Public attitudes to death, dying and bereavement in the UK re-visited: 2023 survey

Summary report, October 2024

SUPPORTED BY

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Further information

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Executive summary

Every year, over 600,000 people die in the UK,[1] leaving more than six million bereaved.[2] Over the next two decades, these numbers are expected to increase substantially due to our aging population and the rise in chronic and often complex health conditions.[3] It is a critical time for health and social care systems in the UK to adapt and prepare for this increase in demand and to tackle existing gaps and inequalities in access to palliative and end of life care. An estimated 90% of people who die in the UK each year are thought to need palliative care,[3] yet one in four die without receiving the care and support they need.[4]

To improve and grow the support available throughout the end of life and into bereavement, it is crucial to understand what care and support people want and need during these challenging times in their lives. Surveying public preferences, priorities and experiences as they relate to the end of life and bereavement can offer such key insights.

Marie Curie commissioned our first UK-wide survey to capture public attitudes to death, dying and bereavement in 2021 (PADDUK 2021).[5] This new report is based on a 2023 survey of 10,500 adults in the UK (PADDUK 2023), building on the findings from the first study to provide up-to-date insights and inform improvements to care and support at the end of life.

The research team at the Marie Curie Research Centre at Cardiff University worked closely with an advisory group to develop the new survey, re-visiting some of the topics surveyed in 2021 to provide up-to-date evidence and exploring several new topics of interest. The PADDUK 2023 survey assessed public views on the following:

- What matters most at the end of life – personal priorities and key needs.
- The perceived availability and adequacy of health and social care services for people nearing the end of life and their families.
- Talking about death and dying – as a society and on a personal level.
- Making plans for end of life care in advance of illness and dying.
- Seeking support after bereavement.
- The perceived support for bereaved children in educational settings.
- Grief education in schools as part of the curriculum.

A total of 10,500 adults living in the UK participated in the PADDUK 2023 survey, with a commercial research company (Opinium) commissioned to carry out data collection and ensure representativeness of the sample with regards to age, gender and UK region.

Key findings from the PADDUK 2023 survey

Being free of pain and other symptoms, able to maintain dignity and self-respect and having their loved ones' company are among people's top three personal priorities in their last year and final days of life. Effective pain relief and symptom control was people's most important priority, with this response selected the most for the last days of life (38%) and the last year of life (36%). This was closely followed by the need for dignity and self-respect at the end of life (36% for the final days and 31% for the last year of life), and wanting to be surrounded by their loved ones (29% for both the final days and last year of life). For the last days of life, being able to feel safe ranked third alongside loved ones' company (29%).

Key needs during people's final days include having their physical needs met, access to care whenever needed, and privacy. Support with physical needs was most commonly selected among people's priority needs at the end of life (54%), followed by timely access to care at all times (45%) and the need for privacy (43%).

Emotional support and being able to have a say in decision-making around one's care become key priorities at the end of life. People who considered themselves to be in the last years of life included their psychological support needs (eg related to feelings of worry, anxiety or depression) among their top three needs in their final days of life (41%). A third included being involved in the decision-making around their care among their top three priorities during their final days (33%) and their last year (33%) of life.

Home is the preferred place of death for many, but for some this preference may change with the experience of illness. Most people would prefer to die at home (56%). Among those who considered themselves in the last years of life due to illness, 42% also expressed a preference for dying at home. However, a fifth (20%) indicated that they would prefer to die in a hospice.

The public have mixed views on the availability and adequacy of health and social care services for dying people and their families. One in four people (24%) didn't think that there were adequate services available for people nearing the end of life and those close to them. One in seven (15%) didn't feel that care and support were readily available whenever needed or that family and friends of those dying had access to adequate support during the end of life and into bereavement.

The gap between feeling comfortable to talk about death and dying and actually having such conversations – a key finding from the PADDUK 2021 survey – remains. More than half (59%) felt that, as a society, we do not talk about death and dying enough. Around two-thirds indicated that they, on a personal level, would feel comfortable discussing topics related to the end of life. Nevertheless, only a minority had actually had any such conversations. One in seven people (14%) had talked to someone about their care wishes for the end of life. Even among people who considered themselves in the last years of life, only a third (31%) had discussed their wishes.

People primarily want to discuss end of life related topics with their families and friends rather than professionals. More than three-quarters of people indicated that they would prefer to talk about their treatment and care wishes at the end of life with their family and friends (78%). Less than half (45%) included their healthcare providers among the people they would prefer to discuss their wishes with.

People nearing the end of life are less likely to want to discuss end of life related topics with those closest to them. Among people who considered themselves in the last years of life, 63% preferred to talk to family and friends about their treatment and care wishes at the end of life. This compared to 78% across all survey respondents.

People generally agree that expressing their future healthcare preferences in advance of serious illness and dying is important. However, some hold views that may deter them from discussing their preferences. Four out of five people (82%) agreed that expressing care preferences is important. Nevertheless, 42% said that they could not anticipate what they would or would not want in the future. A further 42% did not feel the need to express their wishes as they trusted that their family and friends would help make the right decisions about their care. Over a third (38%) thought that expressing their preferences would not make a difference to their care as they doubted that healthcare providers would take their wishes into account.

Not everybody knows what to do and how to get support after a bereavement. A fifth of people (20%) indicated that they would not know what administrative and practical tasks need completing after somebody close to them dies. A fifth of people (19%) also said they would not know how to access support from bereavement services if they felt they needed formal grief support. One in eight people (12%) reported that they would feel uncomfortable about approaching bereavement services for help.

The support for bereaved children and young people in their educational settings is not always adequate. Up to a third of parents and guardians of bereaved children (30%) described their child's teachers and peers as being 'neither supportive nor unsupportive' or 'unsupportive' at the time of their child's bereavement.

Both the general public and parents are supportive of teaching children about bereavement and how to cope with grief as part of the school curriculum. Nearly half (45%) agreed with including age-appropriate grief education in the curriculum for older primary school children (eight years and older) while two-thirds (67%) supported this for secondary school children. Among parents and guardians, 54% were supportive of grief education for older primary school children and 72% were supportive of grief education for secondary school children.

Recommendations

Policy recommendations are made based on the key findings of the PADDUK 2023 survey, to improve support and care for dying people and those close to them throughout the end of life and into bereavement.

Access to care and support wherever people prefer to be cared for and die

Most respondents expressed their preference to die at home, but too often care and support is inadequate to enable this. The findings also highlight that many people would like to access hospice care at the end of life. To enable more people to receive the care they need in the place they prefer, the following actions are recommended:

- Health commissioners must ensure 24/7 access to palliative and end of life care, through a single point of access in every local area offering advice, guidance and support, to ensure people are able to die at home where this is their preference.
- Governments across the UK must act to improve 24/7 access to medicines, with more pharmacies stocking palliative medicines and more professionals trained to prescribe them in local communities, to enable people to die at home where this is their preference.
- All UK governments should deliver a new funding solution for palliative and end of life care, to end the postcode lottery in access and to ensure adequate access to palliative care to meet local need.

Mental health and wellbeing support for people living with terminal illness

Many respondents highlighted the importance of having emotional support needs addressed at the end of life, but mental health support is inadequate for too many people living with terminal illness. To address this, the following is needed in setting direction for mental health services:

- Governments across the UK must include the mental health and wellbeing support needs of people towards the end of life in mental health strategies and guidance.
- Key organisations responsible for providing health and social care guidelines such as the National Institute for Health and Care Excellence (NICE) for England, Wales and Northern Ireland and the Scottish Intercollegiate Guideline Network (SIGN) for Scotland should produce and consult on new guidelines for mental health support for people approaching the end of their life at the earliest opportunity.

Support and understanding for bereaved people

To improve support and understanding for bereaved people, including bereaved children and young people, the following actions are recommended:

- NICE and SIGN must develop guidelines for the delivery of bereavement support, which seek to normalise help-seeking and ensure that easy-to-access information on grief support is provided.
- Governments across the UK should require all schools and other education settings to provide age-appropriate opportunities for children and young people to learn about coping with death and bereavement as part of life, including by ensuring that grief education is a mandatory part of the curriculum in each nation.

Care and support planning in advance of illness and dying

It is concerning that such a high proportion of respondents felt that their willingness to plan for their end of life care needs was undermined by a belief that expressing their wishes would not make a difference to the care that they receive. To address this and ensure that people’s end of life needs and preferences are central to the care they receive, the following steps are needed:

- Governments across the UK should ensure that every individual reaching the end of their life has a legal right to personalised care and support planning, with these plans being shared so they are accessible to all health and social care professionals at the point of care.
- Health commissioners should ensure that they consistently involve people with direct experience of dying, death and bereavement in co-designing local palliative and end of life care services.

1. Introduction

DYING, death and bereavement affect every one of us. Over 600,000 people die in the UK every year,[1] leaving over six million people bereaved.[2] With so many people affected, it is vital that we seek to achieve the best possible end of life experience for everyone. It is also important that we survey public attitudes to capture crucial insights into people's preferences, priorities and experiences which can then inform improvements to support for people at the end of life.

This is all the more pressing as demand for palliative care is high and growing.[3] It is estimated that 90% of people who die in the UK each year need palliative care,[3] but that one in four people do not receive it.[4] Our ageing population and the rise of complex, comorbid, chronic conditions mean that these are likely underestimations of need and unmet need, and inequalities in access to care are common. In this context, it is particularly important to think about the support people want and need at the end of life and following a bereavement, so that we can ensure the necessary resources are available for all who need them.

In 2021, Marie Curie commissioned our first national survey to assess public attitudes to dying, death and bereavement in the UK (PADDUK 2021).[5] The survey was carried out during the Covid-19 pandemic when mortality was very much at the forefront of people's minds.

This new report is based on a 2023 survey of 10,500 adults across all four UK nations (PADDUK 2023) and further builds on the findings from the first study. It both updates our previous findings and explores new areas, including: barriers to expressing future healthcare preferences in advance of serious illness; coping with practical tasks;

reaching out for support after bereavement; and grief education in schools.

The survey findings raise important challenges for resource allocation and practice improvement. People told us that conversations about death and dying rarely happen, despite many people feeling comfortable discussing these topics. A principal reason for this is a belief that their wishes wouldn't be acted on. There is a consistent and pressing need for more open conversations about the end of life, and for health and social care providers to ensure that advance care plans are not only completed, but that they are also listened to and followed.

People also identified psychological support as a key priority near the end of life. The mental health implications of dying, death and bereavement cannot be overlooked, and urgent improvements are needed in psychological support services for people at the end of life.

Overall, it is clear that joined up health and social care is essential to meeting the end of life care needs and priorities of the UK public.

We can only respond effectively to people's needs and preferences at the end of life if we listen carefully to what matters to them. Regular public attitude surveys such as this help with this task, and, in doing so, must play a crucial role in informing change in policy and practice to better support people at the end of life.

2. Survey methodology

Survey development and data collection

We worked closely with our advisory group (comprising clinical and academic experts and a public contributor) to refine the existing PADDUK 2021 question set[5] for use in the PADDUK 2023 survey. Some PADDUK 2021 questions were revised, while others were replaced with questions to capture public views on new key topics of interest.

A commercial research company (Opinium) was commissioned to carry out all aspects of the survey administration, from invitation to participate, to data collection and anonymisation. Adults aged 18 years and over, and living in the UK were eligible to participate. Data was weighted to ensure representativeness of the sample for age, gender and UK region.

In total, 10,500 UK adults from across the UK completed the survey: 8,561 from England (82%), 1,076 from Scotland (10%), 489 from Wales (5%) and 374 from Northern Ireland (4%).

Most respondents (59%; n=6,200/10,500) described themselves as members of the public with an interest in the survey topic when asked to indicate their personal circumstances. Over a fifth (22%; n=2,281/10,500) reported that they had personal experience of end of life and/or bereavement due to illness:*

- 5% of respondents considered themselves to be in the last few years of their life due to progressive and potentially life-shortening illness (n=497).

- 10% indicated that they were a caregiver/family member/partner/spouse/friend to somebody considered to be in their last few years of life (n=1,027).
- 12% had experienced the loss of a person close to them due to long-term illness in the previous 5 years (n=1,244).

Data analysis

'Yes/No' answers and 5-point Likert-type scales (from 'strongly disagree' to 'strongly agree' or 'very unimportant' to 'very important') were used to answer the questions. Some open-ended questions were included to elicit free-text comments.

Descriptive analyses were carried out across all variables using IBM SPSS Statistics v29.0. Rating scale responses were grouped, for example combining 'strongly disagree' and 'disagree' into 'disagree', and 'strongly agree' and 'agree' into 'agree'. Frequencies and proportions, alongside some bar and pie charts, are presented in the main body of this report. Cross tabulations were used to look at associations across respondents'

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* Survey respondents were free to select more than one response option when describing their personal circumstances.

personal circumstances and categorical data. Extracts of text taken from the free text responses in the survey are used to illustrate and support the quantitative survey findings.

Public involvement

Public contributors were engaged throughout the development of the PADDUK 2021 question set, and in refining the survey for use in 2023.

Informed consent and confidentiality

Survey respondents gave written informed consent to participate prior to starting the survey. The pre-survey information clearly stated that participation was voluntary. It outlined the risks and benefits of taking part, including those associated with the sensitive survey topic area, with signposting to support services if needed. Information on confidentiality, data protection and data usage in line with Opinium's terms and conditions and privacy policy was provided. Specific mention of the sharing of anonymised data for research purposes was made along with information on how to withdraw. Respondents were neither able to skip questions, nor to complete the survey more than once.

Ethical approval and data sharing governance

The survey was given approval by Cardiff University's School of Medicine Research Ethics Committee (SMREC23/76). A data transfer agreement governed the sharing of the anonymised data between Opinium and the research team at the Marie Curie Research Centre at Cardiff University (DSA 263299149).

Limitations

Since this survey was administered by a commercial research company, respondents received a small financial reward in exchange for their participation.

Representativeness of the population is limited to age, gender and UK region.

3. Comparing the findings from PADDUK 2023 and PADDUK 2021

THE PADDUK 2023 survey re-visited a range of topics also included in the PADDUK 2021[5] survey to explore whether there have been any major changes with regards to:

- What matters most to people at the end of life: key priorities and needs during the final days and the last year of life (chapter four).
- Views on the availability and adequacy of health and social care services for people nearing the end of life (chapter five).
- Attitudes towards talking about death and dying: as a society and on a personal level (chapter six).

In response to feedback from our advisory group, we made some refinements to the 2021 questions such as clarifying the wording of questions, adding/merging/removing response options, and making response formats more consistent to make the survey more user-friendly. We were therefore not able to make direct comparisons between the 2021 and 2023 data. Nevertheless, when presenting the new PADDUK 2023 data on re-visited topics in chapters four to six, we have included some references to PADDUK 2021 topline findings where appropriate.

Chapters seven to nine report findings on the following new PADDUK survey topics:

- Barriers to expressing future healthcare preferences in advance of serious illness and dying (chapter seven).
- Views on coping with practical tasks and reaching out for support after bereavement (chapter eight).
- Views on grief education in schools, including parent perceptions of support for bereaved children and young people in educational settings (chapter nine).

Chapter ten concludes the report with some comparisons across the four devolved nations in the UK.

4. What matters most at the end of life: key needs, priorities and preferred place of death

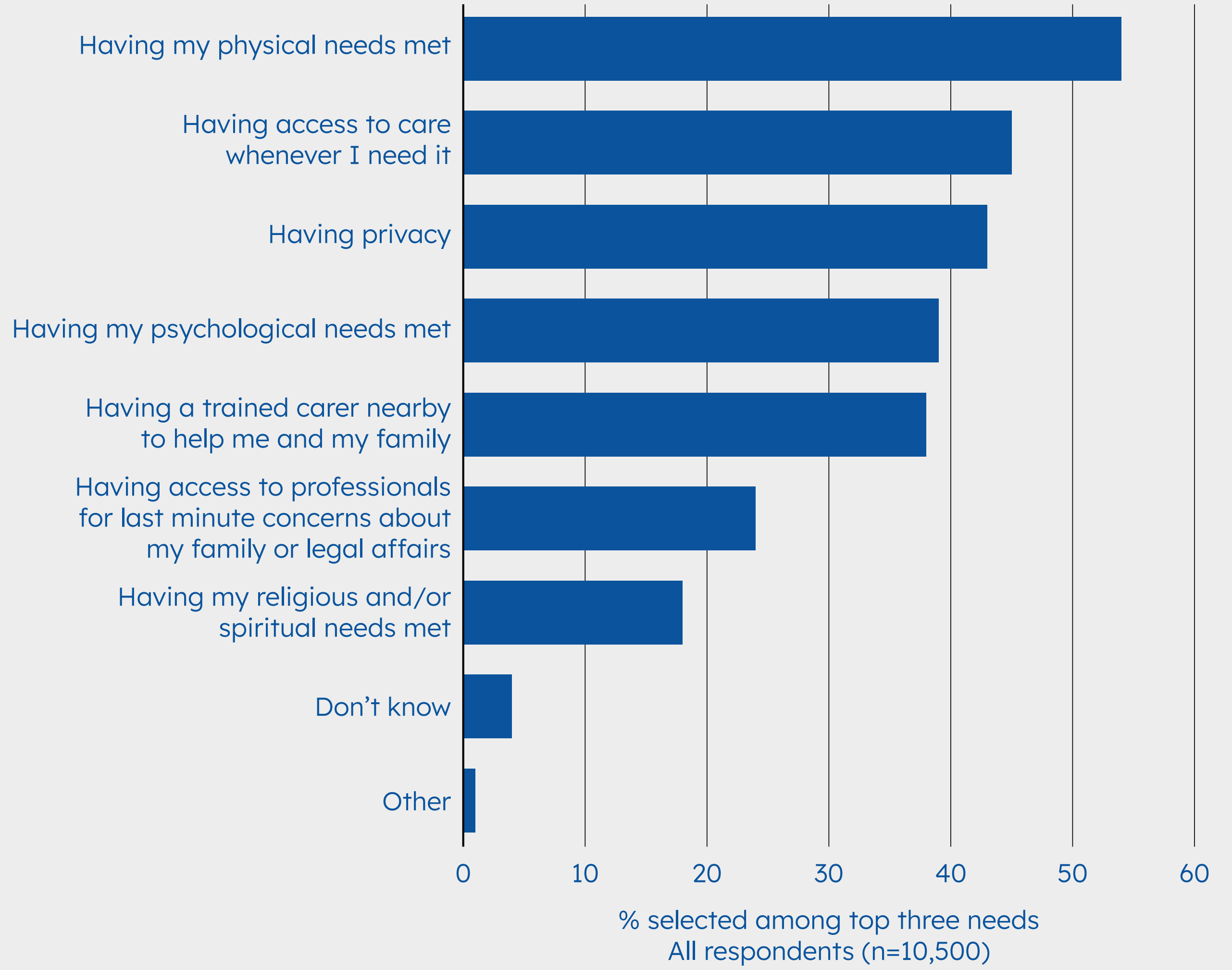
To capture what matters to people at the end of life, survey respondents were asked to select their three most important needs, as well as their three most important personal priorities, during their final days and their last year of life.

Having physical needs met, access to care whenever needed, and privacy are the most important needs in people's final days

The response options given to respondents in the PADDUK 2023 survey were revised

Fig. 1: Key needs during the final days of life

Please select the three most important needs you would like to be managed during your final days of life



from the PADDUK 2021 options to reflect physical, psychological and spiritual/religious needs as distinct, separate domains of need. The **top three ranked needs** people would like to have managed during their **final days of life** were (see Fig. 1):

1. Having physical needs met (54%; n=5,626).
2. Having access to care whenever it is needed, including out of hours and in emergencies (45%; n=4,706).
3. Having privacy (43%; n=4,507).

Support with psychological needs is considered of greater importance by those with personal experience of death, dying and bereavement

Across all UK respondents, receiving support with emotional needs, such as feeling worried, depressed or anxious during the final days of life ranked fourth (see Fig. 1). However, among respondents who considered themselves in the last years of life, this ranked second among their top three needs, which were:

1. Having physical needs met (54%; n=266/497).
2. Having psychological needs met (41%; n=205/497).
3. Having privacy (37%; n=185/497).

Similarly, 47% of respondents who were a current family member/friend of somebody in the last years of life (n=486/1,027) and 46% of respondents who had lost a person close to them to illness in recent years (n=567/1,244) also considered support with psychological needs among their top three needs during the final days of life.

> “People need help as soon as possible to either discuss how you are dealing with it or want someone to talk or let your feelings out.”

> “Support with anxiety around death and what will happen next. The fear of the unknown is very scary.”

This highlights the importance of identifying and addressing emotional support needs that people nearing the end of life and their families and friends may have when it comes to dealing with the often profoundly complex and deeply personal emotions that may arise when faced with the end of life.

Being symptom-free, able to maintain dignity and self-respect and having their loved ones’ company remain people’s top personal priorities at the end of life

The personal priorities most selected among people’s top three priorities for both the final days of life and the last year of life remained the same as those reported in the 2021 survey (see Fig. 2).

Respondents’ **top three priorities** for their **final days of life** in 2023 were:

1. Being free of pain and other symptoms (38%; n=4,006).

Fig. 2: Key personal priorities during the final days and the last year of life

2. Being able to maintain dignity and self-respect (36%; n=3,795).
3. Being surrounded by loved ones (29%; n=3,049), ranking a joint third with 'feeling safe' (also 29%; n=3,072).

Respondents' **top three priorities** for their **last year of life** in 2023 were:

1. Being free of pain and other symptoms (36%; n=3,756).
2. Being able to maintain dignity and self-respect (31%; n=3,253).
3. Being surrounded by loved ones (29%; n=2,988).

Being able to participate in decision-making around care is among the top three priorities of those considering themselves in the last years of life

Among respondents who considered themselves to be in the last years of life due to illness, the **top three personal priorities** during their **final days of life** included being able to be part of the decision-making about their care (see Table 1):

1. Being able to maintain dignity and self-respect (34%; n=167/497).

Table 1: Key personal priorities during the final days of life across all respondents and for respondents in the last years of life.*

	Final days of life			
	Respondents who consider themselves in the last years of life (n=497)		**All respondents (n=10,500)**	
	n	**%**	**n**	**%**
Being able to maintain my dignity and self-respect	167	**34%**	3795	**36%**
Being involved in decisions about my care	165	**33%**	2687	26%
Being free of pain and other symptoms	154	**31%**	4006	**38%**
If I were not able to decide, being able to involve my family or person I trust to make decisions about my care	152	31%	2340	22%
Being at my home	114	23%	2431	23%
Feeling safe	98	20%	3072	**29%**
Having support with practical and/or financial issues	93	19%	1351	13%
Being surrounded by my loved ones	85	17%	3049	29%
Being in a calm and peaceful atmosphere	85	17%	2426	23%
Having support with my psychological wellbeing	67	13%	967	9%
Being surrounded by my personal things/pet	51	10%	882	8%
Being in my familiar surroundings	45	9%	1341	13%
Being surrounded by other people who are going through the same thing, to talk to and provide support	41	8%	411	4%
Don't know	10	2%	333	3%

* Priorities are ranked by '% selected among top three priorities' for respondents in the last years of life. The three most frequently selected priorities are highlighted in bold for both groups of respondents.

Table 2: Key personal priorities during the last year of life across all respondents and for respondents in the last years of life.*

	Last year of life			
	Respondents who consider themselves in the last years of life (n=497)		All respondents (n=10,500)	
	n	%	n	%
Being involved in decisions about my care	162	**33%**	2788	27%
Being free of pain and other symptoms	161	**32%**	3756	**36%**
Being able to maintain my dignity and self-respect	148	**30%**	3253	**31%**
If I were not able to decide, being able to involve my family or person I trust to make decisions about my care	133	27%	1980	19%
Being at my home	130	26%	2955	28%
Feeling safe	117	24%	2749	26%
Being surrounded by my loved ones	89	18%	2988	**29%**
Having support with practical and/or financial issues	82	17%	1621	15%
Having support with my psychological wellbeing	76	15%	1382	13%
Being in a calm and peaceful atmosphere	66	13%	2052	20%
Being in my familiar surroundings	57	12%	1553	15%
Being surrounded by other people who are going through the same thing, to talk to and provide support	53	11%	540	5%
Being surrounded by my personal things/pet	42	9%	1058	10%
Don't know	9	2%	382	4%

* Priorities are ranked by '% selected among top three priorities' for respondents in the last years of life. The three most frequently selected priorities are highlighted in bold for both groups of respondents.

2. Being involved in decisions about care (33%; n=165/497).
3. Being free of pain and other symptoms (31%; n=154/497).

During the **last year of life**, being involved in decision-making was also among the **top three priorities** of those in the **last years of life** (see Table 2):

1. Being involved in decisions about care (33%; n=162/497).
2. Being free of pain and other symptoms (32%; 161/497).
3. Being able to maintain dignity and self-respect (30%; 148/497).

This highlights that being listened to and able to have a say about their care matters greatly to dying people, so that they receive care and support that align with their values, preferences and goals at the end of life.

Dying at home is a preference for many

When asked where they would prefer to die, more than half of all UK respondents (56%; n=5,865) chose 'at home' (see Fig. 3). Just under a quarter (22%; n=2,278) indicated that they did not have a preference. A minority said they would prefer to die in a hospice (8%; n=872), hospital (6%; n=637) or care home (3%; n=317). Respondents' free text responses often expressed that their preferred place of death would depend on their needs for care at the time.

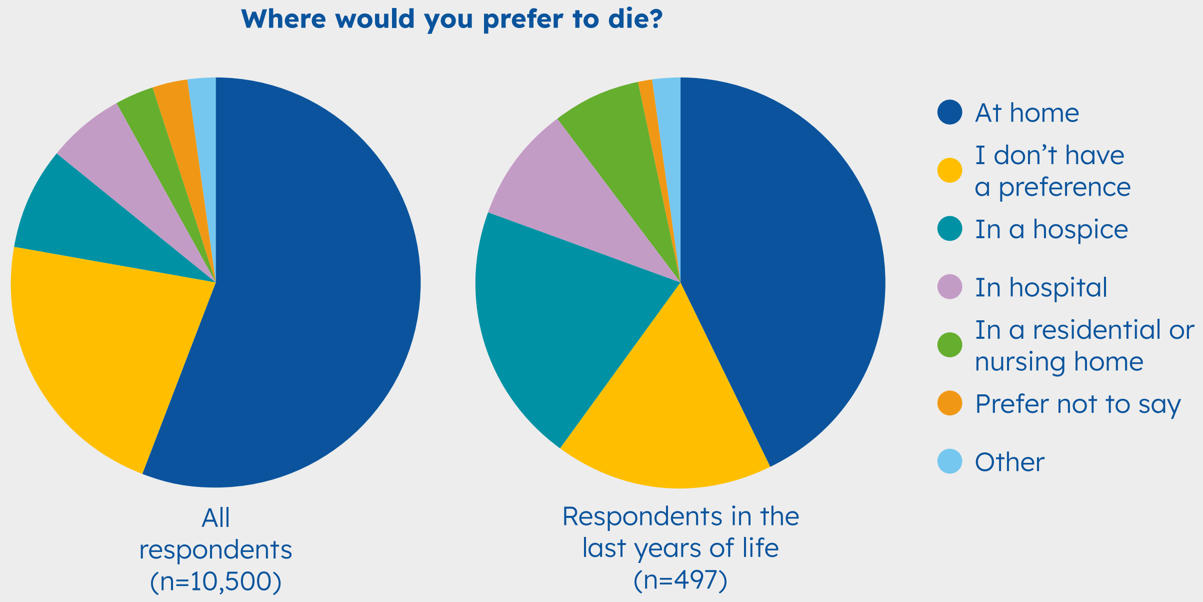
> "At the moment I am undecided. It depends on the circumstances when that time arrives."

> "It would depend on the circumstances. If medical care would be needed then medical facility, if cancer then hospice. But ideally at home."

Where people prefer to die may change with the experience of illness

Among those in their last years of life due to illness, 'home' remained the most preferred place of death, selected by 42% (n=211/497), compared to 56% in the overall sample (see Fig. 3). There was an increased preference for dying in a hospice

Fig. 3: Preferred place of death



among respondents in the last years of life, with one in five (20%; n=100/497) selecting ‘hospice’ as their preferred place of death, as compared to 8% in the overall sample.

Quality of life remains more important to people than length of life when seriously ill

Most respondents (83%; n=8,696) agreed that if they were severely ill with no hope of recovery, their quality of life would be more important to them than their length of life, compared to 77% in the PADDUK 2021 survey.

Respondents with personal experience of end of life and bereavement shared this view in similar proportions: 85% of respondents in the last years of life (n=423/497), 86% of respondents who were a current family member/friend of somebody in the last years of life (n=884/1,027) and 88% of respondents (n=1,090/1,244) who had lost a person close to them to illness in recent years agreed that quality of life would be more important to them in this situation.

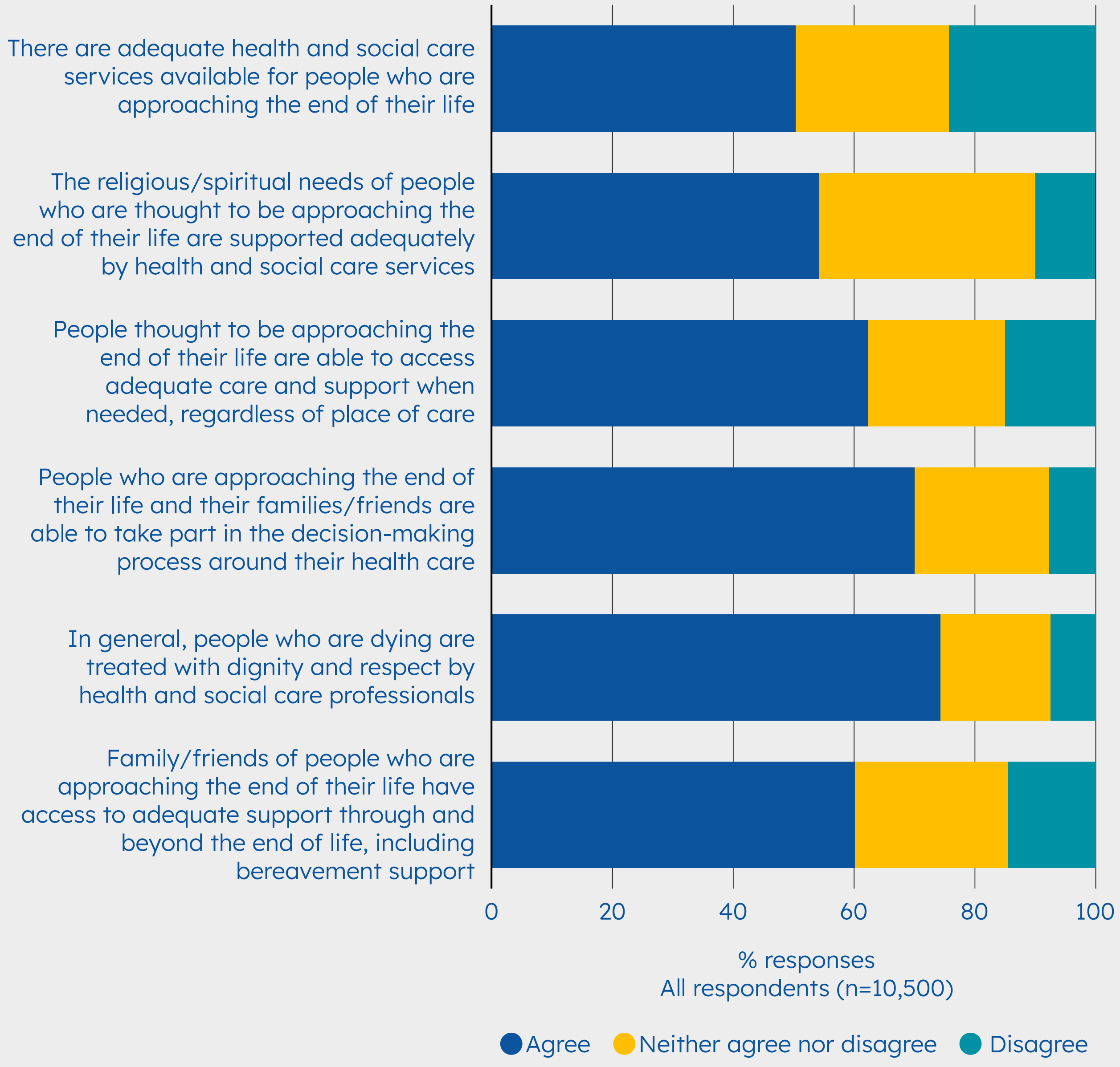
5. Views on health and social care services available to people nearing the end of life

Views on the availability and adequacy of health and social care services for people approaching the end of life are mixed

Public perceptions of the health and social care services responsible for supporting and caring for people at the end of life varied when it came to both the general availability of services and their adequacy in meeting people’s needs. While some respondents

Fig. 4: Views on health and social care services for people nearing the end of life and their families and friends

To what extent do you agree or disagree with the following statements about support and care from services at the end of life?



viewed services positively (see Fig. 4), others expressed more negative views, such as:

- One in four respondents (24%; n=2,555) did not think that there are adequate health and social care services available for people nearing the end of their life.
- One in seven respondents (15%; n=1,570) did not think that care and support are readily available whenever people approaching the end of life need it.
- Similarly, one in seven respondents (15%; n=1,525) did not think that the family and friends of people who are dying have access to adequate support during the end of life and after bereavement.
- One in ten respondents (10%; n=1,044) did not think that services are sufficiently meeting dying people's religious/spiritual needs.

Most respondents in the last years of life and respondents who identified as a current family member/friend to somebody in the last years of life perceived services as available and adequate (see Fig. 5).

However, not all held positive views:

- 18% of respondents in the last years of life (n=89/497) and 20% of respondents who were a current family member/friend of somebody in the last years of life (n=209/1,027) did not think that adequate health and social care services are available for dying people.
- 10% of respondents in the last years of life (n=49/497) and 12% of respondents who were a current family member/friend of somebody in the last years of life (n=124/1,027) did not think that care and support are always accessible to dying people when needed.
- Similarly, 10% of respondents in the last years of life (n=52/497) and 12% of respondents who were a current family member/friend of somebody in the last years of life (n=123/1,027) did not feel that family members/friends of dying people have access to adequate support during the person's end of life and into bereavement.
- 7% of respondents in the last years of life (n=36/497) and 9% of respondents who were a current family member/friend of somebody in the last years of life (n=91/1,027) did not think that services adequately support dying people's spiritual/religious needs.

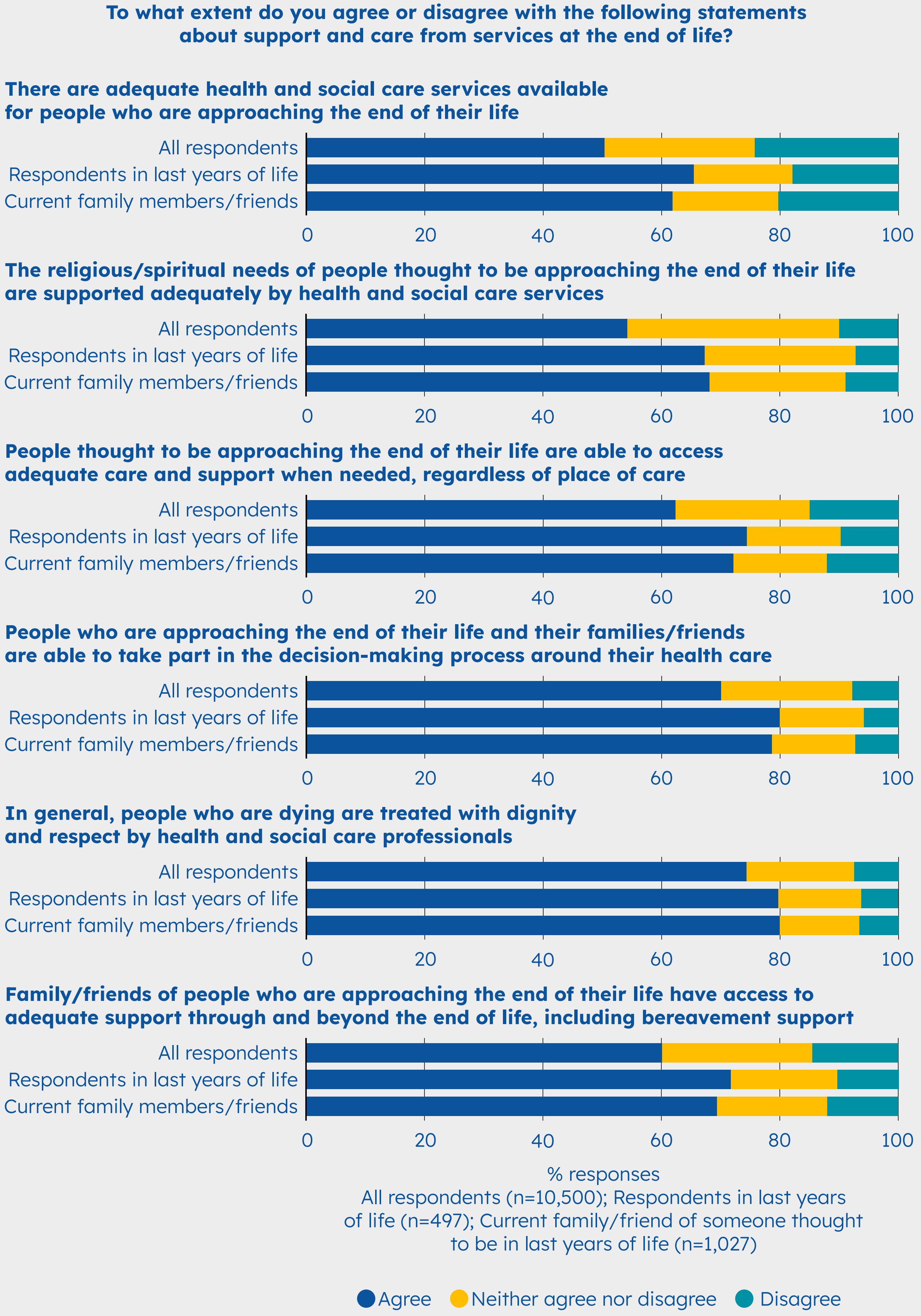
Most people think that end of life care services treat dying people with dignity and respect

Perceptions of how health and social care professionals interact with dying people were generally positive. Nearly three-quarters of respondents agreed that professionals tend to treat dying people and their families with dignity and respect (74%; n=7,798) and involve them in care decisions (70%; n=7,352), (see Fig. 4).

Nevertheless, some respondents were more critical of how professionals interact with the dying people in their care:

- One in twelve respondents (8%; n=791) did not think that people who are dying are treated with dignity and respect by the professionals who care for them.
- Similarly, one in twelve respondents (8%; n=818) did not think that people nearing the end of life and their families/friends are able to participate in the decision-making around their healthcare.

Fig. 5: Views on health and social care services for people nearing the end of life across all respondents, respondents who consider themselves to be in the last years of life and respondents who are a current family member/friend of someone thought to be in the last years of life



> **"… that the person who is terminally ill has their voice and wishes heard and is treated as a valued human being and not a 24/7 patient."**

There was a similar pattern of responses among those who had current personal experience of end of life, with most perceiving health and social care professionals positively (see Fig. 5):

- 80% of respondents in the last years of life (n=396/497) and 80% of respondents who were a current family member/ friend of somebody in the last years of life (n=821/1,027) thought that health and social care professionals treat dying people and their families with dignity and respect.
- 80% of respondents in the last years of life (n=397/497) and 79% of respondents who were a current family member/ friend of somebody in the last years of life (n=807/1,027) felt that professionals involve those nearing the end of life and their families in care decisions.

Some, however, viewed health and social care professionals more negatively in this context:

- 6% of respondents in the last years of life (n=31/497) and 7% of respondents who were a current family member/ friend of somebody in the last years of life (n=68/1,027) did not think that dying people are treated with dignity and respect.
- 6% among respondents in the last years of life (n=30/497) and 7% of respondents who were a current family member/ friend of somebody in the last years of life (n=75/1,027) did not feel that people nearing the end of life and their families/ friends are able to participate in the decision-making around their healthcare.

6. Talking about death and dying

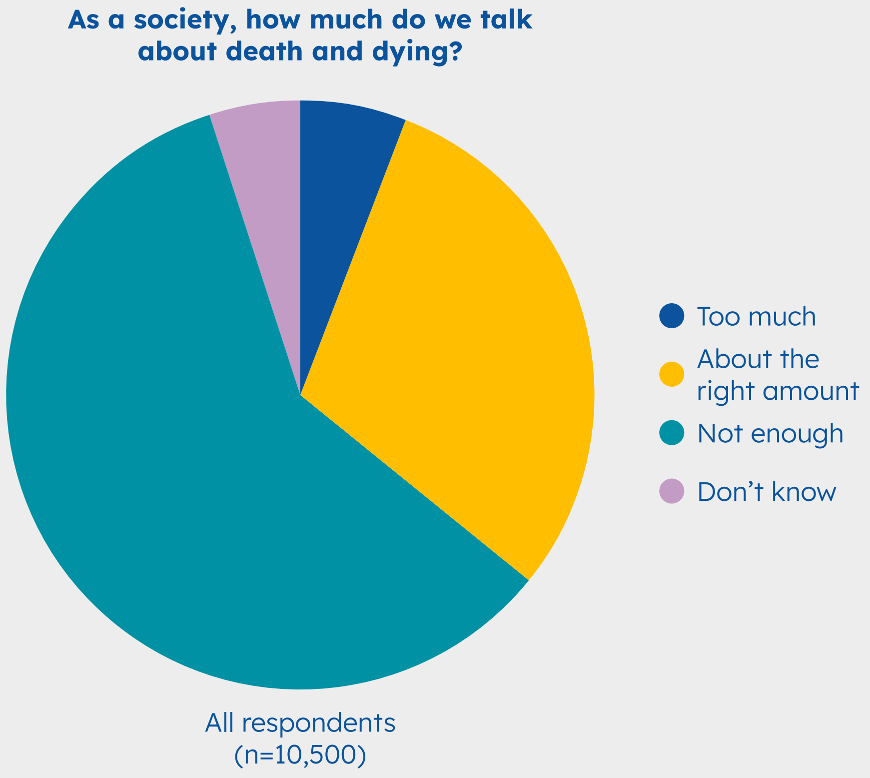
Many think that, as a society, we do not talk about death and dying enough but express that they personally would feel comfortable having such discussions

Across all UK respondents, 59% (n=6,218) felt that, as a society, we do not talk about death and dying enough (see Fig. 6), compared with 51% who expressed this view in our 2021 survey.

> "Death is still seen as a taboo… but it's important for the person and their family/friends to discuss hopes, fears, wishes … it could be a less traumatic situation… if discussed more freely."

> "People need to talk more about death. I am able to talk about it but my family will not discuss it… Cancer was rarely spoken about years ago but now people openly discuss it. Death should be the same."

Fig. 6: Views on how much death and dying are talked about in society

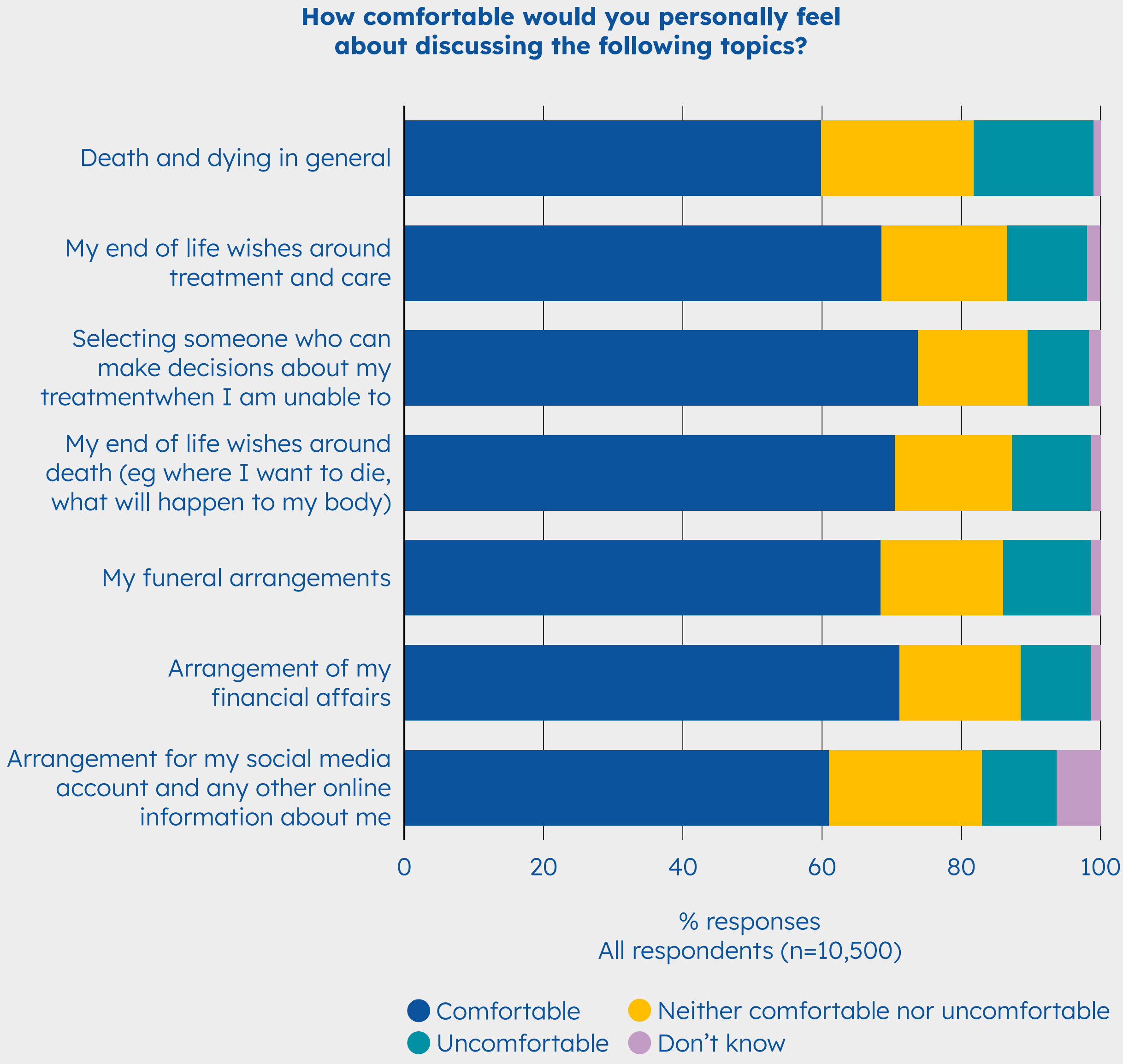


Most people indicated that they personally would feel comfortable discussing a range of different topics related to death and dying (see Fig 7). The topics respondents felt most comfortable talking about included:

- Selecting a person who can make decisions about their care if they were unable to (74%; n=7,742).
- Arrangements for their financial affairs (71%; n=7,464).
- End of life wishes around death (eg where they would like to die or what they would like to happen to their body after their death), (70%; n=7,397).

These findings may challenge the common perception of there being a "taboo" around discussing issues of death and dying. Most people say they are comfortable talking about these topics. Yet the fact that most people think that we don't talk enough about these issues suggests that there is a need for further exploration of why we don't discuss death and dying more in society. This is further explored in chapter seven.

Fig. 7: Levels of personal comfort talking about different topics related to death and dying



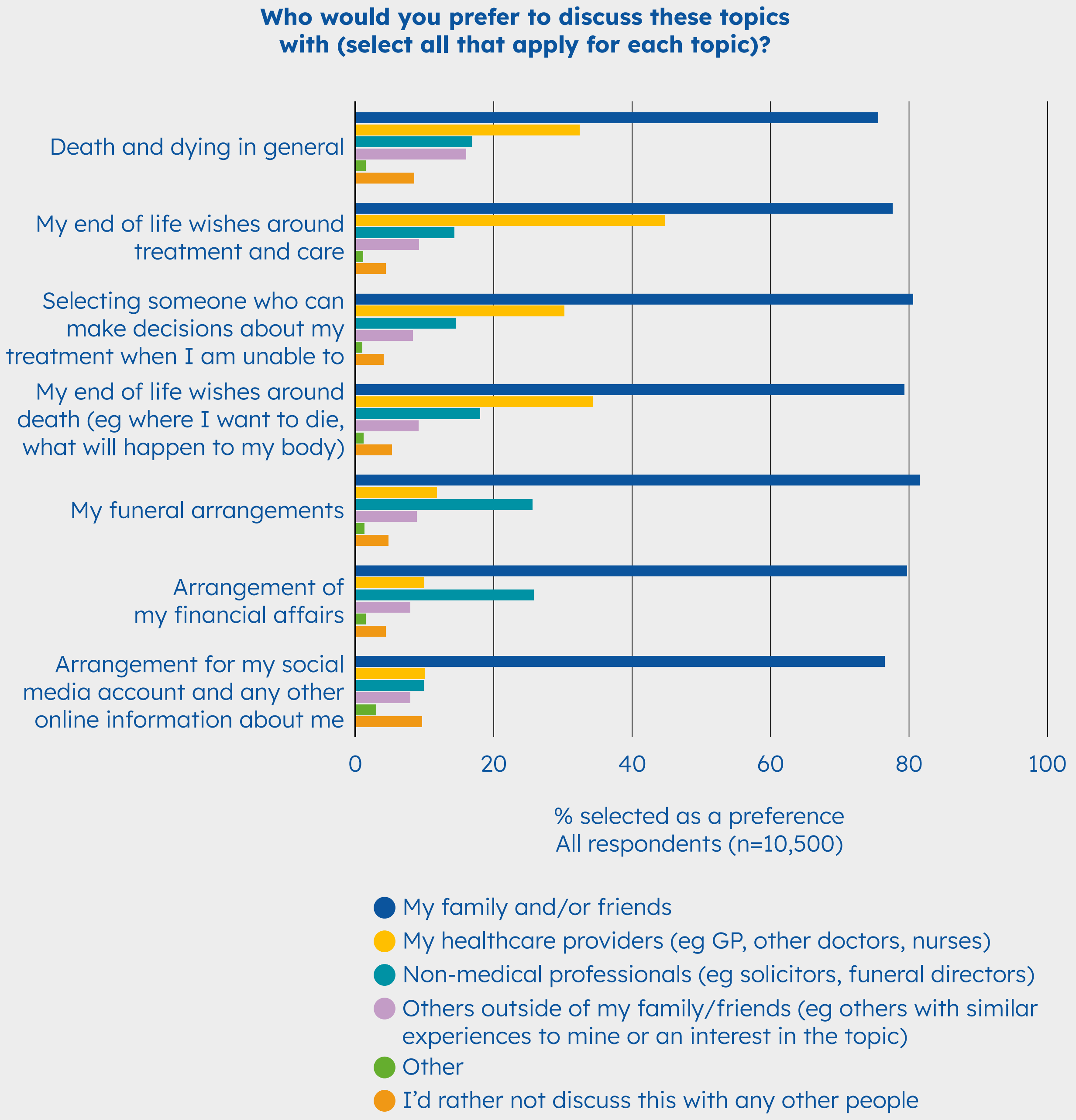
Most people would prefer to have conversations related to death and dying with family and friends

When asked who they would prefer to discuss these topics with, most respondents indicated that they would prefer to talk to family and friends. This ranged from 82% for funeral arrangements (n=8,558), to 76% (n=7,928) for conversations about death and dying in general (see Fig. 8).

For some topics, respondents also considered conversations with their healthcare providers:

- 45% (n=4,695) would prefer to discuss their end of life wishes around treatment and care with their healthcare providers.
- 34% (n=3,602) would like to talk to their healthcare providers about their end of life wishes around death.
- 32% (n=3,406) would like to talk to their healthcare providers about death and dying in general.

Fig. 8: Preferences for who to discuss different death and dying-related topics with



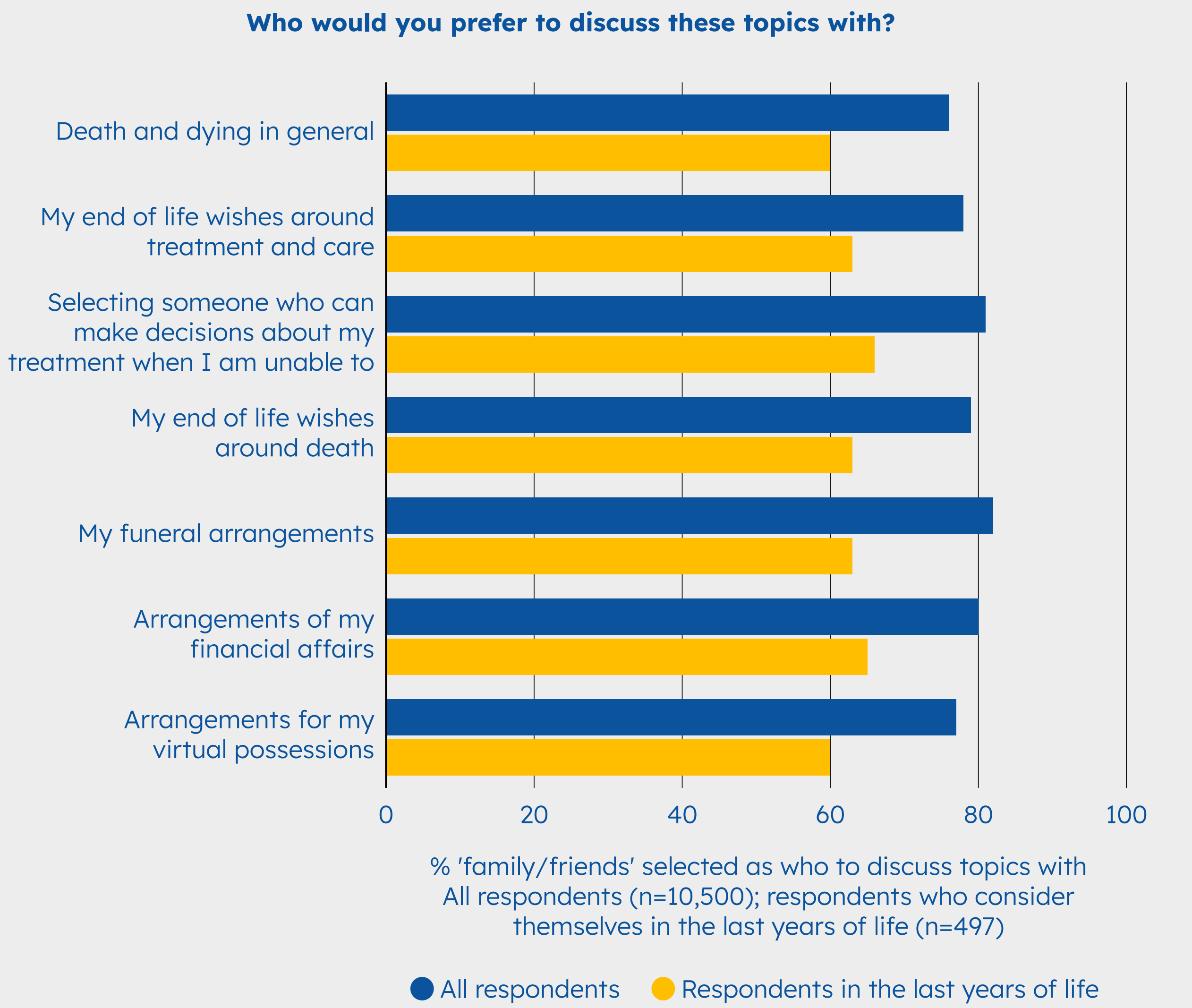
- 30% (n=3,167) would like to talk to their healthcare providers about selecting somebody to make treatment decisions on their behalf.

A quarter of respondents indicated that they would prefer to discuss funerals (26%; n=2,691) and financial affairs (26%; n=2,709) with non-medical professionals such as funeral directors or solicitors. Talking about death and dying-related topics with non-professionals outside of their own social circle, such as with people with similar experiences to theirs or a general interest in the topic, was rarely considered.

Those approaching the end of their life appear more hesitant to discuss death and dying with their family and friends

Compared to the overall sample, respondents who considered themselves to be in the last years of life were less likely to choose 'family and friends' among the people they would prefer to discuss death and dying-related topics with (see Fig. 9). In particular, 63% of those in the last years of life (n=313/497) selected 'friends and family' for discussions about their funeral arrangements, as compared to 82% among all survey respondents (n=8,558/10,500).

Fig. 9: Preference to discuss different death and dying-related topics with family and friends across all respondents and respondents who consider themselves to be in the last years of life



This trend was present across the range of different topics (see Fig. 9) and may point to the difficulty of engaging in such conversations with those most directly and personally affected.

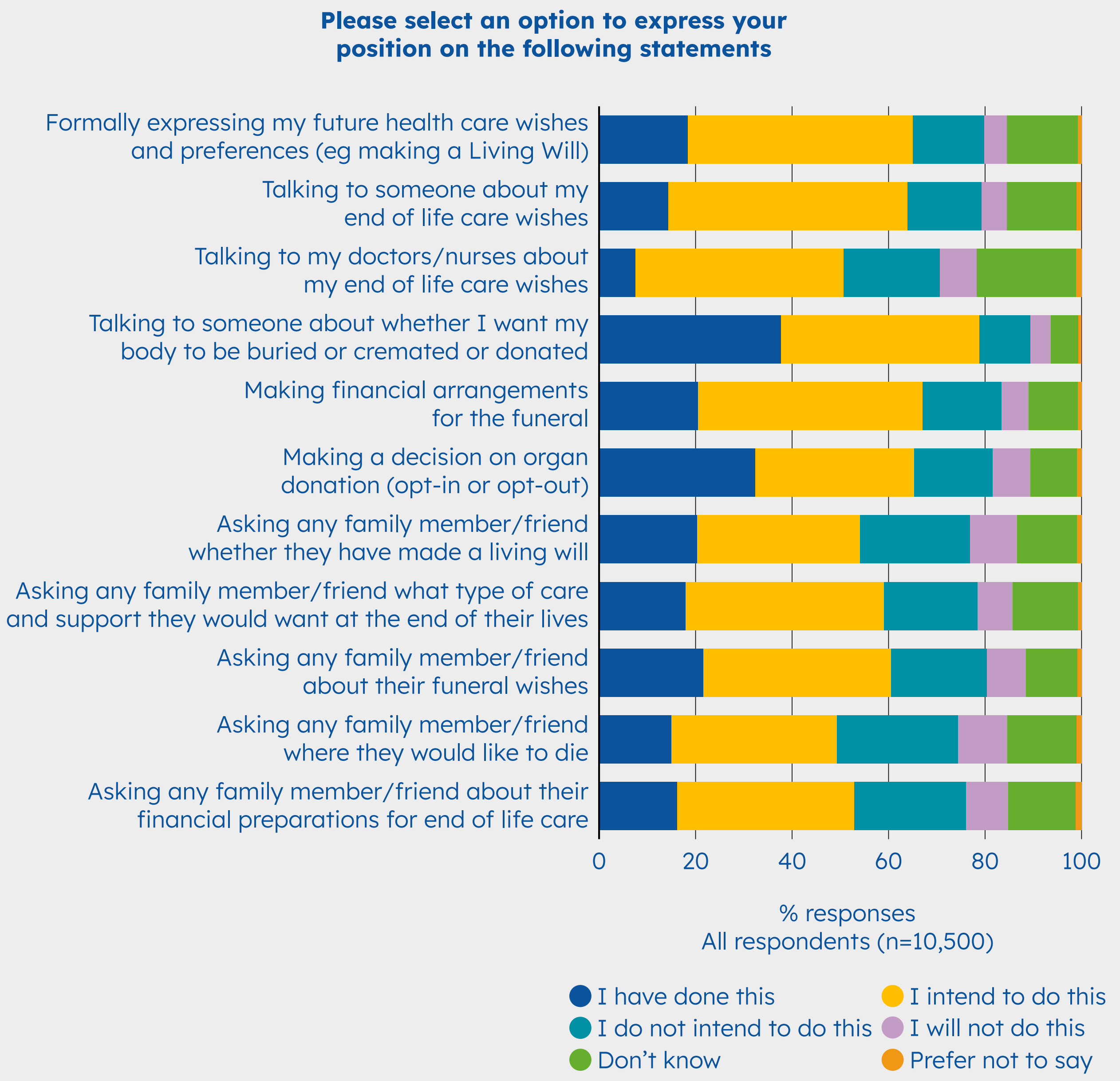
> “Friends and family do not feel comfortable speaking about death with a loved one who is facing this... They say they don’t want to think about their loved one dying... This is hard for those dying who do want to talk.”

Most have not actually had any conversations about death and dying or made any plans for the end of their life

While most respondents indicated that they would feel comfortable talking about death and dying-related topics, preferably with family and friends (see Fig. 8), only a minority of respondents actually had any such conversations or made any formal plans for the end of their life (see Fig. 10), for example:

- 14% had talked to somebody about their end of life care wishes (n=1,500).

Fig. 10: Actions taken towards discussing and making plans for the end of life and dying



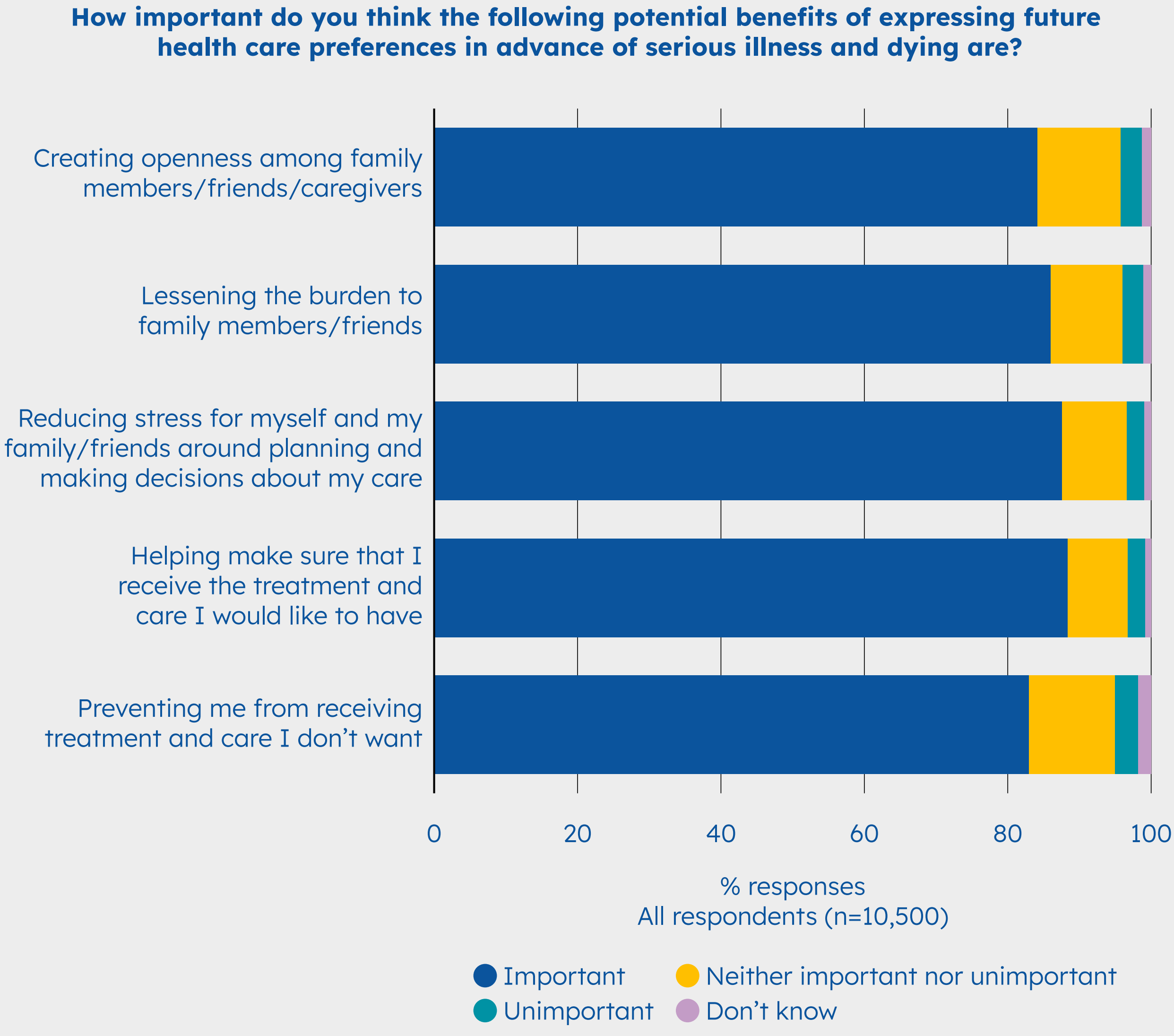
- 7% had discussed their end of life care wishes with their healthcare providers (n=782).
- 18% had asked a family member/friend about the care support they would want at the end of life (n=1,876).

Respondents who considered themselves in the last years of life were more likely to have talked about and made plans for their end of life. Nevertheless, only around a third had discussed their end of life care wishes with somebody (31%; n=154/497), formally documented their preferences, for example in the form of a Living Will (29%; n=142/497), or made financial arrangements for their funeral (33%; n=165/497).

Expressing future care preferences is seen as important and beneficial

The lack of discussion about and planning for the end of life described above is in stark contrast to most respondents (82%; n=8,597) agreeing that expressing future healthcare preferences in advance of serious illness or dying is important, and most respondents saying (as noted above) that they would feel comfortable discussing such issues.

Fig. 11: Perceived importance of potential benefits of expressing future care preferences in advance of illness and dying



> **“The fact that it can happen at any time not just in old age, I have discussed my death/funeral/financial wishes with my daughter as I explained how much it meant to me and that I was not being morbid.”**

Most respondents recognised the potential benefits of planning ahead for the end of life (see Fig. 11). The three potential benefits most often seen as important were:

- Reducing stress for myself and my family/friends around planning and making decisions about my care (88%; n=9,194).
- Helping to make sure I receive the treatment and care I would like to have (88%; n=9,277).
- Lessening the burden to family and friends (86%; n=9,027).

> **“We tend to live our lives not thinking about it until it impacts us directly. At that point, we wish we had been more prepared to deal with it.”**

Three-quarters of all respondents (73%; n=7,671) felt that their preferences related to death and dying should take priority over the preferences of those close to them (eg family/friends). Nearly two-thirds of respondents (60%; n=6,346) thought that their preferences should take priority over their doctors’ medical advice.

Respondents with personal experience of end of life or bereavement stressed the importance of having their preferences prioritised as well:

- 82% of those who considered themselves to be in the last years of life (n=408/497), 79% of current family members/friends of someone thought to be in the last years of life (n=808/1,027) and 80% of bereaved family members/friends (n=990/1,244) indicated they would want their own preferences to take priority over the preferences of those close to them.
- 73% of those who considered themselves to be in the last years of life (n=365/497), 69% of current family members/friends of someone thought to be in the last years of life (n=711/1,027) and 64% of bereaved family members/friends (n=799/1,244) also thought that their preferences should take priority over their doctors’ medical advice.

7. Barriers to expressing future care preferences in advance of serious illness and dying

Many people express doubts about the need for expressing future care wishes in advance of serious illness and dying

The most held views that may deter people from expressing their future care preferences (see Fig. 12) included:

- Feeling unable to anticipate their future care preferences (42%; n=4,412).
- Not feeling the need to express future care preferences, trusting that family/friends will help make the right decisions about what's best for them (42%; n=4,363).
- Not thinking that expressing care preferences would make a difference as healthcare providers would not take their wishes into account (38%; n=3,979).
- Thinking that discussing future care preferences would cause too much distress to their family and friends (32%; n=3,335).
- Not feeling the need to express future care preferences, trusting that their doctors will make the right decisions about what's best for them (31%; n=3,250).

> "People are too scared to upset each other when in reality it may benefit loved ones knowing what you wanted."

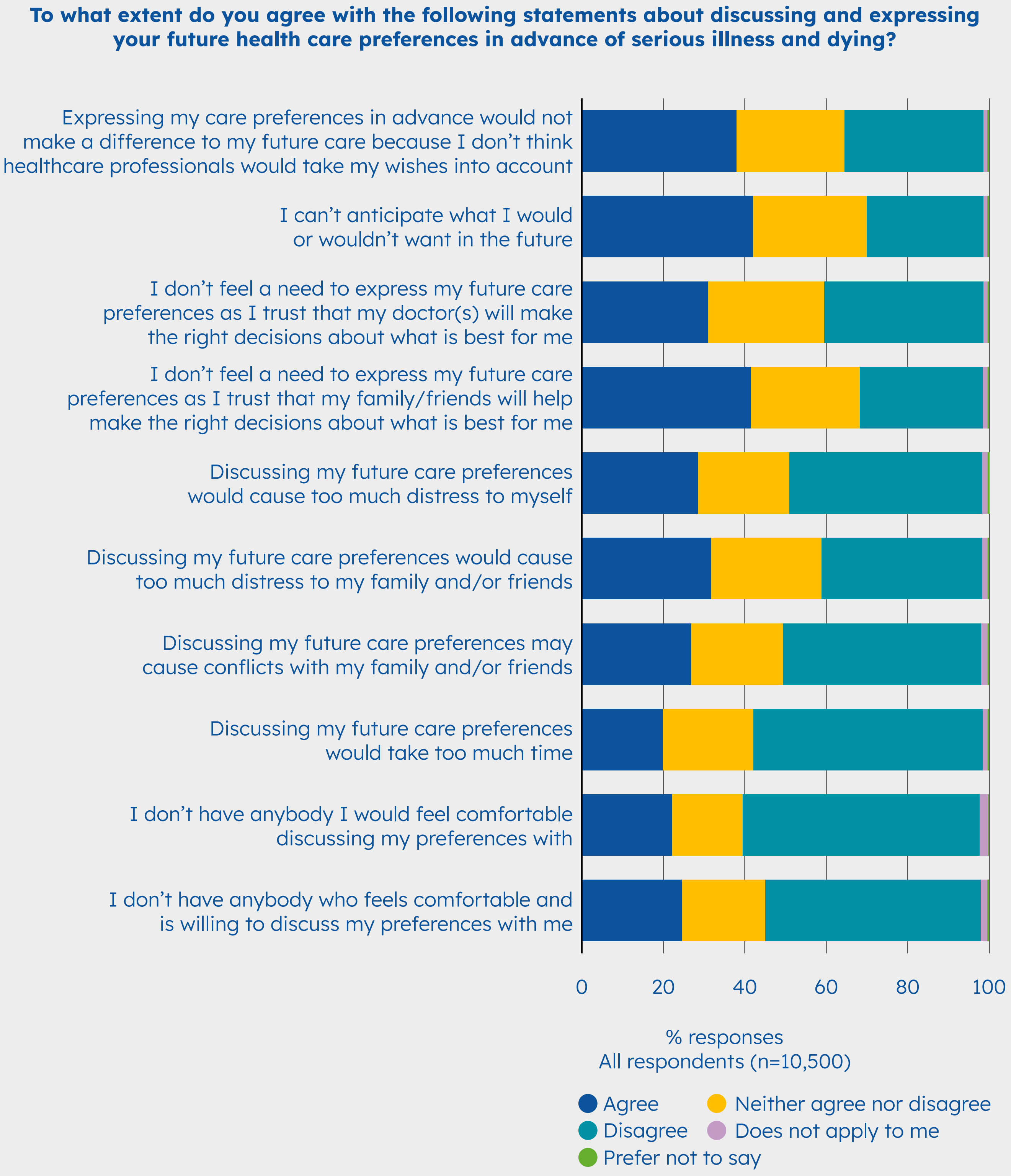
A quarter of respondents indicated they didn't have anybody in their life who was willing to have conversations about their preferences with them (25%; n=2,577).

> "I had a relative who knew she was dying and wanted desperately to talk about it but her family refused... when she did die no one knew what she would have wanted and they regretted not listening to her views."

> "Right now, it can feel very lonely if you are dying because people are afraid to talk to you."

Furthermore, while 45% (n=4,708) of respondents indicated that they would know where to find information on how to plan for their end of life care in advance, 27% (n=2,847) said they would not.

Fig. 12: Attitudes towards potential barriers/concerns related to expressing future care preferences

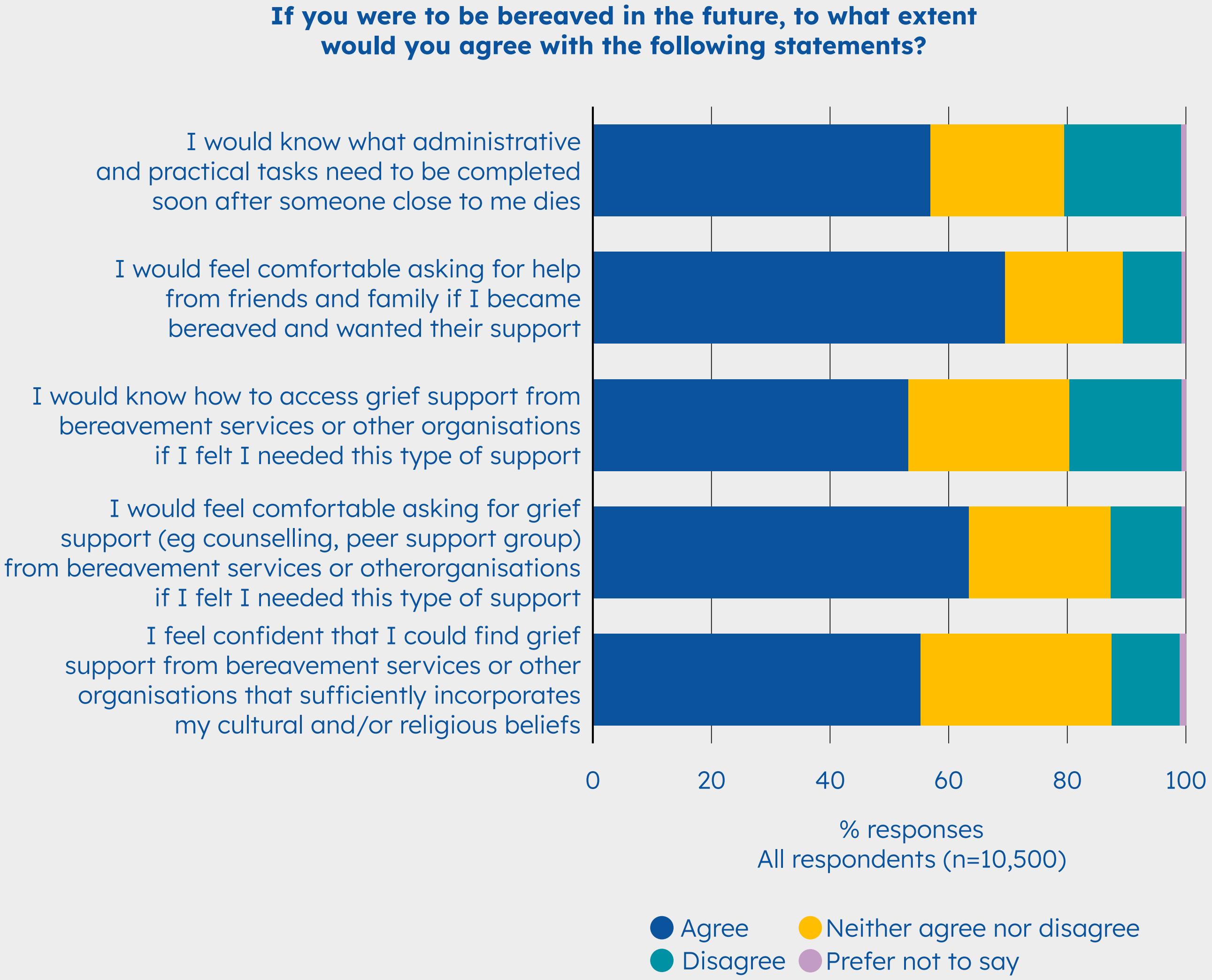


8. Managing practical tasks and reaching out for support after bereavement

Not everyone knows how to manage the practical and administrative tasks after somebody's death

Just over half of UK respondents (57%; n=5,971) felt that they would know what administrative and practical tasks needed completing if somebody close to them were to die (see Fig 13). A fifth (20%; n=2,073) indicated that they would not know what steps would need to be taken after a death.

Fig. 13: Views on coping with practical tasks and seeking support (if needed) after bereavement



> “If a close member of my family were to die now, I would have no idea what to do and would be lost so I think education and awareness is important.”

> “When my grandfather passed, we were like deer in headlights, no one knew what we were supposed to do.”

Not everyone feels comfortable reaching out for support or knows how to access it if they felt they needed help

Most respondents (69%; n=7,296) reported that they would feel comfortable asking for help from family and friends after a bereavement (see Fig. 13). Around two-thirds (63%; n=6,650) also said that they would feel comfortable asking for grief support, for example from bereavement services if they felt they needed this kind of support.

However, not all respondents felt this way:

- One in ten (10%; n=1,033) indicated that they would feel uncomfortable reaching out to family and friends for help.
- One in eight (12%; n=1,256) expressed they would feel uncomfortable approaching bereavement services for grief support if needed.

Nearly a fifth felt that they would not know how to access support from bereavement services (19%; n=1,989). Some also doubted that they would be able to find professional bereavement support that sufficiently addresses their cultural and/or religious beliefs (12%; n=1,211).

Some don’t feel confident that they would be able to support bereaved family and friends

Two-thirds of respondents (67%; n=7,078) agreed that they would feel confident supporting a recently bereaved family member or friend. However, about one in eight (12%; n=1,226) indicated that they would lack confidence offering support. One fifth (20%; n=2,073) neither agreed nor disagreed.

> “I was shocked when I lost my father how few people felt comfortable talking to me about it when I was desperate to mention it.”

> “More people should be able to talk about it without embarrassment. I have watched people cross the street, because they didn’t know what to say to a terminally ill or bereaved person.”

9. Views on grief education in schools

THIS survey also explored parental perceptions of support received by bereaved children and young people in their education settings at the time of their bereavement, and attitudes towards teaching children about bereavement and grief as part of the school curriculum. A full report on topline findings[6] can be found here, with key findings summarised below.

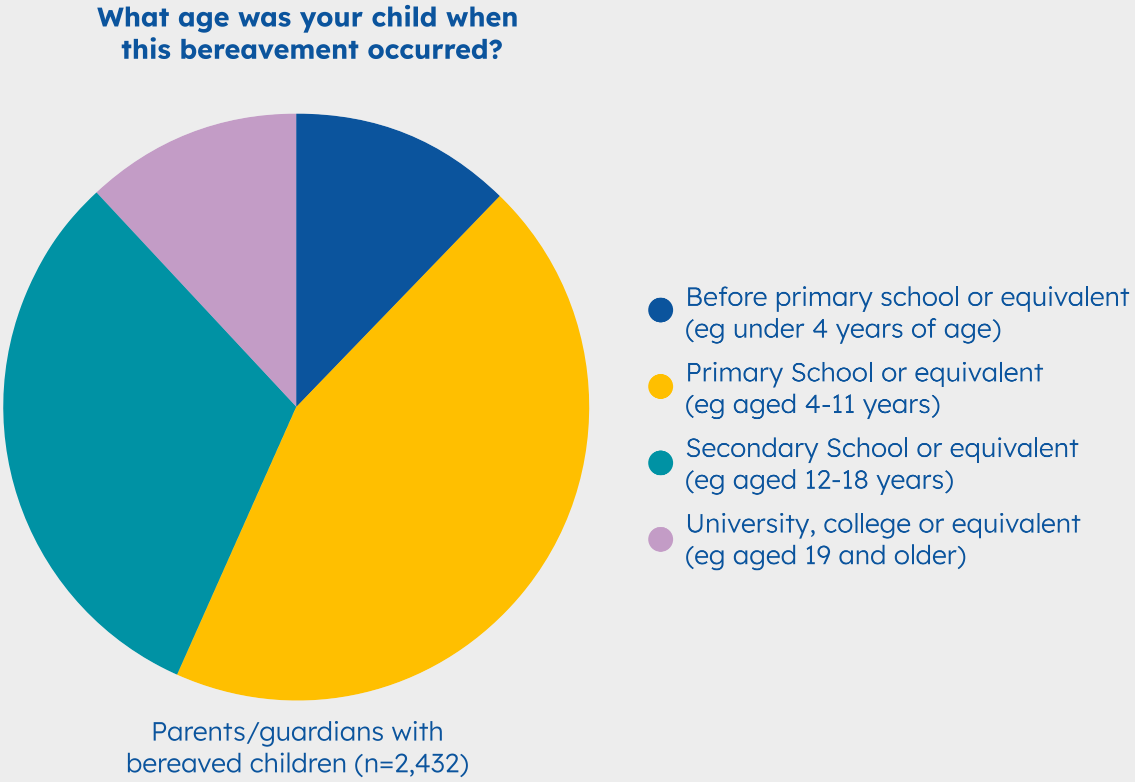
Many children experience bereavement during their school years

Across all survey respondents, 44% (n=4590) identified as parents or guardians to a child/children aged 25 or under. Half of these parents/guardian respondents (53%; n=2,432/4,590) indicated that their child/children had experienced the death of a person close to them, most commonly when they were of primary school age (44%; n=1,076/2,432), followed by secondary school age (31%; n=765/2,432), (see Fig. 14).

Not all bereaved children receive adequate support from their teachers and peers at the time of their bereavement

When asked how well they felt their child had been supported in their educational setting (eg nursery/school/college or university) at the time of their bereavement, half of parents described teachers (53%; n=1279/2,432) and peers (58%; n=1407/2,432) as supportive (see Fig. 15).

Fig. 14: Child's age at the time of the bereavement



> “School was very understanding of the hard times children went through and encouraged them to talk.”

Some, however, also indicated less than optimal support:

- A fifth of parents described teachers (21%; n=506/2,432) and/or peers (19%; n=466/2,432) as ‘neither supportive nor unsupportive’ at the time of their child’s bereavement.
- Nearly one in ten parents reported that teachers (9%; n=212/2,432) and peers (7%; n=180/2,432) were unsupportive.

> “She was only given three days off school, naturally she was upset for months but the teachers... were not at all supportive. I think more training is needed on this topic.”

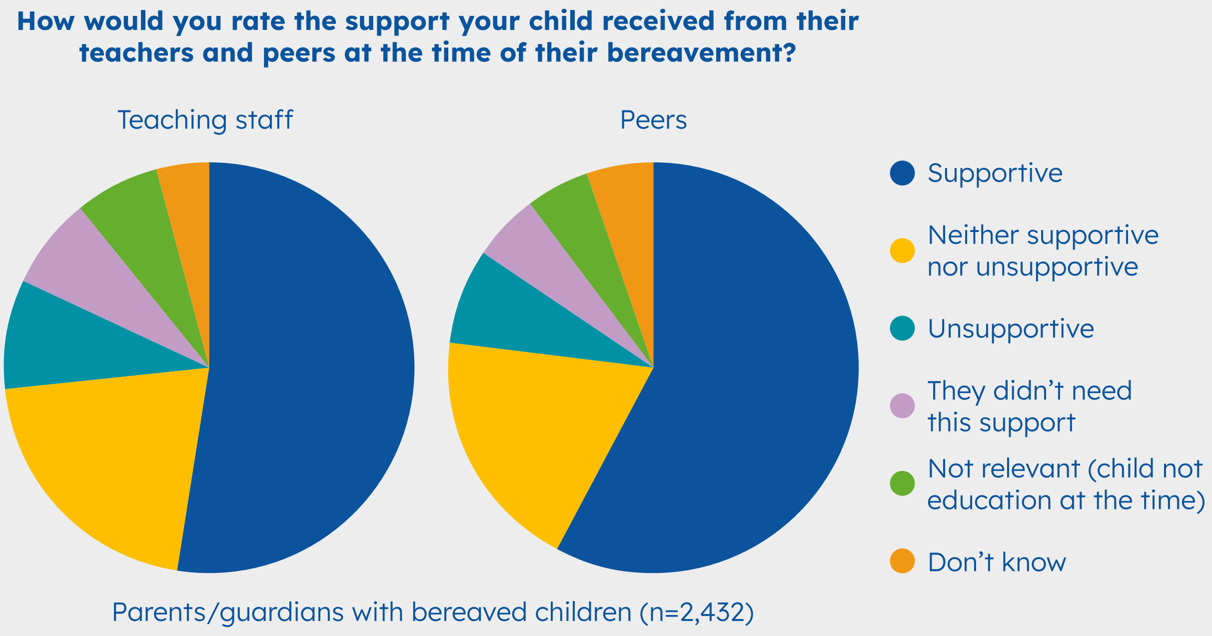
> “My son was playing up in class a few weeks after our loss... the teacher... said the death is in the past... no excuse for bad behaviour... my children needed counselling and someone to talk to, it was a cry for help.”

> “My son and later my god-daughter received good support from their secondary schools but their peers were only sympathetic in the short term.”

Both the public and parents support school-based grief education for secondary school children and (older) primary school children

Many survey respondents agreed with including learning about bereavement and grief in the school curriculum, although

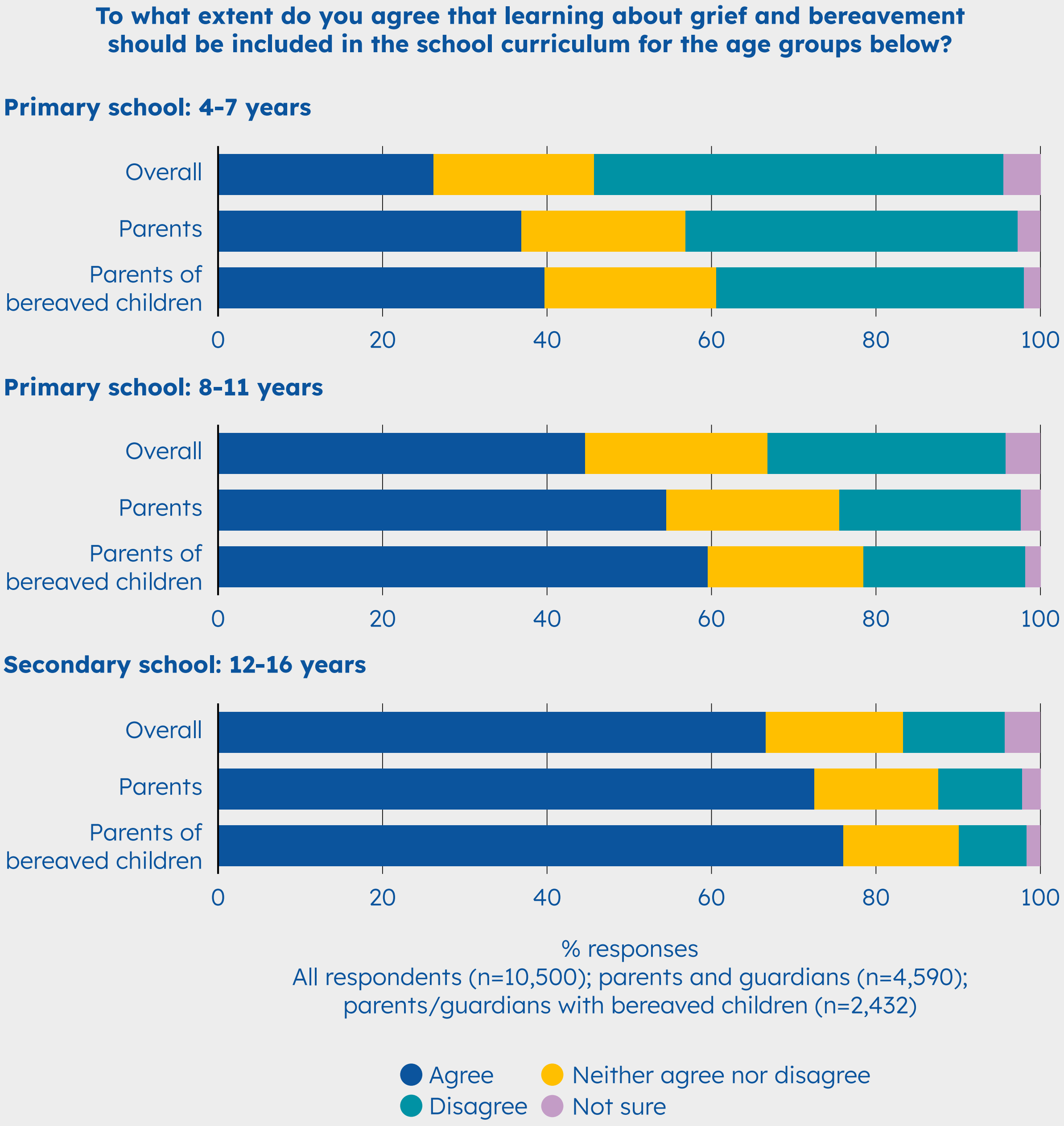
Fig. 15: Parent-perceived supportiveness of teaching staff and peers at the time of their child’s bereavement



this depended on children's age (see Fig. 16). Parent respondents tended to be more supportive of grief education in schools, in particular those whose child had experienced a bereavement:

- For older primary school children (aged eight to 11 years), 45% of respondents in the overall sample (n=4,682/10,500) were in favour of including learning about bereavement and grief in the school curriculum. This compared to 54% among parents (n=2,499/4,590) and 59% among parents of bereaved children (n=1,446/2,432).
- For secondary school children (aged 12 to 16), 67% of respondents in the overall sample were in support of school-based grief education (n=6,990/10,500). This compared to 72% among parents (n=3,328/4,590) and 76% among parents of bereaved children (n=1,848/2,432).

Fig. 16: Attitudes towards including learning about bereavement/grief in the curriculum – all parents/parents of bereaved children

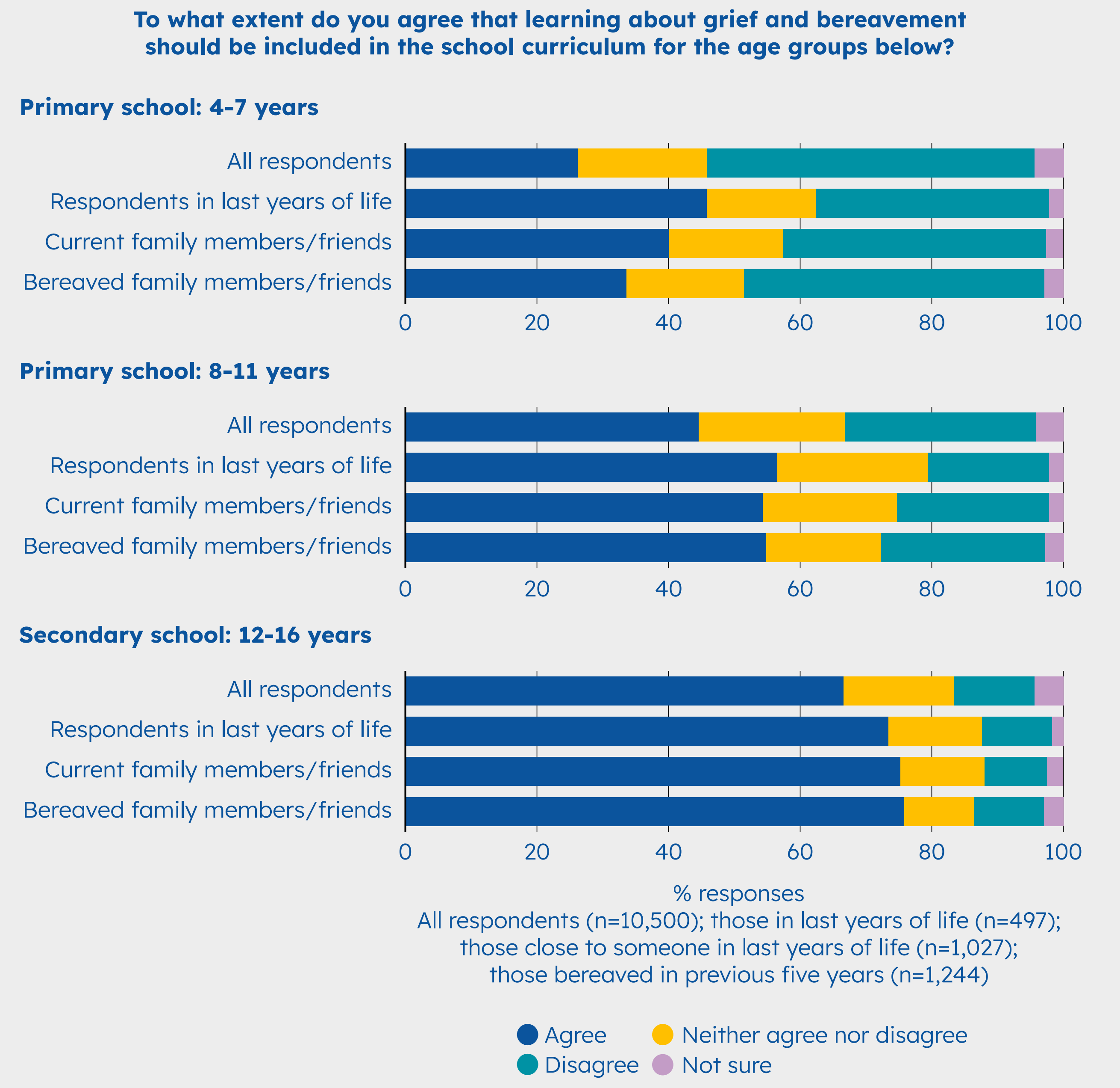


For younger primary school children (aged four to seven), views were more hesitant, especially among the general public:

- In the overall sample, a quarter of respondents (26%; n=2,746/10,500) expressed support for teaching children of this age about bereavement and grief in school. This compared to 37% among parents (n=1,692/4,590) and 40% among parents of bereaved children (n=964/2,432).

> "I'd love to have been exposed to how to deal with deaths in the family at school. I was woefully unprepared as a child. It's a great idea."

Fig. 17: Attitudes to including learning about bereavement/grief in the curriculum – those in last years of life, current family/friends, bereaved family/friends

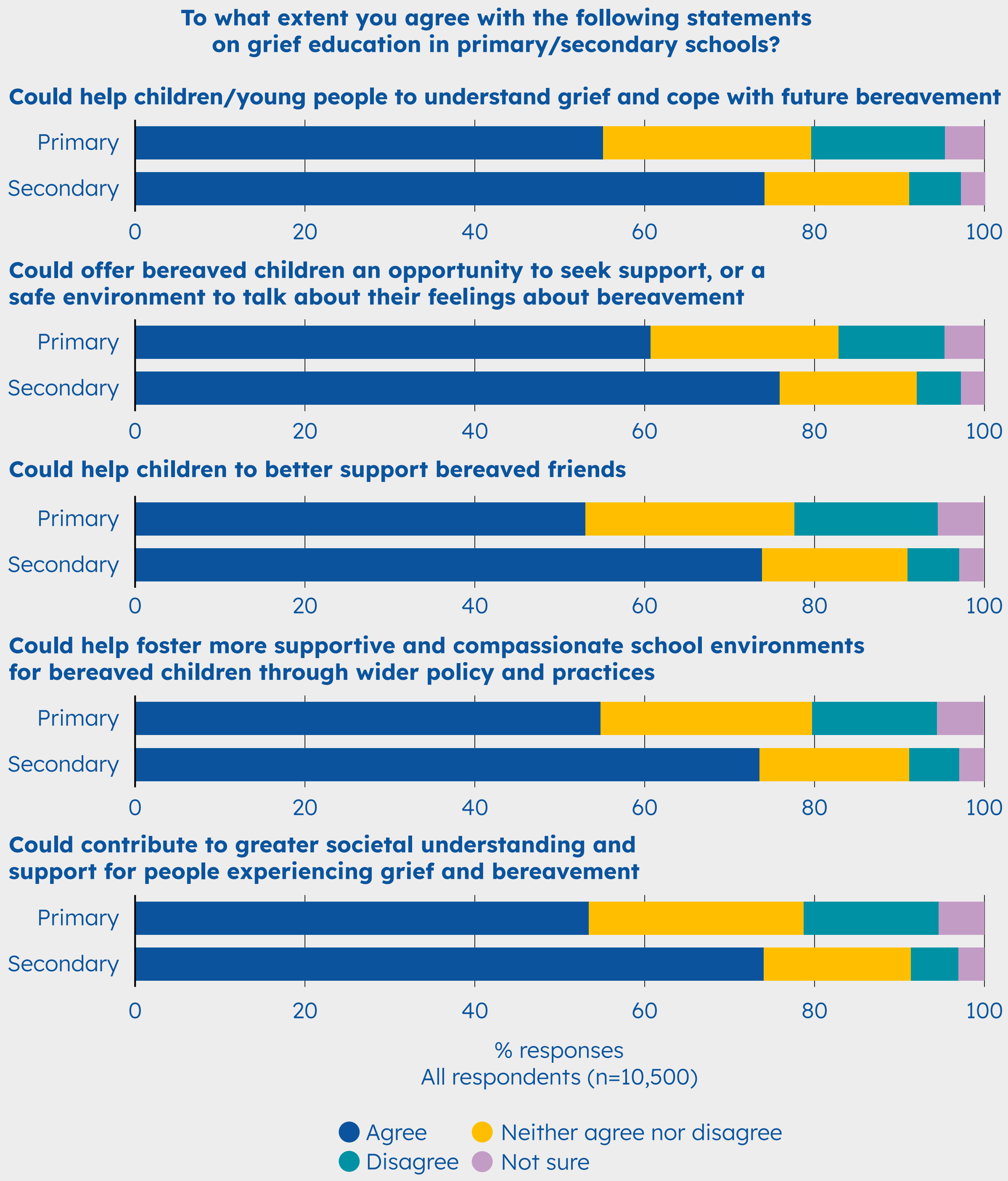


Those with personal experience of end of life and bereavement also support teaching children about bereavement and grief in schools, including early primary school age

Respondents with personal experience of end of life and bereavement were also particularly supportive of school-based grief education, including for younger primary school children (see Fig. 17):

- 46% of respondents who considered themselves in the last years of life (n=228/497), 40% of respondents who

Fig. 18: Attitudes towards potential benefits of including learning about grief/bereavement in the curriculum in primary vs. secondary schools



identified as being close to someone thought to be in the last years of life (n=411/1,027) and 34% of bereaved respondents (n=418/1,244) expressed support for teaching younger primary school children (aged four to seven years) about bereavement and grief at school. This compares to 26% (n=2,746/10,5000) in the overall sample.
- 57% of respondents who considered themselves in the last years of life (n=281/497), 54% of respondents who identified as being close to someone thought to be in the last years of life (n=557/1,027) and 55% of bereaved respondents (n=681/1,244) expressed support for teaching older primary school children (aged eight to 11 years) about bereavement and grief at school. This compares to 45% (n=2,746/10,5000) in the overall sample.

The potential benefits of teaching about bereavement and grief in schools are recognised

Most respondents appreciated the range of potential benefits of learning about bereavement and grief in schools, particularly in secondary schools (see Fig. 18).

Respondents recognised the positive impact that grief education could have for bereaved children:

- 76% (n=7,973) agreed that grief education could provide opportunities for bereaved children to reach out for support and talk about their feelings for secondary school age, and 61% (n=6,375) for primary school age.
- 73% (n=7,714) agreed that grief education could foster more understanding and compassionate school environments for bereaved children for secondary school age, and 55% (n=5,759) for primary school age.

> **“A lot of children experience bereavement and I think if it is openly talked about at school it will help them to cope. It will also, hopefully, encourage them to ask for help and report a lack of support at home.”**

Respondents also appreciated the potential benefits learning about bereavement and grief in schools could have for children who have not yet experienced the loss of a person close to them:

- 74% (n=7,778) felt that grief education could help children prepare for and better cope with future bereavements for secondary school age, and 55% (n=5,787) for primary school age.
- 74% (n=7,754) agreed that grief education could help children better understand and support their bereaved friends for secondary school age, and 53% (n=5,565) for primary school age.

> **“Death and grief are a taboo subject but a part of life. I believe the younger children are taught about death, the more resilient and able to healthily cope they will be.”**

> **“The main reason children should have this spoken about in school is that one of their peers might lose someone before they do and it will help them understand what they are going through.”**

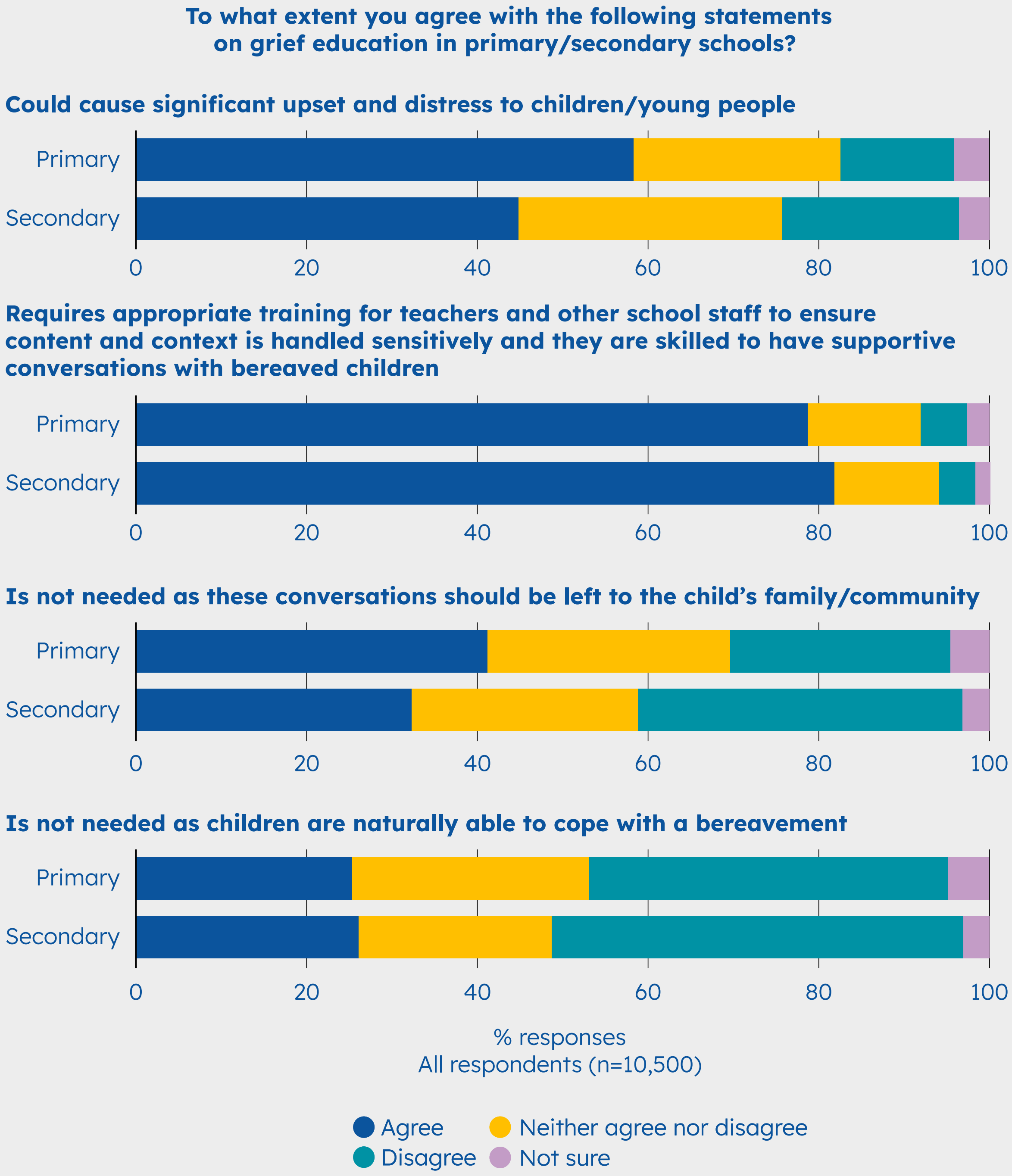
In addition, 74% (n=7,767) agreed that grief education in schools could contribute to greater understanding and support for bereaved people in general in society as a whole for secondary school age and 53% (n=5,604), for primary school age.

> "I think it's really important to teach it young and have conversations to break the cycle we have just now of a society who doesn't talk about death."

Causing children distress is a key concern, with the need for appropriate staff training clearly voiced

Many respondents expressed concern that engaging with the sensitive topics of bereavement and grief could be upsetting

Fig. 19: Attitudes to potential concerns around including learning about grief/bereavement in the curriculum, primary vs. secondary schools



to children, especially in primary schools (58%; n=6,122), with 45% (n=4,704) in secondary schools (see Fig. 19). Four in five respondents agreed that appropriate training is key to ensuring that school staff have the necessary skills to engage with these topics sensitively and to have supportive conversations with bereaved children (primary schools: 79%; n=8,264; secondary schools: 82%; n=8,585).

> **"I think primary school age is a bit tricky as I think it could upset some children who are natural worriers."**

> **"Should be provided by people with proper training. And also need to make sure families are happy for their children to receive this training first."**

Around a third of respondents felt that conversations about grief and bereavement should be left to children's families (primary schools: 41%; n=4,322; secondary schools: 32%; n=3,388). A quarter didn't think grief education was needed as they felt children are naturally able to cope with bereavement (primary schools: 25%; n=2,656; secondary schools: 26%; n=2,736).

> **"This is not a subject which should be talked about at school by teachers. It should be left to the parents or grandparents to handle it at home… amongst family members who know their children better than any outsider."**

> **"Bereavement is a family matter and should stay within the family."**

Overall, there is substantial support for teaching (older) children about grief, death and loss in schools, and recognition of the potential benefits of doing so. Concerns related to school-based grief education are more prevalent for primary schools, yet this is a common age for experiencing a bereavement, highlighting the need to understand and take steps to address these concerns.

10. National comparisons

OVERALL, the four devolved nations were similar in their expressed views. Some differences of interest with regards to findings presented in this summary report are highlighted below.

UK nations: views on expressing future care preferences in advance of serious illness and dying

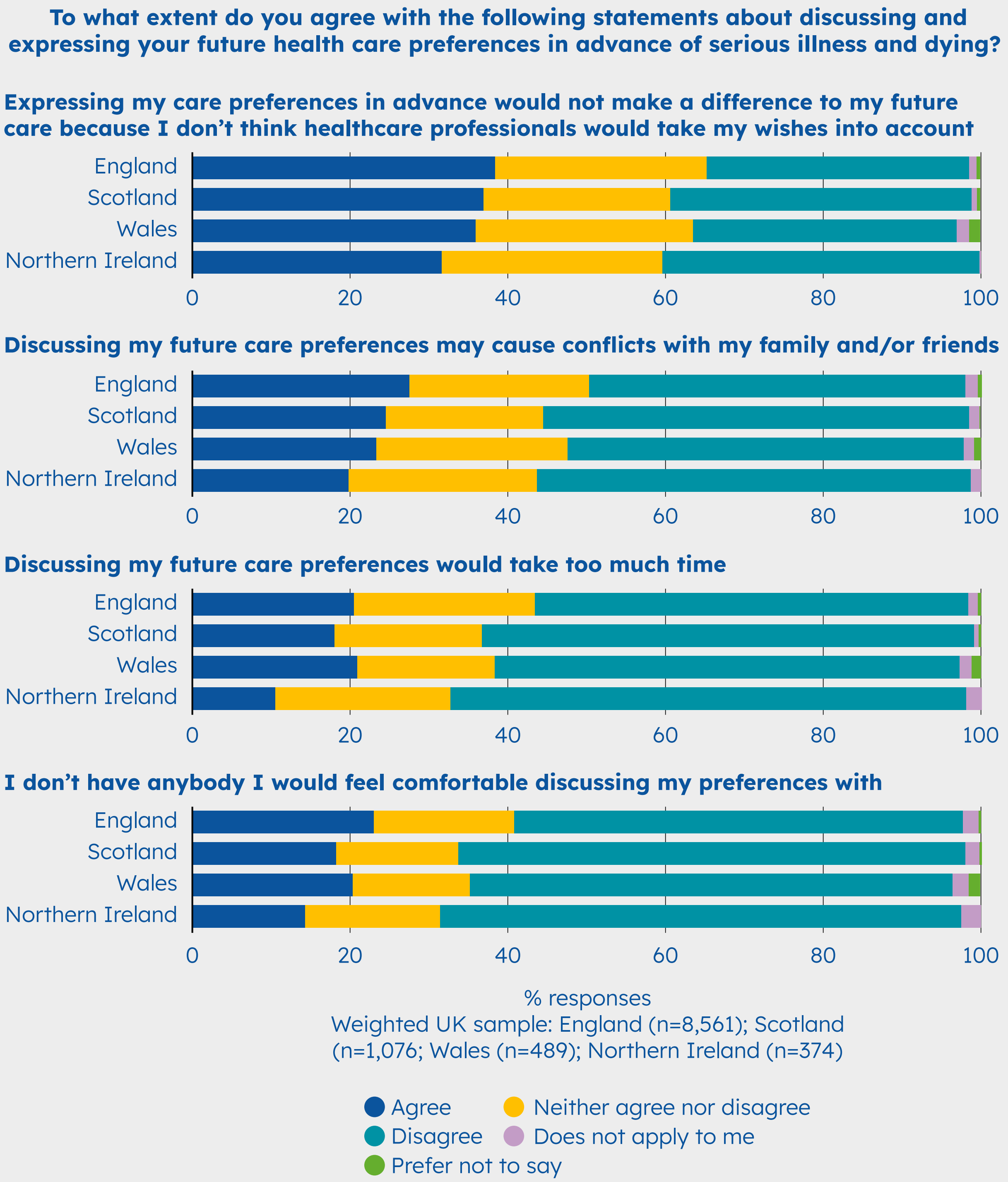
Across the four devolved nations, there were some more noticeable variations relating to some (but not all) of the views that may deter people from expressing and discussing their future care preferences in advance of serious illness and dying. Respondents from Northern Ireland tended to have the lowest levels of agreement among the four nations with regards to the following views (see Fig. 20):

- 32% of respondents in Northern Ireland felt that expressing their care preferences in advance would not make a difference to their future care because healthcare professionals would not take their wishes into account. This compared with 36% in Wales, 37% in Scotland and 38% in England.
- 20% of respondents in Northern Ireland were concerned that discussing their future care preferences with family/friends could cause conflicts, compared with 23% in Wales, 25% in Scotland and 28% in England.
- 11% of respondents in Northern Ireland thought that expressing their future care preferences would take too much time, a view more commonly held in Scotland (18%) and England/Wales (both 21%).
- 14% of respondents in Northern Ireland

reported that they did not have anybody they would feel comfortable discussing their future care preferences with. This compared with 18% in Scotland, 20% in Wales and 23% in England.

Wales had the highest proportion of respondents who reported that they would not know how to access information on how to plan for end of life care in advance (37%), as compared to England (27%), Scotland (26%) and Northern Ireland (30%).

Fig. 20: Attitudes towards potential barriers/concerns related to expressing future care preferences for the four UK nations



To what extent do you agree with the following statements about discussing and expressing your future health care preferences in advance of serious illness and dying?

Expressing my care preferences in advance would not make a difference to my future care because I don't think healthcare professionals would take my wishes into account

Discussing my future care preferences may cause conflicts with my family and/or friends

Discussing my future care preferences would take too much time

I don't have anybody I would feel comfortable discussing my preferences with

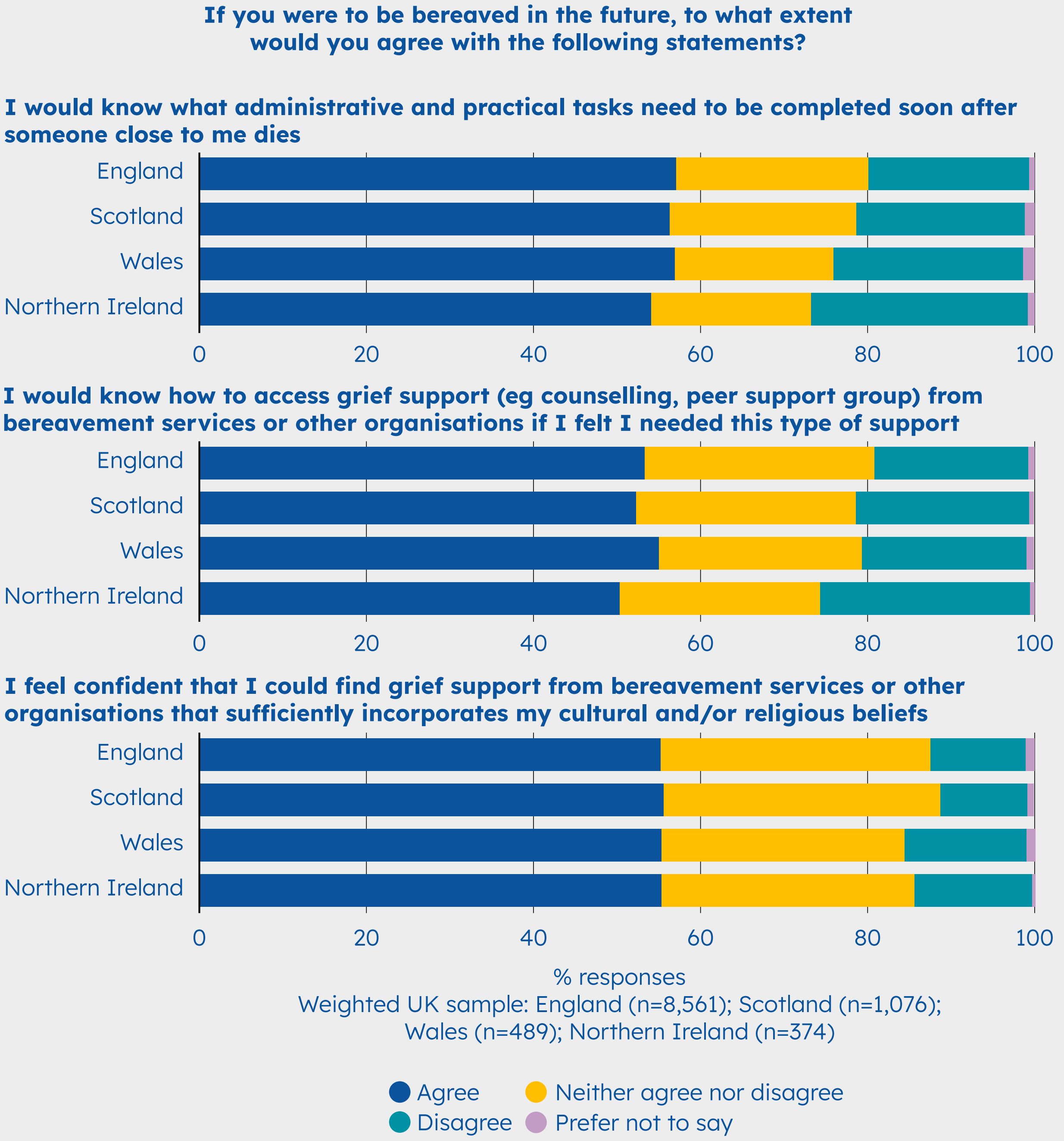
Weighted UK sample: England (n=8,561); Scotland (n=1,076; Wales (n=489); Northern Ireland (n=374)

UK nations: views on dealing with practical tasks and seeking support after bereavement

Perceptions around knowing which administrative and practical tasks need to be completed after a bereavement and attitudes towards reaching out for support (if needed) varied slightly across the four UK nations, with Northern Ireland tending to stand out somewhat (see Fig. 21) as follows:

- 26% of respondents in Northern Ireland expressed that they would not know what administrative and practical tasks need addressing after somebody dies, compared with 19% in England, 20% in Scotland and 23% in Wales.
- 25% of respondents in Northern Ireland also indicated that they would not know how to access grief support services if they felt they needed it, as compared with 18% in England, 21% in Scotland and 20% in Wales.

Fig. 21: Attitudes towards coping with practical tasks and accessing support after bereavement for the four UK nations



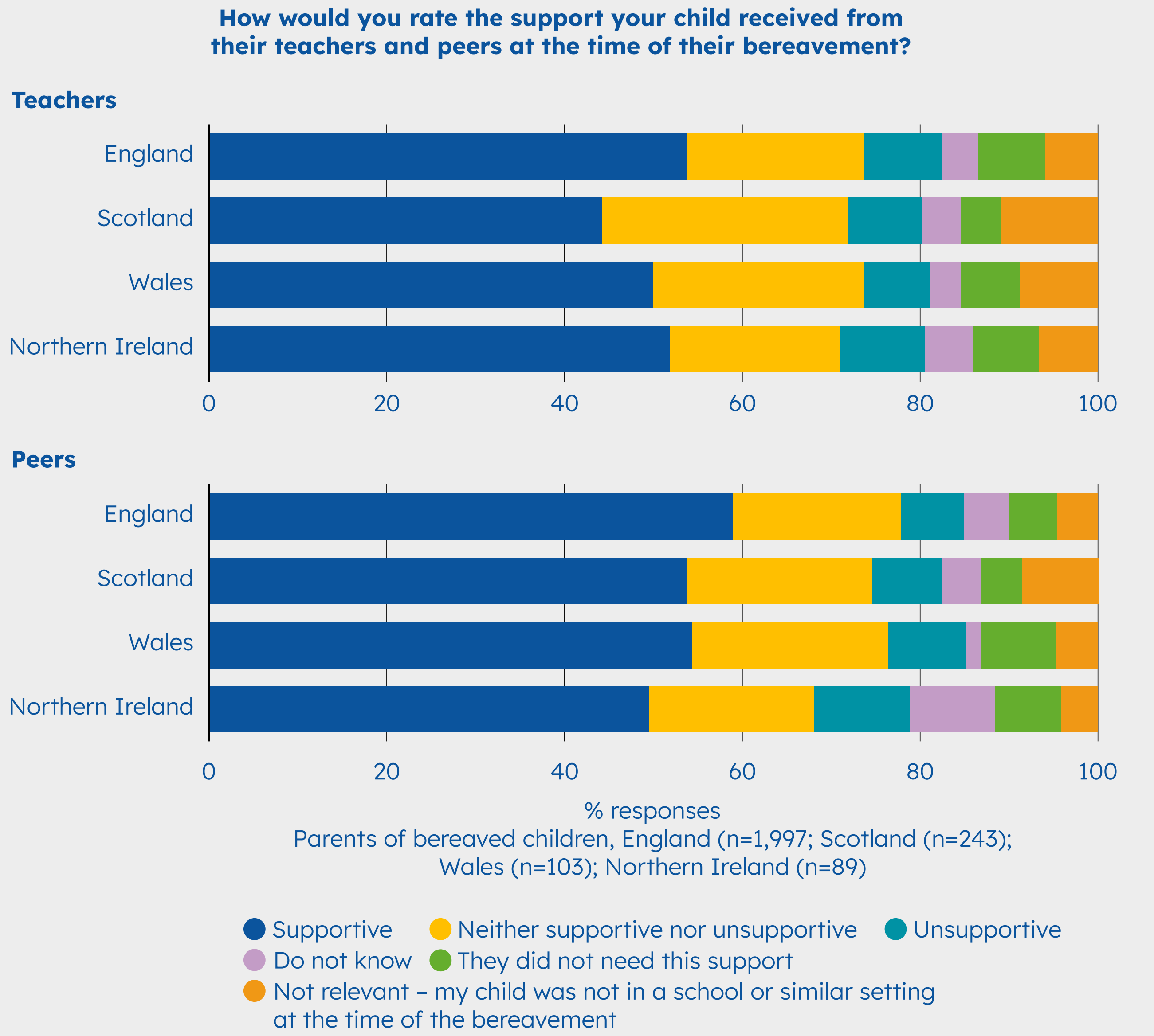
Respondents in both Northern Ireland and Wales expressed more doubt that they would be able to find professional grief support that sufficiently incorporates their cultural and/or religious beliefs (14% in Northern Ireland and 15% in Wales, compared with 11% in England and 10% in Scotland).

UK nations: perceived support for bereaved children and young people in educational settings

Parents' perceptions of how supportive their child's teachers were at the time of their child's bereavement varied slightly across England, Wales and Northern Ireland, with a more substantial difference in perceived supportiveness in Scotland (see Fig. 22). Half or more of parent respondents with bereaved children described teaching staff as supportive in England (54%), Wales (50%) and Northern Ireland (52%), compared with 44% in Scotland.

Across the devolved nations, peers were more commonly seen as supportive than teachers, with 54% teachers vs. 59% peers in England; 44% vs. 54% in Scotland; and 50% vs. 54% in Wales. But this (small) trend appeared reversed in Northern Ireland, with 52% teachers vs. 49% peers.

Fig. 22: Parent-perceived supportiveness of teachers and peers in their child's educational setting at the time of their child's bereavement for the four UK nations



Parents of bereaved children, England (n=1,997; Scotland (n=243); Wales (n=103); Northern Ireland (n=89)

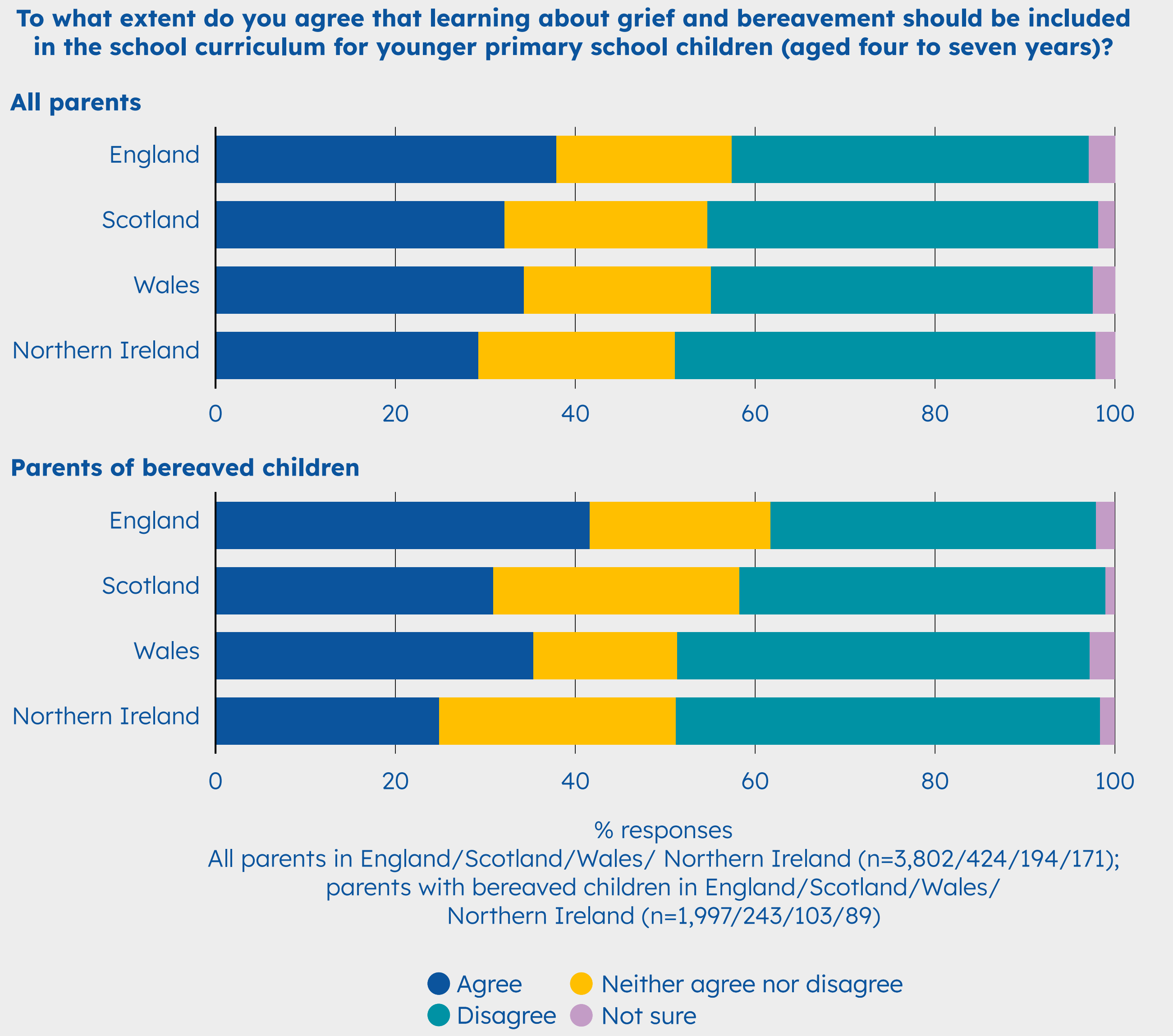
UK nations: public and parental attitudes towards grief education in schools

Apart from minor variations, the overall proportions of respondents in support of including grief education in the curriculum appeared very similar across the four devolved nations, ranging between 24% in Northern Ireland and 27% in Wales for younger primary school-aged children (four to seven years); 44% in Scotland and 46% in Wales for older primary school-aged children (eight to 11 years); and 66% in England and 69% in Northern Ireland for secondary school-aged children (12-18 years).

However, more noticeable variations were observed among the parent respondents in the different nations, with regards to support for school-based grief education for younger primary school children (four to seven years). Agreement levels tended to be highest among parent respondents in England and lowest in Northern Ireland (see Fig. 23):

- 38% of parent respondents in England were in favour of school-based grief

Fig. 23: Views of parents and parents of bereaved children on including bereavement/grief in school curriculum for youngest primary school children, UK nations



All parents in England/Scotland/Wales/ Northern Ireland (n=3,802/424/194/171); parents with bereaved children in England/Scotland/Wales/ Northern Ireland (n=1,997/243/103/89) education for four to seven-year-olds, compared with 29% of parent respondents in Northern Ireland (Scotland: 32%; Wales: 34%).

- Among parent respondents of children with bereavement experience, 42% in England were in favour of school-based grief education for four to seven-year-olds, as compared with 25% in Northern Ireland (Scotland: 31%; Wales: 35%).

11. Conclusion

THIS survey provides up-to-date insights into public views in the UK on dying, death and bereavement. Findings aim to inform improvements to the support provided to dying people and their families and friends – throughout and beyond the end of life, including bereavement.

Findings also highlight the continued need for more open conversations about the end of life. Many people expressed that they would feel comfortable talking about death and dying, preferably with their family and friends, but that in reality, such conversations rarely happen.

What matters most at the end of life

People's top needs and personal priorities have remained largely unchanged since the PADDUK 2021 survey.[5] Access to care whenever it is needed, and support with physical needs and privacy are the most important needs people would like to have managed in their final days. Further priorities were adequate pain and symptom control, the ability to maintain dignity and self-respect, the company of loved ones and feeling safe. Considered together, these needs and priorities emphasise that is essential to provide joined-up health *and* social care to achieve optimal support for people at the end of life.[7] Well-integrated, responsive and easy-to-access social care that supports people in their physical and practical needs is key to enabling people to live as well as they can and in line with their priorities and preferences until they die.[8]

Respondents in the last years of life emphasised two additional vital elements of care and support at the end of life: the ability to be involved in the decision-making around one's care, and having holistic support that not only addresses medical and physical needs, but also emotional support needs. Having to confront dying, death and one's own mortality brings difficult thoughts and feelings for many[9,10] and is an area where support may be needed by some.

The preferred place of death for most was home, in line with previous findings.[11,12] Respondents who considered themselves in the last years of life also most commonly chose 'home', as previously reported;[13,14] a fifth, however, said that they would prefer to die in a hospice. This highlights that people's preferences around where they would like to die can change over time, as they transition through the final stages of their life.[15,16,17] It is a reminder of the importance of ensuring access to care at home for the majority of people for whom this is a preference, but also emphasises the continued importance of securing access to hospice care for those who need or prefer this specialist support in an in-patient setting[11] at the end of life.

Recommendations

The majority of respondents highlighted their preference to die at home, but too often care and support is inadequate to enable this. The findings also highlight that many people would like to access hospice care at the end of life. To enable more people to receive the care they need at the place of their preference, the following actions are key:

- Health commissioners must ensure 24/7 access to palliative and end of life care, through a single point of access in every local area offering advice, guidance and support, to ensure people are able to die at home where this is their preference.
- Governments across the UK must act to improve 24/7 access to medicines, with more pharmacies stocking palliative medicines and more professionals trained to prescribe them in local communities, to enable people to die at home where this is their preference.
- All UK governments should deliver a new funding solution for palliative and end of life care, to end the postcode lottery in access and to ensure adequate access to palliative care to meet local need.

Many respondents highlighted the importance of having emotional support needs addressed at the end of life, but for too many people living with terminal illness, mental health support is inadequate. To address this, the following is needed in setting direction for mental health services:

- Governments across the UK must include the mental health and wellbeing support needs of people towards the end of life in mental health strategies and guidance.
- Key organisations responsible for providing health and social care guidelines such as the National Institute for Health and Care Excellence (NICE) for England, Wales and Northern Ireland and the Scottish Intercollegiate Guideline Network (SIGN) for Scotland should produce and consult on new guidelines for mental health support for people approaching the end of their life at the earliest opportunity.

Beyond the end of life: bereavement

Our survey findings on coping after a bereavement suggest that not everyone would feel comfortable or able to reach out for support (including from their family and friends) if they felt they needed it. In addition, not everybody would feel confident that they would know how to support a recently bereaved person. Discomfort or reluctance to approach bereavement services for help and a lack of awareness of available support options are known barriers to getting support.[2,18,19] Therefore, it is important to normalise help-seeking (if help is needed) and provide easy-to-access information on grief support.[18] Initiatives are also needed to improve the informal support for people who are bereaved (eg from family, friends, neighbours, colleagues), developing compassionate, grief-literate communities in which bereaved people feel safe, supported and understood.[2] Including learning about bereavement and grief in schools is a key step towards this[2,20] and our findings demonstrate public support for this approach in both older primary and all secondary school children, provided adequate training for school staff[21] is in place.

Recommendations

To improve support and understanding for bereaved people, including bereaved children and young people, the following actions are recommended:

- NICE and SIGN must develop guidelines for the delivery of bereavement support, which seek to normalise help-seeking and ensure that easy-to-access information on grief support is provided.
- Governments across the UK should require all schools and other education settings to provide age-appropriate opportunities for children and young people to learn about coping with death and bereavement as part of life, including by ensuring that grief education is a mandatory part of the curriculum in each nation.

Talking about the end of life

Early evidence initially suggested that the pandemic may have increased how much people talk about death and dying and consider their own end of life wishes.[5,22,23,24] There are, however, no indications in our current findings that any such effects were of a lasting nature. Most people continue to think that, as a society, we do not talk about death and dying enough, with the number holding this view having increased from 51% in the PADDUK 2021 survey[5] to 59% in the 2023 survey. Furthermore, the noticeable gap between the proportion of people who say that, in principle, they would be comfortable talking about death and dying, and the proportion of people who have had any such discussions[5] also persists. More research is needed to identify the many factors that are likely to contribute to why these conversations are not happening and to develop approaches to promote and facilitate talking about and planning for death and dying.[25] Importantly, more nuanced considerations might be needed in this context to distinguish between talking about death and dying *per se* – in a hypothetical way when death and dying are seen as distant events in the future – and talking about death and dying when it becomes reality, such as when faced with terminal illness.[23]

People primarily look to their families and friends (rather than professionals) for informal discussions about their end of life care wishes.[23,26] This highlights the importance of finding ways to better equip people in the community with the knowledge and skills to understand and discuss end of life and death care options and to make informed decisions.[27]

When it comes to expressing and discussing care preferences in advance of illness and dying, this survey identified some views that will require further interrogation as they may impact on people's willingness to consider and express their end of life wishes. For instance, 42% of respondents either felt unable to anticipate their future care preferences or indicated that they would rely on family or friends to help make the right decisions about their care; while 38% didn't think expressing their wishes in advance would make a difference, as they doubted healthcare professionals would take them into account. This is of particular interest, given the challenges that surround the successful implementation of previously expressed care wishes in clinical practice.[28]

Recommendations

It is concerning that such a high proportion of respondents felt that their willingness to plan for their end of life care needs was undermined by a belief that expressing their wishes would not make a difference to the care that they receive. To address this and ensure that people's end of life needs and preferences are central to the care they receive, the following steps are needed:

- Governments across the UK should ensure that every individual reaching the end of their life has a legal right to personalised care and support planning, with these plans being shared so they are accessible to all health and social care professionals at the point of care.
- Health commissioners should ensure that they consistently involve people with direct experience of dying, death and bereavement in co-designing local palliative and end of life care services.

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