

Online forums help those with dementia find missing support and companionship

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Online forums for people with dementia provide a much-needed sense

of community and hope and fill an important gap in the support they receive after diagnosis, a new study has found.

The researchers suggest that clinicians, [support workers](#) and organizations could recommend online support forums to people with dementia, in addition to providing their regular in-person care.

Around 55 million people are affected by dementia around the world, and nearly one million people have the condition in the UK. These numbers are expected to rise sharply.

"While there are a lot of online communities for people with a range of health conditions, there has been very little research into the benefits they can have for people with dementia," explained Dr. Catherine Talbot, Senior Lecturer in Psychology at Bournemouth University, who led the study.

"People with dementia have reported feeling isolated, confused, and having a loss of identity after being diagnosed. Our study found that online forums allow them to find companionship with others going through the same experience which can be really valuable to them," she continued.

Dr. Talbot and her co-author, Professor Neil Coulson at the University of Nottingham, analyzed 100 conversation threads of the forum "Dementia Talking Point", hosted by the Alzheimer's Society.

The findings, published in the journal *Age and Ageing*, found three key themes which users found invaluable within their community:

- Sharing their journey through dementia—from first diagnosis, to adjusting to life with the condition and looking to the future.
- Supporting each other through the journey.

- Sharing experiences of creative activities for therapy, such as painting and crafts.

"A lot of people hoped that by sharing these experiences, they would give hope to others who came to the forum," Dr. Talbot continued.

"After people had shared their experiences, often others would come back and give them some sort of support, whether that be signposting them to an organization, or it could be [emotional support](#) as well. This was very important for those who felt isolated."

Users with certain types of dementia, in particular young-onset dementia, commented in their posts about their being a lack of support for specifically for them and they therefore found the forum to be a "lifeline". Others spoke about finding it difficult to talk to their friends and [family members](#) about their condition and taking to the online space allowed them to be honest about what they were experiencing.

Debbie Ellor, Head of Advice Services at Alzheimer's Society, said, "Our Talking Point [forum](#) gives people a community, a space to share experiences and advice with people facing similar challenges. It's great to see Dr. Talbot's research identifying just how crucial forums like this can be throughout someone's dementia journey.

"No family affected by dementia should face it alone, but sadly our research showed that three in five people didn't receive enough support in the last year. While there's clearly power in a likeminded, understanding community that's easy to access online, ultimately we need more support from the health and social care system for families with dementia."

Neil Coulson, Professor of Health Psychology at the University of Nottingham added, "Regardless of age, gender, [geographical location](#) or personal circumstances, [online forums](#) can provide a convenient,

anonymous, and supportive environment. Our study clearly demonstrates the value of online peer support regardless of where in the [dementia](#) journey an individual may be.

"The nature of the communication through written messages means that users can take their time in both reading and replying to messages posted by others."

The research team hope that this study will lead to increased recognition about the value of online support for people living with the condition. And whilst the forums should not replace in-person support, they advise that they can provide an additional, cost-effective way to find advice from others who understand what they are going through.

"I am hoping that we can use these findings to further improve the [support](#) available online, and perhaps develop some training and sites that really respond to their needs," Dr. Talbot concluded.

More information: Catherine V Talbot et al, 'I found it the only place that spoke the same language': a thematic analysis of messages posted to an online peer support discussion forum for people living with dementia, *Age and Ageing* (2023). [DOI: 10.1093/ageing/afac330](https://doi.org/10.1093/ageing/afac330)

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