

# Making your workplace dementia friendly

Information for housing professionals





Building a dementia-friendly B.C.



# INTRODUCTION

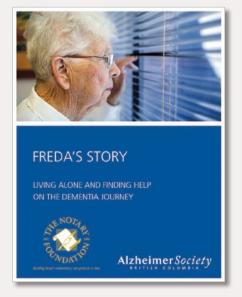
More than 70,000 people in British Columbia currently live with dementia. Without a cure, this number is expected to more than double by 2038. Many people with dementia live in the community for a long time and are able to maintain a good quality of life with some support.

Everyone has a responsibility to help make their community dementia friendly. Dementia-friendly communities are those which support people to be engaged and active where they work, live and play. This resource will help you to:

- Understand and recognize the signs of dementia.
- Learn how to communicate in an effective, respectful way.
- Think about specific ways you can support a person with dementia in your work and how your workplace may become more dementia friendly.

This resource can be read alongside "Freda's Story," a booklet about people with

dementia who live independently without a close support network. "Freda" has some acquaintances but no one in her life who she would call a close friend and no connections to social, community or faith groups. The people Freda interacts with in her community have noticed that her memory problems are getting worse. We will refer to Freda throughout this resource.



## FREDA AND HOUSING PROFESSIONALS

Freda may interact with someone like you for many reasons. She may:

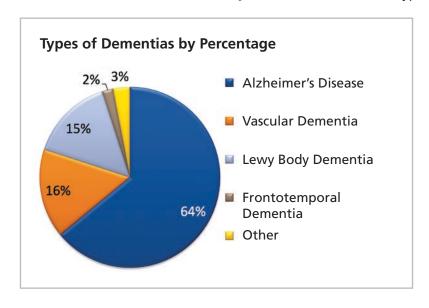
- Reside in assisted living.
- Be a long-time tenant who is starting to show signs of dementia.
- Be in a group living situation for other reasons, such as housing, mental health or substance use challenges.
- Be experiencing housing challenges. For example, she may have forgotten to pay her rent on time.

She may be anxious, stressed or angry. She may need emotional support, more time than usual to process information or questions asked of her in a specific way.

If you understand what dementia is and what its signs are, you may be able to better support someone like Freda in her housing situation. Your understanding can help enhance Freda's ability to live independently or semi-independently and to stay engaged in her community.

## UNDERSTANDING DEMENTIA

The word dementia is an umbrella term that refers to many different diseases. Different types of dementia are caused by various physical changes in the brain. Alzheimer's disease is the most common, accounting for approximately two-thirds of all dementias. You can learn about different kinds of dementia by visiting the Alzheimer Society of B.C.'s website. Other types of dementia include:



- Vascular dementia.
- Lewy body dementia.
- Frontotemporal dementia, including Pick's disease.
- Others, including Creutzfeldt-Jakob disease.

A person's risk for developing dementia increases as they age.
However, dementia does not only affect older adults. It is estimated that over 10,000 people with dementia in B.C. are under the age of 65.

In some cases, a person can appear to have dementia but the symptoms (including memory loss, confusion or disorientation) can actually be attributed to another medical cause such as medication changes, a urinary tract infection or a vitamin deficiency.

In such cases the symptoms may be reversible. However, in general dementia is progressive, which means that Freda's symptoms will get worse over time. This means that, eventually, Freda will no longer be able to live alone.

# SIGNS OF DEMENTIA AND COMMUNICATION STRATEGIES

It is not always immediately evident that a person has dementia. Everyone's dementia journey is unique, with different strengths, abilities and challenges along the disease trajectory. Here are some signs that someone may be experiencing symptoms of dementia and strategies for responding in a supportive way:

#### Signs

#### Problems with memory.

As the disease progresses, Freda may forget things more often, especially more recent experiences. For example, she may forget to pay her rent or try to pay it too often. She may also repeat the same story frequently.

#### **Communication Strategies**

- Do not argue. If Freda does not remember a discussion from a previous interaction it may be because she is no longer able to properly store that memory due to changes in her brain.
- Unless her safety or security is at risk, try to adjust to Freda's reality because she may no longer be able to adjust to yours. Try responding to her feelings, not necessarily the stories she is sharing. For example, if she feels that you forgot to contact her about a repair in her unit, it is better to apologize to her and acknowledge that she feels frustrated (her reality) than to try to convince her that you sent the notice (your reality). You may say something like "I can see how frustrated you are, Freda. Let's get this sorted out as soon as we can."



#### Signs Communication Strategies Difficulty with • If you are providing instructions, slow down the pace familiar tasks. of your speech, speak in simple language and provide one message at a time. This gives more time to digest Challenges in sequential the information and complete a task. thinking may cause Freda to have trouble with tasks that • Try demonstrating rather than providing directions were previously familiar to her, verbally. especially if they have many • Focus on what the person is still doing well, rather steps. Even routine activities than the challenges they are experiencing. such as making a pot of coffee or getting dressed may become • Be patient and supportive. more challenging. • If possible, bring Freda to a quieter space where it is easier to concentrate. Inability to follow a • When possible and appropriate use closed-ended or conversation or find the "yes" or "no" questions. right words. • If Freda feels comfortable with you helping her to Everyone has trouble finding find the right word, for example, you might say the right word sometimes, but something like "Do you mean\_\_\_?" Freda may frequently forget • Repeat the question a different way, or try again simple words or substitute a less appropriate word for • Don't rush – this may mean taking more time with the one she really wants. This Freda. can make her sentences or accounts of events difficult to understand. Disorientation • Encourage other residents to be patient with Freda. of time or place. • TIP: Suggest that Freda put a familiar sign or object It's normal to briefly forget on her door. the day of the week or your destination. But Freda may become lost in a familiar place, even in her building or complex. If there are similar doors in her building Freda may also knock on the wrong door, or mistake someone else's home with hers. It is also possible that Freda will find it challenging to determine what time of the day it is.

Signs	Communication Strategies
Poor judgment.  Freda may experience decreased judgment. For example, she may dress inappropriately for the weather, may experience less social inhibition or may find it difficult to determine what to keep and what to throw out, resulting in her space becoming cluttered.	<ul> <li>Make suggestions tactfully. For example, instead of saying, "Why do you need these? These papers are all very old!" you may say something like, "Those newspapers must be very heavy. Can I recycle them for you?"</li> <li>Changes to certain parts of the brain can result in behaviour that is socially inappropriate such as swearing or inappropriate comments. Avoid drawing attention to the behaviour or criticizing it.</li> </ul>
Problems with abstract thinking. Freda may have challenges with tasks that require abstract thinking. This may make answering open-ended questions difficult. It may also be challenging to make sense of symbols or images.	<ul> <li>Try to use concrete language. Avoid metaphors, for example: "A place to hang your hat."</li> <li>Stay positive and friendly, but avoid jokes or sarcasm, as these require abstract thinking skills.</li> <li>Be compassionate and treat the person as normally as possible. For example, rather than asking Freda if you can show her where her unit or room is, you might ask her if you can walk her there to chat with her as you go.</li> </ul>
Challenges in mood or behaviour.  Everyone experiences changes in mood. But a person with dementia can sometimes become suspicious, withdrawn or even more outgoing than before. Over time Freda may become angry, more apathetic, fearful or even paranoid. She may, for example, think that someone is stealing from her room or that you are doing something dishonest.	<ul> <li>If you feel that Freda may be angry or upset it can be helpful to acknowledge her feelings.</li> <li>Paranoia is common for people with dementia; avoid arguing with Freda if you think she may be experiencing delusions or hallucinations.</li> <li>If you feel that Freda may be experiencing abuse or neglect, it is important that you report this. See the Resources section on page 8.</li> </ul>

# Other tips for communication.

- Remember to make eye contact. If you are making notes or using the computer, take a break and make sure to look at the person.
- A person's ability to understand body language is often maintained for a long time along the dementia journey. Take note of your body language and tone of voice. Keep positive, and watch your gestures, facial expressions and posture.
- It may be necessary to remind someone to put on their glasses or turn on their hearing aid, but do not assume that every person with dementia has a visual or hearing impairment.
- Always speak to the person with dignity and respect.
- Avoid using "elder-speak" or baby talk (for example, "sweetie" or "dear").
- Never speak about the person as if they are not there.

## HOUSING TRANSITIONS AND DECISION-MAKING

As Freda's dementia progresses she will start to have more challenges. It is likely that there will eventually be a time where she will need more support and will need to move into a long-term care facility. Though it may be uncomfortable, it is important to include the person with dementia in these discussions whenever possible.

Here are a few things you can do to provide as smooth a transition as possible:

- In some cases the person might not yet have a formal diagnosis of dementia. If it seems comfortable to do so, you might choose to encourage the person to visit their doctor. With their permission, you might help them write down some of the changes you have noticed recently.
- If it is appropriate and applicable, provide the person's family with information often and early about the changes you are noticing. Explain:
  - What you're noticing.
  - What this will mean in the future (for example, a transition to long-term care or assisted living).
  - When this is likely to take place.
- Keep in mind that the person and their family (if there is one) will be experiencing many emotions including stress, grief, anxiety, guilt or even relief.



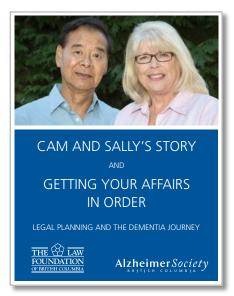
As things continue to progress, Freda may need someone else to help her make decisions about her money and where she lives. Whenever possible, concentrate on Freda's strengths, abilities and the ways she can continue to make her own decisions. Avoid rushing or pressuring Freda to make decisions on the spot.

If someone does not have family members or close friends and there is a crisis (for example, if it becomes clear that Freda is no longer safe to live at home without support) you or your supervisor may need to contact the <u>regional health authority</u>, mental health or geriatric outreach team in your area.

When Freda becomes unable to make her own financial decisions without support there are tools which can help others carry out her wishes. An enduring power of attorney or a representation agreement, section 7, enables a person with dementia to appoint a family member or close friend to make certain financial decisions on their behalf.

- An **enduring power of attorney** is a legal document that allows one person (called the "donor") to appoint another person (called the "attorney") to make financial decisions on his or her behalf after the donor becomes "mentally incapable" (a legal term). It is called "enduring" because it will continue to be in effect when the donor is no longer mentally capable.
- Representation agreements are legal documents in which one person (the "donor") appoints another person (the "representative") to make health-care, personal, and (in the case of a section 7 representation agreement) routine financial decisions on his or her behalf.

Choosing someone to appoint as a power of attorney and/or representative is a very important decision. Freda must choose someone who she trusts and who understands and respects her values, beliefs and preferences. If there is no one in her life to take on that role, or if planning is left too late, a committee may be appointed for Freda by the court.



A committee is the legal term for guardian in British Columbia.
 If a person loses his or her ability to make decisions without having a power of attorney and/or a representation agreement in place, then a committee will need to be appointed as a substitute decision-maker. Committees are required to keep detailed records and, unlike attorneys or representatives, they are also required to provide regular reports to the Public Guardian and Trustee about their dealings with the person's money and property. In some cases they may also be required to provide a report to the court.

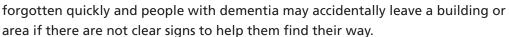
People with dementia or caregivers who would like to explore options for personal, legal, health and financial planning can download "Freda's Story: Living Alone and Finding Help on the Dementia Journey," or "Cam and Sally's Story and Getting Your Affairs in Order." You can also contact your local Alzheimer Resource Centre for more information.

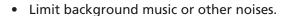
# TIPS TO HELP MAKE YOUR WORKPLACE DEMENTIA FRIENDLY

Here are some more dementia-friendly actions you can implement in your organization.

#### PHYSICAL LAYOUT

- Designate a quiet space away from background noise where it is easier to have a conversation.
- Avoid cluttered spaces; it can be challenging to concentrate with too much visual stimulation.
- Ensure lighting is adequate. Poor lighting can make the environment confusing or even scary.
- If possible, make sure signage for washrooms, bedrooms (if appropriate) and other important areas is large and clear. Verbal directions may be





- Consider displaying large clocks in different areas of the building. If your facility serves meals, consider having a menu board outlining what the next meal is.
- If your organization holds activities think about whether certain times of day are better when scheduling them. For example, some people with dementia experience "sundowning," a phenomenon which results in greater disorientation or confusion later in the day. In these cases, late afternoon or early evening activities may be challenging.

#### WITHIN THE ORGANIZATION

- Everyone in your organization has a role to play in contributing to a dementiafriendly community. Ensuring that all staff know how to recognize dementia and communicate appropriately is key to creating a workplace that is supportive and inclusive of people with dementia.
- Start to create an organizational awareness about dementia by sharing this booklet, by contacting the Alzheimer Society of B.C. for more information or by asking the Society to deliver a Dementia Friends education session at your workplace.
- Designate a person at your workplace to be the "go-to" person about dementia. Ideally, this person would mentor others and help other staff to identify that someone is having challenges.



## RESOURCES FOR FURTHER INFORMATION

#### Alzheimer Society of B.C.

The Alzheimer Society of B.C. is dedicated to helping people build the knowledge, skills and confidence to live well with dementia. The Society is available to answer questions and help you find the professional assistance you need.

- Visit our website to find a Resource Centre in your area for information about dementia: <a href="www.alzheimerbc.org">www.alzheimerbc.org</a>.
- Call the First Link® Dementia Helpline, a province-wide service for people with dementia, their caregivers, family and friends: 1-800-936-6033 or 604-681-8651.
- E-mail us at <u>dementiafriendlybc@alzheimerbc.org</u> for more information about making your organization dementia friendly.

#### BC211

A source to find community, social and government services. Free, confidential, multilingual and available 24/7.

#### www.bc211.ca

Call: 2-1-1

#### **BC Centre for Elder & Advocacy Support (BCCEAS)**

BCCEAS works to prevent elder abuse and to provide assistance and support to older adults that are, or may be, abused and those whose rights have been violated.

#### www.bcceas.ca

Call toll-free: 1-866-437-1940 or 604-437-1940

• Seniors Abuse & Information Line

Older adults, and those who care about them can call the Seniors Abuse & Information Line (SAIL) to talk to someone about situations where they feel they are being abused or mistreated, or to receive information about elder abuse prevention.

Call toll-free: 1-855-306-1443 or 604-428-3359

#### **BC Notaries**

Find a Notary Public office in your community.

#### www.notaries.bc.ca

Call toll-free: 1-800-663-0343 or 604-681-4516

#### **HealthLink BC**

24-hour health information line, medical advice, assistance with navigating the system, and a translation service in 130 languages.

#### www.healthlinkbc.ca

Call 8-1-1 or 7-1-1 for deaf and hearing-impaired assistance (TTY)

#### MedicAlert® Safely Home®

A nationwide program designed to help identify the person who is lost and assist in a safe return home. This is a partnership between the Alzheimer Society of Canada and MedicAlert.

#### www.medicalert.ca/safelyhome

Call toll-free:1-855-581-3794

#### **Nidus Personal Planning Resource Centre and Registry**

Personal planning resources and assistance.

#### www.nidus.ca

Call toll-free: 1-877-267-5552 or 604-408-7414

#### **Public Guardian and Trustee of British Columbia**

Assistance for adults who need support for financial and personal decision-making.

#### www.trustee.bc.ca

Call toll-free: 1-800-663-7867, 604-660-4444 (Vancouver area),

or 250-387-6121 (Victoria area)

#### Wills Clinic Project

Access Pro Bono, in partnership with the federal Department of Justice and the provincial Ministry of Justice, operates a weekly Will and Representation Agreement preparation clinic at the Vancouver Justice Access Centre for low income seniors (ages 55+) and people with terminal illnesses.

#### www.accessprobono.ca/willsclinic

Call: 604-424-9600

### **ACKNOWLEDGEMENTS**

We thank the Notary Foundation of British Columbia for their support of this project.

Based on work by: Margaret Hall

Project manager: Rebecca Morris, Alzheimer Society of B.C.

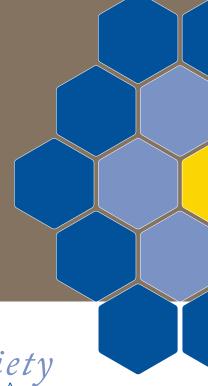
Marketing & communications: Paula Brill, Alzheimer Society of B.C.

Advisory committee: Jill Atkey, Jamie Billingham, City of Vancouver's Housing and Community Operations group, Keiko Funahashi, Gina Hall, Barbara Lindsay, Jim Mann, Maria Przydatek, Jennifer Stewart, Karl Tegenfeldt

Volunteers: Chris Byrnes, Julie Cameron, Doreen Stone, Vivian Tsai

Template design: Black Cat Graphics and Communications

Photography and layout: Flora Gordon





Alzheimer Society

dementia friendly bc@alzheimer bc.org

First Link® Dementia Helpline: 1-800-936-6033