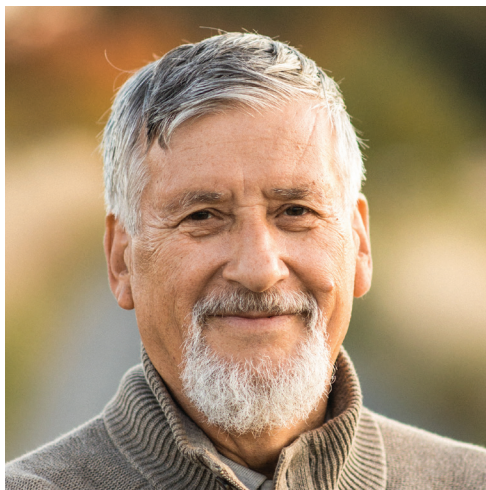
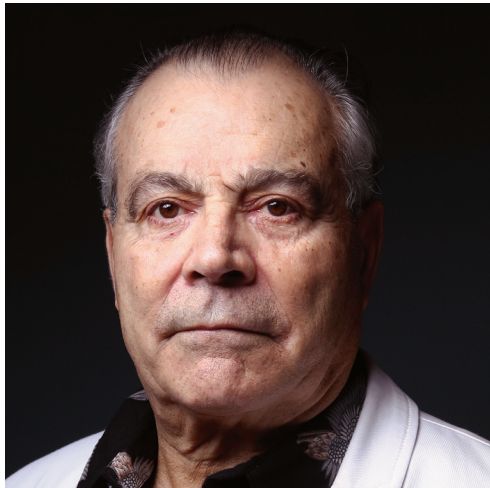


Miyooayaan (Wellness)



A MÉTIS GUIDE FOR
WELLNESS WITH CANCER



Acknowledgments

We would like to acknowledge the Métis Albertans and their families who shared their cancer stories and experiences at the Métis Nation of Alberta (MNA) regional engagement sessions and the Annual Health Forum held between 2018 and 2019. We offer our gratitude and thanks for sharing your journeys and for providing tips and recommendations for other Métis Albertans on their own cancer journey.

This resource was made possible through partnerships with the CANHelp Working Group at the University of Alberta and funding received from the Canadian Partnership Against Cancer (CPAC).

We also acknowledge the Métis Nation British Columbia Living with Cancer resource, which inspired the development of this guidebook.

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Message from the President

Greetings,

The cancer journey can be long and hard affecting the individual, their family, and the larger community in many ways. As the President of the Métis Nation of Alberta, I am pleased to share *Miyooayaan (Wellness): A Métis Guide for Wellness with Cancer* with our community members who may be dealing with this life altering disease.

This guidebook was created by and for Métis Albertans and is reflective of their experiences, stories, and cancer journeys. The recommendations, tips, and quotes that have been shared are featured throughout and will guide the development of the MNA's overall Alberta Métis Cancer Strategy.

Specialized work such as cancer research would not be possible without partnership; therefore, I would like to thank the CANHelp Working Group at the University of Alberta for their research support in creating this important resource for our community.

I wish you happiness, health, and all the best – whatever your journey may be.

Sincerely,

Audrey Poitras
President, Métis Nation of Alberta



Welcome

Welcome to our Métis Guide for Wellness with Cancer designed to help Métis Albertans who have been diagnosed with or are supporting loved ones with cancer. Sharing information and hearing about the experiences of others can often help us through difficult times. Members of our Department of Health at the Métis Nation of Alberta (MNA) gathered the community together to talk about their experiences of living with cancer.

This guidebook shares what was heard.

Each section contains quotes from regional engagement discussions held in 2018 and 2019, where we heard stories of Métis Albertans on their personal cancer journey. These stories helped inform questions, tips, recommendations, and a list of resources they found useful on their own journey.

From these discussions, the overwhelming consensus was to amplify the voice of Métis Albertans and provide a space through which stories and experiences could be both shared and received. We hope this guidebook reflects those cancer journeys and helps others on theirs.

1. HOW TO USE OUR MIYOOAYAAN GUIDEBOOK

This book is organized to reflect four broad themes:



**Screening and
Diagnosis**



Treatment

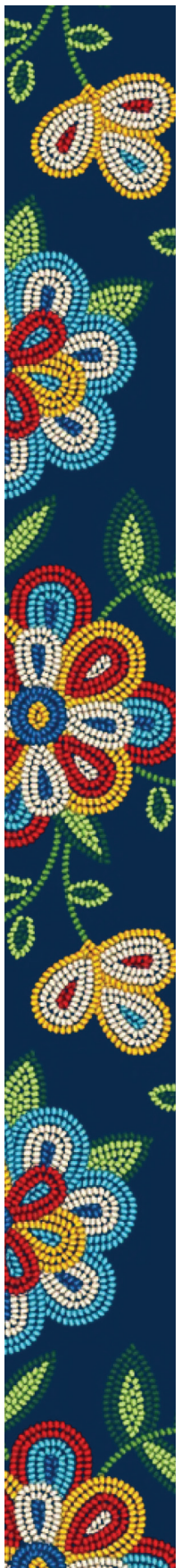


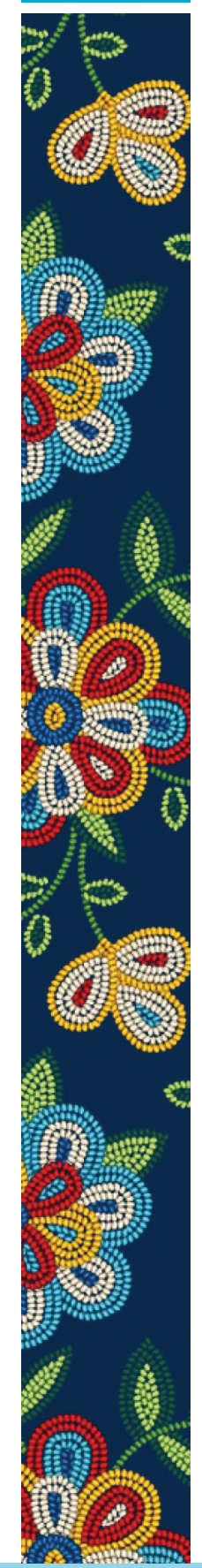
**Caregiver
Experiences**



Post-treatment

In each section, you will find quotes and stories, along with recommendations by Métis Albertans. At the back of the Miyooayaan Guidebook, you will find information providing guidance, insights, and strategies that helped other Métis Albertans and their families through their cancer journey.





Screening and Diagnosis

1. CANCER SCREENING

Detecting cancer at an early stage can improve the effectiveness of treatment and hopefully, the overall quality of your health and wellness. Going for cancer screening can be stressful, so having family, supports, and a trusted family doctor along the way can provide a sense of ease.

Those who attended the engagement sessions received their diagnosis through regular check ups and screening, requesting testing from their family doctor based on a “gut feeling”, or having experienced symptoms commonly associated with cancer. They stressed the importance of early detection through screening or regular checkups, especially for those individuals who have a family history of cancer.

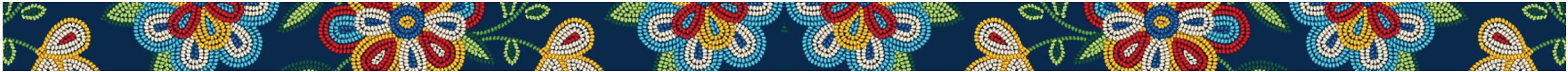
*“My family doctor was great! He suspected it right away. He said, ‘there is something there and we need to get it looked at right away.’”
– Region 3*

CATCHING IT EARLY

For cancer prevention, early diagnosis is paramount to ensuring improved outcomes through providing treatment at the earliest possible stage.

“We are very fortunate, our family doctor is fantastic, he makes us go for... check ups and everything once a year. I had to go for a colonoscopy and was fortunate he was pushy to have this done, even though I don’t like doing it. I went anyways and got it done. It was a good thing because they diagnosed me with very early-stage colon cancer.” – Region 4

“My wife had an appointment with our doctor in May. For some reason, I went with her to the examination room, which I usually didn’t do. As soon as I got in there, I spoke, and was kind of hoarse. He said, ‘you’re hoarse ... how long have you been hoarse?’ I said, ‘since last January.’ ‘I’m not taking any chances,’ he said, ‘you’re a smoker.’ I got tested right away, and it was very, very early voice box cancer.” – Region 4



BEING PROACTIVE

A key element of cancer prevention is knowing when “something is not right.” Often times, we pass it off or think nothing of it. Being aware of early signs or symptoms can assist in early detection.

Some signs and symptoms to look out for include¹:

- ∞ Shortness of breath
- ∞ Unusual bleeding
- ∞ Weight loss
- ∞ Pain in the chest, abdomen, or bones
- ∞ Loss of appetite or change in sense of taste
- ∞ Trouble sleeping
- ∞ Tenderness in arms, neck, or groin

“I was losing my appetite, losing weight, experiencing shortness of breath, and getting fatigued real fast. I just progressively got worse, and worse, and worse. To the point where I couldn’t even function anymore, so that’s when I went and did the colonoscopy test. That’s when they found my tumor.” – Region 2

SELF-ADVOCACY

Standing up and fighting for yourself in an uncomfortable situation can feel intimidating, especially when you’re not sure what your symptoms and diagnoses are. Gathering attendees who had a “gut feeling” felt empowered to advocate for their right to get tested and to know their medical information.

Part of self-advocacy is knowing what your rights are as a patient, which are protected under the Alberta Patient Bill of Rights.

Under the Alberta Patient Bill of Rights, you have a right to²:

- ∞ Receive health services without discrimination and be treated with dignity and respect
- ∞ Have your personal and health information protected from disclosure
- ∞ Have access to your health information
- ∞ Say no to any proposed treatment
- ∞ Seek a second opinion
- ∞ Have access to information relating to any proposed treatment and options

“I felt lumps in my neck, but the doctors kept sending me home after doing X-rays and ultrasounds and then one lady said, “you have to have this looked at! Make sure they take another look at it!” They finally did a biopsy.” – Region 3

ASKING FOR A SECOND OPINION

Receiving bad news can be devastating, not to mention those next steps and recommendations going forward. One way to advocate for yourself is to seek a second opinion. This can help to ensure the diagnosis is correct, and you can find a path and treatment that works for you.

“So always get a second opinion. From the doctor? Yes, but not the same doctor. You go to a different doctor, like I did – If I would have kept going, I would have been dead, you know? Always go to a second doctor, all the time.” – Region 2

MISDIAGNOSIS

Arriving at a diagnosis can be difficult for some types of cancer, as some are more difficult to detect or identify than others. At times, you or your loved one may go for multiple tests before receiving a complete diagnosis.

Asking for a second opinion, preparing questions for your care provider ahead of time, and having people to support you during appointments may help you feel comforted while waiting for a complete diagnosis.

“The doctor said, “You are too young, it is probably just hemorrhoids.” It was brushed off even though I still had symptoms.” – Region 4

“I was diagnosed with non-Hodgkin’s lymphoma. This was in June. The September before that, I felt lumps in my neck, but then they kept sending me home after doing X-rays and ultrasounds. They finally did a biopsy and had to do another one. This was my doctor, not yet the oncologist because you have to have a number and have it completely diagnosed before you get one. So, in the meantime, you have lymphoma; it was as if we were sent home with no support, it was like, who can I talk to, what do I do? What does this mean? Am I dying?” – Region 3

¹ Canadian Cancer Society, 2020, ² Legislative Assembly of Alberta, 1998

2. RECEIVING AND UNDERSTANDING A DIAGNOSIS

It is true — when we have the information we need, we are able to make well informed choices. Many participants felt they had more control over their wellness plan when they had reliable, timely, and easy-to-understand information, especially when making decisions about their treatment options. Asking for help from a loved one when receiving a diagnosis was especially important when making a quick decision on treatment options.

“It was like everything got put on hold. Like everything just came to a life crashing halt. Like you heard that word and it’s like “What?” It’s just a really scary, scary situation.”
– Region 6

ACCESS TO CARE

Depending on your diagnosis, you may have to make quick decisions about your treatment options. Having a list of written questions (refer to page 34) to ask about your diagnosis will help inform the decisions you make for your cancer journey.

“If you don’t get that complete diagnosis, then you don’t get referred. Finally, they did a biopsy of a lymphoid, and yes, it was cancer. And now suddenly I have an oncologist. Once I met with the oncologist, things fell into place real fast.” – Region 3

RESILIENCY AND SOURCES OF STRENGTH

Identifying your sources of strength increases your resilience and ability to cope. Each person has unique sources of courage and strength, and no matter where you are in your cancer journey, finding yours will support you in many ways.

“After my grandson was born, I was diagnosed, and they didn’t know if I was going to make it or not. I was trying to fight it because I had a grandson who needed me.” – Region 4

CHANGING LIFESTYLE PATTERNS AND PRIORITIES

When you or someone you love receives a cancer diagnosis, it helps to ask for support. Support can look different for each of us, but knowing we have someone out there can make a big difference. Reach out to people you trust, who can support you and your family through this emotional and uncertain time.

“When our son was diagnosed, he was 30. With his cancer, no one his age got it, so nobody related to him. He is trying to be a dad to a one-and-a-half-year-old and look after his wife, so it was hard for him.” – Region 3

3. RECOMMENDATIONS FROM MÉTIS ALBERTANS

With so many resources out there, it can be difficult to know which are good and which aren’t. Often times, researching and reading content from someone who has experienced the same things can get us through difficult moments.

“There is like 3,500 different resources. Unless you are being guided to those names, you won’t know where to find stuff.” – Region 4

BOOKS THAT MAY BE HELPFUL IN YOUR CANCER JOURNEY





Treatment

1. EXPLORING AND UNDERSTANDING TREATMENT OPTIONS

Communicating and collaborating with your health care team is an important part of the healing journey. Knowing what to expect and developing a treatment plan starts with understanding the options available based on the type of cancer you have. For the Métis Albertans we spoke with, they had to balance what was right for their cancer and their families when choosing a treatment plan. When planning for treatment options, health professionals may advise some common cancer treatment options such as surgery, chemotherapy, radiation therapy, hormone therapy, and immunotherapy (see definitions in Glossary, page 38). While these options can seem intimidating, your doctor is there to walk you through the process and answer any questions you may have so you can feel confident in your treatment plan.

“What helped me a lot was knowing what was going to happen, knowing what to expect. It was well explained to me, so when I got the side effects, I knew what to expect.” – Region 3

“The oncologist, he more or less saved my life from worry. He explained everything very clear, very thoroughly, not even once, but three times. He was available to me anytime! So was the nurse. She said, ‘you call me anytime.’ She gave me her card and so ... all of this stuff ... the side effects were all explained to me.” – Region 3

“When I was going to the treatment centre, there were about 300 patients a day going in. If I go back there today, there are nurses and oncologists that would recognize me, and they treat you just like family members.” – Region 4

2. TREATMENT OPTIONS

Healing and wellness journeys differ for everyone. For Métis Albertans, a common theme in their journey was balancing the mind, body, soul, and emotion. Some felt their mental health was supported by focusing on positive thoughts and feelings throughout their cancer journey. Connecting to community, culture, identity, land, and traditional medicines as part of Métis health and well-being can often lead to positive outcomes.



Living in harmony with and seeking balance across physical, emotional, spiritual, and mental health was expressed by many at the gatherings. This was reflected as part of integrating western medicines with Métis traditional practices, which included sharing circles, sweat lodges, prayers, and talking to Elders or traditional healers.

“Three things I found to be helpful were: the naturopath, my medicine man, and trying to get our own support group. I think support is key.” – Region 3

“I believe in doing traditional therapy and the medical system. I believe in combining both of them. That is very important. Everybody has their own way of doing things and thank goodness we do.” – Region 4

RESPECTING TRADITIONAL MEDICINE

Many found using traditional medicines in addition to western medicine helped them through their cancer journey. Not only did the medicines help them physically, but it also helped keep them connected to something bigger than themselves. Using traditional medicine isn’t meant for everyone but if you think it might be right for you, look to your community Elders for guidance and teachings.

“I had my surgeries, but I also went into a sweat and I used Indian medicine. It’s what you believe. I believe in God, but I also believe that I am here because of the medicine that I used. I took my Indian medicine to my doctor and asked, ‘this is what I’m using, will that contradict what I’m doing with the surgery the white man made’? He said, ‘your people were here first, if you believe in it, use it.’ I went back to my doctor and was told, ‘I don’t know what you did, but whatever it is, continue doing it because you are cancer free!’ I believe it’s because of that medicine. It’s what you believe.” – 2019 Health Forum Attendee

3. TREATING THE WHOLE PERSON

Treatment and wellness planning should consider the type of cancer you have, what stage it’s in, your lifestyle, and your unique wellness needs. Choosing a treatment plan requires you to make decisions that work for you and your family.

Many Métis Albertans reflected on the importance of incorporating physical, mental, emotional, and spiritual needs in their treatment plan. For some, this included having various health care professionals such as physiotherapists, dietitians, and mental health support workers on their health and wellness team. Everyone’s journey and team will look different, and what is most important is finding the path that works for you.

“I heal through herbal medicines and spiritual healing and I can feel the sickness in your body and I can take it out, right. And then I give you herbal medicine, because your spirit needs to heal first before your body can.” – Region 2

“Everything starts in the gut. Why? Because you are what you eat! All my favourite foods are on that avoid list.” – Region 2

Services accessed by Métis Albertans with cancer included:

- ∞ Physiotherapists

∞ Mental Health Supports

∞ Dietitians
- ∞ Nutritionists

∞ Traditional Healers

∞ Herbalists

4. HAVING SUPPORT

Going through cancer treatment can be overwhelming, challenging, and out right scary. Gathering support from your family, friends, and loved ones is essential in getting through your cancer journey.

“I didn’t want to take chemo therapy, and I was just going to leave it. My son was with me, so he talked me into it. He understood what the doctors were saying. I am glad he was there because he explained it all and talked me into taking the chemo.” – Region 3

“It was important for me to have my wife there as an advocate. Sometimes I don’t hear it right, or I don’t remember.” – Region 3

CHANGING LIFESTYLE PATTERNS AND PRIORITIES

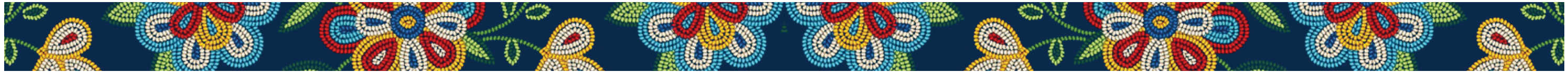
We all live our lives in a certain way. However, receiving a diagnosis with something like cancer can turn your world upside down. Often times, many people with cancer change the way they live, their priorities, and how they see the world.

“Cancer changes your outlook, it changes how you look at everything.” – Region 3

5. RESILIENCY AND SOURCES OF SUPPORT

It can be difficult when dealing with a major life change such as getting diagnosed with cancer. Resilience and support provide strength and may improve your treatment outcomes as you go through your cancer journey.

“My kids are my reason, so they keep me grounded. We get a tattoo every time we go to a cancer appointment.” – Region 4



POSITIVE OUTLOOK

Maintaining a positive outlook can be hard when you feel let down, confused, or angry. Throughout the engagements, we heard that being positive and humor were great ways to feel better and get through the difficult moments. Staying positive can be achieved in different ways and can include having uplifting statements you repeat to yourself everyday, doing something that makes you feel good, or simply listening to your favourite music. There are many different resources out there, such as books, podcasts, and community groups that can help see you through.

“One thing that I went into every treatment with was the idea I was going to make somebody laugh. I spent my whole time there joking with other patients. I’d go around, see how they’re doing, and joke with them. I made my nurses laugh all the time, and they were always happy to see me. I got a round of applause when the bell rung and everything else, I did it for other people. They didn’t really want me to go. I think it’s about attitude. You have to decide if you’re going to be here or you’re not going to be here...” – Region 3

“When you hold on to anger, it affects your cells. After a while it says, I just can’t do this anymore. Let’s now start to heal ourselves and live a happier and cleaner life.” – Region 4

“Through my treatment, I tried to really be positive. I think it was more for my family than for myself. Personally, there was just so much going on, and I’d have a little set back, and my husband would say, ‘it’s going to be okay, you just have to be positive.’” – Region 3

“All during this time, I tried to keep a positive attitude. I didn’t allow myself to go down the dark road of feeling sorry for myself. I wanted to stay positive all the time. I think that is what helped me get through it.” – Region 4

HEALING THROUGH CULTURE AND COMMUNITY

It is said often within our community that connection to culture is one of the most important parts of being Métis. Connection to family, community, ancestors, and land are intrinsically woven throughout like the threads of a sash.

“When I speak to the spirits, the grandfathers, the grandmothers. The spirit of the bear, he’s the healer.” – Region 2

6. WELLNESS PLANNING

Métis Albertans spoke to their care teams about wellness planning to help manage the short- and long-term effects of their cancer treatment. Métis Albertans experienced side effects and long-term effects differently, where some experienced low energy, mobility issues, and changes in their appearance. Many found diet, exercise, and having emotional support helped them manage and cope with the side and late effects of the treatment.

“When I got bad side effects from the treatment, I had to tell myself, this too shall pass. It really helped!” – Region 3

“The side effects and what to expect were all explained to me. This helped me mentally... they gave me three different treatments and for every single one, the main side effect was loss of energy.” – Region 3

“I thought losing my hair was going to be traumatic. When it came out on my brush ... on the one side I had hair and the other side I didn’t. I just shaved it all off at that point. That didn’t bother me.” – Region 3

7. CELEBRATE EVERY MILESTONE

Life during treatment is busy and can have its challenges; however, our engagement attendees want to remind others going through cancer to continue to do things that bring joy to their lives and celebrate the milestones — big or small. Do the things that make you happy.

“Humor – being able to find laughter was just so important. There is some research that people have been sharing with me about the benefits of humor.” – Region 4

8. SHARING YOUR JOURNEY

Often, we feel better after talking it out with someone, whether that be with friends, family, or health care professionals. Remember, you are not alone, and support is available.

“Speaking to other patients at the Cross Cancer Institute when you’re sitting waiting for your treatment was nice to engage in conversation because then you know you’re not alone. Like your partner’s not alone, and you as the individual, as the support, are not alone as well.” – Region 2

“It is much better to hear something like that from someone who has cancer or knew someone who had cancer. To hear it firsthand. To hear it from somebody who has walked the mile.” – Region 3

9. RECOMMENDATIONS FROM MÉTIS ALBERTANS

RESOURCES

It is always comforting to receive advice and resources from trusted sources such as peers and members of our community. Gathering attendees were happy to share a list of resources they found helpful when navigating their own cancer journeys.

MNA Health Programs & Services: albertametis.com

The Department of Health works to provide culturally appropriate, self-directed health and wellness opportunities that address the unique health profile of Métis Albertans and their communities.

MNA Compassionate Care Transportation Program

Offers financial assistance to MNA Citizens who are traveling to a cancer related medical appointment.

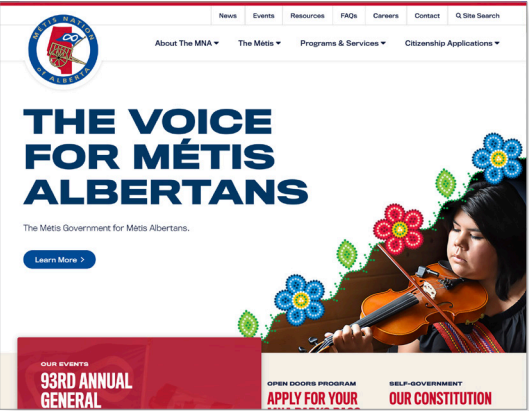
MNA Medical Necessary Accommodations

If you are travelling to Edmonton for your medical appointments and need help finding a safe place to stay, the MNA can help. With the support of Alberta Health and the Urban Programming of Indigenous Peoples program, the MNA created a program where Citizens can have safe, accessible, and free accommodations at the Renaissance Tower in Edmonton for medical appointments.

MNA Cancer Journey Video Supports

As part of our Alberta Métis Cancer Strategy project, we have created the Cancer Journey videos as a resource for Métis Albertans. These four videos feature Métis Albertans sharing their stories. Each illustrates a different aspect of the cancer journey and features tips that may help you on yours.

“A few of us got together to create Light Haven Wellness Retreat Society... We have a support group and a cancer focused yoga group... We offer it for free. We pay for a facilitator, so it's not just a coffee group. We have an actual counselor who comes in and supports.” – Region 3



Gracefully Yours: gracefullyyours.cc

Women's clothing boutique that specializes in providing post-surgery solutions for women.

“They didn't explain to me that Alberta Health covers bras for the first 4 or 5 years. I am due for one here next year. I didn't know about that. The company is called Gracefully Yours. It's a company on the south side of Edmonton. I went without a bra for about a year. I used scarves and I tried to cover, and I was so hot. People need to know where they can access certain things.” – Region 4

Cleaning for a Reason: cleaningforareason.org

Provides free house cleaning services for those living with cancer.

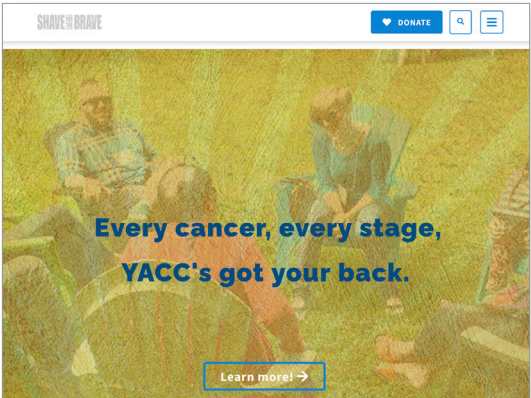
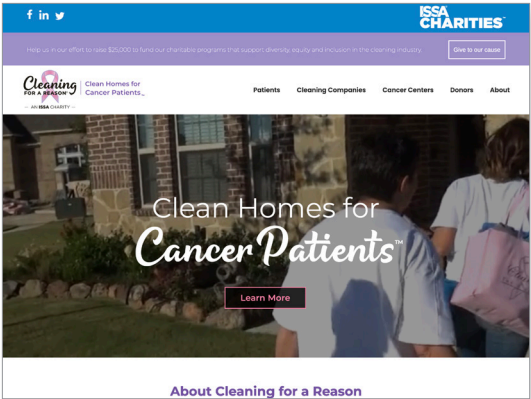
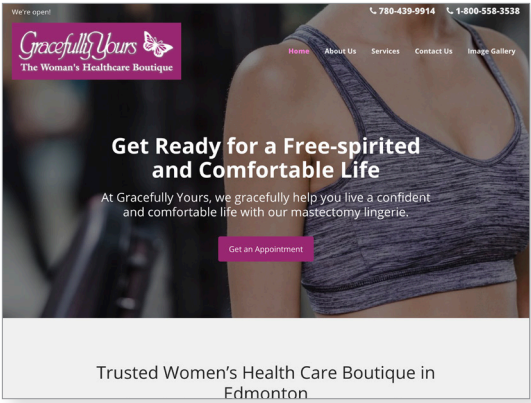
“There is a resource called Cleaning for A Reason. They provide free cleaning services for women undergoing treatment... I could barely get up, let alone look after my two kids, let alone clean my house. I know that I qualified, and I had 3 or 4 cleaning sessions, with a company that was participating in that.” – Region 4

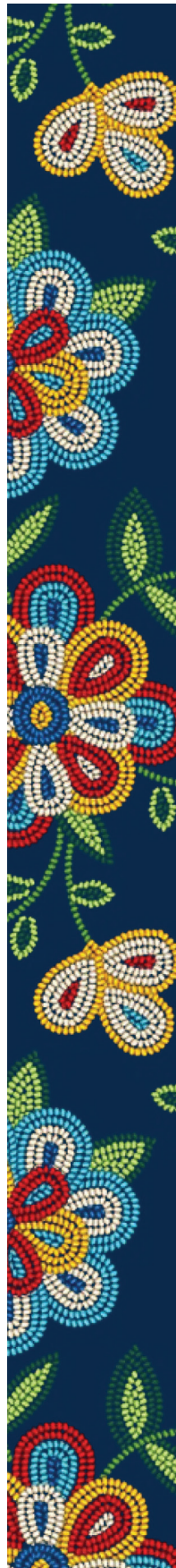
Wellspring: wellspring.ca

Provides supportive care programs to help Canadians living with cancer. Their programs, provided at no charge, help those with any type of cancer, their caregivers and family members, elevate their quality of life through a strengthened mind and body.

Young Adult Cancer Canada: youngadultcancer.ca

Provides young adults dealing with cancer with a support system where they can connect with other young adults going through the same situation.





Being a Caregiver

Métis Albertans diagnosed with cancer mentioned the need for supports, and often cited their spouse, family members, or friends as trusted and reliable sources of support. Caregivers provided mental, physical, and/or spiritual support throughout the cancer journey.

Caregiving can be a challenging and rewarding process. For some Métis families, caregiving means providing transportation, making meals, and attending doctors appointments with their loved one. Sometimes, caregivers experience feelings of being overburdened and overworked. They expressed it was difficult to take time to focus on their health and well-being. Caregivers suggested asking for resources and additional supports to alleviate some of the stresses that come with caregiving. Additionally, some other suggestions were to practice mindfulness, connect with community, and ask for and accept help.

1. SHARING YOUR JOURNEY

As a caregiver, sharing your experience with others can be a reminder you are not alone. Regardless of the stage of your cancer journey, others may be going through a similar experience.

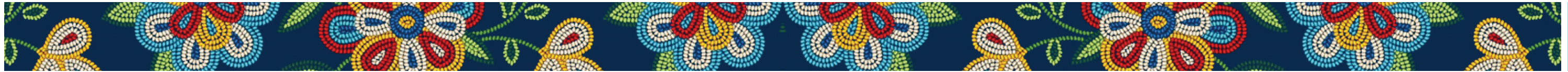
“It has been helpful along the way to share the story with people who have had a similar journey and who understand, so you don’t have to explain everything. I think for myself and for my partner, knowing our experience could be of benefit to other families is really, really important.” – Caregiver Region 4

2. EMOTIONAL IMPACTS FOR CAREGIVERS

Caregivers expressed fear and feelings of uncertainty when their family member, friend, or spouse received their cancer diagnosis. Having appropriate information and a deeper understanding of the stage, location, and type of cancer, eased not only the minds of those with cancer but also the anxiety or thoughts about the diagnosis and treatment of their caregivers.

FEAR, UNCERTAINTY, AND WORRY

“Yeah, and the whole journey itself was just – scary. It was very scary to deal with, and not knowing how to talk to her or what to even say to reassure her.” – Caregiver in Region 6



“I’m feeling better now than what I did when we first got the news. Like, my mind was going crazy too. Like, Oh, my God, what? How long is he going to be around? With his treatment, they did say he could be here for three months. He could be here for three years and that, that kind of frightened me.” – Caregiver in Region 5

PREVENTING CAREGIVER BURDEN AND BURNOUT

Caregiving shifts a family’s priorities and this can feel like an enormous pressure. Métis Albertans found taking care of their loved ones a rewarding but tiring process. Caregivers and their families at times felt like, despite all their efforts, they were not doing enough. Some found themselves having difficulty sleeping, trouble concentrating, and feeling irritable, which can be signs of caregiver burnout.

Recognizing what burnout feels like is crucial to incorporating self-care practices that will help improve your overall outlook and energy (examples of grounding exercises can be found in Tips from Métis Albertans on page 28). Throughout the cancer journey, Métis Albertans emphasized the importance of taking time for yourself and doing the small things like laughing, having date nights, and connecting with community.

“So, it was pretty scary, but now, I think I’m more relaxed and understanding it and the treatment. And then going back to all the information they gave us at the beginning and going through it and bringing different things up to him and saying, ‘Remember when they talked about this,’ and I think just having a better understanding has made me more comfortable, if that’s possible.” – Caregiver in Region 5

“The things that we found helpful were doctors who were direct, medical staff who were direct. Giving clear information without innuendo, without giving good detail, and explaining options, and being very clear about where things were at. It helped me communicate more clearly, which provided better support to the rest of the family and other people that were important in his life.” – Caregiver in Region 4

3. RESILIENCY AND SOURCES OF SUPPORT HEALING THROUGH CULTURE AND COMMUNITY

Healing can take many forms, and though there is no one way of doing so, caregivers found connecting to community, speaking to Elders and spiritual leaders, confiding in a loved one, and practicing gratitude to be some of the ways to live well through a cancer journey.

“I went back and found a traditional circle of women who were a mix of First Nations and Métis. We had a healing circle, we had the smudging, and we talked... we took a ribbon. As we tied the ribbon, we would tell our story. I took that whole course to help other people go through their grief. That was what helped me get back my spirit and get back hope.” – Caregiver in Region 4

“My partner was also Métis and lived a traditional life. I’m grateful our hospitals have physical spaces for Aboriginal people to gather, and there are Elders on call.” – Caregiver in Region 4

“I’ll call our priest and say, ‘Oh, do you have a minute?’ And I’ll go up and chat with him. I always tease him, I said, ‘I have to come and talk to your father because I don’t know if God is taking my calls.’ You know, he laughs when I say that, but he’s been very, very helpful so that’s been a really good resource.” – Caregiver in Region 5

“My partner lived a traditional life, and I am so very grateful that we both have Elders in our lives. It’s easy for us to call and say, ‘Can you please come?’ People would come, and they would offer ceremony. There are restrictions around what kind of ceremony you can offer in hospital without the permission of the Elder who is actually on staff.” – Caregiver in Region 4

4. WATCHING LOVED ONES CHANGE

It is not easy to see someone you love change because of their treatment plan. Emotional, physical, spiritual, and mental health changes can become overwhelming for caregivers. As a caregiver, it is important to set boundaries and know your limits.

“His personality changed because of the treatment he had. It was not the right treatment. He never did go to chemo or anything like that. He did a hormonal treatment, which messed up his mind over the years of taking it. We had to be our own advocates to make sure he wasn’t going crazy, it was the treatment. It got so bad that, like I said, it changed his personality from a kind man to a really angry, raging man, which wasn’t him. He opted to stop his hormonal treatment because of how it was affecting me.” – Caregiver in Region 4

5. CAREGIVERS AS ADVOCATES

Advocates provide a sense of assurance, support, and guidance during treatment and recovery. An advocate can be a survivor, Elder, family member, friend, or any other trusted individual. They attend meetings and can be a helpful resource during treatment planning. In some cases, family members, spouses, friends, or caregivers stepped into the advocacy role.

“I don’t know if it’s having to do with his illness, but he’ll be up in the middle of the night and I’ll get up and I’ll say, ‘Well what... Is anything wrong?’ He says, ‘I just don’t feel good.’ Well, how? You know... and what it is, is anxiety. He’s having these little anxiety attacks and so I put that on the list that he should ask his doctor about.” – Caregiver in Region 5

6. RECOMMENDATIONS FROM MÉTIS ALBERTANS MNA FINANCIAL AND ACCOMMODATIONS SUPPORTS

Often times, people facing cancer can also face other hardships and having support can help. There are many programs, supports, and resources available to help see you through some difficult times. To learn more about what supports the MNA has to offer look to page 18..

“The housing they have through the Métis Nation of Alberta... we’re living in the one-bedroom apartment and with him being on short term disability it’s like our income went from this much to this much... but the program really helped us lots.” – Region 2



Post-Treatment

Métis cancer survivors were joyous when told they have completed their cancer treatment. However, there are some lifestyle adjustments, including going to checkups, and continuing wellness activities that accompany post-treatment life. Most survivors want to celebrate all their hard work, but at the same time they must continue to cope with difficult emotions leading up to recovery and the uncertainty the cancer may return. The post-treatment stage — or as one survivor put it, your “new normal” — may mean attending follow-up appointments, monitoring symptoms, and living with some long-term effects of treatment.

“Before you got diagnosed and you keep going to the doctor and they do diagnose you, then they give you a treatment or they do an operation. After, in the recovery part, you are kind of lost.” – 2019 Health Forum Attendee

1. HEALING AND RECOVERY

“It’s life-long healing – now and after you heal.” – Region 2

“It’s not the old normal. It’s a new normal now.” – Region 3

CELEBRATE EVERY MILESTONE

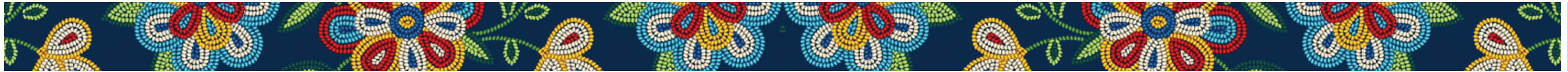
It’s easy to get wrapped up in the trials you face, but it’s important to celebrate the little wins too, especially when you feel there may be no hope. Celebrate every milestone, big or small as a reminder of the triumphs you have achieved along the way.

“The oncologist told me to recognize you have been on this path, that you have gone on a horrendous experience. Now recognize it and go on, make plans and go!” – Region 3

“When I was doing my radiation treatments at the Cross Cancer Institute, there was a little guy who came in. He was about five years old. As soon as he seen me, he came running over to ask how many treatments I had left. I said, ‘I only have three.’ He ran behind the desk and got the list of how many he had left. He said, ‘Oh, I got 13. When is your last treatment?’ I told him next Wednesday, and he said, ‘Oh shoot, I’m not going to be there. Cause that’s when you ring the bell, and everyone claps. Oh shoot, I’m not going to be there to see you.’” – Region 4

HEALING AFTER TREATMENT

The road to healing can be difficult. It’s important to take the time you need to heal properly, including planning your post-care appointments on a schedule that allows for rest, healing, and time in between.



“I followed up the blood work every three months and, it’s been five years last May and I don’t have to go back.” – Region 2

HEALING BODY, MIND AND SPIRIT

It is often said the mind, body, and spirit are all affected by one another. Healing and nourishing them takes many forms and can depend on the individual, their personal choices, and their personal healing journey. Make sure to take care of yourself, in whatever capacity you need.

“I love to learn about how to heal my body. I want to go back to school to take nutritional therapies and learn all that stuff. I do everything for myself at home. I’ve learned a wide range of stuff. I love to play baseball, paint on canvas and ceramics, dry brushing, and am just getting into bead working. I am learning more how to forage because for some reason, something inside of me is telling me to learn it, learn it now.” – Region 4

2. NEW NORMAL

Everyone’s new normal may look a bit different and that’s okay. Whatever your new normal, find things that work for you after treatment and beyond.

“Every time I go back there, I don’t want to. At the same time, you’re thankful you are going back there for a check-up instead of chemo treatment. It’s a reminder! I had this misconception that when I was done my chemo, I was going to be like ‘WOOOH!’ Nope! I was for a time, but not for very long. I was thankful. I was grateful. Then the emotional part hit. So, to me, it’s part of the journey that you just work through.” – Region 3

CHANGES TO QUALITY OF LIFE

Life after cancer might not ever be the same and may include changes in the quality of life you had before. Find supports and resources to help you along the way in both good times and bad.

“I had estrogen positive cancer, so, I am taking Tamoxifen right now, as it keeps my estrogen under control. I will take Tamoxifen for ten years. I had my first yearly mammogram. It is all good. I am all clear.” – Region 4

“I just hit my three-year mark post-surgery this month or last month...They have lowered the surveillance from 5 years to 3 years for colorectal colon cancer.” – Region 4

SHARING YOUR JOURNEY

Often times we can feel better simply by sharing our experience with others. Being able to talk about your journey and hear others who have gone through the same can feel comforting, assuring, and less lonely.

“With cancer survivors, I know in our culture, we are in the past, we were taught to not talk about stuff. Be silent or not talk about certain topics. I think my advice would be to talk

about it. Try to not have that shame and stigma. I know with my sister I didn’t know how to talk to her. Should I talk about it? What if we talk about it and it comes back? Discuss your experiences. We have never had what’s happening here today to come and be so open about it. All of the family, we were all like walking on egg shells around her, like what do we say? Do we talk about it? Even treating the situation with humor helps. Just talking about it and sharing your experiences with support groups would probably help.” – 2019 Health Forum Attendee

COPING WITH EMOTIONS

Dealing with cancer can be an extremely emotional time. Anger, confusion, fear, and sadness are all valid emotions and will play a major role in the cancer journey. Learning tools and having resources can help when experiencing these emotions.

“Your experience doesn’t end when they send you home. You still have the fear. Your family is still not sure how to deal with you being sick, you still have stress, We have to go somewhere past survival and into living. Your journey never really stops.” – 2019 Health Forum Attendee

RESILIENCY AND SOURCES OF SUPPORT

Resiliency is having the capacity to recover quickly from difficulties, and this is no stranger to our community. Staying strong and having a solid mindset can help with some of the more difficult times.

“I was determined. There was no way on this earth that I was leaving. Got my grandkids, got my husband. I just pulled through, and spent seven weeks at the Grey Nuns, and I’m out of the wheelchair, now with the walker, and pretty soon, I hope to be away from the walker. I just keep charging on, because it is not going to get me.” – Region 4

HEALING THROUGH CULTURE AND COMMUNITY

As you have seen through this book, there are many voices in our community who have shared their experiences with you. One of the common themes throughout was healing through our community and through our culture.

“Having community around. One of the most beautiful things I experienced with my partner in his last week of life was seeing his community come out. Just a stream of people. One way, it was very difficult because people thought they were coming to visit in the hospital, and quickly realized they were there to say goodbye. I was helping people navigate that emotion. It was very beautiful to see people come to speak about the impact my partner had in their lives in the different communities he’s been a part of. That was very helpful for him and for his family, and it was very helpful for me, just having other people around who cared about him.” – Region 4



Tips from Métis Albertans

RECORD THE CONVERSATION

Often times we will receive a lot of information and learn new terms which can be hard to remember. Try recording the conversations between you and your health care provider during these appointments so you can refer back to any information you may have missed or forgotten.

“Every time I went to my oncologist, we’d have our phone and turn it on. It was good to have that recording to go back to.” – Region 3

“My loved ones were also in shock at the time and it’s sometimes hard to keep up with, while writing, what the doctor is telling you. I asked my doctor if I could record our conversation so that nothing was missed and we could refer back to it afterwards. He was more than happy to oblige and we all found this to be extremely helpful later on.” – Region 3

BRING A NOTEBOOK

Writing down instructions, terms, or other things we hear during our appointments can help us when trying to remember what our next steps are. Bring a notebook to write down important details mentioned during your appointment.

“Have someone go in with you and write notes for you. You end up getting chemo brain and you cannot remember a damn thing. You don’t even know who you are some days! Or what day it is!” – Region 4

WRITE DOWN ALL THE QUESTIONS

We have all created a list of some sort in our heads we swore we wouldn’t forget. Then when the time comes to remember all the pieces, we wish we would have written it all down. Keep a list of questions you have for your health care provider before your next appointment.

“After we’ve seen the doctor we think, ‘Oh! We should have asked him this question.’ And then you write your question down so you have that to ask him again, because after we see the doctor, my husband and I discuss everything and if we don’t understand something we’ll ask, ‘Well how come?’ And then we’ll question him again like, ‘We didn’t understand what you meant by this.’ So always make sure you have a little book and write down the question while you remember it.” – Region 2



SEEK EMOTIONAL SUPPORT

Feeling alone during a difficult time can seemingly make it worse. As you go through your cancer journey, make sure to find a support system that works in your best interests and can help you through your difficult moments.

“It helps. Just talking about it and sharing your experiences with support groups would probably help.” – 2019 Health Forum Attendee

HAVE AN ADVOCATE

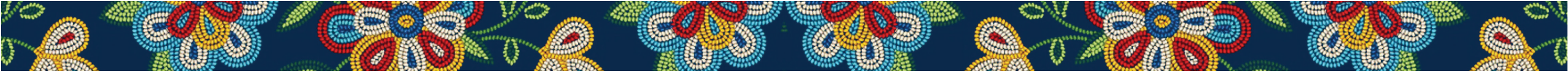
For the Métis Albertans who shared their cancer stories, advocates offered invaluable support during their journey. Advocates did not make decisions, but rather amplified the voices of those with cancer, reduced communication barriers, and provided support when needed. An advocate does not need to be a cancer expert. They are someone you trust to help you throughout your cancer journey.

“Often families have to find the voice of advocacy, and I was so grateful for that small team, the doctor, and those nurses because they made the difference. That man’s sole purpose for being on that unit every morning was to make sure everything possible was done in making my partner as comfortable as possible. That was the only reason he was there. He did it with kindness and compassion, and he was a strong advocate. If he hadn’t been on that unit, we would have had a very different experience. I am grateful for that.” – Region 4

HAVE SOMEONE TO SUPPORT YOU

A support to lean on, an ear to listen, and a shoulder to rest can make all the difference in getting us to the next stage in dealing with cancer. Find someone who can support you through your journey.

“Having my family was so important and my mom was there after my surgery. I wasn’t even able to lift my daughter, so my mom moved in with us and I am so happy to have her. I don’t know what we would have done before I was diagnosed. Just having community made a difference.” – Region 4



MINDFULNESS

Mindfulness can take many shapes and forms but can be an effective way to get through a challenging moment. It can be in the form of a new hobby, taking a moment to breathe in your surroundings, partaking in a guided mediation, and so much more.

“I am practicing gratitude and mindfulness. Staying very positive. My kids are my reason, so they keep me grounded.” – Region 4

“I took up crafts when I was diagnosed.” – Region 4

“Mindfulness is the practice of just being. Even like simple mindful eating, paying attention to when you’re sitting down, and even to what your food looks like, tastes like, smells like, and feels like. Your surroundings, the sights, and the sounds. Enjoying the little things, being present. Living in the moment!” – Region 4

SELF-CARE

Métis Albertans demonstrated resiliency and strength throughout their cancer journey, taking time to care for themselves and support their healing. This included positive self-talk, prayer, reflection, eating healthier, traditional foods, practicing ceremony, and active living.

“Just before you go to sleep, you have to have a list of things you tell your body... what you’re going to do and how it’s going to react. You can program yourself, even if you don’t believe it. As long as you do that before you go to sleep, your brain actually takes over from there. You can even tell yourself you’re going to wake up happy, and you’ll wake up happy!” – Region 3

“What the treatment did for me was teach me how to pray seriously. I asked my higher power every morning to either heal me or take me. You make that choice, not me. I give everything to my higher power and said, you make that decision for me.” – Region 3

“From day one we started a journal on our journey. That way you can go back, reflect, and say, ‘Ok this happened, this happened. This is how I felt. This is the kind of frustration we went through. This is what we were dealing with.’ That helps because you can go back.” – Region 2

HEALTHY BEHAVIOURS

Some Métis Albertans were aware of how smoking affected their health and wellbeing and took it upon themselves to reduce or stop using commercial tobacco. Nicorette patches, self-help resources, and peer support were some of the resources Métis Albertans accessed to reduce smoking. Appendix A (page 40) provides a thorough list of tobacco reduction resources if this is something you are interested in.

“I remember reading if you quit smoking at your time of diagnosis, you have a 50% chance better of healing. I quit that day. With the Nicorette patch and the inhaler I quit. I quit with my daughter.” – Region 4

“I smoked for about 50 years, and I’ve been smoke free for about four. I took one prescription, and I didn’t finish. I had one cigarette left on a Saturday and broke it up into three smokes. That’s it, I quit! No cravings or anything since then. Four years ago!” – Region 4

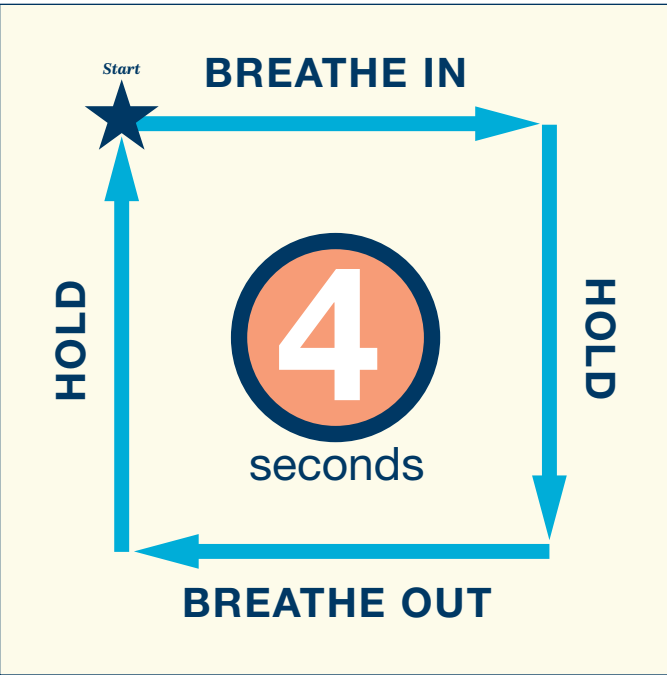
BREATHING AND GROUNDING EXERCISES

Deep breathing and grounding exercises have been known to help in many different situations. See below for two techniques to help you with both.

“Practice deep breathing and mindfulness for anxiety.” – Region 4

Four Square Breathing Technique

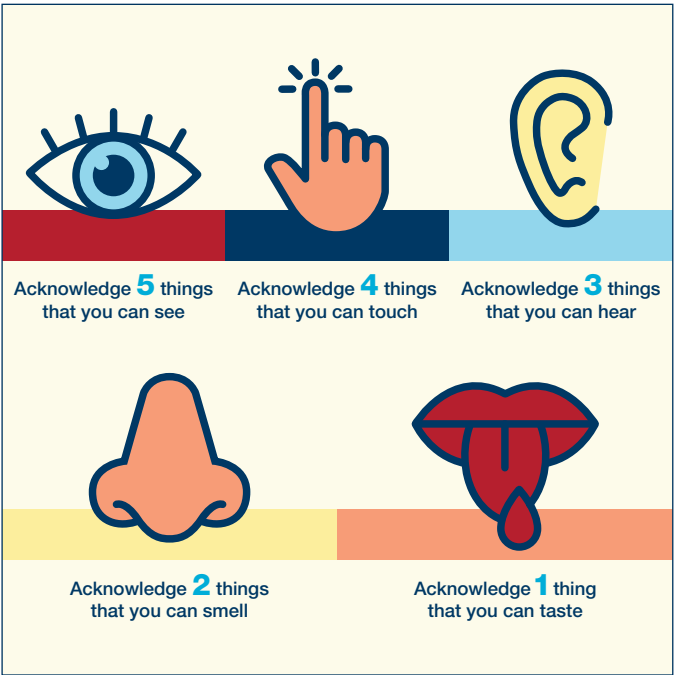
Four square³ — or box breathing — is simple and can be done anywhere. Find a position where you feel comfortable (seated or lying down). Inhale air into your lungs for a count of four, hold your breath for a count of four, exhale for a count of four, hold your breath for a count of four. Repeat.



³ Rollo, 2018

5-4-3-2-1 Grounding Technique

Utilizing your five senses, this exercise can ground you in the present. Take a deep breath and notice what is around you. Acknowledge these things at each step by speaking out loud or taking mental note. If there is nothing around for you to sense at one step, think of a favourite sensation instead.





LAUGH AND DO WHAT YOU ENJOY

Doing things that bring us joy can make us feel happier. Try some of your favourite things to bring joy to your present moment and to build memories to look back on.

“It is also blessing, whatever it is. My journey with my sister, I watched her. I was her main person. I was there when she was diagnosed, and I tried to be there for her as much as I could. How she made light of it because, as they say, we have to have laughter.” – Region 4

LIVE A HEALTHY AND ACTIVE LIFESTYLE

Eating a healthy diet and maintaining regular exercise can make a big difference in our cancer journey, our energy levels, and our overall mood. Try making small changes to start.

“When I finished my treatments at the Cross Cancer Institute, that was the main thing they gave me. It was the vitamin D3, the multi-vitamin, and the calcium. It’s a must.” – Region 4

“The only tip I recommend is to take vitamins.” – Region 4

“I think volunteering is so important! I like volunteering. I like working in the kitchen. I like working with food.” – Region 4

Some examples of healthy and active lifestyle practices include:



REGULAR EXERCISE
(including nature walks)



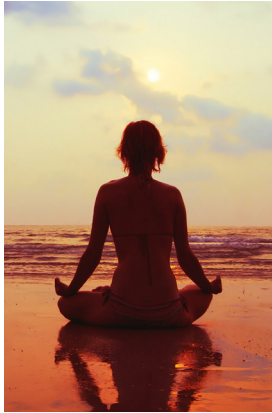
HEALTHY EATING



TAKING VITAMINS



VOLUNTEERING



MINDFULNESS

Conclusion

This guidebook was carefully crafted for our community and is a resource for Métis Albertans and their families going through their cancer journey. Through the voices and experiences shared by fellow Métis Albertans, it is our hope that their stories of strength, community, and resilience will help you on your cancer journey.

If you are someone who has been newly diagnosed, is currently going through treatment, has a loved one who has been diagnosed, or are a caregiver to someone living with cancer, hopefully this guidebook has been able to help you move forward during what could be a very uncertain time.



Tina – Métis Cancer Survivor



Questions for Health Care Staff

QUESTIONS TO ASK YOUR DOCTOR DURING SCREENING AND DIAGNOSIS

What kind of cancer is it?

Where is the cancer?

Has it spread? YES ☐ NO ☐

What other tests and procedures may I need?

What is the wait time for each of these tests and procedures?

What changes to my lifestyle should I anticipate?

What role can I play in my healing?

What resources can you provide for more information?

What next steps do you recommend?

What should I tell my family or community?

Are there any resources for my family or community?

ADDITIONAL NOTES



QUESTIONS TO ASK YOUR DOCTOR WHILE UNDERGOING TREATMENT

What medicines will I be taking?

How long will I have to take the medicines?

What are the side effects?

How can I manage the side effects?

What signs, symptoms, or side effects should I be aware of?

When should I notify my doctor about my side effects?

How long do the treatments last?

Are there any lasting effects I should watch for (e.g. pain, fatigue, etc.)?

What should I consider when making my wellness plan?

What activities can I still do while taking treatment (e.g. work, school, physical, etc.)?

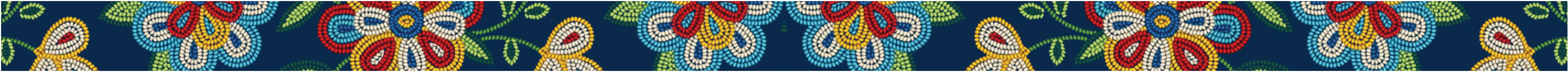
Do I have access to a social worker or dietitian? YES ☐ NO ☐

Do I have coverage for my medication? YES ☐ NO ☐

Can I get a written summary of my health record and my follow-up care plan? YES ☐ NO ☐

Can I drive after my appointment? YES ☐ NO ☐

ADDITIONAL NOTES



QUESTIONS FOR YOUR DOCTOR TO BETTER UNDERSTAND
FOLLOW-UP CARE

Who do I see for follow-up care?

How often will I need to come for follow-up/check-ups?

Why do I need check-ups?

What post-treatment/recovery supports are available to me and my caregiver?

What diet and exercise recommendations should I continue or start now that my treatment is finished?

Is there a genetic component to my cancer? YES ☐ NO ☐

What are the chances my children will be diagnosed with cancer?

ADDITIONAL NOTES

QUESTIONS FOR YOUR DOCTOR TO MANAGE AND MONITOR YOUR
HEALTH AND WELL-BEING

What new symptoms should I look out for?

Who should I contact if I develop new symptoms?

What are some of the possible long-term or late side effects based on the cancer treatment I received?

What resources are available to help me cope with my emotions after cancer (e.g. mental health supports)?

What can I do to prevent the cancer from recurring?

How can I manage my fear of cancer coming back?

How likely is it that my cancer will come back?

What symptoms should I look out for?

Is there anything I can do to improve my current health and well-being?

ADDITIONAL NOTES

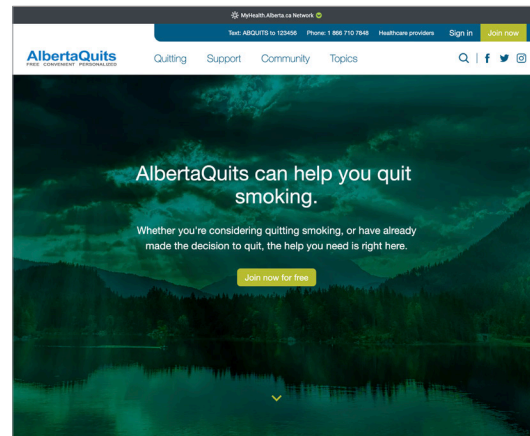
Glossary

Advocate	An individual who provides guidance, advice, and insight for cancer patients on their journey.
Cancer	A group of abnormal cells in the body.
Chemotherapy	Is a treatment that seeks to cure or reduce the growth of cancer cells. It is effective in treating both fast and slow-growing cancer cells.
Diagnosis	A process to identify health issues including images, tests, and biopsies to classify the type of cancer, grade, and location.
Estrogen Therapy	Is a type of hormonal therapy that can come in the form of patches, pills, and suppositories.
Hormone Therapy	Like other therapy procedures, hormone therapy seeks to reduce or stop growth and limit the spread of cancer. Most hormone therapies either lower estrogen or progesterone levels, stopping cancer cell growth.
Immunotherapy	This therapy works to strengthen your immune system to fight off cancer cells and reduce their growth. It uses medications to stimulate or suppress the immune system to fight cancer.
Oncologist	A medical doctor who specializes in diagnosing and treating cancer.
Radiation Therapy	This treatment process uses radiation to shrink the size of the tumor and destroy cancer cells.

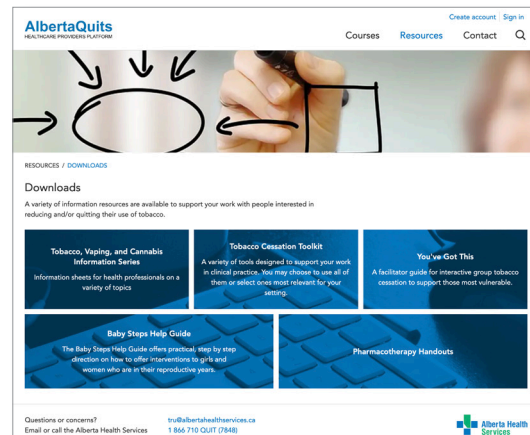
Screening	The tests to search for cancer before symptoms are made aware. The tests are recommended by your doctor based on age, family history of cancer, immunocompromised individuals, and abnormal lab results.
Surgery	Is the most common procedure to remove cancerous tumors. Surgery can also be used to contain cancer cells to prevent it from spreading to other parts of the body.
Targeted Drug Therapy	Targeted therapy introduces drugs that attach to proteins to reduce the spread and growth of cancer cells.
Tumor	A mass of abnormal cells, tumors can either be benign or malignant. Benign means they are not cancerous and malignant means they are.
Ultrasound	High-frequency sounds or vibrations used to create images of the body called a sonogram.
X-Ray	A digital image of the body developed by high-energy electromagnetic radiation.

Appendix A: Resources

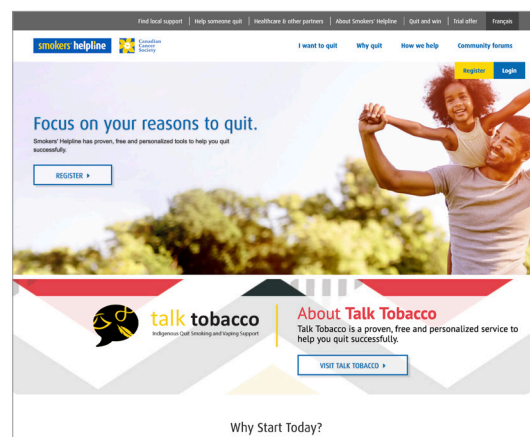
1. TOBACCO REDUCTION SUPPORT LINKS



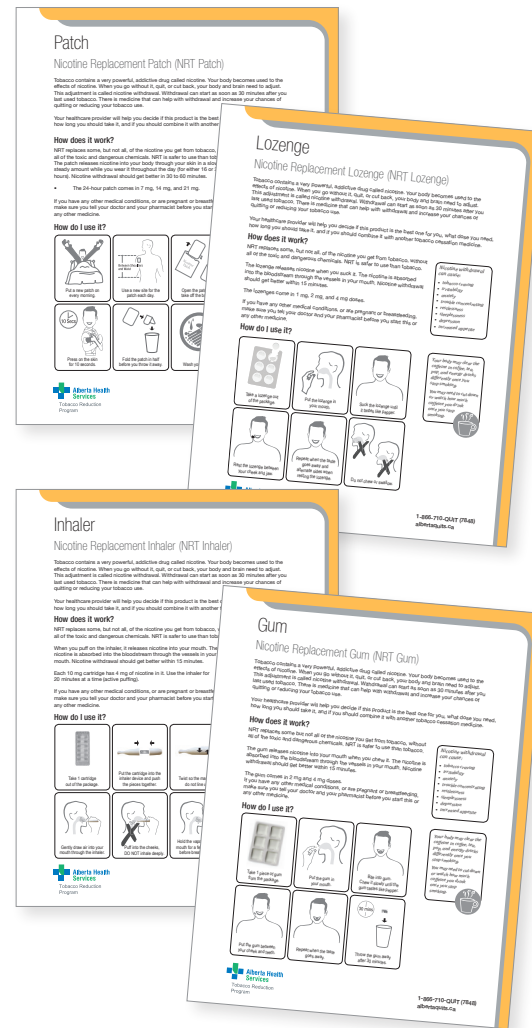
[Government of Alberta](#)



[Downloadable Resources](#)



[Smoker's Helpline](#)



[Pharmacotherapy Handouts](#)

2. RESOURCES & SERVICES PROVIDED BY THE MÉTIS NATION OF ALBERTA

Reach out and connect with us any time. We have many programs, services, and resources available to our community. If you have any questions or need support, we welcome you to reach out to us at 780-455-2200. We also encourage you to visit albertametis.com to stay informed and connected with all that is happening in and around the Nation.

MÉTIS NATION OF ALBERTA PROVINCIAL OFFICE

The MNA has many programs and services that can help you on your cancer journey. When you call our main office, we can connect you with the support best suited for you and your health needs.

780-455-2200
albertametis.com

SUPPORT AND SERVICES NAVIGATOR

Our Supports and Services Navigator (SSN) can point you in the right direction when it comes to looking for resources and supports.

Our SSN is an expert who directs Métis Citizens to various MNA-affiliated programs, provincial and federal government supports, and community resources that are appropriate to each citizen's specific needs.

780-455-2200 ext. 403
mnacfs@metis.org

MÉTIS URBAN HOUSING CORPORATION

Our Urban Housing Corporation can help ensure your housing is secure while you focus on your health and wellness.

1-877-458-8684
metishousing.ca

COMPASSIONATE CARE: CANCER TRANSPORTATION PROGRAM

Traveling for cancer related appointments can take a toll on your finances. The Compassionate Care: Cancer Transportation Program provides financial assistance to MNA Citizens who must travel to their cancer-related appointments. For more information on this program call our health programs administrator.

587-416-3691
health@metis.org



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Métis Nation of Alberta · Department of Health
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