

network news

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Canadian Breast Cancer Network
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Letter from the Chair of the Board of Directors

Since a breast cancer diagnosis can be distressing, this issue of *Network News* aims to relieve some of that distress by offering support to you and your family. In these pages, you'll find supportive articles on how to talk to your children about your breast cancer diagnosis, how important self-care is for your caregivers, when to seek professional help for depression and anxiety, and how hypnotherapy can complement your cancer treatment.

We also feature information and a first-person account about inflammatory breast cancer. As you will read in Caroline Corriveau's article, this form of breast cancer is rare and can be difficult to diagnose. If your breast is red and inflamed, or if you have any other concerns about changes in your breast, contact your healthcare provider.

We hope that these articles will make your life as a breast cancer patient or survivor a little easier with the knowledge that we at CBCN and the wider breast cancer community fully support you in your cancer journey.



Warm Regards,

A handwritten signature in black ink that reads "Cathy Ammendolea".

Cathy Ammendolea, CBCN Board Chair

The Canadian Breast Cancer Network publishes a free monthly e-newsletter, *Outreach*, that highlights current programs, resources & activities for breast cancer survivors and patients. **SUBSCRIBE TODAY**



My inflammatory breast cancer story

By Caroline Corriveau



When the nurse phoned me at 8:30 a.m. on December 15, 2015 to ask if I could make it to the hospital the same day, I knew it was serious. Receiving confirmation that same morning that I had breast cancer was devastating.

The diagnosis: stage III, HER2 positive and hormone receptor-negative inflammatory breast cancer with bone abnormalities located at the sternum and at one vertebra.

As the mom of three young children (two boys, ages 6 and 3, and a thirteen-month-old daughter), I couldn't help but think the worst. I could not stop crying.

It was urgent for me to go through all the required testing to determine the extent of the cancer. I had to get a breast ultrasound with a biopsy, a mammogram, a chest X-ray and an abdominal ultrasound the same day. I met with the oncologist in the afternoon.

It was one appointment after the other, but the tears kept coming. I was telling myself that it wasn't real. That everything was going too fast. That it was impossible. That I couldn't die right now.

The oncologist I met that afternoon said something that I will never forget: "We need to put out the fire. Now." Everything was going quickly and his remark kept my mind busy while bringing me comfort; I was taken care of. The nurse navigator referred me to a psychologist.

Back home, I surfed the Web. Inflammatory breast cancer is aggressive and spreads rapidly. Chances of survival are low. It wasn't very reassuring, so I stopped reading. I had panic attacks and suffered acute anxiety.

My inflammatory breast cancer story cont'd

Getting a diagnosis had taken several weeks. It all started with redness on my breast, which my doctor thought was irritation related to breastfeeding. One week later, there was a small lump and my breast felt warm. Mastitis was the verdict. I left with a prescription for antibiotics for seven days. After six days of treatment, nothing had changed. I then tried a different antibiotic and got an appointment for a breast ultrasound three days later.

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: The verdict was issued on December 15: :
: inflammatory breast cancer. :
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I was told during the ultrasound that everything looked good and that there was no sign of an abscess or cancer. The doctor I then met observed that I was not responding to antibiotics (mastitis is usually almost gone after 48 hours of treatment). He asked for advice from a gynecologist who referred me to a microbiologist. After ten days of antibiotics injected intravenously, the microbiologist on call told me the diagnosis was wrong since the redness and the inflammation were still present. She took pictures and said that she would consult other specialists before getting back to me.

I received a phone call from the breast-screening clinic and an appointment was set on December 10 for a breast biopsy and an axillary lymph node biopsy. The verdict was issued on December 15: inflammatory breast cancer.

I started chemotherapy three days later. I received two treatments of fluorouracil combined with epirubicin and cyclophosphamide and four treatments of Taxotere combined with Herceptin. I was also given Emend for nausea, dexamethasone to dilate my blood vessels, prochlorperazine for nausea and anxiety, Neulasta to promote production of white blood cells that fight the infection, pregabalin for joint and muscular pain, Imodium for diarrhea, Ativan for anxiety, and codeine for headaches.

It was such a relief in February when I learned from a geneticist that I did not have a BRCA1 or BRCA2 gene mutation! However, the geneticist recommended that my sisters undergo annual mammography and a preventive MRI. My daughter will need to begin screening at the age of 25.

According to the surgeon, I require a mastectomy of the left breast. Several lymph nodes are suspect and need to be removed. The muscle seems to be intact. The redness has decreased. I must undergo a MRI in May to verify if the treatments are effective and a bone scan in April to check bone lesions. My operation is scheduled early in June, after my MRI.

Today, I feel more serene and resilient towards the disease because I do not have a choice. I tell myself that surviving will make me the exception for this type of cancer. I focus on my treatments, one day at a time. I would like to know the prognosis in advance, but with this type of cancer, it is impossible to know before the end of treatments and the results of tests to come.

I continue therapy, and so far, everything is going according to plan. I lost my hair, my complexion is paler, I have circles under my eyes. I also suffer from nausea and joint and muscular pain. I feel more tired and less energetic than before. But all of this might save my life. It's not so bad.

Yes, I do sometimes cry. However, I refuse to give any significance to my tears to avoid letting them get to me. I want to be there for my children for as long as possible: that's all that matters.

No one has control over cancer. Treatments exist and research is conducted. But nobody can tell us if our body will respond to it, if the disease will progress, if we will die or survive. We are all different. Consequently, we respond to treatments differently. The only element over which we have control is our perception of the disease and the way we live with it.

Caroline, age 34, lives in Saint-Hyacinthe, Quebec, with her husband and her three children.



Caroline with her three children

Inflammatory breast cancer Q&A

What is inflammatory breast cancer?

Inflammatory breast cancer is rare, accounting for only 1 to 4 percent of all cases of breast cancer. It develops rapidly, making the affected breast red, swollen, and tender. It occurs when cancer cells block the lymphatic vessels in skin covering the breast. This is a locally advanced cancer—meaning it has spread from its point of origin to nearby tissue and possibly to nearby lymph nodes. Inflammatory breast cancer can easily be confused with a breast infection. Seek medical attention promptly if you notice skin changes on your breast, to help distinguish a breast infection from other breast disorders, such as inflammatory breast cancer.

Inflammatory
breast cancer:

1-4%

of all breast cancer
cases

What are the symptoms?

The signs and symptoms of inflammatory breast cancer may include:

- a breast that feels warm to the touch
- skin changes:
 - pink, red or purple in colour
 - the colour can change from a light colour to a darker colour as the cancer advances
 - dimpled or pitted like an orange peel (peau d'orange)
 - bumps or ridges
- breast tenderness or pain
- breast swelling or a sudden increase in breast size over a short period of time
- itching of the breast or nipple
- thickening of the breast tissue
- nipple discharge
- nipple changes
- breast lump – rare
- swollen lymph nodes under the arm (axillary lymph nodes) or above the collarbone

What is the prognosis?



Prognosis and survival depend on many factors. Only a doctor familiar with a woman's medical history, type of cancer, stage, characteristics of the cancer, treatments chosen, and response to treatment can put all of this information together.

Treatment for inflammatory breast cancer often starts with neoadjuvant chemotherapy to reduce the size of the tumour and kill cancer cells that may have spread to other parts of the body. A combination of chemotherapy drugs is usually most effective.

What are the treatments?

If the inflammatory breast cancer does not respond to the chemotherapy, other chemotherapy combinations may be offered but surgery will not be done.

If the inflammatory breast cancer responds to neoadjuvant chemotherapy, surgery may be offered, most likely a modified radical mastectomy with axillary lymph node dissection. Breast-conserving surgery is not recommended for inflammatory breast cancer because of a higher risk of recurrence.

After surgery, external beam radiation therapy is given to the chest wall and lymph nodes in the chest, shoulder and underarm. Also, adjuvant chemotherapy may be prescribed.

If the inflammatory breast cancer is HER2 positive, trastuzumab (Herceptin) is given along with chemotherapy. Hormonal therapy such as tamoxifen or aromatase inhibitors may be offered to women whose inflammatory breast cancer tumours are hormone receptor positive.

Source: Canadian Cancer Society

Telling your child you have breast cancer



Telling your children that you have breast cancer can be a challenge. You don't want to frighten and overwhelm them, but at the same time, you don't want to leave them guessing at what you've been upset about. Since children have an innate ability to sense when something is wrong, and may invent a problem that is much worse than reality if information is lacking, it's important to be honest and to keep the lines of communication open.

Here is a sample script for an older child that you can adapt to your own particular situation. For information on what to say to children of various ages, see the resources listed at the end of this article.

- "I have an illness called breast cancer. It means some lumps are growing inside my breast that shouldn't be there. I am going to have an operation in the hospital to have the lumps taken out. Then I'll have some more treatment to make sure they don't grow back."
- "You don't have to worry because the doctors will take good care of me. I will have treatment soon, and I'll tell you all about it when I start."
- "Just because I have cancer doesn't mean that you'll get cancer too. It's not contagious (you can't catch it)."

- "It's not your fault that I have cancer. It's not caused by anything that you have said or done or thought."
- "Lots of people get cancer. We don't know why it happens. Most people get better and we expect I will get better, too."
- "Even though some things might change at home, you'll still be able to go to your usual activities while Mom is having treatment."
- "Whatever happens, you will always be cared for and loved. "
- "If you think of any questions or have any worries, please don't keep them to yourself. Come and talk to me. It's okay if you talk to someone else, too."

For more information, check out the following resources:

- American Cancer Society. (2002, November 1). Because. . . Someone I love has cancer: kids' activity book.
- Breast Cancer Care. (2014). Talking with your children about breast cancer.
www.breastcancercare.org.uk/information-support/publication/talking-your-children-about-breast-cancer-bcc50
- Eaton Russell, Ceilidh. (2006). Living dying: A guide for adults supporting grieving children and teenagers. Max and Beatrice Wolfe Children's Centre. Order at 416-586-4800, ext. 6664 or max&bea@tlcpc.org.
- Hamilton, Joan. (2007, March 30). When a parent is sick: Helping parents explain serious illness to children. Pottersfield Press.
- Livingstone, Morgan. (n.d.) Talking to your kids about breast cancer: a guide for parents. Rethink Breast Cancer.
rethinkbreastcancer.com/young-families-breast-cancer/
- RTI International. (2012). Telling kids about cancer.
<http://www.tellingkidsaboutcancer.com>
- Stowe, Karyn. (2011, October 5). The kids' guide to mommy's breast cancer. Authorhouse.
rethinkbreastcancer.com/young-families-breast-cancer/



Cancer Coaching clients working with their Coach to develop a self-care plan that meets their needs.

Caring for our caregivers

By Francine Beaupré
Cancer Coach, Ottawa Regional Cancer Foundation

Caregivers play a critical role in the quality of life of a person diagnosed with a life-threatening illness such as cancer. They oversee many practical issues such as scheduling appointments, keeping medical records, overseeing household chores, navigating the health care system, and providing feedback to family and friends. They give of themselves emotionally to their loved ones, listening to their struggles, sharing their concerns, providing encouragement and reassurance, and helping them decide treatment options that are right for them.

Caregivers are so devoted to their loved ones during this time of crisis that they very often put their careers, social life, and personal needs aside. This constant devotion over weeks and months inevitably takes its toll on the health and wellness of the caregiver. Caregivers often report strong feelings of anger, impatience, intense fatigue, irritability, sleeplessness, and many physical ailments. They want to continue helping, but their bodies and emotional being can become totally depleted.

What can caregivers do to manage the stress and demands of everyday life with their loved one in order to prevent these symptoms from increasing and leading to caregiver burnout?

The first step is often the most challenging. Caregivers must acknowledge that their own health and wellness must be addressed if they want to continue care-giving effectively. This self-awareness is a critical step in moving forward with a self-care plan.

Secondly, the caregiver must find the time for personal renewal. Most caregivers will

report that a lack of time in their day is the main barrier to self-care. Part of the solution could involve enlisting the help of family and friends on a regular basis to provide short periods of respite care. Reaching out for support is very difficult for many caregivers who often do not want to burden others. However, it is surprising how many people are willing to help, but are waiting for cues from the caregiver to know what to do. As well, using community resources for support can benefit the loved one and can free up valuable time to allow the caregiver to focus on self-care.

Thirdly, developing a self-care plan that is realistic and will adapt to the changing demands of the loved one's medical status is essential for its success. The self-care plan should include a list of activities that the individual finds helpful. Some suggestions include: take a walk outside, go to the gym, have coffee with a friend, work in the garden, attend an exercise class, or have a massage. When the caregiver feels that it is necessary to remain at home as the loved

.....
Take a walk outside, go to the gym, have coffee with a friend, work in the garden, attend an exercise class, or have a massage
.....

Caring for our caregivers cont'd



one is very fragile medically, she may choose to create a second list of short five to ten minute activities that can be done at different times during the day. These could include stretching, breathing exercises, meditating, talking with a close friend on the phone, listening to music, reading, or watching TV.

Caregivers of individuals with a cancer diagnosis can find the support they need from the Ottawa Regional Cancer

Foundation. They can meet with a Cancer Coach who will support them in developing a self-care plan. Caregivers can also participate in group coaching programs to share common experiences with others who are supporting loved ones with cancer and discuss various ways to meet their personal wellness needs.

The Ottawa Regional Cancer Foundation is helping people living with cancer by providing increased access to person-centered care through the delivery of the Cancer Coaching Health and Social Care Service and the funding of innovative cancer research and a world-class clinical trials program.

To find out more or to start with Cancer Coaching, please contact 613-247-3527 or visit www.ottawacancer.ca.

Another helpful resource is the webinars produced by The Caregiver Network: <http://thecaregivernetwork.ca/tag/breast-ovarian/>.



Do you have clinical depression or anxiety?

If you are a breast cancer patient who is experiencing significant depression or anxiety, you are not alone. Roughly one-quarter of breast cancer patients require psychological intervention during the course of their illness.

The good news is that help is available. It is also helpful to be able to identify changes in the way that we feel or view the world.

Symptoms of clinical depression include at least two weeks of unusual sadness or diminished interest in daily activities, as well as five of the following: change in appetite or weight; change in sleep pattern; fatigue; agitation; feelings of worthlessness or excessive guilt; poor concentration or indecisiveness; and recurrent thoughts of death that are more extreme than simply a fear of dying.

Anxiety disorders can take several forms. Symptoms of a generalized anxiety disorder include a pervasive sense of nervousness characterized by at least half a year of several of the following: edginess or restlessness, fatigue, distractibility, irritability, muscle tension, and insomnia.

Post-traumatic stress disorder includes intrusive thoughts, flashbacks, avoidance behaviours, emotional numbness, and a “fight or flight reaction” following a real or perceived threat to one’s life, such as receiving a cancer diagnosis.

Do you have clinical depression or anxiety?

cont'd



While some sadness or anxiety is normal when you have breast cancer, mood disturbances require treatment if they are severe, persistent, or accompanied by thoughts of death and dying.

If this is the case for you, ask your oncology team to refer you to the psychosocial oncology

department or patient and family support service at your cancer centre. Here trained professionals are skilled at assisting people to receive the help they are seeking.

Treatments include talk therapies, either individually or in a group, and anti-depressants or anti-anxiety agents designed to lift mood disturbances caused by chemical imbalances in the brain that can affect how we are feeling.

You'll be surprised at how quickly you start to feel better with help from professionals who know how to treat mood problems like depression and anxiety.

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The healing power of hypnosis and visualization

By Moira Hutchison

Certified Hypnosis-Visualization Practitioner, Ottawa Integrative Cancer Centre

www.OICC.ca

The introduction of hypnosis and visualization techniques to cancer treatment is a very powerful way of inspiring calmness and hope on many levels—a sense of taking back some control in the journey to restored well-being in mind, body, and soul.

A hypnotherapy session starts with inducing a state of relaxation and clearing the mind of distractions to produce a trance state. This is done by having the client lie down in a comfortable position with her eyes closed. She is directed to focus on slowing her breathing while visualizing herself in a comforting and comfortable environment (such as her favourite place in nature) and feeling all stress, tension and anxiety just dissolve and drift away out of her body and her reality.



The therapist then leads the cancer patient through the following visualizations:

1. Cancer cells are weak and confused, and should be imagined as something that can crumble apart like an oatmeal cookie.
2. The treatment regime is strong and powerful.
3. Healthy cells have no difficulty in repairing any slight damage caused by the treatment, and the immune system stays strong.
4. There is an army of different kinds of white blood cells that can overwhelm the cancer cells.
5. White blood cells are aggressive and want to seek out and attack the cancer cells.
6. The dead cancer cells are easily, naturally, and quickly flushed from the body.
7. The imagery session is a story that ends with the patient healthy and free of cancer.
8. The patient can visualize herself reaching her goals and fulfilling her life's purpose.

The healing power of hypnosis and visualization cont'd



With visualization, the intensity of the images in the mind appears to increase their effectiveness.

Contrary to popular belief, hypnotherapists are *not* the ones in control during a hypnotherapy session. It is up to the patient to follow along with the suggested imagery – the therapist is merely making suggestions (painting pictures with words, so to speak!). As a matter of fact, one of the main goals of

hypnotherapy is to help patients gain *greater* control over their behaviour, emotions, and bodily functions.

Benefits of hypnotherapy for breast cancer patients can include reduced levels of pain, fatigue, insomnia, nausea, anxiety, depression, hot flashes, and increased levels of calmness and a sense of control. Research has shown that what we visualize in our minds is often what we create in our bodies. Thus visualization and hypnosis are powerful techniques for healing mind, body, and soul.

For more information, check out Dr. Bernie Siegel's books, such as *Peace, Love and Healing* and *Love, Medicine and Miracles*. Dr. Siegel is a well-known proponent and developer of the mind-body-spirit connection for healing.

To find a certified hypnotherapist in your area, contact the [Association of Registered Clinical Hypnotherapists](#) (ARCH) or the [Canadian Hypnotherapy Association](#).

Network News is published by the Canadian Breast Cancer Network (CBCN) to provide the breast cancer community with up-to-date and understandable information on issues at the national level, to promote education and awareness, and to highlight the concerns of Canadians affected by breast cancer.

We would like to thank the individuals who wrote and reviewed articles. We welcome your ideas, contributions, and letters, subject to editing and available space. The articles in this issue do not necessarily represent the views of CBCN but are the opinions of the authors. CBCN gives permission to copy with attribution.

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There are many individuals and organizations that make it possible for CBCN to continue to be the voice of Canadians affected by breast cancer. CBCN gratefully acknowledges the hundreds of individuals and groups across the country who choose to support CBCN with your financial contributions throughout the year and our In-memoriam donations to honour the memory of a loved one. We truly appreciate that you see value in the work that CBCN continues to do and are thankful for your ongoing support.

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