Compassion in Dying.
Your end of life. Your way.

Impact Report

2024

Dame Barbara Monroe – Compassion in Dying Chair

Acknowledgements

With great thanks to the people who share their experiences with us, your voices are an important force for change.

And to our **partners**, funders and staff – without you, none of our work would be possible.

Cover image:
Alastair – lifetime supporter and volunteer for Compassion in Dying

Foreword

A message from our Chair, Dame Barbara Monroe

The right to make decisions, with confident and compassionate support from your healthcare team, and to have those decisions respected, are cornerstones of good end-of-life care.

People tell us they want to be in control of decisions about their treatment and care, but often are not given straightforward information, do not know what to ask for, or even that there are choices to make. Some will reach the end of their life without being given an opportunity to think about their options.

At Compassion in Dying we are helping to transform this, to improve what dying looks like in the UK. We are listening to what dying people tell us they want and need, supporting them, and amplifying their voices to change practice for the future.

In this report, you'll find out what we achieved in 2024. To find out more about our finances, please see our latest annual report and accounts: www.compassionindying.org.uk/accounts

Our year in numbers

4,405

people supported through our nurse-led information line

94

people given in-depth support to advocate for their loved ones

9 in 10

people felt peace of mind, in control, and less worried after planning ahead

8 in 10

people recorded their wishes and discussed this with their family after talking to us

1,200

clinicians, professionals and members of the public attended talks, webinars and education delivered by us

2

new reports launched to amplify people's voices and drive changes to healthcare

4,507

people made an advance decision (living will) using our services

> **"Making my advance decision has enabled me to talk freely with my adult children about death and dying but it has also freed up a space for us all to discuss our deaths which has been great and has dispensed with fear and any awkwardness."**

A caller to Compassion in Dying's information line

Supporting people

We support people to make informed decisions, start honest conversations about death and dying with loved ones, and record and revisit their wishes whenever they want to.

Anushka Aubeelack – Specialist Anaesthetist and Compassion in Dying Vice-Chair

Our nurse-led information line

People often tell us they want to be in charge of decisions about their care and treatment, but find it difficult to get the information they need. Sometimes, they are also met with healthcare professionals unwilling to have open conversations about death and dying.

Our nurse-led information line is here to change that. We enable people to be in control of their end-of-life decisions and support them to plan ahead, in case a time comes when they cannot make decisions for themselves. We are here for everyone, whether they are preparing for the years ahead or need us right now.

Demand for the service consistently exceeds our capacity. This year over 4,400 people contacted us for information and support. This is a 10% increase in contacts compared to 2023, and a massive 63% increase from 2022.

Through our service people can make an:

Advance decision (living will) – a form which someone can use to refuse medical treatments they do not want to be given in the future.

Advance statement – a form which someone can use to record the care they do want in the future.

Lasting power of attorney for health and welfare – a form which someone can use to give someone they trust the legal power to make decisions for them.

Our in-depth support service

In 2023 we set up a new service because people making complex treatment decisions or fighting for their loved ones' wishes to be heard told us they could not find help when they needed it most.

People face problems like:

- healthcare professionals ignoring their loved ones' end-of-life wishes
- difficulties adding advance decisions to medical records
- lasting powers of attorney not being respected
- decisions not being made in their loved ones' best interests and end-of-life guidance and law not being followed
- difficulties having open conversations with healthcare teams about voluntary stopping eating and drinking
- trouble accessing the right symptom management when they are dying

Many of our callers were challenging decisions that were not lawful, and advocating for their loved ones. We gave people the information and support needed to draft letters, prepare for meetings and think through the questions they needed to ask.

This service is helping to challenge the power imbalance people often tell us they face when medical decisions are being made about someone they love. We are helping to ensure individuals are at the centre of decisions about their care.

Elizabeth – supported her husband to ensure his wishes were respected at the end of life

☎ In 2024 call volumes to this new service tripled compared to the previous year

> **"Dealing with my mum dying was a terrible shock; but to then be faced with no one caring about her wishes to refuse life sustaining treatment was traumatic. Before I found Compassion in Dying there was no one who could help me contextualise what was happening. When they picked up the phone it was like somebody threw me a lifeline. They gave me the information and suggestions I needed to engage with the system as her health attorney and fight for my mum's wishes to be respected at the end of her life."**
>
> A caller to Compassion in Dying's information line

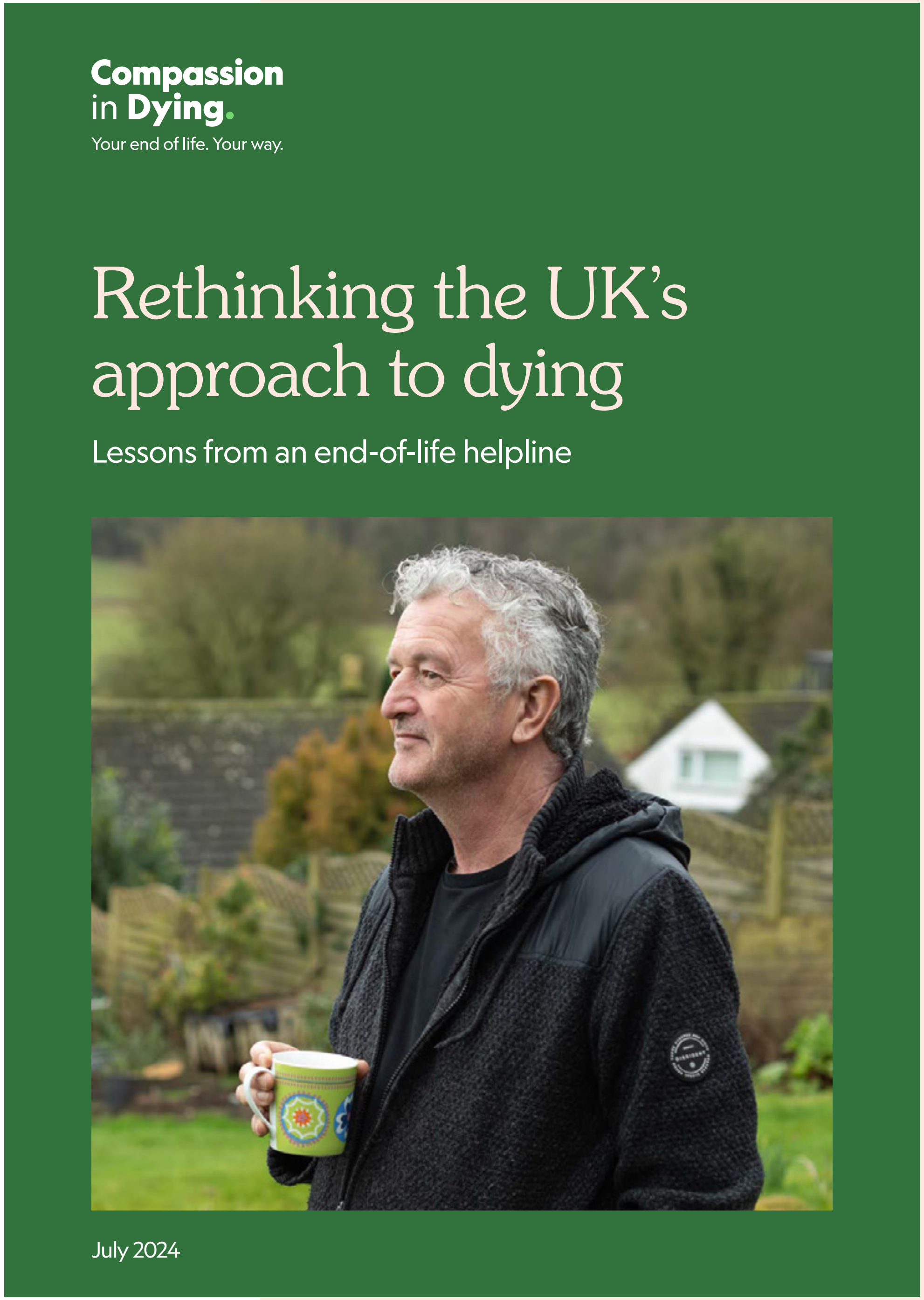
Amplifying voices, driving changes

Everything we do starts with what dying people tell us. We listen to what they say and amplify their voices. We shift attitudes and drive changes to the healthcare system. So people's end-of-life decisions are heard, understood and respected when it matters most.

We published a landmark report revealing what people need in order to be heard and respected at the end of their lives

Dying people and those close to them tell us they are experiencing longer and more difficult deaths than they need to, due to a medical culture that prioritises extending life over allowing individuals to make an informed decision about whether they want this.

Based on the experiences of the people we support we've put forward clear and achievable recommendations that offer a new perspective on how to transform dying in the UK, by rebalancing end-of-life care in favour of people who experience it.



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Rethinking the UK's approach to dying

Lessons from an end-of-life helpline

July 2024

On the cover of our report is Chris. He acted as his mum's lasting power of attorney for health and fought for her wishes to be heard at the end of life

People who are experiencing end-of-life care have told us:

- When they are able to make informed decisions, record their end-of-life wishes and have these wishes respected, they feel relief, peace of mind and it builds trust between themselves and the healthcare system.
- But too often dying people and those who love them tell us a different story where their wishes were ignored and they are given treatments that did not align with their wishes or values.
- Dying people tell us this has devastating consequences, as their hopes of a good death – as they define it – can too often be frustrated by a medical culture and healthcare system where the default is an unquestioning approach of keeping people alive without considering what's right for each person.

8 in 10

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

1 in 4

people say the last close friend or family member they know who died received medical treatment they would not have wanted

Driving changes

Based on the experiences of the people we support, we have put forward policy initiatives that are influencing how people understand and talk about their end-of-life treatment and care.

We are supporting professionals to feel confident seeking people's end-of-life wishes routinely and importantly, ensuring people are at the centre of decisions about their care.

Our landmark report was exclusively launched on Channel 4 News, featured within the British Medical Journal and Lord Darzi's independent investigation of the NHS in England included our research as evidence of the societal change needed in end-of-life care.

And we are not stopping there. To build a safe and compassionate healthcare service that meets people's needs and creates value for people at the end-of-life, we are committed to ensuring those developing the Government's 10 Year Plan for Health listen to what people and communities need.

> **"Compassion in Dying's report is a call to action to us all – the government, the healthcare system, individual healthcare professionals, and the public – to adopt a more open and realistic approach to death and dying and thinking ahead, to help us all have the end-of-life care we would want for ourselves and the people who matter to us most."**

Vinnie Nambisan, Consultant in Palliative Medicine and Trustee of Compassion in Dying

We fight for improvements to DNACPR conversations and decisions

Many people tell us that they have poor experiences of do not attempt cardiopulmonary resuscitation (DNACPR) conversations and decisions. The impact is often significant and leaves a lasting mark on the lives of the people affected.

We were commissioned by the Parliamentary and Health Service Ombudsman (PHSO) to conduct research into older people's experiences of DNACPR conversations and decisions.

The people we spoke to showed us that, when it comes to DNACPR decisions, there are tangible and deliverable changes that could be made to improve people's experiences in the future. We amplified their voices by publishing a new report outlining what they want to see change for others in the future, which included:

- having DNACPR conversations earlier in life
- delivering meaningful education and support for clinicians
- improving communication when a DNACPR decision has been made
- better public information and awareness

What people told us helped to shape the PHSO's recommendations. But getting this right now requires commitment from the government, commissioners, service providers and clinicians to understand what matters to people and their families.

We will continue to listen to the people we support and work with partner organisations to make sure that real experiences inform the improvement of policies and practice around DNACPR.

> **"There needs to be training for all health practitioners, and the training should be about communication, and the absolutely vital need to be compassionate, to be respectful, and to have empathy."**
>
> A research participant

We campaign to overhaul the way end-of-life wishes are shared digitally

Almost everyone we speak to wants an easier way for healthcare professionals to see their end-of-life wishes. How and whether this vital information is available to clinicians when it matters most is a postcode lottery.

We hear time and again that people had bad experiences of end-of-life care because doctors did not know about their documented wishes and health information. Some relied on friends and family to ensure this information was not missed. Many also say they want it to be easier to see and update their own end-of-life records.

In 2024 we worked to influence how digital end-of-life records are delivered. We:

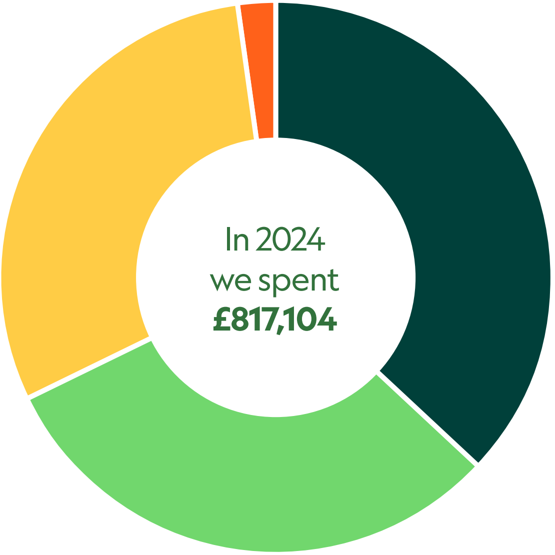
- Collaborated with the University of Leeds on their research, looking at how digital end-of-life records are being used in practice.
- Hosted a solutions-focused webinar, where a hundred researchers, clinicians, policy makers and people with experience of end-of-life decisions considered what is needed from digital end-of-life records.

For too long digital end-of-life records have been built based on what systems and service providers require. Meaningful change in this space requires innovation that starts from what people themselves need.

We are calling for a digital end-of-life record that shares all health and care information required to support a patient across health and care settings and geographical boundaries, with a workforce that is supported to understand and use it. It's vital that patients can edit the record and that families can access this information.

Our expenditure in 2024

Roger and his health and welfare attorney Pat



- ● **37%** on supporting people directly through our nurse led information line, online advance decision service and information for the public.
- ● **31%** on driving changes to the healthcare system through our policy and influencing work.
- ● **30%** on general administration and operational costs, which includes rent and core staff costs.
- ● **2%** on fundraising and income generation.

Thank you to the generous supporters and donors who make our work possible.

What's next for Compassion in Dying

Usha Grieve – Director of Partnerships and Services

In the coming months, we will:

Expand the provision of clinical support on our information services by recruiting two new nurses.

Work collaboratively with policy makers, NHS England and other end-of-life organisations to foster culture change so people and communities can make informed decisions about their end-of-life care.

Embark on a multi-stakeholder project to refine and develop our advance decision to refuse treatment (living will) form.

You can help us continue to improve dying in the UK

Together with our generous supporters, Compassion in Dying continues to grow, evolve and innovate. At the heart of what we do, our free, specialist nurse-led services provide unique support to ensure people's wishes are both known about and respected at the end of life.

Demand is only increasing, yet our team is stretched to capacity helping dying people make the decisions that are right for them. Our specialist knowledge is frequently called upon by both the public and professionals. It's critical that we invest in additional clinical support for our services to meet this need.

Please, will you donate now to support our work?

Visit:
www.compassionindying.org.uk/donate-impact

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At Compassion in Dying, we want people to be in control of their end-of-life decisions because there is no-one better to make them.

We champion everyone's right to make informed decisions. Free of cost and free of judgement.

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