



Dementia – the true cost:

Fixing the care crisis

May 2018





In the UK, one person develops dementia every three minutes (Matthews, F.E et al 2016). It turns lives upside-down and currently there's no cure. Almost everyone knows someone who has been affected. Yet, too many people living with dementia face the condition alone or struggle with inadequate care.

People living with dementia may get a diagnosis and medication through the NHS. But the symptoms can mean they need help with everyday activities – from washing and dressing to visiting the shops. This means most of the support

they get is through social care, so they're disproportionately affected by failures in the social care system.

Every week Alzheimer's Society supports thousands of people with dementia and hears of their daily struggle with failing health and care support. We brought this learning together with a series of listening events in Winchester, Newcastle, Birmingham, Cardiff and Belfast. This report reflects the experiences of those on the front line and builds on our policy and campaigning activity.

Title

Dementia – the true cost: Fixing the care crisis

Publication date

May 2018

Acknowledgements

We'd like to give special thanks to the people affected by dementia who attended our listening events. They gave us a detailed, in-depth understanding of the challenges they face getting and paying for essential care.

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Sandy's story

Sandy Sweet Berkshire

Sandy Sweet, whose mother has dementia:

'Mum was diagnosed with dementia in her early 70s. Dad cared for her at home for many years until the stress became too much and he had a heart attack. We then tried to access home assistance from the local council, but this proved impossible.

The only real option was to move Mum into a care home. Dad sold the family home and bought a small bungalow nearby. We all contributed to the top up fees for over seven years, amounting to hundreds of thousands of pounds. We then tried to access NHS funding for Mum, who was by now in an advanced stage of dementia. [She was] doubly incontinent, no longer able to communicate verbally and unable to feed or dress herself.

The funding was refused. We couldn't understand why. We knew people with cancer, advanced diabetes and brain tumours who had been awarded funding. Why is dementia treated so differently to other diseases?

Eventually we negotiated social care funding for Mum. However, the amount the council pay is significantly less than the fees charged. This subsidisation by private payers is another example of a system riddled with inequalities.'

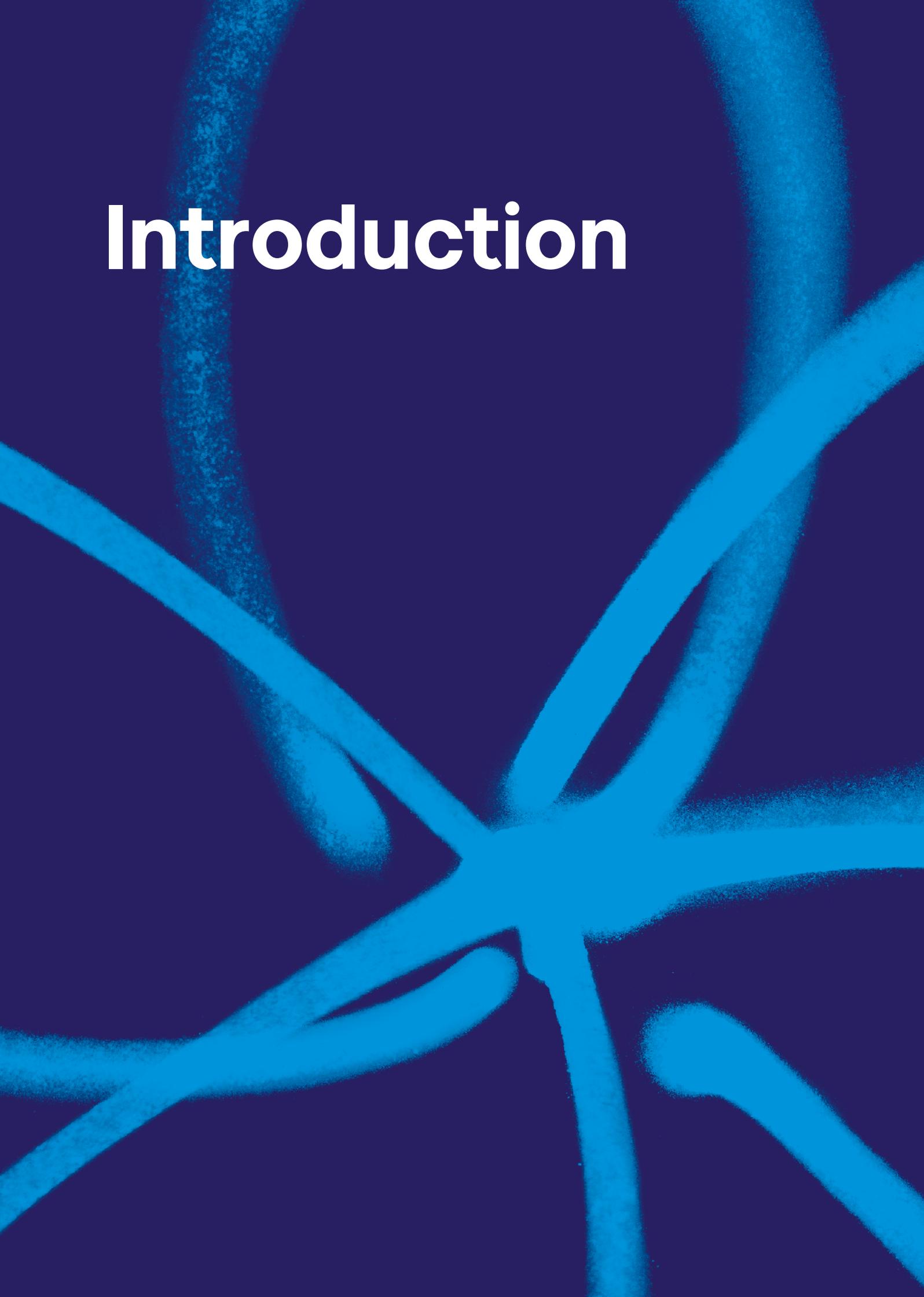
Giving people a voice

'Our Mum is elderly, vulnerable and unable to vote. She no longer has a voice and has become effectively disenfranchised. So we must speak for her and others like her. Society is judged by its treatment of the elderly and this state of affairs is nothing less than shameful.

Dementia is an illness. We cannot throw our hands up and say it's all too difficult. Governments can no longer turn a blind eye and say we can't afford it. We have to act now to ensure that people affected by dementia are treated fairly and properly. We must fund a social care programme which will allow the most vulnerable in our society to be cared for in an environment which allows them to live with dignity. Government must step up to the plate and be honest with the electorate. This situation is not going to go away.

Everyone affected by dementia, either those living with the disease or their carers and relatives, deserve so much better.'

Introduction

The background of the page is a dark blue color. It features several overlapping, semi-transparent, lighter blue shapes. These shapes include thick, curved lines and circular arcs that intersect and overlap each other, creating a complex, abstract pattern. The overall effect is a sense of depth and movement, with the lines appearing to radiate from a central point or to be part of a larger, interconnected structure.

People affected by dementia deserve better

This report is about turning up the volume of the voices of people affected by dementia who rely on health and social care support. It's about the families forced to have 30 separate conversations with different healthcare professionals because the system is so difficult to navigate. The people unnecessarily stuck in hospital because there's little available support in their community. The carers sacrificing their own health to provide round-the-clock care for a loved one with little or no support from the state.

It's about listening to the challenges and frustrations of people across England, Wales and Northern Ireland – and connecting them to decision-makers with the power to change the system. It's about showing politicians, healthcare professionals and the wider public that people affected by dementia deserve better. That they deserve to live well, and that living well is possible.

Now, we all must unite to make it happen.

Facing a social care crisis

In the UK today, two thirds of people using homecare and 70% of people in care homes live with some form of dementia (UKHCA 2013 and Alzheimer's Society 2014). Dementia is potentially the most complex and challenging condition social care has to support. Sadly, it's the recipients who bear the brunt of an under-funded and poorly equipped system.

Through our local services, helpline and online forum we've heard from couples forced to ask their adult children to take on their mortgage because they couldn't cover social care costs. Many others told us that, since diagnosis, the biggest impact on their lives has been financial. For people with dementia, social care is an issue that can no longer be ignored. The social care crisis is a dementia crisis.

Abandoned by the system

This report builds on our existing research and campaigns. It's based on qualitative research from five listening events with people affected by dementia, social care professionals and dementia lead nurses in Winchester, Newcastle, Birmingham, Cardiff and Belfast. In total, we gathered evidence and testimony from over 70 people to get an in-depth understanding of the challenges they face day-in and day-out to get the care they need. Many had been struggling for years, abandoned by a broken system, without any support or anyone willing to listen.

We found that:

- **People are facing catastrophic costs to pay for their care and support. They wouldn't be expected to make this sacrifice if they had another medical condition.**
- **People struggle to access the vital care they need in the first place.**
- **Once people affected by dementia get support, their care is often poor quality.**

Dementia is the channel through which to achieve social care reform. A social care system that works for people with dementia can work for everyone.

Enough is enough

I'd like to sincerely thank everyone living with dementia, the carers, families and healthcare professionals who shared their stories with us and attended our listening events.

Some people told us they took comfort in realising they're not alone in battling a broken care system. Others said they found sharing their experiences cathartic.

But what united everybody was overwhelming anger at the decades of political inaction that has left people affected by dementia enduring inadequate care and crippling costs.

I couldn't say this better than Jean, who has been caring for her husband Rodney since his diagnosis of vascular dementia in 2014:

'Why is dementia treated so differently from cancer or any other life-threatening disease? Why should we be left in this position and faced with forfeiting so much of our income and our home just to get the support he needs to live? I'm happy to pay towards care, but what's expected is just too much.'

At Alzheimer's Society all our work is guided by the voices of people affected by dementia. Last year we carried out our largest-ever survey, reaching over 1,600 people with the condition. Our research, [*Turning Up the Volume: unheard voices of people with dementia*](#), explored a range of issues from loneliness and isolation to loss of identity. People told us how the impact of a dementia diagnosis can be devastating. Coupled with the constant fight to get support to live with the condition, it can become unbearable.

That's why we're galvanising a movement and campaigning hard for reform. Through our [Fix Dementia Care campaign](#) we've exposed poor care across a range of settings. So far, over 150,000 people have joined us to call for and achieve change. We stand with people affected by dementia – supporting them to tell their stories and be heard by those with the power to reform the health and care system.

Turning up the volume on dementia can and does make a difference. In England, Secretary of State for Health and Social Care Jeremy Hunt MP, heard our calls. He specifically addressed the unique challenges people with dementia face in his landmark speech this year on the upcoming Green Paper on social care reform.

After a successful campaign by Alzheimer's Society Cymru, the Welsh Government recently published their first ever [Dementia Action Plan for Wales](#) providing an important opportunity for improving health and social care. In Northern Ireland the [Power to People](#) proposals demonstrate the need for a cross-party approach to transform how care and support is delivered and funded.

We cannot lose momentum and must hold politicians to their word, creating enough noise to make our case for change impossible to ignore. This report is a rallying call from the front line that enough is enough. The social care crisis is a dementia crisis and we need bold reform that ends this inequity.



Jeremy Hughes

Chief Executive Alzheimer's Society

The Dementia Statements

People with dementia have told us what kind of life they want.

The Dementia Statements, launched in May 2017, 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 cry to improve the lives of people living with dementia and to recognise that they shouldn't be treated differently because of their diagnosis.

Alzheimer's Society is championing these statements, working to create a society where those affected are supported and able to live without prejudice.

When it comes to the quality and provision of social care, the hopes and expectations of people with dementia are very different to the experiences shared with us in our research. For too many, compassionate and properly funded care delivered by well trained professionals is the exception, not the norm.

State and society must unite now to establish a future for people with dementia. Together, we must build public understanding, offer quality and affordable care and support people and their families to live the life they wish to lead.

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.

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're calling for change

We're calling on governments in England, Wales and Northern Ireland to reform social care, to end the inequity and deliver the change that people affected by dementia deserve.

We want to see action on:



1. Cost

The cost of extra care charges for a health condition such as dementia must be covered by the state.



2. Quality

All health and social care workers must be given the training and support they need to deliver quality dementia care.



3. Access

Everyone with dementia should have a care navigator to support access to timely, preventative and integrated support.

Cost



People with dementia typically spend £100,000 on the care they need - it would take 125 years to save for this if people saved at the same rate as their pension

£17 bn



People affected by dementia shoulder two thirds of all dementia care costs in the UK



'Dementia care' can cost up to 40% more than care for people without the condition

Quality



23% of 'dementia care services in England are failing, compared to 19% of all services (Care Quality Commission, 2018)



1 in 3 homecare workers told us they have had no dementia training



49% of UK adults agree that people with dementia experience worse care and support than people with other long-term conditions such as cancer or heart disease

Access

1,400



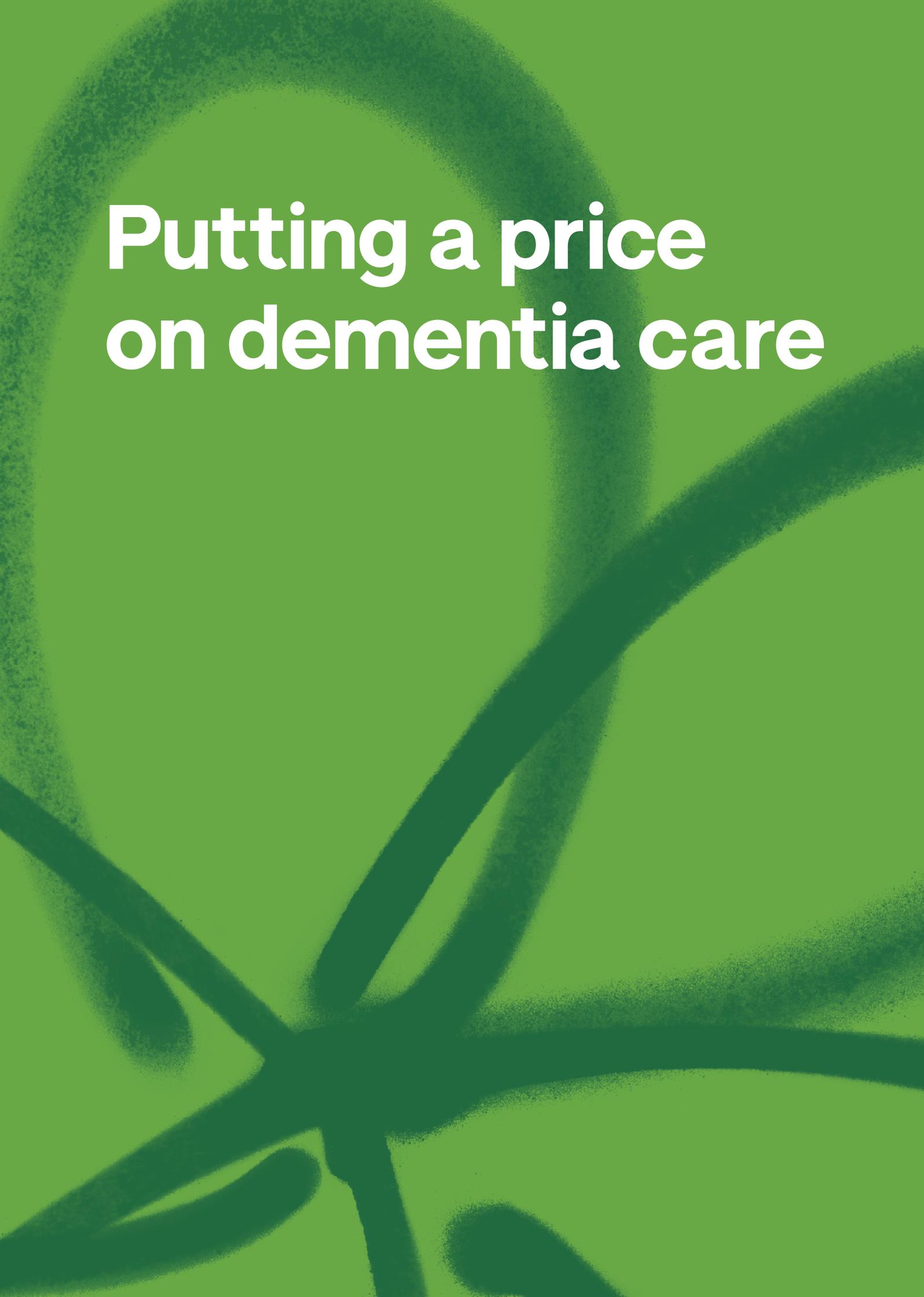
At least 1,400 people with dementia spent Christmas 2017 in a hospital ward, despite being ready to go home



More than 50,000 avoidable emergency admissions for people with dementia in 2016/17



40,000 additional care home places will be needed by 2021 for people with dementia. Current trends suggest only an extra 9000 beds will be available for everyone by 2022 (CQC)

The background is a solid green color with a faint, stylized outline of a human face. The outline is composed of thick, dark green lines that form the forehead, eyes, nose, and mouth. The text is centered in the upper half of the image.

Putting a price on dementia care





Lynda Basford West Sussex

Lynda Basford, whose husband Michael is living with dementia:

‘I’m terrified of what will happen when our savings run out this year.

My husband Michael is 82 and was diagnosed with dementia in 2005. For 12 years we managed at home together. Michael attended a day centre three times a week and we had a sitter come in once a week, all of which we paid for through our savings. Other than that, I looked after him on my own – supporting him to eat, dress and use the toilet. People don’t understand how challenging it is.

In April 2017, Michael moved into a care home after it was decided he was no longer safe at home. The council said he was eligible for some state funding, but the only home I was confident could meet his needs was a private one costing £800 a week.’

Facing a funding lottery

‘The council contribution wouldn’t cover even the most basic homes. Michael and I have ended up paying about £500 a week so he can get the dementia care he needs. You go away thinking you have a pot of money from the local authority, but you don’t. What the local authority pays and what the beds cost don’t match.

I’m terrified of what will happen when our savings run out this year. After nearly a year he’s well settled but if I can’t find any other source of income he might be evicted and we are back to square one. They say we are the ‘never had it so good’ generation, but that doesn’t mean we are all sat on a million pounds. We saved for our retirement but we couldn’t have planned for this.

The care people with other diseases like cancer receive from the NHS is amazing, and rightly so. But people with dementia are not treated like this. The fact he has a tag on called dementia means he has to pay – it’s a real lottery.’

£100,000  £

People with dementia typically spend £100,000 on the care they need – many spend much more

£17 bn 

People affected by dementia shoulder two thirds of all dementia care costs in the UK

40% 

Dementia care can be up to 40% more expensive than standard social care

Shouldering the burden of care costs

Dementia is caused by a disease, just like cancer and diabetes. Yet people with dementia remain the main victims of a broken system. Unlike if they developed another condition, people with dementia are forced to spend hundreds of thousands on care.

Many people who attended our listening events described how shocked and worried they had been when they found out they were responsible for covering care costs.

They have either been forced to pay out huge amounts of money, or rely on state support that has been cut to the bone.

Many participants said this was unfair, and that the care and support system was broken.

‘The whole thing locks around your funding, doesn’t it? How do you get the care? And who decides what care you get? If you had cancer, and you were pretty bad, you get everything for nothing.’

Carer of person with dementia

Taking on catastrophic costs

People at our events were also surprised by the sheer cost of care and support. Our research (2017) shows the typical total cost of dementia care for one person is £100,000. For many it can be much higher.

It would take someone 125 years to save that much if they put away the amount they contribute, on average, to a pension.

It's impossible to expect everyone to be prepared for these costs, and there can be devastating consequences. We often hear from people affected by dementia who have spent everything they have on care and have even sold their home. Others who need significant support have felt forced not to access care because of the expense. This puts their health, and sometimes the health of those around them, at risk.

'Some of us can't afford basic adaptations – I couldn't afford a bed sensor for my mother. She went missing one night and the local police force sent out two helicopters and two cars to search for her. What would've been more cost effective?'

Carer of a person with dementia

People living with dementia face higher charges for care and support than those with other conditions. Dementia can be complex and involve symptoms that need tailored support. This means care providers often charge a premium rate for dementia care. We know that in some places this is up to 40% more than the 'standard' price.

This extra cost isn't covered by the NHS, as many people at our events had expected. Even funding meant to cover both health and care needs, such as NHS Continuing Healthcare, is normally out of reach for people with dementia. Instead, people who need the care to survive end up paying more.

Cash-strapped councils fail to pay, or are unable to cover the extra money needed to provide complex support. When councils can't cover the full cost, people with dementia and their families are forced to pay a 'top up' payment. This can be hundreds of pounds a week.

'My mum's medical condition is what I'm paying extra for. It didn't even occur to me until just now.'

Carer of person with dementia

No one should have to spend everything they have on care. But people living with dementia spend a disproportionate amount of their assets on the care they need. Of the £26 billion a year spent on dementia care in the UK, two thirds is shouldered by those affected. People at our events spoke passionately about how unbalanced the division of responsibility between individual and state currently is. They agreed people affected by dementia should make some contribution towards the cost of their care. But this should be a fair amount that does not impact on their wellbeing or ability to live a normal life.

'It costs us £38,000 a year for home care.'

Carer of person with dementia

Coping with an unfair system

This issue is made worse by the lack of a cap on care costs. In England, the amount after which someone pays for care – assets above £23,350 – has not changed in eight years.

The combination of expensive care, and no limit on what someone can spend, means some people spend nearly everything they have. At the same time, the number of local authorities offering an increased rate to providers to reflect the extra cost of dementia support has dropped. This has meant increased demands for top-up fees from families, poor quality care from providers operating on a shoestring budget, and providers even refusing to accept people with dementia.

‘The big thing at the care home is why should my mum be sitting next to someone who’s getting care, who’s paying nothing? And mum is paying the full whack?’

Carer of person with dementia

Our research (Alzheimer’s Society and YouGov, 2018) shows people’s strong feelings about costs. Nearly three quarters (73%) of the public think it’s unfair people with dementia face using their assets to pay for care, while those with a different condition get support through the NHS.

We also found 79% of respondents believed someone could face spending everything they have on dementia care. Also, three in five people now worry that any savings they have will be spent on care and support, leaving nothing to pass on to their loved ones. This is compared to 40% before the General Election in 2017 (Alzheimer’s Society and YouGov, 2017).

‘Everything is asset-based. We didn’t buy our house to pay for our care, we bought it to provide for our children, grandchildren.’

Carer of person with dementia

Fees paid by social care commissioners often don’t reflect the true cost of care. Research shows that the average fee paid to care homes per resident fell short of the real costs of providing the service by more than £100 a week (LaingBuisson 2017).

We believe the cost of delivering high quality dementia care must have a close and transparent connection to the price that people pay for their care, however that care is commissioned. The care market must not be propped up or subsidised by people with dementia who often have little choice but to pay the prices they are quoted.

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Access to dementia care and support





Penny Bennett Doncaster

Penny Bennett, nursing home owner:

‘If I’m not around, who else is going to look after them?’

For 34 years I’ve owned and run a nursing home in Doncaster supporting people with advanced dementia and behaviours that challenge. It’s harder than ever now as I’m expected to do more and more with less. I’ve had to reduce costs and staff because I’m receiving less money from the clinical commissioning group. I hate it, but I don’t have a choice as I can no longer afford the staff I need.

I care deeply about people with dementia and their families, but it’s so hard to keep the place going. I take in people with dementia most other care homes are already turning away because they have complex,

challenging needs. If I’m not around, who else is going to look after them? Families come to me when they have nowhere else to go. I don’t want to start turning people away, but with such limited resources I worry people won’t be safe. It’s soul destroying.

The powers that be are not being realistic. They don’t recognise people’s needs and the true cost of care. I take a holistic approach and believe that you don’t need drugs, you need staff with expertise and understanding of the condition. But if you can’t pay more than the minimum wage people won’t want to work in this environment as it can be really demanding. People would get paid more working in a supermarket. Care has always been a Cinderella service, but coming into work now is like walking into a burning building without any fire-fighting equipment.’





Arthur Childs London

Arthur has Alzheimer's Disease and was diagnosed in September 2017. His wife Jennifer Childs says:

'Arthur left the house on his own when I was at work and no-one knew where he was. He was found in the street badly bruised, but he couldn't explain why and had to spend the night in hospital. We have only been allowed to have carers coming in for seven hours a week,

I requested 11 hours but social services refused. So Arthur spends hours on his own during the day. Arthur needs more attention, but I can't give up work as we cannot afford to live on the benefits we receive. My health is suffering because of the pressure on me and I find it difficult to sleep because I worry about Arthur constantly when I'm not there.'

1,400



At least 1,400 people with dementia spent Christmas last year in a hospital ward, despite being well enough to go home (Alzheimer's Society, 2017)

50,000



There were more than 50,000 avoidable emergency admissions for people with dementia in 2016/17 (Alzheimer's Society, 2018)

'There's so many different criteria and trying to fit people into boxes. It can become impossible to access social care, even if you are the one initiating it. It's completely out of our control.'

Carer of person with dementia.

Left to fend for themselves

Hundreds of thousands of people affected by dementia in the UK are battling the condition alone. Many people told us they felt helpless and disempowered by the process of getting care.

'I originally accessed social care, but had a reassessment and the care has been taken away as I can feed and clothe myself.'

Person with dementia

People told us about serious challenges they faced getting care. Strict eligibility criteria set by legal frameworks across the UK means only people with severe needs receive state funded support. It wasn't just the low threshold set before someone has to pay expensive care themselves. Annual care cost increases are a growing problem. So are providers who 'cherry pick' people with less challenging needs.

'Cherry-picking' often happens when a council is unwilling or unable to cover the extra costs of dementia care. People with complex needs are then rejected by providers either because of their limited budget or because they do not have the funding to deliver the specialist support needed.

Not only can this be extremely distressing. It can also limit the options available to people searching for support. People told us they felt deserted by the care system at a difficult time. They then had no alternative but to look for care in areas outside of the community they knew and loved.

‘When I said “I’m after dementia nursing” the care home said “oh no, we don’t do that.” I asked the chap in charge if he could recommend any because I couldn’t find any with any spaces. He said, “there’s this one – but it’s the best of a bad job, really.” So, I was absolutely devastated.’

Carer of person with dementia

State-funded care is heavily rationed across the UK. In England people are expected to pay for their own care if they have assets of £23,250 or above. They then have to contribute until they have a little over £14,000 left. This means people are expected to spend nearly everything they have before they’re given any help.

The threshold hasn’t changed for eight years. In those eight years inflation has risen by a fifth and house prices have soared, so thousands more people affected by dementia don’t meet the criteria and are expected to fend for themselves. Our research with Laing Buisson (2017) shows that more than half of people with dementia accessing care are now paying for at least part of their care costs, with many paying massive sums.

‘I rang the local authority and they said, “has your mum got more than £14,000 in savings?” And as she did have a bit, because she’d sold her house that was it. It was just “we can’t help you” and we were just on our own.’

Carer of person with dementia

Families pushed to their limits

As support from the state has been pulled back, family carers are increasingly expected to pick up the pieces. A third of family carers of people with dementia, many of whom are older or in need of support themselves, provide personal care. A fifth give 20 or more hours of care a week and one in ten give 50 hours a week (Alzheimer’s Society, 2017). Many family carers are being pushed to their limits. More than three in five told us how their own health had declined because of caring for someone, making them more likely to need costly care themselves.

Family carers have the right to a better offer. They need information, carer’s assessments and wellbeing at the heart of legislation across the UK. Yet people consistently told us at our listening events and through our helpline they were neither sure of how to access help nor where to turn next.

‘I was completely disempowered, because I couldn’t get the information I needed. I didn’t know where to go to get it. And anytime I rang back, it was somebody else at the council, who gave me different information, which didn’t correlate to the previous information.’

Carer of person with dementia

Finding and paying for costly private care is challenging, and the costs can be unlimited. This means many people delay getting care until their health has declined to the point they have no other choice. We heard from people who received virtually no state support between diagnosis and developing significant care needs. As a result, many told us they felt isolated and abandoned.

‘While dad was in hospital, I applied for NHS Continuing Healthcare funding. He was doubly incontinent, unable to feed himself and confined to a wheelchair, but social

services told me that I didn't stand a chance of getting the funding. When I asked "what does a patient have to be to qualify" her reply was "practically dead"'

Carer of person with dementia

Failing to provide the help people with dementia need, when they need it, is a false economy. Nearly a fifth of carers have given up work to do so. And a quarter more have had to reduce the hours they work to care for someone with dementia (Alzheimer's Society, 2017). The cost to businesses in England is £1.6 billion every year (CEBR, 2014).

'Social services sign you off as "stable" if you've not been in touch, but dementia is not stable.'

Person with dementia

Hidden costs for the NHS

We believe a lack of high quality social care costs the NHS more through poorer health, inappropriate admissions, lengthy stays and delayed discharge.

We sent Freedom of Information requests to NHS Trusts across England in April 2018. We wanted to find out how many people over 65 with dementia had had an emergency admission to hospital for reasons that could have been avoided through improved and earlier support in the community. This included falls, delirium, urinary tract infections, chest infections and dehydration.

From 65 NHS Trusts we found that in 2016/17 there were more than 50,000 hospital admissions for people with dementia that could have been avoided, an increase of 70% over five years. This figure underlines the false economy to the state of limiting access to social care.

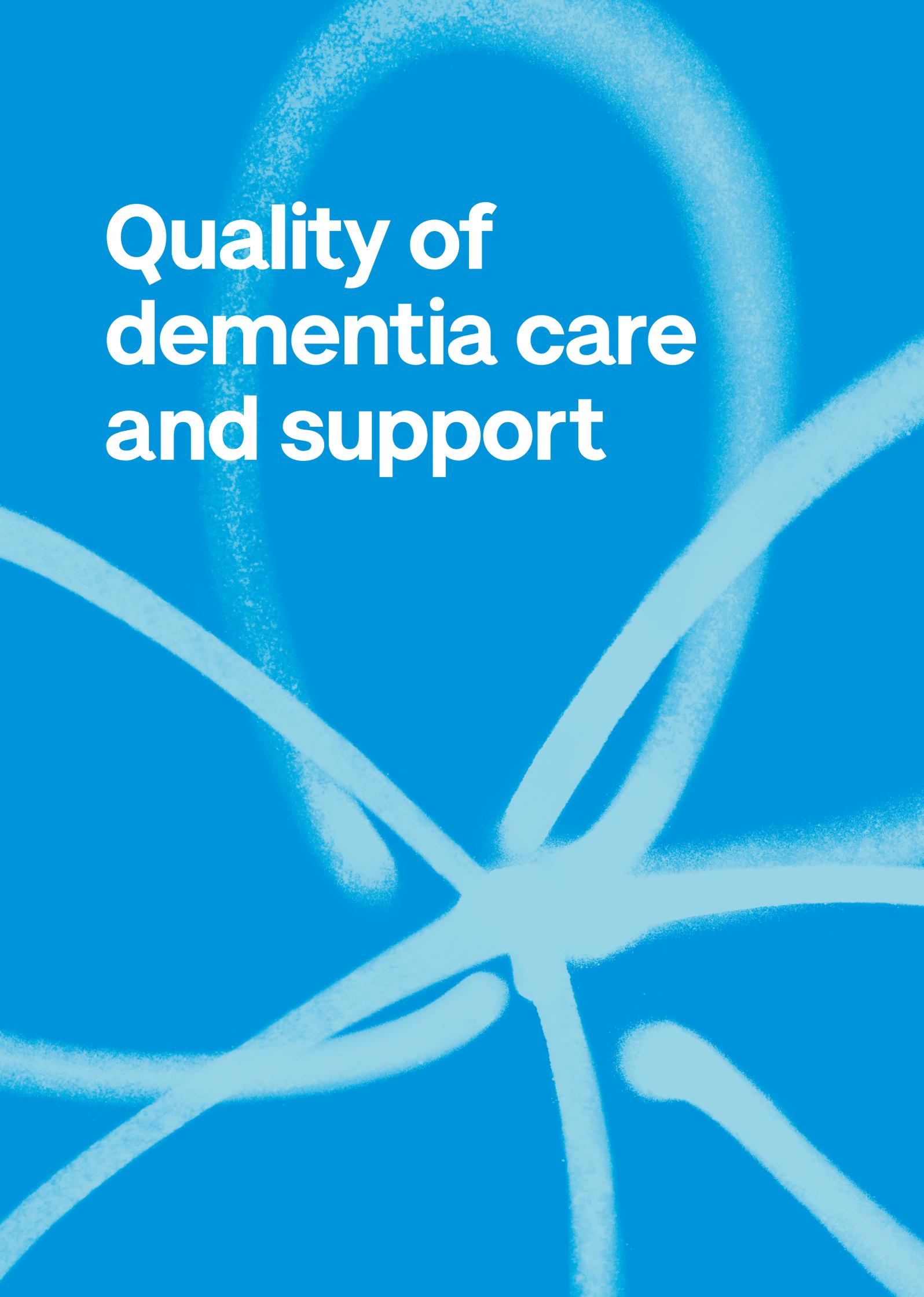
There's also the distress people feel when they're forced to navigate a complex system that is not integrated and continues to work in silos. Through our Fix Dementia Care campaign (2016), we know that once in hospital, people with dementia stay for twice as long as people without the condition, and are more likely to fall.

We also found that more than 1,400 people with dementia spent Christmas 2017 in a hospital ward, despite being ready to go home. Many of them were there because of the lack of social care. Across the year we believe the cost to the NHS totalled £170 million for delayed discharges of people with dementia.

Care and support shouldn't be rationed until people experience the kind of terrifying situations uncovered across our Fix Dementia Care campaign.

'Last I heard, it was something like six to nine months before you get an assessment, unless it's a crisis. If it's a crisis it does get triaged and you hear a bit sooner.'

Carer of person with dementia

The background is a solid blue color with a large, faint white circular pattern in the upper half, resembling a stylized sun or a lens flare. Several thick, white, curved lines intersect in the lower half, creating a starburst or web-like effect.

Quality of dementia care and support





Alex Turner London

Alex Turner, whose mum Susan lives with dementia:

'In 2010 my mum Susan started going missing on a regular basis. The following year, aged just 62, she was diagnosed with early-onset vascular dementia. By this point I'd already moved home and left my job so I could care for her full-time.

After the diagnosis I found a suitable care home for Mum nearby. But she was only there for six months before I was told she was being evicted as they argued they could no longer support her. Being early-onset, Mum was a lot younger than the majority of the other residents, more active and communicative. The carers didn't seem to know how to approach or deal with this when combined with her dementia. On one visit, as soon as I walked through the door I could hear mum screaming – I found her lying on the floor of the corridor with carers just walking around ignoring her.

After Mum was kicked out of the care home, a very distressing experience in

itself, she was then stranded in hospital for two years. While in hospital there was an incident with Mum's medication and she went into a coma. When she woke up she had really deteriorated and needed to be supported to eat and go to the toilet. During this time, I spent almost an entire year trying to find another care home for her, despite her being ready to leave. I visited more than 15 care homes and nowhere would accept her. I'm certain this is because Mum has more specialist needs and these homes were picking people who they perceived would be easier to care for but could charge the same price.

I eventually found a nursing home that would take Mum. She's been there for over three years now, but I still have concerns about the quality of care and the level of understanding they have of her condition. I feel completely stuck. I've lodged numerous complaints but worry if I take it any further it could backfire and Mum will just be treated worse or even face eviction again.'



23% of 'dementia care services in England are failing, compared to 19% of all services (Care Quality Commission, 2018)



homecare workers told us they have had no dementia training



49% of UK adults agreed that people with dementia experience worse care and support than people with other long-term conditions such as cancer or heart disease

Getting it right for people with dementia

Getting and paying for care is just the start. Often, people then find care is poor quality compared to what those with other conditions receive.

Dementia is complex, with symptoms that affect people in a variety of ways. That means person-centred care tailored to people's needs is essential. Unfortunately, people in our listening events told us that this wasn't their experience, with many missing out on even the most basic care.

Our evidence shows that this is often fuelled by a lack of understanding of dementia in the social care workforce. Many people are ill-equipped to support people with dementia. Plus, they have a challenging job with little recognition and low pay. This causes extra problems for a system already under strain. It's unacceptable for people with dementia to experience poor quality care because of their condition. They deserve a high standard of support from a well-trained and confident workforce, supporting them to have the best quality of life, regardless of where they live.

'There were two amazing nurses, who were marvellous. They had the caring skills. Most people – because it's, you know, bottom dollar payment, let's be realistic – we're paying people shit money. You get people who aren't skilled, they aren't trained – that's what you get, you know.'

Carer of person with dementia

Experiencing poor quality care

People with dementia generally experience poorer quality care compared to those without the condition. More than a fifth of services that provide dementia care are rated as failing by the Care Quality Commission, a higher proportion than those that don't (CQC, 2018).

The public agree. Our research found 49% of UK adults agreed people with dementia inevitably experience worse care and support than people with other long-term conditions, like cancer or heart disease (Alzheimer's Society, 2017). This view was echoed at our listening events, with people often sharing negative experiences of even basic care for their loved one.

'I wouldn't call it care. In my experience, they might as well just drop the word care, just call it... institution...'

Carer of person with dementia

In the worst cases, family members had to take food and clean clothing into care homes as they were not provided. People told us their relative was not being treated with dignity or understanding. Some people shared that care staff were not aware of the person's history or relevant information. Lack of communication between staff and disjointed care pathways meant carers did not always know about the person's situation. For example, they weren't aware someone had fallen during the night and bruised themselves.

'I feel there was a breakdown in communication with all the professionals. And, in the end, my mam was just being given medication to try and get her manageable, to the point where I would go and she would be completely out of it. But, at that point, I was thinking, well, it's better than what she was. Because she was covered in bruises. She had black eyes. It was awful. So, I was thinking, well, just knock her out, then. If this is the best, you know? There was no quality of life.'

Carer of person with dementia

As everyone experiences dementia differently, a person-centred approach which takes account of the individual's needs and circumstances is vital. Instead people felt that the care being provided was focused on completing practical tasks in the time given. It was less about delivering what meant most to the person, such as social interaction or building relationships.

'Mum didn't want to keep being moved around because it does make it worse and when she was in the care home, she deteriorated so much that I just couldn't wait to get her back home, just wash her hair, you know, just basic care like that.'

Carer of person with dementia

Training the workforce

‘It’s down to the training that’s being provided. Dementia needs to be part of that training.’

Carer of person with dementia

The system must ensure that care workers are equipped to provide dementia care with confidence and competence. Considering the proportion of people receiving social care that have dementia, it’s essential that staff working in social care receive appropriate training in dementia care. Both people with dementia and care workers have the right to expect this training to be in place. To provide person-centred quality dementia care it’s vital to understand how to help people with daily living, develop communication skills and ways to pick up on personal preferences.

‘Every time we went to visit Dad he was sat in a large communal room with seats all around the edge, just sitting there. The TV was blaring, whether people wanted it on or not. There was no interaction.’

Carer of person with dementia

People with dementia occupy at least a quarter of hospital beds (Alzheimer’s Society, 2016) and up to two thirds of homecare and care home places. This means most health and care professionals support someone with the condition, especially homecare workers who often visit people living alone. Ensuring people are supported well at home can help them stay out of hospital and remain in their own community surrounded by the belongings and people they know and love.

‘I’d like my formal care to match my informal care... my informal care is my friends who know what I want.’

Person with dementia

Seven per cent of the UK’s social care workers are from the EU (Skills for Care, 2017). The UK’s exit from the European Union is fast approaching, which puts extra strain on an already vulnerable, high-turnover workforce. Providers are under constant financial pressure, employing poorly paid workers who get little recognition. Research shows that one in three homecare workers have received no dementia training at all (Alzheimer’s Society, 2016). Care workers told us they were often fearful in their roles, in many cases because they felt unprepared supporting people with dementia. We heard from people at our listening events who recognised that some of these flaws are a result of a poorly-funded, inadequate system, often not the fault of the care workers themselves.

‘What do the carers get paid? Minimum wage. There’s a shortage. We don’t appreciate the good work that they do.’

Carer of person with dementia

To turn this around, the care system must make it a priority to train their staff to provide high quality dementia care. Participants at our listening events echoed this idea. They saw it played out at the expense – both financial and emotional – of their loved ones.

‘The homes now are struggling. They’ve got the minimum wage, they’ve got the councils who are holding them down on the charges, because they haven’t got money.’

Carer of person with dementia

The background features a dark green field with several thick, expressive brushstrokes in a vibrant yellow-green color. These strokes are curved and overlapping, creating a sense of movement and depth. One prominent stroke forms a large, partial circle at the top, while others radiate downwards and outwards from a central point, resembling a stylized sun or a network of connections.

Our recommendations **England**

The social care crisis is a dementia crisis.**Many people affected by dementia rely on costly social care, rather than free NHS treatments. This means dementia can be the channel through which we achieve social care reform.**

This year marks a fresh attempt by government to tackle the crisis. In March 2018 Secretary of State for Health and Social Care Jeremy Hunt laid out his vision for the future of care, shaped around seven principles in a speech that showed he wanted change.

A Green Paper on social care reform will put forward proposals for the public to consider. It's essential that problems facing the biggest user group of adult social care, people with dementia, are addressed as a priority by any new system of care and support.

The Care Act 2014 currently sets out local authorities' duties, including meeting people's needs and their eligibility for publicly-funded care and support. What is set out in the Act must be upheld, as well as working to increase funding so that local authorities can fulfil their duties for people affected by dementia. Currently, too many parts of the Act, from principles of well-being to statutory duties on care assessments, are not being delivered. This legislation has scope to hugely improve the care and support system, but that is yet to be realised.

1. Cost

The cost of extra care charges for a health condition such as dementia must be covered by the state.

To reduce the inequity between dementia and other conditions, we want to see extra charges for dementia care monitored and covered by the state. We agree that some of the costs should be paid by the recipient. But no one should face increased costs for the misfortune of developing dementia.

These extra costs, which can be up to 40% more compared to non-dementia care from the same provider, are to reflect the complexity of dementia care. Dementia symptoms can mean people with the condition require support for a significant length of time, and crippling additional costs build up very quickly. They need to be properly covered and not shouldered by the individual. They must also be monitored by the Care Quality Commission to make sure any extra costs are resulting in specialist care, and are not just used to subsidise an underfunded system.

Funding from the state to address this unfairness should be channelled through the NHS, supported by closer working between the health and care services and joint commissioning. People living with dementia should be able to shape their own support through personal health and care budgets. Specific consideration must be made for how these personal budgets will be accessed and used by people with cognitive impairments, and the funding provided must reflect true costs to the person.

We want the Green Paper to recognise the unfairness that exists for people with dementia, and put forward proposals and promote discussion on how this will be addressed in future. The Green Paper consultation should explore how these costs are covered and put forward proposals which include this call. This could be through a specific NHS Dementia Care Fund or by extension or replacement of NHS Continuing Healthcare/NHS Nurse Funded Placements.

2. Quality

All health and social care workers must be given the training and support they need to deliver quality dementia care.

More than a fifth of organisations offering dementia care are rated as failing by CQC. This is higher than the overall service average, even though dementia care often costs more.

People with dementia occupy at least a quarter of hospital beds, 70% of care home places and 60% of homecare recipients. This means the vast majority of health and care professionals will be supporting someone with the condition. Our evidence shows that at the root of poor quality care is a lack of understanding of dementia from the health and social care workforce, tied to training, support and leadership.

We want to see a funded and sustainable approach to providing the training our health and social care workforce needs to provide quality support to people with dementia. This training would cover the whole health and care workforce and should reflect Tier 2 of the Department of Health and Social Care-backed Dementia Core Skills Education and Training Framework.

This programme would need to be matched by a drive to prioritise quality of dementia care throughout the care sector. Providers, managers and commissioners need to create a supportive environment that empowers and enables care workers to deliver high quality care.

We know this commitment will have positive results. Because the UK is set to leave the European Union, the care workforce is at considerable risk. At a time when hundreds of thousands more care workers will soon be needed, we must make a career in care a desirable option.

We want to see more skilled roles centred around complex dementia care. Greater recognition and job satisfaction could help to increase the number of people who stay in the sector, as well as appeal to potential new recruits.

Offering a higher level of dementia training to staff in both health and social care should help bridge the gap between the two sectors and inspire people to work better together.

3. Access

Everyone with dementia should have a care navigator to support access to timely, preventative and integrated support.

Hundreds of thousands of people affected by dementia are disconnected from the health and care system, forced to face the impact of the condition alone. Two thirds of the £26 billion costs associated with dementia in the UK each year are shouldered by those affected.

As a result many people cannot access the care they need. Or they delay buying care until their health has declined to the point they have no other choice. We often hear of people who have received virtually no support between a diagnosis and developing significant care needs. At the heart of this issue is the challenge of navigating an impenetrable and confusing health and social care system that often leaves people unable to access the information, advice and support that may be available. This is particularly a problem for people from disadvantaged groups and communities.

Family carers are worn out (three out of five told us their own health had declined) and people are more likely to reach a point where they need more costly acute care. As social care budgets have been reduced and access to state support limited, costs to the NHS from poorer health, inappropriate admissions, lengthy stays and delayed discharges have soared.

A care navigator should be accessible to anyone following a diagnosis of dementia. The navigator would give people affected by dementia a point of contact and the support required to navigate the health and care sectors and get the support available to them. They'd understand local services and how to access relevant benefits and advice.

This would help bridge the huge gap between health and social care that many people face after diagnosis. It would also help deliver the policies promised in the NHS Five Year Forward View and Care Act 2014.



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Our recommendations
Wales

Challenges around care and support in Wales are stark. Wales has an older population than any of the other UK nations, the lowest rates of dementia diagnosis and problems helping people in rural areas reach essential care. Nearly three in five local authorities in Wales have had contracts for social care handed back to them by providers unable to continue the service (BBC, 2017).

With our support, the Welsh Government is taking action to support people affected by dementia. We now have the first ever Dementia Action Plan for Wales. This sets targets for improving services, increasing diagnosis rates and is driven by the rights of people affected by dementia. The plan is supported by the largest ever investment in dementia support in Wales.

But this isn't the whole story. We know that people affected by dementia in Wales are struggling. At our listening events they told us how difficult it is to afford costly means-tested social care. It's also difficult to communicate with staff who don't understand dementia, and navigate the complex health and social care system. To address these issues we make the following calls:

1. An end to catastrophic care costs and instability within the social care sector

Welsh Government has to prevent catastrophic costs for people affected by dementia. No one should be forced to spend everything they have to get essential care.

At the same time, the social care sector desperately needs government to provide stability. High turnover means a lack of consistency, extra costs for providers recruiting and training new staff and strain on staff covering vacant positions. Recent funding increases are welcome but we fear it won't keep pace with demand.

To address this, Welsh Government is looking at establishing a new social care levy to bring new funding into the social care system. Welsh Government must understand how it would work in practice. Also, any levy must prioritise the needs of all people with dementia and be combined with a lifetime cap on care costs.

2. All health and social care workers must be given the training and support they need to deliver quality dementia care

The new Dementia Action Plan sets out goals to make sure all NHS employed staff that come into contact with the public are trained in supporting people with dementia. But we believe this should also include commissioned staff, not just those directly employed by the NHS. We also want to see a roll out of improved training to social care staff, developed in partnership with people affected by dementia.

3. Teams around the individual that enable people with dementia to access the services they need no matter what area they live in, rural or urban

Welsh Government is introducing a 'teams around the individual' approach to support. This means everyone with dementia will be offered access to a dementia support worker to refer and signpost them to other services. People with dementia at our listening events told us they want a key point of contact like a support worker to help them navigate the complex health and social care system. But Welsh Government has to make sure this new approach provides access to a range of services at any time, no matter where in Wales people live. That way no one is locked out of services that will help them live well in their community for longer.

The background features a dark green field with several thick, expressive brushstrokes in a lighter green and yellow-green hue. These strokes are fluid and organic, creating a sense of movement and depth. One prominent stroke curves from the bottom left towards the center, while others intersect and radiate from the right side.

Our recommendations
Northern Ireland

In December 2017, the Department of Health published Power to People proposals. These were based on evidence from an independent expert panel set up to look at reform of adult care and support. We hoped they would inspire a “social movement for change” on how adult care and support is organised, delivered and funded.

The current political situation in Northern Ireland is complex, as there is currently no Assembly sitting. Despite this, the Power to People proposals present a significant opportunity to start a conversation which cuts across party divisions and drives forward change.

At its core is a call for an inclusive public conversation that shares insight, increases public understanding and changes attitudes around the true value of social care. Over 20,400 people are living with dementia in Northern Ireland, supported by thousands of informal carers. It is vital that their voices are heard as part of this conversation. 35% of all people with dementia in Northern Ireland don't have a diagnosis and rates vary across Trusts (Alzheimer's Society, 2014).

Diagnosis is the start of people getting information, care and support. It is a right – it should not be down to luck and location. Social care services are disjointed and have complex funding arrangements. Many people give up the struggle for support and face constant stress and social isolation.

Power to People is an important catalyst to changing the conversation around social care support in Northern Ireland. We want to see action in three key areas, echoing the things that people with dementia have told us need to change.

A social care system that recognises people with dementia have the right to support

1. The Departments of Health and Communities must help create and promote public discussion and debate on reform, to reach a broad agreement.

Much of Power to People rests on the need for a frank public discussion about the value of social care to society – not only to those who use it. Funding a care system that supports a person's quality of life and averts costly health crises must enjoy wide public understanding and support from the start. Building understanding of dementia as a serious and progressive health condition, its impact on the person and on family carers, can tackle damaging and discriminatory practice.

Action to ensure people with dementia and their carers are given high quality support at every stage

- 2. All health and social care workers to be provided the training and support required to deliver quality dementia care**
- 3. The Departments of Health and Justice must work to implement the Mental Capacity Act (2016) NI**
- 4. The Department of Health must take the lead in exploring the potential for legal rights for carers to be developed, with input at the earliest stage from carers of people with dementia**

Everyone caring for a person with dementia must demonstrate understanding and commitment to good care through good practice, especially in the home.

It's essential that conversations about advance care planning start early. People must have the opportunity to share and document their wishes. This will help ensure that care is co-ordinated and personalised to the individual's circumstances.

Care commissioners have a responsibility to make quality care a reality. To do this, costs must reflect quality. Ensuring people with dementia can get high quality care also means recognising the input and needs of informal carers. Legislation that establishes legal rights for carers to information, financial support, health care and employment protection would help address the most stressful effects of being a carer.

Commitment to a funding model that works for people affected by dementia

It's outrageous and unjust that even people with modest assets have to pay for essential care.

Power to People proposes a means-tested system of homecare. We'll work to ensure the voices and experiences of people affected by dementia are heard in this conversation.

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We are the UK's leading dementia charity.

Every day, we work tirelessly to find new treatments and, ultimately, a cure for dementia. We provide expert information, training, and support services to all those who need our help. And we are creating a more dementia-friendly society so people with the condition can live without fear and prejudice.

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Alzheimer's Society operates
in England, Wales and
Northern Ireland
Registered charity no. 296645

Date of Publication May 2018
18019SO

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Publication code
980

