

*Alzheimer's & Dementia*

S U P P O R T   S E R V I C E S

# Evaluation of the impact of our services

May 2022

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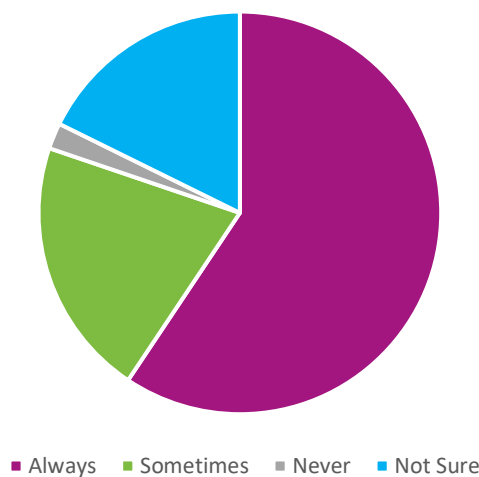
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## Summary

Almost one million people in the UK are living with dementia<sup>1</sup>, 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<sup>2</sup>. Living with dementia can bring challenges for the person with dementia and those around them. Alzheimer's and Dementia Support Services (ADSS) provides a variety of services to support people throughout their experience of dementia. We are carrying out an Annual Evaluation to help us understand the impact our services have on the people we support. A total of 99 people took part in the survey (59 people with dementia and 40 carers or relatives). From this point forward, when we use the term 'carer' we are including family members and/or friends that support those living with dementia. The evaluation was facilitated through 1-2-1 discussions with a member of the relevant team or through an online form. Sixty people took part in the 1-2-1 discussions, and 39 people completed the online form. The discussions took place face-to-face, wherever possible, otherwise over the phone or by video call. They were focussed on the specific service being accessed; however, we also had a survey that reflected people's overall experience of the charity where they access multiple services. The key findings throughout the evaluation addressed six broad statements as follows:

### 1. We are supported to access or find the correct and relevant specialist information and advice about my condition and its impact on me, my family and or carer(s).

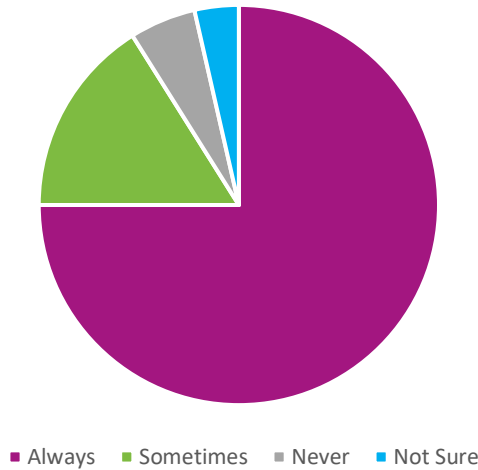
59% of people we spoke to always feel this way. Only two people stated that they never feel this way - one of those people stated that no other care agency is involved at this time and, unfortunately, the other person did not tell us more about why they feel this way. Amongst those that were not sure, it seemed the question may have been too complicated for some, others stated that they had not needed information or advice. However, this has highlighted that more can be done regarding specialist information and advice. Our new Dementia Coordinator service will increase our capacity to enable us to provide this. We will also be ensuring speakers at groups, such as our Dementia Café, are covering topics that are relevant to attendees.



“Questions always answered I think it is a pretty good service you give. I feel very comfortable with asking anything, we are like old friends.”

## 2. I am able to access social activities that I enjoy, in a safe space.

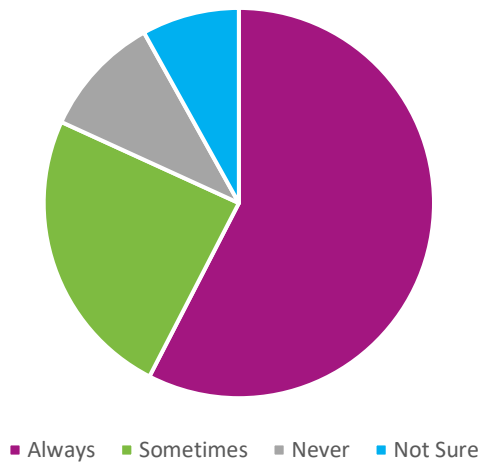
75% of people asked stated they always feel this way. Only three people stated 'never' but further explained that they either have no interest in activities or don't feel able to take part anymore.



"I love the physical activities. Love dancing. I don't have to think about it, I just know that I am safe at The Beacon."

## 3. I feel less lonely.

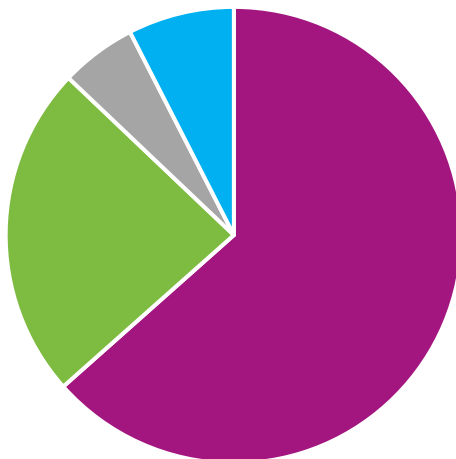
57% of people always feel this way. Although eight people stated they never feel less lonely, six of those further explained that they have never felt lonely. Several people informed us that, whilst they do not feel lonely while accessing our support, they are lonely at other times. This is something we hope our new Befriending service will help address; we will also consider this when developing our services.



"I was very down and, since I've been going out, I feel much better, especially with a person I know."

#### 4. I feel supported in, and by our local community.

59% of people stated they always feel this way. Five people stated they never feel this way, one carer talked about the impact of Covid, the inability to get a face-to-face GP appointment, and the person they care for deciding to not attend groups.

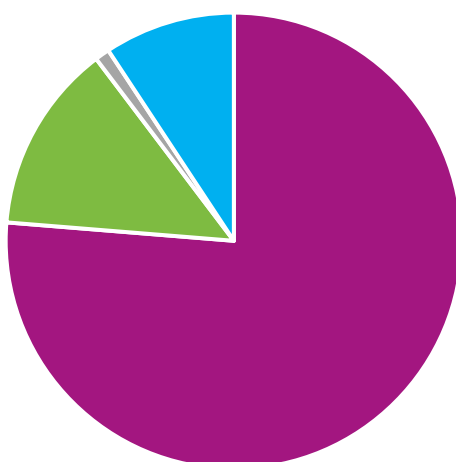


■ Always ■ Sometimes ■ Never ■ Not Sure

“Staff making us feel like WE matter. Being friendly, telling us about events, encouraging us to join in new ventures..... My husband appears to have forged some good friendships ..... I have started to get to know some other carers and feel I can talk to them now in a relaxed way. That is a big thing for me.”

#### 5. I feel listened to, by someone with the knowledge and understanding of dementia.

74% of people stated they always feel this way. Only one person stated they never feel this way but went on to state that they have only met one member of staff, but that he is fantastic. Amongst those that stated they were not sure, some explained that they have not had to ask any questions about dementia and others explained that they, or the person they care for, do not like to talk about dementia.

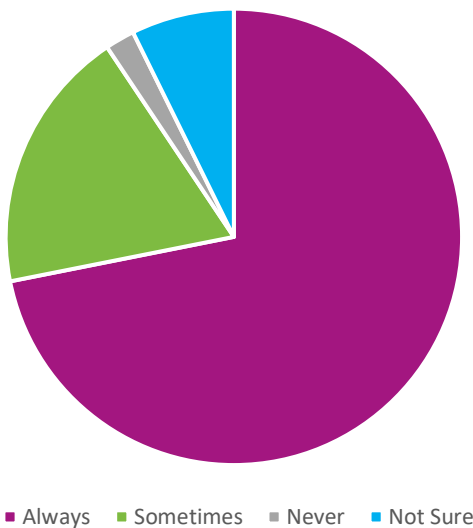


■ Always ■ Sometimes ■ Never ■ Not Sure

“I feel that my carer has great knowledge and really supports me. I don't feel I'm as bad with my dementia.”

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

72% of people told us they always feel this way. Only two people stated they never feel this way, one of whom stated that she lives with the person she cares for and provides everything required.



“The staff always give me choices by asking questions. If I have any changes in my needs the staff respond very well. I always feel I am a priority that why I love coming here.”

### Conclusions

It is clear from the feedback received that our services have had a very positive impact on people. Over 50% of people answered ‘always’ to all questions, demonstrating that people that access our services feel less lonely, feel supported, feel listened to, and are accessing activities that they enjoy. In cases where people stated ‘never’, they gave reasons that in most cases are beyond the services’ control.

With regards to our telephone system, 95% of people that answered those questions are always able to speak to a person when they phone us, and 60% said that it’s extremely easy to get through to the person or team that they wish to speak to.

Across the whole evaluation people praised our staff, explaining how helpful, friendly, polite, professional, and responsive they are.

## Developments since last year's evaluation

In last year's evaluation we responded to some specific requests for development. Here's what we have done as a result of this feedback.

You said...	Our response...
<b>Bring ADSS to Bexley</b>	We are very conscious that it can often be difficult for people to travel outside of their own community to attend support services. As part of our strategy to expand our services, we are working to create 'Satellite Services' that can be delivered across a multitude of venues, as well as increasing our range of social activity opportunities for people living with dementia and their Carer(s).
<b>Set up a Carer's forum or provide a newsletter</b>	We do have a private Facebook group for people living with dementia and their Carer's who can join if they wish. Please contact <a href="mailto:info@alz-dem.org">info@alz-dem.org</a> for more information. The intention of this group is to create opportunities for people to share their experiences and build relationships within a safe, non-judgemental environment. We also provide a quarterly newsletter to our members.
<b>The prices of your paid for services has increased</b>	Unfortunately, due to the rise in inflation and service costs, we were unable to freeze our rates this year. We have tried to only increase the price of our services by a small amount, but this is essential for us to be able to continue delivering a high quality service.
<b>Have young onset specific support within The Beacon</b>	This may be something we could look towards facilitating in the future but, at the moment, we are yet to see an increase in this type of service being required. Something we are considering as more appropriate would be facilitating a 'Club' environment within Safeharbour, so that those who wish to can choose to drop in and partake in an array of activities or just be around friends.
<b>Transport to community groups</b>	Transportation can often be a stumbling block for those wishing to attend our community groups; unfortunately, we don't have the funds or the capacity to support with this. However, with the recruitment of our new volunteer coordinator, we are working hard to increase our volunteer capacity to enable us to be able to provide assistance when possible.
<b>More emphasis on activities, rather than meetings</b>	Due to securing the contract from KCC, our wellbeing service model is beginning to take shape within the community. We now have a Wellbeing Team, who have already made great progress in securing new venues to hold our sessions and new experiences for people to enjoy. An 'active' activity group was requested by the people who use our services, and this has recently commenced in Northfleet. Our fortnightly Tea Dance sessions have proved extremely popular with long time service users and new attendees alike. Over the last year, we were also able to facilitate overwhelmingly popular day trips to Herne Bay and the Rochester Christmas Market, as well as a Disco too!

<p><b>Groups later in the day rather than the morning as this time can be difficult for people living with dementia</b></p>	<p>Since the easing of lockdown restrictions, we have been focused on recommencing groups face-to-face as well as creating new ones. We now have sessions available at various times throughout the week, including evening sessions.</p>
<p><b>More raising of awareness locally</b></p>	<p>Over the last year, we have piloted the Dementia Coordinator service across all GP surgeries in Dartford, Gravesend and Swanley, and as we successfully bid for the contract to continue providing this service, hundreds of people living in our community will now automatically be made aware of our service. This ensures people are never alone on their dementia journey as they'll be encouraged to access the support available to them.</p>

## 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<sup>1</sup>. There are estimated to be 23,940 people over the age of 65 living with dementia in Kent<sup>2</sup>. Between April 2021 and March 2022 ADSS supported 1,788 individuals.

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 aims 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 family members, or others involved, are supported. This report describes the findings from evaluation discussions undertaken throughout February and March 2022 between ADSS staff and people that use the services. It also includes responses from additional people that completed an online survey. This is the second annual evaluation to take place following a pilot evaluation that took place in 2021.

It is important to be aware that, at the time of this evaluation, we were still working within restrictions brought about by the Covid-19 pandemic. This 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 opt for phone calls or video calls. This was also evident in some of the feedback we received.

The evaluation questionnaires were designed based on our learning from the Evaluation Pilot and outcomes developed by Kent County Council (KCC) for their wellbeing contracts. 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, enabling everyone to take part.

In June 2020, we implemented a new telephone system which meant a change from a person answering the phone to an automated message with options to choose from to get through to the person they wish to speak to. It is important to us that people are comfortable with negotiating the new system and that they can speak to the right person. Therefore, we took the opportunity of our annual evaluation to also ask people about their experience of the new telephone system.



## Aims of the Evaluation 2022

Our evaluation aimed to answer two broad questions:

1. How do the services we provide impact on the people we support?
2. How easy have people found our new phone system?

## How did we gather people's views?

To explore these questions in detail we conducted evaluation discussions with those affected by dementia that have accessed our services. In total, 99 people gave us their views, an increase from the 79 that took part last year. The evaluations were carried out through 1-2-1 discussions, face-to-face, or over the phone with a member of the relevant team, or by completing an online form.

## Who took part in our evaluations?

Of the 99 people who took part, 59 were people living with dementia, an increase from 32 last year, and 40 were carers or relatives, a decrease from 47 last year.

## Interpreting the findings

Selection of those living with dementia invited to take part was carried out by the relevant service leads to ensure they had accessed the service recently and could therefore provide current feedback, and were also not going to be caused any distress by taking part. The online form was sent to all family carers, who either access a service themselves or support someone that does.

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 who access multiple ADSS services tell us about their experience?

A total of seven people responded to this survey, six carers and one person living with dementia. The people who responded to this survey have accessed either one or more of our Support Services/Activity Groups.

57% of the people we spoke to, told us that they ALWAYS **feel less lonely** due to accessing our services. One person told us that they feel you don't realise how lonely you are, until you cannot attend a group for some reason or another. Another told us how attending The Beacon has made such a big difference to their lives; living alone means that they don't get to see many people, but since attending The Beacon, they have made lots of new friends, enjoy the social activities, and having a hot meal prepared for them is a treat.

29% of the people we spoke to told us that they **SOMETIMES feel less lonely** and describe how not being able to access activities/groups due to mobility problems or because some of the groups are now on an invitation-only basis can be frustrating.

'My wife attends Safeharbour 2 or 3 times a week, with or without me. I can talk to others with similar problems. She has tried additional things, but due to her having physical problems as well, she gets shattered very quickly if there are two in one day and we then cancel her less-liked activity. This then gets us both frustrated.'

'Yes, your various groups have made a big difference to us and the quality of our lives... The days at The Beacon have certainly changed our life experiences and happiness levels... Staff and peers are very friendly and helpful in every type of group we have experienced and a big help on trips too. Staff giving help to us, as and when needed in every situation (always with a smile)'

One person told us that they **NEVER** feel less lonely but did not give any feedback as to how they do feel.

57% people told us that they **ALWAYS** feel supported in and by their local community, describing community warden's and neighbours as supportive, as well as feeling supported by ADSS.

'Staff making us feel like **WE** matter. Being friendly, telling us about events, encouraging us to join in new ventures. Always ready to have a laugh with us, which is a good uplift for us.'

One person told us that they **SOMETIMES** feel supported in and by their local community and told us how they feel very much included in ADSS' services that they attend as well as having neighbours close by who they could call on if needed. One person told us they're **NOT SURE** how supported they feel, and another told us that they **NEVER** feel supported, but neither gave feedback as to why they feel this way.

71% of the people we spoke to feel listened to by the team at ADSS, with many members of the team receiving a mention by name. People told us that they feel supported to be themselves when in the company of the team, and feel confident that, if they needed to access any information, then they would be supported to do so.

'The team in the office and also the carers always provide sound advice, compassion and empathy.'

'Definitely Tom and Tracey, lovely people, they have helped a lot with supporting my husband, encouraging him to have a happy experience at singing group. Also, making various other activities really enjoyable and possible... Making us feel important and that we can ask them for help anytime. Very caring and compassionate. They also said I could ring the office if I had any concerns... Vilma was a big help on a day trip. She was with my husband all the time, another jolly person, and also giving practical help when needed too.

It made such a difference to our experience. Which probably would have been difficult without her.... Jackie, on the bus for The Beacon, has always been very cheerful/friendly and letting me know what my husband has done/eaten at The Beacon and especially jolly with my husband helping him enjoy the experience. Danielle, my husband's home plus carer, is a lovely, friendly, kind, and supportive person. My husband feels really comfortable with her and enjoys talking to her. He likes to have a 1 to 1 chat with her. He doesn't really make comprehension of regular conversation but she knows how to respond so that he feels what he says is valued, which is very important to him and his self-esteem.'

One person told us that they **SOMETIMES** felt listened to by the team, and explained that they tend not to discuss dementia, as they don't have any need for advice at present. One person told us that they were **NOT SURE** whether they felt listened to by the team and did not provide any feedback on this question.

86% of people who responded to this question told us that they **ALWAYS** feel supported in and by their local community. The feedback received showed us that the people who responded to this question feel that they belong to the ADSS community, but that they also feel supported by their local community because of the services they have been able to access. One person explained that they feel supported by their community warden; another explained how Kent County Council had supported them to access home adaptations, and also how Carers First has supported with referrals into other services.

'The **BEACON** is very very important to us and keeping us at home/independent. It is very good for my husband, and he enjoys it. It is **ESSENTIAL** to me. For so long (about 18 months) I was 24/7 caring for my husband, literally as he was awake in the night too ) I just focussed on my husband, no time to shop, even for food (a friend did it for us), no time to do the many things that needed addressing in the house and garden, intricate phone calls to sort household things etc and no quality time for me to see friends. (Often, he doesn't like me talking to others as he prefers the attention on him most of the time, he probably feels confused by our conversation and maybe on the outside sometimes, which is understandable.) I now have that time thanks to The Beacon Day Centre. A life saver. Sounds dramatic but true as it enables me to continue caring for my husband.'

One person (14%) told us that they **NEVER** feel supported in and by their local community but did not provide any comments as to why they feel this way.

57% of the people we spoke to told us that they **ALWAYS** feel supported to access information. They gave examples of times when this has been the case, such as when support was needed to pursue applications for Power of Attorney, reductions in Council Tax and applying for Attendance Allowance. People told us that they feel confident that ADSS will support them to access correct services when needed.

29% of people told us that they **SOMETIMES** feel supported to access information but did not provide feedback as to why they feel this way. At this point in the survey, one person told us that, although they understood our need to gather feedback, they felt that there had been too many questions asked of them and they were feeling a little stressed. One person told us that they **NEVER** feel supported to access information but, again, did not expand on why they feel this way.

43% of people we spoke to told us that they **ALWAYS** feel supported to access activities they enjoy and gave details of all the various events and groups that they had attended. One person told us that the activities provided are tailored to suit her husband's abilities and that the staff make them feel safe. One person also told us how an activity their husband enjoyed participating with at a group has now been taken up at home, too.

'10 pin bowling. Carers support group. Day trips. Beacon Day Centre. Only downside is invitation needed now for carers group once a month, so it will impact on making friends, consistency and missing activities. Activities always tailored to my husband's abilities and enjoyment.'

29% of people told us that they **SOMETIMES** feel supported to access activities that they enjoy. One person explained that some activities have been facilitated at venues that were

too far away for them attend, even though they would have enjoyed the opportunity to participate. It is also apparent that people feel not all the activities are suitable for everyone, with references made to physical restrictions/poor mobility and inability to 'keep up' with the rest of the group in relation to Singing Back the Memories. One person told us that they NEVER feel supported to access activities that they enjoy but, again, did not provide any further comments as to why they feel this way.

All seven respondents provided us with feedback as to the difference accessing our services has made to their lives. One person told us that they feel that no difference has been made. One person told us that they feel they haven't really needed our support for themselves yet but knows that, if and when she does, she can turn to us.

Five people gave us examples of how accessing our services has made a positive difference to their lives. One person explained how they had no idea about the support that was available to them until they connected with ADSS and how, as things have progressed, they feel they've had great support and are confident in accessing any of our services. People describe feeling less lonely and how attending groups together has made a massive difference to their quality of life.

'I was very lonely before The Beacon club it is now the highlight of my week and I have made so many friends.'

'For me as the daughter of someone with Alzheimer's having ADSS has changed my life, I feel a weight lifted off my shoulders since having the carers visiting my mum.'

'It has changed our lives for the better as already explained before in other answers. I am hoping (and think it is) that the various interactions and activities are stabilising my husbands' levels of understanding and in fact making his clarity a bit sharper, as well as adding variety and enjoyment to his life.'

When asked if they had any other comments about our services, one person, who answered NEVER to all previous questions without providing any further feedback, took this opportunity to share how isolated and unsupported they feel due to services being unavailable during lockdown, facilities being closed, Covid restrictions or volunteer shortages. People also told us that whilst they understand our reasonings for changing our process to 'Invitation Only' with regards to attendance of the Carers Support Groups, they feel that this process could affect their and other people's abilities to form friendships with peers, which is one of the main purposes of the Carers Support Groups. Another person told us that they have had problems communicating with the right people when needed – such as to confirm attendance at a group. They explained that there have been occasions when they couldn't get through on the phone and have instead sent emails to our info mailbox which haven't been picked up/sent to the right people in time. Please see page 31 for our response to this feedback.

People express there is a definite need for the services that they access and how grateful they are to be able to access them through such a supportive team.

'I am so grateful to the team at ADSS. Everyone works hard to look after my mum, all the carers are compassionate, caring and thoughtful.'

## What did people tell us about their experience of our Dementia Information, Advice and Guidance services?

We received a total of 28 responses to this survey, from people who have been supported by the Dementia Support Team, including the Dementia Coordinators. Out of the 28 people who responded, eight responses were from people living with dementia, and 20 responses were from carers.

### I feel less lonely

46% of people told us that they ALWAYS feel less lonely due to the impact of our service, with people describing noticing improvements in their loved one's confidence and overall, feeling less lonely because of accessing the support that is available to them. One person described feeling 'left' by their GP after diagnosis but, due to accessing services through ADSS, they now feel reassured that support is there.

'Yes, I feel less lonely. I feel more supported. It's good to have somebody to chat to.'

'I think just knowing there is support there. I have support over the phone and carers coming in to see my mum.'

36% of the people we spoke to, told us that they SOMETIMES feel less lonely and detailed the various support available to them that help them feel less lonely, such as regular visits from family and friends, as well as monthly check-in calls provided by the Dementia Coordinators. One carer explained that, as much they enjoy having a monthly catch up with their Coordinator, their role is 24/7 so they still feel alone a lot of the time.

People also spoke about feeling lonely, despite having their loved one with dementia with them at all times.

'I feel like I am back to where I was when I come to the groups. Seeing other people and talking to people makes you feel better, doesn't feel like people were saying something I didn't understand.'

'PLWD spends a lot of time in bed and their Carer feels isolated as PLWD does not want to go to any of the support services offered. For the Carer, it feels like from the moment PLWD gets up in the late afternoon, they have to be with them all of the time.'

14% of the people we spoke to, told us that they were NOT SURE whether they felt less lonely, with two people explaining that they had been made aware of the services available to them but have not yet needed to access them.

One person (4%) told us that they NEVER feel less lonely but did not provide any feedback as to why they feel this way.

### I feel supported in and by my local community

57% of the people we spoke to told us that that they ALWAYS feel supported in and by their local community and, as displayed throughout the Evaluation of each service, it is clear the 'Community' means something different to each individual. People who ALWAYS felt supported within their community described feeling supported by the staff and other members of the groups they attend, by their neighbours and families, and by community services facilitated by ADSS, such as interventions from OTs and GPs.

'An extremely supportive service who always make me feel comfortable.'

'I feel very supported by my local community. I feel more included. I know of the groups, and it is something to think about for the future. I have a lot of friends who take me out.'

18% of the people we spoke to, told us that they **SOMETIMES** feel supported in and by their local community. Some people completing the survey on behalf of someone with dementia felt unable to answer this question, as they themselves live out of the area. Some people told us that they were aware of services available to them, but that these were not appropriate to them at this present time.

'Staff are very friendly as are most of the people attending but think it's too early to really know.'

I know there are groups, but I like my own company. I could go later down the line.'

'Support provided and a point of contact for the future.'

18% of the people we spoke to told us that they were **NOT SURE** how often they felt supported by their local community, with one person explaining that they like to keep themselves to themselves. Another person detailed how they're now beginning to feel more involved with the groups but feel uneasy about sharing experiences with peers; however, they feel confident and relaxed when speaking with members of staff.

7% (two) of the people we spoke to told us that they **NEVER** feel supported in and by their local community and one person gave us feedback and explained that this is due to the impact of Covid; GPs are still not seeing their patients face-to-face. They also shared frustration that, despite reaching out to MIND for help with symptoms of depression, the person with dementia was denied support due to their condition. They also explained that their loved one is aware of the groups and services available but refuses to attend.

### **I feel listened to**

75% of the people we spoke to told us that they **ALWAYS** feel listened to, and many of the respondents named the staff members that had interacted with. It is clear that the support the Dementia Coordinators offer to people is very much appreciated, and some people even commented that they feel they have made a friend in their Coordinator.

People told us that they feel comfortable when speaking with their Coordinator about their diagnosis or any other problems, as they're friendly, responsive, and supportive.

'I feel the staff make me feel comfortable and make me understand it better.'

'Staff make me feel comfortable and relaxed and are always friendly I feel that we have a good relationship with Tom and Tracy who I feel I can talk with them about any problems.'

'They have provided a huge amount of information and support explaining what services are available and how to obtain these.'

'Yes, I do, I do now since ADSS. I did not feel emotionally supported prior to ADSS. Yes, I have respite offered but I do not feel it would help as my husband would be more confused.'

14% of people told us that they **SOMETIMES** feel listened to by someone with the knowledge and understanding of dementia, with one person sharing with us that they feel better after having a chat with their Coordinator.

7% of people told us that they are NOT SURE whether they feel listened to, and 4% of people told us that they NEVER feel listened to but did not provide us with any feedback as to why they feel this way.

### **I am supported to live safely and independently**

64% of people told us that they ALWAYS feel supported to live safely and independently through their contact with their Dementia Coordinator, with examples provided of support given to access better outcomes from GPs, and reassurance is given that as people's dementia progresses, they and their loved ones know they are not alone, and support services are available to be accessed as and when people feel ready.

'The support we have received has been invaluable. I know mum has support as things progress. Knowing you are not alone, and the resourcing have been brilliant.'

'Yes, I feel mum has been supported to continuing living well at home, I feel we as a family being supported.'

'Yes, the team supports us. No changes but I can make my own choice. I choose not to go to groups yet.'

22% of people told us that they SOMETIMES feel supported to live safely and independently, and described how support from ADSS has contributed to these feelings, such as knowing there is someone at the end of the phone.

'I feel ADSS is quite responsive, and My mother has been supported and prioritised.'

'The Beacon is a great help and goes once a week and is on the waiting list for a second day.'

14% of people told us that they are NOT SURE whether they feel supported to live safely and independently; people feel that because of the nature of the disease, true independence is not always possible, but loved ones do try to encourage independence by supporting their family member to access services such as The Beacon Day Centre, which helps people feel independent of their carers.

### **I am supported to access information and advice**

79% of respondents told us that they ALWAYS feel supported by ADSS to access relevant information, with the majority of people describing feeling lost and unsure of where to turn for support, before being made aware of ADSS. People find that attending groups helps them to access relevant information. Speakers who attend the groups to share information about other services have also been beneficial to those in attendance. People also expressed how appreciative they were with help in applying for benefits such as Attendance Allowance and Council Tax reductions.

'The information is good. We did not need groups, but the Dementia Coordinator was very helpful. They helped to support us with choice.'

'Yes, I have lots of information available. The ADSS website is very good and is a good website to visit.'

'Yes, I feel there is lots of information. All the information can be over whelming, but we had an information pack provided.'

'I feel we are now supported and can find the correct information now we have the support and advice from ADSS''

11% of the people we spoke to, told us that they SOMETIMES feel supported to access relevant information. One person explained that they felt it was too early for them to comment as their diagnosis has been very recent, but they have been provided with information and intend to make contact with necessary organisations as and when the time is right for them.

11% of people told us that they were NOT SURE if they feel supported to access relevant information, again, because the individuals' dementia journeys have only just begun, but all commented that they had been provided with relevant information regarding their individual circumstances.

'Dementia is all new to me and it has become sensitive, and I am still trying to get used to my mother having this. But I know can call ADSS and the helpline for support.'

### **What difference has accessing this service made to you?**

When asked what difference accessing the service has made to them, all 28 respondents gave us their feedback and one word that is seen in the majority of all the comments is 'support'.

People were overwhelmingly positive about the support they had received from the team, and how this support has made a difference to their lives. Even people who have yet to access our services directly, commented on the difference having their own Dementia Coordinator has made to them; just to know there is someone at the end of the phone to reach out to, if they needed to do so.

A person who responded on behalf of a loved one with dementia shared that, although there are support services such as activity groups available, their loved one refuses to attend them, which can often leave carers feeling isolated. Despite this, having the support of the Dementia Coordinators means that people have an opportunity to share their highs and their lows with someone who understands what they're going through, and as people's needs and circumstances change, the coordinators can offer the most relevant services/support mechanisms, every step of the way.

'The main thing, as a carer I now feel I have someone (who is readily available) to refer with whenever I get 'stuck'.'

'I feel more confident having been contacted by the organisation and speaking with someone who understands how I am feeling and my needs going forward.'

'Has been a weighed lifted off your shoulders. So much support. It felt like there a bomb going to go off and then we had this wave of relief and I feel so much better.'

'It has had a big effect on me, we go out every single day, every day is consequently happier than it would normally be.'

### **Other comments about our services**

People were overwhelmingly positive about their interactions with our service and were happy to share why they feel this way.

'I feel you are person centred and I feel you provide a personable service that we can rely on and know that we always get a prompt response. I know that things get sorted and my



mum's problems always have great support. I feel ADSS has taken the time to help and support us as other organisations have been too busy to help.'

People also shared with us that, although they have been grateful to have accessed our service, they felt that they would have liked to have been made aware of the support available earlier in their journey. This is something we wholeheartedly agree with, and our Dementia Coordinator Pilot really did demonstrate the need for diagnosis, guidance, and community support services. As we have been awarded the contract to continue the Dementia Coordinator service across Kent, we are confident that this service will change the lives of people with dementia from pre-diagnosis and beyond.

'You are just invaluable, friendly, helpful. Social media is very uplifting it has made things look brighter. It is not all doom and gloom. There are positives that can come out of this. It has been comforting.'

'I do find like a lot of services that operate a 9-5, it can be a little frustrating as we all know being ill or having dementia does not operate on working hours, but I understand everyone needs a break and no one can be around 24/7. I do have the 24/7 helpline number and have used it which was great.'

'From my recent experience I am very happy with the service and the advice and suggestions I was given. This was my first contact regarding my new diagnosis, and it was reassuring to know I had someone I could talk to who totally understood the disease and was able to give me honest and reliable information.'

## **What did people tell us about their experience of Community Support Groups?**

We received a total of 19 responses to this survey from people that attend Peer Support and/or Dementia Cafes. Eleven responses were directly from the person living with dementia and eight responses were from carers

### **I feel less lonely**

Of the 19 people surveyed, 53% said that they ALWAYS feel less lonely by accessing our service. People described feeling a sense of companionship and enjoying spending time with other people who understand what living a life with dementia is like. People described always being made to feel welcome by friendly and approachable staff, looking forward to attending, and being provided with lots of knowledge.

26% of people surveyed said that they SOMETIMES feel less lonely by accessing our service, with one person noting that other issues (not just living with dementia) contribute to their feelings of loneliness. One person commented they find it remarkable that they chat and feel included in the group. People expressed their gratitude for the opportunity to meet others who are in a similar situation, and for the reassurance that there will always be someone on the end of the phone, should they need any help.

Three people told us that they NEVER feel less lonely but went on to explain that this is due to having supportive families and fulfilling social lives. One person told us that they were NOT SURE but went on to say that they didn't feel lonely at all.

### **I feel supported in and by my local community**

Of the 19 people surveyed, 84% told us that they ALWAYS felt supported in and by their local community. All respondents in this survey took 'community' to mean the community within ADSS, as opposed to other surveys where people have interpreted the meaning of community differently. People responding to this survey, expressed that they have made friends by attending the groups; they feel supported, comfortable, included, and valued.

'Living on my own, I enjoy meeting new people. I do feel supported in the community. I am made to feel included – the venue at Meopham is fine.'

'We enjoy attending the dementia café as we get to join in with activities and talk to others. Attending the café makes us feel supported.'

'I feel very conscious of being included. I feel included in all that happens.'

'We love to have a laugh and a joke. It does make me feel included and I've made new friends.'

16% of people told us that they SOMETIMES feel supported in and by their local community and describe feeling included and having made new friends. One person commented on the well-placed signage at the venue they attend.

### **I feel listened to**

84% of the people surveyed told us that they ALWAYS feel listened to, and many have mentioned a particular member of staff by name. People reported feeling assured that if they ever had a question to ask or, if they were unsure of where to turn, they would speak to us.

'Ross is very knowledgeable. All staff I have met, volunteers also are very friendly.'

People found knowledge gained from speakers at the groups has been helpful – and the free tea and biscuits are appreciated too!

'The staff at ADSS are marvellous and very professional and they put in so much work helping PLWD and staff are very knowledgeable.'

16% of people told us that they SOMETIMES feel listened to, commenting on how compassionate the staff and volunteers are.

### **I am supported to live safely and independently**

79% of respondents told us that they ALWAYS feel supported to live safely and independently, with people commenting on the way they are made to feel by the team – people reported feeling included, supported and encouraged to make their own choices.

'Very helpful. I would like to think so. Always feel the team would take the feedback and use it to do better.'

16% of people who responded told us that they SOMETIMES feel supported to live safely and independently, with one person commenting that some of the help they've received has gone above and beyond. Another person shared an example of how the team has been helping to get a referral back into the memory clinic. One person told us that they were NOT SURE but did not provide further comment.

### **I am supported to access information and advice**

63% of people asked, told us that they ALWAYS felt supported to access relevant information and advice and some explain how ADSS have made them feel this way:

‘People are active in helping me get to goals.’

‘Anything I have asked for; you have come up with.’

‘I have been provided with a ADSS information pack and I find this useful.’

‘We have always felt respected and supported when attending the memory café.’

Five people told us that they SOMETIMES felt supported to access relevant information and advice, with one person detailing the impact of lockdown and how this led to them feeling ‘lost’ at times, with what was happening and when. Two people told us they were NOT SURE if they felt supported to access relevant information and one person expressed that they do not wish to think about the future.

### **I am able to access social activities that I enjoy**

89% of people told us that they are ALWAYS able to access social activities that they enjoy, in a safe space. The majority of responses included comments about feeling safe within a group; not feeling like an outsider, making new friends and having the option to participate in activities. People who have caring responsibilities expressed that the groups enabled them to enjoy time with other carers and not have to worry about their loved one, as they are doing the same with their peers.

Two people reported that they SOMETIMES feel able to access social activities, one of whom noted that sometimes activities overlap and another fed back that their loved one is not always keen on some of the activities provided.

‘I only take us to the Carer Peer support group at the moment as my husband likes to meet up with friends and go out for coffee. I enjoy the 2 hours of meeting other carers and not having to worry about my husband.’

### **What difference has accessing the service made to you?**

When asked what difference our service has made to them, all of those that answered gave positive feedback. The majority of people commented on how attending the groups has enabled them to meet new people, make new friends and get out of the house, broadening their outlook on life and giving them more confidence. One person expressed that since accessing our service, they now have a greater understanding of their individual situation and of themselves.

‘Getting out and socialising with others, ADSS are always go above and beyond helping the wider community who need support and a social life.’

‘Knowing what is available to us and all the help I have received over the past 16 months has been invaluable to us.’

‘I really enjoyed the trips out; this is something I would have not been able to do initially.’

‘It has certainly made life better for me, through the knowledge of your group’

### **Other comments about our services**

When asked for any other comments, all 19 respondents shared their thoughts with us. All comments were positive, with no suggestions as to how to improve. One person

commented that sending invitations to groups via post was a 'wonderful thing to do' (as opposed to phone calls). Everyone who responded expressed their positivity towards the Community Support Groups and described feeling good about getting out of the house, socialising and meeting new people.

'You seem well integrated with the active support of managers.'

'If I had not met your organisation, I would be in my chair at home staring out the window.'

'Just keep up all the good work, we need you.'

## **What did people tell us about their experience of Community Activity Groups?**

We received a total of five responses to this survey from people that have attended Singing Back the Memories and other activity-based groups. Four responses were directly from the person living with dementia, and one response was from a carer.

### **I feel less lonely**

80% of people surveyed told us that because of the service, they ALWAYS felt less lonely. 20% of respondents SOMETIMES felt less lonely. People who said they ALWAYS felt less lonely expressed that they enjoy the opportunities provided to get out and meet new people. People enjoy being part of an active group and are glad that services are resuming face-to-face.

### **I feel supported in and by my local community**

60% of the people surveyed reported that they ALWAYS feel supported in and by their local community. One person commented on how they feel more supported now that they are attending the Community Activity Groups as, before this, they had no support in place. People were appreciative of the fact that Singing Back the Memories was continued online throughout the pandemic.

40% of people SOMETIMES felt supported in and by their local community, commenting on the fact that all staff are very friendly but that not all activities on offer are appropriate for all.

### **I feel listened to**

Of the five people asked, three of them said they ALWAYS felt listened to, describing how being part of a group helps them feel more supported, as everyone is experiencing similar circumstances, things are open and talked about and the staff are very nice and approachable.

One person said they SOMETIMES felt listened to and gave positive feedback about staff who had been present online during the pandemic; how they had been empathetic towards people's abilities and requirements. One person said they were NOT SURE if they felt listened to but did not provide a comment.

### **I am supported to live safely and independently**

Of the five people surveyed, two people told us that they ALWAYS felt supported to live safely and independently, with one person commenting on how the Activity Group enables them to be more independent. Another person acknowledged how support is given to carers, as well as the person living with dementia.

Three people told us that they **SOMETIMES** felt supported to live safely and independently, with comments including how involved people are made to feel and how they are supported to make their own choices. Another person explained how they still feel lonely, and another praising the team for always giving providing opportunities to get involved and prioritising providing support where needed.

### **I am able to access social activities that I enjoy**

Of the five people surveyed, four people felt they were **ALWAYS** able to access social activities that they enjoy, in a safe space, commenting that they always feel safe and that during activities, people are supported to do as much as they can and aren't put under any pressure to participate.

One person told us that they **SOMETIMES** feel they're able to access social activities in a safe space and detailed all of the services that they're engaged with. A suggestion was

### **What difference has accessing the service made to you?**

All five respondents gave feedback about what difference accessing this service has made to their lives. Four people were very positive, commenting on how they now have something to look forward to, how attending the groups makes them want to be more active, how enjoyable it is to all be together and one person commented in how their family had noticed a difference in how they feel. One person expressed that although ADSS has helped, they struggle with the fact that at the end of the day, it is down to them alone to cope.

*'My wife's illness has progressed since starting to use the services, the support from The Beacon has come in line with this, no at home services used yet. The social groups have been important to keep the social contact which my wife enjoys. The activities and the groups make a huge difference in social engagement. We try to go to different group situations independently of ADSS, although we did a couple of theatre trips with Kindred Spirits.'*

### **Other comments about our services**

All five respondents gave additional comments; three people commented on feeling happy and supported, one person shared their frustration that their family member had been on the waiting list for a second day at The Beacon for quite some time and one person shared their view that it is not entirely clear who they should contact when they have a query.

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

We received 21 responses to the survey. Seventeen responses were from people living with dementia and directly accessing the service, while four responses were given by the carer of the person using the service.

### **I feel less lonely**

Out of the 21 people surveyed, 16 of them said they **ALWAYS** felt less lonely having accessed this service. Two respondents felt less lonely **SOMETIMES**, whilst two people were **NOT SURE** and one person **NEVER** felt less lonely as their family has a lot of input.

It is clear that loneliness means different things to different people – one person who said they **SOMETIMES** felt less lonely commented on how they never feel lonely at home but that they enjoy coming to The Beacon to meet new people.

Another person who said they weren't sure if their loved one felt less lonely, commented that their loved one doesn't remember their time at The Beacon, so cannot comment on whether they felt less lonely, but that staff had commented that the person does engage and enjoy their time when present.

Of the 16 people who responded that they **ALWAYS** felt less lonely, comments given explained that the majority of these people feel that, because of their attendance at The Beacon, they are not lonely.

One person commented on how they don't get to see anyone where they live and that they're isolated there; coming to The Beacon means that they get to enjoy social time with friends. Another person commented on how nice it is to socialise with people other than family. Another person shared that they enjoy coming to The Beacon and observing other people having fun and enjoying themselves.

### **I feel supported in and by my local community**

Of the 21 people surveyed, 13 said they **ALWAYS** feel supported in and by their local community, five people felt this way **SOMETIMES**, one person was **NOT SURE**, and two people stated that they **NEVER** feel supported. Again, it is clear that the word 'Community' means different things to different people.

Of the two people who said they **NEVER** feel supported by their local community, one person had completed the survey on behalf of a loved one who attends The Beacon, and stated they never felt supported as they don't live in the same community. Another stated that their loved one has no connections/friendships within the community.

Of the five people who said they **SOMETIMES** felt supported in and by their local community, again, those that completed the survey on behalf of a loved one commented that they themselves do not live within the same community, however, The Beacon has provided them with reassurance that their loved one **IS** part of a community within Safeharbour. Another person commented that, within their community, they had a couple of good neighbours to call on, should they need to.

Thirteen people said they **ALWAYS** felt supported in and by their local community and gave many examples of how The Beacon promotes feelings of inclusion, belonging and community. The majority of people who responded shared that they feel the staff within The Beacon help ensure that people feel included, by encouraging participation and developing relationships.

People said that they feel at home within The Beacon and part of the community because of the way the staff interact with them.

*'The fact that the carer comes into my house to get me is reassuring. I feel safe here. They are all my friends. I love everybody here.'*

### **I feel listened to**

Of the 21 people surveyed, 17 of them said that they **ALWAYS** felt listened to at The Beacon. 19 people made reference to how the staff within The Beacon contribute to feelings of friendship, belonging and inclusion.

'I feel all the staff are very good and listen to me if I am worried about anything. I think my shyness has been helped by my visits to The Beacon. I am confident that if there is anything I don't like, I can talk to any member of staff.'

One person who responded on behalf of the person living with dementia said they **SOMETIMES** feel listened to and commented on how every member of staff she has met has been caring and compassionate, and demonstrated patience and understanding with regards to her loved one's dementia.

Three people responded that they were **NOT SURE**, but all three commented on how they were confident they could speak to a member of staff if they needed to, and one person commented that, although they cannot often remember what has happened during their day at The Beacon, they always know they have enjoyed themselves and ended the day happy.

### **I am supported to live safely and independently**

When evaluating the feedback regarding being supported to live safely and independently, it was clear that some of the feedback provided was not in direct relation to peoples' experiences within The Beacon but in relation to how people manage their independence at home.

Out of 21 people, 14 said they **ALWAYS** felt supported to live safely and independently and some gave examples of what this means to them:

'The staff always give me choices by asking questions. If I have any changes in my needs the staff respond very well. I always feel I am a priority and that's why I love coming here.'

'Whenever I come to The Beacon, I am able to do whatever I can by myself such as going to the bathroom. But I know I can ask for help if necessary.'

'I need help with some things. I am listened to when I want or need anything.'

Two people responded that they **SOMETIMES** felt supported to live safely and independently, with one person commenting that they didn't need any specific support yet, but they know if they do need help, they only have to ask. Another person explained that although they can manage some things independently, they do require extra support with participating in some of the activities.

### **I am supported to access information and advice**

Of the 21 people asked, 13 people were either **NOT SURE** or said **NEVER** when asked about access to specialist information. From the comments provided, it is apparent that the majority of people feel that they have yet to experience the need to access information through The Beacon, but were confident that, when needed, they would feel able to approach the team for advice.

Five people said they **ALWAYS** felt supported to access specialist information and gave examples of when the team has helped to arrange a GP appointment, and when people have been referred to other community organisations for relevant support.

One person commented that they have complete confidence in all the staff, and that they will always help in whatever way they can.

### **I am able to access social activities that I enjoy**

75% of people surveyed told us that they are ALWAYS able to access social activities that they enjoy in a safe space. People shared their feelings about the different activities they have experienced, with some commenting on their love of the quizzes and group activities/games and others sharing how just being a part of The Beacon makes them feel.

'I love the physical activities. Love dancing. I don't have to think about it I just know that I am safe at The Beacon.'

'I like what we do at The Beacon. I don't have to if I don't want to. I can't think of anything else I want to do.'

'You make sure we tell people what's going on in the world. Bingo drives me up the wall, but I join in to be social. I like the dancing and quizzes.'

Two people told us that they SOMETIMES feel able to access social activities that they enjoy, with one person commenting on how much they enjoy dancing, and another expressing their joy at having recently been informed that they can be supported to do some knitting whilst in The Beacon. One person told us that they feel safe because they have a personal alarm.

One person told us they were NOT SURE whether they/their loved one was able to access activities that they enjoy, another person was unable to provide a response, and one person told us that their loved one NEVER accesses social activities as they do not have any interest in this.

### **What difference has accessing the service made to you?**

Of the 21 people asked, 18 gave feedback as to what difference accessing The Beacon has made to their lives; 13 of those were people living with dementia.

All commented that they enjoyed attending The Beacon; one person shared how attending The Beacon has helped them come out of their shell and boost their confidence and another explained how attending makes them feel more alive and active as a person, as before they attended, they had started to become complacent. Since attending, they feel more confident and comment on how their family say they always come back full of beans!

Family members who completed the survey expressed how The Beacon has been like a lifeline to them, in the respect that their loved one is safe and happy and that they can then be afforded some much-needed time out.

'By coming in, it gives me a break from home life and also gives my wife a break. I have made more companions. I enjoy chatting and having a laugh with other people.'

'My mum is always positive about her time spent at Beacon although she is not able to recall any specifics.'

### **Other comments about our services**

Out of the 21 people surveyed, 17 were happy to provide additional comments about The Beacon, all of which were positive.

One person expressed that the only thing they could think of that could be improved, was the capacity of the service, as they feel it is a top-notch service, and a shame that more people aren't able to access it. One person commented on how their loved one can become anxious of the bus journey home in the afternoons, but that the staff reassure them. Another expressed that they feel the service may not be appropriate for all who



attend, and this can sometimes have a negative impact on other peoples' experience. One person commented on how sometimes the background noise can be too loud, especially because they live alone and so aren't used to such volume levels. People expressed that they really enjoy the hot meals prepared - one even said that this was one of the reasons they keep coming back!

'I just know that from the moment they come to collect I get a lovely feeling and love coming in.'

'I always feel looked after and I appreciate everything you do for me.'

'No bad comments. I always get the support I need. I feel happy to speak to any staff member if there was something worrying me. I don't like people shouting.'

'We are extremely happy with the service and have had no issues.'

'You have been excellent because caring people enable me to care for others. The staff are dedicated to each other and to all of the clients.'

'Mum has only been attending for a few months, I have always felt supported and can approach the staff with any concerns I may have.'

'I really enjoy the banter we all have together here.'

'The team is great; whoever answers the phone or emails is pleasant and helpful.'

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

A total of 12 people were surveyed about their thoughts on the Support at Home Service. Of those 12 respondents, 11 were from people living with dementia and receiving the service, and one respondent was the family member of someone receiving the service.

### I feel less lonely

50% of the people we spoke to told us that they ALWAYS feel less lonely. People told us that because of the visits they receive, they feel less lonely. One person told us that she looks forward to her carers arrival and it makes her day. She noted that having a visit meant that she felt in contact with the outside world.

'Mum really values the time and with Tracey. She makes Mum feel valued and like a friend. Mum looks forward to the visits and the lovely relationship Tracey has built with her.'

25% of the people we asked told us that they SOMETIMES feel less lonely and explained that they don't feel this way when they are with the Care Team. All three respondents explained how they look forward to their weekly visits, and one person told us that before they started to receive our visits, they felt very down, but since she's been going out and about, she feels much better, especially because she is with someone that she knows.

25% of people told us that they NEVER feel lonely and gave reasons such as living with family and an active social life as their reasons for this.

### I feel supported in and by my local community

When asking this question, it was clear that people interpreted the word 'community' differently, with some taking this to mean how often they go out, and some interpreted this question in relation to their neighbours.

33% of people told us that they ALWAYS feel supported in and by their local community. They explained that they feel supported because they get to go out with the Care Team and are invited to organisation-wide events.

'The service has enabled Mum to attend special days out such as the coach trip to Broadstairs in September and the Christmas Market visit in December. These trips helped Mum to feel independent and sociable accessing experiences she might otherwise find hard to do. Mum has talked fondly of how kind and friendly everyone was in the service community and how they celebrated her birthday and made her feel special.'

25% of people told us that they SOMETIMES feel supported in and by their local community and all three respondents related their feelings of inclusion with how often they leave the house/see their neighbours.

'Yes, by Eileen, she is in our local community. Neighbours will walk their dogs, bring in bins. I haven't really made any new friends, apart from Nadia (care worker).'

One person told us they were NOT SURE how they felt about their community and explained that they don't really use any Community Services, but they do see their regular care worker on a weekly basis.

Four people (33%) were unable to gauge how often they felt supported in their local community, but they were able to express how they felt about the care workers that visit them and how this makes them feel included

'I really get on with my carer Jane and she has helped me get out into the community, places that I love to go to.'

'I'm mixed and settled in, you make me comfortable. Without a doubt I have made new friends.'

'It has been a great help, been nice to have someone to talk to. Not made any new friends apart from you girls that have been good to have a chat with.'

'I just feel like one of you is going to come and it's nice to see your face.'

### **I feel listened to**

From the 12 people we asked, eight of them (67%) told us that they ALWAYS feel listened to. Some described feeling 'at home' when their care workers are present, how they don't really need them for anything but that they enjoy their company.

Two people (17%) told us that they SOMETIMES feel listened to and gave feedback about how their care worker makes them feel. One told us that she feels better when her care worker visits as she's nice, friendly and brings her sweets! Another told us how ever since she met her care worker, they clicked straight away; she knew she was the 'right one'.

One person, who responded on behalf of their loved one with dementia, told us that they were NOT SURE how often they felt listened to and explained that although Mum doesn't talk about having dementia, she does feel listened to and appreciated by her care worker.

'Mum doesn't talk about having Dementia. However, she does really feel listened to and appreciated by Tracey. Tracey is so understanding and respectful of Mum's dignity.'

One person was unable to gauge how often they felt listened to, but when asked if she felt that her Care Team, who visit, listen to her and provide her with choice and control, she told us that she feels comfortable with the team and that they encourage her.

### **I am supported to live safely and independently**

84% of the people we spoke, told us that they ALWAYS feel supported to live safely and independently. One person told us that although she ALWAYS feels supported to live safely, she doesn't feel 'mollycoddled' by the Care Team. Another explained how they receive a lot of support from their family as well as their care worker and this helps them to stay independent.

'The (care) visits give Mum the opportunity to go out and to do things she used to do independently such as shopping and going out for a coffee. The (care worker) has enabled Mum to still go out and deals with Mum's toileting difficulties with kindness and understanding.'

One person told us that they SOMETIMES feel supported to live safely and independently and described what this means to her.

'They are helping because they ask me once and if I say "no" then they don't ask again. You don't interfere with me. Yes, they always say, "do you want to" and not "let's go there"'

One person was unable to gauge how often they felt supported to live safely and independently but did tell us his memories of his very first care worker, who has since left the team. He also told us that he is always given choices.

### **I am able to access information and advice**

When asked about access to specialist information, this was interpreted differently by each individual and some respondents found it difficult to answer.

42% of people who responded told us that they ALWAYS feel supported to find correct and relevant information, explaining that they felt confident they would be able to access information from us if they needed to, and that if they've asked any questions in the past, they've always had an answer.

17% of respondents told us that they SOMETIMES feel supported to access information and explained that their family usually seek advice and information on their behalf.

33% of people were NOT SURE how often they felt supported and explained that they didn't understand the question being asked.

8% of respondents were unable to gauge how often they felt supported but did go on to tell us that their families were very good at finding things out for them if they ever had a question, and that they felt comfortable to ask the Care Team questions about their health.

### **I am able to access social activities**

50% of respondents told us that they ALWAYS feel able to access social activities and gave feedback about lots of different places they had been to with their care worker. One person spoke about how much they enjoy the ADSS 'functions' and how they 'love it' when they are with their care worker, Leah.

'I like going out walking around the shop, I feel safe that you are with me and when we go on walks. Or just sitting and chatting.'

34% of people told us that they **SOMETIMES** are able to access social activities, and one person expressed their love of walking, and how safe they feel when their care worker is with them. She especially appreciated that the care worker doesn't hang on to her when they're out and about.

One person told us they're **NOT SURE** if they're able to access social activities, and explained they feel 'too old for all that', and one person told us that they **NEVER** feel able to access activities and explained how they don't really get to go out much at all, but used to enjoy tap dancing, acrobats, sewing and knitting, but doesn't feel she has the energy to do it anymore.

### **What difference has accessing the service made to you?**

All 12 respondents were able to provide us with a detailed explanation of how the Support at Home service has changed their lives and all 12 responses were very positive. People clearly look forward to planning visits out and appreciate that the Care Team encourage them to do things they might not otherwise be able to do alone. People told us that their lives feel happier, that the team of care workers are fantastic, friendly, caring and look after people well.

'You made my life like Christmas.'

'I personally feel Tracey goes above and beyond on every visit. She has organised pick-ups for Mum on special trips because we have been unable to get Mum to the pick-up point so she can be included. She has dealt with Mum's incontinence with discretion and kindness and just always makes Mum feel valued and accepted.'

'Yes, because someone comes in and helps me and has meant I can stay at home. Gradually my life has changed because I can't do the things I used to, and it's changed my life so I can stay in my own home. Nadia knows I like football and she always makes sure she tells me when it's on and helps me find the channel.'

### **Other comments about our services**

Nine people gave us additional comments and described how much they like the care workers that visit, and no one provided any suggestions for improving the service.

'I think they are very good, I lead a happy life to a certain extent, she's so nice.'

'Nothing you could do better your company is fine just the way it is.'

'I really look forward to Nadia coming she is a good friend and had made a lot of difference. She is wonderful. Everyone always been very helpful.'

'This is a wonderful service - thank you!'

'No issues, you couldn't do better you're all very patient.'

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

We received six responses to the survey and all the responses were from people living with dementia and accessing the Support at Home Plus service.

### **I feel less lonely**

Five people responded that they ALWAYS feel less lonely, and one person reported that they SOMETIMES feel less lonely. People related their feelings of loneliness with their visits from the Care Team, with all respondents reporting that they enjoy having company and people to talk to. One person commented that they felt the staff 'knew what they were doing'. The person who SOMETIMES felt less lonely described how they enjoy knowing that someone will be coming to see them.

### **I feel supported in and by my local community**

Three people responded that they ALWAYS felt supported in and by their local community. Three people reported that they feel this SOMETIMES. It was clear from reading the responses that the word 'community' was interpreted in different ways. Some people related this to the neighbourhood in which they live and others in relation to the visits they receive from the Care Team.

One person who told us that they ALWAYS feel supported and commented that the Care Team make them feel included in the community. Another person who reported that they SOMETIMES felt supported by their local community, commented that although they have friends in all different places, they also feel they have made friends with the Care Team, as they keep coming back!

### **I feel listened to**

Out of the six people asked, five told us that they ALWAYS feel listened to, and one person felt they were listened to SOMETIMES.

When asking the questions to the respondents, the team has focused on gathering insight into whether the individual felt listened to by the Care Team, whether that be about dementia or anything else of importance to them.

People commented that the team is always honest, make them happy and encourage them to speak freely. One person couldn't remember the names of any of the ladies who visited her but commented that they were always very nice.

### **I am supported to live safely and independently**

Of the six people asked, three said they ALWAYS felt supported to live safely and independently. Two people felt they were supported SOMETIMES and one person was unable to answer the question. Someone who told us they ALWAYS felt supported commented that the team always put their wellbeing first. Another person always felt supported because of the help they receive from the Care Team.

People who SOMETIMES felt supported to live safely and independently explained that they are independent and are supported to make their own choices. One person commented that to her, it was a good service that was worth it, and that we responded to her needs.

### **I am able to access information and advice**

Of the six people asked, three people reported that they ALWAYS felt supported to access relevant information, two people felt they were SOMETIMES supported, and one person was unable to respond. This was a difficult question to break down for people and not everyone understood what was meant by the question. Instead, the team focused on obtaining comments from people about whether they felt they could ASK for help.

One person who said they ALWAYS felt supported, commented that they absolutely knew, that if they needed anything, we would help. Another person said all questions asked were always answered. Another commented that they couldn't remember any specifics but wanted to state that she ALWAYS felt supported.

Although one individual was unable to gauge how often they felt supported, they did comment that the Care Team always help them with anything they needed from the GP.

### **What difference has accessing the service made to you?**

When asked about the difference this service has made to them, all commented on how much they enjoy having company and someone to listen to them. One person said she didn't just like the girls who visit, she likes them a lot. She commented on how the girls help her husband, as well as her, and she prefers it that way. One person stated they thought, because of the visits they receive, they perhaps aren't as selfish as they may have been with just their own opinion to think about! Another person said that things have got a lot better for them since the team started to visit; they couldn't put their finger on what has got better, they just knew that it had. One person commented that having their visits gave them good company and a good atmosphere, and she knows that the team is always there for her – if she wanted anything, the team would do it. One person stated that the service had 'totally changed their lives'..

### **Other comments about our services**

Five people provided additional comments. No one gave any suggestions on how they thought we could improve the service but were happy to share that they hadn't had any issues, that the team works well together and how they look forward to their visits:

'No nothing better. I look forward to the girls coming in, always have a laugh, good for the soul. I am either laughing or singing.'

'I like to hear other people's views and ideas it's nice to know that I'm sharing my views. I think you are very nice and considerate and very friendly towards me. I feel that the best way you can get information by being kind you are more than just visitors you are my friends as well.'

'It all seems quite good.'

'I think you all work well together'.

'Noooo, no issues.'

### **What did people tell us about their experience of our telephone system?**

Out of the 99 people who responded to our surveys, 39 of them were willing to provide us with feedback about our telephone system.

95% of these people told us that they were ALWAYS able to speak to someone when they called us.

60% of respondents told us that they felt it was EXTREMELY EASY to get through on the phone, to the person or team they wanted to speak to. Only 5% of respondents (two people) told us that they felt it was NOT EASY to get through to the person or team they wanted to speak to.

Comments received provided evidence that people feel that, whoever they get through to on the phone, they're always met with a helpful response and are either connected to the relevant person or a message is taken so that the staff member can call back when available.

One person shared that they find the telephone system very confusing as they're unsure of which option to choose, but also commented that once connected to someone, the staff are always very helpful.

## You said, our response.....

You said.....	Our response.....
I was isolated and unsupported due to services being unavailable during lockdown, facilities being closed, Covid restrictions or volunteer shortages.	From the point of the first lockdown we acted quickly to ensure that people were still able to access some form of support. This started with our singing group going virtual during the first week and progressed to a variety of virtual support groups and activities. We also carried out regular welfare calls for those that were most vulnerable and sending weekly activity packs by post. Our support at home service continued thanks to the dedication of our care staff and the safety protocols that were put in place. However, we understand that none of this replaced our usual face-to-face services and were pleased to be able to start reopening these services.
'Invitation only' for support groups affecting ability to form connections and access peer support.	Restrictions due to Covid resulted in an invitation only approach when resuming groups, however we are pleased to now be able to start opening up the groups to full capacity.
Emails to <a href="mailto:info@alz-dem.org">info@alz-dem.org</a> not being dealt with in time / a shared mailbox address would be helpful, sometimes I send an email to someone who is on holiday.	We are currently looking at how people contact us to make it as easy as possible to get to the right person. We have set up some more shared email addresses and we have also given more staff access to the info email inbox to ensure timely action. We will also ask all of our team to ensure good practice by having an email out of office reply with alternate contact details for when they are away.
Please repeat the boat trip.	We are pleased to be able to expand the types of activities and events we offer so that there is something for everyone.
Long waiting time for second day at The Beacon.	We try to facilitate attendance on people's preferred day of the week, but this isn't always possible. If you have been on the waiting list for a second day at The Beacon, we would urge you to consider choosing a different day to attend. In any case, as soon as a place becomes available, you will be notified.
Unclear which member of staff to contact.	Over the past few years our resources have been tight and so we have had to sometimes all do a bit of everything. However, with our new dementia coordinators and changes to our phone systems we it should be clearer who to contact when.

Want to be able to see what's on each week on the ADSS website.	We currently share a schedule for the week ahead every Monday on social media however we agree that this will be useful to also have on our website. The development of this is currently in progress.
Increasing capacity at The Beacon.	We have capacity to support 18 individuals each day, Monday-Saturday. We cannot increase the capacity within The Beacon, as the room is simply too small. We plan, as part of our strategy, to facilitate 'satellite' day centre services where the same level of support provided within The Beacon can be replicated in other areas within our catchment areas.
Noise levels in The Beacon can be too high.	We have received funding to go ahead with our plans for a garden area, accessed via The Beacon, to not only provide people with the opportunity for fresh air, pottering in the shed or tending to plants, but to also create another space for small group activities, which in turn will help reduce the amount of time all attendees are together in one room.

To view our 5-year Strategy (2021-2026), please visit our website [www.alz-dem.org](http://www.alz-dem.org)

“ADSS is a very good service, and it is there if you want it. It is brilliant! If I feel I am getting worse, I will know to turn to ADSS.”

“You are just invaluable, friendly, helpful. Social media is very uplifting it has made things look brighter. It is not all doom and gloom. There are positives that can come out of this. It has been comforting.”

“I feel you are person-centred care and I feel you provide a personable service that we can rely on and know that we always get a prompt response. I know that things get sorted and my mum's problems always have great support. I feel ADSS has taken the time to help and support us as other organisations have been too busy to help.”

## References

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