

Compassion in Dying briefing on Baroness Finlay's Question for Short Debate

14th March 2017

...To ask Her Majesty's Government how they intend to ensure that Clinical Commissioners respect the undertakings made in 'Our Commitments to you for end of life care: The Government Response to the Review of Choice in End of Life Care'.

About Compassion in Dying

Compassion in Dying is a charity that informs people of their options for planning ahead for care and supports them to do so through patient planning tools:

- **Advance Decisions to Refuse Treatment** – legally binding documents which can be used to set out in advance what treatments you would want to refuse if you lose capacity
- **Advance Statements** –to set out care preferences and things you would want those caring for you to know if you lose capacity
- **Lasting Powers of Attorney for Health and Welfare** – which allow you to appoint a trusted person/people to make decisions about your care and treatment if you lose capacity

To do this, we provide free support to people to plan ahead through an Information Service and online tools, and through face-to-face outreach work in communities. We also supply training to health, care and community professionals on advance care planning.

We recently launched a public awareness campaign on planning ahead, called **Make It Your Decision** with 20 campaign partners which reached over 170,000 people via social media during its launch week. The campaign was also covered on ITV, Channel 5, Sky News.

There is a clear and growing need for end of life care: around 470,000 people die each year in England and this is projected to rise by 20% over the next 20 years (ONS 2016 and 2015).

Initiatives intended to meet the challenges facing the NHS and social care services may not address the ongoing need for end of life care. Only 6 of 44 Sustainability and Transformation Plans have clearly stated plans for end of life care, with 20 making only fleeting or no reference to end-of-life care.

Background to the debate:

The Review of Choice in End of Life Care

The Government commissioned the Review of Choice in End of Life Care in July 2014 to provide independent advice on improving the quality and experience of care for adults at the end of life, their carers and others who are important to them, by expanding choice.

The Review board published its report '*What's important to me*' in February 2015. This recommended that:

"Each person who may be in need of end of life care is offered choices in their care focused on what is important to them. This offer should be:

- *made as soon as is practicable after it is recognised that the person may die in the foreseeable future;*
- *based on honest conversations with health and care staff, which supports the person to make informed choices; and*
- *consistently reviewed through conversations with health and care staff."*

The Government Response to the Review of Choice in End of Life Care

Government issued its response to the Review, '*Our Commitments to you for end of life care*', in July 2016. In it, the Government pledges that people will be given opportunities and support to:

- have honest discussions about their needs and preferences for physical, spiritual and mental wellbeing to allow them to live well until their deaths;
- make informed choices about their care with access to clear information on quality and choice in end of life care;
- develop a personalised care plan, including any advance decisions, which is reviewed regularly and shared with professionals so they can take into account patient's care preferences;
- involve, if they want to, their family and carers in discussions about their care; and
- know the right person to contact for help and advice so care is delivered seamlessly.

In addition, the Government's response gave commitments that:

- NHS England will work with commissioners to identify effective models of end of life care and support work on adapting models to local needs and developing new approaches.
- Commissioners will be provided with data and tools to help them identify palliative care needs locally, and the best ways to commission services to meet those needs, improving care provision through local strategic planning and commissioning.

Learning from Compassion in Dying's services

- Over 80% of our service users report that planning ahead for their future care has given them peace of mind. Making a care plan allows people to enjoy life in the present.
- Many people who accessed the face-to-face support provided by Compassion in Dying had high support needed and would not have been able to plan ahead for future care without that level of support. Tailored services that meet the needs of people who are particularly likely to benefit from Advance Care Planning (such as those with long-term conditions, or who are facing a likely loss of capacity) or people who may face challenges when accessing health services (such as BAME and LGBT* communities) should be funded and developed.
- Healthcare professionals who attended Compassion in Dying training report that they feel more comfortable talking to patients about their preferences for end of life care as a result.
- Healthcare professionals have an important role to play in the process, but they often have very limited time to support individuals to plan ahead – especially those who are not based in end of life care services. Therefore Commissioners should seek to work with trusted voluntary organisations that can provide this support to patients.

Public and professional awareness of advance care planning

Enabling patients to make informed choices about their future care and treatment is at the core of the Government's Commitment. However, there is still a long way to go in educating the public and professionals about the rights we all have to plan our care in advance :

- 82% of us have strong views about end-of-life care and treatment, yet only 4% have made an Advance Decision or appointed a Lasting Power of Attorney (YouGov 2014).
- Around half of us (48%) wrongly believe that we have the legal right to make care and treatment decisions on behalf of family members (YouGov 2014).
- Healthcare professionals lack awareness and confidence with regard to end of life discussions. This was a key finding of the House of Lords Committee on the Mental Capacity Act, which reported in 2014.
- A review of Compassion in Dying's Information Line service shows that 8% of its callers report that their GP had never heard of an Advance Decision, and 7% had had a negative reaction to their Advance Decision by a healthcare professional (2014).

Benefits of planning ahead

It is vital that the Government and clinical commissioners support work by the voluntary sector to provide information and support to the public on how they can exercise choice in their end of life care. Doing so would both improve people's experience of end of life care,

and in doing so, reduce pressure on hospitals by reducing unnecessary emergency admissions.

Whilst structural and planning changes are needed, we could go a long way towards enabling more patient choice by simply asking dying people what they want. The surgeon, writer and 2014 BBC Reith lecturer, Atul Gawande has commented:

*“We need to recognise that dying people have other priorities apart from living longer. **It turns out the best way to find out people’s priorities is to ask them**....When people did have those conversations they were less likely to choose intervention, less likely to suffer and less likely to die in hospital. And they lived as long or longer than those having desperate medical interventions at the end of life.”*

Research shows that advance care planning results in:

Better person-centred care. People who have completed an advance care plan have earlier access to palliative care, receive care and treatment that is more closely aligned with their preferences and are more likely to die in the place of their choice.

Improved relationships and communication between families and healthcare professionals. Having early conversations about preferences and creating an advance care plan helps build relationships and reduces conflict within families and between families and staff. Family members of people with an advance care plan also have a more positive bereavement process.

Reduced costs for healthcare providers. Advance care planning is associated with fewer hospital admissions in the later part of life, fewer hospital deaths and fewer interventions of limited clinical value.

For further information:

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