



Bereaved Family Member Information Sheet

Title of the Study: Strengthening a Palliative Approach to Care (SPA-LTC) in New Brunswick's Long-Term Care Homes: Phase 2

Principal Investigators:

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Summary

You are being invited to take part in this study because your family member or friend lived in a nursing home in New Brunswick and passed away on or after January 1, 2022. Please read this sheet to help you decide if you want to participate in the study and complete a survey about your experience. It explains the activities, risks, and benefits.

Why is this study being done?

The Strengthening a Palliative Approach in Long Term Care SPA-LTC is a program being introduced in New Brunswick. The goal is to make sure residents and their families get good palliative care that focuses on their quality of life from admission until after they pass away. Family and friends are part of the care team but we do not know what they think about the care their loved one received at the end of life.

What is the purpose of the study?

This study aims to learn about family and friends' experiences and satisfaction with end of life care in nursing homes in New Brunswick. It will help us see if the new SPA-LTC program improves care over time.

What will I have to do if I join the study?

If you join you will complete an **anonymous online survey** that takes about **20 to 30 minutes**.

If you would prefer to complete the survey on **paper or by telephone** please call **1-833-777-6135** (toll-free). Leave your name and phone number and we will call you back.

At the end of the survey, you will have the choice to say if you are interested in participating in an optional telephone interview. Only a few people will be contacted for interviews.

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Are there any risks?

Thinking about the care your family member or friend received at the end of life might bring up sad feelings. You do not have to answer any question you do not want to and you can stop the survey at any time. If you want you can withdraw from the study. We will give you a list of free counseling services if you need support.

What are the benefits?

Sharing your experience might help you feel better. It could also help improve care for future residents and their families.

Will my information be kept private?

Your information will be private. The survey is anonymous so you won't have to give your name unless you want to be in an interview or entered into a draw for a gift card. In these cases you will need to give your first name and email. If you share your contact information we will use a Study ID Code to remove your name from the survey.

The survey will be done online using LimeSurvey which is safe and secure. All electronic data will be stored on a secure server at the University of New Brunswick. If you decide to also participate in an interview it will be recorded but the recording will be deleted after it is written down transcribed. All identifying details will be removed from the transcript.

Your information won't be shared outside the research team without your permission. All data will be destroyed seven years after the study ends. When we share the results with nursing homes all the data will be combined and your name will not be mentioned.

How many people will be in this study?

We hope that 100 family members or friends will complete the survey and that 10 people will do interviews.

Will I get paid?

If you finish the survey and give contact information you will be entered into a draw for a \$100 dollar grocery gift card. If you do an interview you will get a \$25 dollar grocery gift card.

Can I leave the study early?

Yes, participation is voluntary. You can leave at any time by emailing or calling the Research Assistant. If you leave by July 1, 2025 we can remove your data. After that your data will be combined with others and cannot be removed. We can however destroy any copies of your specific information.



How do I join?

To join click on the survey link provided to you or at the end of this document. You will be asked if you want to participate. If you select “yes” you can complete and submit the survey.

How will I know the results?

A summary of the study results will be emailed to you and published in a New Brunswick SPA-LTC newsletter by Summer 2025. The results will also be published in academic journals and presented at conferences but no identifying information will be shared without your permission.

What is informed consent?

If you do an interview we will ask you to sign a consent form. Informed consent means that we give you detailed information about the study including risks and benefits and answer all your questions. You can then decide if you want to participate.

What is implied consent?

Implied consent means that by completing and submitting your survey you are giving your consent to be in the study

If you have any questions about this study please contact,

Rachel MacLean, RN, MN(c)

SPA-LTC Research Assistant (focus on Families)

Spa-ltc@unb.ca

Toll free number (Dr. Pam Durepos) **1-833-777-6135**

This study has been reviewed by the University of New Brunswick Research Ethics Board (File # REB 2024-164) and the Université de Moncton Research Ethics Board (File # 2025-027). If you have any questions about this study, please contact Daphne Noonan at dnoonan@unb.ca, or Caroline Gibbons PhD at caroline.gibbons@umoncton.ca. You may also contact Dr. David Coleman, Chair of the UNB Research Ethics Board, at ethics@unb.ca, or the Office of Research at the Université de Moncton at fesr@umoncton.ca or (506) 858-4310.

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Implied Consent Statement for Survey

Thank you for considering participating in this survey. By completing this survey, you are giving your implied consent to participate in the study. This means that you understand and agree to the following:

- The survey is designed to collect information about your experiences with end-of-life care in nursing homes, in order to understand and improve the quality of that care.
- Participation in this survey is completely voluntary. You may choose not to participate or withdraw at any time without penalty or loss of benefits to which you are entitled.
- All responses will remain anonymous. Your identity will not be revealed in any publications or reports related to this study.
- The survey will take approximately 30 minutes to complete.
- Although you will not receive any direct benefit, your responses will contribute to improving end-of-life care for future nursing home residents.
- Reading the survey questions and thinking about end-of-life may trigger feelings such as grief and sadness. A list of support services is provided. Please do not hesitate to ask for help if needed.

Informed Consent Statement (during interviews only)

- I have read the information sheet and have been given the opportunity to have all my questions about the study answered.
- As a participant, I agree to participate in an interview by videoconference or telephone with a Research Assistant that will be recorded.
- I consent to participate in this study.
- If I provide my email address or contact information in the survey I consent to receive email or telephone communication from members of the research team regarding this study.
- I provide consent for my organization to participate in this study.
- I understand that the information collected is kept strictly confidential. I understand that I am free to withdraw from this study at any time if I wish.

Signature of participant

Date

Name of participant (please print)

I certify that I have explained the study and my participation in this research to the person signing. I certify that I have answered the questions asked about the project and that I have

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made it clear to this person that they are free to withdraw from this study if they wish. A copy of this signed consent will be provided to the individual.

Signature of research team member

Date

Name of research team member (please print)