This draft charter was produced in partnership across health, social care and other organisations in the North East of England, and with the involvement of patients, carers and their representatives.

It has been updated and amended to take account of the views expressed by members of the public and professionals during the consultation exercise which ran between October and December 2009.

To access more information on ‘a good death,’ the charter and the consultation carried out, please visit our website: www.agooddeath.co.uk
Breaking the taboo

The concept of a good death is uncomfortable for some people. Let’s face it - who gives a second thought about dying when driving the car, walking the dog or doing the weekly shop?

It is understandable that any thought of planning ‘a good death’ gets pushed aside when it can seem like such a long way off. Although the media remind us frequently that we can all expect to live longer than our parents the reality can be somewhat different. Death is a part of life for us all, young and old alike.

The challenge we face is to break the taboo and make death easier to talk about, so that when the time comes our wishes and plans can be openly shared with others. This is why we have developed a charter that can help start conversations and set standards of what we can all expect for the care we receive at the end of our lives (see pages 4 and 5).

“Our vision at NHS North East is that the region will have the highest quality services to support individuals - along with their families and carers - in the choices they make as they approach death. By ‘a good death’ we mean one which is free of pain, dignified, in the place of one's choosing, and with family and friends nearby.

Our pledge is to create a charter for end of life care. This includes a statement of the rights and entitlements that should be honoured for the individual preparing for death, as well as for their carers and families.

To make sure that the charter we developed reflected all of this, we asked patients, carers, the general public, charities and clinicians what makes ‘a good death’ and invited them to share their views on the charter. The overwhelming response was that the charter could help break the taboo and encourage people to talk more openly about death, whilst also giving people information on what they could expect for their end of life care.

Surprisingly the charter does not focus on dying – it is about living with dying and ensuring we live life to the fullest of our potential.

Our next steps

Our top priority is to encourage everyone to read and adopt the principles of the charter, to make sure that our key goals are achieved as follows:

• Make sure that the charter is adopted in all parts of the North East
• Work with communities and organisations so that death is seen as a normal part of life that we all need to plan for
• Make sure services provide the best and most sensitive care for dying people and their families when they need it
• Assess and improve the quality of all services, on a continual basis

We are also taking a number of actions to make sure that our goals can be achieved:

• Working closely with local communities to identify the issues that matter to them most, taking account also of equality, diversity, faith and belief
• Developing workforce training and encouraging employers to develop policies sensitive to the needs of people with a terminal diagnosis, their carers and the bereaved
• Encouraging education of school children and students to make sure that death starts to be seen as a normal part of life in all parts of our society
• Working with housing providers and planners, addressing the North East preference to die at home

The coming months and years following the launch of the charter will see individuals, organisations and wider society coming together to create more compassionate communities within the North East to the benefit us all.
Will the charter make a difference?

Over 55% of the population die in hospital, but our research shows that 90% of us in the North East would choose somewhere else. This is a key example of how the charter will improve experience as it sets out to break the silence when no one seems to know what to say. Use it as a way to spark discussion of what you want, whatever your circumstances, to make sure that when the time comes you will experience what to you is ‘a good death.’

From an early age we are encouraged to plan for all possibilities, turning to experts for education, careers advice, training or financial guidance. But 70% of the North East population have no plan for death. By creating a society where death is accepted as a normal part of life, we can take a giant step in shifting attitudes and recognising that we all have a responsibility to be compassionate to the needs of those who are dying.

Our vision

Our vision at NHS North East is that the region will have the highest quality services to support individuals - along with their families and carers - in the choices they make as they approach death. By ‘a good death’ we mean one which is free of pain, dignified, in the place of one’s choosing, and with family and friends nearby.

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Surprisingly the charter does not focus on dying – it is about living with dying and ensuring we live life to the fullest of our potential.
The charter: compassion at the end of life

All of us should have the right at the end of life to experience a good death and our family, partners or other carers deserve support and compassion at this time.

Sensitive and appropriate end of life support should begin at the time illness is identified and continue throughout ill health, during death and in bereavement. It should be available to people coming to the end of life at any age and from any condition.

This charter will guide health, social care, community, voluntary and other organisations, groups or individuals who plan, develop and provide end of life care or support. It will help to ensure the right services are available at the right time for individuals who are dying, their families and carers.

All care providers should be aware of the charter, and its impact on their work, not only those who work specifically in end of life services.

Principles of a good death

Respect:
- To see death acknowledged as a part of life
- To be treated with dignity, respect and privacy, according to our wishes
- To value each individual and the contribution we may still wish to make to our family, job or social network, in a caring and supportive way
- To have clear, honest and tailored information and good communication throughout illness or frailty

Care:
- To have access to end of life care in the location we choose, with every effort made to support this
- To have a named key worker who will organise and coordinate care, including where this cuts across organisational boundaries
- To have clear information about whom to contact around the clock and seven days a week if advice or care is needed at home
- To be given the opportunity to make a plan for our care in advance, which takes account of our wishes and to have that respected by health, social care and all other services
- To have access to appropriate specialist support, including counselling if required, for families, partners, carers and staff. This may be before or after death occurs
- To receive speedy, practical help for the end of life
- To receive the best care and support with any social difficulties
- To have help to control physical pain and to alleviate emotional distress, if they occur

Support:
- To have support with the practicalities of dying, death and matters after death
- To receive appropriate emotional or spiritual support, with our beliefs and values honoured
- To have access to appropriate specialist support, including counselling if required

Time to plan:
- If appropriate, to be told clearly and compassionately the reality that death is coming
- To be provided, where possible, with a sense of how long illness may last and information about what can be expected, to allow time to plan
- To be given the opportunity to make a plan for our care in advance, which takes account of our wishes and to have that respected by health, social care and all other services