

Informed Consent Form

Study Name: Caregiver Resilience and Coping Resources

Researchers: Joanna Cheung Kwan Leung: joanche8@my.yorku.ca & Tonino Iafrate: tonino8@my.yorku.ca

Purpose of the Research: There is an increase in informal caregivers and a concern for their overall well-being. Informal caregivers are at increased risk of conditions that may negatively contribute to their overall health leading to caregiver burden. Therefore, the first aim of this study is to add to the knowledge of caregiver social support use by examining the relationship between caregivers' confidence, ability, and resilience when managing caregiving responsibilities and their attitude towards social supports. The second aim is to better understand the concept of resilience in caregivers and to gain insight on how self-efficacy and language as a resource influences coping mechanism and resilience. Ultimately, the result of this research may help service providers improve supports and interventions to increase caregiver support resources such as personal skills and abilities and support networks.

What You Will Be Asked to Do in the Research: Complete questionnaires through one of three methods: online, mail-in paper form, or interview using paper form. The approximate time it may take to complete the questionnaires is 30 minutes. *Note: Participants may have another person help them complete the questionnaires by reading questions or filling in participants' responses.

Risks and Discomforts: We do not foresee any risks or discomfort from your participation in the research. In the event that you experience discomfort or distress while answering questions, you can choose to refrain from answering those questions.

Benefits of the Research and Benefits to You: The results of the study may help caregivers gain knowledge on how to fully utilize and manage their intrapersonal resources, such as self-efficacy and language, to increase coping mechanism and resilience and handle caregiver burden more proficiently. Also, caregivers will gain insight on their attitudes towards the process of considering informal/formal caregiver supports. Furthermore, the research will provide resources to policy makers and service providers to create and improve community services and supports that are available to caregivers.

Voluntary Participation: Your participation in the study is completely voluntary and you may choose to stop participating at any time. Your decision not to volunteer will not influence the nature of the ongoing relationship you may have with caregiver associations or groups and/or any program you are enrolled in with York University either now, or in the future.

Withdrawal from the Study: You can stop participating in the study at any time, for any reason, if you so decide. If you decide to stop participating, you will still be eligible to receive the promised remuneration, if any, for agreeing to be in the project. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with the researchers, York University, or any other group associated with this project. In the event you withdraw from the study, all associated data collected will be immediately destroyed wherever possible.

Confidentiality: All information you supply during the research will be held in confidence and your name will not appear in any report or publication of the research. Data will be collected electronically through online questionnaire or by paper copy through mail-in questionnaire or by interviewer through in person interview. Do not put your name on any of the documents that we provide to you with the exception of this Informed Consent Form (ICF). This form will be kept separate from any other material that you are given so that we will never be able to identify who completed what tests etc. Your data will be safely stored in a locked facility or digital data will be encrypted and password protected and only research staff will have access to this information. If this study includes observational data collection- the researchers will never disclose the name of the participant associated with any such obtained data. Data in paper form will be stored in a locked cabinet and digital data will be encrypted and password protected. Both will be kept for a period of seven years and then archived. Confidentiality will be provided to the fullest extent possible by law.

Questions About the Research? If you have questions about the research in general or about your role in the study, please feel free to contact Dr. Ed Haltrecht either by telephone at (416) 736-2100, extension 66178 or by e-mail (haltrech@yorku.ca) This research has been reviewed and approved by the Human Participants Review Sub-

Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact the Sr. Manager & Policy Advisor for the Office of Research Ethics, 5th Floor, York Research Tower, York University (telephone 416-736-5914 or e-mail ore@yorku.ca).

Legal Rights and Signatures:

I (fill in your name here), consent to participate in *Caregiver Resilience and Coping Resources Study* conducted by *Joanna Cheung Kwan Leung* and *Tonino Iafrate*. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

Signature _____
Participant

Date _____

Signature _____
Principal Investigator

Date _____