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Informed Consent Form Caring for Cognitively Impaired Family Member in Your Home

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Other Research Team Members: Dr. Laura Funk (University of Manitoba); Dr. Dale Spencer (Carleton University)

Sponsor: Social Sciences and Humanities Research Council

This form gives you the basic idea of what this research is about and what your participation will involve. If you would like more detail or information, just ask. Please read this carefully.

Project Description

“Caring for Cognitively Impaired Family Member in Your Home” We are hoping to collect diaries from 10-15 people who are caring for a cognitively impaired family member who they are living with, about their partners’ changing behaviours. We want to know how family members experience, interpret and respond to their partners’ behavior.

What Participation Involves

To participate, you would be interviewed twice in-person by a trained research interviewer [*provide name*], at a mutually convenient time and quiet location. Each interview will last approximately an hour. The purpose of the first interview is to gather background information about your caregiving experience and answer any questions you have about the diary keeping process. You would then be asked to write 6 weekly diary entries about your experiences. We anticipate that each weekly diary entry will take approximately one hour. The second interview would last approximately 1 hour and focus on understanding your entries. Participation in this study is voluntary. You can stop at any time and are not required to complete all stages of the project.

What will I be asked to do?

First, you would be asked to provide some contextual information such as your age and how long you have been caring for your family member. You will also be asked questions about how your family member’s behavior has changed. We will also provide you with some questions to answer in the weekly diary, to prompt your thinking, although we would ask you to decide and

write about the experiences and feelings that were most important to you that week. You may also choose to draw pictures or include photographs (though try not to include identifying information or photos of people). In the final interview we will explore your diary reflections together.

Confidentiality

Any information gathered in this research will be kept strictly confidential. All information from the interviews and diary will be kept in a secure location (password-protected computer for electronic versions; locked cabinet for hard copies) and authorized access will be restricted to the research team (Dr. Laura Funk, Dr. Rachel Herron, Dr. Dale Spencer and research assistants who have signed a pledge of confidentiality). Any potentially identifying information (e.g., names of persons or places) in interview transcripts and diaries will be deleted or removed (rendering it anonymous) from the documents.

You will not be named or identifiable in any study reports, presentations or publications (i.e., statements you make will be attributed to an anonymous source). Information containing personal identifiers (e.g., this consent form; audio recordings; images that may identify a person) will be deleted or destroyed by July 2020; other files will be destroyed or deleted five years after project completion (July 2023).

Communication of Results

Results from this research will be provided to all participants (see below), as well as shared in presentations at professional meetings, in academic journals, and through possible future press releases and researcher media interviews. Any images that may identify a participant will also not be used in the publication and presentation of results. Your personal confidentiality will be maintained throughout.

Risks and Benefits

Discussing some of your challenging experiences as a caregiver might be upsetting or cause you to feel distressed. It is important to know that you do not have to answer any questions that you do not want to, and you can stop the interview and diary keeping at any time. There may be a short-term benefit of having the opportunity to talk about your experiences. In the long-term, we hope that the information learned from this study will inform policies and programs that better support caregivers of persons with cognitive impairment in Manitoba.

In rare situations where we learn that a person is in immediate danger as a result of abuse or neglect, we must disclose this information to a relevant authority such as the police. When the threat is to a person residing in a health facility, we are legally obligated to do so.

Consent

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in this research project and agree to participate. This does not waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any

time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. You can withdraw by phoning or emailing Dr. Funk. If you do withdraw from the study the information you provided will not be used unless you consent to this at the time of withdrawal. You are also entitled to keep the honorarium you received for participating. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

The University of Manitoba Research Ethics Board(s) and a representative(s) of the University of Manitoba Research Quality Management / Assurance office may also require access to your research records for safety and quality assurance purposes.

This research has been approved by the Psychology/Sociology Research Ethics Board at the University of Manitoba as well as the Brandon University Research Ethics Committee. If you have any concerns or complaints about this project you may contact Dr. Funk or the Human Research Ethics Secretariat (474-7122/humanethics@umanitoba.ca). A copy of this consent form has been given to you to keep for your records and reference.

If you agree to each of the following, please place a check mark in the corresponding box. If you do not agree, leave the box blank:

- I have **read or had read to me** the details of this consent form.
- My **questions** have been addressed.
- I, _____ (print name), **agree to participate** in this study.
- I agree to have the interview **audio-recorded**.
- I agree pictures provided in my diaries may be used in presentation and publication of results as long as they do not contain people or places that could be identified
- I agree to have the findings (which may include quotations) from this project **published or presented** in a manner that does not reveal my identity.

Do you wish to receive a **summary** of the findings? Yes No
How do you wish to receive the summary? E-mail Surface mail

Address: _____

Participant's Signature _____

Date _____

Researcher's Signature _____

Date _____