healthwatch Oxfordshire

"Pain free, with dignity, and with familiar people"

Views and experiences of palliative and end-of-life care in Oxfordshire

July 2026

Contents

Acknowledgements

Healthwatch Oxfordshire would like to thank everyone who participated in our surveys, Oxfordshire Community Education Group, and those who talked to us in more detail about their experiences of end-of-life care in Oxfordshire.

Executive summary

Everyone has different hopes, fears and wishes about what happens when they die. Although it is a difficult topic for many people to think and talk about, most of us have hopes, fears and wishes about where we die, who will be with or near us, and what care and support we will receive. It is important that those who design and deliver end-of-life and palliative care services understand what is important to the people they support, to make sure that people receive the care and support they need and that, as far as possible, their wishes for the end of their life are met.

Recent national and local policy and strategy are bringing about changes to end-of-life and palliative care. These include a shift to providing **'care closer to home'** through a focus on Neighbourhoods; encouraging **early conversations and planning** about people's wishes for when they die, for example through the ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) process; **improving the quality** of end-of-life and palliative care services; and making sure these services work together in a **joined-up way**. There is also a growing focus on addressing health inequalities and making sure support is available to and meets the needs of those who may need it most.

Healthwatch Oxfordshire heard from local residents about their views and experiences of palliative and end-of-life care for adults in Oxfordshire. We asked in detail about what is important to people towards the end of their lives, and what might support people to have conversations about their wishes with family, friends, or health and care professionals. We also asked people about any experiences they had had of end-of-life or palliative care services.

This report summarises what we heard from **over 110 people** across:

- An online and paper survey
- In-depth phone interviews
- An Enter and View visit to a local hospice
- Outreach engagement with community groups.

Summary of results

We heard that many people had clear and consistent priorities about what mattered to them most at the end of life. Most people said they would **prefer to die at home or in a hospice** rather than in a care home or hospital. These preferences were influenced by wider factors such as **being close to loved ones**, **feeling safe and comfortable**, and receiving **good quality care.**

The findings highlighted several key aspects of good end-of-life care. These included having **control over decisions**, **management of symptoms and pain**, being treated with **dignity and compassion**, and receiving support that recognised both **the patient as a whole person** and those close to them.

Emotional and social aspects of care were often described as being as important as medical care.

While many participants shared positive experiences of care and support, others experienced challenges. These included **difficulties accessing support** and services, **gaps in communication**, **lack of coordination** between different health and care providers, and **inadequate quality and continuity of care**. Some participants also described experiences of a lack of information or poor communication about end-of-life care.

Although many people had thought about or discussed their wishes, not everyone had made formal plans. **Awareness of advance care planning and ReSPECT appeared to be limited**, and some people said they were unsure about how and when to have end-of-life conversations.

We heard several ways in which **care could be improved**. These included improving information and access to support and services, ideally being able to find these in one place; improving communication and encouraging earlier conversations about end-of-life wishes; strengthening coordination between services to support seamless, person-centred care, strengthening staff capacity and skills (for example in culturally appropriate care), and increasing support for families. Throughout, we heard about the importance of care and support that builds on people's existing networks, assets and communities, that is culturally appropriate, and that takes into account the wishes of people who are dying and their loved ones, supporting them to live and die well.

Recommendations

We would like to make the following recommendations based on what we have heard and people's suggestions.

- Recommendations are for attention of and response from the following system partners – including Thames Valley Integrated Care Board (TV ICB), Oxford University Hospitals (OUH), Oxford Health (OH), and Oxfordshire County Council (OCC) – as to how they will address them.
- It will also be shared with Oxfordshire Palliative Care Network, Oxfordshire Place Based Partnership, Oxfordshire Association of Care Providers (OACP) and Oxfordshire GP network as well as in emerging Neighbourhood Health planning.

Recommendation 1: Support meaningful, timely conversations and planning around death

We heard that people have clear ideas about their preferences for when they die – but did not always know how to have conversations about this with their loved ones and with professionals. There was limited awareness of ReSPECT (Recommended Summary Plan for Emergency Care and Treatment). People also told us about negative experiences where conversations about ReSPECT or DNACPR were not well handled by health and care professionals.

We would like to recommend:

- Health and care system to work together to promote public awareness of the importance of end-of-life planning, working closely with the voluntary and community sector to reach Oxfordshire's diverse communities and build trust
- Training for health and care professionals across the system in having these conversations in a sensitive and culturally appropriate way – including supporting conversations in emergency situations when there has not been earlier planning
- Work with local community groups to co-produce activities and strategies that encourage discussion about death and dying, and the importance of making plans.

Recommendation 2: Improve information and access to support and services

- Health and care system to work together to promote public awareness and accessible information on the range of palliative and end-of-life care services available and how to access these. Promote this via a range of means including through outreach and working closely with the voluntary and community sector
- Work with communities to tackle myths around palliative and end-of-life care services and build trust, for example by highlighting 'live well' programmes and the possibility of 'hospice at home' for some patients
- Address gaps in and barriers to accessing funding for care, for example Continuing Healthcare (CHC) funding, including improving information, advice and support for those applying for funding or looking for support.

Recommendation 3: Join up care around and with people and their loved ones

- Use learning from INTs and the potential direction of travel for Neighbourhood Health to address issues of fragmentation, communication, uneven geographical coverage, choice and support co-production of pathways
- Continue to support care coordination for those receiving care from the Palliative Care Hub, and explore the potential to improve care coordination for those receiving end-of-life care from other services ensuring quality of care is maintained between different providers
- Work collaboratively with communities to co-produce guidance and training for culturally appropriate and accesible care
- Recognise and build on the role of people's 'circles of care' in supporting good palliative and end-of-life care, including loved ones, neighbours, and community and faith groups, and bringing care closer to home.

Background

Why end of life and palliative care?

The care we receive when we are dying can have a profound effect on us and our loved ones. Although it is a difficult topic for many people to think and talk about, most of us have hopes, fears and wishes about where we die, who will be with or near us, and what care and support we will receive. It is crucial that those who design and deliver services understand what is important to the people they support, to make sure that people receive the care and support they need and that, as far as possible, their wishes for the end of their life are met.

This report looks at views and experiences about the kind of care people receive when they are dying. We use two key terms to talk about this:

- Palliative care is for people with a terminal or life-limiting illness, to help them to be as comfortable as possible. It includes managing symptoms and providing emotional, social, and spiritual support to the patient and their family or carers.
- End-of-life care is care and support for those who are dying and in the last months or years of life.

People have the right to decide where they would like to receive care and where they would prefer to die. Most people in the UK say they want to die in their community, either at home or in a hospice.[1] However, patients and their families or carers often find navigating palliative and end-of-life care services confusing. Many do not know where best to turn for information, advice, and other support. In addition, people don't always spend their last days in the place they had imagined or hoped for. The dying process can be unpredictable, and people's preferences can change towards the end of life.[4]

Having early conversations and planning is important for people's preferences and wishes to be known, and for them to get the care they want. Despite this, many do not have an advance care plan. Recent research found that 70% of UK adults had never heard of an advance care plan and only 3% had one in place.[2]

Demand for palliative and end-of-life care is growing, as the number of people in England with more than one long-term health condition is increasing, as well as they number of people dying. [3] Palliative and end-of-life care have also recently come under greater public scrutiny – including debates around the Assisted Dying Bill, which has brought to the fore questions around what it means to live and die well, and research from the Palliative Care Commission, which has found challenges including a 'postcode lottery of provision' and

[1] Marie Curie, 2024, Public attitudes to death, dying and bereavement in the UK re-visited.
[2] YouGov online survey of 2189 adults in 2024.
[3] The Commission on Palliative and End-of-Life Care, 2025 (Vol 1.)

fragmentation in the delivery of palliative and end-of-life care services. National research has also shown that health inequalities tend to worsen around death.[4]

Work to address these challenges includes the **NHS 10 Year Plan**, which highlights aspects of palliative and end-of-life care. The **three shifts** – from hospital to community, analogue to digital and treatment to prevention – are intended to support people to stay at home rather than be admitted to hospital, encourage early planning, support services to work in a more joined-up way, and focus not just on dying well but also on living well towards the end of life.[5] The **NHS England Neighbourhood Health Framework**[6] has set out the government's plan to deliver health and care 'closer to home' and more tailored to their needs. One of its aims is to better identify people with palliative and end-of-life care needs, and to reduce the number of non-elective hospital admissions. In some areas, this shift is reflected in the adoption of a public health approach to palliative and end-of-life care, recognising the importance of people's social networks in supporting them to live and die well – known as **compassionate communities.**[7]

End-of-life and palliative care in Oxfordshire

In Oxfordshire, palliative and end-of-life care and support for adults is provided at different stages by a range of many different services, including hospitals, GP practices, hospices, community nursing and other community services, social care providers, faith groups, and voluntary and community organisations. Providers are working to deliver consistent care, but have different geographical footprints, meaning that some areas may have more support or choice than others (for example, there are no local in-patient hospice settings in West Oxfordshire or Vale of White Horse. End-of-life care can be delivered at home or in a care home, hospice, or hospital, depending on the person's needs and wishes.[8] Table 1 below sets out some of the key providers of end-of-life and palliative care in Oxfordshire. Family, friends and neighbours also provide vital support and care.

In 2024-25, place of death data showed that the Buckinghamshire, Oxfordshire and Berkshire area performed better than the national picture in supporting people to die at home or in a care home (50% of deaths), or in a hospice (8%), rather than in hospital (36%).[9] However, everyone's journey will look different, and different services have different funding – for example, medical care is provided free on the NHS, social care is means-tested, and some people may be eligible for funding via Continuing Health Care (CHC) funding[10] – which can be complex to navigate. Hospice care may be funded by charities as well as by the NHS. Different parts of the county are served by different hospice or palliative care charities working in partnership with Oxford University Hospitals NHS Foundation Trust (OUH), Oxford Health NHS Foundation Trust and other health and care services.

[4] Sue Ryder review on inequity

[5] Note that working towards this direction is nothing new – see e.g. Compassionate Communities in Black Country and Birmingham)

[6] NHS England, 2026, Neighbourhood health framework.

[7] Mills et al, 2024, The role and contribution of compassionate communities. *The Lancet.* 404: 10448, 104-106.

[8] NHS England, Palliative and end of life care.

[9] Department of Health and Social Care: Place of Death factsheet

[10] Thames Valley Integrated Care Board information on Continuing Healthcare funding

Table 1: List of key palliative and end-of-life care providers for adults in Oxfordshire (non-exhaustive)

Provider name	Examples of service offered	Geographical area
Oxford University Hospitals	• Acute hospital care, hospital at home • Katharine House and Sobell House hospices and associated services • Palliative Care Hub, e.g. 'hospice at home'	Countywide
Oxford Health	• Palliative and anticipatory care specialist team • District nursing and other community services (e.g. community therapy service) • Care home support services[11] • Community hospitals including provision of end-of-life care beds in partnership with Sue Ryder Care[12] • Out of Hours GP service • Urgent community response teams • Single Point of Access.	Countywide
GP teams	• Primary care • Integrated Neighbourhood Teams supporting those living with multiple complex conditions • Referrals to specialist care	Local to patient
Social care (Oxfordshire County Council, social care providers, care homes)[13]	• Home domiciliary care (e.g. support with washing and dressing) • Care and support following discharge from hospital (e.g. Home First) • Respite care • Residential care, including some specialist care (e.g. for those with dementia)	Countywide
Katharine House Hospice	Palliative care including in-patient hospice, hospice at home, hospital care, lymphedema clinic, Living Well services and bereavement support	Oxfordshire and South Northamptonshire (excluding 5 GP

[11] Oxford Health care home support services
[12] Specialist palliative care beds for South Oxfordshire patients
[13] Oxfordshire Association of Care Providers

Provider name	Examples of service offered	Geographical area
		practices served by Sue Ryder)
Sobell House	Palliative care including in-patient hospice, hospice at home, hospital care, lymphedema clinic, Living Well services and bereavement support	Oxfordshire and South Northamptonshire (excluding 5 GP practices served by Sue Ryder)
Sue Ryder	Palliative care including hospice at home and in-patient care at Wallingford Community Hospital	South Oxfordshire
Lawrence Nurses	End-of-life care at home	Northwest Oxfordshire (Chipping Norton, Bloxham and Hook Norton)
Marie Curie	Palliative care including overnight care	Countywide
Community pharmacy	• Support with medications including for pain and symptom management (each area of Oxfordshire has designated pharmacies with guaranteed provision of palliative care medications)	Countywide
Voluntary and community sector	Wide range including: • Support for carers, for example via Carers Oxfordshire and local groups • Support for living with or caring for those with specific conditions, e.g. Dementia Oxfordshire; Maggie's Oxford for cancer support • Bereavement support • Support to live well	Various

Locally, work to improve people's experiences of palliative and end-of-life care has included promoting the ReSPECT process (Summary Plan for Care and Treatment) to support conversations with health and care providers about end of life, and the collaborative Rapid Intervention for Palliative and End of Life care (RIPEL) project. RIPEL has worked to improve access to personalised palliative care and reduce health inequalities, including through expansion of a 'home hospice' team, coordination through a palliative care hub, and focused work with people with lived experience of homelessness.[14] Providers have also been working together on bringing 'care closer to home', reducing non-elective admissions to hospital and longer than necessary hospital stays through support from multi-

[14] Dying Matters Week – our project to personalise palliative care

disciplinary teams including Integrated Neighbourhood Teams, Urgent Community Response and Home First. Palliative and end-of-life care remain high on the agenda of local providers and commissioners: it is a quality priority of OUH in 2026-27, Buckinghamshire, Oxfordshire and Berkshire West (now Thames Valley) Integrated Care Board has been developing a Dying Well strategy, and Oxford Health has developed a three-year Palliative and End of Life Care strategy with a similar emphasis on personalised, well-coordinated, high quality care.

Hearing people's voices about their wishes and experiences is crucial to help shape strategy and develop effective, person-centred services. Healthwatch Oxfordshire were approached by the Oxfordshire Palliative Care Network (OPCN), which brings together representatives from key end-of-life and palliative care providers.[15] OPCN had been supporting some targeted insight gathering with specific communities but were interested in hearing from the wider population about people's experiences of end-of-life and palliative care, their thoughts about what is important to them towards the end of their life, and what might help them to talk about their wishes with family, friends or health and care professionals.

[15] Note that at time of writing, funding for OPCN's coordinator role ended.

What did we do?

Healthwatch Oxfordshire developed a survey to hear from the general population of Oxfordshire, with input from the Oxfordshire Palliative Care Network, BOB ICB, and Sue Ryder. We also sought feedback on the survey design from members of local Patient Participation Groups (PPGs).

The online survey ran from November 2025 until February 2026. We shared it through our networks including PPGs, local community and faith groups, death cafés, and our health and care partners. Paper copies and translated versions were made available, as well as the option to complete the survey over the phone. Survey participants who were interested in sharing their experiences in more detail were invited to leave their contact details at the end of the survey questionnaire. We followed up 8 of these with a telephone interview.

In January, we held a discussion with members of a local community group supporting older African and Caribbean adults in Oxford. In March 2026, Healthwatch Oxfordshire's Enter and View team visited Katharine House Hospice where we heard from patients and family members,[16] and we collected additional information about people's experiences relating to end-of-life and palliative care through signposting, our Feedback Centre, and outreach activities.

In total we heard from **over 110 people**:

- 93 people who responded to our survey
- Eight people who took part in follow-up telephone interviews
- Six people who shared experiences of palliative and end-of-life care services via our signposting (information and advice) service or online Feedback Centre
- One patient and seven carers and family members who shared their views with us during our Enter and View visit to Katharine House Hospice
- Three members of a community group supporting older African and Caribbean people.

We carried out a thematic analysis of the qualitiative data.

[16] See the full report on Healthwatch Oxfordshire's Enter and View webpage here.

Who did we hear from?

Of those who responded to the survey, 65 participants (76%) were women, 18 (22%) were men, and two people self-described or preferred not to say. [17] Most participants were in older age groups. Almost half (48%) were aged 65-79 years, a quarter (24%) 50-64 years, and 16% aged 80 or over (**Table 1** below).

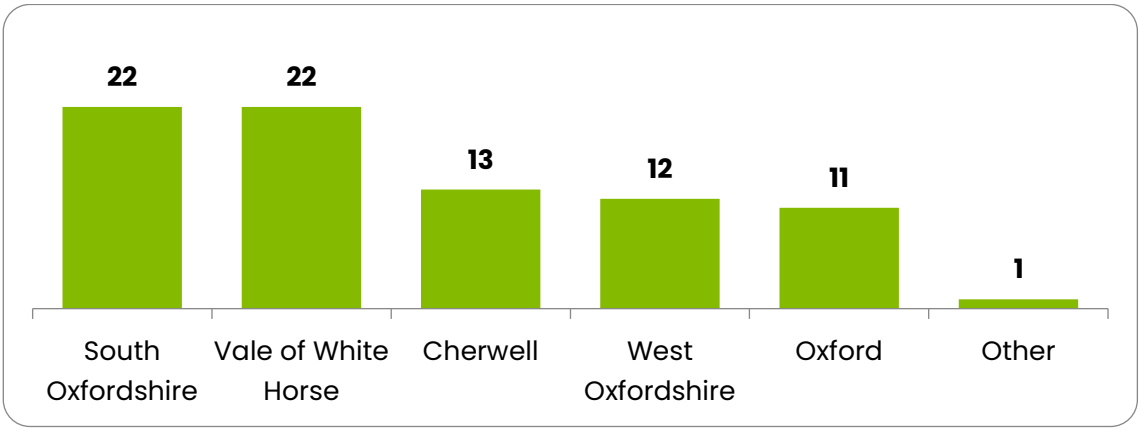
Table 2. Survey participants by age group (84 responses)

Age group	Number	Percent
18-24	0	0%
25-49	7	8%
50-64	20	24%
65-79	40	48%
80 or over	16	16%
Prefer not to say	1	1%
Total	**84**	**100%**

Most people we surveyed said they were White British (86%). Three people (4%) were of in the 'other white background' category. 7% of participants were from non-white ethnic backgrounds including Asian/Asian British: Indian and Black/Black British: African.

We received survey responses from across Oxfordshire's five districts (Figure 1 below), although around twice as many from South Oxfordshire and Vale of White Horse as from other districts.

Figure 1. Survey participants by district (81 responses)



[17] Not all participants answered all questions. Each table or figure heading includes the number of responses received for that question.

A note on data

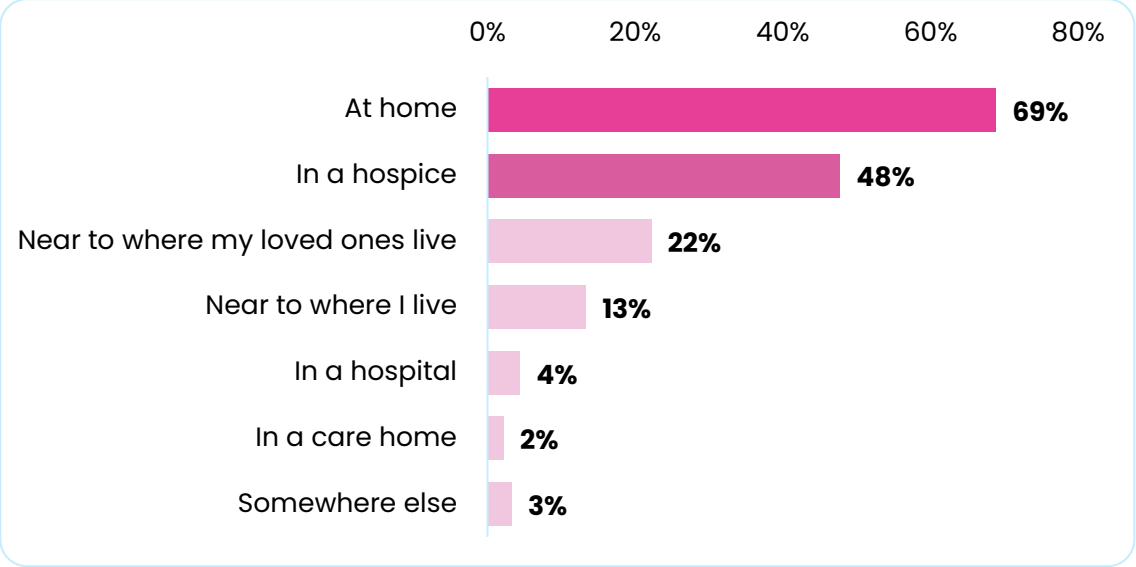
The nature of surveys can mean that people will give feedback when they want to comment on a particular poor experience, or a very positive experience, so overall this may present a less representative view. The scope of this project was to gather insight from the general Oxfordshire population, and therefore did not include targeted work to hear from more seldom heard groups. The data gathered is not geographically or demographically representative of Oxfordshire's population, and the number of responses is small. Some of the experiences we heard about are historic and may not reflect current services. However, qualitative insight is valuable: analysis of people's comments brings out common themes, giving insight into views and experiences of palliative and end-of-life care, and highlighting areas for potential improvement and change.

What matters to people around their death?

Where do people want to be at the time of their death?

In the survey, we asked whether people had thought about what care and support they would want at the end of their life. Eighty people (89%) said they had and ten (11%) had not. We asked those who had thought about it to tell us their preferences for where they would like to be when they die.[18] The results are shown in **Figure 2** below.

Figure 2. Where would you prefer to be when you die? (90 responses)



Note: participants were able to select more than one option

Many more people said they would prefer to die at home (69%) or in a hospice (48%) than in a hospital (4%) or care home (2%). Being at home was important because it meant they could spend their last days in safe, familiar surroundings with the people and things that are important to them.

"I feel I would be more comfortable to die at home, surrounded by family and friends in a familiar setting."

[18] Preferences do not reflect current data trends – as noted in 'Background: end-of-life and palliative care in Oxfordshire' above, 36% of deaths in 2024-25 were in hospital in the Buckinghamshire, Oxfordshire and West Berkshire area. The complexity and unpredictability when people are seriously ill or dying can mean that people's preferences cannot always be met, but as noted, services are increasingly working to support people to be cared for and die at home, if they want to and where clinically feasible.

"Depending on my abilities at home before death, I would prefer to die at home where I might have better access to religious aspects of dying and the closeness of family and friends."

Some responses highlighted the importance of privacy and comfort of home, while others suggested a sense of attachment to their home and belongings.

"We've lived in this house for 34 years. Providing my husband was still alive, I'd prefer to die at home with him."

"At home, in my own bed with my own possessions around me."

This preference was supported by a participant who had been involved in end-of-life care for several of their family members:

"I have plenty of experience of home, hospice and hospital deaths and there is no doubt in my mind that, with appropriate support, home is best for all concerned."

However, one person also noted that family or friends might not be well equipped to provide the necessary care for them at home:

"Family are too close, and memories afterwards might not be good; they would not know what to do at different stages."

Responses reflected a lack of awareness of recent improvements to palliative and end-of-life care provision in the community, such as hospice at home and hospital at home services, suggesting a need for further communication and engagement with the public about these changes.

Of those who said they would prefer to be in a hospice at the end of their life (as a first or second choice), most said it was to have access to trained staff who have the range of skills and equipment necessary to meet patients' care needs.

"Hospice staff are trained in end of life care and make terminally ill patients comfortable. This is not something which can be offered in a private residence."

"I think a hospice would have to hand any items/equipment necessary to keep me comfortable and in as little distress as possible."

People sometimes contrasted the specialist care, medication, and equipment they thought would be available in a hospice with what they thought would be possible if they stayed at home. Other people felt that hospices provided a calmer environment and were family-friendly.

Responses showed that, rather than name a preferred place of death, people sometimes identified places they would *not* want to die in, usually a "*medical facility*" such as a hospital, or a care home. The reasons focused on wanting to avoid an institutional setting, the lack of personal and emotional support, and the possibility of not being near loved ones. They were also influenced by poor perceptions of care or experiences of family members.

"Every member of my family has died in hospital and it has always been a dreadful experience. Lacking care and kindness."

"I would not like to be in a hospital or care home or similar and then be left alone."

Few people said they would *choose* to die in a hospital (4%) or a care home (2%). When they did, the reasons included having access to medical care and wanting to donate their body for scientific and education purposes.

What aspects of end-of-life care and support do people feel are important?

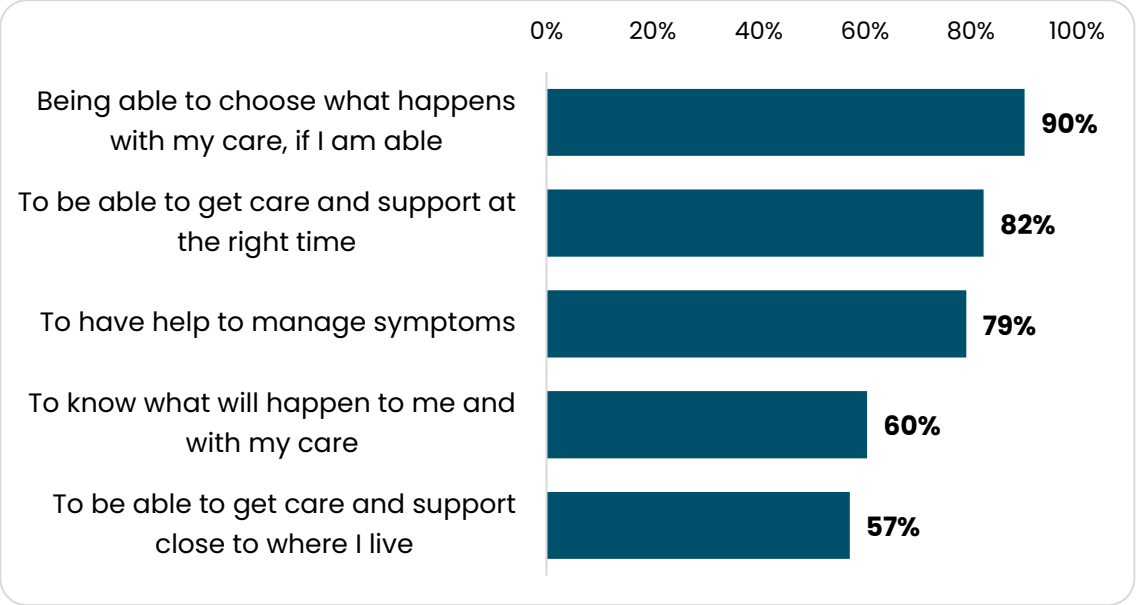
Survey participants identified several aspects of care and support they felt would be important to them at the end of their life. Some people said their responses depended on where they thought they might be at the time, reflecting many of the wishes and concerns noted above.

Figure 3 below summarises participants' responses.

Figure 3.

Thinking about the care and support you might receive when dying – what would be important to you?

(91 responses)



Note: participants were able to select more than one option

Survey results showed the top priority was being able to choose what happens with their care (90%). This was closely followed by getting care at the right time (82%) and help to manage symptoms (79%). Although lower priority, more than half of participants also said it was important to be informed about what will happen to them (60%) and to be close to where they live (57%).

Additional comments gave more insight into what aspects of care and support people felt were important. They focused on:

- Control, choice, and involvement
- Comfort, relief, and clinical support
- Dignity and respect
- Family, relationships, and not being alone
- Familiarity, safety, and emotional reassurance.

Control, choice, and involvement

Several people told us that having control over their end-of-life care, choices, and being involved in decisions were very important. This included having a say in where and how their care should be. For some people this also meant being able to choose *when* they died, as well as being given clear and honest information about what was happening and the available options.

"To be able to talk about what might happen next and have choices where possible for me and/or family members."

"To be able to make my own decisions, if I am still able. If not, for the person with my power of attorney to be able to make decisions on my behalf. To be able to

choose to end my life when my quality of life has deteriorated to the point I no longer want to go on."

For these people, being informed and able to make decisions about their own care were considered important, including – for some – the possibility of assisted dying. One participant said:

"I suffer with a terminal lung problem and when I can no longer cope with my daily needs I want to decide when I take my last breath."

Responses showed that planning in advance was often difficult or impossible because of the unpredictability of patients' circumstances and needs, because they might change their decision nearer death, or because they might not have much choice.

"Would prefer to be at home with family but obviously that could be out of one's control when the time comes and could be dependent on the situation."

"Circumstances rarely allow for a choice. I knew someone who always said they didn't want to die at home, but when it came to it, that's exactly what they wanted."

In cases where the person would not be able to make decisions themselves, people said they wanted others they trusted or those with recognised authority (e.g. Lasting Power of Attorney) to make them.

Comfort, relief, and clinical support

A common wish emphasised by many people in the survey was to be comfortable, pain-free, and free from other suffering. Good care involved having access to trained and capable people, and the necessary treatment to provide appropriate clinical care and manage symptoms.

"Good care whilst dying is being made as comfortable as possible."

"To get the right pain relief, to make life comfortable and not to have to suffer."

"I want to die with dignity and not in pain."

The possibility of suffering or dying in pain was a concern for some people who wanted to die at home, because of perceptions about the difficulty of accessing the necessary support at the right time. One person highlighted a lack of palliative care support for people with life-limiting conditions.

"I think there is a lack of care around people with chronic and life-threatening illness, their chance of death is significantly higher than most but they only meet criteria for very routine care and this is never discussed."

Dignity and respect

People told us they wanted to experience the end of their life with dignity and respect. These were described in different ways. An important aspect was for patients to be able to make their own decisions about their care, including the option of ending their life at the time they choose.

Respect also meant keeping people informed about what was happening and being involved in planning for their care and dying. People highlighted the importance of their wishes being carried out in the event they are no longer able to communicate or make decisions.

This also meant being listened to, or "*being heard and not dismissed*". People said that, even when dying, they should be treated as an individual and whole person rather than being labelled as a patient or a "case". What mattered was the knowledge that they would receive good quality care and support, wherever they are.

Aspects of personal wellbeing were central to the idea of respect and dignity in dying for many participants. This included cleanliness and personal hygiene, and maintaining their appearance. We also heard about the importance of culturally appropriate, person-centred personal hygiene – such as skin moisturising and proper hair care for Black people (see **Quality, continuity and responsiveness of care** below).

"Good care would be that my physical, mental, and spiritual needs are met."

"I would like to be clean and washed and smell nice using perfume. I would like to wear clean and nice bedwear and have clean and nice bedding."

"Being spoken to properly as a person…properly considering the whole person, not just the one set of symptoms/illness."

Some people felt privacy was important, such as when providing personal or intimate care. Respect also meant having time to oneself and ensuring a quiet and peaceful environment. Some people suggested being able to have certain things with personal importance near them such as pets, fresh air and nature, and music of their choice.

Family, relationships, and not being alone

Many people said they wanted to be supported by family and friends, and not be alone at the time of their death.

"I would like to feel supported and for there to be support available for my family members too."

People told us how local faith and community groups could be an important sources of support, helping patients and their families remain connected with their community.

"Our community is very supportive – whether you're supporting that person directly or their family – 'Tell them I'm thinking of them, I'm praying for them.' It's part of that connectedness – being held, cared for, supported."

However, they were also aware of the impact that caring for them and their death might have on family and friends. Besides the emotional toll, several people told us it was important that they did not feel like a burden or that their relatives did not have responsibility for their care.

"I want to die as I've lived, and be remembered for who I am/was, not as a sad story of someone gradually falling apart and being a burden on their loved ones."

"I would prefer the calm and specialist care of a hospice if I was dying with complex medical needs that were too much for my family. If I was dying with less complexity I would like to be tucked up in my bed at home."

People said they wanted their loved ones to be supported throughout the process, whether they were being cared for at home or in a hospice. Good support and consideration for family and loved ones included providing practical support for those caring for them at home. It also meant health and care providers welcoming their friends and family by facilitating regular visits, involving them in the person's care, and allowing them to support and advocate for them.

"It worked best when various friends came. One time there were 6 of us sitting around her bed, talking to each other, and she was aware of us all there."

Familiarity, safety, and emotional reassurance

As highlighted in the section above, feeling a sense of familiarity during their end-of-life care was a priority for many participants. They told us it was important for them to feel safe and reassured at the time leading up to their death, and often included being in a calm, safe, comfortable environment, whether at home or in a health or care setting. People said they wanted *"peaceful surroundings"* or *"a private, quiet atmosphere."* Others said that end-of-life care should be positive and about *"not taking hope away from patients."*. One person summarised it as:

> "I would want to be pain free and with those I love - not necessarily with constant professional health carers but with their support if needed. To hold someone's hand and see nature somehow, hopefully my garden with birds and flowers. Idealistic I know but family, friendships, animals and nature have been a big part of my life so I would like them there at the end."

Other comments included ensuring the person had practical comforts and care, ensuring their everyday needs are met, such as having the food and drink they like, food that is culturally appropriate, or enjoying a final luxury such as a glass of whisky and a cigar. For some people, spiritual or religious considerations would be important, including having access to people of their faith or church and religious practices, especially surrounding death.

Who do people want support from and what type of support might they provide?

People identified various sources of support they might want when they are dying, although some did not specify this because they felt it would depend on the circumstances at the time. Those who did highlighted the following:

- Family and friends
- Health and care professionals
- People from the local community, or church/faith group
- Local voluntary groups or services

The types of support they would like to receive included:

- Help from health and care professionals to **manage symptoms and pain**
- **Emotional support** to provide companionship and not to feel alone – such as occasional or regular visits from family, friends, and people from their faith group, to spend time with them and help maintain a cheerful, positive atmosphere

- **Information and clarity about the dying process** from trained or experienced professionals
- Trusted people to **advocate for them** and take decisions on their behalf, if necessary
- Support with everyday domiciliary care and practical help.

The following comments illustrate the types of response we received:

"Depends so much on the nature of decline and final stages but overall - health professionals for symptom management and candour about the likely process of death. Care professionals for support in day-to-day living when/if faculties fail. Family is dispersed so occasional practical help and care but a constant emotional support and the joy of contact. Friends for distraction and laughs."

"Support from health professionals with experience of dying. Friends and family to be with me so I don't feel alone."

"I would want support from my church family… and from the hospital chaplaincy service. I'd also appreciate visits from friends and relatives."

These responses highlight the importance of different **circles of care**, and the assets and links that health and care professionals should join up with and strengthen to improve the support around a person.

What fears and worries do people have about death and dying?

Several people commented that they were not worried about death and dying. Some said they were not afraid of death itself but did have some fears about aspects of the dying process. Of those who did share fears, most said they worried about suffering with symptoms or pain as they were dying.

Another common fear was dying alone, including being overlooked or forgotten by health professionals or carers. People with no immediate family also shared concerns about being alone and not being able to die at home. Even when patients have family, people pointed out it was not always guaranteed that they would receive support from them, and that professionals should avoid making assumptions about what support people might have from unpaid carers, for example on the basis of someone's ethnicity or culture.

"It's hard for elderly people living alone, if you don't have that family proximity. There's an assumption with certain cultures that there will be family support, but it's not always there."

Some people told us they worried about lacking control over decisions or for their wishes not to be respected, and included the possibility of loss of identity due to mental incapacity.

"Inability to express my wishes, e.g. after a stroke, is something I worry about. I fear loss of self-identity due to dementia and the impact this has on loved ones."

"My only fear is that I will lose my mental capacity and no longer be able to exercise choice. I have tried to put in place as much as I possibly can - LPA For Health and Welfare, Advance Decision, Expression of Wishes, etc. etc. and have discussed my wishes over decades with my family and attorneys. But I know (I have seen) that despite all that, health professionals are determined to keep you alive long after you are ready to die, and will override the patient and family's wishes to that end. That prospect frankly terrifies me."

As the above quote indicates, some people worried that doctors might administer treatment without their ability to consent or that their lives might be unnecessarily prolonged beyond what they would want.

People with previous experiences sometimes said they feared poor quality care, undignified treatment, or receiving care in an inappropriate place. For example, some said they had seen a loved one spend their final days in a busy or noisy hospital ward or receive inadequate care before dying.

Participants from an African and Caribbean support group told us that people in their community associated the name of a local hospice with finality and hopelessness for the patient. They said that the expectation that someone going into a hospice is going to die hospice might make families reluctant to welcome visitors.

"One word that makes us go, "Oh my God, it's the end," is [X Hospice], that word alone sends ripples of sadness, anguish, pain through our community. Even though we know it's very good. If you say "hospital" there's a glimmer of hope, wellness, coming home."

This contrasted with a comment from a person currently receiving palliative care, challenging the perception that hospice care is about end-of-life care only rather than palliative care. This reflects the need for better communication with Oxfordshire's communities about the role of hospices in palliative and end-of-life care.

"Everyone thinks hospice is doom and gloom and it's not – the main objective is still to get you better!"

A Muslim participant expressed concern about being able to access the body of a dead loved one to adhere to their religious practices. They worried about:

"Health and care staff understanding of and willingness to releasing the body after death for burial and making the process easier for families who are grieving and need to get the burial done within 24 hours/asap… Muslims need all this help to make the process easier at this difficult time when they are grieving and need help to coordinate all the services within very strict timeframe."

We heard from another Muslim participant who expressed a perception that being cared for in a hospice, rather than a hospital, could go against their belief in an obligation to seek a cure for illness.[19]

Again this reflects the need for services to proactively reach out to build stronger relationships with different communities to improve communication, trust and cultural competence – for example, highlighting the role of chaplains in ensuring that people's cultural and religious needs are met.

A few people feared **dying with unresolved issues** such as family disputes, problems with wills, and other administrative tasks resulting from the person's death.

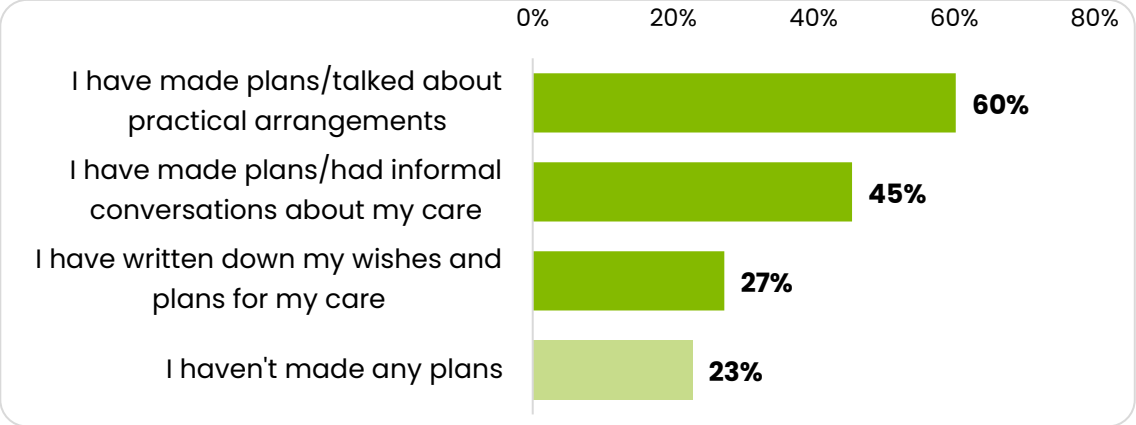
[19] See also, Suleman et al, 2019: Elderly and End of Life Care for Muslims in the UK, Muslim Council of Britain.

Communicating wishes and making plans

What plans have people made about their wishes for when they die?

Our survey asked whether participants had made any plans, or had conversations with family, friends, or health and care professionals about their wishes for when they died. People were able to select one or more option from a short list of choices, as shown in **Figure 4** below.

Figure 4. Have you made any plans or had conversations with others about when you die? (88 responses)



Note: participants were able to select more than one option

As the figure shows, most people said they had made plans or had conversations with family, friends, or health and care professionals about their wishes. 60% had made plans or talked about the practical arrangements for their death while 45% had made plans or had informal conversations about their end-of-life care. This relatively high proportion may reflect self-selecting bias (those who have thought about their death may be more willing to complete a survey about it). However, only 27% had written down their wishes and plans, and 23% had not made any plans.

People who said they had had conversations or made plans for their death mentioned making a will, arranging (and sometimes pre-paying) a funeral plan, and making a Lasting Power of Attorney (LPA) agreement. A few people also said they already had an Advanced Decision (also known as a living will) in place, including instructions to cease certain treatment or a 'Do Not Attempt Cardiopulmonary Resuscitation' order (DNACPR, previously known as DNR)[20].

[20] NHS webpage on DNACPR

Those who had made formal plans considered it important to ensure their wishes would be respected, as well as to reduce the burden on family members during their care and after death.

> "Nobody wants to do this, but it is best to do this while you are happy and healthy so all parties know when the time comes."

> "I have done as much preparation as possible so that my family find it straightforward to deal with practical arrangements. LPA, living will, and will. These plans will make it easier for my loved ones to deal with my death."

However, not everyone felt completely sure that formal agreements would guarantee their wishes. One person said:

> "I honestly don't know what more I could do, and yet I'm still not confident that I will get the death I want."

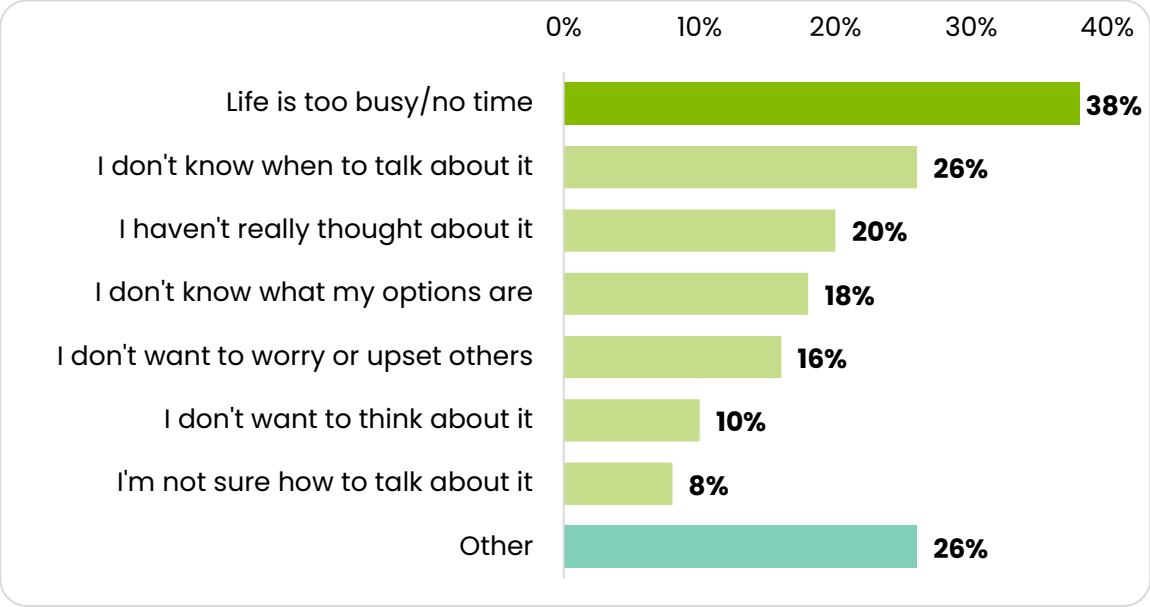
We also heard from people who had prepared personal instructions and information about their wishes, although it was not clear whether it was instead of, or in addition to, legal documents.

> "I have a folder of information about what needs officially to happen and my wishes for funeral, disposal of assets, etc. Want to make everything as straightforward as possible for my family when having to deal with everything which will need to happen."

What prevents some people from making plans or having conversations about their death?

We heard about the various reasons for not making plans or having conversations about end-of-life wishes, as summarised in **Figure 5** below.

Figure 5. What has prevented you from making plans for your end-of-life care or death? (50 responses)



Note: participants were able to select more than one option

As the graph above shows, most people (38%) said they were too busy or lacked the time to discuss or make plans. Others said they were not sure when was the right time to have the conversation (26%) or had not thought about it (20%). 18% said they did not know what the care options were. Others said they had avoided making plans because they did not want to upset others (16%). Fewer people said they did not want to think about it (10%) or were not sure how to talk about it (8%). Other reasons (26%) included feeling it was too early (e.g. they felt they were too young), having nobody appropriate to discuss it with, and because assisted dying is illegal in the UK.

Below are examples of comments we heard:

"The only thing I have made plans for is to have my organs donated if applicable. I am still relatively young so haven't really thought about it this far."

"Although I'm living with various life-limiting conditions, I'm not ready yet."

"The large bureaucracy that is the NHS is extremely intimidating when it comes to understanding the options around death and what I am entitled to or what I can access."

Several participants said they were reluctant to think or talk about death and dying because they are sensitive or fearful topics.

"I fear dying so don't want to think about it or talk about it."

"Don't like to think too much about dying."

"People don't want to talk about it because it's dark."

Not wanting to discuss death and dying was also barriers to making plans for end-of-life care. In one example, a wife described initiating plans herself as a way of motivating her husband (who had recently been diagnosed with an incurable condition) to prepare his own:

"We got support to do a Lasting Power of Attorney for health and welfare. I think we got a leaflet from Carers Oxfordshire about it. I said, 'I'll do mine, would you like to do it with me?' because I knew he wouldn't do it on his own." (From Story 2, Appendix 2)

We asked survey participants whether they had heard of the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT). A ReSPECT plan involves having a conversation with a health care provider to record the types of care and treatment that will or will not be carried out in an emergency.[21] Only 27 (30%) of the 90 people who answered said they had heard of ReSPECT and, of these, only one had made a ReSPECT plan. Most people who had heard of it, said they had done so through working in health or end-of life care.

What support or information would people find useful?

We heard a variety of responses about what support or information people thought would help them or their loved one prepare for death.

Several people highlighted the need for more widely available information about the process of death and dying, and how to plan for end-of-life care. Suggestions about sources of information included websites, leaflets, or booklets left in places like GP practices or libraries. Some people said they wanted to

[21] See the full ReSPECT guide on the Resuscitation Council UK website.

understand more about death, including the process of dying, what happens to your body after death, and the role of undertakers.

Others wanted "good honest information" from health and care professionals about medical aspects and options at end-of-life. People wanted advice on the legal and financial steps they can take and to know what their next of kin would need to do after their death. Several people specifically asked for information about ReSPECT.

Types of support that were highlighted included emotional and faith-based support, and access to independent lay people or advisors from trusted organisations to discuss plans with or without family, or advocate for people who lack support. (See Useful Links below for resources and advice.)

"Opportunities to have structured discussions, i.e. prompted by someone else or some sort of resource provided by a trusted organisation."

Two main areas of support that people said they would like from the health system were good communication with health and care professionals, and assurances of good end-of-life care.

"Clinicians being ready, skilled and comfortable to talk about death and palliative care and not focus only on what treatment options they can offer me. It is a great pity, I think, when doctors behave in such a way that if the person doesn't want active treatment they become "no longer a patient of interest". I want all illnesses to be discussed in the context of my life as a whole."

"Doctors need better training in how to speak to people regarding options. From what I've seen too many have no clue how to speak to people, and therefore cause unnecessary distress. People are made to feel like a burden, rather than being cared for. Surely nothing can be more detrimental to their wellbeing."

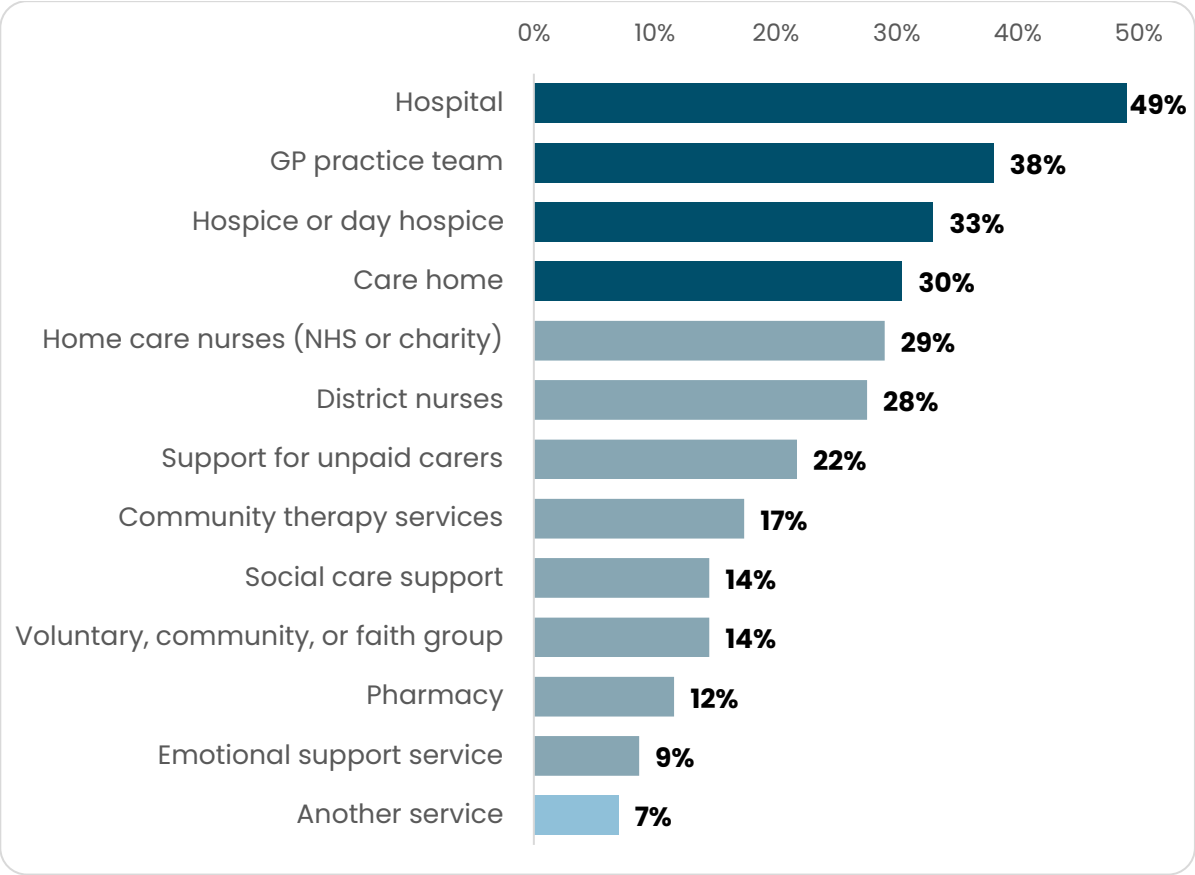
Making information widely available and in various formats and languages (leaflets, booklets, websites, videos) was seen a way of increasing awareness and access to information. This could include working with communities to co-design information and communications to ensure they are culturally appropriate and relevant. Another idea was for representatives from palliative and end-of-life care services to talk to community groups to improve awareness about what support is available and hear what people want in terms of culturally appropriate support.

Experiences of end-of-life and palliative care

Sixty people (70%) in the survey said that a friend or family member was receiving, or had received, care and two participants were currently receiving it themselves. Around half of the responses about care experiences related to 2022 or earlier (see **Tables 3** and **4** in **Appendix 1** for more information).

Figure 6 below summarises the health and care services that had provided palliative or end-of-life care and support.

Figure 6. What health and care services provided support? (69 responses)



Note: participants were able to select more than one option

Most people who had received palliative or end-of-life care were supported by one or more health and social care service – although some people also noted that they did not always know which service was providing care. Hospitals provided care for almost half (49%), followed by GP practices (38%), hospices (33%), and care homes (30%). Support from community-based services included district nurses (28%), unpaid carers such as friends or family (22%), community therapy services such as physiotherapists and occupational therapists (17%). Few people (9%) reported accessing an emotional support service.

What aspects of palliative or end-of-life care worked well?

Responses highlighted aspects of service responsiveness and coordinated care; communication, information, and involvement; compassionate and high-quality care; family support and inclusion; and practical support.

Service responsiveness and coordinated care

In one interview, a participant described the prompt responsiveness and support of a specialist palliative care team:

> "I was amazed at how the palliative team kicked into action. When I'd first taken her to the palliative care people at the [hospital] and [hospice]… they kicked into action very quickly… the team got straight onto [DWP – about benefits] and suddenly a lot of money appeared into our bank account."

Another participant recounted the effective coordination of health and care providers with the family, to help someone to be supported at home:

> "We had a hospital bed delivered on the Monday, a live-in carer arranged to come on the Tuesday. A care agency to supply the additional carer for double handed care and the district nurse and GP all involved and liaising with each other. Communication was excellent and timely. I don't know who organised what, who came from where – I just know that everything that happened was seamless." (Story 4, Appendix 2)

Communication, information, and involvement

People said they had valued being kept informed of their own or their loved one's condition, including the "stages of decline." A hospice patient told us:

> "The communication is very good. I haven't been left in the dark at all. At every turn I've understood what's happening."

Similarly, people told us that it made a difference when health and care professionals listened to and respected patients' wishes and gave them a choice over their treatment, and that this was helped by having a good care plan.

We also heard that family and carer support groups were helpful as a "safe space" for people to talk and share feelings and practical advice. Participants

said it helped them understand and accept what was happening, and to move forward.

"I would like to say how helpful this group has been – to share how we're all feeling, even though we've all been living with it for different lengths of time. It's helped me feel it's natural and normal to feel what I'm feeling. It's a safe space. Sharing the feelings is really supporting, and hearing others going through them. It helps with the path of acceptance – which is crucial for peace of mind, but not easy. Instead of overthinking and always anticipating what's coming."

Compassionate and high-quality care

We heard many examples where health and care professionals, including district and specialist nurses, hospice and live-in carers, had provided exemplary support and care. Several accounts demonstrated caring and compassionate attitudes of health and care professionals.

"Hospice care is absolutely vital to our lives. I have seen first hand how wonderful caring supportive and genuine they are. They talk to me as if I'm not a patient but one you would treat as if I was a family member."

"Some of the nurses, care assistants, desk staff were excellent and treated patients as if they were caring for a family member."

"There was one really good young man who came to wash and change her and the bedding [in the hospital], he was brilliant. So gentle, he treated her like someone he cared about."

Being treated with respect and compassion helped patients and their relatives in their final days. Some people said this gave them *"comfort and solace"*, knowing that their loved one was treated well.

Family support and inclusion

People told us they appreciated care and support being extended to family members, not only during end-of-life care but also during the grieving process and beyond. This included emotional support but also help with planning and reviews, and coordinating with the GP so that unpaid carers did not have to do this. We heard how important and meaningful it was for some people to be involved in their loved one's care.

"Later F needed cleaning up 2-3 times a night, she wasn't capable of doing it so I had to do it, so I wasn't getting enough sleep. But looking back, I'm pleased I did it." (See Story 1, Appendix 2)

There were some examples where community advocates had stepped in to help or voluntary or community organisations and services had provided support for bereaved family members.

"There's a man whose wife had passed away, the housing association was going to evict him, so we got involved. People want familiarity when they come out of hospital, and neighbours that they know."

We also heard about the importance of recognising community relationships, friendships and 'chosen family', for example for LGBTQ+ people:

"When my friend was dying of cancer, I was her 'person' but I had to lie to get in to [the hospital to] see her, by saying I was her wife. The staff were good on being aware about LGBT stuff but not understanding other kinds of relationship."

Practical support

A small number of people said they valued receiving practical help during palliative or end-of-life care. These included being provided with equipment to help their loved one be cared for at home (e.g. a hospital bed) and having care in a private room in the hospital.

What aspects of palliative or end-of-life care could have been better?

Several people told us that "very little" or "nothing" had worked well during their loved one's palliative or end-of-life care. Survey and interview participants described various concerns about the quality and reliability of care. These included access to care and support; communication and involvement in care; and quality, continuity and responsiveness of care.

Access to care and support

Some responses described difficulties accessing or navigating aspects of care and support. This included being able to admit a loved one to a hospice or care home, finding help with the costs of palliative and end-of-life care including home care, and availability of some community health care support such as district nurses. Some people said more generally that they had not been supported with the care needs of their loved ones.

"I didn't receive any kind of support for my mother while she was dying in the [hospital]."

"As unpaid carers when they [parents] were at home, we had virtually no support from social services (apart from statutory care provision) and struggled to have our opinions listened to by hospital staff and social services. It was horribly stressful."

People also told us about challenges navigating a fragmented landscape of care and support for some conditions, such as dementia.

"One of the problems with dementia care is that you're entirely on your own. There's a need for a single point of contact. Because I'm a nerd, I'd be the one saying to the [support] group, 'If you need help with this thing, you need to speak to this person, this is the phone number…' The argument is always, 'We will support you,' but what they actually mean is, 'We'll give you a list of websites and phone numbers.'"

We also heard about a lack of joined-up, holistic support between primary care and other services.

"I have just completed a course of chemotherapy at the Churchill Hospital. I cannot fault the care and treatment I have received. In contrast I have not had any contact with my GP throughout this difficult time which included the death of my father for whom I was a carer."

Communication and involvement in care

In several examples, people reported not being sufficiently informed about aspects of their loved one's care. A lack of communication from some health and care teams meant they sometimes had to specifically seek or ask for information and support, rather than it being offered when care was needed.

We heard examples where health professionals had been insensitive and conversations upsetting for patients and their families and carers. The following two interview excerpts describe discussions about DNACPR orders:

"When we had the DNR discussion with the GP, it was a home visit, which was good, but I've never seen my mother more distressed. He was too brusque, though she'd tried hard to connect with him. He didn't read the room, and tried

to get it signed there and then. He should have left us to have the conversation. She just shrank into herself, dropped her head on her chest, her shoulder came in. It felt like being told, 'If you're going to die, get on with it.' They were new patients to the practice, and could have done with a double appointment when they registered: 'Let's review your medications, tell us about you, what are your wishes.' My husband and I do now have DNRs in place – but those conversations need to happen earlier."

"I had a bad experience with end of life conversations. I have [condition] which I'm used to but I was so short of breath that I went to A&E. The doctor came in and said, 'It's a [serious condition], have you signed a DNR?' I said no and she said, 'Oh well, I'll have to book you an ICU bed then.' It felt like, 'Oh, we'll have to go through the motions.' It alarmed me a bit afterward, and you feel a bit worthless, like your decision isn't the right one. It would have helped if she'd said something like, 'I'm sorry I have to ask, but have you…?' and been more pleasant, maybe explained if I'd crashed what would have happened – being a bit less cut and dried about what the outcome would be." (Story 3, Appendix 2)

A small number of people reported a lack of communication in an in-patient hospital setting, between departments and with the patient's support workers and GP. We heard some cases of language and communication barriers between patients and health and care professionals. Besides making it difficult for patients and families to understand what was happening, some people felt it had compromised their loved one's care and safety.

"She was on oxygen which meant she couldn't hear very well, and some of the [hospital] staff, especially the young doctors, were hard to understand. She felt more and more that they didn't care, and when they talked to her about DNR, she felt she had no future. It wasn't necessarily the right time to do it, and the junior doctor who did it maybe didn't have an appreciation of how she felt like she was a burden."

Quality, continuity and responsiveness of care

Several people highlighted negative experiences of poor quality care. They covered different types of care arrangement, including live-in carers, a local authority-administered care facility, hospice care, and in hospitals. We heard about challenges with social care, and with the interface between social care and other care services.

"R had falls in the care home – 22 falls in 11 months. They weren't helping him shower or dress, and he couldn't charge his hearing aids. One time I went to see him at 10am and he had nothing on but a cardigan, with a cold tea and a cold meal in front of him. He was so bewildered." (From Story 2, Appendix 2)

"My [relative] came [to the hospice] for pain management last year, and once it was under control went to a care home. I was not happy with the medical or personal care there, although relatives can help with personal care we can't help if the medical care isn't adequate. There was a lack of staff and a lack of communication. The doctor came once a week but the process to change her pain medications was very slow, it took an hour and a half. She was getting pressure points from not being turned enough."

In one case, someone described how they felt there was a negative change in hospital nurses' attitude when their spouse was placed on a palliative care pathway:

"...and that's when the doctor said, 'I can tell you he'll never recover,' and arranged for the move to palliative care. When that happened, the nurses' attitudes towards me completely changed. He was stuck in a room on his own, it was incredibly sad." (From Story 2, Appendix 2)

We heard some accounts of poor basic care, lack of attention to patients' dignity in care, personal care needs, and unprofessional staff behaviour. Several people highlighted a difference between 'hospice at home' provided by social care providers compared to palliative care services.

"Local Authority carers were very irregular with their times, often did not seem to know what they were doing, e.g. how to operate the hospital bed, did the bare minimum e.g. removing her dirty clothes but leaving them in the floor for me to wash when I visited - or any of her friends if they arrived first. Humiliating."

"...the end of life live-in carer provided by the NHS who was dreadful! All she was interested in was whether we had Sky TV, the WiFi password and what was for dinner! The district nurse had to call her out for her lack of any hands-on care (while I was helping her to move my Mum) and she went to bed during my Mum's final hours, so I had to wake her when my Mum died only for her to get into a panic about what to do next! She was worse than useless."

"There was another guy who checked her catheter, he just flung back the sheets and started poking her, and she flinched. And you shouldn't just fling back the sheets like that."

We also heard how a lack of understanding and appropriate training led to a lack of appropriate, person-centred care – which in some cases exacerbates existing health inequalities. In this example, community workers highlighted a lack of understanding of how to care for Black people's hair and skin appropriately, leading to discomfort and lack of dignity in care.

"Culturally there's a really big gap in care provision for skin conditions and hair. Like moisturizing after bathing, or not washing hair every day, hair getting matted because they're not looking after it properly. When there are staff from that background, they do it right."

Some comments focused on issues with staff availability and continuity of care. This included not having access to staff during a critical time and there being nobody available to attend to their loved one.

"Hospital treatment worked well but a bit disappointed with [the hospice] as [the] patient was left in a state overnight, and in the morning I requested help but they were busy having a meeting. Staff [should be] available at all times to assist dying patients when the care is required."

"Appropriate care available 24hrs, consistent staff."

"Opportunity to talk to the same doctor and/or nurses i.e. more continuity at hospital."

A small number of people described inadequate pain management in both hospital and hospice settings.

One bereaved husband recounted a communication and coordination breakdown when his wife was due to go into a care home. This caused delay and confusing in arranging the appropriate care.

"With the help of the palliative care team, I was looking at her going to a care home. It was all set up and arranged and then we heard nothing from them. She was deteriorating quite rapidly. The palliative nurse visited and couldn't work out what had happened with the care home, but said that they had empty beds at

[X hospice] and would she like one? We agreed she would go there. We had to get the ambulance team to help her downstairs. While the nurse was making arrangements, I took a call from the care home manager, saying they couldn't take her because they had no experience of a nephrostomy bag. That seemed strange because nephrostomy bags are unusual so you wouldn't expect people to have experience of them, but also it's quite straightforward to manage – it was a [poor] explanation." (From Story 1, Appendix 2)

Improving end-of-life and palliative care

What improvements would support people who are dying and their loved ones in Oxfordshire?

We asked people for their ideas and suggestions on how patients and their loved ones could be better supported during the end-of-life process. Responses focused on the following themes:

- Improving access, capacity, and funding of services
- Better information, communication, and conversations
- Better coordination and navigation of care
- Improving staffing, skills, and quality of care
- Better support for families and carers
- Greater choice and autonomy
- Support to live well

Each of these are described in more detail below.

Improving access, capacity, and funding of services

Survey participants highlighted the need for more access to palliative and end-of-life care in general. In particular we heard the need for more hospices, community health care staff, and home care. Comments included:

"Invest in palliative care."

"Hospice places should be available for all who are dying. They do such a good job."

"[Hospice], their rooms are lovely and big, with doors onto the garden. It's a wonderful place, with a little chapel as well. They should be supported more."

"More affordable access to live in carers trained in end of life care."

Some people who also supported greater funding and prioritisation for palliative care, not just as increasing access, but also from a cost-effectiveness and impact perspective.

"Put palliative care higher up the agenda - especially regarding funding. I am certain that it would save money from the health budget as a whole."

Better information, communication, and conversations

Many people asked for more honest and open communication with health and care professionals about dying and end-of-life care. People said they wanted clearer information – including about what support was available and how to access it, what someone's options for care were, what they could do to support a loved one in their last days and hours, and what to expect when someone dies in terms of paperwork and physiological changes. People said they wanted to be kept up to date about treatment and prognosis, and to be involved more in discussions and decisions about their care[22].

There was a sense that conversations about death need to become normalised, where people feel more comfortable talking about it and planning for it. Some people suggested that earlier conversations about death and dying would give families more time to prepare and make informed decisions.

"More opportunities to discuss, read about and understand options."

"…talk more, at an earlier stage…Thinking about the end of our life should be part of the planning for living a good life, threaded through health care."

Better coordination, continuity, and navigation of care

People sometimes described end-of-life care services as fragmented and difficult to navigate, particularly when more than one was involved. Some called for better coordination between all sectors involved in supporting people in palliative or end-of-life care.

"It feels disjointed, underfunded and ill equipped for future need… Better coordination between hospitals and GP's and the hospice sectors."

"The [hospital] need to liaise with support workers and the patients GP more closely. We were offered no support whatsoever…There should be a one-person contact who can direct the relatives to which ever group is more beneficial."

[22] See also Parliamentary and Health Service Ombudsman July 2026 report: Conversations that matter most: improving communication in end of life care.

The need for a **single point of contact** was seen as an important way of supporting patients and families to access prompt, appropriate information, advice, and support in one place rather than having to find out through multiple channels.

Suggestions for improving home care included ensuring patient care assessments and home care packages are planned early on so that the patient's needs and the level of support are clear in advance, and improving continuity of care by making sure the patient's GP is involved in their end-of life care.

Improving staffing, skills, and quality of care

When reflecting on their loved ones' care, some people highlighted the perceived need for more qualified staff, targeted training, and improvements in aspects of quality. This included ensuring that health and care professionals have enough time for caring duties and the necessary skills to deliver both basic and holistic care.[23]

People also told us that patients at the end of life must be treated as a 'whole person' with individual needs.

> "Treat people like the individuals that they are… Make sure you spend time communicating with them clearly and caringly."

Some people emphasised education and capacity-building for health. These included training medical staff to focus attention on the patient as a person and not reducing them to a terminal health condition. Another suggestion was for all staff to have a better understanding of cultural and religious beliefs and practices.[24]

> "…teach doctors particularly, to focus on people and their lives in their discussions and decision making, not so much on the diseases they are treating, valuable as their expertise is"
>
> "Ensure that carers are aware of cultural and religious views around death requirements."

Some felt these barriers might be addressed through awareness training or by employing people with the relevant cultural knowledge or experience, or involving communities in co-production. Involving family members might also

[23] Note existing training for health and care professionals on end-of-life and palliative care and support, including via OxCERPC/Sobell Education

[24] See also Oxfordshire Care Cooperative 2026 report which highlighted a need for culturally appropriate social care.

inform care staff but this might only be effective when there is continuity of carers and not frequent changes.

Better support for families and carers

We heard a range of suggestions around improvement in support for families and carers. They included access to counselling and emotional support, opportunities to talk generally or discuss death and dying with others, and practical help and support before and after the person's death.

"Have local voluntary groups where possible to explain and talk about this subject."

Another person felt unpaid carers should have more access to support from palliative care specialists.

"More opportunities for family carers to talk things through, preferably in person, e.g. with [specialist] Nurses."

More support for people without close relatives also came up in some survey responses.

"Pity there isn't more care to prepare and support people without family and friends."

Greater choice and autonomy

Several people felt strongly about the need for more support to make individual choices and have control over their end-of-life care and death. This included more discussion of assisted dying.[25]

"To be able to access assisted dying from a professional when pain gets unbearable and takes away all quality of life."

"Voluntary entry of death i.e. for wishes to be respected. Give the person the choice… Assisted dying, open conversations"

"My partner and I are both in favour of assisted dying. I'm not afraid of coercion, if I didn't know I was being coerced or not, it wouldn't matter to me. I don't

[25] See information on the Terminally Ill Adults (End of Life) bill, at time of writing at committee stage in the House of Lords.

believe you have to suffer to the bitter end. For me it's about avoiding unnecessary suffering. When the time has come, if there's an easy way and a hard way, we'd take the easy one. I've talked about it with my wife. I wouldn't want to go through what my parents had of being kept alive."

However, not all participants were supportive. One interview participant highlighted the some of the risks:

"The assisted dying bill concerns me because to me there's no way you can tell if someone's six months away from death. Money comes into, the cost of the nursing home. It would have been easy for the family to put pressure on her, if there was a young relative who needed the money, for her to say, "I don't need the money, I don't need to be here anymore."

Support to live well

Throughout this project, we heard about the importance of support to live well towards the end of life – including thoughtful and timely conversations about planning, well-coordinated care in a place that works for the person and their loved ones, and good information and advice from health and care services as well as community and voluntary organisations.

"We used to go up to a place on the Downs and have coffee, with blankets round our legs and a view over the countryside, and once she said, 'This is how my life should be.' She shouldn't have been thinking about her demise, she should have been enjoying her life."

"My Vision Oxfordshire were awesome. They set up [a smart speaker] for her originally. They showed her how to have a black tray, with a white plate with food on it, to give her a fighting chance of eating. And they did coffee mornings [locally] – Mum and Dad were living in a new place so it was good to meet some new people."

"My friend who had cancer was cared for at home instead of [hospice]. His wife did the nursing, they turned his sitting room into his bedroom. The care he had at home was fantastic, the support system in place. He had an environment where he was cared for, he knew he was cared for and loved, it was beautiful."

Appendix 1. Additional data tables

Table 3. Have you, or a friend or family member, experienced support from palliative or end of life care?

Answer Choice		Response Percent	Response Total
1	Yes - I have received or am receiving this kind of care	2.3%	2
2	Yes - a friend or family member is receiving or has received this kind of care	69.8%	60
3	None of the above	16.3%	14
4	I have another experience (please describe):	15.1%	13
answered			86
skipped			7

Table 4. When did you experience this care?

Answer Choice		Response Percent	Response Total
1	2025	18.8%	13
2	2024	13.0%	9
3	2023	18.8%	13
4	2022 or earlier	49.3%	34
answered			69
skipped			24

Appendix 2. In-depth stories

The following selected case 'stories' are interviews with people who shared their experiences of palliative and end-of-life care. They are included here to provide more detailed accounts of people's journeys.

Story 1: "Looking back, I'm pleased I did it"

F had been ill for more than two years, but she coped very well. With her [medical] training, she knew how to make the best use of medications and was able to control the amount and frequency she used. She had experience of cancer treatment back in her first job and a lot hadn't changed since then. I'm pretty sure she knew it was getting to the very last stages. She knew it was her last Christmas, and she was determined to celebrate our golden wedding anniversary – which we did. She coped pretty well on the surface, but I knew what was going on underneath.

The tipping point for me was when she stopped wanting to eat. And one night after that she was very sick, which is very difficult when you haven't eaten anything. I was wondering what the green stuff was in her sick when she pointed out that some of her tablets had a green coating. We used the emergency out of hours contact, and I got someone to speak to me and hear what was going on. I was sitting there for over an hour answering questions. She was very uncomfortable, very unwell, so when the original person I spoke to said they'd arrange a specialist to talk to me, I changed handset so I could talk to them and sit with her upstairs.

That was about [2 months] before she died, and things just got worse and worse, we were managing as best we could.

The palliative care team came pretty soon – initially we had two visits, making sure we had what we needed and they ordered various bits of equipment. Like a hospital bed with buttons to move it up and down. As soon as that stuff was delivered, we put it up in the downstairs room that is normally a study. She wasn't keen on it, the room she'd been sleeping in, a loft conversion, had a bathroom and she could do most of what she needed. She had a nephrostomy bag that needed changing, and that worked well upstairs. She thought about it for about 3 days, and decided to try going downstairs – with a lot of help from me, going down backwards in front of her to support her. She got herself onto the bed, and when she needed the bathroom I helped her get there but she got stuck on the toilet. I couldn't

move her without hurting her. So she went back upstairs and stayed there until she went to [hospice].

F was changing the nephrostomy bag OK when it was once a night, but later she needed cleaning up 2-3 times a night, she wasn't capable of doing it so I had to do it, so I wasn't getting enough sleep. But looking back, I'm pleased I did it.

A lot of it was finding out what worked. It got to the point it was almost beyond me. With the help of the palliative care team, I was looking at her going to a care home. It was all set up and arranged and then we heard nothing from them. She was deteriorating quite rapidly. The palliative nurse visited and couldn't work out what had happened with the care home, but said that they had empty beds at [hospice] and would she like one? We agreed she would go there. We had to get the ambulance team to help her downstairs. While the nurse was making arrangements, I took a call from the care home manager, saying they couldn't take her because they had no experience of a nephrostomy bag. That seemed strange because nephrostomy bags are unusual so you wouldn't expect people to have experience of them, but also it's quite straightforward to manage – it was a poor explanation.

We waited and waited for absolutely ages for an ambulance to [hospice], and didn't get her there until after 10 at night. That was no fun either – I rode with her in the ambulance, and there were quite a few places where the road has potholes. Every time we went round a roundabout or hit a pothole, F would scream. It was such a relief to hand her over to someone who knew what they were doing.

They sedated her and after the first day she wasn't remotely able to communicate, though I tried to spend as much time with her as possible. It worked best when various friends came. One time there were 6 of us sitting around her bed, talking to each other, and she was aware of us all there. You do run out of things to say eventually.

One day, I'd been at a quiet day, and a friend who'd been to see her in the morning said she was much more comfortable. I went in to see her, and when I got there the nurse said, "I'm terribly sorry, F has died."

At least I know she was more comfortable that morning.

With support, I've been very fortunate in that regard. We hadn't been away while she was ill except for one awful drive through floods – so I've spent time visiting family, and I've got a lot of support from family and friends.

I was amazed at how the palliative team kicked into action. When I'd first taken her to the palliative care people at the [hospital] and [hospice], she had a lymphedema, and they kicked into action very quickly. F's GP had applied 6 months before for attendance allowance, and we hadn't heard anything at all, but the team got straight onto DWP and suddenly a lot of money appeared into our back account, backdated to the GP's application – no marks to DWP, full marks to [hospice].

She was an amazing person and did so much for the community. With all her voluntary work she brought her [medical] training, she was so precise and accurate in everything that she did. It was amazing to look round at all the people at her funeral – all from different parts of her life. She was an exceptional person.

Story 2: "It took the worry off my shoulders"

I lost my son and my husband (within a two year period). Both my son and my husband ended up at [the same hospice] in different ways. The worst experience of palliative care was my husband, even though we'd planned everything.

When I lost my son, he was only [in his 40s], he had cancer and he had no plans. My husband, R, had Parkison's, and we knew we couldn't be in the same position again, so we got support to do a Lasting Power of Attorney for health and welfare. I think we got a leaflet from Carers Oxfordshire about it. I said, "I'll do mine, would you like to do it with me?" because I knew he wouldn't do it on his own. I had it all set up, I handwrote a will which my neighbours signed, and lodged it with the local funeral directors. If you fully paid for a funeral within a year, you wouldn't pay any interest.

R's behaviour really changed as his illness progressed. [Because of my personal history this had a severe impact on my mental health]. The social worker said, "You can put him into respite," but I'd used it all for operations, I'd only have a week to recover and then I'd be a carer again. So he said, "We'll give you another week," and R went into a care home. My friend [who is

experienced in working with carers] said, “Just leave him there if you can’t cope.”

I told [my Mental Health Support worker] that I’d left him in the care home, and she asked me had I told anyone I’d left him there – I said, “I’m telling you now!”

R had falls in the care home – 22 falls in 11 months. They weren’t helping him shower or dress, and he couldn’t charge his hearing aids. One time I went to see him at 10am and he had nothing on but a cardigan, with a cold tea and a cold meal in front of him. He was so bewildered. I took a picture and showed it to the social worker.

Then the care home said I had to look for a dementia place for R as they couldn’t cope with him. I applied three times, and each time the home said yes, but then when we approached the time for him to move, the home said they couldn’t take him – R’s care home had told them he was difficult so they refused.

R had another fall and got taken to the hospital, he’d got sepsis. The hospital staff said, “Don’t worry about the care home, we’ll find him somewhere.” That was lovely – it took the worry off my shoulders.

I used to stay with him during the day and go home at night to sleep. I got a message at the end of the week saying they were going to move him to another ward, and I thought that must mean he was getting better. But I went in to see him and heard this terrible rattling in his chest. All this time he’d been asking me to end it for him, he’d say, “Help me, I don’t want to live any more.” I said, “I can’t, it’s illegal, I can’t spend time in prison.”

I told the doctor about R’s LPA for health and welfare. They rang me late on the Saturday night and went through it all, “Are you sure that’s his wishes?” I had to be the one to speak, to ask for “compassion in dying”, and that’s when the doctor said, “I can tell you he’ll never recover,” and arranged for the move to palliative care. When that happened, the nurses’ attitude towards me completely changed. He was stuck in a room on his own, it was incredibly sad.

On the following week they said he could go to [the hospice]. I’d had experience of that with my son and was very happy. They got him there in two hours, in a room with four beds, but only one of the other beds was occupied. He died about a week later. This big, strong man, I could see his body going. He refused food and drink, and shut down completely. There was nothing that

could make it easier. The hospice told me that young people die quickly and older people die more slowly, and that was true, my son died in a day but R took a long time to go. I was halfway home when they called me, I still remember where I pulled over.

It is hard, and I don't know what we can do to make it easier. Fortunately I have a strong faith. The Bible says, "Do not be anxious about anything, the peace and understanding of God will fill your heart." And it does work.

These nurses are under such pressure, but they do need more training, to be empathetic to the family. But in the emergency admissions unit, the care and the staff were wonderful. There was a big difference when he was moved to the other ward. At [hospice], the staff were so sweet, they remembered me from before even though it was 2 years previous. And there was wonderful support after the person has died. I didn't ask for it after R, but was offered it. Though it's different when someone's had a long life.

My son was was juggling different types of treatment, and it wasn't joined up, so they'd say, "You have to come here for chemo now," and he'd be in the middle of something else – I was shocked.

I have claustrophobia and it's horrendous, worse since lockdown, so I wouldn't want to be locked up or shut in a room. If it was [hospice], their rooms are lovely and big, with doors onto the garden. It's a wonderful place, with a little chapel as well. They should be supported more.

Recently I went into hospital, if you go in by ambulance they don't triage you, so you're left until a doctor sees you. My blood pressure was taken and it was sky high, but not followed up, I was left in a corridor. I worry about people who are elderly, or quiet or on their own.

The LPA is quite clever, because it's down to the person and their wishes, not the family. But I went in for an operation and was told I had a DNACPR which was shocking and frightening.

Story 3: "She shouldn't have been thinking about her demise, she should have been enjoying her life"

I had a bad experience with end of life conversations. I have [condition] which I'm used to but I was so short of breath that I went to A&E. The doctor came in and said, "It's [condition], have you signed a DNR?" I said no and she said, "Oh

well, I'll have to book you an ICU bed then." It felt like, "Oh, we'll have to go through the motions." It alarmed me a bit afterward, and you feel a bit worthless, like your decision isn't the right one.

It would have helped if she'd said something like, "I'm sorry I have to ask, but have you…?" and been more pleasant, maybe explained if I'd crashed what would have happen– being a bit less cut and dried about what the outcome would be.

I had an experience of a conversation about a ReSPECT plan with someone I support as a volunteer befriender, I took her to the doctor as she doesn't have a good relationship with them. She wasn't prepared, she had cancer and knew she had it, but it was one of those things she was putting off. She wasn't prepared for the questions. It was done reasonably well by the GP, but afterwards my friend said, "Oops, I shouldn't have said that." She felt it was very final, and that now she had nothing to live for – she was quite depressed afterwards. We used to go up to a place on the Downs and have coffee, with blankets round our legs and a view over the countryside, and once she said, "This is how my life should be." She shouldn't have been thinking about her demise, she should have been enjoying her life.

There used to be a befriending network in Oxford around end of life. People wouldn't discuss things with their families, and even when I took them to the GP and I would ask, "Have you brought that list of things to ask about?" they wouldn't – I think that panic sets in. It happened to me, years ago, I had a chest infection and the GP implied I was end of life and I was in a panic, "Should I buy that big pot of mustard, if I'm going to die I might not finish it…"

The Oxford befriending network was incredible, we did a lot of training. It's a shame that more money isn't put into supporting those informal conversations. People can talk to their befriender about things that they wouldn't talk to their family about. I remember asking "Have you told your family?" and they'd say "Oh no, I wouldn't want to upset them." The network helped with practical things but it could be a bridge as well between the person and their family.

There was an Age UK death café, it was more about the practical side of things, preparing for the end of life – like clearing your house.

I think GPs are better now at being more honest. But it would be good to have some help afterwards, coming to terms with it, meeting people's mental health needs at the end of their lives. It's about planting the seed, starting to think about your wishes. It's your own attitude too. On TV I see adverts for

funerals and cremations and it's a shame that those can't be linked in as well, so that it isn't a complete taboo subject.

Story 4: "The whole experience was seamless"

This is my experience of being a family member of someone in receipt of end-of-life care. Although this story relates to our family experience over 7 years ago, the experience is very relevant to today.

My father-in-law who was bright as a button, loved a small bet and always lived in hope of a big lottery win so he could take care of his family. He lived alone in a one-bedroom flat and was having ongoing treatment for a blood cancer. This treatment had been ongoing for years and left him at times feeling debilitated and exhausted. We supported him daily and paid for a carer to come in and support him daily with personal care and household chores.

One evening he had fallen and forgotten to press his pendant alarm, we found him on the floor in the morning. We called the paramedics, and they took him to the community hospital for an Xray – he had a broken shoulder, and he was given a walker to mobilise with. Due to his frailty, it was decided he would go into a residential care home to support him to get "back on his feet". He was not amused!

He was so well cared for in the home for over two weeks, after which time he informed us that he had someone coming to see him from Sobell House. We spoke to the team from Sobell House, and they explained the reason for their visit. They went off to have a private conversation with him before coming back to talk to us – his family.

He had decided that he did not want any more clinical treatment for his cancer. He was tired, fed up of feeling ill and had just had enough of hospitals, needles and not feeling any better. He knew that his decision would ultimately mean his care was going to be EOL and he asked us to accept that he was doing it "his way" – and no, his surname isn't Sinatra!

We were at that stage trying to convince him to carry on with the treatment and I suppose after talking to the team from Sobell House and to him we realised that we were trying to encourage him to carry on because we wanted him to. But it wasn't what he wanted -it was difficult, but we accepted his decision and started to process the "what happens next".

He made his decision on Thursday and by the following Tuesday he was home, back in his comfortable surroundings with his personal possessions and most importantly where he wanted to be. We had a hospital bed delivered on the Monday, a live-in carer arranged to come on the Tuesday. A care agency to supply the additional carer for double handed care and the district nurse and GP all involved and liaising with each other. Communication was excellent and timely.

I don't know who organised what, who came from where – I just know that everything that happened was seamless. We were asked to be home for the delivery of the bed, and we met the carer on the day of him coming home. We had no responsibility apart from being with him, supporting him emotionally, sharing memories and creating a memory board of photographs on the wall beside his bed.

We are a big family but there were occasions when someone couldn't be there especially overnight, which was why the live-in carer was so important. The live-in carer was amazing, we knew she was there but the respect she demonstrated to my father-in-law and to the family was a credit to her. When we visited, she quietly and unobtrusively went into the bedroom or for a walk and let us have quality family time.

Pain relief/ medication wasn't an issue, the live-in carer kept on top of everything and liaised with the appropriate people when necessary.

To be honest the whole experience was seamless, as a family we didn't know who did what, we just know it happened. The care and support he received meant his end of life was just what he wanted.

He passed away at his home with his family around him and I couldn't praise the people involved in ensuring it happened his way – they were amazing.

This is what end of life care should be for everyone who chooses to die at home.

Useful information

Conversations about end of life

- ReSPECT – Summary Plan for Emergency Care and Treatment
- Talking About Death and Dying – Hospice UK guide
- Starting the conversation – Compassion in Dying resource
- End of Life care planning toolkit for people with learning disabilities

Navigating end of life and palliative care

- Hospice UK – guide to end-of-life care and local hospice care finder
- Marie Curie – information and support line **0800 090 2309**
- End-of-life and Palliative Care Resource Centre
- Oxford Health – Patient guidance: last day of life care plan
- Care Choices – End of Life and Palliative Care resources
- End of Life resources with Nepali voiceover – Thames Valley ICB

Support for carers

- Carers Oxfordshire – including support groups and helpline **01235 424715**

Support with grief and bereavement

- Sue Ryder Grief Guide
- Marie Curie telephone bereavement support service – for anyone, whether or not they have received support from Marie Curie previously
- At a Loss – signposting and support for bereaved people
- Widowed and Young – peer support network for those aged 50 or under whose partner has died
- Cruse – support including local support groups and helpline **0808 808 1677**
- Good Grief Trust – signposting to tailored grief support organisations
- The Grief Table Oxford – local grief support group
- Age UK Oxfordshire – local support groups and Bereavement Guide
- SeeSaw – grief support for children and young people in Oxfordshire
- LiveWell Oxfordshire – comprehensive directory of activities and support groups across Oxfordshire

healthwatch Oxfordshire

Healthwatch Oxfordshire
Office F20, Elmfield House,
New Yatt Road,
Witney OX28 1GT

www.healthwatchoxfordshire.co.uk
t: 01865 520520
e: hello@healthwatchoxfordshire.co.uk