

Collaborative Futures: A Technology Design Approach to Support Positive Experiences in Younger Onset Dementia

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the degree of

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under the supervision of
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Certificate of Original Authorship

I, Jeanette Bell, declare that this thesis is submitted in fulfilment of the requirements for the award of Doctor of Philosophy in Computing Sciences, in the School of Computer Science, Faculty of Engineering and Information Technology, at the University of Technology Sydney.

The thesis is wholly my own work unless otherwise referenced or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

This research is supported by the Australian Government Research Training Program.

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The following is a list of publications arising from my candidature:

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Dedication

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Abstract

Digital technologies are firmly embedded in the day-to-day lives of people living with Younger Onset Dementia (YOD), like their peers who do not live with dementia. This unexpected insight is one of several from this research into the lived experiences of people with YOD and their use of digital technology.

Dementia is complex and multifaceted. It is a term used for a range of symptoms affecting cognition which go beyond memory loss. Essentially, dementia is a state of cognitive decline with a pathology that manifests in sensory changes affecting language, perception, social cognition, sight, smell, and executive decision-making—all dynamics that can make the dementia experience unique to each person.

Younger Onset Dementia (YOD) is a subset of dementia, and an unexpected event in this age group, often resulting in a greater negative impact on their lives. However, most research to date is situated in Late Onset Dementia (LOD). This is problematic as the experiences and circumstances in YOD are vastly different from that of their older counterparts—as is their use and uptake of digital technologies.

In the HCI setting, as in other research sectors (medical, social, disability, and psychiatry), researchers have couched YOD as one homogenous (dementia) group. This has resulted in technologies designed to support people in a later stage of life, and perhaps in more advanced stages of dementia, e.g., surveillance technologies, reminiscence technologies, and assistive technologies. While this work in LOD is vital, the needs and wants of people within the younger group has been largely overlooked.

This HCI research revealed that people with YOD have very different needs and wants. They are being diagnosed when still in employment, and generally in good physical health. They are also highly engaged with digital technology. Furthermore, people with YOD rally for greater inclusion in YOD research activities. However, current methods in dementia research are often not suitable for this younger group who seek agency and independence.

This study is the first working example of Participatory Action Research and Ethnography in YOD. The PAR cycles include a 2-year ethnographic fieldwork with a group of tech savvy people with YOD. This research culminated in a series of recommendations for HCI researchers and designers to consider when working in dementia and other sensitive settings.