



Beyond 5 Years

A NAVIGATOR FOR LONG-TERM SURVIVORS



YSC | YOUNG SURVIVAL
COALITION®

Young women facing breast cancer together.

Acknowledgements

This guidebook would not have been possible without the generous support of YSC's funding partners and individual contributions. Young Survival Coalition would also like to acknowledge appreciation for the individuals who served as invaluable writers:

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Special thanks to the following individuals for their input and review: Mary Ajango; Andrea Byrne; Debbie Chase; Emily Helck; Roz Kleban, LCSW; Lillie Shockney, RN, BS, MAS; and the YSC Staff. We'd also like to extend great appreciation to Tiffany Barrett, MS, RD, CSO, LD, for her expertise in creating the nutrition and wellness worksheet found at the end of the guidebook.



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Introduction

For breast cancer survivors, every cancer-free year after completing treatment is an important milestone. They are anniversaries worth celebrating! With each passing year, you might feel more confident that you are done with breast cancer for good, and for many women five years marks their start as a long-term survivor.

Still, there are challenges that come with being a long-term survivor. Your family and friends might assume this difficult chapter of your life is over, but you're probably still dealing with the impact of breast cancer physically, emotionally, professionally and financially. You may feel like you are aging out of the young survivor community but have trouble connecting with older or more recently diagnosed peers. You're likely to have questions about how breast cancer will affect you as you advance beyond young adulthood.

Young Survival Coalition (YSC) has created this guide, *Beyond 5 Years: A Navigator for Long-Term Survivors*, to help you manage the issues you may face years beyond diagnosis and treatment. The guide is designed as a companion piece to *What's Next? A Young Woman's Post-Treatment Navigator*, developed by YSC. It features a wealth of advice that is still relevant to you—about everything from treatment side effects to exercise, healthy eating and family relationships. In *Beyond 5 Years*, though, we aim to address some of the unique concerns women have as they transition to long-term survivor.

As you move further away from your initial diagnosis, you may be optimistic, but you may also be wondering, "Where do I fit in? What can I expect?" There is still so much we don't know about the long-term

needs and experiences of women who were diagnosed with breast cancer at a younger age. As research continues, rest assured that YSC is here for you as a resource and advocate. We hope you find *Beyond 5 Years: A Navigator for Long-Term Survivors* useful.

Get to Know YSC

Young Survival Coalition 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 postmenopausal 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 needs of young women affected by breast cancer. Along with its nationwide Face 2 Face networks and vibrant online community, YSC hosts the YSC Summit—the only national conference dedicated to the unique issues of young women with breast cancer. YSC also hosts Regional Symposia, and it produces free educational resources such as the the Navigator series, brochures and fact sheets, which include information about every phase of treatment and survivorship.

Disclaimer

Young Survival Coalition has provided this guidebook for educational, informational and community purposes only as a resource for young women and other 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 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.



Managing Your Medical Care & Physical Health

In the first few years after your diagnosis, you probably were used to seeing many doctors at least a couple of times a year. These may include your primary care physician, medical oncologist, radiation oncologist, breast surgeon or other breast specialist, and gynecologist. Depending on your diagnosis and the treatment you received, it is likely you've been scaling back on these visits. This can be liberating but also frightening; some women miss the feeling of being followed closely.

You may also wonder about your risk of recurrence going forward, whether lingering side effects will go away, and what the longer-term effects of cancer treatment could be. This section of the *Navigator for Long-Term Survivors* is intended to help with these medical concerns. Many potential long-term side effects are covered in YSC's *Post-Treatment Navigator*, so you may find it helpful to use the two resources together.

Working With Your Medical Team

As you pass five, 10 or more years post-treatment, you can review your current schedule of doctor visits and decide what makes sense moving forward. Generally, concerns about recurrence are greatest during the first two to five years after initial treatment ends. Five years is often considered an appropriate time to scale back to a once-yearly physical exam, medical history and screening.

Of course, every woman's situation is different. One approach would be to see your primary care physician and gynecologist regularly, along with the member of your cancer treatment team who has been most involved in your care during the past year or so. This might be a nurse practitioner rather than the oncologist. If you're on tamoxifen, this will likely be a member of your medical oncology team. You would then see the other cancer specialists as needed. Ask your doctors what they usually recommend and, together, craft an individualized plan.

Your doctors also can help you understand your risk of recurrence moving forward. If that risk is considered higher than average, you may need to continue with a more frequent schedule of visits, approximately every six months. (See the next section, "Understanding Your Risk of Recurrence," for more information.) The same holds true if you have a strong family history of breast and/or ovarian cancer or a genetic mutation that increases risk. You also may need to investigate what visits your insurance will cover.

Questions for Managing Your Healthcare Going Forward

These questions may be helpful in guiding conversations with your team as you move ahead:

- How often do you recommend I see you from now on?
- Are you willing/able to serve as my main "team leader" as I move ahead? Or do you think another specialist would be better suited for this role?
- If you are my team leader, can your office help me keep other members of the team informed, since I won't be seeing them regularly?
- If you are not my team leader, how can I best keep you up-to-date about my care? Should I have all of my records sent to you after every visit with another member of my treatment team? How do you handle this with other patients?
- What schedule of breast screenings (mammogram, MRI, ultrasound, etc.) do you recommend for me?
- When should I call your office? Are there symptoms or side effects that I should bring to your attention, even if I am not seeing you regularly?



Tamoxifen for Five or 10 Years?

Tamoxifen is often the treatment of choice for premenopausal women with estrogen receptor-positive breast cancer. Doctors formerly recommended women take the medication every day for five years. The standard recommendation was that women take the medication every day for five years to reduce their risk of recurrence for years to come. However, many doctors now recommend that tamoxifen use continue through 10 years, based on recent clinical trial results that suggested longer use can reduce the risk of recurrence or death from breast cancer. You and your doctor can weigh the benefits and risks of taking tamoxifen longer than five years and examine what makes the most sense for you, depending on factors such as:

- Your risk of recurrence.
- How well you are tolerating tamoxifen (Are you having multiple side effects that really bother you? None at all? Somewhere in between?)
- Whether or not you plan to try to get pregnant.
- Whether or not you have already gone through menopause (your monthly periods have stopped and are not expected to return). If you are postmenopausal, your doctor might switch you to another form of hormonal therapy called an aromatase inhibitor, which is used in postmenopausal women.
- Your personal preferences (Do you have a strong desire to end your treatment at five years, regardless of potential added benefit from

more treatment?)

- Ask your doctor whether the Breast Cancer Index test can help you decide if 10 years of tamoxifen would be beneficial.

Some young women stop taking tamoxifen after a few years so they can try to get pregnant. If you're in this camp, talk to your doctor when to go back on tamoxifen, so you can get the benefit of the full five or 10 years. If you want to get pregnant, your doctor may recommend that you wait to try to conceive until two to three months after stopping the medication. Also consider enrolling in the POSITIVE trial, which is following women who take a tamoxifen "baby break" in the hopes of becoming pregnant. The goal of this trial is to determine the safety of taking a "baby break," as well as the suggested timing. For more information on the POSITIVE trial, visit <https://clinicaltrials.gov/ct2/show/NCT02308085>.

Understanding Your Risk of Recurrence

As you've done research on the web, you've likely found references to the fact that the risk of recurrence is higher for women diagnosed with breast cancer before age 40. As you've passed into long-term survivorship, you may be wondering what your risk of recurrence actually is now. Breast cancer is more likely to recur within the first one or two years after initial treatment, with risk decreasing through year five to year 12, so you've reached an important milestone! For most women, the odds of not recurring are much greater than the odds of ever having a recurrence.

If you were eligible for the Oncotype DX®, MammaPrint® or Mammostrat® tests, then you may already have some estimate of your risk of recurrence. Additionally, the Breast Cancer IndexSM (BCI) provides you and your doctor information to help decide whether to extend or end anti-estrogen therapy beyond year five. BCI analyzes your risk of late recurrence and your likelihood of benefit from extending anti-estrogen therapy. It tests your original tumor specimen and the results are available in a few weeks.

Generally, these tests are reserved for women with early-stage, estrogen receptor-positive breast cancer that hasn't spread to the lymph nodes—although MammaPrint can be used in estrogen receptor-negative cancers. They are all genomic tests that measure the activity levels of different sets of genes to predict the risk of recurrence within 10 years as low, moderate or high, with specific risk percentages associated with each category. This information probably helped guide your treatment decisions. If you had any of these tests, you can ask

your doctor to revisit the results with you to understand your risk of recurrence now that you are five years or more out. (Genomic tests are different from genetic tests, which look for inherited gene mutations that increase cancer risk. See Section 5 for more information.)

Even if you didn't have these tests, your doctor can help you understand your risk of recurrence based on (1) the treatments you had and (2) the characteristics of the cancer. Examples include:

- **LYMPH NODE INVOLVEMENT:** Did cancer spread into the lymph nodes, and if so, how many?
- **TUMOR SIZE:** How large was the tumor?
- **GRADE:** How different did the cancer cells look from normal, healthy cells?
- **TUMOR MARGINS:** Was there a rim of healthy tissue surrounding the cancer when it was removed? If so, how wide was it?
- **HORMONE RECEPTORS:** Did the breast cancer have receptors for the hormones estrogen and/or progesterone or HER2/neu?

You may need to retrieve the original pathology report to get this information. Use caution if you look at studies of recurrence risk in large groups of women, since the details of your diagnosis or treatment plan might have been different from theirs.

Following your treatment plan was the most important step you could take to reduce your risk of recurrence. If you have any concerns about your treatment, raise them with your doctor or seek a second opinion. Sticking to healthy lifestyle choices such as good nutrition and regular



exercise also can help. Ask your doctor to review the best way to examine your breasts between imaging studies and what exactly you should be looking for as a long-term survivor. See Section 4 for more information about how to manage the fear of recurrence.

Managing the Long-Term Effects of Treatment

Even years after breast cancer treatment, you can still experience related side effects. When YSC conducted a national needs assessment of young women five or more years past breast cancer treatment, we found that the overwhelming majority of women still reported side effects and wanted more information. Some women described feeling as if they are decades older than their chronological age in their 30s or 40s. If you are still on hormonal therapy such as tamoxifen or an aromatase inhibitor, you may experience ongoing side effects. This section, however, deals with long-term effects of completed treatments, such as surgery, chemotherapy, radiation therapy and Herceptin (trastuzumab).

Although physicians are becoming more aware of long-term survivorship issues, it is beneficial for you to be your own advocate. If you never took part in a breast cancer rehabilitation program, or if you did but are still experiencing side effects, try to connect with a program or specialist. Ask your doctor for recommendations or check with the hospital or cancer center where you were treated. Many large medical centers now have cancer survivorship clinics that may be helpful.

Most of these side effects—along with tips for dealing with them—are covered in YSC’s Post-Treatment Navigator. The following is intended as an overview of the effects that can persist or even crop up for the first time years after your diagnosis. Just remember: You’re not alone, it’s not all in your head, and you may have to persist to find a solution that works for you.

Possible Side Effects

Early Menopause

Chemotherapy, which destroys fast-dividing cancer cells, can be harmful to your ovaries, which also contain rapidly dividing cells that produce eggs. Some chemotherapy drugs can send the body into menopause: your periods end, the ovaries stop releasing eggs,

estrogen levels fall, and you're not able to get pregnant. For younger women who have chemotherapy, this is usually temporary. Even if your periods return after chemotherapy, however, you could enter menopause earlier than the average age of 51.

As you naturally age, you might begin to experience menopausal symptoms, such as changes in your cycle and hot flashes, earlier than your peers. It can be hard to tell the difference between true menopausal symptoms, the effects of natural aging, and the longer-term effects of the cancer experience. If you're still taking tamoxifen, that can make things even more confusing because it, too, can cause menopausal symptoms.

There are strategies that may help relieve these side effects. You may have used some of them during and immediately after your chemotherapy treatments. You can find numerous suggestions for managing side effects in the resources at the end of this section.

Even if your periods appear to be tapering off, you aren't considered postmenopausal until you go one full year without a period. It's important to know you can still get pregnant during that time. If you're sexually active and do not want to get pregnant, be sure to consult with your medical oncologist and/or gynecologist about the best birth control method for you. Hormone versus non-hormone types should be considered. The *Post-Treatment Navigator* features information about birth control, along with sex and intimacy.

Menopausal Symptoms Resources

BREASTCANCER.ORG

610-642-6550

breastcancer.org

Breastcancer.org is a nonprofit organization dedicated to providing the most reliable, complete and up-to-date information about breast cancer. Search for "managing menopausal symptoms," which offers practical advice on finding relief.

THE NORTH AMERICAN MENOPAUSE SOCIETY

440-442-7550

menopause.org

A nonprofit organization dedicated to promoting the health and quality of life of all women during midlife and beyond through an understanding of menopause and healthy aging. The NAMS website and Menopause Guidebook (2012) feature advice about improving menopausal symptoms and specific information about early menopause. The guide is available for purchase in print and digital formats (iBook, Kindle).

Infertility

Chemotherapy also can impact your fertility years after treatment ends. If you're having menopausal symptoms and want biological children, talk to your gynecologist and possibly a reproductive endocrinologist. You might want to have blood tests that can help you gauge whether you truly are heading into menopause. These include tests for levels of follicle-stimulating hormone (FSH) and luteinizing hormone (LH), which are proteins made by the brain that stimulate ovulation, and estradiol, which is the main form of estrogen in the body. You may encounter other "menopause tests" that you can do at home using urine or saliva, but they aren't considered reliable.

Even if you're having regular periods and no menopausal symptoms, you still could have trouble getting pregnant. Hopefully your doctor discussed the fact that having chemotherapy could narrow the window for having children. If you're trying to get pregnant, stay in close contact with your gynecologist and ask how long you should try before seeing a fertility specialist—preferably someone who works with cancer survivors. If you're over 35, an age at which fertility starts declining naturally, you may wish to consult with a fertility specialist right away. The same holds true if you're not ready to have a baby right now but think you might want to in the future. It may be possible to freeze and store your eggs or even some of your ovarian tissue for future use.

If you cannot get pregnant on your own, there are other options for having a child, such as:

- **IN VITRO FERTILIZATION:** Your egg or an egg from a donor is fertilized with sperm outside the body (in vitro or in glass) and then implanted in your uterus.
- **SURROGACY:** Sperm is used to fertilize another woman's egg or your own, and she carries and delivers your baby.
- **ADOPTION:** Although many breast cancer survivors adopt successfully, some adoption agencies may have guidelines that do not allow cancer survivors to adopt. At a minimum, they will want evidence that you're likely to be able to raise a child to adulthood.

Each method has its own financial and emotional costs, so be sure to investigate your options thoroughly. The following resources can help.

Infertility Resources

LIVESTRONG FERTILITY

855-844-7777

[livestrong.org](https://www.livestrong.org)

LIVESTRONG Fertility provides targeted information for individuals with questions regarding fertility after cancer diagnosis and treatment. Tools are available to assess infertility risk, personalize family planning options and find financial assistance.

MYONCOFERTILITY.ORG

866-708-FERT

[myoncofertility.org](https://www.myoncofertility.org)

This is a patient education resource created by the Oncofertility Consortium at Northwestern University, a national initiative designed to explore the reproductive futures of cancer survivors. It provides information on the potential effect of cancer and cancer treatments on fertility, options for preserving fertility, and resources for discussing these issues with a doctor.

For additional information on family building options, like adoption and surrogacy, search YSC's online ResourceLink database: [youngsurvival.org/directory](https://www.youngsurvival.org/directory).

Chemo Brain

During and after chemotherapy, some women experience a range of symptoms that have come to be known as “chemo brain”—for example, feeling less mentally sharp, not remembering facts as easily, misplacing objects, and finding it difficult to concentrate. Although this side effect tends to get better over time, some women report having trouble for many years. YSC's *Post-Treatment Navigator* offers tips for working around chemo brain.

If you're still having cognitive problems years later, talk to your doctor. There may be a definite underlying cause, such as insomnia and fatigue, depression, anxiety, or medical conditions such as thyroid disorders or anemia. If you're entering menopause, mental foginess can sometimes be a symptom of that, as well. Your doctor can take a detailed history and perform a full workup to figure out what's happening. If all of these causes are ruled out, consult with a neuropsychiatrist, a specialist with training in disorders of brain functioning.

Fatigue

Fatigue is a feeling of excessive tiredness that isn't related to your level of physical activity and isn't relieved by rest. You just feel drained of energy all the time and may not be interested in attempting very much beyond your "must-dos," such as work, chores, and childcare—and even those can be a struggle. Fatigue usually improves after cancer treatment ends, but sometimes it can hang on for many years. This can be hard for family members and friends to understand, so you might have to educate them about the fact that fatigue is a long-term problem for some women.

You and your doctor should work together to figure out if there is an underlying cause of your long-term fatigue. Conditions such as insomnia, anemia, thyroid disorders, depression and anxiety—among others—can all contribute to fatigue. If you find and remedy those, fatigue often improves. Healthy eating, exercise, stress reduction and adequate sleep can be helpful, as well.

Lymphedema

Lymph is a thin, clear fluid that circulates through your body's system of lymph vessels and nodes to remove waste, bacteria and other substances from tissues. Breast cancer surgery removes some of the lymph nodes and vessels under the arm, and radiation therapy can damage those that remain. In some women, this disrupts the flow of lymph out of the hand and arm and sometimes the chest area. If the body can't compensate, the lymph starts to build up in the tissues, causing symptoms such as swelling, tingling, and pain. This is the condition known as lymphedema.

Generally, the further out you are from treatment and the smaller the number of lymph nodes you had removed, the less likely it is that lymphedema will become a problem for you. There have been cases, however, in which lymphedema developed years after treatment. In addition to having multiple lymph nodes removed, risk factors include:

- Being overweight
- Injury, trauma, or infection affecting the hand or arm on the same side where you had surgery
- Subjecting your arm or hand to extreme heat or overuse

If you ever feel anything unusual in your hand or arm, such as numbness or tingling, or you sense any changes in appearance, no matter how minor, see your doctor and a lymphedema physical therapist. Changes can include slight puffiness or swelling, smoother skin, or noticing that

the veins, tendons or knuckles on your hand seem less pronounced. At first, these symptoms tend to come and go, and they can seem like no big deal. Left unchecked, lymphedema can lead to more visible swelling and changes in the skin that may be irreversible. In addition, research suggests that gentle exercise involving the upper body—such as stretching, swimming, and lifting light weights, among others—may help reduce the risk of lymphedema.

Lymphedema Resources

BREASTCANCER.ORG

610-642-6550

breastcancer.org

Breastcancer.org features a detailed section on lymphedema that covers everything from risk reduction and exercise, to diagnosis and treatments, and finding a lymphedema therapist. Search for “lymphedema” from the home page.

LYMPHEDIVAS

866-411-DIVA

lymphedivas.com

LympeDIVAs creates medically correct and fashionable compression apparel to aid breast cancer survivors in their lymphedema management; the products can be found online and at select retailers. The company’s website also includes a comprehensive list of Frequently Asked Questions (FAQs) and helpful information for those experiencing the effects of lymphedema.

THE NATIONAL LYMPHEDEMA NETWORK

800-541-3259

lymphnet.org

The National Lymphedema Network (NLN) is a nonprofit organization that provides education and guidance to lymphedema patients, healthcare professionals and the general public about lymphedema management and risk reduction. The website features information for patients, as well as a searchable directory of lymphedema clinics and therapists.

Upper Body Pain and Tightness/Axillary Web Syndrome

Sometimes pain, tightness and limited range of motion in the arm and upper body can be a persistent problem after breast cancer treatment. Another possible side effect is axillary web syndrome, also called cording, in which tight, rope-like strands stretch from the underarm and down the inner arm to the wrist. It can be painful to lift the arm any higher than shoulder level.

If you experience these issues, seek help from a breast cancer rehabilitation therapist, who often can help resolve the issues with exercise, stretching, and gentle massage. Just make sure that he or she has significant experience working with breast cancer survivors.

Weight Gain

Some hormonal treatments and chemotherapies can cause weight gain during and after cancer treatment. Even years later, it can be difficult to take this weight off, especially in addition to the natural effects of aging and changes in metabolism. This may feel particularly frustrating as you are continuing to feel healthy and confident in other ways.

You are not alone in these challenges, but the good news is that there are positive steps that you can take to tackle weight gain. See section 3 on Health and Wellness for nutrition and exercise tips, as well as worksheets at the end of this guidebook that will help you to set realistic and effective nutrition and exercise goals. You may need to work with a professional trainer or nutritionist to get back on track.

Peripheral Neuropathy

Some chemotherapy medications can cause pain, numbness or tingling in your fingers or toes—a side effect known as neuropathy. It usually gets better over time, but for some people it can be a persistent problem. If you experience long-term neuropathy, you might:

- Find a physical therapy or exercise program designed for people with this type of condition
- Consider complementary treatments such as acupuncture and massage
- Ask your doctor to recommend a specialist with experience in treating neuropathy

Pain is not normally indicative of cancer recurrence or other more serious concerns.



Breast Reconstruction

If you chose not to have your breast(s) reconstructed after surgery, or you couldn't do so right away because of additional treatments you needed, maybe you are considering reconstruction now. Also, if you had reconstruction, but you're not satisfied with the results or are having problems with an implant, you can investigate options for repairs.

Thanks to the 1998 Women's Health and Cancer Rights Act, most insurers will cover reconstructive surgeries, even if they take place years after your initial diagnosis. You might have to do some homework with your insurance plan and the plastic surgeon you choose, just to make sure you don't get stuck with an unexpected bill, but the law is generally on your side.

Many different types of reconstructive surgery are available. Make sure you understand your options, consult more than one board-certified plastic surgeon, and ask about how much experience he or she has with each procedure. Good information resources include:

Frankly Speaking about Cancer

Spotlight on Breast Reconstruction from Cancer Support Community

YCS contributes to this comprehensive resource, which explores procedures, expectations and other factors regarding breast reconstruction. Order or download a free copy at cancersupportcommunity.org by searching breast reconstruction or call 1.888.793.9355. Now available as an e-book.

Johns Hopkins Breast Center

The Breast Center site features detailed information and video clips about breast reconstruction options, along with a chart that compares the advantages and disadvantages of each procedure:

hopkinsmedicine.org/avon_foundation_breast_center.



Pain Management

It is not uncommon for survivors to experience long-term pain or discomfort as a result of their cancer treatment, surgery and rehabilitation. This can include lymphedema, nerve pain, general muscle pain and fatigue, as well as increased susceptibility to infection.

The most important thing to remember is that these are common long-term side effects and not normally indicative of cancer recurrence or other more serious concerns. You should discuss any persistent issues with your healthcare provider and ask for guidance in managing pain and discomfort. Through traditional medical and complementary methods, you may be able to alleviate some of these effects to improve your physical strength, quality of life and peace of mind.

Other Health Effects

Bone and Dental Health

Some breast cancer treatments can put you at greater risk of bone loss because they lower estrogen levels in the body. They include the hormonal therapy tamoxifen, medications given to suppress the ovaries, and chemotherapy medications that cause either temporary or permanent menopause. Start taking steps to prevent bone loss and keep your bones strong and healthy, such as:

- Getting 1,200 milligrams of calcium a day through a combination of diet and supplements. Good sources of calcium include:
 - Low-fat dairy products such as milk, cheese and yogurt
 - Foods such as leafy green vegetables, almonds and certain beans
 - Calcium-fortified foods such as fruit juices and cereals (check the label)

- Taking Vitamin D at 800-1,000 IU/day or more. Multivitamins typically include 400 IU, so you may need an additional supplement. Consult your oncology team about what strength to take to make sure that it will not interact negatively with your other medications.
- Smoking cessation
- Practicing weight-bearing exercises that help strengthen bones
- Maintaining a healthy body weight
- Limiting alcohol use

Ask your doctor if there are any tests that should be done to monitor your bone health, such as blood and urine tests to measure calcium levels and DEXA scans (dual energy x-ray absorptiometry) to test for bone mineral density. If you have excessive bone loss, treatment may be needed.

As a result of chemotherapy and other treatments, some women may also experience dental issues, which can affect the teeth, gums and jaw. Ask your oncologist what your increased risks may be because of your treatment, and request a written summary of what your dentist needs to know. Keep up on your dental care, schedule regular check-ups as recommended by your healthcare providers, and advise your dentist of your breast cancer treatments.

Heart Health

You'll also want to pay close attention to your cardiovascular health. Menopause is known to increase the risk of conditions that can affect the heart and blood vessels, such as high cholesterol, plaque buildup in the arteries and heart disease. If you go through menopause at a younger age than most women, your risk of these conditions could be higher. Treatments such as radiation therapy, Herceptin and some chemotherapies can cause direct damage to the heart, which can increase the risk of heart problems now or in the future.

Ask your doctor to review any heart-related risk factors that may be associated with your treatments and how you should be regularly screened. Make sure your blood pressure, cholesterol and triglyceride levels are checked regularly, and know your healthy levels to target. Certain lifestyle changes can help to keep your heart healthy, such as:

- Smoking cessation
- Getting regular exercise (see section 3, "Overall Health and Wellness")
- Eating a diet that is high in fruits, vegetables and fiber, and low in saturated fats, sodium and cholesterol

- Keeping your Body Mass Index (BMI) in the healthy range and losing weight if needed
- Using relaxation techniques such as meditation, deep breathing or yoga

For some women, though, a healthy lifestyle isn't enough to lower cholesterol or blood pressure levels into a good range. In these cases, medications may be needed.

Other Cancers

You may be concerned about the risk of another type of cancer due to your breast cancer treatment. Keep in mind that the benefits of your treatments far outweigh the risks of any future cancers. Some treatments have been associated with slight elevated risk of second cancers, such as:

- **TAMOXIFEN:** While tamoxifen has been found to increase the risk of endometrial cancer (cancer of the inner lining of the uterus), the risk is much greater for postmenopausal women. The risk to younger, premenopausal women is considered small.
- **RADIATION THERAPY:** There is some increased risk of lung cancer and sarcomas, which are cancers affecting soft or connective tissues, such as the blood vessels (angiosarcoma) or bone (osteosarcoma) in the immediate area that was radiated.
- **CHEMOTHERAPY:** There is a very small increased risk of leukemia after chemotherapy treatment.

Again, all of these risks are minimal, but if you're concerned, discuss them with your doctor.

Creating a Survivorship Care Plan

Just as you had a written treatment plan, you may find it helpful to create a written (or electronic) survivorship care plan. This plan typically includes information about your diagnosis and treatment history, all of your physician contacts, recommended follow-up testing and appointments, side effects and how you're treating them, and any longer-term treatment effects to be aware of—all in one place. YSC's *Post-Treatment Navigator* contains worksheets you can use to create this plan. You will find them on our website at youngsurvival.org/learn/resources-and-tools/educational-materials.

You will also find interactive worksheets with Penn Medicine's OncoLink Survivorship Care Plan: oncolink.org/oncolife.



Overall Health & Wellness

When you were diagnosed with breast cancer, you probably heard and read about the benefits of healthy eating, regular exercise, weight control, and stress reduction—for feeling better and possibly reducing recurrence risk. Breast cancer has a way of forcing us to take a closer look at these areas of our lives. But let's face it: as the years pass, our busy lives tend to get in the way, and it's hard to stay focused. Now is the time to take stock of your habits and tune up your health and wellness plan.

The American Cancer Society (ACS) offers online tools and quizzes you can use to assess your current habits. Go to [cancer.org](https://www.cancer.org) and search “staying healthy.” Although the information is designed for people who haven't had cancer, you may find them helpful. In addition, you can review the ACS Guidelines on Nutrition and Physical Activity.

The interactive worksheets at the end of this guidebook will help you establish personal nutrition and wellness goals!

Physical Activity/Exercise

Regular physical activity is encouraged as a part of your life as a long-term survivor. There is a growing body of evidence suggesting that exercise can reduce the risk of recurrence and improve side effects, such as fatigue and menopausal symptoms. If you're having trouble meeting the American Cancer Society's recommendation of at least 150 minutes of moderate activity or 75 minutes of vigorous activity each week, it's time to kick-start your efforts.

Summary of the ACS Guidelines on Nutrition and Physical Activity

- Achieve and maintain a healthy weight throughout life.
- Be physically active. Get at least 150 minutes of moderate-intensity or 75 minutes of vigorous-intensity activity each week (or a combination of these), preferably spread throughout the week. Limit time spent sitting or lying down.
- Eat a healthy diet, with an emphasis on plant foods. Limit processed meat and red meat; eat at least 2 ½ cups of fruits and vegetables each day; choose whole grains instead of refined grain products.
- If you drink alcohol, limit your intake. Drink no more than one drink per day.

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If you didn't work with a certified rehabilitation therapist after your diagnosis, it's not too late to do so. This person can teach you how to exercise safely and build up your strength to minimize the risk of injuring or over-stressing your upper body. Injury can increase the risk of lymphedema on the side of your body where you had surgery (see page 15). Even if you did take part in rehab after surgery, it can be helpful to schedule some sessions with an exercise trainer who has experience working with breast cancer survivors. Your needs are different now, and you may require a new plan. Make sure it includes three types of exercise:

- **AEROBIC (ALSO CALLED CARDIO):** gets your heart rate up and makes you breathe harder (aerobics, running, brisk walking)
- **FLEXIBILITY:** stretches your muscles (yoga, Pilates, tai chi, floor stretches)
- **STRENGTH/RESISTANCE:** targets and strengthens the muscles (light weights, resistance bands)

If you've been sedentary for awhile, review any new plan with your doctor before getting started.

Maybe you're doing well and your exercise plan just needs a fresh take. If you have a smartphone or tablet, try one of the many health and fitness apps that help you keep track of your physical activity, monitor progress, and get feedback and reminders. Most are free or fairly inexpensive. Examples include:

- Nike Training Club
- Gain Fitness Cross Trainer
- Workout Trainer
- Couch To 5K
- Run Keeper
- Pocket Yoga
- My Fitness Pal

Hold Yourself Accountable for Exercise! Some tips:

- **Put exercise in your calendar as an appointment.** Set digital reminders if you use an electronic calendar and sync it to your smartphone.
- **Set a regular time to meet others for exercise.** Join a friend, a small groups or a scheduled class.
- **Exercise while you work, read or watch TV.** Some people are buying or even rigging up their own treadmill desks and exercise bike desks so they can walk or pedal while doing other activities.
- **Take advantage of the Internet and TV.** Look around on the web for exercise routines you can follow. See if your cable or digital TV subscription comes with a library of free fitness videos.
- **Mix it up and find some activities you love.** If you don't love jogging, it will be hard to fit 150 minutes of that into your week. But if you jog on two days and do something else you really love—dancing, yoga, Zumba, swimming—on the others, you're more likely to succeed.

If you want to go high-tech, you can try a wearable device like the Nike® FuelBand or Fitbit®, which track information such as steps taken, activity level, and calories burned and send it to an app on your smartphone, where you can monitor your progress and share your results with like-minded friends in your social community.

You also can try a basic pedometer to increase your steps each day, or keep an exercise journal on paper. The point is to see what you're doing and gradually increase your activity level. You can also find individuals in your area who are interested in group exercise, like walking, hiking and local fitness classes, by searching websites like meetup.com.

Physical Activity/Exercise Resources

BREASTCANCER.ORG

610-642-6550

breastcancer.org/tips/exercise

Breastcancer.org is a nonprofit organization dedicated to providing the most reliable, complete and up-to-date information about breast cancer. The exercise section of the website provides helpful information about exercising safely during and after treatment.

LIVESTRONG AT THE YMCA

800-872-9622, ext. 889

[livestrong.org/What-We-Do/Our-Actions/
Programs-Partnerships/LIVESTRONG-at-the-YMCA](http://livestrong.org/What-We-Do/Our-Actions/Programs-Partnerships/LIVESTRONG-at-the-YMCA)

LIVESTRONG's partnership with YMCAs across the U.S. provides a free 12-week fitness training for adult cancer survivors. The program aims to help survivors gain strength and address fatigue as they move forward in their lives in a healthy way.

Healthy Eating

It can be challenging to eat healthy in a society filled with restaurants, take-out options and processed convenience foods. But good nutrition and a healthy weight are vital to your long-term health. If there is room for improvement in your eating habits, spend a few weeks keeping a food diary. Write down everything you eat and drink during and between meals to determine what changes you need to make.

There's no shortage of electronic diet tracking tools, and you may find them more helpful, engaging and fun to use than a written diary. Many are available both as websites and mobile apps, and they often allow you to track physical activity along with your eating and tailor a plan to your needs. Use a couple of examples:

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- **MYPLATE APP** by LIVESTRONG: liverstrong.com/myplate
- **SUPERTRACKER** by the United States Department of Agriculture: supertracker.usda.gov

Tracking your food intake will show you how much your eating habits need to change. If you're struggling, and especially if you're overweight, ask your doctor about working with a registered dietitian (RD), preferably one who is a Certified Specialist in Oncology Nutrition (CSO). This health professional can assess your eating habits and help you come up with a plan. You also might try taking a healthy cooking or healthy eating class for some new ideas about recipes or foods to try.

Healthy Eating Resources

ACADEMY OF NUTRITION & DIETETICS

800-877-1600

eatright.org

oncologynutrition.org (cancer-specific)

This is the world's largest organization of food and nutrition professionals, with more than 75,000 members. In addition to its educational tools, the website features a searchable online directory of registered dietitians.

THE CANCER PROJECT

202-686-2210

pcrm.org/health/cancer-resources

A program of the Physicians Committee for Responsible Medicine, The Cancer Project promotes cancer prevention and survival through a better understanding of cancer causes, particularly the link between nutrition and cancer. The site features educational publications and other resources, as well as a link to find Food for Life: Cancer Project classes in your area.

CHOOSEMYPLATE.GOV

choosemyplate.gov

A public information campaign created by the U.S. Department of Agriculture to educate the public about healthy food choices, the site offers interactive options like creating personalized food plans.

COOK FOR YOUR LIFE

212-799-3894

cookforyourlife.org

Cook for Your LIFE is a nonprofit organization whose mission is to improve the health of people touched by cancer by giving them the practical knowledge, tools and inspiration to cook their way through treatment and into a healthy survivorship. Through the website, you can sign up for the e-newsletter and browse recipes, including those



for individuals on special diets.

Stress Reduction

Even years or decades later, you can experience stressful moments related to your breast cancer experience: going to the doctor, having a mammogram and reading a news item about breast cancer. On top of that, there are the stresses of everyday life: work, school, kids, finances — you name it. It's good to develop a toolbox of strategies for combating stress and its physical symptoms: headaches, shallow or rapid breathing, muscle tension or a racing heart, for example.

One of the best tools is regular exercise. Some women find that yoga, Tai Chi and other forms of exercise that involve controlled movements and breathing work especially well. There are also several complementary medicine techniques you can learn, such as:

- Mindfulness training
- Daily meditation and visualization
- Relaxation and breathing exercises

Chronic stress can put your health at risk, so get the help you need. Your doctor may be able to recommend a class or complementary medicine practitioner in your area. Some hospitals and medical centers now offer clinics that teach mindfulness-based stress reduction; search this term online and you'll find examples. If stress is greatly impacting your quality of life, you may need to work with a mental health professional, such as a psychologist, social worker or psychiatrist. Many cancer centers have them on staff.

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Other tips: Try to build activities you enjoy into your week—time for hobbies, social events, a movie, a shopping trip—and focus on those in your moments of stress. You may find it helpful to connect with women who are facing similar issues. A support group may no longer be the right place for you, but you can connect with other long-term survivors through organizations such as Young Survival Coalition. If you prefer online support, check out the discussion boards on YSC’s website (community.youngsurvival.org). For more information, see page 52, “Crafting Your Life after Breast Cancer.”

Complementary Medicine Resources

AMERICAN CANCER SOCIETY

800-227-2345

cancer.org

Search home page for “Complementary Medicine.”

ANNIE APPLESEED PROJECT

561-749-0084

annieappleseedproject.org

Annie Appleseed is an all-volunteer nonprofit that provides information, education and advocacy for people with cancer who are interested in natural therapies, lifestyle issues, complementary and alternative treatments from the patient perspective.

You may find it helpful to connect with women who are facing similar issues.

Green Living

We're not sure what role chemicals, pesticides and other environmental contaminants might play in the development of breast cancer. Some chemicals, however, appear to mimic the effects of estrogen, which could make them harmful. After breast cancer, some women decide they want to "live greener" and eliminate these substances from their lives as much as possible. They may feel even more strongly if they have daughters at home, because their breast tissue is still developing and could be more vulnerable to the disruptive effects of chemicals.

Green living often means:

- Choosing more organic or natural foods
- Using natural products, such as cleaners and cosmetics, instead of chemical-based ones
- Eliminating the use of plastics as much as possible
- Cooking food in stainless steel, cast iron, or ceramic pots and pans instead of nonstick options
- Filtering tap water before using it

If you're concerned about possible connections between cancer and your environment, you may feel empowered by greener living. Organic and green products tend to be more expensive, so you might have to make some choices about what's doable for you. Great resources for product information are the Environmental Working Group (ewg.org), an environmental health research and advocacy organization; Keep A Breast's Non Toxic Revolution (nontoxicrevolution.org), which provides comprehensive information on the harmful chemicals found in your environment and food supply and choices you can make to eliminate toxins in your life; and Breast Cancer Prevention Partners (formerly Breast Cancer Fund) (bcpp.org), an organization that works to eliminate our exposure to chemicals and radiation in our everyday environments that have been linked to breast cancer. Breast Cancer Prevention Partners offers some great tips on using inexpensive, everyday household items to make your home more "green."

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Cancer Screenings

In addition to paying special attention to your bone and heart health (see page 19), keep up with recommended cancer screenings. Talk to your doctor about what's right for you; your cancer history, treatments, family history, and/or genetic test results (see page 42) might suggest the need for earlier or more frequent screening. General recommendations include:

- **COLORECTAL CANCER AND POLYPS:** Screening generally begins at age 50 using an imaging test such as colonoscopy and/or tests that require a stool sample.
- **CERVICAL CANCER:** Screening is recommended even if you had the HPV (Human Papillomavirus) vaccine:
 - Ages 21-29:** Pap test every 3 years
 - Ages 30-65:** Pap test every 3 years or Pap test plus HPV (Human Papillomavirus) every 5 years
 - Over 65:** No screening if results have been normal; otherwise work with your doctor
- **ENDOMETRIAL (UTERINE) CANCER:** Postmenopausal bleeding or spotting is the main symptom. Screening is not recommended for most women. Premenopausal women being treated with tamoxifen have a slightly elevated risk for endometrial cancer. Discuss with your doctor your possible risk factors for developing this type of cancer and possible ways to lower that risk.
- **OVARIAN CANCER:** Screening is not recommended for most people, although your doctor may wish to follow you if you have a strong family history or are BRCA-positive.
- **SKIN CANCER:** Check your skin monthly for any unusual moles or growths or changes in appearance of existing moles. See a dermatologist if there are any changes. Ask your doctor if you should see a dermatologist for regular screenings based on your family history and other risk factors.

Emotional Health and Relationships



As the years pass, you'll probably find that your family life and relationships return to a normal routine—or close to it. Still, having breast cancer at a young age changed you in fundamental ways, and it can continue to affect you emotionally. Given the amount of time that has passed, this might be hard for loved ones and friends to understand. Although it can feel obvious, you may need to educate them about how you're feeling and what you need from them.

You'll also have to figure out when and how much information you wish to share with people who come into your life after breast cancer—future romantic partners, for example, or children who weren't yet born or were too young to really understand what was happening.

This section of the Navigator provides an overview of some of the issues you may face and some advice for dealing with them.

Your Own Emotional Health

As someone who faced cancer at a young age, you might feel an emotional disconnect from your peers, even as you grow older. You were forced to face the prospect of your own mortality years before you expected. You may feel as if you lost your youth, and this can be compounded by the loss of fertility and/or early menopause, as well as disruptions in your school or work life. Even years later, you may mourn the loss of the life you might have had without breast cancer—the life you see your friends having.

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You also may experience emotions that are common to long-term survivors of all ages:

- **SURVIVOR GUILT/PULLING AWAY FROM SUPPORT GROUPS:** Over time, you may feel the need to pull away from support groups, which often have members who are newly diagnosed or in treatment. Some people feel guilty about letting the group down by leaving, but hearing about others' day-to-day experiences "in the trenches" may not be what's best for you. This is a natural change and one you can think about in terms of your current needs. Also, as more time passes, inevitably you will hear about a friend or acquaintance whose breast cancer recurred or who died. This can lead to difficult emotions such as survivor guilt—"why her and not me?"—and anxiety about your own future.
- **FEAR OF RECURRENCE/"SCANXIETY:"** Fear of recurrence often fades over time, but it can still rush in at certain moments. Some women find that a change in the treatment plan, such as stopping tamoxifen or seeing their oncologist less often, can cause fear and anxiety. Mammograms, doctor appointments, and breast self-exams can trigger what some call "scanxiety"—the fear of another abnormal finding. Other possible triggers include an unusual pain or ache, the anniversary of your diagnosis, or a news item or obituary that mentions breast cancer.

These emotions are a normal part of being a long-term cancer survivor. In fact, some studies suggest that anxiety can last for many years after diagnosis. As mentioned in the previous section on stress reduction, there are tools you can learn to calm yourself down in those intense

moments, such as deep breathing and meditation. It's also important to talk to someone about your feelings. This might be a close friend or family member who is a good listener and "gets it" or another cancer survivor who's been there, too. Bring that support person along when you're entering a situation that could trigger anxiety, such as a doctor visit or mammogram.

Even if a support group for newly diagnosed patients is no longer the right place for you, organizations such as Young Survival Coalition can connect you with other young, long-term survivors, either directly or online. For more information, see page 52, "Crafting Your Life after Breast Cancer."

Relationships with Spouses/Partners

If you were married or in a committed partnership at the time of your diagnosis, your relationship probably has been challenged in ways you never expected. It may also have been supportive in ways you never expected. The first years after diagnosis are often about treatments and doctor appointments, making sure you're okay, and keeping the household running and the bills paid. Our *Post-Treatment Navigator* features some advice about communicating with your partner and supporting your relationships as you move forward with your life. Breast cancer, however, can have a long-term impact, so you may find it helpful to revisit the following questions with your partner from time to time.

HOW'S OUR SEX LIFE AND RELATIONSHIP?

COULD WE USE SOME HELP?

Usually, the sexual side effects of breast cancer treatment get better with time, but some women continue to have difficulties long term. The onset of menopause also can cause vaginal dryness and irritation that make intercourse more difficult and less satisfying. These are common and normal side effects. If you're having problems, work with your gynecologist, primary care physician, and/or a licensed sex therapist or counselor to find solutions. Also, keep your partner involved by:

- **ASKING WHAT HE OR SHE IS FEELING AND BEING SPECIFIC ABOUT ANY SYMPTOMS THAT MAKE YOU RELUCTANT TO HAVE SEX.** Acknowledge your partner's needs while letting him or her know what's holding you back. If it's vaginal dryness, for example, try a daily vaginal moisturizer or a lubricant designed for use before and during intercourse. If it's fatigue during the work week, plan for intimate dates on the weekends. The point is not the frequency of sex, but the effort to communicate openly so that satisfying encounters are possible again.

- **SPENDING DEDICATED TIME TOGETHER.** Schedule time for date nights and special days out, just for the two of you. Also, some couples find that hugging, kissing, and touching without the pressure of intercourse can be fulfilling—and ultimately make intercourse easier.
- **ARE WE STILL ANXIOUS ABOUT BREAST CANCER?** What are our triggers? Partners have a tendency to want to protect each other and put up a brave front. Just as you may continue to have anxiety triggers years after diagnosis, your partner may worry about you when you look tired, or you complain about an ache or pain, or when you're going in for a mammogram. Talk about your respective anxiety triggers and try to support each other during those times.
- **DO WE WANT TO HAVE CHILDREN/MORE CHILDREN?** If you're still fertile, you need to have this conversation now because breast cancer treatment can narrow your window of fertile years. If you're not, maybe you want to explore adoption or surrogacy. Or maybe you're happy with just the two of you or the family size you have now. These are all important issues to revisit with your partner over time.
- **ARE WE SATISFIED WITH OUR RESPECTIVE HOUSEHOLD ROLES?** All couples have to negotiate roles such as breadwinner, housekeeper, mechanic, accountant, childcare provider and dog-walker. Breast cancer might have forced your partner to shoulder more of the burden. As the years pass, it makes sense to re-examine the division of labor and see what makes the most sense for you as a couple. If your career has been sidelined since your diagnosis, you may want to spend more time at work to get back on track, requiring your partner to do more at home. Maybe your partner is still trying to take care of you and could benefit from spending more time on his or her career. Every situation is different and changes over time.
- **DO WE NEED PROFESSIONAL COUNSELING?** Breast cancer can challenge even the strongest relationships, and it can be especially devastating for young couples who are just starting their lives together. Even many years later, your relationship can feel the impact. A marriage or relationship counselor may provide the objective sounding board you need to sort through your issues and concerns.

The natural course of any relationship does not usually account for the crisis of a major illness. While we all like the idea of the promise of “in sickness and health,” the truth is that a serious illness turns our lives upside down. The trauma of a cancer diagnosis can be something from which one or both partners are unable to recover. Relationships

ending is a sad but real result some survivors experience. The most important thing to remember, should this happen, is to not beat yourself up about it, thinking “if only I hadn’t” (you fill in the blank, with “gotten cancer” at the top of the list). Relationships can come to an end, and we encourage you to be gentle with yourself, love yourself, and move on—staying open for love to come back into your life.

Relationships with Potential Future Partners

No matter how long it’s been since your diagnosis, dating a new person raises certain challenges: when to tell, how to tell, what to tell. Some women find that they are pickier about who they date and more cautious about getting involved with a new partner. Building trust in someone over a few dates is important before you share your experience. If you have visible scars from surgery or reconstruction, any sexual side effects due to early menopause, or loss of fertility, you’ll likely want to do this before you become physically intimate. These tips may help pave the way:

- **GIVE IT SOME TIME.** Let the person get to know you before bringing up your history. Breast cancer doesn’t define you.
- **PRACTICE WHAT YOU’RE GOING TO SAY.** Rehearse with a friend or in front of a mirror. Be simple and direct about the diagnosis, the treatment, and how you’re doing now.
- **GIVE YOUR PARTNER TIME TO DIGEST THE NEWS.** It can be difficult to learn that someone you’re starting to care about had a serious illness or maybe can’t have biological children. Think about a male partner telling you that he can’t have children due to testicular cancer or that he has problems with sexual function due to prostate cancer. This may help you understand the other perspective.
- **DON’T MOVE FORWARD IF YOUR PARTNER REACTS BADLY.** Your partner’s reaction is likely to tell you a lot about whether or not this relationship is right for you.

If you’re eager to have children of your own and are concerned that your window of fertility is narrowing, it can be very hard to be patient. If you find yourself getting serious with a new partner, you might want to make sure he or she is on the same page. Be honest and direct about your feelings and concerns.

Breast cancer survivors who identify as lesbian, bisexual or transgender (LBT) may face a unique set of unanswered questions in their personal relationships. Find more information or connect with other survivors through the **NATIONAL LGBT CANCER NETWORK** [cancer-network.org/programs/support-groups-for-survivors].

Talking With Children

If you had very young children at the time of your diagnosis, or children have come into your life since then, you may grapple with the issue of when and how much to tell them.

If your children were aware of your illness and side effects such as surgery scars and hair loss, they may ask more about what happened as they get older. Be open and honest with them, but tailor the information to their age and ability to understand. “Cancer” can be a scary word for children.

Tips:

- They’ll likely need your reassurance that everything is fine now and that you see your doctor for regular checkups to stay healthy, just as they do.
- If they ask about it in the future, you may decide to reveal more about the experience if you feel they can handle it.
- Answer their questions as honestly as you can.

With children who have no idea about your breast cancer history, there’s no easy answer about when to bring up the subject. They need to know because it’s part of who you are and, beyond that, your history is now part of their own medical history —especially if there is evidence that breast cancer runs in the family (see Section 5). You will obviously think about girls in terms of their future risk of breast cancer, but it is also important to remember that your sons also could be at higher risk of certain cancers, including breast cancer. The most important thing to remember is to be honest with them and address their questions directly.

At some point, your child is likely to hear of a classmate’s mother being diagnosed or he/she may see a breast cancer story in the news. You may find that this is a good opportunity to talk about your cancer journey. Use your best judgment to gauge what and how much you share about your experience. Above all, remind them that your cancer is in the past, and you are healthy now.



Raising Girls

As girls enter puberty and begin to develop breasts, they need good information about lifestyle habits that will help keep their breasts healthy. Regular exercise, nutritious foods, a healthy weight, and choosing not to smoke and drink alcohol can all make a difference.

You can also find helpful information in YSC's *Breast Health and You* booklet, which educates healthy young women on breast cancer risk and taking care of their bodies [youngsurvival.org/learn/resources-and-tools/educational-materials].

You can also let your daughter know that:

- **CHANGES IN HER BREASTS THROUGHOUT PUBERTY ARE NORMAL.** Over the coming years, her breasts will continue to grow and change, and that's to be expected. Lumpiness and tenderness are often part of the process—and one breast might even be bigger than the other. Her skin and nipples might look odd or just plain weird to her. Reassure her that such changes have nothing to do with cancer. If something concerns her, though, she can always see her doctor to be sure.

For adolescent and young adult girls, it may be appropriate to discuss your breast cancer history in more detail. Plan out what you want to say, and bring up the topic at a relatively stress-free time when you're in a position to answer all of your daughter's questions. As she reaches adulthood, it is a good time for her to share family history with her primary care physician and gynecologist.

- **YOUR BREAST CANCER DOESN'T MEAN THAT SHE'LL GET BREAST CANCER.** Just as she didn't inherit every single one of your physical traits, she isn't automatically destined to get breast cancer because you had it. As an adult, she will be considered at higher-than-average

risk, especially if other family members are affected. This isn't a 100 percent risk, but it's higher than the risk that most American women face: 12 percent over the course of an average lifetime of 80 years. So for her, breast cancer screenings may be something she thinks about in her 20s or 30s versus age 40. When to begin screening may be recommended based on when you were first diagnosed. It's important information for her to share with her doctors as she gets older.

If you tested positive for BRCA1, BRCA2 or another genetic mutation that increases cancer risk, ask your genetics counselor about the appropriate time to discuss the mutation with your children and their healthcare provider. You should also ask if s/he can provide any resources and individual screening recommendations specifically for daughters of women who carry a genetic mutation.

Emotional Health and Relationships Resources

Some of these resources address the needs of women who are in treatment or recently finished treatment. You may, however, still find the advice helpful.

YOUNG SURVIVAL COALITION SEX AND INTIMACY AFTER BREAST CANCER DIAGNOSIS

Available online at: youngsurvival.org/learn/living-with-breast-cancer/quality-of-life/sex-and-intimacy

Young Survival Coalition's **"HELPING CHILDREN COPE WITH BREAST CANCER"** fact sheet is a useful resource in communicating with your children: youngsurvival.org/learn/living-with-breast-cancer/quality-of-life/communicating-with-children.

Additionally, **LIVING BEYOND BREAST CANCER** provides a comprehensive overview for children at every age: lbbc.org/Learn-About-Breast-Cancer/Talking-to-Children-About-Breast-Cancer.

TAKING CARE OF YOUR GIRLS: A BREAST HEALTH GUIDE FOR GIRLS, TEENS, AND IN-BETWEENS, by Marisa Weiss, MD, and Isabel Friedman (Random House, 2008)

This informative and engaging guide can allay some of the anxieties young girls may experience as their breasts begin to develop—especially if there is breast cancer in the family. Available through major retailers as a print or digital book.

Family Risk and Genetic Counseling



Getting breast cancer before age 40 is much less common than developing it later in life. So it often raises a red flag that an inherited genetic mutation may be to blame. If you haven't already done so, you may wish to investigate your family history and consider genetic counseling and testing.

A mutation is an abnormal change in a specific gene passed down through families. As you may know, researchers have identified two genes, BRCA1 and BRCA2, which play roles in keeping breast cells growing normally and preventing cancerous changes. Mutations in either gene, which can be inherited from your mother or father, significantly increase the risk of developing breast cancer, as well as ovarian cancer.

If you test positive for the BRCA1 or BRCA2 mutations, you would be considered at an increased lifetime risk of developing another breast cancer and/or ovarian cancer. This knowledge can help you and your doctor consider strategies to decrease your risk, such as additional treatments or more intensive screening. After all you've been through, though, you may not want to deal with finding out that you're at higher risk for a future cancer—at least not yet. This is a very personal decision, often made in cooperation with family members, because they will also be affected by the information.

If you test negative, it doesn't guarantee that you won't have another, yet-to-be-discovered genetic mutation that may cause breast cancer. This is why genetic counseling is so important before any testing is done. Having your family tree, known as a pedigree, reviewed by a

genetic specialist can be very helpful in determining the likelihood you and other family members may have a gene that predisposed you to getting the breast cancer for which you've been treated. Genetic counseling provides a thoughtful dialogue about what your risks are, what risk your family members may also have (particularly first-degree relatives—mother, siblings, children), and an opportunity to discuss before testing what steps you may choose to take, based on the results.

How Do I Get Started?

Decisions about genetic testing start with a formal risk assessment by a genetic counselor, a health professional with a degree and/or advanced training in genetics and family risk. He or she can help you understand the pros and cons of genetic testing, whether or not you're a candidate, and how you and your family members can use the results.

To find a genetic counselor, you can ask your doctor, check with cancer centers in your area, or search these two directories:

- **NATIONAL CANCER INSTITUTE, CANCER GENETICS SERVICES DIRECTORY**
800-4-CANCER
cancer.gov/cancertopics/genetics/directory
- **NATIONAL SOCIETY OF GENETIC COUNSELORS**
312-321-6834
nsgc.org

It's helpful to know the type of cancer and age at diagnosis for any family members who have had cancer. Your genetic counselor will use this information to build a family tree that includes you and all other first- and second-degree relatives affected by cancer on both your mother's and father's sides.

First-degree relatives include parents, siblings and children; second-degree relatives include aunts and uncles, grandparents, grandchildren, nieces, nephews and half-siblings. Any relatives who have already tested positive for the BRCA1 or BRCA2 mutation will be noted on the tree, as well.

According to the National Cancer Institute, the following family patterns suggest the possibility of the BRCA1 or BRCA2 mutation. African-American women and those of Ashkenazi Jewish descent—Jewish women with family roots in Central or Eastern Europe—are at greater risk.

For women NOT of Ashkenazi Jewish descent:

- Two or more relatives diagnosed with breast cancer, especially before age 50
- A combination of relatives diagnosed with either breast cancer or ovarian cancer
- A family member with cancer diagnosed in both breasts
- A combination of two or more relatives diagnosed with ovarian cancer, regardless of age at diagnosis
- A family member diagnosed with both breast and ovarian cancer, regardless of age at diagnosis
- A male family member with breast cancer

For women of Ashkenazi Jewish descent:

- One or more relatives diagnosed with breast or ovarian cancer

For African-American women:

- Any family history of breast cancer, combined with your young age at diagnosis, suggests a mutation could be present

In general, the younger your age at diagnosis and the more relatives affected, the greater the odds of a BRCA mutation (or another possible inherited mutation). Your genetic counselor will ask about other types of cancer in the family, such as colorectal cancer and prostate cancer in men, and endometrial, ovarian and uterine cancer in women. These can be more common in families with BRCA mutations, or they may suggest that some other genetic mutation could be at work. Your genetic counselor will help you understand your family patterns and whether genetic testing is warranted. You may, however, decide to proceed with genetic testing based on your young age at diagnosis.

Note that just because you have a strong family history of breast cancer does not mean you carry the BRCA1 or BRCA2 mutation. This is only one set of mutations that has been discovered, and there is ongoing research to determine others. Multi-gene panel testing can now show mutations in other genes potentially linked to breast cancer (such as PALB-2). However, at this time, even if another non-BRCA mutation is found, we lack good evidence on what, if anything, should be done. This is another area where your genetic counselor can provide crucial information and support.

What's Involved?

The Test Itself, Costs, Privacy Issues

Here's what you can expect:

- First, you will be asked to sign an informed consent document stating that you understand the benefits and risks of testing. The test itself isn't risky, but the results can cause some people emotional distress and anxiety.
- Then a sample of your blood is drawn and, in most cases, sent to a genetic testing company. Different versions of the BRCA test are available, depending on whether or not a BRCA mutation has already been found in your family.
- If you have the BRCA test as part of a research study, the research lab will handle the testing.
- If a family member who was diagnosed with breast cancer has already tested positive and can share the specific DNA location with you, then you may only need to have a test that looks at the same specific site in your DNA, which can reduce the cost of the test dramatically.

Depending on the type of test, the cost for genetic counseling and testing can range from approximately \$400 to \$4,000. Many health insurance plans do cover the cost, but, as with all medical testing, it's a good idea to check your plan benefits before meeting with the genetic counselor.

Your results are protected by health information privacy laws, and the 2008 Genetic Information Nondiscrimination Act (GINA) prohibits health insurance plans and employers from discriminating based on genetic information. Other types of insurance, however, such as disability, life, and long-term care insurance, are not subject to this law. You can always ask about keeping your genetic test results out of your medical record. If the cost of the test isn't a financial burden, you may choose to pay for it out-of-pocket and have it done anonymously or under an assumed name or code number. Ask your doctor and genetic counselor for options.

Expect to get the results in approximately one month during an appointment with your genetic counselor. Your counselor will tell you whether you tested positive or negative for BRCA1 and/or BRCA2 mutations or whether the results were uncertain. Sometimes the test can show a variation in the gene that hasn't been linked to cancer risk, but is still unusual.



How Can I Use the Results?

For women with the BRCA1 or BRCA2 mutation, the lifetime risk of breast cancer is about 60 percent versus 12 percent for the general population. The lifetime risk of ovarian cancer can range from 15 to 40 percent versus about 1.5 percent for the general population. These are just estimates, though; your risk may be higher or lower, depending on the type of mutation you have and your family history. There is a chance that some of your relatives are carriers of the mutation and may wish to get tested.

- If you test negative for BRCA1 and BRCA2 mutations, and you already have family members who tested positive, then you know that you did not inherit the mutation—and this is reassuring. A negative result can also be reassuring if you have no family history of breast or ovarian cancer, or a weak history (for example, just one distant relative affected).
- If, however, you have a strong family history of breast, ovarian and possibly other types of cancer, and these have not been traced to a BRCA mutation, testing negative does not rule out the possibility that the cancers are due to some other genetic mutation. We know there must be other inherited genetic mutations that cause breast cancer, and researchers are working to identify them and develop testing options. In the meantime, you would still be considered higher-than-average risk.
- If you have also been previously tested for BRCA1 or 2 and screened negative for a mutation, you may ask your oncologist or genetic counselor about new genetic panels and whether it makes sense for you to get re-tested.
- If it is determined you are at higher risk, you, your genetic counselor and your doctor can discuss strategies to lower your risk of a future breast cancer or ovarian cancer, or at least increase your odds of early detection. Possibilities include:

- **PREVENTIVE SURGERY:** Some women choose to have all remaining breast tissue removed (double mastectomy) to reduce the risk of breast cancer. Others choose to have both ovaries and fallopian tubes removed (prophylactic oophorectomy), once they are finished having children, to reduce the risk of ovarian cancer. This also reduces breast cancer risk, because the ovaries are the body's main source of estrogen.
- **MEDICATIONS:** If your breast cancer was estrogen receptor-positive, you may decide to take tamoxifen or another hormonal therapy, such as an aromatase inhibitor, for several more years.
- **ENHANCED SCREENING:** Some women choose to be screened more frequently for breast cancer through a combination of tests such as mammogram, ultrasound, MRI and/or digital tomosynthesis (3-D mammography). For ovarian cancer, women can be followed by a gynecologic oncologist (a doctor who specializes in cancers of the female reproductive tract) with regular physical exams, imaging tests, and tests for a blood protein called CA-125.
- **LIFESTYLE CHANGES:** Eating well, exercising, losing weight if needed, and limiting alcohol use can all make a positive difference in cancer risk.

Your genetic counselor can help you understand your results and the different options open to you.

Genetic Counseling and Testing Resources

The American Cancer Society ([cancer.org](https://www.cancer.org)), the National Cancer Institute ([cancer.gov](https://www.cancer.gov)), and Breastcancer.org ([breastcancer.org](https://www.breastcancer.org)) offer information about genetic testing. Other resources:

BRIGHT PINK

312-787-4412

[brightpink.org](https://www.brightpink.org)

Bright Pink is the only national nonprofit organization focusing on the risk reduction and early detection of breast and ovarian cancer in young women, while providing support for high-risk individuals.

FORCE: FACING OUR RISK OF CANCER EMPOWERED

866-288-RISK

[facingourrisk.org](https://www.facingourrisk.org)

FORCE is the only national nonprofit dedicated to improving the lives of individuals and families affected by hereditary breast and ovarian cancer. Its website offers information about genetic testing, family risk and action steps for women affected by breast and ovarian cancer.

Financial, Legal and Employment Concerns



Breast cancer raises a wide range of practical concerns—about finances and insurance, your legal rights, and how best to deal with current and future employers. In this section, we'll highlight some of the most pressing concerns for long-term survivors and suggest places you can turn to for more information.

Finances: Have I Recovered Financially After Breast Cancer?

Even if you have health insurance, breast cancer can take a major financial toll due to out-of-pocket costs such as plan deductibles, co-pays and medications. Cancer's financial impact can be worse for younger adults, who often are still in school or just getting their careers off the ground.

If you haven't already done so, take some time to get your finances in order, whether on your own or with your spouse/partner. Make a list of all of your assets and liabilities, create a monthly household budget, set some financial goals and start saving for retirement. You may wish to use financial planning software such as Quicken (quicken.com) or the online tool Mint.com (mint.com) to collect all of your financial information in one place. Each has an app that allows you to view the same information on your smartphone. The goal is to make your financial information visible so you can start using it more effectively.

You also might benefit from working with a financial planner, a professional trained to help people manage their finances and set goals. Few of us have the time or knowledge to do all of this planning on our own. Through the American Cancer Society, you can access a publication titled *How to Find a Financial Professional Sensitive to Cancer Issues: Financial Guidance for Cancer Survivors and Their Families*.

If you fell behind paying your bills, ran up excessive debt, or even had to declare bankruptcy, you can feel the effects for years. A credit counselor can help with strategies for restoring good credit and recovering from bankruptcy; just make sure you are working with a reputable agency. The National Foundation for Credit Counseling (nfcc.org) can provide educational resources and help you find an accredited counseling agency in your area. You also can use NFCC's My Money Checkup tool (mymoneycheckup.org) to get a snapshot of how your finances are doing and areas where you can make improvements.

If you haven't checked your credit lately, you can get a free copy of your credit report every 12 months at AnnualCreditReport.com. This service was created by the three national consumer credit reporting companies to give consumers a way to see what is in their credit file and could be reported to third-party lenders. For more information about your credit score, check out the Federal Trade Commission's consumer website [consumer.ftc.gov].

Insurance: Will I Be Able to Get Health Insurance? Other Kinds of Insurance?

In the past, health insurance plans could deny coverage or even charge higher premiums for people with a history of cancer. Since January 2014, though, the Affordable Care Act prohibits insurers from denying coverage due to a pre-existing condition. If you need to apply for a new health insurance plan — because you or your spouse change jobs, or you are applying for an individual insurance policy — your cancer history should not be an issue. The National Coalition for Cancer Survivorship's booklet *What Cancer Survivors Need to Know About Health Insurance* (canceradvocacy.org/resources/health-insurance) is a great resource to have on hand if you find yourself in the market for health insurance.

Due to ongoing policy discussions regarding Americans' health coverage, always check reliable sources for the most updated information. Triage Cancer (tragecancer.org), for example, frequently posts blogs and fact sheets on this and other insurance topics.

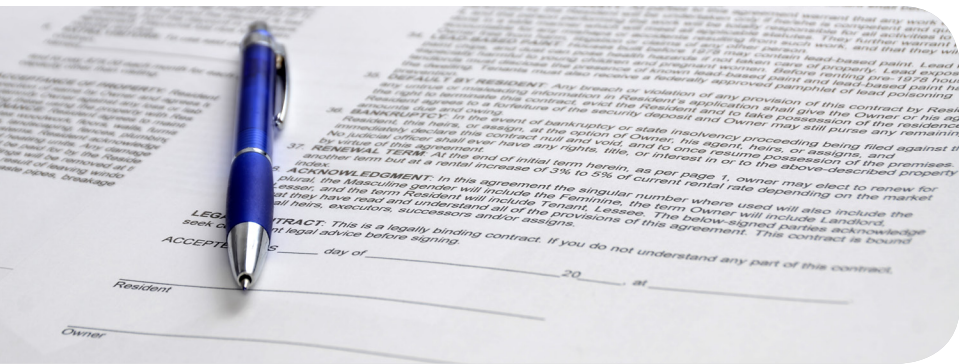


Even though you are doing well now, having cancer at a young age showed you that you aren't invincible, and you may be interested in getting other types of insurance. Your cancer history, however, can make it difficult to qualify — and if you do qualify, the policy may be more expensive than it is for others. Examples of these policies include:

- **LIFE INSURANCE:** This pays a designated beneficiary a sum of money upon your death. If you are supporting or caring for family members, this money can be critical for their care and shelter.
- **DISABILITY INSURANCE:** It pays some portion of your salary if you become ill or injured and are unable to work.
- **LONG-TERM CARE INSURANCE:** This is insurance that covers the costs of care if you are no longer able to care for yourself. For example, this might include home care, assisted living, hospice care or private nursing.

If your employer offers these types of insurance, start there first, as this is your best bet for getting insured at a reasonable cost. Or you can shop around, either on your own or with the help of an insurance agent, to research options. Your state's department of insurance can provide information about insurance companies that offer these policies. Also, you should be able to get price quotes without disclosing your personal information.

If you apply for a policy, be honest about your health history; not disclosing the information can be considered insurance fraud. Insurers might look more favorably on you if it has been more than five years since you completed treatment; they also might ask for more specific information about your diagnosis.



Legal Documents: What Do I Need?

It's a good idea for everyone—not just cancer survivors—to draw up legal documents that will make your wishes known to loved ones if you are unable to make decisions for yourself. These include:

- **WILL:** This document specifies where your assets will go upon your death and who will raise your children, if you have them. Everyone should have a will, but it's especially important if you have children, or you are single and supporting family members financially. If you are indicating who will raise children, also look into guardianship documentation.
- **DURABLE POWER OF ATTORNEY:** This allows you to name someone to handle your finances if you are no longer able to do so.
- **HEALTHCARE PROXY** (also called medical or healthcare power of attorney): This document allows you to name someone to carry out written, specified decisions made by you, and/or make healthcare decisions for you, if you are no longer able to do so.
- **LIVING WILL:** In a living will, you can specify what medical treatments and life-prolonging interventions you would or would not want if you are no longer able to communicate. This is sometimes also called an advance directive.

If you don't have these in place, now is a good time to work on them. If you can afford it, hire an attorney who specializes in estate planning to draw up these documents with you. A less expensive option is [LegalZoom.com](https://www.legazoom.com), which charges a set fee for each document. If this is still out of reach, find a legal aid clinic in your area to get assistance. To find legal aid services or other free resources in your area, contact any of the organizations listed at the end of this section.

Employment: What Are My Rights?

Most people can expect to change jobs several times over the course of a career. When you are job hunting, you are under no obligation to tell prospective employers about your cancer history, unless you have long-term side effects that could interfere with your ability to do the job. For example, if you have lymphedema (see page 15) or upper body pain and the job involves carrying or lifting, you would have to let the employer know. A potential employer also cannot ask about your health history. If you have a gap in your resume due to cancer and the employer asks about it, you can simply state that you had a medical issue but that it was resolved several years ago. Bring the focus back to your skills and what makes you the right candidate for the job.

Keep in mind that employers sometimes search candidates' names online to learn more about them.

Tips:

- If you have a Facebook, Twitter, or other social media account that mentions your breast cancer, or you have participated in breast cancer-related events, your prospective employer could find this information.
- If this concerns you, do whatever you can to minimize your “digital trail.” At the very least, make sure your social media accounts have their privacy settings turned on.
- Be prepared to discuss anything else a prospective employer might find out about you online.

In your current job, you have the right to accommodation if you develop a late effect of cancer treatment — such as lymphedema, upper body pain or limited range of motion, or heart problems — that makes it difficult for you to handle your responsibilities.

- The Family and Medical Leave Act (FMLA) allows you to take up to 12 weeks unpaid leave to heal from a serious health condition, while keeping any benefits you may have and maintaining your position with the company. It applies to companies that employ 50 or more people, and you must be a full-time employee with the company for at least a year to use this leave.
- The Americans with Disabilities Act also requires employers to provide “reasonable accommodations” for people with physical limitations due to medical conditions.

A good source of information about what's covered is the Job Accommodation Network at askjan.org and Cancer and Careers at cancerandcareers.org.

If your employer knows about your cancer history, he or she cannot let it affect how you are treated as an employee. If you feel that you are being treated differently — given less challenging assignments, passed over for promotions, and paid less — keep a detailed record of any such incidents over time, including the date, time, place, who was present and what was said. Also keep a record of your accomplishments at work as evidence of your ability to do the job. If you're concerned about possible discrimination, talk to your direct supervisor or human resources department. If a pattern of discrimination persists over time, you may wish to file a complaint with the U.S. Equal Employment Opportunity Commission at eeoc.gov or with your state's own Fair Employment Practices Agency. There is a time limit of 180 to 300 days from the original incident to your filing of a complaint. Talk to a legal expert first to get his or her take on your situation; the Cancer Legal Resource Center below is a good starting point.

Financial, Legal and Employment Resources

CANCER AND CAREERS

646-929-8022

cancerandcareers.org

Cancer and Careers empowers and educates people with cancer to thrive in their workplace by providing expert advice, interactive tools and educational events. Through a comprehensive website, free publications, career coaching, and a series of support groups and educational seminars for employees with cancer and their healthcare providers and co-workers, Cancer and Careers strives to eliminate fear and uncertainty for working people with cancer.

CANCER LEGAL RESOURCE CENTER

866-THE-CLRC

cancerlegalresourcecenter.org

Cancer Legal Resource Center (CLRC) is a joint program of Disability Rights Legal Center and Loyola Law School, Los Angeles. The CLRC provides information and education about cancer-related legal issues to the public through its national telephone assistance line. The CLRC also conducts national education and outreach programs for community groups, employers and healthcare professionals, and it is actively involved in community activities to raise public awareness of cancer-related legal and public policy issues.

NATIONAL CANCER LEGAL SERVICES NETWORK

nclsn.org

The National Cancer Legal Services Network is a unified voice of over 40 programs that are seeking to promote access to healthcare and increase the availability of legal services for people living with cancer. In addition, the network supports the efforts of individuals and organizations that provide free legal assistance and referrals. The website features an interactive map of program partners across the country where you can seek help.

PATIENT ADVOCATE FOUNDATION

800-532-5274

patientadvocate.org

Patient Advocate Foundation is a national nonprofit organization that serves as an active liaison between the patient and their insurer, employer, and/or creditors to resolve insurance, job retention, and/or debt crisis matters relative to their diagnosis through case managers, doctors and attorneys. Patient Advocate Foundation seeks to safeguard patients through effective mediation, assuring access to care, maintenance of employment, and preservation of their financial stability.

TRIAGE CANCER

424-258-4NAV

triagecancer.org

Triage Cancer is a national nonprofit organization that provides education and resources on the entire continuum of cancer survivorship issues to survivors, caregivers and healthcare professionals. Check out their website for more information about health insurance, employment issues and the impact of the Affordable Care Act on cancer survivors.





Crafting Your Life after Breast Cancer

As the years pass, breast cancer will tend to fade into the background and become less of a daily presence. By now, you may have achieved your “new normal” or close to it. Still, it can be helpful to think about how you wish to live your life after breast cancer. It’s natural to pull away from full immersion in the breast cancer community, but how do you want to stay informed and involved? As a young survivor, your voice is important, given that only about 12 percent of women are diagnosed in their 20s, 30s or early 40s. Anything you can do to connect with other women and bring attention to younger survivors’ unique needs can make a difference.

On a more personal level, you may have found that breast cancer changed your feelings about your career path, work/life balance, even how you wish to spend your free time. If you haven’t yet figured out what changes you wish to make, now can be a good time to do so.

Keeping Up With Breast Cancer Research

Try to keep your finger on the pulse of what’s happening in breast cancer research, in case any new information could benefit you. This doesn’t mean spending hours a day on breast cancer websites; instead, once a month or even every few months, mark your calendar with a reminder

to check out the “news” sections of breast cancer organizations. Better yet, sign up for a monthly email or an RSS feed that is delivered to your inbox, so you don’t even have to think about it. Another option is to follow organizations on Facebook or Twitter, where they often post major research news—although this may give you more daily exposure to breast cancer than you want. Scan the items quickly, see if there is any information relevant to you, and move on.

YSC’s blog also aims to bring you the most up-to-date information on breast cancer research and other developments relevant to young women affected by breast cancer: blog.youngsurvival.org. You may also want to learn more about YSC’s Research Agenda, which outlines the most pressing research questions that must be answered to improve the quality and quantity of life for young women affected by breast cancer. These priorities were identified by more than 50 advocates, researchers and physicians through YSC’s Research Think Tank. Read more about the Research Agenda and how YSC is working to influence scientists, researchers, physicians and funders: youngsurvival.org/research-agenda.

Seek out this information in whatever way works best for you without making you feel overwhelmed. If you need to take a break from time to time, that’s okay.

Breast Cancer Research Resources

AMERICAN SOCIETY OF CLINICAL ONCOLOGY

cancerprogress.net

Check out the American Society of Clinical Oncology’s annual report on progress against cancer, called Clinical Cancer Advances. It summarizes the most significant research findings of the year for various forms of cancer and survivorship care.

GOOGLE ALERTS

google.com/alerts

Enter a search term such as “breast cancer research” or “breast cancer studies” and your email address, and Google Alerts will automatically email you any of the latest Google search results relevant to your query. You can control how frequently you receive the emails.

JOHNS HOPKINS BREAST CENTER

443-997-8282

hopkinsbreastcenter.org/artemis

This is a free electronic medical journal written in layperson’s terms and published monthly online to provide the most recent evidence-based research information since its last posting.



SCIENCEDAILY

240-454-9600

sciencedaily.com

Since its founding in 1995, ScienceDaily has become one of the internet's most popular science news websites. If you go to their Health and Medicine section, you can access the latest breast cancer research news stories. You also can sign up for an email newsletter or RSS feed that brings information about the latest research studies to your inbox.

Supporting Other Women

You might feel as if you have moved beyond support groups or are starting to “age out” of the young survivor community. But there are still ways that you can help women who are in treatment or just finishing. YSC is a great place to start: youngsurvival.org/connect.

- If you have a Young Survival Coalition Face to Face (F2F) group in your area, you can go to a meeting and share your story, even if you're not comfortable being an active member.
- Through YSC's SurvivorLink program, you can also mentor someone who wants to connect with a long-term survivor.
- Share your experience through online discussion boards, such as those YSC hosts at: community.youngsurvival.org. Contributing your perspectives as a long-term survivor can help other women. This is something you can do on your own time, with little disruption to your schedule.

- For the caregivers in your life, contact an organization such as Imerman Angels at imermanangels.org or 1-877-274-5529, which matches patients and caregivers with mentors who had the same type of cancer and diagnosis.
- For more information on resources in your community, take a look at YSC's ResourceLink Guidebook: youngsurvival.org/directory.

If you still need support as a long-term survivor, you can take advantage of these resources for yourself, too.

Finding Your Niche in the Breast Cancer Movement

There are many outlets for using your breast cancer experience to make a positive impact on research and awareness. Think about how much time you can dedicate and how actively you wish to be involved. YSC's volunteer program is always providing new opportunities for you to help increase awareness, provide support to other survivors and lend your creative fundraising skills: youngsurvival.org.

The following suggestions can help you get started!

Become an advocate

Becoming an advocate means stepping forward to be the face of young breast cancer to members of the public, the news media and policymakers. Use this opportunity to find the type of advocacy that is most fulfilling and meaningful to you. Activities can take many different forms, such as:

- Allowing breast cancer organizations to publish your story
- Serving on committees that advise breast cancer organizations or programs
- Raising your voice in support of legislation and federal funding that supports women with breast cancer
- Helping to organize an event or conference

Young Survival Coalition offers many resources to learn more and help you get started: youngsurvival.org/be-an-advocate. Of particular note is YSC's RISE program, which trains young breast cancer survivors to be advocates. Applications for this highly competitive program open each year.

Participate in survivorship research or surveys

There is much we don't yet know about the needs of women diagnosed with breast cancer before age 40. By taking part in a research study or survey, you may be able to help researchers gain insight into the unique issues of young women. Follow YSC on social media to learn about study opportunities open to young survivors.

Advocacy Resources

AMERICAN ASSOCIATION FOR CANCER RESEARCH (AACR): SCIENTIST↔SURVIVOR PROGRAM

215-440-9300

aacr.org

The AACR Scientist↔Survivor Program is designed to build enduring partnerships among the leaders of the scientific, cancer survivor and patient advocacy communities worldwide. The program exposes advocates to special lay-language lectures, small group discussions and other interactions that provide a solid background in cancer research.

NATIONAL BREAST CANCER COALITION

800-622-2838

breastcancerdeadline2020.org

The National Breast Cancer Coalition (NBCC) influences change in the world of breast cancer — in public policy, science, industry and advocacy — by creating new partnerships, collaborations, research funding opportunities and avenues for access to quality care. NBCC's hallmark initiative — Breast Cancer Deadline 2020 — is a call-to-action for policymakers, researchers, breast cancer advocates and other stakeholders to know how to end the disease by 2020.

RESEARCH ADVOCACY NETWORK

877-276-2187

researchadvocacy.org

The Research Advocacy Network advances patient-focused cancer research by fostering interaction among advocates, researchers and related organizations. Find out how you can get involved in advocacy and influence change in the cancer community.

Support, participate and fundraise

Donate to the support programs, organizations or cancer center/hospital that helped you. Choose one or two of these organizations and

start supporting them annually, at whatever level you can. Nonprofits such as the Young Survival Coalition depend on private gifts to fund programs and services. YSC's Champions Program provides a variety of creative ways for you and your loved ones to fundraise and give back: yscchampions.org.

Participate in a fundraising event.

There are many events that allow you to turn your walking, running or cycling into a source of support for research and awareness. A few examples include the Young Survival Coalition's Tour de Pink bicycle rides; the Avon Walk for Breast Cancer; and Susan G. Komen's Race for the Cure and Breast Cancer 3-Day. Many survivors are empowered by getting physically active to support the breast cancer cause. Such events also provide a way for you to involve family and friends, either as participants or sponsors.

Attend a conference.

No matter how old you are, you'll always be considered a "young survivor." Attending a conference enables you to network with other young survivors and learn more about many of the topics introduced in this Navigator for Long-Term Survivors. YSC hosts a national YSC Summit annually, as well as Regional Symposia where young survivors can learn and connect no matter how much time has passed since their diagnosis.

Living "Beyond Pink"

Crafting your life after breast cancer also means figuring out how you want to live your best life — personally and professionally. Cancer has a way of focusing our attention on what's really important, but it can be hard to make changes while you're in treatment or just getting your life back on track. As a long-term survivor, many years have passed, and things have settled down, so you might want to think about setting some new goals.

Rethinking Your Career

Cancer often leads people to think more about what difference they want to make in the world. After having cancer, work may be less about money and prestige and more about how you want to impact others. If your current career path isn't fulfilling or interesting to you any more, you might consider making a change, either by switching jobs or going back to school.



For other people, financial security and solid benefits become more important after the cancer experience. If your job doesn't provide you with those, you may wish to focus on finding a job that will bring more security and peace of mind.

Your decisions will depend on your current life situation, whether you have a spouse or partner providing income, and your responsibilities at home. Spend some time thinking about what's most important in your career and make a plan for getting there.

Career and Education Resources

CANCER AND CAREERS

212-685-5955

cancerandcareers.com

The site provides advice and career coaching for cancer survivors who are seeking employment or changing jobs.

CANCER FOR COLLEGE

760-599-5096

cancerforcollege.org

Cancer for College is a national nonprofit that provides partial scholarships to cancer survivors enrolled in an accredited college.

CANCER SURVIVORS' FUND

281-437-7142

cancersurvivorsfund.org

Cancer Survivors' Fund is a nonprofit organization developed to provide college scholarships for cancer survivors to give them new purpose and meaning in life.

LINKEDIN

[linkedin.com](https://www.linkedin.com)

Available as a free social networking site and app, LinkedIn is a great tool for building your own professional profile, sharing it and connecting with others in fields that interest you. If you haven't joined yet, check it out. If you have a profile, keep it current and build your network.

NATIONAL CAREER DEVELOPMENT ASSOCIATION

866-FOR-NCDA

[ncda.org](https://www.ncda.org)

Here you can search for certified career counselors in your area. Just be sure to investigate the credentials of anyone you are considering.

CRAFTING
YOUR LIFE
AFTER
BREAST
CANCER

7

Your employer cannot treat you differently because of your cancer diagnosis.

Achieving Work-Life Balance

Related to career choice is the issue of work-life balance. If you have children at home, you may feel strongly about having a job that allows you to spend time with them. If they are very young, you may decide to take a break from the workplace. Climbing the corporate ladder may not be as important to you as it was before, especially if your household has a second source of income.

On the other hand, if you love your job, you may feel more focused than ever on advancing your career and taking on ever-increasing levels of responsibility. This can provide a real sense of satisfaction and push breast cancer even further into the background.

Whether or not you have children, time for other pursuits outside of work may become more important to you: hobbies, travel, taking classes, volunteering and spending more time with family and friends. If you expected to have children but aren't able to because of cancer treatments, consider the many ways to shape your life now.

Every situation is different. Think about what matters most to you and what kind of life you wish to have.

Cultivating New Interests

Just about everyone has a list of things they want to do “someday:” travel, learn a new language, master an instrument, paint, volunteer, train for a marathon. Cancer often has a way of turning that “someday” into now. Once you bump up against the reality that your life — along with everyone else’s — isn’t permanent, you may feel more determined to pursue interests you had put on the back burner.

Organizations like First Descents [firstdescents.org] and Casting for Recovery [castingforrecovery.org] provide free outdoor adventures to help cancer survivors connect with nature and physically challenge themselves through activities like whitewater rafting, rock climbing, surfing and fly-fishing.

Now is the time to make your list and get started, to whatever extent your life situation will allow. Shaking up routines and pursuing new goals can be a great way to seize every moment of your life after breast cancer.



Survivorship Resources

As always, you can find a wealth of information from YSC and its partners at: youngsurvival.org.

YOUNG SURVIVAL COALITION

877-972-1011

youngsurvival.org

Young Survival Coalition (YSC) is the oldest and largest national organization focused exclusively on the unique needs of young women affected by breast cancer. Headquartered in New York City, with Face 2 Face (F2F) Networks nationwide and a vibrant online community, YSC hosts the YSC Summit, the only national conference dedicated to the unique issues of young women with breast cancer. The organization also holds Regional Symposia throughout the year, and it produces free educational resources that provide useful information about every phase of treatment and survivorship.

AMERICAN CANCER SOCIETY

800-ACS-2345

cancer.org

American Cancer Society is 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

asco.org

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

SURVIVOR
RESOURCES

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CRITICAL MASS : THE YOUNG ADULT CANCER ALLIANCE

512-553-3556

criticalmass.org

The Young Adult Cancer Alliance is a unifying voice of the adolescent and young adult cancer movement focused on eliminating barriers and identifying solutions. Critical Mass provides tools and support for young adults, as well as key information regarding advocacy for research and policy change.

LIVING BEYOND BREAST CANCER

855-807-6386

lbbc.org

Living Beyond Breast Cancer is a national education and support organization with the goal to connect people with trusted breast cancer information and a community of support, regardless of educational background, social support or financial means.

LIVESTRONG

866-235-7205

livestrong.org

LIVESTRONG inspires and empowers people affected by cancer to focus on living. It provides practical information and tools for survivors to live life on their terms.

NATIONAL CANCER INSTITUTE

800-4-CANCER

cancer.gov

The National Cancer Institute conducts and supports programs regarding the cause, diagnosis, prevention, treatment, rehabilitation and continuing care of cancer patients and their families. It offers a telephone and web-based information and education network for patients and their families.

NATIONAL COALITION FOR CANCER SURVIVORSHIP

877-NCCS-YES

canceradvocacy.org

The National Coalition for Cancer Survivorship is a national nonprofit organization that advocates for quality cancer care for all Americans and aims to empower cancer survivors. This website includes patient resources on financial assistance, health insurance, employment rights, cancer advocacy and clinical trials, as well as an online resource guide.

STUPID CANCER

877-735-4673

stupidcancer.org

Stupid Cancer is a supportive community for the next generation of patients, survivors and caregivers ages 15-40, providing community resources through social media and health technology.

NOTES

NOTES

9

NUTRITION GOALS

The most important reasons why I want to maintain a healthy weight:

1. _____
2. _____
3. _____

Goals

- 1 month _____
- 3 months _____
- 6 months – 1 year _____
- Long term _____

Steps to reaching those goals:

1. _____
2. _____
3. _____

For Example:

- Increase fiber in my diet by:
 - Changing from white bread to whole wheat
 - Eating beans at least three times per week
 - Cooking quinoa or barley once per week

What could interfere with my goals, and what will I do to tackle those obstacles?

FOLD LINE

Don't think you have time for exercise?

TIP: Take a 30-minute walk during lunch or grab a pair of hand weights while you're watching TV and do some strength training.

FITNESS GOALS

Aim for an exercise program that includes:

Aerobic Activity, Strength Training and Flexibility

What can you do to make exercise more enjoyable? What activities do you like to do? _____

A few suggestions: swimming, dance class, biking, walking, yoga

Stick to a workout regimen. Make an exercise plan each week including time of day, type of exercise and duration.

What could interfere with my goals, and what will I do to tackle those obstacles? _____

** Please consult with a physician before making any significant changes to your exercise regimen*

Ways to maintain a healthy weight

- Keep track of daily fruits and vegetables for one week and make a plan to get more in your diet, if necessary.
- Eat smaller meals throughout the day.
- Eat lower and healthier fat foods (lean proteins and those high in fiber, for example).

- Increase water intake.
- Decrease refined sugars and processed sweets.
- Create a strategy for adding exercise and activity.

Your Quick Guide to Fitness Recommendations:

Get at least 150 minutes of moderate-intensity or 75 minutes of vigorous-intensity activity each week (or a combination of both), preferably spread throughout the week.

A Healthier You Worksheet

Whether you're looking to lose weight or maintain a healthy weight, the first step is setting realistic goals that fit your life. Breast cancer put your body through a lot, and these tools will help you to nourish it in a healthy, positive way.

This worksheet is meant to help you set goals for nutrition and exercise. For resources to help you implement the goals and track your progress, here are just a few suggestions:

MYPLATE APP BY LIVESTRONG

liverstrong.com/myplate

**SUPERTRACKER BY THE UNITED STATES
DEPARTMENT OF AGRICULTURE**

supertracker.usda.gov

MYFITNESSPAL

myfitnesspal.com

FOLD LINE

NUTRITION & FITNESS NOTES

A HEALTHIER
YOU
WORKSHEET

10

← OPEN HERE FOR THE WORKSHEET

Long-Term Navigator Evaluation

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 <http://bit.ly/2j7yfbv>. As a thank you, you will receive a special gift from YSC.

1. To what extent has the Long-Term Navigator and its contents helped you better understand what to expect for your long-term survivorship?

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. The Long-Term Navigator was easy to understand.

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

3. After receiving the Long-Term Navigator, I am more aware of the resources available to me.

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

4. How did you receive your copy of the Long-Term 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 Long-term Navigator?

- Less than 5 years after the end of treatment
- 5-10 years after the end of treatment
- More than 10 years after the end of treatment

6. Please check which section(s) of the Long-Term Navigator you are using or plan to use.

- Information presented:
 - Managing Your Medical Care and Physical Health
 - Overall Health and Wellness
 - Emotional Health and Relationships
 - Family Risk and Genetic Testing
 - Financial, Legal and Employment Concerns
 - Crafting Your Life after Breast Cancer
- Resources
- Worksheets

7. Which part(s) of the Long-Term Navigator did you find most useful? Check all that apply.

- Information presented:
 - Managing Your Medical Care and Physical Health
 - Overall Health and Wellness
 - Emotional Health and Relationships
 - Family Risk and Genetic Testing
 - Financial, Legal and Employment Concerns
 - Crafting Your Life after Breast Cancer
- Resources
- Worksheets

8. I would recommend the Long-Term 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 Long-Term Navigator?

CONTINUED ON REVERSE SIDE

FOLD LINE

FOLD LINE

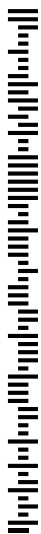
GLUE FLAP

FOLD LINE

INSIDE OF ENVELOPE

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 connection to 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? _____

How would you describe the place you live?

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

What was your breast cancer stage at initial diagnosis?

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

Do you have a family history of breast cancer?

- Yes No

Which breast cancer treatment(s) did you undergo?

- Chemotherapy
- Hormonal therapies
- Radiation
- Other: _____
- Lumpectomy
- Mastectomy
- Double Mastectomy

FOLD LINE

With which racial/ethnic group(s) do you most identify?

- White
- Black or African American
- Asian
- American Indian or Alaskan Native
- Native Hawaiian or other Pacific Islander
- Hispanic, Latino or Spanish origin
- Other: _____

What type of medical insurance do you have?

- Private insurance (employer provided)
- Private insurance (paid for by self)
- Don't know/not sure
- Other: _____
- Medicaid/Medicare
- I do not have medical insurance

What is your current employment status?

- Working full-or part-time
- Stay-at-home mom/homemaker
- Student
- Retired
- Not working/unemployed
- Unable to work
- 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



877.972.1011

youngsurvival.org

 /youngsurvivalcoalition

 @YSCBuzz

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