DEVELOPING CULTURALLY GROUNDED DEMENTIA EDUCATIONAL MATERIALS FOR INDIGENOUS COMMUNITY–BASED CARE

Drs. Kristen Jacklin and Melissa Blind
Memory Keepers Medical Discovery Team
University of Minnesota Medical School, Duluth

CCNA
Canadian Consortium
on Neurodegeneration
in Aging

CCNV
Consortium canadien en
neurodégénérescence
associée au vieillissement

MEMORY KEEPERS MEDICAL DISCOVERY TEAM

UNIVERSITY OF MINNESOTA
Medical School
DULUTH CAMPUS

Introduction to our research team

Jerry Otowadjiwan

Karen Pitawanakwat

Melissa Blind

Louise Jones

Sharlene Webkamigad

Wayne Warry

Kristen Jacklin

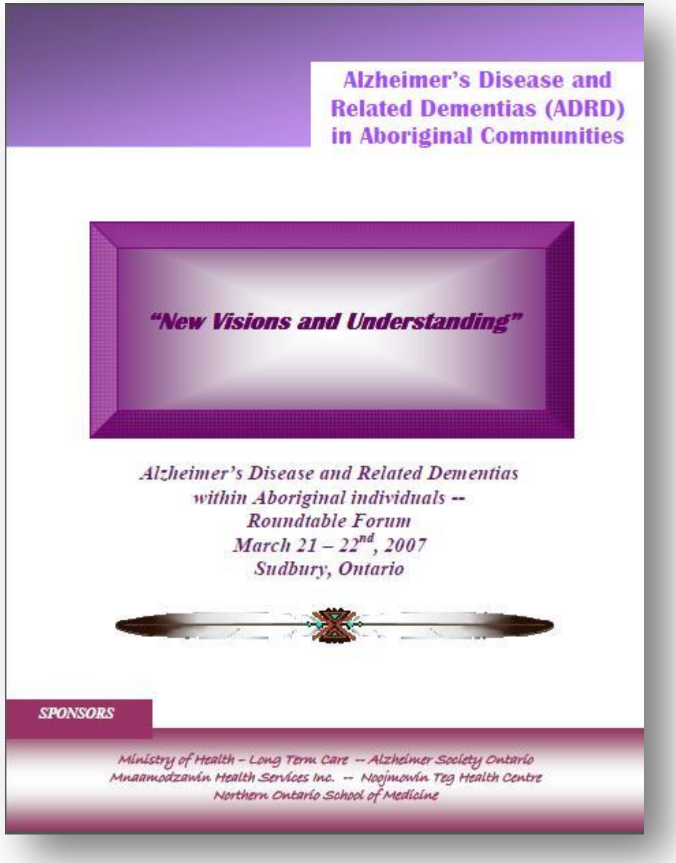
Overview

i. Background – Dementia in Indigenous Populations
ii. Underlying Frameworks: Cultural Safety & Two-Eyed Seeing
iii. Indigenous Understandings of Memory Loss and Aging
iv. Fact Sheets: Dementia Care for Indigenous People and their Families

BACKGROUND

Community Identified Dementia as an Emerging Health Priority - 2007

- Culturally appropriate approaches to care:
  - screening tools,
  - Clinical and supportive services
  - health promotion materials
- Cultural sensitivity training for health care workers and physicians.
- Capacity building and training of Aboriginal health care workers



Alzheimer's Disease and Related Dementias (ADRD) in Aboriginal Communities

"New Visions and Understanding"

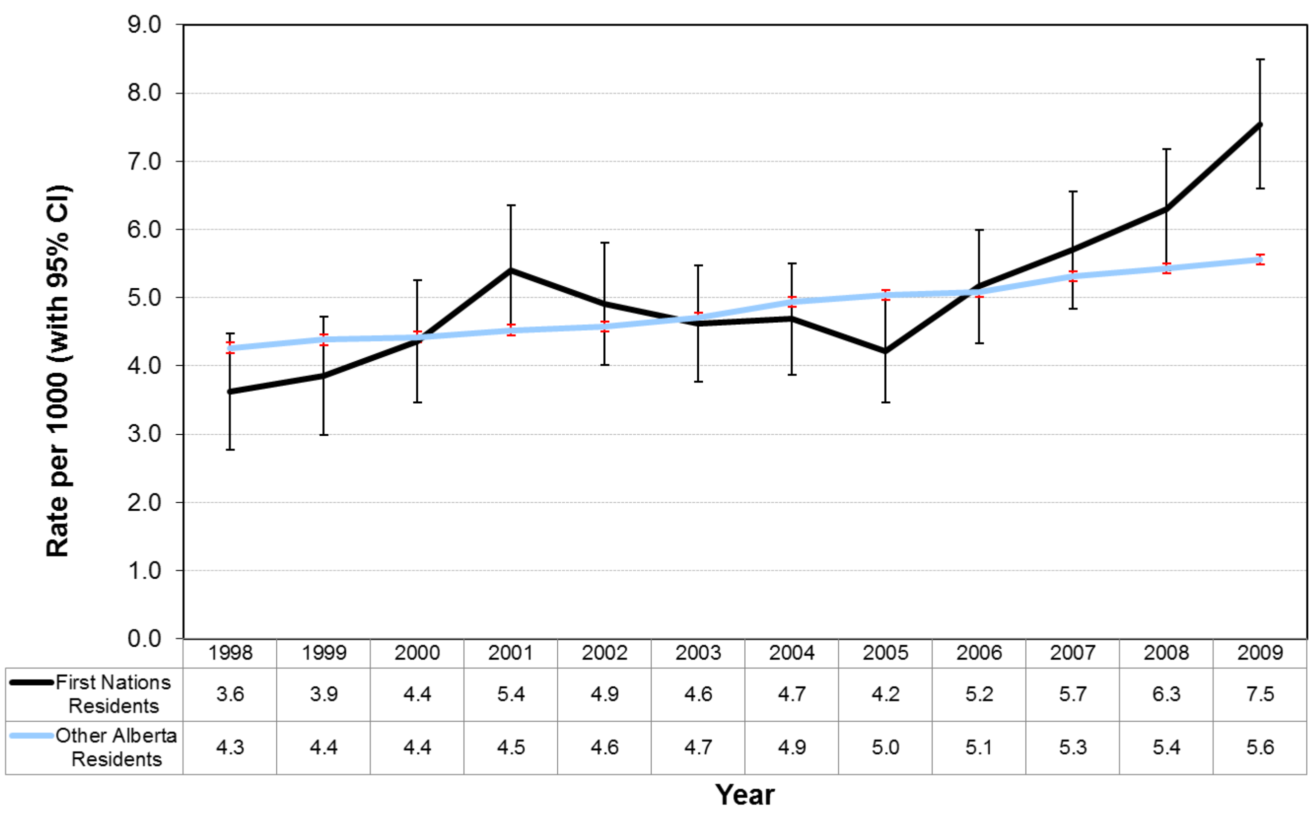
Alzheimer's Disease and Related Dementias
within Aboriginal individuals --
Roundtable Forum
March 21 – 22nd, 2007
Sudbury, Ontario

SPONSORS

Ministry of Health – Long Term Care -- Alzheimer Society Ontario
Mnaamodzawin Health Services Inc. -- Noojmowin Teg Health Centre
Northern Ontario School of Medicine

Dementia in Indigenous Peoples in Canada

- Prevalence **34%** higher in First Nations
- Average age of onset **10 years** younger
- Greater proportion of males **diagnosed**
- Dementia **increasing** at a faster rate in First Nations



	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
First Nations Residents	3.6	3.9	4.4	5.4	4.9	4.6	4.7	4.2	5.2	5.7	6.3	7.5
Other Alberta Residents	4.3	4.4	4.4	4.5	4.6	4.7	4.9	5.0	5.1	5.3	5.4	5.6

Source: Alberta Health Physician Claims Data and Alberta Health Care Insurance Plan Population Registry, Most Responsible Diagnosis of 290 or 331.0

Age-adjusted treated prevalence of Alzheimer's disease and dementia, Alberta, 1998-2009

Jacklin K, Walker J & Shawande M (2013) Canadian Journal of Public Health

Some Risk Factors for Dementia

Age-related dementias arise from a combination of risk factors.

- Increasing Age
- Head Trauma
- Cerebrovascular Disease & associated factors - hypertension, stroke, smoking, obesity
- Diabetes
- Social and Economic Status
- PTSD
- Genetics

Diamond, J. (2008). A Report on Alzheimer's Disease and Current Research. Toronto: Alzheimer Society of Canada.
Patterson, C., et al. (2007). General risk factors for dementia: A systematic evidence review. *Alzheimer's and Dementia, 3*(4), 341-347. doi: 10.1016/j.jalz.2007.07.001

Aging Trends and Projections

- Population growth in older adults -First Nations population in Canada is expected to increase by 1.4 times between 2006 and 2030 with a disproportional amount of growth among those aged 60 and older (an increase of 3.4 times)[1].
- Projections based on only age as a risk factor suggest the number of First Nations people over the age of 60 with dementia of will increase 4-fold by 2031, compared to a 2.3-fold increase in the non-First Nations population [2].

[1] E. Caron Malenfant and J. Morency, "Population projections by Aboriginal identity in Canada, 2006 to 2031," Statistics Canada, Ottawa, 2011.

[2] J. D. Walker and K. M. Jacklin, "Current and projected dementia prevalence in First Nations populations in Canada," in *Indigenous peoples and dementia: Experiencing and understanding memory loss and memory care in three settler nations*, Vancouver, UBC Press, in press.

2010-2014 Foundational Knowledge: Alzheimer's Disease and Related Dementias in Aboriginal Peoples in Ontario, Canada

health people
care providers with dementia
2009 to 2014 5 168 traditional caregivers
knowledge keepers seniors
YEARS PARTICIPANTS
6 RESEARCH QUALITATIVE community based
Thunder Bay
Six Nations
SITES METHODS ethnographic participatory
Ottawa Manitoulin Island Indigenous epistemologies action
Moose Cree First Nation
Sudbury

K. Jacklin & W. Warry

Société Alzheimer Society
CANADA

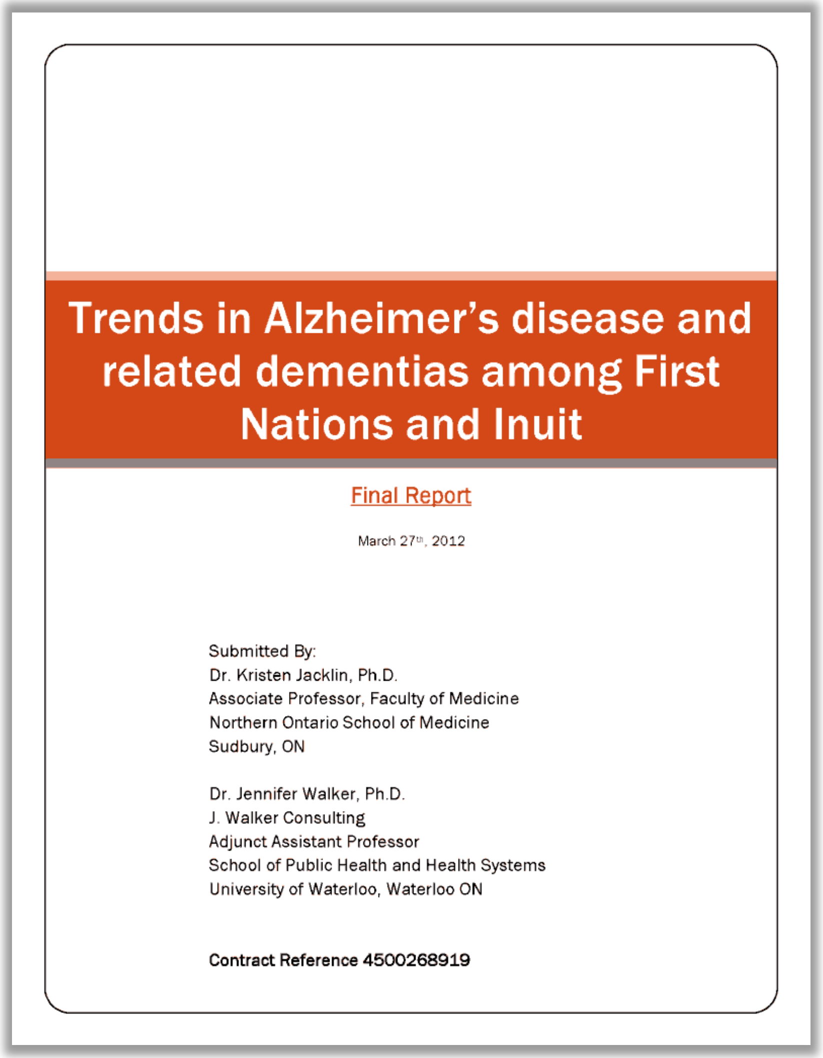
OM HF The Ontario Mental Health Foundation
La Fondation ontarienne de la sante mentale

Literature Review

Dementia in Indigenous Peoples in Canada

- Limited published information indicates possible **higher prevalence** of dementia in First Nations than in general Canadian population.
- Cultural understandings of dementia **vary from biomedical** perspectives, affecting prevention, diagnosis, and treatment
- Cognition is **culturally constructed**
- Caregiving was identified as more **complex** for Indigenous families

(Jacklin & Walker, 2012)



Trends in Alzheimer's disease and related dementias among First Nations and Inuit

Final Report

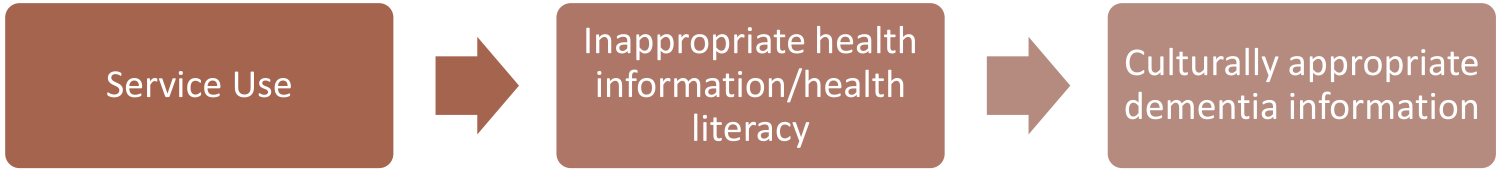
March 27th, 2012

Submitted By:
Dr. Kristen Jacklin, Ph.D.
Associate Professor, Faculty of Medicine
Northern Ontario School of Medicine
Sudbury, ON

Dr. Jennifer Walker, Ph.D.
J. Walker Consulting
Adjunct Assistant Professor
School of Public Health and Health Systems
University of Waterloo, Waterloo ON

Contract Reference 4500268919

Need: Appropriate Dementia Awareness



Service Use → Inappropriate health information/health literacy → Culturally appropriate dementia information

- What is dementia?
- Signs and symptoms of dementia
- Warning signs of dementia
- Dementia Prevention/Healthy Aging
- What to expect following a diagnosis of dementia – Patient
- What to expect following a diagnosis of dementia – Caregiver
- Path of dementia

UNDERLYING FRAMEWORKS

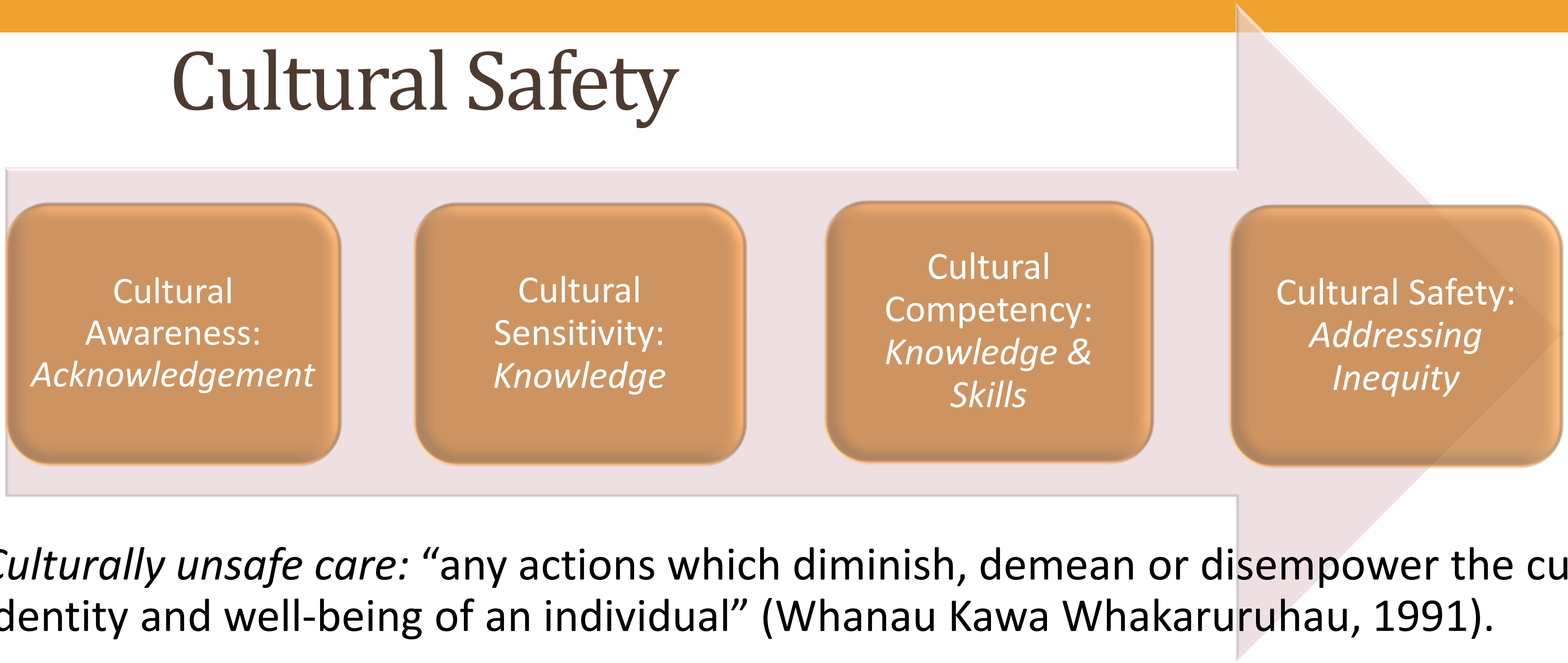
Privileging Indigenous Ways of Knowing

Two-Eyed Seeing

Mi’kmaw Elder Albert Marshall explained that two-eyed seeing was a gift where we learn to see from one eye with the strengths of Indigenous knowledge and ways of knowing, and from the other eye with the strengths of Western knowledge and ways of knowing.

An explicit Two Eyed Seeing approach involves addressing the power imbalance between the two knowledge systems and placing Indigenous knowledge on equal ground with Western knowledge.

Cultural Safety



Cultural Awareness: *Acknowledgement*

Cultural Sensitivity: *Knowledge*

Cultural Competency: *Knowledge & Skills*

Cultural Safety: *Addressing Inequity*

Culturally unsafe care: “any actions which diminish, demean or disempower the cultural identity and well-being of an individual” (Whanau Kawa Whakaruruhau, 1991).

“While cultural sensitivity and cultural competence focus on learning about the culture of the service user, cultural safety pays explicit attention to power relations between service user and service provider, charging the service provider with the responsibility to consider and address the role of their socially-constructed power in contributing to culturally safe or unsafe care” (DeSouza, 2008)

A message from the research team: Loving and Giving

You will notice that instead of “person with dementia” we use **loved one**. Throughout this work, we spent time with Elder Jerry Otowadjiwan to make sure that work was done in a good way. Elder Jerry shared teachings about love with us. He shared that a person with dementia is someone who needs a lot of love and will need to be reminded that they are loved. And whether or not their caregiver is someone who loves them, the act of providing care is a loving act, and somebody, somewhere loves this person. Using the term **loved one** reminds us of how we should be treating and respecting the person with dementia.

Community advisory groups, participants in studies, and community partners all reacted well to **loved one** and found it appropriate in an Indigenous context.

We also use the term **caregiver** instead of the more recent “care partner.” This is because to provide care is to offer a valued gift to another. **Caregiver** was also preferred by all of the community stakeholders and participants in the research.

INDIGENOUS UNDERSTANDINGS OF MEMORY LOSS AND AGING

Cultural views of aging

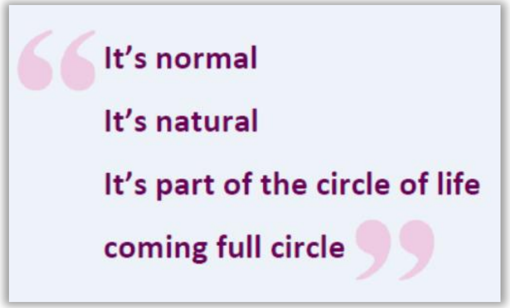
> *I've watched elderly people and how they do things to try to be like them. And we have a song that goes with that. And we sing those songs... The song goes, "When that time comes, when my hair turns white, silver, silver hair, will I be able to sound like they sound?" That's how the song goes. "I wonder if I'm going to sound how they sound, now, when I get there."*
>
> \- Elder Jerry Otowadjiwan

Cultural views of aging

Karen Pitawanakwat, RN, Manitoulin

Normalization and Acceptance

> *"The code talks about… it's more of a natural thing. It's not looked at as a disease, you know. Some people go back that way, and this is how they're going back to the Creator."*
>
> - Knowledge Keeper, Six Nations



It's normal

It's natural

It's part of the circle of life

coming full circle

- Memory loss in aging may be considered natural and normal by Indigenous loved ones, caregivers, and their families. This way, it is not a negative experience, but just another part of the circle of life.
- Since memory loss is not always associated with illness, loved ones and caregivers may not access health and social services in the early stages of dementia.

Teachings from the languages

> *"The older people they always refer to that term of going back into their childhood, but they use the Anishnaabe word for that, and that term is "keewayabinoocheeaway." That's returning back to childhood."*
>
> - Older Adult, Thunder Bay

- There are no specific words for "dementia" in Indigenous languages in the communities included in the research.

- There are gentle or humorous descriptions of being confused, forgetful, or mixed up.

- Inability to remember also did not mean that memories were lost . In Manitoulin Island communities, the term *ngwosh kaa ni we ga kendung* was used to describe memories as "buried" or "covered" for the time being, but not lost.

Unique Descriptions

- Mind changes
- Brain not functioning
- Thoughts mixed up
- Forgetful
- Confused
- Going back to childhood / second childhood
- Something wrong with my head
- Coming full circle
- Buried memories
- Old timer’s

- We note that Indigenous people might use different terms to describe their dementia or symptoms of dementia.

- This might be due to a view of memory loss as normal, or it could be because of a fear of stigma and not wanting to be labelled with a disease.

- It could also be because the loved one and their family want to keep it private or fear repercussions from diagnosis (like losing a driver’s license).

Buried Memories

Karen Pitawanakwat, RN, Manitoulin

Spirituality

> *"Elders with dementia [are] in a time of preparation to leave this physical earth. When the Elder with dementia is not making sense in conversation or talking about another place or time that is not being experienced by all those listening, their spirit is actually travelling and amongst their next life (after life experiences/on the other side). These experiences are verbally passed on in stories and not considered hallucinations but a real part of what we know as the circle of life."*
>
> – Anishinaabe Expert Language Group
> Manitoulin Island

- Perceptions of memory loss in aging are deeply affected by spiritual beliefs and practices.

- The loved one was often viewed as **coming full circle** or experiencing their **second childhood** as they returned to the Creator.

- **Visions** were viewed as the result of being closer to the spirit world, and were not to be confused with hallucinations.

Visions as strength

“We were somewhere and somebody was asking her about like seeing people that are dead or gone and they were acting as if it was a bad thing. And it’s something that it’s a sign of dementia and for me that is clearly not a sign of dementia. That’s an expected behaviour and it’s expected in little ones and in older people and I found it irritating and demeaning to have to explain it and for them to just dismiss it as a sign of dementia. Because I expect her to be able to see um, people who have gone on, I expect her to be able to see things that aren’t accepted in the main stream. So that was one point of irritation. I can’t remember who asked that question but to me that was a culturally insensitive question. Well not even just elderly too, we look at it as a better ability to be able to have that connection and we talk about the points of, of life and that when you get close to the, the portal or the time of change the birth, death area. The closer you are to both birth and death the more your able to see and experience so we don’t dismiss it we accept it and we use it and were actually happy when that happens.”

- Caregiver, Six Nations

Further Reading: Henderson, J. N., & L. C. Henderson. (2002). Cultural construction of disease: A “supernormal” construct of dementia in an American Indian tribe. *Journal of Cross-Cultural Gerontology,* 17: 197-212.

Balance / Out of Balance

this Elder said to me, "you're out of balance," you know? When I first went to him for help all he said was, "you're out of balance," so I think that Alzheimer's is being out of balance, for me anyways. So that's why I look at it not being able to function in a balanced way to your thoughts your feelings and your actions and acceptance.

- Older Adult, Manitoulin Island

- Loved ones, caregivers, and knowledge keepers talked about balance a lot.
- The rise in dementia was viewed as a symptom of being out of balance due to historical changes in diet and lifestyle, disconnection from the land and culture, trauma, intergenerational trauma, and unresolved grief.

FACT SHEETS: DEMENTIA CARE FOR INDIGENOUS PEOPLE AND THEIR FAMILIES

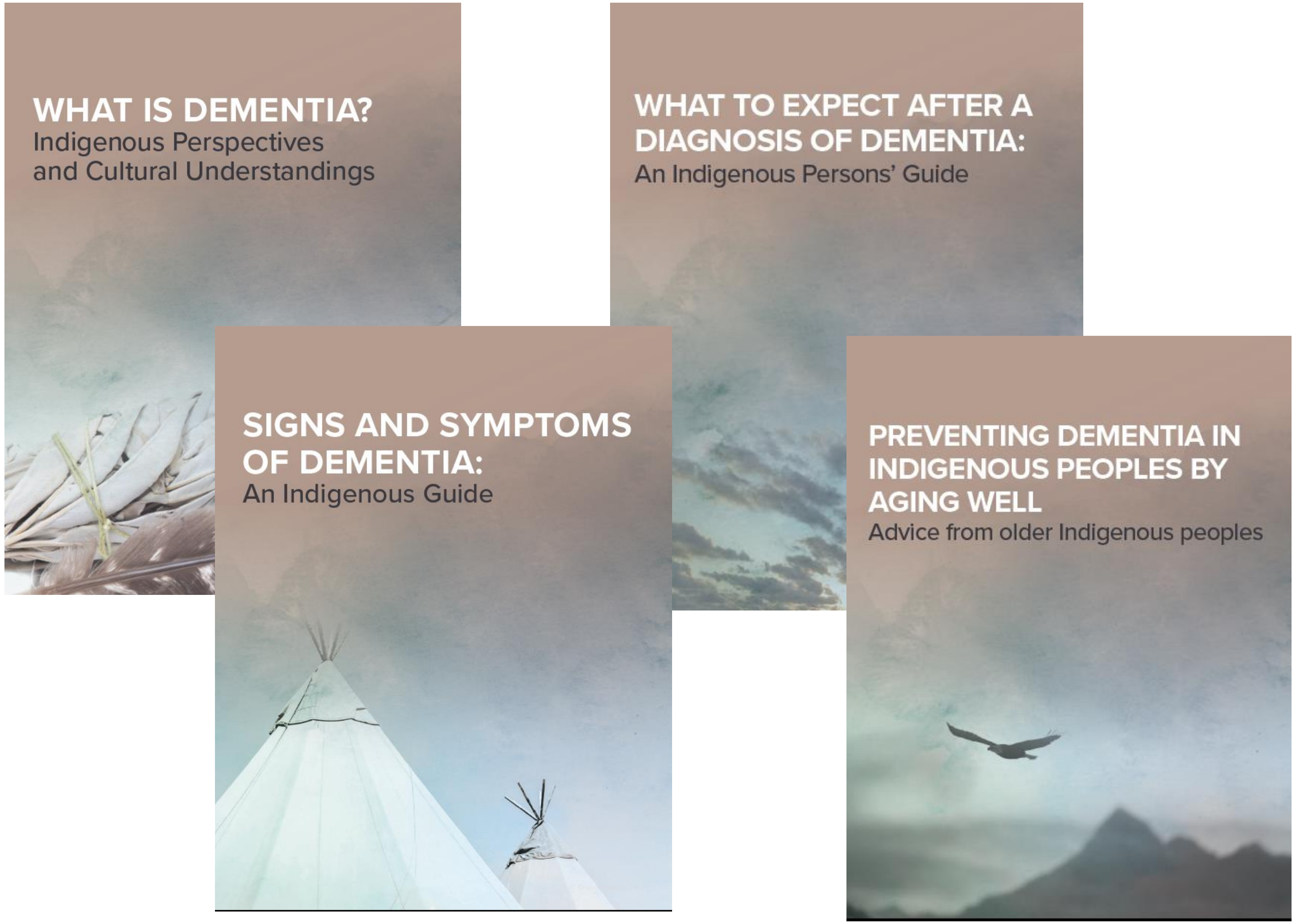
Available at https://www.i-caare.ca/factsheets

Fact Sheet Development

Our aim is to increase awareness and promote access to care, without interfering with Indigenous understandings of dementia

- Environmental scan of currently available health promotional materials for Indigenous people in Canada
- Literature Review
- Qualitative research results from the *Perceptions of Alzheimer's Disease and Related Dementias among Aboriginal Peoples in Ontario* project.
- Knowledge Translation Activities – moving the evidence into the materials
  - Supports: Elder Jerry Otowadjiwan, First Nation and Inuit Health Home, Community and Preventative Care Program & Behavioural Supports Ontario Northeastern Ontario Medical Advisory Council

Fact Sheets

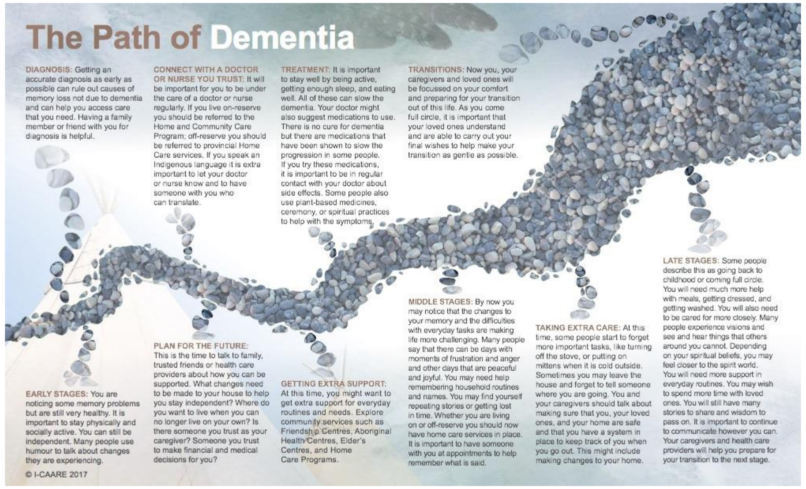


WHAT IS DEMENTIA?
Indigenous Perspectives
and Cultural Understandings

WHAT TO EXPECT AFTER A DIAGNOSIS OF DEMENTIA:
An Indigenous Persons' Guide

SIGNS AND SYMPTOMS OF DEMENTIA:
An Indigenous Guide

PREVENTING DEMENTIA IN INDIGENOUS PEOPLES BY AGING WELL
Advice from older Indigenous peoples



The Path of Dementia

DIAGNOSIS: Getting an accurate diagnosis as early as possible can rule out causes of memory loss not due to dementia and can help you access care that you need. Having a family member or friend with you for diagnosis is helpful.

CONNECT WITH A DOCTOR OR NURSE YOU TRUST: It will be important for you to be under the care of a doctor or nurse regularly. If you live on-reserve you should be referred to the Home and Community Care Program; off-reserve you should be referred to provincial Home Care services. If you speak an Indigenous language it is extra important to let your doctor or nurse know and to have someone with you who can translate.

TREATMENT: It is important to stay well by being active, getting enough sleep, and eating well. All of these can slow the dementia. Your doctor might also suggest medications to use. There is no cure for dementia but there are medications that have been shown to slow the progression in some people. If you try these medications, it is important to be in regular contact with your doctor about side effects. Some people also use plant-based medicines, ceremony, or spiritual practices to help with the symptoms.

TRANSITIONS: Now you, your caregivers and loved ones will be focussed on your comfort and preparing for your transition out of this life. As you come full circle, it is important that your loved ones understand and are able to carry out your final wishes to help make your transition as gentle as possible.

EARLY STAGES: You are noticing some memory problems but are still very healthy. It is important to stay physically and socially active. You can still be independent. Many people use humour to talk about changes they are experiencing.

PLAN FOR THE FUTURE: This is the time to talk to family, trusted friends or health care providers about how you can be supported. What changes need to be made to your house to help you stay independent? Where do you want to live when you can no longer live on your own? Is there someone you trust as your caregiver? Someone you trust to make financial and medical decisions for you?

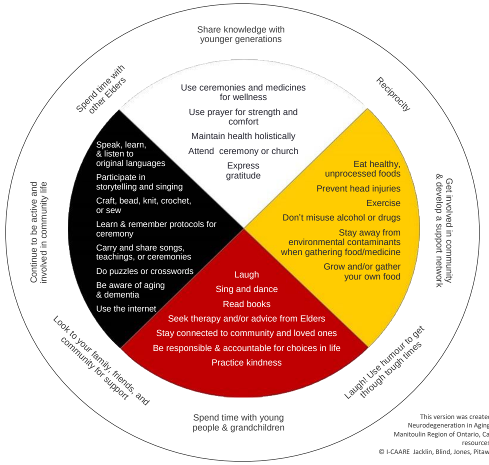
GETTING EXTRA SUPPORT: At this time, you might want to get extra support for everyday routines and needs. Explore community services such as Friendship Centres, Aboriginal Health Centres, Elder's Centres, and Home Care Programs.

MIDDLE STAGES: By now you may notice that the changes to your memory and the difficulties with everyday tasks are making life more challenging. Many people say that there can be days with moments of frustration and anger and other days that are peaceful and joyful. You may need help remembering household routines and names. You may find yourself repeating stories or getting lost in time. Whether you are living on or off-reserve you should now have home care services in place. It is important to have someone with you at appointments to help remember what is said.

TAKING EXTRA CARE: At this time, some people start to forget more important tasks, like turning off the stove, or putting on mittens when it is cold outside. Sometimes you may leave the house and forget to tell someone where you are going. You and your caregivers should talk about making sure that you, your loved ones, and your home are safe and that you have a system in place to keep track of you when you go out. This might include making changes to your home.

LATE STAGES: Some people describe this as going back to childhood or coming full circle. You will need much more help with meals, getting dressed, and getting washed. You will also need to be cared for more closely. Many people experience visions and see and hear things that others around you cannot. Depending on your spiritual beliefs, you may feel closer to the spirit world. You will need more support in everyday routines. You may wish to spend more time with loved ones. You will still have many stories to share and wisdom to pass on. It is important to continue to communicate however you can. Your caregivers and health care providers will help you prepare for your transition to the next stage.

PREVENTING DEMENTIA IN INDIGENOUS PEOPLES BY AGING WELL
Advice from older Indigenous peoples



Share knowledge with younger generations

Reciprocity

Get involved in community & develop a support network

Laugh! Use humour to get through tough times

Spend time with young people & grandchildren

Look to your family, friends, and community for support

Continue to be active and involved in community life

Spend time with other Elders

- Use ceremonies and medicines for wellness
- Use prayer for strength and comfort
- Maintain health holistically
- Attend ceremony or church
- Express gratitude

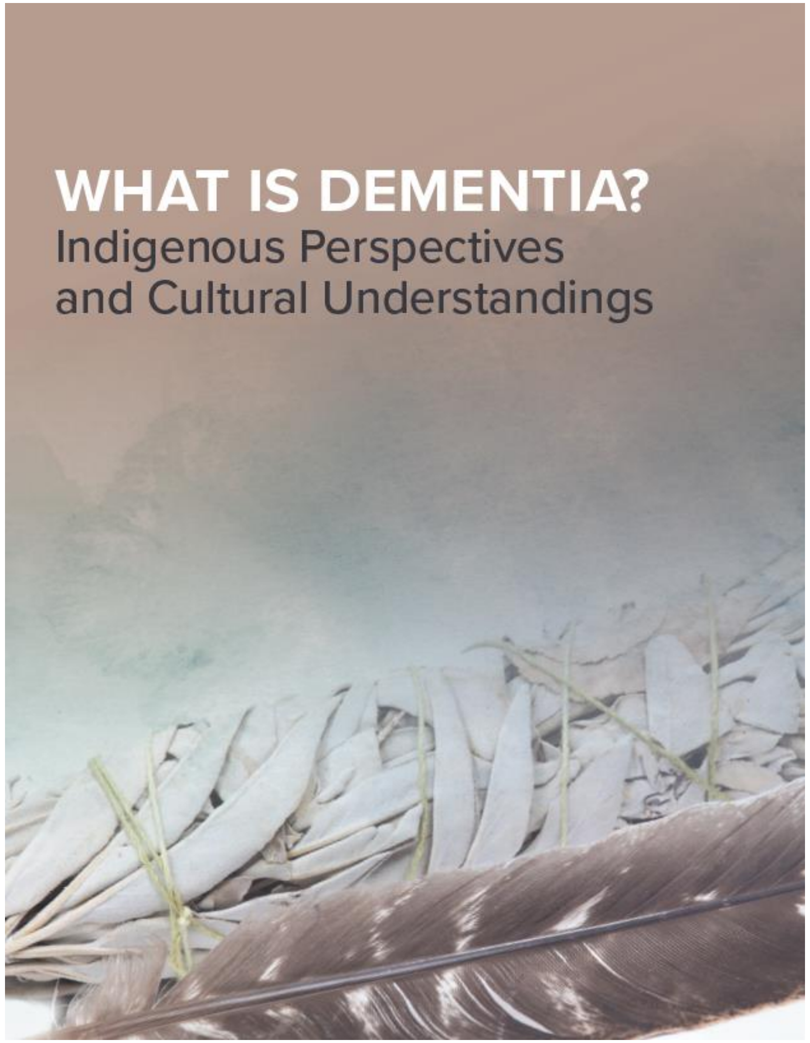
- Eat healthy, unprocessed foods
- Prevent head injuries
- Exercise
- Don't misuse alcohol or drugs
- Stay away from environmental contaminants when gathering food/medicine
- Grow and/or gather your own food

- Laugh
- Sing and dance
- Read books
- Seek therapy and/or advice from Elders
- Stay connected to community and loved ones
- Be responsible & accountable for choices in life
- Practice kindness

- Speak, learn, & listen to original languages
- Participate in storytelling and singing
- Craft, bead, knit, crochet, or sew
- Learn & remember protocols for ceremony
- Carry and share songs, teachings, or ceremonies
- Do puzzles or crosswords
- Be aware of aging & dementia
- Use the internet

This version was created by the Canadian Consortium on Neurodegeneration in Aging Team 20 Advisory Group for the Manitoulin Region of Ontario, Canada. Other versions and further resources are available at www.i-caare.ca.

What is Dementia? Indigenous Perspectives and Cultural Understandings



WHAT IS DEMENTIA?
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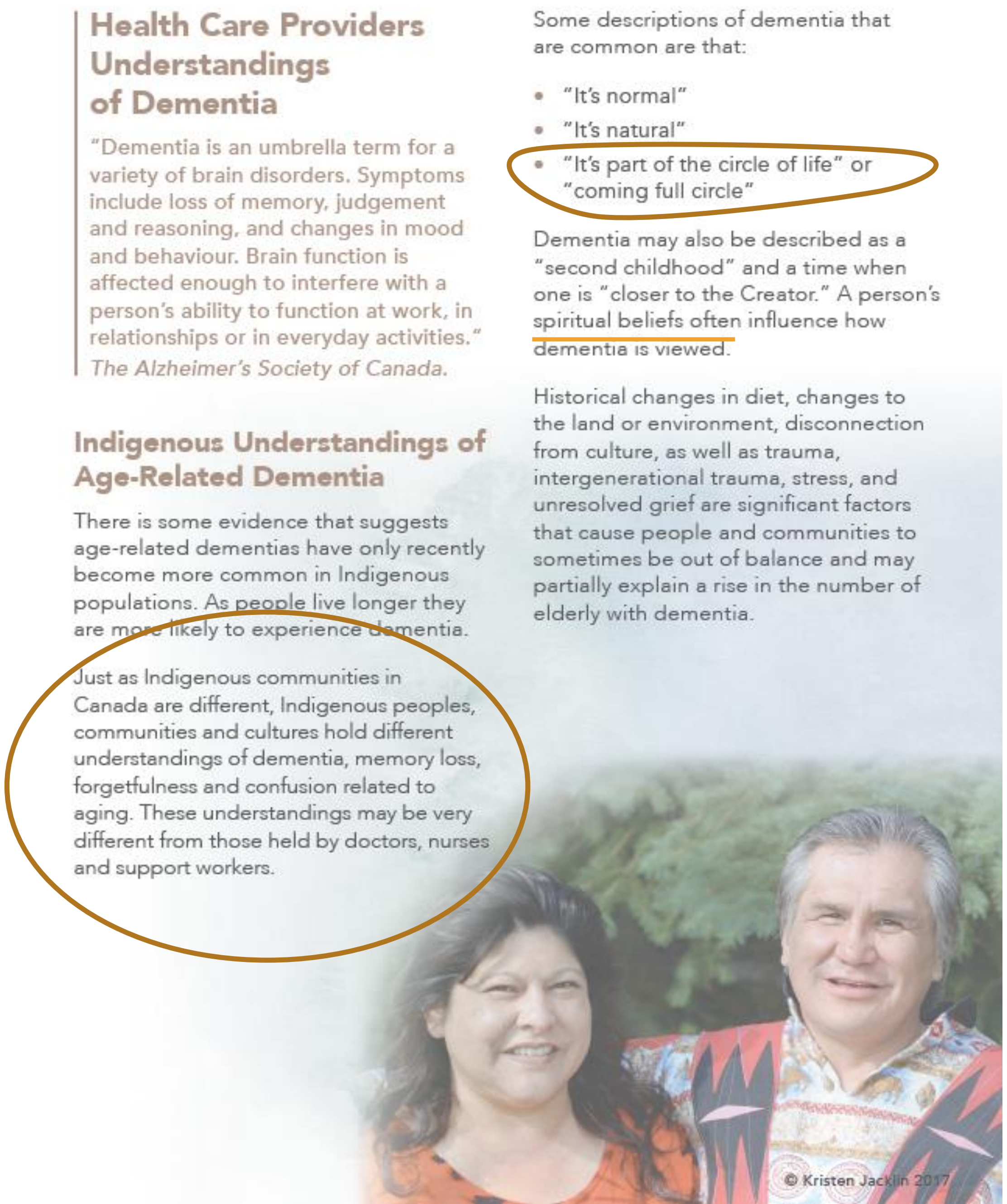

Health Care Providers Understandings of Dementia

> "Dementia is an umbrella term for a variety of brain disorders. Symptoms include loss of memory, judgement and reasoning, and changes in mood and behaviour. Brain function is affected enough to interfere with a person's ability to function at work, in relationships or in everyday activities."
> *The Alzheimer's Society of Canada.*

Indigenous Understandings of Age-Related Dementia

There is some evidence that suggests age-related dementias have only recently become more common in Indigenous populations. As people live longer they are more likely to experience dementia.

Just as Indigenous communities in Canada are different, Indigenous peoples, communities and cultures hold different understandings of dementia, memory loss, forgetfulness and confusion related to aging. These understandings may be very different from those held by doctors, nurses and support workers.

Some descriptions of dementia that are common are that:

- "It's normal"
- "It's natural"
- "It's part of the circle of life" or "coming full circle"

Dementia may also be described as a "second childhood" and a time when one is "closer to the Creator." A person's spiritual beliefs often influence how dementia is viewed.

Historical changes in diet, changes to the land or environment, disconnection from culture, as well as trauma, intergenerational trauma, stress, and unresolved grief are significant factors that cause people and communities to sometimes be out of balance and may partially explain a rise in the number of elderly with dementia.

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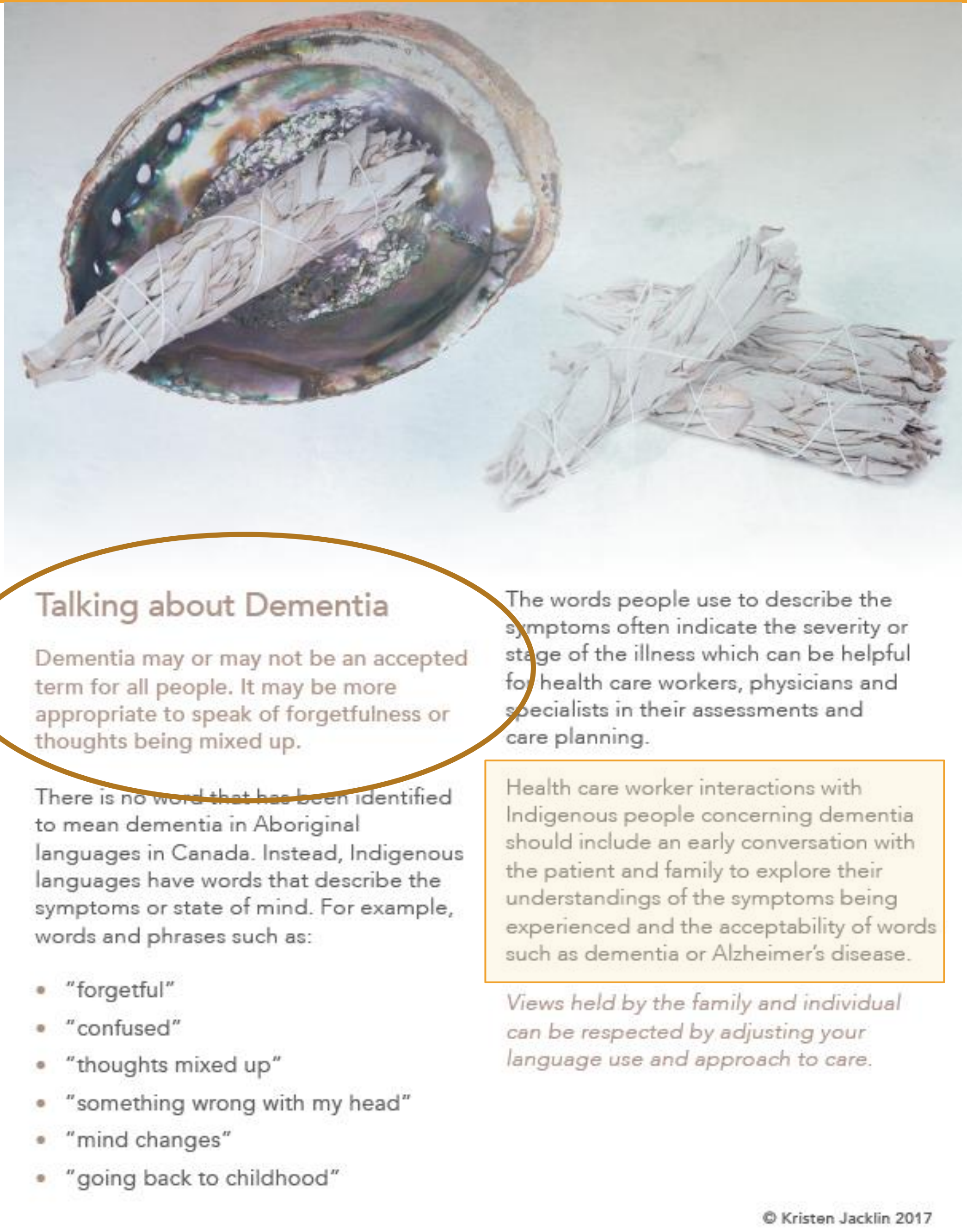
What is Dementia? Indigenous Perspectives and Cultural Understandings



Talking about Dementia

Dementia may or may not be an accepted term for all people. It may be more appropriate to speak of forgetfulness or thoughts being mixed up.

There is no word that has been identified to mean dementia in Aboriginal languages in Canada. Instead, Indigenous 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"

The words people use to describe the symptoms often indicate the severity or stage of the illness which can be helpful for health care workers, physicians and specialists in their assessments and care planning.

Health care worker interactions with Indigenous people concerning dementia should include an early conversation with the patient and family to explore their understandings of the symptoms being experienced and the acceptability of words such as dementia or Alzheimer's disease.

Views held by the family and individual can be respected by adjusting your language use and approach to care.

For more information...

Indigenous Inuit Home and Community Care
www.hc-sc.gc.ca

Alzheimer's Society of Canada
www.alzheimer.ca

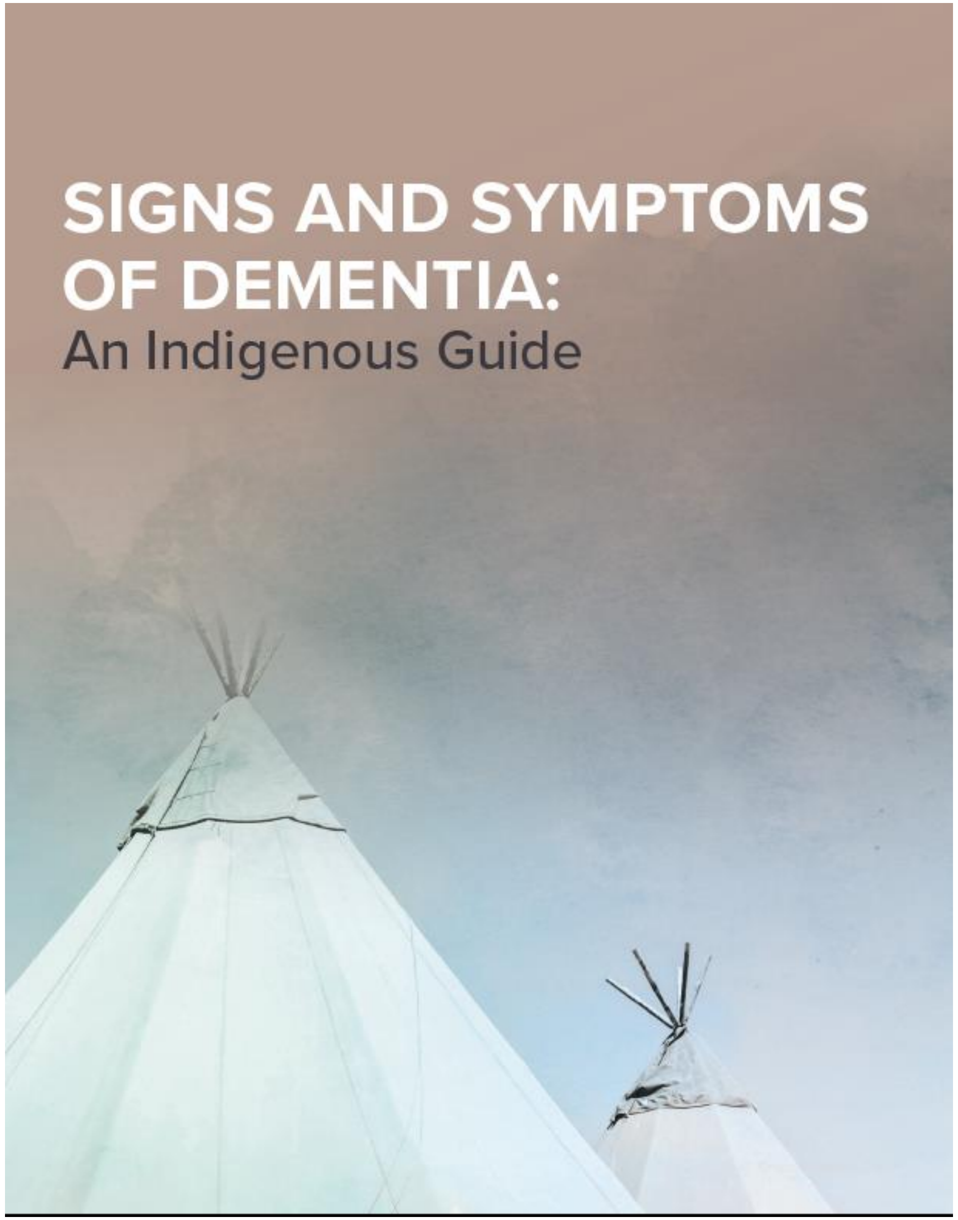
Indigenous Cognition & Aging Awareness Research Exchange (I-CAARE)
www.i-caare.ca

Government of Canada
www.seniors.gc.ca

End-of-Life Care in Indigenous Communities
http://eolfn.lakeheadu.ca/

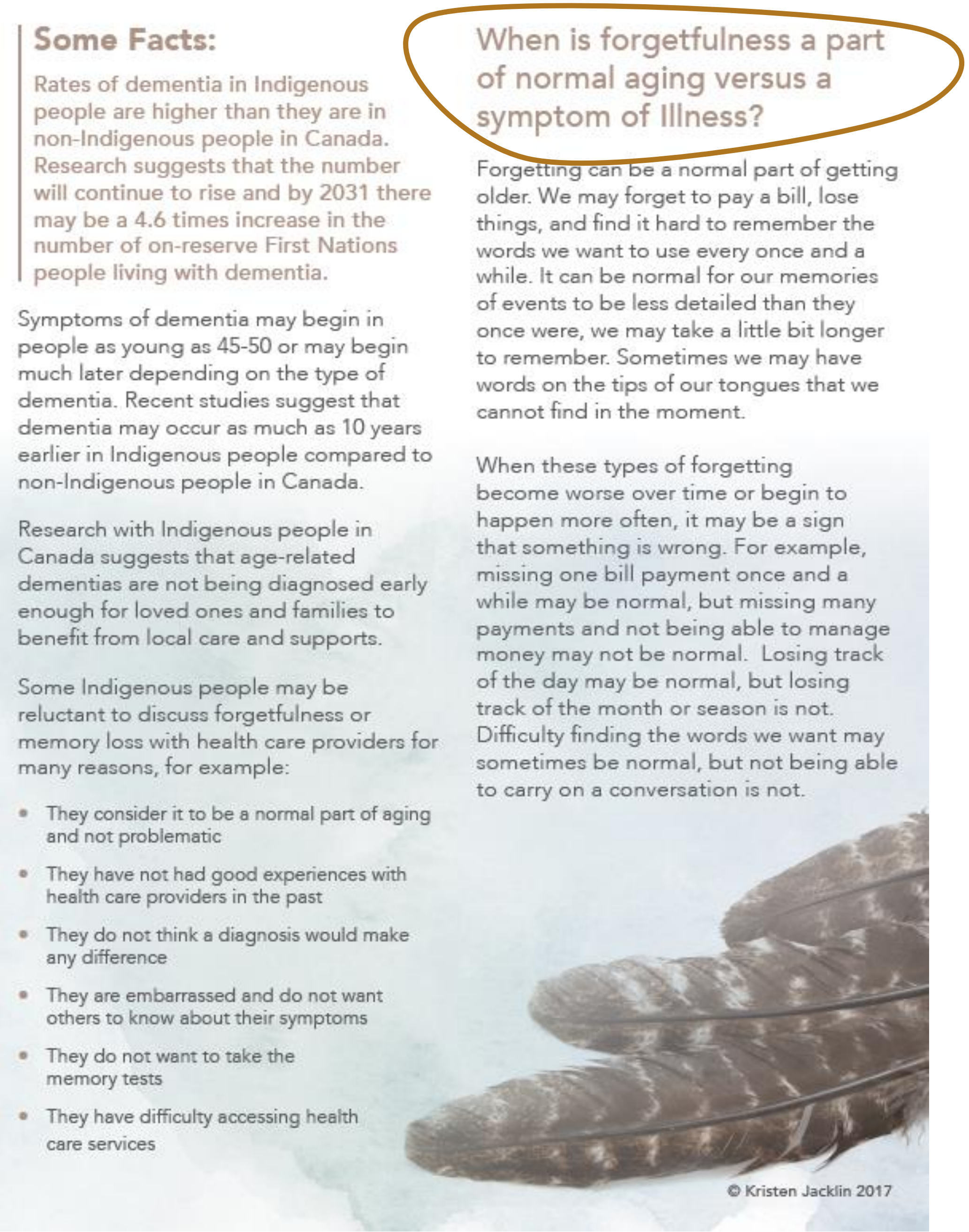
CCNA Canadian Consortium on Neurodegeneration in Aging
CCNV Consortium canadien en neurodégénérescence associée au vieillissement
Lakehead · Laurentian · Medicine
Northern Ontario School of Medicine
École de médecine du Nord de l'Ontario
Health Canada

Signs and Symptoms



SIGNS AND SYMPTOMS OF DEMENTIA:

An Indigenous Guide



Some Facts:

Rates of dementia in Indigenous people are higher than they are in non-Indigenous people in Canada. Research suggests that the number will continue to rise and by 2031 there may be a 4.6 times increase in the number of on-reserve First Nations people living with dementia.

Symptoms of dementia may begin in people as young as 45-50 or may begin much later depending on the type of dementia. Recent studies suggest that dementia may occur as much as 10 years earlier in Indigenous people compared to non-Indigenous people in Canada.

Research with Indigenous people in Canada suggests that age-related dementias are not being diagnosed early enough for loved ones and families to benefit from local care and supports.

Some Indigenous people may be reluctant to discuss forgetfulness or memory loss with health care providers for many reasons, for example:

- They consider it to be a normal part of aging and not problematic
- They have not had good experiences with health care providers in the past
- They do not think a diagnosis would make any difference
- They are embarrassed and do not want others to know about their symptoms
- They do not want to take the memory tests
- They have difficulty accessing health care services

When is forgetfulness a part of normal aging versus a symptom of Illness?

Forgetting can be a normal part of getting older. We may forget to pay a bill, lose things, and find it hard to remember the words we want to use every once and a while. It can be normal for our memories of events to be less detailed than they once were, we may take a little bit longer to remember. Sometimes we may have words on the tips of our tongues that we cannot find in the moment.

When these types of forgetting become worse over time or begin to happen more often, it may be a sign that something is wrong. For example, missing one bill payment once and a while may be normal, but missing many payments and not being able to manage money may not be normal. Losing track of the day may be normal, but losing track of the month or season is not. Difficulty finding the words we want may sometimes be normal, but not being able to carry on a conversation is not.

Signs and Symptoms

Warning Signs and Symptoms of Dementia

Your are encouraged to speak with your health care provider about memory loss when you become worried that it is impacting your day-to-day life. Having a few of these symptoms more than once in a while may be a sign of memory loss caused by dementia or another illness.

The following are some examples of the signs and symptoms described by Indigenous people with dementia and their families. When these signs and symptoms are experienced *more than once in a while* they may indicate the early stages of age-related dementia.

Forgetfulness and memory loss that affects day-to-day living

- Misplacing things like your keys, purse or wallet
- Having a hard time remembering the names of people who you know, especially family members
- Forgetting to turn off the stove, leaving the fridge door open, forgetting to turn off the water
- Repeating yourself; telling the same story over many times in the same day
- Needing lots of reminders, missing appointments
- Walking into a room and forgetting why you went there
- Forgetting if you took your pills or forgetting to get cleaned up in the morning
- Forgetting things that happened through the day but remembering things from way back

Difficulty performing familiar tasks

- Trouble driving a car or cooking
- Forgetting how to sew, quilt, knit, crochet, or do crafts
- Having trouble with daily routines such as getting cleaned up in the morning and getting dressed

Problems with language

- Forgetting words
- Having trouble finding the words you want to use
- Stopping part way through a sentence because you cannot remember the rest of what you wanted to say

Disorientation in time and space

- Forgetting the month or season
- Forgetting when you last had something to eat
- Getting lost either on foot or while driving or not remembering where you are going
- Confusing morning with evening

Impaired judgement

- Leaving the house without a coat when it is cold outside
- Wearing unusual clothing
- Making questionable purchases

Changes in mood, behaviour, and personality

- Feeling frustrated and sometimes angry
- Hiding things
- Emotional outbursts
- Losing interest in things you once enjoyed
- Not participating in social events
- Hearing or seeing things that other people cannot

Why should we seek care for forgetfulness or memory loss?

Forgetfulness caused by dementia progresses from mild to moderate to severe over time. Seeking help for memory loss early is important. If you are worried you should speak to a health care worker or your doctor. An accurate diagnosis can determine if the forgetfulness is related to dementia, what type of dementia it could be, or other illnesses. For example, medication errors, drug interactions, and complications arising from other infections or diseases can also cause forgetfulness and confusion. If memory loss is found to be caused by a dementia illness, an early diagnosis will help to make sure you are receiving the most appropriate treatment, information, and supports.

For more information…

First Nations Inuit Home and Community Care
www.hc-sc.gc.ca

Alzheimer's Society of Canada
www.alzheimer.ca

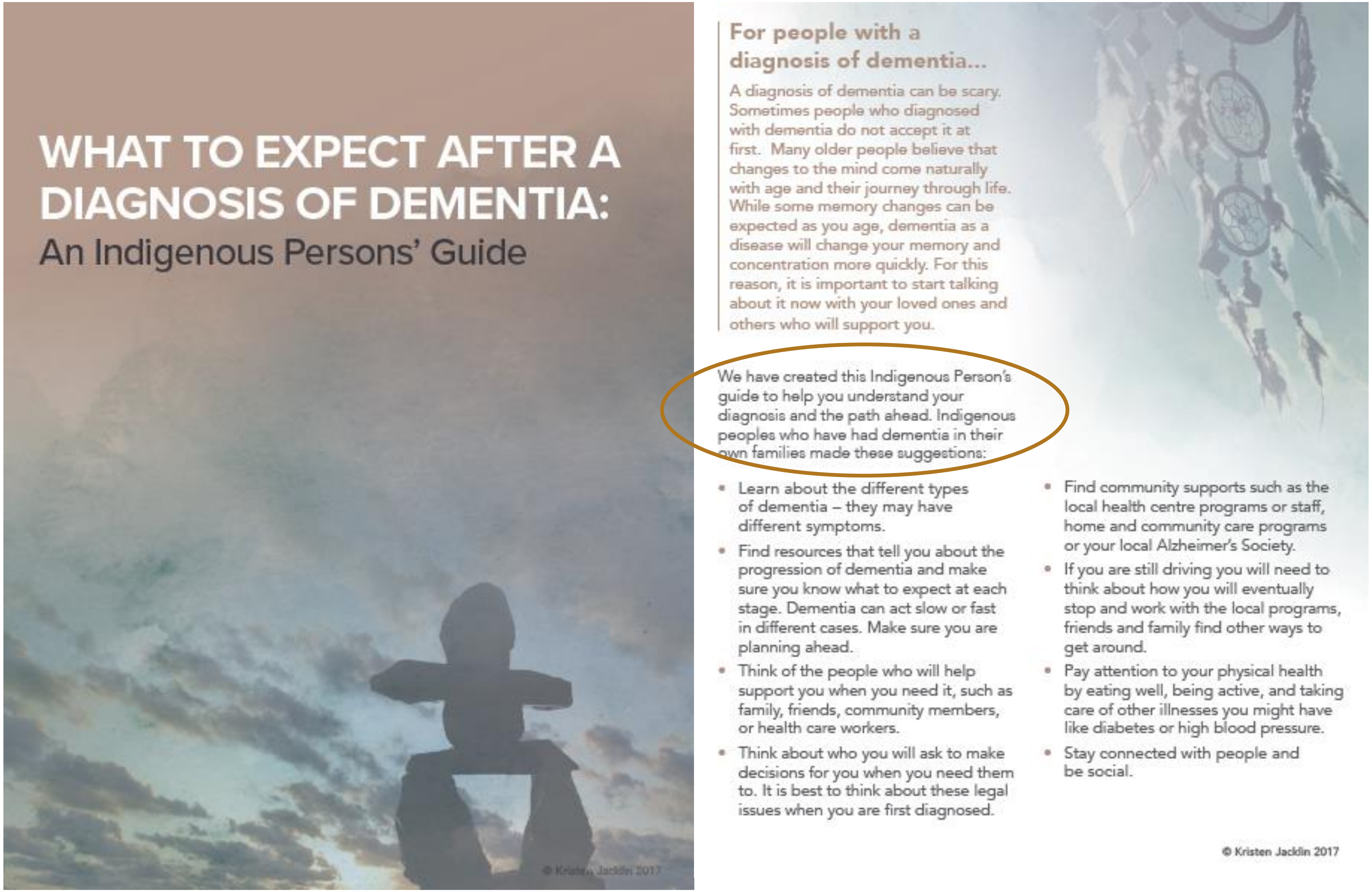
Indigenous Cognition & Aging Awareness Research Exchange (I-CAARE)
www.i-caare.ca

Government of Canada
www.seniors.gc.ca

End-of-Life Care in First Nations Communities
http://eolfn.lakeheadu.ca/

CCNA Canadian Consortium on Neurodegeneration in Aging
CCNV Consortium canadien en neurodégénérescence associée au vieillissement
Northern Ontario School of Medicine
École de médecine du Nord de l'Ontario
Health Canada

What to Expect



WHAT TO EXPECT AFTER A DIAGNOSIS OF DEMENTIA:

An Indigenous Persons' Guide

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For people with a diagnosis of dementia…

A diagnosis of dementia can be scary. Sometimes people who 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 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.

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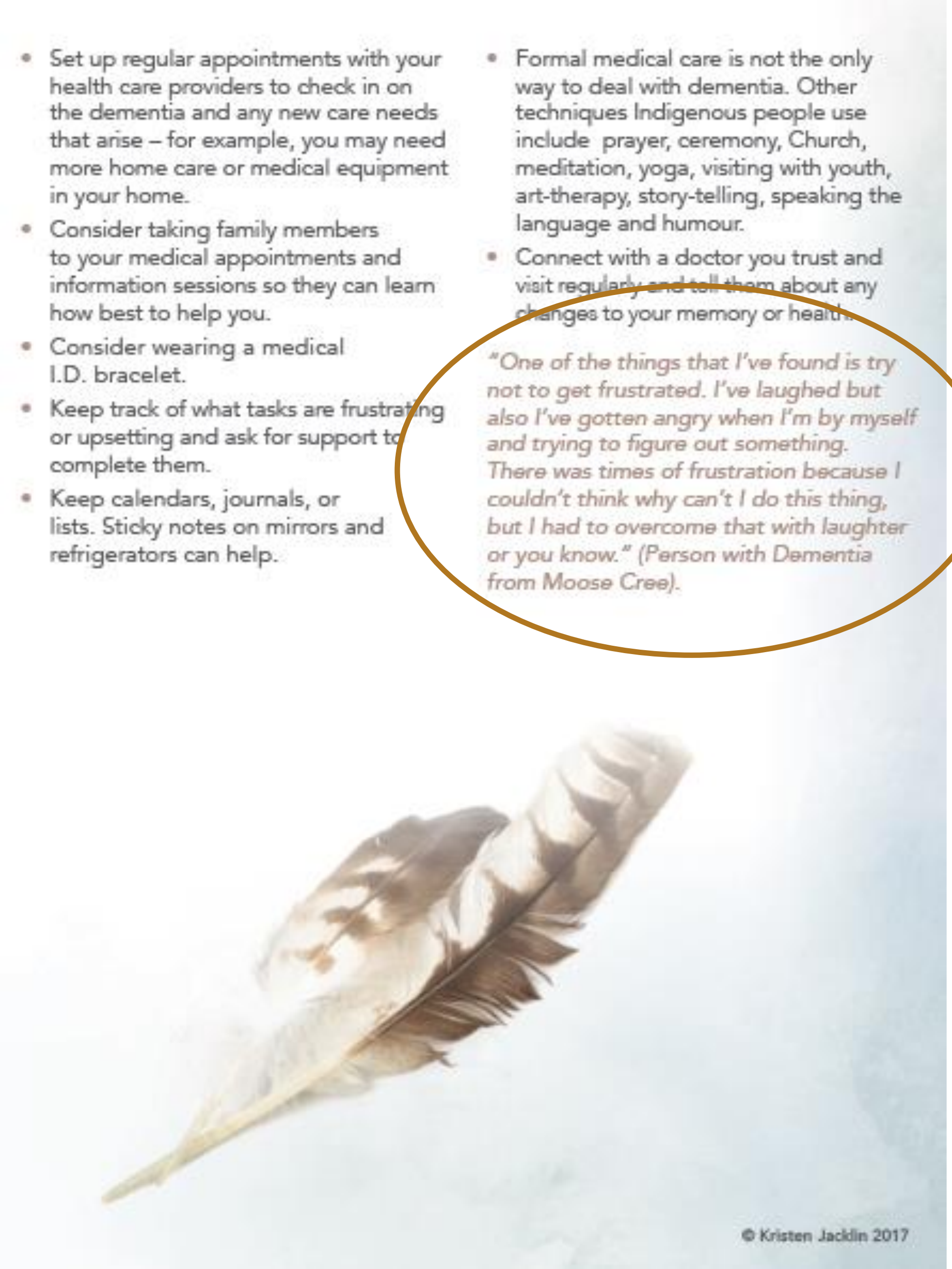
What to Expect



- 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 with Dementia from Moose Cree).

For caregivers...

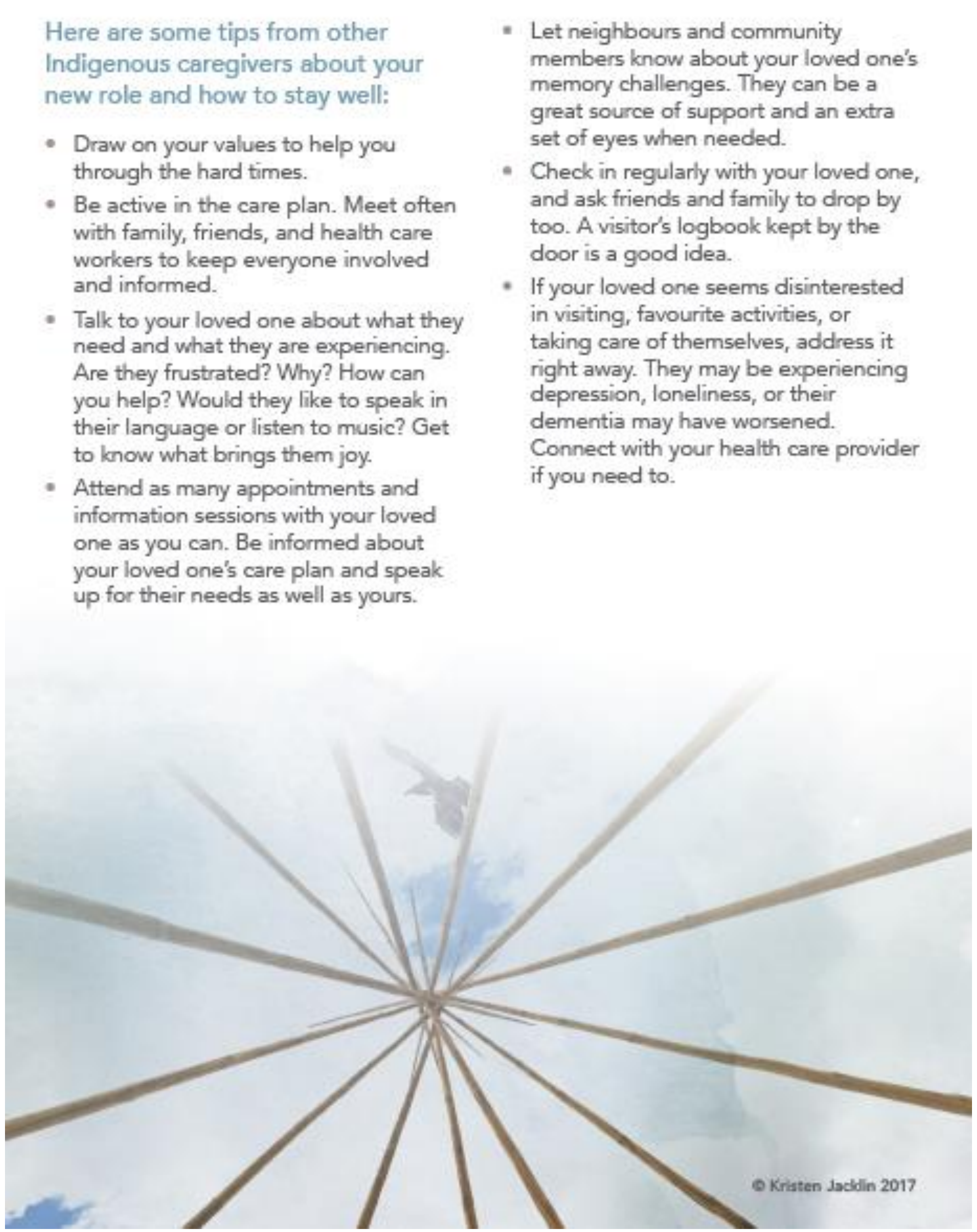
There is much to consider following a diagnosis of dementia. Your role as a support person or caregiver is very important. Caregiving can be challenging but many Indigenous caregivers stories also show that they have found the role rewarding in many ways. Some found it a way to reconnect with loved one 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)

What to Expect



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.

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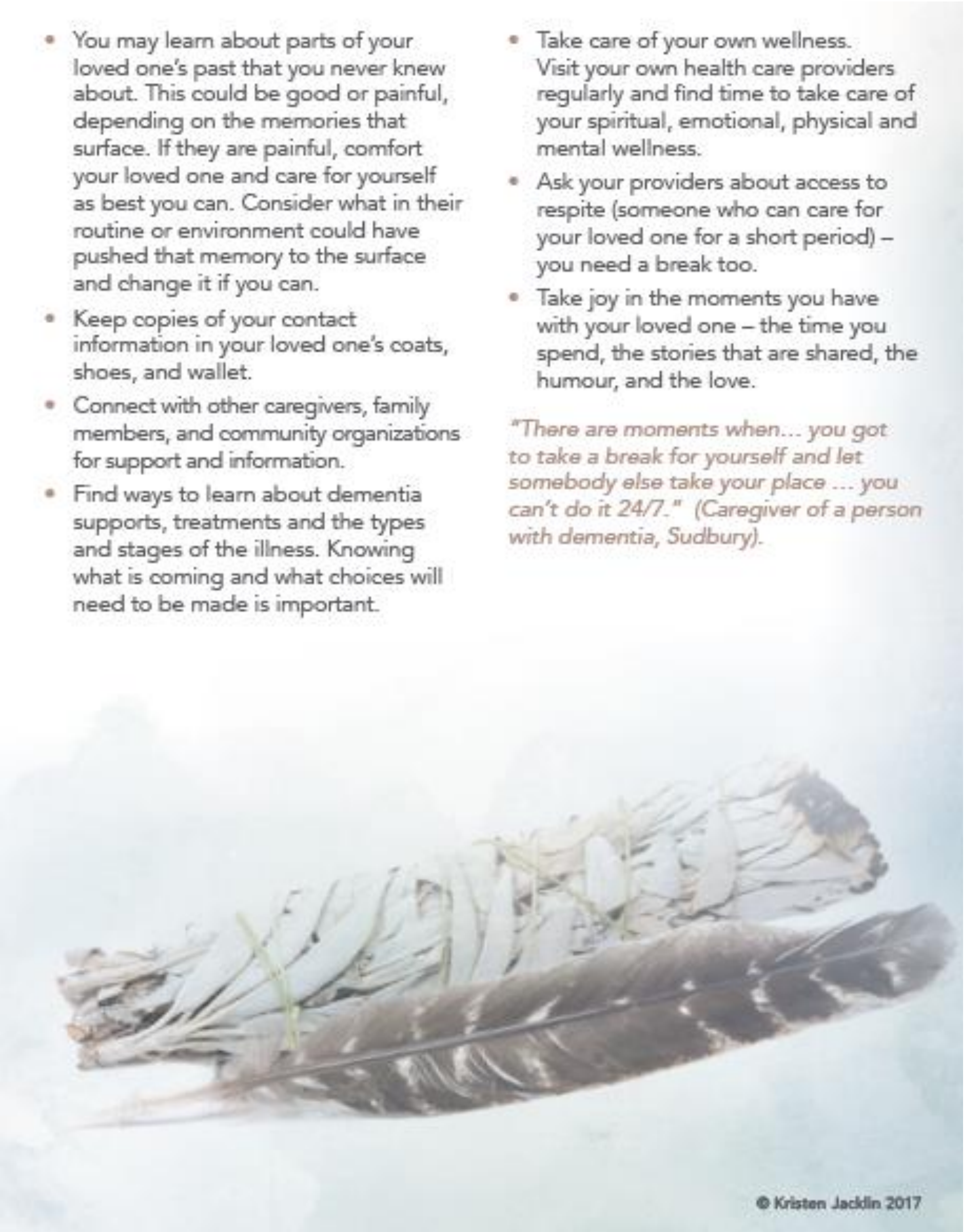

- You may learn about parts of your loved one's past that you never knew about. This could be good or painful, depending on the memories that surface. If they are painful, comfort your loved one and care for yourself as best you can. Consider what in their routine or environment could have pushed that 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 of a person with dementia, Sudbury).

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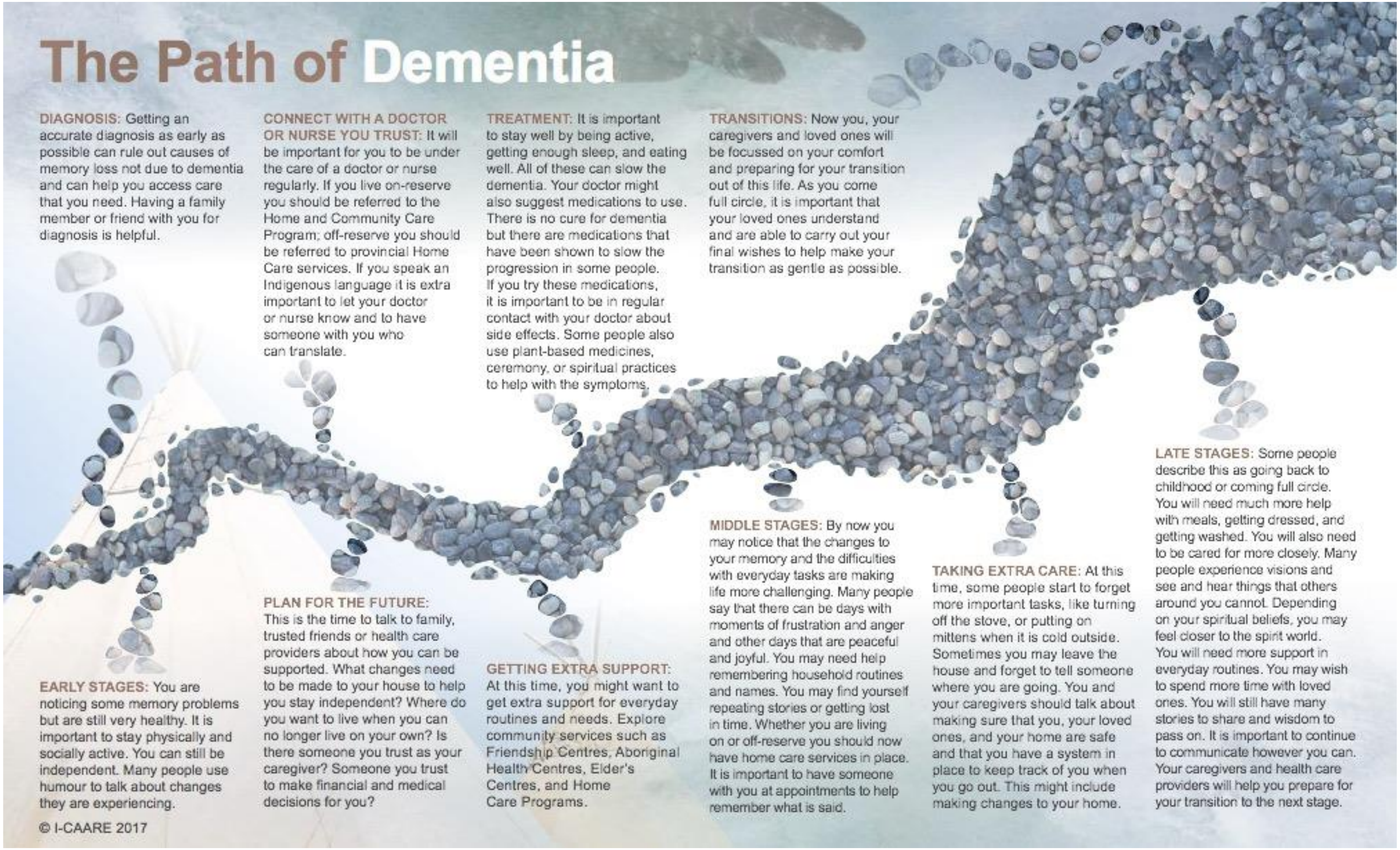
The Path of Dementia



DIAGNOSIS: Getting an accurate diagnosis as early as possible can rule out causes of memory loss not due to dementia and can help you access care that you need. Having a family member or friend with you for diagnosis is helpful.

EARLY STAGES: You are noticing some memory problems but are still very healthy. It is important to stay physically and socially active. You can still be independent. Many people use humour to talk about changes they are experiencing.

CONNECT WITH A DOCTOR OR NURSE YOU TRUST: It will be important for you to be under the care of a doctor or nurse regularly. If you live on-reserve you should be referred to the Home and Community Care Program; off-reserve you should be referred to provincial Home Care services. If you speak an Indigenous language it is extra important to let your doctor or nurse know and to have someone with you who can translate.

PLAN FOR THE FUTURE: This is the time to talk to family, trusted friends or health care providers about how you can be supported. What changes need to be made to your house to help you stay independent? Where do you want to live when you can no longer live on your own? Is there someone you trust as your caregiver? Someone you trust to make financial and medical decisions for you?

TREATMENT: It is important to stay well by being active, getting enough sleep, and eating well. All of these can slow the dementia. Your doctor might also suggest medications to use. There is no cure for dementia but there are medications that have been shown to slow the progression in some people. If you try these medications, it is important to be in regular contact with your doctor about side effects. Some people also use plant-based medicines, ceremony, or spiritual practices to help with the symptoms.

GETTING EXTRA SUPPORT: At this time, you might want to get extra support for everyday routines and needs. Explore community services such as Friendship Centres, Aboriginal Health Centres, Elder's Centres, and Home Care Programs.

MIDDLE STAGES: By now you may notice that the changes to your memory and the difficulties with everyday tasks are making life more challenging. Many people say that there can be days with moments of frustration and anger and other days that are peaceful and joyful. You may need help remembering household routines and names. You may find yourself repeating stories or getting lost in time. Whether you are living on or off-reserve you should now have home care services in place. It is important to have someone with you at appointments to help remember what is said.

TAKING EXTRA CARE: At this time, some people start to forget more important tasks, like turning off the stove, or putting on mittens when it is cold outside. Sometimes you may leave the house and forget to tell someone where you are going. You and your caregivers should talk about making sure that you, your loved ones, and your home are safe and that you have a system in place to keep track of you when you go out. This might include making changes to your home.

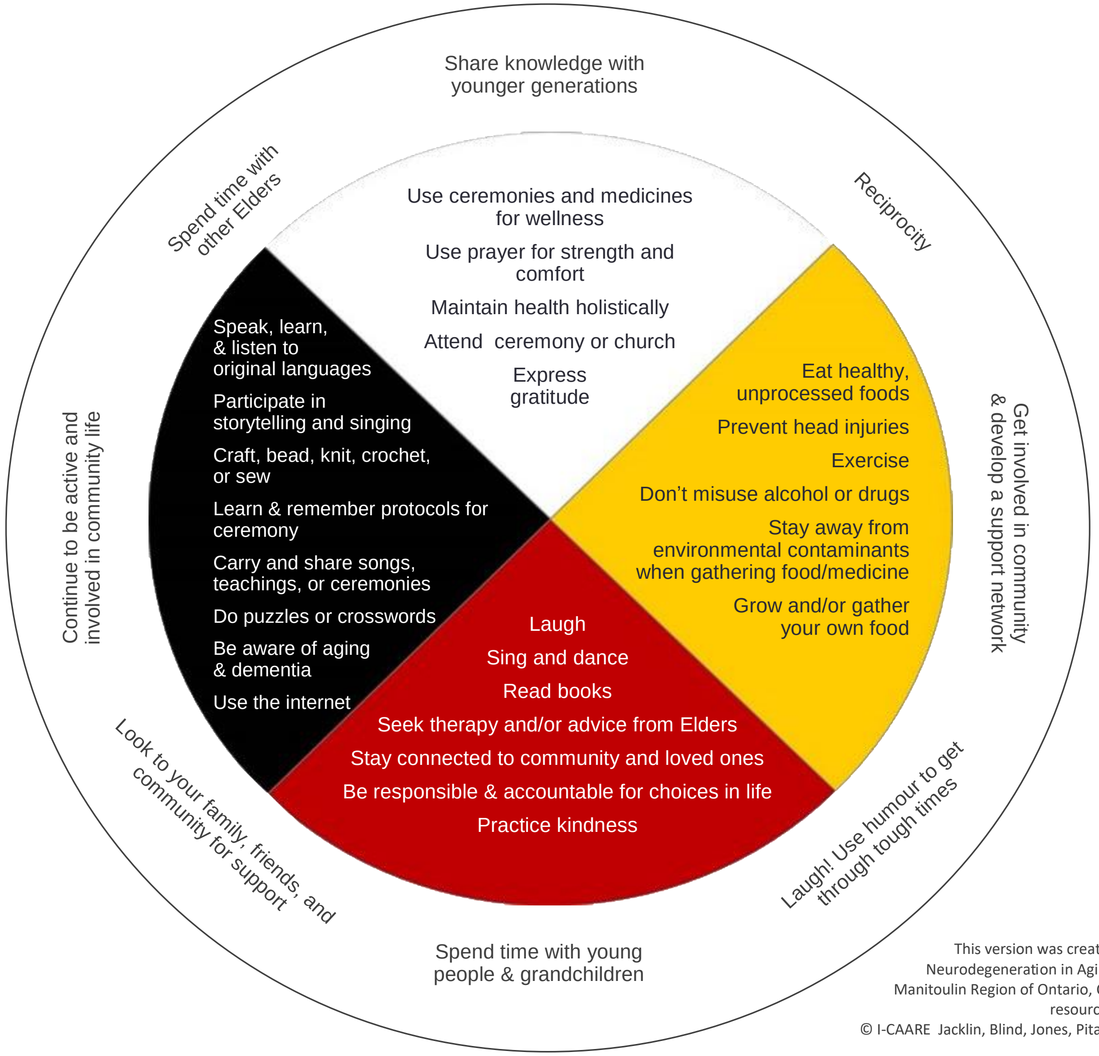
LATE STAGES: Some people describe this as going back to childhood or coming full circle. You will need much more help with meals, getting dressed, and getting washed. You will also need to be cared for more closely. Many people experience visions and see and hear things that others around you cannot. Depending on your spiritual beliefs, you may feel closer to the spirit world. You will need more support in everyday routines. You may wish to spend more time with loved ones. You will still have many stories to share and wisdom to pass on. It is important to continue to communicate however you can. Your caregivers and health care providers will help you prepare for your transition to the next stage.

TRANSITIONS: Now you, your caregivers and loved ones will be focussed on your comfort and preparing for your transition out of this life. As you come full circle, it is important that your loved ones understand and are able to carry out your final wishes to help make your transition as gentle as possible.

Developed with Anishinaabe CCNA Project Elder and Advisory Council members from Manitoulin Island

PREVENTING DEMENTIA IN INDIGENOUS PEOPLES BY AGING WELL

Advice from older Indigenous peoples



Share knowledge with younger generations

Reciprocity

Get involved in community & develop a support network

Laugh! Use humour to get through tough times

Spend time with young people & grandchildren

Look to your family, friends, and community for support

Continue to be active and involved in community life

Spend time with other Elders

Use ceremonies and medicines for wellness

Use prayer for strength and comfort

Maintain health holistically

Attend ceremony or church

Express gratitude

Eat healthy, unprocessed foods

Prevent head injuries

Exercise

Don’t misuse alcohol or drugs

Stay away from environmental contaminants when gathering food/medicine

Grow and/or gather your own food

Laugh

Sing and dance

Read books

Seek therapy and/or advice from Elders

Stay connected to community and loved ones

Be responsible & accountable for choices in life

Practice kindness

Speak, learn, & listen to original languages

Participate in storytelling and singing

Craft, bead, knit, crochet, or sew

Learn & remember protocols for ceremony

Carry and share songs, teachings, or ceremonies

Do puzzles or crosswords

Be aware of aging & dementia

Use the internet

This version was created by the Canadian Consortium on Neurodegeneration in Aging Team 20 Advisory Group for the Manitoulin Region of Ontario, Canada. Other versions and further resources are available at www.i-caare.ca.

Key Takeaways

- Health care providers should be familiar with Indigenous understandings and terminology. Even if you are not comfortable using them yourself, loved ones might use them to describe their experiences, and understanding will help you provide better care.

- Consider the repercussions of a possible diagnosis for the loved one and caregiver(s) and be ready to talk about this.

- Words like dementia might also be unwelcome and culturally inappropriate. Follow the lead of the person you are working with. Do they use the word “dementia”? If not, how do they talk about memory loss?

- When in doubt, ask! “What do you call your forgetfulness?”

Institutional Support

MEMORY KEEPERS MEDICAL DISCOVERY TEAM

UNIVERSITY OF MINNESOTA
Medical School
DULUTH CAMPUS

OMHF The Ontario Mental Health Foundation
La Fondation ontarienne de la sante mentale

CRaNHR
Centre for Rural and Northern
Health Research

Société Alzheimer Society
CANADA

Health Canada Santé Canada

CCNA
Canadian Consortium
on Neurodegeneration
in Aging

CCNV
Consortium canadien en
neurodégénérescence
associée au vieillissement

CIHR IRSC
Canadian Institutes of
Health Research
Instituts de recherche
en santé du Canada

Contact Information

Dr. Kristen Jacklin
Associate Director
Memory Keepers Medical Discovery Team
University of Minnesota Medical School Duluth
kjacklin@d.umn.edu

Dr. Melissa Blind
Senior Research Associate
Memory Keepers Medical Discovery Team
University of Minnesota Medical School Duluth
mblind@d.umn.edu

www.I-CAARE.ca