

Common Views and Facts About Dementia

Also available in Punjabi, Hindi, and Urdu | ਪੰਜਾਬੀ ਵਿੱਚ ਵੀ ਉਪਲਬਧ ਹੈ | ਹਿੰਦੀ ਮੈਂ ਭੀ ਤਪਲਬਧ ਹੈ | ਅਰਦੂ ਮਿੰ
ਬਹੀ ਡਸਤਿਯਾਬ ਹੈ

This is a resource for the South Asian community. It was developed together with caregivers of people living with dementia within the South Asian community in Canada. A caregiver could be a family member, friend, or another person who is supporting a person living with dementia.

This resource provides information about:



Common views about dementia within the South Asian community



Facts to reduce stigma



Stigma refers to the assumptions, negative attitudes and/or mistreatment of people based on a trait or characteristic. People living with dementia may experience stigma when others find out about their diagnosis. Many people living with dementia also experience self-stigma. This means they feel negatively or ashamed about themselves because they have dementia. Stigma can be reinforced by inaccurate views, stereotypes and misinformation about dementia. Let's have a closer look at some of these views, and some facts about dementia that may help reduce stigma.

View 1: Dementia is a normal part of aging.

Fact 1: Dementia is not a normal part of aging.

The risk of developing dementia increases as you age, however many people do not develop dementia. Some people report mild challenges with memory (for example, forgetting events from a long time ago), planning and decision-making (for example, finding it hard to multitask), language (for example, occasionally forgetting a word), and managing new information (for example, taking longer to learn a new device) as they age. When developing this resource, some members of the South Asian community shared that, in some cultures, signs of dementia may be viewed as an older person connecting with God, which is an expected part of aging. Changes in memory and problem solving that impact daily life, challenges completing routine tasks, and frequent difficulty with finding words and following conversations are not a normal part of getting older. It is a good idea to speak to your family doctor or another healthcare provider if you are concerned about any changes with your memory, thinking or functioning. Even if it's not dementia, it may be helpful to rule out other causes for the changes you are experiencing.

Visit the [Alzheimer Society of Canada](https://www.alzheimer.ca) to learn more differences between normal aging and dementia.

View 2: People with dementia are victims who are suffering and incapable.

Fact 2: Many people with dementia are capable, content, and happy.

A common stereotype about people living with dementia is they are victims suffering and being robbed of their memories, identity, and life. People living with dementia are often shown on television, in books, and described in the news as powerless, incapable and dependent.

Many people living with dementia do not meet this stereotype. While people may experience sadness, uncertainty, and fear after being diagnosed, many adjust to the diagnosis and live fulfilling lives. People living with dementia may have symptoms such as changes in memory or concentration, but they know who they are and may hold onto important memories. Many do a lot for themselves, and for others, and are in control of their lives, even if they need help with some tasks. As dementia progresses, many people living with dementia still feel joy, have awareness, preferences, and the ability to communicate in different ways, including verbally, through body language or touch. Caregivers and others can support the person living with dementia by acknowledging their feelings, reminding them of their abilities and value, and treating them with dignity and respect.

Occasionally, people in the community including some doctors and other healthcare providers may also view people living with dementia as dependent and/or incapable. This may be shown by not including the person living with dementia in decisions about their care, talking to the caregiver instead of to the person living with dementia directly, or not giving the person living with dementia information, choices or hope. It is important to speak up to ensure that the person living with dementia is directly included in conversations and decisions about care and quality of life.

View 3: People living with dementia are mentally ill or “crazy”.

Fact 3: Dementia is a term describing changes in the brain. It is not defined as a mental illness.

Dementia is a term that describes a set of symptoms such as changes in memory, mood, thinking, problem-solving, communication, mobility and perception that can affect daily life. Due to changes in the brain, people living with dementia may experience changes in their personality, behaviour, and ability to communicate with others. As a result, they may communicate their needs using words (for example, shouting), actions (for example, pushing away) and expressions (for example, crying) that are confusing, hurtful or difficult for others to understand. For example, someone living with dementia may be trying to tell others they are thirsty, the room is too loud, or they are in pain but are unable to put these needs into words. It is important to remember that behaviour has an underlying meaning, and to try to uncover what the meaning is, rather than say the person living with dementia is “crazy”, “difficult”, or “aggressive”.

View 4: People who develop dementia are receiving a punishment for doing something wrong.

Fact 4: Anyone can develop dementia.

Dementia is not something to be ashamed of, just like other health conditions such as arthritis or heart disease. There are some factors that may increase the risk for developing dementia such as high blood pressure, smoking, alcohol use, diabetes, depression, low physical activity, social isolation, poor diet, brain injury, hearing loss, age, gender, and genetics.

View 5: Caregiving is always a burden to caregivers.

Fact 5: Supporting a person living with dementia can be hard, but with planning and support it can also be rewarding.

Caregivers acknowledge that supporting a person living with dementia can be physically and mentally tiring. Caregivers from the South Asian community described that caregiving is often seen as a familial obligation. Some symptoms of dementia are more difficult to manage than others, and may become more challenging as dementia progresses. There may be pressure and disagreements within families about how to best care for the person living with dementia.

Despite the many challenges associated with being a caregiver, there can also be rewarding experiences. Some family members view caring as an opportunity to return the support they received from the person living with dementia in the past. Many find joy from being able to spend time with the person living with dementia and perhaps build an even stronger relationship.

Some caregivers said it takes a team to support both people living with dementia and caregivers. Planning ahead and using available resources and supports, can help caregivers feel comfortable taking breaks. These breaks may help caregivers relax or do something for themselves. They can also give caregivers more energy to care for the person living with dementia.

It is important for caregivers to recognize when they need a break, and to communicate with others about the support they need.

Visit forwardwithdementia.ca for more information about **Learning About Programs and Services** and **Caregiver Self-Care**.



View 6: People living with dementia cannot learn new things.

Fact 6: People living with dementia can continue to learn!

Some types of dementia may impact a person's short-term memory. They may not remember things that happened recently, and it can also take more time and effort to learn new things. However, it is possible, especially earlier in the progression of dementia. For example, many people living with dementia learned to use Zoom to video-chat during the pandemic. Even as dementia progresses, people living with dementia may retain new information. For example, a person living in a care setting may remember their seat in the dining room, develop familiarity with a particular staff member, or learn the rules to a new activity.

It can be stressful for a person living with dementia to go into a situation where they have to learn something new. Some people living with dementia have told us it's frustrating and they sometimes avoid these situations. Some strategies that may assist with learning something new are: taking your time, using pencil and paper to take notes, and asking for help when needed. Caregivers can provide support by repeating information as often as needed, providing encouragement, and assisting the person living with dementia when required.

View 7: There is nothing that can be done for people living with dementia.

Fact 7: There are many treatments and strategies that can help to slow progression and manage symptoms.

It is true there is not a cure for dementia, but there are treatments and strategies that can help improve quality of life, and functioning in daily life. There are medications that may help slow the progress of dementia, and non-drug treatments, such as memory strategies, and music, speech, and occupational therapies that can support well-being. Living a healthy lifestyle, including diet, exercise, and being mentally and socially active is a strategy that promotes happiness and well-being, and reduces stress. You can continue to enjoy living your life while living with dementia or supporting someone living with dementia.

Visit forwardwithdementia.ca for more information about **Managing Symptoms and Changes** and **Having Hope and Living Well**.