



**NHS**

*Lincolnshire*

**Does Dying Matter?**

**End of Life Care  
in Lincolnshire**

**Lincolnshire**  
COUNTY COUNCIL 



## Does dying matter?

**Death and bereavement affect us all and we need to talk more about the end of life. Not talking about it can mean that people may not express their wishes about their care or funeral, or have made a will. Talking about death doesn't bring it nearer.**

"Dying is a lifetime's work, if you do it properly" – Rt. Revd. Dr. John Saxbee, Bishop of Lincoln.

Hospital workers, GPs, community nurses, social workers and care home staff are just some of the people already making improvements to how end of life care is delivered. Providing end of life care is complex and it is everyone's responsibility.

This is the first time we have consulted on this subject. We want to raise your awareness about death and dying and we want your views. This consultation forms part of the national Department of Health campaign "Dying Matters". There is a short questionnaire at the end of this document to complete and help shape the future plans for end of life care.

Everyone at the end of life in Lincolnshire should:

- Have the right to access high-quality end of life care services, appropriate to their needs, wherever they are being cared for.
- Receive effective control of pain and other physical and emotional symptoms regardless of their diagnosis.
- Be able to exercise choice about where they are cared for at the end of life and to die in the place that they want to, where possible.
- Receive dignity and respect in all aspects of end of life care.

We want to:

- Help people talk about dying so that they, and their families, are prepared.
- Make sure family and carers are central and critical partners in end of life care.
- Make sure that people will be in the company of others who care about them when they die.
- Provide end of life care that is available to patients locally during the day and night.
- Help people be cared for and die in their preferred place of choice where possible.

This is what we think, what do you think? Complete the questionnaire at the end of this document to have your views heard.

## Looking forward

We are currently experiencing the lowest number of deaths per year in the last century; however the death rate is predicted to rise due to population changes between 2012 and 2030. This will mean a rise in the number of people dying in Lincolnshire from 20 to 24 per day. It is essential that we take action now to develop sustainable changes to how end of life care is delivered.

For every death (if each dying person has four relatives or friends on average) there will be 30,000 people in Lincolnshire experiencing bereavement each year. As the numbers of people dying increase each year, this number will also increase.

A challenging economic climate means we will need to make tough choices and balance differing needs to ensure the widest possible number of people benefit from improved end of life care.





## Where are we now

These are some achievements in the last year to improve end of life care:

1. Raising public awareness of death and dying through:
  - Developing a webpage on 'Facebook' for people to have open discussions about planning for end of life. [www.facebook.com](http://www.facebook.com) Search for Five Things To Do Before I Die.
  - Engaging with local organisations about how we are all responsible for raising awareness of death and dying issues.
2. Improving end of life communication skills with all professionals.
3. Recruiting a number of new nurses to help people at the end of life.
4. Developing a checklist to help carers who are caring for someone at the end of life.
5. Recruiting a nursing team to provide advice and deliver care in a variety of settings across the county through the night.
6. Increasing the number of end of life care beds outside of hospitals.
7. Created a new welfare benefits service to ensure people at the end of life and their carers receive appropriate financial entitlements.

There is still more to be done so by completing the questionnaire you can help shape the future plans for end of life care.

Most people in Lincolnshire currently die in hospital, but nationally more people say they want to die at home. A local survey of Lincolnshire GPs in 2009 highlighted that less than half of people died in their place of choice.

Cancer is the underlying cause of a third of deaths in Lincolnshire, yet the majority of those who access specialist end of life care services are people with cancer.

Lincolnshire's population aged 65 years and over is projected to grow by 2030 and the number aged over 85 years will increase considerably. People are living longer, often with serious multiple illnesses, and with fewer people available to care for them.

The number of older people living alone in the county is projected to increase by 2030, from 53,110 to 96,348.





## Getting it right everywhere

Most people think end of life care is mainly provided by hospices and hospitals. This is not the case as we can see below:

In Lincolnshire in 2009:

- 3807 people died in hospital (54%)
- 1462 died at home (21%)
- 1390 died in a care home (20%)
- 115 died in a hospice (1%)
- 290 died in a community hospital (4%)

Hospital will continue to be the most appropriate place for some people at the end of life however care still needs to be improved – Nationally “54% of the most serious complaints in acute hospitals relate to the care of the dying and bereaved” (Healthcare Commission 2007).

Training professionals in end of life care is a key priority. The specialist end of life workforce (palliative care doctors, Macmillan Nurses etc) will never be able to meet everyone’s needs. It is important that other professionals are trained and feel skilled to provide end of life care. The total health and social care workforce in Lincolnshire (who may care for someone at the end of life, at some point) is estimated to be in excess of 20,000 people.

**If you would like a copy of this document in large print, Braille or in another language please contact Customer Services Centre on 01522 782060**

## Feedback

Death and Dying has often been called the last taboo and we need your help and ideas. If we don't talk about what we want at the end of life, we will not be able to make improvements that really matter to you. Only a third of people have discussed their end of life wishes with anyone. We would really appreciate it, if you could take the time to answer the following questions, tear off this sheet and return it to the freepost address overleaf.

You will then be entered into a free prize draw to win a Tastes of Lincolnshire Hamper worth £50

**Q1.** All of these are important, however which are the most important to you?  
(1 being most important, 5 being least important)

- Help people talk about dying so that they, and their families, are prepared
- Make sure family and carers are central and critical partners in end of life care
- Make sure that people will be in the company of others who care about them when they die
- Provide end of life care that is available to patients locally during the day and night
- Help people be cared for and die in their preferred place of choice where possible

**Q2.** Have you ever discussed with someone what your wishes would be at the end of life in any of these areas?

	Yes in detail	Only a bit	No not at all
Medical needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Spiritual and religious needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Privacy and peace	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dying with dignity (eg respectful care and support)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Where you would prefer to die	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain relief	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Q3.** If you ticked no to any of the above, please tick below why you have not discussed this issue with anyone? (tick all that apply)

- I don't feel comfortable talking about death
- Death feels a long way off
- I'm too young to discuss death
- There is no one available to me to talk about death
- Other people do not want to talk to me about my death

Other, please specify

**Q4.** How confident are you in planning the following?:

	Very confident	Fairly confident	Not very confident	Not confident at all
Getting the right sort of end of life care and support from family and friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Getting the right sort of end of life care and support from professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your finances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your funeral arrangements	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Q5.** Thinking about yourself when the time comes, where would you prefer to die? (please tick one only)

- At home
- In a hospice
- In a care home
- In a hospital
- In a nursing home
- Don't mind
- Don't know

Somewhere else, please specify

**Q6.** When the time comes for your death, please tell us what would be the most and least important thing for your end of life care by ranking the options below? (1 being most important, 6 being least important)

- To be pain free/to be without pain
- To retain my dignity eg respectful care and support
- To be with my family/friends
- To be peaceful/calm
- To be sure I am not a burden on other people
- For people to listen and be respectful of my wishes

**Q7.** Are there any other issues important to you?

## About You

Please take a moment to complete the information below, we will not use it to identify you, only to help us analyse the data more effectively

**Q8.** Are you?

Male

Female

**Q9.** What is your age group?

Under 18

51-60

91 plus

18-30

61-70

Prefer not to say

31-40

71-80

41-50

81-90

**Q10.** What is your religion/belief system, even if you are not currently practising?

Christian (including C of E, Catholic, Protestant and all other Christian denominations)

Hindu

Humanist

Jewish

Atheist

Muslim

Agnostic

Buddhist

Sikh

Prefer not to say

Any other religion/belief, please specify

**Q11.** Do you consider yourself to have a disability?

Yes (go to Q12)

No

**Q12.** If 'yes' please tick any of the boxes that apply to you

Visual Impairment

Mental Impairment

Physical Impairment

Learning Disability

Hearing Impairment

**If you would like to be entered into a free prize draw. Please complete your details below**

Name

Address

Telephone number

Email address

**Please return the completed questionnaire to:  
Freepost L148, PPI Team, Cross O'Cliff Court, Bracebridge Heath, Lincoln, LN4 2BR (no stamp is required)  
Closing date: 4 January 2011**

All data provided will remain confidential and will only be used for the purpose of service improvement and will be processed in accordance with relevant legislation, in particular the Data Protection Act 1998.