Alzheimer's & Dementia
SUPPORT SERVICES

Evaluation of the impact of our services

April 2021

Report produced by Denise Kilshaw (Dementia Support Manager) and Sarah Taylor (Joint CEO)

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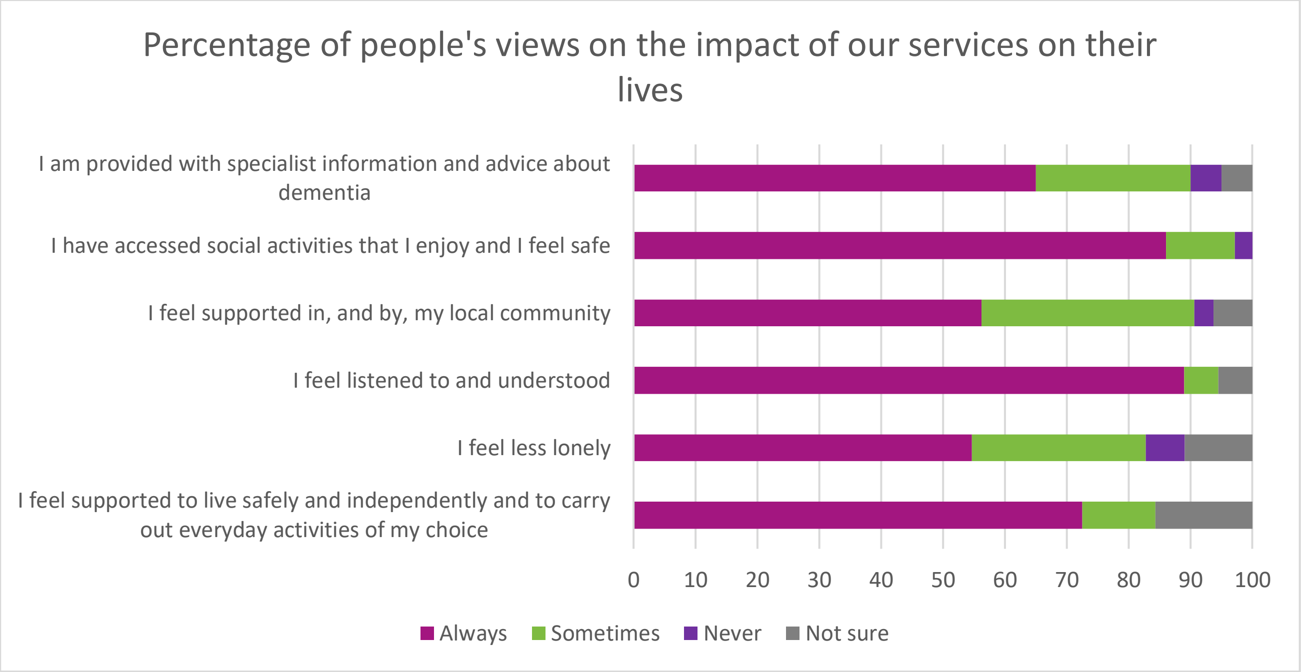
Summary

Almost one million people in the UK are living with dementia[1], and the majority of these are over the age of 65 years and living with other health conditions. There are estimated to be 23,940 people over the age of 65 living with dementia in Kent[2]. Living with dementia can bring challenges for the person with dementia and those around them; Alzheimer's and Dementia Support Services provides a variety of services to support people throughout their experience of dementia. We carried out a Pilot Evaluation Project to help us understand the impact our services have and to help us determine how we will evaluate our services on an ongoing basis. A total of 79 people took part in the survey (32 people with dementia and 47 carers or relatives). The evaluation consisted of a 1-2-1 discussion with a member of the relevant team. Wherever possible, the discussions took place face-to-face, otherwise they were carried out over the phone or by video call. The discussions were focussed on the specific service being accessed; however, we also held some discussions that reflected the person's overall experience of the Charity where they access multiple services. The key findings throughout the evaluation addressed 6 broad 'I' statements as follows:



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[1] Prince, M et al. (2014) Dementia UK: Update Second Edition report produced by King's College London and the London School of Economics for the Alzheimer's Society

[2] Wittenberg, R et al. (2019) Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040

1. I am provided with specialist information and advice about dementia.

65% of people we spoke to said that they feel this way ‘always’. Only one person stated that they ‘never’ feel this way, however they did add that their partner had thrown away the information that had been provided.

2. I have accessed social activities that I enjoy and I feel safe.

86% of people we spoke to said that they ‘always’ feel this way. Only one person stated ‘never’, but had explained that their relative would prefer not to have the service as they lack the insight into the help they need, therefore cannot say they enjoy it.

3. I feel supported in, and by, my local community.

56% said that they ‘always’ feel this way. We received lots of feedback showing that people took this statement to refer to the wider community, as opposed to the community created within our services. Whilst some people talked about supportive friends and neighbours, others felt there is a lack of understanding and empathy in the general community. Many people commented on how they feel part of a community within the support groups they access.

4. I feel listened to and understood.

89% of people stated that they ‘always’ feel this way when accessing our services. Comments about the staff they have come into contact with were very complimentary and included words such as empathetic, sympathetic, informative, comfortable, attentive, supportive and responsive.

5. I feel less lonely.

55% of people said that they feel this way ‘always’. Those that only feel this way ‘sometimes’ or ‘never’ explained that, whilst they may not feel lonely in the moment of accessing the services, at other times they do still experience loneliness. A few people commented on how living with dementia can make them feel lonelier because of the challenges it brings and the lack of understanding.

6. I feel supported to live safely and independently and to carry out everyday activities of my choice.

73% of people told us that they ‘always’ feel this way. Many people commented on how the COVID-19 pandemic had restricted their choices, for example those in receipt of Support at Home were going to lots of places of interest beforehand but then had to stop due to shielding.

Conclusions

It is clear from the feedback received that our services have had a very positive impact on people. The majority of people answered ‘always’ when asked if they feel safe, supported, listened to, and understood. The majority of people also answered ‘always’ when asked if they are provided with specialist information and advice and have been able to access their choice of activities. In cases where people stated ‘never’, they gave reasons that would be beyond the services’ control. Wherever the people taking part referred to individual staff members their comments were extremely positive.

With regards to the evaluation process itself, most people found the process simple. Constructive feedback was provided, and this will help inform how we undertake our organisation-wide evaluation in the future. It was clear that face-to-face evaluation discussions were key to ensuring a positive experience.

Background

Around 850,000 people in the UK are living with dementia, and the majority of these are over the age 65 and living with other health conditions[3] There are estimated to be 23,940 people over the age of 65 living with dementia in Kent[4]. On average, ADSS supports 580 people each month.

Alzheimer's and Dementia Support Services (ADSS) is Kent's biggest independent charity dedicated to providing support to people affected by dementia. Working within the Dartford, Gravesham and Swanley area since 1991, ADSS provides a range of services including information and guidance, community support and activity groups, 1-2-1 support in people's own homes, and day support. The services provided aim to ensure that those diagnosed with dementia feel supported throughout their experience of dementia and can live the life they want. They also aim to ensure that family members, or others involved, are supported. This report describes the findings from evaluation discussions undertaken throughout March 2021 between ADSS staff and people that use the services, looking at the impact of these services on people living with and affected by dementia. ADSS has always valued the feedback of those it supports, however evaluation methods have been sporadic.

It is important to be aware that at the time of this Evaluation Pilot we had been working within the restrictions brought about by the COVID-19 pandemic. This meant that some services could not be evaluated as they had not been able to run in their usual way, for example Memory Cafes and Peer Support had been merged into regular virtual support groups. This also meant that, whilst our preferred method of facilitating evaluation discussions would have been face-to-face, it was not always possible to do it this way therefore we had to sometimes opt for phone calls or video calls.

A working group consisting of Joint CEO, Dementia Support Manager and Dementia Care Manager designed the evaluation questionnaires based on their combined experience and knowledge of conducting this process. It was a key priority to ensure that those living with dementia could actively partake in the discussions, offering a combination of minimal multiple-choice responses, and the opportunity to speak freely was identified as the most enabling method. However, it was also identified that a lot could be learnt about the accessibility of the evaluation process through this pilot hence additional questions about the evaluation itself were added. The 'I' statements were based on the draft outcomes proposed by Kent County Council (KCC) in their Dementia Wellbeing tender.

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[3] Prince, M et al. (2014) Dementia UK: Update Second Edition report produced by King's College London and the London School of Economics for the Alzheimer's Society

[4] Wittenberg, R et al. (2019) Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040

Aims of the Pilot Evaluation Project

The project aimed to answer two broad questions:

1. How do the services we provide impact on the people we support?
2. How should we evaluate our services on an ongoing basis moving forward?

How did we gather people's views?

To explore these questions in detail we conducted evaluation discussions with those affected by dementia (either a person with dementia or a carer or relative) that have accessed our services. In total, 79 people (32 people with dementia and 47 carers or relatives of those with dementia) gave us their views by taking part in a 1-2-1 discussions with a member of the relevant team. The discussions took place face-to-face, wherever possible, or otherwise over the phone or by video call.

Who took part in our evaluations?

Of the 79 people who took part, 32 (40%) were people with dementia, and 47 (60%) were carers or relatives. We asked 59 people how long they had been accessing our services; 18 said less than 6 months; 12 said 6-12 months; and 23 said longer than a year; 6 were not able to recall the length of time. Seventeen people had found out about the service they were evaluating through health services, such as their GP and the Memory Service; nine people used an online search or saw a leaflet; twelve people were by word of mouth or by attending our Community Café; eleven were told about us by a family member; and the remainder were by other local organisations, were already involved in our services, or were not sure.

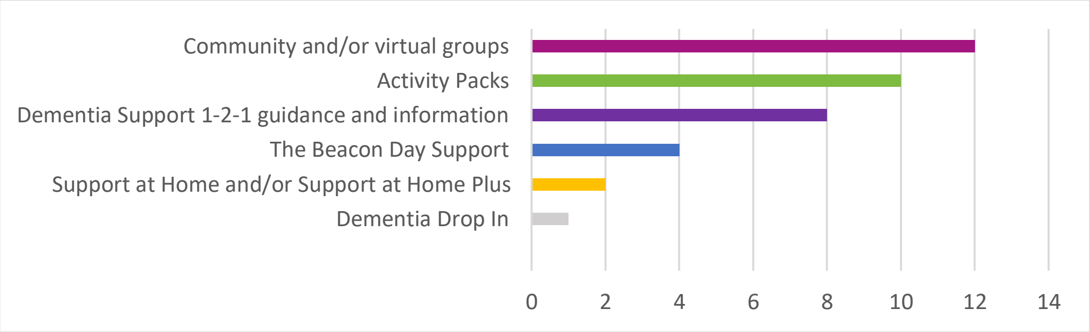
Interpreting the findings

Selection of those invited to take part was carried out by the relevant service's managers to ensure that those invited had accessed the service recently and could therefore provide current feedback. This, added to the preference of this pilot to carry out evaluation discussions rather than offering forms to be filled in, limited the number of people involved. 14% of the average number of people supported each month by ADSS took part.

Although carers or relatives are not directly supported through The Beacon, Support and Home or Support at Home Plus services they were invited to take part in evaluation discussions so that the impact of this support on their caring roles could be measured. They could also provide feedback regarding their observations of the impact on the person with dementia.

What did people tell us about their overall experience of our Charity?

Twelve people (three people living with dementia and nine carers) took part in discussions about how they feel the Charity as a whole has impacted on them. Eleven of those people have been accessing our services for longer than a year, and one had been accessing our services for 6–12 months. Eleven people accessed our services due to receiving a diagnosis of dementia, either for themselves or the person they care for, and one person accessed our services because they were having difficulty coping. Between them they have accessed several services that we offer:



Seven people felt that they 'always' receive specialist information and advice about dementia, and four people felt that was 'sometimes' the case. One person felt they had 'never' received specialist information and advice about dementia, however upon further discussion we were informed by that person that they had been given an information pack but the person living with dementia had thrown that away. People commented that information has been provided that they could refer back to, and they could contact us as and when they needed further information. Another person stated that they felt the COVID-19 pandemic had impacted on them being able to access information and advice through the usual support groups.

"There is always someone to talk with to get needed information."

Eleven people stated that they have always been able to access activities that they enjoy and feel safe doing; one person did not answer. All twelve people had lots of positive things to say about the activities they've accessed using terms such as 'feeling relaxed', 'fun', 'enjoy', 'safe', 'supportive', 'sharing', and 'company'. Many people explained that being with people in a similar situation, and having activities tailored for those with dementia, was an important part of what we provide. One person queried who the Memory Cafes and Support groups are aimed at, was it the person with dementia or the family carer, and this is understandable as they are for both.

"In lockdown it has been a God send."

When asking if people feel supported in, and by, their local community, five people stated 'always'; and seven stated 'sometimes'. Some people referred to the area where they live, and specifically the support, or lack thereof, from their neighbours. However, others talked about feeling part of a community within the support groups we provide.

“The sessions you offer, without we would feel abandoned and isolated. We’ve made friends within the groups.”

Nine people ‘always’ feel listened to and understood; two people feel that way ‘sometimes’; and one person ‘wasn’t sure’ how they felt. All comments about the support provided by us were positive; one person stated that we pick up on how they are feeling as well. There were a few further comments demonstrating how we take this a step further by offering support and taking action.

“I'm not necessarily that vocal anymore but people will listen to me in a nice way.”

When asking if people feel less lonely, we received a mixed response with six saying ‘always’; three saying ‘sometimes’; and two saying ‘never’; one person did not answer. All further comments regarding our services were positive, all demonstrating that people would feel lonelier if they were not accessing our services. However, even with services such as ours, people do still experience loneliness because of their situation, for example coping with the carer role or coping with the challenges that dementia brings.

“I feel very lonely and emotional at times. I very often sneak into the other room to have a good cry.”

“If it hadn't of been for ADSS doing the virtual singing back the memories we would have been quite lonely (during COVID pandemic). In very difficult times ADSS acted quickly in a very difficult time. We have support from other service users we have become friends and ADSS is the link.”

Eight people ‘always’ feel supported to live safely and independently, and to carry out everyday activities of their choice. Two people stated they feel that way ‘sometimes’, and two people were ‘not sure’. Carers that responded generally felt this statement was more aimed at the person with dementia, however a couple did add that they have been able to ‘get things done’ whilst the person they care for attended our services. 1 person living with dementia specifically talked about the support her husband gives her which helps her in her own home, others talked about how they enjoyed attending services and how they feel they could get help if they needed it.

“John couldn't live independently, but it helps me to care for John myself. In normal time I was able to drop John off and do my shopping, with peer support, very helpful for John and myself.”

We then asked what difference accessing our services had made to their lives; all responses were very positive. Responses included increased confidence, opportunities to meet others in a similar situation, development of friendships, ability to cope with the diagnosis, and ability to do things they enjoy.

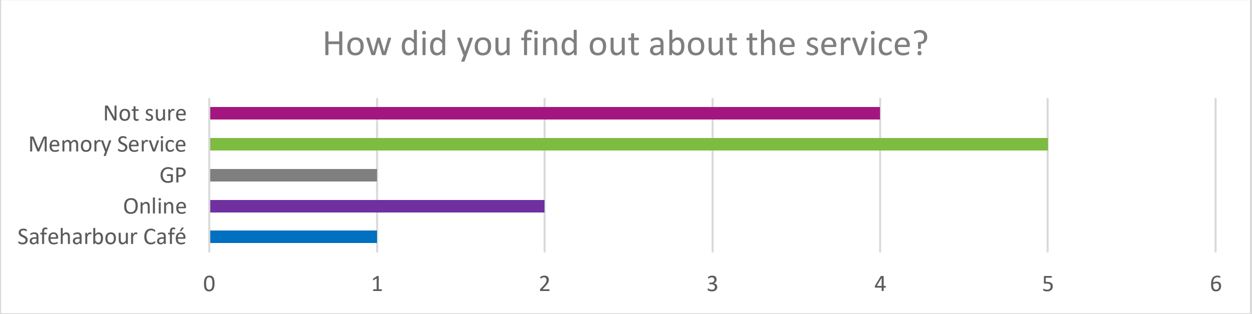
“I like to meet people and be friendly and has made me happier. I like to help people, I like that I can do different things I liked going on the boat and playing different games and caring for the others. I enjoy the singing the best.”

Lastly, we asked for any other comments about our services, and again responses were extremely positive. There was a common theme of how friendly and supportive people feel we have been; one person stated that we have helped them more than any other organisation. However, there were also a couple of constructive comments for us to take on board which we will explore further in this report.

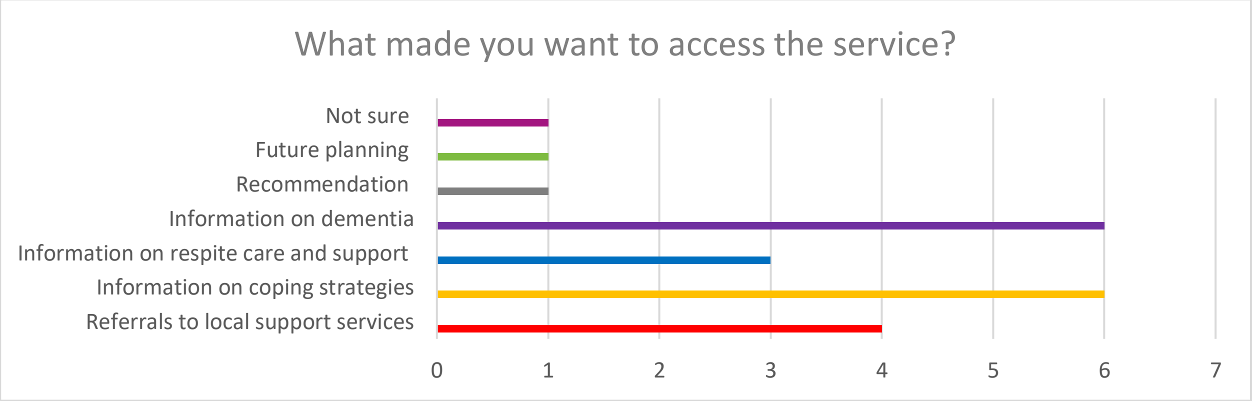
> **"Everything has been good, we have been very happy with all the help we have received over the years, ADSS has helped us more than any other organisation."**

What did people tell us about their experience of Dementia Support?

A total of fourteen people were asked to take the survey. This consisted of four people living with dementia and nine carers or relatives; one person chose not to take part.

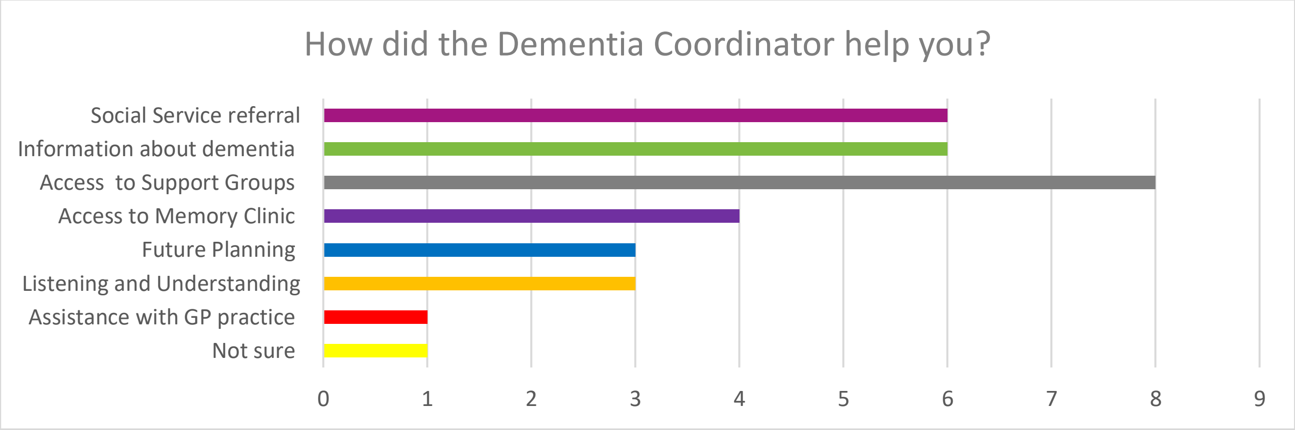


It became apparent, when selecting people to take part, that people who had recently used the service were able to give more detailed feedback of the help they had received from the team. We also concluded that some people who were in crisis, such as returning home from hospital, were unable to identify the specific support we provided as there were several agencies involved at the same time.

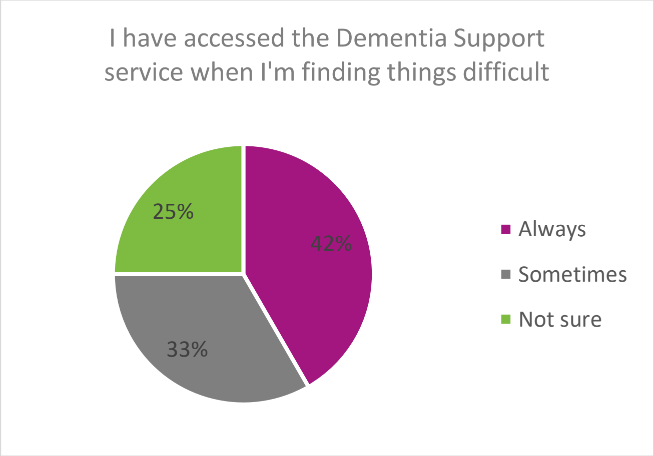


Out of thirteen responses, nine people stated they had been provided with specialist information; two people said 'sometimes'; and one person was 'unsure'. The responses indicate that people are receiving the information they require, whether it be about the types of dementia, symptoms and behaviours, or practical advice. Information had been shared by email, post and follow-up calls. The responses evidence that people accessing the service felt supported and were given good information at the time they needed it. The Carer's Learning Group was also mentioned as a valued source of information.

“The Dementia Coordinator helped me understand the behaviours of dementia that can happen, it helped me to understand the way my mum behaves better and how I could maybe help her. It was nice to have someone there for me.”



Ten people expressed they ‘always’ feel listened to and understood; one person said ‘sometimes’; and one person was unable to answer. Twelve people stated the Dementia Support Coordinators ‘always’ understand how dementia impacts on their life; one person was ‘not sure’. People told us they felt able to call with any issues to get help and support, and people did not feel so alone when having to deal with the challenges of dementia.



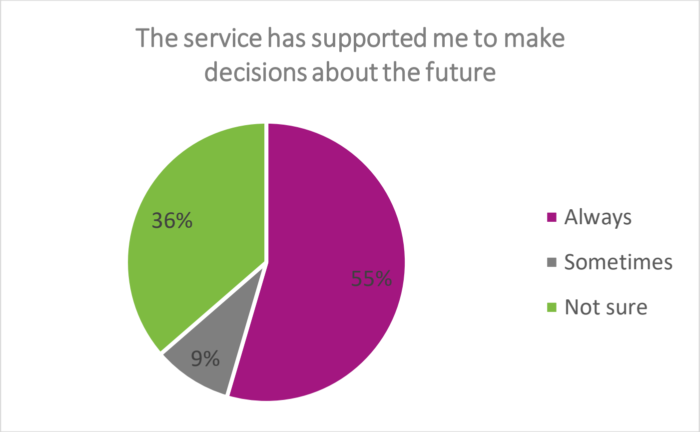
“The Dementia Support Coordinator tries to support all aspects, help by getting through day to day issues, makes me calmer.”

“The assessment the Dementia Support Coordinator completed gave my mum a chance to talk herself instead of just me explaining how life is. That is nice because my mum is still a person, and she may not understand everything but at least she was given a chance.”

The people we surveyed told us the service has assisted them in a range of ways, such as arranging reviews with the Memory Clinic, liaising with health and social care professionals, hospital discharge planning, and information on benefits and paying for care.

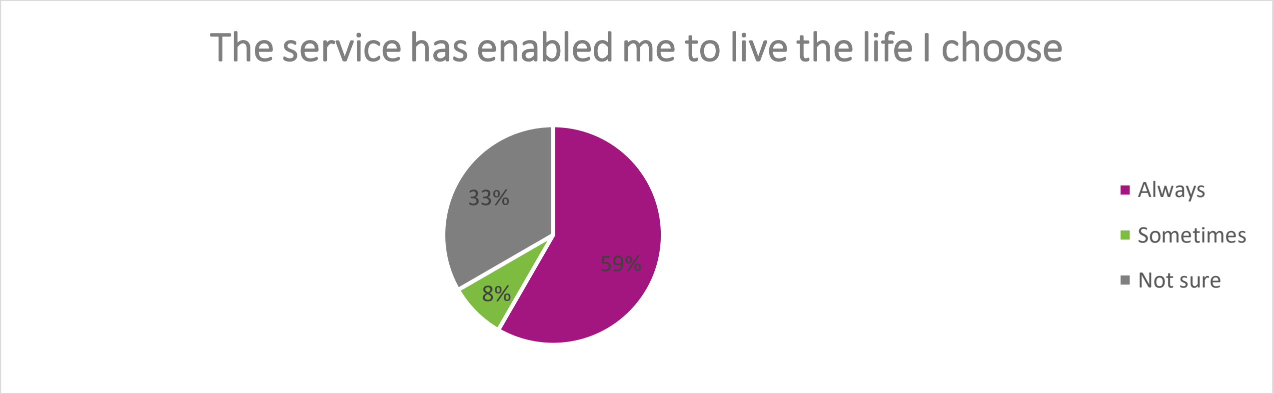
“After we got the diagnosis, we were just handed leaflets, just didn't know what to expect and by getting in touch with you really helped me understand and helped with how to cope in different situations.”

We asked those living with dementia, and their carers or relatives, how the service had helped when planning for the future. People told us they received help and support to arrange medical procedures and their transport to and from the hospital, arrange support for family members, including children's services. People found our assistance particularly useful at point of hospital discharge, having a point of contact for help and knowing about other local services. The information and support have given people the confidence to plan ahead.



"100% help, I feel I couldn't have made the plans without their input, it's new to me, you are the professionals."

"Power of attorney was explained to me and made me understand the need to get it done and that's done now."



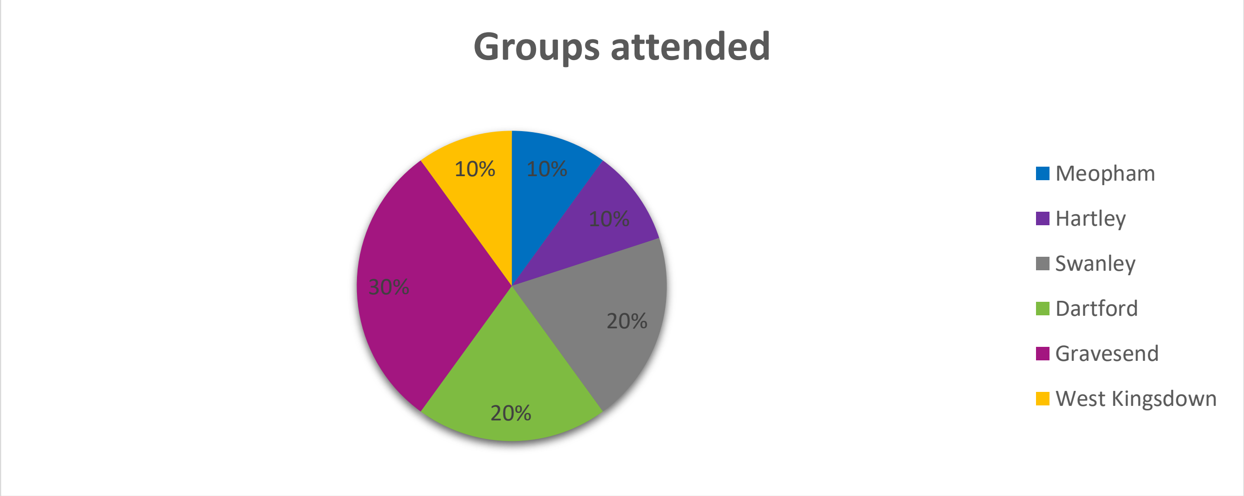
"The Dementia Support Coordinator helped with suggestions in appropriate care or social support for my mum whilst I am at work. It has been difficult looking after mum, working and taking care of the kids. But a referral was made to social services to see how they can help me."

Over half of the people who completed the survey expressed that they had benefited from accessing the service**.** Having a point of contact and someone to talk to that understands has proved to be valuable. Social groups have prevented people from feeling isolated and have given a sense of belonging. Digital technology has played an important part in keeping people connected at a crucial time. Having an advocate onside has helped people to overcome challenges and keep positive. The responses indicate that people accessing the service gained a better understanding of dementia and the impact on daily life.

"Helped me through this terrible time, I know I'm not what I was, I love talking to you."

What did people tell us about their experience of Virtual Support Groups?

A total of fourteen people were asked to take part in the survey; seven were carers or relatives; and six were people living with dementia; one person chose not to take part. Over half of those attend more than one support group in a month; three people had attended three different groups in the month. We asked how people had heard about the virtual support groups; nine had been invited by the Dementia Support Coordinator; three had been told by friends; and one person had been informed by his GP.

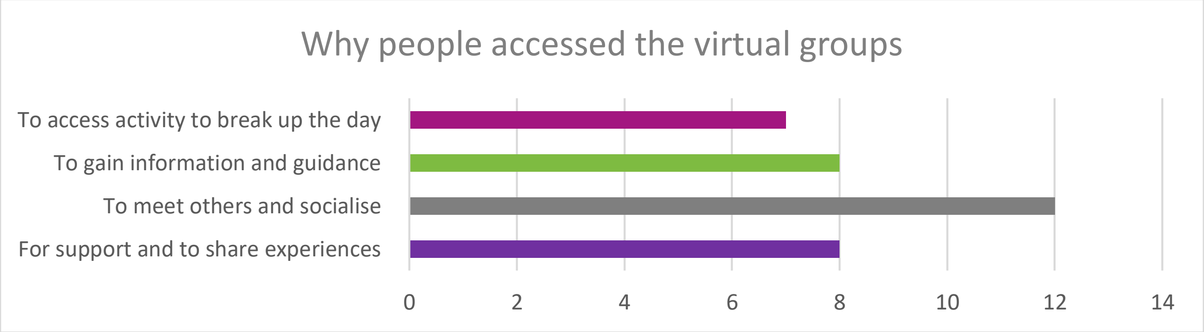


Nine people received support from the Dementia Support Coordinator in using Zoom; two people did not need help; and two people did not think the question was applicable to them.

"When we have had difficulty accessing the groups or dealing with mute/unmute, putting the camera on! the DSC's have been great as well as the other group members."

Most of the people attending the groups felt the coordinators have a good understanding of how dementia affects daily life. One person living with dementia was 'not sure', and one carer or relative stated they feel the groups are aimed at the person with the diagnosis.

"The fact they are there makes a difference and helps me with making friends. The staff give good advice, although this is not one to one. I think I could ask for their time if I needed it. I find the team have a really good understanding of what's going on."

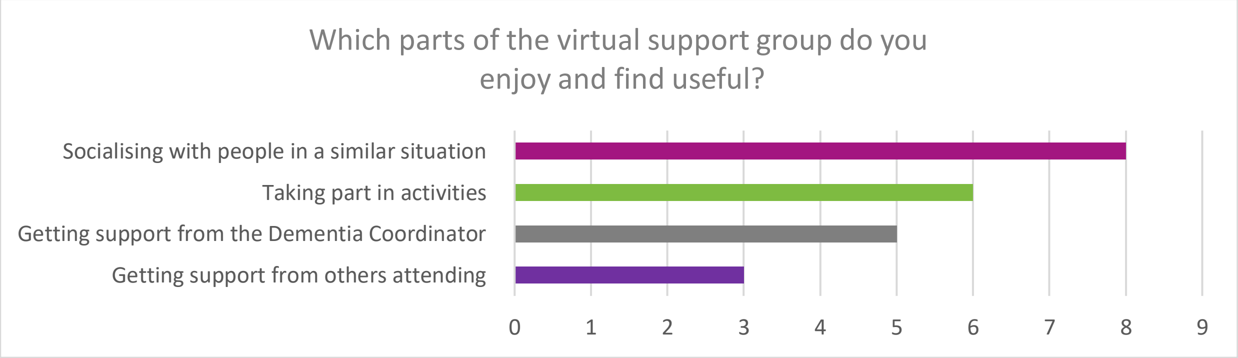


Ten people stated they ‘always’ felt listened to and understood; whilst one carer said ‘sometimes’, but went on to say, ‘I can always call them if I need to talk’. One person living with dementia ‘wasn’t sure’. Ten people also ‘always’ feel included and an equal member of the group; one person stated they ‘sometimes’ feel this way, and further explained that sometimes it’s hard to get a word in over the more outgoing group members. One person stated ‘never’; however, they then explained the reason is that they choose to step back to enable their partner to be independent within the group.

We received a mixed response when asking if people feel less lonely. Seven people confirmed that is this case; one person said ‘sometimes’; and one said ‘never’, however, they then further explained that they have never felt lonely. Three people remained ‘unsure’.

“Getting dementia has been a barrier to communication as the dementia develops, I feel more lonely, but feel the group helps.”

“People do start distancing themselves from me but nice to have people who share similar issues.”



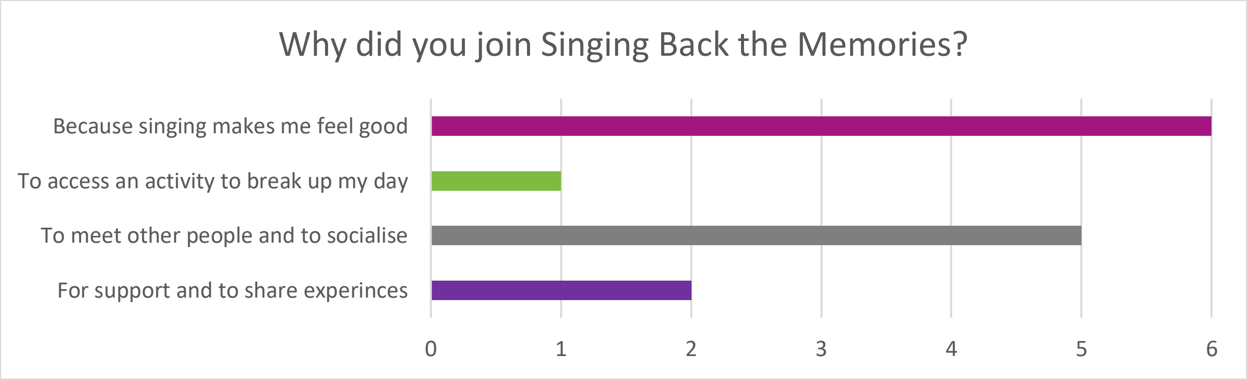
We asked people to tell us what difference the virtual support groups had made to them. Everyone that answered felt they had benefited from the groups and felt involved. People were grateful for the opportunity to share with others and make new friends; the groups were something to look forward to and break up the week when being unable to get out. One person commented that they prefer the virtual groups as they are much easier to access and hopes that we will continue with them in the future.

“The groups helped people to stay connected at a crucial time. It's part of my week and the feeling of being involved.”

“Having the virtual groups has made lockdown a lot more bearable and given my wife something to look forward too. Having contact with others in a similar position helps us to know we are not the only ones having to deal with this problem.”

What did people tell us about their experience of Singing Back the Memories?

Eight people (three people living with dementia, and five carers or relatives) took part in discussions about Singing Back the Memories. The most popular reason for attending is because singing makes them feel good, however they are also looking to be able to meet others and socialise.



Everyone that took part stated that they always feel listened to and understood by the Group Coordinators and volunteers. They also all stated that they always feel included and an equal member of the group. When we asked if they feel the Group Coordinators and volunteers understand how dementia impacts their life, seven people stated ‘always’; and one person stated ‘sometimes’, however they went on to say that they can`t really remember who the coordinator is but was sure they do.

“The way the facilitators communicate and speak to people, even when a person says something that may not be appropriate, its ok, it’s no big deal. They encourage and involve people to have a nice time.”

“They always ask me how I am and stuff. I do not remember their names but I recognise their faces.”

“[The facilitator] always asks us if there are songs we want to include, she will tailor the sessions around her audience for instance, my mum is Welsh and so she will include a Welsh theme, another person that attends loves Buddy Holly and so there will be something for everybody.”

We then asked if, since attending the group, did people feel less lonely. Five people said ‘always’; one person said ‘sometimes’; and two people were ‘not sure’. There was no explanation for why people do not always feel that way, however one person stated that they look forward to attending.

“My mum loves the groups and looks forward to them. She loves seeing people and having a sing song..... it makes her feel like she's had a trip out!”

“Being part of the group lifts our spirits in lots of ways, its an opportunity to join in to have some fun as a carer and a person living with dementia.”

When we asked people if attending Singing Back the Memories has made them feel more confident and improved their wellbeing, seven people stated ‘always’; and one stated ‘sometimes’. Seven people also said they ‘always’ enjoy Singing Back the Memories and feel safe when attending; one person said ‘sometimes’, and further explained that they enjoy listening to music.

“I am always happy after the singing and my mood is relaxed.”

We asked people what difference attending Singing Back the Memories had made to their lives. One person said that they feel less isolated, and another person said they feel they have come out of their shell a bit.

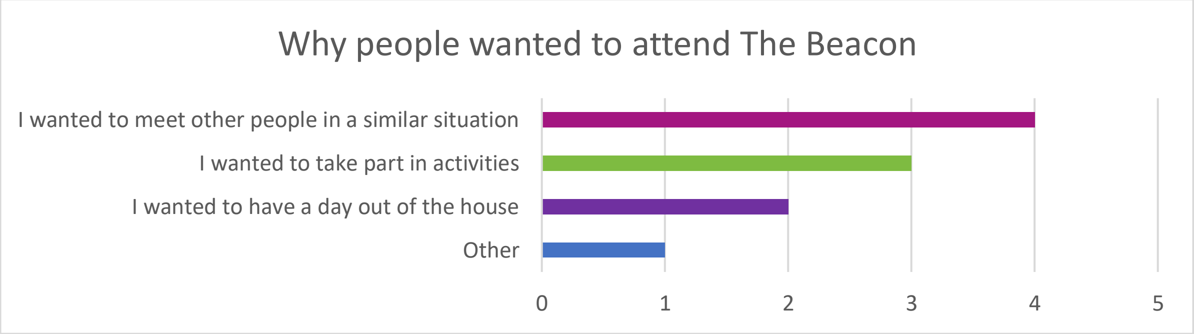
“This is invaluable to my mum, the session brings her alive, in a way it wakes her up, she is always happy and feels good after the group.”

“I really enjoy singing so I have enjoyed this and seeing other people …. especially being part of a concert!”

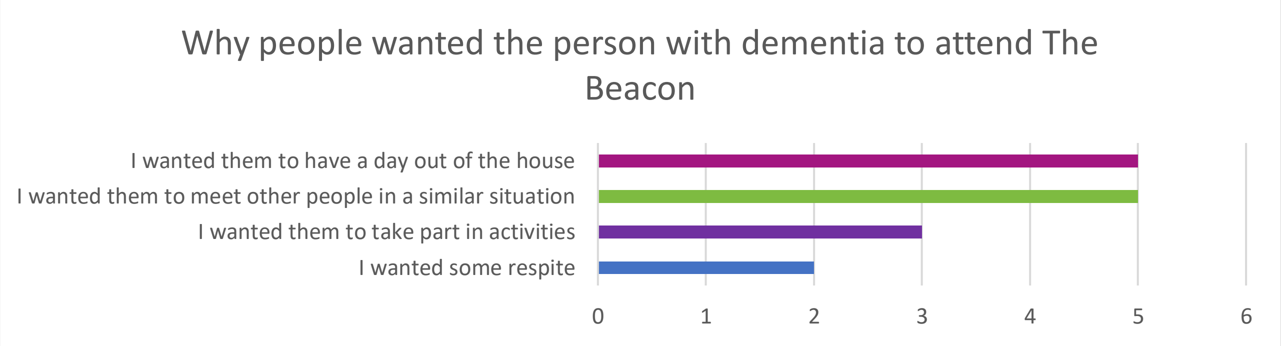
What did people tell us about their experience of The Beacon Day Service?

Ten people (five people living with dementia, and five carers or relatives) took part in the evaluation discussions. One of those had been accessing The Beacon for less than 6 months; three for between 6 and 12 months; five for longer than one year; and one person was not sure. Three of those living with dementia also access our Support at Home or Support at Home Plus service, and one attends the community support groups.

When we asked why people wanted to attend The Beacon, they were able to select more than one option, however the most popular response was to meet other people in a similar situation.



We also asked carers and relatives why they wanted the person they support to attend The Beacon; they agreed it was mainly for them to be able to meet other people in a similar situation, however, equally they thought it would be good for them to get out of the house.



All ten people stated that they ‘always’ feel listened to and understood by the staff they have contact with. All five people living with dementia stated they ‘always’ enjoy attending The Beacon; four carers or relatives agreed, but one was ‘not sure’ about the enjoyment of the person they support. When asked if they were offered choices in activities, all five people living with dementia stated ‘always’; three carers or relatives also stated ‘always’; but two were ‘not sure’. However, all five carers or relatives stated they ‘always’ feel that the person they support enjoys the activities and is able to do them in a safe place. All five people living with dementia agreed. When we asked about loneliness, four people living with dementia stated they feel less lonely due to attending The Beacon, whereas one person stated they ‘sometimes’ feel less lonely. However, three of the carers or relatives stated they believed the person with dementia was ‘sometimes’ less lonely; one stated ‘always’; and the other ‘wasn’t sure’. Three people living with dementia felt that attending The Beacon helped them to feel part of the community; one said ‘sometimes’; and one ‘wasn’t sure’. Three carers or relatives stated that they ‘always’ feel that, by the person they support attending The Beacon, it made them feel part of the community, and gave them the time to do activities they would otherwise find difficult; one felt that way ‘sometimes’; and one ‘wasn’t sure’.

“I like to be listened to and the staff do listen. Meeting different people and talking about their problems and my problems. I always feel safe here.”

“Everything! from the bus ride to my whole day at The Beacon. Val's quizzes and the banter. Can I do more days? Just being with us all makes me feel very safe.”

“Mum always enjoys it as you can tell from her face and she wouldn't go in so happily if she didn't want to. She doesn't remember it but is happy in that moment.”

“Thursday is the only day of the week I really get peace of mind. I know he is safe and enjoying company. He is also keeping his brain active. I feel I can breath easy on Thursday.”

We asked those living with dementia what difference attending The Beacon had made to their lives; they explained it gave them the opportunity to meet other people which they feel is nice. One person stated that it helps to talk, and another person stated it had made them happier. When we asked the carers or relatives the same question, they explained that it gave them the time to get things done, gave them a day where they don’t have to worry about the person they support and gives them a break. We asked if there were any improvements that could be made to The Beacon, most felt none were needed, however one person asked for more musical activities; and one person asked for more help with crossword clues.

“I would just like to say thank you from me. [The person I support] has always been happy with ADSS.”

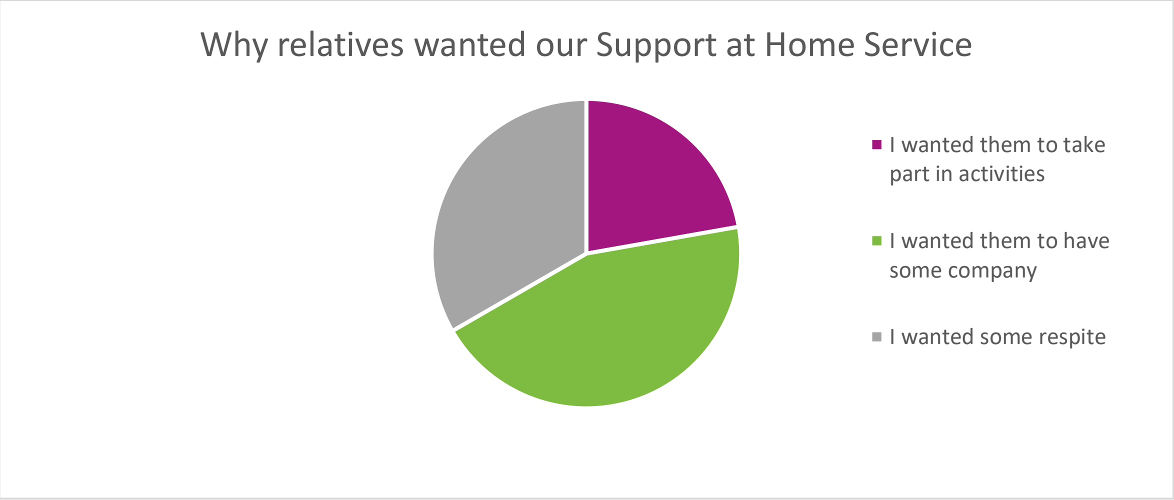
“I am very happy here.”

What did people tell us about their experience of Support at Home?

Ten people (six living with dementia, and four carers or relatives) took part in evaluation discussions. Most have been accessing the service for less than 6 months, and one person for longer than a year. Two of those people stated that they do not access any other forms of support; the remainder informed us they are also supported by family and other voluntary organisations. Two people stated that they also have care workers for support with daily living, and another person recalled being very impressed with our Dementia Support service which had made contact following the diagnosis.

“Girls are all nice, best having them with me, we laugh, walk around the garden, we do exercise.”

When asked why they wanted to access this service, one person stated that they wanted some company; another said it was to give it a try; and three people informed us that their family encouraged them. When we asked relatives the same question, most were looking for their loved ones to have some company. One person also told us it was to make sure the person was OK if they weren’t able to visit themselves; another referred to working full time and not being able to visit as much; and another person felt it would help ensure safety and for regular feedback.



Nine people felt that they are ‘always’ listened to, and that their dementia and individual needs are understood. One person ‘wasn’t sure’, but did state that her care worker sympathises, and they feel she understands but are not sure how much. Nine people stated that the visits are always enjoyed; one person stated their loved one enjoys the visits ‘sometimes’ but would rather be independent. Seven people informed us that there is ‘always’ a choice in activities, whereas three people stated there was only a choice ‘sometimes’; however, all three added that the choices had been limited due to the pandemic.

“Never lonely with the support of the carer and my family network. Going to have street party when all this is over.”

When asked if, during visits, people are able to do the things they enjoy and feel safe, six people stated ‘always’; and two people stated ‘sometimes’. Again, the pandemic was referred to. One person did not answer this question; and another person, a relative, stated ‘never’ however did not provide further comment. This was the same person that informed us their relative would prefer to be independent, so this may have been a factor.

“I feel safe with any of the carers. I love having company and being able to put the world to rights.”

When discussing if the service helps to reduce loneliness, four people stated ‘always’; five people stated ‘sometimes’; and one said ‘never’. A few people referred to experiencing loneliness outside of the visits. One person stated they would like to increase the visits but can’t due to cost, and the person themselves wanted to be independent. Seven people informed us that they ‘always’ feel part of the community and are able to carry out everyday activities that they choose; and two people feel that way ‘sometimes’; one of those people again referred to the pandemic. One person stated ‘never’, however, did not provide further comment, this was the same person referring to their loved one wanting to be independent so, again, this could have been a factor.

“I have felt supported a great deal by the staff at the support at home service and the wider ADSS team. Mum’s support worker is very supportive and always involves both mum and I in deciding what to do when she visits. It has given us a way to get mum to accept some kind of help, as Social service care package did not work out. (The) visits have given mum something to look forward to and a bit of social time and independence. This makes me feel better because I never have the energy to take mum out as much as she'd like, so it relieves some of the pressure off me.”

Most people receiving the service told us that it had made a difference to them by providing them with some company; all relatives stated that by having the service they worried less. Nine people stated that no improvements are needed; one person said they would like to be able to regularly talk directly to the care worker rather than just when they happen to cross paths, however, they stated that they understand why communication has to go through the office.

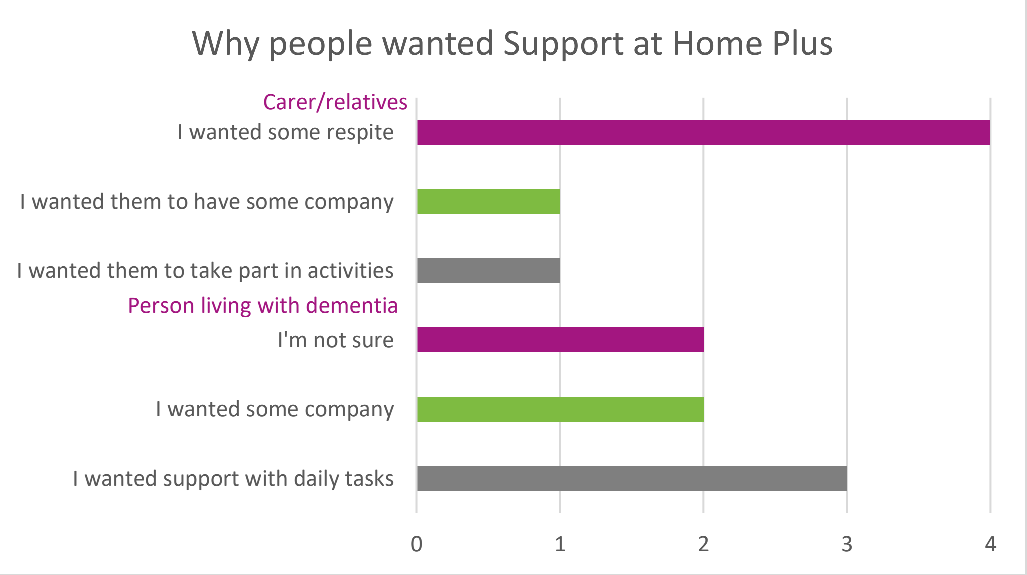
“I wouldn't think so you are all so nice. I feel listened to. I have cried to myself thinking about the kindness the ladies have shown me.”

What did people tell us about their experience of Support at Home Plus?

Thirteen people (six living with dementia, and seven carers or relatives) took part in evaluation discussions. There was an even spread of how long the service had been accessed, from less than 6 months to over 1 year. Most people are in receipt of other forms of support, such as our Support at Home service, The Beacon and other community groups.

"Communication had started to break down with him before the visits started, now he is communicating more and more."

When we asked people why they had accessed this service, respite was a popular reason for carers/relatives; and support with daily tasks was a key reason for those living with dementia.



In addition, two carers/relatives stated that they wanted their loved one to be provided with the support that they cannot provide themselves; another two also referred to them having help with activities of daily living, such as personal care and medication; and another mentioned for their loved one to be given reassurance.

"Carer workers are always up to date with me. They know how to get me moving and motivated."

All thirteen people stated that they feel listened to by people that understand their situation. When we asked if people felt that they had choice and control over their care, and if they are asked what they would like the care workers to do when they visit, eleven said 'always'; and two said 'sometimes'; one person explained further that it is more about their own frustration of what they can and can't do.

"I think they are very understanding, very good with whatever i am doing. They are lovely."

When we asked those living with dementia if they are able to do things they enjoy, and if they feel safe when the care worker visits, five said 'always'. One person said 'sometimes', but further explained that they do 'always' feel safe, they would just prefer not to need the support the care workers give them. Five carers/relatives informed us that they feel their loved ones are now 'always' able to do things they would otherwise not have been able to do without the service; two said 'sometimes', one of whom explained that the care workers have been able to improve nutrition and hydration.

“I know what I'm doing. I have faith in my carers. They encourage me to go for a walk to improve mobility. I was wary at first but I trust the carers.”

Two people living with dementia informed us that they feel less lonely ‘all the time’; three feel that way ‘sometimes’; and one was ‘not sure’. One person further explained that they feel lonely at night-time. Whereas six carers/relatives said that the visits ‘always’ make their loved ones feel less lonely; one said this is ‘sometimes’ the case. Eleven people, including all of those living with dementia, feel having this service helps them to live the life they want; two people feel that way ‘sometimes’.

“Although it's not the life we would have imagined for ourselves, I take comfort from the service ADSS provide.”

When we asked what difference having this service has made to people, carers/relatives talked about reduction in stress, being able to relax, and feeling reassured. Those living with dementia talked about having company and being supported to do things they now have difficulty with; one person said that it has helped his wife to be his wife rather than a carer.

“I would like to add that the carers have been wonderful and that they will go the extra mile to help. Some more than others but they have helped get us out of some tight spots. We are very grateful and can't praise your service highly enough.”

You said, our response……

Bring ADSS to Bexley	We are becoming increasingly aware that there are gaps in services and support beyond the area we currently serve. Within our 5-year Strategy (2021-2026) we have set ourselves an objective to expand our services. Whilst we cannot guarantee that we will be able to provide services in a specific area, we will always be able to help you find support in that area.
Send me a birthday card	We support, on average, 580 people each month, therefore it would not be possible for us to commit to sending everyone we support a birthday card. However, those that attend The Beacon are given a birthday card, and we are currently working towards those that access Support at Home and Support at Home Plus being given birthday cards.
Set up a carer's forum, or provide a regular newsletter	We do provide a regular newsletter to our members. Membership is free - to find out more please call 01474 533990. We also provide regular stories and news on our website and through social media.
The prices of your paid for services have gone up	Due to annual inflation, we do have to review the prices we charge each year. We are pleased to have been able to freeze prices for the last two years, however this year we had to increase them to be able to continue delivering on our standards of excellence.
Produce a guide on local services, information should be available at each group	We have always provided information at our Memory Cafes and will resume doing this when face-to-face groups return. We are aware that there is lots of work going on locally to develop a pack of relevant information. If anyone wants to know more about services that are available, we would encourage you to arrange to speak with one of the Dementia Support team who can provide relevant information for your situation.
Have a young onset specific support within The Beacon	The Beacon day service is inclusive to people of all ages living with dementia. However, we do understand that for younger people with dementia their interests and abilities can be quite different to those that are older, therefore, we are working towards having a day each week dedicated to those with young onset.
More carer support groups, benefit of open discussion without upsetting the person they care for	We can put you in touch with the organisation that is funded to provide specific support for carers. As part of our strategy, we are looking at what everyone affected by dementia needs and carers support groups are something we would like to set up.
Transport to community groups	We are aware that transport can be an issue for some people. Unfortunately, this is not an area that we have the capacity or funds to support, however we can put you in touch with local services that provide this support.

More emphasis on activities, rather than meetings	We were providing two activity specific groups, Active Bodies Active Minds and Kindred Spirits (for those with young onset dementia) but unfortunately had to stop due to COVID-19.We have included coproducing a wellbeing service model that offers flexibility and choice and includes evidence-based activities as an objective in our 5-year Strategy (2021-2026).
Groups later in the day rather than the morning as mornings can be challenging for people with dementia	With the restarting of our groups after lockdown we are working towards offering a variety of times and days in order to offer more flexibility, whilst maintaining a routine for those that attend.
Make the singing group longer	Singing Back the Memories sessions are usually two hours when facilitated in person. The session was reduced to one hour when it went virtual as the group's members at that time felt more than one hour would be too much when using a screen. We look forward to the group returning to two hours when able to get back to in person.
More raising of awareness locally	Historically, we have carried out a lot of local awareness raising, but with the increased numbers and complexities of people needing our support we have had to reduce our capacity to do this. However, we are active members of the local Dementia Friendly Communities group who are responsible for local awareness raising.

To view our 5-year Strategy (2021-2026), please visit our website

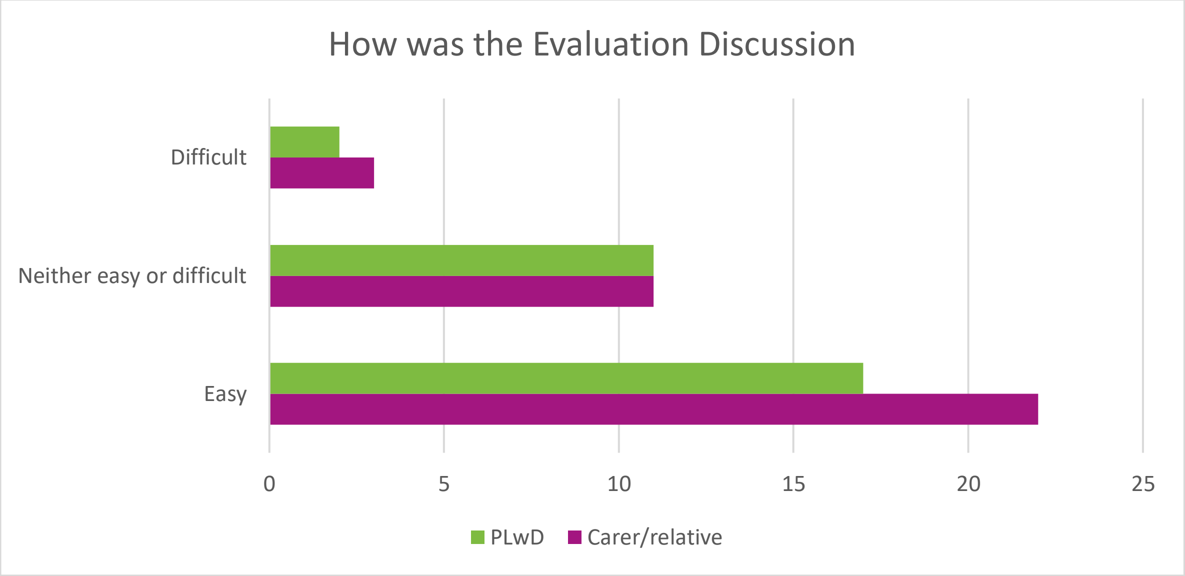
www.alz-dem.org/our-5-year-strategy/

"We are doing so many things now than before we joined the groups. We consider ourselves lucky to have ADSS there. We know others out of your area who have struggled to get any support whatsoever."

"Everything has been good, we have been very happy with all the help we have received over the years, ADSS has helped us more than any other organisation."

What did people tell us about their experience of this Evaluation?

Sixty-six people (thirty living with dementia and thirty-six carers or relatives) kindly agreed to answer two extra questions to help us to ensure that future evaluations are as easy to take part in as possible. We were very happy to see that most people found the discussion either easy, or neither easy nor difficult.



We received lots of constructive comments to help with our planning of future evaluations which include:

- Reducing the number of questions.
- Reduce the length of questions.
- Ensure relevance of question for person living with dementia or carer/relative.
- Ask straight questions rather than statements.
- Simplify questions and be more specific.
- Avoid repetition.
- Offer copy of the questionnaire prior to the discussion.
- Keep asking for opinions rather than a number scale.
- Keep using helpful prompts.
- Keep as a discussion with a member of the team.

We are very grateful for this feedback and we will review this when further developing our evaluation process. Following the analysis of the feedback we would also suggest that the questions relating to the KCC ‘I’ statements are more consistent across the services to enable a comparative analysis, however we will need to provide the staff facilitating the questions the tools to be able to further explain in order to ensure they do not come across as ambiguous. We would also suggest that a postal and online version is made available, in addition to face-to-face discussion, to enable us to reach more people.