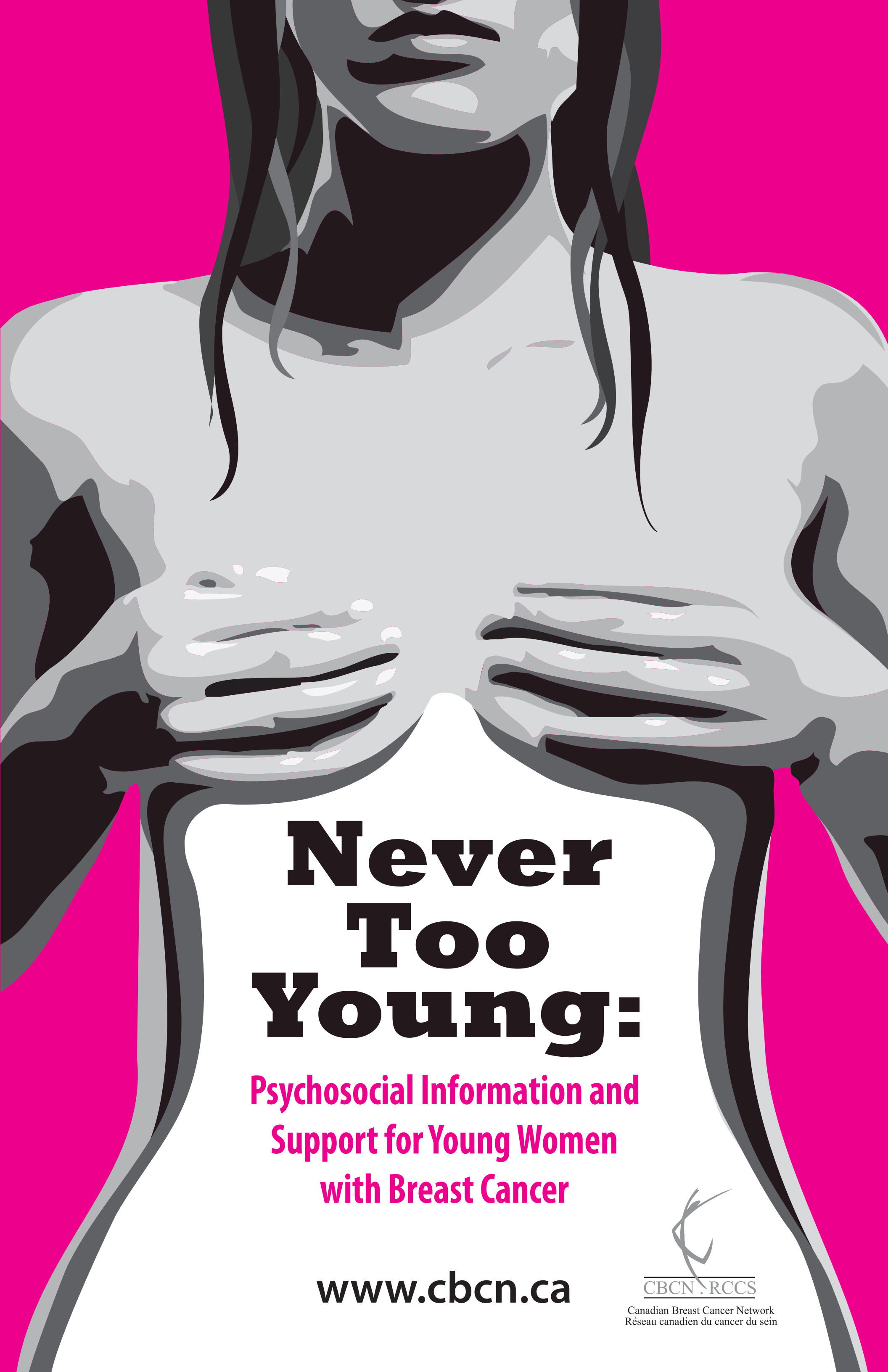

Never Too Young:

Psychosocial Information and Support for Young Women with Breast Cancer

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Introduction

> *"You're too young to have breast cancer."*

Contrary to this refrain — heard by many women from their family, friends, coworkers and medical professionals — young women do get breast cancer. Every year, more than 23,000 Canadian women are diagnosed with breast cancer. Though they represent a smaller percentage than older women, 23% percent of women diagnosed with breast cancer are under the age of 50,[1] and breast cancer is the most commonly diagnosed cancer in women aged 20–49.[2] More women below the age of 40 die of breast cancer than any other type of cancer, and the disease in young women can be more aggressive. Young women diagnosed with breast cancer represent a significant group whose unique needs are often not addressed.

> *"Yes, breast cancer, damn it, happens to young women and something's got to be done for the women 45 and younger."*

In 2002, the Canadian Breast Cancer Network (CBCN) undertook a project to better understand the unique needs of young breast cancer survivors. Consultations were held with 70 young women from across the country, all of whom had been diagnosed with breast cancer before the age of 45. The results of this survey were compiled and released in CBCN's 2002 report *"Nothing Fit Me": The Information and Support Needs of Canadian Young Women with Breast Cancer*. The findings showed that these young women overwhelmingly felt that the information available to them did not address their issues.

> *"I was bombarded with pamphlets and booklets and I read everything possible [that] I could get my hands on, but I found that none of it really suited me or my specific situation…I found that* ***nothing fit me****."*

Never Too Young: Psychosocial Information and Support for Young Women with Breast Cancer was developed with this issue in mind. Its objective is to address the psychosocial effects of breast cancer in several aspects of young women's lives. It provides an overview of common issues and problems, and seeks to empower young women by providing them with the information required to make educated decisions about their psychosocial wellbeing during diagnosis, treatment and recovery.

Though this handbook was developed and written for young women with breast cancer, it may also be a helpful resource for family, friends and caregivers who may feel overwhelmed and unable to deal with these issues at the present time. We encourage all members of a young survivor's support team to make use of this handbook to improve their understanding of her journey.

Overview

With your diagnosis of breast cancer, you have entered into a new phase of your life, one that brings with it many new questions and concerns. Remember that you are not alone. In 2001, the Canadian Cancer Society estimated that 23% of women with breast cancer were under the age of 50.[3] This is a large group of women, yet one that often lacks recognition within the healthcare system.

Many young women diagnosed with breast cancer feel that their issues are not being dealt with, as the majority of resources are developed for older women. You may feel the same. We hope that this handbook will provide you with an understanding of psychosocial issues commonly faced by young survivors, and help you feel in control of your diagnosis, treatment and recovery. If you are not familiar with the term "psychosocial," the word is used to describe the relationship between your personal, internal environment, and the wider social world; that is, the influence of social factors on an individual's mind or behaviour or, simply put, what happens and how it makes you feel and act. These issues often fall outside of direct medical care like treatment plans, surgeries or medications. Psychosocial issues can affect every part of your life, and can impact you as much as medical ones.

In this handbook, we will talk about 16 main topics, each of which could have a major psychosocial impact on your life. They are listed somewhat in order, although every woman's experience is unique and yours may follow a different path. You may choose to read these sections in order or to read only the ones you feel apply to you at this time. We hope that the information and resources presented in these sections help you feel prepared to face the psychosocial issues that come with a breast cancer diagnosis, and that the handbook itself offers useful information to help you cope with them.

Mental Health and Emotional Issues

> *"At the age of 37, I was diagnosed with stage II breast cancer. I was sad, shocked and very depressed, as I had always thought cancer was an automatic death sentence. I was scared as I felt myself sinking into a black hole that I thought I would never get out of. I was so lucky that my surgeon realized that I was having a real problem dealing with the diagnosis and what the treatment would entail. He sent me to see the oncology psychiatrist and the oncology psychologist at the hospital. I was immediately put on medication for the depression and the anxiety, and between the medication and talking to both the psychiatrist and psychologist, it made my journey so much easier to cope with. I don't know what I would have done without them."*

When you are diagnosed with breast cancer, the immediate focus will be on treatment. It is important, however, for you not to lose sight of how your diagnosis is affecting you emotionally. In fact, these symptoms will carry through to every aspect of your life during treatment and recovery, and as such, are touched upon in each section of this handbook.

A 2004 report entitled *Depression Experienced by Young Women Newly Diagnosed with Breast Cancer* states that "due to their roles as mothers, wives, and job-holders and the demands imposed by both their families and their careers, younger women are more likely to experience unhappiness and greater need for social support when diagnosed with breast cancer."[4] As a young woman, you are in a unique situation when it comes to the stress and pressure surrounding diagnosis and treatment, and although the main focus of treatment is fighting the cancer, an awareness of how you are feeling and dealing with these feelings is an important part of the recovery process.

Emotional wellbeing is crucial to quality of life, and thus very important to your overall wellbeing. A breast cancer diagnosis can be emotionally draining, and can cause a huge upheaval in your life. It is important to address these issues and get any treatment you may need, because ignoring them will not make them go away. In fact, it may make the problem worse. When faced with a disease like breast cancer, it is important for you to feel mentally healthy and able to fight it.

The Lance Armstrong Foundation has a very informative page on their website dedicated to mental health and how to distinguish normal sadness from clinical depression. You can check it out at www.livestrong.org. Sadness is a normal response to upsetting events, and though the feeling can be very strong at times, it usually does not last for extended periods. Depression, however, is more severe. It can be a constant in your life, and cause you to lose interest in the people, places and things you once enjoyed.[5]

It is important to be able to tell the difference between normal, understandable bouts of sadness and a more debilitating, overwhelming depression. If you feel that you are experiencing depression, or that your sadness is becoming a problem, seek counselling. The Canadian Mental Health Association can point you in the direction of local resources around the country, and is an important tool for understanding the signs and symptoms of mental illness; they can be reached at www.cmha.ca. You can also ask your family doctor, oncologist or nurse for a referral to a counselling service in your cancer centre or hospital.

Beyond sadness and depression, there are many other emotional issues you will likely face. A breast cancer diagnosis can turn your world upside down. You will likely experience a range of emotions, from confusion and disbelief to anxiety. You may feel fear: fear of the disease, fear of the treatment, fear of losing your breast or hair, or fear of losing or leaving your loved ones. These are normal reactions, and though they may hurt and cause disruption in your life, they are normal.

Breast cancer can leave you feeling as though you lack control over your own self. This is an emotionally difficult time, and though the feelings you experience will not always be good ones, know that they are common. It is also important to remember that there is no shame in seeking help for your sadness, depression or other mental health issues.

The Canadian Mental Health Association estimates that 20% of Canadians will experience a mental illness at some point in their lives.[6] It is more common than many believe. The stigma or shame surrounding mental illness can be a huge obstacle to getting proper treatment and consequently feeling better. Remember that emotional issues and mental illness are not something to be embarrassed or ashamed about.

Breast cancer support groups offer a caring environment in which to explore your feelings toward your diagnosis and treatment. Many people take comfort in knowing that there are others with the same issues. There are also many online chat rooms and message boards where you can find supportive peers, answers to your questions, and discussions of important issues. There are several lively and informative online forums run by several organizations, such as:

- Willow (http://community.willow.org/)
- Young Survival Coalition (www.youngsurvival.org) (American, but the bulletin board has a significant Canadian presence)
- breastcancer.org

Some women aren't comfortable sharing in group situations, and feel more comfortable in a one-on-one setting. If that is your case, you can contact the Canadian Mental Health Association or ask your physician to refer you to a counsellor or therapist. Don't be afraid to ask everyone — your nurses, surgeons, oncologists — if there are services or groups at your cancer centre or hospital. Your faith or spiritual community may also be able to provide meaningful counselling or other support services.

> *"I had a million thoughts running through my head...they kept circling and circling until I got them out. I felt that once I wrote down what was consuming my mind, I had dealt with it and I could move on. It provided some relief from navigating this new world I had been dumped into."*

In addition to counselling or group therapy, there are also different coping strategies you can engage in on your own. Many women find that writing helps them keep track of treatment and focus on their emotional journey. Try to jot down each day's events, and describe your mood or any issues that have arisen.

You can also maintain a blog or website to keep family updated on your treatment. There are even websites dedicated to offering free hosting for people dealing with critical illness, such as Caring Bridge (www.caringbridge.org). Keeping a journal can help you track your emotional highs and lows and help keep your mind clear.

Be creative with how you choose to personally cope. Maybe you find solace in painting, running, meditation, prayer or taking a long, relaxing bath. Whatever it is, it's important for you to feel strong and prepared. Mental health is vital to your wellbeing and quality of life, and should not be ignored!

Partners

> *"Being so sick and looking after a new baby was difficult, but I was coping. Unfortunately, my husband wasn't coping and detached himself from the situation as much as possible…It is difficult to predict how people will react when faced with adversity and I would never have guessed my husband would react the way he did…"*

Breast cancer can be called a "relational cancer" because of the strain and distress it can place on relationships, especially between partners.[7] For young women with breast cancer, this pressure is more likely to affect newer relationships rather than long-term ones. Partners often feel overwhelmed, anxious, angry, frustrated, scared — a huge range of emotions. Common issues partners face can be broken down into three main groups discussed below.

Communication Issues

The stress of a breast cancer diagnosis and treatment can be hard on your relationship, particularly if there are already problems with communication. It is vital in any relationship to communicate, but it becomes really important when a severe illness such as breast cancer is involved. In fact, a 2008 study found that couple-based intervention, where couples were taught how to effectively communicate and share feelings and thoughts during breast cancer treatment, helped improve "individual, medical and relationship functioning for couples."[8]

Breast cancer is unfamiliar terrain for most couples, so it is important for both of you to communicate how you are feeling and coping. Even if you don't know what you are feeling, say so. Saying "I'm confused and sad and I don't really know what to think right now" can help your partner understand your thoughts, and also know that they are not alone.

Understanding each other is very important. Is one of you quieter while the other is more emotional? Is either of you more likely to talk about your feelings while the other dislikes sharing? Be certain first to understand how your partner communicates to help make sure you aren't misunderstanding or misreading any actions or words. It is important to understand your partner's thought process and coping methods, and if they are different from your own, then talk about it.

Be honest with your partner so they know how to support you. If your partner is trying to be strong, unemotional and unflappable but you need someone who shares your fears and is honest rather than unconcerned, tell them! Be clear about what you need from them, and ask that they be equally clear with you. Different coping strategies can lead to resentment and anger, which is the last thing you want to be dealing with during your breast cancer treatment.

New Responsibilities

Your breast cancer diagnosis may shake up not only emotions, but also schedules. Appointments, recovery time, hospital stays, work, and fatigue can all contribute to new household divisions of labour. If you were originally the primary caretaker for children or elderly family members, this responsibility may be shifted in large part to your partner. The same goes for many housekeeping, cooking or community obligations which were previously your responsibility. Your partner may now be helping you deal with such things as insurance issues, appointment times, medications, etc.

Beyond this, you may also need their physical support, including transportation to and from appointments, caring for you post-treatment, and help with dressing. These new responsibilities can be a difficult adjustment for your partner.

Support Issues

The confusion and stress of a breast cancer diagnosis can cause an emotional strain on your partner. It is important to be aware if they are struggling. Encourage them to be open and honest if they are feeling overwhelmed, and ask family and friends to help. You and your partner need to remember that there is no shame in not being able to handle everything alone. In addition to family and friends, there are many support groups, online communities and individual counsellors who can offer support and guidance in difficult times.

Many cancer or breast cancer-specific websites have a section for partners, but there are also sites created specifically for partners. Organizations such as Young Cancer Spouses and Men against Breast Cancer are excellent examples of online groups dedicated to the issues faced by spouses of cancer patients. In particular, Young Cancer Spouses has excellent advice, a discussion board, as well as a collection of handy forms to help partners remember appointments, medications, etc. These organizations can be reached at www.youngcancerspouses.org and www.menagainstbreastcancer.org.

If your partner is not comfortable sharing in a group or online, they may benefit from some books written with their experiences in mind. The majority are written for those in heterosexual relationships, but they may have valuable and useful information regardless of you or your partner's gender or sexual orientation. They include:

- *Breast Cancer Husband: How to Help Your Wife (and Yourself) During Diagnosis, Treatment and Beyond*, by Marc Silver. This book is a heartfelt, emotional and informative guide for men whose wives or girlfriends have been diagnosed with breast cancer. Through interviews with professionals and breast cancer couples, Silver helps guide the reader through the experience of breast cancer from the passenger side.

- *It Takes a Worried Man*, by Brendan Halpin. Halpin's memoir of his wife's experience with breast cancer is unflinching and honest, discussing everything from her medical experiences to their family's reactions.

- *Couples Confronting Cancer: Keeping Your Relationship Strong*, by Joy Fincannon and Katherine Bruss. Fincannon and Bruss share information and methods to deal with conflict and help create intimacy to better navigate the cancer experience.

- *Confronting the Cow: A Young Family's Struggle with Breast Cancer, Loss and Rebuilding*, by C. B. Donner. *Confronting the Cow* is a heartfelt account of Donner's wife's struggle with breast cancer and his young family's efforts to rebuild after her death.

It is also important to consider how you feel in relation to your partner. As previously mentioned, communication is key to keeping your relationship healthy through the stress of breast cancer. Some of your partner's actions may not be helpful or may even be hurtful. Is this purposeful? Is your partner not providing the type of support that you need? Every breast cancer patient is different, just as each relationship is different. Be vocal about your wishes, desires and needs. Hopefully your partner will be receptive and equally direct in return.

In some cases, your partner may pull away or not be as supportive as you wish. If communication between you and your partner has broken down and you feel that your relationship is in danger, it is important to get professional counselling. The possibility of separation or divorce while facing breast cancer can be devastating, and a therapist can help you work through issues and problems in a safe and well thought-out way. The Canadian Mental Health Association (www.cmha.ca) can help provide you with information, support, and links to mental health professionals in your area, as can social work departments or counselling services in your cancer centre, hospital or faith community.

Children

> *"I first learned about breast cancer when I was 16, when my mom was diagnosed at the age of 42. I had no idea what breast cancer was, what the outcomes could be, or if my mom was going to live or die. It was a lot to take in for a 16-year-old. I have a younger sister who would have been 11 at the time, and she really didn't understand what was happening to our mom… I remember everything my mom went through, I learned all about radiation, treatments, Tamoxifen, and recovering after breast surgery. I learned about surviving breast cancer."*

Young women are more likely to have younger children when diagnosed with breast cancer. Discussing your cancer diagnosis with your children or other young family members such as nieces or nephews can be an incredibly daunting task. Remember that you know your children best, and be confident in your ability to determine what they need to know and what they don't. Many cancer or breast cancer-specific websites have pages dedicated to how to discuss cancer with children. Their advice generally falls into four main categories.[9]

Be Honest

Don’t try to hide your illness. Even very young children will be able to tell when something is wrong, when you are stressed out or upset or when their schedule is changed. In the absence of a reason, they may imagine something much worse. Be sure to be open, honest and age appropriate.

If they are young, a simple explanation may do, such as, “Mommy is sick and she’s going to try and get better, so I’m going to be going to the hospital more often, and getting medicine.”

With older children, you may feel comfortable describing your type of cancer, where it is located, and so on. Don’t be afraid to use the word “cancer.” Avoiding it may create a taboo around the word, leaving your children feeling like your diagnosis may be worse than you explained. Try to answer them as best you can while encouraging their questions.

Explain and Prepare

It is important to prepare your children for what effects the treatment will have on you. If they are aware and prepared, they will have an easier time dealing with them. If they are young, be direct but gentle, using phrases such as “the medicine Mommy takes to get better is going to make her feel tired and sick, so she’s going to need to sleep quietly in her room, okay?” Be sure to explain to them some limits to their activities, such as asking them to play a little quieter, or if they are more clingy, explaining that you may not be able to cuddle for a while after your surgery.

If they are older and you feel comfortable, you can be much more detailed about where your cancer is and what your treatment plan is. Older children or teens may even want to attend some appointments with you to get a chance to meet your doctors and ask some questions themselves.

Reassure

Although you cannot say for sure that you will be "fine," it is important to assure your children that you and your doctors are working as hard as you can to get better. It is above all important to tell a younger child that just because you are sick doesn't mean you are going away. Younger children may also have false ideas about your illness which need to be tackled. Assure them that they did not in any way make you get sick, and that they can't "catch" cancer from you. Since colds and flus may be the only illnesses they have been exposed to, this may worry them.

Whether your children are young or old, assure them that their emotions are normal, and that it is okay to feel sad, confused, angry, unsure or anxious.

Encourage

Remind your children that even though you may look different or feel sick or tired, you are still the same mom. Tell them that even though you might sometimes be too tired, sick or sore to play, you still love them. Your children may also respond well to small responsibilities. Even something simple, such as asking them to get mommy a glass of water or an extra pillow, can make them feel helpful and supportive. Encourage them to ask questions and talk to you about their feelings and concerns. Communication between you and your children is incredibly important to the emotional wellbeing of everyone involved.

There are also several age-appropriate books that may help you talk to your children about your diagnosis and treatment. Some useful titles include:

- *Sammy's Mommy Has Cancer*, by Sherry Kohlenberg. This story can help children understand and accept changes that may occur in their lives when a parent is diagnosed with breast cancer. The book is designed to help explain illness and its effects so that children can be better prepared for the challenge.

- *Tickles Tabitha's Cancer-tankerous Mommy*, by Amelia Frahm. This humourous book aims to help children develop an understanding about how illness can affect a family, and can help open a dialogue about cancer.

- *Butterfly Kisses and Wishes on Wings*, by Ellen McViker and Nanci Hersh. *Butterfly Kisses* was originally written by McViker for her cousin Hersh, to help her explain her breast cancer diagnosis to her two young children. The book aims to educate and support children as they face a diagnosis of cancer in a parent, family member or loved one.

- *Kemo Shark*, by H. Elizabeth King. Available for download from www.kidscope.org, *Kemo Shark* is a comic book designed to help explain the purpose of chemotherapy and the effects it can have on mom.

- *The Year My Mother Was Bald*, by Ann Speltz, takes the form of a journal written by Clare, a pre-teen whose mother has been diagnosed with cancer. It can help children understand cancer, its treatment and its side-effects.

- *When Someone You Love Has Cancer*, by Alaric Lewis, addresses common worries and fears that young children may have in the face of the cancer diagnosis of a family member or loved one.

- *Michael's Mommy Has Breast Cancer*, by Lisa Torrey, is a sensitive, loving story which encourages parent-child discussion about breast cancer and its treatment.

- There are also some books written for adults which can help you educate and inform your children throughout the cancer journey. Some examples are:

  - *When a Parent Has Cancer: A Guide to Caring for Your Children*, by Wendy S. Harpham. This understanding and educational resource deals with parenting issues surrounding illness, and gives practical advice for dealing with specific problems that may arise.

  - *Cancer in Our Family: Helping Children Cope with a Parent's Illness*, by Sue Heiney, Joan Hermann, Katherine Bruss and Joy Fincannon. This book outlines ways to help children understand and cope with the effects of a breast cancer diagnosis.

Each child will react to the news of a cancer diagnosis differently. Your child may become quieter and worry about your health. Or they may act out, looking for attention in this new and different situation. They may wish to be closer to you, physically and emotionally, or they may pull away for fear of you leaving them. It is important to be open with your children, not only about your diagnosis, but also about your and their feelings. Reassure them that nothing they are feeling is wrong, and encourage them to share their emotions with you. You may not be able to change the way they react, but through open discussion, you will be able to better understand the reasons behind their behaviour. It is also important to notify your child's school so that they can watch for any serious changes in academic performance or behaviour.

Discussing your diagnosis with children can be a very emotional ordeal. Fear can be a large part of your emotional relationship during diagnosis and treatment. Fear of leaving your children, fear of exposing them to the realities of serious illness, fear of scaring them. Beyond fear, you may experience a variety of feelings from sadness to despair, confusion to anger.

Your children can be catalysts for some of the deepest emotions you may experience during your breast cancer journey. Remember that it is important to be honest with your children, even explaining to them that you feel scared or sad or confused. But children also need to feel supported and confident that you are still the same mother they know and love. Remind them that what you are feeling is normal, and that they may feel the same way sometimes.

Parents and Siblings

> *"A diagnosis of cancer in your child is devastating. You become caught up in a world of cancer treatment that is both foreign and frightening. You put your faith in the healthcare system and trust the medical professionals that hold your child's life in the balance."*

Breast cancer can affect your whole family, and for young women, this is much more likely to include living parents. For parents, a daughter's breast cancer diagnosis can be traumatic since they may have thought of breast cancer as an older woman's disease and most likely never considered it a possibility for you. Older mothers are likely to be getting regular mammograms and worrying about their own breast health, not yours! Your mother may struggle with questions like "Why can't it be me?" and feel guilt about having lived a full life while you are suffering at such a young age. It is important to be open with each other. Let your mother air her worries and fears. You may both feel better after discussing the way you feel.

Your siblings may also struggle with your diagnosis. Depending on their age, they may feel the same kinds of guilt and worry that your parents do, and wonder why you were diagnosed and not them. If your siblings or any other close family members are much younger, other issues may arise. Young children may not fully understand the implications of your illness, and may feel jealous of the attention you are getting from the family. If they are somewhat older, they may be confused by your diagnosis, and feel cut off from their worry-free friends.

As with any family member, parents and siblings are likely to feel scared, confused, worried and anxious. Unlike a partner or children, however, they may not be living with you so they may feel a little out of the loop. Remember to communicate with them and share as much about your diagnosis and treatment as you and they feel comfortable with. Explain that you will do your best to keep them updated, but that you will not always feel up to regular emails, calls or visits. Assure them that you still care for them and want to keep them informed, but that your health and wellbeing have to come first.

If you want your parents to be included in your medical treatment decisions and for staff at your hospital or cancer care centre to keep them informed, it is important to put this in writing. There may be times when you are too tired or sedated to talk with your doctors, and you might want your family to speak on your behalf. Make it very clear to your healthcare team that you want to have your parents and/or siblings involved and informed about your diagnosis, treatment and care.

Another thing to remember in considering your parents is genetics. Mutations in the inherited BRCA1 and BRCA2 genes have been shown to increase chances of breast and ovarian cancers. It has been estimated that for women who carry a BRCA1 mutation, the risk of developing breast cancer is up to 87% by the age of 70.[10] The fact that these genes are inherited is the cause of emotional turmoil for some families. Sadness and guilt are common and understandable feelings for both parents and children, and these feelings should be dealt with. You may feel angry that you have inherited a breast cancer gene, and your parents may feel guilty about your diagnosis. Discuss your feelings with your parents and encourage them to do the same with you.

It is important that no matter what your feelings are — anger, despair or confusion — you are able to work through them together.

Family members such as parents and siblings often want to help, but don't know where to start. You will probably hear "what can I do?" day after day. Don't be afraid to answer honestly! They want to help, so suggest a way they can. They can pick up your kids from school, mow the lawn, help with groceries or cooking, do some laundry…any number of things. You may feel guilty that your parents are taking care of you during their retirement years. Or you may worry about your siblings needing to carry the responsibility of helping you and your elderly parents. Remember, you did not bring this illness on yourself, and it is not your fault. Though the situation is far from ideal for everyone involved, it is not avoidable. Your parents and siblings will most likely relish feeling helpful during such a hard time in your life. Don't hesitate to put them to work — they may feel much better and more helpful with something to do.

Friends and Coworkers

> *"I had to tell the staff. Our group is fairly small and I felt it important that they hear the news from me. The initial reaction was shock and tears. All were overwhelmingly supportive even though I know they must have been afraid."*

Dealing with friends and coworkers involves issues of disclosure on your part. With immediate family or close friends, the assumption is that you will discuss your diagnosis; but what should you do about other friends, acquaintances and coworkers? Decisions about telling them will be different for each woman. If you are more reserved or private, you may wish to share your breast cancer diagnosis with just a few close friends. Or you may wish to tell more people, including coworkers and friends, so they are prepared for changes you may experience. Who to tell can be a difficult issue to deal with, and you may feel conflicted, guilty and angry. Each woman's choice will be different, depending on her circumstances. Remember that this decision is yours alone, and no one should try and influence it. It is up to you to decide who to tell about your diagnosis.

Like family members, the friends and coworkers you choose to tell may feel a range of emotions after hearing about your diagnosis. They will likely feel a little lost, helpless, awkward and unsure of what to do or say. They may say the wrong thing, or even say nothing at all. This is completely normal.

The best thing to do is to be honest with them. Don't overwhelm them, but do let them know how you are feeling, what your plans are and what they can do to help. Like with family members, don't be afraid to take them up on their offers to help. They will most likely relish being able to help out in any way, whether cooking, cleaning, shopping or driving.

Tell them about some websites or books if you feel it would help. Cancer and Careers has a section on their website called "Coworkers and Caregivers" which offers information and tips for coworkers or friends. You can find Cancer and Careers at www.cancerandcareers.org.

You may also feel that they would benefit from learning more about breast cancer itself. If so, there are many websites that can offer introductory information, such as the Canadian Breast Cancer Network (www.cbcn.ca), BreastCancer.org (www.breastcancer.org) and the Canadian Cancer Society (www.cancer.ca).

There are also several books which may prove helpful and informative for coworkers and friends. They include:

Cancer Etiquette: What to Say, What to Do When Someone You Know or Love Has Cancer, by Rosanne Kalick. Kalick, a two-time cancer survivor, lays out general guidelines on how (and how not) to interact with a family member, friend or acquaintance who has been diagnosed with cancer.

The Etiquette of Illness: What to Say When You Can't Find the Words, by Susan P. Halpern. *The Etiquette of Illness* outlines how to comfort a friend, loved one, or acquaintance living with a serious physical or mental illness.

Help Me Live: 20 Things People with Cancer Want You to Know, by Lori Hope, presents a heartfelt and practical guide to what words and actions are most helpful to those diagnosed with cancer.

Medical Appointments and Hospitalization

> *"The patient is often left waiting for hours for transport back and forth or waiting because of a backlog in testing. At one point, it took my daughter four hours for a 20 minute procedure."*

Your breast cancer journey will without a doubt lead to some time spent in the hospital, whether through longer stays for recovery from surgeries or shorter trips for tests. Between doctors' appointments, biopsies, scans, chemotherapy and other treatments, you will be spending many hours in medical surroundings, even when not admitted to a hospital. It is important to be prepared for these appointments. Expect long wait times, and plan accordingly: bring plenty of water and snacks, books, magazines or work to keep you occupied. If you have children, make sure that your babysitter, family member or daycare provider is aware of the appointment and can meet your schedule.

Hospitalization poses its own unique challenges, and they may be ones that you were not expecting. You may have thought your hospitalization would feel welcome — after all, this is where you are fighting your cancer. However, you may be surprised to find that your reaction is different. Time spent in the hospital can be challenging. Multiple appointments and frequent trips can be tiresome, and delays can lead to a sense that you need to "hurry up and wait." Medical jargon can be confusing and frustrating if you feel you are not being kept fully informed by your medical team. Seeing the other patients being treated may also have an impact.

There are many things you can do to fight the negative psychosocial impact of hospitalization. First and foremost, it is important to stay informed about your treatment. Do not be afraid to ask questions, and ask about terms or procedures that you may not be familiar with. Question the need for each test and treatment, and have your doctors explain the likely outcomes and side effects. Ask for clarification and do not hesitate to do your own research on medications and treatments. Many hospitals also employ patient advocates or representatives who can serve as an intermediary between you and your medical team, if you feel it necessary. They can answer questions and help you and your family understand your treatment process.

Along with staying informed, the key to a more positive hospitalization experience is comfort. Caring for your health is a priority when in the hospital, but so should caring for your comfort. When hospitalized, patients often feel alienated and uneasy in an environment so different from home. If permitted, make your living space more personally comfortable with sheets, blankets and pillows from home, favourite clothing, books and your laptop to stay in touch with friends and family who cannot visit. Don't forget to ask if you can use your cell phone in your room.

Daily personal care can also be an important factor for feeling your best when hospitalized. Rethink Breast Cancer has published a handbook entitled *Chemo Care*, a guide which outlines useful products to help lessen the physical side effects of chemotherapy. The sensitive, unscented and often hypoallergenic products may also be useful for the effects of other treatments such as radiation or surgery. This guide can be found at http://rethinkbreastcancer.com/breast-cancer/diagnosis-treatment/chemo-care/.

School

Attending school during diagnosis and treatment creates unique issues whether you are working toward an undergraduate, graduate or professional degree. The workload of course work and any other responsibilities you may have can complicate the process of your breast cancer diagnosis and treatment. It is important to be informed about your options, and to look objectively at your situation.

Many university health centres are very busy, and often over-worked and under-funded. Medical check-ups can be hard to come by, and they are often rushed. In these situations, you have to be your own health advocate. If your fears or suspicions are dismissed, be clear and precise. Demand that your health be treated as a priority. Do not be afraid to ask, clearly, "Could this be cancer?"

However, if you attend a large university, it may be heavily involved with breast cancer research and treatment at surrounding hospitals. This may give you the opportunity to connect with medical professionals you may not have had the opportunity to meet otherwise.

After diagnosis, more and more questions are likely to come. You may be overwhelmed with information and decisions. It is important to take this new journey step by step. Key to this is being informed about your situation. Make sure to look into what insurance you have beyond your provincial coverage. Get in touch with your Student Union or if you are a teaching assistant, your labour union, for information about coverage.

The social environment of school means that you may feel that you have to tell a wide range of acquaintances about your diagnosis. This is not the case. There are several people who will need to know about your treatment, such as professors whose classes you may be absent from. It is also important to advise your university registrar's office of your diagnosis, as they may be able to reschedule exams and other official matters if required. Beyond this, however, it is your choice who you tell. If you feel comfortable, you may wish to share your diagnosis with a wider range of fellow students, researchers or professors. You may also decide that you are more comfortable keeping this news to a select few. As is the case with friends, acquaintances and coworkers, the choice of who you tell is yours and yours alone.

Balancing your workload and time commitment of course work or teaching responsibilities and classes can take a toll when you are trying to focus on your health. You may feel motivated to finish your semester or year, but will likely need to lighten your course load. Many universities have on-campus associations for people with disabilities that often work with students with chronic or long-term illnesses. These services may be able to help you with alternative arrangements for tests or exams, note-taking services if you are temporarily unable to attend classes, and liaison services between you and the university administration.

You may however need to take time off from your program completely to focus on treatment and recovery. It is important to meet with your registrar, program coordinator and/or faculty advisor to discuss your specific options. Remember that taking time away from your studies is by no means a failure, and does not mean you cannot return to them. Treating your breast cancer and recovering physically and mentally is your priority. Listen to your body and mind and trust your decisions.

You may find it helpful to speak with other students in a similar situation as you. Some online support groups and bulletin boards, such as Willow (http://community.willow.org/), Breastcancer.org and Young Survival Coalition (www.youngsurvival.org), may have members who are or were recently students during treatment.

There are also some organizations focused specifically on youth and young adults with cancer — a population that is much more likely to be in school. Young Adult Cancer Canada (www.youngadultcancer.ca) can connect you with other young people with cancer, and may help you feel less isolated in your experiences.

INFUSION Canada is an organization focused on the unique needs of youth and young adults by promoting innovation, leadership and personal involvement in cancer survival. Most importantly, INFUSION Canada offers annual bursary programs for post-secondary education. The organization awards $2,000 bursaries each year to help cancer survivors further their education. You can reach them at www.infusioncanada.org.

Work

> *"Why did I work? I craved a sense of normalcy. Going to work, dealing with problems other than my own, and enjoying what I was doing helped me to deal with what I was going through… I'm also a bit stubborn and I didn't want to have to 'give up' more than I had to for this disease."*

If you are in the workforce when diagnosed with breast cancer, it is also important to understand how it will affect this aspect of your life. The decision whether or not to continue to work full or part-time is an individual one. Many people feel they need to take time off to focus 100% on themselves in order to get healthy again. Others do not have the financial stability to leave their jobs, or feel that they could benefit from the sense of accomplishment or distraction from cancer that their jobs provide them with. Whatever your decision, it can be emotionally troubling. You may feel exhausted and stressed if you need to work despite not wanting to. You may feel that you have lost your way if you have left a job you enjoyed. These are all normal reactions.

If you are working throughout your treatment, it is important to consider telling some people about your diagnosis. Under no circumstances do you need to tell everyone, but it may be helpful to let a few coworkers know. They may be able to help with projects or deadlines when you have appointments or if you are too sick to go to work.

It is important to tell your employer or supervisor. Though you may be capable of working during treatment, it will take a toll on you. Your productivity may be reduced, and you will have to miss work for appointments and treatments. You may also experience what is often referred to as "chemo brain," or thinking and memory problems commonly experienced by breast cancer survivors. Chemo brain can significantly alter your productivity and working style. You may need to write more notes or reminders for yourself, ask people to repeat themselves more often, organize your work space more efficiently, and give yourself more time to complete tasks.

Chemo brain is a recently recognized medical problem, but currently very under-studied. There are no treatments or cures as yet, so it is important to talk about your diagnosis with your supervisor and explain these changes in your day-to-day activities rather than have them reflect badly on you.

There are also resources which may prove helpful in dealing with returning to the workforce. Cancer and Careers is an organization committed to providing tools and information for employees with cancer, and can be reached at www.cancerandcareers.org. You may also find the following book helpful:

- *Your Brain after Chemo: A Practical Guide to Lifting the Fog and Getting Back Your Focus*, by Dan Silverman, presents findings from his research on the effects of chemotherapy on brain function, and presents easy-to-understand steps you can take to improve your memory and focus.

Financial Guidance

> *"I have savings of course… I will use them all… What happens when I do not have savings anymore?"*

Breast cancer, like any serious illness, can also put a strain on your financial situation. The Canadian Breast Cancer Network recently released *Breast Cancer: Economic Impact and Labour Force Re-Entry*, a research report based on a national survey of Canadians with breast cancer. The findings show that breast cancer is a financial as well as a health issue, with 80% of respondents reporting a financial impact.[11] Medical procedures, transportation, drugs and time off work can all add major costs to your day-to-day budget. This can severely increase levels of stress, anxiety and anger, combined with the emotional turmoil of the breast cancer itself. Financial guidance may not be as intimate as many other psychosocial issues, but it can profoundly affect your quality of life.

Many breast cancer organizations and websites contain information and advice for financial options during breast cancer. In addition, many other websites and organizations present similar financial information and advice, focusing on areas such as:

RRSPs, Home Equity and Similar Personal Financial Resources

Most advice for situations of financial strain brought on by an illness like breast cancer centre around using already acquired equity; that is, financial resources you already have. This may mean cashing in your bonds, RRSPs or other investments, taking a second mortgage on your house or cashing in a life insurance policy.

Supplementary Health and Disability Insurance

Whether this is a health plan at work or one you have purchased independently, supplementary insurance can help cover costs such as drugs, medical procedures and time off work. It is important to familiarize yourself with the terms and conditions of your coverage.

Employment Insurance Sickness Benefits

Employment Insurance Sickness Benefits can be paid up to 15 weeks. To qualify, you must be unable to work due to "sickness, injury or quarantine," and have worked 600 hours in the last 52 weeks. You can reach the information service at 1-800-206-7218 between the hours of 8:30 am and 4:30 pm, or go to www.servicecanada.gc.ca. Unfortunately, 15 weeks is often not adequate if you are going through radiation and especially chemotherapy.

Employment Insurance Compassionate Care Benefits

Compassionate Care Benefits can be paid out to someone who is temporarily away from work to care for a family member who is "gravely ill." To learn more, or to see if you or a family member may qualify, you can contact the information service at 1-800-206-7218 between the hours of 8:30 am and 4:30 pm, or go to www.servicecanada.gc.ca. Benefits last a maximum of six weeks. However, this benefit is generally not of use to recently-diagnosed breast cancer patients as they are not "gravely ill."

These are all valid options, but your circumstances may mean that you cannot make use of them. Young women are less likely to own a home or have contributed in large amounts to an RRSP. What if you have only been working part-time? Or have been at home caring for children? What if your employer doesn't provide supplementary healthcare? In these cases, the above options may not work, Employment Insurance Sickness Benefits may not last long enough, and Employment Insurance Compassionate Care Benefits as they are currently defined, generally do not apply to recently diagnosed breast cancer patients. Young women once again deal with a very different set of circumstances, this time financially. So what can you do?

It is important to check out every option available even if you may not qualify for all of them. Contact your cancer centre or hospital's Social Work Department where you can speak with a social worker who will help you find resources and discuss your financial options. You can also do research on your own to get an idea of what services are available.

The Canadian Cancer Society maintains province-specific web pages with information about financial assistance in your province or territory. You may also want to supplement any government or insurance-related remuneration with independent fundraising. Gather a group of family, friends and coworkers who want to help, and brainstorm ideas. Can you have a multi-family garage sale? A silent auction? A barbeque? Though these options may seem minor, every little bit of money can help when faced with breast cancer treatment and recovery. In addition, the outpouring of support you will get from events like this can be really encouraging.

Willow Breast Cancer Support Canada has also developed detailed, province-specific reports entitled *Coping with Your Financial Concerns When You Have Breast Cancer*, which can be accessed through their website at http://www.willow.org/get-information/publications/.

Wellspring, a network of cancer support centres across the country, also offers assistance with financial planning and getting back to work after a cancer diagnosis. Contact them at www.wellspring.ca.

Fertility

> *"Hearing you have breast cancer at the age of 37 is like being hit by a truck. Hearing you may not have children is like having the truck back up on you after you have been hit. I was lucky enough to have been given information about temporary menopause and fertility options in a timely manner. I think timing is key because if I had not been informed almost immediately I don't think I would have had enough time to freeze my eggs. Although I was an emotional mess, I was quite adamant about preserving my eggs before chemo, and refused to let cancer rob me of my right to someday be a mother."*

As a young woman, you are part of a unique population of breast cancer survivors for many reasons. One factor which dramatically sets you apart from older women is the issue of fertility. Young women like you are far more likely to have not yet had children, and if you wish to do so in the future, maintaining your fertility is an important issue.

Treatment that affects your fertility can increase your feelings of anger or lack of control. Facing the possibility of not being able to give birth can be devastating for some women. Fertile Future (www.fertilefuture.ca) is an organization dedicated to the unique fertility issues of cancer patients. Although they are not specifically focused on breast cancer, they may still provide you with useful information and support. Fertility problems combined with breast cancer treatment can be an emotional minefield. To deal with the issues that may arise, it is important to understand how your fertility will be affected and what your options are to maintain it.

Adjuvant therapy for breast cancer carries with it risks and side effects, some of which can cause harm to the ovaries and in turn affect fertility. There are many factors to consider when looking at your fertility options after a breast cancer diagnosis, including what type of cancer you have as well as what drugs you will be taking.

Radiation therapy for breast cancer is generally not considered to be an important factor in fertility issues, given that it targets an area far away from the reproductive organs. Chemotherapy, however, can have an effect. Some drugs in chemotherapy cocktails can pose a risk to the viability and longevity of your fertility. According to a Breast Cancer Care fact sheet, a group of drugs known as ''alkylating agents" are those most likely to cause infertility. One of these drugs, cyclophosphamide, commonly known as Cytoxan, is frequently used in combination with others to treat breast cancer."[12]

Don't hesitate to talk with your doctor about fertility side effects from your chemotherapy drugs. Obviously the first priority is eradicating your cancer, but if your treatment can include your fertility concerns, it should be discussed as an option. Most oncologists and medical professionals will be pleased to address your concerns and help you work out a treatment plan that takes your fertility into consideration. In the rare event that your oncologist does not consider this an important issue, you should seek out a second opinion.

Even when chemotherapy is finished, you may undergo treatments which can negatively affect fertility. Women with ER+ breast cancer are often prescribed Tamoxifen, a drug which interferes with the activity of estrogens. Tamoxifen is most often prescribed for a five-year period post-treatment. Although it affects each woman differently, the drug often causes menopause-like symptoms, such as fatigue, irregular or absent periods and vaginal dryness.[13]

A main concern for women taking Tamoxifen is time. It is crucial for women taking the drug to avoid getting pregnant, as studies have shown that its use during pregnancy can be harmful to a fetus.[14] For women who are closer to natural menopause, the window for childbearing may be rather small, and spending five years on Tamoxifen can interfere with this timeline. Some women choose to spend some time on Tamoxifen, go off the drug to get pregnant, and resume Tamoxifen after giving birth. It is important to explain your fertility goals to your doctor so a treatment plan can be worked out which you both agree on.

Now that you know some of the risks to fertility, it is important to know how to deal with them. Although this is not an option for every woman, you can try to work out a treatment plan that doesn't pose as much risk to your fertility. Several actions can be taken to safeguard fertility in the future, including cryopreservation and hormonal suppression of the reproductive organs.

Please note that there are advances in the area of fertility all the time, and you should always consult your healthcare team for up-to-date information on these and newly developing fertility options.

Cryopreservation

Cryopreservation involves the freezing of reproductive tissue, such as eggs, embryos or ovarian tissue, to be implanted after treatment. Fertilized embryos have been found to be more viable than eggs, although both treatments have been successful. Ovarian tissue cryopreservation involves removing one or both ovaries and freezing the tissue. The tissue can then be re-implanted post-treatment with the hope that it will start producing hormones and mature eggs again. Ovarian tissue freezing is still experimental and as of yet, there have been no documented pregnancies from eggs produced by the frozen tissue.[15]

The process of freezing both embryos and eggs involves stimulating the ovaries to produce mature eggs which are then surgically harvested, fertilized (in the case of embryos) and frozen. This process can be lengthy (lasting on average from two to six weeks),[16] expensive, and often involves hormonal stimulation. For these reasons, they may not be appropriate for you. It is important to speak with your doctor about your options.

Hormonal Suppression of the Reproductive Organs

Another option for fertility preservation during treatment is the hormonal suppression of the reproductive organs. This process involves using drugs (such as Lupron and Zoladex) to suppress the ovaries' production of estrogen, causing the ovaries to temporarily shut down or "hibernate" during treatment. This treatment is still considered experimental. Talk with your doctor to determine whether it could work for you.

Another issue to consider is your BRCA gene status. Women who have inherited mutations in the BRCA1 or BRCA2 genes from their family have an increased chance of developing not only breast cancer, but also ovarian cancer. Some women choose to have a proactive oophorectomy (removal of the ovaries) before there is a chance for cancer to develop, and some women must undergo the procedure after a diagnosis. The loss of one's own ovaries, and therefore the possibility of conceiving, will dramatically affect any family planning you may have done.

For some, it may be difficult to conceive post-treatment. For others, it may be impossible. Fertility is a deeply personal issue, and for many women it is linked to feelings of self-worth and control. Anger, sadness, guilt and grief are all normal emotions to be feeling, among others. Being unable to have biological children in the future can be devastating, but there are other options. Adoption and surrogacy are both viable choices, should you wish to have children. Services such as Canada Adopts (www.canadaadopts.com) and Canadian Surrogacy Options (www.canadiansurrogacyoptions.com) can provide you with introductory information and links to services in your area.

Pregnancy during Diagnosis and Treatment

For some women, concern about future fertility is overshadowed by concern about their current pregnancies. Women who are pregnant at the time of diagnosis are faced with a situation that is rare and under-studied, despite the fact that pregnancy-related cancers are on the rise. Where the options were once to either terminate the pregnancy or wait until birth before beginning treatment, thereby increasing the risk posed by the cancer, new treatment options are now being explored.

Increasing numbers of women who are pregnant when diagnosed are undergoing chemotherapy.[17] Chemotherapy treatment while pregnant is quite rare, as are the doctors who will endorse it. It is important to know that many medical professionals you encounter may not approve such a treatment course. Talk with your doctor and get a second opinion. Understand your desires, your options and your limits.

Breastfeeding

Women who have just recently given birth also face unique circumstances when it comes to breast cancer diagnosis and treatment. If you are breastfeeding, many suspicious lumps are brushed off as mastitis or other breastfeeding-related ailments. In addition, mammograms can be more difficult to read or inconclusive. If this is the case, a needle biopsy, or even an excisional (surgical) biopsy may be appropriate.

Lactation can make these procedures more complicated, and some medical professionals may refuse to do them before you wean your child. This process can take weeks, even months. Waiting to diagnose a suspicious lump can be nerve-wracking, and can give the cancer time to grow. Though the presence of milk during these procedures can be messy and may slow healing, it will not negatively affect recovery.[18]

If you do not wish to wean before these treatments, seek out a doctor or surgeon who is willing to work with you while you are lactating. In some cases, for example if an invasive surgical biopsy or lumpectomy is needed, you may not be able to continue to breastfeed.

Renowned breastfeeding expert Dr. Jack Newman suggests that you wean on one side, a process that can be done, although many healthcare professionals are not familiar with it. However, once treatment begins, it may be prudent to wean your child. The drugs included in your chemotherapy cocktail as well as other medications you may be taking are dangerous and not suitable to be ingested by a breastfeeding infant.

In addition to medical concerns, weaning can have an emotional impact as well. The bonding you and your child experience during breastfeeding can play a profound part in the development of your relationship. If you have weaned, you and your child may both feel that something is missing in your relationship, particularly if feeding is now being performed by another, such as a partner or parent. It is important to replace the physical contact that may have been lost. Ensure that you take time to bond with your young child through activities such as cuddling and playing.

Intimacy, Sexuality and Self-Image

> *"Music, singing and dancing has been a huge outlet for me in regaining my sexual confidence… Nothing makes me feel more confident and sexy. When I dance, I don't care about the extra weight on my thighs, or my wrinkles that are starting to show around my mouth, I'm happy. When I'm happy, I feel great and when I feel great I feel sexy and alive!"*

Intimacy and sexuality issues are common among breast cancer survivors, but are often overlooked by healthcare professionals whose attitude is often that intimacy and sexuality are not important when you are battling breast cancer. Of course fighting cancer is the priority, but it should not overshadow your quality of life, and intimacy and sexuality are often a crucial part of life.

Although it is an under-recognized problem, there are efforts being made to expose and discuss intimacy and sexuality post-cancer by authors such as sexuality counsellor Anne Katz, who addresses the issue in her book *Women, Cancer, Sex*. Intimacy and sexuality problems are most often caused by two equally powerful forces: physical changes related to breast cancer treatment and self-image. Both can be powerful and disruptive in your intimate life, and it is important to be aware of the issues they will raise and ways to deal with them.

Another book of specific interest to women with breast cancer is *Intimacy after Cancer: A Woman's Guide*, by Dr. Sally Kydd and Dana Rowett. This book features the voices and wisdom of cancer experts and the shared personal and intimate stories of cancer survivors. It also proposes solutions for rekindling libido and facilitating open communication. It includes interactive material like self-questionnaires, checklists and facts you should know.

Young women going through adjuvant breast cancer treatment often experience early-onset menopause or "chemo-pause." According to a Yale-New Haven Hospital report, 10–50% of women under 40 and 50–94% of women over 40 experience chemotherapy-induced menopause.[19] In addition to chemotherapy, some medications such as Tamoxifen may induce menopause or menopausal symptoms due to interference with estrogen production and absorption.

Physical Side Effects

Though side effects vary widely from woman to woman, some common ones include (but are not limited to): loss of libido, vaginal dryness, vaginal tightness, and in some cases, vaginal atrophy. These symptoms can all have profound effects on your sexuality and feelings (both mental and physical) towards intimacy.

Premature menopause and menopause-like symptoms of treatment will affect each woman differently. However, many women find that during and after treatment, their desire for sex and/or intimacy decreases. Advice on how to deal with a lessened sex drive differs and can range from exercising more to using sex toys.

Kydd and Rowett advise survivors to follow the "use it or lose it" guidelines. You may have zero desire for sex and in fact the act itself may be painful or uncomfortable, but these problems will not go away if ignored; in fact, the issues will probably be compounded and become harder to deal with. If sex and intimacy are important to your quality of life, it is best to face the problem head on. The primary thing to remember is that what works for one woman may not work for you, so experiment! Don't be afraid to try different things, and be honest with your partner about your feelings. Openness is key and miscommunication or silence can aggravate the problems you are already experiencing.

Vaginal dryness is often a result of natural menopause, but is also known to be caused by chemotherapy, as well as certain drugs, such as Arimidex, Aromasin, Femara, Tamoxifen and Faslodex.[20] Vaginal dryness is a very common occurrence. Less common, though not rare, is vaginal atrophy. Vaginal atrophy is marked by a severe thinning and inflammation of the vaginal walls. It can also cause the vaginal canal to shorten or tighten. These symptoms can make sexual intercourse extremely painful or uncomfortable. Many treatments for vaginal dryness or vaginal atrophy are location-specific estrogen replacements. Though the estrogen is released only in the vagina, and not designed to be absorbed into the blood stream, these products may not be appropriate for some breast cancer survivors, particularly if your cancer is ER+. Some of these treatments include the following.

Estring

The Estring is a ring inserted vaginally which releases Estradiol (a synthetic estrogen) over the course of three months. It is designed to "reduce the vaginal pH levels and to mature the vaginal mucosa."[21] The ring releases estrogen to improve vaginal lubrication and to increase moisture in the vaginal wall cells. Although it is not officially recommended for breast cancer patients, particularly those who are ER+, some believe that the estrogen is not absorbed into the blood stream in doses that would be of concern. It is important to speak with your doctor about whether or not this treatment is appropriate for you.

Vagifem

Vagifem is a tablet which, when inserted in the vagina, releases Estradiol to reduce vaginal dryness. It needs to be inserted every day for the first two weeks, and twice a week following that. As with the Estring, it is not officially recommended for breast cancer survivors. Again, talk with your doctor about whether this could be an appropriate treatment.

Many breast cancer survivors may find that estrogen-replacement products are not appropriate for their situation, and must therefore turn to a vaginal moisturizer. There are several products designed for menopausal symptoms, such as:

K-Y Liquibeads

K-Y Liquibeads are vaginally-inserted "beads" containing moisturizer, which are designed to relieve symptoms of vaginal dryness for up to four days. Many women enjoy the fact that they last several days, which means that spontaneity can still be an active part of their sex lives.

Replens

Replens is a vaginal moisturizer, to be applied internally, which lasts for several days. It is designed to restore vaginal moisture, rejuvenate the vaginal lining, and help eliminate dead skin cells.

Along with an everyday vaginal moisturizer, you will likely still need an additional lubricant when engaging in sexual intercourse. You may need to try several different brands or types (water-based or silicone-based) to find which one works best for you and your partner. If there is a feminist sex shop in your area, the staff will likely be very informed and able to help you find a product suitable for your needs. Otherwise, you may wish to investigate different brands online, and read reviews. The online support groups and bulletin boards mentioned in the Additional Resources section of this handbook may also proved helpful, as some of their members have likely experienced similar issues and may have advice to share.

Vaginal atrophy can cause shortening or tightening of the vaginal canal as the vaginal cells themselves shrink and lose elasticity. This can lead to painful and uncomfortable intercourse and a waning desire for intimacy. Where vaginal dryness can often be treated with topical remedies, vaginal tightness can be more difficult. Oftentimes, doctors will recommend vaginal dilators to slowly stretch the vagina to the point where sexual intercourse is comfortable again. Dilators can be purchased online, at www.vaginismus.com/products/dilator_set, or can often be obtained through your doctor or hospital. A dilator set is designed to be used over the course of several weeks or months. The dilator is used by gently inserting it into the vagina with the help of lubricant and leaving it in for a few minutes. The goal is to be able to move through the different sizes, until the largest dilator is no longer painful. This may take time, so patience is key!

Self-Image, Intimacy and Emotionally-Induced Loss of Libido

Not all intimacy issues are physical. No matter how dilated and lubricated you are, intimacy and sex may still be uncomfortable. Beyond menopausal symptoms, your sexual drive can also be strongly affected by your emotional state. Depression is a known cause for significant loss of sexual drive, but it is not the only one.[22] Women going through treatment may not be clinically depressed, but may be suffering from loss of libido nonetheless. Hormonal therapies and other drugs can also lower the libido of some women. Breast cancer treatment can leave you tired, anxious, scared and sad, and the last thing you may desire is sexual contact.

Cancer can also wreak havoc on one's self-image and self-esteem. Dramatic changes in physical appearance and health can have a profound effect on your ability and willingness to engage sexually or intimately with a partner. Breasts in particular have become such a sexualized body part that a breast cancer diagnosis can be particularly disruptive to your sex life, and losing one (or both) can cause upheaval in your feelings of sexuality and femininity. You may feel like you have lost a major part of who you are. You may wonder if your partner will still find you attractive, or if you will ever feel the same. Difficulties in adjusting are nothing to be ashamed of or worried about, yet these feelings may lead to a dramatic shift in your sexual experiences. A loss of self-confidence can diminish sex drive, make intimacy emotionally uncomfortable and generally alter your sexual self.

A 2006 report in the journal *Psycho-Oncology* entitled *Body Image and Sexual Problems in Young Women with Breast Cancer* found that a significant number of women experienced body image issues and sexual problems post-diagnosis. In those women who were sexually active, the most frequent body image issues were related to common psychosocial issues such as "mastectomy and possible reconstruction, hair loss from chemotherapy, concern with weight gain or loss, poorer mental health, lower self-esteem, and partner's difficulty understanding one's feelings."[23]

Young women with breast cancer were also found to have more body image issues and be less sexually active than healthy women in the same age range.[24] The study stresses the importance of getting proper information from your healthcare professionals as well as practicing open communication between you and your partner. It is important for you to know that these issues are common among survivors; you are not alone. Talk to your doctors, your therapists and your nurses, your friends in the survivor community. Ask what you can expect as a result of your diagnosis and treatment, and what they suggest.

Be open and honest with your partner. Do not try to hide your issues, as it will likely only compound the problems. Your treatment involves caring for yourself physically, but do not forget your emotional and sexual self. They are deeply important to your well-being and quality of life.

In addition to seeking professional guidance, you may find that there are things you can do yourself to regain some of the self-confidence and sexy feelings that you are missing. Some women find that being physically active in sports or dance helps them reconnect with their bodies in a safe, healthy and happy way. Try a new activity like a dance class, yoga or swimming to see if you can benefit.

Single Women

Dealing with issues surrounding altered sexuality during diagnosis and treatment can be particularly hard for single women. It is difficult enough to regain your sexuality with a significant other; what happens when there is no permanent partner?

In an article entitled *My Body My Self: Body Image and Sexuality in Women with Cancer*, sexuality counsellor Anne Katz discusses the difficulties faced by single women in this area. In particular, she mentions the unique issue of when and how to tell prospective sexual partners about their breast cancer history.[25] Disclosure issues are important in this situation. Emotions can run high in new relationships to begin with, and breast cancer can complicate things. Fear, anxiety and confusion are common feelings in new relationships, particularly with the added stress of deciding whether or not to discuss your present or past experiences with breast cancer.

There is, unfortunately, no universal remedy in these situations. Some would argue that being honest about your breast cancer status upfront is best, to avoid the possibility of being hurt later on in the relationship. Others would argue that this information is best revealed only to those you have gotten to know and trust, so they aren't intimidated by it. In any case, when or if to tell someone about your history with breast cancer is a personal choice, and each situation is different. What is important is to do what feels right for you. Don't be pressured into discussing your diagnosis when you don't feel comfortable, and don't hold back if you feel that the time is right to disclose this information.

Reconstruction

> *"At my initial appointment with my surgeon, my main concern of course was my mortality, especially being a young mother. However, I still found myself very concerned with my body image and losing my breasts, and insisting that I have reconstruction at the same time as my bilateral mastectomy. I knew the challenges ahead that I needed to face, and that it wasn't going to be easy. I knew I would lose my hair and my feeling of good health for awhile. I didn't want to have to deal with the loss of breasts as well."*

If the treatment for your breast cancer included a single or double mastectomy, you may be considering reconstruction. For some women, the idea of living without one or both breasts is a hard adjustment to make. Some want an immediate reconstruction after mastectomy, others want or are required to wait a period of time before reconstruction, and others choose to not get one at all. Reconstruction is an option, but not a necessity. Remember that whatever you feel most comfortable with is the right choice for you. Just as the loss of one or both breasts is an immensely difficult adjustment, reconstruction can be an equally emotional process. Take your time, talk to your doctors, family and friends, and decide what is best for you.

If you do choose to get a reconstruction, there are many different options. The procedure you will undergo depends on many different factors, including your body type and which breast is to be reconstructed. Though the type of procedure may be beyond your control, it is important to be familiar with some common types of reconstruction.[26]

Breast Implants

Breast implants are a more common type of reconstruction for slim or small-breasted women, who may not have adequate stomach tissue for an autologous reconstruction (plastic surgery that uses your own tissue to replace lost tissue). The breast implant procedure involves first inserting an expander, which is a balloon-like device placed under the chest muscle.

The amount of liquid in the expander is increased over time so that the new breast skin expands and allows a more natural look when the implant is later inserted. The implant itself may contain saline or silicone, depending on which type is chosen.

Autologous Reconstruction

Autologous reconstruction is a procedure whereby skin, fat and muscle is taken from the abdomen, back or buttock and used to reconstruct a breast. Using one's own tissue flap for the reconstruction is advantageous as it can maintain original blood vessels, and has the most "natural" breast feeling for anyone touching it. There are several types of autologous reconstruction, including:

TRAM flap

A TRAM flap reconstruction, named for the transverse rectus abdominus muscle, uses skin, fat and muscle from the lower abdomen to reconstruct the breast. The tissue is slid up under the skin, which allows many of the primary blood vessels to remain intact.

DIEP flap

A DIEP flap reconstruction, named for the deep inferior epigastric perforator — a primary blood vessel — uses tissue from the same area as a TRAM flap. With a DIEP flap, however, only skin, fat and blood vessels are removed, not muscle. This tends to make the recovery easier and more comfortable.

Latissimus Dorsi flap

A Latissimus Dorsi flap is named for the muscle which wraps around from under the armpit to below the shoulder blades. For the reconstruction, skin, fat and muscle from this area is slid under the skin into the breast area. This tends to be an option for women with smaller breasts, as there is less excess tissue here than in the lower abdomen.

Buttock crease transfer

For a buttock crease transfer, skin, fat and muscle are removed from the buttock and transplanted into the chest. This procedure is rarely performed, as it is much more complex than other autologous reconstructions because of the very delicate work needed to reconnect blood vessels to keep the tissue alive.

Self-Care and Healthy Living

> *"I was diagnosed with Stage II breast cancer, colon cancer and skin cancer in 1987; with 3 primary cancers I figured my life was almost over. My husband had other ideas and coached me to believe that I could live to see our children grow up. With support, I decided to make healthy lifestyle choices in many areas: nutrition, exercise, sleep, deep relaxation, stress management and others which promote good mental, physical, spiritual, and emotional health. Now I've been cancer free for 22 years, and I'm so grateful that I chose this path."*

After a diagnosis of breast cancer, your life can become incredibly busy, confusing and hectic. Throughout your treatment, you will be focused primarily on beating cancer. As previous chapters of this handbook show, however, it is likely that you will also be concerned with other aspects of your life, such as family, work and finances. During diagnosis, treatment and even post-treatment, it is important to focus on you. Not just on your cancer or your treatment schedule or your side effects, but *you*.

As described in the chapter on Mental Health and Emotional Issues and throughout other sections of this handbook, breast cancer profoundly affects your emotional wellbeing and quality of life. It is important to remain realistic and to recognize and understand your diagnosis and treatment plan as well as its potential side effects and success rate.

However, you should not focus exclusively on the negative aspects of your new life. Focusing energy on building a positive outlook regarding your treatment and recovery can help you feel better mentally and physically. You will probably have many other parts of your life that require your attention and energy, from children to work to marriage. It is still important to make time to focus on yourself, because by re-energizing and focusing on feeling better inside, you will have more to offer those around you. Whenever you can, take time for something that calms, relaxes or rejuvenates you.

Whether it's reading a book, taking a walk, having a bath, or watching a movie, participating in an activity you enjoy can help toward increasing your emotional wellbeing.

It is also important for you to have healthy living habits in order to maintain your physical strength and health. Taking care to monitor nutrition and exercise levels is an important part of a healthy, post-treatment lifestyle; being overweight has been linked to lower survival rates and increased rates of breast cancer recurrence.[27] For this reason alone, it is important for you to maintain a healthy weight after your treatment. Eating well and exercising regularly can also have other positive side effects, such as raising energy levels.

Nutrition

A healthy lifestyle does not start with a fad diet. Instead, you need to take a critical look at your eating habits, and make permanent, healthy changes. Canada's Food Guide (which can be found at www.hc-sc.gc.ca) outlines what a healthy diet looks like. By following the recommended number of servings and including a variety of food, the nutritional requirements can easily be met. There are also many breast cancer-specific websites that offer additional nutrition information, including the Canadian Breast Cancer Network (www.cbcn.ca), the Canadian Cancer Society (www.cancer.ca), the American Institute for Cancer Research (www.aicr.org), BreastCancer.org (www.breastcancer.org) and Susan G. Komen for the Cure (www.komen.org). Their advice follows general suggestions about healthy eating habits.

Eating more fruits and vegetables

Canada's Food Guide recommends that adult women aged 19–50 should be eating 7–8 servings of fruits and vegetables per day. This number may seem high, but it is a healthy goal to strive for. You can increase your fruit and vegetable intake by adding them to regular meals and by having them as snacks. Try including berries or bananas with your morning cereal, and eating a salad with lunch and dinner. Avoid boredom by trying new and different fruits and veggies such as passion fruit, papaya, bok choy, chard…try to pick a new one every time you go to the grocery store. You may be surprised by how much variety there can be! For more tips and recipes you can go to the Half Your Plate website (www.halfyourplate.ca).

Including whole grains

A food is described as “whole grain” when the entire grain seed is used, including the fibre, vitamin and mineral-dense germ and bran parts. Whole grains, including oatmeal, brown rice, air-popped popcorn and barley, can help you feel full and have numerous other health benefits. They have been shown to help reduce the risk the of heart disease, stroke, diabetes and hypertension.[28] Canada’s Food Guide recommends having six to seven servings of grains a day, at least half of which should be whole grain.

Limiting saturated and transfats

Saturated fats (found in animal fats, butter, cheese, etc.) and transfats (found in some animal fats, shortening, some margarines and many deep-fried fast foods) can increase your risk of developing heart disease.[29] Instead, try healthier fats such as olive, canola and sunflower oils, and foods such as nuts, salmon and avocado, which are all high in healthy fats. Remember that all fats are high in calories and even foods high in healthier fat should be eaten in moderation. Canada’s Food Guide recommends limiting the total amount of added fat to two to three tablespoons per day.

Limiting red meat

Red meat is an important source of iron, protein and vitamin B12, but consuming an excess amount can contribute to an increased risk of some cancers and difficulty maintaining a healthy body weight.[30] Try to use only the leanest cuts of red meat and limit your consumption overall. Instead, try to include poultry, fish or other meat alternatives.

Managing portion sizes

It is not only important to eat healthy foods, but to do so in proper proportions. This is particularly essential when eating out, as many restaurants provide far more food than is required for a healthy adult to eat. You don’t have to eat it all! Eat a healthy portion, enough so that you are comfortably full, and ask for the rest to go. That way, you can stretch the food (and money) for two days. Even when you are at home, take the time to plan meals and be aware of how much you’ve already eaten. Don’t eat mindlessly, as you will be more likely to overeat.

Getting enough calcium and vitamin D

Studies have shown that decreased levels of estrogen in women with premature menopause increases the risk of osteoporosis.[31] To maintain healthy bones and reduce the risk of developing other chronic diseases, ensure that your diet is providing you with enough calcium and vitamin D, and use additional supplements if necessary. You can learn more at the Osteoporosis Canada website (www.osteoporosis.ca/index.php/ci_id/5533/la_id/1.htm).

Whether you are looking to lose or gain weight or maintain your shape, it is important to be healthy. Everyone's body shape and height are unique, and so are their dietary needs. The above tips are general ideas to improve eating habits, but you may need more direction. Dieticians of Canada can provide you with more detailed information and help connect you with a registered dietician in your area. They can be reached at www.dietitians.ca. You may also benefit from books which can help provide you with descriptions of healthy foods and methods to prepare them, including:

- *What to Eat if You Have Cancer: Healing Foods that Boost Your Immune System*, by Maureen Keane and Daniella Chace, provides an analysis of the body's physical make-up, outlines how nutrition affects their function and provides nutrition tips to help make treatment more effective and reduce its side effects.

- *Foods that Fight Cancer: Preventing Cancer Through Diet*, by Richard Béliveau and Denis Gingras, explains the science of the food we eat and outlines the cancer-fighting properties of some.

- *Eating Well, Staying Well, During and After Cancer*, by Abby Bloch, outlines ways in which proper nutrition can help you feel better, keep up your strength and energy, lessen side effects and maintain your weight during cancer treatment.

Exercise

Being active is another important part of leading a healthy life. Regular exercise is a key factor in maintaining a healthy weight, and studies have shown that women who do not exercise regularly are at a higher risk of developing breast cancer.[32]

Canada's Physical Activity Guide recommends that adults get 30 to 60 minutes of moderate physical activity every day. This activity does not need to be exceedingly strenuous, nor does it have to be done all at once. Try to integrate healthier choices into your daily routine, such as walking to work, taking the stairs, playing at the park with your kids or even doing extra yard work. On days when you have more time, try to organize a more structured activity, such as jogging around your neighbourhood, a family bike ride or swimming at your local pool. Being active can help you look and feel better and can be beneficial to your health, so try to incorporate new and exciting activities into your life.

Many breast cancer survivors also get involved with Dragon Boating. The sport has clubs and teams comprised of breast cancer survivors throughout North America. You can find links to groups in your area at the Canadian Breast Cancer Network (www.cbcn.ca) and information about the national Dragon Boat movement at CanadiansAbreast (www.canadiansabreast.com).

Survivorship

> *"For me, I found that once my last treatment ended I was thrilled, and so were the people around me. For most people that seemed to be the end of their cancer experience; I thought it would have been for me as well, but it wasn't. The events of the last year started to sink in, emotions were high, and I had to try to figure out how to start life over as a very different person — someone that has to live with the constant fear of the 'Big C.'"*

Young women with breast cancer face a variety of issues unique to their age, some of which do not end when treatment does. Due to their age, young women will spend a much larger period of their lives as survivors, and with this comes emotional and physical challenges. When treatment ends, most women hope that everything will go back to normal, and that their lives will return to what they were before breast cancer. However, this may not be the case. Many women struggle with breast cancer, physically and emotionally, long after treatment ends.

When treatment ends, life changes and a "new normal" begins. During treatment, you may have had many people — family members, friends and coworkers — offering their help and support. When treatment is over, they may assume that you no longer want or need their help anymore. But your life may not be back to normal; you may be heading back to work or school, looking for a new job and adjusting to life as a survivor. With these changes comes a huge emotional shift, which can be harder than you may think. Don't be afraid to tell those close to you that you are still struggling and still need their support. It is healthier to be honest rather than try to contain your feelings of being overwhelmed, distressed or anxious.

For many women, fear of recurrence can be a huge emotional burden. Women who have had breast cancer have an increased chance of getting a new breast cancer, and this can weigh heavily on your mind. It is important to be aware of your risks and work towards a healthier lifestyle, but you should not dwell on "what-ifs". It is true that there is a chance that you will be diagnosed with breast cancer again. But if you are in the recovery stage, you have the freedom to live without surgeries, chemotherapy or radiation and countless medical appointments. You have the opportunity to live your life how you want to live it, and you should take full advantage of this. Do not focus on the negative possibilities but rather the positive certainties.

Many breast cancer survivors also struggle with "survivor's guilt" when faced with the reality of friends or family lost to the disease. Along with feelings of happiness or relief that come with finishing treatment, you may be burdened with feelings of grief and guilt. "Why me?" may be a question you ask yourself often, wondering how it is that you have survived when others haven't. This is a normal reaction. A breast cancer experience is traumatic, tumultuous and profoundly affecting, and the emotions that come along with it are not going to go away as soon as treatment ends. It is important not to ignore the feelings of guilt you may have, but rather to understand and work through them.

You have survived although many have not; do not let this fact control the life you still have to live. Remember those who have lost their battle with breast cancer, and live your life to its fullest in memory of them.

Metastatic Breast Cancer

> *"When I was diagnosed, my breast cancer was already at Stage IV. I had metastases to my liver, spleen and bones…Even though I still battle this disease and have been told there is no real chance for a cure, I consider myself lucky in some ways. I am young enough that I can tolerate many of the treatments better than I probably would if I were older, and I am outspoken enough to push for more aggressive treatment."*

As a young woman with breast cancer, the possibility of a recurrence may weigh heavily on you. Studies have shown that that breast cancer in young women is often more aggressive[33, 34,35] and young women are often diagnosed at a later stage than their older counterparts.[36, 37] It is perhaps no surprise, then, to know that young women also have a higher risk of a recurrence.[38, 39]

Breast cancer recurrences can take one of three forms:

- Local, where the cancer returns to the breast (or surrounding tissue) where it originally occurred
- Regional, where the cancer returns in the lymph nodes near the breast or on the chest wall after mastectomy
- Distant (metastatic), where the cancer returns in another part of the body [40]

Metastatic breast cancer, also referred to as advanced or Stage IV breast cancer, is a cancer that has not only returned, but has spread through the blood stream to other organs. An original occurrence of breast cancer may also be diagnosed at Stage IV if the cancer is not discovered until it has already metastasized. The most common organs for metastases are the bones, lungs and liver.[41]

There is no cure for metastatic breast cancer. Unlike local or regional recurrences, where the cancer may be operable, metastatic breast cancer cannot be completely removed once it has spread to other organs.[42] However, this does not mean it cannot be treated. Some women believe that a diagnosis of metastatic breast cancer means that death is inevitably near. This is not necessarily the case! Your cancer can be treated, and some women go on to live many years — even decades — with the disease.

Treatment for metastatic breast cancer will be different than the treatment you received for your original occurrence. Because it cannot be cured, the treatment now focuses on managing the cancer and minimizing its side effects. The goal of treatment is to help you live as well as you can for as long as you can. Your quality of life is important, and the treatment regimen you and your healthcare team agree upon should treat that as a priority. Treatment for metastatic cancer falls into three main categories:[43]

- Systemic (whole-body) Treatments
  - This includes hormonal treatments for cancers that are hormone-receptor-positive (ER+ or PR+), chemotherapy, and drugs like Herceptin, if the cancer is HER2+
- Local Treatments
  - This includes surgery or radiation on a particular metastasis
- Pain Management
  - This can range from Aspirin, acetaminophen or ibuprofen to more powerful opioids, depending on the location, cause and severity of your pain

Metastatic breast cancer changes your life. Treatment becomes a constant, ever-evolving element rather than a scheduled hurdle to overcome. Your treatment plan may vary often if the cancer stops reacting to certain drugs. The disease and its treatment can cause numerous side effects, some of which can be disruptive to your quality of life. Fatigue and decreased appetite are common, and may need to be addressed through medication or other therapies. If your cancer has metastasized to your bones, you may require bone-strengthening drugs (bisphonates).

You may wish to integrate alternative or complementary therapies into your treatment regimen, including physical therapy, acupuncture, massage and yoga.

You will find that you are more comfortable with treatment when you are educated about the different options available. AdvancedBC.org (www.advancedbc.org) is a website dedicated to providing information and support for women with metastatic breast cancer as well as their friends and family. Many other websites, including the Canadian Breast Cancer Network (www.cbcn.ca). Susan G. Komen (www.komen.org) and BreastCancer.org (www.breastcancer.org) have information on their websites about metastatic breast cancer along with common treatments and current clinical trials.

Along with the physical side effects from the disease, the emotional impact of metastatic breast cancer can be profound. You may grieve the loss of a way of life you had grown accustomed to, one without the burden of breast cancer and treatment. This grief is important. Do not try to ignore your feelings. Rather, be honest with yourself. It is important to face your fears, in order to overcome them. Be honest with your family and friends about the ways in which you are reacting. It is important to remember, and be encouraged by, the many women who live long, productive lives with metastatic breast cancer.

Different women deal with the shock of diagnosis in varied ways. Your doctors and nurses can refer you to a mental health professional to help you work through your emotions surrounding the illness. If you would benefit from sharing your story with other women in a similar position, you may wish to look into support groups in your area. Your doctors, nurses, and hospital social workers may be able to help with recommendations. If you feel that you would be more comfortable sharing in an online format, the Young Survival Coalition's bulletin board includes an informative, helpful and supportive section for metastatic breast cancer concerns. It can be reached at www.youngsurvival.org/metslink.

You may also find comfort in the above-mentioned alternative therapies, or in other activities like yoga, journaling, art, guided imagery or meditation. There are also several books which may prove helpful, including:

- *100 Questions and Answers About Advanced and Metastatic Breast Cancer*, by Lillie D. Shockney, which presents informative and practical answers to many questions about metastatic breast cancer and includes comments from patients.

- *With the Help of Our Friends From France: Stabilizing and Living With Advanced Breast Cancer*, by Carol Silverander, which presents the story of Silverander’s diagnosis of metastasis to her liver and her subsequent treatment journey, including her discovery of an innovative treatment pioneered by French doctors.

Metastatic breast cancer will be uncharted territory for you, and it is best to approach it with an open mind to help discover what is useful for your situation.

End of Life

> *“My daughter always took a positive outlook on life. She accepted the tests and breast cancer treatments with determined optimism and said “let’s get this show on the road.’ Sadly the predictions of hope were not to be realized. Shan passed away a few months after her initial diagnosis. Her cancer was not detected early and it spread quickly. Shanna was only 24.”*

Treatment for metastatic breast cancer is a long, hard process. Eventually there will come a time when treatment ends, either by your own choice or by necessity. While metastatic breast cancer is treatable and women can live for many years with the disease, the treatment can take a toll on the way you live your life. If the disease has progressed significantly, you will reach the point where the treatment has a considerable impact on the quality of your life. Pursuing every new treatment can be a burden — physically, financially and emotionally — for you and your family. You may reach a point where your body, mind and soul are telling you “enough!”

Reaching your treatment limit can be devastating. Even if you have fought as hard as you can, there will come a time when treatment is no longer effective, and you must instead start planning for the end of your life. This shift in focus can be very emotionally challenging, and you may run through a battery of emotions from shock and disbelief, denial and anger, to grief, fear, and anxiety — sometimes it may seem like you feel these emotions all at once.

It may be comforting for you to know your range of options so you can decide how you want to experience your end of life. Now is the time for palliative care, a treatment which focuses on ensuring you have the best possible quality of life leading up to your death. During this time, your healthcare team should focus on keeping you and your family comfortable. Organizations such as Canadian Virtual Hospice (www.virtualhospice.ca) and the Canadian Hospice and Palliative Care Association (www.chpca.net) can provide much valuable information and support about this subject.

During this challenging time, it is important to be communicative with your family and your healthcare team about your wishes, especially whether you wish to live out your final time in hospice care or at home. Look at your situation with a critical eye, and ask yourself, "How do I want to live the rest of my life?"

You now face the incredible struggle to hold your family close to your heart while coming to terms with letting go. The emotional impact of end-of-life care will be felt by everyone close to you. Remember and respect the fact that everyone has their own way of coping. One family member may be overcome with grief and quite open with their feelings, while another may pull away and adopt a stoic attitude. Remember that this does not mean that they feel differently about their love for you.

Studies have shown that patients who feel that they are a burden on their family or other caregivers are more likely to experience end-of-life distress.[44] Thus, it is important to have open channels of communication with your family members, friends and other loved ones regarding your care. If you understand their reactions to this situation, it will likely be easier to focus on *you* during this time rather than spending time worrying about *them*.

You cannot control the way others react to your situation, but you can control the way you react to your situation. Remember that your attitude is what you make of it. You may feel profound grief at the loss of your future. Try to shift your thinking from focusing on what you may miss in the future to appreciating what you have now. Strive to remember that you have much to live for in the moment. At this time, seeking professional help is greatly encouraged. Your healthcare team can refer you to an appropriate mental health professional, who can help you work through your emotions surrounding this difficult situation. Your spiritual or religious leaders and others who are part of your community of faith can also help you centre your faith and assist you with your transition from this world to the next, if that is part of your beliefs.

There are also small ways in which you can help yourself cope. If you are able, you may take solace in gentle activities such as yoga, meditation or prayer. If it is important for you to leave something meaningful behind for your partner, children or other family members, you may wish to write letters, paint pictures, or record your thoughts for them. Many women find this time an opportunity to share feelings and discuss things they never thought they would, or could, with their families and loved ones.

Navigating such an unknown part of your life can be incredibly daunting. Written resources can help you work through some of the confusion surrounding your end of life and can provide information and support for your caregivers and family members. Some useful titles may include:

- *Dying Well: Peace and Possibilities at the End of Life*, by Dr. Ira Byock, which explains the end-of-life process using numerous case studies and discusses not only the sadness and grief associated with death, but also the wisdom, hope and joy that can be found.

- *Handbook for Mortals: Guidance for People Facing Serious Illness*, by Dr. Joanne Lynn and Dr. Joan Harrold, which offers sensitive and practical advice for both caregivers and the dying about the final stage of life.

- *What Dying People Want: Practical Wisdom for the End of Life*, by Dr. David Kuhl. Ideal for caregivers and family members as well as the patient, Kuhl's book effectively presents strategies on how to foster good communication during the end of life process.

- *I Don't Know What to Say: How to Help and Support Someone Who's Dying*, by Dr. Robert Buckman. Written for caregivers, family or friends, Buckman's book provides practical, straightforward suggestions for providing comfort during end of life.

Dying is an overwhelming process for everyone. Trying to come to terms with it will be a challenge, never more so when there are children involved. Explaining your situation to your children or any other young family members and loved ones will be an incredibly difficult process. Talk with your partner, other family members and your healthcare team about what you feel is the best way to approach the issue. Religious or spiritual leaders in your community will also be able to take part in this process if you and your family belong to a religious community.

It is particularly important that you and your partner be in agreement on how to approach the discussion with your children. If kids receive conflicting messages from their parents, it may increase their confusion and intimidate them. Every child will react differently. Some may be vocal with their fear and sadness about losing you. Others may try to block these feelings out, or try to pull away from you to protect their emotions. If your children are very young, they may not understand at all, and show little interest in discussing it. It is important for you and your partner to be flexible and open to altering your approach to fit each child.

You may wish to use books as an aid to explain your end of life, and help your children understand their feelings. Some helpful titles include:

- *Help Me Say Goodbye: Activities for Helping Kids Cope When a Special Person Dies*, by Janis Silverman. Silverman's book presents art therapy activities to help children express their emotions and cope with the death of a loved one.

- *I Miss You: A First Look at Death*, by Pat Thomas. Thomas' straightforward and direct book discusses death as a natural part of life, and encourages children to understand their emotions in order to work through them.

- *Aarvy Aardvark Finds Hope*, by Donna R. O'Toole. In her book, O'Toole presents the story of Aarvy, an aardvark who loses his mother and brother. The book is a sensitive, loving story of coming to terms with loss.

- *Why Do People Die?* by Cynthia MacGregor. This poignant and straightforward book aims to answer questions that children may have after the death of a loved one.

End-of-life is an experience for which no one can truly offer advice, only suggestions. Seek guidance and support from family and friends. Be honest and open with your loved ones. Take solace in your religion or spiritual beliefs if they have been part of your life or if you have rediscovered them through this part of your journey. Take time to appreciate the memories your life has provided you, and those with whom you spent those years.

Ultimately, it is your experience, and your choice how to spend this time. Each person is unique, and so is each end-of-life experience. Trust yourself to know what you want and what you need during this time.

Conclusion

We hope that this resource has provided you with valuable information that you feel can benefit your understanding of and approach to the psychosocial impact of fighting breast cancer. It is important to remember that the suggestions presented in this resource are just that — suggestions. Every woman's breast cancer experience will be unique. Don't feel as though these suggestions are hard and fast rules. The main message we hope to present here is that you should *trust yourself*. Only you can truly know what the best approach is, so remember that while everyone may offer valuable insight, it is important for you to synthesize the information you receive for *your* situation.

The breast cancer journey is a constant learning curve. Seek out information from resources, friends, medical professionals and people who have walked in your shoes. Knowledge is power, and can provide much comfort during this time. In addition to the resources we have included in the previous chapters, we have provided additional lists following this section. Please take advantage of these wonderful organizations and services during this time in your life.

Remember, every day you fight breast cancer is a day you survive it. You are, and will forever be, a survivor.

Definitions

Please note that this information should not replace medical advice and that new information, procedures and treatments may be developed that are not described here.

Adjuvant therapy

Adjuvant therapy is a term used to describe treatment given following primary treatment. In the case of breast cancer, primary treatment is usually lumpectomy or mastectomy, followed by adjuvant radiation or chemotherapy.[45]

Biopsy

Needle biopsy

A needle biopsy consists of the removal of tissue from a suspicious lump for further examination, with either a thin needle (fine-needle aspiration biopsy) or wide needle (core biopsy).[46]

Incisional / excisional biopsy

More akin to regular surgery, incisional and excisional biopsies are performed using a scalpel. For an incisional biopsy, a portion of the suspicious tissue is removed. An excisional biopsy is more invasive, and the entire suspicious mass is removed, as well as a small layer of normal tissue around it (a "margin").[47]

BRCA 1 / BRCA 2

BRCA 1 and BRCA 2 stand for Breast Cancer susceptibility gene 1 and 2, respectively. Mutations in these genes are linked to hereditary breast cancer. Having a BRCA1 or BRCA2 genetic mutation does not guarantee that you will develop cancer, but it does increase the chances. For example, American estimates show that approximately 12% of women in the general population will develop breast cancer, versus 60% of women with a harmful genetic mutation.[48]

Chemotherapy

Chemotherapy is a treatment which uses drugs passed through the blood stream to interfere with rapidly dividing cells. Each patient's chemotherapy "cocktail" and regimen will be different, based on their unique breast cancer factors.[49]

Chemo-pause

Chemo-pause is a slang term used to describe the temporary, chemical-induced state of menopause or menopause-like symptoms experienced by some women during chemotherapy.

ER+ / ER–

ER+ and ER– are terms used to designate Estrogen Receptor positive and Estrogen Receptor negative breast cancer. The growth of ER+ breast cancer is fuelled by estrogen. The growth may be inhibited when treated with drugs that block estrogen from binding (such as Tamoxifen).[50]

HER2/neu

HER2/neu, or Human Epidermal growth factor Receptor 2, is a protein shown to be associated with higher levels of aggressiveness in breast cancer.[51]

Mastitis

Mastitis is a breast infection which occurs regularly in breastfeeding women which can cause small blockages or lumps.[52] When a breastfeeding woman presents with a suspicious breast lump, it is often assumed to be mastitis.

Neo-adjuvant therapy

Therapy (usually radiation or chemo) administered before the primary treatment (usually surgery) in order to shrink a tumour.[53]

Palliative care

Palliative care refers to treatment that focuses on reducing the severity of side effects or symptoms of an illness, rather than reversing the progress of the illness itself.

PR+/PR–

Similar to ER+ or ER– breast cancer, PR+/PR– refers to whether or not the cancer's growth is fuelled by the hormone progesterone. The growth of PR+ breast cancer may be inhibited by drugs which block progesterone from binding.[54]

Radiation therapy

Also called radiotherapy, radiation therapy uses high-energy beams to damage the DNA of cancer cells and thus inhibit their replication.[55]

Triple negative breast cancer

Triple negative refers to breast cancers which are ER–, PR– and lack HER2/neu. They will not respond to hormonal treatments, and are thus treated primarily with chemotherapeutic agents.[56]

Additional Resources

Information

Canadian Breast Cancer Network
www.cbcn.ca

The Canadian Breast Cancer Network is a survivor-directed, national network of 225 organizations and hundreds of individuals. The Network aims to develop and encourage linkages between groups and individuals concerned about breast cancer, and to focus national attention on breast cancer, ensuring that issues faced by Canadians affected by breast cancer influence decisions of research and healthcare policy. CBCN is a place to turn to for breast cancer patients and survivors. The Network's website has a special section for young women living with breast cancer.

Breast Cancer Society of Canada
www.bcsc.ca

As a national, not-for-profit charitable organization, the Breast Cancer Society of Canada works to fund Canadian research in the aim to ultimately find a cure.

Canadian Breast Cancer Foundation
www.cbcf.org

Established in 1986, the Foundation works to fund, support and advocate for breast cancer research and education. Their annual CIBC Run for the Cure has raised millions of dollars for research since its inception.

Canadian Cancer Society
www.cancer.ca

The Canadian Cancer Society is a national organization dedicated to eradicating cancer and enhancing the quality of life of those living with cancer. Their support services can be reached at 1-888-939-3333. Here individuals can speak to a Cancer Information Specialist about medical questions, get information about community and financial support, and have the opportunity to connect with the peer support program, where they can speak with a cancer survivor who has had a similar experience.

PYNK: Young Women's Breast Cancer Program
www.sunnybrook.ca/glossary/item.asp?i=275&page=2140

The objective of this program at Toronto's Sunnybrook Hospital is to enable young women diagnosed with breast cancer to benefit from new treatment options and to provide them with knowledge about prevention and screening. Young women across Canada are encouraged to call with questions or to schedule a formal second opinion. PYNK's program coordinator can be reached at 416-480-5000 ext 1059.

Rethink Breast Cancer
www.rethinkbreastcancer.com

Rethink Breast Cancer is dedicated to making the breast cancer cause more relevant and accessible to young people through education, research and support programs. Rethink's Peer Support line can connect you with a young woman who has had a personal experience with breast cancer, and can provide one-on-one support.

Team Shan Breast Cancer Awareness for Young Women
www.teamshan.ca

Team Shan is named for Shanna Larsen, who was only 24 when she lost her life to breast cancer. This not-for-profit organization was founded in her memory and is dedicated to raising awareness that breast cancer is not just a disease of older women. Team Shan works to educate young women, healthcare professionals and the public about early detection, risk reduction and prevention of breast cancer.

Wellspring
www.wellspring.ca

Wellspring is a network of cancer support centres across the country which can help you connect with support groups and programs in your area.

Willow Breast & Hereditary Cancer Support
www.willow.org

Willow provides free support and information for those affected by breast cancer. Willow's Peer Support Service offers the opportunity to connect with breast cancer survivors trained to provide emotional support, help navigating medical information, and information on local support groups. Willow also offers an online community where you can meet, connect and share with other breast cancer survivors.

Online Support

Caring Voices
www.caringvoices.ca

Caring Voices is an online community for all cancer survivors, and provides chats and discussions as an opportunity to connect with other survivors like you.

Young Survival Coalition
www.youngsurvival.org

Young Survival Coalition is an international organization based in the United States dedicated to increasing the quality and quantity of life for women ages 40 and under, diagnosed with breast cancer. Their website offers a lively and informative bulletin board where you can connect with other survivors and gain insight, information and support.

Books

Fighting for Our Future: How Young Women Find Strength, Hope and Courage While Taking Control of Breast Cancer, by Beth Murphy. Murphy's book presents a clear, informative and non-judgmental resource to help young women navigate through treatment and live with breast cancer. Murphy provides readers with information about treatment options, questions to ask doctors and first-hand accounts of young women who have experienced breast cancer.

Dr. Susan Love's Breast Book, by Susan Love. Widely seen as the "bible" of breast health books since its release in 1990, Love's book covers everything breast and breast cancer-related, from risk factors to alternative treatments, with everything in between.

The Breast Cancer Survival Manual, by Dr. John Link. Dr. Link's book provides clear help through the challenge of breast cancer, with information on many important subjects, such as how to read a pathology report and to how to get a second opinion.

Memoirs

Breastless in the City: A Young Woman's Story of Love, Loss and Breast Cancer, by Cathy Bueti. Bueti's memoir explores her experiences going through breast cancer treatment while in pursuit of love. Balancing chemotherapy treatments, doctor's appointments and dates, Bueti's story is filled with honesty and laughter.

Cancer Vixen: A True Story, by Marisa Acocella Marchetto. In this graphic novel, cartoonist Marchetto takes the reader along with her on her breast cancer journey, surrounded by her fiancé and her fabulous friends, all with the glamorous backdrop of New York City.

Eating Pomegranates: A Memoir of Mothers, Daughters and the Breast Cancer Gene, by Sarah Gabriel. Gabriel's attempts to come to terms with the fallout of the genetic link she shares with her mother — BRCA1 — is presented in her passionate, honest and ultimately hopeful memoir.

I'm Too Young to Have Breast Cancer!: Regain Control of Your Life, Career, Family, Sexuality and Faith, by Beth Liebson-Hawkins, which presents personal stories from 16 young breast cancer survivors.

Reflections of a Woman: My Memoir of Breast Cancer: Loss, Love and Laughter, by Lisa Tugnette. Diagnosed at 36 on the same day as her mother, Tugnette's memoir presents her breast cancer journey with passion, warmth and honesty.

The Red Devil: To Hell with Cancer — and Back, by Katherine Russell Rich. In this hard-hitting, honest and witty memoir, Rich holds nothing back as she describes her experience with breast cancer. Through problems with doctors, fundamental shifts in relationships and her disease's progression, Rich details her journey from confused and fearful to a "kick-ass cancer patient." Rich's blunt descriptions of her experiences can be harrowing; as such, this book may not be for everyone.

Why I Wore Lipstick to my Mastectomy, by Geralyn Lucas. In her memoir, Lucas presents a witty, heartfelt and honest look at her breast cancer journey, from her diagnosis at 27 years old, through her treatment and recovery, to the birth of her daughter.

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