

Young Onset Dementia: A Pilot Study Exploring Multi- and Intergenerational Support (2023-2024)

Support for families affected by a young onset dementia (YOD) is primarily focused on the spouse and partner rather than considering the needs of other family members and providing support appropriate to age and needs. We found that children of a person living with dementia and older family members want to support the person with YOD, but there are significant gaps in how they are supported and provided with information. Six children (aged 12-24 years) of a parent living with YOD shared their experience via direct messaging on Instagram over a four-week period and a group interview at the end of the project. They focused on shared time spent together and making memories, often being involved in activities they had shared previously. Unlike other research that focuses on negative experiences of having a parent with YOD, our participants highlighted the positive and fun time spent with their parent. Yet, they emphasized their need for age-appropriate support and finding information relevant to them, which is rarely available. Five parent-in-laws took part in virtual interviews. They wanted to be involved in supporting not just their child (the spouse of the person living with YOD) and grandchildren, but also their son/ daughter in-law, yet expressed a lack of relevant information and support for themselves to support their family.

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