



# What's Next?

## **A YOUNG WOMAN'S POST-TREATMENT NAVIGATOR**



**YSBC** | YOUNG SURVIVAL  
COALITION®

Young women facing breast cancer together.

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# TABLE OF CONTENTS

<b>1 Introduction</b> .....	<b>4</b>	<b>6 Mental Health and Emotions</b> .....	<b>28</b>
Get to Know YSC .....	5	Fear of Recurrence.....	29
<b>2 Life After Treatment: What to Expect</b> .....	<b>8</b>	Anxiety .....	30
<b>3 Diagnosis and Treatment Summary</b> .....	<b>10</b>	Depression.....	31
<b>4 Your Follow-up Care plan</b> .....	<b>12</b>	Self-Image .....	33
<b>5 Potential Long-Term Side Effects</b> .....	<b>14</b>	Relationship Changes.....	35
Fatigue .....	14	<b>7 Healthy Lifestyle Choices</b> .....	<b>38</b>
“Chemo Brain” .....	15	Nutrition.....	39
Loss of Fertility.....	16	Physical Activity.....	40
Hormonal Therapy Effects on Fertility.....	17	<b>8 Financial Planning and Responsibilities</b> .....	<b>42</b>
Fertility After Treatment .....	18	Financial Assistance.....	42
Early Menopause .....	19	Career and Job Transitions .....	44
Birth Control.....	21	<b>9 Survivorship Resources</b> .....	<b>46</b>
Sex and Intimacy.....	21	<b>10 Glossary</b> .....	<b>48</b>
Lymphedema .....	23	<b>Post-Treatment Navigator Worksheets</b> .....	<b>52</b>
Cardiotoxicity .....	26	<b>Post-Treatment Navigator Evaluation Form</b> .....	<b>67</b>
Bone Health .....	26		
Delayed Reconstruction .....	26		
Weight Management .....	27		
Other Common Physical Effects.....	27		

# Introduction

The day you wished for is finally here—treatment is over. You thought you'd be jumping for joy, right? Instead you may be exhausted, anxious and confused. 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 back 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. You no longer have a treatment schedule on which to focus your energy, and there is no one else keeping a close eye on your symptoms. For many survivors, the real healing begins as treatment ends.

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

## 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, we encourage you to consult your healthcare provider, as treatment for each patient varies with individual circumstances. The content in this Navigator 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. We do 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 healthcare 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 Navigator.

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## GET TO KNOW YSC

INTRO

Young Survival Coalition (YSC) was founded in 1998 by three young women who were under the age of 35 when diagnosed with breast cancer. They were discouraged by the lack of resources available and the underrepresentation of young women in breast cancer research. Today, YSC is the go-to organization for young women facing a breast cancer diagnosis.

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. YSC strives to educate, empower and connect young survivors, while advocating to increase the number of research studies about breast cancer in young women.

Headquartered in New York City, YSC is the oldest and largest national organization focused exclusively on the unique needs of young women affected by breast cancer. Along with our nationwide Face 2 Face networks and vibrant online community, we host the YSC Summit — the only national conference dedicated to the unique issues of young women with breast cancer. We also host Regional Symposia, and we provide free educational resources such as the ResourceLink program and Navigator series, which includes information about every phase of treatment and survivorship.





YSC Sync programs connect, educate and support young women affected by breast cancer.



## CONNECT TO OTHERS

Find women who know what it's like to face breast cancer at a young age. There are four easy ways to connect:

### 1. YSC Online Discussion Boards

Share experiences and information at any time of day or night—even from a smartphone. Connect online 24/7 at [community.youngsurvival.org](https://community.youngsurvival.org).

### 2. YSC Face 2 Face Networking

YSC Face 2 Face (F2F) peer-led networking groups bring together survivors in their local communities. Groups can be based on location, similar diagnosis, interests or even age. To find a YSC F2F group near you or learn how easy it is to start one, visit [youngsurvival.org/ysc-f2f](https://youngsurvival.org/ysc-f2f) or call 877.972.1011.

### 3. YSC SurvivorLink

Get one-on-one peer support from a trained volunteer who shares a similar diagnosis, life experiences or concerns. To be connected or inquire about becoming a trained SurvivorLink mentor, call YSC's toll-free number at 877.972.1011, or email [resourcelink@youngsurvival.org](mailto:resourcelink@youngsurvival.org).

### 4. Online Video Support Groups

Talk monthly with other young women with breast cancer from the comfort of your home. To learn more visit [youngsurvival.org](https://youngsurvival.org).



## TOOLS YOU CAN USE

YSC offers free resources unique to young women affected by breast cancer and those who care about them. Resources can be accessed online or mailed.

### Knowledge is Power. Visit [youngsurvival.org](https://youngsurvival.org).

It's the most comprehensive resource for and about young women with breast cancer. Find information on medical research and updates on clinical trials. Read survivor stories. Download fact sheets, learn about upcoming educational offerings and access podcasts on past topics.

### ResourceLink

Includes hundreds of national and local resources in a print guidebook and online at [youngsurvival.org/RLGB](https://youngsurvival.org/RLGB). Also, you can call 877.972.1011 or e-mail [resourcelink@youngsurvival.org](mailto:resourcelink@youngsurvival.org) for assistance.

### YSC Summit and Regional Symposia

These conferences feature inspirational speakers and special wellness activities for young women affected by breast cancer and their co-survivors (relative, partner or friend). You'll also have the opportunity to connect with a community of other young survivors and their co-survivors. Find out more at [youngsurvival.org/conferences](https://youngsurvival.org/conferences).

### Virtual Programming and Online Chats

YSC offers virtual programming and online video support groups for young women with breast cancer. Past podcasts are available on the Audio/Video Library page of YSC's website. View additional videos and YSC news on YSC's YouTube channel. For more information, visit [youngsurvival.org/sync](https://youngsurvival.org/sync).

# Life After Treatment: What To Expect



The end of active treatment often brings a wide range of emotions. You may be finished with chemotherapy, surgery and radiation but continue to take hormonal therapy for 5-10 years. Feelings of joy may be overshadowed by 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 after treatment ends:

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



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TREATMENT

2

# Diagnosis and Treatment Summary

## 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 the 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. Many healthcare systems now have electronic medical records. Make sure you know how to access them, as printed records can be costly.

**Ask for a copy of your medical records. It's your right.**

Some of the most crucial items you should have in your diagnosis and treatment summary are:

- 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 and 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
- A plan for who will be overseeing your post-treatment care and with what frequency

Some oncology practices offer their patients a comprehensive, written summary of their diagnosis and treatment. Since 2015, all cancer centers are required to provide cancer survivors with a treatment summary and survivorship care plan. Ask your physician for more information. The following are also available to you at no cost:

- YSC planning worksheets (included in this Navigator and online)
- LIVESTRONG Care Plan: [livestrongcareplan.org](http://livestrongcareplan.org)

# Your Follow-up Care Plan

After treatment is complete, it's normal to worry about the future. It may ease your mind to have a written follow-up care plan. 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. 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:

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



It may seem surprising, but the 2015 American Cancer Society/American Society of Clinical Oncology Breast Cancer Survivorship Care Guidelines do not recommend looking for breast cancer recurrence through routine lab tests or imaging, unless you have physical signs or symptoms of a recurrence. Talk to your oncologist about the best course of action for you.

As part of your plan, you should also discuss which doctors you will see. For follow-up care, many women choose the same doctor who treated their cancer. For regular medical care, many see their main healthcare 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 treatment you had.

# Potential Long-Term Side Effects of Treatment

You may have some lingering side effects or develop new ones 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. Consult your physician about any side effects you experience.

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, but knowing what to look for and communicating with your medical team can help alleviate symptoms and worry.

## Fatigue

Feeling less energetic is a common side effect of cancer treatment. How long fatigue lasts and how much fatigue one feels varies from person to person. Sometimes it is short-term, and sometimes it lasts for years. Don't be hard on yourself if you are constantly tired. Your body needs time to recover.

Talk 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.

## Tips 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 water.
- Set reasonable goals for the day. Don't try to do everything at once.
- Create a bedtime routine. For example, go to bed and wake up at the same time each day.

## “Chemo Brain”

Cancer survivors have worried about, joked about and been frustrated with mental cloudiness. “Chemo brain” is a term used by cancer survivors to describe thinking and memory problems that may occur after cancer treatments such as chemotherapy. This can be an irritating and debilitating side effect.

Here are a few examples of what patients call “chemo brain”:

- Forgetting things 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 last a short time, while others have long-term cognitive changes. Usually the changes that patients notice are subtle, and others around them may not even notice. Many people do not tell their healthcare team about this problem until it affects their everyday life.

## Sharpen your mental abilities and help manage the problems that come with “chemo brain”:

- Use a daily planner or online calendar to keep track of appointments and schedules, to-do lists, important dates, phone numbers and addresses.
- Exercise your brain by taking a class or doing word puzzles.
- Get adequate rest, sleep and hydration.
- Be active. Regular physical activity is not only good for your body, but it also improves your mood and makes you feel more alert.
- 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.
- Ask your doctor about neurocognitive testing, which may be possible through a neurologist or psychiatrist.

## Loss of 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. Remember that breast cancer itself has no effect on fertility, but treatments such as chemotherapy and hormonal therapy 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 received. Surgery and radiation therapy rarely affect your ability to have children. Make sure to get clearance from your medical oncologist before trying to conceive.



Targeted therapies 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.

## Hormonal Therapy Effects on Fertility

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 for a family in the future. Hormonal therapies include:

**TAMOXIFEN OR AROMATASE INHIBITORS** (anastrozole, exemestane, letrozole) may be prescribed for 5-10 years and potentially cause a major delay. These drugs can cause birth defects if you get pregnant during treatment, so wait to conceive until treatment ends. You can sometimes take a break from hormonal treatment after a few years to conceive a child. Ask your doctor if this is an option for you. You should wait at least three months to allow Tamoxifen or an aromatase inhibitor to leave your system before trying to conceive.

**OVARIAN SUPPRESSION** is a shot sometimes given in conjunction with hormonal therapy and temporarily shuts down your ovaries. Your period returns after stopping this therapy, but during treatment you will usually be unable to get pregnant.

**OOPHORECTOMY** is only recommended in women with BRCA 1 or 2 genetic mutations to lower their risk of a future ovarian cancer. Oophorectomy permanently removes one or both ovaries through surgery. The removal of one ovary greatly reduces your chances of

POTENTIAL  
LONG-TERM  
SIDE EFFECTS  
OF  
TREATMENT

5



getting pregnant naturally. The removal of both prevents natural pregnancy. Speak to your doctor about what family options are possible after this surgery—including using frozen eggs or ovarian tissue.

## Fertility After Treatment

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, and Tamoxifen can also affect results. 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 [americanpregnancy.org/infertility](http://americanpregnancy.org/infertility) or the fertility page on [youngsurvival.org](http://youngsurvival.org) for additional information.

## Fertility Resources

### LIVESTRONG FERTILITY

855.220.7777

[livestrong.org/we-can-help/fertility-services](http://livestrong.org/we-can-help/fertility-services)

Provides reproductive information, support and hope to cancer patients whose medical treatments present the risk of infertility.

### MYONCOFERTILITY.ORG

866.708.3378

[myoncofertility.org](http://myoncofertility.org)

Provides information on the potential effects of cancer and treatment on fertility, options for preserving fertility and resources for discussing these issues with a doctor. Includes a physician finder resource to search for a doctor who can assist with fertility preservation options. Available in Spanish.

## Early Menopause

Menopause occurs when a woman's ovaries stop producing hormones and menstrual periods stop. It happens naturally with age, but in young women, cancer treatment can cause early menopause by damaging the ovaries. 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 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 interfering with your daily activities.

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LONG-TERM  
SIDE EFFECTS  
OF  
TREATMENT

5

## Tips for lessening the effects of menopause:

- Notice what triggers your hot flashes, such as caffeine, alcohol, stress, fatigue or spicy foods, and avoid those things when possible.
- Dress in layers. Use a portable fan in your office or home to keep cool.
- 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.
- Stay physically active.
- Join a support group for young women affected by breast cancer. Talking to others experiencing early menopause can be helpful.



## Birth Control

There is a lot of information out there about what birth control 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 impact long-term fertility.

Generally, hormonal contraception like the birth control pill is not recommended for breast cancer survivors. Hormonal methods, which also include injections like Depo-Provera, most 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, which should be avoided by women who have had a hormone-receptor-positive breast cancer.

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. A copper IUD is also a contraceptive option for breast cancer survivors, as it does not contain hormones. It is best to consult your oncologist and gynecologist to determine what contraceptive options are best for you.

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 probably not significant enough to impact your risk of breast cancer.

## Sex and Intimacy

Whether single, partnered or in a long-term relationship, breast cancer survivors can face intimacy issues after treatment. The treatment of breast cancer causes changes in your body that can affect your desire for and enjoyment of sex. 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. Although it may be difficult, talk with your doctor

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LONG-TERM  
SIDE EFFECTS  
OF  
TREATMENT

5

## Get to know your body's needs. They may be new or different than before you began treatment.

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.

The main concerns expressed by young survivors that impact their sex life are:

**VAGINAL DRYNESS:** Vaginal dryness can cause pain during intercourse. Lubricate! There are many different kinds of lubricants intended for use during intercourse, and there are moisturizers that are meant to moisten and strengthen the walls of the vagina. For optimum efficacy, remember to use water- or silicone-based lubricants, especially if you are using barrier methods of contraception. 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. Companies such as Pure Romance ([pureromance.com](http://pureromance.com)) and Babeland ([babeland.com](http://babeland.com)), sell lubricants, as well as other sexual enhancement products.

**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. If you are having pain with intercourse, get it checked out by your doctor.

**BODY IMAGE:** 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's 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.

**REDUCED LIBIDO:** It is not uncommon for breast cancer survivors to be less interested in sex after treatment. Be patient with yourself. Practice being intimate without having sex. Being close together without the pressure of having sex allows one or both partners to relax and focus on feeling 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.

## Sex and Intimacy Resources

### BABELAND

866.525.1439

[babeland.com](http://babeland.com)

Provides a variety of sex products, encouragement and education to promote the sexual health and pleasure of all women. Babeland believes in sexual exploration and finding new ways to be intimate.

### PURE ROMANCE

866.766.2623

[pureromance.com](http://pureromance.com)

Offers an exclusive line of lubricants and bedroom accessories, including products that can improve intimacy for women affected by breast cancer. Pure Romance is dedicated to empowering women and speaking frankly about sexual health through their products and education.

### SEXY AFTER CANCER

[sexyaftercancer.com](http://sexyaftercancer.com)

Explores leading edge information and support with groundbreaking tools, tips and processes for healthy intimacy and sexuality after cancer comes into your life.

## Lymphedema

Because of the serious effects cancer can have on the lymph system, some cancer survivors also face the challenges of lymphedema—swelling of the arm or other body parts due to a 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.

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SIDE EFFECTS  
OF  
TREATMENT

5

## Slow, carefully controlled exercise is safe and may even help prevent lymphedema.

For women with breast cancer, lymphedema usually happens in the arm. It can be temporary or permanent and can occur soon after surgery or at a much later date.

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 take some important steps to manage them:

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

It is a common misconception that exercise increases the risk of lymphedema. In the past, doctors told women not to exercise the affected arm. However, upper-body exercise does not increase the risk of lymphedema. Studies now show that slow, carefully controlled exercise is safe and may even help you prevent lymphedema. Talk to your doctor about what exercises are right for you.

## Lymphedema Resources

### LYMPHEDIVAS

866.411.3482

[lymphedivas.com](http://lymphedivas.com)

Provides stylish and medically appropriate compression garments for those affected by lymphedema after breast cancer surgery and/or treatment.

### NATIONAL LYMPHEDEMA NETWORK

800.541.3259

[lymphnet.org](http://lymphnet.org)

Provides education and guidance to lymphedema patients, healthcare professionals and the general public.

POTENTIAL  
LONG-TERM  
SIDE EFFECTS  
OF  
TREATMENT

5

## Cardiotoxicity

Depending on the prescribed treatment for breast cancer, survivors may be at a higher risk of developing cardiac problems. Treatments that may cause heart damage include (among others) Adriamycin, Herceptin and radiation on the left side of the body. In addition, if you were premenopausal before treatment and become postmenopausal during or after, that can also affect your heart. The risk of heart disease increases in postmenopausal women, with the decline of estrogen levels possibly playing a role.

There are steps you can take to care for yourself and your heart. If you are smoking, stop. Maintain a healthy diet, check on your blood pressure and cholesterol, exercise and reduce stress.

Signs and symptoms of heart problems can include puffiness in hands and feet (due to fluid retention), dizziness or weakness, shortness of breath, coughing and racing or irregular heartbeat. If you have any concerns or think you may be having a heart attack, call your doctor or 911 immediately.

## Bone Health

Breast cancer treatments can also cause women to lose bone density at a greater rate than the general population, especially if your treatments put you into menopause. Ask your doctor about obtaining a dual-energy x-ray absorptiometry (DEXA) scan, which can check on your bone density and whether you should take calcium supplements. Healthy lifestyle choices are also good for your bones. These choices should include physical activity, weight-bearing exercise, avoiding tobacco and limiting alcoholic beverages.

## Delayed Reconstruction

Some women choose not to undergo breast reconstruction after a mastectomy. Now that you are out of treatment, you may be revisiting the idea but are not sure what a delayed reconstruction would entail. Remember, this is a personal choice. Talk to your breast surgeon and plastic surgeon to explore your options. For more information on breast reconstruction options, refer to the YSC Newly Diagnosed Navigator.



## Weight Management

Some women gain weight during or after cancer treatment, and it can be difficult to lose that weight. Why this occurs is not entirely known, but it is likely a combination of the treatment impacting your metabolism and treatment-induced menopause. It is normal to feel some frustration. Be patient with yourself. Do the best you can to eat a healthy diet, get plenty of exercise and speak with your healthcare providers for additional help and support. See the section on “Self-Image” for more information.

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, nutritious meals throughout the day.

## Other Common Physical Effects

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

You may also have to deal with neuropathy (pain, numbness or tingling in hands and feet) as a long-term side effect of chemotherapy. As part of your follow-up plan, discuss with your doctor ways to alleviate pain/discomfort and what symptoms can indicate worsening neuropathy.

POTENTIAL  
LONG-TERM  
SIDE EFFECTS  
OF  
TREATMENT

5

# Mental Health and Emotions



Breast cancer can leave you feeling like your emotions are not your own. It may take time to fall into a routine that feels comfortable. Young women commonly express concerns about fear of recurrence, anxiety, depression, self-image and relationship changes.

If you find that your anxieties, worries or fears 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 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 you may fear making plans for a future that seems uncertain. This can leave you experiencing uneasiness and feeling a loss of control.

You also may be mourning the loss of the immortality you once felt as a healthy young woman and facing feelings that your body betrayed you.

### Tips for coping with a 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 or meditation.** 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.
- **Maintain a healthy lifestyle,** getting enough exercise, sleep 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

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

The severity, frequency and duration of symptoms depend on the individual. Symptoms may 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



## Depression

Depression is common among cancer survivors. While everyone occasionally feels sadness or grief, depression is more serious and interferes with daily life and normal functioning. Even the most severe cases of depression are treatable with 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 include:

- Persistent sad, anxious or “empty” feelings
- Feelings of hopelessness and/or pessimism
- Feelings of guilt, worthlessness and/or helplessness
- Irritability or 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 or suicide attempts
- Persistent aches or pains, headaches, cramps or digestive problems that do not ease even with treatment

### Tips 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. Your doctor 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.

## If you are having symptoms of depression, consider these suggestions:

- 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 a prescription for anti-depressants or anti-anxiety medications.
- Engage in mild activity or exercise. Go to a movie, a ballgame or another activity that you once enjoyed. Participate in spiritual, social or volunteer 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. Changes resulting from breast cancer treatment and surgery add even greater complexities that others often can't imagine.

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 changes last a short time, while 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.

Find opportunities to speak with other young women who have struggled with many of the feelings you have. They can offer advice, understanding and support—even a wry joke or two.

## 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 you look or what happens to you in life.
- Remember to be kind to yourself.

## Support for the Emotional Effects of Cancer

YSC is here to support you at every phase of your diagnosis. Learn more about our SYNC program just for young women affected by breast cancer, including how to connect in person through Face 2 Face networking groups and our SurvivorLink peer mentoring program, at [youngsurvival.org](http://youngsurvival.org).

### AMERICAN PSYCHOSOCIAL ONCOLOGY SOCIETY

866.276.7443

[apos-society.org](http://apos-society.org)

A toll-free helpline through which cancer patients and their caregivers can obtain referrals for local counseling services in their community.

### ASSOCIATION OF ONCOLOGY SOCIAL WORK

847.686.2233

[aosw.org](http://aosw.org)

Works to advance excellence in the psychosocial care of people with cancer, their families and caregivers through networking, education, advocacy, research and resource development.

### CANCERCARE

800.813.4673

[cancercare.org](http://cancercare.org)

Provides free, professional support services to people with cancer, caregivers, children, loved ones and the bereaved. CancerCare programs—including counseling and support groups, education, financial assistance and practical help—are provided by professional oncology social workers.

### CANCER SUPPORT COMMUNITY

888.793.9355

[cancersupportcommunity.org](http://cancersupportcommunity.org)

Offers 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. It can be awkward to discuss your challenges—having a history of a life-threatening disease, sexual problems, the need for extra lubricants or your loss of fertility.

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 relationships that will be meaningful to you. 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.

Wait until you develop a feeling of trust and friendship before talking about your cancer. Consider practicing what you will say to someone. 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 a person 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. Open communication will help you feel understood and contribute positively to your quality of life. Talk about your experience, how it affected you and how others can help.

Often after treatment, women go through an adjustment period in these relationships. Friends and family are excited that you are “cancer free”

**Open communication is key. Talk about your experience, how it affected you and how others can help.**

and may assume you no longer need 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.

## The Changing Role of Partners

Being in a relationship is tough. Being in a relationship during and after breast cancer can bring additional challenges. Your ability to maintain a healthy relationship with your partner post-treatment mainly relies on you 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 shifted.

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 your partner will try to 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.

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

An open attitude towards communication and frank 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!

If you find that your relationship is not as strong after treatment has ended or changed in a way that is upsetting to you, do not hesitate to seek professional help or counseling. Some couples may need additional assistance to heal from the stress of a breast cancer diagnosis.

## Other Emotions

Your experience with cancer is unique, and so is your emotional response. 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 Resources

YSC cares about you and your co-survivors as you settle into life post-treatment. Visit [youngsurvival.org](http://youngsurvival.org) for comprehensive resources for your loved ones during and after your diagnosis and treatment.

### CANCERCARE

800.813.4673

[cancercare.org/tagged/caregiving](http://cancercare.org/tagged/caregiving)

### CANCER SUPPORT COMMUNITY

888.793.9355

[cancersupportcommunity.org](http://cancersupportcommunity.org)

### IMERMAN ANGELS

866.463.7626

[imermanangels.org](http://imermanangels.org)

Provides personalized connections that enable one-on-one support among cancer fighters, survivors and caregivers.

# Healthy Lifestyle Choices



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

Remember, you don't have to do everything all at once—start slowly and add these healthy practices to your life over time.

## Nutrition

Researchers continue to explore how healthy food choices may help reduce the risk of cancer or recurrence. We do know 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 you have.

### American Cancer Society and American Institute for Cancer Research 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 5-9 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.
- 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 it is easier to stick with an exercise program if they work out with a friend or in a group.
- Avoid constricting or overstretching an arm prone to lymphedema when exercising. For example, stick to light upper-body movements after breast cancer surgery until you have permission from your surgeon and oncologist.

## Healthy Living Resources

### AMERICAN DIETETIC ASSOCIATION

800.877.1600

[eatright.org](http://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

[aicr.org](http://aicr.org)

Answers questions about diet, nutrition and cancer through its "Nutrition Hotline" phone and email service. Has many consumer and health professional brochures, plus health aids about diet and nutrition.

### COOK FOR YOUR LIFE

212.799.3894

[cookforyourlife.org](http://cookforyourlife.org)

Teaches healthy eating and living to those touched by cancer and provides healthy recipes designed with the cancer survivor in mind.

### NATIONAL CANCER INSTITUTE'S SMOKING QUITLINE

877.448.7848

[smokefree.gov](http://smokefree.gov)

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

### YOGA BEAR

[yogabear.org](http://yogabear.org)

Provides cancer survivors with opportunities for wellness and healing through the practice of yoga. Check the website for participating yoga studios, as well as free online yoga and meditation webcasts.

### LIVESTRONG AT THE YMCA

[livestrong.org/what-we-do/our-actions/livestrong-programs/ymca](http://livestrong.org/what-we-do/our-actions/livestrong-programs/ymca)

Partners with more than 400 YMCA locations to provide cancer survivors with free or low-cost training programs to improve physical fitness and strength after cancer. Through the ENCOREplus Program, the YWCA also offers support and exercise groups focusing on physical strength, health and psychological well-being. Call your local YWCA or YMCA 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—charity care, sliding fee scales, payment plans—can ease this burden. If you have credit cards and need to use them to pay remaining medical bills or household expenses, be careful of 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.

For a list of tools to help you keep track of your medical bills and manage medical expenses, visit [healthit.gov/patients-families](https://www.healthit.gov/patients-families).

## Financial Assistance

The following organizations can help with financial assistance:

- The American Cancer Society (ACS) provides information on local sources of financial assistance. To reach your local ACS, call 800.227.2345 or visit [cancer.org](https://www.cancer.org).
- The Patient Advocate Foundation Co-Pay Relief (CPR) provides direct financial assistance to qualified patients and assists with prescription drug co-payments. Contact the CPR program at [copays.org](https://www.copays.org) or 866.512.3861. Patient Advocate Foundation is also a great resource advocating for your cancer care, medical debt and job retention: [patientadvocate.org](https://www.patientadvocate.org).



- The CancerCare AVONCares program provides financial assistance for homecare, childcare and transportation. CancerCare's Linking A.R.M.S.™ program provides financial assistance for hormonal and oral chemotherapy, pain and anti-nausea medication, lymphedema supplies and durable medical equipment. Contact [cancer.org](https://www.cancer.org) or 800.813.4673.
- The United Way has programs to help those in need. See [unitedway.org](https://www.unitedway.org) or call 703.836.7112 to contact your local United Way office.
- Reach out to local religious organizations to which you belong. These organizations may provide help to their members and people in their community.
- Check our ResourceLink Guidebook or our online financial and insurance resources at [youngsurvival.org](https://www.youngsurvival.org).

## Career and Job Transitions

For many people, work matters tremendously—and it can become even more important during and after cancer. Many survivors get 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. Re-engaging in a full-time schedule, if you have not already done so, can be a transition. Asking for help does not make you any less smart, competent or capable. You just need to take care of yourself. Sometimes the people at work become 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. Don't be afraid to ask.**

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. Don't be afraid 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 much you tell them.

It's important to learn about your rights and protections. The Americans with Disabilities Act (ADA), Genetic Information Nondiscrimination Act (GINA) of 2008 and the Family and Medical Leave Act (FMLA) give employees tremendous protection against disclosure and discrimination.

## Career Resources

### CANCER AND CAREERS

646.929.8032

[cancerandcareers.org](http://cancerandcareers.org)

Empowers and educates cancer survivors to thrive in the workplace by providing expert advice, interactive tools and educational events.

### CANCER LEGAL RESOURCE CENTER

866.752.6679

[disabilityrightslegalcenter.org/cancer-legal-resource-center](http://disabilityrightslegalcenter.org/cancer-legal-resource-center)

Provides free information and resources on cancer-related legal issues for survivors, caregivers, healthcare professionals and employers.

### TRIAGE CANCER

424.258.4628

[trriagecancer.org](http://trriagecancer.org)

Provides a variety of services and resources for survivorship, including those that pertain to career, finances and legal issues.

FINANCIAL  
PLANNING

8

# Survivorship Resources

## Young Survival Coalition

877.972.1011

[youngsurvival.org](http://youngsurvival.org)

YSC Worksheets (see fold-out pages)

- Creating a Summary of Your Diagnosis and Treatment
- Creating Your Follow-up Care Plan

## AMERICAN CANCER SOCIETY

800.227.2345

[cancer.org](http://cancer.org)

Provides information and referrals to numerous education, community and patient support services.

## AMERICAN SOCIETY OF CLINICAL ONCOLOGY

888.282.2552

[asco.org](http://asco.org); [cancer.net](http://cancer.net)

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

## LIVESTRONG

866.235.7205

[livestrong.org](http://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

800.422.6237

[cancer.gov](http://cancer.gov)

Conducts and supports programs regarding the cause, diagnosis, prevention, treatment, rehabilitation and continuing care of cancer patients and their families.



## NATIONAL COALITION FOR CANCER SURVIVORSHIP

877.622.7937

[canceradvocacy.org](http://canceradvocacy.org)

Advocates for quality cancer care for all Americans and aims to empower cancer survivors. Offers patient resources on financial assistance, health insurance, employment rights, cancer advocacy and clinical trials.

## STUPID CANCER

877.735.4673

[stupidcancer.org](http://stupidcancer.org)

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

# Glossary

**A**

## **AMENORRHEA**

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

## **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.

## **AXILLARY LYMPH NODE INVOLVEMENT**

The spread of cancer from the primary tumor to the axillary lymph nodes, which are located in the armpit area. The axilla is typically the first site of spread in breast cancer.

**B**

## **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.

**C**

## **CARDIOTOXICITY**

Damage to the heart, which causes it to become weaker and not as efficient in pumping blood.

## **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 bloodstream and travel throughout the body. Chemotherapy can therefore kill cancer cells outside of the breast.

## **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.

## **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.

**D**

## **DUAL-ENERGY X-RAY ABSORPTIOMETRY (DEXA) SCAN**

A form of x-ray technology that can measure bone density and/or loss.

**E**

## **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. Many breast cancer treatments include the use of drugs such as tamoxifen that block the receptors in the breast cancer cells and prevent estrogen from getting to them.

## **ESTROGEN-RECEPTOR STATUS**

This refers to whether the tumor is ER-positive or ER-negative.

**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.

## **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.

## **HORMONAL THERAPY**

See Endocrine therapy

**I**

## **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.

## **IPSILATERAL**

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

**L**

## **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.

### **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 MASTECTOMY**

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

### **METASTASIS**

The transfer of disease from one organ or part to another not directly connected with it. The capacity to metastasize is a characteristic of all malignant (cancerous) tumors.

### **N 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 a variety of circumstances including cancer and its treatment. Also called peripheral neuropathy.

### **O 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.

### **P 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.

### **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.

### **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**

### **SENTINEL LYMPH NODE BIOPSY**

A staging and therapeutic technique used in breast cancer to determine the presence and extent of 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.

### **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.

### **U**

### **UNILATERAL**

Having to do with one side of the body.



## Post-Treatment Medical Appointments

HEALTHCARE PROVIDER	SUGGESTED FREQUENCY OF VISITS	PURPOSE OF VISITS
PRIMARY CARE PHYSICIAN		
MEDICAL ONCOLOGIST		
BREAST SURGEON		
GYNECOLOGIST		
OTHER:		

## Post-Treatment Testing

TEST	HEALTHCARE PROVIDER TO ORDER	SUGGESTED FREQUENCY	WHO PROVIDES RESULTS AND EXPLANATION?
SCANS AND XRAYS (MAMMOGRAMS, MRIs, PET SCANS, CT SCANS, ETC.)			
LAB TESTS AND BLOOD DRAWS			
BONE DENSITY			
CARDIOVASCULAR SCREEN			
OTHER:			
OTHER:			
OTHER:			

# Other Questions and Concerns

POST-TREATMENT ISSUES	CONCERN	WHAT TO EXPECT	WHO TO CONTACT
SUPPORT GROUPS AND COUNSELING			
FEAR OF RECURRENCE			
RELATIONSHIPS WITH LOVED ONES			
DATING AND INTIMACY			
INFERTILITY			

POST-TREATMENT ISSUES	CONCERN	WHAT TO EXPECT	WHO TO CONTACT
DIET AND EXERCISE			
SMOKING CESSATION			
FINANCIAL AND CAREER			
HEALTH INSURANCE			
DELAYED RECONSTRUCTION			



# Healthcare Team

Primary Care Doctor			
Office / Hospital / Facility Name			
Telephone Number		Date of First Visit	

Medical Oncologist			
Office / Hospital / Facility Name			
Telephone Number		Date of First Visit	

Breast Surgeon			
Office / Hospital / Facility Name			
Telephone Number		Date of First Visit	

Radiation Oncologist			
Office / Hospital / Facility Name			
Telephone Number		Date of First Visit	

Cancer Treatment Center			
Office / Hospital / Facility Name			
Telephone Number		Date of First Visit	

Gynecologist			
Office / Hospital / Facility Name			
Telephone Number		Date of First Visit	

Other			
Office / Hospital / Facility Name			
Telephone Number		Date of First Visit	

Other			
Office / Hospital / Facility Name			
Telephone Number		Date of First Visit	

Other			
Office / Hospital / Facility Name			
Telephone Number		Date of First Visit	

Other			
Office / Hospital / Facility Name			
Telephone Number		Date of First Visit	

# Breast Cancer Diagnosis Summary

Date of Diagnosis	
Stage at Diagnosis	
Was Your Breast Cancer In Lymph Nodes?	YES / NO
If Yes, How Many Nodes?	
At diagnosis, had your cancer spread to other parts of your body? If so, where?	
Are You PR+, ER+, OR HER2+? If Yes, circle all that apply.	
Healthcare Provider who Provided Diagnosis	
Phone Number	
Do you have a copy of your pathology, surgery and treatment reports?	YES / NO
If Yes, where do you keep these copies?	
If No, can you obtain copies?	
Date of Recurrence (if applicable)	
Indicate any information that differs from above.	

# Breast Cancer Treatment Summary

## Surgery

Date	
Name/Number of Surgeon	
Procedure	
Pathology	

Date	
Name/Number of Surgeon	
Procedure	
Pathology	

Date	
Name/Number of Surgeon	
Procedure	
Pathology	

Date	
Name/Number of Surgeon	
Procedure	
Pathology	

Notes:

## Radiation Therapy

Date			
Name/Number of Radiation Oncologist			
Type		Field	
Dose		# of Sessions	

Date			
Name/Number of Radiation Oncologist			
Type		Field	
Dose		# of Sessions	

Notes:

## Chemotherapy, Hormone Therapy, Targeted Therapy

Date	
Name/Number of Oncologist	
Agents Received	
# of Cycles	

## Chemotherapy, Hormone Therapy, Targeted Therapy (cont.)

Date	
Name/Number of Oncologist	
Agents Received	
# of Cycles	

Date	
Name/Number of Oncologist	
Agents Received	
# of Cycles	

Date	
Name/Number of Oncologist	
Agents Received	
# of Cycles	

Date	
Name/Number of Oncologist	
Agents Received	
# of Cycles	

Notes:

# Clinical Trials

Date	
Name/Number of Oncologist & Sponsor Institution	
Agents Received	
# of Cycles	

Date	
Name/Number of Oncologist & Sponsor Institution	
Agents Received	
# of Cycles	

Date	
Name/Number of Oncologist & Sponsor Institution	
Agents Received	
# of Cycles	

Date	
Name/Number of Oncologist & Sponsor Institution	
Agents Received	
# of Cycles	

Notes:

# Post-Treatment Navigator Evaluation Form

Your feedback is important to us. Please complete the survey below and return it to us by postal mail or fill it out online at [youngsurvival.org/PTN](http://youngsurvival.org/PTN). As a thank you, you will receive a special gift from YSC.

## 1. To what extent has the Post-Treatment Navigator and its contents helped you better understand what to expect after treatment?

### PHYSICALLY?

- Not at all
- To a small extent
- To a moderate extent
- To a great extent

### EMOTIONALLY?

- Not at all
- To a small extent
- To a moderate extent
- To a great extent

## 2. I found the Post-Treatment Navigator easy to understand:

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

## 3. After receiving the Post-Treatment Navigator, I am more aware of resources available to me:

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

## 4. How did you receive your copy of the Post-Treatment Navigator?

- I contacted YSC (online, phone, mail)
- A doctor, nurse or other healthcare provider gave it to me
- A friend or family member gave it to me
- I got it at a support group
- I don't remember
- Other: \_\_\_\_\_

## 5. When did you receive your Post-Treatment Navigator?

- Less than 6 months after the end of treatment
- 6 months to 1 year after the end of treatment
- More than 1 year after the end of treatment

## 6. Please check which sections of the Post-Treatment Navigator you are using or plan to use:

- Getting a Written Summary of Diagnosis and Treatment
- Getting a Written Summary of Your Follow-Up Care Plan
- Understanding Your Potential Long-Term Side Effects of Treatment
- Understanding Your Emotions
- Making Healthy Lifestyle Choices
- Financial Planning and Responsibilities
- List of Resources
- Worksheets

## 7. Which part of the Post-Treatment Navigator do you find most useful? Check all that apply.

- Getting a Written Summary of Diagnosis and Treatment
- Getting a Written Summary of Your Follow-Up Care Plan
- Understanding Your Potential Long-Term Side Effects of Treatment
- Understanding Your Emotions
- Making Healthy Lifestyle Choices
- Financial Planning and Responsibilities
- List of Resources
- Worksheets

## 8. I would recommend the Post-Treatment Navigator to another breast cancer survivor.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

## 9. What other types of resources or topics would you like to see included in the Post-Treatment Navigator?

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FOLD LINE

FOLD LINE

GLUE FLAP

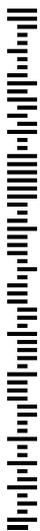
FOLD LINE

INSIDE OF ENVELOPE

CONTINUED ON REVERSE SIDE

Back of envelope

FOLD LINE



POSTAGE WILL BE PAID BY ADDRESSEE  
YOUNG SURVIVAL COALITION  
SUITE 1700  
80 BROAD STREET  
NEW YORK NY 10275-0788

FIRST-CLASS MAIL PERMIT NO. 5781 NEW YORK, NY  
**BUSINESS REPLY MAIL**

NO POSTAGE  
NECESSARY  
IF MAILED  
IN THE  
UNITED STATES



**Optional: Please tell us a little about yourself!**

**Please indicate your involvement with breast cancer.  
Check all that apply.**

- I have been diagnosed with breast cancer.
- I am a caregiver/family member/friend of someone diagnosed with breast cancer.
- I am a healthcare provider.
- I am an advocate/ volunteer for YSC.

**In what year were you diagnosed with breast cancer (primary)?** \_\_\_\_\_

**At what age were you diagnosed with breast cancer (primary)?** \_\_\_\_\_

**If you were diagnosed with a recurrence, what year were you re-diagnosed?** \_\_\_\_\_

**Please describe the place you live:**

- Rural
- Urban (city)
- Suburb (small town)

**With what stage of breast cancer were you initially diagnosed?**

- Stage 0 (carcinoma in situ)
- Stage I
- Stage II
- Stage III
- Stage IV

**Do you have a family history of breast cancer?**

- Yes  No

**Your treatments include(d):**

- Chemotherapy
- Hormonal therapies
- Radiation
- Other: \_\_\_\_\_
- Lumpectomy
- Mastectomy
- Double Mastectomy

FOLD LINE

**With what ethnic/racial group do you most closely identify?**

- American Indian or Alaskan Native
- Asian
- Black/African-American
- Hispanic or Latino or Spanish any race
- Native Hawaiian or other Pacific Islander
- White
- Two or more races
- Other: \_\_\_\_\_

**Do you have young (under age 17) children at home?**

- Yes  No

**What type of insurance do you have?**

- No insurance
- Medicare/Medicaid
- Don't know
- Private insurance (employer provided)
- Private insurance (paid for by self)
- Other: \_\_\_\_\_

**Please provide your current employment status:**

- On medical leave
- Not working/unemployed
- Working full or part time
- Stay-at-home mom/full-time homemaker
- On disability income
- Other: \_\_\_\_\_

First Name \_\_\_\_\_

Last Name \_\_\_\_\_

Email \_\_\_\_\_

Phone \_\_\_\_\_

Address \_\_\_\_\_

Address Line 2 \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

**Are you interested in receiving updates and news from YSC?**

**Please choose how you'd like to connect with us.**

- Email  Standard Mail  Text Alerts





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