

You are invited to participate in a research study that examines

Shared Decision-Making about Living Well with Dementia to the End of Life



Information about a research study



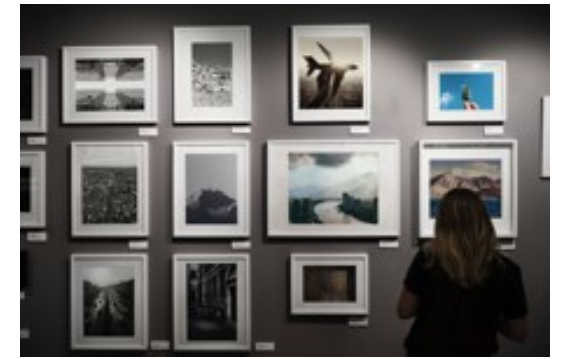
Interviews

- One 1-hour interview at a place of your choosing.
- You may choose to be interviewed with your care partner.
- You will be asked about living well to the end of life and health & social care decision-making.



Art-Making Workshop

- One 4-hour art-making workshop.
- No experience needed.
- The kind of art you make is your choice and a professional artist will help you if you want.
- Starts with a group discussion on living well to the end of life.
- Refreshments provided.
- One 30-minute follow-up conversation about your experiences in the workshop.



Arts Exhibition

- If you want, your artwork will be shown at an exhibition.
- If you want, an artist will help you decide the best way to display your art.
- A gala event with you, friends and family, care providers, researchers, and the public.

- With your permission, the interview and workshop will be audio or video recorded and the exhibition photographed.
- With your permission, your artwork will be photographed for display in a photobook and other study materials.
- We will cover the cost of art supplies and exhibiting your work. We will also cover any cost for parking or transit.

Who is conducting the study?

Primary Investigator:

Dr. Susan Cox
W. Maurice Young Centre for
Applied Ethics
University of British Columbia
(UBC)

Co-Investigators:

Dr. Gloria Puurveen (UBC),
Dr. Alison Phinney (UBC),
Dr. Deborah O'Connor (UBC),
Dr. Carol Ann Courneya (UBC)
Dr. Lee Burnside (University
of Washington),
Dr. Vikki Entwistle (National
University of Singapore)

Who should I contact if I have any questions?

Dr. Gloria Puurveen
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Risks to you for participating

- Talking about living well with dementia to the end of life might be difficult.
- You may get tired during the interview or art workshop.
- You might feel a little nervous about participating in a group activity and making art.
- Others might know you in the workshop or art exhibition.

Benefits to you for participating

- It might be rewarding to share your thoughts and feelings about living well with dementia to the end of life.
- You may find the art workshop and art exhibition enjoyable.
- Your contribution will help build awareness about living with dementia.
- There may not be other direct benefits to you.

Lessening the risk

- You can decide how much you want to share.
- You do not have to answer any questions you don't want to.
- You can take a break or continue the activity on a different day.
- You may choose which activities to participate in.
- You can withdraw completely from the study.
- Your name or other identifiers will not be shared.
- Photographs or video will not be shown to anyone without your

How will results be shared

- We will write a report and make a photobook of the artwork created and share it with you.
- We will hold public events to share the results.
- We will present results at conferences and publish them in journals.

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