



The Scottish  
Government

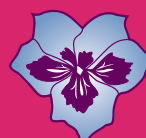
# Facing Dementia Together: Initial Report of the Lothian Dementia Project



April 2009



UNIVERSITY OF  
**STIRLING**



The Dementia Services  
Development Centre



**Alzheimer Scotland**  
*Action on Dementia*

# Introduction

The Scottish Government has funded the Dementia Services Development Centre (DSDC) at the University of Stirling to run a programme in Lothian until March 2011 to develop measures that can improve the care and support provided to people with dementia after diagnosis. It follows a similar project carried out by the DSDC in the Forth Valley area that produced positive service changes and increased the knowledge, confidence and skills of staff working across the many agencies and businesses involved in dementia care.

The programme is based on determining the policy imperatives that already exist in relation to the needs of people with dementia; identifying what services are currently available; identifying what is working well and what needs to be different, thus developing ways of improving the care provided to those with dementia. It aims to engage with all agencies and groups that are involved in planning and delivering care and support from local authorities and the NHS through to police and community leaders such as faith leaders and voluntary groups and many others.

One of the key strengths of the improvement model being used is that it asks those employed in existing services what needs to change in order to make them best able to do their work well. It is based on the sound principle that if staff know what they are meant to be doing, they can tell you what is getting in the way of that. The DSDC provides support to help make change happen. To that end, a one day convention was held in March to bring together a wide range of people working in dementia care who were asked to identify priorities for action and consider potential solutions that will improve dementia services for people who have been diagnosed with this problem. The focus of the meeting was on workshop sessions to gather as many ideas as possible on the best way forward.

Those who took part were from health, social services and the independent sector. The staff groupings included psychiatrists of old age, physicians of old age, acute general hospital staff, community and hospital psychiatric nurses, managers, social workers, social work staff including home care workers and day care workers, allied health professionals – too many to list here, but the membership can be provided on request. In addition, the draft report was circulated to hundreds of people for review in a relatively short time. This is the conclusion of that process, but even when this is printed and circulated, new ideas will be welcomed and will be included.

An action plan is being developed based on the findings of the convention. A proposal will be circulated among service providers who will be supported to take leadership for the actions outlined and evaluate their impact. They will be supported in this by the DSDC. A website has already been developed ([www.dementia.stir.ac.uk](http://www.dementia.stir.ac.uk) – click on Special Projects, then select Lothian Project) to provide on-going information and support for the project over the next two years. The ranking of the change ideas will be confirmed at a good practice conference which is planned for June 2009.

This report captures the ideas that emerged from the convention workshops. There were hundreds of suggestions of potential improvements that could be made, all of which are listed in the report. It is unhelpful, however, to list everything that was said verbatim so the ideas have been summarised and edited to avoid repetition and duplication. There were strong areas of agreement across the 10 separate workshop groups.

There are already many examples of good practice in Lothian, some of which are explained briefly later in the report. It is also clear that staff in Lothian are working extremely hard to deliver high quality care and support. However, they know that further improvements can be made. There was evident enthusiasm at the convention for change, demonstrated by the many positive ideas that were generated. It is a solid foundation on which to build.

# Chapter 1. Incidence and forecasts

The number of older people in Scotland is rising and, with that will come a higher incidence of dementia. It is estimated that the number of people with dementia in Scotland will increase by 75% over the next 25 years. Currently there are estimated to be between 58,000-65,000 people with dementia in Scotland and that total is expected to rise to 102,000-114,000 by 2031.

This level of increase will pose huge challenges for health and social care services which has led the Scottish Government to make tackling dementia a national priority.

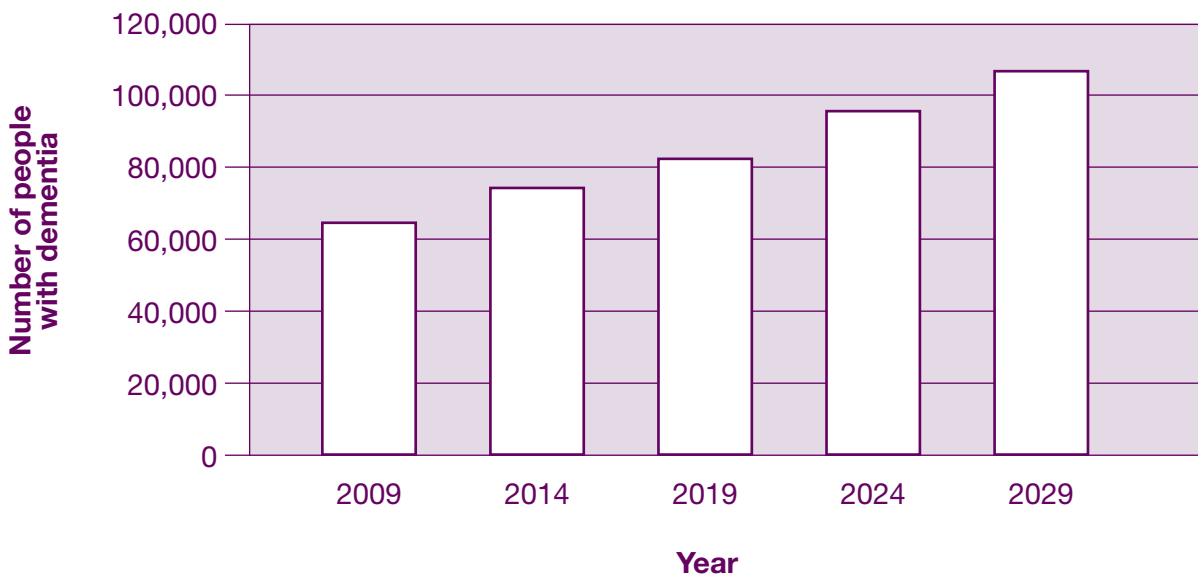
The first step in preparing services to meet this challenge is to understand the situation, both locally and nationally.

## Dementia in Scotland

**Fig 1. Projected estimates for number of people with dementia in Scotland**

Year	Scottish population	Number with dementia
2009	5,117,000	65,758
2014	5,124,000	73,431
2019	5,128,000	83,151
2024	5,119,000	94,664
2029	5,086,000	108,206

**Graph 1. Projected estimates for number of people with dementia in Scotland (2009–2029)**



Figures taken from [www.alzscot.org.uk](http://www.alzscot.org.uk)

Most people with dementia continue to live in the community. It is estimated that around 60% of people with dementia live at home, often supported by a range of community and health care services. Around 70% of people with dementia living in the community live with their carer. Research shows that most carers are the spouse or daughter of the person with dementia. The remaining 40% are in institutional (long stay) care.

A comparison of NHS Board areas shows slightly higher rates of dementia in the Borders and Dumfries and Galloway than in Fife, Lothian and Forth Valley.

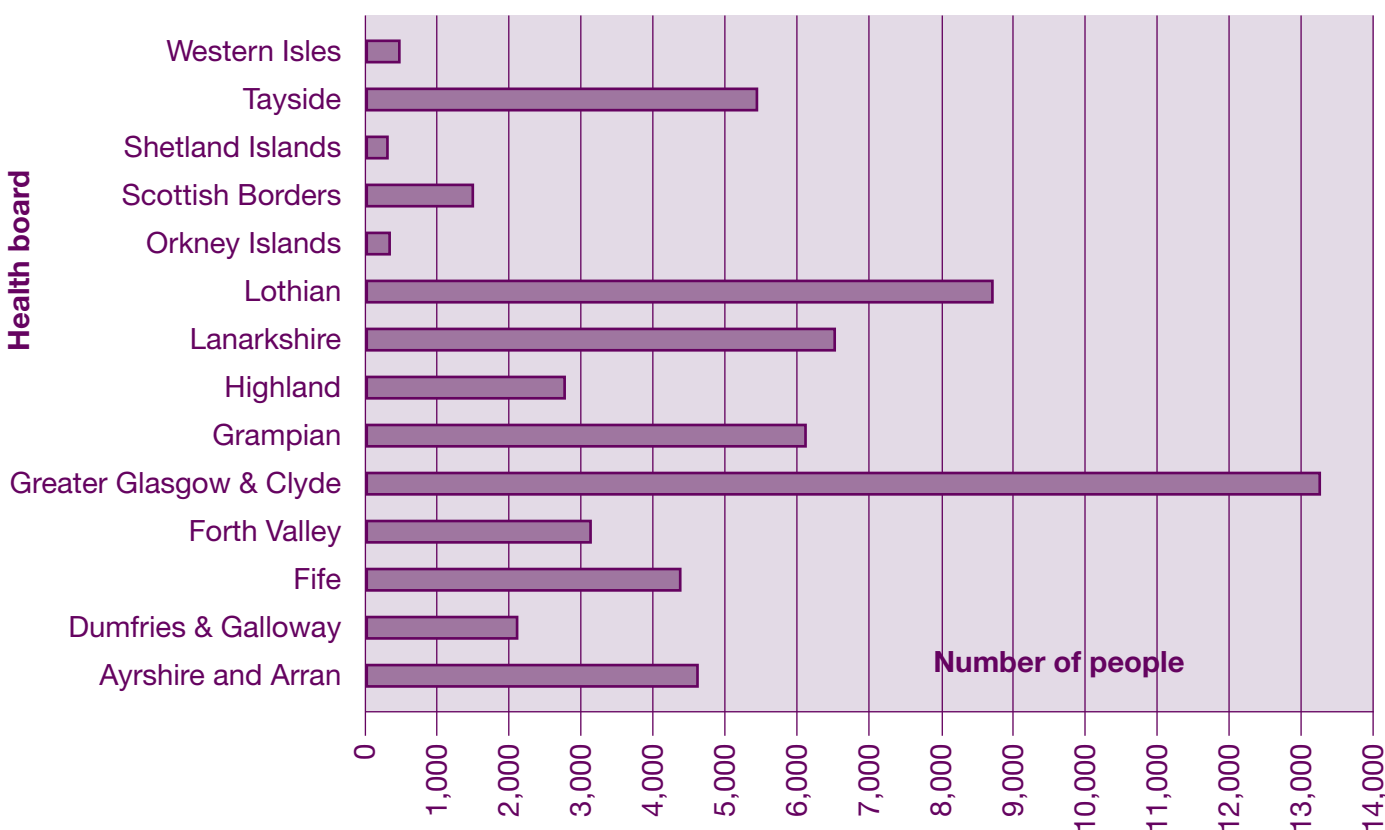
**Fig 2. Estimated number of people with dementia in 2009 by NHS Board**

(Figures taken from [www.alzscot.org.uk](http://www.alzscot.org.uk))

Health Board	No of People
Ayrshire and Arran	4,635
Dumfries & Galloway	2,165
Fife	4,428
Forth Valley	3,146
Greater Glasgow & Clyde	13,316
Grampian	6,173
Highland	2,811
Lanarkshire	6,569
Lothian	8,686
Orkney Islands	264
Scottish Borders	1,501
Shetland Islands	264
Tayside	5,430
Western Isles	398

**Graph 2. Estimated number of people with dementia in Scotland in 2009**

(Figures taken from [www.alzscot.org.uk](http://www.alzscot.org.uk))



# Dementia in Lothian

**Fig 3. Estimated number of people with dementia in Lothian in 2007**

	Under 65	Over 65	Total
<b>Edinburgh</b>	106–143	4,953–5,504	5,059–5,647
<b>East Lothian</b>	25–31	1,129–1,262	1,154–1,292
<b>Midlothian</b>	22–26	836–940	858–966
<b>West Lothian</b>	43–56	1,380–1,559	1,423–1,615
<b>Lothian</b>	197–256	8,298–9,265	8,495–9,521

**Fig 4. Projected number of people with dementia in Lothian in 2024**

	Under 65	Over 65	Total	Increase
<b>Edinburgh</b>	125–161	6,494–7,355	6,619–7,515	31%
<b>East Lothian</b>	30–31	1,689–1,918	1,718–1,949	49%
<b>Midlothian</b>	22–23	1,278–1,428	1,300–1,452	51%
<b>West Lothian</b>	56–63	2,600–2,995	2,656–3,058	87%
<b>Lothian</b>	232–278	12,276–13,696	12,508–13,974	47%

**Graph 3. Number of people with dementia in 2007 and projected estimates in 2024 in Lothian areas**



**Graph 4. Projected increase of people with dementia in Lothian in 2024**



Figures supplied by NHS Lothian

This table and graphs show that the number of people with dementia is expected to increase by just under half in Lothian over the next 15 years. The greatest impact is expected to be in West Lothian which faces an 87% increase – almost three times the rate that is expected in Edinburgh city.

## Progress against targets in Lothian

The Scottish Government has set targets for improving dementia care. These include improving the early diagnosis and management of patients, reducing the proportion of older people admitted to hospital as emergency in-patients and providing more care at home for older people with complex care needs.

Early identification of dementia is important in helping with treatment, supporting carers, providing information and overall patient management. Compiling registers of dementia patients is a key tool in care management. Progress is being made in Lothian in both these areas.

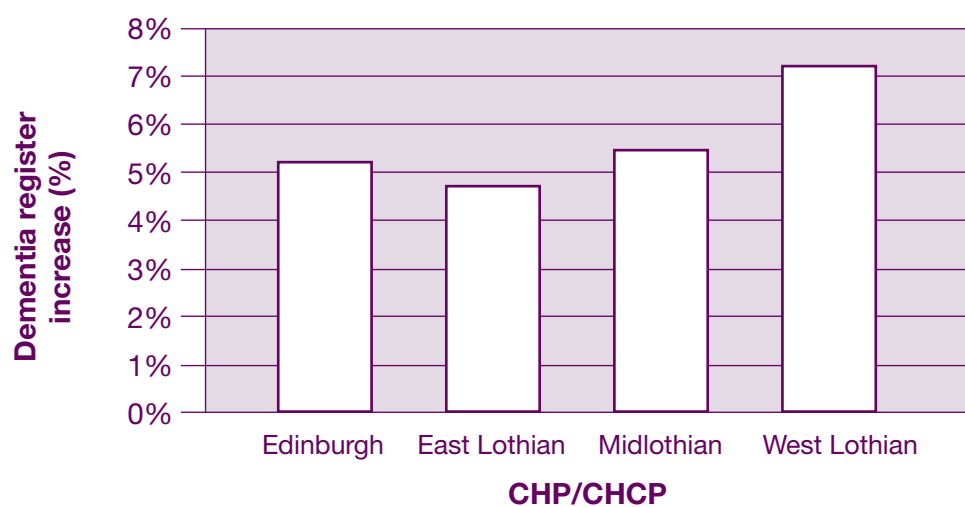
**Fig 5. Improvements in early diagnosis and management**

	Mar 07 Baseline	Mar 08 Target	Mar 08 Actual	Improvement over target
<b>Edinburgh CHP</b>	2,761	2,844	2,907	63
<b>East Lothian CHP</b>	806	830	844	14
<b>Midlothian CHP</b>	490	505	517	12
<b>West Lothian CHCP</b>	736	758	791	33
<b>Total</b>	<b>4,793</b>	<b>4,937</b>	<b>5,059</b>	<b>122</b>

Fig 6. Number of patients on dementia register

CHP/CHCP	Estimated no. of people with dementia	No. patients on dementia register 2007	No. patients on dementia register 2008	Dementia register increase 2007–08	Proportion of people on register
Edinburgh CHP	5,208	2,761	2,907	5.29%	56%
East Lothian CHP	1,118	806	844	4.71%	71%
Midlothian CHP	846	490	517	5.51%	61%
West Lothian CHCP	1,305	736	791	7.47%	61%
<b>Total</b>	<b>8,547</b>	<b>4,793</b>	<b>5,059</b>	<b>5.55%</b>	<b>59%</b>

Graph 6. Dementia register increase 2007–08



## Chapter 2. Good Practice in Lothian

There are many high quality services provided in Lothian and across the rest of Scotland that make a real difference to the lives of people with dementia and their carers. These include day care services; home support; information and advice; and supported breaks. Learning from what works and adopting good practice is central to improving services for people with dementia.

The following 10 examples describe how innovative approaches or service improvements can help deliver higher standards of care. These are far from being the only examples of good practice in Lothian but they help to highlight a range of approaches that have proved successful. We would welcome information on other initiatives taking place in Lothian. Details should be submitted to [dementia@stir.ac.uk](mailto:dementia@stir.ac.uk) and they will be placed on the website at [www.dementia.stir.ac.uk](http://www.dementia.stir.ac.uk) (special projects, Lothian Project).

### Newbyres Village

Newbyres Village is a purpose built care home in Gorebridge, Midlothian which has used a range of design features to promote a high quality of life for its elderly residents.

All the rooms are en-suite and have a door to the garden with a separate patio for each resident. There are memory boxes outside each room which residents can fill with personal treasures to remind them which is their room.

The building is filled with natural light and has five “streets” leading into the separate colour-coded wings. The streets are called First, Second, Third, Fourth and Fifth, taking the same names as streets in nearby Newtongrange where some residents previously lived.

Newbyres can accommodate up to 60 elderly people and is run by Midlothian Council. Advice was taken from a range of experts, including the Dementia Services Development Centre, in finalising the design. It is a shining example of how good design can promote a homely environment and prevent buildings having an institutionalised look and feel.

For further information contact Jane Fairnie, Resources Manager (Older People), 0131 271 3642, [jane.fairnie@midlothian.gov.uk](mailto:jane.fairnie@midlothian.gov.uk)

### The Corstorphine Dementia Project

A computer database system has been developed at the Corstorphine Dementia Project which gives staff access to important up-to-date information on all the project’s members.

The Project runs a day care centre and the system allows a wide variety of information to be recorded and retrieved by staff. This includes:

- family and care related details on members’ attendance record and the pattern of their visits
- personal information including what is important to the individuals concerned, details of their assessment, medication, on-going reviews
- transport arrangements for getting them to and from the centre and any risks that need to be accommodated

This is proving to be a valuable tool in helping to provide the best care for people with dementia who attend the centre and ensuring that their individual needs are met. It also provides an auditable record of everything the project carries out for the members.

For further information contact Eilidh Grant, Project Director, 0131 478 7784, [cordempro@aol.com](mailto:cordempro@aol.com)

## Compassionate Care initiative

The way in which care is delivered is extremely important in ensuring a good quality of life, particularly for older people. A three year initiative from NHS Lothian and Napier University aims to support staff to engage and build relationships with their patients in what is known as compassionate care.

Compassionate care is about valuing and developing relationships between patients, relatives and staff and focusing on the way in which care is delivered. The Leadership in Compassionate Care project is being funded by the Stagecoach co-founder and former nurse Ann Gloag. A lead nurse and four senior nurses have been appointed to lead the project in designated wards in the Lothians which will act as beacons of good practice. Indicators for compassionate care practice will be developed from the work with the Beacon wards and this will provide a way of promoting and identifying compassionate care practice across NHS Lothian and Napier University undergraduate nursing programmes.

The project will provide support and guidance for nursing staff to ensure they are able to incorporate compassionate care into everything they do. The lessons from the project will also be disseminated widely and incorporated into the curriculum of trainee nurses to ensure the benefits are spread as widely as possible.

For further information contact: Stephen Smith, 0131 455 5674, [ste.smith@napier.ac.uk](mailto:ste.smith@napier.ac.uk)

## Training for care home staff in managing behaviour

Dealing with difficult behaviour is a common part of dementia care. However not all care home staff understand the problem or are equipped to handle it well. Too often, this can result in over medication or referral on to other services.

A community psychiatric nurse led project in north west Edinburgh has countered this problem by offering support to care home staff in managing behaviour. It ran from August 2000 to September 2005 and, in that time, referrals from care home staff to GPs and consultant psychiatrists reduced by up to 80%. Care home staff worked directly with the community psychiatric nurse leading the project and felt more confident in managing the problems. As a result, people with dementia faced much less risk of being over medicated or unnecessarily admitted to hospital.

The project was based around educating staff about dementia and promoting an understanding of how behavioural problems can be one of the symptoms of the illness. Armed with this knowledge, staff have been empowered to use their own skills to take control of the problem. Care home interventions are offered by each city locality in Edinburgh but the hope is to provide a more uniform citywide approach by the Dementia Care Coordinators. This will promote and sustain management of behavioural difficulties within the homes and reduce reliance and pressure on other NHS services.

For further information contact: Niall Grant, 0131 536 9774, [niall.grant@nhslothian.scot.nhs.uk](mailto:niall.grant@nhslothian.scot.nhs.uk)

## East Lothian Information and Support Service

This service was established across East Lothian seven years ago to provide support to people who were newly diagnosed with dementia and their carers. It followed the development of memory clinics which were set up to offer an improved diagnostic service.

Every person diagnosed is supplied with an information pack which contains a wide variety of material including an explanation of what dementia is, practical information about benefits and a list of contacts for further help. In addition, an invitation is issued for people with dementia and their carers to take part in a five week education and support programme.

The five week programme is based on presentations from nursing staff, occupational and speech and language therapists and social work staff on different aspects of dementia. The voluntary group, Carers of East Lothian, which offers a wide range of support for carers, are also actively involved in the programme.

The sessions are made as informal as possible to encourage people to ask questions and to get as much out of the programme as possible. Although the feedback from those taking part is very positive, the number of people attending the sessions remains on the low side. The stigma surrounding dementia is thought to be one of the reasons for the low attendance and different ways of providing education and support are now being considered to try to reach more people.

For further information contact: Marion Small, 0131 536 8069, marion.small@nhslothian.scot.nhs.uk or Helen Wilson, 01620 823828, Helen.wilson@nhslothian.scot.nhs.uk

## Joint working across services

A number of advances have been made in recent years in Edinburgh which have led to greater co-ordination of care across different services. This is helping to speed up access to services and improve the care offered to people with dementia.

A system of joint assessment known as CARENAP has been introduced which is available electronically and allows health service and local authority staff to share, analyse and review information about clients. This is contributing to improved co-ordination of care. Similarly, the Dementia Education Group offers joint training programmes where people from different disciplines come together to share learning and experiences. The different perspectives they bring can help improve understanding of the different roles involved in providing care.

A central group has also been formed to streamline referrals to day care centres. This is made up of representatives from health, social care, the voluntary sector and day care providers. It reviews and prioritises all referrals for day care places and manages the waiting list. It replaces a system where individual staff would be responsible for finding a day care place for an individual client, resulting in several referrals being made to different centres.

None of this is very radical but it is making a big difference to the efficiency and effectiveness of service delivery.

For further information contact: Andrew Gillie, 0131 536 6270, andrew.gillie@nhslothian.scot.nhs.uk

## Post diagnosis care and support

People in Edinburgh with dementia and their carers can benefit from a range of support provided by the city's five dementia care co-ordinators. Although it includes a number of courses that are open to groups, the largest part of the service is offering one-to-one support to people with dementia, their carers or both. This lasts as long as the person receiving the service wants it to continue. A number of carers, for example, have continued to use the service after their loved one has died.

People are offered this option when they are first diagnosed but the service is available at any stage in the illness. The service takes referrals from families themselves and from all services including GPs, social workers and hospital consultants.

The group courses that are offered cover a number of topics. They include basic information on dementia and how best to manage the illness, along with legal advice and an introduction to services. Another course, run with the voluntary organisation Vocal, is designed to help people in the later stages of the illness. There is also a carers-only course that provides emotional support to cope with the loss involved in dementia.

For further information contact: Katrina Balmer, Dementia Care Co-ordinator, 0131 666 5174, katrina.balmer@nhslothian.scot.nhs.uk

## Tor nursing home

The presence of an in-house bistro at the Tor nursing home in Edinburgh marks it out as a home with a difference. That becomes even clearer on studying the packed social and leisure diary that lists the activities on offer every day for the 50 residents.

There are arts and crafts sessions, storytelling, life story work, nostalgia, memory and reminiscence sessions, discussions of new books, regular outings to places of interest and a variety of musically based activities. The accent is very much on meaningful activities with a broad appeal that are designed to provide something for everyone. In addition to the social and leisure programme, the home boasts a sensory garden and an aviary while residents can benefit from the services of a pet therapist.

Tor nursing home aims to provide the highest standard of person-centred care to achieve the best quality of life for its residents. That includes involving residents in how the home is run through monthly meetings between residents and staff and by conducting focus groups to determine what residents want. The home is committed to meeting the individual spiritual, physical, mental and emotional needs of each resident.

For further information contact: Cheryl Henderson, Nurse Manager, 0131 337 8199, [ch@tornursinghome.co.uk](mailto:ch@tornursinghome.co.uk)

## West Lothian Home Safety Service

The West Lothian Home Safety Service has been described as one of the most innovative schemes using smart technology to support the care of older people anywhere in the world. It has pioneered a new approach to service delivery which supports people to live securely and safely in their own homes.

The service was established in 2002 and, since then, West Lothian Council has installed smart technology in 12,000 homes including 3300 occupied by vulnerable or disabled older people. Four housing with care units have also been built with the same technology installed. Smart technology involves installing various alarms such as motion, flood, heat and smoke detectors in homes, linked remotely to a call centre. If an alarm is triggered, a response can be sent to check on the individual concerned. Special adaptations that support people with dementia include sensors that monitor if beds and chairs are occupied and outside doors are opened.

An evaluation of the project which reported in 2006 concluded that it had produced high quality care at low cost. One of the key benefits was that it helps people to live at home for as long as possible, maintaining control over their daily lives.

For further information contact Anne Sheriff, 01506 775623, [anne.sherriff@westlothian.gov.uk](mailto:anne.sherriff@westlothian.gov.uk)

## Co-working with GP practices

Ensuring people with dementia get an annual review is an important part of effective patient management. An electronic memory treatment database was created to help community mental health teams in Edinburgh organise this process. However, problems with the system meant that data was being lost, leading to some reviews being missed.

A new system is now being piloted in north west Edinburgh which involves close working with GP practices to produce accurate, timely information. Early results show it is proving to be successful in co-ordinating the process and ensuring that annual reviews are scheduled on time. It involves practice managers passing on care and treatment details along with annual review dates for older people in the area. These are then passed on to community psychiatric nurses who carry out the reviews and report back to the practice. The majority of practices are now using the new system and, if positive results continue to be reported, there is the potential to extend it across the city.

For further information contact: Neil McCafferty, 0131 537 5158, [neil.mccafferty@nhslothian.scot.nhs.uk](mailto:neil.mccafferty@nhslothian.scot.nhs.uk)

## Better care for people living and dying in care homes in Midlothian

All seven nursing care homes in Midlothian, in conjunction with the University of Edinburgh and the Marie Curie Hospice Edinburgh have been working to develop a comprehensive framework to address the end of life care needs of frail older people living and dying in their nursing care homes. Care home staff and local GPs have introduced a “Gold Standards Framework for Care Homes” which means that residents’ needs are being anticipated with appropriate attention to improved communication and control of symptoms. As a result unnecessary emergency admissions to hospital in the last 8 weeks of life have decreased by nearly 40% and there has been a 50% reduction in the number of frail older people being rushed in to hospital to die. Instead they are being cared for more peacefully by staff whom they know in their own nursing home. The project was sponsored by St Columba’s Hospice, The Robertson Trust, Macmillan Cancer Support, and the Marie Curie Hospice Edinburgh.

August 27th 2008 marked the official end of the 18-month project. Professor Elizabeth Ireland, who leads the Government’s new Palliative and End-of-life Care Initiative in Scotland, opened the evaluation event. Statistics documenting some remarkable improvements in care delivery were presented, supported by information from interviews with relatives whose loved ones had died during the project. Care home staff also gave their insights.

For further information contact:

Dr Jo. Hockley, Research Fellow/CNS (palliative care), University of Edinburgh, jo.hockley@ed.ac.uk  
Professor Scott A Murray, Professor of Primary Palliative Care, St Columba’s, scott.murray@ed.ac.uk  
Dr David Oxenham, Medical Director, Marie Curie Hospice Edinburgh, David.Oxenham@mariecurie.org.uk  
Professor Elizabeth Ireland, National Clinical Lead for Palliative and End of Life Care, Scottish Government; elizabeth.ireland@stir.ac.uk

# Chapter 3. The National Policy Context

According to the Alzheimer's Society, dementia costs in the UK are greater than stroke, heart disease and cancer put together (over £17 billion for the UK and £1.4 billion for Scotland in 2007).

The Scottish Government has responded to the challenge by making dementia a national priority. That has been followed by a series of actions designed to improve the care and treatment of those with the illness and their carers.

These measures include:

- improving early identification and support

For the first time, NHS Boards across Scotland have been set a target for delivering improvements in the early diagnosis and management of patients with a dementia. The Scottish Government is looking for a 33% improvement in this area by March 2011.

A Mental Health Collaborative has been established to support NHS Boards in delivering this and other mental health targets. A toolkit was published in December 2008 to help Boards analyse their dementia service and identify where improvements should be made.

- improving standards of care

An Integrated Care Pathway for dementia was published in December 2007. It sets the standard for care, underlines the need for partner system developments while incorporating an accreditation process and systems support.

The Scottish Government has also supported a dementia improvement project led by the Dementia Services Development Centre. This focused initially on Forth Valley and introduced improvements to services based on an analysis of where change was required.

- investing in post diagnosis support and information

Alzheimer Scotland and the Dementia Services Development Centre are leading a project to provide structured intervention, support, and information following first diagnosis. The Government is investing £600,000 over three years on pilots in Lothian, Shetland and East Renfrewshire and Renfrewshire. Work is also being carried out through the See Me campaign on the need for and design of a national awareness raising and information campaign on dementia. At the same time, the range of publications and information materials available for people with dementia, carers and staff is being expanded.

- establishing dementia registers and annual reviews

The latest figures indicate that almost all general practices now have a dementia register and significant numbers of those registered receive an annual review assessment.

Reviews are designed to address the support needs of the individual and carer. They should cover the physical and mental health needs for the patient; the carer's information needs and the impact of caring on the carer (if applicable); and communication and co-ordination arrangements with secondary care (if applicable).

- improving quality of life

The Scottish Government is providing £30,000 over three years to support the Elderflowers initiative which helps elderly people with dementia in hospital and other care settings. The programme engages and stimulates people with dementia to reach the person behind the illness. Funding is also being provided to the Befriending Network Scotland and Alzheimer Scotland to develop a national training pack to enable volunteer befrienders to understand dementia. The funding will help to develop a training toolkit and good practice guidelines.

- establishing a dementia research network

A Dementia Clinical Research Network has been established in Scotland to support clinicians and clinical academics in their research efforts. This is designed to improve understanding of dementia and advance the care of people with the condition.

- supporting staff

A Framework for Mental Health Nurses has been developed which outlines the knowledge, skills and values mental health nurses require to work with older people's mental health services. It is based on six main themes – respect, rights and choice; communication; relationships; health and wellbeing; dementia care; and end of life care.

- developing dementia-friendly premises

Information and guidance has been issued giving advice on how buildings can be designed to meet the needs of those with dementia. All NHS Scotland Boards now have a team of accredited auditors to advise on the suitability of existing and new NHS facilities for people with dementia. Fourteen pilot audits have already taken place to inform and improve the design of facilities.

# Chapter 4. The Dementia Convention

The workshops were divided into two sessions. In the morning, participants were asked to identify current problems in the delivery of services. This sounds unremittingly negative but is an important part of the process in identifying where change needs to take place. The afternoon session was devoted to examining changes that will help overcome these problems. These are the solutions which will help to shape the action plan for service improvement.

## Session One: What's wrong with the care of people with dementia in Lothian?

Other issues raised in the workshop groups included:

General issues:

- services are too inflexible
- care is not individualised – too often it is “one size fits all”
- inconsistencies in service delivery across Lothian
- difficulties and delays in getting a diagnosis
- stigma leads to denial and delays in seeking help
- lack of cognitive stimulation therapy
- lack of focus on prevention and awareness of risk factors for dementia
- lack of political lobbying for improved funding
- funding levels compare poorly with, for example, children’s services
- insufficient input from Allied Health Professionals (AHPs)
- not enough joined-up working between health and social services
- cheapest care options prevail – residential care is cheaper than home care
- lack of specialist dementia care units
- no consistent support along the patient pathway leading to people being passed from one professional to another
- different systems in place in Lothian – not one cohesive system
- inflexible work patterns
- lack of understanding among decision makers about how services operate on the ground
- lack of age-appropriate care, especially for younger people
- lack of dementia-friendly premises
- lack of appropriate use of available technology
- lack of uniformity in post-diagnosis support
- lack of recognition of palliative care needs
- lack of focus on meaningful activities
- too few services available at weekends
- lack of counselling and emotional support services
- lack of focus on outcomes of care – it is about more than just money
- lack of integrated services
- poor discharge processes
- too much talking, not enough action
- lack of clarity about which services people with early onset dementia should be referred to: the age-specific under-65s mental health service or the experience-specific psychiatry of older people service

User and carer issues:

- a lack of information for carers on dementia
- insufficient carers, befrienders and support groups
- lack of carer involvement
- lack of advocacy services
- inadequate follow-up post-diagnosis
- lack of non-pharmacological options such as social support and memory clinics
- lack of awareness of direct payments
- insufficient diagnosis/support services for those aged under 65
- unpaid carers are undervalued

- insufficient investment in services to support family carers
- lack of services to help with financial issues
- risk of over medication due to lack of person-centred care
- lack of confidence among families to provide low level support
- poor availability and access to transport hinders access to services
- limited out-of-hours access to socialisation services such as outreach and befrienders
- limited access to fresh air and outside space for people with dementia in care home whose accommodation isn't on the ground floor

### Education and training

- large variation in quality of diagnosis between GP practices
- too few neuropsychologists trained to work with older people
- lack of training for private care home staff
- lack of knowledge and engagement among GPs
- completed training is not always being put into practice
- insufficient education offered to people with dementia and carers around the time of diagnosis
- lots of training opportunities but not always delivered appropriately
- training not always effective and not always monitored
- training not always accessible to the right people
- lack of skills and competence among some staff
- too many barriers for untrained staff in accessing training

### Information

- inadequate information on local services
- insufficient information included in the primary care dementia record
- lack of information on the care and support options that are available
- IT systems not able to talk to each other
- communication gaps between partners

### Hospital care

- too many moves from ward to ward in acute hospitals
- unsuitable environments in hospital
- hospitals focus on other symptoms, not dementia
- long waiting times in outpatients
- poor awareness of dementia on medical and surgical wards
- inadequate staffing levels in admission units
- dementia seen as less important than conditions like cancer or heart disease
- beds are blocked while care packages are put in place
- lack of dementia nurses in hospital
- culture of indifference and ignorance in acute hospitals

### Community services

- home care is divided into too rigid time slots
- service too task-oriented with too little time to complete tasks
- inadequate delivery of care packages in people's homes such as the failure to check that meals are eaten
- home care packages are stopped on hospital admission and have to be re-arranged on discharge
- bar set too high for admission to supported housing
- insufficient use made of volunteers to support paid carers
- inadequate respite leads to carer burn-out and earlier than necessary admission to long term care
- care packages offer too few choices and options
- too few respite services and too limited in range
- respite not available in the right form early enough
- no easily accessible, short term respite

- lack of investment in day care services
- privatisation of home care services poses problems
- lack of consistency in home care services with different workers appearing all the time
- standard care packages do not fit individual needs
- lack of staff in day care services
- too much of a hit and run approach in home care
- lack of quality supported housing

#### Care homes

- too many care homes use low paid, low skilled staff
- many care staff do not have English as their first language
- lack of specialist nurses in care homes
- lack of behaviour management in care homes
- over reliance on untrained staff

#### Standards and processes

- big variation in adherence to care standards
- Care Commission does not address poor performance

### **Session Two: What do we need to do for dementia in Lothian?**

During the afternoon session, participants shared their suggestions for improving standards of dementia care. This was a very positive exercise that identified solutions to many of the problems outlined during the morning session. Everyone involved was very enthusiastic about putting good ideas into practice, and it was heartening that so many of the solutions were already known to the participants. While some of these will require significant resources or effort to achieve, others can be implemented quickly and cheaply.

#### User and carer issues

- increase the availability of meaningful activities
- develop personalised budgets to fund respite care as needed
- improve support for carers
- expand advocacy services
- raise awareness of and promote advance directives
- promote NHS Lothian carers' information strategy
- ask employers to donate employees' time to help, starting with health and social services staff
- make dementia-friendly supported housing available for people to buy to retain independence and avoid spending life savings on residential care
- provide a post-diagnosis support session for every patient and their family carers
- develop a Maggie's Centre type one stop shop for dementia patients providing information, counselling, activities etc.

#### Education and training

- provide joint training for health and social care staff
- provide a minimum standard of training across the different sectors and settings where people with dementia receive services
- follow up basic training with specific packages that reflect different workplace settings
- create a new role of dementia specialist care assistant to allow career progression
- develop education programmes on dementia awareness in schools
- provide education and training to tackle ignorance among staff
- develop training packages that can be delivered flexibly
- make training accessible and realistic
- develop criteria for training requirements for care home staff
- develop dementia training for GPs
- promote greater use of practice-based training

- introduce an SVQ in dementia care
- introduce dementia training earlier in the nursing curriculum
- develop mandatory dementia awareness courses
- develop dementia-specific multidisciplinary teams to improve access to the full range of services for people with dementia

## Information

- develop a high profile public awareness campaign on dementia
- develop a database of services and good practice across Lothian
- provide information on how to access services and respite care
- create a campaign to raise the profile of dementia
- develop one point of contact for professionals and patients
- provide information on dementia to churches, pubs, supermarkets etc.
- improve clarity of information to patients and carers to help them know what happens next
- establish a Lothian dementia knowledge network
- develop clear, easy to read information on dementia
- ensure that information given to people with dementia and their carers is consistent and of a uniformly high standard
- encourage more positive reporting of dementia in the media
- develop a dementia passport/communication folder with all key patient information that staff can access easily
- work towards shared data systems with appropriate access
- standardise reporting from GPs to other care services
- establish a forum for sharing good practice
- improve information sharing
- highlight positive dementia role models to reduce stigma
- make single shared assessment information more accessible
- create a one page summary of the patient record to provide key information on admission
- offer people bracelets with an identifying number linked to their medical notes

## Policy

- make better use of available technology
- eliminate waits for the AHP service and assessment
- develop crisis care in all areas
- increase awareness of dementia-friendly design
- promote awards for dementia-friendly buildings
- develop age-appropriate services
- work with shops and services on interacting with people with dementia
- increase AHP capacity
- appoint a dementia czar in Lothian
- stop taking the voluntary sector for granted
- provide more flexible services
- invest more in finding a cure
- increase awareness of diet and healthy living to help prevent dementia
- improve staff/patient ratios
- provide better environments for delivering care
- make assessment services for people with dementia uniform across Lothian

## Hospital care:

- establish an older people's mental health team in acute hospitals along the lines of the model that exists in Leeds
- develop opportunistic screening in hospital to pick up signs of early dementia
- develop role of liaison nurse for dementia patients
- ensure hospitals and care homes provide social interaction
- arrange transfers of staff from community services and care homes to work in hospital

- take services to care homes instead of patients always going to hospital
- reduce number of moves within hospital for dementia patients
- develop set procedures in A&E units for dementia patients
- put a discreet sticker on a patient's notes to flag up if they have dementia

### Community services

- establish rapid response teams to manage care and prevent hospital admissions
- develop a volunteer database to help with transport
- pay neighbours to keep an eye on people with dementia
- develop night time care service where people can sleep and return to their own homes during the day
- develop an easy way to enable volunteers and neighbours to help
- provide GPS tracking for patients in the community
- co-ordinate support for newly diagnosed patients and their carers
- develop respite as a planned package of support, not as an add-on
- develop dementia-specific day care
- develop a dedicated transport service
- give individualised budgets to people to use as required
- use guest houses and hotels for respite breaks
- make better use of technology to keep people in their own homes
- increase the range of respite care
- establish an independent counselling service
- establish dedicated community teams
- two weeks respite each year to include a full clinical work up and assessment of telecare need and provision of social and recreational activity
- two or three days live-in respite each month in the person's home
- establish older people's teams within social work

### Care homes

- provide Wiis (interactive computer game/activity system) in every care home
- attach AHPs to care homes
- develop small 7-9 bedded homes in the community
- cap patient levels for private care homes
- provide one-to-one stimulation for continuing care patients
- educate non-dementia residents in care homes about the condition
- move towards learning disability model of small stand-alone units
- appoint dementia champions for care homes
- build dementia-friendly care homes
- develop a better career path for staff in care homes
- provide training and support to care homes

### Standards and processes

- establish a minimum standard for dementia care
- appoint a link person/care manager for every patient
- streamline the process for social work referral
- create joint budgets for health and social work
- establish joint health and social work teams
- develop a standard system for communicating a diagnosis
- review medication every three months
- rethink the protocol for prescribing
- increase the number of people who can prescribe
- audit practice
- develop more advanced care planning
- create role of care co-ordinator
- ensure every person with dementia has a named worker
- improve medication planning

- offer access to a support group or one-to-one service three months after diagnosis
- ensure staff have adequate time to perform duties
- develop faster assessment and access to treatment
- agree maximum waiting time targets for diagnosis and treatment
- use opportunities like the annual flu jab to screen for signs of dementia in over 75s
- ensure greater consistency in care standards
- clarify issues of consent, confidentiality and legal measures
- strengthen role of Care Commission to be more proactive
- map services to ensure partnership working happens in practice

Following the workshops, the various groups were asked to report back with three key solutions – one they considered would be easy to implement, one that was harder and the one that offered the greatest challenge. The last category was also reserved for “off the wall” ideas that could contribute to improving dementia care. This is what emerged:

### Easy solutions

- improve education and support for carers
- develop more individualised respite care
- rethink the protocol for memory treatment
- create an information folder in every person’s home
- conduct a scoping exercise to identify people under 65 with both a learning disability and dementia
- reduce unnecessary hospital admissions by implementing improved assessment processes in A&E
- raise awareness about dementia through information leaflets
- encourage entertainment venues to donate tickets free to people with dementia
- develop a volunteers’ database that carers can use for support
- pay neighbours to provide support
- enshrine the right of people with dementia to participate in research projects, ensuring that the results are relevant to them and their opinions are taken into account

### Harder solutions

- promote early diagnosis and continuity throughout the illness
- develop a culture of understanding through training and education
- promote advance statements to help people control what happens to them
- develop a one-stop shop for information, advice and counselling
- develop a career structure for staff in care homes
- create a dementia passport with all the information about the person
- provide mandatory training across all services
- encourage employers to donate one hour a week of their employees’ time to spend with someone with dementia
- develop an SVQ in dementia to upskill staff in care homes
- develop a specialist dementia care assistant role
- provide one point of contact for professionals and carers post diagnosis

### Most challenging solutions/radical ideas

- implement a high profile public awareness campaign
- expand and develop respite care to ensure service matches need
- create dedicated specialist teams based on joint working
- challenge stigma through television advertising and education in schools
- reduce the number of institutional placements by 50%
- streamline and improve IT systems
- promote community responsibility to contribute to dementia care, through developments such as neighbourhood schemes
- be more creative in the settings in which respite care is offered
- develop an accreditation system for dementia-friendly buildings and services
- appoint a dementia czar for Lothian to co-ordinate services

## Chapter 5: Next steps

An action plan will be developed based on the ideas generated at the Convention. It will be based on:

- changes that can be introduced from within existing resources
- changes that will require extra support that will need to be ranked in order of priority and feasibility
- identifying measurable outcomes that can be used to demonstrate the change that has been achieved

It is vital to recognise that this programme over two years is to supplement the good work that was already happening and not to replace it. The work is designed to improve dementia care in support of the aim of improving the whole health and social care system in the Lothians. The programme is not intended to introduce new targets, but to help staff to achieve the targets that already exist. Evaluation will be undertaken to measure this change.

The action plan will be circulated in May in draft form, and confirmed in June after the good practice conference.

This process is flexible and inclusive, so any comments, additions or suggested changes can be addressed to [jemma.galbraith@stir.ac.uk](mailto:jemma.galbraith@stir.ac.uk) or [june.andrews@stir.ac.uk](mailto:june.andrews@stir.ac.uk).





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