

briefing

Living well with dementia: a summary of the
National Dementia Strategy for England

March 2009



A summary of the Department of Health's *Living well with Dementia: A National Dementia Strategy*

The Department of Health published the National Dementia Strategy for England in February 2009. With the Welsh Assembly Government developing its own policy work on dementia services, our members may find the following summary of the English proposals useful ahead of a similar strategy being published in Wales.

The strategy is available to download from the Department of Health website on the link below:

<http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/NationalDementiaStrategy/index.htm>

Purpose and scope of the strategy

Over 570,000 people in England are living with dementia. This figure is likely to double over the next 30 years in the absence of any medical breakthrough in treatment.

Equivalent figures for Wales show there are 37,000 people with dementia in Wales, which is set to rise by 35% in the next 20 years.

The Department of Health strategy is backed by £150 million over the first two years. Its aim is to increase awareness of dementia, ensure early diagnosis and intervention and radically improve the quality of care that people with the condition receive.

Currently only a third of people with dementia receive a formal diagnosis or have contact with specialist services at any time in their illness. The level of UK diagnosis and treatment of people with dementia is generally low. International comparisons suggest that the UK is in the bottom third of European performance in terms of diagnosis and treatment, with less than half the activity of France, Sweden, Ireland and Spain.

The strategy also aims to address the issue of carers. Family carers are often old and frail themselves and have high levels of carer burden, depression and physical illness, and decreased quality of life.

The implementation plan is being modelled over five years, although the strategy states that there is no expectation that all areas will necessarily be able to implement it within five years.

How the strategy is structured

The strategy aims to deliver significant improvements to dementia services across three key areas:

- Raising awareness and understanding
- Early diagnosis and support
- Living well with dementia

The strategy contains 17 key objectives, which are to be implemented largely at a local level.

Raising awareness and understanding

Objective 1: Increased public and professional awareness of dementia

From speaking to people with dementia, the DH found that many were prevented from accessing diagnosis, and therefore treatment and support, by a counter-productive cycle of stigma and misapprehension, leading to inactivity. They identified a low priority being given to developing the necessary professional skills to care for people with dementia, and a widespread mis-attribution of

symptoms to 'old-age' amongst professionals. The effect of these factors is that people currently wait up to three years before reporting symptoms of dementia to their doctor. Research also found just 31% of GPs believe they have received sufficient basic and post-qualification training to diagnose and manage dementia.

The strategy advocates a general public information campaign with a strong prevention message to improve understanding of dementia and address the stigma associated with it.

Early diagnosis and support

Objective 2: Good quality early diagnosis and intervention for all

Currently, under-diagnosis is the norm. When diagnoses are made, it is often too late for those suffering from the illness to make choices. Early diagnosis can improve quality of life and prevent unnecessary admissions into care homes.

Evidence confirms a marked reluctance on the part of primary care to be directly involved in the diagnosis of dementia for reasons that include: the belief that nothing can be done for dementia; concerns about competency; and concerns about the availability of resources. New specialist services need to be commissioned to deliver good quality early diagnosis and intervention. Such services would need to provide a simple single focus for referrals from primary care. Services would also focus on breaking the diagnosis sensitively to the person with dementia and their family.

Objective 3: Good quality information for people with dementia and carers

Good quality information on the illness and services to be made available, both at diagnosis and throughout the course of their care. Information will be tailored to make local service provision clear.

Objective 4: Enabling easy access to care, support

and advice following diagnosis

Faced with a serious illness where there is inevitable long-term decline and increase in dependency, people want to feel that there is continuing support available to them when they need it. The strategy recommends a dementia advisor to facilitate easy access to services for people with dementia and their carers. Service models would be piloted and evaluated prior to implementation.

Objective 5: Developing structured peer support and learning networks

Direct local peer support for people with dementia and their carers will provide practical and emotional support, reduce social isolation and promote self-care, drawing on existing activity and models of good practice. It will enable people with dementia to take an active role in developing and prioritising local services.

Living well with dementia

Objective 6: Improved community personal support services

The strategy identifies home care as probably the single most important service. Current practice means care workers often have to make rushed, short visits, and there is not enough time or consistency to build a relationship. Flexible and reliable services, responsive to the personal needs and preferences of each individual, should also take into account the person's broader family circumstances. The aim is to provide home care that is reliable, with staff who have basic training in dementia care.

Objective 7: Implementing the Carers' Strategy for people with dementia

Family carers are the most important resource available for people with dementia. Carers have a right to an assessment of their needs and can be supported through an agreed plan that will include

good-quality, personalised breaks.

Objective 8: Improved quality of care in general hospitals

Up to 70% of acute hospital beds are currently occupied by older people, up to half of which may be people with cognitive impairment, including dementia. The majority of these patients are not known to specialist mental health services and are undiagnosed. The impact of institutionalisation on these people is not widely appreciated by clinicians, managers and commissioners, the strategy says. The National Audit Office also found that some general hospital services worked hard not to make the diagnosis of dementia, for fear it would delay discharge.

The recommendation is that every general hospital identifies a senior clinician to take the lead for quality improvement in dementia. The strategy also recommends the commissioning of specialist liaison older people's mental health teams to work in general hospitals, consisting of three to four members of staff (part-time consultant, staff grade doctor, nurse and psychologist/therapist).

Objective 9: Improved intermediate care for people with dementia

Pressures to reduce lengths of stay in acute care, combined with risk-averse discharge planning, can mean that people with dementia are rushed into long-term residential care prematurely. Staff working in intermediate care, like any other staff group, need to have core training in dementia and access to advice and support from specialist mental health personnel.

Objective 10: Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers

As evidence emerges, commissioners should consider providing options to prolong independent living and delay reliance on more intensive services. Staff working in housing-related services to develop skills needed to support people with dementia.

Objective 11: Improving care for people with dementia in care homes

The need for workforce development in this sector is profound. At least two-thirds of all people living in care homes have a form of dementia. Explicit leadership is needed for dementia care within care homes. A senior staff member within the care home should take the lead for quality improvement in the care of dementia, working alongside specialist in-reach services from older people's community mental health teams.

Objective 12: Improved end-of-life care for people with dementia

Better end-of-life care needs to reflect personal preferences and link into palliative care networks. People with dementia and their carers should be involved in planning end-of-life care.

Delivering the National Dementia Strategy

Implementation of the strategy is based on four guiding principles:

1. Co-production. Implementation to be decided in partnership with the NHS, local authorities and other key stakeholders.
2. Subsidiarity. DH will play an enabling role, but details to be determined locally.
3. Clinical ownership and leadership. DH staff to be participants and leaders.
4. System alignment. The wider system needs to be aligned around the same goals.

Objective 13: An informed and effective workforce for people with dementia

DH workforce strategies will take on board the implications of the dementia strategy, and commissioners will specify necessary dementia training for service providers. All health and social care staff involved in the care of people who may have dementia to be trained in the necessary skills.

This is to be achieved by effective basic training and continuous professional development in dementia.

In the medium and longer-term, curricula for undergraduate professional qualifications for doctors, nurses, therapists and other relevant health and social care staff should all contain modules on dementia care.

Objective 14: A joint commissioning strategy for dementia

As people with dementia will live with their conditions for a number of years, and their care needs will change over time, their need for health and social services will change. It is important therefore for PCTs and local authorities to consider the need for the commissioning of coherent joint services.

Objective 15: Improved assessment and regulation of health and care services

The Care Quality Commission (CQC) will be operational from April 2009 to protect and promote the health, safety and welfare of people who use health and social care services. Assessing the real-life experience of people with dementia will be an important part of the inspection process.

Objective 16: A clear picture of research evidence and needs

Evidence to be available on the existing research base on dementia in the UK and the gaps that need to be filled. The Medical Research Council (MRC) with DH will convene a summit of parties interested in dementia research.

Objective 17: Effective national and regional support for implementation of the strategy

DH will provide national support for local implementation, with good-quality information to be available on the development of services.

Performance monitoring and evaluation

PCTs and local authorities will be expected to demonstrate continued progress towards meeting the 17 key objectives. Priorities for improvement will be for local determination but feedback from consultation responses suggest that particular attention should be paid to early diagnosis and intervention, workforce development, and improving care in care homes.

Finally, the strategy acknowledges that this work is part of the process, not an end in itself. Even if all the recommendations are fully implemented, the strategy acknowledges there will still be much more to do. It finishes by stating that although there are costs to the system in making these changes, the cost of not making the changes would be immeasurably higher, both in financial and human terms.

THE **WELSH NHS** CONFEDERATION
CONFFEDERASIWN **GIG CYMRU**



Unit 3
Waterton Park
Bridgend
CF31 3PH

Tel 0845 33 00 499
E-mail info@welshconfed.org

About the Welsh NHS Confederation

The Welsh NHS Confederation represents the organisations making up the NHS in Wales: trusts and local health boards. We act as an independent voice in the drive for better health and better healthcare through our policy and influencing work, and by supporting members with events, information and training. To find out more about us go to -

www.welshconfed.org