

Disease-modifying therapies

Exploring attitudes and perceptions among British Columbians affected by dementia

Background

- There is currently no cure for Alzheimer's disease. Existing medications help manage symptoms, but do not slow the progression or change the course of the disease.
- Health Canada announced its conditional approval of the **disease-modifying therapy (DMT)**, lecanemab, in late October 2025.
- While lecanemab is only for people in the early stages of Alzheimer's disease (i.e., mild cognitive impairment or mild dementia due to Alzheimer's disease), Health Canada's decision represents an important advancement in how we approach treatment and care.
- We don't know much about the opinions of people affected by dementia about these treatments.

What we did

- We hosted seven virtual focus groups for people affected by dementia to learn about their attitudes and perceptions of these therapies.

What are disease-modifying therapies?

Disease-modifying therapies are treatments that aim to change how a disease develops over time. Unlike current medications that focus on managing symptoms, drugs like lecanemab target changes in the brain linked to Alzheimer's disease by reducing amyloid plaques.

Who participated

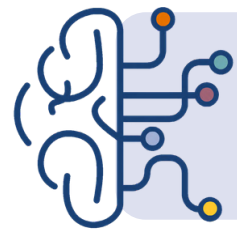
12 people living with dementia

- Predominantly women aged 60 to 70 living with either mild cognitive impairment or dementia.
- Most resided with family in Metro Vancouver or the Fraser Valley.
- Nearly all identified as white, with one person also identifying as Indigenous.

21 care partners

- Most were spouses or common-law partners in their sixties, with just over half being women.
- About half cared for someone living in the same household, while a third supported someone living in long-term care.
- The majority identified as white, while others identified as Chinese, Indigenous or Filipino.





What we found

Therapies as a source of hope and progress

- Many described DMTs as “little glimmers of hope” and as an opportunity to regain a sense of agency in the face of a difficult diagnosis.
- For care partners, DMTs offered a sense of optimism about the possibility of gaining more time with their family member.

I would hope that the treatment would give my husband longer quality of life so that we can continue to get out and do the things with people that we love, which would mean he could stay at home with me longer and enjoy life in the golden years [in which] we've... worked so hard to stay healthy.



– Mia, care partner

- For people living with dementia, new treatment options generated both excitement and frustration.
- The promise of innovation provided reassurance, but delays in drug approval processes left some feeling discouraged.



Concerns about equitable access

- Participants highlighted both personal and systemic barriers that could create inequities across the province.
- People without access to a family physician worried about how they would even get the referrals needed for diagnostic testing.
- These concerns were especially strong among participants living in rural and remote areas.

We don't have access to doctors... so that continuity of care – even after diagnosis – can be challenging. And then the long waitlist for testing. So for MRI or anything like that, we have to travel down to Vancouver, which is a 13-hour drive... or flying, which is expensive.



– Roy, care partner

- Beyond financial barriers, care partners were identified as essential support for accessing therapies, including transporting to appointments, monitoring side effects and supporting the overall treatment process.

I think your spouse would have to... be your partner in this. Whether they are going to be driving you there or seeing the reaction you might get from the drug... they would have to buy into this as well. You'd have to have the support.



– Ash, person living with dementia



Family-centred decision-making

- Weighing the risks and benefits often reflected personal circumstances, stage of disease and tolerance for serious side effects like brain bleeds or swelling.
- Participants living with dementia were generally more cautious, emphasizing potential impacts on quality of life and fear of severe complications.

I might not have a lot of years ahead of me, and that the impact on my life... a brain bleed could just be so swift... it is devastating to think that the life I've come to love is going to be taken away so quickly.



– Jin, person living with dementia

- Others expressed similar hesitation while also noting their acceptance of living with cognitive impairment.

I'm not sure I'd be willing to take the risks given that I'm in quite a good place these days... if I stayed the way I am right now that would be fine.

– Sam, person living with dementia



- In contrast, many care partners were more willing to tolerate potential side effects, motivated by a desire to slow progression and preserve quality of life for their family member.
- Across all focus groups, participants agreed that decisions about DMTs would ultimately be a shared, family-centred process, involving mutual willingness to manage risks together.



The Alzheimer Society of BC and Yukon as a trusted guide and advocate

- Participants consistently identified the organization as a trusted and reliable source of information to help navigate their dementia experience, including emerging treatments like DMTs.
- Often described as their “go-to” for reliable and accessible information in an online environment crowded with misinformation, the organization was viewed as a safeguard in their search for resources.

People can fall down a rabbit hole looking up dementia and what type of dementia and what kind of medications. And it's really hard sometimes to know what the trusted sites are and what is trusted information.

– Lee, care partner



- Care partners emphasized that updates from the organization, via newsletters, webinars or support groups, helped them stay informed and feel confident as new treatments options become available.
- Consulting other credible sources and having access to clear, current and trustworthy information was seen as essential, particularly given the risks linked to current anti-amyloid therapies.



Key takeaways

- The Alzheimer Society of BC and Yukon as an information provider, community connector and advocate is ideally positioned to support people affected by dementia as they navigate emerging treatment developments.
- Findings underscore the need for a clear, step-by-step roadmap for the entire progression of the disease that will allow families to make informed choices and equitably access the benefits of new therapies.
- Including the voices of people living with dementia and their care partners in discussion around these therapies helps anchor policy and research in the realities of day-to-day life with dementia.

I rely on you... to provide that up-to-date information... because I feel that you [have] the finger on the pulse of all the newest kind of innovation.

– Jay, care partner



Learn more

- **Online** at alzbc.org/research.
- **Email** the Research & Knowledge Mobilization team at research@alzheimerbc.org.
- **Call** the First Link® Dementia Helpline at 1-800-936-6033.



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