What does voice, rights and choice mean for people at the end of life?

Jonathan Ellis,
Director of Advocacy & Change

Outline

- What do we mean by ‘end of life’?
- What rights do we have at the end of life?
- What choices do we have at the end of life?
- Different rights for different settings?
- Equal rights?
- Making people’s voices heard

What do we mean by ‘end of life’?

‘**End of life**’ is often used to refer to people who are likely to be in the last 12 months of their life.

‘**Palliative care**’ describes “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” (WHO)

What rights do we have at the end of life?

The Human Rights Act covers all health and care services provided by, or commissioned by, public bodies

The rights apply in 3 different ways:

- Respect – respecting people's rights
- Protect – taking action to protect people's rights
- Fulfil – taking steps to action people's rights

The Human Rights Act and end of life care

Article 2: Right to life	Article 3: Right to be free from inhuman or degrading treatment	Article 5: Right to liberty
e.g. making decisions about withdrawing treatment, or resuscitation	e.g. where a person may be neglected; or where the continuation of invasive treatment may cause harm	e.g. where a person has restrictions placed on their freedom (e.g. DoLS)

Source: End of Life Care and Human Rights (2016)

The Human Rights Act and end of life care

Article 8: Right to respect for private & family life	Article 9: Right to freedom of thought, conscience & religion	Article 14: Right to enjoy these human rights without discrimination
e.g. balancing decisions about pain relief with a person's wish to be able to communicate with family; or decisions about resuscitation	e.g. where people might refuse life-prolonging treatment because of religious beliefs	e.g. treating somebody differently because of a characteristic or status, or failing to treat someone differently because they have additional needs

What choices do we have at the end of life?

- There is only one chance to get it right at the end of life
- Choice matters in a variety of ways:
    - Place of care and place of death
    - Involvement in and control over decisions about care
    - Recognising preferences and wishes
- Important to remember, and protect, the right we all have to change our minds too

Why choice & control matters

"People should have choice, as much as possible within the constraints of their illness, about how they spend their time and with whom. Care should be planned with them and around them……This applies whether the person is receiving care at home, in a care home, hospital or hospice."

"The most important choice for people is to be given the time and opportunity to express their choices, as all too often individuals are not included in the decisions regarding their care."

Source: What matters to me (2015)

Why choice and control matters

"My mother died earlier this year from pancreatic cancer. Although the clinical care was generally good, I really found the clinicians did not want to talk about how her death would be managed."

"My wife wished to die at home and she did. I believe she was pleased but I feel I could have done more for her. At my then age (64), I had no idea what to do to help her and no notion of what to expect as my wife got progressively worse. I could possibly have done more for my wife and done it better if I had been given instruction in what dying entailed and what sort of care would help. Witnessing death is beyond the experience of the vast majority of people in the modern world."

Source: What matters to me (2015)

Ambitions for Palliative & End of Life Care

01 Each person is seen as an individual

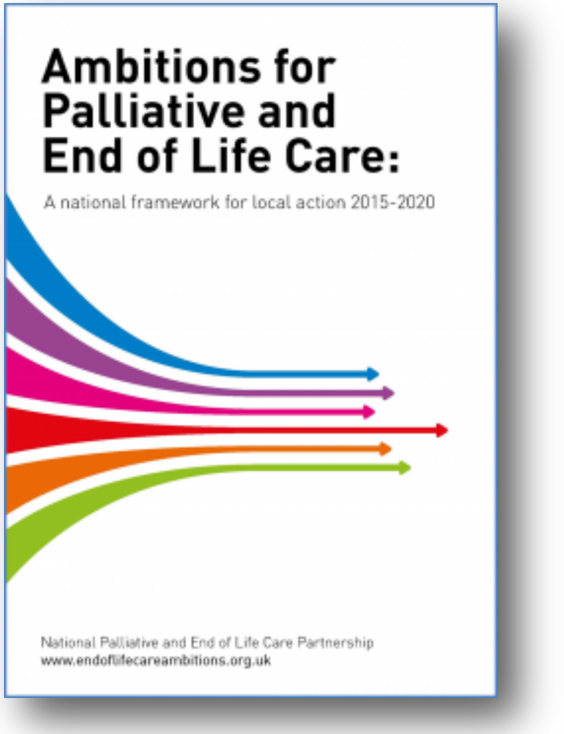
02 Each person gets fair access to care

03 Maximising comfort and wellbeing

04 Care is coordinated

05 All staff are prepared to care

06 Each community is prepared to help



Ambitions for Palliative and End of Life Care:

A national framework for local action 2015-2020

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

01

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.

02

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.

03

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.

04

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.

05

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.

06

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.

National commitment on end of life care

Our commitment to you is that, as you approach the end of life, you should be given the opportunity and support to:

- have **honest discussions** about your needs and preferences for your physical, mental and spiritual wellbeing;
- make **informed choices** about your care, supported by clear and accessible published information on quality and choice in end of life care;;
- develop and document a **personalised care plan**, based on what matters to you and your needs and preferences, including any advance decisions and your views about where you want to be cared for and where you want to die, and to review and revise this plan throughout the duration of your illness;
- **share your personalised care plan with your care professionals**, enabling them to take account of your wishes and choices in the care and support they provide;
- involve, to the extent that you wish, your **family, carers and those important to you** in discussions about, and the delivery of, your care;
- **know who to contact** if you need help and advice at any time.

Source: Our Commitment to you for end of life care (2015)

Different rights for different settings?

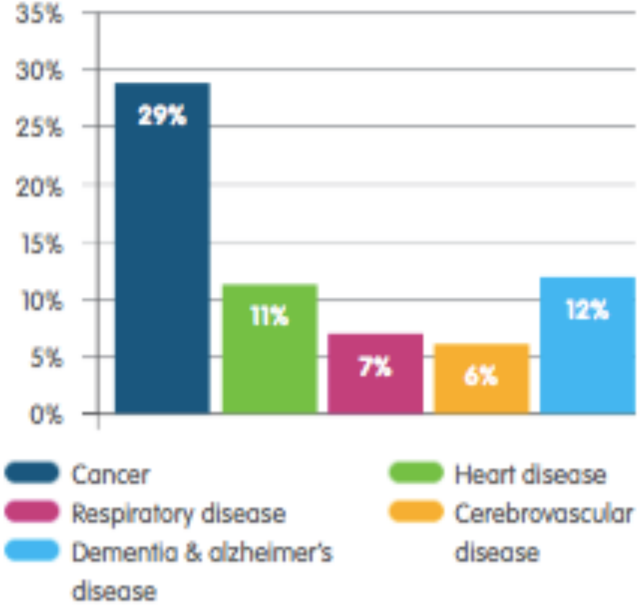
- People's rights and choices at the end of life are often addressed differently in different settings:
    - Hospices
    - Hospitals
    - Care Homes
    - People's own homes
    - Secure & detained settings etc.

Equal rights?

There are significant inequalities in end of life care:

- Between cancer and non-cancer diagnoses
- Between population groups

There is also significant unmet need – estimated c.118,000 people dying each year



Principles for inclusive end of life care

- Good **communication** which includes engaging with people in a way that is meaningful for the individual and so enables people to make informed decisions about their care.
- An approach founded on **dignity and respect**, and investing in a relationship of trust.
- The provision of **workforce training and support**.
- Enabling **partnership working** at a strategic level.
- Recognising that people are all different so inclusive, equitable care is **not about treating everybody the same way**.

Source: Care Committed to Me (2018)

Making people’s voices heard

- Advocacy plays a vital role in protecting people’s rights and helping them to be heard at the end of life
- Advance care planning is extremely useful in helping people to express wishes and preferences
- People have the right to refuse specific treatment in specific circumstances
- Also important to remember the rights and voices of families and carers too, which can often differ

A word on the current crisis

- There are unique challenges associated with the COVID-19 crisis in end of life care relevant to this agenda;
    - Doctors making tough decisions about treatment and care
    - Decisions about resuscitation
    - People dying without friends and family at their side
    - Care home residents not being visited by friends and family

Giving people a voice, protecting rights and supporting choice is more important than ever

Useful sources

What matters to me: A review of choice in end of life care (2015)
https://www.gov.uk/government/publications/choice-in-end-of-life-care

Ambitions for Palliative & End of Life Care (2015) http://endoflifecareambitions.org.uk

Our commitment to you for end of life care (2015)
https://www.gov.uk/government/publications/choice-in-end-of-life-care-government-response

End of Life Care and Human Rights: A practitioners guide (2016)
https://www.sueryder.org/for-healthcare-professionals/education-and-training/human-rights-end-of-life-care/download

Care Committed to me: Delivering high quality, personalized palliative and end of life care for Gypsies & Travellers, LGBT people and people experiencing homelessness (2018)
https://www.hospiceuk.org/docs/default-source/Policy-and-Campaigns/briefings-and-consultations-documents-and-files/care_committed_to_me_web.pdf?sfvrsn=0

Jonathan Ellis
Director of Advocacy & Change
Hospice UK

j.ellis@hospiceuk.org
@jonnyellis74