

WHAT TO EXPECT AFTER A DIAGNOSIS OF DEMENTIA:

An Indigenous Persons' Guide



For people with a diagnosis of dementia...

A diagnosis of dementia can be scary. Sometimes people diagnosed with dementia do not accept it at first. Many older people believe that changes to the mind come naturally with age and their journey through life. While some memory changes can be expected as you age, dementia as a disease will change your memory and concentration more quickly. For this reason, it is important to start talking about it now with your loved ones and others who will support you.

We have created this Indigenous Person's guide to help you understand your diagnosis and the path ahead. Indigenous peoples who have had dementia in their own families made these suggestions:

- Learn about the different types of dementia – they may have different symptoms
- Find resources that tell you about the progression of dementia and make sure you know what to expect at each stage. Dementia can act slow or fast in different cases. Make sure you are planning ahead
- Think of the people who will help support you when you need it, such as family, friends, community members or health care workers
- Think about who you will ask to make decisions for you when you need them to. It is best to think about these legal issues when you are first diagnosed
- Find community supports such as the local health centre programs or staff, home and community care programs or your local Alzheimer's Society
- If you are still driving you will need to think about how you will eventually stop and work with the local programs, friends and family to find other ways to get around
- Pay attention to your physical health by eating well, being active and taking care of other illnesses you might have like diabetes or high blood pressure
- Stay connected with people and be social

- Set up regular appointments with your health care providers to check in on the dementia and any new care needs that arise – for example, you may need more home care or medical equipment in your home
- Consider taking family members to your medical appointments and information sessions so they can learn how best to help you
- Consider wearing a medical I.D. bracelet
- Keep track of what tasks are frustrating or upsetting and ask for support to complete them
- Keep calendars, journals or lists. Sticky notes on mirrors and refrigerators can help
- Formal medical care is not the only way to deal with dementia. Other techniques Indigenous people use include prayer, ceremony, church, meditation, yoga, visiting with youth, art-therapy, story-telling, speaking the language and humour
- Connect with a doctor you trust and visit regularly and tell them about any changes to your memory or health

“One of the things that I’ve found is try not to get frustrated. I’ve laughed but also I’ve gotten angry when I’m by myself and trying to figure out something. There was times of frustration because I couldn’t think why can’t I do this thing, but I had to overcome that with laughter or you know.” (Person diagnosed with Dementia from Moose Cree).



For caregivers...

There is much to consider following a diagnosis of dementia. Your role as a support person or caregiver is very important. Caregiving can be challenging but many Indigenous caregivers stories also show that they have found the role rewarding in many ways. Some found it a way to reconnect with loved one and as an opportunity to learn about them and their life in a new way. Caring for a loved one with dementia is demanding on your mind, emotions, body and spiritual self. Some Indigenous caregivers find that they lose sleep, worry often, become frustrated with their loved one and find it tough to balance work, caregiving and their own lives.

“I’m doing a lot of working from home right now which is hard; another challenge is that I don’t have any down time.” (Caregiver from Sudbury)

At the same time, many caregivers find that dementia gave them the opportunity to become closer to their loved one.

“It brought us, both of us closer since she had to rely on me too. It just brought us closer as a mother and daughter. And then having someone to depend on me and needing me helped to change my attitude. I learned to enjoy the simple things like she would, we would go outside and just look at the trees, at colours of the trees of the leaves, we would go outside and look at the birds sitting on the wires.” (Caregiver from Six Nations)



Here are some tips from other Indigenous caregivers about your new role and how to stay well:

- Draw on your values to help you through the hard times
- Be active in the care plan. Meet often with family, friends and health care workers to keep everyone involved and informed
- Talk to your loved one about what they need and what they are experiencing. Are they frustrated? Why? How can you help? Would they like to speak in their language or listen to music? Get to know what brings them joy
- Attend as many appointments and information sessions with your loved one as you can. Be informed about your loved one's care plan and speak up for their needs as well as yours
- Let neighbours and community members know about your loved one's memory challenges. They can be a great source of support and an extra set of eyes when needed
- Check in regularly with your loved one and ask friends and family to drop by too. A visitor's logbook kept by the door is a good idea
- If your loved one seems disinterested in visiting, favourite activities or taking care of themselves, address it right away. They may be experiencing depression, loneliness or their dementia may have worsened. Connect with your health care provider if you need to



- You may learn about parts of your loved one's past that you never knew about. This could be good or painful, depending on the memories that surface. If they are painful, comfort your loved one and care for yourself as best you can. Consider what in their routine or environment could have pushed that memory to the surface and change it if you can
- Keep copies of your contact information in your loved one's coats, shoes and wallet
- Connect with other caregivers, family members and community organizations for support and information
- Find ways to learn about dementia supports, treatments and the types and stages of the illness. Knowing what is coming and what choices will need to be made is important



- Take care of your own wellness. Visit your own health care providers regularly and find time to take care of your spiritual, emotional, physical and mental wellness
- Ask your providers about access to respite (someone who can care for your loved one for a short period) – you need a break too
- Take joy in the moments you have with your loved one – the time you spend, the stories that are shared, the humour and the love

“There are moments when... you got to take a break for yourself and let somebody else take your place ... you can't do it 24/7.” (Caregiver, Sudbury).



For more information...

Indigenous Inuit Home and
Community Care

www.hc-sc.gc.ca

Alzheimer's Society of Canada

www.alzheimer.ca

Indigenous Cognition & Aging Awareness
Research Exchange (I-CAARE)

www.i-caare.ca

Government of Canada

www.seniors.gc.ca

End-of-Life Care in Indigenous
Communities

<http://eolfn.lakeheadu.ca/>

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