

Making Evaluation Count

Report for one-to-one
services 2023-2024



**Alzheimer's
Society**

Together we are help & hope
for everyone living with dementia

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“Without your service I
would be drowning”

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Introduction

The annual evaluation of Alzheimer’s Society’s one-to-one dementia support services, *Making Evaluation Count (MEC)*, was conducted between 1st July 2023¹ and 31st March 2024. During this period, we **interviewed 1696 people affected by dementia**. Of these, a third (545) were people living with dementia, and two thirds (1151) were carers. Our Dementia Support Line and 154² of our community Dementia Support Services, across England, Wales and Northern Ireland contributed to this evaluation. Our evaluation includes a mix of closed (quantitative) and open (qualitative) questions. The quantitative questions align with key outcomes identified by Dementia Support and Partnerships for one-to-one support services, ‘I am informed’, ‘I feel supported to manage’, and ‘I have choice’. This year we analysed the qualitative data collected in the context of the six change points identified in our Impact Framework³, which outline a person’s journey through dementia from diagnosis to end of life.

Executive summary

This evaluation highlights the significant positive impact of Alzheimer’s Society’s one-to-one support services, while also identifying areas for improvement to enhance overall effectiveness and user satisfaction.

Positive Impact of Services

- **Key outcomes met:** Over 90% of respondents felt they received useful information and felt more supported since using the service. Nearly 80% reported increased confidence in decision-making.
- **Service Ratings:** 90% agreed the service met their needs. 97% of respondents who gave an opinion said the service they received was good (very good (78%)/ good (19%)).

¹Data for quarter one of 2023-24 is not included in this report. During quarter one we concluded a MEC improvement review. As a result, new survey questions aligning with our impact framework were developed and implemented from quarter two.

² Representing 58% of our dementia advice and dementia support one-to-one services.

³ Infographic of the impact framework appended

Key insights at change points

For people affected by dementia, key contact with our one-to-one support services is often in the earlier stages of a person's journey through dementia. The qualitative data from this evaluation reflects this focus, as it mainly relates to support immediately following diagnosis, adjusting to life with dementia and the need for increased care. However, dementia advisers do also assist individuals through the other significant transitions: hospitalisation, needing a new home, and end-of-life. While we have received some feedback on how our services impact hospitalisation and the need for a new home, there is a lack of feedback on end-of-life support, preventing us from drawing any conclusions about our effectiveness in this area at this time.



1. Diagnosis

- **Initial support:** Many respondents met with a dementia adviser soon after diagnosis, praising their knowledge and empathetic approach. Advisers help users understand dementia and provide information and guidance on key issues like benefits and legal matters such as Lasting Power of Attorney.

2. Adjusting to life with dementia

- **Confidence building:** Information provided helps users plan for and be less anxious about the future.
- **Combatting loneliness:** Services reduce loneliness by offering direct support from the dementia adviser and signposting to peer support groups.

3. Greater support with care

- **Tailored support:** The findings demonstrate that services adapt based on need, from signposting to making referrals to other services for onward support.

4. Hospitalisation

- **Preventative support:** Services may help reduce hospital admissions by providing information and guidance on equipment and services to enable the person living with dementia to keep safe.

5. Needing a new home

- **Decision support:** Dementia advisers assist with the transition to supported living or care homes, helping families navigate difficult decisions.

6. End of life

- **Limited reference:** The lack of spontaneous feedback about end-of-life care and planning from our service users is likely because those interviewed were not at that stage but might also indicate a reluctance to discuss this issue.

Recommendations for improvement

Feedback from service users was overwhelmingly positive, but there were some areas for improvement identified.

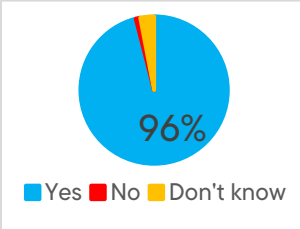
- **Tailored support:** A small minority of respondents indicated that they needed better tailored support. A few people commented that they felt overwhelmed by the volume of information and wanted better tailored advice and guidance.
- **Follow-up:** A need for better follow-up to maintain connection with the service was noted by a small number of respondents.
- **Face-to-face support:** A few users who accessed only telephone support at a local level would have preferred the option of face-to-face connection with the Dementia Adviser.
- **Expectation management:** Clearer communication about the scope of services may be necessary to manage some service users' expectations.

Lack of feedback about end-of-life support raises the question as to whether we should:

- Consider offering **end-of-life information and guidance earlier** in the dementia journey. Opportunities to enhance our training and partner with end-of-life care specialist organisations are being explored.

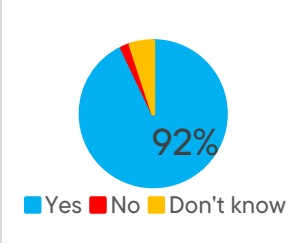
Key findings at a glance

As shown in the figure below, this year’s evaluation results are overwhelmingly positive and meet three key outcomes identified from our impact framework. Over 90% of respondents agreed that they had been given useful information and felt more supported since using our services. Nearly 80% of service users interviewed agreed that they felt more confident about decision making thanks to the support they received.



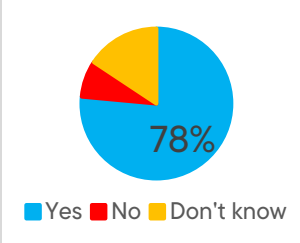
I am informed

Were you given useful information by the dementia advice/support service?



I am supported to manage

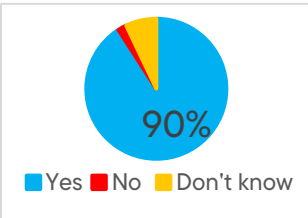
Do you feel more supported since using the service?



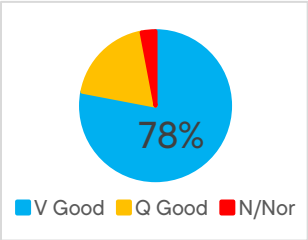
I have choice

Has the service helped you feel more confident to make decisions?

Our evaluation also included two general satisfaction questions, that indicated an overall high level of approval with the services as illustrated below.



Did you get what you needed from the service?



Thinking about the service you received from us, how was your experience overall? Scale very good to very poor.
(NB Based on all who expressed a preference. Those saying Poor and Very poor less than 1%.)

Qualitative findings

Diagnosis

Individuals who access and use our services are often in contact with a dementia adviser soon after their diagnosis. This year's evaluation, consistent with previous years, highlights the high opinion service users have of the dementia advisers they speak to. Not only are dementia advisers perceived as being very knowledgeable but their empathetic and compassionate approach makes a significant positive impact for people affected by dementia at a challenging time.

'I felt I was talking to someone completely non-judgmental. I was able to say whatever I needed to and she listened patiently with no interruption or advice unless asked. Because the Dementia Adviser rings without fail every six months I feel I have a "friend" and supporter who I know I can call on.'

Respondents acknowledged that advisers helped them to understand dementia and how the disease may progress. They also spoke about how they had been given useful information about benefits they may be entitled to and legal issues such as Lasting Power of Attorney, things that they might not have known about before.

'The Dementia Adviser spoke to myself and my sister about Lasting Power of Attorney (LPA) and if we can put it into place, how much it could help us in the near future. We know our mum has a will but now we understand the importance of LPA we will be looking into this very soon.'

Adjusting to life with dementia

There is clear evidence that our services enable people to adjust to life with dementia. Firstly, the provision of information was said to give people the confidence to plan for and feel less anxious about the future. The ability to reconnect with Alzheimer's Society at any point is key to fostering this increase in confidence.

'I'm happy to make decisions now as I feel a lot more informed about what is available to me and I know you [Alzheimer's Society] can help with any questions I have.'

People are also supported to adjust to life with dementia through our Universal Services, which complements their one-to-one support by providing another platform for information, advice and support.

'I most definitely [feel more supported], especially now we have the advanced care planning team involved and I used the online forum a lot for advice.'

A recurring theme that emerges from the data is loneliness and isolation accompanying a dementia diagnosis. Many respondents said the service helped them feel less lonely, either through direct support or by enabling access to peer support.

'I feel we are not alone. We have to deal with my disability and me in a wheelchair and with his early dementia. Through the Young Person With Dementia support group we know we aren't alone and can talk to other people who won't judge us and will understand us.'

One-to-one services also connect people to Alzheimer's Society's Companion Call service which further reduces isolation.

'The companion caller is so good for me as I have someone to talk to and have someone to trust to call you each week.'

More generally, information, guidance and support offered by our services was said to enable people affected by dementia to better understand and accept the changes that dementia may bring, and for carers to be more empathic towards and better able to care for the person they support.

Alzheimer's Society one-to-one support services also connect people to our group services such as Singing for the Brain which further supports people to adjust to life with dementia by improving wellbeing, reduced isolation and supporting memory. Read more about the impact of Singing for the Brain [here](#).

'At these groups [Singing for the Brain] I have found the people to be very nice and caring, and having contact with people with similar experiences has been of great comfort. I have come to realise that I am not alone.'

Greater support with care

At the point where people living with dementia need greater support with care, evidence from the evaluation illustrates how our support services can adapt to offer different levels of support based on need. At one end of the scale, those able to self-manage may be signposted onwards for further support.

'I now know where to go and which organisations can help me. Mum now has a social worker and will be going to a day centre. I'm in touch with the Admiral Nurse for my own stress-related issues brought on by my caring role and we're currently looking at respite care too. All things that I had no idea about.'

Where extra support is needed people affected by dementia appreciate it when a dementia adviser can step in and provide practical support, for example by referring on to specialist agencies.

'The Dementia Adviser explained what benefits I am eligible to and made referrals for us to services that can help with that as she wasn't able to. She offered help with chasing up the day centre and wet room for my husband.'

Hospitalisation

Our support services also play a role in supporting people affected by dementia at risk of hospitalisation. Specifically, findings from our evaluation demonstrate how we reduce the risk of people having to go into hospital by providing information and guidance around safety issues including access to relevant equipment and services.

'[the Dementia Adviser] helped us to get the right equipment in and social services became involved to increase the care package...they [person living with dementia] were becoming unsafe to cross roads etc. but now they understand to wait in for a carer to help them, which has given us reassurance.'

As well as playing a role in reducing the risk of hospitalisation, Alzheimer's Society are directly working with a growing number of hospitals on the role that Dementia Advisers play to support a better experience for people with dementia while they are in hospital, and throughout hospital discharge.

'Dad was in hospital and we couldn't get to speak to the right people we were just getting the run around. She [the Dementia Advisor] was able to cut through the noise and give us clear concise advice.'

Needing a new home

While our support services primarily assist in the early to middle stages of dementia, we may also provide support to those moving from their home to supported accommodation or a care home. Qualitative data in this study demonstrates that our staff can support people when they are making these decisions.

'My sister moved into supported living accommodation a couple of years ago. That was the most difficult decision I had to make. I felt like I was choosing my husband over my sister but something just had to give as I was stressed and exhausted. The local worker helped me to see that by my sister moving into supported living, I wasn't failing her or letting her down. In fact, she settled in really well and loves having the company, which she didn't have at home. The local worker helped me through all this.'

End of life

There is very little reference to end of life in our evaluation data set. This may reflect respondents not being near to end of life, but it also might indicate a reluctance to discuss the topic.

Areas for improvement

While our evaluation highlights many successes, we don't always get things right. A few respondents felt **overwhelmed by the volume of information** given or wanted information better tailored to their circumstances. A small number of service users interviewed cited that they wanted **better follow-up** to feel more connected to the service. Additionally, a few who had only accessed telephone support said that they would have preferred to **meet with a dementia adviser in person**. Other concerns generally related to people's **unrealistic expectations** of what the service should provide, suggesting a need to better manage expectations.

Appendix

Our Impact Framework

Our **Impact** Framework

