



Leading the fight against dementia



social care institute for excellence



National Dementia Declaration for England

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A call to action

Dementia is one of the greatest challenges facing our ageing society. There has been major progress in recent years in securing public and political commitment to responding more effectively to dementia. We now need to ensure that this commitment is turned into concerted action. With the publication of this National Dementia Declaration we announce the launch of a Dementia Action Alliance and a major plan of action to change the experience of living with dementia in England for good. The organisations signed up to this Declaration call on all families, communities and organisations to work with us to transform quality of life for the millions of people affected by dementia.

The scale of the challenge

There are 750,000 people living with dementia in the UK now and by 2025 there will be over one million. Dementia is an incurable condition caused by diseases of the brain which over time seriously impairs the ability of someone with dementia to live independently. Symptoms can include severe memory loss, mood and personality changes and behaviour that challenges others such as serious confusion, agitation and aggression. Many people with dementia also have other medical conditions or develop them during the course of their illness.

Families currently provide the majority of care and support for people with dementia and this can be both tiring and stressful – physically, emotionally and financially. A large number of people with dementia also live alone and can be at particular risk of isolation or abuse. However, if people with dementia are diagnosed early, and they and their families receive help, they can continue to live a good quality of life.

The financial cost of dementia in the UK is £20 billion a year and rising. Two thirds of people with dementia live in their own homes and one

third live in care homes. One in four people in hospital have dementia and two thirds of people in care homes have dementia.

This National Dementia Declaration has been created by people with dementia, carers of people with dementia and a large number of organisations who seek radical change in the way that our society responds to dementia. We seek a similar level of change as has been seen in our society's response to cancer over recent decades.

All organisations that are signatories to this National Dementia Declaration are setting out publicly what they intend to do by 2014 to transform quality of life for people with dementia and their family carers.

In 2011 the Dementia Action Alliance will seek support from partners in civic organisations, businesses and professions to deliver dementia supportive communities. For more information visit www.dementiaaction.org.uk

Why is there a need for a National Dementia Declaration?

- Public awareness of dementia is high but understanding about it is still very poor. Fear of dementia also remains high; there is a reluctance to seek help and few people understand that it is possible to live well with dementia. In addition there is limited understanding of the fact that dementia can affect people in many different age groups.
- NHS and social care systems have not historically developed to reflect the fact that people with dementia are now a key group using many services.
- Only one third of people with dementia receive a specialist diagnosis and many are receiving that diagnosis late. GPs often report being reluctant to diagnose dementia either because they lack the knowledge to do so, do not see the benefits of early diagnosis or because they are aware of the lack of specialist support and services available for people after a diagnosis.
- Following diagnosis many people with dementia and carers report receiving no information about their condition or about what support might be available.
- Reports from regulator the Care Quality Commission (CQC) and its predecessor the Commission for Social Care Inspection (CSCI) show that although there are examples of excellent dementia care in care homes, many providers are struggling to deliver quality of life for people in the later stages of the condition.
- Equally, some people with dementia struggle for too long in their own homes without the help they need when better person-centred care or a good care home could provide a more stimulating and supportive environment.
- The All-Party Parliamentary Group on Dementia and Professor Banerjee have both produced reports revealing people with dementia are being inappropriately prescribed or over-prescribed antipsychotic drugs which increase risk of death and reduce quality of life.
- Health and social care staff routinely report that they have not received training in how to treat or care for people with dementia, despite the fact that they are now increasingly in contact with people with dementia.
- The National Audit Office and Parliamentary Public Accounts Committee have found that there is very ineffective use of current resources to deliver quality of life for people with dementia. For example the NAO has highlighted the potential for the NHS to identify savings of at least £284 million per year through improving dementia care. In addition to the costs borne by public services people with dementia and carers face high costs for care.
- UK spending from all sources on dementia research is low compared to other disease groups and by international standards.

Government action on dementia

In 2009 the then government in England published a five-year National Dementia Strategy. As part of this work, strategies on end of life care and carers are also in place. NICE/SCIE guideline 2006 and Dementia Quality Standards describe what good dementia care should look like.

The coalition government has stated its commitment to implement the National Dementia Strategy; however, it can only do so much. The Department of Health, as a signatory to the Declaration, will set out what it intends to do to help improve the lives of people with dementia. However, radical and sustainable change will only come about through the action of individuals and organisations working together locally and nationally to challenge what is wrong and to do things better.

Desired outcomes for people with dementia and their carers

People with dementia and their family carers have described seven outcomes they would like to see in their lives.

There is overlap between these outcomes and the draft outcomes in the Department of Health's National Dementia Strategy Implementation Plan. Both the Department of Health's draft outcomes and those described below will need to be developed further. In addition work will need to be done to better understand how to measure these outcomes.

1 I have personal choice and control or influence over decisions about me

I have control over my life and support to do the things that matter to me.

I have received an early diagnosis which was sensitively communicated.

I have access to adequate resources (private and public) that enable me to choose where and how I live.

I can make decisions now about the care I want in my later life.

I will die free from pain, fear and with dignity, cared for by people who are trained and supported in high quality palliative care.

2 I know that services are designed around me and my needs

I feel supported and understood by my GP and get a physical checkup regularly without asking for it.

There are a range of services that support me with any aspect of daily living and enable me to stay at home and in my community, enjoying the best quality of life for as long as possible.

I am treated with dignity and respect whenever I need support from services.

I only go into hospital when I need to and when I get there staff understand how I can receive the best treatment so that I can leave as soon as possible.

Care home staff understand a lot about me and my disability and know what helps me cope and enjoy the best quality of life every day.

My carer can access respite care if and when they want it, along with other services that can help support them in their role.

3 I have support that helps me live my life

I can choose what support suits me best, so that I don't feel a burden.

I can access a wide range of options and opportunities for support that suits me and my needs.

I know how to get this support and I am confident it will help me.

I have information and support and I can have fun with a network of others, including people in a similar position to me.

My carer also has their own support network that suits their own needs.

4 I have the knowledge and know-how to get what I need

It's not a problem getting information and advice, including information about the range of benefits I can access to help me afford and cope with living at home.

I know where I can get the information I need when I need it, and I can digest and re-digest it in a way that suits me.

I have enough information and advice to make decisions about managing, now and in the future, as my dementia progresses.

My carer has access to further information relevant to them, and understands which benefits they are also entitled to.

5 I live in an enabling and supportive environment where I feel valued and understood

I had a diagnosis very early on and, if I work, an understanding employer which means I can still work and stay connected to people in my life.

I am making a contribution which makes me feel valued and valuable.

My neighbours, friends, family and GP keep in touch and are pleased to see me.

I am listened to and have my views considered, from the point I was first worried about my memory.

The importance of helping me to sustain relationships with others is well recognised.

If I develop behaviour that challenges others, people will take time to understand why I am acting in this way and help me to try to avoid it.

My carer's role is respected and supported. They also feel valued and valuable, and neither of us feel alone.

6 I have a sense of belonging and of being a valued part of family, community and civic life

I feel safe and supported in my home and in my community, which includes shops and pubs, sporting and cultural opportunities.

Neither I nor my family feel ashamed or discriminated against because I have dementia. People with whom we come into contact are helpful and supportive.

My carer and I continue to have the opportunity to develop new interests and new social networks.

It is easy for me to continue to live in my own home and I and my carer will both have the support needed for me to do this.

7 I know there is research going on which delivers a better life for me now and hope for the future

I regularly read and hear about new developments in research.

I am confident that there is an increasing investment in dementia research in the UK. I understand the growing evidence about prevention and risk reduction of dementia.

As a person living with dementia, I am asked if I want to take part in suitable clinical trials or participate in research in other ways.

I believe that research is key to improving the care I'm receiving now.

I believe that more research will mean that my children and I can look forward to a range of treatments when I need it and there will be more treatments available for their generation.

I know that with a diagnosis of dementia comes support to live well through assistive technologies as well as more traditional treatment types.

What do organisations signing up to the National Dementia Declaration commit to?

Separate to this Declaration, each signatory organisation will be setting out what it intends to do by 2014 (the date when the current National Dementia Strategy comes to an end) in order to deliver better quality of life for people living with dementia and their carers. These plans are being published separately. Each organisation is committed to the following principles:

- Ensuring that the work they do is planned and informed by the views of people with dementia and their carers and showing evidence for this
- Being an ambassador for the National Dementia Declaration and securing commitment from partners for the second phase of the Declaration
- Reporting publicly on their progress against the plan they have set out to support delivery of the National Dementia Declaration
- Working in partnership with other organisations to share knowledge about best practice in dementia
- Improving understanding about dementia.

How will the Declaration be tracked and monitored?

Organisations signed up to the National Dementia Declaration commit to making public the information about what they are doing to deliver better quality of life for people with dementia. They will be expected to publicise their contribution to the Declaration widely, especially to people with dementia, carers and the organisations representing them. In that way organisations can be held to account, particularly by their local population, to ensure they deliver what they have signed up to. There will be quarterly reporting on the outcomes and an annual report so it is possible to see what progress there has been.

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Dementia Action Alliance



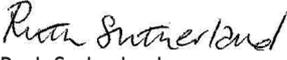
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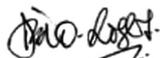
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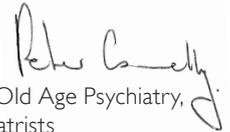
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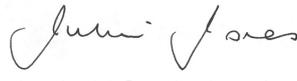
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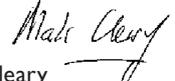
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