Compassion in Dying.
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Theory and practice in future care planning: Lessons from an end-of-life helpline

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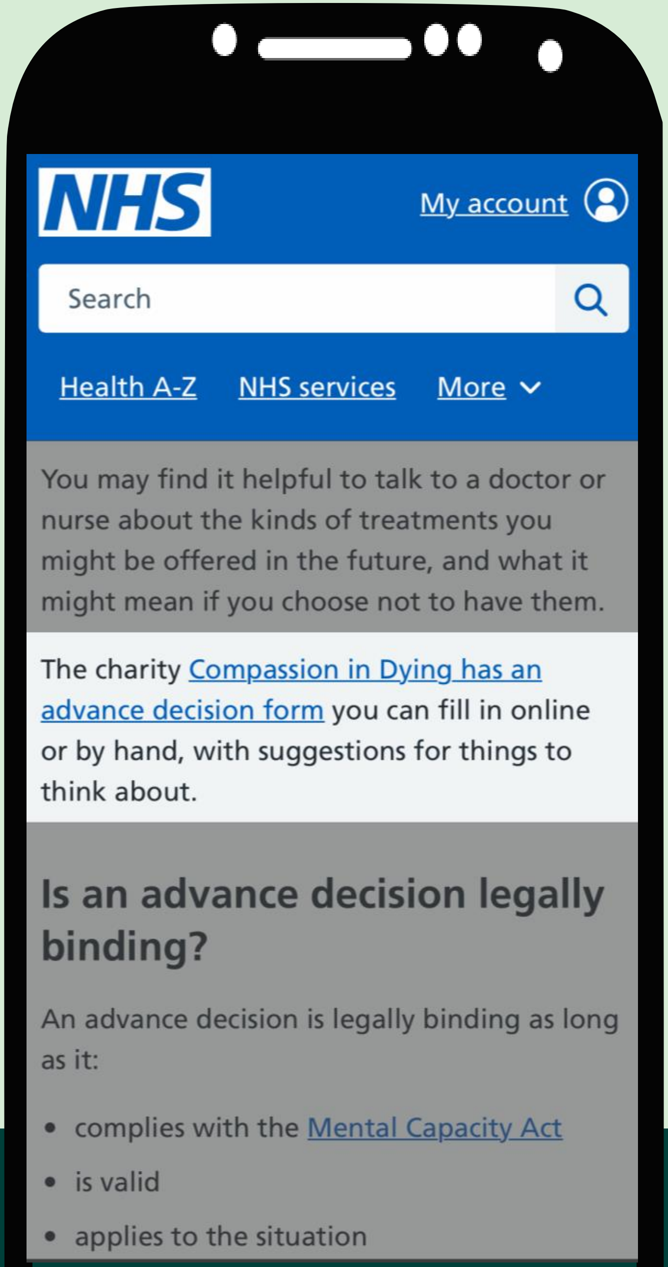
We help people record their wishes online

We offer information and support by phone

We help when wishes aren't respected



You may find it helpful to talk to a doctor or nurse about the kinds of treatments you might be offered in the future, and what it might mean if you choose not to have them.

The charity Compassion in Dying has an advance decision form you can fill in online or by hand, with suggestions for things to think about.

Is an advance decision legally binding?

An advance decision is legally binding as long as it:

- complies with the Mental Capacity Act
- is valid
- applies to the situation

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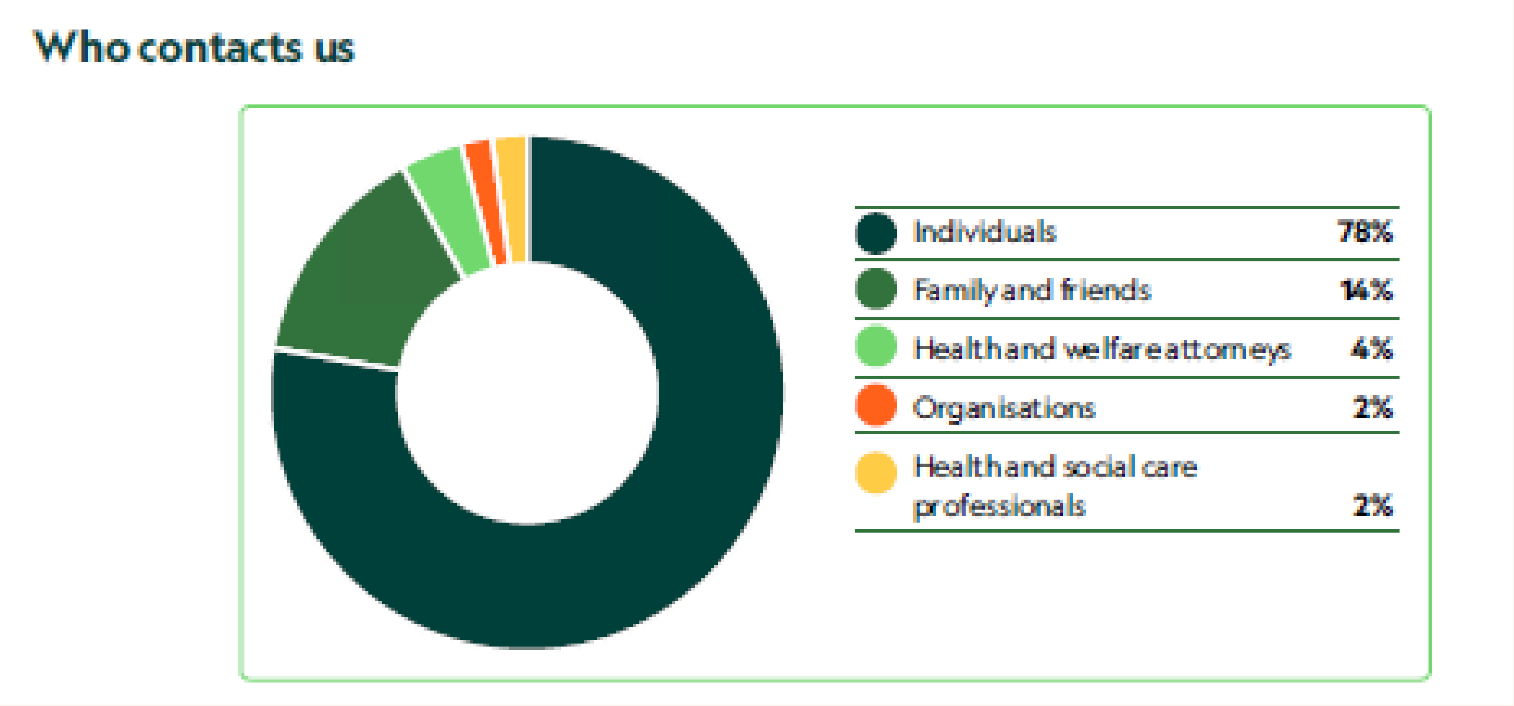
Rethinking the UK's approach to dying

Lessons from an end-of-life helpline

July 2024

The nurse-led information line service



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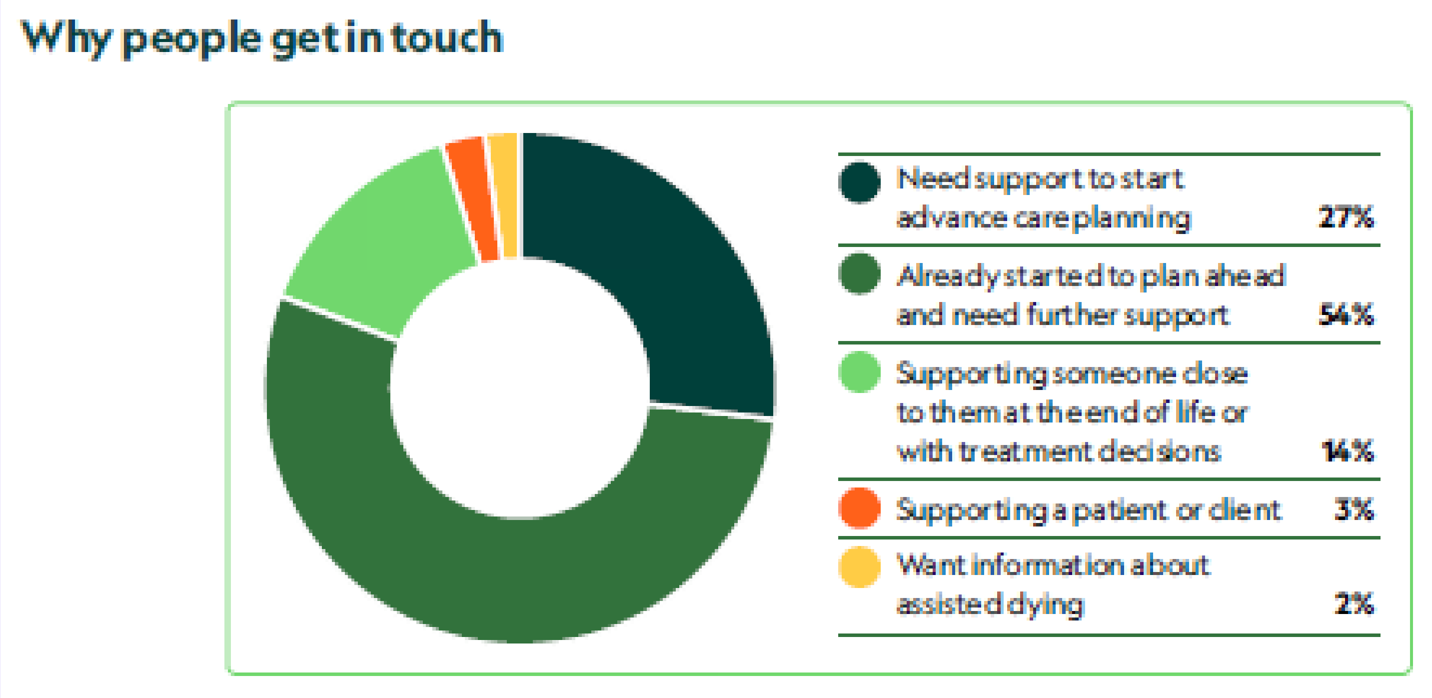
The nurse-led information line service



Why people get in touch

●	Need support to start advance care planning	27%
●	Already started to plan ahead and need further support	54%
●	Supporting someone close to them at the end of life or with treatment decisions	14%
●	Supporting a patient or client	3%
●	Want information about assisted dying	2%

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What people tell us

1. People need realistic and straightforward information to make informed decisions
2. Opportunities to help people consider and record their wishes are sometimes missed
3. Talking about dying isn’t always enough to ensure people’s wishes are followed
4. Confidence in the law on advance directives and welfare powers of attorney is vital so that they can be followed when it matters most

Some stats to start….

83%
want to prioritise their quality of life over living longer in the last years of their life

26%
said the last close friend or family member they know who died received medical treatment they would not have wanted towards the end of their life*

People need realistic and straightforward information to make informed decisions

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“Alan was diagnosed with stage 4 lung cancer and died 6 months later. We were never told that his condition was terminal. We were told it was stage 4 lung cancer and were expected to know what this meant. Alan said to the oncologist “I am very relieved because I thought I was coming in here today for you to tell me to get my affairs in order” nobody challenged this. If he’d known his condition was terminal he would never have put himself through the gruelling chemo that he did.

After Alan had died I raised this issue as to why the words terminal or life limiting were never used to us. The hospital responded to say the consultant didn’t tell patients they were terminal unless they specifically asked.

How do we know what questions to ask when we rely on healthcare professionals to guide us ? Not having honesty and proper communication, robbed Alan of the right to plan how he wanted to live with his diagnosis. It also robbed us of the ability plan how he died. “

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People need realistic and straightforward information to make informed decisions

Challenges/barriers that exist

- Language barriers
- Organising interpreters
- Euphemisms and jargon
- Fear of delivering bad news

Opportunities to help people consider and record their wishes are sometimes missed

"Beryl was 73, and had a brain tumour that was operated on. The operation left her with a swallowing disorder that meant she couldn't eat or drink. She was fitted with a PEG feed which was hard for Beryl as her life revolved around her food.

Beryl began to refuse her PEG feed and she was adamant in her decision. She wanted to have the right support in place so we called her GP practice to discuss her decision.

Instead of listening to her they rang the mental health team. The next week was full of doctors and a psychiatrist visiting constantly. The first time they came they all agreed she had capacity to make this decision and was not depressed. The next day they decided she should be taken to hospital to reinstate the PEG feeding.

The palliative care team who supported Beryl's decision were working to manage her symptoms and kept telling the visiting doctors that she was weak and she was dying. But, at midnight the next day the police, paramedics and social workers arrived to take her to a high security mental health hospital as they were sectioning her.

Finally she was allowed home, the palliative care team came out again, a syringe driver was fitted and she died three days later. Her wish to refuse treatment was so hard for the doctors to hear."

Opportunities to help people consider and record their wishes are sometimes missed

In conversations

- Told they are too young or healthy
- Unfairly brings into question emotional/mental state
- Erodes trust
- Important opportunities missed

Practice is improving

Talking about dying isn’t always enough to ensure people’s wishes are followed

“Dad was fiercely independent and strong. For our family, death has always been a normal part of life. We don’t fear it and dad certainly didn’t. Years before his stroke he went to a solicitor to get an advance decision and an LPA, but the solicitor didn’t know what to do and dad never went back. This meant he never recorded his wishes.

After his stroke he was able to communicate for around two weeks and he started to refuse food and drink. Although at the start his medical team were certain he had capacity to make this decision, once the hospital’s legal team got involved this changed. Against his wishes, they started an NG tube.

He then lost capacity to make treatment decisions. For the next seven years dad was a body that laid in bed and stared at me. I knew this was the opposite of what he wanted. We had multiple meetings with healthcare teams where I told them this is not the situation my dad would have wanted. In the end they took the case to the Court of Protection, but even this took four years.

No one understands what it’s like trying to convince multiple people that your dad is better off dead, but in my heart I wanted him to live forever.

Talking about dying isn’t always enough to ensure people’s wishes are followed

What happens and the impact

- Family and friends often not invited to participate in decisions, despite having deep knowledge of what the person did or did not want
- Lack of a proper process to determine what it is that would genuinely benefit the adult in question
- Lasting trauma and distress at witnessing people being given treatments that don’t align with the person’s values

Confidence in the law on advance directives and POAs is vital so that they can be followed when it matters most

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For more than two decades before she died, my mum, Dione, repeatedly asked me to make sure she would be allowed to die when she was ready to go. She had a DNACPR decision, appointed me as welfare power of attorney and had an advance directive.

In November 2021 mum had a stroke and was moved into hospital, things moved quickly and in her second week she suffered a heart attack followed by a second stroke. We knew mum was dying, and by this point there was no doubt what her wishes were: she wanted to die naturally without having her life prolonged.

As her health attorney, it was my job to make sure the hospital respected her wishes. I wasn't listened to and she kept being given antibiotics for life-threatening infections.

When I was finally able to speak to the senior consultant, I had rehearsed what I wanted to say. However, he opened that meeting by saying that he didn't need to hear anything from me, he told me in situations like this they'd "do their best" for their patients. In the end, mercifully, my mum was moved to palliative care and I finally felt I was being treated the way I would have liked to have been from the start.

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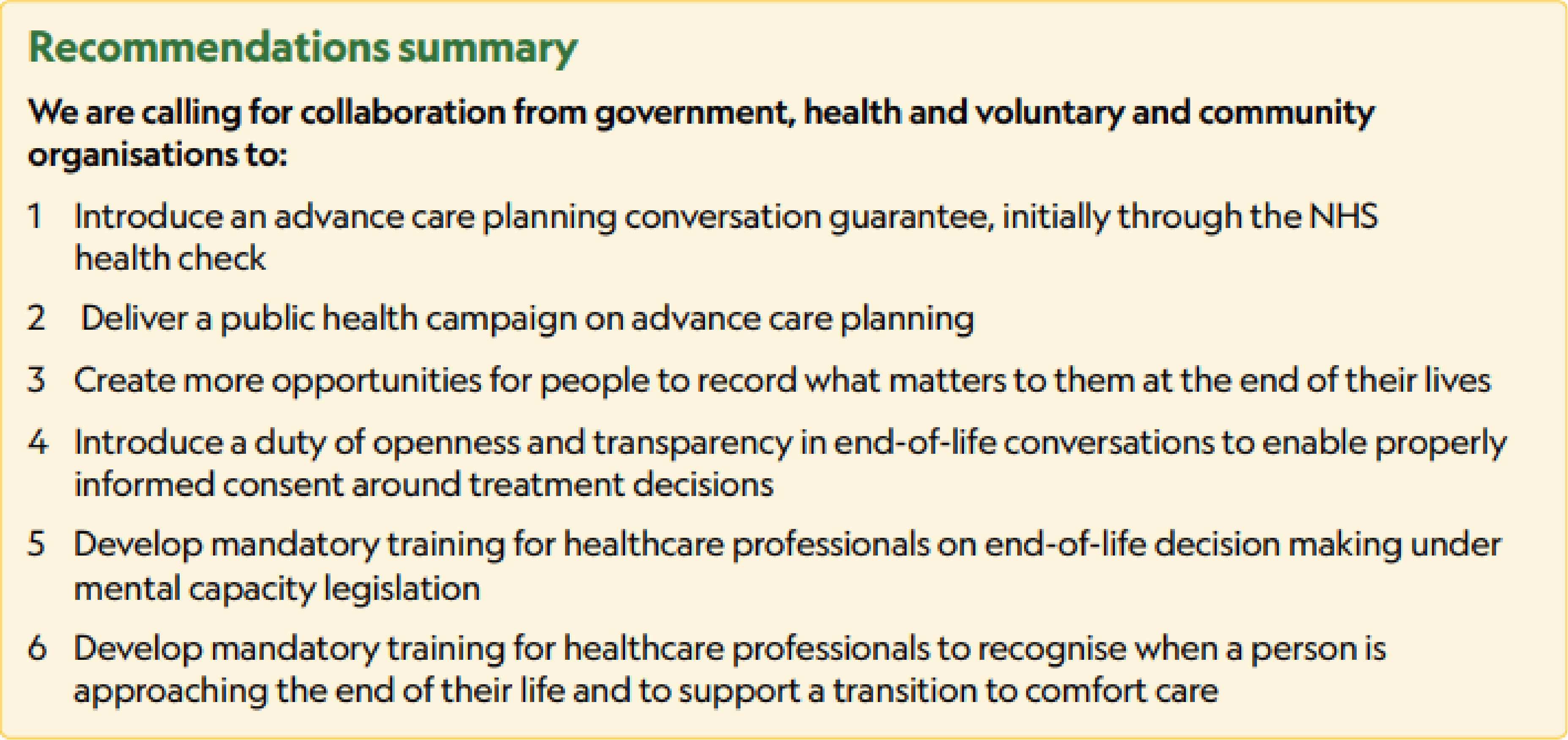
What happens and the impact

- Health attorneys sometimes ignored
- Advance decisions/directives sometimes dismissed
- Needlessly drawn out deaths, impacting on bereavement
- It can be challenging to know when to make the transition from active treatment to ‘comfort care’
- Ultimately, it’s vital to understand what is right for each person as an individual

A different approach:
How we can drive changes



Recommendations summary

We are calling for collaboration from government, health and voluntary and community organisations to:

1 Introduce an advance care planning conversation guarantee, initially through the NHS health check

2 Deliver a public health campaign on advance care planning

3 Create more opportunities for people to record what matters to them at the end of their lives

4 Introduce a duty of openness and transparency in end-of-life conversations to enable properly informed consent around treatment decisions

5 Develop mandatory training for healthcare professionals on end-of-life decision making under mental capacity legislation

6 Develop mandatory training for healthcare professionals to recognise when a person is approaching the end of their life and to support a transition to comfort care

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Journey mapping

Think about a person's journey to palliative care (you might want to pick one person/condition/pathway or think of several). This might be based on your personal experience of practice or what you observe elsewhere.

(10 minutes) In groups, map out the moments/touchpoints where:

- An opportunity to participate in future care planning could have the most impact on a person's experience
- Future care planning conversations could help but are often missed
- Something gets in the way of respecting a person's preferences. What is it?
- You would find a change to policy/practice most helpful to enable more people's preferences to be known and followed. What would that change be?

What has not been said that should be?

Reconvene to discuss together (10 minutes)