

## Briefing for House of Commons debate on end of life care

Estimates day debate, Wednesday 2<sup>nd</sup> March 2016

Compassion in Dying supports people to plan ahead for their end of life care and enable them to die well. We are the UK's leading provider of free Advance Decisions (previously known as living wills) and produce a range of publications for individuals, carers and healthcare professionals. We also provide support to help people to complete Advance Decisions, Advance Statements and Lasting Powers of Attorney for Health and Welfare.

We operate a free information line and provide online information and tools to enable end-of-life decision-making. Compassion in Dying also works in partnership with seven local Age UKs to deliver the innovative *My Life, My Decision* outreach service which raises awareness of planning ahead for care and treatment; offers one-to-one support to older people who wish to set out their wishes; and delivers accredited training to professionals, volunteers and community groups.

The Health Select Committee's report into end of life care, published in March 2015, included a number of valuable insights into how end of life care could be improved for patients in England. The Committee's recommendations on advance care planning were well-founded and deserve attention.

Compassion in Dying specialises in providing information and advice on Advance Decisions, Advance Statements and Lasting Powers of Attorney (LPAs) for Health and Welfare. These planning tools allow people to make decisions about their healthcare in advance, in case they lose capacity. Advance Decisions and LPAs are legally binding under the Mental Capacity Act (MCA) 2005. Advance Statements have legal standing as they must be taken into account when someone is deciding what is in a person's best interests.

### Planning ahead is crucial

There is a strong case for planning for the end of life. Research tells us that empowering people to become involved in end-of-life decisions can reduce time spent in hospital and can reduce costs, as well as giving people control and peace of mind. In a YouGov poll last year, we asked respondents to consider the experience of the last close relative or friend who had died from a short or long-term illness.

Based on the views of friends and family who had lost someone, we found evidence that **having one's end-of-life wishes formally recorded can make a positive difference to the dying person having the 'good death' they want.** In addition, we found that **planning ahead can reduce unwanted, emergency hospital admissions.**

Even a small reduction in the number of unplanned end-of-life hospital admissions would allow a significant number of patients to die at home or in their usual place of residence, giving them a better death, and resulting in cost savings for the health service. An independent analysis of data from the South West of England showed that for people registered on an electronic palliative record system (a formal recording of patient preferences), under 10% died in hospital, which compares positively to 50% of the general population who die in hospital. This study also calculated a cumulative net benefit of £270,000 for a population of 200,000 people over four years, with recurrent savings of £100,000 per year.

## Advance care planning must be fixed

A 2014 YouGov poll showed that only 7% of people would want their doctor to make final end-of-life treatment decisions on their behalf: 52% would rather make these decisions themselves, with their wishes written out in advance, and 30% would prefer a family member or friend to make decisions for them. There is clearly a need for people to make their wishes known in whatever way they deem best, however there are obstacles preventing people from doing so.

Compassion in Dying's service users report a number of barriers to planning ahead:

- **There is a lack of awareness of Advance Decisions.** We agree with the Health Select Committee that healthcare professionals should be given training to ensure they are aware of and understand the implications of these important tools. Providing information on advance care planning in primary care settings would also encourage more discussion between people around diagnosis of a life-limiting condition or those approaching the end of life and their healthcare professionals, *before* they reach a stage at which they can no longer speak for themselves.
- **Whilst Advance Decisions are legally binding, they are not stored in a central register.** This leads to unwanted or unnecessary hospital admissions if a person is not known to have recorded their care preferences. We believe a central register of Advance Decisions is needed so that people are not given medical treatments against their wishes. At present if a patient gives an Advance Decision to their GP, it should also be recorded in their Summary Care Record to ensure that the existence of an Advance Decision is known to other health and care professionals in other settings.
- For many people, **formal planning can only be completed with support from professionals or charities** to help them think about how their concerns and preferences translate into treatment decisions and with support to complete the documents. This raises significant questions over costs for people who cannot afford legal advice, or over access for people not in contact with relevant charities.

### Our service users' experiences

These two contrasting experiences from Compassion in Dying service users illustrate the consequences of the gap between what people want for end of life and what they have done to ensure their wishes are respected:

Ellie's mother, who had dementia, was taken into hospital following an accident. The doctor decided to operate, despite Ellie telling medical staff that their mother did not want surgery:

*"The doctor's decision left us all feeling very upset and angry. Before dementia set in Mum had told us many times that she did not want surgery at any cost. It seemed to us at the time that our views were being deliberately ignored and, because we were trying to convey the strongly held wishes of our mother, this was deeply upsetting. We understand now that legally we could not make decisions on behalf of our mother."*

In contrast, Jenny and her father made their Advance Decisions together:

*"Five years before my father died aged 91, he and I spent time together filling in our Advance Decisions. That conversation helped me to understand his wishes. When he was admitted to hospital the last time I made a point of telling every health professional that he had made an Advance Decision and that he was now so weak and ill that he just wanted palliative care. Not one person tried to argue with me and my father slipped away less than 24 hours later. Having an Advance Decision gave me the confidence, determination and, ultimately, the authority to ensure my father's wishes were respected. I was so grateful for that."*

## **More research is needed**

Much of the recent policy and practice focus has been on getting end-of-life care right in the last days and hours of life. While this is important, people should be introduced earlier to advance care planning when diagnosed with a progressive disease. There should also be encouragement of the 'well' population to record their medical treatment and care wishes in advance. This has been hindered by a lack of detailed research into the barriers preventing advanced care planning, and the benefits of doing so.

We agree with the key recommendation from the Health Select Committee that the Government should fund further research on the areas of greatest importance to people at the end of life, and their families and carers. The VOICES survey of bereaved people provides robust and important evidence on people's experience of the end of life care of their loved ones, but this should be extended.

It is important, for instance, that research is conducted into whether peoples' end-of-life treatment and death is in line with their recorded preferences, and into how dying people define quality of life during their last months and weeks of life. Whilst it may be within the remit of the VOICES survey - or indeed other research - to gather this data, additional funding would be needed to do this.

## **About our services**

The Health Select Committee in its report on end of life care recommended that the Government engage with services such as *My Life, My Decision* in order to learn lessons on how advance care planning can be promoted to older people.

*My Life, My Decision* has been running in conjunction with local Age UKs across England to provide face-to-face support to complete an advance care planning tool such as an Advance Decision, Advance Statement or LPA for Health and Welfare. Thousands of health and social care professionals have attended a *My Life, My Decision* training session to increase their knowledge and awareness of the ways in which end-of-life wishes can be expressed and recorded. Our experience from these sessions has given us huge insight into the challenges faced across the country, from differing populations..

Aside from this service, we provide direct information and support through our Information Service. Last year we provided 8,600 publications, including an aid to having difficult conversations about end-of-life wishes, in response to requests from members of the public, health professionals and carers. We launched *MyDecisions.org.uk* in January this year, a free online support tool for completing Advance Decisions and Advance Statements. In the first month over 4,000 people have accessed the site and 500 people have completed an Advance Decision or Advance Statement.

### **For more information:**

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