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Rare Dementia Support
Advice Community Learning



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THE WORLD'S LARGEST STUDY ABOUT SUPPORT FOR YOUNG ONSET AND RARE DEMENTIA

Are you:

1. Living with a young onset or rare dementia (e.g. Alzheimer's Disease; Fronto-temporal Dementia; Posterior Cortical Atrophy, Dementia with Lewy Bodies; Primary Progressive Aphasia)?
2. Supporting or caring for someone (e.g. relative or friend) living with a young onset or rare dementia?
3. Working with or have a professional interest in people affected by a young onset or rare dementia?
4. 18 years or older?

If you answered yes to the above questions, you are invited to take part in a research study which is running from 2020-2024 and aims to investigate the impact of support groups for people living with a young onset or rare dementia. This is the first major study of its kind and will examine the specific challenges, support needs and care preferences of people affected by a young onset or rare dementia, and the value of a support group such as that run by Professor Sebastian Crutch in the UK (for more information please see www.raredementiasupport.org). The study is a collaboration between University College London (UCL), Bangor University, Wales and Nipissing University, Canada.

Around a quarter of people with dementia have one of the less common forms (listed above). These rare dementias are more common in young people (under 65 years old), who are often still managing work, childcare and a mortgage. The symptoms usually start before the age of 65 but because getting a diagnosis is often slow and difficult, most people do not know they have a rare or young onset dementia until much later. The services available, after diagnosis, sometimes do not meet people's needs.

The research has multiple parts (work packages) which will happen at different times over the five-year period; the major package will involve two-hour interviews and completion of a questionnaire twice a year for the duration of the study, while the other packages will involve either an interview or completion of a questionnaire or creative activity (such as, drawing and poetry), which will last for one-hour. Your participation is completely voluntary and you do not have to participate in all aspects of the study; you can choose to take part in multiple parts of the study or just one if you would prefer.

If you are interested in participating in this study or for more information, please contact the research team at Nipissing University, North Bay, ON Canada:

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