



A narrative for
person centred
coordinated care
for people near the
end of life

Every Moment Counts



THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE



National Voices
People shaping health
and social care

About this narrative

- Produced by National Voices and the National Council for Palliative Care, in partnership with NHS England
- Supported by the Association of Directors of Adult Social Services
- Core production groups included: Carers Trust, Compassion in Dying, Hospice UK, the MND Association, Sue Ryder and Together for Short Lives. Contributions from Macmillan Cancer Support
- Describes some critical outcomes and success factors in end of life care, support and treatment, from the perspective of the people who need that care, and their carers and families
- Extends, and should be used together with, the ‘generic’ Narrative for person centred coordinated care
- Based on: a literature review; bespoke research on the experience of bereaved carers; coproduction with people with experience, including carers and professionals; a workshop with national organisations

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I have honest discussions and the chance to plan

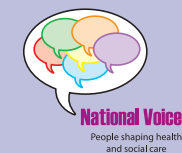
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Foreword

Dame Cicely Saunders, the founder of the modern hospice movement said:

“You matter because you are you, and you matter to the end of your life.”

As we commemorate the tenth anniversary of her death, this quote remains as relevant as ever and must remain a guiding light for us. We all face the prospect of dying one day. Most adults, and many children, experience the loss of those dear to them well before that happens. This is an intensely personal human experience. Every moment counts because, once passed, it can never be regained.

This narrative is an important milestone. It has been carefully and painstakingly produced under the leadership of National Voices working in partnership with National Council for Palliative Care and other organisations. It tells us, unequivocally, what person centred care means from the point of view of someone approaching the end of life. We use this narrative as the centrepiece for NHS England’s Actions for End of Life Care.

As a front-line clinician, I know that in the real world, it is difficult to achieve perfection for everybody every time. There can be a mismatch between what services can offer, what professionals hope to achieve and what the person, and their families, carers and those close to them seek or expect. Finding out what really matters to them – you can almost ‘hear’ the voices in this report – has to be a fundamental starting point for all of us, and establishes a proper partnership in care.

Everyone’s experience is unique: one size cannot fit all. This narrative reminds professionals and volunteers to stop, think and respond in a way that is, and feels, honest and personal to that person in front of them. It helps service providers and commissioners to look at the service they are entrusted to deliver through the eyes of the person who needs that care.

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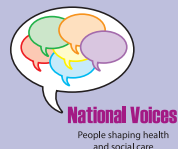
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In many statements this narrative refers to **‘the people who are important to me’**.

This group can include family, friends and other contacts, some of whom may be their carer(s).

This phrase highlights that:

- it is for the person nearing the end of life to decide who they want close to them in that period
- there are people with different kinds of importance
- professionals and services should recognise and involve carers, and others who are important to the person.

We still wish to emphasise the important role of carers and the need for services and professionals to involve them and to provide information, advice and support for their needs and their role.

Thus, where most relevant, we also use the term **‘carer(s)’**.

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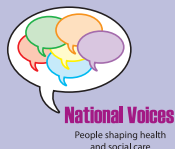
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“I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).”

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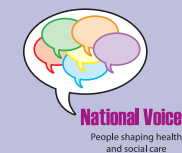
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Person centred coordinated care near the end of life

“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).”

Honest discussion and planning

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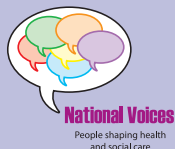
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We work for my goals and the quality of my life and death (i)

- I am respected as a whole person, not treated as an illness.
- My care plan records information about who I am: my life and past, what people value about me, my strengths and abilities, and my values.
- People who care for and support me make a special effort to understand my life.
- People who care for and support me and the people who are important to me, care for ‘the whole of us’.
- I can remain in control as much as possible. This is recognised as a key goal in my care.
- Everyone who cares for and supports me works together so that I, and the people who are important to me, can make the most of the time we have left together.

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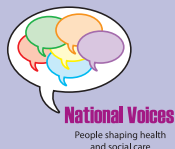
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We work for my goals and the quality of my life and death (ii)

- I can continue to achieve leisure or work-related goals that are important to me, for as long as possible.
- I can maintain my social contacts.
- I am supported to manage my symptoms and conditions as successfully as possible.
- I am able to live as actively and independently as possible at all stages of my care and treatment.
- I have time to say goodbyes and to do things which are important to me.
- My preference for my place to be cared for and to die is respected.
- I am supported as much as possible to stay where I want to be.

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I have honest discussions and the chance to plan (i)

- I have timely and honest conversations with those engaged in my care, support and treatment.
- I am confident that staff and professionals are able to have difficult conversations with me, in order for us to decide the best treatment, care and support together.
- The professionals I meet check that these conversations are happening and enter them on my record.
- I can expect these conversations to be followed up, and revisited at key times during the course of my care and treatment.
- I and my carer(s) are always given an explanation of terms that are new to us, like ‘palliative’.

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I have honest discussions and the chance to plan (ii)

- I and the people who are important to me, including my carer(s), are informed about and understand our options in relation to:
 - the illness and its uncertainties
 - the risk, likelihood and unpredictability of dying
 - what will happen in the future.

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I have honest discussions and the chance to plan (iii)

- I have information, in the format I need and that I understand, about all aspects of end of life care, including how to make choices and decisions in advance. This includes how to decide on things I don't want to happen.
- This information will include the following potential choices:
 - an advance care plan
 - advance decisions
 - creating a lasting Power of Attorney for my property and finances
 - creating a lasting Power of Attorney for my health and welfare
 - organ and tissue donation.
- I am informed that, even where I have made advance plans and choices, I have the right to change my mind at any point.
- I can understand the impact of my health and care on my finances, and make informed financial decisions.

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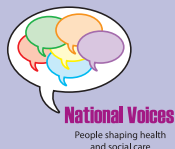
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The people who are important to me are at the centre of my support (i)

- I can decide the people who are most important to me, and how involved I wish them to be in decisions about my care.
- I may choose to put care and support from the people who are important to me, including my carer(s), at the centre of my care plan. If so, other care, treatment and support fits around us and our preferences.
- If I do not have an unpaid carer, this is recognised in my care plan and the organisation of my care and support takes account of it.
- The people who are important to me, including my carer(s) are given information, advice and support to care for me and to ensure their own needs are met.
- My carers are recognised as expert partners in my care. They are respected for their skills and for the vital knowledge they have about me, my condition and my preferences.

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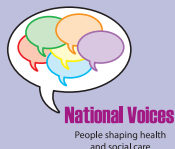
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The people who are important to me are at the centre of my support (ii)

- Whether I am at home, or somewhere else – such as a care home, a hospice or in hospital – the people who are important to me, including my carer(s) are:
 - welcomed
 - listened to, supported and respected
 - made to feel ‘part of the team’
 - given timely information
 - involved in discussions and decisions.

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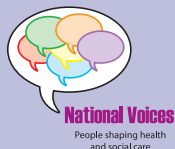
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The people who are important to me are at the centre of my support (iii)

- My carer(s) are appropriately informed about what is involved in caring for a dying person at home, and given permission and support to make choices about their role.
- My carer(s) receive the training they want and need to care for me. This may include personal care and some nursing or clinical tasks such as giving pain relief and managing medicines.
- I am satisfied that my carer(s) are informed about how to balance work and care at all stages.
- My carers are signposted to information about how to access services that provide respite from their caring role.
- I am confident that the people who are important to me will have the opportunity to get support with bereavement before and after my death.

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My physical, emotional, spiritual and practical needs are met (i)

- My care plan is designed to meet my faith, spiritual needs, or other values and beliefs.
- Taken together, the information, care and support I receive helps me feel ‘at peace’ about what will happen in the future. This may include, for example:
 - the likely course of my illness
 - what is involved in the dying process
 - anything practical I should have done but haven’t got round to
 - money
 - what will happen to me after I die (spiritually)
 - what will happen to my body after I die, including cultural or religious practices that I wish to be followed, and any wishes regarding organ or tissue donation
 - how the people who are important to me will cope after I die, and be supported to do so.

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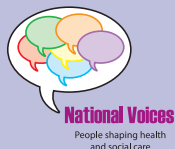
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My physical, emotional, spiritual and practical needs are met (ii)

- Wherever I am cared for, I am helped to feel
 - safe
 - in control of my pain
 - comfortable and dignified,
 - with as little fear as possible.
- There is someone at hand to help with my worries and fears, or those of the people who are important to me.

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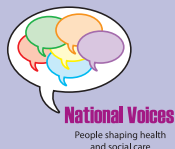
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I have responsive, timely support day and night (i)

- I have a care coordinator who supports me through decision making and acts as a problem solver to get things done quickly.
- Help is available to meet my needs at any time, day or night, from people who know about me.
- Wherever I am, I have access to pain relief and help to manage difficult symptoms.
- I have a GP practice that is aware of me, anticipates my needs, and commits to acting quickly and helping to coordinate my care.
- There are nurses available to me when I am at home. They have enough time for my care. They have time to train my carer(s) if this is wanted.
- In the time near to death, I and all those caring for me are backed up by access to specialist advice at any time of day or night.

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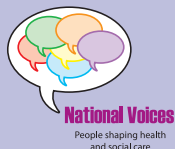
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I have responsive, timely support day and night (ii)

- Things that need to happen, do so quickly
- If my ability to communicate or to make decisions deteriorates, those working with me understand my needs. They support me to remain as involved in my care as possible
- When appropriate, I have the opportunity to visit a hospice and/or to experience hospice care at home
- When I am in hospital there are facilities designed for people in my situation, especially for the last days and hours of my life
- The hospital can accommodate people who are important to me, with a place to rest and sleep, and the chance to mix with other people doing similar caring
- Support and advice from people who have been through the same experiences is recognised as an important service, and we are given the opportunity to use it
- I can have access to a personal care budget that is easy to understand and use.

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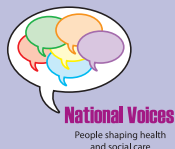
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1. Advance Decisions

- An Advance Decision allows me to make a legally binding refusal of medical treatment, in advance of a time when I lose the ability to make decisions for myself.
- I can use it to set out the specific circumstances in which I would not want a treatment to be given, or in which I would want a treatment to be stopped.
- I can use it to refuse any treatment, including life-sustaining treatment such as resuscitation, breathing machines, antibiotics or feeding tubes.
- My Advance Decision will only come into effect if I lose the capacity to make decisions for myself.
- Advance Decision is short for an Advance Decision to Refuse Treatment (sometimes referred to as an ADRT). It is also commonly known as a Living Will or an Advance Directive.

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2. Advance Statements

- An Advance Statement (also called a Statement of Wishes) is a general statement of what I want and what is important to me.
- It is written down and contains information I feel it is important for others to know, such as my food preferences, religious beliefs or daily routine.
- It will help people involved in my care to understand what I want and what is important to me if I cannot speak or make decisions for myself.
- It is not legally binding like an Advance Decision is, but it should be taken into account by health and care professionals when deciding what is in my best interests.

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3. Advance Care Plans

- Advance Care Plans will normally be made in partnership with my health team when I enter the end-of-life phase.
- An Advance Care Plan is used to record my care and treatment wishes. It should be attached to my medical notes and easily accessible to those involved in my care.
- For example the plan could set out where I want to receive care, where I want to die, who I want to be with me, and my religious or spiritual preferences.
- The most common type of end-of-life care plan is a Preferred Priorities for Care (PPC) document. If I have made an Advance Decision, Advance Statement or Lasting Power of Attorney this should be noted in my Advance Care Plan.
- My Advance Care Plan is not legally binding. But it helps people involved in my care to know what is important to me. Doctors will try to follow my wishes and take the plan into account when deciding what is in my best interests.

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4. Lasting Power of Attorney – two kinds

- These give legal power to another person or persons to make decisions on my behalf. I can choose to use one or both kinds. Each kind involves a separate application to the Office of the Public Guardian and registration fee.
- A health and welfare lasting power of attorney allows me to choose one person or more to make decisions about things like: my daily routine (such as eating and what to wear); medical care; where I am cared for; treatments that keep me alive. These powers will only be used when I am not capable of making my own decisions.
- A property and financial affairs lasting power of attorney allows me to choose one person or more to make decisions about things like collecting benefits, paying bills or selling property. If I give them permission they can start using this power straight away.

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5. Donating my organs and/or my body

- I have the right to decide what may happen to my body after my death.
- If I wish my organs to be used for donation to other people, I need to let people close to me know, and register myself on the NHS Organ Donation Register.
- I can have the choice of which organs to donate.
- If I wish to donate my body for the training of medical professionals I need to make direct contact with the medical school I wish to donate to.
- I can obtain a list from the Human Tissue Authority.

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6. For children and young people

- Children and young people under the age of 18 years who are nearing the end of life have a different legal standing to adults.
- It can be useful for them to make an Advance Care Plan to record their wishes, and those of their parents.
- This can help inform their health and care professionals in circumstances, such as an emergency, when the child or young person is unable to give informed consent for themselves and/or their parent(s) or next of kin cannot be contacted.

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National Voices

People shaping health and social care

National Voices is the national coalition of health and social care charities in England. We work together to strengthen the voice of patients, service users, carers, their families and the voluntary organisations that work for them.

We have more than 160 members with 140 charity members and 20 professional and associate members. Our broad membership covers a diverse range of health conditions and communities and connects with the experiences of millions of people.

www.nationalvoices.org.uk

 [@NVTweeting](https://twitter.com/NVTweeting)

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.

www.ncpc.org.uk

 [@NCPC_tweets](https://twitter.com/NCPC_tweets)

NCPC leads the Dying Matters Coalition which aims to raise public awareness about the importance of talking more openly about dying, death and bereavement and of making your end of life wishes known.

www.dyingmatters.org

 [@DyingMatters](https://twitter.com/DyingMatters)

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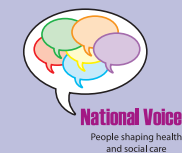
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