

MEDIA RELEASE FROM THE NATIONAL PALLIATIVE AND END OF LIFE CARE PARTNERSHIP

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NEW AMBITIONS RAISE THE BAR FOR END OF LIFE CARE

National framework for action urges local leadership to be at forefront of improvement in end of life care

The National Palliative and End of Life Care Partnership, made up of statutory bodies including NHS England, the Association of Adult Social Services, charities and groups representing patients and professionals has developed a framework for action in making palliative and end of life care a priority at local level.

Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020, is aimed at local health and social care and community leaders. It builds on the Department of Health's 2008 Strategy for End of Life Care and responds to an increased emphasis on local decision making in the delivery of palliative and end of life care services since the introduction of the Health and Social Care Act 2012.

Since the publication of the strategy, good progress has been made in end of life care but there is still much more that needs to be done. Research by Hospice UK and the National Council for Palliative Care, carried out last year, show that only around four in ten (43 per cent) Health and Wellbeing Boards in England include the needs of dying people in their key strategies that shape health and social care services [1].

Yet over the next 25 years, the number of deaths will increase by around 100,000 more deaths each year [2]. The UK is considered a world leader in end of life care but a recent Ipsos MORI survey commissioned by Marie Curie found that carers say seven out of 10 people with a terminal illness in the UK do not get all the care and support they need [3].

This national framework for action sets out six 'ambitions' – principles for how care for those nearing death should be delivered at local level

1. Each person is seen as an individual
2. Each person gets fair access to care
3. Maximising comfort and wellbeing
4. Care is coordinated
5. All staff are prepared to care
6. Each community is prepared to help

The framework identifies measures such as personalised care planning and shared electronic records that are needed to realise each of the six ambitions, and calls on Clinical Commissioning Groups, Local Authorities and Health and Wellbeing Boards to designate a lead organisation on palliative and end of life care and to work collaboratively to bring people together to publish local action plans based on population based needs assessments.

The partnership of organisations with responsibility for end of life care, including NHS England, Public Health England, CQC, Marie Curie, the National Council for Palliative Care, Macmillan Cancer Support, Sue Ryder, Hospice UK, Together for Short Lives, and groups representing patients and professionals such as the Association of Adult Social Services, the Patients Association and the Royal Colleges of Nursing, GPs and Physicians, are committed to support a drive in improvement of care for people of all ages, babies, children, young people and adults', and in all social settings, to monitor progress and influencing change.

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Quotes from members of the partnership steering group:

Prof Bee Wee, National Clinical Director for End of Life Care, **NHS England** said: "This framework represents a shared vision for the quality of care that people should expect to receive towards the end of their lives, and a shared commitment to help local decision makers, service providers and people to improve the services in their area."

Dr Jane Collins, Chief Executive, **Marie Curie** and Co-chair of the National Partnership for End of Life Care said: "We welcome the development of these Ambitions for End of Life Care. While much progress has been made since the 2008 End of Life Care Strategy, more needs to be done and particularly in service delivery at local level. This document provides us with a new opportunity to support local leaders of health and social care services to implement what is needed to improve end of life care for everyone. We also welcome the commitment of our partners in the National Partnership for Palliative and End of Life Care to continue to work together to influence change. Marie Curie provides care and support for people living with a terminal illness and their families in their own homes or in one of our nine hospices across the UK. We are committed to working with our NHS partners at local level ensure that this framework's ambitions are realised."

John Powell, Policy Lead for End of Life Care, **Association of Adult Social Services** said: "The role of social care in delivering the Ambitions locally is essential to ensuring that personalised support plans for people with palliative and end of life care needs are in place. Putting people at the centre of their support planning is key to getting things right and I am delighted that ADASS is a partner in developing and promoting these Ambitions and this will allow social care to play its part in improving outcomes for people approaching their end of life."

Claire Henry, Chief Executive of the **National Council for Palliative Care** said: "Just as it's often said that it takes a village to raise a child, it takes communities working together to ensure that people who are dying receive the care and support that is right for them. That's why we welcome the ambitions set out in this document and the commitment to partnership working that runs throughout it. We very much hope this leads to strong and sustained national and local leadership and action, so that end of life care is made universally available for everyone, wherever they live, whatever their diagnosis, wherever they choose to be cared for, and whenever they need it."

Adrienne Betteley, End of Life Care Programme Lead at **Macmillan Cancer Support** said:

“This welcome document gives clarity to what good end of life care looks like, as well as who is responsible for ensuring everyone is enabled to die in a place and manner of their choice. Too often people with cancer at the end of life tell us they aren’t able to access support they so badly need, resulting in expensive emergency hospital admissions, and ultimately a lack of choice for people at an incredibly important time. It is now vital that these important steps become more than just ambitions and that they are fully adopted and implemented so that we can ensure consistent access to high quality palliative and end of life care.”

Commenting on *Ambitions for Palliative and End of Life Care* Professor Edward Baker, deputy chief inspector of hospitals, said: “The **Care Quality Commission** welcomes the ethos of the Ambitions that a person’s care in the last stage of their life should be as good as it can be.

“Our role is to inspect the quality of end of life care services. We know from our inspections so far there are services that are providing good and outstanding care for people at the end of their lives across hospitals, care homes and hospices. However, there are many services that are not delivering this. The priority now must be for services in all areas to adopt the Ambitions and take action to ensure that services are consistently of high quality.

“Where people are cared for – whether that is in a hospital, a nursing home, in a hospice or in a person’s own home – should not matter. What is important is that the person is able to access co-ordinated and individual care based on their needs, delivered with compassion and sensitivity by caring health and care professionals and that there is regular and effective communication between staff and the dying person and their family.

“Our upcoming thematic review will look at the inequalities and variation of care, particularly examining why certain groups of people have less than positive experiences.

“We are committed to ensuring the quality of end of life care continues to improve across all the services that we inspect.”

Commenting on the new national framework – *Ambitions for Palliative and End of Life Care* - Jonathan Ellis, Director of Policy and Advocacy at **Hospice UK**, said:

“This welcome, new national framework sets out a clear vision to leaders of local services about what needs to be in place for the provision of high quality end of life care.

“We hope these ambitions will provide fresh impetus for change and galvanise leaders of health and care services to take active steps to improve end of life care for all. This urgently needs to happen if more terminally ill people are to have more choice about where they receive care and so they receive support that is right for their needs.

“Hospices across the country are working with hospitals, care homes and other providers to promote best practice in end of life care and improve service provision. Hospice UK is committed to working with hospices to expand this work and to turn this new framework’s ambitions into reality across all care settings.”

Katrina McNamara, Director of Service and Practice Development, **Together for Short Lives** said:

“Planning and talking about end of life care for babies, children and young people is challenging. Many professionals tell us that they struggle to talk about childhood death. Yet when families are supported to make choices that are right for them and plan for their child’s end of life care, it can make all the difference. Families need to know that their child will be given the best end of life care that is based on the child’s and families individual needs and is right for the child or young person’s age. And excellent care and pain and symptom management for a dying child should be central to their care.”

“This Ambitions document provides a much needed framework to develop a culture of good end of life planning for all at a local level – based on quality of care and on the wishes of the individual, regardless of their age. Everyone should be supported to have as good death as possible. It’s so hard for anyone to cope with childhood death; so we must do everything we can to help fulfill families’ end of life wishes for their child as these memories will stay with the family forever.”

Professor Julia Verne, Clinical Lead, National End of Life Care Intelligence Network at **Public Health England**, said:

“Ensuring that local services are informed of, and have access to reliable data that is useful and timely is key if we want services to improve. PHE is committed to providing the best possible data and intelligence, building on the evidence base and communicating this effectively. We aim to support the NHS and its partners to deliver against these ambitions and improve the quality end of life care in England.

“There are a number of existing services doing good work to make sure people end their days with options and access to high quality care, but there is room for improvement. We are pleased to be part of this partnership and hope this new framework will inspire local teams and organisations to understand their own situation and what they can do to progress.”

Sam Cheverton, Assistant Director of Palliative Services at **Sue Ryder**, said: "We are delighted to be working in partnership in producing this new framework which aims to improve care for people nearing the end of life.

"Sue Ryder research shows that the two main factors most important to people when they are dying are: being free from pain and discomfort (78% of people surveyed) and being surrounded by their loved ones (71%). This was followed by: having privacy and dignity (53%); being in familiar surroundings (45%) and being in calm and peaceful atmosphere (45%)

"Fulfilling patients’ needs and preferences as much as possible is the cornerstone of good end of life care and helps to ensure someone has as good a death as possible. A good death is all about coordinated, personalised and compassionate care, where the dying person and their loved ones have access to the support services that they need and want 24/7. It’s also about making someone as comfortable as possible through pain and symptom

management - whilst also providing psychological, social, emotional and spiritual support to the individual as well as their carers and family.

"Across our hospices, in our neurological care centres and out in the community, we work closely to find out what the most important elements of end of life care are for our patients and their loved ones to ensure they have can have a good death. We are pleased this new framework encourages such best practice to be implemented at a local level.

"Sue Ryder is committed to supporting the aims and ambitions set out within this framework and will be working with our partners and independently to encourage the implementation of the changes needed to improve end of life care."

Notes to editor

About the National Palliative and End of Life Care Partnership

The National Palliative and End of Life Care Partnership has been formed from members of the Association of Directors of Adult Social Services; Association of Ambulance Chief Executives; Association of Palliative Care Social Workers; Association for Palliative Medicine; the Care Quality Commission; College of Health Care Chaplains; General Medical Council; Health Education England; Hospice UK; Macmillan Cancer Support; Marie Curie; National Bereavement Alliance; National Care Forum; National Council for Palliative Care; National Palliative Care Nurse Consultants Group; National Voices; NHS England; Patients Association; Public Health England; Royal College of GPs; Royal College of Nursing; Royal College of Physicians; Social Care Institute for Excellence; Sue Ryder; and Together for Short Lives.

This statement of our collective ambition represents the start of our work. We will follow this statement of intent with our own actions and commitments, as individual organisations and collectively.

Download Ambitions for End of Life Care at www.endoflifecareambitions.org.uk

References

[1] Hospice UK and National Council for Palliative Care (2014) *Mapping England's Health and Wellbeing Boards' vision for dying people*

[2] ONS (2014) *2012-based National Population Projections*

[3] On behalf of Marie Curie, Ipsos MORI interviewed a sample of 1,067 adults aged 16 – 75 online who had cared for a family member, friend or neighbour who was, or is, terminally ill in the last 3 years. This sample was screened from a nationally representative sample of 6,136 online adults aged 16-75 within the UK. Interviews took place between across the UK using i: Omnibus, Ipsos MORI's online omnibus between 3rd and 29th October 2014. Data are weighted by age, gender, region, working status and social grade to match the profile of the target audience.

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