



DementiaUK

Helping families face dementia

Strategy 2020-2025

Specialist dementia care –
closer to those who need it





How Admiral Nurse services will grow

Dementia diagnosis rates are increasing.

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This strategy has been created with the input of our staff, our dementia specialist nurses, the families we care for, our Lived Experience Advisory Panel (LEAP), and clinicians and dementia professionals, and shows our plans for working towards this vision during the five year period 2020-25.

There is no cure in sight and new, effective treatments are years away. More than one million people will be living with a form of dementia as of 2022, and this is set to rise significantly by 2025. As this number rises, so too does the number of families impacted by dementia, and the need for specialist advice and support.

Dementia does not just affect the person with the diagnosis – partners, children, friends and relatives all have their lives turned upside down too. While the need for help becomes ever more pressing, local support services struggle to meet the demand – leaving already stretched GP and community services feeling the pressure.

We believe that every family affected by dementia should have access to specialist help. That is where our Admiral Nurses come in. Experienced, compassionate dementia specialists, they offer the practical solutions and emotional support that helps families face dementia with more confidence, dealing with the challenges of today and preparing for the future.

Dementia UK is the only UK charity dedicated to caring for people affected by dementia through specialist Admiral Nurses. Our

vision is that every family who needs one has access to the life-changing support of an Admiral Nurse.

A changing world – dementia care during the COVID-19 pandemic

Towards the end of the development of this strategy, we very quickly saw a changed world as a result of the COVID-19 pandemic.

We adapted accordingly, ensuring we were by the side of families affected by the virus: our Helpline and local Admiral Nursing teams gave unrivalled support and advice to some of the most vulnerable people across the UK. We worked hard to influence the UK Government on their provision of support to vulnerable people, and their position on testing and personal protective equipment in care homes and across social care. We supported our health and social care colleagues, and provided national commentary on the impact of the virus in the UK.

We recognised, early on, the long-term effects the pandemic would have on the emotional health and well-being of people with dementia and their families. We have embedded our response to this in our strategy for the next five years.

1

Closer to those who need it

In the community



In 2020, some 670,000 people were the primary carer for someone with dementia in the UK. These carers are often required to put their own lives on hold. Their work, health, and other family relationships can suffer as a result. Caring for someone with dementia can be a 24-hour a day job; one that can be both physically and emotionally exhausting.

Access to specialist dementia support can be life-changing; giving carers the skills to care for the person more effectively and with more confidence, while looking after their own health.

What we'll do:

Develop new Admiral Nurse posts each year across the UK, investing in new and existing services to increase our geographical coverage

Provide appointments with Admiral Nurses at clinics in areas without full-time nurse services, to reach even more families



Katie Dixon had been an Admiral Nurse in Kirklees for six years, before joining the new service in Bradford, when it opened in 2020. Here she tells us about the value of community-based Admiral Nursing.

“Bradford is a large, diverse city with high levels of deprivation, which is linked to more complex health needs and poorer outcomes, particularly for those in older age. The purpose of the Bradford Admiral Nurse service is to work in a multi-disciplinary team, offering holistic assessments of need, and delivering preventative interventions to support better health outcomes. We will help to deliver improvements for those individuals with the most complex levels of need.

Admiral Nurses act as a lifeline to families. We help individuals ‘live well’, supporting and guiding them through the most challenging times. The families we support are truly inspirational in the ways they face dementia. I’m very excited about our future achievements, alongside our colleagues and the community of Bradford.”



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Closer to those who need it In hospital



Sarah Merrill was the first Admiral Nurse to join the University Hospitals of Leicester NHS Trust in April 2019.

“There are now two Admiral Nurses here at one of the UK’s largest teaching hospitals, with a busy A&E Department.

We provide a person centred approach, learning about the person with dementia, then providing specialised care for their individual needs. This might include issues with nutrition, anxiety and disorientation, challenges with medication or concerns about mobility. These factors can all contribute to a person’s health deteriorating – leading to more time in hospital. There are often a range of complex issues for the families we work with. A key priority for us is to involve patients and their families in their care and decision making.

Admiral Nurses in hospitals improve patient and family experience, aiming to reduce the time people are in hospital and avoid readmission. I’m extremely proud of the work we do, helping families to feel more empowered.”



When people with a diagnosis of dementia end up in hospital, it is often because of another reason, such as an infection or a fall. Once they are there, the additional challenges dementia presents mean that their condition can deteriorate rapidly.

Admiral Nurses in hospitals ensure that patients with dementia have their additional needs considered, so that their time in hospital is not made worse by difficulty

eating and drinking, confusion around treatment or medication, or disorientation. They keep families informed of decisions and advocate on behalf of patients and families, to ensure that people with dementia receive the best care possible and are discharged in a timely manner.

What we’ll do:

Create new Admiral Nurse posts within acute hospitals

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Closer to those who need it

On the Admiral Nurse Dementia Helpline



Family carers have usually had no training, no preparation, and have very little support in their role. The toll of watching their loved one change, of contending with increasingly challenging behaviour, and the physical impact of helping them to wash, dress and eat, can build up over years. Many phone the Admiral Nurse Dementia Helpline in crisis: feeling that they are unable to go on, but seeing no way that anything can change.

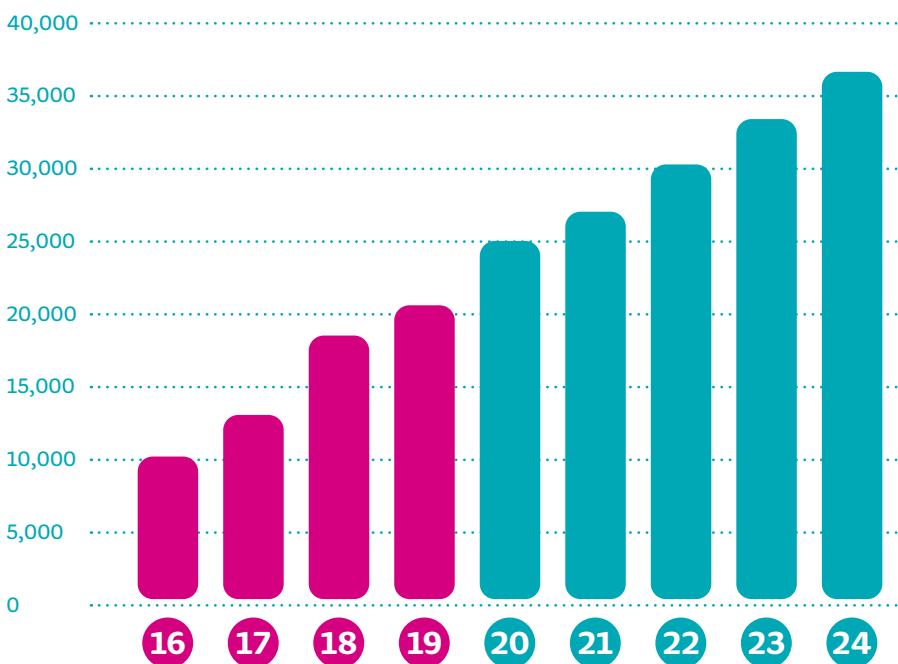
Admiral Nurses take the time to listen; to get to understand each family’s unique situation. They can recognise the touchpoints that are causing the most stress; and they have the expertise and experience to suggest coping mechanisms or support networks to alleviate some of that pressure. For many carers, it can feel as though they are being listened to and understood for the very first time.

What we’ll do:

Invest in the Admiral Nurse Dementia Helpline, to increase opening hours, and to expand the number of nurses on shift, so that the maximum number of calls can be answered in real time

Develop the digital side of the Helpline so carers can access the most relevant information and support resources when they need it, complementing the support that the Admiral Nurses give

Helpline Case Activity - Projection to 2025



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Closer to those who need it

In the workplace



For people of working age, caring for someone with dementia has its own unique challenges. With proper advice about their legal entitlements, and timely emotional support to suggest new coping strategies and patterns of working, carers can continue to work for longer – improving their family’s financial situation, and maintaining their interests and quality of life.

What we’ll do:

Develop our ‘Dementia at Work’ resource, offering guidance to working age carers, as well as guidance for employers on how best to support their staff and customers

Provide a specialist dementia support programme to corporate partners and other companies, for carers while they are at work, including at-work Admiral Nurse clinics

Excerpt from our Dementia at Work offering:

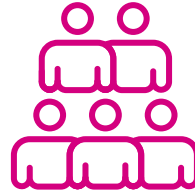
Workplaces are well-placed to provide an anchor of support, giving structure and stability when other aspects of daily life can be unpredictable and fragmented. Dementia UK has developed resources and support services delivered by our Admiral Nurses to help employees and customers live more positively with dementia and build a wider understanding of the condition.

“I just wanted to offer a heartfelt thanks for today’s session. I am so grateful for the advice and kind words. The nurse provided clarity on a topic which has consumed me and left me puzzled for so long, and I truly can see my whole families’ day to day life improving upon the strength and guidance she has provided. This may all sound rather dramatic, but words can’t express the struggle it has been so far, and today it felt like there may be light at the end of the tunnel.” – Employee feedback

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Closer to those who need it

In areas of specialism



Black, Asian and other diverse communities

Getting the best care can sometimes be more challenging for families when there are other factors affecting their needs and access to support. Some families from Black, Asian and other diverse communities may experience stigma and discrimination due to a lack of understanding of dementia within their cultural group, family or wider support networks. In addition, they may be unaware of the support available, and how to access it. This may also lead to a reluctance to seek a diagnosis, or get help.

Young onset dementia

In 2020, there were approximately 44,000 people in the UK diagnosed with dementia before the age of 65. People with young onset dementia can face challenges in receiving a diagnosis, and may be still in employment, as well as raising children and possibly even caring for their own parents.

Learning disability

The life expectancy for people with a learning disability is rising – alongside their chance of

developing dementia, a chance already higher than within the general population. One in 10 people with a learning disability will develop dementia in their lifetime. One in three people with Down's syndrome will be living with dementia in their 50s.

Specialist Admiral Nurses dedicate themselves to understanding the needs and challenges of the diverse people and communities they work with. They work alongside these groups to find solutions to the barriers they face, and help overcome these challenges.

What we'll do:

Develop dedicated Admiral Nurse services for those living with learning disability and dementia

Develop dedicated Admiral Nurses for other currently underserved communities, including people from Black, Asian and other diverse groups within the UK

Develop dedicated Admiral Nurse services for those diagnosed with dementia under the age 65



Bahman's wife, Kathleen, was diagnosed with Alzheimer's in her early 80s.

Bahman said: "I was horrified. I couldn't think of anything worse happening to my wife than the deterioration of her mental state. At first, everything seemed quite bleak: there was no cure and very little support.

But then we were introduced to our Admiral Nurse, Vincent. He gave us ongoing support through those few years. His regular meetings with me and my wife helped a great deal. We had – and still have – a very close connection, even after Kathleen died. Vincent is from a part of the world I know well and it is nice to talk to him about that.

Without Vincent, life would have been far more difficult for us to cope, both physically and financially. I only have praise for them. It's an excellent service."

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Closer to those who need it

Developing our digital offer



Caring for someone with dementia is a 24-hour a day job. The moments of crisis that can push carers to the brink can happen at any time: dealing with sleep disturbances; helping a person with incontinence; understanding agitation behaviours and offering reassurance.

When problems happen in the middle of the night, access to support and advice needs to be available in the middle of

the night too. And when face to face support is not available, there needs to be an effective alternative. This is when our digital advice and support comes in. Dementia UK’s advice leaflets and videos are some of the most visited and viewed pages on our website, offering the practical and emotional expertise of Admiral Nurses that can mean the difference between people coping or not.

What we’ll do:

Expand our series of Admiral Nurse advice leaflets and videos to cover every symptom and challenge that dementia presents

Constantly update our website to ensure our advice is accurate, contemporary, and supported by clear, intuitive functionality

Develop and test ways to signpost carers to the most relevant information and support services

Promote our digital offering so that everyone who needs it knows there is clear, practical advice available to them at all times

Investigate and implement online access to Admiral Nurses, on our Helpline and in the community – trialling video calling and text message services



We listen, learn and collaborate

Families facing dementia need support and understanding. Listening to their needs informs everything we do. Admiral Nurses specialise in working alongside families, listening to their concerns and understanding which challenges can be alleviated, and how. They collaborate with other clinicians involved in their care, ensuring each family gets the best care for their situation.

This underpins all of our work. We are constantly learning how best to serve families facing dementia and working with those who share our vision and values. We listen to people with dementia and their families, and to clinicians and our colleagues, our supporters and fundraisers.

We are empowering, supportive and respectful

People with dementia and their families can feel invisible and unheard. We campaign on their behalf, demanding parity of dementia care. We champion the rights of families: to understand what options they have regarding care, support and practical assistance. We help families to stay together longer, with support and coping strategies. We empower families to know what they are entitled to and advocate for them so that they receive it.

Dementia UK values



We act with integrity, transparency and accountability

Every penny we spend comes directly from our supporters – and we are committed to full transparency regarding how we spend this money. Dementia UK’s strategic direction is decided in consultation with the families we work with, people with dementia, our supporters, our nurses and partner organisations and our staff. We answer to a Board of Trustees, appointed from across the charitable, clinical and business sectors, who are committed to full oversight of the charity’s performance and governance.

We encourage creativity and innovation

Dementia UK is committed to applying innovation and creativity to everything we do, including finding solutions to challenges: from new ways to fundraise, to creative ways to deliver the expertise of Admiral Nurses through technology, to ways of developing and championing our staff. We are inspired by the creativity of our supporters, nurses and staff, and we are committed to encouraging that spirit throughout all of our work: the confidence to try new things, the encouragement and support of our colleagues, and the communication of our learning and successes throughout the charity and our networks.

Families facing dementia are at the centre of everything we do. As their numbers grow and their needs evolve, we will constantly challenge ourselves to adapt and grow alongside them. We will take into account their feedback and thoughts, and work towards a day when every family facing dementia has the life-changing support of a specialist Admiral Nurse.





“Admiral Nurses’ knowledge and understanding of dementia is at a completely different level. Their empathy and understanding of what it is like to be a carer is unparalleled. I cannot thank them enough.”

Emma Scattergood

Emma Scattergood's story



We were fortunate enough to come across Admiral Nurses twice in the course of my mother's dementia.

My mum, Nancy, was a bright, sociable woman with a sense of humour and a vibrant spirit.

Around her 80th birthday, we noticed she was asking the same questions over again. I lived about three hour's drive away then, so it was hard to judge the extent of the problem. But the next time we met, I saw her struggling to find her way around once familiar streets.

Mum had a brain scan at a Memory Clinic and was eventually diagnosed with mixed dementia.

Mum moved into the house next door to me, which was something she had often talked about. She was delighted at first, but then, inevitably, confusion set in and she was constantly knocking, or on the

phone. I went looking for support and found out about the Admiral Nurse Dementia Helpline.

The nurse told me that I needed to look after myself. I'd been so focussed on mum that I'd given no time to making sure I wasn't exhausted. They wrote me a long, invaluable email about getting help from carers and respite. There were links to organisations that I wasn't aware of, and lots of extra tips too. It went beyond anything I had found online myself as it was so personal and tailored to our situation.

We managed fairly well for four years. But mum became increasingly anxious and unhappy to be alone. One of mum's companions suggested she might benefit from being in a care home, where she would have company all day. I had concerns, but I could see that she was probably right.

I looked at lots of places which were not right. Finally, I visited a care home about 45 minutes from me, and discovered they had an Admiral Nurse there. I knew that, at last, we were in the right place. I sat down with the Admiral Nurse, Linda, told her everything, and could have wept with relief at her understanding and compassion.

We moved mum in immediately and Linda was such a support: if there was a meeting about medication, she would come with me. If mum got distressed, Linda would take her to a quiet corner and look at photographs with her to settle her. She brought an extra level of care which I had not seen before.

After mum passed away, Linda sat with me at her bedside for some time. I felt so supported by her, and was pleased to have the opportunity to thank her for everything she had done in the intense last weeks of mum's life. Linda was there for such key moments; seeing my mum for who she was and what she needed, supporting her following a stroke, then supporting me when she died and was finally at peace.

Admiral Nurses' knowledge and understanding of dementia is at a completely different level. Their empathy and understanding of what it is like to be a carer is unparalleled. I cannot thank them enough.

Why we need your support

Dementia UK is only able to provide the life-changing specialist support of Admiral Nurses due to the incredible generosity and energy of our supporters. We receive no government funding and are reliant on donations from members of the public and organisations who choose to support our work.

This strategy will only be made possible through the continued generous support of people across the UK. We will work hard to raise the funds for, and awareness and understanding of, both Dementia UK and Admiral Nursing in order to make it a reality.

The charity was founded in the mid-1990s by the family of Joseph Levy (“Admiral Joe”), with three nurses, based in London. We have spent the intervening years growing our services across the UK, with hundreds of nurses working across the community, in hospitals, in care homes and on our Helpline, so that thousands of families facing dementia have access to their expertise.

But there are so many people still struggling on alone. We want to reach them – all of them – over the next five years.

If you would like to speak with us about how you can support us further, please contact our Supporter Care team on 0300 365 5500 or supportercare@dementiauk.org or visit our website at www.dementiauk.org/get-involved

Do it for Dementia Nurses

Dementia is on the rise in the UK. Every three minutes someone is diagnosed, plunging another family into a crisis that can push them to the brink.

Dementia UK is here to help families live positively with dementia in the present, and to face the challenges of tomorrow with more confidence and less fear. But we need your help to continue our life-saving work. Here are some ideas how:

Fundraise



Whether you want to run, trek, cycle, bake or do your own thing to raise funds for us, your support will help us provide more dementia specialist Admiral Nurses, so families facing dementia get the help they need.

Contact our friendly Community and Events team for ideas and inspiration. Email fundraising@dementiauk.org or call **020 8036 5440**

Support us in your workplace



Nominate Dementia UK as your employer's Charity of the Year. This is a great way to raise awareness of Dementia UK with your colleagues and raise funds to support more families facing dementia.

Email our Corporate Partnerships team corporate.partnerships@dementiauk.org

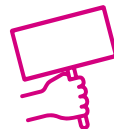
Leave a gift in your Will



A gift in your Will is an amazing way to make a lasting difference to a cause you feel passionately about. Friends and family come first; but once you've looked after those closest to you, please consider leaving a gift in your Will to Dementia UK.

For a free information booklet, visit dementiauk.org/giftinwill

Campaign



Thousands of families affected by dementia do not have access to the care and support they need.

Join our Campaigns Network and together, we can help improve the support available to people affected by dementia. dementiauk.org/campaigns

Volunteer



Join other passionate people who are committed to supporting Dementia UK by becoming a Volunteer Ambassador. Our Volunteer Ambassadors work alongside Dementia UK to help us reach out to individuals who may need the support of an Admiral Nurse, as well as developing new fundraising opportunities.

Get in touch and volunteer at dementiauk.org/volunteer

Donate



Just £5 could cover the telephone costs of two families calling our free Helpline, whenever they need support. £33 could pay for a new Admiral Nurse for an hour, reaching a family in crisis with nowhere else to turn.

To make a donation or to sign up to give monthly, call our Supporter Care team on **0300 365 5500** or visit dementiauk.org/donate



If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

**Call 0800 888 6678 or email helpline@dementiauk.org
Open Monday – Friday, 9am – 9pm
Saturday and Sunday, 9am – 5pm**



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