



SCOTTISH EXECUTIVE

Health Department
Director of Service Policy and Planning

11th November 2004

Dear Colleague

THE PLANNING, ORGANISATION AND DELIVERY OF JOINED UP SERVICES FOR THOSE WITH DEMENTIA AND THEIR CARERS

Summary

1. Attached to this letter is an expanded addition to the Service Profiles section of the Framework for Mental Health Services in Scotland together with a report of The Scottish Executive and Alzheimer Scotland Short Life Working Group.

Background

2. A working group was set up as a joint initiative of the Scottish Executive and Alzheimer Scotland to identify and offer solutions for planners and commissioners of services to remove obstacles or other difficulties in the development and improvement of health care, social care and support for those with dementia and their carers

3. The attached report and template (which offers a planning and audit tool for the design of dementia services) will help inform the approaches adopted by partners in each NHS Board area on how they wish to respond to the assessed and forecast needs in their area.

4. The approaches set out in the template and the recommendations in the associated report are for the attention of all with an interest in the organisation of care, support and accommodation for those with dementia and their carers.

Addresses

For action

Chief Executives, NHS Boards
Chief Executives, Local Authorities
Directors of Social Work/Chief Social
Work Officers

For information

Chief Executive, COSLA
The State Hospitals Board for
Scotland
Chief Executive, NES National
Services Scotland
Chief Executive, NHS Education for
Scotland
Chief Executive, NHS Health
Scotland
Chief Executive, NHS Quality
Improvement Scotland
Secretary, Mental Welfare
Commission for Scotland
Chief Executive, Scottish
Commission for the Regulation of
Care
Scottish Partnership Forum
Appropriate voluntary/professional
organisations

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INVESTOR IN PEOPLE



Action

5. Agencies are invited to consider, and where appropriate incorporate, the advice offered for local application and delivery of service and support arrangements within their planning processes.

6. This HDL is also available at (www.show.scot.nhs.uk) and on the Mental Health and Well Being Support Group site (www.show.scot.nhs.uk/mhwbsg/)

Yours sincerely

IAN GORDON

Director of Service Policy & Planning

**Overcoming the obstacles to
the improvement of
dementia care**

**Report of the Scottish Executive and
Alzheimer Scotland
Short Life Working Group**

November 2004

Executive Summary

The working group was set up in 2003 as a joint initiative of the Scottish Executive and Alzheimer Scotland (see appendix A for membership). The remit of the group was “to identify and offer solutions to overcome/remove obstacles or other difficulties in the development/improvement of health care, social care and support for those with dementia and their carers”.

The intention has been to complement the recommendations which have been made in *Planning Signposts for Dementia Care Services*ⁱ; *Adding Life to Years, Report of the Chief Medical Officer’s Expert Group on the Healthcare of Older People*ⁱⁱ; *Needs Assessment Report*ⁱⁱⁱ, *National Mental Health Services Assessment*^{iv} *Towards Implementation of the Mental Health (Care and Treatment) (Scotland) Act 2003* and the forthcoming *Better Outcomes for Older People: Framework for Joint Services for Older People*^v.

The Group’s advice and recommendations are as follows:

- 1 Planning for dementia services should be an integral part of joint planning for older people’s mental health services, with specific arrangements for joint commissioning, integration and joint management of these services to improve outcomes. The different and special needs of younger people with dementia should be addressed within these joint plans.**
- 2 The Scottish Executive should enhance its support for awareness raising programmes for dementia as part of the National Programme for Improving Mental Health and Wellbeing and the work of NHS Health Scotland. It should also encourage a wider range of channels of communication.**
- 3 Local NHS and local authority service planners and commissioners should address and remove any negative attitudes and perceptions of dementia in the planning, development and delivery of services.**
- 4 Training programmes for doctors, nurses, social workers, care home staff, other professionals and people who have contact with those with dementia and their carers should be reviewed for currency and relevancy. Training materials should be widely distributed and all materials should be kept under regular review.**
- 5 As a first step towards the development of clinical standards for dementia, all local partners should combine to develop integrated care pathways for people with dementia that reflect the multiple entry points to the assessment and care systems. These pathways should take account of the particular needs of people under 65. They should be subject to ongoing audit.**
- 6 Community Health Partnerships should use every opportunity to encourage clinicians and other professionals to develop innovative and alternative models for diagnosis early in the illness, using the full range of practitioner skills and experience.**

- 7 There should be a national standard for information about dementia and services. NHS and care partners should give people with dementia and their families appropriate general and local information at the time of diagnosis.**
- 8 At the time of diagnosis, support should be available to assist each person and their family with forward planning, and to establish continuing support which can give early warning of increased need.**
- 9 The Template for Dementia Services (attached to this report) offers NHS Boards and local authorities a planning and audit tool that will help them to identify the needs of local users and carers and design services that meet those needs. The Template should be used alongside the Health Department Letter (2004) 37, to inform the development of Community Health Partnerships.**
- 10 The Public Partnership Forums attached to Community Health Partnerships should ensure that people with dementia and their families are involved in discussions on the organisation and further development of local dementia services.**
- 11 NHS Boards and local authorities should review local data collection on services for people with dementia and their carers, both to inform local, regional and national approaches to the organisation of dementia care and to inform the range of accountability, audit and review processes.**
- 12 NHS Quality Improvement Scotland should consider care standards for all hospital and other services for people with dementia. This could include ‘critical care triggers’ that influence the quality of services.**

1 Introduction

Dementia is the name given to a number of illnesses characterised by the progressive loss of mental functions and the ability to look after oneself. The most common forms are Alzheimer's disease, vascular dementias and Lewy body dementia. Dementia has an increasingly profound impact on the life of the person with the illness and their family members as the person with dementia becomes increasingly dependent.

There are around 62,000 people in Scotland with dementia and the number will steadily increase for the foreseeable future in line with the aging population. Dementia occurs most frequently in older groups with prevalence rates rising from around 2.2% of men and 1.1% of women aged 65-69, to 31.6% of men and 36% of women aged 95-99. Dementia can also occur in younger people: there are approximately 1,600 people with dementia in Scotland under the age of 65.

The financial impact of dementia on personal and public finances is significant. The direct costs of Alzheimer's disease in the UK^{vi} in 2001 were estimated to be between £7.06 billion and £14.93 billion, which was substantially greater than stroke (£3.2 billion), heart disease (£4.05 billion) and cancer (£1.6 billion excluding informal care costs).

2 What should good dementia services look like?

2.1 Template for services

A Template for Dementia Services from pre-diagnosis through to continuing care has been developed by the working group, based on the following principles and service outcomes, the recommendations of *Planning Signposts for Dementia Care Services*^{vii} and the *Needs Assessment Report*^{viii}. The template provides descriptions of needs, ways in which services may be provided, critical factors to be considered by planners and outcomes for the following essential groups of services:

- pre-diagnosis
- diagnosis
- post-diagnosis support
- community services
- continuing care
- co-ordination and care management.

2.2 Principles of good services

The *Needs Assessment Report*^{ix} identifies the principles of good services:

- care should be based on a continuing good knowledge of the individual
- people with dementia should be trained, informed, and empowered

- family and informal 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 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.

2.3 Principles of intervention

Services must also be based on the intervention principles outlined in the Adults with Incapacity (Scotland) Act 2000 which states that decisions made on behalf of an adult with incapacity 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
- encourage the adult to use existing skills or develop new skills.

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

2.4 Service outcomes

For best outcomes, services need to reflect the progressive nature of the illness, the increasing dependency of people with dementia and the demand generated by the number of people with dementia. Services also need to be flexible and capable of offering choice to users; for example, people with dementia and their carers should be able to choose the type of short break/respite care^{**} which best meets the needs of both.

Services should be designed to help the person with dementia:

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

For carers, services should:

- enable them to continue caring for the person with dementia in their own home for as long as practical
- support the maintenance of a caring relationship between them and the person with dementia
- help them to feel fulfilled and satisfied in their caring role.

3 All is not well with dementia

There is no doubt that services for people with dementia have got better in recent years. The number of old age psychiatrists has nearly doubled in the last 10 years; and the number of specialist community psychiatric nurses for older people has also increased. Local authorities increasingly recognise the need to either provide dementia services or commission the voluntary sector to provide them. The problem of the “postcode prescribing” of the cholinesterase inhibitor drug treatments for people in the early to moderate stages of Alzheimer’s disease^x has largely been addressed. However, there is also evidence that there is a need for more and faster introduction of improvements.

Recently the Mental Welfare Commission for Scotland^{xi} highlighted the case of Mr C who had dementia and was blind. Mr C was a patient in a continuing care ward and had to wait for over two years before he was admitted to a nursing home. “For most of his stay in hospital, he had no regular occupational therapy or activities. He therefore spent his days walking up and down the ward corridors.” While not necessarily typical, Mr C’s case illustrates the poor quality of life that can be experienced by those with dementia on continuing care wards and highlights also how delayed discharge can be detrimental in some cases.

^{**} 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.

The absence of post-diagnosis support services for people with dementia, other than the prescribing of drug treatments to some, does not best reflect good practice in community based care, which should help prevent or at the very least delay admission to long stay or continuing care.

Better data sets and collection, with more dementia-specific information, would inform what and where services are being provided and to how many. This in turn would inform planning decisions. Statistics included in a recent publication, *Short Break Services for People with Dementia and their Carers in Scotland*^{xii}, show that the majority of people with dementia in the community are not receiving the full range of services they need. The average percentage of people with dementia living in the community who received local authority arranged overnight short breaks was 12%; 7% received day care; 10% received home care and 4% received day patient hospital care. Unfortunately, it is not known how many people with dementia received more than one of these services. If Isaac and Neville's^{xiii} intervals of need model is applied to the number of people with dementia living in the community, approximately 69% are in need of regular or constant care and supervision and might be expected to need these services. The failure to offer many people with dementia intensive support in their homes^{xiv xv} may be one of the reasons that the balance between long term care in hospital or care homes and care in the community does not appear to have changed.

People with dementia can only begin to receive the full range of services they require when they need them if they are offered and/or present for an early diagnosis of the illness. Although the Audit Commission only collected data in England and Wales, lessons may be learned from their *Forget me Not* report^{xvi}. They found that for GPs:

- two-thirds were reluctant to diagnose dementia early
- the majority did not use protocols to help diagnose dementia or depression
- fewer than half of GPs used specific tests or protocols to detect dementia
- less than half felt they had received sufficient training on dementia
- fewer than two-thirds felt they had ready access to specialist advice.

4 Potential Obstacles

The Short Life Working Group produced a list of obstacles to the development and improvement of services for people with dementia and their carers. These clustered into eight groups:

- the illness
- attitudes – public, professional/front line staff
- information
- the extent to which services should be generic or dementia specific
- planning, commissioning and delivery
- the priority given to dementia in comparison with other health and community services
- funding

- training.

A questionnaire was created which asked the following questions for each obstacle:

- is this an obstacle?
- if it is an obstacle, is it significant or serious?
- are there examples of what has already been done to deal with this obstacle?
- what more could be done and how?

The questionnaire was circulated to a range of professional organisations and a number of carers' groups; members of a number of organisations made presentations to the Short Life Working Group and meetings were held with three organisations (see Appendix B).

The detailed analysis of the completed questionnaires is attached at Appendix C.

The critical obstacles to improving services were identified as follows:

- i) the lack of effective, integrated planning and service delivery;
- ii) negative attitudes to dementia;
- iii) problems in getting diagnosed and getting 'into the system';
- iv) dealing with complexity of needs, the lack of adequate data about needs, levels of service provision, and the requirement to think creatively beyond what is currently available.

Interestingly, these obstacles are similar to those that have been reported from a recently completed European Union funded programme (See Appendix D).

5 Overcoming the critical obstacles

5.1 Where does dementia fit into service planning and delivery?

There is a need to identify a responsible lead agency within partnerships to ensure that dementia services which cross health and social care boundaries are planned and delivered jointly and effectively. However, it is also important to recognise that because no single service or agency will become responsible for all dementia services, there will have to be delegated responsibilities within all service-providing agencies. For many parts of Scotland it is not clear which agency or planning group has lead responsibility and this can lead to dementia being given a lower level of priority than it deserves.

Four broad options (see appendix E) for overcoming this obstacle were considered by the working group:

- i) let the decision be made by NHS Boards and local authorities, but insist that there should be a clearly designated lead agency for planning, commissioning and co-ordination;

- ii) require NHS Boards and local authorities to produce specific dementia plans jointly in addition to their other plans and have specified arrangements for commissioning and co-ordinating services;
- iii) require NHS Boards and local authorities to produce generic older people's plans covering the special needs of those with dementia as a sub group;
- iv) require NHS Boards and local authorities to include dementia explicitly in joint older people's mental health plans: these plans should be cross referenced to plans for older people and adult mental health.

Recommendation

1 Planning for dementia services should be an integral part of joint planning for older people's mental health services, with specific arrangements for joint commissioning, integration and joint management of these services to improve outcomes. The different and special needs of younger people with dementia should be addressed within these joint plans.

5.2 Negative attitudes to dementia

Negative attitudes to dementia were identified as being a serious obstacle because they:

- are among the reasons why people with symptoms of possible dementia fail to seek an early diagnosis and help
- explain, in part, why friends and neighbours often find it difficult to maintain contact with the person with dementia
- have held back the development of services which are seen as 'merely palliative'.

Surveys^{xvii} carried out by Alzheimer Scotland have shown that a significant minority of the population still believes that dementia is a natural consequence of old age and more worryingly that people with dementia are 'figures of fun'.

For the last two years the Scottish Executive has assisted Alzheimer Scotland to expand its awareness raising programme with funding from the National Programme for Mental Health and Wellbeing. The working group welcomed this development. It would like it to continue, be given similar emphasis to adult mental health, and evolve to include a wider range of channels of communication; for example, through networks outwith the mental health field. However, the working group believes that this activity alone will not be enough to change deeply embedded negative attitudes.

The working group would like to see dementia more effectively covered in the training of the professions who work with people with dementia; for example, GPs and social workers.

Recommendations

- 2 The Scottish Executive should enhance its support for awareness raising programmes for dementia as part of the National Programme for Improving Mental Health and Wellbeing and the work of NHS Health Scotland. It should also encourage a wider range of channels of communication.**
- 3 Local NHS and local authority service planners and commissioners should address and remove any negative attitudes and perceptions of dementia in the planning, development and delivery of services.**
- 4 Training programmes for doctors, nurses, social workers, care home staff, other professionals and people who have contact with those with dementia and their carers should be reviewed for currency and relevancy. Training materials should be widely distributed and all materials should be kept under regular review.**

5.3 Getting into the “system”

The working group identified two sets of obstacles to people with dementia early in the illness - getting a diagnosis and getting appropriate services subsequent to diagnosis.

Firstly, receiving a diagnosis depends on the person with dementia and/or a member of their family recognising that there is something wrong and going to see a doctor: they will be less likely to do this if they think their symptoms are an inevitable consequence of aging or if they think there is nothing that can be done. This is why there needs to be improved understanding that dementia is an illness and that there are treatments, services and other actions that can help throughout the illness, even though there is as yet no cure.

Secondly, for a range of reasons, some GPs may be reluctant to diagnose dementia, give the diagnosis to the person with dementia, or refer them to secondary health services.

The introduction of the cholinesterase inhibitor drug treatments for Alzheimer’s disease strengthened the case for early diagnosis because the benefits are greatest in the earlier stages of the illness.

Even without the treatments there are important arguments for early diagnosis with regard to forward planning, including making a will, powers of attorney, advance statements, care planning, driving and maintaining social involvement and activities.

There should be clearly understood procedures set out in a locally agreed Care Pathway with multiple entry points, which can be followed when someone is suspected as having dementia, designed to make best use of available staff and financial resources. Regard should also be taken of the Health Technology Board for Scotland’s guidelines on Alzheimer’s disease drug treatments^{xviii}. The separate and distinct needs of younger people diagnosed with dementia should be recognised and not simply merged with services and arrangements more applicable to older people.

After diagnosis, some people with dementia may remain in touch with medical services because they have been prescribed one of the Alzheimer's disease drug treatments or because they have other medical needs. However, most will not. This is because in most parts of Scotland there are no post-diagnosis support services and these people will not yet need community services such as day care or short breaks/respite care. This is a care and support 'vacuum' in which people with dementia and their families usually have to find their own way without support until needs mount or a crisis occurs.

Recommendations

5 As a first step towards the development of clinical standards for dementia, all local partners should combine to develop integrated care pathways for people with dementia that reflect the multiple entry points to the assessment and care systems. These pathways should take account of the particular needs of people under 65. They should be subject to ongoing audit.

6 Community Health Partnerships should use every opportunity to encourage clinicians and other professionals to develop innovative and alternative models for diagnosis early in the illness, using the full range of practitioner skills and experience.

7 There should be a national standard for information about dementia and services. NHS and care partners should give people with dementia and their families appropriate general and local information at the time of diagnosis.

8 At the time of diagnosis, support should be available to assist each person and their family with forward planning, and to establish continuing support which can give early warning of increased need.

5.4 Complexity of the illness/multiplicity of needs

Dementia is a set of illnesses within which there are significant diversities. Life expectancy after diagnosis is on average 5 to 6 years; however, some people live for 10 to 15 years. Needs not only cross over the health and social care divide and involve housing, recreational and transport issues, but also extend to legal arrangements to protect the rights of people with dementia with diminished capacity on a variety of matters.

In addition, people with dementia have varying needs as they pass through the increasingly dependent stages of the illness, and their needs are modified by the type of illness, the age of the patient, and a range of physical, psychological and social factors.

The working group noted that people with dementia who enter general hospital and other generic services have particular needs arising from their dementia which require attention.

The Template for Dementia Services is intended to give planners practical guidance on how they should respond to the complexity of the illness and the multiplicity of needs that people with dementia and their carers have.

The lack of adequate data quantifying the diverse needs of people with dementia and their families and relating it to current service provision not only makes it difficult to plan ahead, but also inhibits the development of specialist services because it may be assumed that generic services will meet those needs.

Additionally, there is a tendency to think that new services should simply provide more of what is currently available rather than respond to what is needed. The planning and organisation of dementia services should always be “needs” based and determined by regular review. This points to the importance of thinking critically about existing services and being prepared to redesign where this can be shown to better meet the needs of people with dementia and their families.

The Scottish Commission for the Regulation of Care is important in informing local service improvement priorities and should continue to carry out practice management reviews to assess how well services are meeting the needs of people with dementia.

The working group considered a range of options which could assist NHS Boards, local authorities, the voluntary sector and other providers to take the next steps to improving their services for people with dementia.

Recommendations

9 The Template for Dementia Services (attached to this report) offers NHS Boards and local authorities a planning and audit tool that will help them to identify the needs of local users and carers and design services that meet those needs. The Template should be used alongside the Health Department Letter (2004) 37, to inform the development of Community Health Partnerships.

10 The Public Partnership Forums attached to Community Health Partnerships should ensure that people with dementia and their families are involved in discussions on the organisation and further development of local dementia services.

11 NHS Boards and local authorities should review local data collection on services for people with dementia and their carers, both to inform local, regional and national approaches to the organisation of dementia care and to inform the range of accountability, audit and review processes.

12 NHS Quality Improvement Scotland should consider care standards for all hospital and other services for people with dementia. This could include ‘critical care triggers’ that influence the quality of services.

6 Conclusions

As the number of people with dementia increases it becomes even more important to ensure that there are sufficient services of good quality available to meet their assessed needs. The working group believe that the recommendations made in this report will, if implemented, lead to the needs of people with dementia and their families in Scotland being given the recognition they deserve and to better designed services to meet those needs.

Current opportunities such as the development of Community Health Partnerships, the progress of the Joint Future agenda and responses to the 2004 National Mental Health Services Assessment Project provide opportunities for many of this report's recommendations to be implemented. We believe that our recommendations are in harmony with these opportunities and that consequently they are timely, desirable and workable.

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Appendix A

Members of the Scottish Executive and Alzheimer Scotland Short Life Working Group

Alan Jacques (chair)	Convener, Alzheimer Scotland
James Barbour	Chief Executive, Lothian NHS Board
Kathleen Bessos	Scottish Executive Primary Care Division
Sylvia Cox	Planning Consultant, Dementia Services Development Centre
Colm Cunningham	City of Edinburgh Council until 16 July 2004. Senior Fieldworker, Dementia Services Development Centre from 19 July 2004
Anne Hawkins	Chief Executive, Forth Valley Primary Care NHS Trust
Jim Jackson	Chief Executive, Alzheimer Scotland
Theresa James	Highland Council
Sheila Logan	Carer representative
Tim Montgomery	Scottish Executive, Joint Future Group
Ian Pullen	Scottish Executive, Psychiatric Advisor
Liz Taylor/Linda Reid	Scottish Executive, Social Work Services Inspectorate
Alison Thomson	Nursing Officer, Mental Welfare Commission

Appendix B: Consultations

Meetings held with organisations

Association of Directors of Social Work (Community Care Committee)

Care Commission

Scottish Dementia Working Group

Presentations made to the Short Life Working Group

British Association of Social Workers

Royal College of General Practitioners

Royal College of Psychiatrists

Scottish Federation of Housing Associations/Hanover Housing Association

Social Work Services Inspectorate (Susan Buckle on the use of equipment and adaptations)

West Lothian Council (use of SMART technology)

Other organisations who responded to the questionnaire

Aberdeen Carers Panel – Alzheimer Scotland

Alyth and District Carers Group, Alzheimer Scotland

British Association of Social Workers

College of Occupational Therapy

Glasgow Carers Panel – Alzheimer Scotland

Mental Welfare Commission

NHS Quality Improvement Scotland

Royal College of General Practitioners

Royal College of Nursing

Royal College of Psychiatrists

Scottish Federation of Housing Associations

West Lothian Council

Appendix C: Analysis of completed questionnaires

More than 50% of respondents classified the following as significant or serious obstacles:

- complexity of the illness (stages, types, multiple problems, different ages and social groups)
- negative attitudes to dementia
- getting into the system
- uncertainty or disagreement about where dementia should be dealt with in planning and service delivery.

40-49% classified the following as significant or serious obstacles:

- competition with other priority groups
- lack of help at early stages
- lack of help at the later stages and after
- people are grateful for what they get and therefore do not ask for more
- information not available to the public
- the gap between what's available and what's needed
- over emphasis on process v provision for real needs
- short term funding for new projects.

20-39% classified the following as significant or serious obstacles:

- sub-groups of people with dementia having different needs (eg younger – older, Lewy body dementia, ethnic groups)
- ageism – public
- ageism – professional
- lack of attractiveness of the subject
- insufficient development of risk assessment
- dementia-friendliness (or unfriendliness) of services and communities
- demographic changes
- insufficient data on needs and service use
- inadequate access to information
- information – professional
- unmet needs
- not asking for what you don't know about
- generic v specialist services
- uncertain responsibilities

- coherence in initiatives
- workforce planning
- poor involvement of users and carers
- competing priorities
- lack of a ‘scandal’
- insufficient funding
- flexibility of funding
- very few intensive care packages
- perverse incentives
- training of staff.

Less than 19% classified the following as significant or serious obstacles:

- differing philosophies of care
- labelling by diagnosis
- uncertain or conflicting professional roles
- structure – level of responsibility for dementia
- undeveloped advocacy services
- flavour of the month
- inadequate training for commissioners.

Appendix D DIADEM – Timely DIAGnosis and management of DEMentia in primary care across Europe

Experts from eight European countries (Belgium, France, The Netherlands, Ireland, Italy, Portugal, Spain and the United Kingdom) met in 2003 to explore recognition of dementia and response to dementia in general practice. Focus groups were used to identify issues and common themes.

The conclusions were:

- change is the core issue in dementia care
- multiple pathways of change need to be understood at clinical and organisational levels
- practitioners and people with dementia are engaged in managing emotional, social and physical risks
- boundary between generalist and specialist services is a particular problem
- specialised dementia health care services are necessary but not sufficient to ensure timely recognition of dementia
- stigma is an important cultural determinant in timely recognition
- European dementia guidelines should use specific national facilitators to target identified obstacles
- timely diagnosis more relevant than early diagnosis
- stigma-reducing intervention at three levels – the person, the family carer and society – is a priority for future research.

Source: Book of Abstracts
14th Conference Alzheimer Europe
Prague, 20-23 April 2004

Appendix E Advantages and disadvantages of options for lead responsibility

Lead responsibility	Advantages	Disadvantages
NHS Board/local authority choice	Respects local decision making	No guarantee that this will lead to improvement; lack of consistency makes it difficult to compare different parts of Scotland and bench mark similar areas
Joint dementia plans	Gives dementia a distinct and unique identity; puts younger people with dementia on an equal footing with older people with dementia	Could fragment services, eg old age psychiatry; although there are 62,000 people with dementia in Scotland, is this enough to justify distinct planning arrangements?
Generic older people's plan	Encourages inclusive thinking	Needs of people with dementia may swamp those of others or vice versa. Younger people with dementia potentially sidelines
Joint older people's mental health plans	Avoids fragmentation of old age psychiatry; complements current developments in adult mental health services; sufficient critical mass to justify a distinct planning identity; may also assist neglected other mental illnesses that affect older people, eg depression, anxiety disorders	Special arrangements will need to be made for younger people with dementia where not already included in the old age psychiatry service

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**Scottish Executive and Alzheimer Scotland
Short Life Working Group**

Template for Dementia Services

November 2004

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 Servicesⁱ; Adding Life to Yearsⁱⁱ; Our National Healthⁱⁱⁱ; Partnership for Care^{iv}; Reinvigorating the Joint Future Agenda^v; Needs Assessment Report^{vi}; and National Mental Health Services Assessment^{vii}.

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)^{viii} and Harvey (1998)^{ix} 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)^x 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)^{xi} 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^{xii} and adapted by Melzer^{xiii} for application to people with dementia. This has been used in the template alongside the EURODEM and Harvey prevalence figures.

Interval of need for people with dementia	% of people with dementia
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.

* 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*^{xiv}. 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^{xv}. 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.

Critical factors to be considered	Ways in which service may respond	Outcomes	Local Action
<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

Critical factors to be considered	Ways in which services may respond	Outcomes	Local Action
<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 incidence 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

Critical factors to be considered	Ways in which service may respond	Outcomes	Local Action
<p>Through ongoing assessment of needs</p> <ul style="list-style-type: none"> • 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. • This should take into account that some may require these services for only a short time before they need more intensive care arrangements. • Local protocols that link diagnosis, community services and care management, allowing for multiple entry points. 	<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.

Critical factors to be considered	Ways in which service may respond	Outcomes	Local Action
<p>Local and regional assessment of numbers and needs.</p> <ul style="list-style-type: none"> • 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 • the estimated number of people with dementia living alone is 13% of people with dementia in an area • 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. <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.

Critical factors to be considered	Ways in which service may respond	Outcomes	Local Action
<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. 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

Critical factors to be considered	Ways in which joint services may respond	Outcomes	Local Action
<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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- ^{xiii} 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 - 1st Series*, 2nd edition, Abingdon: Radcliffe Medical Press Ltd
- ^{xiv} Op cit
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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.

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.