



advice and support for older age

**Independent
Age**

Good grief

Older people's experiences
of partner bereavement



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Executive summary

Death and bereavement are not subjects that are well recognised or prioritised within UK society. Where policy does exist, it is disparate and unconnected.

Support for bereaved older people is therefore highly localised and depends on the availability and attention of third sector organisations.

Older people's experiences following the loss of a partner vary hugely. Independent Age set out to learn more about those experiences and understand what can be done to ensure more have positive outcomes.

Why is this important?

Older people are more likely to experience bereavement than any other age group. They tell us that losing their (often lifelong) partner, the person they would turn to for solace and support, is one of the hardest of life's transitions. Partner loss is the most severe common form of bereavement.

Older bereaved people are less likely to seek help than younger bereaved people. And they are also less likely to be referred for bereavement support than younger people. Many people don't get the death they want. Most want to die at home, but nearly half of all deaths happen in hospital.

We set ourselves six questions to inform our research

- 1 What are older people's experiences of losing their partner?
- 2 In what ways are people affected by the loss of their partner?
- 3 What support is available for older people experiencing partner bereavement?
- 4 What choices do older people make when coping with life without their partner?
- 5 Are older people under-served when it comes to bereavement support?
- 6 What are the best ways for people to cope with the impacts of bereavement?

Who are affected the most?

- The older old (people aged 85 and above).
- People who have experienced multiple bereavements in a short space of time.
- People whose partner did not receive some form of support or care at the end of their life.
- People who felt that their partner did not have “a good death” or where there were traumatic circumstances around the death.
- Those without family or close friends to support them.

Men are more likely to experience loneliness and social isolation in bereavement than women. Women experience more negative impacts to their income and on practical matters than men.

How are people affected?

Loneliness and isolation

- Nearly a third of bereaved people over 65 see themselves as very lonely, compared to just 5% of people of the same age who have not lost their partner.
- More than 1 in 5 people said that loneliness was the hardest thing to cope with after the death of their partner.
- Older people who are carers for their dying partner are at greater risk of feeling lonely both before and after their partner dies.
- Family and friends are usually the route to alleviating loneliness, but for those without family, it can be difficult to know where to start.



Mental and physical health

- Older people are more likely to have worse mental health as a result of bereavement than younger people and older bereaved people are up to four times more likely to experience depression than non-bereaved people.
- An older person whose partner has died is more likely to die in the three months following their partner's death than someone who hasn't been bereaved.
- Older people's health also worsens *prior* to bereavement, while caring for a dying partner.
- Getting help can be a lottery: GPs have no standard training in helping their patients to cope with grief and NICE has no pathways to guide GPs.

Financial and practical considerations

- Being independent is (ironically) harder when you're single. A person's ability to manage the essentials of day to day living typically decreases following their partner's death.
- Many people feel overwhelmed by the burden of dealing with multiple systems following their partner's death and often struggle with funeral and estate costs.
- Women's household incomes typically fall after the death of their partner, while men tend to see their incomes increase.

- More than two thirds of older people who have lost a partner say that they felt unprepared, either financially or practically, for bereavement, even though in most cases they knew that their partner was going to die.

Feelings and grief

- Grief is more than just sadness. Feelings of relief or release, anger, altered identity, confusion, guilt or a sense of hopelessness, are all common and normal.
- A good death means a better bereavement. Family members of older people given the opportunity to plan ahead and have their wishes enacted, had fewer symptoms of post-traumatic stress, depression and anxiety after their loved one's death.
- Fewer than 1 in 5 people aged over 60 have received counselling following a death and more than half said it was not something of interest to them.
- Nearly half of older people said that their preferred way of remembering their loved one was by talking about them.

Our vision

Our vision is that every older person who experiences partner loss is aware of the support options available to them and is able to access the type of support with which they feel most comfortable. As we age, we are mindful that planning ahead, for death and for living without a partner, can be beneficial. In the future, we want everyone to have the confidence to hold difficult conversations.

Call to action

Bereavement support can be difficult to navigate, with multiple small providers and no single approach to availability, quality of provision, or access to services.

- ▶ The government should establish a bereavement point of contact and pathway to signpost people through to services and support.
- ▶ Caring responsibility does not stop at the point of death. Those working closely with older people at the end of life must recognise that when a person dies, another person is bereaved.
- ▶ All older people are entitled to bereavement support that is tailored to their needs and preferences. In particular, attention must be given to meeting the needs of distinct groups of older people such as LGBT+ and BAME communities or people with dementia.

Many people only recognise the benefits of planning ahead for death and living without their partner when it's too late.

- ▶ More work is needed to remove stigma from talking about death and bereavement.
- ▶ People need more effective support to broach the difficult conversations of death and bereavement that help them to plan ahead.

A person's death and quality of life in their final months has a significant impact on the bereaved person.

- ▶ Every older person must receive good quality end-of-life care and be supported to die in the place they choose.

Talking about a personal experience of death and grief (to someone you trust) is almost always felt to be beneficial.

- ▶ More opportunities must be available to help older people keep memories of their loved ones alive.

There is no consistency in the approach to grief provided by health and social care staff.

- ▶ All health and social care staff working with older people must be trained to provide quality support to people who are grieving.

People who don't get support at the time of grieving are more likely to develop complicated grief.

- ▶ Bereavement support providers must recognise older people as a group needing special attention for support with their grief.
- ▶ Family and friends should not be solely relied upon for bereavement support. Those without family need alternative sources of support.



Introduction

No talk means no action

In older age we are closer to death. And the prospect of losing friends, partners and family members becomes more real. Unfortunately, as a society, we don't like to talk about death or our feelings to do with death, even with those we are closest to. This doesn't set us up well for changing things for the better. Usually, the people directly affected by these issues are either dying or recently bereaved – but, with more immediate concerns to deal with, they are unlikely to be championing grassroots change.

Death and bereavement are not subjects that are well recognised or prioritised within UK society. Hundreds of thousands of people are affected every year, with over 603,000 deaths in the UK in 2015 (and 85% of these being people aged 65 and older)¹, and yet death and bereavement barely feature in public policy.

The funeral industry (worth £1 billion annually) is largely unregulated. Over half of deaths are in hospitals, but the NHS is already overstretched and has no contingency for another 56,000 deaths every year². As many as 92,000 people miss out on end-of-life care every year³. There is no nationwide bereavement service. Therefore GPs are often the first port of call for people struggling with a bereavement, but they have no standard training in helping their patients cope with grief, and NICE pathways are scant on the subject.

The number of bereaved older people is set to increase by more than 100,000 people in the next 20 years, from 192,000 in 2014 to 294,000 newly bereaved people every year by 2039⁴.

Where policy does exist, it is disparate and unconnected. The NHS, local authorities (through their social care responsibilities), independent social care providers (such as care homes), and the voluntary sector (including hospices), all play a role in bereavement support, but they are not well integrated and none has overall responsibility.

So support for bereaved older people is highly localised and depends on the availability and attention of third-sector organisations⁵. Bereavement services are also provided through lots of individual, small providers.

"It was necessary to break down taboos relating to childbirth in my lifetime. Now we must address the other great area of non-communication: wider discussion is needed amongst older people to remove the taboos around dying and death."

Dorothy, 79

These sorts of services are often on a local basis, offering different delivery models with varying suitability for older people, and varying levels of quality. Gaps in provision are not consistently managed and older people miss out on much-needed support. And crucially, no system or authority has overall responsibility for the quality of support available.

We are approaching the 10 year anniversary of the government's end-of-life strategy (launched in July 2008). The strategy recognised that "support for family and carers both during a person's illness and into bereavement is often inadequate". It stipulated that "information on how to access comprehensive and culturally appropriate bereavement and support services should be available from all health, social care and other emergency organisations". Now is a good time to review the effectiveness of this strategy for bereavement.

People's experiences following the loss of a partner vary hugely. Some people are able to find joy in life again, revive interest in activities and get pleasure from other relationships. Others never "get over it". What influences these experiences? And what support could we provide to ensure more of those experiences have positive outcomes?

This report brings together what we already know about older people's experiences of bereavement along with new research centred on older people whose partners have died. We focus on some of the issues faced by those living with the grief of losing a loved one. Our research also reveals how talking about death, at an individual and a policy level, can start to provide the help that older people need when faced with the most difficult moment of their lives.



What we mean when we talk about bereavement

In this report, we often refer to bereavement and grief (and talk about different types of grief) so a common understanding of the terms is important.

Bereavement is the period of time after the loss of a loved one.

Grief refers to the psychological components of bereavement: the feelings evoked when that person dies.

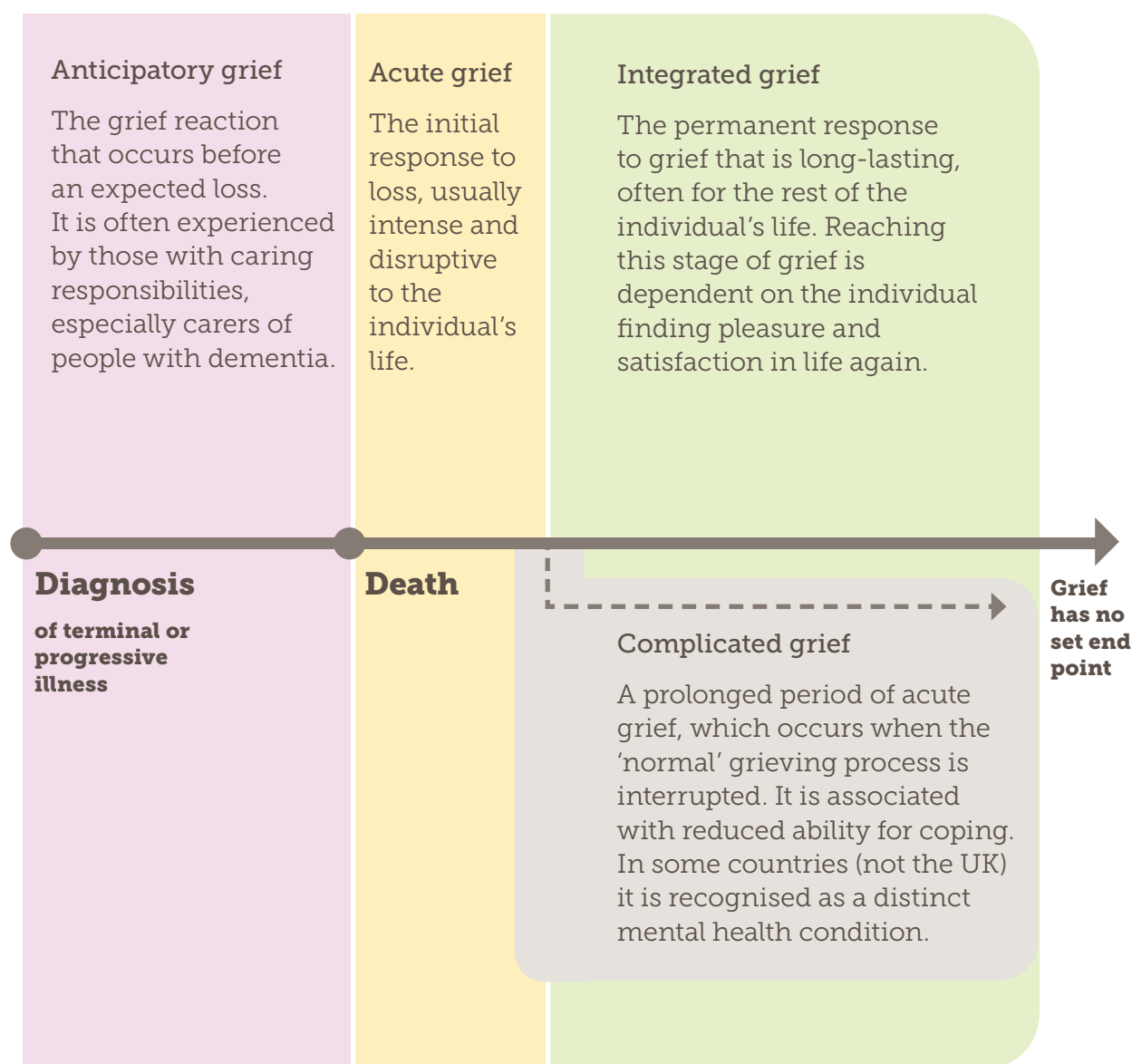
In western society, when we talk about grief in the long term, we tend to refer to the adjustment that the bereaved person must make following their loss. This usually involves developing a new routine, making new connections, envisaging a new future and even adopting a new sense of identity.

Each person has an individual response to their loss. No one way of grieving is better than another. Some people are more emotional and will explore their feelings. Others may seek distraction as a way of coping. Cultural, as well as circumstantial, factors contribute to how people express and cope with it.

For example, the generation of older people who lived through wartime may have a more stoical grief reaction than many younger people.

There is no timeline for grief and bereavement never really ends. Psychologists tend to describe grief as “not linear”. It ebbs after a while, but can then emerge on anniversaries and significant dates, in certain places, or be triggered by something like a song or a memory.

The diagram (on the right) explains some recognised forms of grief which we will refer to in this report. It also illustrates that our approach to bereavement begins at the point in time where death is known, rather than death itself. This is because the period of time between knowing a person will die and their death provides an important window. It can enable planning and preparation for death and bereavement. It also carries with it the risk of a particular form of grief – anticipatory grief.



Why we are interested in older people's experiences of bereavement

Older people are more likely to experience bereavement than any other age group

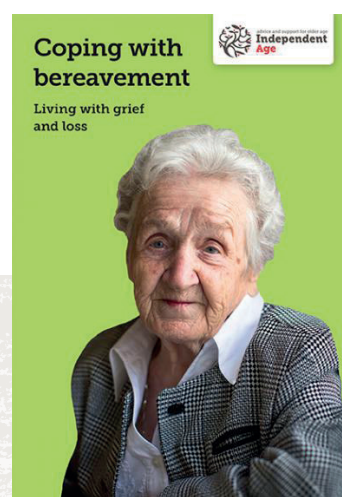
The vast majority of people experiencing bereavement are older people. A study from the US found that 7 out of 10 older people experienced bereavement in a two and a half year period⁶. Our increase in life expectancy in the UK means that we are most likely to die in our 80s and 90s and the partners we leave behind will be of a similar age. More than 200,000 older people will lose their partner this year.

Older people tell us that losing their (often lifelong) partner, the person they would turn to for solace and support, is one of the hardest of life's transitions.

Table 1: The average age at which people in the UK die has increased every decade over the last 60 years:

	Male	Female
1961	68	74
1971	69	75
1981	71	77
1991	73	79
2001	76	81
2010	79	83

Nearly 9 in 10 people who have ordered Independent Age's *Coping with bereavement* guide said that bereavement was dominating their lives⁷. Some of the people we spoke to, as part of this research, mentioned feeling "all at sea" and a sense of "being adrift". Many people define themselves by their partner and feel a loss of identity or sense of purpose without them. The length of the relationship, closeness of the partnership and how entwined their lives are, can all have an impact on these feelings.



We produce advice guides such as *Coping with bereavement*, which helps people deal with grief and loss.

Older bereaved people are less likely to seek help than younger bereaved people

Organisations that provide support to people struggling with bereavement, tell us that they are least likely to be contacted by people aged 65 and over (unless the service is specifically targeting older people). This is despite nearly three quarters of bereaved people in England being 65 and above⁸.

Over a quarter of older people told us that they didn't seek any help or support at all with their bereavement, even from family or friends⁹. One bereavement counsellor told us that older people don't ask for help because they "don't want to be a burden" or they don't feel entitled to special help because, at an older age, this is "just how life goes".

Older people are also less likely to be referred for bereavement support than younger people

People aged 65 and above are less likely to be referred by their GP for "talking therapies" (Improving Access to Psychological Therapies or IAPT) for depression and anxiety than younger age groups. Those who are referred tend to be under 75, with extremely few people aged over 90 receiving this therapy. This is despite evidence suggesting older people are likely to benefit more than younger people from this form of therapy. NHS England states that 56% of over 65s showed "reliable recovery" after receiving psychological therapies compared with 42% of working-age adults¹⁰.

All too often, older people's mental health needs go unrecognised (possibly because older people are less likely to recognise their own needs). There is also a common assumption that older people have the resilience to cope with loss as a "normal" part of later life.

Older people are also less likely to receive end-of-life care, especially in the early stages of their illness¹¹. Lack of end-of-life care means they are more likely to be in pain at the time of their death than younger people. The charity Marie Curie found that people with dementia are particularly unlikely to receive good end-of-life care¹².

People don't tend to plan ahead for death and bereavement

With most deaths in the UK of over 65s being from terminal or progressive illnesses¹³, there is usually a window of opportunity to prepare for bereavement as well as for death itself. However, we don't tend to have conversations that enable us to be well-prepared for living without our partner. Nearly a quarter of people aged 75 and above have not had discussions about their wishes regarding death¹⁴. When we do talk about death, it tends to be the practical, rather than emotional aspects, that are easiest to deal with, and these conversations are often limited to funeral plans and wishes.

Why are difficult conversations so difficult?

From Independent Age's previous work on *Dealing with Difficult Conversations*, we know that the main reasons people don't tackle uncomfortable issues are:

- People feel they lack the knowledge and confidence to begin a conversation.
- They worry about the reaction of family members.
- People want to avoid facing undesirable possibilities.
- They feel the time is not right.
- Attempts are hindered by distance or a lack of time for discussion.

[www.independentage.org/
information/personal-life/
difficult-conversations](http://www.independentage.org/information/personal-life/difficult-conversations)

Many people don't get the death they want

If we do think about planning for our own death, the place of death tends to be what we focus on. The place of death is perhaps the single biggest issue for people's sense of quality in dying. Mostly people want to die at home, with close family members nearby, but this rarely happens. As many as 9 out of 10 people would prefer to die in their own home or in a hospice, but less than a third of people achieve this, and 47% of people die in hospital¹⁵. Evidence also shows that, of all age groups, it is people aged 65 and over who are most likely to die in a hospital setting¹⁶.

Your partner dying in hospital, rather than at home, can have a huge negative impact on your emotions. Feelings of guilt ("I couldn't give him the death he wanted.") or even trauma ("She died in pain and there was nothing I could do.") can complicate the grieving process.

Where do people die?¹⁷

47% in hospital

24% at home

22% in a care home

6% in a hospice

Society's attitudes to death and bereavement are not helpful

In western society, we are generally wary of discussing death and dying. Feelings and grief may be hidden, especially by older generations due to a sense of stoicism or "stiff upper lip". Some older people may find it too personal or intrusive to be asked about it by people who are not close family or their GP.

We also tend to have an overinflated view of our willingness to hold difficult conversations about death. We found 7 out of 10 people (of all ages) say they are comfortable talking about death but less than 1 in 4 actually do it¹⁸. There is a small, but growing, interest in talking about death and dying – reflected by the emergence of the death café movement¹⁹. However, this is more about death in the abstract and it remains a taboo subject for many, especially where our own death, or that of loved ones, is concerned.

Partner loss: the most severe common form of bereavement

We usually experience bereavement in later life. Increasing life expectancy means we often don't lose our parents until we are of pension age. Losing siblings and friends is also a common experience in older age. Each and every bereavement is a significant event and brings its own set of challenges.

We chose to focus specifically on partner bereavement to understand the impact of losing an interdependent relationship. Couples have made a life together: (usually) living together, sharing finances, mutually caring for one another and making complementary contributions to their life together. For instance, one partner may do the cooking and driving; while the other makes social plans and organises household finances.

Grief is influenced by the strength of our attachment to our lost loved one and how central he or she was to our lives. By focusing on the loss of a life partner, a constant companion, we are examining one of the most severe yet common forms of grief that older people encounter.

We have interpreted "partner" and "partnership" to mean any relationship where the people involved recognise and self-define the relationship as a partnership.

What happens at a death café?

The purpose of a death café is "to increase awareness of death with a view to helping people make the most of their (finite) lives".

To date, thousands of death café events have taken place across 48 countries (mostly in Europe and America). Death cafés give "permission" for people to talk about what can be considered a taboo topic in a relaxed setting.

Conversations can range from living wills and power of attorney to funerals, last words of loved ones and being around dead bodies.

For more details, visit
www.deathcafe.com

What we wanted to find out

We set ourselves six key questions to inform our research:

- 1 What are older people's experiences of losing their partner?
- 2 In what ways are people affected by the loss of their partner?
- 3 What support is available for older people experiencing partner bereavement?
- 4 What choices do older people make when coping with life without their partner?
- 5 Are older people under-served when it comes to bereavement support?
- 6 What are the best ways for people to cope with the impacts of bereavement?

Pam's story – Let's talk about bereavement

Pam lives in the north west of England. She was married to her husband, Bill, for 14 years after first meeting in 1988. Bill had had a history of heart disease and from 2011, he became more seriously ill, leading to many trips in and out of hospital. One day in 2013, the nurses told Pam that Bill would be unable to come home this time and he would have to stay in hospital.

"That caused me a tremendous amount of grief as his wishes were to die at home but I couldn't get him home," says Pam. "I did ask but it was too late to move him."

Bill passed away in hospital later that year.

What followed was an intense and traumatic period of bereavement for Pam as she tried to come to terms with a new way of life without Bill.

The loneliness was overwhelming. Having spent many years with a routine centred on Bill's care, Pam was left not just without close companionship, but a complete void of how to spend her time. Despite having strong family and friendship ties, Pam was faced with evenings and days on her own with no one to talk to: "I was on my own; I'd never lived on my own, and sometimes I just needed to hear a voice."

But it was not just the lack of someone to talk to that made Pam feel lonely. During the period after Bill's death, her family were incredibly supportive, spending time with Pam and helping her with various things around the house. However, they sometimes found it hard to deal with Pam's grief and said things that unintentionally made Pam feel quite alone with her grief. As well as feeling sadness, Pam also experienced guilt, regret and anger. She wanted to talk about these feelings, but family members tried to move Pam to more positive ground and sometimes dismissed her feelings by saying things such as "Don't say that", "You don't mean that" and "It's early days".

These comments, while well-intentioned and not meant to be hurtful, made Pam feel she was not able to be honest about how she was feeling. People did not like what she was saying, but she couldn't change how she felt. She even started to question herself – if everyone was saying, "You don't mean that," why did she feel that way? Was there something wrong?

"They're only trying to help but it has the opposite effect," she explains. "People just don't want to talk about it."

Eventually, Pam sought help through grief counselling. Bill had received care from a hospice where she knew counselling was available and so she contacted them.

This changed everything for Pam. The opportunity to talk without judgement enabled her to explore her feelings fully. Pam felt her counsellor was someone who would listen, was trustworthy and experienced. She felt so much better from having her feelings acknowledged and was given reassurance that the emotions she was experiencing were normal.

Pam acknowledges that what works for one person might not work for another. However she is firm in her belief that we need to talk about death and become more comfortable around bereaved people. Not talking about it made it harder to deal with in her experience.

Pam also reminds us of the importance of acknowledging bereavement as a long process. It doesn't change overnight but with support, it is something we can learn to cope with better: "I also think that grief is a process of gradual adaptation. There is no switch."



Picture posed by models

How older people are affected by the loss of their partner

The impacts of bereavement identified in our research can be grouped into four areas:

- 1 Loneliness and social isolation**
- 2 Mental and physical health**
- 3 Financial and practical considerations**
- 4 Feelings and grief**

The chapters that follow examine each of these areas in more detail.

Within these areas, who are affected the most?

Across our four impact areas, we found some groups to be more severely affected than others.

- **The older old (people aged 85 and above).** The older you are, the more likely you are to be negatively affected across all four impact areas. The older old are also less likely to seek help such as counselling or even just information to help them cope with bereavement²⁰. This compounds existing problems associated with ageing such as declining health and mobility, reduced social connections and increased poverty. People aged 85 and above may be more reluctant to ask for help than those who are slightly younger.
- **People who have experienced multiple bereavements in a short space of time.** For instance, losing a parent, sibling and partner in the space of two or three years. This appears to have a “compound effect” of impacts and lessens the person’s ability to cope with a subsequent bereavement. We should not assume that one loss increases resilience to another.

- **People whose partner did not receive some form of support or care at the end of their life.** Whether it is through NHS end-of-life care, a hospice or a voluntary organisation, being in a “system” in the final months of life means a higher likelihood of support being offered, both before and after their partner’s death.
- **People who felt that their partner did not have “a good death”** or where there were traumatic circumstances around the death. Traumatic circumstances might be that their partner died suddenly, in pain, or died (against their wishes) in hospital rather than at home.
- **Those without family or close friends to support them.** A consistent thread in our research is that older people derive considerable support from family and friends during bereavement. Family members also often play a role in helping older people access support from other sources too. However, this heavy reliance on family means that people without family or close friends can feel they have nowhere to turn. This is a significant number of people: in 2012 there were 1.2 million people aged 65+ who had never had children²¹.

“One of us will die before the other and the idea of one of us being left alone without the other overwhelms me with grief. For us no element of our love will live on; there’s no child who with a sudden expression or sudden smile will recall to mind his smile or my eyes. When the other is gone, they are gone with total finality.”

Kirsty Woodard, Ageing Without Children

Nearly two thirds of older people say they turned to family and friends for support when they experienced bereavement²².



Men and women are affected in different ways

Men are more likely to experience loneliness and social isolation in bereavement than women. Independent Age's previous work on isolation found that 3 out of 4 older men without partners reported themselves to be lonely compared with 7 out of 10 women²³. On the other hand, women experience more negative impacts to their income and on practical matters than men.

Surprisingly, not all impacts are negative

As expected, the vast majority of impacts (across all four areas) were negative impacts. However, for self-reported health, quality of life, social isolation and loneliness, *more people experience positive impacts than no change at all*.

Some people may experience a sense of relief, or even release, in bereavement. In some cases, this may be because they had a lot of caring responsibility for their partner, which has now gone, or because the needs of their dying partner compromised their own. Alternatively, it may simply be that they are now more able to pursue their own interests or live more freely.

Importantly people, at any age, can rebuild their lives following their partner's death and find meaning and joy in life. It is Independent Age's vision that more older people are able to do so.

"Life was terrible after my husband died... it took me a long time to get over losing him. I had been with him for a lifetime. We had a son, who is now 70, but I didn't have any brothers or sisters so it felt as if my life had finished."

Mildred, 88

Our vision

Our vision is that every older person who experiences partner loss is aware of the support options available to them and is able to access the type of support with which they feel most comfortable. As we age, we are mindful that planning ahead, for death and for living without a partner, can be beneficial. In the future, we want everyone to have the confidence to hold difficult conversations.

Impact 1:

Loneliness and isolation

Many bereaved people are surrounded by friends yet still feel lonely

It is important to recognise that loneliness and social isolation are different things and that bereavement can have an impact on both.

"One of the loneliest things: not knowing anyone closely enough who'd had this experience."

Pam, 61

Loneliness is how a person feels. Social isolation is about contact, or lack of contact, with other people. Social isolation doesn't always mean a person feels lonely and it is possible to be surrounded by family or friends and still feel intensely lonely. We found this distinction was well-recognised by the older people we spoke to. Many reported feeling acutely lonely despite being well-supported by family members. One of our research participants described the feeling to us: "When I lost him it was more or less 'well you're on your own and that's it'."

Bereavement breeds loneliness

Nearly a third of bereaved people over 65 see themselves as very lonely, compared to just 5% of people of the same age who have not lost their partner.

More than 1 in 5 people said that loneliness was the hardest thing to cope with after the death of their partner²⁴. In our research interviews, loneliness was frequently the first thing older people mentioned when talking about losing their partner.

Loneliness that comes from losing a life partner isn't necessarily offset by other social connections. In fact bereaved people report lower levels of social isolation than others. Data from the English Longitudinal Study of Ageing (see page 46) showed that this social connectivity was driven by increased contact with friends, possibly because friends step in to support the bereaved person following their loss.

"The empty bed blues, a large double bed on your own... that was such a lonely time."

David, 84

"At the beginning everybody's ringing, it's all happening and then it eases off... people have busy lives and have plenty of other things to get on with."

Caroline, 75

This experience was shared by many of our research participants, who said that friends and family were quick to offer support and help after their partner's death. A few noted that these social connections lessened over time. Some felt that friends had their own lives to get on with and a few months after the death, perhaps the need for support had lessened in their view. Others worried they were a burden and reduced social contact to avoid this.

Loneliness is harder to tackle for bereaved people

In older age, people are likely to have fewer social connections. Friends and family members of similar ages die and your mobility difficulties or ill-health might restrict you from taking part in social activities. The lack of a social support system compounds the loneliness you feel as a result of a bereavement.

Losing a partner can make it harder to attend social functions if you were previously accompanied by your partner for most of your life. Going through the door can be much more of a challenge on your own. This may be felt more by men than women, as women tend to be the lynchpin for wider links with family and friends.



One person we spoke to was faced with an almost complete loss of social connections. When his wife passed away, the nursing staff who visited regularly to help his wife stopped their visits. He lost the only form of contact he had with the outside world: "The Admiral Nurse [a specialist dementia nurse] used to come and visit me every two weeks to help me understand what dementia was and see if I was alright... but the day that [my wife] died, that stopped and then I had no one at all." Ron, 92



We produce advice guides such as *If you're feeling lonely*, which looks at ways to reduce loneliness and stay connected.

Many people feel extremely lonely in the time before their partner dies

Older people report feeling very lonely in the period of time shortly before their partner dies. This suggests they may be experiencing anticipatory grief²⁵. Anticipatory grief occurs before the person dies. It is most common among carers, especially carers of people with dementia, who tend to be older. Carers in particular face losing regular social contact due to their role, which can lead to feelings of loneliness. With 1 in every 14 people aged 65 and over currently living with dementia, this impact is becoming increasingly important.

Family helps, but only if you have one

Family and friends are usually the route to alleviating loneliness. However, for those without family or close friends, it can be difficult to know where to start.

"It was only if I went to a counsellor or someone I knew and trusted that I could actually open up. The rest of the time was just sheer loneliness but I never wanted to do anything."

Pam, 61

Faith and bereavement

We often explore questions about spirituality and faith when someone close to us dies. Existing faith may be challenged, even dashed, while for others it will be a comfort. For some people, faith may be a new exploration, prompted by the loss of their loved one. Faith and bereavement are of particular importance to older people. For people of Christian faith, the average age of churchgoers in the Church of England is 61 and rising²⁶.

Cruse Bereavement Support say that "belief in an afterlife and in eventual reunion... can bring comfort and the view that death has a purpose and is not a random, meaningless event, can be reassuring"²⁷. The community that often comes with having a faith can also be a huge help for bereaved older people. Attending a place of worship such as a mosque or church provides social connections and a reason to leave the house and join in activities.

Churches may offer regular meetings for bereaved individuals or a synagogue might organise a telephone rota to contact recently bereaved people.

Faith leaders play an important role in offering solace and support to the bereaved members of their community; many regularly visit bereaved people, not just immediately but sometimes long after the death has happened.

This was echoed by the older people we spoke to. One mentioned that "having a church family" after her husband died had been very comforting. And another told us that "if someone has got faith... [death] is like there's a door rather than a wall". We found a particular resonance with faith at a time of bereavement for people aged over 75. They were more aware of the support offered by a faith leader than older people aged 65-74²⁸.

Addressing loneliness while grieving can be especially hard. Bereavement can cause a loss of identity and a lack of confidence, especially if the other partner was previously the one to take the lead on social connections.

Many older people spoke to us about their family stepping in and helping following the death of a partner and how helpful this had been, especially in keeping the memory of their partner alive. Others found that helping other family members (such as adult children) process their own grief was, in turn, a helpful way of working through their own emotions and feeling a sense of purpose.

Loss of routine is a contributor to loneliness

This may be particularly the case when the bereaved person performed a caring role for their partner. During the caring period, which in many cases can span multiple years (particularly for people living with dementia), the bereaved person's life was shaped by caring for their partner. Without that focus, the bereaved person may lose their identity or sense of purpose in life. Even for couples without a caring role, a strong routine may have developed simply because two people's lives were so closely entwined, but without one half of the partnership, the routine is not meaningful.

Of the older people we spoke to, those who were in work or heavily involved with interests and hobbies saw these roles as a key part of combating the loneliness they experienced, with some even suggesting that, "it was the job that rescued me", David, 84. What was beneficial was the sense of routine as well as the regular social contact and communication with others.

Of course, problematically, the vast majority of those in older age are no longer in work and are sometimes too frail to keep up with activities outside the home.

"I can think of other friends of mine who have lost husbands... the ones who weren't working or didn't have something else to occupy [them] probably found it harder to get over... it benefits you because you can't sit and feel sorry for yourself."

Elizabeth, 66

Independent Age's Friendship Services are here to help alleviate loneliness which many older people experience. Our friendly and dedicated volunteers offer regular company and conversation too. This can include a regular weekly or fortnightly friendly social chat over the phone or, in some locations, face-to-face conversations.

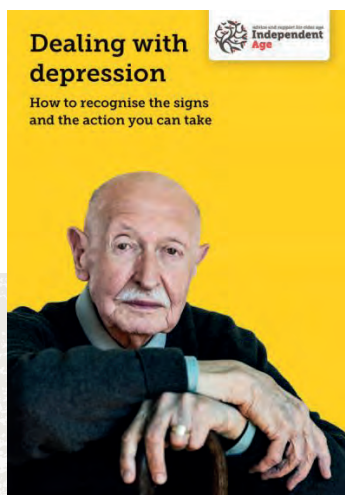
"The most important thing for older people is you have someone to visit you. I have a wonderful visitor from Independent Age." Mildred, 88, who reached out to Independent Age when she experienced loneliness after her husband's death.



Impact 2:

Mental and physical health

The impact of bereavement on your mental health is reasonably well recognised, in part because grief and depression share many similar symptoms. Less well understood is that bereavement can directly affect your physical health – in some cases, quite severely. Your mental and physical health are very closely related and worsening mental health can have a detrimental effect on your physical health. For people experiencing a bereavement, this may be through self-neglect, but there are also physiological changes that can happen as a result of grief. Our *Dealing with depression* guide (pictured) offers older people support to combat such issues.



We produce advice guides such as *Dealing with depression* to help support people who are experiencing depression.

Older people are more likely to have worse mental health as a result of a bereavement than younger people

When a person experiences a bereavement, it is normal to feel depressed. In fact, older people are four times more likely to experience depression in bereavement²⁹. This is known as “acute grief”, when the reaction to loss is intensive and disruptive. Most people will gradually come to terms with this grief, as they are able to resume normal activities and find pleasure in life again. However, for some people this doesn't happen, and they experience a persistent period of acute grief, interfering with daily functioning for an extended period of time. This is known as complicated grief.

In some countries, complicated grief is classed as a mental health condition whereas in the UK, it is not. Rather than arguing whether it should be or not, we want to stress that complicated grief carries serious risks and is something that most people need support to overcome. People with complicated grief are twice as likely to die by suicide compared to bereaved people without complicated grief. It also increases the risk of hypertension (high blood pressure) tenfold, which can lead to heart attacks and strokes.



Complicated grief is twice as common for older people than for bereaved younger adults. Nearly 1 in 10 bereaved older people develop it (double the risk of younger adults) and women are more at risk than men³⁰. People who don't get support at a time of bereavement – either from friends and family or from more formal sources such as counselling – are more likely to develop complicated grief³¹. People who have suffered multiple bereavements in a short space of time are also at greater risk. Additionally, for people who have previously struggled with depression, the death of a significant other can be the catalyst that brings it to the fore through complicated grief.

“Dying of a broken heart” is a real thing (sort of)

An older person whose partner has died is more likely to die in the three months following their partner's death than someone who hasn't been bereaved. This is known as the *widowhood effect* or, more commonly, as *dying of a broken heart* and is a result of the severe toll that bereavement can take on physical and mental health.

Negative health impacts on older bereaved people include increased risk of heart attacks, high blood pressure, problems with immune functioning, and sleep disturbances. The bereavement of a close loved one, such as a partner, weakens the immune system against lethal infections (such as pneumonia). Researchers found that this only happens in people over the age of 65³², putting older people at greater risk of ill health, or even death, in the months following a death.

In addition, losing a partner means people are less likely to look after their health. Bereaved people are less likely to eat well and exercise regularly. They are also less likely to prioritise existing needs such as attending scheduled medical appointments, or recognise and seek help with new health needs.

In most relationships, there is an element of interdependence. The person who died might have been the main carer of the bereaved person (we shouldn't assume that a person being cared for will always die before the carer). The surviving partner is then left without someone to help with daily activities or to take them to medical appointments. It may simply be that they no longer have anyone to remind them to take their medication or drink enough during the day.

There is a risk of isolation, as the surviving partner withdraws from physical and social activities that they previously enjoyed as a couple. As well as neglecting their own health and nutritional needs, they may drink more alcohol or become more accident-prone because they are paying less attention to their personal safety³³.

For a person already in poor health, or with a degree of frailty, a small change such as not eating well or not getting enough fluids, and being unable to seek help when things start to go wrong, can have a significant impact and result in their own death.

Older people's health also worsens prior to bereavement

In a partnership where one person is dying, the focus tends to be on the needs (health, emotional, psychological, or practical) of that individual and less so on the person who will be bereaved. This is natural and hard to avoid. However, it can mean that the physical and mental health of the surviving partner (whether or not they are a carer) can be neglected and only recognised following their partner's death. Given people can live for years with a progressive or terminal illness, this can lead to many years' worth of declining health for the bereaved person.

End-of-life care is typically provided in the last 12 months of life. It is healthcare and holistic support to help the dying person and their family to prepare for death. End-of-life care can provide relief of pain and other symptoms as well as any spiritual, social or psychological needs. It helps the dying person to die with dignity. Importantly, end-of-life care also offers continuity of support to the bereaved family members, both in anticipation of death and after death.

When we spoke to individuals who had been a carer for their loved one prior to their death, it was clear that during this period, the needs of the partner of the dying person took a much lower priority, and in some cases this led to ill health. Pam, who's 61, told us, "When your loved one is so ill for that long, your focus is on him... The counsellor said you have suffered trauma for all that time and you couldn't process and recover from it... that's why I was very, very ill."

Getting help can be a lottery

The GP is the first port of call for most people who are experiencing health problems or who feel their grief is unmanageable. Surprisingly though, GPs receive no standard training in helping their patients cope with grief and there are no NICE pathways for grief to which GPs can refer. Older people therefore experience varied responses from their GPs.

This variation was evident in the experiences of the older people to whom we spoke. Most had found their interactions with their GP to be positive. One person directly attributed their positive change in mental health to their GP's understanding of their situation and consequent signposting to counselling. Sadly, however, others found their GPs' responses to be less helpful. Some felt their GPs did not take their feelings seriously or did not provide any options for getting help. Pam said, "I was suicidal for nearly two years and what didn't help was my GP and family kept saying – 'it's early days'. I didn't feel it was being taken seriously... I feel that I wasn't fully supported earlier on, it prolonged it for me..."

Health and social care professionals, who are often present at the time of death, may not necessarily have the knowledge, expertise or confidence to cope with bereaved individuals. Greater understanding of grief and bereavement, especially the ways in which individuals can be affected by a bereavement, would enable a better response to older people's needs at this time.

A GP's view

It is natural to experience grief and an intense sense of loss after the death of a partner, loved one or someone who has played a significant role in your life. Death brings a mixture of emotions varying from intense sorrow, sadness and loneliness to relief and sometimes guilt, depending on the nature of the relationship. All of these emotions are normal, and there is no set time frame for them to appear or reduce.

For some people, bereavement can be prolonged and can start to have a negative effect on their ability to move forwards. When grief continually reduces a person's ability to look positively to the future, it may be useful to seek the advice of a GP. The loss of a partner can change almost every aspect of your life, including your role, your home, your finances, your routine, your social life and not least your emotional responses.

Each GP may have an individual approach to discussing your bereavement, and may or may not have known your partner and understood your relationship.

Try to let go of any expectations you'd placed on yourself about how you should be feeling at any given time. Don't be embarrassed or ashamed to seek help if you are worried about how you are feeling. Often just acknowledging you are experiencing grief and being reassured that it is normal can be a huge relief and helpful in itself.

Dr Emma Poyner, GP



Impact 3:

Financial and practical considerations

Bereavement is about more than just emotions. For many people, living without their partner has practical implications for day-to-day living. These can be an added burden at a time of emotional crisis. For some, practical impacts can be the most difficult aspect of their loss. In our research interviews, we found that people spent more time talking about the practical impacts of living without their partner than they did about the emotional impacts. Our research also found that older people who have lost their partner report lower quality of life and lower levels of life satisfaction.

Coping with day-to-day necessities is a whole lot harder

Interdependency within a partnership means that practical contributions are sorely missed after death. For most couples, there is a division of labour for managing their life together. One partner may be more likely to take care of the meal planning, food shopping and cooking, and the other might deal with financial matters or household maintenance. For many older people in heterosexual relationships, these contributions will be divided along traditional gender lines. When one partner dies the other may be left unable to pick up that role.

Related studies tell us that:

- Older people report particular difficulty taking on responsibility for managing the household and finances³⁴.
- More than 1 in 5 women no longer had access to a car following their husband's death, compared to just 1 in 20 men who found themselves without private transport³⁵.
- Many bereaved older people are found to have poor nutrition. Loss of appetite is a common symptom of grief³⁶, but there is also a large number of older men for whom cooking is completely new. Without their partner, or a friend or family member to step in, they do not eat a healthy diet.

"[My wife] mostly organised her own funeral... it would have been a struggle to try and work things out without that. It was all straightforward. And at that time straightforward was good."

Chris, 65



- People are less aware of support for dealing with the practical effects of losing a partner, compared to the emotional ones. Only 1 in 5 bereaved people aged 65 and over are aware they can go to a group to learn a new skill that was previously the domain of their partner – for instance, cooking, DIY, driving or household finance. In comparison, over half of people are aware of similar support groups for emotional difficulties³⁷.

“What I wasn't prepared for at all was the tremendous amount of involvement that John had in financial matters [when he was alive]... I was in a wilderness and to an extent still am”.

Pauline, 77

These findings are particular to today's older people, and traditional gendered roles (such as men doing most of the driving and women most of the cooking) change, so these impacts may, in time, become less gender-specific.

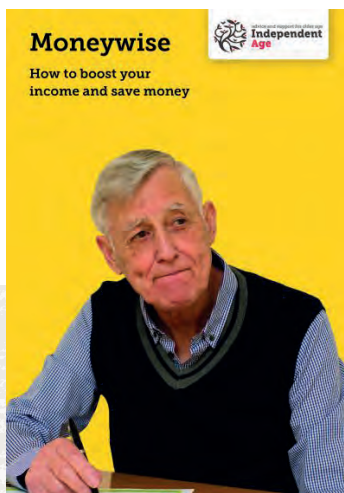
Being independent is harder when you're single

A person's ability to manage “activities of daily living” (basic self-care tasks such as getting dressed, bathing, going to the toilet), and “instrumental activities of daily living” (shopping, cooking and managing medications) typically decreases following their partner's death. Without the help of their partner, the bereaved person is less able to cope with everyday tasks.

The uptake of disability benefits following the death of a loved one tends to increase too. A disability may have previously been unacknowledged or hidden when the now-deceased partner performed a caring role or was able to provide considerable support.

Things get tricky immediately after the death

One immediate practical impact of bereavement is having to deal with everything that needs to be done after a person's death. Most of us are unaware of how to report a death or arrange a funeral. And with the average cost of a funeral and estate administration now standing at £8,905 per individual (up 50% from ten years ago)³⁸ the cost of death leaves many bereaved people struggling financially. Many people also feel overwhelmed by the burden of dealing with multiple systems following their partner's death. *Tell Us Once*, the government service that notifies various government departments when a death is registered, has simplified the process somewhat. But a bereaved individual may still need to liaise with the DWP, HMRC, local authority, pensions and insurance companies, banks and building societies, mortgage and loan companies and the Probate Service to resolve outstanding issues.



We produce advice guides such as *Moneywise* to advise older people how to boost their income and cut their bills.

Sometimes the dying person can help relieve this burden on their partner. Some of our research participants described how their partner, in their final months, not only arranged their own funeral but also set all their affairs in order. This made the administrative tasks after their death much more straightforward for the bereaved person and avoided any additional stress at this difficult time.

Women get poorer, men get richer

Women's household incomes typically fall after the death of their partner, while men tend to see their incomes increase³⁹. A 2008 study by the University of York found that women's household income decreased by £34 per week and men's increased by £12 per week and the number of older women feeling worse off financially doubled after the death of their partner⁴⁰.

This is largely reflective of the gender differences in pay and employment for today's generation of older people. In the same study, women were found to be twice as likely as men to have lost their partner's work-related disability benefit, and three times as many women as men lost their partner's occupational pension. Pension savings are a key factor. In 2018, pension provider Aegon found that women aged 50 have on average only accrued half the pension savings of men: £56,000 compared with £112,000 saved by men.

For future generations of pensioners, as increasingly both men and women work, this imbalance may readjust slightly. However, with a gender pay gap and women being more likely to take time out from work to raise families, this is about more than just both partners being in work.

Financial difficulties appear to cause greater concern for women than men. Women whose financial situation worsened were more likely than men to report high levels of emotional distress⁴¹. This is possibly because, in a heterosexual relationship, women are less likely to have responsibility for financial matters and may therefore be unaware that their income will drop after their husband dies.

Lack of involvement with financial matters may leave older women particularly at risk of unexpected negative financial shocks after their partner's death. These shocks could include holding unfounded assumptions about pension entitlements, debt repayments, inheritance or entitlement to benefits. Bereavement Support Payment, the government benefit for people whose married partner has died, is not available to people beyond state pension age.

i Independent Age offers free, impartial advice to older people and their friends or family to help with concerns including care and support, benefits and housing options. We support people who have been bereaved in older age with a range of advice and information. This can include a benefit check to see if you may be missing out on money you could claim.

Independent Age's free Helpline:
0800 319 6789

One area where men and women are equally affected is fuel poverty. The University of York study found that both sexes were at double the risk of fuel poverty immediately following their partner's death⁴².

Our research found just 2 in 10 older people had sought financial advice following the death of a partner. This advice could be about pensions, benefits or other financial matters and might be from a private financial adviser, from Citizens Advice or Independent Age.



More than twice as many women had sought advice as men, which could be a reflection of their worsened financial situation in bereavement, as well as women's increased tendency to seek help.

Most of this never occurs to us before our partner dies

More than two thirds of older people who have lost a partner say that they felt unprepared, either financially or practically, for bereavement⁴³, even though in most cases, they knew that their partner was going to die.

The vast majority of deaths over the ages of 65 are from terminal or progressive illnesses⁴⁴. There is therefore an opportunity to prepare for bereavement as well as for death itself. Currently, most people do not use this opportunity to plan ahead or have conversations about coping without their partner. Less than half of people aged over 65 say they have considered talking to their partner and planning for practical impacts after their death. Another 1 in 5 said they had discussed it, but only vaguely⁴⁵.

As many as 9 out of 10 older people are aware that having a will in place is helpful⁴⁶, but almost a quarter of people aged 75 and over do not have a will⁴⁷. Dying without a will (dying intestate) can lead to confusion about what the deceased person wanted to do with their possessions. It also adds complexity and draws out the bereaved person's role in settling their partner's affairs. It is not a foregone conclusion that loved ones will receive what the deceased person would like them to have, without a will. For couples who are not married, or in a civil partnership, it is even more important to write a will to make their wishes clear.



Some of the people we spoke to raised interesting issues where planning ahead would have been useful but did not occur to them. Many cited everyday problems such as not knowing a password to unlock a personal computer or where the shed key was kept. Couples who did plan ahead were more likely to cover existential issues such as wanting the surviving partner to remarry.

Our participants found the stresses of these everyday struggles aggravated their grief and prolonged the "in limbo" stage of their bereavement. Many were baffled why it hadn't occurred to them to ask about the basic day-to-day things, but few people want to confront a scenario of life without their partner before they must.

"We had problems accessing his computer... I would have said it jokingly – oh what's your password in case you don't make it through to tomorrow morning?"

Gail, 73

How do experiences of partner loss differ for older LGBT people?

The charity Marie Curie's 2016 report on bereavement experiences of lesbian, gay, bisexual and transsexual (LGBT) people found that partners may feel isolated or unsupported during bereavement because of their sexuality. Some LGBT people report feeling a lack of recognition or respect as next of kin to the deceased. They may also struggle to have their grief recognised, and to recognise their own grief, particularly if their relationship was not validated by others.

This "disenfranchised" grief can reduce the support available to the bereaved partner and can make it harder for them to access the usual sources of support during an already isolating time.

"We're not in a formal partnership... for a variety of reasons that's not happening in the near future. Of course being in a formal partnership and being able to wave your papers is the easiest and quickest way of being recognised as next of kin, and we've got to work on that, but I suspect that straight couples don't actually have to wave their marriage lines." Carol, 70, whose partner is living with bowel cancer and lung disease⁴⁸.

Opening Doors is a charity that provides information and support services specifically aimed at older LGBT people. They recognise that people in same sex relationships may have a different experience to heterosexual couples.



They say, "Older LGBT people may be less likely to be married than their heterosexual counterparts, and therefore may experience greater financial uncertainty after their partner's death. Because of prejudice and discrimination, older generations of LGBT people may have reduced social support in bereavement, especially from family members.

They are also less likely to have children and grandchildren to offer support. Same-sex partners may be treated differently by health and social care professionals during end-of-life care, at the time of death and following their partner's death. Bereaved partners may not be as respected or recognised as next of kin to the deceased or their role as partner to the deceased may be downplayed, for instance, being referred to as a "friend" rather than partner or husband/wife in the eulogy."

Impact 4:

Feelings and grief

The emotions of bereavement include more than just sadness

We shouldn't assume that people in later life have had stable, happy marriages, just because of their age. Relationships, at any age, can be dysfunctional but older generations are less likely to have separated despite an unhappy marriage.

Feelings of relief or release, anger, altered identity, confusion, guilt or a sense of hopelessness, are all common and normal. The nature of a person's relationship with their partner influences their feelings in bereavement and the course that their grief will take.

This range of emotion was well represented by the individuals to whom we spoke. Many recognised the multiple, and often conflicting, emotions experienced and described how they experienced many of these in quick succession. "You blame them like they consciously decided to die and leave you which is ridiculous but it's a way of coping... There's an anger thing as well. I did get very, very depressed and I started to get panic attacks as well." Gail, 73

An older person may feel relief when their partner who has been ill for a long time dies, particularly when they have been in pain and their suffering ends.

When the partner no longer has to assume a caring role, and all the limitations on individual freedom that entails, there is also often a sense of relief.

A double whammy of grief

Older people are more likely to experience anticipatory grief (grief that can occur before a person dies) perhaps because they are more likely to have been long-term carers. Dementia carers are twice as likely to experience anticipatory grief as cardiac disease carers. This tends to be a reaction to the losses experienced with dementia – loss of cognitive functions such as reasoning, memory and communication – and the change in relationships as a result.

One gentleman we spoke to had experienced anticipatory grief when his wife was diagnosed with breast cancer, but he didn't recognise it as grief at the time. Following his wife's death, he was worried about his emotional response: "I was quite distressed I wasn't grieving more... I asked my GP... and he said, 'No, you've been grieving for a long time.'" David, 84

While we might expect anticipatory grief to ease the grief following the loss of a partner, it is often not the case for many older people. Many report experiencing a "double whammy" of grief: anticipatory grief while their partner is alive but nearing the end of life, and acute grief when that person dies.

"We had done advance decisions back in 1996... I suddenly remembered that John had wanted to leave his body to medical research. I thought, 'oh my goodness I've failed him', I forgot."

Pauline, 77

A good death means a better bereavement

A poor experience of death and dying will often leave long-lasting, distressing memories for bereaved people and can have an impact on how well people will personally deal with their loss. The ONS National Survey of Bereaved People (VOICES), showed that 1 in 8 carers aged 65-79 felt that their loved one received poor quality care in their final three months.

Talking about dying makes it more likely that you, or your loved one, will die as you might have wished and it will make it easier for your loved ones if they know you have had a 'good death'.

Dying Matters, part of Hospice UK

How do we ensure we or our loved one gets a good death? Planning ahead helps. It's helpful to discuss and document the dying person's wishes about their death, ideally with family members and health or social care teams. A study of the benefits of Advance Care Planning (where preferences are agreed with healthcare professionals) found that family members of elderly people given the opportunity to plan ahead and have their wishes enacted, had fewer symptoms of post-traumatic stress, depression and anxiety after their loved one's death than those who didn't have the same opportunity.

A 'good death' is a profoundly individual experience. It may include being surrounded by the important people in a person's life, being cared for in a certain place, being kept pain free, or taking part in religious prayer. In order to have a compassionate, personalised end-of-life experience, people need high quality information and support so that they are able to make informed decisions about treatment and care options, in line with their personal values and beliefs. Health and care professionals, and others involved in their care, can then understand the person's priorities and offer truly personalised, holistic care throughout the person's life, including the end of their life.

Compassion in Dying

Those who were dying reported "relief" at having done everything possible to die the way they wanted to and relatives reported greater satisfaction with their loved one's death: "His death was really peaceful and everyone knew what to do"⁴⁹.



We produce advice guides such as *Planning for the end of life*, which can help readers think about their wishes, rights and needs at the end of life.

Unfortunately, we know that older people are less likely to receive end-of-life care⁵⁰. Studies by the University of Edinburgh found that many health professionals are unsure when to start palliative care for people aged over 70. The prevalence of older people living with multiple complex conditions means they were more likely to be viewed as “old” or “frail” than terminal. But older people living with multi-morbidity is a growing demographic (more than two thirds of people aged 65 and over have two or more long-term conditions), so finding a way through this confusion must be a priority⁵¹.

We know that place of death is often the biggest issue for people’s sense of quality in dying. Honouring a person’s wishes to die at home would go a long way to giving bereaved people peace of mind that their partner had the death they wanted. Given that more than 9 out of 10 people want to die in their own home but less than a third actually do, there is much work to do here and some difficult decisions to face about going into hospital at the very end of life. It might prolong life very slightly, but the trade-off may be that hospital, not home, becomes the place of death.

“She desperately needed that pain relief... she literally had to go 12 hours before [a nurse could come to give pain relief injections].”

Chris, 65

The interviews we conducted also showed the importance of place and circumstances of death for an individual’s experience of grief, and this can provoke feelings of guilt: “He really wanted to die at home. It distressed me that I couldn’t look after him at home...

I really would have liked for him to be nursed at home. It was awful him being in hospital.” Jean, 75

One of the benefits of end-of-life care for the surviving partner is the increased opportunity to talk about their feelings and find support, both before and after their partner’s death. Good quality end-of-life care plays a role in supporting the family as well as the dying person. This support can range from informal conversations to more formal counselling sessions, including pre-bereavement counselling or signposting to other support services. However, in some cases, care provided to the dying person does not adequately take into consideration the feelings or needs of the bereaved. Support may also disappear immediately after their death: “Nurses came to take away his bed and other equipment the day after he died. Suddenly he, and everything to do with him, had disappeared.”

Finding a new identity as a single person

In addition to the loss of their partner, individuals can experience a loss of their own role (as a carer or simply as a partner) and status following the death of a loved one. For example, when someone is known by friends or others as their partner’s ‘wife’ or ‘husband’, on losing their partner they sometimes lose the reason that friendship existed in the first place. “Most [local] people knew him more than they knew me. I was always down in London working, so I wasn’t as much a part of the community as he was.” Jean, 75

As well as the potential loss of a link to other people, for some this can mean the loss of an identity. For many older people, their identity is a product of their relationship with their partner.

To lose that partner can leave you feeling as though you are lacking a sense of purpose without your partner.

What support is available for coping with grief?

Family and friends play a big role in helping the surviving partner to adjust to life without their loved one. As many as 4 in 5 older people say they spent time talking to family and friends as a way of coping with their grief. Nearly three quarters of older people said they would advise another older person experiencing bereavement to keep in touch with family and friends⁵².

However, it should not be assumed that a wide or strong social support network will necessarily help to minimise the burden of grief. We must also remember that many older people are without family or close friends, especially at older ages, and this number is increasing.

Family members, however, cannot be expected to play the same role as more formal therapeutic options such as grief counselling. This is especially important where the grief emotions are more than just sadness – guilt or relief, for instance. These can be difficult emotions for family members to understand, especially if their grief experience is different: “I felt I couldn’t talk to them [family] anymore about this; it’s upsetting for us all but I still needed to talk.” Pam, 61

Well-meaning friends and relatives may also unintentionally dismiss feelings of grief. “He had a good innings” is a commonly used phrase with the intention of offering comfort. But the bereaved person will not feel the loss of their partner any less because they lived a long and happy life.

Many of the older people who shared their stories with us described feeling that their grief was being “minimised” by comments such as this.

Of the older people involved in this research, those who had received counselling or used a support group following a death told us they found it highly beneficial and would recommend it to others. “It was helping me get over my panic attacks and my depression and looking for the future and so, it was good, it was very good... I do think counselling is terribly important.” Gail, 73

Yet fewer than 1 in 5 people over 60 have received counselling to cope with a bereavement and more than half said it was not something of interest to them⁵³.

Just over half of older people said their advice to another person losing their partner would be “share your feelings with a person you trust”. What if the surviving partner doesn’t have a person like this within their family or friendship circle? Counselling is one option, but there are also less formal options such as talking to a community leader, GP or a spiritual leader if the person has a faith.

Today’s pension-age population may be less likely to seek therapy when their partner dies; they were a generation brought up to be self-reliant and even to see strong emotions as a kind of weakness. Is the lack of uptake of bereavement counselling about stoicism? Is there stigma attached to seeking help or a fear of the unknown about counselling? Or are older people simply less likely to know what’s available to them?

As well as therapy, there are many more forms of support available. These include help and advice given over the phone and written information on coping with bereavement, which could be online or printed.

Women may be more likely to look for written advice than men; 88% of people who request a copy of Independent Age's *Coping with Bereavement* guide are female⁵⁴.

Many more bereaved women than bereaved men told us they were aware that their GP could offer advice and support with grief (53% compared to 38%)⁵⁵. Differences between age ranges show up when we consider accessing different forms of support.

Perhaps not surprisingly adults aged 75 and over are much less likely to access support via the internet, with just 1 in 5 using online methods, compared to 2 in 5 for those aged 65-74. But people aged over 75 also tend to make use of telephone support for grief less than the younger group – 41% compared to 58% of people aged 65-74⁵⁶.

Bereavement and black and minority ethnic (BAME) older people

While 20% of the UK population are people from BAME groups, just 8% are aged 60 and over⁵⁷. As our population ages, we will see a significant increase in the number of older people from BAME groups.

Certain types of dementia are more common among the BAME population, increasing the risk of anticipatory grief for the surviving partner.

The emotional loneliness that comes with bereavement is difficult for everyone, but for BAME older people there can be additional challenges. Many older BAME people will have been born abroad, and bereavement can bring about reflection on growing old far from home, perhaps far from close relatives and friends. Where to retire and funeral arrangements may be brought to the fore, causing additional stress.

Although BAME older people tend to have larger social networks and household sizes, 24%-50% of those born in China, Africa, the Caribbean and Pakistan report feelings of loneliness.



The quality of interactions matter. Having a larger extended family does not necessarily guarantee quality socialising with people of a similar age and background who share similar interests.

For this reason, we should not assume that this larger family network will necessarily make coping with grief easier. With nearly half of Bangladeshi and Pakistani pensioners living in poverty, compared to 18% of white pensioners, social activities can be limited by this lack of financial security. Affordable bereavement support, that takes these cultural needs into account, is vital.

Runnymede Trust

The role of grief counselling

It is often assumed that older people have the resilience to cope with loss as a “normal” part of later life and as a result of this, they may not be offered bereavement counselling following a loss. Often older people have experienced multiple deaths – they are likely to have lost friends and family members. Despite this, it is wrong to assume that closeness to death automatically leads to resilience.

Loneliness and bereavement are closely linked. We all seek human contact, we all want to be heard and noticed, perhaps never more so than when dealing with the loss of loved ones. Often an older person may explain that they don’t want to be a burden;

perhaps this prevents some people from even asking for or seeking help.

Counselling changes lives. Older clients often say that they are surprised how much their counselling sessions have helped them. This therapy can give hope to bereaved older people, helping them to regain a sense of purpose, to see that they matter and deserve to be happy as much as anyone else.

My message to any older person struggling with their grief: counselling is a safe place for you to tell your story and be heard.

Petia Richardson, BACP registered counsellor who has worked with many older bereaved clients.

Talking is good, listening is even better

We need to talk more, and worry less about saying the wrong thing. Nearly half of older people said that their preferred way of remembering their loved one is by talking about them⁵⁸. Others are sometimes reluctant to talk to a bereaved person about their partner for fear of upsetting them, but ironically not mentioning the deceased person can feel upsetting to the bereaved person. Talking about their partner is exactly what would help.

“I was always very happy to talk about Lynn from the instant that she died. I’d very happily talk about Lynn all day long.”

Chris, 65



We also need to focus less on trying to fix the “problem” and simply let the bereaved person explore their feelings and grief. “One thing that would have helped was if people had an idea of how to just be with you and not come up with ‘why don’t you do this’ and ‘why don’t you do that’. They’re only trying to help but it has the opposite effect. I think it’s because people just don’t want to talk about it.” Pam, 61

Dementia presents a unique set of challenges to bereavement

Losing a partner to dementia

Anticipatory grief (the grief reaction that occurs before an expected loss) is common among older people and those who are caring for a partner with dementia are twice as likely to experience it. Relationships may start to change as a result of dementia and grief may be the prime reaction to the losses experienced. Carers may also grieve for the loss of a planned future with their partner, or their own freedom or lifestyle.

Particular points over the course of someone’s dementia may trigger feelings of anticipatory grief for their partner. Moving to a care home is a frequent trigger point or during the final stages of dementia, when a person may not be able to recognise or communicate verbally with their partner.

A quarter of carers report feeling cut off from society, which can be difficult to reverse once their partner has died. This increased isolation can make the process of bereavement more challenging; the surviving partner may become withdrawn or find it difficult to fill their time without their caring responsibilities. For those who have been full-time carers for a long time, life after their partner’s death may require significant adjustment.

How people with dementia experience bereavement

People living with dementia experience bereavement in a similar way to people without dementia. However, the process of bereavement can be complicated by their dementia and how much they understand about their loss. This may be a recent bereavement or one that happened a long time ago.

People can experience ‘new’ grief every time they are reminded of the death of their partner, or they may create alternative explanations for why the person is missing. For example, a bereaved lady with Alzheimer’s disease living in a residential home, might repeatedly ask when her husband is visiting but then experience repeated intense grieving when reminded of his death.

The person with dementia may also experience feelings of anticipatory grief, especially in the early stages, where they may grieve the loss of their own skills, abilities and independence.

Alzheimer’s Society

Conclusion and recommendations

Independent Age's vision

Our vision is that every older person who experiences partner loss is aware of the support options available to them and is able to access the type of support with which they feel most comfortable. As we age, we are mindful that planning ahead, for death and for living without a partner, can be beneficial. In the future, we want everyone to have the confidence to hold difficult conversations.

Unfortunately, the reality is far from this vision. There is an absence of coordination between the main players (the NHS, local government, social care providers and the voluntary sector including hospices), a lack of integration between death and bereavement services, and little recognition of older people as a group needing attention. Death and bereavement remain taboo subjects, and most people are uncomfortable discussing grief.

Call to action

Bereavement support can be difficult to navigate, with multiple small providers and no single approach to availability, quality of provision, or access to services.

- ▶ The government should establish a bereavement point of contact and pathway to signpost people through to services and support.
- ▶ Caring responsibility does not stop at the point of death. Those working closely with older people at the end of life must recognise that when a person dies, another person is bereaved.
- ▶ All older people are entitled to bereavement support that is tailored to their needs and preferences. In particular, attention must be given to meeting the needs of distinct groups of older people such as LGBT+ and BAME communities or people with dementia.

Many people only recognise the benefits of planning ahead for death and living without their partner when it's too late.

- ▶ More work is needed to remove stigma from talking about death and bereavement.
- ▶ People need more effective support to broach the difficult conversations of death and bereavement that help them to plan ahead.

A person's death and quality of life in their final months has a significant impact on the bereaved person.

- ▶ Every older person must receive good quality end-of-life care and be supported to die in the place they choose.

Talking about a personal experience of death and grief (to someone you trust) is almost always felt to be beneficial.

- ▶ More opportunities must be available to help older people keep memories of their loved ones alive.
-

There is no consistency in the approach to grief provided by health and social care staff.

- ▶ All health and social care staff working with older people must be trained to provide quality support to people who are grieving.

People who don't get support at the time of grieving are more likely to develop complicated grief.

- ▶ Bereavement support providers must recognise older people as a group needing special attention for support with their grief.
 - ▶ Family and friends should not be solely relied upon for bereavement support. Those without family need alternative sources of support.
-

We would like to thank the following people for giving us their time, sharing their stories with us and providing us with such rich insights for this report.

**Eleonore, 79,
was married to
Omar for 53 years**

"They have to go out every day and not just go out by themselves... Being alone is not good."

Gail, 73, was married to Brian for 26 years

"I have made a lot more plans now for myself and told my son where things are... I've written down my passwords... In a way it's good to do that while you are still very able."

Pam, 61, was married to Bill for 14 years

"Everyone has their own way. There is no right and there is no wrong way. Talk about it if you feel you can to someone you trust... Don't expect too much of yourself."

Chris, 65, was married to Lynn for 40 years

"Be with people. Communicate with people. Join anything. Walking groups, whatever you can do..."

Geoffrey, 93

"I would encourage all families to talk to each other about what they want to happen at the end of their lives. It's comforting to know that my wishes will be met."

Elizabeth, 66, was with David for almost 30 years

"In hindsight, I would have liked to have actually discussed what arrangements he would like... it's helpful because it semi prepares you."

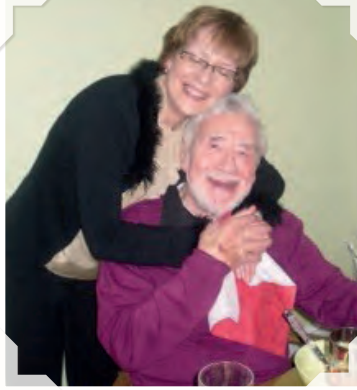


Caroline was married to Douglas for 27 years

"I was going through a very bad patch and I needed a holiday... after that I felt very much more composed."

David, 84, was married for 26 years

"In retrospect, I should have talked when I was doing that full-time caring... to come to terms with her not surviving."



Pauline, 77, was married to John for almost 50 years

"Stay involved with things that you have been involved with in the past... I would always recommend counselling...if only there was somebody that I could talk to."

Ron, 92, was married to Betty for 35 years

"You need someone to talk to who understands and who has all the knowledge of what is available to help you."



Mildred, 88, was married to John for 54 years

"The church where we were married has been knocked down... but you can still go and stand in the same spot where we stood on our wedding day – and I still do sometimes."



Jean, 75, was married to Michael for 35 years

"It's quite important to talk about death before it happens, really about how you want it – we did talk about death before it happened."



We would also like to thank those individuals who wished to remain anonymous for their time and for sharing their stories with us.

Methodology

A range of sources and methods were used to investigate the impact of partner loss on older people.

- The following research was completed by Independent Age, in conjunction with the International Longevity Centre-UK (ILC-UK).
 - An evidence review of older bereavement research to date.
 - An analysis of the English Longitudinal Study of Ageing (ELSA) – a sample on the health, social, wellbeing and economic circumstances of the English population aged 50 and older. This data gave an insight into the prevalence of partner loss and the health effects of bereavement in older years.
 - An analysis of current and future mortality trends to demonstrate how life-expectancy shifts are changing the distribution and experience of bereavement among older people.
- During 2017, Independent Age gathered information on possible bereavement interventions available at different stages of grief. This intelligence gave an indication about the kinds of support mechanisms on offer to older people who had been bereaved.
- In December 2017, Independent Age commissioned the polling agency ComRes to survey 200 older British adults. All participants had experienced the death of a partner over the age of 65 and 52% of the group were older than 75 years of age. Participants were asked about their support networks and their knowledge of bereavement services.
- In depth interviews were conducted with 12 older people who had been bereaved of a partner in later years. Participants were found through gatekeeper organisations, such as Open Age and Compassion in Dying. The final group of participants were a mix of genders above the age of 60. Interviews were semi-structured so participants had the freedom to talk about their experiences in greater depth. Questions focused on individual experiences of grief, the circumstances of bereavement and awareness of bereavement interventions. Interviews were completed over the phone or face to face for between 30 and 90 minutes.
- One-to-one interviews were conducted with GPs and bereavement counsellors to find out more about their interactions with bereaved older patients and experience of managing grief.

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Acknowledgements

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Date: April 2018

With thanks also to Ray Mitchell, Paul Cann and Jane Butler for their input and guidance.

We would also like to thank Gillian Creaser and Liz Jones at the Methodist Homes Association, as well as Open Age, Compassion in Dying and The Loss Foundation for helping us find participants for our research.



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advice and support for older age

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