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# Good practice in needs-based post-diagnostic support for people with young onset dementia: findings from the Angela Project

Vasileios Stamou<sup>1</sup> , Jan Oyebode<sup>1\*</sup> , Jenny La Fontaine<sup>1</sup> , Mary O'Malley<sup>2</sup> ,  
Jacqueline Parkes<sup>2</sup>  and Janet Carter<sup>3</sup> 

<sup>1</sup>Centre for Applied Dementia Studies, Faculty of Health Studies, University of Bradford, Bradford, UK, <sup>2</sup>Centre for Applied Mental Health Research, Faculty of Health and Society, University of Northampton, Northampton, UK and <sup>3</sup>Division of Psychiatry, Faculty of Brain Sciences, University College London, London, UK

\*Corresponding author. Email: [j.oyebode@bradford.ac.uk](mailto:j.oyebode@bradford.ac.uk)

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## Abstract

Evidence on post-diagnostic support for people with young onset dementia is scarce. Previous studies have employed a problem-focused approach; however, evidence on 'what works' in real-life practice is essential to develop recommendations for service design and delivery. This study aimed to provide insight into 'what works' from the perspectives of people with young onset dementia and their supporters. We gathered free-text responses on positive service experiences via a UK cross-sectional survey. Inductive thematic analysis was used to identify the objectives of positive services and the needs these met. Follow-up interviews enabled in-depth insights from people with diverse diagnoses, ages and social situations. These were analysed using a template drawn from the survey. The 233 survey respondents gave 856 examples of positive support. Analysis of 24 follow-up interviews led to 16 themes clustered under three superordinate themes: 'maintaining autonomy', 'being myself' and 'togetherness'. We found that positive services address the disruptions to sense of agency, selfhood and meaningful relationships that are experienced by those with young onset dementia. The study provides an in-depth understanding of the needs met by positive services for younger people with dementia. Our nuanced findings on good practice can inform age-specific guidelines for young onset dementia and indicate how personalisation can work in practice to help people with young onset dementia to maintain identity, autonomy and connections.

**Keywords:** young onset dementia; early onset dementia; younger people; needs; post-diagnostic support; selfhood; good practice

## Introduction

Young onset dementia (YOD) is defined as dementia diagnosed before the age of 65 (Draper and Withall, 2016). Global prevalence is estimated at 119 per 100,000

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population between the ages of 30 and 64 (approximately four million individuals globally), with no significant differences in rates by gender (Hendriks *et al.*, 2021). YOD cases are currently estimated to account for 5–9 per cent of dementia prevalence, affecting more than 42,000 individuals in the United Kingdom (UK) (Prince *et al.*, 2014).

Significant differences between YOD and dementia with late onset (LOD) have underlined the need to recalibrate the scope and objectives of services offered to people with YOD and their families (National Institute for Health and Care Excellence (NICE), 2018). Higher prevalence of rarer aetiologies and earlier life-stage result in delays in diagnosis and access to post-diagnostic care (van Vliet *et al.*, 2013). Once in the system of services, people with YOD struggle to find needs-specific and age-appropriate support (Millenaar *et al.*, 2016), due to the lack of YOD-specialist services and the provision of care from older adult-centred dementia services (Stamou *et al.*, 2021a). As people with YOD have distinct needs compared to their older counterparts, generic dementia services often fail to provide support for individuals to remain physically and socially active, care for their parents and children, and address financial concerns resulting from employment loss (Chaplin and Davidson, 2016; Roach *et al.*, 2016; Mayrhofer *et al.*, 2018); such unmet needs can negatively impact neuropsychiatric symptoms of the person with YOD (Williams *et al.*, 2001) and the wellbeing of the person living with the condition and their supporters (Bakker *et al.*, 2010).

Notwithstanding the distinct differences between YOD and LOD, YOD-specialist services in the UK remain scarce (Rodda and Carter, 2016) and are often discontinued (Cations *et al.*, 2017). Previous studies have underlined that current services for people with YOD lack a clear care pathway (Chemali *et al.*, 2012) and often fail to meet the needs of people with YOD for social participation, disease management, age-appropriate day-time activities, and maintenance of health and meaningful relationships (Sansoni *et al.*, 2016). This not only places a burden on people with YOD and families but also on services. Annual care costs for people with YOD are estimated to be twice as high as for LOD due to higher prevalence of rarer dementia types, such as vascular and frontotemporal dementia (Kandiah *et al.*, 2016), with additional indirect costs due to employment loss. Though some of these costs may be preventable (Kandiah *et al.*, 2016), many people with YOD receive little or no specialist services, with most of the support provided by family members whose care is valued at more than 20 times the cost of statutory services (Stamou *et al.*, 2021a).

Evidence on what works in real-life practice is currently scarce. Previous studies have explored the needs of people with YOD and families in depth (Greenwood and Smith, 2016; Millenaar *et al.*, 2016; Ramluggun and Ogo, 2016; Rabanal *et al.*, 2018) and suggested that care should be age-appropriate (Roach *et al.*, 2012), tailored to individual needs and family-oriented (Westera and Fildes, 2014; Hutchinson *et al.*, 2020). Notwithstanding the value of problem-oriented approaches that identify shortcomings in service design and delivery, complementary evidence on what works in real-life service provision is essential to inform optimum care (Carter *et al.*, 2018), develop recommendations for practice and prevent excessive care costs (Roach and Drummond, 2014). A recent systematic review of age-appropriate services for people with YOD (Mayrhofer *et al.*, 2018) identified only seven UK-based primary research studies using the ‘what works’ approach across a 26-year span, concluding that evidence on YOD experiences is not matched by

research to inform good practice. The paucity of primary studies is further highlighted by the NICE guidelines (NICE, 2018) which included evidence from only seven small-scale YOD studies with service recipients, reflecting the need for larger-scale high-quality studies representing the voices of those affected by the condition (Sait and Brown, 2012; Mayrhofer *et al.*, 2018).

The Angela Project was a national UK study aiming to develop recommendations on good practice in diagnosis and post-diagnostic support for YOD. To identify what works and acquire in-depth understanding of positive post-diagnostic services from the perspective of people with YOD and family members/supporters, we (a) carried out a nationwide survey of positive experiences of support, service use and service satisfaction, and (b) conducted in-depths interviews to gain insight into the needs met by positive services. The findings presented here focus on *what* was experienced as positive (objectives of services) by people with YOD and *why* (needs met by services). Findings on positive services for family members/supporters will be reported separately.

## Design and methods

We employed a qualitative design via a national cross-sectional survey and in-depth follow-up interviews with people with YOD and supporters in England. Survey data were analysed using inductive thematic analysis which provided an initial template for analysis of the interview data (*see* the online supplementary material). Ethics approval was received from the Health Research Authority in England (South Central Berkshire Research Ethics Committee).

### Recruitment

Participants were recruited via a broad range of third-sector organisations, 14 purposively selected English National Health Service (NHS) sites (to ensure recruitment of those diagnosed in neurology, all-age dementia services and YOD-specialist teams) and Join Dementia Research (a register of people interested in joining dementia research studies).

### Participants

Participants were individuals diagnosed with dementia, as defined by DSM-5 (American Psychiatric Association, 2013), under 65 years or self-identified as a 'family member/supporter' of a person living with YOD. As people with dementia caused by Down's syndrome, Huntington's disease, traumatic brain injury, alcohol-related dementia or HIV usually receive different specialist services, they were excluded. Confirmation of diagnosis was provided by services for NHS participants and via self-report for those recruited via other routes. The study was exploratory; therefore, we did not predefine sample size but aimed for maximum recruitment.

### Data collection

#### Survey

The survey, developed by the research team, was available from August 2017 to September 2018 (*see* Table 1). We gathered information on positive service

**Table 1.** Example of survey question

<i>During the year after diagnosis, can you think of times when the help and assistance you received was helpful?</i>	
Yes	No
<i>If you answered yes, please provide a detailed description of these experiences. We would like to know:</i>	
(a) What was helpful?	
(b) Who was it helpful for?	
(c) Why was it helpful?	
(d) Who was involved (e.g. social worker, family doctor, nurse, etc.)?	
(e) What was the name of the service(s)?	

*Note:* The same questions were asked in relation to three time periods: (a) between seeking help and receiving a diagnosis, (b) during the year post-diagnosis, and (c) end of the first year post-diagnosis to the present.

**Table 2.** Survey briefing notes, developed with the Patient and Public Involvement Group, to assist recall

<p>We would like to know about good examples of help and assistance that have benefited <i>younger people with dementia and/or family members/supporter(s)</i>. These could include:</p> <ol style="list-style-type: none"> <li>1. <i>A service or form of support</i> which has: <ul style="list-style-type: none"> <li>• helped you to maintain or improve your quality of life,</li> <li>• made your life easier or</li> <li>• addressed a concern you may have.</li> </ul> <p>This could include, for example:</p> <ul style="list-style-type: none"> <li>• help with your finances,</li> <li>• your health or</li> <li>• maintaining activities that are important to you.</li> </ul> </li> <li>2. <i>Advice or information</i>. This could include, for example: <ul style="list-style-type: none"> <li>• information about dementia,</li> <li>• information about how to cope with specific symptoms or</li> <li>• how to find the right services to meet your needs.</li> </ul> </li> <li>3. <i>The approach or attitudes</i> of a person who has provided help and assistance that has benefited you.</li> </ol>
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experiences, service use, satisfaction with care and socio-demographic background. This article focuses exclusively on positive experiences with services; other aspects have been reported elsewhere (Stamou *et al.*, 2021a, 2022). Three people living with YOD and three carers from the Patient and Public Involvement (PPI) Group piloted the survey via cognitive interviews (Willis, 2004), to ensure appropriate content, wording, format and length. We also developed briefing notes with the PPI Group, giving examples of generic helpful outcomes, to assist with recalling experiences (see Table 2).

The questions on positive experiences of services referred to three time periods: (a) between seeking help and receiving a diagnosis, (b) during the year post-diagnosis, and (c) end of the first year post-diagnosis to the present. For each, there was a closed question ('Can you think of times when the help and assistance you received was helpful?') and an open-ended question, asking for free-text details. Multiple examples could be reported. This article focuses on responses from the point of diagnosis onwards, based on the perspectives of younger people with dementia and their supporters.

The survey could be accessed via Bristol Online Surveys (<https://www.onlinesurveys.ac.uk>) and on paper. It could be completed by people with YOD (alone or with help from a family member or paid carer), or by a family member/supporter alone. When family members were involved, participants were asked to focus on examples of positive support for people with YOD. Capacity to consent was assumed for those completing the survey online or on paper. Where a researcher's help was required (via phone, Skype or face-to-face), capacity was assessed and written consent obtained. The researchers (VS, JLF, MOM) had received training on informed consent with adults lacking capacity through the UK National Institute for Health Research. They primarily focused on participants' capacity to: (a) understand, retain and recall the information conveyed to them about the study, their participation and what this would entail, and (b) communicate and briefly elaborate on their preferred mode of participation (*e.g.* in-person, via Skype or phone) (Gilbert *et al.*, 2017). The process took place during phone conversations with participants prior to the interviews, as well through additional conversations on the day of the meeting before the beginning of each interview. None of the respective participants lacked capacity to consent. All respondents were given a list of useful sources of support.

### *Interviews*

To acquire in-depth insights into positive experiences with services, we conducted semi-structured follow-up interviews between September 2018 and January 2019 with a purposively selected sample of those survey respondents who had expressed an interest. Selection aimed to ensure diverse voices (*e.g.* people living alone, with rarer dementias or from minority ethnic communities) and allow us to explore specific survey themes further. Interviews lasted 45–70 minutes. Capacity was established using the processes described above. All participants were deemed to have capacity and provided written consent.

The interview guide was developed by the research team after consulting the PPI Group (*see Table 3*). We employed two different approaches to ensure inclusion of people with different levels of cognitive impairment. The approach taken was decided during a phone conversation with each participant prior to interview. If the person recalled the survey and their responses, a direct approach was used to explore their experiences with services in more depth. Where this was not the case, an open in-depth discussion took place which did not necessitate participants recalling their responses but rather focused on what had been important in participants' lives since diagnosis and the services that met the relevant needs.

### *Analysis*

#### *Survey*

Participants' socio-demographic information was analysed via SPSS (for more details, *see Stamou et al.*, 2021b). The free-text responses were analysed via inductive thematic analysis (Braun and Clarke, 2006, 2013). Two researchers (VS, JLF) repeatedly read the transcripts and engaged in manual coding. Comparisons of coding, reflexive notes and discussions within the research team were employed to ensure a nuanced insightful approach and promote inclusion of important

**Table 3.** Interview guides to ensure inclusion of people with different levels of cognitive impairment (version 1 for participants who recalled the survey and their responses; version 2 for participants who did not recall their responses)

Version 1 (direct semi-structured approach):
Open discussion about the service examples provided in the survey. Where possible explore the needs of the person with young onset dementia and the family members/supporters separately. Then explore any additional examples of helpful experiences with services.
For each example given ask:
Can you tell me about the events/experiences you had leading up to being referred to/receiving this service? (prompts include)
<ul style="list-style-type: none"> <li>(a) What prompted the referral?</li> <li>(b) What were you feeling/needing at the time?</li> <li>(c) Tell me about the process that you went through to get the service.</li> <li>(d) What happened when you saw them/began to receive the service?</li> <li>(e) What specifically was good about it?</li> <li>(f) Why was it helpful to you?</li> <li>(g) How was the person's/services approach helpful?</li> <li>(h) How did it make you feel?</li> <li>(i) How was this different from how you felt before?</li> </ul>
Version 2 (open approach):
1. I would like to understand what is important in the lives of people living with young onset dementia and their families and supporters since receiving the diagnosis of dementia. Some people find that life changes quite significantly and that some aspects of their lives become more important. Others describe how important it is to keep living life the way you have always done.
I would like to know what is important to you now in your life?
2. I would like to discuss what helps you to achieve the things in your life that are important to you. Some people find that they require help and assistance to live well with dementia and achieve the things that are important to them.
I would like to know what help and assistance you have received that has helped you to achieve the things that are important to you?
<ul style="list-style-type: none"> <li>(a) What did they do for you?</li> <li>(b) How have they helped you?</li> <li>(c) What exactly was helpful about that?</li> <li>(d) Why has it been helpful to you?</li> </ul>

aspects of participants' experiences. After repeated iterations, the research team (VS, JLF, JO) clustered the codes into sub-themes and themes by consensus, based on similarities in meaning. The dataset was re-checked against the final themes by two researchers (VS, JLF) to ensure accurate representation of participants' accounts and the final thematic map was shared with the PPI Group and wider project team to check plausibility and relevance.

This lengthy iterative process resulted in the emergent codes being clustered into three distinct groups representing fundamental aspects of positive experiences with services: *what* was provided, *how* it was provided and *why* it was useful. Here, we report on *what* and *why* codes; other aspects have been reported elsewhere (Stamou *et al.*, 2021b, 2022).

**Table 4.** Superordinate themes and themes on objectives of ('*what*') and needs met ('*why*') by positive services for people with young onset dementia (YOD)

Superordinate themes	Themes
Maintaining autonomy	YOD-specific advice and information ( <i>what</i> )
	Access to age-appropriate services ( <i>what</i> )
	Having a voice ( <i>what</i> )
	Supported activities of daily living ( <i>what</i> )
	Maintaining independence ( <i>why</i> )
Being myself	Addressing physical and mental health ( <i>what</i> )
	Continuity in meaningful occupation/activities ( <i>what</i> )
	Maintaining health ( <i>why</i> )
	Retaining a sense of normalcy ( <i>why</i> )
	Recover a positive outlook ( <i>why</i> )
A sense of togetherness	Maintaining identity ( <i>why</i> )
	Support for the family as a whole ( <i>what</i> )
	Opportunities to share with others ( <i>what</i> )
	Feeling held and supported ( <i>why</i> )
	Giving/contributing ( <i>why</i> )
	Maintaining meaningful relationships ( <i>why</i> )

Note: N = 259; comprising survey N = 233, interviews N = 26).

### Interviews

Audio-recorded interviews were transcribed verbatim and analysed using template analysis (Brooks *et al.*, 2015). We adopted a 'subtle realist' approach (Hammersley, 1992), acknowledging that although our perspectives could be influenced by our own social position and multiple perspectives may be possible, the phenomenon being explored (*i.e.* good practice, defined as specific services meeting specific needs for younger people) was independent of the researchers and could be revealed through our research processes. The survey themes were used as an initial template (*see* Table 4) to label relevant meaningful *what* and *why* segments with any new emerging codes being clustered under existing or new themes. Analysis was conducted concurrently with data collection. At the first stage, three researchers (VS, JLF, JO) read and re-read three transcripts and carried out independent coding, before jointly discussing their codes and themes. This led to some modification of the template which was then used to code consecutive sets of three transcripts. Following analysis of each set, the template was further refined by consensus. Data collection and analysis only ceased once saturation had been reached, at which point no new codes contributed to the construction of existing or additional themes (Bowen, 2008). The final template was re-applied to the entire dataset (by VS) and it was decided that further refinements were not needed.

To examine potential differences in the examples reported by people with YOD and family members, we considered how each respondent group contributed to

themes. We found that people with YOD, family members and dyadic responses all contributed to 15 of the 16 themes, while only people with YOD and dyads contributed to the theme ‘Supported activities of daily living’.

### Quality assurance

A number of quality criteria have been proposed to ensure the trustworthiness of qualitative research (Shenton, 2004), though some of these have been contested (Bryman *et al.*, 2008). We employed multiple data collection methods, including in-depth interviews, and recruited a wide range of participants across different sites in England, including those commonly under-represented in research (*e.g.* people with rarer dementias or living alone), to enhance credibility. Furthermore, we held regular team meetings and shared the themes with the project PPI Group, Steering Committee and wider research team, to gain feedback on the relevance and plausibility of the findings and enhance confirmability.

### Results

There were 233 usable survey responses. Those with YOD had an average age of 58.15 years (standard deviation = 5.18, range = 37–65) and it was 3.77 years on average since they had received their diagnosis (for further details, *see* Stamou *et al.*, 2021b). Positive examples of support were reported by 193 respondents. The remaining 40 did not report positive experiences, either because they had been recently diagnosed or because there were none to report. In total, 856 positive examples were given. Thematic saturation was reached after analysis of 502 examples, at which point the coding template was finalised.

Twenty-four follow-up interviews were conducted, with 26 participants (since two interviews were with dyads; for socio-demographic data, *see* Stamou *et al.*, 2022). The open approach was employed in eight interviews with people with YOD, nine interviews with family members and two interviews with dyads. Five interviews took place with family members using the direct semi-structured approach.

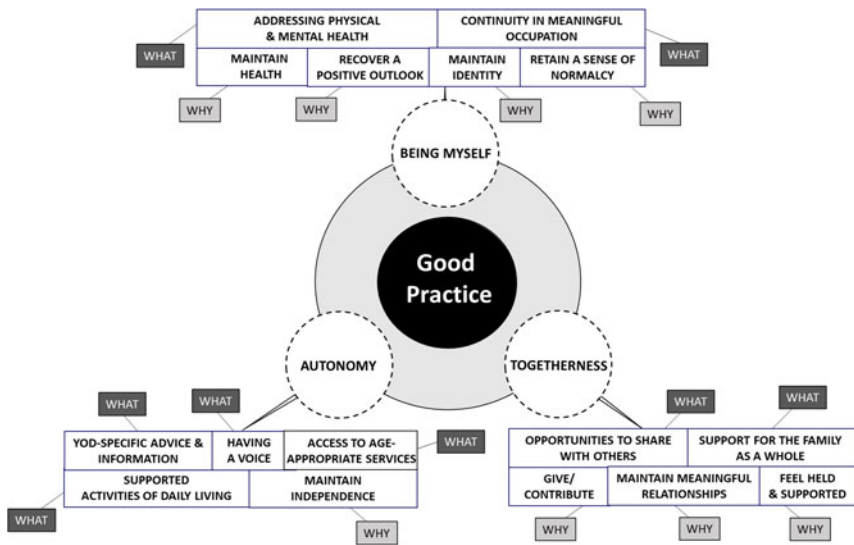
The refined template resulting from the analysis includes three superordinate themes reflecting fundamental needs met by positive services for people with YOD (*see* Table 4). Each superordinate theme includes both *what* and *why* themes. Figure 1 provides a diagrammatic illustration of the superordinate themes and associated themes, which are described in detail below.

### Maintaining autonomy

This superordinate theme incorporates five themes related to the need of people with YOD to maintain autonomy. The provision of advice and information specific to YOD, access to age-appropriate services, support with activities of daily living and opportunities for people with YOD to have their voices heard enabled younger people to maintain their independence and had a positive impact on their well-being, self-esteem and confidence.

Expert advice and information specific to YOD facilitated maintaining independence. Participants underlined the importance of clear information shared openly which enabled understanding the impact of the condition and how to cope. A younger person reported:





**Figure 1.** Good practice in post-diagnostic support for younger people with dementia, as reported by younger people and family members/supporters.  
 Note: YOD: young onset dementia.

My local [charity] have provided stellar support in the quality of information they have supplied to me, time allotted to giving me time to talk about my own struggles and how to make the most of my abilities ... The information gave me straight and honest facts ... They have helped me rebuild my confidence and enabled me to live more positively with dementia. As a result of this, I have [been] able to move on and support others with a young onset diagnosis. (Person with unspecified YOD, aged 55 at point of participation, female, white British, rural area)

This response illustrates how age-specific advice and information enabled younger people to gain insight into the limitations posed by YOD and ways to continue using their strengths and abilities. The respectful, attentive nature of the interaction facilitated tailoring advice and information to individual needs, which had a positive impact on the person’s self-esteem and enabled them to adapt and remain active. Similar experiences were reported by others who participated in online communities and social media for people living with dementia:

Positive internet support groups like Dementia Alliance International. Being able to access information and help online was helpful. (Person with YOD, unsure of type, aged 72 at point of participation, female, white British, rural area)

In this case, the knowledge of other ‘experts by experience’ enabled younger people to better understand their condition and gain insight into coping with the symptoms and impact of YOD.

Access to age-appropriate services appeared to be essential in enabling younger people to maintain their independence. A younger person emphasised how important this need is and how it was met via age-specific support:

My independence is really important to me. It's important to get care and support that is age-appropriate ... When you find people who are willing to talk to you on your level, appropriate to your needs, rather than just try to apply your needs to fit old people services, which is what dementia usually fits into. (Person with young onset Alzheimer's disease, aged 56 at point of participation, female, white British, rural area)

In this extract, the younger person elaborates on how independence can be facilitated by services which focus on tailoring support to individual age-specific needs due to distinct differences between the needs of younger people and those of their older counterparts. Another younger person provided an example of age-appropriate support that enabled maintaining independence:

I would just like to have one day a week, my day of the week ... When I retired at the age of 47, I started making furniture. I've got a lovely workshop in the garden with all these lovely woodworking tools that I am not allowed to go into and use unless supervised. So now I have a buddy who helps me to decide the things we can do ... It works very well with him, it's just like having a more able version of myself. I have a project in my head, I develop a masterplan and we go out walking and collecting bits of wood ... It's great because it enables me to have my own space and time to do things that are important for me. (Person with young onset behavioural-variant frontotemporal dementia, aged 55 at point of participation, male, white British, rural area)

This response showcases how the person benefited from the assistance of a professional who provided non-intrusive supervision to ensure that he could safely engage in meaningful activity and maintain his woodworking abilities. Instead of dismissing the idea due to safety risks, the professional employed a flexible approach which enabled the person to retain his own personal space and time for the one activity he enjoyed after being forced into early retirement.

In addition to having personal space and time, participants stressed the importance of support with activities of daily living to maintain their independence, particularly when living with a rarer form of dementia. A younger person living with YOD reported:

I receive support from two organisations, I have both of them usually for four hours each week ... They provide practical help, they help me with the garden, they help me to go shopping, they pick me up when I'm done and help to put the shopping away once we come back, they make sure all the washing up and cleaning is done, we do the post, we work through filing, and they accompany me when I need to travel ... It's really good and helps me with my everyday life. (Person with YOD, probable progressive non-fluent aphasia, aged 62 at point of participation, female, white British, rural area)

In this extract, the varying impact of diagnosis is implied, as the daily needs and routine of people living with rarer types of dementia may be more severely affected. People with such diagnoses may require regular practical support both at home and outside to ensure they can effectively run their household and maintain access to provisions essential for their wellbeing.

Participants reported how maintaining autonomy was achieved via opportunities to have their voices heard. One person with YOD reported:

Working with [NHS Trust] both individually and as part of a service user group I helped to set up was really helpful. I also work with [charity organisation] as an ambassador and with lots of other third-sector and NHS organisations and universities on young onset dementia projects ... It gives me a sense of purpose and helps me understand myself and my dementia better. (Person with young onset Alzheimer's disease, aged 62 at point of participation, male, white British, urban area)

Having a voice through being part of a service user group and as an ambassador enabled this younger person to experience a sense of agency. This not only enabled better understanding of the condition and how to cope, but also elicited a sense of 'being in the driving seat' of advocacy initiatives and research projects.

### **Being myself**

The second superordinate theme groups together six themes related to the need of younger people to maintain their sense of self. This was achieved through services which addressed challenges related to mental and physical health, and forms of support which enabled continued engagement in meaningful occupation. Through these services, younger people were able to maintain their sense of identity and normalcy, and recover a positive outlook.

Participants referred to the usefulness of services which maintained their physical health and cognitive skills. The usefulness of interventions that enable engagement in preventive strategies to maintain physical health was highlighted by a person with YOD and their carer:

The adult services of [local] council have a six-week living well course, that helps us see the need to eat well and be active. (Person with young onset Alzheimer's disease, aged 64 at point of participation, female, white British, urban area; supporter/husband, aged 65 at point of participation, male, white British, rural area)

Similarly, a person with YOD underlined the importance of regular monitoring of physical health by an expert who understands YOD symptoms:

[Name of support worker] visits me every 6 months or so and helps with tips on my swallowing and my mobility. (Person with young onset dementia with Lewy bodies, aged 64 at point of participation, male, white British, rural area)

These responses highlight the importance of focusing proactively and monitoring aspects of physical health, such as nutrition and physical exercise, to reduce the

impact of YOD and prevent further deterioration. However, many participants emphasised the need for additional support to continue engaging in physical exercise while living with YOD. A younger person in early stages of the condition wrote:

[Charity] offer me a mentor and we go on bike rides. This helps me get out and stay fit. (Person with young onset Alzheimer's disease, aged 48 at point of participation, male, white British, rural area)

In later stages of the condition, the focus was placed on minimising the multifaceted impact of YOD on physical health. A family member was concerned about weight gain and declining health of the person they cared for due to the mobility difficulties resulting from the condition:

Because my husband walked so slowly, he was getting no aerobic exercise and he was putting on weight and losing muscle tone and bulk ... I found a weekly exercise class specifically for people with dementia ... This is excellent as my husband can work hard and achieve aerobic exercise without fear of falling, his health and confidence improved ... His mood also improved. (Person with young onset frontotemporal dementia, aged 69 at point of participation, male, white British, urban area; supporter/wife, aged 72 at point of participation, female, white British, urban area)

These quotes illustrate how people with YOD need to remain physically active to prevent health deterioration and reduce the impact of YOD. The support needed varies according to the stage of the condition. While earlier stages require support with physical activity to maintain fitness, support at later stages necessitates needs-tailored exercise in a safe environment, to promote health improvements which indirectly influence the impact of YOD on aspects of psychological well-being. Participants also reported the helpfulness of services aiming to facilitative maintaining cognitive skills. One person described:

Towards the end of the first year after diagnosis I was invited by [memory clinic] to go on a cognitive stimulation therapy group course. This was so helpful, the advice given, the ideas for stimulation of the brain was a huge help to me and indeed are still practised by me. (Person with young onset Alzheimer's disease, aged 60 at point of participation, female, white British, rural area)

This response implies that such interventions did not only improve cognitive functions in the short term, but further enabled positive long-term effects via continued self-practice. The sessions appeared to act as a form of training enabling younger people to acquire access to a set of exercises which they used in their own pace and time to maintain cognitive skills. Overall, support focusing on enabling younger people to maintain a physically active lifestyle and prevent deterioration of physical health and cognition not only helped to maintain health and physical independence but further appeared to enable maintenance of their sense of identity as an able rather than a disabled person.

Maintaining identity appeared to be a fundamental need acknowledged by many participants. A younger person reported how continuing to engage in age-specific meaningful occupation enabled maintaining their sense of identity and pursuing personal fulfilment:

I am still full of the person who I used to be, who I am. I am still full of the youngness, full of energy and enthusiasm ... So, what's important for me is something that's compatible with who I am ... What's been good for me has been music and situations where people allow me to express myself or recognise what I want to do is relevant. [Charity] offered their premises for me to deliver a creative writing workshop. That's been good because sometimes you need to be validated or your aspirations need to be validated as more than just a little whim or excitement ... It makes you feel still valued and relevant ... Once you've got a diagnosis of dementia, most people define you by the diagnosis and not based upon your potential and who you really are, and that makes you reluctant to engage with anything. (Person with young onset Alzheimer's disease, aged 58 at point of participation, male, mixed heritage, urban area)

In this example, the younger person highlights the need for identity validation and how this was met. Services appreciated the person's need and provided the space and context for the younger person to express themselves and continue fulfilling their potential through a leading role in an arts workshop. The strengths-focused approach appeared to be pivotal in the process. In other cases, younger people appreciated engaging in valued activities, even if these were novel. A supporter of a person in advanced stages of the condition reported:

[The organisation] gave [husband] the opportunity to draw and paint [for] a couple of years. It made him feel like a human being, that he could still do something. When he felt everything had been taken away from him, the idea that he could create something was extremely valuable to him. Anything that makes you feel you've not been written off can be tremendously helpful. It is important to have things that do not make you feel like an old person or be treated like a physically and mentally incapable person. (Supporter/wife of person with young onset Alzheimer's disease, aged 67 at point of participation, female, white British, urban area; person with YOD, aged 67 at point of participation, male, white British, urban area)

As in the case of physical and mental health, this extract shows that meaningful occupation also helps to conserve self-identity as an able person in people with YOD. While earlier stages of the condition may favour active participation in activities promoting the validation of personal aspirations and identity, later stages may require more subtle activities promoting creativity and a sense of feeling valued. Arts-based activities that promote self-expression and do not require expert skills appear to provide a useful tool to this end.

Meaningful activities also enabled younger people to maintain or recover a positive outlook. Through participation in such activities, younger people appeared to feel more positive about living with YOD. A supporter reported:

The local memory clubs and local walking group kept my wife positive giving [her] something to look forward to. (Supporter/husband of person with young onset vascular dementia, aged 62 at point of participation, male, white British, rural area; person with YOD, aged 59 at point of participation, female, white British, rural area)

A carer supporting her brother added:

We got great support from the [local charity] people, they have been amazing support with their workshops. My brother was given some purpose and enjoys the classes. (Supporter/sister of person with young onset Alzheimer's disease, aged 54 at point of participation, female, white British, rural area; person with YOD, aged 57 at point of participation, male, white British, rural area)

These responses show how meaningful activities can enable younger people to experience positive aspects of their lives without dwelling on the declining nature of the condition. Such activities seem to help people with YOD to focus on and enjoy the 'here and now', which increases their confidence and creates a sense of purpose in life.

Participants reported the usefulness of services which enabled them to retain a sense of normalcy in their everyday lives. A supporter described how her partner enjoyed cycling, which became one of his favourite activities after having to give up work following diagnosis, but could not continue engaging in the activity safely without support:

They have standard bikes and adapted bikes ... My husband used to cycle a lot and he can get on a bike and ride. The people who are doing it have a bit of an understanding of dementia ... The fact that [he] could still get on a bike and turn a wheel and be active was enormously valuable to him. (Person with young onset Alzheimer's disease, aged 67 at point of participation, male, white British, urban area; supporter/wife, aged 67 at point of participation, female, white British, urban area)

In this example, the person with YOD was enabled to maintain an activity that gave their life meaning and structure and made them feel they could continue to achieve something they had always enjoyed. According to the person's supporter, this was particularly helpful for the younger person's confidence and sense of identity.

### ***A sense of togetherness***

This superordinate theme encapsulates five themes which reflect the need of younger people to maintain a sense of togetherness in their family and social lives. Sensitive services which employed a person-centred approach, offered support for the family as a whole and opportunities to contribute to the lives of others enabled younger people to maintain meaningful relationships within their families and social circles, remain active members of their communities, and feel held and supported during challenging periods of their experience with YOD.

Participants emphasised the importance of services which sustained family relationships and the wellbeing of the whole family as a unit. A carer described an intervention focused on improving communication between herself and her husband who lived with frontotemporal dementia:

We attended seven sessions of speech, language and communication therapy together ... We had got into the habit of not communicating well, because it becomes more difficult with things like frontotemporal dementia ... It made such a difference in our relationship, because we learned how to communicate properly without getting all het up and then trying to hide it ... It's helped our relationship really, it's like relationship counselling. (Supporter/wife of person with young onset frontotemporal dementia, aged 72 at point of participation, female, white British, urban area; person with YOD, aged 69 at point of participation, male, white British, urban area)

This response illustrates how the need for togetherness within the family may require tailored support to address dyadic relational challenges resulting from diagnosis. In other cases, a family-oriented approach was needed to address the needs of all affected by the condition and ensure that family bonds were not weakened. A younger person said:

The support of all the care team (nurse, doctor, social worker) have been great with my family, they were affected more than me, the support I have had is amazing. They were helpful for all the family ... I needed all my family to be involved with hospital appointments and train ... so they would understand better ... It has helped them to understand me. (Person with young onset Alzheimer's disease, aged 50 at point of participation, female, white British, urban area)

This response highlights how continuous support for the whole family enabled the younger person to feel held and supported, and maintain their family bonds which were important both for their psychological wellbeing and the quality of informal care they received. An important aspect of the process involved family members being supported to better understand the challenges experienced by the person with YOD and so prevent emotional detachment. Similar experiences were reported by participants with diverse ethnic backgrounds. A South Asian supporter reported:

[Support group for South Asian people with YOD and carers delivered by a South Asian facilitator] was very good for us as a family because of the discussions we had. We were nearly 25 people, had a cup of tea, shared experiences with each other, and that encouraged you to be brave and be prepared because you were not alone. (Supporter/husband of a person with young onset vascular dementia, aged 73 at point of participation, male, South Asian, urban area)

This quote indicates the benefits of a support group which helped people with YOD and their carers to keep their families together through challenging periods of life with YOD. The camaraderie and sense of belonging within the group instilled a sense of confidence and security and enabled families to feel held and supported

without losing hope. Although similar needs were reported by white British participants, the empowering impact of support groups in this case may be related to the culture-specific nature of support and sense of belonging. Participants also placed particular emphasis on services addressing the needs of children. A supporter said:

My younger daughter was probably 5 and my elder daughter was 11 when my husband was diagnosed ... [Charity] did sessions with my children to guide them through the changes that were happening ... They took the girls away for an hour or so once a week and tried to talk to them or get them to talk about how they were feeling. They also talked to them about the changes that were going to be going on in a friendly non-threatening play-based scenario ... Like many teenagers, my elder daughter suffers from anxiety and clearly the added pressures and strain of living with a father with dementia and some of the emotional upset that goes with that, made it much harder. (Supporter/wife of person with young onset Alzheimer's disease, aged 53 at point of participation, female, white British, urban area; person with YOD, aged 51 at point of participation, male, white British, urban area)

In this extract, the supporter underlines the need to ensure the wellbeing of young children who were also affected by the diagnosis and protect the sustainability of family bonds. Children appeared to experience a psychological burden resulting from changes in family roles and dynamics. Services addressed this through informal activities which enabled children to have their own time and space to be heard and gently preparing them for future challenges to minimise their impact.

Participants reported the importance of developing and maintaining meaningful social relationships beyond their close families. This often included participation in social groups for people with YOD and supporters. A younger person described:

The group normally has about six to eight of us and we go out and do fun things ... We've been to pubs for lunches, garden centres ... for walks around churches, we have done all sorts of just fun things ... It's really good because you can relax, you are amongst people that are just like you, you've got no worries. It's very buzzy, I always come away on a high. (Person with young onset Alzheimer's disease, aged 60 at point of participation, female, white British, rural area)

In this example, the person with YOD describes how their need to maintain an active social life was met by engaging in social activities that were meaningful, fun and relaxing. The presence of other people with YOD seemed pivotal, as they understood the challenges associated with the condition and enabled the person to feel secure, accepted and included without worrying about social discomfort resulting from condition-related behaviours or symptoms.

Participants emphatically referred to the significance of services which enabled them to share with others and make a difference in the lives of people in their communities and wider society. A younger person reported:

Through the gardening group we produce plants and plant seedlings out in a place just outside the town ... It's a weekly group of six or seven people ... You have the



opportunity to sit with other people who are in a similar situation and have conversations, but it feels really good to get on with a job in hand ... I have probably planted 50 or 60. It goes to a proper purpose, they sell them to the public ... I am happy and if it makes a difference to others it makes me feel happy as well ... There is nothing worse than the feeling of not being of any use. (Person with young onset vascular dementia, aged 65 at point of participation, male, white British, urban area)

This response showcases the need of people with YOD to remain active members of their communities and continue contributing. Inclusion and participation in collective initiatives seemed to provide fertile ground for this need to be met, as younger people felt connected with their fellow workers and local communities. Participants also described how they valued opportunities to make a difference in the lives of other families affected by YOD by providing them with advice and raising awareness of the condition in the public. A dyad reported:

[We received an] invitation ... to take part in [charity group], a way for raising awareness and training newly diagnosed ... it helps people and she says it's almost like 'having a job'. It allows us both to 'put something back' by raising awareness of dementia issues and to give advice for those living with dementia on living well. (Person with young onset posterior cortical atrophy, aged 63 at point of participation, female, white British, urban area; supporter/husband, aged 65 at point of participation, male, white British, urban area)

This extract illustrates how the person with YOD experienced a sense of belonging via sustained opportunities to contribute to the wellbeing of others living with YOD; the latter involved initiatives aiming to elicit a positive impact at both the individual and wider societal level.

## Discussion

This study aimed to identify what works in real-life practice and gain insight into helpful post-diagnostic services for people with YOD. Through a nationwide survey and follow-up in-depth interviews, we identified eight themes reflecting the objectives of helpful services (*what* codes) and eight themes depicting the needs these met (*why* codes), based on the accounts of younger people and their supporters. These were grouped into three superordinate themes representing fundamental needs met by positive services for people with YOD: 'maintaining autonomy', 'being myself' and 'togetherness'.

Previous research has shown that maintaining autonomy is highly important for younger people (Greenwood and Smith, 2016). Bannon *et al.* (2022) conducted a meta-synthesis of preferences for supportive services among younger people and their care-givers, and reported younger people's preference for services that enable managing symptoms while maintaining autonomy. Contrary to findings related to LOD (Holroyd *et al.*, 2002), our study implies that younger people prefer to have honest facts about the condition and its prognosis to understand how to cope with symptoms and maintain control over their experience with YOD. Our study also confirmed that younger people find relevant online

initiatives helpful for understanding YOD and accessing sources of support (Talbot *et al.*, 2021). These may constitute a useful complementary resource, particularly where people with YOD are at a geographical distance from in-person services or where services need to suspend in-person support, as in the case of the COVID-19 pandemic. Support sensitive to age-specific needs was reported as pivotal for maintaining independence. In line with previous findings (Westera and Fildes, 2014; Westera *et al.*, 2016), active collaboration via a strengths-based approach seemed to enable younger people to maintain their abilities and remain active. Furthermore, the symptoms of dementia and the associated needs for support may vary greatly in rarer types of dementia, such as posterior cortical atrophy (Harding *et al.*, 2018). In our study, younger people with rarer types of dementia, such as progressive non-fluent aphasia and fronto-temporal dementia, appeared to be more severely affected by diagnosis and required additional support with activities of daily living and communication. Given the higher prevalence of rare diagnoses in YOD (van Vliet *et al.*, 2013) and the dominance of 'all-age' dementia services in support provision, professionals need to receive specialist training to develop a nuanced understanding of YOD and avoid erroneous assumptions that younger individuals would not encounter such challenges; such instances could delay access to needs-appropriate support and accrete preventable distress in younger people (Williams *et al.*, 2001). Our findings also imply that autonomy is enhanced by an increased sense of agency. Previous studies have reported that younger people may experience powerlessness due to loss of agency after diagnosis (Clemerson *et al.*, 2014). Our study shows that younger people experience enhanced sense of agency not only when they are actively involved in disease management (Bannon *et al.*, 2022) but also through public advocacy initiatives and cross-sector collaborations aiming to bring changes in real-life practice and public awareness of YOD.

The theme 'being myself' reflects the need of younger people to maintain their sense of self throughout their experience with YOD. Rabanal *et al.* (2018) reported a link between employment loss and reduced sense of identity, and suggested meaningful activity as a protective coping strategy to remain positive while living with YOD. Similarly, Clemerson *et al.* (2014) associated employment loss with the expected loss of a predicted future and reported maintaining specific self-concepts or redefining self-identity as strategies employed by younger people to restabilise their sense of self. Our study findings provide different insights into the importance of continuity in meaningful activities and occupation; younger people do not only wish to maintain their identity but further wish to continue fulfilling personal aspirations as a means of continued growth and self-actualisation. To this end, strengths-based person-centred interventions can validate identity and personal growth, and counteract the disability identity that is imposed by the social environment and personal experience of symptoms (Greenwood and Smith, 2016; Thorsen *et al.*, 2020). Of interest, creative arts-based activities that do not require a special skillset appear to be useful as they enabled younger people to feel valued and important, and recover a positive outlook without dwelling on the declining nature of dementia. Consistent with previous research (Clemerson *et al.*, 2014), our study showed that identity can also be affected by declines in physical and cognitive skills. Our findings indicate that services need to provide support

both proactively and in response to emergent or changing needs to enable younger people to maintain their physical health, continue exercising in a safe manner and retain their cognitive skills for as long as possible. This approach did not only prevent the deterioration of physical health and cognition, but also enabled younger people to maintain their confidence and sense of identity.

The theme 'togetherness' represents the need of younger people to maintain a sense of connectedness with their families, social circles and local communities. Maintaining family relationships, including dyad relationships and relationships with young children, required needs-tailored interventions to address relational challenges associated with diagnosis-specific symptoms (*e.g.* timely provision of speech and language therapy to couples/families affected by young onset fronto-temporal dementia due to difficulties with interpersonal communication) and family-oriented services to maintain family bonds and address the needs of all those affected by YOD, including young children. Our findings show that such interventions prevented the emotional detachment of family members/supporters and enabled the younger person to feel held and supported, especially during challenging stages of the condition. Emotional detachment has been previously reported as a distinct stage of adapting to YOD for underage children (Svanberg *et al.*, 2010). In light of our findings, future research could further explore how relationships are affected during this stage and how these are experienced by the person with YOD, particularly when children may contribute to informal care. Although the majority of our sample consisted of white British participants who reported the importance of services that promote a sense of security and belonging, our findings indicate that these needs were met by culture-sensitive support groups for families from other ethnic backgrounds. This is in line with previous findings (mainly in LOD) which highlight that even though families with diverse ethnic backgrounds share similar service needs with white Caucasian families (Ho *et al.*, 2000; Dourado *et al.*, 2018), they tend to avoid sharing negative dementia experiences with 'outsiders' and services that lack cultural relevance (Zhan, 2004; Brijnath *et al.*, 2022). Given the limited number of non-white British participants in our study and the paucity of relevant research in YOD, future cross-cultural studies should consider the potential interplay between age- and culture-specific factors in YOD post-diagnostic support. Consistent with Mayrhofer *et al.* (2018), our findings indicate that people with YOD need to maintain social relationships which extend beyond the familial circle. People with YOD may avoid social exposure due to stigma and discomfort resulting from dementia symptoms, which can lead to social isolation (Greenwood and Smith, 2016). The study findings show that social outings with others living with YOD offer a secure, accepting and inclusive social environment, in which younger people feel understood and experience social reconnection. Finally, people with YOD emphasised their need for social belonging through a sense of connectedness with local communities. Previous studies have shown that enabling people with YOD to contribute to the lives of others constitutes part of the social reconnection process (Clemerson *et al.*, 2014). Our study confirms this finding and further indicates that younger people experience an increased sense of belongingness and self-worth when engaging in opportunities to help others with YOD to live well and when involved in collective actions which reach members of the wider community.

Overall, we aimed to recruit a sample as diverse as possible to be inclusive of needs met by positive services, across a range of diagnoses, localities (rural or urban), living conditions (alone or with family), gender and ethnicity. Apart from some differences related to type of diagnosis (e.g. speech and language therapy to couples/families living with frontotemporal dementia due to difficulties in communication) and ethnicity (e.g. culture-specific support groups) we were not able to substantiate systematic differences according to characteristics. This may be related to our focus on positive experiences, as people with diverse ethnic background, rarer types of dementia, and living alone or in remote areas are often under-served (McDonald and Heath, 2008; Miranda-Castillo *et al.*, 2010; Czapka and Sagbakken, 2020). However, given the diversity in gender, age, rurality and diagnosis within our sample, we are confident that our themes, which were present in most participants' interviews and survey responses, reflect common issues across a diverse population who have age of dementia onset in common (<65 years of age). There is likely to be intersectionality regarding these influences, but future research could consider some key ones, such as ethnicity, rurality, living conditions and type of dementia, in greater depth.

### **Strengths and limitations**

Although we pursued recruitment via a wide range of NHS sites, charities and social media, and provided different options for participation in the survey and interviews, most participants were well-educated and received support from services. We put significant effort into recruiting from ethnic minority communities through relevant charities and social media; however, our sample included only a few individuals with diverse ethnic backgrounds. We also faced difficulties recruiting participants living in care homes or receiving end-of-life care. In mitigation, we used purposive sampling for follow-up interviews to gain diverse voices (e.g. younger people living alone or with rarer dementias), to increase trustworthiness and transferability. It is possible that the briefing notes we used in the survey prompted recall of certain positive service experiences. Nevertheless, the variety and specificity of the responses attest to the credibility of the data. Despite the clear instructions, family members/supporters may have found it difficult to provide the perspectives of the person with YOD. The comparisons between respondent groups revealed contribution to all our themes from both younger people and supporters, which may enhance the credibility in this respect. We held frequent team meetings and received feedback on the relevance and plausibility of the study themes from the project PPI Group, Steering Committee and wider research team, increasing the confirmability of our findings.

### **Implications**

Our findings have the potential to inform recommendations for real-life practice. The NICE Guidelines stressed the significance of social activities and services that promote independence in younger people (NICE, 2018). Furthermore, the drive towards Universal Personalised Care places emphasis on social prescribing (Sanderson *et al.*, 2019). Our study provides significant insights into how this

can be achieved. For example, our superordinate themes of ‘maintaining autonomy’ and ‘being myself’ provide clear examples of how services can enable people with YOD to experience enhanced sense of agency and maintain their identity. The wide range of themes expands on the NICE Guidelines and provides a clear blueprint of services that need to be commissioned for YOD. For instance, the themes provide examples of services aiming to address dyadic relationships and prevent the emotional detachment of family members to protect family bonds and informal care. Such findings could be used to inform needs-based service provision, and evaluation and provide the basis for service improvements.

Needs similar to our findings have been previously reported in studies across different countries (Johannessen and Möller, 2013; Millenaar *et al.*, 2016; Cations *et al.*, 2017). Our findings therefore have international resonance. Future research could provide insight into cross-country differences in younger people’s needs and how these are met by services, particularly given the variations in culture across different countries.

Our superordinate theme labels may appear to lack specificity to YOD. However, the associated themes and examples highlight the specific context of YOD, revealing the need for age-appropriate services. We feel confident that our study has contributed to an in-depth understanding of how the fundamental needs of those living with YOD can be met by services. Given the knowledge we now have, it is time for future research to: (a) investigate the implementation, evaluation and cost-effectiveness of evidence-based changes in service provision, and (b) contribute to the development and operationalisation of YOD-specific guidelines and their inclusion in England’s Dementia Strategy. This would promote good practice and facilitate the development and spread of YOD-specialist services, from which younger people seem to benefit the most (Stamou *et al.*, 2021a). Finally, the effectiveness and cost-effectiveness of novel co-produced interventions associated with our needs-based themes (*e.g.* family-oriented interventions) could be investigated to enable appropriate, focused service commissioning.

## Conclusions

Our study themes provide rich insight into the objectives of positive services and the needs these meet for people with YOD, as reported by those directly affected. Positively experienced services addressed the disruptions of YOD in younger persons’ autonomy, selfhood and meaningful relationships. Our findings are primarily informed by younger persons’ lived experiences and include rich direct quotations and a broad range of examples of positive support. As such, it would be safe to consider our findings on good practice as representative of younger people’s voices and experiences.

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**Data.** The data of this study are not available to protect the privacy of research participants.

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