



DementiaUK

Helping families face dementia



Impact report
2021-2022

We are Dementia UK

The specialist dementia nurse charity.

Our nurses, called Admiral Nurses, offer life-changing support for families affected by dementia.

When families don't know where to turn, our nurses are there to help, providing the practical advice and emotional support they so desperately need.

Working in the community, in hospitals and hospices, on the Dementia Helpline and in virtual clinics, Admiral Nurses know exactly how to help – from before a diagnosis of dementia to the end of life and beyond.

For families who feel exhausted, overwhelmed and alone, they are a lifeline.

We are constantly growing the number of Admiral Nurses across the UK so that no one has to face dementia alone.

“The need for our dementia specialist Admiral Nurses has never been greater. It is only by working together that we can support more families facing dementia when they need us most, and I am truly grateful to our many supporters who make this happen.”

Dr Hilda Hayo
Chief Admiral Nurse and CEO



Did you know...?

There are over 200 types of dementia – the most common are Alzheimer’s disease, vascular dementia, Lewy body dementia, frontotemporal dementia and mixed dementia.

Memory loss is only one possible symptom of dementia. Other common symptoms include:

- confusion
- problems with speech and communication
- difficulties with decision-making and problem-solving
- changes in behaviour and personality

Dementia is the leading cause of death in the UK.



Over **940,000** people in the UK are thought to be living with dementia.



In the UK, someone develops dementia **every three minutes.**



Around **70,800** people with dementia are affected by young onset dementia – where symptoms develop before the age of 65.



700,000 people in the UK are informal carers for a person with dementia.



How we supported people

Joanna's story

My mum was diagnosed with vascular dementia in 2015, aged just 59.

The signs were there for some time – she found it hard to engage in conversation and would sit staring into space. I found lots of unopened letters in her flat, including unpaid bills. She had been in a car accident and hadn't responded to the insurance claim, invalidating her insurance – but was still driving.

I was devastated by her diagnosis – especially as we were informed by letter, with no phone call or follow-up.

Mum moved into a retirement property for extra support, with visits from carers, but she had a number of bad falls. She became incontinent and would go unchanged for hours.

I gave up my job as a police officer to support Mum. I also had three young children and

was at burnout. I couldn't get through a day without crying.

Thankfully, there was a dementia specialist Admiral Nurse, Louise, in my area. The first time I spoke to her, I knew she understood what I was going through. It was such a relief.

Louise told me how important it was to look after myself and gave me lots of practical advice. She helped me apply for care home funding and came with me to important meetings.

Louise also said I could call the Dementia UK Helpline whenever I needed. That felt like a safety blanket, helping me cope with the emotional trauma of seeing Mum deteriorate before she eventually passed away in 2021.

Mum's dementia was a very rocky road for our whole family, but when I didn't know where to turn, Louise was there for me. She was my guardian angel.



“My Admiral Nurse Louise was my guardian angel.”

A year of successes

Despite the 'long tail' of Covid-19, Dementia UK went from strength to strength in 2021-2022. Here are some of our highlights.



As Covid-19 restrictions eased, our annual **Time for a Cuppa** event took place, raising over **£165,000**.



We launched our **Closer to Home virtual clinics**, offering families affected by dementia the opportunity to book a free, confidential phone or Zoom appointment with an Admiral Nurse.

We also launched our **Memory Wall** where people can post tributes in remembrance of a loved one, with the option to make a donation.



We became one of the first charities in the world to start hosting **monthly Twitter Spaces**, where Admiral Nurses, other professionals, people with dementia and their families can connect and discuss dementia-related topics in a live 'audio room'.

We held our first online **Summer School for health and social care professionals**. Over 600 people attended, growing their knowledge and understanding of dementia.

We appointed our first **Consultant Admiral Nurse for Diverse and Under-served Communities**, supporting people from ethnic minority backgrounds, the Travelling community and other diverse groups who often face barriers in accessing dementia care.

Ask an Admiral Nurse
Dementia in South Asian communities

Thursday 11th August, 5.30-6.30pm

 @DementiaUK





Around 17,000 people signed up for our Walk 30 Miles in September challenge, raising an amazing £922,000.



We ran an awareness campaign for Black History Month, including videos, supporter stories, a blog post and a Twitter Space.

A team of 171 runners completed the London Marathon 2021 for Dementia UK – up from 122 in 2019, when the Marathon last took place in person. Another 232 supporters ran the Virtual London Marathon for us.



We launched our 'Guiding the way' campaign, highlighting the challenges many families face when applying for NHS continuing healthcare (CHC) funding for a person with dementia, and calling for improvements to a complex and often unfair system.



Georgia Kousoulou, one of our Celebrity Supporters, fronted our Remember a Star Christmas appeal in honour of her grandmother, who has dementia. She also shared her experiences in OK! magazine.

Our popular carol concert at St George's Church in London returned after being cancelled in 2020 due to Covid-19.



We carried out our first National Admiral Nurse Census in March 2022, recording our nurses' activity on one selected day. The results demonstrate the uniqueness, complexity and impact of their essential roles.



Our year in numbers

100%

of people said they would recommend our Admiral Nurse services to family and friends



33,199

calls and emails to our Helpline



We published **nine** new leaflets, including:

- A stay in hospital
- End of life care
- Understanding frontotemporal dementia
- Employment and young onset dementia



28

new Admiral Nurse services were opened across the UK

Our nurses supported over

1,300

people in our new virtual clinics in the first six months after launch



Our Facebook Challenge participants raised an incredible

£2.1m



Around 100 people joined our new Twitter Spaces each month



Our social media growth in 2021-2022



LinkedIn
56%



Instagram
24%



Facebook
24%



Twitter
3%



Bringing dementia care Closer to Home

In June 2021, we launched our new Closer to Home virtual clinics. Originally, the intention was to establish the service as a mobile support centre travelling the UK. But as a result of lockdown, the model evolved into Admiral Nurse-led virtual clinics offering appointments by phone or video call.

Families can book a free 45-minute appointment at a time to suit them at dementiauk.org/book-a-clinic-appointment.

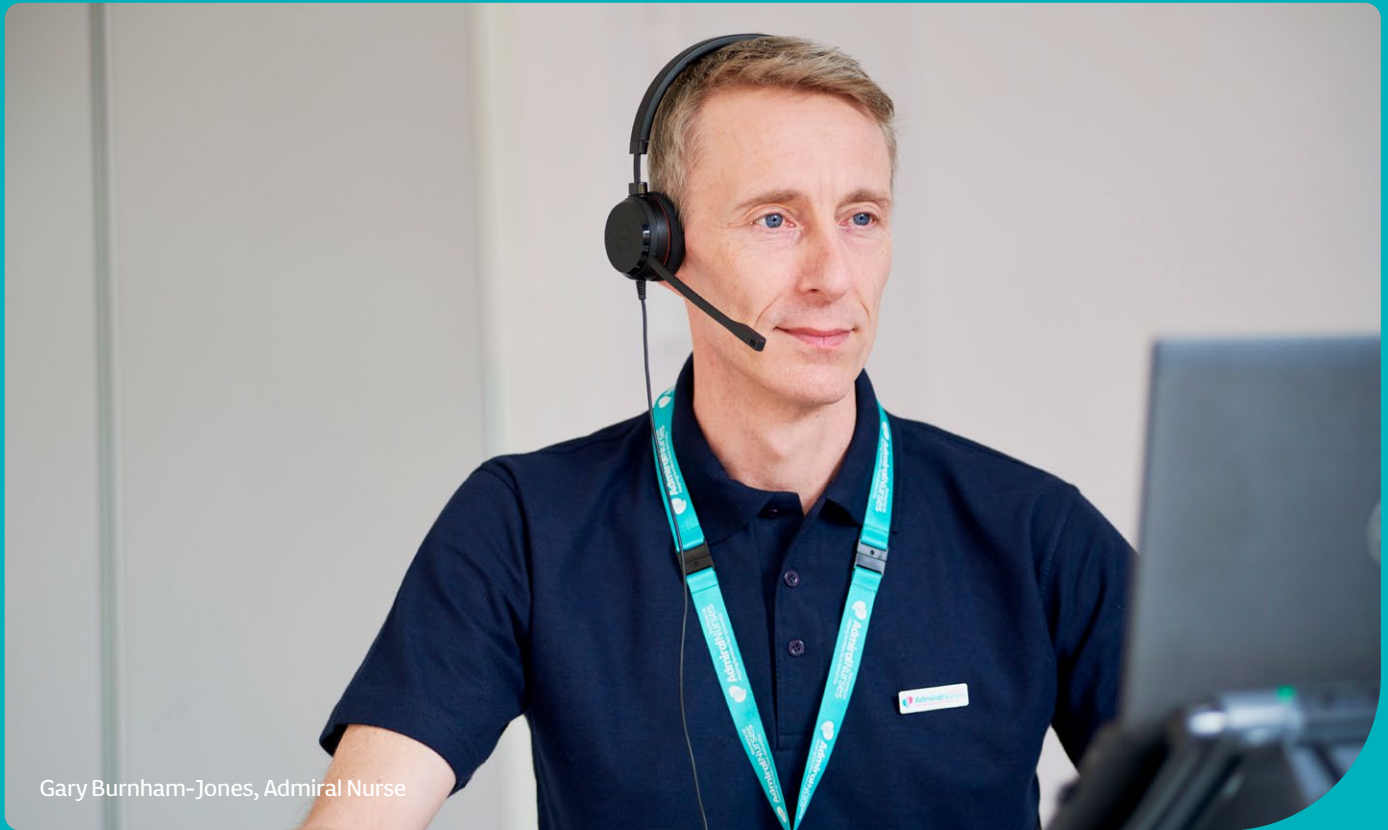
Virtual clinics have the advantage of supporting people living in areas without an Admiral Nurse service and those who cannot easily leave their

home. They also allow family members who live in different areas – even overseas – to participate in the same appointment.

Virtual clinics allow people in all areas of the UK – and even overseas – to access the support of a specialist dementia nurse.

Initially, we offered clinics three days a week, but due to demand, we expanded to four days a week in February 2022. We have also created four new full-time Admiral Nurse posts to work in the clinics.

We are currently working on plans to launch face-to-face clinics visiting locations across the UK in early 2023, alongside virtual clinics.



Gary Burnham-Jones, Admiral Nurse

“As a person with dementia it’s not easy knowing who to turn to for advice, as my GP has no specialist knowledge of my condition. This is a specialist consultation with someone who really understands and has time to listen. I cannot praise this service too highly.”

– Person living with dementia

How we raised our money

Together, we raised an incredible
£17.1m in 2021-2022
– over £1.3m more than
in the previous year.



12,570 supporters

took part in one of our four
Facebook Challenges – walking,
jogging, cycling or walking their
dogs for families facing dementia.



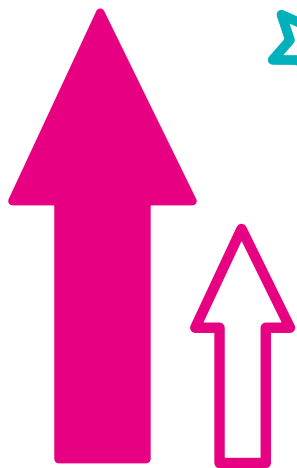
Our London Marathon and
Virtual London Marathon
runners jointly covered

10,558 miles

– the equivalent of
running from London to
Melbourne, Australia.

We increased the number of In Memory regular givers by inviting them to share tributes on our

Memory Wall.



Our regional corporate partners raised **£193,000** – smashing their collective fundraising target by **£78,000**.



Over 4,500 bakers and tea-makers made Time for a Cuppa for Dementia UK.



82% more people pledged to leave a gift in their Will than in the previous year.

300 people

sang their hearts out at our Christmas carol concert, which raised over **£40,000**.



“When I saw the Dementia UK Dog Walking Challenge, I knew I wanted to get involved. I’ve always wanted to help raise money for the charity, but I can find it hard to ask people to sponsor me. But with my dog Nova on my team, I felt more comfortable fundraising, as we were in it together. Who could resist him?”

– Barbara, March Dog Walking Challenge participant

How we supported people

Fred's story

I fought for two long and difficult years to get a diagnosis of vascular dementia for my wife, Lynne.

She had a long career as a music teacher, university lecturer and semi-professional opera singer, and had managed to rebuild her life after suffering a stroke in 2010. But in 2017, she had a second, more serious stroke, and from that point, I knew she was deteriorating.

Lynne's dementia meant I had to give up my job in the ambulance service. I was getting her up in the morning, dressing her, taking her to the toilet, lifting her. She could no longer remember our conversations; her cognition, sight and hearing were rapidly declining, and she became incontinent.

Eventually, I reached crisis point – and that's where our amazing Admiral Nurse, Trace, stepped in. When I first spoke to her on the phone, I cried for an hour and a half – everything came to the surface.

Trace arranged to visit us at home, and she made me see that I couldn't care for Lynne alone anymore. Moving Lynne into a care home was the most difficult decision I've ever made, but Trace supported me and reassured me that it was the right time.

Dementia takes over someone's life, and it's so hard to get help. Whenever I had asked, the door had always been closed on me. Trace opened that door when no one else would.

We urgently need more Admiral Nurses so that every family that needs their support is able to get it.



“We urgently need more Admiral Nurses so that every family that needs their support is able to get it.”

Paulette Winchester-Joseph,
Consultant Admiral Nurse for Diverse and Under-served Communities



Supporting under-served communities

Too many families are left to face dementia alone – and for people from diverse and under-served communities, people with learning disabilities and those with young onset dementia, finding the right support can be even more difficult.

That's why in 2021-2022, we introduced new Consultant Admiral Nurse posts for Diverse and Under-served Communities and Young Onset Dementia, and secured ongoing funding for the Consultant Admiral Nurse for Learning Disabilities post.

Over the year ahead, we aim to recruit new Admiral Nurses who are themselves from diverse backgrounds so that families feel better represented and understood, and more able to access life-changing dementia support. We will also upskill our existing nurses through webinars, forums, conferences, special interest groups and communities of practice so they can support families from diverse and under-served backgrounds to have a better quality of life with dementia.

Paulette Winchester-Joseph is Dementia UK's first Admiral Nurse for Diverse and Under-served Communities. She says:

“Accessing dementia care can sometimes be more challenging for families from Black, Asian and other diverse communities. Some of the challenges that these communities face include lower levels of understanding and knowledge of dementia; higher levels of stigma associated with the condition; and a lack of knowledge of how to access services.

In addition, people from some communities are reluctant to ask for and accept formal support from ‘outsiders’, believing that it is the responsibility of family members to care for a person with dementia.

My new role will support our Admiral Nurses to work alongside these communities to help them overcome the barriers they face and ensure that they have a better experience of dementia support.”

Your support changes lives

We believe that no one should have to face dementia alone – and we can only achieve that aim with your support.

These are some of the things you helped us achieve in 2021-2022.

We supported our nurses and other professionals to develop their dementia knowledge and skills through our online Summer School, Admiral Nurse Academy, Annual Forum and a new leadership pathway.

We launched 32 new Admiral Nurse services across the UK so more families can access support in their area.

We adopted new ways of sharing dementia information, including animations, Twitter Spaces, Instagram Reels and social media takeovers.

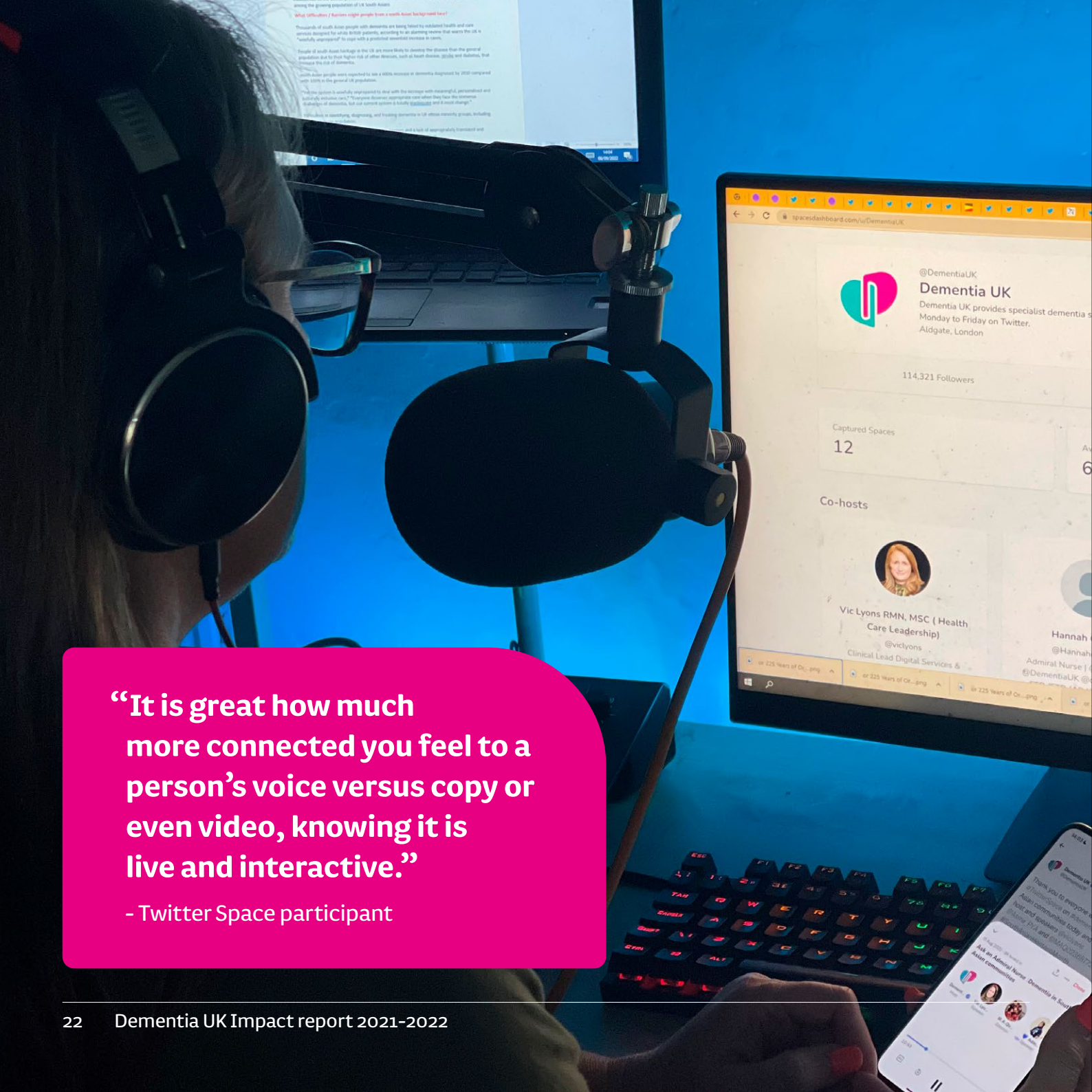
We adapted to ever-changing Covid-19 restrictions, for example by reinstating some in-person events, developing our virtual fundraising challenges, and supporting staff to work flexibly.

We created a specific young onset dementia section of the Dementia UK website with resources including information pages, blogs, family stories, films and a database of support services.

We increased the number of nurses working on our Helpline from 14 to 16 on weekdays and from five to six during evenings and weekends.

We supported our Helpline nurses to develop their expertise in helping families with complex needs, including supporting suicidal callers and managing safeguarding concerns.





“It is great how much more connected you feel to a person’s voice versus copy or even video, knowing it is live and interactive.”

- Twitter Space participant

Making connections – our Twitter Spaces

In July 2021, we became one of the first charities in the world to start hosting monthly Twitter Spaces, called ‘Ask an Admiral Nurse’.

Twitter Spaces allow real-time conversations with Twitter audiences about subjects that are important and relevant to them.

Our Twitter Spaces are hosted by Admiral Nurse Vic Lyons, with other nurses, people living with dementia, family carers and professionals joining us as speakers. They provide an opportunity for members of the public to join a live discussion – whether to listen or participate – in a space that is inclusive and non-judgmental.

Topics have included getting a dementia diagnosis; challenging stigma; cultural barriers to dementia diagnosis and care; young onset dementia; becoming an Admiral Nurse; understanding behavioural changes; and a stay in hospital.

Approximately 100 people have joined each Twitter Space, and we also record the discussion for people to catch up after the event, with roughly 200 to 300 people listening to each recording.



What we'll do next

We have big ambitions for the year ahead. In 2022-2023 we will, with your help:



Increase the number of Admiral Nurses throughout the UK – including at least 15 in primary care and 10 in acute care.



Support more people than ever on our Helpline – and grow our team to meet the increasing demand.



Expand our virtual clinics service and launch face-to-face clinics visiting locations across the UK.





Grow the number of Young Onset Dementia Admiral Nurses – we aim to recruit at least three per year over the next two years.



Introduce more specialist Admiral Nurse services, including a new service for the Chinese community in London.



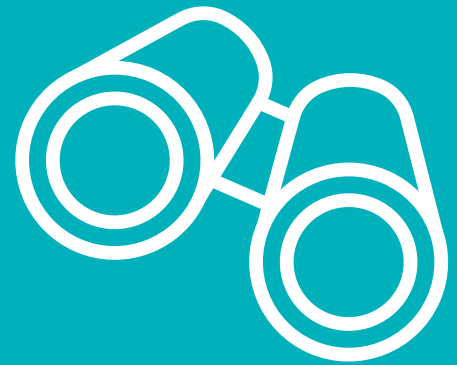
Launch our first ever brand awareness campaign, 'I live with dementia', spreading the word about the life-changing support our nurses provide.



Establish a new Accelerator Learning Programme – a six-month programme enabling current Registered Nurses to become Admiral Nurses.



Ensure more people have dementia information and advice at their fingertips – online, in our leaflets, in publications and on social media.



Julie Green,
Deputy Clinical Lead, Helpline

Thank you!

We are so grateful to the thousands of amazing supporters who helped us offer a lifeline to families facing dementia in 2021-2022.

“I’m leaving a gift in my Will to Dementia UK because no one should face dementia alone. It is an honour to support their vital work.”

- Jan, legacy pledger

Could you help us continue our life-changing work in 2022-2023 and beyond?

Donate

If you would like to make a one-off donation, a regular gift, or a gift in memory or celebration of a loved one, please visit

dementiauk.org/donate

Pledge

Gifts in Wills help us make a difference to families facing dementia far into the future. For more information, please visit

dementiauk.org/leave-a-gift-in-your-will

Fundraise

Whether you walk or run, cycle or skydive, cook or craft, there are lots of ways to raise vital funds for families facing dementia.

For inspiration, head to

dementiauk.org/events-and-fundraising

Volunteer

Become a Volunteer Ambassador or help us cheer on our amazing Challenge Events participants – find out more at

dementiauk.org/volunteer-for-us

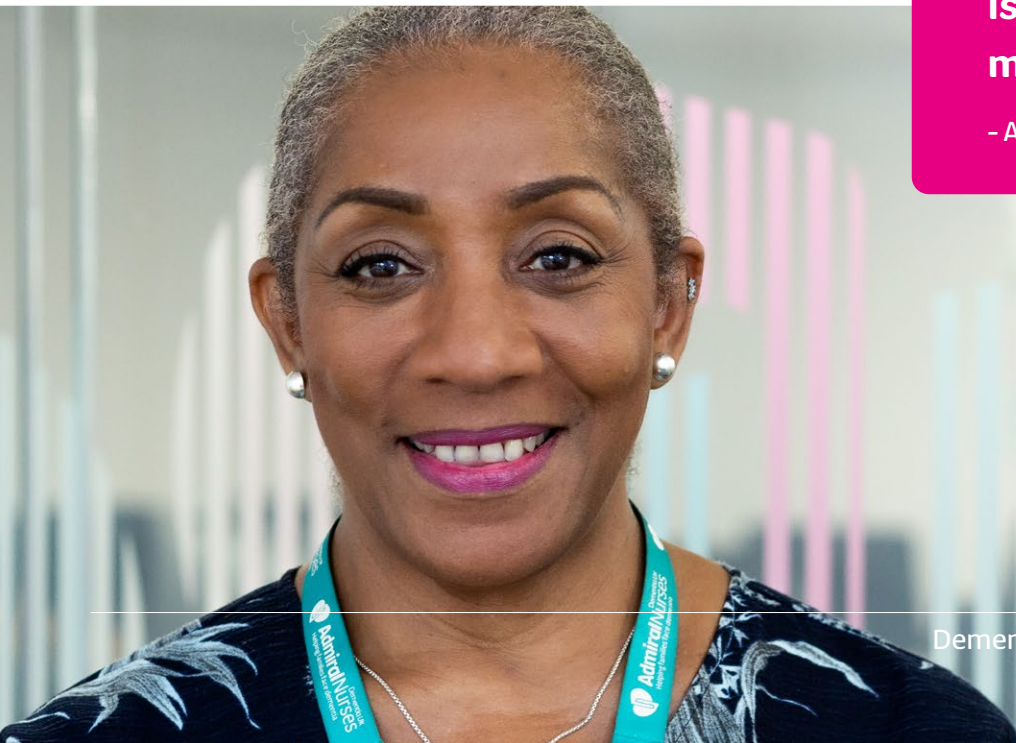
Campaign

Join us to call for improvements in dementia care and support by becoming a member of our Campaigns Network at

dementiauk.org/campaigns

“I am totally dedicated to raising funds and awareness for Admiral Nurses. I will continue to do whatever is within my power to make a difference.”

- Angela, Volunteer Ambassador



Susan Drayton,
Head of Helpline and Clinical Lead



We receive no government funding and rely on voluntary donations, including gifts in Wills. For more information on how to support Dementia UK, please visit dementiauk.org/donate or call 0300 365 5500.

Dementia UK Helpline

Call **0800 888 6678**

Email **helpline@dementiauk.org**

Virtual clinics

Visit **dementiauk.org/book-a-clinic-appointment**

dementiauk.org • info@dementiauk.org

Dementia UK is a registered charity in England and Wales (1039404) and Scotland (SC 047429.) Company number: 02944156.

