



Alzheimer's Society services evaluation 2019

July 2020

Spotlights
on evidence



Spotlights on evidence

'I feel more reassured and less worried, I am much more relaxed now.'

Person with dementia

These 'spotlights on evidence' present key findings from an evaluation of Alzheimer's Society services in 2019. There is one 'spotlight on evidence' for each service that was evaluated.

The services evaluated in 2019 were:

- Dementia advisor
- Dementia support
- Side by Side
- Singing for the Brain
- Carer Information and Support Programme (CrISP)
- Live Well with dementia.

Key findings



people who have used an Alzheimer's Society service took part in the 2019 evaluation



of people agreed that the **key service outcomes have been met**



Alzheimer's Society services help **people affected by dementia to feel more positive**, and these feelings are sustained beyond direct service contact



Our staff understand the importance of inclusivity, which enables people affected by dementia to share their experiences and feel less stigma

Our approach to the evaluation

The 2019 evaluation of Alzheimer's Society services was based on the following person-centred principles.



Appropriate

Feedback is typically collected using the method of communication used to deliver the service – usually a face-to-face or telephone conversation using semi-structured questions.



Meaningful

The questions are designed with input from people with dementia.

Local staff are encouraged to use their expertise to rephrase questions or ask follow-up questions as necessary. Data is collected 'in the moment', to avoid some difficulties for people who have memory problems.



Proportionate

The number of people who are asked to take part in the evaluation reflects the size and scope of the service. For example, for one-to-one services at least six people who use the service are asked to participate for every full-time equivalent member of staff. For group services it is recommended that six groups are evaluated for each type of group in the area.



Ethical

Feedback is collected from people who directly use the service. **The Mental Capacity Act principles are followed** which means that people with dementia are assumed to have mental capacity until evidenced otherwise. People provide informed consent, and information governance procedures for handling data are followed.

What outcomes do we measure?

Alzheimer's Society services aim to achieve a number of outcomes – that is, changes we expect people affected by dementia to experience as a result of engaging with our services.

We measure key outcomes to assess whether people using the services are:

Supported by staff/volunteers
(‘Staff support’)
Example question: ‘Do you feel that [the staff member] understands your needs?’



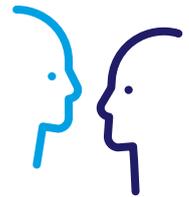
Enabled to access useful information
(‘Information’)
Example question: ‘Has [the service] provided you with useful information?’



Enabled to have social contact
(‘Social contact’)
Example question: ‘Are you able to socialise at [the service]?’



Supported by peers
(‘Peer support’)
Example question: ‘Do you feel able to share your experiences at [the service]?’



Enabled to live well
(‘Life better’)
Example question: ‘Has [the service] made your life better in any way?’



We ask questions relating to one or more of these key outcomes, depending on which service the person has used. We also ask people affected by dementia how they think the service could be different – local service staff then use this feedback to make improvements.

Find out more about our services online:

Support services

alzheimers.org.uk/info/20172/activities_and_services

Dementia Connect

alzheimers.org.uk/dementiaconnect

Evaluation participation 2019

Evaluation data was collected from 4,279 people who had used one of the six Alzheimer's Society services between April and December 2019. This included 1,982 (46%) people with dementia and 2,297 (54%) carers. The number of people who gave feedback for each service is shown in **Table 1**.

		People with dementia	Carers	Total per service
Table 1 People involved in the 2019 evaluation	Dementia adviser	216	157	373
	One-to-one services			
	Dementia support	321	993	1,314
	Side by Side	503	-	503
Total for one-to-one services		1,040	1,150	2,190
Group services	Carer Information and Support Programme (CrISP)	-	444	444 people (92 groups)
	Live Well with dementia	78	-	78 people (18 groups)
	Singing for the Brain®	864	703	1,567 people (142 groups)
Total for group services		942	1,147	2,089
Total for all services		1,982	2,297	4,279
		46%	54%	100%



Overall findings 2019

Figure 1

Percentage of participants who agree that key outcomes have been met (2019)

■ People with dementia
■ Carers

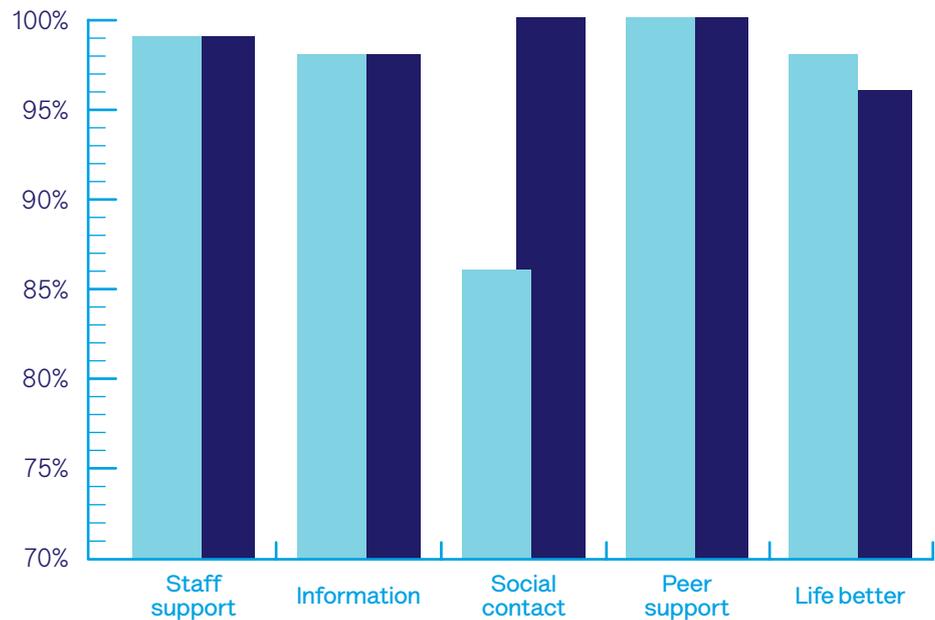


Figure 1 shows that at least 86% of the people who took part in the evaluation agreed that the Alzheimer’s Society services met the five key outcomes.

This result is slightly lower than in previous years, specifically because of the ‘social contact’ outcome. The biggest factor in the decrease is that we evaluated only six services in 2019 – a drop from 14 services in previous years – and services that typically had a very high agreement rate to this question are no longer included in the average. ‘Social contact’ is now based on only two services: Side by Side and Singing for the Brain®. We explore the reasons behind a lower agreement rate in the Side by Side Spotlight on evidence.

To give us a better understanding, people were asked to tell us more about their response to each outcome question. A key theme was that people affected by dementia feel more positive because of engaging with Alzheimer’s Society services, and that these feelings can be sustained. This means:

Our services create a safe and confidential atmosphere where people can talk freely and without stigma, making them feel more confident and less anxious.

Our staff and volunteers understand the importance of inclusivity, and promote the engagement and participation of people with dementia in our services. In turn, service users enjoy sharing their experiences with other people and forming support networks. They feel valued.

The impact of our services extends beyond those who received direct service provision. Extended family and friends of people with dementia also benefit – for example, they feel more positive and gain an increased understanding of dementia.

Positive feelings are sustained because our service users feel reassured and confident that they can turn to Alzheimer’s Society for support. They feel we’re there for them both now and in the future.

Having difficult conversations about the future

Not all service users feel they will be able to keep living well as their dementia progresses. Some people with dementia and carers told us they were unable to face the future and resistant to having conversations about future planning. It can feel overwhelming to discuss the progression of dementia, decisions about where to live, lasting power of attorney, finances and end of life care. However, not having these conversations may mean that a person's wishes are not communicated early enough in their dementia journey, and this could make important decisions more difficult later on.

Nevertheless, feedback from service users showed that Alzheimer's Society staff were able to facilitate these sensitive and difficult conversations, where people were open to this. People who had taken part in such conversations told us this helped them feel more confident in making difficult decisions around dementia care.

Using evaluation data to improve our services

Alzheimer's Society is committed to continuous improvement to make sure our services meet the needs of people affected by dementia. People who took part in the 2019 evaluation were asked how they thought the service they used could be improved. We asked this question to inform local changes that could make the services more relevant and helpful to the people who use them. People's suggestions for improvements included more frequent follow-ups and face-to-face support:

'I think face-to-face meetings are best, meeting our dementia support worker face-to-face gave me time to ask questions without awkward silences that you would get on the phone. It encouraged conversation both ways and allowed me time to make notes.'

Carer

We collected this evaluation data during the transition period into our new Dementia Connect service model, which includes face-to-face support. Our dementia advisers can meet service users to offer support, information and practical advice.

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Alzheimer's Society operates in England, Wales and Northern Ireland. Registered charity number 296645.