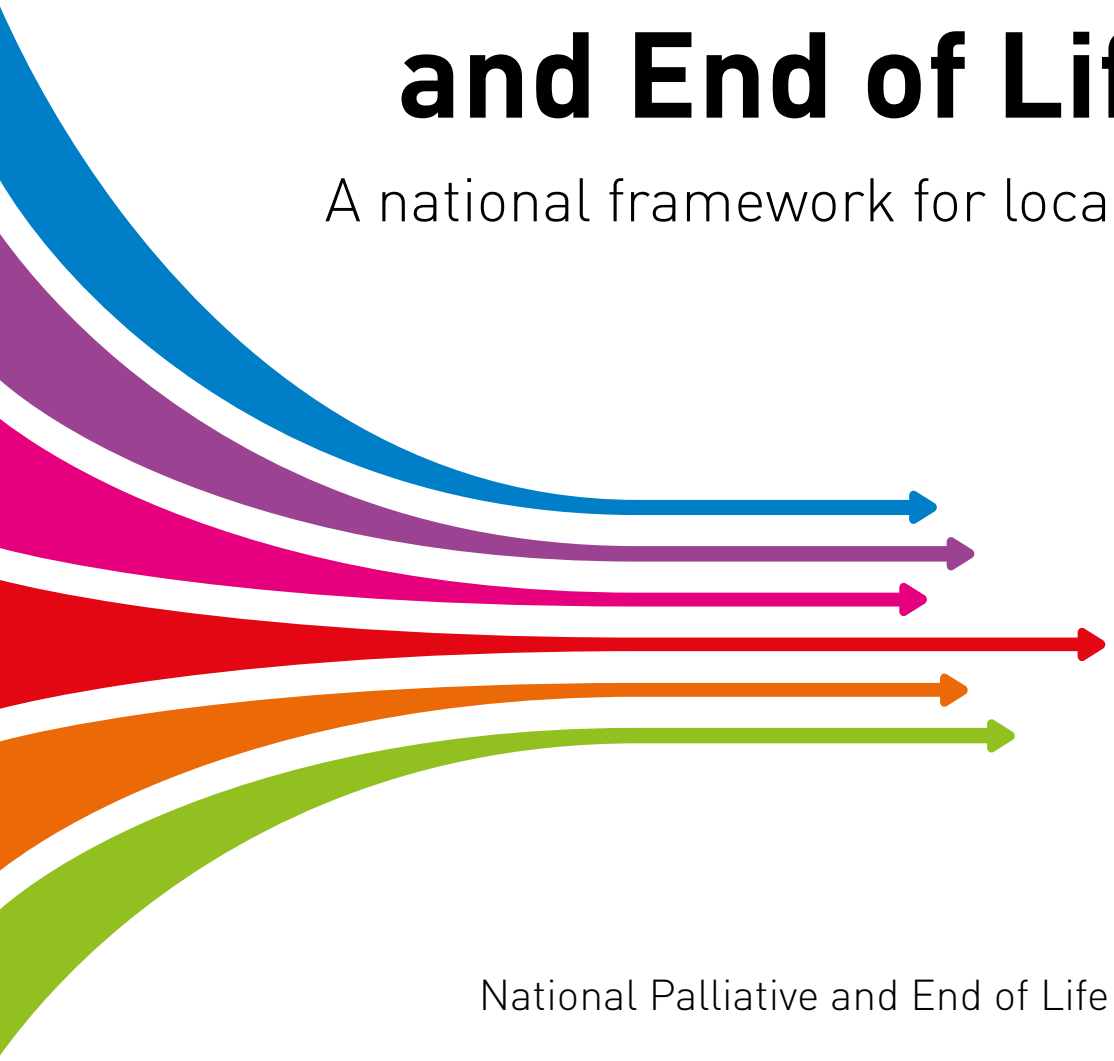
Ambitions for Palliative and End of Life Care:

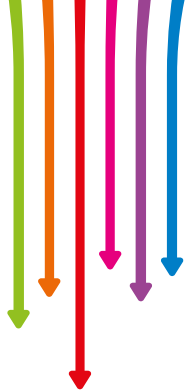
A national framework for local action 2015-2020



National Palliative and End of Life Care Partnership

National Palliative and End of Life Care Partnership

Association for Palliative Medicine; Association of Ambulance Chief Executives;
Association of Directors of Adult Social Services;
Association of Palliative Care Social Workers; Care Quality Commission;
College of Health Care Chaplains; General Medical Council;
Health Education England; Hospice UK;
Macmillan Cancer Support; Marie Curie;
Motor Neurone Disease Association; National Bereavement Alliance;
National Care Forum; National Council for Palliative Care;
National Palliative Care Nurse Consultants Group; National Voices;
NHS England; NHS Improving Quality;
Patients Association; Public Health England;
Royal College of General Practitioners;
Royal College of Nursing; Royal College of Physicians;
Social Care Institute for Excellence;
Sue Ryder and
Together for Short Live



"As organisations with experience of, and responsibility for, palliative and end of life care we have made a collective decision to act together to do all we can to achieve for everyone what we would want for our own families."

Executive Summary: Ambitions for Palliative and End of Life Care

National Palliative and End of Life Care Partnership
www.endoflifecareambitions.org.uk

"The will, determination and innovation of organisations working collaboratively to find new ways of delivering better care will, and must, make a difference".

The Foreword: Ambitions for Palliative and End of Life Care



"We are sharing this framework for action with local leaders in every community whether they work in the statutory, private or voluntary sectors. We expect them to plan and act, using this framework, so that these ambitions can be brought into reality."

Introduction: Ambitions for Palliative and End of Life Care



- Palliative and end of life care must be at the heart of an integrated approach to care and support
- We want to work collectively to make the care that surrounds dying, death and bereavement as good as possible, for all
- We need to set our collective sights on these six ambitions
- We ask you to designate a local lead, whether this is the Health and Wellbeing Board, Clinical Commissioning Group, or Local Authority, to lead and coordinate a process for working towards these ambitions.

Our overarching vision

"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."

'Every Moment Counts' National Voices,
National Council for Palliative Care and NHS England.



Six ambitions to bring that vision about

01 Each person is seen as an individual

02 Each person gets fair access to care

03 Maximising comfort and wellbeing

04 Care is coordinated

05 All staff are prepared to care

06 Each community is prepared to help

"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."



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The foundations for the ambitions

Personalised care planning	Shared records
Education and training	24/7 access
Evidence and information	Involving, supporting and caring for those important to the dying person
Co-design	Leadership



Foundations for the ambitions

Personalised care planning

Everybody approaching the end of their life should be offered the chance to create a personalised care plan. Opportunities for informed discussion and planning should be universal. Such conversations must be ongoing with options regularly reviewed.

Shared records

To ensure the plan can guide a person centred approach it has to be available to the person and, with their consent, be shared with all those who may be involved in their care.

Evidence and information

Comprehensive and robust data are necessary to measure the extent to which the outcomes that matter to the person are being achieved. This, alongside strengthening the evidence-base, will help to drive service improvements.

Involving, supporting and caring for those important to the dying person

Families, friends, carers and those important to the dying person must be offered care and support. They may be an important part of the person's caring team, if they and the dying person wish them to be regarded in that way. They are also individuals who are facing loss and grief themselves.

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Foundations for the ambitions

Education and training

It is vital that every locality and every profession has a framework for their education, training and continuing professional development to achieve and maintain competence and allow expertise and professionalism to flourish.

24/7 access

When we talk about end of life care we have to talk about access to 24/7 services as needed, as a matter of course. The distress of uncontrolled pain and symptoms cannot wait for 'opening hours'.

Co-design

End of life care is best designed in collaboration with people who have personal and professional experience of care needs as people die.

Leadership

The leadership of Health and Wellbeing Boards, CCGs and Local Authorities are needed to create the circumstances necessary for action. Clinical leadership must be at the heart of individual service providers.

Each person is seen as an individual

I, and the people important to me,
have opportunities to have honest,
informed and timely conversations
and to know that I might die soon.
I am asked what matters most to me.
Those who care for me know that
and work with me to do
what's possible.

01

Each person is seen as an individual

The building blocks for achieving our ambition

Honest conversations

Everybody should have the opportunity for honest and well-informed conversations about dying, death and bereavement.

Systems for person centred care

Effective systems need to reach people who are approaching the end of life, and ensure effective assessment, care coordination, care planning and care delivery.

Helping people take control

Personal budgets and integrated personalised commissioning are some of the potentially powerful tools for delivering tailored and personal care for many more people.

Clear expectations

People should know what they are entitled to expect as they reach the end of their lives.

Access to social care

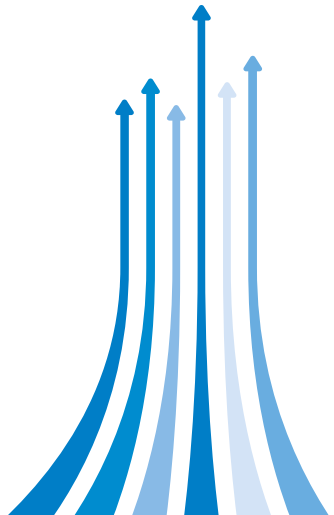
People must be supported with rapid access to needs-based social care.

Integrated care

End of life care is part of new models of integrated health and social care being promoted across the health and social care system.

Good end of life care includes bereavement

Caring for the individual includes understanding the need to support their unique set of relationships with family, friends, carers, other loved ones and their community, including preparing for loss, grief and bereavement.



Each person gets fair access to care

I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.



02

Each person gets fair access to care

The building blocks for achieving our ambition

Using existing data

Local end of life care organisations must use aggregate data to understand and remedy the partial reach of their services.

Community partnerships

Local plans should include partnerships between different faith groups and cultural communities, as well as the diverse organisations that support children and young adults, people living with different life shortening illness, and those managing the difficulties of older age.

Generating new data

Individual organisations and local systems of care should engage with initiatives to generate much more robust and useful statistical data. This can guide care, drive organisational strategies and inform local and national progress.

Unwavering commitment

To achieve equity in access, provision and responsiveness requires unwavering commitment. This should be backed up by local contracts that embed evidence-based measures of equity in provision.

Population based needs assessment

Locally, Health and Wellbeing Boards should lead the development of population based needs assessment for end of life care services. Commissioners and providers need to use this to influence their organisation of care so that they can demonstrate increasingly equitable outcomes.

Person centred outcome measurement

The comprehensive use of person centred outcome measures will enable services to be held to account. With independent analysis of a consistent data set, improvement can be tracked and regulatory actions taken to ensure all providers are enabling fair access to care.

Maximising comfort and wellbeing

My care is regularly reviewed
and every effort is made for me
to have the support, care and treatment
that might be needed to help me
to be as comfortable
and as free from distress
as possible.



03

Maximising comfort and wellbeing

The building blocks for achieving our ambition

Recognising distress whatever the cause

It is important to recognise all sources of distress quickly, to acknowledge distress and to work with people to assess its extent, its cause and what might be done.

Addressing all forms of distress

The experience of suffering associated with physical symptoms may be exacerbated, or sometimes caused, by emotional, or psychological anguish, or social or spiritual distress. Addressing this requires professionals to recognise, understand and work to alleviate the causes.

Skilled assessment & symptom management

Attending to physical comfort, pain and symptom management is the primary obligation of clinicians at this time of a person's life and their skills and competence to do so must be assured and kept up to date.

Specialist palliative care

People approaching the end of life should have access to Specialist Palliative Care when this is needed. This should include a clear understanding of how to access medicines and equipment as part of the rapid response to changing needs.

Priorities for care of the dying person

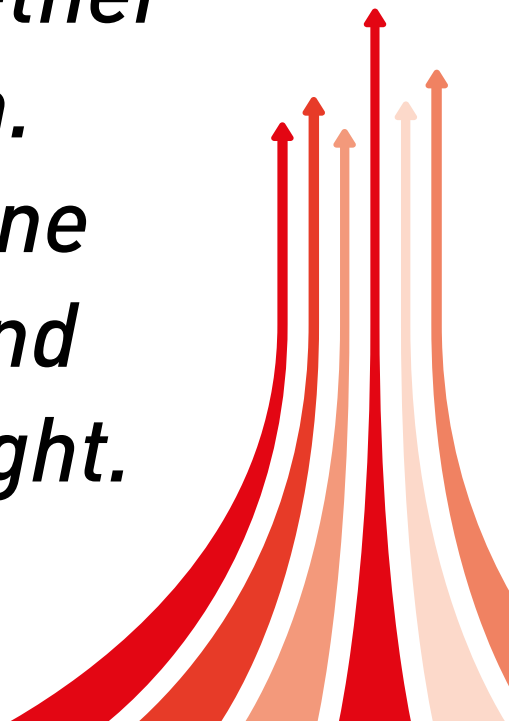
People approaching death should expect local systems to accord with the priorities identified by the Leadership Alliance for the Care of Dying People.

Rehabilitative palliative care

Maximising the person's independence and social participation to the extent that they wish requires professionals to work with, and support, the person in helping them to achieve their personal goals.

Care is coordinated

I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them.
I can always reach someone who will listen and respond at any time of the day or night.



04

Care is coordinated

The building blocks for achieving our ambition

Shared records

Care records for all people living with a long term condition must encompass their needs and their preferences even as they approach the end of life. With the person's consent, these records should be shared with all those involved in their care.

Clear roles and responsibilities

Organisational leadership is vital and information for families, carers and individuals should be joined up in a way that provides a clear oversight of the respective roles and responsibilities of providers within that system.

A system-wide response

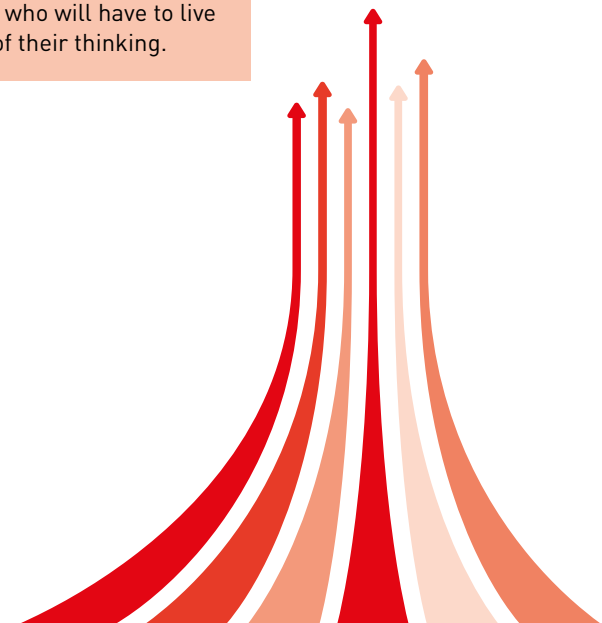
As new models of care emerge approaches have to develop to enable a better system-wide response to dying people, using a full range of coordinated services deployed in the community.

Everyone matters

Local systems of care have to put the needs of dying children and young adults, those living with frailty including at older age, and the need to anticipate and support those who will have to live with loss, at the centre of their thinking.

Continuity in partnership

Joined up care requires joined up thinking and working by individuals and by organisations. This will require active partnerships particularly between the NHS, social care and the voluntary sector.



All staff are prepared to care

Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.



05

All staff are prepared to care

The building blocks for achieving our ambition

Professional ethos

To ensure people receive the care they need paid carers and clinicians at every level of expertise need to be trained, supported and encouraged to bring a professional ethos to that care.

Support and resilience

To give care day in and day out requires organisational and professional environments that ensure psychological safety, support and resilience.

Knowledge based judgement

Only well-trained, competent and confident staff can bring professionalism, compassion and skill to the most difficult and intensely delicate physical and psychological caring.

Using new technology

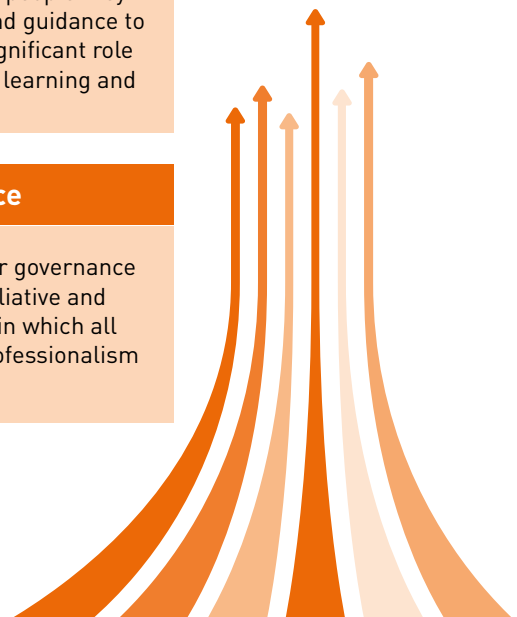
Professionals have to adapt to new ways of learning and of interacting with the people they are supporting and they need help and guidance to do so. Technology can also play a significant role in enhancing the professionals' own learning and development.

Awareness of legislation

All those who provide palliative and end of life care must understand and comply with legislation that seeks to ensure an individualised approach.

Executive governance

Every organisation should have clear governance at Board level for high quality palliative and end of life care and environments in which all staff can provide the best of their professionalism and humanity.



Each community is prepared to help

I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.

06

Each community is prepared to help

The building blocks for achieving our ambition

Compassionate and resilient communities

Public health approaches to palliative and end of life care need to be accelerated and support given to people and communities who can provide practical help and compassion.

Public awareness

Those who share our ambition should work to improve public awareness of the difficulties people face and create a better understanding of the help that is available.

Practical support

Local health, care and voluntary organisations should find new ways to give the practical support, information and training that enables families, neighbours and community organisations to help.

Volunteers

To achieve our ambition more should be done locally and nationally to recruit, train, value and connect volunteers into a more integrated effort to help support people, their families and communities.

"Death and dying are inevitable. Palliative and end of life care must be a priority. The quality and accessibility for this care will affect all of us and it must be made consistently better for all of us. The needs of people of all ages who are living with dying, death and bereavement, their families, carers and communities must be addressed, taking into account their priorities, preferences and wishes."

Foreword: Ambitions for Palliative and End of Life Care



"As a Partnership we are committed to act, help and support, both as individual organisations and by working together. This is the start of our collective engagement to turn ambitions that should by now have been standard, into a reality for all."

Foreword: Ambitions for Palliative and End of Life Care



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