

Alzheimer*Society*

S A S K A T C H E W A N

Learn More **Live Well**

Dementia Friendly Community Resource

Building Dementia Friendly Communities



"If you focus on setting the tone of making everyone feel welcome and included when they walk in the door, then everybody follows that lead. That is the atmosphere to try and create."

- Joan Michael, Head Librarian Saltcoats Public Library

The Alzheimer Society

Community of Support

The Alzheimer Society of Saskatchewan's programs and services help people with dementia, their care partners, families, and friends by providing information, support, education, and referral to other community services.

When you choose the Alzheimer Society, you join a community of supporters and experts committed to helping each of us thrive. Our role as a Society is creating and fostering a community of support in the management of dementia in the lives of those living with the disease.

Dementia friendly communities are important in Saskatchewan to support people living with dementia, promote inclusion and understanding, and help reduce stigma and discrimination. By working together to create more dementia-friendly communities, we can help improve the lives of those affected by dementia and build a more compassionate and supportive society.

Approximately 60 per cent of people living with dementia live in their community and, with support, they can maintain a good quality of life.

Our Role in Supporting Dementia Friendly Communities

Goals:

- Reducing stigma to build a society that is more accepting and supportive of people living with dementia.
- Promoting and educating the general public about dementia.
- Increasing inclusion and accessibility of people living with dementia.

Invite your local Alzheimer Society to **host a presentation** in your community – it's a great way to **share information about dementia** with other community members.



Community definition:

The term "community" can refer to geographical parameters but also includes groups of people gathered around shared interests or features. This means that cities and towns can become dementia friendly, as can organizations, a book club, a business, a local coffee shop, a faith-based group, or a grocery store.

This resource will help you to:

- Understand, recognize, and support the signs of dementia.
- Mindfully communicate in an effective and respectful way to people living with dementia.
- Understand more specific actions you can take in your community to be more welcoming, inclusive and accessible for people living with dementia.
- Build and sustain dementia friendly actions for yourself and your community.

**Call our Dementia Helpline at
1-877-949-4141 or, email
helpline@alzheimer.sk.ca.**

**Our Dementia Helpline is available
Monday to Friday – 8:30am - 4:30pm.**

What is Dementia Friendly

Dementia friendly communities are places where people with dementia and their care partners are supported to live well by feeling included, welcomed, and understood in the activities they are participating in outside their homes.

Dementia friendly communities promote locally based supports and address barriers experienced by individuals living with dementia and their care partners.

**“If you’ve met one person with dementia,
you’ve met one person with dementia.”**

Four key components of building dementia friendly communities:

Awareness

Building awareness of dementia is the first and most important part of building dementia friendly communities. Increased education around dementia, including its symptoms, how it is experienced, and how it can be managed will help us reduce the stigma and stereotypes that keep people living with dementia feeling isolated and misunderstood.

Meaningful Engagement

This involves ensuring people living with dementia are understood and given room to have a voice. This also includes understanding the changes in communication for people living with dementia, for the right to be talked to with respect, and given patience in conversations.

Accessibility

Accessible communities are safe and inclusive for people living with dementia and their care partners while promoting comfort and independence. This includes how people experience both social and physical aspects of a community.

Community Involvement

The continued engagement for dementia friendly communities involves collaboration and community involvement. Advocacy and a sustainable long-term plan for your community is crucial for the success of dementia friendly communities.

Dementia friendly initiatives will:

- Improve the quality of life for people with dementia, their care partners, and social circles by building awareness and understanding through increased education efforts throughout professional sectors and community service providers.
- Reduce stigma and address barriers around dementia that prevent people with dementia from engaging in community activities due to misunderstandings of dementia.
- Amplify the voices and perspectives of those living with dementia and those who are caring for someone with the disease.
- Create safe, supportive, and welcoming environments for people with dementia to remain in their own communities and continue their daily activities for as long as possible.
- Build a greater understanding of dementia experiences in the professional sector, reducing stressful interactions for staff and clients/customers.
- Develop and maintain a community of support for people living with dementia and their care partners, across different sectors in our community.



Awareness

In Saskatchewan, there are 20,000 people living with dementia and 60% of them continue to live in their homes in communities.

Education

Some people may announce to you that they have dementia, some may carry a card such as a Companion card or Independence card to silently be able to share that they have dementia, others may not say anything at all.

People will not always inform you about their needs or ask for help.

Being dementia friendly does not mean that you must identify all people who have dementia or ask difficult/intrusive questions.

It is important to respond appropriately if a person is experiencing any of the following:

- Appears to be lost; looking around frantically and possibly upset.
- Experiencing challenges navigating the environment to the point of visual confusion or frustration.
- Confused about the time or location they are in.
- Notably having problems remembering what they are doing or what to do next.
- Having difficulties in communicating clearly; may not be able to form complete sentences or talking "gibberish".
- Challenges with word finding or identifying items properly.
- Struggling to read and comprehend written information.

Research has projected the number of people living with dementia in Saskatchewan to grow by 142% in the next 30 years (Alzheimer Society of Canada's Landmark Study).

Actions you can take to increase your education on dementia:

- Attend one of the regularly held presentations by the Alzheimer Society of Saskatchewan, view a previously recorded presentation on Alzheimer Society of Saskatchewan's YouTube page, or request a live presentation for your community from your local Alzheimer Society.
- We offer presentations on the ABC Signs of Dementia, Reducing the Risks of Dementia, and multiple sector specific information sessions.
- Request and review the specific tools created for building dementia friendly communities.
- Work with your local Society staff to understand and implement the appropriate education and changes for your community.

To increase understanding and empathy, dementia friendly communities must include opportunities for dementia education and awareness. The Alzheimer Society has many tools and resources to support you in this aspect and will continue to update you as new ones are released.

"It is not possible to determine someone is living with dementia simply by looking at them."

Inclusion

Stigma surrounding dementia encompasses any negative attitude or discriminatory behaviour against people living with dementia, just on the basis of having the disease. **Stigma not only hurts people living with dementia, it discourages their families from confiding in others or getting the support they need.**

Stereotypes and misinformation can intimidate friends and family into not providing help. Due to unfounded myths about dementia, people believe that “nothing can be done” or dismiss symptoms as “just a normal part of old age.” This isn’t helpful to hear for a person living with dementia. Assuming that nothing can be done to help, the people in person’s circle may start to withdraw, no longer interacting with the person living with dementia.

“The biggest barrier to inclusion people living with dementia and their care partners report facing is stigma.”

Dementia friendly communities can help promote greater understanding and awareness of dementia among the general public. This can help reduce stigma and increase empathy and support for those affected by the condition. It can also help improve access to services and resources for people living with dementia and their families. **People living with dementia often face stigmatization and discrimination, which can lead to feelings of isolation and exclusion.** By creating dementia-friendly communities, people living with dementia can feel more included, valued, and supported. This can help improve their overall quality of life and wellbeing.

Dementia-friendly language:

- ✓ A person living with dementia
- ✓ Challenging, life changing, stressful
- ✓ Changes in behaviour (speak to how behaviour has changed)
- ✓ Reactive behaviour
- ✓ Responsive behaviour
- ✓ Respectful terms that acknowledge the person is an adult (e.g., “clothing protector” or “smock”)

Language to avoid:

- ✗ Sufferer, demented person, victim, patient
- ✗ Devastating, hopeless, tragic
- ✗ [A person is] being difficult
- ✗ Aggressive
Referring to behaviour resulting from frustrations as “reactive” or “responsive” rather than “aggressive” shows that you understand the reality of the person living with dementia
- ✗ Terms that are typically associated with children and inadvertently infantilize people living with dementia (e.g., “bib”)
- ✗ “Elder speak” / patronizing language such as “sweetie” or “dear”

Communication

How does dementia affect communication?

Dementia affects how people express themselves and understand what is being communicated to them. For the person living with dementia, maintaining relationships can be a complex process, especially when verbal communication is affected. The following changes are common:

- Difficulty finding a word.
- Creating new words for ones that are forgotten.
- Repeating a word or phrase (perseveration).
- Difficulty organizing words into logical sentences.
- Cursing or using other offensive language.
- Reverting to the language that was first learned.

Believe that communication is possible at all stages of dementia. Difficulties with communication can be discouraging for the person living with dementia and families, so consider creative ways to understand and connect with each other. Remember:

- What a person says or does and how a person behaves has meaning.
- Never lose sight of the person and what they are trying to tell you.
- The key to positive conversations with people living with dementia is respectful, sensitive and consistent communication.

Meaningful Engagement

Meaningful engagement is a person-centred approach that encourages and invites people with dementia to purposefully participate in the activities of organizations/communities. Participation includes actively contributing ideas, skills, and abilities, while recognizing that individual participation will vary, depending on abilities, personal histories, and available opportunities.

Meaningful Engagement Requires:

- A welcoming, encouraging attitude.
- Being knowledgeable about the effects of dementia on the person.
- Encouraging people with dementia to speak for themselves.
- Active listening and engagement in dialogue.
- A safe environment for expression of opinions without fear of being judged or dismissed.
- Opportunity to influence what happens and make decisions that matter.
- Recognition of skills and abilities.
- Meaningful and useful participation.
- Being listened to and understood and having views respected and heard.

Benefits of meaningful engagement for the person with dementia include:

- Being listened to as an equal.
- A sense of purpose and routine.
- Being offered an appropriate outlet for empowerment, skills, and experiences.
- An increased self-esteem and sense of accomplishment.
- Being able to address issues related to living with dementia.
- Being offered opportunities to influence policies and programs which can improve quality of life.
- Being able to provide the perspective of a person with dementia and affect decision making.

Accessibility - Friendly Spaces

Dementia friendly communities are safe, accessible, and inclusive in both the physical and social environment. This includes having proper signage, minimizing visual and auditory distractions, and comfortable physical environments that are easy to understand. This will help promote people to independently navigate their environments and feel a sense of security in the community.

Dementia Friendly Environments aim to:

- Empower and include individuals experiencing dementia symptoms.
- Reduce social isolation for people with dementia and their care partners.
- Challenge the stigma surrounding dementia.
- Raise awareness of dementia- including the warning signs and ways to reduce the risks of dementia.
- Support people living with dementia.
- Include people living with dementia in the process of changes and accommodations through meaningful engagement- “nothing about us, without us”.

Simple changes in the physical environment may contribute to a more welcoming and accessible space in which people with dementia are supported to navigate more independently and can improve the universal accessibility of the space. Whether incorporating small changes now or identifying considerations for future renovations, creating welcoming and accessible spaces starts with assessing the physical environment through a dementia friendly lens. Whenever possible, encourage the input of people with dementia and care partners when identifying ways to improve the physical environment. They may be able to provide valuable insight into the most important areas for improvement and can help to ensure any efforts will truly be useful.

Consider:

- Entrances/Exits
- Directional Signage
- Available Furniture and Seating Areas
- Surfaces/Flooring
- Landmarks
- Accessible Bathrooms
- Lighting
- Quiet Spaces



For a detailed checklist on environmental changes you can make in your space, contact the Alzheimer Society of Saskatchewan.

Steps to Becoming Dementia Friendly

Awareness

The first stage of a dementia friendly community is raising awareness about dementia. With a better understanding of dementia, individuals and communities can begin to think of community solutions to make their community or organization more accessible and welcoming to people with dementia.

Participate in an Alzheimer Society learning opportunity (online or in-person) or contact your local Alzheimer Society to learn more about local resources and upcoming events.

Engagement

With an increase in dementia awareness, individuals and organizations become more open to engaging in a conversation about what dementia means for them and how issues of accessibility and inclusiveness can be addressed.

Engagement is really about moving from an awareness monologue to a community dialogue about what is possible.

Collaboration

A successful community collaboration generates a map for the organization's journey to become more dementia friendly. The detail, complexity and elements involved are different from organization to organization. Our role is providing as much information and resources as possible to assist the organization in its efforts to become more dementia friendly. Often this is a two way learning process for us and the organization involved.

Community Involvement

Once individuals are engaged through awareness building and provided support through resource sharing, mobilizing the caring power of the community becomes possible – generating the potential for a more inclusive community. Community involvement turns hope into action, creating the solutions that work for the community.

All types of organizations can all play a role in helping Saskatchewan become a more dementia friendly province by learning more about how services can better meet the needs of people experiencing dementia.

For more information on how you can make your community/organization dementia friendly, contact our Public Awareness Coordinator: Erica Zarazun at ezarazun@alzheimer.sk.ca

