

# DIVIDED IN DYING

## DOES THE RECORDING OF END-OF-LIFE TREATMENT AND CARE WISHES MAKE A DIFFERENCE TO THE QUALITY OF PEOPLE'S DEATHS?

This report highlights the key findings from a survey of the general public on the recording of end-of-life treatment and care wishes. It also draws on people's individual's experiences of their loved one's end of life and makes recommendations for practice.

### KEY FINDINGS

Of those where a close family member or friend died recently, approximately half felt they died well (42%) and a half felt they died badly (45%).

Of those who died badly, people believe better communication (39%), improved coordination of care (33%) and being able to die in place of their choice (31%) could have made a positive difference.

25% of respondents said their friend or relative had made their wishes for end-of-life medical treatment and care known to them.

18% said the deceased person had formally recorded their wishes (for example through completing an Advance Decision or on their medical records).

58% of those whose end-of-life wishes had been formally recorded were reported as dying in a good way.\* Those who didn't have their wishes formally recorded were nearly 20% less likely to die well.

***“ Making all these arrangements is satisfying -  
I’ve done what I can to put my affairs in order and can now  
get on and do as much as I am able.”***

Mary, London

***“I feel a deep relief at having made a Lasting Power of Attorney,  
I now have no concerns about my end of life care”***

Rev Carter, West Sussex

***“It has given me a certain peace of mind knowing that I have  
done all I can possibly do to exit my life in a smooth  
uncomplicated way”***

Hazel, Yorkshire

# INTRODUCTION

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Compassion in Dying believes that people should, as far as possible, have what they consider to be a good death by ensuring their wishes are respected at the end of their life. An important part of this is making sure people know what their end-of-life rights are and that healthcare professionals must act on patients' wishes if they are valid and applicable.

'Gaps in discussing, recording and acting on end of life preferences' has been identified in recent research as a key driver of poor service journeys at the end of life.<sup>1</sup> The 2008 End-of-Life Care Strategy referred to the importance of Advance Decisions and Advance Care Planning, and the Mental Capacity Act (2005) gives people specific legal rights to plan ahead in terms of their care or treatment for a time when they may lack capacity.<sup>2</sup> The General Medical Council's guidance on end of life care stresses the importance of recording decisions made about treatment and care and recent National Institute for Health and Care Excellence Quality Standards state that healthcare professionals should be competent in providing support to patients and carers on Advance Decisions.<sup>3,4</sup>

In order to understand if these types of policy bear-out in practice, Compassion in Dying commissioned a YouGov survey about dying patients' end-of-life treatment wishes. 2,400 consenting members of the general public were able to think back to their last close relative or friend who had died from a short or long-term illness, and so were eligible to answer the questions. Those whose relative or friend had died suddenly were discounted. This was done to ensure the deceased, in principle at least, should have had planned end-of-life care where they could be involved in decision making.

1 Paget A, Wood C (2013) *Ways and Means* Demos/Sue Ryder

2 End of Life Care Strategy (2008) Department of Health

3 GMC (2011) *Treatment and care towards the end of life: good practice in decision making* General Medical Council

4 NICE (2011) *Quality standard for end of life care for adults* National Institute for Health and Care Excellence

\* 'Some people talk about people dying well or in a good way...Thinking back to the last close relative or friend of yours who has died, generally speaking do you think they died in a good way or bad way?'



## COLETTE MCNEIL

My sister Marian was diagnosed with Motor Neurone Disease in Spring 2011 and died a year later.

Marian was very definite in her wishes about end of life, and gave my brother and I Lasting Power of Attorney for her health decisions. We also investigated Advance Decisions, and while her GP was somewhat reluctant to go through the form with her, the hospice palliative care team were most sympathetic and supportive. They agreed to discuss the Advance Decision with her, as well as sign and witness it.

The consultant on the palliative care team discussed with Marian her wish not to be fed by artificially, and agreed to ensure she was hydrated and kept as comfortable as possible and pain free when she could no longer swallow. She also expressed her wish to die in the hospice. She was able to choose this on her Advance Decision form, and the palliative care team had her forms on file, and were all fully aware of her wishes.

As it happened her deterioration was rapid, and Marian had her final admission to the hospice a week before she died.

It is devastating to lose a beloved sibling and inevitably one thinks of the things that could have been done better, but we know she had the best possible care. It was a great source of comfort to her to know her wishes would be carried out should she be unable to communicate these at the end of her life.

# DISCUSSION

**Kay, Wales** *"I have always wanted things to be in order. Even after death I want to be in charge! Both the Advance Decision and the Lasting Power of Attorney gave me peace of mind and I feel satisfied that I have taken control of the last decisions that need to be made on my behalf"*

Between 3-5% of the 'well' general public have an Advance Decision or similar,<sup>5,6</sup> so it is encouraging that 18% of dying patients in our survey were reported as having an Advance Decision or recorded end-of-life treatment and care wishes.

Many dying patients do not want to discuss their end-of-life and will avoid negative information<sup>7</sup> and the recent VOICES survey of bereaved relatives and carers loved ones found that a minority (32%) of patients knew they were going to die.<sup>8</sup> So on the one hand some patients resist confronting their end-of-life and, on the other hand, some healthcare professionals are not telling patients that they are dying, thus reducing the chances of effective planning.

**Ruth, Somerset** *"Of course I do not know whether it [Advance Decision] will be needed but it is reassuring to know that the matter is arranged and I can forget about it now"*

Research also shows that there is a lack of a systematic approach to the recording of discussions with patients or carers about end-of-life issues, and that care professionals often carry information about patients 'in their heads' rather than relying on recorded notes to support the transfer of information between staff across organisational boundaries.<sup>9,10,11</sup> This has implications for effective end-of-life treatment and care planning, especially when many dying patients are in receipt of 24/7 care which might involve community nurses, out-of-hours GPs and specialist palliative care – all of whom need to have access to patients treatment and care wishes, especially if the patient has lost mental capacity.

Our survey findings indicate that patients who have their treatment wishes formally recorded are more likely to have a good death than those that do not. This strengthens our belief that care teams have a duty to ensure that patients know about their end-of-life rights and can record what their treatment and care wishes are. Whilst we acknowledge that there are issues with identifying and engaging with dying people in order to be able to place them on an advanced care plan,<sup>11</sup> there are clear advantages to doing so for the both patient, the family and their care team.

**58% of those who had their wishes formally recorded died in a good way, whereas 33% were reported to have died in a bad way. In contrast, 40% of those who did not have their wishes formally recorded died in a good way and 51% were reported to have died in a bad way.**

**Roger, Lancashire** *"Having an Advance Decision makes me happier in the knowledge that any decisions will be made with my wishes being the most important"*

Clarity is needed around end-of-life rights and planning. Increased awareness of end-of-life preference tools such as Advance Decisions and Advance Care Planning amongst care professionals (especially those working outside of palliative care) is needed, and we know that there is confusion amongst patients about what Advance Decisions are.<sup>12</sup> The results from our survey are encouraging, however much more is needed to ensure our end-of-life wishes are known, recorded and can be respected.

5 British Social Attitudes Survey (2013) *Dying: Discussing and planning for end of life* NatCen Social Research

6 YouGov (2011)

7 Barnes KA et al (2011) Advance care planning discussion in advance cancer: analysis of dialogues between patients and care planning mediators *Palliative and Supportive Care* 9(1): 73-79

8 DH (2012) *First national VOICES survey of bereaved people: key findings report* Department of Health

9 Cox K et al (2011) Is it recorded in the notes: Documentation of end-of-life care and preferred place to die discussions in the final weeks of life *BMC Palliative Care* 10(18) doi:10.1186/1472-684X-10-18

10 Munday D, Petrova M, Dale J (2009) Exploring preferences for place of death with terminally ill patients: qualitative study of experiences of general practitioners and community nurses in England *British Medical Journal* 339:b2391

11 Paget A, Wood C (2013) *Ways and Means* Demos/Sue Ryder

12 Shale S (2012) *How do people approach decision making at end of life? A secondary analysis of narrative interviews with patients about experiences of living with terminal illness* Compassion in Dying <http://www.compassionindying.org.uk/sites/default/files/HTO%20long%20report%20.pdf>





## TERRY COLLINS

My mother died in a hospital - she was in her nineties. I saw my mother as belonging to the independently minded English working class generation, who had lived through two world wars; a generation to which 'having one's own front door' was the peak of aspiration.

In the last few years of her life my mother developed signs of encroaching dementia and failing circulation. She was moved into the local general hospital and my sister told me that she was unlikely to live much longer. When I got to the hospital my mother was no longer coherent, sometimes wildly raving in her speech.

This situation was everything she would have hated. We knew this because it was our mother, but it was nonetheless only our judgement - there was nothing else to go on. Sadly, my mother did not have an Advance Decision or Lasting Power of Attorney and when the medics from the geriatric department, who were very kind and conciliatory, told us that they could re-hydrate my mother which would keep her alive, but suffering for another few weeks, even months.

Thankfully the doctors involved understood from us what my mother would have wanted and, so it would seem, by pure good fortune had made the judgement that we had our mother's own interests genuinely at heart. They therefore agreed that the re-hydration and any intrusive medical intervention would prolong her suffering and was not what she wanted, instead they did everything possible to keep her as comfortable and free from pain and stress as possible.

Both my sister and I realised we had been lucky in that we had received a good few hints from my mother about what she wanted and that there were doctors around who accepted and were sympathetic to our point of view. From this experience I decided that having an Advance Decision and a Lasting Power of Attorney was a necessary thing to do, so that my own wishes would definitely be respected at the end of life, without having to rely on healthcare professionals to decide on my behalf.

# RECOMMENDATIONS

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In order to have a good death, people must be enabled to plan for their end-of-life and for a time when they may lose capacity. Policy and practice needs to address those patients who do not have their wishes formally recorded, or are reluctant to engage in end-of-life decision making.

- **The number of people with an Advance Decision or Lasting Power of Attorney needs to increase.** Early planning is crucial to ensure our wishes are recorded, can be re-visited and then acted upon. We support recommendations from Sue Ryder<sup>13</sup> that there needs to be a strengthened focus on people being enabled to express their end-of-life wishes and that proposed Clinical Commissioning Group's indicators should reflect this. **There needs to be equal emphasis on what people want, alongside where people want to die at the end-of-life.**
- **Healthcare professionals' across all settings should be encouraged to formally record end-of-life treatment and care conversations they have with patients.** This could take the form of an Advance Care Plan, which ideally would incorporate an Advance Decision or equivalent. It should also include wishes around preferred place of care and death alongside other preferences. All such tools – in order to be effective – require practitioners to be trained and guided in their use and communication. **The principles of continued engagement with patients, recording their wishes and planning apply regardless care of setting.**
- **There is little evidence on how effectively patient's end-of-life wishes are being recorded and whether they are adhered to.** There is a need for a national system of recording Advance Decisions and Lasting Powers of Attorneys, which all relevant professionals can access and which is regularly audited.

# **CONTACT US.**

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