

'Let's talk about it'

National Background

- As a society, we need to talk more about dying and death. As individuals, we all need to have a conversation about our end of life choices and wishes with our family, friends and loved ones.
- Talking about death doesn't bring it nearer. It's about planning for life - because it allows you to make the most of the time that you have.
- There are 101 ways people find to talk about dying; there is no right or wrong way.
- Not talking about one's wishes towards the end of their lives with friends, family and loved ones can mean that people may not get what they want, or die where they want. They might not have expressed their wishes about their care or funeral, or have made a will. They may simply not have said what they wanted to say.
- Talking about dying makes it more likely that you, or your loved one, will die as they might have wished.
- Dying Matters is a broad based Coalition that has been set up by the National Council for Palliative Care (NCPC) to raise public awareness of dying, death and bereavement, to support the implementation of the Government's End of Life Care Strategy.
- The Dying Matters Coalition mission is to promote awareness and support changing knowledge, attitudes and behaviours towards dying, death and bereavement, and through this to make a 'good death' the norm.
- Everybody - whatever their age or state of health - needs to talk about their wishes towards the end of life with their friends, families and loved ones. The earlier we talk about it the easier it is emotionally and practically for everyone.
- The Dying Matters Coalition has just under 10,000 members with an interest in supporting changing knowledge, attitudes and behaviours towards dying, death and bereavement. This includes organisations from across the NHS and the voluntary and independent health and care sectors, including hospices, care homes, charities supporting old people, children and bereavement, from social care and housing sectors, from a wide range of faith organisations, community organisations, schools and colleges, academic bodies, trade unions, the legal profession and from the funeral sector.
- Most people (around 70%) would prefer to die at home, but most (around 60%) die in hospital - in many cases unnecessarily.
- While more than 70% of people report feeling confident about planning for their end of life, less than a third (29%) of people have actually discussed their wishes around dying.

In the checklist below are some of the areas that people can leave too late to discuss.

- The type of care someone would like towards the end of their life
- Where they'd like to die
- Whether they want to be resuscitated or not
- Funeral arrangements
- Care of dependents
- Save other lives - through organ donation
- How they'd like to be remembered
- Whether they have any particular worries they'd like to discuss about being ill and dying
- What they'd like people to know before they die
- The Westminster Government published the End of Life Care Strategy in July 2008. It promotes high quality care for all adults at the end of life in England by providing people with more choice about where they would like to live and die. Similar strategies for the end of life have also been developed in Wales, Scotland and Northern Ireland.
- About 500,000 people die in England every year. The majority of deaths occur in adults over 65 years old, and following a period of chronic illness related to conditions such as heart disease, stroke, liver disease, renal disease, diabetes, cancer, chronic respiratory disease, neurological diseases and dementia.
- The Department of Health End of Life Care Strategy says there are many challenges to be overcome to ensure that everyone attains 'a good death' irrespective of their background.
- Everybody deserves 'a good death' and this is more likely to be achieved by talking about it early on. Although every individual may have a different idea about what would, for them, constitute 'a good death', for many this would involve:
 - Being treated as an individual, with dignity and respect
 - Being without pain and other symptoms
 - Being in familiar surroundings
 - Being in the company of close family and/or friends

Case Study: Real life example

Tony Bonser's story

I should explain that my son, Neil, died last March 4th at the age of 35, from a sarcoma. He had first been diagnosed five years earlier, although we, that is Neil, myself and my wife, had been told that the chances of survival for five years were only fifty fifty.

No further reference to dying was made by any medical professional until two days before his death, when my wife and I were told, in Neil's hearing, that he would not be revived if he suffered a heart attack.

This information was given without any forewarning, or follow-up. At no time did Neil or the two of us have any discussion with any professional about likely outcomes, nor was any offer of support given.

Because of this, we lived in hope, probably long after there was, in fact, no hope. Neil was put to the trouble of long journeys to attempt to take part in clinical trials, when more realistic information may have saved him what were, in fact, fruitless journeys which were, in addition, emotionally and physically draining.

As a family, we were not able to plan anything in advance. We had hoped to make Neil's life as beneficial and happy as possible, but in fact most of his last six months was spent in a fruitless search for a cure, which denied him the opportunity to enjoy the time he had left. It also meant that all of us suffered high levels of anger, as his health steadily declined, and we were not aware of the likely outcome. This anger was not at medical staff, but an irresolvable anger against the disease. This manifested itself in very high levels of family tension, as the displaced anger was directed within the family. Neil, in particular, lashed out verbally at all of the rest of the family, causing great hurt, until I realised what was the root cause, being, as I was, in therapy for entirely unconnected reasons.

Another result of this lack of information was that every member of the family, Neil, myself, my wife, his sister and brother-in-law were in various stages of denial throughout the last six months of Neil's life. I still do not know at what stage Neil realised that his condition was terminal. There are signs that he had such thoughts some seven months before his death, but even two days before it, he was telling me that he would beat the cancer. I am still not sure if he was in denial or was trying to protect us. I was probably the first to accept the inevitability of his death, as I had regular recourse to therapy groups where I could discuss my feelings openly. In family discussions, although we discussed how to help Neil seemingly endlessly, it was difficult to admit to others that he might not survive.

His death caused massive stresses within the family, many probably inevitable, but I feel strongly that if we had more time to prepare, we might have found the events leading to his death easier to accept, and would certainly have been able to move through the grieving process with greater understanding.

While it might have seemed (and perhaps in the short term was) kind to spare us the anguish of knowing the likely outcome of his illness, in the long term it left us tortured by doubts as to whether we had done everything possible for him, and painfully aware that his last six months of life could have been much more pleasant and enriching for both him and the family.

In conclusion, as I gain more of a perspective on the events, I become more and more convinced that, although many people might not want to know the reality of such a situation, the effects on Neil, and subsequently on the whole family could have been made much more positive with caring, expert counselling and care from an early stage in his illness.

The estimated rise of 17% in ageing deaths which is projected for 2012 and the lack of facilities to accommodate the large increase projected has become fundamental in end of life care and dying matters (Gomes & Higginson, 2008).

Most complaints are made following the death of the patient and the Healthcare Commission suggests recurring themes including poor communication occurring between health professionals and families (Healthcare Commission, 2007; Lowson, 2007).

DNs report spending forty per cent of their time with patients providing EoLC; however over fifty percent of the complaints received by the Healthcare Commission are related to death and dying (Healthcare Commission, 2007; Sutton & Sam, 2009).

Many relatives report that they felt health professionals failed to acknowledge or communicate effectively with the patient or themselves during the EoLC they received (Healthcare Commission, 2007; Sutton & Sam, 2009). The evidence suggests patient and relatives would rather there was an acknowledgement of the unpredictability of their condition than no discussion at all (Sutton & Sam, 2009). Therefore, suggesting that healthcare professionals are often reluctant to have conversations with patients and relatives about death and dying.

Local Campaign

A multi agency project between NHS West Essex, Macmillan Cancer Support, St Clare Hospice, Social Care and Princess Alexandra Hospital.

In collaboration we aim to have a month of awareness raising locally. Throughout November we will be distributing promotional and information material, holding information stands in public places, and encouraging health and social care professionals throughout West Essex to pledge to do whatever they can to improve end of life care for their patients and encourage them to discuss and make plans, as patients do have choices.

Services Locally

- Macmillan information services/Macmillan cancer support nurses
- St Clare Hospice including 24 hour advice-line
- Marie Curie service
- Night sitters
- Out of hours drug boxes