End of life care

4

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Summary

- This chapter reports data about people's experiences of providing end of life care to someone who was close to them who died within the last five years of a terminal illness. It explores the levels, frequency and duration of care participants provided, other care services involved, and the impact on the person providing end of life care.
- Around a quarter of participants reported that someone close to them had died from a terminal illness in the last five years. Overall women were more likely than men to report that someone close to them had died (26% of women and 23% of men).
- For both men and women, the likelihood of reporting anyone close to them having died in the last five years differed with age. This peaked in the middle age groups, being highest between the ages of 45-64.
- The pattern of relationship of the person who died to the participant changed with age in a way that may be expected. Among younger adults relatives other than immediate family were the most frequently mentioned, while parents accounted for more of the deaths in participants in the middle age groups, and sibling and spouse/partner deaths were more common among the older age groups.
- 74% of women and 69% of men reported cancer as the illness the person close to them had died from. The next most frequently reported illnesses, emphysema or other lung disease, and end stage heart failure, were mentioned by fewer than one in ten.
- Men and women most commonly reported that the place the person close to them had died was a hospital (47% of men and 42% of women). Home was the next most common place of death (31% and 33%) followed by a hospice (14% and 16%).
- Overall 33% of men and 43% of women provided either personal care, other care or both types of care to the person close to them that died. More women than men reported having provided care, and higher proportions of older and middle age groups than younger age groups had provided care.
- Women were more likely than men to have provided care daily. For both men and women, the likelihood of providing daily care increased with age.
- More women than men had provided personal care for months or more than a year rather than a shorter period. Among women 11% had provided care to the person close to them who died for more than a year, and a further 12% had provided it for months. Equivalent proportions for men were 8% and 9%. A similar pattern was seen for other types of care.
- Participants who reported the person close to them had died of cancer were twice as likely to mention use of palliative care compared with those reporting other illnesses (68% of men and women for cancer, 31% and 34% respectively for other illnesses).
- More than three quarters of men and women said that they would definitely take on the role of caring again in similar circumstances (76% and 78% respectively).
- Around nine out of ten men and women said that they had been able to continue with

their life following the death of the person close to them (92% and 89% respectively). The likelihood of reporting problems with being able to continue with their own life generally increased with age and was higher among women than men.

4.1 Introduction

End of life care has become an increasing priority within recent years for government, health service commissioners and health and social care professionals. The Department of Health published its ten year End of Life Care Strategy for England in July 2008.[1] The aim of this strategy was to promote high quality care for all adults at the end of life. In addition to this, the National Institute for Health and Care Excellence (NICE) published a quality standard for end of life care in 2011.[2] This sets out high quality markers for end of life care for terminal and acute conditions and includes support for the families and other informal carers of people at the end of their life. Complementing work to change the way end of life care is delivered among health care professionals and carers, there has also been a push to improve public awareness of issues around end of life care, and to influence behaviour. Dying Matters[3] is a coalition set up in 2009 and led by the National Council for Palliative Care[4] which aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life.

Approximately 500,000 people die in England each year.[2] When asked, most people say they would prefer to die at home.[5,6] However, mortality statistics show that place of death is most commonly in hospital.[7] Evidence from VOICES, the national bereavement survey, also suggests there are differences in perceived quality and experience of care in different settings and by illness type.[8] As forecasts predict an increase of around 17% in the numbers of people dying by 2030,[9] there needs to be debate about meeting people's preferences for where they die and the care they receive, and the services that are required need to be planned.

Dying at home often means relying on family and friends. If the increase in deaths over the coming years and achievement of increased patient choice in place of death is realised, many more people will be dying at home. This means that more families and carers will be affected by end of life care. Evidence suggests that providing care for someone at the end of life can have negative physical and mental health impacts as well as negative financial and social impacts.[10,11]

This chapter reports data from the Health Survey for England (HSE) 2013 about people's experiences of providing end of life care to someone who was close to them who died within the last five years. Questions established brief details of the person's death, and also explore the levels of care participants provided, other care services provided, and the impact on the participant.

4.2 Methods and definitions

4.2.1 The person who died

A short module of questions about end of life care was included in the HSE 2013. The full questionnaire is available in Volume 2 of this report, *Methods and documentation*, Appendix B. The questions were adapted from a set of questions used in the South Australian Health Omnibus Survey (HOS) from 2000-2007.[12] Participants were asked whether in the past five years anyone close to them had died of a terminal illness like cancer, motor neurone disease or emphysema. What constituted 'close to' them was not defined in the questionnaire and so this was self defined by the participant. If more than one person close to the participant had died in that period, participants were asked to think about the person who had died most recently.

4.2.2 The illness the person died of

Participants who said that someone close to them had died of a terminal illness were asked what illness the person had died of. They were shown a card listing options, and could also give other answers, or indicate that they did not know the illness.[13] More than one illness

could be selected, although most participants mentioned only one. The illnesses were as reported by participants rather than official causes of death. Because of this, and because participants were asked only to report deaths from a terminal illness, the causes reported will not correspond with data on all causes of deaths recorded by the Office of National Statistics. For instance, deaths from a terminal illness will often have excluded sudden deaths if they were not preceded by an illness. It was left to participants' judgement about what counted as a terminal illness, for instance whether to include someone's death from a heart attack if they had suffered from heart disease before they died.

4.2.3 Personal and other care

All participants who reported that someone close to them had died in the last five years were asked whether they had provided any personal care for that person. They were also asked whether they had looked after or given special help in any other way. These types of care are presented separately in this chapter.

Personal care is defined as things like help with washing, dressing, going to the toilet or eating.

Other types of care are defined as things like keeping the person company, doing errands, laundry, shopping, giving lifts, taking to appointments or taking out for recreation.

4.2.4 Services used

Participants were asked whether a palliative care service was used for the person who had died and separately about whether any other care services were used.

Palliative care was described as a service which aims to care, not to cure, to relieve pain and distress for people who are dying and to support patients, families and friends in approaching death and coping with grief. Typical services include use of a hospice, and visits from Marie Curie and/or Macmillan nurses.

Other care services were defined as things like social services, a private care company, meals on wheels and support from voluntary groups.

4.3 Experience of anyone close dying in the last five years

4.3.1 Experience of someone close dying in last five years

Around a quarter of participants reported that someone close to them had died from a terminal illness in the last five years. Overall women were more likely than men to report this (26% of women and 23% of men). For both men and women, the likelihood of reporting anyone close to them having died in the last five years differed with age, as shown in Figure 4A. This peaked in the middle age groups, being highest between the ages of 45-64.

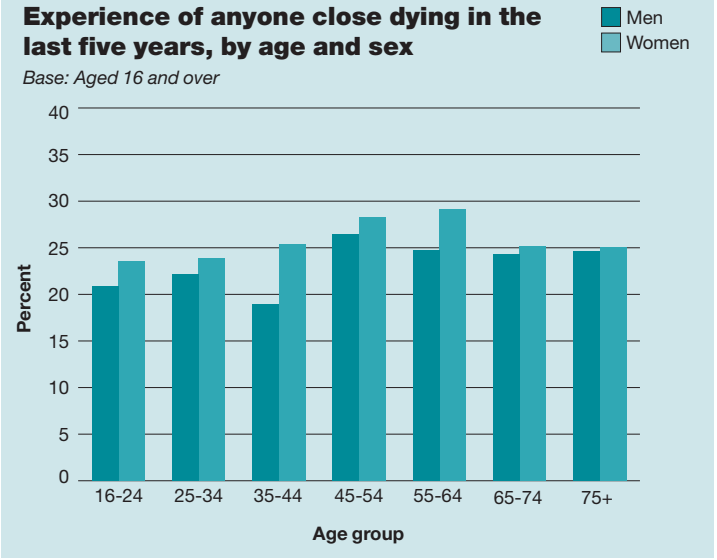
Table 4.1, Figure 4A

There was no statistically significant variation by region in the likelihood of participants reporting anyone close to them dying in the last five years. Similarly, across quintiles of equivalised household income and area level deprivation (Index of Multiple Deprivation) people were equally likely to report a close death. **Table 4.2-4.4**

4.3.2 Relationship to the person who died

The most commonly reported relationship of the person who died to the participant was a relative other than immediate family (spouse/partner, parent, child, brother and sister). These other relatives accounted for just under half of the people who had died (mentioned by 48% of men and 46% of women who knew someone close who had died). The next most common relationship was a parent (20% of those reported by men and 19% of those reported by women), followed by friend (13% and 12% respectively), sibling (9% and 11%), spouse or partner (6% for both men and women) and child (3% and 4%).

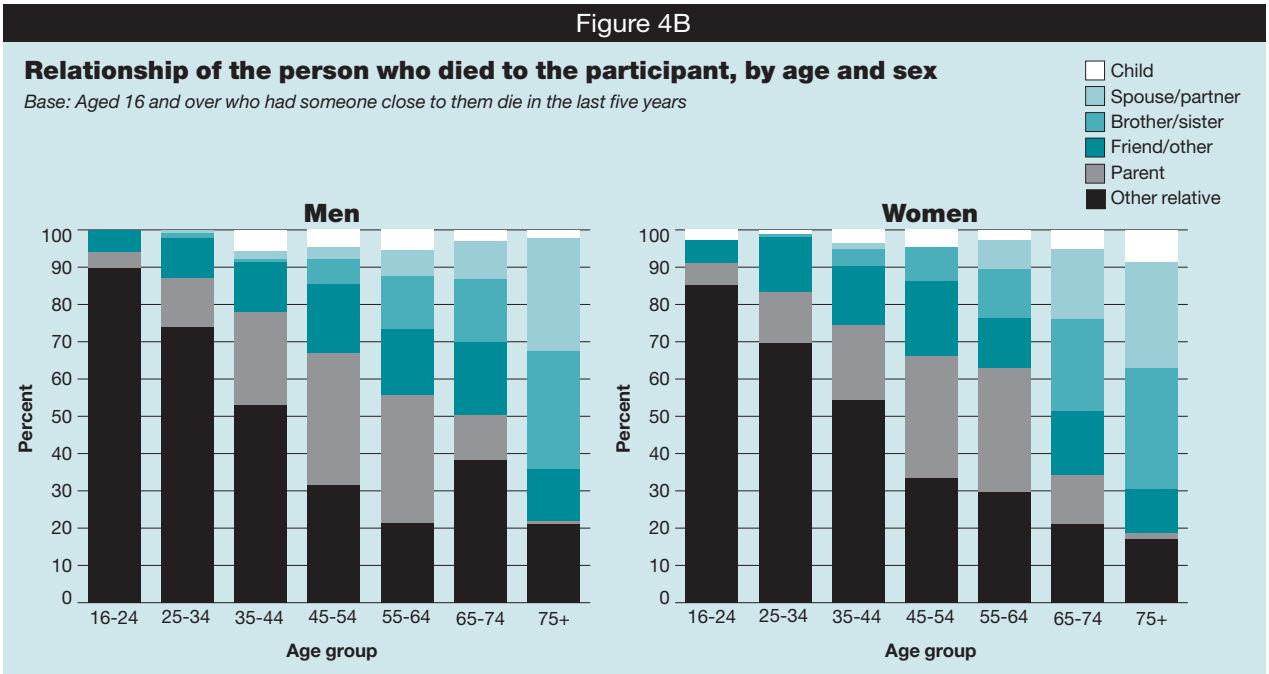
Figure 4A



The pattern of relationship to the participant changed with age in a way that may be expected, as shown in Figure 4B. Among younger adults 'other relatives' (which might include grandparents, older aunts and uncles) were the most frequently mentioned, while parents accounted for more of the deaths in participants in the middle age groups, and sibling and spouse/partner deaths were more common among the older age groups. A higher proportion of women than men in the 65-74 age group mentioned spouse/partner deaths. This is likely to reflect the difference in life expectancy between men and women.

Table 4.5, Figure 4B

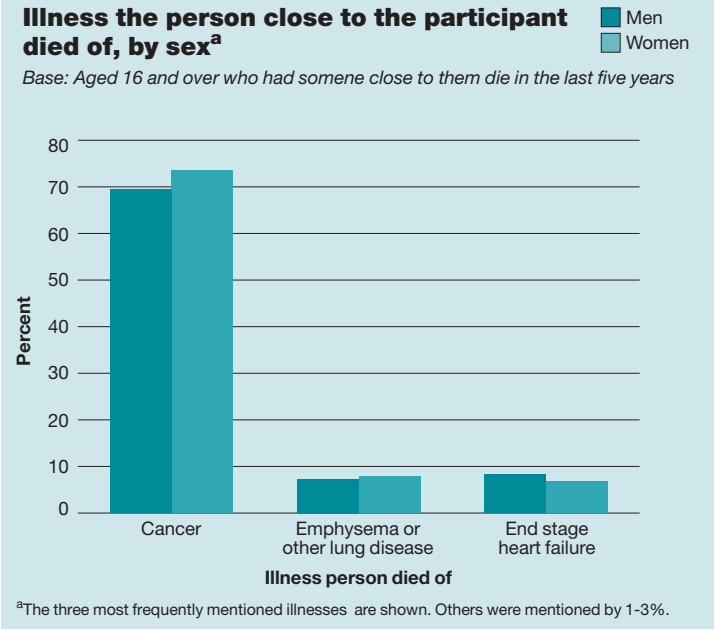
Figure 4B



4.3.3 Illness person died of

Participants were asked to indicate which terminal illness the person close to them had died from. A large majority had died of cancer, with more women than men reporting this (74% of the deaths reported by women and 69% reported by men). This was much more common than the next most frequently reported illnesses; emphysema or other lung disease, and end stage heart failure (7% and 8% respectively among men and 8% and 7% respectively among women) as shown in Figure 4C. Other illnesses such as end stage liver failure, motor neurone disease, multiple sclerosis, end stage kidney failure, dementia, stroke or Parkinson's disease were given in only a small number of cases (between 1% and 3% for each illness).

Figure 4C



[a]The three most frequently mentioned illnesses are shown. Others were mentioned by 1-3%.

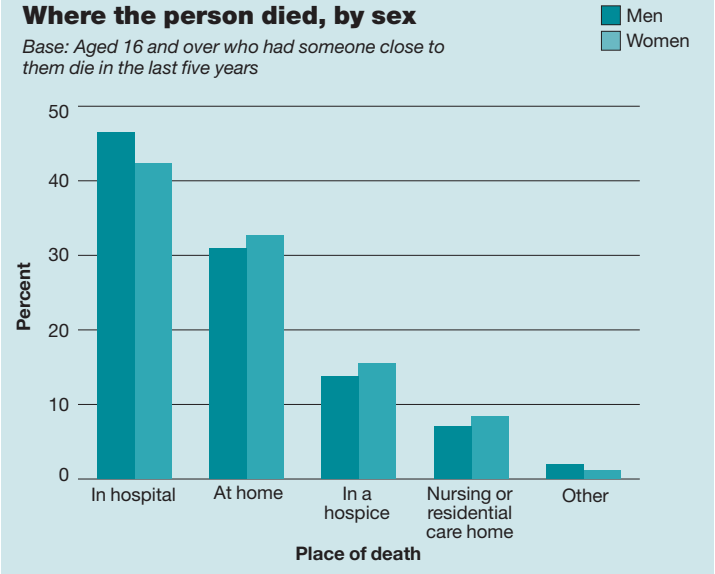
The illness participants mentioned the person close to them had died of varied by age. Younger people were more likely to mention someone close to them dying of cancer. This is likely to be a function of the participant's relationship with the person and their life stage. With increasing age, participants were more likely to report deaths of parents, partners and siblings who would themselves be older people. Therefore it is to be expected that middle and older age groups were more likely than younger groups to report other types of illnesses which are more age related, such as lung disease and heart failure.

Table 4.6, Figure 4C

4.3.4 Where the person died

Men and women most commonly reported that the place the person close to them had died was a hospital (47% of men and 42% of women). Home was the next most common place of death (31% and 33%) followed by a hospice (14% and 16%), as shown in Figure 4D.

Figure 4D



Deaths at home included the home of the person who died (not shared with the participant), and the participant's home – either because they shared the home, or the person had stayed there in the time up to their death. The likelihood of the death happening at the participant's home increased among older age groups. This reflects the fact that older participants were more likely to report the death of a spouse. The likelihood of dying at

home in general (either the participant's or the deceased's) showed no significant variation by age. **Table 4.7, Figure 4D**

4.4 Level and frequency of care provided

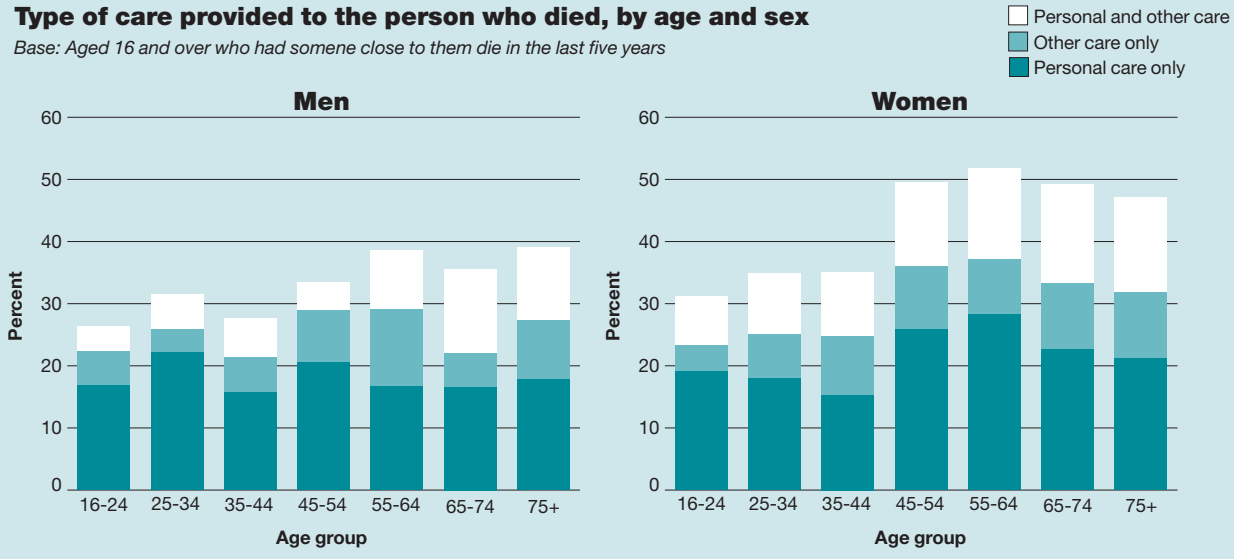
4.4.1 Providing personal and other care

Overall 33% of men and 43% of women provided personal care, other care or both for the person close to them who died. More women than men reported having provided personal care to the person who died (34% compared with 26%), and similarly more women than men provided other care (21% and 14% respectively). Therefore women were also more likely than men to provide a combination of both kinds of care. The proportions providing care were higher in older and especially middle age groups, as shown in Figure 4E.

Figure 4E

Type of care provided to the person who died, by age and sex

Base: Aged 16 and over who had somene close to them die in the last five years



Participants were asked whether they had provided personal and other care daily, occasionally or rarely. Women were more likely than men to provide care daily. For both men and women, the likelihood of providing daily care increased with age. Figure 4F shows the pattern for personal care, and Figure 4G for other care. **Table 4.8, Figures 4E-4G**

Figure 4F

Frequency of personal care provided, by age and sex

Base: Aged 16 and over who had someone close to them die in the last five years

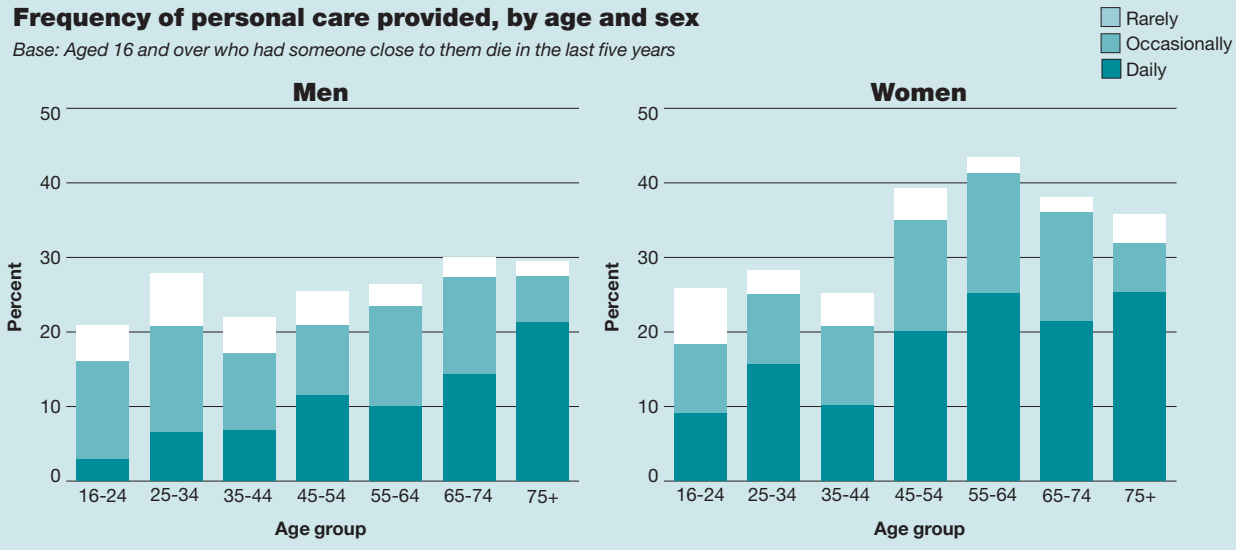
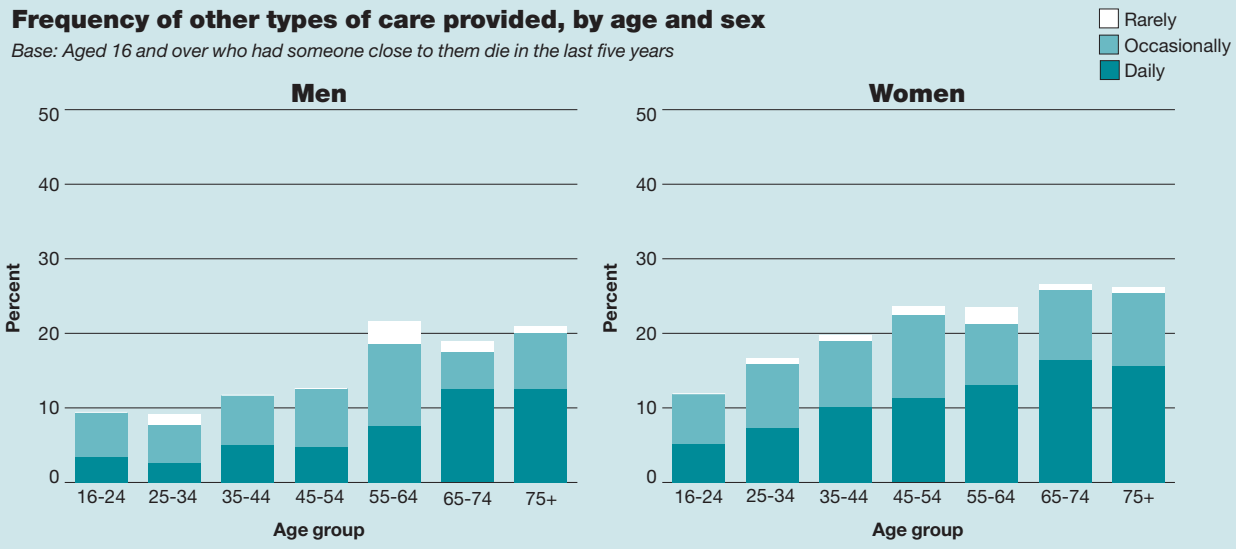


Figure 4G

Frequency of other types of care provided, by age and sex

Base: Aged 16 and over who had someone close to them die in the last five years



4.4.2 Duration of care provided

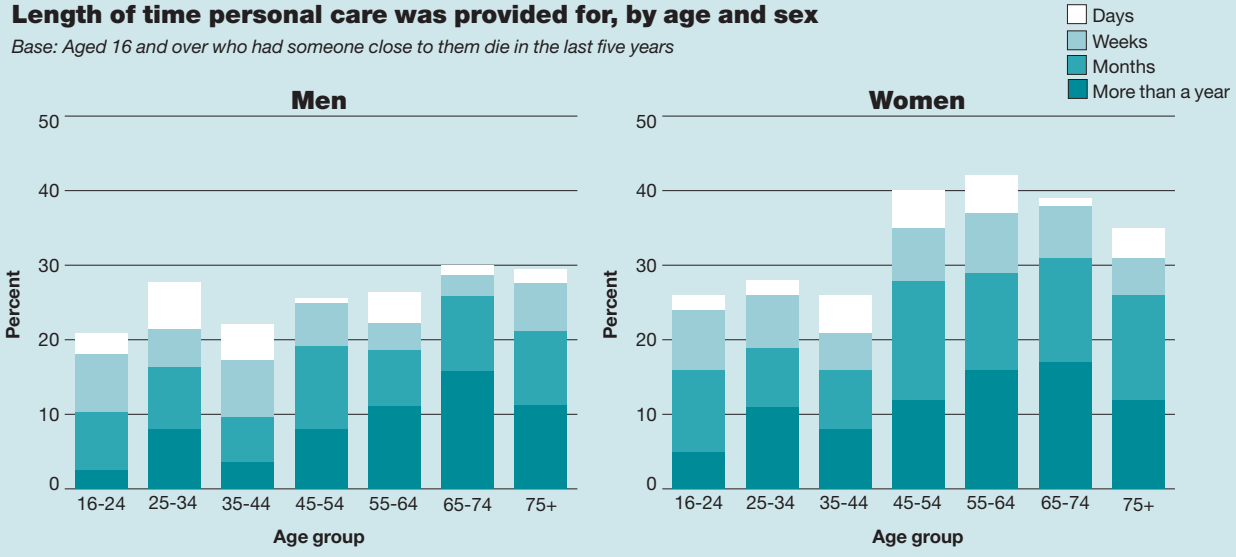
Personal care

8% of men and 11% of women had provided personal care for more than a year to someone close to them who died in the last five years. A further 9% of men and 12% of women had provided personal care for months, 6% and 7% provided it for weeks and 3% and 4% for days. The likelihood of providing personal care for months or more than a year varied by age, as shown in Figure 4H, and was more common among women than men.

Figure 4H

Length of time personal care was provided for, by age and sex

Base: Aged 16 and over who had someone close to them die in the last five years



Other care

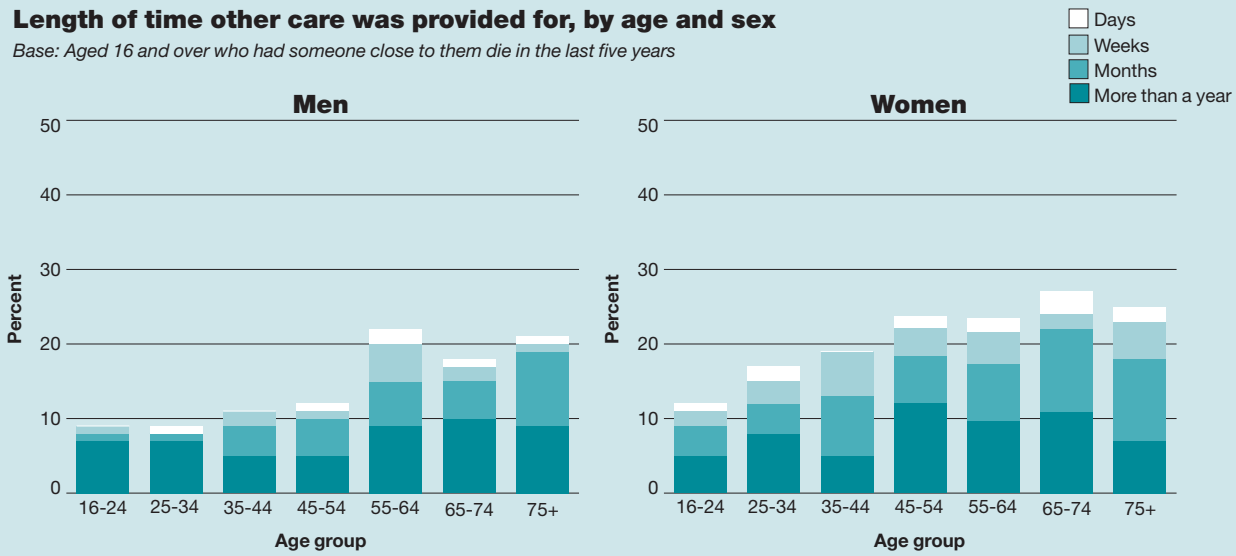
7% of men and 8% of women had provided other types of care for more than a year to someone close to them who died in the last five years. A further 4% of men and 7% of women had provided it for months, 2% and 4% provided it for weeks and 1% of both men and women had provided it for days. As with personal care, the likelihood of providing other care for months or more than a year varied by age (see Figure 4I), and was more common among women than men.

Table 4.9, Figures 4H, 4I

Figure 4I

Length of time other care was provided for, by age and sex

Base: Aged 16 and over who had someone close to them die in the last five years



4.4.3 Use of palliative and other services

Participants were asked whether a palliative care service or other support/care services (such as private carers, meals on wheels or voluntary support) were used.

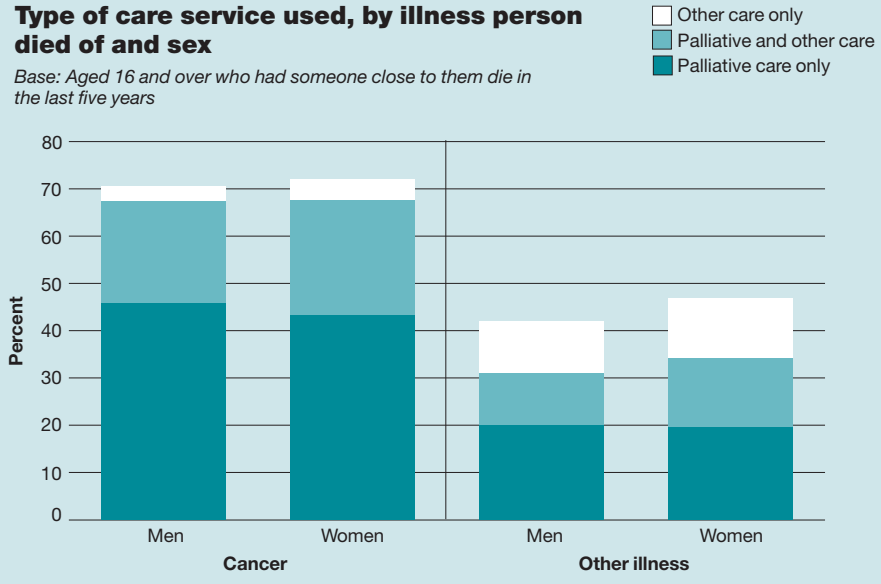
Participants who reported that someone close had died of cancer were twice as likely to mention palliative care use, compared with those reporting other illnesses. As Figure 4J shows, 68% of men and women reported that a person with cancer used a palliative care service, either on its own or in combination with other services, compared with 31% of men and 34% of women for people who had died of other illnesses.

Looking at those who used no care service at all there were also differences by illness. More than a quarter of men and women who reported that the person close to them died from cancer had not used a care service of any type (29% and 28% respectively). In contrast, around twice as many said the same thing about people who had died from an illness other than cancer (58% and 53% respectively).

Figure 4J

Type of care service used, by illness person died of and sex

Base: Aged 16 and over who had someone close to them die in the last five years



Reasons for not using a palliative care service

The most commonly cited reasons for the person close to them not using a palliative care service were that the person had died in hospital (37% of men and 36% of women) and the

death was sudden (29% and 25% respectively). Around one in eight said they did not want palliative care (13% of men and 12% of women). Much less commonly cited reasons were that a service was not available (6% and 7% respectively) and that the participant did not know about a service (3% and 5% respectively). There were no significant differences between the reasons given according to whether the person had died from cancer or another illness.

Reasons for not using another type of care service

For those who said the person close to them had not used another type of care service, the most commonly cited reasons were that the person had died in hospital (34% of men and 29% of women) and that family and friends had looked after the person (25% and 29% respectively). One in five said that they had not wanted other services (20% of both men and women). As with palliative care services, few said that another type of care service was not available or that the participant did not know about a service (3%-4%). Those who were talking about a person who had died from cancer were more likely to say that a reason another type of care service was not used was that family and friends looked after the person close to them (30% of men and 32% of women, compared with 17% and 22% respectively where the person died of another illness). Those who were talking about a person who died from an illness other than cancer were more likely to say the death was sudden (21% of men and women, compared with 13% and 12% respectively for cancer).

Table 4.10, 4.11, Figure 4J

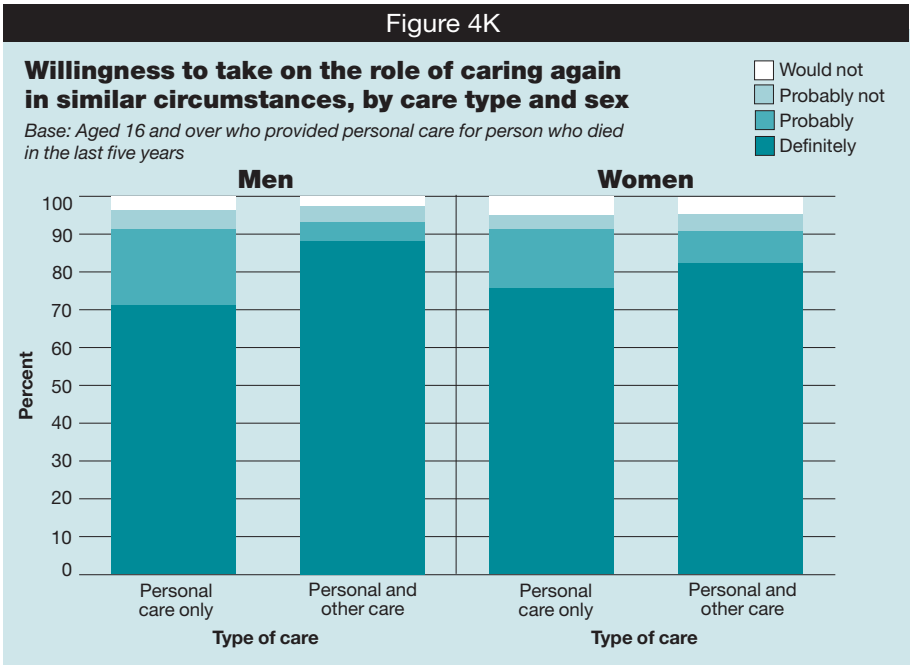
4.5 Impact of providing end of life care

4.5.1 Willingness to take on the role of caring again

More than three quarters of men and women said that they would definitely take on the role of caring again in similar circumstances (76% and 78% respectively), as shown in Figure 4K. Those who had provided both personal care and other care were more likely than those who provided personal care only to say this (88% compared with 71% for men and 82% compared with 76% for women). Fewer than one in ten men and women said that they would not or probably would not take on the role again (8% and 9% respectively).

Table 4.12, Figure 4K

Figure 4K



4.5.2 Ability to continue with life after the death of the person

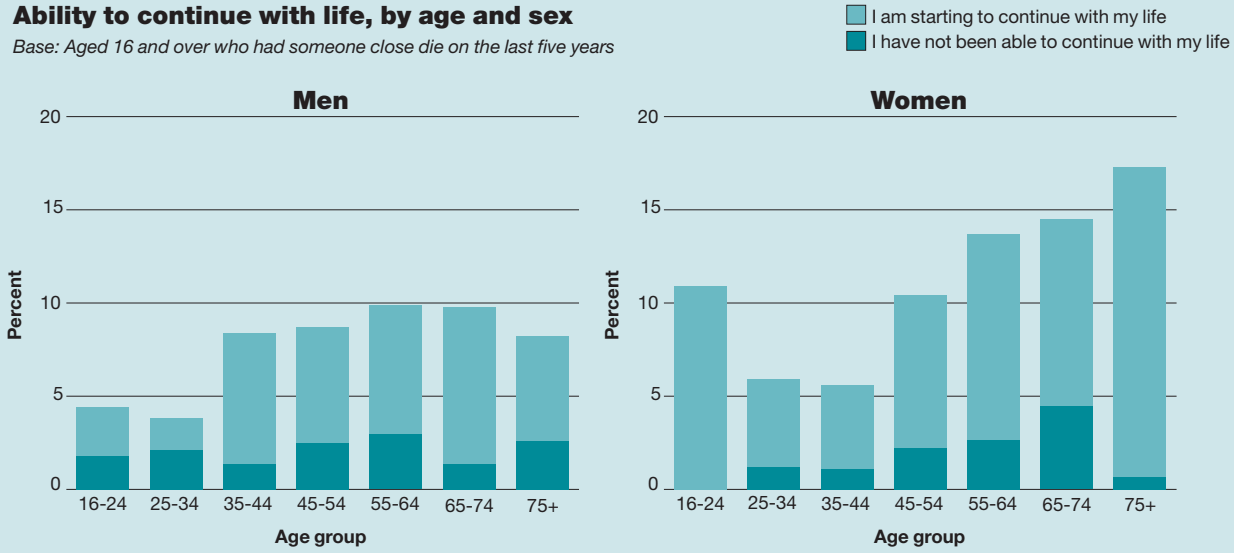
Participants were asked whether, since the person close to them had died, they had been able to continue with their life. Most reported that they had been able to do so (92% of men

and 89% of women). Overall 2% of both sexes said that they had not been able to continue with their life, while 5% of men and 9% of women said that they were starting to do so. The likelihood of reporting problems with being able to continue with their own life generally

Figure 4L

Ability to continue with life, by age and sex

Base: Aged 16 and over who had someone close die on the last five years



increased with age, as shown in Figure 4L. **Table 4.13, Figure 4L**

4.6 Discussion

4.6.1 Demographic patterns in provision of end of life care

The data in this chapter demonstrate that the provision of end of life care affects a substantial proportion of the population. Around a quarter of participants had experienced the death of someone close to them from a terminal illness in the last five years. Of these, 33% of men and 43% of women had provided care at some level to the person that died. The proportion of the population providing care for people who are at the end of their life increased with age. This is at a time when people themselves may experience poorer health. As forecasts suggest an increase in the numbers of people dying by 2030,[9] and an ageing population,[14] end of life care is an important issue that needs to be debated and planned.

More women than men said that someone close to them had died of a terminal illness in the last five years. This difference may be a function of women having wider social circles and perhaps being more likely to think of others as close to them. This, coupled with women traditionally being cast in the role of carer, goes some way to explaining why more women than men had provided end of life care. However, the data show that it is not just women who are providing care; many men provided personal or other care to the person close to them that died.

There were also significant differences by age groups. Middle age groups were more likely to have experienced the death of someone close to them and were more likely to have provided care to that person. Parental deaths were most commonly recorded in these age groups. Spouse and partner deaths were most commonly reported in the older age groups. The differences seen by age of the participant in this report may be more related to the relationships with the people who die when participants are at different life stages, rather than age *per se*. Further research of the data examining the differences by relationship type would prove useful in understanding more detail. In terms of planning and adapting services, support services for carers need to take account of the diversity of carers that exist in terms of sex, age and relationship types. For example, older people who are more likely to be experiencing ill health themselves and are also caring for their spouse may have different needs to younger adults who are caring for their parents. For men and women of

working age, providing care to someone close to them at the end of their life is something that may need to be balanced with work and family life.

4.6.2 Service provision at the end of life

The findings presented in this chapter about place of death correspond with other sources in that most deaths happen in hospital.[7] Data from the National Bereavement Survey (VOICES) show that the overall quality of care in the last three months of life was least likely to be rated as outstanding or excellent for those who had died in hospital, compared with other places.[8] There is a real need to consider what services are needed to support end of life care for people who are dying and their families and carers. This should take account of people's wishes about where they would like to die but also address the differences that exist in perceived quality of care and access to services.

This is particularly important for illnesses other than cancer. The data in this chapter show that there are differences in service use by illness type, with palliative and other care services being more likely to be used for those with cancer than for those with other illnesses, a finding which is supported by other research.[15] While the large majority of end of life care provision identified in this chapter was for people with cancer, this by no means accounted for all the deaths reported. With rates of illnesses like liver disease increasing,[16] it is important to ensure that the services provided at end of life reach the people they need to and meet their needs. While palliative care service use was highest among those who had died from cancer, not everyone reported that people who had died from cancer had used these services. Equity of provision and access to services regardless of illness type will help to ensure that people have the services they need to achieve the death that they want. It would be interesting to examine the data further to see whether those who reported palliative and other care services were used provided different care patterns from those who reported that only informal carers were used.

The reasons given by participants for not using palliative care services tend to be common regardless of the illness the person died of. Encouragingly, only small numbers of participants reported a service not being available or not knowing about a service as the reason. The death being in hospital or being sudden were the most common reasons for not using a palliative care service. The questions asked in the HSE did not explore preferences about where to die. Other surveys have established that most people would prefer to die at home[5,6] and it is possible some reporting a death in the HSE would have preferred a palliative care service outside of hospital.

Looking at the reasons given for not using other types of care services, some differences existed between those who had died from cancer and those who had died from other illnesses. Participants thinking of those who had died from other illnesses were more likely to report a sudden death as a reason. It would be interesting to find out more about people's perceptions of sudden death in the context of terminal illnesses. Lack of service availability in these cases may sometimes be inevitable, but it may be that building more efficient and connected services for end of life care might mean that even among more sudden deaths, services are available for people to use.

Another interesting finding about the reasons why care services were not used was that a sizeable group of participants reported that such a service was not wanted. This is an important point which highlights that perhaps aiming for everyone to be using services may not accurately reflect what people want or need. Family and friends looking after the person close to them who died was another commonly cited reason for not using services, particularly other types of care services. It is not clear whether this was through choice. Further research into the choices people make about care services at the end of life would be useful to tease out the motivations and perceived expectations for looking after and being looked after informally.

Differences would not be expected in the demographic characteristics of people who experience the death of someone close to them, as death is an inevitable factor irrespective of wealth or advantage. However, provision of care and access to services may be different.

Other data sources about the provision of social care more generally have shown that those from lower income households are more likely to provide informal care than those from higher income households.[17] It would be interesting to explore further who provides care at the end of life and whether this differs by factors such as employment status, health and family composition, particularly within the middle and older age groups where end of life care provision is more prevalent. Providing informal social care is a demanding role. Again, there is evidence from other data sources on social care more generally that providing care has negative impacts such tiredness, stress and changes to employment patterns.[17] If this burden of care is coupled with the fact that the person being cared for has a terminal illness, this adds another emotional level and further challenges of bereavement.

4.6.3 Impact on those providing end of life care

The majority of people reported having been able to move on with their lives following the death of the person close to them. This ability to move on is likely to be affected by a variety of factors, including relationship to the person who died, time since the death, whether care was provided and many other things. Further research may help to identify key characteristics that help to make people resilient and any risk factors that could be picked up by service providers for those who may be at risk of struggling to continue with their life following the death of someone close to them.

A positive finding from the data was that the majority of participants who provided care said they would be willing to take on the role again in similar circumstances. This was more common among those who provided personal and other care, in contrast to personal care on its own. It may be that being more involved in the care of someone close to them at the end of their life is more satisfying; it may also reflect the fact that people are more likely to provide both types of care to someone like a spouse or partner and it is the relationship, rather than the type of care, which is important.

References and notes

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Tables

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Notes on the tables

1. The group on which the figures in the table are based is stated at the upper left corner of the table.
2. The data in most tables have been weighted. See Volume 2, Chapter 7 of this report for more detail. Both unweighted and weighted sample sizes are shown at the foot of each table.
3. Apart from tables showing age breakdowns, data have been age-standardised to allow comparisons between groups after adjusting for the effects of any differences in their age distributions. See Volume 2, Chapter 8.4 of this report for more detail.
4. The following conventions have been used in tables:
   - \- no observations (zero value)
   - 0 non-zero values of less than 0.5% and thus rounded to zero
   - [ ] used to warn of small sample bases, if the unweighted base is less than 50. If a group's unweighted base is less than 30, data are normally not shown for that group.
5. Because of rounding, row or column percentages may not add exactly to 100%.
6. 'Missing values' occur for several reasons, including refusal or inability to answer a particular question; refusal to co-operate in an entire section of the survey (such as the nurse visit or a self-completion questionnaire); and cases where the question is not applicable to the participant. In general, missing values have been omitted from all tables and analyses.

Table 4.1

Experience of anyone close dying in the last five years, by age and sex

Aged 16 and over *2013*

Experience of anyone close dying of a terminal illness in the last five years	Age group							Total
	16-24	25-34	35-44	45-54	55-64	65-74	75+	
	%	%	%	%	%	%	%	%
Men								
Yes	21	22	19	26	25	24	25	23
No	79	78	81	74	75	76	75	77
Women								
Yes	24	24	25	28	29	25	25	26
No	76	76	75	72	71	75	75	74
Base (unweighted)								
Men	*392*	*542*	*629*	*703*	*604*	*615*	*437*	*3922*
Women	*476*	*755*	*826*	*883*	*742*	*651*	*530*	*4863*
Base (weighted)								
Men	*632*	*733*	*748*	*763*	*620*	*478*	*341*	*4314*
Women	*636*	*752*	*758*	*778*	*637*	*516*	*470*	*4547*

Table 4.2

Experience of anyone close dying in the last five years (observed and age-standardised), by region[a] and sex

Aged 16 and over *2013*

Experience of anyone close dying of a terminal illness in the last five years	Region								
	North East	North West	Yorkshire & the Humber	East Midlands	West Midlands	East of England	London	South East	South West
	%	%	%	%	%	%	%	%	%
Men									
Observed									
Yes	24	23	19	23	25	22	22	26	23
No	76	77	81	77	75	78	78	74	77
Standardised									
Yes	24	22	18	23	26	22	23	26	23
No	76	78	82	77	74	78	77	74	77
Women									
Observed									
Yes	26	26	24	31	27	28	20	28	25
No	74	74	76	69	73	72	80	72	75
Standardised									
Yes	26	26	24	32	27	28	21	28	25
No	74	74	76	68	73	72	79	72	75
Base (unweighted)									
Men	*340*	*569*	*353*	*363*	*388*	*413*	*492*	*624*	*380*
Women	*430*	*662*	*463*	*441*	*481*	*505*	*645*	*739*	*497*
Base (weighted)									
Men	*217*	*590*	*410*	*388*	*453*	*474*	*643*	*712*	*427*
Women	*225*	*587*	*462*	*398*	*484*	*483*	*696*	*727*	*484*

[a] Regions defined as the former Government Office Regions.

Table 4.3

Experience of anyone close dying in the last five years (age-standardised), by equivalised household income and sex

Aged 16 and over *2013*

Experience of anyone close dying of a terminal illness in the last five years	Equivalised household income quintile				
	Highest	2nd	3rd	4th	Lowest
	%	%	%	%	%
Men					
Yes	24	23	23	25	24
No	76	77	77	75	76
Women					
Yes	25	26	26	30	26
No	75	74	74	70	74
Base (unweighted)					
Men	*712*	*697*	*579*	*590*	*556*
Women	*720*	*800*	*734*	*768*	*786*
Base (weighted)					
Men	*813*	*766*	*616*	*585*	*638*
Women	*695*	*760*	*680*	*679*	*706*

Table 4.4

Experience of anyone close dying in the last five years (age-standardised), by Index of Multiple Deprivation[a] and sex

Aged 16 and over *2013*

Experience of anyone close dying of a terminal illness in the last five years	IMD quintile				
	Least deprived	2nd	3rd	4th	Most deprived
	%	%	%	%	%
Men					
Yes	22	23	23	24	24
No	78	77	77	76	76
Women					
Yes	26	23	28	26	25
No	74	77	72	74	75
Base (unweighted)					
Men	*796*	*853*	*840*	*714*	*719*
Women	*973*	*999*	*1025*	*945*	*921*
Base (weighted)					
Men	*845*	*921*	*930*	*824*	*795*
Women	*900*	*944*	*964*	*915*	*824*

[a] The Index of Multiple Deprivation 2010 combines a number of indicators, chosen to cover a range of economic, social and housing issues, into a single deprivation score at the small area level in England.

Table 4.5

Relationship of the person who died to the participant, by age and sex

Aged 16 and over who had someone close to them die in the last five years *2013*

Relationship to participant	Age group							Total
	16-24	25-34	35-44	45-54	55-64	65-74	75+	
	%	%	%	%	%	%	%	%
Men								
The participant's...								
Parent	4	13	25	36	34	12	1	20
Brother/sister	-	1	1	7	14	17	32	9
Spouse/partner	-	1	2	3	7	10	30	6
Child	-	-	6	5	5	3	2	3
Other relative	90	74	53	31	22	38	21	48
Friend	5	10	12	16	17	19	14	13
Other	1	1	1	2	1	1	-	1
Women								
The participant's...								
Parent	6	14	20	33	33	13	1	19
Brother/sister	-	1	4	9	13	25	32	11
Spouse/partner	-	-	2	-	8	19	29	6
Child	3	1	4	5	3	5	8	4
Other relative	85	70	54	34	30	21	17	46
Friend	2	11	11	18	12	15	12	12
Other	4	3	5	2	1	2	-	3
Base (unweighted)								
Men	*82*	*121*	*122*	*184*	*154*	*148*	*109*	*920*
Women	*113*	*185*	*211*	*251*	*213*	*165*	*133*	*1271*
Base (weighted)								
Men	*132*	*163*	*142*	*201*	*153*	*116*	*84*	*991*
Women	*150*	*180*	*193*	*220*	*185*	*130*	*118*	*1175*

Table 4.6

Illness person close to the participant died of, by age and sex

Aged 16 and over who had someone close to them die in the last five years *2013*

Illness person died of[a,b]	Age group							Total
	16-24	25-34	35-44	45-54	55-64	65-74	75+	
	%	%	%	%	%	%	%	%
Men								
Cancer	81	75	68	65	64	66	70	69
Emphysema or other lung disease	6	8	5	10	7	5	8	7
End stage heart failure	4	5	9	10	12	11	6	8
Dementia or Alzheimer's disease	1	2	3	3	2	4	3	3
Motor neurone disease or multiple schlerosis	2	1	6	1	5	3	2	3
Stroke	-	0	2	2	2	2	2	2
End stage kidney failure	4	-	2	3	1	1	3	2
End stage liver failure	-	2	-	2	0	1	2	1
Parkinson's disease	-	-	1	-	2	-	2	1
Other	2	2	6	8	4	8	6	5
Women								
Cancer	81	79	82	70	67	65	67	74
Emphysema or other lung disease	6	6	3	10	12	10	7	8
End stage heart failure	4	2	7	7	11	8	8	7
Dementia or Alzheimer's disease	-	5	4	3	3	2	2	3
Motor neurone disease or multiple schlerosis	1	2	2	4	1	3	4	2
Stroke	1	1	2	1	1	3	2	1
End stage kidney failure	2	0	-	2	3	2	2	1
End stage liver failure	3	3	2	1	1	1	1	2
Parkinson's disease	-	-	1	0	2	2	-	1
Other	1	1	2	5	5	8	5	3
Base (unweighted)								
Men	*82*	*121*	*122*	*184*	*154*	*148*	*109*	*920*
Women	*113*	*185*	*211*	*251*	*214*	*165*	*133*	*1272*
Base (weighted)								
Men	*132*	*163*	*142*	*201*	*153*	*116*	*84*	*991*
Women	*150*	*180*	*193*	*220*	*186*	*130*	*118*	*1176*

[a] Cases where the participant did not know the illness the person died of are excluded from this table.

[b] Participants could select more than one illness and so columns here may not total 100%.

Table 4.7

Where the person died, by age and sex

Aged 16 and over who had someone close to them die in the last five years *2013*

Where person died	Age group							Total
	16-24	25-34	35-44	45-54	55-64	65-74	75+	
	%	%	%	%	%	%	%	%
Men								
In hospital	45	37	48	48	54	47	47	47
At home: person who died	34	38	24	28	24	24	17	28
At home: participant's[a]	2	1	4	3	1	5	7	3
In a hospice	13	17	14	12	10	15	15	14
Nursing care home	2	5	3	5	6	8	11	5
Residential care home	2	1	4	0	2	1	1	2
Other	1	2	3	3	2	-	1	2
At home[b]	*36*	*39*	*27*	*31*	*26*	*29*	*24*	*31*
Not at home	*64*	*61*	*73*	*69*	*74*	*71*	*76*	*69*
Women								
In hospital	49	33	45	47	40	40	44	42
At home: person who died	27	35	29	27	31	26	22	28
At home: participant's[a]	5	1	1	1	5	10	12	4
In a hospice	12	18	18	16	14	14	14	16
Nursing care home	5	12	4	7	7	7	7	7
Residential care home	1	1	2	2	2	2	1	1
Other	1	-	1	1	2	1	2	1
At home[b]	*32*	*36*	*30*	*28*	*35*	*36*	*33*	*33*
Not at home	*68*	*64*	*70*	*72*	*65*	*64*	*67*	*67*
Base (unweighted)								
Men	*81*	*121*	*122*	*183*	*153*	*147*	*108*	*915*
Women	*111*	*185*	*210*	*250*	*213*	*165*	*131*	*1265*
Base (weighted)								
Men	*131*	*163*	*142*	*201*	*152*	*115*	*83*	*987*
Women	*147*	*180*	*192*	*220*	*185*	*130*	*116*	*1169*

[a] This includes cases where the participant lived with the person who died, and cases where they did not but the death occurred at the participant's home.

[b] This includes the home of the participants and the home of the person who died.

Table 4.8

Type of care provided to the person who died, by age and sex

Aged 16 and over who had someone close to them die in the last five years *2013*

Level of care provided	Age group							Total
	16-24	25-34	35-44	45-54	55-64	65-74	75+	
	%	%	%	%	%	%	%	%
Men								
Personal care[a]								
Daily	3	7	7	12	10	14	21	10
Occasional/intermittent	13	14	10	9	13	13	6	12
Rare	5	7	5	5	3	3	2	4
No care provided	79	72	78	74	74	70	71	74
Other types of care[b]								
Daily	3	3	5	5	8	13	12	6
Occasional/intermittent	6	5	7	8	11	5	8	7
Rare	-	1	-	-	3	1	1	1
No care provided	91	91	88	87	78	81	79	86
Personal care provided only	*17*	*22*	*16*	*21*	*17*	*17*	*18*	*18*
Other care provided only	*5*	*4*	*6*	*8*	*12*	*5*	*10*	*7*
Both personal and other care	*4*	*6*	*6*	*4*	*9*	*13*	*12*	*7*
No personal or other care provided	*74*	*68*	*72*	*67*	*61*	*65*	*61*	*67*
Any care provided daily	*5*	*8*	*10*	*14*	*14*	*18*	*24*	*13*
Any care provided, but not daily	*21*	*24*	*18*	*19*	*24*	*17*	*15*	*20*
Women								
Personal care[a]								
Daily	10	16	10	20	25	21	25	18
Occasional/intermittent	9	9	11	15	16	15	7	12
Rare	7	3	4	4	2	2	4	4
No care provided	73	72	75	61	57	62	64	66
Other types of care[b]								
Daily	5	7	10	11	13	16	16	11
Occasional/intermittent	7	9	9	11	8	10	10	9
Rare	-	1	1	1	2	1	1	1
No care provided	88	83	80	76	77	73	74	79
Personal care provided only	*19*	*18*	*15*	*26*	*28*	*23*	*21*	*22*
Other care provided only	*4*	*7*	*10*	*10*	*9*	*11*	*11*	*9*
Both personal and other care	*8*	*10*	*10*	*13*	*15*	*16*	*15*	*12*
No personal or other care provided	*69*	*65*	*65*	*51*	*48*	*51*	*53*	*57*
Any care provided daily	*11*	*18*	*16*	*25*	*29*	*28*	*29*	*22*
Any care provided, but not daily	*20*	*17*	*19*	*25*	*22*	*22*	*18*	*21*
Base[c] *(unweighted)*								
Men	*82*	*120*	*120*	*182*	*153*	*148*	*108*	*913*
Women	*112*	*183*	*209*	*247*	*209*	*163*	*129*	*1252*
Base (weighted)								
Men	*132*	*162*	*139*	*199*	*151*	*116*	*84*	*983*
Women	*149*	*178*	*191*	*217*	*181*	*128*	*115*	*1159*

[a] Personal care is defined as things like helping with washing, dressing, going to the toilet, or eating.

[b] Other types of care is defined as things like keeping company, doing errands, laundry, shopping, giving lifts, taking to appointment or out for recreation.

[c] This table contains data taken from a number of questions. A small number of participants did not answer all of the questions. This means the bases are slightly different for each. The bases shown are for the provision of personal care. Bases for other questions in this table are of a similar magnitude.

Table 4.9

Length of time care was provided for, by age and sex

Aged 16 and over who had someone close to them die in the last five years *2013*

Time care provided for	Age group							Total
	16-24	25-34	35-44	45-54	55-64	65-74	75+	
	%	%	%	%	%	%	%	%
Men								
Personal care[a]								
Days	3	6	5	1	4	1	2	3
Weeks	8	5	8	6	4	3	6	6
Months	8	8	6	11	8	10	10	9
More than a year	2	8	4	8	11	16	11	8
Other types of care[b]								
Days	-	1	0	1	2	1	1	1
Weeks	1	-	2	1	5	2	1	2
Months	1	1	4	5	6	5	10	4
More than a year	7	7	5	5	9	10	9	7
Women								
Personal care[a]								
Days	2	2	5	5	5	1	4	4
Weeks	8	7	5	7	8	7	5	7
Months	11	8	8	16	13	14	14	12
More than a year	5	11	8	12	16	17	12	11
Other types of care[b]								
Days	1	2	0	1	2	3	2	1
Weeks	2	3	6	4	4	2	5	4
Months	4	4	8	6	8	11	11	7
More than a year	5	8	5	12	10	11	7	8
Base[c] *(unweighted)*								
Men	*82*	*120*	*120*	*182*	*153*	*148*	*108*	*913*
Women	*112*	*183*	*209*	*247*	*209*	*163*	*129*	*1252*
Base (weighted)								
Men	*132*	*162*	*139*	*199*	*151*	*116*	*84*	*983*
Women	*149*	*178*	*191*	*217*	*181*	*128*	*115*	*1159*

[a] Personal care is defined as things like helping with washing, dressing, going to the toilet, or eating.

[b] Other types of care is defined as things like keeping company, doing errands, laundry, shopping, giving lifts, taking to appointment or out for recreation.

[c] This table contains data taken from two questions. The bases shown are for the provision of personal care. Bases for other types of care are of a similar magnitude.

Table 4.10

Type of care service used, by illness person died of and sex

Aged 16 and over who had someone close to them die in the last five years — *2013*

Use of care services	Illness person died of		Total
	Cancer	Other illness	
	%	%	%
Men			
Used palliative care service only	46	20	38
Used both palliative and other care services	22	11	18
Used other care service[a] only	3	11	6
Used neither	29	58	39
Used palliative care service[b]	*68*	*31*	*56*
Women			
Used palliative care service only	43	20	37
Used both palliative and other care services	24	15	22
Used other care service[a] only	4	13	7
Used neither	28	53	35
Used palliative care service[b]	*68*	*34*	*59*
Base[c] (unweighted)			
Men	*552*	*270*	*822*
Women	*858*	*320*	*1178*
Base (weighted)			
Men	*603*	*283*	*887*
Women	*788*	*294*	*1082*

[a] Examples of other services were social services, a private care company, meals on wheels, voluntary groups.

[b] Includes those who had used a palliative care service only and those who had used a palliative care service together with other services.

[c] Data in this table comes from two separate questions. Cases where both answers were not present have been excluded from the base.

Table 4.11

Reasons why a care service was not used, by illness person died of and sex

Aged 16 and over who had someone close to them die in the last five years and had not used a care service — *2013*

Reasons why a service was not used[a]	Palliative care service			Other care service[b]		
	Illness person died of		Total	Illness person died of		Total
	Cancer	Other illness		Cancer	Other illness	
	%	%	%	%	%	%
Men						
Died in hospital	38	35	37	33	36	34
Death was sudden	27	31	29	13	21	15
Family and friends looked after the person	17	12	15	30	17	25
Service not wanted	12	14	13	21	19	20
Service was not available	6	7	6	3	5	4
Didn't know about service	4	3	3	3	3	3
Other	8	7	8	6	4	5
Women						
Died in hospital	36	36	36	28	30	29
Death was sudden	24	26	25	12	21	15
Family and friends looked after the person	18	16	17	32	22	29
Service not wanted	11	14	12	21	19	20
Service was not available	8	6	7	4	6	4
Didn't know about service	5	5	5	4	3	4
Other	9	5	7	6	5	6
Base (unweighted)						
Men	*178*	*188*	*366*	*411*	*206*	*617*
Women	*277*	*208*	*485*	*609*	*232*	*841*
Base (weighted)						
Men	*194*	*196*	*390*	*455*	*218*	*673*
Women	*256*	*195*	*451*	*561*	*215*	*776*

[a] Participants could select more than one reason and so columns here may not sum to100%.

[b] Examples of other services were social services, a private care company, meals on wheels, voluntary groups.

Table 4.12

Willingness to take on role of caring again in similar circumstances (age-standardised), by type of care provided by participant and sex

Aged 16 and over who provided personal care for the person who died — *2013*

Willingness to take on role again in similar circumstances	Type of care		Total
	Personal care only[a]	Both personal and other types of care[b]	
	%	%	%
Men			
Would definitely take on role again	71	88	76
Would probably take on the role again	20	5	16
Would probably not take on the role again	5	4	5
Would not take on the role again	4	2	3
Women			
Would definitely take on role again	76	82	78
Would probably take on the role again	15	9	13
Would probably not take on the role again	4	5	4
Would not take on the role again	5	4	5
Bases (unweighted)			
Men	*157*	*69*	*226*
Women	*263*	*153*	*416*
Bases (weighted)			
Men	*176*	*68*	*243*
Women	*242*	*138*	*380*

[a] Personal care defined as things like helping with washing, dressing, going to the toilet, or eating.

[b] A combination of personal care and other types of care. Other types of care defined as things like keeping company, doing errands, laundry, shopping, giving lifts, taking to appointment or out for recreation.

Table 4.13

Ability to continue with life, by age and sex

Aged 16 and over who had someone close to them die in the last five years *2013*

Ability to continue with life	Age group							Total
	16-24	25-34	35-44	45-54	55-64	65-74	75+	
	%	%	%	%	%	%	%	%
Men								
Able to continue with life	96	96	92	91	90	90	92	92
Starting to continue with life	3	2	7	6	7	8	6	5
Not able to continue with life	2	2	1	3	3	1	3	2
Women								
Able to continue with life	89	94	94	90	86	86	83	89
Starting to continue with life	11	5	5	8	11	10	17	9
Not able to continue with life	-	1	1	2	3	5	1	2
Base (unweighted)								
Men	*82*	*121*	*122*	*184*	*154*	*148*	*109*	*920*
Women	*113*	*185*	*210*	*251*	*214*	*165*	*132*	*1270*
Base (weighted)								
Men	*132*	*163*	*142*	*201*	*153*	*116*	*84*	*991*
Women	*150*	*180*	*192*	*220*	*186*	*130*	*117*	*1175*