

Dementia Oxfordshire Impact Report

Contents:	1
Executive Summary	2
1. Introduction: Background	3
2. Core Service: Place-based and person-centred	4
• The challenge	
• What we do	
• The difference we make	
• Core service in action: Email from client's son	
3. Admiral Nurse: Bringing dementia awareness and expertise to Oxfordshire	9
• The challenge	
• What we do	
• The difference we make	
• Admiral Nurse in action: Case study	
4. Education and Pre-diagnostic offer	14
4.1 Education: Improving quality of life for PWD and carers through increased knowledge	
• The challenge	
• What we do	
• The difference we make	
• Education in action: Interview with two Experts by Experience	
4.2 Pre-diagnostic offer: Memory Support Service	
• The Challenge	
• What we do	
• The difference we make	
5. Beyond the Contract	19
• Groups	
• Clinics	
• Digital	
• Information Events	
6. Dementia Oxfordshire in the wider dementia community	21
Appendix A: Email analysis	
Appendix B: Client Survey	
Appendix C: Professional Survey	

Executive Summary

We know that dementia can be a long and lonely journey, not just for the person living with dementia, but also for their friends and family.

Dementia Oxfordshire aims to provide practical and emotional support to make that journey easier. The 2024 Impact Report examines the ways in which we do that, and, through a combination of qualitative and quantitative approaches, reveals the difference we make to the lives of those affected.

Building on the work of our previous impact report, this report aims to show that by supporting families by providing a dedicated Dementia Adviser, free information sessions, the Support Line and community activities, we continue to achieve three crucial outcomes:

- 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 (and information).

In particular, our analysis of 75 spontaneous emails received during 2024, reveals just how important the support of a Dementia Adviser is. Three recurring themes emerged, with clients expressing:

- They felt well supported, both practically and emotionally
- An appreciation of the timely and appropriate advice and information that enabled families/carers to make better decisions
- Their gratitude for being provided with emotional comfort during difficult times

We have also explored the significant benefits of our recent two-year pilot to embed an Admiral Nurse (specialist dementia nurse) in the service for the first time. Her role includes strengthening relationships with Oxfordshire health and social care teams, as well as providing specialist advice and training for professionals who are working with people with a dementia diagnosis. This means that we have been able to dramatically scale up the improvement in services for those living with dementia and their families across the county, as well as providing clinical expertise to our Dementia Advisers in complex cases.

With almost a decade of supporting people living with dementia and their families, Dementia Oxfordshire continues to adapt and evolve. In the past twelve months alone, we have taken over the full management of the Young Onset Dementia team (previously overseen by Dementia UK), we have rolled out our Memory Support Service for those living with memory worries but without a diagnosis, and have introduced a dedicated Benefits Adviser, specifically focussed on providing financial information and advice for families affected by dementia.

For a pdf summary of the report, please see our website www.dementiaoxfordshire.org.uk/our-story/our-impact/

Section One: Background

“Dementia should be seen as one of the major societal as well as medical challenges for our generation to address.”

Chris Whitty, Chief Medical Officer (2023)

Currently around 1 million people across the UK are living with dementia. By 2040, it is estimated that around 1.4 million people will have the disease, rising from 1.4% of the population to 1.9%. In Oxfordshire, NHS data shows that approximately 6150 people are diagnosed with dementia, up from around 5600 in 2020.

The rise is largely due to a decrease in mortality rates in those aged under 90. As we live longer, more of us will be diagnosed with dementia. Caring for those living with dementia will become more difficult as, across the UK, people continue to move away from cities as they age, choosing to live in peripheral, rural or semi-rural areas, often with relatively sparse services and transport links, and reduced access to healthcare and social services.*

Nationally, it has been estimated that dementia costs the UK around £42bn per year. Approximately 63% of this cost is borne by the individual and their families. Local authorities fund around 20% through the provision of social care, with the NHS responsible for the remaining 17%. Diagnosis and dementia specific drugs (which currently only ameliorate symptoms) account for less £100m.**

Treatment for the disease itself remains elusive. In 2024, NICE took the decision not to license two new MRHA approved drugs which, for the first time, would delay onset of symptoms, on the grounds that the benefits are too small to justify the costs.

Without any medical treatment available, most people diagnosed with dementia at a memory clinic are discharged on diagnosis.

However, other drugs are in the pipeline which will slow disease progression and work is underway to simplify diagnosis, with promising results on blood tests. In addition, there is increasing evidence that addressing 14 key risk factors can reduce the likelihood and/or delay the onset of dementia. These include keeping both socially connected and physically active. Tackling these factors may also help delay progression of the disease. **The importance of early diagnosis is becoming increasingly clear.**

In the meantime, Dementia Oxfordshire supports people with dementia to live as well as possible for as long as possible in the community, working to ensure people have a sense of meaning and purpose in their lives. We strive to provide a service that is evidence-based and person centred.

*Chief Medical Officer's Annual Report 2023: [health in an ageing society](#)

**Carnall Farrar's [The Economic and Healthcare Cost of Dementia: presentation at Alzheimer's Society Annual Conference 2024](#)

Section Two: Core service - place-based and person-centred

The challenge

“...caring for a loved one with dementia is often an emotionally and physically demanding experience which has a significant impact on the carer’s quality of life and wellbeing. The effects of being a family caregiver can bring about a complexity of emotions, and though sometimes positive, undoubtedly provide major challenges (Doris et al., [Citation2018](#); Peacock et al., [Citation2010](#)). Often the caregiving experience can be described as **a time filled with anxiety, heartache, uncertainty and fear** (Holley & Mast, [Citation2009](#)).”

Taken from: Gilsenan, J., Gorman, C., & Shevlin, M. (2022). Explaining caregiver burden in a large sample of UK dementia caregivers: The role of contextual factors, behavioural problems, psychological resilience, and anticipatory grief. *Aging & Mental Health*, 27(7), 1274–1281. <https://doi.org/10.1080/13607863.2022.2102138>

What we do

During 2024, Dementia Advisers supported over 6430 people across Oxfordshire: (2845 people who are living with dementia, 3585 unpaid carers) and conducted 4558 case reviews.

At the heart of the Dementia Oxfordshire service is a team of around 22 Dementia Advisers.

We take referrals from all sources, but well over half come directly from Memory Clinics. At clinic everyone is offered a referral at the point of diagnosis and everyone referred to Dementia Oxfordshire is allocated a named Dementia Adviser.

The Dementia Adviser will make contact within two weeks of referral and will keep in regular contact, providing ongoing, tailored support as necessary, until end of life or a move to a residential care home.

Each Dementia Adviser is attached to one or more GP surgeries and all have an in-depth understanding of the health and social care provision in their immediate area, as well as a broad knowledge about local amenities, activities and opportunities for those living with dementia and their families. As part of the wider Age UK Oxfordshire family, they can also quickly and easily draw on information and advice from other Age UK Oxfordshire teams.

In addition, we have a specialist team of three Young Onset Dementia Advisers (YODAs) who support around 115 clients across the county with dementia diagnosed before the age of 65.

The difference we make

Analysis of 75 spontaneous emails (received during 2024) reveals just how important the support of a Dementia Adviser is. Three recurring themes emerged, with clients expressing:

- They felt well supported, both practically and emotionally
- An appreciation for being given timely and appropriate advice and information that enabled families/carer to make better decisions
- Their gratitude for being provided with emotional comfort during difficult times

The email analysis and results of our 2024 client survey (103 responses, see Appendix B) reveals that the conclusions drawn in our 2022 impact report still hold true. Our service has three major impacts. Dementia Oxfordshire:

- Reduces carer stress through tailored practical and emotional support
- Prevents people living with dementia and their carers experiencing isolation and loneliness
- Increases confidence of carers in their caring role and improves the carer-cared-for relationship, through education (and information).

In addition, wider information and support is provided via the Support Line, the website, our information sessions, the activities of our Admiral nurse plus numerous activities that fall outside the remit of Dementia Oxfordshire's contract with Oxfordshire County Council (see Section 5).

Our service continues to reduce carer stress through tailored practical and emotional support

89% of carers or people with dementia who were in regular contact with their Dementia Adviser agreed or strongly agreed with the statement "During conversations with my DA or YODA, I feel listened to and heard."

"Thank you so much. You have no idea how much of a difference you have made already just by listening and helping to get things moving."

Email from client.

"Thank you so so much. You are a true star - really really appreciate your time, enormous care and hugely helpful advice."

Email from client.

87% of carers or people with dementia who were in regular contact with their DA agreed or strongly agreed with the statement "My DA or YODA has provided me with practical advice and information which has been helpful"

"We are greatly appreciative of your many suggestions, bits of helpful advice and thoughtfulness by providing support that will be of valuable use. I'll follow up on your suggestions and shall keep in touch with you on progress."

Email from client.

[Dementia Oxfordshire has made a difference as I am} being kept in regular contact and being provided with eye-opening ideas & practical advice, without me having to search for it and it all comes with constant empathy & deep understanding as the best, invaluable mental support for us carers, especially when caring for family members.]

Comment from survey respondent.

In addition to personalised support, the Dementia Advisers also staff our Support Line, using their knowledge and experience to help anyone who needs immediate access to advice.

In 2024, the Support Line took 789 calls, an increase of 9% on 2022.

81% of respondents to our survey agreed with the statement “It is reassuring to know that the Support Line is available to me.” This rises to 87% among people who have called the Support Line at least once.

Our service continues to prevent people living with dementia and their carers experiencing isolation and loneliness

60% carers or those living with dementia who were in regular contact with their Dementia Adviser agreed or strongly agreed with the statement “Support and signposting from my DA or YODA has helped me to feel more connected, less isolated.”

“I feel really buoyed knowing you're a part of our support team for M and D at this increasingly difficult time.”

Email from client.

“[Dementia Oxfordshire] provides activities and events that are the highlight of our week and give us both a sense of belonging to a group of people who are working through the same issues.”

Comment from survey respondent.

Our service continues to increase confidence of carers in their caring role

65% of respondents to the 2024 survey who identified as carers and who are in regular contact with their Dementia Adviser or Young Onset Dementia Adviser agreed or strongly agreed with the statement “Support from Dementia Oxfordshire means I am more confident in my caring role.”

66% carers who had attended one of our Understanding Dementia for Informal Carers information sessions agreed or strongly agreed with the statement “I feel more confident in supporting my loved one with dementia.”

86% of respondents to the post information session survey agreed or strongly agreed with the statement “I feel I can make a positive difference to the person I support.”

“[Dementia Oxfordshire} has given me massive knowledge on the disease and [how} best to cope, care & support.”

Comment from survey respondent.

“...today helped me tremendously in gaining knowledge for my future as a carer for the health and safety of my 93-year-old mother-in-law. “

Comment from post information session feedback.

Use of the Dementia Oxfordshire website is high, with around 74% of survey respondents using it regularly or occasionally. Of those who didn't use it, reasons were largely balanced between not feeling a need (information from elsewhere) and not knowing it existed.

Core Service in action: Overview of service, provided in an unsolicited email.

I am reaching out to you today just to express my, and my sibling's, sincere appreciation of your very kind help and assistance in relation to our mother who suffers from dementia.

Mum lives in X whilst both I and my sibling are based in and around Leeds with our own families. Around 10 years ago we noticed a gradual decline in our mother's mental acuity and last year she was officially diagnosed as having mixed Alzheimer's and vascular dementia. Over the last few years we were not sure who to turn to

It was not until yourself and Dementia Oxfordshire were contacted did the situation start to markedly improve for my mother. Following your very kind visit in February 2024, we had a clear action plan on what to implement. You very kindly provided much valued and needed advice, information, support and a steer on the way forward.

Unlike the relevant support authorities, you easily understood and took on board issues with my mother's dementia and provided some excellent practical and actionable advice in relation to access to self-hygiene approaches, frequency and roles of carers, keeping tabs on medication, the importance of social activities and weekly routines, and finally recommending some regular clubs that she could attend (i.e., the group on a Friday, which I now cannot stop her from going to she loves it so much).

Under your kind steer and direction we have actioned all of these and she now has two regular social activities per week, has a secure medical box for her prescription, has a key lock fitted at the front door, and is visited twice a day by carers who help provide access to the required medication for mum to take.

Whilst the onset of dementia is clearly not reversible, we have seen a marked decrease in the rate of decline of my mother's mental state since your original visit and advice, so we are extremely grateful for your help and intervention.

We wanted to make it clear to you our heartfelt thanks and to express that we feel your assistance in all of this is immeasurable,

Thank you and Dementia Oxfordshire again for having such a marked and positive impact upon the quality of life of our mother.

Section Three: Admiral Nurse: Bringing dementia awareness and expertise to Oxfordshire

The Challenge

“People with dementia and carers can face many barriers, or inequalities, in accessing a diagnosis or care. These barriers are unjust and can be addressed by the right interventions, to ensure that everyone receives equitable access to diagnosis and care. A lack of knowledge about dementia in the health and social care workforce is a recognised barrier.”

Taken from Giebel C, Marshall H, Cannon J, et al. The impact of game play on dementia knowledge: A student evaluation of the Dementia Inequalities Game. Dementia. 2024;0(0). doi:10.1177/14713012241306489

What we do

In July 2023 we started a 2½ year pilot to embed dementia specialist Admiral Nurse (Fran Mada) within the Dementia Oxfordshire service (funded by Dementia UK).

Her role is threefold:

- To raise awareness of the services offered by Dementia Oxfordshire and integrate the service into the wider health and social care landscape of the county, leading to better outcomes for individual clients.
- To provide training focussing on how best to support people living with dementia for professionals working with an ageing population. She has also led on an initiative to drive up rates of Advance Care Planning.
- To support the Dementia Oxfordshire Dementia Advisers with complex cases, working with individual families and liaising with external agencies where necessary, as well as heading up the team of Young Onset Dementia Advisers and presenting at Dementia Oxfordshire groups.

This work has brought her into contact with over 20 other health and social care teams over the past 18 months, as well as local charities, private healthcare companies and education providers.

- | | |
|---|--|
| • Single Point of Access (SPA) teams | • Neurology department/Cognitive Disorders Clinic at JRH |
| • Occupational Therapists | • Palliative care teams: Sobell House, |
| • Individual GP surgery teams | • Keystone Mental Health and Wellbeing Hub, Banbury |
| • Adult Social Care | • Parkinson's Nursing Team |
| • Continuing Health Care Teams | • Community Neurology Specialist Nurse Team |
| • GP Hubs | |
| • District Nurses | |
| • Older Adult Community Mental Health Teams | |
| • Elms Memory Clinic | |

- Clinical Lead for Supportive & End of Life Care
- MND nurses
- Witney Community Hospital
- Abingdon Community Hospital
- Physiotherapists
- Community Matron Teams (end of life care)
- Castle Group (interested in opening a specialist residential care home for people living with young onset dementia in Oxfordshire)
- Sobell House Hospice
- Katherine House
- Sue Ryder

Nationally, she has presented at the Dementia UK Summer School (a free online event for all health and social care practitioners supporting families living with dementia) and also at the 18th UK Dementia Congress (the largest multi-disciplinary dementia-focussed event and exhibition in the UK).

As well as providing training to other professionals, the Admiral Nurse also supports formal education in dementia. Over the past 18 months, she has reviewed the dementia training materials for OUH Trust and has consulted/presented on external education courses:

- Dementia Masters Module – Oxford Brookes University
- Teaching session for Students on the Advancing Practice in Dementia Care course by Oxford Health | Learning and Development Centre.

The difference we make

Her work has increased the breadth and depth of Dementia Oxfordshire's work across Oxfordshire, achieving three clear outcomes.

1. Raising awareness of and integrating the service provided by Dementia Oxfordshire

In December, following a meeting with the Admiral Nurse, Katherine and Sobell House Hospices reviewed their procedures, addressing some problems with previous referrals from Dementia Oxfordshire to the Hospice service, and confirmed that there should be no further issues.

“Our service accepts referrals from any healthcare professional, so you should certainly qualify to make referrals as you see specialist palliative care needs in the community. I am sorry that this didn't happen on some occasions in the past.”

(The service also requested the Admiral Nurse provide dementia training for the hospices staff teams.)

“Thanks for your support with Mrs X and I hope to work with you again.”

Social worker following Admiral Nurse support on CHC assessment

2. Raising awareness about how best to support people living with dementia for professionals working with an ageing population

Sharing dementia expertise with other health and social care teams. Recurrent themes include:

- pain and dementia
- end of life care
- distress in dementia
- transitions in care
- dementia friendly approaches to spaces and services
- the importance of advance care planning

“I had discussions with E yesterday about the amazing work you do and how we are linking in together Dementia Oxfordshire/Oxford Health with bitesize training, care planning and specifically pain training for staff with those who have dementia.”

Community Matron

“We used the Dementia Friendly Environment checklist you sent me. Our focus will be on clear signage with drawing where appropriate, toilet sitting contrast colour, clock [with] time, date, day, landmark / large plant, grab rails Thank you so much for your help!”

Abingdon Hospital Outpatient Department.

“At Sue Ryder South Oxfordshire Palliative Care Hub we started weekly Quality Clubs, where we take one of the Sue Ryder quality priorities, further our education and knowledge, then reflect on how this could be incorporated into patient care. For our dementia quality club, we collaborated with Dementia UK where Dementia Oxfordshire’s Admiral Nurse and one of its Dementia Advisers came to the hub to deliver an introduction into dementia care in palliative and end-of-life care. This was a brilliant opportunity for collaboration and to improve shared care, understanding what support and services our patients and those important to them can access.”

Taken from Sue Ryder Annual Report

3. Supporting Dementia Advisers with complex cases, working with individual families and liaising with external agencies where necessary, as well as heading up the team of Young Onset Dementia Advisers.

“Wow Fran that is such comprehensive information. Thank you so much. When I telephone the client’s son, I will give him space to share his concerns and will talk through some of the advice that you have offered. Thank you again for taking the time to provide this guidance”.

Dementia Adviser

The Dementia Oxfordshire Young Onset Team became an integrated part of Dementia Oxfordshire in April 2024, the service having previously been sub-contracted to Dementia UK. Young Onset clients account for just under 5% of Dementia Oxfordshire clients. The Admiral Nurse manages this specialist team,

providing expertise on individual cases and an overview of the particular needs of people living with Young Onset Dementia.

In addition to personalised support, the Young Onset team currently run monthly sessions and regular outings to support those with Young Onset Dementia

“[The YODA team] are lifesavers really. And it’s just so relaxing to be with people who are in the same boat.”

Young Onset client at Bike and Banter event

“nice to feel part of a group of people who understand the very particular challenges of caring for someone with young dementia. “

Attendee at Family Group

Admiral Nurse in action: a case study

Mrs B reached out for support as she was concerned about a planned short-stay hospital appointment for her husband who was living with dementia and cancer. Admission to treat his cancer happened infrequently but regularly. Past experiences “of these unpleasant treatments” had been very negative. Mr B had been “extremely agitated” both before and after the appointment. Mrs B contacted Fran via her DA to ask for advice about how to best manage the planned hospital admission. She had made up her mind that if there was no viable advice, he was not going to have the procedure.

Fran advised Mrs B to talk with the hospital team as soon as possible about her concerns, help them reflect on past admissions, and to consider how agitated Mr B had been pre and post op. Fran suggested she ask the following questions:

- Is an overnight stay the only way?
- Could she stay overnight or ask someone who knows him to stay overnight?
- Could they provide one-to-one support? She was happy to pay for it.
- Could he be in a room closer to the nurses?
- Could the nurses reduce noise levels?
- Could they let all staff know that it was essential to call him by name, talk about his work (drawing on the Knowing Me document), refer to his wife by using her name and to avoid asking questions unless necessary?

After three cancellations the operation took place. Mrs B felt empowered to negotiate with hospital staff to ask for the earliest available time, avoiding the necessity of an overnight stay, “explaining why it was in no one’s interests for Mr B to stay overnight”. They agreed and put in place simple but effective measures to ensure Mr B. was comfortable. His treatment was scheduled as the first in the day and he was discharged later in the afternoon.

Positive impacts:

- A planned short-stay hospital admission.
- Positive experience of caring for hospital team. Improved staff confidence/ competence/ knowledge.
- Positive experience of care/ reduction in complaints, improved well- being / quality of life for carers.
- Positive impact on discharge planning & transitions in care settings.
- Showcases the complex role of a Dementia Adviser / an Admiral Nurse and the various ways we can have an impact within the wider health and social care services.

Email feedback via email from Mrs B to Fran, detailing his treatment:

“(The hospital nurses) were so kind and supportive. He was given the first operating slot of the day. When he came out of the operating theatre, he was put in a room directly across from the nursing station where they could easily check on him. Then they made every effort not to keep him waiting. They sent us home as soon as they were assured that he was well enough. We both arrived home early afternoon feeling relatively relaxed. It was very good advice. Thank you.”

Section Four: Education and Pre-Diagnostic offer

4.1 Education: Improving quality of life for people with dementia and their carers through increased knowledge

The Challenge

“Persons with dementia found it important to know what the dementia diagnosis entailed and how it develops over time. Informal caregivers viewed information as a requirement to care for someone with dementia.”

Taken from Persons with dementia and informal caregivers prioritizing care: A mixed-methods study
Joost D. Wammes, Nanon H. M. Labrie, George O. Agogo, Joan K. Monin, Esther W. de Bekker-Grob, Janet L. MacNeil Vroomen First published: 06 August 2021

What we do

Information sessions are a key part of the Dementia Oxfordshire offer. We run two different types of session for people affected by dementia (Understanding Dementia for Informal Carers and Post Diagnostic Information Sessions). Additionally, we run Dementia Awareness sessions for the wider community and people working with those who are living with dementia.

In 2024, we have delivered

- **Understanding Dementia for Informal Carers:** 15 sessions, 117 participants
Delivered online or in person – a 2 hour session designed to help equip informal carers with knowledge and skills to support them in their caring role.
- **Post Diagnostic Information Session:** 12 sessions, 95 participants
Delivered in person over two sessions, designed to explain more about different types of dementia plus practical advice and peer support
- **Dementia Awareness Session:** 23 sessions, 318 participants
Chargeable sessions for companies and other community groups, raising awareness of the challenges faced by people living with dementia.

All our information sessions are designed with the help of our Experts By Experience groups, made up of people living with dementia and their informal carers. These groups not only ensure our content is relevant and appropriate, they also provide peer support to the members.

The difference we make

In feedback following Understanding Dementia for Informal Carers sessions, 83% of attendees agreed or strongly agreed with the statement “I have a better understanding of what dementia is.”

66% carers agreed or strongly agreed with the statement “I feel more confident in supporting my loved one with dementia.”

“The whole session was very useful as I had very little understanding of Dementia before this.”

Participant

“Very glad I was able to attend this session”

Participant

“I would like to thank you once again for the incredibly informative and well-presented dementia awareness session which you kindly delivered last Monday. A number of the participants said that they wished they had access to the training years ago, and that they have learnt more from the session than any other source at any other time.”

Green Pastures Nursing Home

“[It was great] to come away feeling positive, more learned and feeling the empathy and respect of all present. It made us feel part of something.”

Expert by Experience group member

Education in action: Interview with Glenn and Christine

Glenn was diagnosed with dementia in December 2020 and is part of our Experts by Experience groups which meet regularly. Glenn often co-presents the Post Diagnostic sessions alongside the Education Team. His wife, Christine is his carer and is also part of the Experts by Experience group.

Melissa: *What do these sessions mean for you?*

Christine: *These sessions have been a lifesaver for me. I was so devastated by the experience (of diagnosis), I couldn't talk about it. But since coming to these meetings and going out with Glenn when he talks to people who are newly diagnosed has really helped me to come to terms with things and to cope. I've got lots of strategies from other people who are here, that I've got in place now – separate bank accounts and all that sort of thing – it's all from this group. All the help that I've got has been absolutely invaluable.*

Melissa: *And you Glenn?*

Glenn: *Yes, as I've said before, I've found that talking to people about dementia who are diagnosed, who know about dementia, makes my dementia easier to manage, because I can see that it's not just me, I can see that other people have problems like me and there are ways round them and I think we've found some of those ways round them in this meeting, so I find it very valuable.*

I retired quite recently. I used to be the expert on European public procurement – which you wouldn't want to know about, don't worry about it! But essentially I went all over the country, all over Europe, telling people about it, so my business has been telling people about stuff so that they understand it. So in the same way, this is telling people about dementia stuff that I now know about which I didn't before. So in a sense I'm extending my performance as a speaker!

4.2 Pre-diagnostic offer: Memory Support Service

The Challenge

“Despite the considerable policy, practice and fiscal emphasis, a diagnosis of dementia is not the starting point for the experience of living with the condition” (Campbell et al. 2016).

It is known from qualitative research involving those at the onset of their condition (Alzheimer's Society, 2010a, Alzheimer's Society, 2010b, McCleary et al., 2013, Robinson et al., 1997, Steeman et al., 2006), influential reports (All-Party Parliamentary Group, 2012) and from the autobiographies written by people living with dementia (for a review, Page & Keady, 2010), that the first subtle signs of onset are often difficult for the person to understand and translate into their everyday frames of reference and meaning making.

What we do

Without a dementia diagnosis, people with memory concerns and their families struggle to access support from organisations like Dementia Oxfordshire. The new Memory Support Service changes that.

Following a successful pilot in 2023, Dementia Oxfordshire launched the Memory Support Service in April 2024. Anyone worried about memory loss can be referred to the service by a health or social care professional. They will receive a one-off support session from a trained Dementia Adviser. This includes:

- Memory strategies
- Keeping safe and well
- Explaining how Memory Clinic appointments work
- Making healthy lifestyle choices
- Providing support (and hope for an active life post-diagnosis) through information about groups and activities
- Support from health, social care & local services
- Assistive technology and aids around the home
- A benefits check
- Planning ahead, including discussions around Power of Attorney / Advance Care Planning

The service supports anyone with memory concerns, or with a Mild Cognitive Impairment diagnosis, or who is already on the diagnostic pathway.

The difference we make

We supported 33 people during the pilot and have supported a further 124 people with our memory support offer in 2024. Referral rates are increasing as the service becomes more well known.

The service provides vital emotional and psychological support for people who are living with uncertainty.

Section Five: Beyond the Contract

In addition to the statutory requirements of the contract with Oxfordshire County Council, Dementia Oxfordshire provides a range of other support and services, and undertakes additional activity to ensure that those living with dementia and their informal carers are supported and informed.

This work includes communicating information about dementia to all Oxfordshire residents. With one in 20 people now living with the disease in the UK, everyone will be touched by dementia in their lives – through friends, family or neighbours. Increasing awareness of and knowledge about dementia helps to ensure that the community provides a safe and welcoming place for anyone living with dementia and their carers. It also encourages earlier diagnosis as more people come forward with memory concerns, confident that there is support available.

- **Groups**

Dementia Oxfordshire currently runs 13 regular (usually monthly) groups across all five districts. It also supports a further 36 groups.

Active Minds	Games and Gossip (Young Onset)
Ampleforth Carers	Kidlington Making Memories
Bicester pop in memory café	Abingdon Peer Support and Wellbeing
Care2Share (x2)	Walk and Talk (Young Onset)
Coffee and Chat (Young Onset)	Wellbeing Walk
Family Members (Young Onset)	Young Minds (Young Onset)

Of the 46% survey respondents who attended groups occasionally or regularly, 79% (37/47) agreed with the statement “Dementia support groups have a positive effect on my wellbeing.” This figure stayed the same whether people were regular or occasional attendees.

“Attending the meeting was invaluable...there were two carers who had recently put their husbands into care homes. They spoke so eloquently about their experiences....it allowed me to gain some much-needed perspective on my situation. The work you all do is so helpful and keeps us going.”

Care2Share Attendee

“We come every month and look forward to it. He benefits a lot from the walks.”

Wellness Walk Attendee

- **Clinics**

Dementia clinics are held across the county in health centres, libraries and other, easily accessible venues. The clinics offer bookable appointments and are run by Dementia Advisers. They are open to anyone who has questions about dementia or is looking for advice on how best to support someone who is living with dementia

In 2024, Dementia Oxfordshire ran 15 clinics at the following venues:

Faringdon Library	Deddington Health Centre
Carterton Library	Wheatley Memory Clinic
Chawley Grove Care Home (Oxford)	Thame Dementia Clinic
Chinnor Forget-me-knot café	Marcham Road Family Health Centre
RVS Cornhill (Banbury)	(Abingdon)
Banbury Cross Health Centre	Hollow Way Medical Centre (Oxford)
The Leys Health Centre (Oxford)	White Horse Medical Centre
Southerndown Care Home (Chipping Norton)	(Faringdon)
	Manor Surgery (Oxford)

- **Digital**

The Dementia Oxfordshire website has expanded significantly over the past two years and now includes a location-based events page and regular news items covering Dementia Oxfordshire activities and news about wider dementia developments.

The recent client survey found that use of the Dementia Oxfordshire website was high, with around 74% of respondents using it regularly or occasionally. Of those who didn't use it, reasons were largely balanced between not feeling a need (information from elsewhere) and not knowing it existed.

Two online newsletters (one general and one with a focus on Young Onset Dementia news and events) are sent out each month to subscriber lists (total 486 subscribers), which include professionals, clients and supporters.

An actively managed Facebook page now has over 1000 followers. In December 2024, two posts reached over 6000 people, one featuring general advice about spending Christmas with someone with dementia, and another with details of where to find advice and support over the Christmas period.

- **Information Events**

Dementia Oxfordshire hosts four information events each year, inviting other relevant Age UK Oxfordshire services to take part, alongside local companies and service providers. The events increasingly popular and our latest event had over 100 members of the public attend.

"Thank you for inviting us. It was a wonderful event and so well run. We had an amazing time talking to people. "

Stallholder at Autumn Information Fayre

"(I came because I was) worrying about whether my dad needs to go into a care home. Very good advice from Age UK, Citizen's Advice and the council about what I need to do."

Visitor to Autumn Information Fayre

Section Six: Dementia Oxfordshire in the Wider Dementia Community

Oxfordshire

Dementia Oxfordshire works closely with a number of other health and social care professionals across the county, including GPs, Memory Clinics, Community Nurses, Occupational Therapists and Social Prescribers. A recent survey, completed by 25 Oxfordshire professionals working within the dementia community, showed the service is widely respected and valued.

100% of respondents to our professional survey agreed with the statement:
“Dementia Oxfordshire makes a positive difference of the lives of people with dementia and their families.”

100% of those who had interacted with our Dementia Advisers or Admiral Nurse agreed with the statement:
“In my experience Dementia Oxfordshire Advisers and the Dementia Oxfordshire Admiral Nurse always act in a professional manner.”

“Very friendly and helpful, patients appreciate having a point of call for questions and advice. I have received positive feedback from patients that you have been able to support individuals accessing and getting useful aids in the home i.e. dementia clock and radio.”

Assistant Psychologist, Memory Clinic

“I just wanted to say what a great Dementia Adviser service you and your colleagues provide. It is very reassuring when I see someone at the clinic and share the diagnosis of dementia to know that there is such good post diagnostic support out there.”

Email from Alistair Burns, p/t consultant at Oxfordshire Memory Clinic and National Clinical Director for Dementia and Older People’s Mental Health at NHS England and NHS Improvement.

“Dementia Oxfordshire is an extremely professional, established and well thought of organisation. Their support line and acceptance of both professional and self-referral over a full county geography makes it simple for carers and professionals to know where to go, reducing reliance on statutory services, carer breakdown and potential crisis.”

Health/Social Care Professional

Nationally

In addition the Admiral Nurse’s presentation at the Dementia UK Summer School, Peter Johnson (Head of Service) and Melissa Spearman (Education Lead) presented at the 2024 UK Dementia Congress, on the theme of **Co-Producing and Delivering a Post-Diagnostic Educational Offer for People with Dementia and their Families**, showcasing the success of involving those living with dementia and their families in designing and presenting information sessions.

APPENDIX A

Email Analysis

Analysis of 75 unsolicited emails/messages sent to Dementia Oxfordshire over 12 months between 1.1.24 and 31.12.24.

Spreadsheet with further details can be found [here](#).

1. Dementia Adviser support

The majority of the emails (50 = 66%) related to the support provided by dementia advisers for the family and family carers.

Prompts

The emails were unsolicited, and were sent at varying points in the relationship between the Dementia Advisers and the clients, although most were prompted by the three following events:

- **First (or early) visit/conversation with a DA following diagnosis**

“Thank you so much for taking my call and calming my panicked mind! There are such big changes ahead for my little family and my heart is absolutely breaking for David so it’s good to know there is support out there. I am grateful.”

- **Change in circumstances/new challenge**

“[We] thank you very much for your prompt help earlier today. It spurred us on to sort out respite care arrangements immediately...We now have gained a pause to take stock and think of a longer-term plan. Thanks again, your help and guidance appreciated.”

- **Death of the person living with dementia**

“Please keep doing what you’re doing. - it made such a difference to us and the phone calls to check everything was ok were always a real boost. Many thanks for looking after us.”

Themes

Recurring themes in the emails included:

- **Feeling well supported, both practically and emotionally**

“Thank you again for all the support you offer, know that you make a big difference”

- **Appreciation for being given timely and appropriate advice and information that enabled families/carers to make better decisions:**

“It was really helpful to better understand his condition and has allowed us to make better decisions for him”

- **Being provided with emotional comfort during difficult times**

“It was very comforting and reassuring to hear the gentle advice that your years of experience has given you...”

Many of the emails cover all these aspects of support provided by Dementia Advisers.

Language

After “thank you”, the most frequently occurring words in these emails (as analysed by a wordcloud) are:

- Advice
- Assistance
- Support
- Helpful

2. Professional appreciation of the service

6 of the emails received over the twelve months were from other professionals working in the field, one from a social worker, one from an NHS psychologist and two from memory clinic staff, including Alastair Burns, National Clinical Director for Dementia and Older People’s Mental Health at NHS England and NHS Improvement and currently working part-time in an Oxfordshire memory clinic:

“I just wanted to say what a great Dementia Advisor service you and your colleagues provide. It is very reassuring when I see someone at the clinic and share the diagnosis of dementia to know that there is such good post diagnostic support out there.”

Additionally, a local care home commented on a DOX facebook post, and 2 carer organisations spontaneously gave feedback on the Autumn Information Fayre:

“It was a fabulous day and very well organised, I met some lovely people as I did at the Abingdon one.”

An additional email from a past employee stated that Dementia Oxfordshire was the loveliest team she had ever worked in.

3. Experts by Experience

3 emails received were positive feedback on Experts by Experience sessions, part of Dementia Oxfordshire's co-production initiative to ensure people living with dementia and their carers are involved in the design and content of education sessions and literature.

"I find the sessions helpful as I used to find it difficult to talk about G's dementia, but since talking in a smaller group I am much more comfortable about it. I also find the importance of other people's ideas and how they cope useful too,"

4. A Straightforward Guide to Dementia booklet/other literature

4 emails were sent in praise of resources, 3 concerning the Straightforward Guide to Dementia booklet (published April 2020):

"I think it's a great resource; particularly as it's co-written by people themselves experiencing memory loss "

The fourth was from an occupational therapist, requesting further leaflets about our services, which her clients found helpful.

5. Education Sessions

Everyone attending an education session is asked to evaluate the session. In addition, 2 spontaneous emails were received praising the professional nature of the delivery and usefulness of content.

"The delivery was very professional and presented in such a way that was suitable for the older participants to follow and understand."

6. Groups

7 emails were received in praise of different group activities run by Dementia Oxfordshire, one referencing Singing at the Amp in Oxford, another referring to the Wellness Walk at Blenheim Palace, 3 praising the Young Onset group visit to the Christmas lights at Blenheim Palace and 2 giving feedback on the online Care2Share sessions:

"Attending the meeting was invaluable...there were two carers who had recently put their husbands into care homes. They spoke so eloquently about their experiences....it allowed me to gain some much needed perspective on my situation. The work you all do is so helpful and keeps us going."

7. Admiral Nurse

1 email highlighted the delight at being introduced to Dementia Oxfordshire's Admiral Nurse, Fran Mada:

"Thank you so much for putting me in touch with Fran Mada, the Admiral Nurse - she is lovely!"

APPENDIX B
Client Survey

APPENDIX C
Professional Survey



Dementia Oxfordshire Survey 2024 (PAPER VERSION)

Thank you for taking time to fill in our survey. It's important for us to understand how well Dementia Oxfordshire is working, and how we can improve.

It should take no more than 10 minutes to complete. When you have finished the survey, please hand it back to a member of the Dementia Oxfordshire team or post it back to: **FREEPOST, Age UK Oxfordshire** before 15th November 2024. Please make sure that FREEPOST is in capital letters. No other details are needed on the envelope and it doesn't need a stamp.

We would like hear the views of people living with dementia and/or their carers, although please be aware there are two questions that are only for carers, which are clearly marked.

The survey is divided into four sections:

1. About you
2. Which services do you use?
3. How well do those services work for you?
4. Your thoughts

* Required

About you

1. Please tell us about yourself. Are you: *

- ☐ Living with dementia
- ☐ A family carer for someone living with dementia
- ☐ An informal (unpaid) carer for someone living with dementia, who is not related.
- ☐ Other

2. Whereabouts in Oxfordshire do you live? Just let us know which district. *

- ☐ Cherwell
- ☐ West Oxfordshire
- ☐ South Oxfordshire
- ☐ Vale of White Horse
- ☐ Oxford city
- ☐ Not sure

3. How long have you been in contact with Dementia Oxfordshire? *

- ☐ Less than 6 months
- ☐ 6 - 12 months
- ☐ 1-2 years
- ☐ More than 2 years

4. Were you/the person you care for diagnosed with dementia before the age of 65? *

- ☐ Yes
- ☐ No

Which Dementia Oxfordshire services do you use?

5. In the past six months, have you spoken to one of our Dementia Advisers or Young Onset Dementia Advisers (YODAs), either in person or on the phone: *

- ☐ Yes
- ☐ No
- ☐ Not sure

6. If you answered no, please tell us why not.

7. Have you ever attended any of our Education Sessions? We currently run two different types of session: Post Diagnostic Education Session and Understanding Dementia For Informal Carers *

- ☐ Yes
- ☐ No
- ☐ Not sure

8. If you answered no, please tell us why not.

9. Do you attend any of our dementia support groups (for example memory cafes/wellbeing sessions/walks/coffee and chat)? *

- ☐ Yes, regularly
- ☐ Yes, occasionally
- ☐ Not sure
- ☐ No

10. If you answered no, please tell us why not.

11. Do you use the Dementia Oxfordshire website? *

- ☐ Yes, regularly
- ☐ Yes, occasionally
- ☐ No
- ☐ Not sure

12. If you answered no, please tell us why not.

13. Have you ever contacted the Dementia Oxfordshire Support Line for additional support? *

- ☐ Yes, once
- ☐ Yes, more than once
- ☐ No
- ☐ Not sure

14. If you answered no, please tell us why not.

How well do our services support you?

Let us know if you agree or disagree with the following eight statements.

15. During conversations with my Dementia Adviser or YODA, I feel listened to and heard.

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree

16. My Dementia Adviser or YODA has provided me with practical advice and support that has been helpful

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree

17. **Carers only:** Support from Dementia Oxfordshire means I am more confident in my caring role.

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree

18. Support from Dementia Oxfordshire means I feel better able to cope with the challenges of dementia.

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree

19. Support and signposting from my Dementia Adviser or YODA has helped me feel more connected and less isolated.

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree

20. **Carers only:** Support and signposting from my Dementia Adviser or YODA has helped the person I care for feel more connected and less isolated.

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree

21. Dementia support groups (eg memory cafes/wellbeing sessions/walks/coffee and chat) have a positive effect on my wellbeing.

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree

22. It is reassuring to know that the Support Line is available to me.

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree

Your thoughts

Dementia Oxfordshire may want to publish your comments to let people know more about the services we offer. Are you happy for us to do this? We may use them anonymously, or, if you agree, we may attribute them to you, using your first name only, Even if you don't want us to publish your comments, we would still like to hear what you think so that we can continue to improve our service.

23. Can we use your comments to help let other people know about the work we do? *

- ☐ Yes and I am happy for you to use my first name
- ☐ Yes, but please make the comments anonymous
- ☐ No, please don't publish my comments.

24. What is your first name?

25. What do you value most about the support Dementia Oxfordshire provides?

26. How has Dementia Oxfordshire made a difference to your experience of living with dementia or caring for someone who lives with dementia?

27. Would you recommend the services of Dementia Oxfordshire to others in similar situation?

- ☐ Yes
- ☐ No
- ☐ Maybe

28. If you answered no, please tell why not.

29. We'd love to hear more about the ways in which you have used our services. If you are happy for us to get in touch with you for a chat, please fill in your name and contact details below. THIS IS ENTIRELY OPTIONAL.

This content is neither created nor endorsed by Microsoft. The data you submit will be sent to the form owner.

 Microsoft Forms

Dementia Oxfordshire feedback: Professional

This survey is anonymous. We will use your responses to look at where we can improve our service. We may use the results to publicise the service and demonstrate our impact.

* Required

1. Please tell us your job title: *

2. Please tell us your place of work (eg hospital/community/GP surgery etc): *

3. Let us know about your understanding of the service offered by Dementia Oxfordshire.
(Please choose all that apply) *

- ☐ I am aware that Dementia Oxfordshire has a team of Dementia Advisers supporting people living with dementia and their families across the county
- ☐ I am aware that Dementia Oxfordshire has its own Admiral Nurse (dementia specialist nurse).
- ☐ I am aware that Dementia Oxfordshire organises a number of support groups and activities.
- ☐ I am aware that Dementia Oxfordshire has a support line.
- ☐ I am aware that Dementia Oxfordshire runs free information sessions for carers and for people who are newly diagnosed with dementia.
- ☐ Other

4. Let us know how you have interacted with Dementia Oxfordshire. (Please choose all that apply) *

- ☐ I have referred clients/patients to Dementia Oxfordshire
- ☐ I have received training or a presentation from the Dementia Oxfordshire Admiral Nurse.
- ☐ I have worked with the Dementia Oxfordshire Admiral Nurse to support specific clients/patients
- ☐ I have attended events organised by Dementia Oxfordshire
- ☐ I am involved with groups organised by/supported by Dementia Oxfordshire
- ☐ I have hosted Dementia Oxfordshire information/education sessions
- ☐ I haven't interacted with Dementia Oxfordshire
- ☐ Other

5. Let us know if you agree or disagree with the following statement: **Dementia Oxfordshire has increased my understanding of dementia and associated symptoms.** *

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strong disagree
- ☐ Don't know or not applicable

6. Let us know if you agree or disagree with the following statement: **Dementia Oxfordshire makes a positive difference to the lives of people with dementia and their families.** *

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strong disagree
- ☐ Don't know or not applicable

7. Let us know if you agree or disagree with the following statement: **In my experience Dementia Oxfordshire Advisers and the Dementia Oxfordshire Admiral Nurse always act in a professional manner.** *

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strong disagree
- ☐ Don't know or not applicable

8. Let us know if you agree or disagree with the following statement: **Having the services of an Admiral Nurse (specialist dementia nurse) in Oxfordshire is vital for increasing recognition of the health and social care needs of people who are living with dementia.** *

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strong disagree
- ☐ Don't know or not applicable

9. Let us know if you agree or disagree with the following statement: **The Admiral Nurse has proved an important part of the Multi-Disciplinary Team looking after someone with dementia.** *

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strong disagree
- ☐ Don't know or not applicable

10. Let us know if you agree or disagree with the following statement: **Dementia Oxfordshire is well integrated into the overall health and social care systems in Oxfordshire.** *

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strong disagree
- ☐ Don't know or not applicable

11. Please tell us anything else about your experience of working with Dementia Oxfordshire in a professional capacity.

12. We sometimes include quotes/comments from our feedback surveys in reports, literature and publicity. If we include any quotes/comments from you, please tell us if it is okay to include your job title and setting: *

- ☐ Yes - I am happy for you to use my job title and setting. (I understand that this might make me identifiable.)
- ☐ No - please only refer to me as a Health/Social Care Professional.

This content is neither created nor endorsed by Microsoft. The data you submit will be sent to the form owner.