

Caring Ahead: Preparing for End-of-Life in Dementia Study

What is this study for?

1. To understand what information, support and planning family/friend caregivers have (or need) to feel more prepared for end-of-life
2. To evaluate a questionnaire called Caring Ahead designed by family caregivers and researchers at McMaster University
3. To guide the design and evaluate the effectiveness of palliative care strategies like Goals of Care Conversations, *in the future*

Why is helping family caregivers prepare for end-of-life important?

- More than 50% of CGs feel unprepared
- 2x less likely to experience intense debilitating grief, depression and anxiety
- Higher satisfaction with care, improved quality of dying, care aligned with values

What does the study involve?

- Family/friend caregivers of a person currently living with dementia in long-term care are needed to complete the 15-minute, self-administered, paper questionnaire by postal mail
- More than one person in a family can participate (e.g., spouse and child)
- Study will be running until April 2020 or until 200 persons are reached

How can I help?

- ⇒ Please spread the word about the study (e.g., allow us to post a flyer, add to newsletter)
- ⇒ Consider having a staff person contact families to see if they are interested in participating Research funding available to reimburse staff wages

For more information please contact:

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This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB), project #4503. If you have any questions about your rights as a research participant, please call the Office of the Chair, Hamilton Integrated Research Ethics Board at 905.521.2100 x 42013.

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