

# End of Life Decisions:



the information we need on the conversation that no one wants to have...

Summary of issues debated by  
**Baroness Greengross' Expert Roundtable on End of Life**

**Human mortality remains at 100 percent; we all eventually die. Ideally, we should all be well informed on end of life choices, and how we die should be in our own control.**

## What are end of life decisions?

*End of life care* helps all those with advanced, progressive, incurable illness 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. (National Council for Palliative Care, 2006).

*End of life decisions* are directives detailing an individual's preferences regarding how they would like to be cared for when they are no longer able to make decisions for themselves.

## Why does no one want to talk about it?

- Death is an understandably emotive topic.
- There is often a failure to understand that palliative and supportive care can be given at the same time as active treatment.

## What are the problems?

- Over 70% of people would prefer to die at home but 60%<sup>1</sup> die in hospital. Yet 40% of end of life care patients have no medical need to be in hospital<sup>2</sup>. There needs to be a better balance between meeting the needs of those who want to die at home and those who require hospital or hospice care.
- When people lack capacity others have to make decisions for them. When relatives, loved ones, and doctors are unaware of an individual's preferences, they may make decisions about care that the dying person does not want.
- Doctors, nurses and patients all find end of life decisions hard to talk about. Significant ignorance and misunderstanding

## Where would you choose to die?

### Preferred



**70%**

die at home

### Actual



**60%<sup>1</sup>**

die in hospital

### Reality



**40%<sup>2</sup>**

end of life care patients have no medical need to be in hospital

about palliative care continues to exist, and death and dying remain taboos.

- Previously many of the illnesses people died of meant individuals had a short period of evident decline before death. Medical advancements meaning that people live for longer have resulted in many individuals experiencing a much longer period of gradual decline which is much harder to manage.
- Many people are unaware of how best to support a person who is close to death. This can result in those nearing death feeling isolated, distressed or frightened.
- There is often a failure of doctors at the end of life to fully understand the law, and lawyers often do not understand medicine.

### What does it mean to lack capacity?

- The term ‘capacity’ refers to the ability to make a decision about a particular issue at the time the decision needs to be made or to give consent to a particular act<sup>3</sup>.
- Capacity is assessed on a decision specific basis. An individual may retain the ability to make a simple decision but not a more complex decision.
- There are many reasons why someone could lack capacity. Common reasons include dementia, a stroke, or because they are sedated.

### What can be done in preparation for the end of an individual’s life?

#### Advanced Care Planning

- Advanced Care Planning is a discussion between an individual and their care providers. It aims to make clear the individual’s wishes in anticipation of a deterioration in their condition which may mean they lose the capacity to make decisions or the ability to communicate their wishes.
- With the individual’s consent, such discussions should be documented, regularly reviewed and shared with the individual’s carers and family.
- Advanced Care Planning should be personalised. It should take in to account and individual’s values and concerns, their goals and their understanding of their illness and prognosis.

#### Advance Statement of Wishes

- An advance statement sets down an individual’s preferences, wishes, beliefs and values

## Policy Context

### 2008/9

The Department of Health published their End of life Strategy. It stressed the crucial nature of advanced care planning, one where all people with capacity who are approaching the end of life, have an assessment of their needs, and a discussion of their wishes and preferences with agreed actions. It called for coordination of care across sectors and set up an Electronic Palliative Care Coordinating System (EPaCCS) to be included in an integrated care system.



### 2011

An independent commission reviewed the whole issue of palliative care. The commission recommended a per-patient funding mechanism for palliative care for adults and for children.

### 2012

UK College of Physicians end of life training report recommended that palliative and end of life care training be included in all professional healthcare undergraduate and postgraduate programmes.



### 2013

The World Innovation Summit for Health recognised there is no time to waste, as ending unnecessary suffering is an achievable goal.

### 2013

In November 2013 an ILC-UK report titled *End of Life Care* published the findings of a group of expert stakeholders from government departments, clinicians, lawyers, NGOs and academics. The report gave a number of recommendations including the creation and communication of a national End of Life Care Register, increased professional education for both lawyers and doctors, and schemes to promote greater public awareness regarding end of life issues.



regarding their future care. It aims to provide a guide to anyone who might have to make decisions regarding an individual's care in the event that they lose capacity.

- An advance statement can cover many things, including individuals' religious beliefs, whether they would prefer someone to be cared for at home or in a hospice and practical concerns such as an individual's preferences regarding their everyday routine.
- An advance statement is not legally binding but care providers must take it into account when planning an individual's care.

### **Advance Decisions**

- An Advance Decision is a legal document that allows you to make a legally binding refusal of treatment in advance of a time when you can't communicate your wishes, or don't have the capacity to make a decision. For example, it would allow you to refuse life-sustaining treatment such as resuscitation, or breathing machines if you were in a coma. However, you cannot use an Advance Decision to ask for your life to be ended.
- An Advance Decision can also be used to state what kind of treatment you *would* like to consent to in the event that you lack capacity.

### **Lasting Power of Attorney**

- A Lasting Power of Attorney (LPA) is a legal document giving a trusted person the legal power to make decisions on your behalf in the event that you lose capacity.
- There are two types of LPA, one which covers your finances and property, and another which applies to decisions about your health and welfare.
- LPA forms are available from the Office of the Public Guardian.

## **What could policymakers and key professionals do to improve people's end of life experiences?**

**Increased professional education for both lawyers and doctors and schemes to promote greater public awareness regarding end of life issues, through creation and communication of a national End of Life Care Register.**

**Policymakers must ensure that palliative care services deliver best practice in terms of the integration between health and care.**

- There is a need for multidisciplinary learning, training and support among healthcare professionals on end of life care. Health

professionals should be encouraged to continuously improve.

- Improving the training of doctors and lawyers should be a priority as both need each other's perspectives on this issue. Doctors and lawyers should share their experiences and help develop training materials for their respective colleagues. Methods need to be developed to support working in a more co-ordinated fashion in discussing end of life issues with members of the public.

**Policymakers should ensure that there are no unnecessary barriers to data sharing between health and Social Care services and the family.**

- The Electronic Palliative Care Coordination Systems (EPaCCS) enables the recording and sharing of people's care preferences and key details about their care at the end of life. It is currently implemented in CCG's (Clinical Commissioning Groups) across England but should be made available across the UK.
- A national End of Life Care Register should be created to support the implementation of EPaCCS in each locality. NHS guidance on advance care planning should be used as core to any changes to end of life systems.

**Policy makers should ensure that there is an adequate provision of advice and support to help people plan for end of life.**

- Family discussions need to happen early and be ongoing. The Neuberger Report emphasised the importance of training, education and good communication with the whole family.
- There needs to be a major public relations programme to make more in the population at large (not only those in their last year of life) aware of the ways in which they can make things easier for themselves and their loved ones by planning ahead.
- Policy makers and professionals should encourage individuals to make advance decisions and LPAs.

## Where is support available from?

### Office of the Public Guardian

The Office of the Public Guardian protects people in England and Wales who may not have the mental capacity to make certain decisions for themselves, such as about their health and finance.

[www.publicguardian.gov.uk](http://www.publicguardian.gov.uk)

Tel: 0300 456 030

### Compassion in Dying

Compassion in Dying is a national charity that supports people at the end of life to have what they consider to be a good death by providing information and support around their rights and choices. We are the leading provider of free Advance Decisions in the UK and we also conduct and review research into rights and choices in end-of-life care. They provide free Advance Decision forms.

[www.compassionindying.org.uk](http://www.compassionindying.org.uk)

Information Line - 0800 999 2434

### Dying Matters

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. Members include organisations from across the NHS, voluntary and independent health and care sectors (including hospices, care homes, charities supporting old people, children and bereavement); social care and housing sectors; a wide range of faith organisations; community organisations; schools and colleges; academic bodies; trade unions; the legal profession and the funeral sector.

[www.dyingmatters.org](http://www.dyingmatters.org)

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