

## RESEARCH STUDIES

### 1. What is the name of the study?

Assistive Devices Used to Support Community-dwelling Older Adults with Dementia and their Family Caregivers

### 2. When does the recruitment start and finish?

Recruitment will begin in February. Recruitment will hopefully finish by the end of March, but may carry over into April.

### 3. How is the study being funded?

This study is not funded.

### 4. What is being investigated?

This study will identify and describe the assistive devices being used in the community by older adults with dementia and their family caregivers to support everyday occupations that have been impacted by dementia.

### 5. Why is the study important?

The findings from this study provide will valuable knowledge to occupational therapists and other health care professionals about the assistive devices used by older adults with dementia and their family caregivers to support daily occupations, as well as the factors influencing assistive devices use. The outcomes of this research will also begin to highlight the design requirements of assistive devices for older adults with dementia and their caregivers, and therefore has important implications for engineers in this field. Finally, the methodologies employed in this study are intended to inform a larger, international study in order to gain a broader understanding of the research problem. As such, the focus of this study is on the creation and piloting of methodology to be used in future research.

### 6. Who can participate?

**Family caregivers** who live with a family member with a diagnosis of dementia or related disease, perceive themselves as the primary caregiver and report dependence of the person with dementia in at least two Activities of Daily Living (ADLs) (e.g. dressing, bathing, toileting) or Instrumental Activities of Daily Living (IADLs) (e.g. meal preparation, medication management, driving). Participants must also have access to a telephone (or email) in order to be contacted by the investigator and must live in the Greater Toronto Area.

### 7. Who cannot participate?

Individuals who are not fluent in English or who are unable to provide informed consent will not be able to participate in this study.

### 8. What is required of the participants?

Participants will be asked to take part in a single interview at their home (or another mutually agreed upon location). The interview will take approximately 60 minutes to complete. The researcher will contact the participant by telephone beforehand to explain the study in more detail and to set a mutually agreeable date and time for the interview. With the participant's permission, some of the assistive devices used may be photographed and the interview will be audio-recorded. Participants have the right to refuse audio-recording of the interview and/or having pictures being taken of assistive devices used.

9. What are the potential benefits and limitations of participating?

**Potential Benefits:** Upon completion of the study, each participant will be provided with a pamphlet containing information about the various assistive devices that are available to support the occupations of both themselves, as family caregivers, and their loved ones. This information is useful for the day-to-day lives of both the study participants and those they care for. Participants will also have the option to request copies of any dissemination materials that result from this research.

**Potential Limitations:** There are no socioeconomic or legal ramifications such as stigma, loss of employment, deportation or economic or legal ramifications associated with study participation. However, the methods employed to collect data (an interview at the participant's home) may be seen as more invasive than a traditional paper and pen survey. As well, the information collected is related to a loved one's health condition (dementia) and related impairments, thus it may be at times stressful or anxiety-provoking when thinking about the difficulties this loved one is encountering on a day-to-day basis.

10. Has the study been approved by an ethics committee? (please provide details)

The study has been approved by the University of Toronto Office of Research Ethics, which can be contacted by **telephone: 416-946-3273** or by **email: ethics.review@utoronto**.

11. How large is the study?

This is pilot study meant to inform a larger, international project. As such, there will be 10 participants for the study.

12. Where are the study sites?

The main study site is at the University of Toronto, in the Intelligent Assistive Technology and Systems (IATS) Lab. However, interviews will take place in the community at participants' homes (or another agreed upon location).

13. Where can one obtain more information?

For more information, please contact **Naomi Turcotte**, Occupational Therapy Student, Department of Occupational Science and Occupational Therapy (University of Toronto) via phone: **416-946-8573** or email: **iatsl@utoronto.ca**

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