Caregiver / Care Partner Information and Consent Form

TITLE: Canadian Platform for Research Online to Investigate Health, Quality of Life, Cognition, Behaviour, Function, and Caregiving in Aging (CAN-PROTECT)

SPONSOR: Gordie Howe C.A.R.E.S Foundation

PRINCIPAL INVESTIGATOR: Zahinoor Ismail, MD
Faculty of Medicine, Department of Psychiatry
Tel: 403-210-6900, Fax: 403-210-9665
Email:ismailz@ucalgary.ca

Invitation to take part in the Caregiver / Care Partner sub study

As part of the CAN-PROTECT study, in which you are participating, we are trying to learn about health and stress in persons who care for those with dementia, whether informally as a friend or family member (i.e., care partner), or formally as a paid caregiver. Providing care for persons with dementia can be stressful. Knowledge in this area is lacking. We are interested in exploring caregiver specific experiences as they relate to overall health. The duration of this sub study will be for 20 years, matching the duration of the main study.

Why have I been invited?

You are =18 years of age and participate in the care for a person with dementia, either as a friend or family member, or as a paid caregiver.

What will happen if I take part?

If you decide to take part the following steps will happen:

1. You will be asked to confirm you have read this information sheet and sign the online study consent form on the website.
2. You will then be asked to complete additional questionnaires on the website about caregiver experiences.
3. For informal care partners (i.e., family / friend), you will complete 2 questionnaires; one will be on the experience of stress in being a care partner, and the second will explore what supports and resources you have.
4. For formal (i.e., paid) caregivers, you will complete 2 questionnaires; one will be on experience of stress in caregiving, and the second will ask about caregiving work history and roles, health status, quality of life and function.
5. These additional questionnaires will complement the assessments you have already completed as part of CAN-PROTECT.

Will my taking part in this study be kept confidential?

The responses you provide for the Caregiver / Care Partner Sub Study will be confidential and anonymized, just like the responses you provided to the main CAN-PROTECT questionnaires. Similarly, you can withdraw at any time, as described in the Participant Information Sheet.

What if there is a problem?

If you have a concern about any aspect of this study, information and Frequently Asked Questions are available on the study website www.can-protect.ca. If this does not answer your query you can contact the research team on (403) 210-7737 or email us on CAN.PROTECT@ucalgary.ca.

Further Information

Thank you for taking the time to read the information about this study. If you would like to take part, please register for the study at https://www.canprotectstudy.org/. If you would like more information about the study before you decide whether or not to take part, you can contact a member of the study team by calling the study helpline on (403) 210-7737 or emailing your query to CAN.PROTECT@ucalgary.ca.

If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403- 220-7990.

Consent to Take Part

- I confirm that I have read and understand the information for the study. I have had the opportunity to consider the information, seek clarification and understand my involvement in the study.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
- I understand that I can end my participation as Caregiver / Care Partner in caregiver study without also withdrawing from CAN-PROTECT main study. I have the information that if I withdraw from CAN-PROTECT, I cannot continue in the caregiver study.
- I agree to take part in the Caregiver study. By selecting "I agree," I am electronically signing this consent form.