Listening in challenging times
An evaluation of the Admiral Nurse Dementia Helpline in 2020

“In the world of dementia, the Admiral Nurse is the front line. They are the ones who get their feet wet and get their hands dirty. They are the ones who are there every day, every week, every month. They are the ones who are there to support the families of people with dementia.”

About the Admiral Nurse Dementia Helpline

Admiral Nurses are specialist dementia nurses. They provide life-changing support for families affected by all forms of dementia, including Alzheimer’s disease. Admiral Nurses working on the Dementia Helpline are there when people need help, with the time to listen and the knowledge to solve problems.

Our methodology

We collected information about contacts to the Helpline, including number of contacts, when they called, their demographics, and their reasons for contacting us.

We surveyed carers about their experiences of using the Helpline.*

We asked our Admiral Nurses about the support they provided on the Helpline during the Covid-19 pandemic in 2020.

* A total of 460 carers responded to our survey between 2017 and 2020 (25% response rate). Response rate to each question varied depending on whether carers felt it was applicable to them.

27,624 contacts to the Helpline

There were an amazing 27,624 contacts to the Helpline in 2020 – an increase of 34% on 2019. And we don’t just help once – we had over 8,000 reopened cases, where people contacted us twice or more.

“I sometimes struggle a lot, and the Admiral Nurses on the end of the phone have given me so much help.”

Carer
Supporting carers and families

- 90% of contacts to the Helpline were from carers
- 68% of these were the son or daughter of the person with dementia
- 20% were the spouse or partner
- 76% were female carers

Why people contact us

The most common reasons people contacted the Helpline were:

- accessing support
- Covid-19
- behaviour
- psychological and emotional support
- getting a diagnosis

Making a difference

Carers said that the Admiral Nurse was helpful in:

- sharing information and explaining the impact of dementia (100%)
- providing emotional support (97%)
- providing ways of responding to and coping with changes in behaviour (97%)
- providing support to manage risk and prevent possible crisis (96%)
Carers said that the Helpline has made a positive difference to:

- their ability to make important decisions about the care of the person they look after (95%)
- their ability to take better care of the person they look after (94%)
- their knowledge of local services offering support (92%)
- their confidence in their ability to cope (91%)
- their ability to communicate with the person they look after (90%)

**Without the Helpline...**

- 73% of carers said they would have struggled on their own
- 30% would have seen a GP about the needs of the person they look after
- 10% would have seen a GP for their own needs

**Here when you need us**

64% of calls were answered first time.
79% of those who left a message said they were called back within 12 hours, and 95% within 24 hours.

“The option to get a call back is a really great feature.” Carer

* Information taken from our Carer Experience survey

**Proud to be recommended**

99% of carers said that the Admiral Nurse was good at listening to them, showing compassion and explaining things in a way they could easily understand.

96% of carers would recommend the Admiral Nurse Dementia Helpline to someone who needs similar support and advice.

**Above and beyond**

Carers who contacted the Helpline said the support of our Admiral Nurses was different from that given by other health and social care professionals in the following ways:

- their specialism, experience, expertise and knowledge of dementia
- their compassion, empathy and understanding
- their ability to listen

“The Admiral Nurses know what you as a carer are going through. They show true empathy and understanding of the situation.” Carer
Caring in Covid-19 times

The Admiral Nurse Dementia Helpline is a lifeline to families affected by dementia, and supported many people with the extra challenges posed by the pandemic. Twenty percent of all contacts to the Helpline during 2020 were related to Covid-19. Our Helpline nurses told us:

“Calls are more complex, and intensity has increased. The carers/callers are not only dealing with the everyday struggles of caring for a person living with dementia, but added onto that are the additional challenges they are now facing.” Helpline nurse

“A lot of calls came from people who would visit their parents daily. They were asking: ‘Can we still do that?’”

“With the lockdown, the call volume suddenly exploded.” Helpline nurse

“Calls started to come through about the person with dementia not understanding the situation and difficulties around this.” Helpline nurse

April and May 2020

Contacts related to Covid-19 peaked in April and May, where this was recorded as a reason for the contact in 45% and 38% of all cases in those months.

How we helped

We offered advice on:

- visiting care homes
- difficulty getting a dementia diagnosis
- lack of support in the community
- coping when they were at crisis point
- keeping loved ones safe during the pandemic

and many other issues related to Covid-19.

“I was at breaking point before I picked up the telephone and called. It put everything into a clearer picture and gave me a way forward.” Carer

“I rang for specific practical advice, which I got, but I also got a load of personal psychiatric help for myself to help me cope with the challenges of the situation. I love your service, and thank you for providing it!” Carer