

## **SERVICES FOR PEOPLE WITH DEMENTIA**

### **1 Introduction**

#### **1.1 Purpose of template**

This template provides guidance for NHS Boards, local authorities, Community Health Partnerships and other agencies when they plan and commission services for people with dementia and their carers. It also stands as a benchmark against which available services can be compared. The template has been produced by a Scottish Executive and Alzheimer Scotland Short Life Working Group. The context for the template comes from a number of publications: Planning Signposts for Dementia Care Services<sup>i</sup>; Adding Life to Years<sup>ii</sup>; Our National Health<sup>iii</sup>; Partnership for Care<sup>iv</sup>; Reinvigorating the Joint Future Agenda<sup>v</sup>; Needs Assessment Report<sup>vi</sup>; and National Mental Health Services Assessment<sup>vii</sup>.

#### **1.2 Information about dementia**

Dementia is characterised by a progressive loss of mental functions and is caused by a range of conditions: the most common is Alzheimer's disease, which affects roughly 50-60% of people with dementia. Vascular dementia occurs as a result of strokes or problems with blood circulation in the brain and affects around 10-20% of people with dementia. 10-20% of people with dementia have both Alzheimer's disease and vascular dementia. There are also less common forms of dementia: dementia with Lewy bodies; Pick's disease; Huntington's disease; Korsakoff's syndrome; and HIV and AIDS related dementia. This group of conditions affects around 15-20% of people with dementia.

The symptoms of mild dementia are, among others, a difficulty in recalling events and in coping with unfamiliar situations and increasing errors in activities of daily living but without loss of ability for self-care. These symptoms will progress through the mild and moderate stages to severe dementia, which is characterised by: complete dependence on others for basic personal care; incoherent speech; disorientation of time, place and person; failure to recognise close relatives; and incontinence of urine and faeces.

Alzheimer Scotland estimates that there are at present 62,000 people with dementia living in Scotland, of whom around 1,600 are under the age of 65. This estimate uses General Register Office for Scotland's population figures for mid year 2003, and EURODEM (1991)<sup>viii</sup> and Harvey (1998)<sup>ix</sup> prevalence figures.

This figure is expected to increase with the ageing population. Dementia occurs most frequently in older age groups. Prevalence rises from 2.2% of men and 1.1% of women in the 65-69 age group, to 31.6% of men and 36% of women aged 95-99.

A study by Wolfson et al (2001)<sup>x</sup> noted that "*estimates of median survival after the onset of dementia have ranged from 5 to 9.3 years*". However, a more recent (American) study by Larson, Shadlen et al (2004)<sup>xi</sup> calculated the life expectancy for people with Alzheimer's disease to be lower: 4.2 years for men and 5.7 years for women.

The template assumes that life expectancy after diagnosis is between 5 and 6 years.

The frequency with which care or supervision may be required by older people has been measured by Isaacs and Neville<sup>xii</sup> and adapted by Melzer<sup>xiii</sup> for application to people with dementia. This has been used in the template alongside the EURODEM and Harvey prevalence figures.

<b>Interval of need for people with dementia</b>	<b>% of people with dementia</b>
Independent	6
Long interval (care needed once a week)	11
Short interval (care needed at regular intervals during the day for dressing, meals etc)	48
Critical interval (constant care or supervision required)	34

### **1.3 Intended outcomes**

Services that help those with dementia:

- live as normal a life as possible, whether in their own home or a care home;
- successfully re-adjust to living in their own home when they return from a period away; and
- have the best possible quality of life within the limitations of their condition.

Services that help Carers\*:

- to continue caring for the person with dementia in their own home for as long as practical;
- maintain a caring relationship between them and the person with dementia; and
- feel fulfilled and satisfied in their caring role.

The outcomes listed in the following service profiles are a combination of targets that can be monitored through data collection and assessed during clinical and service audits.

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\* In the template 'carers' refers to the family and informal carers of people with dementia, not their formal and paid care workers.

## 2 Principles of service organisation

### 2.1 Principles of good service

The principles of a good service are listed in the *Needs Assessment Report*<sup>xiv</sup>. They are:

- 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; and
- services, including home care, should be available 24 hours a day 7 days a week.

### 2.2 Intervention principles

The intervention principles in the Adults with Incapacity (Scotland) Act are also helpful when decisions about services have to be made on behalf of an adult with impaired capacity. These decisions must:

- benefit the adult;
- take account of the adult's wishes as far as they can be ascertained;
- take account of the views of relevant others, as far as it is reasonable and practicable to do so;
- restrict the adult's freedom as little as possible while still achieving the desired benefit; and
- encourage the adult to use existing skills or develop new skills.

### **3 Local and Regional Joint Agency Service Planning**

Local and regional approaches to service planning for dementia diagnosis, care and support should be based on ongoing assessments of incidence and prevalence of dementia in their area. This Template will aid that process.

In addition reference is made throughout this template to the need to provide responsive services to a wide range of specific needs. These services will include people with learning difficulties who develop dementia, those from ethnic minority communities, those with alcohol related brain damage, those with physical disabilities and sensory impairment, those with HIV and AIDS, and those with a lesbian, gay, bisexual and transgender background. It also underlines the importance of age appropriate responses to dementia for people with dementia aged under 65.

The importance of support for the carers of people with dementia throughout the course of the illness must not be underestimated<sup>xv</sup>. Carers also come from a wide variety of backgrounds and diverse needs.

Current national and local population and prevalence figures and projections can be determined by application of Hofman, Rocca et al (1991) and Harvey (1998) to the national and local population profiles available each year from the General Registry Office. Age and sex profiles can also be drawn from these sources and partners are encouraged to use this information in planning for dementia services in their local area, and for projections of future needs.

This Template takes into account the progressive nature of dementia. Although this is true in general, individual cases show great variation in how the illness manifests itself and therefore some people with dementia and their carers may need services that are categorised as appropriate to more than one stage of the illness, not necessarily in the sequence given in the Template. This underlines that successful and responsive services will be dependent on the local development of integrated care pathways for people with dementia that reflect the multiple entry points to the assessment and care systems.

In all cases only a partnership approach to local and other needs assessment, planning and delivery of care will deliver the seamless care and approaches needed.

The template covers the following service considerations:

- Pre-diagnosis services
- Diagnosis
- Post diagnosis support
- Community services
- Continuing care
- Co-ordination

**Agencies may wish to adapt the Template to reflect local approaches to the changing needs of people with dementia and their carers as well as local circumstances.**

### 3.1 Pre-diagnosis services

**Aims:**

- to understand that dementia is an illness
- to recognise the possible significance of symptoms
- to recognise that mild cognitive impairment does not necessarily lead to dementia.

<b>Critical factors to be considered</b>	<b>Ways in which service may respond</b>	<b>Outcomes</b>	<b>Local Action</b>
<p>Anti stigma and awareness programme.</p> <p>Assessment of current and forecast local and regional needs.</p> <p>Assessment of existing services and identification of gaps in provision.</p>	<p>Local participation in and promotion of national and other initiatives designed to fit local circumstances and need.</p> <p>Design of services to align with assessed current and future needs.</p> <p>Improved local access to services including Memory Clinics and old age psychiatric assessment services.</p> <p>Support, information and advice on memory problems and mild cognitive impairment.</p>	<p>Increasing presentations for early diagnosis where symptoms have persisted.</p> <p>People are more likely to retain friendships and relationships with people with dementia.</p> <p>More sympathetic understanding.</p> <p>Local comprehensive services that meet the needs of service users and carers.</p> <p>Jointly planned and delivered responsive local services.</p>	

### 3.2 Diagnosis

#### Aims:

- for the person with possible dementia to know if symptoms are caused by a form of dementia and to seek appropriate medical response
- to identify the type of dementia
- comprehensive advice to service users and carers on dementia and the organisation of local services and support

<b>Critical factors to be considered</b>	<b>Ways in which services may respond</b>	<b>Outcomes</b>	<b>Local Action</b>
<p>Assessment of local and regional needs for diagnosis.</p> <p>Local multiple entry points care pathway document(s) and protocols in place that reflect the needs for those under and those over age 65.</p> <p>GP practices to develop specialisation in dementia diagnosis and follow up.</p> <p>The potential roles of the primary care team as a whole.</p> <p>Dementia has an <b>incidence</b> of 17-20% of the number of people with dementia in an area.</p>	<p>GP and wider primary care team services.</p> <p>Memory clinics.</p> <p>Neurology services.</p> <p>Old Age Psychiatry services.</p> <p>Dementia Community Psychiatric Nurses.</p> <p>Appropriate drug treatments.</p>	<p>The offer of a diagnosis becomes the norm in line with the incidence of dementia.</p> <p>An increasing number of people with Alzheimer’s disease are diagnosed at an early stage and given access to drug treatment where appropriate. Those not given drug treatment are offered appropriate follow-up.</p> <p>Earlier treatment for those with vascular dementia to reduce risk of further cognitive decline.</p> <p>Appropriate information on dementia and access to local services for people with dementia and their carers.</p>	

### 3.3 Post diagnosis support

#### Aims:

- to plan for the future, including initial advice about the Adults with Incapacity Act (Scotland) 2000
- to receive the support, advice and information that are required to live with the illness until community services are required
- to help maintain independence

<b>Critical factors to be considered</b>	<b>Ways in which service may respond</b>	<b>Outcomes</b>	<b>Local Action</b>
<p>Through ongoing assessment of needs</p> <ul style="list-style-type: none"> <li>• The estimated number with dementia who are independent or require help once a week is 17% of the total number of people with dementia in an area.</li> <li>• This should take into account that some may require these services for only a short time before they need more intensive care arrangements.</li> <li>• Local protocols that link diagnosis, community services and care management, allowing for multiple entry points.</li> </ul>	<p>Up to date and accessible information and advice.</p> <p>Accessible local, on going, counselling and emotional support.</p> <p>Available education and training for Carers.</p> <p>Access to local independent advocacy.</p> <p>Help to sustain employment for those with dementia and their carers.</p> <p>Information on Welfare benefits and financial advice with established links to local Department of Work and Pensions.</p>	<p>Improved opportunities for those with dementia to live as normal a life as possible in their own homes, with sustained family and community relationships.</p> <p>Access to the full range of post-diagnostic services for all with a diagnosis of dementia and their supporters.</p> <p>Trained and supported Carers, better able to cope with the current and future effects of the condition.</p>	

	<p>Assistance to help those with dementia and their carers to plan for the future, eg powers of attorney, advance statements and wills.</p> <p>Steps to nurture and promote peer support.</p> <p>Improved local day opportunities and services.</p> <p>Consideration of sheltered housing and extra care housing options.</p> <p>Introduction of assistive technology.</p>		
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### 3.4 Community services

- **Aim:** to enable people with dementia to remain in their own home for as long as they wish and it is possible.

<b>Critical factors to be considered</b>	<b>Ways in which service may respond</b>	<b>Outcomes</b>	<b>Local Action</b>
<p>Local and regional assessment of numbers and needs.</p> <ul style="list-style-type: none"> <li>• the estimated number of people with dementia needing care at least once daily is 44% of the number of people with dementia in an area</li> <li>• the estimated number of people with dementia living alone is 13% of people with dementia in an area</li> <li>• if it is assumed that all people living alone in the community and 50% of those living with families require services, this give a ‘working’ target for service users of 28% of people with dementia in an area.</li> </ul> <p>Capacity of existing Agency partners’ services to meet the</p>	<p>Practical assistance and other support in the home.</p> <p>Help with housing issues</p> <p>Day services/day opportunities.</p> <p>Crisis response services.</p> <p>Rapid response teams.</p> <p>Intensive support and rehabilitation.</p> <p>Short breaks/respite care * .</p> <p>Help for people who have had to give up driving.</p> <p>Household aids and adaptations.</p> <p>Assistive technology.</p>	<p>People with dementia continue to live as normal a life as possible in their own homes, sustaining family and community relationships.</p> <p>Access to the full range of support services as and when needed.</p> <p>Reduced/delayed demand for continuing care.</p> <p>Extended training and support for carers to enable them effectively to fulfil their roles</p> <p>Reduced delays at all stages.</p>	

\* In the past respite services referred to services designed to give carers a break from caring; nowadays it is preferable to refer to short breaks where the objectives are to give the carer a break from their caring responsibilities and at the same time give the person with dementia a stimulating break from their usual routine.

<p>assessed levels of need.</p> <p>The role of assistive technology in managing risk and helping people with dementia maintain their independence.</p> <p>Availability of intensive packages of support to contribute to changing the pattern of long term care.</p> <p>Multiple entry points local protocols to link with post diagnosis support and continuing care.</p>	<p>Carer support.</p> <p>Social and cultural stimulation.</p> <p>Access to other health and welfare services.</p>		
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### 3.5 Continuing care

**Aims:**

- to care for people who can no longer be cared for in their own homes
- to provide for the end stages of dementia or dying of other causes.

<b>Critical factors to be considered</b>	<b>Ways in which service may respond</b>	<b>Outcomes</b>	<b>Local Action</b>
<p>Approximately 40% of people with dementia receive continuing care.</p> <p>Availability of accessible intensive home support services.</p> <p>Local capacity plans for older people's services.</p> <p>The balance of care between hospital and care home care.</p> <p>The potential for expansion of extra care housing.</p> <p>The need to reduce delayed discharges.</p> <p>End of life palliative care will be needed for 17-20% of people with dementia in an area.</p> <p>Multiple entry points - protocols to link with community services and care management.</p>	<p>Extra care housing.</p> <p>Care homes.</p> <p>Hospital care.</p> <p>Palliative care.</p> <p>Social and cultural stimulation.</p> <p>Challenging behaviour service.</p> <p>Continuing support for carers, including bereavement support.</p>	<p>Improved quality of life for those with dementia and their carers.</p> <p>Enhanced opportunities for carers to continue a caring relationship with the person with dementia.</p> <p>Palliative care for those with dementia.</p> <p>Timely bereavement support for the carer and family.</p> <p>Reduced delays for necessary services.</p>	

NB The above services have been listed separately; in practice there will be considerable overlap and some may be provided by the same agency.

### 3.6 Co-ordination

**Aims:**

- to ensure that people with dementia have their needs assessed and receive the services they need seamlessly
- to apply the principles and process of the Adults with Incapacity (Scotland) Act 2000
- to ensure that the carers of people with dementia have their needs assessed and receive the assistance they require
- to ensure a partnership approach to local and other needs assessment, planning and delivery of dementia care

<b>Critical factors to be considered</b>	<b>Ways in which joint services may respond</b>	<b>Outcomes</b>	<b>Local Action</b>
<p>Continued contact at all levels between the statutory and other agencies on the joint planning and delivery of care.</p> <p>Consideration of lead agency, where thought appropriate.</p> <p>Joint services for the person with dementia and their carer.</p> <p>Agreed local arrangements to share and access information between agencies.</p>	<p>Care management.</p> <p>Assessment and re-assessment of the person with dementia and their carers.</p> <p>Appointment of key workers.</p> <p>Multi-disciplinary and joint agency working.</p> <p>Multiple entry points local care pathways that are sensitive to the transitions between services and levels of dependency.</p>	<p>Well organised and seamless services.</p> <p>Reduce waiting times for assessment and re-assessment.</p> <p>Services that recognise and anticipate changing needs of the person with dementia and their carer, including capacity.</p>	

#### **4 Quality of Services**

The main purpose of the Template is to provide an audit and planning tool for agencies to apply and refer to within an ongoing review of local and other dementia services.

This supports the aim of providing good quality services and support that are sensitive and responsive to the assessed needs of people with dementia.

Effective on going assessment of current and future needs will be required, as will investment in design, workforce, training and facilities with reference to the special needs of those with dementia and their carers.

#### **5 Information for future services**

Ideally, the use of the Template needs to be accompanied by a standard way of recording service levels and take-up that is part of the returns that NHS Boards and local authorities make to the Scottish Executive. The availability of this data would make future modelling and assessment of services for people with dementia more authoritative. In the report, "*Overcoming the obstacles to improving dementia services*" the working group have recommended that there should be a review of the appropriateness of the data collected by the Scottish Executive about dementia services. Information also needs to be collected from people with dementia and their carers about their perceptions of their needs, the adequacy of existing services, and priorities for new developments.

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## References

Appendix 1 : Service profiles in percentages

Appendix 2: Dementia prevalence rates

## References

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- <sup>i</sup> Alzheimer Scotland (2000) *Planning Signposts for Dementia Care Services*. Edinburgh
- <sup>ii</sup> Scottish Executive (2002) *Adding Life to Years. Report of the Expert Group on Healthcare of Older People*. Edinburgh
- <sup>iii</sup> Scottish Executive (2000) *Our National Health. A Plan for Action, a Plan for Change*. Edinburgh
- <sup>iv</sup> Scottish Executive (2003) *Partnership for Care*. Edinburgh
- <sup>v</sup> Scottish Executive (2004) *Re-invigorating the Joint Future Agenda*  
<http://www.scotland.gov.uk/about/HD/CCD2/00017673/NextSteps8March04.pdf>
- <sup>vi</sup> NHS Health Scotland (2003) *Needs Assessment Report. Dementia and Older People*.
- <sup>vii</sup> Scottish Executive (2004) *National Mental Health Services Assessment. Towards Implementation of the Mental Health (Care and Treatment) (Scotland) Act 2003*. Edinburgh
- <sup>viii</sup> Hofman A, Rocca WA, Brayne C, Breteler MM, Clarke M, Cooper B, Copeland JR, Dartigues JF, da Silva Droux A & Hagnell O (1991) The prevalence of dementia in Europe: a collaborative study of 1980-1990 findings. *International Journal of Epidemiology*. 20, 736-748
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- <sup>xii</sup> Isaacs B and Neville Y (1975) *The measurement of need in old people*. Edinburgh, Scottish Home and Health Department, Scottish Office
- <sup>xiii</sup> Melzer D, Pearce K, Cooper B and Brayne C (in press - due June 2004) in Stevens, Raftery, Mant and Simpson (eds) *Healthcare needs assessment: the epidemiologically based assessment reviews - 1<sup>st</sup> Series*, 2nd edition, Abingdon: Radcliffe Medical Press Ltd
- <sup>xiv</sup> Op cit
- <sup>xv</sup> Alzheimer Scotland (2003) *Signposts to support: understanding the special needs of carers of people with dementia*. Edinburgh

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## Appendix 1:

### Service profiles in percentages

Service		Approximate percentage of people with dementia who will need the services
Diagnosis	The incidence of dementia gives the target number of people with dementia to be diagnosed each year	17-20%
Post-diagnosis support services	The incidence of dementia gives the annual number of people with dementia requiring post diagnostic support	17-20%
	People with dementia who are independent or require care at least once a week	17%
Community services	People with dementia who need care at least once daily	44%
	People with dementia in the community living alone	13%
	Target number of users of community services	28%
Continuing care	Scottish average	40%
	End of life palliative care	17-20%
Co-ordination		100%

These figures can be applied to the local projected number of people with dementia for individual NHS Boards or local authorities.

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## Appendix 2:

### Dementia prevalence rates

Age	Prevalence rate (% of population affected)	
	Males	Females
65 – 69	2.2	1.1
70 – 74	4.6	3.9
75 – 79	5.0	6.7
80 – 84	12.1	13.5
85 – 89	18.5	22.8
90+	31.9	34.1
90 – 94	32.1	32.2
95-99	31.6	36

Source: Hofman, Rocca et al (1991) The prevalence of dementia in Europe: a collaborative study of 1980-1990 findings. *International Journal of Epidemiology*, 20 (3), 736-748.

Age	Prevalence rate (% of population affected)
30 – 64	0.067 (for both sexes)

Source: Harvey (1998) Young Onset Dementia: Epidemiology, clinical symptoms, family burden, support and outcome. Dementia Research Group, Imperial College School of Medicine.