

Young people with dementia need new approaches to care

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Research conducted by academics at the University of Hertfordshire outlines new approaches to care for people diagnosed with young onset dementia.

There are currently around 42,000 people under the age of 65 living with young onset dementia (YOD) in the UK. Their [support](#) needs are different to the care required by older people. However, little is known about what should be put in place to provide age-appropriate care.

In order to understand how services could be improved, academics from the University of Hertfordshire ran discussion groups to explore perceived [service](#) priorities with people with (or with experience of) YOD. They also conducted a literature review, focusing on services available for people affected by YOD. Of the 31 discussants, 11 had a diagnosis of YOD and 20 were spousal caregivers. Academics also interviewed representatives of service providers. Findings of this study were published in *Dementia: The International Journal of Social Research*.

The research found the best way to improve services for younger people with dementia is for people affected by YOD to work closely with service providers to co-design and co-ordinate support that is locally sustainable.

Michael Walker, Old Age Psychiatrist at the NHS' Hertfordshire Partnership Foundation Trust and co-author on the paper, commented on the challenges of providing age appropriate care for people diagnosed with YOD: "In the past we've been unsuccessful in trying to recreate services for [older people](#) to look the same but with a younger patient group. One challenge is the relatively small number of younger people with dementia in a given locality, another is how to keep up a group for younger people with dementia when the original members may no longer be so young. We need to look at how services can work together to ensure a consistency of service for those diagnosed with young onset dementia."

Suggestions from the research

There were suggestions that charities and service centres could act more as a catalyst for self-organisation of peer support groups, as well as a safety net for those who struggled to make connections. Organisations could offer an 'introduction service' where people with YOD and their [family carers](#) could 'opt in' to be introduced to each other and still be in line with the new General Data Protection Regulations, to help develop peer support networks.

One discussion group suggested that charities could act as 'anchors' and 'meeting hubs,' enabling peer support through initiatives such as 'skills swapping' – where transport (driving skills) might be traded for home cooked meals (cooking skills) – or gender-specific support around leisure activities such as swimming, shopping and watching football games.

It was felt that voluntary organisations had an equally important role to play as advocates to liaise with local clubs, restaurants and buses to make their services more accessible and dementia friendly. Practical suggestions included: negotiating reduced rates for leisure centres for people with YOD, organising 'slow swimming lanes' during quiet times of the day, providing a closed-off room in a restaurant a few evenings a month and negotiating reduced rates on buses for families affected by YOD.

The 'right' services

Dr. Andrea Mayrhofer, Senior Research Fellow in Dementia Care at the University of Hertfordshire, said: "People with [young onset dementia](#) do not necessarily ask for more services, but for the 'right' services that allow them to maintain their independence for as long as possible. Long-term support becomes increasingly important when families' needs change as the illness progresses, but our study found that continuity of

care was lacking the most.

"The support currently available is designed for individuals who develop dementia much later in life, and is largely unsuitable for younger people who are physically fit, active, and carry financial responsibilities for children and/or an older parent. Age therefore is a factor when designing support for younger people diagnosed with dementia as the challenges they face are very different to those of older individuals. Interviews with service providers showed that some good quality age-sensitive services are being offered, but often only regionally and therefore not accessible more widely for younger people with [dementia](#)."

Issues for people with YOD and their carers

The research also highlighted issues relating to specific service provision; [service providers](#) outlined difficulties in delivering services specifically for people with YOD and their carers.

Roma Mills, from Carers in Hertfordshire, a countywide charity providing free advice and services to unpaid carers, said: "Carers who are looking after a relative with YOD often struggle to find services or activities that match their age and interests. This can be even more difficult when looking for a respite service or a residential care home. Carers have told us how distressing it is to leave their husband or wife in the company of people who may be more than 20 years older than them, who are far more frail and consequently much less active. Carers are asking for holistic, person-centre services which match the needs of someone with YOD."

More information: Andrea M Mayrhofer et al. Young onset dementia: Public involvement in co-designing community-based support, *Dementia* (2018). [DOI: 10.1177/1471301218793463](https://doi.org/10.1177/1471301218793463)

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