

Dementia study launched within the deaf community

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Researchers have launched a unique project to improve early diagnosis and management of dementia among Deaf people who use British Sign Language (BSL).

The research, funded by Alzheimer's Society, will examine how to identify dementia in Deaf people and explore how they might best cope with their condition. The study will also investigate how to provide support services for the Deaf community and develop assessment tools in BSL.

The University of Manchester team, working with colleagues at UCL (University College London), City University London, and the Royal Association for Deaf people, brings together Deaf and hearing researchers from a range of disciplines, including dementia care, social work, old-age psychiatry, psychology, Deaf studies and Sign Language research.

Lead researcher Professor Alys Young, from the Social Research with Deaf People programme at The University of Manchester, said: "Nobody knows whether Deaf people are more or less likely to experience dementia than hearing people. Our assumptions about what might be valued in care and support are based on hearing people's preferences, not rooted in an understanding of Deaf people's cultural experiences. Information about dementia and related services does not exist in Deaf people's preferred or only language - BSL.

"There are no validated assessment tools in British Sign Language for diagnosis of dementia among Deaf people and using assessments designed for English speakers with an interpreter can lead to misunderstandings; some terms do not mean the same thing to people from different cultures."

The researchers will study normal ageing amongst Deaf signing people with the help of several hundred Deaf people who come together annually for a holiday organised by the English Deaf Darby and Joan Club. The team will also work with Deaf people with a diagnosis of dementia and their carers to explore their experiences of living with the illness, their priorities for care and how to improve early identification and support services.

Professor Bencie Woll, at UCL's Deafness, Cognition and Language research centre, where the BSL assessments will be developed, said: "Early identification of dementia brings many potential benefits, including access to medications, more time for people with dementia and their families to make decisions about care and support and the potential for a better quality of life.

"For Deaf people, the current lack of information in BSL and poor awareness in the Deaf community about dementia, combined with no diagnostic tools in BSL, means early identification is unlikely to happen. This research project aims to resolve that problem."

Professor Jane Marshall, at City University London, added: "The benefits of this project will be felt by Deaf people with dementia, their families and the health professionals who support people with this devastating diagnosis. The project should also add to our general understanding of dementia by studying its manifestations in a previously neglected language and cultural group."

Dr Susanne Sorensen, Head of Research at Alzheimer's Society, said:
"This exciting piece of research will, for the first time, look into the experiences of Deaf people with dementia. A person with dementia may have difficulty communicating and this can become a more complicated problem for Deaf people.

"The fact that many [Deaf people](#) struggle to get a diagnosis of dementia means that they're unable to access treatment that could help relieve some of their symptoms and enable them to remain independent for longer. One million people will develop [dementia](#) in the next 10 years. We must act now."

Provided by University of Manchester

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