

Société Alzheimer Society

C A N A D A

DEMENTIA JOURNEY SURVEY

LIVING WITH DEMENTIA EXPERIENCE

You have been invited to participate in this study by the **Alzheimer Society of Canada** & the **College of Family Physicians of Canada** as you are either a person living with dementia or you are supporting someone with dementia in taking this survey.

*If you are a caregiver helping someone with dementia to complete this survey **you must respond from their perspective.***

*If you would like to complete this survey from your perspective, complete the **Caregiver Experience** survey as well.*

While the questions do not directly relate to the COVID-19 pandemic, you are welcome to share experiences that relate to the pandemic.

The **Alzheimer Society of Canada** wants to understand your experiences of dementia care and your interactions with your family doctor or other healthcare provider.

Your feedback will help us learn what healthcare professionals are doing well, as well as how we can improve care for people living with dementia.

The survey will take **around 5 minutes** to complete.

Please read through the information pages and the consent form that follow carefully, and direct any questions you might have to members of the study team (details on next page).

Thank you!

INFORMATION ON THE STUDY & CONSENT

CONFIDENTIALITY

- All information supplied during this study is **strictly confidential**.
- You will not be asked for any personal information that identifies you (e.g. names, contact information). **Please do not provide** personal information in your responses.
- Personal information (names, family doctor name etc.) will be de-identified or removed by the research team and will not be used in the evaluation process.
- Information collected will be **stored securely** on a protected server until the study ends. It will be stored for no longer than 7 years and then destroyed.
- The survey is hosted by **SurveyMonkey** and stored on servers in the United States under US privacy laws.
- **SurveyMonkey will not look at, or interfere with** any collected data on their website.
- The data from the survey may be used in additional studies, reports, journals etc., but no personal reference will ever be made at any time.

RISKS & BENEFITS

- **There are no risks or benefits with your participation in this study.**
- Any commercial benefits will remain with the Alzheimer Society and the College of Family Physicians of Canada.

VOLUNTARY PARTICIPATION

- **Participation in this study is voluntary** and you will not be paid for your time.
- You can **end your participation at any time** for any reason.
- If you choose to withdraw and want to have your existing survey removed, reach out to one of the lead investigators at the Alzheimer Society of Canada in the contact information below.

INVESTIGATOR CONTACT INFORMATION

For any questions or concerns about this study, please contact:

Haridos Apostolides

- research@alzheimer.ca
- 1-800-616-8816 ext. 2969

Ngozi Iroanyah

- research@alzheimer.ca
- 1-416-669-5715

*If you would like more information on this study before you participate, please contact either **Haridos** or **Ngozi** on the contact information listed above.*

Any contact information provided will not be associated with your completed survey and your answers will remain confidential.

CONSENT FORM

By consenting below, you confirm:

- All your questions have been answered
- You understand the information provided
- You understand the requirements of participating in this study
- You understand the risks and benefits of participating in this study

I am...

- ...a person living with dementia, consenting and completing the survey on my own behalf
- ...a caregiver, family member, or other decision-maker consenting and completing the survey on behalf of the person living with dementia

Please confirm your consent below

- I consent to take part in this survey**

*Thank you. The survey will begin on the next page. Once it is completed, please return it **by uploading it on the website**, or emailing it to research@alzheimer.ca.*

Please note that we will de-identify your personal information before your responses are evaluated.

Your responses will not be affiliated with your email if you choose this method.

DEMENTIA JOURNEY SURVEY: *Living with Dementia Experience*

1. Have you been formally diagnosed with dementia?
 - Yes ▶ **Go to Question 3**
 - No ▶ **Go to Question 2**
2. Do you see any of the following healthcare providers for their undiagnosed dementia?
 - Social Worker ▶ **END OF SURVEY**
 - Nutritionist ▶ **END OF SURVEY**
 - Alternate specialist (*naturopath, homeopath, etc.*) ▶ **END OF SURVEY**
 - No, I don't see any other healthcare providers ▶ **END OF SURVEY**
 - I don't know ▶ **END OF SURVEY**
 - Other (*Please list the other healthcare providers below*) ▶ **END OF SURVEY**

END OF SURVEY - THANK YOU FOR PARTICIPATING

The remaining questions require participants to have a formal diagnosis of dementia. Thank you for your support.

GET HELP & SUPPORT FOR YOUR DEMENTIA

The first step to navigate care is through a formal diagnosis. The Alzheimer Society recommends reaching out to your family doctor or finding one in your province. You can either call **HealthLine** at **811** or the Alzheimer Society at **1-800-879-4226**.

The Alzheimer Society can also provide information on anything related to dementia, including support and educational resources. Contact us at the number above, and make sure you find out about *First Link*.

There is support available & the Alzheimer Society can provide it.

3. Do you currently have a family doctor?

Yes

No

▶ Go to Question 5

▶ Go to Question 19

4. How often do you see your family doctor for dementia-related needs?

Once per month

Once per year

Once every three months

Less than once per year

Once every six months

5. Do you have support connecting with your family doctor (for appointments, check-ups etc.)?

Yes, I have support from a family member or friend

Yes, I have support from the doctor's office

Yes, I have support from another source

No, and I already asked for support

No, but I do not need support

I don't know

6. Does the family doctor offer virtual or telephone care?

Yes, but I'm not interested

Yes, and I'm already using it

Yes, but I don't know how it works

No, but I would like this service

No, and I don't want this service

I don't know

7. If the family doctor offers virtual or telephone care, which options do they use?

Please check all that apply.

Telephone calls

Video calls (Zoom etc.)

Email

I don't know

8. Has the family doctor made referrals to any of the following community resources since diagnosis?

Please check all that apply.

- Local Alzheimer Society
- First Link®
- Local support agency (meals-on-wheels, transportation services, etc.)
- Home support services (e.g. help with personal care)
- The family doctor didn't offer any community resource referrals
- I don't know
- Other (Please list the community resources below or provide further comments)

9. As part of your dementia care, do you see any of the following healthcare providers?

Please check all that apply.

- Memory Clinic
- Specialist (Geriatrician, Neurologist, Psychiatrist, etc.)
- Nurse or Nurse Practitioner
- Social Worker
- I don't know
- No, I don't see any other healthcare providers
- Other (alternate specialists (naturopath, homeopath), nutritionists, etc.):
(Please list the alternate healthcare providers below)

The following questions ask about your care from the family doctor. Do not use any personal information. Please be as detailed as possible.

10. **Has the family doctor been helpful in any of these ways?**

Please check all that apply.

- Spent time explaining what their diagnosis and dementia means.
- Made the effort to answer all or most of our questions.
- Provided information or guides about dementia or dementia care.
- None of these.
- I don't know.
- Other (*please explain how the family doctor has been helpful*):

11. **Has the family doctor been unhelpful in any of these ways?**

Please check all that apply.

- Did not properly explain the diagnosis or dementia.
- Failed to answer or find answers to our questions.
- Did not provide information or guides about dementia or care.
- I don't know.
- None of these.
- Other (*please explain how the family doctor has been unhelpful*):

12. Did the family doctor ever make you feel ignored by focusing their attention on your caregiver?

For either option, please provide any comments you wish to share.

- Yes, the family doctor mostly focused on my caregiver.
 No, the family doctor mostly spoke to me.

13. Has your family doctor been sufficiently patient or comforting when speaking to you about your dementia?

For either option, please provide any comments you wish to share.

- Yes, the family doctor has been patient or comforting.
 No, the family doctor has not been patient or comforting.

14. Did the family doctor respect your racial, cultural or religious needs; provide translators or information in other languages?

For either option, please provide any comments you wish to share.

- Yes, the doctor's office provided care in a culturally sensitive way
 No, they did not provide care in a culturally sensitive way

15. Please comment on any other experiences you have had with the family doctor

16. Do you see an occupational therapist or physiotherapist?

- Yes
 No

▶ Go to Question 22

▶ Go to Question 27

17. Please explain why you don't currently have a family doctor

- Never had a family doctor
- Family doctor retired/died/moved and was not replaced
- No family doctor available in the community
- Not comfortable with the formal medical system
- Prefer the convenience of a walk in/drop off clinic
- I don't know
- Other (*Please explain below*)

18. Do you see another healthcare provider for your dementia care?

- Yes ▶ **Go to Question 19**
- No ▶ **Go to Question 27**
- I don't know ▶ **Go to Question 27**

19. Which other healthcare providers do you see for your dementia?

Please check all that apply.

- | | |
|---|--|
| <input type="checkbox"/> Memory Clinic | <input type="checkbox"/> Psychiatrist |
| <input type="checkbox"/> Geriatrician | <input type="checkbox"/> Nurse or nurse practitioner |
| <input type="checkbox"/> Neurologist | <input type="checkbox"/> Social Worker |
| <input type="checkbox"/> Other (<i>alternate specialists (naturopath, homeopath), nutritionists, etc.</i>) (<i>Please list the other healthcare providers</i>) | |

20. Why do you see this healthcare provider for your dementia instead of a family doctor?

- I don't like my family doctor
- I don't trust my family doctor
- The other healthcare provider was recommended to me
- The other healthcare provider offered more useful information
- My family doctor does not have sufficient understanding or knowledge of dementia care
- Other (*Please explain below*):

21. Do you see an occupational therapist or physiotherapist?

- Yes
- No

▶ **Go to Question 22**

▶ **Go to Question 27**

22. How often do you see your occupational/physiotherapist?

- Once every three months Less than once per year
 Once every six months I don't know
 Once per year

23. Has the occupational/physiotherapist offered therapy for dementia?

- Yes I don't know
 No

24. If the occupational/physiotherapist was being seen before your diagnosis, did they identify any early dementia symptoms?

- Yes Wasn't seeing the therapist
 No before diagnosis
 I don't know

25. Has the occupational/physiotherapist helped in any of these ways?

Please check all that apply.

- Supported you in becoming more independent/physically active.
 Helped with seating and positioning to avoid aches and pains.
 Treated pain caused by physical or everyday activities.
 Offered exercises to improve balance/strength to reduce risk of falls.
 Reduced strain often caused by daily household activities.
 They have not helped in any of these ways.
 Other (*Please provide details or further comment below*):

26. Has the occupational/physiotherapist been more useful for dementia care than the family doctor or other healthcare provider?

- Yes. I don't know.
 No.

▶ **GO TO QUESTION 27**

DEMOGRAPHIC DETAILS

27. Please select **your** age range:

- | | | |
|-----------------------------------|----------------------------------|----------------------------------|
| <input type="checkbox"/> Under 30 | <input type="checkbox"/> 50 - 59 | <input type="checkbox"/> 75 - 79 |
| <input type="checkbox"/> 30 - 39 | <input type="checkbox"/> 60 - 69 | <input type="checkbox"/> 80 - 84 |
| <input type="checkbox"/> 40 - 49 | <input type="checkbox"/> 70 - 74 | <input type="checkbox"/> 85 plus |

28. What is your gender?

- | | |
|---------------------------------|--|
| <input type="checkbox"/> Female | <input type="checkbox"/> Other |
| <input type="checkbox"/> Male | <input type="checkbox"/> Prefer not to say |

29. What is your ethnic background?

- | | | |
|---|---|--|
| <input type="checkbox"/> African | <input type="checkbox"/> Indigenous | <input type="checkbox"/> Pacific Islander |
| <input type="checkbox"/> Black | <input type="checkbox"/> Inuit | <input type="checkbox"/> South Asian |
| <input type="checkbox"/> Caribbean | <input type="checkbox"/> Latin | <input type="checkbox"/> Southeast Asian |
| <input type="checkbox"/> East Asian | <input type="checkbox"/> Metis | <input type="checkbox"/> White |
| <input type="checkbox"/> First Nations | <input type="checkbox"/> Middle Eastern | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> Other/Mixed: <i>Please provide details of your ethnic background</i> | | |

30. Which province or territory do you live in?

- | | | |
|---|--|---|
| <input type="checkbox"/> Alberta | <input type="checkbox"/> Northwest Territories | <input type="checkbox"/> Prince Edward Island |
| <input type="checkbox"/> British Columbia | <input type="checkbox"/> Nova Scotia | <input type="checkbox"/> Québec |
| <input type="checkbox"/> Manitoba | <input type="checkbox"/> Nunavut | <input type="checkbox"/> Saskatchewan |
| <input type="checkbox"/> New Brunswick | <input type="checkbox"/> Ontario | <input type="checkbox"/> Yukon |
| <input type="checkbox"/> Newfoundland | | |

31. Please select which kind of community you live in:

- Large population (more than 100,000 people)
- Medium population (between 30,000 and 100,000 people)
- Small population (between 1,000 and 30,000 people)
- Rural population (fewer than 1,000 people)
- I'm not sure

THANK YOU FOR COMPLETING OUR SURVEY!

We really appreciate your time. Your support will help make positive changes in the relationship between people living with dementia and their family doctor.

If you'd like more information and support you can find your local Alzheimer Society by calling 1-800-879-4226.

Get involved with the Alzheimer Society's advocacy work

The views and experiences of people living with dementia or their caregivers is vital to the Alzheimer Society's work and direction. If you would like to support our advocacy work, to ensure everything we do focuses on people living with dementia, their families and caregivers, then you can get involved in a number of ways:

- Join the Alzheimer Society Advisory Group of people living with dementia to advise on our strategic direction
- Help review our educational materials to ensure they are relevant to your experience
- Get involved in our Research Program, by reviewing and learning about current research
- Be a spokesperson for our communications initiatives so we can erase stigma across the country
- Advocate for the Alzheimer Society, and dementia care broadly, at a federal level

If you'd like to be involved, let us know by contacting either:

- research@alzheimer.ca
- 1-800-616-8816 Ext. 2969

Thank you for your support!