

National Council for Palliative Care (NCPC) Briefing

Debate on access to medicine for people with terminal illnesses

Westminster Hall, 23 January 2013

NCPC is the national umbrella charity for palliative and end of life care. We also lead the Dying Matters coalition which has been set up as part of the government's national End of Life Care Strategy (DH, 2008) to raise public awareness, and change attitudes and behaviour in relation to dying, death and bereavement.

We believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition. The condition of people with terminal illnesses approaching the end of life can change rapidly, thereby requiring an urgent response. Adequate and timely provision of services and medicines is vitally important in the provision of high quality care at the end of lifeⁱ. We only have one chance to get it right for people at the end of life, so more needs to be done to ensure that people receive the care, treatment and death they wish, in the setting that they choose.

More people are **scared of dying in pain** (83%), and dying in hospital (59%), than of going bankrupt (41%) or losing their job (38%).ⁱⁱ Pain is common in advanced and terminal diseases. The *General Medical Council's guidance on end of life care* states that care towards the end of life includes palliative care that focuses on managing pain and other distressing symptomsⁱⁱⁱ. However, despite the increased availability of strong opioids to help control this pain, published evidence suggests that pain which results from advanced disease, remains under-treated^{iv}. The *National End of Life Care Strategy* clearly states that "adequate and timely provision of services and medicine" is vital to ensuring good end of life care and therefore NCPC believe that more needs to be done to ensure that people at the end of life have access to the right medicine and pain relief.

NCPC believes that the debate on access to medicine for people with terminal illnesses must be informed by the facts. Please consider that:

a. "At any time of day and night"

The National Institute for Clinical Excellence (NICE) has produced a quality standard for end of life care. The quality standard has been developed with, and endorsed by, a number of organisations championing the needs of people at the end of life and their carer(s), including NCPC. Quality statement no.4 states that:

*"People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met **at any time of day or night**, including access to medicines and equipment."^v*

We know that too many people don't get the information & care that they need when they need it. The government's independent Palliative Care Funding Review estimated that **92,000 people who need palliative care currently do not receive it.**^{vi}

Access to 24/7 care was one of the central themes of the End of Life Care Strategy (2008) and should be an area of continuing national priority. However, evidence suggests that significant gaps in provision remain. The 2011 Freedom of Information request by Macmillan Cancer Support revealed that nearly half of PCTs in England are not providing 24/7 community nursing to all patients at the end of their life.^{vii}

Effective pain relief, at any time of day and night, can vitally improve the quality of life for people approaching the end of life. NCPC do not believe that it is acceptable to only offer pain relief during certain hours of the day, or to people suffering with certain conditions. We believe that everyone should be entitled to effective pain relief and to be made as comfortable as possible during their last few months of life.

b. Poor pain relief at home

Almost **two thirds (63%) of people in England would prefer to die at home**^{viii}. However a recent national survey of bereaved relatives (VOICES) showed that pain relief at home for people in their last 3 months of life was poor.

When asked “how well was the pain relieved?” **only 17% of people reported that their loved ones had been completely relieved of pain, all of the time, whilst being at home.** Pain relief was reported most effective in a hospice setting with 62% of people reporting complete pain relief, followed by 45% of people in care homes and 36% of people in hospital^{ix}.

NCPC believe that more needs to be done to ensure that people with terminal illnesses approaching the end of life, can die in their place of choice, free from pain. Better access to pain relief medication at home is vital in enabling this to happen. However, there are a whole host of other issues involved that we must also get right, including communication and coordination of all care teams involved in the person’s care, for the care staff to be well trained in the use of opioids at the end of life, the role out of ‘just in case’ boxes to ensure medication is always available, and for the carer(s) to feel fully supported at all times.

c. Reducing unplanned admissions

For people approaching the end of life, effective medication to manage symptoms and pain is essential to ensure that people can be cared for in the setting they prefer. If the person approaching the end of life and their carer(s) do not feel fully supported in the access to or use of such medication then unplanned, and often unnecessary, hospital admissions can occur.

Being rushed back and to from hospital in the last few months of life can be extremely unsettling and distressing for people with terminal illnesses. In some cases this is due to the person or their carer not having the right medication or support to manage their symptoms or pain. Better information and access to medication would go some way in reducing these hospital admissions and ensuring that people with terminal illnesses can be cared for in their preferred setting, right up until the end of life.

Unplanned hospital admissions are extremely costly meaning that there is an economic case for change as well as the moral case: by meeting people’s wishes we can reduce the enormous costs associated with unnecessary admissions to hospital, inappropriate and unwanted medical interventions and inappropriate care. An inpatient admission in the last year of life that ends in death costs the NHS approximately £2,352 - £3,779. Getting end of life care right can help the government save money and redeploy funds to where they are most needed to meet people’s wishes^x.

d. The public are scared of talking about dying

As previously stated, more people are **scared of dying in pain** (83%), and dying in hospital (59%), than of going bankrupt (41%) or losing their job (38%).^{xi} Given the economic downturn, this truly says something about the force of the taboo in our society.

With open discussion and planning there is no good reason why people should die in pain or (in the great majority of cases) in hospital. And whilst we cannot prevent people from dying or being told they are terminally ill or dying, we can ensure that people’s experience of death is as good as possible, through early discussion, planning and timely access to palliative medicine. People are more likely to receive the care and treatment they desire if they discuss their end of life wishes with their doctor and loved ones.

e. Professionals are reluctant to discuss dying

A survey published in March 2012 by the Royal College of Physicians found that **only a third of doctors had attended end of life care training in the last five years**. NCPC believe that this lack of training could be seen as a barrier to people approaching the end of life accessing the effective medicine they need. We have welcomed the College's call for all hospital doctors, not just palliative care doctors and geriatricians, to receive training in end of life care, starting at undergraduate level and continue through postgraduate training.^{xii} A better understanding by professionals of palliative and end of life care is vital in ensuring that people get the treatment and pain relief they need in a timely and effective manner.

GPs play a crucial role in end of life care. They oversee the care received by people approaching the end of life, including their access to medication. NCPC & Dying Matters are currently rolling out low-cost, effective training to build the confidence of GPs to initiate end of life care conversations with people that are terminally ill. This leads to better communication and planning and therefore more people having their end of life care wishes met.

Quality of life for people approaching the end of life

NCPC believe that we need to get it right for people with terminal illnesses when they are approaching the end of life. Allowing people who are terminally ill to live as well as possible for as long as possible is essential. NCPC believe that everyone should experience an excellent quality of life, right up until the very end. Access to the right medication and timely pain relief can ensure that someone's last few months of life are not made more painful or complicated than they need to be. We only have one chance to get it right for people at the end of life, and the memory of their death will live on in the memory of others forever. Better communication, training and planning are all vital to ensure that people who are terminally ill can access the right medication at the right time.

Further information

We would be happy to provide any parliamentarian with further background information on the current state of palliative and end of life care to inform this debate. Please contact:

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About NCPC & the Dying Matters coalition

The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. We work with government, health and social care staff and people with personal experience to improve end of life care for all.

NCPC is a registered charity number 1005671 and a company limited by guarantee number 2644430. Visit www.ncpc.org.uk for more information.

We lead the national Dying Matters coalition, which currently has over 16,000 members, to change knowledge, attitudes and behaviours towards dying, death and bereavement, and through this to make 'living and dying well' the norm. Visit www.dyingmatters.org for more information.

References

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- ^{iv} National Institute for Health and Clinical Excellence (May 2012) *Quality Standard: Opioids in palliative Care* [<http://www.nice.org.uk/nicemedia/live/13745/59285/59285.pdf>]
- ^v National Institute for Health and Clinical Excellence (August 2011) *Quality standard for end of life care for adults* [<http://publications.nice.org.uk/quality-standard-for-end-of-life-care-for-adults-qs13/quality-statement-4-holistic-support-physical-and-psychological#quality-statement-4>]
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- ^{xii} *Care of patients at the end of their lives must improve, says Royal College of Physicians*, March 2012 www.rcplondon.ac.uk/press-releases/care-patients-end-their-lives-must-improve-says-royal-college-physicians