I may not have all the answers, but at least I have the questions to get the proper care guidelines.
Hi,
Being diagnosed with breast cancer is tough at any age, but being diagnosed when you’re young makes it even more complicated. We won’t tell you we know how you feel. But we will say you’re allowed to be sad, scared or even angry.

As a young woman with breast cancer, you may be facing challenges such as a diagnosis during pregnancy, the effects of treatment on fertility, risk of menopausal symptoms or osteoporosis, or feelings of isolation. Or you may have questions about sexuality, childcare, relationships, dating, employment or finances. Your healthcare team should address all of these topics with you, but we know sometimes your needs can get missed. That’s why we’ve created these Care Guidelines and are working to ensure they are implemented in every cancer treatment centre in Canada.

Use this book to help you and your loved ones navigate your diagnosis and treatment, and ensure that your unique needs are addressed in a timely manner. Write down any questions that you have, keep notes and important contact information, and share this information with your friends and family so they can help you get access to the resources you need.

We know that treatment is no easy feat, and it’s not one-size-fits-all. But we believe that knowledge is power, and the only way you can properly advocate for yourself is to be informed. And just remember: you are not alone. There are a lot of people who really Give-A-Care about you, including us. So we’re here to help you get the care you really need.

SINCERELY,

MJ DECOTEAU
FOUNDER + EXECUTIVE DIRECTOR
OF RETHINK BREAST CANCER
If you are a young woman with breast cancer and are looking for support, resources or community, please get in touch with us at SUPPORT@RETHINKBREASTCANCER.COM or visit us at RETHINKBREASTCANCER.COM
As a Young Woman with Breast Cancer, You Should...
You should receive treatment and care from healthcare professionals who are sensitive to the unique needs and concerns that you may face as a young woman with breast cancer.

- Ask your doctors and nurses if they’ve ever treated a young woman with breast cancer before—just to get a handle on the situation.
- If you’re one of the first young patients they’ve seen, you can share a copy of these Care Guidelines if they are not already aware of them.
- Oncology nurses can be very helpful to connect you with resources and help to manage side effects. Some hospitals even have nurse navigators who can help you navigate the system by making sure you know what’s happening next, telling you when and where you need to be, and connecting you with other professional and community resources.
2. BE ASKED ABOUT BREAST CANCER IN YOUR FAMILY

You should have a full family history taken as soon as possible as it relates to inherited cancer risk. If appropriate, you should be offered a referral to a genetic specialist for testing and counselling.
Most breast cancer cases occur by chance, but some people are at higher risk because of their genetic makeup.

Only 5%–10% of breast cancer is hereditary, and when it is, treatment may be available that can help reduce the risk of recurrence and of other cancers.

Hereditary breast cancer may also affect family members and the choices they make for further testing and reducing their own risk.
You should be told about the risk of menstrual irregularity or early menopause as a result of some treatments.

You should also be given advice on how to cope physically and emotionally with these and other possible effects of treatment, which can impact body image and sexual health, or result in brain fog.
Knowledge is power—but when and how you absorb information is unique to you. Our research has shown that when a young woman is well prepared for what is about to unfold, she copes better.

Ask your healthcare team to share a full list of side effects at each stage of treatment and to advise you on the best ways to manage them.

For more information, check out Rethink Breast Cancer’s Live Laugh Learn video series at RETHINKBREASTCANCER.COM/LIVELAUGHLEARN which offers practical tips on these issues and advice from other young women who have been through this before.
You should be given a full explanation during initial treatment planning about the possible impact on fertility.

If appropriate, you should be referred promptly to a fertility specialist to discuss options for preserving fertility before starting chemotherapy or hormone therapy. You should also be given information on contraception and pregnancy after treatment.
You should be asked about fertility whether you have a partner or not.

Every breast cancer clinic should have a process for referring women promptly to a fertility specialist who can provide treatment.

Our research has shown that this is one issue that is often overlooked. You might need to be assertive or assign a friend or family member to help advocate for you in early meetings with your healthcare team to ensure a referral is made, and all of your options are considered before treatment or surgery.

In the conversation with the fertility specialist, be sure to ask about the chances of success from fertility treatment as well as the possible impact of delaying treatment.
You should be offered counselling if you are diagnosed with breast cancer during pregnancy or within a year of giving birth to help you cope with the impact on you and your family.

- Parenting a newborn is tricky at the best of times, so it’s normal to feel overwhelmed—especially with the added burden of treatment. Therapeutic and social support is helpful to get through this difficult time.
- If you have to be treated with chemotherapy during pregnancy, speak to your healthcare team about your options.
- A mastectomy and/or surgical treatments will have an impact on breastfeeding. If this is important to you, contact a lactation consultant to explore your options.
If you have kids, you should be informed about community-based resources to help you with childcare during your treatment and recovery, as well as domestic services and support resources to help other family members cope.
Being diagnosed while you have small children can cause a lot of stress for parents. Ask if your hospital can make a child life specialist available to help support you and your family.

Our expert advisors recommend trying to keep kids’ routines as similar as possible to before your diagnosis, which may involve asking friends and family for help. Most people are happy to help out—they just need to know how. Meal preparation, babysitting, and help with driving or household chores are some of the things you could ask for help with.

Check out Rethink Breast Cancer’s tools and resources for talking to children about cancer and explaining changes in your family and home at

RETHINKBREASTCANCER.COM/YOUNG-FAMILIES-BREAST-CANCER
You should have the opportunity to discuss some of the complex life decisions you may be facing in a supportive environment with a skilled counsellor, especially if you are having difficulty coping with making major life decisions sooner than you expected.

- It’s important to have support to help you cope with your diagnosis and maintain the best quality of life.
- Professional support comes in many different forms. Most hospitals have counsellors who specialize in helping people with cancer on-site, and there are programs available to accommodate different needs and personalities.
- If you’re feeling overwhelmed, tell your oncology nurse or nurse navigator that you would like to speak to one of the staff psychologists.
You should be fully informed about breast reconstruction options, including the option to opt out altogether. You should also be told about the possible risks, as well as the reality of the look and feel of reconstructed breasts.
There are many different types of reconstruction. It is important to consult with a surgeon to determine the right choice for you.

The timing of reconstruction depends on your personal treatment plan. Some women are able to start the process right away, and others need to wait until after treatment ends. Either way, it’s important to start the conversation early.

Some women choose to not have reconstruction and use a prosthesis. Some don’t use anything at all. Choose what feels right for you.

If you have questions about reconstruction, this is a great place to start:

BRA-DAY.COM/BREAST-RECONSTRUCTION
You should be given, if needed, the opportunity to be put in touch with community agencies to discuss the financial implications associated with breast cancer, including employment rights, benefit plans, coping with a loss of income, and the effects on mortgage and insurance.

- Young women, in particular, may find a cancer diagnosis to be a very difficult disruption in their careers. Speak to a counsellor and/or your company’s HR department about all of your options for cutting back or pausing work.

- Consult a financial planner to create a strategy for the costs associated with cancer care.

- There are programs and services available to you if you are in need of financial assistance. For more information, check out rethinkbreastcancer.com/financial-resources
You should have the opportunity to be connected with other young women who have been diagnosed with breast cancer. You should also be told about long-term sources of post-treatment peer support.
No one knows what you are going through more than a person who has walked in your shoes. Peer support is a powerful tool to help break the isolation a young person may feel with a cancer diagnosis.

If you would like to meet others who can relate to what you’re going through and would like to share your experience with other young women to help them through their treatment, please join Rethink Young Women’s Network. Learn more at RETHINKBREASTCANCER.COM/RYWN
Life After Treatment: Your New Normal
AFTER YOU’VE COMPLETED YOUR BREAST CANCER TREATMENT, YOU MAY FIND THAT IT’S A STRUGGLE TO ADJUST TO YOUR “NEW NORMAL.” YOUR FRIENDS AND FAMILY MIGHT EXPECT YOU TO BOUNCE BACK AND NOT REALIZE THE PHYSICAL AND EMOTIONAL TOLL THAT GOING THROUGH CANCER CONTINUES TO HAVE ON YOU, LONG AFTER YOU’VE HAD THAT LAST TREATMENT OR SURGERY. IN FACT, MANY PEOPLE FIND THE END OF TREATMENT THE MOST DIFFICULT STAGE OF CANCER TO NAVIGATE. IF YOU’RE HAVING TROUBLE COPING WITH MOVING FORWARD, THESE TIPS CAN HELP YOU GET THROUGH IT.
1. Don’t Rush

You might feel pressure to return to work and jump right in because you feel people expect you to get back to it now that you’re “finished.” Take it slow and don’t be afraid to ask for medical approval to take some extra time off. When you do return to work, find out if it’s possible to start with part-time hours or a gradual return-to-work plan. This will help you ease back into your routine without exhausting yourself.
2. Find Support

Talking about how you’re feeling now that you’ve finished your treatment can be very helpful to your recovery. Whether it’s a support group or a therapist, don’t be afraid to seek out help as you work your way through this stage. If you’re looking to connect with other young women who have been in the same boat, register for the Rethink Young Women’s Network and join our private Facebook group.
Unfortunately, some side effects have a tendency to linger after treatment is over. If you are taking hormone therapy such as tamoxifen, you might have some long-term side effects such as bone pain or hot flashes. Talk to your doctor about solutions to deal with ongoing side effects and make sure to communicate your concerns, even after your treatment has finished. Don’t be afraid to speak up.
After you finish treatment, you might find that your anxiety levels actually increase. Fears over having a recurrence may overwhelm your thoughts, and you may have difficulty adjusting now that you’re not being constantly monitored by your healthcare team. This anxiety should lessen in the future, but in the meantime, it’s important to find healthy ways to cope. Journaling, exercising and meditation are a few methods that may help lower your stress levels. There are also programs that have been created specifically for cancer patients. If you find your anxiety is interfering with your daily life, talk to your doctor.