



# Scottish Needs Assessment Programme



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## Dementia

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## Scottish Needs Assessment Programme

### Priority Services Network

# Dementia



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August 1997

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**Acknowledgements**

The authors wish to record their thanks to Mrs Avril Harrison and Mrs Anne McCulloch for their help in finding material for the report and to Mrs Morag Calder and Ms Jackie Gegan for their help in preparing the report for publication. The lead author would like to acknowledge the helpful suggestions provided by Ms Isobel MacPherson, Mr Charlie Murphy, Professor Ian Philp and Dr Jill Warrington.

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## EXECUTIVE SUMMARY

Dementia is a term used to refer to a variety of conditions which result in a decline in intellectual functioning, personality changes and behaviour problems which disrupt independent living skills and social relationships. The level of disability associated with dementia depends not only on the severity of cognitive impairment but also on the available social supports. As dementia is largely, although not exclusively, a disorder of old age, people with dementia commonly have co-existing medical conditions (e.g. arthritis and cardiovascular difficulties) and experience difficulty with activities of daily living (e.g. cooking, walking). Dementia does not only affect the person with the illness but also the family with whom the person lives. There is widespread acknowledgement that community care would collapse without informal carers.

Prevalence rates for dementia increase with age. About 7% of all people 65 years and over have a dementing illness and this figure rises to 18% in those 80 and over. Given demographic trends which suggest a growth in the absolute number of older people, in particular the unprecedented growth in those over the age of 80, the absolute number of people with dementia will continue to rise. Estimates suggest that there were 55 000 people over 65 in Scotland in 1995 with a dementing illness. It is estimated that this number will rise to 66 000 in 2010.

At least half of people with dementia live at home, often cared for by their family. The majority of family carers are women. The physical and emotional consequences of family caring have been amply documented, many of which can either be prevented or treated. Risk factors for the negative effects of caring have been identified and these should be included in an assessment protocol. In coming years, there will be fewer family carers available because of increases in female employment and divorce, social mobility and possibly also looser family ties.

Obtaining data on current services for people with dementia is difficult. There are few specialist services either in community or institutional settings. People with dementia are cared for in a variety of care settings and by numerous parts of the NHS and other agencies. Provision of services across Scotland is not uniform. Rather, services are provided in a patchwork fashion, varying considerably from one area to another. Currently, services in Scotland provide assessment, domiciliary care, day care, respite and long-stay care. There is a need for earlier diagnosis and for more effective management and coordination of services. Training is needed for key groups such as the primary care team and care staff, including those in non-specialist settings. Major deficiencies in current services are summarised.

There is no coherent evidence which would serve as the basis for a primary prevention strategy for dementia. The main aims of the health services concern the care of people already affected by dementia:

to maximise the quality of life of people with dementia and their family carers, assist in maintaining their dignity and preserve the best possible level of independence.

There is a need for coordinated research into the aetiology and consequences of the dementias, the scope for preventive intervention and the effectiveness of current services for people with dementia and family carers.

Commissioning services for people with dementia and their carers requires development in:

- evaluating health gain
- assessing needs
- formulating strategy: defining the balance of care
- specifying service: setting out the principles of a good service
- evaluating and monitoring outcomes

The report discusses these and makes cogent recommendations.

Key roles for Health Boards and their commissioning partners are auditing the level of met and unmet need and the appropriateness of how assessed needs are being met. Priority areas for action are outlined.

The case for inter-agency and multidisciplinary approaches in dementia provision and care is overwhelming. It is not possible to make a distinction in this field between health and social care given that people with dementia have constantly varying needs for both and there is considerable overlap between what health and social service can provide. The distinction between services which ought to be given by health and social services can be unhelpful as these boundaries are changing and the optimal balance has yet to be established. Because of this, the components of a balanced range of services to meet the spectrum of needs in a community is outlined. Commissioners should compare the availability of this range against an assessment of overall need to define key strategic objectives.

Guidance to commissioners is provided on the principles of a good service for people with dementia. These should be considered for inclusion in service specifications.

Findings from studies assessing the effectiveness of services have been undermined by methodological difficulties including insufficiently potent interventions and inappropriate outcome measures. Principles for evaluation and monitoring services for people with dementia are set out. Recommendations are made for areas of priority research.



## RECOMMENDATIONS FOR PRIORITY ACTION

1. Commissioners should, at least biennially, through their public health professionals;
  - audit the level of met and unmet need for services for people with dementia and their carers
  - review the appropriateness of how assessed needs are being met
2. There is a clear need for change and extension in the current pattern of services, given the growth in the number of people with dementia. Commissioners should develop strategies which:
  - strive to ensure the availability of a sequence of care
  - clearly state the strategic priority of services for people with dementia in Community Care Plans
  - pool resources and define the required balance of services for their local population
  - ensure services offer different service options at different stages of patients' condition and have mechanisms to ensure continuity in planning and service delivery
  - set clear planning priorities for each dementia related service
3. It is impossible to be prescriptive about who will provide how much of what service for what number of people with dementia. Rather, what is needed is a mix of services, the exact mix being partly a function of what already exists. Because of this, commissioners should clearly set out in strategies the required balance of care for their populations which should include the required mix of the following services:
  - Education to sensitise care staff and the public to dementia
  - Assessment and diagnosis
  - Crisis services
  - Intensive services
  - Rehabilitation and monitoring of functioning
  - Assistance for carers
  - Ongoing care
  - Palliative care
  - Care co-ordination and care management services

Exclusion of any one of the above leads to gaps in care.

4. Commissioners should develop service specifications which are based on the following principles:

- Services should:
  - \* be based locally in the community
  - \* be flexible and adaptable
  - \* be available 24 hours a day 7 days a week
  - \* respond effectively in a crisis
- Day and residential services should:
  - \* be accessible
  - \* be delivered in small, domestic, home-like settings
  - \* promote a domestic, home-like philosophy of care
- Attention should be paid to the design of the built environment
- Respite and 24 hour care services should be affordable
- Care staff should be trained in appropriate competencies and supported
- Informal carers should be trained, informed and empowered
- People with dementia should be trained, informed and empowered
- Care should be based on a good knowledge of the individual

5. There is a clear need for the evaluation and monitoring of dementia services to move beyond service description and assess the effect of services on people with dementia and their formal and informal carers. To help develop this, routine monitoring of one or more of these areas is recommended:

- For people with dementia
  - \* activities of daily living
  - \* quality of life
  - \* cognitive functioning
  - \* depression
  - \* behaviour problems
  - \* psychotropic drug use
  - \* satisfaction with services
  - \* social activities
  - \* engagement in activities
  - \* weight loss
- For family 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
  - \* satisfaction with services

- For formal carers
  - \* communication skills
  - \* job satisfaction
  - \* adequacy of leadership
  - \* quality of care

6. The information base required for effective commissioning is lacking. It is recommended that the Chief Scientist Office commission research into:

- the extent of the disability and need for services associated with dementia
- the development and/or adoption of instruments which assess outcomes for people with dementia and their carers
- the identification of the unique needs of younger people with dementia, including those with AIDS and Down's syndrome
- the primary health care response to dementia and the benefits and drawbacks of early diagnosis and of sharing the diagnosis with the person with dementia
- the optimal palliative terminal care for people with dementia
- the extent and effects of relocation of people with dementia between and within care settings
- the quality of care provided for people with dementia in nursing home and residential care home settings, and in particular, the extent of reliance of neuroleptic medication in these settings





## 1 THE PROBLEM

Dementia refers to a global impairment of brain function which can be caused by a variety of illnesses. The most prominent early impairment is in memory. However, 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 (Absher & Cummings, 1994). These changes cause significant disruption to everyday living skills (e.g. shopping, handling finances), work and social roles.

Dementing illnesses are commonly classified as either progressive or treatable. The most common cause of progressive dementia is Alzheimer's disease (AD) followed by vascular dementia. Causes of Alzheimer's disease are still under investigation but there is some evidence that in a minority of cases it is associated with genetic conditions (e.g. abnormalities on chromosome 21 associated with Down's syndrome). There is, as yet, no evidence that health behaviours play a role. Vascular dementia, caused by a disruption of blood supply within the brain, may be related to health behaviours and may be preventable (Miller & Morris, 1993). Less common causes of progressive dementia include Pick's disease, Lewy Body disease and Huntington's disease. Some people have a mixed dementing illness - both Alzheimer's disease and vascular dementia.

Treatable conditions include normal pressure hydrocephalus and vitamin B12 deficiency. Distinguishing progressive from treatable dementia is one of the key tasks of health services regarding dementia care.

The level of disability associated with dementia depends not only on the severity of cognitive impairment but also on the available social supports (American Psychiatric Association, 1994). Dementia is a biopsychosocial syndrome: the result of an interaction between the disease (aetiology, degree of damage to brain, presence of comorbid conditions and disability), the individual (personality and previous coping style) and the environment (both physical and social). Therefore, the precise course for an individual is not predictable. Rather, the nature and degree of impairment varies both within and between people such that people progress through the disease at different rates and with different symptoms (Buckwalter, 1990; American Psychiatric Association, 1994). This variable degree of impairment results in a variable need for care.

As dementia is largely, although not exclusively, a disorder of old age, people with dementia commonly have co-existing medical conditions (e.g. arthritis and cardiovascular difficulties) and experience difficulty with activities of daily living (e.g. cooking, walking). For example, Levin et al (1983) report that half of the 150 confused elderly surveyed experienced difficulties with activities of daily living due to physical illness.

Dementia does not only affect the person with the illness but also the family with whom the person lives (Zarit et al., 1985). Estimates suggest that over a half of those with dementia live in households in the community, most commonly with a family member (Gordon et al., 1995). Carers are generally women, either a daughter or spouse, although there are a significant number of male spouse carers. There is ample documentation that caring is associated with mental health problems (such as depression and anxiety) (Gilleard, 1984; Levin et al., 1983; Schulz et al., 1995). 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 affects have been identified. Services should assess carers for these risk factors and should target resources at those groups at highest risk of negative sequelae (Schulz et al., 1995). Any needs assessment of people with dementia also demands a needs assessment of the informal carer, with particular emphasis on identifying risk factors and appropriate supports. CarenapD is a useful assessment protocol for people with dementia and their carer (McWalter et al., under review).

There is widespread acknowledgement that community care would collapse without informal carers (Levin et al., 1989; Parker, 1990; Twigg, 1992). The decline in availability of informal carers following increasing numbers of women in the workforce and other social and demographic trends (Wicks, 1989) will affect the care needs of people with dementia (Copeland, 1993).

A significant minority of people with dementia live alone. Their needs for support will differ from their counterparts who live with family.

Dementia can be classified according to its amenability to treatment (progressive or treatable), underlying pathology (Alzheimer's disease, vascular dementia), age group (e.g. young onset), severity (mild, moderate or severe) or by its effect on the person's ability to function and need for care. The focus of this report will be on the people with dementia, on their need for care and on their carers' ability to cope.

## 2 THE SCALE OF THE PROBLEM

### 2.1 Number of people with dementia

Studies on the prevalence of dementia present a confusing picture partly because of different definitions, assessment strategies (e.g., psychiatric assessments, questionnaires, brief assessment procedures, or semi-structured standardised interviews) and population samples employed (e.g. general practitioners' lists or by visits to every house) (Livingston 1994). Nevertheless, there is general agreement that the prevalence of dementia increases at least up until the 90's (Hofman et al., 1991; Jorm et al., 1988; Kay & Bergman, 1980; Nilsson & Persson, 1984; Preston, 1986; Rocca et al., 1991a and b; Skoog et al., 1993; Wright & Whalley, 1984).

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 (Hofman et al., 1991; Rocca et al., 1991a and b). The overall prevalence estimates yielded are the most useful available for three reasons: 1) 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; 2) they are based on studies which included institutionalised populations; and 3) they provide details of prevalence rates according to age group and gender (Gordon & Spicker, forthcoming).

Table 1 presents EURODEM estimates of the prevalence of dementia by age group and gender in Europe (Hofman et al., 1991). The prevalence of dementia increases with age, and the rise is particularly marked in the 80 years and over group. It is the age group 75-85 years which is the fastest growing segment of the population (Delaney, 1993). As can be seen in Table 2, the total number of people with dementia in Scotland increases with advancing age. As can be seen in Table 3 and Table 4, growth in the absolute numbers of people with dementia will largely be in the over 75 age group.

As can be seen in Table 1 and Table 2, there are gender differences both in the prevalence rates of dementia and in the number of people with dementia. The gender differences in the prevalence rates of dementia occur before the age of 70 when men have almost twice the rate of dementing illness than women. However, at the age of 70 and over the rates for women and men become more similar. Regarding the number of people with dementia, it is clear, from Table 3, 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 rates below the age of 70 and the latter can largely be attributed to the smaller numbers of men in the population of adults over 75.

Table 4 shows that gender differences in the number of people with dementia will continue into the early part of the next century. Estimates of the number of people with dementia across various regions of Scotland following Hofman et al (1991) are presented in Appendix 1.

While the overall prevalence rate of dementia is the same for both women and men over the age of 70, 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 (Jorm et al., 1987).

There are relatively few studies on the prevalence of dementia which include people below the age of 65 years (Black et al., 1990; Brayne & Calloway, 1990; Burvill, 1993). Nevertheless, it is estimated that the prevalence of early onset dementia in Britain is approximately just short of one in one thousand (Alzheimer's Disease Society, 1992). Common causes of dementia which occurs below the age of 65 include Down's syndrome (Holland, 1994), alcohol-related dementia, Pick's disease, head injury, and AIDS dementia complex (Navia, 1994). (See Cox & McLennan 1994 for a more complete discussion of early onset dementia).

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.

**Table 1      EURODEM Prevalence rate (percentage) of dementia by age group and gender**

age group	both sexes	women	men
30-59	0.1	0.1	0.2
60-64	1.0	0.5	1.6
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: Hofman et al., 1991

**Table 2** Estimate of number of people with dementia in Scotland in 1995 by age group and gender

age group	both sexes	women	men
30-59	2545	946	1599
60-64	2570	642	1927
65-69	3815	1444	2371
70-74	8805	4664	4141
75-79	8781	6003	2779
80-84	13862	9598	4264
85-89	12079	9335	2745
90+	7840	6415	1426
<b>Total</b>	<b>60298</b>	<b>39046</b>	<b>21251</b>

Source: EURODEM Prevalence rates applied to General Register Office (Scotland) 1992-based population projection by D S Gordon, 1996.

**Table 3** Projected estimate of growth in the number of people with dementia in Scotland by age group

age group	1995	2000	2005	2010
30-59	2545	2657	2675	2563
60-64	2570	2596	2676	3206
65-69	3815	3758	3827	3960
70-74	8805	8678	8648	8879
75-79	8781	9936	9948	10 030
80-84	13 862	13 080	15 058	15 469
85-89	12 079	13 099	12 747	14 875
90+	7840	10 191	12 097	12 891
<b>Total</b>	<b>60 298</b>	<b>63 994</b>	<b>67 675</b>	<b>71 873</b>

Source: EURODEM Prevalence rates applied to General Register Office (Scotland) 1992-based population projection by D S Gordon, 1996.

**Table 4** Estimates and projections of the number of people with dementia in Scotland by age group and gender over time

	60-69 years			over 75 years		
	women	men	Total	women	men	Total
1995	2086	4298	<b>6384</b>	31 351	11 214	<b>42 565</b>
2000	2042	4312	<b>6354</b>	33 609	12 697	<b>46 306</b>
2005	2060	4442	<b>6502</b>	35 422	14 428	<b>49 850</b>
2010	2203	4963	<b>7166</b>	37 090	16 177	<b>53 267</b>

Source: EURODEM Prevalence rates applied to General Register Office (Scotland) 1992-based population projection by D S Gordon, 1996.

behaviour problems than in other institutional settings may have as much to do with tolerance for behaviour problems in these settings as their prevalence.

Opit (1990; 1991), re-analysing OPCS data, found that most people with moderate to severe dementia had medium or major difficulty with self care and needed continuous supervision.



**Table 6** Percentage of people with dementia by place of residence and the kinds of help they need

	Community Household (n=91)	Residential Care Home (n=43)	Nursing Home (n=54)	Psychiatric Ward (n=49)	Geriatric Ward (n=49)	Weighted Total Percentage
<b>Mobility</b>	29	56	81	84	86	57
<b>Personal Care</b>	73	98	100	100	100	89
<b>Personal Care at Night-time</b>	30	66	94	98	92	62
<b>Domestic Assistance</b>	80	92	97	not asked	not asked	----
<b>Behaviour Problems</b>	61	95	80	94	78	76
<b>Behaviour Problems at nighttime</b>	33	77	74	82	69	57

Source: Gordon et al (1995)

**Table 7**      Percentage of people with dementia by place of residence and the kinds of help they need more than once daily

	Community Household (n=91)	Residential Care Home (n=43)	Nursing Home (n=54)	Psychiatric Ward (n=49)	Geriatric Ward (n=49)	Weighted Total Percentage
<b>Mobility</b>	25	34	74	71	86	49
<b>Personal Care</b>	56	60	91	98	90	72
<b>Domestic Assistance</b>	77	90	97	not asked	not asked	----
<b>Behaviour Problems</b>	45	91	57	69	57	59

Source: Gordon et al (1995)

### **3 CURRENT SERVICES**

Health 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 (Keen, 1993).

There is great diversity in the provision of specialist services for people with dementia across the regions of Scotland (Jacques, 1994). This diversity reflects the differing provision of other related services, local history, geography and circumstances. Joint provision and management of services for people with dementia are rare while joint planning of services has developed in a patchy fashion (Jacques, 1994).

#### **3.1 Assessment and Diagnosis**

##### ***GPs and Primary Care Teams***

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 practice (O'Connor et al., 1988; Philp, 1989; Tyrrell, 1993). While, as yet, there has been no empirical work which examines the benefits of an early accurate diagnosis, anecdotal reports suggest that carers would like to have an accurate and early diagnosis.

##### ***Specialist Domiciliary and Out-Patient Assessment***

Most people with dementia who receive specialist assessment are seen on domiciliary visits by consultants (average 5 per 1,000 over the age of 65) (Jacques, 1994). The average rate of attendance by people with dementia to all out-patient clinics was 0.8 per 1,000 over the age of 65 years, few of whom had been seen at home. Data gathered in 1990 suggests that at that time memory clinics had been set up or were in the plans to be set up in only one or two areas (Jacques, 1994).

##### ***Specialist In-patient Assessment***

Most Health Board areas have old age psychiatry assessment wards or designated beds, although there is a substantial difference between regions regarding their number. Jacques (1994) notes a wide range of policies regarding the concept and use of in-patient assessment. He argues that the range of provision of assessment beds has more to do with the balance of care than with differences in need for such services.

##### ***Specialist Multidisciplinary Dementia Teams***

Specialist resource teams have been shown to lead to improved rates of detection (O'Connor et al., 1991). However, in Scotland, staffing levels in multidisciplinary teams are low and many areas are deficient in clinical psychology, occupational therapy, physiotherapy, and social work (Jacques, 1994).



### 3.2 Care in the Community

#### *Informal carers*

Health and social care policy is directed toward supporting people in their own homes or in homely settings for as long as possible. It has long been recognised that care in the community is largely provided by informal carers (Keen, 1993). As such, community care will succeed only in so far as services address informal carers' needs (O'Connor et al., 1989). People with dementia who live alone are more likely to be admitted to residential care and thus warrant special attention from social and medical services (O'Connor et al., 1989).

Most community-based services for people with dementia are designed to support carers than to 'treat' dementing illness (Levin et al., 1994).

<b>COMMUNITY CARE SERVICES FOR PEOPLE WITH DEMENTIA</b>	
<b>day services</b>	<b>day hospital day care</b>
<b>home support</b>	<b>home help sitter services crisis response</b>
<b>respite</b>	<b>hospital other residential settings</b>
<b>carer support groups</b>	<b>advocacy mutual support</b>
<b>health care services</b>	<b>primary care specialist teams</b>

Recent surveys in Scotland provide an indication of service provision and use by carers (Gordon & Spicker, forthcoming; Gordon et al., 1995; Philp et al., 1995). Findings from these studies present an inconclusive picture.

In the Gordon et al (1995) survey of 91 informal carers in Forth Valley almost all the people cared for (82%) had had contact with some service in the preceding month. However, less than half of the carers reported use of general practice (42%), home help (40%) or district nursing (32%) at least once in the previous month. Small percentages of carers reported use of social work (16%), day sitter (14%), day hospital (14%), day centre (15%) and meals on wheels (14%) services at least once in the previous month.

Philp et al (1995) in their survey of 114 informal carers to people with dementia in Dundee found almost all the people they cared for (94%) had been to the general practitioner in the preceding 3 months. Only a minority of the carers sampled reported use of Community Psychiatric Nurse (CPN) (12%) or Health Visitor services (14%) for the people they cared for in the preceding 3 months. This low use may be due to ignorance as 38% of the sample were unaware of CPN services and almost a third (29%) had not heard of the health visitor service.

Over half of the Philp et al (1995) sample of informal carers reported the person they cared for had had contact with district nursing (58%) in the preceding month. In the

preceding week, over half (57%) of the informal carers reported use of home help, while almost half (48%) reported use of the day hospital service. A small percentage of the people cared for had used day centre (18%) or meals-on-wheels (18%) in the preceding week and only 13% had used the sitter service in the preceding month.

Surveys by Gordon and colleagues (Gordon & Spicker, forthcoming 1995) suggest that between 25% and 40% of carers in Tayside used any form of institutional respite in the previous year. Twelve percent (12%) of the sample used it on a regular basis. Philp et al (1995) 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.

It must be emphasised that the choice of service demonstrated in these studies depends partly in their availability in the area studied ('balance of care'). The balance between care services provided by the primary care team, voluntary organisations, private organisations, social work and hospital outreach varies enormously from area to area. Only through proper joint planning and inter-agency working can it be ensured that the range of services is available to the community and to the individuals who have particular needs.

In some areas greater use might be made of more specialist services for dementia including sitters and specialist day centres, community psychiatric nurses and social workers with a special interest in dementia. For example, Jacques (1994) found disparate provision of day hospital services across regions. In addition, Jacques (1994) found institutional respite to be most well developed in more scattered population areas and in cities. In particular parts of Scotland a significant minority of people with dementia are not known to services (Gordon & Spicker, forthcoming; Gordon et al., 1995).

The apparent underuse of the services is problematic and may be a result of a variety of factors including: carers' ignorance about the service (Philp et al., 1995); reluctance on the part of the person with dementia to attend (e.g. day services) (Moriarty & Levin, 1993); transportation difficulties (Jacques, 1994); and the appropriateness of the service for the carers' needs (Levin et al., 1994). For example, while carers have expressed a preference for home-based day care and respite services (Levin et al., 1994), at this time, there is no information available as to the extent of its provision or use in Scotland.

### **3.3 Long-Stay Care outwith the home**

People with dementia live in a variety of institutional settings which include residential care homes, nursing homes and a range of hospital settings. Between 1985 and 1991 there has been a growth in institutional care in Scotland for older people in general. In 1991 approximately 6% of those aged over 65 were in institutional care compared to only 4% in 1985 (Primrose, 1993). Most of the growth in institutional provision can be attributed to the growth in the nursing home sector. The rate of this growth has varied between Health Board areas.

The percentage of people with dementia in different institutional settings according to Scottish (Gordon et al., 1995) and English (Schneider et al., 1993) estimates may well have changed in recent years since the introduction of the 1990 NHS and Community Care Act. It is possible that people who would formerly have lived in NHS



hospital settings are now living in private and voluntary sector nursing and residential care home settings.

### ***Hospitals***

Almost half of people with dementia in institutional longstay care in Scotland are cared for in hospital settings. The kind of hospital setting varies. Jacques (1994) found that a substantial proportion is provided in old psychiatric hospitals, in wards originally designed for young adults with psychiatric difficulties. Gordon and Spicker (forthcoming) found that at least half of people with dementia who were living in hospital settings were cared for in geriatric facilities.

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 (Jacques, 1994).

The closure of NHS long stay beds has resulted in some contracts between Health Boards and nursing home companies, which Jacques (1994) points out are often providing quite large facilities.

### ***Residential Care Homes and Nursing Homes***

The number of residential care and nursing homes in Britain has been increasing since the early 1980's and this has been attributed largely to their growth in the private sector (Tinker, 1992). The proportion of people with some kind of cognitive difficulty in residential care homes has also been increasing (Tinker, 1992) such that approximately one third to a half of residents have some kind of dementia (Ineichen, 1990) and up to 37% of people with severe dementia are cared for in these settings (Schneider et al., 1993).

There are fewer older people in residential care homes in Scotland than in England. The bulk of long-stay care in Scotland is provided in nursing environments - hospitals and nursing homes. Recently concerns have been raised about the inappropriate use of neuroleptics in nursing homes in Scotland (McGrath & Jackson, 1996).

As the NHS reduces its provision of long-stay care, Health Boards will have to provide increased community health projects (including respite) to support older people in their own homes. In addition, existing residential and nursing homes will absorb former patients.

### ***Specialized long-stay care outwith the home***

Some 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 in recent years (Thomas, 1995). Jacques (1994) found few 'Timbury' continuing care homes. Special care units within nursing and residential care homes while well established in the US (Coons, 1991; Peppard, 1991; Sloane & Mathew, 1991; Zarit et al., 1990c) are only recently developing in Scotland.

In Scotland, housing associations have a long tradition of providing housing for older adults, but it is only recently that they have turned their attention to people with dementia (Foster, 1994). 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 (Foster, 1994).

### **3.4 Service deficiencies**

Philp et al (1995) asked carers in Dundee about their unmet service needs. The authors conclude that there is a high level of unmet need for mainstream medical services and domiciliary support. 34% reported needing one hour a day or more of help with supervision, 20% needed one hour or more a day of help with housework and only 10% needed similar levels of help with personal care. The authors advocate for the need for developing innovative domiciliary support services. In particular, the development of services which would assist carers with aspects of caring they find most difficult - keeping the person with dementia occupied and providing supervision.

Carers reported needing additional support from almost all services. At least a fifth of carers mentioned needing additional help from the following services: 33% need additional home help support; 28% require additional respite support; 27% need additional help from general practitioners; 26% from day hospital services; 25% from day care and meal on wheels services; 24% from sitter services and 20% require additional support from sheltered housing (Philp et al, 1995).

Donaldson et al (1991) have identified areas of service deficiency in Grampian which, based on joint community care plans which address dementia and recent Scottish studies (Jacques, 1994; Philp et al 1995) suggest that this work has relevance for the rest of Scotland. Areas of service deficiency include: concentration of care on hospital sites; lack of adequate day and respite facilities; lack of adequate domiciliary services; inadequate information giving, education, and training for carers. In addition, they produced a wish list for the expansion of services. The items on this list are presented below and include: extended home help service; transport for day care in rural areas; sheltered housing; flexible day and respite care; support groups and social service support for carers; smaller more homely homes; a register of information; and keyworkers.

#### **Services Needing Expansion**

- home help
- transport for day care
- sheltered housing
- flexible day and respite care
- support groups for carers
- social service support for carers
- smaller, more homely residential settings
- register of information
- key workers

Source: Donaldson et al (1991)



## 4 HEALTH GAIN

A key role of Health Boards is assessing their population's state of health and appraising how and to what extent it can be improved, i.e. what is the health gain.

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. Debate on the impact of this has centred around two contrasting theses. The first, named by some the "compression of morbidity", states that although life expectancy is increasing, the effects of this in leading to greater numbers of people with ill-health are mitigated by a later onset of the disabling consequences of chronic degenerative diseases. This postponement of onset is postulated to be due to the general rise in the standard of public health and to measures impacting on cardiovascular disease (Fries).

The second is that increasing life expectancy does lead to rising numbers of people suffering from disabilities as the onset of underlying diseases is an inevitable part of the ageing process (Crimmins, Roos).

There is no definitive evidence to support either thesis, particularly in the United Kingdom where there appears to be little published research on this subject. There is some indication from the United States that there may be a compression of morbidity but this is not uniform throughout society (Manton). Some have found a decline in the age of onset of chronic conditions to be positively related to educational status (Leigh).

With regard to dementia the picture is even less clear. Numbers should rise with the doubling of the annual incidence of dementia every 5 years after the age of 75 years old (Paykel, Ryan). However as has been pointed out, dementia is not a single disease. There are therefore distinct aetiological factors for the different types of condition which will influence the overall size and rate of the increase. Prevalence rates and incidence rates have been found to vary in different countries (Eastwood). Predicting trends in the overall numbers of people with dementia in a population may be more complex than first appears.

Two areas of study which will help shed light on the public health dimension of dementia: investigation of the ageing process and elucidation of factors which predispose to or protect against the dementias.

In the former, a key research topic is cognitive impairment. Studies have found that its levels in populations are associated with higher levels of mortality as well as being a significant predictor of dementia (Kelman). Borderline impairment has been found to be also related to higher mortality (Clarke). Some postulate that Alzheimer's disease may be the end point of a continuum of cognitive impairment.

The relation of the risk of dementia to educational status has been noted in a number of studies although this appears to be more marked in vascular dementia than Alzheimer's disease (Cobb). Other significant risk factors for dementia are stroke particularly in vascular dementia (Maoroney, Tatemichi) and depression (Kokmen) although the latter may be an early manifestation of the disease (Devanand). Programmes targeted at reducing the risk of cardio-vascular disease, and which as a

consequence may have an impact on the risk of vascular dementia, have been evaluated with other end points in mind. It is therefore unclear if they are of value.

There is, therefore, no coherent evidence which could serve as the basis for a primary prevention strategy for dementia. Given the major public health significance of the disease, it is apparent that more research is required. A recent international conference in Edinburgh highlighted the need for a research strategy which brings together different disciplines, particularly epidemiology, genetics, neuro-sciences and sociologists (Eastwood).

Most emphasis in health gain in dementia, therefore, is on secondary (early detection) and tertiary prevention (the prevention of complications). Key health gain objectives for the Health Service, as derived from various reports, are summarised below:

***To maximise the quality of life of people with dementia and their carers, assist in maintaining their dignity and preserve the best possible level of independence by:***

- \* minimising cognitive impairment;*
- \* reducing the psychological distress of people with dementia;*
- \* minimising behavioural and other associated disabilities;*
- \* improving and maintaining self care in people with dementia;*
- \* reducing family carers' burden and stress.*

Unfortunately, the evidence of major health gain related to these objectives from current services is limited. This is partly due to the difficulty of defining and measuring outcomes in this field; lack of information on the case-mix of people with dementia participating in trials; and a lack of differentiation between the levels of intervention or service provision being assessed. Research into the effectiveness of health and social care interventions for people with dementia and their carers should be a priority.

The management of behavioural and psychological aspects of dementia is currently being reviewed as part of the development of SIGN guidelines.

The introduction of acetylcholinesterase inhibitors, especially tacrine, as new treatments for cognitive impairment will heighten the need for scrutiny of the cost effectiveness of current services. The benefit -risk ratio for tacrine is small (Lyketsos) and it is recommended that its use should be governed by guidelines.

In conclusion, there is a need for co-ordinated research into the aetiology of the dementias and the scope for preventive interventions and the effectiveness of current services.



Key public health contributions are :

- ***auditing the level of met and unmet need***

A variety of techniques can be used :

- \* a census of known people with dementia by case finding through hospital and primary care record reviews and comparison with expected levels from population prevalence rates (Gordon);

- \* a review of "waiting lists" for admissions to hospital and community services.

- ***auditing the appropriateness of how assessed needs are being met***

- \* a review of age-specific neuroleptic prescribing in primary care, especially melleril (in collaboration with Medical Prescribing Advisers)

- \* a review of admissions from nursing and residential homes to NHS psycho-geriatric hospital services

- \* a review of admissions to NHS continuing care against joint eligibility criteria



## 6 DEFINING THE BALANCE OF CARE

### 6.1 Key Principles

***Commissioners' basic approach should be to ensure the availability of a sequence of care***

Given the diversity within Scotland in terms of existing provision by all types of providers and in term of history, geography and culture and the relative lack of sound intervention research, the authors resisted the customary approach of guidelines specifying actual buildings and precise numbers of beds, staff, and units. We have also deliberately avoided the customary listing of professionals in some sort of order of importance. We took the view that the Health Boards and their partners should approach the commissioning of services from the basis of ensuring the availability of a sequence of care to meet the needs of people with dementia and their carers from the beginning to the end of the disease.

***Commissioners should clearly state the strategic priority of services for people with dementia in their Community Care Plans***

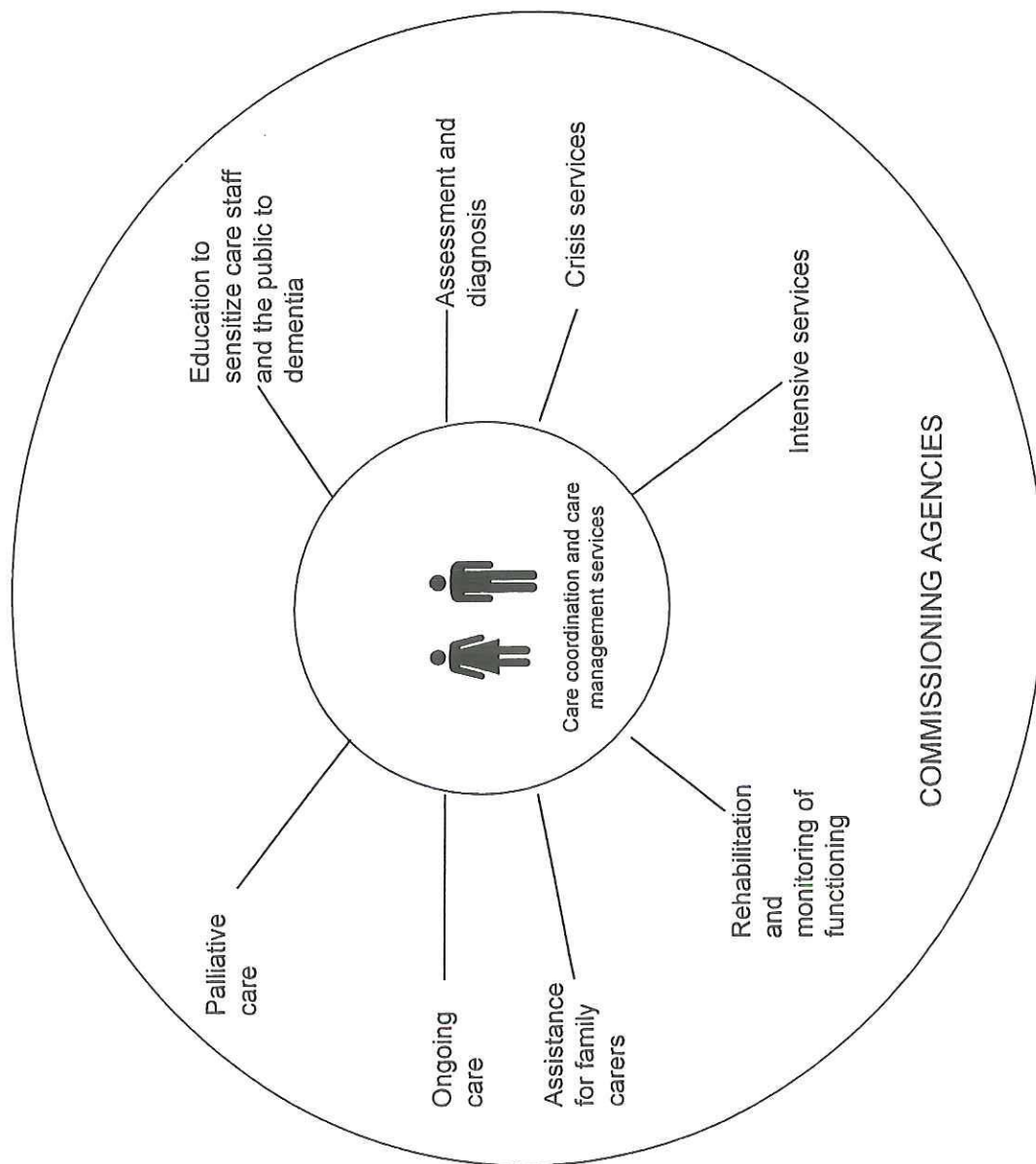
The authors wish to emphasise that people with dementia and their carers are currently a disadvantaged group in terms of both the number and quality of services. This shortfall is particularly serious in view of the continuing increase in the numbers of people with dementia. Given the Management Executive's priority for mental health, Boards need to review the level of resources available and clearly state the strategic priority of services for people with dementia.

***Commissioners should base strategies on pooled resources and a definition of the required balance of services for their local population***

Those with moderate to severe levels of dementia have requirements for co-ordinated packages of care. Their needs are met more effectively and flexibly by joint planning and commissioning by health and social work departments. This entails the pooling of resources which has implications for the commissioning and provision of services since authorities will wish to ensure that some, if not all, providers are in a position to deliver services in a flexible way as the condition develops.

The need for a specific dementia service is linked to the level of provision of other services, the mix of these services and their quality. Reduction in one service can lead to reduced quality of care in another. The emphasis on normative planning for dementia services is therefore not useful. Boards and other commissioners need to develop methods to compare the pattern of provision against overall levels of need. Based on such considerations, Boards and their partners should define the required balance of services for their local population.

# THE BALANCE OF SERVICES REQUIRED TO DELIVER A SEQUENCE OF CARE



***Commissioners should commission services which offer different service options at different stages of their condition and have mechanisms to ensure continuity in planning and service delivery.***

Health Boards and other commissioners should be aware that different groups of people with dementia and their carers will require different service options at different stages of their condition (see Appendix 3). Community care plans and strategies for people with dementia must take cognisance of this.

Whilst the pattern of deterioration will vary between individuals with dementia, health care providers will have to continue to provide appropriate levels of care up to and including the terminal stages. Health Boards and their partners must ensure therefore that there are mechanisms to facilitate continuity in planning and service delivery .

***Commissioners should set clear planning priorities for each dementia related service***

Within an overall definition of the balance of services required, Boards and their partners should set clear planning priorities based on existing patterns of resource use, the costs of programmes of care and planning agreements with social work and housing authorities and existing contractual arrangements with statutory, voluntary and private providers.

## **6.2 The balance of care: the main elements**

### **Education to sensitize care staff and the public to dementia**

Care staff and the public need to be educated about dementia to improve referral rates; to promote a proactive approach to the identification and care of people with dementia; and to enhance understanding of the therapeutic potential in dementia care.

Such education could be commissioned from and undertaken, for example, by health education, primary health care, voluntary organisations and in staff training organisations. It could take place in acute hospitals, older people's organisations, primary care and residential and nursing establishments.

### **Specialist assessment and diagnosis**

People with suspected dementia should be assessed to identify those who actually have a treatable cause of mental impairment (e.g. depression, diabetes, infection); to establish a differential diagnosis (e.g. Alzheimer's or vascular); to identify and treat concomitant medical (e.g. heart problems) and psychiatric disorders (e.g. depression); to identify the needs of carers and people with dementia; and to improve referral practices.

Assessment and diagnosis can be conducted in a variety of settings including the person's own home, in a memory clinic, in primary care, in a day centre or hospital and in an inpatient unit.



The teams of personnel needed to conduct assessment and diagnosis include: GP, social worker, occupational therapist, old age psychiatrist, psychologist, medical staff (includes geriatrician and general practitioner), and psychiatric nurse.

### **Crisis response**

Crisis services should be provided for people with challenging behaviour; people with very complex combinations of medical and psychiatric care (e.g. heart failure in combination with extreme agitation and wandering); and for people who have a sudden breakdown in their support network.

The aim of these services is to prevent unnecessary deterioration and distress for people with dementia and their carers; and to improve and strengthen carers' coping mechanisms.

These could be provided in a variety of settings including: in-patient or day settings, in the person's own home or in other home-based settings, and in a non NHS residential crisis unit. The latter does not exist at present.

The staff needed in such settings include trained care staff who have ready access to the following professionals: social worker, occupational therapist, old age psychiatrist, psychologist, medical staff (includes general practitioner) and psychiatric nurse.

### **Intensive care and therapy**

Intensive services are needed for people with challenging behaviour (e.g. agitation, hitting or yelling); and for people with very complex combinations of medical and psychiatric care (e.g. treatment of a broken neck of femur in someone with severe confusion and disorientation).

The aim of these services is to reduce the incidence or severity of challenging behaviour; to treat medical conditions without creating behavioural complications; to review medication; and to reduce excess disability. These services can be provided in a variety of settings including in patient settings, and day settings.

The staff needed to provide this service include a high ratio of trained care staff who have ready access to the following professionals: social worker, occupational therapist, old age psychiatrist, psychologist, medical staff (includes general practitioner), and psychiatric nurse.

The essential characteristics of intensive services are that they be short term, provided in small care settings, with access to technology (e.g. brain scan equipment).

### **Rehabilitation and monitoring of functioning**

Rehabilitation services are useful for those whose functioning has deteriorated or who are felt to have the potential for improvement (e.g. people with dementia with combinations of medications who would benefit from a drug review or people with depression and dementia).