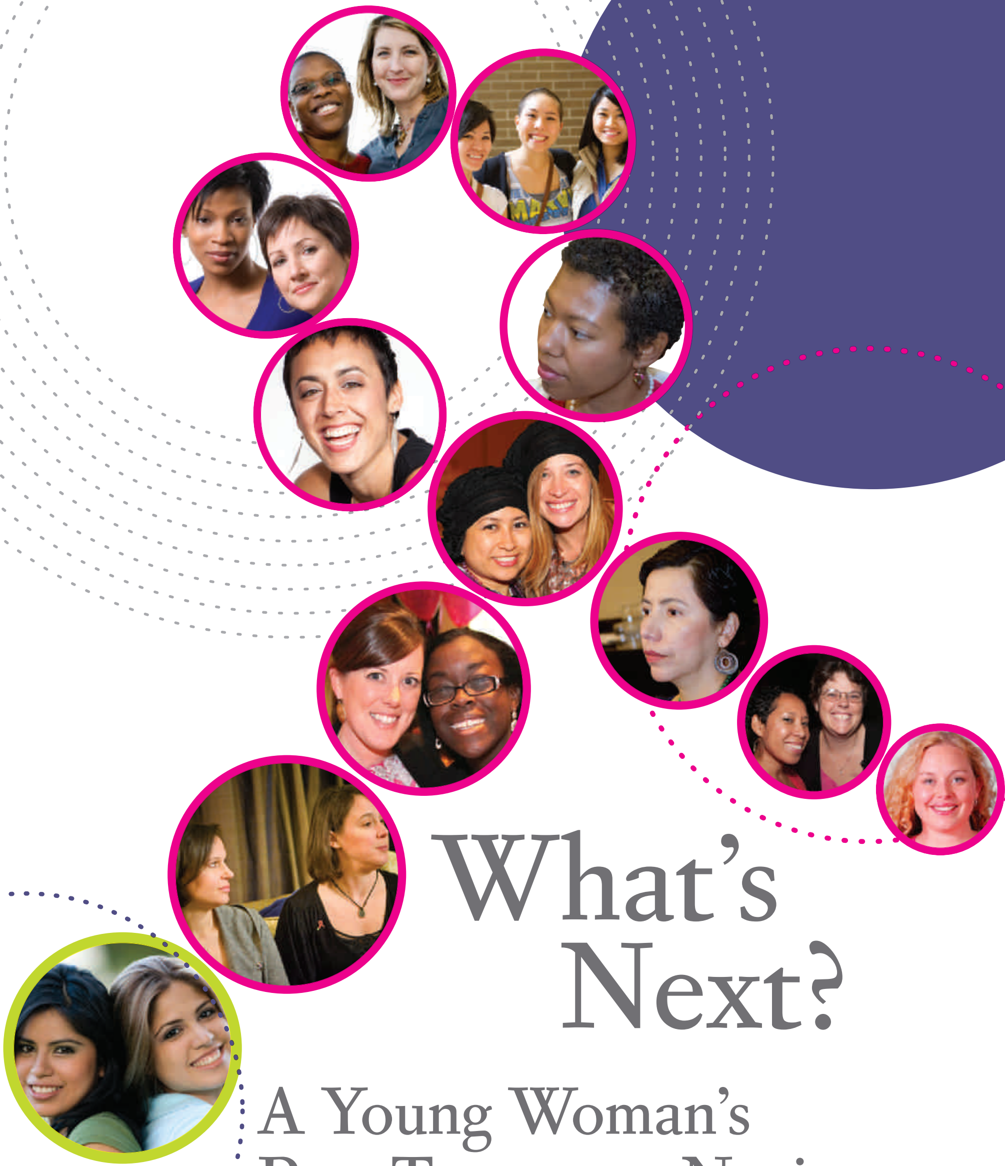

What's Next?

A Young Woman's Post-Treatment Navigator

YSC YOUNG SURVIVAL COALITION™

Young women facing breast cancer together.

ACKNOWLEDGEMENTS

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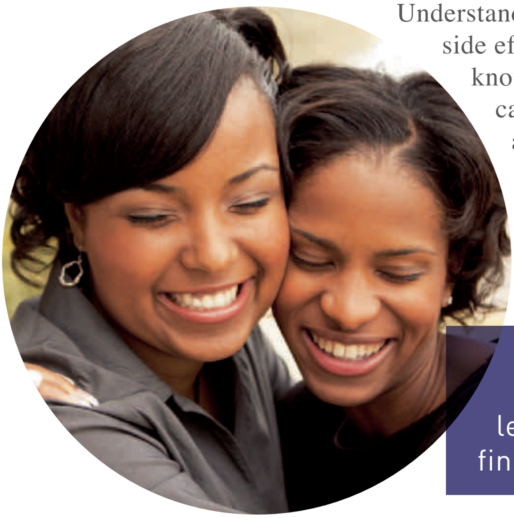
INTRODUCTION

We Hear You!

The day you wished for is finally here – treatment is over. You thought you'd be jumping for joy when you were finished with surgery, radiation, hormonal therapies, or chemotherapy, right? Instead you may be exhausted, anxious, confused, and may not feel particularly healthy. Everyone around you wants to throw a party, but the last thing you want to do is celebrate. You'd rather stay home and research that ache in your toe on the Internet.

We hear you! What you are feeling is normal. In fact, most people feel less than excited when they finish cancer treatment. For many survivors, the real healing begins as treatment ends. You no longer have a plan of attack on which to focus your energies, and there is no one else keeping a close eye on your symptoms. Adjusting to your "new normal" is a topic rarely discussed.



Understanding how to cope with the long-term side effects of your cancer treatment and knowing the details of your follow-up care plan will help ease your mind and maintain a sense of control. This guidebook has the information, tools, and resources to help you adjust to life post-treatment so that you can enjoy living and worry less.

> What you are feeling is normal. Most people feel less than excited when they finish cancer treatment.

Get to Know Young Survival Coalition – Connect in Your Community

Young Survival Coalition (YSC) was founded by three young breast cancer survivors in 1998. All under the age of 35 at diagnosis, they were discouraged by an appalling lack of information and resources for young women and extremely concerned about the under-representation of young women in breast cancer studies. Unlike their post-menopausal counterparts, young women diagnosed with breast cancer face higher mortality rates, fertility issues, and the possibility and ramifications of early menopause.

Today, YSC has grown to become the go-to organization for young women affected by breast cancer. YSC is reaching its 15th anniversary as a vibrant network of over 25,000 breast cancer survivors and supporters with a national network of volunteers, an engaged Board of Directors, and a dynamic staff of dedicated professionals. YSC was the first organization to focus exclusively on the unique issues facing young women with breast cancer. It provides comprehensive resources, support and education to address every phase of a young woman's breast cancer experience.

You are never alone.
Find out how you can be involved with YSC:
youngsurvival.org or 877.YSC.1011.

Disclaimer

YSC has provided this guidebook for educational, informational, and community purposes solely as a resource to young women and the people whose lives are affected by breast cancer. For specific answers to questions or concerns, YSC encourages you to consult your healthcare provider, as treatment for each patient varies with individual circumstances. The content is not intended in any way to be a substitute for professional counseling or medical advice. You should not rely upon information found in this publication without seeking the advice of a qualified healthcare provider. YSC does not endorse, recommend, or make any warranties or representations regarding any of the materials, products, or information provided by organizations referred to in this guidebook. Always seek the advice of your physician or other qualified health service provider with any questions you may have regarding a medical condition or treatment. Never disregard medical advice or delay in seeking it based on information you have read in this guidebook.

LIFE AFTER TREATMENT: WHAT TO EXPECT

The end of treatment often brings with it a wide range of emotions. You may be finished with some treatments, but may take hormonal therapy for awhile. Feelings of joy may be overshadowed by feelings of anxiety and confusion. Allow time for yourself to heal emotionally and physically. The good news is there are ways to regain some sense of control.

There are six main things you want to add to your to-do list after treatment is over:

- Get a written summary of your diagnosis and treatment.
- Get a written summary of your follow-up care plan.
- Understand your potential lasting side effects of treatment.
- Strive to understand your emotions.
- Make healthy lifestyle choices.
- Plan for your financial and career future.

Feelings of joy may be overshadowed by feelings of anxiety and confusion.

Get a Written Summary of Your Diagnosis and Treatment

Why Keep Your Records?

Keeping track of your personal medical history is a key part of managing your health. As time passes, it becomes increasingly hard to remember when and what procedures, tests, and treatments you received. Getting a copy of your medical reports will help you and your future healthcare providers understand the full picture of your diagnosis and care. Consider requesting electronic copies if available on a disk or jump drive. Medical records, even when they are our own, can be costly to have copied.

Some of the most crucial items you should have in your diagnosis and treatment summary are listed below. Don’t hesitate to ask for them; it’s your right.

- Contact information for doctors and other healthcare providers who oversaw your care
- Dates and results from diagnostic tests (e.g. mammograms, ultrasounds, MRIs, PET/CTs)
- Pathology or laboratory reports
- Date of diagnosis
- Description of your breast cancer, including type, stage, size, number of lymph nodes involved, hormone receptor status (ER, PR, and HER2)
- Dates of all treatments received including drug names and prescribed doses
- Dates and number of all radiation and/or chemotherapy treatments received
- Dates and types of all surgeries
- List of any treatment related side effects you experienced
- Information on any clinical trials in which you enrolled
- Follow-up/maintenance recommendations
- Who will be overseeing your care post-treatment and with what frequency

Some oncology practices offer their patients a comprehensive, written summary of their diagnosis and treatment, which contains the items listed here. By 2015, all cancer centers will be required to provide cancer survivors with a treatment summary and survivorship care plan. Ask your physician if this is something s/he offers to patients now. If not, there are free worksheets available to help you quickly create a written summary of your diagnosis and treatment, as well as follow-up care:

- YSC worksheets (included in this guidebook)
- LIVESTRONG Care Plan: www.livestrongcareplan.org

Get a Written Summary of Your Follow-up Care Plan

After treatment is complete, it's normal to worry about the future. Many young survivors feel they have their whole lives ahead of them and are concerned about recurrence (cancer coming back).

It may ease your mind to have a formal, written follow-up care plan created with the help of your doctor. This may come from your oncologist, breast surgeon, and/or other member of your breast cancer care team. Follow-up care is important because it helps to identify and address new or ongoing problems due to cancer or its treatment.

> It may ease your mind to have a formal, written follow-up care plan created with the help of your doctor.

Because everyone's cancer is unique, ask your doctor for the details of your specific follow-up plan. Some of the most important items you should include are listed below:

- What breast cancer related exams you need and how often you should have them, such as blood work, body scans, or mammograms
- What symptoms to report to your doctor in between check-ups, such as new lumps, bleeding, or pain, and to which doctor
- Ways to manage lingering effects of treatment, such as neuropathy, sleep problems, depression, physical disability, weight or appetite change, or pain

- What potential long-term effects of treatment you may develop in the future, such as cardiovascular disease, infertility, lymphedema, or osteoporosis
- Recommended screening tests for other cancers, such as colonoscopy for colon cancer or PAP test for cervical cancer
- Suggestions for healthy living, such as quitting smoking, being physically active, and eating a healthy diet
- Surgical follow-up and options: delayed reconstruction, implants, nipple reconstruction
- List of prescribed medications, reasons for taking them, and any possible side effects/contraindications

As part of your plan, you should also discuss which doctors you will see for follow-up cancer care and other medical care. For follow-up care, many women choose the same doctor who treated their cancer. For regular medical care, many see their main provider, such as a family doctor. For specific concerns, you may want to see a specialist. Talk to all of your doctors as you make this transition. Remember, always tell new doctors about your breast cancer history including the type of cancer and the type of treatment you had.

Understand Your Potential Long-Term Side Effects of Treatment

You may have some lingering side effects once you have completed treatment for breast cancer. Young women most commonly express concerns about fatigue, “chemo brain,” infertility, menopause, sexual difficulties, lymphedema, and weight management after treatment. They are also sometimes faced with long-term decisions, such as delayed reconstruction and birth control. This section addresses each of these topics, as well as other common physical effects, and suggests ways to cope with them. Please consult your physician about the side effects you are experiencing for suggestions specific to your unique situation. Where you once felt like a healthy young woman, you may now encounter what feels like constantly changing physical ailments. It is natural to become frustrated with these issues, but knowing what to look for and open communication with your medical team can help alleviate symptoms and worry.

Fatigue

Fatigue (feeling tired and having less energy) is a common side effect of cancer treatment and affects many patients afterwards. How long fatigue lasts and how much fatigue one feels varies from person to person. Sometimes this fatigue is short-term, while others experience fatigue that lasts for years after treatment or surgery.

Discuss your concerns about fatigue with your doctor. He or she can rule out any medical reasons, such as anemia (low amounts of red blood cells in the body) and make suggestions specific to your situation.

Below are suggestions for reducing the effects of fatigue in your daily life:

- Start an exercise program once your doctor says it is okay to do so. People who exercise may have more physical energy and an improved sense of well-being.
- Take short catnaps.
- Eat a well-balanced diet and drink plenty of fluids.
- Set reasonable goals for the day. Don't try to do everything all at once.
- Create and keep a bedtime routine. For example, go to bed and awaken at the same time each day.

"Chemo Brain"

Cancer survivors have worried about, joked about, and been frustrated with the mental cloudiness they notice during and after chemotherapy. "Chemo brain" is a common term used by cancer survivors to describe thinking and memory problems that may occur after cancer treatment. This can be an irritating and debilitating side effect of cancer and its treatment.

Here are just a few examples of what patients call "chemo brain":

- Forgetting things that they usually have no trouble recalling
- Trouble concentrating
- Difficulty remembering names, words, dates, and sometimes larger events
- Trouble multi-tasking
- Taking longer to finish things

For some people, these effects happen quickly and only last a short time, while others have long-term cognitive changes. Usually the changes that patients notice are very subtle, and others around them may not even notice a difference. Many people do not tell their healthcare team about this problem until it affects their everyday life.

Below are suggestions for sharpening your mental abilities and managing the problems that may come with “chemo brain”:

- Use a daily planner to keep track of appointments and schedules, to-do lists, important dates, phone numbers, and addresses.
- Exercise your brain. Take a class or do word puzzles to stimulate your mind.
- Get adequate rest, sleep, and hydration.
- Be active. Regular physical activity is not only good for your body, but also improves your mood, makes you feel more alert, and decreases tiredness (fatigue).
- Avoid distractions. Work, read, rest, and play in a peaceful environment.
- Organize your environment so things are in familiar places.
- Focus on one thing at a time.
- Track your memory problems and report them to your doctor. Keep a diary of when you notice problems and the events that are going on at the time. Be sure to address your concerns with your doctor if they worsen.
- Neurocognitive testing may be possible through a neurologist or psychiatrist. Ask your doctor about this testing.

Fertility

Ideally, your healthcare team discussed fertility options with you before the start of treatment, and you received the appropriate information to make the best decision for you. It’s important to remember each individual case must be examined uniquely and that breast cancer itself has no effect on fertility. However, treatments — particularly chemotherapy and ovarian suppression — can affect your ability to have children. Chemotherapy can damage or destroy eggs, which can reduce fertility right away or years later when early menopause may result. Your risk depends on your age (women under 35 have the best chance of remaining fertile), as well as the amount and type of chemotherapy treatment you receive. Surgery and radiation therapy, for early stage breast cancer, rarely affect your ability to have children. Make sure to get clearance from your medical oncologist before trying to conceive.

Hormonal treatments won't damage eggs, but they can delay or change your pregnancy plans. No matter what hormonal therapy you and your doctor choose, it's important to know there are many options and avenues for a family in the future:

- Tamoxifen (or an Aromatase Inhibitor) treatment can last five years or longer and potentially be a major delay. These drugs can cause birth defects if you get pregnant during treatment, so you have to wait to conceive until treatment ends. You can sometimes take a break from hormonal treatment after two years. Ask your doctor if this is an option for you. You should wait at least three months to allow Tamoxifen to leave your system before trying to conceive.
- Ovarian suppression uses a regular shot to temporarily cause early menopause. Your period returns after stopping this therapy, but during treatment you will usually be unable to get pregnant. For those women who would like to get pregnant in the future, this provides an option for decreasing estrogen temporarily. The treatment will, however, delay your childbearing window.
- Oophorectomy permanently removes one or both ovaries through surgery. The removal of one ovary greatly reduces your chances of getting pregnant naturally. The removal of both prevents natural pregnancy. Speak to your doctor about what family options are possible after this treatment — including using frozen eggs or ovarian tissue.

Targeted therapies, likewise, will not damage eggs, but can cause delays. If you take Herceptin, you should wait at least six months after treatment ends before trying to get pregnant.

It's important to know there are many options and avenues for a family in the future.

After treatment, your period can take a year or longer to return. For more than half of all women under 35, it takes less than a year. However, don't think of your period as a perfect test for fertility. Regular periods, while a good sign, don't prove that you're able to get pregnant, while absent periods don't necessarily show that you can't get pregnant. A reproductive endocrinologist can perform more reliable tests.

Remember, since your fertility can change over time, these tests might only describe your status for the time being. For women who have received chemotherapy within the past one to two years, the tests may not accurately predict future fertility. Tamoxifen can also affect results from these tests. Chemotherapy can cause infertility years later, so even women under 35 who remain fertile may have a narrower window for having children.

If it is determined that you are infertile, there are several other options for motherhood. Many women explore in vitro fertilization (IVF) and adoption, as well as the use of egg or embryo donors and/or surrogates (gestational carriers). Couples often feel strong and fulfilling connections to their children after using these methods—non-matching genes don't lessen that bond. Visit: http://www.americanpregnancy.org/infertility for additional information.

Fertility Resources

Fertile Hope
866-965-7205
www.fertilehope.org

A program of LIVESTRONG, Fertile Hope is dedicated to providing reproductive information, support, and hope to cancer patients whose medical treatments present the risk of infertility.

MyOncofertility.org
866-708-3378
myoncofertility.org

A website that provides information on the potential effect of cancer and treatment on fertility, options for preserving fertility, and resources for discussing these issues with a doctor. The website has a physician finder resource to search for a physician who can assist with fertility preservation options.

Early Menopause

Menopause occurs when a woman's ovaries stop producing hormones and menstrual periods stop. Menopause happens naturally as a woman ages. In young women, however, cancer treatment can cause early menopause by damaging the ovaries and affecting their ability to produce hormones. As a result, menstrual periods stop. For some cancer survivors, menopause is temporary and menstrual cycles resume. For others, menopause is permanent.

Symptoms of menopause may include:

- Hot flashes
- Night sweats
- Sleep problems
- Trouble concentrating
- Vaginal dryness
- Painful or uncomfortable intercourse
- Loss of interest in sex
- Depression, anxiety, irritability, mood swings
- Weight gain
- Memory problems

Talk to your doctor about your symptoms of menopause, especially if they are bothering you or interfering with your daily activities. He or she may have suggestions specific to your situation.

Below are suggestions for lessening the effects of menopause on your daily life:

- Notice what triggers your hot flashes, such as caffeine, alcohol, stress, fatigue, or spicy foods, and avoid them when possible.
- Dress in layers. Use a portable fan in your office or home.
- Use a water-based vaginal lubricant to ease vaginal dryness. This may also make sex more comfortable.
- Try drinking something warm before bedtime to help you sleep, such as caffeine-free tea or warm milk.
- Keep your bedroom dark, quiet, and cool and use it only for sleep.
- Look for ways to reduce your daily stress.

- Keep physically active.
- Join a support group for young women affected by breast cancer. Talking to others experiencing early menopause can be helpful.

Birth Control and You

There is a lot of information out there about birth control and what method is best for young women with histories of breast cancer. You may have heard that the hormones in many birth control pills, injections, or patches increase a woman's risk of breast cancer or that they impact long-term fertility.

Generally, for women who have a personal history of breast cancer, hormonal contraception like the birth control pill is not recommended. Hormonal methods, which also include injections like Depo-Provera, intrauterine devices (IUDs), birth control patches, and vaginal rings, can prevent pregnancy by interrupting the normal female cycle and decreasing the chances of ovulation and conception. They typically contain a combination of estrogen and progesterone. As such, particularly for women who have had a hormone-receptor type breast cancer, these contraceptive methods are generally advised against.

Barrier methods, such as male and female condoms, diaphragms and vaginal caps, do not contain hormones and work by physically blocking fertilization and conception. When used correctly and consistently, they are a safe and effective form of birth control. They may be used in conjunction with spermicide gels for additional protection. In order to work effectively, these methods must be used each time you have sexual intercourse.

Young women may also wonder about the safety of hormone levels in emergency contraception- sometimes known as the morning after pill. Because of the short-term use of these pills, the increase of hormones in your body is not significant enough to impact your risk of breast cancer.

Sex and Intimacy

Whether you are single, partnered, or in a long-term relationship, breast cancer survivors can face intimacy issues after treatment. It causes changes in your body that can affect your desire for and enjoyment of sex. The main concerns expressed by young survivors that impact their sex life are vaginal dryness, vaginal pain, body image, and reduced libido (interest in sex). These are suggestions for coping with each of these side effects:

- Body image is a significant issue for many young women with breast cancer. Scars, the loss of breasts, changes to erogenous zones, weight changes, and hair loss can also contribute to feeling unattractive or less than sexy. Remember that feeling sexy is about self-esteem, and that can only come from within. Get to know your body and its needs as they may be new or different than before you began treatment. Concentrate on your own well-being and believe that you deserve to be admired, loved, and able to experience intimate pleasure. If you are having trouble overcoming these issues, you may want to see a licensed therapist to help you work through them.
- Although it may be difficult, talk with your doctor about changes in your interest in sex and any physical changes that may make sex difficult. Problems with sexuality and intimacy can be physical, biological, psychological, social, and/or spiritual.
- Cancer treatments can cause early menopause or menopausal symptoms that may contribute to vaginal dryness. Hot flashes may happen during intimate moments. Antidepressants can cause lower libido. If you are not comfortable talking with your oncologist, see a licensed sex therapist or counselor who specializes in working with cancer patients. Taking care of physical symptoms may solve problems that you thought were more difficult to treat.
- Treat vaginal pain if you have it. There are several causes of vaginal pain. Certain chemotherapies can cause painful ulcers in the vagina. Steroids and antibiotics can increase the likelihood of getting yeast infections in the vagina. Low estrogen levels cause vaginal tissue to thin, dry, and lose elasticity. The good news is help is available for vaginal pain. If you are having pain with intercourse, get it checked out by your doctor.
- Lubricate! If the cause of pain with intercourse is vaginal dryness, use personal lubricants. There are many different kinds of lubricants intended for use during intercourse, and there are moisturizers that are meant to generally moisten and strengthen the walls of the vagina. Remember to use water- or silicone-based lubricants, especially if you are using barrier methods of contraception for optimum efficacy. There are also some products that can restore elasticity and moisture to the tissue of the vagina. It is important when thinking about such products that you make sure they are not estrogen-based. You should also avoid products that contain petroleum, glycerin or oil-based lubricants as they may increase your risk for bacterial and/or yeast infections. Female-focused companies, such as Pure Romance (www.pureromance.com) and

Babeland (www.babeland.com) sell lubricants, as well as other sexual enhancement products. Pure Romance has a program, Sensuality, Sexuality, Survival, devoted to the unique needs of breast cancer survivors (www.pureromance.com/sss).

- Practice being intimate without having sex. Being close together without the pressure of having sex may allow one or both partners to relax and focus on feeling close and connected again.
- Open the lines of communication. Take time for both of you to talk about your fears and concerns, as well as your wants and needs. The time to talk about sex with your partner is outside the bedroom. It's best not to bring up concerns about intimacy during intimacy or when one partner is trying to initiate intimacy. When you feel you are ready for intercourse, go slow and keep your partner informed of what hurts, what feels good, and when lubrication is needed.
- Remember that practicing new behaviors takes time and practice. Try to approach and experience these with an open-mind, patience, and a sense of play.

Kegel exercises strengthen the pelvic floor muscles. To "find" these muscles you can practice cutting off your urine flow when you are urinating. The muscles that contract to stop the flow are the same ones you should contract when doing Kegel exercises.

How to do Kegel exercises:

1. Contract your pelvic floor muscles.
2. Hold the contraction for three seconds then relax for three seconds.
3. Repeat 10 times.
4. Once you've perfected three-second muscle contractions, try it for four seconds at a time, alternating muscle contractions with a four-second rest period.
5. Work up to keeping the muscles contracted for 10 seconds at a time, relaxing for 10 seconds between contractions.

Sexuality and Intimacy Resources

Pure Romance
866-ROMANCE (866-766-2629)
www.pureromance.com/sss

Offers an exclusive line of lubricants and bedroom accessories including products specifically for women affected by breast cancer. The Sensuality, Sexuality, Survival Program focuses on helping survivors recapture their sexuality.

Lymphedema

Because of the serious effects cancer can have on the lymph system, some cancer survivors also face the challenges of lymphedema — the build-up of fluid in soft body tissues. This happens when the lymph system gets damaged or blocked, which often happens because of cancer, lymph node removal, and cancer treatment. Because of cancer, lymphatic system damages or blockage can occur due to infection, removal of lymph nodes, radiation to the affected area, or scar tissue from radiation therapy or surgery. For women with breast cancer, lymphedema usually happens in the arm.

Lymphedema may develop within a few days or few years after breast cancer treatment. Some conditions increase your risk: slow healing of the skin after surgery; a tumor that blocks the lymph duct or lymph nodes, or vessels in the neck, chest, underarm, pelvis, or abdomen; scar tissue in the lymph ducts under the collarbones caused by surgery or radiation therapy; and removal or radiation of lymph nodes in the underarm. The risk of lymphedema increases with the number of lymph nodes affected.

When surgery only removes the sentinel lymph node (the first lymph node to receive lymphatic drainage from a tumor), you have less risk of lymphedema.

Lymphedema can cause long-term physical, psychological, and social challenges — but you can also take some important steps to manage it and them. Inform yourself or take action with these tips:

- Talk to your healthcare team about your concerns and any symptoms you might have.
- Consider consulting a physical therapist who specializes in lymphedema. This expert advice can help you deal confidently with your symptoms.
- Contact the National Lymphedema Network for research updates and additional information that might tell you how to better manage or treat this condition.

Please note one misconception: exercise does not increase the risk of lymphedema. In the past, doctors told women not to exercise the affected arm. Studies now show that slow, carefully controlled exercise is safe and may even help you prevent lymphedema; in breast cancer survivors, upper-body exercise does not increase the risk of lymphedema.

Lymphedema Resources

National Lymphedema Network
800-541-3259
www.lymphnet.org

Internationally recognized non-profit that provides education and guidance to lymphedema patients, healthcare professionals, and the general public.

Delayed Reconstruction

Many women choose not to undergo breast reconstruction after a mastectomy. If you had a similar experience, you are not alone in your decision. Now that you are out of treatment, you may have revisited the idea, but are not sure what a delayed breast reconstruction would entail. Remember, this is a personal choice that your breast surgeon (or general surgeon) and plastic surgeon are ready to discuss with you. Fully exploring your options will help you make the best choice for your body and your life after cancer.

One thing to consider while making your decision is your overall health; surgeons may advise that you may not be able to have reconstruction if you are obese, too thin, or have blood circulation problems. If you are a smoker, many surgeons say that you must quit smoking at least two months before reconstructive surgery to allow for better healing.

When making your decision, there are some important things to consider, including how any further treatment such as radiation will affect the reconstructed area, existing mastectomy scarring to the chest wall, and your overall feelings around body image. Even when delayed, reconstruction is likely covered by insurance.

Breast Reconstruction Resources

Johns Hopkins Breast Center
www.hopkinsbreastcenter.org

Provides direct patient care and educational resources, including in-depth information and videos on breast reconstruction options and procedures.

Weight Management

Some types of chemotherapy and hormonal therapy may leave women with challenging weight problems during and after treatment — they can cause survivors to gain weight in a particular way by losing muscle and gaining fat tissue. Unfortunately, this can make losing weight more difficult since many of the usual ways won't work. It's normal to feel some frustration — but be patient with yourself. You have the ability to control a lot of things and make some positive choices, like eating a healthy diet and engaging in regular physical activity. Many YMCAs have partnered with LIVESTRONG to offer fitness programs designed specifically for cancer survivors. Contact LIVESTRONG or your local YMCA for details.

Some young women face a different challenge after their diagnosis — they have no desire to eat, and they lose weight. Talk to your doctor or nutritionist about your appetite and weight challenges. Try eating several, smaller nutritional meals daily. Eat healthy.

Other Common Physical Effects

Some women experience long-term changes to their skin complexion and hair texture after breast cancer treatment. This should not be a cause for concern, but feel free to contact your doctor if you experience any changes that seem extreme or unusual.

You may also have to deal with neuropathy as a side effect of chemotherapy and may continue to after treatment. As part of your follow-up plan, discuss with your doctor ways to alleviate pain/discomfort and what symptoms can indicate worsening neuropathy.

Understand Your Emotions

Breast cancer can leave you feeling like your emotions are not your own. Take time to transition into your life after treatment. It may take some time to fall into a routine that feels comfortable, but know that this is natural. Young women most commonly express concerns about fear of recurrence, anxiety, depression, self-image, and relationship changes. This section addresses each of these topics and suggests ways to cope with them.

If you find that your anxieties, worries, or fears are becoming overwhelming and are interfering with your day-to-day activities or sleep habits, talk to your doctor. You may be experiencing symptoms that need to be treated professionally.

Fear of Recurrence

The fear of recurrence (cancer coming back) is by far the most common concern among cancer survivors. Every ache and pain may cause you to think, “Is my cancer back?” When treatment ends, you may feel like you don’t have a plan of action or may be anxious to make plans for a future that seems uncertain. This can leave you experiencing uneasiness and a loss of control.

You may be mourning the loss of immortality you once felt as a healthy young woman and facing feelings that your body betrayed you. The good news is there are ways to ease your fears. Here are suggestions for coping with the fear of recurrence:

- Accept your emotions. Talk about your fears with a healthcare provider, licensed mental health professional, trusted friend, or other survivors.
- Practice mindfulness. Awareness in the moment often helps reduce anxiety, stress, and fear of recurrence.
- Take control of your health. Ask your doctor for a written follow-up care plan, including what exams you need in the future and how often you should have them.
- Recognize important indicators. Ask your doctor for a list of symptoms you should report to him/her in between check-ups, such as new lumps, bleeding, or pain.
- Make healthy lifestyle changes, such as increasing your physical activity and eating a healthy diet.
- Join a support group for cancer survivors. Getting to know other cancer survivors will help you feel less alone as you learn how they are coping with the same worries.

Anxiety and depression are normal and common reactions to stressful life events, such as cancer. These are also normal and common side effects to treatment and how cancer brings up questions of identity – for example, who am I now?

Anxiety

When treatment ends, you may feel like you don't have a plan of action or may be anxious to make plans for a future that seems uncertain.

Anxiety is a normal reaction to cancer. After treatment is completed, you may face new anxieties. Your appointments with your healthcare provider naturally decrease once treatment is complete, which may leave you feeling abandoned or uncertain. This feels out of the comfort zone for many cancer survivors and is a normal, common reaction. Other causes of anxiety include changes in body image, sexual dysfunction, reproductive issues, or post-traumatic stress.

People with anxiety do not all experience the same symptoms. The severity, frequency, and duration of symptoms depend on the individual. Symptoms of anxiety include:

- Feeling shaky, jittery, nervous, or dizzy
- Feeling tense, fearful, or apprehensive
- Avoiding certain places or activities because of fear
- Racing or pounding heart
- Trouble catching your breath when nervous
- Sweating or trembling
- Feeling a knot in your stomach or a lump in your throat
- Worrying about follow-up exams or tests weeks in advance
- Fear of losing control or going crazy

The good news is that there are ways to manage your anxiety. Below are suggestions for caring for yourself if you are experiencing anxiety:

- Ask your doctor for help. He or she can refer you to a licensed social worker, psychologist, or other mental health resources in the community. He or she may also recommend anxiety-relieving medications.
- Learn more about your cancer and your follow-up care plan. A plan can help you feel more in control. Ask your doctor for specific signs and symptoms of a cancer recurrence if that is one of your biggest sources of anxiety.
- Explore relaxation techniques, such as guided imagery, meditation, exercise, or yoga.
- Find survivorship programs and support groups in your community.

Depression

Depression is common among cancer survivors. While everyone occasionally feels sadness or grief during their cancer journey, depression is more serious and interferes with daily life and normal functioning. The good news is that even the most severe cases of depression are treatable. The most common treatments for depression include counseling and/or medication.

People with depression do not all experience the same symptoms. The severity, frequency and duration of symptoms depend on the individual. Symptoms of depression may include:

- Persistent sad, anxious, or “empty” feelings
- Feelings of hopelessness and/or pessimism
- Feelings of guilt, worthlessness, and/or helplessness
- Irritability, restlessness
- Loss of interest in activities or hobbies once pleasurable, including sex
- Fatigue and decreased energy
- Difficulty concentrating, remembering details, and making decisions
- Insomnia, early-morning wakefulness, or excessive sleeping
- Overeating or appetite loss
- Thoughts of suicide, suicide attempts
- Persistent aches or pains, headaches, cramps, or digestive problems that do not ease even with treatment

Below are some suggestions for self care if you are having symptoms of depression:

- Ask your doctor for help. He or she can refer you to a licensed social worker, psychologist, or other mental health resources in the community.
- Request that your thyroid function be tested through blood work. This is routinely a first step prior to anti-depressants or anti-anxiety medications being prescribed.
- Engage in mild activity or exercise. Go to a movie, a ballgame, or another event or activity that you once enjoyed. Participate in spiritual, social, volunteer, or other activities.

- Set realistic goals for yourself. Break up large tasks into small ones, set some priorities, and do what you can as you can. Celebrate your successes no matter how big or small.
- Try to spend time with other people and confide in a trusted friend or relative. Try not to isolate yourself, and let others help you.
- Expect your mood to improve gradually, not immediately. Do not expect to suddenly “snap out of” your depression. Often during treatment for depression, sleep and appetite will begin to improve before your depressed mood lifts.
- Remember that it will get better. Positive thoughts will replace negative ones as your depression responds to treatment. You are going forward with your life!

Self Image

Femininity, society, sexiness, womanhood, and body image…it’s already complex enough. Changes resulting from breast cancer treatment and surgery add even greater complexities that others often can’t imagine. You may have strong emotions about your body right now, but you can also feel hopeful about adapting to the changes you may experience.

As women, we learn early in life that breasts matter. Breast cancer and treatment bring changes to the body, especially these parts we’ve learned to value so highly. Some body changes last just a short time, and others last forever. With the loss of a breast or breasts, scars, hair shedding, hair growth in unexpected areas, complexion changes, and weight gain or loss, many young women feel ashamed or afraid that others will reject or feel sorry for them.

Even after the signs and symptoms of treatment fade, you might feel troubled by your body’s changes. Your loved ones might also have some difficulty dealing with changes in the way you look. This can be hard on you, too. Feelings of anger and grief are natural. Feeling badly about your body can also lower your sex drive. And a loss of or reduction in your sex life can make you feel even worse about yourself. Learn more about facing this challenge in our section on sexuality and intimacy.

Don't ignore what you feel — it can help to express your emotions. Find opportunities to speak with other young women who have struggled with many of the feelings you might be experiencing. They can offer advice, understanding, and support — even a wry joke or two to help you smile as you face your new challenges.

These tips can help you cope:

- Try to focus on the ways that coping with cancer has made you stronger, wiser, and more realistic. There is so much that makes you valuable.
- Mourn your losses. They are real, and you have a right to grieve.
- Look for new ways to feel good inside and out. A new outfit, makeup, or spa treatment may give you a lift — and remind everyone how good you feel.
- If you find that your skin has changed from radiation, ask your doctor about ways you can care for it.
- Try to recognize that you are more than your cancer. Know that you have worth — no matter how you think that you look or what happens to you in life.
- Remember to be kind to yourself — today and every day.

Support for the Emotional Effects of Cancer

American Psychosocial Oncology Society
866-276-7443
www.apos-society.org

Professional organization offering a toll-free helpline through which cancer patients and their caregivers may obtain referrals for local counseling services in their community.

Association of Oncology Social Work
215-599-6093
www.aosw.org

A non-profit organization dedicated to the enhancement of psychosocial services to people with cancer and their families. The AOSW mission is "to advance excellence in the psychosocial care of persons with cancer, their families, and caregivers through networking, education, advocacy, research, and resource development."

Cancer*Care*
800-813-HOPE (800-813-4673)
www.cancercare.org

A national nonprofit organization that provides free, professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones, and the bereaved. Cancer*Care* programs — including counseling and support groups, education, financial assistance, and practical help — are provided by professional oncology social workers and are completely free of charge.

Cancer Support Community
888-793-WELL (888-793-9355)
www.cancersupportcommunity.org

A national organization that provides support groups, stress reduction and cancer education workshops, nutrition guidance, exercise sessions, and social events.

Relationship Changes

Dating after Cancer

For many young women affected by breast cancer, body image and sexual issues can make dating more challenging. As you struggle to accept the changes yourself, you may also worry about how someone else will react to physical things like mastectomy scars or a reconstructed breast. You might find it awkward to discuss your challenges — living with a life-threatening disease, sexual problems, the need for extra lubricants, or your loss of fertility. This can make it even harder to have conversations and feel close with your new partners.

Like many young women, you may wonder how and when to tell a new person in your life about your cancer and body changes. Understandably, you may have some fears of rejection — but don't let them keep you from finding the social relationships that will be meaningful in your life. Don't turn cancer into an excuse for not dating or trying to meet people. Like anyone, you won't have a perfect experience on every date, but you will always learn.

Find out what you can about this new relationship until you develop a feeling of trust and friendship — then you can talk about your cancer. Consider

Keeping lines of communication open will contribute positively to your quality of life.

practicing what you will say to someone if you worry about how you will handle it. Think about how he or she might react, and prepare a response. Remember that we all face rejection — it often has little to do with your breast cancer. And if it does, that's not who you want to be with anyway.

Family and Friends

Relationships with your partner, parents, siblings, children, friends, and colleagues continue to be important after breast cancer treatment and surgery. Keeping lines of communication open will help you feel understood and contribute positively to your quality of life. Be open about your experience with breast cancer, how it affected you, and how others can help. There is support available for you and for loved ones. Ask Cancer*Care*, Cancer Support Community, or YSC for resources and upcoming events specifically for family and friends.

Often after treatment, women go through an adjustment period in these relationships, as well. Friends and family are excited for you that you are "cancer free" and may assume you no longer need constant support. They may have trouble understanding that it will take time to rediscover who you are and the life you want to build post-treatment.

However, as you know, you are still facing many conflicting emotions. This is why it is important to keep an open dialogue about your needs and also seek out women who can relate. Look for support groups and events in your area.

The Changing Role of Partners

Being in a relationship is tough. Being in a relationship during and after breast cancer can bring additional challenges. The impact of surgery, chemotherapy, radiation, or hormonal therapy on your body can impact interpersonal relationships and intimacy in a profound way. Your ability to maintain a healthy relationship with your partner post-treatment mainly relies on your and your partner's abilities to interact, communicate, and support each other. The role of your partner is now changing after treatment, and the support that was once focused on you throughout diagnosis and treatment may have now shifted towards the relationship and its "new normal."

The changing role of your partner in your relationship post-treatment may be a positive or negative one as some things may be easier to cope with than others. You may find that the roles you and your partner had before and during your breast cancer diagnosis have changed. You may find your partner will try and continue in his or her role as caregiver or revert back to how things were before diagnosis. However your partner responds, it is important to communicate any concerns or fears. Points to incorporate into your relationship's "new normal" are:

- Make time to talk.
- Stay open-minded.
- Get reacquainted.

An open attitude towards communication and open discussion can prevent a great deal of anxiety and fear for both of you post-treatment. Many couples find that although breast cancer puts their relationship under a considerable amount of pressure, they came out of it feeling closer than ever – celebrate that!

Other Emotions

Your experience with cancer is unique and so is your emotional response. The emotions you feel as a survivor need to be acknowledged and expressed. Be honest with your feelings of fear, anxiety, anger, joy, grief, or guilt. Talk to a trusted friend, family member, or licensed mental health professional. Treat yourself gently and allow yourself to heal both physically and emotionally. If your feelings begin to interfere with your daily activities or normal functioning, seek the help and guidance of a healthcare professional right away.

Relationship Resource

Cancer*Care*
800-813-HOPE
www.cancercare.org/tagged/caregiving

Make Healthy Lifestyle Choices

Many survivors are inspired to make healthy lifestyle choices after cancer treatment is complete. By taking better care of yourself, you will feel more in control of your health and may reduce some of the long-term side effects you are experiencing, such as weight gain or fatigue. Some lifestyle choices, such as quitting tobacco products, will even reduce your chance of getting other cancers in the future.

Young breast cancer survivors are most commonly interested in learning how they can eat well and be more physically active after treatment. Below are suggestions that you may find helpful. Remember, you don't have to do everything all at once — start slowly and add these healthy practices to your life over time to ensure success.

Nutrition

Researchers continue to explore how healthy food choices may help reduce the risk of cancer or recurrence. We do know, however, that eating well will help you regain your strength and feel better overall. Talk with your doctor or a nutritionist to find out about any special dietary needs that you may have.

The American Cancer Society and the American Institute for Cancer Research have developed the following nutrition guidelines for healthy living after cancer:

- Fill your plate with more plant-based foods. Animal-based foods should take up 1/3 or less space on your plate.
- Choose fish and lean poultry more often and red meat only occasionally. Avoid processed meat.
- Try to eat at least five to nine servings of fruit and vegetables daily.
- Eat plenty of high-fiber foods, such as beans and whole grain cereals and breads.
- Choose foods low in fat and low in salt.
- Work toward and maintain a healthy weight.
- If you choose to drink alcohol, limit the amount.
- Hydrate!

Physical Activity

While researchers continue to explore the effect that healthy lifestyles can have on reducing breast cancer risk, we know for certain that regular exercise is an important part of any healthy lifestyle. Exercise continues to be important for women after breast cancer. Before getting started on an exercise program, consult your physician, who will help you assess your current fitness level.

It's not just about weight loss. Some of the benefits of physical activity include:

- Increased blood flow, flexibility, mobility, and range of motion
- Increased energy
- Reduced stress
- Better sleep habits
- Reduced risk of lymphedema, cardiovascular disease, and osteoporosis
- Appetite control and maintenance of a healthy body weight

Get started!

- You do not need to join a gym or spend a lot of money on exercise equipment to be active.
- Explore your options and find a low-cost activity you enjoy, such as dancing, yoga, or walking.
- Strive to be physically active 30 minutes a day. Choose comfortable clothes and shoes to wear and get moving!
- Stay motivated. To help keep on a regular exercise program, try to set realistic goals, allow for setbacks, create a self-paced program, and schedule exercise as you would any other appointment. Some people find that it is easier to stick with an exercise program if they work out with a friend or in a group.
- Avoid constricting or overstressing an arm prone to lymphedema when exercising. For example, avoid weight lifting after breast cancer surgery until you have permission from your surgeon and oncologist.

Healthy Living Resources

American Dietetic Association
800-877-1600
www.eatright.org

The nation's largest organization of food and nutrition professionals, which can help you find a dietitian in your area.

American Institute for Cancer Research
800-843-8114
www.aicr.org

Answers questions about diet, nutrition, and cancer through its "Nutrition Hotline" phone and e-mail service. Has many consumer and health professional brochures, plus health aids about diet and nutrition and their link to cancer and cancer prevention.

The Cancer Project
202-244-5038
www.cancerproject.org

Provides classes, books, and other educational materials on cancer prevention and survival. The Cancer Project's free hands-on nutrition classes (Food for Life) help cancer survivors and their families learn new tastes and easy food preparation skills.

Cancer Support Community
888-793-WELL (888-793-9355)
www.cancersupportcommunity.org

A national organization that provides support groups, stress reduction and cancer education workshops, nutrition guidance, exercise sessions, and social events.

National Cancer Institute's Smoking Quitline
877-44U-QUIT (877-448-7848)
www.smokefree.gov

Free assistance from the National Cancer Institute's smoking cessation counselors. Available in English or Spanish.

Yoga Bear

www.yogabear.org

A national non-profit organization dedicated to providing cancer survivors with more opportunities for wellness and healing through the practice of yoga. Check website for participating yoga studios, as well as free online yoga and meditation webcasts.

YWCA

www.ywca.org

Through the ENCOREplus Program, offers support and exercise groups focusing on physical strength, health, and psychological wellbeing. Water toning and pool work are stressed. Call your local YWCA for more information.

Financial Planning and Responsibilities

Breast cancer treatment, surgery, and medical visits may create substantial medical bills and can strain any budget in both the long and short term. However, good financial planning and opportunities for financial assistance can ease this burden. Seeking financial help often involves making many phone calls to agencies and organizations that seem only to lead to more phone calls. However, financial planning and assistance options are available. For example, inquire about charity care, sliding fee scales, and payment plans.

If you have credit cards and need to use them to pay remaining medical bills or household expenses, be careful of not getting into credit card debt. Don't wait until you have maxed out your cards to seek help. Creative thinking early on might make a difference in long-term financial planning and peace of mind.

There are several computer and web-based programs available to help people organize and manage medical expenses, and many are free of charge. Below are a couple of systems that many young women have found helpful:

- **Quicken® Medical Expense Manager** is a computer software program that allows you to keep up with the various aspects of your health-related spending. This system allows you to track spending, manage Flexible Spending Accounts and installment payments, follow claims and payments of multiple insurance companies, and find and fix errors and overcharges. It also features tools to remind you and your family of upcoming appointments and important dates, consolidate healthcare contact information and track your medical and prescription history.

To request your free copy of Quicken Medical Expense Manager from YSC, email resourcelink@youngsurvival.org or call 877.YSC.1011. Supplies are limited.

- **Intuit® and Intuit Health**, maker of Quicken Medical Expense Manager, has generously donated a limited number of software packets to YSC. This CD-ROM is compatible with Windows 2000, XP, or Vista. To learn more about this software, visit healthcare.intuit.com. If your insurance carrier is United Healthcare, CIGNA or Medical Mutual of Ohio, Quicken Expense Health Tracker is a free tool that may be available to you. This online service is designed to help you understand insurance claims, correct errors, easily make payments, track expenses, and prepare medical cost information at tax time. For more information, speak to your insurance company, healthcare provider or visit healthcare.intuit.com.

The following organizations can help with financial assistance:

- The American Cancer Society can provide information on local sources of financial assistance. The ACS website lists many resources that provide financial assistance, including their resource, "Health Insurance and Financial Assistance for the Cancer Patient." To reach your local ACS, contact the national office at 800.ACS.2345 or visit www.cancer.org.
- The Patient Advocate Foundation Co-Pay Relief (CPR) provides direct financial assistance to qualified patients, assisting them with prescription drug co-payments their insurance requires. Contact the CPR program at www.copays.org or 866.512.3861.
- The Cancer*Care* AVONCares program provides limited financial assistance for homecare, childcare, and transportation. Cancer*Care*'s Linking A.R.M.S.™ program provides limited financial assistance for hormonal and oral chemotherapy, pain and anti-nausea medication, lymphedema supplies, and durable medical equipment. Contact Cancer*Care* at www.cancercare.org or 800.813.HOPE (4673).
- The United Way has programs to help those in need. See www.unitedway.org or call 703.836.7112 to contact your local United Way office.

- Reach out to religious organizations that you belong to or that are near you. These organizations provide help to their members and people in their community in a variety of ways.
- Check Young Survival Coalition's *ResourceLink Guidebook* or online databases for more financial and insurance resources.

Career and Job Transitions

For many people, work matters tremendously — and it can become even more important during and after cancer. Many find a sense of purpose and value from their jobs. Returning to the office in full or increased capacity can bring a welcome sense of normalcy.

Balancing your career comes with challenges, however. Re-engaging in a full-time schedule, if you have not already done so, can be a transition. That means you might need help — anyone would. Asking for help does not make you any less smart, competent, or capable. You just need to take care of yourself during and after this time. Sometimes the people at work make up another vital network of support — don't be afraid to rely on it.

Co-workers and managers can best help if they know what you need. That could mean an extended deadline when possible, changing a meeting time or working from home sometimes to accommodate follow-up appointments or fatigue — the important thing is to ask.

Protect your privacy. You have no obligation to tell everyone at the office about your experience with breast cancer — whether you work there now or are interviewing. Treat this as a very personal decision — it's up to you who you tell and how you tell them.

YSC encourages you to learn about your rights and protections. The Americans with Disabilities Act (ADA), Genetic Information Nondiscrimination Act of 2008, and the Family and Medical Leave Act (FMLA) give employees tremendous protection against disclosure and discrimination. Find in-depth information about your rights under these acts at The Cancer Legal Resource Center of the Disability Rights Legal Center.

Career Resources

Cancer and Careers
866-THE-CLRC
www.cancerandcareers.org

An initiative dedicated to empowering and educating cancer survivors to thrive in the work place by providing expert advice, interactive tools, and educational events.

Cancer Legal Resource Center
disabilityrightslegalcenter.org/about/cancerlegalresource.cfm

A national program providing free information and resources on cancer-related legal issues for survivors, caregivers, healthcare professionals, and employers.

SURVIVORSHIP RESOURCES

Young Survival Coalition
1-877-YSC-1011
www.youngsurvival.org

American Cancer Society
800-ACS-2345 (800-227-2345)
www.cancer.org

A national, community based organization that provides information and referrals to numerous education, community, and patient support services.

American Society of Clinical Oncology
888-282-2552
www.asco.org; www.cancer.net

A professional oncology society committed to conquering cancer through research, education, prevention, and delivery of high quality patient care.

I'm Too Young for This! Cancer Foundation
877-735-4673
stupidcancer.com

Supportive community for the next generation of patients, survivors, and caregivers between 15-40, providing community resources through social media and health technology.

Lance Armstrong Foundation
866-235-7205
www.livestrong.org

Inspires and empowers people affected by cancer to focus on living. Provides practical information and tools for survivors to live life on their terms.

National Cancer Institute
800-4-CANCER (800-422-6237)
www.cancer.gov

Conducts and supports programs regarding the cause, diagnosis, prevention, treatment, rehabilitation, and continuing care of cancer patients and their families. Offers a telephone and web-based information and education network for patients and their families.

National Coalition for Cancer Survivorship
877-NCCS-YES (877-622-7937)
www.canceradvocacy.org

A national nonprofit organization that advocates for quality cancer care for all Americans and aims to empower cancer survivors. Website includes patient resources on financial assistance, health insurance, employment rights, cancer advocacy, and clinical trials, as well as an online resource guide.

Planet Cancer
library.planetcancer.org

Connects young adults with each other, to empower them and to help them access support and resources they wouldn’t have known about otherwise. Also advocates in the medical and research communities on behalf of young adults.

Free YSC Worksheets (see the following fold-out pages)
- Creating a Summary of Your Diagnosis and Treatment
- Creating Your Follow-up Care Plan

BREAST CANCER GLOSSARY

A

Ablation: Using surgery or radiation to remove or stop the function of an organ or tissue in the body.

Amenorrhea: The absence or halting of the menstrual cycle in premenopausal women.

Adjuvant therapy: In the case of adjuvant chemotherapy, it is treatment given to lower the chance of cancer coming back. Adjuvant chemotherapy is given after surgery in breast cancer.

Angiogenesis: The formation of new blood vessels that cancer cells need to grow.

Anthracyclines: A type of chemotherapy that comes from certain types of Streptomyces bacteria. Anthracyclines are used to treat many types of cancer. Anthracyclines damage the DNA in cancer cells, causing them to die.

Antiemetics: Medications that reduce nausea and vomiting.

Aromatase inhibitor: A drug that prevents the formation of estradiol, a female hormone, by interfering with an aromatase enzyme. Aromatase inhibitors are used as a type of hormone therapy for postmenopausal women who have hormone-dependent breast cancer.

Atypical cells: Cells that are not typical, are abnormal. Atypical is often used to refer to the appearance of precancerous or cancerous cells.

Autologous bone-marrow transplantation: A procedure in which healthy bone marrow is removed from a patient, stored and then replaced following cancer treatment (chemo or radiation therapy). This is done in order to preserve the marrow from the damaging effects of the therapy, as in the case of high-dose chemotherapy.

Axillary lymph node involvement: The spread of cancer from the primary tumor to the axillary lymph nodes, which are located in the arm pit area. The axilla is typically the first site of spread (metastasis) in breast cancer.

B

Benign: Not cancerous.

Bilateral: Affecting both sides of the body.

Biological therapy: Also known as immunotherapy or biotherapy, this term refers to treatments designed to use the body's immune system (either directly or indirectly) to fight cancer or reduce side effects of cancer treatment. Cancer vaccines, now in development, are a type of biological therapy.

Biopsy: The removal of a sample of tissue for examination under a microscope to check for cancer cells. Physical exam and imaging can show that something abnormal is present in the breast, but a biopsy is the only sure way to know whether the problem is cancer. In a biopsy, the doctor removes a sample of tissue from the abnormal area, or may even remove the whole tumor. If cancer is present, the pathologist can usually tell what kind of cancer it is and may be able to judge whether the cells are likely to grow slowly or quickly.

Bisphosphonates: A group of drugs routinely used in the treatment of osteoporosis. In cancer, bisphosphonates may reduce the incidence of metastasis to the bones and, when cancer has spread to the bones, they have been shown to prevent fractures, promote healing, and reduce pain.

Boost dose: An extra dose of radiation administered in addition to the regular dose.

BRCA1 and BRCA2: Genes located on chromosome 17 and 13, respectively, that help to suppress cell growth under normal circumstances. An altered version of this gene predisposes the carrier to breast, ovarian or prostate cancer.

Breast parenchyma: The complete essential elements of the breast, the complete breast, not including the supportive framework.

Breast-conservation therapy (BCT): A treatment modality for early-stage breast cancer involving surgery, in which the tumor and a portion of the surrounding breast tissue are removed (amount varies), followed by post-operative radiation therapy. Lumpectomy (also called excisional biopsy, or wide or wide-local excision), partial/segmental mastectomy, and modified radical mastectomy (MRM) are all types of breast-conserving surgery, each designating the removal of an increasingly large portion of the breast. BCT usually involves the removal of some of the axillary lymph nodes. If nodes are found to be clinically positive for disease, a complete axillary lymph node dissection is usually performed. For many women with small tumors, BCT represents an effective and appealing alternative to mastectomy, allowing good disease control and improved cosmetic results.

C

Chemotherapy: Often referred to simply as chemo. The use of drugs to kill cancer cells. Chemotherapy can be taken orally or by needle into a vein or muscle. Chemotherapy is called a systemic therapy because the drugs enter the blood stream and travel throughout the body. Chemotherapy can therefore kill cancer cells outside of the breast.

Chest-wall recurrences: The subsequent reappearance within the chest wall of a breast cancer in a patient who underwent treatment and was found to be disease-free. This is a particularly serious recurrence.

Clinically significant findings: Findings considered important on clinical evaluation.

Comorbid: The presence of additional or coexisting disease. Comorbidity may be considered a factor in prognosis.

Contralateral: Affecting or located on the opposite side of the body. The opposite of ipsilateral.

CT Scan: A series of detailed pictures of areas inside the body taken from different angles. The pictures are created by a computer linked to an x-ray machine. Also called CAT scan, computed tomography scan, computerized axial tomography scan and computerized tomography.

Cyst: A closed sac or capsule, usually filled with fluid or semisolid material.

D

DCIS: Ductal carcinoma in situ. Often referred to as pre-cancer, DCIS is the term for a type of cancer consisting of cancer cells that remain where they originated, in the ducts of the breast.

DIEP Flap: A type of breast reconstruction in which blood vessels called deep inferior epigastric perforators (DIEP), and the skin and fat connected to them are removed from the lower abdomen and used for reconstruction. Muscle is left in place. For more information about breast reconstruction procedures, contact YSC.

Dominant masses: A prominent, suspicious mass requiring further clinical evaluation.

Dysplasia: Cells that look abnormal under a microscope but are not cancer.

E

EIC: Extensive intraductal component. The term used to describe situations in which 25% or more of the primary tumor consists of DCIS and in which DCIS is seen in ducts extending beyond the primary mass. EIC is more common in young patients and is associated with a higher incidence of positive margins and residual tumor in the surrounding breast.

Endocrine therapy: Treatment that adds, blocks, or removes hormones. To slow or stop the growth of certain cancers (such as prostate and breast cancer), synthetic hormones or other drugs may be given to block the body's natural hormones. Sometimes surgery is needed to remove the gland that makes a certain hormone. Also called hormonal therapy, hormone therapy, and hormone treatment.

ER-negative (-): See ER-positive.

ER-positive (+): This is an indication of whether the individual cancer cells in the tumor express an estrogen receptor, which means that they are receptive and sensitive to estrogen. In general, tumors that are sensitive to hormones, such as ER+ tumors, are slower growing and are thought to have a slightly better prognosis than tumors that are not sensitive to hormones, such as ER- tumors. Young women are more likely to have ER- tumors; older, postmenopausal women are more likely to have ER+ tumors. Many breast cancer treatments include the use of drugs such as tamoxifen that block the receptors in the breast cancer and metastatic cancer cells and prevent estrogen from getting to them.

Estrogen-receptor status: This refers to whether the tumor is ER-positive or ER-negative.

Excision: The act of cutting out; the surgical removal of part or all of a structure, such as a breast mass, or organ.

F

Fibroadenoma: Benign fibrous tissue of the breast. Such tissue is most commonly found in young women.

FISH: A laboratory technique used to look at genes or chromosomes in cells and tissues. Pieces of DNA that contain a fluorescent dye are made in the laboratory and added to cells or tissues on a glass slide. When these pieces of DNA bind to specific genes or areas of chromosomes on the slide, they light up when viewed under a microscope with a special light. Also called fluorescence in situ hybridization.

Fine-needle Aspiration (FNA): Aspiration of a suspicious lump using a small-gauge hypodermic needle in order to remove a sample of tissue (from the abnormal area) for pathological evaluation.

H

HER2/neu: A protein involved in normal cell growth. It is found on some types of cancer cells, including breast and ovarian. Cancer cells removed from the body may be tested for the presence of HER2/neu to help decide the best type of treatment.

Highly proliferative tumors: The proliferative capacity of a tumor refers to the rate at which the cancer cells within the tumor are dividing (increasing in number). The higher the rate of proliferation, the more aggressive the tumor is considered to be. In highly proliferative tumors, the cells are multiplying relatively quickly. This proliferative capacity is measured using a number of indicators, including S-phase fraction and flow cytometry, which evaluate cell-division behavior and the amount and type of DNA in the tumor cells, respectively. The proliferative capacity of a tumor is considered to be a predictor of risk of relapse.

Histopathological features: The features related to changes in and progress of the cancer. In breast cancer, these include pathologic tumor size, pathologic axillary status, number of metastatic lymph nodes, pathologic stage, lymphatic vascular invasion, estrogen-receptor status, and histologic grade. The histopathologic features of a breast cancer tumor are those characteristics determined by the pathologist under microscopic examination and using a variety of methods of pathologic analysis.

Hormone Receptor: A protein on the surface of a cell to which a specific hormone binds. The hormone causes many changes to take place in the cell.

I

IHC: See Immunohistochemistry.

Imaging: Any one of a variety of radiologic techniques, including x-ray, mammography, and MRI, used to produce a clinical image. Imaging is used to visualize the breast tissue in order to detect any visible, suspicious masses.

Immunohistochemistry: A sophisticated pathologic test in which cancer cells are stained with either fluorescent dyes or enzymes in order to reveal specific antigens.

Incidental findings: Findings made while looking for something else; findings that are found by accident.

IMRT: A type of 3-dimensional radiation therapy that uses computer-generated images to show the size and shape of the tumor. Thin beams of radiation of different intensities are aimed at the tumor from many angles. This type of radiation therapy reduces the damage to healthy tissue near the tumor. Also called intensity-modulated radiation therapy.

Invasive/infiltrating ductal carcinoma: One of several specific patterns of breast cancer. It begins in the cells of the breast ducts and spreads into the surrounding breast tissue. An estimated 65% to 85% of all breast cancers are of this type.

Ipsilateral: Affecting or located on the same side of the body. The opposite of contralateral (the other or opposite side).

L

Lobular carcinoma: Cancer that begins in the lobules (the glands that make milk) of the breast. Lobular carcinoma in situ (LCIS) is a condition in which abnormal cells are found only in the lobules. When cancer has spread from the lobules to surrounding tissues, it is invasive lobular carcinoma. LCIS is a marker for increased risk for breast cancer and not breast cancer itself.

Local-regional recurrence rate: The rate at which cancer cells from the primary tumor are detected in the same location and/or region following the primary treatment for the cancer.

Lumpectomy: See breast-conservation therapy.

Lymphatic invasion: Sometimes called lymphovascular invasion; is one of the many factors that the pathologist looks for when evaluating tissue from the primary tumor obtained by biopsy. If cancer cells are seen (under the microscope) in the middle of a blood vessel or a lymphatic vessel, this is called vascular invasion or lymphatic invasion. Such invasion in the primary tumor suggests that the cancer is potentially more dangerous than if there is no such invasion, as there is a greater likelihood of it metastasizing, via the lymphatics, to the lymph nodes in the axilla.

Lymphedema: A condition involving swelling of the arm that can follow surgery to the axillary lymph nodes and other treatment. It can be temporary or permanent and may occur soon after surgery or at a much later date.

M

Margins: This term refers to the area of normal, noncancerous breast tissue between the tumor and the surgeon's knife. Tumor margins are pathologically assessed following excision of the tumor to see whether they are free of cancer cells. The role of margins as a predictor of local recurrence is an important and controversial issue.

Mastectomy: Removal of the breast for the purpose of removing breast cancer.

Mediastinum: The area between the lungs. The organs in this area include the heart and its large blood vessels, the trachea, the esophagus, the bronchi, and lymph nodes.

Metastasis: The transfer of disease from one organ or part to another not directly connected with it. In malignant tumors, metastasis is due to the transfer of cells. The capacity to metastasize is a characteristic of all malignant tumors.

Metastatic seeding: Surgery-induced tumor cell dissemination. The spread of cancer cells at the time of tumor excision.

Multicentric disease: The meaning of this term, along with that of multifocal disease, is subject to variation. In general terms, multicentric disease involves two or more distinct primary tumors found within the breast, usually in different quadrants of the breast.

Multifocal disease: The meaning of this term, along with that of multicentric disease, is subject to variation. In general terms, multifocal disease refers to breast tumors with more than one focus or area of disease within the breast.

N

Necrosis: Dead tissue.

Negative: Not abnormal, not affirmative of a specific finding, response, presence, condition, etc. For example, negative margins means surgical margins that are found to be free of cancer cells on pathologic evaluation.

Neoadjuvant chemotherapy: Chemotherapy taken before surgery.

Neuropathy: A nerve problem that causes pain, numbness, tingling, swelling, or muscle weakness in different parts of the body. It usually begins in the hands or feet and gets worse over time. Neuropathy may be caused by physical injury, infection, toxic substances, disease (such as cancer, diabetes, kidney failure or malnutrition), or drugs, including anticancer drugs. Also called peripheral neuropathy.

Neutropenia: A condition in which there is a lower-than-normal number of neutrophils (a type of white blood cell).

Node positivity: A finding of cancer cells in the lymph nodes indicating that the cancer has a higher risk of spreading to other parts of your body.

O

Occult metastases: Hidden metastases. Occult metastases are those metastases not seen during routine examination.

Oncologist: A doctor who specializes in treating cancer. Some oncologists specialize in a particular type of cancer treatment. For example, a radiation oncologist specializes in treating cancer with radiation.

Oophorectomy: Removal of the ovaries.

Ovarian suppression: The use of chemicals on the ovaries to halt their functioning and thereby “shut off” the menstrual cycle.

Overexpression: The excess of a particular protein on the surface of a cell. Overexpression of certain proteins is associated with the growth of cancer cells.

P

Paget’s Disease: A form of breast cancer in which the tumor grows from ducts beneath the nipple onto the surface of the nipple. Symptoms commonly include itching and burning and an eczema-like condition around the nipple, sometimes accompanied by oozing or bleeding.

Palliative therapy: Treatment given to relieve the symptoms and reduce the suffering caused by cancer and other life-threatening diseases. Palliative cancer therapies are given together with other cancer treatments, from the time of diagnosis, through treatment, survivorship, recurrent or advanced disease, and at the end of life.

Pathologic confirmation: Confirmation of clinical findings by the pathologist, who conducts a microscopic examination of tissue/cell samples.

PET scan: A procedure in which a small amount of radioactive glucose (sugar) is injected into a vein, and a scanner is used to make detailed, computerized pictures of areas inside the body where the glucose is used. Because cancer cells often use more glucose than normal cells, the pictures can be used to find cancer cells in the body. Also called positron emission tomography scan.

Port: An implanted device through which blood may be withdrawn and drugs may be infused without repeated needle sticks. Also called port-a-cath.

Positive: Abnormal, affirmative of a specific finding, response, presence, or condition. For example, a positive biopsy indicates presence of cancer cells.

Prognosis: A forecast of the probable outcome of an attack or disease, the prospect of recovery from a disease as indicated by the nature and symptoms of the case.

Prophylactic mastectomy: Surgery to reduce the risk of developing breast cancer by removing one or both breasts before disease develops. Also called preventive mastectomy.

Q

Quadrant: The breast is spoken of in clinical terms as having four quarters, known as quadrants: the upper-outer, the upper-inner, the lower-outer and the lower-inner quadrants.

R

Recurrence: Cancer that has recurred (come back), usually after a period of time during which the cancer could not be detected. The cancer may come back to the same place as the original (primary) tumor or to another place in the body. Also called recurrent cancer.

Re-excision: A follow-up surgical excision at the primary excision site for the purpose of excising any residual tumor cells left behind during the initial surgery.

Resection volume: The overall volume of tissue, including disease- free tissue, removed during lumpectomy.

Residual tumor: Tumor cells that remain behind, uneradicated, after an initial attempt has been made to remove the cancer.

Radiation Therapy: Treatment with high-energy rays (e.g., x-rays) to the affected area to kill cancer cells and/or to shrink the tumor. Also called radiotherapy.

S

Second-line treatment: The term used to describe treatment undertaken at the time of recurrence of disease.

Sentinel lymph node biopsy: A staging and therapeutic technique used in breast cancer to determine the presence and extent of metastatic disease in the axilla. It is based on the basic concept that the first lymph node in the axillary basin to receive drainage of lymph from the primary tumor will be the first node to harbor cancer cells. If no cancer cells are found in this “sentinel” node, that basin is considered to be free of cancer. This technique is most successful for staging of early-stage breast cancers and for suitable candidates, offers a less invasive alternative to axillary lymph node dissection.

Supraclavicular lymph nodes: A lymph node located above the clavicle (collarbone).

T

Tamoxifen: An antiestrogen, tamoxifen is an anticancer drug that works by blocking the effect of the body’s natural estrogen. In breast cancer treatment, tamoxifen can be used as a preventive agent to prevent the onset of breast cancer, or as adjuvant therapy to control the spread of breast cancer or delay its return.

Taxanes: A type of drug that blocks cell growth by stopping mitosis (cell division). Taxanes interfere with microtubules (cellular structures that help move chromosomes during mitosis). They are used to treat cancer. A taxane is a type of mitotic inhibitor and antimicrotubule agent.

U

Unilateral: Having to do with one side of the body.

V

Vascular invasion: See Lymphatic invasion.

W

Wide excision: Also called wide-local excision. In breast cancer, this refers to the surgical removal of an area of breast tissue containing cancer cells, along with a rim (~1-cm in width) of normal tissue around the cancer cells (see margins). When referring to treatment of invasive breast cancers, wide excision is also commonly called lumpectomy (see Breast-conservation therapy). When referring to treatment of DCIS, the term wide excision is more commonly used, since there is usually no palpable lump per se.

NOTES

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