



DementiaUK

Helping families face dementia

Young Dementia Oxfordshire

1st January 2022 –
31st December 2022

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Dementia UK is a registered charity in England and Wales (1039404) and Scotland (SC 047429).

About the service

Young Dementia Oxfordshire is a young onset dementia service provided by Dementia UK.

The service offers specialist information, advice and support for people living with young onset dementia (aged 65 and under) and their family members in Oxfordshire via a team of three Young Onset Dementia Advisors (YODAs). This is done by face-to-face, telephone, email and online. The YODAs build a relationship with service members to ensure bespoke support from diagnosis to end of life.

The YODAs run a busy programme of groups and activities which provide valuable opportunities to socialise, connect with others, remain active and build a support network. We offer practical and emotional support and guidance about dementia, financial and legal matters, employment, benefits and planning for the future.

YODAs regularly meet and review with service members to check in and see if any there have been any changes, and if any support is required.

Referral criteria and pathway

The majority of our referrals come to us via the Cognitive Disorders Clinic (CDC) at the John Radcliffe Hospital. People can self-refer and seek support through our Young Dementia Oxfordshire Community Facebook group and via email.

We work in partnership with Dementia Oxfordshire who provide support and advice to people affected by dementia across the county.

Dementia Oxfordshire is a service delivered by Age UK Oxfordshire.



Young Dementia Oxfordshire – what we do

On-going individual support for families and people living with a diagnosis

Monthly groups for people living with young onset dementia and their family members

Advice and information about adapting and living positively with a diagnosis of young onset dementia

Information and signposting to other organisations and support networks

Individual tailored support for people newly diagnosed with young onset dementia

Education and presentations about living with young onset dementia

Highlights and new activities from the past 12 months...

Coffee and Chat and Walk and Talk returned to being face-to-face

Walking football taster session, Turtle Song and theatre trips

Active Minds - Cognitive Stimulation Group designed and delivered

YODAs returned to supporting and meeting service members at the Cognitive Disorders Clinic (CDC)

Specialist support groups for Lewy body dementia and frontotemporal dementia

Service members participated in menopause webinar for Dementia UK

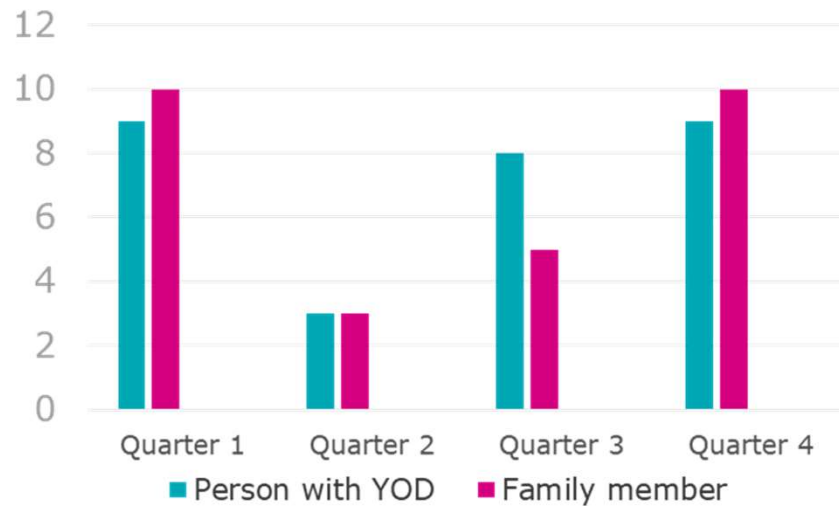
YODAs and service members co-facilitated sessions at the Admiral Nurse Forum and Summer School

**YODA training and development:
Diploma in dementia care,
Cognitive Stimulation Therapy Training, Benefits Training**

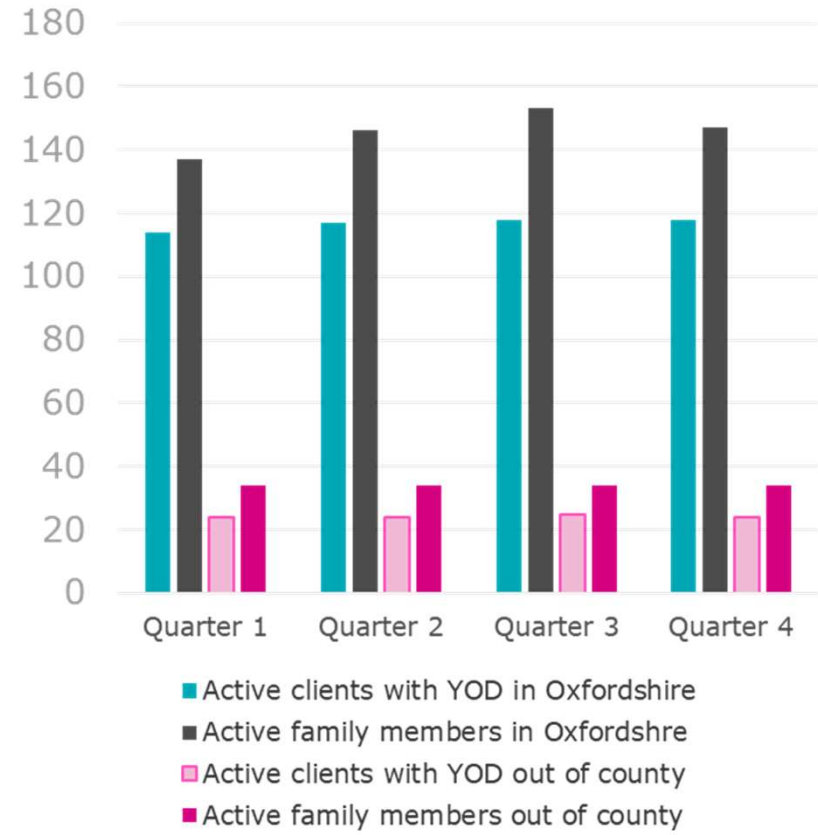
Christmas party for members

New service members referred to Young Dementia Oxfordshire Service and end of quarter totals

New referrals for each quarter (2022)



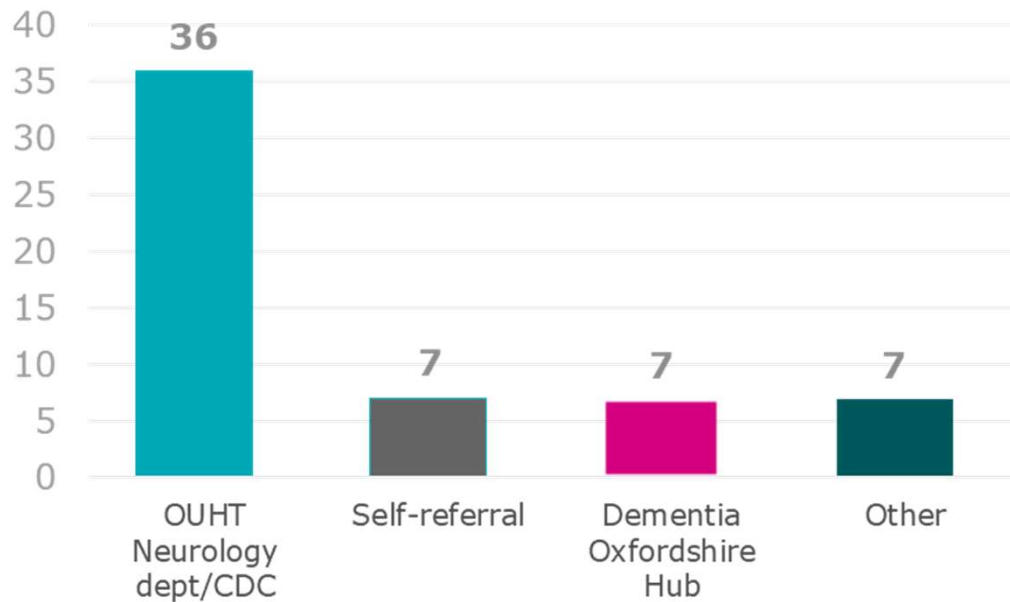
57 new referrals across people with a diagnosis of young onset dementia and family members



On average the YODAs supported **117** service members with young onset dementia and **146** family members per quarter

Source of referrals to Young Dementia Oxfordshire

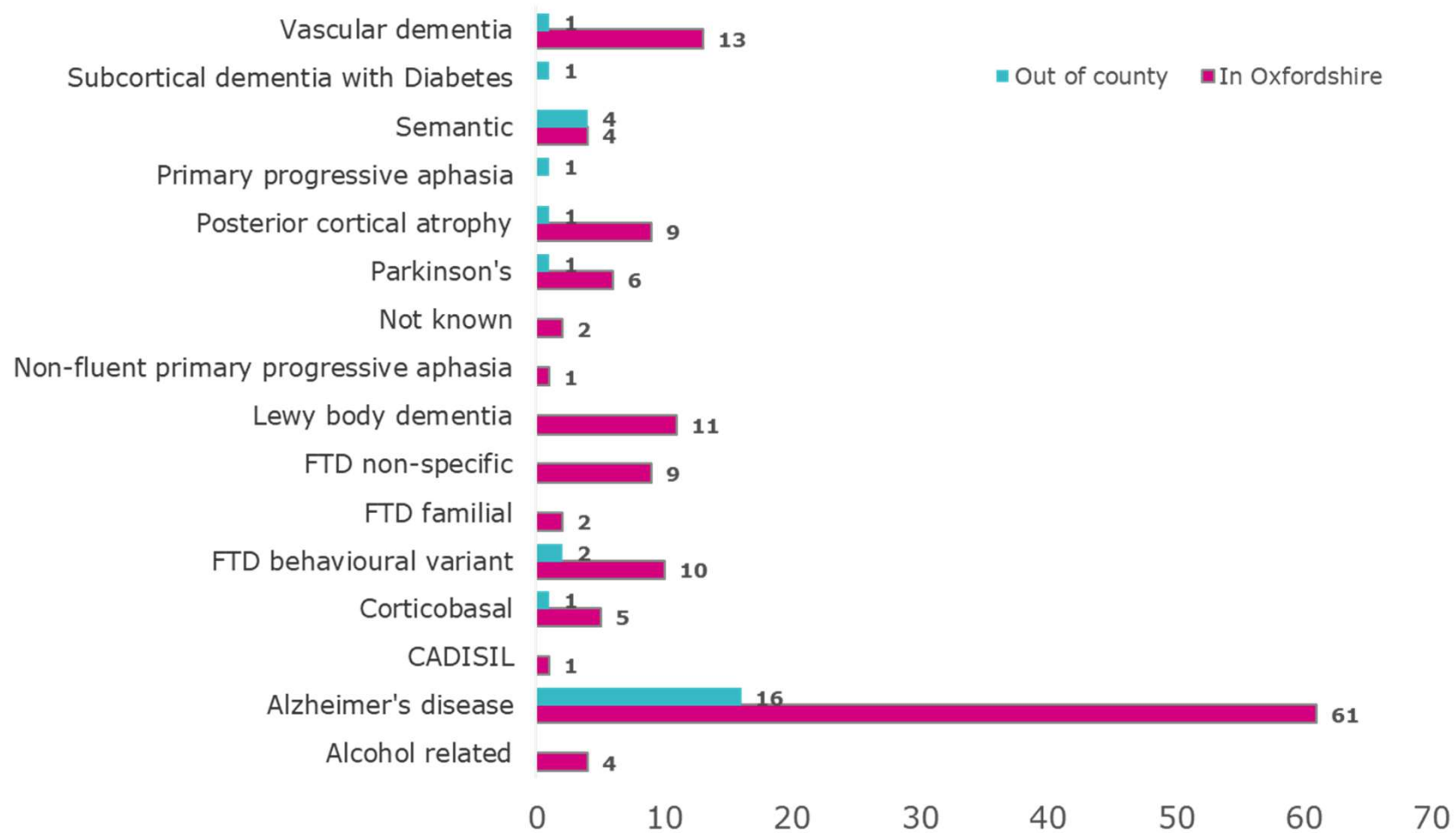
Referral source for all new referrals
(clients with a diagnosis of young onset dementia and family members)



All of the 57 new referrals during this one-year period were contacted within two weeks of the referral being received

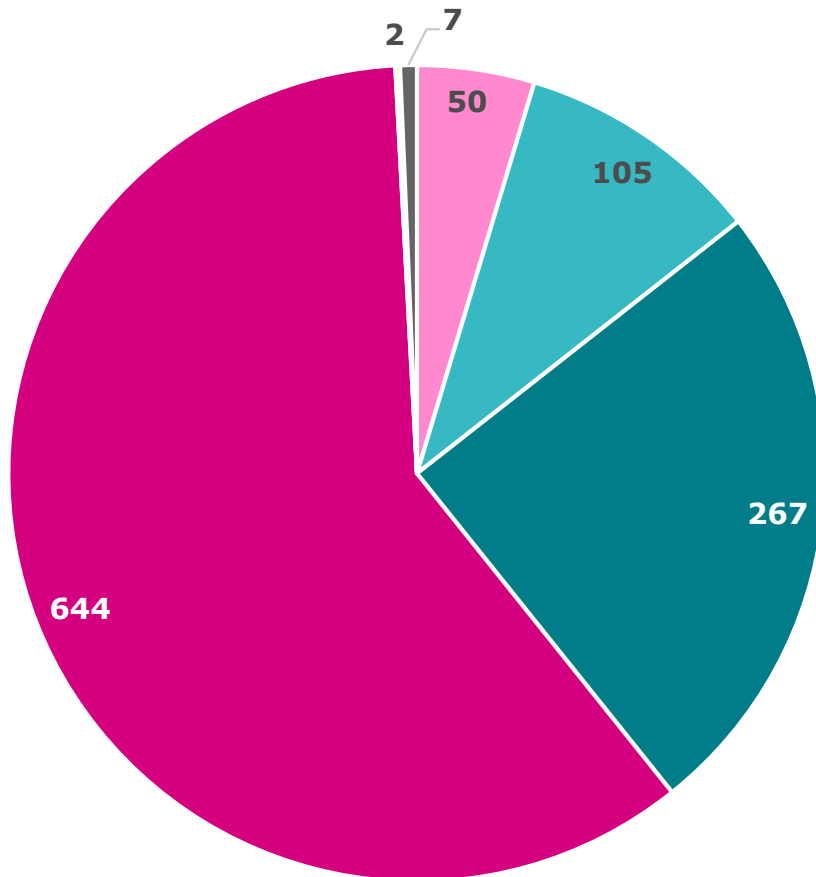
Young onset dementia diagnosis

Dementia diagnosis of YOD active on the 31st December 2022



Type and number of individual support sessions and correspondence

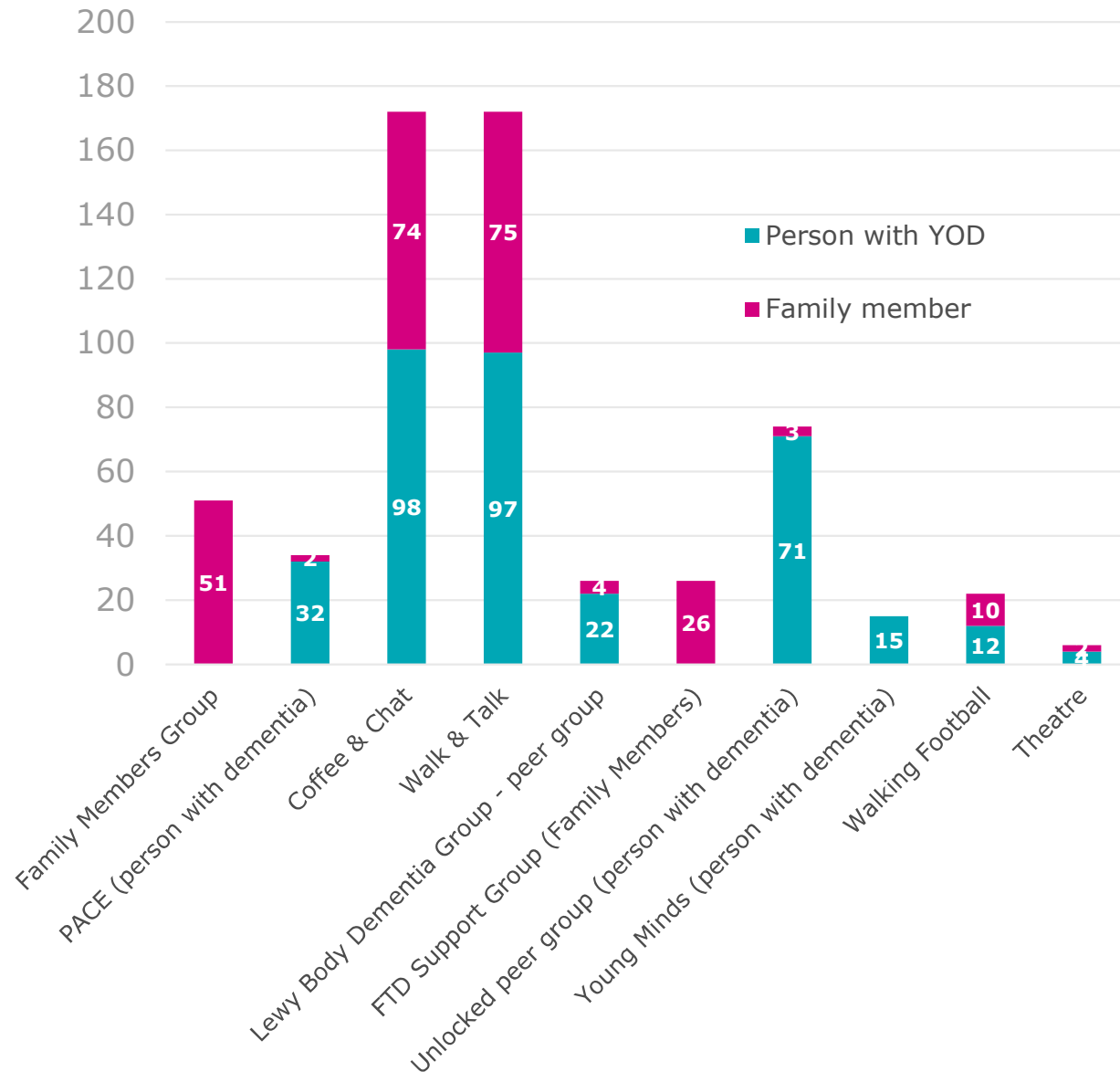
Support sessions/contact for 2022



- Introductions and initial assessment
- 6-monthly review meeting
- Crisis calls
- Support, information and advice
- Correspondence - email, T/C, text
- Adapt Individual Support Sessions

- YODAs completed **267** individual reviews with service members in 2022
- This is in addition to regular contact through group activities

Group attendance by people with young onset dementia and/or family member



In addition to monthly groups, Young Dementia Oxfordshire designed and delivered a new Cognitive Stimulation Therapy group called Active Minds.

This consisted of eight sessions focused on the needs of people living with a diagnosis of young onset dementia.

Feedback from family members about individual support from YODAs

What do you feel about the type of support provided by Young Dementia Oxfordshire? What works well?

Individual support from a YODA

- Around the point of diagnosis, and continuation of support beyond
- Reassurance that you are not alone on the journey
- Regular 'checking in' by a YODA through telephone call or face-to-face
- Empowering family members to take charge of situations through planning ahead whilst staying grounded in the reality of their situation
- YODA facilitation to link in with other forms of support (eg respite services)

Although YODAs are checking in with you, they are also following your journey and focusing you. I think their experience of what's to come - they don't talk you into that, **but they're very good at sensing where you are in the journey and helping you think about what you should be thinking about at that time.** [...] And you could get hijacked by thinking about what's around the corner, but they're very good at understanding that and just nudging you in a very gentle way. That's a big strength of theirs, I think.
(Participant 5)

A Dementia Advisor contacted the family member and helped with an attendance allowance application. The Advisor assisted with things that could help the family member and his wife with dementia including a dementia clock, although the clock didn't work for the person's particular situation. The carer has had several different advisors involved, and the Advisor phones up every few months to see whether there is anything they can help with.
(Participant 1)

Feedback from family members about individual support from YODAs

For me, the importance of being reassured, of not being alone. If there's something I need help with, I can ask. And the YODA has a chat with me every six months or so to see how things are going. She makes you realise what's happening and focus on what's happening and makes you formulate a plan to go forward, rather than just existing. **She makes it clear that things will change, and things will get worse, but in the end, you will deal with it. And that you don't have to just float around but you have some power of what's going to happen and to think about this and make a plan.** If I didn't have someone to talk to about this, then I don't think I'd make a plan or deal with it. (Participant 7)

We were stumbling through it, getting through it. my husband was an academic, so he took a sabbatical and we thought – let's see what happens. And then in January 2018, [YODA's name] was at the clinic, and this was the first we saw of Young Dementia Oxfordshire. It was transformational because [YODA's name] came to our house very soon after we met her, and she facilitated a discussion with us about what we wanted. It was very difficult to focus on this, because my husband was still the same person he was when he went into the diagnosis meeting, and he was still thinking about work and how that could be continued. But when we sat with [YODA's name] and prompted by very good questioning about what we wanted from life and with some realistic statements about longevity, quality of life and what you can expect, we thought about it and thought that we didn't want to spend the rest of [husband's name] good life battling in a work situation, so we then very purposefully moved from that position to medical retirement. (Participant 6)

Feedback from family members about individual support from YODAs

Lisa, Liz and Mandy are really good at what they do and are **very helpful on all sorts of stuff**
(Participant 3)

I had some conversations with [YODA] yesterday, and what came out is that she is there. **It's just nice knowing that you've got somebody who is only a phone-call away.** She sent me some links which hopefully I will find useful. (Participant 4)

It was four or five months after diagnosis, and I was in touch with the YODAs. The lady came to see us at home, and **I'll never forget – I thought at last, somebody understands, somebody is listening to me, somebody can give me advice.** And it was overwhelming to think I don't have to solve this on my own, I've got somebody with me. Although I don't know them, it's worth trying. From then it just got better and better and better. (Participant 2)

Feedback from family members about the groups

What do you feel about the type of support provided by Young Dementia Oxfordshire? What works well?

The groups provided by Young Dementia Oxfordshire

- The value to family members of peer support from other people who empathise because they understand what it's like
- The chance to share and to speak openly and frankly
- The group as a mainstay of support
- Sharing laughter and humour and the social side of connecting with others

The family group, the Walk and Talk group, and the Coffee and Chats group enables us to talk to like-minded people in similar situations. It has also enabled us to learn from each other – **tips and tricks and support to help our daily routines.** (Participant 2)

And in this group, you can laugh at some of the things you hear. Somebody says what's happened with their husband or wife and you can have a bit of a laugh at it, without being out of order. (Participant 1)

And then we went on the courses – the Adapt course, and we started meeting everybody. I support everything other people have said about the social side, and the consultant can't help with that. **You have to live your life and these groups help us to live a more positive life than being on one's own.** I cannot emphasise how valuable they have been all through. (Participant 5)

Feedback from family members about the groups

Even though initially the family member was reluctant to go to the group:

It has been the best thing, the most supportive thing, for the reasons [previous participant] said – that everybody's in the same boat, and you can feel very isolated especially through COVID, but you can feel very isolated anyway. Because I'm the only one in my friends, my social who is actually dealing with [husband's] type of dementia, or any dementia. So, they've got absolutely no idea how it affects the carer, because you do put on a brave face. I don't portray the way I am when I'm on my own with [husband's name], and it's very, very lonely. **You don't know if it's just you but in this group you can find out quite often things, that you're not the only one feeling it.** I know, whatever I say, that someone in the group has been through it and can often throw up some information, **but even just the support of it has been absolutely fantastic. Sometimes we have a really good laugh, we just laugh on our Zoom meeting.** After we've all said what we want to say, somebody says something funny – and it's usually [another participant's name], and we just laugh. And we go out of the meeting feeling better for it. (Participant 3)

I do like the way they've started to try to grow these meetings, such as the assistive technology speaker – they pulled out of one but are now due in – to provide a bit more structure.
(Participant 5)

...to meet other people in similar situations and with similar problems. This has been very good. (Participant 1)

I don't know about anyone else, but I find humour really does get you through it and it is nice to share that with other people because **we all know what we're all going through.**
(Participant 4)

Other feedback from family members about Young Dementia Oxfordshire

I think they [the YODAs] try so hard to be everything for us. I really feel that if I was at some sort of crisis point, I really could pick up the phone to [YODA's name] to talk it through with her and if she didn't know the answer, she would make sure she found someone who could help me, and so it's really, really been a lifeline for us, it has really made a huge difference. **I think we'd be totally lost without it.** (Participant 5)

Participant 7 highlighted the benefit of Young Dementia Oxfordshire to people with a diagnosis. There are five or six men living with a diagnosis who are roughly the same age and receive an enormous amount of support from each other. They are benefitting from each other. Three of the men are the spouses from this group.

They're not unique or weird anymore because there's other people going through the same as they are.
(Participant 7)

Feedback from the Admiral Nurse Forum presentation

I just wanted to feedback to you all that a clinician was talking about how useful the young onset dementia Forum session was. They said it really helped them reflect on work they were doing with a couple of young onset families in their community caseload. And they took some of the reflection into their practice on the next visit.

What they found particularly useful was the strength of the point of the early intervention with the person with dementia themselves (and how this is often not done in mainstream practice) and the financial impact and future implications where breadwinners go into residential care and what this leaves, or does not leave, for a partner with children and mortgage.

Case study 1: Mrs R - Supporting a person with young onset dementia to remain in work

Mrs R was diagnosed with Lewy body dementia (LBD) in late 2019, aged 57. She works as a professional and lives with her husband and dogs. The diagnosis came as a shock to both Mr and Mrs R. Mrs R had read and understood a little about the condition but wasn't keen to look too far ahead or consider how the condition might progress. Mr R had retired some years earlier due to ill-health. They had an outstanding mortgage on their home with many years left to pay; this was a concern to the family as Mrs R's income is important to them.

How has Young Dementia Oxfordshire supported Mrs R?

Initially, Mrs R found it difficult to talk about her diagnosis and to engage with other people in a similar situation. However, with encouragement, she now fully engages in Young Dementia Oxfordshire groups and activities. She attended an 'Adapt workshop' for people newly diagnosed with dementia and found the sessions helpful. "The workshop has been very useful and helped me to come to terms with my situation."

She also received five Adapt Individual Support Sessions to talk about her fears and anxieties. Mrs R was experiencing symptoms but wasn't sure if they were related to her Lewy Body disease. She was anxious that her condition was progressing at an alarming rate and needed reassurance and support to seek advice from health care professionals for her symptoms. Adapt support enabled Mrs R to explore activities she could continue and new hobbies to remain active (especially important for LBD).

The sessions gave me the opportunity to talk about my diagnosis and what I was finding difficult. I feel that I built a relationship with my Young Onset Dementia Advisor (YODA) and know that you are there to support me through each stage. Adapt support has helped me to understand my diagnosis and connected me into other sources of information and helpful organisations. If I hadn't had the early support from a YODA I would be feeling lost. I would have received my diagnosis and been left to get on with it! I wouldn't have had anyone to go to with questions or when I needed support.

Case study 2: on-going support from a YODA

Mr and Mrs A first had contact with us in Autumn 2019. Mrs A was referred to us by the Cognitive Disorders Clinic (CDC) in September of that year. Mrs A had been seen by the CDC in 2016 and 2018 and a diagnosis of Alzheimer's disease was confirmed in 2019. Mrs A was currently on sick leave from her job at a school as she was finding it stressful with her symptoms. Mr A was still working full time.

How has Young Dementia Oxfordshire supported Mr and Mrs A?

At the time of referral, Mr A was working full-time, but had reduced his duties as much as possible to assist Mrs A. Mrs A had a good routine and support network in place and was keeping active and socialising regularly with family and friends. Adapt support was offered to help Mrs A come to terms with her diagnosis and develop ways to manage day-to-day and live as independently as possible.

Mrs A received 4 Adapt individual support sessions. During the sessions Mrs A worked through her emotions around her diagnosis, and how she dealt with these. She received practical help about managing day-to-day and how to maintain her independence whilst still accepting help when it was offered. Mrs A also spoke about communicating her worries and struggles with Mr A. After the sessions, Mrs A reflected on how they had helped:

I certainly value the sessions, it is a little bit of help about what I can hold onto, who I am and what I like. I could ask questions, I could listen to what Liz had to say, I could voice any issues I was having. It was an easy step into a conversation - it was open, and I wasn't worried about what I said. Liz seems to know exactly what to say, in an easy and understandable way, with a sense of humour which makes conversations fun and helpful. Liz is very patient. Adapt Support helped me with the issue of being kind to people and not judging them and making things fun for me and the time I've got to enjoy myself. I valued the confidentiality of the sessions.

Case study 1: Mrs R - Supporting a person with young onset dementia to remain in work

Mrs R became anxious about work and found adjusting to working from home challenging. YODA support enabled Mrs R to work through practical steps and to overcome some of the challenges she was facing (such as working without paper files and visual aids). Mrs R found visits to the office overwhelming which added to her stress and anxiety.

Following a period of furlough, YODA support helped Mrs R to successfully return to work by enabling her to articulate her needs to her employer and negotiate reduced responsibilities and work hours.

Mrs R has continued to successfully remain in employment. YODA support is ongoing and helps Mrs R to prepare for workplace HR and OT meetings by considering what reasonable adjustments are required.

During the three years that Mrs R has been supported by the Young Dementia Oxfordshire Service, she has received support to consider financial plans including gathering information about pension pots, applying for Personal Independence Payment, and downsizing to reduce their mortgage.

Mrs R regularly attends the Walk and Talk group and has taken part in the online Lewy body dementia group.

With support, Mrs R has presented at a Dementia at Work conference for local employers.

Mrs R continues to receive regular individualised support where she can discuss any issues or areas of concern with her YODA.



Case study 2: on-going support from a YODA

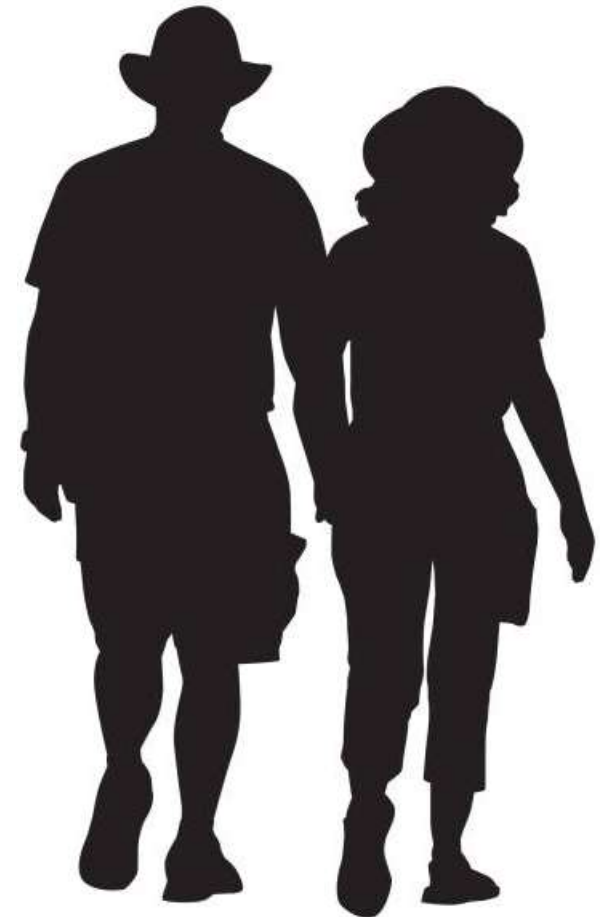
Mr and Mrs A received continuing support from the YODAs before, during and after the pandemic in the form of six-month reviews - these have been face-to-face, both at their home and at the Cognitive Disorders Clinic, and online in the form of a Zoom meeting when home visits were not permitted.

During this time Mrs A retired on the grounds of ill-health and received support with planning activities and structuring her day. They also received support and signposting in order to complete wills and Lasting Power of Attorney. Both have received continuing support with managing Mrs A's progression and the changes this brings.

Mr and Mrs A have been active participants in the group support offered by the Young Dementia Oxfordshire service. During the Covid-19 pandemic, Mr and Mrs A continued to attend groups together online, as well as Mr A attending the family members group independently, and Mrs A attending an online social group for people with a diagnosis of dementia.

Mr A commented: "Thanks very much for hosting Unlocked today. Mrs A keeps saying how much she enjoyed it. There aren't too many things where Mrs A feels confident and a fully contributing member of a group but that's definitely not the case with Unlocked and all the other great Zoom groups you run."

Mr and Mrs A both regularly attend our Walk and Talk and Coffee and Chat groups. They also attended a one-off walking football session held in September 2022.





Young Dementia Oxfordshire

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