

Online peer support for young onset dementia is a promising resource, but not a panacea: A commentary from the INTERDEM Young Onset Dementia Taskforce

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Abstract

Young Onset Dementia (YOD) affects almost 4 million people globally and presents unique challenges related to diagnosis, employment, family life, and access to appropriate age-appropriate care. Peer support can help people with YOD navigate these challenges, but access to tailored support remains limited and inconsistently available across regions. In this commentary, the INTERDEM Young Onset Dementia Taskforce explores the potential and limitations of online peer support as a tool to address the needs of this population. We highlight how online peer support can overcome geographic barriers, offer flexible modes of engagement, foster a sense of belonging, and overcome stigma. However, these benefits are not universal and issues relating to digital exclusion, lack of awareness, online safety, and dementia-related symptoms can hinder participation. Additionally,

there is currently a lack of robust quantitative evidence on the effectiveness of online peer support, with existing research confined to small-scale qualitative studies. To address these challenges, we propose several recommendations, including: increasing awareness among professionals and support services; developing dedicated YOD online communities; using trained moderators to promote safety and inclusivity; partnering with digital inclusion initiatives to improve access and literacy; co-designing digital platforms with people affected by YOD; and protecting funding for in-person services to ensure online support complements, rather than replaces, offline services. We call for further research to evaluate the effectiveness, implementation, and long-term impacts of online peer support.

1 Introduction

Approximately 3.9 million people worldwide live with young-onset dementia (YOD), where symptoms occur before the age of 65 [1]. A dementia diagnosis at any age can be challenging for the person and their families, but those under the age of 65 face distinct challenges, including frequent misdiagnosis and the onset of symptoms occurring during a time of heightened financial, work, and family responsibilities [2]. Therefore, people affected by YOD require age-appropriate care., and Peer support has been recognised as a valuable resource, helping those affected to better cope with symptoms and regain hope, purpose, and belonging [3, 4]. However, the availability of specialised YOD services, including in-person peer support groups, varies widely across and within countries, and mainstream dementia services are not always equipped to meet the distinct needs of this group [5]. Online peer support offers a promising far-reaching alternative [6, 7] but a push towards digitalised services risks excluding those without digital skills or resources, potentially exacerbating existing inequalities [8]. Furthermore, increased digitalisation could divert funding from essential offline services. As younger, more digitally engaged generations age, online peer support will become increasingly relevant in dementia care. In this commentary, we, a pan-European taskforce of experts in young-onset dementia, argue that while online peer support can benefit people with YOD, health and social care professionals and support organisations must remain responsive to its challenges to ensure equitable access to support. We call for further large-scale research investigating the effectiveness and implementation of online peer support initiatives to inform best practice in this area.

2 Unique benefits of online peer support

Online peer support offers unique benefits compared to in-person groups and may be particularly suitable for people with YOD. Firstly, younger people often have higher levels of digital literacy and are more frequent adopters of digital technologies [9], meaning many people with YOD may already possess the skills and devices needed to access online support. Second, online peer support can overcome geographical barriers, which is particularly important given the low prevalence of YOD, making it difficult to connect with peers locally. By connecting people across regions, online peer support can foster a sense of belonging and provide effective coping strategies without the need for travel [6, 10]. Third, online peer support provides flexibility, allowing users to choose the format that best suits their needs. Asynchronous platforms, like the YOD sub-forum of the Alzheimer’s Society Dementia Support Forum, offer 24/7 access and reach a wide audience facing similar challenges [7]. Conversely, videoconferencing (e.g., via Zoom) facilitates real-time interaction within the home environment, creating a sense of togetherness [10]. This flexibility can allow people affected by YOD to engage with online peer support in their own time and at their own pace, which is crucial for those balancing work, family, and social responsibilities. Lastly, the stigma associated with dementia, especially for younger people who do not fit the stereotypical image, can make support-seeking

difficult [11, 12]. However, online peer support can offer a degree of anonymity, enabling people to share experiences openly without fear of judgement.

3 Potential challenges of online peer support

While online peer support holds promise, health and social care professionals and support organisations must be mindful of several challenges when implementing these initiatives. First, digital inclusion remains a significant issue [10]. People with YOD living in rural areas and/or facing socioeconomic disadvantages may lack access to suitable devices, reliable internet, or the necessary digital literacy skills to engage with and benefit from online support [13]. Second, many people with YOD report being unaware of available online support or being unsure of how to find it, highlighting a need for greater awareness of these resources and their benefits [6]. Third, online peer support raises concerns about safety and security. People with YOD may be vulnerable to scams and misinformation, increasing the caring load of unpaid carers who may need to monitor and support activities [11]. Finally, cognitive decline in dementia affects not only memory but also the practical skills required to use technology. As dementia progresses, difficulties with attention, problem-solving, visuospatial skills, and language can hinder engagement with digital platforms, which are typically not designed to accommodate these challenges. For example, commonly used online support spaces on social media often lack features such as simplified navigation, clear visuals, or adaptable communication formats to support people living with dementia [14, 15]. Furthermore, rare forms of dementia, for example Frontotemporal dementia and Primary Progressive Aphasia, are relatively more common in younger people [16] and can come with non-memory-led symptoms such as difficulties with speech and language or vision impairments. Such symptoms could potentially pose additional challenges to using technology and engaging in online communication; however, more research is needed to better understand how different forms of dementia affect engagement with online peer support.

4 Discussion

While research investigating online peer support for people with YOD is growing, significant gaps in our understanding remain. Much of the existing evidence is drawn from relatively small-scale qualitative studies [e.g., 6, 7, 10], which provide valuable information about users' experiences but are limited in their transferability to the wider population of people living with YOD. There is a clear lack of robust quantitative research assessing the effectiveness of online peer support for people with YOD, particularly regarding its long-term impact, the formats which are most effective (e.g., asynchronous versus synchronous), its effectiveness and adaptability across the disease trajectory, and the contexts in which it is best applied. Furthermore, research on effective recruitment and marketing strategies to raise awareness of online peer support among people with YOD and their families is lacking, which hinders efforts to ensure equitable access to these services. This evidence is essential to inform best practices, guide resource allocation, and support the development of inclusive, evidence-based support models that can be effectively scaled and sustained.

In response to these gaps in evidence and the challenges people with YOD face in accessing online peer support, our pan-European taskforce of experts in dementia proposes the following recommendations:

- Raise awareness of online peer support: Health and social care professionals, dementia advisors, and support organisations should improve signposting to online peer support specifically for YOD.
- Expand online peer support for YOD: Dementia support organisations should develop dedicated online groups specifically designed for people with YOD, to foster a sense of belonging and enable the sharing of similar experiences and effective coping strategies. In support of this work, two of the authors (CT and ELG) are currently conducting a Scoping Review to generate an overview online peer support opportunities for people with dementia, including people with YOD [17].
- Use trained moderators: Organisers of online support groups should employ trained moderators to facilitate safe, respectful, and supportive interactions. Research with other groups has found moderators can provide additional guidance and reduce online risks [18].
- Improve digital access and literacy: Dementia support organisations and digital poverty initiatives (e.g., Digital Poverty Alliance; Good Things Foundation) provide people with affordable access to digital devices and reliable internet, particularly in rural and socioeconomically disadvantaged areas, and support digital literacy training. By raising awareness of YOD and online peer support in such organisations, they could assist people with YOD in accessing online support services.
- Co-design digital interfaces with people affected by YOD: Technology developers, researchers, and organisations offering online peer support must collaborate with people affected by YOD to co-design platforms that are intuitive and accessible for users with diverse abilities and symptom profiles.
- Expand YOD online peer support research: More research is needed on the long-term impacts and effectiveness of online peer support, to identify support gaps and ensure that emerging technology meets the needs of those affected.
- Maintain a balance between online and offline support: Dementia support services should ensure that online support complements offline services rather than replacing them. Funding for in-person services should be protected to ensure that people who prefer in-person interactions or struggle with digital engagement are not excluded and disadvantaged.

In conclusion, online peer support offers significant potential for people with YOD by overcoming geographical barriers, offering flexibility and anonymity, and fostering community. This is particularly important for people with YOD, who often still balance different roles and responsibilities, such as work and family life, and for whom traditional dementia support groups may not be suitable and may find it particularly challenging to meet peers in their local area. However, the implementation of online peer support services should be approached with care. Challenges relating to digital access and literacy, awareness of available support, online safety, and symptom-related barriers must be addressed. To ensure online peer support is effective and equitable, we recommend using trained moderators, involving people with YOD in co-design, supporting digital device access, offering digital literacy training, and raising awareness of available resources. Additionally, further large-scale research is needed on the design, implementation, and outcomes of online support for people affected by YOD. Importantly, online peer support should complement – not replace – offline support to prevent existing inequalities in dementia care from being exacerbated. By addressing these

163 challenges with thoughtful, inclusive solutions, online peer support can be a powerful tool for
164 improving the lives of people affected by YOD.

165

166 **5 Conflict of Interest**

167 The authors declare that the research was conducted in the absence of any commercial or financial
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169 **6 Author Contributions**

170 AHK took the lead in writing the manuscript with support of CT and ELG. All other authors
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175 For further information on the Young Onset Dementia Taskforce or to join INTERDEM, please visit
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177 **9 References**

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