

Tips, Advice, and Guidance for the Newly and Recently Diagnosed





TABLE OF CONTENTS

2

Stay Calm and Mentally Strong: Three Ways to Motivate, Inspire and Empower Yourself for Optimum Health

9

Getting a Second Opinion in our Public Health System

14

Tips and Checklist to Prepare for Your Medical Appointment

18

Coping With Scanxiety

22

Radiation Prep. Three Tips You Need to Help You Feel in Control and to Support Yourself

26

Three Things to Know Before Your Lumpectomy

35

Post-surgery Tips from Women Who've Been There

38

Eight Items That Helped Me Recover from Breast Cancer Surgery

46

What You Need to Know: Accessing Clinical Trials Out of Province and Out of Country

50

Sexual Health and Intimacy Tips for Breast Cancer Patients

55

Why It's Important to Be Your Own Advocate

59

Self-Advocacy Tips: For Patients, From Patients

If you've recently been diagnosed with breast cancer, you may be feeling overwhelmed, confused, and/or scared. You may still be having a hard time accepting being diagnosed and may not know where to begin to find out more about your diagnosis; or, maybe you're trying to prepare yourself emotionally for what's to come. While you have likely received some type of handout from your medical team, you may still be looking for additional information in order to wrap your head about this huge change in your life. Maybe you have searched Google for non-medical information but are having a hard time finding what you're looking for.

A cancer diagnosis comes with many questions and while some of those questions can be answered by your healthcare team, or educational resources, some questions may only be able to be answered by someone who has lived it, who has been there, who has had breast cancer. ***Tips, Advice, and Guidance for the Newly and Recently Diagnosed*** has been put together to do this. It provides those who have been newly and recently diagnosed with the answers to questions that may not be easily answerable. This magazine also helps patients be aware of, and prepare for, some of the challenges that they may face in the upcoming months. This magazine features a collection of blogposts from Our Voices blog that have been written by CBCN, breast cancer patients, or informed by breast cancer patients.

However, there are many other CBCN-developed resources that also walk new and recent patients through their diagnosis, including:

[*Metastatic Breast Cancer Handbook: A guide for individuals living with stage IV breast cancer*](#)

[*Breast Cancer and You: A guide for women living with breast cancer.*](#)

[*Never Too Young: Psychosocial Information and Support for Young Women with Breast Cancer*](#)

[*Breast cancer and bone health: What you need to know*](#)

[Breast Cancer Stages and Types Explained](#)

[FinancialNavigator](#)

[MedSearch](#)

[SurgeryGuide](#)

[CBCN's Advocacy Guides](#)

[Canadian Breast Cancer Patient Network](#)

Stay Calm and Mentally Strong: Three Ways to Motivate, Inspire and Empower Yourself for Optimum Health



By Adriana Ernter

Tell me if any of this rings a bell...

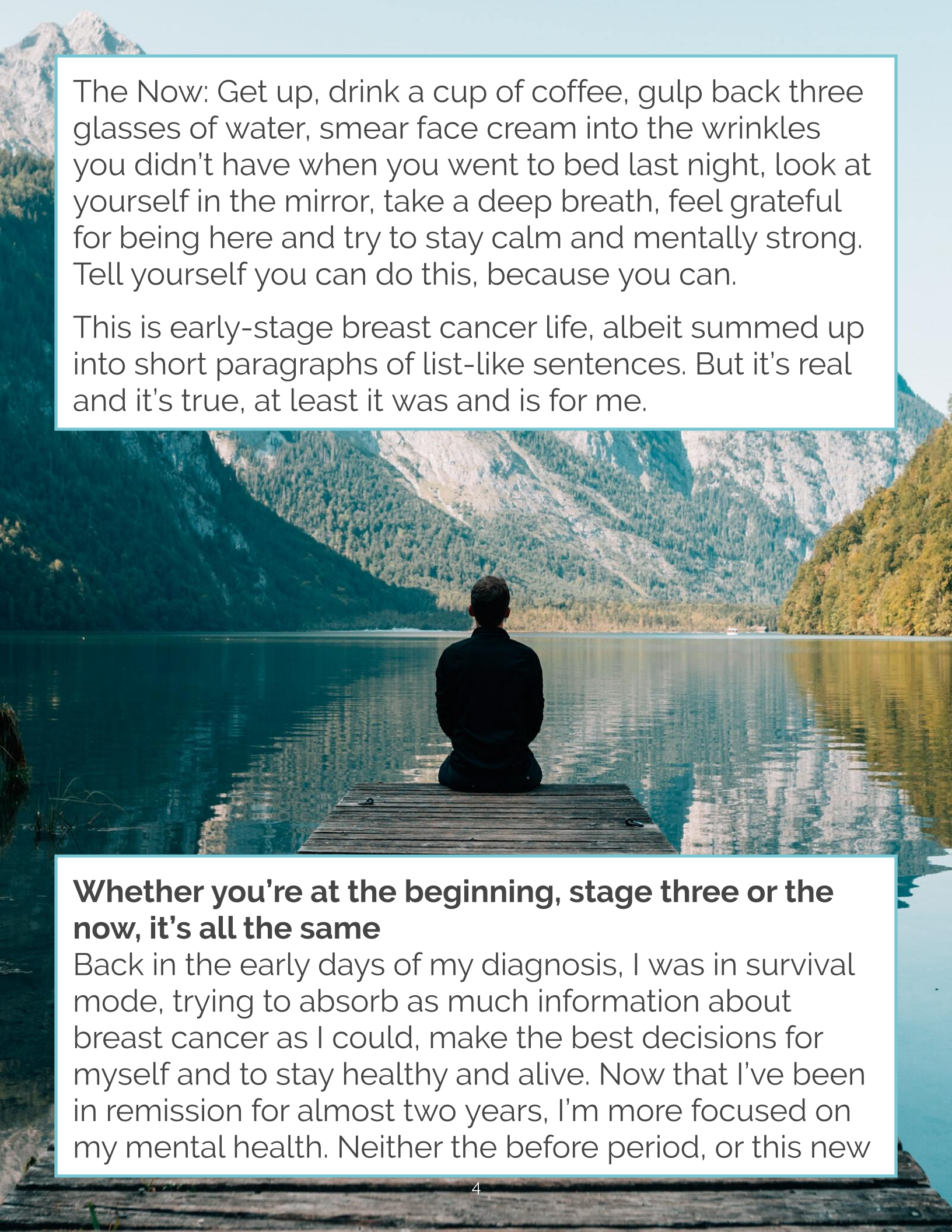
The Beginning: Get up, find a lump, feel confused, panic inside, see the doctor, see a specialist, get a mammogram, see an oncologist, have an ultrasound, get an MRI, biopsy the lump, do it all over again and again and again, receive a breast cancer diagnosis, feel in shock, go home, make a plan, fall into bed and don't fall asleep.

Stage One: Get up, shower with special soap, zip-up your hoodie, forego underwear, pull on sweatpants, hug your support person, head to the hospital, put on a surgical gown, say a prayer, have surgery, wake up from surgery, get driven home, take pain meds, slowly, carefully crawl into bed and sleep fitfully.

Stage Two: Get up, eat breakfast, lie on the couch, wait for your oncologist to share your tumour's Oncotype DX results, surf through Netflix, take a nap, wake up, eat soup, talk to your support person, have another nap, eat dinner, brush your teeth, take pain meds, watch *Law & Order SVU* and fall asleep after 15 minutes, let your support person help you to bed and have weird dreams.

Stage Three: Get up, pack your breakfast and a lunch, go to the office, eat a hard-boiled egg, grab your purse, go to the hospital, have radiation and/or chemotherapy, go back to work, try to eat lunch, try to stay alert, try not to throw up, come home, take two Tylenol, try to remember to take your work clothes off before falling into bed and sleeping like a rock.

Stage Four: Get up, feel dehydrated, drink three glasses of water, pop a Tamoxifen pill, head to work, have hourly hot flashes, drink more water, go to the bathroom every 45 minutes, eat salty Goldfish crackers instead of lunch, try not to fall asleep, go home, pop a second Tamoxifen pill, eat dinner, go to bed, wake up soaking wet in a pool of your own sweat, change the bed sheets and your pyjamas, go back to bed, fall asleep and repeat the night sweats/pyjama process three or four more times.

A person is sitting on a wooden dock, looking out at a large, calm lake. In the background, there are steep, forested mountains under a clear sky. The water reflects the surrounding landscape.

The Now: Get up, drink a cup of coffee, gulp back three glasses of water, smear face cream into the wrinkles you didn't have when you went to bed last night, look at yourself in the mirror, take a deep breath, feel grateful for being here and try to stay calm and mentally strong. Tell yourself you can do this, because you can.

This is early-stage breast cancer life, albeit summed up into short paragraphs of list-like sentences. But it's real and it's true, at least it was and is for me.

Whether you're at the beginning, stage three or the now, it's all the same

Back in the early days of my diagnosis, I was in survival mode, trying to absorb as much information about breast cancer as I could, make the best decisions for myself and to stay healthy and alive. Now that I've been in remission for almost two years, I'm more focused on my mental health. Neither the before period, or this new

While my focus continually shifts, my long-term goal to achieve and be in topnotch health remains the same.

phase in my life has been or is easy, but both are manageable. Well, at least they are when I am realistic about my priorities and simplify what I want to accomplish each day, like being proactive about maintaining my doctors appointments, especially during the pandemic.

While my focus continually shifts, my long-term goal to achieve and be in topnotch health remains the same. Which means that I have to maintain and grow my faith in myself and in my body every single day in order to succeed.

This is not an always-easy feat for me, so I rely on regular hits of motivation and inspiration to keep me going.

No, I don't dress in yoga pants and squirrel away to a special meditation room where I sit silently, cross-legged and Zen out for half an hour. That's not my style, plus I live in a 700-square foot condo with one door (the bathroom's) and two very curious kittens who are either

playing, sleeping or purring on top of me. (I love it.) Still, I'm routine about my self-care, psychotherapy practices, healthy food and long walks. I also make a point to tap into easy-to-access resources including Instagram, books and music and so can you. Let me share how they benefit me.

Instagram

Specifically, handles: [@theedora](#) and [@merlinragdoll](#). Yup, these Instagram accounts feature cows and a cat and no, I haven't completely lost my mind. Neither have their collective 419,000 followers. I love animals and their antics and expressions. Plus, the funny captions that the humans write for these two hook me every time. There's just something fun and light, refreshing and full of life captured within each of their tiny image-filled squares. Taking five minutes to scroll through and look at them on my screen each day makes me smile and somehow, feel like life is simple again.

Tip: You don't actually need to post your own pictures on Instagram to enjoy this social media platform. Simply set up your handle (mine is [@adrianaermter](#)), hit the magnifying glass icon at the bottom of the screen and scroll through the images until you find the ones you'd like to follow. Along with cows and cats, travel, interior design and architecture-based pages equally inspire me.

Books

From the moment I was first diagnosed and right up until about a year after I started taking Tamoxifen, I couldn't concentrate for any significant amount of time. And I

really struggled with reading; my memory was too slippery to hold onto the words typed on each page. Pain, sleep, work, treatment and doctors appointments had already forced me to give up so much though, that I refused to let go of books. So I didn't. That said, because I couldn't consume a book a week anymore, I became super picky-pants about what I wanted to read, choosing only stories about real-life women who, against all odds, overcame enormous challenges like, religious freedom, genocidal war and terminal cancer. Books such as, Jenna Miscavige Hill's *Beyond Belief: My Secret Life Inside Scientology and My Harrowing Escape*, Judy Batalion's *The Light of Days: The Untold Story of Women Resistance Fighters in Hitler's Ghettos* and Suleika Jaouad's *Between Two Kingdoms: A Memoir of Life Interrupted* were hugely motivating. Their stories fuelled me with fire, spurred me to fight and opened my eyes to the light at the end of my dark tunnel.

Tip: Most public libraries have free apps, like Libby and OverDrive, where you can borrow their e-books and audiobooks. If you're having a hard time concentrating or even reading, go for the audiobooks. All you have to do is press play, close your eyes, listen and feel your spirit rise.

Music

I came late to the music Playlist-game, but once I discovered how much fun it was to curate some of my favourite songs and albums into specific lists I was all in. And boy, did my Chill, Instrumental and Latin Playlists

get a ton of airtime while commuting back and forth to work and to the hospital every day, as well as when I was laying on the couch too tired to do anything but be still and let my mind drift. I still depend on these beats to get me through a multitude of emotions. When I can't sleep at night, because my body aches or I'm dripping in sweat yet freezing cold, The Cinematic Orchestra & The London Metropolitan Orchestra's album *The Crimson Wing* soothes and relaxes my mind and my body. Often, during moments when I feel vulnerable and need a soft nudge, I'll play a song from Ben Howard's *Every Kingdom*. Hitting shuffle on my Latin Playlist pulls up artists such as, Elvis Crespo, Grupo Extra and Daddy Yankee, who never fail to put a swing in my step (even if it's imaginary) and to make me feel alive and invincible.

Tip: If you're old school like me and still subscribe to Bell, Telus or Rogers, you probably have music channels on your television that you can listen to including, Classical, Pop and Latin options. Alternately, Google Play Music, Spotify, YouTube Red and Amazon's downloadable apps can do the thinking for you with their free and paid-for curated playlists.

Whichever, whatever you choose, know that these simple acts of the ordinary can make an extraordinary impact on your heart, mind and sense of self-worth.



Getting a Second Opinion in our Public Health System

When we hear stories about people's experiences receiving a diagnosis like breast cancer, we often hear the empowering message to trust your gut and get a second opinion if the answers aren't sitting well with you. These messages, while meant to be inspiring, can often feel impractical. In other countries, like the US, getting second opinions may be fairly straightforward, but in Canada, second opinions may be a bit trickier to come by.

Our public health system offers a lot of financial assurance. We don't have to worry about paying for costly medical bills when we see our doctors or take a trip to the emergency room. And we don't have to worry about paying for *most** of the standard breast cancer treatments. But when we are uncertain about a diagnosis or a treatment plan, getting a second opinion may feel daunting and uncomfortable. Here's how to do it.

Who to ask when requesting a second opinion

Getting an appointment with a specialist requires a referral from another physician. The first step is to talk to your family doctor and ask for a referral. This conversation may be an easy or difficult one to have. If the second opinion you are seeking is about the decision or diagnosis made by your family doctor, it may be uncomfortable to go to them for such a request. But remember that if you truly believe you need another physician's input, it's an important discussion to have. Have a conversation with them. Be open and honest about your concerns and why you feel a second opinion is important. You can use tips from our [Digital Advocacy and Storytelling Toolkit](#) to help you frame your message when communicating your needs to your doctor.

According to the Canadian Medical Association's *Code of Ethics and Professionalism*, physicians are to "respect the patient's reasonable request for a second opinion from a

Physicians are to "respect the patient's reasonable request for a second opinion from a recognized medical expert."

recognized medical expert.”^[ii] This means that you have the right to a second opinion. Even seeking reassurance about a diagnosis can be considered a reasonable cause for requesting a second opinion. The Canadian Medical Protective Association believes that just because a patient is seeking a second opinion it “should not be interpreted as a breakdown in the doctor-patient relationship.”^[iii]

Another option is to ask the specialist you have already seen for a referral to a second doctor. Another uncomfortable conversation may be had, but many specialists would hopefully understand your concerns about seeking additional input.

If you don't have a family physician or cannot get a referral from one, you can seek advice from a doctor at a walk-in or urgent care clinic. While they will not have a complete history of your health, you may be able to explain your circumstances and reasoning for a specialist referral. Make sure to bring along any documents or results you may have so that the doctor has as much information available to make an informed decision about referring you.^[iii]

Finally, you may be able to reach out to your private insurance company to see if they have the capacity in your plan to refer you to another specialist for a second opinion.^[iv]

If you're successful in getting a second opinion, you may want to come prepared with the name of a physician

that you would like to be referred to. Reach out to friends, peers or other patients that you may connect with through [support groups](#) to see if they know of a particular specialist they recommend. The recommended physician may not be available to see you, but it is helpful to try.

Going to your second opinion appointment

Once you have your referral, it may take time to get an appointment to see the specialist. You may receive the same diagnosis or treatment options, or you may be given a different set of options. If you're able, try to record the session on your phone. This may help if there is a discrepancy between the recommendations made.

If the recommendations are the same, it might give you some reassurance that you are on the right path. But having conflicting options may leave you more confused. It's always important to ensure that results or recommendations from the second opinion are shared with your primary care team (whether that is your family doctor or the main specialist). Speak with your family doctor or with the original specialist about these options to help you decide what path to take.

Gaining a second opinion will require [self-advocacy](#) on your part. Use your voice and advocate for what you feel is necessary and important.



**Not all breast cancer drugs are publicly funded by provincial governments. Access to certain breast cancer drugs in Canada can be largely dependent on where a person lives. This forces many patients to jump through hoops to find supplemental funding for their treatments or find alternative ways to cover these costs like paying out of pocket. Read our post on ways to access funding for your treatments [here](#).*

[i] [Code of Ethics and Professionalism](#) from Canadian Medical Association. (Page 5)

[ii] [When a patient seeks a second opinion](#) from Canadian Medical Protective Association

[iii] [What to do if your doctor won't send you for a second opinion](#) from Sunnybrook Health Sciences

[iv] [Getting a second opinion](#) from Canadian Cancer Society



Tips and Checklist to Prepare for Your Medical Appointment

Preparing for a specialized medical appointment can be a daunting task for some. You may encounter many questions that you would like to address, ask about your possible diagnosis, understand your treatment plan, ask about other options, and so forth. Many patients who have felt content or fulfilled after their appointments are those who were well prepared beforehand. Even though many medical practices will vary in terms of office administration, most will generally have a similar setup.

Before the appointment

- ❑ Plan for your appointment in advance: start thinking about and writing down thoughts and concerns you may have.
- ❑ Highlight your concerns from most important to least important, the majority of the most important questions will likely be answered by the health team.
- ❑ Set up your questions as a checklist so it is easy to cross off as the questions are addressed.
- ❑ Make a list of all the medications you take. This includes prescriptions, non-prescriptions, vitamins, minerals, topical ointments/treatments, pain relievers, herbal remedies, and natural products. If you are taking any dietary supplements, or protein shakes, these are important to list as well.
 - ❑ It is also important to list the dosage of the medications you take. If you are not sure of the dosage, bring your medications with you to the appointment. Most pharmacies can also provide you with a printout of all the active medications on file at that location.
- ❑ Make a list of your medical history including other medical conditions, allergies, medication allergies, and relevant family history.
- ❑ Collect and bring all medical reports, copies of scans, film CDs, and mammogram reports with you.
- ❑ Create a health binder, use this to collect and organize your notes, medical reports, and resources you are given. Keeping your important documents in one place reassures you will have everything you need for your appointments.

- ❑ Bring contact details of your referring doctor (name, address, telephone number, fax number, or email). Pharmacy contact information is also helpful to bring with you.
- ❑ Are you covered under an insurance plan for medications? Let the health team know, it will be taken into consideration when prescribing and suggesting alternatives. This will also allow the team to give you [samples and pharmaceutical rebates](#) if they are available, don't be shy to ask for samples.
- ❑ Confirm with the clinic if you can bring a support person with you to the appointment. Having two people at the appointment will help in taking notes and remembering points from the discussion. If you are not be able to bring someone in with you, ask if you can call a support person and put them on speakerphone or have them on a videoconferencing for your appointment. This will also be beneficial if you do not have a support person that can physically attend the appointment for any other reason.
- ❑ If English is not your first language and there is no one to bring with you to the appointment, ask about interpreter services. Plan for this service in advance, as it may take time to book for an interpreter.
- ❑ If you can, arrive early for the appointment; waiting 15-20 minutes will help ease the tension. This time will also allow you to fill out any required questionnaires in the office.

During the appointment

- ❑ Ask if the health team feels comfortable with you voice recording the discussion during the appointment.
- ❑ Bring a note pad and pen or use your smartphone device to take notes.
- ❑ Don't feel afraid or shy to ask questions, most doctors appreciate it when you ask questions.
- ❑ Ask the health team if they have any publications, handouts, or if they can recommend online resources.
- ❑ Some medical appointments require you to see another health care professional, such as a registered nurse, before being seen by the doctor, take this opportunity to ask questions. The nurse will also provide you with guidance on how your appointment with the doctor will go.
- ❑ During the appointment, clarify with the doctor:
 - ❑ What are the next steps?
 - ❑ When is the next appointment?
 - ❑ Are there any prescriptions or laboratory blood test orders?
- ❑ Be honest and share relevant details about your medical history and concerns without feeling embarrassed or fear of being judged. The details you share will help the doctors help you.

Other resources

[Preparing for a Medical Appointment](#) from Ottawa Regional Cancer Foundation

[Working with your healthcare team](#) from Canadian Cancer Society



Coping With Scanxiety

Scanxiety may not officially be a real word, but the feelings it brings about are real. [Very Well Health](#) defines scanxiety as the term used to “describe the anxiety people with cancer feel while waiting for scans”. Regardless of whether the scans are for diagnostic purposes, monitoring treatment, checking recurrence or as a check-up, individuals can experience apprehension before, during, and while waiting for the results of their scans. The apprehension and fear that is felt can range from feeling claustrophobic in the scan machine to imagining the worst-case scenario of the scan results. Many people experience scanxiety so it is important to learn coping techniques that help eliminate the anxiety.

Scanxiety may not officially be a real word, but the feelings it brings about are real.

Acknowledge your feelings

The first step to reducing your fears is admitting that they are there to yourself, and to your healthcare team if needed. It's important to admit that you are in fact feeling anxious and to know that you're not alone in what you are feeling. If the fears are overwhelming, letting your healthcare team know about it is helpful. They can help make the experience as smooth as possible.

Do research and make plans

If you're feeling anxious before your scans, finding out what will happen during your scans can be helpful. Visit highly reputable websites, read brochures, or ask questions about your upcoming scan. You'll want to know what the machine looks like, how the scans are done, how long it is expected to take, and whatever else you can gather. By being aware of what will happen, you leave little room for being anxious about the unknown. It



also means that you can make plans for the day of your scans. Some places give you headphones to wear. By knowing this, you can make a playlist of your favorite songs to calm your nerves during the process. You might also be able to bring someone with you. Knowing this beforehand will be helpful so that you can speak to who you want to have with you about your fears beforehand. While doing research is helpful, do not go overboard with it as this may lead you right back to where you started.



Join a support group

While admitting your fears to yourself and healthcare team is recommended, it also helps if you can speak to others who have been in the same situation. You can join in-person or online support groups so that you can speak to others who have gone through scanxiety or currently going through it. People who have gone

through or are going through the same thing can help validate the fact that you are not alone and share coping strategies that worked for them. They will also be able to provide a balance between acknowledging the reality of your fears and providing positive support and reassurance.

[Canadian Breast Cancer Patient Network](#) is CBCN's Facebook group where patients provide and seek support from each other and is a great place to get started.

Distract yourself

If the anxiety you feel is before the scan or while waiting for the scan results, find a positive avenue to distract yourself. Watch TV, read a book, surround yourself with family and friends, or pick up a new hobby. Simply keeping yourself busy and distracted means that you'll spend less time worrying about things that are out of your control. Meditating, practicing mindfulness, doing yoga or light exercise are great ways to distract yourself while also promoting good mental health. While our [Complementary Therapies](#) magazine is geared towards individuals in active treatment or those dealing with the side effects of treatment, it provides helpful coping techniques.



Radiation Prep. Three Tips You Need to Help You Feel in Control and to Support Yourself

By Adriana Ermter

Having radiation treatment is something you can never truly be emotionally ready for. At least I wasn't. The doctors shared the basic need-to-know information, but the rest felt vague, unknown and definitely out of my control. Of course I Googled radiation treatment and what to expect, but again, something was missing. Where was the insider insight I desperately wanted? Rationally, I knew there would never be a guide tailored to my breast cancer experience; everyone experiences

it differently as treatment is unique to your cancer and your body. But after the surgery, after I was told I had Stage 1 cancer, after my lump was sent to California for Oncotype DX testing to determine whether or not it would spread, have the likelihood of a recurrence and what my best treatment plan should be, it was my turn. And I always wished there was a checklist I could refer to or a step-by-step action plan I could walk to make my journey into the unknown a little better. There wasn't, so I'm sharing what I've learned along the way so that if you need this insight or know someone else who may, it is here for you.

1. Freak out if you want to

Becoming an individual who survives a breast cancer diagnosis, maybe a surgery and is about to undergo treatment whether it's radiation, chemotherapy or both, deserves to have a freak out moment...or eight or 20, I mean really, who's counting? And how you choose to express yours is entirely up to you. For me, it was going to a dive bar for vodka martinis at 11:00am on a workday with my best friend. We made a beeline for the bar almost immediately after the appointment where I received my Oncotype DX results from the oncologist. I downed three cocktails before walking home. I wasn't drunk, I didn't scream or cry. I could have had a big old tantrum if I'd wanted to and that would have been perfectly fine too. The important thing isn't what I did for my freak out moment, it's that I took it. I owned it and when I did, weirdly, I felt more in control.

2. I made a plan

I like lists and I like adding a little autopilot to my daily routine because it keeps me on track, purposeful and all of the stuff I need to get done, like laundry on Saturday mornings, gets done. So after I requested that my radiation timeslot be first thing in the mornings, I created a plan to ensure everything that I needed or knew I had to get done during the rest of the week happened. I boiled five eggs on Sunday nights so that I always had something ready to grab and eat before heading to the hospital. The hospital's address was plugged into my Uber account on my phone so that on the days when I didn't have the energy to walk to and from the subway station, I could easily order a ride. I picked five work outfits, hung them at the front of my closet and then alternated wearing them each week, because I worked throughout treatment. I kept bottles of Tylenol and Advil on my kitchen counter and in my purse to help relieve the blinding headaches I inevitably got every single day. I stocked my cupboard with bags of Goldfish crackers, the only food that helped with my nausea. And I kept a cozy pair of sweatpants and a sweatshirt folded on the end of my bed to change into the minute I came home. They're little things, but they made my life easier.

As soon as I was diagnosed with breast cancer, I was also flooded with dark thoughts.

3. Identify your “vulnerable” person

I'm a fairly optimistic person and I thrive on finding silver linings and that sort of thing. But as soon as I was diagnosed with breast cancer, I was also flooded with dark thoughts. These thoughts and feelings are normal. I don't know how you can have a cancer diagnosis and not have at least one of them. And they need an outlet. If I'd had the energy, I would have written them in a journal, but I didn't. So I picked a friend who I knew could handle hearing them and that I felt completely comfortable sharing them with. And I did. Sometimes, he'd take me for a drive and we'd just listen to music or he'd hold my hand while we'd say nothing for hours. Other times I'd rant angrily. We'd have and still continue to have serious talks too, like how I want him to be the one with me should I ever have a recurrence and die. It's not morbid and we certainly don't dwell on the negative, but having someone in your life to share this part of your head and heart-space with is life saving.

Three Things to Know Before Your Lumpectomy



When I was diagnosed with breast cancer, I was tossed into a sea of medical terminology without a life jacket.

By Adriana Ernter

I'm a talker. I like to communicate and sometimes, okay often, I'm an over-sharer. I need to know what's going on and why and in my version of yin and yang, I believe that because I'm an open book everyone else will be too. Except, not so much.

When I was diagnosed with breast cancer, I was tossed into a sea of medical terminology without a life jacket.

Fortunately, I'm a pretty good swimmer. I also ask a lot of questions to get the information I need, plus I know how to research and fact-check credible sources online such as the [Canadian Cancer Society](#) and the [World Health Organization](#) (no, Wikipedia, social media and YouTube are not credible

sources), so I buoyed through these unchartered waters by learning as much about breast cancer as I could. When I couldn't find what I was seeking, I politely stalked the holders of said information, which was almost always a member of the medical staff at the clinic, until they coughed it up. As a writer and editor, this process usually works in my favour. Except this time, again, not so much.

Your own research is necessary

Here's the thing, well, at least the thing from my perspective. The average woman's breast cancer diagnosis (and mine was no exception), has become such a relatively straightforward procedure with a frequency among women that is far too regular and consistent that doctors and/or oncology teams are unable to provide the hand-holding that the breast cancer patients, myself included, deserve. It's kind of like the KitKat of cancers, it's everywhere, easily and randomly acquired and because of its universality, somewhat on the boring side. Based on the [Canadian Cancer Society](#)'s 2020 predictive statistics that put breast cancer in first place, owning 25 percent of all new cancer cases in Canadian women, I get it.

My cancer diagnosis and surgery was a dime a dozen. And if you've ever sat in the waiting room of any breast

My cancer diagnosis and surgery was a dime a dozen.

cancer clinic or hospital you'll agree. Every seat is filled. Often, there's a line of women standing in their hospital gowns in the hallway and around the perimeter of the room just waiting to sit down. We are many, too many and the medical staff available to support us is spread too thin. The Canadian Cancer Society says 27, 400 women will be/have been diagnosed this year, alone. That's 2,300 new cases a month, which means that 575 women are checking into clinics and hospitals across the country to be tested and diagnosed every week. And that's only the new cases of breast cancer.

When I was a new case, I remember wondering where the nurse or doctor, you know, the one who is good at talking, explaining, listening and answering questions to help navigate my cancer journey was? It wasn't the surgeon's sweeping generalizations after delivering the news, "you have breast cancer" or the nurse who highlighted every single word in a paper pamphlet in yellow ink before pressing it into my hands 20 minutes after I'd been told my diagnosis. And trust me when I say it absolutely wasn't the teaching doctor, one of four who biopsied the four lesions in my breasts over a series of two weeks, who glared in my direction and scribbled in my medical file before exiting the examination room I was lying in half-naked without a backwards glance or an answer to my questions. In short, there is no person to walk you through the process from start to finish, although I wish there was. Gathering the information you need is up to you.



Reading renowned, credible, health-based websites, like [Health Canada](#) and the [Mayo Clinic](#) were very empowering to me, because they offer extensive breast cancer information along with easy to understand and helpful Q&A and treatment decision sections. Educating myself about the disease, the different procedures available, in my case a lumpectomy (otherwise known as a partial mastectomy) and so much more made me feel in control in a very out-of-control situation. This type of due diligence is not to be confused with clicking onto WebMD and trying to self-diagnosis, which is terribly difficult to do accurately, but rather reading and learning to gain truthful and fact-based insight into the facts, choices and options available, to provide a sense of calm. If I hadn't had this and had simply relied on the reading materials and vague generalizations shared by the clinic's staff, I would have felt ill prepared to join in the conversation about my body. And that lack of knowledge paired with blind trust, in my opinion, is too much for anyone.

What isn't too much and is actually right on point, is the feeling of wanting to throat punch everyone who tells you to breathe.

Breathing isn't everything

What isn't too much and is actually right on point, is the feeling of wanting to throat punch everyone who tells you to breathe. I'm not sure when the stay-calm-and-carry-on catchphrase became so popular, but telling a new cancer patient to breathe, as though this will magically make everything easier feels condescending. I loathed it. Yes, deep breathing is calming and grounding, but I was never hysterical, out of control or unreasonable. I never yelled at anyone, spoke harshly or broke down sobbing, although it may have been cathartic if I had. I was smart, prepared, level-headed, proactive and curious throughout. It doesn't mean I wasn't overwhelmed though. Not by the medical jargon, that's just words and there are dictionaries and once you look up what you don't understand the language part is super easy. I was overwhelmed by the emotional weight of it all.

Ironically, for someone who likes to

be an open book, since my divorce I've become choosy about who I show the depth of my vulnerability to. Being single and divorced, I don't have a built-in security blanket any more. And the friend I typically turn to with my deepest emotions was dating, distracted and unavailable, which was understandable, but still hurt. Yet, it also forced me to accept the help of my inner circle and let them into my journey. This sounds simple enough, but for me it wasn't. I knew I had built a few walls after my divorce, I just hadn't realized how high they were. Letting my three closest friends in and sharing my fears and unanswered questions with them was a huge release for me as they gave me a sounding board and fresh perspective. I still went to almost every doctor's appointment alone. Pre-lumpectomy surgery, my appointments were practically daily and I didn't feel it was fair to ask someone to constantly take time off work to accompany me, plus none of my friends could have accompanied me into the examination rooms where I would have wanted and needed them most.

So I used them to talk through my medical updates instead. Having someone, besides me, to review the questions I wanted answers to and to share their point of view with me was invaluable. It's amazing how your circle steps up when you ask them to. My sister Alida made the decision to be with me for my surgery and aftercare by telling me she'd booked a flight from Calgary. I would have never asked her to do this and somehow she knew that, didn't wait for an invitation and

just took the lead. If I'd known then how helpful and necessary this level of support would be, I would have asked. But I didn't know, so I didn't ask. I'm forever grateful to Alida for leaving her family for a week to take charge of my situation. I needed someone and not a pop-by, but rather someone to stay in my home, cook my meals, give me my medication at the right time, feed my cat Trixie, boss me around, tell me when to nap, when to eat and when to go back to bed. I live alone, so I assumed I'd be okay healing from surgery alone, but now I know that going solo is too isolating and that this way is so much better.

You can never have too many naked-boobs selfies

Having a soft bra to sleep in also makes breast cancer lumpectomy surgery better. This fact is highlighted in yellow in one of the many pamphlets I acquired in the early days. But it's noted as a bullet-point suggestion tucked in between other vague recommendations, so I never paid it any attention until a friend in my larger friend circle, who had undergone breast cancer a few years earlier, talked to me about it.

Shopping for an underwire-free, cotton bra was not a positive experience though. I don't know why this was so emotionally charged for me. Maybe it was because I'd crammed the shopping trip into my lunch hour and was trying to get it done and off my to-do list quickly so that I could move on to the next thing, I'm not sure. The depressing bra options didn't help either nor did the other women shopping in the store. Like the waiting

room at the clinic, these women were at least 10 years older than me, making me feel like my body had betrayed me. Perusing the shitty bra section compounded these negative thoughts, complete with the feeling that I'd be single for the rest of my life. I mean, come on, who wants to date a divorced woman in her forties with a mangled right boob? I'm not saying this was rational thinking, but it's what I thought.

Pre-breast cancer diagnosis, I only had positive thoughts about my boobs. They were perky B-cups, sat upright, looked good in everything and yet, didn't cause so much commotion that I felt compelled to take extra measures to cover them up in public. So when I was in the change room trying on the sad-looking bras, I took advantage of the full-length mirror and despite having bandages on both breasts courtesy of the biopsies I'd had the day before, took photos of them naked. I wanted to remember them as they were, how they looked and

I mean, come on, who wants to date a divorced woman in her forties with a mangled right boob?

to capture the pride I'd once had in my boobs, my body. It's funny how knowing that part of my breast was going to be removed challenged my sense of femininity. Rationally, I know this is crazy self-talk and I still struggle with the way my body, my right breast, looks now. Having my naked-boobs selfies though, infuses me with strength, so when I start spiraling into a place of negative self-imagining I pull up these pictures, look at them and smile. They are a reminder of who I was and of who I have become.





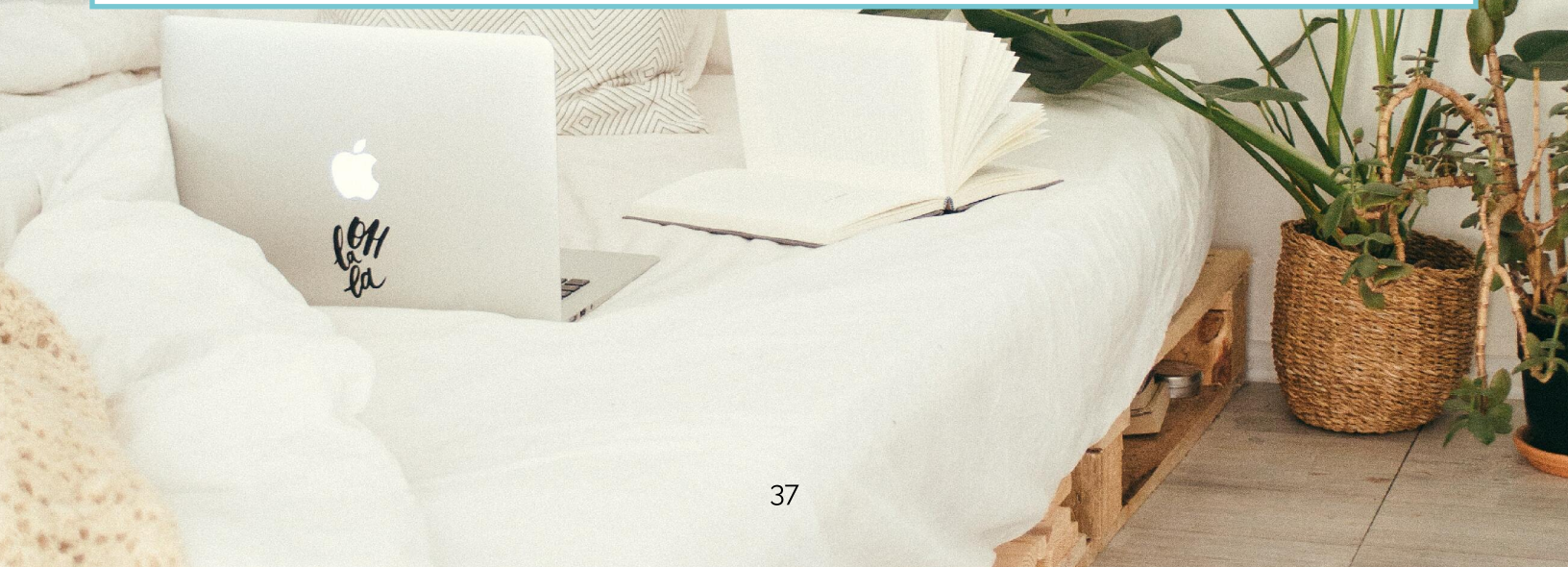
Post-surgery Tips from Women Who've Been There

Simply put, surgery is awful. Your body is recovering from some major trauma. And if you were feeling rather healthy before surgery, afterwards can feel a bit like a train wreck. We asked women for their tips on making recovery a little more bearable.

- After surgery, you will have drains on one or either side of your arms. These drains remove any fluid that could build up around your surgical area and help reduce infection. But they can be painful and uncomfortable when you try to walk or sit up. Post mastectomy camisoles with pockets to hold your drains are available but they can be expensive. Instead you can take a large pin and pin your drains to a loose-fitting camisole. This way you can have a bit more mobility without putting weight on your incisions.
- Don't try to wear anything that goes over your head. It's hard enough to change after surgery so it's best to reduce as many obstacles as possible. Loose-fitting, button up shirts that are made from soft materials can help reduce painful movements and skin irritations.
- Do your arm exercises! Your surgeon will give you exercises to do to help speed up recovery and prevent stiffness; they really work. It may be uncomfortable, but they are key to preventing discomfort and lymphedema in the long run.
- Take all the help you can get. People will offer to help after your surgery. Don't be too proud to take them up on their offers. You may notice that offers for help start to fade the farther you are from your surgery so reach out and ask people for specific things you need, like food or rides.
- Hydrate. Hydrate. Hydrate. Hydration is really important for everyone but especially after surgery. It

- helps prevent complications and speed up recovery.
- If you're feeling nauseated after your surgery, ask someone to get you a cold wet cloth to put on the back of your neck.
 - Pain killers can cause constipation. Mobility equals motility so, get up and walk a bit even when you don't want to. It can help get things moving again.
 - Speaking of pain killers; they can really work to relieve your pain. Even if your brain tells you your feeling back to normal, your body is still healing so take it easy! Don't do too much too fast or it can take its toll. And definitely don't lift anything heavy!
 - Take pain meds about an hour before you empty your drains. This process can be painful, and this is the best way to minimize the pain.
 - Put a pillow under your arms when you are sleeping or lying down to help relieve any pressure.

Remember that every day will get better. It may feel slow and you may get restless but just remember that you will start feeling better again soon.



Eight Items That Helped Me Recover from Breast Cancer Surgery

By Adriana Ernter

The day my doctor told me I had breast cancer was the same day I met my surgeon and was scheduled for a partial mastectomy (otherwise known as a lumpectomy), breast-conserving surgery. It's not surprising. The Canadian Breast Cancer Society attributes breast cancer as being the most commonly diagnosed cancer among Canadian women and the second leading cause of cancer death in Canada, so booking a surgery right away is a priority.



What's more challenging to figure out is the personal, little discussed insider information women facing breast cancer surgery need.

This is the case for not just for me, but for the 565-plus women from British Columbia to Newfoundland who are newly diagnosed each week. Just take a look at the Canadian Institute for Health Information's [hospital and surgery data](#). It lists surgery as a common and important component of and often, the first step in breast cancer treatment. In fact, from 2007 to 2010 alone, nearly 58,000 Canadian women had breast cancer tumors removed by lumpectomy, double mastectomy or otherwise. But that's just the math, the statistics anyone can find in a simple Google search. What's more challenging to figure out is the personal, little discussed insider information women facing breast cancer surgery need, starting with what to have on hand at home or to pack in a post-surgery care bag. Here are eight items to consider before you head to the hospital.

1. Cash

Depending on where you live and how far away you are from the hospital where your surgery

is scheduled, make sure to hit the ATM a few days before you go in. Ideally, having \$60 to \$100 in your wallet should do the trick. This covers the cost of the post-surgical prescription for painkillers, antibiotics or other medications your doctor suggests. With most breast cancer surgeries now being performed as day surgeries, you'll want to fill these prescriptions before you head home, because trust me, once the floating feeling from the general anesthetic wears off, the pain will kick in. If you don't have a personal ride to the hospital and don't have an Uber account (or if it's not in your city yet), put a couple of twenties aside for a taxi to drive you and your post-surgery buddy (be it a spouse, BFF, family member etc), to and from the hospital.

2. Cozy clothes

Prior to my surgery, one of my friends recommended I buy one or two soft, cotton, underwire-free bras with a front closure. She said it was non-negotiable and that I would literally live in it, day and night. She was right. I bought two, a grey and a black bra and trust me, neither were even remotely cute looking. But they were comfy and held my boobs in place, most importantly my right breast. Having my breasts upright and forward facing 24/7, minimized movement and helped me feel more comfortable, particularly when I was trying to sleep and my incision area was throbbing. It

has been almost two years since my surgery and I still sleep in these bras. The pain is gone, so essentially the bra is more of a security blanket for me now than anything else, but I like it.

You'll also want to pack or have on hand, a pair of thick fluffy socks, super soft pajamas, a housecoat and a cozy sweat suit, even if you're not staying in the hospital. The socks will keep your feet warm in the hospital during the surgery and at home afterwards. The PJs are obviously to sleep in, while the sweat suit is perfect for lounging on the couch, which you will do all day long. Like the bras, choose PJs and a sweat suit made from super soft and breathable cotton. I'm sharing this because after my surgery, I couldn't pull on underwear (or any pants that weren't loose, baggy and lightweight with an elasticized waistband), so I had to go commando and live in my sweats for four weeks. So pick these up if you don't already have them, because, umm... chafing, so.... .

3. Cream

Not just any cream, this one is for your incision area. My sisters' hairstylist had undergone a double mastectomy about 18 months before I was diagnosed and one day, while my sister Alida was getting her hair cut, she called me and put her stylist on the phone. Knowing that every breast

cancer is unique and my post-surgical treatment was yet unconfirmed, the stylist's one piece of advice was to buy the biggest tub of Wellskin Glaxal Base moisturizing cream that I could find and to start rubbing it all over my right breast and armpit, stat. So I did, and at her recommendation, continued to, multiple times a day once the incision was fully closed. Not only did the cream help reduce the itchy, pulling and tight feeling of my wound healing, it also hydrated and soothed my skin during radiation treatment.

4. A squishy pillow

Long before I knew I had breast cancer, I'd been on the lookout for the perfect pillow. My favourite one had finally kicked the bucket and I had been having the worst time finding its replacement, like, for two years. Then, about a month before my diagnosis I discovered "the one," online at Canadian Feather & Down Company. Extra-long, extra squishy and soft, this cruelty-free Hutterite goose down-filled pillow was, and is, magical. It was a major splurge for sure, never have I ever, spent more than two digits on feathers, but it was heaven and I'm grateful I bought it.

Having an extra long, easily manipulated pillow enabled me to wrap my body around it to find a comfortable sleeping position post-surgery. And this

was not an easy feat. Sleeping was rough and the discomfort stretched beyond the initial post-surgery pains. Weeks of exhaustive, daily radiation treatment, work and then, the Tamoxifen-induced night sweats, hot flashes, joint pain and more made having a great night's sleep something I would have gladly paid money for. Considering the [Canadian Cancer Society](#) notes six to eight hours of sleep per night as imperative for optimum healing and brainpower, buying a luxurious, expensive, yet sleep-worthy pillow is, in my opinion, oh-so worth the price.

5. Slippers (or flip-flops)

At home, I walk around in slippers or flip-flops, depending on the weather. Post-surgery was no different, except this time I made sure that each pair came with sturdy rubber soles to prevent slipping on the carpeted stairs and the hardwood floors. My slippers are also warm and snuggly with thick, faux sheepskin lining that keep my feet toasty even if I'm not wearing socks, which came in handy since I couldn't put on socks by myself for four weeks after my surgery. Because I had day surgery, I didn't take my slippers with me to the hospital. I did wear my slippers every single day afterwards though and then, when summer weather rolled around, I traded them in for a quality pair of flip-flops with grippy soles.

6. Travel-size toiletries

Everyone has a beauty product they can't do without and I'm no different, except that I probably have ten feel-good, do-good items on my list. They include lip balm, deodorant, face cream, Young Living peppermint and lavender aromatherapy oils, perfume, brush, hair elastic, toothpaste, toothbrush and dental floss. So even though I didn't spend the night at the hospital, I did put together a travel-sized stash of each (minus the teeth stuff) of my favourites to keep on my night side table for the days when I didn't get out of bed. I also kept a lip balm in every room in my house for the same easy access and a couple in a drawer in the coffee table because I was rotating between my bed and the couch so frequently.

7. Books

I'm a voracious reader, so I stocked up on books at my local bookstore before I went in for my surgery. I bought everything from Paul Coelho's *The Pilgrimage* and Ruth Wariner's *The Sound of Gravel: A Memoir* to Karen Connelly's *The Change Room* and Grace Coddington's *Grace: A Memoir*, but I only brought one to the hospital to occupy my mind while I waited for my turn in the OR. I kept the rest of the books stacked next to my bed and the coffee

table by the couch. While I slept a solid 14 to 18 hours of every waking day for the two weeks I recovered from surgery at home, I also snuck in several uninterrupted hours of book time. I also kept a journal and pen close by. While I'm not a dear-diary kind of girl, I do like to make note of the things I'm grateful for each day along with keeping track of any unusual or interesting dreams. So if you're staying overnight or longer in hospital, make sure to pack these items along with a copy of *Vanity Fair* or *Harpers Bazaar* magazines to help pass the time and distract you from your pain.

8. Cell phone, charger and ear buds

Last but not least, make sure to pack or have on hand, your cell phone, charger and/or cable cord and charging dock. You never know when you're going to need to call or text someone or to watch the latest episode of *The Crown* on Netflix (or *Golden Girls* on Prime!). Pack your ear buds too, so that you can chat or stream as long and as quietly as you like regardless of if you're having day surgery or staying overnight. Pre-surgery, I bought an additional, extra long cable cord to keep plugged in next to my bed. Now I can rely on having a fully charged iPhone that I can use whether I'm laying stretched out, curled up or even sitting up and on either side of my bed. It doesn't sound like much, but when you're spending the better part of each day and all night there, it is.



What You Need to Know: Accessing Clinical Trials Out of Province and Out of Country

By Heather Douglas

Heather, who lives in Calgary, Alberta, shares her experience with accessing clinical trials in the United States as well as in Toronto, Ontario. She shares some helpful insights on what she's learned and what others may want to consider.

I have been living with metastatic breast cancer for over eight years. While I am usually averse to using battle analogies for living with and dying from cancer, finding the best care has required a fight, considerable perseverance, and hard work. Fortunately, my ER+/PR+ tumours (pleura/liver/lymph) have responded well, but not great, to hormonal therapies. I'm onto my seventh line of treatment.

Over the past three years, I have participated in three clinical trials:

- phase 2 trial at Dana Farber Cancer Institute (DFCI) in Boston for 2 years
- phase 2 at DFCI for 3 months in Boston
- phase 1 at Princess Margaret Hospital (PMH) in Toronto, at the time of writing

Here's what I've learned:

It's work!

Trials are not for everyone, and require extensive leg work, planning, and self-reliance. Perseverance is key. I heard "no" a lot. Ask questions - lead investigators often

The best time to access trials is during earlier lines of treatment.

respond to emails.

It took me 18 months (and 2 conventional treatments), to find my first trial. I listened to research webinars, scoured canadiancancertrials.ca and clinicaltrials.gov, read publications, and monitored patient discussion boards. I learned about potential treatments, compiled a lengthy spreadsheet, and identified the best prospects for which I got feedback from my local oncologist. I learned it was best to keep to 3 questions.

Serendipitously, I found my first trial the same week in June, 2015 that I discovered my pleural mets had progressed on capecitabine. From a discussion board, I learned that a Phase 2 trial for a promising new combination was opening in Boston.

Don't wait!

The best time to access trials is during earlier lines of treatment. Trials, still - perhaps unfairly - exclude patients based on having too many previous lines of treatment. I unfortunately

discovered this in October 2013 when I started to look for trials after my second progression.

Paraphrasing something I once read on twitter – the crappy chemotherapies will always be there.

It's expensive!

We don't like to talk money but it's an unfortunate reality. While I didn't pay for the drugs on my U.S. trial, I covered SOC (standard of care) scans and labs and monthly travel to Boston. This adds up! US cancer centres usually provide estimates for additional costs. I'm using my retirement funds. Put bluntly, because of the reality of MBC; at 50, I don't expect to need them. Fortunately, PMH in Ontario accepts my Alberta health insurance, but I still need to cover travel and hotel.

Travel is energy-sapping!

Ironically, one must be fairly healthy to travel for trials. Phase 1 trials involve a lot of testing. For this PMH trial, I travelled weekly to Toronto for the first six weeks. It was a real grind.

I have pretty good research skills for finding trials on my own, but not everyone is so inclined. Our clinicians are busy taking care of us. We need dedicated coordinator/navigator positions to help us find appropriate clinical trials, connect with investigators, ensure transfer of records, and coordinate between health care teams. Clinical trial coordinators/navigators could ensure that we aren't repeatedly making mistakes or missing opportunities. It would be wonderful if health services or charities could step in to fill this gap.



Sexual Health and Intimacy Tips for Breast Cancer Patients

By Jennifer King

Adapted from Jennifer's book, '[Holding Your Hand: A Breast Cancer Companion](#)', a guide with ways of coping with fears of the unknown path ahead, from someone who has dealt with the emotional and physical challenges and found some sort of solace on the way to recovery.

Sex may be something that isn't frequently discussed by doctors or oncologists or even friends, but the sexual changes and adjustments you go through following a breast cancer diagnosis can be enormous for you and your partner, depending on how big a part it was in your life before diagnosis and treatments.

Personally, I found that sex was the last thing on my mind as I struggled with the new realities of breast cancer and the effects of the treatments. My breast cancer was ER positive, so it became important to decrease the estrogen in my body which I found virtually killed my libido. Cuddling and just being held was a big comfort to me and I expressed this to my husband. Being open and communicating this need helped us, and we focused on the pleasure and closeness this brought to both of us.

Some form of sexual dysfunction is common in most women suffering from breast cancer. The effects of treatment, self-esteem and body image, anxiety and fear as well as fatigue kills the libido in most women. Some women who have had a mastectomy feel a sense of disconnection with their body and see themselves as being deformed and unsexy. The following tips are offered to help you regain a sense of self and maintain good sexual health as a breast cancer patient. Some are

Personally, I found that sex was the last thing on my mind as I struggled with the new realities of breast cancer and the effects of the treatments.

tips that I have tried, while others are tips that I have heard from other sources. Feel free to try only what you are comfortable with.

1. Finding clothing and lingerie that makes you feel attractive and desirable helps to ignite the coals of desire to a point. I found some lovely sexy nighties that added spice to the moment and covered my mastectomy scar and missing breast. Erotic videos as well as literature can also help you feel more sexual. Sex toys, like vibrators, might also be a good addition to your sex life.
2. Pampering yourself can also help to make you feel special and lovable. Bubble baths with candles are a nice way to enjoy your body.
3. The decrease of estrogen creates a loss of lubrication and vaginal dryness which can make sex uncomfortable. Vaginal dryness can be managed with regular use of a vaginal moisturizer with supplemental vaginal lubricants for sexual activity. Look for vaginal moisturizers that are water-based gels and free of hormones. These are designed for regular use (two to three times a week) to maintain or replenish vaginal moisture. I have found that ['Replens'](#) has helped me, but there are several other brands available. In addition to regular use of a moisturizer, a vaginal lubricant used immediately

prior to sexual activity can increase comfort.

There is a quite costly laser treatment for vaginal dryness called the 'Mona Lisa touch' with a possible improvement after three to five sessions. I don't know anyone who has tried it, but it could be an option.

Soap can apparently have a drying effect on the vagina, so bath washes without soap are recommended. This can also help with mild incontinence that can sometimes develop.

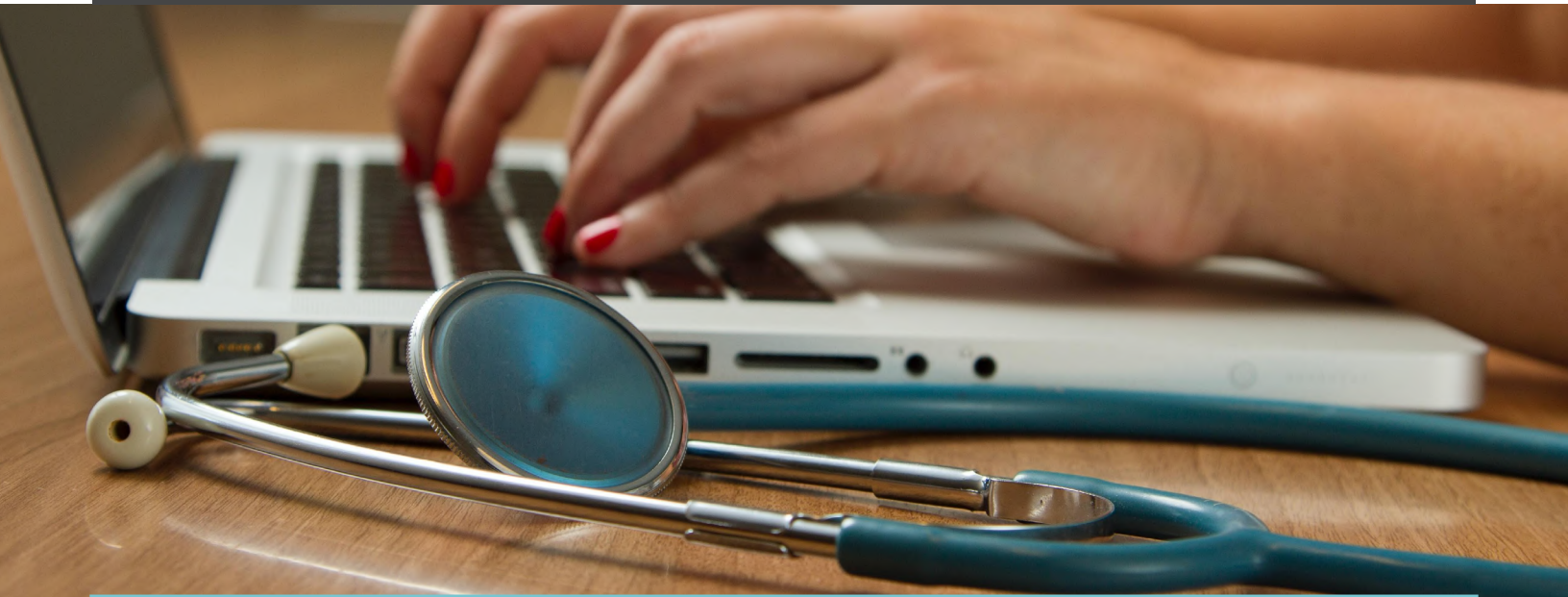
4. I found exercise helped me feel more vital and less frumpy as well as keeping my body in reasonable shape. I tried to keep a daily exercise routine of yoga and pilates stretches as well as a walk or bike ride.
5. Counselling is another option that might help to look at the emotions that are creating the loss of positive body image.
6. Communicating with your partner is really important to help your partner understand how you are feeling physically and emotionally and what you need. My husband and I would schedule days for lovemaking which might just be cuddling but making time for intimacy was important. I would set the scene with candles and soft light which also helped me feel the

missing breast was less obvious. Scheduling an intimate date might feel contrived, but it takes the pressure off feeling like you should be more available and interested in sex all the time.



While sexual health will be different for everyone, I think intimacy is an important aspect for healthy relationships. It is worth making the effort to have honest conversations and finding what works for you and your partner. Regardless of what tips and steps that you take, try not to be too serious about the outcome of your lovemaking. Enjoying each other and the intimacy from open and honest communication can be quite satisfying as the goal should be increasing and maintaining closeness.

Why It's Important to Be Your Own Advocate



The [Merriam-Webster dictionary](#) defines 'advocate' as a verb that means "to support or argue for". 'Self-advocacy' is defined as "the action of representing oneself or one's views or interests".¹ While the word, advocate might make us think of protests or political signs, that is not always the case. As someone with a breast cancer diagnosis, self-advocacy and being an advocate simply means being a part of your health care team. It means knowing yourself and speaking up for yourself to make sure that your needs are met.² Self-advocacy is part of participatory medicine where

'Self-advocacy' is defined as "the action of representing oneself or one's views or interests".

“patients are actively working alongside their physicians to choose the best course of cancer treatment.”³

You might have been told before to self-advocate when you had certain concerns about your health when it comes to breast cancer and may have wondered what that looks like exactly. Here, we outline how to become an advocate for yourself in order to ensure your needs are being met and your input is being considered.

Know yourself

To advocate for yourself, you must first know yourself. This means reflecting on what's most important to you, what you value, what your priorities are as you consider treatment options, knowing your body, knowing what your normal is, and paying attention to your symptoms. It is easier to know when something is off if you are in tune with your body. When something feels off, it is important to pay attention to it. Make note of any symptoms you experience, take pictures if you're able to and speak to your doctor about them as soon as possible.

Do your research

Part of being an advocate for yourself is also knowing as much as you can about your breast cancer diagnosis and understanding what's most important to you as you make treatment decisions. Keep a record of your reports and take notes whenever you meet your doctor or visit your cancer care centre. Make sure your notes can be easily accessed at a later day by recording dates and times.



In addition to taking notes, ask your doctor questions and conduct research from credible cancer sources. If you have treatment or surgery decisions to make, it is important to find out what you can about your treatment options. Your doctor may provide you with several options so it's important for you to consider how these options, side effects and outcomes align with your priorities, values and overall goals of treatment. By doing this, you can weigh the pros and cons of each option to know what works best for you. When you are doing your research, write down any questions that come to mind and keep track of whether your research is answering them. Once you have conducted your research, any unanswered questions can be directed back to your doctor.

Outside of asking your doctor questions and doing research, speaking to other breast cancer patients can provide you with valuable information. This can be

as easy as joining an online breast cancer support community, such as our [Canadian Breast Cancer Patient Network](#). If you go this route, keep in mind that this is simply to get more information and to know about other options that may be available to you that your doctor may not have mentioned. What worked for one person may not be the best course of action for you and the information from these communities should not be used to substitute professional medical advice.

Have a support system

While the term self-advocacy implies advocating for yourself, by yourself, it doesn't actually mean that you have to do it by yourself. A breast cancer diagnosis is overwhelming and distressing which means that constantly taking notes of everything might sometimes be too much to do alone. Whenever possible, try to bring a friend or family member with you. They can help you take notes. They also help to provide emotional support as self-advocacy can seem draining. A support system is also vital in practicing self-advocacy if you struggle with finding your voice and speaking up for yourself. A more outspoken family member or friend can give you a voice. While an individual or a few individuals are the ideal support system, organizations can also lend support in self-advocacy. If you have any questions regarding your cancer care, feel free to reach out to the Canadian Breast Cancer Network by emailing us cbcn@cbcn.ca or calling us at 1-800-685-8820. We can be your voice if you are having trouble finding yours.



Self-Advocacy Tips: For Patients, From Patients

Advocating for yourself is an important part of being a breast cancer patient. While steps and tips on how to go about becoming an advocate and being a part of your healthcare team is valuable, we believe that the best way to learn is to hear from people who have been there already.

Laura Lehne on knowing yourself

Was told I had eczema and to see a "skin doctor". I advocated for more tests and was eventually diagnosed with [Pagets Disease](#).

Adriana Ernter on having a support system

One woman, a former colleague, along with a new friend who I'd known of for years, thanks to working in the same industry, became invaluable finds, candidly, thoroughly and compassionately sharing their firsthand experiences with me. At the recommendation of a mutual friend, I chose to seek out the first woman when I was diagnosed. She, not my oncology team, emotionally prepared me for my surgery, encouraged I buy not one but several soft, underwire-free bras to sleep in to help minimize the pain. She was the one who forewarned me that I would be tattooed with grid-like dots prior to beginning radiation, how I would feel utterly and completely exhausted throughout the process and validated that it was okay to sleep every non-working hour of each day.

The second held my hand through recovery and the brain-fogged road I would and continue to walk, encouraging me by acting as a soundboard for the feelings of inadequacy I still feel as I continue to shed my former pre-breast cancer self. I chose to hear and learn from these women and their breast cancer journeys. They empowered me to make informed decisions for myself, which in turn has helped me better tune into my gut instincts and to follow them.

Rebecca Wulkan on having a support system

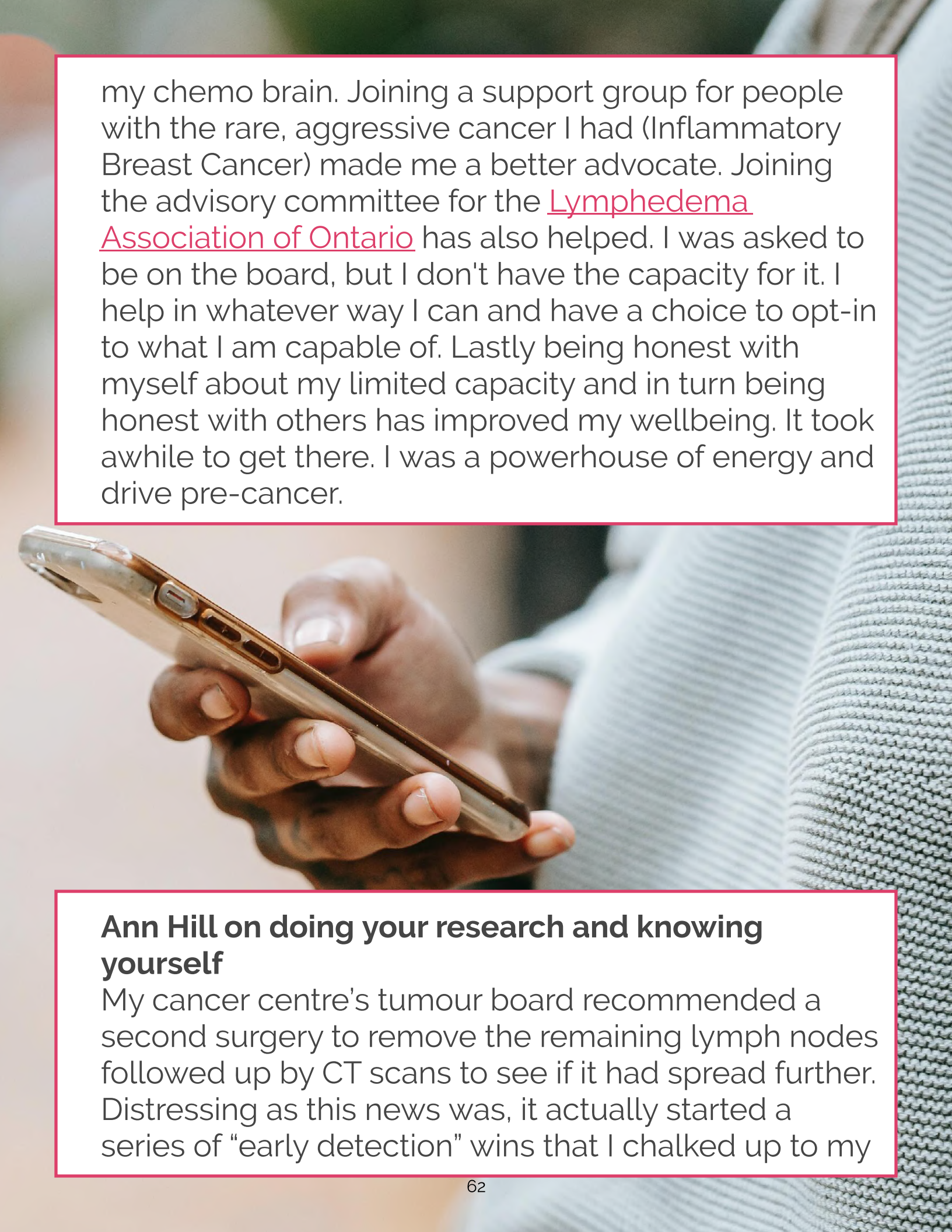
Our family system is slowly becoming a system for nurturing and curiosity. A place for growth and

I was able to better advocate for myself by tracking everything.

exploration. A place for failure and grace and compassion. And as our fears subside, we are able to affect each other in beautiful, positive ways, building a system that is strong enough to withstand any storm.

Janet Vanderveen on having a support system and knowing yourself

I was fortunate to have a treatment team that listened well and a dear friend who was an RN and attended every appointment for the first two years. She helped me advocate and understood the medical systems in a hospital setting. I was able to better advocate for myself by tracking everything in My Chart, an online program where you can record prescriptions, pain, symptoms and journal. I was able to look back over details and better understand where I was in treatment and the years afterward. If this is not available at a treatment hospital, I think it is important to track it all in a journal. It certainly helped jog



my chemo brain. Joining a support group for people with the rare, aggressive cancer I had (Inflammatory Breast Cancer) made me a better advocate. Joining the advisory committee for the [Lymphedema Association of Ontario](#) has also helped. I was asked to be on the board, but I don't have the capacity for it. I help in whatever way I can and have a choice to opt-in to what I am capable of. Lastly being honest with myself about my limited capacity and in turn being honest with others has improved my wellbeing. It took awhile to get there. I was a powerhouse of energy and drive pre-cancer.

Ann Hill on doing your research and knowing yourself

My cancer centre's tumour board recommended a second surgery to remove the remaining lymph nodes followed up by CT scans to see if it had spread further. Distressing as this news was, it actually started a series of "early detection" wins that I chalked up to my

new-attitude, take-charge TIP: be Thorough, Inquisitive, Persistent. I spent the time leading up to the second surgery finishing chemo and doing a lot of research. I learned about TNBC and the increased risk of recurrence. I learned that with dense breasts, the risk of developing a second (contralateral) cancer in the other breast is greater. And I listened to my fear that if a tumour developed, it may be missed again. So, for my second time under the knife, I requested, and received, a double mastectomy.

We hope these words from those who have been there and faced situations that have required them to practice advocacy help and prepare you to do the same.

So, for my second time under the knife, I requested, and received, a double mastectomy.



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