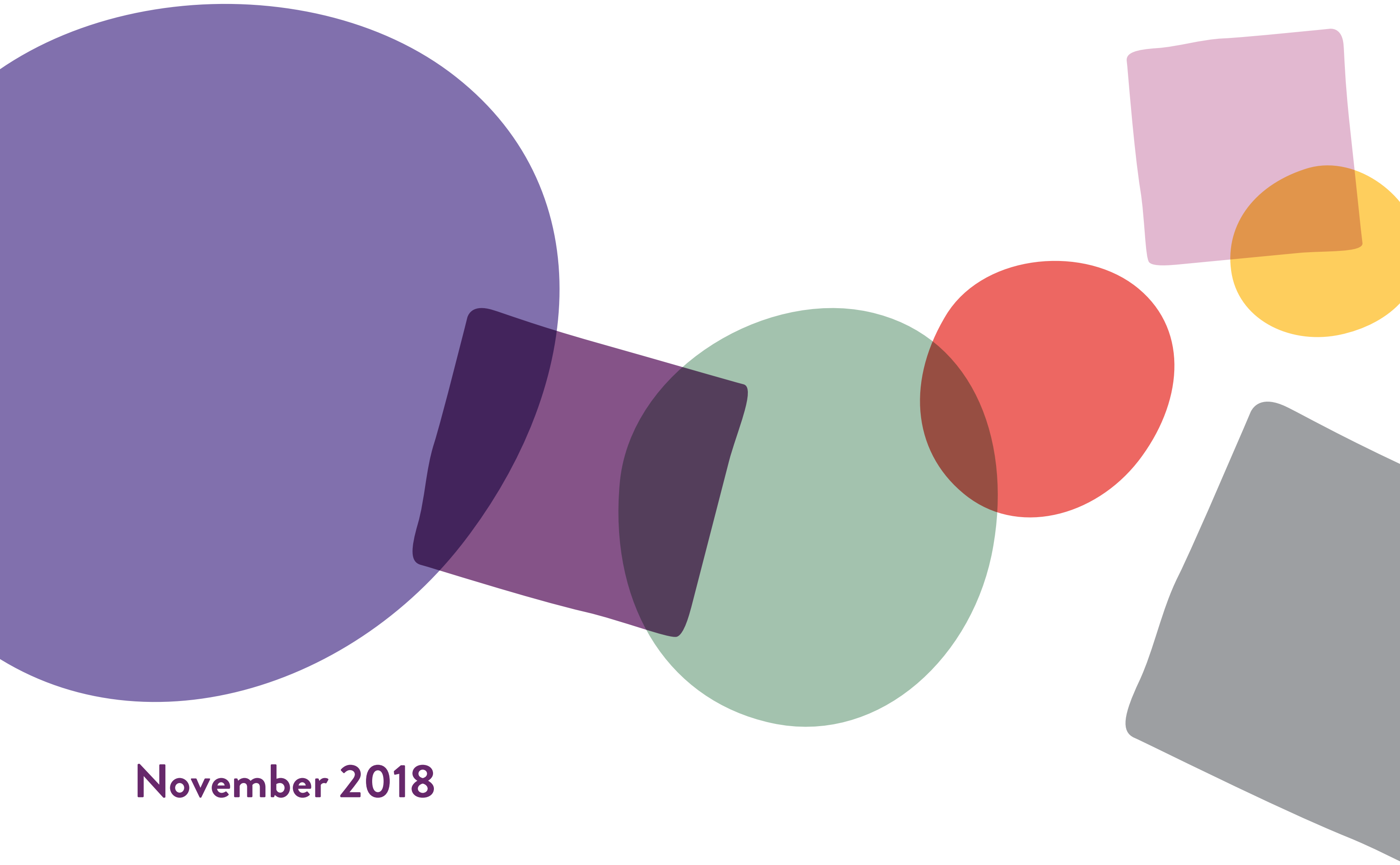
COMPASSION
IN DYING.
SUPPORTING YOUR CHOICES

“I wish I had known...”

Reflections from supporting 25,000 people plan for the end of life



November 2018

Introduction

Through our information and outreach services we have supported over 25,000 people to make decisions about their treatment and plan their care.

We have learned a lot from the people we have spoken to, including what people approaching the end of their lives wished they had known prior to their diagnosis.

This report shares some of that learning.

People tell us they want...

Conversations about the end of life

Honest information so they can make informed decisions

Recognition that priorities can differ

Support to plan before they reach the end of life

Context

In 2017 Compassion in Dying completed an extensive piece of discovery research in which we spoke to over 600 dying people and bereaved carers. This research built on the ongoing monitoring we do with people we support through our services.

We found that people:

- **often do not feel supported to make the decisions they are faced with**
- **are not always given an honest prognosis**
- **do not know what options and choices are available**
- **do not know the right questions to ask their doctor**

Our findings are consistent with recent reports from the Royal College of Physicians,[1,2] the Care Quality Commission[3] and the Health Ombudsman.[4]

In 2018 we began a new project to learn more about a specific problem we have identified; that people who are given a life-changing diagnosis often want information but feel that it is hard or impossible to find. Essentially, they are not able to access the information they want when they most need it. We have also published findings from Freedom of Information requests to Ambulance Trusts[5] and Clinical Commissioning Groups,[6] to better understand the difficulties people tell us they encounter.

Through this work it has become clear that despite the attention these problems have received in recent years, they have not yet been addressed fully. There remains a significant disconnect between policy and practice.

By sharing what we know about what is and is not working for the people we support, we hope to accelerate the pace of a much needed culture change around death and dying across the UK.

All quotes in this report come from people who have been supported by Compassion in Dying's services or have engaged in our research.

People tell us they want...

Conversations about the end of life

Research has recognised that the reluctance of health and social care professionals to instigate end-of-life conversations can lead to a "perpetual cycle of non-discussion".[7]

Through our own work we have learned how this has denied dying people the opportunity to talk about their wishes and make decisions and plans for the future.

"I wasn't prepared for how quickly my husband went downhill and I think if someone had told him earlier on about what may happen we might have been more prepared to ask about what choices he had for his care."

"Looking back I do wish I could have discussed death and dying with my husband. Towards the end he could not talk about it: it leaves an uncertainty in whether you have done the right thing."

Discussing death and dying is considered by some as a "taboo"[8] despite the fact we know **two-thirds of people feel comfortable having such discussions with family and friends.**[9]

"You meet people in the same situation when your parent is ill. I've met people in hospital, I've met people at the care home and we've talked about whether our parent made plans for their care and how they can do it if they're still able to. Even friends and neighbours are now talking about it with their relatives."

"I had conversations with my parents and in-laws regarding Lasting Power of Attorney and found this was a relief to them and my siblings. It certainly proved helpful towards their care, and after their death."

"A living will and prior discussion with GPs will help smooth the final process of dying. Don't be afraid - dying is an inevitable rite of passage whatever your beliefs. Talk. Share the process without taboos. That will help everyone around you."

As well as being willing to discuss with family and friends, we know that only 14% of people would feel *uncomfortable* having a conversation about their end-of-life wishes with a healthcare professional. But crucially, our polling also found that just 52% of people would *instigate* this conversation themselves.[10]

This highlights the risks of healthcare professionals assuming that if somebody does not start a conversation it means they do not want to talk.

> **"I never felt I could talk to Mum about what she wanted. It would have been amazing for someone to bring that up with us as I feel that she would have been happy to talk about it. She was protecting us and didn't want to upset us."**

It is common in policy documents and training aimed at healthcare professionals to describe conversations about the end of life as "difficult"[11] or "challenging".[12] We believe labelling such conversations in this way exacerbates people's reluctance to instigate them. It is promising that there have been recent attempts from within the medical profession to dispel the myth that people do not want to talk about death and instead to show how important and necessary these conversations are.[13] This thinking is much more in line with our experience of supporting people.

People tell us they want…

Honest information so they can make informed decisions

People have told us that healthcare professionals made them aware of decisions that needed to be made about their care, but they did not necessarily involve them in the decision making process.

"I was treated for cancer and was shocked at how little the doctors took notice of my views and how little information they were willing to give me."

"As a social care professional myself I have felt prepared due to my own knowledge and research but know that other people have felt unprepared to make informed decisions about so many aspects of their situation."

"My first treatment drug produced terrible side effects that put me in hospital for three weeks and took six months to recover from. I wish I had known enough to put my foot down and insist that my then oncologist either reduced the dose or changed the medication. At the time I was new to all of it and could have done with a source of informed support in achieving this."

This kind of practice falls a long way short of person-centred care and risks breaching the law around consent.[14]

In reality, people want clear and honest information so they can make decisions that are in line with their personal values and goals. This requires an explanation of the advantages and disadvantages of different treatment options, including any potential risks and side-effects.

"The oncologist was really sweet and kind and I liked her a lot. What she said was the drugs I could give you at this stage would actually make you more ill than you are now. This was great. It was frank and honest. Direct."

"They talked me through some of the more sensitive decisions that you have to make. I have to say I was quite challenged by some of the points raised, in the sense of, 'Gosh I've never thought of that'. I need to go back, talk to the family and think about what I actually want. So, it was very useful from that point of view."

A third of dying people we have spoken to say they have not been given enough information about the different treatment options available to them. Half of bereaved carers we have spoken to said their loved one was not given enough information on the physical symptoms they were likely to experience at the end of life.[15]

"Many on our medical team would not offer the information we needed unless we asked for it."

"The professionals involved waited for us to ask questions but we often didn't know what questions to ask until it was too late."

Having information allows people to make decisions that are right for them.

"I believe that my husband's death, although far from easy, was easier than it would have been if he had allowed his life to be prolonged with all the treatments that were offered. He had more control, and was able to stay at home, with his friends and family around him because of this. No tubes. No ventilators."

"It makes living easier. It's liberating. It is good to have discussed these important things with loved ones. It can bring you closer together. Having all these decisions made saves a lot of worry and probably prevents family arguments."

In addition to information on treatment options, people also want other support to enable them to make decisions. This might include time to reflect on what they have been told about their circumstances, help to anticipate what questions they might want to ask and signposting to opportunities for peer support.

"Write down what the doctor says to you, and check you have asked all your questions. If you do not get an answer, ask who could give you an answer."

"Talk about how you feel and what you want. If there are support groups in your area, try them out. I found it really helpful to talk to others."

People tell us they want...

Recognition that priorities can differ

In supporting people to plan we have found that people have widely differing views about their priorities for treatment and care at the end of life. Therefore, all-encompassing, proxy measurements for person-centred care are ineffective.

“Always respect people’s wishes no matter how odd they may seem or sound. It’s the dying person that really matters, they only get to die once and you get to grieve for longer so helping someone achieve their goals and wishes can help with the healing.”

Most people, when asked, say they want to die at home[16] and place of death is used as a key performance indicator in end-of-life care.[17]

But this policy focus does not reflect the inconclusive evidence on whether or not dying at home compared to other settings results in better clinical outcomes, or the fact that surveys cannot take into account respondents’ knowledge of the practical realities of dying at home.[18]

To find out more, we asked people what was most important to them when thinking about the end of life. Respondents were twice as likely to say ‘being involved in decisions about my care’ than they were to say ‘dying at home’. In fact, 76% of respondents did not rank being able to die at home as one of the top three factors that would be important to them.[19]

This shows that care should not just be person-centred, as defined by values prioritised by care providers or policy makers, but person-led, as defined by the individual themselves. Only they can determine what matters most to them and the information and support given to them should be tailored around this fact.

“The important thing is taking control of your situation as much as you can, questioning things and looking and asking about alternatives and dealing with what’s important for you and not just doing what the doctor says.”

“The medical professionals have been great in terms of information on current treatments but not much use for information on emotional support or lifestyle.”

We know that when people are asked about their goals and preferences it opens up the possibility of honest conversations and establishes a relationship of trust and understanding with healthcare professionals.

“Talking to my doctor about my Advance Decision was a good experience. We got to know each other much better, which will be a help on future medical visits.”

However, we know that people who plan ahead still sometimes face resistance to their goals, values and preferences being acknowledged and respected.

“The GP thought that my Advance Decision meant I did not want any further treatment as of now! I explained that it was a refusal of treatment for when I lost capacity to make decisions myself. The administrative department refused to record my Advance Decision on my medical notes and destroyed the copy I had given them.”

People tell us they want...

Support to plan before they reach the end of life

Research[20] and personal testimony have shown that advance care planning leads to a broad range of benefits to individuals, family members and care providers.

"Making an Advance Decision helped to start a conversation with my family and doctor. It gave me peace of mind - my family now know exactly what I want and won't have to make difficult decisions on my behalf."

"My wife drifted into a coma and her Advance Decision which refused all further treatment for her heart condition, was followed. She died three weeks later surrounded by her family. I am so grateful that she had written her wishes down, and did not have to suffer any more pain."

"An Advance Decision will enable doctors to know some of my wishes. Also it gives me a voice. I too have feelings. Medical staff will realise that I am a person - not just a body, still breathing."

"I made an Advance Decision to preserve my autonomy as much as possible, to enable clinicians to make better decisions and to make things clearer and simpler for my family and friends."

"A very dear friend died a few months after a massive stroke. The doctors and staff at the nursing home honoured her request for pain relief alone. Her family knew all about it. I go to her funeral in 10 days time. I am sad but so relieved that notice was taken of her wishes."

There is a latent public appetite to plan ahead. A fifth of over 65 year olds say they want to set out their wishes to refuse treatment in an Advance Decision but say they haven't got around to it yet.[21] 87% of people think it is important that healthcare professionals know about their preferences for treatment and care.[22]

However, just 4% of people have made an Advance Decision and just 7% have appointed someone they trust to make decisions on their behalf through a Lasting Power of Attorney for Health and Welfare.[23]

There is clearly a need to raise public awareness about the benefits of planning ahead and the ways in which people can do so. However, we've learned that healthcare professionals have a key role to play in encouraging individuals to document their wishes and/or appoint someone to make decisions on their behalf.

"I am very clear about my wishes – I do not want to be resuscitated or have any interventions to prolong my life. I want to be able to go when the time comes. With the support of Compassion in Dying I was able to put these wishes on paper, knowing that they are legally binding. I have been to see my GP – who has a copy of my Advance Decision and she is in agreement with my wishes. It is wonderful!"

Crucially, when plans are put in place before people reach the end of life, it prevents situations where decisions have to be made in a crisis and makes it more likely that any decisions that need to be made will be in line with the person's wishes. This also reduces the decision-making burden on healthcare professionals and families.

"My mother's death was not as she wished. She had not made any arrangements before her dementia stopped her being able to do so. She had discussed death with me 40 years before. I was unable to help my mother in the way she had told me and I regret that."

"I have witnessed occasions where the dying person has not had their wishes respected because not all members of the family knew about them and there was nothing written down."

"I made an Advance Decision to give family members the confidence that these are my wishes and that they have been the same for a very long time."

"My mom was a former nurse and she decided to make an Advance Decision refusing all life-sustaining treatment. She was later diagnosed with myeloid leukaemia. She had made it totally clear in her Advance Decision that she didn't want emergency interventions and that she wanted to stay at home. My mom died in her sleep at home a few months later, with me and her partner by her side. It is never easy to lose the people we love but we took some comfort from knowing what mom's wishes were and respecting them. She directed her own path, just the way she had done all her life."

What we are doing to support culture change

Informing

- Our free, nurse-led information line provides information and support to people who want to plan ahead and take control of their care: call us on **0800 999 2434**.
- We provide information, give talks and deliver CPD-accredited training for healthcare professionals.

Empowering

- We specialise in supporting people to make Advance Decisions (‘Living Wills’) and to talk about their goals and priorities when living with a life-changing illness.
- Our free *MyDecisions* website helps people to record their wishes for treatment and care in a legally binding way.
- Our community outreach work focuses on supporting ‘less heard’ population groups.
- We develop free resources that give people with a life-changing illness the tools to take control of their own care, including finding out what questions to ask their healthcare team to get the information they need to make meaningful decisions.
- We produce resources in different languages and for LGBT and faith communities.

Learning

- Our information and outreach services, and the training we deliver, allow us to hear from individuals, carers, health and care professionals and community workers. This learning informs and underpins all of our work.
- We commission research, including polling, focus groups and in-depth interviews to explore public perceptions and behaviour around end-of-life care and advance care planning.

Leading

- We have run national campaigns to raise awareness of the benefits of advance care planning.
- We share the research that we conduct, commission and review in order to inform end-of-life policy, guidance and practice.
- We provide public commentary and reaction to legal judgements that clarify the law in relation to mental capacity and the treatment and care people receive at the end of life.
- We share our resources using Creative Commons licencing, to ensure that as many people as possible have access to high quality information.

Endnotes

1. End of Life Care Audit – Dying in Hospital: National report for England, Royal College of Physicians, 2016
2. Talking about dying: How to begin honest conversations about what lies ahead, Royal College of Physicians, 2018
3. A Different Ending: Addressing inequalities in end of life care, Care Quality Commission, 2016
4. Dying without dignity: Investigations by the Parliamentary and Health Service Ombudsman into complaints about end of life care, Parliamentary and Health Service Ombudsman, 2015
5. The role of Ambulance Trusts in respecting people's end-of-life wishes, Compassion in Dying, 2018
6. Advance care planning in general practice – does policy match reality?, Compassion in Dying, 2018
7. Brighton LJ and Bristowe K, Communication in palliative care: talking about the end of life, before the end of life, Postgrad Med J 2016;92:466–470
8. 'We doctors can't prescribe a "good death"', The Guardian, 22 May 2016
9. ComRes, 2016
10. YouGov, 2018
11. Difficult conversations with dying people and their families, Marie Curie, March 2014
12. Challenging Conversations at End of Life, St. Christopher's Hospice training course, November 2018
13. 'Yes, doctors need to talk about dying, but what if patients start the conversation?', BMJ, 5 November 2018
14. Montgomery v Lanarkshire Health Board [2015] UKSC 11
15. Compassion in Dying discovery research, 2017
16. What People Want to Live and Die Well, National Council for Palliative Care, May 2011
17. Number and proportion of deaths by place of occurrence, National End of Life Care Intelligence Network, Public Health England, 2018
18. 'Is home always the best and preferred place of death?', BMJ, 7 October 2015
19. YouGov, 2018
20. Literature review on the impact of advance care planning – produced by the International Longevity Centre on behalf of Compassion in Dying, 2016
21. YouGov, 2018
22. YouGov, 2018
23. YouGov, 2018

All quotes in this document come from people who have used Compassion in Dying's services or have engaged in our research.

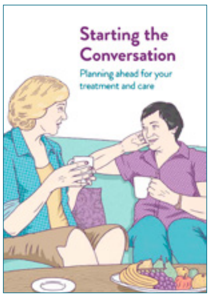
Compassion in Dying has a range of resources, all available for free:

My Decisions

My Decisions is a free and simple website which takes you through scenarios to help you think about what's important to you. At the end it will create an Advance Decision (a legal document about your wishes for treatment and care) for you to print, sign, witness and share.

Planning Ahead

This guide provides an introduction to the ways you can plan for your treatment and care. It will support you to record your preferences to help ensure they are respected if you cannot make a decision for yourself, or tell people what you want.



Starting the Conversation

This booklet supports you to talk about your wishes for care and treatment with your family, friends and doctor.

What Now?

This booklet helps you find information and ask questions, so that you can make decisions about your treatment and care. It will help you think through what you want to know, and offers ideas for questions to ask to get the information you need.

Advance Decision ('Living Will') forms and guidance

If you have wishes about how you would or would not want to be treated in the future, making an Advance Decision will help ensure those wishes are respected if you cannot make decisions. You can use an Advance Decision to refuse any treatment, including life-sustaining treatment.

We can help you prepare for the end of life. How to talk about it, plan for it, and record your wishes.

Have any questions? Talk to us.

We help people through our free information line, publications and resources, and through our work with diverse communities. We specialise in supporting people to make Advance Decisions ('Living Wills') and to talk about their goals and priorities when living with a life-changing illness. Our free *MyDecisions* website helps people to record their wishes for care in a legally binding way.

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Contact us

181 Oxford Street, London, W1D 2JT

T 0800 999 2434
E info@compassionindying.org.uk
W www.compassionindying.org.uk

f www.facebook.com/compassionindying
@agooddeath