



DementiaUK

Helping families face dementia

Impact Report 2018/19





Key information

There are currently 850,000 people living with dementia in the UK

This is predicted to increase to over one million by 2021 and over two million by 2050

Dementia and Alzheimer's disease are the leading cause of death in England and Wales



Helping more families than ever stay together

It has been a really busy and successful year and we now have more Admiral Nurses – specialist dementia nurses – working within a range of settings including local communities, GP surgeries, hospices and hospitals.

We are also providing Admiral Nurse Clinics in some local communities that do not have access to an Admiral Nurse; and this model is being tested in some businesses.

Our Admiral Nurse Dementia Helpline is open seven days per week and, compared to last year, the number of calls and emails responded to has increased by 35%, meaning we were able to support more families than ever before. Family members who phone our service are given the time to talk through any issues they may be facing, and our nurses provide specialist advice and support which they can use to help them cope with the complexities dementia can bring.

We have made a significant investment in our services this year, as we know that the need for our specialist help has never been greater, with an estimated one million people in the UK living with dementia by 2021. It continues to be our ambition to provide an Admiral Nurse for every family that needs one.

Thank you for playing a part in these successes; we can only do what we do with the wonderful support given by people who donate to us, volunteer with us and commission and host our Admiral Nurses. A sincere thank you to you all.

A handwritten signature in black ink that reads "Hilda." with a period at the end.

Dr Hilda Hayo

Chief Executive Officer and
Chief Admiral Nurse



**“Without our Admiral Nurse,
life would have been far more
difficult physically
and financially. I only have
praise for Vincent. It’s an
excellent service.”**



How we supported people Kathleen and Bahman's story

When Bahman found out his beloved wife Kathleen – a former GP – had Alzheimer’s, he said he couldn’t think of anything worse happening to her than the deterioration of her mental state.

Admiral Nurse, Vincent Goodorally, provided Kathleen and Bahman with regular one-to-one support for five years. He offered suggestions about financial assistance, such as Attendance Allowance, and arranged for the district nurse to visit their home every week. This was a great help, as it meant not having to struggle to GP appointments.

Kathleen also had sleep

apnoea, a disorder that meant she could fall deeply asleep at any moment. Vincent told Bahman about a taxi service that could carry Kathleen in her wheelchair, so even if she fell asleep while out and about, Bahman could get her home.

Kathleen died at home in spring 2019. “She went peacefully with her whole family around her”, says Bahman. “We were very fortunate in that.”

Vincent and Bahman still keep in touch. “Vincent was here only a few days ago,” says Bahman. “He’s planning to come every now and again just to see how I’m getting on, now that I am living by myself.”

**“I looked
Alzheimer's up online,
learning there was no cure
and it could mean forgetting
who your own children were.
This was very difficult
to learn.”**

HIGHLIGHTS OF THE YEAR

April

We had our largest team ever at the London Marathon, with 117 finishers.

May

91-year-old Norma Howard from Fleet, Hampshire, climbed onto the top wing of a biplane and flew at 500 feet above an airfield in Cirencester, Gloucestershire, to raise money for us and set a new record for being the oldest female wing walker.



September

We hosted our annual two day Admiral Nurse Forum on the topic of 'Working with families'. Topics included research in family centred approaches, atypical dementias and young onset dementia.

October

We relaunched our LinkedIn profile including more information about the work of Admiral Nurses and our staff. By the end of March our followers had increased by 62%.

November

We reached 260 Admiral Nurses in post, coming ever closer to our goal of 300 by 2020.

June

We offered people the chance to see an Admiral Nurse in a one to one clinic appointment at the Alzheimer's show in London. Over the two days, 72 appointment slots were taken up by family carers. 94% said speaking to the Admiral Nurse would make a difference to their ability to make important decisions about the care of the person they look after.

July

We set up a new regional fundraising team, so that we can better support people across the country who are raising money for us.

August

Two of our Admiral Nurses featured on Women's Hour. Paulette Winchester-Joseph talked about health inequalities relating to Alzheimer's and Zena Aldridge discussed sex and intimacy for those living with dementia.



December

More than 500 people attended our sell out annual Carol Concert in London, raising over £100,000.

January

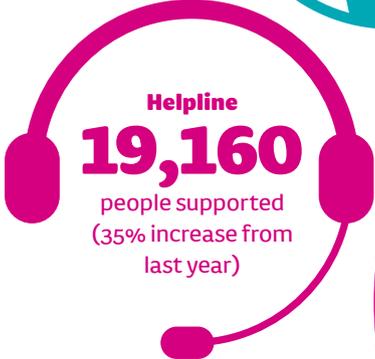
We received a grant from The Andrée Griotteray White Charitable Trust to set up a brand new young onset dementia service at Imperial College Healthcare NHS Trust. We have already received many referrals to the much-needed service.

February

We launched our next six Admiral Nurse advice videos to join the existing suite, bringing the total number in the series to 12.

March

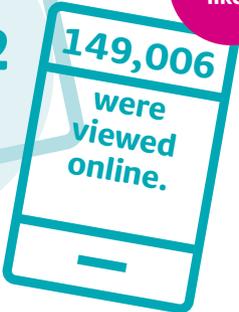
The Leicestershire fundraising group held the 'Leicestershire Tigers Dinner' on 8th March, raising around £7,000.



More than 60,000 people supported...
... by Admiral Nurses, helping families to live more positively with dementia in the present, and to face the challenges of tomorrow with more confidence and less fear.

...including dealing with unexpected incontinence, what to do if someone wants to leave the house, and coping with distress.

Our popular series of specialist advice leaflets expanded to
36



We also provided guidance, support, updates and advice to people via our social media channels...



Fundraising through Time for a Cuppa



“Dementia affects every family differently. Time for a Cuppa means that families are brought together to raise awareness and funds for more desperately needed Admiral Nurses, to help them get that individual support they need.

My Admiral Nurse, Bob Graham and his colleague Helen Springthorpe, ran a support group for people going through similar challenges as me. It was this sense of bringing people together which

encouraged me to have a go at hosting my very own Time for a Cuppa party in 2009. Then I kept on going, hosting one every year since then!

There was a Mad Hatter’s tea party one year where everyone pulled out all the stops for their outfits! One time I even headed out to town with a couple of friends, complete with Dementia UK billboards, and we became the town criers for a Time for a Cuppa event in the town hall. It’s

a great way to acknowledge the invaluable support of the Admiral Nurses who got me through the toughest moments.”

Helen Fowler

Time for a Cuppa runs in March every year. To find out more and register for the 2020 pack visit www.dementiauk.org/timeforacuppa





“Lizzie is the continuity throughout it all. She gives me the intellectual and emotional support that I need.”



How we supported people Neil and Hannah's story

It was reassuring in a way when Hannah was told that her 51-year-old husband, Neil had Alzheimer's. After months of inexplicable behaviour, both at home with his two young children, and at work as a police officer, Hannah finally knew for sure that there was something medically wrong with him.

However, Hannah explains: "After leaving work, Neil was at home all the time, often unhappy, angry, irrational, and struggling to find his role in the house." It was Admiral Nurse, Lizzie who talked this through with him, and enabled Hannah to understand why Neil was behaving how he was. Lizzie also helped Hannah to organise art therapy sessions for their

daughters and other children whose parents had dementia.

Hannah said: "Lizzie is very honest and open with me about what might happen in the future. She doesn't 'sugar coat' things. Yes, it's sometimes depressing to think today is the best Neil is ever going to get, because tomorrow or next month his Alzheimer's will be worse. But I've got Lizzie's support to face that future.

"I see her at least every six weeks and can call her any time and see her more often if I need to. Often it feels overwhelming because I can't see solutions to the problems that are coming. But as a family we are going to have to deal with it. I know Lizzie will be there to help us."

"I can get things off my chest with Lizzie so that when I go back home to Neil, I can be a nicer person and more supportive."

HOW WE RAISED OUR MONEY

Our income this
year was

£8.9m



up from £6.9m in
2017/18. That's all
down to our amazing
supporters – we can't
thank you enough

1,881
people organised
Time for a Cuppa
events

5,599
people chose to
celebrate their
birthdays by setting
up Facebook
Fundraisers for us

Our supporters took
part in fundraising
events in 20 countries
from a skydive in Dubai
to sailing the Arctic
Circle



There was a
6.9%
increase in
the number of
remembrance
funds set up for us

Our youngest event
challenger was five
years old and our oldest
was 91-year-old Norma
who undertook a wing
walk for us!

We built strategic
partnerships with
charitable trusts and
foundations to set up
new services and grow
our national Helpline

We secured
17
new corporate
partnerships with
companies of all
different sizes and
sectors



907
runners ran
13,007
miles for us, the equivalent
of London to Edinburgh
32 times

Our partnership with Central England Co-operative

The second year of our partnership with Central England Co-operative has gone from strength to strength, with staff across the company getting involved in all manner of fundraising activities and events to raise much-needed funds for families facing dementia. Some highlights include employee Lucy who faced her fears and completed a skydive, raising over £900; and colleagues across Central England Co-operative stores taking part in Dementia UK's annual Time for a Cuppa Week – raising an incredible £10,000 through baking sweet and savoury treats.

During the year, we were delighted to partner with Central England Co-operative on a joint initiative to create some support materials for teenagers affected by dementia. The talented team at the Co-operative volunteered their own time and skills to produce seven films featuring teenagers affected by dementia across the year. We are incredibly grateful to Central

England Co-operative for their expertise and support to create such an important resource for young people.

To top off a fantastic year of fundraising, we were over the moon when Central England Co-operative reached an incredible £1million in their fundraising for us. This included £483,500 in the form of donations and a further

£516,000 from their carrier bag levy. This fantastic amount will fund new dementia specialist Admiral Nurses and the running of our free national Dementia Helpline, as well as provide training and support for existing Admiral Nurses.

We look forward to our third year of partnership with Central England Co-operative.



Why I've left a gift in my Will to Dementia UK



Colin had been looking after his beloved wife, Trixie, for around three years before she was diagnosed with Alzheimer's disease. As Trixie's condition deteriorated, Colin felt alone, confused, anxious, and they were both struggling to cope.

When the couple were referred to Dementia UK they were visited by Admiral Nurse, Loraine, whose support became a lifeline.

Colin said: "Loraine lifted a huge weight off my shoulders. She helped with the practical challenges of caring for someone

with dementia, and helped me deal with my own feelings and emotions. As well as supporting us in the home, Loraine opened up a whole community, introducing us to a memory café where I was able to meet other carers, and relax for a few hours, knowing if Trixie wandered off or needed something, someone else was there to help.

"Loraine was by my side throughout our whole journey. I can't tell you the difference it made knowing that there was someone I could call on who understood what I was going through. I don't know

what I would have done without her.

"That's why I've left a legacy in my Will to Dementia UK. Physically, I can't do a lot now, but I do have a little money to spare, so I wanted to leave something to the wonderful charity that provided the Admiral Nurse, that became a 'God-send' to myself and my darling Trixie."

You can watch Colin and another supporter, Susan, explain more about why they have left a gift in their Will at www.dementiauk.org/donate

HOW WE SPENT YOUR MONEY



£1,555k
in new grant
commitments
for 2019/20
and 2021/22

There was significant investment in new Admiral Nurse services across the UK, prioritising parts of the country where there were none

We spent
£7.15m
on our charitable
work with families

£2.07m (41%) more
than the year before

Once again, we had a significant increase in voluntary income, which reflects the organisation's investment in fundraising and communications; as well as the increase in the number of families affected by dementia



For every
£1
we spent...



76p went on
charitable
activities

24p went on
fundraising...

...and for every
£1 we spent on
fundraising...



we raised
£3.78



2020-2025 strategy

We are currently working on our 2020-2025 strategy, consulting with stakeholders to ensure we get it right. Over the next five years we want to ensure that our support is closer to the people who need it: closer to the workplaces of people juggling caring responsibilities while holding down a job; closer to hand, so every call to the Helpline is answered in real time, and so advice and support is easily found at the click of a button on a phone or computer; and closer to people across the UK in their local communities and hospitals.

Our priorities for 2019-20 will help us to start achieving these aims. They are:

- Increase the number of community-based Admiral Nurse clinics in areas of the UK which currently do not have an Admiral Nurse
- Focus on the growth of Admiral Nursing in primary and acute care settings, and specialist areas such as learning disability and young onset dementia
- Increase the number of Helpline nurses available
- Continue to grow our popular series of specialist advice leaflets and videos and provide advice and guidance on our website, emails and social media channels
- Launch and implement Dementia UK's first campaign to help improve local support for families following a diagnosis of dementia

Help us continue to reach more people who need us

A sincere thank you for helping us to support so many people in 2018-19. We couldn't have done it without you.

However, we know there is still a lot of work to be done. As diagnosis rates rise, local support services are actually reducing. Demand for care home and hospice places outstrips supply. More and more onus for support is being pushed towards GPs who are already overstretched. People with dementia, and the people who care for them, are at risk of slipping through the gaps of an overextended health and social care system that does not make adequate provision for them.

This is where Admiral Nurses come in. They can help close those gaps – making specialist, family-centred dementia care more accessible to the people who need it.

This is why we need your continued support.

To read more on the many ways you can do this please go to

www.dementiauk.org/get-involved

or call **0300 365 5500**.



DementiaUK

Helping families face dementia

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 www.dementiauk.org/donate or call 0300 365 5500.



Dementia UK is a registered charity in England and Wales (1039404) and Scotland (SC047429).

