

# Sharing a Dementia Diagnosis

Also available in Punjabi | ਪੰਜਾਬੀ ਵਿੱਚ ਵੀ ਉਪਲਬਧ 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:

- ✓ Sharing the dementia diagnosis with others
- ✓ A “Planning to Share” worksheet to help you plan conversations about your diagnosis



## Sharing a dementia diagnosis

Caregivers from the South Asian community shared it is common for a dementia diagnosis to be delayed due to the lack of awareness and acceptance of dementia. People living with dementia and caregivers may also be hesitant to tell others about the diagnosis because of the stigma and feelings of shame that are often associated with dementia. By not talking about dementia, people living with dementia and caregivers may feel isolated, and may delay accessing treatment, services and support from others, and planning for the future.

Talking openly and addressing misinformation helps to challenge the stigma related to dementia. Visit [forwardwithdementia.ca](http://forwardwithdementia.ca) for information that may be helpful when sharing with others, such as **What is Dementia?** and **Common Views and Facts About Dementia**.

Sharing the diagnosis with others can have benefits, including:

- Helping friends and family understand what you are going through (as a person living with dementia or a caregiver), and how they can better support you.
- Helping to explain changes in behaviour or mood that other people have noticed, and avoid misunderstandings.
- Making connections with others who may open up about similar experiences

Sharing a dementia diagnosis with certain people can be difficult. For example, people who are still working will need to think about telling their employer. Human Resources staff might be able to help you understand your rights at work and help you talk to your manager. Some employers are supportive and might make adjustments to your role if needed, others are less supportive. It can be helpful to talk with your doctor, caregivers, family members and/or friends about how to best approach difficult conversations.

You can also read about the [Canadian Charter of Rights for People with Dementia](#) and the [Work and Employment](#) article of the United Nations Convention on the Rights of Persons with Disabilities for information about rights of persons living with dementia.

## Tips for sharing a diagnosis

There is no right or wrong way to share a dementia diagnosis. We have provided some tips for sharing a diagnosis with others.

- Include people living with dementia in the conversation. The person living with dementia should be in control of how, when, and with whom their diagnosis is shared if they are able. Relationships and cultural values may affect whether these decisions are made independently or with a caregiver. If the person is diagnosed later in the progression of dementia, caregivers may have more responsibility for sharing.
- The person living with dementia may ask a spouse, child or person close to them to share the news so they have support during a difficult conversation.
- Find a way to help people understand what dementia is. Some members of the South Asian community shared that they found it easier to explain dementia as “changes in the brain” to others.
- The privacy and feelings of the person living with dementia should always be respected when caregivers consider what, how much, and with whom information is shared.
- When caregivers are sharing the diagnosis, they should consider sharing what the person living with dementia is still able to do, rather than focus only on their challenges.
- Share the dementia diagnosis at your own pace. Some may choose not to tell others right away, others may share the news gradually, and some may share it immediately.
- Share the dementia diagnosis in your own way. Some people chose to tell others face to face, by telephone, letters or by e-mail.

Planning and writing down what you want to say before sharing the dementia diagnosis, may be helpful. You can include your diagnosis, symptoms, type of support you need, etc.

## “Planning to Share” Worksheet

The “Planning to Share” worksheet is a tool designed to help you share the dementia diagnosis with others. This worksheet can be used by a person living with dementia, caregiver, or by both together to identify who you want to share the diagnosis with. The first few boxes are filled out to provide examples.

<b>Who</b> Who you want to share the diagnosis with	<b>What</b> What, and how much you would like to tell them	<b>Where/When/How</b> When, in what location, and how you would like to tell them	<b>Why</b> Reasons for sharing, or requests for support
My sister	My diagnosis	In-person, by inviting her over for tea	Ask her to come to my next doctor’s appointment
Friends from temple	Explain the changes with my memory	Over the phone this month	Ask for them to not tell others for now
My financial advisor	My diagnosis	Email them to set up an appointment	To discuss our family’s finances, and setting up a power-of-attorney

<b>Who</b> Who you want to share the diagnosis with	<b>What</b> What, and how much you would like to tell them	<b>Where/When/How</b> When, in what location, and how you would like to tell them	<b>Why</b> Reasons for sharing, or requests for support