



### Admiral Nurse Dementia Helpline

Evaluation summary 2021-22

#### **About the Admiral Nurse Dementia Helpline**

Admiral Nurses are specialist dementia nurses who are there for the whole family. They provide free, tailored advice, support and understanding to anyone affected by dementia. The Admiral Nurses on our Helpline are there when people need them most – sharing practical tips for caring, offering compassionate emotional support and helping families plan for the future.

"I am and will always be truly grateful for the help and compassionate support I have always received each time I have rung. Without them, I can't bear to think of what might have happened to me. It was a priceless gift to be able to talk to someone who understood the problems of dementia and completely understood what I was going through [...] After every call, I felt totally supported, lifted up and strengthened and able to carry on another day."

Daughter, aged 65-74

#### Our Helpline at a glance



- Open Monday-Friday 9am-9pm; Saturdays, Sundays and bank holidays 9am-5pm – every day except 25<sup>th</sup> December
- Call **0800 888 6678**
- Email **> helpline@dementiauk.org**
- Fill in the form at **O** dementiauk.org/helpline-form

#### **Evaluation methodology\***

This report brings together data collected about our Admiral Nurse Dementia Helpline during the 12-month period from April 2021-March 2022.



We collected information from our clinical database about contacts to our Helpline, including number of contacts, method of contact, their demographics, and their reasons for contacting us.



We surveyed carers about their experiences of contacting the Helpline.

\*Statistics have been rounded throughout.

#### **Number of contacts**

In 2021-22 our Helpline received **33,199 contacts** from people in need of support. And we're here for as long as people need us – **39% of people** got in touch with us more than once.

The Helpline received contacts from **carers**, **people living with dementia**, and **professionals**.

### Here for the whole family

- **76%** of carers were female
- **67%** of the carers supported were the child of the person with dementia
- 20% were the spouse/partner
- **10%** were other relatives
- **3%** were friends/neighbours

#### Method of contact





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1,286 contacts to the Helpline related to young onset dementia (where symptoms develop before the age of 65)
- 4% of all contacts.

Phone 80%

Email 20%

## Supporting people with and without a formal diagnosis

Contacts to the Helpline related to the following types of dementia:

- suspected dementia but no formal diagnosis (26%)
- Alzheimer's disease (20%)
- dementia origin non-specific (18%)
- vascular dementia (16%)
- mixed Alzheimer's and vascular dementia (9%)

In 11% of cases, the contact related to a different type of dementia, or the diagnosis was unknown at the time of the first contact.



#### Supporting people across the UK

- 94% of contacts were from England
- 3% were from Wales
- **2%** were from Scotland
- 1% were from Northern Ireland

Within England:

- 24% of contacts were from the Midlands
- 23% were from the South-East
- **16%** were from the East of England
- **12%** were from the North-West
- **11%** were from the North-East and Yorkshire
- **10%** were from the South-West
- **4%** were from London

#### The advice people need

The main reasons for contacting the Helpline were:\*\*



**36%** Accessing support



**18%** Getting a diagnosis



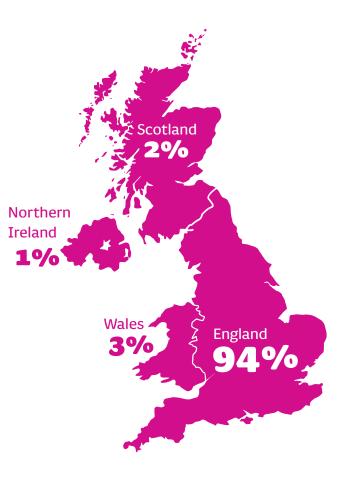
**17%** Dementia: understanding and support



**17%** Behaviour

\*\*Percentages are the proportion of people who gave this reason. People could give more than one reason.

"[The Admiral Nurse] was totally excellent at her job and without her I would not have been able to cope at the time. She knew so much about Lewy body dementia, which my mother has, and was always supportive of me as a kind of trusted counsellor and knowledgeable friend." **Daughter, aged 65-74** 



**15%** Care options

**12%** Psychological/emotional support



**11%** Wants an Admiral Nurse



#### The difference we make

Carers told us the support of the Helpline improved:

- their ability to make decisions about the care of the person with dementia (90%)
- their understanding of dementia (89%)
- their ability to take better care of the person with dementia (88%)
- their ability to cope in their caring role (84%)
- their knowledge of other services that could help (82%)

# On the NHS Friends and Family Test, 91% of carers rated their experience of the Helpline as 'very good' or 'good'.

#### Providing the right advice, information and support

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- 86% of respondents said they received all or most of the information, advice or support that they needed
- **84%** felt that the information, advice or support received made them feel much more or a little more positive about their current situation
- **72%** said that the information, advice or support that they received helped them to make changes which improved their current situation

"I needed advice about how to handle the introduction of carers. I felt more confident after the call with how to broach the subject and it worked really well." **Wife, aged 55-64** 

#### Carers told us that without the Helpline...



"Without the ongoing support and, at times, crisis support that the Admiral Nurses gave me I would not have had the strength, knowledge or ability to support my mum properly and I think there would have been a crisis that meant she could have moved into a care home." Daughter, aged 35-44

#### Sources of support

For information and advice on all aspects of dementia, please visit:

#### Odementiauk.org/information-and-support

To speak to an Admiral Nurse on our Helpline, call **0800 888 6678** or email **O helpline@dementiauk.org** 

To book a phone or video call appointment in our virtual clinic, please visit **O dementiauk.org/book** 

For further information about this evaluation, email **> evaluation@dementiauk.org** 



Dementia UK is a registered charity in England and Wales (1039404) and Scotland (SC 047429).