

PARTICIPANT INFORMATION PACKAGE FOR PROXY DECISION MAKER AND INFORMATION PROVIDER CONTACT

Title: Canadian Longitudinal Study on Aging (CLSA)

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Why am I being asked to make choices for my future involvement in the CLSA now?

- As a research study about health and aging it is important that we are able to follow the changes that happen as you age.
- There may come a time when you are not able to make decisions or take part in the study for yourself because of health reasons.
- While it may be difficult to think about this now, we would like you to consider how you would like to take part in the CLSA in the future, should this occur.
- Expressing your wishes now will help those close to you know how you
 would like to be involved in the CLSA if you become unable, for any
 reason, to take part on your own.

1. Who can make decisions on my behalf?

- It is possible for another person, known as a "proxy decision maker", to act on your behalf if you are no longer able to make decisions for yourself in the future.
- If you have already named a person to look after your affairs, such as a
 power of attorney, this person would also be your proxy decision maker for
 the CLSA.
- If you don't have such a person named, we would like you to think of a person who could make decisions for you about the CLSA. This could be your spouse, adult child or care-giver.



How will my proxy decision maker know what I would like to happen if I am no longer able to take part in the CLSA for myself?

- You can give direction to your proxy decision maker now about what you would like to have happen in the future.
- Your signed consent indicating your wishes will be given to your proxy decision maker at the time they are contacted.

2. What if my proxy decision maker isn't the best person to answer questions about me?

- While your proxy decision maker may be the best person to make <u>decisions</u> on your behalf, they may not be the best person to answer questions about your health and well-being.
- If this is the case, we would like you to think of the best person to answer questions about you on your behalf i.e., someone who knows you well or sees you often, such as a family member, friend or caregiver. This person is called your "proxy information provider."

3. What will I be asked to do if I agree to give the name of a proxy decision maker and proxy information provider?

You will be asked to:

- Discuss with the person(s) about acting on your behalf.
- Sign a consent form that says the CLSA can contact the person(s) about acting as your proxy decision maker or proxy information provider if it becomes necessary in the future.
- Give the CLSA the person's name(s), phone number(s), and address(es).



What if I change my mind about who I want as my proxy decision maker or proxy information provider?

- You may change your proxy decision maker or proxy information provider at any time.
- Each time we contact you, we will ask you to confirm the person(s) you named as your proxy decision maker and proxy information provider.
- You may also let the CLSA know if you want to change your proxy decision maker or proxy information provider at any time by telephone, regular post, or e-mail.



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, Manitoba, Ontario, Quebec 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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