Compassion in Dying.

Your end of life. Your way.

Bridging the gap

How to ensure people's decisions are respected at the end of life

July 2026

Contents

Acknowledgements

With thanks to all the people who shared their experiences with us. Your voices are an important force for change.

We are also grateful to our research partner, Abi Morris at Supernova Insight, for delivering the clinical interviews.

Introduction

The people we support desperately want a different approach to care at the end of their lives: less hospital based, less invasive, and more accepting of their wishes to prioritise quality over quantity of life. This preference for fewer interventions and more comfort care is not unusual – 8 in 10 people say they want to prioritise their quality of life over living longer in their last years.[1]

However, the experiences of the people we support show that, too often, people's wishes for the end of their life are frustrated by a medical culture which defaults to tests, interventions and hospitalisations, without prioritising whether individuals themselves would want this. Increasingly, people contact Compassion in Dying's services because plans they have made are not respected when it matters most. For people and those who love them, this causes irreversible harm. For the healthcare system, it is the epitome of poor value care.

Getting end-of-life care right is high on the political and policy agenda. The NHS 10 Year Plan and the neighbourhood framework both confirm that dying should not be built around crisis escalations, A&E waits, and emergency admissions. A new Modern Service Framework for palliative and end-of-life care is on the horizon, striving to deliver high quality, sustainable, and personalised care for everyone who needs it.

What all these conversations and initiatives have in common is their potential to deliver care at the end of people's lives that is driven by their priorities and underpinned by their own informed decisions. Existing policy has long emphasised the importance of this too – of people being seen as individuals, with the opportunity to have honest and timely conversations about what matters most.[2]

So, if this is what people want, and where policy aims to go, why are so many people still experiencing care that is not aligned with their decisions and preferences?

To understand this, we spoke with health and care professionals across levels and specialisms about their experiences of decision making at the end of people's lives. This report brings together both perspectives – health and care professionals and dying people and those who love them. It shines a light on how sometimes, delivering care aligned with people's preferences is the hardest thing for a clinician to do. This should be a wake-up call to everyone working to improve the experiences of people at the end of their lives.

We set out practical, achievable recommendations to bridge the gap between policy intention and practice to ensure that care at the end of life is universally driven by what people want for themselves.

Summary findings

The experiences of the people we support show that too many people are dying in ways they explicitly said they did not want. The impact of this is devastating. People can endure unwanted treatments, needlessly drawn out deaths and feel powerless over their care.

This research shows that the problem is rarely a lack of compassion. People speak about comfort, dignity and control, while health and care professionals navigate fragmented systems, institutional pressures, and a culture that defaults towards intervention and escalation.

> **"Most of the time, people aren't making bad decisions—they're making decisions in bad conditions." (Consultant)**

We heard about a form of "death denial" in professional culture, which is not primarily personal but deeply embedded in the structures that underpin healthcare practice. It is reinforced by training, hierarchy, system pressures and fragmented record systems. Professionals described environments where time for meaningful conversations is limited, accountability mechanisms reward action over restraint and 'doing more' feels safer than avoiding unnecessary treatment.

The result is that, even when people's wishes are discussed and recorded, they are becoming lost in translation as individuals move between services, settings and moments of crisis.

We found:

- Respecting people's preferences and decisions to refuse treatment can feel risky and exposing for health and care professionals
- Opportunities to understand and record people's decisions are missed or avoided
- When preferences and decisions are recorded, this information is not always visible when it matters most

Taken together, these findings help to explain why the gap between people's wishes, declared policy, and practice remains stubbornly wide.

Summary of recommendations

These recommendations will help to create a system where respecting people's preferences and decisions feels normal, safe and supported through better conversations, clearer records, stronger community care and greater professional confidence in end-of-life decision making.

Ensure people have opportunities to consider and record their decisions and preferences if they want to:

1. Deliver a public health campaign on end-of-life conversations and decisions
2. Increase opportunities for people to consider and record decisions and preferences

Ensure health and care professionals have access to people's recorded choices:

3. Make end-of-life decisions and preferences visible when it matters most through a digital single patient record

Ensure health and care professionals feel confident and supported to follow people's decisions when these are known, and to make best interests decisions when they are not:

4. Strengthen health and care professionals' confidence in end-of-life decision making, particularly when active treatment may no longer be appropriate
5. Expand education and training on how to support good end of life care
6. Ensure the policies that guide professional practice take into account the experiences of those who are most affected

Methodology

This report brings together insight from two pieces of research: experiences of people engaging with health services at the end of life, and the perspectives of health professionals who are responding to their needs.

The findings represent the frequent themes that people who contact our in-depth support service need help with. These themes informed what we sought to better understand from health and care professionals about their experiences. For each finding, we show clinicians' perspectives and experiences of the issue, followed by the impact of this on people and their families.

A thematic analysis of the first two years of calls to a new in-depth support service

Our in-depth support service launched in 2023, as an extension of our long-standing nurse led information line and in direct response to the increasing complexity of calls we were receiving. We conducted a thematic analysis of the first two years of calls and emails to this new service. This data comprised 421 calls and emails received between July 2023 and June 2025.

The quotes used throughout are from the people supported by the service. They are taken from call notes from our service data or from interviews we conducted with those who we followed up with for this report. All quotes are anonymised and some have been edited for clarity.

15 interviews with clinicians across settings and specialisms

Compassion in Dying commissioned 15 in-depth interviews with health and care professionals with the aim of better understanding their attitudes, experiences and behaviours towards end-of-life decision making and how these decisions are role modelled, supported and taught.

The interviews took place between December 2025 and January 2026. The sample consisted of clinicians from a range of levels, specialisms, settings, gender, ages, ethnic and cultural backgrounds, working within England.

The sample focused on the specialisms most frequently represented in the experiences of the people we support from the thematic analysis of call data.

Research participants

District nurse – Band 5 – Community nurse
District nurse – Band 8 – Nurse working with people receiving palliative care
Care/Nursing home manager
Registered nurse – in care/nursing home
Registered nurse – in hospital, stroke ward
GP – working with community and care/nursing home residents x 2
GP – advanced clinical practitioner/palliative lead
Consultant – Haematology
Resident doctor – Oncology
Consultant – Neurology
Resident doctor – A&E x 2
Paramedic x 2

The voices in this report: Our in-depth support service

Since Compassion in Dying was established in 2008 our services have ensured people are informed and supported to make decisions about their future treatment and care, particularly through advance care planning tools such as advance decisions to refuse treatment, advance statements and lasting powers of attorney (LPA) for health and welfare.

Although people tell us that putting plans in place brings a sense of clarity and peace of mind, in growing numbers, people contact us because those plans are not respected when it matters most. It has become increasingly clear that providing advance care planning support alongside information on capacity and decision making legislation is not, on its own, sufficient to ensure people's decisions are respected.

In response to this, we launched an in-depth support service that provides help to people who feel that their decisions, or the decisions of their loved ones, are not being respected or followed.

The support the in-depth support service provides to individuals and families

Many of the people this service supports are navigating complex decisions when they do not have clinical backgrounds. Our nurses give people the information and support they need to draft letters, prepare for meetings and think through the questions they need to ask. We break down what can feel like abstract law, policy and guidance into practical steps: what someone can say, who they can speak to, and how they can ensure their voice is heard.

At its core, the in-depth support service aims to level the playing field, ensuring people have the knowledge, language and confidence to participate meaningfully in decisions about their own, or their loved ones', treatment and care.

This service continues to develop as the needs of the public evolve. What remains constant is the focus on ensuring people feel heard, informed and able to make decisions about their treatment and care.

Increasing demand

Since the in-depth support service was launched in 2023, we have supported 326 individuals across 601 calls and emails. Demand continues to grow and in 2025, annual contacts increased by 59% compared to the first year of operation.

A note on the people we support

Many of the people that we support through this service are able to advocate for themselves in different areas of their life and sometimes have above average levels of health literacy, yet still struggle to ensure they are listened to.

Professionals throughout this research have also emphasised the common reality of many parts of medicine, where decisions are made with limited or no relationship with the patient, and no one has spoken to the person or their family previously about what matters to them at the end of their life.

We know that having a sense of autonomy and control over health decisions is a privilege too often unavailable to people, especially those who do not have the time or resource to proactively engage in decision making whilst struggling to have other basic day to day needs met.[3]

Our work with South Asian Elders and the wider community in Newham has shown that people who are singly or multiply marginalised, either as a result of practical barriers like language or systemic barriers like racism, are less likely to ask questions or articulate what matters to them unless directly prompted. Additionally, those who struggle to get basic health information or support that is accessible and in their language do not feel like they have a 'choice' in health matters on a day to day basis.[4]

We know this lack of conversations and planning across communities in the UK is widespread, and we work to address this through both our broader information line service and community partnerships.

Finding 1: Respecting people's preferences and decisions to refuse treatment can feel risky and exposing for health and care professionals, resulting in people's deaths being drawn out needlessly

Health and care professionals' perspectives

The health and care professionals we spoke to consistently expressed a commitment to acting in people's best interests and respecting their decisions and preferences. However, they described four distinct cultural, systemic and practical themes that contribute to recorded decisions to refuse treatment being ignored or decisions not being made in the person's best interests.

Interventionist culture and defensive practice

Professionals described that death is often automatically viewed as failure rather than as an expected and unavoidable outcome of some illnesses. For that reason, stopping active treatment sometimes felt personally exposing and professionally risky. For many, stepping outside the safety nets of investigation, escalation and treatment was a difficult decision that carried with it significant emotional burden.

> **"Stopping feels like failing. We're trained to intervene; death doesn't fit comfortably with that." (Consultant)**

For the participants we interviewed, difficulties and failures in end-of-life decision making were rarely driven by a lack of compassion or by ethical disregard. Rather, it was often the fragile conditions they were working in that caused decision making to break down: emotionally charged and distressing environments, the real or perceived threat of professional repercussions, and limited support if the decisions were challenged.

> **"You're always thinking, 'What if someone questions this later?" (Senior Nurse)**

On page 27, you can read more about the tools that exist to enable people to make decisions in advance, and how they should still be considered and support best interests decision making, even if written statements such as advance care plans or advance decisions to refuse treatment do not meet the requirements to be valid and applicable to the situation at hand.

Doctors, in particular, talked about an "interventionist reflex", which they described as a tendency to escalate treatment rather than considering if a transition to comfort care could be in the person's best interests.

> **"It's often easier to do something than to explain why you're not doing anything when things are going south." (Resident Doctor)**

> **"It feels safer to act than not act." (Resident Doctor, ED)**

When increased escalation felt like the safest default option, the likelihood of unwanted or avoidable treatment being provided increased.

> **"For consultants, it's a medical legal issue so it's easier to prolong life as more likely to get sued for not trying than trying." (Specialist Nurse)**

Sometimes, professionals did not trust that community services would guarantee timely review or symptom management. They worried both about the person deteriorating without support and about professional accountability if something went wrong. That fear intensified when staffing was insufficient, continuity was poor and when family members were worried or distressed about their loved ones' care.

This resulted in them choosing the pathway that felt most defensible, which was to admit, treat or escalate, even when this conflicted with people's preferences.

Planning that is completed too late, lacks clarity or is inaccessible

Health and care professionals expressed frustration when advance care planning documents were introduced too late in the illness trajectory, which they said happened often. They also described how too often, these documents were written in ways that did not translate into actionable guidance when a person deteriorated.

Participants did not experience advance care planning as a coherent system, but instead as a patchwork of forms with varying levels of legitimacy, accessibility, and authority. This was exacerbated by professionals' lack of awareness and understanding of their legality. Where multiple documents coexisted, health and care professionals described how the result was noise rather than clarity. This was particularly problematic in emergencies where paramedics and other professionals needed a single, trusted source of truth.

Participants said they felt on "shaky ground" because they lacked confidence in how forms work, the difference between them and other clinician-led documentation, when they apply, and how to apply them in practice.

Some plans "look fine on paper" but collapsed under the specificity and speed of real world decision making. A recurring issue was that documentation often did not fit the situation the individual was in, leaving teams uncertain about what to do next.

> **"We see plans that don't actually cover the situation you're facing so you're still left guessing." (Clinical Nurse Specialist)**

Participants described how people's preferences can shift in nuanced ways – not always a simple 'yes/no' to treatment, but conditional decisions about which interventions are acceptable and which are not. When those nuances were not recorded, or when plans were not updated as preferences changed, documentation misrepresented what the person wanted at the point of deterioration.

> **"A patient changed his mind; he didn't want CPR but did want IV antibiotics and non-invasive oxygen but it [his record] wasn't updated to reflect this so [when he went into cardiac arrest] he was resuscitated." (GP)**

These mismatches left clinicians feeling exposed and families uncertain, particularly when rapid decisions were needed and there was little time to clarify preferences or decisions in the moment.

When care was split across GP, district nurses, hospital teams, ambulance services, and out-of-hours providers, usually no one person held the whole picture of an individual's circumstances and preferences. Under pressure, clinicians were often not able to locate or trust the most current plan. In this situation escalation was viewed as the safer path.

System pressures and service capacity

System pressures stopped clinicians honouring people's decisions and preferences in very practical, tangible ways, especially when someone wanted to remain outside of hospital or prioritise comfort over further treatments.

> **"Most elderly people want to die at home I would say but it's difficult to keep them there as there is no resource." (Care Home Nurse)**

Professionals told us how insufficient community capacity meant that "home" was not always a safe or viable option. Even if a person wanted to die at home, that depended on having enough district nursing capacity, palliative support, carers, equipment, and a reliable and timely out-of-hours response. When those services were stretched, clinicians felt they could not safely leave someone at home when symptoms escalated or family carers were exhausted. The system defaulted to conveyance and admission to hospital because it felt like the only place that could provide 24/7 monitoring and rapid intervention, despite the person's preference to remain at home.

Limited training and confidence in end-of-life care outside of specialist palliative care

Very few clinicians told us they had received specific end-of-life training beyond what they had learnt at medical or nursing school, or an occasional learning day off site.

Across the interviews, clinicians were clear that confidence, rather than compassion was the key limiting factor in delivering good end-of-life care. Confidence, they said, was developed primarily through experience, exposure, and role modelling, alongside formal training and guidelines. It was learnt from the professionals around them, not through policy alone.

Participants consistently rejected the idea that poor care reflected a lack of caring or moral commitment.

> **"It's not that people don't care, it's that they're terrified of getting it wrong." (Senior District Nurse)**

Several participants expressed concern that opportunities for informal end-of-life learning and mentorship were diminishing due to workforce pressures, rota gaps, and high staff turnover.

Palliative care teams consistently emerged as exemplars of good end-of-life care, modelling confidence, skilled communication, and comfort with uncertainty. There was appetite across participants for ensuring that core palliative competencies, communication, symptom management, and relational care become foundational skills for all clinicians involved in end-of-life decision making.

> **"Death and dying doesn't come naturally to me but I've got better at it over the years. The palliative care team are much better; they are the experts." (Consultant)**

The impact this has on individuals and their families

People and their families told us that recorded refusals of treatment were ignored or dismissed when it mattered most. For family members, this meant they watched their loved ones endure the situations they specifically wanted to avoid at the end of their life.

Sometimes, advance decisions to refuse treatment were disregarded when decisions about life-sustaining treatment needed to be made.

> **"As soon as my mother was diagnosed with dementia she made an advance decision [to refuse treatment], refusing all life-sustaining treatment once she lost capacity. This was signed and witnessed and the GP at the time added it to her medical records. As the dementia advanced, she lost capacity and was taken into a care home with a new GP. The care home management and new GP refused to follow her advance decision, they told me that to follow it would be "murder". They told me they would treat her for any infections, but I knew this was not what she would have wanted."**

Health and welfare attorneys told us their decisions or opinions were not respected in treatment and care decisions. Almost exclusively, this happened when they were advocating for stopping or withholding a treatment that they knew their loved one did not want at the end of life.

> **"My wife has MND. A few months ago she was alert and sound of mind. She had many discussions with the hospice and did write a basic wishes form that stated DNR and that she wanted quality of life over length. After writing the form it was recommended she have a PEG fitted. She was worried at the time that this would take away her choice if she wanted to stop food and water at a later date. She was told that this wasn't the case and she could request to stop all nutrition and hydration at any time. This wasn't ever transferred to her wishes document and none of this appears to have been written down.**
>
> **She quickly deteriorated and was moved into a nursing home. After further deterioration, last month my wife stopped eating and drinking, it was like she had made the decision that all was good and she was ready to die.**
>
> **Since then I have had to fight the GP to get them to stop PEG nutrition, and to stop giving antibiotics. It seems they are keeping her alive to ensure she has the worst death possible. If she hadn't had the PEG, or if they had allowed PEG food and water to stop at the same time, she would have peacefully passed away by now. It's so traumatic for all of the family and it's awful to see her in pain.**
>
> **Even though we have power of attorney we are told our wishes in relation to hydration don't count and that it's the healthcare professionals' decision. They are using language like "starving to death" and "basic human right to live" it makes me feel terrible. We are at a loss. I hate the fact I am having to fight for my wife's right to die."**

For other people whose wishes were not recorded, family members told us that knowing and explaining what their loved one did or did not want was not enough to ensure their wishes were upheld. People told us that in such situations, they found participating in decision making processes extremely challenging. If their loved one's preference went against the grain of treatment and escalation, they were shut out of conversations and made to feel guilty for trying to explain what the person would have wanted.

> **"My aunt has spent over 10 years in a nursing home with a very poor quality of life. She is deaf, blind, confused and agitated, has kidney disease and recently had some bowel obstruction. I'm preparing for a meeting with the GP and I want to ensure she is not given treatments I know she wouldn't want. Our relationship with the home is breaking down and the care has been poor. She has been given CPR when she has a DNAR form in place and the GP is continuing to give antibiotics for chest infections because "she is not right at the end of life". The doctor rang and told us "your mother deserves life" and "I'm not here to withdraw treatment" they said "this is what we do, the bottom line is it has to be the doctor's decision"."**

Finding 2: Opportunities to understand and record people's decisions are missed or avoided, resulting in unwanted treatment being given and people feeling powerless over their care

Health and care professionals' perspectives

Professionals in our interviews agreed that advance care planning is clinically valuable and ethically sound. They said that it allows people to start conversations early, and that providing opportunities to consider their treatment preferences and preferred place of care can reduce the burden of decision making for family members.

> **"And if you can get that right (ACP), you can avoid a lot of distress. If it's all in place you know what's going on, you can do your job well and you won't hit a crisis. Ultimately no one wants a crisis at that point." (District Nurse)**

> **"When it's done well and early, it's brilliant. But that's the exception I would say." (GP Partner, Frailty)**

However, professionals acknowledged that translating their support for patient autonomy into practice can be very challenging. Clinicians explained they do not always feel confident leading complex conversations about dying or navigating uncertainty around risks or benefits of certain decisions.

Health and care professionals described how they can feel unsafe and exposed during conversations with people about refusing treatment and some feel more comfortable opting for clinical interventions over communicating clearly about prognosis, trade-offs, and the rationale for non-escalation.

> **"We aren't trained in how to move from [active] treatment to care – it's a really hard shift for doctors to grasp." (Resident Doctor)**

> **"We, i.e. us doctors, aren't very good at death conversations and defer to palliative care teams often." (Resident Doctor, Oncology)**

You can read what UK law, policy and guidance says on the importance of timely, honest end-of-life conversations and the recording of people's preferences on page 27.

Professionals described a form of 'death denial' embedded across the healthcare system, where acknowledging death or recommending less intervention feels counterintuitive, as success is so often measured through action, escalation, and rescue. In acute and intervention focused specialties such as oncology, conversations about death can be obscured by the range of treatments on offer and the dominant optimism in the sector and in the media, for example, 'battling cancer'.

> **"We send out optimistic messages but there are no guarantees.' (Resident Doctor)**

On top of this, system and time pressures limit opportunities for good conversations and shared decision making. Professionals described that clinicians may not have the time to hold repeated, sensitive conversations.

> **"I know GPs are under pressure, but it would help if they pushed for more planning and had more conversations earlier about dying better." (Paramedic)**

Professionals described the emotional burden felt by both themselves and families in moments of crisis, exacerbated by an absence of good practical preparation and planning.

> **"They discharged him from hospital as he was dying and wanted to go home. The GP told the family and they were in shock; they were unaware he was even at the end of his life." (Nurse)**
>
> **"An Advanced Directive takes the pressure off the family too. They tell us, 'I wish you'd had that conversation with them and not me, I don't want to choose'." (Resident Doctor A&E)**
>
> **"You go home and replay it all. There's no space to talk about it." (District Nurse)**
>
> **"It's just assumed you'll cope. That's part of the job." (Senior Nurse)**

The impact this has on individuals and their families

Polling shows that while only 3% of people would want a doctor to make final decisions about their treatment, just 9% have made a lasting power of attorney for health and welfare, and only 5% have made an advance decision to refuse treatment.[5] For some people near the end of their lives, their experiences showed that their ability to make and record treatment decisions was undermined by a lack of opportunities to have and record those conversations.

For the people we support, this happened on two levels:

- Some people were not given an opportunity to consider treatment preferences, even when it was relevant to them
- When people did want to proactively plan, healthcare professionals were not always ready or willing to have those conversations

Some people who had life-limiting conditions were not encouraged to discuss and consider their preferences for treatment or understand what the future might look like. People told us that professionals shied away from talking about and confronting the realities of dying, and that conversations about symptoms that may be experienced at the end of life were sometimes approached overly optimistically.

People caring for a loved one in community settings told us they felt unprepared for deterioration due to a lack of information about what to expect and the symptoms that may arise. This resulted in unwanted hospital admissions and treatments.

"My mum was diagnosed with MSA [Multiple System Atrophy], she steadily deteriorated over five years. However, in this time no professional had a conversation with her or us about advance care planning or what to expect from the dying process. When she suffered respiratory arrest, she was taken to A&E. Nothing was discussed with her and she was taken to theatre straight away and when she woke, she had a tracheostomy, and a PEG inserted. Importantly, if she was given that choice, she wouldn't have consented to either. She lived for years following the intervention with a very poor quality of life."

"I have widespread mets [cancer metastases] and being treated with chemo. I'm tired and don't want active treatment anymore, as it makes me feel awful. I find the support very optimistic and they won't allow me to explore what I want, which is an understanding of what dying will involve and my options."

Furthermore, when people did want to proactively plan, health and care professionals were not always ready to have these conversations. When people attempted to start pragmatic conversations about treatment or interventions they might not want if they were to lose capacity in the future, it was discouraged or dismissed.

Sometimes people told us that their clinician seemed uncomfortable with them wanting to refuse treatment and felt that their attempts to have such a conversation were avoided. People were also told they were too young or too healthy to be thinking about refusing treatment, despite living with frailty or having a progressive condition. For some, their capacity or emotional state to make these decisions was questioned. In most of these cases, it was the decision to refuse or stop treatment which the healthcare professional disagreed or felt uncomfortable with.

Not only does this go against clear best practice and guidance,[6] it caused people to feel powerless and lose trust in their care. It also meant that in critical moments, people's preferences or decisions were not recorded or known about by professionals looking after them. This resulted in people feeling fearful and worried about the future.

"I'm doing an advance decision [to refuse treatment] and hitting obstacles trying to speak to my GP about it. They just tell you how busy they are. I'm 83 with conditions that mean I have regular contact with the GP. Twice I've asked about refusing CPR and, from two separate doctors, their response has been 'let's talk about that next time'. I'm going round in circles and just need a way in. When I speak to the receptionist they say you have to speak to a doctor, but they won't book an appointment for this as it's not urgent. I feel like I'm wasting their time and this is causing me anxiety and it exacerbates my conditions. I want to make sure this is done, it's worrying me a lot."

"I have suspected cancer but I'm sure that I don't want to pursue any further investigations and wouldn't want treatment. I talked to my GP about an advance decision to refuse treatment, but they told me that a solicitor needs to do it and if I kept talking about refusing treatment I may be sectioned. This really frightened me."

"I have been very unwell since being resuscitated while having heart surgery. I've asked for a DNACPR form from my GP multiple times, but they have declined to do this. They stated that they value my life."

Finding 3: When preferences and decisions are recorded, this information is not always visible when it matters most, resulting in unnecessary treatments

Health and care professionals' perspectives

Even when preferences and decisions have been recorded, professionals repeatedly described them being unavailable, inaccessible, or not complete enough to be confidently followed at the point of an individual's deterioration, particularly in emergency environments and during handovers.

In emergency settings, where rapid decisions needed to be made and professionals had limited or no prior relationship with the person, documentation needed to be readily available through digital records in order to reliably inform decision making. We were told that too often, this was not the case. Poor system integration meant that while people's decisions and preferences might have been recorded, they failed to travel with the person across care settings and therefore could not be translated into confident action.

Health and care professionals said that in these moments, escalation then became the default response, meaning preferences were overridden simply because they were not accessible or because professionals did not feel confident following incomplete information.

> **"If I can't see the plan, I follow the trust's policy, so the default is to jump on and resuscitate." (Paramedic)**

> **"If there's nothing visible and no one knows their wishes, you default to doing everything, even if you suspect it's not what they'd want." (Paramedic)**

On top of this, delays and administrative gaps were also described as creating real-time risk, especially in care homes where staff were forced to act before paperwork caught up with the person's wishes.

> **"We are waiting for the signed DNACPR form from the GP but it's 4 weeks late. We are all anxious in case he goes into cardiac arrest and we have to start CPR knowing he doesn't want it." (Care Home Manager)**

You can read what commissioning requirements and national policy say about the provision of digital end-of-life records on page 27.

The impact this has on individuals and their families

When information is not clear or accessible at the point of need, it resulted in traumatic experiences and unwanted interventions.

> **"Over a year ago the care setting where my husband, who has dementia, lived asked for a meeting with me about placing a DNAR on his record due to the complications that could arise from resuscitation. This was something I did not take lightly and took over a week to discuss with other family members and consider the advice from medical professionals. In the end I fully agreed with the decision. Yesterday morning I got a call at 3.30 in the morning to tell me that my husband had suffered a suspected stroke and had stopped breathing, yet he had been resuscitated."**

People told us that documents such as advance decisions to refuse treatment or clinician-led documents such as DNACPR forms or the ReSPECT process were not shared digitally or transferred with a person when they moved care settings. People then worried about what would happen to them or their loved one in the future should a crisis happen. It also caused people to lose trust in the healthcare system caring for them.

One caller told us about their aunt's experience, where system failure led to her carefully considered and expressed decisions being unseen, resulting in unwanted treatment and blame.

> **"After watching my father die, who had suffered with dementia, both myself and my elderly aunt put an advance decision [to refuse treatment] in place to ensure we had a sense of control over our treatment and care decisions.**
>
> **14 years before this my aunt had had emergency surgery and as a result was left with a colostomy that seriously affected her quality of life. She told me at the time that she would not want to be given any life sustaining treatment if she couldn't be wholly independent and had lost cognitive function. Her advance decision clearly stated this.**
>
> **She succumbed to Alzheimer's disease years later and when emptying her home to sell for care home fees, we came across the advance decision. I took it to the nursing home, where it was added to her files there. Sometime after we were notified that she had been taken to hospital with a severe chest infection. The home said the paramedics knew of the advance decision and I trusted that her wishes would be adhered to.**
>
> **When ringing the hospital, I was told she was very poorly with pneumonia in one lung and sepsis. I asked if they were aware of her advance decision, and the nurse answered yes. However, she was treated with antibiotics against her stated and recorded wishes and she was taken back to the nursing home. Later I checked with Medical Records at the hospital to see if the advance decision was on her records and available to the hospital staff who treated her, I was told it just commented "an advance decision was in place", nothing more and no information about what the advance decision had said.**
>
> **The care home had given copies of the form to the paramedics but it felt like everyone involved was not reading the form and passing responsibility and decisions on to the next person down the line. Instances like this occurred more than once, the nursing home kept calling paramedics to take her to hospital and she continued to be treated by the nursing home's GP practice with antibiotics for chest infections too.**
>
> **This experience has really worried me, I have an advance decision myself and no family members to fight for me. I should be able to trust that doctors will listen to my wishes if my advance decision is ever needed."**

Recommendations

How we can collaboratively bridge the gap between policy intention and reality

Our research shows clearly the substantial obstacles which prevent people's wishes being respected at the end of life despite law, policy and guidance consistently stating that people's preferences for less invasive care should be respected.

End-of-life care is higher on the political agenda than ever before and this is an important opportunity to get it right for people, their families and for the professionals caring for them. In the wake of the 10 Year Health Plan for England and the Neighborhood Health Framework, and with a new Modern Service Framework for palliative and end-of-life care on the horizon, Government and the health and care sector are tasked with aligning palliative and end-of-life care more reliably with people's decisions.

However, this ambition and the vision for the new Modern Service Framework will not be realised without addressing the problems, anxieties and systemic beliefs this report shines a light on.

The urgent challenge for those working to improve end-of-life care is how we actively and collaboratively address the clear gap between people's wishes, policy intent and practice. It is noteworthy that most of the experiences in this report take place in settings outside of specialist palliative care. Therefore, attempts to improve dying in the UK must look to support practice across specialisms and include touchpoints along a person's healthcare journey before a palliative care referral is made, in addition to the important work already underway to improve access to sustainable, high quality palliative care.

These recommendations set out an approach to improving dying that starts upstream with public health approaches and better conversations, and reaches downstream into better community provision. They provide the mechanisms we need to create environments where acting on the decisions of people and their loved ones feels normal, safe and supported.

The experiences in this report show that decisions about dying and end-of-life treatment need attention from clinicians across all specialisms and across all stages of a person's healthcare journey.

We hope these recommendations will kick-start a national conversation about how to better allow people to make their own informed decisions. It is possible to forge a more compassionate approach to dying in this country, where people's autonomy is fostered and choices are respected.

These recommendations have been developed in collaboration with sector leaders from across emergency medicine, primary and secondary care, palliative and end-of-life care, and the hospice community.

They require collaboration from Government, Department of Health and Social Care (DHSC), the Parliamentary and Health Service Ombudsman (PHSO), NHS England (until its functions are transferred to DHSC), ICBs, Royal Colleges, people with lived experience, voluntary community and social enterprise (VSCE) organisations, NHS England Digital, medical schools, health and social care professionals, research leads in academic institutions and research funding bodies.

Ensure people have opportunities to consider and record their decisions and preferences if they want to

1 Deliver a public health campaign on end-of-life conversations and decisions

We need to treat the lack of societal knowledge and information about end-of-life decisions and care planning as a serious problem requiring a serious response.

An ongoing cross-sector, collaborative public health campaign would help to address the urgent need for better public information on what dying looks like, how people can plan for the end of their lives and why doing so can help. It should include:

- The sorts of decisions people might face and how their preferences and priorities can inform these decisions
- How and why planning can help
- That people do not have to plan ahead if they do not want to
- That any decisions can be revisited over time
- The different ways people can plan for and make decisions about their treatment and care at the end of their lives

The aim should be not just to inform, but to help familiarise people with the language and reality of end-of-life care and bring it more fully into public awareness and normalise conversations about death and dying as part of life, not just healthcare.

This must be developed in multiple languages and formats and co-designed with different communities, both those living with serious illness and those who have never engaged in such conversations.

What Compassion in Dying is doing to help

Compassion in Dying is convening a wide group of organisations and individuals who want to work together to consider the need for a public health campaign, with the intended outcome that people's experiences at the end of their lives are aligned with their priorities and wishes; and inequity of experience is acknowledged and reduced.

We have conducted a literature review of existing evidence, and begun to commission focus groups with different public audiences, broadly looking at what each audience believes and feels about end-of-life treatment and care, why they believe what they do, what is holding people back from considering and discussing their priorities, and what will enable them to take action if they want to.

Once the insight phase is complete, we will consider what the evidence says about focus, messaging and which audiences could most benefit from a public health campaign, as part of a wider public health approach to death and dying. If you would like to stay up to date with or be involved in this work please get in touch.

Learning from local innovation

Libraries as Beacons of Death Literacy

In Tower Hamlets, East London, Let's Discuss Death CIC is working to transform local libraries into "beacons of death literacy." This grassroots initiative is built on a straightforward vision: libraries are trusted community hubs, open to all, where people often feel more comfortable and safe than in clinical settings. By using these existing community spaces, they move conversations about dying, death, and grief out of the hospital and into the heart of the community.

The initiative provides a year-round, free programme co-designed with a broad coalition of partners, including the local NHS Trust, ICB, charities, and librarians. Annual national weeks such as events for Dying Matters Awareness Week in May and the Day of the Dead festival in October - provide entry points for the community to engage with these topics in a range of formats. These include practical talks by death doulas on Advance Decisions and Lasting Powers of Attorney (LPA) as well as creative workshops for all ages.

This work could form part of a wider public health approach to dying, and responds directly to the fact that that many essential end-of-life conversations do not require a healthcare professional and are often not happening early enough in clinical trajectories. By fostering a death-literate society where GPs can eventually signpost patients to these community spaces, Let's Discuss Death aims to ensure that every individual has the knowledge, language, and confidence to participate in their own future care decisions.

2 Increase opportunities for people to consider and record decisions and preferences

The neighbourhood health framework[7] states a bold ambition to reduce the number of non-elective admissions and hospital bed days and increase identification of people as they approach the end of life. This focus on people at the end of their lives is significant but must be underpinned by an understanding of what people themselves want, otherwise there is a clear risk that this push for identification and hospital avoidance will end up undermining people's sense of agency and safety, which will in turn reduce trust in services.

We need to create earlier, routine opportunities for people to have important conversations about their priorities and preferences for care and to record their decisions if they want to. This requires developing and building on touchpoints throughout life, including beyond healthcare, where people can consider and record their priorities.

This should be achieved through multiple channels and opportunities:

- The forthcoming Modern Service Framework for palliative and end-of-life care should mandate that planning conversations are offered and documented, and ensure commissioning frameworks enable this to be embedded into clinical pathways and regular practice.
- Include end-of-life conversations in neighbourhood health contracts and services. There should be a requirement for every person facing the prospect of deteriorating health due to a long-term condition or life-limiting illness, including people living with frailty, to be offered an advance care planning conversation in the community as a priority cohort. Existing mechanisms well suited to incorporate this include the QOF in Primary Care and as a mandatory part of the enhanced health in care homes programme.

- Encourage the development of innovative digital tools, including person-held digital records, that support people to explore, record and share their end-of-life priorities and preferences. This should include the option for people to make and record advance decisions to refuse treatment and advance statements. The NHS App should be trialled as a front door to this. These tools should be co-designed with patients, families and professionals and build on existing well tested services.
- Use NHS health checks, GP registration, admission to hospital and moving into a care or nursing home to prompt and support people to consider and record their priorities.
- Use models that build on community assets and volunteering, through partnering with VCSE organisations and communities to start and embed these conversations.

Learning from local innovation

Care Choices Service[8]

In Ipswich and East Suffolk, GP and senior partner of Peninsula Practice in Alderton, Dr Lindsey Crockett, has set up a successful, NHS-supported, Care Choices service. The service helps people, who have been identified as being in their last year of life or living with severe frailty, to discuss and record wishes and priorities for the end of their lives.

The grassroots community-based initiative trains and manages volunteers to facilitate these conversations and support people to document their future care choices. Volunteers spend two or three visits with people, having focused conversations exploring what matters most to them towards the end of their life, and how to avoid stressful or unwanted admissions and interventions. Volunteers have 'the resource of time' which health and care professionals are often short of.

Importantly, it allows the local, rural, elderly population of East Suffolk to approach the last stages of their lives in the confidence that their wishes, which often are about staying home and out of hospital, have been understood.

The service is positioned to reduce inappropriate hospital admissions, create GP access and capacity and save unwanted ambulance conveyances.[9]

Ensure health and care professionals have access to people's recorded choices

3 Make end-of-life decisions and preferences visible when it matters most through a digital single patient record

Digital records need to communicate people's decisions and end-of-life wishes seamlessly across care settings and geographical boundaries. At a minimum, people want to be able to view their end-of-life record to see what information is available to healthcare professionals.[10] It is essential that preferences and ceilings of treatment are known across all relevant healthcare teams and that, when a deterioration happens, whoever attends the dying person knows the right action to take. This will reduce unnecessary hospital transfers and prevent admissions which result in treatment that ultimately, the person did not want.

- The single patient record (SPR) being developed for the English NHS must include people in the last year of life as a priority cohort. It should focus on and enable people's right to record their end-of-life decisions, with these wishes visible up front rather than buried in lengthy care records.
- While different patient records still operate across settings, services, and areas, commissioning frameworks must ensure interoperability and full visibility of end-of-life decisions between all providers, including 111, out-of-hours services, and ambulance services.
- Any digital tools developed to support people to explore, record and share their end-of-life decisions and preferences (as detailed in recommendation 2) must ensure that such information is visible to those caring for them when it matters most.

What Compassion in Dying is doing to help

White labelling the UK's leading free online advance decision service

Our pioneering online advance decision service is the largest of its kind in the UK. It's based on the experiences of the 45,000 people who we have supported to plan ahead online for free. We developed and tested the service in partnership with people, clinicians and legal professionals. The paper version of this online service is already white labelled by NHS Trusts, primary care networks, hospices and national charities, and is signposted to by the NHS.

We also allow other organisations to white label this online service for free. This means that they can integrate it with their own website or app using their branding. We share openly because we want as many people as possible to be able to plan for the end of life. Our mission is to make sure everyone receives the information they need to be in control of their end-of-life decisions, regardless of who they turn to for support.

Ensure health and care professionals feel confident and supported to follow people's decisions when these are known, and to make best interests decisions when they are not

4 Strengthen health and care professionals' confidence in end-of-life decision making, particularly when active treatment may no longer be appropriate

We must foster a healthcare culture where death can be acknowledged and planned for, and where less intervention can be recommended when clinically justified and aligned with what matters to the person, without this feeling counterintuitive or professionally risky.

To help realise this:

- Make 24/7 senior and expert advice available on end-of-life decisions for front-line teams, staffed by experienced palliative care or geriatric clinicians who can discuss and share responsibility for decisions to stop escalation, tests and active treatment as someone approaches the end of life.
- Apply relevant learning from the implementation of Martha's rule,[11] which has led to improvements in patient safety for significant numbers of patients. Careful attention needs to be given to the fact that end of life treatment decisions do not just play out in hospital but across different care settings (primary, community, social care).
- Clinical, managerial and regulatory stakeholders should co-design test and learn projects to better understand how such senior support with end-of-life decision making could be implemented and what is required to change frontline clinical practice at scale.

The urgent need for reliable, 24/7 community-based end-of-life care

Our findings show strongly how strengthening professional confidence in moving away from hospital-based care also requires building community services that are responsive, reliable, and accessible.

Compassion in Dying therefore strongly supports the work already being taken forward through the Modern Service Framework and by colleagues across the sector to build and mainstream evidence-based community care models. These models must ensure seamless, coordinated 24/7 provision through neighbourhood contracts that bring together primary care, community services including VCSE partners, social care and out-of-hours support.

Learning from local innovation

The South West End of Life Matters Health Integration Team (ELM HIT) is an example of regional innovation designed to strengthen confidence, shared responsibility, and collaboration in end-of-life care. The HIT provides a platform for co-production between public contributors, academics, health and social care providers, voluntary sector partners, and community organisations. Through convening events, sharing expertise, supporting local initiatives, and co-developing research and improvement projects, the HIT helps create the conditions for people and professionals across different settings to feel more connected and supported when navigating decisions about future care, treatment escalation, and individuals' priorities and preferences.

Examples of initiatives include co-developing guidance for social care staff to support advance care planning conversations, and partnership working with Marie Curie, University Hospitals Bristol and Weston NHS Foundation Trust, and the One Weston Care Home Hub to establish a shared strategic vision for palliative and end-of-life care across North Somerset. The HIT also hosts in-person, system wide network events that bring together diverse perspectives to better understand current challenges and opportunities.

5 Expand education and training on how to support good end of life care

Health and care professionals should be supported to feel confident in end-of-life decision making. Health and care professionals told us that this confidence is generally socially transmitted, and develops through permission, exposure, experience and role modelling.

Opportunities for informal learning and mentorship should be fostered and core palliative care competencies – communication, symptom management, relational care – need to be seen as foundational skills for all clinicians.

Specifically:

- Education on the realities of dying, professional conduct, regulation and the legal frameworks that underpin end-of-life care should be given more time during medical school, with content and learning woven throughout year one to final year.
- Ensure early career professionals shadow senior clinicians making best practice end-of-life decisions in a compassionate and person-centred way, through structured role modelling and mentoring.
- Mandate continuing training for postgraduate professionals on end-of-life decision making under mental capacity legislation – including the legal status of advance decisions to refuse treatment, the best interests process, the rights of health attorneys and the work of the Court of Protection. When identifying cohorts for this training priority should be given to senior decision-makers as well as resident doctors.
- Ensure every health and care professional has end-of-life training in community settings, including in people's homes, to understand the reality of care delivery away from clinical settings.
- Develop training in collaboration with people with lived experience of end-of-life decisions and their families.

What Compassion in Dying is doing to help

We know that supporting practice at a frontline level plays an important role in improving how decision-making frameworks are understood and applied. Through education, case discussion, and collaborative learning, Compassion in Dying's nurses deliver tailored education sessions across health, academic and community settings.

Our education work spans national webinars for the public and disease-specific organisations, collaborative curriculum development with universities, and specialist teaching for nursing, palliative care, and multidisciplinary clinical teams.

Sessions are tailored to audience need and professional context, with emphasis on translating complex legal, ethical, and clinical knowledge into practice. We support health and care professionals to build confidence in advance care planning conversations, understand the legal status of advance decisions to refuse treatment and other planning tools, and feel more comfortable working in partnership with people and families.

This equips professionals to lead compassionate, person-centred conversations and support decisions in complex and emotionally sensitive situations.

6 Ensure the policies that guide professional practice take into account the experiences of those who are most affected

NHS trusts, other health and care providers and independent public bodies should ensure that policies relating to treatment decision-making and mental capacity legislation (such as policies on Advance Decisions to Refuse Treatment) are designed, developed and reviewed in meaningful partnership with people, families, carers and communities who have experience of navigating these decisions within the health and social care system.

Organisational policies that directly reflect the needs of the people they affect will help to address the misplaced fears that health and care professionals often have about respecting some decisions, as highlighted in this report. Policies that are grounded in the realities of people's experiences can increase confidence and ensure that professionals have a meaningful understanding of how people want these decisions to be made and communicated in practice.

The new Patient Experience Directorate within the Department of Health and Social Care has the potential to be a vehicle for this work, but our research shows this shift in policy design needs to happen consistently at national and local levels.

Appendix

What law, policy and guidance says should happen

There are considerable examples of policy that try to ensure decision making towards the end of people's lives is person centred. Key law, policy and guidance relevant to the experiences in this report are included here to support best practice.

The importance of honest discussions and an opportunity to plan for the end of life

The importance of honest discussions and having opportunities to plan for the end of life have long been recognised by key policy documents such as the Ambitions framework for palliative and end-of-life care,[12] the Universal Principles for Advance Care Planning,[13] and NHS priorities for end-of-life care.[14]

The Ambitions frameworks states how each person should be seen as an individual, with opportunities to have honest, informed and timely conversations.[15]

The Lancet Commission on the Value of Death[16] recommended that national programmes should be initiated to ensure that everyone has the opportunity to make an advance care plan.

Academic research which has shown how enabling different conversations to take place reduces unplanned emergency admissions and leads to reports of better experiences, including for those who are bereaved.[17]

Making informed decisions

The General Medical Council (GMC) guidance on decision making and consent[18] requires clinicians to explore what matters to a person, so they can share information about the benefits and harms of proposed options. This should include reasonable alternatives and the option to take no action.

GMC guidance on good medical practice[19] sets out overarching principles, including that clinicians should recognise that people are individuals with diverse needs; not make assumptions about the options or outcomes someone would prefer; and consider how their own life experience, culture and beliefs might influence their interactions with others or impact on their decisions and actions.

The GMC guidance on treatment and care towards the end of life[20] explains that there is no absolute obligation to prolong life.

Refusing treatment

Anyone over the age of 18 with capacity to do so can make a voluntary and informed decision to consent to or to refuse particular treatments even if refusing a specific treatment would result in their death.[21]

Furthermore, anyone over 18 with capacity can also write down specific treatments, including life sustaining treatments, they wish to refuse in an advance decision to refuse treatment in case they become unable to make or communicate those decisions in the future. A valid and applicable advance decision to refuse treatment is legally binding in England, Wales[22] and Northern Ireland.[23] In Scotland,[24] national focus on anticipatory care planning includes how these forms must be taken into account when deciding on how to treat the person.

There are clear policies regarding the refusal and/or the withholding of cardiopulmonary resuscitation (CPR), an important component of advance care planning. Guidance from the British Medical Association, Resuscitation Council UK, the Royal College of Nursing[25] and the NHS[26] show how these decisions, once made, should be communicated and followed.

Health attorneys

The legal status of a lasting power of attorney recognises the value people place on enabling those they trust to make decisions on their behalf. The right to give legal authority to someone they trust to make treatment and care decisions on their behalf when they are no longer able to is set out in the Mental Capacity Act 2005 and in the Adults with Incapacity (Scotland) Act 2000. An appointed 'attorney' has legal authority to make health and care decisions and has a duty to make those decisions in the person's best interests.

Making decisions in someone's best interests

The law states that if someone lacks capacity to make a decision, that decision needs to be made by someone else. Unless they have made an advance decision to refuse treatment or a lasting power of attorney for health and welfare, decision making power and responsibility falls to professionals. Whoever is making the decision must act in the person's best interests.

The Mental Capacity Act 2005, the Adults with Incapacity (Scotland) Act 2000 and the Mental Capacity Act (Northern Ireland) 2016 provide the framework for how a person's best interests or benefits should be identified. The law states that the person's past and present wishes, feelings, beliefs and values must inform the decision making process, and the views of other people who are close to the person who lacks capacity should be considered.

The British Medical Association guidance[27] on best interests decision making states that those close to the person must be consulted as part of the process. It also explains that any written statements such as advance care plans or advance decisions to refuse treatment, which do not meet the requirements to be valid and applicable, are important to consider as they still help to give a clear indication of the person's preferences for medical treatment and care.[28]

Digital end of life records

The Labour Government has promised to deliver a Single Patient Record to give every clinician a real-time, comprehensive view of a person's health and care information across settings. It should deliver one, joined up record accessible across the NHS and social care so information flows between GP, hospital, community, mental health, ambulance, pharmacy, and care providers, alongside better access to this information for people themselves.

Progress on the Single Patient Record will likely be incremental and completion will take considerable time. In the meantime, current commissioning guidance is explicit that key information about individuals' needs and priorities should be shared digitally via Shared Care Records, and that ICBs should consider full implementation of Electronic Palliative Care Coordination Systems (EPaCCS) to make people's preferences visible across settings when it matters.[29]

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Compassion in Dying.

Your end of life. Your way.

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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