapeutic factor in their success.

In one of the CADE units there is a large, strong man with early onset dementia who was very aggressive in his long-stay ward. In the CADE unit, with its emphasis on domestic chores, it was found that he had skills in ironing and hoovering which proved a very successful means of using up his restless energy, and gaining him a lot of appreciation and self esteem. In the same unit there are always people who make a cup of tea for visitors and, in this way, gain self-esteem and appreciation.

5.56 The implementation of 'Supporting People' should provide opportunities to reshape the commissioning and development of services in the longer term. The changes in housing policy and funding envisaged in 'supporting people' are only likely to have an impact on people with dementia if assessment and care and support planning can be introduced at an early enough stage in the process. Housing models are also dependent on the ability of services to deliver flexible health, social care and practical support to meet the needs of person with dementia and carer.¹¹⁴ An understanding of the design issues,¹¹⁵ assistive technology, and adaptations to the environment (ASTRID)¹¹⁶ are also required.

5.57 The options for future development include:

- New build/remodelled housing which includes dementia friendly design features
- Alterations to the structure of the property/adaptations to assist with mobility and with cognitive impairment
- The provision of a range of assistive technology.^{117,118}

SERVICES FOR PEOPLE IN CARE HOMES AND CONTINUING NHS CARE

5.58 It has been suggested that most people with moderate to severe dementia have medium or major difficulty with self-care and need continuous supervision.¹¹⁹ Intervals of care estimates used in 'Planning Signposts for Dementia Care Services', by Alzheimer Scotland – Action on Dementia, suggest that 6% of people with dementia are independent, 11% have long interval, i.e. weekly needs for assistance, 48% have short interval needs for support regularly during the day, and 34% have a critical need for constant care or supervision.

Mr J was very stressed about meal times. He found the crowds of noisy people in the dining room at his nursing home quite intolerable and as a consequence often failed to eat anything. He would stand up after one mouthful and refuse anything else. He needed to have his meals quietly. However the cook-chill trolley system meant that the food could only be consumed between certain times and extending the time to accommodate him was not allowed.

5.59 A large number of people with dementia receive this 'short interval' and 'critical' care in a variety of institutional settings, which include care homes and a range of hospital settings. It has been suggested that up to 37% of people with severe dementia are cared for in these settings.¹²⁰

5.60 People with dementia have a higher risk of entry to long term care.¹²¹ Long term care tends to be offered only to people with the highest levels of functional and cognitive disability and challenging behaviour.¹²² The practice of providing a 'home for life' to patients is being replaced in many areas with a medium term intervention and discharge to a care home once the needs are primarily for physical care.

5.61 Although homes are all now registered as 'care homes', Table 9 presents information from the time when nursing homes were separately registered. Such homes may have residents of all ages, but the information presented is for people of 65+ years. There may be issues about the classification of residents and the figures should therefore be treated with some caution. However, they suggest that there are very significant differences both in the percentage of residents with dementia and the rate of numbers admitted between different NHS Board areas. This also suggests wide variations in practice across Scotland.

Table 9. People over 65 and with dementia in nursing homes

Older People Resident in Nursing Homes Aged 65 and over; year ending 31 March 2000					
Health Board area	No. residents with dementia	% residents with dementia	All Residents	Estimated pop. with dementia	Residents per 1000 pop. with dementia
Argyll & Clyde	400	6%	1,107	4,675	85.6
Ayrshire & Arran	820	49%	1,685	4,441	184.7
Borders	142	42%	337	1,545	91.9
Dumfries & Galloway	94	24%	390	1,992	47.2
Fife	491	44%	1,124	4,057	121.0
Forth Valley	416	40%	1,039	2,944	141.3
Grampian	850	43%	1,968	5,579	152.3
Greater Glasgow	1,039	33%	3,168	9,525	109.1
Highland	251	34%	734	2,375	105.7
Lanarkshire	711	34%	2,081	5,122	138.8
Lothian	1,498	49%	3,082	8,172	183.3
Tayside	496	31%	1,578	5,057	98.1
Western Isles	18	30%	60	3,98	45.2
Scotland	7,226	39%	18,353	56,349	128.2
Source: ISD Scotland (ISD (S) 34) Scottish Health Statistics 2000					

5.62 The proportion of residents with dementia in 1999 according to Table 9 is consistent with previous data,¹²³ which found approximately one third to a half with dementia in 1992. However the number of nursing home places also significantly increased over that period, and it seems probable that the actual number of people with dementia in care homes also increased significantly, especially given the reduction in NHS 'Psychogeriatric' beds during those years.

5.63 Between 1983 and 2000 (Table 10) there has been a growth in institutional care in Scotland for older people in general. Most of the growth in institutional provision can be attributed to the growth in the nursing home sector, although the rate of growth has varied across Scotland, and there has also been significant growth in residential care places for older people.

5.64 The trend data for psychogeriatric beds can be misleading and appear to suggest a significant growth in this form of provision between 1983 and 1993. In fact this change was mostly the result of 'psychiatric' beds being re-designated, many of them already occupied by older people with dementia. Indeed, a substantial proportion of this 'psychogeriatric' hospital provision was in old psychiatric hospitals, in wards originally designed for young adults with psychiatric difficulties.¹²⁴ A study found that at least half of people with dementia who were living in hospital settings were cared for in 'geriatric' facilities.¹²⁵ Conversely a significant proportion of people in psychogeriatric wards have extensive physical disabilities and (conditions) other than dementia.

Table 10. Trends in the provision of Care Homes and NHS Long Stay provision

	1983	1992	2001
Geriatric Assessment	2266	2702	3845
Nursing Home	2500	14556	22882
Psychogeriatric	3731	6692	4007
Residential Home	9982	13693	15126
Geriatric Long Stay	7959	8522	4089

5.65 The change in balance between hospital and care home provision means that the percentage of people with dementia in different institutional settings must have changed in recent years. People who would formerly have lived in NHS hospital settings are now living in private and voluntary sector nursing and residential care home settings.

5.66 Difficulties with hospital-based care include the size of the wards (range from 20 to 40) and the travelling distance required because of the size of the catchment population.¹²⁶ Whilst opinions vary about the implications of the size of care homes for older people, the standard expectation for a younger adult with mental health problems or a learning disability would be to receive support in a single or shared tenancy, or in supported accommodation with under 10 people. Whilst there may be subunits, with smaller numbers, the average number of beds in nursing homes is over 40.

NHS ACUTE TREATMENT AND CARE

5.67 NHS Scotland provides a range of health services annually for older people in Scotland including:¹²⁷

- 3,769,000 GP consultations
- 287,000 new outpatient referrals
- 206,000 day cases and elective inpatient admissions
- 185,000 emergency inpatient admissions

5.68 The Scottish Executive Report of the Expert Group on Healthcare of Older People, "Adding Life to Years" says that:

"Older people with mental health problems who need admission for the treatment of physical illness face additional difficulties. They are more prone to acute confusional states and may become distressed and even disruptive. However, they should not be excluded from appropriate treatment simply because their mental problems make that treatment difficult. Good psycho-geriatric consultation and liaison services in acute hospitals will be of great help in their care and may even reduce delayed discharges or inappropriate placement in long-term care settings."

5.69 The Report indicates that:

“Confusion is common in older people admitted to acute care. Pre-existing mild dementia is a common underlying factor. Following admission many other influences - including sensory difficulties, a strange environment, infection, sleep deprivation, dehydration, necessary drug treatment, and inadequate explanation of what is going on - can make things worse. For people with more severe dementia, acute admission can be extremely stressful, as understanding may be very limited and their distress may be expressed in ways that are seen as disruptive. Care of such patients can be a considerable challenge in the acute setting.”

5.70 The Report goes on to say:

“However, most confusional states in acute care are self-limiting, or respond to straightforward treatment of underlying causes. Poor management of confusion e.g. inappropriate or excessive sedative drug treatment or - worse still - physical restraint can greatly add to pre-existing difficulties. All acute and post-acute hospital services now deal with older people who are confused. Knowledgeable and sympathetic management of such patients greatly diminishes their distress and is a very rewarding part of the acute and post-acute care of older patients.”

Miss J was delighted to be asked to complete a ‘getting to know you’ form about her sister when the latter was admitted to an acute surgical ward. She was able to explain that her sister would talk a lot about Jimmy (her dog) and would be awake a lot during the night having worked for many years on the night shift in a care home.

SIX

QUALITY STANDARDS AND REGULATION

THE REGULATORY FRAMEWORK

- 6.1 A quality assurance framework for the NHS in Scotland was set out in *'Our National Health – A plan for action, a plan for change'* which proposed that individual health bodies should establish their own standards but within national policy and advice on national clinical standards and condition-specific standards.
- 6.2 Within this context the functions of NHS Quality Improvement Scotland (QIS) are important to the quality and development of dementia services, as these include:
- developing and running a national system of quality assurance and accreditation of clinical services
 - improving the quality of health service care and the quality of life for people with a mental illness, people with a learning disability or physical disability and frail older people by reviewing and reporting on services
 - providing evidence-based advice to the NHS Scotland on the value for money of innovations in healthcare, including new drugs and treatments
 - developing policies on clinical effectiveness
 - supporting the professional development for nurses on a national basis
 - overseeing national audits.
- 6.3 *'Rebuilding our National Health Service – a change programme for implementing Our National Health'*, published in April 2001, also identified a new Performance Assessment Framework (PAF) for the NHS in Scotland, a new accountability review process, and a programme to establish and implement further NHS service standards.
- 6.4 In Scotland, the Scottish Commission for the Regulation of Care has the role to register, inspect and enforce care standards with respect to care services, including care homes and home care, on the basis of the newly established National Standards. Fundamental to this development in the regulation of care has been a recognition of the need to determine and make publicly available more explicit standards for service delivery and outcomes to be achieved for service users. Following the principle of consistency in approach means that there are no separate standards for dementia services. The same standards are being applied to distinct service areas for all care groups. At the same time the Scottish Social Services Council has the role of regulating the social care workforce.

WORKFORCE ISSUES

- 6.5 The NHS in Scotland has around 132,000 staff, including more than 63,000 nurses, midwives and health visitors and over 8,500 doctors. There are also more than 7,000 family practitioners, including doctors, dentists, opticians and community pharmacists, who are independent contractors providing a range of services within the NHS in return for various fees and allowances.
- 6.6 Within the NHS the 6,600 nurses who work in the community carry out a wide variety of nursing tasks, but over 70% of those they work with are over 65 years old. Similarly, whilst the 25,000 nurses in acute hospitals work with the full range of diseases, 65% of patients admitted are over 65 years old. The NHS provides a range of geriatric and psycho-geriatric long stay and assessment facilities, with a further 8,700 nurses employed for this 'care of the elderly'.
- 6.7 The total number of Whole Time Equivalent staff employed by Scottish Social Work Departments in 1997 was 36,470.¹²⁸ 48% of all WTE staff (17,500) were involved in providing a service specifically for adults; this includes those staff based in residential and day care establishments. 36% and 26% respectively of these staff were Care Staff (6,300) and Home Care Staff (4,550). Generic Provision Staff made up 24% (8,750) of all Social Work Staff throughout Scotland. 71% of staff involved in Generic Provision were Home Care Staff (6,200). The total number of staff was 49,578. Of these 59% were part time with a WTE of 15,901, i.e. 44% of all WTE. The majority of part time staff were Home Care Staff.
- 6.8 Estimates for the Scottish Voluntary Sector¹²⁹ suggest that it employs around 4% of the Scottish workforce, 100,000 paid workers or 80,000 full-time equivalent jobs, and that 44% of paid employees work in the top 1% of organisations. The Scottish voluntary sector, therefore, employs a large number of staff in a relatively small number of organisations. Clearly not all of these people work in care services, but a very significant proportion of voluntary sector activity involves such services.
- 6.9 The private sector in health care in Scotland is relatively small, but there are probably around 40,000 people employed to work in private care homes across the country and additional numbers of people working in private home care agencies.
- 6.10 Across all social work, social care and health services in Scotland there are therefore likely to be more than a quarter of a million workers.
- 6.11 The quality and effectiveness of social care and health care services for people, including those with dementia, is determined by the way those people working in these areas are trained,^{130,131} supported and managed in their work. Improvement in the quality of the service to people with dementia depends to a considerable extent on improving staff skills, such as communication.^{132,133}
- 6.12 New arrangements are now underway in relation to both the regulation of health and care services, and the workforces involved in delivering those services. The three major workforce issues are perhaps recruitment and retention; skill levels and training; and the development of integrated services. These issues will all continue to receive attention nationally and locally. It is, however, important to note in this Report for planners and service commissioners, that the way that all of these issues are taken forward will have important implications for dementia services. It is also important to

note that staff shortages, training and integrated approaches are as significant to private and voluntary sector providers as they are to the NHS and local authorities.

6.13 In order to deliver care of good quality, staff should have appropriate skills and competencies, the most appropriate skills mix and good managerial support. Five significant requirements for effective management and to produce good quality care are:

Leadership

- leadership is crucial in determining the delivery of good quality care
- it is important for managers to praise staff, relate well to all staff, be open and approachable
- good work satisfaction is associated with good quality of care
- managers need to establish clear and attainable goals, acting as advocates for ideas and resources
- managers should encourage innovation, imagination, risk-taking and new ideas
- staff will then develop perceptions of self worth, with good work re-affirmed
- senior managerial support and recognition is required
- appointments to managerial posts and the appointment process is important.

Policy implementation

- new policies and approaches to care should be operationalised with the knowledge, consent and, ideally, backing of the relevant direct care staff
- staff learn from audit exercises and use findings to a greater degree if they are involved
- involvement of care staff in decision making and policy implementation maintains and enhances job satisfaction
- management should make the decision process visible and be accessible to answer questions or points of clarification.

Training

- it is important to engage with staff about training needs and opportunities
- training starts with sound induction when dementia related issues should be introduced to new staff
- appropriate systems for supervision, support, appraisal and assessment to ensure identification of training needs and development of individual training plans
- feelings of self worth and the worth of the job can increase with training
- staffing establishment should allow appropriate time to release staff for training.

Support Services

- the relationship, organisation and quality of support services (e.g. laundry, catering etc.) may affect staff perceptions about its importance to care
- support services which are accommodating, flexible and helpful and which work with, rather than against innovations encourage direct care staff to perceive their role as positive and lead to feelings of self worth and job satisfaction.

Job Security

- staff's perceptions of their security of contract is a factor in the quality of care
- staff on secure long term contracts are more able to take risks and develop innovative care practices, and more motivated to create high standards of care
- skills mix, the economics of staffing, and the availability and training of new staff are all important.

SEVEN

PLANNING AND COMMISSIONING OF SERVICES

- 7.1 Within the framework of national plans and strategies, Community Plans will require to identify the major issues for local action and the key developments required locally. New Local Health Plans to run from 2002/03 should link with Community Plans and regional and national plans. These should all identify mental health and older people's services, both including dementia, as a particular priority. Local Outcome Agreements and Joint Community Care Plans should then present detailed proposals for dementia services.
- 7.2 User and carer involvement in planning is now expected at all of the levels identified above, and this presents particular challenges in relation to people with dementia, and calls for the deployment of special skills and creative approaches to consultation and involvement.
- 7.3 Traditionally, estimates of need for services have been based on a combination of expert opinion, existing service use, waiting lists, and, to a lesser extent, demographic data. This report proposes that commissioners should not only ensure the availability of a sequence of services to meet the needs of people with dementia and their carers from the beginning to the end of the condition but also that there should be a reconfiguration of existing services that recognises the needs of people in the early stages of the illness and their desire to be cared for in their own homes for as long as is practical. New thinking is required if the best use of current resources and the challenge of the rising number of people with dementia is to be met.
- 7.4 Until recently, planning activity has become very focused on individual pathologies and specific client groups. The shift towards a broader view encompasses both health promotion and community planning. People with dementia and their carers are largely hidden from public view as one of the most socially excluded groups in Scotland. It would therefore be particularly appropriate for community planning to seek to build 'dementia friendly communities', not simply in relation to the built environment but also with respect to public knowledge and attitudes, and access to the social, cultural and spiritual life of the wider community.

DEFINING THE BALANCE OF CARE

- 7.5 General guidelines for the scale and distribution of services in relation to the number of people with dementia in a standard population of 100,000 were helpfully proposed in the report 'Planning Signposts for Dementia Care Services' by Alzheimer Scotland-Action on Dementia. Likewise, this report emphasises the importance of developing a full range of services, although it is recognised that the need for some services e.g. community based care is linked to the level of other services e.g. long-term care in care homes or hospitals. It is essential that the full sequence of services from diagnosis to palliative care must be available. The exclusion of any leads to reduced quality of care.
- 7.6 It is therefore proposed that the basic approach of Commissioners should be to:
- meet the needs of people with dementia
 - require services to be based on needs of individual service users
 - structure budgets in such a way as to enable creative new services to be commissioned on an individual basis to meet user focused assessments
 - develop services which offer different service options at different stages of a service user's condition, and have mechanisms to ensure continuity in planning and service delivery
 - define the required balance of services for their local population and pool resources accordingly
 - set clear purchasing priorities
 - ensure the availability of a sequence of care.
- 7.7 The main elements required for the pathway of care for people with dementia are already known (Table 11). The problem in most areas of Scotland is either that the full sequence of elements is not available, or, as is widely acknowledged, that service levels are insufficient to meet need. This shortfall is particularly serious in view of the continuing increase in the numbers of people with dementia. People with dementia and their carers are therefore currently a disadvantaged group in terms of both the number and quality of services.
- 7.8 Services for older people and mental health services are both seen as priority areas by the government. Local Outcome Agreements will be expected to show how local authorities and NHS Boards have reviewed the level of resources available and are planning and investing in a range of services which adequately meet the needs in the sequence detailed below. Table 11 defines a series of requirements, without being definitive about where or how they are to be provided. Specialist assessment and crisis response services are, for example, needed by people with dementia and their carers in every area of Scotland, but how they should be provided will be different across the country, depending on a variety of factors.
- 7.9 Choices will require to be identified and made for commissioning. There is a strong case for additional resourcing for earlier packages of care. There is also evidence to suggest, for example, that investing in housing, clinical inputs including acute services and drug treatments, and rehabilitation, can make the acute period of dementia less disabling and can reduce the need for long stay care home placement.¹³⁴

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Table 11. Pathways of Care: The Main Elements

<p>Information and awareness of care staff and the public to dementia Provide readily accessible information available in range of formats and locations. Sessions could be commissioned from health education, primary health care, voluntary organisations, local authorities or colleges.</p>	<p>Rehabilitation and monitoring of functioning For people with deteriorated functioning or who have the potential for improvement, for people who would benefit from a drug review or with depression and dementia, monitoring through carer and staff communication.</p>
<p>Health promotion and prevention Link with campaigns re. heart/strokes, and promote recognition of memory problems.</p>	<p>Housing For those needing a safer and more supported environment including extra care housing, use of technology for communication, monitoring and safety.</p>
<p>Team development Establish teams for assessment, diagnosis and care management with old age psychiatrist, social worker, occupational therapist, psychologist, medical staff (includes geriatrician and general practitioner), and psychiatric nurse.</p>	<p>Carer support Includes education, counselling, training, and respite, with flexible hours of operation (e.g. evening, weekend), availability at short notice, appropriate transport arrangements, in small, homely, domestic settings or at home.</p>
<p>Specialist assessment and diagnosis Identify those who actually have a treatable cause of mental impairment, establish a differential diagnosis (e.g. Alzheimer's or vascular), treat concomitant medical (e.g. heart problems) and psychiatric disorders, identify the needs of carers and people with dementia, provide information and advice.</p>	<p>Social and cultural stimulation Support, especially in the early stages, to help people continue everyday activities. Provide day opportunities at home, in day hospitals, day centres, and evening care.</p>
<p>Maintaining Independence Provide flexible, individualised care packages, which combine support to maintain independence with personal care, domestic help, shopping, cleaning, preparation of meals and practical help. Available also during evenings, weekend and overnight.</p>	<p>Ongoing care Provide homes for life, to maximise functioning and independence, ensure quality of life, and prevent excess disability. Needs small, homely, domestic environments with carer involvement, and with a prosthetic design, and which are culturally appropriate.</p>
<p>Crisis response services Provide for people with challenging behaviour, for very complex combinations of medical and psychiatric care, and for sudden breakdowns in their support network.</p>	<p>Palliative care Provide for end stages of dementia or dying of other causes.</p>
<p>Intensive care and therapy Provide for people with challenging behaviour (e.g. agitation, hitting or yelling), and for people with very complex combinations of medical and psychiatric care. Provide short term services, in small care settings.</p>	<p>Care coordination and care management services Staff needed to coordinate and manage services for people with dementia and their carers, acting on a remit and to a plan formulated by a dementia team, and seeking the perspective of the carer and person with dementia.</p>

THE PRINCIPLES OF A GOOD SERVICE

7.10 Over the last ten years the Dementia Services Development Centre has formulated and refined principles of good practice from observing practice, listening to staff and carers, and research findings. These principles are constantly tested with different audiences.

Table 12. The principles of a good service

- care should be based on a good knowledge of the individual
- people with dementia should be trained, informed and empowered
- carers should be trained, informed and empowered
- services should reflect ethical practice, balancing risk and protection
- services should be based locally in the community
- care staff should be trained in appropriate competencies and supported
- day and residential services should be delivered in small, domestic, home-like settings
- day and residential services should promote a domestic, home-like philosophy of care
- attention should be paid to the design of the built environment
- all services should be accessible
- services should respond effectively in a crisis
- services should be flexible and adaptable
- services, including home care, should be available 24 hours a day 7 days a week

7.11 The key features of these 13 guiding principles will be highlighted in turn.

1. *Care should be based on a good knowledge of the individual*

- as in any field of care, good practice is associated with individualised care, i.e. care that respects the uniqueness of an individual and meets his or her individual needs
- good quality dementia care depends on staff who have the fullest possible knowledge of the person prior to their dementia, including their beliefs, interests, ability and personality – records should contain this information
- there is a need for high quality individualised care, despite scarce resources, and against what are sometimes the conflicting needs of families/groups and the community, public ignorance and fear of dementia
- services and staff need to meet the challenge of relating positively to individuals with a progressive and terminal illness
- conflicts of interest must be acknowledged and staff trained to resolve them
- a comprehensive assessment which includes information about the person's preferences and former lifestyle can facilitate planning and review if used regularly
- care plans and programmes should take account of all aspects of the social and the built environment
- care plans should empower people with dementia and their carers, rather than just staff
- care plans should incorporate the views of people with dementia and their carers
- care plans should be reviewed when there are changes or at a minimum of three monthly intervals.

2. *People with dementia should be trained, informed and empowered*

- the person with dementia is also a partner in this process
- the perspective of the person with dementia in service design and evaluation and in learning about the experience of the illness is also important
- earlier diagnosis allows greater potential to share and discuss the diagnosis with people with dementia

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- sharing the diagnosis allows people to plan for their future
- professionals should be trained in the issues and skills of sharing the diagnosis
- training in communication skills is required for all staff
- staff need to be allowed the opportunity and time to talk to service users with dementia, and this should be seen as an important part of their work.¹³⁵

3. Carers should be trained, informed and empowered

- carers' ability to cope is improved by training in problem solving and stress reduction for carers as well as general information about dementia
- carers want diagnostic information and about the services to be provided
- carers feel they are the experts in the needs and history of the person with dementia
- carers need to feel respected and part of the care process
- carers should be involved in service planning and design, and evaluation
- carers feel cut off but can help when long term care is provided
- carers' groups are appreciated as sources of information and as opportunities to share feelings but may not be empowered to join the decision making process
- planners and managers should consult with carers
- commissioning staff should work with partner and voluntary agencies to train, inform and empower carers.

Mrs A's husband attended a day hospital. She was very concerned about the purpose of these visits since her husband came home bewildered and anxious. She would like to have attended with him for a day but this was considered inappropriate.

4. Services should reflect ethical practice balancing risk and protection

- the use of tranquillising drugs, restraints or technological surveillance must reflect people's rights and be user focused
- the ethics of care and nursing practices must be considered and the principles of avoidance of restraint might be adopted
- quality standards should define restraint policy, and its implications for care planning, decision making, the review schedule and practice, and recording
- staff need training in how to recognise, clarify and address ethical issues and dilemmas.¹³⁵

The Royal College of Nursing have formulated an excellent protocol for the use of restraint which is equally applicable to the use of neuroleptics and surveillance/control technology.

5. Services should be based locally in the community

- local services have positive effects for people with dementia, assisting in orientation and pursuit of normal, everyday activities, and local services
- it is much easier for relatives and friends to keep in touch
- the active involvement from the broader community is much greater
- local units minimise or obviate the need for transport.

6. Care staff should be trained in appropriate competencies and supported

- management should be accessible
- there should be inspiring and motivating leadership at the direct care level
- staff should be skilled, self-directed learners, secure in their jobs and involved in change.

7. Day and residential services should be delivered in small, domestic, home-like settings

- the size of settings not only affects people with dementia but also care staff
- stress and insecurity are caused by an unfamiliar and confusing environment
- there is evidence that function is improved in smaller settings
- fewer people for residents and staff to get to know in a small-scale setting
- it may be important to choose who lives with whom
- the social characteristics and sociability of residents may be as important as clinical criteria
- there is a trend towards 24-hour care in small-scale settings including community placement (i.e. in the house of a paid carer), supported normal housing, care housing, subunits and clusters of small specialist units
- there is also a trend towards small-scale dementia-specific units in larger residential and nursing homes
- the need for small-scale establishments is relevant to both 24-hour care (NHS, nursing home and residential home) and day care.

8. Day and residential services should promote a domestic, home-like care philosophy

- settings should also be domestic in terms of atmosphere and philosophy of care
- people with dementia can engage in normal activities of daily living
- this can maintain existing domestic and social skills, building confidence and self esteem, providing relaxation and enjoyment and reducing the incidence of difficult behaviour
- a more accurate assessment of the person's day-to-day abilities can be made
- use of the homes of paid carers should be explored.

9. Attention should be paid to the design of the built environment

- impaired memory, learning abilities and reasoning skills lead to severe distress
- the social and built environment must provide the information, support, and stimulation people with dementia need
- there is a need to build on remaining abilities and memories
- there is consensus about principles of design for people with dementia in the literature and from practice
- buildings need to make sense to their users and maximise independence
- people need to find the places they need such as the toilet and should be independent of staff as much as possible
- design which helps people with dementia should apply to any public building.

Principles of design include: small, domestic-style settings; different rooms for different functions; toilet door or access visible at all times; lots of visual cues (signs, landmarks, bright colours for important doors etc.); controlled stimuli (e.g. low noise); enough space to move about, safe outside and/or conservatory space; good facilities for staff; and absence of corridors. One vital aspect of domestic-style care is the provision of single rooms, furnished to suit the individual's taste rather than using fitted furniture. Total visual access may be appropriate for the care of people with very challenging behaviour.

10. All services should be accessible

Physically accessible

- people with dementia (especially those who are active and restless) need safe, accessible outside space
- locked doors and technological advances (alarmed doors, passive alarms, tagging devices and video cameras) only if tailored to meet individual needs.

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Mr Y was a big active man in his sixties, in a continuing care ward because no care home could manage his behaviour. He was unable to access the garden because it was not considered safe to allow him out on his own. He rampaged up and down the corridors and twice hit female patients.

Culturally accessible

- second languages, cultural traditions (e.g. food preparation, gender of staff) and religious observances must be recognised
- these are important to older people, and to relatives in accepting services.

Access to assessment and services

- there is a need for timeous assessments
- interim access to services should be arranged as necessary during assessment.

11. Services should respond effectively in a crisis

- continuity of care is a key principle
- crisis care requires an appropriate level of intervention which does not pre-empt future care plans
- the tendency is for excessively radical action to be taken in a crisis, e.g. permanent admission to a long stay facility
- services provided in a crisis should be appropriate and short term, containing the situation rather than radically changing it
- if the person and their family are well known then the reasons for the crisis are understood and the care plan can be modified sensitively
- a team approach helps to ensure that one professional does not act adversely but instead has full knowledge of the person and the plan.

12. Services should be flexible and adaptable

- carers feel very strongly about flexibility
- services should adapt to the individual rather than the individual having to adapt to the service
- flexibility has cost implications
- the cheapest services may be rigid and fail meet a complex range of needs
- sensitive and frequent needs assessments are a prerequisite for a flexible approach to changing needs
- there is a need for creative problem solving
- commissioning must require needs-led assessment, person-centred care, training and measuring individual outcomes, not just focus on inputs.

The St James day centre found that their members got up after lunch and put their coats on to go home. They seemed to see the meal as if it was a cafe or a lunch club. The transport did not arrive until after 3.00 pm. The staff got round this by serving a mid morning snack at 12.30 pm and not serving lunch until 2.00 pm. The members were then able to get up from the meal and leave on the bus with a minimum of fuss.

13. Services including home care should be available 24 hours a day 7 days a week

- carers often need most help during evenings, weekends and public holidays.
- sleepless nights are a known stress factor for carers
- stand alone services which are available 24 hours a day 7 days a week are expensive
- it is cost effective to make better use of units staffed to provide 24 hour care
- carers feel strongly that they need to be able to ask for help round the clock
- when carers know that help is only a phone call away whenever they need it, they feel better able to cope and such a service is rarely actually used.

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- 8.1 The Report *“Adding Life to Years”*,¹³⁶ which has been referred to above says that, *“NHS Boards and Local Authorities should assess population needs for dementia and other mental health services and plan appropriate capacity at all levels.”*
- 8.2 This report recommends that staff involved in planning and commissioning services for people with dementia and their carers need to consider the needs of those people holistically and within the context of the full pathway of care required. Expectations, objectives and quality standards for services should also be determined in any strategy for the development of services.

NUMBER OF PEOPLE WITH DEMENTIA

- 8.3 The demographic structure of Scotland will continue to change over the next fifty years. The ‘baby boomers’ of the 1950s and 60s will be moving into their 70s and 80s from 2020 to 2040, and the ageing of this generation will be the major factor in the growth in the number of people over 65 in Scotland from 787,000 in the year 2000 to 1,238,000 in 2040, an increase of 57%.¹³⁷ (Table 15). Over the same period the number of people over 80 will rise by 103% from 183,000 to 373,000. Improvements in living conditions and better medical care will also continue to extend life expectancy, contributing to the growth in the number of older people.
- 8.4 Whilst, therefore, age is a risk factor, rather than a cause of dementia, one major consequence of the greater number of older people, and of their increasing longevity, will be a significant growth in the number of people with dementia. Dementia is primarily, though not exclusively, a disorder of old age.
- 8.5 Prevalence increases with age. About 1% of women and 2% of men aged 65 to 69 years have a dementing illness and these rates rise to 23% and 18% respectively for women and men aged 85 to 89. Given demographic trends, which suggest a growth in the absolute number of older people, and in particular the extent of the growth in those in the upper age groups, the absolute number of people with dementia will continue to rise. Estimates suggest that there were 56,000 people over 65 in Scotland in the year 2000 with a dementing illness. It is estimated that this number will rise to 73,000 by 2020, and 104,000 by 2040.
- 8.6 Studies on the prevalence of dementia present a confusing picture partly because of different definitions, assessment strategies (e.g., psychiatric assessments,

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questionnaires, brief assessment procedures, or semi-structured standardised interviews) and population samples employed (e.g. general practitioners' lists or by visits to every house).¹³⁸

8.7 The European Community Concerted Action on the Epidemiology and Prevention of Dementia (EURODEM) re-analysed original data from 12 prevalence studies of dementia conducted in eight countries in Europe between 1980 and 1990.^{139,140,141,142} The overall prevalence estimates yielded are the most useful available for people aged 65+ for three reasons:

- they only included data from studies with rigorous inclusion criteria - those studies which had used a DSM III or equivalent definition of dementia and had ascertained a dementing illness by individual examination;
- they are based on studies which included institutionalised populations
- they provide details of prevalence rates according to age group and gender.

8.8 In addition, prevalence ratios have been established for dementia of different severity levels, and suggest, of all older people with dementia, 30% will have mild dementia, 42% will have moderate dementia and 28% will have severe dementia.¹⁴³

8.9 Other prevalence ratios are suggested for the population aged 30 to 64 from a more recent study by Harvey on younger people with dementia, which is more accurate than EURODEM for this age group.¹⁴⁴

Table 13. Prevalence (%) of dementia by age group & gender

Age group	Both sexes	Women	Men
30-64	0.067		
65-69	1.4	1.1	2.2
70-74	4.1	3.9	4.6
75-79	5.7	6.7	5.0
80-84	13.0	13.5	12.1
85-89	21.6	22.8	18.5
90-94	32.2	32.2	32.1
95-99	34.7	36.0	31.6

Source: Harvey, 1998 for rate 30-59, Hofman et al., 1991 for EURODEM rates 65+, as quoted in Planning Signposts for Dementia Care Services Alzheimer Scotland Action on Dementia, Nov. 2000

8.10 The prevalence ratios in Table 13 can be applied by planners and commissioners across Scotland to local populations to establish estimates of the number of people with dementia.

8.11 As illustrated by Table 13 the prevalence of dementia increases with age and the rise is particularly marked in the 80 years and over group. As can be seen in Table 14, the total number of people with dementia in Scotland increases with advancing age.

Table 14. Estimate of number of people with dementia in Scotland in 2002

Estimated Population with dementia - 2002			
Age group	Both sexes	Women	Men
30-64	1,321		
65-69	3,732	1,395	2,337
70-74	8,587	4,486	4,101
75-79	9,892	6,600	3,292
80-84	12,950	8,852	4,098
85-89	12,540	9,466	3,074
90+	8,299	6,512	1,786
Total	57,321		

Source: EURODEM and Harvey prevalence rates applied to Government Actuaries Department GAD figures based on the Registrar General's estimate of the resident population at mid-2000

8.12 As can be seen in Table 13 and Table 14, there are gender differences both in the prevalence ratios of dementia and in the number of people with dementia. The gender differences in the prevalence ratios of dementia occur before the age of 70 when men have almost twice the ratios of dementing illness than women. However, at the age of 70 and over the ratios for women and men become more similar. Regarding the number of people with dementia, it is clear from Table 13, that below the age of 70 there are almost twice as many men than women with dementia, whereas in the 75 and over age group women with dementia far outnumber men. The former is because of the gender difference in prevalence figures below the age of 70 and the latter can largely be attributed to the smaller numbers of men in the population of adults 75+.

Table 15. Projected estimate of growth in people with dementia by age group

Population projections for people with dementia in Scotland						
	2000	2005	2010	2020	2031	2040
Persons 30-64	1,321	1,408	1,492	1,616	1,438	1,128
Males						
65+	18,688	20,461	22,602	28,623	36,319	41,749
75+	12,250	13,845	15,687	20,137	26,426	32,186
Females						
65+	37,311	38,028	39,241	44,437	54,160	62,992
75+	31,430	32,221	33,330	37,334	45,988	55,011
Persons						
65+	55,999	58,489	61,843	73,060	90,479	104,741
75+	43,680	46,066	49,017	57,471	72,414	87,179

Source: EURODEM and Harvey Prevalence rates applied to Government Actuaries Department (GAD) projections based on the Registrars General's estimate of the population at mid-2000.

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- 8.13 While the overall prevalence of dementia is the same for both women and men over the age of 70, there will continue to be a significant gender difference in the number of older men and women in the overall Scottish population. Table 15 therefore shows that gender differences in the number of people with dementia will continue to apply in future.
- 8.14 Whilst the overall prevalence is similar between the genders, the prevalence for specific types of dementia differs along gender lines. Men are more likely to have vascular dementia whereas women are more highly represented in the group with Alzheimer's disease.¹⁴⁵

YOUNGER PEOPLE WITH DEMENTIA

- 8.15 There are relatively few studies on the prevalence of dementia, which include people below the age of 65 years.^{146,147,148} Nevertheless, it is estimated that the prevalence of early onset dementia in Britain is approximately just short of one in one thousand.¹⁴⁹ Common causes of dementia which occurs below the age of 65 include Down's syndrome,¹⁵⁰ alcohol-related dementia, Pick's disease, head injury, and AIDS dementia complex.¹⁵¹ Studies have been published which provide more complete discussion of early onset dementia,¹⁵² and the SNAP Report, "*Huntington's Disease, Acquired Brain Injury and Early Onset Dementia*", published in 2000, fully explores the issues in Scotland.

ETHNIC MINORITY GROUPS

Although the numbers of older people from minority ethnic groups is not great it is increasing. There are small concentrations of people from particular groups, but it should be remembered that the problems of single people or single families can be particularly acute and present a challenge to service providers.¹⁵³

Table 16. Population in Scotland by Ethnic Origin from the 2001 Census

%	White	Black & Others	Indian	Pakistani	Bangladeshi	Chinese
	98.04	0.53	0.3	0.63	0.04	0.32

Note: This table provides figures about the numbers of people in Scotland who define themselves as belonging to a minority ethnic group.

- 8.16 Numbers of people with dementia are insufficient on their own for planning purposes. Rather what is needed is information on the impact of dementia on functional problems and the need for care: the numbers requiring what kinds of help, whether this be provided by family or formal carers. There are few studies, which provide a count of the number of people with dementia according to their need for care and availability of informal carers.
- 8.17 From a broader public health perspective, dementia is one of a range of disorders whose prevalence in the overall population is predicted to rise as life expectancy increases. Predicting trends in the overall numbers of dementia sufferers in a population may be more complex than first appears.

NINE

EVALUATING AND MONITORING DEMENTIA SERVICES

BACKGROUND TO THE EVALUATION OF DEMENTIA SERVICES

- 9.1 Until the mid 1990s most evaluation of services tended to rely on describing what the service provides (e.g. number of customers, length of stay with service). Such descriptions provide little information about the effect of the service on people with dementia or their informal or formal carers.
- 9.2 Evaluations concerned with the effect of services have focused almost exclusively on family carers. In addition, they have measured a limited number of outcomes, notably carer stress and coping.^{154,155} The main outcome investigated regarding the person with dementia has been the likelihood of entering institutional care, which has been argued not to be an appropriate measure of the effectiveness of community based services.^{156,157,158} The need for alternative measures has been stressed.¹⁵⁹
- 9.3 There is a clear need for the evaluation and monitoring of dementia services to:
- move beyond service description;
 - assess the effect of services on people with dementia and their formal and informal carers;
 - include a variety of outcome measures, which reflect the aim(s) of the initiative.
- 9.4 Whilst principles for evaluation and monitoring services for people with dementia are set out below, it is also proposed that a number of research priorities be adopted with respect to dementia, including:
- the availability of a sequence of care
 - different service options at different stages of the condition
 - continuity in planning and service delivery
 - the pooling of resources
 - the pattern of provision against overall levels of need
 - including a person-centred perspective.

MONITORING AND OUTCOME INFORMATION FOR THE EVALUATION OF DEMENTIA SERVICES

- 9.5 Work at the Social Policy Research Unit at York University has identified a framework for examining social care outcomes for older people, including those for people with dementia (see Figure 1).¹⁶⁰

9.6 What is monitored or included as outcomes in an evaluation should be determined by what the 'initiative' has been set up to achieve. The following represent examples of monitoring and outcome areas, which might be considered. Measures of some of these areas have been discussed elsewhere.^{161,162,163,164,165} Routine monitoring of some of these areas is recommended to facilitate evaluation.

1. For people with dementia

- extent to which service is led by person with dementia e.g. involvement in decision making
- maintenance of lifestyle, hobbies, interests
- extent to which service is individually focused and takes account of the person's life history
- involvement in planning services (even on a day-to-day basis)
- activities of daily living
- quality of life
- cognitive functioning
- depression
- behaviour problems
- psychotropic drug use
- satisfaction with services
- social activities
- engagement in activities

2. For carers

- carer stress or burden
- carer coping ability
- knowledge about dementia, its prognosis and management
- physical health (objective and subjective ratings)
- mental health (objective and subjective ratings)
- life satisfaction
- involvement in planning services
- satisfaction with services

3. For paid staff

- communication skills
- job satisfaction
- continuity of staff
- number of key co-ordinators
- adequacy of leadership
- quality of care
- evidence of 'learning' from person with dementia

4. For primary care

- identification of people with dementia
- identification and treatment of reversible dementia

5. Service utilisation

- number of people attending the service
- number of admissions to long-stay care
- number of acute hospital admissions
- number of specialist assessments
- number of comprehensive assessments
- number of packages of support assisting rehabilitation

APPENDICES

APPENDIX ONE RISK FACTORS FOR DEMENTIA

Since dementia is largely a disorder of old age, and since the numbers of people in the oldest age groups is predicted to increase dramatically, there has been enormous interest in investigating factors that might increase or decrease susceptibility to the condition. A knowledge of 'risk factors' can indicate possible protective interventions as well as improving understanding of the mechanisms involved in the development of dementia. These causal processes are not well understood, although there are hypotheses. A 'threshold' model suggests that dementia will develop below a critical level of brain function, as a result of both the diminishing immunity of the brain with increasing age and specific damage (Mortimer, 2000).

Research examining risk factors for dementia is being carried out in a number of countries. Early research consisted mainly of case-control prevalence studies. However, longitudinal studies of incidence have been seen as preferable, in order to avoid possible bias from survival rates (van Duijn, 1998) and to distinguish between association and causality. Early studies were hampered by the variety of definitions of dementia, assessment strategies and population samples, but the introduction of improved clinical and neuropathological diagnostic criteria has now made it more feasible for population-based comparative studies to be carried out.

SOCIO-DEMOGRAPHIC CHARACTERISTICS

Age is the most important risk factor for dementia. The risk of dementia, particularly Alzheimer's disease, increases exponentially with age, at least up to age 90 (Gilleard, 2000; Jorm, 2000; Solomon, 1999). There are also gender differences in the prevalence of dementia in different age groups. Details of the prevalence rates of dementia by age and gender are given on table 13 of the report. Some variations in the prevalence of different types of dementia between countries and between ethnic groups have been suggested by cross-cultural studies (Gilleard, 2000).

Little is known about the relationship between dementia and social class. There is some evidence of an association between low educational level and the occurrence of both vascular dementia and Alzheimer's disease. Commentators have noted, however, that the association is less evident in incidence, compared with prevalence, studies (van Duijn,

APPENDIX ONE

RISK FACTORS FOR DEMENTIA

1998), and where the diagnosis is clinically verified, rather than based on psychological tests (Gilleard, 1997). The need to control for cohort effects has also been emphasised (Gilleard, 1997). The findings of a possible relationship between low educational level and dementia have been interpreted in various ways. Some have argued that any association might be explained by factors associated with low socio-economic status rather than by education itself (Mortimer, 2000). Others have suggested explanations in terms of the protective or compensatory effects of 'brain reserve', whether because of innate capacity, mental stimulation or a combination of the two (Jorm, 2000).

HEALTH BEHAVIOURS AND NUTRITION

Research investigating smoking and dementia has produced equivocal results (Jorm 2000; van Duijn 1998). There is evidence, however, that a high alcohol intake is associated with a significantly increased risk (van Duijn 1998). There is also clinical and epidemiological evidence linking low levels of vitamin B12 and folate to dementia (Reynish, Andrieu et al. 2001) and to Alzheimer's disease in particular (Wang, Wahlin et al. 2001). Raised levels of homocysteine - which can be associated with vitamin B12 and folate deficiency - have been found in people with Alzheimer's disease (Jorm 2000), but it is unclear whether these changes are cause or effect (Reynish et al. 2001).

RISK FACTORS FOR VASCULAR DEMENTIA

The risk factors for vascular dementia are relatively well understood. The effects are thought to be caused by a disruption of the blood supply to the brain, although the concept of 'mini-strokes' in the brain (hence multi-infarct dementia) has been replaced by more sophisticated models suggesting a spectrum of vascular causes (Erkinjuntti 2000). Factors that have been implicated in the risk of vascular dementia include cerebro-vascular disorders (CVDs) and vascular risk factors such as hypertension and diabetes, although it has been noted that the roles that the various factors play in causation have not been identified in detail, nor is it clear which mechanisms are of primary importance (Erkinjuntti 2000).

RISK FACTORS FOR DEMENTIA OF THE ALZHEIMER TYPE

A number of risk factors for Alzheimer's disease have been investigated. The condition is characterised by the presence in the brain of amyloid plaques, neurofibrillary tangles and neuronal loss, and evidence suggests that the pathophysiology is very complex (Nourashémi, Gillette-Guyonnet et al. 2000).

FAMILY HISTORY AND GENETICS

Family history is an important risk factor for Alzheimer's disease, particularly early onset. The occurrence of dementia of the Alzheimer type in specific families is well documented, and the pattern of inheritance is consistent with autosomal dominant transmission with age-dependent penetrance (Mortimer 2000). Genetic testing has shown that single gene mutations on chromosomes 1, 14 and 21 account for a high proportion of early onset cases of Alzheimer's disease (Prince 2000).

A number of conditions are known to predispose to dementia of the Alzheimer type, and it has been suggested that these associations indicate a common genetic component or shared susceptibility, in at least a sub-group of those affected (van Duijn 1998). Another genetic factor, the 4 allele of the APOE gene on chromosome 19, has been indisputably linked with late onset forms of Alzheimer's disease, though the presence of the allele is neither necessary nor sufficient to cause the condition (Prince 2000). Recently, the APOE 4 allele has been shown to be associated with other forms of dementia including vascular

dementia, Lewy body disease and Creutzfeldt-Jacob disease, and to increase the risk of athero-sclerosis (van Duijn 1998). The APOE gene codes for apolipoprotein E, a plasma protein thought to be involved in cholesterol transport and neuronal repair (Jorm 2000). Other genetic risk factors are being investigated.

BRAIN DAMAGE

A number of risk factors can be seen as associated with possible brain damage, whether in response to trauma, exposure to infection or toxins. There is some evidence to support a link between a history of head trauma with loss of consciousness and an increased risk of Alzheimer's disease, although commentators have noted the possibility of bias because of the use of recall as a measure of head injury (Jorm 2000). Also, a neuro-pathological study has indicated that herpes simplex virus type 1 in the brain is a risk factor for Alzheimer's disease in individuals who carry the APOE 4 allele (Itzhaki, Lin et al. 1997). In addition, there is some evidence of links to diet, toxins and other hazards although, again, reviewers have drawn attention to methodological limitations of the studies (Jorm 2000; Mortimer 2000; van Duijn 1998).

More positively, some research has found an inverse relationship between Alzheimer's disease and the past use of non-steroidal anti-inflammatory drugs (NSAIDs) (Flynn & Theesen 1999; Jorm 2000; van Duijn 1998); however the side effects of the drug have made it difficult for randomised controlled trials to be carried out. There have also been suggestions that other vitamins (A, C, E) and micronutrients, and also oestrogen, might play a protective role against Alzheimer's disease through their antioxidant effect, although the evidence has been felt to be inconclusive (Haskell, Richardson, and Horwitz 1997; Nourashémi et al. 2000).

PSYCHOSOCIAL FACTORS

Depression may be a feature of, or an early sign of Alzheimer's disease, but there is interest in whether it could also be a risk factor. There is some evidence from early case-control studies that people with late-onset Alzheimer's disease are more likely to have a history of medically treated depression, but the findings from prospective studies have been inconclusive (Jorm 2000). Recent research has also investigated associations with attitudes to life, psychosocial factors (Persson and Skoog 1996) and social networks (Fratiglioni, Wang et al. 2000), but the findings of possible correlations remain to be confirmed.

VASCULAR FACTORS

There is evidence from a number of recent studies of an association between vascular disorders and risk factors [such as raised systolic blood pressure] and Alzheimer's disease (Abate, Zito et al. 2001; Birkenhager, Forette et al. 2001; Kalaria and Skoog 2000; Kivipelto, Helkala et al. 2001), although the mechanisms involved are unclear (Skoog 1999). High cholesterol levels are thought to contribute towards vascular damage, but it is also thought possible that cholesterol might play a role in the pathophysiology of Alzheimer's disease (Reynish et al. 2001; Wolozin 2001).

In relation to prevention, the point has been made that the evidence of any effect of anti-hypertensive treatment on the incidence of dementia remains unclear (Erkinjuntti 2000). Two recent studies have indicated, however, that a group of cholesterol-lowering drugs, the HmG-CoA reductase inhibitors (statins) can reduce the risk of developing Alzheimer's disease (Jick, Zornberg et al. 2000; Wolozin, Kellman et al. 2000); the findings remain to be confirmed by randomised controlled trials.

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RISK FACTORS FOR DEMENTIA

SUMMARY

Reviewers of epidemiological work have concluded that, at the moment, the only risk factors for Alzheimer's disease confirmed beyond reasonable doubt are old age, a family history of dementia, Down's syndrome and the APOE 4 genotype (Jorm 2000). Although there is felt to be substantial evidence of a prospective association between vascular factors and Alzheimer's disease - as well as vascular dementia - (Prince 2000), the significance of possible relationships between dementia and other factors is felt to need further investigation (van Duijn 1998). It has also been pointed out that some causal factors might not yet have been identified (Mortimer 2000). Conclusions have been tentative, and there have been calls for large, longitudinal studies to provide more reliable evidence. A number of such studies, some multi-centre, are currently ongoing (Jorm 2000), as are clinical trials of putative protective agents (Hendrie 1998).

IMPLICATIONS OF CURRENT KNOWLEDGE FOR POLICY AND PRACTICE

None of the known risk factors for Alzheimer's disease is felt to give scope for preventive action (Jorm 2000). Although research suggests that it would be prudent to avoid - where possible - head injury (from road accidents for example), or a deficiency of folate or vitamin B12 (which can result from a high alcohol intake or malnutrition), causal links between these and other 'risk factors' and Alzheimer's disease have not been proven. The association with vascular disorders and risk factors suggests that some dementia might be 'preventable' to the extent that susceptibility can be modified, whether by public health measures or by management of putative risk factors and the promotion of potential protective factors.

The point has been made that any intervention to prevent dementia or delay its onset can only be effective if it starts when the process of neurologic deterioration is in its early stages (Nourashémi et al. 2000). An improved understanding of the mechanisms involved in the development of dementia is needed to identify the 'early stages' at which it might be felt right or beneficial to intervene.

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APPENDIX TWO

FURTHER NOTE ON RESEARCH AND EVALUATION METHODS

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Schneider et al (1993) conducted a secondary analysis of data gathered in the OPCS survey of adults with disabilities conducted in 1985-1986. The authors used the OPCS intellectual functioning scale as a proxy for clinical assessment. They included only those people with the greatest number of problems in intellectual functioning. Thus, they focus on people most severely impaired intellectually whom they term 'people with advanced cognitive impairment.' They consider that this group of people is comparable to those classified as having moderate or severe dementia according to DSM III.

Gordon et al (1995) asked services in the various agencies in Forth Valley to identify older people over 65 with memory problems or confusion. This resulted in a sample of 2060 older people with memory problems or confusion who are subsequently referred to as 'people with dementia'. A needs assessment was conducted largely by postal questionnaire with a sample of their formal (n=195) or informal carers (n=91). This included assessment of presence of cognitive impairment using a checklist developed by Levin et al (1989). No clinical assessment of mental impairment was undertaken.

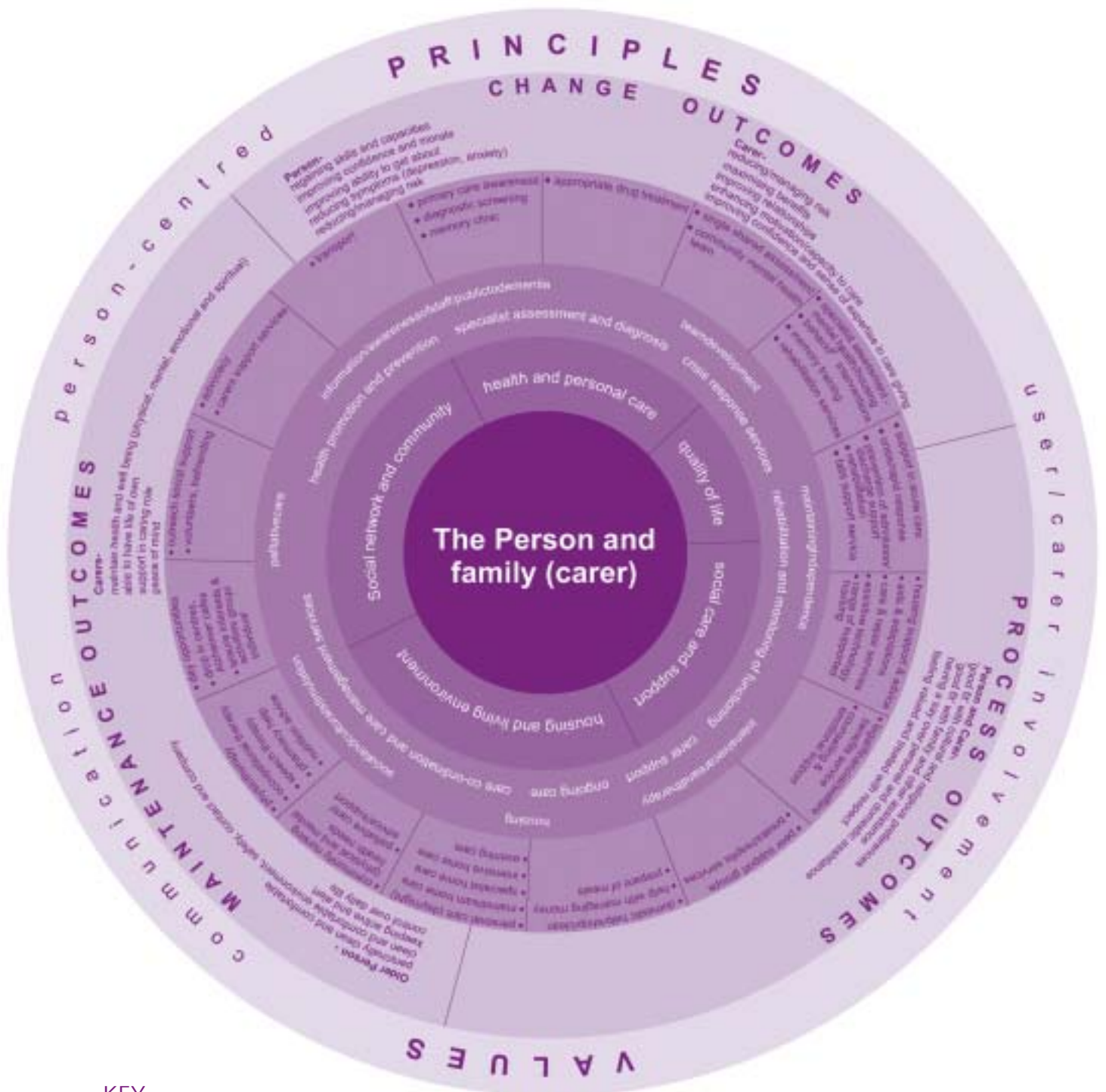
Gordon and Spicker (forthcoming) asked services in the various agencies in Tayside to identify older people over 65 with memory problems or confusion. This resulted in a sample of 2238 older people with memory problems or confusion who are subsequently referred to as 'people with dementia'. A needs assessment was conducted largely by postal questionnaire of a sample of their formal (n=614) or informal carers (n=191). This included assessment of presence of cognitive impairment using a checklist developed by Levin et al (1989). No clinical assessment of mental impairment was undertaken.

KEY POINTS WHEN COMMISSIONING EVALUATION OF DEMENTIA SERVICES

1. be clear who the service is aimed at (e.g. people with dementia and/or their family carers)
2. be clear what the service is trying to achieve (e.g. reduce depression in family carers and/or provide them with time away from their relative)
3. include open-ended questions in order to learn about unanticipated outcomes as knowledge about the therapeutic potential of services is only emerging
4. include a variety of outcome measures, while dementia itself cannot be cured, many of its symptoms can be managed or ameliorated
5. ensure that the evaluation gathers information about individuals, as there is a great deal of individual variation in the course of dementia
6. gather information directly from people with dementia about services. Where this is difficult, alternative information-gathering approaches can be used (e.g. observation, family or staff completed rating scales or questionnaires, or interviews).

APPENDIX THREE NEEDS, SERVICE, RESPONSES AND OUTCOMES

Appendix 3 – Detailed Version of Figure 3



KEY

- I. The person and family
- II. Aspects of life
- III. Main elements of care and support pathway
- IV. Range of service responses to meet needs
- V. Outcomes for users and carers
- VI. Values and principles

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ISBN 1 84485 029 3