Fix Dementia Care

The case for the Dementia Fund
Executive Summary

Health and social care in England is stuck in the past. The NHS is limited in what it can do for people with dementia because there’s currently no cure, so the main responsibility for supporting people to live well with their health condition falls to a creaking social care system, supplemented by unpaid, often poorly supported family carers. While the NHS Long Term Plan (LTP) sets out a vision of a new person-centred model of care, supported by £20 billion in funding, we’re still waiting for a Green Paper to improve social care that was promised two years ago. Meanwhile, the 850,000 people living with dementia across the UK are waiting for change. The system is facing significant challenges. Falling social care funding has led to an increase in A&E admissions in over 65s. The number of patients over 65 years old increased by nearly half (46%) over the last decade. The need for funding is urgent – adult social care services face a funding gap of £1.03 billion in 2019/20 just to stand still. The LTP itself acknowledges how frustrating it is “for the emergency patient in A&E waiting for a bed still occupied by someone stuck in hospital waiting for a social care package at home”. We desperately need to see the longer term reform that’s been delayed for decades to build a sustainable, integrated health and social care system that pools risk across society. But this alone won’t address the challenges that people with dementia face today, or end the exclusion from the care they so desperately need.

Of the top ten leading causes of death in the UK, dementia is the only one we cannot cure, prevent or even slow down. Most health conditions are treated by the NHS, free at the point of use. But as dementia progresses, the majority of costs people face are associated with the help they need to do the things they can no longer do for themselves. These costs are not covered by the NHS. People end up paying enormous social care costs, typically being charged £100,000 to cover dementia care costs, although for some people this could be up to £500,000. They also face higher fees for the complex care they need. This is the Dementia Penalty – the extra cost people with dementia face to cover their needs as a direct result of the health condition they have developed. The Government needs to modernise dementia care. We must transform health and social care by putting people at the centre, giving control and choice to people and their families, supported by a team of professionals. We need to drive more integration and person-centred care. We need urgent investment to keep social care afloat. A Dementia Fund will do this.

The Government needs to modernise dementia care. We must transform health and social care by putting people at the centre, giving control and choice to people and their families, supported by a team of professionals. We need to drive more integration and person-centred care. We need urgent investment to keep social care afloat. A Dementia Fund will do this.

We are calling for £2.4 billion for the Dementia Fund, which should be paid for with the unallocated funding for community care attached to the NHS Long Term Plan. People with dementia need quality care in the community. The LTP commits to boosting ‘out-of-hospital care and dissolving the divide between primary and community health services’ – modernising dementia care must be a key element of this. This would benefit the NHS in the long term, meaning fewer people with dementia are forced to go to A&E in crisis, and having better support in place helps enable them to leave hospital as soon as they are well enough. There were more than 70,000 potentially avoidable emergency admissions of over-65s with dementia at an estimated cost of £400 million in 2016/17; inefficiencies like this not only harm people with dementia, but drain the system of the resources it needs to provide better care.

We propose the following recommendations for the Government to act upon, as a matter of urgency.

Recommendations

1. Improve dementia care by investing in a £2.4 billion Dementia Fund.

2. Publish the Green Paper on Social Care with proposals for long-term funding reform that shares the cost of dementia care more fairly across society.

3. Address the Dementia Penalty to ensure that costs associated with a health condition like dementia are covered by the NHS.
1. Establishing the Dementia Fund

The cost of doing nothing

We are calling for the Government to establish a Dementia Fund. We need to end the unfairness faced by people with dementia, and make sure they are supported to live well with the symptoms of their condition. We know social care is under pressure and the NHS is facing rising hospital admissions and delayed discharges. In the absence of longer term reform, we need urgent investment in the sector through better integrated and person-centred care and support services. All this can be addressed with a Dementia Fund.

We know the cost of doing nothing. All too often we hear concerning stories of people with dementia not supported properly at home – spending the day in soiled clothing, or going without food or water, or their medication, resulting in being admitted to hospital with conditions that should have been prevented. We also hear of people who are discharged from hospital without the right care in place, only to be readmitted shortly after. This is hugely distressing for individuals and their families and a massive cost to the NHS. We know more funding for social care and improving access to nursing and residential care is associated with fewer hospital readmissions, fewer delayed discharges, reduced length of stay and lower expenditure on healthcare services. When the NHS’ new funding settlement was agreed, the UK Government committed to ensure adult social care is funded to avoid imposing any additional pressure on the NHS. We have the opportunity to improve outcomes for people with dementia facing crises that can be prevented by tackling these challenges head on.

More than 70,000 potentially avoidable emergency admissions of people with dementia in 2016/17. This is an increase of 70% in just 5 years at a cost of around £400 million to the NHS. At least a quarter of delayed discharges were people with dementia – costing £170 million a year in 2017. Around half of delayed discharges are due to a lack of appropriate residential or nursing care places, waiting for a care package at home, or waiting for community equipment and adaptations. Improving care in the community can enable people with dementia to stay at home far longer and have a lower likelihood of going into long-term care. Better integrated approaches to dementia care can improve quality of life without being more expensive.
What we need to see

The Dementia Fund will end the unfairness faced by people with dementia in paying extortionate costs for care. People with dementia and their families should not have to shoulder this cost alone. This cost results from supporting someone with a health condition to live well with their symptoms, and should be treated as such by central government and the NHS. People with dementia often need support with eating, bathing, and dressing so that they can still live within society and live fulfilling lives. All of this is more difficult when someone has dementia. For example, professionals need to be properly trained in helping people with swallowing and to take more time to help someone get out of bed and get dressed, and care homes need more staff to deliver this one-to-one support. This would help us move towards a system where all individuals with social care needs find themselves on a level playing field when it comes to paying for care.

People with dementia need person-centred support, and also know best what care and support they want and need. We need to transform health and social care by putting people at the centre of their own care, giving control and choice to individuals and their families, supported by a multi-disciplinary team of professionals. This will provide care and support when they need it and in the way that best suits the impact of their own symptoms. We know everyone is affected differently by the symptoms of dementia, and no one-size solution will fit everyone.

How to deliver a Dementia Fund

Alzheimer's Society commissioned the Social Market Foundation (SMF) to produce an independent report examining how a Dementia Fund could work. Drawing on the SMF’s analysis and recommendations, Alzheimer’s Society describes below a method for commissioning a Dementia Fund. The NHS LTP acknowledges the need to improve access to community based care and support and aims to increase access to personal health budgets (PHBs). The development of the Dementia Fund could act as a catalyst for the rollout of PHBs as people would seek support from the Dementia Fund. PHBs can lead to improvements in wellbeing and help people live more independently – and we want to see a step change for people with dementia. Sadly, people still sometimes struggle to access a diagnosis. GPs and professionals are often reticent to diagnose dementia due to the lack of targeted treatments and support. The introduction of a Dementia Fund would increase confidence that people would be able to access some form of support to help meet their needs. It could also widen access and best practice in establishing PHBs in a Dementia Friendly way and make sure more people with dementia can access PHBs.

At present, this would be administered through Clinical Commissioning Groups (CCGs), but in the future Integrated Care Systems (ICSs) may be responsible, where NHS organisations in partnership with councils take collective responsibility for managing resources, delivering NHS standards, and improving the health of the population they serve. Delivering on modern, integrated care for people with dementia will be the test for these new systems.

How the Dementia Fund could work:

- The Dementia Fund would be situated within the NHS. It should be jointly commissioned by health and social care to align incentives.
- Everyone diagnosed with dementia would be eligible for support from the Dementia Fund. This funding would go towards supporting people’s healthcare needs while they’re in the community, helping maintain their independence for as long as possible.
- After diagnosis, it is expected that a care plan is drawn up and reviewed at least annually to establish what is important to the person. It should be personalised, unique to the individual and owned by them. Professionals should work in partnership with the person affected by dementia to agree goals, identify support needs, develop and implement action plans, and monitor progress for a care plan. Dementia Advisers working as part of a multidisciplinary team would initiate the care plan, which could be augmented by GPs, and a named care co-ordinator should be identified.
- Services and support for people with dementia would be funded through a PHB. PHBs are sums of money to support someone’s health and wellbeing needs, planned and agreed between the person and the local CCG or NHS team, which give more choice and control to people. Funding would be drawn from the Dementia Fund into individuals’ PHBs and be allocated to achieving the outcomes established in their care plan.
- PHBs are managed through a notional budget (held by the CCG), a third party budget (held by an independent organisation), or a direct payment
Fix Dementia Care The case for the Dementia Fund

(with money transferred to a bank account). No one is expected to have more control than they would be comfortable with having23 and for many people, especially those with more advanced dementia, the budget can be managed on their behalf by their care coordinator.

■ Funding would be made available to self-funders and to local authority clients. A set amount of funding to pay for the Dementia Penalty would be paid out, and vary according to the individual’s needs and the severity of their dementia. The Dementia Penalty is the extra cost people with dementia face to cover their needs as a direct result of the health condition they have developed. Local authorities can pay care providers higher rates to support people with dementia but this does not cover the whole cost of delivering complex care. People with dementia pay top up fees to cover the remaining cost of their complex care needs and these top up fees are often higher than those faced by people without dementia. Dementia is a health condition – people with most other health conditions don’t experience this unfairness.

■ The Dementia Fund should be set up as an independent Fund with legal status. Spending should be overseen by the Office of Budget Responsibility (OBR) and outcomes monitored and reported on annually. It could be channelled through the Better Care Fund (as with the Disabled Facilities Grant) and be one of the terms of the revised BCF, or it could be channelled through other local joint commissioning approaches.

Funding from these budgets could be used collectively by care providers to plan services to ensure shared outcomes will be effectively met, for example by ensuring higher dementia-specialist training levels, more staff time, therapies and activities, and more. Using PHBs means funding is less likely to seep into covering other policy areas than including it in general commissioning budgets, where it would be more likely to stay in NHS or local government commissioning structures to benefit the system, and will therefore benefit individuals’ outcomes. For those in residential care, increased funding into care homes could be matched by improvements in quality.

There are other potential options considered in the independent report from the SMF. For example, funding allocated to local authorities based on dementia prevalence would be simple and easy to administer. It would give local authorities flexibility to link funding into other services, particularly at a time when there is more movement towards total place and community budgets, and a council could benefit from lower costs and overheads as it commissions services to support all people affected by dementia in its area. However, this approach would have a greater risk that funding would leak into other programmes, so would need to be carefully monitored. Other options include a supply-side subsidy paid directly to providers; a competitive fund open to bids from CCGs; or distribution through cash transfers such as Attendance Allowance. To test the best approach, the Dementia Fund could be piloted in volunteer CCG areas with collaboration from local authorities. A Task and Finish Group should be established to oversee this pilot.

Consideration could also be given to how Dementia Fund assessments and eligibility interact with NHS Continuing Healthcare (CHC). We know that people with dementia in particular struggle to access CHC and have to deal with a system and assessors with little understanding or awareness of dementia. As a result they fail to get the support they need.

A sustainable future

In the longer term, we have an ageing population and rising diagnosis rates for dementia. We need to see commensurate increases in funding for social care and this will require a new model of paying for care so that the risks of catastrophic care costs are shared across society. For people with dementia and their families, this reform cannot come soon enough. The UK Government can’t delay any longer. As one in three people born today24 will develop dementia, it is impossible to tell who will require care and support in the future - and with a growing and ageing population it is vital that we find new ways to provide and pay for care for future generations, providing reassurance to individuals and families. As such, we believe that sharing the costs of social care is the fairest solution. We can draw on lessons from prominent systems in Germany and Japan for this, where people have contributions to paying for social care deducted automatically from their wages, similarly to pensions, with employers also making payments. This would go into a transparent fund that is ring-fenced for paying for social care, to guarantee long-term sustainable funding. But this alone won’t tackle the unfairness faced by people with dementia every day. We need an interim solution for people with dementia – we need a Dementia Fund.
Case study:

John\textsuperscript{25} retired five years ago from a career in the NHS. He has always been very gentle and intelligent – in his spare time, he liked to write poetry, and even had some published. He walked every morning, and wrote in his journal. He enjoyed astronomy. His wife and he had plans to travel overseas in their retirement.

John recently moved into a care home, shortly after the New Year. Sadly, he can no longer have a conversation – it can be quite difficult for his family and staff to understand his attempts to communicate as his dementia is getting more severe. He has become very cranky since moving into the care home, so it’s possible that he won’t co-operate if he isn’t feeling like it.

The care home he is in is very supportive; however, it has come at a huge cost to him and his family. He is paying an extra £156 a week in fees because he has dementia. Overall, he is paying over £8,000 extra a year. The family is aware that their money will run out by November.

John and his family have a right to live their lives without unfair cost and discrimination. In the system of modern dementia care we’re proposing with a Dementia Fund in place, John would work with his Dementia Adviser to set out what personal outcomes matter to him. His Dementia Adviser would work with him, his family, and his GP and other professionals to draft a care plan. The CCG would then set up a personal health budget for John. Alongside a personal budget from the local authority, John has more money that he can use how he decides, in order to improve his quality of life and meet his health outcomes.

Early on in his journey, John would have an amount of money from the Dementia Fund paid directly to him – to pay for things like home adaptations to keep him active. In the care home, he would no longer face the Dementia Penalty – the Dementia Fund would be there to eliminate the extra cost of his care that currently John and his family have to pay out. John may not have the extra money in his bank account, but the CCG and local authority will pay extra money to the care provider to make sure his needs are met while he lives there. This would help ease the financial pressure and may mean John could stay in the care home longer. The care home could use this funding to provide improved training to their staff on how to better communicate with John. He may still get upset and confused in his new home, but the care home staff could be better trained in how to support him.

The cost of dementia is currently \textbf{£26 billion} a year, with an average annual cost of £23,250 per person.
The Dementia Fund in practice

Step 1
Person diagnosed by NHS clinician or given an update on their diagnosis

Step 2
Individual has a care plan drawn up/reviewed in partnership with their GP and multidisciplinary team including Dementia Advisers. This will enable people with dementia to have more choice and control over their care.

Step 3
Funding for care will follow the person living with dementia. The Dementia Fund will be available through CCG and local authority joint commissioning arrangements and placed into a Personal Health Budget for the person with dementia, to help them achieve the outcomes in their care plan.

Step 4
Person with dementia (or their agent) uses the Dementia Fund to help access services that deliver on their care plan. Services will be able to better provide innovative and high-quality person-centred care – such as dedicated dementia training for staff, environmental changes or appropriate and engaging activities.
2. The challenge of dementia

Everyday unfairness

People with dementia are treated very differently to those living with cancer, diabetes or a host of other health conditions. Those with other long-term illnesses can routinely access medicines, treatments, surgery and support services on the NHS without charge, but because of the lack of effective medical treatments the same is not true for those with dementia. As a result, people with dementia have to turn to the social care system to support them in managing their dementia symptoms and can find themselves paying significant amounts of money for their care. In addition, we know people with dementia can face costs for care of up to 40% more than someone without the condition when they’re in residential or nursing care. This is the Dementia Penalty – the unfairness people face in paying for social care to cover their healthcare needs, and in paying higher care costs than other people.

Dementia can be a financially punishing condition. We know that people with dementia are typically charged £100,000 to cover their dementia care costs, although this can be as much as £500,000. If people were to save for the typical cost of their dementia care at the same rate as their pension, they would need to save for 125 years. It’s just impossible for most people to pay this scale of cost for essential dementia care.

In our survey of the general public undertaken last year, half of people incorrectly believed the costs of dementia care are covered by the NHS – whereas in reality they would have to pay themselves through the social care system. Eight in ten people don’t know the typical cost of care. Almost half (47%) of the public have not started saving for the care and support they may need in the future. Nearly half (43%) of people over 65 have not done anything to prepare for the financial impact of long-term care.

People with dementia should have the same right to care as people with other conditions, without excessive, unfair costs. Similarly, it is only fair that in a modern health and social care system it should be central government that supports the needs of people with dementia as a result of their health condition. The NHS is committed to the principle of access “based on clinical need, not an individual’s ability to pay.” It is time that people with dementia were treated the same.

Costly but necessary

We know dementia care is complex and costly to deliver. Providers of homecare or residential care often don’t have the resources to provide the high quality and innovative care we know they want to provide. Quality dementia care cannot be done on the cheap, but these additional health costs should be covered by the state. People affected by dementia have told us they regularly face issues with a lack of continuity of care, short home visits from care staff meaning they can be left having to choose between a wash or a meal, and lack of training and awareness of dementia among staff.

We have spoken to dozens of care home providers in recent months about the cost of providing complex care for people affected by dementia. Priorities for care home providers included training, staffing, environmental changes, and more appropriate and engaging activities. More funding for dementia care through a Dementia Fund would help tackle all of these and mean people with dementia living in their own homes would have improved care. There would be better training for staff in both homecare and residential care, and more sensitive and person-centred care overall.
When providers do have extra funding to cover complex care, they often spend it on vital areas such as:

- **Training** – particularly dedicated dementia training, training in specialist areas like communication and dealing with challenging behaviour, and paying for qualifications.

- **More staff**, higher staff to service user ratios, and higher wages.

- **Environmental changes** – refurbishing premises to be more dementia-friendly and accessible.

- **Appropriate and engaging activities**, such as reflexology and music therapy.

### False economy

A generation of underfunding services that support the most vulnerable people in society is starting to show the strain.

- Local authorities are struggling to balance budgets and face an estimated funding gap of £5 billion by the end of the decade.
- Local authorities responsible for social care overspent budgets by £1 billion in 2016–17 and used £858 million of reserves.
- Over 100 care home operators collapsed in 2018 alone.
- Almost a third of councils (48) surveyed by the Association of Directors of Adult Social Services (ADASS) in 2018 saw homecare providers close or cease trading during a six month period – including one local authority where four homecare providers have closed.
- Contracts were handed back by homecare providers to 44 councils, and 17 councils have seen contracts handed back from care home providers.

The system is in crisis. We have been waiting for reform for decades. Over the last 20 years, there have been numerous failed green papers and commissions looking to answer the challenge of funding social care.

Since the first iteration of the Prime Minister’s Challenge on Dementia (2012), great progress has been made – diagnosis rates have increased, research funding has never been higher, and there are over 2.8 million Dementia Friends. Despite these and other successes, people with dementia still face unfairness and there is still anxiety – the fear of developing dementia is the number one age-related concern for the over 55s. We need the NHS Long Term Plan and the forthcoming Green Paper on social care to recognise and understand the importance of dementia to the whole health and social care system, break the deadlock on reform, and deliver a modern health and social care system that supports people with dementia with person-centred practical and financial help.
3. The Dementia Penalty

People with dementia often face a “Dementia Penalty”. This is the unfairness and extra cost they face to cover their support needs as a result of the health condition they have developed – where the NHS is unable to provide clinical support because of the lack of a treatment.

Dementia is the most complex and challenging condition to support. When local authorities set their rates for care providers of residential and nursing care, they can set higher rates for supporting people with dementia – but this does not cover the whole cost of delivering complex, specialist care. We know that care providers then often pass this cost on to families affected by dementia or absorb these costs, resulting in a negative impact on quality of care. Publically available data and specific figures for the Dementia Penalty are difficult to ascertain.

In order to base this project on as robust an evidence base as possible, Alzheimer’s Society commissioned the SMF to model the cost of the Dementia Fund using available data to establish a reliable estimate of the Dementia Penalty. More information on this can be found in their report Designing a Dementia Fund.

We have also surveyed local authorities and providers to seek their views on the Dementia Penalty. Our findings are that local authorities pay a Dementia Penalty – paying out rates that are around 10% higher than for people without dementia to providers for supporting someone with dementia, to cover their complex needs. People with dementia then pay further top up fees of an extra 28% in order to cover the remaining cost of their complex care needs. They would not have to do this if they had other conditions where they would receive more care from the NHS. These top up fees are often 5-8% higher than fees people who don’t have dementia have to pay.

According to our survey, the top up fees people with dementia have to pay are on average £108.50 or around 8% higher than the average final amount care homes charge to people without dementia. The equivalent for self-funders is £72.86 (3% higher than charges for those without dementia). Local authorities should also receive extra funding from the Dementia Fund to cover the costs of complex, specialist care for people with dementia.

We believe this total Dementia Penalty of around 15% should be covered by the NHS – to support people with the increased top up fees they face as a result of their condition and provide additional funding for local authorities to support people with dementia. For a Dementia Fund that covers this Penalty for everyone with a diagnosis, we estimate a cost of around £2.4 billion. On an individual level, we estimate this would mean everyone with a diagnosis of dementia would have between £74 and £179 per week allocated to them to stop the Dementia Penalty in their care. Some of this should go towards ending the Penalty councils face in higher rates.

The Dementia Penalty:

- **Local authorities pay 10%** higher than standard rates to support the complex needs of people with dementia.
- **People with dementia pay 5-8%** higher top up fees than people without dementia.
The NHS already accepts some responsibility for the impact of supporting people with health conditions outside the healthcare system through paying for community care and Funded Nursing Care. The NHS could use unallocated funding for community care attached to the NHS Long Term Plan to go towards this Dementia Fund. This would be an essential part of maintaining the independence of people with dementia in the community.
Appendix: Methodology

Alzheimer’s Society commissioned the Social Market Foundation to derive estimates for the potential cost of the Dementia Fund based on estimating the scale of the Dementia Penalty. We also surveyed local councils and care providers to get their feedback on the Dementia Penalty that they face. We had responses from 54 councils and 38 care providers that provided services across 44 local authorities.

Utilising the Family and Childcare Trust’s Older People’s Care Survey 2017, the SMF has developed estimates for the average amount each region’s local authority is willing to pay in rates for residential care. This shows the average additional rate that local authorities in England pay for people with dementia is 7.1% for those in standard residential care and 4.3% for those in homes with nursing care. The SMF has used evidence from Paying for Care suggesting people in residential care face higher costs by 2.1%, and 3.4% for those receiving nursing care. Information from the Competition and Markets Authority suggests self-funders pay an additional 41% for their care compared to the local authority rates. The SMF assume that the Dementia Penalty faced by those receiving domiciliary care is the same as the Penalty for self-funders in residential and nursing care.

In our survey, Alzheimer’s Society found local authorities acknowledge a Dementia Penalty of 9.9% in residential care and 8.9% in nursing care that they pay out in rates to support people with dementia. This is a Penalty shouldered by local authorities but this doesn’t go the whole way towards supporting the needs of someone with dementia in a care home.

According to our survey of providers, people with dementia pay an additional 28.8% (an average of £152.67) Dementia Penalty. These are top up fees providers charge people with dementia, above the standard weekly rate they receive from councils. This is a Penalty paid by people with dementia that would be supported by the NHS for other health conditions.

According to our survey, for people in local authority funded places, additional fees for supporting people with dementia are £108.50 or 8.1% higher than the average final amount care homes charge to people without dementia. The equivalent for self-funders is £72.86 (3.7% increase) higher than people without dementia.

These averages are likely to hide significant variation and there are various potential estimates. As such, the Government should carry out a full evaluation of the Dementia Penalty in advance of applying the policy. It should then increase in line with inflation, before fully reviewing the scale of the Penalty every five years.

Eighty per cent of care homes and 68% of councils that responded offered clear support for a Dementia Fund. A further 20% of councils offered qualified support or required more detail.

Below is an estimate of the value of the Dementia Fund to people in each English region. This estimate is based on the number of people living with dementia in each region. In practice, this amount would vary based on the amount of support for each individual, which would vary based on whether someone self-funds or is local authority funded; how many people live in the community, in residential or in nursing care; or how many people live with mild, moderate or severe dementia. This is based on an average allocation of £5,274.

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<th>Region</th>
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<th>Value of Dementia Fund</th>
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References


7 Alzheimer’s Society FOIs of 86 NHS Trusts in 2018.


25 This case study has been anonymised.


Dementia Friends is the biggest ever initiative to transform how the nation thinks, acts and talks about dementia. A Dementia Friend is somebody that learns about dementia so they can help their community. Too many people affected by dementia feel that society fails to understand the condition they live with. Dementia Friends help by raising awareness and understanding, so that people living with dementia can continue to live in the way they want.


This figure comes from https://www.payingforcare.org/calculators/residential-care-costs/ and is based on LaingBuisson in the Care of Older People UK Market Report 29th edition 2018.

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.