

Executive Summary

Dementia Oxfordshire is a service provided by Age UK Oxfordshire (AUKO), commissioned by Oxfordshire County Council (OCC) and jointly funded by OCC and Oxfordshire Clinical Commissioning Group (OCCG).

Dementia Oxfordshire provides free, ongoing support for people living with dementia and their families in Oxfordshire. Support is available from the point of diagnosis until move to residential care or end of life, through a framework of six-monthly reviews.

This is Dementia Oxfordshire's first impact research. Its purpose is to progress evaluation from solely counting output. This research provides a more robust qualitative analysis of our work, offering a better insight into the impact Dementia Oxfordshire has on the lives of the people we support.

This report describes the methodology and provides details and transcripts in the appendices. Our 2022, impact report draws on this research and can be found on our [website](#).

Dementia Oxfordshire supports over 2300 people with dementia (PWD) and over 2700 unpaid carers; in 2022 the service received just over 1100 referrals.

This report identifies three significant ways Dementia Oxfordshire impacts on people's lives:

1. Reducing carer stress through tailored practical and emotional support
2. Preventing people living with dementia and their carers experiencing isolation and loneliness
3. Increasing confidence of carers in their caring role and improving the carer-cared-for relationship, through education.

Dementia Oxfordshire works closely with a wide range of professionals across the county including:

- Memory Clinics
- GPs
- Adult Social Care (ASC)
- Care homes
- Third sector organisations including our AUKO partners, day centres, and memory cafes.

Our close relationship with these partners is key to enabling us to deliver a quality service to our clients and carers.

Summary:

- This report provides strong evidence for growing dementia education programmes
- This report has identified an aspect of Dementia Oxfordshire's work, preventing loneliness and isolation, that was previously only recognised to a limited extent and was not promoted.
- A lot of the work Dementia Oxfordshire does to support people living with dementia is indirect, through their carer.

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1. Introduction

Dementia Oxfordshire is a service provided Age UK Oxfordshire (AUKO). It has been running since November 2015, commissioned by Oxford County Council (OCC) and jointly funded by OCC and what was Oxfordshire Clinical Commissioning Group (OCCG) (now the BOB Integrated Care Board). Dementia Oxfordshire provides free support and advice for people living with dementia and their families in Oxfordshire, from the point that a dementia diagnosis is made. We do not discharge until end of life or a move to a care home. The service aims to support people to live for as long as possible and as well as possible in the community, working to ensure people have a sense of meaning and purpose in their lives.

This is our first impact research and is part of our ambition to move away from solely counting our output and develop a better understanding of how our service supports PWD (People with Dementia) and carers. We believe that investigating impact will help us to identify where the service can improve and increase its impact further.

This research has been conducted internally. We have worked hard to produce an unbiased report and not be driven by our preconceived notions of what we believe the service offers. To achieve this aim, we have used an inductive methodological approach to uncover how Dementia Oxfordshire impacts our clients and carers. The author of the report is also new to the service (Recruited October 2021) and is academically trained in qualitative analysis.

We have collected qualitative data through surveys, interviews, and case studies, which have then been analysed using an approach based on thematic analysis¹.

Overall, we conclude that Dementia Oxfordshire impacts on our clients and carers in three ways:

- Reducing carer stress through tailored practical and emotional support
- Giving carers an increased amount of confidence around understanding dementia and how to manage it, through education, thus supporting carers to care well and improving the relationship between the carer and person with dementia
- Preventing people living with dementia and their carers experiencing isolation and loneliness

This report will describe and explain:

- The methodology undertaken
- Our output since January 2021
- Our main qualitative findings
- The importance of our partnerships
- Our conclusions
- Proposed Future Steps

2. Methodology

Quantitative Data

We have captured quantitative data about our output and service activity since Dementia Oxfordshire launched in 2015. This was originally collated in an off-the-shelf database, however we have since built a custom database, designed by Oxford Code Lab, which has been used since early 2021.

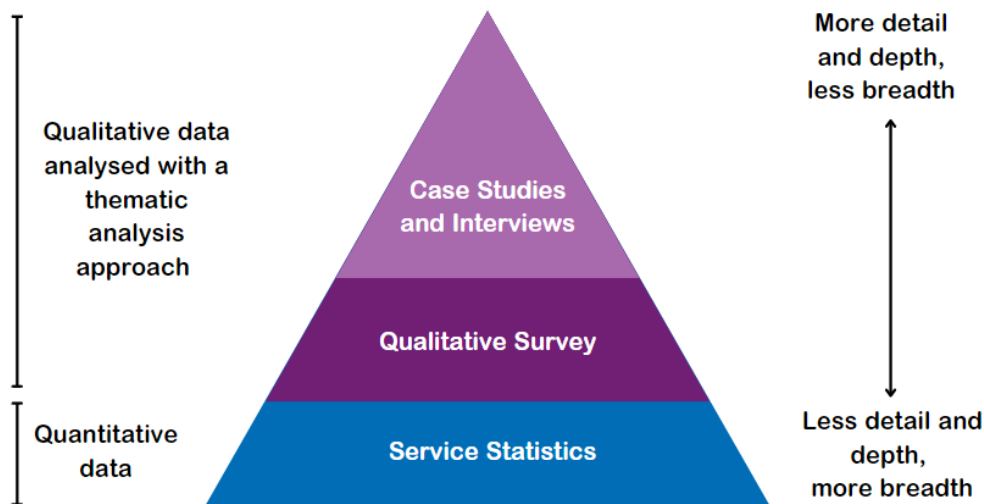
The new platform provides more granulated and detailed data and continues to be developed to support the needs of the service. We can now access statistics about our service more readily, reflecting recent output with a high degree of confidence and accuracy. These quantitative measures allow us to report on the KPI's set by OCC quickly and accurately and allow for better management of caseload and the service in general. It is however limited in what it tells us about *how* our clients and carers experience our service.

Qualitative Data

Our qualitative data is drawn from surveys, case studies and interviews with carers using a qualitative analysis method based on thematic analysis as proposed by Braun and Clark¹. We chose to use several data sources to help find a balance between data that provides more breadth, and is more generalisable, and data that provides more depth and detail (see figure 1).

¹ Braun, V and Clarke, V. (2006) Using thematic analysis in psychology.

Figure 1: Data Sources in relation to their level of detail and breadth



We designed a qualitative survey in Microsoft Forms (See Appendix 1) to capture responses from clients and carers that provide more detailed information on our impact which our quantitative data struggles to illustrate. It captures feedback from a relatively wide segment of our audience. In total, we received 61 responses, most of which were from carers. The survey also acted as a recruitment tool to find interview participants.

We analysed 11 case studies, (See Appendix 2) that were produced by Dementia Advisers between December 2017 and October 2021. Case studies look in-depth at particular cases to help explore both the typical and the range of experiences of people who use our service. They are commonly used in the third sector to illustrate service activity in a more qualitative way, however they carry a risk of bias.

We provide guidelines on what to include in case studies to help avoid over emphasising any changes that occurred but instead simply state the ‘before situation’, the intervention that was carried out and the resulting situation for the client and carer. They were not asked to comment on what they believe the outcome or impact was. This provided a way of taking a snapshot of clients across the county, including clients that did not complete the survey or take part in interviews, reducing the element of self-selection. Additionally, case studies have been historically collected by Dementia Oxfordshire as a monitoring tool and therefore have been used to make the most of available data.

We carried out four semi-structured interviews (See Appendix 3). The questions asked were designed to help clients elaborate on their survey answers. The questions therefore differed between each interview to draw out what the carer believed was most important to them as indicated by their initial responses.

The interviewees were four carers that had very different home lives, covering a broad cross-section of our clients and carers. One was a single mother of young children caring for her mother, one was a husband caring for his wife, one was a son caring for his mother and one was a wife caring for her husband.

Qualitative Analysis

The qualitative data collected was analysed based on a thematic analysis approach. Thematic analysis is the process of identifying patterns or themes within qualitative data². We chose this method as it is a flexible approach that can be deployed in a range of contexts³ and as such could be easily implemented in this context. The inductive nature of this methodology, draws out what is important to the service user, helping to create an assessment that goes beyond our initial beliefs of what the service offers.

The analysis was conducted by a new member of the team who is not involved in client and carer facing work, to help limit bias in the analysis. This person has training and experience in qualitative analysis gained as part of both their undergraduate degree and from studying for a Masters Degree in Social Policy at Oxford University.

The first step in this analysis process was to code the data, a process designed to organise the data in a meaningful and systematic way. 15 codes were identified (See Appendix 4). After searching, reviewing, and defining themes, stages three, four and five of Braun and Clarkes (2006 process of thematic analysis), three themes were identified.

We used a Computer Aided Qualitative Data Analysis Software (CAQDAS) package called [Taguette](#) to conduct the analysis. This is a basic CAQDAS, however it has significant cost benefits in that it is a free, open-source tool.

3. Our Output

Dementia Oxfordshire supports:

- 2336 people living with dementia.
- 2738 unpaid carers.

Thus, in total, the service supports over 5000 people across Oxfordshire.

Our output measures since the start of the new contract in January 2021 are shown in the table below:

² Maguire, M and Delahunt, B. (2017) Doing a Thematic Analysis: A Practical, Step-by-Step Guide for Learning and Teaching Scholars.

³ Bryman, A. (2012) Social Research Methods. 4th Edition.

Measure	2021 (Calendar year)	2022 (first three quarters data)	2022 (annual projection)
New referrals processed	966	908	1,211
Re-referrals processed	N/A	152	203
Reviews completed	3618	3383	4,511
Support line phone calls	1587	1519	2,025
Education sessions delivered	31	30	40
Total attendance at education sessions	328	150	200
Awareness sessions delivered to professionals and organisations	7	13	17
Total attendance at awareness sessions	50	46	61

Currently we also:

- Host or support 20 in-person support groups
- Host 3 virtual support groups
- Run clinics in 4 GP surgeries (Pilot initiative)

4. Qualitative Findings

Our qualitative research has highlighted three main ways we have an impact on our clients and carers.

- Reducing carer stress through tailored practical and emotional support.
- Preventing people living with dementia and their carers experiencing isolation and loneliness.
- Increasing confidence of carers in their caring role and improving the carer-cared-for relationship, through education.

Reducing Carer Stress Through Tailored Practical and Emotional Support

Nine in ten carers for people with dementia experience feelings of stress or anxiety several times a week ⁴. Without support, this stress and anxiety can become overwhelming for carers, and they can experience carer breakdown. Dementia Oxfordshire provides tailored practical and emotional support which helps to support carers to avoid overwhelming stress.

Practical Support

Dementia Oxfordshire provides practical support to carers through:

⁴ Alzheimer's Society. (2018) [Carers for people with dementia struggling in silence | Alzheimer's Society \(alzheimers.org.uk\)](https://www.alzheimers.org.uk)

- Signposting to other services
- Helping to find respite, providing information and education around dementia and how to support someone with dementia, including how to deal with difficult behaviours
- Identifying what assistive technology may be useful

Dementia Advisers have in-depth knowledge of their localities and take time to get to know their clients. As a result, they can make tailored recommendations based on what is available in the area and what would most suit that client and carer. This tailored knowledge helps carers to find support that is more likely to suit them more quickly.

One interviewee said:

"It was useful having 1 to 1 catch ups and speaking to an individual rather than just an organisation. They will touch base and see how things are going. I tend to collect questions to ask for when I speak to the Dementia Adviser. The information she has given has been really helpful and personalised.

Mum started to wander and was getting lost in town. The adviser sent a bunch of links to GPS technology and it's on my to-do list to order this week.

I'm more likely to call a named person contact as they know my personalised case so can give me specific information."

Another said:

"[redacted DA name] also recommended a dementia day centre, daybreak.

This meant I had about 5 hours of free time where I could go on walks, which is my hobby really. After a while we couldn't attend the [redacted day centre name] one anymore because of mum's behaviour.

But these gave me respite time in Oxford where I went for walks and sometimes around the Oxford Museums."

A good understanding of the client, carer and whole family allows Dementia Advisers to find practical solutions that work for everyone.

This is illustrated through this case study extract:

OCC had recommended that Mrs B have a live-in carer but Mrs B refused this. The DA suggested to the daughter that the carer visits could be extended gradually, particularly in the evening when Mrs B was most lonely.

This is also illustrated through a survey response:

"Q: What type of support did you find most beneficial?

A: Knowing that there is always someone I can contact. Also sometimes it will be easier for my advisor Julia to see what help is appropriate with her knowledge of what is available."

However, this impact and how useful clients believe our service to be, is lessened when clients live in areas with fewer services or groups to signpost to.

“Everything seems to be in Oxford city which is hard to get to. Everything stopped during the pandemic and memory clinic and age concern doesn’t do much in the area. You seem to be the only ones doing stuff but it’s too far.”

Emotional Support

Dementia Oxfordshire provides emotional support to carers through allocating a Dementia Adviser to talk through challenges and support groups for people living with dementia and carers.

‘Having someone to talk to’ came out strongly in the survey answers and interviews. Carers feel understood by Dementia Advisers and this enables them to offload worries and concerns and gain reassurance.

One survey answer said:

“What type of support did you find most beneficial? All of it and having someone at the end of the phone to ask questions if needed.

What effect has this support had on you? It is reassuring to know that as a family we have support from such knowledge people.”

Another said:

“Someone to talk to who understands the journey I am on”

Carers also discussed that they are reassured to know there is a service available to support them in the future, even if they are coping well now. This is particularly important as dementia is a progressive condition, meaning many families’ circumstances and ability to cope may change.

What effect has this support had on you? “One of relief as I now know there will be help as my husbands symptoms get worse”

Reducing Stress

Carers highlighted that this practical and emotional support has helped them to feel less stressed.

One carer’s answers in particular show this clearly:

“What support have you received from Dementia Oxfordshire? information, support

What type of support did you find most beneficial? personal contact

What effect has this support had on you? made it easier to cope”

Another said:

“What type of support did you find most beneficial? Knowing there was someone to turn to

What effect has this support had on you? Lowered anxiety level”

In answer to the question, “What effect has this support had on you?”, carers answered:

- “peace of mind”
- “made our lives easier”
- “Feel supported”

Increasing confidence of Carers and Improving the carer-cared-for relationship through Education

Dementia Oxfordshire provides both formal and informal dementia education. We provide formal education through our Carer Education Sessions and more informal education through the daily conversations we have with clients and carers. This education we provide gives carers more confidence in their caring role, helps to support the quality of care they are giving and helps improve the relationship between the carer and the person with dementia.

Informal

Our DAs' daily work involves educating clients about dementia so they have more confidence in managing their condition and carers to better support their loved one. They often educate on how to communicate better with someone living with dementia, or how to manage certain behaviours. They also regularly challenge preconceptions and misinformation about dementia that both PWD, carers and families hold.

This 'informal education' which DAs do daily, but is not part of our more formal education offer, is illustrated within an extract from a case study:

"The DA explained how dementia can affect different people, the different strategies for how to communicate, how to apply these in the specific situations with their mother and ensure their mother still felt a sense of autonomy.

Coping strategies for his memory loss were discussed with the DA and included signage/labelling within the home, white board reminders, calendar clock and reminiscence work."

"What type of support did you find most beneficial? Help line advice & information

What effect has this support had on you? Gave me more confidence"

Formal

Our more formal carer education sessions also help to improve carers' confidence. This is reflected in a case study:

"Mr C has attended 'Carer Information Sessions' provided by Dementia Oxfordshire learning new skills, which has enabled him to feel more confident in his carer role. He has also attended Dementia Oxfordshire Information Days regularly where he can discuss problems and find solutions and help."

They have helped to improve relationships between people with dementia and their loved ones as carers often become more patient and less frustrated. This is especially important for the relationship between carers and PWD as they can be a lot more sensitive towards non-verbal cues.

This is illustrated through quotes from two separate interviews with carers:

“Understanding that midterm memory becomes more exciting and that understanding why perhaps my wife thinks her mother is here even though she passed away 30 years ago. I’m more understanding of where her mind and memory is. I can be more responsive and softer and understand I need to fit into her way of thinking.”

“Explaining the way mums dementia affects her, and how to help. Makes me more patient with mum.”

And

“Since completing the survey I did attend the Dementia Information Day in Cowley and there was a presentation by Katie, she was really explaining the illness and how it affects people’s behaviour. I attended with my wife and we understood that Mum’s aggression is due to an unmet need and we need to ascertain what that is.

Q: Do you feel this has helped your relationship with your Mum?

A: Sort of yes, I know now that when she’s not being cooperative, I can understand it more, not to say it’s still not frustrating at times, but it has made me more tolerant.”

Academic literature corroborates these findings. Sørensen and Conwell⁵ argue that carers are less frustrated and angry if they have a greater understanding of dementia. They also argue that this in turn can help improve the PWD’s symptoms as the caregiver is more likely to redirect the PWD instead of escalating “problem behaviour”.

Preventing Loneliness and Social Isolation

Receiving a dementia diagnosis or caring for someone living with dementia can be a lonely and isolating experience. Dementia Oxfordshire helps to prevent people living with dementia and carers experiencing loneliness and isolation. The data suggests Dementia Oxfordshire does this in three ways.

Firstly, carers and people with dementia understand that there is a dedicated Dementia Adviser and service there to support them and guide them through their dementia journey and it’s not something they have to face alone.

⁵ Sørensen, S and Conwell, Y. (2013) Issues in Dementia Caregiving: Effects on Mental and Physical Health, Intervention Strategies, and Research Needs

“What type of support did you find most beneficial? Someone to talk to who understands the journey I am on.

What effect has this support had on you? I don't feel so alone”

What type of support did you find most beneficial? Knowing that I can ask advice by phone or email. The individual contact is valuable

What effect has this support had on you? Increased confidence, feeling not alone

“Simply knowing support is there I don't feel I'm on my own, and feel able to make contact when necessary

Secondly, Dementia Oxfordshire prevents loneliness and isolation for people living with dementia by connecting them into their communities, signposting to support groups or for those who are particularly vulnerable supporting them to engage with their communities with the help of Support Workers.

“Mr X had gone from being a sociable gentleman who had been very active and involved in various activities to being very introverted and inactive which his wife was finding increasingly stressful.

Mr X was somewhat reticent to go out, however [support worker name] was able to persuade him to agree to a 1:1 outing which Mr X found positive and enabled [support worker name] to learn more about Mr X and reflect on his life history. This helped her to plan activities that would be of interest to him.

Mr X's wife was astounded when he asked to return at a later date. The project partner worked with Elaine and Mr X to plan activities he might be interested in and his second visit was equally successful.

Mr X now visits the Farm weekly independently of a Support Worker, travelling there by taxi and is re-energised and has re-connected with an old interest”

Finally, Dementia Oxfordshire prevents loneliness and isolation for carers through connecting them with other carers through their own peer support groups and other groups in the community.

“The Care2Share support has been very helpful during the pandemic. Especially important during lockdowns when other carer support services were unavailable. Sometimes one to one discussion is needed but talking to or at least hearing from other carers and the member of staff can make a big difference in terms of feeling connected and having a place to share issues in a supportive environment.”

5. Work with partners

Dementia Oxfordshire works closely with a wide range of professionals across the county including Memory Clinics, GPs, other third sector organisations including our AUKO partners, day centres, ASC, Care Homes, memory groups and cafes. Our close relationship with these partners is key to helping us deliver a valuable service to our clients and carers.

Most of our referrals come from three sources:

- 53.5% from memory clinics
- 14.9% from GPs
- 15.5% from CMHTs

When asked how they found out about Dementia Oxfordshire in our survey, 48% of clients said they were referred through their GP or Memory Clinic. This suggests that a significant proportion of our clients are clear who generated a referral but there is still more work to do to make the referral process more transparent for clients.

"I appreciate the interaction between the GP, Warneford Hospital, Age Concern and Oxford Dementia. You seem to work together well. Truly."

6. Conclusions

This research highlights the impact of Dementia Oxfordshire's work for PWD and their carers. Our qualitative analysis tells us our impact occurs in three main ways:

- Reducing carer stress through tailored practical and emotional support
- Increasing confidence of Carers and Improving the carer-cared-for relationship through Education
- Preventing people living with dementia and their carers experiencing isolation and loneliness

Our contract sets out the following ambition:

People with dementia and their carers feel aware of **choices** for future care and are therefore **in control** of their own journey

People with dementia and their families receive **tailored support** and are better connected to **live well** with dementia, **maintain their independence** and create own well being

People with dementia and their carers receive a responsive, proactive and timely service

Carers of people with dementia have received training and feel more knowledgeable about dementia and different types of management

This research offers evidence that we are largely meeting that ambition. It shows we provide tailored support to ensure people can live well with dementia and create their own wellbeing, how we support people with dementia to be better connected into their communities and provide training for carers of people living with dementia so they feel more knowledgeable about dementia and how to manage the condition.

This research shows that a significant amount of Dementia Oxfordshire's work focusses on supporting carers to care for people living with dementia; thus helping people living with dementia indirectly. This is an effective way to support people living with dementia, as their quality of life is

affected by their relationships, environment, and the support they receive⁶, all of which can be bolstered or hindered by their carers and families.

It is important to note that only some of the direct support Dementia Oxfordshire provides to people living with dementia is captured through this research, given that significantly more carers than people living with dementia completed the survey. Different methods of qualitative data collection could be explored to look at Dementia Oxfordshire's impact on people living with dementia, such as the storytelling methodology as advocated by the [Old Fire Station](#).

Additionally, some of our direct work with people living with dementia may not be captured in this report because it is relatively new. For example, Dementia Oxfordshire has piloted a post-diagnostic education session since the start of this research. The aim is to help people recently diagnosed with dementia to understand and manage their condition sooner for greater longer-term benefits. The impact of this pilot is something we want to better understand.

The important role of education, in increasing carers confidence to care for someone living with dementia and improving the carer - cared-for relationship, provides strong evidence for the expansion of our education programmes. These have already been expanded since this research began, with the introduction of bitesize carer education sessions and post-diagnostic sessions. The OCC has recently provided further funding to expand our education based on preliminary findings of our research and other recent surveys.

This research into our impact, especially taking a qualitative approach, has highlighted the importance of Dementia Oxfordshire's work to prevent loneliness and isolation which is not an area that has been highlighted in their marketing despite it being a significant aspect of their work. This suggests that this form of analysis is beneficial in providing a broader, more accurate picture of service delivery and how it brings value to beneficiaries.

We believe Dementia Oxfordshire's partners play a crucial role in helping us to deliver impact to clients and carers, however this research did not investigate this. It would be useful to conduct more research to investigate this further; to better understand the interdependency of the various organisations that make up the dementia support system in Oxfordshire. We hope to explore this shortly and a survey for professionals is in production. More research could also be conducted to look at the impact of Dementia Oxfordshire's work in the wider community.

Finally, it would be useful to explore the impact of Dementia Oxfordshire's latest programmes including post-diagnostic education and the new GP Clinics which are in their nascent stages.

7. Proposed Future Steps

1. Expand the educational offer of the service.

This work has already begun. Pilots have already been developed and additional funding been provided by OCC through the Better Care Fund to expand the educational offer.

2. Ensure staff and the wider dementia support system are aware of the impact the service has on mitigating loneliness in the people the service supports.

⁶ Alzheimer's Society (n.d.) 'Understanding and Supporting a Person with Dementia' [Understanding and supporting a person with dementia | Alzheimer's Society \(alzheimers.org.uk\)](#)

3. Conduct further qualitative research to further explore:

- Relationships between organisations that make up the dementia support system in Oxfordshire
- The impact of Dementia Oxfordshire on PWD through a story telling approach
- The impact of Dementia Oxfordshire's GP clinic pilots and their pilot educational offers to educate PWD

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November 2022

Appendix 1: Client and Carer Impact Survey

1. Are you a Dementia Oxfordshire client, or a carer of a client?

Client

Carer

Other

2. **When did you first have contact with Dementia Oxfordshire?**

Enter your answer

3. **How did you find out about Dementia Oxfordshire?**

Enter your answer

4. **What support have you received from Dementia Oxfordshire?**

Enter your answer

5. **How beneficial have you found the support you have received from Dementia Oxfordshire?**

0	1	2	3	4	5	6	7	8	9	10
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Not Beneficial

Extremely Beneficial

6. **What type of support did you find most beneficial?**

Enter your answer

7. **What effect has this support had on you?**

Enter your answer

8. **Have you attended any groups or sessions by Dementia Oxfordshire?**

- Yes
- No
- Unsure

9. **If 'yes' which groups/sessions did you attend?**

Enter your answer

10. **If 'yes' what was your experience attending this group/session?**

Enter your answer

11. **Do you have any other comments on our service?**

Enter your answer

12. **Would you be interested in providing further insight into your experience with Dementia Oxfordshire to improve the service through a 30 minute follow-up call with a member of the Dementia Oxfordshire team?**

- Yes
- No

13. **If 'yes' please provide your name and a way to contact you (either email or phone number).**

Appendix 2: Case Study guidance and Case Study list

There is no set format for a case study, however things that you should consider including are:

- Title – what is the Case Study about
- Date case study written
- Name of person writing case study and/or person that supported the client
- Timeframe – what period of support does this cover
- Summary of support/intervention
- Details of any partnership working or collaboration (Identify any partners)
- What is different / what changed because of the intervention – for the client and any carers/ family that you have also supported
- Any feedback, comments or quotes from clients

Date	Title of Case Study
Dec-17	Dementia Adviser Case Study
Nov-19	Living well with Dementia
Dec-19	FarmAbility Case Study
Dec-19	Language Barrier Case Study
Jan-20	Support Worker Reduce Social Isolation
Feb-20	How does a new DA connect with the community?
Feb-20	A dementia journey
Feb-20	Case Study Multiple agencies
Mar-20	Volunteer case study
Jun-20	Dementia Adviser Case Study
Oct-21	DA Case Study

Appendix 3: Interview Transcripts

Interview 1

Q: You said that you found our service online back in 2018, was this shortly after your mum was diagnosed?

A: Yes, quite shortly after.

Q: What sort of information were you looking for online?

A: Just general support, how to deal with the situation. Mum also started wandering and one time she was bought back to us by the police.

Q: Was it [the diagnosis] a surprise?

A: Well I never met anyone with dementia and it wasn't something that was in the family. But it was not a surprise as Mum's short-term memory was going. She was living with my sister at the time and we went to memory clinic and she was diagnosed there.

Q: And then you got in touch with us and were allocated a Dementia Adviser?

A: Yes, our person allocated was [DA name redacted].

Q: In what ways did [DA name redacted] support you?

A: 3 things really. She provided comfort over the phone, it was sympathetic voice and that was very reassuring. She also helped practically. She arranged a buddy tracker device which meant we were able to find her on a couple of occasions. [DA name redacted] also recommended a dementia day centre, daybreak.

Q: How have you found daybreak?

A: We've been to two, the [redacted] and the [redacted]. I'm retired so I would drive from my home in [redacted], pick up my mum and then take her to daybreak. This meant I had about 5 hours of free time where I could go on walks, which is my hobby really. After a while we couldn't attend the [redacted] one anymore because of mum's behaviour.

The [redacted] one we went to for longer, it was run by [name redacted] who was brilliant and got on well with Mum. She encouraged us to take Mum for another day so for a while Mum was attending Monday and Tuesday for several months until last summer, when again her behaviour became too much. But these gave me respite time in Oxford where I went for walks and sometimes around the Oxford Museums.

Q: You said in your survey answer that we put you in touch with social services, can you tell me a bit about that.

A: Yes so [DA name redacted] advised me to speak to Oxfordshire mental health which I think is part of social services to get support for Mum. They are doing a blood test next week to see what's behind her change in behaviour. They've provided practical medical advice.

Q: It can be confusing which services are which sometimes...

A: Yes, this is where Dementia Oxfordshire is great, [DA name redacted] knows where to go for what and who to contact for certain types of information. It's terrific.

The problem I'm having now is trying to find care for Mum when we go away for 10 days in August. We need to find alternative care as the care company we were using have said they can't work with us anymore due to Mum's difficult behaviour. There is a big variation in how much carers know about dementia. Care companies say they offer dementia care as a service but in fact know little about it. We are looking into a new care company so hopefully that will work out.

Q: You said you haven't attended any sessions or groups ran by us, would this be something you'd be interested in doing?

A: Since completing the survey I did attend the Dementia Information Day in Cowley and there was a presentation by [DA name redacted], she was really explaining the illness and how it affects people's behaviour. I attended with my wife and we understood that Mum's aggression is due to an unmet need and we need to ascertain what that is.

Q: Do you feel this has helped your relationship with your Mum?

A: Sort of yes, I know now that when she's not being cooperative, I can understand it more, not to say it's still not frustrating at times, but it has made me more tolerant.

[END OF INTERVIEW]

Interview 2

Q: In the survey, you said you are a carer, who do you care for?

A: My husband, [name redacted]

Q: You said you found out about Dementia Oxfordshire through a pack you were given from the memory clinic, was that when your husband was first diagnosed?

A: Yes, they gave us a pack with different information and you were in there.

Q: You told us that the support you receive were initially visits and then phone and email support, how has that been working for you?

A: We had some home visits pre covid, a lady came out and arranged for another lady to come out. They helped with lasting power of attorney. I think they were from age concern, and they helped with AA. Which is all sorted now.

Q: How does email and phone work for you?

A: The 6 weekly calls from [DA name redacted] are very handy, they prod you for different things you might have forgotten to do and give you different strategies to help with things. My husband started to forget to take his pills, so we were told to get a pill caddy. We were sent the links which was very useful. My husband didn't use it, but I use it to help him, so it's a reminder in a different way now.

I haven't had a phone call for quite a while, seems difficult for her to work this time of day and around my job.

Q: In your survey response, you told us that the most beneficial type of support you receive was the regular check in and advice as you got used to your husband having dementia. How are you feeling about it now, do you feel more used to it?

A: Probably more used it but I also have more support now like the day centre.

Q: You also said that our support has made it much easier for you to cope. I was wondering in what ways?

A: The all-round package really, discussing how to look after my husband and what strategies I can use to cope. And that its okay if you need help.

Q: You said that a lot of the events are too far away from you as a non-driver, what events were you interested in attending?

A: Everything seems to be in Oxford city which is hard to get to. Everything stopped during the pandemic and memory clinic and age concern doesn't do much in the area. You seem to be the only ones doing stuff but it's too far.

Q: Would you be interested in taking part in an online group?

A: Online is possible but they are often during the day which is hard for me as I work.

[END OF INTERVIEW]

Interview 3

Q: You found out about us at the Memory Clinic, was this verbally or through leaflets?

A: I think it was part of our care plan. As part of that they referred us to Dementia Oxfordshire.

Q: You said you were given lots of literature by us, I was wondering how helpful you found this?

A: Yes, I was given a massive pack of information when Mum was first diagnosed. It wasn't that relevant at the time as Mum was just newly diagnosed and to be honest, I haven't got round to reading it yet.

Q: And you said you found phone calls with your Dementia Adviser useful?

A: Yes, it was useful having 1 to 1 catch ups and speaking to an individual rather than just an organisation. They will touch base and see how things are going. I tend to collect questions to ask for when I speak to the Dementia Adviser. The information she has given has been really helpful and personalised.

Q: Has all the support been in relation to caring for your mother or has there been support for your own wellbeing as a carer?

A: It has been in relation to caring for my mother, apart from being signposted towards a carers group.

Q: You said that we've given some information on technology – have you got an example of this?

A: Mum started to wander and was getting lost in town. The adviser sent a bunch of links to GPS technology and it's on my to-do list to order this week. I was also signposted to dementia-friendly mobile phones but I don't think we'll use those as Mum would find it difficult to use any mobile phone now.

Q: You said you feel relieved to know who you can call if you need to, would this be a call to your Dementia Adviser or the service?

A: I'm more likely to call a named person contact as they know my personalised case so can give me specific information.

Q: You haven't attended any of our groups or sessions, is this something you'd be interested in doing? Are there any barriers you face in doing so?

A: I would like to but it's hard with time as I work full time and am a single mother to my children as well as a carer and I can't leave my kids.

Q: One of the carer education sessions is 3 hours and often in the afternoon, would you attend if the sessions were shorter or at different times?

A: I wonder if it could be broken up into 3 one-hour sessions, that would make it easier for me to attend.

Q: Would you be interested in watching a recording of the sessions?

A: No, I think I'd prefer the interaction to help clarify any points and ask questions. One of the things I would really like to do is to meet someone in a similar situation to myself who is also a carer.

Q: What's the one thing you have found most helpful about Dementia Oxfordshire?

A: I think what I've covered already really, just having a named person that touches base, I can contact her when I have questions or an issue arises and the information she gives is genuinely very useful.

[END OF INTERVIEW]

Interview 4

Q: It's your wife you care for?

A: Yes.

Q: And you found out about our service when a Dementia Adviser got in touch following a referral?

A: Yes, Katie got in touch in February 2020 after my wife left hospital. She made contact and we received the opportunity to join an online dementia discussion which was very helpful and enlightening. This was a video discussion on Teams, and it was so informative. I had no prior medical training or understanding of the fundamentals of dementia, but it really put it all into perspective.

Q: When you say these sessions have given you greater awareness of dementia, is that about the condition itself or about how to help support someone with dementia?

A: It's a greater understanding of what dementia is. The session is split into 3 parts; what is dementia, the behaviours and enabling to live well. I think we may have missed a small part of the session and couldn't stay for the whole thing.

Q: And what in these sessions did you find most helpful to learn?

A: Understanding that you should validate behaviour, focus on person centred care and personhood, the importance of socialising and that there is 850,000 people living with dementia, 700,000 carers and therefore the significance of dementia and that we really need to be responsive.

Also, that you are an enabler not always a carer. The classification of memory and understanding the different stages was helpful.

Q: I have been told by another carer that the session could be improved by being broken up into 3 separate sessions, what do you think?

A: I think possibly two, one and a half hour sessions and that slight tuning would help. This is because it's not just about availability but if the recipient can pick it up and remember the information for that time.

Q: Would you like to attend future sessions if perhaps they were on a different topic or focussed on a specific area?

A: We are very fortunate with the support we get from family, carers and cleaners, whose visits have become a highlight as they see my wife and it's like a reunion. So, we are running along smoothly and get a lot of support. Given the opportunity we'd be interested if there was good topics and it was at the right time.

Q: How has your ability to care changed since attending the session?

A: Well, the classification of memory, lack of knowledge, learning there is 400 types of dementia was fascinating. Understanding that midterm memory becomes more exciting and that understanding why perhaps my wife thinks her mother is here even though she passed away 30 years ago. I'm more understanding of where her mind and memory is. I can be more responsive and softer and understand I need to fit into her way of thinking.

Q: When you said in the survey that "being there and available is incredibly important and reassuring" are you referring to the service as a whole or having a specific Dementia Adviser to speak to?

A: I think the service as a whole. I can see the benefit of a nominated person for other people and I think that is good for consistency but as I said I don't feel like our need is particularly high at the moment and things are going along smoothly.

Q: Is there anything you think we can do more of as a service?

A: I think Dementia Oxfordshire are doing the best job they can. It's nice to know they are there and it's so important being able to contact someone. If possible a quarterly phone call, in a relaxed style like this, for only 5-10 minutes would be good. 6 months is a long gap, as you get older, one's memory reduces and its harder to hold all of the information in. I think that would help increase the value of the service.

Q: Is there a way you think we could improve our communication?

A: I know that Age UK have a booklet for Oxfordshire and maybe you could insert a couple of pages in that.

Q: Do you prefer information that is printed off or online?

A: I am online all the time, but I find written material useful because you can pick it up again and come back to it each week, we get some local news and read it copiously. So yes, I think hard copy.

Q: Are there any questions you have for me or anything you'd like to know more about?

A: I like the communication we receive with information such as the event at Blenheim palace and the sale in Oxford, but because a lot of our life is in the house except for medical appointments and we can only go to places that are accessible, those occasional messages with more events would be useful.

[END OF INTERVIEW]

Appendix 4: Taguette codes

We used Computer Aided Qualitative Data Analysis Software (CAQDAS) software package called [Taguette](#) to conduct the analysis. This is a basic CAQDAS package compared to commonly used solutions however it has significant cost benefits in that it is a free, open-source tool.

The 15 codes created in Taguette and their incidences are shown below, these were used to identify the three themes.

