

## RESEARCH STUDIES

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

The study is named Autobiographical Memory and Alzheimer's Disease and Related Dementias (ADRD).

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

Recruitment is ongoing, until we are able to recruit the target number of research dyads required for the study.

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

The study is funded by The Social Sciences and Humanities Research Council of Canada

### **4. What is being investigated?**

The study will investigate the extent to which the details and emotional quality of autobiographical memories in individuals with ADRD, (compared with older adults without dementia), change over time. The study will also examine whether the quality of autobiographical memories, and changes in these qualities over time influence the ability of the person with ADRD to use these memories as a social tool, i.e. sharing stories to maintain important and intimate relationships in their life.

### **5. Why is the study important?**

While there has been an explosion of research on the etiology, diagnosis, and treatment of Alzheimer Disease and Related Dementias (ADRD) in recent years, comparatively little is known about how ADRD affects ones autobiographical memories. Practically speaking, this gap in research has meant that clinicians have difficulty effectively informing people with Alzheimer's Disease of the changes they can expect in terms of remembering the details and emotions surrounding their memory of important past events. This gap in the literature is indefensible because it is precisely the loss of these memories that individuals with ADRD and their loved-ones often fear most.

### **6. Who can participate?**

Older adults (60+) with early stage dementia and their primary caregiver can participate in the study.

### **7. What is required of the participants?**

Each participant with ADRD will be asked to participate in two interviews, scheduled 4 months apart. Each interview is expected to last at least 2 hours with a built in break. Interviews will be scheduled around individual time preferences and locations.

The primary caregiver will be asked to complete a survey that asks about themselves and the person they care for. This survey will take approximately 30 minutes to complete.

### **8. What are the potential benefits and limitations of participating?**

To the best of our knowledge, participation involves no more risk of harm than one would experience in everyday life. For their time, participants with ADRD will be compensated with \$25 after the second interview session. If the participant should stop participating before the study is over, either during an interview session or before the second interview session, the participant will be paid \$10. The participant with ADRD will also be given the opportunity to receive a transcript of the memory portion of their interview, if they would like.

There is no risk of harm or benefit associated with participation for the primary caregiver.

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

This study has been given ethics approval by The University of North Carolina Wilmington, the University of Toronto Mississauga and Sheridan Institute of Technology and Advanced Learning.

**10. How large is the study?**

The study involves 150 participants in total.

**11. Where are the study sites?**

The study site related to the current request is the Sheridan Elder Research Centre, 1430 Trafalgar Rd. Oakville On; although interviews can be arranged at another location to suite the participants needs.

There is also a second study site at The University of North Carolina Wilmington.

**12. Where can one obtain more information?**

More information can be obtained by contacting:

Research Assistant: Rebecca Hart, 905-845-9430, ext. 8616; [rebecca.hart@sheridaninstitute.ca](mailto:rebecca.hart@sheridaninstitute.ca)

Principle investigator: Professor Kate McLean, 905-569-4956; [kmclean@utm.utoronto.ca](mailto:kmclean@utm.utoronto.ca)

**13. Any additional comments?**

Consent forms and a more detailed summary of the study available upon request.

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