

Background: Young onset dementia means that a person was diagnosed with dementia before the age of 65. A significant factor in this condition is that there are several sub-types of dementia which require various types of support along an unpredictable illness progression. This complicates the design of longer-term age-appropriate support. An additional factor is the lack of visibility of physical functional decline in the early years which, combined with the limited experience of assessors of working with people with YOD, makes social care assessments difficult. This frequently translates into limited and/or unsuitable social care support.

Aim of the study: The study aimed to understand which types of support services were available for younger people and their family carers.

Key findings: The evidence on the experience of living with YOD is not matched by the innovation needed to support people with YOD to live as well as they can. The study found that the inclusion of people with YOD and their caregivers in service design provided a pragmatic and realistic view of what is important and achievable for people with YOD. Their involvement is critical when planning support in order to sustain quality of life and ultimately delay institutional care.

Recommendations: Recommendations for service providers are to involve people with young onset dementia in all aspects of service design and delivery. The co-design of services provides opportunities to shape service provision. A recommendation for researchers is to involve people diagnosed with young onset dementia and their families in shaping research questions and, where applicable, contribute to research projects throughout the research project.

References

- Mayrhofer A, Mathie E, McKeown J, Bunn F and Goodman C. 2017. Age-appropriate services for people diagnosed with young onset dementia (YOD): a systematic review. *Aging & Mental Health*. <https://www.tandfonline.com/doi/abs/10.1080/13607863.2017.1334038>
- Mayrhofer A, Mathie E, McKeown J, Goodman C, Irvine L, Hall N, Walker M. 2018. Young onset dementia: Public involvement in co-designing community-based support. *Dementia: The International Journal of Social Research*. <https://journals.sagepub.com/doi/abs/10.1177/1471301218793463>
- University of Hertfordshire Press release: (28th of November 2018) <https://www.herts.ac.uk/about-us/news/2018/november/young-people-with-dementia-need-new-approaches-to-care>

What is NIHR CLAHRC East of England?

The National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) East of England is a five year programme of applied health and social care research which focuses on the needs of people with complex problems, often vulnerable, when multiple agencies are involved in their care: young people, frail older people, those with dementia, learning disabilities, acquired brain injuries or mental ill health.

The CLAHRC East of England collaboration encompasses some thirty-six organisations, with research hubs in the Universities of Cambridge, Hertfordshire and East Anglia working closely with individuals and organisations involved in the whole care pathway.

Service users and carers are at the heart of what we do, in parallel with an ambitious public health research programme.

Co-production and collaboration at all stages of the research process are fundamental to making a positive impact through applied health research.

For more information about the study

<https://www.clahrc-ee.nihr.ac.uk/2016/06/care-pathways-individuals-diagnosed-young-onset-dementia-yod/>

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