

PARTICIPANT INFORMATION SHEET

Title of Study: Caring Ahead: Development of a Questionnaire to Measure Preparedness for End-of-Life in Family Caregivers of Persons with Dementia

Student Investigator: Pamela Durepos, RN, PhD Student, School of Nursing, Faculty of Health Sciences, McMaster University

Principal Investigator: Dr. Sharon Kaasalainen, RN, PhD, Professor, School of Nursing, Faculty of Health Sciences, McMaster University

You are being invited to participate in a research study conducted by Ms. Pamela Durepos because you have experience providing care to a family member or friend with dementia. This is a student research project conducted under the supervision of Dr. Sharon Kaasalainen at McMaster University. This study will help the student learn more about how family and friend caregivers prepare and cope with the end of the person with dementia's life. The student will also develop skills in research design, collection and analysis of data, and writing a research paper.

In order to decide whether or not you want to be a part of this research study, you should understand what is involved and the potential risks and benefits. This form gives detailed information about the research study, which will be discussed with you.

WHY IS THIS RESEARCH BEING DONE?

Often family caregivers of people with dementia do not feel prepared for the loss of their family member or friend. This can affect their ability to adjust and cope for a long time after the death has occurred. Advance Care Planning may help caregivers to feel more prepared, but we currently do not have a questionnaire to measure what information and support family caregivers have, and if planning is effective at helping caregivers feel more ready for loss.

WHAT IS THE PURPOSE OF THIS STUDY?

The purpose of this study is to learn about the needs of family or friend caregivers preparing for end-of-life in dementia. Family caregivers together with researchers have developed a questionnaire titled 'Caring Ahead' which aims to measure how prepared caregivers feel for the loss of their family member with dementia in different areas (e.g., practical, spiritual, medical). In the future, the questionnaire will be used to identify caregivers who need support in preparing for end-of-life, and highlight the areas where support is needed most. The questionnaire will help us to understand if Palliative Care and Advance Care Planning are helping caregivers feel prepared for death, or if new practices are needed to meet their nee

WHAT WILL MY RESPONSIBILITIES BE IF I TAKE PART IN THE STUDY?

If you volunteer to participate in this study, we will ask you to complete 1 copy of the 'Caring Ahead questionnaire. Participants receive the questionnaire by mail, and return it to the student researcher Pam Durepos in a postage paid envelope. More than 1 family member can also complete a questionnaire so please contact us if anyone else in your family would like to participate.

The questionnaire will take approximately 15 minutes to complete. The questionnaire will ask you to rate how strongly you agree or disagree with 31 statements about preparing for the loss of your family member or friend (e.g., funeral planning, having difficult conversations, understanding your family member's health). You will also be asked to complete a short questionnaire about your age, gender and demographics.

WHAT ARE THE POSSIBLE BENEFITS FOR ME AND/OR FOR SOCIETY?

By participating in this study, you may benefit by becoming more aware of your own feelings and preparations for the loss of your family or friend. The questionnaire may help you reflect on plans, conversations or actions you want to take. Your participation will help us understand if the questionnaire includes appropriate statements to measure preparedness. If the questionnaire is accurate, it will help us design more effective supports to help family caregivers.

The findings of this study will be shared in Canada and internationally through research journal publications, conference presentations, public seminars and workshops with long-term care homes. Results may also be posted on websites such as the Alzheimer Society of Canada. The questionnaire 'Caring Ahead' will be available for use after testing by researchers, nurses and others throughout the world that are working to help family caregivers in dementia, and potentially in other diseases.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

Completing the questionnaire and thinking about the death of your family member or friend may be difficult. You may experience feelings of sadness or grief. Your questionnaire will not be shared with health care providers, therefore we encourage you to reach out to family, friends and professionals (e.g., your family doctor) for support and help with grief. The researchers are also available to help connect you to resources.

If you complete and return the questionnaire you are giving your consent to participate in this study. Participation in this study is completely voluntary and you may choose not to participate. All questions are also voluntary and you may choose not to answer or to withdraw from this study at any time. Any decision not to participate or to withdraw from the study will have no impact on your relationships or care. Information about grief and supportive services (e.g., counselors, support groups) is included with the questionnaire.

WHAT INFORMATION WILL BE KEPT PRIVATE?

Your data will not be shared with anyone except with your consent or as required by law. All of the information you share in the questionnaires is confidential. Only members of the research team will have access to your information. Your identity will be protected by replacing your name and any identifying information with a code, known only to the research team. All information will be kept in a locked cabinet, stored in password protected, encrypted files.

For the purposes of ensuring the proper monitoring of the research study, it is possible that a member of the Hamilton Integrated Research Ethics Board, may consult your research data. By returning the questionnaire, you authorize such access.

If the results of the study are published, your name will not be used and no information that discloses your identity will be released or published without your specific consent to the disclosure. All information that is gathered in this study will be kept confidential. You will not be identified in any published results of the study. All information that you give will be kept in a locked cabinet at McMaster University for up to 7 years, after which it will be destroyed. Only members of the research team will have access to the information.

CAN PARTICIPATION IN THE STUDY END EARLY?

If you volunteer to be in this study, you may withdraw at any time and this will in no way affect you. You have the option to withdraw from the study or remove your data from the study, by contacting Pamela Durepos at 905-484-3546, lapospm@mcmaster.ca. You may also refuse to answer any questions you don't want to answer and still remain in the study.

HOW MANY PEOPLE WILL BE IN THIS STUDY?

Initially we interviewed 16 bereaved family caregivers and then surveyed 17 caregivers and professionals to create the questionnaire. In this last phase of the study we will recruit over 200 current family caregivers to test the questionnaire.

WILL I BE PAID TO PARTICIPATE IN THIS STUDY?

Participants will not receive any payment.

IMPLIED CONSENT STATEMENT

By returning this survey, you are agreeing to have your confidential responses used for research purposes. Your responses to the survey will help the research team learn more about the information and support that family caregivers have or need to feel more prepared for end-of-life.

Should you have any questions about this study or if anyone else in your family would like to complete a questionnaire as well, please don't hesitate to contact:

Pamela Durepos, RN, PhD Student
lapospm@mcmaster.ca or caringahead@gmail.com
905-484-3546 or 1-833-998-1280
www.caringahead.com

Dr. Sharon Kaasalainen, School of Nursing, McMaster University
kaasal@mcmaster.ca
(905) 525-9140 extension 22291.

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). The HIREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. 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

Questionnaire Instructions and Study Results

Thank you for agreeing to participate in this study. The questionnaire statements are very sensitive and may bring up difficult emotions. Please take your time and reach out for support if needed.

In this questionnaire, 'end-of-life' refers to the last stage of someone's life (approximately one year) and death. On the questionnaire, please select one number indicating how much you agree or disagree with each statement.

Study results will be posted on www.caringahead.com.

If you would like a copy of the study results sent to you, please write your email or mailing address here: _____

Thank you again, Sincerely, Pam Durepos

Date: _____

Date: _____

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

1.

Medical Preparations	Strongly Disagree	Strongly Agree
1. I believe I understand my family member's current health status.	1 2 3 4 5 6 7	
2. I believe I know what changes to expect as dementia advances, for example: swallowing, eating difficulties.	1 2 3 4 5 6 7	
3. I understand I may be faced with decisions such as: transferring to hospital, treating infections.	1 2 3 4 5 6 7	
4. I believe I know what treatments my family member would choose.	1 2 3 4 5 6 7	
5. I have shared my family member's wishes with health care providers, for example: focusing on living longer, maximizing comfort.	1 2 3 4 5 6 7	
6. Health care providers and I have discussed our end-of-life care preferences for my family member, for example: location, pain management.	1 2 3 4 5 6 7	
7. I have discussed end-of-life care preferences with the important people in my family member's life, for example: friends, family.	1 2 3 4 5 6 7	
8. I have learned what the dying process may be like for my family member.	1 2 3 4 5 6 7	

Date: _____

9. I understand that dementia (and Alzheimer's) is a condition that leads to death.	1	2	3	4	5	6	7
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Relationships and Personal Preparations	Strongly Disagree Strongly Agree						
10. I believe I can carry out my responsibilities, for example: decision-maker, companion, advocate.	1	2	3	4	5	6	7
11. I would like to be more involved in planning care with health care providers.	1	2	3	4	5	6	7
12. I accept that I am doing my best for my family member.	1	2	3	4	5	6	7
13. I have someone to go to for emotional support about my family member's health.	1	2	3	4	5	6	7
14. I understand what my grief process may be like after my family member has died.	1	2	3	4	5	6	7
15. I worry that disagreements will make my family member's death more difficult, for example: with family, friends, health care providers.	1	2	3	4	5	6	7
16. I am making the most of my time with my family member, for example: by saying what I need to say to them.	1	2	3	4	5	6	7
17. I am helping my family member with activities they would want near end-of-life, for example: seeing old friends.	1	2	3	4	5	6	7
18. I am spending time reflecting on my family member's life, for example: by sharing stories.	1	2	3	4	5	6	7

Spiritual Preparations	Strongly Disagree Strongly Agree
19. I have a plan to honour traditions or practices my family member would want, for example: personal, cultural, spiritual, religious.	1 2 3 4 5 6 7
20. I have discussed our family's practices or traditions with health care providers, for example: privacy, prayers, opening a window.	1 2 3 4 5 6 7
21. I have someone I can talk to about the meaning of illness or dying.	1 2 3 4 5 6 7
22. I worry about having purpose in my life after my family member has died.	1 2 3 4 5 6 7
23. I am practicing activities which give me strength such as: spending time in nature.	1 2 3 4 5 6 7

Practical Preparations		Strongly Disagree				Strongly Agree		
24.	My family member's affairs are in order, for example: decision-maker, will, banking, credit cards, insurance.	1	2	3	4	5	6	7
25.	I have someone I can contact if I need help managing my family member's affairs.	1	2	3	4	5	6	7
26.	I know how to notify family and friends when my family member dies.	1	2	3	4	5	6	7
27.	After-death services are arranged for my family member such as: burial or cremation.	1	2	3	4	5	6	7
28.	I believe I can manage my personal affairs after my family member has died, for example: finances, housing.	1	2	3	4	5	6	7
29.	I am aware of after-death policies I will need to follow, for example: moving belongings in long-term care.	1	2	3	4	5	6	7
30.	I am thinking about memorials appropriate for our family such as: gathering, funeral, celebration, private time.	1	2	3	4	5	6	7

Overall Preparedness		Not Prepared At All				Prepared As Much As Possible		
31.	*If your loved one were to die soon, how prepared would you be for his/her death?	1	2	3	4	5	6	7

*Re-printed with permission of the authors, Schulz, R., Boerner, K., Klinger, J., & Rosen, J. (2015). Preparedness for death and adjustment to bereavement among caregivers of recently placed nursing home residents. *Journal of Palliative Medicine*, 18(2), 127-1

Caring Ahead: Demographics

Please complete the following questions by placing a 'check-mark' in boxes or filling in the blanks.

1. What is your age (in years)? _____

2. What is your gender identity?

☐ Male

☐ Female

☐ Other

☐ Prefer not to say

3. What is your highest level of education?

☐ Less than
High School

☐ College /
University

☐ Other

☐ High School

☐ Graduate School

4. What is your annual household income?

☐ Less than 50,000

☐ 101-150,000

☐ 51-100,000

☐ Greater than 151,000

☐ Prefer not to say

5. What is your ethnic origin (other than Canadian)? (e.g., British, South Asian)

6. Are you a member of a visible minority? (e.g., Black, Hispanic)

☐ Yes, if so what minority?

☐ No

7. Do you have a religious or spiritual affiliation? (e.g., Christian, Agnostic, Muslim)

- ☐ Yes, if so what is your affiliation? ☐ No

8. What is your relationship to the family member/friend you provide care for?

- ☐ Spouse / Partner ☐ Other, Please Explain (e.g., daughter-in-law)

- ☐ Adult Child of the Person with Dementia

9. What is the age of your family member/friend (in years)? _____

10. What is the gender identity of your family member/friend?

- ☐ Male ☐ Female
☐ Other ☐ Prefer not to say

11. Does your family member have a religious or spiritual affiliation? (e.g., Christian, Agnostic, Muslim)

- ☐ Yes, if so what is their affiliation? ☐ No

12. How long has your family member/friend had dementia (in years)? _____

13. What type of dementia does your family member/friend have?

- | | | |
|--|--|--|
| <input type="checkbox"/> Alzheimer's | <input type="checkbox"/> Lewy Body | <input type="checkbox"/> Korsakoff's |
| <input type="checkbox"/> Vascular / Stroke | <input type="checkbox"/> Fronto-Temporal | <input type="checkbox"/> Unknown/ Unsure |
| <input type="checkbox"/> Mixed | <input type="checkbox"/> Other, Please explain | |

14. How long has your family member/friend lived in a care facility (in years)? _____

15. What city and province / territory is the care facility located in? _____

Thank You for Completing and Returning the Questionnaire

The results of your questionnaire will not be shared with anyone outside of the research team. If you have questions or concerns about support or preparing for your family member's end-of-life, please reach out to a health care provider and the Director of Care / Administrator at your family member's care facility.

Support for Coping with Grief, Stress and Care Planning

Caring for someone with dementia and thinking about end of life can be difficult. Please consider reaching out to a health care provider or fellow caregiver (e.g., physician, nurse, social worker, Family Council, Director of Care/Home Administrator in the care facility) and/or services for support:

Alzheimer Society (multiple branches)	'Dementia in the Later Stages Class', information, free counselling, support	https://alzheimer.ca/ 1-800-616-8816
Crisis Services Canada	Free counselling	www.crisisservicescanada.ca 1-833-456-4566 (24-7) Text 45645 (4pm-12am)
Center for Loss and Life Transition	Information	www.centerforloss.com
Canadian Mental Health Association	Free counselling	https://cmhanl.ca Toll free 1-888-737-4668
Speak Up	Free advance care planning resources for families	http://www.advancecareplanning.ca/ 1-800-349-3111 ext 31

Recommended Reading

Understanding Your Grief: Ten Essential Touchstones for Finding Hope and Healing Your Heart by Alan D. Wolfelt, PH.D.