



**‘I can be me
again’ – Enabling
people with
dementia and
carers to live
well**

**Alzheimer’s Society
local services
evaluation 2016**



Acknowledgements

The Evaluation team would like to acknowledge and thank all service users and operational staff across Alzheimer's Society who contributed to this evaluation.

Report written by:

Dr Jane Tooke
Evaluation and Impact Programme Manager,
Alzheimer's Society

Natasha Morgan
Evaluation Manager, Alzheimer's Society

Carly Tillyer
Evaluation Officer, Alzheimer's Society

E: evaluation@alzheimers.org.uk
T: 020 7423 3517

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Alzheimer's Society
43–44 Crutched Friars
London EC3N 2AE
0330 333 0804

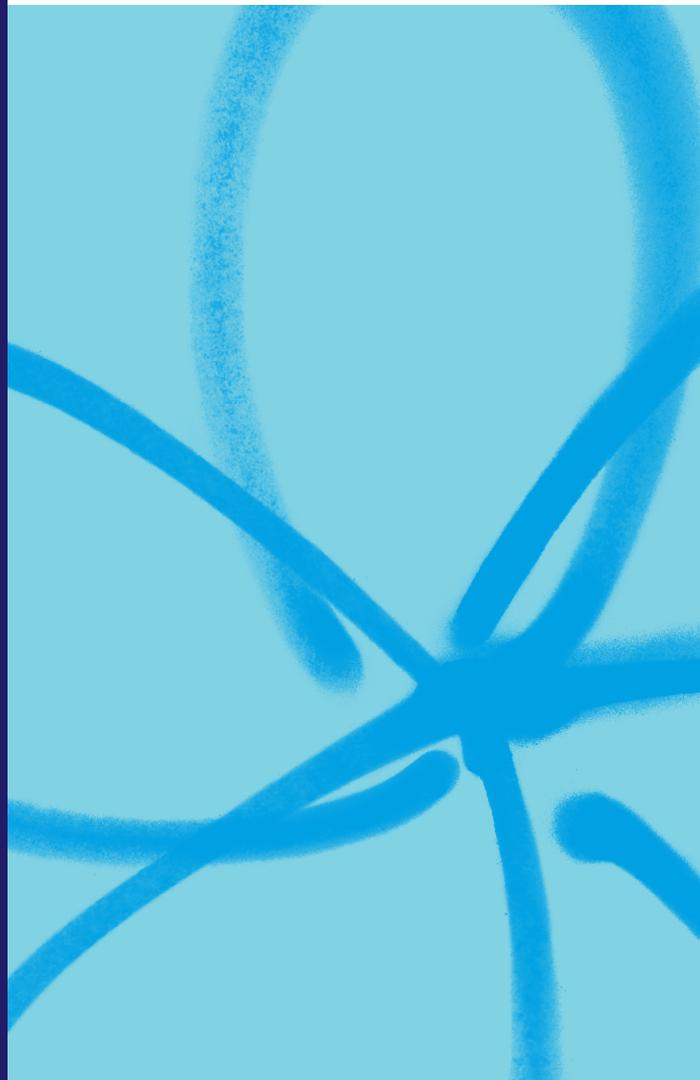
info@alzheimers.org.uk
alzheimers.org.uk

Code 884

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

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**‘I can be me again,
not someone who
has to be cared for.
Treated like the
person I used to be.’**

Introduction

This report highlights the views of more than 10,000 people who used Alzheimer's Society local services in 2016. It demonstrates how the people with dementia and carers who use these services are enabled to live well, highlighting how the support provided helps them to cope better with the challenges posed by dementia. This is because they can identify appropriate information and feel more connected and in control of their lives.

Our services

Alzheimer's Society provides a range of specifically designed services locally across England, Wales and Northern Ireland. We offer:

- **One-to-one services** including dementia support, dementia advisers, community support, homecare and support, day support, advocacy and befriending.
- **Group services** including dementia cafés, Singing for the Brain® (SftB), Carer Information and Support Programme (CrISP), peer support and activity groups.

Our approach

To understand the difference that our services make to people with dementia and carers, we have developed an appropriate and proportionate evaluation approach. These important person-centred principles are explained in more detail below:

Appropriate

- Feedback is collected using the same **method of communication** that is used to deliver the service. For one-to-one and group support, this usually involves a face-to-face conversation using semi-structured questions.

Proportionate

- The amount of **evaluation activity reflects the size and scope of the service** so as not to overburden staff, volunteers or service users.

'I can be me again, not someone who has to be cared for. Treated like the person I used to be.'

Person with dementia

Meaningful

- Questions are **as straightforward and accessible as possible** This is so that people providing feedback are able to understand what they are being asked and so answer as directly as possible.
- We **empower local staff to use their expertise** to rephrase questions as necessary or ask for additional information, if appropriate.
- We collect data **'in the moment'** – while the person is attending the service – to overcome some of the difficulties with recall.

Ethical

- We always seek feedback from the person who directly uses the service. For people with dementia, we **assume mental capacity** and always give them the opportunity to feed back themselves rather than asking a carer to answer for them.
- We gain **informed consent** from all those who participate in evaluation and handle their data in line with information governance procedures.

Outcomes

Our services aim to achieve a number of outcomes for the people with dementia and carers who use them. The main outcomes measure whether people using the services agree that they are:

- enabled to access useful information
- enabled to have social contact
- supported by staff/volunteers
- supported by peers
- enabled to live well.

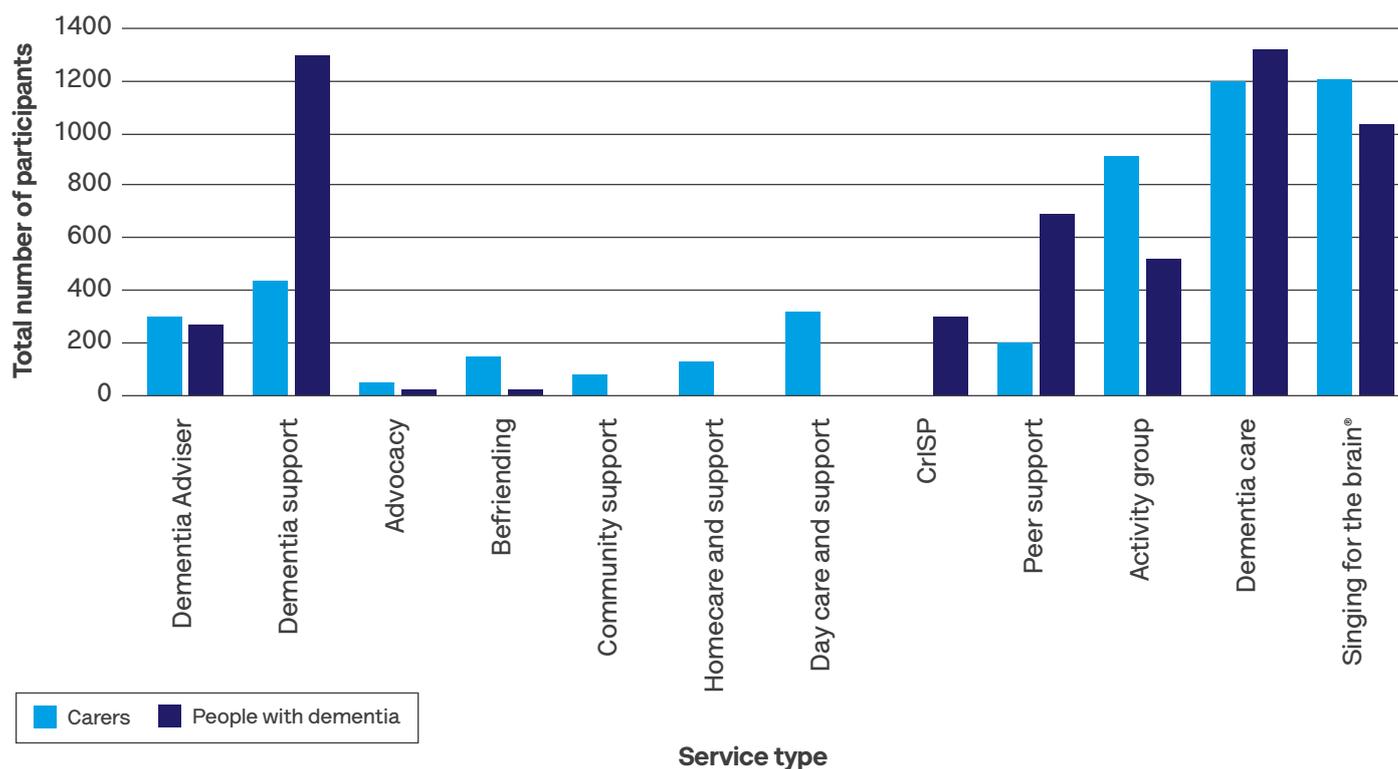
Alongside service outcomes, we also gather feedback on how satisfied people are with the services they receive and how they think the service could be improved.

Participants

Between April and September 2016, evaluation was conducted with 10,396 service users, made up of 4,959 (48%) people with dementia and

5,437 (52%) carers. The number of service users who gave feedback for each service type is shown in the graph below.

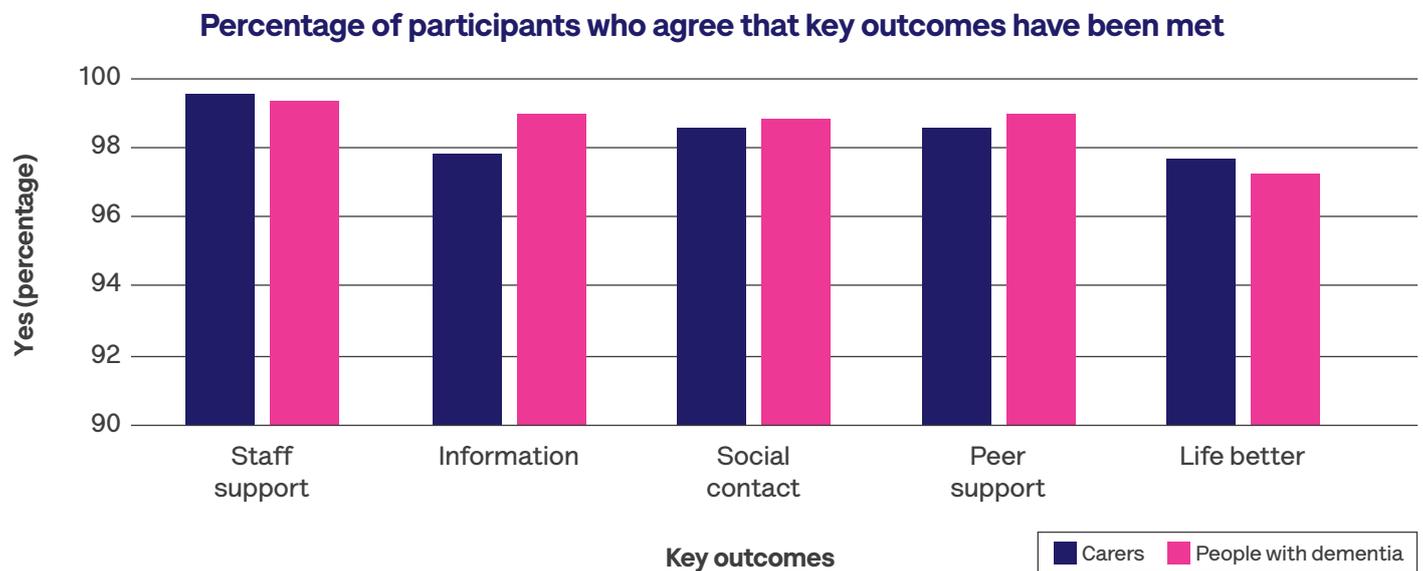
Number of people with dementia and carer participants by service graph



Our findings

Overall, the findings are very positive. The graph below shows that, for each of the five key outcomes, positive responses from

both people with dementia and carers were all over 96 per cent.



To further investigate the extremely positive results, we have analysed people's comments and identified a number of themes. Some of these matched those of last year, including the fact that services work well because they:

- provide information in a range of formats
- use an empathetic approach to supporting people
- have continuity of support
- facilitate social interaction
- enable peer support.

This year we have also been able to understand more about how our person-centred approaches respond to the diversity of people's needs and interests in three important ways:

- 1. Navigation of available information and support.**
- 2. Development of a sense of connection, free of stigma.**
- 3. Personhood – having choice and control that can provide hope for the future.**

These themes are explored further in the following sections.

1. Navigation of available information

A key theme that ran through much of the feedback was how people are enabled to identify appropriate information and support as and when they need it. This allows them to navigate the complex landscape of health and social care.

People particularly appreciated dementia advice and support services for being able to guide people towards useful information: 'It's a minefield and without [the dementia adviser] we would not have got things sorted.' (Carer about Dementia Adviser service)

Some people specifically commented on the fact that information was provided according to their individual needs: 'I was inundated with printed information, [but the dementia support worker] selected what was appropriate.' (Person with dementia about dementia support service); 'The information ... provided was in a timely manner and always seemed to be the right information for that time.' (Carer about dementia support service)

'We were really in the dark about the things out there for people like us. We found it easier to talk to an adviser about finances, coming to terms with the diagnosis – even telling us simple brain exercises.'

Person with dementia about Dementia Adviser service

The feedback also suggests that this navigation is successful because staff enable communication. People felt able to talk about the challenges they are facing: 'She relaxes you straightaway and makes it easier to talk about a difficult subject.' (Carer about Dementia Adviser service)

'I felt, for the first time, that someone was actually listening to me, and that I was being focused upon. It was so unusual to be given time to talk and discuss issues without being ushered out of the room in five minutes.'

Carer about dementia support service

Enabling people to talk and hearing what they say is only the first part of the conversation. It is also important that staff can communicate information back in ways that are understood: 'The dementia adviser... spoke to me in a way I could understand but still treated me as an adult.' (Person with dementia about Dementia Adviser service.); 'You explain things to me in a way I can understand. You don't get emotional or fussy about things like my friends do. You help me more than you know.' (Person with dementia about Dementia Adviser service)

'I can talk properly and understand what the worker is saying to me. It's good to have someone who can speak Gujarati.'

Person with dementia about community support

When people understand what is being said to them it enables them to cope better with the challenges posed by dementia. It enables independence: 'Through understanding, we can manage it better on a day-to-day basis. When you explained some things, I suddenly understood.' (Carer about dementia support service); 'It helps me to understand, and that helps me to choose better ways of reacting to and managing difficulties.' (Carer about Dementia Adviser service)

Specific examples of this include people being able to stay in their own home: 'If we had not had the information and pursued the course of action we would not now be able to buy our own property. He would not have been able to stay at home. It's had a real impact on the quality of our life.' (Carer about dementia support service)

It can also help to prevent crises: 'It took a big heaviness off my shoulders – the unknown was dragging me down. I was getting depressed.' (Carer about Dementia Adviser service). People have also commented on being able to live active lives: '...helps to keep me able doing what I want on my own for longer.' (Person with dementia about Dementia Adviser service)

In summary, what dementia advisers and support workers do well is enable people to navigate and access appropriate information and support in a timely way. This is possible because these staff have the skills required to encourage people to talk, hear what they say and talk back to them in ways that are understood. This means that people can absorb and process what is being said to them. This in turn enables people to cope better, to prevent crises and to live active lives.

2. Development of a sense of connection, free of stigma

A second theme was that many people felt more connected.

Carers describe this connection: 'I feel "part of a population," not a single individual struggling with making sense of the experience of dementia.' (Carer about dementia support service); 'My life has turned around in the last 12 months because of the care and the support we now get. It was getting very isolated – it has made us appreciate that we are not on our own.' (Carer about dementia café)

Feeling more connected also helps people with dementia to cope with some of the emotional aspects resulting from a diagnosis: 'You calmed me down and you've made me feel much better about things. You – and my daughter – helped me to realise that I needed to accept my diagnosis.' (Person with dementia about Dementia Adviser service)

It gave people confidence and a sense of control: 'When diagnosed it made me feel very low. I felt like I had lost who I was. Since coming to the memory café I feel like I am myself again – I have my confidence back.' (Person with dementia about dementia café)

'When my husband was first told he had dementia I started to grieve – I felt lost and out of control. But just by enrolling into CrISP it helped me to gain control. I now feel I am in control of my life and things again.'

Carer about CrISP

Group services had additional benefits in terms of people feeling connected, as spending time with others in a similar situation was often something that helped them feel at ease with their diagnosis: '[I] get upset that relationships change with people once they know about my dementia. This [group] has made me feel more at ease and respected.' (Person with dementia about peer support group); 'I was ashamed about my diagnosis; I feel normal now.' (Person with dementia about dementia café)

Feeling 'normal' is important to people with dementia because the condition can make them feel like they have lost their previous identity, that it has been replaced by one that is stigmatised. People attending group services felt accepted for who they are. 'I tell things here that I wouldn't be able to say to my family.' (Carer about peer support group)

'You feel safe to say what you want. I feel able to chat about dementia in this group. It's like a big family ... I can't speak about dementia outside; I'm able to let it all out at the club.'

Person with dementia about day support service

Being able to open up in different ways helps people to cope with the challenges they experience. 'You can share with everyone here. Not everyone can understand what we are feeling inside, but here everyone understands.' (Person with dementia about peer support group); 'You can talk to people who don't judge you the way others do.' (Person with dementia about peer support group)

Carers outline the specific benefits of being more connected: 'Talking to others going through the same thing can be a great stress reliever. We have laughed and cried together.' (Carer about peer support group); 'Telling our experiences often helps others think of other possible ways of dealing with things.' (Carer about peer support group); 'Knowing somebody else in the same situation provides me with motivation to continue.' (Carer about dementia café)

In summary, services enable people to come to terms with a diagnosis because they feel more connected, which gives them confidence and a sense of acceptance. This is often reinforced through being in contact with other people affected by dementia. This contact, particularly in group settings, enables people to talk more freely and share coping strategies with each other. This in turn helps them to cope better.

3. Personhood – having choice and control that can provide hope for the future

The previous themes have highlighted some of the common experiences but it is important to remember the diversity of preferences and interests that people have. These can change from day to day for an individual person as well as varying between different people.

Being aware of and open to this diversity is essential to delivering good person-centred care. People felt that Alzheimer's Society services enabled them to be themselves. 'It allows people to just be themselves.' (Person with dementia about dementia café); 'If I don't feel like socialising I can have some quiet time.' (Person with dementia about day support service); 'I did not feel pressured into engaging in activities which I don't wish at this stage.' (Carer about dementia support service)

'I prefer to solve my own problems and the [dementia support worker] respects that.'

Carer about dementia support service

Staff also encouraged people to have ownership over activities: '[We are] not just part of it but we are encouraged to help plan it and make suggestions.' (Person with dementia about Singing for the Brain®). Enabling people to be themselves and to have choices is important because it helps them to gain a sense of power: 'I realise I have choices now.' (Carer about dementia café); 'You gave me control and some power back.' (Carer about Dementia Adviser service)

The services help people to feel more confident and in control while living with dementia. This helps them to feel more positive about their future. 'It has built up my confidence in carrying on with life.' (Person with dementia about Dementia Adviser service); 'I am more confident about the future and more informed as to what help there is available.' (Carer about CrISP service); 'You know you are not on your own. It's about getting some hope.' (Person with dementia about dementia café)

'You have made me see I can have a life even with this condition. Without you I would be lost.'

Person with dementia about Dementia Adviser service

In summary, treating people as individuals and enabling them to exercise choices not only recognises their different needs but can help them to feel more confident and in control of dementia. Reinforcing personhood in this way gives people a sense of their own identity and greater independence. It is important in giving them hope that they can live well.

Conclusion

The feedback captured from people with dementia and carers who use Alzheimer's Society services highlights that these services are effective in supporting people to cope better with the challenges of dementia. The specific ways in which the services meet the needs and interests of people with dementia and carers are summarised below.

Navigation of available information and support

- People feel listened to and understood. They are directed to what they need at that particular time. Knowledge of how to manage the symptoms of dementia and additional support available is communicated to them. This enables people to have choices and remain active and independent.

Development of a sense of connection, free of stigma

- People feel connected and not alone. They are able to spend time with people who understand and do not judge them. This gives people the freedom to talk about dementia without fear of being stigmatised. This in turn helps them to share and to cope better.

Personhood – have choice and control that can provide hope for the future

- People feel that they can maintain a sense of who they are. They are supported to have choice and control over how they live their lives. This helps people to feel more confident about coping with the future.

Overall therefore, while dementia can pose significant challenges for both the person diagnosed and the people who care for them, with the right information and support people can live well.

Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.

If you have any concerns about Alzheimer's disease or any other form of dementia, visit **alzheimers.org.uk** or call the **Alzheimer's Society National Dementia Helpline** on **0300 222 1122**. (Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)

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43–44 Crutched Friars
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