

Canadian Longitudinal Study on Aging

Information Page for Proxy Decision Maker

What is the purpose of the CLSA?

The CLSA is a Canada-wide study that looks at health and aging over a 20-year period. People who are between the ages of 45 to 85 are being invited to take part. We will collect a wide range of information about people's health as they age, such as physical, emotional and social health and functioning, as well as the onset of health conditions and diseases. The information collected as part of the CLSA will be used by many researchers over the next four to five decades.

What is the purpose of a proxy decision maker?

With a longitudinal study there may come a time when a participant is not able to make decisions or take part in the study due to health reasons. Because of this, participants over 70 years of age are asked to provide the name of a proxy decision maker. They are also asked to express their wishes about how they would like to be involved in the CLSA if they become unable, for any reason, to take part on their own.

What is a proxy decision maker?

- A proxy decision maker is someone who makes decisions on the participant's behalf
- A proxy decision maker can be a person who has been named to look after a participant's affairs, such as a power of attorney.
- If a participant doesn't have such a person named already they may want to name a person, such as their spouse, adult child or care-giver to make decisions for them about participating the CLSA.

What is the role of the proxy decision maker?

As the proxy decision maker for the participant, you will be asked to make decisions
about participating in CLSA on the participant's behalf. This includes whether or
not the participant will remain in the study and how the participant will continue to
participate.

Is there any guidance for me as a proxy decision maker for the participant?



- The Proxy Consent that the participant signed provides direction as to what their
 wishes are if they are no longer able to make their own decisions with regard to the
 CLSA.
- The participant may also have discussed their wishes for future participation in the study with you at the time that they designated you as their proxy decision maker.
- This document is available to you and will inform you as to the participant's wishes at that time.

How can I get more information about the CLSA?

- You can choose to be sent regular updates about the study progress through electronic or mailed newsletters.
- Information about ongoing research, the research team, and general study results will be posted on the CLSA website (<u>www.clsa-elcv.ca</u>).

How do I contact the CLSA?

Any time you have questions about the study you may write, call the CLSA toll-free number or send us an e-mail message:

For Residents of British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, New Brunswick, Prince Edward Island, or Nova Scotia PLEASE CALL:

Toll-free: 1-866-999-8303
French and English
e-mail: info@clsa-elcv.ca
mailing address:
McMaster University-CLSA
1280 Main Street West

Hamilton ON L8S 4K1

For Residents of Newfoundland or Labrador PLEASE CALL:

English Toll-free: 1-888-908-4988 French Toll-free: 1-866-999-8303

(Dr. Gerry Mugford, Site Investigator, Memorial University)

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