



In February the government published its first ever National Dementia Strategy. This long awaited document received mixed reviews. Hailed by some as a 'landmark' step in the transformation of the quality of care for people with dementia, the strategy was criticised in equal measure as a half hearted, inadequate response to what many see as the UK's fastest growing health crisis.

With opinion so divided, **You First** takes an in depth look at the new five year strategy and asks our experts – what really needs to be done in the battle against this frightening condition?

# Spotlight on dementia

"People are living for longer and dementia, in all its forms, has become one of the biggest health challenges we face," explains CIC's North West Senior Care lead manager, Helen Cook. "There are currently around 700,000 dementia sufferers in the UK, a figure which is set to double in the next 30 years." With the promise of an initial £150 million in funding, the strategy's 17 core objectives aim to make significant improvements to dementia services across three key areas: improved awareness; earlier diagnosis and intervention; and better quality of care.

## Stigma and fear

The perception of dementia remains a stumbling block in the battle against the condition. Fear, stigma and lack of knowledge prevent many people from seeking help with their symptoms, thus deterring early diagnosis.

The debate surrounding whether dementia is a physical or mental health issue seems to add to the problem. Although classed as a mental health condition, largely due to the psychiatric symptoms sufferers present, dementia itself causes physical deterioration of the brain, creating problems with memory loss, thinking and reasoning. With mental health issues having historically been regarded as the 'poor relation' in the health arena, dementia seems not to have received the recognition it deserves.

A recent Alzheimer's Society report, *'Dementia – Out of the Shadows'* (2008), also found that perceptions about the

condition are still overwhelmingly negative, with many sufferers believing others see them as inadequate, incapable, useless, and even mad.

With dementia taking on average three years to be diagnosed, sufferers and their families often face an agonising, confusing and frustrating wait for answers. Couple this with horror stories about late or incorrect diagnosis (including trips to the doctor only to be told that 'forgetfulness' is something

which comes to us all) and it is no wonder that improved awareness and earlier diagnosis are at the top of the government's agenda. Plans are now afoot for every GP in Britain to be trained to spot the first signs of the condition,

for every hospital to have a trained senior clinician with special responsibility for dementia care and for dedicated memory clinics to be set up in every town in England. This will allow for early diagnosis and the prescription of drugs and therapies which can delay progression and maintain patients' independence for longer.

"Early diagnosis will afford patients the opportunity to better plan their futures, particularly in terms of their care and finances," comments Helen Cook. "However, there is a worry that there may be an element of the 'postcode lottery' to these provisions, or that they won't be given the

funding they really need to succeed," she adds. "Some critics also argue that as there is no cure for dementia, funding may be better spent on improving the quality of care for those thousands of sufferers in the latter stages of the disease."

## Improvements needed

Recognising that improvements do need to be made in the quality of care available for dementia patients, the new strategy

demands better community services, more accessible and suitable intermediate care, and improved provision in care homes.

Sandra Watkins, CIC's dedicated dementia specialist,

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appointed to help lead the organisation's practices in this area, believes that on the whole, the dementia care currently available is, at best, patchy. "There are some organisations providing exceptional standards of care, but many do not invest the time and money needed. Hopefully, the government's improvement drive will mean standardisation and create a better benchmark in this field," she comments. According to Sandra, the key principles for good quality dementia care are: providing individualised support, ensuring patients are afforded dignity and respect, and recognising the needs of families and loved

ones. "Communication, with both sufferers and their families, is key to achieving all of these goals," she says. "Genuine person centred care can not be achieved without *talking* to patients and their families. This means getting a detailed biography and translating this into a care plan specific to that person, reflective of their likes and dislikes, their personality and their needs." Improved care pathways are also called for, meaning that care homes will now need to better facilitate their dementia patients to access community services such as physiotherapy and occupational therapy, speech and language therapy and district nursing. "We see this as a vital part of the care for our dementia patients and we work hard on building relationships with external professionals who can provide these services on site," Sandra adds.

### Innovative techniques

A stimulating environment can also delay progression of the disease and provide a better quality of care. Sandra advocates, "We employ a range of techniques at CIC including music therapy, reminiscence sessions and life story work, as well as in-house 'snoozelems' - sensory relaxation rooms which incorporate light and sound therapy. We've also started a new programme called SONASapc in which small groups with varying advancements of dementia follow an audio programme that takes them on a sensory journey - they sing songs, taste new or familiar foods, smell different things and touch unusual or interesting objects, all to evoke the senses. The programme has been hugely successful, with even the most advanced dementia sufferers showing an amazing reaction to it."

As well as activity, physical environment has a significant role in the wellbeing of dementia sufferers. Nigel Kendrick, CIC's property surveyor, has recently completed a course at the world renowned Sterling Dementia Services Development Centre (DSDC), looking at best practice in building design and environment for dementia patients.

"Creating the right environment for dementia patients is vital; it can help avoid confusion,

safeguard residents and generally create a more uplifting environment for both patients and staff. Good design helps support residents to retain function and skill by maximising autonomy and control over their own environment."

Running the course was Colm Cunningham, Director of Operations at DSDC, noted as being the driving force behind a new buildings audit tool, which assesses the physical environment provided for dementia sufferers to facilitate a better quality of care. "The course demonstrated simple and easy ways of making a care home more

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dementia-friendly" explains Nigel. "It's all about making lots of small changes which together, make a big difference. So for example, using contrasting colours in bathrooms, or on dining room tables, to allow dementia patients to more easily identify objects; painting doors on a long corridor different colours and not using very 'loud' patterns on carpets or curtains. Some of these suggestions are things which we already do in our homes, but there were lots of things we simply hadn't thought of and will now look to implement."

As well as physical changes, assessing noise and light levels also helps create a therapeutic ambience for people with cognitive impairments.

"The key is to achieve a balance of sensory stimulation," says Nigel. "We've recently commissioned an external design consultant to formulate a design scheme for all of our care homes which will reflect best practice in this area, and incorporate items which are specifically suitable for our dementia residents."

### Seeing the person

According to Sandra Watkins, "respect and dignity" need to go hand in hand with these good practices. "Too often people fall

into the trap of seeing the dementia, not the person," explains Sandra. "At CIC we have at least one NHS registered 'Dignity Champion' in each of our homes, so all our staff understand that dignity means treating people how they would want to be treated themselves. This can include anything from giving patients choice and control over their care, to simple home comforts that make all the difference such as clothes patients choose themselves and nice crockery and bed linens. The things a person enjoyed before they came to stay in our care." Sadly, as it is a progressive neuro-generative condition, 'end of life' care inevitably forms part of the support given to dementia sufferers. A 2007 National Audit Office investigation into the quality and cost effectiveness of services for people with dementia concluded that end of life care is 'limited' and services are not being delivered 'consistently' or 'cost effectively'. In response to such criticism, the Department of Health published its 'National End of Life Care Strategy' in 2008, the principles of which are reflected heavily in the new dementia strategy.



Julie Cowen, CIC's Senior Care lead manager for Scotland said, "The strategy addresses this issue and means we will see better practices developing, including patients having more choice and control over how they are cared for in their final weeks or months of life."

"All of our homes follow the Gold Standards Framework, the government's programme aimed at achieving best practice in supporting people near the end of their

# Dementia special report

lives. Several of our homes are even in the process of applying for Gold Standard Beacon Status, the highest possible rating for end of life care, so it really is something we put a lot of energy and commitment into." She adds.

The government wants to see such practices rolled out across the country, and recognises that better levels of care can only be achieved through a more informed and effective workforce for people with dementia. Julie agrees, "At CIC, all staff receive basic dementia awareness training. Additionally, staff working directly with dementia patients take part in regular in-house and external training, attend conferences, and share best practice with colleagues right across the organisation."

## Caring for loved ones

However, professional carers still form only a small part of the support available for dementia patients.

Not to be ignored are the hundreds of thousands of 'informal carers' who care at home for their loved ones with dementia. Many are forced to give up their jobs to look after their relative or friend, saving the government an estimated £6bn a year by plugging the gaps in the social care system.

"To care for someone with dementia can be one of the most emotionally exhausting things a person can experience. Giving families information, holding workshops and linking them to support groups as we do at CIC, goes part of the way to providing the support families so desperately need," says Julie. "Aside from that, more money needs to go to providing families and other informal carers with respite from their role and giving them additional support in the home from professional staff."

Whilst the government has promised to carry out more assessments of the needs of carers, and increase the provision of good-quality, personalised breaks for them, many people are still left wondering how much of the £150m funding, will actually

be dedicated to this vital need. A central aim of the strategy is to develop services which enable dementia patients to stay at home for longer. Whilst this goal is certainly something many dementia sufferers welcome, questions do have to be asked about how, with only £150m in funding (none of which is specifically 'ear-marked' for dementia) these goals will be financially supported, without placing even more pressure on already strained family carers. Criticism over the lack of funding underpinning the strategy, particularly for research, has been raised by many

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dementia charities and high profile figures, who have spoken out about their shock and disappointment over the lack of focus in this area. With cancer research receiving eight times more funding than that allocated to research into dementia, it seems that these criticisms are not without substance.

## Research is the key

Kathy Farmer, Director of CIC's Senior Care services says: "CIC are constantly working to ensure we are carrying out the best, and most informed practices of care and we believe that research is one of the primary ways of making sure we are doing this." Reflecting this commitment, CIC have recently joined up with The Academic Palliative and Supportive Care Studies Group at University of Liverpool, to participate in a study exploring end of life issues for people with dementia and their carers. 'Advanced Dementia – what care do patients and carers need' is a three year

PhD study for Project Researcher, Jackie Crowther, a mental health nurse who has spent several years working on research projects into various aspects of the disease. Jackie hopes that the project will help inform local and national policy in terms of end of life care and support for carers.

"The phenomenal response I have had to my appeal for participants proves that the estimate that 25 million people in Britain are affected by dementia in some form is no exaggeration. People want to do something to help tackle dementia and research is one of the best ways we can do this."

For many professionals and campaigners then, there is a direct comparison between dementia's status now with that of cancer in the 1950's, when few treatments were available, fear of the disease was prominent, and patients were commonly not told their diagnosis to avoid distress. Both supporters and critics of the strategy are united in their view that there is still much to be done if the government

is to elevate this condition to the status of other life-limiting illnesses.

It is clear that the public want increased provision for dementia care to become a priority. High profile figures such as broadcaster John Suchet, who has publicly spoken about his feelings of loss at his wife's Alzheimer's diagnosis, and author Terry Pratchett, who has highlighted his own struggles since being diagnosed with early-onset Alzheimer's, have provided a public face to the private sufferings that many families experience.

But along with this rise in awareness must come support from the government. The new strategy is only the start to facing this growing crisis. There is still a long way to go and success will ultimately depend on whether the government is willing to provide the money needed to properly support its strategy. The aspirations appear to be there, but only time will tell whether it has the real ambition and breath needed to achieve its goals.