Working together to face dementia

Our annual review 2016/2017

DementiaUK
Helping families face dementia
Dementia’s devastating impact

Dementia is the key health issue of our time. More than 850,000 people now have the condition – and that’s set to rise to 1 million by 2025.

Dementia can have devastating effects on a person’s memory, ability to communicate, personality, behaviour and mood. The toll on families can be huge. There are 670,000 relatives and friends caring for people with dementia, and 40% of those experience significant depression or anxiety as a result of their caring responsibilities.

The difference we make

Nothing can truly prepare families for how dementia can turn their lives upside down. But Dementia UK makes sure they don’t have to cope alone.

Our Admiral Nurses provide the specialist dementia support families need. When things get challenging or difficult, our Admiral Nurses work alongside families, giving the one-to-one support, expert guidance and practical solutions that can be hard to find elsewhere.

If communication gets hard, our Admiral Nurses are on hand with skills and techniques to help families stay connected. If someone with dementia is scared or distressed, we’ll work with their family to help them manage this. If families are struggling to cope, we’ll get them the best possible care and support.

Continually trained, developed and supported by Dementia UK, Admiral Nurses work with families across the country in the community, hospitals, care homes, hospices and other settings. They’re also at the end of the phone and on email seven days a week on the Admiral Nurse Dementia Helpline, as well as training other professionals to give outstanding dementia care.

Why ‘Admiral’ Nurses?

The family of Joseph Levy, who had vascular dementia, founded Dementia UK in 1994. Joseph was known affectionately as ‘Admiral Joe’ because of his love of sailing, and Admiral Nurses were named after him.
Our most successful year - but still much to do

For people with dementia and their families, life poses constant challenges. Isolation, fear and lack of support are common.

Dementia UK’s Admiral Nurses provide the specialist support these families need – and we are very pleased to say this year we helped more families than ever before, thanks to our generous supporters and partners.

I hope the stories you’ll read over the following pages, from our nurses and the families they help in all kinds of settings, will make the difficulties of dementia clear – and show the huge difference Admiral Nurses make.

I’m exceptionally proud of our achievements. Our 2014-2017 strategy aimed to double the number of Admiral Nurses working across the UK to 200, which we achieved. We also expanded our Admiral Nurse Dementia Helpline, answering 83% more calls and emails compared with last year.

But we want – and need – to do so much more. More than a million people will have dementia by 2025. For every person diagnosed, husbands, wives, partners, children, friends and neighbours are also affected. They all need our expert support.

In 2017 we set out a new three-year strategy to increase the number of Admiral Nurses by another 50%, to 300. We can’t thank our supporters enough for their immensely generous support so far. But we still need your help to make this ambition a reality.

Every family facing dementia deserves expert, specialist support. Dementia UK’s Admiral Nurses are uniquely placed to provide that support, and with your help, we will continue towards our goal of providing an Admiral Nurse to every family that needs one.

We look forward to working with you in 2018 and beyond.

Dr Hilda Hayo
Chief Executive Officer and Chief Admiral Nurse
Dementia UK
More nurses supporting more families across the UK

We now have 200 Admiral Nurses working across the UK, supporting over 40,000 people affected by dementia to live more positively. That’s a 19% increase on 2015-2016, and a 60% increase on the 125 nurses we had in 2014. We’ve also been able to add £300,000 to our previously designated £800,000, making a total of £1.1 million to fund expansion of our services.

Our Admiral Nurses work with families across the country, face-to-face, in the community, in hospitals and within other care providers.

Beyond supporting families, Admiral Nurses educate, lead and support other health and social care professionals to raise the standard of care that people with dementia receive.

Our impact in 2016-2017

This year has been the most successful ever for Dementia UK – thanks to our generous supporters and partners.

Our Admiral Nurse Dementia Helpline - helping more families to cope

Families who don’t have access to an Admiral Nurse in person can contact the Admiral Nurse Dementia Helpline, where an Admiral Nurse with the necessary skills, experience and empathy can give them expert support via phone or email with no time limit, often on incredibly complex problems.

The 32 Admiral Nurses working on the Helpline supported 11,264 families during the year. That’s 83% more phone calls and emails than last year, and treble the amount of three years ago.

We also extended our opening hours until 9pm during the week, so people can call us after work, or after a difficult day. We are open on Saturdays and Sundays, meaning Admiral Nurses are available on the Helpline at times when many local services or other sources of support are closed.

Whether in person or through the Helpline, Admiral Nurses are reaching more families than ever before.
Admiral Nurses receive significant support to develop in their roles. Maintaining their skills is crucial, so they can continue providing the very best support for families.

We have a national team – which we expanded this year – who provide a unique and full programme of professional and practice development to all Admiral Nurses, underpinned by the Admiral Nurse Competency Framework. This includes an induction programme, monthly clinical peer group supervision and practice development days, an annual Admiral Nurse Forum and access to relevant training and education.

We also set up ‘communities of practice’ this year for Admiral Nurses to share ideas and best practice, within different settings and around specialist topics. We introduced masterclasses on issues such as relationships, frailty and end of life care too.

Showing the effectiveness of Admiral Nursing

Evaluating the work of the Admiral Nurses is key to providing the best services possible. Demonstrating the difference Admiral Nurses make helps us to form new partnerships and best maintain existing ones.

This year, our dedicated Service Evaluation Team expanded. They support existing and new Admiral Nurse teams with developing their evaluation plans, as well as supporting analysis and reporting.

The team enable Admiral Nurses to develop their evaluation skills so they can gather evidence of the great work they do through our new ‘Getting Evidence into Admiral Nurse Services’ (GEANS) programme.

GEANS has gained national recognition. The team presented at the 2016 national Dementia Congress and was shortlisted for a Nursing Times Award for innovation. We are also delighted that NHS England has included information about GEANS in their ‘Best Practice Repository’.
Doreen

“"All the way through, Admiral Nurses have been there for us – Jo Brown in particular – visiting us regularly both when Freddie was at home and when he spent his last months in a care home. She’s seen me through a lot of difficult times, and still does. My husband loved Jo – he used to call her his sister. She’s become a great friend really.

It’s a cruel disease. I cared for Freddie at home until I was ready to drop. He was up and down all night. It’s 24 hours and you don’t get any rest. If he moved I woke up – it’s like having a child.

When Freddie was in the care home she saw me through it. I had a horrible experience with a social worker. It seemed like she just wanted to talk about the money for his care. Jo put herself in front of me and said it wasn’t the time to talk about money – I was very grateful.

Freddie ended up in a care home that I didn’t choose, 30 miles from where we live. I don’t drive. Jo put me in touch with a lady down the road going to the home so she could take me too. Jo also liaised with social services, and the care home manager. We were trying to get him moved when he passed away.

Freddie died 11 months ago yesterday. I miss him every day, and still cry a lot. Jo keeps in touch to see how I am, and I still go to the local dementia support group. There are so many people there – which is a good thing, because they’re getting support. But it’s a bad thing too. It shows how widespread the problem of dementia is, which is very sad.

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Jo

"On an average day I’m out in the community seeing a couple of families in their homes. They can be at any stage in the dementia journey, from just diagnosed, to people who have been bereaved, like Doreen.

I can help carers with anything from medication questions and changes in behaviour, to how to get access to services, benefits and planning for the future. I take the time to listen and provide them with everything they need.

I think people caring for loved ones with dementia really struggle to find the services they need, and Admiral Nurses fill that gap. We can make a huge difference to people.

The training I get from Dementia UK is second to none. I’ve never had any training that matches it before, and it really helps us give the best possible care. I have a Professional Practice Day every month, plus regular masterclasses to top up my expertise. I also have clinical supervision to talk about difficult cases that have cropped up, which is fantastic."

"The training I get from Dementia UK is second to none"

Jo is Doreen’s Admiral Nurse, based at a GP surgery in South Norfolk.
Leisa & Angela’s Story

Leisa

“My dad Alan was more than just my dad – he was my best friend. My mum died when I was a baby and we only had each other.

After he retired, he used to pick me up from work. Then one day he just couldn’t remember where my work was. He was diagnosed shortly after that. I cared for him for the next seven years. It was as bad as everyone says it is. I was isolated, I couldn’t go out. It’s a 24 hour job. Dad slowly lost his speech, his ability to eat… everything.

I cared for him at home until the last six months, when he declined rapidly, and was in and out of Hinchingbrooke Hospital in Cambridgeshire. I work there as a support medical secretary, and a colleague introduced me to Angela, the hospital’s Admiral Nurse. She went above and beyond what we could have expected. She was a lifesaver when we were let down by so many others.

Dad was often put in side rooms, and wasn’t getting the care he needed, like help to eat. Angela was caring and compassionate throughout. She did her upmost to get my dad moved onto a main ward, where he could get the care he needed. When she was around, Dad seemed to get more appropriate care. She was always popping in to see him. Dad’s face seemed to light up when he saw Angela. She was so good.

She helped me fill out the paperwork to get Dad transferred to a care home. I still cry when I think about how difficult the process was. But Angela was there to support me. Angela supported me with work too. I was at the hospital round the clock and still trying to work. She helped me explain the situation to my bosses and get time off.

She was fantastic when he was in the home. She helped me put together a palliative care plan when no one else had. In situations like that, Admiral Nurses are such a vital link. Even after Dad passed away in August 2017, Angela stayed in touch – she calls me and we’ve been for a coffee.

I believe my area has some of the fewest Admiral Nurses in the UK – they provide such a crucial service and we need more. I am so grateful to Angela, but we would have benefitted from Admiral Nurses’ help from the time Dad was diagnosed, not just when he reached hospital seven years later.
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Making families feel involved and supported is the biggest impact of my work.

Angela Moore has been an Admiral Nurse at Hinchingbrooke Hospital for the past 18 months, supporting patients with dementia and their families.

Angela

What carers and families need is someone who’ll listen. The biggest challenge is families don’t feel they’re involved in conversations in hospitals. I have the privilege of being able to spend time with families – I regularly spend up to two hours speaking to them, using non-medical terminology, and taking the time to listen.

Making families feel involved and supported is the biggest impact of my work. Often the people I meet are at breaking point and don’t know where to go, like Leisa.

Another big impact is providing support to other hospital staff, without specialist dementia training, to improve care. I do lots of quality work with other staff, for example, on recognising dementia and delirium, improving ward environments and providing equipment for theatre staff dealing with people with dementia.

The training and support I get from Dementia UK is absolutely incredible. It’s really helped me develop as a person and as a practitioner. Practice Development Days, clinical supervision and the Admiral Nurse Forum are really useful. Dementia UK is funding and supporting me to complete a Master’s in dementia care too.
Margaret & Sharron’s Story

Margaret

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It’s been four years since Brian was diagnosed with dementia, but we knew years before that. He wouldn’t go and see about it. I’d make appointments but he’d cancel them.

Last year I was at the end of my tether with caring for him. I was doing it all myself, and I couldn’t cope any more. My son went on the internet to see if he could find any support, and found Sharron, our Admiral Nurse. He got her to phone and we spoke for ages and ages – over an hour.

At that point I was close to killing myself. I wouldn’t be here without her. She’s helped me through some right lows.

All I wanted was some time by myself, and some conversation. I didn’t want social services involved at first, but it got so bad with Brian that Sharron convinced me it would be a good idea, and came out to see me with a social worker. It was the best thing she ever did. They organised some respite care, and now he goes for 12 hours a week, giving me some time to myself.

Sharron’s helped me more than anybody. Anybody. I think the world of her. I wouldn’t cope without her. I’d panic if she wasn’t at the end of the phone.

Brian’s deteriorated a lot. I have to dress him, bathe him, shave him, help him with the toilet. I’ve got to do everything for him. He’s a bit nasty sometimes. He resents me an awful lot. He’s taken over my life. I’m so sleep deprived because he’s up a lot of the night.

Brian used to be a bricklayer and stonemason. He was a lovely man. He was always on the go, and loved darts. We never thought it would happen to him. We had a good 39 years married before the dementia. But it doesn’t compensate. The good years are just a memory to us now. I’ve never known anything like this illness, it’s horrendous.

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“I was close to killing myself, I wouldn’t be here without her”

Margaret, from Durham, cares for her husband Brian, supported by Sharron, her local Admiral Nurse.
Sharron

"When I started three and a half years ago, I was the first Admiral Nurse based in a hospice in the UK. There are still only seven or eight of us.

I think my role is vital in the hospice – as well as in the community. People with dementia can benefit from hospice care as much as anyone else, but staff need the knowledge and skills to look after them well.

I give access to the hospice for those with dementia who need it. I bring the hospice walls down, take it out into community and reach people with dementia and their families who might not have thought about using a hospice.

I support staff to develop new ways of working, teaching them about issues like pain management, delirium and best interest decision-making. It’s all about giving them confidence, compassion and an interest in looking after people with dementia.

I’ve also helped set up dementia-specific services in the hospice, including a Sporting Memories group, cognitive stimulation therapy and a community choir for people with dementia.

I work closely with families to guide them through the advanced stage of dementia too, helping with things like changes in eating, hygiene and continence. I can also support people to stay at home to die. It’s about helping people feel a bit less scared and a bit more prepared. I spend time with families that other staff might not have to spend.

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Helping more people than ever before - thanks to you

Our achievements this year were only possible because we raised £5.4 million - compared to just £2.7 million three years ago.

We rely on the generosity of our supporters, and we are hugely grateful to everyone who has donated time or money, often in honour or memory of a loved one. It’s thanks to you we were able to invest and expand Admiral Nursing and help more people than ever before.

Challenge events

A record number of people took on challenge events to raise money for Dementia UK, from treks through Iceland to running 251km through the Sahara in the Marathon Des Sables.

We can’t thank you enough for your amazing efforts.

Richard Burt raised an incredible £25,000 by completing a 12 day challenge on Britain’s top 100 cycling climbs, in honour of his mum Peggy, who has Alzheimer’s.

Giving in memory

We’re also very grateful to everyone who has donated to Dementia UK in memory of a loved one, for example by setting up an online tribute page or collecting funeral donations, helping us reach more families who need our support.

Community fundraising

We’re hugely grateful to the incredible groups and individuals in communities and schools around the country that raised money for Dementia UK this year, in creative and fun ways ranging from craft parties to darts tournaments.

Val Wilson, who with the Purbeck Fundraising Group raised enough money to fund the area’s first Admiral Nurse, Rachel Murray.

The Empire Cinema in Wigan raised £2,000 for Dementia UK by organising coffee mornings.
Giving in Wills

We are particularly grateful to the growing number of people who think of Dementia UK when making their Wills. No matter how big or small, every gift in every Will helps to increase the number of Admiral Nurses we have providing specialist dementia support.

Dick decided to leave a gift in his Will due to the support he gets from his Admiral Nurse to care for his wife.

Carol concert

Our London carol concert raised over £63,000 - thank you to everyone who came and our wonderful Carol Concert Committee for making it happen. We were delighted that Emily Laing, Phyllis Logan, Judy Parfitt and John Suchet spoke at the event.

Corporate giving

Thank you as well to all the companies that donated and raised money for Dementia UK, and that chose Dementia UK to be their charity partner for the year.

“...we have really enjoyed working with everyone at Dementia UK and the support from the Head Office team has been invaluable in our fundraising efforts...”

Dawn Dove, Charles Russell Speechlys

Money from trusts

Thanks also to the many trusts who have given money to Dementia UK this year – our work wouldn’t be possible without you.

Our fundraising approach

Our fundraising approach is to enthusiastically nurture our relationships with our current fundraisers as well as attract new supporters. We want to continue to grow all areas of our income and move into new areas to help drive the expansion of our Admiral Nursing service.

Giving to Dementia UK should be a great experience. So, we have a fundraising promise on our website providing a set of standards for how we work, and the service our donors and fundraisers can expect from our dedicated team. If our donors ever feel we’re falling short of our standards, we make it easy for people to contact us and we always take care to put it right.

We have a privacy policy available on our website and also a vulnerable person’s policy, which we regularly review. We have a corporate partnerships ethical policy too, which sets out guidance about the types of companies and events that we will and won’t work with.

We always take care to be direct and honest with everyone who shares their money or time with us. We know greater transparency means greater confidence in us as a charity.

This year we registered with the new Fundraising Regulator and adhere to their code. We’re also a member of the Institute of Fundraising and make sure staff are fully trained and understand their responsibilities.
Thank you
Thank you...

...to all the people, trusts, partners and other organisations who have supported Dementia UK this year. We couldn’t do our vital work without your support.

The Adint Charitable Trust
Anne Duchess of Westminster’s Charity
Berwin Leighton Paisner LLP
Bill & Melinda Gates Foundation
Bill & Vera Chappell Charitable Foundation
Jan Burt
Richard Burt
Calleva Foundation
The Carol Concert Committees
Charles Russell Speechlys
Angel Collins
The Constance Travis Charitable Trust
Cornwall Fundraising Group
David Wilson Homes, Southern Division
Janina Dowding
East Sussex Fundraising Group
Friends of the Mede
Garfield Weston Foundation
Anna Goadby
Terrence Hallahan
Harewood Downs Golf Club
Isle of Wight Fundraising Group
Jane Jason OBE
Joseph Levy Charitable Foundation

Knight Frank
Daniel Lawrence
John Lebus
Jules Osmany
Plymouth University Raising & Giving Society
Purbeck Fundraising Group
Rotary Club of Ashford
Schroders
Sid Valley Memory Cafe
The Sobell Foundation
Sompo Canopius
The Steel Charitable Trust
St Mary & All Saints Church
Stonegate Pub Company
John Suchet
Swire Charitable Trusts
Joanna Tibbitt
Mary Troughton
Sheila Wainwright
The Welton Foundation
The Zocononis Charitable Trust

And to all of our Ambassadors across the UK, and our supporters who wished to remain anonymous.
Our finances

Because you gave so much this year...

£5,430,887

an increase of 28% from 2015/16

We were able to invest a further...

£359,280

towards kick-starting Admiral Nurse services where they are most needed

And get started sooner on plans for even more Admiral Nurses. We were able to put...

£300,000

into our Admiral Nurse Strategic Development Fund, to ensure we are on track to meet our goal of 300 Admiral Nurses by 2020
For every £1 we spent:

- 73p went on charitable activities
- 26p went on fundraising
- 1p went on governance

For every £1 we spent on fundraising we raised £4.28

Thank you for your support

Anna and Sheridan, two Admiral Nurses working in a hospital.
Our 2017-2020 strategy

Stories like Margaret’s, Leisa’s and Doreen’s show just how vital Admiral Nurses are. We want every family facing dementia to have access to the specialist support they need. We have developed our strategy for the next three years with that aim in mind and we need your help to make it a success.

Goal 1: Increase Admiral Nurse coverage across the UK, so all families that need an Admiral Nurse can get access to one

Demand for Admiral Nurses has never been greater. We’re aiming to grow the number of Admiral Nurses across the UK by 50%, to 300, by 2020, using local evidence and insight of the requirement in particular areas to inform our growth strategy and investment. We’ll grow our Helpline by 50% too.

We will continue to share our dementia care expertise locally with health and social care colleagues, supporting and enabling them to operate the highest standards of dementia care, while continuing to train, develop and support Admiral Nurses.

Goal 2: Raise awareness of Admiral Nursing throughout the UK, to enable the charity to further develop services and support

We know how much difference Admiral Nurses make. But to drive expansion of our services, we need to make sure potential partners, our health and social care colleagues and the families who could benefit from an Admiral Nurse know too.

We’re planning a series of publicity campaigns to increase awareness of Admiral Nursing, as well as new fundraising initiatives, to increase the brand recognition of Dementia UK and Admiral Nursing, and to build on the excellent reputation of the existing services.

Goal 3: Provide robust evidence for the effectiveness of Admiral Nursing

We will show how effective Admiral Nursing is across clinical settings in the community, acute care, care homes and hospices, as this is vital for us to make the case for further expansion.

We will continue collecting evidence of the tangible difference Admiral Nurses make, by rolling out GEANS to more services. We will continue to actively participate in the development of national policy, guidance and plans on dementia, and explore and evaluate different models of Admiral Nursing to meet the changing health and social care environment.
Help make our ambitions a reality

We know that the new strategy for 2017-2020 will be challenging, but we’re committed to increasing support to all of the families who need us.

We can only do this with continued help from our donors and supporters. If you want to support our work, or would like more information, please get in touch – call us on 020 7697 4160 or email info@dementiauk.org or visit www.dementiauk.org