

# Rising to the **PRIME MINISTER'S** Challenge on Dementia

A spotlight on end of life care



THE  
**NATIONAL  
COUNCIL FOR  
PALLIATIVE  
CARE**

A National Council for Palliative Care briefing  
for delegates at the 7th annual conference on  
dementia and end of life care, December 2012

**In March 2012 the Prime Minister made history by identifying dementia as a national priority.**

**David Cameron's Challenge on Dementia presents a unique opportunity to make major improvements on the way people with dementia and their families are supported in their communities and by the health and care system.**

**Care at the end of life is a key part of this...**



## What is the Dementia Challenge?

The Prime Minister launched his Challenge on Dementia on 26<sup>th</sup> March 2012, saying: *“Dementia is one of the biggest challenges we face today – and it is one that we as a society simply cannot afford to ignore any longer [...] I am determined that we will go further and faster on dementia – making life better for people with dementia and their carers [...] With a sustained and concerted effort from all parts of society, I believe we can make a real difference – and we are determined to do so.”*

## What does good look like?

There are examples of good practice which can be learnt from and rolled out to help support more people with dementia and their families. Here are three we've found:

*A community based approach in Wigan features five villages based on a 'Home for Life' philosophy. Dementia-friendly design and non-invasive assistive technology are used to support people with dementia from diagnosis until the end of life. A 'Thinking Ahead' process is used to help residents plan their care and support at the end of life.*



*A psychiatry based approach in Greenwich centred around a regular home visiting service by the Old Age Psychiatrist and mental health team. 100 people with dementia have been cared for since 2005, 75% died at home. Other outcomes include 25% rate of hospital admission in last year of life (compared with 80% elsewhere) and an estimated £304,400 in savings.*

*A primary care based approach in Cornwall has established a system of end of life care planning with people with dementia and their families in 11 care homes, with sign up from 40 GP practices. Engagement with the coroner, out of hours GPs, emergency services, acute hospitals, hospices, primary care and mental health, advocacy services, social care and voluntary sector ensures a joined-up approach. Outcomes include a 54% reduction in hospital admissions (104 admissions reduced to 52 in one year) and an estimated £105,000 in savings.*

# Rising to the PRIME MINISTER'S Challenge on Dementia

Care at the end of life is a key part of the Challenge:

*“We know that too many people with dementia are not supported to have early discussions and make plans for their end of life care. This means that difficult, emotional decisions are often made in crisis and the person with dementia's wishes, including for example where they want to die, cannot be taken into account.”*

The Prime Minister's Challenge on Dementia: A report on progress, Department of Health, November 2012

## Why is dying well part of the Dementia Challenge?

- Over half a million people die each year in England, Wales and Northern Ireland
- One in three older people die with dementia
- The number of people dying with dementia each year is rising
- Many people with dementia aren't given the opportunity to plan for their end of life while they still can, and access to high quality palliative care is still a postcode lottery

## Myth busting

- |  |   |
|--|---|
| <input checked="" type="checkbox"/> Losing your memory or getting confused is an inevitable part of getting older          | <input checked="" type="checkbox"/> Dementia is a disease and should be treated as such   |
| <input checked="" type="checkbox"/> Dementia is incurable and so nothing can be done                                       | <input checked="" type="checkbox"/> There are things that can be done, like helping people plan for their future after diagnosis  |
| <input checked="" type="checkbox"/> 'Challenging behaviour' is part and parcel of having dementia, and nothing can be done | <input checked="" type="checkbox"/> Pain and distress can affect people's behaviour but there are things that can be done to help |

## Achieving a good death for the person with dementia *is* possible

## What's next?

NCPC is a member of the PM's Care and Support Champion Group and through that is working to improve care and support at the end of life, beginning with the pain and distress booklet being launched today. We will also be supporting an in-depth mapping project, led by Newcastle University with University College London, commencing in June 2013.

We have been exploring this issue with support from our dedicated Dementia Group since 2006. Visit [www.ncpc.org.uk/dementia](http://www.ncpc.org.uk/dementia) for our full range of resources.

## About us

The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. We lead the Dying Matters Coalition to change knowledge, attitudes and behaviours towards dying, death and bereavement.

Visit [www.ncpc.org.uk](http://www.ncpc.org.uk) and [www.dyingmatters.org](http://www.dyingmatters.org) to find out more.

## Comments

This is an evolving area of work for us and we'd love to hear what you think. Please email us at [policy@ncpc.org.uk](mailto:policy@ncpc.org.uk)

## Other resources on this topic

- How would I know, what would I do: How to help someone with dementia who is in pain or distress (2012) NCPC
- Time to talk, Doc? (2012) Dying Matters Coalition
- Difficult Conversations: Making it easier to talk to people with dementia about the end of life (2011)
- Time To Talk? Starting end of life care conversations with people affected by dementia (2012) Dying Matters Coalition
- Good Decision-Making – the Mental Capacity Act and End of Life Care: Summary Guidance (2012) NCPC
- The Power of Partnership: Palliative care in dementia (2009) NCPC
- Out of the Shadows: End of life care for people with dementia (2009) NCPC

For more information visit our stand today or  
[www.ncpc.org.uk/dementia](http://www.ncpc.org.uk/dementia)

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