



DementiaUK

Helping families face dementia

Put dementia on the agenda

General Election manifesto 2024



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Foreword

Dementia is the leading cause of death in the UK and there is currently no cure. One in two of us will be affected by this complex condition in our lifetime – either by caring for a loved one with the diagnosis, developing it ourselves, or both.

So many of us live with dementia, but no one should face it alone.

Yet the stark reality is that too many people living with dementia, their families and loved ones do not have the specialist support, advice and understanding that they need. Too often, they are left feeling exhausted and overwhelmed as they try to manage everyday life alongside the challenges that dementia can bring. Many simply do not know where to turn.

The impact on families living with dementia can be devastating, pushing their wellbeing, relationships and finances to breaking point. The impact is felt not just by the families, though, but by our health and care systems as well, placing pressure on already strained resources through unnecessary hospital admissions and the need for more intensive support.

It doesn't have to be this way. The time to act is now.

The number of people living with dementia is set to increase to over one million in the UK by the first year of the next Parliament. Currently, there are too many barriers to diagnosis and care. Too many strategies have been announced but not delivered for people affected by dementia. And too many families have fallen between the gaps.

We must deliver real change with a new long-term strategic vision for the growing number of families living with the daily challenges of dementia.

Dementia care in the UK must be transformed so that all families affected by the condition can access the specialist, compassionate support they need, when they need it.

We stand ready to work with the next Parliament and Government so that together, we can ensure that no one faces dementia alone.



Dr Hilda Hayo, Chief Admiral Nurse and Chief Executive



Recommendations for the new Government



Addressing the impact of living with dementia requires focus, strategy and vision so that:

- everyone affected by dementia receives the person-centred information and specialist support they need, at the point they need it, for as long as they need it
- a unique dementia care pathway is developed that connects and coordinates specialist care and support across all services to be responsive to the needs of families affected by dementia. This comprehensive pathway should last from pre-diagnosis through to end of life care and bereavement



The next Government has the ability to transform dementia care to help meet this vision. Dementia UK believes that the next Government should:

1 Fix the funding

Urgently review the NHS continuing healthcare (CHC) process so there is greater understanding and recognition of the health needs of people with dementia. This includes a specific focus on how their cognitive and behavioural needs are assessed, and ensuring dementia specialists are involved in the CHC assessment process.



2 Ensure no one faces dementia alone

Deliver improved dementia support in primary care for families affected by dementia through greater access to a clinical point of contact such as a specialist dementia nurse; comprehensive annual health, care and wellbeing reviews for people with dementia and their families; and joined-up care and data-sharing between all professionals.



3 Address the age inequality

Introduce a young onset dementia national framework to include timely and accurate diagnosis, age-appropriate and immediate post-diagnostic support, and a coordinated care plan.



4 Relieve hospital pressure

Commit to providing guidance and ring-fenced funding to ensure that there is a specialist dementia nurse service within every NHS Acute Trust by the end of the next Parliament.



1



Fix the funding: making care fairer for people with dementia

NHS continuing healthcare funding (CHC) can be a lifeline for people living with long-term complex health needs in England, covering costs such as domiciliary and residential care. But all too often, families affected by dementia are missing out on this crucial funding because of a flawed assessment process. Instead of spending precious time together, they are having to focus on making sense of an unworkable process.

CHC is a package of care that is fully funded by the NHS for people with long-term and complex health needs. Yet right now, families affected by dementia are finding themselves cut off or waiting years to access it, weighed down with the worry of who will provide and fund the care that their loved ones need.

Ensuring the needs of the person with dementia are considered on an individual basis during the CHC process requires expert input and support. Yet despite current guidance, assessments often take place without the involvement of a dementia specialist and their essential knowledge and expertise. Instead, assessors rely on a Decision Support Tool which fails to consistently recognise the impact of the behavioural and cognitive needs of people living with dementia, and how they can fluctuate in intensity and complexity.

People with dementia who should be eligible end up missing out, leading to increased and often unmanageable caring responsibilities as well as serious financial worries for families who are left to foot the cost of care themselves. Families feel frustrated and demoralised by a system that appears to work against them by failing to recognise the complex health needs of people with dementia.

Recommendation

The next Government must urgently review the CHC process so there is greater understanding and recognition of the health needs of people with dementia. This includes a specific focus on how cognitive and behavioural needs are assessed, and ensuring dementia specialists are involved in the assessment process.



Annette's story

Dad was diagnosed with late-stage vascular dementia in March 2019. He was also registered blind, had diagnoses of depression and type 2 diabetes, and had an indwelling catheter which he pulled out on many occasions.

My mum is in her 80s and her health deteriorated significantly whilst caring for my dad full-time. I gave up my job as a litigation solicitor in May 2020 so I could be around more to help care for him.

When I applied for NHS continuing healthcare funding in September 2019, I felt angry, frustrated and stressed throughout the entire process. I didn't feel the assessors understood the complexities of dementia and they didn't take into account Dad's cognitive and psychological needs. They were focused on finding reasons why he was not eligible rather than taking a balanced approach.

Dad's needs were minimised and my views were discounted and ignored. There was no dementia specialist involved in the process, which would have helped the assessors to better understand Dad's needs.

My initial CHC application was turned down. Dad then had a further assessment carried out in March 2021, with the decision being yet again that he was not eligible for funding. He was in full-time care at this stage as his needs were so high and we were unable to safely care for him at home.

I appealed the decision again, but Dad sadly passed away in May 2021. The appeal was once again rejected, but then I was notified in May 2022 that on verification of the minutes, the appeal had been successful.

People living with dementia are vulnerable and families are physically and emotionally exhausted and drained due to providing care. We should not have to undergo a process that is so tortuous and unfair. Dad is no longer here but the CHC process has left a huge scar on me, and I feel incredibly angry about the way he was treated.



2



Ensure no one faces dementia alone: improving primary care support

GPs remain the first port of call for people who need post-diagnostic dementia support, yet they face issues with time, capacity, a lack of specialist dementia knowledge, and fragmented systems. This leaves them unable to meet many of the complex challenges faced by families before and after diagnosis.

Dementia specialist Admiral Nurses fulfil a specific and unique role, helping families manage complex needs through providing clinical support and care coordination between health and social care. Where they work within primary care, Admiral Nurses provide wraparound dementia care through a multidisciplinary approach to supporting families.

Admiral Nurses' proactive support can help prevent crises through timely interventions and reduce the need for hospital admissions or other more intensive and costly treatments. This also relieves pressure on GPs and wider health and social care systems. It is vital that people affected by dementia have greater access to specialist dementia nurses within primary care.

Research has found that following a diagnosis of dementia, only 25% of people reported that they or their loved one had had their annual dementia review within the past year. Two out of five (39%) said it was at least two years ago. Action is needed to ensure annual reviews do happen. They are a crucial component of support for people living with dementia and are key to identifying and addressing

needs and avoiding crises. It is essential that carers' needs are also assessed in the review to ensure their health and wellbeing are supported as well.

Joined-up care and data-sharing can make a significant difference to the quality of support that families facing dementia receive. With the appropriate safeguards and consent in place, data should follow a person with dementia across all health and social care settings, with a clinical point of contact in primary care to help coordinate care and ensure timely access to all services and support needed.

Recommendation

The next Government must deliver improved dementia support in primary care for families affected by dementia by ensuring that families have greater access to a clinical point of contact such as a specialist dementia nurse; that people with dementia and their carers have comprehensive annual health, care and wellbeing reviews; and that there is joined-up care and data-sharing between all professionals.



Jonathan's story

My mum was diagnosed with mixed Alzheimer's and vascular dementia in 2012. I had been worried that she had a brain tumour so was relieved that this wasn't the case, but I did not appreciate the seriousness of dementia at the time.

My mum had some initial outpatient appointments to review her medication, and again when she had changes in her mood. However, her post-diagnostic support has never seemed adequate, and she hasn't had any recent follow-up or annual reviews.

My mum needs support with communicating and attending GP appointments. Even though I don't live very close, I know I need to be there to help her, otherwise things won't be done. Her short-term memory is bad so she would not remember to respond to an invite from the GP surgery by phone, text or email.

My mum has mobility issues which impact on her ability to get to the GP surgery. Recently, there was also an issue with medication not being delivered to her because of an electronic prescribing problem. A good GP surgery needs a way to avoid inadvertently excluding people who are not easy to reach and ensure reviews take place.

Care needs to be holistic. The physical, mental, psychological and social aspects of wellbeing should be considered. The current measures of good care seem to be about box-ticking rather than what matters to the patient. There should be a greater focus on treating the person as a whole. It should be an opportunity to see whether there is anything that can help them to do what they want to do – to make life happy.

People who support someone with dementia may not see themselves as a carer and struggle on without help themselves. They need a named point of contact from the beginning: someone who coordinates care for the person with dementia and who can also signpost to support and provide information and advice.



3



Addressing the age inequality: meeting the unique needs of people affected by young onset dementia

70,800 people in the UK are estimated to have young onset dementia (where symptoms develop before the age of 65). Yet shockingly, the published national diagnosis target excludes those aged under 65, and even getting a diagnosis can take twice as long as for older people with dementia. Families are left in limbo as they struggle with misdiagnosis and long waits to see specialists for an accurate diagnosis.

On average, it takes four years for younger people to get a dementia diagnosis – twice as long as for those aged over 65. Even after a diagnosis, many are left with little or no support. Families at their most vulnerable face living with a terminal illness, the loss of social identity and the financial and psychological consequences of leaving employment early and supporting dependent children.

To compound these issues, families must also navigate complex and fragmented health and social care systems designed for older people, with limited or no age-appropriate services available to them.

There is an urgent need for a mandated young onset dementia pathway based on:

- diagnosis rates: the national diagnosis target rate and reporting must be extended to include people diagnosed under 65

- a young onset dementia pathway within every Integrated Care System (ICS), providing a timely and accurate diagnosis, immediate post-diagnostic support and a coordinated care plan for those affected
- young onset dementia lived experience panels: ICSs and NHS Trusts should actively support the involvement of those affected and their families in the design and review of young onset dementia specific services
- a young onset dementia clinical and commissioner network within every ICS to coordinate care, assess provision, embed relationships between clinical and social care and upskill professionals

Recommendation

The next Government must mandate every ICS to develop a young onset dementia pathway – putting those of working age with dementia at its heart. This includes providing a timely and accurate diagnosis, immediate post-diagnostic support and a coordinated care plan.



Michael's story

I first started noticing symptoms of dementia in myself at the age of 44 when my mother was dying from Alzheimer's disease. She was 51 when she first started showing signs but was not formally diagnosed until she was in her late 50s, by which time she was severely cognitively impaired and receiving palliative care.

At first, my GP thought I was suffering from stress resulting from my mother's illness and prescribed me antidepressants. However, I knew something was wrong and with the help of the nurses who were treating my mother, I was able to access cognitive and neurology tests that confirmed young onset Alzheimer's disease. This was just three months after my mother died. I was 46 years old.

I didn't receive any support following my diagnosis other than numerous and disparate pieces of literature on local authority care services, much of which was inappropriate for my age and means-tested. Nor did I get a care plan or counselling; I was just referred back to my GP for ongoing support.

I had to leave work immediately as a director of a local company and I can no longer drive but my partner and I did not receive any specialist care. Accessing social and benefits services has been a constant challenge as there is little understanding of the impact of dementia on people of working age.

In my journey with young onset dementia, I have met many others in similar circumstances and have helped set up peer support groups so people can share their stories and help each other get the support they need.



4



Relieving the pressure: the need for dementia specialist nurses in acute care

One in four people in hospital beds are estimated to be living with dementia and this number only risks increasing as dementia becomes more prevalent. Specialist dementia nurses make a real difference to people living with dementia when they are in hospital, and to their families and carers. They are proven to deliver high-quality dementia support and substantial savings for hospitals and wider local health and care systems. Yet only 5% of hospitals in England have a dementia specialist Admiral Nurse service in place.

People with dementia face significant risks from hospital stays, including deterioration in their condition, wider physical health and wellbeing; and unnecessary admission into care homes upon discharge. Yet hospital care for individuals with dementia is often inadequate, leading to distress while in hospital, unnecessarily long admissions and preventable readmissions.

Hospital staff lack specialist dementia knowledge. Delivery of high-quality care, involvement of family and friends in decision-making and person-centred discharge planning are often lacking.

Specialist dementia nurses, such as Admiral Nurses, in acute settings improve wellbeing and care outcomes, reduce the length of hospital stays, and save costs for local health and care systems. Admiral Nurses use specialist knowledge to provide emotional and practical support, coordinate transitions in care, and advise health and care professionals on dementia care best practice.

An acute care specialist dementia nurse service can ensure that people with dementia are better supported during hospital stays and mitigate the risks that an admission currently brings, preventing readmission into hospital or unnecessary care home placements. An Admiral Nurse service delivered estimated savings of over £790,000 to a Trust whilst relieving pressure in an overstretched system.

Recommendation

The next Government must commit to providing guidance and ring-fenced funding to ensure that there is a specialist dementia nurse service within every NHS Acute Trust by the end of the next Parliament.



Derek's story

My wife Margaret was diagnosed with Alzheimer's disease in early 2018. In 2022, she was admitted to hospital after she collapsed, lacerating her left hand.

During Margaret's hospital stay, I was told by the occupational therapists that they could not assist her with walking because of a lack of staff and unavailability of a hoist. Since leaving hospital, she has been confined to a hospital bed in the lounge, unable to walk unassisted, and will probably need a wheelchair for the rest of her life. Ward management should fully understand the need for people with dementia to walk, otherwise they lose their cognitive ability.

Whilst Margaret was in hospital, errors in her treatment continued to impact on her wellbeing and safety. This included nurses bringing her the incorrect doses of medications that could have had very serious consequences if I hadn't been there to intervene.

In the third week of Margaret's stay on the elderly persons' ward, we were advised that she was able to go home. We were visited by a discharge coordinator and told that everything, including her care package and living equipment, would be sorted in the next few days. But some four days later we were visited by the social worker who said that nothing had been arranged.

The saving grace is that we now have our Admiral Nurse who is with us for the foreseeable future. She is a breath of fresh air and has helped to relieve the emotional stress on me as Margaret's full-time carer.



Key statistics



The number of people living with dementia in the UK is expected to increase to 1.1m by 2030, 1.4m by 2040 and 1.6m by 2050.



An estimated 7.5% of people with dementia in the UK are living with young onset dementia. The diagnosis rate is estimated to be just 45.9%, compared to 64% for those aged 65 or over.



One in three people in the UK will care for someone living with dementia in their lifetime.



Prevalence rates for young onset dementia in Black and minority ethnic groups are higher than in the population as a whole.



The total costs of dementia in the UK in 2019 amounted to £34.7bn. Social care accounted for 45% of costs (£15.7bn).



Only 25% of people affected by dementia reported having an annual health check in the previous year.



40% of the total costs for dementia care in the UK are attributable to care provided by families and unpaid carers.



One in four people in hospital beds are estimated to be living with dementia.

For more information about how Dementia UK is working to put dementia on the agenda please visit dementiauk.org/dementia-agenda or scan the QR code.

For any questions about our manifesto or to request our policy briefings please email campaigns@dementiauk.org



About Dementia UK

We are Dementia UK – the specialist dementia nursing charity that is there for the whole family. Our nurses, known as Admiral Nurses, provide free, specialist advice, support and understanding to anyone affected by dementia, whenever it is needed. We are here to make sure no one faces dementia alone.

For more information visit dementiauk.org



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