Helping families stay connected
Impact Report 2017/18
Dementia can be devastating. It can affect someone’s memory, ability to communicate, behaviour and mood, leaving them feeling worried and anxious. One in 14 people over the age of 65 have dementia and this figure grows to one in six in the over 80s.

These changes don’t just impact the person with dementia. 670,000 relatives and friends in the UK care for someone with the condition, watching their loved one change in front of them. It can be a huge strain; 40% of these carers have depression or anxiety.

That’s where Dementia UK’s Admiral Nurses come in. When things get challenging or difficult, our nurses work alongside people with dementia, their families and carers. These highly trained, specialist nurses work in communities, hospitals, hospices, care homes and on our Admiral Nurse Dementia Helpline to provide the expert care families affected by dementia need – support which is often lacking elsewhere. Continually supported and developed by Dementia UK, they educate and lead other health and social care professionals to provide great care too.

Admiral Nurses work with families during the toughest of times, giving families the support and strength they need to cope, day after day. They have the empathy and understanding of dementia to help families anticipate the ways in which their relative might change, and techniques to keep them communicating with each other.

Their work helps families avoid crises, reduces unnecessary hospital admissions and GP visits, and delays admissions to care homes. Thanks to Admiral Nurses, families can stay together, at home, for longer – and the NHS and social care system saves money too.
Every single day we hear about the struggles families affected by dementia face.

"Is my mum’s medication right?"; "How do I know if my dad is in pain if he can’t tell me?” and “How do I cope with changes in behaviour?” are typical of the questions our Admiral Nurses get asked. Families often have to contend with difficult issues like these while working, managing family commitments and dealing with their own health problems.

Our Admiral Nurses give specialist advice and support on how to prevent or manage any complex issues the family are facing. Their specialist dementia support is a lifeline for families who often struggle to find the answers they need elsewhere.

This year, thanks to our incredibly generous supporters, we’re proud to have helped over 50,000 families - more than ever before. At the end of March 2018 there were 224 Admiral Nurses throughout the UK. Our Admiral Nurse Dementia Helpline has been there for a record 14,155 people. And this year we have launched our new Admiral Nurse clinics, to reach carers in areas where we have yet to establish a full Admiral Nurse service. These one off clinics not only spread Admiral Nurse expertise, but also raise the profile of the charity and the service; rolling out the clinics programme more widely is a priority for us next year.

Thank you for helping to make all this possible. The families we help appreciate your support so much.

But despite our progress, Admiral Nurses still aren’t available in person for every family who needs them. We want to change this. More than ever we need your support to make our ambitions happen. We hope you’ll continue to help us strive towards our goal of being there for every family who needs us.

Dr Hilda Hayo
Chief Executive Officer and Chief Admiral Nurse
A lifeline. That’s what Admiral Nurses are most often described as.

When families affected by dementia need support – and are often struggling to find it elsewhere – specialist Admiral Nurses step in. They help families work through extremely complex problems, from dealing with behaviour and personality changes, to helping family members with anxiety or depression brought on by caring.

**More Admiral Nurses UK-wide**

In 2017/18 we made great strides towards meeting our goal of giving every family in need access to an Admiral Nurse. At the end of March 2018 we had 224 Admiral Nurses working across the UK; a 15% increase on 2016/17.

Admiral Nurses are working across more regions and more care settings too. We now have 12 Nurses in hospices, providing crucial end of life support to people with dementia, as well as supporting their families.

**Helping more people via our Helpline**

Anyone can call or email our Helpline to speak to an Admiral Nurse with the specialist knowledge, experience and empathy to find solutions to their challenges.

This year, our Helpline supported a record 14,155 families – a 26% rise on 2016/17 – and 95% of them would recommend the Helpline to someone who is looking after a person with dementia.

To cope with this demand, we now have nine nurses working during the day, up from six last year. We also increased the number of Admiral Nurses answering calls and emails in the evening when other services are closed, from two to three.

We were delighted when the Helpline was nominated for a Royal College of Nursing Innovation Award, out of 700 entries.

**What’s next?**

- Over the next two years, we want to increase the number of Admiral Nurses to 300 nationwide
- We’ll also increase the nurses on our Helpline in the evenings and at weekends, and continue evaluating our Helpline so we can improve it further
At the end of March 2018 we had 224 Admiral Nurses working across the UK, and are in the process of recruiting many more.

We provided expert care and support for over 50,000 people affected by dementia.

We supported a record 14,155 families through our Helpline.

The Admiral Nurses who work on our Helpline have 1,044 years’ combined experience.

...that’s a 26% rise on 2016/17.

That’s a 15% increase on 2016/17.
Lisa Kelynack is determined to look after her mum Doreen, who has dementia, at home for as long as possible. Admiral Nurse Jayne Loader is helping make that happen.

Lisa says:
Mum was diagnosed with dementia eight years ago. Although her behaviour had changed due to depression, I was so shocked by the diagnosis.

My Dad passed away six months after that and I have been Mum’s carer ever since. I just couldn’t have done it without Jayne’s support.

Because of my caring role I have anxiety and depression. I couldn’t see the changes in myself, but Jayne did. She got me to go to my GP for help.

Jayne’s helped with Mum’s problems too. She recently had a fall, and I was worried she was going to end up in a home. But Jayne sorted everything out, organising extra carers at home.

Mum also went through an awful stage of wanting to be in the toilet all the time. I was frightened she was going to hurt herself. Jayne arranged for a doctor to come out.

I want to look after Mum at home as long as possible. Jayne’s support is like a pair of arms around you, making you feel you’re not alone. If I didn’t have her, there’s no way I would still be caring.

Jayne says:
As an Admiral Nurse, there’s no typical day. I’m based in a hospital, so support people there and also in the community.
Today I’m meeting with a lady whose husband has dementia. She needs some respite care, so I’ve arranged that for her. Then I’m running a support group for carers whose loved ones are newly-diagnosed.

People often tell me that I’m their lifeline. They know I’m always at the end of the phone. I provide consistency that people can’t get elsewhere.

I find it satisfying to be able to support people in a person-centred way. It’s great to really get to know people, build relationships up, and work out strategies to make their lives better. Admiral Nurses have the time and skills to do that. What I do prevents hospital admissions and delays admissions to care homes.

Dementia UK has been a great support. The monthly practice development days are second to none, and allow me to provide the best support for families like Lisa’s.
“People often tell me that I’m their lifeline”
How we... learned from our work to make it better

We want our Admiral Nurses to be able to give people the best care and support. This year, we worked hard to gather data we could use to improve what we do, and prove how effective Admiral Nurses are.

Continuously evaluating our services is absolutely key to gathering the data we need to become even more effective. And solid evidence of our impact is also crucial when we’re trying to form new Admiral Nurse partnerships.

In 2017/18, our Service Evaluation team was there to support our Admiral Nurse services nationwide to develop evaluation plans, collect data, analyse their work, and to produce reports enabling us to demonstrate the difference they make to families living with dementia.

Our Getting Evidence into Admiral Nursing Services (GEANS) programme evaluated seven new Admiral Nurse services in depth, publishing evaluation reports packed full of testimonies from families, and data to help us set up new services going forward.

We used our findings from GEANS to shape the academic research we’re increasingly involved with. This year our Head of Research and Publications advised and worked with universities and institutions across the country to investigate different aspects of dementia care.

Projects have included working with the University of Newcastle on developing end of life care interventions for families affected by dementia, and with the Universities of Lancaster and Manchester on dementia training in acute hospitals.

Dementia UK and Admiral Nurses published 19 articles in key journals, including the British Journal of Neuroscience Nursing and the International Journal of Geriatric Psychiatry.

The evidence we collect makes us ideally placed to feed into national and international discussions on dementia care, improving policies for people with dementia and their families. We were members of several key national working groups this year including:

- National Institute for Health and Care Excellence: National Dementia Strategy review
- National Young Onset Dementia Steering Group
- National Young Onset Dementia - Post Diagnostic Support Group
Our surveys this year showed:

95% of carers contacting our helpline would be likely to recommend it to someone looking after a person with dementia.

100% of carers find our Helpline helpful in sharing information and explaining the impact of dementia.

98% of carers thought Admiral Nurses were helpful in supporting them to manage risk and reduce crises.

95% of carers supported by an Admiral Nurse would be likely to recommend the service to someone they know who looks after a person with dementia.

What’s next?

We will make sure all new Admiral Nurse teams have agreed evaluation plans.

We will continue to develop how we collect families’ experience of Admiral Nurse services so that more families can give feedback.

We will continue to analyse this data and disseminate it as widely as possible to influence best practice in dementia care.
Family story
“*It was a big relief to have someone fighting our corner*”

**Sue says:**
Looking back, Mum had all the signs of dementia. She blew all her money; we still don’t know what she did with it.

Eventually, the doctor diagnosed her, and she went into an independent living facility. But she was going round knocking on doors. The police kept coming out, and Mum was sectioned.

I first met Jakki when she assessed mum at the psychiatric hospital. The hospital wanted to discharge her into the care home, but Jakki ensured she wasn’t transferred until her medication was correct and she was ready. It was a big relief to have someone fighting our corner.

A month later, Mum made the move. The care home is fantastic. A lot of that is down to Jakki, and her training of staff. You can always get hold of her if you’re unsure about something, and she regularly reviews Mum’s medication. I feel like a big cloud has come off. Mum’s so well looked-after.

So many other relatives at the home want to see Jakki – it would be great if there was more than one Admiral Nurse, they’re so vital.

**Jakki says:**
I had been a service manager for people with dementia for three years when I noticed there were more people with dementia with complex needs coming into the home. Wanting to give them the best care, the care home supported my application to be an Admiral Nurse so that I could access the best practice training and supervision support from Dementia UK.

The Dementia UK induction was amazing. I thought I knew a lot about dementia, but I didn’t really!

Now my role is to support people with dementia and their families – like Sue and Shirley – in the care home. I also train staff and get great satisfaction knowing that I’ve helped get our carers to the fantastic level of dementia care they’re at now.

I’m in an ideal position to get to know the residents, their families, the staff – and the multidisciplinary team involved in their care. That means I can help facilitate good relationship-centred, co-ordinated support – the kernel of great dementia care.
“Good relationship-centred, co-ordinated support is the kernel of great dementia care”
How we... supported Admiral Nurses to be the best

This year, we provided a unique and full programme of professional development and mentoring to all Admiral Nurses, so they can provide excellent care and support for people with dementia and their families.

We know on-going support and development is at the heart of great practice. Dementia UK’s dedicated Professional and Practice Development team makes sure every Admiral Nurse remains at the forefront of dementia knowledge and skills.

This year, the team grew, enabling us to improve the support we can give our Admiral Nurses. This included the recruitment of four Consultant Admiral Nurses who actively support the development of new Admiral Nursing services within host organisations.

Every month, Admiral Nurses are offered group clinical supervision and practice development workshops in 16 different regions, to share and learn from each other.

We also delivered several courses in the topics most likely to help families, including end of life care and frailty masterclasses. 60 new Admiral Nurses did our induction course, making sure they were ready to provide excellent care as an Admiral Nurse.

We continued to develop our Communities of Practice too, bringing together Admiral Nurses working in similar settings ie: acute care, hospices and care homes to discuss best practice and learn from each other.

Our annual Admiral Nurse Forum was also a great opportunity for 190 attendees to learn about cutting-edge topics, under the theme ‘Complexities in dementia’.

What’s next?

Next year we’ll establish a Community of Practice for those Admiral Nurses who work with families in the community, to join our four current Communities of Practice for nurses who work within hospices, hospitals, the Helpline, and care homes

- We’ll be supporting communities of interest to discuss working with BAME and LGBT communities
- We’re planning the Admiral Nurse Forum for 2018, and will continue to deliver our induction programme
- 2018 will see us evaluating all our professional and practice development work to see how we can sustain and maintain standards and quality
- We’ll continue to expand our Professional and Practice Development team to make all this work possible
We established **21** new Admiral Nurse services this year.

Our new Consultant Admiral Nurse team has begun work as a bridge between the Business Development Team and new and established services, offering continuing support and strategic help to standardise and streamline.

**53** Admiral Nurse services thus far.

**60** new Admiral Nurses took part in our induction programme, readying them to give the best care to families affected by dementia.

**122** Admiral Nurses attended masterclasses on topics including end of life care and frailty.

Our annual Admiral Nurse Forum on ‘Complexities in dementia’ had **190 attendees** who evaluated nearly all sessions as ‘excellent’ or ‘good’.

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Family story
“*When I really need care, Wendy’s there*”

**Penny says:**
My mum is in the later stages of Alzheimer’s. She’s been in a nursing home for seven years, hasn’t spoken a word for two years, and has been in bed for 10 months.

I met Wendy at a support group last year, and she agreed to help Mum and me. My key contact had just left the home, and I was devastated. But Wendy has helped bridge the gap. I can’t thank her enough – when I really need care she’s there.

Wendy’s helped me agree an end of life plan with the home so we all know what’s going to happen in any eventuality. I was really worried that decisions would be taken out of my hands. It’s a great relief to have it settled, and feel like I’ve got control.

Wendy takes the time to explain things too. Recently Mum’s been having chest infections. Wendy said it could be down to food going into her lungs, and arranged for her to see a speech and language therapist to help with her swallowing.

Mum’s all I’ve got and I’ve done the best I can for her – and Wendy has helped so much. I think Admiral Nurses offer a wonderful service.

**Wendy says:**
I’m based in a hospice, so my role mainly involves working with people with advanced dementia and their families, often in their last year of life.

It’s so important people with dementia get specialist end of life care. They have the same right to great care as anyone else with a terminal condition – but don’t always get it. I think I’ve raised awareness of this in the hospice, and got staff to embrace working with people with dementia, through lots of support and training.

I work with families too, helping them plan for end of life, and making sure they understand what to expect at this difficult stage in the dementia journey. It’s about emotional support too. Sometimes relatives can be very upset to hear the word ‘terminal’ and surprised that people do die from dementia.

Dementia can be a lonely journey, especially at the end. End of life care should be comparable to people affected by cancer, but it isn’t. That needs to change, and Admiral Nurses are leading the way.
“It’s so important people with dementia get specialist end of life care”
How we... reached as many people as possible

Dementia UK’s ultimate goal is for every family that needs an Admiral Nurse to have one. Not only does raising awareness of Dementia UK mean more people will benefit from Admiral Nurses, it also helps us raise the crucial funds we need to continue our work.

This year, we appointed two Admiral Nurses to provide clinics and run sessions to raise awareness of what Admiral Nurses can offer around the country. Since November 2017, they’ve delivered 56 Admiral Nurse clinics, providing one-to-one specialist support for people who have a family member with dementia.

As well as providing invaluable specialist advice, clinics are ideal opportunities to showcase what Admiral Nurses can do, encouraging attendees to campaign for local Admiral Nurses.

**Communication initiatives**
In 2017, we also launched our first Admiral Nurse awareness-raising campaign. We created a short animated film, ‘Together Again’, which explores feelings of being lost in dementia – and how Admiral Nurses can help bring families back together again. We also reached one million viewers with a slot on the BBC’s Lifeline Appeal, presented by Jim Broadbent, showing the services we offer and the difference we make.

Our information leaflets not only raise awareness of what Admiral Nurses do, but are also a great source of support for people affected by dementia and health professionals. We now have 27 in the series and this year launched six advice videos too.

**What’s next?**
- We intend to attract even more people to our sessions and clinics so we can support more families living with dementia
- We’ll work closely with universities who train nurses to make sure they know about the opportunities Admiral Nursing can offer. We’ll make sure GPs and pharmacists know about Admiral Nursing too
- We’ll continue to publish our information leaflets at a rate of around one per month, so Admiral Nurses’ expertise is available to everyone
- We’ll continue to produce and publish more advice videos

Our Admiral Nurses are already helping more than 50,000 people deal with the isolation, fear and lack of support dementia can bring. But we want to reach everyone who needs us. That means raising awareness of our services – something we worked hard to do this year.
Since November 2017, we’ve delivered 56 Admiral Nurse clinics supporting people who may not otherwise have access to our services.

This year we published 18 titles in our Admiral Nurse information leaflet series, taking the total to 27.

Our leaflet information pages were viewed 72,160 times.

Our three most popular leaflets this year were...
- “Sundowning” 8,703 views
- “Delirium” 7,801 views
- “Making the home dementia-friendly and safe” 6,686 views

Since our Together Again campaign launched, it has been seen by over 1.7 million people...

...and online donations have increased by 31%.
How we... raised our money

Our income this year was £6.9m – up from £5.4m in 2016/17. And that’s all down to your support – we can’t thank you enough. Here’s a breakdown of how we raised our money this year:

- **1975 people put the kettle on and made Time for a Cuppa.**
  We worked with 33 companies, with employees taking part in activities such as office dress down days, cake sales, sweepstakes and runs.

- **More than 450 people attended our annual Carol Concert in London, raising over £73,000.**

- **There was a 26% increase in the number of donors giving to us by direct debit.**

- **725 people ran a total of 20,233 miles to raise money for Dementia UK – that’s the equivalent of three times round the moon!**
  People put on 455 events like cake sales, golf days, parties, quizzes and raffles.

- **1,590 people did challenge events to fundraise for us, including 86 doing skydives, nine people walking from Lands End to John O’Groats, and eight people walking coast to coast.**
  A record number of trusts and foundations invested in our work, helping to set up new services, grow our Helpline and support our amazing network of Admiral Nurses.

- **Our youngest event challenger was five years old and our oldest was 79.**

- **There was a 153% increase in money left to us in Wills.**
  Eight people shaved their heads to raise £5,326 for Admiral Nurses.

- **People took part in fundraising events in 19 countries, from Morocco to Peru.**
How we... worked with Central England Co-operative

Our biggest company partnership to date, Central England Co-operative has helped to significantly increase awareness of Dementia UK on high-streets across the region and raise vital income.

In 2017/18, colleagues, customers and members across 16 counties raised £280,000 through a number of activities, from jumping out of planes to taking part in cake sales – and a further £516,500 was donated by Central England Co-operative from their 5p carrier bag levy.

This incredible amount has been used to help pay for ten new specialist Admiral Nurse posts, additional vital training and the ongoing staffing of our free Dementia Helpline.

Central England Co-operative Chief Executive Martyn Cheatle said: “It is great to know that, as a community retailer and responsible business, our donation of over £800,000 will help improve the lives of those living with dementia, and those who love and care for them, in our trading area, leaving a lasting impact for many years to come”.

As well as crucial fundraising, Central England Co-operative colleagues have also provided process mapping and project management training for Dementia UK staff, and their creative team has produced an awareness film for teenagers affected by dementia.

In turn, Admiral Nurses have run awareness sessions for Central England Co-operative staff to increase their understanding of dementia and of the services we provide to help families.

We are delighted that the partnership has been extended for a further 12 months and look forward to building on other initiatives, including ways to support Central England Co-operative staff in helping customers affected by dementia.

Careways Trust

In February we were presented with a £400,000 donation following the solvent liquidation of care home and sheltered accommodation provider Careways Trust.

We were thrilled to receive such a large donation, which will help us fund 16 new Admiral Nurses in areas we currently do not cover.
Thanks to the generosity and determination of our donors and fundraisers, this year we raised a record £6.94 million – more than ever before. This meant we were able to spend more on the specialist dementia support families really need. The key stats:

We raised **£6.94 million**

We spent **£5.08 million**

on our charitable work with families...

And for every **£1 we spent**...

77p went on charitable activities

23p went on fundraising...

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

we raised **£4.44**

Dementia UK’s record year of fundraising is the fourth year where we have achieved a significant increase in voluntary income.
Help us continue supporting families to stay connected

All the progress we’ve made over the last year – the first year of our 2017-2020 strategy – was made possible by supporters like you.

For the next two years of the strategy we are focusing on:

- Increasing the number of Admiral Nurses in the UK to 300
- Increasing the number of nurses working on the Admiral Nurse Dementia Helpline by 100% to meet the need and demand
- Increasing the awareness and understanding of Dementia UK, and the support provided by Admiral Nurses, amongst families living with dementia
- Ensuring Admiral Nursing is nationally recognised as essential in the dementia pathway
- Ensuring families receiving the support of an Admiral Nurse will express a high level of satisfaction with the services provided

We need your help

Can you help us achieve these ambitious goals?

Find out how you can support us at www.dementiauk.org/support-us
Thank you

Our work simply wouldn’t be possible without our supporters, donors, partners, volunteers and fundraisers and we want to say thank you. They include:

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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.

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