

Dying

Discussing and planning for end of life

Recent policy, legislation and campaigns advocate greater openness and discussion around dying and planning for end of life care. What are the public's attitudes on this issue and how far do these vary for different sections of the population? How far have individuals put plans in place for the end of life and what factors are inhibiting planning in this area?

Discussing death

Most people express a considerable degree of confidence around discussing death and planning for the end of life.



70% say they feel comfortable **talking about death**; just 13% feel uncomfortable doing this.

Confident about financial plans 73%

Confident about planning support/care 79%

The majority express confidence about **planning** in relation to one or more aspects of the end of life; 73% feel confident about making financial plans for the end of life, while 79% feel confident about planning for the right sort of support and care.

Planning for end of life

Yet this expressed comfort and confidence is not always translated into actual discussions and practical planning, largely because death is seen as far off – even among many older people.

Not discussed their wishes as death seen as far off



Less than half (45%) have discussed what their wishes would be in relation to one or more aspects if they didn't have long to live. 43% have **not discussed their wishes because death seems far off**; this is the case for around one in five (23%) of those aged 75+.



5% have living will/advance care plan

11% have written funeral plans

Only 5% report having a **living will or advance care plan**, while 11% have written plans in place for their funeral.

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Introduction

Thomas Hobbes (1651: xlili) [1] described the life of man in times when warfare and disease were the natural state of things as “solitary, poor, nasty, brutish and short”. In modern Western societies, however, we have largely eliminated both warfare and death from infectious diseases. Most of us will gradually ‘wear out’, predominantly in old age, rather than meet an untimely, brutish or short end. This means that around three-quarters of deaths in the UK are ‘predictable’ and follow a period of chronic illness.

Despite this, we often still seem keen to avoid discussion of dying. This lack of openness has adverse consequences: people can be unnecessarily frightened about the process of dying; others are unable to make crucial decisions about place of death – not least because their family members, doctors and nurses often lack the vocabulary and confidence to initiate such discussions (Mitchell, 2002; Parker et al., 2012) leaving many patients not knowing that they are going to die (Department of Health, 2012). Those who are terminally ill risk being shunned because people feel awkward and embarrassed about dealing with death. The lack of discussion that takes place regarding grief and loss sometimes results in isolation of the bereaved (Hauser and Kramer, 2004).

However, the avoidance of discussion of death is regarded as neither inevitable nor desirable. Kellehear (2005) notes that, in the past, discussing and planning for death and dying was routine for families and communities and suggested that a compassionate society today would try to ‘normalise’ death rather than always treating it as a medical failure. In his advocacy of the compassionate city, for example, he evokes the original philosophy of palliative care, which focused on the task of promoting health through “open and healthy discourse regarding death and dying” (Haraldsdottir et al, 2010:130), a skill which has sometimes been lost outside the walls of the hospice. The World Health Organisation (2010) also suggests that end of life care should affirm life and regard dying as a normal process, offer a support system to help patients and their relatives, and make use of available community resources.

Towards the end of the 2000s, national guidance and legislation also began to emphasise the need for change. The *End of Life Care Strategy* (Department of Health, 2008) proposed that health care organisations should promote awareness and discussion of issues relating to dying, death and end of life care through comprehensive local strategic plans for end of life care. The strategy stated that these should be centred on three levels – the societal level (where there should be actions to raise awareness of, and change attitudes and behaviours towards, death and dying), the individual level (providing integrated service delivery based around an end of life care pathway), and infrastructure (including workforce development, measurement, research, funding and national support). The establishment in 2009 of the Dying Matters Coalition to promote public awareness of dying, death and bereavement sought to address the first of these. Hosted by the National Council for Palliative Care, its foundation was a direct response to the perceived need to campaign for changed attitudes and behaviours on this issue. Its approach has involved the development of a ‘coalition’ between members of the public and both public and private sector organisations. Through a series of events, campaigns and activities it seeks to normalise discussions of death and dying by supporting changing knowledge, attitudes and behaviours towards death, dying and bereavement.

In this chapter, we analyse a set of questions measuring attitudes to dying which were asked as part of the 2012 British Social Attitudes survey to assess current views, motivations and preferences in this area. We begin by exploring the extent to which individuals have experienced or engaged with death within their own lives, before moving on to consider public preference in terms of being told if one has a terminal disease, preferences for place of death and the factors viewed as important in end of life care. We then consider the extent to which the public feels comfortable talking about death and whether people have in practice discussed various aspects of their own deaths with another person. Next, we explore the barriers that have prevented some individuals from having these discussions and the factors that would prompt them to begin to plan for their end of life care. Finally, moving beyond the focus on discussion of wishes, we consider the extent to which people have put specific plans in place for their end of life care and deaths.

Throughout the chapter, in addition to identifying the views held by the public as a whole, we consider how these might vary in different sections of the population. There are a number of factors that might lead us to suspect that attitudes and preferences in relation to dying are not held equally among all sections of society. Age itself might bring with it a more realistic attitude towards planning for one's end of life care and death – many of us do not encounter death (of parents, relatives and friends) until we are in middle age ourselves. There may also be significant variations by social position and wealth, with claims that the 'good death' agenda is a middle class one, not necessarily espoused by people with fewer resources and different cultural habits (Howarth, 2007; Pring and Verne, 2012). Furthermore, relatively little has been done to explore the views of distinctive cultural and religious subgroups within Britain.

While the 2012 British Social Attitudes survey [2] was the first in this study series to include this set of questions on attitudes towards death and dying, they had previously been fielded on a comparable face-to-face survey conducted in 2009. [3] By comparing the results of the two surveys, at the population level and for specific subgroups, we can consider how attitudes and preferences in relation to dying might be changing over time and whether they appear to be moving in the direction of greater openness and discussion, as advocated by recent policy, legislation and campaigning. Notes on the data can be found at the end of the chapter. [4]

Experience of and engagement with death

We begin by briefly examining the extent to which people have encountered and engaged with death within their own lives. This could potentially happen in a variety of ways, for example through experiencing the death of someone close to them or attending a funeral.

 **Most respondents report recent experience of death or dying** 

Most respondents report recent experience of death or dying. The vast majority (96 per cent) have attended the funeral of a family member, friend or work colleague at some point in their lives, while the majority of people (63 per cent) have experienced a death in the last five years. As we might expect, the proportions reporting these different experiences were very similar in 2009 and 2012, although they varied across different sections of the population. Clearly then, the majority of people have some, and often recent, experience of death within their own lives.

A good death: what do people want?

What do people want in relation to their own deaths and what factors and considerations underpin attitudes in this area? To explore people's preferences for their own deaths and end of life care, we first of all asked respondents:

And if you were terminally ill, would you like to be told, or would you prefer not to know?

At the most basic level it is clear that the public would want to know about their own imminent death, rather than be shielded from that knowledge. The vast majority (85 per cent) of respondents state that they would like to be told if they were terminally ill, with very similar proportions of men and women expressing this preference. Only slightly more than one in ten (12 per cent) state that they would prefer not to know. This proportion was identical when this question was asked in 2009 and 2012. Respondents aged 75+ years were the least likely to want to be told that they were terminally ill, with 79 per cent expressing this view.

To measure public preferences regarding place of death, we asked respondents:

Thinking about yourself, when the time comes, where do you think would be the best place to die?

At home

In a hospital

In a hospice

In a nursing home

In a care home

Somewhere else

Don't mind

67%

say they would prefer to die at home

The majority of the public, around two in three, would prefer to die at home: 67 per cent of respondents state that this would be their favoured place to die, while far lower proportions identify a hospital (seven per cent) or hospice (four per cent) as their preferred location. No other location is preferred by more than one in twenty respondents, although four per cent indicate that they would prefer to die "somewhere else" and 14 per cent stated that they do not mind where they die.

An individual might have different preferences regarding their place of death depending on the circumstances in which they were to die and the availability of support. To assess how far preferences were affected by the level of support available, we ask respondents who indicated that they would prefer to die at home the following question:

Would you still prefer to die at home even if you did not have sufficient support from family, friends or the social and medical professionals?

60%

who would prefer to die at home change their mind if doing so without support

The data indicate that the presence of sufficient support is crucial in determining public preferences in this area. Six in ten (60 per cent) of those who initially expressed a preference to die at home report that they would change this view if sufficient support from the various sources listed in the question was not available. Nevertheless, more than one in three respondents who would prefer to die at home retained this preference even if sufficient support were not available. The proportion expressing this preference is virtually identical in 2012 to 2009, indicating that there is an enduring preference for death to take place in the home, even without a certain level of support being available.

How do preferences vary across different groups in society? Preferences are fairly similar across different age groups, and dying at home is by far the preferred option in all age groups. The oldest age group (those aged 75+) are much more likely to express a definite preference regarding where they die (with only seven per cent stating that they do not mind, compared with between 13 and 16 per cent in all other age groups).

Home is more than a physical location. It represents familiarity, comfort and the presence of loved ones, as Gott et al. (2004) have noted. While it is therefore unsurprising that a hypothetical question evokes this level of support for dying at home, their study also showed that many people, as they near the end of their lives or as they acquire familiarity with the deaths of others, anticipate that they would prefer to be cared for somewhere other than at home when dying. Gott et al. note that these findings run counter to assumptions that a medicalised, institutional death cannot be a 'good death'. This is not a finding echoed in the data on public attitudes in 2012 reported here, where there are no significant differences between older and younger age groups in terms of the preference to die at home.

Those from lower socio-economic groups are less likely to say that they would prefer to die at home, and more likely to prefer to die in hospital – this is the case, for example, for 10 per cent of those in a semi-routine or routine occupational group, compared with four per cent of those in the highest occupational group (professional and managerial).

The place where we wish to die has major implications for individuals and families, and a much smaller proportion of us actually achieve a home death than would like one. Preferences in this area also have serious implications for those who plan and fund the National Health Service, as a series of planning forecast exercises have made clear (Gomes and Higginson, 2008; Office for National Statistics, 2011). These note that the ageing of the population is likely to influence future trends in place of death, making it harder to maintain or increase the current proportion of home deaths, given that the oldest and poorest patients are less likely to achieve a home death in practice (Higginson et al., 1999).

To explore individual preferences for dying at home and the factors which underpin them further, we seek to measure individual priorities for end of life care. Specifically, we ask respondents:

When the time comes for your death, what do you think would be the most important thing for your end-of-life care?

To be pain free/without pain

To retain my dignity e.g. respectful care and support

To be with family or friends

To be peaceful/calm

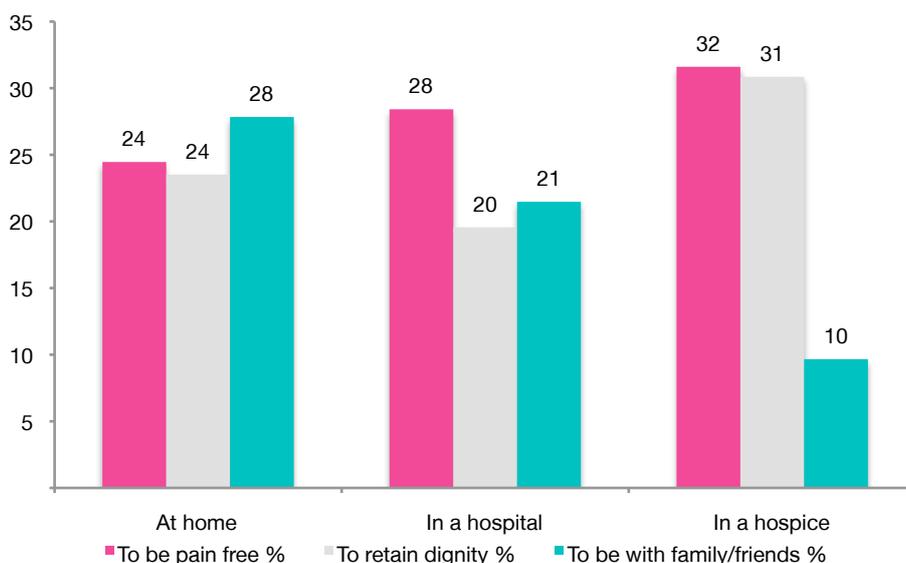
To be sure that I am not a burden on other people

For people to listen and be respectful of my wishes

The preference for a home death appears to be linked to particular priorities for end of life care

Responses to this question for those who identified particular preferences for their place of death are presented in Figure 1, combined for the 2009 and 2012 samples to generate a sufficient sample size for analysis. The preference, expressed by the majority, for a home death would appear to be linked to particular priorities for end of life care. Overall, those who state that they would prefer to die at home feel that the most important aspect of their end of life care would be the presence of family and friends (28 per cent), followed by the need to be pain free (24 per cent) and to retain dignity (24 per cent). People who indicate that they would prefer to die in hospital, however, prioritise the need to be pain free (28 per cent) followed by being with family or friends (21 per cent) and the need to retain their dignity (20 per cent). Meanwhile, those who state that their preferred place of death would be a hospice feel that being pain free and retaining their dignity (31 and 32 per cent), followed by the need to be peaceful and calm (10 per cent) are the most important factors. These findings may reflect respondents' experience of the deaths of others close to them and clearly suggest that priorities for end of life care influence preference for place of death, rather than these being determined in isolation.

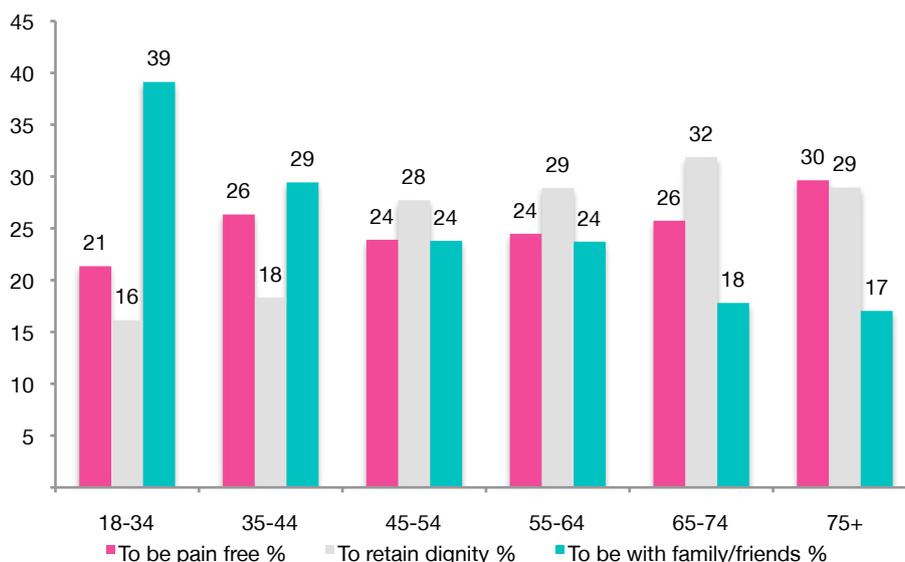
Figure 1 Top three priorities for end of life care, by preferred place of death, 2009 and 2012 combined



The full data on which Figure 1 is based can be found in the appendix to this chapter.

In Figure 2 data from the 2009 and 2012 surveys have been combined in order to obtain a sufficient sample size to explore how priorities for end of life care vary across different age groups, among the subsection of the population who indicated that they would prefer to die at home. The main finding to emerge here is that younger people are more likely to state that being with family and friends would be most important to them (39 per cent compared with 17 per cent of those aged 75+) while older age groups are more likely to state that being pain free would be most important (30 per cent compared with 21 per cent of 18–34 year olds).

Figure 2 Top three priorities for end of life care for people who would prefer to die was at home, by age, 2009 and 2012 combined



The full data on which Figure 2 is based can be found in the appendix to this chapter.

We have seen thus far that the majority of the public would prefer to find out about their impending deaths if they were terminally ill, with an enduring preference for home as the place of death, clearly mediated by priorities for end of life care. But how comfortable is the public in expressing and discussing with others these and other preferences in relation to their own deaths?

We know what we want, but do we talk about death?

To ascertain how comfortable the public feels talking about death, we ask respondents:

And which of the following best describes how you feel when talking about death?

I feel very comfortable talking about death

I feel fairly comfortable talking about death

I have no strong feelings either way

I feel fairly uncomfortable talking about death

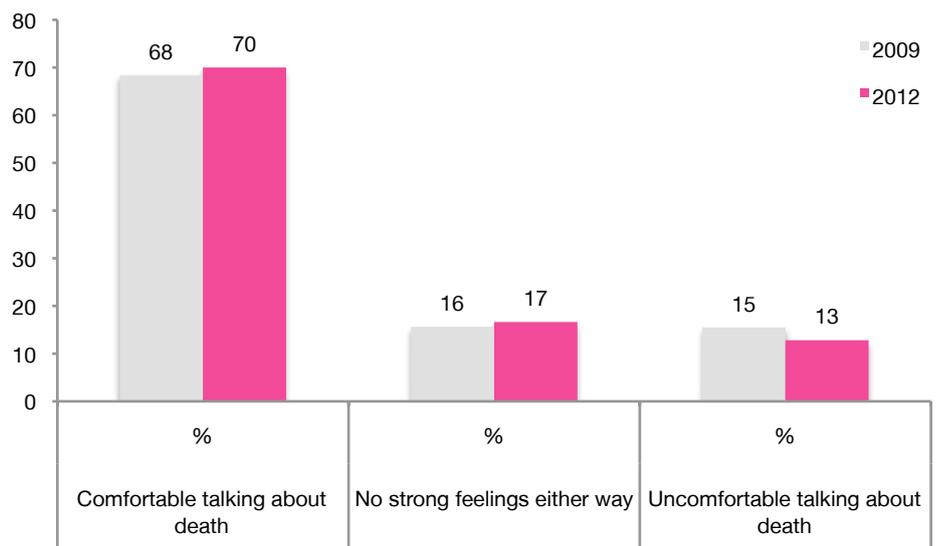
I feel very uncomfortable talking about death

Married people are more likely to feel comfortable speaking about death than single people

Overall, 70 per cent of respondents say they feel comfortable talking about death, while only 13 per cent say they feel uncomfortable doing so. Seventeen per cent indicate that they have no strong view either way. Figure 3 shows how these findings compare with those reported in 2009. Although the results obtained in the two years are broadly similar, there has been a small but significant decrease in the proportion of people stating that they feel very uncomfortable talking about death over the past three years (six per cent in 2009 indicated this, compared with four per cent in 2012). Consequently, the overall proportion of the public who report feeling uncomfortable (very uncomfortable or uncomfortable) has also declined slightly but significantly from 15 per cent to 13 per cent.

The proportions of different age groups who state that they feel comfortable talking about death have not changed significantly since 2009, with the exception of the youngest age group (those aged 18–34) for whom we see a slight but significant decrease from eight per cent to five per cent in the proportion reporting that they feel very uncomfortable talking about death. Interestingly, married people (72 per cent) are more likely to feel comfortable speaking about death than single people (64 per cent). It may be that those who are married are considering their spouses when thinking about their own level of comfort in talking about death.

Figure 3 Comfort with talking about death, 2009 and 2012



The data on which Figure 3 is based can be found in the appendix to this chapter.

Figure 3 shows that the public is fairly relaxed about talking about death in the abstract. However, these feelings may not necessarily translate into actual discussions about one’s own death. In order to explore the nature and extent of any discussions that had taken place regarding specific aspects of respondents’ own deaths, we ask:

And have you ever actually discussed with someone what your wishes would be in any of these areas, if you did not have long to live?

Medical needs

Spiritual and religious needs

Privacy and peace

Dying with dignity - e.g. respectful care and support

Where you would prefer to die

Pain relief

None of these

Around one in three respondents have discussed their wishes in relation to one or more of these areas, (31 per cent in 2012 and 29 per cent in 2009). This suggests that, for a considerable proportion of the public in both years, their reported levels of comfort in talking about dying had not translated into specific conversations about their own deaths. As shown in Table 1, the older age groups – unsurprisingly perhaps – are more likely to have discussed their wishes (45 per cent of 75+ year olds compared with 23 per cent of those aged 18-34).

Table 1 Discussing end of life issues with someone, by age, 2009 and 2012

	2009	2012
Discussed...	%	%
18-34	26	23
35-44	25	28
45-54	27	33
55-64	32	39
65-74	36	35
75+	39	45
All	29	31
<i>Weighted base</i>	1323	2149
<i>Unweighted base</i>	1350	2145

11%

have discussed their spiritual wishes in the event of their death

Despite comparatively low proportions of respondents having discussed various aspects of their deaths with someone else, there is some evidence of change in relation to specific areas of discussion between 2009 and 2012. There has been a slight but significant increase in the number of people who report having ever discussed their wishes in relation to their medical needs (seven per cent reported this in 2009, compared with 10 per cent in 2012). There were particularly marked increases in certain age groups in relation to this issue: for instance, 13 per cent of 35–44 year olds in 2012 said that they had discussed their medical needs with someone, compared with seven per cent in 2009. In addition there has been a significant increase in the number of 55–64 year olds who have discussed their medical needs (six per cent in 2009 compared with 12 per cent in 2012). Overall, women (11 per cent) are significantly more likely to have discussed their wishes in this area than men (seven per cent), with the proportions of both sexes who report doing so having increased slightly but significantly since 2009. When we consider whether discussion of these issues varies across social occupations we find difference between groups in 2009, but not 2012. In 2009 those in managerial and professional occupations were significantly more likely (13 per cent) to mention having discussed their medical needs than respondents from semi routine and routine occupational groups (four per cent). In 2012, differences between social groups were not significant, since a marked improvement was observed for respondents from semi routine and routine occupations feeling able to discuss their wishes (nine per cent) compared with 14 per cent from managerial and professional occupations.

The proportion of the public who report having discussed their spiritual wishes in the event of their death has not changed significantly since 2009 (standing at 12 per cent in 2009 and 11 per cent now). However, this overall stability conceals differences in the reported behaviour of different age groups in this area over time. There has been a significant decrease in the number of 18–34 year olds who reported having discussed their spiritual needs with someone between 2009 and 2012 (12 per cent to eight per cent). However, 55–64 year olds were significantly more likely to have discussed their spiritual needs in 2012 (16 per cent, up from nine per cent in 2009). Respondents in the 75+ age group are most likely to report having discussed their spiritual needs, though the proportion of this group who have actively had such a discussion has not changed between the two years (17 per cent in 2009 and 18 per cent in 2012). It is debatable whether these differences by age reflect the imminence of death or the greater religiosity of the oldest age group. Women (15 per cent) are more likely than men (nine per cent) to have discussed their spiritual needs – reflecting the finding in relation to discussions of medical needs. In both years those from the lower end of the social spectrum were significantly less likely to report having discussed their wishes in relation to their spiritual and religious needs.

Fewer than one in ten respondents (eight per cent) have discussed their wishes in relation to privacy and peace. Within the overall population, 45–54 year olds are significantly more likely to report having discussed their wishes (nine per cent) than they were in 2009 (four per cent), although there is no consistent pattern of change in the other age groups. Overall, women (nine per cent) are significantly more likely to report having discussed their wishes in this area than men (six per cent).

When it comes to discussing dying with dignity, 16 per cent have discussed this (a similar proportion to 2009: 17 per cent). Perhaps unsurprisingly 18–34 year olds are significantly less likely (nine per cent) to have had a discussion on this issue than other age groups (23 per cent for the over 55s). Overall women are significantly more likely than men (20 per cent and 12 per cent respectively) to have discussed this issue – reflecting the trend identified across discussion of a range of aspects of dying.

In nearly all aspects relating to end of life, women are more likely than men to have discussed these issues

Despite the overwhelming preference noted earlier for dying at home, only 12 per cent of respondents have ever discussed with anyone their end of life wishes relating to their preferred place to die. Those in the youngest age groups were least likely to have discussed this (seven per cent), while people in the 55–64 age group were most likely to have done so (17 per cent). Reported behaviour of different age groups has not changed in a consistent way between 2009 and 2012. Again, women are significantly more likely to discuss where they would prefer to die than men in 2012 (15 per cent and eight per cent respectively).

Eight per cent of respondents report having discussed their end of life wishes relating to pain relief. Nine per cent of 55–64 year olds in 2009 had discussed their wishes relating to pain relief; this has risen to 15 per cent in 2012. Overall, women are significantly more likely to have discussed pain relief than men (nine per cent and six per cent respectively).

Although there have been some small shifts since 2009 in terms of whether or not people have embarked on discussions with others on matters relating to their own deaths, the picture overall is relatively consistent – with barely more than one in ten people having had a discussion on any of these issues in both years.

Overall, two-thirds of respondents in 2012 reported not having discussed their wishes in relation to any of the end of life issues we ask about. Men are significantly more likely than women (73 per cent and 62 per cent respectively) to state that they have not discussed any of their wishes relating to these issues – reflecting the findings reported earlier in relation to individual areas of discussion.

Clearly, the level of comfort in talking about death in general reported by a majority of the public has, for all but a minority, not translated into actual discussions of particular aspects of people's own deaths. There is a growing body of research that shows that planning for and talking about end of life – often known as Advance Care Planning (ACP) – is associated with a 'better quality' death (Detering et al., 2010) and less emotional distress for bereaved family members (Teno et al., 2007), suggesting that these data could be seen as a cause for concern. It is therefore important to understand why many people have not discussed various aspects of their deaths, given their reported comfort in discussing this topic in general.

What's stopping people from talking about dying?

We have seen that the public expresses clear preferences and priorities for end of life care, yet more than two in three (68 per cent) have not actually discussed any of these wishes with anyone. To explore why this is the case, we ask the group of respondents who say that they have not discussed any aspects of their own end of life care the following question:

Which of these statements best describes why you have not discussed any of these issues with anyone?

I don't feel comfortable talking about death

Death feels a long way off

I am too young to discuss death

There is no one available for me talk to about death

Other people do not want to talk to me about my death

Don't want to

Keep putting it off/haven't got round to it

Never thought about it

No reason / just don't / just haven't

My family know what I want

Don't want to burden people

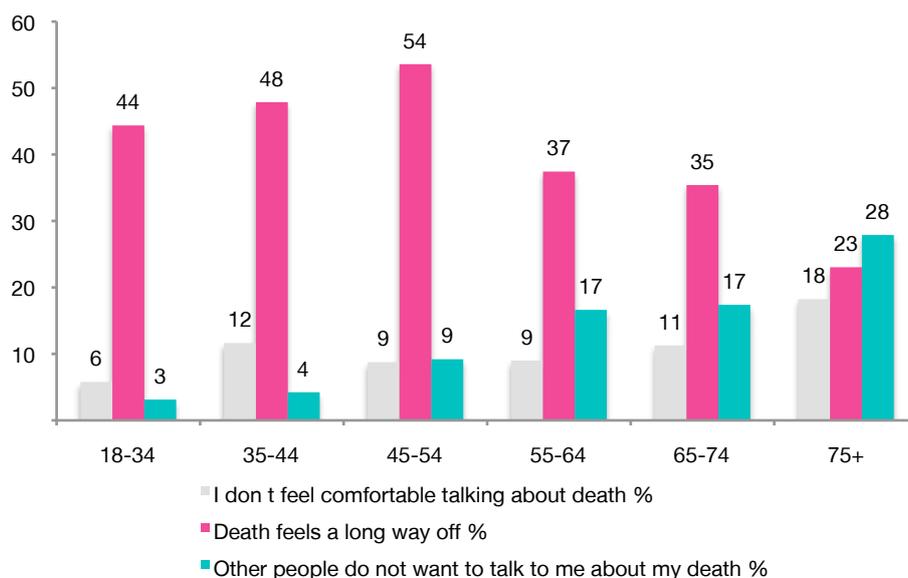
It's just not something you / we talk about

It hasn't come up / never comes up

There's no need

I have discussed something (with someone)

Figure 4 Reasons for not discussing end of life issues, by age



The full data on which Figure 4 is based can be found in the appendix to this chapter.

Figure 4 shows that the main reason provided for not discussing any of these issues is respondents feeling that death is a long way off (similar proportions, 45 per cent in 2009 and 43 per cent in 2012, stated this). Interestingly, among those aged 75+, the proportion of those who have not discussed any aspects of their deaths and gave this reason is 23 per cent (similar to the 19 per cent in 2009 who indicated this). The main reason given by this age group was that “other people do not want to talk to me about my death” (28 per cent in 2012); older people are more likely to say this than younger groups. Furthermore, older respondents are more likely to explain their lack of discussion on the basis that they do not feel comfortable talking about death (18 per cent of those aged 75+ indicated this, compared with six per cent of 18–34 year olds) and that – with a rather depressing complementarity – other people do not want to talk to them about their death (28 per cent compared with three per cent of 18–34 year olds).

Why should this be the case? There is a mounting body of research investigating the factors that encourage or discourage end of life planning, with most studies focusing on health status (Collins et al., 2006) or psychological factors such as death anxiety (Ditto et al., 2006; Zimmermann, 2007). But these approaches can be seen as attempting to ‘medicalise’ the avoidance of discussion about death. A recent Demos discussion paper (Leadbeater and Garber, 2010) offers a more charitable view, noting that, while for some people a ‘good death’ comes about from very openly talking about it, other people will always want only to refer to death obliquely (‘kicking the bucket’, ‘passing away’, ‘giving up the ghost’) and want to hold it at arm’s length by ignoring the reality of the situation for as long as possible, though this may make it less likely that they are ready for some of the difficult choices that must be faced at the end. We are only just beginning to open up our understanding of how people at different stages of life and from different cultural backgrounds view this issue (Carr, 2012).

What would make people discuss dying?

Given that the main reported reason for a lack of discussion around dying is that it feels so far off, we ask respondents to imagine a situation where they do not have long to live, in order to explore what their motivations for planning would be in that scenario. Specifically, we ask respondents:

If you knew you did not have long to live, which of these would be most likely to make you start planning for your death?

To make my death/dying easier for my family

To have the funeral I wanted

To ensure I had the right care and support when I am dying

If it was easy to access information about how to plan for my death

If I got support from someone to help me make a written care plan and end-of-life plan for myself

63%

would start planning for their death to make it easier for family or friends

In 2012, a majority of respondents state that they would be most likely to start planning for their death to make it easier for family or friends (63 per cent), a very similar proportion to that found in 2009.

Another driver for a minority of the public (15 per cent) is the desire to ensure the right care and support for themselves when they were dying.

As we have seen, the fact that death is a long way off is cited by a majority of respondents to justify their lack of discussion of their specific wishes to date; this explanation is also provided by a considerable proportion of older respondents for whom, in reality, this might not be the case. Despite a lack of discussion around death, it might be that individuals have nevertheless begun to make practical plans and provision for their own end of life. We finally turn to consider how far this is the case.

Has the public planned for death and how confident are people about doing so?

To what extent have people taken practical steps to plan for their own end of their life and how confident do they feel about doing this? To identify what plans the public currently has in place, we asked respondents the following two questions:

Do you have any written plans for your own end of life care, financial wishes or a written plan for your funeral?

My wishes and preferences about my end of life care should I become unable to decide for myself (sometimes called a 'living will' or 'advance care plan')

My funeral wishes/plan

My plan for how I would support myself financially when I am dying

Written wishes about organ donation

None of these

Do you have any of the following?

A will

An organ donor card / I am registered as an organ donor

None of these

Overall five per cent of respondents report having a living will or advance care plan (a comparable proportion to the four per cent in 2009 who indicated this). This proportion varies significantly by age, with those aged 18–34 being the least likely to have a living will (one per cent) and those aged 75+ being the most likely to do so (12 per cent). This is unsurprising as we would expect those who are older to be more likely to have put plans in place for their deaths. There are no differences between men and women in terms of the proportions having a living will or advance care plan.

A larger proportion of respondents (11 per cent) stated that they have written plans for their own funeral. Older people, not surprisingly, are more likely to have written down their funeral wishes or plans (31 per cent of those aged 75+ compared with three per cent of 18–34 year olds). Nevertheless, it is worth noting that more than two-thirds of the oldest group do not have a written funeral plan. More women than men (13 per cent and 10 per cent respectively) have a written plan for their own funeral. Differences among social groups were small and not significant.

Extremely small numbers report having a written plan for how they will support themselves financially when they are dying (three per cent report having such a plan, similar to the proportion, two per cent, in 2009 who indicated this). There is no difference between men and women in this regard.

31%

of those aged 75+ have written down their funeral wishes or plans

Extremely small numbers have a written plan for supporting themselves financially when dying

Overall 12 per cent of respondents stated that they have written wishes about organ donations, a proportion comparable to that found in 2009 (11 per cent). Those aged 55–64 are significantly more likely to have written wishes about organ donation in 2012 (17 per cent) than in 2009 (eight per cent). This was also the case for those aged 75+: 11 per cent of this age group report having written wishes about organ donation, compared with four per cent in 2009. Women (15 per cent) are significantly more likely to have written wishes in this area than men (nine per cent).

Overall, just over three-quarters of respondents state that they do not have any written plans about their wishes in relation to dying (76 per cent, the same proportion as in 2009). Reflecting trends identified in relation to specific expressions of wishes, the younger age groups are less likely to have any written plan than those over 75; this is also the case for men, as compared with women.

When we consider responses to the second question, we find that, curiously, in defiance of most other trends, there has been a significant decrease in the number of respondents with a will (35 per cent) since 2009 (39 per cent). In both years, the majority of respondents report not having a will. Why does this matter? Carr and Dmitry (2007, p. 299) note that writing a will may bring people to confront other issues about end of life, either by themselves or with the aid of a solicitor, so that

...it may be a natural step after doing financial or estate planning. That is, actions to protect one's assets, such as the execution of a signed and witnessed will, may trigger other types of planning in tandem.

Men and women are equally likely to say they have a will (35 per cent). Though the proportion of men reporting this has remained relatively steady since 2009, the proportion of women with a will has reduced from 41 per cent in 2009 to 35 per cent in 2012. As we might expect, the proportion of people with a will increases with age. Only five per cent of 18–34 year olds have a will, for instance, whereas 77 per cent of those aged 75+ do so. However, this does mean that nearly a quarter of people in the oldest age group have made no legal provision for their belongings after death. Only 64 per cent of those aged 65–74 years have a will, a significant decrease from the 76 per cent in 2009 who reported this. Respondents in higher social groups are more likely to have a will than those in lower social classes (for example, this is the case for 40 per cent of those in managerial and professional occupations compared with 23 per cent of those in semi-routine and routine occupations). The proportion of different socio-economic groups who report having wills have not changed in a consistent way since 2009.

28%

say they have an organ donor card or are registered as an organ donor

Twenty-eight per cent of respondents say they have an organ donor card or are registered as an organ donor (little change from 2009, when 27 per cent said this). This is despite a range of new measures introduced during this period and designed to make it easier for people to register as organ donors, such as ticking a box on a driving licence application. In 2009 those aged 35–44 were significantly more likely to report having a donor card (36 per cent) than the 75+ age group (20 per cent). However, by 2012, the 45–54 and 55–64 age groups have achieved a similar proportion of committed/registered donors (34 per cent and 32 per cent respectively). The over 75s are least likely to have a donor card. Significantly more women than men have a donor card (33 per cent compared with 24 per cent), though the number of men with a donor card has increased slightly from 2009 (22 per cent). In 2012 36 per cent of respondents in managerial and professional occupations state that they have an organ donor card, while significantly less of those from semi-routine and routine occupations said they have one (19 per cent).

Overall around half (48 per cent) of respondents have neither a will nor a donor card (a similar proportion to the 45 per cent in 2009 who reported this). However, an increase is evident in certain sections of the population. Those aged 18–34 are significantly more likely to have neither a will or donor card in 2012 (71 per cent) than they were in 2009 (64 per cent). More men (50 per cent) than women (45 per cent) state that they have neither a donor card nor a will – though the number of women having neither a will nor a donor card has grown between 2009 and 2012 (from 40 to 45 per cent).

In addition to asking people what actual practical provision they had made for the end of life, we also gauged how confident people feel about being able to plan for their own deaths. We asked the question:

I am now going to read out some issues that might be important to someone if they did not have long to live. For each one, I would like you to tell me how confident you would feel.

So firstly, how confident are you that you would be able to plan to get the right sort of care and support, if you did not have long to live?

How confident are you about being able to plan for your financial support if you did not have long to live?

How confident are you about being able to plan your funeral arrangements?

How confident are you about being able to plan for the right sort of care or support at the end of life?

Three quarters (73 per cent) of respondents say they feel confident (“confident” or “very confident”) that they could make adequate financial plans for the end of life. That said, only three per cent of those who feel confident about this actually have a plan for how they will support themselves financially when they are dying. Similarly, even among those stating that they are confident about being able to plan their own funerals, only 13 per cent actually have a written document containing their funeral wishes/plan. Despite the reluctance to discuss the matter openly – and the relatively low numbers having actually made any provision in practical terms – four in five respondents (79 per cent) state that they feel confident about planning for the right sort of care and support at the end of life.

While the majority of the public report feeling comfortable about discussing death in general and confident about dealing with issues relating to the end of life, in practice, it is clear that, for many, this reported comfort and confidence has not translated into practical plans or specific discussions about their own end of life planning.

Conclusions

In this chapter we have considered public attitudes to dying in relation to the increasingly held premise that there is a need to normalise death and build the conversation about better ways of dying. This stems in part from a desire to give the dying and their relatives more control and choice about the manner of their going, in the belief that a 'good death' is usually one which gives people choice and dignity and which can make it less difficult to come to terms with bereavement. With growing numbers of older and very much older people, it is necessary to think seriously about how we handle death as a society (House of Lords, 2013). Shifting public opinion on such an affecting matter is not likely to be a simple or speedy process.

The evidence reported above reveals an intricate triangle of what people think and feel, what they are prepared to discuss openly and what they have put into action. Despite theoretical discussions about the extent to which death is sequestered or hidden in modern society, a high number of respondents have attended a funeral or had a recent experience of the death of someone close to them. When asked to look ahead to their own deaths, an enduring majority of people, more than two-thirds, express a wish to die at home. Such a desire is understandable, and is tempered for some by the need to be clear that support services would be available.

If people know what they want in terms of a 'good death' for themselves, are they prepared to discuss this and talk openly about death? Irrespective of age, a majority of the public report feeling comfortable talking about death (although not necessarily their own), with older respondents being slightly more likely to feel this, compared with 2009. Married people feel significantly more comfortable than unmarried people in talking about death, possibly reflecting the feeling that talking about this subject still requires for many a level of intimacy and confidentiality, a finding echoed in a later section where we find that an acknowledged barrier to discussion is that many respondents feel hampered by the fact that other people do not want to talk to them about death.

Despite the reported level of people's comfort with talking about death in general and their exposure to bereavement, less than one third of people have actually discussed any aspect of their specific wishes about their end of life with someone. There has been a slight rise since 2009 among older respondents in the proportion who have done this and, in general, the trend would seem to be towards more openness and willingness to talk. However, those in lower socio-economic groups are much less likely to have discussed their spiritual needs, for instance, than others. If the public health view that living well includes the need to plan for dying well, then this begins to look like yet another area where inequalities are evident, with the poorer members of society less likely to achieve a 'good death' and a less distressing one for relatives than those who are better off.

Barriers to discussion for most people revolve around death seeming 'a long way off', even for those in the older age groups, although perhaps that conceals more than a little superstitious belief that not talking about the topic helps keep it that way. The thing most likely to get people to act is the desire to make things easier for their family and friends – with almost two-thirds of respondents acknowledging this would be a potent driver for action.

The big challenge, however, is to see talk being consistently translated into concrete actions. Actions like making a will, setting out funeral or financial wishes, having an advance care plan/living will or registering as an organ donor remain relatively uncommon. While these may be small actions in themselves,

they are likely to trigger conversations about the way in which someone wants to reach the end of life. Within the older age groups one might expect the most serious contemplation of these issues, as people reach that stage of life where care for ageing parents becomes an issue and begin to confront their own mortality. In these age groups there have been small but significant shifts in attitudes since 2009, with higher proportions of people beginning to discuss their wishes and to set these down in the form of written plans. Nevertheless, only one in twenty has an advance care plan, and just over one in ten a funeral plan. Only just over a third of people have made a will and a quarter of people in the oldest age group do not have one.

Despite people's confidence in their ability to manage their affairs at end of life is surprisingly high, and the challenge must therefore be to translate this confidence and the growing ease with which people claim to regard such discussion into clear statements of their wishes and practical actions to achieve these.

There is not likely to be a 'one size fits all' good death, and the data reported above enable us to start unpicking some of the ways in which groups within a diverse society might have different sensitivities and need to move at different speeds on this complex issue. Making our wishes and preferences known either in writing or verbally enables family and friends to provide and care for us, and an environment in which this is allowed and encouraged this is a litmus test for a more compassionate society. The findings reported here indicate that different sections of the British public exhibit varying levels of progress towards achieving this.

Notes

[1] References refer to the Oxford Modern Classics edition (2008).

[2] The British Social Attitudes survey is designed to yield a representative sample of adults aged 18 or over. Since 1993, the sampling frame for the survey has been the Postcode Address File (PAF), a list of addresses (or postal delivery points) compiled by the Post Office. The sampling method involved a multi-stage design, with three separate stages of selection: sector, address, individual. The sample was split into three equally-sized portions. Each portion was asked a different version of the questionnaire (versions A, B and C). Depending on the number of versions in which it was included, each 'module' of questions was thus asked either of the full sample (3,311 respondents) or of a random third or two-thirds of the sample. The structure of the questionnaire can be found at www.natcen.ac.uk/bsa. Questions reported in this chapter were asked on two versions of the questionnaire. Interviewing was mainly carried out between June and September 2012, with a small number of interviews taking place in October and November. Fieldwork was conducted by interviewers drawn from NatCen Social Research's regular panel and conducted using face-to-face computer-assisted interviewing. The overall response rate was 53%, giving 3248 interviews. The weights for the British Social Attitudes survey correct for the unequal selection of addresses, dwelling units and individuals, and for biases caused by differential non-response. The final stage of weighting was to adjust the final non-response weight so that the weighted sample matched the population in terms of age, sex and region. For further details please see the Technical details section here: www.bsa-29.natcen.ac.uk.

[3] The NatCen Omnibus employs a stratified random probability sample drawn from the Postcode Address File (PAF). All sectors in mainland Great Britain (England, Wales and Scotland), excluding the area of Scotland north of the Caledonian Canal were covered. A total of 3,060 addresses were issued addresses, each selected with equal probability. A single adult (defined as anyone aged 16 or over) was then selected at random out of all adults residing at that address to take part in the survey. [For comparability with British Social Attitudes data, anyone under 18 has been excluded from the analysis for this chapter.] Interviews were carried out by NatCen interviewers using computer assisted personal interviewing. Fieldwork ran 23rd July – 20th September 2009. The overall response rate was 49%, giving 1375 interviews. The weighting for the Omnibus survey consisted of two components: selection weights to correct for individuals' differing probabilities of selection, and calibration weighting to adjust the weighted achieved sample to match population estimates. The calibration weights were then scaled to give the final weight.

[4] For table conventions please see www.bsa-29.natcen.ac.uk/read-the-report/table-conventions.aspx. In this chapter the data presented are from 2012 unless otherwise stated.

References

- Blackmore, S., Pring, A. and Verne, J. (2011), *Predicting Death: estimating the proportion of deaths that are 'unexpected'*, London: NHS National End Of Life Care Programme
- Carr, D. (2012), 'The Social Stratification of Older Adults' Preparations for End-of-Life Health Care', *Journal of Health and Social Behavior*, **53(3)**: 297–312
- Carr, D. and Dmitry, K. (2007), 'End of Life Health Care Planning among Young-Old Adults: An Assessment of Psychosocial Influences', *Journal of Gerontology: Social Sciences*, **62B(2)**: 135–141
- Collins, L.G., Parks, S.M. and Winter, L. (2006), 'The state of Advance Care Planning: One decade after SUPPORT', *American Journal of Hospice & Palliative Medicine*, **23(5)**: 378–384
- Department of Health (2008), *End of Life Care Strategy: promoting high quality care for all adults at the end of life*, London: Department of Health
- Department of Health (2012), *First national VOICES survey of bereaved people*, London: Department of Health
- Detering, K.M., Hancock, A.D., Reade, M.C. and Silvester, W. (2010), 'The Impact of Advance Care Planning on End of Life Care in Elderly Patients: Randomised Controlled Trial', *British Medical Journal (Clinical Research Education)*, **340**: 1345
- Ditto, P.H., Hawkins, N.A. and Pizzaro, D.A. (2006), 'Imagining the End of Life: On the Psychology of Advance Decision Making', *Motivation and Emotion*, **27**: 481–502
- Gomes, B. and Higginson, I.J. (2008), 'Where people die (1974–2030): past trends, future projections and implications for care', *Palliative Medicine*, **22(1)**: 33–41
- Gott, M. Seymour, J. Bellamy, G. Clark, D. and Ahmedzai, S. (2004), 'Older people's views about home as a place of care at the end of life', *Palliative Medicine*, **18**: 460–467

Haraldsdottir, E., Clark, P. and Murray, S.A. (2010), 'Health-promoting palliative care arrives in Scotland', *European Journal of Palliative Care*, **17(3)**: 130–132

Hauser, J.M. and Kramer, B.J. (2004), 'Family caregivers in palliative care', *Clinics in Geriatric Medicine*, **20(4)**: 671–688

Higginson, I., Jarman, B., Astin, P., and Dolan, S. (1999), 'Do social factors affect where patients die: an analysis of 10 years of cancer deaths in England', *Journal of Public Health Medicine*, **21(1)**: 22–28

Higginson, I. (2001), *The Palliative Care of Londoners: Needs, experience, outcomes and future strategy*, London: London Regional Strategy Group for Palliative Care

Hobbes, T. (1651) *Leviathan*, Oxford: Oxford Modern Classics (2008)

House of Lords (2013) *Ready for aging? Report of session 2012–2013 – Select Committee on Public Service and Demographic Change*, London: The Stationary Office

Howarth, G. (2007) 'Whatever happened to the working class: An examination of working class cultures in the sociology of death', *Health Sociology Review*, **16(5)**: 425–435

Kellehear, A. (2005), *Compassionate Cities: Public Health and end-of-life care*, London: Routledge

Leadbeater, C. and Garber, J. (2010), *Dying for Change*, London: Demos

Mitchell, G.K. (2002), 'How well do general practitioners deliver palliative care? A systematic review', *Palliative Medicine*, **16**: 457–464

Office for National Statistics (2011), *National population projections 2010-based statistical bulletin*, London: Crown Office

Parker, G.D., Smith, T., Corzine, M., Mitchell, G., Schrader, S., Hayslip, B. and Fanning, L. (2012), 'Assessing attitudinal barriers towards end-of-life care', *American Journal of Hospice and Palliative Medicine*, **29**: 438–442

Pring, A. and Verne, J. (2012), *Deprivation and Death: Variation in place and cause of death*, London: NHS National End Of Life Care Programme

Teno, J.M., Gruneir, A., Schwartz, Z., Nanda, A. and Wetle, T. (2007), 'Association between Advance Directives and Quality of End-of-Life Care: A National Study', *Journal of the American Geriatrics Society*, **55(2)**: 189–194

World Health Organisation (2010), '*WHO Definition of Palliative Care*', available at: www.who.int/cancer/palliative/definition/en/

Zimmermann, C. (2007), 'Death Denial: Obstacle or Instrument for Palliative Care?', *Sociology of Health and Illness*, **29(2)**: 297–314

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Appendix

The data for Figures 1, 2, 3 and 4 are shown below.

Table A.1 Priorities for end of life care, by preferred place of death, 2009 and 2012 combined

	At home	In a hospital	In a hospice	In a nursing home	In a care home	Somewhere else	Don't mind
	%	%	%	%	%	%	%
To be pain free	24	28	32	23	18	16	20
To retain my dignity	24	20	31	21	12	13	23
To be with family or friends	28	21	10	19	40	27	23
To be peaceful/calm	9	12	10	13	14	9	10
To be sure that I am not a burden on other people	9	15	9	20	16	18	12
For people to listen and be respectful of my wishes	5	4	8	4	-	16	10
<i>Weighted base</i>	2259	231	156	36	26	137	438
<i>Unweighted base</i>	2259	231	185	39	25	112	440

Table A.2 Priorities for end of life care for people who would prefer to die was at home, by age, 2009 and 2012 combined

	18-34	35-44	45-54	55-64	65-74	75+
	%	%	%	%	%	%
To be pain free	21	26	24	24	26	30
To retain my dignity	16	18	28	29	32	29
To be with family or friends	39	29	24	24	18	17
To be peaceful/calm	11	10	8	7	11	9
To be sure that I am not a burden on other people	7	9	11	8	8	10
For people to listen and be respectful of my wishes	5	6	5	7	5	4
<i>Weighted base</i>	649	396	392	352	270	198
<i>Unweighted base</i>	462	389	368	384	370	284

Table A.3 Comfort with talking about death, 2009 and 2012

	2009	2012
	%	%
Comfortable talking about death	68	70
No strong feelings either way	16	17
Uncomfortable talking about death	15	13
<i>Weighted base</i>	1323	2149
<i>Unweighted base</i>	1350	2145

Table A.4 Reasons for not discussing end of life issues, by age

	18-34	35-44	45-54	55-64	65-74	75+
	%	%	%	%	%	%
I don't feel comfortable talking about death	6	12	9	9	11	18
Death feels a long way off	44	48	54	37	35	23
I am too young to discuss death	39	21	14	7	2	4
There is no one available for me to talk to about death	1	2	3	5	2	3
Other people do not want to talk to me about my death	3	4	9	17	17	28
Don't want to	-	-	-	1	-	-
Keep putting it off/ haven't got round to it	-	*	*	3	2	1
Never thought about it	2	3	2	3	5	1
No reason/ just don't/ just haven't	-	*	*	2	1	5
My family know what I want	-	-	*	*	-	1
Don't want to burden people	-	*	1	-	*	-
It's just not something you / we talk about	*	-	-	-	1	2
It hasn't come up / never comes up	*	2	1	3	3	1
There s no need	*	1	*	-	3	-
I have discussed something (with someone)	-	1	-	*	*	-
Other	4	6	4	8	7	7
<i>Weighted base</i>	450	263	251	185	164	91
<i>Unweighted base</i>	295	263	232	206	218	133