Meaningful engagement of people with lived experience of dementia

Alzheimer Society
BRITISH COLUMBIA

*This document shares the Society's commitment to the lived experience of dementia

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What is lived experience?

*This framework was informed by and created in consultation with individuals with lived experience of dementia.

Having lived experience means that an individual has been directly affected by dementia. People living with dementia and those supporting them have experienced firsthand the cognitive and emotional changes, as well as the impact dementia has on daily life, relationships and overall well-being. Each person brings a unique perspective and understanding of the dementia journey that can help shape dementia-related initiatives, policies and support services.

"As a volunteer and a caregiver with lived experience, I strive to offer support and hope to others. My commitment to volunteering comes from my belief that volunteers can build compassion and community through participating and contributing to the work of an organization" - Geri Hinton, care partner

"Dementia has given me a cause: being able to present myself through my art with the purpose of advocacy. Discovering that – wait a minute, I can actually help here!"
- Granville Johnson,
person living with dementia

Why it’s important to engage with people living with dementia and caregivers.

- People living with dementia have rights - they are entitled to be included in all that the Society does.
- To embody the idea of "nothing about us without us".
- To hear a perspective that otherwise wouldn't be understood.
- To reduce discrimination and stigma.
- To ensure our programs, services and initiatives are informed by a range of experiences and responsive to people's changing needs.
- To make sure that what matters to people living with dementia, their families and friends is addressed.
- To offer opportunities for skills and empowerment to people affected by dementia.

Guiding principles.

- Creating an environment of inclusivity and flexibility, where people affected by dementia feel welcomed, respected and valued.
- Including diverse voices that are representative of demography and geography.
- Fostering a culture of empowerment and engagement that emphasizes the voices of people who are experts by experience.
- Engaging with transparency and integrity, with a clear sense of why we are engaging.
- Offering options that fit with people's abilities, availability and interest.

Opportunities for engagement.

There will be a range of short and longer-term opportunities available.

For example:

- Participation in focus groups
- Interviews
- Social media opportunities
- Advisory groups
- Committee representative
- Presentations
- Peer-led programs
- Public forums
- Working groups
- Legislative outreach

Taking part in these opportunities will support the Society's work, helping us better assess community needs, develop policy and strategy, support research and staff training.

Recruitment.

Invitation:
An invitation to participate in an upcoming opportunity may come from a Society staff member.

Respond to community posting:
Engagement opportunities may be posted on the Society's website, a community bulletin board, your local place of worship or at a community venue.

Referral:
Individuals may be referred by a family member, friend or organization connected to the Society.

For more information visit: alzbc.org

Our commitment to you.

We will stay in touch with you from the beginning of your engagement and throughout your involvement. We'll also be sure to check in with you to ensure you're getting the support you need.

We will invite you to share:

- Your goals for participation.
- The support you require to participate and express your views.
- Your preferred time, location and method of engagement.

We will be clear about:

- The goal or purpose.
- The timeline.
- Your responsibilities.
- Meeting times and locations.
- The provided training.

There may come a time when you need to step away from your commitment as a lived experience volunteer. If the role is no longer a good fit, we will offer alternative options, we can also provide an opportunity for closure.

We will ensure.

- All information is plain language.
- Information is provided well ahead of time to allow you to be prepared.
- Information is presented in a variety of formats to help with your understanding.
- Any out-of-pocket expenses (e.g., travel, parking) are reimbursed.
- To vary the days and times of participation to allow you to participate around your other commitments and family responsibilities.
- To provide opportunities to share your thoughts and opinions in a variety of different ways.

Recognizing your contributions.

The contributions of people with personal experience of the dementia journey should be valued equally with those of other subject-matter experts (e.g., researchers, health-care providers)

The Society believes it essential to acknowledge the value of contributions from people affected by the disease and the time, energy and expertise they provide.

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