



# ‘We are not alone with this diagnosis’

Connecting people affected by dementia to a network of support

**Alzheimer’s Society services evaluation 2017**



## Acknowledgements

We would like to thank all service users, operational staff and volunteers across Alzheimer's Society who contributed to this evaluation.

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# Introduction

**This report highlights the key findings from the Alzheimer's Society services evaluation 2017.**

It is based upon the views of more than 8,500 people who used our services between April 2017 and December 2017. It presents our findings on the experiences of people with dementia and carers who use our services. It particularly demonstrates how our services connect all these people to a network of support which improves their wellbeing, empowers their decision-making and provides them with continuity.



people who used Alzheimer's Society services took part in our **2017 services evaluation.**



of service users agreed that the **key outcomes of the services had been met.**



Alzheimer's Society services provide people affected by dementia with **a connection to a network of support.**



This connection enables **continuity of support, empowers decision-making and improves wellbeing.**

**'We feel very pleased to have someone to talk to and turn to for support and information. It is nice to know we are not alone with this diagnosis.'**

Carer talking about a Dementia Adviser service



# Our services

Alzheimer's Society provides a range of services across England, Wales and Northern Ireland. We currently offer services delivered on a one-to-one basis and group services. This section explains these in more detail.

## One-to-one services

**Dementia support services** offer practical support from a dementia support worker face-to-face, over the telephone or via written communication.

**Dementia Adviser services** provide support to understand key information around a diagnosis of dementia.

**Community support services** offer personalised one-to-one support to continue with daily living activities and to participate in leisure and social activities.

**Home care and support** offers assistance with personal care in people's own homes.

**Day support** provides care and support during the day in a safe and comfortable environment.

**Advocacy services** provide advocates who support people in their choices and rights. They also provide information and support to enable people to access services across providers.

**Befriending services** offer personalised companionship either in someone's own home or during outings and activities in the community.

**Side by Side** provides one-to-one support offered by volunteers by phone or face-to-face.





## Group services

**Dementia cafés** allow people to meet regularly and talk about living with dementia in an informal social environment.

**Singing for the Brain®** consists of structured group sessions which use music to encourage communication and participation. The sessions also include opportunities to talk to other people.

**Carer Information and Support Programme (CRISP)** provides carer information in a group environment where carers are able to share their experiences.

**Peer support groups** are facilitated sessions which provide the opportunity for sharing experiences and learning from peers in a safe, non-clinical environment.

**Activity groups** include both skill or interest-based activity groups (such as art and craft groups) and informal activity groups.

**The Live well with dementia programme** is designed for people living with the early stages of dementia. It helps them to develop the understanding, skills and practical tools needed to enable them to take an active role in the management of their own health and wellbeing.

As part of our strategy, **The New Deal on Dementia<sup>1</sup>** we have introduced a new service approach called Dementia Connect.

The new approach will give the same support offer throughout England, Wales and Northern Ireland. Through a single point of referral, support will be offered to anyone, from the point of diagnosis to later stages.

This report focuses on evaluation of our current service offer and looks at both one-to-one services and group services. A separate evaluation programme is being set up for Dementia Connect, which draws upon our current approach to evaluation of our services.

You can find out more about our services at [alzheimers.org.uk/info/20172/activities\\_and\\_services](https://www.alzheimers.org.uk/info/20172/activities_and_services)

# Our evaluation approach

Our evaluation approach is consistent with the approach taken for our 2016 services evaluation<sup>2</sup>. We have been developing and improving the approach over time, so the findings are not directly comparable year-on-year and trend data is not presented in this report.

## The approach is based on the following person-centred principles:

### Appropriate

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

### Ethical

We seek feedback from the person who directly uses the service. For people with dementia, we assume mental capacity and 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.

### Proportionate

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

### Meaningful

Questions are as straightforward and accessible as possible so as to elicit meaningful responses. People with dementia have told us they prefer 'yes/no/don't know' answer options to more complex scales.

We empower local staff to use their expertise to rephrase questions or probe as necessary. We collect data 'in the moment' to overcome some of the difficulties with recall.

Our services aim to achieve a number of outcomes for the people with dementia and carers that use them. The key outcomes we measured are listed below. The phrases in brackets indicate how the outcome will be referred to throughout the remainder of this report.

### In line with our key outcomes, we asked if service users felt:

- enabled to access useful information ('Information') – for example service users are asked, 'Has [the service] provided you with useful information?'
- enabled to have social contact ('Social contact') – for example, 'Are you able to socialise at [the service]?'
- supported by staff/volunteers ('Staff support') – for example, 'Do you feel that the [member of staff] understands your needs?'
- supported by peers ('Peer support') – for example, 'Do you feel able to share your experiences at [the service]?'
- enabled to live well ('Life better') – for example, 'Has [the service] made your life better in any way?'

Not all of the outcomes are relevant for each service, depending upon the service's aims. The way that the outcome is measured varies amongst services too. This means that the data is not directly comparable between the different key outcomes. For further details about which outcomes are measured for each service, see Annex A on page 13.

Alongside these service outcomes, we also gather feedback on how service users think that the service could be improved. This is used locally by the services themselves to inform service improvement.

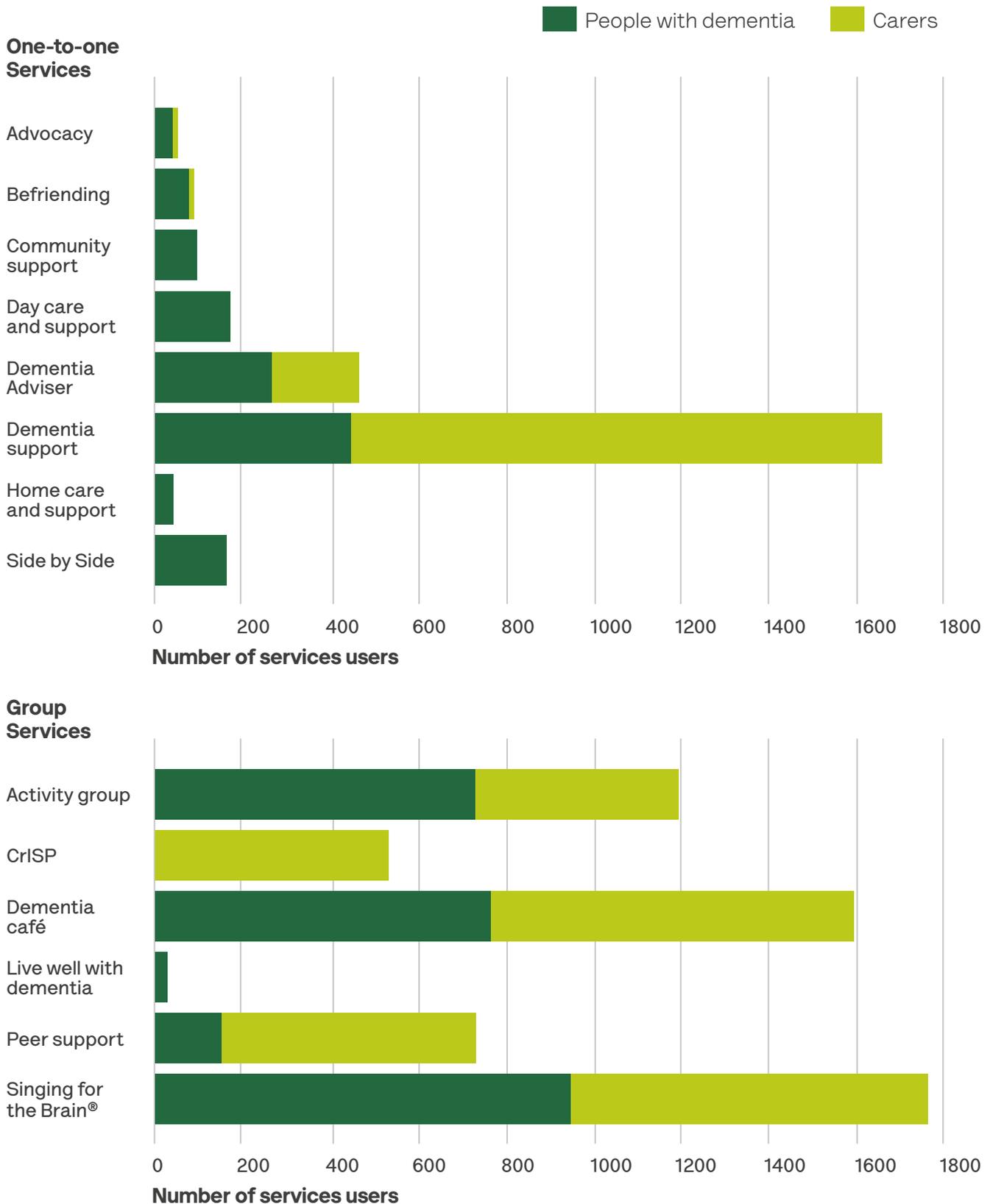
Our sampling approach recommends that for one-to-one services, a minimum number of service users per full-time equivalent member of staff are asked to participate in the evaluation. This is usually a minimum of six service users, but will vary by service. For group services, the guide is for a minimum number of groups to be evaluated per type of group – again this is usually six groups per type, but will vary.

2 [https://www.alzheimers.org.uk/info/20024/strategy\\_and\\_annual\\_reports/1074/evidencing\\_our\\_impact](https://www.alzheimers.org.uk/info/20024/strategy_and_annual_reports/1074/evidencing_our_impact)

## Service users involved in the evaluation

Between April and December 2017 we conducted our evaluation with 8,581 service users. This group was comprised of 3,939 (46%) people with dementia and 4,642 (54%) carers. The number of service users who gave feedback for each service type is shown below in Figure 1 and in Annex B on page 15.

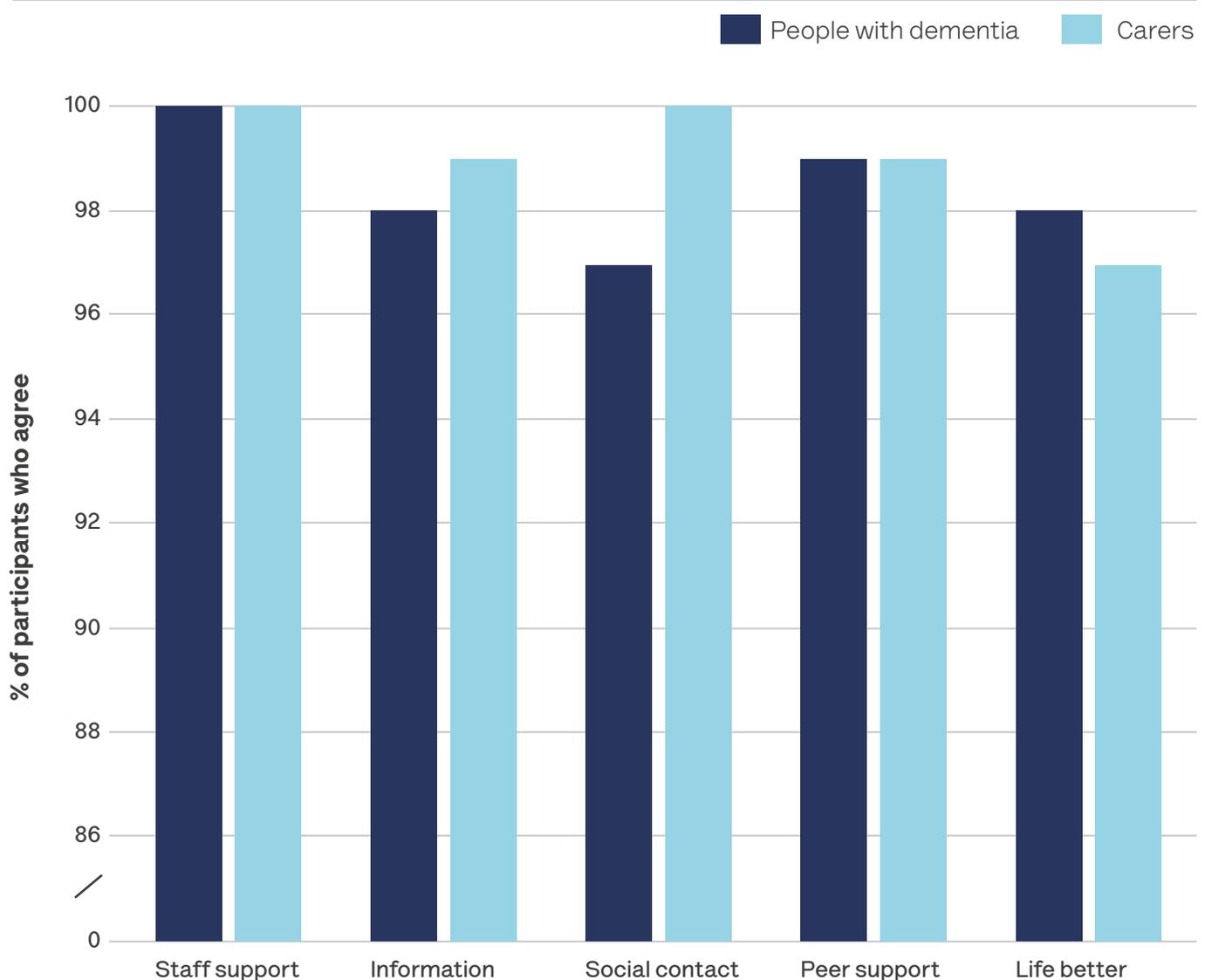
**Figure 1. Number of service users involved in evaluation (2017)**



# Our findings

Overall our findings are very positive. Figure 2 below demonstrates that for each of the key outcomes over 96% of service users agreed that the outcome had been met. This was the case for both people with dementia and carers.

**Figure 2. Percentage of participants who agree that key outcomes have been met (2017)**



To understand the responses in more detail, service users were asked to explain their response for each of the key outcomes. This data has been analysed to draw out key themes. These themes are similar to those identified in previous years, focusing on the importance of an empathetic approach and person-centred support. However, one strong, overarching concept was clear: that our services enable people affected by dementia to be connected to a network.

**Having a connection to a network through Alzheimer's Society services gives a person affected by dementia continuity of support, empowers their decision-making and improves their wellbeing. This happens in a variety of ways, as the remainder of this report will explore.**

## 1. Connection to a network that provides continuity of support

### People affected by dementia who use dementia support and Dementia Adviser services

These service users found comfort in knowing someone is there when they need support. They felt that Alzheimer's Society is an organisation they can trust and rely upon.

**'I feel secure and not alone. Some of the stress has been relieved and I feel I'm coping a bit better now. Just knowing [the dementia adviser] is there relieves some of the pressure.'**

Person with dementia talking about a Dementia Adviser service

**'If [the dementia support worker] wasn't able to answer she wrote the questions down in her notebook to come back to us later which she did. We've never been forgotten.'**

Carer talking about a dementia support service

**'It's not a service but a family. We are part of your family and you are part of ours.'**

Person with dementia talking about a dementia support service

### People affected by dementia who use volunteer-led services (Side by Side and befriending)

These service users said that the most meaningful aspect of the support they receive is the ongoing companionship this gives them.

This companionship is different from the other social and family connections they have. For some people with dementia it is their only social contact outside of their immediate family.

**'Unfortunately my husband died two years ago and my youngest daughter died unexpectedly last year and my other daughter is in Canada. It's nice to know someone's coming for a few hours, have a chat and get out. I enjoy it, she tells me things about her life and I tell her about mine – excellent.'**

Person with dementia talking about Side by Side

**'She understands me and makes me feel at ease. I can have a good chat to her about how I'm feeling. It's nice to have that time to talk. I go out shopping a lot more now and I enjoy doing that.'**

Person with dementia talking about a befriending service



## 2. Connection to a network that empowers decision-making

People affected by dementia told us that our services help them to feel informed about dementia, other services available to them and the social care system.

This includes providing practical advice which helps people to feel confident in the decisions they make – particularly carers. Feedback from service users suggests that staff working in dementia support, Dementia Adviser and CrISP services understand the varied information needs of services users. This enables them to tailor their approach to help people to navigate an often fractured support landscape.

**'I don't think I would have thought about, or known about, half the things like the singing group, and other activities, where to turn to for other help in the community and financial entitlements. It's helped my mental wellbeing. I think I could have had a breakdown otherwise.'**

Carer talking about a Dementia Adviser service

**'If I have a query I can ask [the dementia support worker] and she will help me out. I have nobody in the house to ask. It is good to have somebody to speak with rather than ask myself.'**

Person with dementia talking about a dementia support service

**'The service has provided enormous peace of mind and support in making decisions when providing for someone with Alzheimer's. It's good to know what is "normal" when your world is turned upside down.'**

Carer talking about a dementia support service



### 3. Connection to a network that improves wellbeing

**Feedback suggests that our services impact on various aspects of a person's wellbeing, enabling them to live well.**

**Side by Side, befriending, Singing for the Brain® and day support services support people with dementia in particular to continue the activities they enjoy. This helps them to regain their confidence.**

'I go cycling occasionally with other guys from the gym, but don't do it on my own as I get lost. My befriender means I can cycle more regularly and do longer routes.'

Person with dementia talking about a befriending service

'Since I have been receiving support from Side by Side, I have also now re-joined the Women's Institute which I used to be president for. I attend the meetings and go along with another friend who lives in the same block of flats as me.'

Person with dementia talking about Side by Side

'If I don't come here I don't really go out much, maybe just to the local shops and back, as I can't go much further. I have gained confidence to go out to the shops on my own now.'

Person with dementia talking about a day support service

**Dementia support, dementia cafés and CrISP increase people's ability to cope and reduce stress and anxiety.**

'When I first got diagnosed I was very scared of my future. Now I live well with dementia, taking every day as it comes.'

Person with dementia talking about a dementia support service

'I now have the tools to be able to deal with my diagnosis and tell people what is wrong with me. I feel empowered.'

Person with dementia talking about a dementia support service

'Yes just knowing that you are not alone makes me feel better. Having a chat and support makes my life easier. As a carer you also need time to relax so you are able to carry on with your caring role.'

Carer talking about a dementia café

**In some cases, people with dementia and carers felt that attending services where they can meet and converse with other people can provide some relief and distraction from day-to-day life. This improves their mood and makes them feel more positive about the future.**

'[Having] knowledge of what is available is empowering. [I] enjoyed meeting people. [It] moves you along in a positive way. [I] feel more confident to handle things. [It's] nice to know I'm doing things right!'

Carers talking about CrISP

'I feel that you understand me and I can talk to you about things. My mood is definitely better since we started this, and I can accept things and just get on with it now.'

Person with dementia talking about a befriending service

'I look forward to singing – it makes me forget any pain.'

Person with dementia talking about Singing for the Brain®

'I look forward to it immensely. I always leave with a warm good feel factor that lasts until the next meeting.'

Person with dementia talking about a dementia café

## Despite the support that Alzheimer's Society provides, a dementia diagnosis remains overwhelming and challenging.

**It is important to acknowledge that whilst the vast majority of service users saw value in Alzheimer's Society services, some people explained that no amount of support can make dementia go away, and felt that day-to-day life remains difficult for them. Whilst some find information empowering, others find it distressing to see what the future holds. There are differences in the emotional and information needs of our service users, and a dementia diagnosis can remain overwhelming and challenging despite the support we provide.**

“Better” is not the word I would use, but it has shone a light in what is a dark corridor.’

[Person with dementia talking about a Dementia Adviser service](#)

‘No it hasn't made my life better. My husband still has Alzheimer's.’

[Carer talking about a dementia café](#)

‘Sometimes it's really hard to think ahead when you have an emotional tie with [the person with dementia] and you also have to remember that there may be things that will happen in the future that you will have no control over.’

[Carer talking about CrISP](#)

## Conclusion

Overall for each of the key outcomes, over 96% of service users agreed that the service they received had met that outcome. Our analysis of service users' comments highlighted that by connecting with Alzheimer's Society, service users benefit from a network of support, information and companionship. This network enables them to cope better with the challenges of dementia in the following ways.

1. Providing continuity of support. Service users find comfort in knowing someone is there for them, and view Alzheimer's Society as an organisation they can trust and rely upon.
2. Empowering decision-making. The provision of timely information in a variety of formats helps people affected by dementia to understand the choices available to them, and feel confident in the decisions they make.
3. Increasing wellbeing. Through information provision, facilitation of activities and social contact in a supportive environment, services help people affected by dementia to feel more able to cope, reduce anxiety and feel more positive about the future.

Some of the respondents highlighted that whilst Alzheimer's Society services had been valuable to them, a dementia diagnosis remains overwhelming and challenging. This is an important reminder to us of the need to continually seek to understand the needs of people affected by dementia and to improve the services we offer. Our existing services evaluation approach, and the approach we are developing to evaluate the new Dementia Connect service, are a central part of how we gather evidence, learn and improve our practice.

# Annex A

## Making evaluation count: Service outcomes framework 2017-18



Service-level outcomes					
	I am supported by staff/volunteers (staff support)	I am supported by peers (peer support)	I have social contact (social contact)	I have access to useful information (information)	Service specific (service specific)
Services	Questions				
<b>Advocacy</b>	Do you feel that the advocacy worker understands your needs?			Has the advocacy service provided you with useful information?	Has the advocacy service given you a voice to say what you need to?
<b>Befriending</b>	Do you feel that the befriender understands your needs?		Does the befriending service help you to spend time with other people?		Does the befriending service help you to do the things you enjoy?
<b>Day care and support</b>	Do you feel that staff at the day centre are understanding towards you?		Are you able to socialise at the day centre?		Does the day support service help you to do the things you enjoy?
<b>Dementia Adviser</b>	Do you feel that the dementia adviser understands your needs?			Has the Dementia Adviser service provided you with useful information?	Is the Dementia Adviser service a useful point of contact?

Service-level Outcomes					
	<b>I am supported by staff/volunteers</b> (staff support)	<b>I am supported by peers</b> (peer support)	<b>I have social contact</b> (social contact)	<b>I have access to useful information</b> (information)	<b>Service specific</b> (service specific)
Services	Questions				
<b>Dementia support</b>	Do you feel that the dementia support worker understands your needs?			Has the dementia support service provided you with useful information?	Is the dementia support service a useful point of contact?
<b>Community support</b>	Do you feel that the community support worker understands your needs?		Does the community support service help you to spend time with other people?		Does the community support service help you to do the things you enjoy?
<b>Home care and support</b>	Do you feel that the home support worker understands your needs?		Do you look forward to the home support worker visiting?		Do you feel that the home support worker is reliable?
<b>Side by Side</b>	Do you feel that the volunteer enabled you to make choices?		Do you feel that you have more social contact? (not including with the volunteer)		Do you enjoy the activities that you do with the volunteer?
<b>Activity group</b>	Do you feel that staff at the activity group are understanding towards you?	Do you feel able to share your experiences at the activity group?	Are you able to socialise at the activity group?		
<b>Dementia café</b>	Do you feel that staff at the dementia café are understanding towards you?	Do you feel able to share your experiences at the dementia café?	Are you able to socialise at the dementia café?	Has the dementia café provided you with useful information?	
<b>Peer support</b>	Do you feel that staff at the peer support group are understanding towards you?	Do you feel able to share your experiences at the peer support group?	Are you able to socialise at the peer support group?		
<b>Carer Information and Support Programme (CrISP)</b>	Do you feel that the community support worker understands your needs?	Did you feel able to share your experiences during CrISP?		Did CrISP provide you with useful information?	Through attending CrISP, do you feel more able to plan with and for the person you care for, now and in the future?
<b>Singing for the Brain®</b>	Do you feel that staff/volunteers at Singing for the Brain® are understanding towards you?		Do you feel part of a group at Singing for the Brain®?		Does the community support service help you to do the things you enjoy?
<b>Live well with dementia</b>	Did you feel that the staff/volunteers at Live well with dementia were understanding towards you?	Did you feel able to share your experiences during Live well with dementia?		Has the Live well with dementia service provided you with useful information?	Through attending Live well with dementia, do you feel more confident?

# Annex B

Table 1: Number of service users involved in evaluation (2017)

	Number of people with dementia	Number of carers
<b>One-to-one services</b>		
Advocacy	42	2
Befriending	80	5
Community support	91	0
Day care and support	168	0
Dementia Adviser	269	197
Dementia support	452	1214
Home care and support	35	0
Side by Side	159	0
<b>Group services</b>		
Activity group	731	465
CrISP	0	536
Dementia café	773	826
Live well with dementia	33	0
Peer support	155	582
Singing for the Brain®	951	815

**We are the UK's leading dementia charity.** Every day, we work tirelessly to find new treatments and, ultimately, a cure for dementia. We provide expert information, training, and support services to all those who need our help. And we are creating a more dementia-friendly society so people with the condition can live without fear and prejudice.

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