

# Dignity Newsletter



Adults, Wellbeing and Health

May Edition 2011

Welcome to the seventh edition of the Dignity Newsletter. This newsletter will look at:

- Dignity Challenge 8
- End of Life Care
- The Good Death Charter
- Nothing Ventured Nothing Gained
- Safeguarding Adults Website

## The Dignity Challenge 8

### “Engaging with family and carers as care partners”

Many people who receive care services have informal support from carers, family members or friends. Service providers may come into contact with several friends or relatives of individual service users or residents.

Dignity challenge 8 promotes “engaging with family and carers as care partners”. Social Care Institute for Excellence (SCIE) advise this means:

Welcome relatives and carers and enable them to communicate as contributing partners.

Keep relatives and carers fully informed and provide them with timely information.

Listen to relatives and carers and encourage them to contribute to the benefit of the person receiving services.

Care Quality Commission encourage providers to understand, value and respect the support that carers provide, and work co-operatively with carers when meeting the needs of the people who use their services.

## Dignity Checklist

All service providers should ask themselves the following questions when considering how effectively they engage carers, family and friends of their service users:

Do employers, managers and staff recognise and value the role of relatives and carers, and respond with understanding?

Are relatives and carers told who is ‘in charge’ of the service and who to raise issues with?

Is support provided to carers who want to be closely involved in the care of the individual?

Are relatives and carers provided with the necessary information?

Are you alert to the possibility that relatives’ and carers’ views are not always the same as those of the person using the service? (SCIE)

In County Durham we have a Joint Commissioning Strategy for Carers which provides further information regarding working with carers.

[The strategy is available on the Durham County Council website.](#)

## End of Life Care

End of life care is to help people with advanced, progressive, incurable illness to live as well as possible until their death. It concerns the supportive and palliative care needs of the person and their family during the last phase of life and into bereavement. Partnership between the person, their family and health and social care staff is central to end of life care.

End of life care involves:

- Management of pain and other symptoms
- Provision of psychological, social, spiritual and practical support
- Compassionate care
- Dignity and respect for the person and their family
- Person centred care
- Good communication

### The End of Life Strategy

The End of Life Strategy was published by the Department of Health in July 2008. The strategy aims to improve access to high quality care for adults approaching the end of life. Key areas of the strategy are: raising the profile of end of life care; co-ordination of care; delivery of high quality services in all locations; involving and supporting carers.  
[www.endoflifecareforadults.nhs.uk/strategy](http://www.endoflifecareforadults.nhs.uk/strategy)

### When does end of life care begin?

Opinions vary about when end of life care begins according to individual and professional perspectives. It may be interpreted as care in the last days and hours of an individual's life. End of life care can begin one year before death. In some cases discussions may start at the point of recognition that the condition or illness cannot be cured.

## Models of End of Life Care

There are different models of delivering end of life care. These models are ways of providing care to a person at the various stages of end of life care. The National Institute for Clinical Excellence (NICE) recommend 3 models: Gold Standards Framework; Preferred Priorities for Care and Liverpool Care Pathway.

**Gold Standards Framework** - involves care in any setting, including care homes for people who are in the last 6 to 12 months of life.  
[www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk)

**Preferred Priorities for Care** - to help people and their families decide where they wish to be cared for at the end of life. It refers to a document that is kept by the person themselves about their needs and wishes.  
[www.cancerlancashire.org.uk/ppc](http://www.cancerlancashire.org.uk/ppc)

**Liverpool Care Pathway** - to improve the care of the dying in the last hours, days of life. The pathway aims to transfer the hospice model for end of life care into other care settings, such as people's own homes and care homes.  
[www.lcp.mariecurie.org.uk](http://www.lcp.mariecurie.org.uk)

### Publications

A wide range of guidance and publications regarding end of life care are available on the following websites:

**National End of Life Care Programme** (NEoLCP produce a monthly newsletter)  
[www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

**National Council for Palliative Care**  
[www.ncpc.org.uk](http://www.ncpc.org.uk)

**Social Care Institute for Excellence**  
[www.scie.org.uk](http://www.scie.org.uk)

# The Good Death Charter

NHS North East Launched “the Good Death Charter” in October 2009

The charter includes the “**principles of a good death**”:

**Respect:** to be treated with dignity respect and privacy, according to the persons wishes.

**Time to plan:** to be given the opportunity to plan for end of life care in advance.

**Care:** to have access to end of life care in the location of choice.

**Support:** to receive appropriate emotional or spiritual support, with beliefs and values honoured.

Key areas of the Good Death Charter:

- A good death: one which is free of pain, dignified, in the place of one’s choosing and with family and friends nearby
- Identifying people who are approaching end of life
- To give people the opportunity to plan for their death in advance, taking their wishes into account, and to have that respected by health and social care services
- Ensuring the person’s choices are documented, communicated and co-ordinated care across organisations
- Ensure services provide the best and most sensitive care for dying people and their families when they need it

## Consultation on death and dying by NHS North East (2010)

The consultation found:

- 19% of people are uncomfortable talking about death
- 70% of people have not discussed their end of life wishes
- 90% of people would choose not to die in hospital
- Over 50% of people would prefer to die at home

# “Supporting People to live and die well: A framework for social care at the end of life”

National End of Life Care Programme

NEoLCP have produced a framework for social care at the end of life. The framework identifies the role of social care in identifying needs of service users and carers, and the lack of awareness of this role among health and social care professionals.

Other publications by NEoLCP include:

- “Advanced Care Planning: A Guide for Health and Social Care Staff”
- “Planning for your Future Care- A guide”

[www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

## End of Life Care for People with Dementia

Information and guidance on end of life care for people with dementia can be found on the websites for Social Care Institute for Excellence (SCIE) and National End of Life Care Programme (NEoLCP).

NEoLCP have published “Care towards the end of life for people with dementia. A resource guide”.

The guide provides resources and good practice guidance in end of life care for people with dementia. The guide is primarily intended for professionals working in health and social care. It is particularly aimed at those who work in end of life care or with people with dementia, rather than professionals who are experts in both areas.

SCIE provide guidance on their website regarding end of life care for people with dementia, including pain management and eating and drinking, and carer’s needs.

## Safeguarding Adults Website

County Durham Safeguarding Adults Inter-Agency Partnership launched the Safeguarding Adults website in January 2010. The website contains:

- Information on the different types of abuse
- How to report abuse
- Safeguarding policies and procedures
- Leaflets, posters
- Safeguarding training information
- Information for users and carers
- Information for professionals
- Links to other websites



From 17 January 2010 to 17 April 2011 there have been 6,482 visits to the website by 3,605 individual visitors. The website has had visitors from 39 countries, including: United States, South Africa, Brazil, Trinidad and Tobago, India, Australia and Canada. The majority of visits to the website occur on weekdays, with fewer visitors on the weekends.

To access the website go to:  
[www.safeguardingdurhamadults.info](http://www.safeguardingdurhamadults.info)

## “Nothing Ventured Nothing Gained: Risk Guidance for people with dementia”

(Department of Health, November 2010)

Nothing ventured, nothing gained provides guidance on best practice in assessing, managing and enabling risk for people living with dementia. It is based on person-centred practice and within the context of Living well with dementia: A National Dementia Strategy and Putting People First.

The guidance is for everyone involved in supporting people with dementia using health and care services in any setting. It is based on identifying and balancing the positive benefits of taking risks against the risks of an adverse event occurring.

Nothing Ventured, Nothing Gained aims to compliment rather than replace any existing risk guidance, including safeguarding adults at risk; Multi Agency Public Protection Arrangements (MAPPA) or risk management processes within the Care Programme Approach.

[www.dh.gov.uk/en/Publicationsandstatistics](http://www.dh.gov.uk/en/Publicationsandstatistics)

**If you would like to be involved in future newsletters please contact:**

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