

Native Women's
Association of Canada



L'Association des femmes
autochtones du Canada

NWAC TOOLKIT

Addressing Dementia Related Stigma
with Indigenous Specific Strategies



ACKNOWLEDGEMENTS

We want to acknowledge all the strong, resilient, Indigenous women, gender-diverse people and Elders who graciously shared their stories with us. We also want to acknowledge their family members and friends who are living or have lived with dementia.

While we acknowledge that because of dementia related stigma, seeking a diagnosis and/or support can be frightening, we hope that this toolkit will help empower other Indigenous Peoples living with dementia and their caregivers to share their stories and seek out support.

We honour and acknowledge all the lives that have been impacted by dementia, past, present, and future generations.

ABOUT NWAC

The Native Women's Association of Canada (NWAC) is a National Indigenous Organization representing the political voice of Indigenous women, girls, and gender-diverse people in Canada. Incorporated in 1974, NWAC works to advance the well-being and equality of Indigenous women through advocacy, education, research, and policy. NWAC recognizes Indigenous women in the broadest and most inclusive sense and is inclusive of First Nations on and off reserve, status, and non-status, disenfranchised, Métis, Inuit, self-identified Indigenous, and members of the LGBTQ2S+ community who consider themselves to be included within NWAC's mandate.

Much like a "Grandmother's Lodge," we as aunties, mothers, sisters, brothers and relatives collectively recognize, respect, promote, defend and enhance our Indigenous ancestral laws, spiritual beliefs, language and traditions given to us by the Creator.

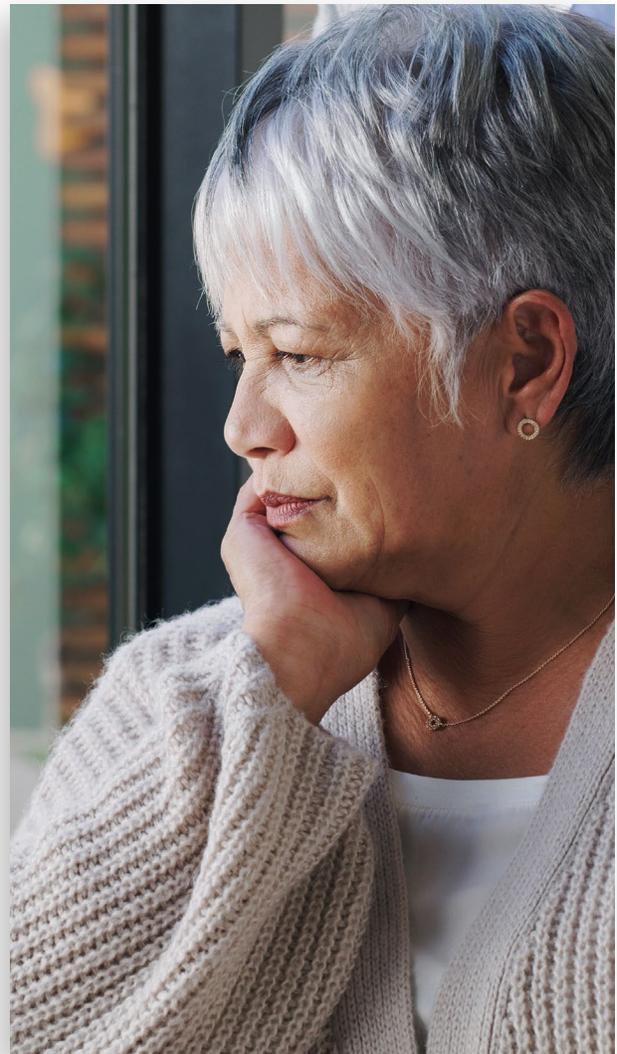
ABOUT THIS PROJECT

In support of the implementation of Canada's first national dementia strategy: A Dementia Strategy for Canada - Together We Aspire, the Native Women's Association of Canada (NWAC) was provided funding to help raise awareness of dementia within Indigenous communities, with a focus on reducing stigma. This toolkit is part of NWAC's project, Stigma: An Exploration of Lived Experiences, Understandings, and Behaviours of Dementia within Indigenous Communities.

This project focused on understanding the impact of stigma for First Nations, Inuit and Métis peoples connected to dementia and is grounded in Indigenous methodologies and ways of knowing. NWAC interviewed 12 Elders and spoke with 57 Indigenous women and gender-diverse people across through three virtual engagement sessions with First Nations, Inuit about their knowledge, understanding and experiences related to dementia and stigma.

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INTRODUCTION

This toolkit combines mainstream and Indigenous specific approaches to reducing dementia related stigma. Importantly, the Indigenous specific approaches and tips to overcoming stigma related to dementia were informed by NWAC's Stigma project where we spoke to Elders and Indigenous caregivers of people living with dementia from across turtle Island and Inuit Nunangat. It is based on this engagement and our work on dementia to date, that we humbly offer these strategies and tips to help Indigenous people living with dementia and their caregiver's overcome stigma. Importantly, quotes from Elders and Indigenous caregivers of people living with dementia are interwoven throughout the toolkit.

This toolkit has been broken down into four sections:

1. Language
2. Culture
3. Knowledge and education
4. Storytelling

LANGUAGE

Language is a unique human gift and a very powerful means of communication. Words can influence our feelings, actions, mood, and self-esteem. Words also help us communicate our needs and desires to others. Reactions to what others say to us and about us can be emotional and physical. Language can strongly affect us. Words used to describe dementia has historically been negative and at times belittling, focusing on the losses experienced by the person living with dementia. While these losses may be common, this has led to the development of stereotypes and approaches to care that focus on the deficits and challenges instead of the strengths and opportunities. This approach influences how others view dementia and contributes to stigma and discrimination experienced by people living with dementia and their caregivers.¹

So, what can we do?

USE PERSON-CENTERED LANGUAGE

Person-centred language focuses on the person instead of their condition. The use of person-centred language helps us deal with the fear and stigma surrounding dementia. By reducing the fear associated with dementia, people are more likely to acknowledge, learn and have discussions about dementia.

What does person-centered language look like?

NOT PERSON-CENTERED LANGUAGE TRY TO AVOID THIS LANGUAGE	PERSON-CENTERED LANGUAGE TRY THIS INSTEAD
Dementia patient	Person with dementia
That person is demented	Person living with dementia
Suffering with dementia	The person; the individual

INDIGENOUS LANGUAGES

As Indigenous People, we know how powerful language is. Our languages are foundational to our culture and history. Indigenous languages hold our stories, songs, dances, protocols, histories, and connections.

What does Indigenous languages have to do with dementia?

There is no word that has been identified to mean dementia in Indigenous languages in Canada. Instead, First Nations languages have words that describe the symptoms or state of mind. For example, words and phrases such as: 'forgetful', 'confused', 'thoughts mixed up', 'something wrong with my head', 'mind changes', 'going back to childhood'.

Indigenous languages hold cultural knowledge and demonstrate cultural beliefs. For example, during NWAC's engagement session with First Nations, Inuit, and Métis Elders, when we asked if they were aware of a term or description of dementia within their traditional language, many described words or terms in their languages related to memory loss which is often understood or described as a "second childhood". One Elder described it as,

"it's not one small word. It's getting ready to move into the next stage of life. Remembering that it's not losing their mind, it's their mind taking them back into the past"ⁱⁱⁱ.

CULTURE

While western beliefs and words used to describe dementia have historically been negative, Indigenous cultural understandings of dementia (as demonstrated through descriptions of dementia in various Indigenous languages) describe cultural norms and strengths such as being closer to the spirit world and Creator.

For example, for some Indigenous people, symptoms of dementia, particularly visions or hallucinations were understood as visions and gifts that individuals could access as they were closer to the Creator . Other common beliefs normalized dementia, as it was thought to be part of the life cycle. Some described this as a second childhood. One Elder who NWAC spoke to described it like this,

“It’s like these people who have this condition are getting ready to go home; it’s like they’re going back into their childhood. They go back and regress back to their childhood. They are starting to experience a joyful time of their life and we should look at it like that...We are only here on this earth, this physical, human journey for a short time, so during the short time that we are here, we have to experience life and be the best human being that we could possibly be. Now, that meant some of us missed our childhood and went through a traumatic time and never really dealt with it in a healthy way. They tried to block it out. You spend a lot of time and energy doing that. You spend a lot of time and energy that should be, could be, doing other things that are probably productive and positive for you and yet, you are choosing to try to forget something that causes pain for you, because you do not know how to deal with that pain. You don’t know how to medicate that pain, so that’s when it comes time to your adult life when you’re older now and you don’t have to worry about trying to forget what happened. Trying to control and medicate that pain. It is a creative way of letting us go back and just experience fun and joy and good relations and whatever it is that the family is doing in the comfort of the family. Just to enjoy that.”

Similarly, a Michi Saagiig (Mississauga) and Ojibwe Anishinaabe man we spoke to about his experience with his late mother who was living with dementia described,

“Over these last few years, there were times that my mom would suddenly transition back into Anishinaabemowin. This would happen more frequently as the Alzheimer’s took charge, and she reverted often to what I can only assume was an earlier time, back to her childhood”.

A Mi’kmaq woman who provided care to her late mother who was living with dementia spoke about traditional teachings that helped her and her mother cope with dementia:

“I recall having to identify people for my mom, as she presented with signs of early dementia. But for us, we always giggled and laughed that we just were getting older and forgetting, things, places, and people. We as Inu people are familiar with the little people playing tricks or being tricksters and hiding things on us until we forget about it. We call these people the Booglatamootj”.

Not only can culturally grounded understandings of dementia help people who are living with dementia and their families cope and understand what is happening to them, it can also help to reduce stigma. In Indigenous cultures, aging and Elders are highly revered. While not all older Indigenous peoples will achieve Elder status, older Indigenous adults are still given a special status and are highly respected members of their communities, recognized for their ability to contribute to traditional roles, such as passing on their knowledge and life experiences. For example, a Mi’kmaq caregiver of a person living with dementia we spoke to shared:

“We all had a chance to learn from her hands on approach as a family, but also the whole community to pass on to the next generation. It is with great pride to be able to acknowledge our ancestors of the past, present, and future. we are all connected in this circle of life to come to a journey of birth, adolescent, adulthood, and elderhood...Until we meet again my mother, I will always love you and cherish the gifts of life you have given to me in this hoop of life we live in. Msit nogoma.”

Caring for a loved one living with dementia can provide an opportunity to gain knowledge and show respect and reciprocity, giving back to those that gave to us. A Métis caregiver of her parents who both lived with dementia explained:

"I looked at it as my parents took care of me when I was younger, nurtured me in my teenage years and guided me through my adult years. They were always there for me, in good times and in bad. Having the opportunity to give something back to a parent who gave you so much, is rewarding".

KNOWLEDGE AND EDUCATION

Knowledge and education can be a powerful tool for reducing stigma. Talking about dementia increases knowledge and can minimize our fears. NWAC has created Indigenous specific resources about dementia that can be accessed on our website. The Alzheimer's Society also has many resources that you can access to learn more about dementia. Once you have informed yourself about dementia, share this information with others and challenge misinformation when you hear it.

"Eventually, once we recognized the signs and understood how insidious this disease is, we looked at this as an opportunity to cherish every moment we had with our father while he was with us in body, mind, and spirit. As early as you can, learn everything you can and then all you can do is treasure the moments you can share with your loved one." (Métis caregiver of a person living with dementia, 2021).



Greater knowledge and education about dementia can help reduce stigma and help people living with dementia to live better. Stigma often acts as a barrier to people seeking and accessing care and support. So, if we address stigma, we can help people living with dementia and their families access better supports.

A Métis caregiver shared:

"Some of those lessons learned are gain knowledge and get prepared. Become educated on dementia as early as you can so you can understand what your loved one is going through and what you and family will need to go through. Seek help and look for respite... Find someone you can talk to about it. Try not to be afraid. I can't say I was successful at that, but I understood if I remained frightened it would manage me, and I needed to manage it. I didn't want it to affect the time I had with my father."

Similarly, a Mi'kmaq caregiver of her late mother who lived with dementia explains,

"We need to educate ourselves on dementia to know the signs and symptoms, so that we can put resources in place before any abuse can happen to our respected elders."

What else can we do?

We must remember that even though dementia may change the person and sometimes it can be hard to recognize the person living with dementia, it is still the same person you once knew. However, for people living with dementia, their family members and friends, feelings of loss and grief are normal. While you might be experiencing grief and loss, it is important to remember that it is possible for people living with dementia to maintain their quality of life for a long time. Find activities that bring your loved one joy and focus on activities that align with their current strengths and abilities. For example, a Métis caregiver of her late father who lived with dementia explained:

“We made sure that he was able to live his life and enjoy those activities he loved for as long as he/we could. My father enjoyed music in his life, but when he developed dementia, his love of music grew. He could always be heard singing, which I think was soothing not only to himself, but to us as well. We played his music every day and it brought all of us joy. It taught us to find something he loved or responded positively to and use that to help find comfort”.

STORYTELLING

Stories can help people overcome misconceptions and stereotypes about dementia and reduce stigma. Storytelling is healing, not only for the one telling the story but for those listening. As Indigenous Peoples with oral histories, no one knows the power of stories more than we do. Storytelling allows us to pass down knowledge and traditions from one generation to the next and ties us to our ancestors. Stories can also be medicine used to heal .

When it comes to learning about dementia and its impacts on the person living with dementia, there is no better way to learn, than from the stories of those living with dementia . Knowledge, education, and stories about dementia should center the voices of those living with dementia. For more stories of people living with dementia, told from people living with dementia, their families, and caregivers, check out these other resources:

- NWAC’s 2022 Storybook, “A Sacred Journey: The Long Goodbye”.
- Danielle Alcock’s 2019 thesis, ‘I Honoured Him Until the End’: Storytelling of Indigenous Female Caregivers and Care Providers Focused on Alzheimer’s Disease and Other Dementias (ADOD).
- Alzheimer’s Society, I Live with Dementia resources: <https://ilivewithdementia.ca/read-our-stories/>

Reminiscing for older Indigenous people is a form of storytelling that promotes social connection and may provide opportunities for intergenerational exchange of knowledge. Sometimes during these exchanges, people with dementia can describe stories from their past and even when fragmented, can give those listening valuable insights into their past. For example, a caregiver we spoke to described:

“One day our mother mentioned something about going to a Residential School when she was very young. We all looked at each other, surprised, as she had never mentioned anything like this before. She said she remembered both the name of the school and the name of a priest. With the internet, we were able to find the residential school she had attended, and the name of the priest was in an article we had found. This is an indication that people living with dementia may clearly recall events of the past even if they can’t remember what occurred the day before, so focus on your loved one’s past.”

A First Nations caregiver explained her experience providing care for her father with dementia:

“Our journey is unique in that we did not really know one another until I became his caregiver, and so I recognize this as a second chance. Over the years, I have been able to learn stories of my dad’s life, his family, and especially his parents including my nookomis. It has been a gift to learn his spirit; he is a person who is kind, introspective, and still has a witty sense of humour.”

LAUGHTER IS MEDICINE

Humour within storytelling provides an opportunity for healing for the storyteller and the listeners⁹. A lot of people in Indigenous communities use humour and laughter to deal with trauma and pain. Laughter is medicine and often, a form of resilience. Devery Jacobs explains:

“In spite of all that we’ve endured, when I picture my community, all I can think about are my aunties laughing; throwing their heads back, slapping each other’s arms, and cackling like hyenas. Indigenous humour is dark. Some call it gallows humour, but whatever it is, it has been our key coping mechanism, helping us survive 500 years of colonization. Indigenous people are masters at taking the hurt and pain that was dealt to us, laughing in the face of it, and weaving it into ridiculous comedy” .



SUPPORTS

Talk 4 Healing

Service languages: Ojibway, Oji-Cree, Cree, English, French
Provides 24/7 culturally sensitive counselling, advice and support to Indigenous women.

1-855-554-4325

Online service at www.talk4healing.com

First Nations and Inuit Hope for Wellness Help Line

Service languages: Ojibway, Cree, Inuktitut, English, French
Provides 24/7 culturally grounded assessment, referrals, support in times of crisis, and suicide intervention.

1-855-242-3310

NWAC Elder Support

Available Monday-Friday from 9-11am EST and 1-3pm EST
Toll Free: 1-888-664-7808

Alzheimer Society of Canada

Toll-free: 1-800-616-8816

Indian Residential Schools Crisis Line

1-866-925-4419

Indian Residential School Survivors Society

1-800-721-0066

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- ii Jacklin, K., Pace, J., & Warry, W. (2015). Informal dementia caregiving among Indigenous communities in Ontario, Canada. *Care Management Journals*, 16(2), 106–120.
- iii Native Women's Association of Canada. (n.d.). Summary of Results - Stigma: An Exploration of Lived Experiences, Understandings, Behaviours of Dementia within Indigenous Communities.
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- vii Jacobs, Devery. 2021. LOLing Is Good Medicine: How Indigenous People Use Humour For Survival. *Refinery 29*. <https://www.refinery29.com/en-ca/2021/06/10477340/how-indigenous-people-use-humour-for-survival>