

Evaluation of Dementia Forward services and support for people living with young onset dementia

Summary report

Report written by: Vanessa Baxter, Victoria Jones and Professor David Sheard, Institute for Health and Care Improvement

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Dementia Forward
Care and Support for Life

YORK ST JOHN UNIVERSITY
Institute for Health and Care Improvement

Background

There are an estimated 70,000 people in the UK living with young onset dementia, however the actual figure could be much higher, as young onset dementia is often not recognised and can go undiagnosed for a long time. Dementia Forward currently supports 426 people living with young onset dementia (referred to as clients in this report) in North Yorkshire and 375 carers.

Dementia Forward offers a range of services and support specifically for people living with young onset dementia, including a helpline, wellbeing and social activities and carers' groups. They wished to evaluate their young onset services in order to support the design of future services and therefore commissioned the Health and Care Research and Evaluation Service at York St John University to undertake an independent evaluation. This report summarises the findings from this evaluation.

Methodology

The evaluation comprised four online surveys with responses from 20 people living with young onset dementia, 42 carers, 17 professionals/referrers from other organisations and 22 Dementia Forward staff. In addition, two focus groups were held with 12 clients in total and interviews were undertaken with five carers (in two of which clients were also present for part of the time).



Feedback on services

Most carers and clients were generally positive about Dementia Forward services and support, although a range of improvements were suggested and a few had had poor experiences, particularly regarding place-related accessibility issues and activities during later stages of dementia. Professionals/referrers were also positive about Dementia Forward services.

Clients and carers reported that Dementia Forward staff are caring, helpful, supportive and approachable.

> "Very responsive, caring & understanding of circumstances. Knowledgeable about dementia & eager to support." (Carer)

The majority of clients and carers said the Helpline is helpful and supportive due to the provision of both initial and ongoing help, the friendliness and responsiveness of staff, and the signposting to other support. The majority also felt that Advisers are helpful and supportive, including their advice, signposting to services or local support, and the knowledge, understanding, empathy, helpfulness and support provided by specific advisers. Two carers interviewed said they would welcome a regular check in from Dementia Forward Advisers but the others said they were comfortable in contacting their named Advisers when needed.

> "A Young Onset diagnosis can be devastating for the person, their carer and their family. The future they have all planned for is not going to look the same anymore. It is essential families are supported through this emotional and difficult time, they may be experiencing many emotions, anger, resentfulness, sadness and also be very worried how this will impact financially and the impact on relationships." (Dementia Forward member of staff)

Wellbeing services (such as Dementia Forward's Time Out Together[1]) are important to clients due to the opportunities for them to interact socially, visit places and keep active while being safe. All carers and clients in the surveys and qualitative research agreed that Time Out Together is helpful and supportive. It provides an opportunity for clients to socialise with others in a similar situation, amongst friends where people are able to be themselves, share stories and issues, and not feel alone. The social aspect of the group is very important to clients who enjoy the day and the companionship. It also helps to build confidence and independence, and the staff are kind and supportive.

> "When I first came here, diagnosed and suddenly I was with nobody. I had no friends, no nothing, lonely, other than my own family. And so, when I came here the first time, just while I walked in, everybody here was friendly. And we're all the same. We all have similar issues and it's like a big family from the day I walked in here." (Client)

A few carers and clients had had less positive experiences of Dementia Forward's services and support, particularly in the later stages of dementia. When a client's mobility or physical activity levels reduce they lose out on the benefits of Time Out Together as they are no longer able to attend, although they still receive support in other ways including from their Dementia Support Adviser.

Most carers felt that the carer support group is helpful and supportive, finding the topics covered relevant, useful or informative. Positive aspects are the peer support provided (including talking to others in a similar situation) the dissemination of information, sharing symptoms and conditions and being able to ask questions, although there is not always sufficient time to talk if a carer has a question or wants to discuss something with the group.

> "I have found that the sharing of information, advice and lived experience between carers is invaluable and has been more helpful than any other source. Spending time with people who understand how you feel, whether you are the one with dementia or their loved one is a positive thing and enabling socialising and having fun in this environment is a welcome distraction." (Carer)

However, carer support groups are not available to everyone: the provision of services generally is not consistent across the county, with carers and clients in some areas not able to access some activities/groups, or they do not cater for younger adults who are still working.

[1]Time Out Together is an outward bound day service providing activity and peer support for clients and a day of respite for carers

"You have to live in the places where Dementia Forward have age-appropriate services in order to access them which is VERY, VERY WRONG. We need to see and be involved with someone like yourself, not like all the areas outside York, Scarborough and Harrogate that have all the help and support needed and everyone else has to make do with going to day centres for the elderly. There is no stimulation even if it is enjoyable. I know that sitting in a room playing games is not age of progress. Doing things like going out riding bikes, going to a museum gym walking possibly even swimming them or age-appropriate activities." (client living in Richmondshire)

Age-appropriate services are important to all clients and also carers. Clients felt it is important to be with people of a similar age from the same generation, who grew up in the same historical period with the same music etc.

"Somebody that's 60 in 2025 is wholly different to somebody that was 60 in 1955." (Client)

As well as the Time Out Together group, clients and carers wanted less sedentary and more physical activities to enable people to continue the activities they enjoyed before their diagnosis, rather than just arts and crafts. Most carers said it is important to have age-appropriate advice and support as younger people are very different to older people living with dementia since they are more physically able and active, can do more to challenge themselves and have different interests to older people. Activities therefore need to be tailored to the physical capabilities and interests of this age group.

The main unmet need for younger people and their families identified by staff was the lack of services/opportunities that are age-appropriate, resulting in a lack of occupation. Staff identified a number of groups whose needs Dementia Forward does not currently meet including people from some ethnicities and backgrounds, people in rural areas, families who need more "walking alongside" to engage with services, people living alone and/or with no family or support network, people with learning disabilities, those who do not like being part of groups and people whose condition has progressed to a point where Dementia Forward is not able to meet their needs at Time Out Together and other activities.

The unmet needs of carers identified by staff were the provision of support and advice for legal and finance matters, emotional support and peer groups for the wider family, carer stress and worry about the unknown, carers having to juggle supporting their loved one as well as teenage children and their own parent/s and lack of appropriate respite services.

Professionals were positive about their working relationships with Dementia Forward, communications and the referrals process. They were not aware of all of the services and activities provided by Dementia Forward, but all but one said that Dementia Forward's service is helpful for people living with young onset dementia and their carers. (The professional saying the service is not very helpful said that it is because there are no specific young onset groups in their area and that they do not have referrals for carers.)



Recommendations

The researchers made a number of recommendations based on the research findings, which Dementia forward is currently addressing through an action plan.

Provision of services

Recommendation	Action
Consider reinforcing staff training around examining the complex balance of "enabling" people in a person-led way rather than steering people into overly organised pre-determined types of activities (which although provided in a person-centred ethos can be perceived as still controlling).	An accredited young onset dementia training package has been developed and rolled out internally and within external care settings.
Ensure equity of access by creating more place-based and age-appropriate services and support for young onset clients across the county, identifying areas with little on offer, with social activities and peer-based support that: • Offer transport options. • Provide support to attend for those living alone. • Accommodate changing needs and physical abilities.	Dementia Forward continues to seek funding to be able to provide more services and options.
Produce marketing information/materials on support and services in various formats.	In progress, co-designed with Dementia Forward Voices.
Advertise services and support more widely, including having something specifically for young onset dementia shown clearly on the Dementia Forward website's landing page.	The website is being redesigned.
Actively promote services, in particular the carers' group, to those who do not attend, engaging with them personally if needed.	Ongoing.
Provide education and training sessions for those living with young onset dementia and their families, as well as for all staff.	An online session has been designed and is being delivered.
Offer various formats of carer support groups, including online as well as in-person options, and different timings outside of working hours/aimed at young adults who are still working.	Ongoing.
Consider offering a specific counselling service for carers and the wider family.	This is not a service that DF can offer, but they signpost to external services.
Offer more opportunity for carer respite.	Funding is being sought to be able to extend opportunities across a wider geography.
Look at options for social activities that clients with limited physical mobility can attend and enable their retention of friendship groups developed at Time Out Together, with flexibility in assessing clients' level of independence and abilities.	This is a priority action for DF to support these transitions.
Promote physical health/exercise type groups.	After obtaining funding, Dementia Forward is working with North Yorkshire Sport to implement physical activity into every group, starting in April 2026.

Provision of support

Recommendation	Action
Encourage a joined-up approach with social care and health, including more awareness and partnership/signposting with GPs.	Dementia Forward continues with the U&Me campaign bringing people together across all agencies into U&Me Action for Change groups.
Set guidance on the information applicable to each stage of contact, to avoid clients and families being "overwhelmed" with everything at once, including how and when to link into social care.	Dementia Forward is developing an infographic to show the young onset dementia journey with transition points and support available at each stage.
Consider providing support during visits to the memory clinic.	Dementia Forward has worked with the local mental health trust to establish a young onset dementia memory clinic within a Dementia Forward building.
Consider having specific Dementia Support Advisors for young onset clients and more tailored advice and support for younger people and carers.	Dementia Forward has introduced a team of young onset dementia Advisers.
Confirm with each client/family the amount of contact they would like with their named advisor.	Dementia Forward recognises the importance of welfare calls but needs to identify funding to grow the resource and capacity.
Set up a mechanism to signpost children/young adults to support.	Dementia Forward is exploring options with an advocate and recognises that there is still work to do in this area.



Strategic development

Recommendation	Action
Evidence of co-production: Consider how to meet the national shift to giving individuals/families budget and service control, demonstrating through co-production and the involvement of younger people that Dementia Forward's services and support are less a central 'shopping list model' with an excellent service ethos but more co-designed by and with people's lived experience.	The Dementia Forward Voices model has been established and the next step is to ensure age-specific input for young onset dementia.
Diagnosis support and coordination: Develop a countywide Dementia Forward younger people case management approach on referrals with GPs and Memory Clinics, with inter agency discussion and agreement on who the provider of this should be (e.g. CMHTs, Admiral Nurses or Dementia Forward).	Ongoing.
Change to person-led[2] service design: while some core services need to exist for all to access, some younger people are highlighting that they are not always person-led, so further explore options to ensure that all services are person-led in design and delivery as well as having a person-centred ethos.	Dementia Forward aims to achieve this but its current work is showing that this is very intensive and therefore requires funding.
Cost effectiveness: Undertake further analysis of the services provided to understand their relative cost effectiveness.	To be developed.
Brokerage: Explore options for an alternative, less traditional model of service provision such as a brokerage model with devolved budgets, where Dementia Forward Dementia Advisors act more as brokers tailoring, purchasing and providing individual care support to meet individual need.	To be discussed with other partners and commissioners.
Partnership working: Explore partnering with providers in the independent care sector, as Dementia Forward has already done in two areas, as a solution to the geographical challenges and lack of equity.	Ongoing.
Whole life experience: Explore ways of improving multi agency coordination with Dementia Forward pre and during diagnosis, as well as in the later stages of dementia, to ensure that an individual's whole life lived experience from early stage/pre diagnosis to end of life is consistently supported.	To be developed, including work to promote a model of support from pre-diagnosis to end of life and throughout different transitional stages.
Later stage experience: Identify a clear inter agency pathway of responsibility and provision for later stages of dementia, in light of what is often a rapid progression into the later stages of dementia for younger people and the complexity of presentation in the later stages.	A lot of work needs to be done in this area, requiring working with partners to achieve this.
Inter-agency training and service development: Consider setting up a county wide steering group to address the strategic findings within this report, including around inter-agency training and service development.	U&Me action for Change groups have been developed to work with other agencies.

[2]Person-led is a more active and direct form of person-centred care, where the individual is in control and makes their own decisions, while person-centred means the individual is at the centre of planning, but decisions are still made with guidance from staff.

Response to findings from Dementia Forward

When we first set about designing support for people living with young onset dementia, we knew it needed to be different from our generic all age support but what did that mean? Understanding of Young Onset dementia is poor and the provision is a vacuum. If we are going to inform the future planning we need to know what those people who are living with the condition want and need.

This study has provided an opportunity to look inward at what we have provided so far, and see this as only the beginning of what is an ambitious, but much needed, blue print for the provision of age-appropriate care and support.

Just picking out 2 examples from this evaluation demonstrates a need to have all partners in all geographical areas on board with this mission:

> "You have to live in the places where Dementia Forward have age appropriate services in order to access them which is very, very wrong."

> "When a client's mobility or physical activity levels reduce they lose out on the benefits of the Time Out together groups run by Dementia Forward."

By setting out to provide specialist services for young onset dementia we have inadvertently created a post code lottery, and perhaps even worse, a cliff edge when we cannot provide the next steps for people and there are not the age appropriate provisions available.

We will take this learning as we move forward and importantly we will use the impetus of the U&ME campaign* to make connections with stakeholders at every juncture of the illness, to begin filling that vacuum.

We are grateful for the support of York St John University and of course to all those people living with Young Onset dementia, who took part in the evaluation.

*U&ME Campaign, Dementia Forward, North Yorkshire's leading dementia charity

Jill Quinn MBE
CEO Dementia Forward

Dementia Forward Helpline 03300 578592
Website: www.dementiaforward.org.uk


Ro'n' Bowl

