

Dementia UK supporter magazine
Summer 2024

Closer to you

**“Our Admiral
Nurse gave
us hope”**



**Andy's story of
living with young
onset dementia**



The difference you make
How you help change lives



**Put dementia on
the agenda**
Support our General
Election campaign



DementiaUK
Helping families face dementia



Did you know you can support families facing dementia and be in with a chance of winning up to £25,000?

When you play our Weekly Lottery from just £1 per week, more people will be able to access the life-changing support of a dementia specialist Admiral Nurse.

Playing our Lottery is a win-win situation – because as well as having the chance of winning a fantastic prize, you'll help us grow the number of Admiral Nurses who offer families a lifeline when they need it most.

Click here → to join our Weekly Lottery today

On average, 21 Dementia UK Lottery players are winners each week – sign up to play today and you could win!



Scan the QR code to sign up to our Weekly Lottery

Full game rules can be found at lottery.dementiauk.org or by calling our player helpline on 0330 678 2711. Players must be 18+. Dementia UK is licensed and regulated by City of London under a small society lottery licence – licence number SSL/202202746. This Unity Lottery is managed on behalf of Dementia UK by Sterling Management Centre Ltd. Sterling Management Centre Ltd is licensed and regulated in Great Britain by the Gambling Commission under account number 3137. Registered charity in England and Wales (1039404) and Scotland (SC 047429). Dementia UK provides a range of services and money raised through the Lottery will go wherever the need is the greatest.



BeGambleAware.org



Welcome to the summer issue of Closer to you.



When my mum was diagnosed with dementia in her fifties, it hit me like a brick wall. That's why supporting people affected by dementia is so important to me as an Admiral Nurse. In your magazine, you can read about how your generosity is ensuring more families like mine get the specialist support they need.

Thank you so much for your support – and enjoy the magazine.

Hannah

Hannah, Consultant Admiral Nurse for Children and Young People and Guest Editor

PS Read more of my story on p16 →

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News and views

Shop and Raise for Dementia UK

Did you know you can support families facing dementia every time you shop online? With the easyfundraising Dementia UK: Shop and Raise app, you can make every purchase count at no extra cost to you.

Shopping through the app is easy: just look up the store you want to shop with and click through to their website. There are over 8,000

well-known retailers to choose from – including Tesco, Sainsbury's, Ocado, Waitrose, John Lewis, AO.com, Etsy and eBay. And for every purchase, a percentage of what you've spent is donated to Dementia UK.

Download the app now → and start transforming your shopping into free donations for Dementia UK. Visit the App Store or Google Play and search **Dementia UK: Shop and Raise**.

New specialist services for families facing dementia

At Dementia UK, we know that having specialist support can be the difference between families coping and not. That's why we have created two important new roles to meet the needs of people who are often overlooked by dementia services.

The Consultant Admiral Nurse for the LGBTQ+ Community will represent the needs of people who identify as LGBTQ+, their families and carers, raising awareness of the challenges they face and advocating for inclusive, affirmative care.

The Consultant Admiral Nurse for Children and Young People will



represent the needs of children and young people living within families facing dementia, including through developing education programmes and resources, raising awareness and providing guidance to other Admiral Nurses.

Please turn to p16 → **to get to know Hannah, the first Admiral Nurse to hold this vital role.**



The Dementia UK team at the RCN Nursing Awards

Awards successes for Dementia UK

We are delighted that over the past year, our amazing support for families living with dementia has been recognised in a number of prestigious awards. These include:

- Patient Experience Network National Awards (PENNA): **winner** in the 'Support for caregivers, friends and family' category
- HSJ Partnership Awards: **bronze** in the 'Most effective contribution to integrated health and care' category



- RCN Nursing Awards: **finalist** in the 'Nursing older people' category
- Nursing Times Awards: **finalists** in the 'Nursing in mental health' and 'Dame Elizabeth Anionwu award for inclusivity in nursing and midwifery' categories
- Helpline Awards: **shortlisted** in the 'Helpline of the year' category

Our hugest congratulations to everyone who contributed to these awards successes, which show just how important Admiral Nurses are to families living with dementia.

The difference you make

Did you know that Dementia UK receives no Government funding? That means we rely entirely on the generosity of people like you to support as many families affected by dementia as possible across the UK.



“The Helpline Admiral Nurses are like tireless friends and mentors rolled into one, not just people giving advice on the end of the phone. They are a light in what can seem like a terribly dreary and arduous journey.”



“The Admiral Nurse listened to all I said and actually heard me, and then gave me extremely good advice. If I had not been able to speak to them, I would have been forced to give up caring for my mother a long time ago.”



“It never felt like our Admiral Nurse was there to do a job. She slotted into our family and was the first person I opened up to. She was like my angel wings.”



You can change a life

Your donation means we can be there for more families when they need us most.

[→ Please click here to give today.](#)

We simply couldn't do it without you – thank you!

Scan the QR code to donate now



£4

could cover the telephone costs of a family carer contacting Dementia UK's Helpline for free.

“Our Helpline supports hundreds of carers every week, advising them on a wide range of concerns and challenges. I love being an Admiral Nurse, knowing that I can use my skills and knowledge to make a real positive difference.”
Gary, Helpline Admiral Nurse



£25

could pay for a carer to receive an hour of one-to-one support in a virtual clinic appointment.

“Virtual clinic appointments give you that focused time with an Admiral Nurse. People can talk to us about any aspect of dementia. We're there to support, no matter what questions people have.”
Joe, virtual clinic Admiral Nurse



£33

could fund a new Admiral Nurse to spend an hour supporting a family in the community.

“Being an Admiral Nurse is about supporting the whole family. Building a relationship with carers is often the thing that makes the biggest difference. Families often say that I have been their lifeline.”
Liz, Community Admiral Nurse



Focus on...

living alone with dementia



Dementia specialist Admiral Nurse Jennifer Poynton shares advice on supporting a person with dementia who lives alone.



Around 120,000 people with dementia in the UK live alone. Over time, this typically becomes harder, but with support, they may be able to manage independently for longer.

Routines and organisation

Having a well organised regular routine can make living alone more manageable – for example, having shopping delivered on the same day each week; keeping important items like keys, wallet, glasses and phone in a set place so they are not mislaid; and using technology like a smart device (eg Alexa) for reminders.

Home safety

Spend some time with the person in their home to check for hazards. Safety adaptations such as a fall alarm, anti-flood sink plugs and

nightlights can give you reassurance. Consider giving a trusted neighbour a spare key, or using a key safe in case a problem arises.

Keeping socially active

Social support is vital for the person with dementia – for example from a dementia support group; befriending service; community groups such as a choir or sports club; neighbours, colleagues and friends. Encourage them to tell friends about their diagnosis so they can offer support.



Reviewing the person's ability to live alone

When you visit the person, review how they are coping. Do they look well? Are there signs that they are neglecting themselves (eg dirty clothes; unwashed hair) or their home (eg overflowing bins; out-of-date food in the fridge)? Ask if they are finding anything challenging. You can also ask local family and friends if they have concerns.

Deciding when the person needs extra support

The person with dementia is likely to reach a point where they can no longer safely live alone. To establish what care and support they need at this stage, you can request a social services needs assessment.

Some people may be able to remain at home with increased support – for example from carers or a family



member who could move in. For others, moving into a retirement property can be a positive next step. Some may need to move directly into a care home.

Many people with dementia who live alone are reluctant to accept support, so ensure they are included in any decisions. If possible, phase in changes gradually and positively – the person may only need support a few times a week at first, but this can be increased as their needs grow.

Support for you

To speak to an Admiral Nurse about living alone with dementia. Please call our Helpline on **0800 888 6678** or click here ➔ to book a virtual clinic appointment.

You can also read our information leaflet by clicking here ➔.



Andy's story

Being diagnosed with young onset dementia was a huge shock to Andy and his partner Christine, but our Admiral Nurses are helping them face the future with confidence.



“My partner, Christine, first noticed that I was behaving differently around two years ago. I was forgetful, clumsy and had started to mix my words up – but I didn’t notice the changes in myself.

I finally went to the GP to reassure Christine that nothing was wrong. But when I was referred to the local memory team, I failed all the tests miserably. I was diagnosed with dementia in March 2023, aged 52. The diagnosis was a complete shock. I felt really angry. I took nine weeks off work as a school sports technician

“Knowing that the Admiral Nurses will be there for Christine is so reassuring. It’s given us both security.”

whilst I came to terms with the diagnosis. It was really difficult for Christine, too. She works in a hospice, so she knows what’s coming. I used to find her crying in the bathroom but now we’ve made a pact that if we cry, we cry together. We hide nothing.

“The Admiral Nurse truly understood what we were going through”

One day, I saw a Facebook advert for an Admiral Nurse clinic in our local area. Christine and I had never heard of Admiral Nurses before, but we booked an appointment straight away with a specialist dementia nurse called Helen.

Helen was amazing. She explained in simple terms what dementia is and how it progresses. She truly understood what we were going through. Helen told me that I might forget who Christine is, but I will always remember how she makes me feel. That gave us both some hope. Nobody had ever told us that before.

“The nurse flicked a switch in my mind”

After the appointment, Christine and I sat outside and let out a massive sigh of relief. It felt like Helen had flicked a switch in my mind. Instead of fighting what was happening, I accepted it.

One of my biggest worries is how Christine will cope when I deteriorate. I won’t be aware that I’ve dipped over the cliff, but she will. But knowing that the Admiral Nurses are there for her is so reassuring. It’s given us both a bit of security. Christine and I are more in love than we’ve ever been, and we now have much more confidence to carry on doing things that we enjoy.

“Instead of fighting what was happening, I accepted it.”

Andy and his partner Christine



You can ensure that more people like Andy and Christine have access to the specialist nursing support they need by donating today.

To make a gift, please [click here](#)

Thank you for your continued support.



Good for the heart...

good for the head

While there's no guaranteed way to prevent dementia, exercise can reduce the risk of health conditions that are linked to it, like heart disease and type two diabetes. Here are five simple ways to be more active every day.

1 One small step...

...Then another, and another – starting slowly is a must if you're not used to exercise. Why not time how long it takes you to walk 1km at a comfortable pace, and see if you can speed up a little each time? Then as your fitness builds, you could step it up by following a couch to 5K running programme or joining an exercise class.

2 Embrace the everyday

Think about all the ways you're active in your daily life. Housework, gardening, washing the car – all these and more count as physical activity. Consider how you could make these everyday tasks have even more impact – could you walk the dog for an extra 10 minutes, or plan a weekly bike ride with the children or grandchildren?



3 Mix it up

If exercise feels like a chore, try varying your routine with a few different types of activity – for example, swimming on Monday, tennis on Wednesday and going for a walk on Saturday. As well as beating boredom, taking part in a range of activities will give your whole body a workout.



5 Embrace the changes

As we get older, our bodies change, so you may need to change your activity too. There are lots of ways to adapt your exercise – from low-intensity fitness classes to gentle health walks and chair exercises – which you can often find through community social media pages, local noticeboards and leisure centres. Many of these are suitable for people with dementia too.



4 Buddy up

Exercise is often more fun with company, so find a family member or friend to join you and keep you motivated. Having a fitness buddy is also great for people living with dementia, providing vital social contact and helping them stay safe while they're exercising outside the home.

Get moving with everyone ACTIVE

- ♥ Since August 2022, our partner Everyone Active has raised nearly £100,000 for Dementia UK through events like spin-a-thons, triathlons and marathons
- ♥ With over 220 leisure and cultural centres across the UK, Everyone Active's mission is to get everybody

doing at least 30 minutes of activity five times a week

♥ Together, Everyone Active and Dementia UK are committed to the idea that what is good for the heart is good for the head. **To see what's on at your local centre, click here** ➔



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We're so grateful to everyone who takes on a challenge for Dementia UK. Whether you're a first-time fundraiser or looking for your next event, here are three ways to get involved in the months ahead.

Challenge yourself, change lives

**WALK
30 MILES**
September

Walk your way through September and complete 30 miles for families facing dementia. Step out in style wearing your free Dementia UK t-shirt and fundraise as much as you can!

"I'm proud that I was motivated to complete the miles. The challenge gave me a reason to get out walking, and on my walks, I was thinking about my mum who had vascular dementia and Alzheimer's. I saw a robin on almost every walk and felt that Mum was with me."

Helen, who took part in Walk 30 Miles

**DOG
WALKING
CHALLENGE**
October

This October, make every dog walk count by covering 100km with your faithful friend. Sign up to receive a free dog bandana so your pawsome pal looks their best – together, you'll make a real difference to families living with dementia.

"I took on the challenge for my mum, who is in the early stages of dementia. It gave me some escape, walking our dog and knowing that I was helping families facing dementia. My mum was so proud and grateful that I was doing something for other people in a similar situation to us." Karen, who completed the October Dog Walking Challenge in 2023

Karen and her dog

SKYDIVE
for
Dementia
UK

Feeling brave? Take on an exhilarating freefall skydive from 10,000 feet. Choose your date and location, fundraise for our Admiral Nurses... and jump!

Book your skydive by clicking here today! ➔

"I thought if I could skydive in memory of my grandad, he would be very proud. It was overwhelming but I was also very excited. Leaving the aircraft and freefalling was out of this world!"

Sarah, who took on a skydive for Dementia UK

Skydiver Sarah and family

More dates for your diary

November 2024

November Knitting Challenge

January 2025

Winter Walk

April 2025

London Landmarks Half Marathon
Brighton Marathon

For more information about our events, click here. ➔

NB all events and dates are subject to change.

Here for children and young people



Hannah Gardner is Dementia UK's first Consultant Admiral Nurse for Children and Young People. She explains why she became an Admiral Nurse and what her role will involve.

Q. Why did you go into Admiral Nursing?

Nursing runs in my family. My late mum was a nurse, first in a hospital and then a matron in a care home, and my dad was a mental health nurse. Unsurprisingly, I was drawn into nursing too, although initially, I wanted to be a midwife.

Mum was diagnosed with young onset dementia aged 56, and went from running a care home to living in one in a matter of seven years. I was only in my twenties so it was hard to process – there was no suitable local support and I felt isolated from other dementia carers.

When Mum died in 2013, aged 60, it hit me like a brick wall. It made me determined to become a specialist dementia nurse, and I have worked as an Admiral Nurse with Dementia UK for six years – Mum continues to inspire me.

Q. Why is your new role as Consultant Admiral Nurse for Children and Young People needed?

Many children have a parent, grandparent or other relative with dementia. Some young people are carers; some have a parent who is a carer, which affects the whole family.

I don't think there is enough recognition of the impact of dementia on young people. We need to do more to understand their needs and give them the right support – and a voice to share their experiences so society understands how they are affected by having dementia in their family.

Q. What will you be doing in your role?

I'm starting by contacting all Admiral Nurses to find out where there are gaps in supporting young people and helping them to develop their skills in working with this age group.

I'm contacting schools to raise awareness of dementia, the needs of children and the support available. And I'll also be influencing policy, research and awareness nationally.

When planning how to engage with and support young people, I want to step into their shoes. I'm super-excited to see how my role develops.

“I don't think there is enough recognition of the impact of dementia on young people.”



Hannah's tips for supporting children and young people

- Make time and space for the child to talk and ask any questions they have
- Look for age-appropriate information and don't bombard them – let them set the pace
- Inform their school so they can look out for any issues and provide support, for example from a school counsellor
- Focus on them spending time with their relative and making memories
- **Click here for our information leaflet that you may find helpful** ➔

Scan the QR code for more information on our website



Paul's story

When Paul was caring for his late dad from a distance, a call to our Helpline gave him the strength to keep going.

“Dad was a lorry driver for most of his working life. He loved drawing and would always draw a map for us when we went somewhere new. We used to love going fishing together; I’ve even got a tattoo dedicated to our fishing trips.

We first became concerned about Dad six years ago. He had a couple of falls, and his walking was badly affected. The GP initially suspected Parkinson’s and prescribed some medication, but didn’t refer him to a specialist.

“Dad forgot I didn’t live close by”

When Mum and Dad moved to Spain, where my sister and brother-in-law live, Dad took a downhill turn. He was referred to a neurologist who diagnosed vascular dementia. He was then referred to a second neurologist about his difficulty walking, and was diagnosed with Lewy body dementia.

It was difficult living so far away from Dad and caring from a distance. I tried to get out to Spain four times a year and speak to him every other day on the phone, but he often forgot that I didn’t live close by. He sometimes asked me to bring him a bag of

chips. I didn’t know whether to keep reminding him or just go along with his version of reality.

I also wished I was closer to support my mum. She tried her best to care for Dad at home, but it reached the point that he just wasn’t safe anymore. We made the very difficult decision to move him into a care home.

“I felt I’d forgotten how to smile”

Dad’s dementia affected me in so many ways. Some days, I just cried because I wanted my old dad back. I felt I’d forgotten how to smile. When I had an anxiety attack at work, I knew I needed some support. I did some research and found Dementia UK’s Helpline, and plucked up the courage to send an email. Within an hour I was on the phone to a dementia specialist Admiral Nurse, Mark.

“It takes courage to realise you’re struggling.”

Speaking to Mark felt like a weight had been lifted off my shoulders. He reassured me that I was doing a good job. He also gave me practical advice like suggesting I video-call Dad rather than speaking to him on the phone. He even helped me understand how

my two adult sons might be dealing with their grandad’s dementia, and my youngest son and I purchased an old Mini Cooper to do up as a kind of therapy project together.

Dad has sadly since passed away, but Mark’s advice kept me going through the darkest days. It takes courage to realise that you are struggling, but I felt so reassured after the call. As much as you can talk to friends and family, there is a huge benefit to talking to a dementia specialist. I literally want to shout about the Helpline from the rooftops.

“Speaking to the Admiral Nurse felt like a weight had been lifted from my shoulders.”

Help us support more families like Paul’s

By making a kind donation today you’ll help more people access the life-changing support of an Admiral Nurse on our Helpline. Please visit dementiauk.org/closetoyou to donate. Thank you.

➔ Please click here to give today.

Put dementia on the agenda



We need you to support our General Election campaign for the next Government to give dementia the attention it needs. Here's how you can help.

Dementia is a huge and growing health crisis. During the first year of the new Government, the number of people with dementia in the UK is expected to exceed one million.

For people affected by dementia, it is vital that they can access the right support at the right time. Tailored, specialist care and support helps them feel more confident, hopeful and in control. It can be life-changing. But for too long, tens of thousands of

people have been left to cope with the devastating effects of dementia alone, battling with health and social care services that are disjointed, difficult to access and inadequate for people with dementia. This is only getting worse. Transforming dementia care cannot wait. With a General Election days away, we need all parliamentary candidates to commit to taking bold action for the growing number of families affected by dementia.

Let's transform dementia care together

Dementia UK is calling on the next Government to lead the way in transforming dementia care so that everyone gets the specialist support they need, when they need it. To make this a reality, we need to persuade all political parties to commit to:

- delivering expert, personalised support for people after a dementia diagnosis
- fixing the NHS continuing healthcare funding process by urgently reviewing it so families can access the care funding they need
- improving diagnosis rates and age-appropriate support for people under 65
- increasing access to specialist dementia nursing in hospitals



Get involved

Ahead of the next General Election, we all have a powerful opportunity to make our voices heard. Here are three ways you can get involved right now:

1

Click here to ask your local candidates to commit to transforming dementia care ➔

2

Read the campaign poster we have included with this magazine and stick it up on your fridge or in your window.

3

Spread the word on social media.

Together, let's urge all parliamentary candidates to place dementia care at the top of the agenda for the one in two of us in the UK who will be affected in our lifetime.

Find out more about the campaign by clicking here ➔

Supporter profile

“We played board games for 10,000 minutes!”

Sofia, 17, has raised an amazing £2,500 for Dementia UK through her board games fundraiser.

Why did you want to fundraise for Dementia UK?

Both my grandparents have dementia. My grandmother and I can still have conversations, but my grandfather's is progressing a lot faster: it's depressing to see how it has affected his daily life. I decided to fundraise for Dementia UK to help people in the same position.

How did you decide to fundraise?

I realised I could combine my passion for board games with a good cause which is personally related to me, and asked family, friends and members of the public to sponsor students at my school to play board games.

Members of the board games society in my school were

extremely supportive, and after some initial difficulties scheduling the fundraiser, I managed to get a good number of students, aged 11-18, to be active players. We collectively played for over 10,000 minutes, raising over £2,500 for the amazing Admiral Nurses. It was so much fun!

What did the fundraiser mean to you?

It was extremely fulfilling knowing that I was helping people with dementia, as I have seen the negative effects that it can have on people's daily lives and relationships. I plan to continue to fundraise for Dementia UK in any way possible by spreading the word and by encouraging others to join in.



A younger Sofia and her grandfather

A tribute to Wendy Mitchell

Everyone at Dementia UK was deeply saddened to hear of the death of dementia advocate and author Wendy Mitchell in February 2024. Wendy lived with young onset dementia and supported Dementia UK as a member of our Lived Experience Advisory Panel (LEAP) and a dedicated fundraiser. Here, staff members who worked closely with Wendy share their tributes.



“Wendy was a powerhouse. She wasn't afraid to challenge people. She always fought for the value of getting a diagnosis, and for accepting how life changes once you get that diagnosis – but doesn't end. I will dearly miss her passion. And I will dearly miss our friendship.”

Hilda Hayo
Chief Admiral Nurse and CEO

“Wendy spoke candidly about how her dementia affected her, and her efforts will leave a lasting impact on the way we understand dementia and approach dementia care.”

Paul Edwards
Chief Nursing Officer

“Wendy's personal drive for independence and autonomy in the face of dementia enabled us all to see what is possible. Her impact on others living with dementia will be felt for decades to come.”

Dr Karen Harrison Denning
Head of Research and Publications

“It was such a privilege to have known Wendy. When speaking to our Admiral Nurses, she captured everyone's attention. Her legacy to support a better experience for others living with dementia will live on.”

Caroline Scates
Deputy Director for Admiral Nurse Development

Click here for more fundraising ideas for children and young people →

Your gift will change lives

There are around 944,000 people living with dementia in the UK, and this number is growing all the time. **By leaving a gift in your Will**, you can help our specialist dementia nurses provide expert, compassionate support to families far into the future.



Make your Will for free

We have three options for you to make your Will for free in the way that suits you best.



In person with a solicitor through our partnership with the National Free Wills Network.



Online via Farewill, the UK's most trusted Will-writing provider.



Over the phone, via Co-op Legal Services.

There is no obligation to include a gift in your Will to Dementia UK, but we would be extremely grateful if you would consider it.

To find out more, click here →

Email giftsinwills@dementiauk.org

Call **0300 365 5500**

Scan the QR code to find out more about leaving a gift in your Will

