



SUPPORTING A
CIRCLE OF CARE

SOUTENIR UN
CERCLE DE SOINS

CREATING A CIRCLE OF CARE **FOR CAREGIVERS**



NATIVE WOMEN'S ASSOCIATION OF CANADA



SECTION 1: SELF-CARE	4
YOU CANNOT TAKE CARE OF YOUR LOVED ONE IF YOU DO NOT TAKE CARE OF YOURSELF.....	4
MY CIRCLE OF CARE.....	5
MAKING SURE YOUR NEEDS ARE MET.....	6
MEDICINE WHEEL ACTIVITY 1:.....	6
PERSONAL CARE.....	7
SELF-CARE EXERCISE:.....	7
SECTION 2: UNDERSTANDING YOUR LOVED ONE'S NEEDS	8
MEDICINE WHEEL ACTIVITY 2:.....	10
TIPS FOR CAREGIVERS.....	11
SECTION 3: RECOGNIZE YOU ARE NOT ALONE	12
REMEMBER YOUR CIRCLE OF CARE.....	12
TABLE 1: SUPPORTS AND SERVICES FOR CAREGIVERS	16
ADVANCED CARE PLANNING.....	17
THE IMPORTANCE OF PLANNING AHEAD AND STARTING EARLY.....	17
WHAT SHOULD BE DISCUSSED AND CONSIDERED?.....	17
LEGAL DOCUMENTS.....	19
SUBSTITUTE DECISION-MAKER(S).....	19
POWER OF ATTORNEY FOR HEALTH CARE.....	19
LIVING WILL.....	19
WILL.....	19
KEEPING YOUR LOVED ONE SAFE.....	20
PREPARING FOR A HOSPITAL VISIT.....	20
SECTION 5: AFTER CAREGIVING ENDS	21
GRIEVING PROCESS.....	21
REMEMBERING YOUR CIRCLE OF CARE.....	22
MEDICINE WHEEL ACTIVITY 3:.....	22
CREATING A CIRCLE OF CARE (SUPPORT GROUP)	26
STRENGTHENING YOUR CIRCLE OF TRUST.....	26
CREATING A SHARING CIRCLE.....	26
GUIDING A SHARING CIRCLE.....	28
CULTURAL CONSIDERATION.....	28
ADVERTISING THE CIRCLE OF CARE.....	28
APPENDIX A – OPEN-ENDED PROMPTS TO ENCOURAGE SHARING	29
APPENDIX B – SUPPORTS	34





SECTION 1: SELF-CARE

YOU CANNOT TAKE CARE OF YOUR LOVED ONE IF YOU DO NOT TAKE CARE OF YOURSELF.

While providing care for a loved one with dementia can be an incredibly rewarding opportunity, it can also take a toll on your mental, emotional, physical, and spiritual well-being. It is not uncommon for caregivers to experience sleep deprivation, psychosocial conditions, cardiovascular degeneration, stigma, financial hardship, and burnout.¹ Complicating matters further, Indigenous caregivers may lack information and knowledge on dementia and not have access to culturally safe supports and services.² These support systems are integral in assisting caregivers in providing compassionate care while coping with the stresses of caring for a loved one with dementia.³

As a caregiver, it is important to learn how to cope with the challenges of caregiving and implement regular self-care. We are not talking about simply performing your usual daily hygiene routines (e.g., showering, flossing); it's a more holistic approach of doing what is necessary to

ensure that overall health is prioritized.⁴ Health-promoting behaviours will not only help improve your well-being, but will also affect the quality of care your loved one receives from you.⁵ As important as it is to understand what your loved one needs, it's equally important to understand your own needs and to make sure those needs are also being met. *"Take care of your body because it's the only place you have to live"* (Jim Rohn).

Caregiving is a journey. At times it can be overwhelming, so it's important to take a break from providing care when you need it. Ask for help, seek out community services, consider who is in your circle of care who may be able to help provide short-term relief. If you feel you need more support, consider options for respite. **Refer to Section 3 for additional supports.**



1 Waligora KJ, Bahouth MN, Han H-R. The Self-Care Needs and Behaviors of Dementia Informal Caregivers: A Systematic Review. *The Gerontologist*. 2018, Jun 21.
2 Finkelstein SA, Forbes DA, Richmond CAM. Formal Dementia Care Among First Nations in Southwestern Ontario. *Can J Aging Rev Can Vieil*. 2012, Sept. 31(3): 257-70.
3 Ibid.
4 Oliveira D, Zarit S, Orrell M, Health-Promoting Self-Care in Family Caregivers of People with Dementia: The Views of Multiple Stakeholders, *The Gerontologist*, Vol. 59, issue 5, Oct. 2019. p. e501-e511.
5 Ibid.

MY CIRCLE OF CARE

The circle of care is a visual representation of a caregiver's support system, which can help them see that they are not alone.

<p>FRIENDS</p> <p>Names & phone #s</p> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>	<p>COMMUNITY</p> <p>Names & phone #s</p> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>
<p>ORGANIZATION</p> <p>Names & phone #s</p> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>	<p>FAMILY</p> <p>Names & phone #s</p> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>

Are you struggling to identify people in your circle of care or who might be able to provide support? Have you considered reaching out to your health care provider? They can connect you with local organizations and support groups that can help you on this journey.

If you require immediate support, try one of these resources:

HOPE FOR WELLNESS HELP LINE: 1-855-242-3310

TALK 4 HEALING: 1-855-554-4325

ALZHEIMER SOCIETY OF CANADA TOLL-FREE: 1-800-616-8816

NWAC ELDER SUPPORTS: AVAILABLE MONDAY TO FRIDAY FROM 9 TO 11 A.M. AND 1 TO 3 P.M., EST, TOLL FREE: 1-888-664-7808





MAKING SURE YOUR NEEDS ARE MET.

As a caregiver, it's common to put the needs of the person you are providing care for above your own. Sometimes this means that we forget about, or neglect, our own needs. To ensure your own needs are met, it's important to identify what your needs are. What do you need in your life to achieve overall health and well-being?

While the Medicine Wheel is a First Nations teaching, it can be a helpful tool for anyone, as it emphasizes the importance of holism and recognizes every colour of race as being equal—yellow, red, black, and white all have a place in the Medicine Wheel. Together, the Medicine Wheel makes up a person's physical, mental, emotional, and spiritual needs.

Using the Medicine Wheel as a guide, can you think about what your mental, physical, emotional, and spiritual needs are? Fueling your body with good food, clean water, physical exercise, and adequate sleep is essential to ensuring your body's physical health. Having good strategies and support in place to cope with stress, grief, and trauma will help you maintain your emotional well-being. Being connected to culture and/or religion, ceremony, and Traditions can contribute to your spiritual well-being. Accessing supportive services and talking to friends and family are important for preserving your mental health. Can you think of supports you need to ensure you are able to meet your physical, emotional, spiritual, and mental health needs?

MEDICINE WHEEL ACTIVITY I:



Source: American Indian Family Centre

Everyone's needs are very different, and it's important to be mindful of what your physical, emotional, spiritual, and mental health needs are to ensure they are met.

PERSONAL CARE

Having support to help you, and your loved one with dementia, is important. But it's also important for you to understand your own needs so you can make sure your mental, emotional, physical, and spiritual needs are met. It can be very difficult to remember to take time for yourself when you are providing care for a loved one with dementia. Here are some suggestions to help you protect your well-being and practice self-care:

- ✓ Seek out counselling to support your emotional healing journey.
- ✓ See an Elder for Traditional teachings, support, and guidance.
- ✓ Look to cultural teachings and ceremony for strength, healing, and guidance.
- ✓ Nourish your body with Traditional and/or wholesome food.
- ✓ Get out on the land—hunt, fish, trap, walk, paddle, swim.
- ✓ Watch your favourite movie or read a good book.
- ✓ Be creative bead, sew, paint (or whatever activity you enjoy most).
- ✓ Seek out support groups to network with other caregivers.
- ✓ Make time for sleep and rest.
- ✓ Write about your feelings in a journal.
- ✓ Talk to supportive friends and family.

When life gets busy and you are overwhelmed with providing care for your loved ones, it can be easy to forget about taking care of yourself.

"The challenge is not to be perfect; it is to be whole" (Jane Fonda).

SELF-CARE EXERCISE:

When you are feeling sad or stressed, think of what you would encourage someone else in your position to do to help them feel better:

1. _____
- _____
- _____
2. _____
- _____
- _____
3. _____
- _____
- _____
4. _____
- _____
- _____
5. _____
- _____
- _____

Now when you are feeling overwhelmed, take your own advice and practice self-care using one of the strategies listed above!





SECTION 2: UNDERSTANDING YOUR LOVED ONE'S NEEDS.

As people living with dementia experience a loss of mental function, they will likely experience a range of symptoms, including:



MEMORY LOSS:	JUDGMENT & REASONING DIFFICULTIES:	CHANGES IN BEHAVIOUR, MOOD, & COMMUNICATION:
"Forgetful"	"Mind changes"	"Coming full circle"
"Thoughts mixed up"	"Memories buried/covered"	"Going back to childhood"
"It's normal"	"Confused"	

In later stages of dementia, it may seem the person you once knew is gone, as they may no longer remember people, places, or things they once did. Situations involving memory loss, confusion, and drastic changes in behaviour, mood, and communication are extremely challenging for caregivers and families of the person with dementia.⁶ Providing care for loved ones experiencing this kind of decline requires a great deal of patience and understanding.

When people living with dementia experience these types of decline, caregivers are often faced with trying to identify what is causing these changes and what the person living with dementia needs.

It's important to recognize that if someone with dementia is "acting out" in a disruptive or aggressive manner, it's often in response to an unmet need that they are unable to communicate.⁷ For example, unrecognized pain often leads to changes in behaviour in people with dementia.

As a caregiver, it's important to learn how to identify the needs of your loved one—not only to improve their quality of life, but also to reduce anxiety and/or aggression due to unmet needs. Dementia patients have shown improvement in health and happiness when they are with someone with whom they have an interpersonal relationship.⁸ This is also known as person-centered care. This approach is not only ethical and respectful,

but is also proven to be useful in effectively managing dementia. Knowing the person is important for successfully integrating strategies to engage the person in activities they enjoy. This improves the self-esteem of the person living with dementia and can give them a sense of purpose to their day.⁹

For person-centered care, it's important to take a step back and remind yourself of the following:

What gives your loved one purpose?

- Is there someone your loved one would like to help?
- Does your loved one have a pet?
- Does your loved one like to build things?
- Does your loved one like to read?
- Does your loved one like music? Do they like to drum?
- What hobbies do your loved one enjoy?
- Do they like to go out on the land?
- Do they enjoy socializing or do they prefer being alone?

What makes your loved one feel...

- Happy
- Valuable
- Comfortable
- Uncomfortable
- Frustrated¹⁰

What does your loved one need for their emotional, spiritual, physical, and mental health?

- Do they speak their Traditional Language?
- Do they eat Traditional or country food?
- Do they smudge?
- Do they like music?
- Do they need books in syllabics?

Indigenous Peoples have always known the rhythm of a drum is healing. For many Indigenous people, a drum represents the heartbeat of Mother Earth. In dementia care, the power of music has also been recognized as healing for people living with dementia. Try playing songs that are meaningful for your loved one and see how they react. Did your loved one drum? If so, try giving them a hand drum to play along with.

6 Thomas, P., Lalloue, F., Preux, P., Haxif-Thomas, C., Pariel, S., Inscale, R. and Clement, J., 2005. Dementia Patients Caregivers Quality of Life: The PIXEL Study. *International Journal of Geriatric Psychiatry*, 21(1), 50–56.

7 Achterberg, W., Lautenbacher, S., Husebo, B., Erdal, A., & Herr, K. 2019. Pain in Dementia. *Pain Reports* 5(1), e803. <https://doi.org/10.1097/PR9.0000000000000803>.

8 Ibid.

9 Ibid.

10 Fazio, S. PhD, Pace, D., NHA, Flinner, Janice., Kallmyer, B., 2018. The Fundamentals of Person-Centered Care for Individuals With Dementia, *The Gerontologist*, Volume 58, S10–S19.





If someone else is providing care for your loved one, share this information with them. It's important for caregivers, including health care providers, to understand what gives your loved one purpose and what makes them happy. Similarly, it's important for them to understand what triggers your loved one to feel sad, frustrated, or uncomfortable.

Knowing this means triggers can be avoided, which can help reduce disruptive or aggressive behaviours.¹¹

MEDICINE WHEEL ACTIVITY 2:

"When referring to a person's well-being, it is important to think about it in a circular form or 'wholeness'. Dementia is a stage in that circle, a stage that is closer to Creator."

– First Nations caregiver, from the South, during NWAC's engagement session in March 2021

If your loved one suddenly becomes disinterested in socializing or no longer enjoys activities they previously liked, you should address this right away. This is likely the result of an unmet need, such as depression or loneliness, or it may be that their dementia may have progressed.

Don't forget to talk to your loved one about what they need and what they are going through. If you understand what they need or why they are acting in a certain way, you can help mitigate potentially disruptive or aggressive behaviours. In some cases, a loved one may need you to communicate their needs on their behalf (at doctors' appointments, for example).



¹¹ Fazio, S. PhD, Pace, D., NHA, Flinner, Janice., Kallmyer, B., 2018. The Fundamentals of Person-Centered Care for Individuals With Dementia, *The Gerontologist*, Volume 58, Pgs S10-S19



TIPS FOR CAREGIVERS

- Check in regularly with your loved one and ask friends and family to check in with them too. Keep a calendar or a visitor's book by the door to track visitors, to remind your loved one that they are not alone.
- Keep to a schedule.
- Keep copies of your loved one's information, as well as yours, in their coats, shoes, and wallet.
- If your loved one keeps asking the same question or repeating the same behaviour, instead of telling them they already asked that, try to not respond and instead help them refocus on something else.
- If your loved one becomes agitated, redirect their attention to something they find calming (music, TV, sewing, beading, drumming).
- Use photo albums as visual cues for storytelling, stimulating memory, and creating positive feelings.
- Write out instructions for routines like brushing teeth. Place picture signs on bathrooms, fridges, and other places of importance or danger zones.
- Have your loved one write their memoirs early on, so their story can be read back to them later or kept for loved ones to read.¹²
- Help your loved one discover things they can do that give them purpose. Here are some examples:
 - Give your loved one a deck of cards and ask them to help you sort them by colour or suit (depending on their ability).
 - Give your loved one a broom or a rag and ask them to help you clean.
 - Ask your loved one to help you take care of a pet or a stuffed animal (depending on their ability).
 - Give your loved one a hand drum or shaker and ask them to make you a beat.

¹² Fazio, S. PhD, Pace, D., NHA, Flinner, Janice., Kallmyer, B., 2018. The Fundamentals of Person-Centered Care for Individuals With Dementia, *The Gerontologist*, Volume 58, Pgs S10-S19





SECTION 3: RECOGNIZE YOU ARE NOT ALONE.

REMEMBER YOUR CIRCLE OF CARE.

It is well understood that dementia interventions and treatments fail unless they consider caregivers. As outlined in Section 1 of this toolkit, taking care of yourself holistically, including your mental, spiritual, emotional, and physical health, is important for both you and your loved one. Knowing you are not alone and having support that comes from sharing thoughts and feelings is very helpful for a lot of people.

Build a circle of care. This can include friends, family, community members, Elders, other caregivers, dementia support groups, and friendship centres, to name a few. 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.

Remember, asking and accepting help is not a sign of poor caregiving and it's very difficult to care for a person living with dementia alone. Sometimes you may not even have to build a circle of care; you may already have people in your circle who care for you and would be available to provide support if you need it. Take time to remind yourself who you already have in your circle. If you don't already have a circle of care, consider building one. There are lots

of supports out there and other caregivers who are going through the same thing as you who also may be looking to connect.

Refer to the table later in this section for some good places to start looking for support and building your circle of care.

You also need to take regular breaks from caregiving. Breaks can give you an opportunity to re-energize, recharge your battery, and continue providing care. Ask your providers about access to respite where someone can care for your loved one for a short period. Make sure you are taking time to take care of yourself, to rest, keep up with your interests and hobbies, and stay in touch with friends and family. Remember to include yourself in dementia care planning and try to do this early so you are not too overwhelmed or stressed to make a plan.



INDIGENOUS SPECIFIC SUPPORTS

AREA OF SUPPORT	SUPPORTS, SERVICES, AND RESOURCES	CONTACT INFORMATION
Knowledge and Education	I-CAARE: Indigenous Cognition & Aging Awareness Research Exchange have developed culturally safe factsheets with Indigenous people living with memory loss and their caregivers.	https://www.i-caare.ca/factsheets
Knowledge and Education	National Collaborating Centre for Aboriginal Health has published a document called Alzheimer's Disease and Related Dementias in Indigenous Populations in Canada: Prevalence and Risk Factors.	Alzheimer's Disease and Related Dementias in Indigenous populations in Canada: Prevalence and Risk Factors (nccih.ca)
Knowledge and Education	The Anishnaabek Dementia Care website culturally safe resources about dementia	http://anishnaabekdementiacare.ca/
Knowledge and Education	Morning Star Lodge's Dementia Caregiver Toolkit provides information and resources for caregivers.	http://www.advancingstates.org/hcbs-programsinitiatives/respite
Emotional Support, Counseling, and Therapy	The Hope for Wellness Help Line offers immediate help to all Indigenous peoples across Canada. It is available 24 hours a day, 7 days a week to offer counselling and crisis intervention.	Call 1-855-242-3310 or chat online www.hopeforwellness.ca
Emotional Support, Counseling, and Therapy	Talk for Healing is a culturally safe, confidential helpline for Indigenous women in Ontario. It provides crisis counselling, advice and support, information and referrals, and telephone counselling sessions.	1-855-554-4325
Emotional support, counselling, and therapy	NWAC Elder Support is available Monday to Friday, from 9 to 11 a.m. and 1 to 3 p.m. EST. NWAC's Elders provide support and aim to build resiliency.	1-888-664-7808
Respite care	The First Nations and Inuit Home and Community Care (FNIHCC) program provides funding and advice on developing home and community care services to Indigenous Peoples living in First Nations and Inuit communities. It provides the following services: <ul style="list-style-type: none"> • Case management and care coordination • In-home respite care • Nursing care • Personal care 	First Nations and Inuit home and community care (sac-isc.gc.ca)
Respite Services	Indigenous and Northern Affairs' Assisted Living/Adult Care Program provides funding for non-medical, social support services to seniors, adults with chronic illness, and children and adults with disabilities (mental and physical) who are on reserve to help them maintain their independence. This includes in-home care, adult foster care, and institutional care.	https://www.sac-isc.gc.ca/eng/1100100035250/150443





INDIGENOUS SPECIFIC SUPPORTS

AREA OF SUPPORT	SUPPORTS, SERVICES, AND RESOURCES	CONTACT INFORMATION
System Navigation	The National Association of Friendship Centres is a network of over 100 friendship centres and provincial/territorial associations. It is Canada's most significant national network of self-determined, Indigenous-owned and -operated community hubs offering programs, services, and supports to urban Indigenous People.	https://nafc.ca/?lang=en
System Navigation/ Financial Support	Non-Insured Health Benefits (NIHB) provides coverage for a range of health benefits for Indigenous Peoples, including vision, dental, mental health counselling, medical supplies and equipment, prescriptions, and medical transportation.	Call 1-866-885-3933 or visit www.sac-isc.gc.ca and search "no insured health benefits."
System Navigation/ Financial Support	Indigenous Services Canada (ISC) provides health services and programs for First Nations, Métis and Inuit Peoples, including noninsured health benefits, estate services, education, housing, as well as social and funding programs.	Call 1-800-567-9604 or visit https://www.canada.ca/en/indigenous-services-canada.html
Culturally Safe Diagnostic Tools	Indigenous Services Canada (ISC) provides health services and I-CAARE, Indigenous Cognition & Aging Awareness Research Exchange, has developed a Canadian Indigenous Cognitive Assessment (CICA) tool, which aims to provide a culturally safe experience for older Indigenous People who need assessments. You can use this tool on your loved ones or ask your physician to use it in place of mainstream tools used in offices.	https://www.i-caare.ca/cica-toolkit

SUPPORTS FOR EVERYONE (NON-INDIGENOUS AND INDIGENOUS), LED BY NON-INDIGENOUS ORGANIZATIONS

Knowledge and Education	Alzheimer's Society provides information, resources, and education sessions about dementia.	https://alzheimer.ca/en
Knowledge and Education	Canadian Mental Health Association provides information and resources for caregivers about dementia.	https://cmha.ca/brochure/care-f-caregiver/ https://ontario.cmha.ca/provinci-programs/living-life-to-the-full/ https://ontario.cmha.ca/news/baycrest-supports-evaluation-living-life-full-caregivers-55/

INDIGENOUS SPECIFIC SUPPORTS

SUPPORTS FOR EVERYONE (NON-INDIGENOUS AND INDIGENOUS), LED BY NON-INDIGENOUS ORGANIZATIONS (CONT.)

Knowledge and Education	Alzlive provides information, tips, resources, and education about dementia and caregiving.	https://alzlive.com/
Emotional Support, Counseling, and Therapy	The Alzheimer's Society provides counselling services (virtual and in person) as well as various support groups.	Call 1-800-616-8816 or email info@alzheimer.ca or visit their website https://alzheimer.ca/en/help-support/programs-services
Emotional Support, Counseling, and Therapy	The Government of Canada's Dementia Dialogue is a podcast series sharing stories on people's journeys with dementia and providing care for people living with dementia.	https://www.dementiadialogue.ca/
Emotional Support, Counseling, and Therapy	Alzlive has a series of candid, real-life stories from caregivers to remind you that you are not alone! A large contributor to these stories is a series (also available on YouTube) called "Alzheimer's—What They Forget to Tell You."	https://alzlive.com/category/share-stories/
System Navigation	The Alzheimer's Society's First Link Program provides information, support, guidance, and links to community services. Through First Link, you can receive counselling and support, get referred to health care providers and community supports, and meet people going through the same thing(s) you are. It allows people to exchange experiences. You will need a physician's referral to First Link.	https://alzheimer.ca/en/help-support/programs-services#Support_programs
Skills building and coping strategies	The Canadian Mental Health Association provides an interactive eight-week course to help caregivers over the age of 55+ cope with life's challenges.	https://ontario.cmha.ca/news/baycrest-supports-evaluation-living-life-full-caregivers-55/





TABLE 1: SUPPORTS AND SERVICES FOR CAREGIVERS.

1. **Learn:** Find out as much as you can about dementia and speak to as many people as you need to. Consider speaking with people living with dementia, caregivers of loved ones with dementia, health care providers, and Alzheimer's societies. Try to learn, and prepare, for setbacks and difficult symptoms of dementia. (To learn more about difficult symptoms, and how to navigate them, refer to Section 2 of the toolkit.)
2. **Find support:** Find support groups near you or attend virtually. NWAC will be holding support groups; alzheimer.ca also holds support groups. There are many online forums and/or groups you can be a part of (e.g., Facebook). Support groups provide a great opportunity to learn from others, receive support, and know that you are not alone.
3. **Plan daily routines:** Daily routines are very beneficial for you and your loved one. These routines can be a source of comfort and mark the day for your loved one. Try to do things at the same time to keep your loved one in sync. Include activities that your loved one enjoys, are quiet, and involve interaction and conversation.
4. **Start self-care routine early:** Prepare yourself to handle stress and take up self-care routines. This can include ceremony, prayer, smudging, or meditating. More information on self-care can be found in Section 1 of the toolkit.
5. **Plan for medical appointments and follow-ups:** Make a list of questions you want to ask during the appointment and give a copy of the list to your doctor or nurse. Take notes during appointments and ask your provider to give you a summary of what was talked about if you found it helpful. Try to keep a journal of your loved one's medications, treatments, appointments, and contact numbers for members of the health care team. This will help you keep track of everything and offers a reference when you need it.
6. **Explore your medical insurance and health coverage, including Non-Insured Health Benefits (NIHB):** Medical expenses and home adaptations can increase the stress of caring for a loved one. Try to find out what coverage is available for their care early on, to help with future planning. A list of medical supports and devices covered by NIHB is provided in Section 5 of the toolkit.

ADVANCED CARE PLANNING

Advanced care planning involves communicating with your loved one about their care, wishes, values, beliefs, and preferences. It involves understanding what your loved one would want in case they become incapable of communicating their wishes, including consenting or refusing care. An advanced care plan puts your loved one in the centre of their care, and provides a voice for them when they can't do so for themselves.¹³

THE IMPORTANCE OF PLANNING AHEAD AND STARTING EARLY

Due to its progressive nature, a person living with dementia may not be able to express their wishes regarding their care, especially in the later stages. While it may be difficult, uncomfortable, or painful to have these conversations, it is important to plan early to ensure you know your loved one's goals and wishes in advance, and are able to determine what to do based on these wishes. This will increase the likelihood that your loved one will be comfortable with their care at the end of their life.¹⁴ Developing a care plan early can reduce stress for everyone involved, and give you a way to anticipate and deal with changes as a result of mental decline.

Dedicate time with your loved one to have this conversation. It's ok to express your emotions, feel sad, and even use humour.

Having an Elder present is helpful for a lot of people, so consider involving an Elder whom your loved one trusts. If your loved one is having difficulty with this conversation, or refuses it, give them their space but try reminding them it's important for you to know their wishes to ensure they are respected when the time comes. There is no right or wrong way to have this conversation, but make sure you are mindful of your loved one's feelings, take breaks when necessary, and follow their lead.

WHAT SHOULD BE DISCUSSED AND CONSIDERED?

- Have your loved one speak with their health care provider to make sure they have enough medical information to make their decisions and understand dementia (you may be present during these conversations, if your loved one prefers).
- What medical interventions, treatments, and procedures would your loved one like to have? Which do they refuse? Think about emergency hospitalization and aggressive medical care, including cardiopulmonary resuscitation (CPR), do-not-resuscitate (DNR) orders, feeding tubes/IV hydration, and respirators/ventilators. Speak with your health care provider to clarify when, and how, these interventions are used, and whether it's what your loved one would like.

¹³ Dening, H., Sampson, E.L., & De Vries, K., 2019. Advance Care Planning in Dementia: Recommendations for Healthcare Professionals. Palliative Care, 12. 1178224219826579.

¹⁴ Ibid





Refer to Box 1 for helpful questions to ask your loved one's health care provider when making decisions about medical interventions.

- Are there any spiritual or Traditional ceremonies your loved one would like to use? Would they like to use Traditional/sacred medicines, like tea, cedar, tobacco, sweetgrass, and sage? Would they like to include sacred or ceremonial items, like feathers, songs, rocks, cloth, drums, and/or bundles in their care? Would they like Elders, Traditional Healers, Medicine Men/Women involved in their care?
- Does your loved one have any wishes at the time of death? If given a choice, do they prefer to die at home, in hospice, or in a hospital? Would they like certain music playing? Would they like family or friends around? Do they want any ceremonies or rituals?
- What comfort/palliative care does your loved one want? Would they like to be transferred to the hospital for care? Or do they prefer to stay at home?
- Would your loved one like to donate their brain/body for research? Would they like to donate their organs?
- What arrangements would your loved one like to make for their funeral, burial, or cremation? What cultural and/or spiritual rituals would they like done to their body before then?¹⁵

- **What are the side effects of this intervention? Will it bring any physical discomfort or pain?**
- **Is the health condition you are attempting to manage with this medical intervention treatable?**
- **Will the health condition and/or medical intervention require hospitalization?**
- **What is the prognosis of the health condition? How will it develop?**
- **What is the outcome of refusing the intervention?**
- **Is there a way to manage the symptoms without the intervention?**



¹⁵ Alzheimer Society of Canada. (2021). "End-of-life Care." Retrieved August 2021, from <https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/end-life-care>

LEGAL DOCUMENTS

Your loved one's verbal wishes can be considered and can be as valid as a legal document. That said, it's always a good idea to have your loved one write down their wishes. Writing it down serves as a good road map for you, the caregiver, for when you need to start making decisions for them. It's also a good idea to speak to a legal representative or lawyer to help draw up legally binding documents. Typically, these papers need to be drawn up and signed while your loved one still has legal capacity or a level of decision-making ability to make legal, medical, and financial decisions.¹⁶ In other words, the earlier, the better!

SUBSTITUTE DECISION-MAKER(S)

Substitute decision maker(s) is the person, or persons, who make medical and personal care decisions when the person living with dementia no longer can. It's a good idea for the person living with dementia to select this person early in their diagnosis. This person is usually a trusted family member or friend.¹⁷The laws about substitute decision-makers vary across Canada. For more information about provincial and territorial guidelines, visit <https://www.advancecareplanning.ca/resources-and-tools/>

POWER OF ATTORNEY FOR HEALTH CARE

A person living with dementia can assign someone (typically a family member or friend) to make medical and/or other decisions on their behalf when they do not have the capacity to make them on their own through a power of attorney health care document. This individual should always make decisions based on the wishes and best interests of the person living with dementia.¹⁸

LIVING WILL

In this document, the person living with dementia can outline their preferences on how they would like to be treated in certain medical situations, health care, and end-of-life care for the future. This document usually provides the substitute decision-maker, power of attorney, or family member with direction on how to make decisions when their loved one no longer can.¹⁹

WILL

Although it sounds the same as a living will, this is a different document. A will usually outlines how property and assets are divided after a person's death. It cannot be used to communicate health care preferences.

¹⁶ Anderson, I., End of Life Care, Module 4, A joint project of Continuing Education and the Joint Centre for Bioethics, University of Toronto and the Temmy Latner Centre for Palliative Care, Mount Sinai Hospital.

¹⁷ Anderson, I., End of Life Care, Module 4, A joint project of Continuing Education and the Joint Centre for Bioethics, University of Toronto and the Temmy Latner Centre for Palliative Care, Mount Sinai Hospital

¹⁸ Anderson, I., End of Life Care, Module 4, A joint project of Continuing Education and the Joint Centre for Bioethics, University of Toronto and the Temmy Latner Centre for Palliative Care, Mount Sinai Hospital

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If you and your loved one have not had these conversations, or if your loved one has not written down their wishes, values, beliefs, and preferences about their care, decisions about their care need to be based on their lifelong values, desires, principles, or what you think they would want. In other instances, you may have to use your judgment and weigh the risks and benefits to determine how to proceed.

KEEPING YOUR LOVED ONE SAFE

Home is a familiar place for your loved one to feel safe and connected to who they are, but you might want to consider modifying your space to make it safer for your loved one. Keep in mind that as dementia progresses, your loved one may experience decreased balance, vision problems, memory impairment, and reduced judgment abilities.²⁰ Some things to consider:

- Adapt your space to your loved one's current ability and make further changes as their abilities change. For example, early after diagnosis, your loved one might be able to handle sharp knives with ease and can lead dinner preparation; in later stages, you may want to consider limiting their use of knives and delegate safer tasks, like washing and tearing lettuce.

- Look for hazards, such as sharp objects, small choking hazards, easily accessible fire hazards, such as gas stoves, cigarettes, lighters, poisons including cleaning products, and fall hazards, including staircases and carpets.
- Consider lowering the hot water heater temperature, securing appliances in the kitchen and bathroom, and locking away medications, cleaning supplies, and other household chemicals.
- Think about installing safety equipment, including grab bars and non-slip mats, in the bathroom, and keeping an eye out for things that can confuse your loved one, including pictures, mirrors, or shadows.
- Consider safety devices and technology, such as Finding Your Way®, which helps people living with dementia, and their families, understand the risk of going missing, be prepared for incidents of going missing, and ensure that people with dementia can live safely in their community. Similarly, think about getting your loved one a MedicAlert bracelet or necklace with your loved one's medical needs and information engraved on it.²¹

PREPARING FOR A HOSPITAL VISIT

The unfamiliar environment, people, noises, and activities of a hospital can be

very confusing and upsetting for your loved one living with dementia. Whether it's a planned admission or an emergency visit, preparing for a hospital visit can improve your loved one's experience. The Alzheimer Society has forms and checklists to help you prepare for a hospital visit.

Visit https://archive.alzheimer.ca/sites/default/files/files/national/core-lit-brochures/all-about-me_booklet.pdf. These forms can help hospital staff provide more personalized care. Try to keep these forms handy (store them with your loved one's health card) and keep them up to date.

SECTION 5: AFTER CAREGIVING ENDS

When caring for your loved one comes to an end, it's common to feel a loss of purpose, as caregiving likely became one of your main roles. When caregivers lose a loved one they were providing care for, it can often feel like a double loss: the loss of your loved one and the loss of your role or purpose. Dealing with loss and grief is often difficult and leaves many people feeling lost, lonely, and hopeless.²²

GRIEVING PROCESS

The first step is to allow, understand, and accept your feelings. In addition to grieving, caregivers may feel relieved that they no

longer need to provide care or that the person they were caring for is no longer suffering. Feeling relief after a loss can also make the caregiver feel guilty. Other caregivers may feel angry with themselves, or someone else, for letting them down.²³ Whatever the feeling, it's important to remember these are natural reactions. Grief is complicated, and everyone feels grief differently. It's important to express whatever it is you are feeling—sadness, anger, relief, and/or loneliness—to learn how to cope with your loss.

The process of grieving can be short for some; for others, it can be long (months to years). For people providing care for someone living with dementia, the grieving process may begin before the person dies—as it may feel like you have already lost the person you once knew. It's important to remember that grief is a personal experience; it's different for everyone. These steps are all essential to the grieving process:

- Accepting the loss
- Working through the pain of grief
- Adjusting to life without your loved one
- Emotionally letting go of your loved one and moving on with your life

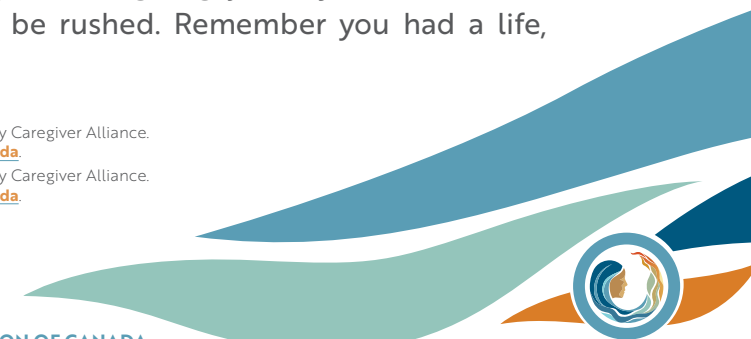
Consider grieving as an important part of your caregiving journey, which should not be rushed. Remember you had a life,

²⁰ Ensuring Safety and Security. Alzheimer Society of Canada. (n.d.) Retrieved October 14, 2021 from [Making your environment safe | Alzheimer Society of Canada](#)

²¹ Ensuring Safety and Security. Alzheimer Society of Canada. (n.d.) Retrieved October 14, 2021 from [Making your environment safe | Alzheimer Society of Canada](#)

²² Schempp, D., LCSW. (2013). *When caregiving ends*. When Caregiving Ends – Family Caregiver Alliance. Retrieved October 15, 2021, from [Finding your way® | Alzheimer Society of Canada](#)

²³ Schempp, D., LCSW. (2013). *When caregiving ends*. When Caregiving Ends – Family Caregiver Alliance. Retrieved October 15, 2021, from [Finding your way® | Alzheimer Society of Canada](#)





hobbies, and a purpose before you became a caregiver. Now that your caregiving role has ended, chances are you have lots of free time. Celebrate having time to focus on yourself and repairing, or maintaining, old and new relationships. Remind yourself of things that give you purpose, and try to find ways to fulfil those purposes.²⁴ If you consider your purpose is helping people, find a cause that you can volunteer for.

reaching out to someone in your circle of care. Do you have a family member, friend, Elder, or community member who could help? If not, consider seeking help from a professional and/or joining a support group.

REMEMBERING YOUR CIRCLE OF CARE

Remember your circle of care. You likely have family, friends, and other caregivers you connected with who would like to spend time with you. Try reaching out to friends you haven't seen in a while, do an activity you enjoy, or just catch up with loved ones over a cup of tea.

Do things that feed your mind, body, and spirit. Revisit the Medicine Wheel activity and self-care activities identified in Section 2 of this notebook.

Maybe it's time to reconsider your needs, as they have likely shifted now that you are no longer providing care for someone full time. What do you need to maintain your physical, emotional, spiritual, and mental wellbeing? Once you identify your needs, come up with strategies to meet your needs. If this isn't something you can do alone, consider

MEDICINE WHEEL ACTIVITY 3:

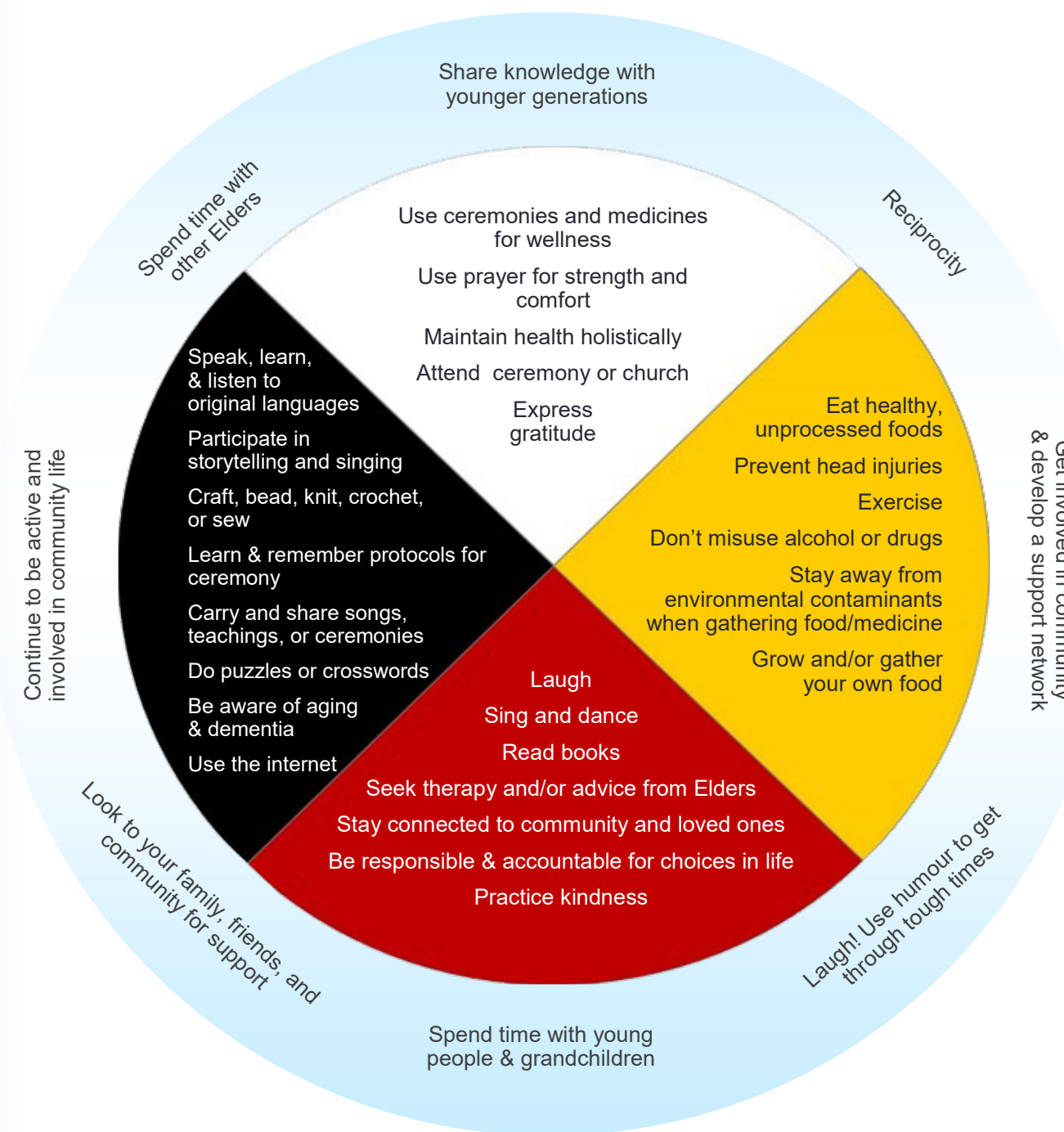


While your caregiving journey, as you knew it, may have come to an end, take time to appreciate the skills you learned while providing care for your loved one. You likely did things you never thought you could. Take time to recognize your strength and resilience.

Honour your loved one's life by living your life to the fullest.

²⁴ Schempp, D., LCSW. (2013). *When caregiving ends*. When Caregiving Ends – Family Caregiver Alliance. Retrieved October 15, 2021, from [Finding your way@Alzheimer Society of Canada](https://www.findingyourway.org/).

Advice from older Indigenous peoples



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.

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SUPPORTING A CIRCLE OF CARE

SOUTENIR UN CERCLE DE SOINS

CREATING A CIRCLE OF CARE SUPPORT GROUP GUIDE



Indigenous Women, Girls, Two-Spirit, Transgender, and Gender-Diverse+ (WG2STGD+) caregivers for people living with dementia will benefit from the program, which is designed to improve their mental, emotional, and physical well-being.

Their capacity to care for their loved ones will also improve, as they will be equipped with an enhanced understanding of dementia, as well as skills to manage their loved one's evolving and ongoing dementia progression.

Those living with dementia will also benefit from the program indirectly, through an improvement in the care received. When their caregiver(s) struggle physically and/or mentally, their level of care is affected as well.

In addition to sharing resources, a support group can help to mitigate stresses and burdens felt by Indigenous caregivers of those living with dementia.





CREATING A CIRCLE OF CARE (SUPPORT GROUP)

STRENGTHENING YOUR CIRCLE OF TRUST

The health status of Indigenous Peoples is an important part of cultural safety, balance, and respect. Indigenous Peoples have applied these principles in their mental, emotional, physical, and spiritual systems. Because health is interconnected with family, community, and the environment, ailments and conditions are seen as the result of imbalances in those systems. By giving equal emphasis to mental, emotional, physical, and spiritual aspects of Indigenous Peoples, and their cultural connections, we can help to improve the overall health of Indigenous Peoples across Canada.

At times, cultural misunderstandings affect the ability of health care professionals to assist their patients in achieving good health. For many Indigenous People, a lack of cultural recognition and access to culturally competent care can result in a disheartening experience.

We are looking to bridge the gap in how health care professionals engage and treat Indigenous People suffering from dementia, as well as their caregivers. This resource toolkit will benefit the patient as well as everyone in their circle of care. The hope is that this toolkit, which is rooted in cultural connection and community, will provide ongoing supports.

CREATING A SHARING CIRCLE

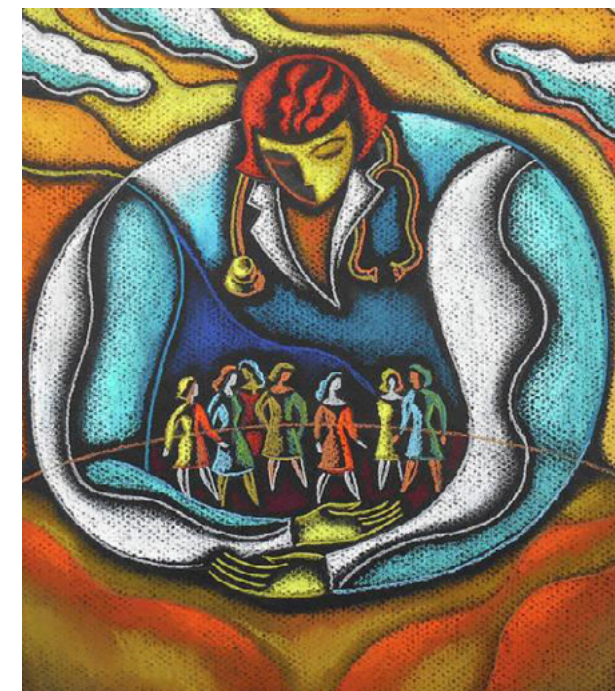
When thinking of community support, it may be beneficial to discuss with the community about having a navigator who specializes in dementia care or community support. A navigator can act as a guide for community members, to meet people where they are and connect them with resources and support. A navigator can support community members by helping to facilitate sessions and inform participants about resources available to support dementia care in Indigenous communities. A navigator can help with appointments, can advocate, or can provide emotional support.

The navigator role could be a professional position—given to someone who typically works in the health care system. However, this often costs money. If funding is an issue, consider a peer navigator. This person usually has experience caring for individuals with dementia and may already know other community members.



When choosing a professional navigator, look for these qualities:

- ✓ Understand the culture, and context, of your community.
- ✓ Has knowledge of the subject matter and can share personal experiences.
- ✓ Has knowledge of the language spoken in the community.
- ✓ Can connect and comfort others with ease.
- ✓ Is knowledgeable of community resources and dementia-specific supports.
- ✓ Is non-judgmental.
- ✓ Can identify when someone is in trouble or in need of care.



It's important to keep Sharing Circles small enough so all participants may be heard, feel comfortable sharing, and have an opportunity to contribute. If meeting online, you can always break out into smaller Sharing Circles.

Will caregivers be able to bring the person they are providing care for?

While it's important to consider that some caregivers might not have someone else to help provide care for their loved one, it's equally important to remember that support groups are intended to give caregivers a break. If meeting in-person,

consider having a community member and/or health care provider hold an activity in a separate room for people living with dementia. This could represent an excellent opportunity for people with early- to middle-stage dementia to engage in social and cultural activities. People in later stages of dementia may need more supervision than can be offered in a community care setting. It could also be suggested that caregivers look into what kind of respite care supports the community has to offer.





GUIDING A SHARING CIRCLE

Sharing Circles should aim to create an environment that makes participants feel comfortable, safe, and heard. This includes having resources and support for community members who identify as 2SLGBTQIA+ and creating a space where community members can share their fears and challenges. Sharing Circles should also be used to celebrate strength and success.

Sometimes people will share freely and there won't be enough time to cover everything. If this is the case, remind people to attend the next meeting and/or connect with one another between circles. At other times, it might be difficult to get people to open up. This is why it's important to have open-ended questions, which can guide the discussion with prompts, and to include follow-up questions to keep the conversation going. It's also helpful to have a navigator who is willing to share their own personal experiences. People are then encouraged to connect and spark ideas and questions that others can relate to. Providing resources that community members can access on their own can also be helpful for those individuals who want information but are not comfortable sharing yet. See Appendix A for ideas.

CULTURAL CONSIDERATION

Is there an Elder you can invite to open your circle of care with a prayer, singing, drumming, or ceremony? Grounding the circle in culture is a good way to make people feel comfortable and connected to one another. It also creates a space to support healing. If an Elder is not available or if providing an honorarium is an issue, consider asking a participant to lead a prayer, smudge, or lighting a qulliq. If meeting in person, consider including Traditional foods to share. If access is an issue, consider providing tea and/or bannock.

ADVERTISING THE CIRCLE OF CARE

Consider advertising the circle of care on social media, through local radio, or in person at your community health centre, cultural centre, arena, or other places where community members tend to gather. Do you know other caregivers? Ask them to share with those they know. Keep in mind that some people may be nervous to sign up because of feelings of stigma or they are struggling to accept they have dementia. Consider some ways you can make others feel comfortable when advertising a circle of care.

Consider asking questions to encourage dialogue on the four following topics.

We encourage you to formulate your questions as a group using the blank spaces below.

REFLECTION

When I learned of my loved one's diagnosis, I felt ...

Today I feel ...

One thing I wish that could've been different is ...

Something in my life that has changed a lot since I became a caregiver ...

This has made me feel ...

Something I've learned about myself is ...

Something I wish others understood about dementia is ...

Blank lined area for reflection notes.





CHALLENGES 

A loss that I experienced was ...

Four horizontal lines for writing.

The hardest part for me has been ...

Four horizontal lines for writing.

Today I am struggling with ...

Four horizontal lines for writing.

My loved one is struggling with ...

Four horizontal lines for writing.

COPING STRATEGIES (SUPPORTS) 

A source of healing, and/or comfort, for me is ...

Three horizontal lines for writing.

Something that gives me hope is ...

Three horizontal lines for writing.

I feel loved and valued when ...

Three horizontal lines for writing.

I take care of my mind, body, and spirit by ...

Three horizontal lines for writing.

My community has helped me by ...

Three horizontal lines for writing.

What helps me when I feel overwhelmed is ...

Three horizontal lines for writing.





COPING STRATEGIES (SUPPORTS) 

A source of healing, and/or comfort, for me is ...

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I take care of my mind, body, and spirit by ...

Three horizontal lines for writing.

My community has helped me by ...

Three horizontal lines for writing.

What helps me when I feel overwhelmed is ...

Three horizontal lines for writing.

CELEBRATING SUCCESSES 

I am proud of myself for ...

Three horizontal lines for writing.

A challenge that I have overcome is ...

Three horizontal lines for writing.

A strategy that I have learned that has helped support my loved one is ...

Three horizontal lines for writing.

I am now comfortable with ...

Three horizontal lines for writing.

I now understand ...

Three horizontal lines for writing.

PROMPTS (TO ENCOURAGE MORE DISCUSSION)

How did that make you feel?

How did you respond to that situation?

What would you like to do differently next time?





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: [Talk4Healing - Beendigen](#)

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 to Friday from 9 to 11 a.m. and 1 to 3 p.m., EST

Toll Free: 1-888-664-7808

Alzheimer Society of Canada

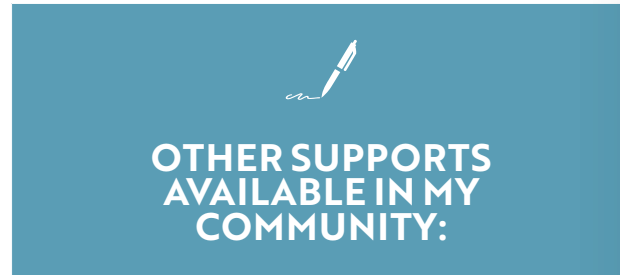
Toll-free: 1-800-616-8816

Indian Residential Schools Crisis Line

1-866-925-4419

Indian Residential Schools Survivors Society

1-800-721-0066



Seven horizontal lines for writing notes.



SUPPORTING A
CIRCLE OF CARE

SOUTENIR UN
CERCLE DE SOINS

CARE PLAN CREATION **TOOLKIT**





TOOLKIT OUTLINE:

Personal Information:

Person Living with Dementia:

- Name: _____
- Nickname: _____
- Date of birth: _____

Key Contacts – Primary:

- Name: _____
- Relationship to person living with dementia: _____
- Phone number: _____

Address:

- Street: _____
- City: _____
- Province: _____
- Postal Code: _____

Key Contact:

- Name: _____
- Relationship: _____
- Phone number: _____

Key Contact:

- Name: _____
- Relationship: _____
- Phone number: _____

Key Contact:

- Name: _____
- Relationship: _____
- Phone number: _____

Health Information:

Family Doctor:

- Name: _____
- Phone number: _____

Specialist:

- Name: _____
- Specialist for what? _____
- Phone number: _____

Specialist:

- Name: _____
- Specialist for what? _____
- Phone number: _____

Local Emergency Contacts:

- Ambulance: _____
- Fire Department: _____
- Police: _____

Diagnosis:

- Type of dementia: _____
- Date of diagnosis: _____
- When were signs first noticed? _____
- What else has the person been diagnosed with?

- Allergies: _____

- Infectious diseases requiring special attention (e.g., MRSA, TB, HIV): _____





Current Medications:

- Type: _____
- What it treats: _____
- Dosage: _____
- Duration and start date: _____
- Side Effects: _____

- Type: _____
- What it treats: _____
- Dosage: _____
- Duration and start date: _____
- Side Effects: _____

- Type: _____
- What it treats: _____
- Dosage: _____
- Duration and start date: _____
- Side Effects: _____

- Type: _____
- What it treats: _____
- Dosage: _____
- Duration and start date: _____
- Side Effects: _____

Daily Routine:

Morning Schedule

- When do they usually wake up? _____
- When do they eat breakfast? _____
- Exercise or activities? _____
- Additional notes: _____

Afternoon Schedule

- When do they eat lunch? _____
- Exercise or activities? _____
- Do they nap? _____
- Additional notes: _____

Evening Schedule

- When do they eat dinner? _____
- What time do they go to sleep? _____
- Nighttime routine? _____
- Additional notes: _____



SUPPORTING A
CIRCLE OF CARE

SOUTENIR UN
CERCLE DE SOINS

CIRCLE OF CARE **TOOLKIT**



NATIVE WOMEN'S ASSOCIATION OF CANADA