

Frailty Consultant Admiral Nurse Service

**Evaluation report
May 2023-July 2024**

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Message from the Consultant Admiral Nurse for Frailty

I am pleased to share with you my evaluation report for May 2023-July 2024.

This covers 15 months* of the Frailty Service's activity and its impact.

Kerry Lyons, Consultant Admiral Nurse for Frailty

*The service was closed for a short period from January-March 2024 to allow for planned leave. The data reported here reflects this, with a decrease in internal referrals and activities during these months.



You can download or order these leaflets at dementiauk.org/our-leaflets

Message from the Consultant Admiral Nurse for Frailty

Between May 2023 and July 2024, I...



received **110**
internal referrals



delivered **3,282**
clinical
interventions

delivered **898** clinical,
administrative and
liaison activities



delivered **281**
supporting best
practice activities



delivered multiple
training sessions to
over **563** attendees



received
feedback from
19 carers



received **feedback**
from 27 Admiral
Nurses about
the service

Reflecting on these achievements, I want to thank the families and colleagues I have worked with. It has been a privilege to support families with their journey and to support colleagues to improve their knowledge and confidence around frailty.

I love my role as Consultant Admiral Nurse for Frailty, and I am proud of the work I have done over the last 15 months to support those affected by dementia and frailty.

Introduction

This evaluation report covers the data collection period from 1st May 2023-31st July 2024. The aim is to showcase the work of the Frailty Consultant Admiral Nurse Service.

The report provides a summary of the Frailty Service, what the Consultant Admiral Nurse for Frailty does, and the positive impact that the service has had on the families and professionals it has supported.

The report includes an overview of:

- the number of families worked with and the number of internal referrals to the service
- demographic information of families supported by the service
- clinical activities delivered
- supporting best practice activities
- training and awareness activities
- training feedback
- carer survey feedback
- Admiral Nurse survey feedback



About the Frailty Consultant Admiral Nurse Service

Admiral Nurses are specialist dementia nurses who provide psychological support, expert advice and information to help families affected by dementia, particularly those with complex needs.

People living with frailty are less able to adapt to stress factors such as acute illness; injury; or changes in their environment, personal or social circumstances. Such changes are more likely to result in adverse health outcomes and loss of independence.

We receive contacts to our Admiral Nurse Helpline in relation to aspects of frailty. Some of these refer to unrecognised frailty, and others relate to seeking an understanding of the signs and symptoms of frailty syndromes.

The Frailty Consultant Admiral Nurse Service was launched in May 2023 to support families affected by frailty as a response to this need, alongside a recognition of an overall need for better national awareness, knowledge, resources, and support around the management of frailty and dementia.

Our methodology

We **collected information** about:

- the number of internal referrals
- families supported by the service, including demographic information
- the reason for referral
- the geographic location of those attending appointments
- the number and type of clinical interventions delivered
- supporting best practice activities delivered
- training and awareness sessions delivered



We **surveyed carers** who engaged with the service, asking about:

- their overall experience of our service
- whether they received the information, advice or support they needed
- any difference the service had made

We **surveyed Admiral Nurses** who engaged with the service about its value and responsiveness.

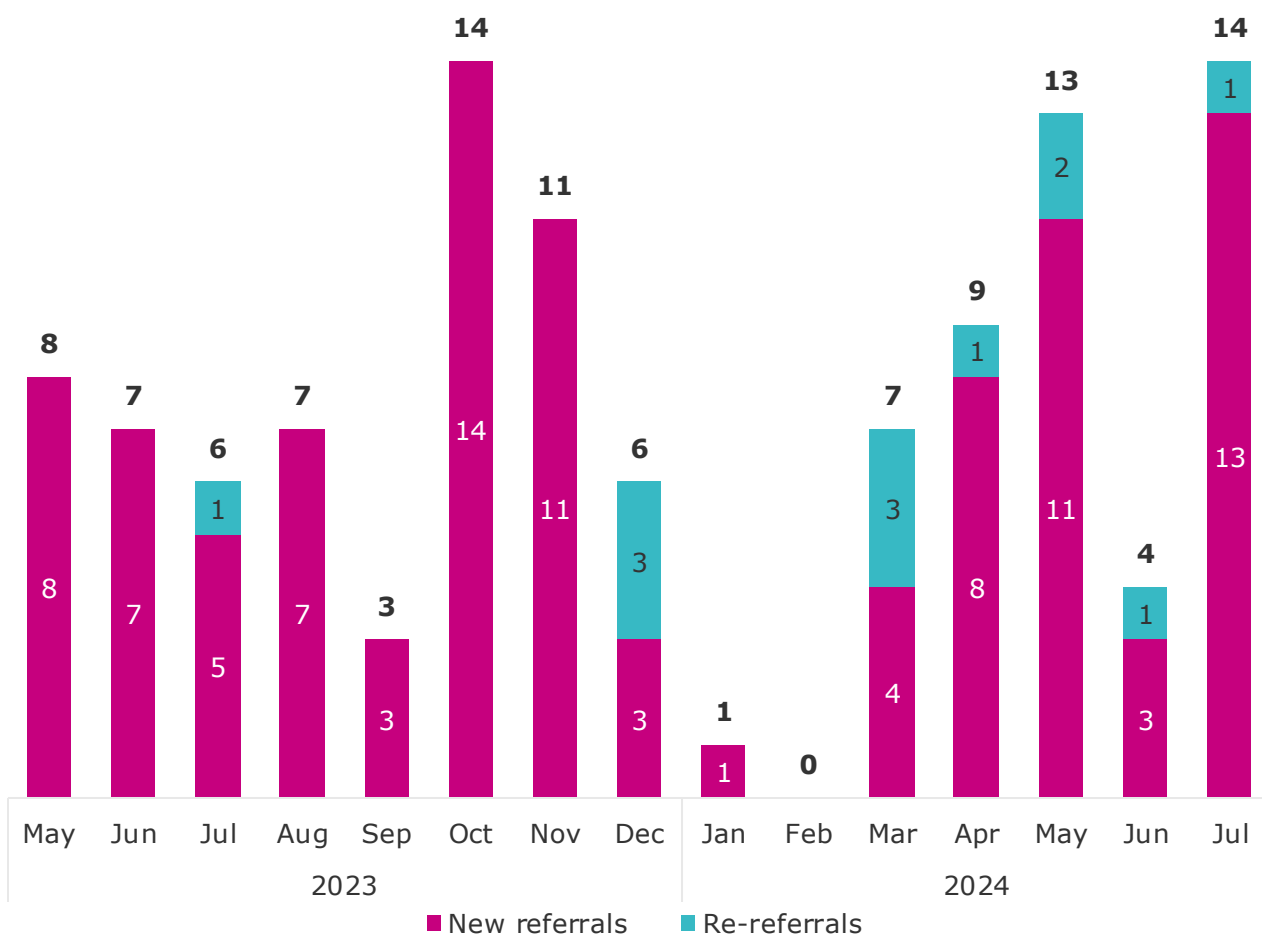
We also collected **feedback from Admiral Nurses who attended training sessions** to see if the training impacted their knowledge and confidence around frailty.

The number of families we have worked with

110 internal referrals were received from Dementia UK Core Clinical Services between May 2023 and July 2024.

- There were **98** new referrals and **12** re-referrals over the reporting period
- There were no inappropriate internal referrals received by the service; all demonstrated the complexity required for engagement with the Consultant Admiral Nurse Service
- For each referral, more than one appointment or contact may have occurred

Number of internal referrals each month
(n=110)



Source of internal referrals

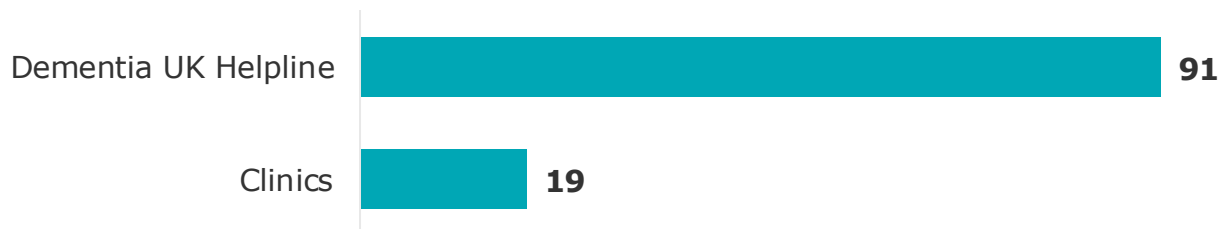
Most internal referrals came from the Dementia UK Helpline.

Between May 2023 and July 2024, of the 110 internal referrals:

- **91** were from the **Dementia UK Helpline**
- **19** were from **clinics**



Source of internal referrals
(n=110)



Location of those attending appointments



Most of those attending appointments came from the South East and London.

Location data shows that people attending appointments lived in all **nine standard geographical regions of England**, with two from **Scotland**.

The most recorded locations for appointments were:

- South East (n=21)
- London (n=20)
- Midlands (n=17)
- North West (n=15)

Appointments by region
(n=103)

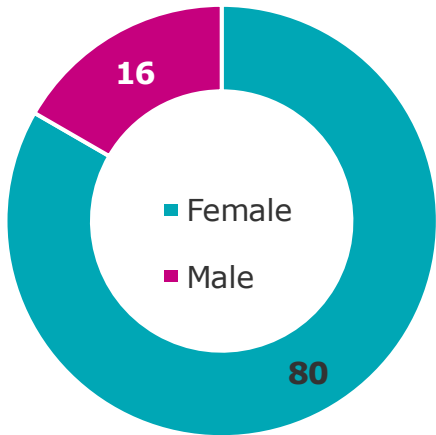


Carer demographics

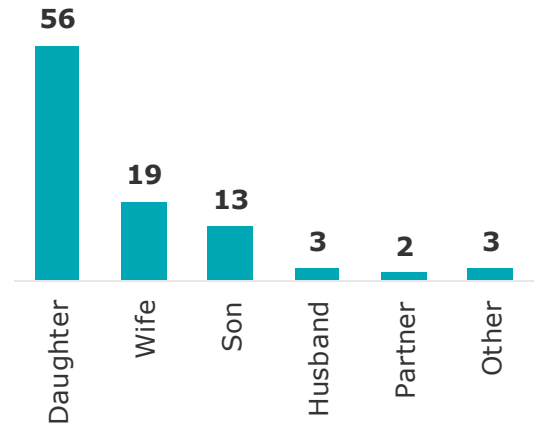
Demographic information* was recorded for 96 carers.

- Carers were mostly **female** (n=80); 16 carers were recorded as male
- The majority of carers were **White British** (n=86)
- The most common relationship to the person with dementia was **daughter**[†] (n=56)

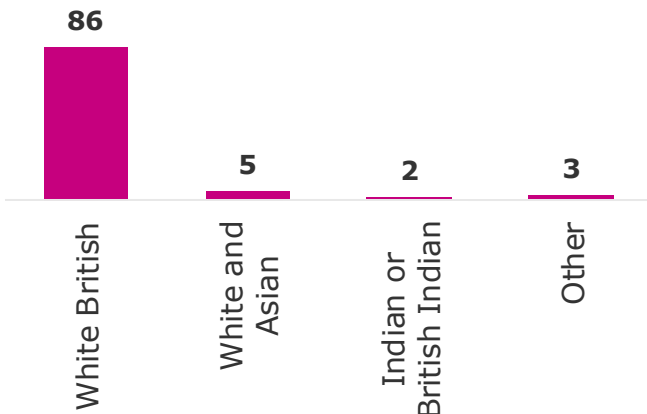
Gender
(n=96)



Relationship
(n=96)



Ethnicity
(n=96)



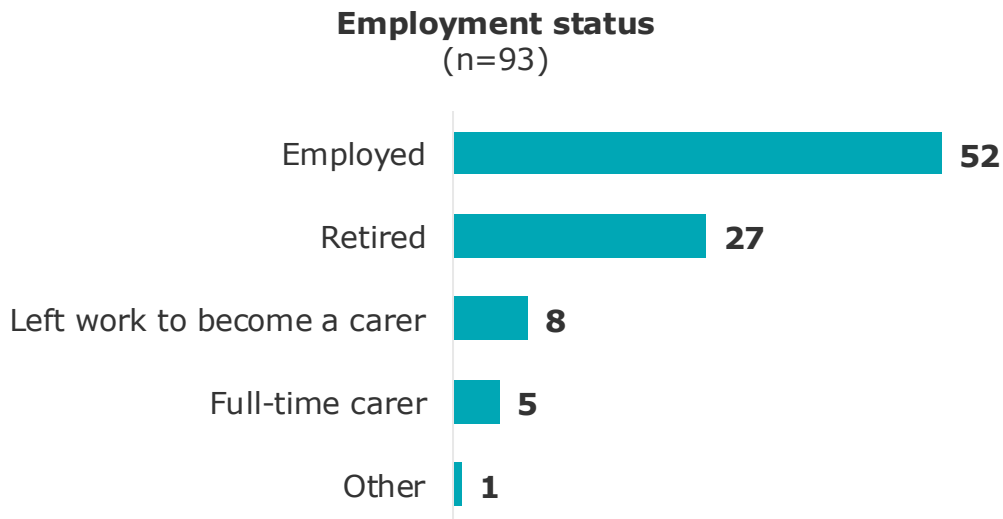
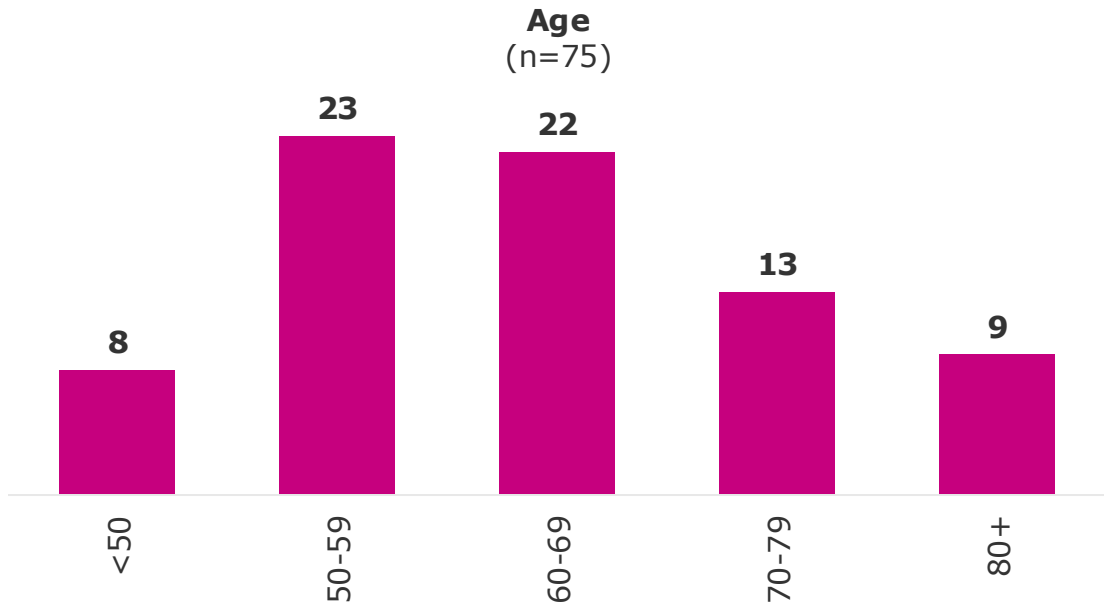
*Demographic questions were not mandatory; response rates may vary for each question

[†]Daughter includes daughter and daughter-in-law

[‡]This includes full-time and part-time employment and self-employed

Carer demographics

- The most commonly recorded ages for carers were **50-59 years** (n=23), followed by **60-69 years** (n=22)
- The majority of carers were **employed*** (n=52)

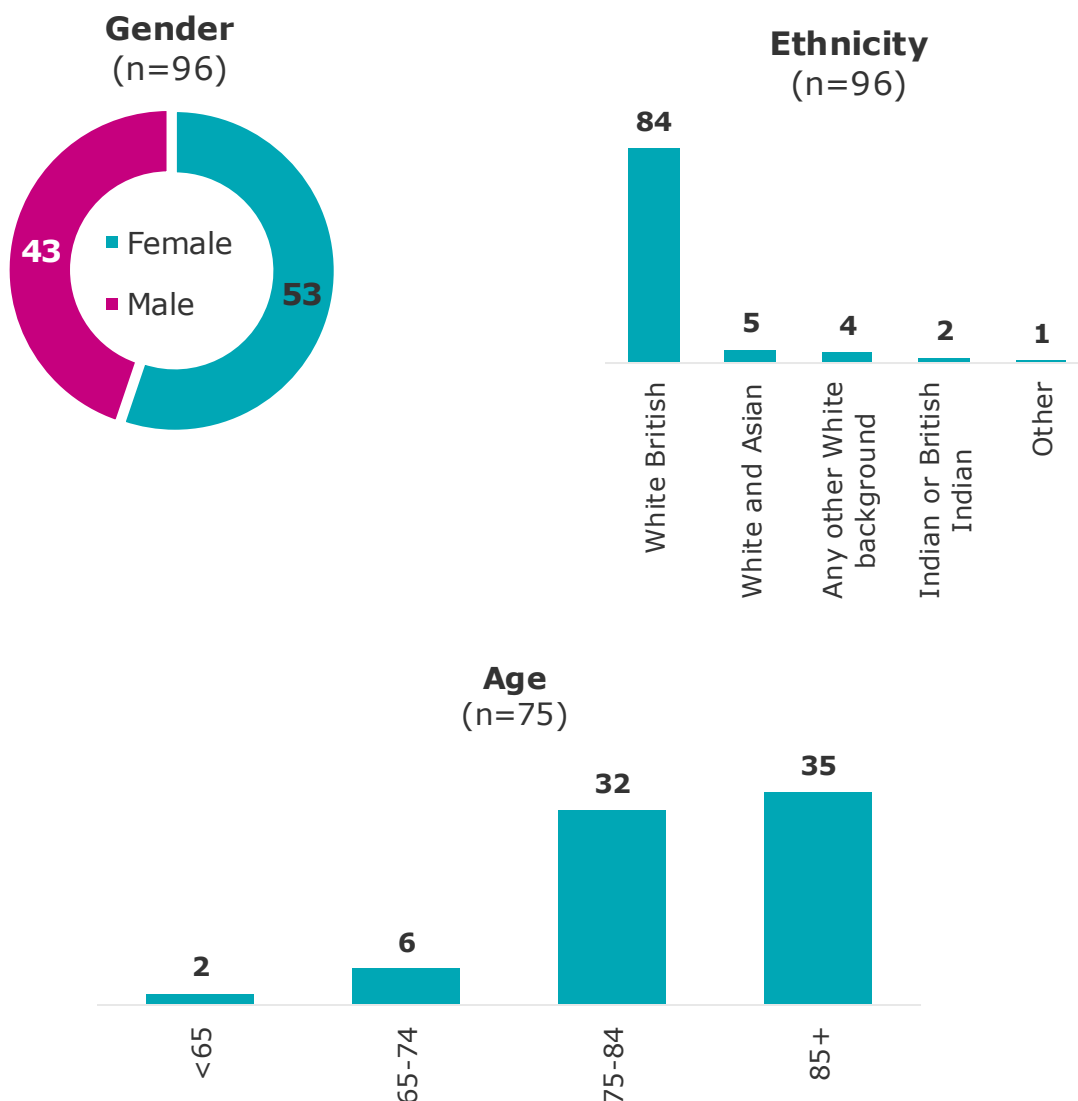


Demographics of person living with dementia

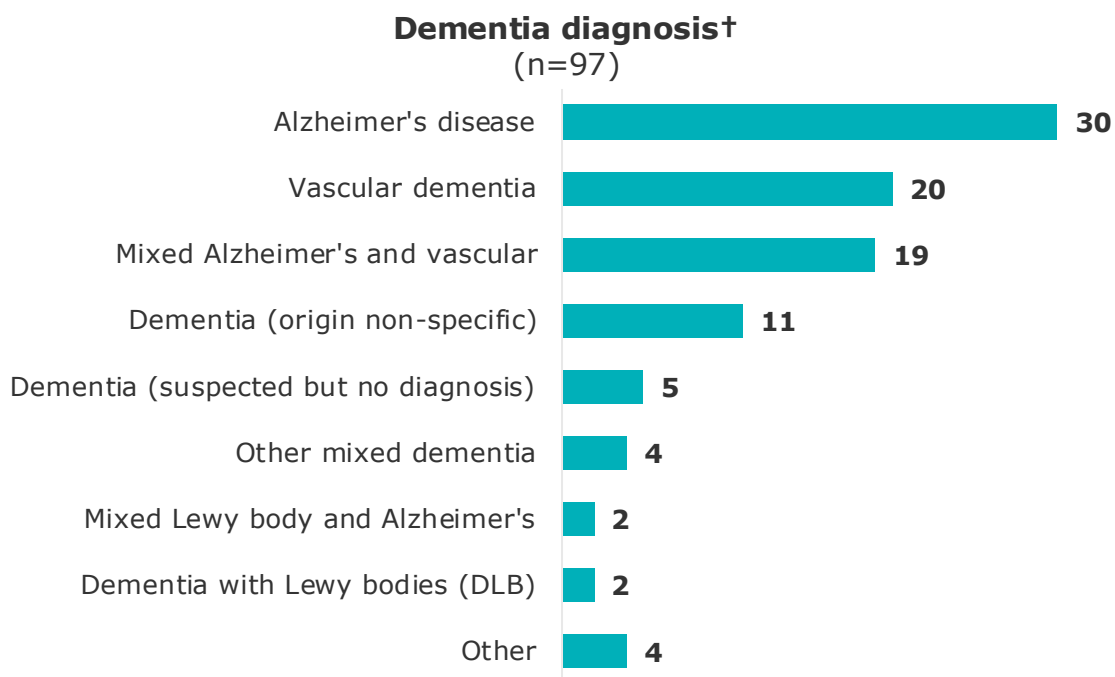
Demographic information* was recorded for 96 people living with dementia.

- The majority of people living with dementia were **female** (n=53); 43 were recorded as male
- Most people with dementia were recorded as **White British** (n=84)
- The most recorded age group was **85+ years old** (n=35)
- Two people were **under 65 years old**
- 30 people had a diagnosis of Alzheimer's disease, 20 had a diagnosis of vascular dementia, and 19 had a diagnosis of mixed Alzheimer's and vascular dementia

*Demographic questions were not mandatory; response rates may vary for each question



Demographics of person living with dementia



†One person had a dual diagnosis



Reasons for referral to the service

A total of 451 primary and secondary reasons for referral to the service were recorded.

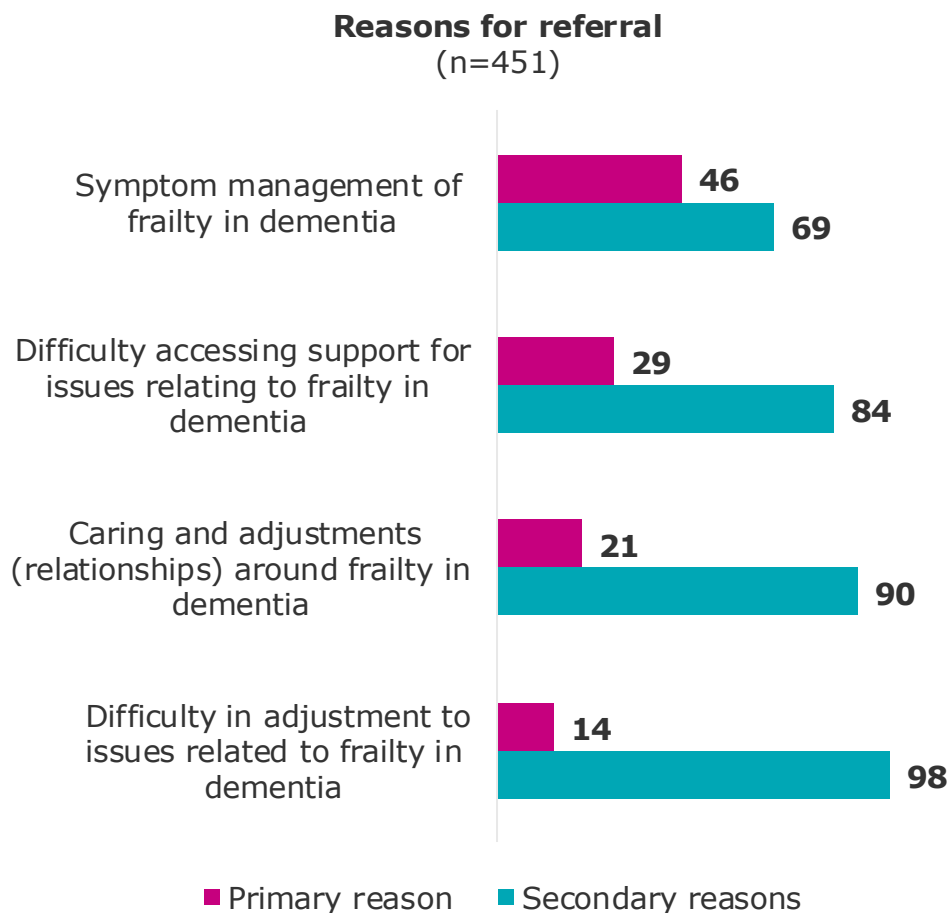
There were **110** primary reasons for referral and **341** secondary reasons for referral recorded.*

The most common **primary reasons** were:

- symptom management (n=46)
- difficulty accessing support for issues relating to frailty in dementia (n=29)

The most common **secondary reasons** were:

- difficulty in adjustment to issues related to frailty in dementia (n=98)
- caring and adjustments around frailty (n=90)



*More than one secondary reason can be recorded for each referral

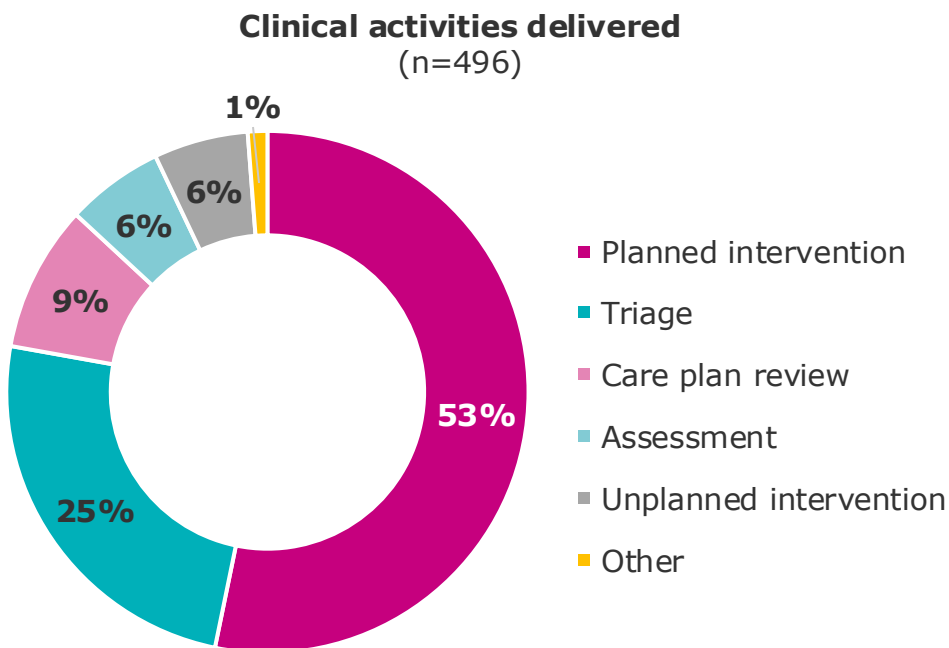
Activities to support families

898 activities to support families were delivered.

The Consultant Admiral Nurse for Frailty delivered a range of activities to support families and Admiral Nurse colleagues. **898** activities were recorded; these consisted of **502 clinical** activities, **392 administrative** activities, and **four liaison** activities.

Clinical activities*

A range of clinical activities were delivered. The most recorded activity was planned intervention (53%), followed by triage (25%).



Clinical activity delivery†

Clinical activities were delivered mainly through telephone contacts, followed by letters/emails/texts, and then video calls.



Telephone call 55%



Letter/email/text 37%



Video call 8%

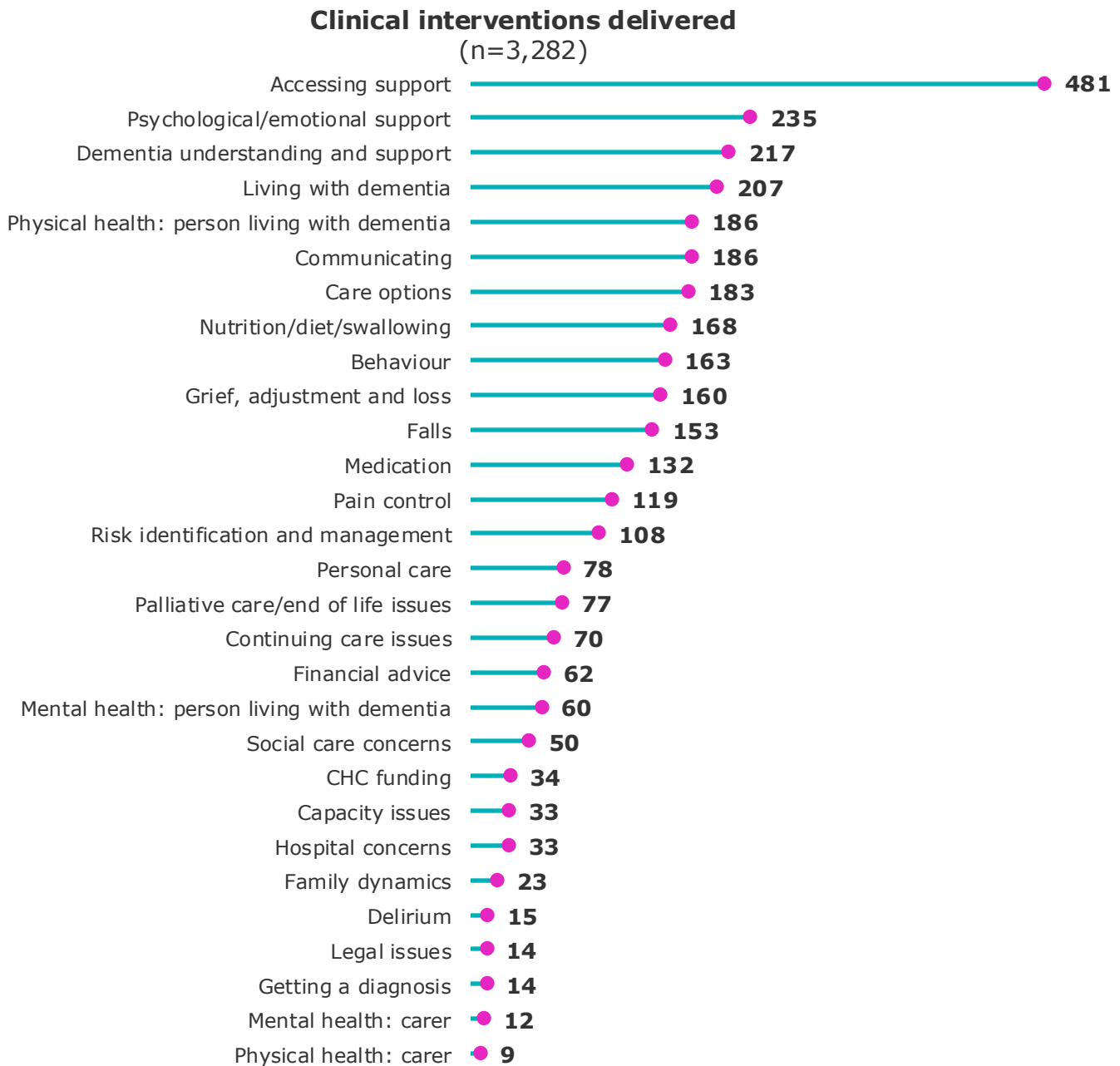
*Six 'not applicable' entries were excluded from the analysis; percentages calculated on 496 applicable activities

†68 'not applicable' entries were excluded from the analysis; percentages calculated on 434 applicable activities

Clinical interventions

3,282 clinical interventions were recorded.

Over the evaluation period, the Admiral Nurse delivered a wide range of clinical interventions to support families. There were 3,282 interventions recorded across 29 types of intervention. The most recorded interventions were **accessing support** (n=481), **psychological/emotional support** (n=235), **dementia understanding and support** (n=217), and **living with dementia** (n=207).



Supporting best practice

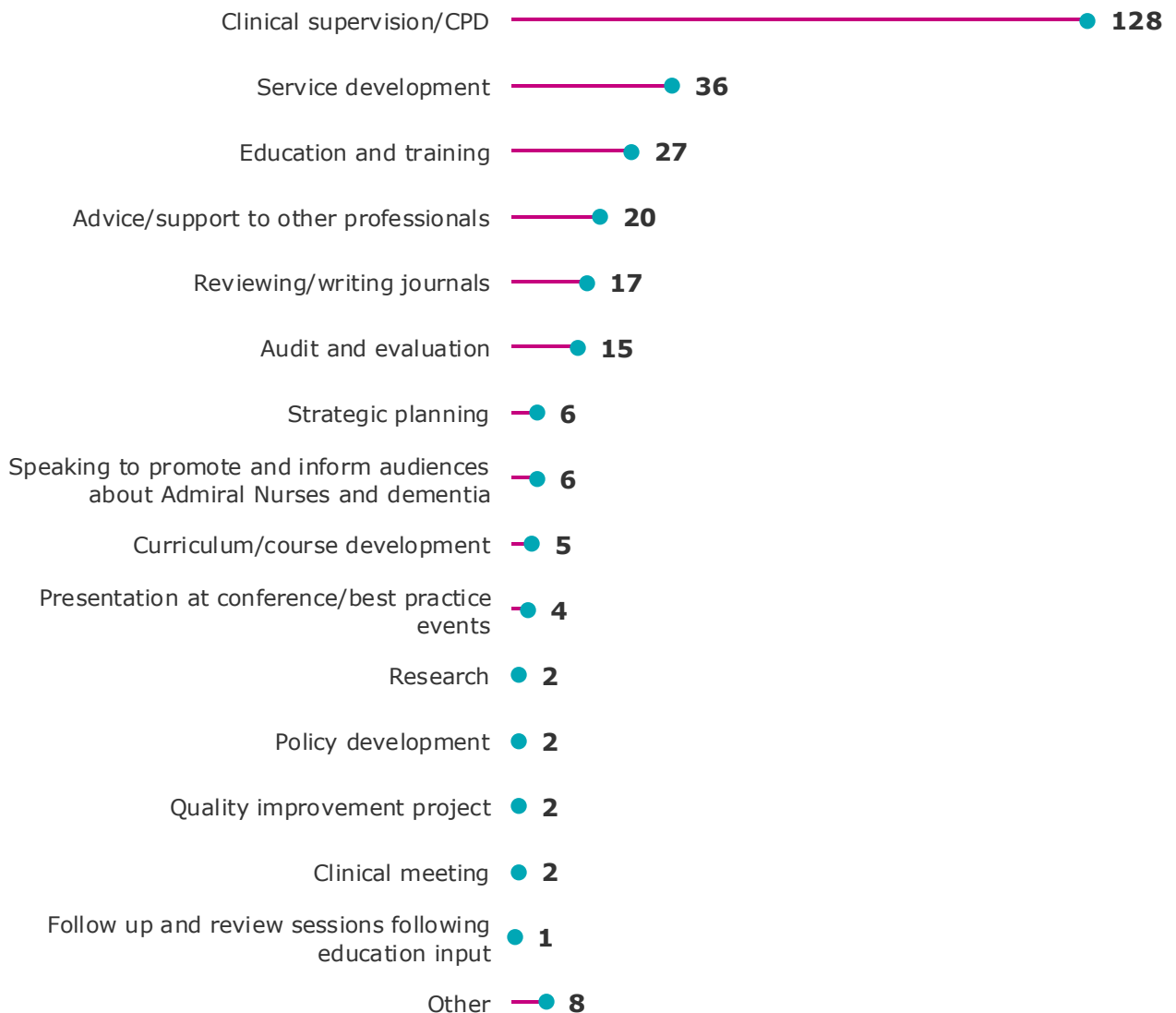


Supporting other professionals

Alongside working directly with families, the Admiral Nurse delivers activities to promote and support best practice in frailty dementia care and to develop and promote the Consultant Admiral Nurse Frailty Service.

281 supporting best practice activities were recorded by the Admiral Nurse from May 2023 to July 2024. The most common delivered activity was **clinical supervision/continuing professional development (CPD) with Admiral Nurse colleagues and other health and social care workers** (n=128).

Supporting best practice activity (n=281)



Frailty awareness training



The Admiral Nurse delivered frailty training sessions and other activities to over 563 attendees. Attendees included Dementia UK Admiral Nurses and other professionals.

Training sessions

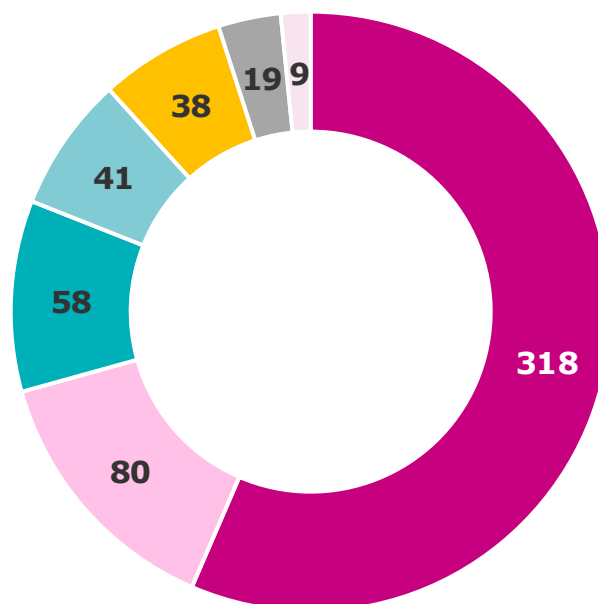
The Consultant Admiral Nurse for Frailty delivered nine separate training and awareness sessions. These were:

- ❑ Dementia UK Summer School frailty awareness session
- ❑ Admiral Nurse webinar
- ❑ Dementia UK Lunch and Learn session
- ❑ Admiral Nurse learning module
- ❑ Consultant Neurologist and Psychiatrist training
- ❑ Palliative care and frailty training
- ❑ Primary Care Network training
- ❑ Frailty Service training session and introduction to referral pathway
- ❑ Alzheimer's Show

Number of attendees

Where the number of attendees were recorded, 563 people attended training and awareness sessions (NB a person may have attended more than one activity and will have been recorded as an attendee each time). There are no attendee numbers recorded for the Primary Care Network training or the Alzheimer's Show as these were national conferences with a large number of attendees.

Attendees by training and activity session
(n=563)



Feedback on the Frailty Admiral Nurse training sessions



The impact of frailty training

Attendees at the Frailty Service training and introduction to referral pathway session were sent a link to take part in a survey which asked for feedback on the session.

Of the 41 people who attended the training session, **23** people have completed the survey to date (August 2024).

Relevance of the training

All attendees said that the session was relevant, and most said it was detailed enough.

- **20 (out of 22)** said the session was very relevant to their role. Two said it was relevant
- **22 (out of 23)** said the session covered frailty in enough detail

Increasing knowledge*

The majority of attendees reported an increase in their knowledge across all categories following the session, with some reporting no change in knowledge.

- All reported that their knowledge on what frailty and frailty syndromes had increased 'a little' (n=11) or 'a lot' (n=11)
- 16 people reported that their knowledge on what the management and monitoring strategies for frailty had increased 'a lot', with three saying it increased 'a little'

My knowledge has...*	Increased a little	Increased a lot	No change	Response total
What frailty and frailty syndromes are	11	11		22
What the vulnerability and risk factors of frailty are	10	10	2	22
What the symptoms and indicators of frailty are	9	12	2	23
The importance of identification and diagnosis of frailty	8	11	4	23
What the management and monitoring strategies for frailty are	4	16	3	23

*Response options were 'increased a little', 'increased a lot', 'no change', and 'not sure'

Increasing confidence*

Almost all respondents agreed or strongly agreed that their confidence had increased following the session.

- 22 reported that they felt more confident identifying frailty
- 22 reported that they felt more confident providing advice to families about frailty
- 21 reported they felt more confident in knowing when to signpost or direct to appropriate services when there are frailty concerns (with 12 strongly agreeing with this statement)

	Strongly agree	Agree	Neither agree nor disagree	Response total*
I feel more confident in identifying frailty	10	12	1	23
I feel more confident in providing advice to families about frailty	8	14	1	23
I feel more confident in explaining what frailty is	10	12	1	23
I feel more confident in knowing when to signpost or direct someone to appropriate services when there are frailty concerns	12	9	2	23

*Response options ranged from 'strongly agree' to 'strongly disagree'

"I feel more confident in approaching the subject of frailty and offering education and advice with regard to the support that Dementia UK provides."



Benefits of the session

Attendees were asked about other benefits of the session.

Of the 22 responding*:

- **20** said they learned something new in the session
- **19** said the training would help them in their role
- **17** said they would be able to immediately apply what they had learned

Respondents provided feedback on the impact and outcomes of the training session.



*Respondents could select more than one response

Benefits of the session

"I will be able to pick up on frailty issues that come to the fore more quickly, to engage further probing where needed."

"I will explore frailty during calls and advise families to discuss this with their GP surgery to ensure that they get local support."

"I shared some of the knowledge with a friend who is training to be a paediatric nurse; it was interesting to cross-reference frailty in different areas of nursing."



"Frailty is not something I have previously considered in its own right in other jobs. I am very glad to have received this training to get me thinking about frailty when supporting families on the Helpline."

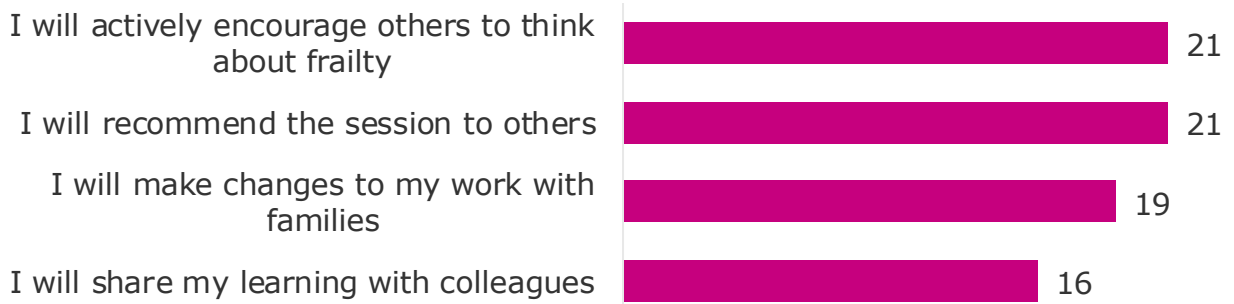
"I have already identified some callers who could benefit from the service in the future – frailty present but no complexity or issues with coping. I have identified one person from the triage emails and suggested the [Consultant Admiral Nurse for] Frailty would be additional support for the future for the same reasons and explained how they can access this support."

Outcomes of the training session

Attendees were asked whether they would carry out any specific actions after the training session.

Of the 22 responding:*

- Almost all said they would actively encourage others to think about frailty (n=21), and would recommend the session to others (n=21)
- 19 reported that they would make changes to their work with families
- 16 said they would share their learning with their colleagues



*Respondents could select more than one response



Outcomes of the training session

Respondents provided some examples and feedback on changes they would make as an outcome of the training session.

"I will be aware of considering frailty when supporting families; what it is and how it is identified and the need for comprehensive assessment."

"[I will] be able to identify and make families aware of frailty and encourage them to advocate for further assessment of whether frailty is an issue for the person they care for."

"I will ensure families are signposted to the appropriate services, eg primary care, Frailty Teams."



"I have already utilised and advised families regarding the diagnostics of frailty, the symptoms, and shared information with them re: the Rockwood Frailty Scale and the Geriatric Assessment."

"I will be able to more readily identify frailty and know when to consider the situation warrants a referral into [the] service."

"[I will] encourage families to recognise frailty as a diagnosis and how to access support around the symptoms of frailty... Read the accompanying supportive literature such as the frailty leaflet to further enhance knowledge... Share the frailty leaflet with families and other professionals for reference."

Further comments about the training session

Attendees were asked for any other feedback they had about the training session.

"[A] complex subject relayed in everyday practical understanding... [I] feel it has enhanced my practice."

"Good to see improvements and recognition of frailty".

"[A] brilliant session... to help me increase my knowledge [in] an important area of clinical practice. Well delivered; [I] enjoyed all the learning styles, quiz, Powerpoint, background, policy, context, risk factors. [A] very comprehensive session in helping create a platform to understand more about frailty and know how to care plan around the needs of this group of people and the importance of assessment and MDT working. Thank you."

"Very good and very informative with practical tips to support families."

"I am a very visual learner and Very good and very informative with practical tips to support families." and the good mix of diagrammatic representations to help, at a glance, is really very helpful when [I am] on a call on the Helpline and need to apply the increased knowledge learned/updated to people in a timely manner."

"[I] really found the quiz helpful in understanding the baseline for where my knowledge is on frailty. [I] found the session helped build my knowledge and develop foundations for learning on frailty."

"I was previously a Frailty CNS in an acute setting so I knew some stuff already, however I was amazed at how much I forgot and needed a refresh so this session was extremely important and was delivered so well. It was interactive and easy to process."

Carer feedback

Positive experience of the service

We collected feedback on the service via an electronic survey sent to those who had an appointment with the Frailty Service.

19 people have responded to our survey.

The survey asked for feedback on:

- overall experience of the service
- whether people responding received the information, advice or support they needed
- whether the service had made a difference

On the NHS Friends and Family Test all carers (n=19) said their **experience of the Admiral Nurse service** was **'very good'** (the highest rating*).

Who responded to our survey?

- All respondents were female (n=19)
- All respondents were White (n=19)
- 15 were the daughter/daughter-in-law, and four were the wife of the person living with dementia
- The most recorded age group was 55-64 years old (n=9), followed by 45-54 (n=6), 65-74 (n=2), and 75-84 (n=2)

No question in the survey was mandatory, so response rate to questions varied as respondents could skip questions. Respondents also had the option of choosing not applicable (N/A) if a question was not relevant to their experience – N/As have been removed from the analysis. The following pages summarise feedback on the service.



"I really cannot emphasise enough how important having Kerry to talk through our situation with my dad has been. We as a family were at crisis point. Kerry's empathy and knowledge really helped us to cope with Dad's care and recent admission to hospital."

*Rating choices: 'very good' to 'very poor,' plus 'don't know'

Outcomes for families

Person-centred care

Empathy is a key element in delivering person-centred care. A validated tool, the CARE measure (Consultation and Relational Empathy), which is designed to measure empathy in the context of a therapeutic relationship within a consultation, was included in the carer survey. It is based on a broad definition of empathy relevant to healthcare. This definition states that empathy in the clinical context involves an ability to:

1. Understand the patient's situation, perspective, and feelings (and their attached meanings).
2. Communicate that understanding and check its accuracy.
3. Act on that understanding with the patient in a helpful (therapeutic) way.

The measure includes 10 items which are scored from 'excellent' to 'poor', or N/A.

© CARE, SW Mercer, Scottish Executive 2004: the CARE measure was originally developed by Dr Stewart Mercer and colleagues as part of a Health Service Research Fellowship funded by the Chief Scientist Office of the Scottish Executive (2000-2003).

Outcomes for families

Results from the survey show that the **care delivered by the service was rated highly**, with carers saying the Admiral Nurse was 'excellent' or 'very good' across all items on the CARE measure.

CARE measure items	Number of carers rating items as:		Response total
	Excellent	Very good	
Making you feel at ease	19		19
Letting you tell your story	18		18
Really listening	19		19
Being interested in you as a whole person	19		19
Fully understanding your concerns	18		18
Showing care and compassion	19		19
Being positive	19		19
Explaining things clearly	19		19
Helping you to take control	17	2	19
Making a plan of action with you	17	2	19

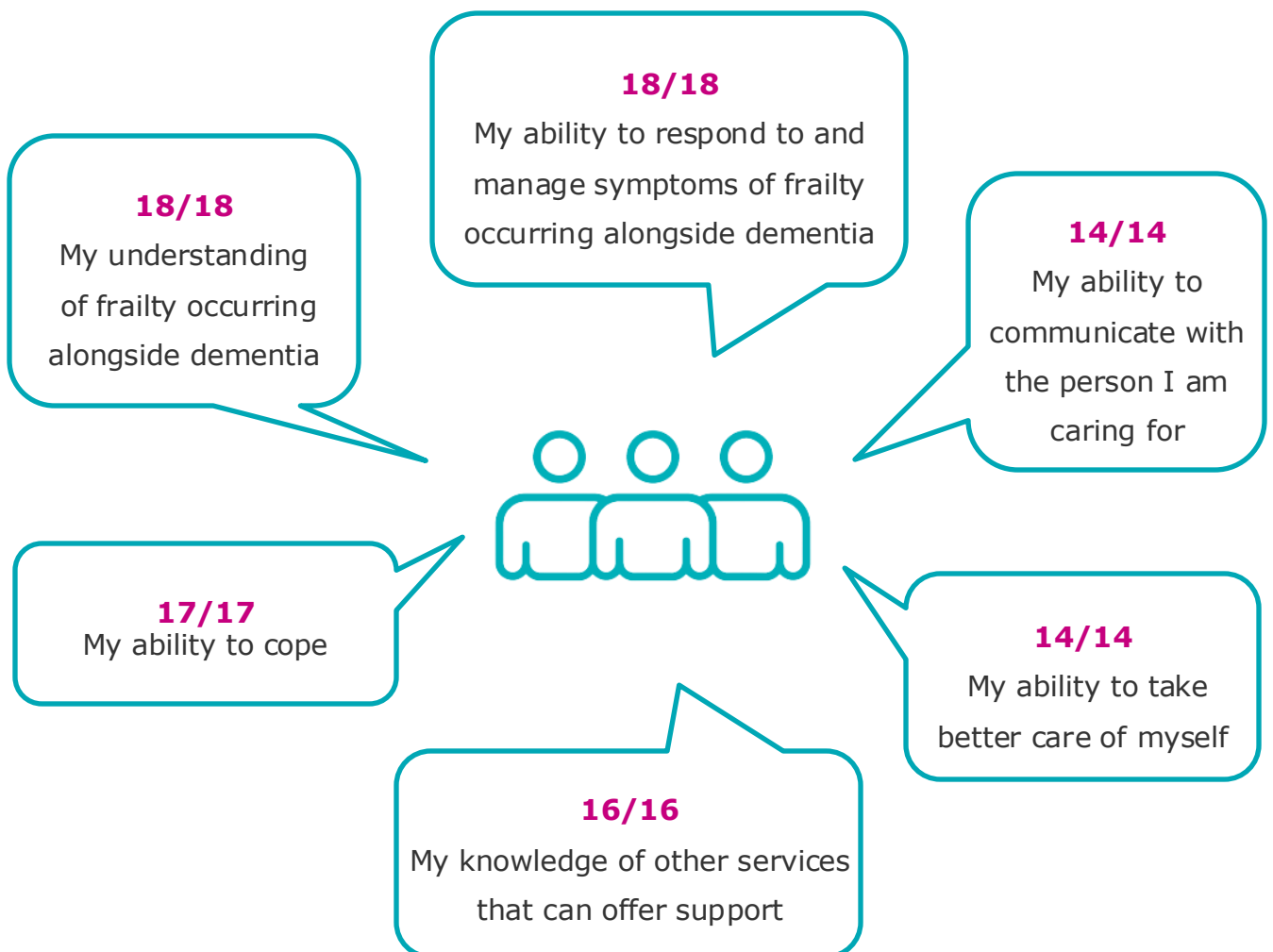
Making a difference

Improving lives

Carers felt that the Frailty Service was making a difference to their lives. All of those who responded said that the service had made a difference to their understanding of frailty; their ability to respond to and manage symptoms of frailty; their ability to cope; and their knowledge of other services that can offer support.

The service has also helped most carers to take better care of themselves, and to communicate with the person they are caring for.

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

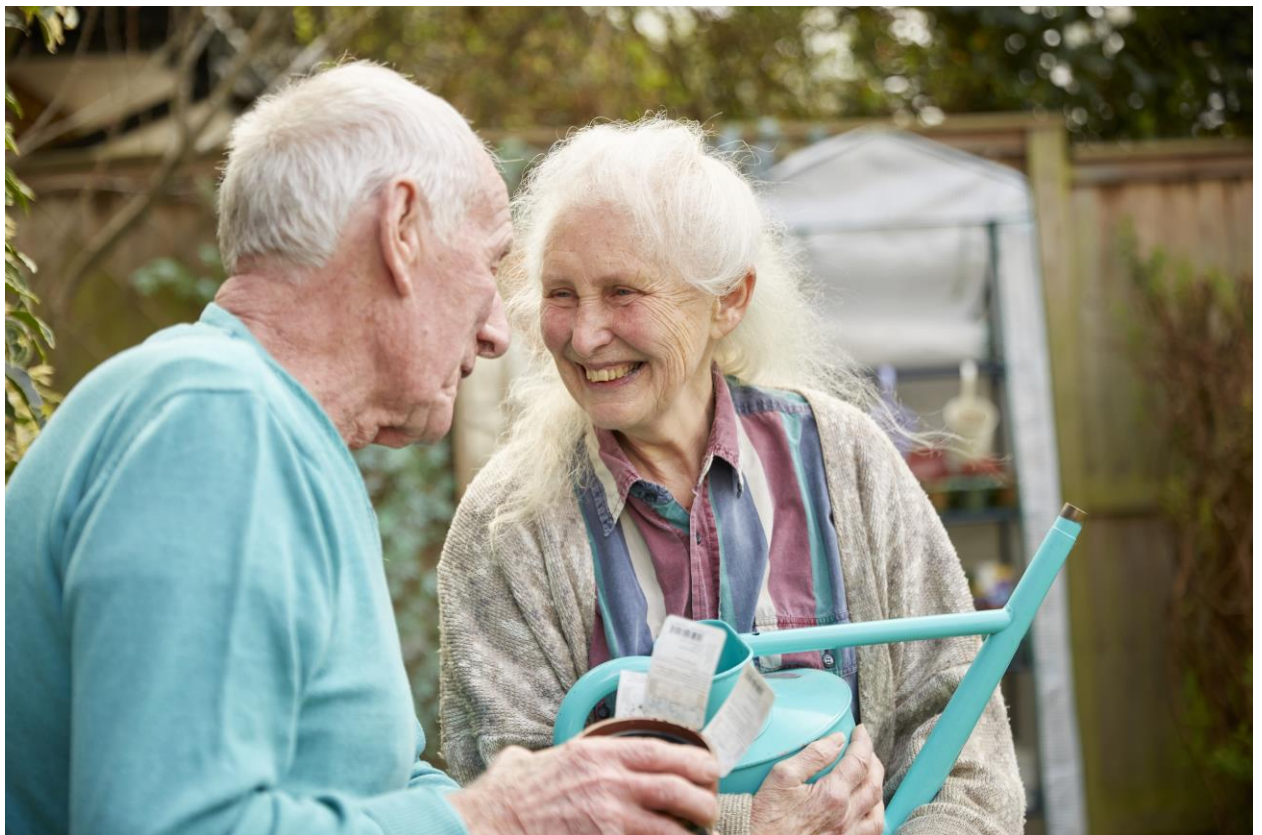


The contribution of the Admiral Nurse service

The carers who responded (n=18) said that the Admiral Nurse had contributed to:

- their **ability to continue as a carer** (n=11)
- **avoiding a care or nursing home move** for the person with dementia (n=5)
- **avoiding A&E visits** for the person with dementia (n=3)
- **reducing the amount of GP appointments** that the person with dementia attends (n=2)
- **reducing the amount of GP appointments** that they attend for themselves (n=1)

“Without Kerry's support **I would most definitely have needed help from my GP for my anxiety/stress.**”



Feedback on the service



Seventeen carers provided additional feedback on the difference the service had made to them and their families. For some carers, contact with the Admiral Nurse helped them to have more understanding of what was happening to the person with dementia. Some carers felt more able to make decisions about the health and care needs of their relative after being in contact with the service. Several carers also felt they could better understand their own emotions and feelings of sadness and guilt.

“Kerry’s help, advice and support has **been life-saving to both myself and my mum**. Mum wasn’t receiving the correct treatment and was put on a drug that was making [her] very sick. With [Kerry's] time and understanding and knowledge, I was able to address this with the right people and get this drug stopped... Just having someone to understand and [who] could help has been life-changing to us both when I was hitting brick walls in the current care service. **I cannot thank Kerry and Dementia UK enough for everything they have done**. I’m not sure where we would be now without this amazing help and support. Thank you again.”

“I found the Admiral Nurse I spoke to... gave me a **better understanding of what was happening with my mum who has Alzheimer’s and also my own feelings of guilt and grieving**.”

“Kerry supported me when my dad was in hospital to talk through the care he was receiving and how to challenge the concerns. She helped me understand what was happening to him. When he passed away, I received a sympathy card which was so touching and then I had a session with Kerry again to talk through and process my dad’s decline whilst in hospital and what alternatives there could/could not have been. She helped me see how much I did for my dad and take comfort from that. **She helped me become unstuck so I can move on and grieve**.”

"Kerry has been fundamental in helping me navigate this sad journey during the rapid decline in my mother's mental health. Not only did Kerry **help me understand what my mother might be going through** – and [suggest] appropriate language to use with my mother to help reduce her anxiety – **she also understood what I was going through and how to manage my own feelings of guilt, sadness and when to take next steps regarding external help for my mother's care**. Kerry's support has made a huge difference during this very difficult time and I shall always be grateful for this. Thank you so much."

"[The] call was absolutely fantastic. All my questions [were] answered and so much extra info given besides. Clear advice [was] given. **[I] felt empowered after the call to take steps to make the care we give Mum better and more appropriate** for her stage of dementia. THANK YOU!"

"[Kerry's] advice meant that we did just have hospice at home care in place by the time my husband died the following day and **we will be forever grateful.**"

"With the information I was given **I felt assured and able to plan ahead**. Now I know the stages ahead and how to relate to my husband's symptoms."

"[Kerry] has been very understanding, supportive in listening to my tears along with asking all the same questions and some impossible questions... She always listened and **gave me her best advice which I took on board and feel a lot better now and understand better [what] lies ahead for me...** I still find it hard not being able to talk to Mum in the old ways but the Admiral Nurse helped me understand why."

"I feel so grateful to have had Kerry Lyons's help throughout the process of understanding my mother's recent and very rapid health deterioration... Talking to Kerry really **helped me and my siblings decide next steps as far as caring for my mother is concerned**. Kerry's compassionate and thoughtful approach really helped me/us come to terms with our mother's illness and also **helped us deal with feelings of guilt and sadness**. It really made a sad situation much more bearable and **we are now better equipped to help our mother** who has been feeling very confused and anxious of late. With Kerry's gentle encouragement, we have now spoken to Adult Social Services who are putting a care package in place which will make a big difference to all of us. Thank you very much for making this service available to us. I do hope it continues so that other families may also benefit from this support."

"I called Dementia UK first as my mum is suffering and I had very little info and didn't know where to start to help her as it was very sudden and she had to go into a care home. The care home and the new GP just kept telling me it was dementia and I didn't know what symptoms were or not. The **help and advice and most importantly support I have received has been life-changing and saving** to me and my mum. I have been able to take charge of her care and make sure she is taken care of fully for what time she has. **I will never be able to thank you enough for everything, and with your help, Mum's care has improved so much**. Thank you so much."

"[Kerry] helped me understand my dad's condition... [She] **made me feel supported, not alone.**"

"**I felt very supported and learnt a lot of useful information.**"

"Mum is in hospital following two falls in 10 days and **now I understand what is happening due to frailty in dementia**... Thanks to Kerry **I can now speak to the doctors and nurses in terms that they understand** and explain to them about Mum's unattended pain, her walking with purpose and what I should expect from the Discharge Team and the next steps. Right now, I feel much better placed to deal not only with the medical and Social Services side of things but being able to explain things to my own two sisters to ensure that all the right decisions are being made. Having Kerry by my side right now is just so reassuring whereas up to this point in Mum's journey I have felt so unsure of everything."

"Kerry is amazing and **so supportive, caring, gentle and informative**. At the moment my husband is in [a care home] but I am finding visiting a struggle... She has been in touch frequently."

"My mum recently passed away... **I could not have coped over the last six months** without this [Admiral] Nurse... She was excellent, professional, kind and caring."

"I really cannot emphasise enough how important having Kerry to talk through our situation with my dad has been. We as a family were at crisis point. Kerry's empathy and knowledge really helped us to cope with Dad's care and recent admission to hospital. Just knowing I could email Kerry and [have] regular telephone conversations really gave me the strength to continue to support my mum with Dad. I'm so very thankful that I made the initial call to the Helpline and was referred by [nurse]. We've also had brilliant support from [name] based at the UHL Hospitals. **I would advise anyone to contact Admiral Nurses for support, information and knowledge**. Thank you so much."

Admiral Nurse feedback



Admiral Nurses who had engaged with the Frailty Service were invited to complete a survey about their thoughts on the responsiveness and the value of the service.

27 Admiral Nurses responded to the survey.

Responsiveness of the service

- **26** (out of 27) Admiral Nurses said that the Frailty Service was either **very responsive** or **extremely responsive***. One Admiral Nurse said the service was **slightly responsive**

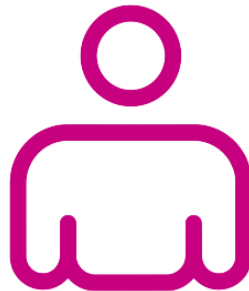
Nurses provided further feedback on the responsiveness of the service:

"Kerry is able to come back to the Helpline nurses to discuss the referral and also goes out of her way to try and support the carers and person living with dementia at short notice if the need arises. She is flexible and attentive."

"The most helpful and reassuring responses to any referral/query made to the service."

"I received a very quick response. A discussion took place regarding the referral and feedback was given regarding the outcome of the referral. The process was very straightforward to follow."

"Top quality, always there with an email response post-referral."



"I like Kerry's relaxed style of managing this service – I never feel anxious about making a referral in and she is available to talk things through if needed. I feel the criteria are really clear."

"Kerry is magnificent, emails immediately when referral is made to her service."

"Always lets us know that the referral has been received and is being triaged within a couple of working days."

"Reassuring to know referral has been received and actioned."

"I have always received an acknowledgement email very swiftly after completing the referral."

*Rating choices: 'not at all responsive' to 'extremely responsive'

Value of the service



Admiral Nurses provided feedback on the value of the service. The nurses found a lot of value in being able to connect families with the Frailty Service, which was able to offer them additional support that might not be available elsewhere. The availability of a frailty expert proved invaluable, particularly considering the complexity of frailty in dementia.

"[The] nurse was able to support [the] family with very complex cases when they were struggling to get appropriate help from [a] local professional. I have no doubt this added to the dignity, care and comfort of the person living with dementia and support, peace of mind and reduction of anxiety for the carer."

"We have many callers who contact [us] with a loved one who has a multitude of complex needs (meeting frailty criteria) and often it's challenging to talk about lots of different factors. They are always thankful for having someone specific to discuss these factors with."

"It's good to be able to have the additional support to offer families; frailty is a complex subject that needs introducing and revisiting with a family. It's great Kerry is able to do that."

"It enabled access to additional support to the family calling the Helpline in very difficult circumstances. It also provided some follow-up from the information I had given the family."

"[It is] great to... be able to forward people on to further and specialist support and guidance."

“Seeking the skills, expertise and knowledge is so reassuring for referrers but more so for families who will receive this high-quality dementia support. Knowing there is a compassionate, skilled senior nurse who can guide, support [and] advise families is just so reassuring.”

“It has enabled families with complex needs relating to frailty to access support, education and guidance around frailty and frailty syndromes, and better care.”

“Often families calling the Helpline are supporting a person with dementia with frailty, with repeated hospital admissions, falls, infections, eating and drinking difficulties, reaching end of life, and these are all very distressing for both the carer and the person living with dementia. Having this additional consistent specialist support is very valuable to be able to offer to family members and is an extremely useful resource for Helpline and clinics.”

“I found a lot of value in referring to the Frailty Service as people who are living with frailty can have very complex needs. I am able to discuss [frailty] on the Helpline/virtual clinics and provide recommendations, however due to time limits especially in clinics it is difficult to go into more depth and detail. I am so grateful for the Frailty Consultant Admiral Nurse to provide that tailored specialist support and look at a person living with frailty holistically. Often on the Helpline we discuss isolated issues and I think it’s so important that the Frailty Team within Dementia UK can help the person bring all this information together in a Comprehensive Geriatric Assessment.”

“It allows for the person’s specific problems to be responded to in greater depth and expands on the advice already given during the original Helpline call. [It is] something more that I can offer a caller.”

"A very valuable service, particularly for areas in the country where there is currently no Admiral Nurse Team available. Kerry has a key role to play in the professional development of other Admiral Nurses with her expert knowledge."

"I have referred family carers when I have felt they would benefit from additional expert support around frailty. Families offered this referral have been extremely grateful to know they can speak to someone with specialist knowledge, and I have been pleased to have this resource to offer them."

"I felt as though I could give a carer who was desperate on the Helpline some support from an expert."

"Good to know that someone is there to support people more than I can on the Helpline."

"The Frailty Admiral Nurse brings an expertise that enhances the work that we do on the Admiral Nurse Helpline. It is good to be able to offer this additional service to our families."

"It lets me offer specific support to families when there isn't a local Admiral Nurse and they are in need of additional support re: poor physical health and frailty."

"It was really helpful to know that I could offer the family an expert in frailty as they were not particularly well supported by their local services."

"[The] value is having an experienced clinician [who] can deliver to families when they need the specialist knowledge and advice on all topics relating to frailty. Kerry is number one in her field; we are fortunate and very grateful to have an inspired leader paving the way in the area of frailty."

Case study

Shara was supported by the Frailty Consultant Admiral Nurse Service while caring for her mum, Anna, who had vascular dementia. Her story demonstrates how the service significantly contributed to her knowledge and understanding of frailty; her ability to navigate the health and social care sector; and communication with healthcare professionals. This resulted in improved care outcomes and carer wellbeing.



As horrible and frightening as dementia is for the person with the diagnosis, it is just as confusing and misunderstood by families and other healthcare professionals – such as the wonderful but ill-equipped nurses on general wards who are caring for people with a condition that they have very little understanding of.

I was so grateful for all the help Kerry gave me to navigate the intricacies of hospitalisation, frailty, and making the right decisions for Mum when it came to moving her to a permanent care facility.

By working with Kerry, I was able to understand what Mum was trying to say in her actions. She wouldn't speak truthfully as she was petrified that she would never be allowed to return home from hospital. With Kerry's support, I was able to talk to the Staff Nurse about Mum's lack of fluid intake, her dehydration, why she was wandering off the ward – all things that they had little time to deal with and were frustrated by too.

Kerry helped me to communicate with the social worker when it came to finding a home that would be right for Mum. I thought we didn't have a say in where Mum was placed as the local authority was footing the majority of the bill, but Kerry helped me understand that the choice was actually ours to make.

Within the home, Kerry helped me navigate the additional care Mum needed, like physio to strengthen her wasted muscles, and how to make her surroundings safe for her with homely items that she felt comfortable with.

After six months in the home, where Mum was relatively happy, she declined quickly. We lost Mum on Easter Saturday – she fought it for five awful days, but she passed quietly and comfortably in the end.

I would never have been able to do any of this without Kerry's knowledge, empathy and understanding and will always be eternally grateful.

Case study continued

Kerry Lyons, Consultant Admiral Nurse for Frailty, says:

Shara was referred to the Frailty Consultant Admiral Nurse Service as a result of a call she made to the Dementia UK Helpline. On first contact, she explained that her mum, Anna, had experienced two falls in 10 days, leading to her being admitted to a hospital ward.

Shara also explained that she was extremely worried about her mum's future and their options as a family in respect to her care needs. She said it had become clear that her mum would not be able to return home on discharge and this was causing the family significant concern.

Furthermore, Shara had concerns about her mum's current care delivery and felt that the nurses did not fully understand dementia and appeared to be struggling to interpret Anna's needs.

During our contacts I gave Shara the time and space to share her concerns and frustrations, and to ask questions so that I could work out how best to support her. We spoke about her immediate concerns with Anna's care, and I offered her practical information, guidance, support and signposting. This helped her to feel confident in expressing her concerns in an informed way, enabling her to advocate for her mum and make her own voice heard.

We spoke about Shara's mum's clinical needs, including her advancing frailty, delirium, continence issues, weight loss, unmanaged pain, poor mobility, and falls risk. We considered steps that could be taken to improve her mum's current situation and spoke about the family's rights and options around safe hospital discharge pathways.

Anna was experiencing periods of significant confusion and distress in hospital. We spoke about ways to better orientate her to her environment; communication strategies to ease her distress around wanting to go home; and how Shara and the ward staff could help reassure her whilst she was experiencing so many unsettling changes.

I met with Shara over a number of video clinic appointments, and we covered a wide range of areas from understanding and managing frailty to transitioning into a residential care setting. We also focused on Shara's needs as a daughter and carer, and I offered emotional and psychological support throughout all of our appointments.

I felt truly privileged to have been able to support Shara and her mum.

For further information contact info@dementiauk.org



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