Baxter, Vanessa ORCID logoORCID: https://orcid.org/0000-0001-8130-5487, Sheard, David, Jones, Victoria and Crewe, Jackie (2025) Findings From a Photovoice Project to Identify Services and Support for People Living With Young Onset Dementia and Their Families. Dementia.

UK/Europe and the rest of the world

Dementia
2025, Vol. 0(0) 1–18

DOI: 10.1177/14713012251365470
journals.sagepub.com/home/dem
Sage

Findings From a Photovoice Project to Identify Services and Support for People Living With Young Onset Dementia and Their Families

Vanessa Baxter[1], David Sheard[1], Victoria Jones[1] and Jackie Crewe[2]

Abstract

There is considerable variation in the provision of support and services for people living with young onset dementia in the UK. This study aimed to elicit the views of people living with young onset dementia and their families on what they want in the community, and identify gaps in support. The Photovoice approach was used to collect views from four groups of participants, over three sessions of each group. A total of four people living with young onset dementia and eight carers took part. People living with young onset dementia want to do a variety of activities, and these need to be age appropriate and "normal" things that they would have done prior to their diagnosis. Activities need to be flexible and fitted to the person rather than the person being fitted to the activity. A number of facilitators and barriers were identified. Carers' lives are now very different to what they had planned or envisaged for the future, and they value peer support. They need support to help understand information and navigate paperwork, systems and processes. The study provided insights based on lived experience into what people living with young onset dementia and their families want from support and services in the community.

Keywords

young onset dementia, younger onset dementia, early onset dementia, services and support, commissioning

---

[1]Institute for Health and Care Improvement, York St John University, York, UK
[2]Dementia Forward, Harrogate, UK

Corresponding Author:
Vanessa Baxter, Institute for Health and Care Improvement, York St John University, Lord Mayor's Walk, York YO31 7EX, UK.
Email: v.baxter1@yorksj.ac.uk

Background

Globally, an increasing number of people are being diagnosed with young or early onset dementia, where symptoms start before people reach the age of 65. Estimated prevalence worldwide is 119 per 100,000 population aged 30–64 (Hendricks et al., 2021) and in the UK is 92 per 100,000 population aged 30–64. This represents 70,800 people living with young onset dementia in the UK, a 69% increase between 2014 and 2020 (Carter, 2022). The cause is not well understood but is thought to be a combination of genetic, lifestyle and environmental factors (Alzheimer's Research UK, 2025).

Younger people living with dementia experience different circumstances to older people and dementia often has an added impact on their lives: when they are diagnosed younger people are more likely still to be working, have significant financial commitments (e.g., mortgages), have children under 18 at home and sometimes have dependent parents. They are usually leading more active lives with hopes and ambitions for their life up to and beyond retirement (Dementia UK, 2024). Young onset dementia affects people's relationships with their partners and children, as well as their social lives and occupational functioning (Jefferies et al., 2009).

The provision of services and support for people living with young onset dementia in the UK varies significantly and in general people living with young onset dementia and their families/carers are not satisfied with what exists and many do not experience high standards of support (Dementia UK, 2024; Mayrhofer et al., 2018). Specialist services should be able to accommodate the challenges faced by younger people living with dementia. Commissioning specialist services for this cohort challenges current service delivery structures within health and social care across the UK (RCP, 2018). Support for the needs of this group have so far been largely distributed across a wide range of services and budgets in neurology, old age psychiatry and mental health. A new and more integrated approach to meeting people's specialist needs is required, alongside the identification by commissioners of new service specific budgets or funding. Coordinated responses are also required from the third sector in relation to the provision of meaningful activity, employment, peer support and advice on legal and financial matters.

The Dementia Forward charity in North Yorkshire provides support, advice and information to anybody affected by dementia across the county. It was seeking to develop a centre of excellence for people living with young onset dementia and wanted to understand more about what people living with young onset dementia want and need in the community, including gaps in existing services. There are few existing qualitative or participatory studies on community support for people living with young onset dementia and their families so this participatory research project aimed to understand more about the experiences of services and support for people living with young onset dementia and their families. The research focused on support needs such as opportunities for activities within the community after diagnosis and so excluded the diagnosis pathway and residential care provision.

Methodology

The study comprised participatory research with people living with young onset dementia and their family members focusing on their experiences of services and support - looking at what is available, what they use and what they would like, including gaps in what is available. The Photovoice approach (Wang & Burris, 1994, 1997) was used to collect feedback. This is a participatory research method where participants take photos to identify and represent themes and activities, then share them via a facilitator-guided group discussion. The approach can provide researchers with rich qualitative data and a greater understanding of the subject under study (Nowell et al., 2006; Palibroda et al., 2009; Wang, 2006).

The methodology involved three sessions in total for each group:

(1) The first session explored what support is available, what was wanted and challenges in accessing support. Participants were then asked to take photos that represent services or support they would like to have, challenges they face or gaps in services. They were given tips and guidance on taking photos, including obtaining consent from any persons who might be identifiable. All used their own phones to take photos and then emailed these to the researcher who printed out a copy to show at the next session.
(2) In the second session, participants discussed all of the photos they had taken and what they represented. They gave verbal permission for the researcher to use the images taken for this study and reporting.
(3) In the third session, participants selected a final set of four to seven photos that they agreed represented the most important messages, dictated captions for each selected photo that the researcher wrote down (including some direct quotes from an individual rather than the group as a whole), and suggested actions/recommendations. After the session, the photos and captions were sent to participants to confirm they accurately reflected what they had said. A selection of the final photos and captions are included in the Results section.

Each of the sessions were recorded and then transcribed, and the content from the three sessions of each group was analysed thematically by two researchers (Braun & Clarke, 2006). The themes and sub-themes emerged inductively from the data and were agreed between both researchers.

The initial plan was to run three different groups: one group of carers and two groups with people who had been diagnosed with young onset dementia within the last 12 months. The rationale for this was that they would still be early on their journey and would not yet be ‘entrenched’ within the health and care system so would not be constrained purely by what services are available.

There are around 350 people living with young onset dementia within North Yorkshire that are known to Dementia Forward, and they were screened for people with a recent diagnosis. Consideration was also given to people’s psychological wellbeing and emotional stress levels at that time to ensure that those experiencing emotional difficulties were not approached. Dementia Forward then recruited participants from its database via phone calls, explaining the purpose of the research and what it involved. Participant Information Sheets were given to every participant, including the voluntary nature of participating, right to withdraw and confidentiality, and consent forms were signed before the start of the first session. People living with dementia were not cognitively assessed but all provided written consent and their carers indicated their belief that their loved one wanted to take part.

There were difficulties in recruiting to the planned groups due to the geography of North Yorkshire (and consequent lack of enough people meeting the requirements who live within a reasonable travel distance), and also since some carers felt they did not have enough time to attend three research sessions due to their caring and work commitments. The decision was therefore taken to revise the composition and locations of the groups to enable more people to take part. All sessions were held in person at a neutral venue, except for one that had to be held virtually due to illness.

Participants

Four groups were held at different locations across North Yorkshire with 12 participants in total: four people living with young onset dementia (two females and two males) and eight carers (seven females and one male). Some sessions were held as separate groups of people living with dementia and carers while others were run with everyone together at the request of the participants.

Group 1: Two couples (one husband and one wife living with dementia). Three had retired before the diagnosis and one was about to leave their job after time signed off sick due to dementia.
Group 2: Four female carers (three with a husband/partner and one with a mother living with dementia). Two carers had stopped working before the diagnosis, and two were still working.
Group 3: Two siblings, where the carer worked full time while the person living with dementia no longer worked and lived alone.
Group 4: One couple (husband living with dementia) who had both retired early before the diagnosis.

Throughout this article, those providing care and support to the person with young onset dementia (i.e., spouse, partner, sibling or child) will be referred to as carers.

Ethics

The study was approved by York St John University's School of Science, Technology and Health Ethics Committee. Informed consent was obtained in writing from all participants before the start of the first session.

Findings

Current Activities

The majority of couples seemed to do many activities together, contrasting with the two people not living with their carers who only did a small number of activities together at weekends when their carers were not working. Not all people living with young onset dementia attended groups or activities.

Three people attended a young onset group, which the carers felt they enjoyed going to as the activities were age appropriate and they felt part of a group of peers. One, who had become increasingly socially isolated, now attended a group as a 'helper' as they would not have gone as an attendee. One person was taken out by someone from the Memory Clinic for a few hours each week as they would not be able to attend groups.

Two people attended sessions run by the charity Golf in Society where they were supported to play a real round of golf in the company of others so there was an added element of social interaction. This was described as a *"fantastic"* activity and an example of a positive activity that is delivered *"exactly right"*.

> "We don't give up anything. We just play this and we have fun and a laugh and it's well done with ease." (Person living with young onset dementia, Group 4)

The same two people also attended a keep fit gym session for people living with young onset dementia and one had just started doing walking football with a group of mixed ages and conditions, which both the person and carer felt was a similar positive experience to that provided by Golf in Society.

Potential Activities

Three people living with young onset dementia were initially unsure about what they might like to do but all said they would like to do more activities. Activities that would interest them included things such as a walking club, anything sport-related, chess, quizzes, music/singing, dancing, animal-related activities and going on outings or visiting historical sites.

Activities suggested by carers were very similar to this but also included going to the pub or out for a meal. One felt that group outings are great for their loved one to allow them to socialise and get out of the house. A similar experience to Golf in Society based on cricket or other sports would be of interest, or other options for staying physically fit. Carers felt that people living with young onset dementia would not wish to attend activities with only much older people.

All carers wanted activities that are age appropriate and *"normal"* things that their loved one would have done prior to the diagnosis. However, several felt that younger people living with dementia are treated like children, with activities *"dumbed down"* for them. Activities should be relevant to the stage that their loved ones are at and be things that they would choose to do, but carers felt that there was little available for younger people (Figure 1).

Age appropriate!

Not being treated like children

Activities offered need to be age appropriate and relevant to each person's ability, something that challenges and stimulates them

"It's an insult to dumb down activities"

In an ideal world everyone is so different: dementia has different stages and presentations

Figure 1. Having Age Appropriate Activities

> "I really don't want to sound ungrateful and I'm not criticising, I'm just pointing out that young people, especially in their early sixties, if they didn't have dementia, what would they be doing? And the likelihood is most of them, especially men, would not be sitting down and doing a jigsaw or doing a painting." (Carer, Group 2)

Carers highlighted differences between individuals living with young onset dementia as an issue that needs to be addressed by those delivering group services - activities cannot be a *"one size fits all"* offer but instead need to be flexible and fitted to the person, rather than the person being fitted to the activity. A sporting activity would not be of interest to everyone but equally some participants living with young onset dementia would not want to do painting, crafts or music as they have no interest in this kind of activity.

Facilitators for Activities

A number of facilitators were highlighted, including the ability to find information about potential activities easily.

> "If there was someone in an office, or like a support that could take on [name]'s needs and liaise with us and say, 'Right, can we organize this for you?' That would be amazing. Because my problem is time, and I feel awful about it." (Carer, Group 3)

People living with dementia would welcome having somebody at the activity to introduce people to each other – a 'meet and greeter' - or a befriender. They suggested it would be helpful to have activities that involve socialising and interacting with others, organised outings to venues of interest, having someone organise a group to play golf with and having a supporter to accompany someone to a new activity or club.

Younger people living with dementia would prefer sessions with activities (e.g., play golf, chess or cards, go walking, or do art/paint) rather than those where people would just sit and chat. Carers felt it is important to offer activities that will facilitate the maintenance of existing skills and obtaining of new skills, including social and communication skills and mental stimulation. Offering someone living with young onset dementia an opportunity to be helpful and to have a purpose was important to one carer.

Carers felt that having a trusted buddy/befriender would be helpful, to get the person living with dementia to and from any group activity safely and accompany them during activities/outings. People diagnosed with young onset dementia who live alone (in contrast to those who are part of a couple) require much more support, including someone to take them out and accompany them to activities.

> "The ideal thing that would really help is like a buddy for [name]. Somebody that would go and see her, and maybe go for a walk with her. Go out for a cup of tea... She spends too much time at home on her own. I don,t have the time to give her, but somebody would relieve a lot of that." (Carer, Group 3)

Carers thought it would also be helpful to have dual activities available in the same place at the same time, where the carer can do one thing and the person living with dementia another.

All participants saw providing transport as key for people living with dementia who were no longer able to drive and whose carer/family were not able to drive them to activities and/or whose dementia symptoms made them too vulnerable to use public transport alone (Figure 2).

Transport is essential

Lack of transport signifies isolation and no ability to still engage with the world

Having transport means support and socialising with people in the same position in their own peer group

Transport needs to be provided alongside any services

Figure 2. Transport is Essential

Barriers to Activities

Carers identified a range of barriers, including a lack of opportunities and activities in certain areas of the county.

Other barriers are formed where someone would not naturally attend an activity on their own, being shy and not forthcoming in social situations. One carer felt their loved one would no longer take the initiative, having to be prompted to do things. Another suggested that while women are usually happy to meet in a group to talk, some men would not naturally seek out support, particularly peer support.

Not being able to access public transport, not having public transport available or not having access to some form of volunteer driving service or transport are barriers reported by all groups. One carer highlighted the inability of those living with dementia to safely get to and from activities as a significant barrier since they and other family members are not always able to make time to take them.

Financial pressures can be a significant barrier, including: activities costing money when families are struggling to pay everyday bills; having to retire early but being too young for a state pension; one care home that accept younger people living with dementia for respite costing nearly £2,000 per week (but the local authority would only finance £1,200 per week); and concerns around what would happen financially to a jointly owned home when the loved one has to go into a care home.

Another barrier for carers who are still working and have a family of their own to look after is the scarcity of their time, meaning they have limited time to spend with their loved one or take them to activities.

Age restrictions for accessing services were brought up by the carers' group. Examples of this are a counselling service via the Memory Clinic that is available for those over 60 but not for younger people and difficulty in finding respite care as most care homes only take people living with dementia who are over 60 or 65.

> “It’s like saying, oh yeah, we’ll look after people with broken legs so long as they’re aged between 30 and 40. Anybody below 30, you just have to hobble for the rest of your life. And anybody above 40 from now on, you’re on your own, crutches for the rest of your life.” (Carer, Group 2)

Support for Carers

One carer highlighted how lonely they feel as their partner is getting increasingly distant – effectively walking away from their life together. Others in the same group also felt that the distance between them and their loved ones is increasing as the dementia advances. Carers acknowledged that their lives are now very different to what they had planned or envisaged for the future, which sometimes resulted in feelings of anxiety or depression. One highlighted that looking after carers allows the carers to look after the person living with dementia (Figure 3).

One carer was unsure what support might be wanted as it was soon after the dementia diagnosis and acknowledgement of it: *“I don’t know what we need until we need it”*.

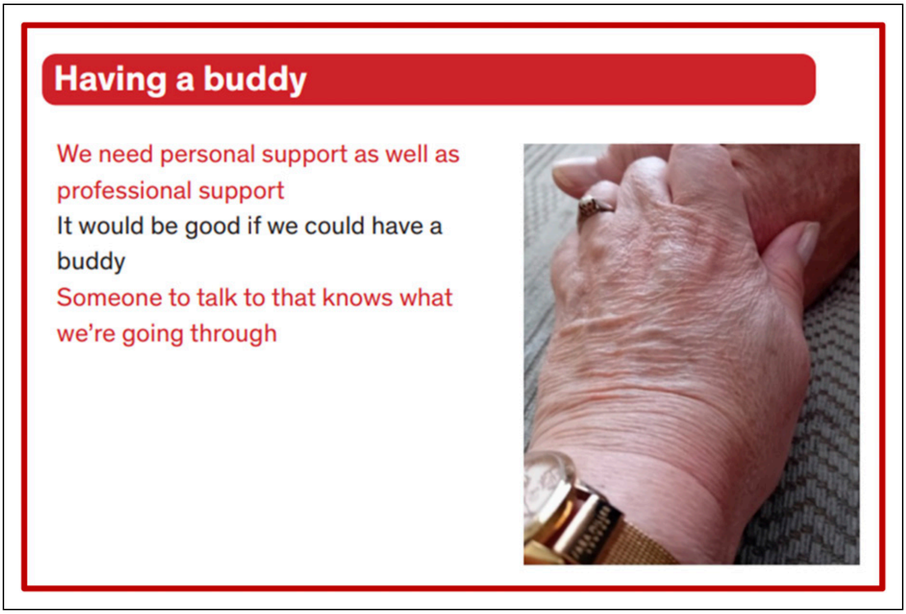
Carers felt they need more than a book to read, but someone to support them personally, listen to them, understand their circumstances and help them with what they are going through. Several would like to have a ‘buddy’, either a professional or a peer who has gone through a similar experience, to help them navigate through all of the steps that need completing. Services need to link together better, both in general and so that someone is not left without support suddenly after a change in circumstances (Figure 4).

Carers feel lonely and sad

“I’m walking away and losing my loved one”

This is the distance between the person I knew and the relationship I had, they’re getting further away
It’s about what we need to allow us to care, if we can look after ourselves
People don’t appreciate the work I do to enable my loved one to have a good life

Figure 3. Carers Feel Lonely and Sad



Having a buddy

We need personal support as well as professional support

It would be good if we could have a buddy

Someone to talk to that knows what we're going through

Figure 4. Having a Buddy for Carers

Many carers wanted training on what to expect and how to deal with situations arising, including coping strategies and seeing things from their loved one's perspective. This would be best done face to face and should be applicable to their loved one's current stage rather than trying to include everything about future stages they had not yet encountered: a suggestion was to have an initial training and then regular 'refreshers'.

> "Basically, I was like, how do I cope? What do I need to know? How do I do it? Oh my God, what do I do?" (Carer, Group 1)

One carer (a cancer survivor) mentioned a helpful restricted Facebook page for cancer patients and survivors in the local area, whose members can ask questions for other members to respond to based on their own experiences.

Several carers would appreciate the possibility of being able to organise someone to spend time with their loved one on an ad hoc basis, for respite or to allow them to attend a specific event.

Peer Support

Many carers felt it would be useful to talk to somebody who has already been through the process. This would be for social interaction and moral support as well as being able to discuss issues and sharing information, experiences, and practical hints and tips.

> "I think the two hours that we have together with fellow carers is as important… and we would all say probably we've learned more from each other than we have learned from any book, any literature or any leaflets." (Carer, Group 2)

Carers in one group were unsure about whether they would prefer a carers' group for anyone whose loved one has dementia, purely for carers of people living with dementia, or for carers of people with other similar conditions to dementia. However, one carer, whose loved one had frontotemporal dementia, would appreciate a group of peers to talk to about this specific type of dementia as it differs vastly from other types. A monthly support group might be about right, but even one every three months would help. It should be as local as possible, no more than 30–45 min travelling distance and in-person to provide social interaction. It would potentially be better if the carer were able to bring their loved one along to do an activity close by.

> "Actually it's not being too prescriptive, because what works for one person, it's not being really prescriptive or really narrow, it is having a broad range…
>
> "Being able to relate to other carers in general." (Carers, Group 1)

Information

Four carers felt that being given information and support, or a copy of the blue book,[1] before the diagnosis would have been helpful, especially with the very long wait times of a year or more before diagnosis.

Most carers were given the blue book after diagnosis, but it was difficult to take everything in all at once and it was *"overwhelming"* for one carer. One referred to a *"brick wall"* to represent the difficulties encountered in finding information and support, in contrast to the help and support they got after being diagnosed with cancer. One carer was not given any information at all by the Memory Clinic. The Memory Clinics did not seem to have provided several participants in different groups with the details about how to contact Dementia Forward.

Some carers would have preferred to receive just the information they needed at that time, for the stage at which their loved one was, that is specific to young onset dementia and the type of dementia, and also to be signposted to what is available in their area. They felt it would be helpful to have a flowchart or checklist of steps they need to take - such as getting a power of attorney in place, putting bank accounts into joint names, benefits they could claim etc. - the order in which to do them and how, or who to contact.

> "You've got to basically hunt for everything, haven't you? I don't want to push everything onto someone else, but if they said like, '[name]'s been diagnosed with dementia. You are going to need to do this, this and this…'" (Carer, Group 3)

It would also be helpful to have someone able to guide carers through the support available and advise those newly diagnosed about the paperwork to complete and practical things that they could do.

> "Rather than being passed from pillar to post and basically signposted a lot when you may be overwhelmed with the amount of information that you've been given. If there was somebody… that has a knowledge about the next steps that you need to be doing." (Carer, Group 2)

One carer had had a *"steep learning curve"* to find out what they could have help with. Another suggested having a 'one-stop shop' to support both the carer and their loved one with relevant, tailored and expert support. Another did initially have someone to support them with financial assessments etc. but they were only available to them for 12 weeks after which their support stopped. One carer did not want to be signposted from one organisation to another, but to be supported by someone who could find out the answers and come back to them (Figure 5).

Paperwork

All of the carers expressed frustration about the paperwork involved, with many feeling that everything needed to be fought for, and that it all took up large amounts of their time. A number had struggled with the paperwork required to claim benefits, reductions in council tax or a blue badge. The processes themselves were very difficult and time-consuming. One carer felt that some people - with less confidence or strength than themselves - would give up if they had an application rejected and not consider challenging the decision.

Several carers felt that there should be greater joining up of processes and systems, rather than them having to provide details on a multitude of forms from various public sector organisations, to make it easier and simpler for people to apply for a range of benefits. One queried why the diagnosis letter was not accepted as sufficient proof by public sector organisations who all want further details.

> “If you’ve got a letter from a consultant saying he has Alzheimer’s, why do we have to fill in another form and then download it, take it to the GP, get the GP sign it?” (Carer, Group 2)
>
> “What part of Alzheimer’s don’t DWP understand? Which is a… degenerative condition that severely impedes people’s ability to do things like that.” (Carer, Group 1)

Two carers (in different groups) suggested that one ID number should join many different systems and applications up, similar to the ‘Tell us Once’ system when someone dies.

We want a one stop shop from professionals

Not being passed from pillar to post or signposted elsewhere!

We need someone with the appropriate knowledge about next steps, rather than us having to navigate the system alone

Relevant, tailored, expert support for all types of young onset dementia

We need a professional, a buddy and a checklist that’s relevant to the diagnosis, not having to plough through lots of paper

Figure 5. One-Stop Shop From Professionals

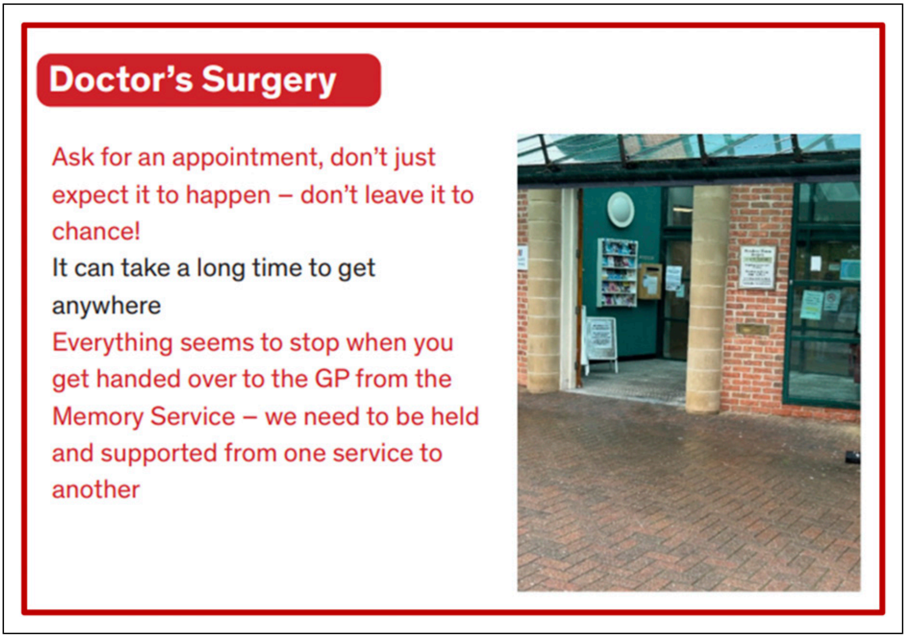
Post-Diagnosis Healthcare

One carer described a very negative experience of the diagnosis for their loved one both while being assessed at the Memory Clinic and being given the diagnosis over the phone by the neurologist. This was followed by no support at all from the Memory Clinic.

All carers complained they had little to no follow up from the Memory Service or other medical professionals after diagnosis. Several were effectively told to go away and come back when they could no longer cope. Two had had a bad experience of post-diagnosis care around getting their loved one's medication and several described it as a *"fight"* to ensure their loved ones were on the right medication.

> "I think the first time I went we're still discussing, wow, they spent ages with us. I thought it was, this is what the support's going to be like. This is great. The second time we went, it was to say, 'Oh, well, this is your diagnosis, from now on you're on your own'… I walked out thinking, what is that? This is what you've got. Here's lots of paperwork, you can read about it. Bye." (Carer, Group 2)

Carers would appreciate being automatically offered a check-up and medication review after 6–12 months, and then an annual review. Two carers were critical that they had heard nothing from their GP in over a year since their loved one's care was transferred to the GP from the Memory Service, not even for a medication review. Another carer, whose loved one had had an annual check-up by someone from the GP surgery, felt that an annual check was not enough to maintain their loved one's physical health. Another carer said that it was down to them to recognise if their loved one had a health issue not relating to dementia and then request an appointment (Figure 6).



Doctor's Surgery

Ask for an appointment, don't just expect it to happen – don't leave it to chance!

It can take a long time to get anywhere

Everything seems to stop when you get handed over to the GP from the Memory Service – we need to be held and supported from one service to another

Figure 6. Support From the GP

In contrast, one couple had a *"fantastic"* and responsive GP, providing longer appointments for a check in and conversation. Initially they saw him weekly, then fortnightly and then longer, with an open-ended offer of going back if things change.

One carer suggested dementia awareness training for GP surgery staff and having a designated person to provide support for people living with dementia and their carers that would be similar to an asthma clinic.

> "So that they have a designated person or persons that know what they're doing specifically with people with people's Alzheimer's etc. And they can give you that support then to you come in say, 'my wife's got Alzheimer's' so you need to see so and so." (Carer, Group 1)

Discussion

Prior research has identified that activities for people living with young onset dementia need to be: age appropriate (Fox et al., 2020; Mayrhofer et al., 2020; Roach et al., 2012; Stamou et al., 2022, 2023); meaningful with opportunities for social participation (Bannon et al., 2022; Fox et al., 2020; Roach & Drummond, 2014; Stamou et al., 2022); flexible and person-centred, tailored to specific and changing needs (Bannon et al., 2022; Beattie et al., 2002; Fox et al., 2020; Novek & Menec, 2023; Stamou et al., 2023); inclusive, easily accessible and allowing them to participate in everyday social and leisure activities (Bannon et al., 2022; Mayrhofer et al., 2018; Stamou et al., 2023).

This study had similar findings and providers must consider how activities can be provided that are age appropriate, relevant to individuals' specific interests and flexible enough for all types and stages of young onset dementia. In general, service design needs to be more person centred and more innovative: the good example of Golf in Society could potentially be replicated for other sports/activities. These activities should have somebody to "meet and greet" participants and a transport option needs to be offered alongside any service provided. It may be possible to tap into the existing provision of 'befrienders' (such as Personal Assistants for people with learning disabilities) to accompany people living with young onset dementia to places/activities they want to do. Younger people generally want to carry on doing their 'usual' activities and more physical activities than older people might be able to do, without the need to rely on carers who are still working. This would be especially helpful for those who live alone. The creation of a directory of the activities available in each area, together with staff support if required, would enable people living with young onset dementia and their families to find out about activities they may be interested in.

Existing literature highlights the importance of enabling people to maintain their physical and mental health (Fox et al., 2020; Roach et al., 2012; Stamou et al., 2022). However, for most participants in this study there was little to no follow up from the any healthcare professionals after the diagnosis. An area for development is that of healthcare support and GPs should formally acknowledge that they've taken over care of the person, with a handover from one service to the other. Regular/annual check-ups and reviews of medication should be offered. All GP surgeries should become dementia aware and have a designated member of staff for dementia and/or a dementia clinic. Awareness and empathy within health services should be improved, as should the artificial inequality and barrier of services only being available to those who are over 65 (e.g., care homes, counselling). Additionally, carers highlighted that looking after them as carers allows them to look after the person living with dementia.

Evidence shows that information and advice should be specific to young onset dementia (Fox et al., 2020; Mayrhofer et al., 2018; Novek & Menec, 2023; Stamou et al., 2022). Participants in this study echoed this view and identified a range of information needs that are not currently being met, such as information: in the time leading up to the diagnosis; that is specific to young onset dementia (rather than dementia generally) and tailored to the type of dementia; with a checklist about what to expect or do at each stage with resources available for each step; and on legal and financial rights and processes. Carers require training on coping strategies, seeing things from their loved one's perspective, and education on how to stop/block scammers.

Information should be provided in different ways, including options for a personal contact to check in with people and ask how they are doing, 1:1 chats (for example talking informally about the next steps to take but followed up by information sent via email), or an advocate/ supporter. The development of a 'Say It Once' style website would be welcomed so carers do not need to provide the same information to every different organisation when applying for benefits, blue badges for disabled people etc. Services should consider developing information for other family members on what is happening and how to support and interact with the person living with dementia.

Carers also feel unsure of what is available (Mayrhofer et al., 2018; Millenaar et al., 2016, 2018; Novek & Menec, 2023; Stamou et al., 2022) and have difficulty in knowing how to access support, so want someone to support them and co-ordinate access to services and benefits (Bakker et al., 2022; Cations et al., 2017; Mayrhofer et al., 2020). Carers participating in this study wanted more than a book to read, but someone (e.g., a "buddy" who is either a professional or a peer) to support them personally, listen to them, understand their circumstances and help them with what they are going through. A 'one-stop shop' to support both the carer and their loved one with relevant, tailored and expert support would be helpful.

Health services (memory clinics, neurologists and GPs) should ensure that all carers and people living with young onset dementia, even before they have a diagnosis, are given contact details for advice and support. This did not seem to be happening automatically for participants in this study and all entry points to this advice and support pathway need to be facilitated. This includes ensuring support is provided for those who would not ask for help. There should be continuous access to support, with follow up after diagnosis, so that carers do not get to a crisis before they get extra support. The provision of respite on an ad hoc basis, as well as a regular service, and of care homes for younger people living with young onset dementia needs to be developed.

Peer support needs to form part of the support available to carers (Mayrhofer et al., 2020; Novek & Menec, 2023) and the carers participating in this study clearly valued it for social interaction and moral support as well as being able to discuss issues and share information, experiences, hints and tips. Face-to-face carer support groups should be provided in every area (not every area currently has them), with the option of activities for loved ones. There should be some form of support group or way to connect specifically for carers of people with frontotemporal dementia or other types that may have very specific presentations. A buddy system of peers could be introduced, including a restricted access Facebook page for peer support and responses to questions.

Many of the actions suggested by participants and the themes from this participatory study echo the desk review findings, and it would be helpful to investigate further why these themes are still arising and why families do not perceive them to have been tackled. We believe that part of the reason for this is due to current and historic commissioning practices. Commissioners do not seem to identify younger people living with dementia as a separate service group and commissioning strategies may still be failing to grasp the distinctive service provision needs of younger people. The purpose of integrated commissioning is to confront the "siloed" service delivery across the various specialisms that younger people living with dementia intersect with, but this would require the setting up of a new specialism that would have cost implications. Integrated commissioning across health and social care still needs to pool resources and services in a coordinated manner across neurology, mental health and old age psychiatry.

There is a historic pattern of failing to provide sufficient and appropriate services for younger people living with dementia. Health and social care services, in the current climate of reducing finances and need for cost savings, seem to be reluctant to tackle these historical deficiencies in funding and to flexibly fund the greater costs for younger people compared to services for older people living with dementia.

Limitations

The study involved just 12 participants, of whom only four were people living with young onset dementia, so it cannot represent the views of all people living with young onset dementia and their families. In particular, all participants were White, reflecting the ethnic composition of North Yorkshire (where 96.7% of the population are White). This homogeneity may limit the transferability of findings to more diverse populations where cultural attitudes towards dementia and care may differ. Sexual orientation and gender identity data were not collected, limiting understanding of diverse experiences. There appeared to be a range of income levels within the participants, but this data was not specifically solicited. While the researchers spent time encouraging those living with dementia to express their views, they had more limited perspectives and had less to contribute than the carers. Future research might better centre their experiences, for example through adapted methods or proxy reporting.

Future Research

Drawing on the limitations of this study, future research could helpfully explore the views of younger people from communities with different ethnicities, cultures, sexual orientations and gender identities. Dementia Forward is using the findings from this research to develop and improve its services for people living with young onset dementia across the county, and it would be helpful to test the service models being adopted.

Conclusions

This study provides insights based on lived experience into what people living with young onset dementia and their carers want from support and services in the community. The findings highlight their desire for more activities that are age appropriate, what people living with young onset dementia would have done prior to their diagnosis, and flexible so that they fit around an individual rather than the individual fitting into the activity on offer. Support is required to understand what activities are available, to introduce people living with dementia to them and enable them to attend (especially for those who live alone). Carers value peer support, for social interaction and moral support as well as being able to discuss issues and share information, experiences, hints and tips. They also need someone - a professional or a peer - to support them and help them navigate the steps, systems and processes.

Acknowledgements

We would like to thank all of the participants who generously gave their time over the three sessions to provide their views. We would like to give deepest thanks to the staff from Dementia Forward for their help and support in recruiting participants for this research, plus organising venues and refreshments to make it a more sociable event for those attending. We would also like to thank the Dementia Forward members of staff who supported participants during the research groups.

ORCID iD

Vanessa Baxter https://orcid.org/0000-0001-8130-5487

Ethical Considerations

The study was approved by York St John University's School of Science, Technology and Health Ethics Committee.

Consent to Participate

Informed consent was obtained in writing from all participants before the start of the first session.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research study was funded by internal funding from the Institute for Health and Care Improvement at York St John University.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Data Availability Statement

Source data is not being made available as it may not be possible to fully anonymise it.

Note

1. The blue book is a summary of activities and support for older people and people living with dementia in Northumberland and North Yorkshire https://www.the-blue-book.org.uk/.

References

Alzheimer's Research UK Website. https://www.alzheimersresearchuk.org/dementia-information/types-of-dementia/young-onset-dementia/risk-factors/#:~:text=For_the_majority_of_people,a_younger_age_than_others (Accessed 13 March 2025).

Bakker, C., Verboom, M., & Koopmans, R. (2022). Reimagining postdiagnostic care and support in young-onset dementia. *Journal of the American Medical Directors Association*, *23*(2), 261–265. https://doi.org/10.1016/j.jamda.2021.12.008

Bannon, S. M., Reichman, M. R., Wang, K., Uppal, S., Grunberg, V. A., & Vranceanu, A.-M. (2022). A qualitative meta-synthesis of common and unique preferences for supportive services among persons with young onset dementia and their caregivers. *Dementia*, *21*(2), 519–539. https://doi.org/10.1177/14713012211048118

Beattie, A. M., Daker-White, G., Gilliard, J., & Means, R. (2002). Younger people in dementia care: A review of service needs, service provision and models of good practice. *Aging & Mental Health*, *6*(3), 205–212. https://doi.org/10.1080/13607860220142396

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Carter, J. (2022). Prevalence of all cause young onset dementia and time lived with dementia: Analysis of primary care health records. *Journal of Dementia Care*, *30*(3), 1–5.

Cations, M., Withall, A., Horsfall, R., Denham, N., White, F., Trollor, J., Loy, C., Brodaty, H., Sachdev, P., Gonski, P., Demirkol, A., Cumming, R. G., & Draper, B. (2017). Why aren't people with young onset dementia and their supporters using formal services? Results from the INSPIRED study. *PLoS One*, *12*(7), Article e0180935. https://doi.org/10.1371/journal.pone.0180935

Dementia UK Website. https://www.dementiauk.org/information-and-support/young-onset-dementia/young-onset-dementia-facts-and-figures/ (Accessed on 07 03 2024).

Fox, S., Cahill, S., McGowan, R., & Kilty, C. (2020). *Young onset dementia: A review of diagnostic and post-diagnostic processes and pathways* (Vol. *8*). University College Cork, Ireland.

Hendriks, S., Peetoom, K., Bakker, C., van der Flier, W. M., Papma, J. M., Koopmans, R., Verhey, F. R. J., de Vugt, M., Köhler, S., & Young-Onset Dementia Epidemiology Study Group. Withall, A., Parlevliet, J. L., Uysal-Bozkir, Ö., Gibson, R. C., Neita, S. M., Nielsen, T. R., Salem, L. C., Nyberg, J., Lopes, M. A., Dominguez, J. C., … Ruano, L. (2021). Global prevalence of young-onset dementia: A systematic review and meta-analysis. *JAMA Neurology*, *78*(9), 1080–1090. https://doi.org/10.1001/jamaneurol.2021.2161

Jefferies, K., & Agrawal, N. (2009). Early-onset dementia. *Advances in Psychiatric Treatment*, *15*(5), 380–388. https://doi.org/10.1192/apt.bp.107.004572

Mayrhofer, A., Mathie, E., McKeown, J., Bunn, F., & Goodman, C. (2018). Age-appropriate services for people diagnosed with young onset dementia (YOD): A systematic review. *Aging & Mental Health*, *22*(8), 933–941. https://doi.org/10.1080/13607863.2017.1334038

Mayrhofer, A. M., Mathie, E., McKeown, J., Goodman, C., Irvine, L., Hall, N., & Walker, M. (2020). Young onset dementia: Public involvement in co-designing community-based support. *Dementia*, *19*(4), 1051–1066. https://doi.org/10.1177/1471301218793463

Millenaar, J. K., Bakker, C., Koopmans, R. T. C. M., Verhey, F. R. J., Kurz, A., & de Vugt, M. E. (2016). The care needs and experiences with the use of services of people with young-onset dementia and their caregivers: A systematic review. *International Journal of Geriatric Psychiatry*, *31*(12), 1261–1276. https://doi.org/10.1002/gps.4502

Millenaar, J. K., Bakker, C., van Vliet, D., Koopmans, R. T. C. M., Kurz, A., Verhey, F. R. J., & de Vugt, M. E. (2018). Exploring perspectives of young onset dementia caregivers with high versus low unmet needs. *Int J Geriatr Psychiatry*, *33*, 340–347. https://doi.org/10.1002/gps.4749

Novek, S., & Menec, V. (2023). Conceptualizing access to community-based supports from the perspectives of people living with young onset dementia, family members and providers. *Dementia*, *22*(1), 180–196. https://doi.org/10.1177/14713012221138145

Nowell, B., Berkowitz, S., Deacon, Z., & Foster-Fishman, P. (2006). Revealing the cues within community places: Stories of identity, history, and possibility. *American Journal of Community Psychology*, *37*(1-2), 29–46. https://doi.org/10.1007/s10464-005-9006-3

Palibroda, B., Krieg, B., Murdock, L., & Havelock, J. (2009). *A practical guide to photovoice: Sharing pictures, telling stories and changing communities*. Prairie Women's Health Centre of Excellence.

Roach, P., & Drummond, N. (2014). Early-onset dementia and purposeful activity. *J Psychiatr Ment Health Nurs*, *21*, 889–895. https://doi.org/10.1111/jpm.12154

Roach, P., Keady, J., & Bee, P. (2012). 'It's easier just to separate them': Practice constructions in the mental health care and support of younger people with dementia and their families. *Journal of Psychiatric and Mental Health Nursing*, *19*(6), 555–562. https://doi.org/10.1111/j.1365-2850.2011.01836.x

Royal College of Psychiatrists. (2018). *Young-onset dementia in mental health services: Recommendations for service provision*. Report CR217. https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr217.pdf

Stamou, V., La Fontaine, J., O’Malley, M., Jones, B., Parkes, J., Carter, J., & Oyebode, J. R. (2022). Helpful post-diagnostic services for young onset dementia: Findings and recommendations from the Angela project. *Health and Social Care in the Community*, *30*(1), 142–153. https://doi.org/10.1111/hsc.13383

Stamou, V., Oyebode, J., La Fontaine, J., O’Malley, M., Parkes, J., & Carter, J. (2023). Good practice in needs-based post-diagnostic support for people with young onset dementia: Findings from the Angela project. *Ageing and Society*, *44*(10), 1–24. https://doi.org/10.1017/S0144686X22001362

Wang, C. (2006). Youth participation in photovoice as a strategy for community change. *Journal of Community Practice*, *14*(1/2), 147–161. https://doi.org/10.1300/j125v14n01_09

Wang, C., & Burris, M. (1994). Empowerment through photo novella: Portraits of participation. *Health Education Quarterly*, *21*(2), 171–181. https://doi.org/10.1177/109019819402100204

Wang, C., & Burris, M. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior: The Official Publication of the Society for Public Health Education*, *24*(3), 369–387. https://doi.org/10.1177/109019819702400309

Author Biographies

Vanessa Baxter was responsible for project management, data collection and analysis, and drafting the paper. She has extensive research experience across public health, adult social care and children’s services gained while working within the public sector and at universities. She currently leads on research and evaluation projects at York St John University that are commissioned by health organisations, local authorities and charities.

David Sheard contributed to the project design and revising the paper. He is Professor of Emotional Intelligence in Care at York St John University and after working as a social worker in mental health and dementia established Dementia Care Matters and was CEO for 23 years, focussing on improving quality of life for people living with dementia, promoting personhood and evaluating care models. Dementia Care Matters developed and accredited Butterfly Homes, which pioneered culture change in dementia care.

Victoria Jones contributed to data collection and analysis, and revising the paper. Her background is in Cognitive Neuroscience and she has undertaken research on various neuroscientific projects and supported several clinical trials. She now works for the Institute for Health and Care Improvement at York St John University facilitating opportunities for researchers and projects that aim to improve health, wellbeing and care in the community.

Jackie Crewe was responsible for participant recruitment, supporting data collection and reviewing the article. She works for Dementia Forward as a Dementia Support Advisor and Research Co-ordinator and is studying for a Professional Doctorate in Health Psychology. Her work at Dementia Forward involves providing practical and emotional support to people living with dementia and carers, as well as being the interface between the charity and other stakeholders relating to research and other projects.