

Preparing an Advance Decision

Learning from Compassion in Dying

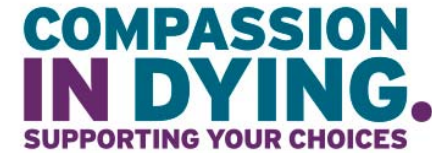
Rachel Hutchings

Legal and Policy Support Officer

Rachel.Hutchings@compassionindying.org.uk



Who we are



Our vision is for a world in which everyone has access to the care and support that is right for them at the end of life

What we do:

- Information and Support – Information Line, publications
- Outreach – My Life, My Decision
- Training, talks & awareness raising
- Policy and research

Benefits of planning ahead



Plan Well, Die Well

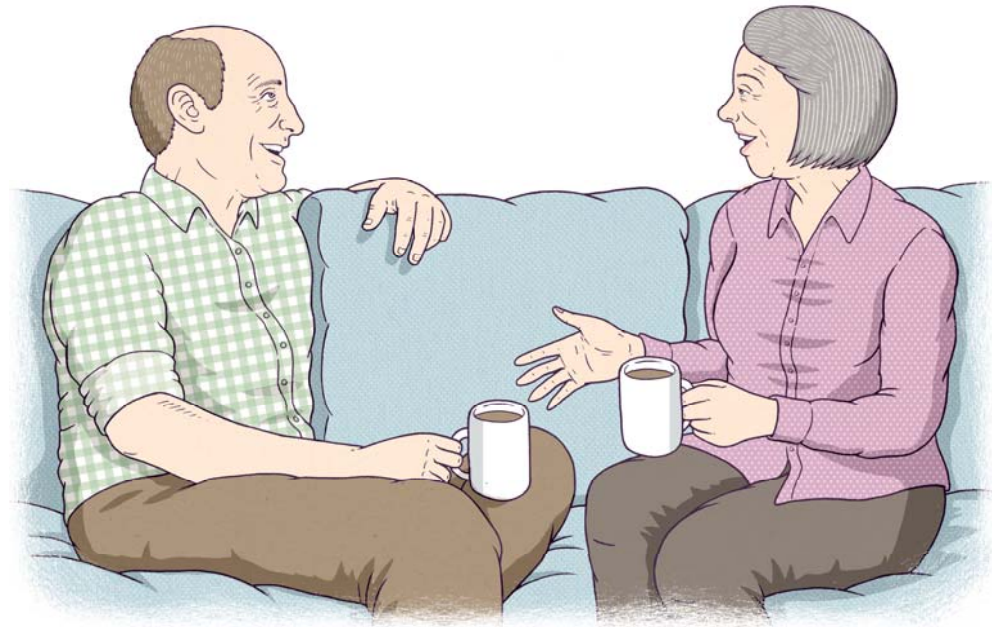
- When end of life wishes are not recorded, people are 53% more likely to receive treatment they would not want
- When wishes are formally recorded, people were 41% more likely to have been judged by loved ones to have died well
- 95% feel more confident their wishes will be respected after contacting us

Benefits of planning ahead

- Better person-centred care. Earlier access to palliative care, care more closely aligned with preferences and more likely to die in place of choice.
- Improved relationships and communication between families and healthcare professionals. Builds relationships and reduces conflict within families and between families and staff, more positive bereavement process.
- Reduced costs for healthcare providers. Fewer hospital admissions in the later part of life, fewer deaths in hospital and fewer interventions of limited clinical value.

Information Line

- Over 4,000 contacts in 2015 – 39% increase on previous year
- 81% of contacts were individuals
- 27% called to request an Advance Decision



My Life, My Decision

- Big Lottery Silver Dreams fund – two years
- Partnership with seven local Age UKs
- 1-2-1 volunteer support
- Outreach work with LGBT and BAME communities
- 129 people have completed an Advance Decision

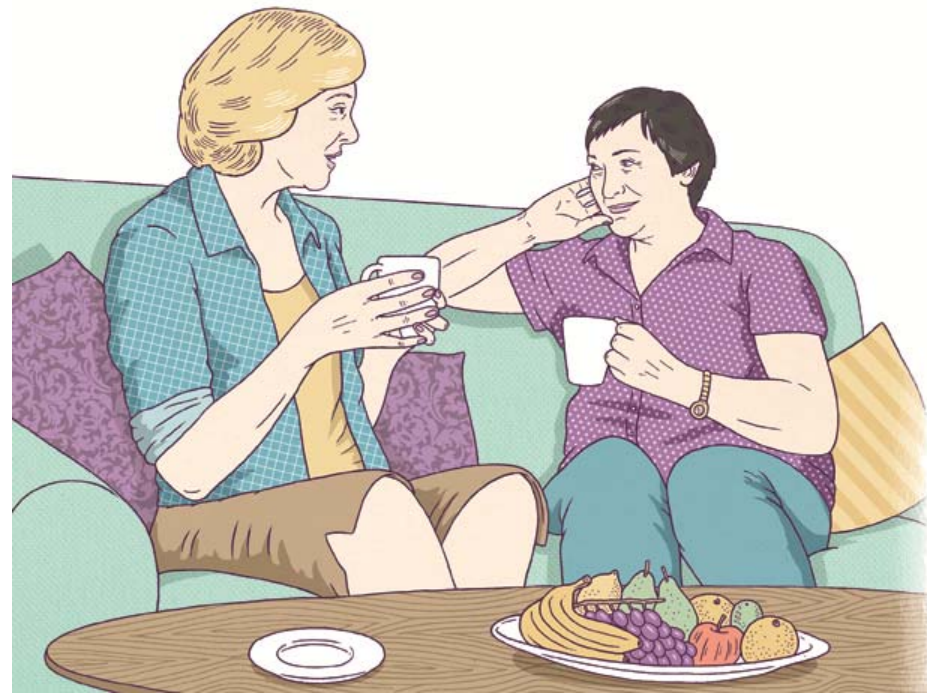
In practice – preparing

- Process
- Form
- Content

The image shows two overlapping forms for Compassion in Dying. The top form is the front side, featuring a header with the organization's name and logo, followed by a section for 'Patient Information' and a large table for 'Medical History'. The bottom form is the back side, containing a section for 'Physician Information' and a large area for 'Comments' with handwritten text. The forms are designed with clear sections and tables to facilitate the collection of medical and personal information.

Information Line story

“It gave her great comfort to know that her Advance Decision was in place. She finally felt as if she was in control of her own destiny again.”



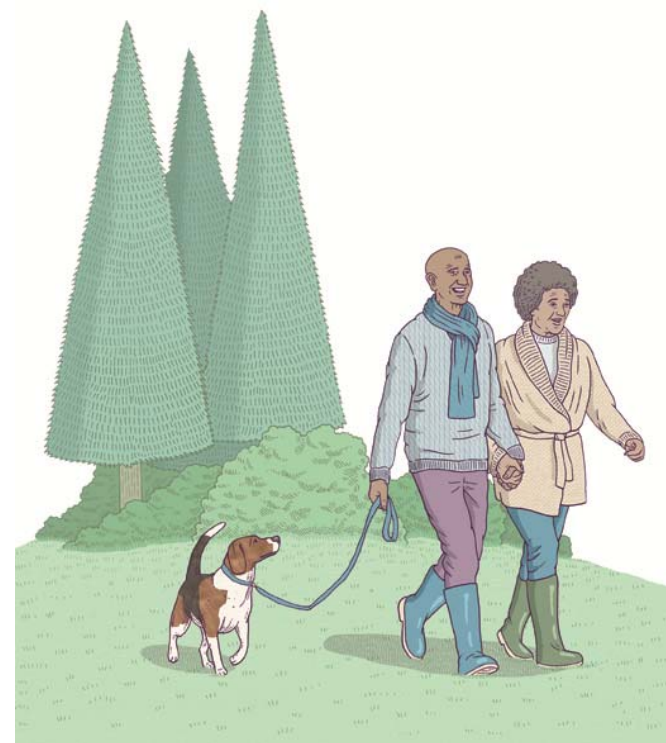
My Life, My Decision story



“It is only when you have been involved personally in a situation like this that you can see the importance of discussing end of life care. It’s not morbid. We simply don’t want our dependants to have to make heart-breaking choices about our future medical care in the future.”

What do these stories tell us?

- Trigger event
- Misconceptions
- Clear illness trajectory
- Reasons



Login



This free and simple website will help you do an important thing:

PLANNING AHEAD FOR **YOUR** FUTURE TREATMENT AND CARE



IT FELT EMPOWERING.
LIKE I HAD TAKEN CONTROL. IT ALLOWED
ME TO GET ON WITH LIVING WELL NOW.

You might not like to think about it but there might come a time when you're too unwell to tell those caring for you - like your family or a doctor - what you do and don't want to happen.

Scenarios

If I have any type of dementia, and I can no longer make or communicate a decision about my medical treatment, and I am unlikely to regain the ability to make these decisions, then... *

I refuse all **life-sustaining treatment**. ?


I refuse all **life-sustaining treatment** if I also show any of the following symptoms or behaviours (tick all that apply): ?

- I am persistently unaware of my surroundings
- I am persistently unable to recognise people close to me
- I am persistently anxious or agitated
- I am unable to attend to my personal hygiene
- I am unable to swallow
- I am unable to interact with others
- Other symptoms or behaviours as specified below

[Save and continue](#) ➔

[Save and continue later](#)

[? Help](#)



? A guide to making your Advance Decision ×

- About this tool
- Advance Decision basics
- Advance Statements
- Brain injury
- Capacity
- Dementia
- Diseases of the central nervous system
- Lasting Power of Attorney
- Life-sustaining treatment
- Making my Advance Decision known
- Mental Capacity Act
- Reviewing my Advance Decision
- Scotland and Northern Ireland
- Signing and witnessing
- Talking to my doctor
- Terminal illness
- Terms and conditions
- What if I change my mind
- Writing my own refusal

Refusing treatment: dementia

The word dementia is used to describe a large group of symptoms that can include memory loss, difficulties with thinking and language, and behaviour or personality changes.

Dementia is progressive, which means that the symptoms get worse over time. How quickly dementia develops will vary from person to person.

Causes

Dementia is caused when the brain is damaged. There are many conditions that cause this. The most common types are:

Alzheimer's disease

Alzheimer's disease causes damage to the brain's cells and to their internal structure. The chemical connections between brain cells are lost over time and some cells die.

Vascular dementia

Vascular dementia is when the oxygen supply to the brain is reduced because the blood vessels narrow or are blocked. Some brain cells are damaged or die. This can happen either suddenly following a major stroke, or over time through a series of minor strokes. Vascular dementia can also be caused by damage to the brain from Alzheimer's disease, so some people can have both Alzheimer's disease and vascular dementia.

Other types of dementia include dementia with Lewy bodies and fronto-temporal dementia (often called frontal lobe dementia).

Symptoms

The symptoms that a person will experience depend on the cause of the dementia and

Reasons

My forms Create Advance Decision

- ✓ About me
- ✓ Refusing treatment
- ✓ **My values**
- ✓ My health
- Review

I'm making this Advance decision because

You don't have to write something here, but if you do it will help your healthcare team to understand your wishes properly. It will also help them to feel confident that you understand and have considered the decisions you are making.


Importantly, if you lost capacity and a situation arose that wasn't covered in your Advance Decision, the information you write here can help your healthcare team to decide how you would want to be treated.

I'm making this Advance Decision because...

[?](#)

Save and continue >

[Save and continue later](#)



Advance Statement


My forms Create Advance Statement

- ✓ About me
- My wishes**
- Likes and dislikes
- Beliefs and traditions
- Diet and daily routine
- Care and treatment
- Wishes for after I die
- Other wishes
- My health
- Review

My beliefs and traditions

My religious or spiritual beliefs

Cultural traditions and practices that I observe

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In practice - sharing

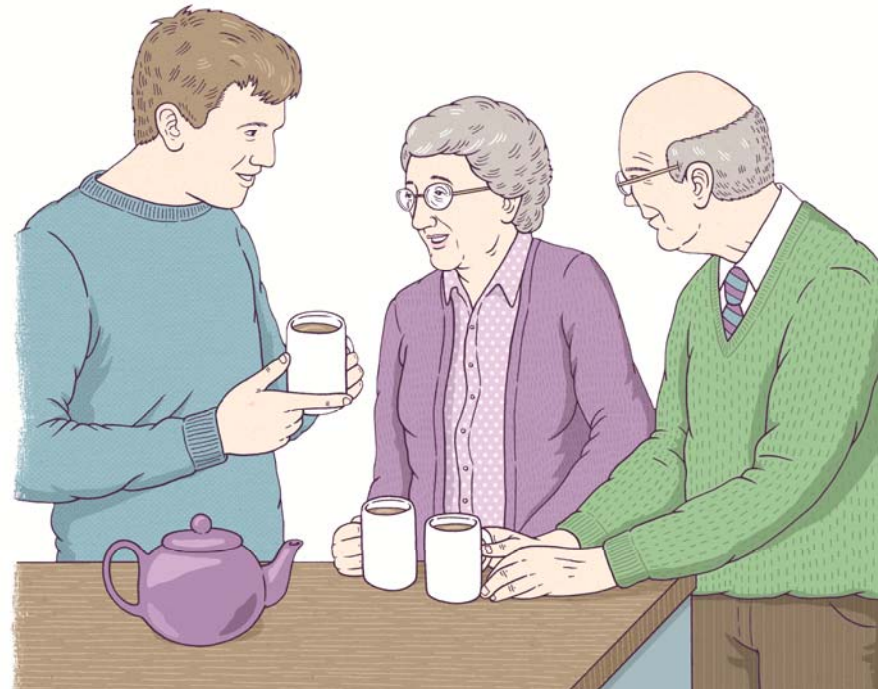
- Code of Practice – “It is the responsibility of the person making the Advance Decision to make sure their decision will be drawn to the attention of healthcare professionals when it is needed.”
- No national register
- Difficulties – some people don’t want to talk about their wishes with loved ones, local system variation, doctors might not be receptive, ill far from home or cannot be identified
- Healthcare professionals must make “**reasonable efforts**” to find out if someone has an Advance Decision

Emergency situations

- MCA Code of Practice – “healthcare professionals should not delay emergency treatment to look for an Advance Decision if there is no clear indication that one exists. But if it is clear that a person has made an advance decision that is likely to be relevant, healthcare professionals should assess its validity and applicability as soon as possible. **Sometimes the urgency of treatment decisions will make this difficult.**”
- But, what if I fall down in the street?

Going forward

- Awareness
- Support
- Recording



Contact us



Email: info@compassionindying.org.uk

Website: www.compassionindying.org.uk

www.mydecisions.org.uk

Information Line: 0800 999 2434