Parliamentary
and Health Service
Ombudsman

# Conversations that matter most: improving communication in end of life care

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We’re changing our name. Later this year, we will become the Public Service Ombudsman. This will make it easier for people to find us and understand what we do. Our service will remain the same. Find out more about our new name.

# About us

We independently investigate complaints about the NHS in England, UK government departments and other public bodies. Our service is free, fair and open to everyone.

We provide a final, independent check when people believe they have been treated unfairly or let down, helping to hold public services to account and improve standards.

We are here to put things right for individuals and to help prevent others from experiencing the same issues. We use evidence from complaints to identify the underlying causes of failings in public services and help to deliver lasting change.

## Our strategy 2026 to 2031

**Our vision is to deliver fair and impartial justice for individuals and to drive improvements in public services for everyone.**

Our 2026 to 2031 strategy sets out how we will deliver this vision. It includes three aims:

1. **impact** – to drive meaningful improvements and system-level changes in public services
2. **user experience** – to provide an accessible, timely and person-centred complaints process
3. **awareness** – to be a recognised and influential voice in improving public services.

Over the next five years we will shift our approach to deliver greater systemic impact that benefits people who use public services. This will be realised within a framework that addresses important themes across a large proportion of the cases we receive. Communication is one of these areas of focus, as we see frequent issues relating to this across our casework.

### Our focus on communication

We know from our complaints and wider best practice how important it is for public services to communicate openly, empathetically and effectively. This applies equally across our work with government departments and the NHS. As modern healthcare becomes more complex, involving joint working between different teams and organisations, good communication becomes even more critical.

This is the first substantive report we have published since the launch of our new strategy. It reflects our focus on having the greatest possible impact on improving public services and working collaboratively with organisations to help them to identify issues earlier and prevent them from escalating further. Our aim is to work with organisations to improve administration and systems of care.

# Foreword from the Ombudsman

Since taking up the post of Ombudsman last summer, I have been clear that alongside our core function to provide individual redress, the mission of my Office must be an ambitious one: improving public services and rebuilding trust between the state and citizens.

The experiences people share with us through complaints give us insight into where things are going wrong in organisations and systems. We have a clear duty to use this information to drive improvements and prevent the same issues from happening again.

As I have talked to our caseworkers, our clinical advisers and stakeholders in the health sector, I have been struck by how often a breakdown in communication sits at the heart of the complaints we receive. This is why, when developing our new five-year strategy, we knew that one of our priority areas must be supporting public services to communicate in an open, empathetic and effective way.

Nowhere is strong communication more important than in the provision of end of life care. When systems and teams communicate well, patients are more likely to receive the right care at the right time and clinicians are better equipped to navigate the complexities of moving between different care settings. When patients and families are given clear explanations, and when crucial conversations happen early and with sensitivity, they feel supported and better equipped to face the next steps, however difficult they may be.

When communication breaks down, the consequences can be severe, both for the quality of immediate care for the patient and the families supporting them. As we have heard so often, families carry with them guilt and upset for a lifetime about how a loved one died, adding to their grief. They tell us about how their trust in the NHS has been eroded and they find it hard to return to places where their loved one died. Clinicians too carry a heavy emotional burden when care at end of life falls short.

In this report, we draw on the experiences of families and clinicians to better define how communication can fail during end of life care, and what is required to drive improvement. I am hugely grateful to everyone who has taken time to speak with us about their own experiences.

Our recommendations focus on three areas:

- **Confident, skilled, compassionate communication with patients and families at the right time.** Gaps in crucial communication skills have been recognised for too long without being fully addressed. We now need to see sustained and consistent action to remove barriers to proactive, compassionate conversations about end of life care.
- **Clear outcome measurement that includes patient and family voices.** The assessment of whether end of life care is improving must be informed by how it is actually experienced by patients and families.
- **Effective information sharing between teams and care settings**. We must get the basics right so that patient information is readily accessible across different settings. As the NHS works to shift care from hospitals to the community, this longstanding policy aim becomes increasingly urgent.

It is a critical time for the development of end of life care, with the Modern Service Framework for Palliative and End-of-Life Care due to be published later this year. This report underlines the urgent need to tackle persistent communication failures that continue to undermine the experience of patients and families at the time that matters most.

**Paula Sussex CBE, Ombudsman**

# Executive summary

## This report uses evidence from our casework to show how communication shapes people’s experiences of palliative and end of life care.

Drawing on complaints brought to us by families, friends and carers about the care their loved one received, it highlights where communication most often falls short and identifies opportunities for learning and improvement across services.

We set out our findings across three areas:

- **Communication with patients**, including delayed or missed conversations about prognosis and poor discussion of preferences around family involvement.
- **Communication with families and carers**, including unclear discussions about poor prognosis, failure to keep families informed, inaccurate or insufficient information about diagnosis and treatment, and not listening to family concerns and wishes with compassion.
- **Communication between teams and care settings**, including failings in information sharing when patients transfer between services and poor coordination around care planning and discharge.

Each section combines evidence from complaints we investigated with direct testimony from families, friends and carers who told us about the communication failings and the impact this had on them. Where communication is unclear or lacks compassion, it compounds distress and shapes long-term experiences of bereavement. Conversely, families consistently highlight the difference that clear, honest and kind communication can make at a difficult time.

We also spoke to clinicians to better understand the barriers to good communication in end of life care. Clinicians highlighted a range of factors, including limited confidence in having difficult conversations at the right time and fragmented information systems. These challenges are compounded by a broader culture in which conversations about death and dying are often avoided, both in healthcare and more widely in society.

## What needs to change

We welcome recent policy developments, including the introduction of a Modern Service Framework for Palliative and End-of-Life Care due later this year and commitments in the neighbourhood health framework to improving outcomes for people receiving end of life care. To deliver the ambitions set out in these plans, the importance of good communication in delivering high-quality services must be recognised.

To help us develop recommendations, we shared our findings with a range of stakeholders in the palliative and end of life care sector, including NHS bodies, charities, healthcare professionals and academics.

Our recommendations are:

- **Recommendation 1. The Modern Service Framework should include a detailed strategy to address skills and confidence gaps in communication.**

  The Modern Service Framework should include a detailed, system-wide strategy to tackle longstanding gaps in confidence and skills in talking about death, dying and palliative care. This should establish communication about the end of life as a core competency across the workforce, supported by mandatory training at undergraduate and postgraduate levels. Training should include psychologically informed approaches, opportunities to practise difficult conversations, and ongoing support to help clinicians build confidence and resilience in real-world settings.

- **Recommendation 2. The Modern Service Framework should develop clear outcome measures to assess the performance of end of life care services, centred on patient and family experience.**

  Clear national outcome measures should be developed to assess the quality of end of life care, including how effectively services communicate with patients and those close to them. These measures should be informed by the experiences of patients and bereaved families and supported by improved data collection across all care settings, not just hospitals. This should include consideration of a broader bereavement survey covering deaths in the community, care homes and hospices, alongside existing sources such as the National Audit of Care at the End of Life (NACEL) survey.

- **Recommendation 3. Prioritise end of life care in the rollout of the Single Patient Record.**

  End of life care should be a priority area for the introduction of a Single Patient Record, which aims to make sure that patient information is consistently accessible across hospitals, primary care, community services, hospices and ambulance trusts. This should include important information such as advance care plans, ReSPECT forms and DNACPR decisions, so that patients' preferences are visible and actionable across settings. The programme must also be supported by sufficient investment in training to improve the quality and consistency of record-keeping and information sharing across the system.

# Introduction

Death is an inevitable part of life, but people's experiences at the end of life vary considerably. How someone dies is shaped by the care and support they receive in their final days. This care also has a lasting impact on the family and loved ones they leave behind.

Recent research published by Marie Curie found that around 170,000 people in England every year spend their final days in pain, distress or without vital support that should be available to everyone at the end of life.

Palliative and end of life care includes planning and providing support to people who are approaching the end of their life, as well as to their families and carers. It involves taking account of people's needs and wishes, including where they would like to receive care and where they would like to die. This is to enable them to live as well as possible in their final days and allow them to die with dignity.

Palliative and end of life care in England is delivered by professionals and services across the health and social care system, including NHS staff, social care organisations and the voluntary sector. We know that the majority work with skill, compassion and commitment to deliver high-quality end of life care, and there are many examples of good practice. But it is evident that these services are under significant pressure. Numerous reports in recent years have called on the Government to address longstanding issues relating to workforce capacity, resources and funding for hospices, variability in local commissioning and provision of services.

The debate around the Terminally Ill Adults (End of Life) Bill 2024 (and its reintroduction in the current session) has brought renewed political and public attention to the provision of end of life care. Recent policy developments have signalled the Government's commitment to addressing the challenges facing the sector. A Modern Service Framework for Palliative and End-of-Life Care in England, led by the Minister of State for Care, is currently in development. It is intended to improve access, quality and the sustainability of services.

The 10 Year Health Plan for England outlines an ambition to shift more care from hospitals to the community, which has major implications for the provision of palliative and end of life care as it is delivered across primary care, community services, care homes and patients' own homes. The recent neighbourhood health framework policy paper has set out a clear commitment to improving outcomes for people receiving end of life care, including better identification of people approaching the end of life. It aims to increase by 10% the number of people identified by March 2029.

## Communication in palliative and end of life care

Our casework evidence tells us that palliative and end of life care services too often provide care that falls short of what is expected.

Over a decade ago, we published our report 'Dying without dignity' on complaints about end of life care. We set out the consistent themes we were seeing in our casework, including issues with communication, care planning and symptom control. More recently, we published 'End of life care: improving "do not attempt CPR" conversations for everyone'. This report looked at complaints involving communication about clinical decisions not to provide cardiopulmonary resuscitation (CPR). We called for urgent improvements to the process and communication surrounding 'do not attempt CPR' decisions, so doctors, patients and their loved ones can make informed choices about their care.

The continued high number of complaints we receive about palliative and end of life care shows that there is a lack of progress in improving people's experiences of using these services.[1] Analysis of upheld cases since 2020 shows that communication is the most common failing we see.

This is also an ongoing concern reflected in recent reports. The Commission on Palliative and End-of-Life Care found that patients, families and carers identified communication and planning as the top priority areas for improvement. It recommended building confidence across the wider workforce so that more staff are equipped to communicate with skill, honesty and sensitivity. Similarly, the Health and Social Care Committee's Expert Panel on palliative care in England highlighted the importance of clear information and effective information sharing, drawing on evidence from people with lived experience of care at the end of life.

## How we developed this report

We analysed the evidence from our investigations into adult end of life and palliative care services since 2020 to identify common themes. We also spoke to families and friends who complained to us about the care their loved ones received. They shared how communication failures affected their experiences.

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[1] Since 2020, we have received over 1,000 complaints concerning end of life care. A case is recorded as end of life care if it relates to the care and treatment someone received in the last 12 months of their life. This includes palliative care.

In addition, we engaged with healthcare professionals from our network of clinical advisers to understand the barriers they face in communicating effectively.

Our findings are set out across three areas:

- communication with patients
- communication with families, friends and carers
- communication between teams and across care settings.

Each section includes case studies from our investigations, supported by insights from clinicians and testimony from people who brought their complaints to us. Although we also found clinical and complaint-handling failings in most of these investigations, the case studies shared here focus specifically on communication failings.

# Communication with the patient

Patients who are approaching the end of their life rely on effective communication about their health. This includes information about their condition, prognosis and treatment options, which is essential to help them make informed decisions about their future care. Our evidence shows that in many cases this communication does not happen adequately or at all.

We found that opportunities to have conversations about a patient's prognosis and end of life planning were missed. This included limited discussions about patients' wishes, such as where they wanted to die, their treatment preferences and who they wanted involved in decisions about their care.

These casework findings are echoed in survey evidence about a lack of early conversations about approaching the end of life. The most recent National Audit of Care at the End of Life (NACEL) survey found that just 18% of patients had talked about personalised care and support plans (including future care planning and advance care plans) before their final admission to hospital.

In one case, we found that a Trust did not communicate clearly or early enough to a patient that he had advanced and progressive cancer. Medical notes said he might not be able to tolerate cancer treatment and was likely to die soon. But there were no clear conversations about prognosis and the fact that treatment might not be possible. This lack of communication meant he and his family had limited opportunity to prepare for his death.

General Medical Council guidance states that doctors must be considerate of those close to the patient and be sensitive and responsive when providing information and support, while respecting the patient's right to confidentiality. It emphasises the importance of establishing with the patient what information they want to share, with whom and in what circumstances.

In some cases, despite patients having sufficient capacity, we found there had been no discussion with them about family involvement or information-sharing preferences. As a result, families were not informed and left unprepared, even if it was likely the patient would have wanted to keep their family informed. It meant families missed the opportunity to spend meaningful time with their loved one in their final days.

## Advance care planning

Advance care planning is a voluntary process of person-centred discussion between an individual and their care providers about their preferences and priorities for their future care. It takes place while the person has the mental capacity for meaningful conversation. The process is likely to involve a number of conversations over time and must always have due consideration and respect for the person's wishes and emotions. As a result, the person should experience a greater sense of involvement and the opportunity to reflect and share what matters most to them.

Examples of good practice exist and tools such as the ReSPECT process, Gold Standards Framework and accompanying forms are widely used to support discussions.

In 2022, the Government published the Universal Principles for Advance Care Planning. It sets out six high-level principles for advance care planning in England:

1. The person is central to developing and agreeing their advance care plan including deciding who else should be involved in the process.
2. The person has personalised conversations about their future care focused on what matters to them and their needs.
3. The person agrees the outcomes of their advance care planning conversation through a shared decision-making process in partnership with relevant professionals.
4. The person has a shareable advance care plan which records what matters to them, and their preferences and decisions about future care and treatment.
5. The person has the opportunity, and is encouraged, to review and revise their advance care plan.
6. Anyone involved in advance care planning is able to speak up if they feel that these universal principles are not being followed.

## Case study 1: Failing to inform a patient that his cancer had spread

### What happened

Mr O visited his GP with abdominal pain and unexplained rapid weight loss. Blood tests suggested cancer, and he was referred to the hospital for further tests and scans. Biopsies confirmed he had colorectal cancer, and a CT scan showed the cancer had spread to his liver.

Despite attempts to treat Mr O, he was eventually admitted to hospital and his cancer was diagnosed as terminal. Mr O was discharged home for end of life care and died a week later.

### What we found

We found that the Trust failed to clearly and promptly inform Mr O that the cancer had spread to his liver and was terminal. This poor communication led to Mr O accidentally finding out that his cancer had spread.

Mr O visited his GP to get help with managing his pain while waiting for cancer treatment. Records showed that the GP knew Mr O had secondary liver cancer, as the Trust had already shared results from earlier tests with them.

During the appointment, the GP made a comment that assumed Mr O already knew the cancer had spread. This caused confusion and distress for Mr O and his wife. It was only when they asked for clarification that Mr O found out the cancer had spread to his liver, which the Trust had not told them about.

The Trust knew the cancer had spread weeks earlier but delayed informing Mr O, meaning he only found out because the GP unintentionally disclosed it. Hospital records confirmed that the Trust did not tell Mr O directly until a month after the tests had identified the spread of the cancer. This delay denied Mr O additional time to prepare for the end of his life.

## Case study 2: Poor communication with a patient about his long-term prognosis and end of life wishes

### What happened

Mr Y was being treated for acute lymphoblastic leukaemia (a rare type of cancer) with chemotherapy. His condition was later classified as high-risk due to a genetic mutation associated with aggressive disease and poor prognosis.

Mr Y’s cancer relapsed and a planned stem cell transplant could not go ahead. He received further treatment, but the cancerous cells remained.

Two months later, his cancer relapsed again. He was considered for treatment through a clinical trial, but this was postponed due to his deteriorating condition. Further tests suggested that he was developing steroid resistance, and his condition became difficult to manage with treatment.

He was readmitted to hospital and his health continued to deteriorate. Three days later, Mr Y’s family were informed that his cancer had relapsed again. The same evening, Mr Y became unresponsive, likely as a result of a stroke. The Trust informed Mr Y’s family that there was nothing more it could do and that he might die in the next few hours. Mr Y died the same night.

### What we found

We found no evidence that the Trust ever had a discussion with Mr Y about his long-term prognosis if the planned treatments were unsuccessful, and how this would affect his life expectancy. We found that the Trust should have known, around three months before his death, that Mr Y was approaching the end of his life.

Although Mr Y was informed about his diagnosis of high-risk acute lymphoblastic leukaemia, he could not reasonably have understood the severity of his condition.

Mr Y’s cancer had already relapsed twice, which was evidence that treatment could not control his disease and that a further relapse was likely.

The Trust did not explore Mr Y’s preferences for end of life care, such as his wishes about dying at home or in hospital. It did not do enough to clarify whether he wanted his family involved in decisions. While confidentiality may have limited what could be shared, there was no evidence that Mr Y asked the Trust to withhold information from his family.

The missed opportunity for advance care planning and discussion of Mr Y’s preferences with him and his family added to their distress and prevented them from preparing for his death.

## Barriers to communicating well with patients: what we heard from clinicians

Clinicians gave us a range of insights into why communicating well with patients about end of life care can be so challenging.

### Managing complex emotions

Clinicians acknowledged that these are difficult conversations, even for those with significant experience. We heard that it can be especially challenging for less experienced clinicians to feel confident managing their own emotions and those of patients:

> ‘It’s really hard and really painful for people to sit with distress in a conversation and just accept that’s ok… You do need to make sure that your clinicians or whoever's having those conversations are not themselves carrying an unreasonable amount of grief, and we are really bad at teaching that to our resident doctors.’

Clinicians highlighted the importance of providing staff, particularly resident doctors, with space and time to reflect before and after these discussions:

> ‘You do need to debrief and offload to someone else about how it made you feel… and within a ward setting that can easily be missed… Just somebody who says, you know, “are you alright? Right, that was a tough one, what are your reflections?” And then sit down and take 15 minutes and just document how that conversation went.’

Even where formal reflection is not required, clinicians felt that simply making support visible and accessible can help to build resilience and confidence.

### Recognising own scope of practice

Clinicians emphasised that developing communication skills and growing confidence happens with experience rather than formal training. Clinicians highlighted the importance of recognising personal limits and knowing when to escalate conversations or get support from more experienced colleagues. Having an experienced colleague available on the ward is critical, particularly when conversations become more complex or emotionally intense. This allows staff to step in, support one another and make sure that families receive clear, sensitive and consistent communication at a highly vulnerable time. A senior nurse told us:

> ‘Training and education should be around people recognising their scope of practice and their boundaries and when to get help.’

## Getting the timing right

Clinicians working in acute settings described feeling as though they were often ‘playing catch-up’ on conversations with patients who have had long histories across multiple clinics or specialist services. In some cases, it is clear that these patients have an illness where the prognosis could end their life or contribute to their end of life. Frequently, they arrive in acute settings without having had conversations that might help them understand their prognosis and feel prepared:

> ‘A frustration of all of us working in acute care is the lack of clarity during care of chronic progressive illnesses regarding the vulnerability and the potential for deterioration. Patients don’t appear to routinely have conversations about the progression of their illness and about what is reasonable expectation of the length of life with their chronic disease team.’

Though there was also an understanding of why these conversations might be missed earlier in someone’s care journey:

> ‘If you do look after someone for years, knowing when the best time to bring it up is difficult. Do you do it at the beginning, but then you risk frightening someone about something that may happen 10 years away. Or do you do it in five years? It can be really difficult pitching it at the right time for the patient to talk about these things. And that’s why we might miss the opportunity to talk about end of life planning for some patients.’

Limited time during appointments was also acknowledged as a barrier. Not wanting to start a sensitive conversation without being able to give it the time it deserves is another reason why these earlier conversations may not happen.

## Continuity of care

We heard that transitions between care settings can disrupt communication. When patients move between settings, responsibility shifts to new clinical teams, and relationships and trust often need to be rebuilt. This can make it difficult to maintain the same level of personalised communication and continuity of care.

In some cases, a clinician who has had little previous contact with the patient may need to have very difficult conversations, including speaking to families about a loved one approaching the end of life:

> ‘It can be incredibly problematic to get communication to the right individuals in a timely way, and for the family and the patient to feel that the same level of individualised care has been continued into that new setting.’

## An avoidant culture

It is also important to recognise the broader culture in which clinicians and patients are working and living. Death and dying remain taboo topics for many, and this inevitably creates additional barriers to having open conversations about the end of life, as one clinician observed:

> ‘Not everyone is very open about what they will talk about, even though it is totally inevitable. That all feeds into it - there is just a general culture of not talking about these things openly… I think because of the sensitivities of talking about these difficult things, people avoid the discussion a bit. Patients avoid it and so do families.’

# Communication with family, friends and carers

Families, friends and carers play a crucial role in supporting people at the end of life. To do this effectively, they need to receive clear and timely communication. They need to be adequately informed and involved in discussions about care.

Where communication breaks down, they are left to take on a greater role in coordinating care at a time when they are already struggling to come to terms with their loved one dying.

One complainant told us about the huge sense of responsibility she felt in her role as next of kin for her close friend:

> ‘I was the person that she [complainant’s friend] had put her trust and faith in and, given that role and responsibility to. I knew that this was the most important thing I would and ever could do for her. I wasn’t going to fail in it.’

A common theme in complaints is that families were not told clearly or early enough that their loved one was deteriorating or approaching the end of life, leaving them unprepared for what followed.

Where there is a communication breakdown with families, it compounds grief and leaves a lasting impact on those left behind. One complainant spoke to us about her mother’s final days of life, and how the communication failings affected their family:

> ‘I couldn’t say it was a memorable ending. And the issue comes because of the lack of communication. We were quite realistic that she was coming to the end of her life. What you’re wanting as a family is for it to be a peaceful time where the family can spend some quality time and talk about memories. I don’t have that. And I can’t take away those scars, those memories live on with me for life.’

## A lack of clear information

In some cases, families reported being given partial or contradictory information about diagnosis, treatment or discharge plans. As a result, families did not understand what to expect and were more likely to perceive care as unsafe or inappropriate, even when there were no clinical failings:

> ‘I just needed to talk to someone… anyone that could inform me about what was going on. It doesn’t cost anything to talk.’

We found that in some cases a lack of understanding about the implications of active treatment left families feeling they had missed the opportunity to explore different care options with their loved one. One complainant described the consequence of not having a full explanation of what active treatment would mean for her mother:

> ‘The consultant asked us, “has nobody explained the implications of having the surgery, because it can be extremely painful”. We should have been told earlier so we could have sat with mum and said, do you really want to go through this? Is it worth going through that pain or is the best pathway forward palliative care? Had we had that option before, not waiting for that surgical team, we could have got her into a care home that does palliative care, or got her home with Macmillan support.’

## Compassion and empathy

Families described times where they felt dismissed or not properly listened to, particularly at emotionally difficult moments when empathy would have made a significant difference:

> ‘There were comments around the fact that I was a nuisance… It was obvious anyway, that I was not welcome.’

Families told us that even if staff could not meet their wishes for their loved one, compassionate communication to explain this and acknowledge their situation would have made them feel much more supported.

Even when their overall experience of communication had been poor, families remembered well the staff who showed them kindness and empathy at a time when they needed it most. A complainant told us about a memorable conversation she had with a cancer consultant caring for her mother:

> ‘She showed empathy and spent time explaining to us… I couldn’t have asked any more from her – it was her understanding, her empathy and she was thinking about my mother and the best way forward for her.’

Another complainant told us about a nurse who made her feel reassured:

> ‘I did notice there was one particular nurse who seemed caring, who seemed as though he knew what was happening. I used to breathe a sigh of relief when he was there.’

Complainants recognised the challenging environment healthcare professionals work in and acknowledged that excellent practice exists. They identified consistency as the real issue to tackle:

> ‘There’s lots of people working very hard to do a very good job and they shouldn’t be undermined by instances of where things fall short. We just need to close that gap.’

## NACEL’s Good Practice Compendium

The National Audit of Care at the End of Life (NACEL) is a national comparative audit of the quality and outcomes of care in the final admission before death. It covers acute hospitals, community hospitals and mental health inpatient providers in England, Wales and Jersey, and looks at the experience of the dying person and those close to them.

The Good Practice Compendium brings together examples of innovation and improvement in end of life care, shared by hospitals through NACEL. It showcases initiatives developed by local teams to address common challenges in end of life care, including communication.

### Example: Dorset County Hospital NHS Foundation Trust - Dorset County Hospital

The hospital introduced several initiatives aimed at improving communication with patients at the end of life and with those close to them.

To provide more personalised and patient-centred communication, the hospital embedded a simple question around ‘what matters most to you now/in the future?’ into training and practice. It introduced an End of Life Support Worker role to provide ward-based and classroom teaching, helping staff build confidence in recognising when patients are dying and in communicating effectively.

As a result, patients known to the palliative care team now routinely have conversations about what is most important to them, staff training has doubled, and communication is more consistent, coordinated and focused on patients and families.

## Case study 3: Missed opportunities to keep a family informed about their mother’s condition

### What happened

Mrs B was admitted to hospital with a suspected urinary tract infection, alongside weight loss and reduced appetite. A CT scan the following day showed enlarged lymph nodes and signs that cancer had spread to her abdomen and liver.

Further tests and a multidisciplinary team review were recommended. Mrs B’s condition deteriorated rapidly. She was moved to end of life care about three weeks after admission and died the next day.

### What we found

We found failings in how information was shared with Mrs B and her family. This caused the family distress and affected their ability to understand what was happening and to make plans.

Despite the Trust’s complaint responses claiming Mrs B had been informed about her diagnosis, we found no evidence in the medical records that a doctor had told her about her possible diagnosis after the CT scan, or that her family had been made aware.

The first clear recorded discussion of a possible cancer diagnosis did not happen until almost two weeks after the first scan results were available. The Trust missed numerous opportunities to share information with Mrs B’s family and keep them informed of the likely diagnosis and prognosis.

Mrs B’s daughter and her family assumed it was something minor from which Mrs B would recover. She said they felt let down by the fact that the Trust knew what was happening but they did not.

## Case study 4: Failing to keep a family updated about their mother’s deteriorating health

### What happened

Mrs G had difficulty swallowing when she was admitted to hospital. She was known to have a progressive lung disease that caused breathing difficulties. The Trust thought she might have a type of lung infection and she was treated with antibiotics and fluids intravenously (into a vein).

The Trust decided Mrs G could not safely eat or drink normally and needed a liquid diet. It inserted a nasogastric tube – a tube passed through the nose and down into the stomach. The Trust did an X-ray and found a pneumothorax (a collapsed lung, which happens when air is trapped between the lung and the chest wall). Mrs G’s condition deteriorated and she died in hospital the following morning. A coroner’s postmortem concluded that her death was due to natural causes.

### What we found

We found that the Trust did not keep the family updated about Mrs G’s condition when it should have. The Trust only spoke with Mrs G’s family when she was admitted to hospital and again when her condition had significantly deteriorated.

An X-ray had shown a small pneumothorax, which the Trust said did not need treatment due to its size. The Trust did not tell Mrs G’s family about this at the time. This was not in line with relevant national guidance.

Following the consultant ward round that took place the day before Mrs G died, the medical and nursing team should have informed her family of the seriousness of her condition and her increasing frailty. There was no documented reason why Mrs G’s family were not informed.

We did not conclude that the failings we identified led to Mrs G’s death, but we did find that the poor communication contributed to her family’s distress and compounded their grief.

## Barriers to communicating well with families: what we heard from clinicians

Clinicians described conversations with families about a loved one approaching the end of life as one of the most challenging aspects of their role. These discussions often happen when families are already highly distressed, shocked or overwhelmed.

### Managing family wishes

Clinicians told us that end of life conversations with families can be especially hard when relatives are not ready to openly acknowledge that their loved one is dying. In some instances, families wish to exhaust all treatment options even when the interventions might cause the patient to experience more pain:

> ‘It can be hard getting the balance right between trying to treat someone in line with family wishes and not causing them suffering. It can bring up difficult situations for the medical and nursing team when we're treating someone when ultimately, we know they are dying, but their family are struggling to come to terms with it and are pushing for treatment, which could be invasive and uncomfortable.’

We heard that family dynamics can surface when their loved one is at the end of life. Family members may have different views about the level of information to share with either the patient or other family members, or about decisions around treatment:

> ‘End of life can bring up some family dynamics which haven’t been resolved. At times these scenarios will harmonise the family dynamic from before, or it may cause more complexities.’

### Cultural values and religious beliefs

Clinicians told us that cultural and religious differences can play a significant role in end of life conversations and decision-making. They explained that people from different cultural backgrounds can have very different expectations of what end of life care should involve and the choices they feel comfortable making. In some cultures, clinicians described a strong drive to ‘do everything possible’, with families finding it particularly hard to accept that someone is approaching the end of life. Clinicians said this requires them to be mindful of cultural values and religious beliefs, and to carefully tailor their communication, drawing on emotional intelligence and sensitivity during these conversations.

## Compassionate care under stress

The clinicians we spoke to are highly motivated to provide compassionate care, but they acknowledged that the reality of working on busy wards can make this challenging at times. They described managing patients with very different needs, often across many specialties at once, while dealing with staff shortages, time pressures and keeping detailed records. When resources are stretched, it can be harder to show the level of empathetic care they want to:

> ‘There are a lot of variables impacting being able to be empathetic all the time… I’m not excusing why someone should be rude anytime, but there has to be a reminder that we still have to deliver, no matter what.’

# Communication between teams and information sharing

Our casework also identified communication failings between various teams involved in the care of a patient. These include delays in decision-making about treatment or next steps, leaving patients and families confused and constantly having to chase for updates.

Patients receiving end of life care often move across settings, for example, between wards, or to a hospice or care home. If information does not follow the patient effectively, it can inhibit continuity of care.

In one case, we found a Trust inappropriately discharged a patient to a nursing home. The home was not briefed properly on the patient's condition and was not equipped to provide the level of care he needed. As he was approaching the end of life, this was a missed opportunity to manage his symptoms better and lessen his suffering.

Our investigations have highlighted communication failings at a system level. We have found that there is unclear ownership of information and a lack of reliable mechanisms to make sure that critical information follows a patient to support continuity of care. This lack of coordination between services creates distressing circumstances for patients and their families.

## Case study 5: Unclear care plan due to poor communication between specialist teams

### What happened

Mrs A was admitted to hospital after her GP referred her with symptoms including a chest infection and a low platelet count. She was also coughing up blood and had reported bruising. During her admission, the Trust arranged tests to find the cause of Mrs A's symptoms. The results showed that Mrs A had oesophageal cancer.

About two weeks later, the Trust discussed Mrs A's condition at a multidisciplinary team (MDT) meeting to consider whether she was suitable for a stent procedure - a palliative treatment to help with swallowing if her symptoms worsened. Mrs A died in hospital a few days later.

### What we found

We found failings in communication by the Trust's medical team on the ward and its specialist teams. The medical team waited for the MDT meeting outcome and input from the gastroenterology team before planning Mrs A's care, including the stent procedure.

Following the MDT meeting, the plan was to carry out the stent procedure while Mrs A was an inpatient. When this was discussed the following day, Mrs A and her daughter decided they wanted to concentrate on symptom control, rather than an invasive treatment such as the stent.

Records showed there was little communication between the teams before this. Had the teams collaborated effectively in line with relevant guidance, they might have reached a plan for Mrs A's care sooner, and the family would have had a clearer understanding of what a stent could offer. A more coordinated clinical approach would have enabled clearer communication with Mrs A and her family. It might also have reduced her family's uncertainty about what treatment the Trust intended to provide.

## Case study 6: Failing to provide critical information to a care centre about a patient's condition and needs

### What happened

Mrs R had ovarian and peritoneal cancer. She went to A&E with symptoms of nausea, vomiting and fever. She also reported abdominal swelling and constipation. She was later diagnosed with a subacute bowel obstruction.

Clinicians decided to fit Mrs R with a syringe driver to administer cyclizine, a medication used to treat nausea and vomiting. About two weeks later she was discharged from hospital to a care centre that provided rehabilitation to enable patients to return to their own homes. After several days, she was taken back to hospital as her condition deteriorated. Mrs R died in hospital the following week.

### What we found

We found that the Trust failed to share critical information about Mrs R’s condition promptly. The referral contained no mention that Mrs R had been admitted with bowel obstruction caused by progressive cancer, or that she was likely approaching the end of life.

The referral also made no mention of the syringe driver that had been fitted. The care centre said this information was essential, as its staff were not prepared or equipped to manage patients with syringe drivers. On the day of admission, the care centre noted concerns about the appropriateness of the referral and raised a formal incident report about the syringe driver.

Although the discharge summary contained this information, it was only shared after Mrs R had arrived at the care centre, rather than when the referral decision was made. Had this been communicated earlier, it is likely the centre would have refused the referral. We also found that earlier communication may have avoided the second hospital admission, and Mrs R could have chosen to receive palliative care at home with minimal medical intervention.

## Barriers to communicating well between teams and systems: what we heard from clinicians

We spoke to clinicians to better understand the challenges they see when communicating with different teams or across settings.

### Poor information flow across settings

Clinicians told us that the movement between settings is where information most often breaks down, as it becomes more difficult to find and access:

> ‘For patients remaining in the hospital setting, in a way that’s easy because they’re within a single system. When you go into any setting that's not the hospital, it’s incredibly problematic to get the communication to the right individuals in a timely way… It is almost impossible to find the right phone numbers, to get the right person to answer the phone or to get the right email address.’

Clinicians agreed that patients’ wishes should be easy to access and shared consistently across services. But we heard that electronic patient records are still not reliably shared across organisations and are used inconsistently, leaving teams without critical background information at important moments:

> ‘What I haven’t seen enough of is, the advance care planning that some patients have made in the community has not filtered enough through to the hospital.’

Electronic Palliative Care Coordination Systems (EPaCCS) were introduced in England from 2008 onwards to support care coordination and delivery in line with patient preferences. But research into the use of EPaCCS suggests there is considerable variation in how they have been implemented across England. Where EPaCCS are present, only a limited proportion of those who may be eligible for an EPaCCS record are receiving one before death, with limited recording of preferences for care. Ongoing interoperability challenges mean there is not consistent sharing across settings such as care homes and ambulance trusts. Clinicians also told us they perceive EPaCCS as a tool more commonly used in primary care and less frequently in hospital settings.

## Quality of record-keeping

Clinicians told us that pressure on time and staffing capacity limits good record-keeping. There is not always a standardised way to record ‘what’s been tried’, what has mattered to the patient or what small adjustments improved comfort.

We heard about the importance of training healthcare professionals on documenting information effectively. One clinician told us:

> ‘[In the context of more multidisciplinary team working] it’s really important to make sure documentation is clear of who you’ve spoken to, what time, what was said, where are you directing the next conversation to, to who. Someone’s about to lose a loved one and not documenting, not getting the right information for the next person to follow through can cause an issue. I think training around platforms and clear directives about which sections and where things need to be documented has to be coordinated very tightly.’

# Recommendations

As the Ombudsman, we use learning from complaints to drive improvement in public services. In this report, we have reflected on the experiences of patients and their families, carers and friends to better understand the ways in which communication can fail during end of life care, and what needs to change. We have also drawn on insights from clinicians about the system changes required to make a difference.

To inform our recommendations, we shared our findings with a range of stakeholders across the palliative and end of life care sector, including NHS bodies, charities, healthcare professionals and academics. Having reflected on this evidence, we have identified three priority areas for action that respond to the issues we see most often in our casework. We set out recommendations for each area.

## Confident, skilled, compassionate communication with patients and families at the right time

We have heard consistently that conversations about the end of life often happen too late. This can leave acute care teams needing to play ‘catch-up’ when a patient deteriorates, managing shock and anger and supporting decision-making under significant time pressure. We know these are difficult conversations to approach, and they require a confident, skilled and well-supported workforce. There should be a shared sense of responsibility across the wider generalist workforce for preparing patients and families for dying.

We strongly welcome the commitment in the neighbourhood health framework to earlier identify patients approaching the end of life. To be meaningful, this must go hand in hand with an increased willingness and confidence to begin complex conversations with patients and families. We know there is more to do to make sure clinicians are resourced and supported to build these skills.

The most recent National Audit of Care at the End of Life (NACEL) survey found that only 62% of staff had received any training in end of life care over the past three years. The survey team noted that this figure is likely to be an overestimate, and it is staff more interested in end of life care who tend to respond to the survey. It is vital that a clear, sustained plan to address communication skills and confidence forms part of any efforts to improve end of life care services.

**Recommendation 1. The Modern Service Framework should include a detailed strategy to address skills and confidence gaps in communication.**

- The Modern Service Framework should include a system-wide strategy to tackle longstanding gaps in confidence and skills in talking about death, dying and palliative care. This should establish communication about the end of life as a core competency across the workforce.
- Clinical education should set the expectation that skilled communication about the end of life is an essential, invaluable part of all healthcare roles. We echo the recommendation of the Commission on Palliative and End-of-Life Care that training on palliative and end of life care should be a mandatory part of undergraduate medical education.
- Mandatory training at postgraduate level in provider settings should include:
    - psychologically informed elements such as understanding common patterns of distress at the end of life, and core skills for responding to and understanding clinicians’ own anxiety so they are able to stay present and sit with distress
    - skills practice with feedback and rehearsal of challenging scenarios.
- To be effective, training must be accompanied by ongoing ‘on-the-job’ support. This needs to be understood as an important part of implementation, not an optional add-on to training. For example, providers should consider developing clinical supervision structures that support professionals to increase their skills and confidence while maintaining their own resilience and wellbeing. This reflects the fact that embedding skills into practice, and seeing them valued in the working environment, is important for consistent delivery.

## Clear outcome measurement that includes patient and family voices

To improve communication around end of life care, we must be able to track the impact of interventions on the experiences of patients and families. At the local level, complaints provide important feedback that can help providers to understand their performance and prioritise further training and investment. Our NHS Complaint Standards set out how complaints can be valued as a vital part of learning. We see good examples of individual trusts that are using patient stories for training and reflection and regularly bringing these to Board discussions.

But there also needs to be better understanding at the national level of how patients and families are experiencing end of life care.

We welcome that the interim update from the Minister of State for Care on the development of the Modern Service Framework recognises the importance of accountability and of clear outcome and performance metrics to assess improvements in the delivery of end of life care.

**Recommendation 2. The Modern Service Framework should develop clear outcome measures to assess the performance of end of life care services, centred on patient and family experience.**

- Outcome measures should include an assessment of how effectively services communicate with patients and those close to them.
- One consideration in this is the role of large-scale surveys that ask bereaved people about experiences of end of life care for their loved one. The National Audit of Care at the End of Life (NACEL) is extremely valuable as a national comparative audit of the quality and outcomes of care experienced by the dying person. But it covers only the final hospital admission rather than experiences across all settings and at earlier points in the care journey.
- The Modern Service Framework should consider options for a bereavement survey that asks for feedback about the experience of all deaths, including deaths at home, in care homes and in hospices, in addition to those in hospitals. This will be particularly important given the ambitions around shifting care, including end of life care, from hospitals to the community.

## Effective information sharing between teams and care settings

We have seen how good care is undermined by systems that do not transfer information effectively across different teams and care settings. This is not a new problem. The first End of Life Care Strategy in 2008 noted that a lack of effective mechanisms for communicating up-to-date, sensitive information between providers presents a major barrier to delivering quality end of life care.

The 10 Year Plan for England promises a Single Patient Record, shared across the system, so that every part of the NHS has a full picture of the patient. At the time of writing, the commentary accompanying the NHS Modernisation Bill has confirmed the first pathways for the rollout of the Single Patient Record as frailty and maternity. We understand from conversations with the team developing the Single Patient Record that the programme is still in its early development. But as it develops, we would like to see an urgent focus on end of life pathways as an important area for the rollout of the Single Patient Record.

**Recommendation 3. Prioritise end of life care in the rollout of the Single Patient Record.**

- Dying patients often move between hospitals, GPs, community palliative care teams, hospices and ambulance services. Patient information must be readily accessible across these different settings.
- The Single Patient Record must make sure that important end of life care information – including advance care plans, ReSPECT forms and DNACPR decisions – is consistently accessible and editable across all care settings.
- The Single Patient Record must build on and learn from the important work that has gone before, including the development of Electronic Palliative Care Coordination Systems (EPaCCS).
- Joined up, accessible systems are necessary, but they also depend on the quality of information that goes into them. The Single Patient Record programme must include sufficient investment in training on how patient record systems should be used on the frontline.

# Annex: national guidance and standards for palliative and end of life care

National Palliative and End of Life Care Partnership ambitions framework 2021 outlines the vision for 2021 to 2026 and the six ambitions the partnership set out to achieve. Every Integrated Care Board is required to commission palliative and end of life care in line with this framework.

Universal Principles for Advance Care Planning 2022 sets out principles for a personalised approach to advance care planning. This guide is for the person, those important to them, practitioners and organisations involved in supporting advance care planning conversations and honouring their outcomes.

The National Institute for Health and Care Excellence (NICE) guideline [NG31] ‘Care of dying adults in the last days of life’ 2015 covers the clinical care of adults (18 years and over) who are dying during the last two to three days of life.

The NICE guideline [NG142] ‘End of life care for adults: service delivery’ 2019 covers organising and delivering end of life care services, and the planning and preparation required to do so.

The NICE guideline [NG197] ‘Shared decision-making’ 2021 covers how to make shared decision-making part of everyday care in all healthcare settings. It promotes ways for healthcare professionals and patients to work together to make decisions about treatment and care.

The NICE quality standard [QS13] ‘End of life care for adults’ 2021 covers care for adults approaching the end of life and support for their family and carers.

General Medical Council (GMC) professional standard ‘Treatment and care towards the end of life: good practice in decision-making’ 2010 (updated 2024) includes principles on mental capacity, treatment decisions, advance care planning, nutrition and hydration, and CPR.

GMC professional standard ‘Confidentiality: good practice in handling patient information’ 2017 (updated 2018) sets out the principles of confidentiality and respect for patients’ privacy that medical professionals are expected to understand and follow.

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