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Better End of Life 2024

Time to care: Findings from a nationally representative survey of experiences at the end of life in England and Wales

Research Report

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Cicely Saunders International
Better care at the end of life

HULL YORK MEDICAL SCHOOL

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Palliative & End of Life Care in Cambridge

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> "When a loved one dies at home with you as their main – unqualified and inexperienced – carer, you find yourself just trying to do everything you can to help them. When they die you feel a sense of numbness. You find yourself analysing whether what you did for them was enough. You ask where you or the system could have been better. So being able to share these feelings in this survey feels positive; someone is listening."
>
> **Survey respondent (F797)**

Foreword

This is a critical time for action to improve palliative and end of life care.

The findings from this nationally representative survey in England and Wales demonstrate the extent to which people are dying without access to the services and support they and their unpaid carers need. In an increasingly over-stretched health and care system, despite their best efforts, many doctors and nurses simply do not have the time to provide the care they know their patients need.

It doesn't have to be this way. In some local communities, innovative models of integrated care are supporting people to die well at home and preventing the distress and expense of ambulance call outs and A&E visits. But the postcode lottery in access to these services still exists.

Without urgent action, current gaps in access to palliative and end of life care are only going to grow in the coming years as our population ages. The legal duty on Integrated Care Boards in England to commission palliative care services and the Welsh Government's introduction of the Quality Statement for Palliative and End of Life Care in Wales are positive first steps. However, there is currently no realistic national or local plan to address the scale of this challenge.

Using the findings from this research and drawing on our own expertise and experience in delivering high quality palliative and end of life care across the UK, Marie Curie will continue to push for the urgent changes needed to improve end of life care for all.

We are calling on the new UK Government to act urgently to make the policy changes needed to ensure that everyone affected by dying, death and bereavement receives the best possible care and support, both now and in the future.

Matthew Reed
Chief Executive
Marie Curie

1 Executive summary

Everyone affected by dying, death, and bereavement deserves the best possible care. Concerns about the quality of care at the end of life came to the fore during the Covid-19 pandemic, which led not only to more people dying but shifted patterns of care for people approaching the end of life, increased pressure on community services, and amplified inequalities in end of life care.

Across the UK, the number of people who need palliative and end of life care is increasing steeply. However, there is an important gap in our understanding of the outcomes and experiences of people affected by dying, death, and bereavement at a national level.

This is the final report from the Marie Curie Better End of Life programme, which is a collaboration, funded by Marie Curie, between King's College London's Cicely Saunders Institute, Hull York Medical School at the University of Hull, and the University of Cambridge. We report findings from a national post-bereavement survey, the QUALYCARE survey, conducted in 2023 across England and Wales. The aim is to describe the outcomes, experiences, and use of care services by people affected by dying, death, and bereavement in England and Wales.

The survey was disseminated through the Office for National Statistics to a nationally representative sample of people who had registered the death of a family member in the prior six to ten months. Only non-sudden causes of death were included. We received responses from 1179 people, making this the largest nationally representative post-bereavement survey in the UK since the 2015 VOICES survey.

Our findings reveal patchy and inconsistent provision of care for people approaching the end of life. While there were examples of excellent care, the overall picture is of overstretched services, with health and care staff lacking enough time to provide care, and where coordination and communication are inadequate. This means that people lack timely management of symptoms and family carers spend precious time struggling to access, navigate, and manage different services, in addition to providing much of the care needed themselves. This leaves carers feeling unprepared, unsupported, traumatised, and let down, which has lasting consequences into bereavement.

Patient and public involvement in this research

This report has been written with our Patient and Public Involvement (PPI) group, who are people with lived experience of advanced illness and caring for family members towards the end of life. These individuals were involved throughout the research process, including shaping the survey through discussions about the choice of questions, and guiding the development of accompanying study information. The PPI group also contributed to analysis of data and identification of the key themes presented in this report.

Throughout, our PPI group emphasised the value of conducting the survey, to learn more about people's experiences at the end of life and understand where improvements must be made:

> **Many respondents told us that they completed the survey in order to make a difference for future care, even though it sometimes brought back**

distressing memories. Their accounts provide crucial evidence about what dying, death and bereavement is like today. We must ensure that the lessons learned from the many people who took the time to share their experiences with us are used, by policy makers, to ensure better care and better support for people approaching the end of their life, their families and carers.

- PPI group members

The PPI group provide further reflections about the findings in section 8 of this report.

Key findings

Use of care services in the last three months of life

- **Use of acute care services:** More than half of the people who died used an ambulance at least once in the last three months of life; almost half visited the Accident & Emergency (A&E) department once or more. One in eight people who died spent more than 30 days in hospital in their last three months of life; more than a third died in hospital.

- **Contact with community-based services:** Most people who died had contact with health and care professionals in the community, most often from general practitioners (GPs), or community or district nurses. However, difficulty accessing health and care professionals in the community was common; one in five had no contact with a GP in the last three months of life. Community or district nurses and health care assistants were heavily relied on.

- **Specialist palliative care services:** Around half of people who died had contact with specialist palliative care teams; this was more common among people who died from cancer and less common among older people.

- **Coordination of care:** Fewer than half of respondents said they had a key contact person to co-ordinate their care. Much responsibility for care fell on informal carers (family and friends), who often felt unprepared and unsupported.

- **Experiences of care:** Respondents reported that staff across health and social care settings did not have enough time to provide care for dying people. Almost half of those surveyed were unhappy with some aspects of the care the person who died received; one in 17 made a formal complaint about the care the dying person received. Recognition of palliative care needs was often considered to be too late. Almost a third of respondents reported that health and care professionals had not discussed with them the fact that their relative might die.

Symptoms experienced in the final week of life

- **Physical symptoms:** The most common physical symptoms in the final week of life were poor mobility, weakness, and poor appetite.

- **Psychological concerns:** Almost two thirds of respondents reported that the family felt anxious or worried most or all of the time about the person's illness or treatment. More than a third of respondents reported that the person who died felt anxious or depressed most or all of the time in their final week of life.

- **Symptoms by setting, cause of death, and financial status:** Prevalence of five key symptoms (pain, breathlessness, feeling anxious, not being peaceful, and not having information needs met) varied across care settings, by cause of death and by financial status. Those who spent their final week of life in hospital had the highest overall symptom burden, while those in care homes had the lowest. Those who died from cancer had the highest prevalence of pain. Those who were financially less comfortable had higher prevalence of all five key symptoms, compared to those who were financially more comfortable. Difficulties with access to services, healthcare professionals, and medication or equipment were identified as barriers to timely symptom relief.

The experiences of informal carers

- **Care provided by informal carers:** Almost three out of four respondents had helped care for the person who died during the final three months of life; half of those who died had received help from additional family members and friends. This often involved helping the person who died go to appointments, helping with medical procedures and being ‘on call’ to be contacted if needed.
- **Financial consequences:** Informal family carers reported financial consequences of having to make time to care for the person who died in the last months of life of the person who died. Half of the respondents who were in paid employment had their work impacted, by either taking paid or unpaid leave, changing their work hours, or stopping work.
- **Impact on carer wellbeing:** One in six respondents met the criteria for disturbed grief. This was more common among respondents who were spouses of the person who died and those who felt that healthcare professionals did not listen and discuss care with them. Of those with disturbed grief, only 25% had accessed support from bereavement services.

Contents

2 Background to the report

Everyone affected by dying, death, and bereavement deserves the best possible support and care. While some receive excellent care, this is often not the case, and experiences of dying, death, and bereavement can be poor.

In England and Wales, over 575,000 people died during 2022 [1], with just over 540,000 deaths registered in England and 35,000 in Wales. Most people who die have several close relationships. The 2022 report by the UK Commission on Bereavement stated that the 1.2 million deaths in England and Wales during 2020 and 2021 left an estimated 6.8 million people bereaved[2].

2.1 Care for people approaching the end of life

Palliative care provides physical, psychological, social, and spiritual support for people with advanced, life-threatening illnesses[3]. It focuses on relief of symptoms and enhancing quality of life, as well as providing support for informal carers, family, and friends[4]. Palliative care is provided in all care settings (hospitals, care homes, private homes, and hospices) by a range of professionals: hospital doctors and nurses, general practitioners (GPs), district and community nurses, social care professionals, as well as palliative care specialists. Palliative care has been shown to be effective at improving care outcomes and experiences such as symptom management and quality of life [5, 6], reducing unplanned admissions [7, 8], and reducing unwanted hospital deaths [9].

Key terms and definitions

Palliative care

Palliative care is defined by the World Health Organisation as an approach that improves the quality of life of people and their families who are facing problems associated with a life-threatening illness [10]. It prevents and relieves suffering through the early identification, correct assessment, and treatment of pain and other problems whether physical, psychosocial, or spiritual [3].

Specialist palliative care

Palliative and end of life care may be delivered by professionals for whom this is only part of their role (called ‘generalist palliative care’ in this context), or by professionals who specialise in palliative care (‘specialist palliative care’).

Specialist palliative care professionals have undergone additional, detailed palliative care training, and work in multi-disciplinary teams. Palliative care specialists work exclusively on this care, unlike, for instance, GPs and district or community nurses who deliver a wide range of other health care services alongside palliative care [6].

End of life care

According to NHS England, the term ‘end of life care’ refers to the last year of life [3]; however, it is also commonly used to indicate the last months or weeks of life.

Community-based care

According to the Social Care Institute for Excellence, community-based health and social care encompasses a range of care services and professionals, including general practice and primary care services [11]. Community-based services work with people in their own homes and within communal settings such as care homes.

It has been conservatively estimated that about three quarters of people who die in the UK have palliative care needs [12]. Estimates which aim to account for the rise in multiple long-term conditions suggest this figure may be as high as 90% [13, 14]. The number needing palliative care is increasing steeply as the UK population ages [15-17]. It is estimated that each year across the UK, 100,000 people die needing palliative care but not receiving it [18]. People with lower socio-economic position, non-cancer diagnoses, and from ethnic minority groups are less likely to access high-quality palliative care [19-21]. The Covid-19 pandemic amplified inequalities in palliative and end of life care provision. It also led to a rise in home deaths, which has persisted, putting community services under greater pressure [22-25].

Hospital deaths in the UK have fallen in the past decades, with increased numbers of people dying out of hospital since the 2008 End of Life Care Strategy [26-28]. However, use of other hospital services in the final months of life, such as emergency departments, are increasing [29, 30]. There is a need to increase care in the community if rises in hospital admissions and deaths are to be avoided [15, 31].

2.2 Understanding experiences of dying, death, and bereavement

One way of understanding the experiences and outcomes of care and support for people approaching the end of life is to survey the bereaved family and friends of those who died, since it is usually not possible to ask the dying person themselves. Such surveys, termed ‘post-bereavement’ or ‘mortality follow-back’ surveys, are especially useful if a nationally representative sample can be obtained. Between 2011 and 2015, the Office for National Statistics (ONS) conducted an annual post-bereavement survey in England using a survey instrument called VOICES (Views of Informal Carers – Evaluation of Services) [32]. The most recent VOICES survey was published in 2016. It showed that 25% of respondents reported care in the last three months of life as only fair or poor [33].

Since the last VOICES survey, over 4 million people have died in England and Wales [1].

Although there have been widespread concerns about palliative and end of life care during this time, there has been no nationally representative picture of the experiences and outcomes of dying, death, and bereavement.

2.3 What research did we undertake and why?

2.3.1
Study design

We conducted a nationally representative cross-sectional post-bereavement survey, using similar methodology to the ONS National Survey of Bereaved People (VOICES). For our survey instrument, we used a modified version of the QUALYCARE survey [34]. QUALYCARE collects information about experiences and outcomes of dying, death, and bereavement through a combination of closed-ended multiple-choice and open-ended free-text responses. QUALYCARE includes validated measures of:

- health and social care service use in the final three months of life, using the *Client Service Receipt Inventory* (CSRI) [35]
- patient symptoms and concerns in the last weeks of life, using the proxy-version of the *Integrated Palliative care Outcome Scale* (IPOS) [36]
- intensity of carers’ bereavement, using the *Traumatic Grief Inventory-Self Report Plus* (TGI-SR+) [37]

More information about these measures is provided in Appendix 1, along with strengths and limitations of the study design.

2.3.2
Patient and Public Involvement

This research was shaped and enhanced by our Patient and Public Involvement (PPI) group, who are people with lived experience of advanced illness and caring for family members with palliative and end of life care needs from across the UK. Our PPI group has been involved in the Better End of Life programme since 2021 as valued members of the research team and played a key role in this research. PPI members shaped the survey instrument and the study information for participants; ensured the survey was sensitively introduced and that the questions were clear; suggested amendments to enhance response rate and simplify processes for opting out; and contributed extensively to the analysis of data, including identification of the most important messages and themes for this report and selection of illustrative quotes.

2.3.3
Recruitment of participants

The survey was administered via the ONS. We invited 3,000 people aged 18 years or older (1,500 people in England and 1,500 in Wales) who had registered the death of an adult family member. We included deaths from any non-sudden cause; sudden or unexpected deaths were excluded (see Appendix 1 for the full list of unique causes of death used for sampling). The deaths were identified using mortality data held by the ONS.

We aimed for a sample that was representative of the general population in England and Wales using a stratified sampling approach. The population was divided into strata based on **(1)** geographical area (regions in England and Local Health Boards in Wales) and **(2)** quintiles relating to socio-economic position using the Indices of Multiple Deprivation (IMD) for England [38] and Wales [39]. Within each stratum, participants were selected based on the age and gender of the person who had died and their cause and place of death to ensure proportional distribution across these factors. More details about the sampling strategy are provided in Appendix 1.

The survey invitation was sent by post to bereaved relatives between six and ten months after the death. All participants were sent a paper copy of the survey (with a pre-paid return envelope) but could opt to complete it online or by telephone according to their preference. Participants could also opt out by returning a pre-paid slip to the ONS or contacting the researchers. If no response or opt-out request was received, the survey invitation was followed up with two reminder letters, the second of which included a further paper copy of the survey. Deaths occurred between August and December 2022, and data were collected between May and September 2023.

In this report, we present results for England and Wales together. Data for each nation separately is provided in Appendix 2 and 3. To reduce the risk of identifying those who responded to survey, or the people who died, we have suppressed small cell counts (ie when there were fewer than three responses for a category) in the tables and figures. Because not all respondents answered all questions, we present the number of valid and missing responses throughout the report.

3 Sample description

3.1 Who responded to our survey?

A total of 1,179 surveys were returned by the end of September 2023 (response rate 39.3%): 1,060 paper surveys, 108 online, and 11 by telephone. Most respondents were the child (n=659, 55.9%) or the spouse (n=322, 27.3%) of the person who died.

Respondents' mean age was 63.2 years (range 23–95 years). The majority identified as female (n=740, 62.8%), and 419 (35.5%) as male. The sociodemographic characteristics of the survey respondents are presented in *Table 1.*

Table 1. Sociodemographic characteristics of survey respondents (n=1179)

	Number	%
Gender		
Male	419	35.5
Female	740	62.8
Non-binary or prefer not to say	6	0.5
Not answered	14	1.2
Ethnicity		
White British	1124	95.3
White other	13	1.1
Mixed	11	0.9
Asian	11	0.9
Any other ethnic group	5	0.4
Black	4	0.3
Prefer not to say or not answered	11	1.0
Employment		
In paid work	517	43.9
In unpaid work	21	1.8
Not employed	630	53.4
Other or not answered	11	0.9

Relationship to the person who died	Number	%
Child	659	55.9
Wife, husband, or partner	322	27.3
Other (eg in-laws, nieces, nephews)	109	9.3
Sibling	65	5.5
Parent	17	1.4
Not answered	7	0.6

View this data presented for: England Wales

3.2 Who were the people who died?

Of the 1,179 people who died, 606 (52.1%) lived in England and 557 (47.9%) in Wales. There were more women (n=605, 51.3%) than men (n=566, 48.0%). The mean age at death was 81.5 years (range 25–105 years). Almost all of those who died were White British (n=1127, 95.6%). This is in line with national statistics on ethnicity of the general population in England and Wales for this age group, which show that 93.6% of those aged 65 years or above are White British [40].

Many of those who died had concluded their formal education at age 15 or younger (n=508, 43.8%); 125 (10.6%) had achieved university degrees. This reflects the age of those who died, as older people generally have a lower level of academic qualifications than younger generations [40]. Most were either married (43.8%) or widowed (40.9%) when they died. Financially, more than three quarters of those who died were reported to be ‘living comfortably’ or ‘doing alright’ during their last three months of life (n=931, 79.0%) whereas 228 (19.3%) were reported to be ‘just about getting by’, ‘finding it quite difficult’, or ‘finding it very difficult’. A majority (58.2%) had owned their accommodation outright. Before their death, or before going into hospital or hospice for the last time, most had resided with the survey respondent (n=407, 34.5%) or on their own (n=339, 28.8%); 228 (19.3%) had lived in a care home.
The sociodemographic characteristics of those who died are presented in *Table 2.*

Table 2. Sociodemographic characteristics of those who died (n=1179)

	Number	%
Gender		
Male	566	48.0
Female	605	51.3
Prefer not to say or not answered	8	0.7
Age category		
85 or older	532	45.1
65-84	526	44.6
18-64	108	9.2
Not answered	13	1.1

Ethnicity	**Number**	**%**
White British	1127	95.6
White other	21	1.8
Asian	14	1.2
Black	5	0.4
Any other ethnic group	5	0.4
Mixed	3	0.3
Not answered	4	0.3
Geographical Area		
England	**606**	**51.4**
North East	31	2.6
North West	91	7.7
Yorkshire and Humber	69	5.9
East Midlands	49	4.2
West Midlands	69	5.9
East of England	44	3.7
London	36	3.1
South East	131	11.1
South West	81	6.9
Wales	**557**	**47.2**
North Wales	136	11.5
Mid Wales	46	3.9
South East Wales	210	17.8
South West Wales	156	13.2
No geographical area specified	**16**	**1.4**
Marital status		
Married or with a partner	516	43.8
Widowed	482	40.9
Divorced or separated	106	9.0
Never married	59	5.0
Not answered	16	1.4
Educational attainment		
Did not go to school	12	1.0
Left school at 15 years old or under	508	43.1
Left school at 16 – 17 years old	288	24.4
Left school at 18 – 19 years old	48	4.1
Post-secondary school vocational qualifications	180	15.3
University	125	10.6
Not answered	18	1.5

Financial circumstance	**Number**	**%**
Living comfortably	538	45.6
Doing alright	393	33.3
Just about getting by	136	11.5
Finding it quite difficult	50	4.2
Finding it very difficult	42	3.6
Not answered	20	1.7
Accommodation		
Owned outright	686	58.2
Owned with a mortgage or loan	74	6.3
Part-owned and part-rented	15	1.3
Rented (with or without housing benefit)	206	17.5
Other	182	15.4
Not answered	16	1.4
Living situation		
On their own	339	28.8
With the respondent (with or without other people)	407	34.5
With other people (but not the respondent)	171	14.5
In a care home	228	19.3
Elsewhere	19	1.6
Not answered	15	1.3

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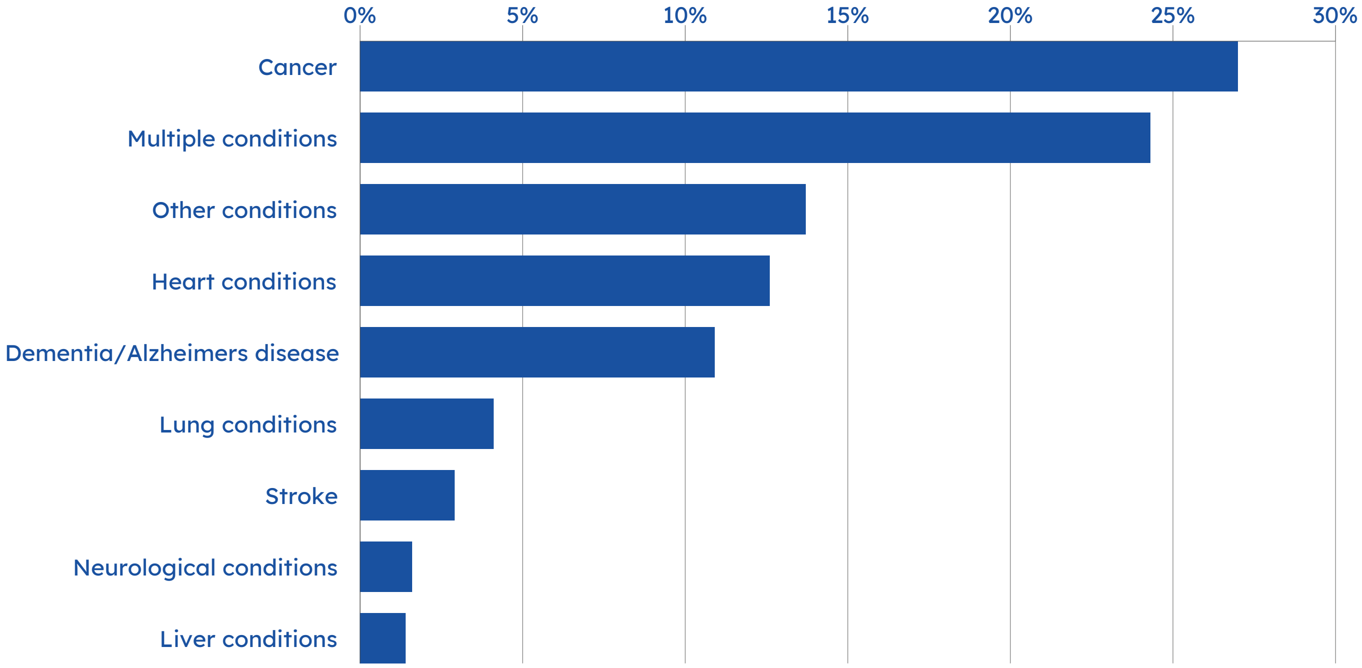
3.2.1

What was the cause of death?

Respondents were asked to indicate the main cause of death of the person who died from a list provided in the survey. The most commonly reported single cause of death was cancer (n=318, 27.0%), followed by heart conditions (n=148, 12.6%), and dementia or Alzheimer's disease (n=128, 10.9%) (*Figure 1*). This reflects the main causes of death in the general population [1]. Many respondents (n=161, 13.7%) selected 'other' as the main cause of death; free-text responses demonstrated that 'other' commonly involved respiratory infections (such as pneumonia, Covid-19, or chest infections), or old age or frailty.

287 (24.3%) selected two or more conditions as the cause of death, most commonly a combination of heart conditions, dementia, cancer, and other conditions. We report these as 'multiple conditions'. It should be noted, however, that the group who were reported to have died from multiple conditions is likely an underestimation, since the question asked for the single main cause of death.

Figure 1. Reported main cause of death of those who died (n=1164)



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3.2.2

What illnesses were those who died living with?

Partly as a consequence of population ageing, many people today live with more than one long-term health condition. The Academy of Medical Sciences defines the co-existence of two or more chronic health conditions as multimorbidity [41]. These can be any physical, infectious, or mental health conditions. To explore the presence of multimorbidity among those who died, we identified individuals for whom respondents indicated two or more chronic health conditions either as cause of death or as additional illnesses (“what other illnesses were they living with?”).

Most of those who died were reported to have been living with multiple health conditions (n=805, 68.3%). This reflects prior research showing that prevalence of multimorbidity increases with age: multimorbidity affects 54.8% of those aged 65–74, and 74.0% of those aged 75–84 [42]. As shown in *Table 3,* respiratory and cardiovascular conditions were the most commonly reported conditions, affecting almost half of those who died (45.5% and 44.6%, respectively). Cancer was also common (37.3%). Dementia was reported to have affected 29.9% of those who died.

Table 3. Prevalence of chronic health conditions among the people who died (selected as either a cause of death or as an illness that the person who died was living with)

	Number	%
Respiratory conditions (eg asthma, chronic obstructive pulmonary disease)	537	45.5%
Cardiovascular conditions (eg heart disease, atrial fibrillation, high blood pressure)	526	44.6%
Cancer	440	37.3%
Dementia (eg Alzheimer's disease, vascular dementia)	352	29.9%
Musculoskeletal conditions (eg osteoarthritis, rheumatoid arthritis)	242	20.5%
Diabetes	222	18.8%
Mental health conditions (eg depression, schizophrenia, anxiety)	121	10.3%
Digestive conditions (eg liver disease, inflammatory bowel disease, stomach ulcers)	115	9.8%
Renal disease (eg chronic kidney disease)	115	9.8%
Neurological conditions (eg Parkinson's disease, epilepsy, motor neurone disease, multiple sclerosis)	65	5.5%
Learning disability	12	1.0%

Note: Since multiple conditions were selected, the total count is higher than the total sample size.

View this data presented for: England Wales

4 Experiences of the last three months of life

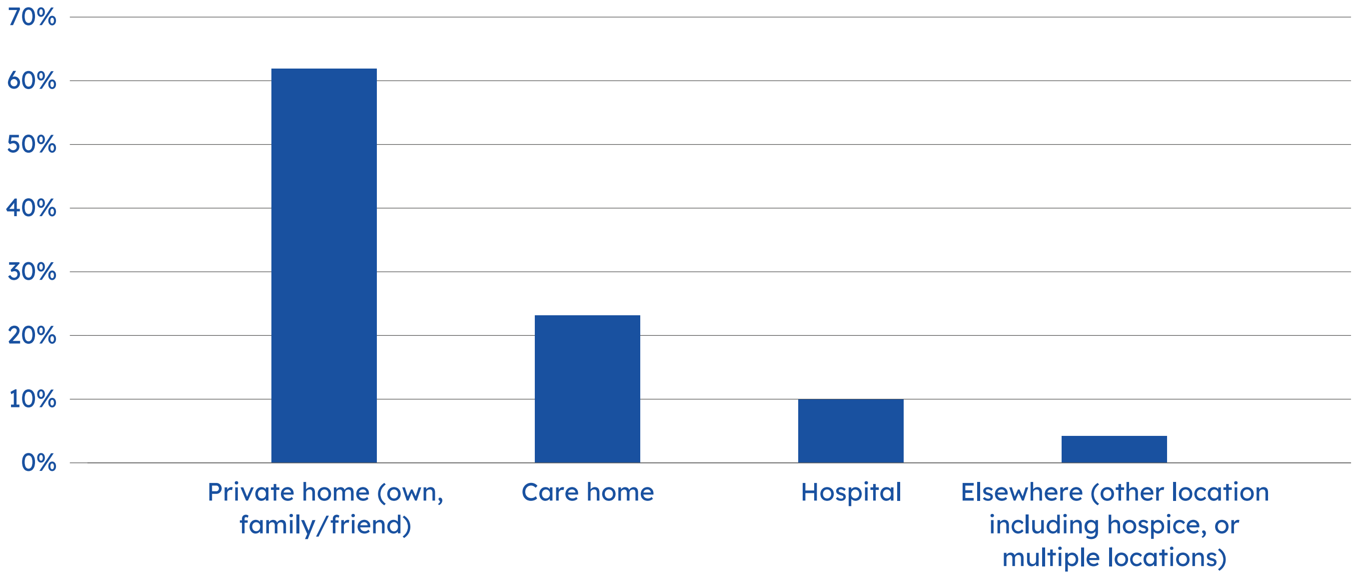
Summary of key findings

- The majority of those who died spent most of their last three months of life in a private home.
- Around half of those who died had used ambulance services, visited the Accident and Emergency (A&E) department, or stayed overnight in a hospital ward. In total, one in eight of those who died spent more than 30 days of their last three months of life in hospital.
- Many respondents had difficulty accessing healthcare professionals, especially when the person who died was living in a private home or a care home.
- GPs were the most contacted healthcare professional. Despite this, one in five had no contact with a GP in their last three months of life.
- Around half of people who died received at least some care from specialist palliative care teams in their last three months of life; people who died from cancer were more likely to have received care from palliative care specialists than those who died from other causes. Specialist palliative care use was less common among older people.
- Overall, recognition of palliative care needs was often considered too late. Almost a third of respondents reported that healthcare professionals had not discussed death and dying with them.
- Fewer than half of respondents said the person who died had a key contact person to co-ordinate their care. This meant that much of the responsibility of care fell to family and friends, often with little support.

4.1 Where did those who had died spend most of their time?

During their last three months of life, the majority of the people who died spent most of their time in their own home or the home of a family member or friend (n=730, 61.9%). 273 (23.2%) spent most of their time in a nursing or residential care home, 117 (9.9%) spent most of their time in hospital, and 50 (4.2%) spent most their time in another location, including a hospice, or in multiple locations *(Figure 2)*.

Figure 2. The places where the people who died spent most of their time in their last three months of life (n=1170)



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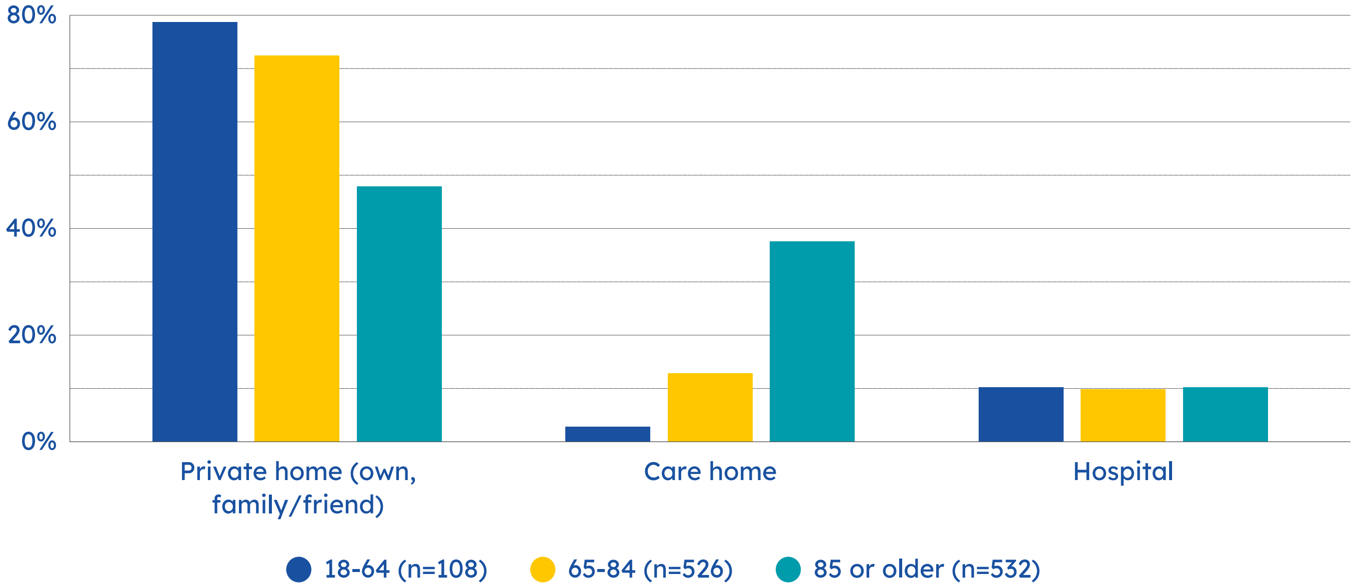
There were differences in place of care by age: almost 80% of those who died aged 18 to 64 spent most of their final months in a private home, whereas this was true for fewer than 50% of those aged 85 or older.

Older people were more likely to spend most of their time in their last three months of life in a care home compared to younger people (*Figure 3*).

Figure 3. Differences in the places in which the person who died spent most of their last three months of life according to their age



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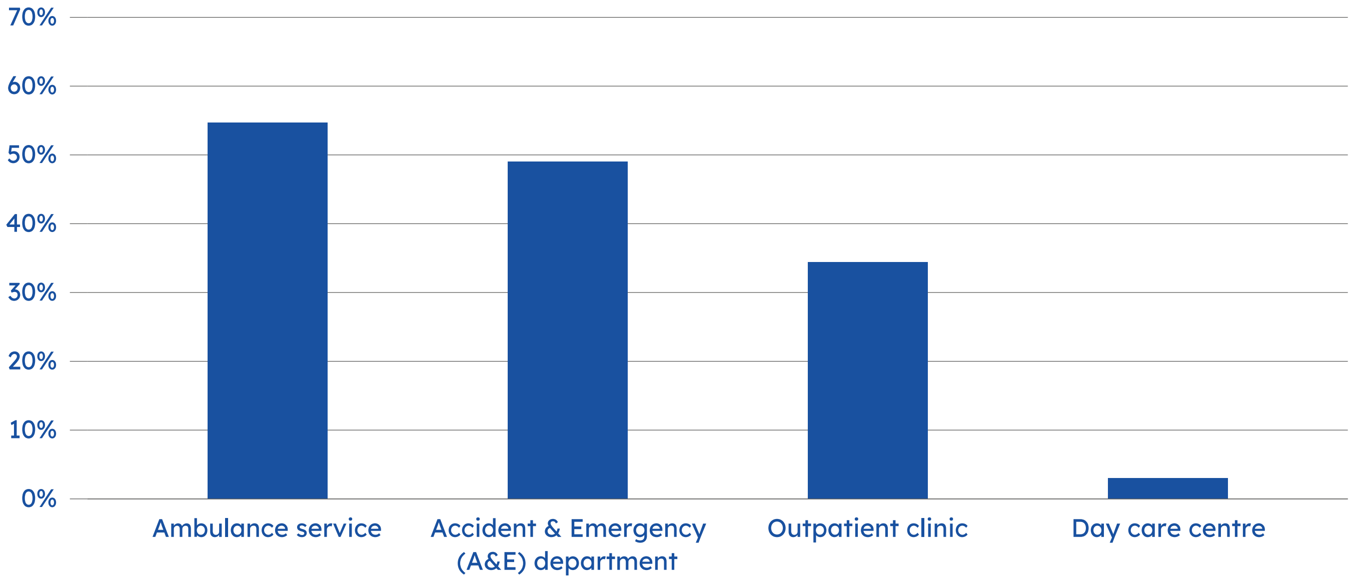
4.2 What care services were used in the last three months?

Those who died used a range of health and care services in their last three months of life (*Figure 4*).

Figure 4. Use of care services among the people who died in their last three months of life (n=1179)



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4.2.1

Emergency care

Contact with ambulance services was common: notably, more than half of those who died (n=645, 54.7%) had used an ambulance at least once in their last three months of life. Among these people, the mean number of ambulance contacts was 1.9 (standard deviation [SD]=2.66, median=1, range: 1-38).

Almost half (n=578, 49.0%) of those who died had attended an A&E department at least once in their last three months of life. Of those who had visited A&E, the mean number of visits was 1.8 (SD=1.75, median=1, range: 1-31). 70.6% (n=408) of A&E visits resulted in overnight stays.

Within the free-text responses, respondents expressed difficulties with timely access to emergency care. They described long waiting times for ambulances to arrive, and spending extended periods of time waiting in A&E.

> **The ambulance took about 7/8 hours, and then she was sitting in the ambulance for around 5/6 hours in the cold weather. Mum wasn't explained about what was happening in hospital, she was upset and confused when she came home.**
>
> (C596, England, died from a heart condition)

> **On his first admission, we were advised to bring him to A&E as there was an 8 hour wait for an ambulance. On his second admission, the same thing. I sat with my brother from 7pm until 5am, where he was eventually seen and admitted. On the third occasion and final one, a doctor called to see him at home. […] She called an ambulance [and] said it was extremely urgent, we waited over 8 hours. He was taken to hospital at 7pm, he lay in the ambulance until 7.30am the following morning.**
>
> (J638, Wales, died from a lung condition)

Previous research has found that poorer socio-economic circumstances correlate with higher use of emergency care at the end of life [20]. We therefore explored whether there were differences in use of emergency services according to financial circumstances. Contrary to prior research, we found similar rates of A&E attendance among those who were financially ‘finding it very difficult’, ‘finding it quite difficult’ or ‘just about getting by’ (52.9% across these groups), compared to 54.9% among those who were ‘doing alright’, and 52.7% among those ‘living comfortably’. Ambulance use was slightly more frequent among those ‘finding it very difficult, ‘finding it quite difficult’ or ‘just about getting by’ (60.9%), compared to those ‘doing alright’ (58.6%) or ‘living comfortably’ (54.8%). It should be noted that our survey used self-reported financial status, however, and not an objective measure of area-based deprivation.

4.2.2

Outpatient care

In total, 405 (34.4%) of those who died had visited an outpatient clinic, either to see a specialist or for other appointments, such as blood transfusions, treatments, or dialysis. Of these, the mean number of outpatient clinic visits in the last three months was 6.4 (SD=6.85, median=5, range: 2-67).

Only 35 respondents (3.0%) reported that the person who died had attended a day care centre. Of these, the mean number of visits was 6.0 (SD=8.28, median=2, range: 1-36).

4.2.3

Overnight stays

When asked about overnight stays during the last three months of life, respondents reported that more than half of those who died (n=660, 56.0%) had stayed overnight in a hospital ward. The mean number of stays was 1.7 (SD=1.09, median=1, range: 1-14). Of this group, the mean number of days spent in a hospital ward was 23.4 (SD=23.74, median=15, range: 1-90). Overall, 12.4% of the people who died spent more than 30 days of their final 90 days in a hospital ward. Prior research has found that people who died in England had on average 4.7 hospital bed days in their final month of life [43].

Overnight stays in other care settings were less frequent. Only 77 (6.5%) of those who died had stayed overnight in an intensive care unit (ICU): of this group, on average they had 1.3 overnight ICU stays (SD=0.60, median=1, range: 1-3) in the final three months, spending on average 10.7 days in total (range: 0-80).

75 (6.4%) of those who died had at least one overnight stay in a hospice. Among this group, the average number of stays was 1.1 (SD=0.41, median=1, range: 1-3), and the total number of days was on average 18.3 days (range: 0-90).

4.2.4

Contact with health and social care professionals in the community

We asked whether those who died had had contact with health and social care professionals in their last three months of life while at home or in a care home (excluding times when they were in hospital or hospice). Information about contact with health and social care professionals is presented in *Figure 5*.

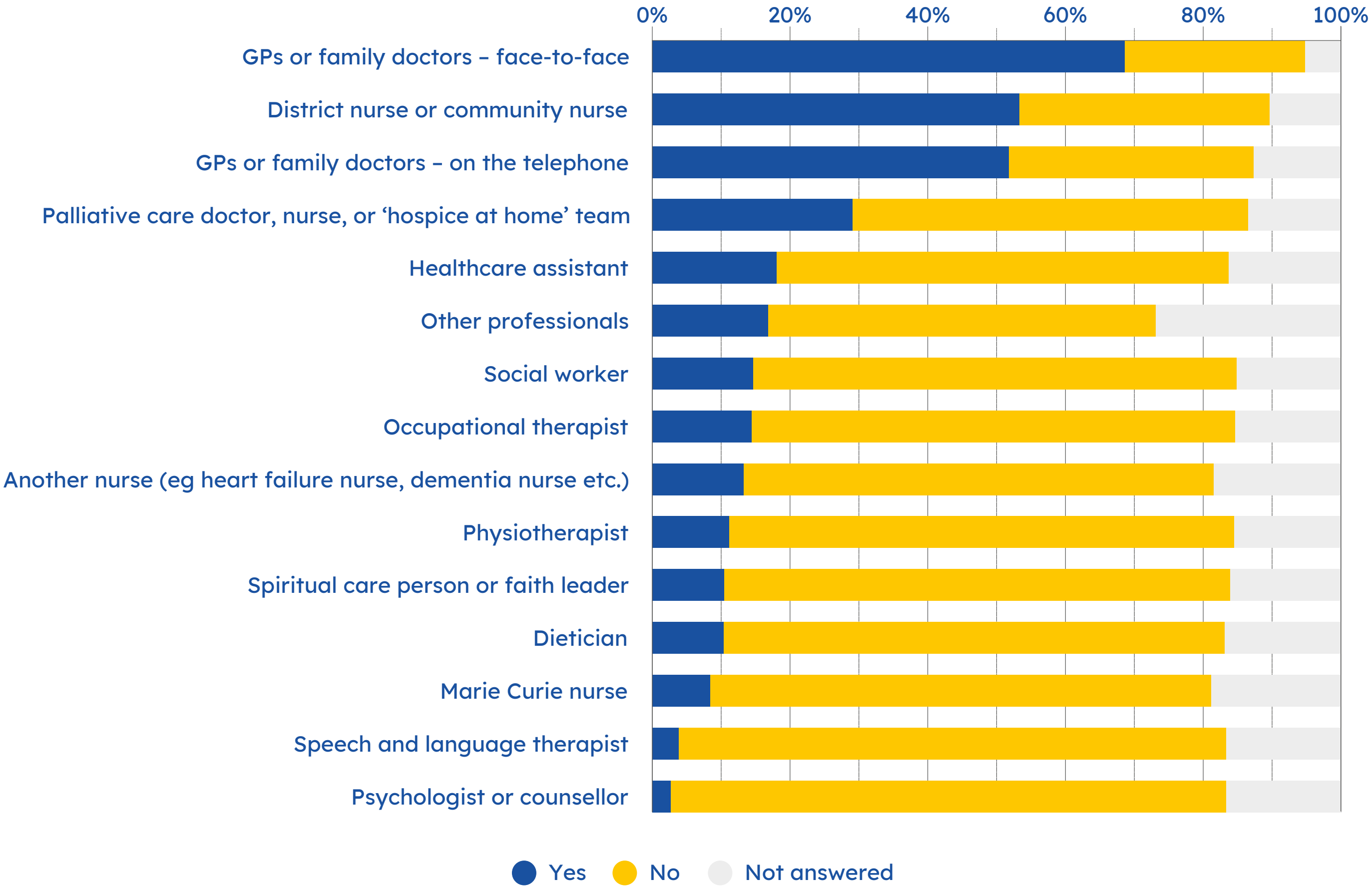
In total, 1,018 (86.3%) of those who died had contact with primary care professionals: 952 (80.7%) had contact with a GP (51.8% over the telephone and 68.6% in person), and 629 (53.4%) had contact with a district or community nurse. Almost one in five (19.3%) people who died had no contact with a GP in their final three months of life (either in person or over the telephone). Problems accessing GPs were common in the free-text responses, with respondents describing struggling to get through to GP surgeries, to make appointments, and to arrange GP home visits.

> **You had to telephone at 8am, but either there were no appointments or you just got cut off.**
>
> (A954, England, died from multiple conditions)

> **[We had] difficulty accessing the GP, as receptionists were not helpful in facilitating this. A hospital avoidance plan was in place but was dependent on accessing a GP.**
>
> (J616, Wales, died from multiple conditions)

Contact with community-based palliative care specialists was less common; 343 (29.1%) reported contact with palliative care doctors, nurses, or ‘hospice at home’ teams. Approximately one in six reported having contact with healthcare assistants (n=213, 18.1%).

Figure 5. Proportion of people who died who had any contact with different health and social care professionals in their last three months of life (n=1179)



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We also asked how frequently the person who died had contact with health and social care professionals in their last three months of life. For professional groups where at least 200 respondents reported contact in the last three months of life, this data is presented in *Table 4*. The mean number of contacts with a GP face-to-face was 3.5 and by telephone was 3.8. The mean number of contacts with a district or community nurse was higher (mean=12.2) with a very wide range (range: 1-360), and some respondents reporting more than daily contact. The mean number of contacts with palliative care doctors, nurses, or 'hospice-at-home' teams was 8.6. Even though relatively few had contact with healthcare assistants, the intensity of contact for this group was high (mean=41.8, range: 1-480).

Respondents described having less contact with professionals in the community than desired, even though the quality of care was often reported as good.

> **The palliative care and district nurses and GP were great but they only came a few times a week for half an hour.**
>
> (F822, Wales, died from cancer)

However, some respondents described poor experiences of care, particularly when considering care provided by GPs.

> **We were unhappy with my husband's GP. [They offered] no help whatsoever, [it was] really poor. [They] only visited once at home, and that was about 2 weeks before he passed, and when she did visit, she just turned up at the door. [There was] no call to say she was coming.**
>
> (E590, England, died from cancer)

Table 4. Contact with health and care professionals in the last three months of life while at home or in a care home ie, not in hospital or a hospice

	No contact	**Had contact**	**Distribution of frequency of contacts**					
	n	n	Mean	SD	Median	Min	Max	IQ range
GPs or family doctors (face-to-face)	309	809	3.5	3.88	2	1	42	1-4
GPs or family doctors (on the telephone)	419	610	3.8	3.61	3	1	40	2-5
District nurse or community nurse	428	629	12.2	25.45	5	1	360	2-10
Palliative care doctor, nurse, or 'hospice at home' team	677	343	8.6	16.33	4	1	150	2-8.25
Healthcare assistant	774	213	41.8	87.19	6	1	480	3-50

Notes: SD=standard deviation, IQ range=interquartile range (range between first and third quartile of the frequency distribution).

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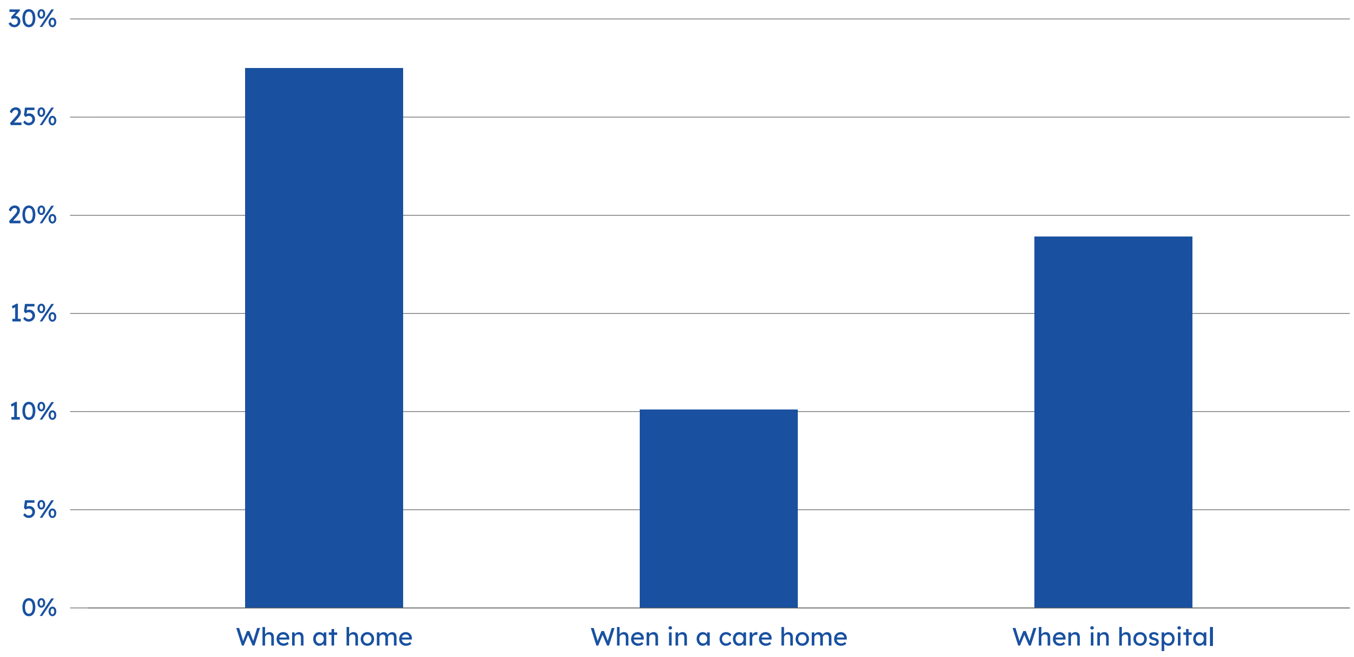
4.2.5

Care from palliative care specialists

Palliative care specialists (see Box 1 in section 2) are trained to care for those with more complex symptoms or concerns who are approaching the end of life [44]. Previous evidence shows that timely care from specialist palliative care services can reduce symptoms, increase quality of life [6], and better support family carers [45].

We asked whether the person who died had received specialist palliative care in any of three settings: when at home, in a care home, or in hospital. Almost half of the people who died (n=543, 46.1%) had contact with palliative care specialists during the last three months of life in any setting; 324 (27.5%) had contact with specialist palliative care when at home; 223 (18.9%) when in hospital, and 119 (10.1%) when in a care home (*Figure 6*). 115 (9.8%) of those who died received specialist palliative care in more than one setting.

Figure 6. Proportion of the people who died who received care from palliative care specialists in their last three months of life (n=1179)



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The free-text responses offer insight into peoples' experiences of specialist palliative care, or lack thereof. Of those who received care from palliative care specialists, experiences were generally very positive. These teams were described as helping to ensure the person could die comfortably, especially when cared for at home, and helped respondents navigate health care services to access support.

> **Once my mum was deemed palliative, I was put in touch with [the community specialist palliative care team], who progressed what was needed. [The manager in that team] was a huge support to me, and I knew I could ring her whenever.**
>
> (J729, Wales, died from multiple conditions)

However, not everyone accessed this care. For example, respondents highlighted that there were issues with delayed referral to palliative care and it was not uncommon to only receive this care in the last days of life.

> **No support [was] offered from the palliative care team. If so, we would have welcomed it. Perhaps information about my wife's care would have been clearer. It felt like a constant battle instead. [It] shouldn't be like this.**
>
> (J902, Wales, died from a heart condition)

Previous research has shown that specialist palliative care is more likely to be accessed by people in higher socio-economic groups [21]. We therefore explored whether there were differences in use of specialist palliative care according to the financial circumstances of the person who died. We found slightly higher use among those who were financially 'living comfortably' (48.9%) compared to those who were 'doing alright' (43.3%) and those who were 'just about getting by' or 'finding it quite/very difficult' (45.6%).

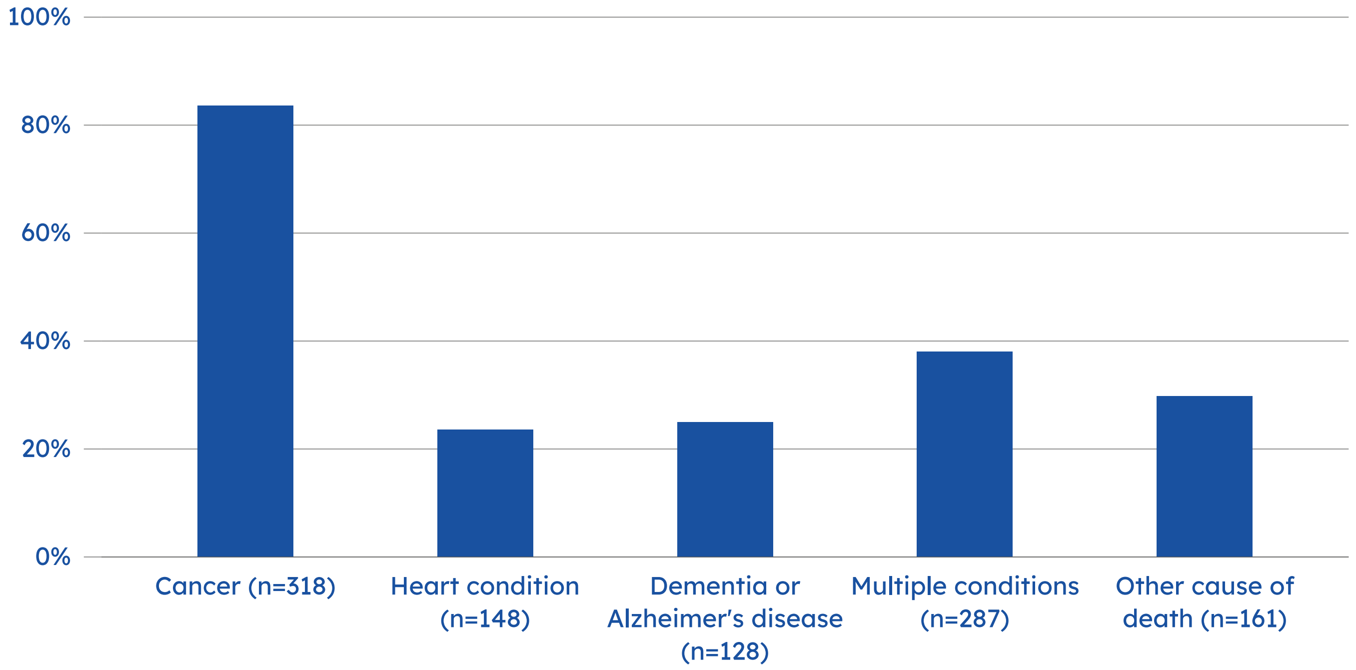
4.2.5.1

Differences in specialist palliative care use

Existing research shows that, overall, symptom burden is similar among people with a range of conditions [46-48]. Nevertheless, people with non-cancer diagnoses are less likely to access specialist palliative care [49, 50].

In line with previous findings, we found that use of specialist palliative care varied by cause of death; care from palliative care specialists was more often received by those who died from cancer (83.6%) compared to those who died from heart conditions (23.6%) or dementia (25.0%) (*Figure 7*). 38.0% of those who died from multiple conditions received specialist palliative care, however, it should be noted that cancer was common in this group (n=81, 28.2%).

Figure 7. Receipt of care from palliative care specialists (in any setting) during the last three months of life across the five most common causes of death



Notes: For information about multiple conditions and other cause of death see section 3.2.1.

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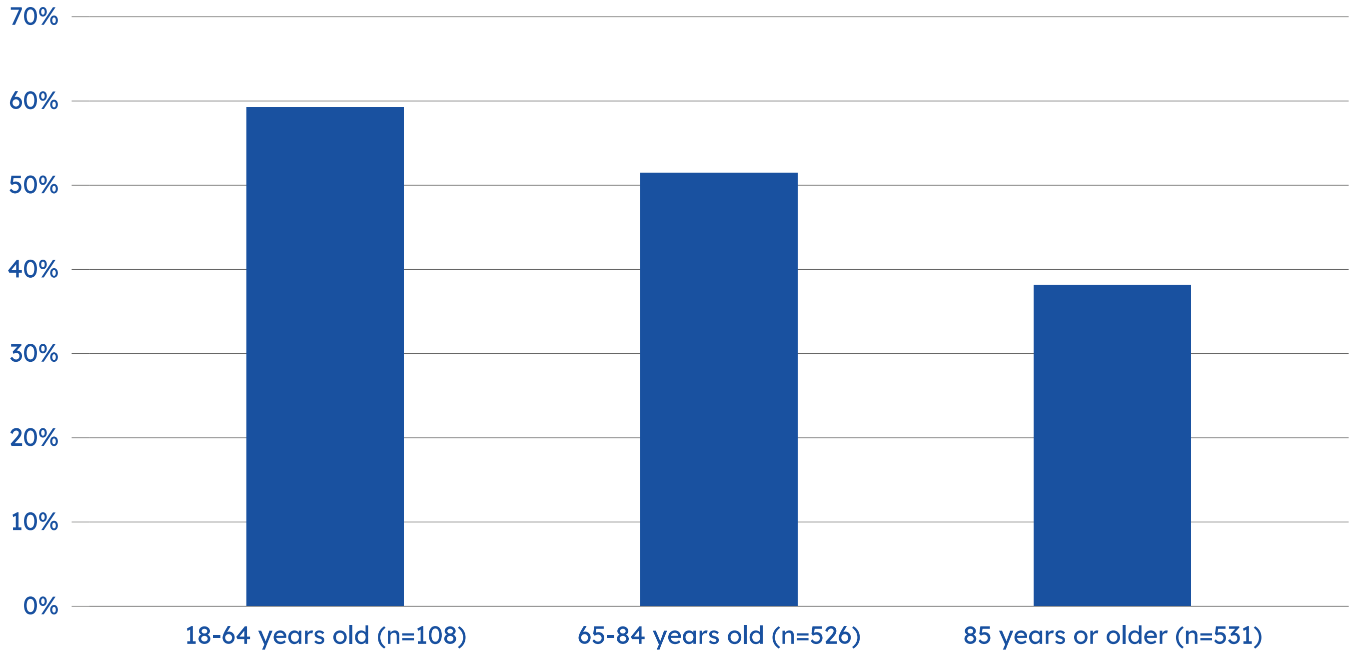
As shown in prior research [49], we also found that involvement of specialist palliative care was less common with older age. Only 38.2% of those who died aged 85 or older received care from palliative care specialists, across settings, compared to 51.5% of those aged 65-84 and 59.3% of those aged 18-64 (*Figure 8*).

Figure 8. Receipt of care from palliative care specialists (in any setting) during the last three months of life by the age of the person who died



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In the free-text responses, many respondents described how they felt that older people, or people with dementia, were not prioritised or even considered eligible for specialist palliative care. Carers of people with dementia also experienced difficulties accessing support and being supported themselves.

> **It is better to die from cancer in this country than dementia. There needs to be more co-ordinated support and care for sufferers of dementia and their families; the practical support you need has to be paid for privately.**
>
> (E564, England, died from dementia or Alzheimer's disease)

> **Access to any services was almost an impossibility. We literally had to fight at every stage of my Mum's dementia journey (8 years) to get anywhere near the level of care she deserved […] No day care centres would accept Mum due to level of care required. Nor would care homes. Yet we as a family were supposed to provide that. [The] Consultant didn't want to know. Community nurses did their best but had constraints. My father's health deteriorated as a result. […] We felt very alone at all times with nowhere to turn to.**
>
> (C904, England, died from multiple conditions including dementia)

> **She was an elderly lady and had become very poorly. It was her time yet I think this is handled very badly in this country. A good death will never be achieved whilst there is a lack of care in the NHS, overworked, badly paid and understaffing in care homes and allowing people to be within hours of death before they are admitted to a hospice for palliative care.**
>
> (A699, England, died from dementia or Alzheimer's disease)

4.2.6
Coordination of care

Having a health or care professional as a key contact person available to co-ordinate care is associated with fewer transitions to hospital at the end of life [51]. We found that during the last three months of life, fewer than half (n=501, 42.5%) of those who died had a health or care professional acting as a key contact person to co-ordinate their care. When a key contact person was not available, respondents often described challenges with navigating the healthcare system, knowing the right person to contact for help, or what help was available and when. In addition, the lack of coordination was described as making the respondent feel abandoned, with a responsibility to provide care but getting inadequate support for this. Some respondents said they felt guilty if they failed to co-ordinate care well.

> **It did get very confusing over who you should contact, especially when the situation is upsetting and lack of sleep is affecting you. It is a traumatic time and overwhelming, sometimes I felt at a complete loss. Without the support of family members goodness knows how I (and my husband) would have coped.**
>
> (C875, England, died from cancer)

> **[I] felt left on [my] own, all responsibility on myself for food, medication, appointments, care, liaising with many different people and services. No single point of contact – many different people dipped in and out but not one person coordinating assistance.**
>
> (F782, Wales, died from cancer)

The importance of care coordination, rather than simply access to care and services, was articulated by some respondents.

> **We met lots of lovely staff (dementia support, cancer nurse at GP etc) but they all just gave us contact details of people I could approach for support and I was already so busy organising shopping, appointment[s], medication, carers, all at a distance. I really felt like screaming!**
>
> (C639, England, died from cancer)

In cases where respondents described high quality of care coordination, this was often delivered by specialist palliative care teams.

> **Care provided by the community palliative care team was exceptional [...] Any issues that needed addressing, they would contact the community nurse, who would then contact [the] GP if needed.**
>
> (F767, Wales, died from cancer)

4.3
How did respondents perceive the care provided from healthcare professionals?

GPs and community nurses provide a large part of the care dying people receive in community settings [52, 53]. This is especially the case following the sustained increase in deaths at home during and following the Covid-19 pandemic [25].

Previous research has shown that GPs consider palliative care as an important and rewarding part of their work, but system-level barriers can limit the time they have to adequately care for people at the end of life, including high workload, limited resources, and reduced opportunity for further training [52, 54]. Home visits, in particular, add considerable workload to an already pressured workforce, but have been identified as essential for high-quality end of life care in the community [55]. This is compounded by ongoing challenges with GP recruitment and retention [56, 57]. The increased number of home deaths that occurred during the Covid-19 pandemic was associated with considerable strain on the GP and community nursing workforce [58].

We asked respondents about the quality of care that the person who died received from different healthcare professional groups (*Figure 9*). In our survey, respondents were least satisfied with the care provided from GPs; of those who received care from GPs, 36.7% assessed it as being very poor, poor, or fair, while 57.4% said GP care was good, very good, or excellent. Free-text responses identified challenges with timeliness of care.

> **While we have an excellent GP it was not always easy to get hold of him and this was very frustrating at times.**
>
> (J555, Wales, died from dementia or Alzheimer's disease)

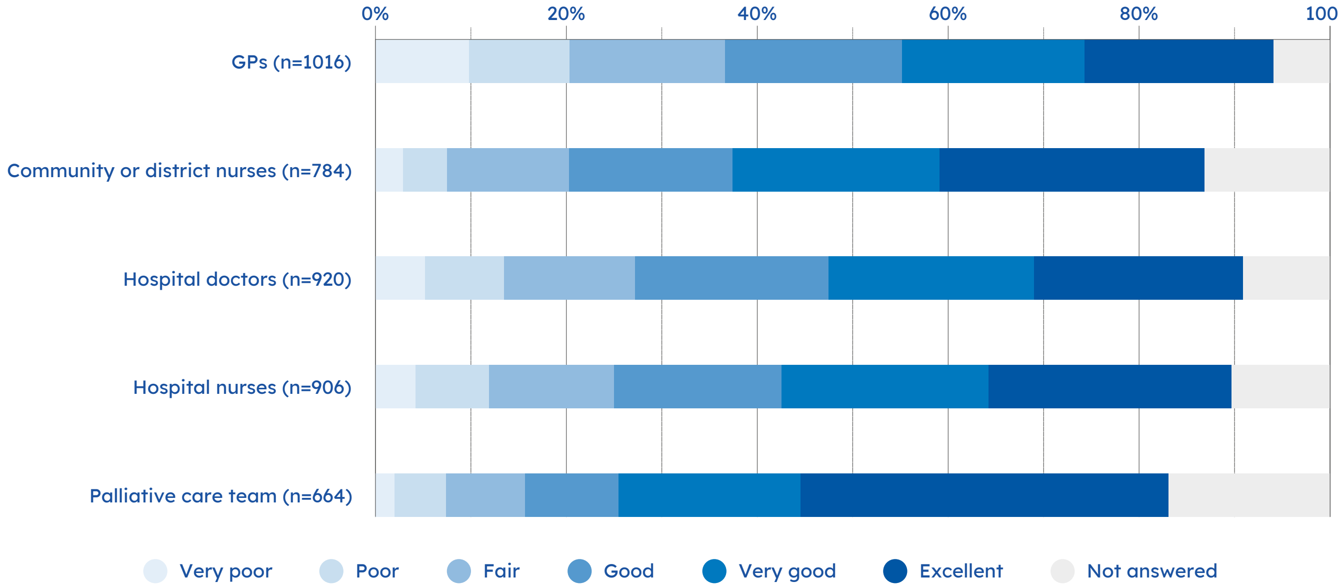
> **Weekends felt more difficult; GPs [care] is good but that is Monday – Friday.**
>
> (E927, England, died from other condition)

> **We were told the GP would visit in 1 hour to sort out my brother's medication, but it took them 7 hours to arrive. […] The hospice at home nurses and care assistants were fantastic. We contacted [the hospice] before my brother came to live with me and they arranged all the necessary equipment without any problems. The district nurses, when [we] needed eg syringe driver and to catheterize my brother were equally efficient.**
>
> (E787, England, died from cancer)

Care provided by palliative care teams and community or district nurses was rated highest in terms of quality; of those who received specialist palliative care, 67.5% rated the care as good, very good, or excellent, while 15.7% rated it as very poor, poor, or fair.

> **Originally, she wanted to die at home but became so poorly and the hospice were so good that she felt safe and secure with them so wanted to end her life there.**
>
> (C725, England, died from cancer)

Figure 9. Respondents' perception of the quality of the care received from different healthcare professionals



Notes: Responses indicating that care had not been received from these professional groups were excluded

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4.4 Carer experiences of access to care services and care provision

4.4.1
Were respondents unhappy with care?

Respondents were asked if there were aspects of the care that their relative received that they were unhappy with. Almost half (n=572, 48.5%) reported they were unhappy with one or more aspect(s) of care, while 569 (48.3%) reported having no such issues. Of the respondents who were unhappy with care, 229 (40.0%) reported that the issue(s) were discussed with health or care professionals and 71 (12.4%) reported that they made a formal complaint. The free-text responses demonstrated that respondents who made complaints often described issues of poor or absent care or long waits, disagreement with discharges or assessments (eg rejected applications for care provision at home), and lack of communication or information-sharing.

> **The GP prescribed a syringe driver for my father to relieve his pain & suffering. The nurse did not carry out the GPs instructions. After a six hour wait the pain team came & set the driver up. The district nurse had failed to communicate aspects of my father's care. I filed a formal complaint.**
>
> (F779, Wales, died from multiple conditions)

4.4.2
What were the main challenges with care provision?

We identified several issues that respondents reported as challenging in terms of care provision.

Coping with navigating services and coordinating care

The caring experience was made more difficult by having to take on the role of care co-ordinator due to lack of coordination between services. Families were often unfamiliar with what care and support was available and how the services operated. It was time consuming and stressful to navigate and manage different services and having to explain their circumstances repeatedly. Carers also felt as though they let the person who died down if they could not access the care required. Out-of-hours care appeared to be particularly challenging to navigate and get timely access to.

> **Accessing all NHS services during the last 2 months of mum's life was very challenging. We couldn't get the services needed at the time needed, and the quality of her life was impacted. Although, I had power of attorney for health and welfare for Mum, it was difficult to co-ordinate care. While working full-time, I had co-ordinated all health appointments, care provision and emergencies. Communication between the relevant organisations was poor or non-existent.**
>
> (A637, England, died from a lung condition)

The free-text responses also illustrate particular concerns among respondents about how health and care services engaged with the care needs of older adults.

> **The health services do not have the funding or the time to make older people's lives more comfortable in their final years. People are living longer but there are not services available to care for their needs.**
>
> (J870, Wales, died from a heart condition)

> **[It was] difficult to find information about options when elderly relative needs more care. [We] felt we were always 'in the dark' about options, doing as best we could.**
>
> (A574, England, died from other condition)

The impact of strained health and social care systems

Many respondents noted that health and social care services in community and inpatient settings were over-stretched. They felt that while staff often did the best they could, the quality and continuity of care was poor overall.

> **I believe that the medical profession, being under severe pressure, were not able to offer my mum and her carers the support they need.**
>
> (C605, England, died from dementia or Alzheimer's disease)

> **Although my father was looked after and contacted regularly, we never felt that we could approach hospital staff and when we did it always seemed to be a problem, they were far too busy and just didn't have the time (they wanted) to dedicate to patients in their care – more so the nurses, less so the doctors who quite frankly didn't seem to care at all!**
>
> (E980, England, died from a lung condition)

General practice was often mentioned in free-text responses as an example where respondents would have liked more involvement.

> **I was dissatisfied and disappointed in the GP support, such that it was. I always understood the GP to be the nexus of care in the community. It wasn't. Maybe my wife and I were naive to think so. The difficulty I had in engaging the GP surely added to my/our stress and grief.**
>
> (C663, England, died from cancer)

Stretched social care services also meant long wait times for getting care packages or other equipment in place at home, and delays in the discharge of patients from hospital. Conversely, respondents also described feeling that the patient was discharged too soon or inappropriately because of the pressure on hospital beds.

> **I was informed that due to pressure of work, [the social services department in hospital] were unable to arrange a care home & mum had to remain in hospital.**
>
> (H918, Wales, died from a stroke)

> **Dad was discharged to an inappropriate setting which resulted in his readmission to A&E within 24 hours.**
>
> (E994, England, died from dementia or Alzheimer's disease)

> **When discharged from hospital we, the family, felt that it was more important for the hospital to clear a bed than to ensure a patient was being appropriately cared for.**
>
> (C809, England, died from a renal condition)

5 Experiences of the final week of life

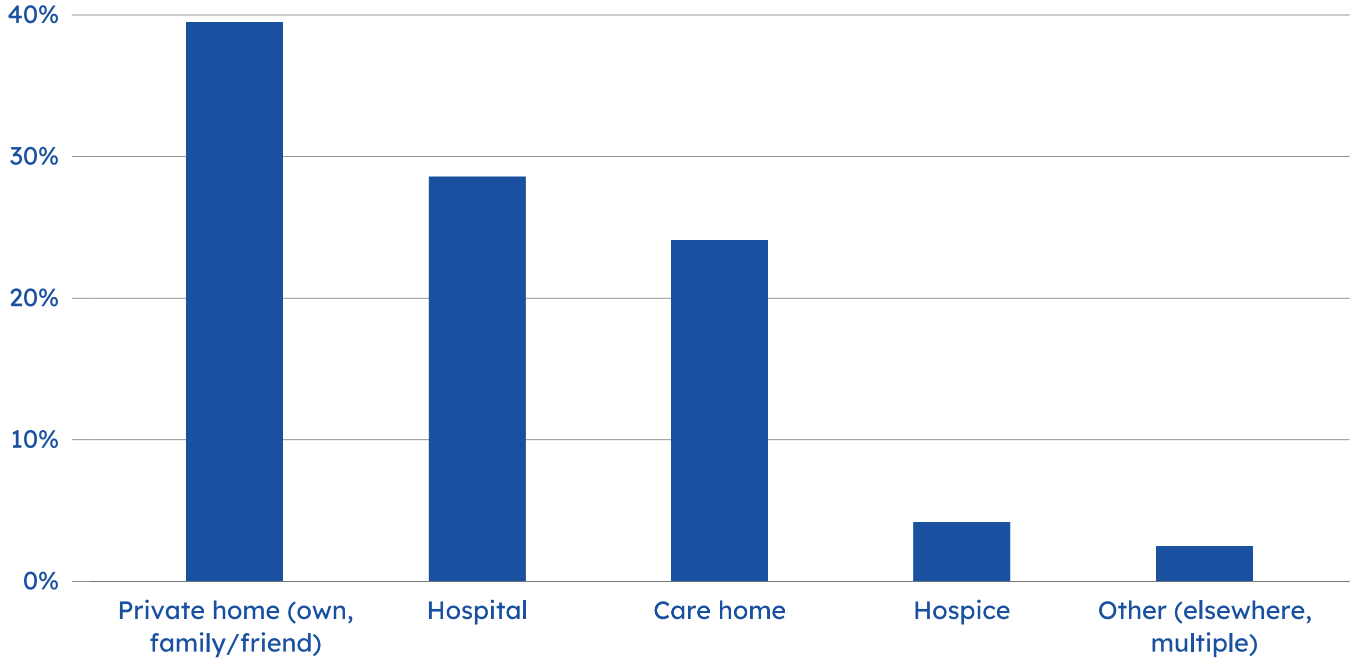
Summary of key findings

- 40% of those who died spent most of their final week of life in a private home; 29% were in hospital and almost 25% were in a care home.
- Hospital was the most common place of death. Even though many respondents described hospital staff as supportive, the hospital was often reported to be an inappropriate environment to die in due to noise and lack of privacy.
- The most common physical symptoms affecting those who died in their final week of life were poor mobility, weakness, and poor appetite. The most common psychological concern was the family feeling anxious or worried about the person's illness or treatment, and that the person who died had felt anxious or depressed.
- Prevalence of five key symptoms (pain, breathlessness, feeling anxious, not being peaceful, and not having information needs met) varied across care settings and cause of death. Those who spent their final week in hospital had the highest overall symptom burden, while those in care homes had the lowest. Those who died from cancer had the highest prevalence of pain, whereas those who died from dementia were least likely to have information needs met. In addition, those financially less comfortable had higher prevalence of all five key symptoms, compared to those financially more comfortable.
- Difficulties with access to services, healthcare professionals, and medication or equipment were identified as major barriers to timely symptom relief.
- Most respondents had been aware that their relative might die, but one in six of those had only became aware a few weeks before their relative's death.

5.1 Where did the people who died spend most of their final week of life?

In the last week of their life, 466 (39.5%) of those who died spent most of their time in a private home (either their own or the home of family or a friend). Many spent their final week of life in a care institution: 337 (28.6%) were in hospital, 284 (24.1%) were in a care home, 50 (4.2%) were in a hospice and 30 (2.5%) were in other or multiple locations (*Figure 10*).

Figure 10. The locations in which those who died spent most of their final week of life (n=1167)



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5.2 What symptoms or concerns were experienced?

Feeling comfortable, and receiving effective symptom management, is a priority for people living with advanced illness. To date, understanding of the symptoms and concerns of people in their last week of life has relied on small-scale studies which are not always representative of the national picture; these studies have found that several factors, including age, diagnosis, and place of care are associated with the pattern of symptoms experienced at the end of life [59- 61].

We asked respondents to report how much the person who died was affected by 18 symptoms and concerns during their final week of life using the *Integrated Palliative care Outcome Scale* (IPOS) [36]. Of note, this section of the survey captured how much those who died were perceived to be affected by symptoms and concerns during the final week, but not whether these symptoms resolved or improved. More information about the IPOS is available in Appendix 1.

Figures 11 and *12* show the physical, psychological, communication and practical symptoms and concerns reported to affect those who died. Poor mobility, weakness or lack of energy, and poor appetite were the most common symptoms during the last week of life. In our survey, 34.9% of those who died were reported to be severely or overwhelmingly affected by pain during the last week of life, and 40.0% were severely or overwhelmingly affected by breathlessness. The prevalence of these physical symptoms aligns with prior research on symptoms at the end of life [46, 47, 62].

The most common psychological, communication or practical concerns were ‘not feeling at peace’, ‘family being anxious or worried about the person's illness or treatment', and 'difficulty communicating'. 62.5% of respondents reported that family members were affected by being anxious most or all of the time in the final week of their relative's life. More than a third reported that the person who died felt depressed or anxious most or all of the time during their final week of life. These findings align with previous research [63].

Figure 11. Physical symptoms and concerns affecting the person who died in their final week of life (n=1179)

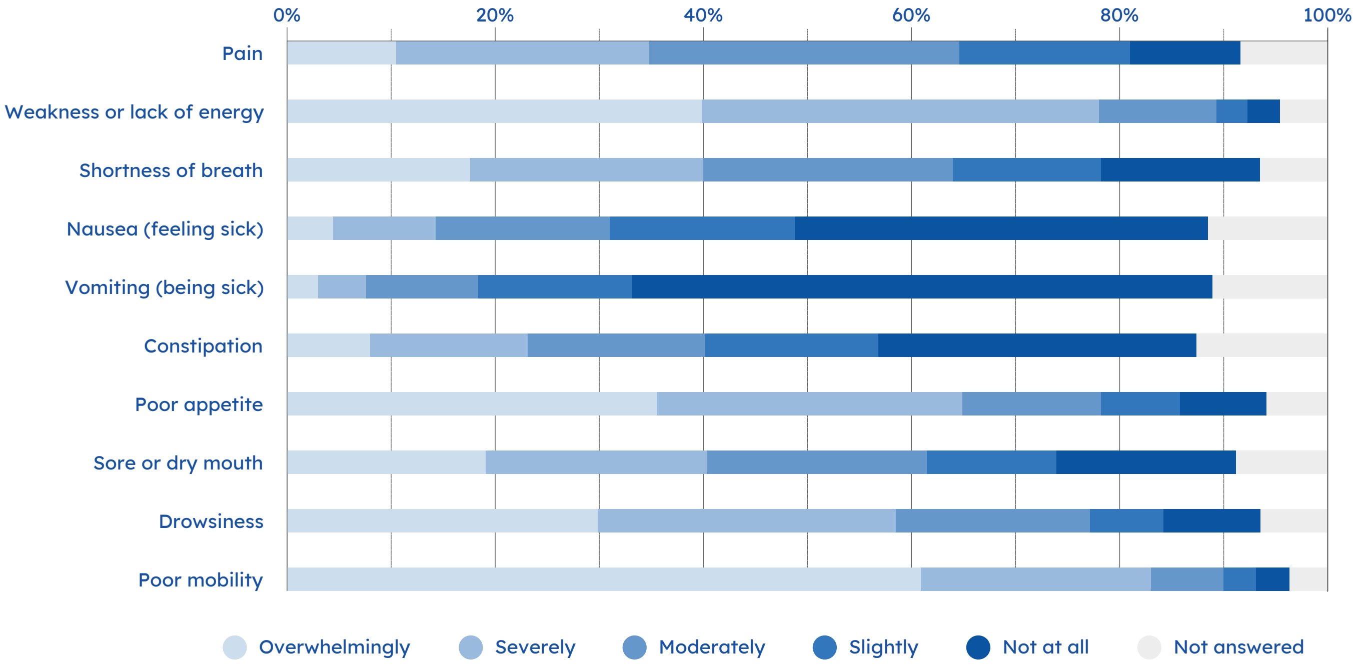

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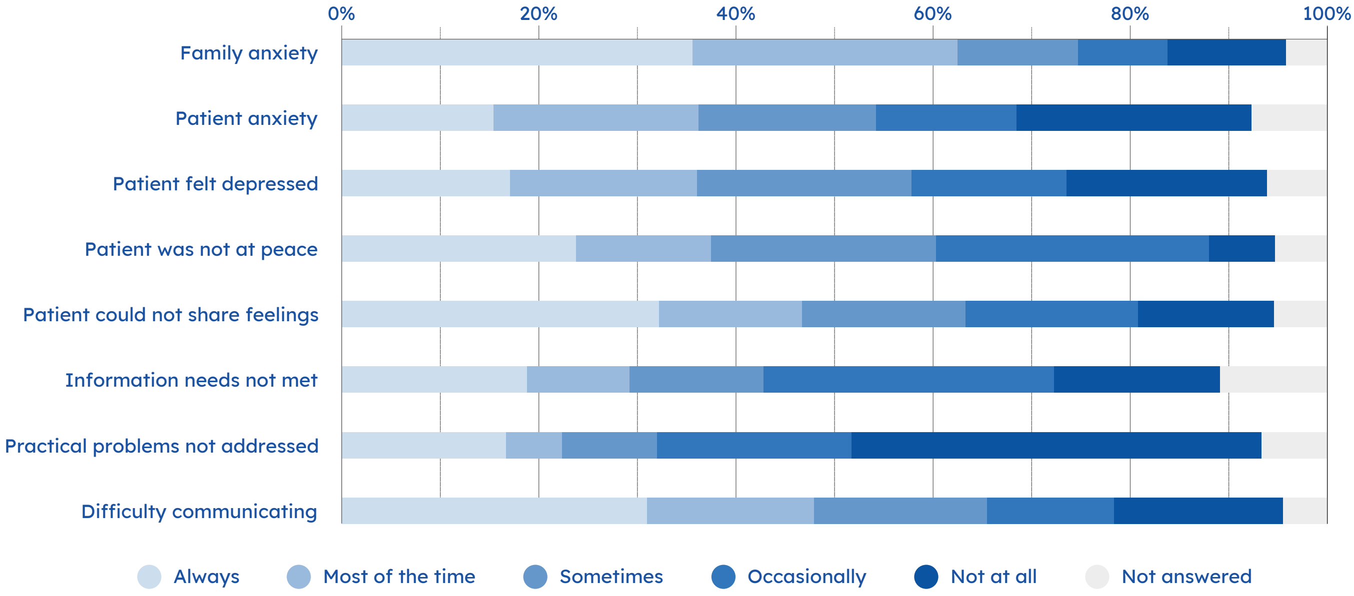
Figure 12. Other symptoms and concerns (psychological, communication, and practical) affecting the person who died, or their family, in their final week of life (n=1179)



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The free-text responses illustrate that there were practical challenges, especially when the person who died was at home, which could impact symptom management and exacerbate patients' and families' anxiety. Difficulties accessing services, healthcare professionals, and medication or equipment were identified as major barriers to timely symptom relief.

> **In the last week, a syringe driver was set up. [The] local pharmacy didn't always have stock of [the] medications [and] weekend opening times of [the] pharmacy could be problematic. These two points resulted in me having to travel 20 miles to pick up prescriptions and medications, which deprived me of precious time with my husband. Plus, [it] caused added stress [of] having to find someone to sit with him. My husband was very anxious with this situation.**
>
> (F816, Wales, died from multiple conditions)

> **My mum received excellent support from GPs, district nurses and the palliative care team. [...] although services were great once you got hold of them, getting hold of someone eg on weekends and evenings for assistance when mum was in pain was challenging and added to stress!**
>
> (H625, Wales, died from cancer)

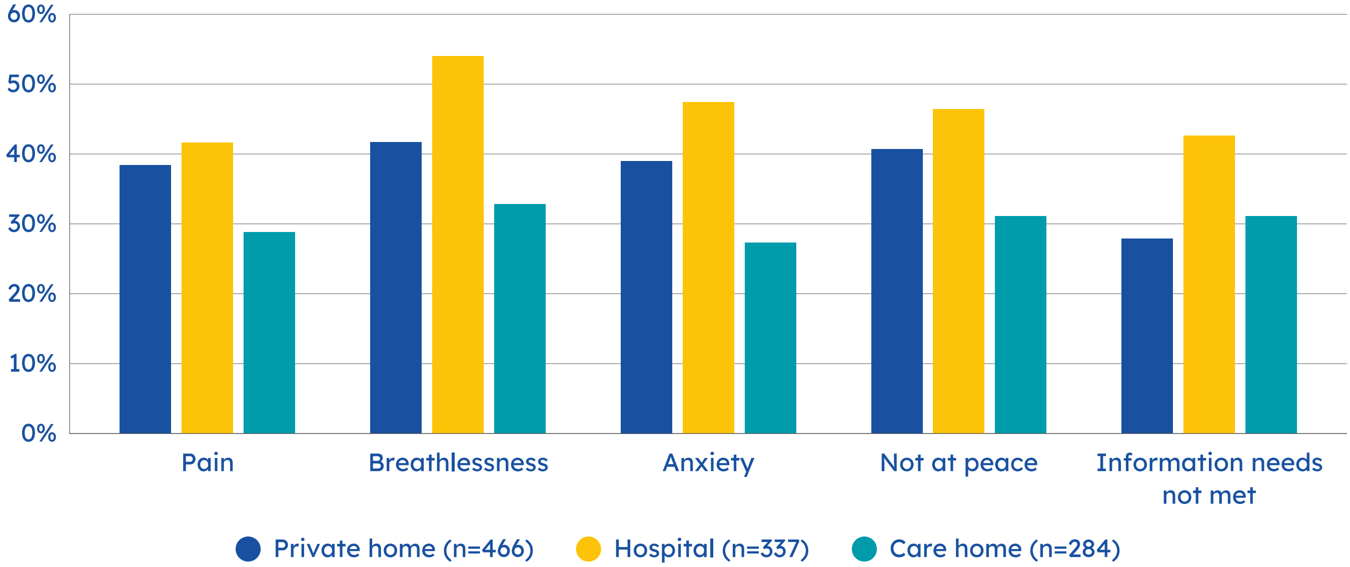
5.2.1

Differences in symptom prevalence across care settings

Five of the IPOS items – pain, breathlessness, feeling anxious, not being peaceful, and not having information needs met – provide an overview of key symptoms and concerns across the physical, psychological, and spiritual dimensions of palliative care [44]. Below we report these symptoms in more detail, focusing on people who died whose symptoms were reported as affecting them severely/most of the time or overwhelmingly/always.

As shown in *Figure 13*, these five symptoms differed across settings of care in the final week of life. Due to the low number of people who spent their final week in a hospice compared to other settings, we have not included this group in the figure as we can be less confident about the accuracy with which this data reflects the national picture. It should also be noted that people cared for across different settings are unlikely to be directly comparable. For instance, those in hospitals may have distressing symptoms as a reason for admission, whereas those in care homes have a different profile of conditions and needs.

Figure 13. Differences by care setting in prevalence of being severely or overwhelmingly affected by five key symptoms and concerns in the final week of life



Notes: Percentages are based on valid responses only, missing data for each item is excluded.

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More than a third of those who spent their final week of life at home or in hospital were reported to be severely or overwhelmingly affected by pain. We do not know from these data whether or not pain was relieved following management at home or admission to hospital. Across settings, the free-text responses illustrated that pain was a particularly distressing symptom for the person who died as well as for family and friends who were present.

> **[My son] died a horrendous death, crying out in agony till he took his last breath. As his mum [his] death will live with me forever – I will never get over how he suffered.**
>
> (A715, England, died from cancer)

Respondents also commented on the positive impact of pain being managed.

> **[Name] struggled with the prospect of death understandably but after time this eased and she was at peace. The fact that they were able to relieve her pain helped considerably.**
>
> (E559, England, died from a heart condition)

Dad wanted to be at home but his cancer progressed rapidly and he couldn't manage pain. Having been fully armed with available info, he chose to go to hospice because he knew they could better manage his pain relief…

(A533, unspecified region, died from other condition)

The highest overall symptom burden was experienced by those who spent most of their final week of life in hospital. Breathlessness was particularly prevalent among this group. Shortness of breath can be extremely distressing and is a common reason for hospitalisation at the end of life: in England, 20% of ambulance presentations to the emergency department are due to breathlessness [64]. Not being peaceful was also most common in hospital, which was described in free-text responses as an environment lacking in both calmness and privacy.

My father died on a busy ward with a very noisy and disruptive man in the bed next to us. Although the curtains were closed it was not a peaceful, respectful or appropriate way to end your life. I wanted to take him home but unfortunately he was too unwell to move.

(A839, England, died from other condition)

Unaddressed information needs were most often reported in hospitals, with respondents describing the importance of information for patients and their families to understand what is happening and what they might expect.

The staff at the [hospital] were constantly overstretched and unable to give sufficient attention to patients on the cancer ward. Doctors were also under pressure and as a result information that we would like to have had was scarce!!

(C868, England, died from cancer)

There is evidence that specialist palliative care provided in hospitals improves the wellbeing of those with advanced illness and the support for those affected and their families [65, 66]. However, the specialist palliative care workforce within hospitals is limited [67]. Notably, only 60% of hospitals have seven day availability of face-to-face contact with specialist palliative care [68] even though this is a recommendation from The National Institute for Health and Care Excellence [69].

For those who spent most of their final week of life at home, high symptom burden was reported for about a third. This is a note-worthy finding since home deaths have increased since the Covid-19 pandemic [25] and are projected to continue to rise [53]. The workforce issues among GPs, community and district nurses highlighted in section 4.3 of this report, impact the system's capacity to meet the needs for end of life care at home [58]. Without increases in resources for community-based primary and palliative care services, people with advanced illness and their families are likely to struggle with symptom management at home.

Even though those who spent most of their final week of life in a care home had the lowest overall symptom burden, more than one in five people were severely or overwhelmingly affected by the five key symptoms and concerns. Anxiety was lower in this group compared to those in other settings. One reason for this could be higher familiarity with the setting and the staff since those in care homes often had been there for longer periods of time than people in, for instance, hospital settings.

My mother made it very clear that her 'home' was the residential facility she was in. She had been there four years.

(E854, England, died from another condition)

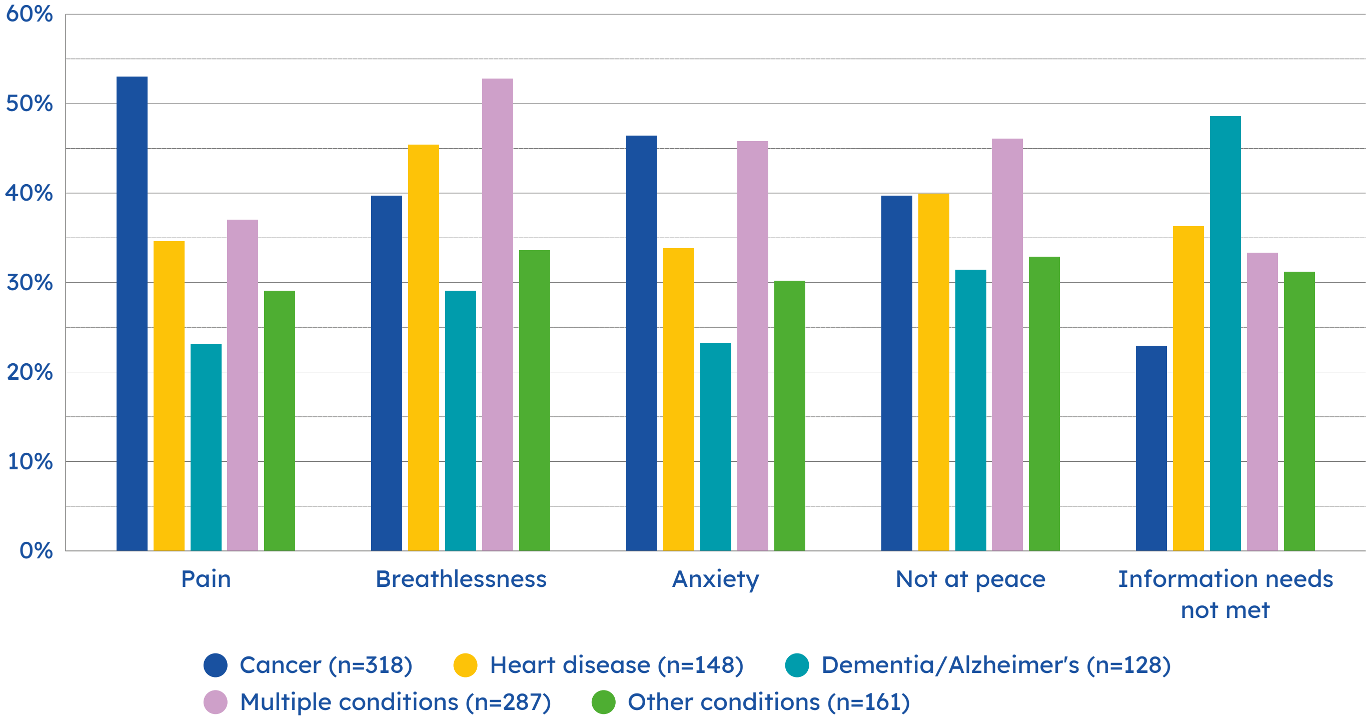
> **Mum and I were lucky to have a positive experience from some of the most amazing people I have ever met. These people (staff) became like family as I visited nearly every day for 6 years.**
>
> (H721, Wales, died from dementia or Alzheimer's disease)

5.2.2

Differences across cause of death

We also found that the prevalence of the five key IPOS symptoms differed by cause of death (*Figure 14*). Pain was most common among those who died from cancer. This supports prior research; even though pain occurs among people with non-cancer diagnoses, it is generally more common among people with cancer [46]. People with multiple conditions had a high prevalence of breathlessness, which is likely because heart and lung conditions were common in this group. People who died from dementia had the lowest overall symptom burden but had the highest prevalence of information needs not being met.

Figure 14. Differences by cause of death in prevalence of being severely or overwhelmingly affected by five key symptoms and concerns in the final week of life



Notes: *Multiple conditions* signify when respondents reported more than one condition as the main cause of death. *Other conditions* signify conditions that were not listed as response options; free-text responses showed that these often involved respiratory infections, or old age or frailty. Percentages are based on valid responses only, missing data for each item is excluded.

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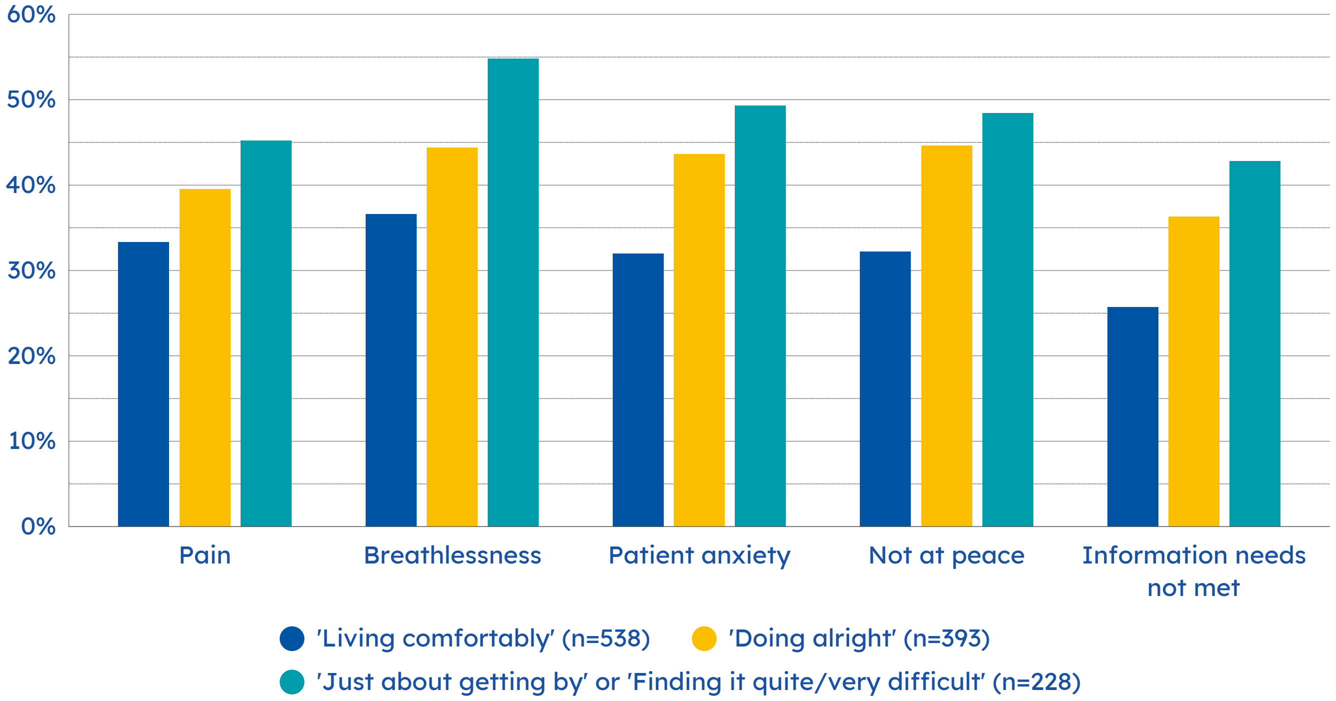
5.2.3
Differences across financial circumstances

Previous research has suggested that poorer financial circumstances are associated with worse symptoms and concerns at the end of life [70, 71]. We therefore explored symptom prevalence in the final week of life according to financial circumstances (*Figure 15*). We found that people who were financially 'just about getting by' or 'finding it quite/very difficult' had higher prevalence of all five symptoms, compared to those who were financially 'doing alright' or 'living comfortably'. In light of the results presented in section 4.2.5 showing that people who were financially worse-off had slightly lower use of specialist palliative care, this finding of higher symptom prevalence indicates that access to specialist palliative care might not be equitable for those with lower socio-economic position.

Figure 15. Differences by financial circumstance of the person who died in prevalence of being severely or overwhelmingly affected by five key symptoms and concerns in the final week of life



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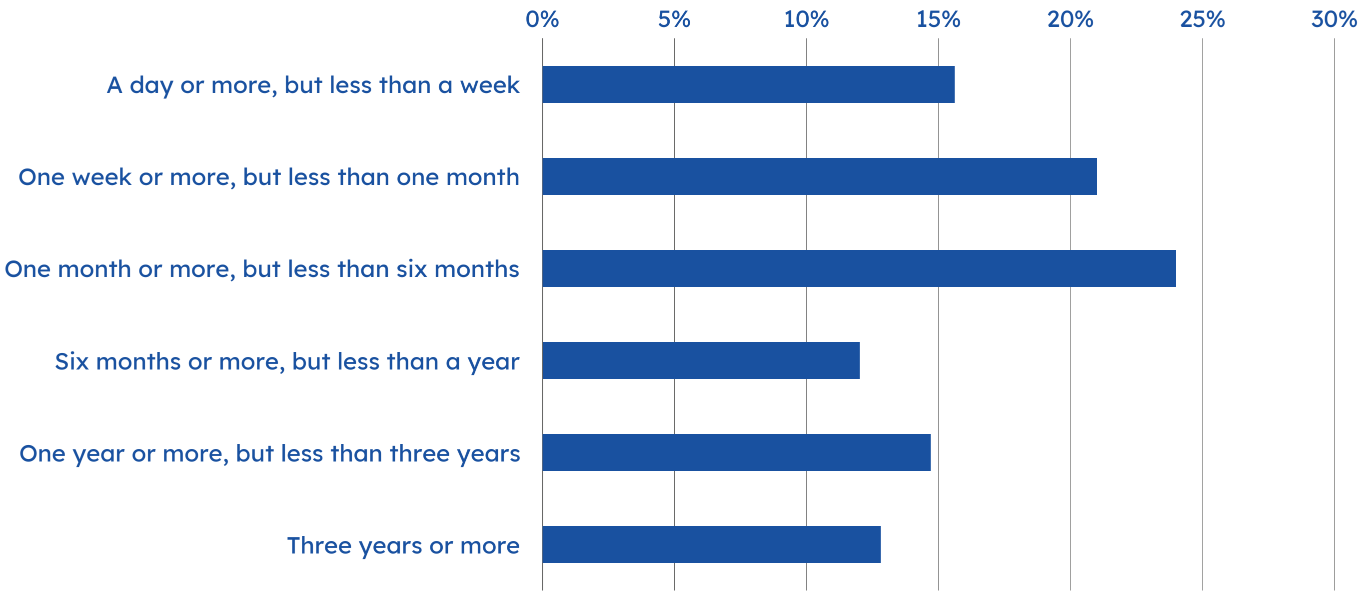
5.3 Awareness and acceptance of death

Most respondents (n=946, 80.2%) reported that they had been aware that their relative might die due to their illness, while 206 (17.9%) reported being unaware. 146 (15.6%) of those who were aware had only become aware in the last week of their relative's life (*Figure 16*).

Figure 16. Length of time that respondents had been aware that their relative might die (n=935)



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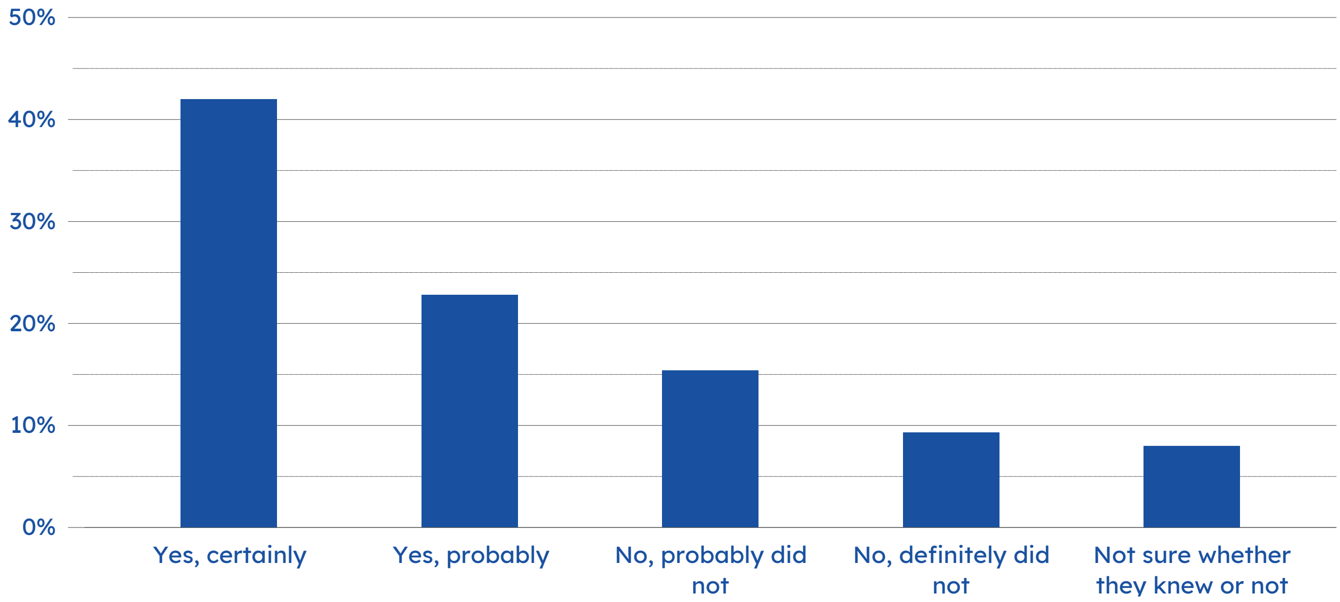
Almost two thirds of respondents (n=764, 64.8%) reported that, as far as they knew, the person who died had certainly or probably known that they might die, while about a quarter (n=291, 24.7%) answered that the person who died had probably or definitely not been aware; 94 (8.0%) were unsure (*Figure 17*). A quarter of respondents said that the person who died had been definitely accepting of the fact that they might die (n=287, 24.3%), whereas 319 (27.1%) were fairly accepting, and 130 (11.0%) had not been accepting at all.

Figure 17. Proportion of those who died who were thought to have been aware that they might die from their illness (n=1149)



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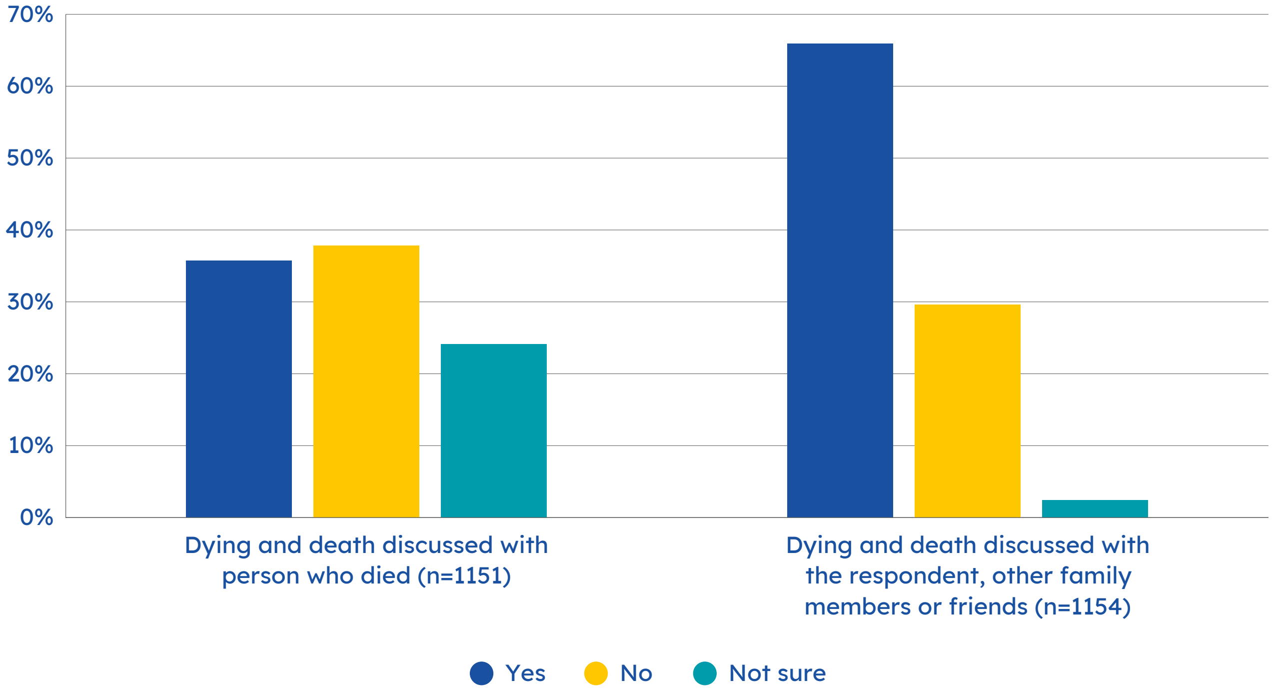
5.3.1

Did healthcare professionals discuss death and dying?

Respondents had varying experiences of healthcare professionals discussing the possibility of death and dying: 446 (37.8%) reported that, to the best of their knowledge, no such conversation had taken place with the person who died, while 421 (35.7%) reported that it had. It was more common for respondents to report that healthcare professionals had discussed death and dying with themselves or other family members or friends (n=777, 65.9%), though more than a quarter (n=349, 29.6%) had not experienced such discussions (*Figure 18*).

Figure 18. Proportion of respondents who reported that healthcare professionals had discussed dying and death with the person who died, and/or the respondent or other family members



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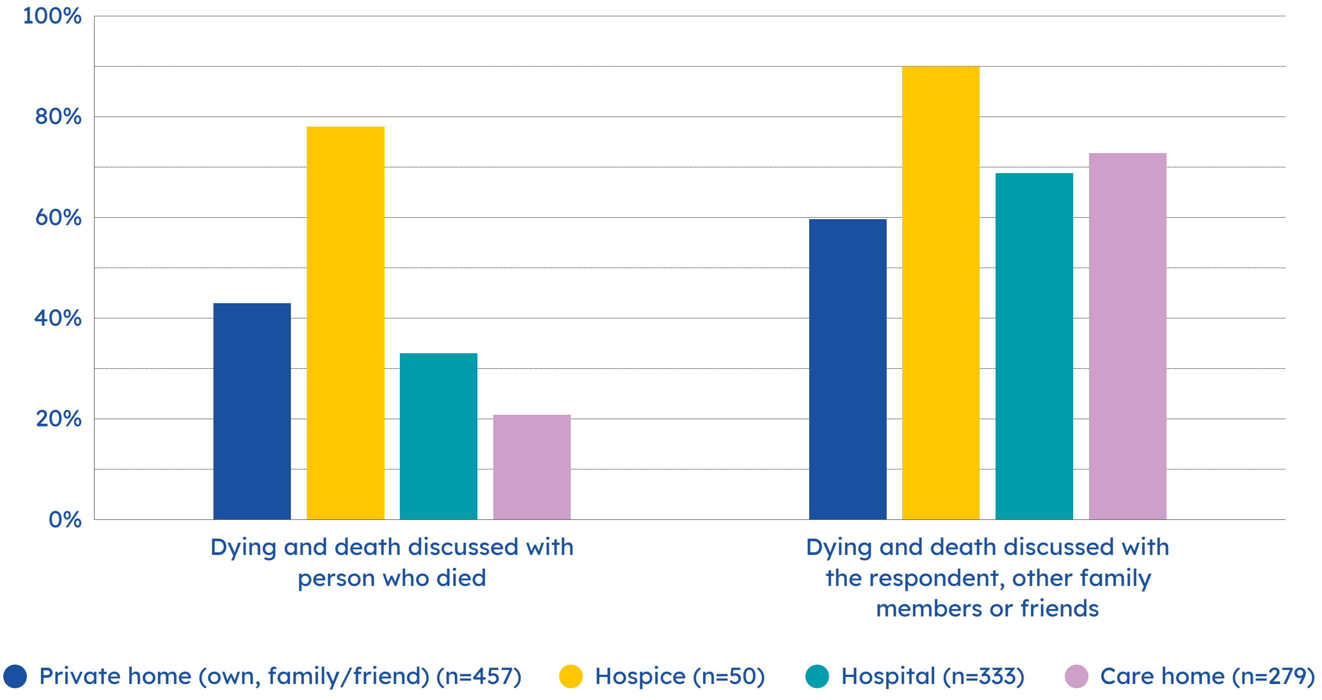
Not being aware that the end of life was approaching could mean that resources and support were not put in place which could hinder the ability for family and friends to be present at the death.

> **My mum chose to go to hospital, rather than a hospice or stay at home because we were led to believe she would get better… Our choices would have been so different, if only someone spoke to us about it.**
>
> (E899, England, died from other condition)

> **Despite being in hospital for 5 weeks, no-one ever said that they believed mum was coming to the end of her life. Only 5 days before she died did the care home staff talk about it. Care home staff were wonderful, despite being understaffed, underpaid and overworked.**
>
> (J880, Wales, died from other condition)

As shown in *Figure 19*, dying and death were more often reported as having been discussed with both the person who died and respondents and/or other family members or friends when the person who died spent their final week in a hospice (78.0% and 90.0%, respectively). Discussions were least commonly reported to have been had with the person who died when the place of care was a care home (20.8%). This may reflect the higher number of people living with dementia in this setting. The lowest rate of discussions with respondents or other family members or friends was when the place of care was a private home (59.7%).

Figure 19. Differences in the proportion of respondents who reported that healthcare professionals had discussed dying and death with the person who died, and with the respondent or other family members or friends by care setting in the final week of life



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The free-text comments suggest that there was wide variation not only in whether these discussions took place, but also in whether the person who was dying wanted to talk about it.

> **This was always a very open discussion with mum and family and healthcare professionals[...] Mum was very lucid to the end so also very aware and accepting of her situation.**
>
> (C699, England, died from multiple conditions)

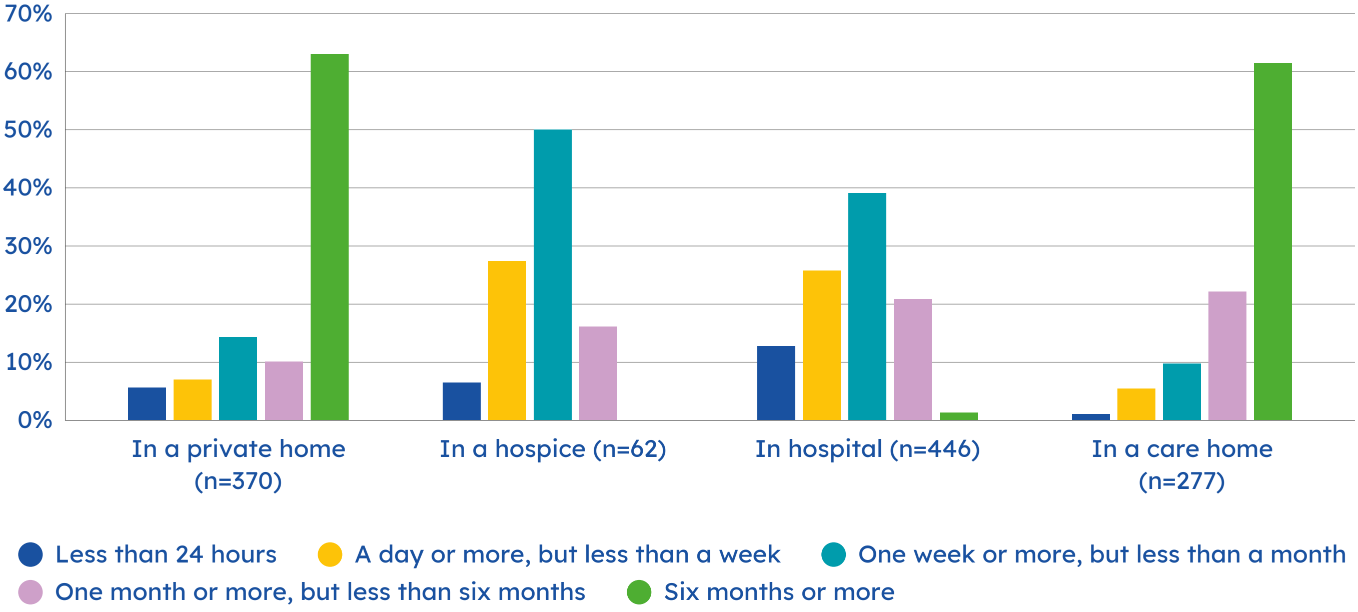
> **When I was called to come in to talk to the doctor, she had plenty of empathy [and] talked to my family as long as we needed, she was straight talking but had compassion for us all. I'm unsure if my mother wanted to know how long she had left to live, she never wanted to discuss it with us. Doctors did discuss it with us and were professional in every way.**
>
> (H871, unspecified region, died from cancer)

5.4 Place of death

While preferences for place of death vary among individuals and across different types of illness, many people wish to be cared for and die at home, if they and their informal carers can access appropriate care and support there [72, 73].

In our survey, hospital was the most prevalent place of death (n=446, 37.8%); 370 (31.4%) died in a private home, either their own or the home of family or friends, 277 (23.5%) in a care home, and 62 (5.3%) in a hospice. Of those who died at home or in a care home, most had spent six months or more in that setting before their death. In contrast, people who died in hospital or in a hospice more commonly spent more than one week but less than one month in that setting. 12.8% of people who died in hospital had spent less than 24 hours there before their death (*Figure 20*).

Figure 20. Duration of time that the people who died had spent at their place of death



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Place of death was highlighted as a complex issue in the free-text responses. Respondents shared instances where the environment the person who died in was not private or calm and contributed towards a negative experience. Hospitals, in particular, were often described as an inappropriate place to die.

> **Mum died in a cramped ward in the bowels of the hospital. When we visited her, after her passing, we had to pass many elderly patients to find her in a bed behind curtains surrounded by others. Although there had been nurses and doctors with her when she died it still felt that she was alone. I would have liked to be there if only to hold her hand. It could not have been easy for the other patients to hear us (8 attended in total) crying by her bedside in the early hours of the morning. Surely she could have been moved to a side ward so that we could spend longer with her and express our emotions fully.**
>
> (E958, England, died dementia or Alzheimer's disease)

> **I feel that my mum suffered an indignity leading up to her death. The final days were impersonal. Her bed was surrounded by a blue paper curtain, no privacy, no dignity. I had to plead with staff to move her to a side room, which they eventually did five hours before she died.**
>
> (F704, Wales, died from a lung condition)

Both the environment, eg privacy, and the behaviour of staff were considered essential components for a peaceful death in hospital.

> **The [hospital] nursing staff were exceptional: thoughtful, sensitive, attentive, constant, despite being run off their feet.**
>
> (E711, England, died from dementia or Alzheimer's disease)

> **The hospital where he died, the nurses and doctors was amazing. The kept us up to date. made sure he was comfortable. If at anytime we thought he was in pain, they would check him over to put us as ease.**
>
> (J584, Wales, died from a lung condition)

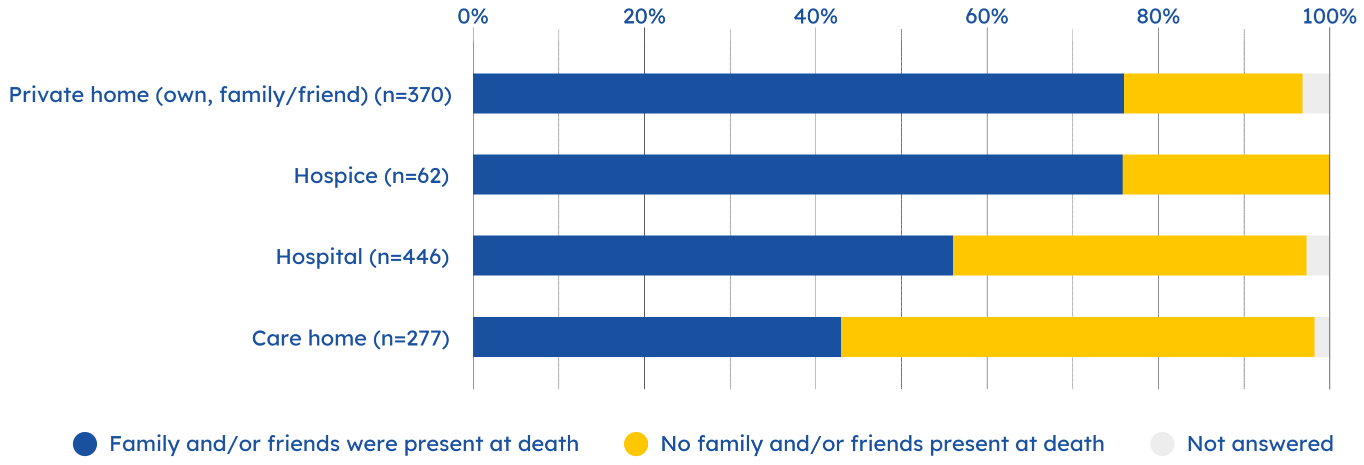
Many people had positive experiences of care homes providing an environment that felt homely. This might be influenced by the fact that it was more common for people who died in these settings to have spent a long time there, and so the space and staff were familiar.

> **The care staff at my Mum's residential care home were incredible. They were diligent, supportive of us and of Mum, professional, compassionate and loving. We felt as if we were surrounded by close family. I feel deep appreciation of their support and hard work through that difficult time.**
>
> (E521, England, died from multiple conditions)

> **The nursing home and their nursing staff in particular were amazing – with my mother and with me. In fact, all the staff were and some came to her funeral.**
>
> (H869, Wales, died from other condition)

In total, 707 (60.0%) respondents reported that they and/or other family or friends were with their relative when they died, whilst 435 (36.9%) said that family or friends had not been present. It was more common for family and/or friends to be present at death if the person died at home or in a hospice, compared to in hospital or a care home (*Figure 21*).

Figure 21. Proportion of those who died with their family members and/or friends present by place of death



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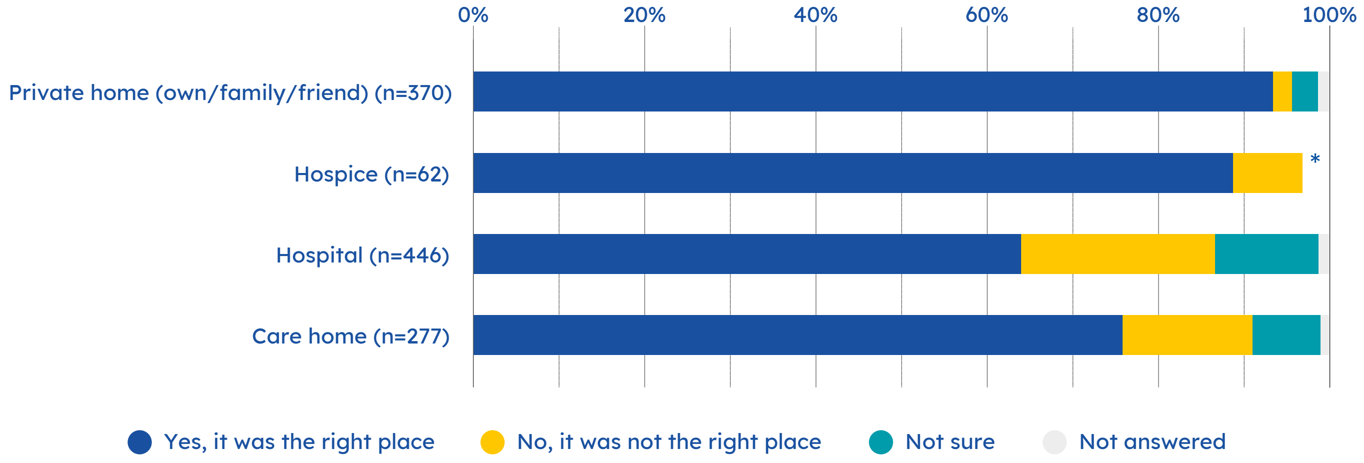
Most respondents answered that they felt that, on balance, the person who died was in the right place (n=906, 76.8%). A private home was most commonly the place of death that respondents felt was the right place of death (*Figure 22*).

Figure 22. Proportion of respondents answering that they felt their relative died in the right place, according to their place of death



Notes: *Small cell counts are suppressed

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Some respondents considered that the person who died passed in the ‘right’ place, even if it was not the preferred place of death, as their care needs could not be met in their preferred place.

> **We knew her wishes were to die at home but this couldn’t be managed safely.**
>
> (E644, England, died from dementia or Alzheimer’s disease)

Others expressed guilt at not being able to support their relative to die in their preferred place.

> **I promised my dad he could die at home but due to the lack of support I had to break the promise. I was unable to provide the care he needed.**
>
> (H650, Wales, died from cancer)

6 Experiences of caring for the person who died

Summary of key findings

- Most respondents were involved in caring for the person who died. The caring responsibility was often shared with additional family members or friends.
- Respondents described the hard physical and emotional work of caring for a person at the end of life, and many were unprepared for the responsibility that they perceived fell to them.
- Many respondents spent considerable time and resources caring for their relative.
- Carers suffered financial consequences of having to make time to care for their relative in the last months of life. Half of the respondents who were in paid employment took paid or unpaid leave or changed their work hours.
- There were mixed experiences of the extent to which healthcare professionals discussed the care of the person who died with family members or friends, or provided sufficient help. Lack of communication was a common source of frustration for respondents.

Family and friends who care for someone with advanced illness perform essential care work by undertaking numerous caregiving tasks. However, lack of knowledge and skills, and limited support from healthcare professionals, can hinder successful provision of care [47].

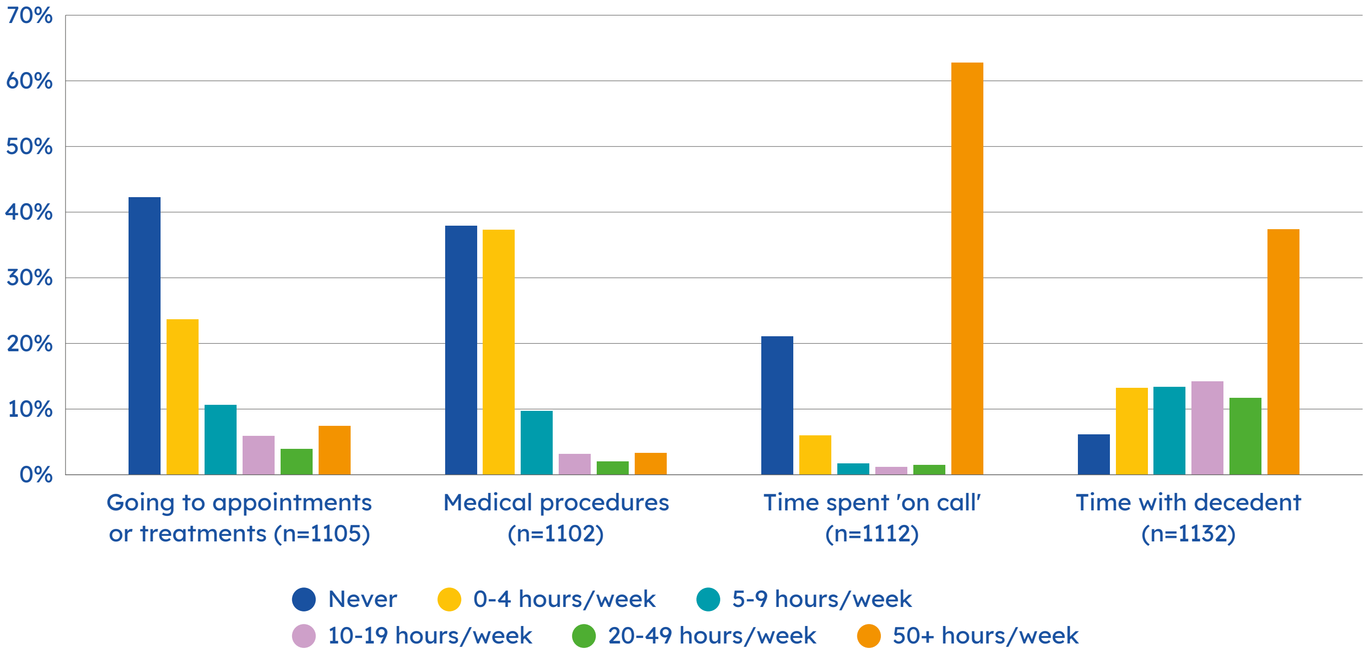
6.1 Who was involved with providing care?

Three quarters (n=881, 74.7%) of the respondents reported that they were involved in caring for their relative during their last three months of life (*Figure 23*). 628 (53.3%) reported that the person who died received care and support from additional family members or friends. Of these, 164 (27.7%) had help from one other family member or friend, 175 (29.5%) from two, and 254 (42.8%) from three or more family members or friends alongside the respondent.

> **There was 4 of us staying with my father towards the end, due to work commitments I wasn't there at the start and my sister set up the care that was in place.**
>
> (H514, Wales, died from cancer)

Overall, most respondents reported that they helped the person who died with various tasks on a weekly basis. In total, 606 (51.4%) reported that they helped the person who died go to appointments or treatments, while 655 (55.5%) said they helped with medical procedures. 863 (73.2%) spent time 'on call' (eg being able to be contacted if needed), and 1060 (89.9%) reported spending time with the person who died. Distribution of how many hours per week respondents spent helping the person who died are shown in *Figure 23*.

Figure 23. Hours per week that respondents spent helping the person who died during their last three months of life



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6.2 What was the emotional impact of caring?

Respondents described family and friends completing the 'work' to support the person who died, which could be challenging and overwhelming. It was apparent from the free-text responses that many families were generally unprepared for the difficulties in accessing and coordinating professional care and the extent of the caring responsibilities that they needed to take on.

> **It was tough going as often, we were not sure if we were doing the right thing. We struggled to lift her, turn her, keep her clean and toileted. That's why we were desperate for carers to come and help – but there was a shortage of carers. So, we soldiered on, on our own, doing the best we could.**
>
> (F974, Wales, died from cancer)

> **Even when social services were contacted still no care was put in place even knowing my brother lived on his own, so as a family and friends we were left with no choice but to put a rota together.**
>
> (J638, Wales, died from cancer)

Many carers were frail or in poor health themselves and struggled physically with caring tasks; some seemed to be caring alone for most of the time.

> **It is quite shocking that a 97-year-old man should have to carry the sole burden of a 90-year-old wife with Alzheimer's. No care was available to my father. He was isolated and lonely.**
>
> (C745, England, died from a heart condition)

> **[There] should be more recognition and support for the family members doing the care – my mother in this case, she felt isolated and depressed as [she] could only leave my father [for] short periods.**
>
> (H682, Wales, died from dementia or Alzheimer's disease)

6.3 What was the financial impact of caring?

Family carers often contribute considerable time and money to help with day-to-day support and care [74]. Costs of family caregiving at the end of life, such as out-of-pocket expenses and impact on employment wages, can be substantial and impact groups in society inequitably [75].

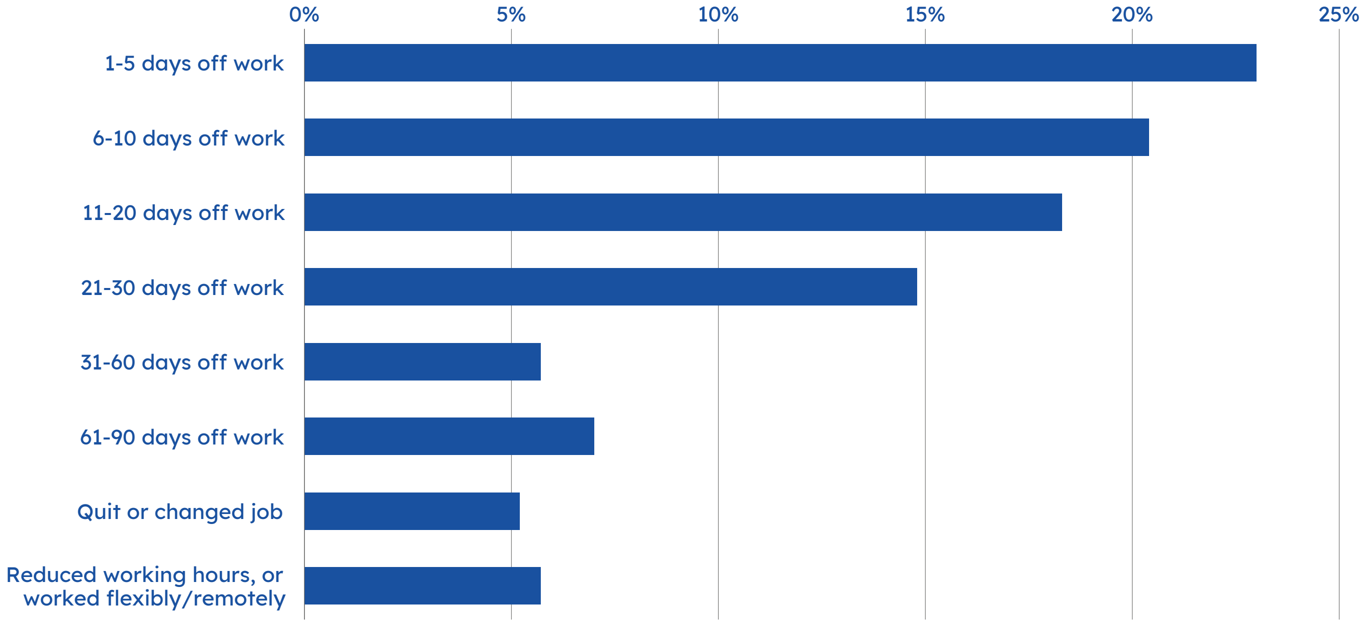
The impact of caring on carers' lives has been found to be influenced by the type of care tasks required and the circumstances of the person providing the care [76]. Respondents described a variety of factors that affected how involved they could be in caring for the person who died, with financial wellbeing and living far away from the person who died being two key factors.

> **My salary was reduced by £450 per month for the 9 months I was caring for my dad. I was not eligible for any benefits.**
>
> (H578, Wales, died from cancer)

> **I live 4 and 1/2 hours drive from my parents and from May to December all barring a couple of weeks worked 2 days at work, travelled to my parents, gave 24-hour support for 5 days and drove back to go to work. There is no support mechanism in place, now that retirement age (state) has increased, for children to support their parents without financially affecting themselves.**
>
> (E503, England, died from a heart condition)

Caring could also impact respondents' professional lives. Almost half of the respondents who were in paid employment (n=260, 48.8%) took days off work (either paid or unpaid) or reduced their working hours to care for their relative during their last three months of life. In contrast, 273 (51.2%) of those working carried on with their usual hours. Of those whose work situation was affected, almost two thirds had taken between one and 20 days of leave (*Figure 24*). It is noteworthy that about 5% of those who took time off work reported having quit or changed their job (including retiring early) to care for their relative.

Figure 24. Impact on work for those respondents who reported taking time off work to care for their relative in last three months of life (n=230)



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> **My brother sacrificed four years of his life and eventually lost his income… Mum wanted to remain in her own home but she needed 24/7 care […] I am convinced that the impact of [his] sacrifice will continue to have detrimental effects for years to come.**
>
> (C779, England, died from dementia or Alzheimer's disease)

> **I became my mum and dad's carer and left work to do so. I am very fortunate and happy to do this but God only knows what would have happened to them if I hadn't been here.**
>
> (E612, England, died from dementia or Alzheimer's disease)

6.4 Interacting with healthcare professionals and services

6.4.1
Did healthcare professionals listen to and have discussions with those who died and their family?

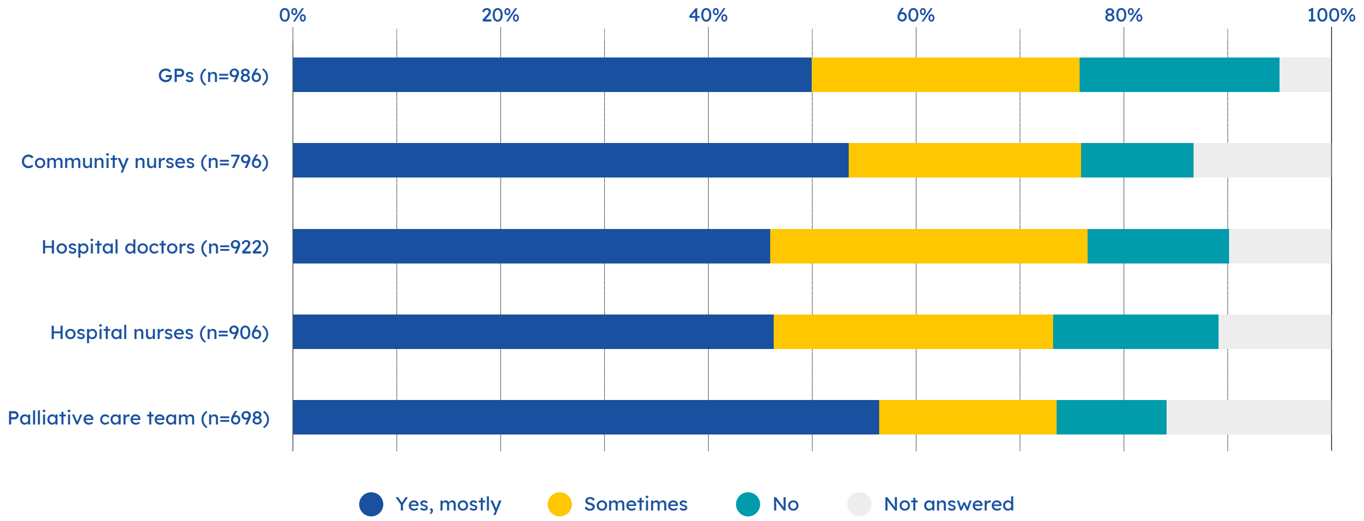
Good communication between patients, family carers and healthcare professionals is essential in end of life care: it can improve patients' quality of life and care satisfaction, and avoid aggressive treatment, which in turn can ease subsequent bereavement [77].

We found that around half of those who had received care from different professional groups said that the professional in question listened to and discussed care with them and/or the person who died most of the time. This pattern was similar across professional groups, though was highest for palliative care teams and community nurses, and lower for hospital doctors and nurses (*Figure 25*). Respondents reported difficulty finding someone to talk to in busy hospital environments.

> **It was hard to get any clarity as we were speaking with different doctors, whoever happened to be around when we visited. We tried to arrange an appointment for a proper conversation but this didn't seem possible. A consistent point of contact with the opportunity to sit down and talk would have helped.**
>
> (E773, England, died from a heart condition)

> **The care team at the hospital where he died was amazing. Credit to the doctors and nurses. They walked us through step by step and let us know at every turn what was going on with him.**
>
> (J741, Wales, died from a lung condition)

Figure 25. Respondents' experiences of how much healthcare professionals listened to and discussed with them and/or the person who died during their last three months of life



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In the free-text responses, respondents described varying experiences of being informed and involved in decision making. Many respondents reported feeling left out of the care loop. They described not being included in conversations, assessments, and care planning, and difficulties accessing services. These challenges were particularly prominent within hospitals and in general practice.

> **No one knew who was doing what and us as a family struggled to know the correct routes and who to contact. We were just expected to know […] We spent plenty of hours being passed about in order to find the right person/department to help. No one communicated with each other.**
>
> (J759, Wales, died from other condition)

> **[It was] difficult to get a [GP] appointment face-to-face, difficult to get advice, difficult having to deal with different personnel every time. All of this added to the immense stress we felt as family exhausted from caring for and supporting Dad, stressful to him too.**
>
> (J528, Wales, died from a heart condition)

> **The lack of joined up care was astounding, everybody passed a problem to someone else and it was extremely frustrating. There were so many holes in the service from help to obtain prescribed medication to complete a [Disability Living Allowance] application. GP service did not seem bothered.**
>
> (H684, Wales, died from cancer)

It was time consuming and stressful navigating and managing the different services and finding the right professional to talk to, which had a negative impact on carers.

> **I am a strong person but I was beginning to lose control at the inefficiency.**
>
> (H817, Wales, died from other condition)

> **The overall experience is that no-one really cares.**
>
> (E611, England, died from multiple conditions)

While information-sharing is central, interpersonal aspects of communication, such as showing empathy and respect, are also essential [78]. Many respondents highlighted the importance of professionals being present, kind, and unrushed, especially when respondents were told that their relative was approaching death. Many experiences were shared, providing both positive and negative examples.

> **One [hospital] doctor was incredibly harsh and lacked empathy when [we] were told my dad was extremely ill and probably in the final stages of life.**
>
> (F964, Wales, died from a stroke)

> **My Mum stayed with my dad for the last couple of days. The [care home] staff were very sensitive, extremely caring in the way they spoke about his end of life care.**
>
> (E640, England, died from other condition)

> **Our GP came out to the house – he was very helpful about the timelines of death, what to do etc.**
>
> (E577, England, died from cancer)

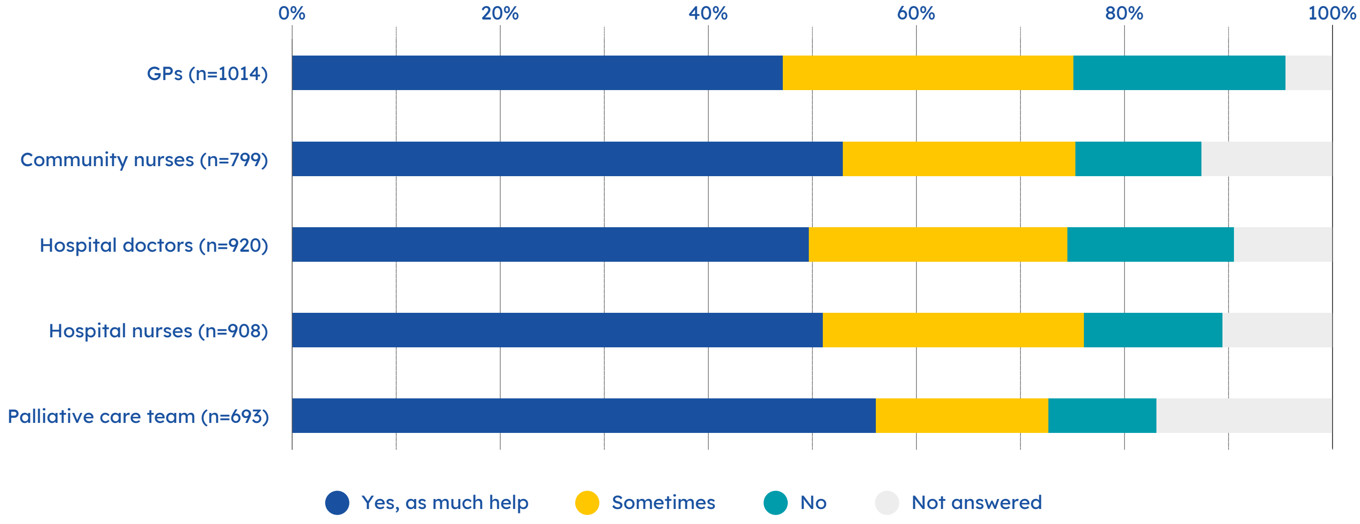
6.4.2

Did healthcare professionals provide sufficient help and support?

Despite family carers being integral to care provision at the end of life, previous research has identified several unmet needs, including psychological support, information, help with nursing and medical care tasks, out-of-hours support, and household and financial help [79].

Only around half of respondents said that healthcare professionals provided them and the person who died as much help as was needed in the last three months of life. GPs were rated the lowest: 207 (20.4%) did not consider that GPs provided sufficient help. Palliative care teams and community nurses were the highest rated: 389 (56.1%) and 423 (52.9%) said that they received as much help as needed from them, respectively (*Figure 26*).

Figure 26. Respondents' experiences of whether healthcare professionals provided enough help to them and/or the person who died during their last three months of life



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> **Our 'hospice at home' support was amazing. They sorted everything and treated my Dad with dignity. Any request was supported. They were also a huge help to me. In particular the night sitting service was a huge help when I was exhausted. I could have hugged the nurse when she arrived.**
>
> (A555, England, died from cancer)

Many free-text comments related to difficulty accessing support from GPs. As described in section 4.3, the shift in care for dying people into the community has contributed to unprecedented pressures on GP services, and respondents noted that services were overstretched. Nevertheless, disappointment in low involvement from GPs was expressed in the free-text responses.

> **GP service far, far, too difficult and remote. Far too much reliance on IT/digital approach way beyond my mother at 89 yrs. NOT EVERYONE CAN USE THE INTERNET!**
>
> (A881, England, died from other condition)

> **[The] out-of-hours GP refused to come out [and] told me to phone [the] paramedics […] resulting in my husband not receiving pain or anxiety medication throughout the night. This was horrendous to watch and totally unacceptable.**
>
> (F962, Wales, died from multiple conditions)

7 Bereavement among family and friends providing care

Summary of key findings

- One in six respondents met the criteria for disturbed grief, indicating persistent distressing symptoms of bereavement. Disturbed grief was more common among respondents who are female, younger, and were spouses of the person who died.
- One in ten respondents had accessed bereavement support, and most of these felt it had been helpful. However, only one in four of those with disturbed grief had accessed support, indicating unmet care needs.
- Two thirds of the respondents who were in paid work took time off after the death of their relative. About half of these took ten or fewer days off work, while almost one in ten took more than 60 days off work.
- Respondents who met the criteria for disturbed grief were more likely to have taken time off work in the three months after their relative's death.
- There were lasting practical and emotional effects of caring for a person at the end of life; respondents contributed considerable resources but also pointed out that the time spent caring was important and meaningful.

The death of a family member can often be a significant life stressor with emotional, physical, behavioural, cognitive, social, spiritual, and financial effects. While grief responses are unique to everyone, some factors are known to impact the severity of bereavement. For example, the bereaved person's relationship to the person who died, with spouses often having more severe symptoms of grief and being less likely to 'move on' following the loss compared to other relationships [80].

It is recognised that in some people, bereavement can become persistent and result in debilitating grief reactions that cause psychiatric distress [37, 81]. Such grief responses are sometimes referred to as *disturbed grief* and can be indicative of prolonged grief disorders, which are estimated to affect about 10% of bereaved adults [82].

We used the *Traumatic Grief Inventory – Self-Report+* to learn about the effects of bereavement among the respondents and explore levels of disturbed grief [37]. Respondents were asked to rate the extent to which they experienced 22 symptoms during the preceding month. A cut-off score of 71 or above was used to identify the prevalence of disturbed grief [37]. More information about the Traumatic Grief Inventory is available in Appendix 1.

7.1 Disturbed grief among respondents

We found that almost one in six of the 1158 respondents (n=182, 15.6%) who completed the Traumatic Grief Inventory had scores that indicated disturbed grief (ie scores ≥71). Disturbed grief was more prevalent among female respondents (19.0%) compared to male (9.6%), younger respondents compared to older (*Figure 27*), and respondents who were the spouse of the person who died compared to other relationships (*Figure 28*).

Figure 27. Prevalence of disturbed grief among respondents according to their age

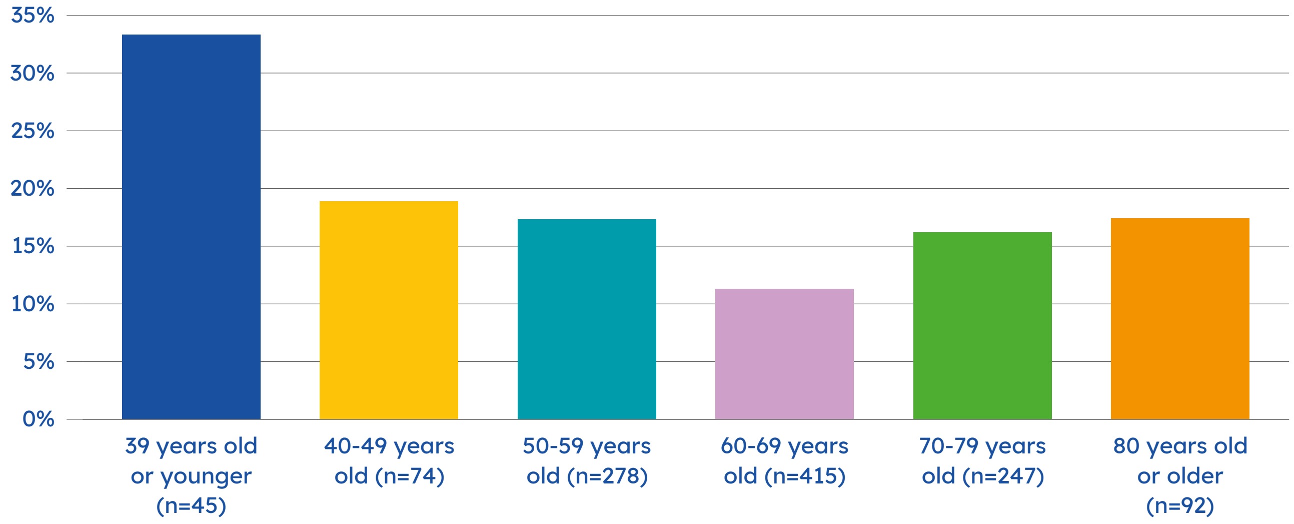

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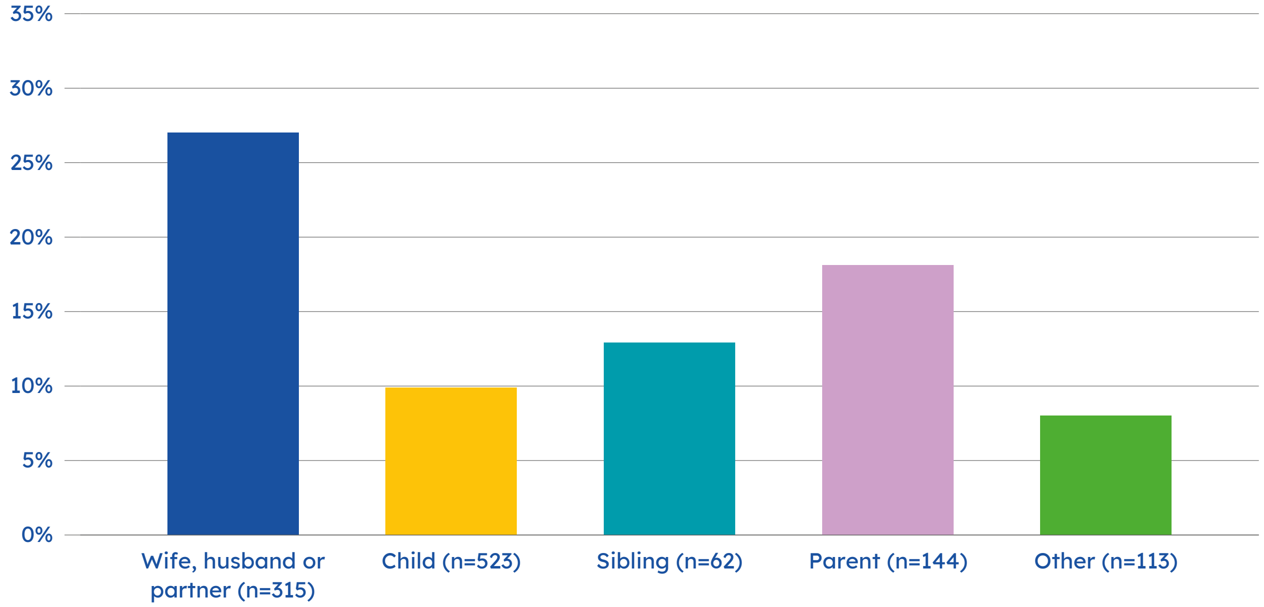
Figure 28. Prevalence of disturbed grief among respondents according to their relation to the person who died



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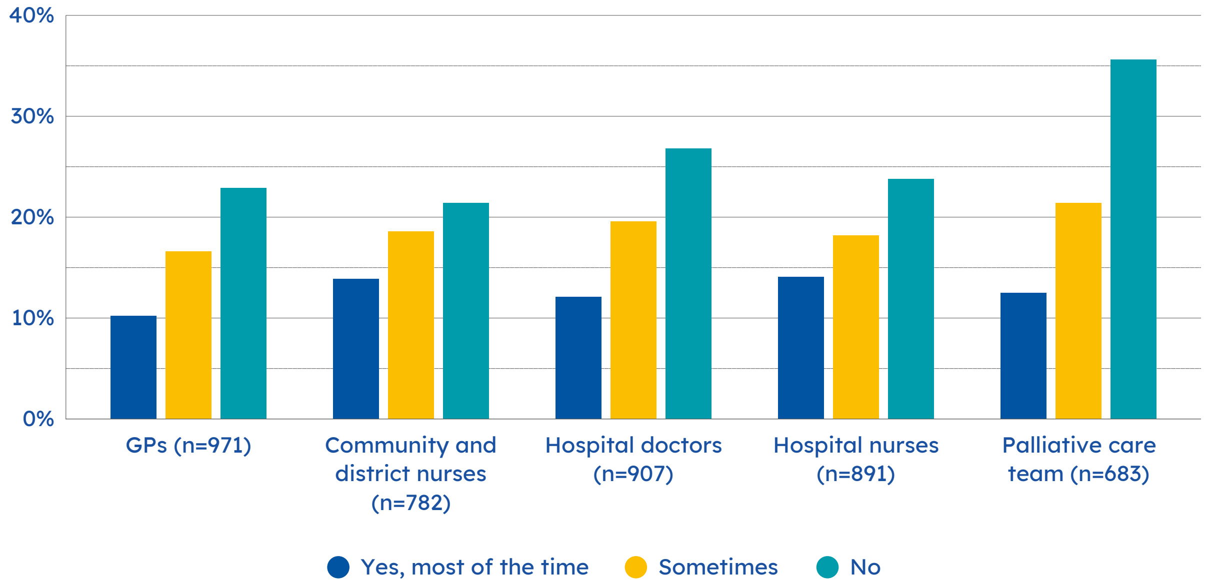
We found that disturbed grief was associated with care experiences and support from services before bereavement. For example, respondents who reported being unhappy with aspects of care had higher levels of disturbed grief (21.9%) compared to those who did not report this (9.4%). Moreover, respondents who reported that healthcare professionals had not listened to or communicated well with them and/or the person who died also experienced higher levels of disturbed grief (*Figure 29*).

Figure 29. Prevalence of disturbed grief in relation to whether respondents felt that healthcare professionals listened and fully discussed with them and/or the person who died



Notes: Percentages are based on valid responses only, missing data for each item is excluded.

View this data presented for: **England** **Wales**

Contextual factors, such as not being present at the time of death, not being able to say goodbye, and poor communication with physicians, can affect bereavement [83]. Previous research has shown that poor end of life experiences can lead to guilt among the bereaved and thereby influence grief [84]. The free-text responses highlighted that respondents who described poor quality of care or those who could not be present at the time of death mentioned experiencing feelings of guilt and regret in relation to their relative's experience at the end of life.

> **We were always dismissed in talking to the consultants during round wards**

> **[…] He was discharged from a respite hospital with no care, no assistance or plan. Essentially in my eyes sent home to die alone.**
>
> (A693, England, disturbed grief indicated)

> **It breaks my heart every time I talk about it… I am broken that I never got to say goodbye to her, and she was on her own.**
>
> (H700, Wales, disturbed grief indicated)

> **She passed away in a [hospital] ward with 4 people in beds around her […] We could have no private words or say proper goodbyes as it was like everyone was listening to your**

> **most precious time. At one point a lady ripped back the curtain, happily shouting "tea or coffee". I have contemplated making a complaint many times but the grief has been so overwhelming that I have needed to come to terms with all that has happened. The pain and guilt never leaves me.**
>
> (J599, Wales, disturbed grief indicated)

7.2 Contact with support services

The need for bereavement support to be recognised as an essential part of health and social care was emphasised during the Covid-19 pandemic. This requires both proactive approaches to identify those who may need support, and increased resources for existing bereavement services to improve coordination and accessibility [85].

In total, 126 (10.7%) respondents answered that they had talked to someone from health and social services or from a bereavement service about their feelings regarding their relative's illness and death. Of those who used support services, 99 (79.2%) felt it had been helpful.

Free-text responses indicated that for some, bereavement support was offered but not needed. Others, however, were unaware of whether support was available, while some respondents described how support was needed – and requested – but not received.

> **There is not a lot of care available after a death […] Something should be in place where you can go to get advice of what you need to do regarding arrangements and getting support when you feel overwhelmed with what needs to be done […] This can be a very difficult time trying to do what's needed without having some sort of support in place. If there is support available I have not been aware of [it] and would have accepted if I had known.**
>
> (E908, England, disturbed grief not indicated, no bereavement support)

> **Since the loss of my husband, I have applied for bereavement counselling but have heard nothing apart from a letter saying I would hear 'soon'. This was received about 6 weeks ago. If it was not for my dog (now my support dog), I would not be here to complete [the survey].**
>
> (C560, England, disturbed grief indicated, no bereavement support)

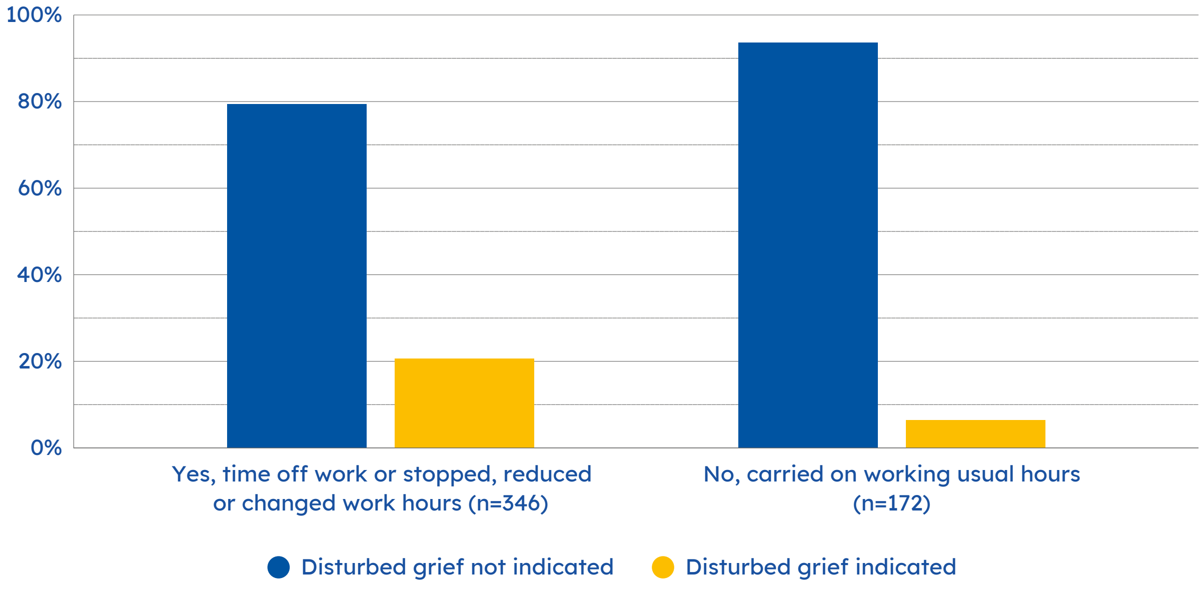
Among those with Traumatic Grief Inventory scores who met the criteria for disturbed grief, 46 (25.3%) had accessed bereavement support, while 136 (74.7%) had not. This indicates that there is a large group of people with unmet need for bereavement support. Our findings support evidence presented in the 2022 report by the UK Commission on Bereavement, which showed that over 40% of respondents who wanted formal bereavement support did not receive it [2].

7.3 Impact on work during the three months after death

Bereavement can greatly impact a person's ability to work, and prior research has identified challenges with returning to work among bereaved people [86, 87]. We asked respondents if they took time off work in the three months after the death of their relative. Of the respondents in paid employment (n=518), one third (n=172, 33.2%) continued to work their regular hours, while two thirds (n=346, 66.8%) took time off work.

326 respondents who took time off work provided further information about how their work was impacted; just over half (n=171, 52.5%) took 10 days or fewer of paid or unpaid leave, whereas 40 (12.3%) took 31-60 days off work and 31 (9.5%) took more than 60 days off work. 11 respondents (3.4%) had quit or changed jobs, or reduced their working hours, following their bereavement. Respondents who met the criteria for disturbed grief were more likely to have taken time off work in the three months after their relative's death (*Figure 30*).

Figure 30. Difference in prevalence of disturbed grief between respondents who had time off work or stopped, reduced, or changed their working hours in the three months after their relative's death, and those who carried on working normally



View this data presented for: England Wales

The lasting effects of providing care for a relative at the end of life were also evident in the free-text responses.

> **We live such sanitised lives, there's a touch of trauma when we witness a loved one leave. Sometimes events can be so seismic they leave us changed and I'm still in the fog left after her loss. I've reduced my hours at work, I'm changed, life is changed. I've had a career committed to my work but I simply can't bring my old energy and drive to bear, work is no longer the same focus, my family is. I see time differently, now I know we don't have forever together, I want to spend less time in work.**
>
> (J852, Wales, disturbed grief not indicated)

Nevertheless, respondents also highlighted that caring for someone at the end of their life could be a positive and very meaningful experience.

> **We consider it to have been a privilege to care for her, laugh with her and love with her for the end of life period.**
>
> (E985, England, disturbed grief not indicated)

> **We cared for her for 3 years and it was at times exhausting but we fulfilled her wishes. […] I feel lucky that we had support even though we were caring for her for up to 4 hrs daily. […] She had a wonderful life and we miss her greatly. But we [her 3 children] all feel that we helped her in so many ways, so no guilt, regrets or anything negative, just fond memories.**
>
> (H814, Wales, disturbed grief not indicated)

8 PPI group members' reflection about report findings

AS individuals with lived experience of dying, death, and bereavement, we are aware of the challenges faced by people who are approaching the end of life, and their family and friends. This report shows that these challenges are experienced widely across England and Wales.

It has been said that "health statistics are people with the tears wiped away" [88]. As PPI members, we were included in the research team and supported the work of analysing the free-text responses from this survey, to 'put the emotion back in'. The survey has provided bereaved people with an important opportunity to share how they feel about the care received before death, and their bereavement experiences. We felt a great responsibility when reviewing the data to make sense of the experiences individuals shared. This meant giving the time, effort, and emotion to represent what people told us.

As this report shows, experiences of and emotions surrounding the care received, and of bereavement, were complex. A finding that resonated strongly with us as carers, and the reason that this report is so important, is how unprepared people were for the situations they found themselves in, and that their needs were not being met.

We also identified that people's expectations of care were not being met. They felt let down because what they were promised did not materialise, and this added to the trauma of the situation. There was a sense of bewilderment and shock running through the quotes, where people detailed issues such as sleepless nights and trying to manage employment and family life alongside having to provide and co-ordinate care.

> **I think most people want to care for their loved one but aren't given enough support to do so. In other words, they want to provide some care but not ALL care – and that's the problem. At times, I think if you appear capable and willing, then you're left to do it on your own and that's when the weight of care can become all-encompassing. There just isn't enough recognition of the toll that it can take.**
>
> PPI group member Cara Duggan

Our hope is that the people who contributed to this survey can see themselves and their experiences reflected in this report and know that they have been understood and acknowledged. We do not want what people have shared to go in vain, and we want this report to be used to improve the experiences of others who are in the same situation.

Unless you have experienced caring for someone close to the end of life, it is impossible to imagine the devasting impact this can have without the right support. Through our work as part of the research team, we aimed to represent the important themes relating to care and bereavement experiences, whilst acknowledging individual and context-specific experiences. Although the experiences shared in this survey varied and were unique to each individual, it is essential to consider what we can learn from them, including what worked well and what must be improved.

9 Summary and implications of report findings

This report provides a nationally representative picture of the experiences and outcomes of dying, death, and bereavement across England and Wales. The report highlights areas where care and support at the end of life is good, but also that too often people who are approaching the end of life experience difficulties accessing the care and support they need.

Almost a decade on from the last national post-bereavement survey in England or Wales, we find patchy and inconsistent provision of palliative and end of life care. While some respondents described high-quality care – especially those who accessed specialist palliative care – many described overstretched services, with health and social care professionals struggling to have enough time to provide the care that was needed. This lack of resources, compounded by inadequate communication and poor coordination, results in high levels of unmet needs among people approaching the end of life and their family and friends. As a consequence, many respondents reported feeling unsupported, let down, and distressed by their experiences.

Our data reveal challenges around provision of palliative and end of life care in the community. Many respondents felt support from their GP and other community-based services was inadequate. This finding is highly concerning in light of projected increases in the proportion of people dying at home. As the number of people dying at home increases, unless there is a corresponding increase in capacity of primary and community care teams to support these deaths, quality of care is likely to suffer.

We found that people who are financially worse off experience a higher prevalence of severe or overwhelming symptoms in their final week of life, but that they do not access higher levels of specialist palliative care. This finding suggests that specialist palliative care provision in England and Wales is not equitable and does not follow need. This is a critical challenge in light of projected increases in population palliative care need, since people in more deprived groups often become further disadvantaged when health care services are strained.

We found that family members commonly spend precious time struggling to access, navigate and manage different services, which adds to the burden of an already distressing situation. Family and friends frequently take on responsibilities as informal carers and provide much of the care needed themselves. When there is adequate support for caring, this can work well and allow family and friends to spend valuable time with the dying person. However, in many cases, we found that carers feel unprepared and unsupported, and let down by health and care services. Our results highlight that the demands of caring have considerable financial and emotional consequences.

We show that insufficient or poor care can lead to guilt and anxiety among respondents, with knock-on effects on use of acute care services as well as debilitating symptoms of bereavement. This report provides important data on the proportion of people bereaved across England and Wales who experience disturbed grief, as well as the impact of bereavement on informal carers including the need to stop or reduce work.

This report should be considered the first step to understanding the reality of care and support for people affected by dying, death, and bereavement, and to improving services to better match existing needs. The findings should be used by policy makers across England and Wales to ensure that health and social care professionals are equipped with the time, skills, and resources to deliver equitable end of life care, across settings. In addition, more focus must be given to supporting informal carers both before and after bereavement. Finally, we recommend that this survey is repeated regularly, using a population-based sampling framework, in order to monitor the quality of dying, death, and bereavement for different groups, to understand whether experiences and outcomes are improved over time, and to highlight areas of priority for investment.

Implications for further research

This report provides the first nationally representative data on symptom burden in the final week of life (using IPOS). Further research should examine differences in symptoms experienced by dying people in more detail, including how these vary by socio-demographic and clinical characteristics, and across settings.

Our data show that informal carers (family and friends) contribute considerably to the care received by people in their last months of life, and that this has emotional and financial consequences. Further research should explore the economic impact of this care at both individual and societal levels.

We provide valuable data on the prevalence of disturbed grief at a national level. Further research should explore, in depth, the groups most likely to be affected by this, the implications of disturbed grief for individuals and society, and the support needed for those affected.

Our data shows that primary and community care teams provide a large proportion of care for dying people in the community but are overstretched and therefore not always able to deliver care that is high-quality. Research is needed to understand ways to improve integration and coordination of primary and community care, and the impact of this on acute care services. While respondents valued having a key contact person, the impact having a care co-ordinator on patterns of care at the end of life should be examined.

Our findings indicate that there are inequities in England and Wales in receipt of high-quality care at the end of life according to socio-economic position; further research is needed to understand how intersecting characteristics contribute to experiences and outcomes, and ways in which inequities can be reduced.

In our survey it was not possible to explore responses by ethnicity, as the number of people from non-White groups who responded to the survey was low. Research to understand experiences and outcomes of care for minoritised ethnic groups is needed.

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11 Appendices

Appendix 1.
Study methods

Contents

1.1
Sampling strategy

Inclusion criteria

Respondents were those aged 18 years or older who registered deaths:

- Of adults aged 18+
- From all causes (excluding sudden deaths). See Table 1 for included causes of death. Deaths due to accidents, suicide or homicide were excluded.
- That occurred 6-10 months before survey distribution (avoiding most acute immediate bereavement period and anniversary of death).

Table 1: Included causes of death

Cause of death	ICD-10 Codes
Malignant neoplasm	C00-C97
Heart disease	I00-I52, I60-I69,
Renal disease	N17, N18, N28,
Liver disease	K70-K77
Respiratory disease	J06-J18, J20-J22, J40-J47, J69,
Neurological disease	G10, G12.2, G20, G23.1, G35, G90.3
Dementia	F01, F03, G30, R54
HIV/AIDS	B20-B24

The sampling strategy was developed by the Office for National Statistics (ONS), and stratified according to the deceased's gender, place of death, age and geographical area (*Table 2*).

Deaths registered by non-relatives, duplicate deaths, deaths subject to inquest, cancelled death records and date of death less or more than six to ten months ago were excluded.

Table 2: Preliminary sampling frame

Variable	Description
Gender	Male and female
Age	Age groups 18-44; 45-64; 65-74; 75-84; 85+
Cause of death	Non-sudden deaths from all causes. See example diagnoses in Table 1
Place of death	Home, hospital, care home, hospice, other
Geographical area	Representation from all areas of England and Wales

1.2

Validated instruments in the survey

Client Service Receipt Inventory (CSRI)

The *Client Service Receipt Inventory* (CSRI) is a widely used measure of service utilisation [1]: in QUALYCARE it is focused on social and health care use as well as support from informal carers. The CSRI collects information on service utilisation in several settings, such as hospital care, primary care, community-based specialist or general health care, social care, as well as cost-related variables in order to describe patterns of resource use and estimate service costs.

Integrated Palliative care Outcome Scale (IPOS)

The *Integrated Palliative care Outcome Scale* (IPOS) is a valid and reliable measure of physical and psychological symptoms, emotional concerns, communication and practical issues experienced by the person who died during their final week of life. IPOS is widely used to assess and monitor symptoms and concerns in advanced illness, to determine the impact of healthcare interventions, and demonstrate quality of care.

IPOS consists of 17 items, which can be reported as individual items, as a total score, or in three subscales (a physical symptom subscale, a psychological symptom subscale, and a communication/ practical subscale) [2]. IPOS exists in different versions that can be either used by patients, or, when patients are not able to answer themselves, by proxy raters, such as family members, informal carers and healthcare professionals.

Each item relates to how a symptom or concern affects the person who died during the last week of life. Items are scored on a scale ranging from 0 to 4, where 0 is 'not at all' and 4 is 'overwhelmingly' affecting the person who died or always present. An additional item on difficulty communicating was added from a version of IPOS that is specific for people living with dementia [3].

Traumatic Grief Inventory-Self Report Plus (TGI-SR+)

The *Traumatic Grief Inventory – Self-Report+* (TGI-SR+) is a valid and reliable measure of cognitive, emotional, and behavioural symptoms of grief [4]. It consists of 22 items, each relating to a symptom of grief such as difficulties with accepting the loss, moving beyond the loss, and inability to engage in fulfilling activities.

Respondents are asked to think about a particular loss (here: the loss that they were surveyed about) and rate the extent to which they experienced the symptoms during the past month on a scale from 1 to 5, where 1 signifies ‘never’ and 5 signifies ‘always’. A summative score of 71 or above has been found to indicate that someone is experiencing disturbed grief [4].

The TGI-SR+ has also been validated as a diagnostic tool, eg, to assess prolonged grief disorder as defined in the International Classification of Diseases (11th Revision) and Diagnostic and Statistical Manual of Mental Disorders (5th Edition) [5]. This disorder is estimated to affect about 10% of bereaved adults [6]. A score of 71 or above does not mean that a person fulfil the diagnostic criteria for prolonged grief disorder but is indicative of debilitating grief that could be pathological [5].

1.3

Strengths and limitations

An important strength of this research is the use of stratified sampling to represent the national population for England and Wales. Our sampling strategy enabled a sample where the age of the people who died, their cause of death and their geographical location is largely representative of the national picture. This in turn means that the conclusions we can make about the experiences related to dying, death, and bereavement are more likely to hold true for the general population of England and Wales.

Another strength was the QUALYCARE survey, which includes validated measures of health and care service use, symptoms, and concerns in the final week of life, and intensity of bereavement symptoms. In addition, the survey incorporates multiple free-text options, enabling rich understanding of experiences through both quantitative and qualitative data. QUALYCARE also provides comprehensive information about formal and informal care use during the last months of life, which allows insights into experiences with care professionals as well as the extent to which family and friends provide care. For more information about the QUALYCARE survey and access to the survey instrument, please contact Professor Katherine Sleeman at katherine.sleeman@kcl.ac.uk.

A further strength is that our Patient and Public Involvement (PPI) colleagues worked with us throughout the study from its conception to analysis and write-up. Our response rate was 39.3%, which is similar to previous comparable post-bereavement surveys [7-9]. Options to complete the survey on paper, online, or by phone are likely to have contributed to a strong response rate.

There are some limitations of this research. While post-bereavement surveys are a validated method for understanding experiences and outcomes of dying, death, and bereavement, they rely on self-reported data based on recall of experiences by proxy-agents, in this case family members. Respondents are likely to have had variable insight into the circumstances of and care received by the person who died. Furthermore, response bias – where participants with extremely poor (or extremely good) experiences are more likely to respond to the survey or individual questions – is likely.

Our survey was sent to respondents six to ten months after the death, which was informed by previous studies [7-9]. However, this may have introduced recall bias. Of note, it has been found that family carers report rates of subjective symptoms such as pain, anxiety, and depression higher than those affected themselves [10]. We found that not all respondents answered all questions. We therefore report the number of valid and missing responses throughout the report.

While we sent surveys to a sample that was representative of the national population of England and Wales, not all groups had similar rates of completing the survey. For example, there were relatively fewer responses from London and more responses from South East England. While the ethnicity of people who died reflects the national population, the numbers of people in non-White groups was too small for meaningful analysis. Therefore, important questions regarding differences between groups based on ethnicity remain unexplored.

Last, as with all observational research, our results describe associations and cannot be used to determine causation. Identification of causal pathways requires further research to examine these associations in more detail.

1.4
Ethical approval

This research received ethical (Institutional Review Board) approval from King's College London Research Ethics Committee (HR/DP-21/22-24690).

The survey protocol also received ethical approval from Dr Matt Short, Senior Research Officer and Operations Lead, Centre for Applied Data Ethics, Data Governance, Legislation and Policy, Office for National Statistics.

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Appendix 2.
Data for England

This appendix presents the English nation-level data for each table and figure in the report. Nation-level data for Wales is reported in Appendix 3. Sixteen respondents did not specify in which nation the person who died had resided; these responses are excluded from the appendices. The appendix follows the same section headings and table and figure numbers as the main report.

3 Sample description

3.1 Who responded to our survey?

Table 1. Sociodemographic characteristics of survey respondents in England (n=606)

	Number	%
Gender		
Male	208	34.3
Female	388	64.0
Non-binary or prefer not to say	4	0.7
Not answered	6	1.0
Ethnicity		
White British	563	92.9
White other	11	1.8
Mixed	8	1.3
Asian	11	1.8
Any other ethnic group	4	0.7
Black	4	0.7
Prefer not to say or not answered	5	0.8
Employment		
In paid work	263	43.4
In unpaid work	15	2.5
Not employed	322	53.1
Other or not answered	6	1.0
Relationship to the person who died		
Child	323	53.3
Wife, husband, or partner	184	30.4
Other (eg in-laws, nieces, nephews)	54	8.9
Sibling	34	5.6
Parent	9	1.5
Not answered	<3	-

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3.2 Who were the people who died?

Table 2. Sociodemographic characteristics of those who died in England (n=606)

	Number	%
Gender		
Male	291	48.0
Female	312	51.5
Prefer not to say or not answered	3	0.5
Age category		
85 or older	278	45.9
65-84	264	43.6
18-64	61	10.1
Not answered	3	0.5
Ethnicity		
White British	564	93.1
White other	18	3.0
Asian	14	2.3
Black	4	0.7
Any other ethnic group	4	0.7
Mixed	<3	-
Not answered	<3	-
Geographical region in England		
North East	31	5.2
North West	91	15.1
Yorkshire and Humber	69	11.5
East Midlands	49	8.2
West Midlands	69	11.5
East of England	44	7.3
London	36	6.0
South East	131	21.8
South West	81	13.5
Marital status		
Married or with a partner	273	45.1
Widowed	238	39.3
Divorced or separated	59	9.7
Never married	29	4.8
Not answered	7	1.2

Educational attainment	**Number**	**%**
Did not go to school	10	1.7
Left school at 15 years old or under	263	43.4
Left school at 16 – 17 years old	130	21.5
Left school at 18 – 19 years old	32	5.3
Post-secondary school vocational qualifications	95	15.7
University	69	11.4
Not answered	7	1.2
Financial circumstance		
Living comfortably	280	46.2
Doing alright	200	33.0
Just about getting by	72	11.9
Finding it quite difficult	26	4.3
Finding it very difficult	21	3.5
Not answered	7	1.2
Accommodation		
Owned outright	359	59.2
Owned with a mortgage or loan	41	6.8
Part-owned and part-rented	5	0.8
Rented (with or without housing benefit)	97	16.0
Other	100	16.5
Not answered	4	0.7
Living situation		
On their own	165	27.2
With the respondent (with or without other people)	222	36.6
With other people (but not the respondent)	79	13.0
In a care home	125	20.6
Elsewhere	10	1.7
Not answered	5	0.8

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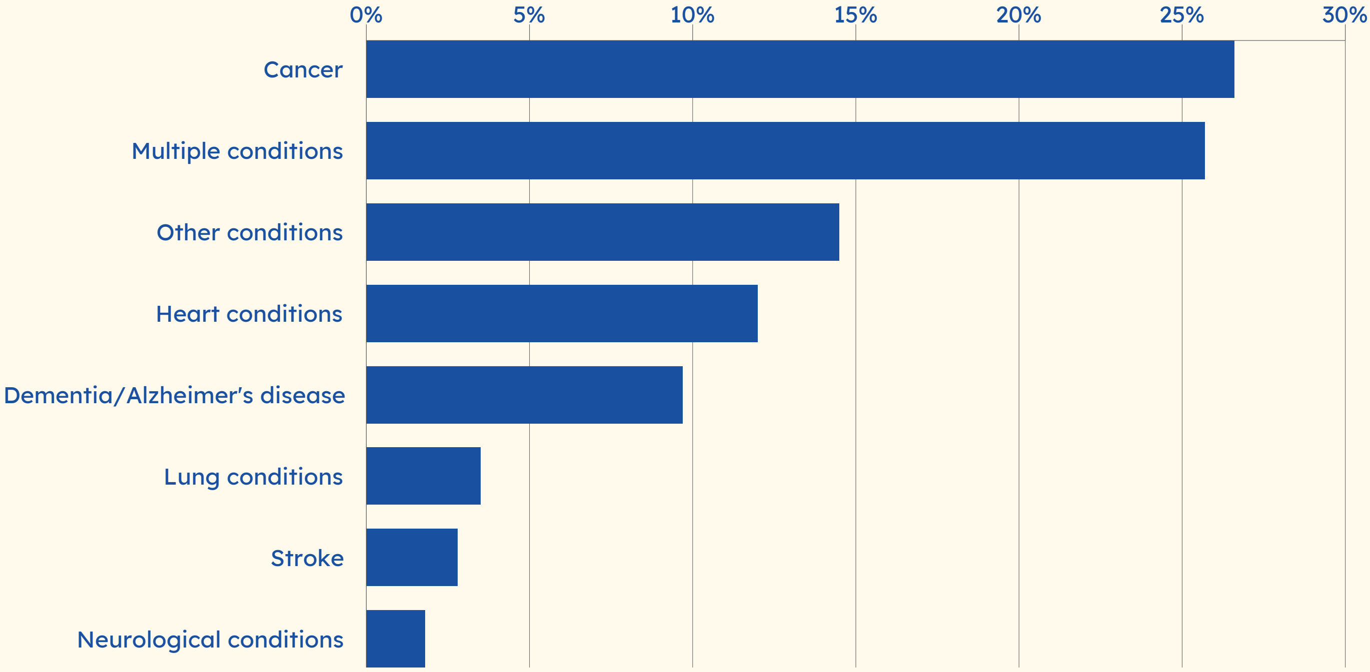
3.2.1 What was the cause of death?

Figure 1. Reported main cause of death of those who died in England (n=598)



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3.2.2 What illnesses were those who died living with?

Table 3. Prevalence of chronic health conditions among the people who died in England (selected as either a cause of death or as an illness that the person who died was living with)

	Number	**%**
Cardiovascular conditions (eg heart disease, atrial fibrillation, high blood pressure)	285	47.0%
Respiratory conditions (eg asthma, chronic obstructive pulmonary disease)	273	45.0%
Cancer	232	38.3%
Dementia (eg Alzheimer’s disease, vascular dementia)	190	31.4%
Musculoskeletal conditions (eg osteoarthritis, rheumatoid arthritis)	122	20.1%
Diabetes	134	22.1%
Mental health conditions (eg depression, schizophrenia, anxiety)	60	9.9%
Digestive conditions (eg liver disease, inflammatory bowel disease, stomach ulcers)	60	9.9%
Renal conditions (eg chronic kidney disease)	68	11.2%

	Number	%
Neurological conditions (eg Parkinson’s disease, epilepsy, motor neuron disease, multiple sclerosis)	38	6.3%
Learning disability	4	0.7

Note: Since multiple conditions were selected, the total count is higher than the total sample size.

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4 Experiences of the last three months of life

4.1 Where did those who had died spend most of their time?

Figure 2. The places where the people who died in England spent most of their time in their last three months of life (n=602)

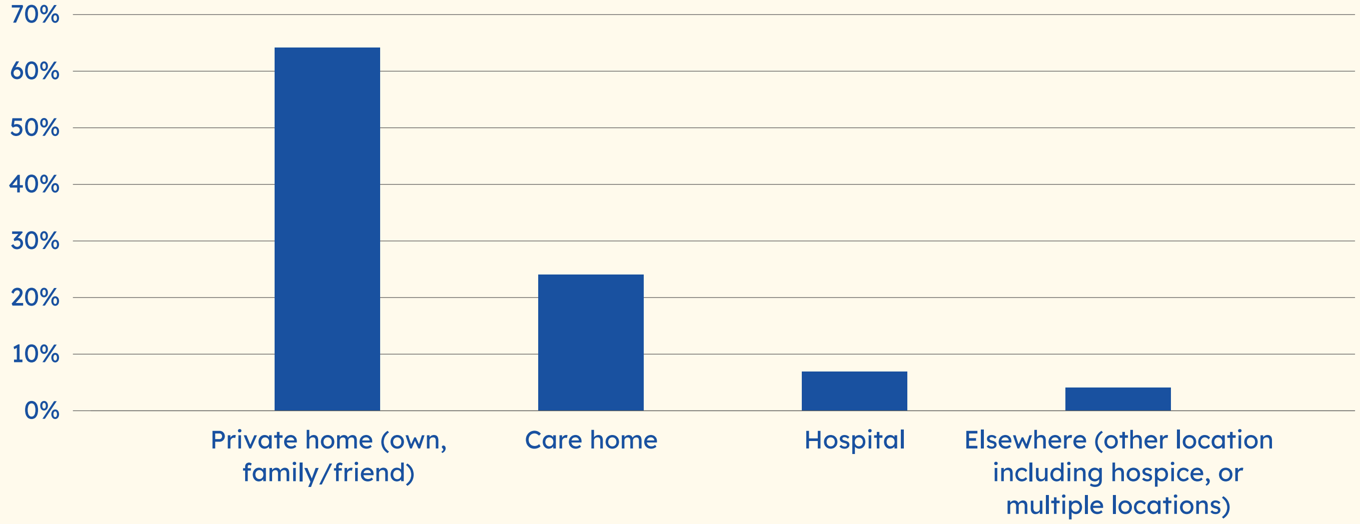

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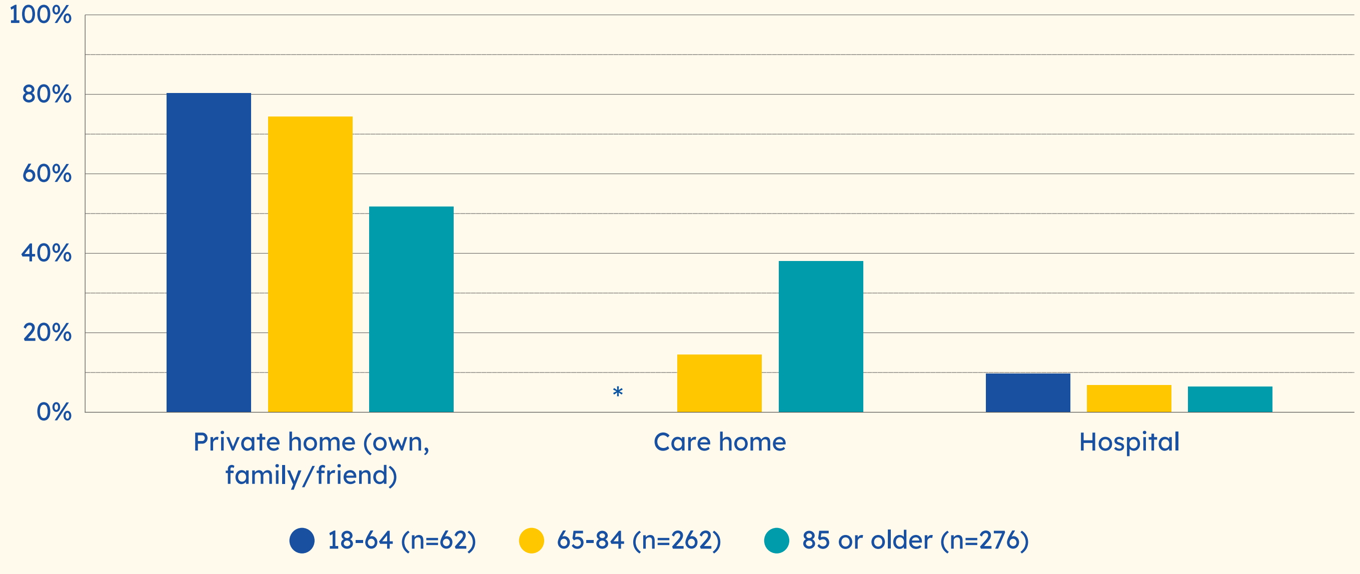
Figure 3. Differences in the places in which the person who died spent most of their last three months of life in England, according to their age (n=599)



Notes: * Small cell counts are suppressed

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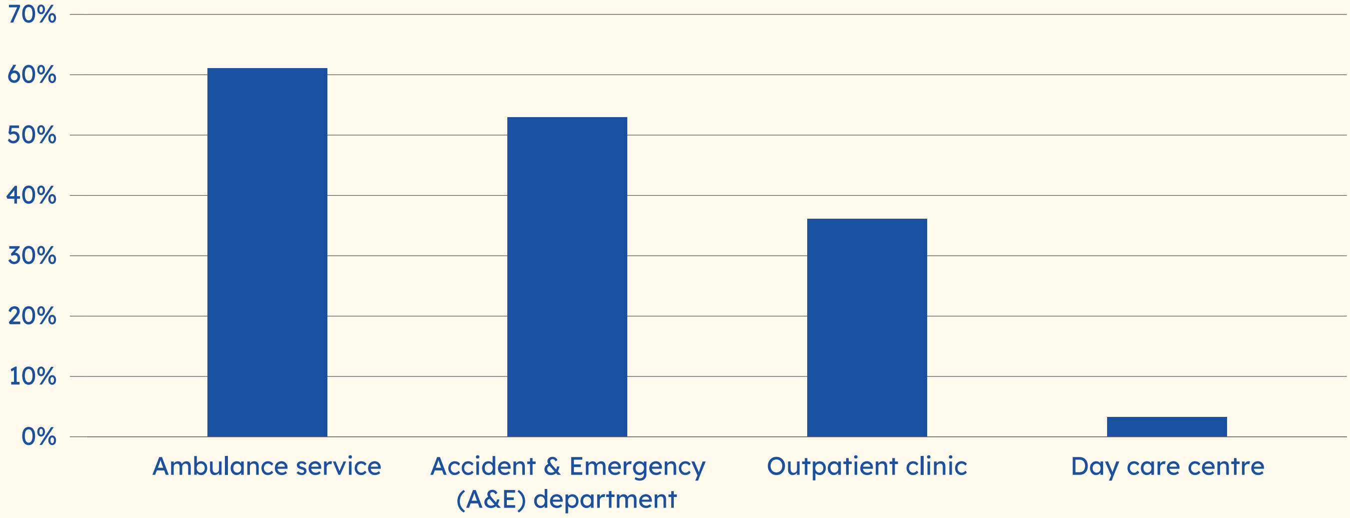
4.2 What care services were used in the last three months?

Figure 4. Use of care services among the people who died in their last three months of life in England (n=606)



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4.2.4 Contact with health and social care professionals in the community

Figure 5. Proportion of people who died in England who had any contact with different health and social care professionals in their last three months of life (n=606)

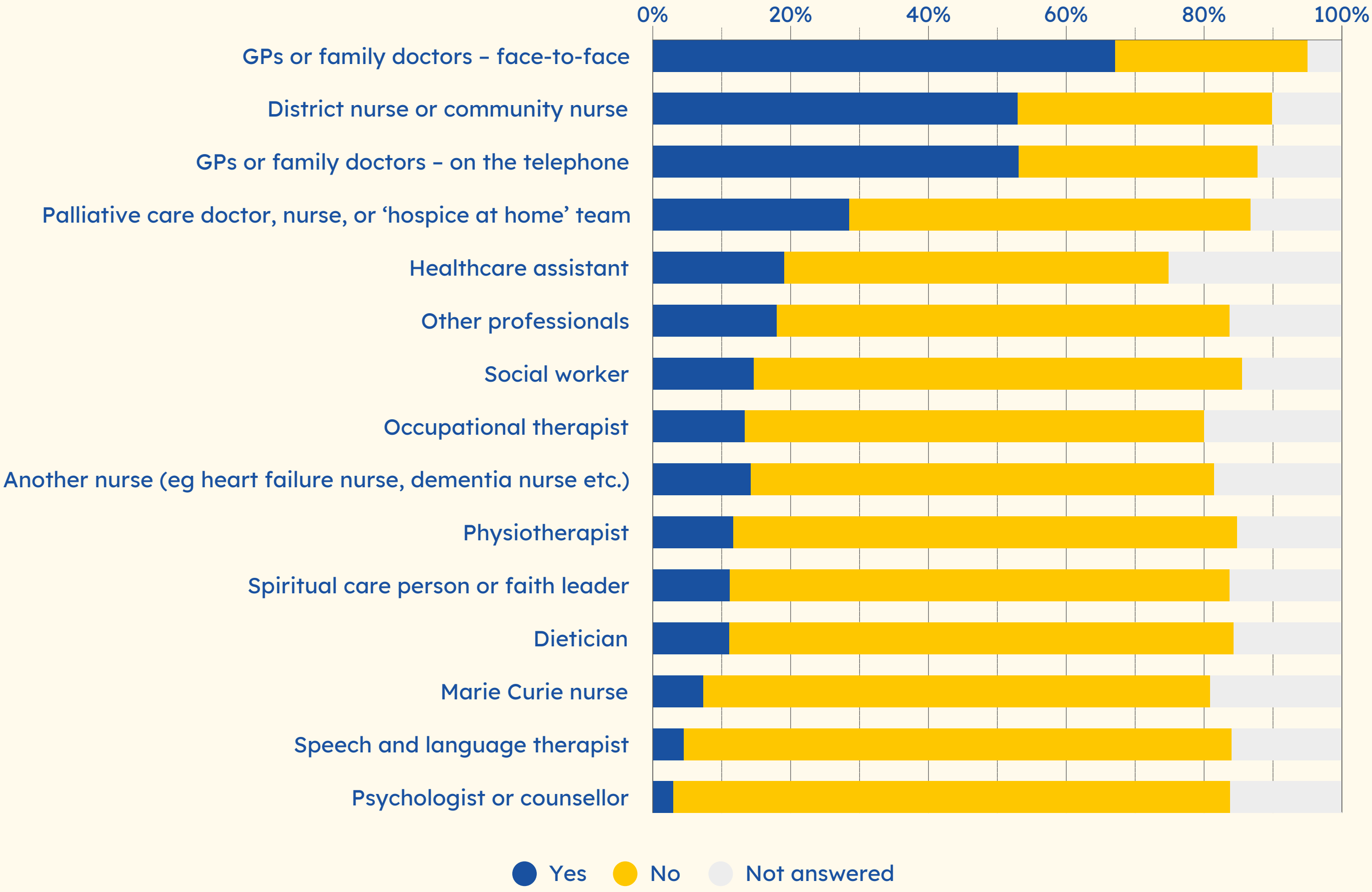

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Table 4. Contact with health and care professionals in England in the last three months of life while at home or in a care home, ie not in hospital or a hospice

	No contact	Had contact	Distribution of frequency of contacts					
	n	n	Mean	SD	Median	Min	Max	IQ range
GPs or family doctors (face-to-face)	169	407	3.5	3.55	2	1	25	1-4
GPs or family doctors (on the telephone)	210	322	3.7	3.25	3	1	25	2-4.25
District nurse or community nurse	224	321	12.2	28.32	5	1	360	2-10
Palliative care doctor, nurse, or 'hospice at home' team	353	173	9.8	17.52	4	1	100	2-10
Healthcare assistant	398	109	47.4	94.48	10	1	480	3-60

Notes: SD=standard deviation, IQ range=interquartile range (range between first and third quartile of the frequency distribution).

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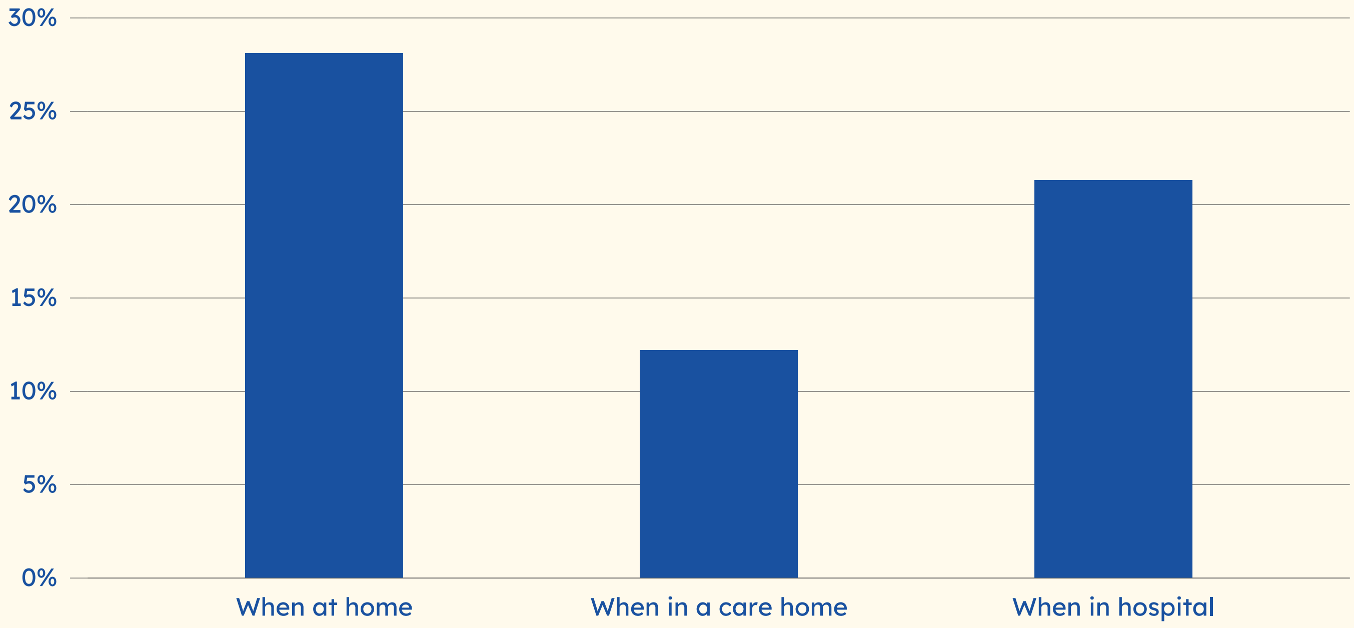
4.2.5 Care from palliative care specialists

Figure 6. Proportion of people who died in England who received care from palliative care specialists in their last three months of life (n=606)



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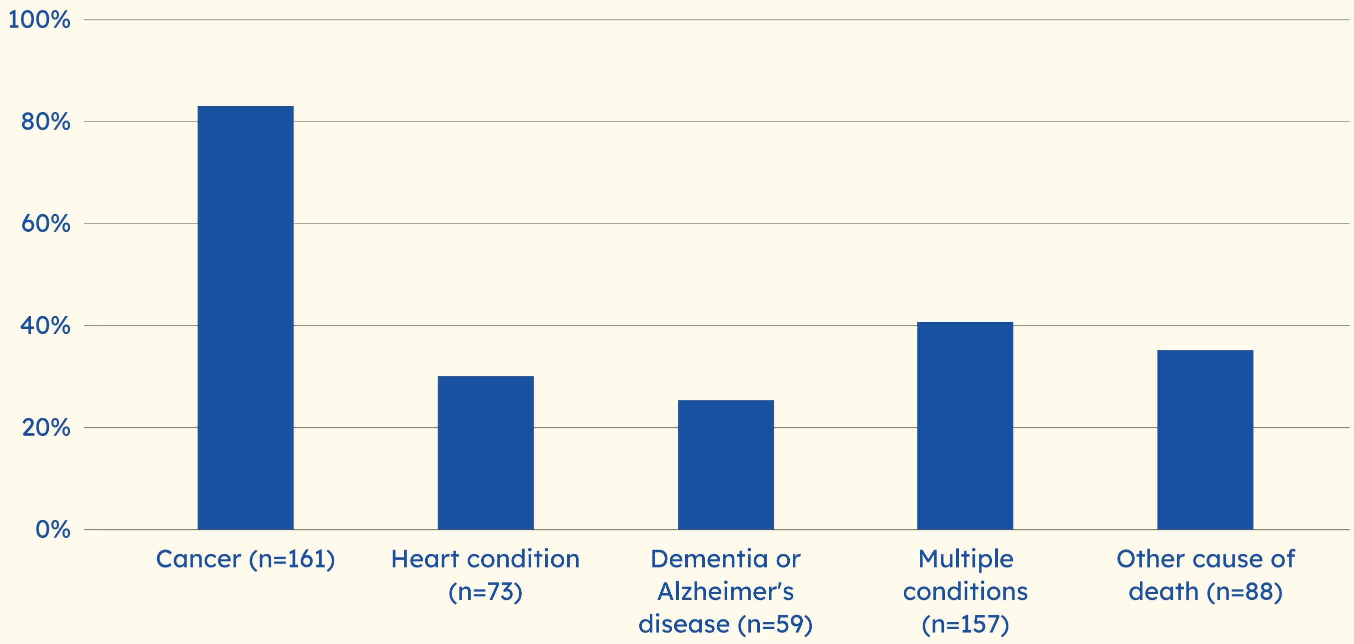
4.2.5.1 Differences in specialist palliative care use

Figure 7. Receipt of care from palliative care specialists (in any setting) in England during the last three months of life across the five most common causes of death



Notes: For information about multiple conditions and other cause of death see section 3.2.1 of main report.

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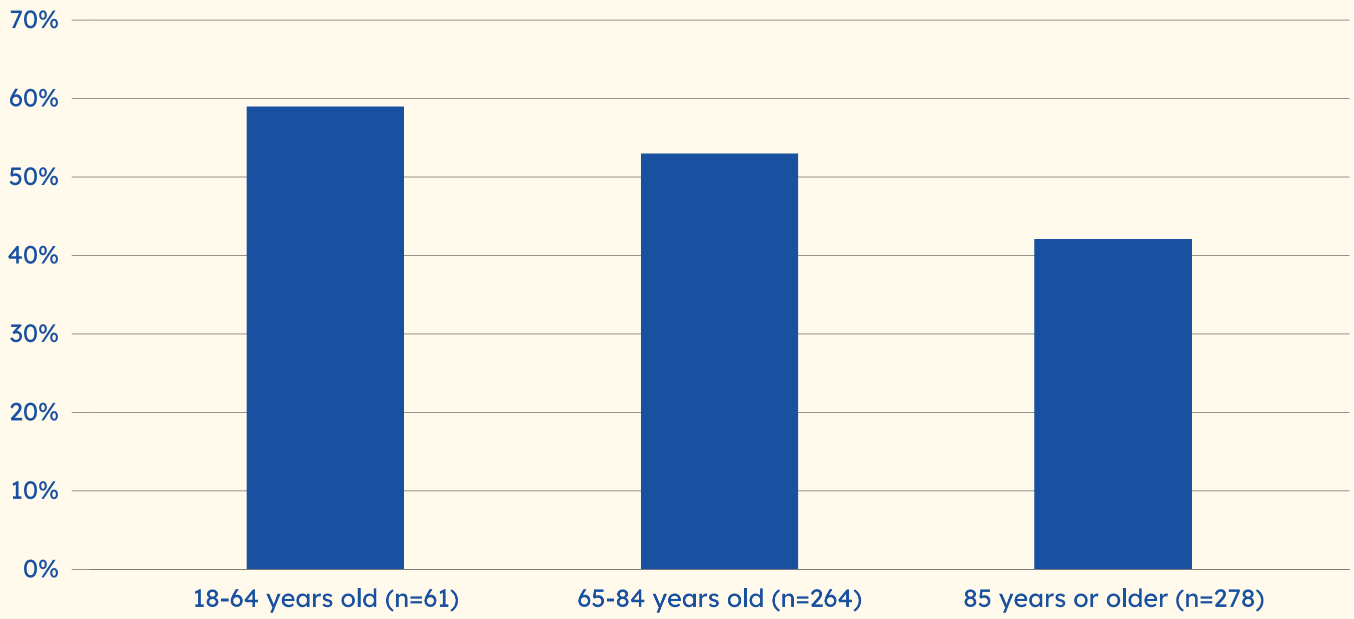
Figure 8. Receipt of care from palliative care specialists (in any setting) in England during the last three months of life by the age of the person who died



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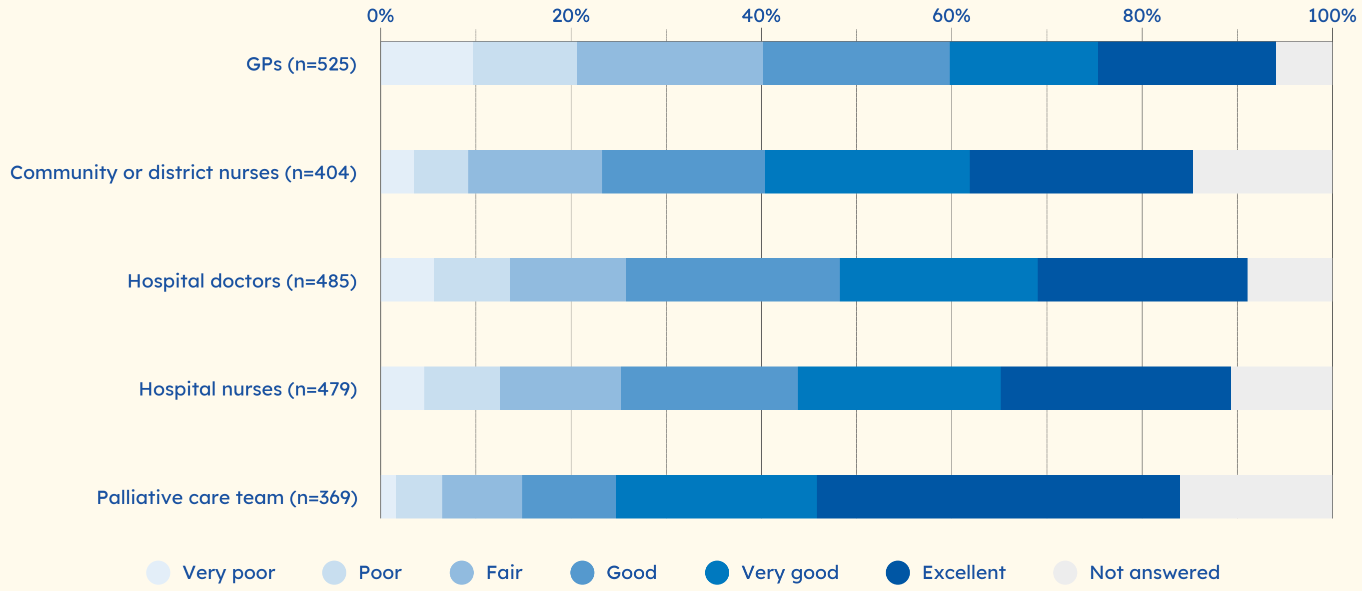
4.2.6 Coordination of care

During the last three months of life, 252 (41.6%) of those who died in England had a health or care professional acting as a key contact person to co-ordinate their care.

4.3 How did respondents perceive the care provided from healthcare professionals?

Figure 9. Respondents' perception of the quality of the care received from different healthcare professionals in England



Notes: Responses indicating that care had not been received from these professional groups were excluded

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4.4 Carer experiences of access to care services and care provision

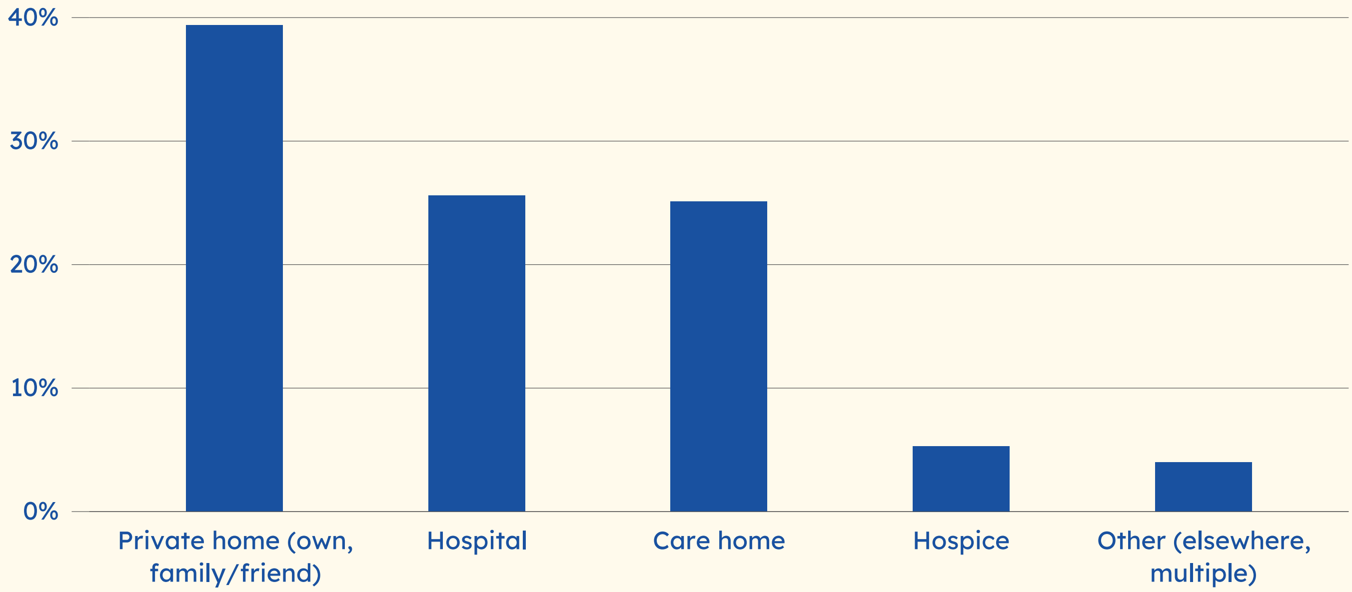
4.4.1 Were respondents unhappy with care?

Half (n=305, 50.3%) of English respondents reported they were unhappy with one or more aspect(s) of care, while 280 (46.2%) reported no issues. Of those who were unhappy with care, 128 (42.0%) reported that the issue(s) were discussed with health or care professionals and 33 (11.1%) reported that a formal complaint was made.

5 Experiences of the final week of life

5.1 Where did the people who died spend most of their last week of life?

Figure 10. The locations in which those who died in England spent most of their final week of life (n=602)



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5.2 What symptoms or concerns were experienced?

Figure 11. Physical symptoms and concerns affecting the person who died in England in their final week of life (n=606)

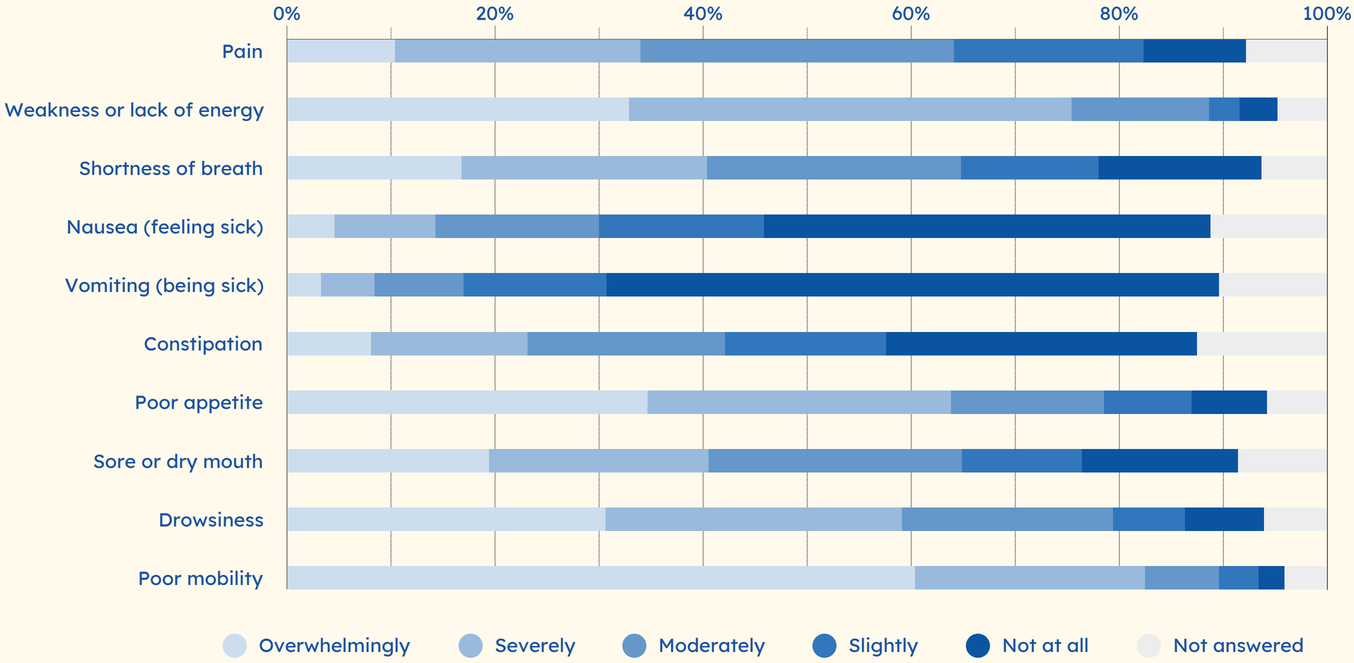

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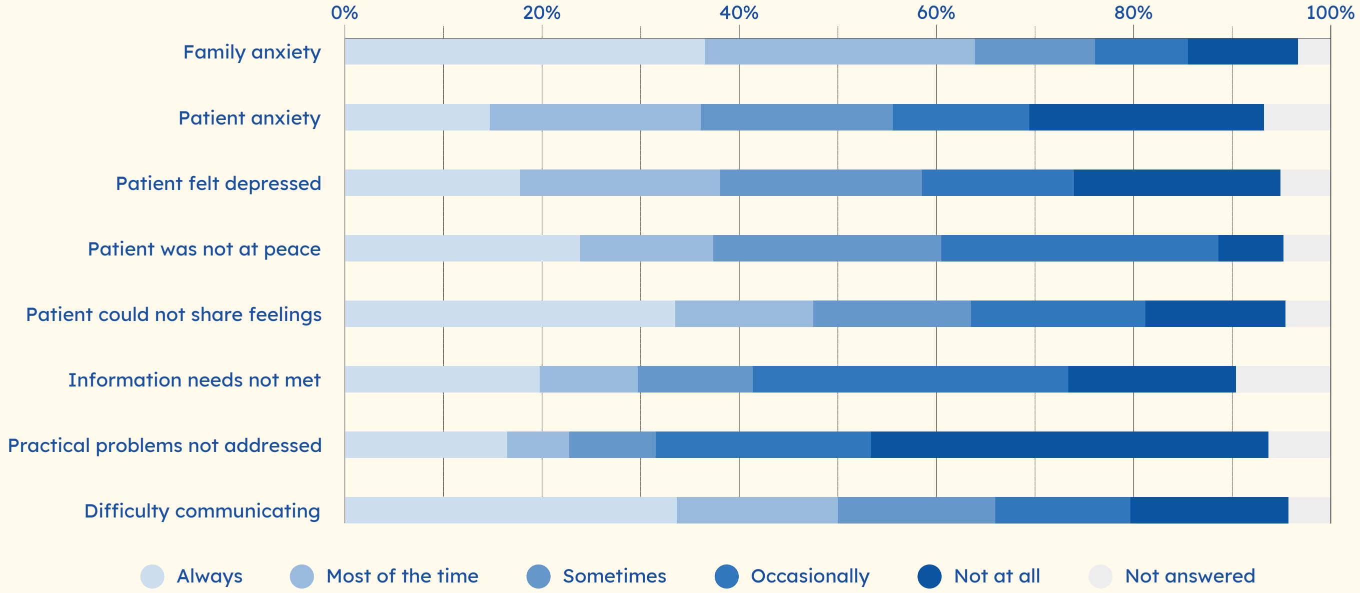
Figure 12. Other symptoms and concerns (psychological, communication, and practical) affecting the person who died in England, or their family, in their final week of life (n=606)



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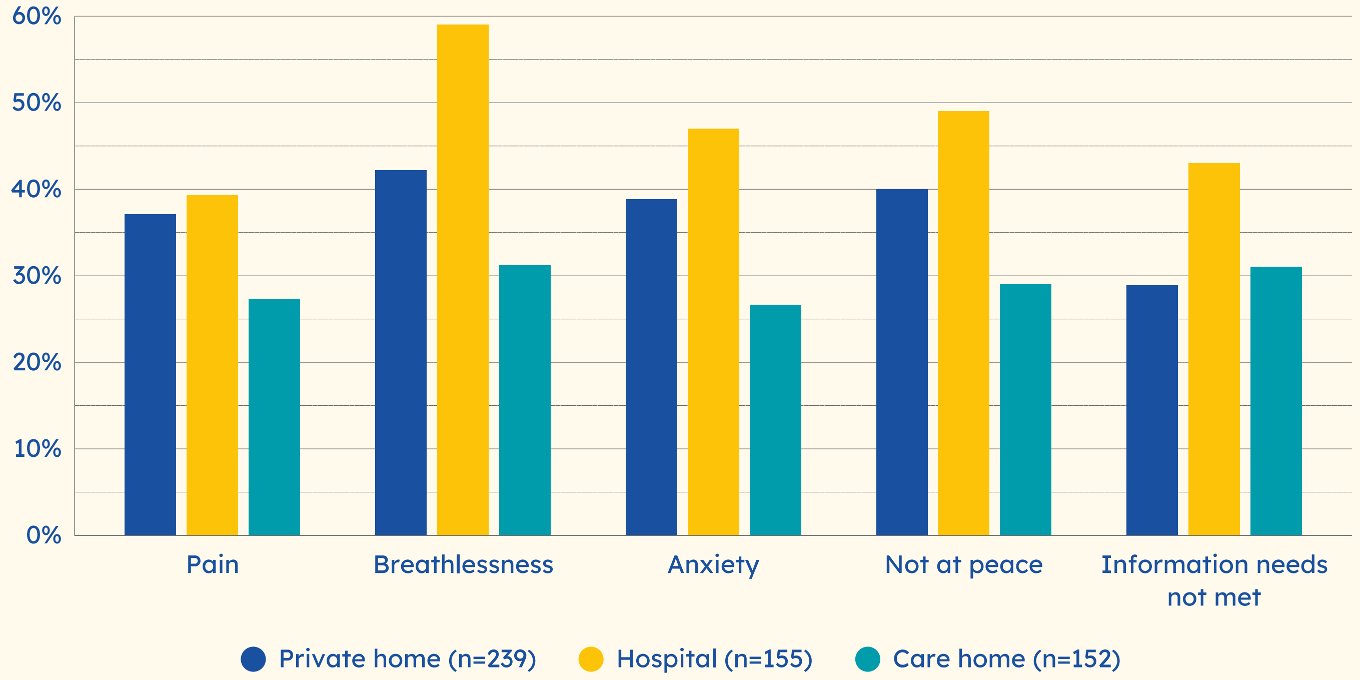
5.2.1 Differences in symptom prevalence across care settings

Figure 13. Differences by care setting in prevalence of being severely or overwhelmingly affected by five key symptoms and concerns in the final week of life among those who died in England



Notes: Percentages are based on valid responses only, missing data for each item is excluded.

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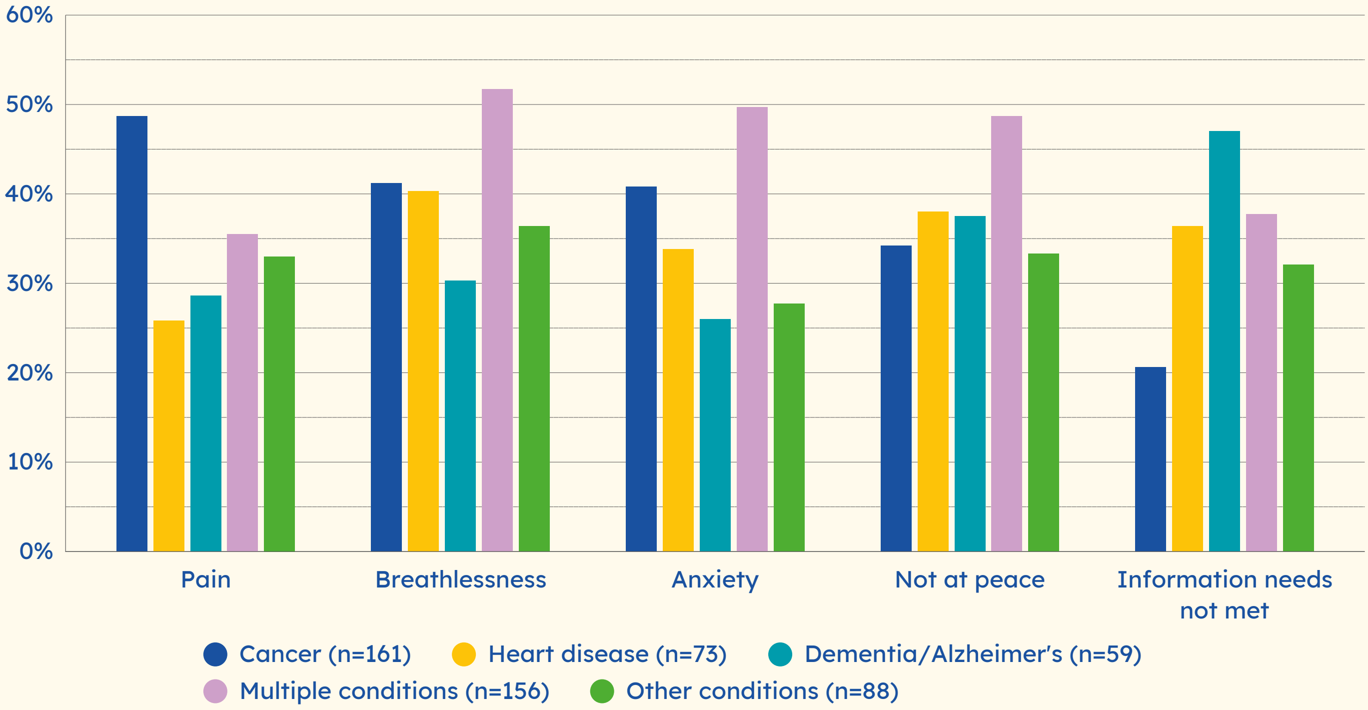
5.2.2 Differences across cause of death

Figure 14. Differences by cause of death in prevalence of being severely or overwhelmingly affected by five key symptoms and concerns in the final week of life among those who died in England



Notes: *Multiple conditions* signify when respondents reported more than one condition as the main cause of death. *Other conditions* signify conditions that were not listed as response options; free-text responses showed that these often involved respiratory infections, or old age or frailty. Percentages are based on valid responses only, missing data for each item is excluded.

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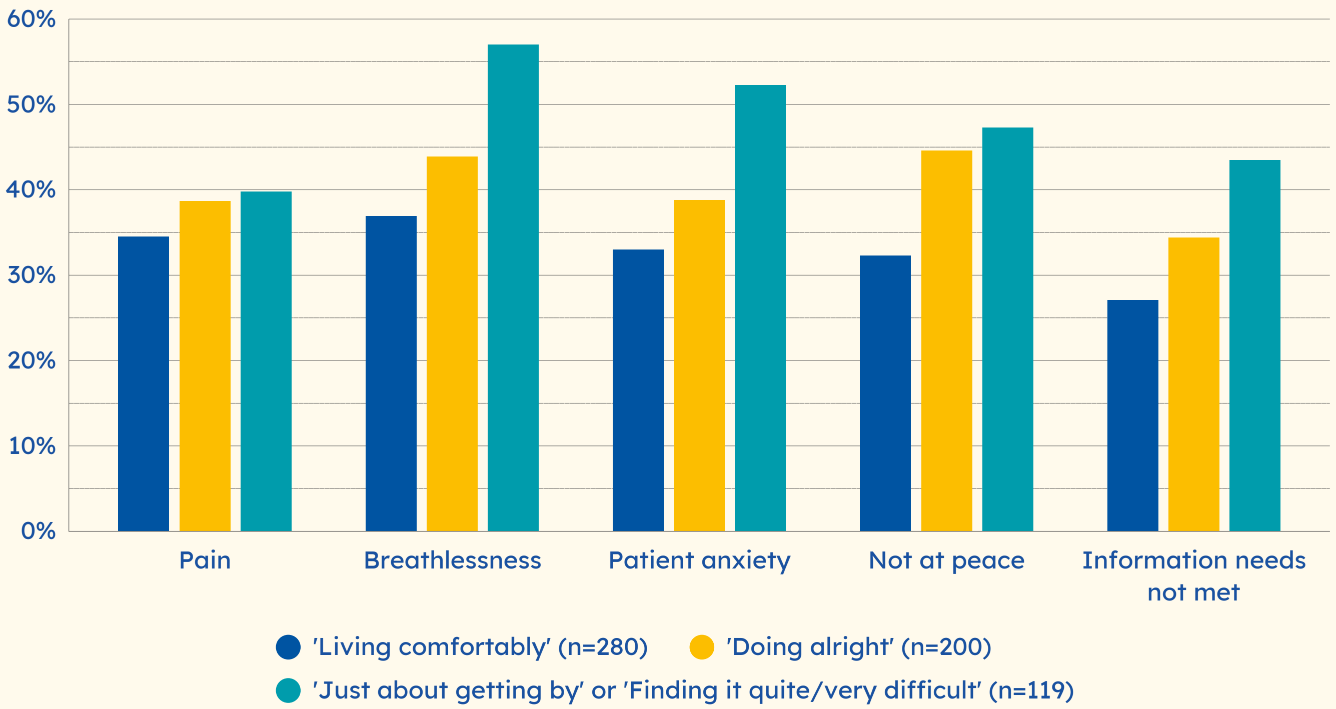
5.2.3 Differences across financial circumstances

Figure 15. Differences by financial circumstance of the person died in prevalence of being severely or overwhelmingly affected by five key symptoms and concerns in the final week of life among those who died in England



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5.3 Awareness and acceptance of death

Figure 16. Length of time that respondents in England had been aware that their relative might die (n=479)

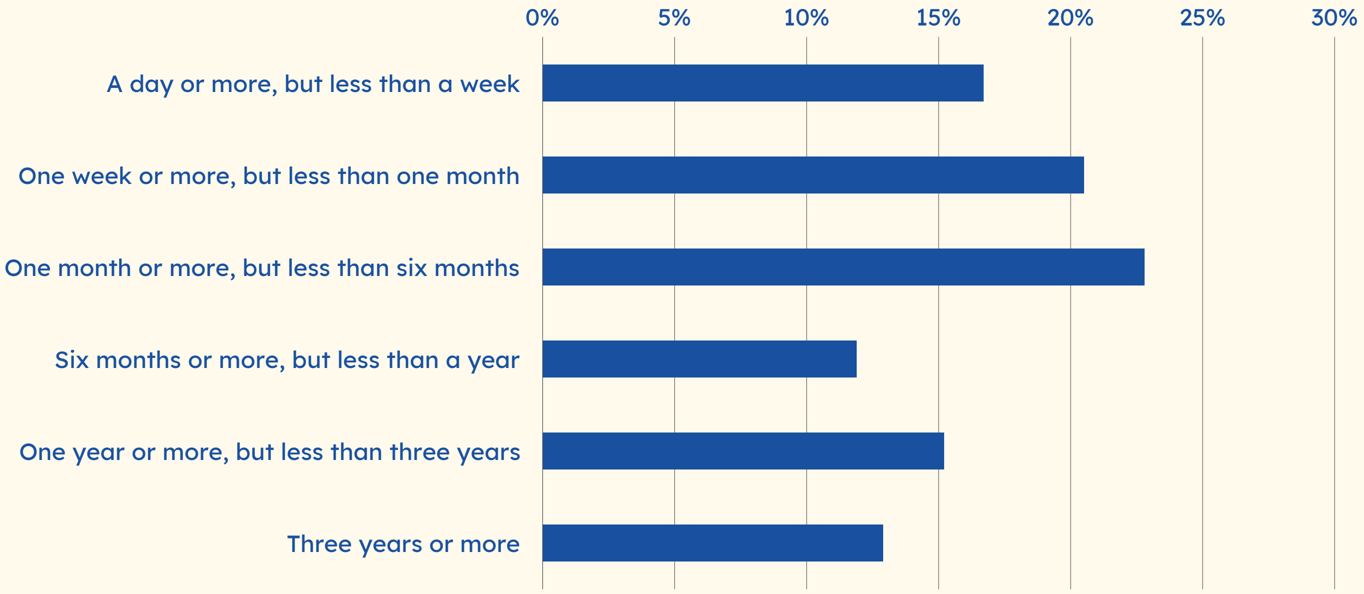

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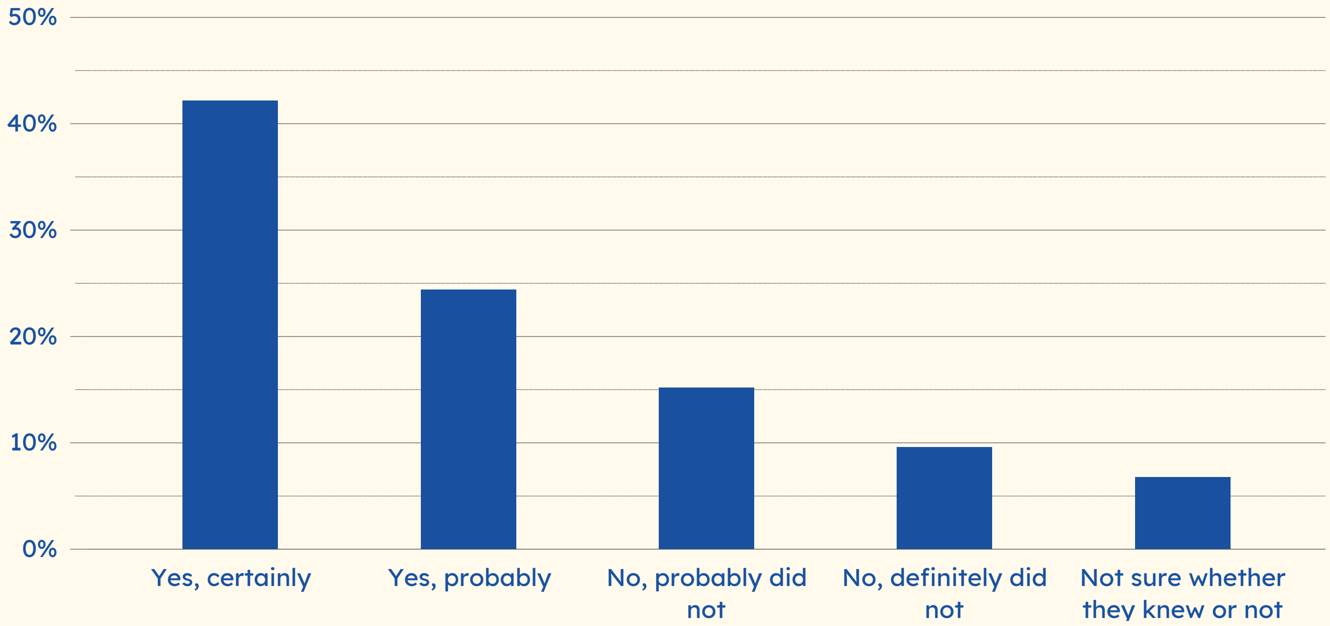
Figure 17. Proportion of those who died in England who were thought to have been aware that they might die from their illness (n=595)



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5.3.1 Did healthcare professionals discuss death and dying?

Figure 18. Proportion of respondents in England who reported that healthcare professionals had discussed dying and death with the person who died, and/or the respondent or other family members

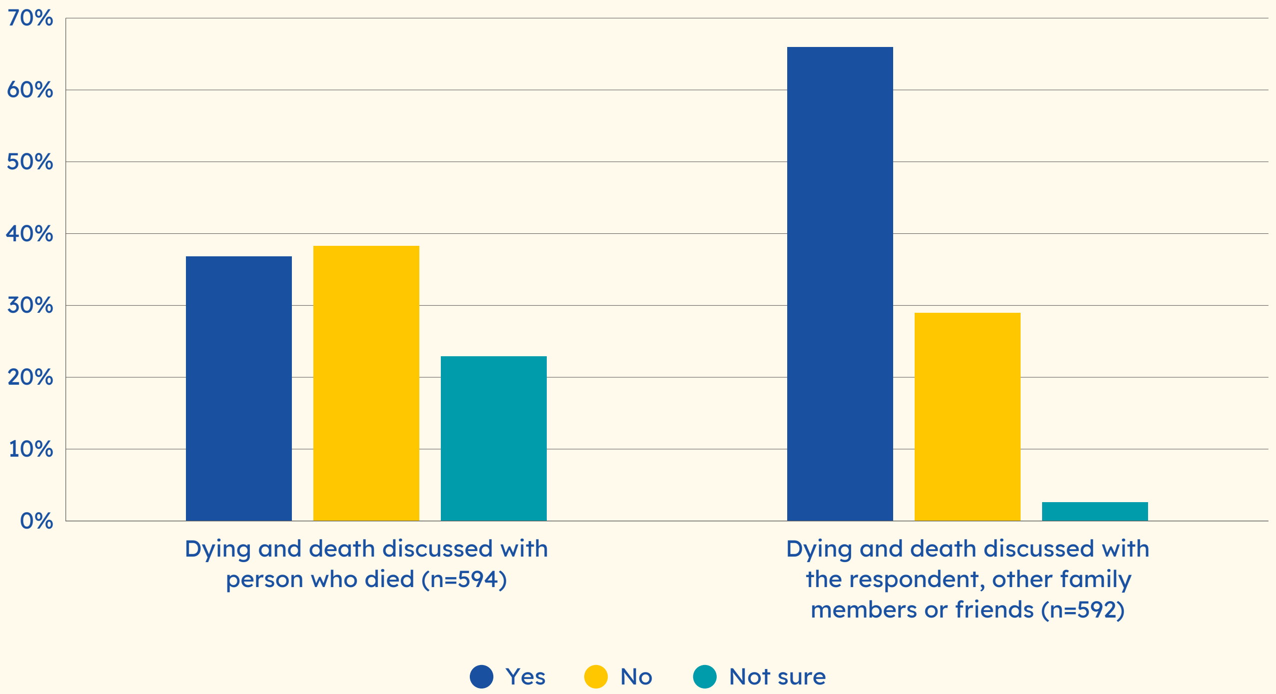

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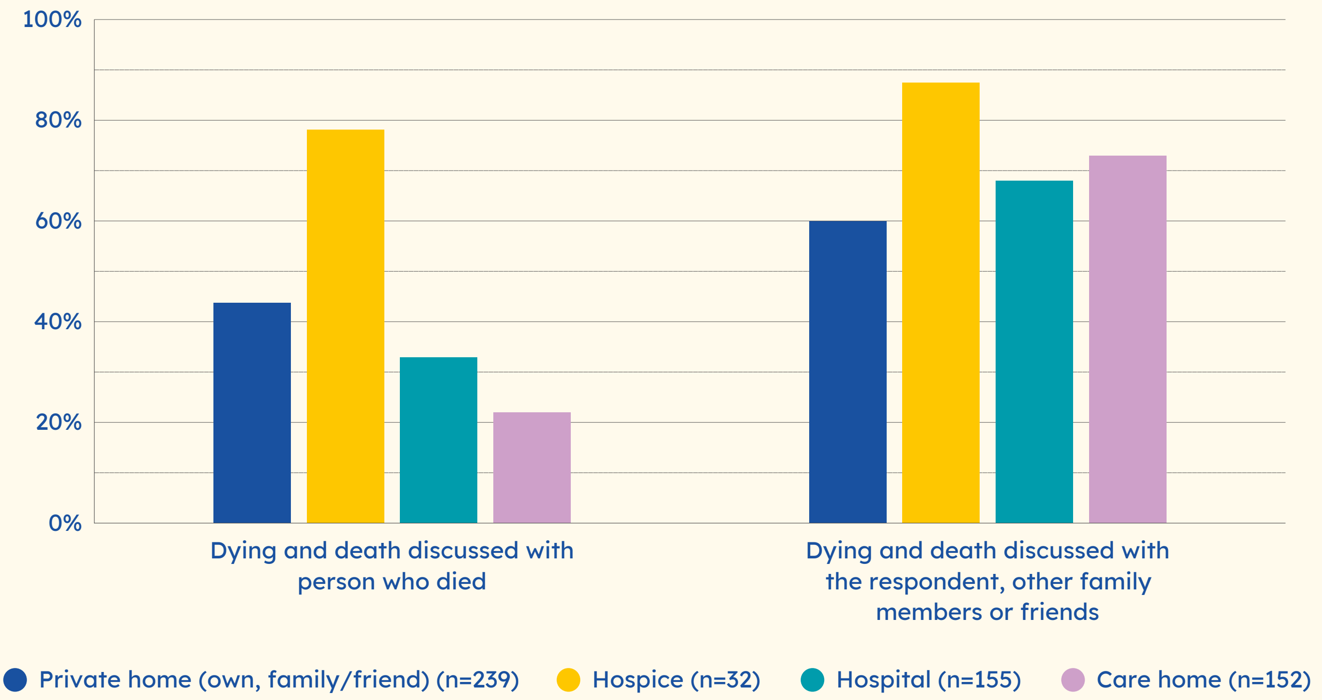
Figure 19. Differences in the proportion of respondents in England who reported that healthcare professionals had discussed dying and death with the person who died, and with the respondent or other family members or friends, by care setting in the final week of life



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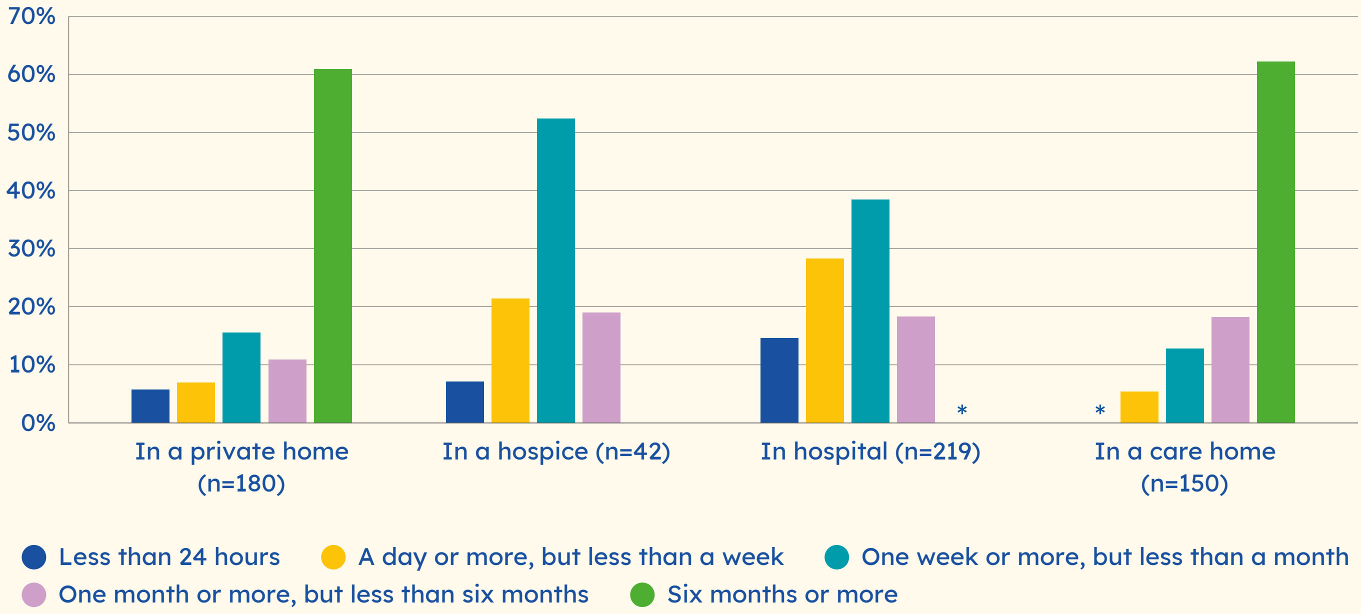
5.4 Place of death

Figure 20. Duration of time that the people who died in England had spent at their place of death



Notes: * Small cell counts are suppressed

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Figure 21. Proportion of those who died in England with their family members and/or friends present by place of death

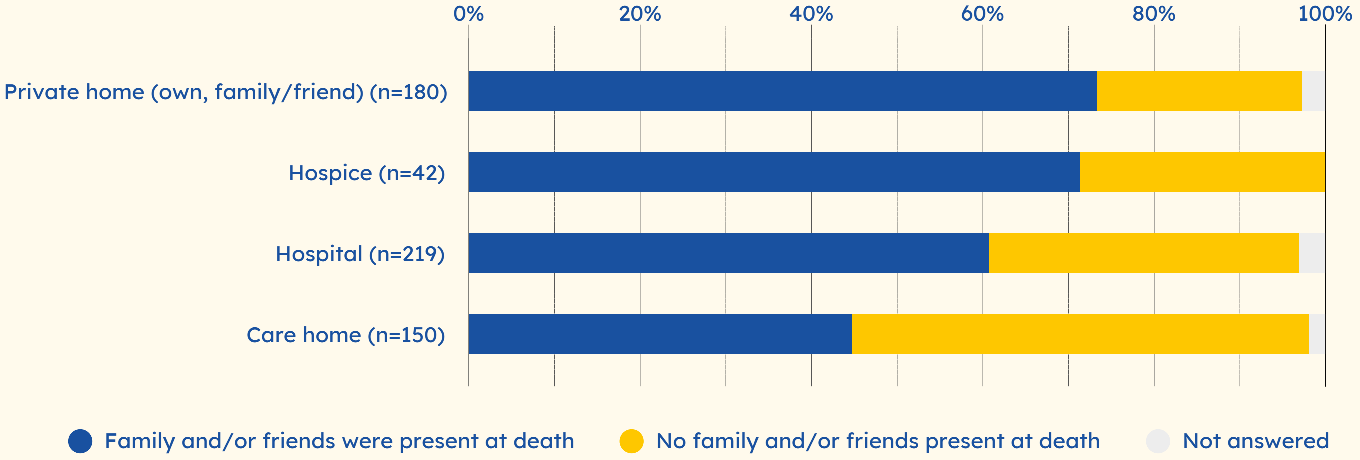

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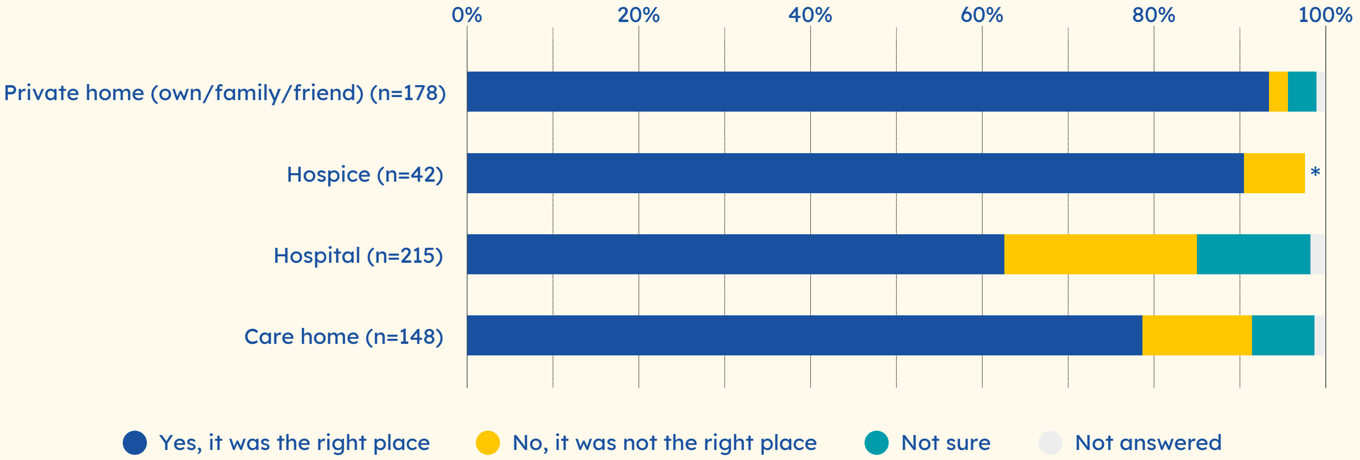
Figure 22. Proportion of respondents in England answering that they felt their relative died in the right place, according to their place of death



Notes: * Small cell counts are suppressed

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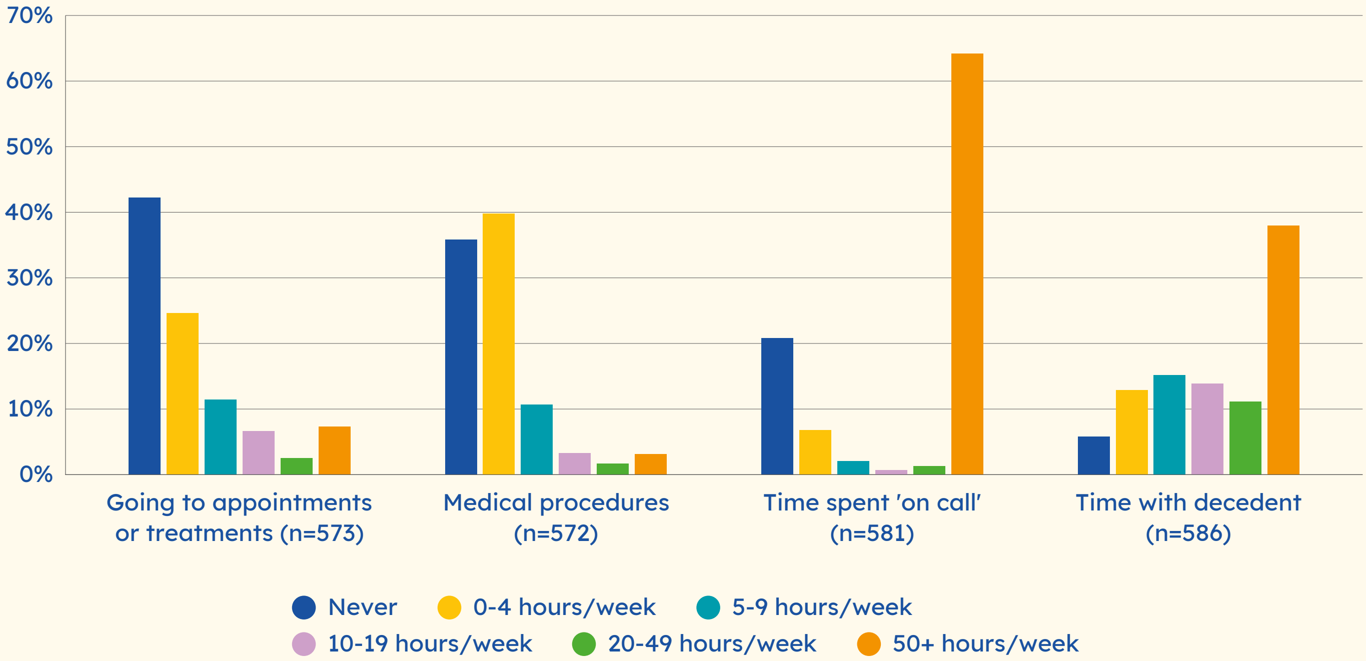
6 Experiences of caring for the people who died

6.1 Who was involved with providing care?

Figure 23. Hours per week that respondents in England spent helping the person who died during their last three months of life



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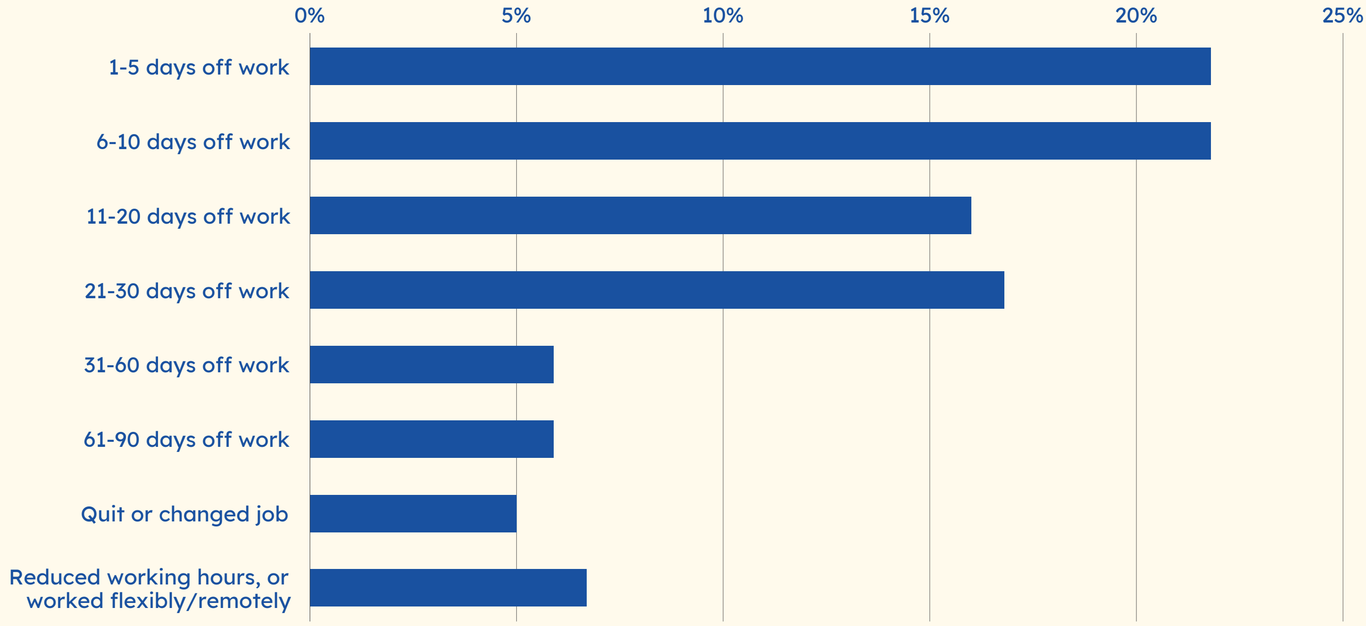
6.3 What was the financial impact of caring?

Figure 24. Impact on work for those respondents in England who reported taking time off work to care for their relative in last three months of life (n=119)



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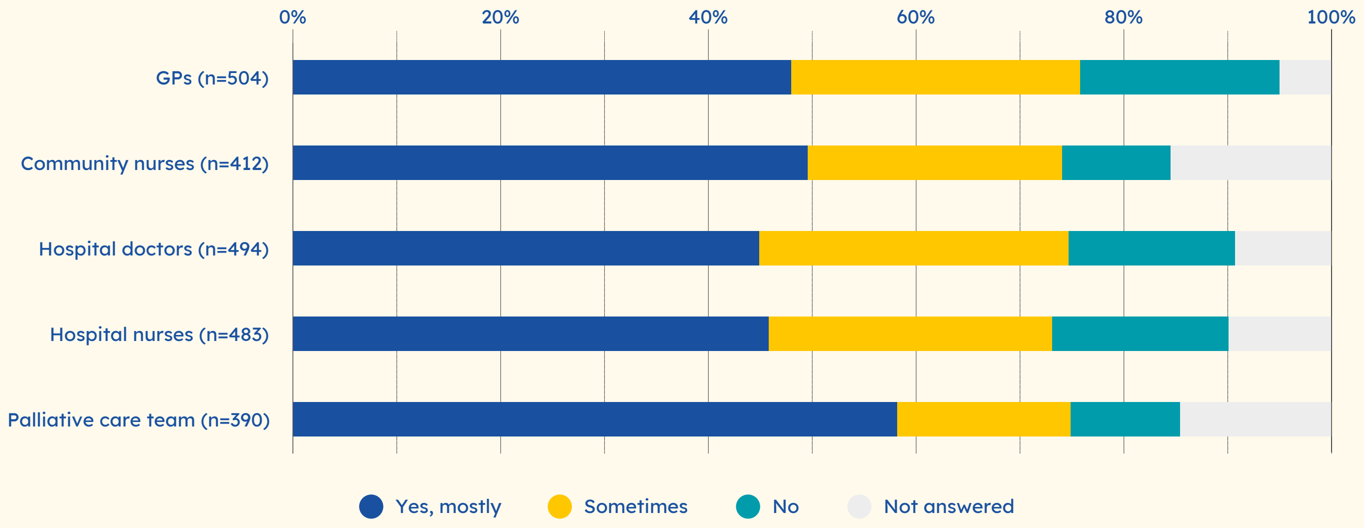
6.4 Interacting with healthcare professionals and services

6.4.1 Did healthcare professionals listen to and have discussions with those who died and their family?

Figure 25. Respondents' experiences in England of how much healthcare professionals listened to and discussed with them and/or the person who died during their last three months of life



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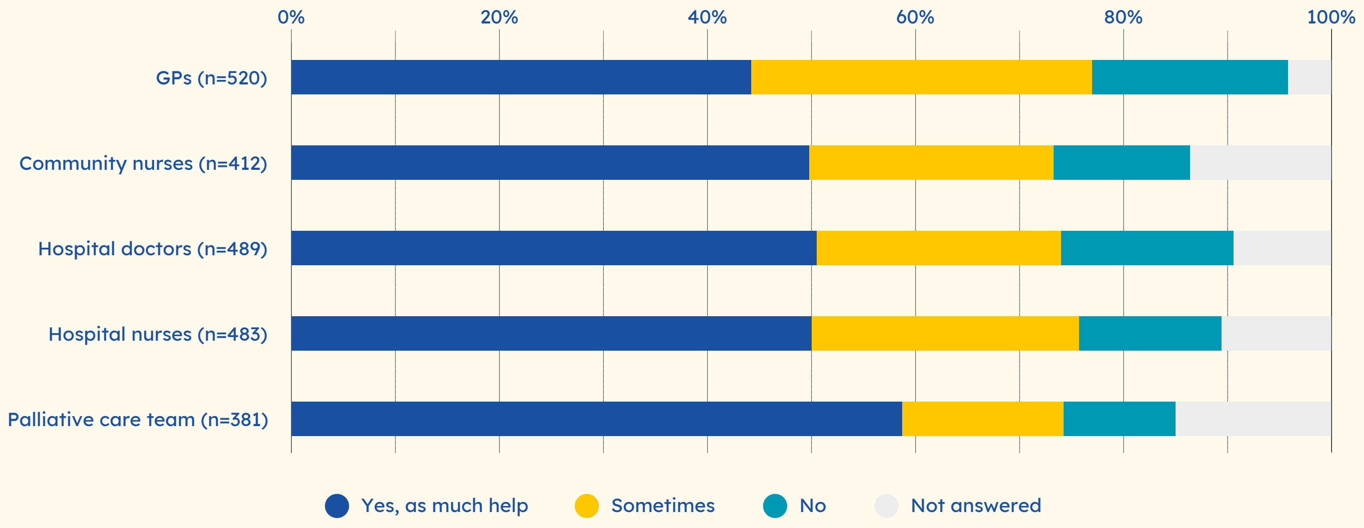
6.4.2 Did healthcare professionals provide sufficient help and support?

Figure 26. Respondents' experiences in England of whether healthcare professionals provided enough help to them and/or the person who died during their last three months of life



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7 Bereavement among family and friends providing care

7.1 Disturbed grief among respondents

91 English respondents (15.2%) who completed the Traumatic Grief Inventory had scores of ≥71, indicating disturbed grief.

Figure 27. Prevalence of disturbed grief among respondents in England according to their age

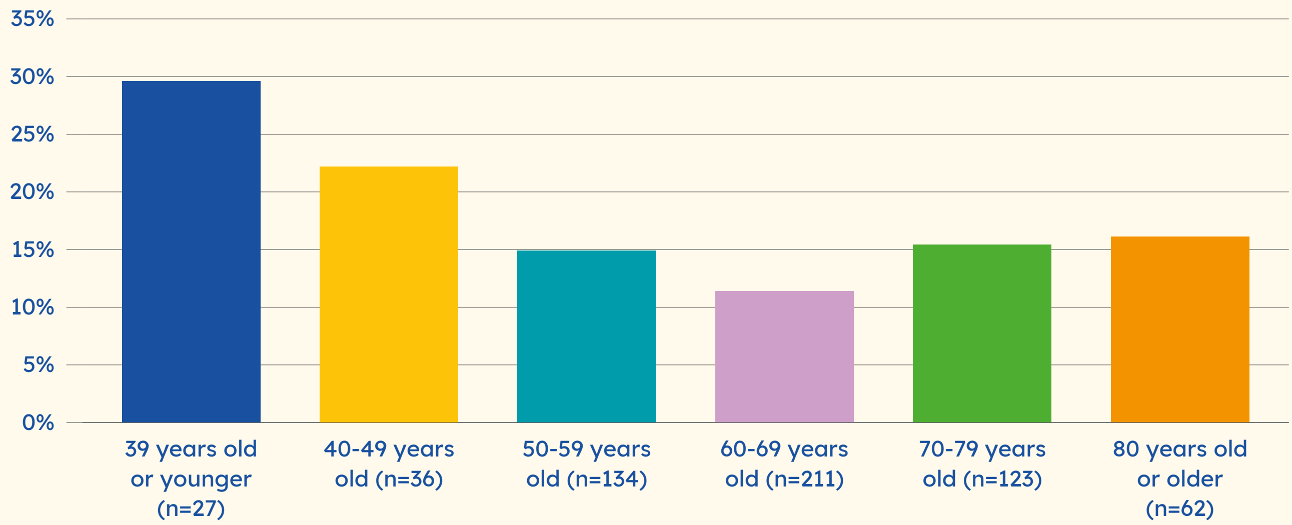

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Figure 28. Prevalence of disturbed grief among respondents in England according to their relation to the person who died

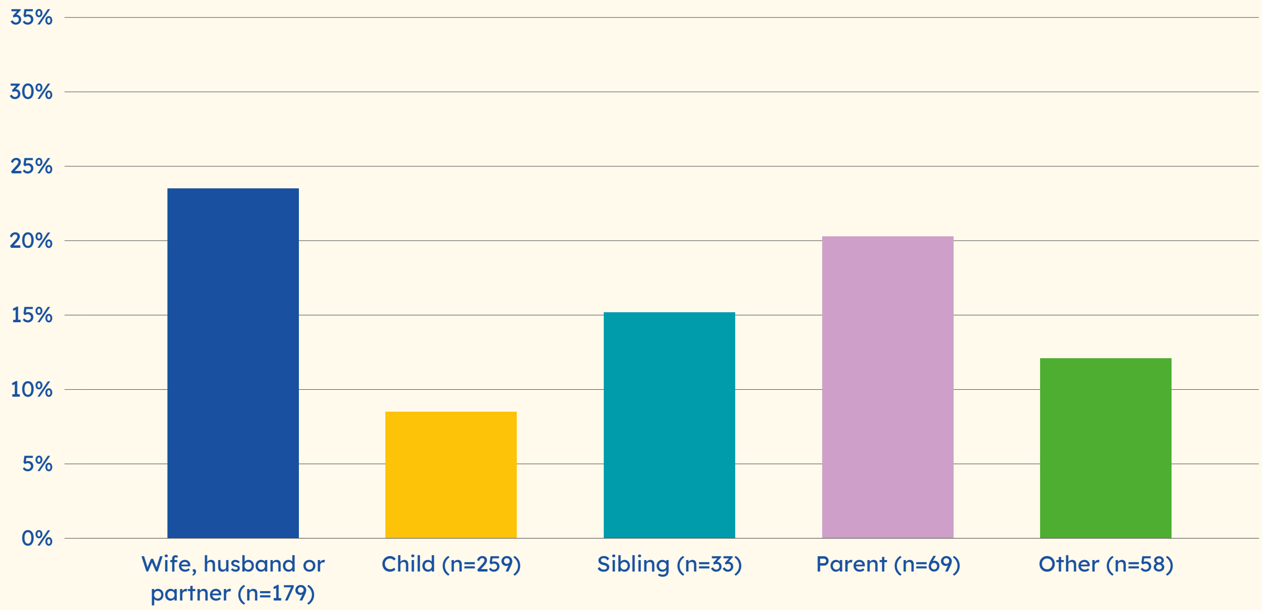

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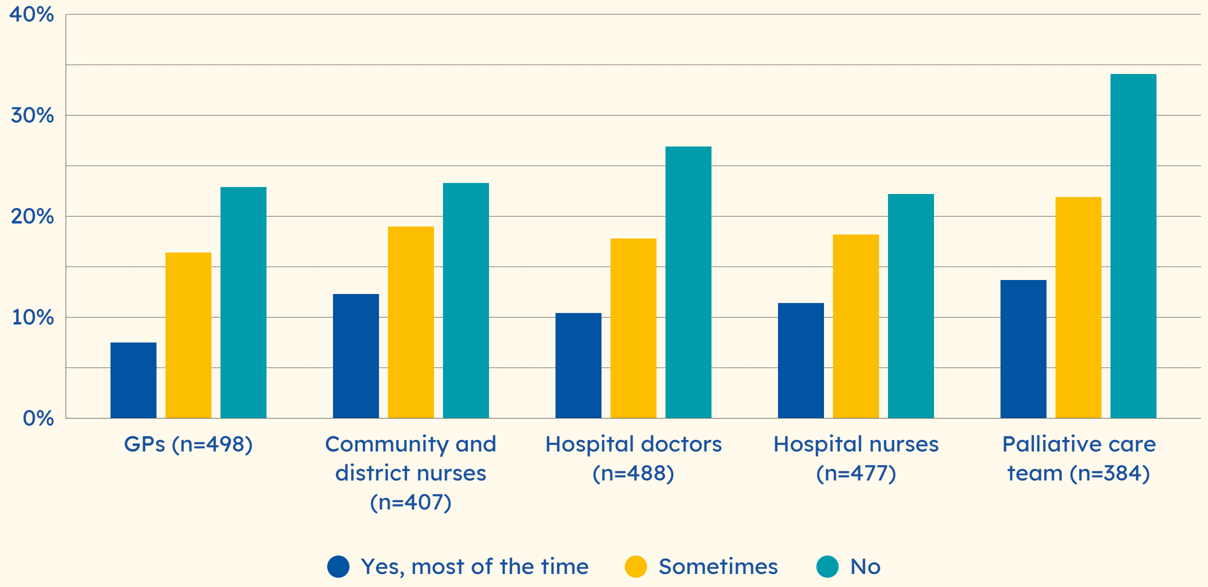
Figure 29. Prevalence of disturbed grief in England in relation to whether respondents felt that healthcare professionals listened and fully discussed with them and/or the person who died



Notes: Percentages are based on valid responses only, missing data for each item is excluded.

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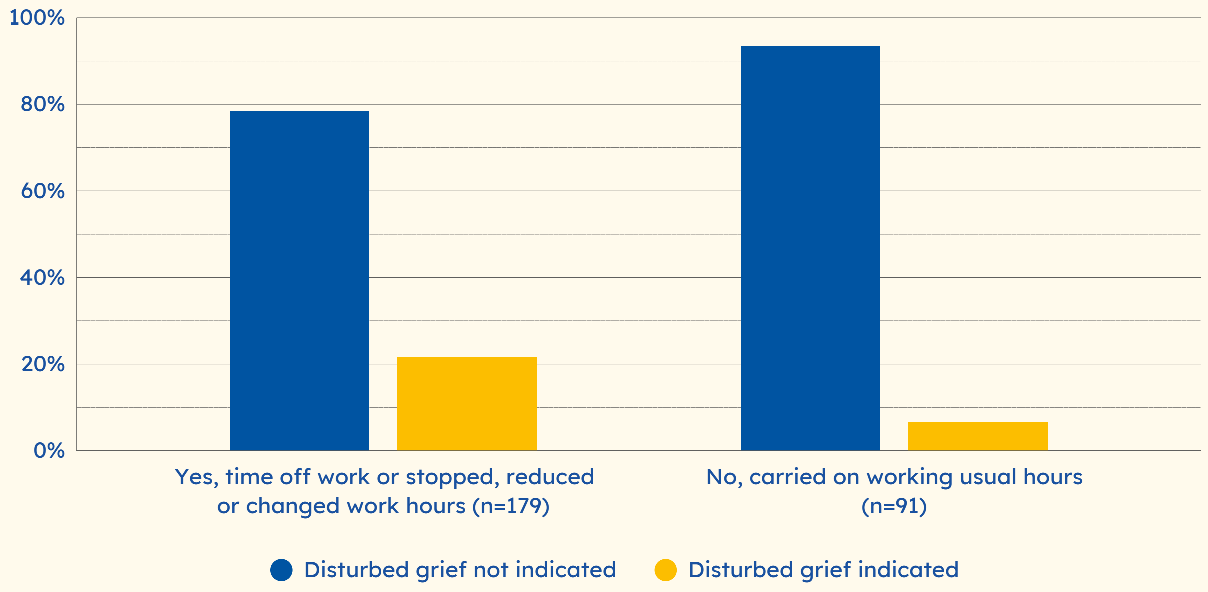
7.2 Contact with support services

Among English respondents with Traumatic Grief Inventory scores that met the criteria for disturbed grief, 26 (28.6%) had accessed bereavement support, while 65 (71.4%) had not.

7.3 Impact on work in the three months after death

Figure 30. Difference in prevalence of disturbed grief between respondents in England who had time off work or stopped, reduced or changed their working hours in the three months after their relative’s death, and those who carried on working normally



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Appendix 3.
Data for Wales

This appendix presents the Welsh nation-level data for each table and figure in the report. Nation-level data for England is reported in Appendix 2. Sixteen respondents did not specify in which nation the person who died had resided; these responses are excluded from the appendices. The appendix follows the same section headings and table and figure numbers as the main report.

3 Sample description

3.1 Who responded to our survey?

Table 1. Sociodemographic characteristics of survey respondents in Wales (n=557)

	Number	%
Gender		
Male	209	37.5
Female	340	61.0
Non-binary, prefer not to say, or not answered	8	1.4
Ethnicity		
White British	549	98.6
White other	<3	-
Mixed	<3	-
Asian	<3	-
Any other ethnic group	<3	-
Black	<3	-
Prefer not to say or not answered	3	0.5
Employment		
In paid work	245	44.0
In unpaid work	6	1.1
Not employed	303	54.4
Other or not answered	3	0.5
Relationship to the person who died		
Child	327	58.7
Wife, husband, or partner	134	24.1
Other (eg in-laws, nieces, nephews)	54	9.7
Sibling	31	5.6
Parent	8	1.4
Not answered	3	0.6

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3.2 Who were the people who died?

Table 2. Sociodemographic characteristics of those who died in Wales (n=557)

	Number	%
Gender		
Male	268	48.1
Female	286	51.4
Prefer not to say or not answered	3	0.5
Age category		
85 or older	249	44.7
65-84	255	45.8
18-64	46	8.3
Not answered	7	1.3
Ethnicity		
White British	550	98.7
White other	3	0.5
Asian	<3	-
Black	<3	-
Any other ethnic group	<3	-
Mixed	<3	-
Not answered	<3	-
Geographical area in Wales		
North Wales	136	24.8
Mid Wales	46	8.4
South East Wales	210	38.3
South West Wales	156	28.5
Marital status		
Married or with a partner	240	43.1
Widowed	239	42.9
Divorced or separated	46	8.3
Never married	30	5.4
Not answered	<3	-
Educational attainment		
Did not go to school	<3	-
Left school at 15 years old or under	239	42.9
Left school at 16 – 17 years old	155	27.8
Left school at 18 – 19 years old	16	2.9
Post-secondary school vocational qualifications	85	15.3
University	56	10.1
Not answered	<5	-

	Number	%
Financial circumstance		
Living comfortably	254	45.6
Doing alright	191	34.3
Just about getting by	63	11.3
Finding it quite difficult	24	4.3
Finding it very difficult	19	3.4
Not answered	6	1.1
Accommodation		
Owned outright	324	58.2
Owned with a mortgage or loan	33	5.9
Part-owned and part-rented	10	1.8
Rented (with or without housing benefit)	104	18.7
Other	81	14.5
Not answered	5	0.9
Living situation		
On their own	170	30.5
With the respondent (with or without other people)	180	32.3
With other people (but not the respondent)	91	16.3
In a care home	101	18.1
Elsewhere	9	1.6
Not answered	6	1.0

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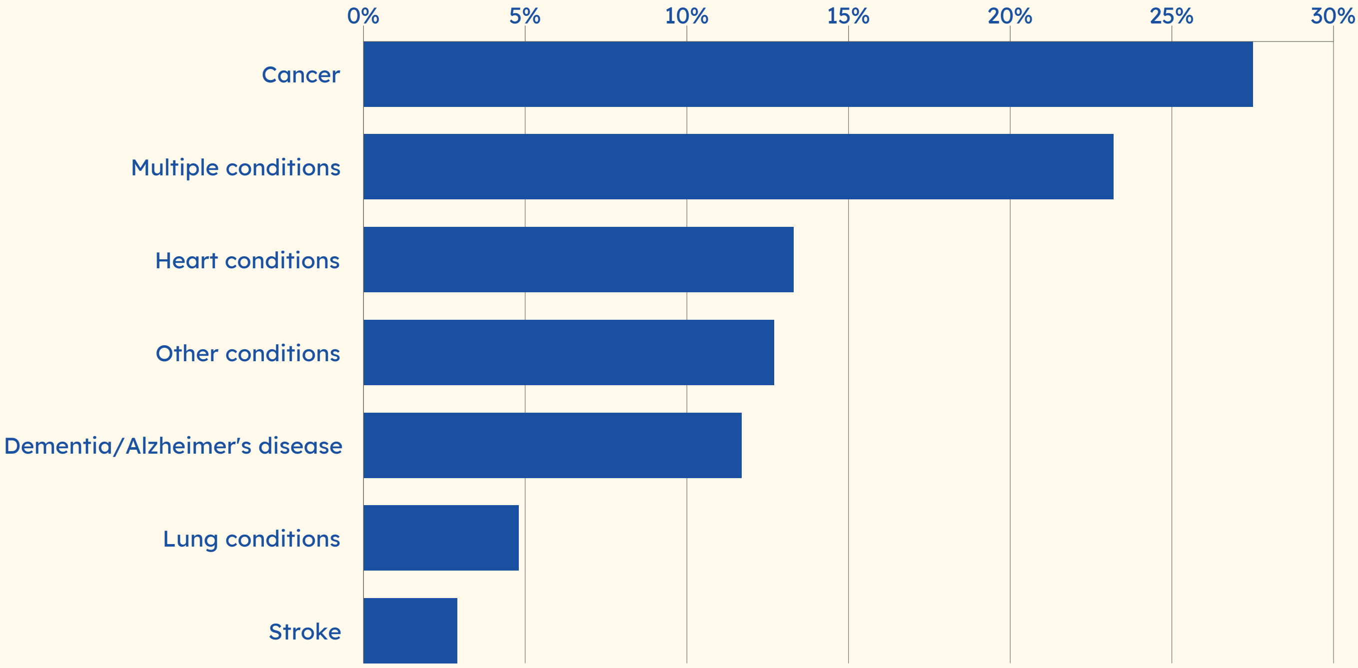
3.2.1 What was the cause of death?

Figure 1. Reported main cause of death of those who died in Wales (n=551)



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3.2.2 What illnesses were those who died living with?

Table 3. Prevalence of chronic health conditions among the people who died in Wales (selected as either a cause of death or as an illness that the person who died was living with)

	Number	%
Respiratory conditions (eg asthma, chronic obstructive pulmonary disease)	257	46.1%
Cardiovascular conditions (eg heart disease, atrial fibrillation, high blood pressure)	237	42.5%
Cancer	203	36.4%
Dementia (eg Alzheimer's disease, vascular dementia)	157	28.2%
Musculoskeletal conditions (eg osteoarthritis, rheumatoid arthritis)	117	21.0%
Diabetes	86	15.4%
Mental health conditions (eg depression, schizophrenia, anxiety)	59	10.6%
Digestive conditions (eg liver disease, inflammatory bowel disease, stomach ulcers)	54	9.7%
Renal conditions (eg chronic kidney disease)	47	8.4%

	Number	%
Neurological conditions (eg Parkinson's disease, epilepsy, motor neuron disease multiple sclerosis)	24	4.3%
Learning disability	7	1.3

Note: Since multiple conditions were selected, the total count is higher than the total sample size.

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4 Experiences of the last three months of life

4.1 Where did those who had died spend most of their time?

Figure 2. The places where the people who died in Wales spent most of their time in their last three months of life (n=554)

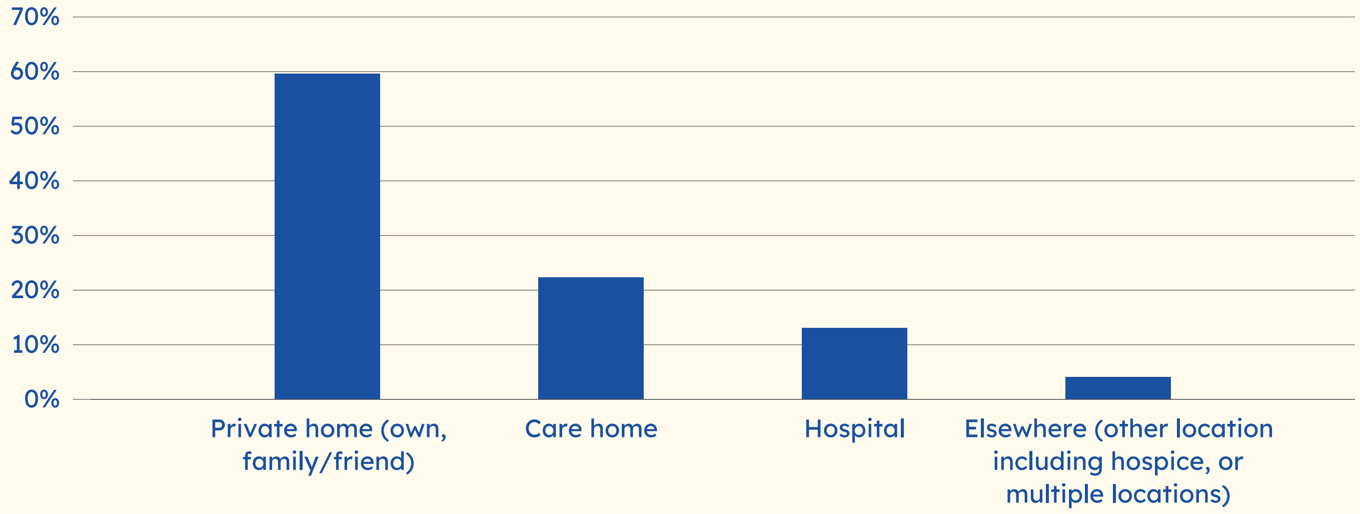

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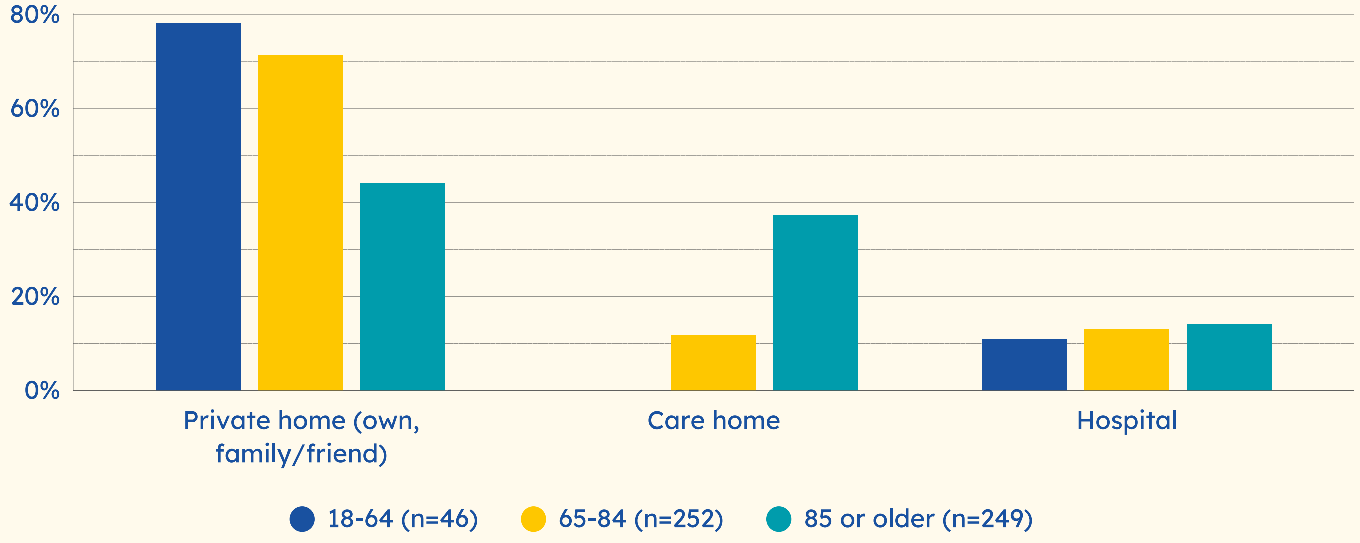
Figure 3. Differences in the places in which the person who died spent most of their last three months of life in Wales according to their age (n=547)



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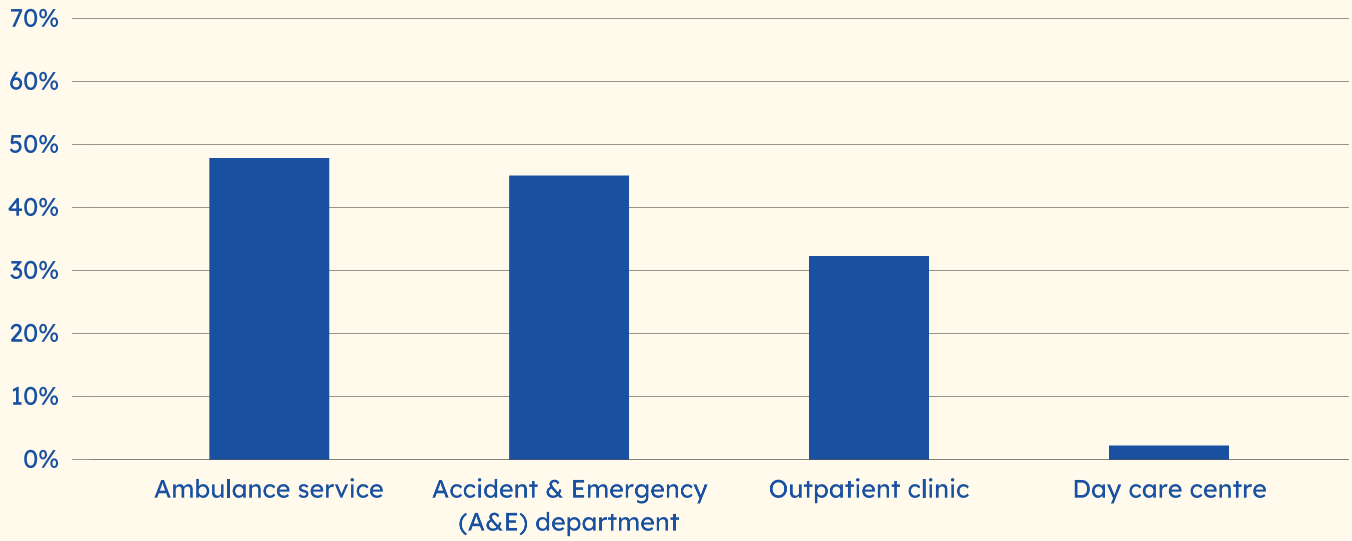
4.2 What care services were used in the last three months?

Figure 4. Use of care services among the people who died in their last three months of life in Wales (n=557)



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4.2.4 Contact with health and social care professionals in the community

Figure 5. Proportion of people who died in Wales who had any contact with different health and social care professionals in their last three months of life (n=557)

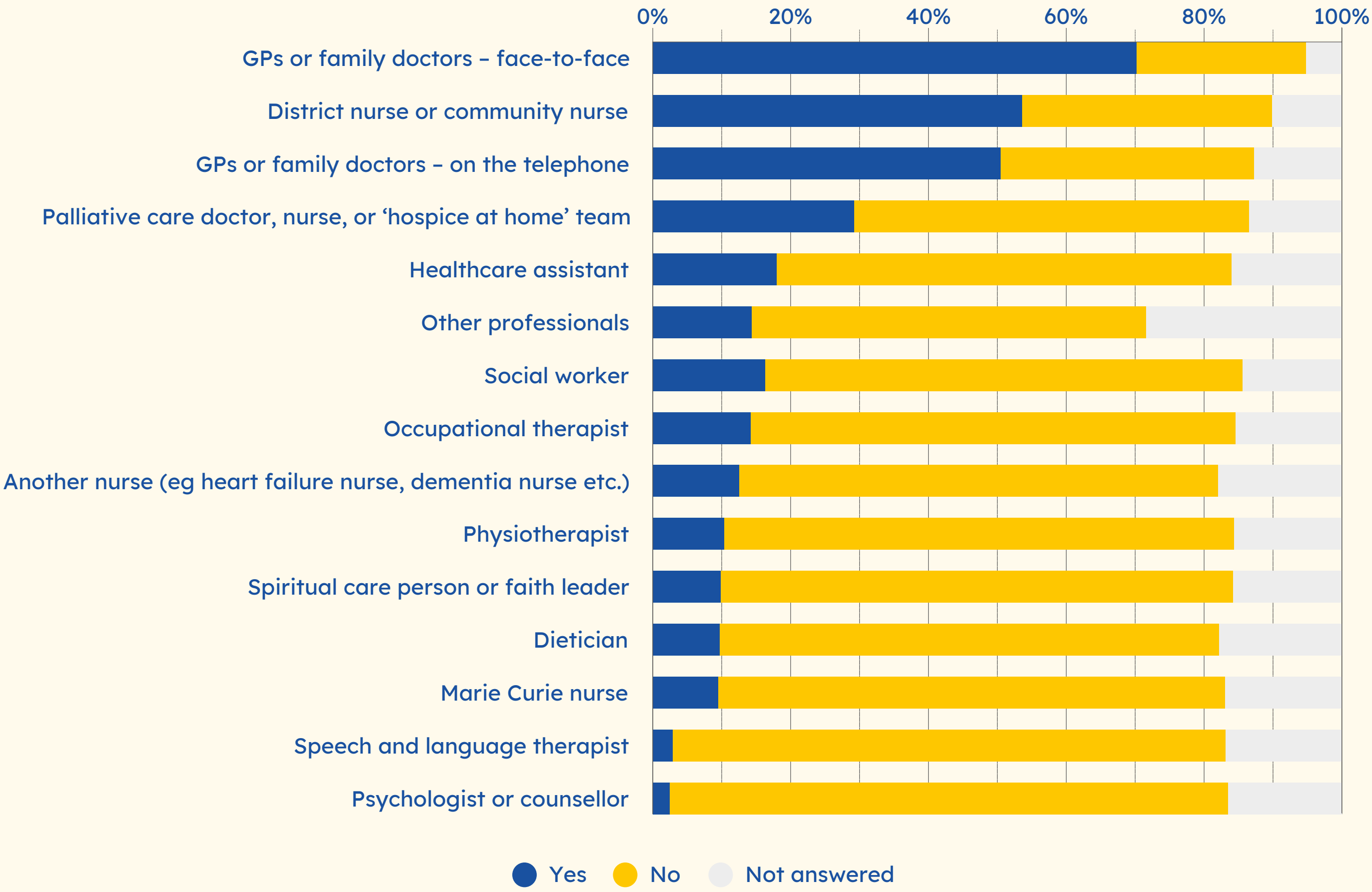

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Table 4. Contact with health and care professionals in Wales in the last three months of life while at home or in a care home, ie, not in hospital or a hospice

	No contact	Had contact	Distribution of frequency of contacts					
	n	n	Mean	SD	Median	Min	Max	IQ range
GPs or family doctors (face-to-face)	137	391	3.5	4.21	2	1	42	2-4
GPs or family doctors (on the telephone)	205	281	4.0	4.01	3	1	40	2-5
District nurse or community nurse	202	299	12.1	21.57	6	1	180	2-12
Palliative care doctor, nurse, or 'hospice at home' team	319	163	7.5	15.05	4	1	150	2-8
Healthcare assistant	368	100	36.6	79.91	6	1	480	2-21.75

Notes: SD=standard deviation, IQ range=interquartile range (range between first and third quartile of the frequency distribution).

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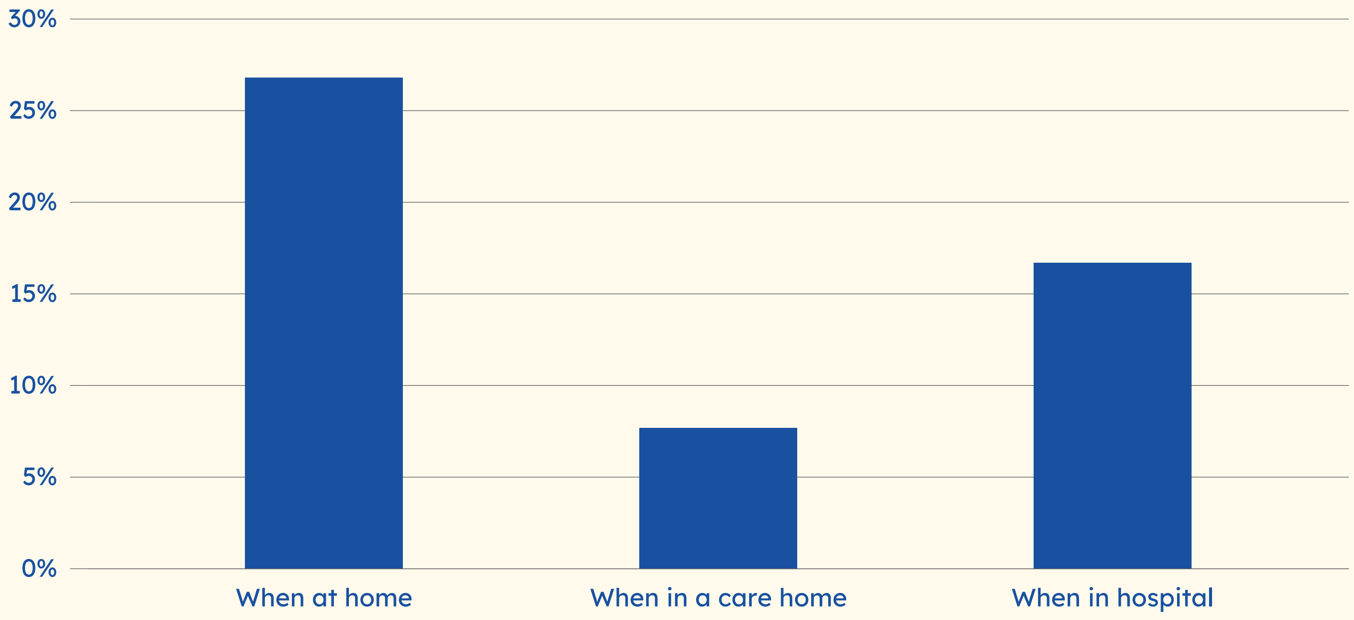
4.2.5 Care from palliative care specialists

Figure 6. Proportion of people who died in Wales who received care from palliative care specialists in their last three months of life (n=557)



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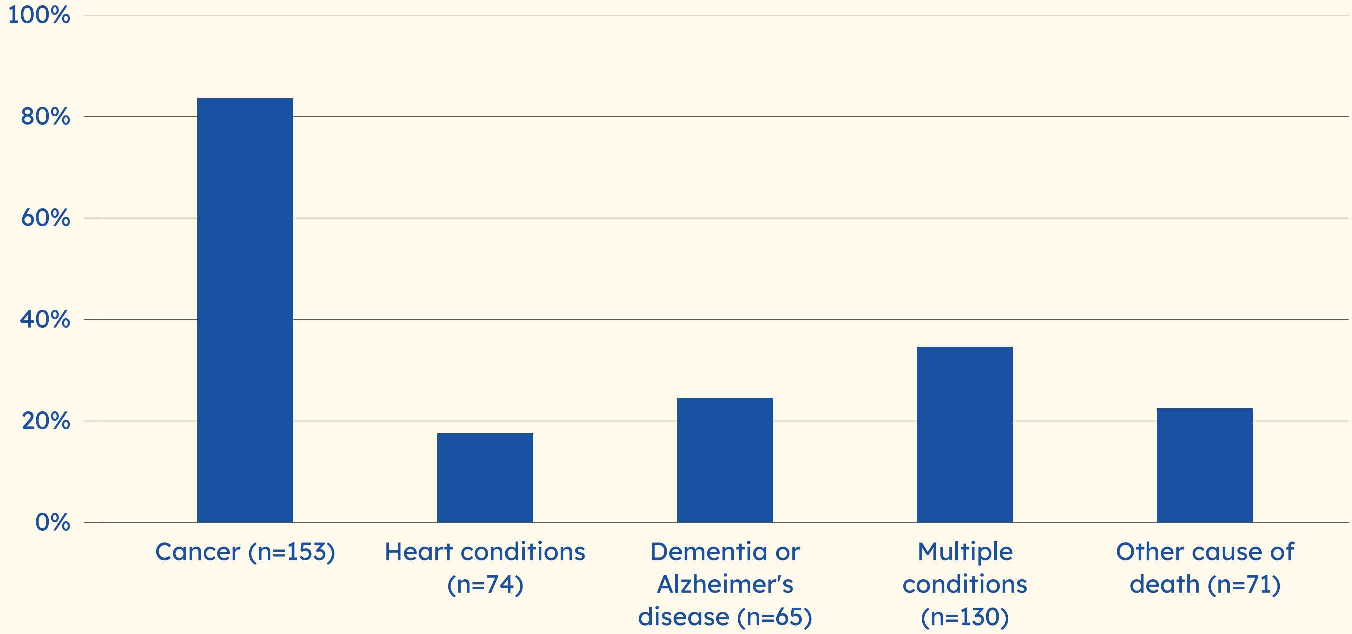
4.2.5.1 Differences in specialist palliative care use

Figure 7. Receipt of care from palliative care specialists (in any setting) in Wales during the last three months of life across the five most common causes of death



Notes: For information about multiple conditions and other cause of death see section 3.2.1 of the main report.

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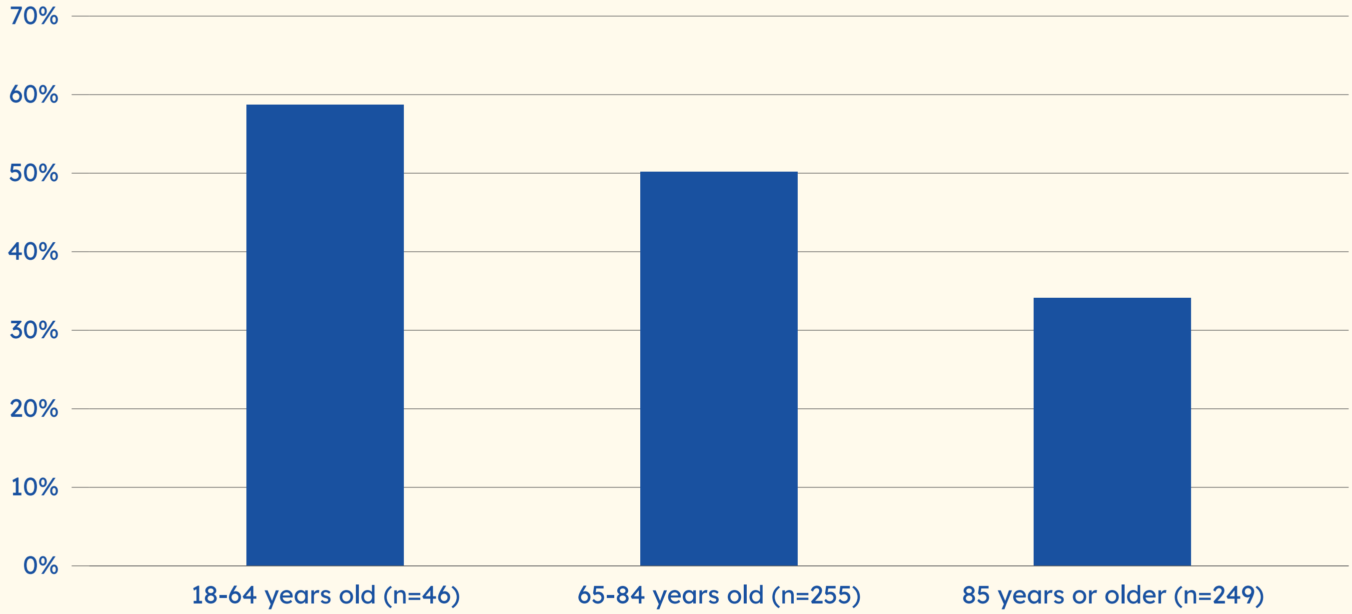
Figure 8. Receipt of care from palliative care specialists (in any setting) in Wales during the last three months of life by the age of the person who died



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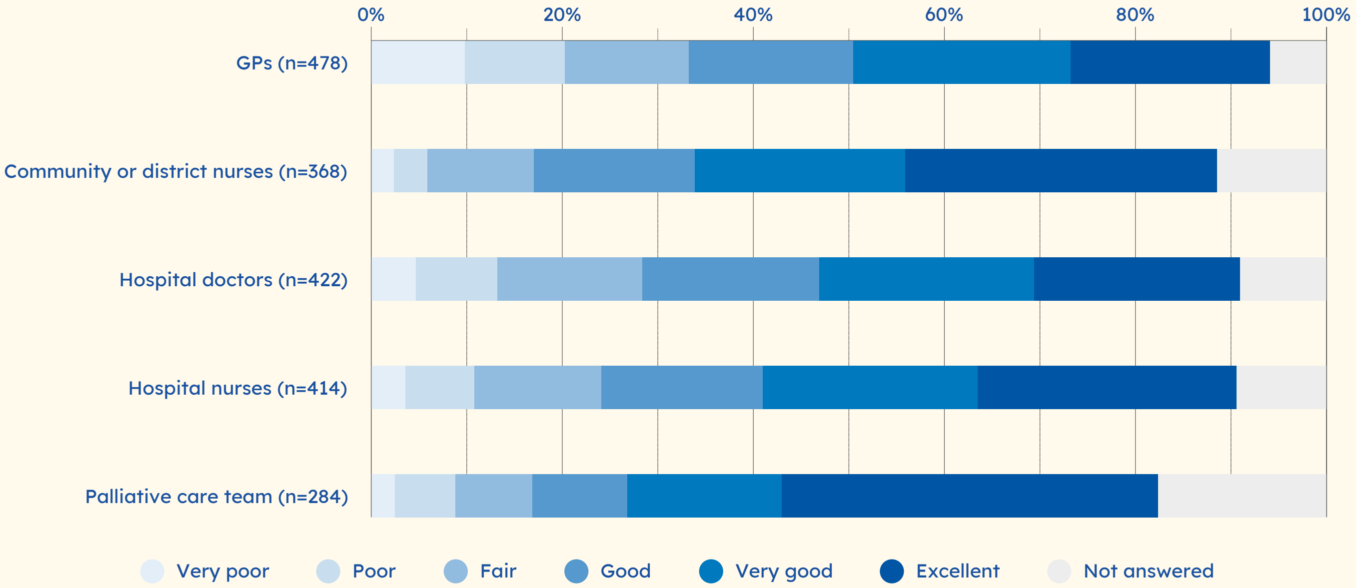
4.2.6 Coordination of care

During the last three months of life, 238 (42.7%) of those who died in Wales had a health or care professional acting as a key contact person to co-ordinate their care.

4.3 How did respondents perceive the care provided from healthcare professionals?

Figure 9. Respondents' perception of the quality of the care received from different health care professionals in Wales



Notes: Responses indicating that care had not been received from these professional groups were excluded

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4.4 Carer experiences of access to care services and care provision

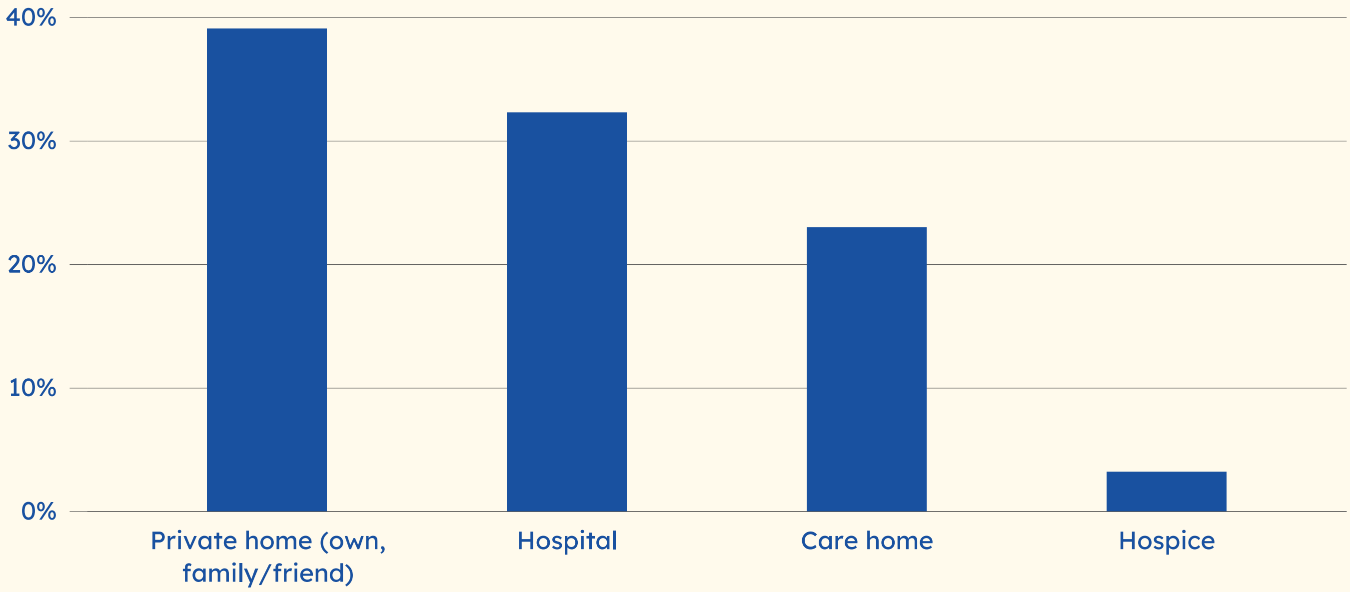
4.4.1 Were respondents unhappy with care?

Almost half (n=259, 46.5%) of Welsh respondents reported they were unhappy with one or more aspect(s) of care, while 282 (50.6%) reported no issues. Of those who were unhappy with care, 101 (39.0%) reported that the issue(s) were discussed with health or care professionals and 37 (14.3%) reported that a formal complaint was made.

5 Experiences of the final week of life

5.1 Where did the people who died spend most of their last week of life?

Figure 10. The locations in which those who died in Wales spent most of their final week of life (n=550)



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5.2 What symptoms or concerns were experienced?

Figure 11. Physical symptoms and concerns affecting the person who died in Wales in their final week of life (n=557)

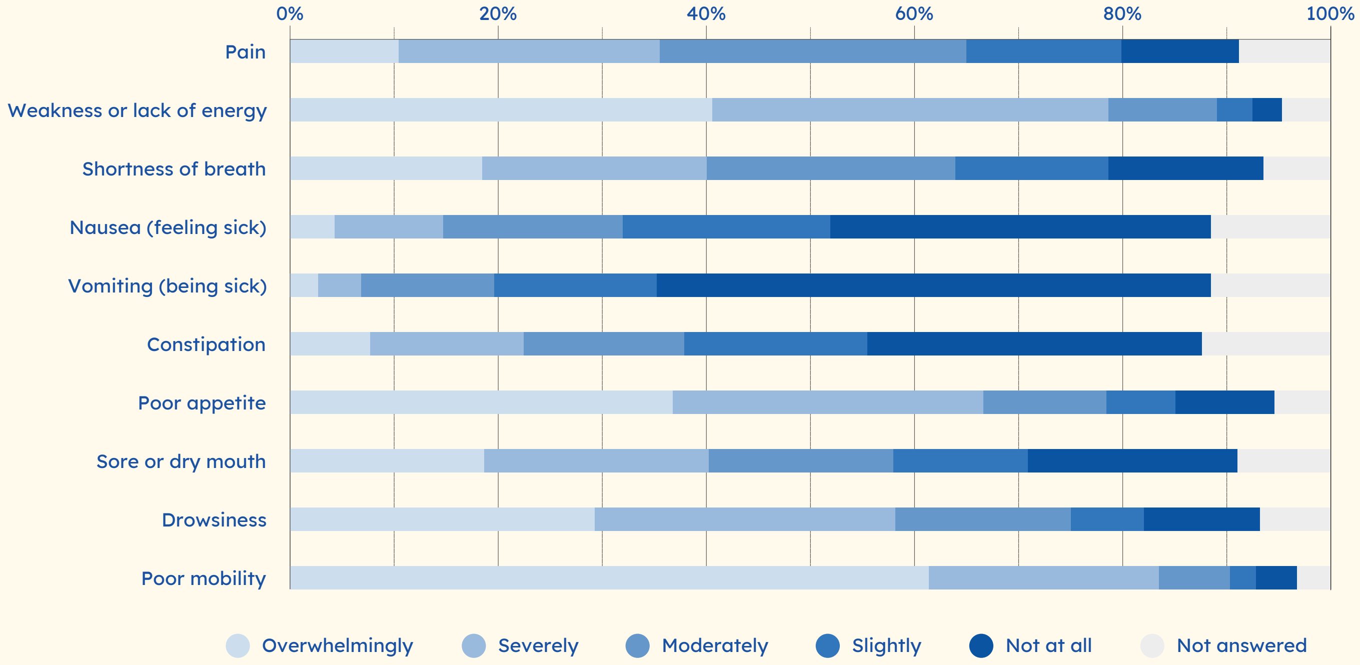

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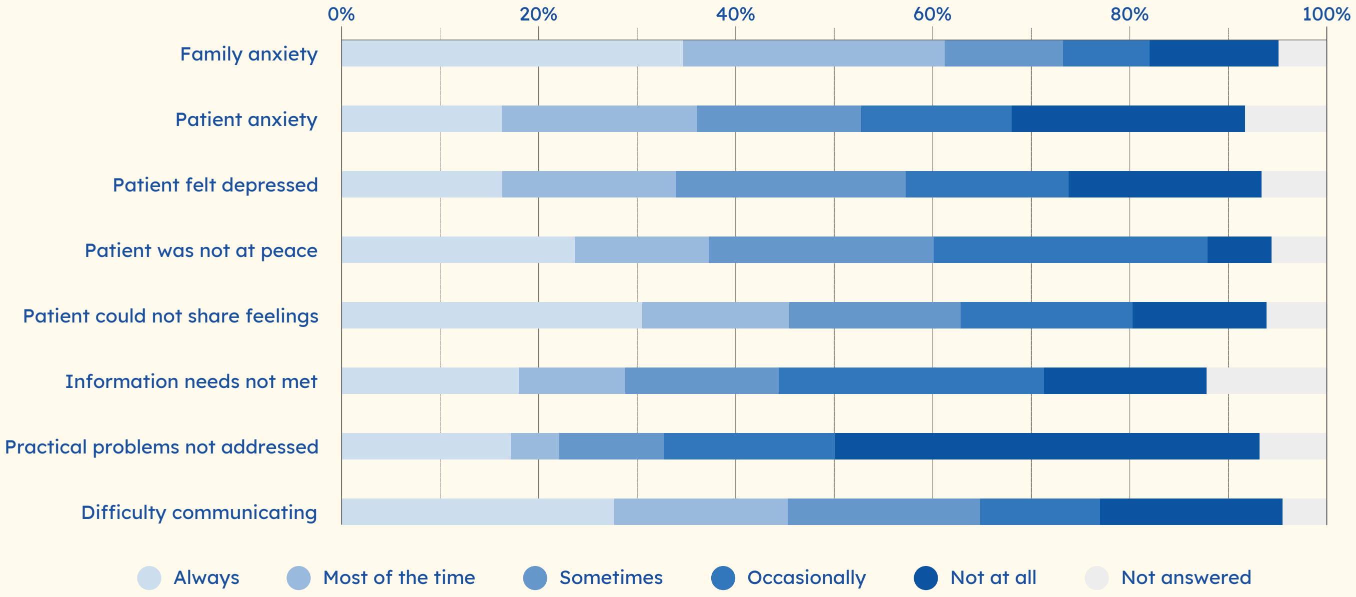
Figure 12. Other symptoms and concerns (psychological, communication, and practical) affecting the person who died in Wales, or their family, in their final last week of life (n=557)



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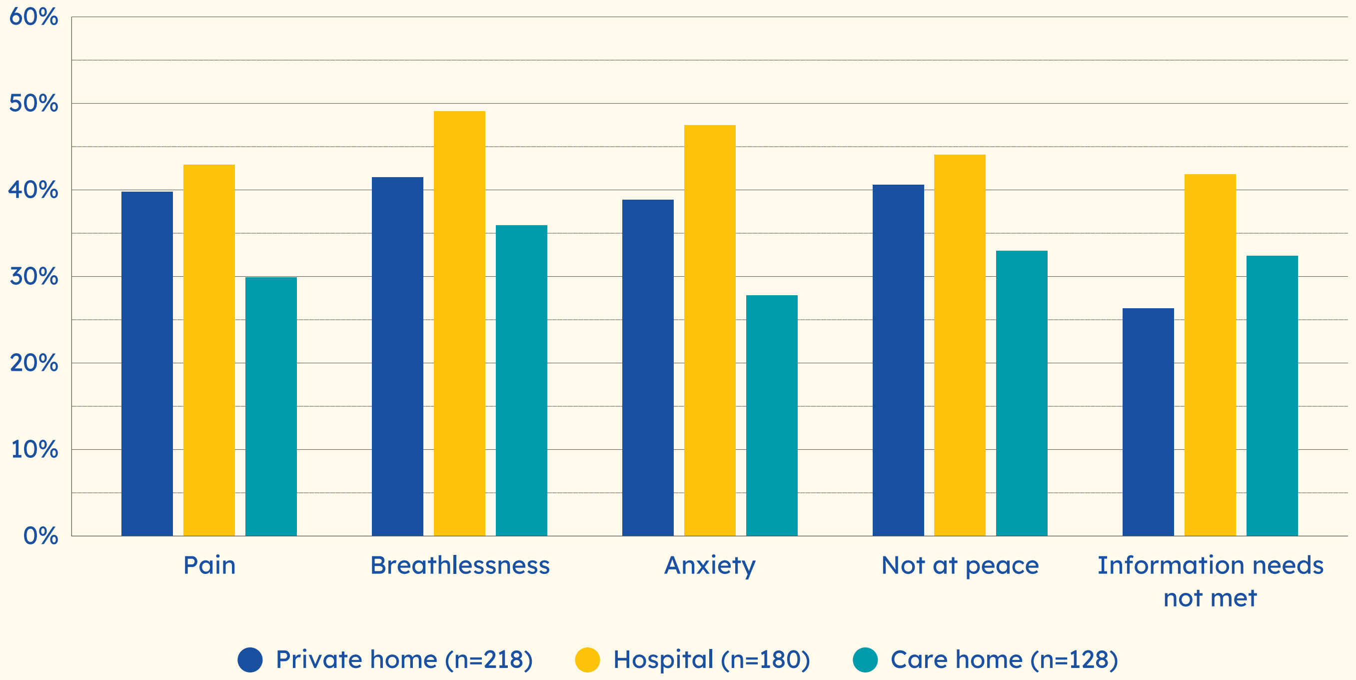
5.2.1 Differences in symptom prevalence across care settings

Figure 13. Differences by care setting in prevalence of being severely or overwhelmingly affected by five key symptoms and concerns in the final week of life among those who died in Wales



Notes: Percentages are based on valid responses only, missing data for each item is excluded.

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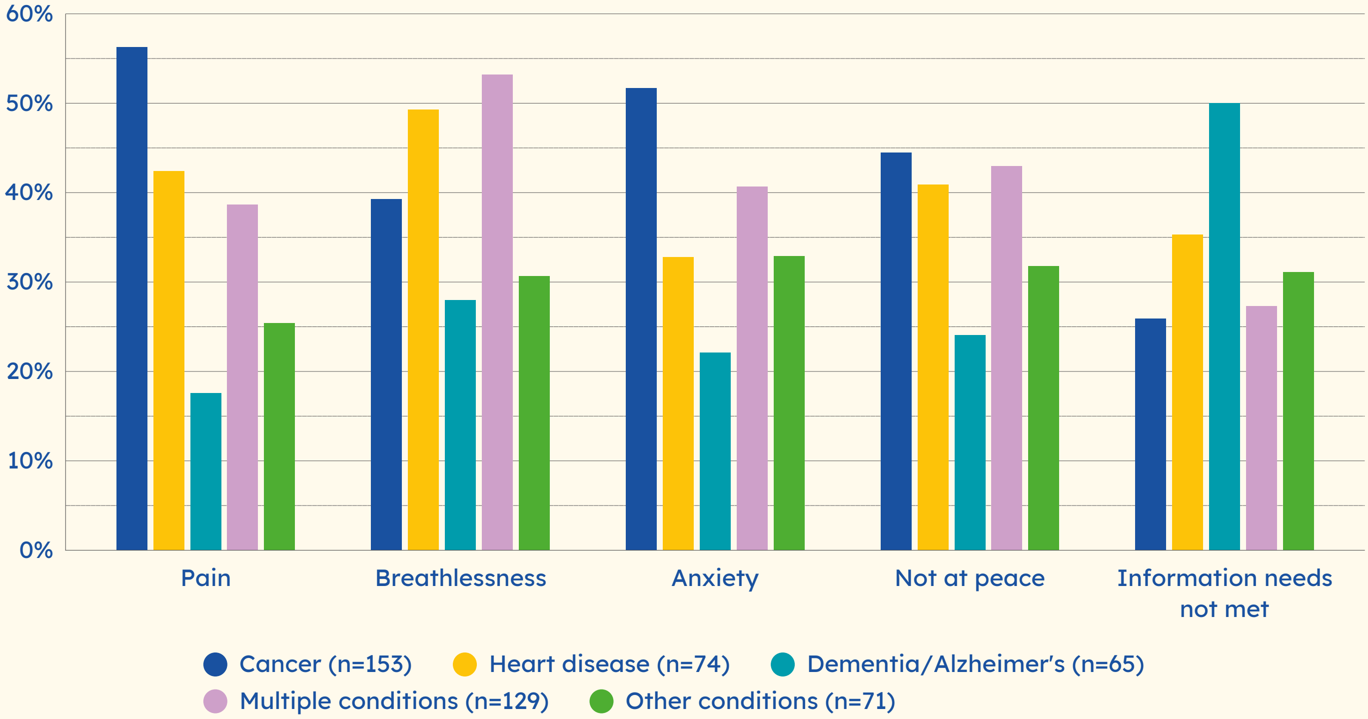
5.2.2 Differences across cause of death

Figure 14. Differences by cause of death in prevalence of being severely or overwhelmingly affected by five key symptoms and concerns in the final week of life among those who died in Wales



Notes: Multiple conditions signify when respondents reported more than one condition as the main cause of death. Other conditions signify conditions that were not listed as response options; free-text responses showed that these often involved respiratory infections, or old age or frailty. Percentages are based on valid responses only, missing data for each item is excluded.

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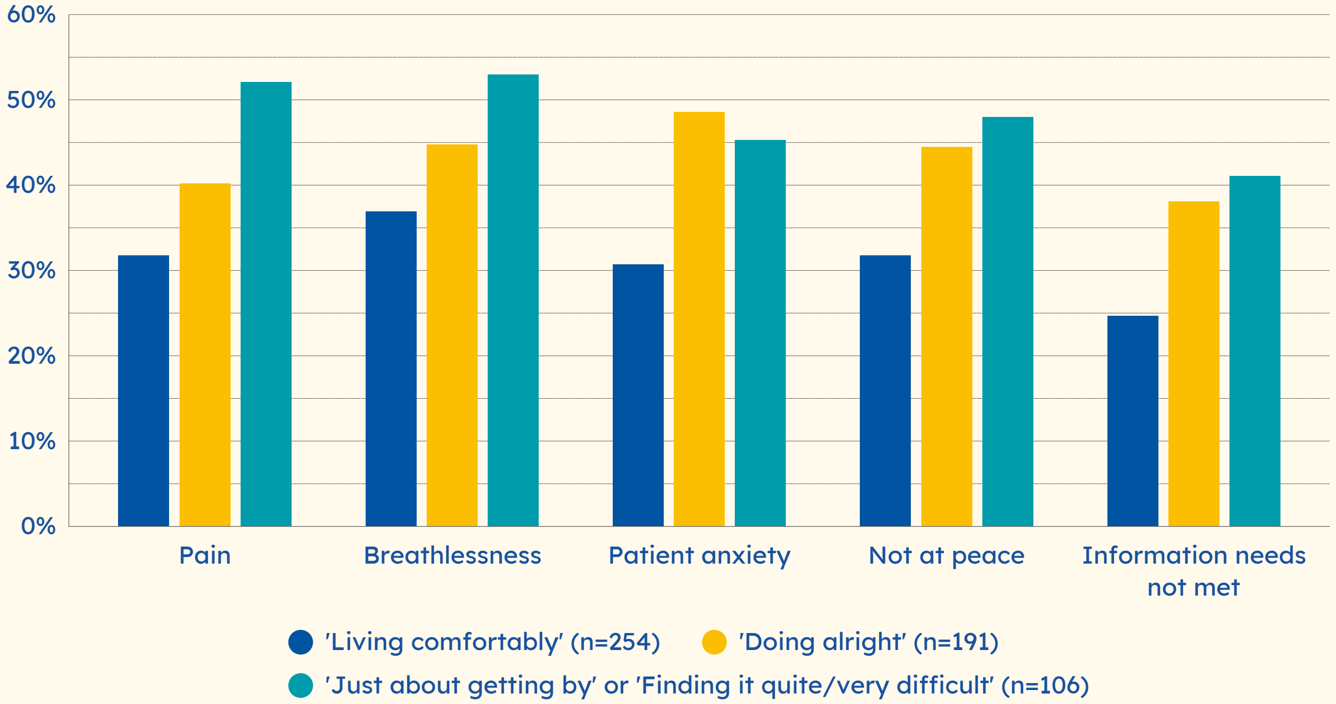
5.2.3 Differences across financial circumstances

Figure 15. Differences by financial circumstances of the person who died in prevalence of being severely or overwhelmingly affected by five key symptoms and concerns in the final week of life among those who died in Wales



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5.3 Awareness and acceptance of death

Figure 16. Length of time that respondents in Wales had been aware that their relative might die (n=443)

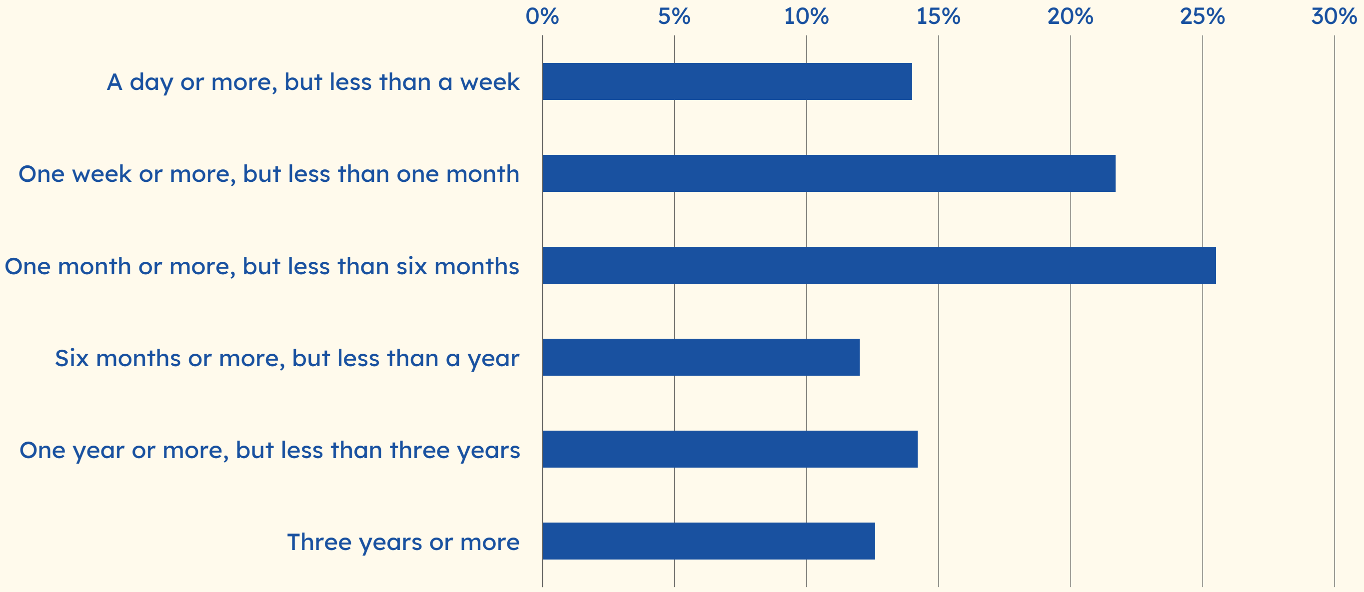

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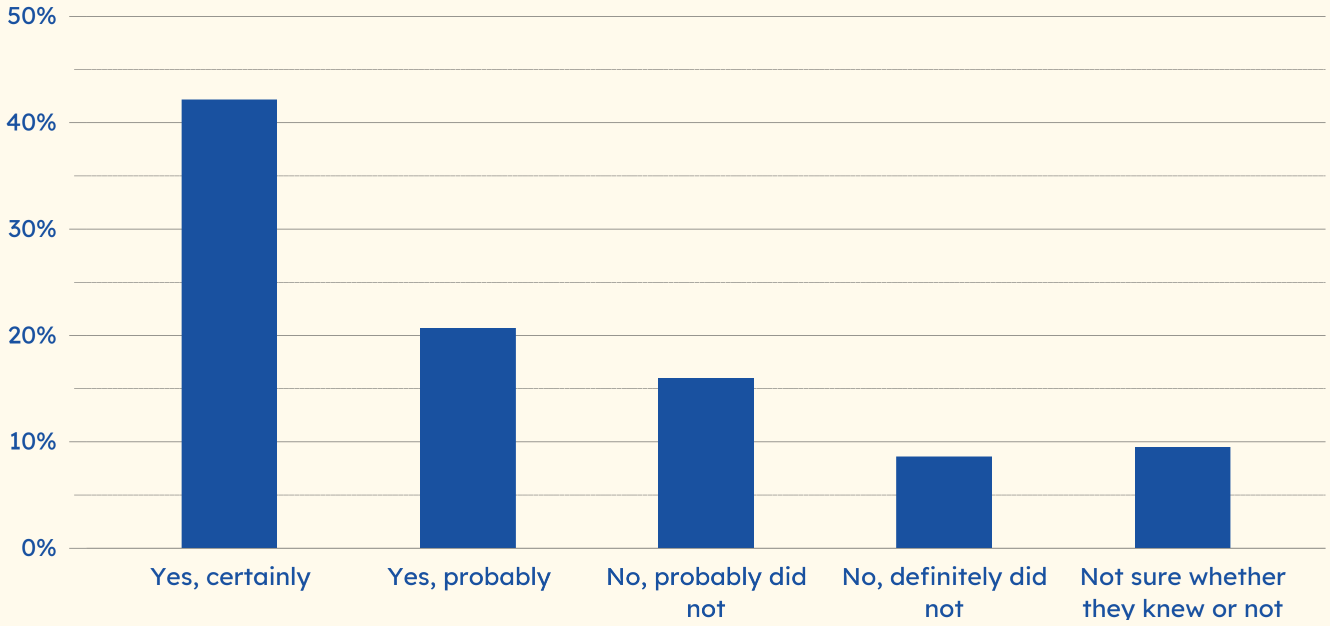
Figure 17. Proportion of those who died in Wales who were thought to have been aware that they might die from their illness (n=540)



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5.3.1 Did healthcare professionals discuss death and dying?

Figure 18. Proportion of respondents in Wales who reported that healthcare professionals had discussed dying and death with the person who died, and/or the respondent or other family members

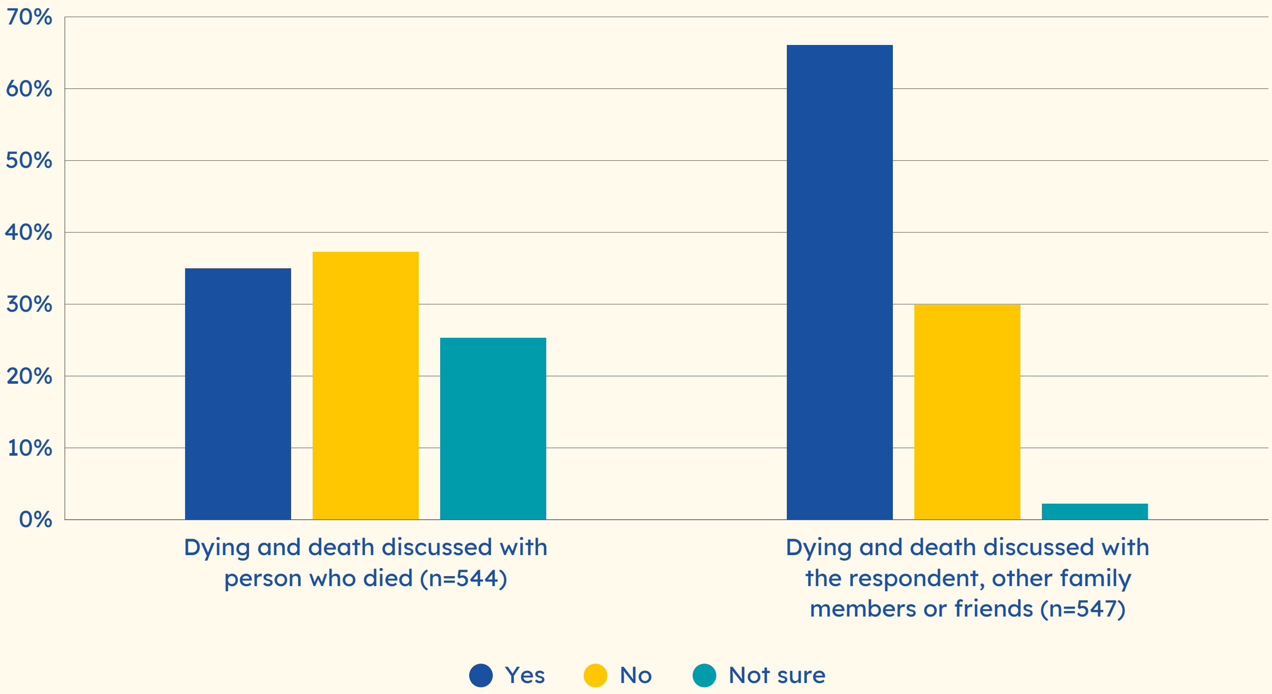

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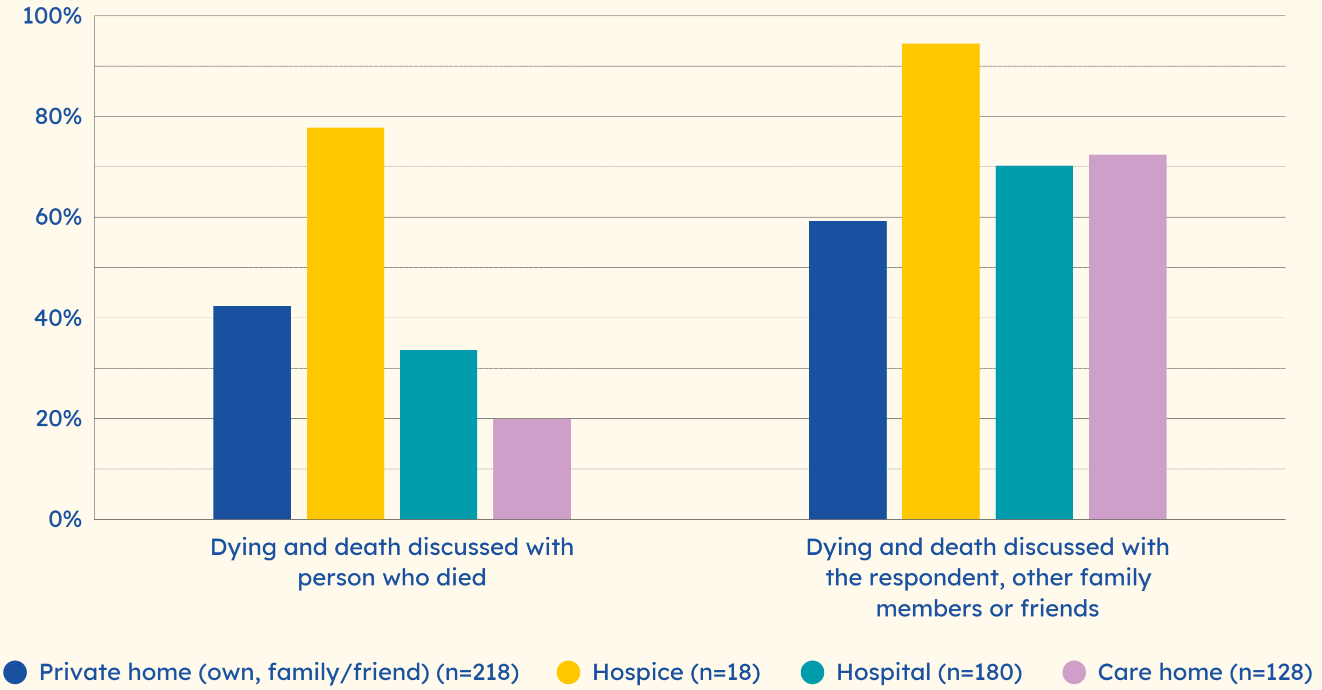
Figure 19. Differences in the proportion of respondents in Wales who reported that health care professionals had discussed dying and death with the person who died, and with the respondent or other family members or friends by care setting in the final week of life



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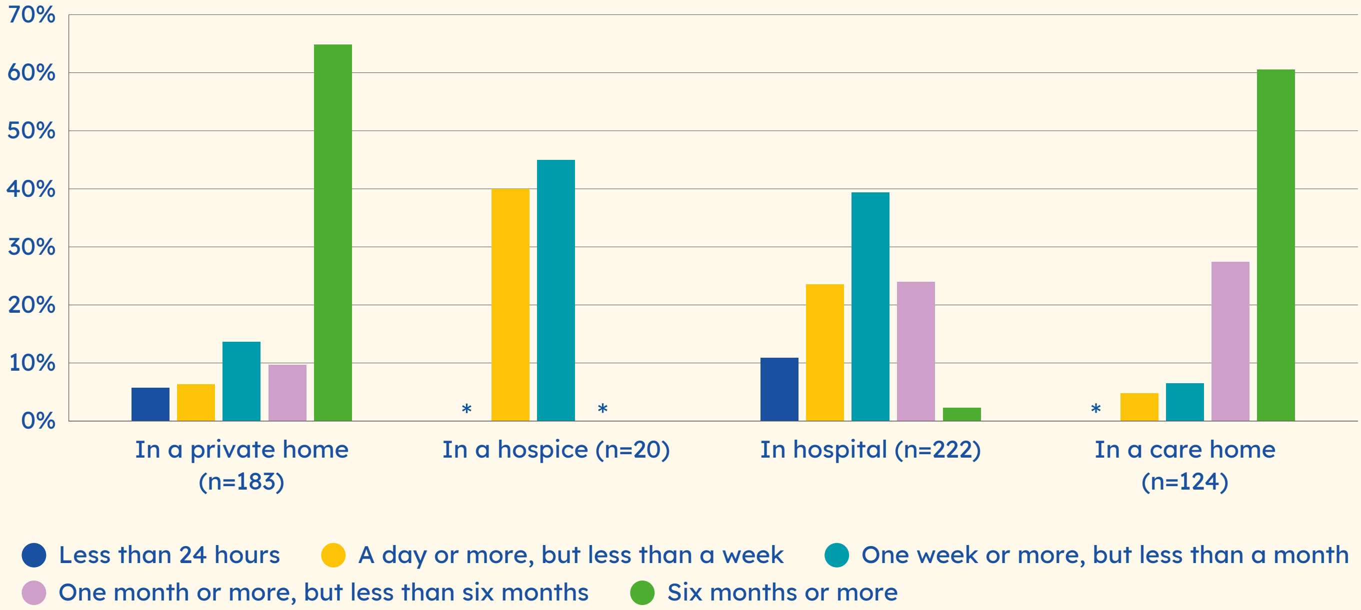
5.4 Place of death

Figure 20. Duration of time that the people who died in Wales had spent at their place of death



Notes: * Small cell counts are suppressed.

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Figure 21. Proportion of those who died in Wales with their family members and/or friends present by place of death

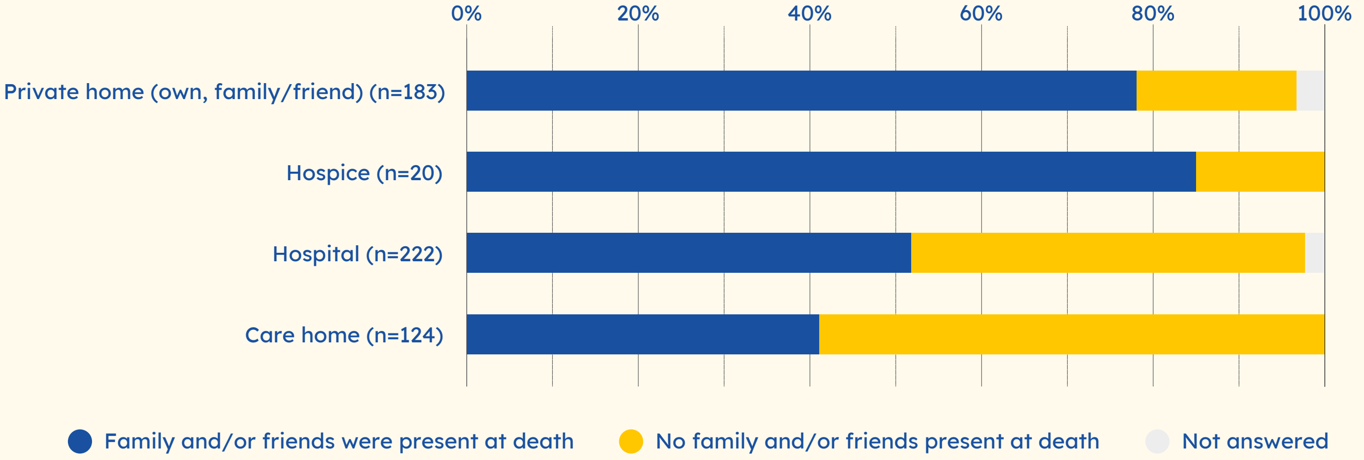

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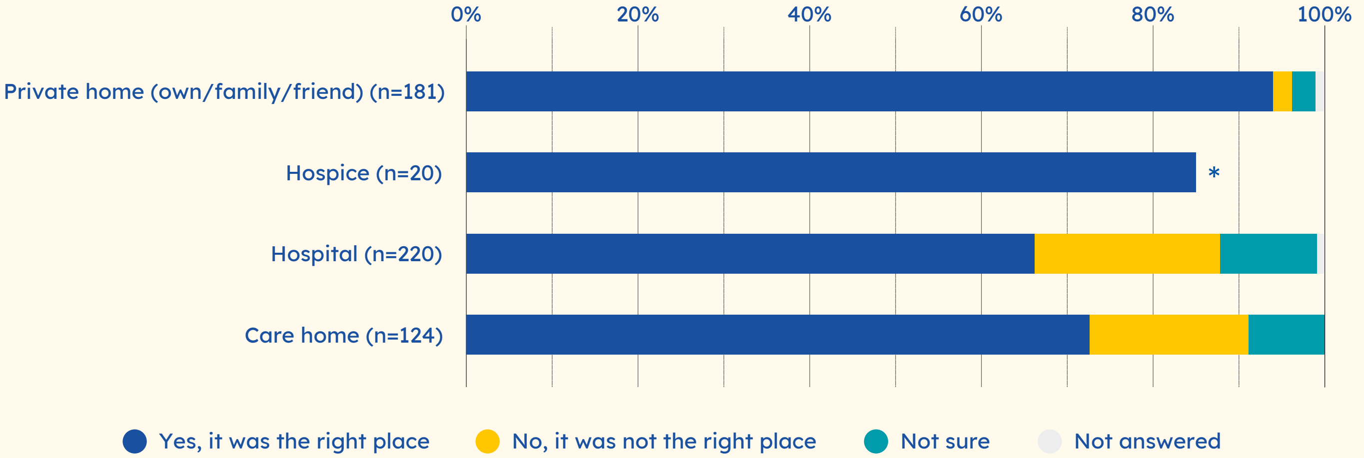
Figure 22. Proportion of respondents in Wales answering that they felt their relative died in the right place according to their place of death



Notes: * Small cell counts are suppressed.

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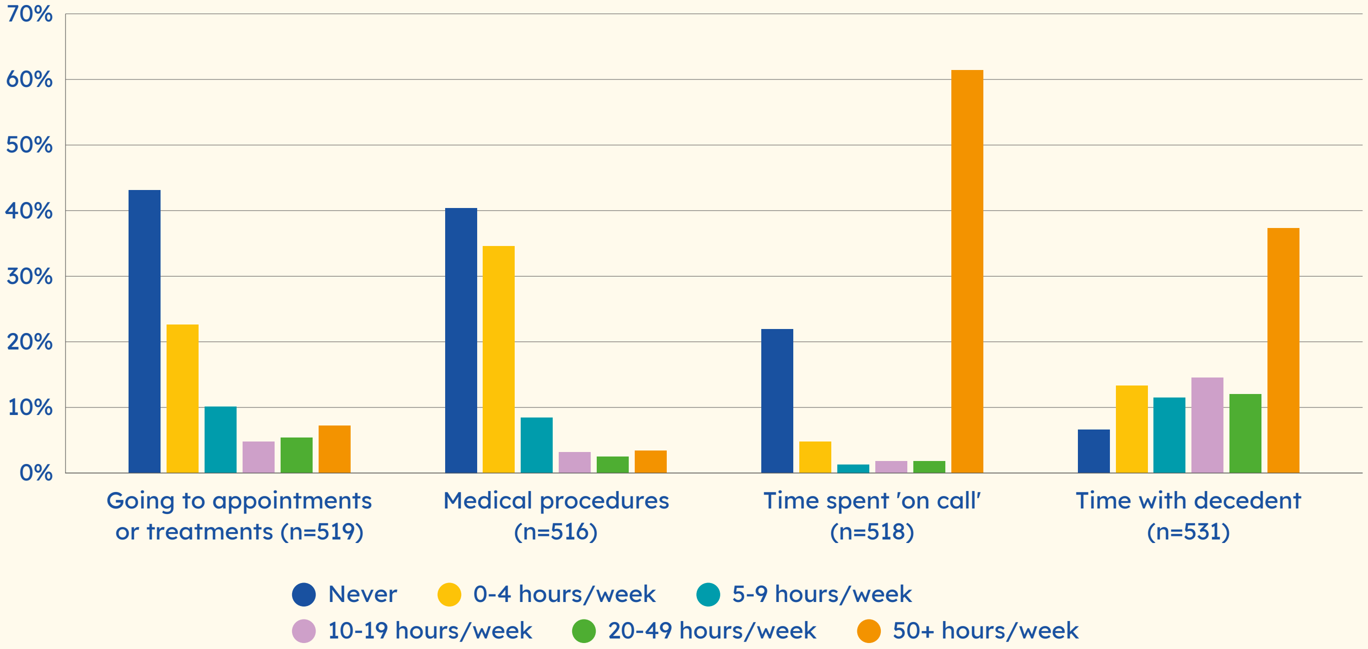
6 Experiences of caring for the people who died

6.1 Who was involved with providing care?

Figure 23. Hours per week that respondents in Wales spent helping the person who died during the last three months of life



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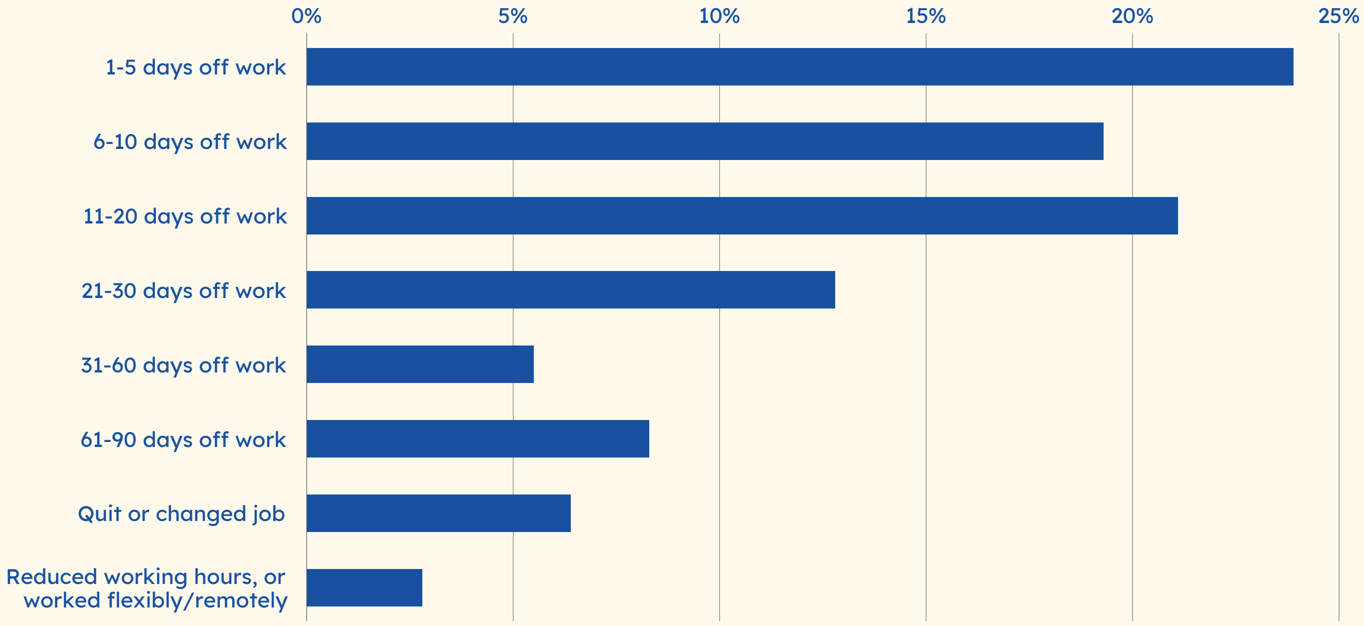
6.3 What was the financial impact of caring?

Figure 24. Impact on work for those respondents in Wales who reported taking time off work to care for their relative in last three months of life (n=109)



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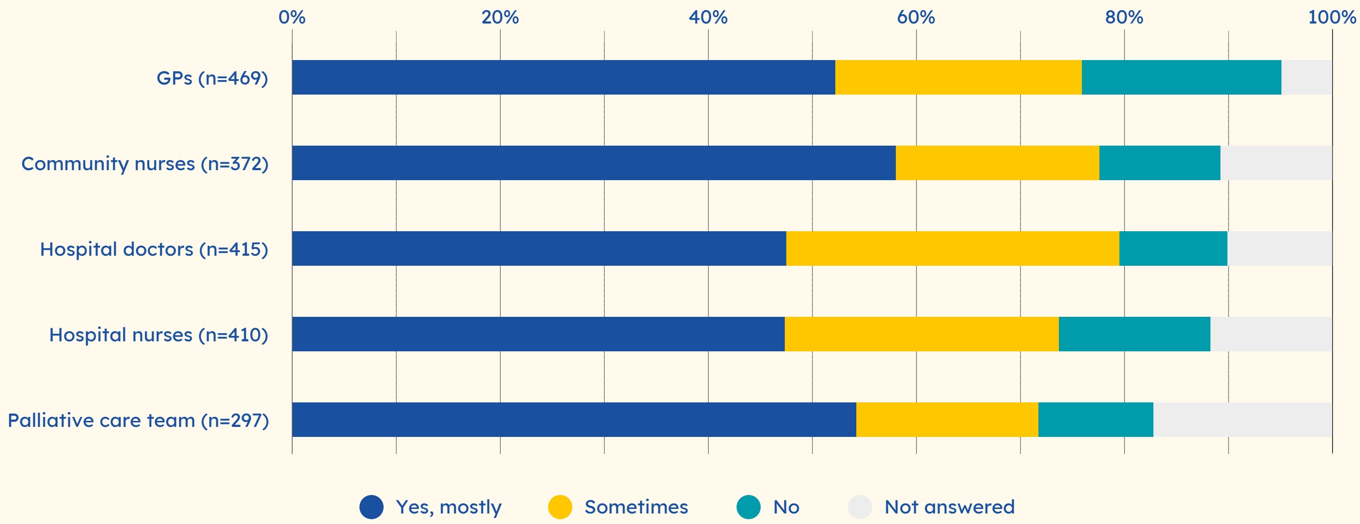
6.4 Interacting with healthcare professionals and services

6.4.1 Did healthcare professionals listen to and have discussions with those who died and their family?

Figure 25. Respondents' experiences in Wales of how much healthcare professionals listened to and discussed with them and/or the person who died during their last three months of life



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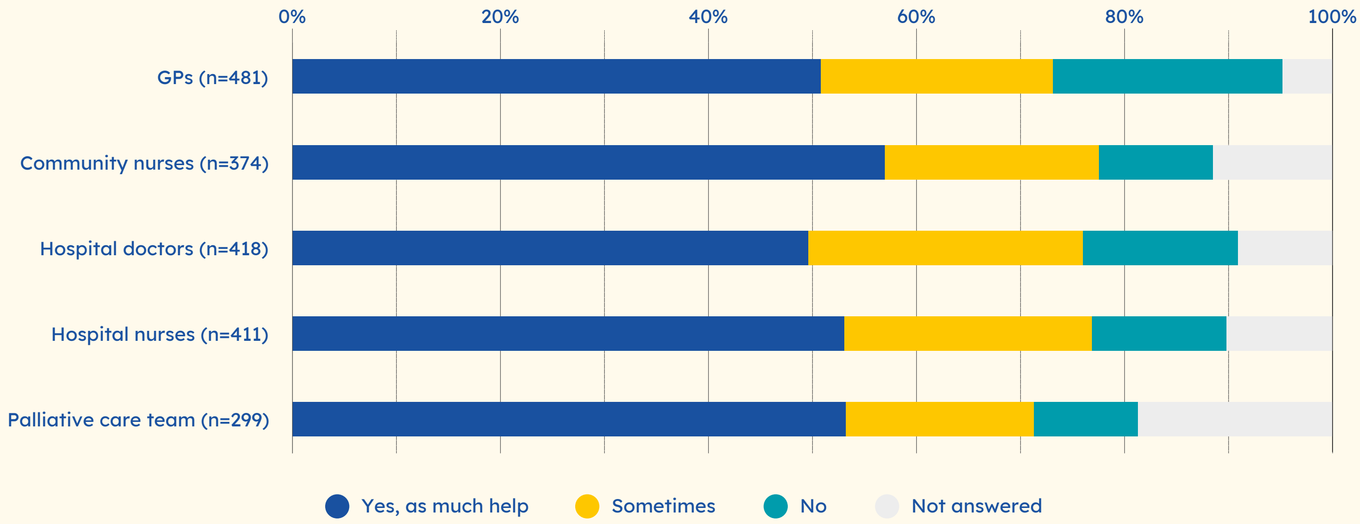
6.4.2 Did healthcare professionals provide sufficient help and support?

Figure 26. Respondents' experiences in Wales of whether healthcare professionals provided enough help to them and/or the person who died during their last three months of life



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7 Bereavement among family and friends providing care

7.1 Disturbed grief among respondents

89 Welsh respondents (16.2%) who completed the Traumatic Grief Inventory had scores of ≥71, indicating disturbed grief.

Figure 27. Prevalence of disturbed grief among respondents in Wales according to their age

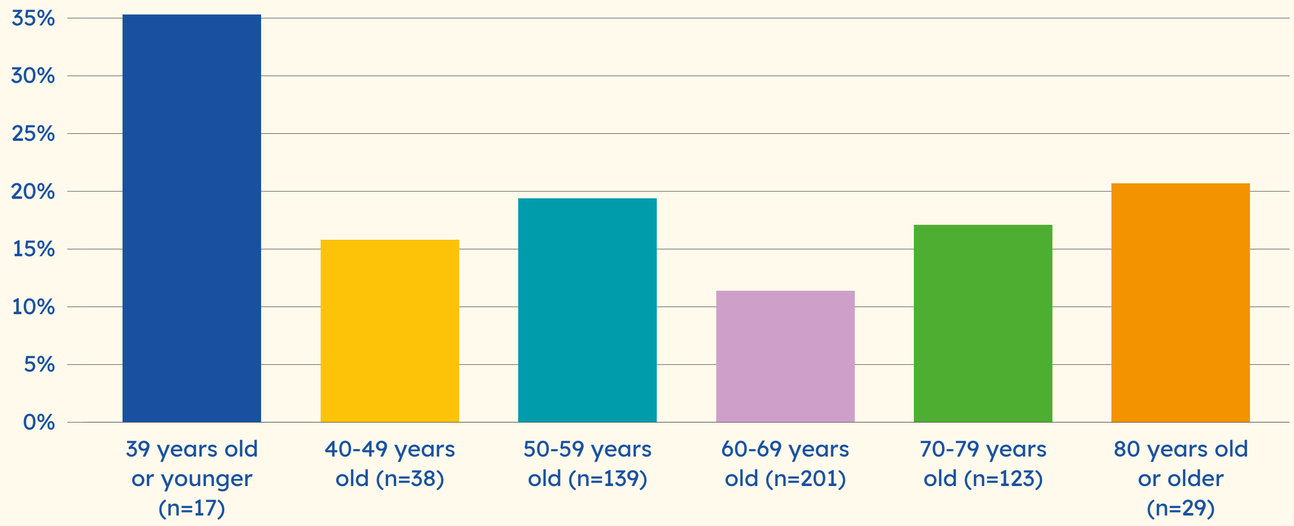

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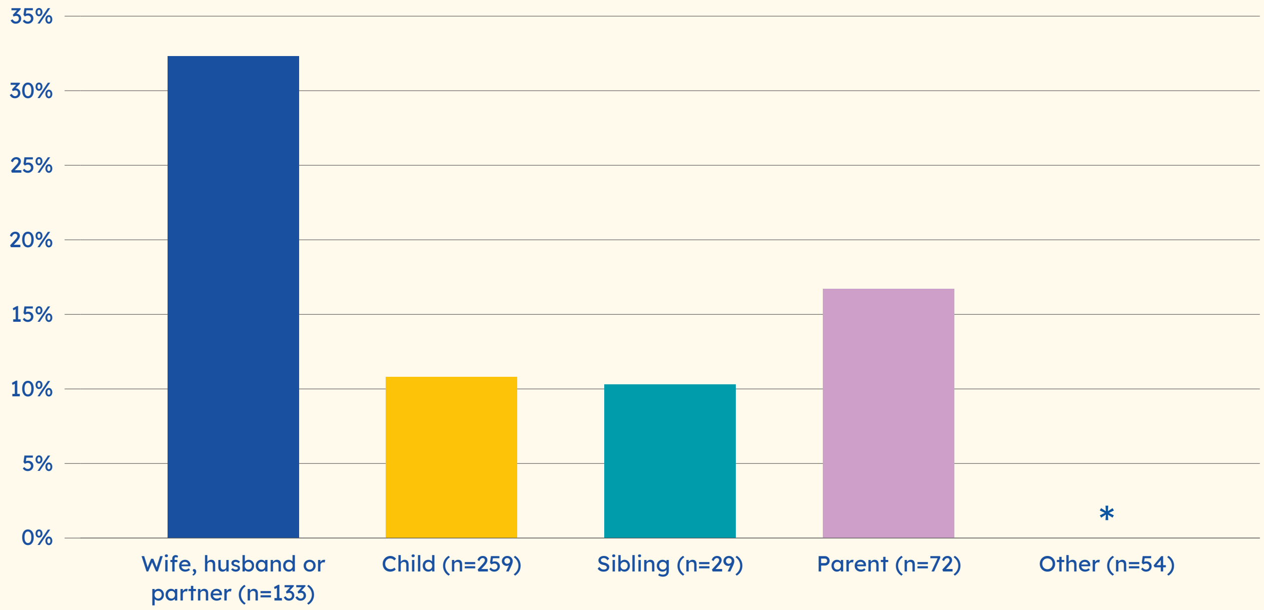
Figure 28. Prevalence of disturbed grief among respondents in Wales according to their relation to the person who died



Notes: * Small cell counts are suppressed.

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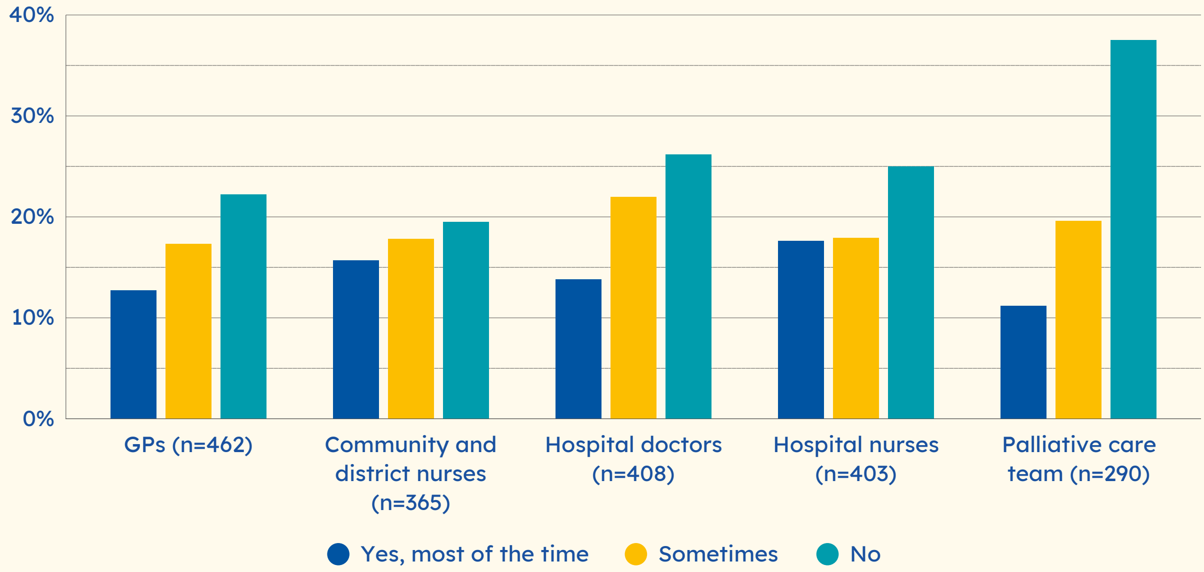
Figure 29. Prevalence of disturbed grief in Wales in relation to whether respondents felt that healthcare professionals listened and fully discussed with them and/or the person who died



Notes: Percentages are based on valid responses only, missing data for each item is excluded.

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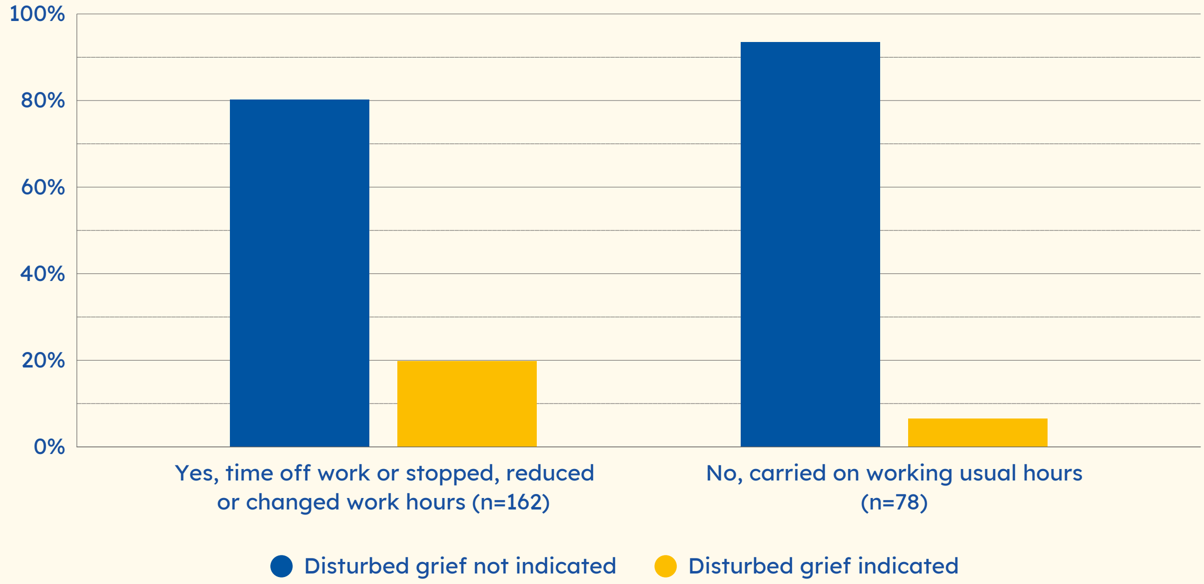
7.2 Contact with support services

Among Welsh respondents with Traumatic Grief Inventory scores that met the criteria for disturbed grief, 19 (21.3%) had accessed bereavement support, while 70 (78.7%) had not.

7.3 Impact on work in the three months after death

Figure 30. Difference in prevalence of disturbed grief between respondents in Wales who had time off work or stopped, reduced or changed their working hours in the three months after their relative's death, and those who carried on working normally



Notes: Percentages are based on valid responses only, missing data for each item is excluded.

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