

Public attitudes to dementia

Scottish Social Attitudes
2017



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Responsibility for the opinions expressed in this report, and for all interpretation of the data, lies solely with the authors.

Foreword

In 2014, the Life Changes Trust and Joseph Rowntree Foundation commissioned the first survey of Scottish Social Attitudes to Dementia. A follow-up survey was commissioned by the Life Changes Trust in 2017 and this report provides the results of that work. A further survey will be commissioned in 2020 to see whether attitudes to dementia have changed, and knowledge deepened, over the course of six years.

As in 2014, the survey results show that a substantial majority of people in Scotland hold positive attitudes towards people with dementia and do not see it as a stigmatising condition, while a small minority display prejudice and fear of dementia and have discriminatory attitudes.

The findings of this report show that a large majority of people in Scotland are very aware of dementia and the challenges it can bring for families. A majority of people in Scotland have provided some level of care and support for someone living with dementia, and it seems that in Scotland knowledge of dementia is very much rooted in experience. It is not surprising, then, that most people would first seek help from a partner or family member if they were diagnosed with dementia. This underlines the need to ensure that clear, accurate information and advice is widely available to the general public and that people know where they can turn for post-diagnostic support through link workers, dementia resource centres, dementia friendly communities and peer support groups.

Awareness about the most well-established symptoms of dementia is widespread but there is room for better understanding of lesser known symptoms, for example the sensory challenges that people with dementia may experience. This is something that dementia campaigners, such as Agnes Houston MBE, have spoken and written about for many years.¹

SSA 2017 shows increased knowledge of the risk factors that could lead to certain forms of dementia, which is encouraging. However, this knowledge seems to be less amongst older people and those who have lower levels, or no, formal educational qualifications.

There are still mixed views about who should fund care for people with dementia, and which elements of care should be means-tested. The Scottish public is keenly aware of the impact of caring for someone with dementia, which can lead to social isolation and poor health. There is evidence to show that those living in the most deprived areas in Scotland are more than twice as likely to care for someone regularly who does not live with them compared with those living in the least deprived areas. The Life Changes Trust will look at this finding in more detail to see how it might be addressed.

Many felt that unpaid carers are currently receiving little or no support from the government. The majority felt that the government should generally spend more to

¹ 'Dementia and Sensory Challenges, Dementia can be more than memory' booklet is available at www.lifechangestrust.org.uk and in hard copy from the Life Changes Trust.

provide care and support for people with dementia, making it the public's top priority for additional government spending.

Worryingly, around a third of people stated that if they had a form of dementia they would not want their employer to find out. While we have seen many employers and employees embracing initiatives such as Alzheimer Scotland's 'Dementia Friends' awareness sessions and Age Scotland's 'Being Dementia Aware' training, there is more to be done to give employees confidence that they would not experience workplace discrimination if diagnosed with dementia.

The vast majority felt that people with dementia should be supported to lead a fulfilling life and that, even when living in a care home with severe dementia, quality of life can be enhanced through visits from family and involvement in appropriate activities.

Where family cannot visit, the Scottish public believes that arrangements should be made for volunteers to visit. Younger people were particularly of the opinion that local authorities should provide funding for this kind of support. The Scottish Government's third National Dementia Strategy 2017-20 recognises the importance of such support and makes a commitment to exploring "the potential to promote and support increased participation in dementia befriending".

The SSA 2017 Attitudes to Dementia findings show that we are making progress but there is more that needs to be done. It should give us greater incentive to increase our efforts and achieve more for people living with dementia and their families. It is our hope that we will see greater progress by the time the 2020 survey is completed.

Anna Buchanan

Interim CEO and Director, Dementia Programme

Life Changes Trust

Executive Summary

Experience and knowledge of dementia

In 2017 nearly three-quarters of people in Scotland knew (or had known) someone with dementia. Over one third of people had a partner or family member with dementia, and around one in six had experience of dementia through working with people with dementia. People in Scotland are more likely to know someone with dementia as they get older; over three-quarters of those aged over 65 knew someone with dementia, compared with around two thirds of those aged under the age of 30.

The most common way that people had learned about dementia was through personal experience; that is, knowing or caring for someone with dementia. Around 1 in 6 had learned about dementia through the media and the same proportion had learned about it through word of mouth. Over half of people in Scotland had provided some form of care or support to someone with dementia, with just over one in five having either cared for someone on a regular basis who did, or did not live with them, around one in seven having helped someone from time to time and a similar proportion having visited someone every now and then. Older people were more likely than younger people to have provided care for someone that lives with them, while women were much more likely than men to have provided care outside of the home.

Knowledge of symptoms and risk factors associated with dementia

There is widespread awareness of some of the well-established symptoms of dementia. Nine in ten people in Scotland knew that 'difficulty in recognising people' is a symptom of dementia, while around eight in ten recognised that 'losing track of time' and 'feeling lost in new places' are symptoms of dementia.

However, there is substantially less knowledge in relation to some other symptoms. Around half of people in Scotland recognise that 'losing your temper easily' or 'feeling depressed' are symptoms of dementia, while just a quarter recognise that 'feeling extremely tired' is a possible symptom of dementia. The proportion of people who were aware that specific sensory changes were associated with dementia ranged from around 6 in 10 for 'having hallucinations' to around 4 in 10 for 'changes to taste or smell' and 'increased sensitivity to noise'.

Almost 6 in 10 people in Scotland thought there were things they could do to decrease their risk of getting dementia, while around a quarter thought there were not. The proportion of people who correctly identified risk factors and protective factors for dementia ranged from just over a quarter who recognised high blood pressure as a risk factor for dementia, to almost 6 in 10 who correctly identified drinking heavily as a risk factor.

There is evidence that knowledge of risk factors is increasing. Between 2014 and 2017 the proportion correctly identifying each of the risk and protective factors has increased by between 5 and 10 percentage points. However, there were still between 4 in 10 and 7 in 10 people in 2017 who misidentified risk factors, or said they 'don't know' or are 'not sure' whether these factors mean someone is more likely to get dementia. Those with higher educational qualifications, higher incomes, and higher levels of self-reported knowledge about dementia were more likely to have greater understanding of the symptoms of, and risk factors for, dementia.

Funding dementia services and providing care

Just over 4 in 10 people felt that dementia should be given priority for more government funding in relation to prevention, placing it second in the list of health problems that the public felt should take priority in this area behind cancer. Almost 7 in 10 felt that dementia should be given priority for more government funding in relation to care and support, making it the public's top priority for additional spending in this area.

Almost 6 in 10 believed that care for someone with mild dementia who lives at home and needs regular help looking after themselves should be funded by the government irrespective of how much money the individual has, while 4 in 10 thought that funding for such care should be means-tested. Two-thirds felt that care for someone with severe dementia who needs to go into residential care should be paid for by the government regardless of how much money the individual has, while around a third believed funding for such care should be means-tested.

Those with no formal educational qualifications, those in lower income groups and those living in the most deprived areas in Scotland were all more likely to feel that the government should pay for the care of someone with mild dementia irrespective of their financial situation, while men were more likely than women to believe that the government should pay for the care of someone with severe dementia regardless of how much money they have.

Over half thought that the government provides either 'not very much' support or 'none at all' to family members who care for a relative with dementia. Older people in Scotland were more likely than younger people to believe that the government does not provide support to family members who care for a relative with dementia, as were those who reported having 'a great deal' or 'quite a lot' of knowledge of dementia.

While almost 6 in 10 believed that family and friends should usually provide most of the care for someone with mild dementia, almost nine in 10 felt that paid carers or nurses should usually provide most of the care for someone with severe dementia.

Perception of people with dementia and their carers

A substantial majority of people in Scotland hold positive attitudes towards people with dementia and do not see it as a stigmatising condition, while a small minority of people display prejudice and fear of (people with) dementia, as well as discriminatory attitudes. Over 8 in 10 agreed that if they had just been diagnosed with the first signs of dementia 'I would want my family and friends to know', while two-thirds of people disagreed that 'I would feel ashamed'. However, around 1 in 5 people in Scotland agreed that 'I would find it hard to talk to someone with dementia', while over a third agreed that 'I would not want my employer to find out'.

People who knew someone or have cared for someone with dementia, those who report they are knowledgeable about dementia, younger people, women, and those with higher educational qualifications were all particularly likely to hold positive attitudes towards people with dementia.

Around 9 in 10 people in Scotland thought that people in the early stages of dementia can lead a fulfilling life. By contrast, just over 1 in 5 believed that those in the later stages of dementia can lead a fulfilling life. Those with higher educational qualifications and those who said they knew 'a great deal' or 'quite a lot' about dementia were more likely to think that people in the early stages of dementia can lead a fulfilling life, while women, younger people, those with higher educational qualifications and those who said they knew 'a great deal' or 'quite a lot' about dementia were more likely to think that people in the later stages of dementia can lead a fulfilling life.

There has been little change in attitudes to caring for people with dementia in Scotland between 2014 and 2017. Although half of people in Scotland agree that caring for someone with dementia is often very rewarding, around 8 in 10 believe that caring for someone with dementia is often very lonely, while around three quarters thought that caring for someone with dementia often means your own health suffers.

Sources of support and information

Just over a third said they would talk to a family member or friend in the first instance if someone close to them was showing the early signs of dementia. A similar proportion said they would talk to the person themselves about the best thing to do. Around a quarter said they would talk to a doctor or nurse. Those educated to degree-level and those in the highest income group were considerably more likely to talk to the person themselves about the best thing to do than those with no educational qualifications and those in the lowest income group.

Over two-thirds said they would seek help from a partner or family member if they believed they had the early signs of dementia. If diagnosed with the first signs of dementia, 3 in 5 believed that they would find meeting with a specialist doctor useful while over half said they would find talking with a dementia counsellor useful. Those

educated to degree-level were significantly more likely than those with no educational qualifications to report finding all the different types of help listed useful in the event of a dementia diagnosis, as were those in the highest income group compared with those in the lowest income group.

Rights of people with dementia to lead a fulfilling life

Over three-quarters of people in Scotland felt that children have a responsibility to visit a parent with dementia, while there is a broad consensus that those with severe dementia who receive residential care benefit from visits from their family.

The vast majority felt that arrangements should be made for volunteers to visit those with dementia who do not receive visits from their family, while two-thirds also felt that such visits should be funded by the council. Younger people were more likely than older people to agree that the council should provide funding for a volunteer in this situation.

The majority of people believed that certain activities have the potential to positively impact upon the quality of life for a person with dementia and that those providing residential care should be expected to make it possible for people to participate in such activities. This belief was consistent across almost all societal sub-groups.

1. Introduction

1.1 Background

Dementia – an umbrella term for a range of illnesses and disease symptoms which primarily or secondarily affect the brain (Alzheimer Scotland, 2013) – is one of the world’s foremost public health challenges (NHS Scotland, 2018). It is estimated that around 44 million people worldwide are living with dementia – a figure set to almost triple by 2050 (Alzheimer’s Disease International, 2014). In Scotland, it is estimated that around 90,000 people are currently living with dementia (Alzheimer Scotland, 2015). Deaths recorded as resulting from Alzheimer’s Disease – the most common form of dementia – rose by more than a third in Scotland between 2016-17 (NRS, 2017), while dementia has overtaken heart disease as the leading cause of death in England and Wales (ONS, 2017). According to the World Health Organisation, the number of global deaths due to dementia is predicted to increase by over 40% between 2015 and 2030 (WHO, 2012).

While there are many different forms of dementia, each condition falling under this definition progressively damages the brain leading to a variety of symptoms including serious memory loss, losing track of the time, getting lost in familiar places and changes in behaviour. Dementia can also lead to sensory changes (such as changes to taste and smell) and changes in personality, which can be particularly distressing for those who care for a person with dementia (Alzheimer Scotland, 2018). While the prevalence of dementia increases with age the condition is not restricted to older people; there are currently estimated to be at least 42,000 people under the age of 65 with dementia in the UK, representing more than 5% of all those with the illness (Alzheimer’s Society, 2018).

Most types of dementia progress gradually, and with the right help and support most people with dementia are able to enjoy a good quality of life for a long time. Evidence suggests that it is important for people with dementia that their interests, skills, and normal life are supported and maintained for as long as possible, and that their capacity to make choices, even if this is limited, and their rights are recognised (Alzheimer’s Society, 2013).

There is no known cure for dementia, and as a result much medical and policy attention has been given to reducing people’s risk of developing dementia and early diagnosis, increasing awareness of dementia and its impacts, improving the quality of life and wellbeing of those with the disease, and supporting those who care for people with dementia.

1.2 The policy context

The scale of the policy challenge presented by dementia was recognised by the Scottish Government in 2007 when dementia was made a national priority. This was followed in 2009 by the release of the Scottish Parliament’s Cross-Party Group on

Alzheimer's 'Charter of Rights for People with Dementia and their Carers in Scotland', aimed at ensuring 'high quality support, services and treatment are in place to assist people with dementia and their carers throughout Scotland' (Scottish Parliament, 2009).

Subsequently the Scottish Government has published three Dementia Strategies, most recently in 2017 (Scottish Government, 2017). The latest document builds upon the foundations laid out by the first Dementia Strategy which focused on improving the quality of dementia services through more timely diagnosis and on better care and treatment (Scottish Government, 2010), and the second Dementia Strategy which focused on improving post-diagnostic support and strengthening integrated and person-centred support (Scottish Government, 2013). The third of these Dementia Strategies emphasises 'the importance of taking a person-centred and flexible approach to providing support at all stages of the care journey'. It sets out 21 new commitments in a move to modernise dementia care and to create an environment where people with dementia and those who care for them have access to timely, skilled and well-coordinated support from diagnosis to end of life (Scottish Government, 2017).

1.3 Researching public attitudes

To achieve these aims, it is vital that the attitudes of the public in this complex area are accurately measured and understood. There remains a perception of stigma surrounding dementia; according to research conducted by the International Longevity Centre, people over the age of 55 fear being diagnosed with dementia more than any other condition and at least 1 in 4 people hide their diagnosis, citing stigma as the reason. Such stigma can make life challenging for those who may be experiencing the first signs of dementia as well as those who have been diagnosed with the condition, with ingrained views of dementia having the potential to affect people's sense of worth and wellbeing and engender a feeling of isolation (Alzheimer's Society, 2017). Measuring the prevalence of such views not only places policymakers in a more informed position, but allows for steps to be taken to reduce societal stigma and raise levels of wellbeing for those with dementia.

It is also crucial that any variations in attitudes towards dementia along demographic or socio-economic divides are highlighted. Understanding levels of knowledge about the possible symptoms of dementia, together with learning more about the kinds of support that would benefit particular groups in society, enables policymakers to ensure that efforts to raise awareness about dementia and to maximise quality of life and support for those with the condition are felt evenly across Scotland.

1.4 Scottish Social Attitudes

The Scottish Social Attitudes survey (SSA) was established in 1999 by ScotCen Social Research, an independent research organisation based in Edinburgh and part of NatCen Social Research, the UK's largest independent social research institute.

The survey, which is conducted annually, provides robust data on changing social and political attitudes in Scotland with the aim of informing both public policy and academic study. SSA has different funders every year - including charities, government and universities. Previous topics in SSA have included, among others, attitudes to inequality, alcohol, discrimination, policing, independence and Brexit. In 2017, the Life Changes Trust funded 45 questions on attitudes to dementia, having previously co-funded 40 items on SSA 2014 (alongside the Joseph Rowntree Foundation). Many questions were repeated in 2017 allowing for analysis of any changes over time, which are discussed throughout the report.

1.5 Data collection and methodology

Run annually by ScotCen Social Research since 1999, the Scottish Social Attitudes survey provides a robust and reliable picture of changing public attitudes over time. Each year around 1,200-1,500 face-to-face interviews are conducted with a representative probability sample of the Scottish population. Interviews are conducted in respondents' homes, using computer assisted personal interviewing. Most of the interview was conducted face-to-face by a ScotCen interviewer, but some questions were asked in a self-completion section where they were particularly sensitive or where there were concerns about respondents giving 'socially desirable' answers. The response rate in 2017 was 50%.

Data are weighted in order to correct for potential sources of bias in the sample and to ensure that they reflect the age and gender profile of the Scottish population. Further details about the sampling, weighting and technical details of how the survey is administered are published in a separate SSA 2017 technical report.²

Fieldwork for SSA 2017 ran between July 2017 and February 2018 and consisted of face-to-face interviews with 1,234 adults aged 16 and over (prior to SSA 2016, SSA interviewed adults aged 18 and over). The survey uses random probability sample which is designed to yield a representative sample of adults aged 16 or over living in Scotland. Probability samples minimise unobserved biases associated with other sampling methods which exclude groups who are initially less likely to respond and who may differ in important ways from those who are more easily available. This is particularly important for a proper representation of national attitudes. Participation in SSA is entirely voluntary and potential respondents are sent a letter in advance of an interviewer visiting their address which includes details on how to opt out of the survey.

1.6 Analysis

This report explores how views differ by a range of different socio-demographic factors: age, gender, education, income, area deprivation (as measured by the

² Available at: <https://beta.gov.scot/binaries/content/documents/govscot/publications/statistics-publication/2018/06/scottish-social-attitudes-technical-annex-2017/documents/00537353-pdf/00537353-pdf/govscot:document/>

Scottish Index of Multiple Deprivation (SIMD)) and urban-rural status (using the Scottish Government's urban-rural classification). Attitudes on a range of different political and social issues are routinely shown to vary by these factors.

All percentages cited in this report are based on the weighted data and are rounded to the nearest whole number. Figures may differ between the charts and tables and those reported in the body of the text due to rounding. All differences described in the text (between years, or between different groups of people) are statistically significant at the 95% level or above, unless otherwise specified. This means that the probability of having found a difference of at least this size, if there was no actual difference in the population, is 5% or less. The term 'significant' is used in this report to refer to statistical significance, and is not intended to imply substantive importance. Further details of significance testing and analysis are included in the separate SSA 2017 technical report.³

1.7 Report structure

The remainder of this report is structured as follows:

- Chapter 2 discusses the extent of people's experience of dementia, the level of knowledge people feel they have about dementia, and the sources of that knowledge.
- Chapter 3 explores people's knowledge of the symptoms of dementia and understanding about whether specific factors are associated with an increased or decreased risk of getting dementia. It also examines whether people think there are things they can do to decrease their own chances of getting dementia.
- Chapter 4 explores levels of support for increased government spending on prevention of dementia and on care and support for those who have dementia. This chapter also discusses people's views on who should be responsible for care – both the question of who pays and who should provide the care.
- Chapter 5 explores people's attitudes to people with dementia, the experience of caring for someone with dementia, the extent to which people hold stigmatising attitudes towards people with dementia and views on whether people with dementia can lead a fulfilling life.
- Chapter 6 explores how people would respond if they were concerned if either they, or a family member or friend, were showing early signs of dementia and the sources of information and support they might use.
- Chapter 7 explores public attitudes towards activities which may impact upon the quality of life of those with dementia, the rights of those with dementia to undertake such activities, and the responsibilities of others to facilitate this.
- Chapter 8 discusses the possible implications of the findings for policy and practice.

³ Available at: <https://beta.gov.scot/binaries/content/documents/govscot/publications/statistics-publication/2018/06/scottish-social-attitudes-technical-annex-2017/documents/00537353-pdf/00537353-pdf/govscot:document/>

2. Experience and Knowledge of Dementia

Key findings

- In 2017 nearly three-quarters of people in Scotland knew (or had known) someone with dementia (74%).
- Over one third (37%) had a partner or family member with dementia and one in six (16%) had experience of dementia through working with people with dementia.
- As people get older they are more likely to know someone with dementia: 78% of those aged 65 and over knew someone with dementia compared with 65% of those aged under 30.
- Over half (56%) of people in Scotland have provided some form of care or support to someone with dementia.
- In 2017, around 3 in 10 people (31%) said that they knew 'a great deal' or 'quite a lot' about dementia and the same proportion said they knew 'not very much' or 'nothing at all' about dementia.
- The most common way that people had learned about dementia was through personal experience; that is, knowing or caring for someone with dementia (45%).

This chapter explores people's experience of, and knowledge about, dementia. The first part examines people's experience of dementia through their own personal experience, through their relationships or contact with others and describes the extent to which people are involved, if at all, in caring for someone with dementia. The second part discusses people's self-assessed knowledge about dementia, and how that knowledge was gained.

2.1 Experience of dementia

Respondents were asked:

Have you ever personally known anyone with dementia or do you have dementia yourself?

Please choose all that apply

- 1 No, I don't know anyone who has, or had, dementia
- 2 Yes, my job involves / involved working with people who have dementia
- 3 Yes, I have dementia myself
- 4 Yes, my partner or a member of my family
- 5 Yes, a friend(s) I know fairly well
- 6 Yes, a friend(s) or acquaintance(s) I know less well
- 7 Yes, a colleague / someone at my work
- 8 Yes, someone else
- 9 (Not sure)

SSA 2017 showed that the majority of people in Scotland know someone, or have known someone in the past, with dementia (74%). This illustrates that despite the low prevalence of dementia, approximately 2%⁴ in the population, most people in Scotland have had some experience of dementia, predominantly through their relationships and contact with other people. The proportion of people who knew someone with dementia in 2017 was slightly, but not significantly, lower than in 2014 (when it was 76%).

Having a partner or family member with dementia was the most common way that people knew someone with dementia (37%). Fewer people had a close friend or an acquaintance with dementia (both 13%). Only 2% of people knew someone at work with dementia. This is perhaps unsurprising as people are more likely to know about the health status of their partner and other family members compared with other types of relationships.

Almost 1 in 6 people (16%) have had experience of dementia because their job involves, or previously involved, working with people with dementia.

Table 2.1: Whether people have ever known someone with dementia

Have you ever personally known anyone with dementia or do you have dementia yourself?	2014 (%) [†]	2017 (%) [†]
Yes, my partner or a member of my family	38	37
Yes, a friend(s) I know fairly well	17	13
Yes, my job involves/involved working with people who have dementia	16	16
Yes, a friend(s) or acquaintance(s) I know less well	12	13
Yes, someone else	11	10
Yes, a colleague/someone at my work	3	2
Yes, I have dementia myself	1	*
No, I don't know anyone who has, or had, dementia	24	26
Not sure	2	1
<i>Unweighted base</i>	<i>1428</i>	<i>1169</i>
<i>Weighted base</i>	<i>1433</i>	<i>1174</i>

Base: All respondents aged 18+ who completed the self-complete

[†]Percentages do not sum to 100% as the question was a multi-code response

*Less than 0.5%

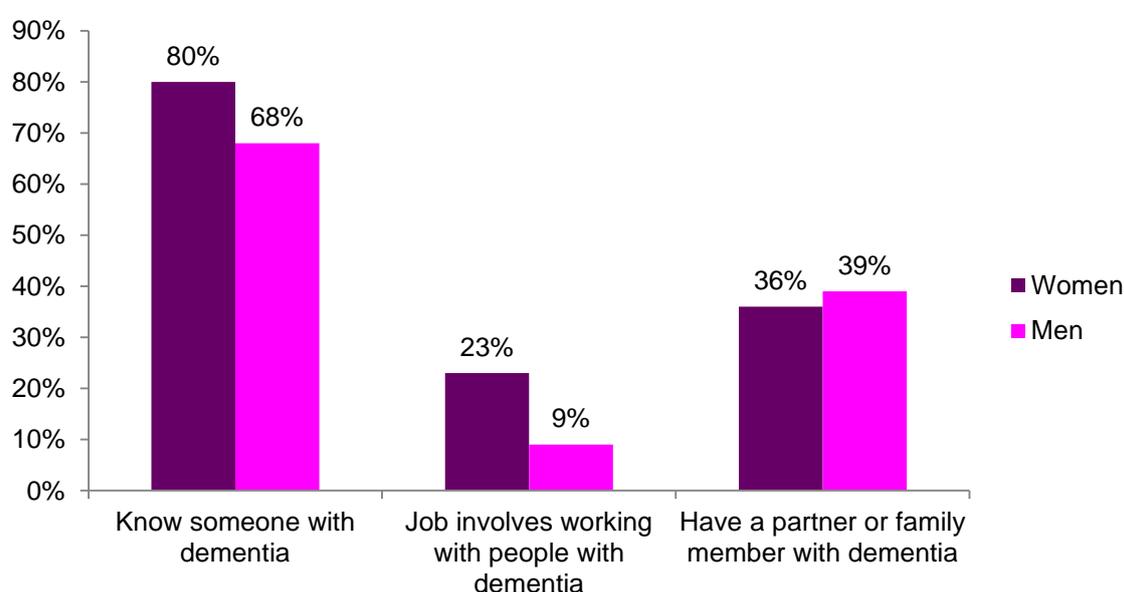
⁴ 90,000 people were estimated to have dementia (Alzheimer Scotland, 2017) out of an adult population of around 4.5 million (Scottish Government, 2016). The prevalence of dementia in the Scottish adult population is therefore 2%.

2.2 How does experience of knowing someone with dementia vary between groups?

Experience of dementia, in terms of knowing someone with dementia, varied depending on a person's gender, age, education, income and the area they live in as measured by the Scottish Index of Multiple Deprivation (SIMD).⁵

Women were more likely than men to know someone with dementia (80% and 68% respectively). Women were also two and a half times more likely to have a job that involves/involved working with people with dementia (23% of women compared with 9% of men). However, men and women were just as likely to know a partner or family member, or have a close friend with dementia.

Figure 2.1 Knowing someone with dementia by gender



Base: All respondents aged 18+ who completed the self-complete

As people age they are more likely to know someone with dementia: 64% of those aged under 30 knew someone with dementia compared with 78% of those aged 65 and over. The likelihood of having a family member with dementia did not increase with age, however, older people were more likely than younger people to have a close friend with dementia: 27% of those aged 65 and over compared with 13% of those aged 40 to 64 and 5% of those aged 18 to 29.

Knowing someone with dementia also varied significantly according to income. People in the lowest income group were less likely than those in all other income groups to know someone with dementia, 67% of those in the lowest income group compared with 75% of those in all other income groups combined. These findings on differences by gender, age and income are consistent with those reported on SSA

⁵ See SSA 2017 Technical Report for more details on the Scottish Index of Multiple Deprivation. Available at: (Publication date to be confirmed).

2014. There were also significant differences observed by education, although in contrast to 2014 the pattern of these differences was unclear.

2.3 Caring for people with dementia

Respondents who knew someone with dementia were asked:

Leaving aside anything you've done as part of your job, please say which, if any, of the following you have done for someone with dementia, either now or in the past?

Please choose all that apply

- 1 Cared for someone (other than myself) who lives / lived with me
- 2 Cared on a regular basis for someone who does not / did not live with me
- 3 Been responsible for making arrangements for someone to be looked after (e.g. arranged for a carer to visit someone at home, or arranged for someone to go into a residential home)
- 4 Helped someone from time-to-time
- 5 Encouraged someone showing symptoms of dementia to seek professional help
- 6 Visited someone every now and then
- 7 None of these
- 8 Other (Please write in)

In addition to people being asked if they knew someone with dementia, respondents were also asked whether they had ever provided care for someone with dementia. Table 2.2 below shows that over half (56%) of people in Scotland had provided some form of care or support ranging from visiting someone every now and then to caring for someone that lives with them, with 44% either not knowing anyone with dementia or not having provided care of any sort for anyone with dementia. Just over one in five (21%) had either cared for someone on a regular basis who did not live with them or cared for someone who did live with them (15% and 6% respectively). Around one in seven (14%) had helped someone from time to time and a similar proportion (15%) had visited someone every now and then. A small proportion had been responsible for making care arrangements (5%) and 1% of people had encouraged someone to seek help.

The findings were broadly similar to SSA 2014, as although the proportion of people that had helped someone from time-to-time had decreased from 20% in 2014 to 14% in 2017, at the same time the proportion that had visited someone every now and then had increased from 10% in 2014 to 15% in 2017. Combining these two categories shows that the proportion of low level support has remained stable between 2014 and 2017 (30% in 2014 compared with 29% in 2017).

Table 2.2 Whether people have ever provided care for someone with dementia

Leaving aside anything you've done as part of your job, please say which, if any, of the following you have done for someone with dementia, either now or in the past?	2014 (%)	2017 (%)
Helped someone from time-to-time	20	14
Cared on a regular basis for someone who does not / did not live with me	12	15
Visited someone every now and then	10	15
Cared for someone (other than myself) who lives / lived with me	8	6
Been responsible for making arrangements for someone to be looked after (e.g. arranged for a carer to visit someone at home, or arranged for someone to go into a residential home)	5	5
Encouraged someone showing symptoms of dementia to seek professional help	2	1
None of these / do not know anyone with dementia	43	44
Don't know/Refused	*	*
<i>Unweighted base</i>	1428	1169
<i>Weighted base</i>	1433	1174

Base: All respondents aged 18+ who completed the self-complete

2.4 How does experience of caring for someone vary between groups?

Among those who knew someone with dementia there were differences in experience of providing care to someone with dementia by both age and gender. Older people were more likely than younger people to have provided care for someone that lives with them (13% of those aged 65 and over compared with 3% of those aged 18 to 29). Conversely, there were no significant age differences associated with providing care for people that they do not live with but this did vary by gender, with women much more likely than men to provide care outside of the home (29% of women compared with 16% of men). Men were however more likely than women to have visited someone every now and then (42% compared with 34% respectively). Those aged 40 and over were more likely to have been responsible for making care arrangements compared with those aged under 40 (20% of those aged 65 and over and 17% of those aged 40 to 64 compared with 8% of those aged 18 to 29 and 9% of those aged 30-39).

In terms of socio-economic factors, people living in the most deprived areas were more than twice as likely as those living in the least deprived areas to provide care for someone who did not live with them (34% compared with 15%). Those educated to degree level were more likely than those with no formal educational qualifications to have encouraged someone with dementia to seek help (12% compared with 4%

respectively). People living in urban areas were significantly more likely than those living in rural areas to have provided care for someone on a regular basis who does not live with them (26% compared with 15% respectively). Similar differences between groups by gender, age and education were found in SSA 2014.⁶

2.5 Self-assessed knowledge of dementia

In 2017, around 3 in 10 people (31%) said that they knew ‘a great deal’ or ‘quite a lot’ about dementia. This is a significant decrease since 2014 when just over 4 in 10 people said they knew ‘a great deal’ or ‘quite a lot’ about dementia (43%). There was a corresponding increase in those that said that they knew either ‘not very much’ or ‘nothing at all’, from 20% in 2014 to 31% in 2017. A similar proportion of people in 2017 and 2014 reported having ‘some’ knowledge about dementia (38% and 37% respectively). This difference may be accounted for by the change in the wording of the introduction to this question which included a description of dementia. In SSA 2017, the information on dementia also referred to changes in sight, taste and smell, all possible symptoms of dementia. These symptoms are shown in Chapter 3 below to not be widely known and this may therefore have impacted on people’s belief in their level of knowledge about dementia.

Table 2.3 Knowledge about dementia

How much, if anything, would you say you know about dementia?	2014 (%)	2017 (%)
A great deal / quite a lot	43	31
Some	37	38
Not very much / nothing at all	20	31
<i>Unweighted base</i>	<i>1428</i>	<i>1218</i>
<i>Weighted base</i>	<i>1433</i>	<i>1218</i>

Base: All respondents aged 18+

2.6 How does self-assessed knowledge of dementia vary between groups?

The amount of knowledge that people considered themselves to have about dementia was closely linked with their personal experience of dementia and whether they had been involved in caring for those with dementia. Among those that knew someone with dementia 40% felt that they knew ‘a great deal’ or ‘quite a lot’ compared with only 4% of those that did not know anyone with dementia. Those that had a job which involved working with people with dementia were the most likely to say that they knew ‘a great deal’ or ‘quite a lot’ about dementia (68%) compared with 42% of those that had a family member, close friend with dementia, or had dementia themselves, and only 15% of those who knew an acquaintance or colleague with dementia.

⁶ Differences by area deprivation and urban-rural were not explored in SSA 2014.

Among those that knew someone with dementia, twice the proportion of people that had cared for someone with dementia said they knew either ‘a great deal’ or ‘quite a lot’ about dementia compared with those that had never provided any care (46% compared with 24% respectively). Around 7 in 10 (68%) people that cared for someone with dementia on a regular basis considered themselves to have ‘a great deal’ or ‘quite a lot’ of knowledge about dementia; among those that had been responsible for arranging care 4 in 10 (41%) felt that they knew ‘a great deal’ or ‘quite a lot’ about dementia; 3 in 10 (31%) of those that had helped less regularly said they were knowledgeable about dementia, and 24% of those who had never cared for someone with dementia.

Self-assessed knowledge about dementia also varied significantly by gender and education. Women were more likely to say they had ‘a great deal’ or ‘quite a lot’ of knowledge about dementia compared with men (36% and 25% respectively). Those educated to degree-level were also more likely to have said that they had either ‘a great deal’ or ‘quite a lot’ of knowledge (35%) compared with those with no educational qualifications (21%).⁷

2.7 Main source of knowledge about dementia

In addition to being asked how much they knew about dementia, respondents were also asked from which, of a list of information sources, ‘you have learnt the most about dementia and how it affects people’s lives’.

Respondents were asked:

There are many ways in which people might learn about dementia. Using this card, please say from which of these, if any, you have learnt the most about dementia and how it affects people’s lives.

- 1 My job, which involves / involved working with people who have dementia
- 2 Personal experience (e.g. knowing someone, caring for someone, having it myself)
- 3 Word of mouth (e.g. through a friend, colleague or acquaintance)
- 4 Media (e.g. newspapers, television, radio, advertising campaigns)
- 5 Phone helpline
- 6 Internet
- 7 Professional(s) (e.g. doctor, nurse, social worker)
- 8 Other (please write in)
- 9 None of these

The most common way that people had learned about dementia was through personal experience, that is, knowing or caring for someone with dementia (45%). One in six (16%) people said it was through word of mouth and the same proportion said it was through the media including newspapers, television and advertising

⁷ Similar patterns by knowing someone with dementia, caring for someone with dementia, gender and education were recorded in SSA 2014.

campaigns (16%). For around one in seven (14%) people their main source of knowledge about dementia was their job which involved working with people with dementia. Only 3% of people said that the internet was their main source of knowledge and a further 3% said it was through professionals.⁸

Table 2.4 Main source of learning about dementia

Please say from which of these, if any, you have learnt the most about dementia and how it affects people's lives	2017 (%)
Personal experience (e.g. knowing someone, caring for someone, having it myself)	45
Media (e.g. newspapers, television, radio, advertising campaigns)	16
Word of mouth (e.g. through a friend, colleague or acquaintance)	16
My job, which involves / involved working with people who have dementia	14
Professional(s) (e.g. doctor, nurse, social worker)	3
Internet	3
Other	2
None of these	1
Don't know/Refused	-
<i>Unweighted base</i>	1175
<i>Weighted base</i>	1181

Base: All respondents aged 18+

Around two-thirds of people who said that they had learned the most about dementia through their job or from professionals assessed themselves as having 'a great deal' or 'quite a lot' of knowledge about dementia (68%). Among those who had learned the most about dementia through knowing someone with dementia around 4 in 10 (39%) considered themselves to be knowledgeable about dementia. People who had learned the most about dementia through word of mouth, the media and the internet were far less likely to consider themselves to have either 'a great deal' or 'quite a lot' of knowledge about dementia (word of mouth – 4%, media – 7% and internet – 4%).

2.8 How does main source of learning about dementia vary between groups?

Women were significantly more likely than men to say that their main source of learning about dementia was through a job that involves working with people with dementia (21% compared with 7% respectively). Men on the other hand were more likely than women to gain their knowledge about dementia through the media (19% compared with 13% respectively).

⁸ Comparable data from SSA 2014 is not available as the question was asked differently in 2017.

There were also marginally significant differences by age and area deprivation. Over half (51%) of those aged 65 and over said personal experience was their main source of knowledge about dementia compared with around 4 in 10 (39%) of those aged 18 to 29. And those living in the least deprived areas were also less likely to say that personal experience was their main source of information compared with those living in the most deprived areas (37% compared with 51% respectively).

2.9 How does main source of learning about dementia vary by experience of dementia?

Whether people knew someone with dementia, and how they knew someone, were both associated with having different main sources of learning about dementia. Those who did not know anyone with dementia were the most likely to have learned the most about dementia:

- through the media (38%)
- word of mouth (30%)

For those who did know someone with dementia, this personal experience was their main source of learning about dementia:

- Among those that had experience of dementia through their job, 75% said that their job was their main source of knowledge about dementia
- 7 in 10 of those who had cared for someone with dementia on a regular basis (70%) and the same proportion of those who had been responsible for arranging care (70%) said their main source of learning was personal experience
- Almost 6 in 10 (59%) of those who had helped someone with dementia less regularly also said that personal experience was their main source of learning
- Among those who knew someone with dementia but had not cared for someone with dementia, personal experience was still the most common source of learning (29%).

The media and word of mouth were chosen more often as the main source of knowledge by those that knew someone with dementia but had not provided care compared with those who had provided care. Around a quarter (27%) of those that had not provided care chose word of mouth compared with 7% who had provided care, and 18% chose the media compared with 6% who had provided care.

3. Knowledge of symptoms and risk factors associated with dementia

Key findings

- The vast majority of people in Scotland are aware of some of the well-established symptoms of dementia. For example, 9 in 10 knew that 'difficulty in recognising people' is a symptom and around 8 in 10 that 'losing track of time' (84%) or 'feeling lost in new places' (79%) are symptoms.
- There is substantially less knowledge about other symptoms. For example, only around half said that 'losing your temper easily' (57%) or 'feeling depressed' (49%) were symptoms of dementia, and just one-quarter (28%) knew that 'feeling extremely tired' was a possible symptom.
- The proportion of people who were aware that specific sensory changes were associated with dementia ranged from around 6 in 10 (57%) for 'having hallucinations' to around 4 in 10 for 'changes to taste or smell' (43%) and 'increased sensitivity to noise' (39%).
- Almost 6 in 10 (57%) thought there were things they could do to decrease their risk of getting dementia, compared with around one-quarter (24%) who thought there were not. Around 1 in 5 (19%) said they were 'not sure' or 'don't know' whether there was anything they could do to decrease the risk.
- The proportion of people who correctly identified a range of 5 risk factors and protective factors for dementia ranged from 28% (in the case of identifying high blood pressure as a risk factor) to 57% (in the case of identifying drinking heavily as a risk factor for dementia).
- The proportion who correctly identified each of the risk factors has increased by between 5 and 10 percentage points since SSA 2014. However, there were still between 4 in 10 and 7 in 10 people in 2017 who misidentified risk factors, or said they 'don't know' or are 'not sure' whether these factors mean someone is more likely to get dementia.
- Overall, those with higher educational qualifications, higher incomes, and higher levels of self-reported knowledge about dementia were more likely to have greater knowledge of the symptoms of, and risk factors for, dementia.

This chapter explores people's knowledge of the symptoms of, and risk factors for, dementia. It also examines whether people think there are things they can do to make it less likely that they will get dementia.

Improving people's understanding of the symptoms of dementia is an important component of increasing the opportunities for early diagnosis and intervention, which can lead to better outcomes for those affected.⁹ In addition, improving people's understanding of the (modifiable) risks for dementia, and thereby reducing their risk of getting dementia in the first place, is a key focus for public policy.¹⁰ The risk factors for dementia include age and genetics, but also medical history, lifestyle and environmental factors.

The questions relating to knowledge of risk factors were also asked in SSA 2014, and so this chapter includes an analysis of how this has changed over time. However, the questions relating to knowledge of the symptoms of dementia, and whether people think there are things they can do to make it less likely that they will get dementia, were asked for the first time in SSA 2017.

3.1 Knowledge of symptoms of dementia

There were two main approaches to exploring respondents' knowledge of the symptoms of dementia:

- Respondents were presented with a card¹¹ which listed a range of 8 symptoms, and were asked to select which, if any, might mean that someone has dementia. (Respondents could select up to eight symptoms.) (Section 3.1.1 below.)
- Respondents were asked whether they thought 3 particular sensory changes that people might experience could be, or could not be, a symptom of dementia (Section 3.1.2 below).

⁹ <https://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf>

¹⁰ <https://www.alzheimersresearchuk.org/about-us/our-influence/policy-statements/dementia-risk-reduction-policy-statement/>

¹¹ Note that there were two versions of the card, and the symptoms were listed in a different order in each version. In order to minimise response bias, respondents were allocated at random to the two versions.

3.1.1 Which symptoms might mean someone has dementia?

Respondents were asked:

Here is a list of things which may or may not be a symptom of dementia. Which, if any, of the following symptoms do you think might mean that someone has dementia?

- Breathlessness
- Difficulty in recognising people
- Feeling depressed
- Losing your temper easily
- Nose bleeds
- Feeling lost in new places
- Feeling extremely tired
- Losing track of time

Table 3.1 below shows the responses to this question, and confirms which of the symptoms are possible indicators of dementia.

Table 3.1 Views on which symptoms might mean that someone has dementia

Which, if any, of the following symptoms do you think might mean that someone has dementia?	2017 (%) ¹
Evidence that symptom may indicate dementia	
Difficulty in recognising people	90
Losing track of time	84
Feeling lost in new places	79
Losing your temper easily	57
Feeling depressed	49
Feeling extremely tired	28
No evidence that symptom may indicate dementia	
Breathlessness	7
Nose bleeds	4
<i>Unweighted base</i>	1218
<i>Weighted base</i>	1218

Base: All respondents aged 18+

¹Percentages do not sum to 100% as the question was a multi-code response

As can be seen in Table 3.1 above, the vast majority of people were aware that 'difficulty in recognising people' (90%), 'losing track of time' (84%) and 'feeling lost in new places' (79%) are symptoms of dementia. These symptoms are well established

in relation to the evidence base, and the public understanding of these symptoms is strong.

Around half recognised that ‘losing your temper easily’ (57%) and ‘feeling depressed’ (49%) were possible indicators of dementia, while only around a quarter (28%) were aware that ‘feeling extremely tired’ could be a symptom. This suggests that these symptoms are not so well established in the public’s mind as potential indicators of dementia.

The list of symptoms contained two (breathlessness and nose bleeds) which, in fact, have no known association with dementia. It was encouraging that very few people (7% in the case of breathlessness, 4% in the case of nose bleeds) identified these as symptoms of dementia.

How does knowledge of symptoms vary between groups?

In order to examine how knowledge of the symptoms of dementia varies between groups a ‘symptom knowledge score’ for each individual was created (ranging from 0-8) by giving each respondent a score of one for every ‘correct answer’ and zero for every ‘incorrect answer’. So, in order to attain the maximum possible score of 8, a respondent would have to correctly select the six symptoms for which there is evidence of a link to dementia and also to not select the two symptoms on the list for which there is no evidence of a link to dementia.

Table 3.2 below shows that the ‘symptom knowledge scores’ were highly skewed with most people (84%) scoring five or more. The median number of correct answers was six.¹² One in ten people (10%) were able to identify the correct answer in every case.

Table 3.2 Symptom knowledge scores

Number of ‘correct answers’	2017 (%)
0	1
1	0
2	1
3	3
4	11
5	25
6	28
7	21
8	10
<i>Unweighted base</i>	<i>1218</i>
<i>Weighted base</i>	<i>1218</i>

Base: All respondents aged 18+

¹² The median score is a better indicator of the average than the mean where the distribution is skewed. The median, or the middle value of the, ‘symptom knowledge score’ was 6.

We defined three groups based on the symptom knowledge scores as follows:

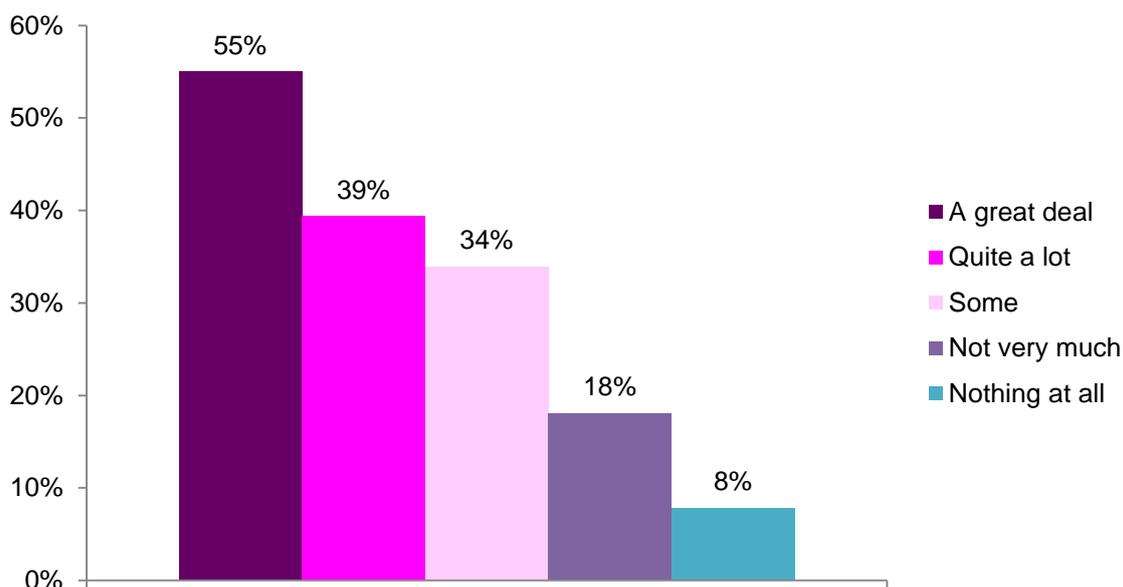
- Those with scores in the range 0-4 are described as having 'low' knowledge of dementia symptoms (16% fell into this category)
- Those with scores in the range 5-6 are described as having 'moderate' knowledge of dementia symptoms (52% fell into this category)
- Those with scores in the range 7-8 are described as having 'high' knowledge of dementia symptoms (32% fell into this category).

There were clear variations between socio-demographic groups in the amount of knowledge people had about dementia symptoms. In particular:

- Women knew more about dementia symptoms than men (34% of women had 'high' levels of knowledge compared with 28% of men)
- Older people (aged 65 and over) knew less about dementia symptoms than other age groups. Just 1 in 6 people (18%) aged 65 and over had 'high' levels of knowledge, compared with 1 in 3 (31%) aged 18-29
- The extent of peoples' knowledge about dementia symptoms differed by their level of educational qualifications. 'High' levels of knowledge about dementia symptoms ranged from 4 in 10 (40%) of those educated to degree-level, to 3 in 10 (29%) of those with Highers or A- levels, and under a quarter of those with Standard Grades or GCSEs (24%) or no qualifications (23%)
- There was also a clear relationship between knowledge of dementia symptoms and income levels. 'High' levels of knowledge about dementia symptoms ranged from 4 in 10 (40%) of those in the highest income group to under a quarter (23%) of those in the lowest income group.

In addition, there was a strong relationship between self-assessed knowledge about dementia more generally and knowledge about symptoms of dementia. Figure 3.1 below shows that over half of people (55%) who said they knew 'a great deal' about dementia had a 'high' symptom knowledge score compared with 39% who said they knew 'quite a lot', 34% who said they knew 'some', 18% of those who said they knew 'not much' and just 8% of those who said they knew 'nothing at all'. This provides some objective confirmation that self-reported knowledge of dementia is indeed a reasonable proxy for actual knowledge.

Figure 3.1 Self-reported knowledge of dementia among those with a 'high' symptom knowledge score



Base: All respondents aged 18+

3.1.2 Which sensory changes might mean someone has dementia?

Respondents were also asked:

As far as you're aware...

- ...if someone becomes a lot more sensitive to noise than before could this be a symptom of dementia?
- ...if someone finds that things taste or smell differently than before could this be a symptom of dementia?
- ...if someone is having hallucinations could this be a symptom of dementia?

Possible answer options were: yes, no, not sure

Table 3.3 below presents the findings in relation to the three specific items mentioned above. Evidence shows that each of these can, in fact, indicate that someone may have dementia.¹³

¹³ <https://www.scie.org.uk/dementia/living-with-dementia/sensory-loss/>

Table 3.3 Views on sensory changes related to dementia

As far as you are aware, could the following be a symptom of dementia...	Yes (%)	No (%)	Not sure / Don't know (%)	Weighted/ Unweighted base
...if someone becomes a lot more sensitive to noise	39	10	51	1218
...if someone finds that things taste or smell differently than before	43	12	45	1218
...if someone is having hallucinations	57	10	33	1218

Base: All respondents aged 18+

It is notable that between a third and a half said they were 'not sure' or 'don't know' whether each of these is a possible symptom for dementia. Given this high level of uncertainty, nearly 6 in 10 people (57%) thought that 'having hallucinations' was a symptom of dementia, with far fewer being aware that being 'more sensitive to noise' (39%) and finding that 'things taste or smell differently' (43%) were symptoms.

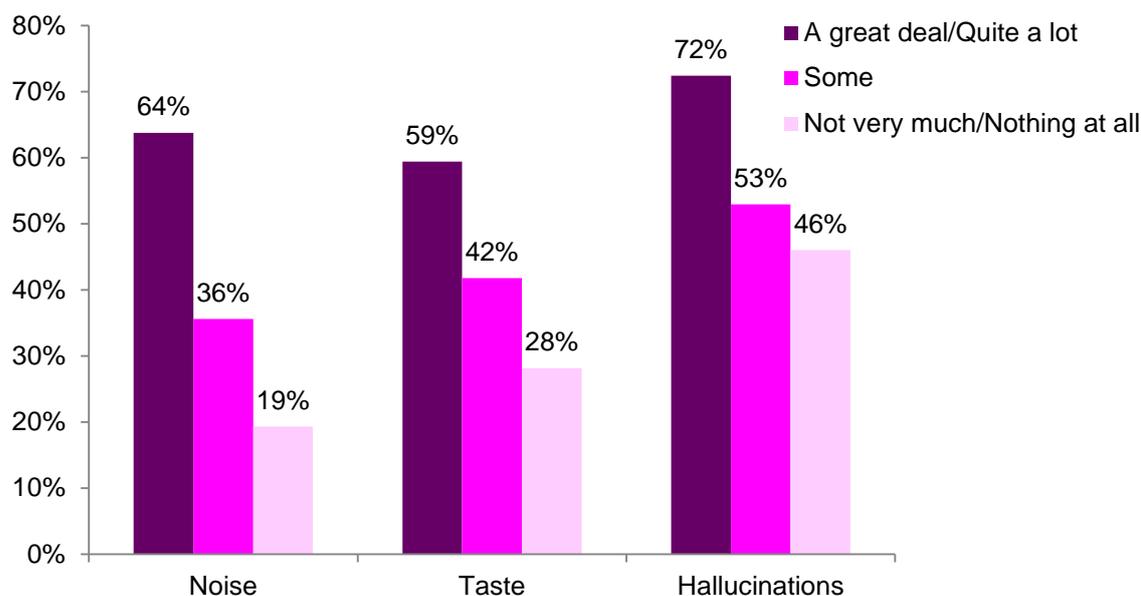
How does knowledge of the sensory changes which are associated with dementia vary between groups?

As far as knowledge of sensory changes as symptoms of dementia was concerned, there were differences by age, gender, education, experience of dementia and self-reported knowledge.

The clearest relationship was with self-reported knowledge (see Figure 3.2 below). Those who said they 'knew a great deal' or 'quite a lot' about dementia were much more likely to recognise each of these sensory changes as possible symptoms of dementia. In particular:

- 64% of those who said they knew 'a great deal' or 'quite a lot' about dementia recognised sensitivity to noise as a potential symptom. This contrasted with 36% of those who said they knew 'some', 19% of those who knew 'not much' or 'nothing at all' about dementia. A similar pattern was seen for knowledge of changes to taste and smell as symptoms.
- Having hallucinations was a possible symptom of dementia which was most commonly recognised. Knowledge of this as a symptom of dementia ranged from 72% of those who said they knew 'a great deal/quite a lot' about to dementia to 46% of those who said they knew 'not very much/nothing at all'.

Figure 3.2 Knowledge of sensory changes linked to dementia by self-assessed knowledge of dementia



Base: All respondents aged 18+

In addition, those who were more likely to recognise that sensory changes were linked to dementia were:

- women (for sensitivity to noise and hallucinations)
- those aged under 65 (for sensitivity to noise and changes to taste and smell)
- those with higher levels of educational qualifications (for changes to taste and smell, and hallucinations)
- those whose job involved working with people with dementia (for sensitivity to noise and hallucinations) and
- caring for someone with dementia on a regular basis (for sensitivity to noise).

3.2 Personal actions to decrease the likelihood of getting dementia

Respondents were asked:

From what you have seen or heard, do you think there are, or are not, things you can do yourself to make it less likely that you will get dementia.

Possible answer options were:

- Yes, definitely are
- Yes, probably are
- No, probably are not
- No, definitely are not

Table 3.4 below shows that almost 6 in 10 (57%) thought there were things they could do to reduce their risk of getting dementia, compared with around a quarter (24%) who thought there were not. Around 1 in 5 (19%) said they were 'not sure' or 'don't know' whether there was anything they could do.

Table 3.4 Views on whether or not there are things you can do yourself to make it less likely that you will get dementia

From what you have seen or heard, do you think there are, or are not, things you can do yourself to make it less likely that you will get dementia?	2017 (%)*
Yes, definitely are	19
Yes, probably are	38
No, probably are not	16
No, definitely are not	7
Not sure / Don't know	19
<i>Unweighted base</i>	1218
<i>Weighted base</i>	1218

Base: All respondents aged 18+

* Does not sum to 100% due to rounding.

The factors which were associated with people thinking that there were things that they could do to reduce their risk of getting dementia were their level of educational qualifications, income, and self-reported knowledge. In particular:

- Around 7 in 10 (68%) of those educated to degree-level thought there was 'definitely' or 'probably' something they could do to reduce their risk of dementia compared with around 4 in 10 (39%) of those with no educational qualifications.
- Two-thirds (67%) of those in the highest income group thought there was 'definitely' or 'probably' something they could do to reduce their risk of dementia compared with half (50%) of those in the lowest income group.
- As far as self-reported knowledge was concerned, two-thirds (67%) of those who said they knew 'a great deal' about dementia thought there was 'definitely' or 'probably' something they could do to reduce their risk compared with 39% of those who said they knew 'nothing at all'.

3.3 Knowledge of risk factors and protective factors for dementia

Respondents were asked how much they agreed or disagreed with the following statements:

- High blood pressure increases your chance of getting dementia
- If one of your parents gets dementia, you are more likely to get it too
- Smoking has nothing to do with dementia
- If you eat a healthy diet you are less likely to get dementia
- People who drink heavily are more likely to get dementia

The risk factors (high blood pressure, genetic factors, smoking, and over consumption of alcohol) and protective factors (eating a healthy diet) asked about in SSA 2017 were identical to those asked about in SSA 2014. They are all substantiated factors in relation to the risk of developing dementia.¹⁴

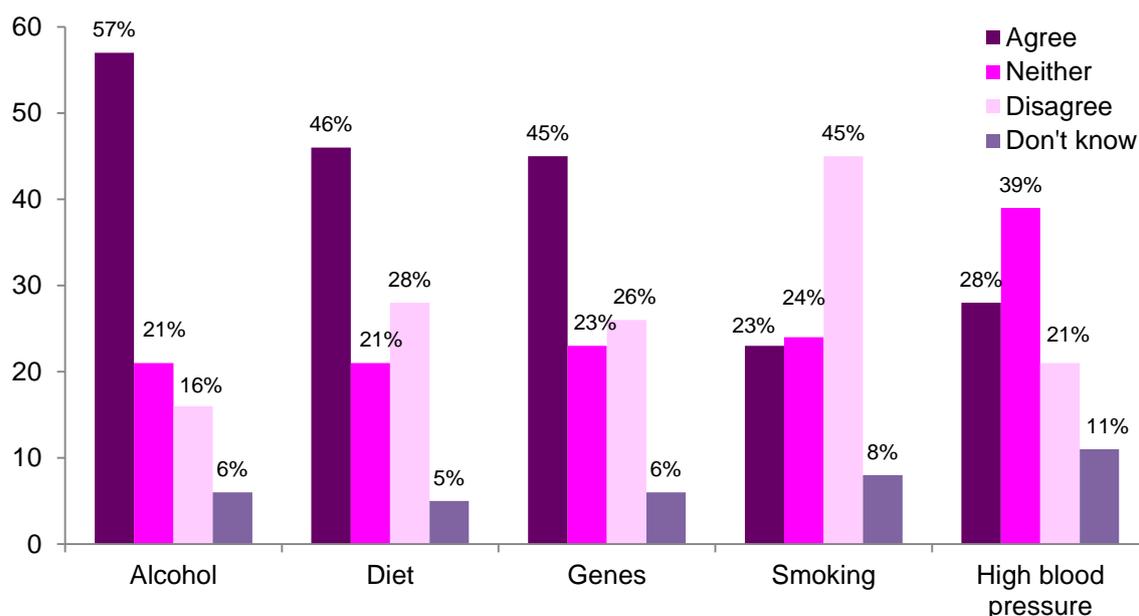
Responses to each of these five statements were recorded on a five-point agree-disagree scale. The statements divide into those for which:

- A response of 'agree' or 'strongly agree' indicates that the respondent understood that this is a risk factor for dementia (this applies to the statements covering high blood pressure, genetic factors, and drinking heavily) or a protective factor for dementia (this applies to the statement on eating a healthy diet).
- A response of 'disagree' or 'strongly disagree' indicates that the respondent understood that this is a risk factor for dementia (this applies to the statement on smoking).

Figure 3.3 below shows that the proportion of people who chose the 'correct answer' (either strongly agree / agree or strongly disagree / disagree) ranged from 28% (in the case of correctly identifying high blood pressure as a risk factor) to 57% (in the case of correctly identifying drinking heavily as a risk factor). For each of the three other factors (eating a healthy diet, smoking, and having a parent with dementia) just under half (45%-46%) correctly identified these as risk factors / protective factors for dementia.

¹⁴ The Blackfriars Consensus on promoting brain health and reducing risks for dementia in the population (Public Health England and UK Health Forum 2014) states that given the evidence that there may be a vascular component to many dementias, interventions to address vascular risk factors (such as high blood pressure, smoking, poor diet, physical inactivity and alcohol) should help reduce the risk, progression, and severity of dementia.

Figure 3.3 Knowledge of risk factors linked with dementia (2017)



Base: All respondents aged 18+

Table 3.5 below shows figures for 2014 and 2017 for the 'correct answer' for all five risk factors. This shows that the proportion who selected the 'correct answers' has increased by between 5 and 10 percentage points for each of the five factors, since SSA 2014.

As in SSA 2014, knowledge of high blood pressure, specifically, as a risk factor was much lower than any of the other factors asked about. The proportion who said they 'don't know' or 'neither agree nor disagree' with the statements has also been fairly stable over time; in both SSA 2014 and 2017 the proportion who were unsure whether the factors were a risk factor or a protective factor varied between around a quarter and a half.¹⁵

¹⁵ In SSA 2014 the proportion who were unsure whether the factors were a risk/protective factor ranged from 28% to 53% and in SSA 2017 the range was between 26% and 50%.

Table 3.5 Proportion selecting the 'correct answer' for risk factors for dementia

Risk Factor	Correct answer (%)	
	2014	2017
Drinking heavily	52	57
Eating a healthy diet	36	46
One of your parents has dementia	39	45
Smoking*	37	45
High Blood Pressure	22	28
<i>Unweighted base</i>	<i>1501</i>	<i>1218</i>
<i>Weighted base</i>	<i>1501</i>	<i>1218</i>

Base: All respondents aged 18+

*In the case of the question related to smoking as a risk factor, the 'correct' answer was 'disagree'. In all other cases, the 'correct' answer was 'agree'

3.3.1 How does knowledge of risk factors vary between groups?

The previous section highlighted that although peoples' knowledge of risk, and protective, factors for dementia has increased to some degree since 2014, there were still substantial proportions of people who were either not aware of, or who misidentified, the impact of various factors.

Certain groups were more likely than others to know about specific risk factors, although the patterns were not completely consistent for all subgroups across all factors. Moreover, the patterning across subgroups was different from the patterns found in SSA 2014.

In SSA 2017, people's level of educational qualifications provided the clearest relationship with their knowledge of risk factors. This is in contrast to SSA 2014 where the strongest relationship was found with self-reported knowledge.¹⁶

In SSA 2017 those educated to degree level were more likely to correctly identify risk factors and protective factors than those with Highers or A-levels, who in turn were more likely to correctly identify risk factors than those with Standard Grades / GCSEs or no educational qualifications. The differences between the most knowledgeable and least knowledgeable groups were substantial. For example:

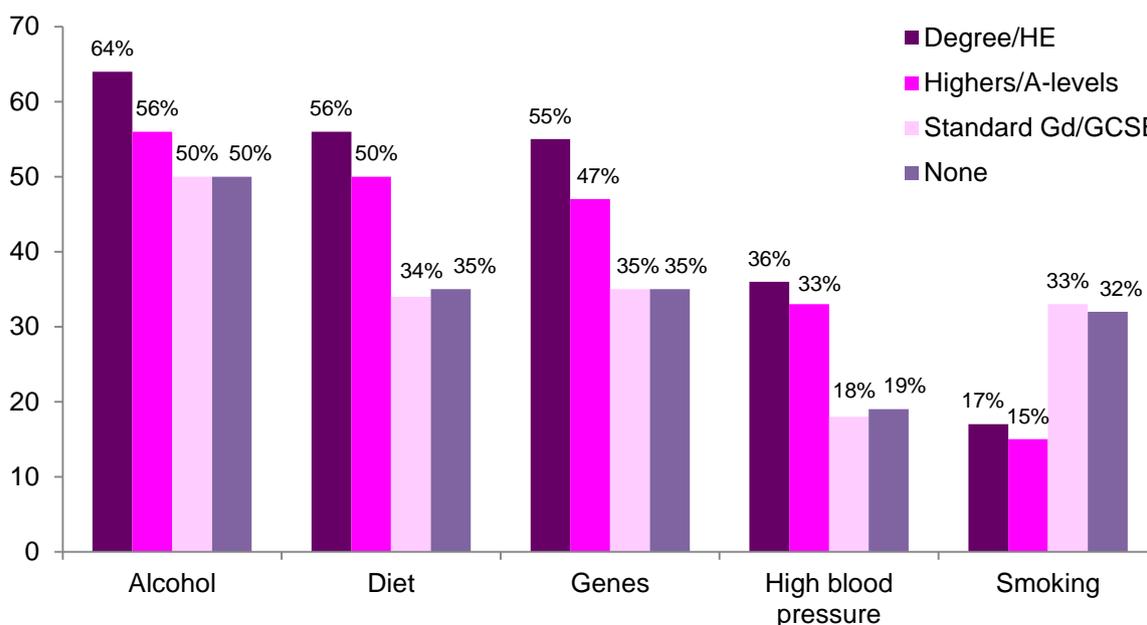
- Over a third (36%) educated to degree-level and a third (33%) of those with Highers or A-Levels correctly identified high blood pressure as a risk factor compared with less than 1 in 5 of those who either had Standard Grades / GCSEs (18%) or no educational qualifications (19%).

¹⁶ However, it should be noted that these two factors (level of educational qualifications and self-reported knowledge) are correlated with each other, and so to some degree can act as 'proxies' for each other.

- More than half (55%) educated to degree-level correctly identified having a parent with dementia as a risk factor compared with just under half of those (47%) with Highers or A-levels, and just over a third (35%) of those with either Standard Grades / GCSEs or no educational qualifications.

The findings for the relationship between educational qualifications and all five risk factors is shown in Figure 3.4 below.

Figure 3.4 Knowledge of risk factors linked with dementia by education



Base: All respondents aged 18+

As far as other differences between groups were concerned, we found that:

- **For the impact of drinking heavily:** self-reported knowledge of dementia, whether you live in an urban or rural area, and knowing someone with dementia, were all associated with knowing that drinking heavily is a risk factor for dementia.
 - Around two-thirds (66%) of those who said they knew 'a great deal' or 'quite a lot' about dementia correctly identified the risk of drinking heavily compared with half (50%) of those who said they knew 'not much' or 'nothing at all'.
 - Those living in urban areas were more likely (60%) than those living in rural areas (47%) to correctly identify the risk.
 - Almost three-quarters (72%) of those whose job involved working with someone with dementia correctly identified this risk compared with around 6 in 10 of those who had a family member or friend with dementia, or who had dementia themselves (58%), and less than half (47%) of those who did not know anyone with dementia.

- For the **protective effect of a healthy diet**: gender and income were associated with knowledge about this protective factor.
 - Men were more likely than women (54% of men compared with 40% of women) to know that ‘if you eat a healthy diet you are less likely to get dementia’
 - More than half (56%) of those in the highest income group knew about the protective effect of a healthy diet compared with around 4 in 10 (42%) of those in all other income groups combined.
- For the **impact of having one or more parent with dementia**: age, income, knowing someone with dementia and caring for someone with dementia were all associated with people being aware of the association between genetic factors and having a higher risk of getting dementia.
 - Those aged 65 and over were less likely to recognise genetic factors as a risk factor for dementia with around a third (34%) of those aged 65 and over knowing that having a parent with dementia was a risk factor, compared with around a half (49%) of those in all other age groups combined.
 - Those in the highest income group were more likely than any other income group to recognise this as a risk factor with around 6 in 10 (59%) in the highest income group selecting the ‘correct answer’ compared with 4 in 10 (40%) of those in the lowest income group.
- For the **impact of smoking**: age and self-reported knowledge were associated with knowing that smoking is a risk factor for dementia.
 - Those aged under 65 were less knowledgeable in comparison with all other age groups. For example, around 4 in 10 (39%) of those aged 65 and over correctly identified smoking as a risk factor for dementia compared with around half (48%) of those aged 18 to 29.
 - As far as self-reported knowledge is concerned, there was a clear pattern, with those with higher levels of knowledge being more likely to know that smoking is a risk factor for dementia. Among those who said they knew ‘a great deal’ about dementia, 63% answered correctly compared with 30% of those who knew ‘nothing at all’.
- For **high blood pressure**: gender, age, income and self-reported knowledge were all associated with the extent to which people knew that high blood pressure is a risk factor for dementia.
 - Men were more likely than women to recognise that high blood pressure is a risk factor for dementia (32% compared with 25% respectively)
 - Those aged 65 and over (22%) were less likely than those aged 18 to 64 years old (30%) to know that high blood pressure is a risk factor for dementia
 - Those in the highest income group (39%) were more likely than those in the lowest income group (22%) to correctly identify high blood pressure as a risk factor

- Those who said they knew ‘a great deal’ about dementia (47%) were more likely than those who said they knew ‘nothing at all’ about dementia (12%) to identify high blood pressure as a risk factor.

3.3.2 Risk factor scores

In order to investigate the variation in knowledge of risk and protective factors and the change since SSA 2014 in more depth, we created a ‘risk factor score’ for each individual (ranging from 0-5) by giving each respondent a score of one for every ‘correct answer’. Table 3.6 below shows the distribution of ‘correct answers’, as well as the average number of ‘correct answers’ given for both SSA 2014 and SSA 2017.

Table 3.6 Risk factor scores

Number of correct answers	2014 (%)	2017 (%)
0	21	15
1	24	20
2	23	24
3	17	18
4	12	14
5	3	9
Average Risk Factor Score	1.86	2.23
<i>Unweighted base</i>	<i>1501</i>	<i>1218</i>
<i>Weighted base</i>	<i>1501</i>	<i>1218</i>

Base: All respondents aged 18+

Table 3.6 shows that there has been a clear shift in the proportion of ‘correct answers’ given between 2014 and 2017. In particular, in 2017 fewer people gave ‘0’ or ‘1’ correct answer, for example, 15% gave no correct answers in 2017 which was significantly lower than the 21% recorded in 2014. At the same time more gave ‘2’, ‘3’, ‘4’ or ‘5’ correct answers, for example, 9% gave 5 correct answers in 2017 compared with 3% in 2014.

Exploring the differences between key subgroups in relation to average risk factor scores, showed that the groups with the highest levels of knowledge in relation to risk factors and protective factors for dementia were:

- those with the highest educational qualifications: those educated to degree level on average gave 2.64 correct answers compared with 1.78 correct answers given by those with no educational qualifications
- those with the highest incomes: those in the highest income group on average gave 2.69 correct answers compared with 2.08 correct answers given by those in the lowest income group

- those with higher levels of self-assessed knowledge: those who knew 'a great deal' or 'quite a lot' about dementia gave 2.61 correct answers on average compared with 1.89 correct answers given by those who said they knew 'not very much' or 'nothing at all' about dementia
- those whose job involved working with people with dementia: those who worked with people with dementia scored on average 2.46 compared with 1.93 for those who did not know anyone with dementia.

4. Funding dementia services and providing care

Key findings

- 43% of people felt that dementia should be given priority for more government funding in relation to prevention, placing it second in the list of health problems that the public felt should take priority in this area behind cancer (62%).
- Almost 7 in 10 (69%) felt that dementia should be given priority for more government funding in relation to care and support, making it the public's top priority for additional spending in this area.
- 57% believed that care for someone with mild dementia who lives at home and needs regular help looking after themselves should be funded by the government irrespective of how much money the individual has, while 40% think that funding for such care should be means-tested.
- Two-thirds (66%) felt that care for someone with severe dementia who is unable to live at home and needs to go into residential care should be paid for by the government regardless of how much money the individual has, while 32% believed funding for such care should be means-tested.
- Over half (54%) thought that the government provides either 'not very much' support or 'none at all' to family members who care for a relative with dementia.
- While 58% believed that family and friends should usually provide most of the care for someone with mild dementia, 87% thought that paid carers or nurses should usually provide most of the care for someone with severe dementia.

In order to further understand public attitudes towards funding services and providing care for those with dementia, SSA 2017 included questions on people's priorities for additional government spending on prevention, and on care and support, and their views on who should be responsible for providing and paying for care. A number of these questions were also asked in 2014, enabling us to investigate whether public opinion on these issues has changed in recent years.

4.1 Government spending priorities

SSA 2017 included two questions requiring respondents to rank a number of health issues in priority order in terms of public spending. The first question asked about public spending on prevention (Section 4.1.1 below), and the second about public

spending on care and support (Section 4.1.2 below). These questions were also included in SSA 2014.

Respondents were first asked:

Which of the following should be **the highest priority** for more government spending on **prevention**? And which should be the **next highest** priority?

Respondents were then asked:

Which of the following should be **the highest priority** for more government spending on **care and support**? And which should be the **next highest priority**?

[The same list of health problems was presented for both questions.]

- Stroke
- Obesity / Being overweight
- Heart disease
- Dementia
- Cancer
- Depression
- None of the above

4.1.1 Priorities for more government spending on prevention

Table 4.1 below presents the finding on views about public spending on prevention in both 2014 and 2017. It shows that, both in 2014 and 2017, cancer was chosen as the top priority for more government spending on prevention by the highest proportion of people (45% in 2014, 40% in 2017). Dementia was chosen as the top priority for more government spending on prevention by the second highest proportion of people (16% in 2014, 20% in 2017). The proportion selecting 'dementia' as either their first or their second priority for additional government spending on prevention was 43% in 2017. As was the case in 2014, this places dementia second in the list of health problems, behind cancer, that the public felt should be given priority for more government spending on prevention (62%).

Table 4.1 Priorities for more government spending on prevention

Which of these should be the highest/next highest priority for more government spending on prevention?	Highest priority (%)		Next highest priority (%)		Combined (%)**	
	2014*	2017*	2014	2017	2014	2017
Cancer	45	40	22	22	68	62
Dementia	16	20	22	24	38	43
Obesity/Being overweight	15	17	11	12	25	29
Heart disease	11	7	25	20	35	28
Depression	7	12	10	14	17	26
Stroke	3	2	9	7	12	9
None of the above	1	2	*	1	2	2
Don't know/Refused	1	1	1	*	2	1
<i>Unweighted base</i>	1501	1218	1464	1193	1501	1218
<i>Weighted base</i>	1501	1218	1462	1187	1501	1218

Base: All respondents aged 18+

* Does not sum to 100% due to rounding.

** Combined highest and next highest priority percentages are rounded

How do views on priorities for more government spending on prevention vary between groups?

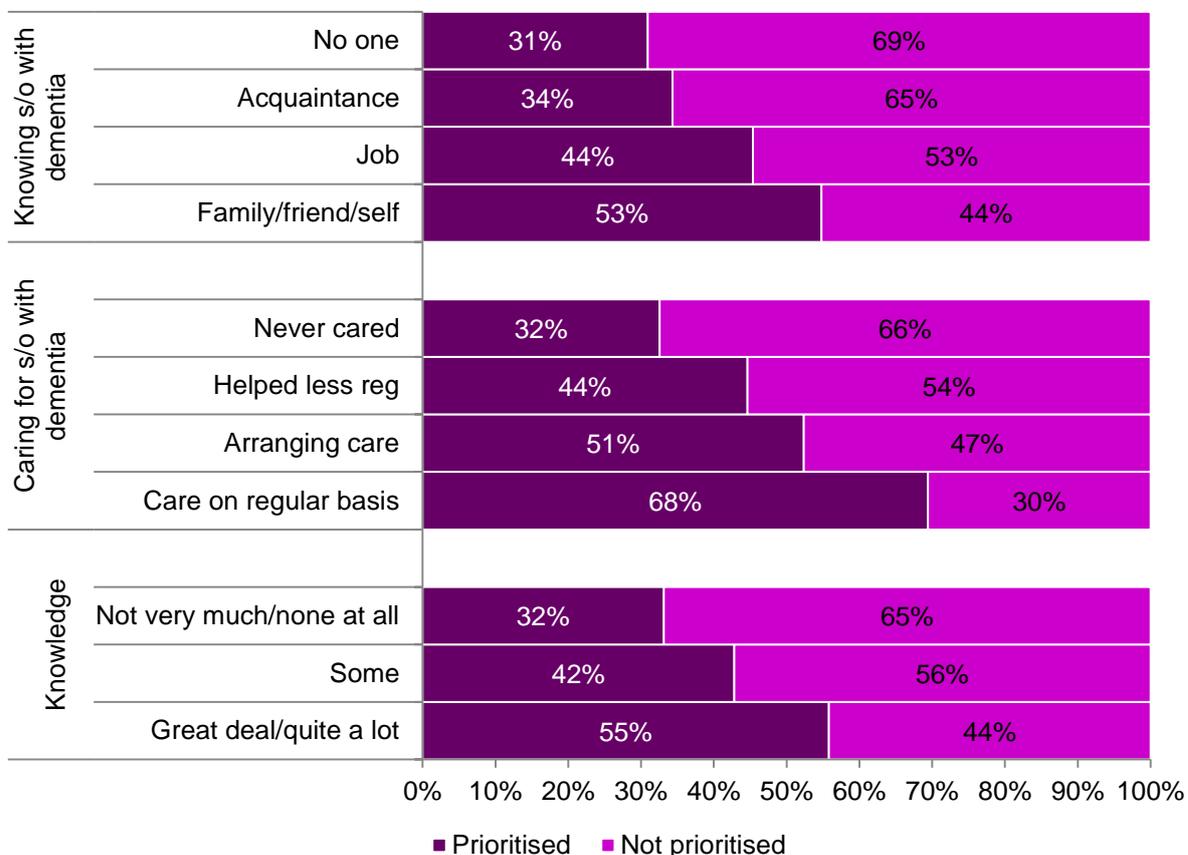
Taking the combined figures for the highest and next highest priority, we explored any differences between groups. As might be expected, age is associated with prioritising dementia as an area for more government spending on prevention, with those aged 65 and over significantly more likely than those in all other age groups to view dementia as a priority (55%, compared with 40% of those aged 18-29, 33% of those aged 30-39 and 42% of those aged 40-64).

As Figure 4.1 below shows, self-assessed knowledge of dementia, caring for someone with dementia, and knowing someone with dementia were all related to prioritising dementia for additional government expenditure on prevention. In particular:

- Those who said that they know ‘a great deal’ or ‘quite a lot’ about dementia were significantly more likely to view dementia as a priority for government spending on prevention (55%) than those who reported knowing either ‘not very much’ or ‘nothing at all’ about dementia (32%).
- Those who had cared for someone with dementia on a regular basis were more likely to view dementia as a priority for more government spending on prevention (68%) than those who had no experience of caring for someone with dementia (32%).
- Those who knew either a family member or close friend with dementia, or had dementia themselves, were more likely to prioritise dementia as an area for more

government spending on prevention (53%) than those who did not know anyone with dementia (31%).

Figure 4.1 Prioritising dementia for more government spending on prevention by experience of dementia



Base: All respondents aged 18+

4.1.2 Priorities for more government spending on care and support

Table 4.2 below shows the findings on views about priorities for government spending on care and support from both 2014 and 2017.

In 2014, dementia was selected as the highest priority for more government spending on care and support by almost half (46%), followed by cancer (30%), and then depression (9%). The latest data shows similar findings with dementia being chosen by 46% of people followed by cancer (27%) and depression (16%). When the answers to both of these questions are combined, similarly to 2014, the proportion selecting 'dementia' as either their first or second priority for additional government spending on care and support was 69% (66% in 2014) and the proportion of those selecting cancer was 53% (57% in 2014).

Table 4.2 Priorities for more government spending on care and support

Which of these should be the highest /next highest priority for more government spending on care and support?	Highest priority (%)		Next-highest priority (%)		Combined (%)**	
	2014*	2017	2014	2017*	2014	2017
Dementia	46	46	20	23	66	69
Cancer	30	27	27	27	57	53
Depression	9	16	16	20	25	37
Stroke	5	3	17	12	22	15
Heart disease	4	3	14	11	18	14
Obesity/Being overweight	3	3	5	6	8	9
None of the above	1	1	1	0	2	2
Don't know/Refused	1	1	*	*	1	1
<i>Unweighted base</i>	1501	1218	1469	1191	1501	1218
<i>Weighted base</i>	1501	1218	1468	1187	1501	1218

Base: All respondents aged 18+

* Does not sum to 100% due to rounding.

** Combined highest and next highest priority percentages are rounded

How do views on priorities for more government spending on care and prevention vary between groups?

Whilst no socio-demographic variables were found to be associated with selecting dementia as either their first or second priority for more government spending on care and support, both self-reported knowledge of dementia and whether or not an individual knows someone with dementia were significantly related to prioritising dementia for more government spending on care and support. Those who reported knowing either 'a great deal' or 'quite a lot' about dementia were significantly more likely to view dementia as a priority (83%) than those who reported knowing either 'not very much' or 'nothing at all' about dementia (57%). Those who knew either a family member or close friend with dementia, or have dementia themselves (77%), or those whose job involves working with people with dementia (80%) were more likely than those who either only knew an acquaintance, colleague or someone else with dementia (62%) or did not know anyone with dementia (51%) to prioritise dementia for additional spending on care and support.

4.2 Government or individual pays?

In addition to exploring the extent to which the public see dementia as a priority for additional government spending on prevention and on care and support, SSA 2017 included two questions aimed at examining public opinion on who should be responsible for funding care for those with dementia.

Respondents were asked:

- Who should pay for someone with dementia who lives at home and needs regular paid help with looking after themselves?
- Who should pay for someone with severe dementia who is unable to live at home and needs to go into residential care?

In both cases, the answer options available to respondents were:

- The government should pay, no matter how much money the person has
- The person should pay, no matter how much money he/she has
- Who pays should depend on how much money the person has

Both of these questions were also asked in SSA 2014.

Table 4.3 below shows the findings for these questions in both 2014 and 2017. In 2017, 57% said that the government should pay for care for someone with mild dementia who lives at home and needs regular help looking after themselves, irrespective of how much money the individual has, while 40% said that who should pay should depend on how much money an individual has. These figures are similar to those reported in 2014 (55% and 42% respectively). In the case of someone with severe dementia, two-thirds (66%) thought that the government should pay for care irrespective of how much money the individual has, while 32% felt that who should pay should depend on how much money the person has. These figures are identical to those reported in 2014. In both scenarios, only 1% thought that the person themselves should pay regardless of their financial situation.

Table 4.3 Responsibility for funding care

Who should fund care for those with...	Mild dementia (%)		Severe dementia (%)	
	2014	2017	2014	2017*
Government	55	57	66	66
Individual	2	1	1	1
Depends on finances	42	40	32	32
Don't Know	1	2	1	2
<i>Unweighted base</i>	<i>1501</i>	<i>1218</i>	<i>1501</i>	<i>1218</i>
<i>Weighted base</i>	<i>1501</i>	<i>1218</i>	<i>1501</i>	<i>1218</i>

Base: All respondents aged 18+

* Does not sum to 100% due to rounding.

4.2.1 How do views on who should pay for care vary between groups?

Education, income, and level of area deprivation were all associated with people's views on who should pay for care for those with mild dementia. In particular:

- Those with no formal educational qualifications (68%) were more likely than those educated to degree-level (49%) to feel that the government should pay for the care of someone with mild dementia irrespective of their financial situation
- Those in the lower three income groups (60%-62%) were more likely than those in the highest income group (48%) to take this view
- Those living in the most deprived areas in Scotland (67%) were significantly more likely than those in the two least deprived areas (48%-52%) to feel that the government should pay for the care of someone with mild dementia irrespective of how much money they have.

In the case of those with severe dementia, gender was found to have a relationship with people's views on who should pay for care, with men (70%) more likely than women (62%) to have said that the government should pay for the care of someone with severe dementia irrespective of how much money the individual has.

Having experience of caring for someone with dementia, knowing someone with dementia, and self-reported knowledge of dementia were not related to views on who should pay for care in the case of those with either mild or severe dementia in either 2014 or 2017.

4.3 Government support

Respondents were asked:

From what you have seen or heard, how much support, if any, do you think the government gives to family members who care for a relative with dementia?

Possible answer options were:

- A great deal
- Quite a lot
- Some
- Not very much
- None at all

This question was asked for the first time in SSA 2017. As shown in Table 4.4 below, over half (54%) thought that the government provides either 'not very much' support or 'none at all' to family members who care for a relative with dementia. While 30% said that the government provides 'some' support to carers in such circumstances, just 8% said that the government provides either 'a great deal' or 'quite a lot' of support.

Table 4.4 Perceived level of support provided by government to those caring for family members with dementia

How much support, if any, do you think the government gives to family members who care for a relative with dementia?	2017 (%)*
A great deal	1
Quite a lot	6
Some	30
Not very much	47
None at all	6
Don't know	9
<i>Unweighted base</i>	<i>1218</i>
<i>Weighted base</i>	<i>1218</i>

* Does not sum to 100% due to rounding.

Base: All respondents aged 18+

4.3.1 How do views on the level of government support given to unpaid carers vary between groups?

There were some significant differences between socio-demographic groups regarding the level of support given by the government to carers. In particular:

- Those aged 40-64 (59%) and 65 and over (57%) were more likely than those aged 18-29 (42%) to believe that the government provides either 'not very much' support or 'none at all' to family members who care for a relative with dementia
- Those who reported having either 'a great deal' or 'quite a lot' of knowledge about dementia (60%) were more likely than those who knew either 'some', 'not very much' or 'nothing at all' about dementia (51%) to feel that the government provides either 'not very much' support or 'none at all'
- Those who had a family member or friend with dementia or who have dementia themselves (60%) and those whose job involved working with people with dementia (62%) were more likely than those who knew either an acquaintance, colleague or someone else (43%) or those who did not know anyone with dementia (49%) to think that the government provides either 'not very much' support or 'none at all'.

4.4 Care to be provided by family or paid carers?

SSA 2017 included two questions on who should be responsible for providing care for those with mild dementia, and for those with severe dementia.

Respondents were asked:

- Who do you think should usually provide most of the care for someone with mild dementia?
- Who do you think should usually provide most of the care for someone with severe dementia?

In both cases, the answer options were:

...the person's family and friends
Or, paid carers or nurses?

These questions were also asked in SSA 2014.

As shown in Table 4.5 below, in 2017, 58% believed that 'family and friends' should usually provide most of the care for someone with mild dementia. This figure has decreased significantly by 7 percentage points compared with 2014, when 65% felt that 'family and friends' should usually provide most of the care for someone with mild dementia. However, this decrease was not due to an increase in those who thought 'paid carers or nurses' should usually provide this care; rather it was because the proportion who said 'It depends' went up significantly (from 15% in 2014 to 21% in 2017).

In the case of those with severe dementia, the vast majority (87%) felt that 'paid carers or nurses' should provide most of the care in such a situation, while just 3% believed that this was the responsibility of 'family and friends'. These figures were similar to those found in 2014 (85% and 5% respectively).

Table 4.5 Responsibility for providing care

Who do you think should usually provide most of the care for someone with...	Mild dementia (%)		Severe dementia (%)	
	2014	2017	2014*	2017
Family and friends	65	58	5	3
Paid carers or nurses	19	21	85	87
(It depends)	15	21	10	10
Don't know	1	*	1	*
<i>Unweighted base</i>	<i>1501</i>	<i>1218</i>	<i>1501</i>	<i>1218</i>
<i>Weighted base</i>	<i>1501</i>	<i>1218</i>	<i>1501</i>	<i>1218</i>

Base: All respondents aged 18+

* Does not sum to 100% due to rounding.

4.4.1 How do views on who should provide care for someone with dementia vary between groups?

In both the case of those with mild dementia and those with severe dementia, opinion on who should provide care was seen to be relatively consistent across socio-demographic groups. The only significant relationship found was between attitudes to

who should provide care for those with mild dementia and age, with those aged 65 and over (69%) more likely than those aged 18-64 (54%-55%) to believe that most of the care for an individual with mild dementia should be provided by their family and friends.

5. Perception of people with dementia and their carers

Key findings:

- A substantial majority of people hold positive attitudes towards people with dementia and do not see it as a stigmatising condition. In particular, over 9 in 10 (91%) think someone in the early stages of dementia can lead ‘a fulfilling life’.
- A small minority of people display prejudice and fear of (people with) dementia, as well as discriminatory attitudes. In particular around 1 in 8 (13%) said they would be ‘ashamed’ if they were told by a doctor that they had the first signs of dementia.
- People who know someone or have cared for someone with dementia, those who report they are knowledgeable about dementia, younger people, women, and those with higher educational qualifications are all particularly likely to hold positive attitudes towards people with dementia.
- Stigmatising and discriminatory attitudes are more likely to be found among men, older people and those who said they do not know much about dementia.
- Overwhelmingly, people thought that those in the early stages of dementia can lead a fulfilling life with 9 in 10 (91%) thinking that people in the early stages of dementia can ‘definitely’ or ‘probably’ lead a fulfilling life. By contrast, only 1 in 5 (21%) thought that people in the later stages of dementia can lead a fulfilling life.
- There has been little change in attitudes to people with dementia and their carers in Scotland between 2014 and 2017.

This chapter examines the evidence from SSA 2017 about attitudes towards people with dementia and their carers, and whether attitudes have changed since 2014.

All respondents were presented with nine statements about people with dementia. These statements covered a wide range of issues including: their attitudes towards people with dementia; what their feelings and expectations would be if they were told they had the first signs of dementia; and their views about caring for someone with dementia. Seven of these statements were also included in SSA 2014.

It is notable that, given the policy attention to dementia (which has been discussed in Chapter 1), there is still a relatively small amount of evidence from beyond the UK

about the general public's attitudes towards dementia.¹⁷ The main exception to this is in Australia, where Alzheimer's Australia published an account in 2017 of the stigma and discrimination experienced both by people with dementia and their carers, as well as the general public's attitudes to dementia.¹⁸ This latter study suggests a lack of understanding of dementia, and concludes that 'although people in the general public are sympathetic towards people with dementia they may be unsure of how they can help'.

5.1 Attitudes towards people with dementia and towards being personally affected by dementia

Respondents were presented with four statements which captured (i) their attitudes towards people with dementia and (ii) their feelings and reactions if they had just been told by a doctor that they had the first signs of dementia. Table 5.1 below shows their responses, and compares these with the findings from SSA 2014.

Respondents were asked how much they agreed or disagreed that:

- 'I would find it hard to talk to someone with dementia.'
- 'If I had just been told by my doctor that I had the first signs of dementia I would want my family and friends to know.'
- 'If I had just been told by my doctor that I had the first signs of dementia I would feel ashamed.'
- 'If I had just been told by my doctor that I had the first signs of dementia I would not want my employer to find out.'

¹⁷ Note that in addition to the modules on both SSA and BSA, Northern Ireland has conducted studies of public attitudes to dementia on a regular basis since 2011. In addition, a summary of public attitudes to dementia in Northern Ireland, The Republic of Ireland and Scotland was published by Queens University Belfast in August 2016. See <https://pure.qub.ac.uk/portal/files/75429587/demcn.pdf>

¹⁸ Alzheimer's Australia (2017). Available at: <https://www.dementia.org.au/files/NATIONAL/documents/dementia-and-stigma-2017.pdf>

Table 5.1 Attitudes towards people with dementia and towards being personally affected by dementia

	'I would find it hard to talk to someone with dementia'		'I would want my family and friends to know'		'I would feel ashamed'		'I would not want my employer to find out'	
	(%)*		(%)*		(%)*		(%)*	
	2014	2017	2014	2017	2014	2017	2014	2017
Agree strongly / agree	19	22	83	83	12	13	39	37
Neither agree nor disagree	10	11	7	8	15	19	18	20
Disagree/ disagree strongly	69	65	7	7	70	66	39	38
Don't know	1	1	2	1	2	2	4	5
<i>Unweighted base</i>	1428	1185	1428	1185	1428	1185	1428	1185
<i>Weighted Base</i>	1433	1174	1433	1174	1433	1174	1433	1174

Base: All respondents aged 18+ who completed the self-complete

* Does not sum to 100% due to rounding.

5.1.1 'I would find it hard to talk to someone with dementia'

Respondents were asked how much they agreed or disagreed with the statement 'I would find it hard to talk to someone with dementia'. Agreeing or agreeing strongly can be viewed as a negative response, demonstrating prejudice, fear, or a lack of awareness around dementia. So, the higher the proportion who agreed with this statement, the more discrimination and stigma is being shown in relation to dementia.

Around 2 in 10 people (22%) agreed strongly or agreed that 'I would find it hard to talk to someone with dementia', with two-thirds (65%) disagreeing or disagreeing strongly and around 1 in 10 (11%) saying they neither agreed or disagreed with the statement. These findings were not significantly different to those recorded on SSA 2014.

There were significant variations between groups in SSA 2017 in relation to this statement. Gender, age, income, experience of dementia, self-assessed levels of knowledge about dementia, and experience of caring for someone with dementia were all strongly related to the extent to which people agreed that 'I would find it hard to talk to someone with dementia'. In particular:

- Men were more likely than women to agree that 'I would find it hard to talk to someone with dementia' (30% of men compared with 16% of women).
- Younger people were more likely to agree with the statement than middle-aged or older people. Almost a third (31%) of those aged 18-29 agreed that 'I would find it hard to talk to people with dementia' compared with a quarter (25%) of those aged 30-39, one in six (17%) of those aged 40-64 and one in five (22%) of those aged 65 and over.

- Those with lower incomes were more likely than those with higher incomes to agree with the statement. Almost 3 in 10 (29%) of those in the lowest income group agreed with the statement compared with around 2 in 10 (18%) of those in the highest income group.
- Those whose personal experience of dementia was limited were more likely to agree with the statement than those who had greater exposure to dementia either through their work or their personal life.
 - Around 3 in 10 (31%) of those who said they did not know anyone with dementia and a quarter (25%) of those who only knew a colleague or acquaintance with dementia agreed with the statement.
 - The proportions agreeing with the statement were substantially lower for those who said they know a family member or friend with dementia, or who have dementia themselves (19%) or whose job involved working with people with dementia (12%). This concurs with earlier research (Ormston et al 2011) which suggests that those who know people with particular characteristics often hold less discriminatory views about people with those characteristics.
- Around twice as many people (29%) who said they know ‘not very much’ or ‘nothing at all’ about dementia agreed with the statement compared with those who said they know ‘a great deal’ or ‘quite a lot’ about dementia (14%).
- In addition, those who have never cared for anyone with dementia were more likely than those who had to agree that ‘I would find it hard to talk to someone with dementia’. Just 1 in 7 (14%) who had cared for someone with dementia on a regular basis agreed with this statement compared with over a quarter (27%) of those who have never had a caring responsibility.

5.1.2 ‘If I had just been told I had the first signs of dementia I would feel ashamed’

This is a strong statement about the degree of stigma that people feel in relation to dementia. Overall, approximately 1 in 8 people (13%) agreed strongly or agreed that ‘if I had just been told I had the first signs of dementia I would feel ashamed’ (see Table 5.1 above). Two-thirds of people (66%) disagreed that they would ‘feel ashamed’ and a further 19% said they neither agreed nor disagreed. The response to this statement has not changed significantly since SSA 2014.

The proportions who said they would feel ashamed did not vary by socio-demographics, whether people know someone with dementia, or their self-assessed knowledge in 2017. This is in contrast to SSA 2014 when there were pronounced differences by gender and age.¹⁹

¹⁹ In SSA 2014 women were twice as likely as men to agree they would feel ashamed (16% compared with 8%); and young people were considerably more likely to feel ashamed than older people. These differences have not been repeated in SSA 2017.

5.1.3 'If I had just been told I had the first signs of dementia I would want my family and friends to know'

A substantial majority of people (83%) said that they would 'want their family and friends to know' if they had just been told they had the first signs of dementia. Indeed, almost half (48%) said they 'agreed strongly' that they would want their family and friends to know. Given the usually low use of extreme points in a 5-point agree-disagree scale, this is a strong endorsement of people's desire to share this information. By contrast, just 7% of people said they 'disagreed' or 'disagreed strongly' with this statement. These figures are virtually identical to those reported in SSA 2014.

Given the strong consensus on this question, it is not surprising that there was little variation in the responses between groups across socio-demographic groups, levels of experience, and levels of knowledge of dementia. Marginally significant differences were found by age however the pattern of these differences was not clear.

5.1.4 'If I had just been told I had the first signs of dementia I would not want my employer to find out'

In contrast to the high proportion of people who would want their family to know if they had the first signs of dementia, a much lower proportion would want their employer to find out. Less than 2 in 5 (38%) disagreed that 'If I had just been told I had the first signs of dementia I would not want my employer to find out', with a similar proportion (37%) saying they agreed and 1 in 5 (20%) that they 'neither agreed nor disagreed' (see Table 5.1 above). These responses were similar to those recorded on SSA 2014.

On the whole, responses to this statement did not vary between groups with one exception, age. Younger people appeared to be less concerned about their employer knowing that they had dementia with around 3 in 10 (28%) of those in the youngest age group (18-29) agreeing that they would not want their employer to find out if they had dementia compared with 4 in 10 (40%) of those aged 30 and over.

5.2 Quality of life for people with dementia

Respondents were presented with two statements which captured their views about whether people at differing stages of dementia can lead a fulfilling life (see Table 5.2 below). These questions were asked for the first time in SSA 2017 so there is no comparable data from 2014.

Respondents were asked:

- 'Would you say that people in the **early stages** of dementia can or cannot lead a fulfilling life?'
- 'Would you say that people in the **later stages** of dementia can or cannot lead a fulfilling life?'

The answer options were:

- Definitely can
- Probably can
- Probably cannot
- Definitely cannot

Overwhelmingly, people thought that those in the early stages of dementia can lead a fulfilling life. Four in ten (40%) said that people in the early stages of dementia 'definitely can' lead a fulfilling life, and a further half (51%) that they 'probably can'. This means that overall 9 in 10 (91%) thought people in the early stages of dementia can lead a fulfilling life.

By contrast, only 1 in 5 (21%) thought that people in the later stages of dementia 'definitely can' or 'probably can' lead a fulfilling life, with only 2% saying that they 'definitely can'. Three-quarters (76%) thought that people in the later stages of dementia 'probably cannot' or 'definitely cannot' lead a fulfilling life.

Table 5.2 Whether someone with dementia can or cannot leading a fulfilling life

Would you say that, in general, people in the early/late stages of dementia can or cannot lead a fulfilling life?	Early stages (%)	Later stages (%)
Definitely can	40	2
Probably can	51	18
Probably cannot	6	45
Definitely cannot	1	32
Don't know	2	3
<i>Unweighted base</i>	<i>1218</i>	<i>1218</i>
<i>Weighted base</i>	<i>1218</i>	<i>1218</i>

Base: All respondents aged 18+

5.2.1 How do views on whether people with dementia can lead a fulfilling life vary between groups?

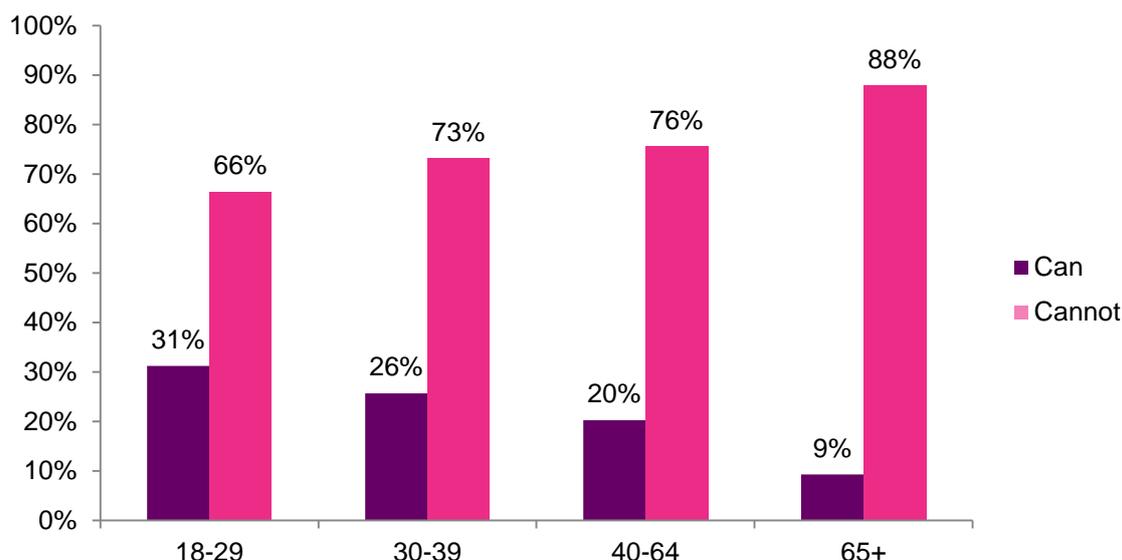
Notwithstanding the strong consensus that people in the early stages of dementia can lead a fulfilling life, two factors – education and self-reported knowledge of dementia – showed variations between groups in the extent to which they supported this statement. In particular:

- Those with higher educational qualifications (educated to degree level and/or Highers or A-levels) were more likely (95%) than those with Standard Grades or GCSEs (88%), or no educational qualifications (82%) to think that people in the early stages of dementia can lead a fulfilling life.
- Those who said they knew ‘a great deal’ or ‘quite a lot’ were more likely to think that people in the early stages of dementia can lead a fulfilling life (95%) compared with those who said they knew ‘not very much’ or ‘nothing at all’ (86%).

There were also clear relationships between agreeing that people in the later stages of dementia can lead a fulfilling life and gender, age, educational qualifications and self-assessed levels of knowledge. In particular:

- Women were more likely than men to think that people in the later stages of dementia can lead a fulfilling life (24% of women compared with 17% of men).
- There was a clear relationship with age, with the youngest age group having the most optimistic perspective and the oldest age group having the most pessimistic perspective. Over 3 in 10 (31%) of those aged 18-29 thought that people in the later stages of dementia can lead a fulfilling life, compared with a quarter (26%) of those aged 30-39, 2 in 10 (20%) of those aged 40-64, and just 1 in 10 (9%) of those aged 65 and over (see Figure 5.1 below).

Figure 5.1 Attitudes towards whether those in the later stages of dementia can lead a fulfilling life by age



Base: All respondents aged 18+

- Those educated to degree-level were the most likely to believe that people in the later stages of dementia can lead a fulfilling life (29%) compared with 18% of those with Highers or A-levels, 14% of those with Standard Grades or GCSEs and 13% of those with no educational qualifications.
- Around a quarter (26%) who said they knew 'a great deal' or 'quite a lot' about dementia said that people in the later stages of dementia can lead a fulfilling life, compared with 21% of those who said they knew 'some' and 16% of those who said they knew 'not very much' or 'nothing at all' .

5.3 Attitudes to caring for people with dementia

Table 5.3 below shows the levels of agreement with three statements on attitudes to caring for people with dementia. Agreeing with the first and third of these statements (that caring can be lonely and that caring often means your own health suffers) would represent an acknowledgement of the negative issues that can face carers. Agreement with the second statement (caring is often very rewarding) would show that people also see the caring role in a positive light.

Respondents were asked how much they agreed or disagreed that:

- 'Caring for someone with dementia is often very lonely.'
- 'Caring for someone with dementia is often very rewarding.'
- 'Caring for someone with dementia often means your own health suffers.'

Table 5.3 Attitudes to caring for people with dementia

Caring for someone with dementia is...	...often very lonely (%)		... often very rewarding (%)		...often means your own health suffers (%)	
	2014	2017	2014	2017*	2014	2017
Agree strongly/ agree	82	81	57	50	77	76
Neither agree nor disagree	11	9	21	23	12	11
Disagree/ disagree strongly	6	8	20	24	10	12
Don't know	1	2	2	2	1	1
<i>Unweighted base</i>	<i>1501</i>	<i>1218</i>	<i>1501</i>	<i>1218</i>	<i>1501</i>	<i>1218</i>
<i>Weighted base</i>	<i>1501</i>	<i>1218</i>	<i>1501</i>	<i>1218</i>	<i>1501</i>	<i>1218</i>

Base: All respondents aged 18+

* Does not sum to 100% due to rounding.

5.3.1 'Caring for someone with dementia is often very lonely'

Around 8 in 10 (81%) said they 'agreed strongly' or 'agreed' that 'caring for someone with dementia is often very lonely', a similar level to the 82% who agreed with this statement in SSA 2014.

There was a clear difference by age, with younger people holding less pessimistic views than older people. Around 7 in 10 (71%) of those aged 18-29 agreed that 'caring for someone with dementia is often very lonely' compared with almost 9 in 10 (87%) of those aged 65 and over.

No other differences were found between groups based on socio-demographic, experience, caring or knowledge-related factors.

5.3.2 'Caring for someone with dementia is often very rewarding'

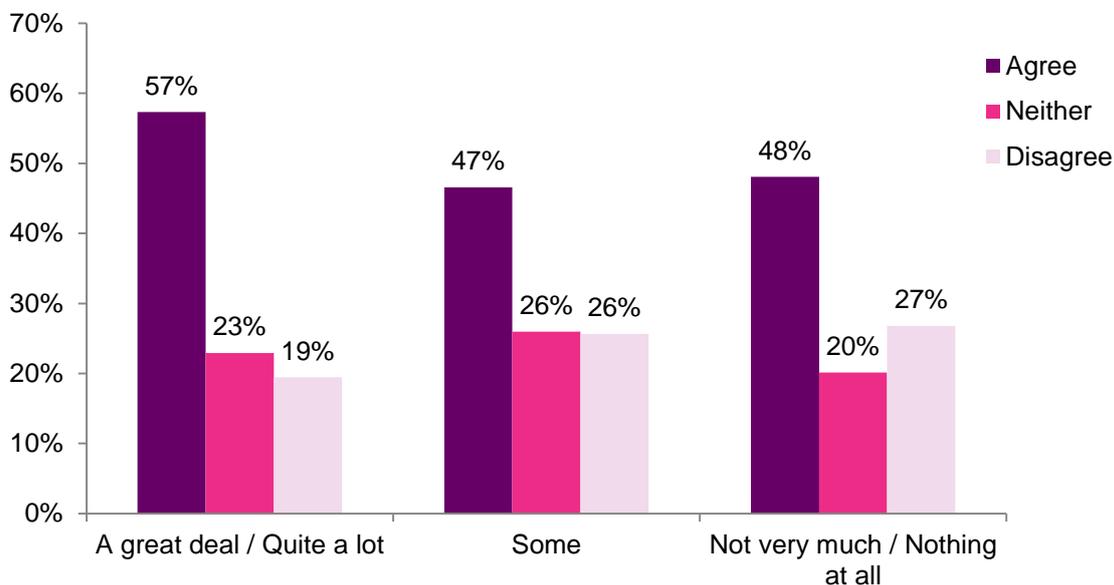
Half (50%) said they 'agreed strongly' or 'agreed' that 'caring for someone with dementia is often very rewarding'. This is a significantly lower figure than the 57% who agreed with this statement in SSA 2014.

The proportions who agreed that 'caring for someone with dementia is often very rewarding' varied by gender, age and self-reported knowledge. Specifically:

- Women were more likely than men to agree that 'caring for someone with dementia is often very rewarding' (54% compared with 47%).
- Younger people were more likely to agree with this statement than older people. Six in 10 (60%) of those aged 18-29 agreed with this statement compared with only around 4 in 10 (42%) of those aged 65 and over.
- Around 6 in 10 (57%) of those who said they knew 'a great deal' or 'quite a lot' about dementia agreed that 'caring for someone with dementia is often very

rewarding' compared with around 5 in 10 of those who said they knew 'some' (47%) or 'not very much / nothing at all' (48%) about dementia. (See Figure 5.2 below).

Figure 5.2 Attitudes towards whether 'caring for someone with dementia is often very rewarding' by self-assessed knowledge of dementia



Base: All respondents aged 18+

5.3.3 'Caring for someone with dementia often means your own health suffers'

Around three-quarters (76%) said they 'agreed strongly' or 'agreed' that 'caring for someone with dementia often means your own health suffers'. This shows that there is a widespread perception that there are detrimental consequences of caring. The level of agreement with this statement is unchanged since SSA 2014 (76%).

There were significant differences by gender and age:

- Women were more likely than men to agree that 'caring for someone with dementia often means your own health suffers' (80% of women compared with 73% of men). This is identical to the pattern in SSA 2014.
- The proportion who said they agreed with this statement rose steadily with age from under two-thirds of those aged 18-29 (64%) to 85% of those aged 65 and over. While the pattern with age is similar to that found in SSA 2014, the gradient is not as steep in 2017 as it was in 2014 when 55% of 18-29 year-olds agreed with the statement compared with 87% of those aged 65 and over.

6. Sources of support and information

Key findings:

- If someone close to you is showing the early signs of dementia, 35% said they would talk to a family member or friend in the first instance, while 31% said they would talk to the person themselves about the best thing to do and 23% said they would talk to a doctor or nurse.
- Those educated to degree-level and those in the highest income group were considerably more likely to talk to the person themselves about the best thing to do than those with no educational qualifications and those in the lowest income group.
- Over two-thirds (68%) said they would seek help from a partner or family member if they, themselves, believed they had the early signs of dementia.
- If diagnosed with the first signs of dementia, 3 in 5 (60%) believed that they would find meeting with a specialist doctor useful and around a half (54%) said they would find talking with a dementia counsellor useful.

Previous chapters have examined people's experiences of, and a range of attitudes towards, dementia. This chapter explores how people would respond if they were concerned if either they, or a family member or friend, were showing early signs of dementia. The chapter summarises findings from SSA 2017, and examines whether or not views have changed since 2014.

6.1 Sources of help for a family member or friend showing the early signs of dementia

Respondents were asked:

'If someone close to you was becoming forgetful or distressed in a way that made you think they might be showing early signs of dementia, which of the following would you do in the first instance?'

The answer options were:

- Talk to the person themselves about the best thing to do
- Talk to a family member or friend
- Talk to a doctor or nurse
- Phone a helpline
- Contact a charity or support group
- Search the internet
- Do nothing
- Other

This question was also asked in SSA 2014.

Table 6.1 below shows people's responses from SSA 2014 and SSA 2017. In 2017, around a third of people (35%) said they would 'talk to a family member or friend' in the first instance, 31% said they would 'talk to the person themselves about the best thing to do' and 5% would 'search the internet'. Around a quarter (23%) said they would 'talk to a doctor or nurse', 3% said they would 'phone a helpline', 1% would 'contact a charity or support group' and less than 1% would 'do nothing'.

There were no significant differences between 2014 and 2017 in the action people would take in the first instance if they were concerned that someone close to them might be showing early signs of dementia.

Table 6.1 What help would be sought if someone close to you showed the early signs of dementia

If someone close to you was becoming forgetful or distressed in a way that made you think they might be showing early signs of dementia, which of the following would you do in the first instance?	2014 (%)	2017 (%)*
Talk to a family member or friend	39	35
Talk to the person themselves about the best thing to do	30	31
Talk to a doctor or nurse	23	23
Search the internet	4	5
Phone a helpline	2	3
Contact a charity or support group (e.g. Alzheimer Scotland)	1	1
Do nothing	1	*
Other	*	*
Don't know / refused	*	1
<i>Unweighted base</i>	<i>1501</i>	<i>1218</i>
<i>Weighted base</i>	<i>1501</i>	<i>1218</i>

Base: All respondents aged 18+

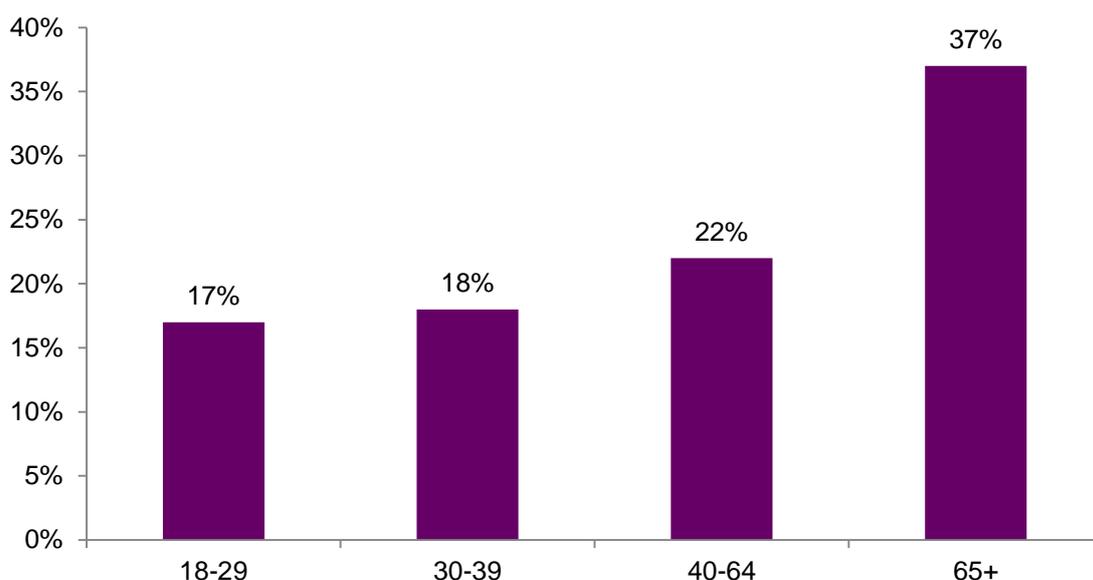
* Does not sum to 100% due to rounding.

6.1.1 How does help-seeking behaviour vary between groups?

There were significant differences in the types of help sought, by a range of socio-demographic factors, as well as by people's experiences of knowing someone with dementia. In particular:

- Men were more likely than women to say they would 'search the internet' (8% and 3% respectively); there was no gender difference by any other source of help.
- People aged 65 and over were the most likely to say they would 'talk to a doctor or nurse' in the first instance (37% compared with 17% of people aged 18-29). (See Figure 6.1 below).

Figure 6.1 Would ‘talk to a doctor or nurse’ if someone close to them might be showing early signs of dementia by age



Base: All respondents aged 18+

- Those educated to degree-level were more than twice as likely as those with no educational qualifications to ‘talk to the person themselves about the best thing to do’ in the first instance (39% and 18% respectively). Conversely, those with no educational qualifications (34%) were much more likely than people educated to degree-level (14%) to ‘talk to a doctor or nurse’ if they had concerns that someone close to them might be showing the early signs of dementia.
- The same pattern was evident for the relationship between sources of help and income. People in the highest income group were much more likely than those in the lowest income group to say they would ‘talk to the person themselves about the best thing to do’ (40% and 26% respectively) while those in the lowest income group were more likely than those in the highest to ‘talk to a doctor or nurse’ (31% and 15% respectively).
- Those living in urban areas were more likely than those in rural areas to ‘talk to the person themselves about the best thing to do’ (33% compared with 25% respectively). Conversely those in rural areas were more likely to ‘talk to a doctor or nurse’ (29% compared with 22% of those living in urban areas).
- Those with an acquaintance or colleague with dementia were the most likely to ‘talk to a family member or friend’ in the first instance (40%), whilst those whose job involved working with someone with dementia were the least likely to say they would ‘talk to a family member or friend’ (19%).

6.2 Sources of help for oneself on showing the early signs of dementia

Respondents were asked:

‘Imagine you kept forgetting the name of someone close to you, and you thought it might be the early signs of dementia. Please say which of the following, if any, you would talk to or seek help from’.

Possible answer options were:

- A partner or family member
- A friend
- A charity or support group
- A doctor or nurse
- A social worker
- A helpline
- The internet
- Other

This question was also asked in SSA 2014.

Table 6.2 below shows the range of response options and the proportion that chose each option. Respondents could choose as many answer options as were relevant. Respondents selected an average of 1.8 responses to this question.

Over two-thirds (68%) said they would seek help from ‘a partner or family member’ if they thought they had the early signs of dementia, while 63% would speak to ‘a doctor or nurse’. Around a quarter (26%) said they would talk to ‘a friend’, nearly 1 in 5 (18%) would ‘seek help from the internet’ and around 1 in 10 (9%) would reach out to ‘a charity or support group’ or ‘a helpline’ (10%). Just 4% said they would seek help from ‘a social worker’.

There were no significant differences between the sources of help people would use if they were concerned they were showing the early signs of dementia between 2014 and 2017.

Table 6.2 Sources of help someone would seek if they thought they might have the early signs of dementia

Imagine you kept forgetting the name of someone close to you, and you thought it might be the early signs of dementia. Please say which of the following, if any, you would talk to or seek help from.	2014 (%) [†]	2017 (%) [†]
A partner or family member	67	68
A doctor or nurse	61	63
A friend	29	26
The internet	21	18
A charity or support group (e.g. Alzheimer Scotland)	12	9
A helpline	7	10
A social worker	2	4
Not sure	2	*
None of these	1	*
Other (Please write in)	*	*
(Can't choose)	2	1
<i>Unweighted base</i>	1428	1169
<i>Weighted base</i>	1433	1174

Base: All respondents aged 18+ who completed the self-complete

[†]Percentages do not sum to 100% as the question was a multi-code response

6.2.1 Differences in the sources of help for oneself on showing the early signs of dementia between groups

There was variation in the types of help sought for oneself by a range of factors, in particular, by age, education, income, area deprivation and whether or not they knew someone with dementia.

Over two thirds (68%) of women said they would talk to a doctor or nurse compared with 57% of men. No other types of help varied significantly by gender.

Younger people were more likely than older people to say they would talk to a partner or family member, a friend, a charity or support group, or seek help on the internet. For example, younger people were significantly more likely than older people to seek help from a charity or support group (16% of those aged 18-29 compared with 3% of those aged 65 and over). Unlike SSA 2014, there was no significant difference by age in the proportion who would talk to a doctor or nurse.

Those with higher levels of education were more likely to say they would talk to a partner or family member, a friend, a doctor or nurse, a charity or support group, or seek help on the internet, than those with lower levels of education. This difference

was particularly notable with regard to looking for information on the internet, where 28% of those educated to degree-level said they would do this, compared with 5% of people with no educational qualifications.

People in the highest income group were more likely than those on lower incomes to say they would talk to a partner or friend, contact a charity or support group, or seek help on the internet. As with differences by level of education, this difference was most notable in seeking help on the internet, with around one third (30%) in the highest income group saying they would look for help on the internet, compared with around 1 in 8 (13%) of those in the lowest income group.

A quarter (25%) of those living in the least deprived areas said they would seek help for themselves on the internet, compared with 1 in 10 (10%) of those living in the most deprived areas. Those living in urban areas were marginally more likely than those living in rural areas to seek help from a partner or family member if they thought they were showing the early signs of dementia (70% compared with 61% respectively).

People who reported that their job involved working with people with dementia were, interestingly, the least likely to say they would talk to a partner or family member if they were concerned they were showing the early signs of dementia (58% compared with 71% of people who reported that a family member, close friend, or they themselves had dementia). The opposite was true for talking to a doctor or nurse; over three quarters (76%) of people who reported that their job involved working with people with dementia reported they would seek help from a doctor or nurse compared with half (50%) of those who did not know anyone with dementia.

Using the internet for help was most likely amongst those who had an acquaintance or colleague with dementia (24% compared with 4% of people whose job involved working with people with dementia). Those with a family member or friend with dementia, or who had dementia themselves were the most likely to seek help from a charity or support group (13% compared with 4% of those with an acquaintance or colleague with dementia).

As in SSA 2014, types of help sought for oneself did not vary greatly by whether people had experience of caring for someone with dementia. The only exceptions were that those who had provided care for someone with dementia or who had helped someone with dementia were more likely to talk to a doctor or nurse (72% and 70% respectively) compared with those who had been responsible for arranging care for someone with dementia (56%) and those who had never cared for someone with dementia (58%).

6.3 Type of help one would find useful if diagnosed with the early signs of dementia

Respondents were asked:

‘Say you had just been told by your doctor that you had the first signs of dementia. Leaving aside family and friends, which, if any, of the following do you think would be useful to you?’

Possible answer options were:

- Using an online forum to talk to other people who have recently been told that they have dementia
- Receiving an information pack about dementia
- Meeting with other people who have recently been told that they have dementia
- Searching for information about dementia on the internet
- Speaking with a support worker about help available in your local area
- Meeting with a specialist doctor
- Talking one-to-one with a dementia counsellor over several sessions
- None of these

This question was asked for the first time in SSA 2017.

Respondents were allowed to select as many answer options as they felt were relevant. People selected an average of 2.7 responses.

Table 6.3 below shows that 3 in 5 (60%) would find ‘meeting with a specialist doctor’ useful, over half (54%) would find ‘talking one-to-one with a dementia counsellor over several sessions’ useful, and almost half (47%) would find ‘speaking with a support worker about help available in your local area’ useful. A further 42% said they would find it useful to receive an information pack about dementia, with 41% saying that it would be useful to meet ‘with other people who have recently been told that they have dementia’, and around a third (31%) that they would find ‘searching for information about dementia on the internet’ useful. One in five (20%) would find it useful to use ‘an online forum to talk to other people who have recently been told that they have dementia’ and just 1% said ‘none of these’ would be useful.

Table 6.3 Type of help someone would find useful if they had been told by their doctor they had the first signs of dementia

Say you had just been told by your doctor that you had the first signs of dementia. Leaving aside family and friends, which, if any, of the following do you think would be useful to you?	2017 (%) [†]
Meeting with a specialist doctor	60
Talking one-to-one with a dementia counsellor over several sessions	54
Speaking with a support worker about help available in your local area	47
Receiving an information pack about dementia	42
Meeting with other people who have recently been told that they have dementia	41
Searching for information about dementia on the internet	31
Using an online forum to talk to other people who have recently been told that they have dementia	20
None of these	1
Don't know/Refused	1
<i>Unweighted base</i>	1169
<i>Weighted base</i>	1174

Base: All respondents aged 18+ who completed the self-complete

[†]Percentages do not sum to 100% as the question was a multi-code response.

Average number of responses given= 2.7

6.3.1 Differences in the type of help one would find useful between groups

There were differences in the type of help people would find useful by a wide range of socio-economic factors. In particular:

- Around half (47%) of women said they would find ‘meeting with other people who had recently been told they have dementia’ useful compared with around a third of men (35%).
- Younger people were more likely than older people to say ‘using an online forum to talk to other people who had recently been told they have dementia’ would be useful (27% of those aged 18 to 29 compared with 9% of those aged 65 and over).
- Those aged 30-39 were the most likely to say that ‘talking one-to-one with a dementia counsellor over several sessions’ would be useful (59% compared with 46% of those aged 65 and over).
- Those educated to degree-level were significantly more likely than those with no educational qualifications to report finding all the different types of help listed useful in the event of a dementia diagnosis. This difference was most notable amongst those who reported that they would find ‘searching for information about dementia on the internet’ useful. Those educated to degree-level or with Highers

or A-levels were twice as likely as those with no educational qualifications to report that they would find searching for information on the internet useful (40% of those educated to degree-level, 38% of those with Highers or equivalent and 15% of those with no formal qualifications).

- As with education, there were significant differences between those in the highest and lowest income groups across almost all sources of information - the most notable difference being the usefulness of 'searching for information about dementia on the internet' (49% of those in the highest income group said that searching for information on the internet would be useful compared with 22% of those in the lowest income group).
- Around 3 in 5 (62%) of those who live in the least deprived areas said they would find 'talking one-to-one with a dementia counsellor over several sessions' useful, compared with less than half (47%) of those living in the most deprived areas.
- Those who had a family member or close friend with dementia, or had dementia themselves were more likely to say they would find 'talking one-to-one with a dementia counsellor' useful (60% compared with 46% of people who did not know anyone with dementia).
- People who had been responsible for arranging care for someone with dementia were more likely to find 'speaking with a support worker about help available in their local area' useful, than those who knew someone with dementia but who had not provided any care (66% compared with 46% respectively).

7. Rights of people with dementia to lead a fulfilling life

Key findings

- The majority of people (77%) felt that children have a responsibility to visit a parent with dementia.
- There is a broad consensus that those with severe dementia who receive residential care benefit from visits from their family.
- The vast majority (85%) felt that arrangements should be made for volunteers to visit those with dementia who do not receive visits from their family, while two-thirds also felt that such visits should be funded by the council.
- The majority of people believed that certain activities have the potential to positively impact upon the quality of life for a person with dementia and that those providing residential care should be expected to make it possible for people to participate in such activities.

In 2017, SSA asked a series of new questions examining public attitudes towards the value of having visitors for someone with dementia, who is responsible for making this happen, the rights of those with dementia to undertake activities which may impact on their quality of life, and the responsibility of others to facilitate this. These questions took the form of scenarios, allowing for a range of different factors to be introduced and for the context to be described. These questions were asked in the self-completion section of the questionnaire in order to reduce the possibility of people responding in a way that they think is socially acceptable, so called 'social desirability' effects.

7.1 Visits from family members

Respondents were first asked to read the following scenario which described someone with dementia named Stuart and a child of his. Respondents either read a version of the scenario which included Stuart's son (Mark) or his daughter (Mary), in order to examine any potential impact that the gender of Stuart's child may have on people's responses.

Stuart lives in a care home and has quite severe dementia. He does not always remember his relatives. He has a son Mark/daughter Mary who works as a lawyer and lives with his / her family 50 miles away.

Respondents were asked:

- ‘How much do you agree or disagree that [Mark/Mary] should feel a responsibility to visit [his/her] father?’
- ‘How much do you agree or disagree that Stuart would benefit from his [son/daughter] visiting him?’

These questions were asked for the first time in SSA 2017.

Table 7.1 below shows that in total, 77% agreed that the child in the scenario should feel a responsibility to visit their father, with no significant differences identified between attitudes towards whether Mark should feel a responsibility to visit his father and whether Mary should feel the same obligation.

Table 7.1 Responsibility of children to visit their parent with dementia in a care home

Do you agree or disagree that Mark/Mary should feel a responsibility to visit his/her father?	Mark (%)*	Mary (%)	Combined (%)
Agree strongly/ agree	78	76	77
Neither agree nor disagree	17	16	16
Disagree/ disagree strongly	4	6	5
Don't know/Refused	2	2	2
<i>Unweighted base</i>	<i>590</i>	<i>579</i>	<i>1169</i>
<i>Weighted base</i>	<i>590</i>	<i>584</i>	<i>1174</i>

Base: All respondents aged 18+ who completed the self-complete

* Does not sum to 100% due to rounding.

There were, however, a number of significant differences identified between groups as to whether a child should feel a responsibility to visit their father with dementia in the care home. When answers to both the ‘Mark’ and ‘Mary’ versions of the question were combined, men (80%) were more likely than women (74%) to say that Stuart’s child should feel a responsibility to visit him. Older people were more likely than younger people to agree that a child should feel a responsibility to visit their father (84% of those aged 65 and over compared with 71% of those aged 18-29). In addition, those who had either a family member or close friend with dementia, or who had dementia themselves (81%) were more likely than those whose job involved working with people with dementia (65%) to agree that Stuart’s child should feel a responsibility to visit him.

Around 4 in 5 (81%) also agreed that Stuart would benefit from a visit from his child (see Table 7.2 below). Once again no significant differences were identified between attitudes towards whether Stuart would benefit from a visit from his son and whether he would benefit from a visit from his daughter.

Table 7.2 Views on whether it is beneficial for someone with dementia to have their son/daughter visit

Do you agree or disagree that Stuart would benefit from his son/daughter visiting him?	Mark (%) [*]	Mary (%) [*]	Combined (%)
Agree strongly/ agree	80	81	81
Neither agree nor disagree	13	11	12
Disagree / disagree strongly	4	4	4
Don't know/Refused	2	3	3
<i>Unweighted base</i>	<i>590</i>	<i>579</i>	<i>1169</i>
<i>Weighted base</i>	<i>590</i>	<i>584</i>	<i>1174</i>

Base: All respondents aged 18+ who completed the self-complete

* Does not sum to 100% due to rounding.

There were differences in attitudes towards whether Stuart would benefit from a visit from his child by education. Those educated to degree-level (85%) and those with Highers or A-levels (83%) were both more likely than those with Standard Grades or GCSEs (74%), or those with no educational qualifications (75%) to agree that Stuart would benefit from his son or daughter visiting him. Taken together, these findings suggest that a majority of people feel that children have a responsibility to visit a parent who has dementia, and recognise that the parent is likely to benefit from such visits.

7.2 Right to have visitors

The above findings suggest that people recognise some beneficial effects of a visit from your children for those with dementia, but how far does the public feel that the right of someone with dementia to have visits extend? And to what extent should those in a position of responsibility ensure that such visits occur?

Respondents were asked:

- 'How much you agree, or disagree that Stuart should usually be able to have visitors if he wants to?'
- 'Say that Mark/Mary can't visit his father regularly, how much do you agree, or disagree that arrangements should be made for a volunteer to visit Stuart?'
- 'Say that [Mark/Mary] can't visit [his/her] father, how much do you agree or disagree that the council should provide funding for a volunteer to visit Stuart?'

Table 7.3 below shows that an overwhelming majority (93%) agreed that ‘Stuart should usually be able to have visitors if he wants to’, with nearly 3 in 5 (59%) saying that they strongly agreed. Over 8 in 10 (84%) also agreed that, should Stuart’s child be unable to visit regularly, ‘arrangements should be made for a volunteer to visit Stuart’, although a considerably smaller proportion strongly agreed with this (35%) compared with the proportion who strongly agreed that Stuart should have visitors if he wants to.

The third question on the right of Stuart to have visitors, explored the impact of the financial consequences of Stuart having a volunteer to visit. Two-thirds (66%) agreed that if Stuart’s child was not able to visit, that ‘the council should provide funding for a volunteer to visit Stuart’, with only 11% disagreeing with this statement. While this still represents a clear majority, it appears that people are less willing to support the rights of those with dementia to have visitors if this is associated with a cost to the taxpayer.

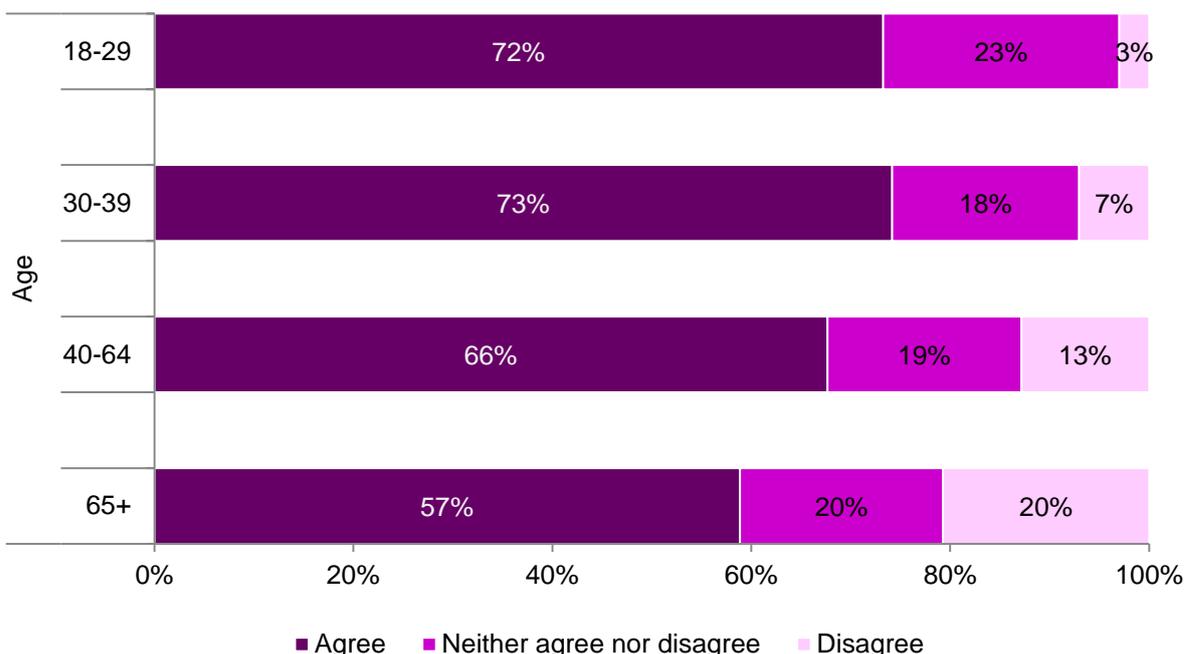
Table 7.3 Views on whether people with dementia have the right to visitors

How much do you agree or disagree...	...Stuart should usually be able to have visitors if he wants to? (%)	...arrangements should be made for a volunteer to visit Stuart? (%)	...the council should provide funding for a volunteer to visit Stuart? (%)
Agree strongly/ agree	93	84	66
Neither agree nor disagree	5	11	20
Disagree/ disagree strongly	1	3	11
Don't know/Refused	1	2	3
<i>Unweighted base</i>	<i>1169</i>	<i>1169</i>	<i>1169</i>
<i>Weighted Base</i>	<i>1174</i>	<i>1174</i>	<i>1174</i>

Base: All respondents aged 18+ who completed the self-complete

Figure 7.1 below shows that there were significant differences by age, with younger people more likely than older people to agree that the council should provide funding for a volunteer: nearly three-quarters of those aged 18-29 (72%) and those aged 30-39 (73%) agreed compared with less than 3 in 5 (57%) of those aged 65 and over. This contrasts with the questions on the right of Stuart to have visitors which did not refer to a financial cost, where the level of agreement was consistent across the population.

Figure 7.1 Attitudes to whether the council should provide funding for a volunteer to visit Stuart by age



Base: All respondents aged 18+ who completed the self-complete

7.3 Right to lead a fulfilling life

SSA 2017 also included questions designed to explore public attitudes towards the right of those with dementia to do activities which may improve their quality of life. These questions were based on the same scenario as described above, but with additional information added about Stuart. The new information provided to respondents about Stuart is provided in the box below.

Stuart used to be a gardener and loves being outdoors. Now that he is in a care home he only goes outside for five minutes twice a week, because there are not enough staff to take him outside more often. Stuart likes sitting near the window so that he can look out at the garden.

Respondents were then asked the following questions:

- 'How much do you agree, or disagree that Stuart would benefit from spending more time in the garden?'
- 'What if Stuart says he wants to go out into the garden more often than twice a week. How much do you agree or disagree that the care home should make sure that Stuart is taken out into the garden more often?'
- 'How much do you agree or disagree that the care home should be expected to make it possible for Stuart to do some gardening?'

An overwhelming majority (93%) of people felt that Stuart would benefit from spending more time in the garden, with well over half (57%) saying that they agreed strongly. Similarly, 95% agreed that the care home should ensure that Stuart is taken out into the garden more often than twice a week.

The only significant difference was seen by age, with those aged 18-29 less likely to agree that Stuart would benefit from spending more time in the garden than those aged 40 or over (87% and 95% respectively). There were no significant differences between groups as to whether the care home should make sure that Stuart is taken out into the garden more often.

A large majority also agreed (84%) that 'the care home should be expected to make it possible for Stuart to do some gardening'. No significant differences were observed between socio-demographic groups; however those whose job involved working with people with dementia (99%) were more likely than those who did not know anyone with dementia (92%) to say that the care home should be expected to ensure that Stuart is able to do some gardening.

The findings discussed above paint a relatively consistent picture of public attitudes towards the rights of those with dementia and the responsibilities of others that may stem from these rights. Broadly, they suggest not only that people think that certain activities have the potential to positively impact upon the quality of life of a person with dementia (such as, receiving visits, being taken into the garden, and actively participating in a task such as gardening), but that carers and close relatives have a responsibility to try to facilitate such activities. Further, while there are a number of instances in which significant differences of opinion appear to exist between groups in society, these differences are often seen to be far from large, and in most cases these views are adopted relatively uniformly across society.

8. Conclusions

Based on the analysis of both SSA 2017 and SSA 2014, this chapter sets out our main conclusions in relation to the Scottish public's understanding of, and attitudes towards, dementia and how these have changed over time. The conclusions focus on areas of key importance to public policy on dementia namely: the priority for funding that the public gives to dementia; views on the rights of people with dementia to access funding and support; the extent of the government's responsibility for funding care and treatment of people with dementia; public awareness of the symptoms and risk factors for dementia; the extent of any stigma associated with dementia and the rights, and ability, of those with dementia to lead fulfilling lives.²⁰

There is a significant majority of people in Scotland who have contact with people with dementia, and in some aspects there are high levels of knowledge about dementia. Around three-quarters of people in Scotland knew (or had known) someone with dementia, around a third had a partner or family member with dementia, and 1 in 6 had experience of dementia through their work (these figures have not changed since 2014). In addition, around a half of people in Scotland have cared for someone with dementia in some form, ranging from visiting someone every now and then to caring for someone that lives with them.

Given that there is no known cure for dementia, public policy is fundamentally concerned with increasing public awareness of the symptoms of dementia, so that an early diagnosis with appropriate support can be implemented at the earliest opportunity, as well as educating people about the risk factors for developing dementia. SSA 2017 showed that there is widespread awareness of some of the well-established symptoms of dementia. For example, 9 in 10 knew that 'difficulty in recognising people' is a symptom and around 8 in 10 that 'losing track of time' or 'feeling lost in new places' are symptoms. However, there is substantially less knowledge in relation to some other symptoms, such as 'losing your temper easily' and 'feeling extremely tired'. Moreover, there was limited awareness that specific sensory changes (e.g. changes to taste or smell, increased sensitivity to noise) could be associated with dementia. There is, therefore, scope to improve people's knowledge of the potential symptoms which in turn could support the early identification of dementia.

Knowledge of risk factors and protective factors among the public has significantly increased between 2014 and 2017 by between 5 and 10 percentage points. However, for four of the five risk factors and protective factors (high blood pressure, genetic factors, smoking and eating a healthy diet), less than half of people in Scotland correctly identified them as risk factors for dementia with only around a quarter being aware that having high blood pressure 'increases your chance of getting dementia'.

²⁰ Note that given that the Scottish Social Attitudes survey selects its respondents using a random probability sample, the findings from the survey are representative of the views of the people of Scotland. (See separate Technical Report for details – publication date to be confirmed.)

Substantial proportions in 2017, therefore, still misidentified risk factors and protective factors, or said they 'don't know' or are 'not sure' about their impacts.

The majority, around 6 in 10, did believe that there are things they could do to decrease their risk of getting dementia, but around 1 in 5 were 'not sure' and around a quarter thought that there were not. This shows that there is a substantial proportion of the public who are not yet aware of the preventive actions they could be taking to reduce their risks of getting dementia.

Those with higher educational qualifications, higher incomes, and higher levels of self-reported knowledge about dementia were more likely to have greater knowledge and understanding of the symptoms (and sensory changes) associated with dementia and the risk (and protective) factors for dementia. These groups were also more likely to say they thought there were things they could do to decrease their risk of getting dementia. Consideration should therefore be given to how to improve the awareness, knowledge and understanding of the less educated groups, and how to target public health messages and initiatives at this group.

An overwhelming majority of people (more than 9 in 10) thought that those in the early stages of dementia can lead a fulfilling life. By contrast, only around 1 in 5 thought that people in the later stages of dementia can lead a fulfilling life. However, there is a strong consensus across all sectors of the public that people living with severe dementia can benefit, in terms of their quality of life, from activities such as receiving visits, being taken into the garden, and actively participating in tasks. And people believe that care providers have a responsibility to facilitate visits and activities which could improve someone's quality of life. However, there is less support where finance would be required to organise a visit, with around a third saying they would not be in support of the council arranging for a paid volunteer to visit someone with dementia.

People in Scotland also believed that the family have a role to play in the care of those living with dementia. There was a widely shared view that children have a responsibility to visit a parent with dementia and that such visits would be beneficial. The public makes quite definite distinctions about where responsibility falls for caring for those in different stages of dementia. In particular, for someone with mild dementia the majority, 58%, think that family and friends should provide most of the care; this is significantly lower than the equivalent figure in 2014 which was 65%. People do not believe that family members who care for a relative with dementia are receiving much support from the government, with less than 1 in 10 saying that the government provides 'a great deal' or 'quite a lot' of support to family members caring for a relative with dementia.

This dependence on family and friends at the early stages of dementia is reinforced by the finding that around two-thirds would seek help from a partner or family member if they believed they had the early signs of dementia and around a third would talk to family or friends if they were concerned that someone close to them might have dementia. However, the findings also suggest that there is a need for a wide range of sources of help and support for people who are diagnosed with dementia, ranging

from meeting with a specialist doctor to talking to other people in a similar situation, either in person or online.

By contrast, the figures for where responsibility lies for providing care in relation to someone with severe dementia, has been very stable over time. The proportion who see this as the responsibility of family and friends is extremely small (3% in 2017 compared with 5% in 2014); overwhelmingly the public see this as a responsibility for paid carers and nurses. This suggests that there is very little public support for families taking responsibility for looking after those who are severely affected, and a decreasing level of support for this even in the case of a milder dementia.

In 2017, a substantial majority of the public said that dementia was in their top two priorities for additional government spending on care and support and more people nominated dementia in their top two priorities than any other condition. A smaller proportion, just under half, said that dementia was in their top two priorities for additional government spending on prevention. In this case, dementia was second to cancer in terms of priorities for additional government expenditure. People who knew either a family member or close friend with dementia, or who had dementia themselves and people who felt they were fairly well informed about dementia were more likely to prioritise dementia for additional spending. In both cases, support for additional expenditure on dementia was slightly - but not significantly - higher in 2017 compared with 2014. This suggests that dementia may be 'gaining traction' in the public's mind, and is seen as a key priority for future investment.

The public has mixed views about who should pay for the care of people living with dementia. In the case of someone with severe dementia who needs to go into residential care, two-thirds of the public think that the government should always pay and a third that payment should depend on how much money the person has. For someone with mild dementia who lives at home and needs regular paid help, around 6 in 10 thought the government should always pay, and 4 in 10 that payment should depend on how much money the person has. Thus there is a substantial minority in both cases who favour a 'means tested' approach. These figures have not changed since 2014.

Finally, evidence from SSA 2014 and SSA 2017 indicates that there has been little change in attitudes to people with dementia and their carers during the last three years. Whilst a substantial majority of people hold positive attitudes towards people with dementia and do not see it as a stigmatising condition, a small minority still display prejudice and fear as well as discriminatory attitudes. For example, around 1 in 8 said they would be 'ashamed' if they were told by a doctor that they had the first signs of dementia, and around 1 in 14 that someone in the early stages of dementia cannot lead a fulfilling life. Stigmatising and discriminatory attitudes are more likely to be found amongst those who said they are not well informed about dementia, as well as among men and older people.

Views on the potential detrimental consequences of caring for someone with dementia have remained unchanged since 2014, with around 8 in 10 agreeing that

'caring for someone with dementia is often very lonely' and three-quarters that 'caring for someone with dementia often means your own health suffers'. Younger people were less likely to hold these pessimistic views than older people. However, in 2017 a smaller proportion than in 2014 recognised the positive element of being a carer, with half agreeing that 'caring for someone with dementia is often very rewarding'.

In conclusion, there is evidence from SSA 2014 and SSA 2017 of some progress in relation to the public understanding of the risks of dementia and a belief in the possibilities for those with dementia to lead fulfilling lives. However, although some well-established symptoms of dementia are recognised, public knowledge does not spread to the wider range of potential symptoms, so there is still work to be done to improve public understanding of this condition and to help promote early diagnosis. And although there continues to be widely held positive attitudes towards people with dementia, there is still a significant minority who exhibit prejudice which needs to be tackled if those living with dementia are going to be able to live without discrimination.

Appendix A

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