

**THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE**



The Road Ahead

Strategy 2015-2018

What do we want to see?

At the National Council for Palliative Care our vision is that everyone who has palliative care needs or is approaching the end of life, dying or bereaved should receive the high quality care and support they need, where and when they need it.

Why are we needed?

Every minute someone in the UK dies but many people who are approaching the end of their life do not get the care and support that they need. This means they are not able to live as well as they can until they die. As a society we are also uncomfortable about discussing dying, death and bereavement and despite welcome progress many remain reluctant to record their end of life wishes. That is why we need to change the nation's approach to dying. The National Council for Palliative Care (NCPC), as the umbrella charity for the sector, provides leadership and support across all sectors in palliativeⁱ and end of life careⁱⁱ, to do this

How do we work to make this happen?

We want to ensure that the quality of care and support that everyone experiences in dying, death and bereavement is of a high standard. We provide leadership and support for palliative and end of life care to:

- Identify key issues and challenges for palliative and end of life care
- Provide solutions, promote innovation and research
- Advance the cause and practice of palliative and end of life care
- Forge collaboration and connections
- Mobilise people to make end of life care better
- Provide a strong voice on end of life issues, including to policymakers, government, opinion formers and the media
- Recognise that people die in many different settings and from a variety of conditions, and ensure that high quality care is available wherever they are
- Gather and use evidence and new thinking to spearhead transformation
- Be a critical friend to all relevant authorities and agencies
- Campaign for high quality palliative and end of life care to be everyone's business, and not just restricted to specialists
- Raise awareness about the importance of discussing and planning ahead for the end of life

As an organisation we will:

- Listen to people with personal experience of end of life care, enable their voices to be heard and ensure that their needs and priorities underpin all of our work. We will ensure that we listen to a diverse range of experiences and views. Expand our reach by increasing the number and range of individuals and organisations we work with, including people with personal experience, NCPC subscribers, members of the NCPC led Dying Matters coalition and our network of partners
- Maintain and improve the benefits we offer to our subscribers and partners
- Maintain and build strong trusted relationships
- Ensure that everything we say is informed by the best available evidence
- Measure and regularly review our reach and impact
- Maintain and grow our income in a sustainable way
- Prioritise our work according to resources

We work with adult services in England, Wales and Northern Ireland, and with our partners in children and young people's services across the UK and Ireland to ensure that end of life and palliative care remains a priority for society, policy makers, politicians, commissioners and service providers.

We work with a broad range of partners and networks, across health, social care and housing, to gather information and evidence to identify and promote good practice and other factors that improve people's experience and quality of care and support. A key part of our work is leading the Dying Matters coalition, which aims to raise public awareness about the importance of talking more openly about dying, death and bereavement, and of taking practical steps to make your wishes known – and we are committed to supporting people to do this.

We believe that

- Dying, death and bereavement are important and inevitable parts of life
- People should be supported to live as well as they can until they die
- People who care for those approaching the end of life should be supported and recognised as partners in care
- Care and support in dying, death and bereavement should be of a universally high quality
- End of life care should be core business for all organisations working in health, care and supportive housing
- Compassionate, dignified and personalised care and support is of paramount importance
- Good end of life care should be sensitive to people's beliefs, whether these have been influenced by their religion, cultural attitudes or ethical perspective

What are we going to do? (Our priorities)

To achieve our vision we will focus on four inter-linked objectives:

Change Attitudes

- Influence decision-makers and mobilise public opinion to ensure that end of life care is seen as a core priority at every level
- Challenge taboos and indifference about dying, death and bereavement

Change Behaviour

- Educate and support health and care organisations and staff to make end of life care a core aspect of their work
- Support people to discuss and plan ahead for dying, death and bereavement in a better-informed and more competent and confident way

Improve Care and Support

- Promote good practice across health and care settings, professional groups and organisations
- Advocate for improved services, care and outcomes

Improve Evidence and Intelligence

- Work in partnership to build the national evidence base for palliative and end of life care
- Encourage innovation by working more closely with research bodies, service improvement bodies and other partners

Definitions of palliative and end of life care

Palliative care has been defined by the National Institute of Health & Care Excellence (NICE) as follows:

Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

Palliative care aims to:

- Affirm life and regard dying as a normal process
- Provide relief from pain and other distressing symptoms
- Integrate the psychological and spiritual aspects of patient care
- Offer a support system to help patients live as actively as possible until death

For end of life we are working from the following definition, which is based on the definition used in the End of Life Care Strategy (2008). We have also combined aspects of the definition used by the General Medical Council (GMC):

End of life care is care that: Helps all those with frailty or advanced, progressive, incurable illness, those at risk of dying from a sudden acute crisis in an existing condition and those with life-threatening acute conditions caused by sudden catastrophic events, to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

About the National Council for Palliative Care

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 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. We work with government, health and social care staff and people with personal experience to improve end of life care for all.

Since 2009 NCPC has led the Dying Matters coalition. Dying Matters is a coalition of 30,000 members across England and Wales which aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life.

NCPC is a registered charity number 1005671 and a company limited by guarantee number 2644430.

NCPC is governed by a Board of Trustees appointed for their expertise in health and social care

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