ywbcp
The YOUNG WOMEN'S
Breast Cancer Program

# TOGETHER

SITEMAN CANCER CENTER AT BARNES-JEWISH HOSPITAL AND WASHINGTON UNIVERSITY SCHOOL OF MEDICINE VOLUME SEVEN: APRIL 2014

inside: Navigating Health Care Reform | Mindful Living and Coping | Reconstructive Surgery | Metastatic Breast Cancer Best Practices

# *welcome*

## A Note From the Director

*Jennifer Ivanovich*

We are pleased to be able to share the seventh edition of *Together*, our magazine for young breast cancer survivors. Where does the time go? In 2013, we celebrated 12 years of working side by side with young breast cancer survivors to bring about positive change for all young adults with cancer.

We are extremely grateful to the young women who make YWBCP what it is today through their hard work, creative energy, and kindness. They might be connecting with another young survivor, singing a piece of music, opening up about a personal experience, or leading a group of survivors in a marathon. We are blessed by women of courage. We are inspired by women who are *Daring Greatly*.

This edition highlights these daring women. The beautiful photographs are of young survivors in the St. Louis area. Their photographs illustrate their decision to keep moving forward and not let cancer define them. Becky Dennington eloquently acknowledges her personal vulnerability and shares how her experience with cancer led to an opportunity, and her caring decision to help other women in need, including her own mother. Three young survivors candidly share their personal experience and decision-making about breast reconstruction. We are grateful for their practical information and honesty.

What other topic than healthcare reform has dominated the news in recent months? Monica Bryant, Esq, from Triage Cancer, takes us through the changes in coverage of healthcare services for cancer survivors. Cynthia Ma, MD, a Medical Oncologist at Washington University, writes on the medical approach to caring for women with metastatic breast cancer. This topic is essential for any breast cancer program, and sadly, especially relevant for young women. "Live in the now," writes Liz Muenkes, PhD, and Jared Israel, MA, in their article focused on mindfulness and coping. They describe what changes you can make to live in and cherish the present. The benefits of exercise may seem rather obvious but the steps to maintain an exercise program can be challenging. Kim Selig, MSW, and Amy Cyr, MD, walk us through some of the research and compel us to make regular physical activity a priority.

Thank you for sharing in the YWBCP. We hope you continue to *Dare Greatly* in 2014.

Jennifer Ivanovich, MS
*Director, Young Women's Breast Cancer Program*

*Daring Greatly* taken from the Man in the Arena speech, Theodore Roosevelt, 1910.

**When a young woman hears those life-altering words "you have cancer,"** likely the last thing on her mind is figuring out how she will get or keep health insurance for the rest of her life. A young woman may have health insurance coverage through her parents, but what happens when she ages out of that policy or if her parents lose their health insurance? Or what if a young woman is just starting out in her career and has a job that does not offer health insurance benefits? What happens when that young woman wants to switch jobs? While it may seem that all of the focus should be on one's health during this time, the reality is these practical and financial issues do arise.

The Patient Protection and Affordable Care Act of 2010 (ACA) is designed to improve the affordability and quality of health care in this country. The ACA contains many provisions that will greatly benefit young women who are dealing with a breast cancer diagnosis. For example, thanks to the ACA, eligible young adults now have the option of staying on their parent's health insurance plan until they are 26 years old. These young adults do not have to be dependents under IRS standards, can live on their own, be married, and even have their own children! This rule gives young adults additional options and helps to bridge the gap that may occur between leaving school and finding a job that offers health insurance benefits.

# NAVIGATING HEALTH CARE REFORM



By Monica Bryant, Esq.,
COO, Triage Cancer

Additionally, most health insurance policies will have to cover preventive services for free. "Free" means that not only will the insurance plan cover the service, but they cannot apply any costs to your deductible, or charge you a co-pay or co-insurance amount. Some of the cancer-related preventive services include:

- Breast cancer mammography screenings every 1 to 2 years for women over 40
- Cervical cancer screening for sexually active women
- BRCA 1 and 2 gene genetic counseling and testing
- Immunizations for Human Papillomavirus (HPV)

Although some of these services will not be considered preventive once you have a breast cancer diagnosis, this provision may still be critical for your family members who may have a higher risk of being diagnosed.

Perhaps the most significant changes to our health care system is that as of January 1, 2014, individuals cannot be denied when trying to purchase an individual health insurance policy because of a pre-existing condition and they cannot be charged more because of that pre-existing condition. This means that even if a young woman is diagnosed with breast cancer, she can still go into the individual market and purchase insurance. She can also be confident that she will not be charged exorbitant rates just because of that diagnosis.

## How can I buy insurance?

Even with the new rule that someone cannot be denied because of a pre-existing condition, choosing health insurance can be daunting. The ACA recognized this and established Health Insurance Marketplaces to help simplify the process. These "Marketplaces," sometimes referred to as "Exchanges," will vary state by state, but in every state there will be four main categories of insurance plans available to individuals, families, and small businesses (under 50 employees). The main difference between these categories of plans lies in how much the insurance company will cover, and how much the individual will pay (otherwise known as a "cost-share"):

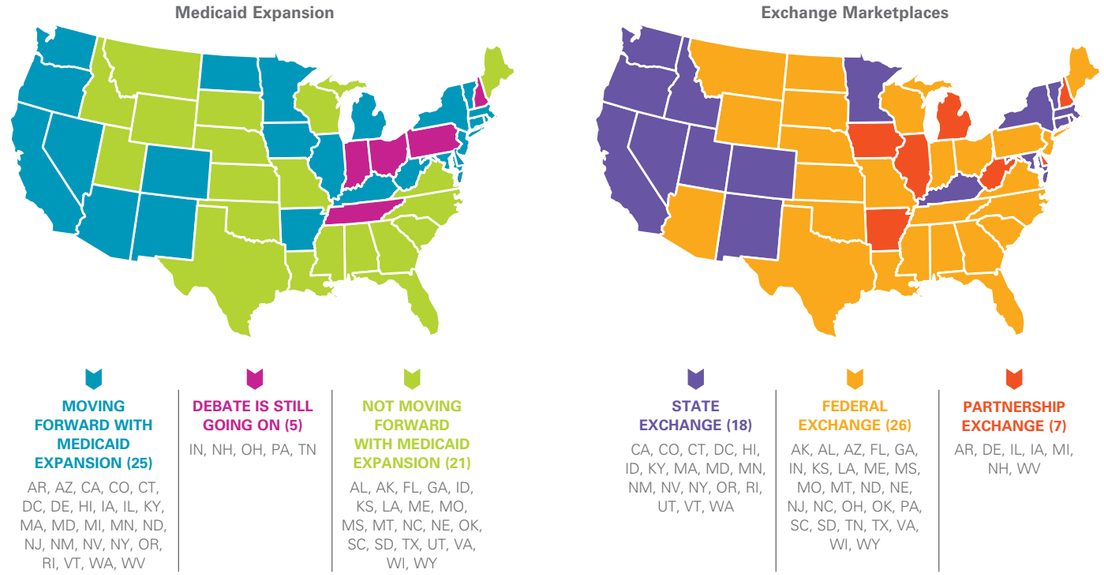
- **Platinum plan:** you would pay 10% of your medical costs and the plan would cover 90%
- **Gold plan:** you would pay 20% of your medical costs and the plan would cover 80%
- **Silver plan:** you would pay 30% of your medical costs and the plan would cover 70%
- **Bronze plan:** you would pay 40% of your medical costs and the plan would cover 60%

There is a fifth category of plan called the catastrophic plan. These very limited plans will only be available to individuals under 30 years old and those who are exempt from the individual mandate because of a financial hardship. In most states, you will have several different plan options within each of these categories from various insurance companies.

For all levels of plans there is a maximum annual deductible of $2,000 for an individual and $4,000 for a family plan. It is likely that a Bronze plan will have a deductible at this limit, whereas a Platinum plan may not have any deductibles. The Bronze and Platinum plans will also differ on what benefits are covered, which doctors are included, and how much the monthly premiums are (e.g., Platinum plans will have the most benefits and the highest premiums).

Perhaps the most significant changes to our health care system is that as of January 1, 2014, individuals cannot be denied when trying to purchase an individual health insurance policy because of a pre-existing condition and they cannot be charged more because of that pre-existing condition.

Additionally, the ACA imposes limits on how much consumers are required to pay out-of-pocket for medical expenses, other than their premiums, when they purchase health insurance plans in the Marketplaces. In 2014, the cap on these expenses is $6,350 and for a family the cap is $12,700. After people reach their out-of-pocket maximum, their insurance plan must pay for all of their covered expenses for the rest of the year. These caps will aid in keeping out-of-pocket costs to a certain amount and stem the tide of people having to declare bankruptcy because of medical debt.




## How much will plans in the Marketplace cost?

The cost of the plans will vary state to state, and will depend on the level of coverage chosen. There will be financial assistance for many people who purchase health insurance policies in the Marketplaces. This financial assistance is based on income and family size. For example, individuals who have incomes between 138% of the Federal Poverty Level (FPL) and 250% FPL, will be eligible for cost sharing subsidies (in 2013, incomes between $15,856 – $28,725). These subsidies will reduce the cost of health care expenses an individual or family has to pay at the time of medical care (e.g., reducing the co-payment you make when you visit the doctor's office). People with annual incomes between 138% and 400% of the FPL, may also be eligible for a premium tax credit (in 2013, incomes between $15,856 – $45,960). This tax credit would reduce the amount you pay monthly for your premium. For example, an individual who qualifies for a premium tax credit may choose a policy that is $242 a month, but may only have to pay $40 a month for coverage. When you complete an application to purchase a health insurance policy in the Marketplace you will be asked to include some of your financial information – this is so the Marketplace can determine if you are eligible for any of these financial assistance options.

Open enrollment in these Marketplaces will last until March 31, 2014; however, if someone has a qualifying event (e.g., turns 26 and ages out of their parent's policy) they would be able to purchase insurance in the Marketplace at that time. Marketplaces vary state by state, with 17 states and Washington, D.C. running their own Marketplaces, 26 states letting the federal government run their Marketplaces, and 7 states partnering with the federal government to run their Marketplaces in 2014. For states that run their own Marketplace you can visit their websites directly to learn more or you can visit www.HealthCare.gov to find information on your health insurance options in any state.

## What if I still can't afford a Marketplace plan?

The ACA also allows states to expand Medicaid to all adults making less than 138% of the federal poverty level (in 2013, less than $15,856 for an individual or $32,499 for a family of 4). However, many states have chosen not to expand their Medicaid programs, leaving many individuals with low incomes without access to preventative screenings and other critical medical care. To date, only 24 states and DC have elected to expand Medicaid coverage. The chart above shows where each state stands; however, please keep in mind that this is a very fluid process and things are changing frequently.

### Do I have to have health insurance?

Perhaps one of the most controversial provisions of the ACA is the requirement that most U.S. Citizens and legal residents are required to have health insurance coverage beginning in 2014. This requirement is also known as the "individual mandate." Because the majority of people in the United States have health insurance coverage, this requirement will only affect those who do not have health insurance.

So, what happens if someone doesn't have health insurance coverage in 2014? Individual adults will have to pay an annual penalty of $95 or 1% of their household income, whichever is more. The penalty goes up each year, and then in 2017, the penalty will be the same amount as the cheapest bronze plan available in the exchange. The goal is not to create a penalty, but to encourage people to buy health insurance coverage.

However, there are a number of exceptions that exclude certain people from having to face a penalty under the individual mandate. For example, people can have up to a three-month gap in health insurance coverage during the year without facing a penalty. Also, individuals whose health insurance would cost more than 8% of their household income, or those individuals who would be eligible for the new Medicaid program but live in a state that does not expand its program, do not have to comply with the individual mandate.

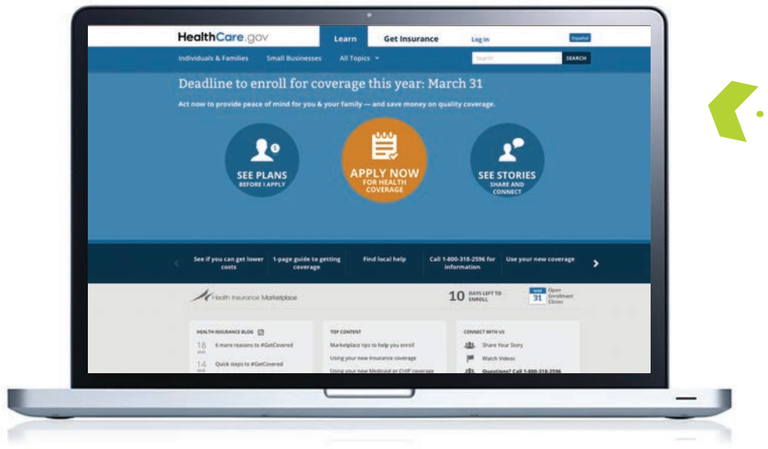
Because coverage will continue through many employer plans, individual insurance policies, Medicare, Medicaid, Veterans Administration health plans, and other types of coverage, many people will not see any change in how they access health insurance coverage in 2014, and will not be affected by the individual mandate.

### How can I get involved?

It is important to remember that no law is perfect and over the next few years we will likely see many changes to the law as it is implemented. As a member of the cancer community you have the opportunity to advocate and affect change. Contact your elected officials and let them know your thoughts on how the ACA is working. For tips on how to be an effective advocate and for more information about the ACA, visit www.triagecancer.org.



**Monica Bryant, Esq**. is a cancer rights attorney, advocate, speaker, and author. She is Chief Operating Officer of Triage Cancer, *a nonprofit organization providing education on the continuum of cancer survivorship issues.*




You can visit www.HealthCare.gov to find information on your health insurance options in any state.



# METASTATIC BREAST CANCER: BEST PRACTICES BASED ON CANCER SUBTYPE

By Cynthia X. Ma, M.D., Ph.D., Associate Professor of Medicine, Washington University School of Medicine

Metastatic breast cancer, also termed stage IV breast cancer, is diagnosed when breast cancer is found at sites or organs outside of the breast or the axillary lymph nodes. Imaging tests, such as body CT scan, bone scan, or PET scan are common detection methods employed at initial diagnosis and during follow up to treatment. In addition, a tumor biopsy is usually required at diagnosis to confirm the cancer originated from the breast.

**THE TREATMENT APPROACH FOR METASTATIC BREAST CANCER IS A CRITICAL ISSUE FOR ALL WOMEN WITH STAGE IV, OR METASTATIC DISEASE, AND IS ESPECIALLY RELEVANT FOR YOUNG SURVIVORS.**

The treatment approach for metastatic breast cancer is a critical issue for all women with stage IV, or metastatic disease, and is especially relevant for young survivors. While few women present with metastatic breast cancer at first diagnosis, research shows there may be an increasing number of young women who present with metastatic cancer at initial diagnosis [1]. Moreover, young women with a history of early stage breast cancer have the highest rate of relapse with metastatic disease. As such, young women have a great deal to gain from advances in the care of women with metastatic breast cancer. The outcome for women with metastatic breast cancer varies depending on the extent of the disease, the status of estrogen receptor (ER) and Human Epidermal Growth Factor Receptor 2 (HER2), and responsiveness to treatments. Although metastatic breast cancer is not curable in most, treatment can prolong survival and relieve cancer-related symptoms. With appropriate therapy, many women with metastatic breast cancer enjoy years of survival with good quality of life.

Breast cancer is subdivided into four main subtypes based on the status of ER and HER2 (Table 1). Systemic treatment, which uses drugs that are delivered throughout the body, differs depending on the breast cancer subtype.

In addition, it is well recognized the genetic make-up of breast cancer is not the same in different women; therefore, response to therapy varies. A major task for the research community is to identify molecular markers or the genetic make-up of the cancer that predicts treatment response so the most effective therapy can be offered. In addition, drugs are being developed to inhibit cancer specific changes, so called targeted drugs, so the side effects to normal cells are minimized. However, it is expected these targeted drugs would only be effective in the target positive population.

Therefore, tumor biopsies are often recommended, or required, prior to, and sometimes after, treatment so that the cancer can be studied for the presence or absence of the tumor and whether treatment has been effective. Understanding a tumor's underlying molecular and genetic make-up are critical aspects of research in many trials focused on targeted drugs.

## Treatment of ER+ HER2- breast cancer

The majority of breast cancers are ER+HER2-, the growth of which depends on estrogen binding, or attaching, to a functional receptor. Hormonal therapy refers to drugs that either block estrogen or disrupt the function of the estrogen receptor (Figure 1). Hormonal therapy consists of drugs that reduce the estrogen levels (aromatase inhibitors, Zoladex), or work to antagonize, or block, estrogen binding to the estrogen receptor (Tamoxifen), and drugs that degrade, or destroy, the estrogen receptor (Fulvestrant) (Figure 1). These drugs are often the first choice of therapy in women with ER+ breast cancer. Aromatase inhibitors, including Letrozole (Femara), Anastrozole (Arimidex), and Exemestrane (Aromasin), are commonly used in postmenopausal women, but they are not effective for pre-menopausal women who have functional ovaries. Similarly, Fuvlestrant works best in post-menopausal women.

In contrast, Tamoxifen could be used in both pre- and post-menopausal women. To reduce estrogen production in pre-menopausal women, the medical oncologist may recommend drugs that inhibit, or disrupt, function of the ovaries (such as Zoladex) so estrogen is reduced. Alternatively, the ovaries may be removed so aromatase inhibitors or Fulvestrant may be used in treatment.

Everolimus (Afinitor), which inhibits, or blocks, mTOR, a mediator of growth factor receptor signaling (Figure 1), has recently been approved to increase the effectiveness of Aromasin for women whose disease has progressed on Femara or Arimidex. mTOR combines the input of various growth factors to stimulate cell growth. Inhibiting mTOR helps to limit cell (tumor) growth.

Many women are treated with hormonal therapy for a couple of years or longer before the need for chemotherapy. The side effects of hormonal therapies are mild for most women, including hot flashes, vaginal dryness, and sometimes joint aches.

A major research focus in the treatment of ER+HER2- breast cancer is to develop drugs that improve the effectiveness of hormonal therapy drugs, and many are being tested in clinical trials.

## Treatment of HER2+ breast cancer

HER2+ breast cancer has overexpression of HER2, or too much HER2, on the cancer cell surface due to multiple copies of the HER2 gene (called amplification of HER2). HER2+ breast cancer is dependent on HER2 for cancer growth and HER2 targeted therapies are essential (Figure 2).

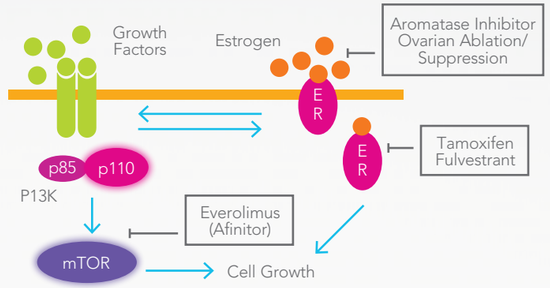
There are four approved anti-HER2 drugs, including Herceptin, Perjeta, Kadcyla, and Tykerb. Herceptin and Perjeta are monoclonal antibodies which attach to the part of the receptor that sticks out of the cell. By binding to the receptor, Herceptin and Perjeta block the function of the HER2 receptor. Kadcyla (T-DM1) is Herceptin that is attached to a drug that delivers chemo specifically to cells that overexpress HER2. Herceptin, Perjeta, and Kadcyla are delivered by intravenous (IV) infusions. Tykerb is an oral drug that blocks the kinase function of the HER2. Kinases help to stimulate cell growth.

Table 1. Common systemic therapy drugs used for metastatic breast cancer based on subtypes

| Breast cancer subtypes | Hormonal therapy | HER2-targeted therapy | Chemotherapy | Other targeted therapy |
|---|---|---|---|---|
| ER+ HER2- | Tamoxifen, Femara, Aromasin, Arimidex, Fulvestrant, Megace | | Xeloda, Paclitaxel, Docetaxel, Gemcitabine, Cytoxan, Methotrexate, 5-FU, Eribulin, Doxil, Navelbine, Abraxane, Carboplatin, Cisplatin | Afinitor |
| ER+ HER2+ | | Herceptin, Pertuzumab, T-DM1, Lapatinib | | |
| ER- HER2+ | | | | |
| ER- HER2- (triple negative) | | | | |



Figure 1. Treatment of ER+ HER2- breast cancer




ER: Estrogen Receptor

Kinases may lose their ability to stop functioning, thereby causing uncontrolled cell growth. Many cancer treatments are designed to block specific kinases from working.

Kadcyla is given alone while the other three drugs are often given in combination with chemotherapy. If the cancer is also ER+, Herceptin and Tykerb could be combined with hormonal therapy as well. The availability of these HER2 targeted drugs has dramatically improved the survival of women with HER2+ breast cancer.

While some HER2 positive breast cancers never respond to these drugs, it's more common for cancer cells to develop resistance during the course of therapy. New drugs are being developed to treat the resistant tumors.

## Treatment of triple negative breast cancer

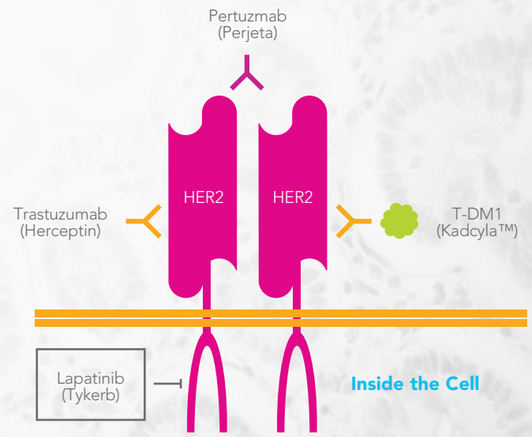
Triple negative breast cancer remains a challenge to treat, as it tends to be more aggressive and there are no approved targeted therapies. Since the ER- tumor is not stimulated by estrogen, hormonal therapies are not effective, which means you need chemotherapy. Chemotherapy refers to a class of drugs that kill cancer cells by inhibiting, or stopping, cell division, DNA production, or causing DNA damage. Consequently, normal dividing cells such as hair follicles, bone marrow cells, and mucosal cells can also be affected, leading to side effects such as hair loss, reduced blood counts, and mucositis, etc.

There are a number of chemotherapy drugs available that help most women with triple negative breast cancer because they shrink the tumor and stop disease progression. If the tumor develops a resistance, it is necessary to change the chemotherapy drugs, as each drug uses a different approach to stop cell growth.

BRCA1 gene mutations are more commonly associated with triple negative breast cancer. Recent studies have demonstrated promising results for PARP inhibitors in people with inherited BRCA1 or BRCA2 gene mutations. Poly ADP ribose polymerase (PARP) is an enzyme that works to fix abnormalities in the cell's DNA. Cancer cells rely on PARP to repair damaged DNA, allowing the tumor cells to continue to grow. PARP inhibitors reduce the enzyme's ability to function, allowing DNA abnormalities to accumulate, or build up, eventually leading to cell death. For this reason, intense study of PARP inhibitors in the treatment of breast, and other cancers, is underway. Currently, PARP inhibitors are only available through clinical trials for women with a BRCA1 or BRCA2 gene mutation.

The research focus in triple negative breast cancer is to develop drugs that target cancer-type specific abnormalities.

Figure 2. Treatment of HER2+ breast cancer



## Participating in Clinical trials

Before a drug is approved as a standard of care for the treatment of cancer, it undergoes vigorous clinical testing for its effectiveness and safety in humans. These tests are called clinical trials. Only drugs that have shown anti-tumor activity in the laboratory (pre-clinical studies) are introduced in clinical trials.

In general, **Phase I trials** will test different doses of a drug and determine the optimum or maximum tolerated dose for future Phase II trials. **Phase II trials** will select a group of people with specific type(s) of cancer and test the anti-cancer activity. **Phase III trials** are usually randomized studies, where participants are randomly placed in different study groups. Typically, two study groups are used, in which the study drug is compared to the standard of care drug, one that's routinely used in treatment. If the study drug works significantly better, an application for FDA approval follows. It can take years for a drug to move from pre-clinical testing to final FDA approval.

**IT IS WELL RECOGNIZED THE GENETIC MAKE-UP OF BREAST CANCER IS NOT THE SAME IN DIFFERENT WOMEN; THEREFORE, RESPONSE TO THERAPY VARIES.**

Participating in clinical trials provides early access to potentially promising drugs that are effective. Ask your treating physician about the availability of clinical trials for the type of breast cancer you have. You can also look online at http://clinicaltrials.gov/ to find clinical trials available in your area. Discussing the eligibility requirements, availability, and specifics of a given clinical trial with your medical oncologist is extremely important.

To learn more about breast cancer, I recommend the following websites:

- **American Society of Clinical Oncology**
  www.cancer.net/portal/site/patient
- **National Comprehensive Cancer Network**
  www.nccn.com
- **National Cancer Institute**
  **1.800.4.CANCER (226237)**
  www.nci.nih.gov
- **American Cancer Society 1.800.ACS.2345**
  www.cancer.org
- **National Library of Medicine**
  www.nlm.nih.gov/medlineplus/healthtopics.html
- **Susan G. Komen**
  www.komen.org

**REFERENCE:**


1. Johnson, R.H., F.L. Chien, and A. Bleyer. *Incidence of breast cancer with distant involvement among women in the united states, 1976 to 2009.* JAMA, 2013. **309**(8): p. 800-805.




The Here and Now:

# Mindful Living and Coping


By Elizabeth M. Muenks, PhD and Jared I. Israel, MA


"Be happy in the moment, that's enough. Each moment is all we need, not more." – Mother Teresa

What is happening right now, this very moment? Look around. What do you see and hear? Look inside. What are you thinking and feeling? This reflection is the basis of mindfulness.

**Mindfulness is active observation of the present moment and the awareness of self and surroundings that results from that.** Purposeful attention is only one step. Maintaining a nonjudgmental, curious, and accepting attitude is also a key component.

**The goal of mindfulness is to help you be present in your life and appreciate the fullness of the moments that are happening now.** By becoming more in touch with yourself, you are better able to enjoy the positive and more prepared to cope with the unexpected. Given how hectic and busy life can be, this is an important goal for all of us. Have you ever found yourself driving down the highway, while at the same time listening to the radio, talking to a friend, drinking a coffee, and wondering what to make for dinner? Or maybe you've had the experience of stepping out of a car and realizing you don't remember any of the trip? It is all too easy to slip into a state of mindlessness, to be on autopilot!

What happens when you're dealing with a major crisis in addition to all of these daily interruptions? Facing a serious illness like cancer is mentally and physically draining, which makes the benefits of mindfulness all the more significant for cancer survivors. Receiving a diagnosis, making treatment decisions, managing side effects and navigating a range of life adjustments make the cancer journey challenging. It can feel as though you're lost in a fog of confusion and worry, your mind stuck turning over the same unanswerable "whys" and "what ifs" again and again. Mindfulness is a way to ease this stress.

In this article, we provide some background on the basics of mindfulness practice as well as suggestions for how to use mindfulness exercises to cope with pain, tough emotions and sleep difficulties. We end with a few recommendations about adding mindfulness to your daily life and a list of useful resources.

**This practice is rooted in ancient Buddhist teachings and plays a central role in yoga and various forms of meditation. In addition, mindfulness practice has been incorporated into dozens of psychological treatments and is part of the healing approach provided by hundreds of health centers, including cancer centers, across the country.**

### Mindfulness Basics

Mindfulness practice includes taking an attitude that is nonjudgmental, gentle, patient and flexible. The goal is to remain open to whatever arises. No thought, emotion, sensation or experience is wrong. Our minds often wander and that is normal. When a puppy wanders off or makes a mess we do not blame the puppy. We respond with understanding because that is just the way puppies are. We can use this forgiving response with our minds as well.

Mindfulness is often used synonymously with relaxation, which is a common myth. This is confusing because relaxation can be a side effect of engaging in mindfulness. Remember, the purpose of mindfulness is not relaxation, it is active awareness. This is an important distinction because it can be discouraging to practice mindfulness if you are expecting a different result.

Remember, the purpose of mindfulness is not relaxation, it is active awareness. This is an important distinction because it can be discouraging to practice mindfulness if you are expecting a different result.

One basic way to become aware of the present moment is to pay attention to the breath, a fundamental aspect of mindfulness practice. We take roughly 20,000 breaths each day, but how many are we really aware of? You do not have to change the way you breathe – simply pay attention to it. Notice the pace of inhalations and exhalations, the coolness or warmth of the breath, the sensation of air moving through your nose and mouth. Counting each breath in and out is a great way to practice mindfulness.

***Exercises***

A specific type of breath awareness is diaphragmatic breathing, or belly breathing. To maximize oxygen intake, it's important to breathe from your abdomen (belly breathing) rather than your chest. Focus on your breath until you feel your stomach rise and fall more dramatically than your chest. When you breathe in, your belly should expand, and when you breathe out, your belly should fall. Sometimes it is helpful to imagine a balloon in your stomach filling up with air when you breathe in and deflating as you exhale. Breathe in through your nose, hold the breath for a few seconds, and then exhale through your mouth. The time it takes to exhale should be about twice what it is to inhale.

### Mindfulness and Pain

We have all encountered physical pain in our lives: headaches, muscle tension, injuries. Those whose lives have been affected by cancer know well how difficult it is to cope with pain. Using mindfulness may not remove the pain, but it can help you cope with it.

Those whose lives have been affected by cancer know well how difficult it is to cope with pain. Using mindfulness may not remove the pain, but it can help you cope with it.

For example, deep breathing can relax the body, reducing the perceived intensity of pain. Pain might be present, but resisting it or trying to block it may make the experience worse. Often times a difficult aspect of pain is thinking that it will never go away. Sometimes a mindful shift in reaction to pain, using an approach of acceptance and letting go of fighting the pain, can help. You can also scan your body to bring awareness to painful areas. You might be thinking, why would I want to pay attention to what is causing pain? That will make it worse! We know this isn't easy to do, but we encourage you to give it a try.

***Exercises***

Imagine a ring of light that starts at the top of your head and moves down your body to your toes. Observe this ring moving slowly. As it travels down and around your body from your head down around your shoulders and arms, torso, hips, legs and toes, notice the areas in pain. Pay attention to it. Is it constant? Does it vary in intensity? Does it stay in one place or radiate outwards? Does it change with time or position? You might notice some tension or tightness around the pain. This tension can sometimes make the pain worse, but it may be released with slow deep breathing. Imagine the breath or warm energy moving into the area in pain. Imagine the pain releasing.

### Mindfulness and Tough Emotions

Cancer is scary and can cause emotional distress. Anger, confusion, fear, sadness, worry, and loneliness are all typical responses. Attempts to avoid or suppress feelings may provide temporary relief, but these efforts only last so long, and in some cases, may actually make circumstances worse.

## Two key points to remember:

1. Difficult emotions will occur, and you are not your emotions. You are much more, and any emotion you feel is merely one piece of a larger whole.
2. Emotional states are transient. Like a wave swells and then disappears in the ocean, difficult emotions will arise, run their course and fade away.

***Exercises***

Notice any emotions you are experiencing. Try to be non judgmental of what you are feeling. Do not rush to try to make a change. Allow yourself to simply observe and accept the emotion(s). What does it feel like? Where do you feel it in your body? Does it have a name? Try to spend three to five minutes doing this.

Or, observe the thoughts and emotions moving through your mind. Imagine them as words written on clouds floating across the sky into the distance. Notice your thoughts or emotions appear, and then choose to let them drift away.

### Sleep Problems and Mindfulness

Sleep is a crucial ingredient for both physical and mental health. Many people often have trouble falling asleep and may wake frequently throughout the night. Stress, medication and treatment effects, bathroom trips and new sleeping locations can all get in the way. Unfortunately, we can't force ourselves to fall asleep; however, mindfulness exercises emphasize the present, and can encourage sleep by distracting our racing minds. Keep practicing! It may take several run-throughs before these exercises lead to change.

***Exercises***

Lie comfortably in bed. Take a few deep breaths in through your nose and exhale slowly from your mouth. Bring your attention to the little toe on your right foot and picture the tension in that toe melting away. Imagine that your toe feels relaxed and at ease. Continue with each toe, then your entire right foot. Now move to your ankle, up to your calf and up further to your thigh. Hold your attention at each area long enough to picture the tension being replaced by a warm, pleasant heaviness. Do not hurry. After you finish your right leg, go on to your left. Continue this exercise by slowly shifting your focus across your entire body. Allow tension to release and relaxation to set in. Move your attention slowly over your pelvis, stomach, back, chest, shoulders, arms, neck and head. Be sure to continue breathing evenly.

### Everyday Mindfulness

## Mindfulness takes practice! The good news is every moment offers us a chance to do just that.

Mindfulness doesn't have to be a formal practice. Mini meditations can happen anytime you pay attention to your moment-to-moment experiences.

We recommend "**Catch AP-ASAP**" to beginners — that is to catch auto-pilot as soon as possible. Our minds spend a lot of time away from the present, just going along on autopilot. A first step in cultivating greater mindfulness is to catch this happening.

You can find cues in your everyday life to help you practice mindfulness. Perhaps, at every red light you notice your thoughts, or when walking you observe sights and sounds. While waiting in a long line at the store, you might take some grounding breaths, notice your emotions and incorporate a nonjudgmental approach. While eating a meal notice the flavors, scents and textures of the food. Try eating slowly, savoring each bite.

A common mindfulness saying is, "**It is what it is.**" This saying can be helpful, particularly because we tend to spend a significant amount of time and mental energy trying to change things we have little control over. **Be open to what the moment offers, for in each moment is an opportunity to learn and grow.**

Be open to what the moment offers, for in each moment is an opportunity to learn and grow.

## RESOURCES:

### Books

- *365 Buddha: Daily Meditations* (2002) – Jeff Schmidt
- *Full Catastrophe Living* (1990) – Jon Kabat-Zinn
- *Wherever You Go, There you Are: Mindfulness Meditation in Everyday Life* (1994) – Jon Kabat-Zinn
- *The Mindfulness Solution to Pain* (2009) – Jackie Gardner-Nix and Lucie Costin-Hall

### Audio

- *Guided Mindfulness Meditation Series 1, 2 and 3* – Jon Kabat-Zinn
- *Meditation for Optimum Health: How to Use Mindfulness and Breathing to Heal* – Andrew Weil
- *Mindfulness Meditation for Pain Relief: Guided Practices for Reclaiming Your Body and Your Life* – Jon Kabat-Zinn

### Siteman Cancer Center Programs

- Mindfulness-Based Stress Reduction and Cancer Recovery Program. Call to register: 314.747.5587.
- Mindfulness Meditation Practice Group. Meets every Tuesday. Call to register: 314.747.9984.
- Gentle Yoga. Weekly (Tuesday) yoga program for cancer survivors and caregivers. Call to register: 314.362.7844

### Community

- Cancer Support Community: 314.238.2000 www.cancersupportstl.org

Free yoga in Saint Louis:

- Check out this link for more information: www.facebook.com/pages/Outdoor-Yoga-in-and-around-St-Louis/171597959565540

Places to practice mindfulness in Saint Louis:

- Meet Up: mindfulness.meetup.com/cities/us/mo/saint_louis/
- Missouri Zen Center: www.missourizencenter.org
- Dharma Town: dharmatown.org

**Mindfulness practice includes taking an attitude that is nonjudgmental, gentle, patient and flexible. The goal is to remain open to whatever arises. No thought, emotion, sensation or experience is wrong.**

## Research Update – Watch your email!

Kimberly Kaphingst, ScD, an expert in health literacy, cancer communication and public health genomics at Washington University, is leading a new study focused on the communication of whole genome sequencing (WGS) test results. Some essential questions that will be examined include: what do women know about WGS, how and when do they want WGS information communicated, and what types of information do young survivors want to learn from WGS?

Women diagnosed with breast cancer <40 years are invited to participate in this innovative study. Phase 1 of the study, which included in-depth, one-on-one interviews with 60 young survivors who live in the St. Louis region, has been completed. For the next phase, an on-line questionnaire will be distributed to young breast cancer survivors who are enrolled in the Identification of Novel Risk Factors that Contribute to the Risk for Breast Cancer study, led by Paul Goodfellow, PhD and Jennifer Ivanovich, MS.

Participants will be invited by email to participate in the online survey. If your email or other contact information has changed, or if you have not yet participated in the study directed by Goodfellow and Ivanovich, contact Jen Ivanovich by email at ivanovichj@wudosis.wustl.edu or by telephone at 314-454-5076. If you do not have an email account, and wish to participate in the online survey, contact Jen Ivanovich for more details.

Why (Not) Exercise:

# THE BENEFITS FOR CANCER SURVIVORS

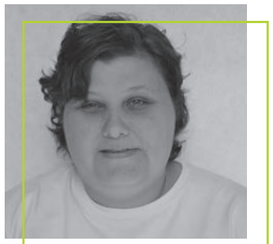

By Kim Selig, MSW
and Amy Cyr, MD










It seems like a no-brainer — if you're breaking a sweat on a regular basis, from running a marathon to cleaning your house, you're doing something that's good for your body. The science seems to be there to prove it too, especially for people facing serious health issues, like cancer. Yet we all know it's not easy to maintain your workout routine, let alone start one, after you've been diagnosed with breast cancer. In fact, it's estimated women decrease their physical activity by two hours each week after a breast cancer diagnosis, and less than one-third of breast cancer survivors participate in physical activity at recommended levels, specifically activity of moderate intensity 30 or more minutes per day at least 5 days a week [1].

But, consider this: survivors who exercise experience positive effects in physical health (symptom control, treatment side effects, health maintenance), functional health (gaining/maintaining independence, balance), and mental health (cognitive function, emotional distress, self-esteem). As research increasingly shows physical activity is associated with improved physical and emotional health and well-being for cancer survivors, starting a regular exercise program could be the first step in experiencing those long-term health and psychological benefits [2-4].

## Survival-Related Benefits

Most important, physical activity appears to be linked to decreases in all-cause and cancer-related deaths. We can all think of ways exercise could impact survival overall, for instance by improving heart health and maintaining a healthy weight, but it may reduce breast cancer-related deaths as well. In fact, there is growing evidence exercise may improve survival in women with breast cancer [2-6].

Many studies have linked being overweight at breast cancer diagnosis and weight gain after diagnosis with poorer outcomes, including survival, recurrence, and other cancer diagnoses. As exercise can help with weight loss and maintenance, a lifestyle change focusing on exercise and diet may be the best approach to take, especially for women who are overweight [1, 3, 7, 8].

## Quality of Life Benefits

A cancer diagnosis impacts not only your physical health but can also impact your quality of life, and cancer survivors have higher rates of distress, i.e., depression and anxiety, and use of mental health services than the general population. Fortunately, we know physical activity has a positive impact on quality of life, not only in the general population but also among cancer survivors. Both aerobic exercise and strength training are associated with positive mental health outcomes, with some benefit noted with only one exercise session per week [2, 4].

Lymphedema is one negative side effect of breast cancer treatment that can dramatically impact quality of life. Many women are told to limit activity in order to reduce lymphedema risk. However, obesity is a significant cause of lymphedema development. Achieving and maintaining a healthy weight may help prevent lymphedema [12]. For women already diagnosed with lymphedema, exercise, specifically strength-training, has been shown to reduce lymphedema symptoms and improve overall function of the affected area [9].

### More Research Needed

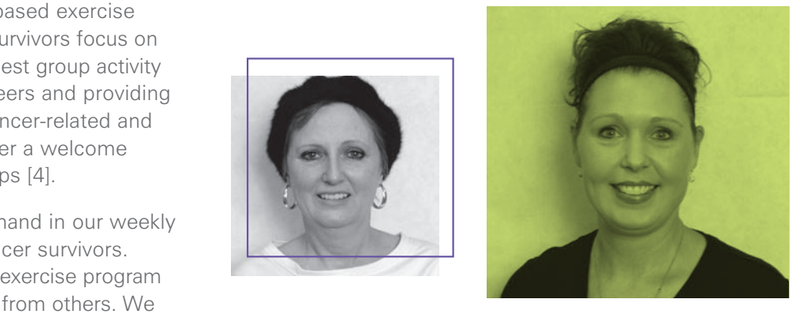
While it may seem straightforward that physical activity would be beneficial to people diagnosed with cancer, systematic evaluation of physical activity and weight management is a relatively newer area of research. Most of the studies published are observational studies or studies that relied on participants' self-reporting of physical activity, without controlled monitoring. Randomized clinical trials provide the most reliable scientific evaluation but are also the most difficult and costly. To date, there has been no randomized clinical trial to examine if weight loss leads to improved survival among women with breast cancer. The ENERGY study is a trial to evaluate recruitment, participation, weight loss and quality of life between two randomized groups: 1) breast cancer survivors who received ongoing cognitive behavioral therapy, and 2) breast cancer survivors who received no additional intervention. If this initial trial proves successful, a larger clinical trial will be conducted to assess weight loss/maintenance on breast cancer survival [10].

Important questions remain, such as what types of activities provide the most significant improvement in survival? Does physical activity performed at a young age have greater benefit? Fortunately, there is significant research interest in understanding the benefits of activity and weight loss among cancer survivors. So, keep an eye on the news and check in with your care team regarding the latest research.

### Social Support Benefits

One area needing more attention is the link between exercise and social support. Research shows survivors benefit from support long after treatment ends, but the type of support that works best may change over time. It makes sense that group-based activities would foster feelings of support and connectedness. The few studies that have been conducted on group-based exercise and social support for breast cancer survivors focus on dragon boating ,and the findings suggest group activity helps by connecting survivors with peers and providing a safe place to share experiences, cancer-related and not. These types of activities may offer a welcome alternative to traditional support groups [4].

We're witnessing these benefits firsthand in our weekly exercise program for young adult cancer survivors. Our program offers not only a guided exercise program but the opportunity to meet and learn from others. We talked with three YWBCP members who're participating in the group, and found their reasons for coming to the group and what they gain from working out with other survivors compelling. Each woman shared it's difficult to get, and stay, motivated, but it pays off if you do. On the following page, read their responses to questions about: 1) motivation to start and maintain an exercise program; 2) being part of a program specifically for young adult cancer survivors; 3) barriers to exercise and how they deal with them; 4) exercising on their own.





## AMY

Diagnosed 2011 with metastatic breast cancer, currently treated with Herceptin and bone-strengtheners

| MOTIVATION | SURVIVOR COMMUNITY | BARRIERS | ON MY OWN |
|---|---|---|---|
| I exercise to improve my shape, well-being, and health. I'm not always motivated honestly, but I know I feel better after I participate in the group. | The exercise group is made up of women dealing with various stages of breast cancer – meeting weekly, some going through treatment, some with hair, some without, some recovering. Being together is motivating. | I may not call it a "barrier," but there are moves I don't do exactly as Joy (personal trainer who leads the group) does them. I may have to modify, which Joy usually demonstrates, if I have any difficulty. | I try to get to yoga class once a week. I have a gym close to home. I go when I'm motivated! I like using the elliptical and various weight-lifting machines. |

## CINDY

Diagnosed 2012 with stage O breast cancer, treated with radiation, now in follow-up care

| | | | |
|---|---|---|---|
| The research I've read shows exercise and weight loss can be just as important as follow-up care in the fight against recurrence, so when I found out about the program, I thought it'd be a great way to start exercising. I think the group is motivating, and the gentle email and Facebook reminders help too. One change I've noticed is I used to be uncomfortable during my MRI/MRI biopsy prior, but at my last MRI, I was able to hold still and was more comfortable because I have better muscle tone since starting the class. | I like that I'm able to participate, or at least modify the exercises for my fitness level. Also, the group members have all had some kind of cancer diagnosis, so we are supportive of each other and where we are in the process of diagnosis and survivorship. | I'm a single mom with two children, 9 and 13, so my biggest barrier is their extra-curricular activities. I'd been attending regularly, but then fall sports started and volleyball practice was at the same time as exercise class, and my 9 year-old came first. Since then, we've been busy with holidays and we've all been sick, but I swear I'm coming back! | When I first started, I was also part of the YMCA Livestrong program for cancer survivors, and that was a great complement to the YWBCP program. Unfortunately, the Livestrong program only lasts 3 months. The new building where I work has a gym, so I just started walking on the treadmill during my lunch hour. |

## ANGIE

Diagnosed 2012 with stage 2 breast cancer, treated with chemotherapy and radiation, now in follow-up care

| | | | |
|---|---|---|---|
| My main motivation to exercise is the well-being of my temple. Taking care of my temple by eating right, exercising, and staying active will help prevent recurrence of breast cancer and many other diseases. | The difference with the young adult survivor group is that it's for cancer survivors, and the exercises are geared toward getting your muscles back and strengthening them, which you may lose during chemotherapy. I found that sometimes I couldn't raise my arms and had numbness in my fingers and toes. You need to regain your strength to keep pressing on through treatment. | The only barrier to being part of the program is pressing on, or coming out to class. Once I attended the class, I looked forward to the next one and the next one. I'm truly thankful to everyone who's made this class possible. | I exercise at home and workout at the YMCA two days a week along with this class. |

| Health Issue | Benefits of Physical Activity | |
|---|---|---|
| Mortality | Decreases:<br>Rates of all-cause mortality<br>Rates of cancer-related mortality | |
| Immune function | Improves:<br>Natural killer cell cytotoxic activity<br>Unstimulates [3H] thymidine uptake by peripheral blood lymphocytes | Decreases:<br>C-reactive protein (CRP) |
| Health-related quality of life | Improves:<br>Physical health<br>Functional health<br>Mental health | |
| Fatigue | Decreases: cancer-related fatigue | |
| Fitness | Improves:<br>Cardiorespiratory fitness<br>Muscle strength<br>Flexibility<br>Diastolic blood pressure | |
| Bone health | Protects against bone loss | |
| Physical well-being | Improves:<br>Sexual functioning<br>Sleep<br>Balance<br>Healthy hemoglobin levels<br>Diastolic blood pressure | Decreases:<br>Incontinence<br>Pain<br>Systolic blood pressure<br>Resting heart rate |
| Psychological well-being | Improves:<br>Quality of life<br>Mood and happiness<br>Body image<br>Self-esteem<br>Perceptions of sexual attractiveness<br>Posttraumatic growth<br>Personality functioning<br>Locus of Control | Decreases:<br>Levels of depression<br>Anxiety<br>Stress<br>Tension<br>Cognitive disorganization<br>Emotional irritability<br>Confusion |
| Social support | Improves:<br>Perceptions of social support<br>Feelings of connectedness | |

*Reprinted with permission: Sabiston, CM, Brunet, J. Reviewing the benefits of physical activity during cancer survivorship. Am J Lifestyle Med. 2012; 6: 167-177.*

## The WHERE'S and the HOW'S

Survivors, researchers and practitioners seem to agree that regular physical activity is a safe and feasible approach for improving physical, psychological, and social well-being for most breast cancer survivors. But, as noted earlier, it's often easier to make recommendations than to follow them when it comes to exercise, and the thought of attending an exercise class may seem daunting, especially when your body's already been through a lot. Here are some ideas that might make it easier to get started or push through a lull (adapted from Sabiston article) [4]:

1. Small changes add up! Start slowly and gradually increase your exercise levels. Seek advice from a certified personal trainer or physical therapist. **YWBCP offers a free weekly exercise group led by a certified personal trainer!**
2. Make exercise a family priority. Studies demonstrate the risk of developing breast cancer is significantly less among physical active women [6, 11]. Remember your children may also benefit from a positive change in your lifestyle.
3. Choose activities you enjoy, whether they're traditional exercise programs or lifestyle activities, like cleaning the house, taking the stairs, or walking instead of driving.
4. Exercise is cumulative – evidence suggests shorter bouts of activity throughout the day are as effective as one longer bout.
5. Set goals and make exercise part of your daily routine. Consider exercise classes that meet on a set schedule or parking your car some distance from your office so that you add a walk to your daily routine. **YWBCP offers a free weekly exercise group, Thursdays at 7 pm, at The HEIGHTS (8001 Dale Ave, STL 63117) – put it on your calendar!**
6. Involve your family and friends, or make new ones. **At YWBCP's weekly exercise group and on our Facebook group about fitness and survivorship** www.facebook.com/groups/580767535320749/, **we're building a supportive, healthy community where you'll meet and learn from other young survivors!**
7. Most importantly, it's never too late to start! Research shows whether you start at diagnosis, during treatment or after, the benefits are there.

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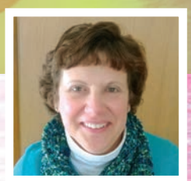
12. lymphnet.org

*There are so many decisions to make when you're facing a breast cancer diagnosis, some with few choices, some with more. For many women, reconstructive surgery is one area where they may have more than one option to choose from.*

Reconstructive Surgery:

# Making the Right Decision for You





By Mirna Rafael-Reyes, Jolie Smith and Tracy Wetteroff

**While having options is a good thing, it doesn't always make deciding any easier. We've found it often helps to talk with other survivors, hear their experiences and perspectives. So, we asked three of our members to answer questions about how and why they chose the reconstructive option they did. Thank you to Jolie (J), Mirna (M), and Tracy (T)!**

**Which option did you choose?**

**J:** I chose bilateral mastectomies without any reconstruction.

**M:** I chose the latissimus flap breast reconstruction only because I wasn't a candidate for the tram flap due to my weight and the risk of hernia.

Latissimus flap reconstruction - surgeon takes tissue from the latissimus dorsi muscle in your back, tunnels it underneath your skin to its new location and uses it to form a new breast mound.
Tram flap reconstruction - surgeon removes abdominal tissue and attaches the tissue in your chest area.

**T:** I had a bilateral mastectomy with silicone implants and nipple reconstruction.

**Do you feel like you were presented with a full range of reconstructive options?**

**J:** I feel I was only given the option for immediate reconstruction with expanders, followed by silicone implants.

**M:** Yes, my plastic surgeon understood fully that I was "new" to the breast reconstruction world and broke the options down in a manner that I understood.

**T:** The option I chose was presented to me as "Plan A." Because I previously had lumpectomies followed by radiation to both breasts, there was some concern about how my skin would hold up. If the implant route failed, then "Plan B" was to follow up with a "tummy tuck" that would use the skin (and fat) from my stomach area. At the time, I thought I'd been presented with all my options. However, shortly after surgery, I learned about "gummy" implants and read about nipple-sparing mastectomies. I remember being particularly upset that the nipple-sparing surgery was not offered to me. Although I'm very satisfied with how my "new" nipples turned out, I'd still prefer to have my own!

**What factors influenced your decision? Were there any medical issues/factors that influenced your decision?**

**J:** I wanted to have the least amount of surgeries, pain and complications. For my peace of mind, I didn't want foreign material inside of me, and I felt I would be able to feel any new lumps if I didn't have implants.

**M:** The explicit information my plastic surgeon provided me about my individual case. I wanted the tram flap option initially, so my surgeon sent me home with instructions to lose weight so I could meet the weight requirement. After six months, I hadn't lost the necessary weight, so I opted for the Latissimus, as he recommended.

**T:** Although I had previously had two lumpectomies, in 1998 and 2007, it took testing positive for the BRCA-1 gene to finally convince me to have a bilateral mastectomy. In terms of reconstructive surgery, I was offered saline or silicone implants. I had saline tissue expanders which gave me a flat, round, pancake look. So, for the implants, I went with silicone in hopes of achieving a more natural looking teardrop shape. I can't say that I see much difference with the silicone. My joke is that, for someone who shouldn't have to wear a bra anymore, I sure spend a lot of time shopping for them! I look for lightly padded bras that help "round out" my appearance. I also wear some of the bras meant to hold prosthetics as they just seem to fit me better than department store bras.

**How did you make your decision?**

**J:** I looked at other options myself. While searching on the Internet, I came across a website called breastfree.org. The website seemed to address all of my concerns and worries.

**M:** My plastic surgeon was available to answer my questions, equipped me with plenty of reading material and provided me with options specific to my medical situation. I also gathered information by attending online workshops, the YWBCP symposium and other conferences and meetings. I heard valuable information from other survivors and medical experts about breast reconstruction.

**T:** I went to see two different reconstructive surgeons. The information they gave me was about the same, so I didn't do much "medical" research beyond that. I did, however, speak with members of YWBCP regarding the pros and cons of having reconstruction. That is where this group is such a benefit… you get honest answers from those who have "been there, done that!" I feel this one-on-one, first-hand knowledge is better than anything you can find on the internet!

**What was your surgery/recovery like?**

**J:** My breast surgeon knew I was not having reconstruction in the future, so she made my chest flat and left no extra skin. After a one-night stay in the hospital, I was discharged home. During the day, I spent time in a recliner and took mild pain medications. At night, I was able to lie in bed and took stronger medication for a few weeks. Four weeks after surgery, I returned to work and exercising. I have required no other surgeries.

**M:** It was just like my plastic surgeon described it would be. I knew what to expect. My recovery took a couple of weeks. I experienced very little pain. The thing that I remember the most is getting used to the feeling of having something "foreign" in my body. Thank goodness, I did not have any complications.

**T:** My surgery and recovery were more or less fine, no infections or follow-up issues. Having the drains for the first week or two afterwards was the worst of it. I work fulltime as a paralegal at a law firm and took the recommended six weeks off for the surgery. By about the fourth week, I think I was starting to feel pretty good and was able to catch up on things around the house. When I first returned to work, I noticed I would "hit a wall" around 2 pm in the afternoon and really have to push myself to get through the rest of the day. Fortunately, my energy came back pretty quickly and soon I was getting through the days just fine. On a side note, my surgery included being part of a clinical trial which involved listening to a "guided imagery" recording while under anesthesia. The CD player and headset were still with me when I awoke in the hospital room. As I would wake up through the night, I would hit the play button and the recording would lull me back to sleep. It's something I still recommend to patients getting surgery.

**How do you feel about your decision today?**

**J:** I feel like I made the best decision for me. I never wear prosthetics, although I do own them, because I am very comfortable being flat. I was concerned about how other people would react to my flat chest, but most people don't notice and no one has ever said anything.

**M:** Six years after my reconstruction surgery, I am still extremely happy with my choice. When diagnosed, I had a mastectomy on the affected breast, and at the time of my reconstruction on the affected breast, my plastic surgeon also performed a "lift" on the other breast for symmetry. Today, I can say that I am even and extremely satisfied.

**T:** I feel pretty good about it although I have lingering doubts about what may be lurking under the implants. I'd like to get an MRI, but the three oncologists I've consulted say the risk of recurrence is so low, MRI's are not part of standard follow-up protocol. In retrospect, I wish I had gone just a little bigger with the size of my implants, mainly because we tend to put on weight when recuperating and from getting older. I also wish I had at least gone to check out prosthetics beforehand. The implants have left a constant tightness across my chest. At night, I wish I could take them off and stretch!



# From the Other Side of Cancer

By Rebecca Dennington

It was just a pap smear. It was just a check on my to-do list. It was just the annual cross I had to bear as a woman in order to get my yearly prescription of birth control pills. That is all. I had barreled through this appointment every year for the last seventeen, ignoring the bruise to my dignity, going to my happy place for a moment or two while a doctor examined the parts I modestly kept covered for the rest of the year.

It was the summer of 2010; however, as my examination began and I lay there, promising myself a shopping trip and some lunch if I behaved and stayed still, it was the moment that everything changed. My gynecologist began the breast exam and, in her first touches, she paused and lingered in one particular spot. "I think there's something here," I remember hearing her say. "Did you know you had a lump here?" I didn't. How could I not know?

I look back now and know the reason. I didn't know because I wasn't looking. And I wasn't looking because it couldn't happen to me. I was safe. I was only 35 years old. I had no family history of cancer, much less breast cancer. There was no need to be checking myself. They don't even recommend getting a mammogram until you're 40. I had five years before I had to start thinking about that. The only thoughts I really had about my breasts were which bra was going to make them look the perkiest and which shirt was going to make them look the biggest.

My doctor told me it was probably a fluid-filled cyst, but she was going to schedule a mammogram and ultrasound just to be sure. Both of those reports came back "suspicious" and I needed a biopsy. Even then, I kept finding excuses. I drank too much caffeine. That was surely the culprit. I really hated to waste everyone's time and our hard earned money on a biopsy because, remember… this stuff doesn't happen to me.

***But it did.***

I had breast cancer. I was diagnosed with invasive and non-invasive ductal carcinoma. The tumor was fairly small and the cancer had not yet reached my lymph nodes. On August 2, only a couple of weeks from the day I received my diagnosis, Dr. Julie Margenthaler, a well-respected and gifted surgeon, performed a lumpectomy on my right breast. Once the surgery was completed, due to my young age and the fact that, although the cancer had not reached my lymph nodes, it was detected in the lymphatic vessels, my superb oncologist, Dr. Timothy Pluard, felt it best to treat the cancer aggressively. So in September, I began the first of 15 chemotherapy treatments. I completed chemotherapy at the end of January and in late February began 6 weeks of daily radiation treatments.

***Fighting means doing everything in my power to live, no matter the outcome. Fighting means never laying down or giving up, but making the choice to do the next thing. I did not choose to get cancer. But I will choose not to let it define me.***

There it is. My journey, my battle, summed up in a tidy paragraph. But if you are reading this and have had cancer yourself, or been a caregiver to someone with cancer, you know as well as I do that it was so much more than that. You recognize that those words are simply like a shell that encompasses a time so full of raw emotion that it is hard to even describe.

As I went through my journey, the creative side of me needed an outlet. Tears obviously weren't enough to wash away what was lying on my heart as I was faced with the "what if's." That is when I found solace in pouring those private thoughts and feelings out on paper, those things inside me that were too selfish to add to my loved ones' already broken hearts. In time, the relief that writing gave me was so great and the release of those emotions so empowering, that I chose to take those words on paper and add them to a blog. Now the journey I was on could be shared with family and friends, and they could stay updated.

It was this blog, www.deepthoughtsbybeck.blogspot.com, which one of my best friends pitched to LazyDay Publishing, who amazingly offered me a contract. So, as I was completing the treatments to rid my body of this awful disease, I became not just a survivor but an author. I was also telling my story in a book entitled *Me And The Ugly C,* which was released in fall 2011 in eBook and print.

When I began my journey, I was just a girl. I was a wife and a mother, a daughter and a granddaughter. Once I was diagnosed, I was afraid and unsure, weak in body and in spirit. I didn't know what I was supposed to do next. I didn't know HOW to be a cancer patient. People talk about fighting cancer but here I was, breast deep in the battle and I wasn't sure what it meant to fight something I couldn't see or feel. I showed up for surgery and treatments. Was this fighting? Was I doing it right? The chemo knocked me down again and again. I must have been doing it wrong. The radiation burned my skin. Was I not strong enough? People told me I was amazing and called me a hero. But they surely didn't know that I cried and that I hurt, that I was weak and I was tired, that I couldn't remember who I used to be and that I didn't recognize who I had become.

It has been three years now since I was diagnosed. I remember a time when I couldn't imagine what life was going to be like on the other side of cancer. Now, here I am. As if I had crossed a canyon deep as death, on nothing but a tattered and broken-down bridge. As if each day that I suffered the treatments that broke me down to build me up were days that I hung heavily from that rickety connection, fumbling for a hand-hold, grasping for the frayed ropes and crumbling boards of the only way across to the other side. I picture that last treatment, that last day, and imagine my dirty hands and bloody fingertips stretching and reaching for the edge of that canyon, God's hand pulling me gently to my feet, dusting me off, wiping my tears, refilling my strength, overflowing my cup.

Today, safe and strong and new, I find myself looking over my shoulder, that bridge swaying with the weight of someone else fighting their way across. Helplessly, I am watching my mother, recently diagnosed with breast cancer, fumble for the next hand-hold, inching her way across. I see where she is and I remember. I see the fatigue in her face and I feel it again. I see her downcast and burdened and I long to take it away, just as she longed to wash that same look from my face three years ago. I see her tears and I tell her I cried too.

I am here, kneeling at the edge, my hand outstretched to her. She is fighting, just like I did. She's doing the next thing, taking the next step, showing up for treatments, resting when she must, eating when she feels she can. I don't know why. Why me? Why her? Why not? We are human just like everyone else. We haven't figured out a way to remove cancer from our lives. But what we can do is be prepared. Early detection saved our lives.

***We can be aware of our bodies and we can check ourselves. We can pass the word to our sisters and our friends. We can empower one another with knowledge about self-examinations and mammograms. We can reach out to the ones in the battle and encourage them, cheer them on. This is how we fight, together.***

For me, it was a breast exam at my annual check-up. For my mother, it was a change in her mammogram. We can be aware of our bodies and we can check ourselves. We can pass the word to our sisters and our friends. We can empower one another with knowledge about self-examinations and mammograms. We can reach out to the ones in the battle and encourage them, cheer them on. This is how we fight, together.

So who am I now on the other side of cancer? I am still just a girl. I am still a wife and mother, forever a daughter and granddaughter. Cancer did not rob me of who I was. The experience, however, changed me… for the better. And now I am so much more. I never knew I was so strong. I never knew I was so brave. I never knew I was so loved. I never knew what it was like to really live, to take chances and go again if I fail. I learned that life is a matter of choices. I understand now what it means to fight. Fighting means doing everything in my power to live, no matter the outcome. Fighting means never laying down or giving up, but making the choice to do the next thing. I did not choose to get cancer. But I will choose not to let it define me. That is how you fight.

*Becky Dennington is the author of Me and the Ugly C, a blog turned to book about her journey through breast cancer. It is available in eBook and print at Barnes and Noble and on Amazon.com, and is also available at some local libraries.*

## YWBCP would like to highlight the following organizations:

**Living Beyond Breast Cancer (LBBC)** – empowering all women impacted by breast cancer. www.lbbc.org

**Young Survival Coalition (YSC)** – addressing the issues that women diagnosed with breast cancer under 40 face. www.youngsurvival.org

**The Breakfast Club** – providing support to African American women diagnosed with breast cancer and their families in the St. Louis region. www.breakfastclub-stl.org

**Sharsheret** – supporting young Jewish women and their families facing breast and ovarian cancer. www.sharsheret.org

**Cancer Support Community of Greater St. Louis** – supporting, empowering, and educating individuals affected by cancer. www.wellnesscommunitystl.org

**Hope for Young Adults with Cancer** – providing social and financial support to young adults battling cancer. www.hope4yawc.org

**Metastatic Breast Cancer Network** – supporting women and men living with metastatic breast cancer. www.mbcn.org

**The Pink Fund** – providing financial support to women and men in active treatment for breast cancer. www.thepinkfund.org

**St. Louis Breast Cancer Coalition** – influencing legislation and funding for breast cancer research and treatment. www.slbcc.org

**Fertile Hope** – providing reproductive information, support, and hope to cancer survivors. www.fertilehope.org

**The Theresa Harpole Foundation for Metastatic Breast Cancer** – improving the quality of life for people with metastatic breast cancer and working to find a cure. www.metastaticfoundation.org

**No Woman Left Behind** – providing assistance with breast prostheses and surgical bras to under- and un- insured women living in Missouri or Illinois. www.nwlb.org

**First Descents** – offering young adult cancer survivors a free outdoor adventure experience. www.firstdescents.org

**Parenting with Cancer** – helping parents and children with the effects of a cancer diagnosis on their children and families. www.parentingwithcancer.com

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Our research program is directed by Dr. Paul Goodfellow and is currently supported by grants received from the National Cancer Institute, as well as the generous support of Celebrate Fitness, Celebrate Spot, and Celebrate Tennis.

## YOUNG ADULT CANCER SURVIVORSHIP GROUP

The Young Adult Cancer Survivorship Group is a free weekly exercise class for any young adult diagnosed with cancer at age 45 or younger. The class is led by a certified personal trainer and meets at 7 p.m. every Thursday at THE HEIGHTS, 8001 Dale Ave., St. Louis, MO 63117.

# Thank you for supporting the Young Women's Breast Cancer Program.

## YOUNG WOMEN'S BREAST CANCER PROGRAM

The Young Women's Breast Cancer Program (YWBCP) is dedicated to serving young women with cancer, young survivors, and their families by providing support, education, and community, advocating for young women, and advancing research focused on early-onset breast cancer. All programs are free of charge. Visit ywbcp.wustl.edu for more information.

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