

North East and North Cumbria Integrated Care Board Palliative and End of Life Care Health Needs Assessment

Supplement 3: Community Engagement

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How to use this report

This report is intentionally comprehensive. It brings together large-scale survey data, detailed qualitative conversations, targeted engagement with inclusion groups, independent evidence review, and additional lived experience submissions.

Because of its size and depth, different readers may wish to navigate it in different ways. This section explains what each part of the report is designed to do.

Key themes identified through the analysis are highlighted in pink and direct quotations are highlighted in green throughout the report to support quick reference and ease of navigation.

Plain English summary

The [Plain English summary](#) provides a short, accessible overview of the work. It explains:

- Why this Health Needs Assessment (HNA) is being undertaken
- What we did
- What people told us
- Why the findings matter

This section is designed for members of the public, community groups, and anyone who wants a concise, non-technical overview.

Executive summary

The [Executive summary](#) provides a strategic overview for senior leaders, partners and decision-makers. It sets out:

- The background and statutory context
- The scale and reach of involvement
- Key findings at a glance
- System-level implications

The 'key findings at a glance' section is summarised from the [key findings \(cross-cutting themes\)](#) chapter.

Key findings (cross-cutting themes)

The [key findings \(cross-cutting themes\)](#) chapter brings together themes across all involvement methods.

It answers the question: “What do all the voices, evidence and methods tell us collectively?”

It identifies the main priorities, concerns and expectations expressed by people across the North East and North Cumbria, before moving into method-by-method detail.

This chapter is summarised from a [summary of key findings by individual involvement method](#) chapter.

Background and context

The [background and context](#) section explains:

- The purpose of the involvement work
- The legal duties and governance framework
- The approach to inclusion and equality
- How people were reached
- Communications and promotion activity
- Overall response and reach

It provides transparency about methodology and demonstrates how statutory duties have been met.

Summary of key findings by involvement method

This chapter provides a [summary of the key findings from each individual involvement method](#).

This allows readers to understand what each method contributed before reviewing the detailed analysis.

Detailed analysis by involvement method

This is the core evidence section of the report. It provides a [detailed full thematic analysis](#) and structured findings for each individual involvement method.

This section is intended for those who wish to review the full depth of feedback, explore topic-specific themes, or examine differences between groups.

Conclusion

The [conclusion](#) draws together the implications of all findings and sets out the overarching messages for commissioning, service design, and system improvement.

Appendices

The [appendices](#) provide:

Breakdown of demographic information

Copies of survey and engagement materials

These support transparency and enable further scrutiny of methods and representativeness.

Caveats and interpretation of findings

This work was carried out as public involvement, rather than a statistically representative survey of the population of North East and North Cumbria. The purpose was to understand people's views, experiences and priorities to help inform decision-making. The findings should therefore be interpreted as indicative of the views of people who chose to take part, rather than statistically representative of the wider population.

A total of 2,395 survey responses and 236 qualitative responses were received from across the North East and North Cumbria. Responses were received from all local authority areas in the region, although participation varied. Some areas such as County Durham, North Tyneside and North Cumbria had higher response levels in the survey, while the qualitative responses included a larger proportion of participants from North Cumbria, Sunderland and Darlington. As with most voluntary engagement activities, participation depended on people choosing to respond, which may influence the profile of respondents.

There was a higher response rate from women. In the survey, 84% of respondents identified as female and 16% as male, with a small number identifying as non-binary. While the number of male respondents was sufficient to include their perspectives, the overall findings are likely to reflect the views of women more strongly due to the higher level of participation.

The age profile of respondents skewed towards older age groups, particularly people aged 45 to 74, with the largest group being those aged 55 to 64. There were relatively few responses from younger people, particularly those under 25.

The ethnic background of respondents was predominantly White (96%), which broadly reflects the demographic profile of the region but means that the views of some ethnic minority communities may be under-represented. Similarly, most respondents identified as heterosexual (96%) and Christian or having no religion.

Around 38% of survey respondents reported having a physical or mental health condition, and among those who answered follow-up questions about impact, a majority reported that their condition affected their daily life. This suggests that people with lived experience of health conditions were well represented in the responses.

Because participation was voluntary and promoted through engagement networks, the findings may reflect the views of people who are more engaged with health services or have stronger views

about the topic. The results should therefore be used alongside other evidence and data sources when informing decisions.

Plain English summary

What's the issue?

Palliative and end-of-life care is the support people receive when they are living with an illness that cannot be cured. It helps people stay as comfortable as possible and supports their families and carers too.

Many people across the North East and North Cumbria will need this care at some point. It is important that services are fair, high quality and meet the needs of all communities.

To plan for the future, the NHS is carrying out a Health Needs Assessment. This helps us understand what people need now, what they may need in the coming years, and what matters most to them at the end-of-life.

What we did

Talking about death can be difficult. We used different ways to help people share their thoughts.

In total, **2,631 people** across the region took part through:

- An online survey
- Group discussions
- One-to-one conversations

We asked about:

- How people feel talking about death
- Where they would prefer to be cared for
- What matters most at the end-of-life
- Cultural or faith needs
- Whether they have made plans
- Experiences of care for loved ones

Local Healthwatch teams helped us reach people who are often not heard, including carers, disabled people, migrants and asylum seekers, LGBTQ+ communities, people in rural areas, faith

groups and people experiencing homelessness or substance misuse. Easy Read materials and supported conversations were used to make taking part easier.

What people told us

What matters most

- People were very clear about what is most important at the end-of-life.
- They want to:
 - Be comfortable
 - Be free from pain
 - Be treated with dignity and kindness
 - Not be left alone
- Pain control was the strongest concern. Many people said their biggest fear was suffering or seeing someone they love suffer.
- Dignity meant being treated with respect, having privacy, being spoken to honestly, and being seen as a person, not just a patient.
- Being with loved ones mattered just as much as medical care.

Where people want to be cared for

- Most people would prefer to be at home, surrounded by familiar things and people they love.
- Hospices were spoken about very positively. People described them as calm, caring and supportive.
- Hospitals were usually the least preferred option because of concerns about noise, privacy and busy staff.
- However, many people understood that plans may need to change depending on illness, care needs and available support.

Talking about death is still hard

- Many people believe it is important to talk about death, but a large number had never discussed their wishes.
- Some said death feels too far away. Others said it feels upsetting. Some did not know how to begin.
- People agreed that earlier conversations would reduce fear and help families feel more prepared.

Families and carers need more support

- Carers spoke about feeling exhausted and overwhelmed. Many felt invisible and expected to cope without enough help.
- They described delays, confusing systems and having to chase services while caring for someone they love.
- People said end-of-life care should support families as well as the person who is dying.

Communication makes a huge difference

- Good communication was described as essential.
- People want:
 - Clear and honest information
 - No medical jargon
 - Time to ask questions
 - To be involved in decisions
- When communication was good, people felt safer. When it was poor, it caused fear and confusion.
- Some groups, including people with learning disabilities, said information was not always given in a way they could understand.

Choice and control are important

- Many people want their wishes respected. This includes choices about treatment, where they are cared for and who is with them.
- Some supported assisted dying within the law because they fear prolonged suffering or losing control.
- Others spoke about planning ahead, writing down their wishes or setting up a Lasting Power of Attorney.

Not everyone has the same experience

Some communities face extra barriers:

- People experiencing homelessness spoke about basic needs like safety and warmth.
 - LGBTQ+ people worried about discrimination.
 - Disabled people raised concerns about dignity and being listened to.
 - People in rural areas talked about access problems.
 - Even though their situations were different, they shared the same core needs: safety, dignity, compassion and being heard.

Services can feel fragmented

- People described:
 - Delays in funding or equipment
 - Not enough hospice beds
 - Staff shortages
 - Poor coordination between services
- These issues sometimes meant people could not die where they wanted to.
- At the same time, hospice and specialist palliative care services were often praised for being compassionate and supportive.

What people hope for

- People want a system that:
 - Starts conversations earlier
 - Is joined up and well-coordinated
 - Treats everyone with dignity
 - Supports families properly
 - Is honest, compassionate and consistent
- Above all, people want end-of-life care to feel human.
- The feedback in this report will help shape future planning and improvements to palliative and end-of-life care across the North East and North Cumbria.

Executive summary

Background

Palliative and end-of-life care is a core part of the health and care system, supporting people with progressive or life-limiting illness to live well and die well. Across the North East and North Cumbria, thousands of people and families are affected each year. As the population grows, ages and becomes more diverse, demand for compassionate, equitable and high-quality care will continue to increase.

Under the Health and Care Act 2022, Integrated Care Boards (ICBs) have a legal duty to commission services that meet the palliative and end-of-life care needs of their population. This includes ensuring equitable access, reducing health inequalities, and enabling people to make informed choices about their care. The ICB must also meet its statutory duties to involve patients, carers and the public in planning and decision-making, and to comply with the Equality Act 2010 and the Public Sector Equality Duty.

To support future commissioning and service planning, the North East and North Cumbria ICB is undertaking a strategic Health Needs Assessment (HNA) for palliative and end-of-life care. This updates the 2014 NHS England Population-Based Needs Assessment and will inform planning across six Locality Delivery Teams and 13 Local Authorities over the next five to ten years.

A central component of the HNA is listening to people's experiences, preferences and expectations. Understanding what matters most to individuals and families ensures that services are not only clinically effective, but person-centred and aligned with the NHS Ambitions for Palliative and End-of-Life Care.

Involvement approach

A mixed-methods approach was used to maximise inclusion and reduce barriers to participation. This included:

- A region-wide public survey
- Focus groups and one-to-one qualitative conversations
- Targeted engagement through Healthwatch organisations
- Community-led engagement delivered by Northern Cancer Voices

- A supporting desktop review of relevant research and reports
- Additional responses shared

Healthwatch organisations were commissioned to lead targeted engagement with seldom heard and inclusion groups, including carers (including young carers), LGBTQ+ communities, disabled and neurodivergent people, people with learning disabilities, migrants and asylum seekers, people experiencing homelessness, people in rural and coastal communities, veterans, faith groups, and people affected by substance misuse.

This approach ensured participation from people who may face barriers to digital engagement, formal consultations, or traditional involvement methods.

Easy Read materials assisted survey completion, and culturally sensitive conversational approaches were used to widen access.

Response and reach

In total, 2,631 people across the North East and North Cumbria contributed to this work:

- 2,395 survey responses
- 212 participants through 22 focus groups and 40 one-to-one Healthwatch led qualitative conversations
- 24 participants through Northern Cancer Voices community engagement

A comprehensive communications campaign supported participation, including regional press coverage, social media promotion, partner networks, newsletters and direct outreach through community organisations.

Purpose of this report

This report summarises what people told us about palliative and end-of-life care:

- What matters most
- Where experiences are positive
- Where barriers and inequalities exist
- What needs to improve

The findings will directly inform future commissioning decisions, service design, and system priorities. By combining population data, clinical evidence and lived experience, the Health Needs Assessment aims to create a shared understanding of how to deliver high-quality, equitable and compassionate palliative and end-of-life care across the North East and North Cumbria.

Key findings at a glance

Across all engagement activity, people were clear and consistent about what matters most. Core themes included:

Comfort and pain relief are the highest priorities

Freedom from pain and good symptom control were described as fundamental to a dignified death.

Dignity, respect and not being alone matter deeply

People want to be treated as individuals, with kindness, privacy and honest communication.

Strong preference for home or hospice care

Most people would prefer to be cared for at home if adequate support is available. Hospices are widely valued. Hospitals are generally seen as a last resort.

Earlier conversations are needed

Many people have not discussed their wishes but believe that proactive, compassionate conversations would reduce fear and crisis-led decisions.

Carers carry significant burden

Families often experience exhaustion, system complexity and lack of practical support.

Communication quality shapes experience and grief

Clear, timely and culturally sensitive communication improves trust and outcomes.

Inequalities affect access and experience

Some communities face additional barriers related to identity, geography, poverty or discrimination.

Public awareness of palliative care is limited

Understanding improves when explained, but knowledge is currently low.

More detail on these themes is included in the section: [Key findings \(Cross-cutting themes\)](#).

These themes inform the system-wide implications set out below.

Implications for the system

The findings from this involvement work highlight consistent priorities alongside clear structural challenges. Together, they point to several system-wide implications for commissioning, service design and partnership working across the region.

Strengthen early conversations and advance care planning

Many people value planning but do not know how to start conversations about death and dying.

The system should:

- Normalise earlier conversations following serious diagnosis
- Increase awareness and understanding of advance care planning
- Improve communication about the GP palliative care register
- Ensure documentation of wishes is clear, accessible and actively used
- Support professionals with training and confidence to initiate compassionate conversations

Proactive planning can reduce crisis-led decision making and improve alignment with people's wishes.

Improve coordination and continuity of care

People consistently described frustration with fragmented systems, repetition of information and delays in funding or equipment. The system should:

- Strengthen coordination between primary care, community services, hospitals, social care and voluntary sector partners
- Improve timeliness of Continuing Healthcare funding decisions
- Ensure smoother transitions between settings
- Reduce administrative burden on families
- Explore named coordinator or key worker models where appropriate

Joined-up care is central to dignity, confidence and quality.

Address workforce pressures and care consistency

Concerns about staffing levels, weekend cover and care variability were common. To maintain public confidence, the system should:

- Prioritise workforce sustainability in palliative and end-of-life services
- Strengthen training in compassionate communication and culturally competent care
- Improve consistency of care standards across settings
- Recognise and elevate the professional status of care workers

Compassionate care depends on a supported and skilled workforce.

Strengthen support for carers

Carers described significant emotional and practical burden. The system should:

- Improve information and guidance for carers early in the pathway
- Expand access to respite and practical support
- Ensure carers are included in communication and decision-making
- Recognise young carers and provide age-appropriate support

End-of-life care quality cannot be separated from carer wellbeing.

Tackle inequalities and improve inclusive access

The involvement work identified differential risks for certain communities. The system should:

- Strengthen culturally competent care and identity-sensitive practice
- Improve outreach to communities less likely to access services
- Address digital exclusion and language barriers
- Work with trusted community organisations to build confidence
- Monitor and reduce postcode variation in service access

Reducing inequalities is both a statutory duty and essential to equitable care.

Improve public awareness and understanding of palliative and hospice care

Awareness of palliative care and the GP register was low, despite positive views once explained.

The system should:

- Improve public information about what palliative care is and when it begins
- Clarify the role and benefits of hospice care
- Use plain language and accessible formats
- Consider community-based awareness campaigns to reduce stigma

Better understanding supports earlier engagement and informed choice.

Ensure dignity and compassion are consistent standards

Across all feedback, dignity, kindness and not being left alone were non-negotiable expectations.

The system should:

- Embed dignity and person-centred care as core quality standards
- Ensure privacy and calm environments wherever possible
- Monitor experience measures alongside clinical outcomes
- Maintain focus on the emotional and relational aspects of care

High-quality end-of-life care is defined not only by clinical effectiveness, but by humanity.

Conclusion

The involvement work demonstrates strong public consensus about what matters most at the end-of-life. It also highlights areas where system pressures, inequalities and fragmented processes undermine confidence and choice.

Responding to these findings will require coordinated action across commissioning, providers, voluntary partners and community organisations. By strengthening early planning, improving coordination, supporting carers, addressing inequalities and reinforcing compassionate standards, the North East and North Cumbria system can deliver palliative and end-of-life care that is equitable, person-centred and aligned with the expectations of the population it serves.

Key findings (Cross-cutting themes)

The involvement work undertaken across the North East and North Cumbria brings together the experiences, fears, priorities and expectations of thousands of people who responded to surveys, took part in community conversations, or engaged through targeted qualitative work.

Together, these voices provide a detailed and emotionally powerful picture of what matters most at the end-of-life, the barriers people face, and the improvements they want to see in palliative and end-of-life care.

This chapter brings together the main themes identified through the [summary of key findings from all involvement methods](#).

End-of-life care is deeply personal

Across all engagement, one theme was unmistakable: end-of-life care is profoundly personal. Experiences and expectations are shaped by identity, culture, family dynamics, past experiences of care, health status and levels of trust in services.

While circumstances differed widely, fundamental priorities were consistent. Above all else, people want to be:

- Comfortable
- Pain free
- Treated with dignity
- Not left alone

Comfort and symptom control emerged as the strongest and most universal priorities. Many described unmanaged pain as their greatest fear, often rooted in memories of loved ones' suffering.

Dignity means respect, humanity and compassion

Dignity was described not as an abstract value, but as something practical and observable. It meant:

- Respectful, honest communication
- Privacy and calm surroundings
- Being treated as a whole person, not a task
- Gentle, compassionate interactions

People also spoke about emotional and spiritual aspects of dignity, including meaningful connection with family, friends, pets and trusted people. Small acts of kindness were described as making a lasting difference.

Home is preferred, but choice depends on support

Place of care was a dominant theme. Most people said they would prefer to be cared for and die at home, surrounded by familiarity and loved ones. Hospices were consistently viewed positively: specialist, compassionate and more conducive to dignity and peace than hospital settings.

However, preferences were rarely absolute. People recognised that illness progression, care needs and available support could change what was realistic. Many said home was only viable if sufficient professional and practical support was in place.

Hospitals were generally the least preferred setting. They were associated with noise, lack of privacy, staffing pressures and fears of dying alone or without dignity.

Relationships and carers are central

Being with loved ones was often described as more important than the physical setting itself. At the same time, many participants expressed concern about burdening family members.

Carers spoke openly about emotional and physical exhaustion. They described navigating complex systems, funding delays and bureaucratic barriers while trying to honour the wishes of the person they cared for. There was a strong sense that unpaid carers are expected to absorb system gaps without adequate recognition or support.

Autonomy, control and advance planning matter

Across communities, autonomy and control were deeply valued. People wanted their wishes listened to and respected, whether about treatment decisions, place of care, or how and when life should be prolonged.

A significant number expressed support for assisted dying within a legal framework, often driven by fears of prolonged suffering or loss of dignity.

Others focused on advance care planning, Lasting Power of Attorney and documenting their wishes. However, many were unsure how to begin these conversations or worried about upsetting family members.

Avoidance and delayed conversations remain common

Although many participants said they felt comfortable discussing death in principle, a large proportion had never spoken about key aspects of end-of-life care.

Reasons included:

- Emotional discomfort
- Death feeling distant
- Cultural taboos
- Not knowing how to start

There was strong agreement that earlier, open conversations would reduce fear, prevent crisis-led decisions and help families feel better prepared.

Communication shapes experience and grief

Communication emerged as one of the strongest cross-cutting themes. Its quality, clarity and compassion directly influenced how people experienced end-of-life care.

Good communication, which is honest, timely, jargon free and culturally sensitive, helped people feel safe and informed. Poor communication created fear, confusion, mistrust and long-lasting trauma.

This was particularly evident for:

- People with learning disabilities who described being talked over or not given accessible information
- Families who felt unprepared because professionals avoided direct conversations

Communication was repeatedly described as either a source of reassurance or a source of harm.

Inequalities and structural barriers restrict choice

Postcode variation, limited hospice beds, workforce shortages, delays in funding or equipment, and poor coordination between health, social care and voluntary services were recurring concerns.

These structural pressures directly affected people's ability to exercise choice.

Communities facing additional barriers, including migrants, people experiencing homelessness, disabled and neurodivergent people, LGBTQ+ individuals, and those in rural or coastal areas, described specific challenges such as mistrust, discrimination, cultural taboo, language barriers, poverty and digital exclusion.

Despite these differences, their core needs were the same: safety, dignity, compassion and being heard.

Culture, faith and spirituality must be respected

For some, faith and cultural traditions were central to how they approached death. For others, spirituality played little or no role.

Those with specific cultural or religious needs emphasised that these were essential, not optional, whether relating to rituals, modesty, spiritual practice or secular values.

Participants called for culturally competent care that respects traditions without making assumptions, and for better support where language or cultural norms make end-of-life discussions more complex.

Experiences of care vary widely

Hospice and specialist palliative care services were consistently described as compassionate, respectful and transformative. Many families said hospice care improved both the final days of their loved one and their own experience of grief.

Experiences of hospital and social care were more mixed. Some described excellent care. Others reported distressing experiences, limited privacy, staffing pressures and unmet needs.

People felt strongly that dying in pain, alone or without dignity is unacceptable. Yet many had witnessed this happen.

A desire for a kinder, more joined-up system

Throughout the involvement work, emotions ran deep. People shared fear: of suffering, of being alone, of not being believed, of losing control. They shared anger and trauma from poor experiences, as well as gratitude for compassionate care.

Many expressed hopes for a system that is:

- Proactive rather than crisis-driven
- Joined up rather than fragmented
- Honest rather than avoidant
- Supportive of families as well as patients

There was a clear call for earlier conversations, better coordination, stronger carer support and consistent standards of dignity across all settings.

Background and context

Palliative and end-of-life care is a vital part of the health and care system. It supports people with progressive or life-limiting illness to live as well as possible and to die with dignity. Across the North East and North Cumbria, thousands of individuals, families and carers are affected each year. As the population grows, ages and becomes more diverse, demand for compassionate, equitable and high-quality end-of-life care will continue to rise.

Under the Health and Care Act 2022, Integrated Care Boards (ICBs) have a statutory responsibility to commission services that meet the palliative and end-of-life care needs of their population. This includes:

- Ensuring fair and equitable access
- Reducing health inequalities
- Supporting informed choice about care and treatment

To fulfil this duty, the North East and North Cumbria Integrated Care Board (ICB) must understand not only clinical demand, but also the lived experiences, preferences, cultural traditions and expectations of the communities it serves.

To support future planning, the ICB is undertaking a strategic Health Needs Assessment (HNA) for palliative and end-of-life care. This updates the 2014 NHS England Population-Based Needs Assessment and will inform commissioning decisions across six Locality Delivery Teams and 13 Local Authorities over the next five to ten years.

Listening to people's experiences is central to this work. Talking about death and dying can be difficult, yet understanding what matters most, whether pain relief, dignity, cultural needs, or being with loved ones, ensures services are person-centred and aligned with the NHS Ambitions for Palliative and End-of-Life Care.

This report presents the findings from the involvement activity undertaken as part of the HNA.

Purpose of the involvement work

The "Thoughts about Palliative and End-of-Life Care" survey and associated qualitative engagement were designed to:

- Understand how people feel about discussing death and dying

- Explore preferences for place of care
- Identify cultural, faith, and community needs
- Assess levels of advance planning
- Capture experiences of care
- Understand barriers to conversation and access

The involvement work aims to:

- Ensure commissioning decisions reflect lived experience
- Identify inequalities in access and outcomes
- Highlight gaps in practical, emotional and cultural support
- Support earlier advance care planning
- Inform service development in response to projected demand

By combining population data, clinical evidence and lived experience, the HNA seeks to create a shared understanding of how to deliver high-quality, equitable palliative and end-of-life care across the region.

Legal duties and governance

The ICB is legally required to involve patients, carers, and the public in its work, as outlined in the [Health and Care Act 2022](#), the [NHS Constitution](#), and other key documents:

NHS Act 2006

ICBs must involve people in:

- Planning commissioning arrangements
- Developing proposals that affect services
- Decisions about how commissioning arrangements operate

The Gunning Principles

While formally applying to consultations, these principles represent good practice for all engagement activity. Consultations must:

- Be undertaken while proposals are still open to change
- Provide sufficient information
- Allow adequate time
- Properly consider responses before decisions are final

Equality and Health Inequalities Duties

Under the Equality Act 2010, the ICB must:

- Eliminate discrimination
- Advance equality of opportunity
- Foster good relations between communities

ICBs also have a duty to reduce inequalities in access to and outcomes from health services. This involvement activity contributes directly to meeting those obligations.

Involvement approach and methods

Approach to involvement and inclusion

A core aim of the involvement work was to reflect the diversity of the North East and North Cumbria population and to ensure participation from people who may experience inequality in accessing palliative and end-of-life care.

A mixed-methods approach was adopted, combining:

- A public online survey
- Facilitated focus groups
- One-to-one qualitative conversations
- Community-led engagement
- A supporting desktop review
- Additional responses submitted by email

This approach enabled participation from people with different needs, backgrounds and communication preferences, including those less likely to engage through traditional involvement methods.

Public survey - The public survey explored:

- Comfort discussing death and dying
- Preferred place of care
- Cultural and faith traditions
- What matters most at end of life
- Advance care planning
- Experiences of care
- Awareness of the GP palliative care register

- Demographic information

Focus groups and one-to-one conversations - Qualitative engagement provided deeper insight into lived experiences, perceptions and concerns. This method was particularly valuable for exploring the perspectives of inclusion groups and understanding the emotional and relational dimensions of end-of-life care.

Northern Cancer Voices - Community-led engagement prioritised storytelling, emotional safety and culturally sensitive discussion. This included tailored one-to-one support for individuals with literacy, confidence or access barriers, ensuring that lived experience was captured in a way that felt safe and meaningful.

Desktop review - The desktop review strengthened the evidence base by triangulating lived experience with existing research. It incorporated evidence from:

- The SR1 Report
- End-of-Life Care Research (Northumberland CCG & Healthwatch Northumberland)
- Research into end-of-life care within BAME communities in Sunderland

Additional submissions - Additional contributions, including lived experience letters and learning disability materials, were incorporated to ensure a broader range of perspectives were reflected.

Targeted engagement with inclusion groups

Healthwatch organisations across the region were commissioned to lead targeted qualitative engagement. Their role was to reach communities who are seldom heard or face barriers to accessing services.

Target groups included:

- Carers (including young carers)
- LGBTQ+ communities
- Disabled, D/deaf and neurodivergent people
- People with learning disabilities
- Migrants and asylum seekers
- People experiencing homelessness
- People living in coastal and rural communities
- Faith and religious communities
- Veterans and serving personnel
- People affected by substance misuse
- People living with severe mental illness

Engagement methods included:

- Survey promotion through trusted networks
- Easy Read materials
- Assisted survey completion
- Focus groups and one-to-one conversations
- Direct outreach to targeted community groups

This partnership approach ensured that involvement activity was grounded in trusted local relationships and community knowledge.

Communications and promotion

A comprehensive communications campaign supported participation across the region. This included:

- A regional press release
- A social media campaign
- Email cascade to partners and NHS organisations
- Inclusion in high-reach bulletins and newsletters
- Promotion through Healthwatch networks and community settings

This multi-channel approach maximised awareness and participation, particularly among underserved communities.

Response and reach

In total, **2,631 people** contributed to this involvement work:

- 2,395 survey responses
- 212 participants through 22 focus groups and 40 one-to-one conversations
- 24 participants through Northern Cancer Voices community engagement

This breadth of engagement strengthens the credibility and representativeness of the findings.

Detailed demographic information is provided in Appendix 1.

Summary of key findings by involvement method

This section summarises the key themes identified within each involvement method. [Detailed analysis for each involvement method](#) is provided later in this report.

Survey key findings

Survey responses show that end-of-life care is experienced as deeply personal and emotionally charged, and that preferences are often shaped by individual circumstances.

While many people are willing to talk about death in principle, a substantial proportion find these conversations difficult, delayed, or overwhelming. Key themes included:

Comfort, pain relief, and symptom control are the highest priorities

Freedom from pain was the most important concern. Many respondents expressed fear about unmanaged pain and distress, often shaped by traumatic past experiences. Comfort was described in physical and emotional terms, including calm surroundings, reassurance, and staying conscious enough to spend time with loved ones.

Dignity, respect, and being treated as a person matter deeply

Respondents emphasised dignity, kindness and being listened to. Dignity was closely linked to respectful communication, privacy and care that recognises the individual rather than focusing solely on clinical tasks. Overcrowded wards rushed care and poor communication were seen as incompatible with a dignified death.

Strong preference for home or hospice care, with flexibility

Most respondents preferred end-of-life care at home. Hospices were viewed positively as specialist and compassionate alternatives when home care is not possible. Preferences were rarely absolute and depended on illness progression, care needs and availability of support. Hospitals were generally seen as a last resort.

Family, relationships, and emotional environment are central

Being with family, close friends, or pets was often more important than the physical setting. Many prioritised not dying alone and wanted loved ones to be supported, informed, and involved. Concerns about burdening family members influenced preferences and planning.

Autonomy, choice, and control are critical

Respondents consistently stressed the importance of having wishes heard and respected. This included treatment decisions, care planning and, for many, the timing and manner of death. There was strong support for assisted dying, often linked to fears of prolonged suffering, loss of autonomy and poor quality of care.

Cultural, faith, spiritual and personal values must be respected

While most respondents said cultural or faith traditions were not important to them, those who did described these needs as essential. Preferences ranged from formal religious rituals to secular, nature-based, or family-centred practices. Respondents emphasised respect for both faith and non-belief.

Conversations about death are often delayed or avoided

Many people had not discussed their end-of-life wishes. Barriers included death feeling distant, emotional discomfort, fear of upsetting others, and not knowing how to start. Conversations often happened late or in crisis.

Need for clearer information and guided support

Respondents often felt uncertain about options and what end-of-life care involves. They wanted clear, honest and accessible information, supported by guided conversations. Specialist palliative and hospice professionals were trusted, but respondents described the need for coordinated medical, legal and emotional support.

Past experiences strongly shape expectations and fears

Most respondents had experienced bereavement. Positive hospice and specialist palliative care experiences helped to build confidence. Negative experiences (particularly poor pain management, fragmented services and lack of dignity) caused lasting harm and shaped fears about their own deaths.

Inequality, access and system pressures are a major concern

Respondents described variation in quality and availability depending on location, diagnosis and capacity. Underfunding, hospice bed availability, workforce pressures and poor coordination were recurring concerns. Deaf BSL users and others with communication needs highlighted significant accessibility barriers.

A strong call for earlier, more open and more honest conversations

Many respondents called for death and dying to be discussed more openly in healthcare and society, with earlier conversations, clearer explanations and better preparation for families.

Healthwatch qualitative conversations key findings

Healthwatch conversations reinforced the survey themes and added depth on lived experience, trust and the emotional impact of system gaps. Experiences were strongly shaped by identity, vulnerability and personal history. Key themes included:

Death is recognised as inevitable, but conversations are often avoided

Many described emotional discomfort, family silence, or cultural taboo. Younger people and those without recent bereavement often felt death was distant. Carers and older adults were generally more ready to engage. Earlier conversations following serious diagnosis were viewed as particularly important.

Comfort, dignity and not being alone define a 'good death'

Comfort and pain management were described as foundational. Beyond this, dignity, privacy and being treated as a person were central. Small acts of kindness and respect shaped overall experience.

Strong preference for home, with hospice as a valued alternative

Home was most preferred, linked to familiarity and identity, but often conditional on support. Hospices were widely praised as calm and compassionate for patients and families. Hospitals were generally least preferred due to concerns about dignity, staffing pressures and privacy.

Planning and coordination are valued but not consistently understood

Participants supported advance care planning and clearer documentation of wishes. Awareness of the GP palliative care register was low but viewed positively when explained. Concerns centred on proactive use, flexibility and data protection. Repetition and delays were common frustrations.

Communication quality shapes emotional outcomes

Participants wanted straightforward language, time to ask questions and involvement in decisions. Euphemisms and avoidance caused confusion and mistrust. Poor communication was linked to distress and complicated grief, good communication improved experiences even in difficult circumstances.

Carers carry significant emotional and practical burden

Carers described exhaustion, invisibility and navigating complex systems with limited support. Delays in funding, equipment and coordination increased strain.

Identity, inequality and vulnerability shape experience

LGBT participants raised concerns about discrimination and identity being ignored. Disabled respondents emphasised risks to dignity and autonomy. People experiencing homelessness prioritised safety and warmth and described mistrust and barriers to GP registration. Young carers reported being excluded from conversations.

Hospice care is highly valued but unevenly understood and accessed

Those who had experience of hospice services often described compassionate care. Barriers included delays, limited capacity and under-resourcing, alongside low public understanding of what hospice and palliative care involve.

System pressures undermine confidence

Participants described underfunding, staffing shortages and bureaucracy. Some feared neglect or poor basic care in overstretched services.

Northern Cancer Voices key findings

Community-led engagement across rural, farming, ethnically diverse, migrant, low-income and homeless communities highlighted the role of culture, faith, trauma, poverty, financial insecurity, service responsiveness and place in shaping end-of-life experiences.

Engagement included rural residents in Northumberland, farmers at Hexham Auction Mart, ethnically diverse women in Sunderland, migrant and no recourse to public funds community insight via Connect360, women experiencing homelessness in Newcastle, a detailed lived-experience case from a low IMD community in Blyth, and 25 individuals supported through one-to-one HNA conversations.

Key themes included:

Talking about death is difficult for everyone

Across all groups, discussions about death were emotionally challenging, but for different reasons. Rural residents often avoided the topic until illness forced it. Some migrant and Muslim women described cultural or spiritual prohibitions, including beliefs about destiny and “inviting death in.”

Women experiencing homelessness prioritised daily survival over future planning, while farmers felt financially overwhelmed. Emotional readiness could not be assumed.

Fear that assessments signal “giving up”

Some participants worried that end-of-life assessments meant care was being withdrawn or that they were being “written off.” Older rural residents raised concerns about age-related deprioritisation. Ethnically diverse women expressed fears about pain relief hastening death, and migrant communities linked acceptance of palliative care with loss of hope in divine intervention. Clear framing as support to live well now is essential.

Barriers to care strongly shape priorities

Practical barriers limited planning and choice. Rural communities highlighted distance and fear of dying in hospital. Farmers described inheritance and succession pressures. Ethnically diverse women raised language, modesty and mistrust concerns. Homeless participants lacked GP access and stability, while the low IMD case showed how fragmented communication and unclear service ownership increase distress.

Culture, faith and community shape decision-making

End-of-life decisions were strongly influenced by faith, cultural identity and family roles. Muslim women described burial rituals and modesty needs; Christian migrant communities emphasised prayer and pastoral presence. Rural participants valued community traditions, while farmers prioritised generational land protection. Care preferences cannot be separated from cultural and relational context.

Service coordination and accountability matter

The low IMD lived-experience case highlighted the impact of fragmented care, including lack of a named coordinator, unclear 24/7 contact pathways and delayed escalation. Similar concerns were echoed elsewhere about assessments becoming tick-box exercises. Visible follow-up, clear responsibility and responsive communication are critical to maintaining trust.

Universal priorities were consistent across all groups

Despite differing circumstances, core needs were consistent:

- Pain relief
- Safety
- Dignity and respect
- Warmth and comfort
- Family presence where possible

These universal priorities underpin expectations of good end-of-life care across all communities.

Desktop review key findings

The desktop review reinforced themes from lived experience and highlighted how structural, cultural and communication factors shape inequity. Key themes included:

System complexity and structural barriers

Administrative failures and fragmented systems created avoidable barriers, including in the benefits system (as highlighted in the SR1 report) and in health and care pathways. Complexity itself was a driver of inequality.

Communication as an equity issue

Clear, honest and compassionate communication was repeatedly identified as essential. Poor communication, lack of interpreters, inaccessible information and inconsistent advice increased distress and mistrust and limited access to support.

Cultural and religious influences on care

Cultural norms and faith beliefs shaped attitudes toward death and planning, preferences for care, and engagement with services. Where services did not recognise these needs, trust reduced and barriers increased.

Choice, control and dignity are not equally achievable

While policy commitments emphasise personalised care, practical barriers (delays, low awareness, poverty, housing insecurity and cultural barriers) limited genuine choice for many people.

The burden on families

Families frequently carried emotional and practical responsibility, including navigating complex systems, providing hands-on care and managing communication with services.

Additional response key findings

Additional insight was gathered through learning disability focus group notes, a lived experience letter, video and podcast contributions, Margaret's story (Learning Disability Network) and Marie Curie insight.

These accounts emphasised how equitable care depends on communication, continuity, accessibility, coordination and reasonable adjustments. Key themes included:

Communication is a consistent risk point

People described unclear, rushed or overly complex explanations that left them frightened or excluded. People with learning disabilities reported being talked over or not spoken to directly. Where communication was honest, paced, accessible and compassionate, people felt reassured and more in control.

Trust, continuity and familiar relationships matter

Positive experiences were strongly linked to consistent relationships with people who understood the individual. Unfamiliar staff increased anxiety and reduced confidence.

Accessible information enables meaningful choice

People wanted to express preferences but lacked accessible information about options and services. Easy Read materials, visual supports and trusted support were repeatedly described as necessary to make planning real rather than theoretical.

Personalised, dignified care depends on emotional safety

People described the importance of predictable, respectful interactions and familiar environments. Calm, personalised hospice experiences were contrasted with fear of settings associated with loss of dignity.

Emotional burden, fear and uncertainty are widespread

People described fear of pain, being alone, and not understanding what was happening. Families described exhaustion, guilt, and feeling unsupported.

System fragmentation increases inequity

Poor coordination between services placed pressure on individuals and families to “push” for help. Unequal access to information and timely support was a recurring concern.

Detailed analysis by involvement method

Survey results

Talking about death and dying

Most people who took part in the survey feel comfortable talking about death and dying. Over half (57%) said they feel either fairly or very comfortable, while around a quarter (29%) reported some level of discomfort. A smaller group (14%) felt neutral about the topic.

Overall, the findings suggest that although many are open to conversations about death, a meaningful number still find these discussions challenging and may need a more sensitive approach.

How do you feel when you talk about death or dying?	N	%
I feel very uncomfortable	172	7%
I feel a bit uncomfortable	527	22%
I don't really mind either way	328	14%
I feel fairly comfortable	778	33%
I feel very comfortable	572	24%
	2377	

Preference for place of care at end-of-life

Most people indicated a clear preference for receiving palliative care at home, with just over half of respondents (51%) selecting this option. Hospices were the next most common choice, preferred by 38%, showing that many value a dedicated, specialist care environment. Very few people said they would choose hospital care (2%) or a care or nursing home (1%), suggesting these settings are seen as less desirable for end-of-life support. A small proportion either did not mind (6%) or chose somewhere else (2%).

Overall, the results highlight a strong desire for care in homely, familiar, or specialist environments rather than clinical or institutional settings.

If you could choose, where would you like to be cared for when receiving palliative care at the end of your life?	N	%
At home	1220	51%
In a hospice	906	38%
I don't mind	146	6%
Somewhere else	52	2%
In a hospital	42	2%
In a care or nursing home	16	1%
	2393	

Respondents who selected 'somewhere else' was asked to specify where. A total of 51 provided a response.

People's responses highlighted that preferences for where they wish to receive palliative and end-of-life care are deeply personal, highly situational, and often influenced by their health needs, family circumstances, and emotional considerations. A strong and recurring theme was that choice cannot be fixed in advance; many individuals felt that their preference would "depend on the circumstances," including their level of dependency, the progression of illness, and the type of care required.

A desire for flexibility and care that meets changing needs

Many emphasised that the most important factor was being in a setting that could meet their clinical and comfort needs at that time. People often voiced uncertainty about what their future needs might be and felt unable to choose definitively without knowing their condition. Several noted that questions about place of care are "too dependent on circumstances" and that the survey format did not capture the nuance required for such sensitive decisions.

Home as an initial preference, if support allows

Home emerged as a common preference, particularly because it represents comfort, familiarity, and the presence of loved ones. Individuals described home as their likely first choice, but many also acknowledged the limitations:

- not wanting to burden family
- concerns about whether medical needs could be safely managed
- recognition that increasing care needs might make staying at home unrealistic

Several people highlighted that home would only remain preferable as long as their family felt able to cope or if appropriate care support was in place.

Hospice care viewed positively and often as a preferred alternative

If home was not possible, hospice care was frequently mentioned as the next best option. People associated hospices with dignity, specialist care, effective symptom management, and a calmer environment than a hospital or care home. For some, particularly those with past cancer experiences, hospices felt like the most suitable and supportive setting.

Hospital generally seen as the least preferred option

Several people expressed a clear wish not to be in hospital unless absolutely necessary. Concerns included lack of privacy, busy wards, and the emotional toll on themselves and their families. A few specified that if hospital care became unavoidable, they would prefer a private or quieter space rather than an open ward.

Family presence and emotional environment matter more than location

Across many responses, the emotional environment: being with close family, loved ones, or even pets, was more important than the physical place itself. Some articulated beautiful or symbolic preferences, such as being “in nature,” “watching the sea,” or simply being “anywhere as long as my husband and pets are with me.”

The importance of dignity, autonomy, and control

Several individuals expressed a desire for control over the manner and timing of death, referencing assisted dying or organisations like Dignitas. These responses reflected a wish for dignity, reduced suffering, and autonomy over final decisions.

Uncertainty, lack of information, and difficulty imagining the future

Many responses reflected not knowing where they would want to be, often because they lacked understanding of what different care settings offer. Others noted they had not thought about end-of-life care before or felt unable to make such a decision until facing that reality.

Protecting family from distress

Some people expressed concern about the emotional impact on those they care about. This included:

- choosing a hospice so the family home was not associated with death
- going somewhere away from home to avoid burdening relatives
- uncertainty about whether family could cope or provide support

Culture, faith, and community traditions

Most respondents (71%) said that cultural, faith, or community traditions were not important to them when thinking about death and dying. Around one in five (18%) indicated that such traditions do matter, suggesting a meaningful minority for whom cultural or spiritual practices play a role in end-of-life preferences. A further 9% were unsure, indicating some uncertainty or variability in how people relate to these traditions.

Overall, while most respondents reported no specific cultural or faith needs, the findings highlight the importance of ensuring services remain sensitive and adaptable for those who do.

Are there any cultural, faith, or community traditions that are important to you around death or dying?	N	%
Yes	432	18%
No	1738	71%
I'm not sure	218	9%
	2365	

Among the 132 people who provided response, a rich and diverse set of cultural, faith, spiritual, and personal traditions emerged. While many described clear religious practices that matter deeply, others emphasised family, environment, dignity, or non-religious values.

Christian and Catholic traditions

A strong theme throughout the responses was the importance of Christian, particularly Roman Catholic, rituals at the end-of-life. Many people expressed a wish for:

- Last Rites, Sacrament of the Sick, or anointing by a priest.
- A visit from a priest, vicar, minister, or chaplain, offering prayer, blessings, reassurance, and spiritual support.
- Access to Holy Communion, the Eucharist, Bible readings, hymns, Christian music, and worship.
- Being recognised and treated as a person of faith, with assurance their beliefs would not be dismissed or deprioritised.

For many, these practices were described as essential to their sense of peace, dignity, and preparation for death. Some emphasised the desire for clergy access to be straightforward and unrestricted.

Muslim traditions

Some respondents highlighted important Islamic practices, including:

- Continuous Quran recitation, particularly specific chapters during final moments.
- Ritual washing, shrouding, and traditional preparations.
- A preference for a quick burial, aligned with Islamic teaching.
- Support for mending relationships, addressing debts, and ensuring spiritual readiness.

These practices were described not only as religious obligations but as part of a meaningful, holistic preparation for death.

Buddhist traditions

A smaller number identified Buddhist traditions as important. These included:

- Access to a Buddhist priest, ideally before death.
- Support with end-of-life practices such as Nembutsu recitation, especially if illness prevented speaking.
- A desire for staff to understand the significance of these rituals.

Pagan, Wiccan, and nature-based beliefs

Some respondents described Pagan or Wiccan traditions, including:

- Visits from a high priestess.
- Use of protective items placed on or near the body.

- Spiritual practices connected to nature, such as open windows, fresh air, and hearing birds.

Others, even if not identifying with a formal tradition, connected strongly with nature and wanted it incorporated into their final days.

Hindu traditions

A small number of people highlighted Hindu customs, such as Hindu cremation rituals and ensuring the ashes return to the family.

Non-religious and secular wishes

Many respondents stated clearly that they were not religious and did not want clergy or religious elements involved. Their wishes included:

- A simple approach with minimal fuss.
- Eco-friendly funerals and low-impact practices.
- A traditional-feeling service with hymns or ceremony for the sake of loved ones, even if they personally did not hold religious beliefs.
- A focus on celebration of life, music, memories, and emotional expression.

Some emphasised wanting equal treatment between those with and without religious beliefs.

Family, community, and emotional traditions

Across all belief systems, respondents frequently described the importance of:

- Having family and close loved one's present, including pets.
- Being able to express emotions freely, without judgement.
- Allowing people to visit the body before burial or cremation, ideally in a calm chapel-of-rest environment.
- Staying at home until the funeral, where culturally customary.
- Celebrations that reflect their life, including music, photos, and participation from their community.

For some, traditions were less about formal religion and more about maintaining cultural or family customs that give comfort to those left behind.

Dignity, autonomy, and personal values

Several people described priorities that were personal rather than faith-based:

- Ensuring dignity and respectful care of the body.
- Freedom to donate their body for medical training.

- Wanting the environment to feel peaceful and meaningful.
- Having their beliefs, whatever they are, acknowledged and upheld.

What matters most in end-of-life care

People were asked to choose the two things they felt were most important for good end-of-life care. After removing 235 responses where more than two options were selected, 2,149 valid answers remained.

The most important factor for respondents was being free from pain, selected by over half of all participants (56%). This was followed by being treated with dignity and respect (40%), reflecting the importance people place on feeling valued and cared for as a person. Being with family or friends was also highly prioritised (36%), highlighting the need for connection and emotional support.

Nearly a third of respondents (28%) said that having their wishes listened to and respected was essential, suggesting that choice and autonomy matter greatly at the end-of-life. A smaller proportion emphasised feeling calm and peaceful (23%), while fewer identified not being a burden to others (8%), showing that although some people worry about this, it is not a dominant concern.

Overall, the findings show a strong emphasis on comfort, respect, meaningful relationships, and personal autonomy, with pain relief emerging as the clear top priority.

What do you think is most important for good end-of-life care?	N	%
Being free from pain	1214	56%
Being treated with dignity and respect	870	40%
Being with family or friends	768	36%
Having my wishes listened to and respected	607	28%
Feeling calm and peaceful	488	23%
Not being a burden to others	176	8%
Other	23	1%
	2149	

When looking at all 2,384 responses to this question, including those where people selected more than two options, the overall pattern remains consistent, as shown below.

- Being free from pain – 60%
- Being treated with dignity and respect – 45%
- Being with family or friends – 40%
- Having my wishes listened to and respected – 33%
- Feeling calm and peaceful – 29%
- Not being a burden to others – 13%
- Other – 2%

The 37 ‘other’ comments reveal that while people were asked to choose just two priorities, many found this difficult because multiple aspects of good end-of-life care are deeply interconnected. Across the responses, people emphasised a blend of clinical, emotional, practical, spiritual, and autonomy-related needs that shaped what “good care” meant to them.

Comfort, safety, and symptom management

Many respondents reinforced the importance of comfort, safety, and effective symptom control. People spoke about:

- wanting timely and accurate clinical assessment,
- competent, compassionate symptom management,
- no suffering,
- and attention to essential aspects of care such as mouth care.

Several mentioned that complete freedom from pain may be unrealistic, especially for those already living with chronic pain, but emphasised that pain should be well-palliated.

Feeling comfortable enough to stay awake and enjoy moments with family was also mentioned, even if this meant accepting some symptoms.

Person-centred, values-driven care

A strong theme was the desire to be seen and cared for as a whole person, not simply as a patient. People described wanting:

- care rooted in individual values,
- recognition of a lifetime of experience,
- staff who know what is needed both for them and their families,
- and support that is prepared, organised, and personal.

Several explicitly used the language of person-centred care, highlighting its emotional importance.

Emotional and relational needs

Connection, presence, and relationships were central. Respondents emphasised:

- not dying alone,
- avoiding situations where their body might go undiscovered,
- being surrounded by family, including children, partners, and pets,
- having their loved ones listened to and respected, not sidelined,
- and the reassurance of round-the-clock support.

Some expressed concern for dependents, such as disabled children or siblings, worrying more about their future care than their own.

Autonomy, choice, and control

Autonomy was a powerful thread. Several people expressed the importance of:

- choosing when and how they die,
- the right to end their life or access assisted dying,
- not being pressured into treatments that might shorten life,
- and having choices respected even when difficult for others.

For some, autonomy also meant being informed, being heard, and ensuring their wishes take priority during decision-making.

Faith, spirituality, and cultural needs

Spiritual needs mattered for some respondents. People described:

- needing others to respect the rituals associated with Christian faith,
- receiving Viaticum, Extreme Unction, or other end-of-life sacraments,
- ensuring their beliefs are honoured even if others find the process emotionally difficult.

For some, faith was linked not only to ritual but to a sense of meaning, preparation, and dignity at the end-of-life.

Accessibility, equity, and communication needs

A smaller but important set of comments highlighted the need for equitable access, especially for Deaf British Sign Language (BSL) users. Respondents emphasised:

- removing communication barriers,
- ensuring Deaf people can maintain control, dignity, and respect,

- and guaranteeing that accessible communication support is always available.

This reflects a broader concern that end-of-life care must be inclusive for all people, regardless of communication, sensory, or cognitive needs.

Difficulty choosing only two priorities

Many people openly stated that the question felt too restrictive. Comments included:

“All of the above,”

“I think all apply,”

“You can’t ask someone to choose – these are all important,”

or noting that they would need to choose more than two to answer honestly.

This reinforces that end-of-life priorities are rarely singular. People value a combination of comfort, dignity, autonomy, and connection.

Practical and social responsibilities

Some respondents reflected on wider responsibilities, including:

- ensuring dependent relatives are cared for,
- wanting assurance that their partner, children, or lodgers would be supported,
- and needing systems in place that take their family context into account.

For some, these concerns outweighed their own physical comfort.

Conversations about end-of-life care

When asked whether they had ever talked with someone about different aspects of end-of-life care, responses showed a wide variation in people’s experiences and levels of preparedness.

The most common topic people had discussed was dying with dignity and respect, selected by 39% of respondents, suggesting that many feel comfortable talking about core values and principles rather than specific practicalities. Around one-third (29%) had spoken about where they would like to die, while just under a quarter had discussed their medical needs (24%) or pain relief (22%).

Topics relating to more personal or emotional considerations were discussed less often. Only 19% had talked about wanting peace and privacy, 16% had spoken about spiritual or religious needs, and just 12% had discussed when they would like to die.

Notably, 43% of respondents said they had not talked about any of these topics at all, highlighting that for many people these conversations have not yet happened, and perhaps feel difficult to start. A further 8% had spoken about something else, suggesting individual circumstances or priorities not captured in the main list.

Overall, the findings point to a mixed picture: while a significant number of people have begun conversations about their values and preferences, many others have not yet explored what matters to them at the end-of-life, underscoring the need for supportive, accessible opportunities to talk and plan ahead.

Have you ever talked with someone about any of the following?	N	%
None of these – i haven't talked about any of these things	1026	43%
Dying with dignity and respect	931	39%
Where i would like to die	699	29%
My medical needs	564	24%
Pain relief	530	22%
Wanting peace and privacy	444	19%
My spiritual or religious needs	379	16%
When i would like to die	294	12%
I've spoken about something else (please say)	181	8%
	2375	

For those who said they had ‘spoken about something else’, 168 people provided a response. These responses reveal a wide range of conversations, spanning practical planning, treatment decisions, funeral wishes, family responsibilities, autonomy, and deeply personal concerns. These responses show that when people do talk about end-of-life issues, the discussions often go far beyond formal care planning and reflect the complexities of preparing for death in real life.

Conversations about funeral wishes and what happens after death

A substantial proportion of responses focused on the practicalities after death, with many people having talked about:

- Whether they want burial or cremation.
- What they want done with their ashes.
- The type of funeral they would like, including music, tone, or specific rituals.
- Wanting a non-religious funeral, or a simple/direct cremation.
- Planning or pre-paying for funerals to avoid becoming a financial burden.
- Leaving instructions about possessions, treasured items, or memorial preferences.

Some had gone further by preparing eulogies, discussing “celebration of life” styles of service, or expressing preferences like green burials, bells ringing, or avoiding certain traditions.

Organ donation, body donation, and medical science

A strong theme was organ and body donation. Many people had spoken to loved ones about:

- Donating organs.
- Donating their body to medical science.
- Having these decisions clearly documented in wills, NHS organ donation registration, or advance directives.

Some also noted discussions about not donating organs, highlighting that personal choice varies widely.

Decisions about treatment, resuscitation, and medical interventions

Numerous responses showed people had discussed their wishes about:

- DNACPR decisions.
- When they would or would not want life support, resuscitation, or further treatment.
- Avoiding unnecessary medical interventions such as antibiotics or invasive procedures.
- Preferences about pain management, recognising limits (e.g., morphine pumps).
- Having an advance directive or advanced decision to refuse treatment.

These conversations often related to previous personal or family experiences and concerns about maintaining quality of life.

Assisted dying, Dignitas, and control over timing

A significant minority had discussed themes related to assisted dying, including:

- The desire to choose when and how they die.
- Considering the possibility of going to Dignitas.
- Wanting the right to end their life if suffering becomes too great or quality of life is lost.
- Worries about being kept alive when they no longer want to be or being denied choices.

Others raised concerns about not being coerced into ending treatment prematurely, especially disabled people who feared assumptions about their quality of life.

Planning for finances, legal matters, and practicalities

Many respondents described conversations about financial and legal arrangements, including:

- Wills, property, and inheritance.
- Lasting Power of Attorney for health and finance.
- Advance care plans and emergency instructions kept in visible places (e.g., yellow envelopes).
- Who should make decisions if they lose capacity.
- Ensuring loved ones know where documents are stored.

These discussions reflect the broader practical burden people want to reduce for their families.

Planning for care responsibilities and dependants

Several respondents discussed their concerns about what would happen to:

- Children, partners, or grandchildren.
- Disabled family members, including adult children, or siblings.
- Pets, especially cats and dogs.
- Lodgers or those who depend on them informally.

These conversations often involved ensuring support is available so loved ones are not overwhelmed.

Preferences for place of care and support needs

Some comments focused on where people would want to be cared for:

- Preferences not to go into a care home.
- Talking about when a hospice might be appropriate.
- Wanting to remain at home unless circumstances change.
- Planning where they would like to live before their final days, not only at the point of death.
- Fears about poorly run care homes.

People also described wanting quiet environments, limited visitors, and care delivered in ways that respect dignity and comfort.

Spiritual, relational, and emotional conversations

Some respondents mentioned spiritual or faith-based discussions, including:

- Asking loved ones to pray or involving specific religious rituals.
- Worries about their spouse coping with their death.
- Passages about the soul or feeling guided by faith.

Others discussed emotional aspects, such as not wanting their children to see them suffer or talking casually (“joking about cremation vs burial”) to ease discomfort.

Communication barriers and accessibility

A small but important set of comments highlighted the lack of BSL-accessible communication for Deaf people. Respondents noted:

- Professionals not knowing how to book interpreters.
- The danger of family members being left out due to communication issues.
- The risk that Deaf people’s wishes are not discussed or understood.

These comments underscore structural barriers in end-of-life communication.

Reflections shaped by personal experiences

Many people referenced experiences with relatives who had died:

- Positive hospice experiences that shaped their own preferences.
- Negative experiences influencing their desire for more control or clarity.
- Awareness that their own wishes might evolve as their health changes.

Some described plans already “fully in place,” while others noted that deeper conversations may only be possible when they know their prognosis.

Not having conversations about end-of-life care

Among those who had not talked about their end-of-life wishes, the most common reason was that death feels far away, selected by over a third of respondents (35%). This suggests that many people see these conversations as something to be addressed later in life rather than something relevant now. A further 16% felt they were too young to be thinking about end-of-life plans, reinforcing the sense that age and perceived distance from illness play a major role in delaying discussions.

Emotional and interpersonal barriers were also significant. Around 10% said they don’t feel comfortable talking about death, and 14% said other people don’t want to talk about it, showing that discomfort is shared across families and social circles. Meanwhile, 10% said they don’t know

how to start the conversation, indicating that even when people are willing, they may lack confidence or language to begin.

A smaller group (4%) reported having no one to talk to, highlighting isolation as a challenge. Finally, 13% said there was another reason.

Overall, these findings show that lack of urgency, emotional discomfort, and uncertainty about how to begin are the main barriers to end-of-life conversations, rather than unwillingness or lack of interest.

If you haven't talked about these things, please tell us the main reason why?	N	%
Death feels far away	353	33%
I think I'm too young to talk about it	166	16%
Other people don't want to talk about it	150	14%
Other reason (please say what)	138	13%
I don't feel comfortable talking about death	110	10%
I don't know how to start the conversation	107	10%
I don't have anyone to talk to about it	41	4%
	1065	

Among the 128 people who gave another reason, the responses highlight a wide range of emotional, practical, personal, and situational factors that make end-of-life conversations difficult. These reasons go far beyond simple reluctance and show how complex, sensitive, and context-dependent these conversations can be.

Emotional pain, grief, and fear

Many respondents described the subject as too raw, especially after recent bereavements. People spoke about losing a partner, child, or parent and feeling unable to talk about their own death while still grieving. Others said they were frightened, uncomfortable, or afraid of upsetting those they love. Comments reflected:

- Avoiding upsetting family members
- Feeling emotionally unprepared

- Fear of burdening others
- Feeling too close to recent loss to talk about death again

Some noted that the topic itself feels painful, overwhelming, or simply “too much” right now.

Not the right time or circumstances

Many people said the opportunity just hasn’t arisen. These conversations haven’t naturally come up, or they feel too abstract because nothing currently prompts the need. Common themes included:

- “It hasn’t come up” or “not relevant at the moment”
- Death feeling too far away
- Wanting to wait for deteriorating health before discussing it
- Feeling healthy, young, or simply not ready
- Wanting to talk “nearer the time” rather than planning too far ahead

Some felt that conversations depend on knowing the specific circumstances of their future illness, which they cannot yet imagine.

Putting it off or being too busy

A large number said they just haven’t got around to it. Life’s demands: caring responsibilities, work, parenting, dealing with other people’s health needs, have pushed their own planning to the background. People described:

- Being too busy looking after others
- Life being chaotic or overwhelming
- Feeling there is “plenty of time”
- Not prioritising the subject
- Acknowledging procrastination (“putting it off”)

For some, completing tasks like wills or care planning books was on their to-do list, but they hadn’t yet started.

Not knowing how to start or what to say

Many respondents simply didn’t know where to begin. Barriers included:

- Not knowing what they would want
- Feeling unprepared or lacking information
- Not knowing who to talk to
- Not wanting to start a conversation they don’t feel able to finish

- Feeling that choices depend heavily on future circumstances
- Uncertainty about what the options actually are

Some described wanting guidance, information, or tools to help them think things through.

Concern about others' reactions

A significant theme was worry about how others might respond. Some felt their family would be too uncomfortable, distressed, or unwilling to talk. Others described partners who cannot handle the topic, relatives with health issues, or family dynamics that make the conversation difficult.

Examples included:

- Family members uncomfortable discussing death
- Not wanting to upset children
- Avoiding additional pressure for carers
- Feeling family would “have enough to deal with”

One respondent noted that loved ones' reactions to a spouse's death made them believe they would not be listened to.

Focus on others rather than themselves

Some people were so absorbed in caring for relatives with serious needs that they hadn't turned attention to their own future. Many were managing:

- Children with high needs
- Disabled family members
- Elderly parents
- Household responsibilities

For these individuals, thinking about their own death felt secondary to urgent caregiving duties.

Feeling confident others will decide well

A few said they trust their loved ones to make decisions when needed. For them, formal conversations feel unnecessary because:

- Their family “already knows” what they want
- They believe decisions will be made sensitively when the time comes
- They prefer to leave choices open until circumstances are clearer

Lack of need, interest, or motivation

A smaller group expressed indifference or apathy, saying:

- They “can’t be arsed,”
- Haven’t given it serious thought,
- Or simply don’t feel it’s important.

Others felt the issue doesn’t affect them yet or were not motivated to think ahead.

Cultural, spiritual, or personal attitudes

A minority held views such as:

- Death being inevitable so not worth discussing
- Avoiding the topic for fear of “tempting fate”
- Seeing death as something not to dwell on
- Feeling “when you’re dead, you’re dead”

These philosophies shaped their reluctance toward planning.

Plans already written but not discussed

A few respondents said they have written everything down (wills, directives, funeral plans) but haven’t talked about their decisions with others. Some preferred written instructions to conversations; others felt writing was enough for now.

Written plans and documents

Just over half of respondents (51%) reported having a will, making it the most common written plan people have in place. Many also held an organ donation card (40%), and a smaller group had written wishes specifically about organ donation (14%).

Planning for practical matters was less widespread, with 17% having documented financial plans and 15% having written funeral wishes. Only 10% had a written statement about their care preferences if they lost capacity, and very few (3%) had a care plan for someone they look after.

Notably, 30% of respondents said they had no written plans or documents at all, suggesting that while some aspects of planning are common, many people have not yet formalised their broader end-of-life wishes.

Do you have any of the following written plans or documents about your care, funeral, or what should happen after you die?	N	%
A will	1206	51%

An organ donation card	953	40%
None of these – i don't currently have any written plans or documents	722	30%
A plan for my money or finances near the end of my life	403	17%
Written wishes about organ donation	329	14%
Written wishes for my funeral	368	15%
A written statement about my wishes for care if i can't make decisions	234	10%
A care plan for someone i look after	67	3%
	2382	

Help to start planning for end-of-life care

When asked what would help them start planning if they knew they were nearing the end-of-life, respondents overwhelmingly prioritised making things easier for their family, with 86% selecting this as a key motivator. Many also said they would be encouraged to plan if it helped them secure the right care and support (68%) or ensure they had the funeral they would like (40%).

Practical help also featured strongly: 41% said that support to write down their wishes would assist them, while 33% wanted help finding information about planning. Three out of ten (30%) people said they would be more likely to plan if someone helped them talk through their wishes, suggesting that guided conversations may make the process feel more manageable.

Only 3% said that none of the listed factors would help them start planning, indicating that most people recognise clear motivators that could support timely end-of-life discussions.

If you knew you were near the end-of-life, what would help you start planning?	N	%
Wanting to make things easier for my family	2055	86%
Making sure i get the right care and support	1617	68%
Getting support to write down my wishes or care plan	972	41%

Wanting the funeral i would like	956	40%
Getting help to find information about planning	793	33%
If someone helped me talk about my wishes	724	30%
None of these	65	3%
	2384	

Getting help and information

Respondents preferred to get information about planning for death from family or friends (24%), followed by charities and voluntary organisations (17%), doctors or GPs (17%) and nurses (13%). Smaller numbers of people preferred solicitors or funeral directors (both 7%), the internet (9%), or faith/community leaders (2%).

Who would you most like to get information from about planning for death?	N	%
Family or friends	566	24%
Charity or voluntary organisation	392	17%
Doctor or GP	391	17%
Nurse	307	13%
The internet	224	9%
Solicitor	167	7%
Funeral director	164	7%
Someone else (please say who):	98	4%
Faith or community leader / representative	53	2%
	2340	

Among the 93 people who provided more detail, the responses reveal that many people do not see a single source as sufficient. Instead, they want information that is trustworthy, knowledgeable, unbiased, and tailored to their situation. Their comments highlight the importance of circumstances, expertise, relationships, and accessibility when seeking support with end-of-life planning.

Desire for specialist expertise in palliative and end-of-life care

A strong theme was the preference for professionals with specialist knowledge, including:

- Palliative care nurses
- Specialist palliative care practitioners
- Macmillan or hospice nurses
- End-of-life care specialists
- Community-based end-of-life planners or doulas

Many felt that general clinicians do not always have the time or breadth of knowledge needed, while specialist teams understand the emotional, clinical, and practical aspects of dying.

Some wanted input from the clinical teams involved in their specific condition (e.g., haematology, oncology).

Wanting more than one source of information

Many respondents explicitly said they could not choose just one source. They described wanting a combination of:

- Solicitors (for legal and financial matters)
- Doctors or GPs (for medical understanding)
- Nurses (for practical care guidance)
- Charities (e.g., Macmillan, Maggie's, disease-specific organisations)
- Funeral directors
- Hospice teams
- Financial advisors

They emphasised that no single person or organisation has a fully "holistic view" across medical, legal, emotional, and practical aspects of death.

Importance of trust, neutrality, and avoiding sales pressure

People expressed concerns about being given advice by individuals or organisations who may:

- Try to sell services

- Lack proper qualifications
- Provide biased or incomplete information

Respondents wanted:

- Unbiased, qualified, informed guidance
- Someone “who understands,” is trained, or can signpost accurately
- Assurance that the person advising them is regulated or accountable

Some explicitly mentioned wanting to avoid being “conned,” reflecting anxiety about financial vulnerability.

Turning to family and close relationships

A considerable number of people felt they would first seek information or guidance from:

- Their spouse or partner
- Their children
- Family members familiar with their health or wishes
- Close friends
- People they already trust

Some respondents already working in end-of-life care said they would talk with professional colleagues or friends with relevant expertise.

Situational or conditional preferences

Many emphasised that who they would speak to depends entirely on context, such as:

- Whether they had received a diagnosis
- The stage of illness
- Whether they were planning early or facing imminent decisions

Examples included speaking to:

- A doctor if diagnosed with a terminal illness
- A solicitor if planning their will or finances
- A hospice team if needing end-of-life support
- Friends or community figures if seeking emotional guidance

Hospice, charity, and community-based sources

Hospices were repeatedly mentioned as trusted sources due to their:

- Expertise
- Compassion
- Breadth of experience
- Ability to support families as well as the person who is dying

Other sources cited included:

- Funeral celebrants
- Humanist celebrants
- Church pastors
- Community organisations
- Death cafés

These were valued for offering safe, open, and non-judgemental conversations.

Accessibility issues for Deaf BSL users

One respondent highlighted serious barriers for Deaf people, noting:

- A lack of accessible services
- Limited availability of BSL-aware professionals
- The absence of family members who can sign
- A risk that Deaf people are excluded from vital information

This underscores inequalities in access to end-of-life planning support.

People who take responsibility themselves

A minority said they prefer to:

- Research independently
- Use the internet
- Rely on their own knowledge
- Make plans in advance without professional involvement

Some already had arrangements made with help from family or funeral directors.

People who are unsure or do not know where to begin

A significant number simply did not know who to speak to:

“Not sure”

“I have no idea”

“Unsure where I would seek this information”

This highlights a gap in visibility and clarity of available support.

Experiences of death, dying, and caring

Most respondents (94%, out of a total sample of n=2395), reported they had lost someone close to them.

Among those whose loved one needed healthcare support, two-thirds (65%) said the person received the right healthcare support, while 29% felt they did not. A further 7% were unsure what care had been provided.

Experiences of social care were more mixed. Of those whose relative or friend needed social care support, just over half (55%) said the right support had been received, whereas 36% felt it had not. 10% were unsure about the care their loved one received.

Overall, the findings suggest that while many people felt their loved one received appropriate support, particularly healthcare, there remains a substantial proportion who did not feel the care met their needs, especially in relation to social care.

Please tell us about the care they received	N	%
Did they get the right healthcare support they needed?	2149	
Yes	1393	65%
No	615	29%
I'm not sure what care they received	141	7%
Did they get the right social care support they needed?	1807	
Yes	985	55%
No	642	36%
I'm not sure what care they received	180	10%

Over half of respondents had experience with specialist end-of-life services. Fifty-nine percent reported that they or someone close to them had received care from a specialist palliative care team, while 37% had not.

Fewer people reported experience of hospice care. Among respondents, 38% said they or someone close had received hospice care, while 60% had not.

Have you or someone close to you had care from:	N	%
A specialist palliative care team	2210	
Yes	1293	59%
No	821	37%
I'm not sure	96	4%
A hospice	2065	
Yes	774	38%
No	1248	60%
I'm not sure	43	2%

Just over half of respondents (56%) said they are not currently in a caring role. However, a significant proportion reported experience of unpaid care: 24% are unpaid carers at present, and a further 15% have been unpaid carers in the past. A smaller group (5%) are paid carers as part of their job.

Do you look after someone who is ill, has a long-term condition, disability, or is elderly?	N	%
No	1276	56%
Yes – I am a carer (unpaid)	538	24%
I used to be a carer (unpaid)	350	15%
I am a paid carer (it's my job)	115	5%
	2279	

Awareness of the GP Palliative Care register

Awareness of the GP palliative care register varied among respondents (n=2377). Most people (64%) had not heard of the register, and a small proportion (2%) were unsure. A third (33%) said they were aware of it.

Despite limited awareness, attitudes toward being included on the register were highly positive (n=2373). Eighty-four percent of respondents said they would be happy for themselves or a family member to be added to the register if appropriate. A further 13% were unsure, while only 4% said they would not be happy to be included.

Final thoughts and comments

People were asked if there was anything else they would like to share about their experiences, thoughts, or wishes regarding death, dying, or end-of-life care. In total 1036 people provided an additional reflection.

The additional reflections reveal an extraordinarily rich, emotional, and often painful set of experiences and beliefs about death, dying, and the care people receive in their final months, weeks, and hours. These accounts span gratitude and admiration, anger and trauma, fear and uncertainty, and strong calls for change.

Deep gratitude for compassionate, high-quality end-of-life care

Many respondents described exceptional experiences with hospice teams, hospice-at-home services, district nurses, Marie Curie nurses, specialist palliative care clinicians, and small community hospitals that were able to offer calm, private, and dignified care. People said hospice care:

- enabled dignified, peaceful deaths
- provided comfort, spiritual support, and time
- supported families as well as the dying person
- treated loved ones as people, not patients
- gave families the chance to be “family again”, not carers
- created an environment of kindness, quiet, respect, and presence

Hospices were described repeatedly as “heaven on earth”, “magical”, “a godsend”, “life-changing”, and “the gold standard”.

Many respondents believed that good hospice care profoundly shaped their grief, allowing them to feel their loved one died peacefully and with dignity.

Concern about the lack of hospice beds and chronic underfunding

Alongside the praise came deep frustration:

- Hospices are not funded adequately and rely on charitable donations.
- Many hospices have cut services, reduced beds, or face closure.
- People described being unable to access hospice beds, even when the dying person desperately wanted one.
- Capacity issues caused distress, rushed decisions, and deaths in less suitable places.

People repeatedly described this as unacceptable, a disgrace, shameful, and a failure of government and commissioning.

Hospital-based end-of-life care varies widely

Many experiences of hospital care were negative, sometimes traumatic:

- people dying behind curtains on busy multi-bed wards
- lack of privacy, noise, lights, interruptions
- being left in bays when a side room was needed
- insufficient pain management or delays in medication
- poor communication, conflicting information, and brusque conversations
- dying alone despite families being willing to be present
- lack of staff time for personal care, dignity, and emotional support

Some described experiences that continue to haunt them years later: deaths without dignity, untreated pain, distress, chaos, and an absence of compassion.

A smaller group had positive hospital experiences, usually when there were specialist palliative staff, side rooms, or unusually attentive teams.

Extraordinary pressure on families acting as carers

A major theme was the burden placed on families, who often found themselves:

- managing complex care
- administering medication
- navigating services alone
- receiving little or no guidance
- caring 24/7 without breaks
- making rapid decisions in crisis
- performing nursing tasks they felt unqualified for
- advocating on behalf of someone who was dying

Many described profound exhaustion, fear, and loneliness:

"I felt like I was drowning."

"We were left to get on with it."

"I didn't know what to do."

"Nobody checked how I was coping."

Families frequently said they were not prepared for what dying looks like and wished someone had explained the process earlier and clearly.

Inconsistent coordination, fragmented services, and systems that don't join up

Across all areas, people described:

- being passed between departments
- repeated assessments
- contradictory advice
- failing communication between GP, hospital, district nursing, palliative teams, and social care
- long delays in equipment, medication, or referrals
- incomplete handovers
- lack of a single point of contact
- bureaucracy and "red tape", especially around discharge and "fast track" funding

This fragmentation created avoidable suffering, stress, and confusion.

Some described good experiences where teams worked seamlessly, but these were outnumbered by stories of gaps, delays, and inconsistency.

Strong and widespread support for assisted dying

Several respondents expressed clear and passionate views about assisted dying. Common themes included:

- wanting control, dignity, and the ability to avoid prolonged suffering
- frustration that animals receive more compassionate deaths
- the trauma of witnessing long, painful, or distressing deaths
- fears of losing autonomy, becoming dependent, or being trapped in unbearable decline
- wanting choice in the context of dementia, neurological illness, terminal cancer, or catastrophic injury

Not everyone supported assisted dying. Some respondents expressed moral, ethical, or religious objections, but most comments on this topic strongly supported legal change.

Importance of dignity, respect, privacy, and being treated as a whole person

People emphasised:

- pain control
- peace and calm
- kindness and honesty
- being seen and heard as a person
- being listened to about wishes
- not being rushed, not being ignored
- having space for family, faith, pets, or rituals
- sensitive communication and timely conversations

Many said dignity is impossible in overcrowded wards or with inexperienced staff.

Distress caused by poor pain management

Many of the most traumatic stories involved untreated or poorly treated pain:

- delays in syringe drivers
- difficulty accessing anticipatory medication
- staff not believing family or patient reports of pain
- inconsistencies in who could administer medication
- failure to escalate when pain worsened
- people dying in visible distress

These memories had lasting psychological impact and were described as “haunting”, “barbaric”, “unforgivable”, “traumatic”, and “inhumane”.

The need for earlier, clearer, and more honest conversations

A recurrent message was that conversations happen:

- too late,
- too vaguely,
- too gently,
- or not at all.

People urged:

- earlier discussions about prognosis
- clear explanations of dying and what to expect
- honesty about limits of treatment

- guidance on practicalities like wills, PoA, care options, finances, funeral wishes
- normalising conversations throughout life
- education for professionals in how to talk about dying
- support for families to talk together

Many said that if they had only known sooner, they could have granted their loved one's wishes.

Stigma, fear, and lack of openness about death

Many respondents reflected on how death is avoided, hidden, or taboo in society. People said:

- we need more openness, honesty, and public education
- children and young adults need age-appropriate learning
- language like "passed away" confuses things
- death cafés, community events, and practical guides are helpful
- talking earlier reduces fear and improves preparedness

Some respondents said this survey alone prompted them to start planning.

Inequity and postcode lotteries in access to care

Many respondents described variations depending on:

- geography (especially rural areas)
- staffing levels
- local commissioning
- availability of hospice beds
- differences between trusts
- differences between conditions (e.g., cancer vs non-cancer)

Some said access to good end-of-life care should not depend on where you live, who you know, or how loudly you can advocate.

Important insights from healthcare workers

Many respondents were nurses, doctors, AHPs, carers, funeral directors, or hospice staff. They described:

- system pressures
- lack of training among generalists
- moral distress when they cannot provide good care
- fear among clinicians about raising end-of-life conversations
- desire for more joined-up working

- the emotional impact of poor care and the pride in good care

Their comments reinforced themes of under-resourcing, skill gaps, and inconsistent practice.

Experiences of trauma, regret, and long-lasting emotional impact

Many people shared deeply painful memories:

- chaotic deaths
- unnecessary suffering
- dying alone
- fear, confusion, and distress
- not being called in time
- lack of dignity
- feeling guilty or helpless
- PTSD-like symptoms
- lasting anger and unresolved grief

These stories show how profoundly end-of-life care shapes the way families remember their loved one.

Positive experiences that offer a model for good care

Amid the difficult accounts were many examples of excellent practice:

- responsive community teams
- compassionate hospital staff
- sensitive communication
- spiritual support
- joined-up pathways
- families feeling informed and involved
- peaceful deaths
- home deaths supported by night-sitting services
- personalised care
- respecting choices and maintaining dignity

These demonstrate what is possible when systems work well.

Overall reflections

Across all comments, the overarching messages are clear.

People want:

- comfort, dignity, peace, and pain relief
- honesty, clarity, and sensitive communication
- coordinated, compassionate care
- earlier conversations and guidance
- support for family as well as the dying person
- equitable access to hospice and specialist palliative care
- investment in services that are currently overstretched
- responsiveness at the time they need help
- and for many, the option of assisted dying

People fear:

- suffering
- dying in pain
- being alone
- being ignored or infantilised
- inadequate care
- chaotic hospital environments
- burdening their families
- lack of access to the right services
- not having their wishes respected

People grieve:

- the traumatic deaths they witnessed
- the things left unsaid
- the lack of planning
- the absence of support at crucial moments

And people hope:

- for a better, kinder, more joined-up system
- for more hospice care
- for a society that talks openly about death
- for investment that matches the importance of end-of-life care
- for choice, dignity, and compassion

Online focus group and community group findings

Talking about death and dying

People described death as inevitable but emotionally difficult. While many recognised the practical value of open conversations, such as recording wishes or planning care and funerals, others described avoidance, fear, or cultural discomfort. Responses showed a clear tension between acceptance and unease.

Death as inevitable but difficult to discuss

Across almost all cohorts, participants acknowledged that death happens to everyone, even if they found it hard to talk about.

"It's the most inevitable thing that happens to us all yet is the conversation I appear to most avoid..."

"It happens to everyone... it doesn't bother me."

"I feel uneasy, uncomfortable, uncertain and anxious."

These comments show the contrast between recognising death as universal and feeling emotionally unsettled by it.

Silence within families was common:

"Family don't talk about anything so death wouldn't be any different"

"Nobody wanted to admit out loud that it could happen."

Many described sadness or fear:

"It can be a depressing topic,"

"I feel sick because it could be any one of us,"

"It makes me feel existential, lonely, regretful, sombre."

Others were more open:

"I'm not bothered about discussing it... death doesn't scare me."

Overall, death was widely accepted as inevitable, but emotional discomfort often limited open discussion.

The practical importance of talking about death

Despite discomfort, many participants saw clear practical benefits in talking about death.

Carers and dementia-related groups emphasised the importance of recording wishes:

“Communication was deemed very important... they weren’t sure that their own [end-of-life] wishes were actually recorded.”

“... most [people] were reasonably comfortable [talking about death]... and accepted that the conversations are necessary to make planning for end-of-life care easier.”

A paramedic highlighted practical consequences:

“I have practical experience of it. DNARs (Do Not Attempt Resuscitation) and people bouncing into hospital when they shouldn’t.”

Others pointed to the impact on families:

“By avoiding it, it causes the most chaos for families left behind.”

Participants consistently linked open conversations with clearer decision-making, fewer unwanted interventions, and less stress for families.

Cultural taboo, upbringing and social norms

Cultural and family norms were often described as barriers.

“Some countries are open about death and dying but England is not typically like that.”

Upbringing played a strong role:

“Growing up in a family where people did not discuss death... it felt like a taboo subject.”

“Switching off the TV when any reference was made to serious illness/death.”

These examples show how early experiences and social expectations can reinforce silence and make later conversations more difficult.

Age, experience and personal loss

Comfort with discussing death often depended on age and experience.

Older participants and those who had experienced bereavement generally found it easier:

“Dealing with the death of loved ones made it easier to talk about.”

Younger participants often felt the issue was distant:

“Dying feels a long way off... it doesn't feel very important right now.”

Others linked their perspective to life circumstances:

“Growing up on a farm has made it quite black and white”

“There's lots of death around me. [I am] Desensitised.”

For some, death felt immediate and familiar, for others, abstract and remote.

Safe spaces and trusted people

Many participants stressed that context matters. They were more comfortable speaking about death when they felt safe and supported.

“Neutral people are easier to open up to,”

“Someone independent to talk to who can be trusted,”

“In small groups like this... outside of home.”

Homeless participants highlighted the need for caution:

“All were comfortable... however they are careful who they speak to about it.”

People with hospice experience noted that familiarity made conversations easier:

“Once you've been through it, it becomes easier to talk about.”

Overall, trust, independence and the right environment were key to enabling open discussion.

Preferences for place of care at the end-of-life

Most people described wanting a peaceful, pain-free death in familiar surroundings. For many, this meant home. If home was not possible, hospice care was the preferred alternative. Preferences were shaped by dignity, privacy, relationships, previous experiences of care, and practical realities such as available support and resources. Differences between cohorts showed how identity, health, life stage, trauma, and social circumstances influence how people imagine the end-of-life.

Home, hospice and hospital

Participants expressed clear views about place of care, shaped by comfort, familiarity and the level of support available.

Home - Across almost all groups, home was the preferred place to die. People described wanting to be:

"... clean, calm, familiar and pain free"

"... at home where I'm comfortable."

Many wanted a quiet death in their own bed:

"I want to die in my sleep at home."

This was closely linked to pets, belongings and emotional attachment:

"Home with pets... with family... nice and warm."

However, this preference depended on support. Several participants said they would only want to remain at home if their family could cope:

"I would be at home if family could take care of me without too much pressure."

Others recognised that complex medical needs might make home unrealistic:

"The only reason I'd be anywhere else is if I needed treatment and equipment that couldn't be provided at home."

Home was strongly associated with comfort and dignity, but most people understood that practical circumstances would determine whether it was possible.

Hospice - If home was not an option, hospices were consistently described positively. Participants viewed them as compassionate and well-supported environments.

"... amazing and provide everything a patient needs to stay comfortable and pain free."

Hospices were also seen as supporting families:

"[Staff] take pressure off family members in terms of care, changing bedding, making meals etc."

Some contrasted hospice care with negative hospital experiences:

"Hospice care is better... I would choose a hospice if family could not cope."

Others valued emotional and spiritual support, including access to chaplaincy described as providing "welcome support and comfort".

Parents of neurodivergent or medically complex young people prioritised gentleness and minimising trauma:

"If my care was too complex then I'd want to be in a hospice."

Hospices were widely seen as offering comfort, dignity and relief for both patients and families when home care was not manageable.

Hospital - Hospitals were generally described as the least preferred setting for end-of-life care. Concerns focused on lack of privacy, dignity and calm.

"Not hospital - had a family member who died on a ward & it was not dignified and private."

Participants raised fears of dying in a "corridor" or "on a ward with random people". A side room was viewed as slightly better than a shared bay, but overall hospitals were seen as:

"not a preferred option unless absolutely necessary".

Hospitals were associated with noise, pressure and impersonal environments rather than comfort.

Dignity, privacy and respectful care

Regardless of location, quality of care was central. Participants wanted staff who were kind, competent and culturally aware:

"It is important that people are cared for by nice people who do their job properly."

"Being cared for by people who understand my culture and heritage."

Dignity was repeatedly linked to privacy, calm surroundings and not feeling like a burden:

"Dignity in death, pain free and without stigma or shame."

Place mattered, but how people were treated mattered more.

Practicalities, resources and the burden on families

Many participants recognised that preferences may not be achievable due to health needs or resource constraints.

Some did not want to die at home because they feared burdening family members:

"Some people did not want to die at home... due to feeling they would be a burden on family/friends."

Professional support was seen as essential, including district nurses and Marie Curie staff. However, concerns about availability were common:

"there are not enough carers"

"sadly a lack of resources is limiting patient choice".

Carers described financial strain:

"... we can't get care without paying which they can't afford".

Participants understood that limited workforce capacity, funding and equipment can restrict choice, even when preferences are clear.

Being with loved ones was a consistent priority:

"Anywhere as long as I'm with loved ones".

Younger people often mentioned pets and familiar possessions. Older adults sometimes prioritised protecting family members from distress, even if that meant not dying at home.

Planning, control and decision making

Advance planning emerged frequently, including wills, inheritance and end-of-life wishes. One participant asked for guidance about wills and probate, unsure what would happen to their money. Others said:

"more conversations were needed".

Participants recognised that circumstances can change:

"You can have in your head a preferred place but things can change."

There was a strong desire for control and clarity, alongside recognition that not all factors are within individual control.

Culture, faith and community traditions

Participants described a wide range of beliefs, values and practices. While experiences differed, there was strong agreement that individual beliefs must be respected and reflected in care. For some, faith and cultural traditions provide comfort and meaning. For others, spirituality plays little or no role, but personal preference and dignity remain central. Across all feedback, people emphasised the need for services to listen carefully and respond flexibly.

Respect for individual beliefs and choices

Many participants were concerned that beliefs might be overlooked.

"I'd be upset... if people didn't honour their wishes"

"services should be flexible to whatever sees you through!"

Participants stressed that care must be based on listening, not assumptions, especially where beliefs differ within families.

"We all have different beliefs".

"It is important to listen to people's beliefs and wishes and make sure this is respected".

Respect was seen as equally important for people with strong faith and those without religious belief:

"I am not religious, wouldn't want a church service."

"I am a Christian... and would want my funeral to reflect this."

There was a clear expectation that end-of-life care should reflect individual choice, whether rooted in faith, culture or personal values.

Faith and cultural rituals as sources of comfort

For many participants, faith and cultural traditions provided reassurance and meaning at the end-of-life. Some described people returning to religious practices even if they had not been observant for many years:

"Some people... returned to religion or religious music for comfort towards end-of-life."

Examples included:

- Christian participants wanting church music or a church service:
"I want church music."
- Religious or cultural traditions around preparing the body:
"Body has to be prepared by male carers."
- Baptism close to death:
"Some people get baptised before death."

Polish traditions were described as shaping more open attitudes:

"All Saints Day and All Souls Day... can be joyful... creating more positive perceptions around death and dying."

Some participants described spiritual interpretations of death:

"Fallen leaves are a sign that lost loved ones are still in contact."

"Lost ones being little angels... guardian angels... guide dying people."

Others shared sensory experiences linked to comfort:

“Warm glows around them... believed her late husband was comforting her.”

These accounts show how faith, ritual and personal spirituality can provide connection, reassurance and meaning at the end-of-life.

Family, memory and meaning making

Participants spoke about the importance of remembrance and shared traditions. Cultural customs and symbolic acts were often central to how families cope with loss.

“Keeping good memories alive... represented in things like candles and things that belonged to their relative.”

There was also recognition of newer forms of memorialisation:

“[there is a] movement to create memorabilia out of the loved one’s clothing, such as memory bears.”

The placement of ashes was described as deeply significant:

“A person’s ashes are important... connecting lost loved ones with others gone.”

Remembrance practices, whether traditional or modern, were described as helping families maintain connection and continuity.

Participants also reflected on changing traditions. Some noted the rise of direct cremations:

“Direct cremations may impact on dealing with death as new traditions are sought and established.”

Others described a move towards more personalised funerals:

“Funerals can be more representative of personality.”
“Push a celebration of life... anything goes now.”

These reflections suggest that cultural practices around death are evolving. While traditional rituals remain important for many, others prefer approaches that reflect personality, individuality and celebration rather than formality.

What matters most in end-of-life

Across all groups, good end-of-life care was described in clear, human terms. Participants consistently prioritised comfort, dignity, honest communication and the presence of loved ones.

Physical comfort and freedom from pain

Being comfortable and free from pain was the most immediate concern. Many responses began with simple statements:

"I wouldn't want to be in pain"

"Being comfortable and not in pain was the first thing people thought about."

"... good pain management is crucial"

"... pain free... feeling safe".

Physical comfort was described as the foundation of good care. Without it, other aspects of care felt secondary.

Dignity, respect and being treated as a person

Participants repeatedly emphasised dignity and humanity. They wanted to be seen as individuals rather than tasks.

"being treated with respect and dignity"

"being treated kindly and with respect."

Dignity in practice meant being clean, having wishes listened to, and avoiding neglect, such as being left in soiled bedding. Respect was not abstract; it was expressed through everyday care.

Choice, autonomy and control

Many participants stressed the importance of agency. This included:

- "choice of where to die!"
- "choosing who should be present,"
- having DNACPR (Do Not Attempt Cardiopulmonary Resuscitation) decisions respected.

One person said:

"I would want to choose when [and] where I die. I want my family safe from any pressure from my decisions."

Another stated:

"My wishes and views [should be] taken into consideration."

Control was closely linked to identity, independence and peace of mind.

Presence of loved ones and human connection

Almost all groups highlighted the importance of not being alone.

“I wouldn’t want to be alone”
“being with family or friends”
“with family and good friends around me”.

Some participants reflected that family presence may matter as much for relatives as for the person who is dying. Human connection was seen as central to a good death.

Clear, honest and sensitive communication

Participants stressed the need for straightforward communication from professionals.

“Some medical professionals speak euphemistically about death... clear understanding is crucial”.

People wanted to know what was happening, what to expect, and what choices were available. They did not want to be shielded from important information or overwhelmed with jargon.

Emotional, spiritual and practical peace

Beyond physical care, participants spoke about wanting emotional calm and resolution. This included:

“no loose ends”
“peace”
“resolution with someone [they] had previously argued with”.

Several people also focused on the wellbeing of those left behind, including emotional support and avoiding unnecessary administrative or financial burdens.

Differences between cohorts

While there was strong agreement on core themes, some groups highlighted specific concerns shaped by identity and circumstance.

LGBTQ+ group - Identity and safety were central. Some feared having to conceal who they are:

“[it would be] unacceptable for a person to have to go back into the closet.”

Concerns included discrimination, access to gender affirming medication, and being cared for by professionals who understand LGBTQ+ culture and HIV-related needs.

Homeless group - Basic needs were prioritised. Participants emphasised “safety and warmth” and being “cared for by people who genuinely care”.

Not being listened to or being overridden by professionals was a recurring concern.

Disabled group - Practical realities were prominent. Concerns included pets being “forgotten about”, and fears of poor basic care, and heightened risk of wishes not being respected.

Veterans - Preparation and order were emphasised. This included getting affairs in order, controlling surroundings (lighting and noise), and having clear choices about place of death and who is present.

Carers - Communication and partnership were key. One participant said: “I would want to be told what was going on... what the choices were”.

Carers also described the emotional strain of navigating complex or unachievable wishes.

Young people and parents of young people - Younger participants feared loss of independence and identity, wanting to “still look and feel like me”, and often preferring a peaceful or quick death.

Parents focused on support for family after their death and minimising burdens such as funeral costs and paperwork.

Written plans and documents

Across all cohorts, discussions about end-of-life planning reveal a consistent pattern: silence, uncertainty, and discomfort sit alongside a strong desire to make things easier for loved ones. While many people avoid the topic, this avoidance is rarely due to lack of care. Instead, it reflects fear, emotional sensitivity, limited knowledge, and uncertainty about how to begin.

Common themes include:

- Reluctance to start conversations
- Emotional barriers and fear of distress
- Limited written planning
- Confusion about legal processes
- A clear need for practical and emotional support

Differences across cohorts show that age, identity, health status, and life circumstances influence how people approach or avoid these conversations.

Talking about end-of-life wishes

Conversations about end-of-life wishes are often shaped by fear, silence, and concern about upsetting others.

Many participants reported that they have never discussed their wishes. One respondent said plainly:

"I haven't talked to anyone about it... it's not a topic that naturally comes up in conversation."

Across some group conversations, around a third of participants had never had any conversations at all. People described avoiding the subject because they "fear death" or "don't feel comfortable talking about it." For some, even thinking about death caused emotional strain:

"Thinking about death makes my mental health worse."

A significant barrier is the desire to protect others from distress:

"People are scared to upset the person they are talking to."

"I don't want to upset them by forcing them to talk about my demise."

Several participants reflected that the difficulty often lies not with the person approaching end-of-life, but with family and friends who may struggle emotionally.

These responses show that silence often comes from care. People hesitate because they do not want to burden or upset those they love. Creating compassionate, supportive environments is therefore essential if honest conversations are to happen.

What makes conversations easier

Although many avoid the topic, certain life events and prompts make conversations feel more natural.

Participants described triggers such as:

- Becoming a parent
"Arranging wills and putting in place who would look after my daughter"
- Funerals
"People tend to talk about death... around funerals"
- Military deployment, where risk feels more immediate

Others noted that preferences change over time:

"What I want now most definitely isn't what I would have told you I wanted when I was 18!"

Small, non-threatening entry points can also help. Talking about favourite funeral songs or sentimental possessions was described as a way to "break into the conversation."

These findings suggest that end-of-life discussions become easier when grounded in everyday experiences, life transitions, or gentle prompts rather than formal or clinical settings.

Written plans and preparedness

Across cohorts, very few participants had written plans in place.

Typical responses included:

“Nothing written down.”

“I don’t know how I’d do it... where to write it down, where I’d leave it.”

While many had thought about their wishes, only a minority had formalised them. Those who had usually mentioned:

- Wills
- Organ donation
- Paying off debts

Processes such as Power of Attorney were widely perceived as complex and intimidating:

“Some people just won’t understand anything about it or have the means to set something in place before it’s too late.”

Overall, there is a clear gap between intention and action. People recognise the importance of planning but lack accessible guidance on how to translate thoughts into documented decisions.

What support people need

Help to start the conversation - Many participants said they simply do not know how to begin, who to talk to, or when to raise the topic.

- Suggested prompts included:
- Conversation starter cards in cafés or community spaces
- Public campaigns or television adverts
- Leaflets appearing “at the right time”

“Something that prompts relevant conversations.”

“Perhaps I might be more proactive if I saw a leaflet somewhere at the right time.”

Participants also stressed the need for professionals to address the issue directly:

“Professionals need training in how to talk about it and not skirt around the issue.”

This highlights the importance of normalising the topic and reducing emotional pressure through supported entry points.

Safe trusted spaces - Conversations are easier when they happen with someone trusted, in a comfortable environment.

Participants emphasised:

“Having the right person to talk to.”

“A safe comfortable environment... not too official like a Solicitor.”

- Preference for support from people they know and trust

At the same time, some valued trained professionals who could facilitate discussions sensitively:

“A trained professional would be more reassuring and be able to act as an intermediary.”

People wanted time, privacy, and reassurance that they would be heard without judgement. End-of-life planning was described not just as practical, but deeply relational and emotional.

Clear accessible information - Across responses, there was widespread uncertainty about what planning involves.

Participants asked for:

- Accurate, proactive information
- Advice they could access at their own pace
- Clear explanations about autonomy

Specific topics where support was requested included:

- Writing a will
- Health and financial Power of Attorney
- Decisions about Do Not Attempt Resuscitation

“People need more information about DNRs... people misconceive what this means.”

There was strong support for plain language guides and structured frameworks:

“It would be good to have a guide book – questions – how to talk to someone – numbers to ring etc.”

People want demystification and practical, step by step explanations without jargon.

Addressing practical barriers - Some participants had not written plans because:

- They did not know how
- They did not feel ready
- They found it overwhelming
- They had not prioritised it

Others faced structural barriers:

“Homeless – writing things down is not a priority.”

“Too expensive.”

This shows that planning is influenced by wider life circumstances, not just willingness.

Continuity and professional support

Many participants valued continuity, especially relationships with GPs or professionals who understand their situation over time.

“Someone with a degree of continuity... for example GP.”

“Services giving the time myself and family need in order to process information.”

There is a desire for practitioners who:

- Do not rush
- Follow up
- Support families as well as individuals

Getting help and information

Across all groups, participants emphasised that information about end-of-life care must be clear, accessible and delivered with empathy. While healthcare professionals were most often described as the primary trusted source, people also rely on family, friends, community organisations and charities. Key themes were clarity, honesty and ease of access.

Medical and professional advice as a core trusted source

Healthcare professionals were widely seen as the most reliable source of accurate information.

“I’d prefer it to come from a medical professional... they’d be best placed to give accurate/reliable information.”

Participants felt that serious diagnoses should prompt proactive conversations:

“Being diagnosed with a serious illness should prompt conversation, perhaps initiated by a GP.”

Others emphasised the need for time and clarity:

“Objective clear advice and information from a professional who has time to talk things through.”

Trust in professional expertise was strong, but participants stressed that conversations must be honest, compassionate and unhurried.

Family, friends and personal networks

Many people rely on existing relationships for guidance. Trust was often rooted in familiarity.

“would get information from a friend because they know it would be good information from a trusted source”.

Several groups said they would:

“get their information from family or friends”.

Younger participants highlighted preference for direct, personal communication:

“my mum... face to face rather than online”.

Others described feeling safer with people who:

“know me best and this would feel safer”.

Personal networks were often the first point of contact, particularly when trust in formal systems was uncertain.

Charities, community groups and signposting organisations

Voluntary and community organisations were frequently described as valuable and accessible sources of support.

Carers spoke positively about services such as “Dementia Hub” and “Carers Together,” describing them as providing:

“the most support and best information”.

Participants also recognised the role of celebrants, undertakers and Healthwatch-style organisations in helping people understand options and navigate services.

These reflections show the importance of local, community-based support alongside statutory services.

Proactive information and public awareness

Some participants suggested that public messaging can help normalise conversations about death.

“advertises on TV or radio perhaps do prompt people to think about practical aspects of death”.

Others suggested posters that might:

“catch someone’s eye to get those thought processes going”.

Schools were also mentioned as possible settings for early conversations about death and planning.

Participants recognised that proactive communication could reduce avoidance and encourage earlier preparation.

Practical planning and non-medical advice

Beyond clinical information, people wanted clear guidance on practical matters.

“I need a plan for my money and who I am going to give it to”.

Solicitors and funeral directors were commonly cited as trusted professionals:

“we have put our trust in the funeral service... they have this experience”.

“most people would go to a funeral director”.

Planning for wills, inheritance and funeral arrangements was seen as part of end-of-life preparation.

Barriers: fear, complexity and mistrust

While many participants knew where they would prefer to seek information, barriers were also identified.

Some described healthcare information as overly complex. Others, particularly people experiencing homelessness, reported deep mistrust of professionals. Digital exclusion was also raised, with some visually impaired participants and carers unable or unwilling to access information online.

These barriers highlight the need for information that is simple, transparent and available through multiple routes, not solely digital platforms.

Experiences of palliative and hospice care

Participants described a wide range of experiences. Many reported compassionate and supportive care. Others described delays, limited access, or confusion about what palliative care involves.

Compassionate and person-centred support

Across several groups, hospice and palliative services were described positively. Participants valued privacy, dignity and the attitude of staff. Positive accounts were particularly strong among LGBT respondents and carers.

“They had a room of their own, and the care was very good.”

“Excellent experience staff so caring, nothing too much.”

Hospice environments were associated with calm, attentiveness and personalised support.

Barriers to access and delays in care

Some participants, especially carers, described difficulty securing hospice places or delays in funding approval. In some cases, this significantly affected the end-of-life experience.

“It was what we wanted but there was a delay in getting funding in place and was too late.”

“They didn’t have room at the hospice when we needed it... We had to pay to go into a care home.”

Limited availability and financial barriers were seen as restricting choice at a critical time.

Uncertainty and misunderstanding about palliative care

Several participants, including LGBT and disabled respondents, expressed confusion about palliative care: what it means, when it begins, and how to access it.

“Nobody explained what palliative care meant to those who needed to know.”

“I am not sure how I would know this... it is all a bit of a blur.”

This suggests a lack of clear communication and proactive explanation at key points in the care pathway.

Emotional strain on carers and families

Carers described high levels of emotional and physical strain. Some spoke about exhaustion and lasting guilt linked to gaps in support.

“It was stressful for the husband as he had to care for her 24/7.”

“This made me feel guilty forever.”

These accounts highlight the impact of service gaps not only on patients but on families.

High value of services alongside funding and awareness concerns

Participants recognised the quality and importance of hospice care but raised concerns about underfunding and limited public understanding.

“Hospice care not sufficiently understood by the wider public and currently underfunded.”

“Want people to know this service is not one thing to worry yourself.”

There was a clear view that hospice care is valuable and reassuring, but not always well explained or consistently available.

Experiences of death, dying, and caring

Most participants had experienced the death of someone close. Their accounts covered hospital care, care homes, hospices and sudden deaths where planning was not possible. Some described compassionate and skilled support. Others reported delays, inconsistent care, communication problems and system pressures that increased distress.

Quality of healthcare and end-of-life support

Many participants described high quality care, particularly when staff were attentive and pain was well managed.

“Yes I lost my husband. He received the best care, with pain relief and his wishes were listened to.”

Others described distressing experiences, including prolonged interventions and loss of dignity:

“He laid in bed and was tube fed for a long time and that was his life. He eventually refused food because that was the only thing he had control over.”

These accounts show how quality of care shapes not only comfort but also a person’s sense of control.

Hospital care: communication, staffing and environment

Experiences of hospital care varied significantly. Some described compassionate support. Others described isolation and lack of presence:

“I felt that they were left in a hospital bed with nursing staff simply observing from a distance – no one went to check on them or sit with them.”

Staffing levels, particularly at weekends, were a recurring concern:

“They received good care in hospital except at weekends when there was not enough staff. Students helped a lot during the week, but they had the weekends off and this really made a difference to the care.”

Communication problems added to distress. A disabled participant described being excluded from discussions about a relative’s care. Young carers spoke about not being told promptly about a death, which damaged trust.

Care homes: responsiveness and safety

Care home experiences ranged from compassionate to concerning. Some families felt deterioration was not recognised or basic care was missed.

One example involved an avoidable hospital admission:

“Hospital staff immediately spotted that their catheter was blocked. This should have been noticed by the care home staff before they were taken to hospital.”

Another participant described feeling unable to leave because of concerns about care quality:

“Care very poor for mother in a nursing home, had to go in every day all day as did not feel she was receiving the right care and felt guilty for leaving her”

Trust in care provision was a key factor in how families experienced the final phase of life.

Social care systems and practical barriers

Delays in funding, equipment and assessments were significant sources of frustration. In some cases, delays prevented people from dying where they wished.

“Had to wait for funding so he could come home and die at home. Too late, need health funding to be quicker.”

Interactions with social services were sometimes confusing or distressing:

“We received a call from social services telling us that our relative (despite having enough of their own funds) couldn’t be expected to pay for their own care and that us, the family, had to pay instead. This caused a lot of anxiety at the time.”

Carers described the emotional and practical burden of navigating multiple systems during an already difficult time.

Emotional impact and family dynamics

The emotional experience of loss was shaped not only by the death itself but by the quality of care and communication.

One participant reflected:

“Some have suffered and experienced painful horrible deaths, others have been well cared for and their death has not been as awful, I do not think any death can be called good, but some deaths can be more awful than others which makes it harder to grieve and recover.”

Young carers described the impact of delayed honesty:

“L said that when their granda died, people did not tell him straight away in case they were upset and this made him 'more upset because I did not know if I could trust them'.”

Communication and trust were closely linked to how families processed grief.

What worked well

Participants consistently praised kindness, clarity and specialist hospice support.

“Great care at Marie Curie. They received the care and social care they needed. Everything worked well”

Another participant highlighted both compassion and clear explanation:

“Care team was wonderful. Healthcare was explained. Felt cheated at first, wanted more time with them, hard to say goodbye.”

When care was coordinated, compassionate and clearly communicated, families described it positively even in very difficult circumstances.

What could be improved

Participants identified several areas for improvement: faster funding decisions, less bureaucracy, better communication, consistent staffing and improved training.

Concerns included visiting restrictions, ward moves and variable quality of carers.

One participant summarised this more broadly:

“There needs to be a serious shake up of the system. The care industry needs to be given status. Care workers should be properly vetted, trained and remunerated. The business needs to be professionalised.”

These reflections point to system-level pressures that directly affect individual experiences at the end-of-life.

Awareness of the palliative care register

Across all cohorts, awareness of the GP palliative care register was low. Most participants had not heard of it before. Young carers were particularly unfamiliar:

“All young carers did not know what a hospice was... They weren’t sure about this and said they would need more information.”

A smaller number were aware of the register and generally viewed it positively:

“Yes, it is necessary medically and logistically.”

“Yes I was aware, and think it is helpful.”

“Yes, I was aware, and it can be useful, but like any resource needs to be used and kept right.”

Overall, initial reactions were cautious but open, particularly when the purpose was explained.

Perceived benefits

Most participants felt the register could be helpful if used proactively. Planning and preparation were recurring themes:

“They’ll be able to make suitable preparations and plan ahead.”

“I can see how this would help to prepare and plan for individual needs.”

“It could have the benefit of them being able to line up services ready for when needed e.g. a wheelchair could have been lined up.”

Continuity and coordination were also valued:

“Would be great as a named person overseeing process. Avoids re-telling history.”

Carers focused on practical benefits for delivering appropriate care, although many had not previously heard of the register:

“I do agree with it. I can see how it will help services provide better and more appropriate care.”

For many, inclusion felt acceptable if it improved support:

“I would be fine with this.”

“It would give a connection to the GP.”

“Hadn’t heard of this but it would be ok for people to be put on this list for help and support.”

The register was generally seen as positive when linked to better coordination and clearer responsibility.

Concerns and conditions

Support was often conditional on how the register is used. Participants stressed that it must not become a passive or administrative exercise.

“Just having people on list doesn’t mean services will use it proactively.”

Flexibility was a concern, particularly for people with disabilities or fluctuating conditions:

“Circumstances may change quickly – would any plans made be flexible enough to meet changing circumstances?”

Confidentiality and data protection were also raised, especially by those with experience of stigma or discrimination:

“No concerns as it would be confidential.”

“Many people... expressed concerns about data protection and the handling of their information.”

Trust in primary care influenced willingness to be included. Some participants experiencing homelessness highlighted both mistrust and lack of GP registration:

“I would be fine with this. However, would not trust my GP... unsure how they would manage a register well.”

“It’s not something they would do, not everyone had GP’s.”

Others simply needed clearer explanation:

“I will need to understand what it is. If it is simply putting one’s name on the register, why?”

“They weren’t sure about this and said they would need more information.”

Overall, participants were broadly supportive of the principle but emphasised the need for clear explanation, proactive use, flexibility and strong data governance.

Final thoughts and comments

Participants shared wide-ranging reflections on end-of-life care. These included personal fears, practical challenges, views on autonomy, and concerns about the wider system. Carers, LGBT respondents, disabled people, young carers and people experiencing homelessness highlighted distinct priorities shaped by lived experience and vulnerability.

Emotional realities of thinking about death

Many participants described the difficulty of discussing death, even while acknowledging it is inevitable. This was especially evident among carers, LGBT respondents and people with long-term conditions.

“Death is hard for me to talk about, but doing this has made me realise I do need to think ahead.”

“I think most people don’t want to think about death or dying, but it is the one thing in life we all share.”

Young carers described sadness and emotional strain linked to their parents’ health, showing how end-of-life concerns affect families long before death occurs.

Desire for choice, control and autonomy

A strong theme, particularly among LGBT respondents and carers, was the desire for greater personal control. This included decisions about treatment, place of death and, for some, assisted dying within a legal framework.

“Pro choice people should have the opportunity to choose when and where they die with a long term illness.”

“I think that people should have a bit more say in prolonging life unnecessarily... a quicker more dignified death should be a choice.”

Autonomy was also linked to advance care planning, including Lasting Power of Attorney and documenting wishes.

Fears about being let down by the system

Concerns about service reliability and compassion were common. LGBT participants, carers and disabled respondents in particular described fears about neglect, discrimination or overstretched services.

“I worry I will die neglected by an underfunded, understaffed and over worked service.”

“As a trans person I worry the person in charge of my care might not respect my identity.”

Disabled participants expressed concerns about isolation. Some LGBT respondents raised fears about dementia and identity not being recognised.

Impact of caring and the need for better support

Carers frequently described exhaustion and lack of recognition. Many felt that systems rely heavily on unpaid care without sufficient support.

“Carers are invisible... unpaid carers are getting to the end of their tether.”

“I’m a carer... we need better information, help and available support for this to happen without taking its toll on us.”

Women’s groups and older carers particularly highlighted the long-term physical and emotional toll of caring.

Inequalities and vulnerability at end-of-life

People experiencing homelessness described risks focused on safety and basic needs rather than formal care planning.

“His only focus would be that he is warm, safe and cared for when the time comes.”

“Following surgery he was discharged... he slept in the doorway because the CCTV would see him if anything happened.”

Young carers also described feeling unseen and unsupported, highlighting generational inequalities in how end-of-life impacts families.

Practical and structural barriers

Participants across cohorts raised concerns about underfunding, staffing shortages and slow funding processes.

“There’s not enough resources put into hospices and there is a lack of understanding of what they can offer.”

“I felt with Dad it all became about the money and funding and that the health authority let us down.”

Some suggested a need for more sheltered housing options to support independence in later life.

Importance of communication and coordination

Communication between services and with families was described as critical, particularly during hospital discharge and care transitions.

“Around end-of-life care everyday matters so it is important services are available quickly and communication between departments is quick.”

“We don’t get told enough about our parents’ conditions... no one really even knows about us.”

Good communication was linked directly to dignity and trust.

Planning and preparedness

Several participants reflected on the value of planning ahead. Some said the discussions had prompted them to take action.

“Get a Lasting Power of Attorney! Write down your plans.”

“I know that I want my cremated ashes scattered at sea... perhaps I will now tell my family.”

Planning was particularly emphasised by disabled participants and those with prior caring experience.

Northern Cancer Voices feedback

Between November 2025 and February 2026, Northern Cancer Voices worked across the region to understand what really matters to people at the end-of-life. This work focused deliberately on communities who are seldom heard or who face barriers engaging with statutory services. Conversations were held in trusted local settings, using gentle, trauma-informed facilitation to create space for people to speak openly about their fears, experiences, and priorities.

This narrative brings together what Northern Cancer Voices did, who they spoke to, and the key messages that emerged across rural communities, farming communities, ethnically diverse communities in Sunderland and Middlesbrough, people experiencing homelessness in Newcastle, and a lived-experience case from a low-income community in Blyth.

What Northern Cancer Voices did

Northern Cancer Voices delivered a programme of engagement designed around what people said they needed, not what services traditionally expect. They:

- Ran multiple in-depth community conversations across Northumberland, Sunderland, Middlesbrough, Blyth and Newcastle.
- Held a focused discussion with farmers at Hexham Auction Mart to understand the distinct pressures of agricultural life.
- Conducted a detailed lived-experience review with a family from a low IMD community to understand breakdowns in the palliative pathway.
- Adapted their approach after early learning, moving away from written questions and towards culturally sensitive, conversational engagement.
- Supported 25 people individually to complete the survey through one-to-one conversations, which is important for people with literacy needs, low confidence, emotional vulnerability, or complex social circumstances.
- Used targeted social media outreach to widen awareness, recognising that formal routes alone would not reach everyone.

Who they spoke to

A total of 24 people participated in group conversations, which included:

- **Rural Northumberland (8 people)** - Mostly older residents from Wooler, Berwick and nearby villages, with strong community traditions.
- **Farming community (3 people)** (Hexham Auction Mart) – Three working farmers aged 50–65, facing financial, legal and generational pressures linked to inheritance and succession.
- **Ethnically diverse women in Sunderland (9 people)** - A mix of Bangladeshi, Asian British, Afghan Muslim and Nigerian Christian women, many migrants with rich cultural and faith-based expectations around illness and death.
- **Migrant and no recourse to public funds community (1 participant)** (Middlesbrough, Connect360) – Community insight into migrant groups where faith, destiny, mistrust and limited knowledge of hospice care shape attitudes.
- **Women experiencing homelessness in Newcastle City Centre (2 people)** - Both without a GP, phone, or stable environment, focused on day-to-day survival.
- **Low IMD lived-experience case (Blyth) (1 person)** A daughter recounting her father’s final 18–24 months of care, highlighting system fragmentation, delayed escalation and unclear ownership of care.

These communities each brought different lived realities but also shared fundamental hopes and fears.

Key themes across communities

Talking about death is universally difficult, for different reasons

Across all groups, people described discomfort, fear, or cultural resistance to discussing death.

- Rural residents said they only confronted death after cancer made them unable to avoid it.
- Muslim and ethnically diverse women said conversations about death are considered inappropriate or spiritually risky: “inviting it in.”
- Migrant communities described strong beliefs in divine protection, destiny and miracles, which made anticipatory planning difficult.
- Farming participants said financial pressures left them emotionally unable to think about dying well.
- Women experiencing homelessness felt unable to think about the future at all. Survival took all their energy.
- In the Low IMD case, conversations about entering the palliative phase were described as unclear and late, leaving the family unprepared.

For every community, conversations had to be introduced with exceptional care.

A deep fear that an assessment means 'giving up'

Many worried that an end-of-life assessment could signal:

- the NHS withdrawing care
- that they were “being written off”
- or that death was expected soon

Feedback reinforced the need to frame the HNA around living well now, not predicting death.

- Older rural participants raised fears that “once you hit 60 the NHS aren’t interested anymore.”
- Ethnically diverse groups feared medication could hasten death (“injections of death”).
- Migrant communities worried that accepting palliative care might mean giving up on God’s plan.
- Families in the Low IMD case felt treatment changes were not clearly explained, reinforcing anxiety about what was happening.

Barriers to accessing care profoundly shape people’s priorities

Barriers varied but were consistently significant.

- **Rural residents:** Distance from hospices, reliance on Hospice at Home, fear of dying in hospital where they felt unsafe or out of control.
- **Farming community:** Anxiety about inheritance tax, farm succession, financial burden on children; limited time and emotional bandwidth to plan.
- **Ethnically diverse women:** Language difficulties, mistrust of hospital settings, modesty requirements, lack of understanding of religious rituals, and fears around pain relief
- **People experiencing homelessness:** No continuity of care, no phone, no GP, no ability to make appointments or to think beyond immediate needs.
- **Migrant communities:** Limited understanding of hospice care, reliance on pastors or faith leaders, mistrust of statutory systems.
- **Low IMD case:** Unreturned calls, lack of named coordinator, delayed infection response, delays in anticipatory medication, unclear responsibility between services.

For some groups, particularly homelessness and low-income communities, fragmented or inaccessible services created fear and mistrust that shaped their willingness to engage at all.

These barriers directly affected whether people felt able to plan, ask questions, or express preferences.

Financial anxiety and generational responsibility

A distinct theme emerged within farming communities:

- Fear of inheritance tax changes
- Fear of losing family land
- Fear of burdening children

Participants described being “scared to die” because of what it might mean financially for their families.

This connects to a wider cross-community theme: end-of-life conversations cannot be separated from economic reality.

Family, faith, community and culture drive decision-making

Across groups, people drew on personal networks and cultural identity to guide end-of-life preferences.

- Muslim and Bangladeshi women described detailed washing rituals (Ghusl), modesty requirements and the need for Imam involvement.
- Christian migrant communities emphasised prayer, pastoral presence and belief in miracles.
- Rural participants described community events, traditions, and a wish for “living wakes.”
- Homeless women focused on warmth and being pain-free, with their cultural reference point being the struggle to survive each day.
- Farming participants prioritised land continuity and family protection.
- In the Low IMD case, family members carried the burden of coordination, crisis management and practical home adaptation.
- The HNA will need enough flexibility to honour these very different contexts.

Service coordination and accountability matter deeply

A distinct theme emerged from the Low IMD lived-experience case:

- No named care coordinator
- No clear 24/7 contact point
- No consistent follow-up after deterioration
- Delays in infection management and symptom control

This echoed concerns from other groups that the HNA must not become a tick-box exercise. People want reassurance that:

- Someone is responsible
- Calls will be returned
- Actions will follow assessment

Without visible follow-through, trust deteriorates quickly.

Universal human priorities emerged across all groups

Despite different experiences and identities, every group highlighted the same fundamental needs:

- Being pain-free
- Feeling safe
- Being treated with dignity and respect
- Warmth and comfort
- Being with family (where applicable)

For people experiencing homelessness, this meant simply being warm and pain-free. For faith communities, it meant dignity and ritual. For rural and farming communities, it meant safety and calm at home. For the Low IMD family, it meant coordinated, compassionate care without crisis.

These universal themes cross all cultural, social and geographical boundaries.

What this means for end-of-life care

Northern Cancer Voices' engagement shows that end-of-life needs are shaped not only by illness, but by:

- Culture
- Faith
- Trauma
- Geography
- Poverty
- Financial insecurity
- System responsiveness

A one-size-fits-all approach will not work. Support must therefore be:

- Trauma-informed, recognising that many people are not emotionally ready to talk about death
- Culturally safe, with space for rituals, modesty needs, and family roles
- Flexible, allowing unstructured, conversational approaches where needed
- Practical, acknowledging barriers such as distance, homelessness, inheritance concerns and language
- Action-oriented, with clear follow-up so it never becomes a tick-box exercise

Above all, the voices gathered through this programme emphasise that people want the end-of-life to reflect dignity, safety, compassion, and respect; values that must sit at the heart of the HNA.

Desktop review

This review brings together feedback from three key sources:

- The SR1 Report¹, which examines failures in the benefits system for people approaching end-of-life.
- End-of-Life Care Research² (Northumberland CCG & Healthwatch Northumberland), exploring public attitudes and options for co-designing an End-of-Life care agreement.
- Understanding End-of-Life Care within BAME Communities³, focusing on cultural, religious, and socioeconomic factors affecting Muslim Bangladeshi and Pakistani communities in Sunderland.

Collectively, these reports highlight how structural, social, cultural, and institutional factors shape end-of-life outcomes across the North East and North Cumbria (NENC). A consistent pattern emerges; despite policy ambitions, people's experiences of end-of-life care remain highly variable and often inequitable.

Overview of reports

Financial security and system performance at end-of-life (SR1 Report)

The SR1 Report highlights significant and deeply concerning failures in the Special Rules (SR1) process, which is intended to fast-track financial support for people with a prognosis of less than 12 months. Rather than providing timely and compassionate assistance, the evidence shows a system that frequently falls short of its purpose.

¹ Citizens Advice Gateshead and Society Matters CIC (2025) SR1 Report. June 2025. Available at: <https://citizensadvicegateshead.org.uk/wp-content/uploads/2025/07/New-Investigating-Special-Rules-for-claimants-with-terminal-illness.pdf> (Accessed: 18 February 2026).

² Northumberland CCG and Healthwatch Northumberland (2021) End of life care research: Research report. July 2021. Produced by Explain Market Research. Internal report.

³ Ali, S.K. (2024) Understanding End-of-Life Care within BAME Communities. Sunderland Bangladesh International Centre (SBIC), in collaboration with Macmillan Cancer Support and South Tyneside & Sunderland NHS Foundation Trust. Internal report.

Drawing on 294 evidence forms submitted through the Citizens Advice network, the report presents a stark picture of systemic dysfunction within the Department for Work and Pensions (DWP). The findings reveal a widening gap between policy intent: fast, simple access to support, and the lived experience of people nearing the end of their lives.

Delays, lost forms, and incorrect routing

Delays of 12–13 weeks are common, undermining the core purpose of the fast-track pathway. SR1 forms are frequently lost, not processed, or not correctly linked to benefit claims. In many cases, claims are incorrectly routed through the standard process instead of the Special Rules route.

These failures affect multiple benefits, including Attendance Allowance, Personal Independence Payment (PIP), Universal Credit, and Employment and Support Allowance (ESA), as well as linked entitlements such as Carer's Allowance and Pension Credit. The consequences can be severe: in some cases, individuals died before any financial support was put in place.

Administrative burden and poor coordination

Instead of a streamlined process, people who are terminally ill and their families often face unnecessary administrative hurdles. Individuals are asked to complete lengthy forms, provide repeated medical evidence, or attend assessments that should not be required under SR1 rules.

Poor coordination between DWP teams, for example between PIP and Universal Credit, leads to duplication, repeated requests for information, and additional delay. Families frequently have to resubmit forms or restate information multiple times, creating avoidable stress and confusion.

Communication failures and emotional impact

Communication problems further intensify these difficulties. Many people report being unable to access clear, consistent advice, with helplines difficult to reach or providing conflicting information. Families are often left uncertain about what is happening with a claim or how long decisions will take.

For people who are seriously unwell and for carers already carrying significant responsibilities, this uncertainty can be profoundly distressing. The impact is not simply administrative; it adds emotional strain at an already devastating time.

A gap between policy and compassionate delivery

Financial security is widely recognised as a core determinant of quality end-of-life care. However, the current operation of the SR1 system reveals a significant gap between policy design and real-world delivery.

Rather than offering simple processes, joined-up communication, and swift decisions, the system too often presents complexity, inconsistency, and delay. Where it fails, the consequences extend beyond paperwork. They affect dignity, stability, and peace of mind at the end-of-life, undermining the compassionate intent on which the Special Rules were founded.

Public attitudes, choice, and the conditions for a good death (Northumberland research)

The Northumberland end-of-life research provides detailed insight into public attitudes towards death, dying, and what constitutes a good death, highlighting both enduring priorities and evolving perspectives since 2010. Commissioned by Northumberland CCG and Healthwatch Northumberland, the study combined an online survey of 282 residents with a five-week citizens' panel to inform the development of a local End-of-Life Agreement.

A central finding is that discomfort discussing death remains common. Over half of respondents (56%) said they felt fairly or very uncomfortable talking about death, with younger people particularly uneasy. However, this discomfort sits alongside a notable cultural shift: conversations are happening more often than in the past. In 2021, only 10% reported never having discussed their end-of-life wishes, compared with 55% in 2010. This suggests that while death remains a sensitive topic, openness is gradually increasing.

The COVID-19 pandemic also influenced perspectives. Around one third of respondents felt their views about death and dying had changed as a result, particularly those working in health and social care. For some, this prompted practical steps such as making a will or discussing wishes with family.

Preferences and the conditions for a good death

When asked what matters most at the end-of-life, respondents consistently prioritised effective pain relief, dignity, being with family and friends, and having the option to die at home. These priorities closely reflect findings from wider literature and reinforce long-standing principles of quality end-of-life care.

Just under half (46%) identified home as their preferred place of death, followed by hospice (21%) and hospital (16%). Younger respondents were significantly more likely to prefer hospital care. While preferences vary, the emphasis on comfort, respect, and personal choice remains consistent.

Participants largely endorsed core principles of a good death: respect, time to plan, appropriate care, and practical support. Some felt these principles should more explicitly include family support, spiritual needs, and access to necessary equipment or resources.

Communication, coordination, and shared responsibility

Communication emerged as a defining theme throughout the research. Respondents repeatedly stressed the importance of skilled, honest, and compassionate conversations about prognosis, treatment options, and preferred place of death. There was a strong view that staff require better training and confidence to talk sensitively about dying.

Barriers to open discussion were also acknowledged, including fear, stigma, and the perception that talking about death is inherently distressing. Many participants suggested that public education, media campaigns, community workshops, and normalising conversations earlier in life would help reduce these barriers.

A distinctive contribution of the research is the development of an End-of-Life Agreement: a shared understanding of expectations between individuals and care providers. Participants expressed strong support for the proposed local strategy and its six ambitions, including individualised care, fair access, comfort, coordination, prepared staff, and prepared communities, although some called for clearer definitions in relation to workforce and community readiness.

Within this agreement, individuals were seen as responsible for communicating their wishes, planning ahead, and considering the emotional needs of their families. Care providers, in turn, were expected to deliver respectful and compassionate care, minimise pain, coordinate effectively across services, maintain dignity, and ensure clear communication. There was also a strong view that the agreement should be widely accessible across health settings, digital platforms, and personal records.

Cultural, religious, and linguistic influences on end-of-life care (SBIC/Macmillian report)

The Sunderland BAME (SBIC/Macmillan) report provides an in-depth exploration of how cultural identity, religious belief, language, and socioeconomic circumstances shape experiences of palliative and end-of-life care among Muslim Bangladeshi and Pakistani communities.

Drawing on 47 focus-group participants, a survey of 120 community members, and engagement with Islamic scholars, NHS Lead chaplains, and stakeholders, it presents a detailed equity-focused analysis of the structural and cultural barriers affecting access and experience.

Deep-rooted taboos and fear of discussing death

A central finding is that conversations about death remain highly taboo within many families. Participants, particularly women and those aged 50+, often expressed fear or discomfort in discussing end-of-life care.

- 61% of female participants described feeling fearful or sceptical about end-of-life discussions.
- Many believed that raising the topic of death could be seen as challenging fate or faith, reflecting Islamic teachings that life and death are in God's hands.

This reluctance limits early planning, informed decision-making, and engagement with supportive services. Without culturally sensitive approaches, conversations may be delayed until crisis point.

Misconceptions about medication and pain relief

The report highlights widespread misunderstandings about palliative medications, particularly morphine.

- Many women aged 50+ associated morphine with hastening death.
- Some described it as a “killing drug” or equated it with euthanasia, which is religiously forbidden.

These fears sometimes led to resistance to pain management or reluctance to discuss medication options. Islamic scholars consulted in the study clarified that Islam does not prohibit medication that alleviates suffering. However, this reassurance is not consistently communicated in clinical settings, underscoring the need for trusted, culturally aligned education delivered through respected community and faith leaders.

Family responsibility, modesty, and community presence

Family care is regarded as both a religious obligation and a moral duty. Caring for a dying relative at home is widely viewed as an expression of love, honour, and faith.

Many participants expressed a strong preference for home-based care and felt that using hospice or external services could be interpreted as failing in familial responsibility. Visiting the sick is also considered a religious duty in Islam, meaning that visitor restrictions in hospitals or hospices can feel spiritually distressing.

Modesty and gender-appropriate care are also critical considerations. Women reported they would only feel comfortable discussing pain or personal care needs with female staff or trusted female relatives. Concerns about maintaining modesty and receiving gender-sensitive care can reduce engagement with services perceived as culturally unsafe.

Religious and spiritual requirements at end-of-life

The research makes clear that religious practices are integral, not optional, to dignity and comfort at the end-of-life. Participants identified specific needs, including:

- access to prayer spaces
- positioning the bed towards the Qibla (Mecca)
- facilities for ablution before prayer
- access to an Imam or spiritual leader
- respect for rituals at the time of death
- rapid certification to enable burial within 24 hours

Participants expressed concern that healthcare providers do not always understand or accommodate these requirements. Religious leaders stressed that spiritual safety is essential to culturally competent care.

Language barriers, mistrust, and miscommunication

Low English proficiency, particularly among older community members, significantly affects understanding and decision-making.

Many participants reported that they:

- relied on family members to interpret
- struggled to understand written materials
- would prefer spoken, visual, or video-based information

Reliance on family interpreters, often women, can create pressure and compromise clarity or confidentiality. Rushed consultations and limited interpreter availability further compound these challenges.

Some participants also described mistrust of healthcare providers, fearing:

- they may not be told the full truth about their condition
- decisions might not fully reflect their beliefs
- medications could be misrepresented

This mistrust is rooted in past experiences of racial or religious insensitivity, as well as structural barriers to clear communication. The report emphasises that trust-building requires sustained engagement with community leaders rather than one-off interventions.

Limited awareness of services

Awareness of palliative and hospice services was often low, particularly among women.

Many participants reported limited understanding of:

- what palliative care is
- how referral pathways work
- what support is available for families

Without culturally tailored, accessible information, families may delay seeking help until late in the illness trajectory, reducing opportunities for coordinated and supportive care.

Socioeconomic and structural barriers

The report situates these cultural factors within broader structural inequalities, including:

- higher poverty rates
- lower literacy levels
- unstable or overcrowded housing
- limited access to specialist equipment
- restricted access to transport

Although many families prefer home-based care, economic precarity can make this difficult to sustain. Poverty and housing constraints can limit space for equipment or visiting professionals, while transport challenges can restrict access to appointments. These structural inequities magnify existing cultural and linguistic barriers.

Towards culturally responsive and community-aligned care

The report concludes that equitable end-of-life care requires proactive, culturally resonant service design rather than expecting families to adapt to systems that do not reflect their identity.

Key recommendations include:

- structured cultural competency training for health and care professionals
- improved access to trained interpreters and translated materials
- gender-sensitive communication options
- stronger partnerships with mosques and religious leaders
- better coordination between hospitals, hospices, community services, and faith groups
- timely planning conversations delivered in culturally respectful ways

Cross-cutting themes identified through reports

These reports show how end-of-life experiences in the North East and North Cumbria (NENC) are shaped far more by structural, social, and cultural barriers than by clinical need. Despite progressive policy ambitions, care remains highly variable and heavily influenced by people's socioeconomic circumstances, cultural identities, and ability to navigate complex systems. Several cross-cutting themes emerge across the three evidence sources.

System complexity and structural inequity

Across all reports, system design and administrative processes emerge as powerful determinants of end-of-life outcomes. The SR1 Report provides the clearest example: delays, lost forms, and misrouted applications create avoidable suffering and financial instability at a critical stage of life. These failures undermine the principle of compassionate, timely support and expose structural vulnerabilities within the benefits system.

This theme resonates strongly with the SBIC/Macmillan findings. Here, bureaucratic systems intersect with language barriers, limited health literacy, and mistrust, resulting in late engagement with services and reduced access to pain management, planning conversations, or hospice care. Even the Northumberland study, while focused on attitudes rather than access, highlights persistent public confusion about services, the need for coordinated care, and frustration when communication between providers breaks down.

Across the region, complexity itself becomes a barrier, disproportionately affecting those already facing socioeconomic disadvantage or cultural marginalisation. The evidence suggests that unless administrative systems become simpler, more navigable, and culturally safe, inequities will persist.

Communication quality as a universal predictor of care experience

Communication emerges as one of the strongest shared themes across all three sources.

- Northumberland participants stressed the importance of honest, skilled, and compassionate conversations, identifying communication as essential to dignity, choice, and planning.
- SBIC/Macmillan participants described deep mistrust linked to rushed interactions, lack of interpreters, fear of not being told the full truth, and culturally unsafe communication about prognosis and medication.
- SR1 respondents experienced inconsistent advice, inaccessible helplines, and contradictory information, resulting in confusion, delays, and emotional strain.

Collectively, this highlights that communication is not merely an interactional skill but an equity issue. Poor communication disproportionately harms those with lower literacy, limited English, or

heightened vulnerability when facing administrative systems. Conversely, effective communication: clear, compassionate, culturally aligned, has the potential to reduce anxiety, build trust, and support personal choice at the end-of-life.

Cultural identity, beliefs, and social norms shape engagement and preferences

All three reports emphasise that cultural norms influence comfort with discussing death, willingness to engage with services, and perceptions of what constitutes a good death.

In Northumberland, more than half of participants still felt uncomfortable discussing death, despite increasing openness since 2010.

Among Muslim Bangladeshi and Pakistani communities, taboos around discussing death were even stronger, particularly among older women, with concerns that such discussions conflict with religious teachings or could challenge fate.

Misconceptions about morphine, concerns about modesty, and strong expectations around family caregiving further shape care preferences and influence when and how services are accessed.

These findings illustrate that end-of-life care cannot be culturally neutral. Services that do not recognise religious practices, gender norms, or spiritual needs risk being perceived as unsafe, leading to late or low engagement. For many families, the good death is as much about spiritual comfort, community presence, and maintaining religious obligations as it is about clinical care.

The importance of choice, control, and dignity. And the barriers that limit them

All three reports highlight the importance of choice, whether regarding preferred place of death, financial independence, communication style, or spiritual practices.

However, the ability to exercise choice is unevenly distributed. Structural failings (SR1), cultural taboos (SBIC/Macmillan), and discomfort discussing preferences (Northumberland) all reduce the likelihood that individuals will articulate or achieve their wishes.

Common barriers include:

- late planning conversations (due to taboo, fear, or mistrust)
- administrative systems that delay access to financial security
- limited awareness of services and referral pathways
- cultural or linguistic barriers that impede shared decision-making
- socioeconomic constraints that limit home-based care options

The result is a persistent mismatch between policy commitments to personalised, choice-led care and the lived experiences of many people across NENC.

The emotional and practical burden on families

Each evidence source highlights the heavy burden placed on families, though the drivers differ.

- In the SR1 findings, families shoulder administrative burdens, repeatedly submitting forms and chasing lost documentation.
- In the Northumberland research, families are expected within the end-of-life agreement to play an active role in planning and communication, but may lack the skills, confidence, or support to do so.
- In the SBIC/Macmillan study, families often feel a deep religious obligation to provide care themselves, but are limited by poverty, crowded housing, or lack of equipment, amplifying stress and reducing access to professional support.

Across all communities, care at the end-of-life is experienced as a shared family responsibility, but one that is intensified when systems fail or are culturally misaligned.

The need for shared understanding, trust, and co-designed care pathways

Across all sources, a consistent conclusion emerges: improving end-of-life care is not merely a clinical challenge but a relational, structural, and cultural one.

- The Northumberland study proposes a shared End-of-Life Agreement as a model for collaborative expectation-setting.
- The SBIC/Macmillan report emphasises community-based, culturally grounded engagement through mosques, Imams, women's groups, and trusted leaders.
- The SR1 findings highlight the need for integrated systems, competent administration, and compassionate delivery aligned with policy intent.

This points toward a broader regional requirement for co-designed pathways that include communities, families, frontline staff, and system leaders, ensuring that services reflect real-world needs, cultural values, and lived experiences.

Conclusion

Collectively, these findings reveal that end-of-life inequities in NENC are shaped by avoidable structural failings, cultural misalignment, and inconsistent communication within and across systems. While clinical priorities at the end-of-life: pain relief, dignity, comfort, are widely shared across communities, the ability to realise them varies significantly.

Creating equitable, culturally safe, and person-centred end-of-life care requires:

- simpler and more compassionate administrative systems
- culturally competent communication
- early, trusted conversations
- community-aligned models of care
- recognition of the interplay between poverty, identity, and access

Additional responses

In addition to the survey responses and qualitative conversations, We received the following additional submissions:

- Learning disability focus group notes (from Nov 21)
- A lived experience letter
- Video and podcast contributions from people with learning disabilities
- Margarets story: Learning Disability Network
- Marie Curie insights

Overview of individual responses

Learning Disability Focus Group (Nov 2021)

The focus group, facilitated by a learning disability charity on behalf of Healthwatch, brought together six people with learning disabilities to explore their thoughts about end-of-life care through a creative, story-based exercise. Using a neutral puppet character (Sam) allowed participants to talk safely and indirectly about difficult themes. The session revealed several important insights into the needs, fears, and preferences of people with learning disabilities when thinking about end-of-life care.

Importance of trust and long-term relationships

Participants consistently expressed that they placed their trust in professionals they already knew; usually doctors and specialist teams they had seen over many years. Most had significant long-term health needs and were therefore familiar with medical environments, but their trust was personal, not institutional. They valued professionals who knew them, treated them respectfully, and communicated clearly. New or unfamiliar professionals, in contrast, could feel unsafe or worrying.

Limited awareness of end-of-life options

The group had very little knowledge of the choices available at the end-of-life. None were aware of local hospices, end-of-life advocacy services, or options for personalised care planning. Their only familiar settings were home and hospital. Hospices, care homes, and specialist support providers were either unknown or misunderstood. Care homes in particular attracted strong negative reactions: “for old people” and “awful places”, showing a deep emotional and cultural barrier to considering them as a place of care.

Need for clear, simple information and supported decision-making

Participants highlighted that although they wanted to express their wishes, they would need structured support to do so. Many could not write or organise their thoughts independently. They described wanting a plan, but one that was explained in easy-read format, co-produced with someone they trusted, and flexible enough to change over time. They emphasised that they may need help understanding choices, navigating discussions, and translating their preferences into formal plans.

Desire for impartial advice and advocacy

The group valued having someone impartial, not necessarily a family member, who could explain things clearly and advocate for them. Some did not want to “upset Mam” by asking questions, and others did not have close family relationships. The idea of professionals or support workers acting as trusted advisors was seen as helpful, especially where topics were frightening or unfamiliar. This highlights the risk of hidden disadvantage for people who rely heavily on professionals for guidance.

Emotional safety, familiarity, and comfort

Participants described wanting to feel safe, happy, and comfortable at the end-of-life, in surroundings that felt like home. They referenced their own bed, their familiar belongings, and “nice own food.” Dignity and privacy mattered deeply. While hospital was seen as safe because of access to medical teams, it was also described as noisy, frightening, and lacking privacy, especially with time-limited visiting and unfamiliar environments.

Awareness of support needs and fears about coping alone

A majority believed they would struggle alone with the emotional, physical, and practical aspects of being seriously ill. They identified gaps in confidence and understanding. For example, knowing what to expect, how to manage symptoms, or who would look after them. Many expressed fears around being in pain, feeling scared, or being left without help. This points to the need for enhanced wrap-around support for people with learning disabilities at end-of-life.

Mixed views on the role of family and friends

While many trusted family to handle arrangements well, not everyone had supportive family networks. Some preferred the emotional support of friends, who “cheer them up” or “know what they like.” The responses showed that social networks vary widely, and that services should not make assumptions about family involvement or capacity.

Concerns about capacity, protection, and being taken seriously

Participants worried about whether others thought they could cope with discussions about death or dying. One person was prevented from attending the group by their family for mental health reasons, illustrating the gatekeeping that can occur, sometimes based on assumptions rather than the person's wishes. The group also expressed fears of being talked down to or not being spoken to directly, signalling the need for respectful, accessible communication that treats them as equal partners.

A strong preference for familiar environments at the end-of-life

Home was overwhelmingly preferred, associated with safety, sanctuary, comfort, and dignity. Even so, people acknowledged challenges such as lack of medical help, unwanted visitors, or fear of pain. Hospital was seen as medically safer but emotionally harder. No one wanted to die in a care home. These views underscore the importance of choice, familiarity, and personal control in shaping end-of-life experiences.

Lived experience letter

One respondent shared a deeply personal and emotionally charged account of caring for an elderly parent at the end-of-life. Their experience reveals significant gaps in communication, coordination, and emotional support across the health and care system.

Lack of clear, honest communication about dying

A major theme was the absence of open conversations about the parent's prognosis. Despite clear signs of deterioration, the family was never explicitly told that the parent was approaching the end-of-life. Questions about whether the parent was dying were met with vague or inconsistent responses, including unclear terminology such as "not actively dying," which left the family confused and unprepared. This lack of direct, compassionate communication meant the family received no guidance on what to expect, how symptoms might change, or what practical and emotional support would be needed.

Fragmented and procedural care

The respondent described care that felt procedural rather than personal. Each day brought different staff, with little continuity and no clear sense of a coordinated plan. Some professionals lacked essential equipment during visits, and nursing input often felt limited to administrative tasks rather than hands-on care. Carers were inconsistent, rushed, and at times unaware of the parent's needs or preferences. This inconsistency created distress for both the parent and the family.

Heavy burden on family caregivers

The letter highlights the enormous pressure placed on family members to make complex decisions, particularly around medication, without adequate professional support. The respondent was expected to interpret symptoms, adjust medication doses, and manage rapidly changing needs, often feeling “wrong” or uncertain about whether they were helping or causing harm. Despite reaching out for guidance, the support provided was limited and reactive. This led to feelings of fear, guilt, and deep emotional exhaustion.

Poor coordination between services

There were significant disconnects between professionals involved in care, including between the hospital, GP practice, district nursing team, and social care. The respondent described having to “make a fuss” to secure basic support such as daily nursing visits or social work assessment. No single professional body appeared to take responsibility for coordinating care, leaving the family to manage communication across multiple teams while also providing complex physical and emotional care.

Distressing hospital experience

The parent experienced considerable distress during a hospital admission, which the family felt contributed to a decline in their wellbeing. The hospital environment was overwhelming, and the family perceived a level of “compassion burnout” among staff due to extreme pressures. The parent expressed a strong desire to leave hospital and never return, raising concerns for the family about what this signalled regarding the quality and approach to care within the ward.

Emotional trauma and lingering questions

After the parent’s death, the respondent was left with unanswered questions about the final hours, including whether the medication administered provided comfort or contributed to distress. These unresolved concerns had a profound emotional impact, forming part of a long and painful grieving process. The letter conveys a strong sense of sadness, disappointment, and a wish that things had been different, both for the parent and for future families.

A desire for compassion, guidance, and system change

Above all, the account is a plea for empathetic communication, coordinated care, and proactive guidance for families facing end-of-life situations. The respondent stressed that better support, clearer conversations, and more joined-up services could have reduced the distress experienced and helped the family to feel less alone during an incredibly difficult time. They emphasised that how society cares for people at the end-of-life reflects its values and called for meaningful change to prevent similar experiences for others.

Video & podcast contributions from people with learning disabilities

This short video (end-of-life choices, inclusion north / stop people dying too young group was created by members of the Stop People Dying Too Young group to support conversations about end-of-life choices for people with a learning disability.

Video: <https://www.youtube.com/watch?v=Rv-8Sdbye6A&t=1s>

It highlights:

- The importance of being able to talk openly about death, dying and planning ahead in ways that feel safe and understandable.
- People's desire for clear information about what choices they have at the end-of-life (e.g., where they can be cared for, what support is available).
- The value of trusted relationships, as people with learning disabilities often rely on familiar staff or supporters to help them understand information and express their wishes.
- The need for accessible communication, including Easy Read, supported decision-making, and taking time to check understanding.
- Encouragement to involve people earlier, not waiting until a crisis, to make plans that reflect what matters to them.

Overall, the video emphasises dignity, autonomy, and making sure people with learning disabilities are fully included in their own end-of-life choices.

Podcast: <https://www.youtube.com/watch?v=fLtzuyz0oaQ>

The podcast episode (Podcast episode: my ordinary life – thinking about our own deaths, s2:e2) forms part of a wider series that brings together people with learning disabilities to talk openly about death and dying. The episode includes members of Inclusion North's Stop People Dying Too Young group and health professionals from hospice and learning disability services. Key themes include:

- What makes a good life and how this connects to what a good death means for different people.
- Personal beliefs about what happens when we die, acknowledging that ideas vary widely and should be respected.
- Fear, uncertainty and the need for supportive conversations, especially for people who may not have had opportunities to talk about death before.
- How to help people feel safe discussing end-of-life topics, including involving familiar supporters, using plain language, and creating calm, non-judgemental spaces.

- The importance of planning, including deciding who should speak for you, where you want to be cared for, and what matters most at the end-of-life.

The episode illustrates how people with learning disabilities can explore complex emotional topics when supported well, and how these conversations can shape better, more person-centred end-of-life care.

Key themes from this video and podcast include:

People with learning disabilities want earlier, gentler conversations about death - Across both the video and podcast, people said they don't get the chance to talk about death until something terrible happens. When conversations only happen in crisis, they feel frightening and rushed.

People said they want space to talk about end-of-life at the same pace as everyone else: slowly, sensitively, and with people they trust.

Trust is everything - A major message from both sources is that trusted relationships matter more than services. Participants said they rely heavily on:

- familiar staff
- long-term doctors or specialist teams
- supporters who already "get them"

When new professionals appear suddenly, especially around end-of-life decisions, it creates anxiety and reduces people's ability to express what they want.

People need much clearer, more accessible information - Many contributors said they didn't know:

- what choices exist at the end-of-life
- what hospices do
- who can support them
- how to make an advance plan

This shows a widespread lack of accessible information, meaning people can't make meaningful decisions even when they want to.

Feedback emphasises the need for Easy Read materials, supported decision-making, videos, and repeated conversations.

People want choice, but they need help to understand what those choices are - A powerful theme was that people do want control over:

- where they die
- who is with them
- how they are cared for

But they often don't know these choices exist - People said they want someone they trust to help them think through options, rather than family members who may be distressed, or professionals they don't know.

Care homes were viewed very negatively - Care homes were described as:

"for old people"

"awful places"

- somewhere they couldn't imagine being at the end-of-life

This highlights a significant cultural fear and a gap in accessible information about quality, purpose, and options for residential end-of-life care.

People want honest conversations about what a 'good death' means to them - The podcast showed people can talk deeply about:

- what makes life good
- what a good death means
- spiritual or personal beliefs about dying

Given the right support, people with learning disabilities can explore these themes thoughtfully, so the barrier is not the topic, but how the conversation is facilitated.

Planning ahead feels reassuring, but only if support is available - People liked the idea of having a plan if:

- someone helps them make it
- it's written in clear language
- it reflects what they want
- their family and supporters understand it

Advance care planning was seen as empowering, not scary, when introduced safely.

Emotional support is essential for both the person and those around them - Participants said they sometimes avoid asking questions because they don't want to:

- upset their mum
- worry staff

- feel like a burden

They said it helps when professionals create an environment where everyone's emotions are acknowledged, not avoided.

Margarets story: Learning Disability Network (11-minute film)

Margaret is a woman with a learning disability who is living with a life-limiting condition. At the time of filming, she is palliative and chose to share her experience so that health, social care, and community professionals can better understand the challenges faced by people with learning disabilities at the end-of-life.

Throughout the film, Margaret describes the ongoing difficulties she experienced trying to get her concerns acknowledged. She explains that she often felt dismissed, not believed, or talked over. These experiences created anxiety and made it harder for her to seek help when she needed it. The video shows the cumulative emotional impact of being repeatedly unheard.

Margaret also talks about her communication needs in more depth. She explains that she needs information given slowly, clearly, and with patience. When this does not happen, she feels overwhelmed and unable to express herself. The film highlights how much effort she must put into advocating for herself, especially when unwell.

Importantly, Margaret also shares positive experiences, describing the trust she felt when professionals took time to understand her, listened without rushing, and respected her way of communicating. These moments demonstrate what good, person-centred care looks like and the difference it makes to her emotional wellbeing.

The film encourages viewers to reflect more deeply on how services respond to people with learning disabilities, how small changes in approach can significantly improve experience, and how essential reasonable adjustments are to ensuring dignity, safety, and comfort at the end-of-life.

Key themes identified are summarised below.

Feeling unheard and unseen

Margaret gives further examples of times she tried to describe pain or concerns but felt ignored or dismissed. She talks about how frightening it is when you know something is wrong yet struggle to get professionals to listen.

Communication barriers

The narrative shows how often communication was not adapted to her needs. She explains that explanations sometimes felt too fast or too complex, making it difficult to take in important information.

Emotional strain and exhaustion

Margaret expresses how emotionally draining it is to continually advocate for herself. The film captures the fear, frustration, and sadness that accumulate over months and years of struggling to be heard.

What good care looks like

She reflects positively on times when care was compassionate, consistent, and tailored to her. These examples help illustrate achievable ways professionals can create safer, more trusting relationships.

Importance of reasonable adjustments

Her story demonstrates how systemic barriers add up for people with learning disabilities. It reinforces that reasonable adjustments are essential for equitable end-of-life care, not optional extras.

Learning for professionals

The film explicitly prompts viewers to consider why Margaret felt unheard and what changes could improve care. It encourages a reflective, person-centred approach across services.

Marie Curie insights

Additional qualitative insight was gathered through feedback from people using Marie Curie hospice and community services between November 2024 and January 2026. This includes comments from patients, family members and carers who completed the Marie Curie Experience and Support Questionnaire or shared their experiences directly with Patient Experience Volunteers.

The findings provide further evidence about the conditions that support high-quality end-of-life care, and the areas where systems and services can strengthen consistency, communication, and support.

Staff

Across all feedback, staff were consistently described as the defining positive feature of the service. People highlighted a workforce characterised by warmth, compassion, and a sustained focus on person-centred care. This applied not only to clinical teams but also to reception, catering, household and wellbeing staff, who collectively contributed to a safe, welcoming environment.

Respondents frequently emphasised how staff created time to listen, provided reassurance, and built trusting relationships. Their approach was perceived as genuine and attentive, contrasting with more pressured or clinical environments. The relational continuity and emotional presence offered by staff were central to people's experience of feeling supported and understood.

Care of the patient

Feedback showed consistently high levels of confidence in the quality of clinical care. People reported that staff offered personalised support, clear communication, and timely symptom management, particularly in relation to pain. Several respondents described significant improvements in comfort following admission, including rapid stabilisation of pain and anxiety.

Individuals felt involved in decisions about their care, and many valued the combination of medical support, practical help, and therapeutic services such as jacuzzi baths, complementary therapies, and access to outdoor spaces. The overall experience was described as calm, unhurried, and focused on what mattered to the person.

Mental health support

Emotional and psychological support emerged as an important theme. People spoke about feeling safe to express fears, worries, or uncertainty, and many described the positive impact of counselling, group sessions, and informal conversations with staff. For some, accessing therapy helped them adjust to diagnosis, manage isolation, or reduce distress. The Wellbeing Centre was particularly valued for its supportive, non-judgemental atmosphere.

Social support (wellbeing centre)

The Wellbeing Centre played a significant role in reducing loneliness and enabling peer support. People highlighted the value of meeting others in similar circumstances, sharing coping strategies, and spending time in an environment where they did not have to explain their illness. This social connection contributed to improved wellbeing, motivation, and a sense of belonging.

Support for family members and carers

Family members reported feeling unexpectedly well supported within the service. They appreciated being asked about their own wellbeing, having space to talk, and being offered

complementary therapies. Many described the relief of knowing that their loved one was receiving compassionate care and that they themselves were welcome, reassured, and emotionally held.

Some families highlighted the value of bereavement support, particularly for teenagers who had experienced the loss of a parent. Feedback illustrates the importance of holistic family-centred approaches in reducing stress and enabling carers to cope.

Environment

Views on the hospice environment were consistently positive. People described calm, peaceful surroundings and valued the warm welcome offered on arrival. Access to gardens, natural light, single rooms, and space for loved ones to stay overnight contributed to a sense of dignity and comfort. Cleanliness and attention to detail were frequently praised, reinforcing the perception of a safe and supportive setting. Minor suggestions for improvements were individual and small in scale.

Catering

Catering was a recurrent area of positive feedback. People valued the quality, variety, and adaptability of meals, and several noted that catering staff made additional efforts to meet individual preferences or accommodate limited appetite. The hospice café was also appreciated as an additional social space for patients and visitors.

Information

Some individuals noted uncertainty about what to expect before arriving at the hospice. This appeared linked to limited information from referring agencies or the difficulty of absorbing information during stressful periods. Once in the service, people felt well-informed, though the comprehensiveness of written materials presented on admission sometimes made key information hard to identify. Work is underway to develop a clearer, more accessible summary for new admissions.

Public perception of hospice care

Several respondents reflected on their misconceptions about hospice care prior to admission. Many had expected a sombre or clinical environment and were surprised to find a positive, welcoming, and hopeful space. Awareness of the Wellbeing Centre and the breadth of available services was especially low, suggesting opportunities for improved public understanding.

Charitable status

Some people expressed concern on learning that the service is heavily dependent on charitable income and fundraising. This raised questions for some about service sustainability and equitable access, highlighting the importance of secure funding models for specialist palliative care.

What could be improved

Most respondents said that they could not identify anything that needed to be improved. Where suggestions were made, they tended to relate to small environmental preferences or light-hearted ideas (e.g., pool table, TV services). These comments largely reflect the high overall satisfaction reported.

Feedback from community-based services

Feedback from community services mirrored the patterns seen in hospice-based care. Staff were described as respectful, professional, and highly supportive. Families noted that night-sitting services and regular checks provided essential reassurance and reduced stress. People frequently referenced trust in staff and the relief of knowing their loved one or relative was in safe hands.

Summary

Overall, the additional responses reinforce core themes seen across broader engagement: the central importance of compassionate staff; personalised and dignified care; emotional and social support; and the need for clear, accessible information. These insights further highlight the value of relational, holistic approaches in specialist palliative care, and the need for coordination and clarity across referral pathways to support people and families at every stage.

Cross-cutting themes identified from responses

These additional responses present a wide range of perspectives on end-of-life care. While each source represents a different community or issue, there are clear, recurring themes that cut across all of them. Together, they offer a richer understanding of what people need at the end-of-life, where services work well, and where significant gaps remain.

Communication: an essential foundation and a consistent weakness

Across all additional submissions, communication emerged as the strongest and most consistent theme. People described unclear, rushed, or inaccessible communication that left them frightened, confused, or excluded from decisions. People with learning disabilities reported being talked over, given information too quickly, or not being spoken to directly. Margaret's story highlights the

emotional impact of feeling unheard or dismissed, while the lived-experience letter describes inconsistent, vague explanations that left the family unprepared for dying.

In contrast, where communication was honest, gentle, and paced, people felt calmer and better supported. The video and podcast contributions reinforced the need for earlier, clearer conversations using accessible formats such as Easy Read, supported decision-making, and repeated explanations. Communication that is honest, compassionate, and tailored to individual needs is a fundamental requirement for safe and equitable end-of-life care.

Trust, continuity, and the importance of familiar relationships

A strong message from people with learning disabilities, Margaret's story, and families was that trust is personal, not institutional. People felt safest when supported by professionals who knew them, understood their communication style, and could anticipate their needs. New or unfamiliar staff caused anxiety, reduced confidence, and limited people's ability to express their wishes.

Marie Curie insight reinforces this: relational continuity and the emotional presence of staff were central to positive experiences of care. Trusted relationships, built over time, were repeatedly cited as the foundation for dignity, comfort, and confidence at the end-of-life.

Accessible information, choice, and supported decision-making

Participants across all sources expressed a desire for choice and control, but many lacked the information or support required to make informed decisions. People with learning disabilities were often unaware of care options such as hospices, advocacy services, or planning tools because they had never been offered accessible information. Margaret described how complex or fast explanations made it difficult for her to understand what was happening.

Where accessible formats were provided, people felt empowered rather than overwhelmed. Easy Read documents, visual resources, trusted supporters, and pacing conversations emerged as essential elements of equitable decision-making. People want to express their wishes, but they need information that is clear, honest, and matched to their communication needs.

Personalised, familiar, and dignified care

Across all feedback, people emphasised that good end-of-life care is personal, respectful, and grounded in emotional safety. People with learning disabilities valued familiar environments, their own belongings, and feeling comfortable and unhurried. No one in the learning disability focus group wanted to die in a care home, revealing strong emotional associations and the need for sensitive conversations about options.

Marie Curie feedback echoed this, highlighting calm environments, dignity, and personal attention as defining features of good care. When staff took time to listen, adapt, and reassure, people felt valued as individuals.

Emotional burden, fear, and uncertainty

Fear, emotional strain, and uncertainty were present across all accounts. People with learning disabilities described fears of being in pain, being alone, or not understanding what was happening. Margaret's experience showed the emotional exhaustion of having to advocate repeatedly for herself. Families in the lived-experience letter described intense stress, guilt, and trauma caused by unsupported decision-making and lack of preparation.

People said that emotional support for both the person and those around them is essential. When emotional needs were acknowledged rather than avoided, people felt more secure, more informed, and more able to cope.

System fragmentation and the burden placed on families

System fragmentation was a major theme across narratives. The lived-experience letter described disconnected teams, repeated chasing, and the absence of a single coordinating professional. For people with learning disabilities, reliance on professionals for navigation created hidden vulnerability particularly when services were inconsistent or poorly joined up. Margaret's story illustrated the cumulative impact of needing to advocate for oneself in a system not designed for people with communication needs.

Families frequently had to take responsibility for care coordination, advocacy, symptom management, and navigating multiple services. In contrast, where services such as Marie Curie provided seamless, coordinated care, the burden on families was significantly reduced.

Inequity in access to services and information

The additional responses highlight significant inequities for people who rely on adapted communication, accessible information, or advocacy. Lack of awareness of hospice services, planning options, or entitlements disproportionately affected people with learning disabilities. The lived-experience account showed how inconsistent access to nursing and social care support left families vulnerable. These inequities intersect with communication needs, housing, social networks, and familiarity with services, resulting in unequal experiences at the end-of-life.

Distinct group-specific needs and considerations

People with learning disabilities:

- Need accessible, repeated, and well-paced communication.

- Depend heavily on trusted relationships for emotional safety.
- Require support for advance planning that is sensitive, not rushed.
- Strongly prefer familiar environments.
- Experience significant risk of exclusion when communication is not adapted.

Families and unpaid carers:

- Carry substantial emotional and practical burdens when systems are fragmented.
- Need clearer guidance, earlier conversations, and coordinated support.
- Experience long-lasting emotional trauma when communication is poor.

Overall

Together, these additional responses reinforce that high-quality end-of-life care depends on:

- Clear, honest, and accessible communication
- Trusted and continuous relationships
- Person-centred, dignified, and familiar care
- Early, supported planning
- Emotional support for individuals and families
- Coordinated, equitable systems

They also highlight the significant risks created when these foundations are absent, particularly for people with learning disabilities and families navigating end-of-life care without adequate support.

Conclusion

The results of the involvement work present a clear and consistent message from people across the North East and North Cumbria: palliative and end-of-life care must be compassionate, coordinated, equitable, and grounded in what matters most to individuals and those close to them.

Across all engagement methods: survey responses, Healthwatch conversations, community-led engagement, desktop evidence and additional lived experience submissions, people described the same core priorities. They want to be comfortable and free from pain. They want to be treated with dignity and respect. They want honest, clear communication. They want trusted relationships and coordinated support. Above all, they want reassurance that they will not be left alone or unsupported at the end-of-life.

These priorities were remarkably consistent, regardless of age, diagnosis, culture, geography or life circumstances.

The findings demonstrate that the quality of end-of-life care is judged primarily through relational experience rather than clinical intervention alone. Being listened to, being spoken to honestly, having time to ask questions, and feeling known as a person rather than treated as a task were repeatedly described as central to a good death. Where communication and coordination were strong, particularly within hospice and specialist palliative services, experiences were described as compassionate and transformative. Where communication and coordination were weak, families reported distress, confusion and lasting trauma.

The findings also highlight structural pressures that undermine confidence and choice. Participants described fragmented pathways, delays in funding or equipment, limited hospice capacity, workforce constraints and inconsistent communication across settings. These pressures reduce the reliability and continuity of care and place additional strain on families at a vulnerable time.

Inequalities in access and experience emerged as a critical concern. People experiencing homelessness, rural isolation, disability, neurodivergence, poverty, language barriers or discrimination described additional obstacles to receiving timely and personalised care. Cultural and faith needs were not always understood. Communication was not always accessible. Trust in services was not always assured. Despite these differences, the expectations remained the same: dignity, safety, compassion, autonomy and recognition of identity.

The involvement work reinforces the importance of earlier and more proactive conversations. Many people had not discussed their wishes, often due to emotional discomfort, uncertainty about how to begin, or lack of information. There is a clear opportunity for the system to normalise advance care planning, improve public understanding of palliative care, and support clinicians and community partners to initiate sensitive, timely discussions.

This work sits firmly within the ICB's statutory duties to involve people, advance equality of opportunity and reduce health inequalities. The findings provide a robust and credible evidence base for commissioning and system development. They show not only what people value, but where current structures risk falling short of those expectations.

The implications are clear. Strengthening coordination across health and social care, supporting carers, embedding culturally competent practice, improving communication standards, and addressing workforce and resource pressures must remain central priorities. At the same time, the system can build on the strong foundations already present within hospice and specialist palliative services.

By acting on these insights and continuing to work alongside communities, voluntary partners and people with lived experience, the North East and North Cumbria Integrated Care Board can deliver a more compassionate, consistent and equitable palliative and end-of-life care system. One that honours people's wishes, supports families, and ensures that every person can expect dignity, comfort and respect at the end-of-life.

Appendix 1 – Demographics

	Survey	Qualitative
Area – live in	N=2355	N=158
County Durham	15%	1%
Darlington	5%	15%
Gateshead	5%	1%
Hartlepool	3%	7%
Middlesbrough	5%	8%
Newcastle-upon-Tyne	10%	3%
Northumberland	8%	13%
North Cumbria	13%	24%
North Tyneside	14%	4%
Redcar and Cleveland	5%	6%
South Tyneside	4%	1%
Stockton	6%	4%
Sunderland	8%	14%
Age	N=2368	N=148
11 - 14	-	4%
16 – 24	2%	5%
25 – 34	7%	8%
35 – 44	14%	7%
45 – 54	21%	9%
55 – 64	27%	20%
65 – 74	18%	30%
75 – 84	9%	11%
85+	1%	5%
Gender	N=2361	N=177
Female	84%	63%
Male	16%	37%

Non-binary	0.1%	1%
Same gender as birth	N=2353	N=102
Yes	99.7%	94%
No	0.3%	6%
Ethnic background	N=2337	N=149
White Includes: English, Welsh, Scottish, Northern Irish or British; Irish; Gypsy or Irish Traveller; Roma, or any other white background	96%	97%
Asian or Asian British (Includes: Indian, Pakistani, Bangladeshi, Chinese or any other Asian background)	1%	2%
Black, black British Caribbean or African (Includes: black British Caribbean, African or any other black background)	1%	1%
Mixed or multiple ethnic groups (Includes: white and black Caribbean, white and black African, white and Asian or any other mixed or multiple background)	1%	
Other (Includes Arab or any other ethnic group)	0.2%	
Religion	N=2302	N=70
Christian (including Church of England, Catholic, Protestant)	55%	54%
No religion or belief	41%	43%
Islam / Muslim	1%	1%
Buddhist	1%	
Spiritualist (suggested in other)	1%	
Other	1%	
Pagan / Wicca / earth-based (suggested in other)	0.4%	1%
Hindu	0.2%	
Agnostic (suggested in other)	0.1%	
Humanist (suggested in other)	0.1%	
Jehovahs Witness (suggested in other)	0.04%	
Jewish	0.04%	
Sexual orientation	N=2281	N=72
Straight or heterosexual	96%	82%
Gay or lesbian	2%	10%
Bi or bisexual	2%	4%

Pansexual / Sapiosexual / Demipansexual (suggested in other)	0.1%	4%
Physical or mental health conditions	N=2309	N=82
No	62%	37%
Yes	38%	63%
Health condition affects daily life	N=1064	N=34
Yes – a little	81%	44%
Yes – a lot	19%	56%
Armed forces	N=2347	N=77
No	97%	96%
Yes, the regular or reserve armed forces	3%	4%

Appendix 2 – Involvement materials

Survey

We know this can be a difficult subject to think about or talk about. Please only answer the questions you feel able to. You can stop the survey at any time.

Thank you for taking part in this survey. Your answers will help us understand how people feel about death, dying, and care at the end-of-life.

To help you with the questions, here are some simple explanations:

- Palliative care – This is care that helps you feel as comfortable as possible when you have an illness that cannot be cured. It can help with pain and symptoms. It also offers emotional, social, and spiritual support for you and your family or carers. You may receive palliative care while still having other treatments.
- End-of-life care – This is a type of palliative care for when someone is close to the end of their life.

Please answer honestly – there are no right or wrong answers.

This survey is anonymous, which means no one will know who you are. Your views will help shape kind and caring support for people at the end-of-life.

Thoughts about Palliative and End-of-life Care - Talking about death

Q1. How do you feel when you talk about death or dying? (Please choose one only)

- I feel very uncomfortable
- I feel a bit uncomfortable
- I don't really mind either way
- I feel fairly comfortable
- I feel very comfortable
- Prefer not to say

Where you would prefer to die

Q2. If you could choose, where you would like to be cared for when receiving palliative and end of your life? (Please choose one only)

- At home

- In a hospital
- In a hospice
- In a care or nursing home
- I don't mind
- Prefer not to say
- Somewhere else (please say where):

Cultural, faith, or community traditions

Q3a. Are there any cultural, faith, or community traditions that are important to you around death and dying?

- Yes
- No
- I'm not sure

Q3b. If yes, please tell us what:

Most important aspects of end-of-life care

Q4. We know everything in the below list is important. But what do you think is most important for good end-of-life care? (Please choose TWO answers only)

- Being free from pain
- Being treated with dignity and respect
- Being with family or friends
- Feeling calm and peaceful
- Not being a burden to others
- Having my wishes listened to and respected
- Other (please say)

Talking about your wishes

Q5. Have you ever talked with someone about any of the following? (Tick all that apply)

- My medical needs
- My spiritual or religious needs
- Wanting peace and privacy
- Dying with dignity and respect
- Where I would like to die
- When I would like to die
- Pain relief

- None of these – I haven't talked about any of these things
- I've spoken about something else (please say)

Please only answer question 6 if you ticked 'none of these' in the last question.

If you have already talked to people about your wishes, please tick 'Next' at the bottom of the screen and continue to question 7.

Q6. If you haven't talked about these things, please tell us the main reason why. (Please choose one only)

- Does not apply - I have already talked to people about my wishes
- I don't feel comfortable talking about death
- I don't know how to start the conversation
- Death feels far away
- I think I'm too young to talk about it
- I don't have anyone to talk to about it
- Other people don't want to talk about it
- Other reason (please say what)

Written plans or wishes

Q7. Do you have any of the following written plans or documents about your care, funeral, or what should happen after you die? (Tick all that apply)

- A written statement about my wishes for care if I can't make decisions (advance statement)
Written wishes for my funeral
- A plan for my money or finances near the end of my life
- Written wishes about organ donation
- A will
- A care plan for someone I look after
- An organ donation card
- None of these – I don't currently have any written plans or documents

What would help you start planning?

Q8. If you knew you were near the end-of-life, what would help you start planning? (Tick all that apply)

- Wanting to make things easier for my family
- Wanting the funeral I would like
- Making sure I get the right care and support

- Getting help to find information about planning
- Getting support to write down my wishes or care plan
- If someone helped me talk about my wishes
- None of these

Where you'd like to get information from

Q9. Who would you most like to get information from about planning for death? (Please choose one only)

- Solicitor
- Funeral director
- Doctor or GP
- Nurse
- Family or friends
- The internet
- Charity or voluntary organisation
- Faith or community leader / representative
- Someone else (please say who):

Experience of losing someone

Q10. Have you ever lost someone close to you?

- Yes
- No

If you have not lost someone close to you, please tick 'Next' at the bottom of the screen to go to question 14.

Please tell us about the care they received.

Q11a. Did they get the right healthcare support they needed?

- Yes
- No
- I'm not sure what care they received
- They did not need this support

Q11b. Did they get the right social care support they needed?

- Yes
- No

- I'm not sure what care they received
- They did not need this support

Have you or someone close to you had care from:

Q12a. A specialist palliative care team (in hospital or at home)?

- Yes
- No
- I'm not sure

Q12b. A hospice?

- Yes
- No
- I'm not sure

Q13. Do you look after someone who is ill, has a long-term condition, disability, or is elderly?

- No
- Yes - I'm a carer (unpaid)
- I used to be a carer (unpaid)
- I am a paid carer (it's my job)

Any other comments

Q14. Is there anything else you'd like to share about your experiences, thoughts, or wishes regarding death, dying, or end-of-life care?

GP palliative care register

GP practices keep a list of patients who may be in the last year of their lives. This is to help them care for people. It is called a GP palliative care register.

Q15a. Have you heard of the GP palliative care register?

- Yes
- No
- Not sure

Q15b. Would you be happy for yourself or a family member to be included on the register if it was appropriate?

- Yes
- No

- Not sure

About you

Q16. Which part of the North East and North Cumbria do you live in?

- County Durham
- Darlington
- Gateshead
- Hartlepool
- Middlesbrough
- Newcastle-upon-Tyne
- Northumberland
- North Cumbria
- North Tyneside
- Redcar and Cleveland
- South Tyneside
- Stockton
- Sunderland

Q17. Where do you access any health care you may need?

- County Durham
- Darlington
- Gateshead
- Hartlepool
- Middlesbrough
- Newcastle-upon-Tyne
- Northumberland
- North Cumbria
- North Tyneside
- Redcar and Cleveland
- South Tyneside
- Stockton
- Sunderland

Q18. What age are you? (Please select one only)

- 16 – 24
- 25 - 34

- 35 – 44
- 45 - 54
- 55 - 64
- 65 - 74
- 75 - 84
- 85+
- Prefer not to say

Q19. Which of the following best describes you? (Please select one only)

- Female
- Male
- Non-binary
- Prefer not to say
- Prefer to self-describe (please write in)

Q20. Is the gender you identify with the same as your sex registered at birth? (Please select one only)

- Yes
- No
- Prefers not to say

Q21. What is your ethnic group? (Please select one only)

- Asian or Asian British (Includes Indian, Pakistani, Bangladeshi, Chinese or any other Asian background)
- Black, black British Caribbean or African (Includes black British Caribbean, African or any other black background)
- Mixed or multiple ethnic groups (Includes: white and black Caribbean, white and black African, white and Asian or any other mixed or multiple background)
- White (Includes English, Welsh, Scottish, Northern Irish or British; Irish; Gypsy or Irish Traveller; Roma, or any other white background)
- Other (Includes Arab or any other ethnic group)
- Prefers not to say

Q22. What is your religion or belief? (Please select one only)

- No religion or belief

- Christian (including Church of England, Catholic, Protestant, and other Christian denominations) Buddhist
- Hindu
- Jewish
- Muslim
- Sikh
- Prefer not to say
- Other religion or belief (please write in)

Q23. Which of the following best describes your sexual orientation? (Please select one only)

- Straight or heterosexual
- Gay or lesbian
- Bi or bisexual
- Prefer not to say
- Other sexual orientation (please write in)

Q24. Do you have any physical or mental health conditions or illnesses lasting or expected to last 12 months or more? (Please select one only)

- Yes
- No
- Prefer not to say

Q25. Do any of your conditions or illnesses reduce your ability to carry-out day-to-day activities? (Please select one only)

- Yes, a lot
- Yes, a little
- No

Q26. Do you or have you previously served in the in the UK armed forces? (Please select one only)

- Yes, the regular armed forces
- Yes, reserve armed forces
- No
- Prefer not to say

Community group conversations

1. Talking about death

Question: How do people feel about talking about death or dying?

Prompts:

- What makes it hard to talk about?
- What makes it easier?
- Are there times when talking about it feels more okay?

2. What matters most at the end-of-life

Question: When someone is near the end of their life, what do you think matters most to them?

Prompts:

- Being comfortable and free from pain
- Being treated kindly and with respect
- Being with family or friends
- Feeling calm and safe

3. Where people would like to be

Question: If people could choose, where do you think they would like to be at the end of their life, and why?

Prompts:

- At home
- In a hospital or hospice
- Somewhere else
- How might this change in different situations?

4. Culture, faith, and family

Question: How do culture, faith, or family traditions affect how people think about death and dying?

- Prompts:
- Are these traditions important to people?
- Do services usually understand and respect them?
- How could care be more supportive?

5. Talking about wishes and planning

Question: What helps people talk about their wishes for the end-of-life, and what gets in the way?

Prompts:

- Not knowing how to start the conversation
- Feeling too young or not ready
- Having the right person to talk to
- Wanting to help family and friends later

6. Getting help and information

Question: What would help people feel more supported to plan or talk about end-of-life care?

Prompts:

- Clear and kind information
- Help from a doctor, nurse, or trusted person
- Support from family, faith, or community groups
- Knowing where to go for help

Qualitative survey

Introduction

Thank you for talking with me today.

We want to understand people's thoughts, experiences, and wishes about death, dying, and end-of-life care.

There are no right or wrong answers. You can skip any question or stop at any time.

1. Talking about death and dying

- How do you personally feel when the topic of death or dying comes up?
- What makes you feel that way?
- Is this something that's easy or difficult to talk about for you?
- Has this changed over time?

2. Preferences for care at the end-of-life

- If you could choose, where would you ideally like to be cared for if you were nearing the end of your life?
- What is important about that place?

- Are there any other places you'd consider?
- What might make it hard to be cared for there?

3. Culture, faith and traditions

- Are there any cultural, faith, spiritual, or community traditions that are important to you when thinking about death or dying?
- Can you tell me more about those?
- How important is it that services understand and respect these?
- Have these needs been met in your experience?

4. What good end-of-life care looks like

- When you think about good end-of-life care, what matters most to you?
- Why is that the most important thing?
- Are there things you worry about not happening?
- Are there things you wouldn't want?

5. Talking and planning ahead

- Have you ever talked with anyone about your wishes for the end-of-life or what might happen after you die?
- Who did you talk to?
- What did you talk about?
- How did that conversation feel?
- If you haven't talked about it, what do you think has stopped you from having those conversations?
- Is there anything that would make it easier?

6. Written plans and documents

- Have you ever written anything down about your care, your funeral, or what you want to happen after you die?
- What have you written, if anything?
- What helped you do this?
- If you haven't, what has made this difficult?

7. Support for planning

- If you knew you were nearing the end-of-life, what do you think would help you most with planning?
- Information?

- Support from people?
- Time, money, or professional advice?
- Something else?

8. Trusted sources of information

- Who would you most trust to give you information or advice about planning for death and end-of-life care?
- Why them?
- Would you prefer this information face-to-face, written down, or online?

9. Experiences of loss

Have you ever lost someone close to you? If yes

- Would you be willing to tell me a bit about the care they received?
- Do you feel they received the healthcare support they needed?
- Do you feel they received the social care support they needed?
- What worked well?
- What could have been better?

10. Experiences of palliative and hospice care

- Have you or someone close to you ever received care from a palliative care team or a hospice?
- What was that experience like?
- What stood out as positive or negative?
- What do you think people should know about these services?

11. GP palliative care register

- GPs can keep a list of patients who may be in the last year of their life to help plan and coordinate care.
- Had you heard of this before?
- How would you feel about yourself or a family member being included on such a register if appropriate?
- What concerns or benefits do you see?

12. Final reflections

Is there anything else you'd like to share about your experiences, thoughts, worries, or wishes around death, dying, or end-of-life care?