

Acknowledgments

The stories in this book were shared with us at the Telling Our Stories Conference in June, 2016, Prince George BC. We thank everyone for their generous teachings and words of support for all those on a cancer journey.

This project has been a joint initiative between the Métis Nation of BC, First Nations Health Authority, BC Cancer Agency, and the BC Association of Aboriginal Friendship Centres.

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BC Cancer Agency

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BC Association of Aboriginal Friendship Centres

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LIVING WITH CANCER everyone deserves support



Everyone deserves support

If you or someone you love has received a cancer diagnosis, you don't have to face this journey alone. This book offers information and insights through the voices of Métis and First Nations people who have lived and are living through a cancer journey, as well as space for your own reflections.

We're brave. We're warriors. I'm here today because I decided I am a proud, brave warrior.

We have to tell that to our people. If your body is talking to you, you go to the doctor and you get it checked out.

~ Larry Tiljoe, Wet'suwet'en



When you're faced with cancer, so many people say you have to be positive. You have to be strong. When I found out I had cancer, I thought of all my children and my grandchildren and my great-grandchildren. I ask my Creator to help me every day. And I'm just happy I'm here for another day. And I know we have to be medicine for one another.

~ Reverend Lily Bell, Haida Nation

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YOUR RIGHTS



To seek support

To have a support person of your choice advocate for you

To advocate for yourself

To receive culturally safe cancer care

To have mutually respectful interactions with all health care practitioners

To be treated as a whole person and not only as a patient

To have a medical professional clearly explain your health problems and treatment options to you

To ask questions or express concerns you have about your health or treatment

To ask for clarification

To ask about what is happening to you, as often as you need to

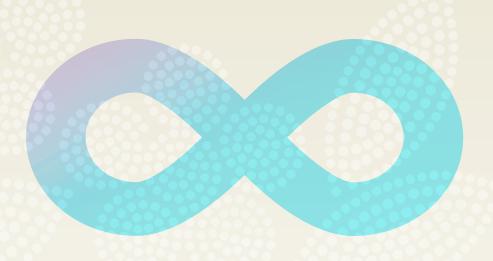
To request a Second opinion

To participate in decisions with your health care provider

To give or refuse consent for any procedure, for any reason

To have privacy and to be assured that personal information is confidential and not shared without your consent

To request access and protect your personal health information records



Whatever
decision you make,
it's your body.
Whatever journey
you opt for,
it's yours.

Your contact information	
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Home Phone	
Cell Phone	00000000
Address (street, city, postal code)	
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Emergency contact	

Home Phone	
Cell Phone	20000
Your local cancer centre	
Name	
Phone	
Address (street, city, postal code)	

We have created space for your notes and reflections throughout the booklet. "My Wellness Plan" at the end of this book has space and a calendar to help you organize and keep track of your contacts, questions, notes, and appointments. The back cover flap is a folder for you to put handouts.

Every BC Cancer Agency centre has patient and family counselling services, and various support programs. You are encouraged to contact your local cancer centre and make an appointment. There are no fees for these services.

The services provided can support you in:

- Assessing your emotional/mental wellness
- Creating a wellness plan to support your emotional/mental wellness
- Reviewing and identifying supports and resources that may be useful for you on your cancer journey





GATHERING SUPPORT

THE PERSONAL JOURNEY was difficult, and it's been a long time because I didn't think I could tell people I was angry. I was angry with people who offered me advice.

What if I couldn't be strong? What if I can't be cheerful?

What if I can't be happy? What if I can't be hopeful? All I can do is be in this moment, whatever it is, and I just need you to be there for me. That's what makes me strong. That's what makes me smile. That's what makes me whole. Thank you.

~ Jan Ovans, Métis

I just need you to be there for me. That's what makes me strong.





Receiving a cancer diagnosis

When you or someone you love receives a cancer diagnosis, it can be a shock. You may have questions. Be gentle with yourself.

Depending on your diagnosis, you may need to make decisions quickly. It helps to gather support. Reach out to people you love and trust, and who are good medicine for you.

Telling a loved one about your diagnosis may be the first step in your journey. There are many ways to share this information. Some people find it helpful to share with people they trust. Give yourself permission to ask for help from those around you.

Ever since I started this fight,
I have had great support from
my family and my partner of
twenty plus years. I will not give
up this fight with cancer.

~ William Samson, Tsimshian, Lax Kw'alaams

gathering Support

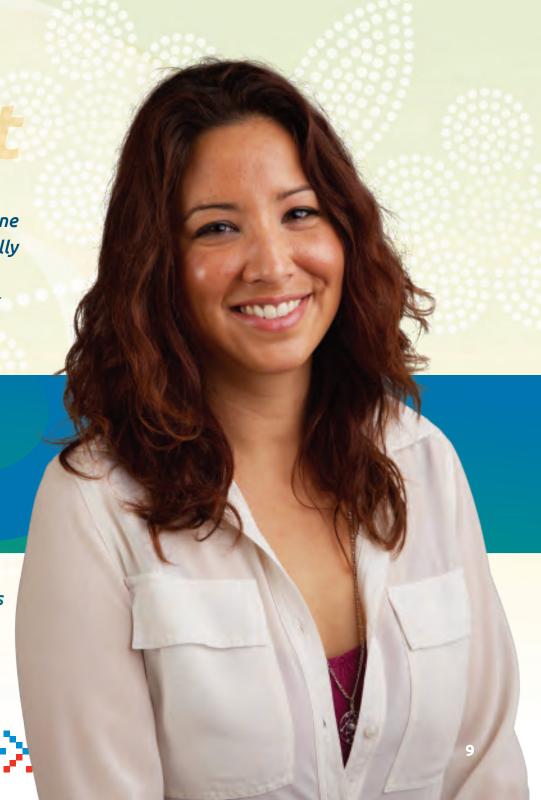
WHEN THE DOCTOR phoned to tell me about my diagnosis, I was at work. I remember my cell phone ringing or maybe it was my office line. I can't really remember those details. I remember picking up the phone and he told me he got the results back and that I needed to come in for further testing because there were signs of papillary carcinoma.

I didn't have time to process. I just remember feeling like I'd been hit by a truck.

I didn't have time to think about it. And I wept.

I just wept. He opened the space to ask questions
but I couldn't really process anything.

~ Amanda Engen, Dene Tha, Chetah Alberta and Métis





I think writing down your questions is a good thing.

And maybe find somebody who can take you to an appointment or just sit in with you. Write notes for you. It's good to always have that support.

~ Health Care Provider

AT TIMES IT FEELS like, why is it taking so long for the test results to come in? It feels like everything's going very fast and then at times it feels like time just stopped.

~ Health Care Provider

IF YOU DON'T understand, ask the question because if you don't tell me or ask somebody, we don't know what you need. You have to ask.

I've sat in with patients with the doctor, and we talk about it after. They didn't say anything or ask questions so I'll write them down for them and help them make a list of what to ask the doctor.

~ Patient Navigator

I understand exactly what they're going through because I was there.

I'm a survivor of breast cancer 15 years now.
I've also been helping other breast cancer
survivors in my community just by being
with them, being supportive. I'm finding that
communication is really important to get them
to connect with people, and I let them know
that I understand exactly what they're going
through because I was there. I had to lose part
of myself in order to live.

~ Marilyn Belleau, Esk'etemc from Alkali Lake

gathering Support

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TIPS

when seeking information about your cancer

- · Write your questions down on a piece of paper before you visit your health care provider, and ask all the questions you may have. You may also want to write the responses to your questions on a piece of paper to help you remember them.
- Record your conversations with your health care provider. Most cell phones let you do this. If you need help, ask a family member. The audio recording of your visit may help you remember the answers to your questions if you forget.
- Bring a family member, friend or support person to your appointments to help you ask questions. They can also help you remember what was said by the health care provider.
- · When seeking information online, be sure to use only credible and reputable information sources, like the BC Cancer Agency

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QUESTIONS

you may want to ask yourself when diagnosed with cancer

- Am I experiencing new feelings after being diagnosed with cancer, such as being sad, scared, angry or confused?
- Do I have someone who I can express my feelings to (parent, grandparent, sister, brother, auntie, niece, uncle, son, daughter, nephew, close friend, counsellor, etc.)?
- Do I have someone who I can ask to come with me to my appointments to support and advocate for me?

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QUESTIONS

you may want to ask your health care provider about your diagnosis

- What type of cancer do I have?
- Is my cancer slow or fast growing? What does it mean if my cancer is fast or slow growing?
- Is my cancer in only one place, or is it in other parts of my body? What does it mean if my cancer has spread to other parts of my body?
- · What are the chances that my cancer will get worse?
- What are the chances of me surviving this cancer? How many people survive the same type of cancer that I have?

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Your notes



I think when you have good family support, it makes a world of difference.

> WHEN YOU HAVE a family that stands behind you, that cares about you and are concerned, it helps a long ways. Because you know you're not alone. Maybe that's how it is with a lot of the Métis community. For people that don't have family, maybe they can find solace in the fact that knowing they're not alone. There are other Métis people there. There's a support group there. And I think that is probably as important. Because you have somebody you can talk to.

> > ~ Lou Romailler, Métis



gathering Support

My care person was my daughter.

My family was there for me all the time, and my doctor. They were there. My daughter stayed with me every trip to chemo. My kids were down there on the weekend for me if I needed them. There were phone calls saying, 'Mom, you can beat it. Mom, you can beat it.'

My whole family encouraged me. Without them, I don't know how I would have made it.

~ Adeline Sarver, Métis

I said, 'I do feel afraid.' He said, 'That's okay Auntie. Feel however you feel. Don't be ashamed because you feel scared. Just accept whatever feelings come at the moment.'

> ~ Reverend Lily Bell, Haida Nation





The one thing I know from when I was going through this with my niece.

It is your cancer.
It is your decision
and your body. What
you need to do on your
journey is your decision.
This is you.

~ Gail Gus, Tseshaht First Nation

gathering support



THE THING that first came to mind and still does: I don't want to hurt anybody. I don't want to put this on anybody else and I don't want anybody to feel guilty about my illness.

I had to go to my children first.

Even though I was divorced from their dad, he needed to be there for them like I was, and I needed to tell him that. I needed to make sure I had all those bases covered before I started thinking about me. And making it meaningful for them because they're younger so that they would know how they could care and who would care for them as well.

It's a huge thing when you say cancer.

Let's not say the big C. It's cancer. Initials don't mean a thing. It just means that you're covering it up more. That's what it was for me anyway.

~ Gwen Campbell McArthur, Ojibway/Saulteaux Métis

Practical support

You may need support with your daily tasks and responsibilities, to take time off work, or be away from family. If you need to travel for tests and treatment, this may require planning and resources.

TALKING TO CHILDREN ABOUT CANCER

You may feel overwhelmed talking about your cancer, especially if you are managing anxiety and fears brought on from your diagnosis. When talking to children about cancer, you may want to have the support of a loved one or trusted Elder with you.

When speaking to children, the age of the child and your knowledge of them should be kept in mind. A conversation with a younger child may be different than with an older child, and it may be different based on their understanding of cancer and their relationship with you.

Keeping cancer a secret may be stressful, especially if people around you sense that something is happening to your wellness. It is important to remember that it is your decision who you tell and when.

SUPPORTING each other.
Sharing all that knowledge,
even the financial part of how
to use the medical travel that
you access through your wellness
centre or health station.



Making sure that everyone is taken care of in a good way.

~ Dawn Francois, Secwepemc Nation

practical support

TIPS

for discussing your cancer diagnosis with children

- Discuss the basics and use words that the child can understand.
- Find out what the child already knows about cancer and clear up any misleading information or myths they may have.
- Be clear about the name of the cancer, the part of the body that has the cancer, and how it will be treated.
- Let the child know that it is OK to ask questions, and that feeling worried is a normal reaction to hearing a loved one has cancer.
- Don't assume children will have the same fears as you.
 Ask them what they want to know, and try to only answer questions they ask.

Tell children if you don't know the answer to a let them know you will find out the answer for the second sec	
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Your notes		
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QUESTIONS

you may want to ask your health care provider about support

- Are there support people at the cancer centre, such as patient navigators or social workers that I can talk to for support?
- How can I find support and help for the new thoughts and feelings I am having after being diagnosed with cancer?
- If I have to fly or travel far for medical appointments, where can I get information on support for transportation and accommodations?
- Who can help me and my family cope with a cancer diagnosis, and the changes that accompany it?
- Are there brochures or pamphlets that can help me learn about my diagnosis and treatment, and the services that are available?

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ON APRIL 16TH, I got my diagnosis of breast cancer. And I had my mastectomy a week later. Everything just happened so fast.

I work with home and community care, and I have a lot of supportive colleagues there. They were there for me any time I needed anything. They would ask if I need my dressing checked because I came to work and still had drains in.



They checked on me to make sure everything's looked well. They asked how they could support me, even just talking.

I think that's what got me through having the diagnosis of breast cancer is staying positive. Now I'm looking forward to having breast reconstruction.

My work also supported me going to appointments and stuff. Like with this knee replacement that I also had at that time. So any medical things I go to, they're definitely accommodating when it's time for me to go and do that.

~ Shelly Henderson, Weiwaikum (Campbell River) First Nation



I WAS AFRAID, afraid to talk to my children. Ken was worried about me. And it's difficult when you want to be independent.

Basically, women all over don't want people to take care of us because we're the caregivers. We're the ones that take care of everybody so it was difficult to get help or even ask for help. But when the Kwakiutl District Council (KDC) staff came

they would say, 'I'm just here, I can keep you company, talk to you."

And I do have a support person in the Canadian Cancer Society who calls me every few months to ask me what's happening for myself. She's two years ahead of me so she's experienced a lot. So now I can, if I'm afraid of something, I can talk about what I'm going through.



The Canadian Cancer Society has been wonderful, wonderful all the way through. They're really supportive and the KDC was great because they sent me people to help me cook and drive me to and from the doctors. They were just there for me.

You know, I was grateful people didn't tell me everything.

Just little steps help me not to get overwhelmed

because I wasn't sure if I was going to have do chemo or radiation. And I was afraid. I was more afraid for my family then I was for myself.



And I'm grateful to have First Nations input, First Nation words and sharing because I'm not sure where to go from here.

I'm grateful to hear a First Nations perspective because that's closer to home than the non-Native ways. My friend came to do some holistic healing with me three times before the mastectomy surgery, and three times after for follow up healing.

I came out of that and I just felt like the Creator has plans for me. I'm still here. I'm great with that.

~ Georgina Hunt, Tlatlasikwala and Kwakiutl territories

My cousin was my advocate. She went on the entire journey with me. She didn't leave my side. She learned along the way.

> She helped me find the resources that I needed and she helped me put things into place. A lot of things went wrong that required somebody to help me think. She stayed with me, she never left me.

~ Patricia Prince, Health Care Provider and cancer survivor

Advocacy

WHAT IS AN ADVOCATE?

An advocate is someone you choose to speak up for you. There may be moments along your cancer journey where you may need to use the strength of another person to be your voice, support you in decision making, or advocate for your needs. An advocate may be a family member, Elder, trusted friend or professional. You can also be your own advocate.

An advocate doesn't make decisions for you but helps ensure your needs are heard and respected. They don't have to be an expert, only willing to help get the information you need, ask questions, and support your decisions. You can have more than one advocate.



It's important to have somebody there to speak on behalf of people who are unable to speak for themselves, to help communicate in the most effective way. When something is such a traumatic experience, it doesn't have to be awful.

Advocacy supports people in a better way, to speak in a way with practitioners and people with power, to be able to feel comfortable with what's happening to them.

And they have a right to be taken care of, to be heard and to know what's going on within their diagnosis.



It's scary to go into something where you're putting your trust into a group of people and system you don't know.

~ Amanda Engen, Dene Tha, Chetah Alberta and Métis



I WENT THROUGH the cancer journey with my mom. She never spoke up for herself so when I found out I had breast cancer, I took everything that I witnessed and went through with my mom and used it to the best of my knowledge to do what would be best for me.

I went to my doctor because I knew something was wrong.

I felt a lump and I went to the doctor and he kind of blew me off. Just because your mom died of breast cancer doesn't mean you're going to get it. And he gave me that look so I just left.

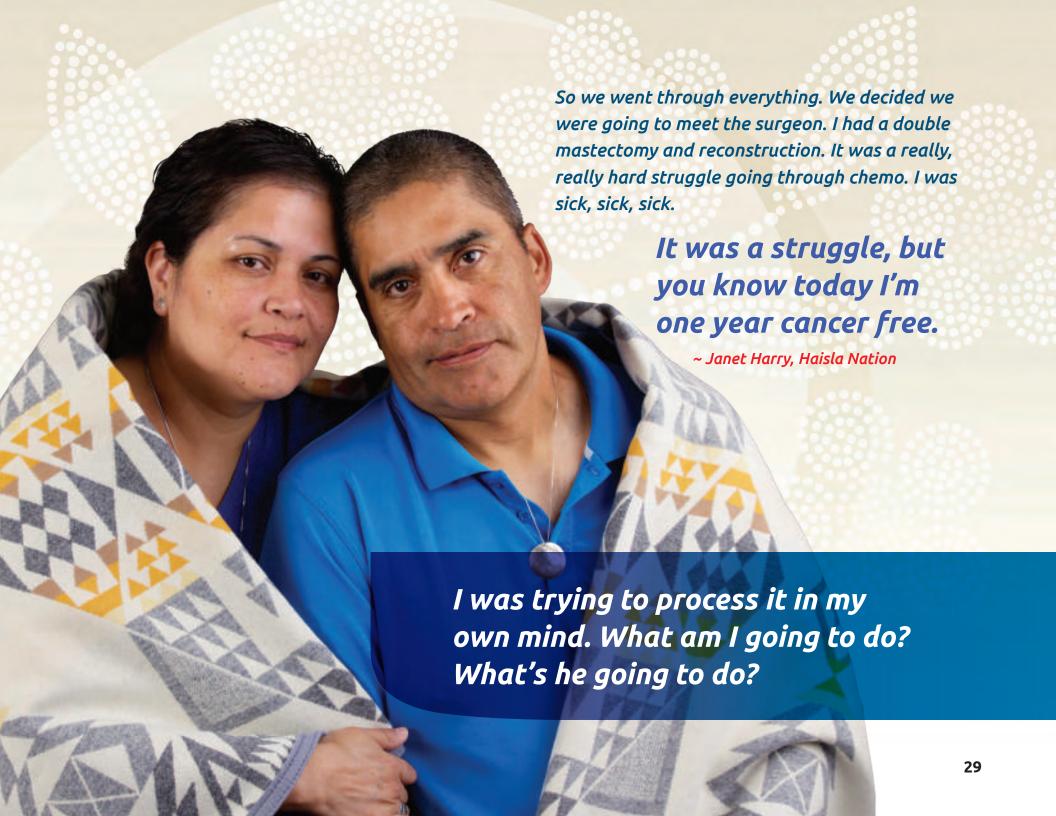
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advocac;

I think a week went by and my husband made me go, because it was getting painful. We asked if we could be referred to Vancouver for the biopsy test. We did and I went through hours and hours of testing and biopsy.

When you're told that you have cancer, it's like you're going to die. That's what I thought. I was trying to process it in my own mind. What am I going to do? What's he going to do? What are the kids going to do?





QUESTIONS

you may want to ask yourself about advocacy and support

- Do I need an advocate?
- Who is the best advocate for me?
- Who makes me feel better and gives me strength? Who in my life can navigate the medical system with me and advocate on my behalf?

on my behalf?	
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I'M SO GLAD I can tell the people, this is the journey that I went through.

Awareness,
education, prevention
and screening.
That's what is
needed.

Cancer care everywhere in this whole world, that's what is needed.

~ Della Gladue, Gitxsan Nation



Understanding cancer

We know that cancer is more than just a disease, it happens to a person. It affects more than our physical selves. Being diagnosed with cancer is an event that may impact all aspects of our lives - from our relationships to our mental, spiritual, emotional and physical wellbeing.

Cancer is a disease that can start anywhere in the human body, which is made up of trillions of cells. Normally, human cells grow and divide to form new cells and keep our bodies healthy and whole. However, occasionally things go wrong for a variety of reasons. Cells start to grow and reproduce into an unorganized mass or tumour and may start to invade surrounding healthy tissues.

Tumours - or lumps - are classified as either benign (not cancer) or malignant (cancer). A benign tumour is one that does not spread or invade nearby tissues, and does not usually cause life-threatening health issues. A malignant tumour is one that can grow quickly and affect nearby tissues, and can also spread to other parts of the body, interfering with the proper functioning of an organ or body system.

I REMEMBER there was a time that it felt like my body was so drained.

And I had to make a choice right there. To either let myself go or to be a warrior and fight.

I kept thinking about my family, my mom and dad, my wife and everybody who loves me, and especially my granddaughter. And I said, 'I'm a warrior, I'm going to fight, I'm going to fight until the end.' And right there and then, I survived and now I'm cancer free. Because I'm a warrior. I fought it. And if it comes back again, I'm not going to give up. And I don't want any of you guys to ever give up on me.

~ Larry Tiljoe, Wet'suwet'en



TIPS

for being a caregiver and supporting someone diagnosed with cancer

- Remember that being an advocate requires permission and an invitation.
- Discuss the treatment desires and health care needs of the person diagnosed with cancer.
- Help the person diagnosed with cancer understand or gain access to medical, traditional or other supports they need.
- Discuss the practical needs of the person diagnosed with cancer, such as providing daily care, maintaining the home, or providing child care.

QUESTIONS

you may want to ask yourself if you are a caregiver

- Do I have anyone I can talk to about my feelings?
- Is there a support group for caregivers in my area?
- Does my cancer centre have emotional support for caregivers?
- What do I need for my own personal wellness?
- Will I know when I need to ask for help to support my own wellness?
- Who will I reach out to for help when I need physical and emotional support?

	Where can I learn more about being a caregiver?
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Supporting a loved one on the path

Being a caregiver is often defined as someone who provides physical and emotional support to a cancer patient, but does not get paid to do so. Caregivers can provide help with daily care, such as feeding, bathing, house cleaning, making meals, giving medicines and discussing feelings. It's a big job!

A caregiver may be a spouse, family member or close friend. Acting as a caregiver can enhance the physical and emotional wellbeing of the person going through cancer, but can also challenge the caregiver's own wellness. Being a caregiver can be very rewarding, as well as overwhelming and stressful. It's important that when providing emotional and physical supports that a caregiver also takes the time to focus on their own personal wellness.





Your notes	





MANY WAYS OF HEALING

For myself, I was trying to find that balance between western and traditional, that was what was going on with me. It was something I was already practicing before. I put my faith in both and it all came down to my faith. I didn't rank one against the other. I didn't do that. It was really important for me to put my faith out there. And I had such a huge team without me even asking for it.

It's like when I was in the hospital, somebody sent a traditional healer there for me and he did some work on me. He did some chanting and after it was all done, the nurse who came in and did my vitals says she found that every time there was traditional work, the vitals were really good. She was open to it.

We need more medical staff to be open to our traditional values.

~ Gail Gus, Tseshaht First Nation





Medical terminology can be confusing to cancer patients. Similarly, the beliefs and practices of Indigenous traditional healing and wellness can be unfamiliar to health care providers.

many ways of healing

Many Ways of Healing

Every person with cancer deserves to know what is happening to them, to understand their options, and to have their questions heard. Even if our questions fall outside of the medical system's view of health, we must be able to respectfully discuss our healing and wellness needs and choices with our medical team.

Historically, all cultures hold traditional wellness and healing knowledge and practices. Many of these traditional wellness and healing practices are still in use. The Western medical ways to treat cancer can be complemented with other traditional and holistic practices that address the disease while respecting a person's overall wellbeing.

Medical terminology can be confusing to cancer patients. Similarly, the beliefs and practices of Indigenous traditional healing and wellness can be unfamiliar to health care providers. A conversation can help bridge these two streams of medicines in order for doctors and patients to learn from each other.

Traditional wellness is a term that encompasses traditional medicines, practices, approaches and knowledge.

Traditional wellness is based on a holistic model of health, and can include drumming, singing and ceremony.

Wellness is about the whole person and striving for the best life while living with cancer.



many ways of healing

It's a journey that you have to do on your own

People need to collect as much information from any place and every place they can. And have the attitude that you're going to do what it takes to beat it. For me, I never believed that I would I die. I just wouldn't accept it. If I did, then it was meant to be.

~ Lou Romailler, Métis



THAT WAS THE BEST thing I ever did. And my support worker helped me and before I went for my surgery, my best friend, an Elder, took me out to a very isolated area. She smudged me down with juniper. As a Southern Carrier person we use juniper. She sweeped me all and then I went into surgery. I had my surgery and they told me I had to walk.

So just like nothing, because of the smudging, I was able to walk because smudging was so powerful.

~ Ellie Peters, Lhtako Dene Nation (Red Bluff Band)

many ways of healing

Medicine for the whole person

Complementary medicine refers to healing that we can do in addition to treatments received by the health care system. Complementary medicine can include massage, naturopathy, acupuncture, meditation, yoga, and First Nations and Métis traditional wellness.

Traditional wellness and healing

Traditional medicines balance the use of indigenous plants and foods with philosophy and ceremonies. Each Nation has their own teachings and practices when it comes to healing and wellness. Some of these traditions are incorporated into mainstream society while many remain unique to specific communities.

Some people may want to bring traditional healing and wellness into their cancer journey. Those who add a path of traditional healing can reach out to cultural teachers and informed community members.

It's up to you to decide what you need. Be sure your choices are safe and informed. Consult with your doctor before ingesting any plant medicines and participating in traditional healing practices, as some may cause dangerous side effects.



It's up to you to decide what you need. Be sure your choices are safe and informed.



Talking to your medical team can help you understand which traditional healing practices and medicines may or may not be compatible with your medical treatment or present state of wellbeing. It's important to communicate your choices to your medical team to keep you safe.



Wellbeing and healing

Healing is about treating the whole person and striving for the best quality of life while living with cancer.

Traditional foods and healing can be used as part of a holistic approach to healing alongside Western approaches. Food and culture also sustain our wellbeing. Consuming traditional foods and cultural practices may support spiritual and nutritional needs.

Traditional wellness encompasses traditional practices, approaches, medicines and knowledge. Reflecting a holistic model of health is often overlooked in the treatment of disease.

many ways of healing

WE ALL HAVE a physical being and when we do get cancer, and get sick,

that's the time we'll be asking the Creator to give us a hand.

Spiritually speaking, that's the first thing that I grasp to understand – our physical end of it, our emotional end of it, our mental and our spiritual. That works just like old mother earth. Everything kicks in and we start to work.

I had to get my healer in there to do a ceremony for me while I wasn't dead. And he did a ceremony in there. The hospital let him do that, and I was glad he did. I had a fifty-fifty chance and that's it. And then when I got my cell transplant, he came in again, traditionally. And that's what I'm saying.

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We have to connect with the doctors, we have to connect with our own people

who are doing the traditional and the cultural ways of doing things as well.

~ Wayne Price, Cree Métis

QUESTIONS

you may want to ask yourself about traditional wellness and healing

- · Am I interested in traditional wellness and healing?
- Do I know how to access traditional wellness and healing?
- Do I understand how traditional wellness and healing may or may not interact with the treatment I am receiving at the cancer center? (Note: Its important to discuss with your healthcare provider how traditional wellness and healing may interfere with your treatment)
- If I am interested in traditional wellness and healing, am I comfortable discussing it with my health care provider?
- If I am interested in traditional wellness and healing, and I am not comfortable discussing it with my health care providers, do I know someone who can help me?

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TIPS

for talking to your health care provider about traditional wellness and healing

- Ask for extra time at your next appointment with your health care provider to be able to discuss traditional wellness and healing.
- Gather as much information as possible about the traditional wellness and healing practices you are interested in.
- Bring a close friend or an Elder/healer with you to support you in your discussion with your health care provider.
- Be prepared that the health care professional may not have knowledge about or believe in traditional wellness and healing practices and medicines.

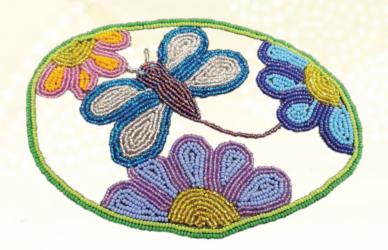
Write down or record your conversation with your health care

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I hear all the time that people don't know how to tell their doctors.

I have patients who tell me they won't tell their doctor. They say, 'They'll just tell me to quit.' Well you don't have to, you can still choose to do whatever you want, right? I say, 'That's your decision. I just want to make sure that you're safe.' There's no danger in talking about it.

~ Dana Marshall, Aboriginal Patient Navigator



nany ways of healing

If I am interested in traditional wellness and healing, and I am not comfortable discussing it with

my health care providers, do I know someone who can help me?
I believe that the earth is true medicine for everyone.

~ Reverend Lily Bell, Haida Nation



many ways of healing WHEN WE START to define what culture is, it can be a slippery slope.

My culture is who I am.
It's my soul, it's the way
I walk in the world.
It is my everyday life.

That's what makes me a cultural being even if it doesn't look the way it might look written in a text. Whether it's smudging, drumming, going to the water for a spirit bath, just being a good human being makes us stronger individuals.

~ Amanda Engen, Dene Tha, Chetah Alberta and Métis



Our health and wellbeing is strongly tied to our community and culture.

The Métis people are strong and resilient with our own cultural and spiritual practices that support our needs, beliefs and our health. We are a unique culture but have blended parts from our First Nations and European heritage into practices that work best for us. This continues into the present and must be reflected in the health care we receive.

~ Dr. Curtis Smecher (Métis), VP of Quality and Patient Safety, BC Anesthesiologists' Society

Your notes			

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CHOOSING TREATMENT PATHS

When deciding your treatment path, it's important that you feel comfortable with what is being recommended for you. Understanding why certain treatments are being recommended, what to expect from them, and what the outcomes might be will help you make an informed decision.

Your health care team may recommend surgery, chemotherapy, radiation therapy or any combination of these to treat your cancer. The next few pages will discuss the different types of treatments and questions you may wish to consider.

Remember, it is your right to ask as many questions about treatment as you need to feel comfortable making a decision.

They said, 'You really know your body.' I said, 'Yep, I was raised with my grandmother, and I listened to her.'

~ Dora Laurent, Nazko First Nation



Types of medical treatment and cancer drugs

The type of treatment that is required for each person's type of cancer is unique and will be determined by many factors. The three main types of cancer treatment are surgery, chemotherapy and radiation; however, there are other forms of cancer treatment that may be prescribed to you.

SURGERY

Surgery can be used for many reasons including diagnosing and treating cancer. For example, it can be used to remove a tumour (lump) or reduce the size of a tumour. Aftercare and recovery following surgery depends on a number of factors, including the type of surgery and the type of treatments you may be receiving. Surgery can be overwhelming but asking questions and learning about your surgery will help in understanding what's happening.

choosing treatment paths

CHEMOTHERAPY

Chemotherapy uses special medicines or drugs to treat cancer. These special medicines may be given as pills, through special injections or intravenously (IV) into the body. The drugs are carried by the blood to each cell of the body to reach cancer cells wherever they are. The frequency and length of your chemotherapy treatment will be unique for your cancer. Chemotherapy is often given every day, every week or every month at regular intervals. There are many types of cancer drugs and combinations of cancer drugs used to treat cancer. This can be confusing. It's important that you know that you can ask any questions you may have about your treatment plan.

RADIATION THERAPY

Your cancer may be treated using radiation, which uses high-energy rays to kill or shrink tumours (lumps). It does so by destroying or slowing down the production of cells. Radiation therapy can be used in treatment on its own or in combination with cancer drugs. Radiation can also be used to assist in shrinking a tumour before surgery.

I asked my doctor, 'What are my options?' He told me some people go for the operation or chemo.

At that time he wanted to know more.

He suggested I go for the biopsy in Prince
George which verified I had prostate cancer.

My family doctor confirmed I had prostate
cancer and then we talked about the
options again. Only this time it was for real.

He asked me what I wanted to do and I said
that I wanted to fight the cancer.



I left the doctors office feeling angry that it was confirmed. I spoke to my family of what I had to deal with. It was an emotional time for everyone.

My family encouraged me to fight it. My mom said, 'Don't you give up!'

So I went back to see my family doctor and told him I want to have the cancer removed. He began to make arrangements for the operation.

~ William Samson, Tsimshian, Lax Kw'alaams

TIPS

for working with your health care providers

- Bring your support person or advocate with you. They can take notes, ask questions on your behalf, and help you remember instructions.
- · Record information and instructions (you can use the "My Wellness Plan" at the back of this book for this).
- · Make sure you understand the medications and procedures being prescribed.
- · Inform your health care provider if you are using Indigenous traditional medicines and healing.

•	Draw on the supports you may need to help follow medication and treatments plans as prescribed.	on
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QUESTIONS

you may want to ask your health care provider about your treatment

- · What is the most recommended treatment at this stage?
- · Will I need surgery? Chemotherapy? Radiation?
- · Will I need multiple types of treatment?
- · Are there any other recommended treatments?
- · Who will be providing my treatment?
- How often will I need to receive this treatment? For how long?
- What are the short-term and the long-term side effects of this treatment?
- · Have other patients found this treatment painful?
- Where will I go for treatment? How far will I need to travel?
- · How will this treatment affect my day-to-day life?
- · Will I be able to work?
- Will I be able to continue my regular daily activities? (House work, driving, yard work, etc.)
- What can I eat on this treatment? Are there foods I need to avoid?

•	How will I know if this treatment is working?
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Your notes
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Chemo was the hardest thing for me. It took over my energy, everything.

My family supported me. My late husband and my nephew and my granddaughter, my grandson.

They fed me ice and they slept with me, just kept me company. And when my hair fell out from chemo they used to feel my head, they liked it. So that was a comfort.

~ Ellie Peters, Lhtako Dene Nation (Red Bluff Band)



I told the doctors, I know my body. They both went out and they got the nurse to take the needle off my spine because that's where they were giving me the painkillers. And then after that, I said, 'I'm not taking them anymore. I may be in pain but I can live with pain because I've had five kids. I know the pain.'



And then after when they
took out that needle,
I was able to get up off the
bed. And I told them,'See,
that's all you had to do.'

And they were really surprised. They said, 'You really know your body.' I said, 'Yep, I was raised with my grandmother, and I listened to her.'

~ Dora Laurent, Nazko First Nation

QUESTIONS

you may want to ask your health care provider about chemotherapy treatment

- · What type of cancer drug is this?
- · How many drugs are recommended?
- Do I need to take the entire quantity of all of these different drugs that have been prescribed?
- How will these drugs be given to me? Orally? Through injection?
- Where is the closest place I can go to receive this treatment?
- Will I be able to drive without assistance after treatment?
- · Will I need to receive treatment at the BC Cancer Agency site?
- How long and how often will I need to take these drugs?
- · Is there any pain associated with taking these drugs?
- · How can I manage my pain?
- Will this affect my mobility or ability to work? If so, for how long?
- How successfully has this treatment been for other people with my type of cancer?
- How will I know if the treatment is working?
- How will this affect my body? Will I lose my hair? Will I gain or lose weight? Will there be other side effects, such as memory loss or confusion?
- What can I eat during this treatment? Are there foods I should avoid?
- · What should I be aware of before, during and after treatment?

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QUESTIONS

you may want to ask your healthcare provider about radiation treatment

- Is this treatment being used in combination with another treatment?
- Are there other treatments that would give me the same effect?
- · How many sessions are you recommending?
- · How long will each session take?
- · What will the immediate side-effects be?
- · Will treatment be painful?
- · Can the treatment harm me or healthy parts of my body?
- What are the known short-term and long-term effects of radiation?
- How have other cancer patients with my cancer type reacted to this treatment?
- Will the affected area of my body need special care?
 Will treatment affect my skin?
- · Will I be able to work during treatment?
- Will radiation treatment affect my day-to-day activities? Are there activities I should avoid doing while undergoing this treatment?

Your notes	

TIPS

for balancing treatment & work

- If possible, explore flexible working options such as working from home some days. This can help reduce fatigue and allow you to take care of yourself more easily.
- · Keep your employer up-to-date on your schedule or other work-related changes.
- · Getting help at home can mean more energy for work. Explore the idea of sharing daily chores amongst friends and family members who have offered to help.
- · Where possible, adapt your work schedule to accommodate your treatment plan. This may look like extra days off, working part-time, working from home, or changing your office or desk location to be closer to the bathroom.

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POST TREATMENT

MY CANCER is in remission. It's been 5 years and nothing has come back.

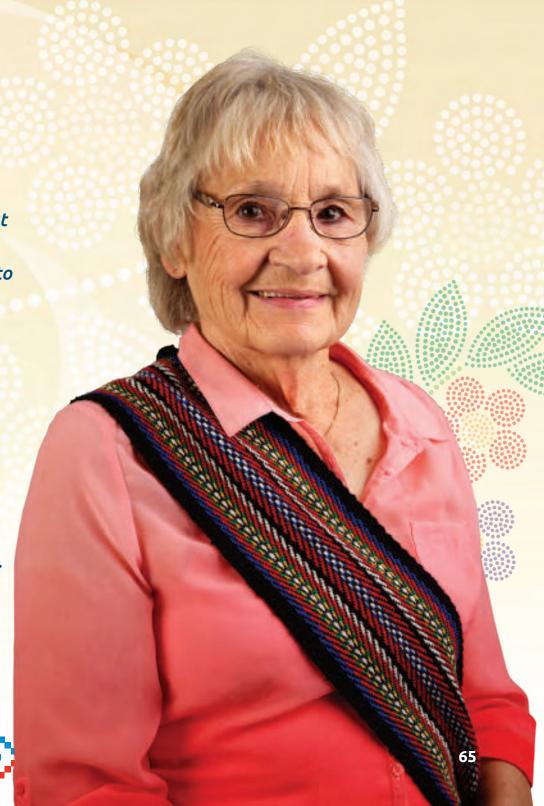
At first it felt like when they told me to leave, that I was fine. It left me in a turmoil because I was getting such good care and all of a sudden, I had to take care of myself. All my medical support group was gone and I had to take care of myself. It was something I had to work through which I did with the support of my family.

Cancer has definitely made me more aware of the preciousness of life.

It's changed my attitude toward people, made me humble because I know that I'm not in control. And who's in control is God. And that's one way I got through it. I completely gave my cancer to God because I wasn't in control.

~ Adeline Sarver, Métis

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The path to recovery

When active treatment is over, people are discharged from the BC Cancer Agency. Many people require recovery time and follow up care. This process may take time and also involve travel to and from treatment centres. This part of the journey can uncover mixed emotions. Taking care of your wellbeing is important during this time. Many cancer centres have counsellors available as a resource.

You may feel a little confused or lost on what to do next.

Loved ones, work colleagues and managers or community
members may expect you to return to pre-diagnosis
routines. However, this may not be possible right away.

RETURNING TO WORK

When returning to work, some people find talking to a counsellor can help with developing a return-to-work plan, finding healthy ways to cope, learning relaxation exercises, supporting time management or understanding feelings of depression or anxiety.

The best support is being present, just being there.

~ Janet Harry & Trevor Amos, Haisla Nation



I STILL HAVE the cancer, it won't go away.
I took the treatment. It was intravenous.
It was like a chemo but I never lost
my hair. It was only four treatments,
seven hours at a time. Four weeks, four
treatments, one treatment a week for
four consecutive weeks.

The doctor said it will never be cured, but it's at bay.

It's been four years now. Basically I'm in limbo.

~ Lou Romailler, Métis



QUESTIONS

you may want to ask your health care provider about post treatment

- Will information about my treatment be sent to my family doctor or nurse practitioner in my home community?
- Can I receive a copy of my treatment? For example, the list of surgeries, name of cancer drugs or hormone therapy, information surrounding radiation treatment, etc.
- Who can help me find a family doctor or nurse practitioner if I don't already have one?
- Who do I speak to if I have questions regarding my health or side effects?
- Will I need to undergo regular check-ups? How often and where?
- When can I expect to return to my normal routines and habits after treatment has ended?
- · How can I expect to physically feel after treatment has ended?
- · How might I feel mentally after treatment has ended?
- · What if I need help at home or help in returning to work?
- Should I wait to go back to work?

TIPS

for returning to work post treatment

- · If it feels helpful, explore drawing on a counsellor for support.
- Discuss with your health care team about a time-frame for returning to work.
- Keep your employer informed about your progress and your plan for going back to work. Make sure you and your employer have realistic expectations about what you can do when you return to back to work.

•	Ease back slowly. If possible, try some practice days with light
	duties, reduced hours and frequent breaks to make sure that
	you are both physically and emotionally ready to return to
	work

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QUESTIONS

you may have for your health care provider about follow-up care

- · Are there long-term effects from my treatment?
- · Are there signs and symptoms if my cancer comes back?
- · Can I lessen the chances that my cancer will come back?
- · Who should I ask if I have concerns about my health?
- · What sorts of follow-up tests will I need? And how often?
- · Are there side effects from follow-up testing?
- · How long will I need for follow-up testing?
- Can my regular doctor or nurse practitioner do follow-up tests?
- If I have to travel for follow-up tests, are supports available for travel and accommodations?
- Will my follow-up test results be shared with my family doctor or nurse practitioner?

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TIPS

for wellness post treatment

- Be gentle with yourself. Your physical body, mind and emotions may take time to catch up and feel whole.
- Continue to share your experiences and emotions with your advocates and support people.
- Remember that even when you have completed treatment, your emotional supports can still be part of the journey.

•	Consider whether you want to include traditional wellness as
	part of your wellness path post treatment.

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to recover

I GO SEE a doctor every 15 months and not too long ago, I had chemo, radiation and internal radiation treatments.

The meditation practices were so important. I had to learn how to do prayer and meditate while I was going through everything. Learning how to meditate got me through. I had to learn how to relax and stay in the moment because if I was taken out of the present, then I was into the future and then I was in a place of anxiety and worry, and that's not where I want to be.



To soothe my soul and spirit, I sought out places that were Aboriginal in nature

where I could find other Aboriginal people, and who I could pray with and drum with. Drumming for me was healing was so important and helped me feel grounded and happy, and I felt comfortable about being around other people who were Aboriginal.

~ Patricia Prince. Health Care Provider and cancer survivor

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The path of advanced cancer and palliative care

Sometimes, despite the best efforts of your medical team, cancer advances to the point that it is unlikely to be cured. This can be referred to as "advanced cancer" or "terminal cancer" and may lead to palliative care. Palliative care focuses on providing good quality of life to ensure you are as comfortable and pain free as possible. Palliative care may involve medicines, treatments, physical care, psychological/social services and spiritual support for you, your family and others who are helping to care for you

Receiving a diagnosis of advanced or terminal cancer can be difficult. You may experience a wide range of emotions upon finding out. You are not alone and your care team is there to support you. You may want to discuss the physical symptoms of advanced cancer with your health care provider. You may also want to ask your care team if there are any professional supports available to you while you process this news.

Many decisions accompany the news of advance cancer. You may want to discuss your end of life plans with your friends and family, such as how you want to be remembered through a celebration of life, funeral or a cultural event. There are also several legal documents, or advanced directives, that you and your family may wish to discuss.

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THE BEST SUPPORT is being present, just being there. Physically be there to hold each other when we need to be held. To let each other vent when we need to vent and not taking it personally. To be family support for one another whether it's happy, frustration, anger, whatever. It's said and then it's done.



With my mom it was a tough one. We've had so much cancer in our family. Support is hard to keep up. We try to be not so glum and the positivity was a tough thing to keep but we did our best.

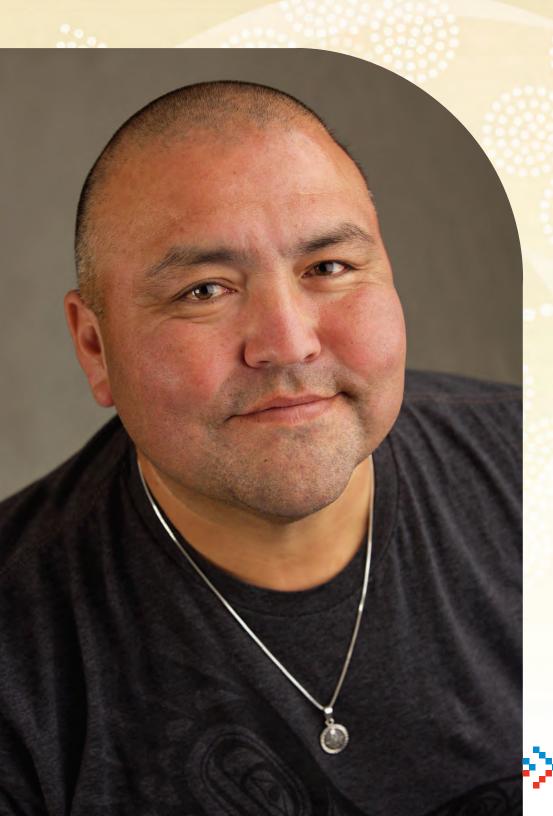
My mom, she was a very quiet, very introverted person. I talked to her almost daily. I'm getting emotional thinking about it.

I tried not to talk about the cancer as much as I could but in the end, we needed to acknowledge the feelings.

It was a tough thing to acknowledge her pain but we had to, to help her out. We had to cry with her.

I was taught not to show emotions, so to do that with my mom and my sister was hard for me.

*>>>>>>>* 



And that helped a lot. It helped us a lot. Before my mom was on her last few months there, she really opened up and she told me her story when she went to residential school. She never shared that with anybody else. She shared it with me before she died and that was so tough to hear. She was abused, she was badly abused in the school. For her to say that was a huge, huge step for her.

It was healing for her.
So I think she passed on knowing that she was okay.

~Trevor Amos, Haisla Nation

#### **DOCUMENTS**

#### and legal matters to consider

- · Advance Directives provide instruction about your wishes for medical care if you are unable to communicate or make decisions yourself.
- · Representation Agreements allow you to appoint a Temporary Substitute Decision-Maker to make certain decisions on your behalf related either to your personal care or health care treatment, or your financial affairs.
- · Wills are legal instruction about how you wish your estate to be handled when you pass.

| • | Enduring Power of Attorney is a person or persons that you   |
|---|--------------------------------------------------------------|
|   | give the legal authority to act on your behalf if you can no |
|   | longer do so.                                                |
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### **QUESTIONS**

# you may have for your health care provider about palliative care

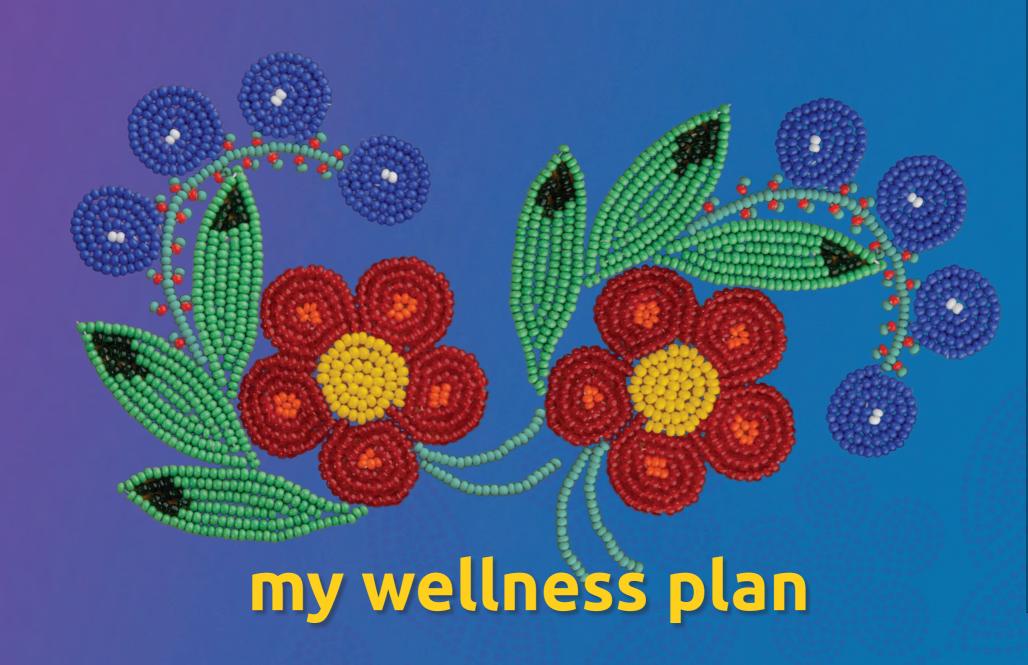
- For people who have the same cancer I have, how long do they usually live?
- Are there any treatments that will make me feel better or will help me live longer?
- · What is a hospice and is this a place I can go to?
- If I have to go to a hospice, what are the steps my family and I would need to take?
- Can I choose which hospice I go to and what kind of services I receive?
- · When can my loved ones visit me in palliative care?
- · Can I go home while in palliative care?
- Will there be physical side effects from the palliative care drugs?
- Will the medications affect my mental state at all?
- · What does the end of life look like?

· What are the best ways to manage pain?

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### **MY WELLNESS PLAN**

This section is here for you to record your own notes, as well as information from your medical team about the treatments that are being recommended.



| INFORMATION & CONTACT DETAILS     | Support people                                          |
|-----------------------------------|---------------------------------------------------------|
| Personal                          | TRADITIONAL WELLNESS SUPPORTS (names and phone numbers) |
| Name                              |                                                         |
| Address                           |                                                         |
|                                   |                                                         |
| Phone                             |                                                         |
| Health card number                | SOCIAL WORKER/PATIENT LIAISON                           |
| Family doctor                     | Name                                                    |
| Name                              | Phone                                                   |
| Phone                             | INTERPRETER                                             |
| Emergency Contact                 | Name                                                    |
| Name                              | Phone Phone                                             |
| Address                           | Cancer centre                                           |
|                                   | Name                                                    |
| Phone                             | Address                                                 |
| Relatives (names & phone numbers) |                                                         |
|                                   | Phone Phone                                             |
|                                   | DIAGNOSIS                                               |
|                                   | Date                                                    |
|                                   | My diagnosis is:                                        |
|                                   |                                                         |
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| My questions about my diagnosis are:           | Transportation supports and resources |
|------------------------------------------------|---------------------------------------|
|                                                |                                       |
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|                                                |                                       |
|                                                | Accommodation support and resources   |
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| GATHERING SUPPORT                              | Financial supports and resources      |
| My best support people (names & phone numbers) |                                       |
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# August

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# October

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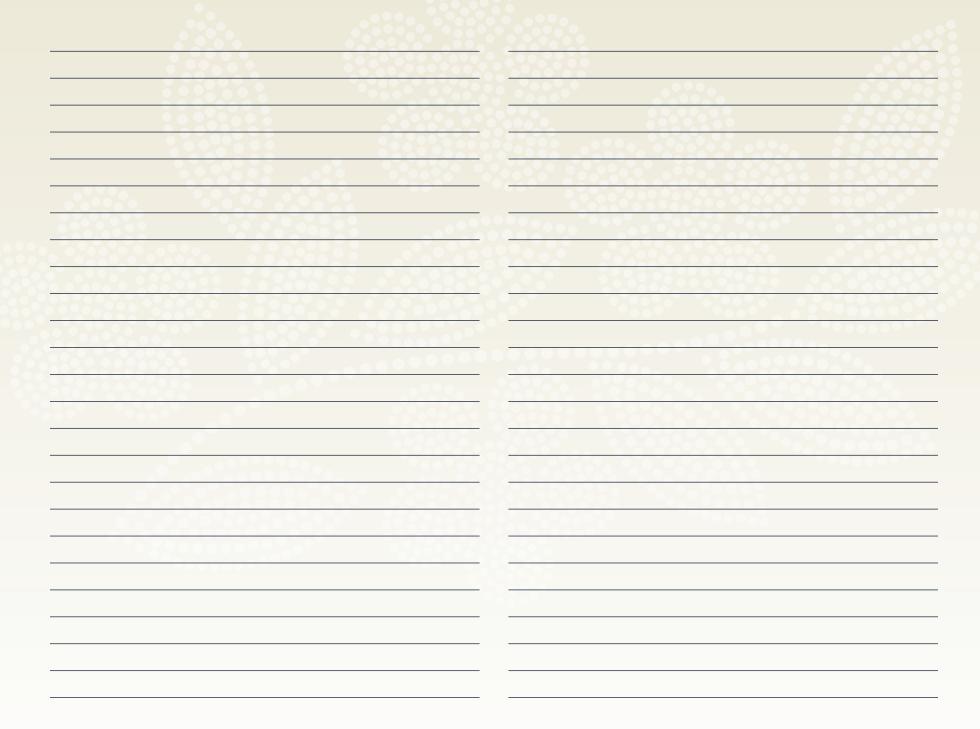
### November

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### **GLOSSARY**

#### **Active Surveillance (also called Watchful Waiting)**

Using tests and exams on a regular basis to watch for changes in a person's health.

#### Advocate

A person asked to publically provide support and speak on your behalf if you request it.

#### **Aggressive**

When cancer is fast growing or treatment is more intense than usual.

#### **Anesthetic**

A drug that causes the loss of feeling or numbing of pain in some or all of the body.

#### Benign

Not cancer.

#### **Biopsy**

Taking cells or tissues from the body to look at them under a microscope.

#### **Bone Scan**

A test that injects a very small amount of radioactive dye into the blood to create images of bone.

#### **Bowel Movement**

Poo or stool, often recorded on medical charts as "BM".

#### **Brain Cancer**

Cancer that starts or spreads to the brain.

#### **Brain Scan**

A test that injects a small amount of a radioactive substance into the blood to create an image of the brain.

#### **Brain Tumour**

A tumour in the brain that may be benign (not cancer) or malignant (cancer).

#### Cancer

The name for diseases in which abnormal cells grow out of control and can spread to other parts of the body.

#### Carcinogen

Anything that is capable of causing cancer.

#### Cell

The most basic, smallest unit of all living things.

#### Cervix

The lower, narrow end of the uterus that opens into the vagina.

#### Chemotherapy

Treatment that uses drugs to kill or destroy cancer cells.

#### Colon

The longest part of the large intestine, sometimes called the large bowel (where poo comes from).

#### Colonoscopy

A test that uses a hollow tube with a light and camera to look inside or treat the colon.

#### **Colostomy**

An operation to make an opening from the colon to the outside of the body through the belly. A special bag (colostomy bag) is attached to the outside of the body to collect poo from the colon.

#### **Complementary Treatment**

An approach to wellness and healing which incorporates non-western practices (eg. acupuncture, mindfulness, Indigenous traditional medicine, etc).

#### **Cone Biopsy**

Removing a tiny cone-shaped piece of tissue from the cervix to look at the cells under a microscope.

#### Consent

Giving permission.

#### **CT Scan (Computed Tomography)**

A test that uses a computer to put many x-rays together to create a 3-D picture of organs, tissues, bones and blood vessels in the body.

#### **Cultural Humility**

A process of self-reflection to understand personal and systemic biases, and to develop and maintain respectful processes and relationships based on mutual trust. Cultural humility involves humbly acknowledging oneself as a learner when it comes to understanding another's experience.

#### **Cultural Safety**

An outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the health care system. It results in an environment free of racism and discrimination, where people feel safe when receiving health care.

\*In July 2015, all Health Authority CEOs in BC signed a Declaration of Commitment to advancing cultural humility and cultural safety within their health service organizations. This health system commitment to the declaration gives all health professionals a mandate to advance cultural humility and safety in their practices with First Nations in BC.

#### **Diagnosis**

The process of finding out a person's health problem.

#### **Endoscope**

A hollow tube with a light and a camera to look at or treat organs or structures inside the body.

#### **Family History**

The medical history of a person's family including mother, father, brothers, sisters and grandparents. A family history may show a pattern of certain diseases in a family.

#### **Fatigue**

Feeling extremely tired or not having enough energy.

#### **FIT Test (Fecal Immunochemical Test)**

Testing a small poo sample for traces of blood.

#### H. pylori bacteria (Helicobacter Pylori)

A type of bacteria that causes inflammation and ulcers in the stomach and small intestine. H. pylori infection is associated with an increased risk of developing stomach cancer.

#### Histology

The study of cells or tissues types by viewing through a microscope. This method can be used to classify tumour types and best treat each individual cancer.

#### **Hormonal Therapy**

A common method of medical treatment for certain cancers and other conditions that involves the use of hormones for management of the illness.

#### Hormone

A chemical produced by the body that is released by a gland or cell in an area of the body that signals and affects cells in another region of the body. Responses to hormones depend on the signal sent and can involve, but are not limited to, mood, immune function, metabolism and reproduction.

#### Hospice

A place to care for people who are near the end of life. This type of specialized care is focused on providing patients with relief from symptoms, pain and stress. The goal is to improve quality of life for both patient and family.

#### **Immune System**

The warrior cells and organs that defend the body against infection, disease and other materials that enter the body.

#### **Inoperable**

A disease or tumour that cannot be treated with an operation.

#### **IV (Intravenous)**

Within or into a vein (eg. IV drip).

#### Leukemia

Cancer that starts in blood-forming tissue such as bone marrow. It causes large numbers of abnormal blood cells to form and enter the bloodstream.

#### Lumpectomy

An operation to remove a lump or tumour in the breast along with a very small amount of healthy tissue around it.

#### Malignant

Cancer or cancerous.

### Mammogram (also called Screening Mammography)

An x-ray picture of the soft tissue of the breast.

#### **Medical History**

A record of someone's risk factors, symptoms and past medical events and problems.

#### MRI (Magnetic Resonance Imaging) Scan

A test that uses a magnetic field to make very detailed pictures of the inside of the body.

#### **Mastectomy**

An operation to remove part or all of a breast or breasts. Different types of mastectomy include total mastectomy, modified radical mastectomy and radical mastectomy.

#### Melanoma

A type of skin cancer.

#### Metastasis

The spread of cancer from where it started to other parts of the body.

#### **Nerve Damage**

Damage to nerves or the nervous system resulting in a variety of symptoms.

#### **Nurse Practitioner**

A registered nurse with extra training and education.

#### **Oncologist**

A cancer doctor.

#### **Operable**

Can be treated with an operation.

#### **Operation (also called Surgery)**

Cutting into the body to look for disease, or to remove tumours, or to remove or repair an organ, or a part of the body. Operations are done in a hospital with anesthetic.

#### **Palliative Care**

This type of specialized care is focused on providing patients with treatment and support from symptoms, pain and stress of a serious illness that cannot be cured. The goal is to improve quality of life for both the patient and the family.

#### **Pap Smear or Pap Test**

A test that swabs cells from the cervix and looks at them under a microscope.

#### **Platelet**

A type of blood cell that helps blood to clot (slow or stop bleeding). Also called thrombocyte.

#### **Polyp**

A small growth on the lining of an organ or body part.

#### **Prognosis**

The expected outcome or course of a disease.

#### **Radiation Therapy**

A treatment that uses high-energy rays to kill cancer cells or shrink tumours.

#### Recurrence

Cancer that has come back after remission (a period of time when there were no signs or symptoms of disease).

#### **Recurrent Disease**

The return of a disease after remission.

#### Remission

A period of time when the signs and symptoms of cancer get better or go away.

#### **Rights**

Principles of freedom and entitlement.

#### **Risk Factor**

Something that increases the chance of developing a disease.

#### Safe and Informed

A phrase used to draw attention to the need to communicate to ensure that any medically prescribed treatments, medications or procedures will not have adverse reactions (side effects) when combined with other chosen treatments.

#### Screening

Checking for cancer when there are no symptoms. Early detection can better the chance of a cure. Examples of cancer screening tests include mammography, colonoscopy and Pap test.

#### **Side Effects**

Unwanted symptoms caused by a treatment or procedure such as fatigue, nausea, vomiting, pain, brain fog, hair loss and mouth sores.

#### Stage

Stages (on a 1-4 scale) are based on specific criteria for each type of cancer in relation to the size of the tumour, whether there are cancer cells in the lymph nodes and how far cancer has spread in the body.

#### **Steroid**

Examples of steroids include cholesterol, estradiol, testosterone and anti-inflammatory drugs.

#### **Support**

To give assistance in any way.

#### **Surgery**

Cutting into the body to look for disease, or to remove tumours, or to remove or repair an organ, or a part of the body. Surgery is done in a hospital with anesthetic.

#### **Symptom**

A physical or mental sign that may indicate a person has a disease or condition.

#### **Toxicity**

The extent or degree to which a substance can damage an organism (or portion of).

#### **Traditional Medicine**

Traditional medicine means different things to different people. Can include cultural practices from singing, drumming, ceremony or ingesting substances.

#### **Traditional Wellness**

Traditional wellness is a term coined by the First Nations Health Authority to encompass Indigenous traditional practices, approaches, medicines and knowledge, and to reflect a holistic model of health.

#### **Tumour**

An abnormal mass of tissue formed when cells grow and divide more than they should. Tumors may be benign (not cancer) or malignant (cancer).

#### **Tumour Marker**

A substance in the blood or body fluids that may suggest a person has a certain type of cancer.

#### **Ultrasound**

A test that uses high-frequency sound waves to make pictures of structures and organs inside the body.

#### Wellness

An approach to overall health which strives to balance mind, body, emotional and spiritual elements in a person's life.

#### X-ray

A type of high-energy radiation that produces a picture of the bones and other structures inside the body. In low doses, x-rays are used to diagnose cancer by making pictures of the inside of the body. In high doses, x-rays are used to treat cancer.



Métis Nation of BC www.mnbc.ca

First Nations Health Authority www.fnha.ca

BC Cancer Agency www.bccancer.bc.ca

BC Association of Aboriginal Friendship Centres www.bcaafc.com

Canadian Cancer Society www.cancer.ca







First Nations Health Authority Health through wellness



