

THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE

END OF LIFE CARE MANIFESTO 2010

....3 million people will
die in the United Kingdom
during the next Parliament...
millions more will be
bereaved...most people won't
die where they want to....

**Dying
Matters**

*'Let's talk
about it*

Introduction

The way in which we care for people who are dying is a litmus test for our society. We call on all political parties to commit themselves to the continuous improvement of end of life care as a major national priority for the next parliament and beyond.

We believe that everyone should:

- *Have the right to access high-quality palliative care services appropriate to their needs*
- *Be able to exercise choice about their place of care at the end of their life and to die in the place that they want to, where possible.*

Pledges

We call on political leaders to take 5 key actions in order to achieve these outcomes:

1. Ensure that the End of Life Care Strategy is fully

implemented. This must include maintaining real terms expenditure at least at 2010-11 levels in the lifetime of the next parliament, including allowance for predicted rises in numbers of deaths from 2012.



2. Give strong political leadership and commitment to end of life care by establishing a Cabinet Committee for End of Life Care, so that it becomes a cross-departmental priority at the top of government.



3. Put in place comprehensive out of hours services to ensure 24/7 access to specialist palliative care advice, nursing and pain relief in every area for everyone who needs end of life care.



4. Ensure that training in palliative and end of life care is a core curriculum requirement for all health and social care staff, both pre-registration and as part of their continuing professional development.



5. Equip people and the nation to become confident about discussing their wishes and priorities for end of life care, through supporting the awareness-raising activities of the Dying Matters coalition.



Context

We all need good end of life care and more people will need palliative care than any other service. We estimate that around two-thirds of people have palliative care needs in the last year of their lives. Many of us will also have to care for relatives and close friends at the end of life.



End of life care has not had the priority in the past that it should have had, as the Department of Health has acknowledged. Whilst that is now beginning to change, it is vital that current momentum continues. Money spent on end of life care works harder; good care will also help deliver other important objectives including:

- *Improving people's dignity and choice*
- *Supporting carers*
- *Meeting the challenge for people with dementia*
- *Caring for our ageing population, with many people now living with multiple conditions*
- *Reducing serious complaints about the NHS and increasing satisfaction levels*
- *Enabling people to remain in the community*

Some snapshots

- *There is a mismatch between people's preferred place of death (home, for most people) and where they actually die*
- *Cancer is the underlying cause in only 25% of all deaths, yet 95% of those who access specialist palliative care services are people with cancer*
- *83% of all deaths are of people aged 65 and over; only around 65% of them access specialist palliative care services*
- *There are significant geographical variations in services*
- *The specialist palliative care workforce is about 7,700 doctors, nurses and allied health professionals*

Those professionals will never be able to meet everyone's needs. Other specialists and staff must be trained so that they can provide palliative care for people who do not have complex needs, in their own practice and setting.

Where we are now

In March 2009 the House of Commons Public Accounts Committee published a report on End of Life Care. Its findings included:

- *Most people would prefer to die at home, but 60% die in an acute hospital even when there is no clinical need for them to be there*
- *End of life care for people who die in*

Almost 3 million people will die in the United Kingdom during the next Parliament alone

Around 12 million people will suffer family bereavement (if each dying person has 4 relatives on average)

hospital should be improved

- *There are insufficient community-based services to enable people to remain in their preferred setting*
- *Health and social care services should be better co-ordinated*
- *Training health and social care staff in end of life care is a key priority*

Those findings were in the context of the 10 year End of Life Care Strategy for England (July 2008) although they are also applicable across the whole of the United Kingdom.





Getting it right everywhere

Commissioning and providing end of life care is particularly complex. No other service depends so heavily on the voluntary sector, which currently provides about 80% of specialist palliative care beds, as well as many community-based services.

There is a common misperception that end of life care is largely or exclusively both the preserve of hospices and a healthcare issue. This is not the case. 503,000 people died in England & Wales in 2006, in the following places:

- 290,000 in hospital
- 95,000 at home
- 47,000 in care homes with nursing
- 33,000 in other care homes
- 24,000 in hospices

Hospital will continue to be an appropriate place for

some people at the end of life, even with a significant move towards people remaining at home until they die. The quality of end of life care services and the environment in many acute hospitals needs to be improved.

- *54% of the most serious complaints in acute hospitals relate to care of the dying and bereavement (Healthcare Commission 2007)*

Workforce training is crucial to improving care in all settings, including hospitals. Too many professionals are trying to care for dying people without having had proper training. Core training in palliative care should be a compulsory part



of the curriculum for all health and social care staff, including support workers, both before registration and as part of their continuing professional development.

End of life care is provided in all settings across all sectors by multi-professional teams. Fragmentation of care and support is a major problem. Ensuring co-ordination of care is a key objective of care particularly across health and social care for example by using joint needs assessment frameworks.

End of life care is a vital issue not just for the NHS, but also for Local Authorities, who are responsible for much of the social care that is provided



in homes, care homes and supported housing. Voluntary and independent sector providers also have a vital role.

Many people want to die at home. They need to know that they can access round the clock services whenever they need them. Everybody should have access to comprehensive 24/7 out of hours services to ensure they have nursing care, symptom control and specialist advice whenever needed.

Leadership at every level

Committed leadership is required at every level, locally and nationally, hence our call for a Cabinet Committee dedicated to end of life care, given the importance of the issue to the nation and the need for cross departmental collaboration. Policy areas that need to be engaged



include: health and social care, housing, education, families, work and pensions, and transport.

Locally, every Health and Local Authority commissioner should be required to publish an annual report on their progress in improving end of life care for their population, to include details of their expenditure.

Helping people talk and plan

Death and dying has often been called the last taboo. Only 34% of people have discussed their end of life wishes with anyone.

Changing this culture is essential; if people don't talk about what they want, they will not get what they want. NCPC has established the national Dying Matters coalition to change the way people think, talk and behave in relation to death dying and bereavement, making dying well a natural and recognised part of living well.



rates to start rising again in the lifetime of the next parliament, with a consequent pressure on services.

Forecasters predict that:

- *The annual numbers of deaths will rise from 503,000 in 2006 to 586,000 in 2030*
- *Dementia incidence will rise from 700,000 people currently to 1 million in 2025*

With an aging population and as death rates increase, there is insufficient capacity to allow for further deaths in hospitals or hospices. This will demand greater capacity in care homes and other supported housing as well as planning for more home deaths. New services will be required to ensure that people receive good end of life care, whatever setting they are in.

A window of opportunity

Medical advances mean that people are living longer and so death rates in Britain have been declining since the mid-1970s. However demographic changes will cause death

The political decisions taken in the lifetime of the next parliament will have a significant impact on people's end of life care over the next 20 years. The time for action is now.

What the next government must do...

- 1. Ensure that the End of Life Care Strategy is fully implemented.** This must include maintaining real terms expenditure at least at 2010-11 levels in the lifetime of the next parliament, including allowance for predicted rises in numbers of deaths from 2012.
- 2. Give strong political leadership and commitment** to end of life care by establishing a Cabinet Committee for End of Life Care, so that it becomes a cross-departmental priority at the top of government.
- 3. Put in place comprehensive out of hours services** to ensure 24/7 access to specialist palliative care advice, nursing and pain relief in every area for everyone who needs end of life care.
- 4. Ensure that training in palliative and end of life care is a core curriculum requirement** for all health and social care staff, both pre-registration and as part of their continuing professional development.
- 5. Equip people and the nation to become confident** about discussing their wishes and priorities for end of life care, through supporting the awareness-raising activities of the Dying Matters coalition.

THE NATIONAL COUNCIL FOR PALLIATIVE CARE

About The National Council for Palliative Care

Our Mission is to improve palliative care for all who need it. We are the umbrella organisation for all those involved in providing, commissioning and using palliative care services in England, Wales & Northern Ireland.

Please visit our website or email Alice Fuller on a.fuller@ncpc.org.uk for further information.

www.ncpc.org.uk

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About the Dying Matters Coalition

The Dying Matters Coalition is raising public awareness of dying, death and bereavement in England. It is led by the National Council for Palliative Care.

Call freephone 08000 21 44 66, visit our website or contact Rose Parker on r.parker@ncpc.org.uk for more information.

www.dyingmatters.org