



advice and support for older age

**Independent
Age**

We need to talk about caring: dealing with difficult conversations



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Executive summary

As we get older, talking to family about what might happen in the future is often fraught with difficulty. Asking questions about where we will live and how we will be cared for forces us to confront complex emotions. Often, we avoid discussing the matter altogether.

This report summarises new research from Independent Age, looking into how and why families avoid talking about challenges they may face in older age.

Which topics are most difficult to discuss?

Our findings reveal that the topics people find most difficult to discuss, of those tested, relate to future care and housing needs. The topics most respondents reported as being among the most difficult to discuss are as follows:

- 1 My preferences for end of life care** (46% include this in their top three 'most difficult')
- 2 Who will care for me when I'm older** (42% include this in their top three 'most difficult')
- 3 Where I would like to live if I can no longer live at home** (34% include this in their top three 'most difficult')

Our research

In April 2016, we commissioned the polling agency ComRes to survey a nationally representative sample of 2,066 adults online (including 520 people aged 65 and over). We asked them about their attitudes to different conversation topics, as well as their own experience of having some of these conversations. The full results are available to download from our website: independentage.org/difficult-conversations-report

A month earlier, we ran three focus groups in different locations: Sutton (Surrey), Middlesbrough and Eastbourne. We asked participants about their own attitudes and experiences of family conversations around ageing. One group (Sutton) comprised participants aged 75 and over to ensure we captured the experiences of older people. The other two groups comprised participants aged 50-65. We wanted to include adult children who might want to broach some difficult issues with their ageing parents.

We also conducted a small number of interviews with older people who were not able to attend a group, and a housing and care adviser. In total, we had detailed conversations with 30 people for the qualitative part of this research.

How many conversations are taking place?

While nearly four out of five people (79%) judge each of these difficult conversations to be either 'fairly' or 'very' important, less than a quarter have actually had them with family members.

There are around 7 million people aged 65 and over who have never had a conversation with family about these important topics¹:

- 67% of 65-74 year olds and 61% of over 75s have not had a discussion about where they would live if they could no longer live at home.
- 63% of 65-74 year olds and 53% of over 75s have not had a discussion about who will care for them when they are older if they need it.
- 63% of 65-74 year olds and 59% of over 75s have not had a discussion about their preferences for end of life care.

Over a third of respondents said they are planning to have at least one of these key care conversations. But our research reveals that many people are putting this off:

*"It's when something happens – I think that's when the big, proper conversations will happen."
(Female, 55-65).*

There are more than 3 million over 65s who we categorise as 'delayers' – those who are planning these conversations but have not yet had them².

Worryingly, there are also more than 3 million over 65s we have dubbed 'deniers' – those who are not planning to have these conversations around key care topics with their families at all³:

- 26% of 65-74 year olds and 30% of over 75s are not planning to discuss their preferences for end of life care.
- 32% of 65-74 year olds and 27% of over 75s are not planning to discuss who will care for them when they're older if they need it.
- 29% of 65-74 year olds and 28% of over 75s are not planning to discuss where they would like to live if they could no longer live at home.

This leaves a huge number of families and individuals in a state of uncertainty, having never explicitly discussed how they will manage if relatives need care and support.

The numbers of people initiating these conversations with their older relatives are even more worrying:

- 82% think it is important to talk to an older relative about where they would like to live if they could no longer live at home, but just 23% have discussed this with them.
- 82% think it is important to talk to an older relative about who will care for them when they're older, but just 24% have discussed this with them.
- 81% think it is important to talk to an older relative about their preferences for end of life care, but just 20% have discussed this with them.

This goes for those planning conversations too – overall, less than one in four respondents said that while they have not had any of the conversations we asked about with their older relatives, they are planning to do so in the future.

Key barriers to conversation – why aren't these conversations happening?

Major barriers to having conversations with family about what might happen as we age include:

- **families lacking the knowledge and confidence to begin a conversation**

"Good information and advice, I think, is one of the barriers... I think people are worried that they're going to suggest the wrong thing to their older relatives." (Advice worker)

- **anticipating the reaction of family members**

"I think, 'oh I won't say anything'... you don't always tell them because they're going to worry." (Female, over 75)

- **avoiding facing undesirable possibilities – especially residential care**

"We all have a natural instinct to denial... if it looks pretty horrid, you'd rather pretend it's not there." (Female, 55-65)

- **feeling the time is not right**

"I broach it and we'll talk about it but then she'll be like 'oh well, that's not something to talk about yet'." (Male, 55-65)

- **distance and a lack of time for discussion**

"When I do see them, there isn't much time to talk about things like that... it's mainly giving them something to eat and drink, or presents – it's usually a birthday or something. There's never time." (Female, over 75).

Why does this matter?

The failure to have these conversations has real consequences.

On an individual level, older people may feel more anxious about the future⁴. And adult children may be overwhelmed by responsibility if they find themselves having to make decisions on behalf of relatives without having ever discussed their wishes⁵. Studies also suggest that where there has been no explicit discussion, the choices that adult

children make when acting on behalf of their parents are significantly different from those the parents would have made themselves⁶.

A lack of discussion and planning also has a major impact on end of life care. The charity Compassion in Dying found that when patients' wishes were formally recorded, they were 41% more likely to be judged by a loved one to have died well⁷.

The pressures on families are only set to increase. In the future, many more of us will need care and support in our later years, but declining funding means fewer people will get state support. In many cases, family members will need to fill the gaps. The Personal Social Services Research Unit (PSRRU) project that the numbers of disabled and older people receiving informal care will increase by 63% to around 3.5 million by 2035⁸.

Our recommendations

What can we do to remove some of the barriers currently preventing many people from talking with relatives about what might happen as they get older? Some of the barriers we found relate to specific family dynamics and circumstances. These mean that for some families, important conversations about ageing are always going to be tough to initiate. This is not something the government, policymakers or the third sector could or should try to fully 'solve'.

But there are a host of strategies we can use to increase the number of families talking explicitly about ageing and their future, based on our findings in this report.

Addressing the information problem

A lack of information can lead to fear and unwillingness to begin a discussion. The care system is extremely complex and difficult for people to navigate. A range of key agencies – from information and advice providers, to local authorities, to the NHS – must make their care information more accessible, to help facilitate meaningful, informed conversations.

Along with others in our sector, we will continue to support people struggling to make sense of their options through our advice publications (available online at www.independentage.org/information) and our Helpline (0800 319 6789).

We will also continue to signpost families to organisations with specialist expertise on particular conversation topics.

Addressing unwillingness to consider residential care

Developing a clearer picture of what goes on in care home settings would help tackle a widespread feeling of fear of residential care environments.

- There should be an anonymous survey of staff working in care homes, asking them to identify the extent to which they have witnessed neglect or abuse.
- Care homes should increase their outreach activities to break down barriers with local communities, and show more people what living in a care home is like. Initiatives such as Care Home Open Day are a great start but this is just one day a year – outreach needs to be ongoing.

We also need to improve the information people rely on when making decisions about residential care. We will be publishing a report in autumn 2016 summarising what we have found about specific problems older people and their families face in making informed decisions about moving to a care home.

Addressing the denial problem

Families need to be supported to initiate some of these difficult conversations.

We would like to see more health and care professionals consciously encouraging the families they work with to think about the five conversation areas we have identified as most crucial to discuss (see page 36).

We also need to make conversations about care in later life more natural and normal by ensuring these start much earlier in life⁹. We want to see conversations about ageing, dementia and care included in Personal social health and economic (PSHE) education in schools.

Independent Age has also published an information resource to help families have these conversations. It's available at: independentage.org/difficult-conversations

Introduction

Talking to family about sensitive subjects is often difficult. What's especially hard is discussing the future and what might happen as we get older. As we ask questions about where we will live and how we will be cared for as we age, we are forced to deal with complex emotions. For the older person, it can be difficult to face the prospect of losing independence and autonomy. For relatives, there may be feelings of responsibility and guilt, as well as an unwelcome reminder of a parent's or loved one's mortality.

Unsurprisingly, a natural reaction is to avoid discussing such topics altogether. Researchers have found that fewer than half of those adult children who had thought about the possibility that a parent might need help in the future had actually discussed it with that parent¹⁰. The tendency seems to be to wait until there is some kind of crisis that creates an urgent need for discussion^{11,12}. Some have attributed this to adult children's unwillingness to think about their parent's mortality¹³. Others have shown (when studying mother-daughter interactions) that there can be an assumption that children would implicitly know what the parents want without the need for further discussion¹⁴.

Why does it matter if these conversations do not happen?

Firstly, on an individual level, avoiding explicit conversation can have negative consequences. Older people may suffer increasingly from the anxiety that accompanies not knowing what will happen to them in the future¹⁵. And they may be less likely to make financial plans for care. The most recent Health Survey for England showed that when asked whether they have thought about how they will pay for care, 40% said that they hadn't thought about it at all¹⁶.

Adult children may feel overwhelmed by responsibility if they find themselves in the position of having to make decisions on behalf of relatives, without being confident of their wishes¹⁷. Several studies have shown that where there has been no explicit discussion, the choices that adult children make, when acting as proxies for their parents, are significantly different from those the parents would have made themselves¹⁸. A lack of discussion and planning also has major implications for end of life care. The charity Compassion in Dying found that when patients' wishes were formally recorded, they were 41% more likely to be judged by a loved one to have died well¹⁹.

All of these scenarios are familiar to our Helpline advisers who regularly speak to older people and family members facing just these sorts of situations:

“Every day we speak to people who need to make a choice about future healthcare, housing or social care options, for themselves or for others. Making a big decision for someone else – like whether or not to move into a care home or choosing between different treatments – can be stressful at the best of times.

We regularly hear how difficult and overwhelming these decisions can be when the relatives or friends, who are trying to do their best on behalf of a loved one, do not know what that person wanted, or don't have the authority to make that decision.

(Anna, Independent Age Helpline Adviser).

Secondly, the challenges of ageing and care will only become more widespread. Demographic changes mean that by 2040, nearly a quarter of us will be over 65²⁰. The Personal Social Services Research Unit (PSSRU) at the London School of Economics project that the numbers of older people who are defined as disabled (unable to perform key activities of daily living) will rise by 65% between 2015 and 2035 from around 2.9 million to around 4.8 million²¹.

3.5 million

disabled older people will receive informal care by 2035

– an increase of 63%

(PSSRU projection)

Yet funding for care continues to decline, meaning fewer and fewer older people will be getting the support they need from the state. In 2013/14 400,000 fewer people were receiving social care services than in 2009/10²², according to the Association of Directors of Adult Social Services (ADASS). Further, the Nuffield Trust, the King's Fund and the Health Foundation have estimated that the gap in social care funding will be at least £2.8 billion by the end of this Parliament²³.

An underfunded system means that family members will increasingly need to fill the gaps. PSSRU project that the numbers of disabled older people receiving informal care will increase by 63% to around 3.5 million by 2035²⁴.

Given this context, the question of whether families are able to discuss the needs of their older members looks increasingly urgent.

This report summarises the findings of research we conducted in spring 2016. We have structured the report around some key questions which are addressed in the chapters that follow:

- 1 What conversations are taking place?**
- 2 Which family members are hardest to talk to?**
- 3 Which topics are hardest to talk about?**
- 4 What are the barriers to talking about ageing?**
- 5 What can we do to encourage more of these conversations to happen earlier?**

This report reflects our desire to see more older people and their families prepare for their later years, so that they have a better chance of living with independence and control.

Of course, talking about aspects of ageing does not shield people from all the negative outcomes. And for many older people, especially the oldest and the one in five people over 50 who don't have children²⁵, there may be no living family members around to support them.

But there is clearly a significant group that would benefit greatly from having earlier and more frequent conversations with family members about their wishes and expectations – and we all have a responsibility to help those conversations take place.

1

What conversations are taking place?

- Almost four out of five people agree it is important to talk with family about what will happen as they get older, but less than a third have actually had conversations about any of the issues we tested.
- Around a third said they are planning these conversations in the future but a minority (around a quarter) do not intend to have them.
- People are less willing to initiate conversations about older relatives than they are about themselves.
- Men tend to be less willing than women to initiate key conversations with older relatives.

When thinking about themselves, almost four out of five respondents think it is either 'fairly important' or 'very important' to talk to their family about five of the six issues we raised about getting older relating to housing, care and finances.

People told us that these conversations are important and should be broached, ideally, early on:

"If you don't talk about things and don't let your family know what your wishes are... then they are going to worry, 'Is this what she would have wanted?' So to take that worry away from them, I think it's best."
(Female, 55-65)

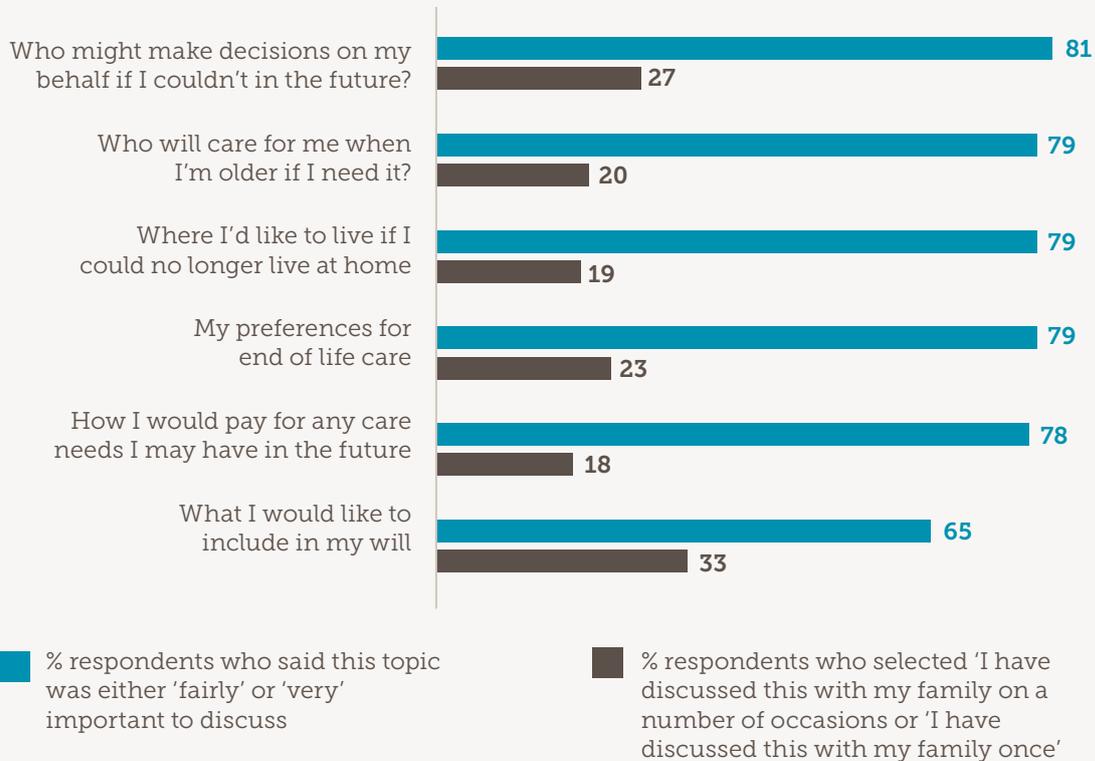
"It's something that shouldn't be thought about when you're 70 – it should be thought about much earlier than that." (Female 55-65, on decisions about residential care)

Older people also talked about wanting to ensure that their affairs are well managed and do not create a burden for others in the family:

"The experience of losing my wife made me think when someone passes away it's a stressful time... The thing is not to leave any trouble behind you." (Male, over 75)

However, these concerns do not reflect how many people have actually engaged in conversation with their families about the topics we tested. Only around a quarter, and in some cases less than one in five, have had any key conversations with their families about end of life care, where they will live, and who will care for them (**Figure 1**):

Figure 1: Importance of different topics and whether they have been discussed



Responses to the following questions: How important, if at all, do you think it is to talk to your family about each of the following issues?

Below are a number of things that people may wish to discuss with their family when thinking about getting older. For each topic, which statement best represents your own situation?

- 79% said it was important to discuss where they'd like to live if they could no longer live at home, but just 19% had ever discussed this.
- 79% said it was important to discuss who would care for them when they were older, but just 20% had discussed this.
- 79% said it was important to discuss their preferences for end of life care, but just 23% had discussed this.

Age differences

As expected, the likelihood of having had a conversation tends to increase with age, as the topic gets closer to home.

However, even among those aged 65 and over, across key topics relating to finances, housing and care, nearly two thirds of people have still not had a conversation with family (Figure 2).

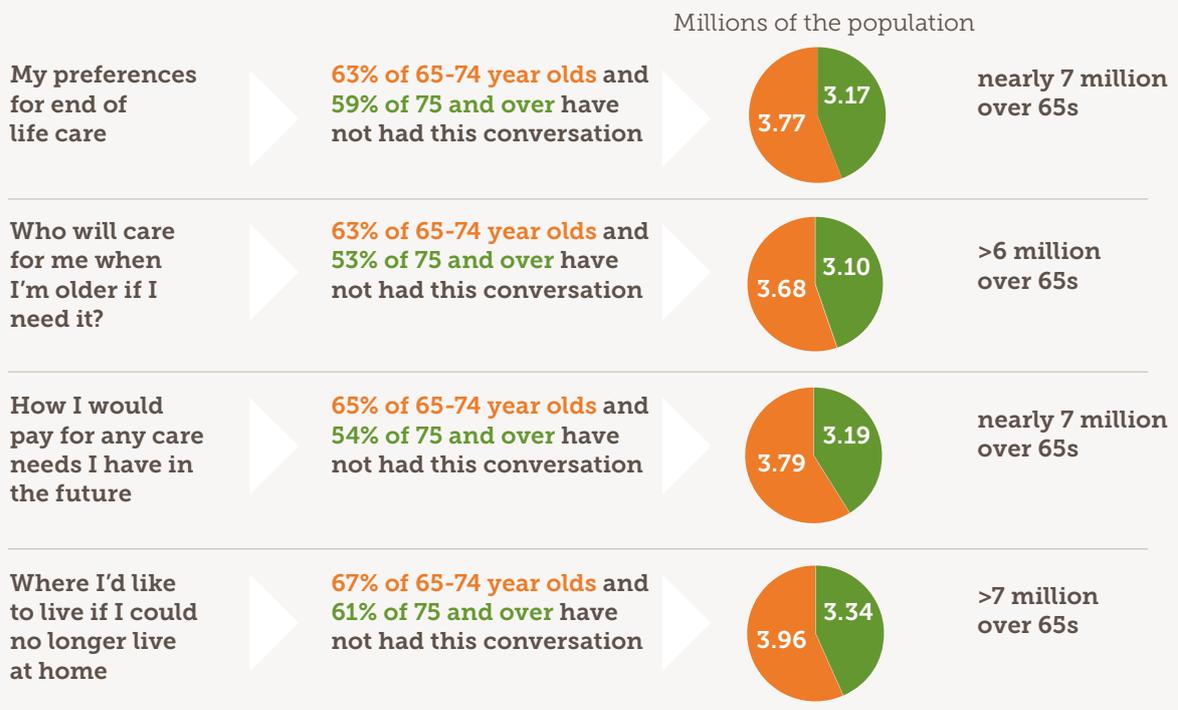
On the subject of where people would like to live if they could no longer live at home, age makes little difference to the likelihood of having discussed this with family. Less than a quarter (24%) of those aged 65-74 and those aged 75 and over had discussed this. That rate is comparable to the proportion of 18-24 year olds who said they had discussed this with their family (25%), despite the latter's significantly less pressing need.

Thinking about needing to leave your home is one of the hardest issues to face, as several older people explained:

"I've got my bungalow... it's a lovely place. We bought it with the intention of staying there until such time as we were no more. I didn't let my wife stay in hospital; she stayed in the house until her last day... I'd hate to go in a home, sit there all day and do nothing." (Male, over 75).

While many people will be able to continue living in their homes, a minority of older people (around 16% of those aged over 85²⁷) will need the extra support offered by residential care. Not engaging in discussion about this possibility can make the transition even harder to manage for older people and their families.

Figure 2: Over 65s who have not had the conversation with family²⁶



Response to the following question: Below are a number of things that people may wish to discuss with their family when thinking about getting older. For each topic, which statement best represents your own situation?

65-74
75 and over

Delayers

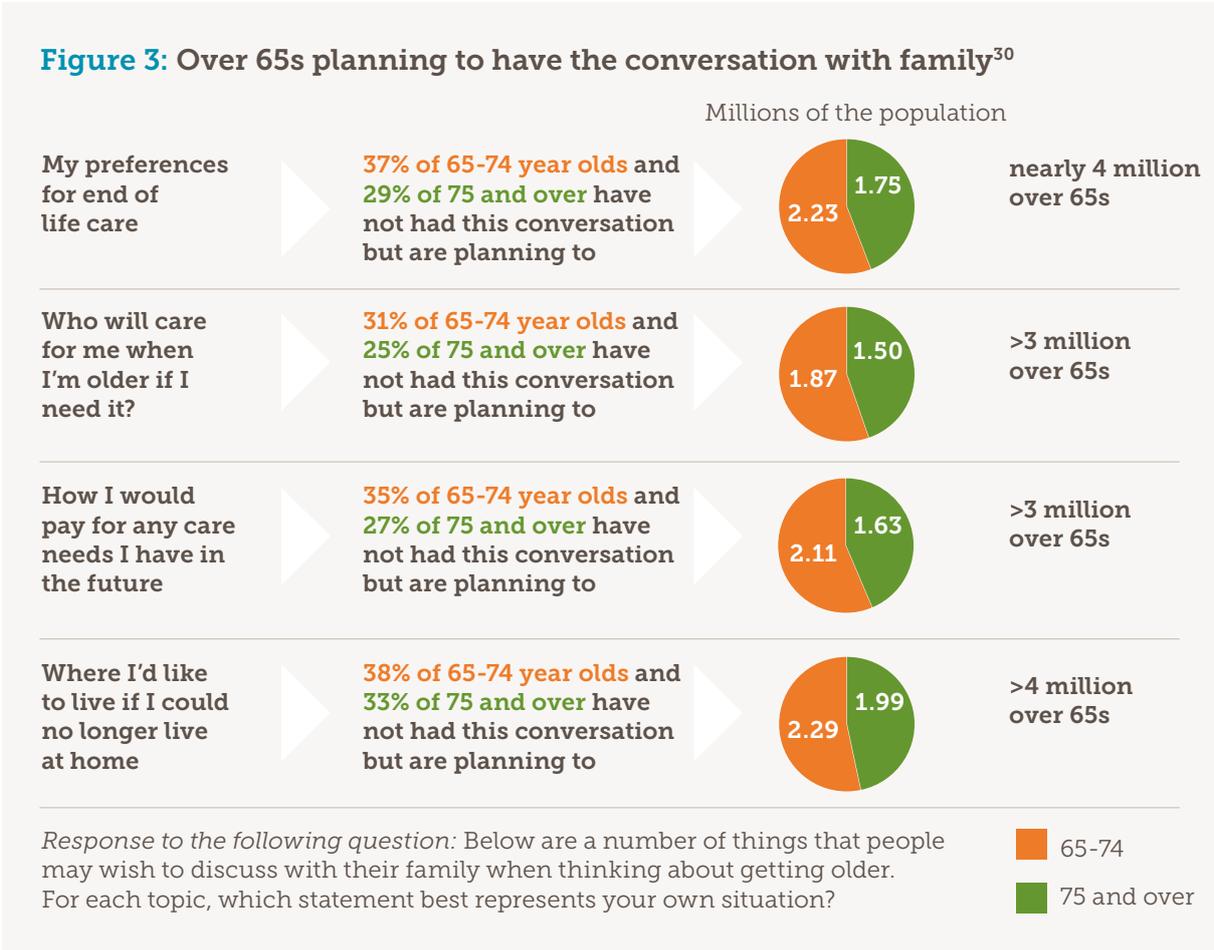
Over a third (35%) of all those surveyed are planning to have a discussion about key care topics²⁸, but have not yet got round to it. For each of these issues, this equates to over 3 million people aged 65 and over who are delaying these conversations²⁹ (Figure 3).

We have dubbed this group ‘the delayers’ because we find that even as people age, many of them are still putting off having these conversations. In fact, the proportions planning these conversations are similar all the way up to those aged 65-75 before dipping for the oldest age group (those over 75). Putting off a conversation is a common response, as many people told us:

“It’s like a tax form – you know you’ve got to do it but you leave it until the last minute.” (Female, 55-65).

But leaving these conversations to the last minute can often make them harder to have – particularly when families are overtaken by the very events the conversations are supposed to help prepare for.

For example, more than a million people are expected to be living with dementia in the UK by 2025 – up from 850,000 last year, and including 40,000 younger people³¹. Choosing a care home, and discussing end of life care decisions can be stressful and difficult at the best of times. However, having these conversations at a crisis point – for example, when you or a loved one has been diagnosed with dementia and requires extra support – is considerably harder.



Deniers

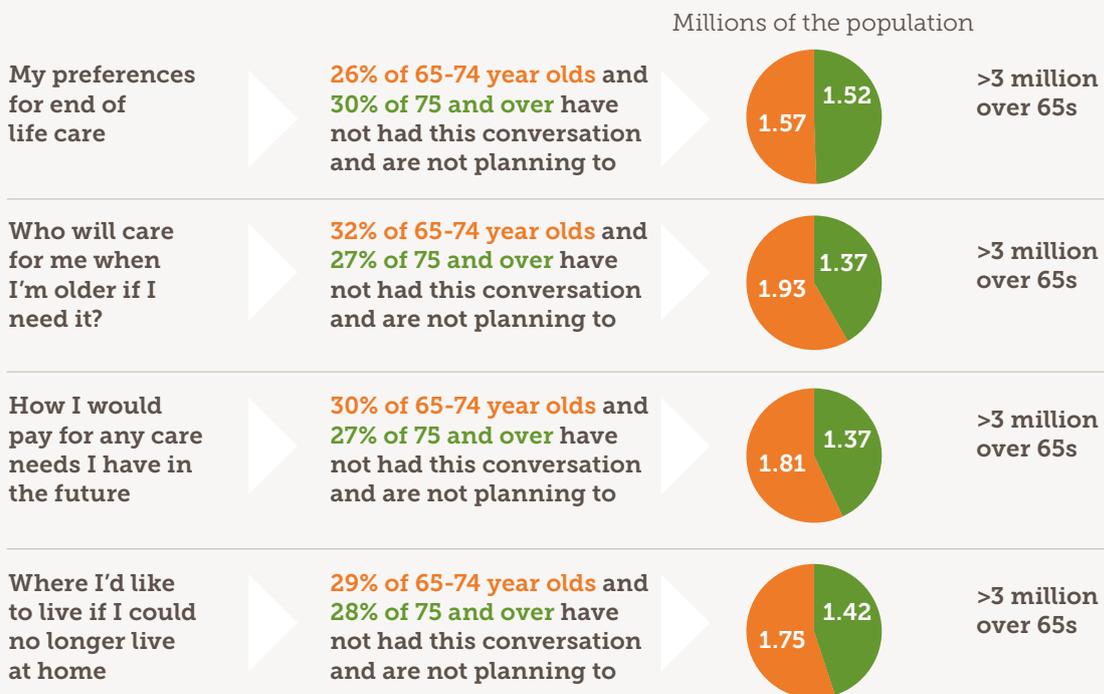
Even more strikingly, across all of the issues we asked about, at least one in four respondents said they had not discussed these key topics and did not intend to.

More than a quarter of those aged 65-74 and over 75 do not intend to have key conversations around key care topics (Figure 4). For each of these issues, this equates to around 3 million 'deniers' aged over 65 who are not planning to have these conversations³².

So while there is evidence that some people have good intentions about having difficult conversations that they have not yet acted on, there is also a significant minority who do not plan to tackle these conversations at all.

Given what we know about the large numbers of older people who will need additional care and support in their later years, this is especially worrying.

Figure 4: Over 65s not intending to have the conversation with family³³



Response to the following question: Below are a number of things that people may wish to discuss with their family when thinking about getting older. For each topic, which statement best represents your own situation?

■ 65-74
■ 75 and over

What about conversations with older relatives?

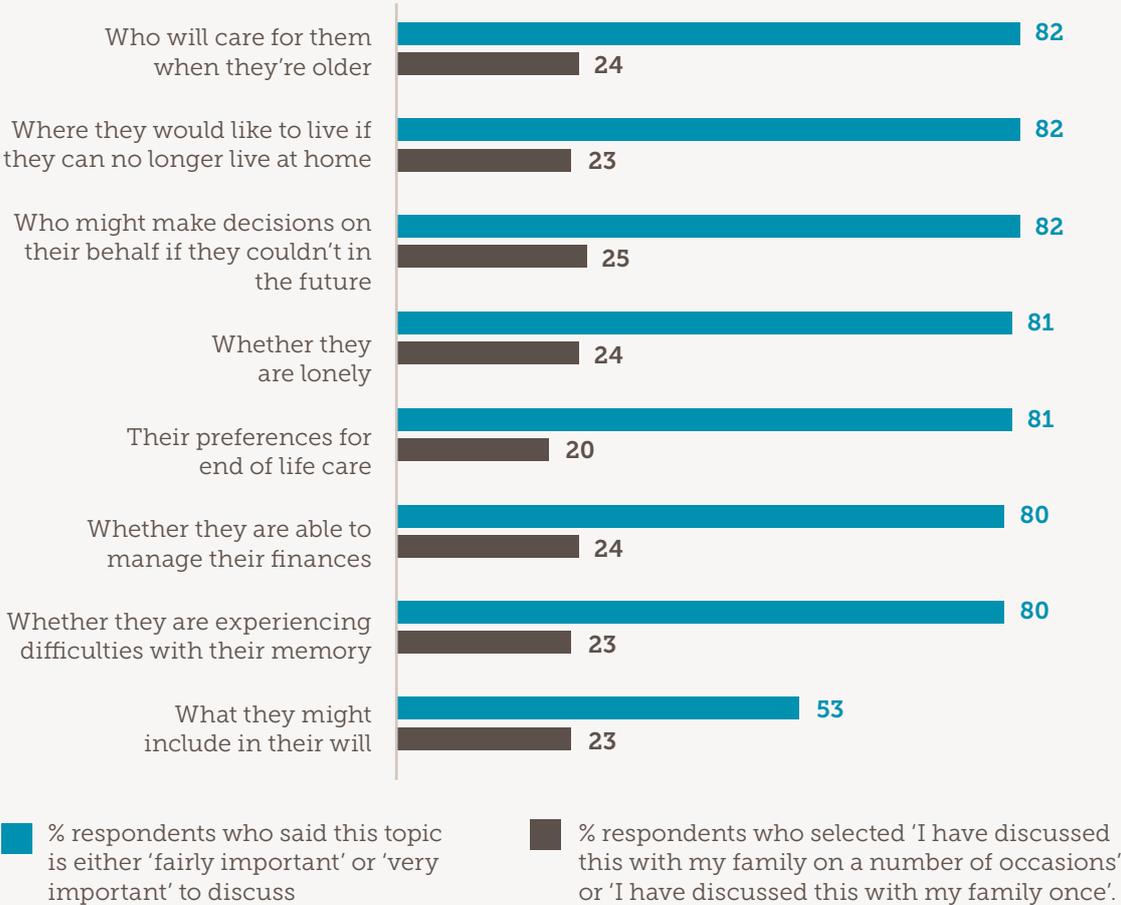
The evidence shows that many older people find it difficult to initiate important conversations. But how do their relatives compare? To find out, we asked respondents what conversations they had initiated with their older relatives (Figure 5).

For seven of the eight issues we looked at, at least four out of five respondents think it is either 'fairly' or 'very' important to talk about the issue with their older relatives.

But only around one in four adults have actually discussed each of the topics we asked about with an older relative.

- While 82% think it is important to talk to an older relative about where they would like to live if they could no longer live at home, just 23% had actually discussed this with them.

Figure 5: Importance of different topics and whether they have been discussed with older relatives.



Responses to the following questions: How important, if at all, do you think it is to talk to elderly relatives about the following topics?

Which, if any, of the following statements best describes your interaction with elderly relatives on each of these topics?

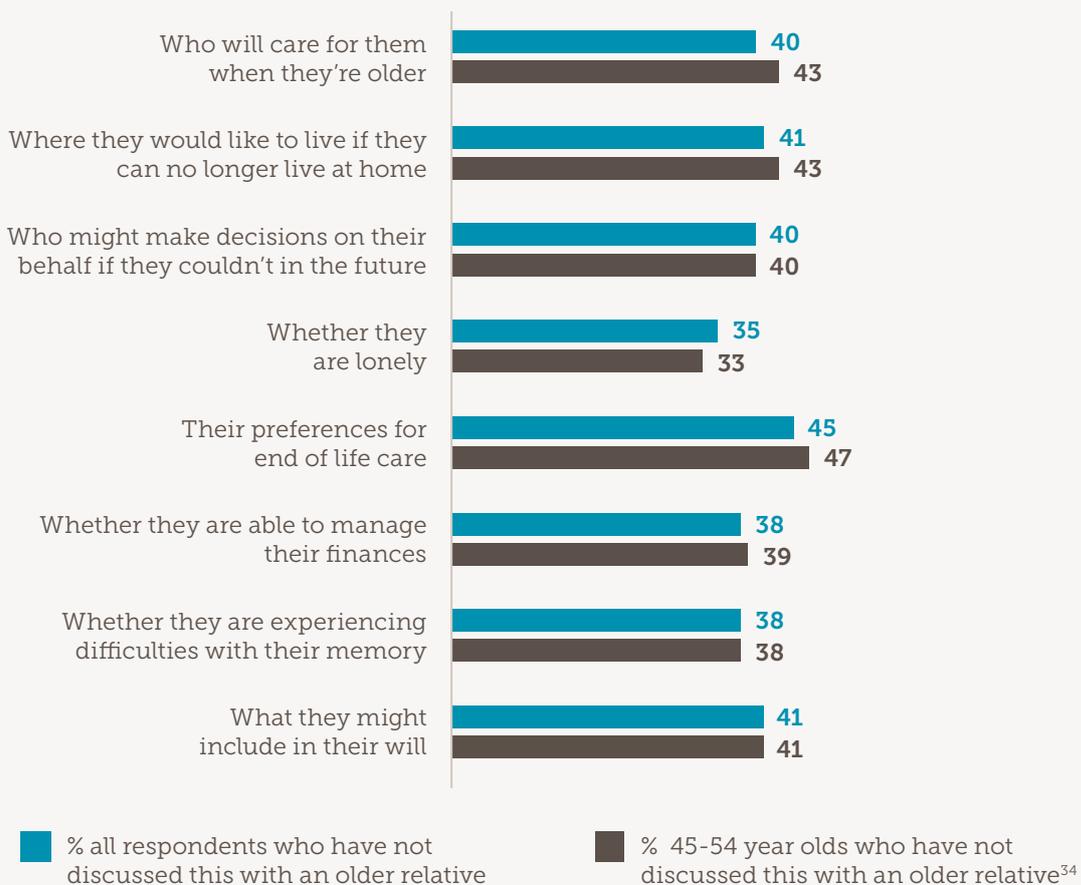
- While 82% think it is important to talk to an older relative about who will care for them when they're older, just 24% had actually discussed this with them.
- While 81% think it is important to talk to an older relative about their preferences for end of life care, just 20% had actually discussed this with them.

We might expect that the numbers who have had key conversations about ageing will be significantly higher for those in age groups most likely to have older parents.

But when we focus on this age group (45 to 54), we find they are just as likely as other respondents to have failed to bring this up with relatives (**Figure 6**).

In population terms, this means that for each of these key issues, there are as many as 2 to 3 million people in this key 45-54 age group who have not yet had these important conversations with an older relative³⁵.

Figure 6: Conversations with older relatives among 45-54 year olds compared to all respondents



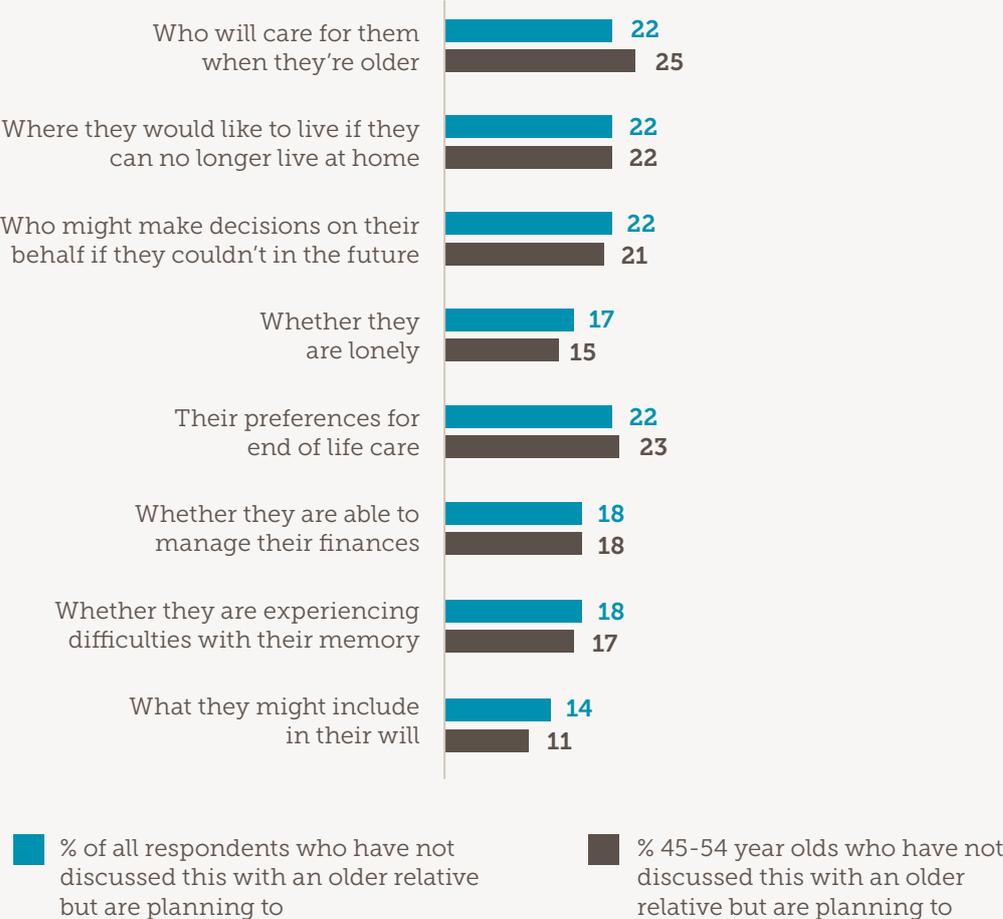
Responses to the following question: Which, if any of the following statements best describes your interaction with elderly relatives on each of these topics?

Delayers and deniers

Delaying and avoiding conversations is also common when it comes to discussions with older relatives. People aged 45-54 are also not much more likely than younger people to be planning to have a conversation of this kind with an older relative, as the chart below shows (Figure 7):

Overall, willingness to consider initiating conversations about older relatives is actually lower than when we asked people about themselves. While around a third of respondents stated they were planning on having the relevant conversation in relation to themselves, less than one in four said that they are planning to have these conversations with an older relative.

Figure 7: All respondents and those aged 45-54 planning to have the conversation with an older relative



Responses to the following question: Which, if any of the following statements best describes your interaction with elderly relatives on each of these topics?

This suggests that bringing up an issue relating to yourself is easier than when someone else is the subject of the discussion. This echoes research testimony that the person affected by an issue often feels more comfortable bringing it up than their loved ones:

"Alice was brilliant. I wasn't ready for that conversation but she'd tell me, 'I want you to do this, I want you to do that'. It was good to talk about it and I appreciate it now." (Male, over 75, discussing his wife's last days).

"I find she brings things up with me more than I will with her." (Female, 45-55, discussing elderly mother).

Gender differences

Women are more likely than men to say that it is important that they discuss all of the conversation topics we looked at. The biggest gender differences are around:

- their own preferences for end of life care: 84% of women see discussing this as important compared to 74% of men
- who will care for them when they're older if they need it: 84% of women see this as important compared to 75% of men
- where they would like to live if they could no longer live at home: 83% of women see this as important compared to 74% of men.

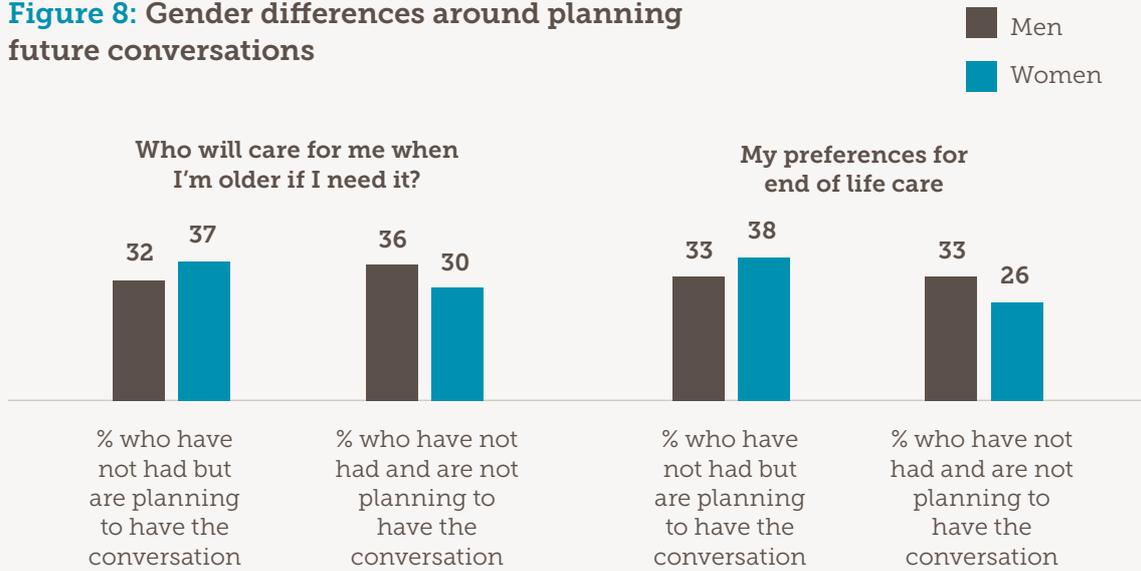
But the importance they attach to these topics does not translate into more frequent discussions. Women have only discussed a topic more than men in two cases:

- where I would like to live if I could no longer live at home: 22% of women have discussed this compared to 17% of men
- what I would like to include in my will: 35% of women have discussed this compared to 30% of men.

We do, however, see different attitudes to future conversations. Women are more likely to be 'delayers': planning to have the conversation but not yet having it, while men are more likely to be 'deniers' and say they are not planning to have it at all (**Figure 8**).

Perhaps more concerning is the gender gap we find when we look at whether people have initiated conversations with and about their older relatives. Across all the topics we tested, men are more likely to be 'deniers', to say they have not had the conversation and do not intend to have it.

Figure 8: Gender differences around planning future conversations



And the biggest gender difference can be seen in relation to the top three most difficult issues:

- 1 Who will care for them when they are older:** 22% of men said they have not discussed this with a relative and do not intend to, compared to just 14% of women
- 2 Where they would like to live if they could no longer live at home:** 23% of men said they have not discussed this with a relative and do not intend to, compared to just 14% of women
- 3 Their preferences for end of life care:** 26% of men said they have not discussed this with a relative and do not intend to, compared to just 19% of women.

Given that men are less willing to broach these subjects with their older relatives, it is not difficult to see how the burden of discussing and planning caregiving will fall more heavily on women. We know that women are already more likely to take on caring responsibilities than men; in fact, one in four women is already providing care for an older, ill or disabled loved one³⁶. Some of the women we spoke to clearly felt under stress when thinking about future caring responsibilities:

*"You can't do everything can you... be everything to everyone? That's going to be a worry in the future as more grandkids come along. That's when I think I will feel the pressure because I work full time as well. So I'm not looking ahead at all."
(Female, 55-65)*

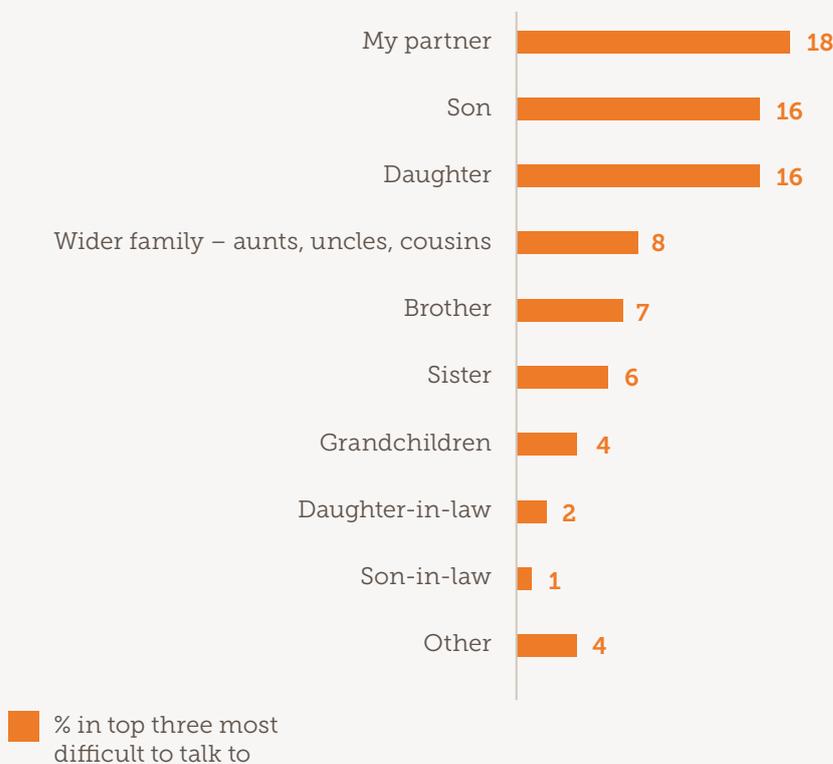
This gender gap suggests we need to work harder to persuade more men to be open to talking about the issues concerned with getting older with their families.

2

Which family members are hardest to talk to?

- Close family is the hardest group to talk to about getting older.
- There is a potential role for trusted professionals outside the family to help facilitate these conversations.
- Conversations with siblings about how to divide up care responsibilities can also be problematic.

Figure 9: With which of the following family members, if any, would you find or have you found it most difficult to talk to about preparing for getting older?³⁷



Partners and children

People are most likely to identify their closest relations (partners and children) as the most difficult to talk to about getting older. But there are key variations by age group. Those aged 25-34 are more likely to consider their partner difficult to talk to: 28% of this age group place their partner within their top three most difficult to talk to, compared to just 11% of those aged 65-74 and 75 and over. This reinforces comments made by older people in focus group discussions about the ease of talking to their partners:

*"I think if you've lived with someone a long time, you automatically share things with that person."
(Female, over 75)*

For older groups, children are the most difficult to talk to about ageing. More than one in five adults aged over 75 said that they have or would find it most difficult to talk to their son (23%) or daughter (21%). It seems that discussions with adult children are most difficult because talking about a parent's frailty can upset the dynamics of the parent/child relationship:

*"I think sometimes they don't always want to approach the subject. My girl now, it's switched, reversed. She's the mother and I'm the daughter now."
(Female, over 75)*

As a consequence, older people may feel frustrated and unlikely to take on board their child's advice.

*"He'll say to me on the phone, 'Are you getting about ok and don't you think it's about time you sold the house and bought a bungalow?' I said, 'Well, it's not going to come to that!'"
(Female, over 75)*

*"If my girls said to me, you need one of those things to hold onto [a walker], I'd go 'no I don't'.
(Female, over 75)*

So, for conversations about important issues related to ageing: care, finances and housing, helping families to tackle parent/child conversations can be challenging. We have produced an advice resource which is available online to specifically address this issue: independentage.org/difficult-conversations

Professional involvement

In circumstances where the parent and child dynamic is more complicated, and conversations are more difficult, input from outsiders, such as health professionals can be helpful:

*"We asked the doctor to talk to her about it – somebody independent – but nobody would."
(Male, over 75)*

Several people commented that they felt family members would be more likely to listen to a doctor than someone in the family:

*"I went to the doctor about it... because she would take it from the doctor but she wouldn't take it from me."
(Female, 55-65, discussing worries about her mother's driving)*

An advice worker, who deals with these issues regularly, agreed this could be an effective strategy:

“Sometimes they won’t listen to their children but they will listen to a GP, solicitor or a financial adviser – someone who they perceive to be in a position of authority that they trust. They will then say, well ok, maybe actually that’s a good idea.”
(Advice worker)

This suggests that as well as encouraging people to face difficult conversations with family members, there may also be an important role for professionals to help families broach sensitive topics.

Siblings

This is another group that can be problematic, specifically in the context of agreeing who takes most responsibility for caring for an older relative. Sometimes this simply hasn’t been discussed, with the burden of responsibility just being assumed:

“
Although my mother’s good now, I think it was more or less assumed that I would take on the most care.
”
(Female, 55-65)

Questioning the current set up is not always easy:

“People say to me, ‘You should be talking to your sister, she should be more involved’, but she’s not that approachable.” (Male, 50-65, discussing care for his mother)

A lack of frank discussion about who is responsible for the care of parents can also cause family tensions:

“I think the assumption when my father was alive and he was ill was, ‘Frank will take me to the club, Frank will do this with me...’ I should have organised it with my brother and sort of said, ‘Look, I’m not taking him out this week...’ We did have a bit of a family argument when we should have had conversations about it.” (Male, 50-65)

These experiences demonstrate that even before issues like end of life care and moving house need to be dealt with, assumptions and expectations can arise that cause problems for the family dynamic. The earlier these issues are discussed, the more opportunity families have to make plans and share responsibilities. Our message therefore to both the ‘delayers’ and the ‘deniers’ is to start talking early and often.

3

Which topics are most difficult to talk about?

- Conversations about who would care for them in the future, end of life care and where people will live in older age emerged as the most difficult to initiate.
- Stopping driving and financial struggles also emerged in our focus groups as particularly challenging.

We found a clear consensus about which issues are most difficult to discuss. The issues most often selected within the top three most difficult conversations to have with family all relate to care needs in the future:

- My preferences for end of life care (46% of respondents include this in their top three)
- Who will care for me when I'm older if I need it (42% of respondents include this in their top three)
- Where I would like to live if I can no longer live at home (34% of respondents include this in their top three)

These same three issues emerge as most difficult to discuss whether we look at all respondents, or those in the older age groups (64-74 and 75 plus). They are also the issues most often selected by people when we ask them about initiating conversations about older relatives rather than about themselves.

And this is still the case if we focus on the 45-54 age group (for whom these conversations may be particularly relevant when thinking about ageing parents).

Death – not such a taboo?

However, in discussions we found some older people were, in fact, rather candid with family about what they wanted for end of life care:

"My mum's already told me, she's told all of us, she's very strong on it that she wants one of these DNRs [Do Not Resuscitate Order]. I mean it's difficult for us to hear, very difficult, but you've got to respect their wishes, haven't you?"
(Female, 50-65)

"My mother hasn't done it legally, she's just told us – she's said if anything happens to me, don't resuscitate me. It was a conversation you don't want to have with your mother or your father."
(Female, 55-65)

We could infer that older people may be more willing to talk about end of life care than their relatives assume. Certainly, making preparations for death did not seem especially taboo for many of the older people we spoke to. Several had already made plans and discussed these with family:

*"I've already told my oldest daughter that I have written my will and she knows I'm paying for my funeral."
(Female, over 75)*

As an advice worker notes, willingness to talk about making preparations for death may come from the fact that it is a certainty:

*"I've not yet spoken to an older person who doesn't want to talk about funerals. I think that's because it is something that happens to everyone."
(Advice worker)*

“
I've chosen hymns for my funeral. I've put them in a drawer and told family, 'I definitely want that one.'
(Female, 55-65)
”

It seems plausible that older people feel able to face the more 'procedural' elements of thinking about death such as creating a will and planning a funeral. In contrast, conversations relating to what might happen if someone can't look after themselves in their own home are much harder for families to initiate.

Tools for end of life care planning

In England and Wales, there are three key tools available to help people record their wishes and plan ahead when thinking about their end of life care:

- 1 An Advance Decision** allows you to write down any medical treatments you do not want to be given in the future, in case you later become unable to make or communicate decisions for yourself. It is legally binding which means that health professionals must follow it.
- 2 Lasting Power of Attorney for Health and Welfare** allows you to give someone you trust the legal power to make decisions on your behalf, in case you later become unable to make decisions for yourself. This can include refusing medical treatment, where you are cared for and the type of care you receive.
- 3 An Advance Statement** allows you to write down anything that is important to you, for example to explain any preferences for care or any values or beliefs that affect the way you would like to be treated. This is not legally binding but any wishes recorded in an Advance Statement must be taken into account when a decision is made on your behalf.

Compassion in Dying has more information on all of these tools and step-by-step guides on how they can be used: compassionindying.org.uk/

*"The only thing we've never brought up is if my mum goes [passes away] before my dad. She can manage on her own but he couldn't and it would be awful to put him in a home, but he couldn't really live with any of us. That is a bit taboo with us I think."
(Female, 55-65)*

Adult children told us that their parents are struggling to discuss or even contemplate the idea of leaving their own home:

*"My mam rents a house; she's been in it 50 years. She's always putting it off – 'well after this happens, after this wedding, I'll think about it.' I don't think she can let go."
(Female, 55-65)*

“
I think if they left the house that would just be it. They've been there since it was built.

(Female, 55-65)

”

Thinking about needing to leave one's home becomes understandably harder as people get older. The topic of 'where I would like to live if I can no longer live at home' was among the top three most difficult conversations for people in the oldest age bracket (41% of those aged over 75 included it compared to just 21% of those aged 18-24).

Other issues of concern: driving and money struggles

We have focused largely on difficult conversations around care, housing and end of life in this report. However, older people and their families also mentioned a number of other important topics.

An issue brought up by many adult children was concern over older relatives' safety when driving. Several wanted to talk to relatives about how safe they were on the road, but were wary about broaching the subject:

*"To say 'you shouldn't be driving now', at the moment, is like talking to a brick wall... it is really, really difficult."
(Female, 55-65)*

This is a sensitive subject because people recognise how important driving is in providing a sense of autonomy and independence:

*"She was absolutely mortified at the thought because she lives in a village where there's no bus service. If she can't drive she can't get about."
(Female, 55-65, discussing sister)*

A major concern is that not being able to drive will make you reliant on someone else:

*"She probably thinks that if she wants to go to mass, she has got to ask someone to give her a lift and then it comes to a point where you don't want to bother them anymore."
(Male, over 75)*

Because this is such a sensitive issue, many felt it was one where advice from outside the family would be particularly helpful. Several people described how they approached their GP separately and asked if they would bring up driving with the older person so that the concern came from a professional rather than someone in the family.

Organisations like IAM RoadSmart³⁸ also offer independent assessments of older people's driving abilities, which can help to calm nerves, and ensure that difficult decisions can be informed by facts rather than assumptions.

Talking about how well older relatives are coping financially is another potentially difficult area. And many felt this issue couldn't be tackled directly. Some described strategies they had developed to ensure an older relative had enough money without having to talk to them about it.

"My dad lived on his own and he was over 90, but the thing we never said to him was, 'Do you need money?' We'd say, 'Have you got your bill there, Dad?' and we'd take the bill and pay it for him and then give it back. And that was how we used to deal with it." (Female, over 75)

Reluctance to talk about money struggles also goes in the other direction with older people not wanting to admit having difficulties to their adult children:

"My girls say to me, 'Have you got enough money for the heating?' and I go, 'oh yes'. I wouldn't tell them unless I was really desperate. I think I might have done it twice in the last 15 years." (Female, over 75)

We know that poverty among older pensioners is a significant problem, particularly for many people aged over 75. Recently published research from [Independent Age](#)³⁹ revealed that a fifth of those aged 75 and over are living below the poverty line, including a quarter of single women aged 75 and over. Over 75s are also twice as likely as under 75s to have been in poverty persistently for the last four years. So while this is a sensitive issue, it is clearly one that is important for families to be aware of.

A common thread in all the issues that are identified as particularly difficult is the fear of the unknown and the threat of loss of independence. This makes older people, themselves, less willing to think about the scenario, and family more likely to avoid bringing it up. In the next section we look, in more depth, at why conversations about ageing are avoided – what are the specific barriers to talking?

4 What are the barriers to talking about ageing?

Key barriers

- Families lacking the knowledge and confidence to begin conversations
- Anticipating the reaction of family members
- Avoiding facing undesirable possibilities – especially residential care
- Feeling the time is not right
- Distance and a lack of time together

Families lacking knowledge and confidence to begin conversations

Nearly half of all respondents (49%) said 'not knowing how to start the conversation' might or has stopped them having a discussion with family. In particular, younger age groups tend to lack the confidence to start a difficult conversation with relatives, according to our findings.

Twice as many of those aged 18-24 thought 'not knowing how to start the conversation' might stop them from having a conversation compared to the oldest group (50% of those aged 18-24 compared to 25% of over 75s). Similarly, 46% of 18-24 year olds said 'being concerned that I don't have enough knowledge about the subject' might stop them from having a conversation compared to just 25% of those aged over 75.

This worry about not having enough knowledge is particularly concerning for families trying to support an older person:

*"[Lack of] good information and advice, I think, is one of the barriers... I think people are worried that they're going to suggest the wrong thing to their older relatives."
(Advice worker)*

When we asked how people might prepare for a difficult conversation with family, 72% said they were likely to prepare what they might say in advance and 63% said they were likely to look online for information about different options.

Younger age groups were also most likely to say that they would look online for information about how to begin a conversation. For example, 54% of those aged 35-44 said they would be likely to look online for this advice, compared to 27% of those aged 65-74.

To help address this, our online advice resource includes suggestions on how to break the ice on these issues – including suggested conversation starters and ways to get the ball rolling: independentage.org/difficult-conversations

Anticipating the reaction of family members

Nearly two thirds (62%) of respondents said that ‘not wanting to worry or upset the person I am talking to’ might or has stopped them having a conversation about preparing for older age. This is the barrier that most often prevents people from having a conversation, or might stop them from having a conversation in the future. It is also a particular concern for women: 21% of women said this concern has stopped them from having a conversation compared to 15% of men.

This was also confirmed by our focus group discussions. The older people we spoke to told us that wanting to protect family members from worry or upset was a key reason for not speaking up. Many perceive that the lives of their adult children are busy and complex enough and they don’t want to add to their concerns by bringing up future worries:

“Her family have had such bad luck. To talk about that would only add to her problems.” (Female, over 75)

“I think, ‘Oh I won’t say anything’... you don’t always tell them because they’re going to worry.”

(Female, over 75)

Conversely, some families feel that talking wouldn’t have any impact and this is a reason not to have a discussion. Some people may feel they already know the outcome of a particular conversation, so there would be no point in initiating it:

“I just know that if I broached that with my mother, she’d tell me ‘I’m not moving so don’t even talk about it...’ If I did bring it up, I’d know what she’d say.” (Male, 55-65)

Avoiding facing undesirable possibilities – especially residential care

Many people did not want to think about the possibility of difficult circumstances ahead. This is one of the strongest barriers to having conversations, according to our research. Our poll found that nearly half of all respondents (49%) said ‘not wanting to face up to the issue’ might or has stopped them from having a conversation with family.

Where future scenarios involve something upsetting or frightening like a loss of independence, conversations are likely to be avoided or put off.

“I can’t discuss a will with my children because they say, ‘I don’t want to talk about it’... I have tried but they just say, ‘I don’t want to talk about that’.” (Female, over 75)

This is particularly true when thinking about the need to move out of your home. Care homes are considered the obvious alternative to staying in your home and provoke very negative reactions:

“
I have said the last thing I would want would be to be in a home.
(Female, over 75)
”

“There’s a lot in the media and inevitably it’s because they are bad not good. And so people believe they are going into some sort of life sentence.” (Female, 55-65)

This makes it difficult for family members to initiate conversations about moving into residential care, even when it’s necessary:

“I heard Dad say, ‘Under no circumstances must you let me get put into a home,’ and now I don’t know how to talk to him about it.” (Male, 55-65)

But avoiding such conversations can have the most significant negative consequences.

For example, it is much easier to make an informed decision about which care home you would consider moving into – and which you wouldn’t – when you are at home, with information resources at your fingertips and time to make the right decision. Whereas making the right choice is much harder if you are lying in a hospital bed following a hip operation.

Having these discussions earlier could also mean that the anticipated negative outcomes could be avoided entirely. If someone moved into sheltered housing, or installed a stairlift, before they tripped on the stairs and broke their hip, for example, then they may never need to move to a care home at all.

Feeling the time is not right

Given these topics are viewed so negatively, it is not surprising that conversations tend to be put off. We often heard people saying the timing wasn’t right and that a conversation should wait until their situation had got worse:

“I think if I was getting to the stage where I wasn’t well or my mind was going, then I think that might be the right time.” (Female, 55-65)

“
I broach it and we’ll talk about it but then she’ll be like ‘Oh well, that’s not something to talk about yet.’
(Male, 55-65)
”

Others implied they were waiting for a ‘trigger’ event before having a meaningful conversation:

“It’s when something happens – I think that’s when the big proper conversations will happen.” (Female, 55-65)

However, we know from our interactions with older people and their families through our Helpline, that waiting until a situation becomes urgent means decisions have to be taken under pressure, and solutions are harder to find.

This is particularly hard if families are discussing the issue for the first time, or have little idea of their relatives' preferences. Having discussions earlier can ensure families are better prepared if and when their circumstances change.

Dealing with issues early can often lessen their severity – as in medicine, when it comes to difficult life decisions, prevention is better than cure. For example, talking about the need to install a grab rail or a stairlift is significantly easier than talking about the need to move to a bungalow.

Distance and a lack of time together

As well as these more emotional barriers, family circumstances can also get in the way of having conversations about ageing. For some families that live far apart, time together is limited and it may not feel appropriate to use this time to broach sensitive topics:

*“When I do see them, there isn't much time to talk about things like that... it's usually a birthday or something. There's never time.”
(Female, over 75)*

And for some families, geographical distance means they may have lost the emotional closeness that enables these conversations to happen:

“Well, I don't see them very often. It's an occasional phone call to say how are you getting on and that's about it.” (Female, over 75)

“I think when they've been gone a long time as well, the distance seems to get further away, doesn't it.” (Male, 55-65)

What can be done about some of the barriers we have identified here?

In the next section we look at what might help more families to engage in conversations about ageing.

Our recommendations:

Addressing the barriers to conversation

What can we do to remove some of the barriers currently preventing people from talking with relatives about what might happen as they get older?

Some of the barriers we found relate to specific family dynamics and circumstances. These mean that for some families, important conversations about ageing are always going to be tough to initiate. This is not something government, policymakers or the third sector could or should try to fully 'solve'.

But there are a whole host of strategies we can use to increase the number of families talking explicitly about ageing and their future, based on our findings in this report.

To help families have these difficult conversations, we must:

- **address the information problem**
- **address unwillingness to consider residential care**
- **address the denial problem**
- **provide practical conversation tips for older people and their families to consider.**

Addressing the information problem

A lack of information can lead to fear and unwillingness to begin a discussion. We found that 72% of adults would like to prepare what to say in advance and 63% would be likely to look online for information about different options before having a conversation with family about ageing.

Before having a conversation with family about ageing

72%

of adults would like to prepare what to say in advance

63%

would be likely to look online for information about different options

What can be done?

The care system is extremely complex and difficult for people to navigate. If we want individuals and families to consider their care options at an earlier stage, we need to simplify and better explain those options.

Yet the older people and families who call our Helpline often tell us they struggle to know where to begin. And while local authorities are often the first port of call for families and older people, many are struggling to meet the information and advice requirements placed on them⁴⁰.

It is vital that reliable information is available for those who need it. A range of key agencies – from information and advice providers, to local authorities, to the NHS – must improve the accessibility of their information on care, to help facilitate meaningful, informed conversations. Local authorities have clear legal duties set out in the Care Act and these must be met.

What we will do: Along with others in our sector, we will continue to support people struggling to make sense of their options, through our advice publications (available at independentage.org/information) and our Helpline (0800 319 6789).

We will also continue to signpost families to organisations with specialist expertise on particular conversation topics, such as ‘Compassion in Dying’ which works to empower people to exercise their rights and choices around end of life care⁴¹.

Addressing unwillingness to consider residential care

Thinking about needing to leave one's home is probably the biggest taboo subject we came across in the course of this research. The prospect can be so daunting and undesirable that few people discuss it with family until it becomes a necessity.

What can be done?

Firstly, we can make sure that people are more aware of the support options that will allow them to remain in their own homes rather than move into residential care. Too many people see care homes as the only option and fail to realise that adaptations and home care can enable many people to continue living in their own homes. Wider availability of supported housing would also be welcomed.

However there will always be a proportion of older people who need more intensive support in residential care. For many of them, their image of care homes is driven by overwhelmingly negative media coverage, focusing on high profile cases of neglect and abuse. While clearly this does not tell the whole story of care homes and those who live in them, it is no surprise that it shapes popular imagination when there is little hard data with which to counter it.

Developing a clearer picture of what goes on in care homes would help tackle the widespread feelings of fear of residential care environments.

To take this forward, we propose the following:

- **There should be an anonymous survey of staff working in care homes, asking them to identify the extent to which they have witnessed neglect or abuse. The results of the survey would either reassure anxious older people and their relatives or act as a wake-up call for the sector to stamp out poor practice.**

It is also vital that care homes increase their outreach activities to break down the barriers with local communities, and show more people what living in a care home is like. Initiatives such as Care Home Open Day are a great start, but this is just one day a year – outreach needs to be ongoing.

What we will do: We are currently undertaking research on the specific problems older people and their families face in making informed decisions about moving to a care home.

Our report is due to be published in autumn 2016, and will be accompanied by information for older people and families to help them compare different care homes. We will also be campaigning to improve transparency in the care home sector.

Addressing the denial problem

We estimated there are around 7 million people aged over 65 who have never talked to family about who might look after them as they age, where they'd live if they could no longer manage in their home and what their preferences are for end of life care.

This leaves a huge number of families in a state of uncertainty, having never explicitly discussed how they will manage if relatives need more care and support in the future.

What can be done?

Families need to be supported to initiate some of these difficult conversations. Our research discovered a considerable desire for greater input from trusted professionals, who could provide an outside perspective and validate the need for a conversation.

But, we know that conversations about sensitive topics like care and health are sometimes missed, even by professionals⁴². We would like to see more health and care professionals consciously encouraging the families they work with to think about the five conversation areas we have identified as most crucial to discuss (see page 36).

For this to happen, more space must be made available within our health and care systems. For example, a 2015 BMA survey of 15,560 GPs found that only one in 10 felt that current appointments were long enough⁴³. This pressure is likely to make difficult conversations even less likely to happen. But sufficient investment for GPs to offer consultations of at least 15 minutes would offer the opportunity to increase in-depth discussions of this kind.

We also found that younger people tend to be more likely to acknowledge barriers to conversation. Other research recommends that conversations about elder care happen much earlier in life in order to make them much more natural and normal⁴⁴. We would like to see conversations about ageing, dementia and care included within the relationships component of Personal, social, health and economic (PSHE) education in schools so that this is something people are encouraged to think about from an early age.

What we will do: Independent Age has published an information resource to help families have these conversations. It's available at: independentage.org/difficult-conversations

Tactics for talking

The older people and family members we talked to also told us about some of the strategies they thought would be helpful in initiating sensitive conversations:

1 Using prompts and triggers

"Sometimes it's good to talk to about someone else's experience. You say, 'I was talking to somebody the other day and they were telling me they were thinking about going into a nursing home.' That sort of thing, to get going." (Female, 55-65).

2 Little by little works best

"Often it's not something that can be addressed in just one initial conversation... it can take a long time." (Female, 55-65)

3 Humour can be useful

"I find if it is brought up, it's brought up in jest to start with... to break the ice a little." (Male, over 75)

4 Think about when and where

"A conversation can easily be stopped if someone puts the phone down. Whereas with face to face [situations] you can talk it through and chew it around more." (Female, 55-65)

5 Planning ahead

"I think you have to plan in your own head what you might say, so that it's fair and not too much of a jumble." (Male, 55-65)

Five conversations for older people and their families to consider

Independent Age is launching a new online resource with guidance for families wanting to begin conversations about sensitive areas relating to ageing: independentage.org/difficult-conversations.

As part of this, we are also calling on people to think about the five key conversations we believe it is important for all families to have.

Some of these conversations are more likely to be initiated by family members and some by older people themselves. It doesn't matter who brings it up – the important thing is that these questions are considered.

1 Where will I live in the future?

None of us wants to think about having to leave our own home. But if circumstances were to change and you became less mobile, how suitable would your current home be? Are there adaptations you could make (eg a stairlift, grab rails) that would allow you to continue living there? Do you know about other housing options especially designed for older people locally?

2 Who in the family might be able to support me?

All families work differently and there is no right way of supporting each other. If you needed more care and support in the future, how likely is it that children or other family members could look after you? Is this something you have ever discussed directly? Are different family members (eg siblings) aware of each other's expectations and assumptions about who might be able to take on more of a caring role if necessary?

3 What are my options if I need more care and support?

If you were to need extra support with daily life, have you considered how you might get this? Are you aware of the different options for home carers who can offer support with everyday activities? There may come a stage when it's increasingly difficult to manage at home, even with extra support. Do you know what local care or nursing homes are like? Have you talked to family members about the kinds of things that would be important to you in a home?

4 Who could make decisions on my behalf if I'm no longer able to do this myself?

If you were to become ill and weren't able to make decisions yourself, have you thought about who could do this on your behalf? Have you considered giving someone you trust the legal power to deal with your affairs in the future if you lost capacity to make decisions yourself?

5 Have I recorded my wishes about how I want to be looked after at the end of my life?

Do you have strong ideas about treatments you would not wish to be given to you? Is this something that you have ever discussed with family? Have you considered writing these wishes down formally so that family members are clear about what you want?

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Executive Summary

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- 25 Ageing Without Children, <https://awoc.org/> accessed 06/06/16
- 1 What conversations are taking place?**
- 26 Calculated using mid-2014 ONS population figures: <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland>
- 27 Laing and Buisson, 2014, Care of Elderly People Market Survey 2013/14,
- 28 Preferences for end of life care; who will care for them when they're older if they need it; where they'd like to live if they could no longer live at home; and how they would pay for care needs they may have in the future.
- 29 Calculated using mid-2014 ONS population figures: <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland>
- 30 Calculated using mid-2014 ONS population figures: <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland>
- 31 Dementia 2014 report, Alzheimer's Society, 2014
- 32 Calculated using mid-2014 ONS population figures: <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland>
- 33 Calculated using mid-2014 ONS population figures: <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland>
- 34 These rates are unlikely to include those who do not have older relatives – between a quarter and a third of respondents selected 'NA' in response to these questions, which likely reflects the distribution of those without parents or grandparents. While the vast majority of Britons aged between 20 and 44 have at least one living parent, this falls to around three quarters of individuals in their late 40s and less than a quarter by the time people reach their early 60s. Further, just one in 10 British adults aged 40-44 have one or more grandparents.
- 35 Calculated using mid-2014 ONS population figures: <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland>
- 36 Carers UK, Women and Equalities Committee Gender Pay Gap Inquiry, December 2015
- 2 Which family members are hardest to talk to?**
- 37 19% selected 'don't know' and 25% selected 'not applicable'.

3 Which topics are most difficult to discuss?

- 38 <https://www.iamroadsmart.com/courses/mature-driver-assessment> accessed on 06/06/16
- 39 www.independentage.org/policy-research/research-reports/overlooked-over-75s-poverty-among-silent-generation-who-lived

Our recommendations

- 40 Research from Independent Age found that almost three quarters (70%) of local authorities are not providing online information in all the areas required under the Care Act.
- 41 <http://compassionindying.org.uk/>
- 42 Dying Matters found that 60% of the GPs involved rated themselves as 'not confident' or 'not very confident' in initiating conversations about end of life. http://www.dyingmatters.org/gp_page/breaking-news See also discussion of social workers and difficult conversations: <http://www.communitycare.co.uk/2012/05/08/how-to-handle-difficult-conversations/>
- 43 <http://www.pulsetoday.co.uk/your-practice/practice-topics/access/more-than-90-of-gps-think-10-minute-consultations-are-inadequate/20009668.fullarticle>
- 44 Pitts, M. J., Fowler, C., Fisher, C., Smith, S. A. (2014). Politeness strategies in imagined conversation openers about elder care. *Journal of Language and Social Psychology*, 33, 27-46.

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A full breakdown of the survey results is available on the ComRes and Independent Age websites.

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ComRes interviewed 2,066 GB adults online – including 116 aged 75+ – between the 13 and 14 April 2016. Data were weighted to be representative of all adults in Great Britain aged 18 plus.



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