

Breast Cancer Resource Guide

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Introduction & Background

Breast cancer diagnosis and the steps
that may follow for HR+ patients

How this guide can help



Beating breast cancer is a marathon, not a sprint. No matter how long your battle is, this resource guide can help you along the way. Inside this booklet, you'll find general information about breast cancer, tips for health and wellness plus a collection of other helpful resources.

Steps after an HR+ diagnosis



Deciding what's right

This is your breast cancer diagnosis—so empower yourself to take an active role in your care and treatment. Ask questions that will help you better understand your diagnosis, evaluate the risks and benefits of treatment options and work with your healthcare provider to choose treatment that best fits your needs.

Choosing your treatment

For patients with early-stage hormone receptor-positive (HR+) breast cancer, following surgery and chemotherapy, your healthcare provider may prescribe anti-estrogen (hormonal) therapies, such as tamoxifen or an aromatase inhibitor. Asking the right questions about treatments will help you feel knowledgeable and well-equipped to weigh your treatment options.

Understanding your risk

Patients with early-stage HR+ breast cancer typically receive anti-estrogen therapy for 5-10 years to help lower the risk of recurrence. However, extending treatment past the initial 5 years may not be for everyone due to serious side effects and long-term safety risks. Additionally, research suggests prolonging these regimens may only help a small percentage of patients.²⁻⁷

Understanding HR+ breast cancer



What are hormones?

Think of hormones as chemical messengers that give instructions to the different cells in your body. For example T3 and T4 hormones regulate your body temperature, metabolism and heart rate, while estrogen from your ovaries controls sexual development in women. Estrogen also plays a role in cholesterol levels, bone density and brain function, impacting tissues in both men and women.

How do hormones affect cancer?

When your body releases hormones, they flow through your bloodstream until they find specific cell receptors to bind to, like keys made for a single lock. So when an estrogen binds to its receptor on a breast cancer cell, it will unlock a signal for the cell to grow and multiply. These are considered “hormone sensitive,” also known as HR+ cancer. There are two major hormones that can fuel breast cancer growth: estrogen and progesterone. Your healthcare provider will likely tell you whether you are estrogen receptor-positive (ER+ breast cancer, about 80% of all breast cancers) and/or progesterone receptor-positive (PR+ breast cancer, about 65% of all breast cancers).*

* Reference: breastcancer.org



How does anti-estrogen therapy work?

There are two main types of anti-estrogen therapy for women with HR+ breast cancer. The first works by blocking estrogen from reaching cancer cells. This class of drugs is called Selective Estrogen Receptor Modulators (SERMs). Tamoxifen is the most commonly used SERM, which binds to the estrogen receptors in place of estrogen in the breast cancer cells, and it's prescribed for both pre- and postmenopausal women.

The second type of anti-estrogen therapy centers on stopping the body from producing estrogen altogether. These medications are called Aromatase Inhibitors (e.g. Arimidex, Femara, Aromasin). They work by inhibiting the function of the enzymes that lead to the production of estrogen. Typically, postmenopausal women are prescribed these medications. While it's true that women don't produce estrogen from their ovaries after menopause, other glands such as your adrenals, liver and fatty tissue will continue producing estrogen. Aromatase Inhibitors suppress the production of estrogen in these estrogen producing organs.

Wellness & Self-Care

How to combat side effects and
nourish your body, mind and spirit

Combating Arimidex® side effects



Osteoporosis

Since estrogen plays a key role in bone remodeling, anti-estrogen therapy can weaken your bones. This leaves you more susceptible to breaks or fractures, especially in your hips, wrists and spine. Make sure that you're getting enough exercise to help strengthen your bones, and talk to your healthcare provider to make sure you're getting enough calcium and vitamin D.

Joint pain

While healthcare providers aren't entirely sure what causes joint pain during anti-estrogen therapy, it usually shows up in the first three months of treatment. Your oncology team may recommend anti-inflammatory drugs and vitamin D, and some studies suggest that gentle stretching, restorative yoga, acupuncture and a balanced diet can also help.

Learn more at [arimidex.com](https://www.arimidex.com)

Combating tamoxifen side effects



Cataracts

Like many other organs, estrogen receptors have been found to be expressed in the eyes, and estrogen deprivation can sometimes lead to cataracts. Call your physician immediately if you notice changes in eyesight, double vision or blurriness.

Blood clots

Tamoxifen increases your risk for blood clots, which often form in the legs. Reduce your risk by following your healthcare provider's advice, eating a healthy diet, cutting out smoking and staying active.

Hot flashes

Hot flashes can be caused by tamoxifen blocking your estrogen receptors. By being mindful of your alcohol, caffeine, spicy foods, stress, anxiety and cigarette smoking, you can help prevent them. Dress in layers so you can adjust your outfit accordingly, keep a portable fan with you, and if you feel the onset of a hot flash, drink ice water immediately.

Combating tamoxifen side effects



Nausea

It's suspected that fluctuating estrogen and progesterone levels can cause nausea. Try taking your tamoxifen with or without food at different points in the day to see what might work best for you. Try eating crackers or plain foods and practice rhythmic breathing to settle your stomach.

Mood swings

Tamoxifen may create sudden feelings of sadness or irritability. In addition to speaking with your healthcare provider, we recommend exercising, conscious eating, yoga, mindfulness and meditation. Of course other things can affect mood, too. Staying social, joining support groups and nurturing relationships with loved ones can also help.

Learn more at [drugs.com/tamoxifen.html](https://www.drugs.com/tamoxifen.html)

Sexual health



How anti-estrogen therapy may affect sexuality

Breast cancer survivors may find it harder to get aroused and reach orgasm, and this is a physical response of reduced or blocked estrogen in the body. While undergoing treatment, try to focus on the pleasure from kissing and touch, rather than intercourse. De-emphasizing vaginal orgasm may actually allow it to happen again sooner than expected.

Vaginal dryness can also make sex painful or itchy and can cause anxiety. There are options for breast cancer survivors dealing with this issue, and talking with your healthcare provider will allow you to find an option that is best for you. Some options include estrogen-containing soft rings, vaginal estrogen suppositories and vaginal estrogen creams.

Throughout the whole process of bringing intimacy back into your relationship, communication is key. Your femininity has changed, so be open and honest with your partner about what that means for both of you. Letting your partner know what feels good is a great way to include them in your healing process. Be patient with each other and use this as an opportunity to reconnect and try new things.

Dealing with fear of recurrence



Be patient with yourself

Remind yourself that things will get better, and with every passing day, you're that much closer to resuming your normal life. For most women, fear of recurrence decreases over time, but if you're not there yet, or if you've recently entered remission, understand that you owe yourself time to heal. Things will get better.

Identify triggers

Be aware of things that trigger worry, fear or dread about your cancer recurrence. Whether this is an anniversary of your diagnosis, anxiety before a follow-up exam or pain that can trigger emotions, whenever you feel this way, stop. Breathe. And trace your thoughts back to the exact moment these emotions were triggered. Work to understand that these triggers are not actually signs of recurrence.

Don't worry alone

Find other survivors who are coping with the fear of recurrence in a positive atmosphere. Instead of commiserating with other women trapped in fear, gather in a safe, welcoming atmosphere with women who are determined to move beyond their fears. This can be a tremendous boost to your quality of life.

Dealing with fear of recurrence



Focus on wellness

Activities like music, yoga, acupuncture and mindfulness techniques can not only bolster your health, but can help you feel more in control of your life. Focusing on your passions can also re-instill a sense of control and help to reduce anxiety and worry.

Make a plan

Take deliberate steps to be patient with yourself, identify triggers, connect with other survivors and get back to what you love. While it's perfectly justified for you to feel fear, make a commitment to move forward. If you find that fear of recurrence is still overwhelming, talk with a friend, medical professional or even a cancer psychologist for help.

Four questions after five years of treatment



What is my personal risk after five years?

While each patient's breast cancer is unique and has its own biological factors that help determine the potential for recurrence, there are tools available to help determine your personal risk of cancer coming back. If you are an HR+, early-stage breast cancer patient it's important for you to stay informed about the options available to you. Do your research and come prepared to talk to your healthcare provider about the best way to determine your risk of recurrence.

Can the cancer be prevented from coming back?

Cancer recurrence is different for every breast cancer patient. Surviving five years after diagnosis and treatment is generally the yardstick for measuring treatment success – but HR+ breast cancer is not just a five-year disease. To prevent HR+ breast cancer from returning, some patients who have completed their initial five years of treatment may be prescribed anti-estrogen therapy (typically tamoxifen or an aromatase inhibitor) for an additional five years.



Is another five years of anti-estrogen therapy likely to help me?

While extending anti-estrogen therapy may help 3-5% of women, it may not be for everyone.²⁻⁷ Women making this decision should keep in mind that this should be based on a personalized decision. Consult with your healthcare provider to discuss your options and Breast Cancer Index, a genomic test that can help assess if continuing anti-estrogen therapy will likely be beneficial for you.

What are the effects and risks of prolonged anti-estrogen therapy?

Anti-estrogen therapy (e.g., tamoxifen, aromatase inhibitors, etc.) has well known potential side effects. These can range from day-to-day tolerability issues like hot flashes, joint and muscle pain, and sexual dysfunction, to potential long-term safety concerns such as heart disease, endometrial cancer, and fractures. Some of these effects can worsen and become more pronounced with prolonged treatment.

References: 1. breastcancer.org. 2. Davies C, et al. Lancet Oncol. 2013;381: 805-816. 3. Gray R et al. J Clin Oncol 2013; 31: (suppl; abstr 5). 4. Jakesz R, et al. J Natl Cancer Inst. 2007;99: 1845-1853. 5. Goss PE, et al. J Natl Cancer Inst. 2005;97: 1262-1271. 6. Goss PE et al. N Engl J Med. 2003;349. 7. Mamounas EP et al. NSABP B-42. GS4-01. SABCs 2019. Dec 12, 2019.

Nutrition and exercise



Recommended activity and intake

Studies have shown that just a few hours of exercise per week may help breast cancer survivors live longer, and this is particularly helpful for women diagnosed with estrogen receptor positive breast cancer. The American Cancer Society recommends at least 45 minutes of moderate exercise at least five days a week. Speak to your healthcare provider and your cancer care team to develop an exercise routine that is best for your current state of health and fitness level.

Maintaining a healthy diet and cutting out vices can be very helpful in your fight against breast cancer. For starters, achieving and maintaining a healthy weight is key. Increase your intake of fruits, vegetables and whole grains while trying to decrease your fat intake to less than 30% of your daily calories. Smoking cigarettes and drinking alcohol can increase your risk of breast cancer recurrence, more specifically contralateral breast cancer. This means the risk of a new tumor forming in the opposite breast than what was initially diagnosed is higher for women who smoke and drink alcohol. Drink in moderation, if at all, and make a plan to quit smoking for good.

Cutting through brain fog



For women taking anti-estrogen therapy, changes in cognitive function have been described as brain fog, a term used to describe mental confusion, forgetfulness or lack of mental clarity. For women who experience these symptoms, it may be due to low estrogen levels, which can tamper with specific cells in your brain. Try these simple five tips to stay sharp.

Five tips

- Do brain exercises
- Get some sleep
- Exercise
- Reduce stress
- Do things you like

Being selfish about self-care

General self-care tips and ideas



Start a journal to keep track of your journey

This can often help you expand upon or release any feelings.

Make sleep a priority

There's nothing that restores you like a good night's sleep.

Try aromatherapy

Many believe this is a good way to calm the body and mind.

Spend time with loved ones

But don't feel obligated to go to more social gatherings than you're comfortable with.

Block off time for activities you enjoy

Whether it's exercising, baking, crafting or anything else, block off time for these restorative activities.

Protect your time

This means being able to say no if you're feeling overwhelmed or simply want to relax.

Staying as positive as possible

Tips for maintaining a positive mindset



Schedule a time to worry

It's natural to worry, but don't let these thoughts dominate your day. Instead, get these thoughts all out of the way with a 15 or 20 minute worry break so your mind can return to other things.

Stay in the here-and-now

By being mindful of your present feelings and observations, you may feel more at-peace and resilient. Mindfulness can be improved through simple breathing and meditation techniques.

Reach out to others in need

Whether you reach out to a fellow cancer patient or someone who just needs a hand, lending a hand or an ear to others can be incredibly rewarding and fulfilling.

Find an outlet

Identifying your passions can help you find fulfilling outlets. Whether that's art, yoga, cooking, playing music, hiking or whatever else, filling your days with activities you're passionate about will occupy your mind and create a sense of accomplishment.



Consider a mantra

Self-affirmation can be a powerful tool for staying positive. Some cancer patients have found that repeating an empowering mantra, phrase, poem or song can help negative thoughts melt away. Create your own, or try starting with a strong, simple mantra like this: “I CAN do this. I WILL do this. I will NEVER give up. I will NEVER surrender.”

The effects of positivity on you

Your attitudes and emotions can change from day to day, even from hour to hour, and this is normal. While it’s not realistic to stay positive the whole time, a more optimistic outlook might help you and your support team feel better about your cancer diagnosis and treatment.

Additional Support

More resources and tips for getting
the support you need



Your support team

Having a strong support system during your treatment can make a huge difference. The first step to assembling your supporters is to simply tell friends and family about your diagnosis and treatment, helping them to all feel informed. Many will be eager to help, but they won't always know how to. So don't be afraid to specify how you could use their help. If you could use some help with the kids or dinner, ask for help with those tasks specifically.

Joining an advocacy group

Connecting with others who are facing cancer treatment can be incredibly empowering. We've learned that sharing common experiences about coping with cancer can build strong bonds and foster close friendships. To search for supportive networks in your area or to find an advocacy group online, visit the sites below to learn more.

- [cancer.org/treatment/support-programs-and-services](https://www.cancer.org/treatment/support-programs-and-services)
- [community.breastcancer.org](https://www.community.breastcancer.org)

Web resources and blogs



- [Breastcancer.org](https://www.breastcancer.org)
- [American Cancer Society \(cancer.org\)](https://www.cancer.org)
- [National Cancer Institute \(cancer.gov\)](https://www.cancer.gov)
- [Living Beyond Breast Cancer \(LBBC.org\)](https://www.lbbcc.org)
- [Young Survival Coalition \(youngsurvival.org\)](https://www.youngsurvival.org)
- [Breast Cancer Action \(bcaction.org\)](https://www.bcaction.org)
- [National Breast Cancer Coalition \(stopbreastcancer.org\)](https://www.stopbreastcancer.org)
- [TigerLily \(tigerlilyfoundation.org\)](https://www.tigerlilyfoundation.org)
- [Alamo Breast Cancer Foundation \(alamobreastcancer.org\)](https://www.alamobreastcancer.org)

Glossary of terms



Adjuvant Therapy: Treatment used in addition to the main treatment. The term usually refers to hormone therapy, chemotherapy or radiation therapy added after surgery to increase the chances of curing the disease or keeping the cancer from coming back.

Anti-Estrogen Therapy (also referred to as “Hormone Therapy” or “Endocrine Therapy”):

Hormone receptor positive (HR+) breast cancer grows in response to estrogen and/or progesterone. Anti-estrogen therapy is used to prevent these hormones from fueling cancer growth in the body by either blocking the action of estrogen on cancer cells in the breast or stopping the body from producing estrogen altogether. There are two main types of anti-estrogen therapy:

- **Tamoxifen:** Blocks the action of estrogen on cancer cells in the breast. Tamoxifen is commonly used for pre-menopausal women

- **Aromatase Inhibitors:** Focus on stopping the body from producing estrogen altogether. Examples of this type of treatment include anastrozole (Arimidex), letrozole (Femara) and exemestane (Aromasin). Aromatase inhibitors are commonly used in treating post-menopausal women.

Glossary of terms



Disease-Free: Your breast cancer has not returned.

Ductal Breast Cancer: Ductal means that the cancer began in the milk ducts, which are the “pipes” that carry milk from the milk-producing lobules to the nipple. “Invasive ductal carcinoma” refers to cancer that has broken through the wall of the milk duct and begun to invade the tissues of the breast whereas “Ductal carcinoma in situ” or “DCIS” is “non-invasive” because it hasn’t spread beyond the milk duct into any normal surrounding breast tissue. Invasive ductal carcinoma is the most common type of breast cancer.

Early/Late Recurrence: Early recurrence in breast cancer refers to a recurrence that happens within the first 5 years following your diagnosis, while late recurrence refers to a recurrence that happens more than 5 years after your diagnosis.

Early-Stage: Breast cancer that has not spread beyond the breast or axillary lymph nodes. This includes stage I, IIA, IIB, and IIIA breast cancers.

Glossary of terms



Hormone Receptor-Positive (HR+): Having hormone receptor-positive breast cancer means your breast cancer is fueled by estrogen and/or progesterone. Hormone receptor positive refers to either estrogen receptor positive (ER+), progesterone receptor-positive (PR+), or both (ER+/PR+).

Invasive Breast Cancer: Invasive breast cancer means the cancer has “invaded” or spread to the surrounding breast tissues. Most breast cancers are invasive. Note that non-invasive cancers stay within the milk ducts or lobules in the breast. They do not grow into or invade normal tissues within or beyond the breast. Non-invasive cancers are sometimes called carcinoma in situ (“in the same place”) or pre-cancers.

Lobular Breast Cancer: Lobular means that the cancer began in the milk-producing lobules, which empty out into the ducts that carry milk to the nipple. “Invasive lobular carcinoma” refers to cancer that has broken through the wall of the lobule and begun to invade the tissues of the breast.

Glossary of terms



Lymph Node Status (or Nodal Status): Lymph node status indicates whether or not the lymph nodes in the underarm area (axillary lymph nodes) contained cancer. Lymph node-negative means the axillary lymph nodes did not contain cancer, while Lymph node-positive means the axillary lymph nodes did contain cancer (or were “positive” for cancer). Part of your lymph node status also includes how many of the lymph nodes were positive (for lymph node-negative 0 nodes contained cancer, whereas for lymph node-positive there may be 1, 2, 3, or more lymph nodes that tested positive for containing cancer).

Metastatic (or “Metastasize”): When the cancer has spread from where it began to other structures or organs in the body.

Neoadjuvant Therapy: Therapy taken before surgery to help shrink the tumor.

Glossary of terms



Recurrence (local, regional, distant): When cancer comes back or returns it is called a recurrence. Local recurrence means the cancer has come back in the same place as the original cancer. Regional recurrence means the cancer has come back in the lymph nodes near the original cancer site. Distant recurrence is when the cancer metastasizes to distant organs or tissues (such as the lungs, liver, bone marrow or brain).

Tumor Size: Tumor size is categorized into different groups defined by the size of your tumor: Tis (carcinoma in situ), T1 (2 cm or smaller), T2 (larger than 2 cm, but no larger than 5 cm), T3 (larger than 5 cm), T4 (any size, but has spread beyond the breast tissue to the chest wall and/or skin).

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References: 1. breastcancer.org. 2. Davies C, et al. Lancet Oncol. 2013;381: 805-816. 3. Gray R et al. J Clin Oncol 2013; 31: (suppl; abstr 5). 4. Jakesz R, et al. J Natl Cancer Inst. 2007;99: 1845-1853. 5. Goss PE, et al. J Natl Cancer Inst. 2005;97: 1262-1271. 6. Goss PE et al. N Engl J Med. 2003;349. 7. Mamounas EP et al. NSABP B-42. GS4-01. SABCS 2019. Dec 12, 2019.