

A SACRED JOURNEY

THE LONG
GOODBYE



Native Women's
Association of Canada



L'Association des femmes
autochtones du Canada





ACKNOWLEDGEMENTS

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

We are honoured to be able to help share these stories. It is our hope that by putting names and faces to people's journeys with dementia, we can collectively break down the stigma that many people face.

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

We know that as Indigenous Peoples, our strengths are embedded in our families, cultures, teachings, languages, and stories.

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

ABOUT NWAC

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

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



ABOUT THIS PROJECT

In support of the implementation of Canada's first national dementia strategy: A Dementia Strategy for Canada - Together We Aspire, the NWAC was provided funding to help raise awareness of dementia within Indigenous communities, with a focus on reducing stigma. This book is part of NWAC's project, *Stigma: An Exploration of Lived Experiences, Understandings, and Behaviours of Dementia within Indigenous Communities*. This work is incredibly important because for those living with dementia, stigma creates increased risk for abuse and neglect, and can result in barriers to care and support. Additionally, people living with dementia and caregivers of people living with dementia may experience several challenges related to accessing services, participating in their community, and working while still able.



While stigma impacts many people living with dementia, for Indigenous Peoples, there is often the added layers of racism, sexism, and discrimination that many experience while accessing healthcare. This might look like differential treatment by healthcare providers as well as barriers to accessing health services on reserve and throughout Inuit Nunangat, and in other rural and remote Indigenous communities. These challenges are often compounded by additional challenges of daily care including poverty, inadequate housing, poor infrastructure, mistrust of the healthcare system, institutional barriers, and a lack of access to tailored, culturally safe supports and services. Therefore, NWAC knows that for initiatives targeting dementia related stigma within the Indigenous population to be successful, initiatives must be culturally specific and centered on the personal experiences of Indigenous Peoples living with dementia and their caregivers.

It is with this spirit and intent in mind that we share these stories.





BECKI LABELLOIS is Mi'kmaq from Eel River Bar First Nation. Becki wrote this story in memory of her mother, *"until we meet again, my mother. I will always love you and cherish the gifts of life you have given to me in this hoop of life we live in. Msit nogoma"*.

My mother was once an icon all over Canada, the United States, and even overseas. She fought for her heritage, culture, beliefs, and for her way of life. She was a strong Inu Epiit. She grew up to be the first from her reserve of Eel River Bar, to graduate with high honours. She was the first female Chief elected in the province of New Brunswick. She was a strong advocate for having the Mi'kmaq language taught in schools, to ensure that the children of Eel River Bar, would know who they are. She hoped to reconnect the severed ties caused by Residential Schools and to heal their effects on the reserve.

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

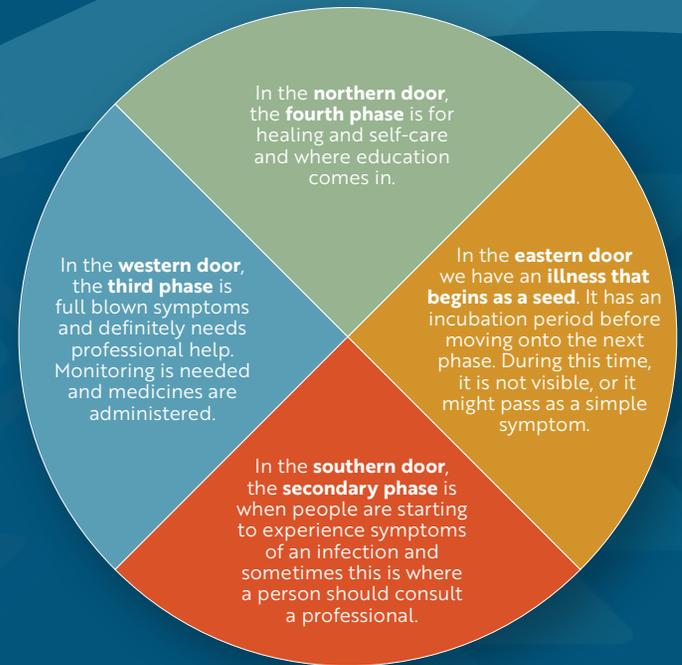
I learned to compensate for mom early on by identifying people, places, and things to what they were connected to, to help jog her memory.

It was my great honour to get to know the circle of people that she was surrounded by in her years of dedication to the Union of New Brunswick Indians, and the various boards and associations with which she was involved. The powwow's, gatherings, and conferences were the time to meet, greet, trade, and reflect upon ideas, while also reminding us that whatever we learn is not ours to keep for ourselves, but rather, to be passed on. That is the circle of life.

Her presence and wisdom were sought after at various gatherings and meetings. It was after these gatherings that she would ask me who certain people were, and we would giggle. She would talk to everyone as if she knew them, everyone's voice mattered in her eyes. She was a great listener. She gifted me with the listening ear. Many times, we would have to jog her memory and then she would recall who that person was and the connection. We would just giggle and say, **"we are not lost, we are just taking a different way to get there"**. The best one was when she would say, **"well we are here, better late than never"**.

I recall many times waking up early to travel to meetings all over North America. We were well known as the road runners. I had my youngest daughter Jenna travel with us most of the time.

My mom needed someone to take her because she never had a license or a vehicle, so all the siblings, nieces, nephews, and even the Chief would drive her to meetings. She was always busy with her crafts, and she would sell them at every event, trying to keep the Apitjipeg crafts alive. This was her connection to her cycle of life. Our family and our whole community had a chance to learn from her hands-on approach, so we can pass it on to the next generation. It is with great pride, to be able to acknowledge our ancestors of the past, present, and future. We are all connected in this circle of life. We come to a journey of birth, adolescence, adulthood, and elderhood. We need to educate ourselves on dementia to know the signs and symptoms, so that we can put resources in place before any abuse can happen to our respected elders.





COLLEEN GAUVIN is Mi'kmaq from Eel River Bar First Nation. Colleen shares her story in memory of her late mother who lived with dementia.

Mom, Mother, Wife, Sister, Daughter, Nurse, Photographer for WWII, Chief, Educator, respected Elder, Grandmother - these are some of the titles in life she held; but to me the most important name was Mom.

She was so much - so full of life, so intelligent, so humble, so loving, so forgiving and always giving. Giving of her love, lending an ear, giving financial help, feeding everyone, and uplifting people's spirits.

Her life was not easy. She was raised by a single mother - her father a wanderer and an alcoholic. She became the first in a great deal of important roles. But first, she was a mother to 14 children, and so many grandchildren. She was the first Mi'kmaq woman to graduate from high school. The first Mi'kmaq woman to enroll in nursing school and the first Mi'kmaq woman to become Chief. She lived her life to the fullest.

When the family noticed she was losing some of her faculties, I started on a heart-breaking journey. Being the eldest daughter, I took her up to the Healthy Aging Clinic. With each visit, the facts became clearer that mom had the beginnings of dementia. With each visit, I came to the realization that I was slowly losing the mother I knew, but she still knew who I was. Signing her into a Nursing Home was my nightmare. She was my mom. She gave me everything, and here I am making this decision for her. Although I knew it was for the best, it still destroyed me. The nursing home allowed us private time when she passed into the other world so we were able to do traditional rites for her and healing for us.

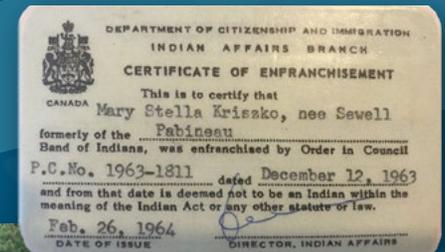
MARIE KRYSZKO is from Pabineau First Nation in New Brunswick. She wrote this story in honour of her beautiful Mi'kmaq Mother who meant the world to her and her family.

My mother was the life of the party. She loved to dance and listen to old country music. She was both a realist and an optimist. She loved a challenge, and she loved and respected ALL of our people.

She was one of the strong, full blooded, Mi'kmaq women who was born and raised on the Pabineau First Nation Reserve. I will always look up to this beautiful woman's strength and wisdom, and I will always carry on her courage. She stood up for her rights when her Indian status was taken from her because she married my dad, a non-native man, and moved off the reserve. Because she lost her Indian Status (as you can see in the photo of her Certificate of Enfranchisement) she lost her right to vote, and she lost the right to be a band member. She would say, **"all of a sudden, I was not an Aboriginal woman, according to the Indian Act"**.

She was one that lobbied and used her voice, for our women to gain their Indian status back.

In 1972, my mother became president of local 15 – Bathurst. Immediately thereafter, she was elected to the Board of Directors and continued to sit on the board until early 2000. She also sat on the Board of Directors for Skigin-Elnoog Housing Corporation. She has been recognized for her contributions and she is a lifetime member of the New Brunswick Aboriginal People Council.



When my mother became sick with dementia, I asked her to move in with me, so that I could take care of her, as she took care of me all my life.

During the time she lived with me, I could see more and more signs of dementia. She always left the water running. She would leave the stove on. She would forget to take her daily medications, and she would ask me the same question over and over. One day, she asked me how old I was, and she asked me over, and over, and over again. I always answered her like it was the first time she asked me.

She said she felt lost at my house. She would tell me that I lived in the woods and there was only one car that passes by all day. I kind of laughed because it was probably my vehicle. One day, I drove in the yard, and I stayed in the truck talking on the phone with my sister because we were having this great conversation. I noticed my mom peeking through the curtains (a few times). Not too long after, I see an RCMP cruiser driving by slowly, and it kind of flashed its lights my way. I said to my sister, HOLAY MOLAY!!!! I think mommy called the cops on me. And yes, that's exactly what she did! She said she didn't recognize my truck sitting in the yard and she thought it was someone that was going to break in. The cops drove into the yard, we went in the house, and the officer had to make a report. Mommy and I had a good laugh after the cops left.

Dementia is the hardest. It was not easy watching my mom forgetting, losing mobility, and living with no quality of life. She would say to me, I know I am forgetting things. Finally, she agreed to move into a senior's residence. A few years later, she ended up in the hospital as she could no longer remember to walk. After six weeks in the hospital, she passed away in 2019, on November 11 at 11:11 am.

Loving you always and forever and ever MOM, my angel.

Here is one of her favorite prayers. She would open our annual powwow, at workshops or at gatherings with this prayer (she made a few changes and made it her own, she said, it was easier to read - her way).

PRAYER OF SAINT FRANCIS OF ASSISI

Lord, make me an instrument of your peace,
Where there is hatred, let there be love,
Where there is offence, let there be pardon,
Where there is discord, let there be union,
Where there is error, let there be truth,
Where there is doubt, let there be faith,
Where there is despair, let there be hope,
Where there is darkness, let there be your light,
Where there is sadness, let there be joy,
O Master, let me not seek as much to be
consoled as to console,
To be understood as to understand,
To be loved as to love,
For it is in giving that one receives,
It is in self-forgetting that one finds,
Is it in pardoning that one is pardoned,
It is in dying that one is raised to eternal
life.
Amen



PEARLEEN KANEWOPASIKOT shared this photo in honour of her late aunt Julie, a former university professor. After she was diagnosed with dementia, she ended up in a care facility because there was no one to care for her at home.





KELLY CAMACHO shared the story of her late father's journey with ALS.

I am sitting here writing this with tears welling in my eyes. I cannot think what to say. I know I am grieving the loss of my father, Paul Henri Dufault who passed away on August 14, 2021. He had a long journey with ALS, and he fought hard. He would say to me, "I am getting Dodie".

I was living in Ontario, and he in Manitoba, so I found myself traveling back and forth often. My older brother and sister were caring for him. Dad was a strong man and was determined to live to a thousand years old. He loved life on the farm. So even when it was evident that he needed care, he stood his ground to pass on the family Red River Farm. His father had built it with his 5 sisters, 2 brothers, and wife.

He moved in with me in August 2019. He was absolutely devastated and most of the time he was confused and lost. Immediately, I began making my home a mirror to his home the best I could. I started buying anything to help him, hospital beds, canes, walkers, and grab bars. 24-hour care was tough, he slept days and became blind and with diabetes type 1. He would wander, get confused, be overcome with sadness, and at times he would also be very cognizant. He would have memories living in those moments, over and over.

He would question why, what, and where he was.

I was no longer able to care for my father, and I had to place him in long-term care. Covid-19 made everything hurt more. I was not able to visit more than four hours a week. After five months in care, my father passed. I cherish the years I had with my father. I cry because I lost my hero. I cry because our love was strong. I cry because I lost my best friend. I think of him every day, in a good way. ALS took my father's mind, but it did not take his spirit.



Our wolf pack

DORIS TOURANGEAU is a Cree woman who shares the story of her brother Joe who is currently living with dementia.

I remember this picture so well. It is in the summer of '64. Joe is nine and I am eight. I am the only girl among all my brothers. It was a time when we were in 'awe' with the beauty of our ancestors' land. We roamed freely with not a care in the world. We ran like wild, feral kids, all summer long. Free from the regimental clutches of the Residential School. Our faces tanned brown from the scorching summer wind and our wolf pack was so happy.

Nothing could ever go wrong ...

Joe is the oldest of my six brothers and is always the leader of the pack. In this photo, we are on our way to our Kokum's house in Doghead to eat after a long morning swim in our swimming hole, that we had christened 'Shitpoint.' We cut through the mission grounds yelling and screaming, and Joe yells, ***"the last one is a rotten egg!"***.

I can still smell the summer clover as we ran wildly with the crickets singing their summer song. While crossing the mission yard, we came upon a Métis kid hauling water with a sleigh dog. Just then, Father Bègin appeared out of the parish and asked us to pose with the kid and the dog. As always, he had his camera tucked under his arm.

He is wearing his signature black tam. His black pipe lazily rests on his left lip, and smoke bellows out, just like my papa's smokestack. **"I take a picture of you kids and the dog"**, he says. He disappears behind the black camera and yells, **"smile!"**. Joe poses happily, beaming brightly, and his white shirt reflects his joy.

It is February 2022 and the leader of our wolf pack, Joe, is diagnosed with early onset dementia. He is sixty-nine, and I am sixty-eight. He has become another person in front of my eyes. My heart aches when he gets angry with me or forgets our conversation. Occasionally, he shows me a glint of hope and gets witty. But more recently, I notice he can speak our language fluently, which is Cree. Often, he shares his fears of being alone and yet, refuses any help, especially any white aid coming into his home. It's a mission thing we never forget, I guess.

We live in an urban setting, and I do not want to place my brother in an old folk's home. The resources are limited. Especially if you are First Nations person living in the city. We left our communities to better our lives, but, as we age, we find more barriers. The leader of our wolf pack is changing...





JUNE SMART shares a story of her late father's dementia journey.

My father developed dementia at around 80 years of age. As expected, his physical health was in decline and then we began seeing small signs that something wasn't quite right with his memory and behavior. It was a gradual process, and we were hopeful it might level off, but we became better educated on dementia and we realized that he would only continue to decline. Eventually, once we recognized the signs and understood how insidious this disease is, we looked at this as an opportunity to cherish every moment we had with our father while he was with us in body, mind, and spirit. Learn everything you can as early as you can and then treasure the moments you share with your loved one.

As my father continued to decline, our care for him increased, and our watch over him became constant. We made sure that he was able to live his life and enjoy those activities he loved for as long as he/we could. My father enjoyed music in his life, but when he developed dementia, his love of music grew. He could always be heard singing, which I think was soothing not only to himself, but to us as well.

He had a wonderful voice and one of his favorite songs was ***"Edelweiss"*** from the movie *The Sound of Music*. I can still hear him singing with his deep voice and it makes me want to cry as I love this memory. He also loved to sing the song ***"My Way"*** by Frank Sinatra and we played this song for him at his funeral. We put together 3 CDs of music that he and my mother enjoyed, along with a few campy ones, such as ***Hello Muddah, Hello Faddah, Barney Google with his Goo Goo Googly Eyes and the song I Love Beer, It Makes Me A Jolly Good Fellow***. They

loved those songs. We played his music every day and it brought all of us joy. It taught us to find something he loved or responded positively to and use it to help find comfort. We had a camera monitor in his room and if we were in the kitchen preparing meals, we could hear him singing away, and those are the special moments you remember. We could also hear my parents' private conversations and we would often hear them tell each other how much they loved each other. My dad loved to tease my mom by saying **"bow wow"** repeatedly and she would say **"if you say that one more time"** and my dad would respond by whispering **"bow wow"** or saying, **"one more time"**.

My father had a career in the military and with the RCMP. During his army days he was posted to Sault Ste Marie, Ontario as the Chief Clerk. He had three clerks and they were his three daughters, myself being one of them. I was highly encouraged by my father at the age of 17 to join the reserves. I had a 36-year career with the military, and I loved it, mostly. I flourished in my career and when I would go home on leave, I would often say, **"my dad made me join the army when I was 17 years old, thanks dad."** My father and I had a fondness for happy hour, especially wine. Later, with dementia and medication, my dad could not enjoy it as much as we used to. So, I would put apple juice in his goblet, and he thought it was wine and we would toast together, laugh, tell stories and just enjoy each other's company. My sister once tried to take his goblet away and he got very cross at her and demanded she give him back his wine, which she did promptly. This was one of the many strategies we learned to ensure he drank more and avoid dehydrating.





Our father loved his room and his bed. We had family pictures all around. He enjoyed routine and did not like clutter. We tried to have him participate in a dementia day program so that my sister could have some respite, but it did not work out because he liked to be home in his surroundings. We were a very lucky family as we were able to have a self-care management program in place so that we could keep him at home.

Dementia impacted our family deeply and changed our lives completely. I went from being a loving daughter to being a loving caregiver. Yet, despite this impact, I consider myself fortunate. How can someone who becomes a caregiver to her father suffering from dementia have such a positive outlook? I was fortunate that my father developed dementia so late in his life. He was 80 when we started to notice the signs. Through dementia, you lose a part of the person you love, so you look for those special moments. I remember walking in his room one day and he said my name, **"June"** and it was music to my ears! I would say, **"dad I love you so much"**, and he would say, **"oh, you don't know how much I love you"**. Sometimes you would see a sparkle in his beautiful blue eyes.

Caregiving is difficult. It's tiring, and it's filled with emotional ups and downs. But it is also giving care to people you love, and who now need you. I looked at it as my parents took care of me when I was younger, nurtured me in my teenage years and guided me through my adult years. They were always there for me, in good times and in bad. Having the opportunity to give something back to a parent who gave you so much, is rewarding.

Our father passed away at home on January 19, 2020, just before COVID at the age of 88. He passed away early in the morning in his sleep with my mother by his side. We knew the end was near, we just did not know the exact moment he would leave us. All seven of his daughters were there and my two brothers came quickly. We were very grateful that he had his own personal nurse, his daughter Dorothy, who he called **"my nurse"**. We are now taking care of our mother who is suffering from dementia, which is another journey. The lessons we have learned will help immensely with our mother. As a daughter and a member of our large family, I take great solace in the fact that we fulfilled our duty. I will always remember when my sister sent me this quote **"the dementia person is not giving you a hard time the dementia person is having a hard time"**. This quote resonates with me to this day.

I feel honored to have been able to tell you my story, but more importantly, to have been able to give you an insight into my dad's dementia journey.

Chi Miigwetch!





DOROTHY EASTMAN is a Métis woman who shares her mother's dementia journey. Our mother started developing dementia at 85 years of age. Her Métis grandfather was born in 1860 and came from North Dakota, USA up through the Red River Colony and settled in Manitoba. Her father was a farmer and although they did not have much, they had a happy home.

As a nurse with 46 years experience and experience with our father's journey, it was easy for us to see the tell-tale signs. The lessons learned from our father's journey were invaluable to us as, especially now as we face the same dilemma with our mother. While everyone is different, many of the strategies and how we dealt with issues as they arose, remained the same, and we simply adjusted to the different habits my mother developed.

We were able to tap into many of the services that were provided for dad for our mother, and because of the experience we had, we knew who to reach out to, and the processes we needed to follow. I would encourage anyone who is just seeing the signs of dementia in a loved one to become educated as quickly as possible and look for those services in your area. Moreover, I would suggest you look for any support groups. They will not only help with linking you to services but will also provide you with the emotional support you may need.

Fortunately, at this point my mother's dementia is not overly debilitating, and so we are simply cherishing each moment we have. We have gotten her into a nice routine, and we try to surround her with familiar things and memories. She can go outside the home and participate in a dementia day program which she enjoys. She often calls the people she attends with, "**the old people**". Her short-term memory is getting worse, so she often repeats herself and asks the same questions. She forgets if we have told her something and becomes adamant that we did not tell her. At times she can get very aggravated. Like our father, she does not like to take showers and she detests being cold. She can become easily annoyed with us and very impatient. Before dementia she was not like this at all. When she gets in these moods, we make every effort to lighten the air by singing or smiling and reminding her of a nice memory. Her soft side returns, and we have harmony again. It's small strategies like this that not only help your loved one, but also helps you with lessening your strain.





My mother loves to play bingo and whenever we can, we play. It's a simple game and one that is ingrained in her memory. While we may have to help her with a missed number or two, she still plays it well and takes such joy from it. She used to love to go bowling, and her passion is to watch curling. We always make sure when curling is on, she controls the remote. She was also given a hockey jersey from Jerome Iginla from the Calgary Flames, and she cherishes this hockey jersey to this day and speaks of him often. We find other things that she likes to do and are mindful to bring up memories of the past as that always brings a sparkle to her eye and seems to invigorate her.

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

We try never to ask, ***“do you remember?”*** because she has such difficulty remembering and it can cause anxiety. Instead, we try to just speak about a memory and hope that she will remember and join in, or just like what we are talking about. We are so thankful that she still recognizes all nine of her children and knows who we all are. We tell her daily how much we love her, and she responds all the time saying that she loves us more. We reassure her constantly and make sure she feels safe. If I could give one piece of advice it would be that love, and patience are all you need. Our mother is going to be 90 years old on July first and we are planning a family celebration. We all know our time with our mother is precious and we are determined to make this celebration memorable for all of us.

I am honored to share my mother’s dementia journey with you. Most importantly, her journey continues, and we will make the best of our time together. We will continue to make as many happy memories as we can.

Chi Miigwetch!



Roxanne Blood shares the story of Eva Bereti, a nehiyaw-iskwew (Cree woman) journey with dementia.

Eva humbly volunteered her time without any hesitation. I met her in 2010 through the creators' will. Already for years, Eva helped many mangled hearts in the inner-city school.

Here is where my story starts, in this photo. My daughters and I went to Inner City High school to do research. The high school is a makeshift community center in the inner city of Edmonton, Alberta. Many of the students were homeless, or did not have a good start in life, and so they came down to the high school to pursue an education. While being there, I was distracted by a beautiful Aboriginal woman. She sat at a table and the students approached her with ease. I watched as she made small talk, and soon, they were laughing and telling stories. She engaged with each student and carried on such in-depth conversations. Finally, I met her, and I introduced myself and my daughter.





From that very moment on, I knew that I had met an authentic spirit, and this would become the start of our long friendship. Eva's kind Kokum love made the youth feel so drawn to her because of her deep concern for their well being, and her desire to help them succeed with their education.

Eva shared many stories of her youth with me. She talked about her children and her grandchildren, and her eyes would just light up. I started seeing her at community events and cultural gatherings. She was always so happy to see me and my daughters. She greeted each one by name and always asked how everyone was doing. Once, she invited me to a ceremony in Saskatchewan and when we were supposed to leave, the whole province of Saskatchewan was under a severe weather warning. I was anxious that we wouldn't be able to go but she just said, ***"When you already make plans for the ceremony, the weather is not going to prevent you from keeping your word with the Creator"***. Eva never let me down, she showed me how to be a strong Indigenous woman through the conviction that she had for her faith in our traditional way of life. She had a kind word for everyone, and her life revolved around Indigenous youth and parents. Everyone who had a chance to know Eva, always left feeling complete and recharged on life.

Years passed since our trip and our visits were replaced with phone calls. I noticed her change, and it was gradual. Eva started withdrawing into her own world. As time went on, I heard less and less from her. Concerned about her, I would go to her house, and although I knew she was home, she would not answer her door. Often, she reflected only on her younger years and mentioned all the people in her stories had gone on to the spirit world, so I realized that her circle of friends had become smaller.

I watched her life of independence begin to slip away. Her daughters thought it was best if she did not drive anymore, for her safety. Each day she got more confused, and eventually she became home bound.

My Eva started forgetting things, and eventually, the family hired homecare to help her out with her daily living. Meals were ordered because Eva forgot how to cook. Eventually, Eva was moved into a retirement home. Then COVID hit and our visits stopped. She refused to take my calls because she didn't remember me. All she must do is see my face, and all her memories will come back and remind her of all the fun times and beautiful adventures we shared. If I can have one last visit with her, I will tell her just how much a part of my life she was, and how the love she showed my children still fills their lives today. My girls do not have a Kokum, and she is the next best thing to the Kokum that I had always wished for. I also know that the Creator sent her to remind us that we must treat each other with love, respect, and support, because we are all fighting a battle of our own. Eva Bereti, you have a very special place in my heart and soul that I will cherish for both of us! And when I think of you, I will smile really big!





SHIRLEY CULLEN shares the story of her mother-in-law's journey with dementia.

A Better Understanding of Taking the Long Way Home...

I'm going to share a little of my experience with dementia and being a caretaker for my mother-in-law. It begins and ends with my journey with one of the strongest, and most proud moms I have ever met, my mother-in-law, Thelma Grace. She was a mom who honoured the seven sacred teachings every day of her life. I was blessed to pray and smudge with this beautiful soul, who now guides me from a distance. The creators' love taught me that love is the answer to all things, especially when asked the same question 1001 times. Oh, the strength that was needed some days. I was blessed to have her in my life, even if only for a short seven years. Seven wonderful years.

I was blessed to see such a strong powerful women keep her strength in a time of uncertainty. I am so grateful that I had a chance to learn to help her. I had endless time, love, and support for her. She had blessed me with so much, far more than I could ever repay. Taking this journey with her, allowed us to learn what worked for the both of us on the long way home. For us, adding and practicing the seven sacred teachings and asking for guidance was key.

Although it was not under the best circumstances, taking care of my mother-in-law for as long as I did, was the best healing for me, and a bonding experience for us at the same time. Everyday was a different day. Endless prayers kept us sane, and we got great strength from the prayers of others as well.

Through this journey, I have discovered that our mothers are a bundle of the best medicine a child or person needs. As my mother-in-law was taking the long journey home, she gave me strength. She was fighting to stay and fighting to let go. So, I had to let go. Until we meet again.

From Shirley,

Frank and Liza Ponniuk's daughter.

Xoxo





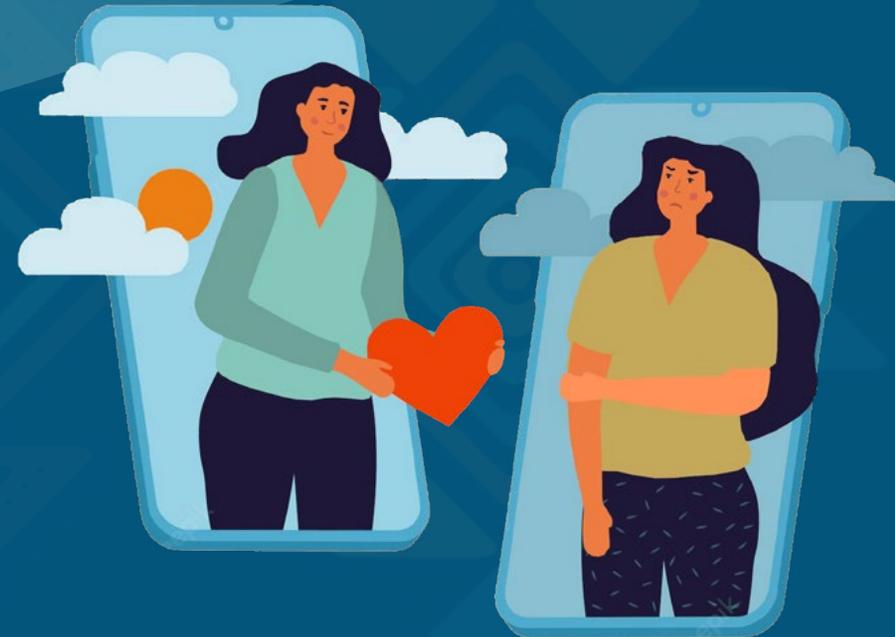
DANIELLE ALCOCK is a member of the Chippewas of Rama First Nation who shares her story as a young caregiver of her father who is living with dementia.

Our journey with dementia is going into the 8th year. It's a strange milestone, since every year means more time with my dad, but also closer to forgetting who I am and getting closer to the spirit world. I have saved this image on my phone because it has resonated with my experience. Every Sunday, my ritual is to check out [postsecret.com](https://www.postsecret.com), where anonymous secrets are shared. This postcard encompasses how I feel, and it is a reminder that I am not alone on those days when I am asked questions that he knew the answer to only months prior, affirming a decline I am powerless to stop.

As a caregiver, I have become so aware of time. I am conscious of how many hours we spend together, and I am learning how to be present and to live in the moment, since this is the space where his memory resides.

I became my dad's caregiver when he was diagnosed with alcohol related dementia in his late 50's. Prior to his diagnosis, we had not spent a lot of time together and did not know one another. I was in my mid 20's and had limited options for accessing long term care. We decided to move him closer to me, but this is also further from his community, home, and extended family. Having to move your parent into long term care was the best of a worst-case scenario decision. I struggle as a young caregiver since most people my age cannot relate. It parallels how I am unable to understand the experiences of husbands and wives in support groups caring for the person they committed their lives to and watching them slip away.

My biggest resources for my wellness are my friends who always answer the phone when I call, and who just listen as I pour out my joy, sadness, anger, and frustration for navigating a role that changes day by day. The man who became my husband does whatever he can to be supportive, whether it is subjecting himself to countless Disney movies, or checking in throughout nights of insomnia.





He is so kind to my dad, and they have developed their own bond over terrible 'dad jokes', and a love of The Beatles. I take care of my spirit through connecting with Elders who provide medicines, ceremony and insight that help me to remember to be present as much as I can, since I cannot control the past or the future.

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

On a sunny Sunday afternoon over a cup of coffee and taking a break from a 1000-piece puzzle, I asked my dad some questions about his experience with dementia.

WHAT IS YOUR DEMENTIA JOURNEY?

It's like being forgetful. I didn't dwell, but now I can't and how many times people ask what you did yesterday, and it drives me crazy. It's scary; the unknown.

HOW DO YOU GET SUPPORT DURING YOUR JOURNEY WITH DEMENTIA?

Family mostly and one special girlfriend. It mostly was a secret. Nobody asked: do you got dementia?

WHAT ARE THE UPS AND DOWNS OF LIVING WITH DEMENTIA?

There are ups? (Said with sarcasm). Missing the day is a down. I don't get pictures in my head of my day like I used to. I guess that's memory, and I don't have memory. I feel l

IKE A DUMMY AT SCHOOL BECAUSE I DON'T HAVE THE ANSWERS.

It's easier to hide away. I'm not able to really care because it's confusing. If you ask me what dementia is, I wouldn't have a clue.

HOW DID YOU HELP YOURSELF BUILD YOUR MEMORY?

I try not to because whatever I try to do, it doesn't come back the next day anyways. I stick to routine, do crosswords, and stay in my own little world. I stay away from crowds because it's too confusing if they all ask you different questions. They don't always say how are you? I should keep notes that will probably help, especially if someone tells you something. I get a lot of I told you. I say tell me again. I hide it and most people would think I'm normal. It's confusion mostly. Why me?

ANY STORY FROM THE PAST YOU WANT YOUR FAMILY TO REMEMBER?

Maybe your story. Weren't you the one that came in through the bathroom window?

I WAS BORN AT HOME BEFORE MY DUE DATE AND MY DAD DELIVERED ME IN THE EARLY MORNING HOURS. I WAS ALWAYS TOLD THAT THE PARAMEDICS AND DOCTORS CALLED HIM DR. DEVON.

The past doesn't run in order; it's bits and pieces. It's not congruent.

ANY ADVICE FOR FUTURE GENERATIONS/PEOPLE LIVING WITH DEMENTIA?

Relax. There's nothing to fight. You are what you are. Do unto others as you would have them do unto you. It doesn't make me cry, it's just weird. I think memory is closing your eyes and looking into your head. But you can't do that anymore.

Since my dad has alcohol related dementia, it's been a slow decline. With this type of dementia, it can be reversed or stagnated, if intervened early enough. With alcohol related dementia, comes an added layer of stigma, and it has taken time to be able to share my experiences in hopes of connecting with others who might be on a similar journey to ours. My advice for caregivers is to care for your spirit because this a journey that affects all aspects of self, and balance is integral because your well-being is paramount to supporting your loved one.

I have shared a photo from my wedding day in September 2021. We didn't know if he would be comfortable attending, so we made sure we were flexible to what worked for him and knew that he might only be there for some of the day. When he wanted to have a father-daughter dance, my husband bolted to the DJ asked him to play something good. My dad rose from his wheelchair, and we danced for as long as he could to 'My Girl' by the Temptations. I was shared a teaching that although a loved one with dementia doesn't remember spending time with you, their spirit does.

As a caregiver, you will have the precious memories of time spent together.

So, although he doesn't remember my wedding day or most days we spend together, I will for the both of us.



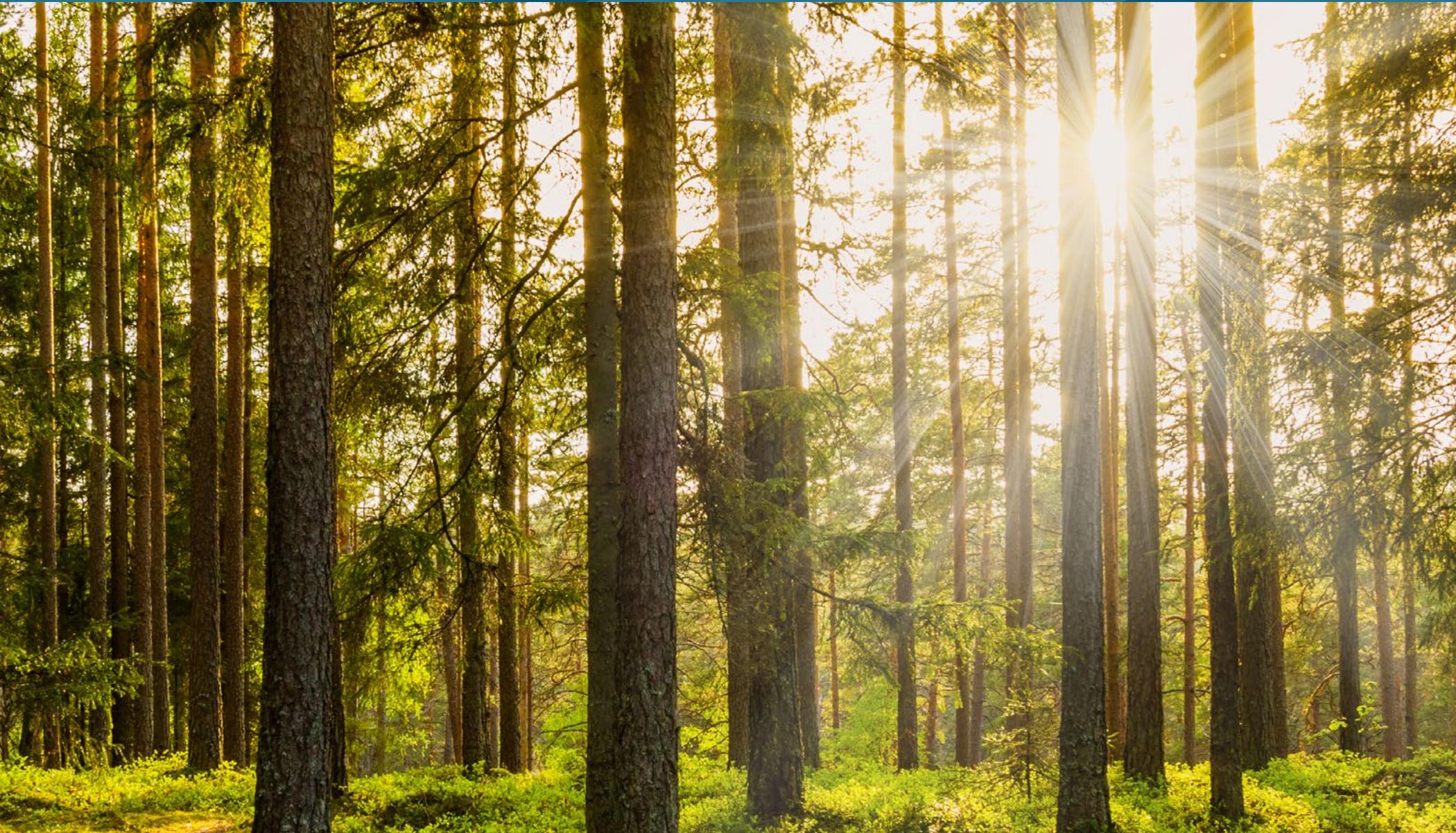
DEDICATIONS

This book is dedicated to those who are living with dementia, their caregivers, and those who no longer walk among us.

To those who are now in the spirit world; ***you are not forgotten; your lives, love, stories, and accomplishments are now forever embedded in this book and the hearts of those who read it.***

We thank the caregivers and families who have shared their stories and at times, painful truths, knowledge, wisdom, and experiences with us. We honour your strength, courage, and perseverance in providing care for your loved ones.





Native Women's
Association of Canada



L'Association des femmes
autochtones du Canada

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