



Turning Up the Volume: unheard voices of people with dementia

A groundbreaking look
at the real challenge of
living with dementia in
the UK today

May 2017



Dementia presents one of the biggest health and social care issues of the 21st century. It is set to be the UK's biggest killer (Office for National Statistics, 2016). One person develops it every three minutes (Matthews, F.E et al, 2016) and yet many face the disease alone or struggle with inadequate care. Despite some advances, stigma and misunderstanding remain compounding issues for those living with dementia.

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Please note that some names and identifying details have been changed to protect the privacy of individuals.

alzheimers.org.uk/turningupthevolume

May 2017

#UnitedAgainstDementia

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Turning Up the Volume

The in-depth interviews we undertook with people with dementia enabled us to tune in to people's views and feelings and build a rich picture of how the condition can affect people. These comments, taken from those interviews, show a spectrum of different experiences at different stages, from the despair of diagnosis to the impact on relationships to finding hope and companionship. Everyone's experience of dementia is unique. The quotes do not represent the views of everyone who took part in our research.

'I got diagnosed and I went into absolute depression and guilt, lost all my confidence and all my self-worth. The guilt I felt because I'd put my family in this position.'

'We went into the consultation husband and wife and came out person suffering from dementia and carer.'

'My brain is just... well it's just leaving me and I don't think you can do anything about that.'

'There are parts of me that have gone.'

'You feel you have lost your identity.'

'Life's completely changed. I'm not very independent. I have to rely on others. Life's going very slowly. Time goes very slowly.'

'Everything has to be structured and routine.'

'You can't socialise because you're not the same as before and people sometimes don't understand.'

'I won't answer the phone and I don't answer the door unless there is somebody coming who I know.'

'When my husband died I thought I'd put myself back on the market. Now with this thing, I'll be deteriorating, and no one will want to be there to see that. I wouldn't wish myself on anyone, not with this diagnosis.'

'A lot of people don't want to know about it because they don't want to think that they may get it.'

'Some [services] aren't stage appropriate. Because you've got dementia you are put into a day activity place or a day centre or in a care home or a nursing home, and then you are sat looking at your future.'

'The Singing for the Brain club is marvellous. When you go in everybody has a wee chat with their friends, you have a cup of coffee and something to eat. It's always packed.'

'It's like therapy really, a good opportunity to meet with people who have got the same problem, you feel like you're understood.'

'Sitting at home can get frustrating and boring but if I do go out, get fresh air, and see and talk to people it keeps me happy.'

'Remember yesterday, look forward to tomorrow, live for today.'



Turning Up the Volume: unheard voices of dementia is an unprecedented look at the real picture of living with dementia today, from the people who know. It dials up the voice of people who have the disease – which is too often muffled or ignored – telling their stories, and presenting a picture of their day-to-day life from the care they receive to the loneliness they may experience, through a groundbreaking series of in-depth interviews and surveys. The compelling findings presented here represent Alzheimer’s Society’s largest ever survey of people with dementia about their daily life. We also spoke to carers and the public, reaching almost 4,000 people in total, to present a composite picture of dementia today.

These include the words of people living with dementia. This extensive piece of work is a bold call to all who have a role in the growing movement for change. This report is for everyone, from the state to the NHS, to other care providers and society at large. We can all do something to urgently improve care, change attitudes and invest more in research.

About this report

Around 850,000 people are living with dementia in the UK today (Prince, Knapp M et al, 2014). One in three children born today will develop it in their lifetime (Lewis, 2015). This report lays bare the real – and sometimes stark – picture of living with dementia.

This ambitious and innovative report, carried out in partnership with our research partner Ipsos MORI, lets the voice of people living with dementia come through. It builds on their stories with the experiences of unpaid carers, and juxtaposes these with insight into public attitudes, exposing a backdrop of stigma. It presents a solid picture of what it is like to be affected by this condition across England, Wales and Northern Ireland today.

That voice is, sadly, telling us that there is a real gap between the things that people living with dementia need to live well and their day-to-day reality.

People living with dementia are the biggest recipients of social care. These findings show, worryingly, that they or their carers often find care not only hard to come by but have to shoulder the cost too.

Misunderstanding about dementia still exists. The report reveals how ingrained views of the condition can make life more difficult for those who are diagnosed with the condition. There is a negativity surrounding dementia which can affect people's sense of worth and increase their feeling of isolation.

We need to see change. By uniting against dementia we can all make a difference. Alzheimer's Society has ambitious plans to transform the landscape of dementia forever. We will reach out to every person with a dementia diagnosis to offer help and support, to change the conversation on dementia, creating a society where those affected are supported, accepted and treated equally, and to drive the research agenda, finding the answers that help us understand and treat dementia better and ultimately find a cure.

However, we know we cannot do everything alone. On page 28, we explain what's needed now, and in the future, from government, the NHS and society at large to create a new deal on dementia.

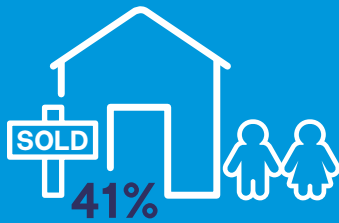
This report is all about turning up the volume on the real voices of people living with dementia. On page 24 we set out the new Dementia Statements. These have been developed by those affected and set out a firm series of ambitions people affected by dementia have a right to expect. We are not there yet. By coming together we can make this vision a reality, capitalising on the growing movement for change. United, we can create a society where those affected by dementia are supported and understood and able to live in their community without fear or prejudice.

This report does not offer the entirety of the findings from our research, but aims to give an overview of the key themes arising and the action that needs to be taken to address them. The research data behind the findings contained in this report can be found at alzheimers.org.uk/turningupthevolume or are available upon request. They are not contained within this report.

Stigma still surrounds dementia. Some people living with dementia believe the public don't understand their symptoms, or how to interact with them.

Many people have a negative view of dementia. This can make those affected by dementia feel worthless and without purpose.

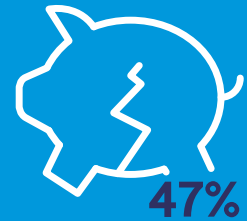
Dementia care can be expensive and hard to access. This means that some people with dementia worry about their finances, and the future.



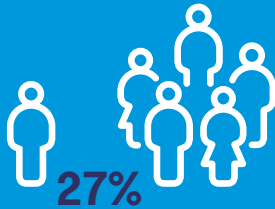
People are twice as likely to agree that they worry (41%) than not (20%) that 'any savings I have will be spent on future care and support and leave nothing to pass on to my children or other loved one'



More than half (54%) of the public agree the government should pay for their care and support if they develop dementia



Almost half (47%) of the public have not started saving for the care and support they may need in the future



Over a quarter (27%) of carers for people with dementia feel 'cut-off from society'



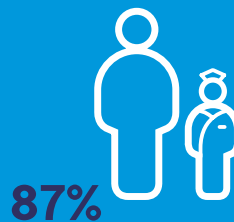
Around three in five carers (61%) say their health has been negatively affected by caring for someone with dementia¹



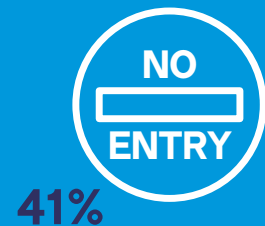
More than half (56%) of the public who do not have dementia agree that if they had dementia they would feel that their life was over



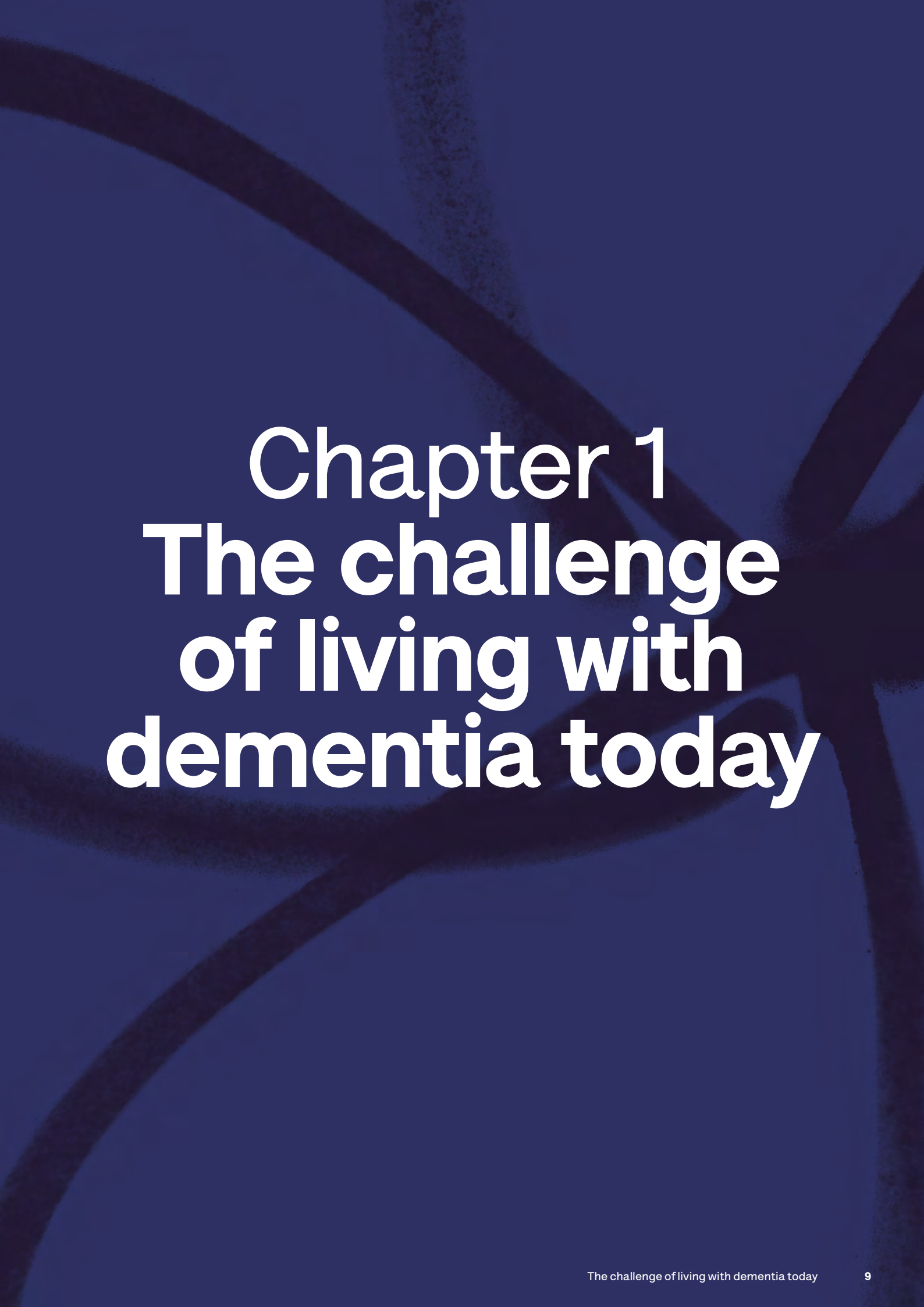
Almost half (48%) of people living with dementia who were interviewed worry about becoming a burden



87% of people with dementia who were interviewed receive help from family in their day-to-day life but only 14% receive help from a paid carer



41% of the public disagree it's just as easy for people with dementia to play an equal part in society as anyone else



Chapter 1

The challenge of living with dementia today



Fear of the unknown

56%

More than half (**56%**) of the public who do not have dementia agree that if they had dementia they would feel that their life was over

please see Appendix 1 for more details on method and sample size

Dementia can devastate lives. For someone with the condition, as well as their families and friends, dementia means that the plans you made, and the future you thought you would have will not always be so.

Coming to terms with a diagnosis can sometimes require extraordinary strength and determination. Many people feel that their life is over. Some people experience denial – struggling to accept their own diagnosis or that of the people around them.

At the same time, people's sense of isolation can be made worse by the misunderstanding and stigma around dementia. People sometimes withdraw or do not know how to behave around someone with the condition.

Stigma and the lack of public understanding

Behavioural and psychological symptoms of dementia such as agitation, aggression, changes in communication and apathy affect up to 90% of people with dementia (Feast, Orrell et al. 2016) and can damage people's confidence.

'My friend got in a taxi and told the driver she had dementia, and he said, "You're not dangerous are you?" So some people don't know.'

Person with dementia

Nearly a fifth (17%) of the public would feel fairly or very uncomfortable 'if someone I knew told me they have dementia'. For people living with dementia, too often this means others are sometimes afraid to develop or maintain a relationship with them. It can also mean people shy away from situations where they might show their lack of knowledge or experience of dementia. Our findings show some people living with dementia can also look to avoid potentially difficult situations, by pushing away or distancing themselves from friends or family, fearing they will not understand. Only 70% of people living with dementia who responded to our survey said they have told friends they have dementia.

Misconceptions of what to expect from dementia, and a simplistic understanding of a complicated condition and set of symptoms can create frustrating situations for people living with dementia.

'A lot of people don't want to know about it, because they don't want to think that they may get it. It has a bit of a stigma, doesn't it?' Person with dementia

Many of the conversations we had with people affected by dementia underscored the belief that stigma prevails and that other people do not understand dementia – or even know how to talk to someone living with it.

'There's still a massive lack of knowledge [among] Joe Public. They only see dementia when it's at its end stages. Even the professionals forget that there's a beginning and a middle, before you get to the end.'

Person with dementia

'It's where cancer was 20 years ago. It was always called the little 'c''

Person with dementia

These personal reflections are supported by our wider research. Only 22% of people who responded to our survey of the general public think that dementia is a condition which results in death.

Our research suggests that some people living with dementia have poor experiences when coming into contact with people outside their immediate circle. This means they sometimes believe that it's them, not society, who is at fault when communication breaks down or they're no longer able to do something they used to.

'I think the public still feels it's just little old ladies that can't remember their children. I've met people who say "so you can't remember anything?" I have told them that's ridiculous, I can remember a lot more than I thought I would.'

Person with dementia

This experience is backed up by separate research funded by Alzheimer's Society, which found children of people living with dementia, particularly young onset dementia, felt anger, frustration and a sense of isolation at the interactions they had with a public and support system who are largely ignorant of dementia as anything other than Alzheimer's and people being affected by memory loss (Sikes, 2016).

Within our in-depth interviews, one carer described how she sometimes has to convince people that her partner has dementia with Lewy bodies, because people tend to automatically associate dementia with advanced Alzheimer's and its symptoms.

‘This is almost the drawback because most people see [him] in the day time; and you see because when you say dementia they automatically think of Alzheimer’s and think he won’t know where he is. People have been very understanding... but they sort of say “you’d never know he had dementia” and I think “I’m not making it up”... and actually have to explain that he does have horrible, horrible nightmares; and to him it’s real and in the evening he doesn’t really remember things sometimes. [They say] “But it’s not real dementia is it?” And I’m like “yes it is”’

Carer of person with dementia

People with dementia can often behave differently at different times of the day. For example, ‘sundowning’ is a common condition closely associated with dementia and Lewy bodies. It means symptoms like memory loss and hallucinations are greater in the late afternoon or evening than in the morning.

Many people assume that living with dementia means rapidly going from being independent to being dependent on others to live. This creates a lot of anxiety. Yet the word ‘dementia’ includes a large number of symptoms and stages. Our findings suggest people experiencing early stages of dementia often do not wish to know what the middle or end stages will be like. This can hold people back from accepting a diagnosis, continuing hobbies or planning for the future.

‘We Googled straight away [after diagnosis] and the only evidence-based thing we could find for death by dementia... it was four to six years. So you think, “Right, well, I’ve been diagnosed halfway through, so I’ve got three years left” and then that puts you straight into depression. You then sit at home, waiting to die. You stop socialising.’

Person with dementia

‘It’s easy to look at [people with] Alzheimer’s and say “God, I hope I never get like that”.’ Person with dementia

It is an area where society often tries to fit the symptoms of dementia into “normal” life. It takes flexibility and empathy to recognise that supporting someone with the condition may need a different and personalised approach.

Fear of the future

Research into good practice in dementia care means that there are a growing number of services and methods of support that can help people to live well with dementia, even if too often people have problems accessing them depending on where they live.

Yet our research found that both for people affected by dementia, and the wider public, a sense of hopelessness can still surround a dementia diagnosis. This is partly fuelled by a lack of understanding of how the condition progresses, which creates fear of what will happen in the future.

‘People need to know that whenever you look at information you are always going to find the most negative thing and assume that applies to you. You are in a world where there are no positives at all. There is no hope. You need to show people “this is a person living with dementia.”’

Person with dementia

Over four in ten (44%) of those that responded to the general public survey agree that dementia is the health condition they most fear developing. This concern is more common for women (49%, compared to 38% of men). More than half (56%) of people who do not have dementia told us that they agree that they would feel their life would be over if they developed dementia.



A disrupted world

41%

41% of the public disagree it's just as easy for people with dementia to play an equal part in society as anyone else

please see Appendix 1 for more details on method and sample size

Living with dementia and dealing with society's view of the condition often means people lose confidence, independence and the ability to live the life they want. It can feel like the physical world around them becomes smaller, as they lose touch with people and activities close to their hearts.

People living with dementia can feel they're losing their identity. Some people we spoke to said they were very aware of their abilities fading. This can have emotional and psychological consequences. A common concern for people with dementia and their carers is isolation and loneliness.

Loss of identity and independence

'You feel like you have lost your identity. You've lost the person who you are.' Person with dementia

The impact of dementia can lead to someone being increasingly more dependent on others as the condition progresses. Some people living with dementia told us about having to give up careers and stop hobbies they had enjoyed. Some also had to deal with the challenge of completing day-to-day tasks that most of us take for granted, like washing, dressing and going to the toilet.

'I can't do the things I used to. I can't read or write. If that's not frustrating, I don't know what is.'
Person with dementia

One person told us how his driving licence was taken away following his diagnosis. He felt a loss of independence and control over his life. Another spoke about the anguish she felt at no longer being able to take her grandchildren out on her own. She also felt sad that the youngest would never know her as she is now, because of the progressive nature of dementia.

'It feels frustrating, confused. You feel angry about it because you don't know what you're talking about, you realise you don't know what you're talking about, then you get frustrated. You try to defend yourself, cos then you realise you haven't got any defence and you get angry about that, cos you feel silly for a starter.' Person with dementia

People with dementia often described how they were gradually losing the things that made them individuals, in the eyes of others and themselves. Someone who used to repair car engines talked about feeling frustrated now they could no longer repair their family car.

'I just had to stand there and watch and think 'I could have done that'. I'd done it before, but I can't now.'
Person with dementia

One person spoke about the impact their increasingly advanced dementia has had on their sense of humour, and their ability to join in with the rest of

'I just sat there for the whole time. I couldn't smile. I couldn't laugh. My brain just couldn't process it. Everyone else around me was laughing – I just couldn't. It was upsetting.'

Person with dementia

Not being able to do, or feeling that they would not be able to do, familiar tasks leads to many people feeling as if their identity had been taken, and lost something that defines them. Frustration is a term that appeared again and again in our in-depth interviews. Some people feel desperate as they compared themselves to who they believe they were before dementia.

Too often people feel like dementia is a label that leads society to believe a person has less purpose and value. Nearly half (48%) of people with dementia who we spoke to said that they worried about becoming a burden.

'I got diagnosed and I went into absolute depression and guilt, lost all my confidence and all my self-worth. The guilt I felt because I'd put my family in this position. The guilt I felt, because I wasn't able to work anymore. The guilt because I was going to die before my children were older.' Person with dementia

society. This was underlined by a trip to see a comedian with their partner.

A number of people spoke about how passing control and responsibility over different aspects of family life to someone else, often their partner, left them feeling demoralised.

One admitted that they struggled with managing finances as a result of their dementia and were no longer able to manage the household budget. For people who had always been in charge of household spending this could be very upsetting, and also highlighted their increasing dependence on others. Many people showed concern about the state of their finances, and worried they weren't financially secure.

A disrupted world

'I can only do five per cent of that [work] now.'

Ray, who has dementia

As someone whose life revolved around work and leisure, early-onset dementia has had a profound impact on Ray's identity. Ray was self-employed with a business involving building and decorating. He had no immediate or even long-term plans to retire, he saw his business as one that he could continue running well past retirement age.

'As my memory and my organisation skills are diminishing, I can only do five per cent of that now, if that.'

He can no longer run the business himself, so to keep it going he has to pay other people to do the work he once did, which he finds very frustrating. This is also upsetting, as it has affected the family's finances and left Ray feeling he doesn't have a purpose.

Because of dementia, Ray also had to give up mountain biking, his main hobby. Balance and co-ordination issues early on affected Ray's ability to cycle – and he felt that he no longer had the necessary skills to do his hobby safely. This was a major blow as his social life revolved around meeting friends at his club. Ray continued to attend the club for a short while after his diagnosis. He was made very welcome, but the dynamic had changed. Typically, his wife had to go with him, and he was only able to sit in on chats and not play an active role. This, along with resentment that he could no longer participate fully, eventually meant Ray gave up his hobby entirely.

Case Study: Ray

As someone whose life revolved around work and leisure, early-onset dementia has had a profound impact on Ray's identity.

Living in denial

Due to the fear that can surround dementia, some are unwilling to accept their diagnosis.

Some people we talked to accepted the symptoms and experiences they were having with dementia but denied the diagnosis, and wouldn't use the word 'dementia' itself. One person was diagnosed seven years ago and had only recently accepted that she had dementia. Another told us that denying her dementia diagnosis was the coping mechanism she used to deal with the resulting depression.

One or two people felt more comfortable telling people around them about the physical symptoms of illnesses, and avoided mentioning dementia. Someone with Parkinson's told us how they and their carer received a huge amount of help and support from a Parkinson's support group. But they didn't want to go to a similar group for people living with dementia.

'Parkinson's, they can cope with that, but when it's Alzheimer's as well, they think "blimey, he's a nutter"'

Person with dementia

Older people with dementia occasionally felt more comfortable associating their symptoms with old age or other illnesses. They appeared to see dementia, and what it would mean for the future, as a 'worst case scenario'.

'Dementia? No I don't think so. The problem is I broke my leg ... I have never had any problems with my memory, well not really, age just catches up with you. That's all it is.' Person with dementia

Facing a shrinking world

Losing independence and confidence in the ability to do what is familiar, in addition to fearing how others will react to the challenges presented by dementia, meant some people we spoke with described actively avoiding situations which had the potential to cause upset or stress. This led to them seeing fewer people and leaving the house less frequently.

'A very good friend of mine is afraid to come and see me. I have contacted him, but he hasn't got back to me. A couple of people are a bit wary of me, because I've got Alzheimer's and they are afraid of what it might be.' Person with dementia

Our research found that 41% of the public disagree that it's just as easy for people with dementia to play an equal part in society as anyone else. This

attitude goes some way to explaining why people with dementia sometimes feel they are left with little option but to increasingly withdraw from their community as the condition progresses. Indeed, over a third (35%) of people with dementia that we spoke to said they have felt lonely recently, a particular concern given wider research into the increased likelihood of mortality from isolation (Holt Lunstad et al., 2015).

'Life's completely changed. I'm not very independent. I have to rely on others. Life's going very slowly. Time goes very slowly. Before it was like going to work; and the day would go fast. Now you just might be sitting at home. I can't always go out, because of health problems. You end up losing friends when you have dementia, because you cannot interact. You can't socialise, because you are not the same as before.'

Person with dementia

The physical world has become smaller for many people living with dementia. Their lives, and to a great extent the lives of their carer and loved ones, can increasingly revolve around the home and a set routine. The daily reality for many people can be isolation and a feeling of being cut off from a society that does not always understand the issues they face.

'If I had to go out I'd have to know at least a week in advance. I won't answer the phone and I don't answer the door unless there is somebody coming who I know is coming. They talk too fast for me and I can't take it in and I get frustrated and these people who are trying to sell you something... I don't know what to say to them, and I get myself in a mess.'

Person with dementia

This feeling of isolation can also be shared by family carers. More than a quarter (27%) of all carers surveyed agreed with the statement: 'as a carer of someone living with dementia I feel cut-off from society'.

'What people see is a manifestation of behaviour and they can't handle that. Or they see it as inappropriate behaviour or unsocial behaviour.'

Carer of person with dementia

Over half (54%) of carers who support someone with dementia for 20 hours or more a week say they've felt lonely recently. In addition to feeling distanced from society this may, in part, be related to findings from a recent literature review on the impact on family carers of behavioural and psychological symptoms of dementia. The review found changes in behaviours, relationships and perceived transgressions against social norms brought about by symptoms of dementia left many family carers feeling bereft. The underlying belief that their relative had lost, or would inevitably lose, their identity to dementia was a fundamental reason why family carers experienced some behaviour as 'challenging' (Feast, Orrell et al. 2016).

Case Study: Ivy

Ivy lives on her own and has recently been diagnosed with Vascular Dementia. She has no other long-term health conditions.

'I know I'm stupid nowadays.'

Ivy, who has dementia

Ivy lives on her own and has recently been diagnosed with Vascular Dementia. She has no other long-term health conditions.

'Was I a teacher? I was! I had the right type of voice to shout them down. I never had a class I couldn't shout down!'

Ivy is very much in denial about her diagnosis. When asked about it she became quite upset and referred to herself as being 'stupid' because 'my brain doesn't work properly any more'. References to the word 'dementia' made her very upset. Her care workers were surprised that she even admitted that her brain no longer works in the way that she would like it to. It's not something that she has ever spoken about to them.

'I don't think anybody has ever told me that. I know I'm stupid nowadays but I don't think that is right.'

When asked whether she had a problem with remembering things she admitted that she did but put it down to old age.

'Yes, if I have got to go somewhere I write it down the night before, and then I know what I am doing in the morning. I don't worry about it. There is nothing I can do about it – I'm too old to change it.'

Memory loss is something that really upsets Ivy.

'My memory is not what it used to be. I have got a degree and a postgraduate something or other so once upon a time I was quite clever.'

'It's fairly obvious to people who know me or who knew me, should I say, that I'm not as clever as I used to be. I don't know what it is. I've never asked them, but I know I am stupid.'



Who pays the price?

61%

Around three in five carers (61%) say their health has been negatively affected by caring for someone with dementia.¹

¹where carers selected one or more items that negatively affected their health please see Appendix 1 for more details on method and sample size

A diagnosis of dementia can be difficult enough. Our report shows that many people find it difficult to access the quality of care they need, or to pay for it. Equally, saving for care that people may need in the future is not always their primary concern – meaning we are storing up a ticking time bomb for the future.

People living with dementia may get an initial diagnosis and medication on the NHS. But the symptoms of dementia affect their daily lives, and may mean they need help with tasks like washing and dressing. This kind of support is covered by social care. In England providing this care is the responsibility of local authorities.

Social care is the majority of care that people with dementia receive. When social care is restricted, dementia care is restricted.

At least 60% of people who receive social care in their own homes live with dementia (United Kingdom Homecare Association, 2013) and 70% of care home places are used by people with dementia (Alzheimer's Society, 2014).

Baseline dementia care in a care home costs on average nearly £700 a week (LaingBuisson, 2017), and good quality dementia care in someone's own home is often at least £20 per hour (UKHCA, 2016). It is therefore not unusual to face total bills of hundreds of thousands of pounds to care for someone with dementia.

‘Yeah, once I get to that stage I’ll have to have people getting me out of bed and people putting me to bed; and the cost is enormous I would fear.’

Person with dementia

Our research found that nearly half (47%) of the public disagree that they ‘have started saving for the care and support I may need in the future’. Just over a third (37%) agree that before completing our survey they had not even ‘considered the cost of dementia care and support’.

When asked whether the UK government should pay for their care and support if they developed dementia, more than half (54%) agreed that the UK government should pay, while just 5% disagreed.

‘I think the biggest impact on us has been financial.’
Person with dementia

Respondents to our public survey are twice as likely to agree that they worry (41%) as disagree (20%) that ‘any savings I have will be spent on future care and support and leave nothing to pass on to my children or other loved ones’.

‘We saved for a holiday but we can’t go. We had planned to sell up and travel around the country, but obviously, that won’t happen now. We’re looking into [our children] taking on the mortgage.’

Person with dementia

One couple talked of needing a more ‘disabled-friendly’ house and recognised that in the future the husband living with dementia will require more formal care before eventually moving into a care home. They also talked about how he may need more specialised equipment such as a wheelchair and bed, though this was always followed by concerns about how they would fund them.

Quality of care

The public are concerned about poor dementia care. Half (49%) of UK adults aged 16–75 that we interviewed agreed that people with dementia inevitably experience worse care and support than people with other long-term conditions (such as cancer or heart disease).

Given the vast amount of money that people are spending on their dementia care, we believe this is simply unacceptable. Having to sell your home to pay for bad care is a situation that no one should face.

'I found that mum and dad were coping less and less'

Brian and Sue both live with dementia. This is the story of their daughters.

Brian and Sue both have dementia and currently live in a residential home together. They moved in recently at the insistence of their daughters. Before moving into the home, Brian and Sue were visited four times a day by carers but their daughters talked of it being evident that their parents were unable to cope with living independently despite the frequent visits.

'Eventually we were having people [carers] go in four times a day, but as time went on my sister and I found that mum and dad were coping less and less and less. At each stage we would have to take things away like the car. Then they weren't taking their meds. Feeding – they weren't feeding [each other] properly.'

Before moving into the residential home, it was not unusual for Brian to spend his whole day in bed. He was very forgetful in taking his medications and was not feeding himself properly. One of his daughters talked of her dismay at the support provided by Brian's carers. She recognised that sometimes the high workloads and short visiting times meant his carers could not provide the support she expected, and also acknowledged her dad's behaviour.

'They found it difficult to handle dad, because he wouldn't get up and wouldn't comply. He's become more aggressive with the dementia.'

She could show a number of photos which captured inadequate care – bowls of food left to go mouldy, medicines left with a note for Brian to take them by himself and small meal portions.

'The care at home wasn't working right; They couldn't always feed them in the time they had, so very often they [parents] hadn't either eaten or drunk... They didn't always have time to change the bedding. They would either forget to do the meds or miss the meds. One time there was a note left to say, "Brian, this is your meds;" and he'd never in a month of Sundays remember.'

Trying to keep on top of the care for both parents was incredibly stressful for Brian's daughters. One talked of coming close to a breakdown before being able to secure a place for her parents in their current residential home. Only after her mother had a fall in the family home, which prompted an emergency meeting with social workers, was it agreed that their parents could be placed in a residential home.

'If people do what they are supposed to do, and if there was enough of it in place, we might have let them stay there for some more time, but because it clearly wasn't working it couldn't go on any longer. Care at home didn't work.'

Case Study: Brian and Sue

Brian and Sue both have dementia and currently live in a residential home together. They moved in recently at the insistence of their daughters.

Who cares?

Our research highlights the invaluable and selfless role played by unpaid carers. Many make significant sacrifices, sometimes without help from statutory services, to be a lifeline for their loved ones.

Eighty-seven per cent of people living with dementia that we spoke to said they receive help from a family member in their day-to-day life, compared to 14% who receive help from a paid carer. 20% of the carers we surveyed provide 20 or more hours of care a week and 9% offer more than 50 hours a week. Many carers are being pushed to their limits.

Most carers who responded to our survey have looked after or provided support to a person living with dementia for a considerable period of time. Over two-thirds (68%) had done so for a year or more. And of this number almost a third (30%) had been looking after or providing support to someone for at least three years.

Some reported feeling that a dementia diagnosis had changed the basis of their relationship, if not in their eyes, then in the eyes of the services designed to support them.

The impact of dementia means that, for some people, the condition will progress to a point where almost constant support is required. Problems with the professional care system can mean big responsibilities and expectations are put on family carers, to the point it often impacts on their health and wellbeing.

‘We went into the consultation husband and wife and came out person suffering from dementia and carer.’

Carer of person with dementia

Nearly two thirds of carers (61%) responding to our survey say that their health has been negatively affected as a result of caring for a person who had dementia.

‘No one from mum’s psychiatric team said to me, “what about you?” I had to say, “what about me?”’

Carer of person with dementia

Around two in five people (37%) caring for someone with dementia that we spoke to report that doing so has affected their personal relationships and social life for the worse.

‘I haven’t had a break for 18 months. There are carers’ helplines that I think you can phone, but I assume that you’ve got to be suicidal before you phone that one.’

Carer of person with dementia

One carer we interviewed spoke of how his caring responsibilities, specifically during the night, have affected his sleep, which in turn impacts on his performance at work. His relationship with his wife is also suffering. His GP led him to believe he could get additional support, but afterwards found that the service did not exist. His experience highlights some GPs’ confusion about the support available for carers, and how to access it.

‘I went to the doctors and burst into tears, because I’ve got a lot on. He [the doctor] says, “What you need is support, and I will get you support”. So I came back from the doctors with a spring in my step, but the support wasn’t there.’

Carer of person with dementia

For many carers the relentlessness of feeling that they must be on-hand 24/7 created one of the greatest challenges. In the survey of carers, as many as a third agreed that ‘it worries me to leave them’.

Difficulty accessing support, or even information on what support is available, contributed to the sense of isolation and feeling that there was no one else to help. Almost a fifth of carers (18%) said they had felt depressed and more than a third (35%) reported feeling stressed.

‘It’s hard for carers 24/7. I’ve still got my mum with dementia at 91, and we’ve got her into a residential home. But it’s hard. I haven’t had a break for 18 months. There are carers’ helplines that I think you can phone, but I assume that you’ve got to be suicidal before you phone that one.’ Carer of person with dementia

Who pays the price?

Demands on carers can also have a significant impact on the wider household. Nearly a fifth (17%) of carers have given up work to provide care. A further quarter (25%) have had to reduce the hours they work in order to care for someone with dementia. So, it's no surprise a similar proportion (26%) said their financial situation got worse as a result of their caring responsibilities.

Less than a quarter of the public (22%) who responded to our survey agree with the statement that they would know where to find care and support if they had dementia. This view is backed up by our conversations with people affected by dementia. Some people we interviewed told us they felt like they had been left to fend for themselves, with no offer of help and little hope for assistance in the future.

Overall, 57% of carers are aware of a Carer's Assessment (as a right in legislation) or of the existence of NHS Continuing Healthcare. Fewer (41%) know that it is also possible to have a Carer's Personal Budget to support them to carry out their vital role.

'I know that if you are given a diagnosis for cancer you've got everybody there – a whole set of people all there to help, not only the person who has got it but the other people who are looking after them – the people it affects. My sister had a social worker. She had [a] Macmillan [nurse]. She had experts in the field. With us, we went to [hospital] for an Alzheimer's test and [the doctor] said "you've got Alzheimer's" and we just walked out of the hospital, and we had nothing. I was heartbroken when we came out.'

Person with dementia

'...[the doctor] said "you've got Alzheimer's" and we just walked out of the hospital, and we had nothing. I was heartbroken...' Person with dementia

'When we had the diagnosis, there was no "this is going to be hard and it's going to affect your life". They were just like – "he's got Alzheimer's, OK, bye"'

Carer of person with dementia

Only a small minority of carers feel supported. Just 17% agree with the statement 'there is enough support available for those who care for people with dementia'. However almost two-thirds (65%) disagree, with 31% saying they strongly disagree. Over a quarter (27%) of carers say that no one has provided them with advice or support about caring for someone with dementia.

Some people living with dementia wanted information and advice on how it would change their lives – including the financial side of facing the condition. Many felt frustrated by the lack of information they received about what they might be eligible for, especially if they had little experience of the benefits system.

Carer: **'Your sister she has got Parkinson's. Her husband [asked us] "are you getting your 25% off?" I said, "no". He said that we should have been having that a long time ago, but nobody gives you that information.'**

Person with dementia: **'You have to find out these things for yourself.'**

Person with dementia and their carer

Who pays the price?

Facing dementia together

Graham, who lives with dementia, and his carer

Graham lives with his partner, who informally cares for him. He was diagnosed with Parkinson's over five years ago and, in the past year, has been diagnosed with dementia with Lewy bodies.

Graham recognises the burden his care places on his partner and talked about needing support for her to have a break from caring. She is waiting for a double knee operation but cannot find a way to provide care for Graham during her recovery period and so this operation is being repeatedly delayed. His partner talked of needing help to navigate the system – completing application forms and reducing the bureaucracy of multiple assessments.

Case Study: Graham

Graham lives with his partner, who informally cares for him.

Chapter 2

The Dementia Statements

What kind of life do people with dementia want to have?

In 2010, 41 national organisations (that went on to form the Dementia Action Alliance or DAA) asked people affected by dementia, and other key stakeholders, what type of care and support they would hope to receive in the future. Informed by these conversations, they created the National Dementia Declaration, a set of seven expectations or Statements of what life should be like for people with dementia. These Statements were used to inform the Prime Minister's Challenge on Dementia published by the Department of Health in 2012.

The Dementia Action Alliance:

The Dementia Action Alliance is a group of 150 national organisations plus local groups who bring together individuals from across England committed to improving health and social care outcomes for people living with dementia, and those who care for them. The Alliance captures and promotes best practice, enabling it to benefit many more people.

For more information visit
dementiaaction.org.uk

A lot has changed since 2010. So, the DAA has reviewed the Statements alongside people living with dementia to reflect what they want today.

The person with dementia is at the centre of these refreshed Statements. They represent everyone living with any type of dementia regardless of age, stage or severity. The 'we' used in these statements encompasses people with dementia, their carers, their families, and everyone else affected by dementia. These rights are enshrined in the Equality Act, Mental Capacity legislation, Health and care legislation and International Human Rights Law.

The Dementia Statements

In April 2017 the Statements were welcomed and endorsed by the Dementia Programme Board that monitors and supports the implementation of the Prime Minister's Challenge on Dementia 2020 across the NHS, social care, the research sector and wider society. Alzheimer's Society is committed to taking them forward.

Championing the rights of people affected by dementia

These Dementia Statements reflect the things people with dementia say are essential to their quality of life – identity, care, community, carers and research.

Grounded in human rights law, they are a rallying call to improve the lives of people with dementia and to recognise that they shouldn't be treated differently because of their diagnosis.

Using these statements, we must now build the growing movement for change. Articulating the needs of people affected by dementia through a rights-based lens, gives more urgency and weight to this movement, and makes dementia something that no one can ignore. We need to move on from the issues identified in this report and unite to fix dementia care, eradicate stigma and see people living with dementia participating on their terms and invest more in research. We must end a culture where people with dementia are treated as second class citizens towards one where their rights are upheld and respected.

By championing the rights of people living with dementia we will transform the landscape of dementia forever.

We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.

We have the right to continue with day-to-day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.

We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.

We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.

We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.

Chapter 3

Delivering a new deal for people with dementia

Support works

The people affected by dementia that we interviewed told us of the positive impact they felt from being well supported. When given the opportunity to make use of readily available information, services and support networks many people report being able to live well with dementia.

‘We had a lovely bloke. He was from the young-onset clinic and he was absolutely fantastic. He was there for both of us. He knew the right things to say. He was just a normal, everyday bloke.’

Person with dementia

Our research highlights a big difference between people that are supported by organisations like Alzheimer’s Society and those that aren’t.

The majority of people living with dementia who responded to our survey and use Alzheimer’s Society’s services were positive about their experiences. 68% said that they get out of their

home nearly every day or every day. Only 8% said that others treated them worse since they have had dementia and 81% felt that they have a say in decisions about their care.

They still had some negative experiences. But our research helps demonstrate that with the right level of support from government, professional care providers and society, we can enable people with dementia to live well.

Why a new deal matters

Without a new deal for dementia, many more people will lose their sense of identity, their independence or face a social care system that fails to provide the support they need.

To make living well with dementia a reality for everyone, we need action from the state, society, and from you, right now.

The hopes and expectations of people affected by dementia highlighted in the Dementia Statements are starkly different to the reality people shared with us in our research.

But it doesn’t have to be this way.

It is expected that by 2021 there will be more than a million people living with dementia in the UK (Alzheimer’s Society, 2014). One in three people born today are expected to develop the condition at some point in their lifetime (Matthews, F.E et al, 2016).

State and society must unite now to establish a future for people with dementia that:

- builds public understanding
- offers quality and affordable care
- supports people and their families to live the life they wish to lead and eradicates stigma and fear



A new deal from government

41%

People are twice as likely to agree that they worry **(41%)** than not **(20%)** that 'any savings I have will be spent on future care and support and leave nothing to pass on to my children or other loved one'

please see Appendix 1 for more details on method and sample size

We challenge those in power to create a long-term, sustainable system for funding dementia care.

This new care system must uphold the rights of people with dementia. It must maintain quality of life, stop catastrophic care costs for families and deliver joined up services that end the inequality of support between dementia and other conditions.

At the moment they need it most, many people living with dementia feel unsupported by the state, and must rely on family members and carers for the support they need. Those in power have the opportunity to create a new deal for dementia, by establishing a long-term solution to the funding crisis facing the adult social care and health systems.

The long-term challenges posed by the growing number of people with dementia needing care will not be solved by a short-term fix. Politicians must show leadership and work with the health, social care and voluntary sectors to create long-lasting plans which work for people with dementia. We need a fair settlement for care which does not leave the 850,000 people with dementia in the UK worried about their future.

Social care is the majority of care that people with dementia receive. When the social care system is broken, dementia care is broken, affecting hundreds of thousands of people day in day out. For someone who may have lost the ability to identify and use the bathroom, or find the front door to go out, social care forms an essential source of support to retain some aspects of normal life.

‘We have a social worker who is very good. We had no help before her. She’s arranged the befriender and had told me about a whole lot of other services, and organised for an occupational therapist to come to the house.’ Person with dementia

Our research shows how many people find it difficult to access the information and services they need. This leaves people living with dementia and their families in situations where they feel isolated, afraid or unsure of where to turn next.

We know many people with dementia struggle to cover the cost of their care. These costs are rising year on year, and it is not unusual for people and their families to face total bills of hundreds of thousands of pounds. In many cases people are faced with making huge personal sacrifices to cover the costs and some may have little option but to sell their home.

We estimate that it could take a lifetime for someone to save for these costs, even if they were able to put aside the same as an average pension contribution. This is not only deeply unjust for the families of people living with dementia, but also an impossible ask.

Successive governments have failed to link the amount of money put into the care system compared to the amount needed to deliver care. As a result the amount of support available is frequently rationed or delivered on a shoestring budget, resulting in people suffering harrowing experiences and unpaid carers facing huge personal demands. Combined, people living with dementia and their carers contribute more than £17 billion towards the cost of dementia in the UK every year (Alzheimer’s Society, 2014).

The Barker Commission found that we spend less on health than countries such as France, Germany, Denmark, the Netherlands and Canada (The Kings Fund 2015).

Closer working between the health and social care sectors has been called a priority by successive governments. Seamless, integrated care across the two sectors is potentially of great benefit for people living with dementia. To them the distinction between the sectors is meaningless. What they want is quality support which meets their needs.

Failing to support people to live independently and well in the community and the environment of their choice has significant and serious consequences for the NHS. Too often the NHS has become a safety net to catch people whose health is failing.

Alzheimer’s Society is a founding partner of the newly established Dementia Research Institute. Last year we made our largest ever single investment in the charity’s history towards the establishment of the Institute, totalling £50million. Our funding was to ensure that the Institute’s remit was broader than biomedical research into finding a cure for the condition. Our investment aims to strengthen and develop research into better care and support for people with dementia. When developed, these care and support interventions could transform the lives of people with dementia to ensure that they are able to live independently and well in the community for longer.

People affected by dementia have the right to care that protects their wellbeing, and the health and financial standing of family carers. They have the right to care that helps to prevent them entering hospital needlessly and reduces the impact of dementia symptoms. People living with dementia have told us these rights are not being met.

We call on care providers to ensure that everyone affected by dementia receives the support they need, throughout the dementia pathway.

Navigating the health and care systems and accessing the professional help people affected by dementia need and deserve can be daunting, from visiting the GP to community-based support.

A number of people we spoke to in interviews shared how desperate and alone they felt following a diagnosis. Rather than being given a range of options and advice and being placed on a pathway of support, they felt discharged by the health service and left to fend for themselves.

We asked carers what advice they would personally give to someone who has recently taken on caring responsibilities for someone living with dementia. More than a quarter (26%) of carers said ‘ask/get as much help or support as possible’. One carer was quite clear on what they felt was needed.

‘When you get the diagnosis it’s devastating. I think they should have some sort of [response], like ‘this is Sue from Alzheimer’s Society, would you mind her giving you a call now that you’ve been diagnosed? Just to talk over how you’re both feeling and to tell you that we’re here and this is what we can do.’ And I think that simple phone call would have made such a difference to us.’ Carer of person with dementia

Getting access to help and support

Half of the public that we spoke to (47%) disagree that if they had dementia they would know where to find the care and support they needed. This is not good enough.

Services at the point of diagnosis that can offer advice, assistance with coming to terms with the diagnosis itself, and information about what options are next, are essential.

The Alzheimer’s Society strategy for 2017–2022 outlines an ambition to significantly extend our reach to everyone affected by dementia by delivering support services in a different way, aiming to establish a relationship with every person with a diagnosis.

We’re aiming to work closely with GPs to ensure they’re able to refer patients for support quickly and effectively. This means offering telephone support, information and advice including signposting to other services and providing written information.

For patients with more complex needs an in-depth face-to-face support service will be provided, while everyone referred will receive a Keep in Touch call every three or six months to reassess need and provide on-going support.

We require support from the health service to implement this strategy, and help people affected by dementia understand what is available so we can help as many people as possible

Fixing dementia care

Poor care in hospital can have devastating, life-changing consequences for someone living with dementia. Our Fix Dementia Care campaign (2016) found standards of care differ so much around England that people are gambling with their health and wellbeing when they’re admitted to hospital.

At the moment, there is no way for patients or their relatives to find out, in advance, what kind of care they’re going to get. This has to change.

We’re calling on all hospital boards to publish an annual statement on the quality of dementia care in their hospitals. Putting this information in the public domain is essential. Doing so will finally put an end to a culture where it’s easier to find out about your hospital’s finances than the quality of care people living with dementia receive.

The Fix Dementia Care campaign also found shocking examples of care delivered to people in their own homes. Homecare workers are often on minimum wage and restricted to incredibly short visits because of sector underfunding and commissioning practices. Staff are asked to provide care for a complex condition like dementia with either minimal or no specific training.

Our Fix Dementia Care investigation found more than a third of homecare workers had received no training whatsoever. Plus, only 2% of people affected by dementia reported they felt visiting homecare workers had received an appropriate level of training.

This led to situations where people living with dementia were left in soiled sheets, without food or declined so drastically they were admitted to hospital.

To enable people living with dementia to live well, all professional care workers must receive appropriate training that allows them to be confident and competent in providing quality dementia care.

Professional care services are essential to helping people with dementia to live well, and to reducing the demands placed on family carers. When these care services fail people affected by dementia, the impact is devastating both for the people concerned and also for the wider health and care system.



A new deal from care providers

87%

87% of people with dementia who were interviewed receive help from family in their day-to-day life but only 14% receive help from a paid carer

please see Appendix 1 for more details on method and sample size



A new deal from society

48%

Almost half (48%) of people living with dementia who were interviewed worry about becoming a burden

please see Appendix 1 for more details on method and sample size

We call on the public to unite with us to create communities where no one with dementia is excluded and no one faces the condition alone.

Too many people affected by dementia feel society fails to understand the condition they live with, the impact of the symptoms or how to approach or interact with them.

A lack of public awareness, understanding and associated stigma negatively affects how many people with dementia view themselves, and how they fit into society.

‘With a little bit of support, stimulation and encouragement most people with dementia can do it.’

Person with dementia

As a result people with dementia and the people who support them lose out. A third (35%) of people with dementia responding to our survey reported feeling lonely, while more than a quarter (27%) of people responding to our carers survey said they felt ‘cut off from society’.

This cuts both ways. People affected by dementia still have an incredible amount to offer to their community. If appropriately supported, they can continue to play an active and valuable role even years after diagnosis.

It is society’s responsibility and duty to support people living with dementia to remain part of the community, to be treated equally and to feel accepted by those around them.

‘Prior to this we had just a group of friends we used to see, but we’ve widened that now through the dementia support group.’

Person with dementia

Rather than feeling that people you encounter will define you by your condition, society must develop everyday ways to understand and accept dementia. Then people will look beyond the symptoms, beyond the label and see people for who they actually are.

Beyond a label

Our Dementia Friends programme is the UK’s biggest-ever initiative to change people’s perceptions of dementia. It aims to transform the way the public thinks, acts and talks about the condition. Since the initiative launched nearly two million people have become Dementia Friends, and it is our ambition to reach four million by 2020.

People we interviewed living with dementia told us how beneficial being in an accepting and understanding environment could be for their wellbeing.

‘She has lived in the house for 50 years so all the neighbours and local shopkeepers know her, it’s always been the same shopkeeper, everyone knows her, she is in a familiar environment.’

Carer of person with dementia

Dementia befriending services were singled out by those who used them as making a significant difference to their lives. Regular visits from a befriender with a shared hobby or similar background to the person living with dementia delivered social interaction. It also provided a way of maintaining independence by helping them carry out practical tasks or taking them to the shops.

Family carers also talked positively about how the presence of a befriender allowed them more time for themselves.

People who have had support to allow them to join groups and build new friendships after a dementia diagnosis, are often those who can continue to lead active lives.

The opportunity to talk about and share experiences with others who are affected by dementia can be invaluable, both for the person living with dementia and their carer.

‘We attend an early-onset dementia group, which is once a month. And, separately, we go for dinner with the group – without the support workers – once a month. There is a [another] group for early-onset dementia which meets the second Thursday of every month. We are going to the theatre with them and we go tenpin bowling with them. We have made a lot of friends through it so we formed a dinner club which meets every month.’

Carer of person with dementia

Everyone has a role to play

Society must seek to create welcoming environments for people affected by dementia to meet and find reassurance through one another. This might be through volunteering with services like Dementia Cafes and Alzheimer's Society Singing for the Brain groups, being involved in dementia research programmes such as Join Dementia Research or becoming a Dementia Friend or Dementia Friends Champion.

Everyone, from local businesses to schools and religious groups, has a role to play. Over 225 communities have been recognised by the Alzheimer's Society Dementia Friendly Communities recognition process since it launched in September 2013, which has exceeded the original targets. However, it is essential that communities continue to sign up to be dementia friendly so that people with dementia, no matter where they live, can continue to be active, engaged and valued.

At a national level, organisations have a part to play across every sector. Alzheimer's Society has seen engagement from across utility providers, emergency services, faith groups and transport providers with best practice guidance already produced for the retail, housing, finance and arts sectors and for employers. Using this guidance, organisations in these sectors can better support their customers and staff affected by dementia and support the growth of local Dementia Friendly Communities.

We spoke to a number of people affected by dementia through our research with Ipsos MORI, are actively involved in raising awareness of dementia through local and national groups to help their community be more dementia friendly. This involves investing a great deal of time and energy in supporting and guiding others through the process of securing practical and emotional support. In turn they have learned more about their condition and talk about how they have learned to 'live very well with it'.

'We do a lot of advocacy – we've done all sorts of things. The alternative would be to sit at home and I know from experience that my progression would be quicker. We got involved in something where we could help other people and along the way we got involved in loads of stuff.'

Person with dementia

Standing side-by-side with people affected by dementia

Alzheimer's Society's new Side-by-Side service helps people living with dementia to keep doing the things they love and get out and about with the support of a volunteer. This extra support is essential to prevent people affected by dementia from feeling isolated and ensuring they remain part of their community for as long as possible. By the end of 2017, we want every person with dementia to have the opportunity to access our Side-by-Side service.

A new deal from society

‘I can give something back – so it helps in that way.’

Natalie, who has dementia

Natalie lives with her husband and dogs. She was diagnosed about four years ago with early-onset dementia. Despite this, she manages to remain fit and is able to communicate well. Her husband puts this down to a combination of factors, but specifically the amount of social activities she undertakes. Many of these activities are based around communicating with others, for example giving talks about what life is like with dementia. She has a supportive social network– so much so, that some of her friends have taken a dementia awareness and carers course to deepen their understanding of her condition.

‘I’ve never been busier. I do an awful lot!’

Natalie is involved with her local community mental health team, raising awareness of dementia and offering peer support to others. Through the team Natalie has been asked to deliver information sharing sessions to people who may be coming into contact with people with dementia for the first time. This includes newly qualified doctors and nurses and other members of hospital staff.

‘[The group’s] been set up to raise awareness of dementia issues and to offer peer support to people who have just been diagnosed. There are professionals involved, but they use people who actually have dementia to tell people what it’s like. It started when we went to a talk, then we went on a course for six sessions which was all about dementia, medication and diet. Eventually I was invited to join this group and it’s almost like a job. It’s great that I am able to give something back. It’s the feel good factor when I’ve done a talk or we’ve set up a new group.’

Living with dementia is still, understandably, difficult for the couple, particularly more recently as Natalie has begun to develop problems with her spatial awareness and vision.

‘I’d much rather not have [dementia], but certainly the dementia talks really give me a boost and I can give something back, so it helps in that way.’

Case Study: Natalie

Natalie lives with her husband and dogs. She was diagnosed about four years ago with early-onset dementia.



A new deal from you

27%

Over a quarter (27%) of carers for people with dementia feel 'cut-off from society'

please see Appendix 1 for more details on method and sample size

We're asking you to be united against dementia. Join the movement and help to find a cure, improve care, and offer help and understanding to everyone affected.

Dementia is set to be the 21st century's biggest killer (Office for National Statistics, 2016). It costs the UK economy over £26.3 billion a year and too many face it alone (Alzheimer's Society, 2014). Despite this, dementia still doesn't get the attention it deserves. We must do more.

At Alzheimer's Society we're committed to being the rallying point for all those who want to make change happen. We'll stand with people affected by dementia – supporting them to tell their stories and be heard, campaigning for their rights and creating communities where people affected by dementia are supported and accepted. We'll also combine local face-to-face support with phone and online advice to help steer people through the maze of health and social care to make sure people get the best support available.

In recent years tens of thousands of people have joined us to call for and create change. Our Right to Know campaign highlighted how many people with dementia were living without a diagnosis, facing distressing symptoms alone and missing out on services to support them. With the support of people affected by dementia and the public, we have been able to significantly increase the number of people who have been given a diagnosis, to more than two thirds. Thanks to our campaign, official targets now exist which allow us to hold key decision makers to account.

Our Fix Dementia Care campaign revealed poor instances of care across a range of settings throughout 2016. Since then 60,000 people have signed a petition calling for change. Turning up the volume on dementia can and does make a difference and we must create enough noise to make the issues identified in this report impossible to ignore.

It's time to unite against dementia. Regardless of background, interests or profession, together we can change society. In our survey of the public, a quarter said they are currently, or had in the past, taken action to make a difference to the lives of people with dementia. Whether through volunteering with services or research, donating to us or taking part in one of our campaigns we want to see many more involved.

Joining our campaign will help to champion the voice of people with dementia, to show decision makers that dementia is not an issue that can be ignored. It can open the door to new information and advice around dementia and further opportunities to be involved in campaigning, fundraising and research.

Search 'Alzheimer's Society – Unite with us' online and together we can transform the landscape of dementia forever. Even simply backing our United Against Dementia campaign on social media, or wearing our pin-badge, is a way of showing your support and spreading the word. Whatever you do, you will be part of a movement that will not rest until people affected by dementia can live the life they want.



Jeremy Hughes CBE
Chief Executive, Alzheimer's Society



Image: Third Sector – Nathan Clarke Photography

**Unite
against
dementia**

What you can do today

To government – We challenge those in power to create a long term, sustainable system for funding dementia care. This system must uphold the rights of people with dementia, maintain quality of life, stop catastrophic care costs for families and deliver joined up services that end the inequity of support between dementia and other conditions.

To providers – We call on care providers to ensure everyone affected by dementia receives the support they need, throughout the dementia pathway.

To society – We call on the public to unite with Alzheimer's Society and create communities where no one with dementia is excluded and no one faces the condition alone.

To you – We ask you to be United Against Dementia, join the movement and help improve care, offer assistance and understanding to everyone affected, and help find a cure.

Appendix 1: Methodology – A new way to listen

We are hugely grateful to the 1,656 people affected by dementia who have contributed to this report. There are no greater experts than them to tell us about what it is like to live with the condition.

This report is based on four strands of research:

1. Survey of 996 people with dementia

A large-scale survey of people living with dementia who access Alzheimer's Society services was carried out between February and April 2017 to explore what life is like for people living with dementia. Due to the ambitious nature of this research, a pilot survey of 148 people with dementia was conducted between November and December 2016 to check the feasibility of the methodology.

Following the pilot, key learnings around consent were built into the main stage survey procedures. Fieldwork was led and carried out by Alzheimer's Society and our team of volunteers across England, Wales and Northern Ireland. The survey was designed to be self-completed by people with dementia or with support from one of Alzheimer's Society's trained volunteers. Volunteers were provided with specific training on gaining consent from people with dementia. Overall, 1071 surveys were completed by people with dementia. In total 966 of these passed our rigorous criteria on consent.

2. In-depth interviews with people with dementia

Between November 2016 and March 2017 Ipsos MORI conducted qualitative research which set out to generate rich, authentic and detailed insights into what life is like for those living with dementia. This research study was made up of in-depth interviews of between 60–90 minutes, with thirty two people living with dementia and five carers of people with dementia. They included people from different ethnic and social groups, people under 65, those living in rural areas and people living alone. Interviews were conducted across a variety of places in England, Wales and Northern Ireland.

The interviews with people with dementia were conducted either in people's own homes, residential care homes or drop-in day centres. The interviews with carers took place over the telephone. People living with dementia were provided with the opportunity to have a carer present during the interview. Moderators were provided with training by Alzheimer's Society before the research.

3. Survey of unpaid carers of people with dementia

To understand the impact on carers of providing help or support to someone living with dementia, Ipsos MORI interviewed a nationally representative quota sample of adults aged 40 years and over between 7 and 8 November 2016. Overall, 500 interviews took place with people who said look after, or give help or support to a family member, neighbour or someone else who has been diagnosed with dementia. Interviews were carried out online. The data was not weighted as the profile of carers of people living with dementia is unknown.

The survey questions were designed to gain an understanding of the type and level of support provided by the carers. They also covered the impact of caring on their relationships, finances and health and what support and advice they receive.

4. Survey of general public

To understand perceptions and attitudes towards dementia and dementia care among the general public, Ipsos MORI interviewed 2,356 adults aged 16–75 in the United Kingdom between 13 and 17 January 2017. Interviews were carried out online on the Ipsos MORI i-omnibus survey. Additional interviews were carried out in the North East and Northern Ireland to ensure at least 100 interviews were completed in these areas. At the analysis stage the data was weighted to the known population profile for the United Kingdom for this audience.

Ipsos MORI, social research agency, said:

'It has been an honour and a challenge to be asked to carry out this groundbreaking research for such a worthy cause and respected charity as the Alzheimer's Society. To undertake to meet the Society's ambitious brief, involving public understanding and views of dementia but also carers and people living with dementia as well, was daunting. We are hugely proud to be involved in this work. Developing methodologies which ensured that people with dementia had the capacity to give informed consent to being involved in the research and give meaningful responses was paramount for both the qualitative and quantitative research strands. We were pleased to involve nearly 1,000 people with dementia in the study as well as the obtaining the views of carers and the general public.'

Sir Robert Worcester KBE DL, Founder, MORI

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Alzheimer's Society (report authors)

Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.

If you have any concerns about Alzheimer's disease or any other form of dementia, visit alzheimers.org.uk or call the Alzheimer's Society National Dementia Helpline on 0300 222 1122. (Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)



Ipsos MORI Social Research Institute

Ipsos MORI

Ipsos is an independent market research company managed by research professionals. Founded in France in 1975, Ipsos has grown into a worldwide research group with a strong presence in all key markets. Ipsos ranks third in the global research industry. With offices in 86 countries, Ipsos delivers insightful expertise across six research specialisations: advertising, customer loyalty, marketing, media, public affairs research, and survey management.

In Britain, Ipsos MORI's Social Research Institute works closely with national governments, local public services and the not-for-profit sector. Its c.200 research staff focus on public service and policy issues. Each has expertise in a particular part of the public sector, ensuring we have a detailed understanding of specific sectors and policy challenges. This, combined with our methodological and communications expertise, helps ensure that our research makes a difference for decision makers and communities.

Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.

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