



Demanding Action on Dementia:

**General Election
Manifesto 2019**



Introduction

In 2017 the 'dementia tax' made headlines, but in the intervening years nothing has been done to address the shocking state of our social care system, which is on the verge of utter collapse. This time, dementia needs to be on the agenda of every political party and, most importantly, at the heart of our next Government's plans.

Dementia is the biggest health and social care issue facing the country. More people than ever are speaking out about dementia and demanding change. As a nation, we can be a global leader in creating a dementia-friendly society – by demanding better care and support, by changing social attitudes, and by investing more in dementia research. This should be delivered by a National Strategy under the name of the Prime Minister.

People affected by dementia have told us they want to get the support they so desperately need through a fair social care system, more investment in dementia research, and better public understanding of the condition. They also told us there is a significant gap between the things they need to live well, and their daily realities.

Recent years have seen improved public awareness of dementia, but it remains the UK's biggest killer – someone develops the condition every three minutes, and there is no known cure. People with dementia struggle to access vital support and face typical costs of £100,000 for the care they need, unlike those who develop cancer, heart disease or diabetes and are supported by the NHS free of charge (Alzheimer's Society, 2017). It is a scandal that up and down the country, people are forced to spend their life savings and even sell their home to pay for care. The next Government must end this unfair dementia tax.

The next Government should:

1

Radically reform social care to address the specific needs of people with dementia, ending the daily injustice they, and their families, face in accessing the good quality care to which they are entitled.

2

Ensure that people with dementia can participate in their communities on the same basis as everyone else.

3

Close the research funding gap between dementia and other disease areas to ensure new treatments and life changing care interventions are available to everyone living with dementia, as soon as possible.

1

Radically reform social care to address the specific needs of people with dementia, ending the daily injustice they, and their families, face in accessing the good quality care to which they are entitled

Dementia is the biggest health and care challenge facing our society. The emotional, physical and financial costs of dementia are borne by both those living with the condition, and by the 1.8 million carers providing support across the UK (CEBR, 2019).

People with dementia occupy 70% of places in residential care (Alzheimer's Society, 2016). For years, Alzheimer's Society's campaigns, helpline and local services have been inundated by those affected, telling us of harrowing experiences, seeking advice and imploring change. Three themes have repeatedly emerged from challenges faced across the health and care spectrum – access, quality and the cost of care.

These challenges affect the whole of society in a myriad of ways – including our economy. Over 112,000 people have left their jobs to care for loved ones with dementia, which is hugely damaging for businesses in England (CEBR, 2019). Without better support for people affected, this loss of workforce will cost businesses as much as £6.3bn a year by 2040 (CEBR, 2019).

We know that the system of support for people living with dementia needs an urgent overhaul to provide effective integrated health and social care and appropriately trained staff. The NHS is committed to the principle of access based on clinical need, not an individual's ability to pay, yet we know that people often spend their life savings or must sell their family home to pay for their social care. Specialist dementia care is on average 15% more expensive than standard social care, and it is only fair that central government covers these costs (Alzheimer's Society, 2019). Why should people with dementia be treated any differently to people with other health conditions?

The Government must commit to universal social care, free at the point of use, including the cost of specialist dementia care. Any long-term reform of the social care system must eliminate the risk of people having to sell their homes to pay for care, and deliver dignity and security for people with dementia.

While agreeing and implementing a long-term solution for social care, there must be immediate investment in an NHS Dementia Fund of £2.4bn to shore up the system and give people with dementia greater access to affordable and high quality care in the shorter term. On an individual level, we estimate this would mean everyone with a diagnosis of dementia would be able to access between £74 and £179 per week to cover the additional costs for their care.

1

Key recommendations:

- Deliver social care reforms now and in the longer-term which create a system that is there for all people with dementia when they need it, offering high-quality and appropriate care. This must be funded like other public services, such as the NHS and education, where the cost of specialist dementia care is spread across society, guaranteeing that it will not fall on individuals and their families.
- Mandate a higher level of dementia training (Tier 2) for all NHS and social care staff providing direct care to people with dementia, accompanied by: protected training time, targets for numbers of staff trained and training standards being a part of inspections by regulators.
- Ensure that everyone with dementia has access to improved post-diagnostic support with a Dementia Advisor who can support them in navigating the complex health and social care system. This should be backed by national targets for people with dementia to receive planned annual care reviews.
- Better support for carers of people living with dementia, including a 75% target for eligible carers to be offered access to the Strategies for Relatives (START) intervention – this has been shown to reduce depression and anxiety for up to six years by giving carers an eight-week programme of individual psychological therapy sessions.

‘My dad, Sharad, was diagnosed with Alzheimer’s disease in 2015. When my mum and I spoke to social services, the third question they asked was ‘How much money do you have in your bank account?’ We were told that if we had more than a certain amount, we wouldn’t be able to get any support.

We were a family facing up to dementia for the first time. We needed compassion, empathy and guidance – but we were spoken to in a way that made us feel it was wrong to ask for support and information. I felt like dialogue was being shut down, not opened up.

I spoke to social services again on the phone after that and was told that dad needed an assessment for his needs to be worked out. But then there was silence. No follow-up letter. No phone call. Nothing.

Now mum is dad’s main carer, but we know this can’t last forever. As a family, we are resigned to having to pay for his care privately.’

This is not how a care system should work. Sadly, Nimisha’s experience of the care system is anything but unusual. At Alzheimer’s Society, we regularly hear from people who are completely physically and emotionally drained due to the difficulties they face trying to get care for themselves or a loved one.

This does not have to be the situation for people living with dementia and their families. We have to act now.

Nimisha, daughter of Sharad who is living with dementia



‘We were told we would have to fight to get dad the right support. But nothing prepared us for how hard it would be.’

2

Ensure that people with dementia can participate in their communities on the same basis as everyone else

The next Government should make the UK the best place in the world to live with dementia. Given the complex nature of the condition, they need to deliver an ambitious national strategy and implementation plan, that brings together a range of partners, to ensure that people with dementia have equal rights across society.

We know people with dementia face many barriers that prevent them from living independently and participating in the community. They often struggle to access information, transport, public services, financial support and social activities, to name but a few.

Two thirds of people with dementia live in the community, with a significant and increasing number living on their own (Alzheimer's Society, 2013). Stigma, misunderstanding and isolation remain issues for those affected. Awareness of dementia must be raised through the continued expansion of Alzheimer's Society's Dementia Friends initiative, which already numbers over 3 million people. This will see understanding turned into meaningful action, resulting in positive change for people living with dementia right here, right now. We must support people with dementia to be part of their community, wherever and however they are living, by building Dementia Friendly Communities that are shaped by those with direct experience.

The next Government should commit to properly funding the National Dementia Strategy for 2020 to 2025 so that meaningful progress can be made. The Strategy must raise awareness of dementia, making it a priority across all government departments, regulators and bodies. We want to see a society where people with the condition have equal access to services, and are socially included and involved in their communities.

Key recommendations:

- Continued investment in the Dementia Friends initiative, including embedding it in the national curriculum and mandatory induction sessions for key publicly funded services such as emergency services, train operating companies and bus providers.
- Support every Local Authority to engage in making their communities dementia friendly.
- Ensure every Government department has a Dementia Lead responsible for reviewing policies, ensuring that they are fit for purpose, and in line with the aims of the National Dementia Strategy.

'I have seen the stigma around dementia affect others – and felt it myself.

I have been an active member of my faith community for as long as it has been possible for me, but from the time my diagnosis was public, I have never been asked to do any kind of job. The excuse has often been “we don’t want to overload you”, but the response to people with any other condition is “they are always free to say no”.

It would seem that I cannot be trusted anymore to prioritise or discern what I can and can’t do. In the same context, when I took a very different view from the majority on an issue, my view was presented, but with the proviso “We must remember that Shelagh has Alzheimer’s Disease”.

I am often introduced as someone with dementia. Firstly, it’s not the most important thing about me, but it also invades my privacy. It should be up to me to decide with whom I share my diagnosis.

Another thing that really bothers me is the way people with dementia who are non-verbal, or who speak very little, are treated as though they are deaf and openly talked about when they are in the room. If we want to make the UK a truly dementia-friendly society, we need to address the misunderstanding most people have of the disease.

Why are these behaviours so stigmatising? Because the underlying message is that we are people who don’t count, that we matter less because of our diagnosis. Stigma that is unconscious is just as hurtful as behaviour that is deliberately stigmatising and makes us feel like we can’t participate in our community the way everyone else can.'

Shelagh Robinson, co-chair of the 3 Nations Dementia Working Group – a group of people who are campaigning, influencing and breaking down the stereotypes about dementia to bring about change, working hard to improve the lives of those living with dementia, their carers and the work of professionals and policy makers.

'Is there still stigma around dementia? The answer is yes – and it’s in the most unexpected places.'



3

Close the research funding gap between dementia research and other disease areas to ensure new treatments and life-changing care interventions are available to everyone living with dementia, as soon as possible

Dementia is the only condition in the UK's top ten causes of death that has no treatment to cure or even slow down its progress. Research will one day end dementia, but without adequate investment, that future may never come. By investing at a fair level, the next Government can play a pivotal role in the discovery of new dementia treatments and the adoption of best practices in care – particularly through continued investment in the world-leading UK Dementia Research Institute.

Dementia research lags far behind other disease areas, impeding breakthroughs in drug treatments and care interventions. In the UK, there is still a huge gap in parity of funding – cancer, for example, currently receives three times more research investment from Government (JPND, 2018).

Dementia costs the UK economy £34.7bn annually (Wittenberg et al, 2019), yet latest figures show that UK Government investment in dementia research is around £85m per year, only about 0.25% of the overall cost (HL Deb 19 Nov 2018 c11541).

Health and social care research makes up only about 14% of total UK investment in dementia research (JPND, 2018). But this should not be considered less important as it can make a tremendous difference in people's lives. Parity with biomedical research is crucial to improve the NHS dementia care pathway, and to make care more effective and efficient.

In addition, given that up to a third of dementia cases could be prevented through lifestyle and environmental modifications, the Government has a responsibility to raise awareness of risk reduction for dementia. This should be done through education in schools, and regularly throughout life, including NHS Health Checks, as well as investing in research to improve our understanding of risk factors and to improve the effectiveness of evidence-based interventions to reduce risk.

Key recommendations:

- Treble investment in dementia research to £250m a year by 2025, closing the gap with other disease areas, including cancer, and enabling breakthroughs in drug treatments and care interventions.
- Give health and social care research parity with biomedical research by ringfencing £100m a year for care research, in order to deliver improvements and innovation to the NHS dementia care pathway.
- Ensure people can access a timely, accurate and appropriate diagnosis, reducing inequalities and variations across the country, and that interventions, new drugs and diagnostic tools are made available to everyone.

'I have been a doctor and researcher in dementia for over 20 years. During that time, I've seen good progress for my patients, but I still have only limited symptomatic treatments to offer them for the different dementias.

A major reason for this has been a long-term lack of funding for dementia research. This has not only meant we've been unable to develop promising avenues of research, but also that we have not been able to keep researchers working on dementia when there is better funding and prospects elsewhere.

Research isn't just about finding cures and new drugs. My own research has shown that up to a third of dementia may be preventable with lifestyle changes. Prevention is of course always better than the cure. We need to invest in research that aims to prevent the disease before it ever starts and use the best public health and behavioural research to achieve this.

And, we can help improve the lives of people with dementia today by supporting intervention research. We've been able to find some ways that can help reduce the impact of dementia and unnecessary harms associated with the disease. We've shown that these can even sometimes save money for the health and social care system. But, there is so much more we could do if enabled by more funding.

Research provides the key to a world where there is less dementia, and a strong commitment from the Government to dementia research funding provides the way to unlock it.'

Professor Gill Livingston, University College London



'We are making great progress in dementia research, but we are so underfunded compared to the need'.

Alzheimer's Society wants to see the next Government commit to a National Strategy under the name of the Prime Minister that delivers positive change for people with dementia across health and care, society and research.



People with dementia
typically spend £100,000 on care
(Alzheimer's Society, 2017)



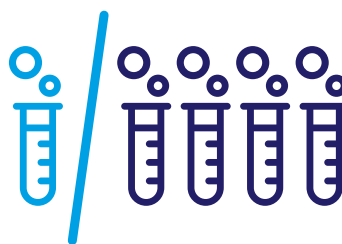
Dementia costs the
UK economy £34.7bn
(Wittenberg et al, 2019)



60% of people using homecare
and 70% of people in care homes
live with some form of dementia
(Alzheimer's Society, 2014)



Over the past two decades,
the average cost of a nursing home place
has almost doubled and is now nearing
£1,000 a week (LaingBuisson, 2017)



The ratio of dementia researchers
to cancer researchers is 1:4
(Alzheimer's Research UK, 2017)



Dementia diagnosis rates
by CCG range from 53.3% in the
poorest performer and 92.7% in
the best (NHS Digital, 2019)



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 (Alzheimer's Society, 2017)

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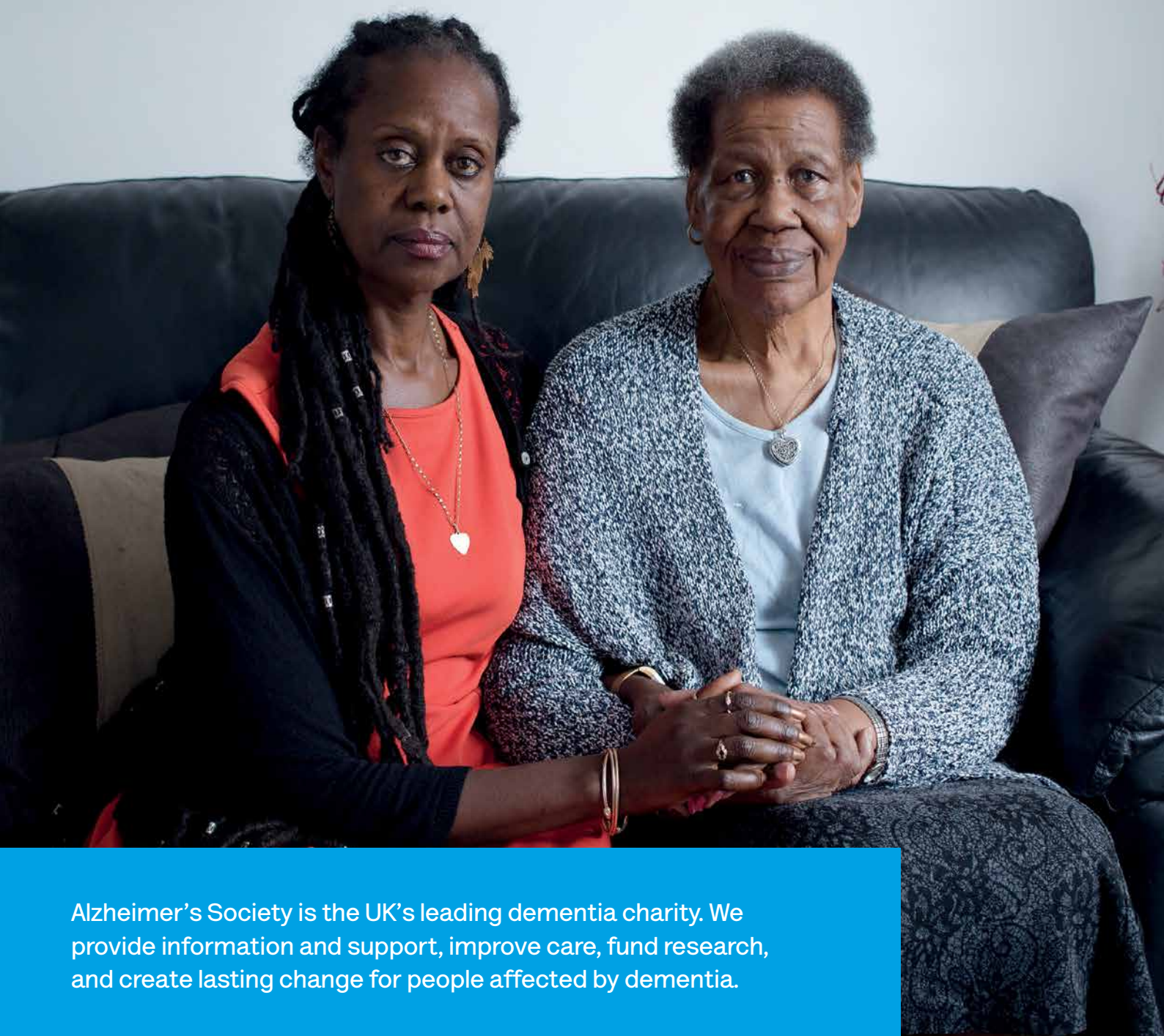
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Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.

For more information or to take action on dementia, visit alzheimers.org.uk/generalelection or contact generalelection@alzheimers.org.uk

Alzheimer's Society is a registered charity in England and Wales (296645); the Isle of Man (1128) and operates in Northern Ireland.

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