The Difference We Make:

Annual Evaluation of the impact of our services

2024

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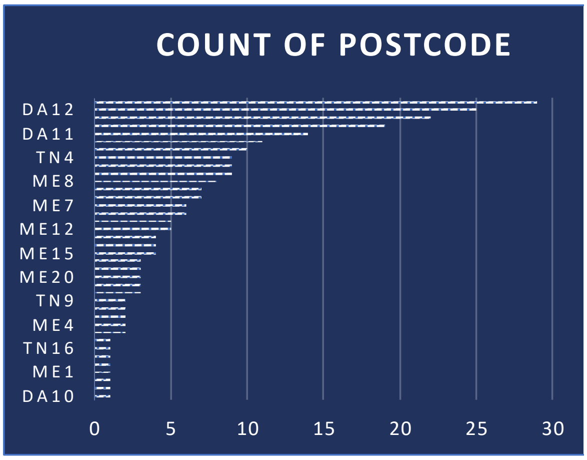
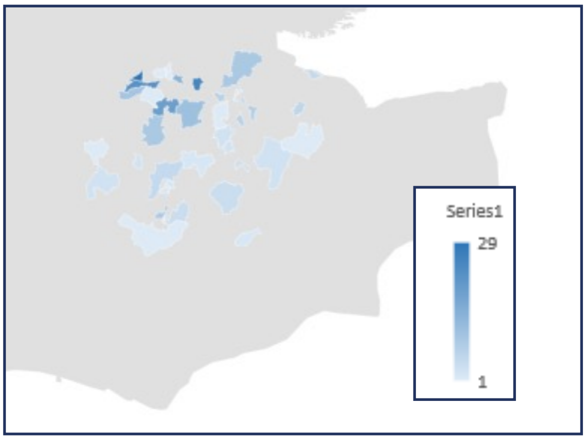
Introduction

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.

Across Kent and Medway[2], there is currently an estimated 27,000 people living with dementia. Of these, approximately **15,000 people have mild dementia**, **8,750 have moderate dementia**, and **3,500 have severe dementia**. Currently, two-thirds of people with dementia live in their own homes, and one-third live in care homes. The number of people living with dementia in Kent and Medway is expected to rise to over 38,000 by 2030.

At **Alzheimer's and Dementia Support Services (ADSS)**, our mission is to give people affected by dementia the knowledge, support and care they need to take back control of their lives, take part in family and community life and manage their symptoms. Our **annual evaluation** not only helps us to ensure we are achieving that, but it also helps us to grow our understanding of what people affected by dementia want us to do to continue achieving that mission. Previous evaluation feedback has helped us to further understand what is needed from us and we are now embarking on a bold new strategy.





By 2030, ADSS will be an **award-winning**, well-known and sustainable charity for people living with dementia and their Carers. We will ensure the delivery of high-quality and evidence-based services to all communities across Kent and Medway, and we will

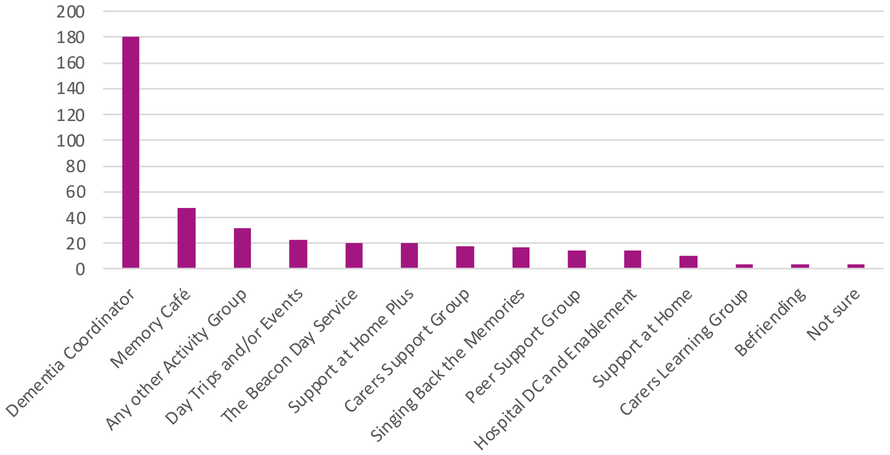
By 2030, ADSS will be an award-winning, well-known and sustainable charity for people living with dementia and their Carers.

champion the rights and aspirations of those affected by dementia. For more information about our new strategy, please visit our website and search **'Strategy 2030'**.

The evaluation was focussed on people's overall experience of the charity; however, we did ask which specific services they had accessed in the last 12 months. The key findings throughout the evaluation addressed nine broad questions. However, there were additional questions relating to Carers, our Hospital Dementia Coordinator and Enablement Service and the experience of other professionals. As you can see from the charts, all of the areas we currently serve were represented in the feedback.

All our services were represented within the feedback received. Our **Dementia Coordinator service** was accessed by a larger number of people taking part, which was to be expected as this is the service that is accessed by most people and is available in all areas that ADSS serves. Of the 232 people that took part, that have accessed our services, 87 have accessed more than one of the services ADSS provides.

Services accessed in the last 12 months



Background

ADSS is Kent's biggest independent charity dedicated to providing support to people affected by dementia. Having worked within the Dartford, Gravesham and Swanley area since 1991.

ADSS expanded its reach and began supporting people living in Medway, Swale and West Kent in April 2022. The services provided aim to ensure that those diagnosed feel supported throughout their experience of dementia and can live the life they want. They also aim to ensure Carers, family members, or others involved, are supported.

There are three types of service offered. **Dementia Support**, which includes information, advice and guidance. **Dementia Wellbeing** which includes community groups and activities and **Dementia Care** which includes Support at Home and The Beacon day service. This report describes the findings from evaluations undertaken throughout May, June and July 2024. This is the third annual evaluation to take place following a pilot evaluation that took place in 2021.

The evaluation questionnaires were designed based on our learning from previous annual evaluations and the Key Performance Indicators (KPIs) set 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, including the option to say they were not sure, and the opportunity to speak freely.

Between April 2023 and March 2024 **ADSS supported 6,225 people**, an increase of nearly **1.5K** people from the previous year.

Aims of the Evaluation

As well as helping us to understand if we are delivering on our mission and purpose, our evaluation aimed to answer two broad questions:

1. **How do the services we provide impact on the people we support?**
2. **Has ADSS met the KPIs set by KCC?**

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, 267 people gave us their views, an increase from 137 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. 178 people took part in the 1-2-1 discussions, and 89 people completed the online form. The total number of questions varied depending on the service/s they had accessed and whether they were people living with dementia or Carers or other professionals.

Who took part in our evaluations?

Of the 267 people who took part, 101 were people living with dementia, an increase from 77 last year. 129 were Carers, an increase from 57 last year. Two people living with dementia and their Carers opted to provide their feedback together. In addition, 35 professionals took part, we have not previously opened the evaluation up to other professionals.

> *I know I have a number that I can contact now. I have friends but this feeling is a different kind of loneliness so being able to reach out to you helps. Friends don't always understand whereas you do.*

> *I felt quite isolated before and thought I had to muddle through, but you took away that feeling and with your support I know now that I don't have to, you have given us the guidance we needed.*

Interpreting the findings

All individuals that accessed our Dementia Coordinator services throughout May, June and July 2024 were invited to take part in the evaluation using their preferred method. We also invited a selection of those that regularly access our other services to take part in evaluation discussions. The purpose of selection was 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 also shared via email, on our website and through our social media channels.

Although Carers are not directly supported by The Beacon, Support at 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.

Whole Organisation:

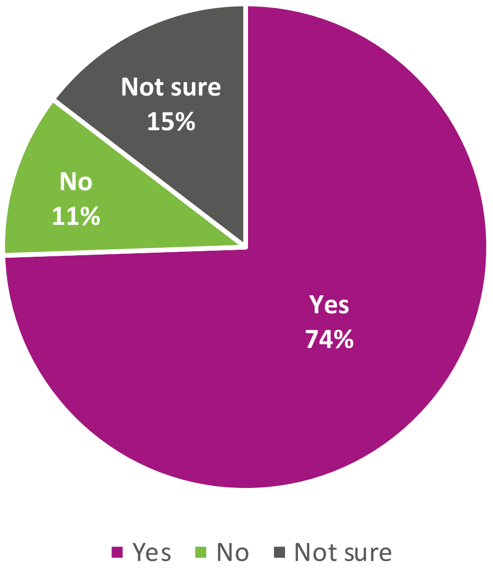
Do you feel less lonely since accessing our service/s?

105 people told us that they had experienced loneliness prior to accessing our services, 32 were not sure. Of those 137 people, 102 people stated that they do now feel less lonely as a result of our services. 20 were not sure and 15 stated they did not feel less lonely since accessing our services. More than half of those that told us they do not feel less lonely live in areas where we currently do not provide Wellbeing or Care services.

When asked if they could tell us more, some stated that lack of motivation impacts on their loneliness and several people talked about being bereaved and missing their loved ones. A couple of people told us that they feel lonely when their mood is low, and a Carer told us loneliness was caused by the person living with dementia declining to access services.

One person stated that they would like more visits from their Dementia Coordinator. Another lady accesses telephone Befriending from another provider and stated she would prefer that to be face to face. Lots of people told us how our services have helped them to form new friendship groups which have become vital support networks for them. Lots of people also talked about what a difference it makes to know they can call ADSS, naming staff members they have regular contact with, but also how reassuring it is that ADSS contacts them

Do you feel less lonely since accessing our services?



> *ADSS Dementia Coordinator was the first point of contact of help after being diagnosed and didn't know what or where to turn to so that has made me feel safer.*

> *I feel safe knowing that ADSS are there to help me and my husband.*

> *Everyone is very caring we feel we can leave dad in a safe environment.*

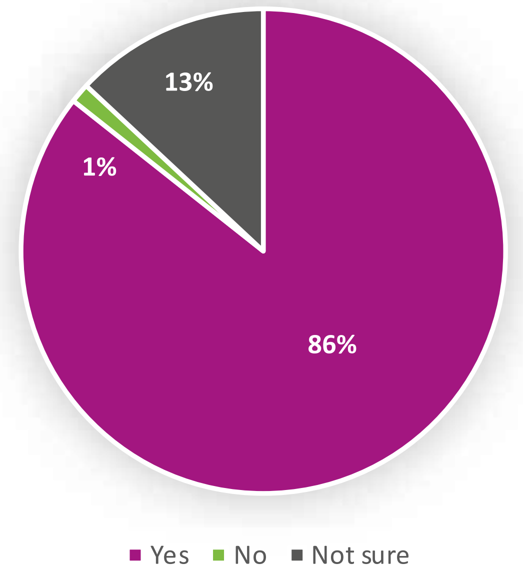
> *I feel more secure with ADSS in my corner.*

> *I'm a bit wobbly on my feet so having you with me gave me more confidence to move around.*

Do you feel our service/s helps you to feel safe?

197 people answered yes when we asked if our services help them to feel safe, 30 were not sure and three answered no. One person who said no told us that, as next of kin, they would feel safer if their loved one was in a residential setting and another told us they would feel safer if they had more visits from their Dementia Coordinator. A few of those that were not sure explained that they had already felt safe, and one Carer explained that they did not always feel safe as their loved one had declined services.

Do you feel our service/s helps you to feel safe?



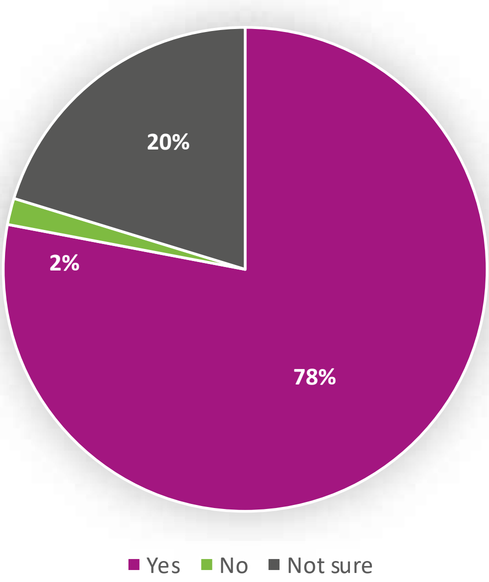
Do our staff encourage you to do the things you are able to do?

This question was worded slightly differently for the Hospital Dementia Coordinator and Enablement service to reflect the aims of that service. We asked people that had accessed that service if we had helped build their confidence to live independently. Out of 12 people, five answered yes, one answered no and six said they were not sure. Unfortunately, the person that answered no was not able to tell us more. Most of those that were not sure explained that they had not lacked confidence in the first place, one person stated that they were not able to leave their home without support.

For all other services, 172 people answered yes, three answered no and 40 were not sure. One of those that answered no stated that they felt they could do more and would like to try, another referred to The Beacon and explained that it was because staff have to support a room full of people. The third person explained that it was because the person they care for suffers with chronic pain therefore is limited in what they can do. Several of those that stated they were not sure explained that the question was not relevant to them, and some felt it was too early in their relationship with us to know.

One person explained that their mobility restricts them, and a few Carers explained that it was because their person living with dementia declines to do things. Most of the people that answered yes explained that they have been encouraged to take part in a variety of activities available to them, there were several references to the variety of options provided by ADSS, including things they would not have tried without our encouragement, such as pétanque and cycling.

Independence enouraged



> *Yes, I have gained more confidence, and I have gained this from Christina. She has given me lots of knowledge and grown my confidence.*

> *We as a family feel we are now more in ‘control’ of the situation.*

> *I am still living very independently but Julia has encouraged me to carry on doing what I am doing and to get out and enjoy life and live each day as it comes.*

> *I am the main Carer of my husband, so I never came out, always stayed at home. Since the launch of the Memory Cafe at the Guru Nanak Wellbeing centre, I have felt encouraged to go out more and feel I am helping the community.*

> *We are now planning to go out and be with people as often as is possible.*

> *ADSS is very professionally run organisation with a person-centred approach.*

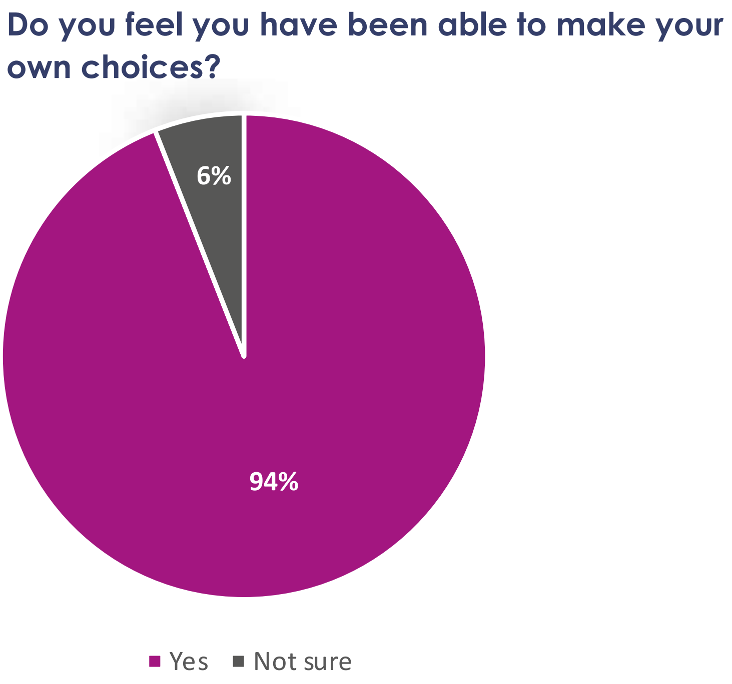
> *I like to support my husband myself and you knew that and did not put any pressure on me to change things but made me aware of what was available.*

> *I was worried about letting mum do things for herself, but Lynne gave me the knowledge to help me to help mum to do more.*

> *I like to make my own choices, it's very important to be heard and our choices listened to.*

Do you feel you have been able to make your own choices?

205 people answered yes to this question, 13 were not sure and nobody answered no. A couple of people that answered not sure explained the question was not applicable to them. A Carer stated that her choices were limited due to her Caring role. Most of those that answered yes explained that we have provided them with all the information they needed to be able to make their own choices.



Do you feel that when you need information, we would be able to give it to you?

This question was rephrased for the Hospital Dementia Coordinator and Enablement service, we asked if they felt we had given them the information they needed during that time. Overall, 218 people answered yes, 14 were not sure and nobody answered no. One of the people that was not sure explained that they have been signposted and then collected their own information from there, another said they hope they have all the information they need. Many people that answered yes talked about the variety of information we had provided, including diagnosis, health, financial support, legal guidance, activities, Carers support and other services that would benefit them. Quite a few people alluded to the fact that they have been able to get the information they need

> ***“I feel that when I reach out to you, you have the suitable connections to support me.”***

> ***“Staff are very cheerful, helpful and kind with very good communication.”***

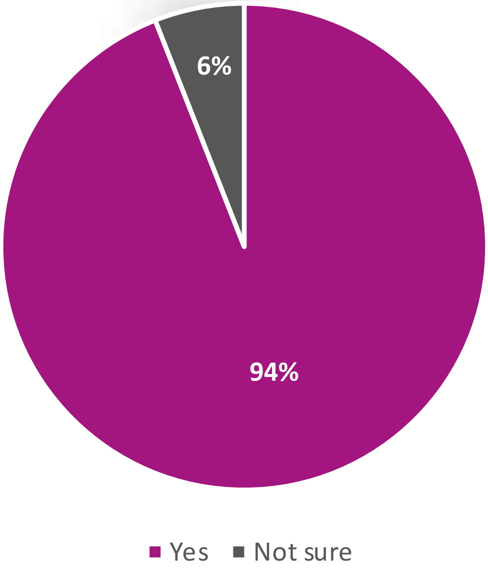
> ***“There is never any pressure to get involved but lots of encouragement and they always follow through with what they say and keep in regular contact, which is very much appreciated.”***

> ***“The staff are knowledgeable and can always provide information.”***

> ***“I feel that I can call ADSS at any time to get advice and help when needed.”***

at that time and then have got further information when their situation has changed, also that they were confident they could contact ADSS whenever they need additional information. A few people mentioned how information provided by various speakers at Memory Cafes has been helpful. One person did state that they were provided with too many leaflets, including ones they may not have needed at that time, others stated they found this helpful as they had them to refer to at a later date. A few people stated that if ADSS could not provide the information they would always either find it and get back to them or refer them on to someone that could.

Do you feel that when you need information, we would be able to give it to you?



Have you been able to access social activities that you enjoy?

An option to answer 'Not Applicable' was included for this question as not all services we provide offer activities, we also learnt from last year that some people did not want to access social activities and therefore could not answer yes or no. Of those who did opt to answer this question, 127 said yes, 34 said no and 17 were not sure.

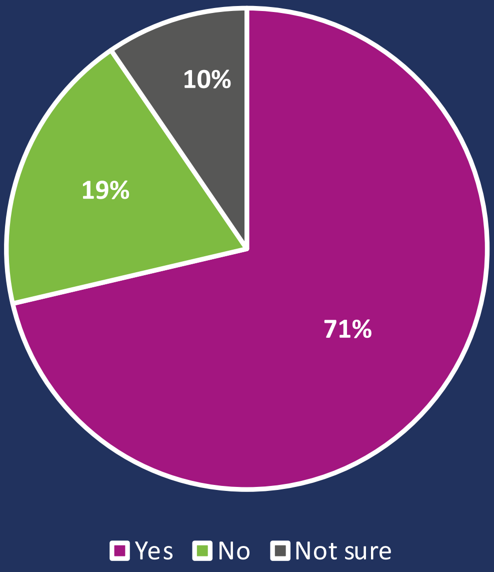
More than half of the people who answered, live in areas where we do not currently offer Wellbeing or Care services. Many people that answered no explained it was either because the person they are a Carer for declines to take part or it is because of their other health issues. Some hadn't had a chance to try the activities available yet. A couple of people talked about not having many people visit them at home and some Carers explained they don't have time to access activities for themselves. One person said they'd like more trips.

Those that were not sure also mentioned the person living with dementia not wanting to take part. Those that answered yes talked about the variety of activities available, such as bowling, golf, pétanque, walking, cycling, chair fit, quizzes, dancing, cards and crafts. A few people talked about how much they enjoyed the ADSS trips and others explained they liked how the activities give them an opportunity to socialise.

> *"I go for walks now when [my person living with dementia] is in his groups which has made a huge difference to my wellbeing."*

> *"Apart from the day centre, there are regular outdoor/ outside activities to choose from too. Something for everyone and at all levels of need & requirement."*

Have you been able to access social activities that you enjoy?



> ***ADSS has linked me in to so many other organisations which just reinforces that I am part of a wider community.***

> ***I feel very much so part of a community. I feel included.***

> ***Made so many new friends, both me and my husband.***

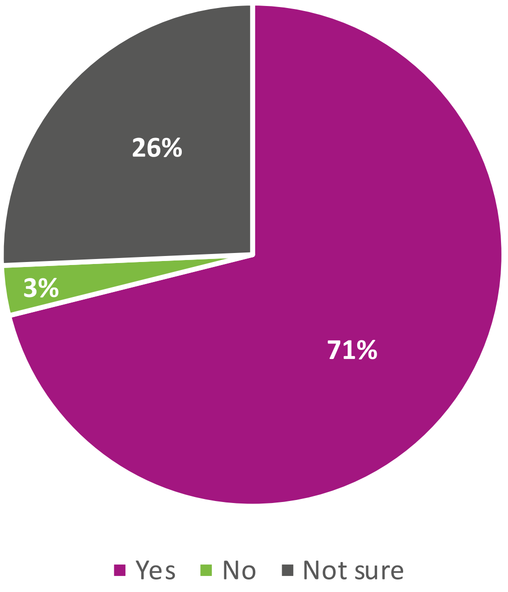
> ***I know that I have someone to speak to if I am just having a bad day or need some advice. We have attended a cafe and now meet some of the others on separate occasions.***

> ***Yes, I do feel part of the community and I know if I wanted to do more you would help and you are all friendly.***

Since accessing our services, do you feel like you are part of our community?

155 people answered yes to this question, seven said no and 56 were not sure. Of the seven that said no, only two explained further, one of whom stated that the person living with dementia had chosen not to engage in our services and the other explained that they have always felt part of a community. Many of those that were not sure explained that it was too early to say as they were new to our services and others explained that it was because the person living with dementia had declined to attend any groups and/or activities. Those that answered yes talked about how they'd made new friends through ADSS and how they now feel like they have access to a support network.

Since accessing our services, do you feel like you are part of our community?



Do you feel listened to by our staff?

229 people answered yes when asked if they felt listened to by our staff and three people were not sure. Nobody answered no. One person that was not sure explained it was because they'd only had contact with one person from ADSS so far, another explained that she had difficulty understanding phone conversations so hands the phone

> *More so than any other service, appreciate how quick the next call came in.*

> *Because she listened to me and acted on my concerns which gave a positive outcome.*

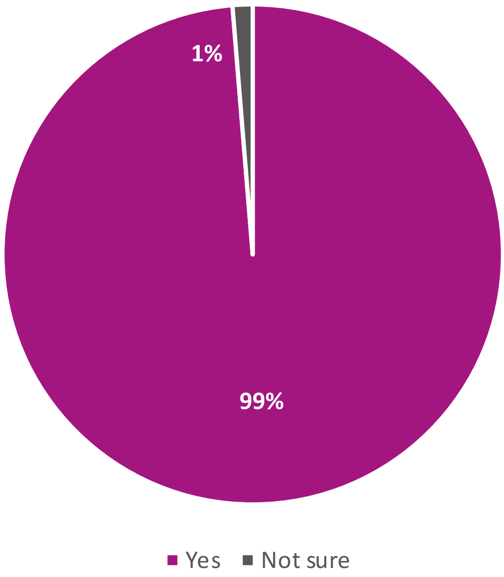
> *I don't feel ignored.*

> *You put us on the right pathway and we appreciate it as it can be a minefield navigating the system - you feel like no one is listening sometimes and you need to shout, but you have made it easier.*

> *Sometimes just need a chat. You help when it's needed.*

to her husband and the other person told us that they didn't think there was any more we could do to make them feel listened to.

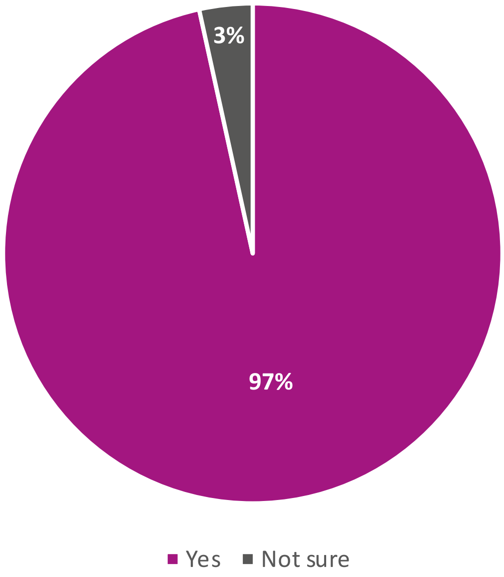
Do you feel listened to by our staff?



Do you feel our staff understand you?

224 people told us that they feel our staff understand them, eight people were not sure, nobody said no. One of the people that was not sure explained that it was because they had only interacted with one person from ADSS. One person told us that as we are not on our own all night we could not understand what it is like for them, and another told us that some of the staff understand but not all.

Do you feel our staff understand you?



kind words about the services we offer at ADSS

I have needed help arranging care for my husband while I have an operation and Christina was very quick to act on my behalf.

I was supported 100% by Sam. I could not obtain the correct dementia patches from the pharmacy (for my husband). Sam promptly liaised with the memory clinic, who liaised with the pharmacy, so I was able to get them in the end. I would have not been able to do this on my own.

I felt I was going to crisis coming to terms with (partners) diagnosis. The Carers learning group really helped me.

Care coordinator is a valuable person to go to, have used ours (Sammie) a lot and having her check in calls at regular intervals is lovely”

Lynne has always had time to listen to me when I phone, even when it was just to let of some steam about my situation.

Care coordinator is a valuable person to go to, have used ours (Sammie) a lot and having her check in calls at regular intervals is lovely

Beth has been in constant contact with me with regards to my Mum showing signs of declining. Mum unfortunately had a fall and broke her arm, and Beth has been absolutely outstanding supporting me for moving forward. Lots of advice and help has been discussed and we are still working together for mums' future support.

Amy helped us immediately and put us in touch with the services who could help us, then she followed this the next day with a call to not only check on mum's situation but also to enquire about my sister, my Dad's and my welfare.

I feel reassured since Su's visit, somewhere to turn to in a crisis, a practical lifeline

There was a breakdown in family relationships which resulted in social services being involved. Christina initially came to see me and helped enormously. Lynne attended a meeting with the family and social services and made sure that all views were heard which resulted in a plan being put in place that all were happy with. I couldn't have got through it without ADSS help.

The coordinator is like the common sense and the glue between dealing with organisations who can be difficult to contact and the NHS.

> *Take away my guilt of not being able to do as much as I'd like.*

> *The regular calls make me feel supported. Kelly always follows through with what she is doing, I felt lost before I had Kelly's support.*

> *I think you have done everything and gone beyond with the support that you have offered; we did not realise the help and support that was available before your visit. I think more people should know about your service.*

Carers

To help us achieve our strategy aims to support Carers, we asked them some additional questions. Firstly, we asked on a scale of 1 to 5, how supported they feel in their Caring role by ADSS for which we received an average rating of 4.53.

44 Carers had experienced a crisis during the last 12 months, 33 of those people felt we were able to support them sufficiently throughout the crisis. Six people that answered no explained it was because the crisis was prior to them knowing about ADSS, two explained it was because they did not reach out to ADSS during the crisis and the remaining three told us that they did not need support from ADSS at that time as they had sufficient support from family and friends.

We also asked them what more we could do. The vast majority of people taking part told us they do not feel we can do any more than we currently do. However, others made some suggestions. This included raising more awareness of ADSS for signposting purposes, in particular with GPs, and to provide clear information about the different services, perhaps providing a directory to include all relevant services and a monthly update for upcoming activities. With regards to groups, a suggestion of having more for just the people living with dementia to free the Carers up was made and to have a drop-in and chat type group just for Carers and more evening groups for Carers that work. A suggestion for The Beacon to be available 9am to 5pm was made. A couple of people mentioned the need for more opportunities to bring together those with rare and young onset dementias. The desire for more visits from the Dementia Coordinator was highlighted, as well as more frequent check in calls, although they also stated they know they can contact us in between.

The people providing that feedback live in areas where we do not currently provide community wellbeing services. One person told us verbal promises had not been kept, unfortunately they did not provide their contact details for us to be able to find out more.

> *I found support at home and birdie really great. They understood that I needed this information to be able to be sure Mum & Dad are ok.*

> *I feel that everyone I have met at ADSS understands the role of the Carer when someone has dementia.*

> *Having help as a Carer from ADSS support at home making me feel less alone, having contact details. Using birdie helps me know what has been done for Mum & Dad.*

We hope that, if you are reading this, you will contact us so that we can rectify this. Another person said we should put down pen and paper and computers and get in the real world to see things from their perspective. We are sorry to hear that someone feels this way. We have to keep accurate records of the support we provide to enable us to ensure consistency and to keep people safe. Many of our staff have personal experience of dementia, and all staff receive training in dementia and have regular contact with those affected. If anyone has these types of concerns, we encourage you to contact us so that we can reassure you and restore your faith in our services. Our annual evaluation helps us to see where we have not got things right or could do things better. Where people have left their details, we have contacted them to make sure we could put things right. We thank everyone who has given us formative feedback as it enables us to keep learning and growing.

We have recently facilitated a Carers Forum to gain further insight into how we can better support Carers. The outcome of this is that we will be starting a co-production group to develop our services. The feedback received from this evaluation and the forum will be used within that development. In the meantime, we have responded to some of the suggestions made in the 'Anything we can do better? You said, we respond' section of the report.

> *I am aware that I'm not the only one going through this journey caring for parents/in-laws with dementia. Learning from others going through this hard journey has taught me a lot. I have made new friends and enjoy going to group's/ outings, we are there to support and advise each other.*
>
> *Good to always know that there will be someone from ADSS at the group's we attend and that they and their help is only a phone call away.*

> *Absolutely feel included, from young to old, from early stages to the end we feel involved. Great new friends made along the way, not only do we make friends we become supportive of each other, even after the journey has ended, we are still there for each other. This is so important as after the end of your journey, the loneliest can start all over again. Bereavement support is so important as well.*

"It is good for us as an organisation to be able to signpost clients and or family members to ADSS, knowing they are a specialist organisation that can offer support to a person with dementia and their families."

"As a company we cover a number of areas, including several not covered by ADSS. I have always been of the view that Dementia support is a postcode lottery. ADSS and their continued expansion is helping to ensure this is becoming less of an issue in the Kent area."

Partnership working

36 professionals provided us with feedback. 28% of those professionals represented NHS Memory Services. The remainder represent GPs, Local Authorities and other organisations. 44% of participants work in the Medway area, 33% work in the Tonbridge area and the remainder work across Gravesham, Dartford and Swanley.

79% were aware of all the services provided by ADSS, the remainder were aware of some of ADSS services, nobody was not aware of any services. When we asked what more we can do to increase awareness of ADSS, suggestions included regular dissemination of printed leaflets, emails and newsletters and attending external team meetings, shared information events and other wellbeing services to talk about our services. One person suggested fundraising events. Many told us they think we already do a great job of raising awareness and talked about the excellent relationship they have with ADSS.

"As Community Wardens we work directly with your service and was initially made aware of the service by direct contact from your amazing Dementia Coordinators. Personally, I think the two-way referral system works well, we will refer to your service and your service will refer to us. It is also good to see representation at the multi-agency networking events. Your social media is also really helpful at reminding people what is on and where."

When we asked participants to rate us out of 10 for partnership working, we received an overall average of 8.31. Unfortunately, it was not clear from the feedback from those who rated us 5 or below what we could do better. One person did tell us they would like more information about our services, another person actually stated that they were happy with the way we are working now. It was suggested by a Community Warden that there could be opportunities for a potential area meeting to raise awareness of potential residents living with dementia. Those from health services explained how they remain aware of our services through the local Multi-disciplinary Team (MDT) meetings.

“You could only improve if you were commissioned to have more of you and the value that you bring in terms of direct intervention or support and psychologically making people feel reassured about having you as a service.”

A fellow voluntary organisation talked about the struggle with referrals into their service from local doctors’ surgeries and whether maybe this is something ADSS could help with.

“I personally have a very good working relationship with ADSS, myself and the Dementia Care Coordinator will discuss patients that we have both encountered. We both attend the PCN MDT and there have been joint assessments and home visits completed by both.”

We received a 9.39 average rating out of 10 when asked if our staff are reactive in a timely manner. One person told us it would make a difference to have a hub, like Safeharbour, in Medway. A representative of Social Services said they need to know the outcome of the work we have done with individuals. One person told us they have an excellent relationship with ADSS management but need to further develop the relationship on a local level.

“Very quick to respond to queries via email, very responsive to referrals and assessments are completed in a timely manner, open communication is good and effective with involving other professionals that could aid in the care of the patient.”

89% answered yes when we asked if our staff are knowledgeable about a variety of aspects of dementia, 11% said most of the time, nobody answered no. The only suggestion made to help us improve was from one person who told us we could increase our knowledge of Behavioural and Psychological Symptoms of Dementia (BPSD). There were many comments about the breadth of knowledge our staff have.

“We have never for one minute doubted the knowledge and skill your teams have. In an ever-increasing world where dementia for us as a team seems to be growing, it is reassuring to know we can contact our Dementia Coordinators, and they are on hand to listen and advise and mostly reassure us that our actions and support were correct and supportive to the families living a Dementia journey.”

When we asked participants to rate us out of 10 for our staff being polite, approachable and helpful, we received an overall average of 9.67. One person rated us 5 but explained that it was because they do not have direct contact with our staff but that the people they have referred are satisfied.

"Always more than happy to help and offer guidance and support, always friendly and always has a smile even when having a very stressful day, still always very professional and kind."

We asked participants if they were aware of our Dementia Coordinator service, all but one were. 32 of those that were aware told us they have a good working relationship with our Dementia Coordinators, three felt it could be better. One of those represents another voluntary organisation and two represent social services, one of whom explained that they would welcome joint visits.

We received a 9.44 average rating when we asked if ADSS makes a difference to people affected by dementia. There were lots of positive comments, including how we have made a difference by supporting where there are Safeguarding and Best Interest matters and it is reassuring for memory services that we are there for people after they are discharged.

Case Study: Doreen

Doreen had been caring for her husband who had been living with undiagnosed dementia for approximately 7 years, they hit crisis point with his poor health where he was then admitted to hospital and the proceedings of his vascular diagnosis commenced.

Although Doreen requires a lot more help these days her family feel that all the support and services from ADSS enable Doreen to stay in her home.

He never returned to the marital home and moved into a nursing home. Whilst Doreen and her family were going through this difficult time, it became evident that Doreen also showed signs of declining cognition, however the family thought this may be stress related. After approximately six months and no improvements with Doreen's declining cognition her family took her to the doctors, where she was referred to the local memory clinic.

Doreen was diagnosed with Alzheimer`s some months later and she found this hard to come to terms with. Her family encouraged Doreen to continue catching the bus to visit her husband at the nursing home, they supported her by taking her shopping and attended local ADSS support groups with her which Doreen was reluctant to do at first but soon grew to love them.

Unfortunately, Doreen`s husband passed away from covid 19 a month after lockdown began, this, along with the isolation caused by lockdown, started to have a detrimental effect on Doreen. It was clear that she was missing socialising, and the reduction in her confidence was evident. Her family continued to support as much as possible but also took into consideration the risks of keeping her safe from the virus. Coming out the other side of covid, Doreen`s Alzheimer`s had deteriorated considerably and she was requiring a lot more direction and support with various activities of everyday living. It was at that time her family had a follow up assessment with Doreen's Dementia Coordinator, and it was explored with Doreen about having a support worker from the ADSS Support at Home team. Doreen was a little hesitant at first but once she developed a rapport with her care worker, she thoroughly enjoyed going on outings to her favourite places, like the bowling alley, where she became the "champion" of air

hockey! Her care worker visited twice a week for 2 hours and Doreen looked forward to getting out of the house, and in the colder months they spent time indoors doing hobbies, such as puzzles and wordsearches. When Doreen started to find household chores and personal care difficult she also had a care worker from ADSS Support at Home Plus team who were able to help her with getting ready for the day and prepping drinks and meals. This was reassuring for the family knowing that Doreen was being supported by well-trained care workers who had been suitably matched to Doreen's personality. The family recognised that, as well as them supporting, it was important to have extra support. Although they are a very supportive family they recognised their own limitations in their caring roles.

Five years on and Doreen`s dementia has declined, she is still very aware that her brain "lets her down", but she still has a positive approach to life. Her mobility has deteriorated but she is still fully mobile with no aids, and she now thoroughly enjoys attending The Beacon Day Centre at Safeharbour three days a week where she has established friendships with other attendees. She loves to have a natter and a dance with her friends. Just recently Doreen has been finding it difficult to use a knife and fork, The Beacon staff recognised this when she was having her lunch and where able to offer support to Doreen by encouraging and supporting her to use a spoon which she finds much easier. Something that her family have mirrored for Doreen when she is at home. Helping her to retain her independence when eating and drinking.

Doreen has been the star focus in many of our photographs, which she loves!

Although Doreen requires a lot more help these days her family feel that all the support and services from ADSS enable Doreen to stay in her home. Her family have had ongoing support from the Dementia Coordinator service and throughout the dips they have helped by acting as a conduit of communication to the GP and the memory clinic, supported with suggestions in how to support and guide Doreen to stay safe in the home and most importantly listen to the family when they have found things a little overwhelming.

Over the years of accessing ADSS services, attending day trips and events, Doreen has been the star focus in many of our photographs, which she loves! Some of the photos have been used on ADSS marketing materials which Doreen takes enormous pride in, so much so that she has kept a copy of each flyer, booklet or poster she has appeared in. We are sure you'll agree from her beautiful smile, it really is evident what a difference all the support she receives makes.

Hospital Dementia Coordinator & Enablement Service

The Hospital Dementia Coordinator and Enablement Service work in Darent Valley Hospital and the local community.

The Dementia Coordinators support people living with dementia and their Carers during their hospital stay, they offer advice and guidance during admission and upon discharge, ensuring further support is provided by our Community Dementia Coordinators. Our Enablement Support workers can help a person living with dementia to settle back into home life upon discharge by working closely to regain confidence.

Everyone taking part in this evaluation that accessed this service said they felt listened to by the Hospital Dementia Coordinators and the Enablement Support workers and nearly all have said we helped them feel safe, with one person explaining they know they can contact us before reaching a crisis.

> *“I couldn’t have gone to any of the activities without your help as my husband and I don’t drive anymore and my family are so busy. I’m looking forward to being picked up by the minibus to go to the day centre soon.”*

> *“My mum went into hospital, and she received continuing care. There was hospital co-ordinators with clear communication.”*

> *“You have gone far and beyond our expectations, the care and respect you showed us both makes us feel worthwhile again.”*

> *“The information about the coordinators are at the hospital when your partner is admitted to help you with the decisions to be made.”*

> *“Claire was a great source of help, information and support during my dad’s stay in hospital. It was a godsend to have Claire to speak to and liaise with the nurses for us.”*

Dementia Coordinator Service

The Dementia Coordinator Service provide information, support and guidance to those affected by dementia and their Carers; they are often the first ADSS staff members people will have contact with. At the time this evaluation took place, ADSS had 29 community Dementia Coordinators working across Dartford, Gravesham, Swanley, Medway, Swale and West Kent.

Carers taking part talked about the positive impact the coordinators made to them when they were experiencing times of crisis.

Their role was conceptualised in 2021 and is funded by Kent and Medway NHS. The coordinators are aligned to the Primary Care Networks (PCNs) with GPs and other health and social care professionals, such as local memory clinics, social workers and voluntary organisations, with the aim of guiding, advising and supporting people to navigate their experience of dementia from diagnosis to end of life.

Many people taking part in this evaluation talked about the value of not only being given information but also about how beneficial it is to have someone be able to do some things for you, such as chasing up other services. Quite a few people also explained how beneficial it is that the Dementia Cordinators keep in contact, making sure no one is forgotten. Some of the Carers taking part talked about the positive impact the coordinators made to them when they were experiencing times of crisis.

In 2022 a team of researchers from the University of Surrey started conducting an evaluation of the Dementia Coordinator service covering the whole of Kent. Dementia Coordinators, service managers, healthcare practitioners, people living with dementia and Carers took part. The evaluation indicated that the Dementia Coordinator service was achieving several of its intended outcomes such as signposting to community support and joining up care across the system and de-escalating potential crises. We were pleased to see the feedback we received through our own evaluation concurred with that.

Case Study: Rosie

Rosie`s Dementia Coordinator, Ruth, identified that Rosie found it difficult to trust new people and that this would be something Ruth would need to help her overcome.

Rosie enjoyed being sociable, walking her dogs with her great granddaughter and attending a local club with a friend. At the club Rosie believed she was volunteering to help run the club, due to her dementia her capacity was compromised around recognising her abilities of everyday tasks.

Rosie`s Dementia Coordinator, Ruth, also identified that Rosie found it difficult to trust new people and that this would be something Ruth would need to help her overcome.

Ruth visited Rosie at home to complete an assessment and to start developing a rapport, to explore options of support for Rosie. A care needs assessment was required from social services; however, Rosie had declined this, and this subsequently left her with minimal support. Her family support her as best as they can, but it was recognised that Rosie needs additional care in the home to help keep her safe and independent in her own home. She also informed Ruth that she had been feeling lonely. Ruth informed Rosie of the ADSS Wellbeing groups that were held in her local area, one of them being just over the road from her house. However, each time Ruth reminded Rosie of the groups she declined the invite. Ruth then offered to attend the groups with her in the hope it would encourage her to give it a try. Rosie agreed to this offer of support and they both put a plan in place to go along to the next group. Ruth escorted Rosie to the group a further 2 times, and it was clear that Rosie found it hard to engage at the groups, however, she very much enjoyed sitting with Ruth and chatting whilst there. Rosie did inform Ruth that she preferred company on a one-to-one basis now, which prompted Ruth to mention about befriending from another organisation called Imago, who ADSS work closely with.

Rosie is now having regular telephone befriending which she is enjoying, Ruth is continuing to work closely with Rosie to build her confidence in accepting support and care. They have also started to discuss and explore Rosie coming along to the ADSS day centre to alleviate her loneliness.

Wellbeing Services

Our Wellbeing Services provide a variety of social engagement opportunities for people living with dementia and their Carers. This includes Peer Support, Memory Cafes, Carers Learning Group, Singing Back the Memories and various day trips and activity groups.

When we asked people if they were able to access social activities they enjoy, a total of 34 people said no and 17 were not sure. However, of those that have accessed our Wellbeing Services only three people answered no, two of whom explained it was because the person living with dementia did not want to take part.

Everyone taking part that has accessed our Wellbeing Services told us they've been able to make their own choices, our staff encourage them to do the things that they can do, they feel like part of a community and our staff listen to them and understand them.

One person did tell us they would prefer to chat or do activities rather than listen to information talks at Memory Cafes. However, others told us it was a helpful way to gain information. Memory Cafes are designed to be a safe place for those affected by dementia to access information as well as providing an opportunity to socialise. In 2025 we are a trialling a new approach where we will facilitate several information sessions throughout the year at our larger Memory Cafes. All other Memory Café sessions will then have the opportunity to experience speakers on topics of interest, entertainers and time for a good catch up with their peers. We provide a range of other groups where activities take place so would encourage those wanting activities to go along.

> “*I chose to come here even though my wife has been coming to groups longer. I didn't want to come at first, glad I changed my mind.*”

> “*Before we accessed groups we felt on our own and isolated. ADSS is like visiting a very welcoming and accepting family.*”

> “*We are able to do the activities like cycling, pétanque and walking also the craft session.*”

> “*Chair fit, cycling, tea dance, memory café, Carer's group have all been very good, everyone appears to be able to take part and do what they can / if not they are helped. Outings a very enjoyable and excellent as you have some you time as well as being together. Parties are very enjoyable as well, great to see everyone enjoying themselves.*”

> “*Attending the ADSS 4 week afternoon dementia course which really helped me prepare for what's happened to my wife.*”

The Beacon Day Service

This is a service for those living with dementia. People join us for the day and are able to take part in activities of their choice, such as games, singing, arts and crafts or gardening. They also have the opportunity to socialise with their peers. They are provided with a lunchtime meal that is freshly cooked on our site.

An added benefit of this service is that Carers can have a break from their caring responsibilities.

Eight people attending The Beacon Day Service told us that they had felt lonely before joining this service but now feel less lonely. Everyone taking part that attends The Beacon told us they have been able to make their own choices, they feel listened to by staff and they feel staff understand them. Only two people answered no when asked if staff encourage them to do the things they can do, one explained it was because staff have a roomful of people to support and the other person stated they feel they could do more and would like to have a go. As a result of having the opportunity to receive that feedback our team will work with those individuals to ensure they are encouraged to do what they can for themselves whilst maintaining safety.

When asked if they were able to access activities that they enjoy, only one person that attends The Beacon said no. They explained that they would like to access more trips out, like the beach. Although we do not specifically organise days out within The Beacon service, we do have regular days out available to all people supported across the organisation. We will ensure those that attend The Beacon are made aware of those trips.

> “*I look forward to attending the Beacon, it gives me a reason to get up in the morning.*”

> “*The staff are wonderful at the Beacon, and make you feel you are part of a family.*”

> “*I am able to relax a bit knowing my loved one is safe and happy at the Beacon. I have made new friends, and I know I'm not alone in this journey.*”

Support at Home & Support at Home Plus

Support at Home and Support at Home Plus are our domiciliary services where our team of care workers support people living with dementia within their own homes.

Support at Home care workers spend a minimum of two hours with people and use that time to support the person to go out or do activities. **Support at Home Plus** care workers spend a minimum of one hour with people and support them with their daily living needs, such as medication, meals and personal care.

25 people who access the Support at Home services took park in this evaluation. They all told us they felt listened to by staff, explaining that care staff spend time with them and enable them to make choices. Nearly all said they also feel understood by staff. Nobody told us they don't feel understood but two people said they were not sure. One of those told us that some staff understand them better than others. Our care team have regular team meetings so this forum will be used to discuss and learn from that feedback. Two people were not sure when we asked if our service makes them feel safe, however everyone else answered yes. We received the same response when asking them if they've been able to make their own choices. When asking if, when they've needed information, have we been able to provide it, one person was not sure but everyone else answered yes.

> *"The confidence of the carers makes me feel safe."*

> *"I feel I can ask carers anything."*

> *"It has made a huge difference, I look forward to my visits. I have someone coming and I feel brighter because of this."*

> *"I feel listened to and confident to share a problem."*

> *"I am keeping my independence, doing things I like to do."*

> *"I would be very lonely if you didn't come round."*

> *"I don't think I could have received better care."*

> *ADSS has changed all of my families lives the service received has been impactful and given us confidence.*

> *I feel more motivated now and able to make better decisions.*

> *I have gone from feeling overwhelmed & lost to being supported, guided and always listened too.*

> *I feel lighter when I have been with you, a weight lifted from me.*

> *I can't remember, but I feel happy talking to you.*

The difference we have made

We asked everyone that took part what difference our service has made to them. The responses we received were overwhelming with gratitude for our service and to our staff.

They talked about how we have increased their awareness and knowledge of dementia, coping strategies and the support that's available, as and when they need it. This knowledge has helped people to adjust to life with dementia. Knowing that someone is there that will listen has made people feel reassured and safe.

Many talked about how they now know they are not alone. Our services have provided a path forward full of purpose and things to look forward to and have enabled them to be more social, more active and part of a community.

The practical support we have provided has not only made a difference in their day to day lives, such as supporting them to get equipment, it has enabled them to be more independent and to remain in their own home. This support has helped make things happen as our team have acted as a 'go-between' and therefore reduced the stress on families.

> *Since accessing these services, not only I have stopped thinking about 'dementia', as the activities normalises everything; but it has given me something to look forward to within my own physical and mental ability; to have fun and be part of something. So, I would say that it has completely changed our life, definitely.*

Anything we could do better?
You said, we respond......

YOU SAID...	OUR RESPONSE...
More awareness of ADSS for signposting purposes i.e. dissemination of printed leaflets, newsletter, attendance at events.	Our team members are happy to attend events to raise awareness of our services, however we do have to balance our time doing this with the time we spending directly supporting people. We have a regular newsletter which can be subscribed to on our website. We also regularly disseminate flyers and leaflets. If you would like us to attend an event, or to provide printed materials to you, or another location you think would be helpful, please email **info@alz-dem.org**
Provide a directory of all services	Those that access our Dementia Coordinator service are provided with an information pack containing information about all services available in the area they live. If you would like to receive a pack, please call **0800 035 2221**. We are also currently working on developing our website. This will ensure that information about the right support for you is easy to find and will include a calendar of upcoming events, groups and activities.
It would be helpful to know about the Hospital Dementia Coordinator sooner	Practical and logistical challenges in Darent Valley Hospital did make it difficult for us to identify the people who needed our support. As of November 2024, we have more team members and are now also working within the Emergency Department and Same Day Emergency Care Centre so everyone coming into hospital with dementia will be referred to our team.
We would like Enablement Service to be longer than 6 weeks	The Enablement Service is designed to be a short-term support intervention. However, if support is needed beyond that, our team will provide guidance on how to find that support.
More visits from Dementia Coordinators and more regular check ins and joint visits with Social Services.	Our visits and check in calls are conducted on a needs led basis but we do ensure that people know how to get hold of us. There are 53 Dementia Coordinators across Kent but an estimated prevalence of 28,000 living with dementia. Where needed, our Dementia Coordinators can attend joint visits with other services and will always share, with consent, relevant information about the people we support.
Activity services wanted in the evenings, more frequently and outside of Dartford, Gravesham and Swanley	We are dedicated to ensuring that everyone affected by dementia in Kent has equal access to support by 2030. Medway is underway but we have had to raise the funds to do this. At ADSS we ensure that when we set up new services, they are sustainable. Whilst specific activities do not take place weekly, there are alternative activities available every week. We do have some activities available during evenings and on weekends, please contact us on **01474 533990** to find out more.

YOU SAID...	OUR RESPONSE...
More services for rare and young onset dementias	We currently facilitate two groups, in Gravesham and Dartford, specifically for those affected by young onset dementia. We are committed to considering the needs of specific groups as we grow our services however we must ensure any new services we set up are sustainable. Those with young onset and rare dementias are always welcomed at all our other wellbeing groups and activities but we do recognise the symptoms of some rare dementias pose different challenges to the person and their Carers.
Regular update with upcoming activities	You can receive regular email updates from ADSS. This will ensure you know about all the services we offer and the exciting upcoming trips and social events. Please just fill in your name and email on the form at the bottom of the home page of our website **https://www.alz-dem.org/**
We would like transport to some of the groups and activities	We appreciate that transport is a common issue for people when accessing services. There are other services available in the community that can provide transport. Please speak to one of our Dementia Coordinators or a member of the Wellbeing Team who can direct you as appropriate.
More information about The Beacon activities that are planned and have been done	We love sharing on our social media what our Beacon members have been doing during their fun filled days with us. Since the evaluation has taken place, we have written to Beacon attendees, family members and Carers to explore how communication can be improved, thank you to those that responded. If you would like to find out more about this, please contact Sherrie Boyd, Beacon Day Care Manager on **01474 555035.**
More support for people living with dementia in their home	We currently offer three services in Dartford, Gravesham and Swanley that support people within their own home. We have volunteer Befrienders, Support at Home and Support at Home Plus. Please contact us on 01474 533990 to find out more. If you do not live in in Dartford, Gravesham and Swanley, your local Dementia Coordinator can signpost you to support available at home in your area. You can contact them on **0800 035 2221**.
Host the Dementia Bus regularly	We were fortunate this year to be able to support the Dartford, Gravesham and Swanley Dementia Friendly Community (DFC) group in hosting the Dementia Bus. Hosting of the bus is a high cost therefore we rely on the generosity of funders to enable this. We hope to make this, or something similar, an annual opportunity.

Developments since last year's evaluation

In last year's evaluation we responded to some specific requests for development. Here's some of the things we have done since then because of that feedback.

We have continued to facilitate day trips and events. In 2024 we facilitated six trips and events, ranging from day trips at seaside towns to attending the Kent Dementia Action Alliance Showcase. 215 individuals joined us across the various trips and events. We held our first Easter Extravaganza where we had 63 people join us for entertainment at Chalk Village Hall. We have extended our invites to our trips and events to those we support across all areas we serve.

Our activity groups in Dartford, Gravesham and Swanley have continued to flourish. This year saw the introduction of a winter and summer schedule ensuring that a variety of activities can be accessed by those living with dementia as well as their Carers. Group participants were involved in selecting the activities that have taken place.

We facilitated a Carers Forum to help us learn what more we could do to support Carers. The next steps for this development will be for us to facilitate a Co-production group. Co-production is a collaborative approach to designing, developing, and delivering services. People who use the services, and the professionals who provide them, work together as equals.

Our staff training plan has been reviewed. We are recruiting a full time Training Manager to enable us to enhance the training and learning opportunities our team can access.

In addition, we have taken great steps to increase our reach and the support we can provide. This has included introducing our Wellbeing services to Medway, enabling people affected by dementia to have access to Memory Cafes, Peer Support and Activity groups. We have also commenced working in partnership with SGN and as a result have recruited a Home Energy Advisor and are able to provide advice, information and equipment to keep people safe and warm. Another development has been our increased presence at Darent Valley Hospital. We have recruited more Hospital Dementia Coordinators and Enablement workers and are now available to people accessing Same Day Emergency Care as well as A&E and inpatient wards.

To keep abreast of our developments please sign up on our website to receive email updates **www.alz-dem.org**.

Conclusions

Dementia presents a variety of challenges to those diagnosed and to those caring for them. For those diagnosed it can result in loss of confidence therefore it is very pleasing to see that nearly half of those taking part in this evaluation are those living with the condition, thus ensuring their voice is heard.

We are aware of the vital role Carers have and so are equally pleased to hear their feedback, particularly this year as additional questions were asked to help us better understand their needs.

Our mission is to give people affected by dementia the knowledge, support and care they need to take back control of their lives, take part in family and community life and manage their symptoms. Therefore, it is very pleasing to see that across all of the questions we asked we have exceeded 71% of people answering yes, an increase of 9% from last year. In fact, for five out of the nine questions asked, we exceeded 80% of people answering yes.

When answering 'Not sure' most people felt this way when being asked if they felt like part of a community. This was also the case last year. Of those that were not sure, the majority were people that do not have access to our Wellbeing services i.e. community groups. This demonstrates the value of those services in proving people with the opportunity to access dementia specialist support and activity groups within their local community.

The question with the most people answering no was regarding accessing social activities that they enjoy. When exploring this further we saw that more than half of the people that answered no live in areas where we do not currently offer Wellbeing or Care services. This makes us firmer in our vision to ensure everyone living with dementia, in Kent and Medway, gets the support they need to live the life they want. Last year the question with the most 'no' answers was regarding loneliness; however, it was identified that the question needed to be reworded to get an accurate response.

It was no surprise to see, as we did last year, that the questions that resulted in the most yes answers were about staff listening and understanding. There was also a very high percentage of people answering yes when we asked if they felt able to make their own choices. Nobody answered no to those three questions. At ADSS we pride ourselves in being authentic and true to the organisation's values. This feedback is evidence that this is the case across our whole team.

We were very pleased to see that 94% of people taking part feel we can give them the information they need and that nobody answered no to this question. It's clear from the additional feedback provided that information is key to people being able to adjust to life with dementia.

We continue to be confident in saying that we are meeting Key Performance Indicators set by Kent County Council. As a result of our services the vast majority of people feel less lonely and can live safely and independently. In addition, those that access our Wellbeing and Care services, can not only take part in activities they enjoy, they also feel like part of a community.

ADSS has a bold and ambitious strategy to do more for people affected by dementia but it is very important to us that we still create a warm and welcoming environment where our team can be truly person centred. This evaluation clearly shows that we are making a life enhancing difference to the people we support and has made us even more determined to ensure we can bring our expertise, care and compassion to those who need our support.

ADSS has a bold and ambitious strategy to do more for people affected by dementia but it is very important to us that we still create a warm and welcoming environment where our team can be truly person centred.

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1. https://www.alzheimers.org.uk/about-us/news-and-media/facts-media

2. https://democracy.kent.gov.uk/documents/s102567/Appendix%20-%20Improving%20Care%20for%20people%20living%20with%20Dementia%20Report%20-%20final%20report.pdf

Let’s get social

To keep up to date with all our latest activities or if you would like to leave a review, please connect with us on social media!!

Alzheimer’s and Dementia Support Services

@alzdemsupport

Alzheimer’s and Dementia Support Services

@alz_dem

Plus check out our website **www.alz-dem.org** for regular blogs relating to dementia and our work.

ADSS
Facing dementia together