



DementiaUK

Helping families face dementia

Admiral Nurse Dementia Helpline

Annual evaluation report

April 2021-March 2022

Summary

An evaluation of our Admiral Nurse Dementia Helpline 2021-22

About our 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 our Dementia Helpline offer support to people who are caring for somebody with dementia – including family, friends and professionals – as well as those living with dementia themselves.

Our Helpline is open **seven days a week**: Monday-Friday 9am-9pm and Saturday and Sunday 9am-5pm, including all bank holidays except 25th December. People can contact our Helpline via telephone, email or online form.

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 about contacts to our Helpline, including number of contacts, method of contact, reasons for contact and the demographics of contacts
- We surveyed carers contacting our Helpline to ask about their experiences of this service (April 2021 – July 2022)

Contacts

33,199 contacts were recorded between April 2021 and March 2022; 80% of these contacts were via telephone.

People contacting our Helpline (unique cases)

20,382 individuals contacted our Helpline. Almost all (98%) were located within the UK.

Contact was made with 19,172 of these individuals; 91% were carers, with most being the child of the person with dementia (67%). 39% had more than one direct contact with our Helpline.

Reason for contact

40,650 reasons for contact were recorded for the 20,382 individuals (an average of two reasons recorded per case).

36% of cases had 'accessing support' recorded as a reason for contact, and **18%** had 'getting a diagnosis' recorded as their reason for contact.

Carer experience survey April 2021 to July 2022

337 carers told us about their experience of our Helpline via an online survey:

- **91%** rated their experience as very good or good
- **86%** said they received all or most of the information, advice or support that they needed and that this made them feel much more (**57%**) or a little more (**27%**) positive about their current situation
- **Just under three-quarters** said the information, advice or support they received helped them to make changes which improved their current situation

Carers also told us how the support from our Helpline had made a positive difference to their:

- ability to make decisions about the care of the person with dementia (**90%**)
- understanding of dementia (**89%**)
- ability to take better care of the person with dementia (**88%**)
- ability to cope (**84%**)

Carers felt that this support helped to maintain relationships – **84%** said it had made a difference to their ability to communicate with the person they cared for and **81%** said it had helped with family relationships/communication.

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Introduction

Our **Admiral Nurse Dementia Helpline** offers support to people who are caring for somebody with dementia – including family, friends and professionals – as well as those living with dementia themselves. The Helpline is fully staffed by Admiral Nurses, who are Registered Nurses experienced in supporting families affected by dementia.

Our Helpline is open **seven days a week**: Monday-Friday 9am-9pm and Saturday and Sunday 9am-5pm, including all bank holidays, except for 25th December. People can contact our Helpline via telephone, email or online.

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

- the clinical database used by our Helpline Admiral Nurses to record information about contacts and cases
- carer experience survey (April 2021 – July 2022)

Section 1

Service activity data

This section of the report provides an overview of the data recorded on the clinical database used by our Helpline Admiral Nurses, including:

- number of contacts
- number of people contacting the Helpline (unique cases)
- reason for contact
- location of those contacting the Helpline
- how people found out about the Helpline
- demographic data recorded about cases
- data recorded relating to young onset dementia cases

Helpline contacts

Most of the 33,199 direct contacts were by telephone (80%):

- **26,713 telephone calls**
- **6,486 emails from the Helpline**

In addition to the direct contacts above, the Helpline nurses also recorded **18,099** admin activities related to cases.

Most direct contacts were with a carer

(NB: an individual case can have more than one contact. The data below reflects the type of person who made contact).

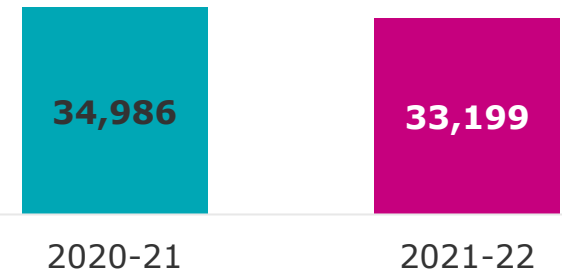
- **92%** of the contacts recorded were with a **carer** (n=30,423)
- **4%** of contacts were with a **person living with dementia** (n=1,183)
- **3%** of contacts were with a **professional** (n=989)
- **2%** of contacts were recorded as being with **'other'** (n=604):
this is when a person does not fit into the other categories, eg a family member or friend who does not identify themselves as a carer

Comparison of contacts with 2020-21

The total number of direct contacts fell slightly (a 5% decrease from 34,986 direct contacts to 33,199 direct contacts in 2021-22).

A total of **33,199 contacts** were recorded between April 2021 and March 2022.

Helpline contacts



Number of people contacting our Helpline (unique cases)

How many individual people contacted our Helpline?

Between April 2021 and March 2022, the Helpline recorded information about **20,382 unique cases**.

- **Contact was made with 19,172** of these cases
- Where contact was made, **91%** were carers, **4%** were professionals, **3%** were people living with dementia, **3%** were 'other'
- **39%** of cases (with direct contact) **had more than one contact** recorded

How did individuals initially contact our Helpline?

The initial method of contact was recorded for almost all (**98%**) of the 20,382 unique cases:

- Most contacts were made via **telephone** (n=14,992; **75%**)
- **Email** was the second highest means of contact (n=3,631; **18%**)
- A small proportion of people made contact via the **Dementia UK website** (n=1,365; **7%**) and **'other'** (n=21; **0.1%**)

Reasons for contact

Reasons for contact were recorded for **94%** of the 20,382 unique cases.

There are 35 categories which our nurses can use to record reasons for contact (including 'other').

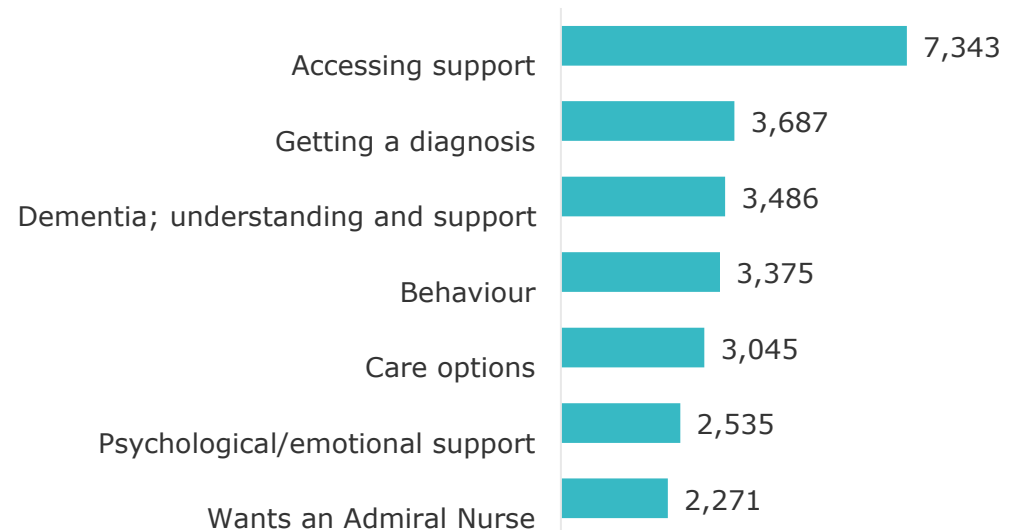
A total of **40,650** reasons were recorded against these categories for the 20,382 cases – representing an average of two reasons recorded per case.

Of the 20,382 unique cases, **36%** of cases had 'accessing support' and **18%** had 'getting a diagnosis' recorded as a reason for contact.

The **seven** most commonly recorded reasons (as a percentage of all unique cases) were:

- accessing support (**36%**)
- getting a diagnosis (**18%**)
- dementia; understanding and support (**17%**)
- behaviour (**17%**)
- care options (**15%**)
- psychological/emotional support (**12%**)
- wants an Admiral Nurse (**11%**)

Number of times the most common reasons were recorded



Geographic location of contacts and how people found out about our Helpline

Where location data was recorded* most people were located in the UK:

- **98%** had a UK location
- **2%** were located outside of the UK

Within England, most contacts came from the Midlands and the South-East:

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

From the data recorded most people found our Helpline through the internet:

- internet – **65%**
- word of mouth – **14%**
- health professional – **11%**
- voluntary sector – **4%**
- other – **5%**

Most of those contacting our Helpline within the UK were from England:

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

Counties with most contacts:

- Kent – **498**
- Essex – **413**
- West Midlands – **398**
- West Yorkshire – **308**
- Lancashire – **299**

Demographic information recorded for carer cases (April 2021-March 2022)

Demographic information can be recorded* for each carer case where contact is made (n=17,411). Data recorded about gender and relationship of the carer to a person with dementia is shown here.

Relationship of a carer to a person with dementia was recorded for **90%** of the 17,411 carer cases where contact was made.

Relationship label**	Total number	%
Child	5,106	33%
Daughter	4,137	27%
Spouse/partner	1,427	9%
Son	1,218	8%
Wife	1,154	7%
Husband	528	3%
Friend/neighbour	477	3%
Other relative	1,552	10%
Total recorded	15,599	
Not entered	1,812	

Gender was recorded for **99.7%** of the 17,411 carer cases where contact was made

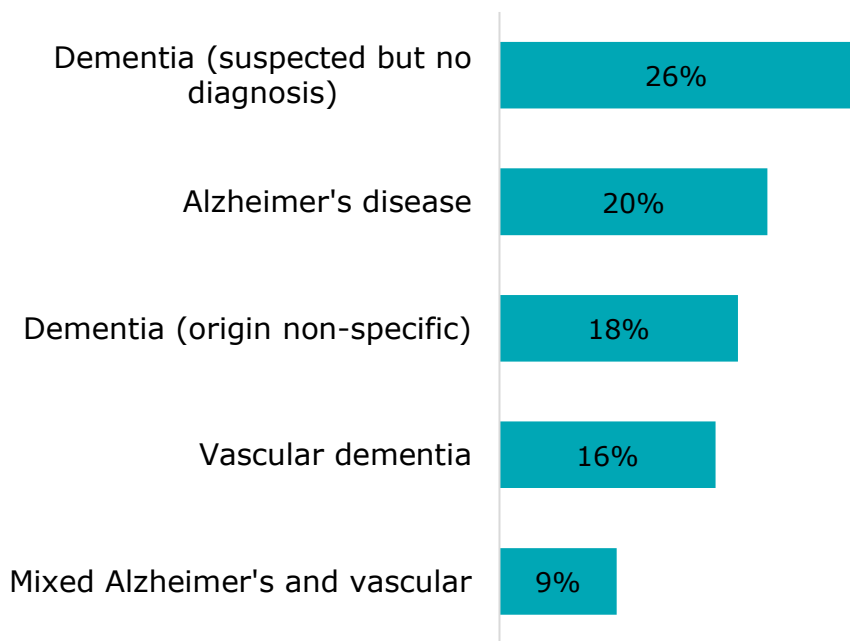
Carer gender	Total number	%
Female	13,245	76%
Male	4,101	24%
Other gender identity	9	
Total recorded	17,355	
Not entered	5	
Unknown	51	

- **67%** of carers were the child of a person with dementia
- **76%** of carers were female

Demographic information recorded about the person with dementia (April 2021-March 2022)

Demographic information can be recorded about people living with dementia* for the three different case types – carer cases, person living with dementia cases and 'other' cases – where contact was made (n=18,410). Data for gender and the five most commonly recorded dementia diagnoses is shown here.

Dementia diagnosis was recorded for 65% of the 18,410 cases where contact was made.



Gender was recorded for **94%** of the 18,410 cases where contact was made

Gender	Total number	%
Female	10,212	59%
Male	7,160	41%
Other gender identity	14	
Total recorded	17,386	
Not recorded	51	
Unknown	973	

- Alzheimer's was the most commonly recorded diagnosis (**20%**)
- **59%** of people with dementia were female

Young onset dementia contacts and cases

Contacts relating to young onset dementia

Helpline contacts relating to young onset dementia

From April 2021-March 2022 there were 1,286 direct contacts recorded relating to young onset dementia (this is **4%** of all Helpline direct contacts):

- 1,068 contacts were by telephone
- 218 were emails sent from the Helpline

Most of these direct contacts were with a carer

(NB: an individual case can have more than one contact. The data below is a count of the contacts by type of person the contact was with).

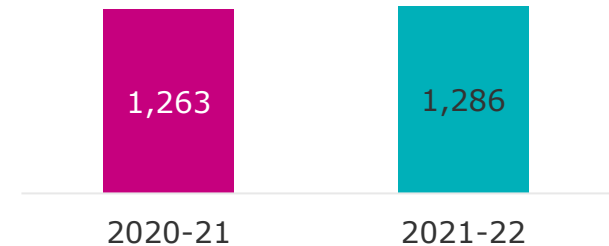
- **80%** of these direct contacts were with a carer
- **18%** were with a person living with dementia
- **3%** were recorded as 'other'

In addition to the direct contacts above, our Helpline nurses also recorded 631 admin activities related to cases.

Comparison of contacts with 2020-21

The total number of direct contacts increased very slightly (**2%**) between 2020-21 and 2021-22, from 1,263 to 1,286 direct contacts.

Helpline contacts



Unique cases relating to young onset dementia

Unique cases

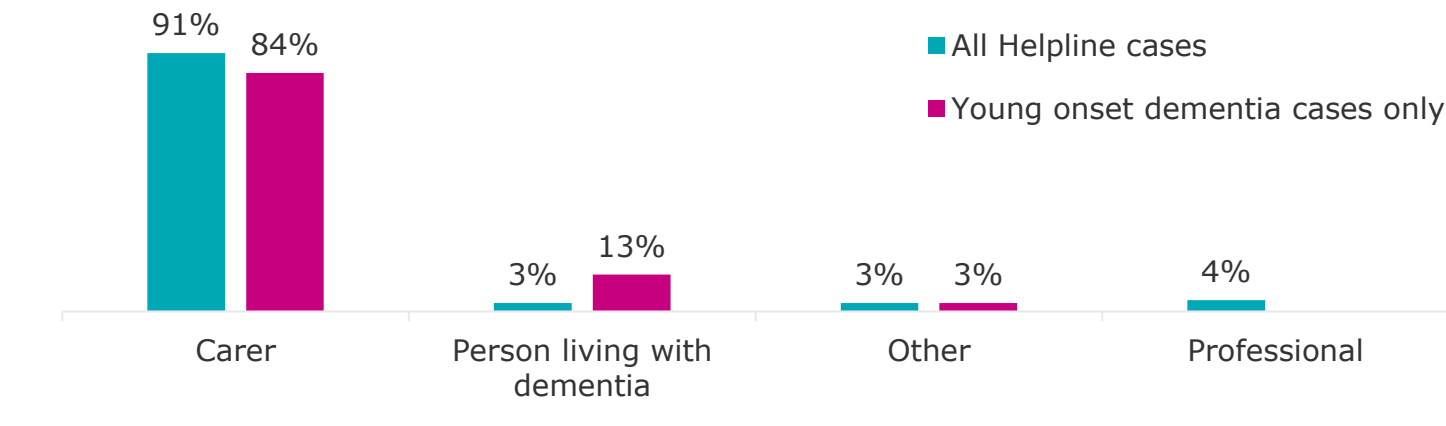
Information was recorded about **658 unique cases** relating to young onset dementia (this is **3%** of all unique Helpline cases).

Contact was made with 644 of these cases:

- **84%** were carers, **13%** were people living with dementia, **3%** were 'other'
- **53%** of cases had more than one direct contact

The initial contact method was recorded for all of the 658 unique cases – **82%** telephone, **11%** email, **6%** website.

Unique cases with contacts (ALL Helpline and young onset dementia only)



Young onset dementia cases

How people found out about our Helpline

From the data recorded most people found our Helpline through the internet:

- internet – **65%**
- word of mouth – **13%**
- health professional – **10%**
- other – **7%**
- voluntary sector – **6%**

Reason for contact

There are 35 categories which our nurses can use to record reason for contact (including 'other').

A total of **1,646** reasons were recorded against these categories for the 658 cases – representing an average of three reasons recorded per case.

The top 10 reasons for contact for young onset dementia cases are shown in the table opposite. More than one reason for contact could be recorded for each case.

Reason for contact

(Total number of times recorded)

Accessing support	248
Dementia, understanding and support	161
Psychological/emotional support	151
Getting a diagnosis	148
Behaviour	121
Care options	96
Communicating	69
Wants an Admiral Nurse	68
Living with dementia	66
Physical health (person with dementia)	47

Of the 658 unique cases, **38%** had 'accessing support', **24%** had 'dementia understanding and support', **23%** had 'psychological/ emotional support', and **22%** had 'getting a diagnosis' recorded as a reason for contact.

Geographic location – young onset dementia cases

Where location data was recorded*:

- **99%** (n=421) had a UK location
- **1%** (n=5) were located outside of the UK

Most of those contacting our Helpline within the UK were from England:

- **96%** from England
- **2%** from Wales
- **1%** from Scotland
- **0.8%** from Northern Ireland

Within England, most contacts came from the South-East and the Midlands:

- South-East – **25%**
- Midlands – **23%**
- East of England – **14%**
- North-West – **14%**
- North-East and Yorkshire – **11%**
- South-West – **9%**
- London – **4%**

Counties with most contacts:

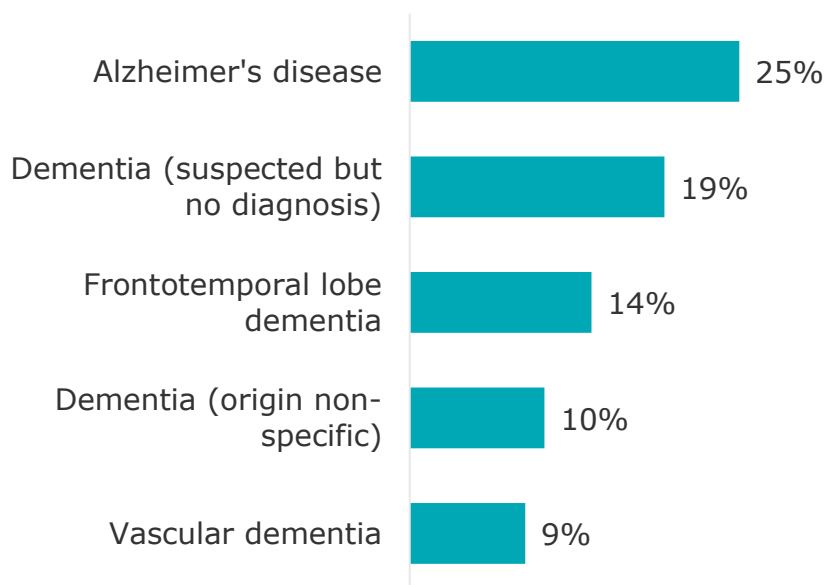
- Kent – **25**
- Lancashire – **18**
- Greater Manchester – **18**
- Essex – **16**
- West Midlands – **14**

Dementia diagnosis: young onset dementia cases

Dementia diagnosis was recorded for 97% of the 644 cases where contact was made.

- Alzheimer's disease (**25%**) and frontotemporal lobe dementia (**14%**) were the most commonly recorded diagnoses
- 19%** did not have a formal diagnosis of dementia

Young onset dementia diagnosis (n=624)



Dementia diagnosis	Total
Alzheimer's disease	154
Dementia (suspected but no diagnosis)	119
Frontotemporal lobe dementia	85
Dementia (origin non-specific)	63
Vascular dementia	54
Other	26
Wernicke-Korsakoff (WKS) or other alcohol-related dementia	25
Dementia with Lewy bodies (DLB)	21
Mixed Alzheimer's and vascular	18
Unknown at time of initial contact	14
Posterior cortical atrophy (PCA)	11
Primary progressive aphasia (PPA)	8
Other mixed dementia	8
Parkinson's disease dementia (PDD)	7
Multiple sclerosis (MS) dementia	4
Mixed Lewy body and Alzheimer's	2
Down's syndrome and Alzheimer's	2
Huntington's disease	1
HIV and AIDS-related dementia	1
Corticobasal degeneration (CBD)	1
Total	624
Not entered	20

Section 2

Carer experience survey

(April 2021-July 2022)

“Having access to the Admiral Nurse Helpline has helped me enormously. 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 when I was screaming inside and feeling utterly desperate, like I could not continue living with such an intolerable amount of stress and fear. After every call, I felt totally supported, lifted up and strengthened and able to carry on another day.”

Carer, aged 65-74, daughter of person with dementia

Positive experience

Calls answered and returned*

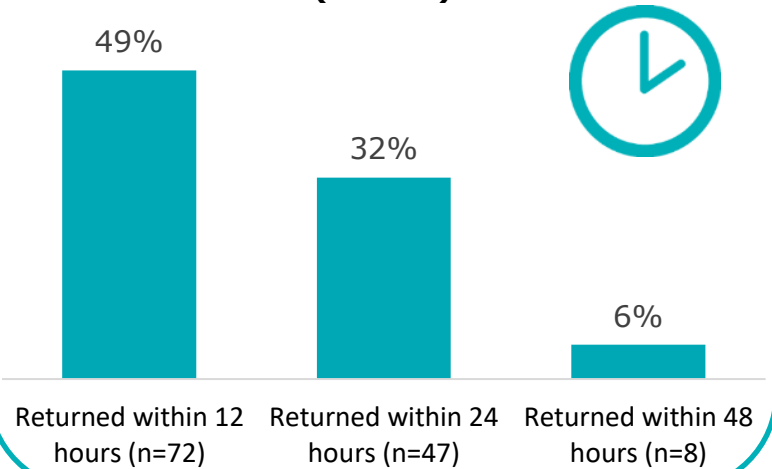
- **41%** said their call was answered immediately (119 out of 291)
- **56%** (n=163) said their call was not answered immediately
- **3%** (n=9) responded 'other'
- **87%** of those leaving a voice message because their call wasn't answered immediately said their call was returned within 48 hours. **10%** said they could not remember

Admiral Nurse attributes

Carers said that the Admiral Nurse was very good or good at:

- explaining things clearly (**94%**)
- giving them enough time (**94%**)
- listening to them (**94%**)
- showing care and understanding (**93%**)
- making them feel at ease (**92%**)

How quickly was your call returned? (n=146)



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

"I would have preferred an 'excellent' option! I can't thank or praise you enough. You helped me to keep my step-dad in his own home for as long as possible."

Providing the information, advice and support families need

- **86%** of respondents said they received all or most of the information, advice or support that they needed. **7%** said they received some of the information, advice or support 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 – **57%** said much more positive and **27%** said a little more positive
- **72%** said that the information, advice or support that they received helped them to make changes which improved their current situation



"Due to the help and excellent advice given... **I now feel much more positive about my future.** I used to get very low and upset after my wife went into a care home... I would have been totally lost without the advice and help from the Admiral Nurse."

Carer, aged 75-84, husband

"**Felt much more positive** about my current situation and received practical advice on my way forward at this time."

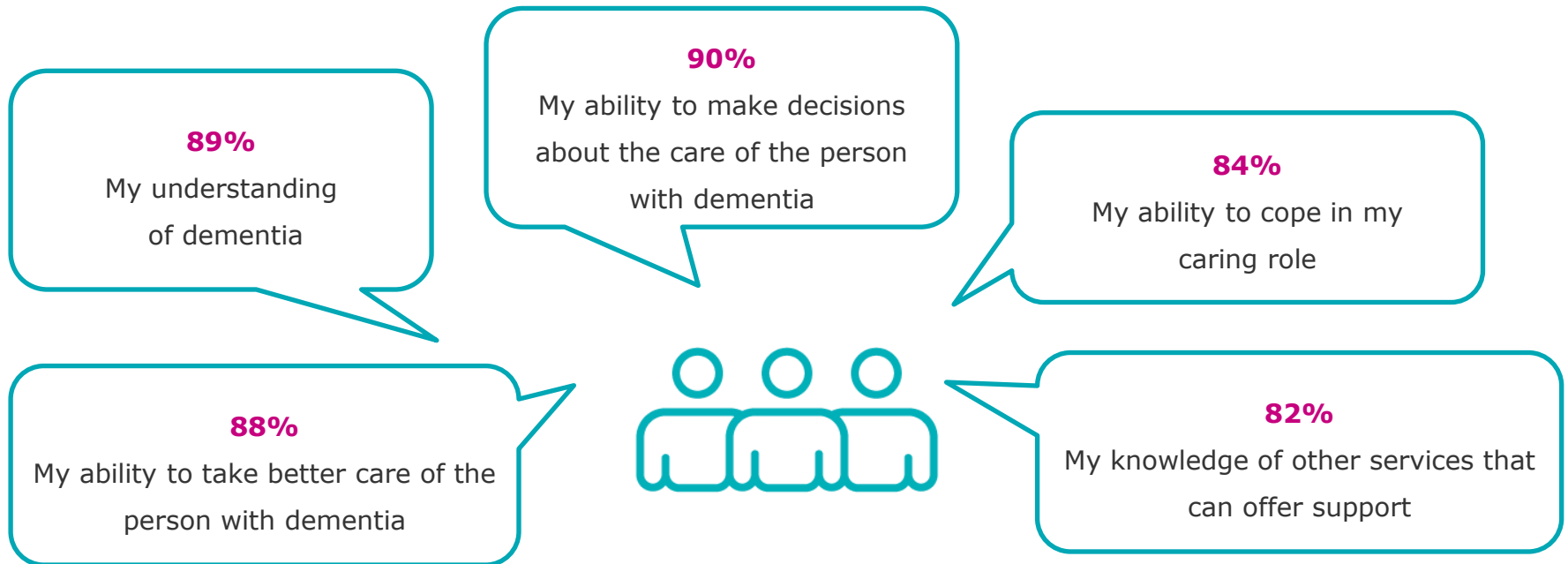
Carer, aged 55-64, son



Making a difference

Carers felt that the service was making a difference to key aspects of their lives.

Support from the Admiral Nurse service has made a positive difference to...



The service **helped families to maintain relationships** – **84%** said it had made a difference to their ability to communicate with the person they cared for and **81%** said it had helped with family relationships/communication. Over three-quarters (**79%**) also said the service had made a difference to their ability to take better care of themselves.

What would have happened without our Helpline?

Use of health and social care resources

214 respondents told us about what would have happened if they had not spoken with a Helpline Admiral Nurse (respondents could choose more than one):

- **36%** would have seen a GP for the needs of the person with dementia
- **15%** would have seen a GP for their own needs
- **10%** would have called NHS 111
- **9%** said the person they care for would have needed to move into a care home or nursing home
- **6%** said the person they care for would have had to go to A&E
- **52%** mentioned other impacts on themselves and their families, including not knowing what to do, negative impact on ability to care, negative impact of their health and wellbeing and struggling on their own

"I probably **would not have been able to cope and would have been overwhelmed with anxiety. Would have called the Samaritans** but as helpful as they are, they could not have helped me with the help I needed which an Admiral Nurse can give and did give."

Carer, aged 75-84, partner

Carers told us that they would have struggled without our Helpline

"I probably **would have had a breakdown.**"

Carer, aged 35-44, granddaughter

"I would have had a complete breakdown in my mental and physical health which was teetering on the edge for a very long time. **The support I received from the Helpline has been immeasurable** and the fact I could contact a nurse anytime has literally saved me on a few occasions."

Carer, aged 65-74, daughter

"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."

Carer, aged 35-44, daughter

"I would have **continued suffering** myself and wouldn't have been able to offer care and support to my dad."

Carer, aged 45-54, daughter

“I cannot express to you sufficiently just how much of an incredibly positive difference this service and the nurses have created for my father with dementia, all of his family members, his carers, and the people that are within the network of everyone involved. The changes we have made as a result of Admiral Nurses are too vast to detail here. I name just the few that come to mind: far greater mental wellbeing of everyone involved; and the capacity of my father to connect, communicate and absorb the help he needs. **Everyone in my family has far greater sanity and capacity to care for my father** because of the Admiral Nurses. We have changed my father's environment, behaviours, moods (and) physical ability; decreased his levels of distress and pain; sought help from many other services recommended by Admiral Nurses; got in touch with solicitors, doctors, memory clinics, occupational therapists, support groups, care companies – we've done it all. **We talk about how we feel about the changes that we as a family have made**, including the increased ability to even have these conversations and not feel guilt about the frustration and burnout that would have persisted in us, my father's carers, had we not received advice from Admiral Nurses. We are forever grateful for that.”

Carer, aged 35-44

Making a difference – themes from free text responses

The strongest themes were...



1. Enabling carers to advocate for the person living with dementia.



2. Accessing support.



3. Providing carers with confidence and reassurance.



4. Caring for the person living with dementia.

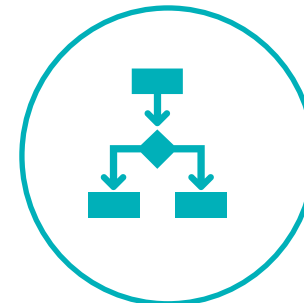


5. Looking after own wellbeing and coping in their caring role.

Other themes (that were not as strong) included...



6. Supporting end of life care and managing grief, loss and bereavement.



7. Making decisions.

1. Enabling carers to advocate for the person

The strongest theme from our analysis showed that many carers were able to advocate for the person living with dementia following calls to our Helpline. For example, carers told us that they felt more confident to challenge poor care in relation to care homes and hospitals.

"I needed advice as I was trying to have my mum referred to a dementia-registered care home near my sister and adult social services weren't being very helpful. **The Admiral Nurse explained my mother's rights**, highlighted the Care Act 2014, the CHC (NHS continuing healthcare funding) checklist and what terminology to use when advocating for my mother. **Honestly, it was brilliant.** I was able to get a social worker assigned to my mother's case and my mum has since been moved to a suitable care home near my sister."

Carer, aged 45-54, daughter

"I was unhappy with my mum's care in a care home and was concerned about aspects of her care... I spoke to an Admiral Nurse about my concerns. **The nurse was very sympathetic and made me realise I must raise a complaint** to the CQC (Care Quality Commission) to protect my mum. I raised a complaint, This was escalated to the local council as a safeguarding affair and the home was asked to investigate. The result was the home admitted Mum's care was not in line with her care plan and procedures were changed. The support and encouragement from your nurse helped me raise a complaint. Thank you."

Carer, aged 55-64, daughter

2. Accessing support

Our analysis showed that many carers were helped to access support for the person living with dementia following calls to our Helpline. Carers told us that the Admiral Nurse gave them suggestions of who to contact for support and that they felt more informed about what they could ask for and their rights.

“The nurse followed up our call with an email that I was able to send to my doctor and get a referral to a neurologist. I hadn't been able to access a referral prior to this.”

Carer, aged 35-44, wife

“We were advised to contact the GP, who, when she heard we had been in contact with you, realised we were really struggling to do what was best. The GP herself asked for the patient to come and see her regarding her 'medication' and took it from there. **Between the advice from the Admiral Nurse and the wonderful GP things started moving.**”

Neighbour, aged 65-74

3. Providing carers with confidence and reassurance

Carers told us that they received reassurance from the Admiral Nurses on our Helpline and felt more confident in their caring roles as a result of speaking to an Admiral Nurse. For example, some carers told us that they felt more confident setting up and introducing carers in the home.

“The advice and support from the Admiral Nurse **helped me believe in myself more** as a carer. The nurse reassured me and said I was on the right track with support I was offering.”

Carer, aged 45-54

“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!”

Carer, aged 55-64, wife

4. Caring for the person living with dementia

Carers told us that speaking to our Helpline had an impact on their care for the person living with dementia. They said that they felt they were able to better look after the person living with dementia by making practical adaptations and changes suggested in their call.

"... **Made some really useful suggestions**... Something as simple as giving her headphones to listen to music while [I] make phone calls related to her has made things much easier."

Carer, aged 55-64, daughter

"I was able to recognise that my father required pain relief."

Carer, aged 65-74 daughter

"I was able to make **positive changes** in feeding routines."

Carer, aged 25-34, granddaughter

4. Caring for the person living with dementia (cont.)

On the theme of caring for the person living with dementia, respondents said that speaking to an Admiral Nurse on our Helpline helped them have a better understanding of the person living with dementia and their condition.

"I have a better understanding of dementia and why/how (my) husband is in his ways. I try to be more patient and not react and keep him occupied." **Carer, aged 65-74, wife**

"The Admiral Nurse listened and was able to confirm things my sisters and I were thinking were reasons for Mum's change in behaviour. She helped us to see things from Mum's point of view and the possible reasons for her distress." **Carer, aged 55-64, daughter**

"You helped me see my dad as vulnerable, not just aggressive or a 'problem'... Thank you. Life-saving and life-changing." **Carer, aged 45-54, daughter**

Having a better understanding of the person living with dementia and their condition enabled respondents to adapt how they responded to and communicated with the person.

"I feel I can better communicate with my mother, who has memory problems and displays behaviour I have found challenging." **Carer, aged 65-74, daughter**

"I was able to use more appropriate techniques in communicating with the person with dementia and to pass the advice on to others who come into contact with her." **Carer, aged 65-74, cousin**

5. Supporting carers to better cope in their caring role

Carers told us that they felt better able to cope in their caring role, having had advice and support from the Admiral Nurses on our Helpline.

“The advice and support gave me ‘tools’ to be able to cope and to understand the nature of dementia. **It is so good to be able to talk** for as long as I need to someone who understands the situation and isn’t judgmental.”

Carer, aged 55-64, wife

“[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. I can't thank her enough for her support at such a difficult time.”

Carer, aged 65-74, daughter

“(The Helpline led to) **changes in mine and my sister's attitude to being able to cope** with our mother's situation. To understand that what she was doing, no matter how bizarre, was completely beyond her control.”

Carer, aged 55-64, son

6. Supporting end of life care and managing grief, loss and bereavement

Some respondents felt that our Helpline helped them provide or access appropriate end of life care. This was either through supporting them to adjust how they provided care, enabling them to advocate for better care, or advising them to access appropriate services. There were also a few comments from carers that specifically highlighted that they had been supported in managing grief, loss and bereavement.

“When Mum died, I was totally exhausted and emotionally very upset. Even at the funeral one month later we could not hug each other [because of Covid-19]. The call I received was the first real chance I had to discuss my grief with a professional... **I could not discuss my real grief until I had this call.** Dealing with a death of a loved one you have cared for over years, still in ongoing isolation, really is emotionally very hard. Your Helpline was a godsend.”

Carer, aged 55-64, son

7. Making decisions

Some respondents said that the advice and support from our Helpline enabled them to make decisions that affected the care of the person living with dementia. Examples included decisions about end of life care, reducing working hours, practical changes to the environment and pursuing or considering referrals/support/additional care.

“The advice **helped me understand**... Helped me formulate a plan for Mum’s end of life care which allowed her to die peacefully at home.”

Carer, aged 45-54, daughter



If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call **0800 888 6678** or email helpline@dementiauk.org

Open Monday-Friday, 9am-9pm

Saturday and Sunday, 9am-5pm

Every day except 25th December

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