

Informed Consent Form

Title of Study: *In-Home Dementia-Centered DIY Adaptations and Innovations*

Principal Investigator: Glen Hougan,
Division of Design, NSCAD University

Contact: ghougan@nscad.ca

Funding: Alzheimers Canada, Brain Canada

Project team: Dalhousie University -

Dr Elaine Moody (Nursing), Dr. Olga Theou
(Health), Dr. David Roach (Business), Dr.

Clifton Johnston (Engineering).

An Invitation to Participate

You are invited to take part in a project study about **do-it-yourself (DIY) home adaptations** created by people living with dementia and their caregivers. This form explains the study and what your participation would involve. Please read it carefully before you decide to join

Purpose of the Study

We want to learn about the creative ways people living with dementia and their caregivers adapt their homes to make daily life easier, safer, or more comfortable. Your insights will help us understand the real-world challenges people face and highlight clever, practical solutions.

What Participation Involves

If you choose to participate, you would be asked to:

- **Share your DIY home adaptations with us.** You can do this by describing them in writing and/or sending photos through a secure online form or by email. You can submit as many examples as you like until the study concludes in May 2027.
- **Potentially have a follow-up conversation.** A member of our research team might contact you by phone or email to ask for more details about your submission. This helps us fully understand your solution.

Benefits of this research

- Your ideas may help other people living with dementia and caregivers.
- The project will help improve design and support for people with dementia.
- Outcomes of what the team learned will be available on SMU website in August 2026.

Ownership of your Ideas

The ideas and adaptations you share remain yours. We will not share your specific submission outside of the confidential research team without seeking your explicit permission again in the future. If an adaptation you share appears to be particularly unique

or have potential for further development, we will contact you directly to discuss options for protecting your idea.

Voluntary Participation

Taking part is your choice. You may stop at any time, for any reason, without consequences or you may also ask us to delete your adaptation submission at any time. There would be no anticipated risks involved with your participation and we will blur or remove any personal details in your submissions. By agreeing to participate, people are not giving up any legal rights in the event of research-related harm. Also during the conduct of the project we are required to report anything illegal.

Confidentiality

- Your submission information will be kept confidential and we will use coded names
- Your submitted adaptation will be stored securely and deleted from our data base after 5 years.

The Saint Mary's University Research Ethics Board has reviewed this research with the guidance of the TCPS 2 based on three core principles: Respect for Persons, Concern for Welfare and Justice. If you have any questions or concerns at any time about ethical matters or would like to discuss your rights as a research participant, please contact ethics@smu.ca or 902-420-5728.

Consent

- ☐ I agree to share photos and/or written descriptions of my home adaptations with the research team.
- ☐ I agree that the research team may evaluate and analyze my submissions.
- ☐ I agree to be contacted by the research team for follow-up questions to clarify my submissions.
- ☐ I agree to be contacted in the future with information about the project's progress or findings. (Optional)

Name (print): _____

Signature: _____

Date: _____

For participants needing support:

This section is to be completed only if the participant who developed the adaptations is unable to provide informed consent themselves.

Substitute decision maker consent

I confirm that I am the authorized substitute decision-maker for the participant named below. I have read this form and understand the study's purpose. I am making this decision based on the participant's best interests.

- ☐ I, on behalf of the participant, agree for them to take part in this project.
- ☐ I agree to the use of photos and/or written descriptions as described.
- ☐ I agree that the research team may analyze these submissions.
- ☐ I agree that the research team may contact me for follow-up questions around conditions of gauging the participants willingness to take part.

Participant's name (print): _____

Substitute decision maker name (print): _____

Substitute decision maker Signature: _____ **Date:** _____

Relationship to participant: _____