

Making your workplace dementia friendly

Information for recreation service providers





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Introduction

It is estimated that 70,000 people in British Columbia are living with dementia. Without a cure, this number is expected to grow. Many people living with dementia live in the community for a long time and with some support they are often able to maintain a good quality of life.

Everyone has a responsibility to help make their community dementia friendly. Dementia-friendly communities support people living with dementia 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 living with dementia in your work and how your recreation centre, or other community space like a seniors centre, may become more dementia friendly.

This guide will provide an introduction to Alzheimer's disease and other dementias and will also help you recognize when someone may be living with dementia. The guide will also provide strategies and helpful tips for communicating with people who are living with dementia, and will make recommendations for programs and services that are mindful of people in the community who are living with dementia. It will conclude with ways that you can adapt your recreation or community centre to be more dementia friendly from a planning and policies perspective.

We appreciate you taking the time to read through this guide. We hope that it will help you to support a person living with dementia to visit the recreation centre and attend activities. Your understanding can help enhance a person living with dementia's ability to live independently or semi-independently and stay engaged in their community. It will also help support the families, friends and caregivers of people living with dementia.



Recreation service providers

Many people living with dementia continue to live in their communities for some time after their diagnosis, so they will need support from their fellow community members. Recreation and community centres are central to our neighbourhoods and can be the primary way in which people living with dementia and their care partners engage with their community. A person living with dementia may interact with someone like you – a staff member at a recreation centre – in many different ways.

They may be:

- A long-time volunteer who is starting to show signs of dementia.
- A person who is finding it difficult to sign up for art classes or a social card playing group.
- A regular participant in Aquafit classes, but has started to have difficulty following the class instructions.
- Someone who is experiencing challenges using fitness equipment.

As a staff person at a recreation centre, seniors centre, neighbourhood house or park, you may meet a person living with dementia when they are having a good day, or on a day when they may be feeling anxious, stressed or angry. A person living with dementia may need your understanding, emotional support and more time than usual to process information or questions asked of them.



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. You can learn about the different kinds of dementia by visiting the Alzheimer Society of B.C.'s website. Types of dementia include:

- Alzheimer's disease.
- 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. Over 5,000 people under the age of 65 are living with a diagnosis of dementia in B.C. Some people living with certain kinds of developmental disabilities such as Downs Syndrome, have a much higher chance of developing dementia as they age.

A person can appear to have dementia, but the symptoms (including memory loss, confusion or disorientation) can actually be attributed to other medical causes such as medication changes, a urinary tract infection or a vitamin deficiency. In such cases the symptoms may be reversible. Dementia, however, is permanent and progressive, which means that a person's symptoms will get worse over time. This means that a person living with dementia may only need a bit of help or an occasional reminder when they are first diagnosed, but eventually, they will no longer be able to attend all the activities they had previously enjoyed.

At the beginning, some people who have been diagnosed with dementia will likely only need a bit of help or the occasional reminder.



Signs of dementia and communication strategies

It is not always immediately clear that a person is living with dementia. Everyone's dementia journey is unique and they will maintain different strengths and abilities and experience different challenges along the course of the disease. Here are some signs that someone may be experiencing symptoms of dementia and strategies for responding in a supportive way:

Signs

Problems with memory.

When a person is first diagnosed with dementia, they may forget the names of people or places once in a while. As the disease progresses, they may forget things more often, especially more recent experiences. For example, they may have difficulty keeping track of a program schedule and may often ask what day a class takes place or repeat the same story frequently.

Communication strategies

- Do not argue. If a person living with dementia does not remember a previous interaction it is likely because they are no longer able to properly store that memory due to changes in their brain.
- Unless their safety or security is at risk, try to adjust to the person living with dementia's reality because they may no longer be able to adjust to yours. For example, if the person living with dementia feels you forgot to remind them about a program start date, it is better to apologize and acknowledge that they feel frustrated (their reality) than to try to convince them that you sent the reminder (your reality). You may say something like "I can see how frustrated you are. Let's get this sorted out as soon as we can."

Difficulty with familiar tasks.

Challenges in sequential thinking may cause a person living with dementia to have trouble with previously familiar tasks, especially if the task has many steps. Even routine activities such as using the change rooms or remembering to scan their card may become challenging as the disease progresses.

- If a person living with dementia is in the early stages of the disease, a helping hand or gentle encouragement may be all they need to continue to do tasks independently. For example, they may forget the code to the locker room, but be fully capable of getting ready themselves.
- Be patient, supportive and speak slowly and clearly.
- If you are providing instructions, give them in a simple, step-by-step way, rather than all at once.
 This gives the person more time to digest the information and complete a task.
- Try demonstrating as well as providing directions verbally.
- Focus on what the person is still doing well, rather than the challenges they are experiencing.
- If possible, bring the person to a quieter space where it is easier to concentrate.

Signs

Inability to follow a conversation or find the right words.

Everyone has trouble finding the right word sometimes, but as the disease progresses a person living with dementia may frequently forget simple words or substitute a less appropriate word for the one they really wanted. This can make their sentences or accounts of events difficult to understand. For example, a person living with dementia may have difficulty explaining to staff at the information desk that they would like to renew their community centre membership.

Communication strategies

- Be patient, don't rush this may mean taking more time.
- Observe the person's body language as sometimes they may have difficulty expressing thoughts verbally.
- When possible and appropriate use closedended or "yes" or "no" questions. For example, instead of asking "what are your favourite activities?" you might ask "do you like swimming?" or "do you like painting?" so the person can give "yes" or "no" answers.
- If the person feels comfortable with you helping them find the right word, you might say something like "Do you mean___?".
- Repeat the question a different way, or try again later.

Disorientation of time and place.

It's normal to briefly forget the day of the week or your destination. But a person living with dementia may become lost in a familiar place, such as the local park they often go to. For example, pathways that look similar might cause the person to get disoriented. It is also possible that the person will find it challenging to determine what time of the day it is.

- A person living with dementia may be disoriented and just need a friendly approach and short conversation that will get them back on track. In the early stages of dementia progression, a little help may be all the person living with dementia needs to continue with their day.
- Consider having greeters at the entrance to the community centre or seniors centre when dementia-friendly activities are planned to help people get to the activity room.
- Ensure all signage is clear, easy to read and placed at eye level.
- If the person looks lost, they may be wandering. Please see the section on wandering on page 12 to learn more.

Signs

Poor judgment.

A person living with dementia may experience decreased judgment. For example, early in the journey, they may start by forgetting to bring a warm jacket to the park on cooler days. As the disease progresses, they may experience less social inhibition; for example, they may laugh or make inappropriate comments during a sad story.

Communication strategies

- Changes to certain parts of the brain can result in behaviour that is socially inappropriate such as swearing or comments that don't fit the context. Avoid drawing attention to the behaviour or criticizing it. Consider taking the person to a quieter space or redirecting them to a different activity.
- Make suggestions tactfully.
- Make signage and instructions clear, e.g. clearly indicate which towel bins are for clean towels and which are for dirty towels.
- Include suggestions in program descriptions. For example, what to bring (e.g. water bottle) or what apparel is best suited for the activity.



Signs **Communication strategies Problems with abstract** Try to use concrete language. Avoid metaphors, for thinking. example: "There is a blanket of snow over the park today!" As the disease progresses Stay positive and friendly, but avoid jokes or sarcasm that a person living with requires abstract thinking skills. dementia may have Be compassionate and use language which emphasizes the challenges with tasks person's agency. For example, rather than asking the person that require abstract if you can show them where the activity room is, you might thinking. This may make ask them if you can walk them there to chat with them as answering open-ended you go. questions difficult. It may also become challenging Mirror image "mimicking" of an activity can be confusing. for the person to make Try facing the direction that participant is also facing. sense of symbols or • Demonstrate what the participant should do but do not images. expect them to follow your directions exactly. Challenges in mood or Remember that whatever the person is experiencing is behaviour. real for them. Everyone experiences If you feel that a person living with dementia may be changes in mood. But angry or upset it can be helpful to acknowledge their a person living with feelings. dementia can sometimes Paranoia is common for people living with dementia;

avoid arguing with the person if you think they may be

or neglect, it is important that you report this. See the

If you feel that a person may be experiencing abuse

experiencing delusions or hallucinations.

resource section on page 22.

become suspicious,

withdrawn or even

more outgoing than before. Over time they

may become angry,

paranoid. The person may, for example, think that someone in the community is stealing from them or that you are doing something

dishonest.

apathetic, fearful or even

Signs	Communication strategies
Other tips for communication.	Be patient, be understanding.
	Always speak to the person with dignity and respect.
	 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.
	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 living with dementia has a visual or hearing impairment.
	When you do not know the person, avoid using "elder- speak" (for example, "sweetie" or "dear").
	Never speak about the person as if they are not there, even if they cannot communicate in a verbal way.
	A person living with dementia may not remember what you said, but they often remember how you made them feel.

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. Watch your gestures, facial expressions and posture, and keep positive.

Key communication strategies



1. Get the person's attention.



6. Use close-ended questions – yes or no answers.



2. Make eye contact.



7. Allow time for response.



3. Bring the person to a quiet place.



8. Respond to feelings, not stories.



4. Speak slowly and clearly.



9. Connect, don't correct.



5. Share one message at a time.



10. Repeat or try again later.



Wandering

People living with Alzheimer's disease or other dementias often experience the need to stay on the move. Wandering behaviour may occur because a person would like to go somewhere specific or accomplish a task. Wandering may occur at any time of day. In itself, wandering is not a harmful behaviour, but for people living with dementia, wandering is a very serious and potentially dangerous situation because it can expose the person to dangers like traffic, falls or exposure related to extreme weather conditions. Changes in the brain can cause a person living with dementia to become confused and disoriented, even when they are in a familiar place. For example, a person living with dementia may not be able to find their way back home from the recreation centre and they may become lost, putting them at risk for injury, or even death.

Although wandering is more common in the middle or later stages of dementia, wandering can occur at any point during the disease. Staff who work in recreation centres, community centres or parks may interact with someone who appears to be wandering. If you notice that someone may be wandering you can:

- Speak to the person slowly, calmly and clearly.
- Offer them a glass of water or a warm blanket if available.
- Stay with the person.
- If an emergency contact is available, contact them immediately. If not, call 9-1-1.

For more information about this important topic please visit the Alzheimer Society of B.C.'s web page on wandering, or contact the First Link® Dementia Helpline at 1-800-936-6033.



Inclusion, staying active and recreation services

At first a person may tell you that they are living with dementia and need little assistance, but as their dementia progresses they will start to have more challenges. It is likely there will eventually be a time when they will need some additional support to participate in activities, such as a gym buddy who can help them use the fitness equipment correctly, or a helping hand to scan their membership card correctly at the reception desk.

Many people living with dementia and their care partners continue to enjoy taking part in a variety of leisure and recreation activities. People living with dementia and care partners often feel that programs that consider the needs of people living with dementia are more welcoming and appropriate for them than those that do not. You could consider creating a special program or group for people living with dementia. It's also important to remember that, for the person living with dementia, attending and participating meaningfully is often a more important goal than mastering the activity.

What are some dementia-friendly activities?

Dementia-friendly activities can be any type of leisure activity that provides an opportunity for people living with dementia to:

- Enjoy an activity.
- Learn or practice a skill.
- Maintain a sense of social connection.

Dementia-friendly activities are not focused on dementia, but are designed in a way that will allow someone living with dementia to participate. They are planned for, and are welcoming to, people living with dementia, their care partners and friends. Existing activities can be adapted, and new activities can be planned and implemented, provided the facilitator or trainer has an understanding of dementia, experience with the activity and the ability to coordinate it. Facilitators, staff and trainers are encouraged to familiarize themselves with the information, support and education programs, and services offered by the Society. This will increase their understanding of dementia, and reduce the likelihood of misinformation or service replication.

You may already have an activity in mind to add to existing programs, or existing activities you would like to see become more dementia friendly. If you are unsure, here are some ideas to help you get started:





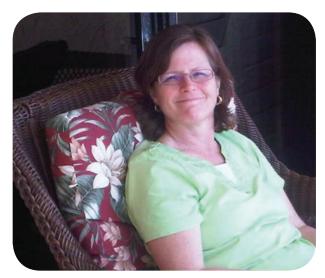


- Memory café social meeting
- Walking group
- Breakfast, lunch or dinner at a restaurant
- Potluck
- Arts and crafts
- Dancing
- Sharing life stories, experiences and memories
- Concerts and other musical shows
- Karaoke
- Choir
- Golf
- Gardening
- Cooking classes
- Games, playing cards
- Bingo
- Movie night
- Indoor or outdoor get-togethers for sporting events
- Relaxation, meditation or yoga
- Book club, poetry or reading group

What makes activities easy to participate in?

There are a variety of ways that programs can be planned to consider the needs of people living with dementia. If programs are mindful of the needs of people living with dementia, the activities can be recommended as good options to stay involved in the community. A program that is dementia friendly would have the following characteristics:

- They cater to adult interests that avoid treating people living with dementia like children.
- They are attentive to inclusivity.
- Participants receive high levels of encouragement.
- Activities are non-competitive and/or slower paced. Lawn bowling is a good example.
- The organizers are mindful of auditory and visual stimulation when considering the environment. For example, it may be helpful to ask participants if they would enjoy having background music, or if they would prefer a quiet environment.
- They allow participants to set their own limits. For example, in a yoga class a person may like to use a chair and have an instructor show modified movements.

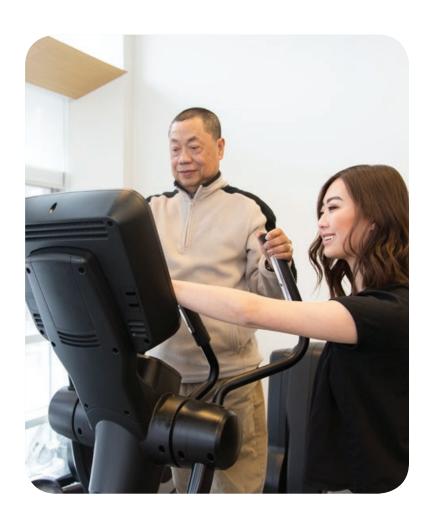


There are many people living with dementia in their early 60s, 50s or even 40s. Activities that younger people living with dementia might want to engage in should be considered as well. On average younger people living with dementia may be more physically able in comparison to older adults living with dementia and may want to take part in more physically challenging activities.

While scheduling programs or choosing from existing programs to recommend to a person living with dementia, here are some considerations to keep in mind:

- The ability to drop in without mandatory weekly attendance because some days may be "bad days." This also means considering drop in and cancellation rates.
- While dropping in is an important option, a routine schedule makes it easy for people to know that they can drop in at the same time as they did two weeks ago; this predictability may be helpful.
- Activities should not be too long 30 to 45 minutes is optimal.
- Smaller class sizes are usually preferable. For example, a class with fewer than 20 participants might be ideal.

Programs that have an assistant or volunteer to help participants (while a separate instructor leads a class) can be dementia friendly as well as beginner friendly. The assistant or volunteer could help correct technique or offer other options to people living with dementia.



When staff and other participants are accepting and understanding of the changes a person living with dementia may be experiencing, the whole community can begin to feel more supportive for people living with dementia.

What makes activities challenging to participate in?

When planning or recommending activities, here are some things to avoid:

- High levels of decision-making related to the activity itself.
- Situations where people are called out for not doing the activity "correctly," by either the organizer or other participants.
- Lack of continuity and cohesiveness in services. For example, when transportation, activities and support services do not align.
- Activities that are planned at times that might make transportation challenging.
 Consider if it will be dark outside, if public transit will be running, and if their family is likely to be able to drive them.
- Unclear roles for care partners. Having clear roles, a waiting area or free admission are examples of possible solutions.

Tips to increase participation rates:

- Sending out invitations can make attendees feel valued, welcome and comfortable.
- Distribute "reminder cards" for people to take home that include the date and time of upcoming activities or programs.



What should facilitators and trainers know about leading activities that include people living with dementia and their care partners?

You may be aware there is a person living with dementia in your activity group or be leading an activity that is designed for people living with dementia. Here are some suggestions to make the activity welcoming to people living with dementia:

- The focus of the activity should be on participation and enjoyment, rather than exact reproduction of the activity.
- Sometimes people living with dementia will want to get up, leave and come back and that is okay. Just be aware of their safety.
- Asking a person living with dementia to start or lead the activity is difficult. It is easier for them to watch first and see what others do.
- Taking breaks during the activity is recommended.
- If there is seating in rows, offer people living with dementia aisle seats so they can get up and move around more easily.
- Provide the support to help people living with dementia participate, but treat them with the same respect as other participants in your program.
- Many people living with dementia have difficulty telling time on an analog clock but can still read the numbers on a digital one. For some though, reading the numbers on a digital clock has no meaning. When referencing time, during a program for example, it might be best to make reference to other clues as well. For example, "Our class will be over in 30 minutes, right after the music ends."

Some people living with dementia experience "sundowning," a phenomenon which often results in greater disorientation or confusion later in the day. In these cases, late afternoon or early evening activities may be challenging.

Tips to help make your recreation centre dementia friendly

Along with providing dementia-friendly programs and services, recreation and community centres can adapt their physical and social environments to be more dementia friendly. Here are some dementia-friendly actions you can implement to improve the experience of people living with dementia.

Physical environment

- Designate a quiet space away from background noise where it is easier to have a conversation with someone living with dementia.
- 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, change rooms, drinking water, and other important areas is large, clear and at eye level. Verbal directions may be forgotten quickly and people living with dementia may accidentally leave a building or area if there are not clear signs to help them find their way.



- Consider displaying large clocks in different areas of the building using both analog and digital clocks can be helpful.
- Lockers can be a challenge if they are unmarked or the matching key is unmarked. Solutions could include that the locker number be on the key, or a staff member could have a key valet.
- Equipment sign-up systems can be challenging or unclear for people living with dementia. It may help to provide assistance when you see a person who might be having challenges signing up correctly indications might be that a person is pacing or standing still for a long period of time.
- As dementia progresses individuals often begin to need some assistance with using the washroom and change rooms. Consider creating mixed or family washrooms and change rooms so care partners and family members can provide assistance if needed.

Social environment

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 living with dementia.

Some ways to achieve this include:

- Creating an organizational awareness about dementia by sharing this booklet or by contacting the Alzheimer Society of B.C. for more information.
- Having staff attend the Dementia Friends workshop for a "dementia 101." More information about these workshops can be located in the resource section on page 21.
- Training staff to recognize the signs of agitation and disorientation.
- Designating 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.
- Making name tags for participants, facilitators, staff and volunteers. For
 example, a person living with dementia may participate in weekly classes
 where they are able to recognize a person but not necessarily remember their
 name. Name tags can help reduce the likelihood of a potentially embarrassing
 interaction.

With the permission of the person living with dementia or their care partner, add a note in the person's file to indicate that the person might have challenges related to their dementia, so that other staff can be aware. Consider adding an emergency contact as well in case the person is found wandering or is very disoriented one day.

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 Alzheimer Resource Centre in your area: www.alzheimerbc.org.
- Call the First Link® Dementia Helpline, a province-wide service for people living with dementia, their caregivers, family and friends. Call toll-free: 1-800-936-6033 or 604-681-8651.
- Email us at dementiafriendlybc@alzheimerbc.org for more information about making your organization dementia friendly, including information on requesting Dementia Friends workshops for your organization.

The Alzheimer Society of B.C. hopes that many community and recreation centres plan and create dementia-friendly programs. Due to the volume of these activities, we are unable to provide official endorsements – a logo, program advertisement, or other promotion – for dementia-friendly programming. The Society encourages recreation service providers to use the resources on page 22 for more information.



Resources for further information

Seniors First BC

(formerly known as BC Centre for Elder Advocacy and Support) 150-900 Howe Street, Vancouver, BC V6Z 2M4

Seniors Abuse and Information Line:

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

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

www.SeniorsFirstBC.ca

Canadian Network for the Prevention of Elder Abuse

A national non-profit organization focused on elder abuse prevention and response.

http://www.cnpea.ca

HealthLinkBC

HealthLinkBC provides 24/7 non-emergency health information to residents of British Columbia.

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® Foundation Canada.

www.medicalert.ca/safelyhome

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

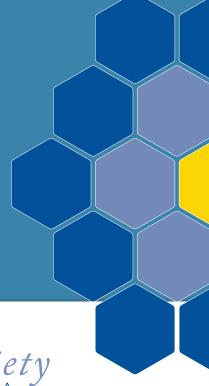


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Alzheimer Society

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

www.alzheimerbc.org