GUIDE TO UNDERSTANDING

Hormonal Therapy

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Thank you for helping Living Beyond Breast Cancer improve our programs and services.

Everyone's journey is different.

If you have stage IV (metastatic) breast cancer, visit LBBC.ORG for resources created just for you.

Dear Friend:

At Living Beyond Breast Cancer, we know you face many choices when it's time to begin treatment for hormone receptor-positive breast cancer. You may wonder which treatments make sense for you, or how to combat side effects. And since hormonal therapy lasts for many years, your concerns may change over time.

This guide aims to address the questions you have today, as well as those that may arise tomorrow. In these pages, you will learn about the role of hormones in your health, the ways they encourage the growth of some breast cancers, and the methods used to treat hormone-driven disease. We give equal time to managing side effects — like menopausal symptoms, sexual impacts and fatigue — that many women tell us affect their daily lives.

No matter where you are in your treatment experience, please know we are here for you with connection, information and support. Our goal is to help you get the most from treatment while enjoying the best possible day-to-day life.

Warmly,

Jean A. Sachs, MSS, MLSP
Chief Executive Officer

LIVING BEYOND BREAST CANCER®

Toll-Free Breast Cancer Helpline
(888) 753-LBBC (5222)
lbbc.org/helpline

All people pictured in this guide are LBBC volunteers whose lives have been affected by breast cancer. We thank them for sharing their experiences.

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Hormonal Therapy Basics

When your doctor recommends hormonal therapy as part of breast cancer treatment, you might wonder why. Perhaps you've heard that hormones contribute to breast cancer. Or maybe you thought hormone-based medicines are used only to treat symptoms of menopause.

Hormonal therapy for breast cancer is not the same as estrogen or hormone replacement therapy, also called ERT or HRT, used in menopause. ERT or HRT replaces or puts back hormones. It is not advised for women diagnosed with breast cancer.

This guide is about **hormonal therapy for breast cancer**, treatment that reduces estrogen in the body. Hormonal therapy for breast cancer is also sometimes called endocrine or anti-estrogen therapy. It can reduce the risk of **recurrence** (the disease coming back after treatment), prevent new breast cancers and improve survival.

Hormonal therapy is given only when breast cancers depend on estrogen or progesterone to grow. This is shown by the presence of receptors for these hormones and is called **hormone receptor-positive breast cancer**. You are likely to receive hormonal therapy as **adjuvant therapy**, treatment given after primary therapy with surgery, chemotherapy or radiation.

Role of Hormones in the Body

Our bodies naturally make hormones such as **estrogen**, **progesterone** and androgen (testosterone). These hormones prompt cell action in our system in different ways. Estrogen is the best known hormone in women, but the body makes all three. They are all important for good health.

Estrogen helps sex organs develop, makes pregnancy possible, strengthens bones and more. In women who have periods or menstruate, called **premenopausal women**, the ovaries make most of the body's estrogen. Hormone levels are usually high. With age, the ovaries slow down, making less estrogen. This "in-between" time, called **perimenopause**, happens several years before menopause. **Postmenopause** is when you have no periods for 12 months in a row.

After menopause, the ovaries no longer make estradiol, the most active estrogen. But your body still makes estrone, an estrogen created by converting the male sex hormone androstenedione from the adrenal glands, fat cells and elsewhere. An enzyme known as **aromatase** converts that hormone to estrogen. This is why anti-estrogen hormonal therapy with aromatase inhibitors (see page 18) helps postmenopausal women.

> When my doctor told me about hormonal therapy, I hadn't a clue. I thought he was saying I should be taking something so menopause wouldn't be so bad."
>
> —PHYLLIS

How Estrogen Makes Some Cancers Grow

Estrogen sends signals that control cell pathways. **Hormone receptors** on the surface of breast cancer cells work like satellite dishes. They detect and bring in hormone signals. These signals can direct cells to grow, multiply and repair damage.

All cells in the breast have receptors so they can respond to hormonal changes. Breast cancer cells have receptors, too. When breast cancer cells have estrogen receptors, the breast cancer is called **estrogen receptor-positive**, or ER+, and estrogen helps the cancer to grow. When progesterone receptors are found, the cancer is called **progesterone receptor-positive**, or PR+, and progesterone helps the cancer to grow.

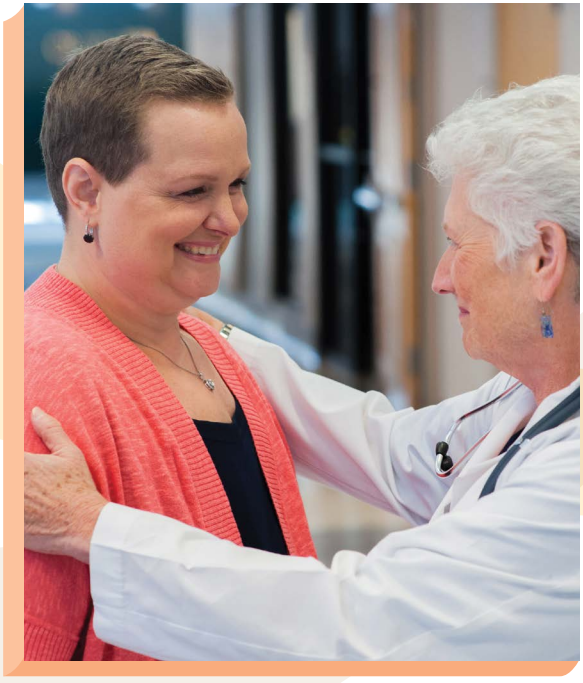
About two-thirds of breast cancers are **hormone receptor-positive**, also known as **hormone-sensitive**. They may be both ER+ and PR+, or ER+ only, or PR+ only. Even if the cancer has only one type of receptor, or tests just slightly positive, studies show hormonal therapy can protect you from having cancer return.

What Hormonal Therapy Does

Hormonal therapy for breast cancer blocks estrogen. It interferes with the signals that hormone receptors send to cells. Depending on the type, hormonal therapy may block estrogen receptors, reduce the amount of estrogen made, or lessen the number of hormone receptors.

Even though they work in different ways, hormonal therapies have been shown in long-term research to be effective against hormone receptor-positive disease. No matter what other treatments you receive, hormonal therapy can lower the chances the breast cancer will come back.

> I feel like I'm doing something every day to keep the cancer away. I'm doing something to give myself a better chance. That feels good."
>
> —KATHI



Your Hormonal Therapy Options

You and your doctors will discuss what factors go into a decision to recommend hormonal therapy and which type of hormonal therapy is best for you.

To decide if you need hormonal therapy, your doctor will look at:

- **The cancer's estrogen receptor (ER) and progesterone receptor (PR) status**: It must be positive for one or both receptors
- **Other treatments you had or plan to have**: Chemotherapy, targeted therapy, radiation
- **Risk profile of the cancer**: How likely it is to come back

To decide what type of hormonal therapy you need, your doctor will look at:

- **Your menopausal status**: Whether you are premenopausal, perimenopausal or postmenopausal
- **Your general health**: Special concerns or chronic conditions, such as high blood pressure or osteoporosis; other medicines you take; if you smoke
- **Lifestyle concerns**: Possible side effects, such as menopausal symptoms

Remember, each woman's situation is different. Your options and your response to treatment may vary from another woman's experience. Take time to consider possible side effects. Talking with your doctor will help you better understand what hormonal therapy means for you.

The Importance of Menopausal Status

You may be premenopausal (still having periods, or menstruating), postmenopausal (after periods stop permanently) or perimenopausal (between the two). Some hormonal therapy is recommended for all women, and some is specific to your menopausal status.

NOTE

Even if your periods stopped during treatment, you still may be premenopausal and making estrogen in your ovaries. Talk with your doctor about your situation.

FOR ALL WOMEN

Tamoxifen is a therapy that blocks estrogen from reaching estrogen receptors. It is in a group of medicines known as **selective estrogen receptor modulators (SERMs)**. It is taken daily as a pill or in liquid form as tamoxifen citrate (Soltamox). Because your body produces estrogen every day, it's important to take tamoxifen every day.

Tamoxifen is standard treatment for premenopausal and perimenopausal women. In postmenopausal women, tamoxifen may be used alone, or before or after an aromatase inhibitor (see page 18).

No matter what your menopausal status, tamoxifen after other treatment reduces the risk of cancer coming back. The benefit happens during the recommended 5 to 10 years of treatment and continues in the years afterward.

TESTING BEFORE TREATMENT

The Oncotype DX test can help you and your doctor decide whether chemotherapy should be part of your treatment in addition to tamoxifen or other hormonal therapy.

By looking at gene patterns, Oncotype DX predicts whether the cancer is likely to return in the next 10 years and if chemotherapy would further reduce your risk for recurrence.

The Oncotype DX test is used in early-stage, hormone receptor-positive disease that has not traveled to the lymph nodes and in stage 0 ductal carcinoma in situ (DCIS).

LEARN MORE

Learn more about this test in our *Guide to Understanding Treatment Decisions, Guide for the Newly Diagnosed* or at LBBC.ORG.

POTENTIAL BENEFITS AND RISKS OF TAMOXIFEN

Tamoxifen's main job is to reduce the risk of cancer returning, but it also can lower cholesterol and lessen menopause-related bone loss if you are postmenopausal. (If you are premenopausal, tamoxifen can cause bone loss.)

> "I can't tell if it's the side effects of the tamoxifen or if I'm getting them because I'm perimenopausal, but I get night sweats, hot flashes and the whole nine yards."
>
> —BONNIE

Some antidepressants can affect the way your body breaks down tamoxifen. Research shows that fluoxetine (Prozac), paroxetine (Paxil), sertraline (Zoloft), duloxetine (Cymbalta) and bupropion (Wellbutrin) may affect how tamoxifen works in your body. It's also possible that common arthritis medicines (Celebrex), antacids (Tagamet, Zantac) and antihistamines (Atarax, Benadryl) could interact poorly with tamoxifen. To keep tamoxifen working as well as possible, tell your doctor about all medicines and supplements you take.

Like all medicines, tamoxifen has side effects (see page 34). The issues may be few or none, cause some problems, or truly disrupt your life. Common side effects include hot flashes, fatigue, pain, vaginal dryness or discharge, mood swings, nausea, hair thinning, dry skin, loss of interest in sex, bone thinning (in premenopausal women) and weight gain. Because tamoxifen can harm a fetus, use safe birth control while taking it if you are premenopausal or still have a period every now and then. Discuss this important issue and any side effects you feel with your healthcare team so they can help you.

"A lot of women talk to me about being afraid to take tamoxifen because of the side effects. I always tell them to try it, because I don't have any noticeable side effects. Even though you hear horror stories, it might not be that bad for you."

—JENNIFER

Serious side effects are rare, but tamoxifen may cause blood clots that could lead to stroke, heart attack or lung blockage. It also increases the risk of uterine (endometrial) cancer. Talk with your doctor if you had a heart attack or blood clots before. Call your doctor immediately if you have chest pain, abnormal vaginal bleeding, dizziness, leg swelling, severe headache or other symptoms.

FOR PREMENOPAUSAL WOMEN ONLY

If you still get your period, you may be concerned about fertility and long-term side effects. You may want to give birth after treatment ends.

First, know that research shows pregnancy after treatment does not appear to increase your risk for recurrence. Before starting any therapy, ask your doctor how treatment might affect your future ability to become pregnant. If you're near the age of menopause, discuss whether you can take breaks from hormonal therapy to become pregnant before your fertility ends. Ask about your birth control needs if you stopped getting your period during or shortly after treatment.

Removing your ovaries by surgery (see page 16) is one way to reduce estrogen but is also permanent. You will not be able to become pregnant afterward. A family history of cancer may play an important role in your decision. If you want to learn more, ask your doctor to refer you to a genetic counselor.

The section of this guide that covers side effects (see page 34) can help you think about the possible long-term physical, emotional and sexual changes that hormonal therapy may cause.

Getting treatment through clinical trials can help us discover more about hormonal therapy in premenopausal women. For more information, visit LBBC.ORG.

HORMONAL THERAPIES FOR PREMENOPAUSAL WOMEN

Tamoxifen (see page 12) is the standard hormonal therapy for premenopausal women. Ovarian suppression and ablation (see page 16) also reduce estrogen's levels and effects. Your treatment plan may include one or more of these hormonal therapies, as well as chemotherapy or targeted therapy to reduce the risk of cancer returning.

Tamoxifen interferes with menstrual function, but it does not put you into menopause. Some side effects of tamoxifen are similar to menopausal symptoms. While you take tamoxifen, you will continue to ovulate. You may not have a monthly menstrual cycle, or your periods may be irregular, but your ovaries will still be working. If you take tamoxifen for 5 to 10 years, your age and other factors could put you into menopause

naturally. If you go into permanent menopause, your doctor may switch your hormonal therapy treatment from tamoxifen to an aromatase inhibitor (see page 18). If your doctor isn't sure whether menopause is permanent, he or she may recommend an aromatase inhibitor with a medicine to suppress your ovaries.

It's possible to become pregnant while taking tamoxifen. Since tamoxifen can harm a fetus, use birth control that does not contain estrogen. Once you finish tamoxifen, wait at least 2 months for it to leave your system before trying to become pregnant. Talk to your doctor about how long you should wait.

Estrogen's effects also may be reduced by using medicines to shut down the ovaries for a time, called **ovarian suppression**, or by removing the ovaries permanently through surgery (**ovarian ablation**). Some doctors use these two terms to mean the same thing. Using medicines to shut down the ovaries puts you into a state called **medical menopause**.

Ovarian suppression can be used to protect your ovaries during chemotherapy with medicines known as **LHRH (luteinizing hormone-releasing hormone) agonists**. These include goserelin (Zoladex), leuprolide (Lupron) and triptorelin (Trelstar). They are given by injection, usually once a month or at longer intervals. This approach remains under study, and it has not yet been proved to preserve fertility.

Research suggests that young women who are still premenopausal after taking chemotherapy benefit when they are then treated with ovarian suppression or ablation followed by 5 years of the aromatase inhibitor exemestane (see page 18).

Surgery to remove the ovaries, known as **oophorectomy**, ends fertility permanently and produces **surgical menopause**. After oophorectomy, you will no longer be able to become pregnant.

Ovarian suppression and ablation can produce symptoms of menopause. These may include hot flashes, night sweats, vaginal dryness, mood swings and more. If you have surgery to remove your ovaries, those symptoms can hit you immediately. (Read more about side effects on page 34.)

"I never had a discussion with the doctor about my options. It was just, 'You have to take tamoxifen.' We never discussed surgical options because my doctor knew I wanted to have children."

—JENNIFER

FOR POSTMENOPAUSAL WOMEN ONLY

After menopause, the ovaries no longer produce estradiol, the primary estrogen in the premenopausal woman. Yet your body still makes estrone, an estrogen created by converting a male sex hormone found in the adrenal glands, fat cells and muscle. An enzyme known as aromatase converts that hormone to estrogen.

Aromatase inhibitors (AIs), medicines that interfere with the enzyme aromatase, reduce the risk of cancer returning. The AIs are letrozole (Femara), anastrozole (Arimidex) and exemestane (Aromasin). They are given as a daily pill.

It is important to take aromatase inhibitors every day, because the body makes aromatase every day.

> My doctor said each aromatase inhibitor has a slightly different side effect profile and that we would just go through each one until we found one that works."
>
> —AMANDA

AIs are given as adjuvant treatment, after primary therapy with surgery, chemotherapy or radiation:

- If prescribed as the first, or primary, hormonal therapy, doctors recommend AIs be taken for 5 years or, for people with higher risk cancers, up to 10 years.
- AIs may also be given for 5 years after
  - 2 to 3 years of tamoxifen, for a total of 7 to 8 years of hormonal therapy, or
  - 5 years of tamoxifen, for a total of 10 years of hormonal therapy

It is not yet known when the best time is to switch from one medicine to the other. Most doctors see the different AIs as being very similar, so ask your providers why they recommend a particular one for you.

AI medicines have side effects that are the same or different from each other, such as bone and joint pain, fatigue, hot flashes, dizziness and more (see page 34). If you have troubling side effects, your doctor might suggest switching medicines.

AIs cause bone loss. For that reason, it's important to do regular aerobic and resistance exercise and take vitamin D and calcium supplements, as recommended by your doctor. If you have osteoporosis or low bone mineral density with other risk factors for bone loss, discuss this with your doctor before taking an AI.

FOR "IN-BETWEEN" OR PERIMENOPAUSAL WOMEN ONLY

Doctors consider you postmenopausal if you do not have your period for at least a year. But what if you get your period every now and then, or it only stopped because of chemotherapy? Tests of hormone levels may help, but they are not used routinely because levels can go up and down dramatically, especially during perimenopause.

If there is any doubt about your menopausal status, your doctor is likely to recommend tamoxifen. Tamoxifen is effective at all menopausal stages. Your doctor might suggest other methods as well. Ask why these options might be right for you.

10 QUESTIONS TO ASK WHEN YOUR DOCTOR RECOMMENDS HORMONAL THERAPY

1. Why do you recommend this treatment for me?
2. Should I get treatment through a clinical trial?
3. What are the potential risks and benefits of this treatment?
4. How long will I be on hormonal therapy?
5. By adding hormonal therapy to my treatment, how much more will it lower the risk of the cancer coming back?
6. Will this interfere with medicines or supplements I take for other reasons?
7. What are the possible side effects (see page 34)?
8. Will my ability to become pregnant, to work at my job or to keep up with my normal activities be affected by this therapy?
9. Will my insurance pay for this treatment? How can I find help with my financial concerns?
10. Where can I go for help with questions or problems? Can I call you? Who else can I call?

Common Questions About Treatment Decisions

You may wonder how hormonal therapy will fit into your treatment plan and life. Many women want to know these basics.

When Does Hormonal Therapy Start?

Hormonal therapy may follow surgery, chemotherapy or radiation. It also might be given while you receive another treatment, such as radiation or trastuzumab. Some women receive hormonal therapy before surgery to shrink the cancer before it is removed.

If you haven't discussed hormonal therapy earlier, you might not feel like doing so right after initial treatment. You've been through so much already. But it's helpful to talk about and understand your choices. Use the questions in this guide to help you find out what you want to know.

How Long Will I Take Hormonal Therapy?

In the past, 5 years of hormonal therapy was the standard treatment recommendation. But recent studies have found that up to 10 years of hormonal therapy can lower your risk of recurrence even more.

Staying on your hormonal therapy for these amounts of time, and taking the recommended dose, is important. Research shows these time lengths are effective in reducing the risk of cancer returning. If you have difficult side effects or want to stop hormonal therapy for any reason, talk with your doctor or nurse. They may be able to help you manage the side effects or explore other options, such as taking treatment breaks.

As research develops, the length of hormonal therapy treatment could continue to change. If you're interested in taking part in research, ask your doctor about clinical trials that are looking at this topic.

Which Hormonal Therapies Should I Use?

Be sure you understand what your doctor's recommendation means for you. Use the questions on page 21 to help you talk with your team. You also may want to think about:

- **Timing**: Hormonal therapy is a commitment. It means taking medicine every day for 5 to 10 years. Doing so keeps an even level of hormonal therapy in your body and makes treatment most effective.
- **Risk reduction**: Hormonal therapy reduces the risk the cancer will return. Yet you might be willing to exchange a higher risk for not taking a specific medicine or not having your ovaries removed. Ask your doctor how much you can reduce your risk with each suggested treatment.
- **Side effects** (see page 34): Learn what these may be for the hormonal therapy you will take. Your family history, past medical history or other personal concerns might affect your choice.
- **Cost**: Many hormonal therapies are available in low-cost, generic form. Talk early with your healthcare team for advice about programs to help you pay for your medicine. Find more help at LBBC.ORG.

"I did my research before my doctor's appointment and brought it to the doctor."

—DEBORRAH

10 WAYS WOMEN FIND ANSWERS TO THEIR HORMONAL THERAPY QUESTIONS

1. Look on the websites of hospitals and nonprofit organizations. Stick to trusted sources from your providers or other women.

2. Don't be afraid to ask your doctor questions. When you're in a calm mood, write a list. Read it to a friend or family member beforehand. Prioritize your questions, and use your whole team to find answers. Bring a trusted person to the doctor's visit with you. That person can listen to what's discussed and help you talk through your decisions.

3. Get a second opinion. If you're still not sure, consider a third opinion.

4. Find books and articles online or in print. Look at the publication date to see if the information is up-to-date.

5. Ask other women about their experiences. Then talk with your doctor about anything you hear.

6. Look within your faith or spiritual community for others who might offer advice.

7. Join a support group.

8. Network with people wherever you can. Discuss the information with your team.

9. Ask to speak with a patient navigator (often a nurse) or an oncology social worker to answer your questions and help you manage the details of treatment.

10. Remember to ask the same questions of more than one source. Sometimes you need to hear information in several different ways before it makes sense.

CALL LIVING BEYOND BREAST CANCER

Contact our **Breast Cancer Helpline** toll-free at **(888) 753-LBBC (5222)** to learn how our volunteers made decisions about hormonal therapies and what questions they asked their doctors.

SECTION 4

Making Hormonal Therapy Part of Your Routine

Which of these statements about hormonal therapy do you think is true?

1. Hormonal therapy significantly reduces the risk of breast cancer returning and improves survival in hormone-positive disease.

2. Many women don't take hormonal therapy as prescribed or stop taking it long before reaching the end of treatment.

As you might have guessed, both statements are true. Only about half of women prescribed hormonal therapy take the correct dose for the full recommended time. Many women skip doses or take less than the prescribed daily amount. Others stop taking the medicine without switching to another hormonal therapy. Some don't even fill their first prescription.

There are many reasons you might find it hard to stick with, or what your doctor might call "comply with" or "adhere to," hormonal therapy. If you're having trouble, know that you aren't alone! There are solutions.

> My hormonal therapy is as important to me as the surgery I had or the chemo I had. I certainly wouldn't blow off a chemotherapy appointment or skip a surgery."
>
> —KATHI

Why It's Important to Take Hormonal Therapy as Prescribed

Hormonal therapy can be as powerful in your treatment as chemotherapy, surgery or other targeted therapy.

You deserve to get the most from your hormonal therapy. That can happen only when you take the recommended amount of medicine every day, for as long as prescribed. Doing so is an important act of self-care.

When you take hormonal therapy as recommended, you keep the level of medicine in your body steady so it can be as effective as possible. If you skip days or take smaller doses, your hormonal therapy might not work as well. A steady level of medicine may also reduce side effects.

Common Reasons for Not Taking Hormonal Therapy as Recommended

More than any other factor, women cut back on — or quit — hormonal therapy because of side effects. Side effects are real! Talk with your doctor and health-care team about ways to prevent or minimize problems. Find advice from other women, as well as tips on dealing with side effects, beginning on page 34.

To save money, some women stretch their medicine by skipping days or cutting pills in half. Doing either could make hormonal therapy less effective. Here are ways to save money on prescriptions and find help paying for treatment:

- Ask your doctor about patient assistance programs. These programs — offered by your treatment center or the pharmaceutical company that makes the medicine you need — may help pay for treatment.
- Tell your doctor that you prefer generic medicines. Generics usually cost less than brand-name medicines. All three aromatase inhibitors and tamoxifen are available as generics.
- If your medicine is available by mail-order, you might be able to get several months' supply for one copay.
- Before you begin hormonal therapy, tell your providers if paying for medicine or copays is a problem. Patient assistance plans are available. Learn more at LBBC.ORG.

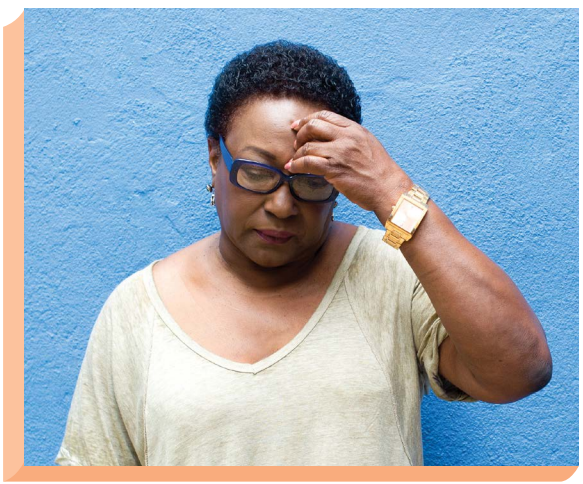
Taking a pill every day for 5 or 10 years can feel like an intrusion or burden. Even though hormonal therapy is "just a pill," it is doing a very large job — keeping the cancer from returning. To keep treatment from feeling like a burden, address side effects (see page 34) that interfere with your physical activities, work, social life or sexual enjoyment.

You might sometimes miss a pill because you forget or because daily life takes your mind off breast cancer. Missing one dose won't hurt effectiveness. If you miss more often, try our tips for remembering (see next page).

Sometimes taking a daily pill reminds you of the trauma of breast cancer. It may also stir fears of recurrence or potential side effects. Connecting with other women who have had breast cancer, or talking with a social worker or counselor, can help you with your worries. The act of taking the medicine might also help you feel in control. See page 52 for more about the emotional impact of hormonal therapy.

If You Have Trouble Taking Your Medicine

You are not alone if you find it difficult to take your medicine. Other women have had similar experiences. Try to set aside any worries and talk with your health-care team. They can find ways to help you. This empowers you in your care and helps ensure you and your providers agree on the most effective plan for you.



5 TRICKS TO HELP YOU REMEMBER TO TAKE YOUR MEDICINE

1. Put your pills in a place where you will see them every day. When you link the pills to a certain daily activity, you'll remember better. You might place them by your toothbrush or near your coffee pot.
2. Use a weekly pill organizer. Fill it once a week. Carry it with you if you travel overnight.
3. Mark an "X" on your calendar every day, right after you take your medicine.
4. Set an alarm on a clock or cell phone to remind you, or schedule it on your computer.
5. Take it at the same meal every day. When you won't be home for that meal, tuck the pill into a tissue or a little box and bring it with you.

Coping With Side Effects

We don't know why some people experience difficult side effects from hormonal therapy when others, taking the same medicine, have mild or no problems. Remember, just because someone else had side effects on the therapy your doctor prescribes for you doesn't mean you will have the same troubles.

Your healthcare team can help you manage your side effects. Always talk with your doctor about what you're feeling. If side effects become too difficult or interfere with your ability to function, your doctor might suggest another medicine for you.

You may hear that having certain side effects shows the treatment is working. That doesn't mean you must have problems to have a good result. Even if you have no side effects, the treatment could be working well.

> "When you're weighing how much benefit you're going to get versus how much risk, you have to realize that hormonal therapy might not impact your quality of life at all. You won't know until you try it. If it's awful, tell your doctor so you can try something else."
>
> —KATHI

Prepare yourself for side effects by learning about them. Knowing what you might encounter helps you note symptoms quickly, so you can promptly tell your healthcare team. Please don't suffer in silence!

By getting help, you'll be better able to stay on hormonal therapy and gain the full advantage of treatment.

More Common Side Effects

After each side effect, you will see in parentheses the treatments associated with them [*ai* (aromatase inhibitor); *t* (tamoxifen); *mm* (medical menopause); *sm* (surgical menopause)].

"I started taking an aromatase inhibitor and I felt pain in my bones. My doctor told me it would go away within a few weeks or a month; otherwise, we would have to talk about it. It came and then it went, for which I was eternally grateful."

—PHYLLIS

BONE AND JOINT ACHES/PAIN (*ai, t, mm*)

As many as half of women who take aromatase inhibitors feel aches or pains in their joints, bones and muscles, as well as general stiffness. Some women say these medicines worsen arthritis. LHRH agonists may cause similar side effects.

Acupuncture has been shown to be effective for joint pain related to AIs. Yoga and regular exercise may help. Talk with your doctor about over-the-counter pain relievers. If pain is severe and ongoing, your doctor might change you to another medicine.

LEARN MORE

For more information about acupuncture, yoga and other practices that can ease side effects of breast cancer treatment, read our *Guide to Understanding Complementary Therapies*.

BEEN-THERE ADVICE:

Hang in there. The pain may subside after a month or so. Walk and stretch as much as you can to combat stiffness. Some women use vitamins or glucosamine and chondroitin for joint pain.

"I had bone aches, mostly at the joints. Every joint that could possibly be a joint, even my head, hurt. I can press my joints and I can still feel it in my elbows. It gets so you ignore it. I didn't know it was a side effect because nobody told me."

—MARGARET

BONE THINNING (OSTEOPENIA AND OSTEOPOROSIS) (*ai, sm, mm*)

Aromatase inhibitors speed up loss of bone mineral density, resulting in thinner bones and a higher risk for fractures, or bone breaks. A bone density DEXA scan before treatment will show your baseline bone strength, so your providers can monitor your bones during treatment.

Your doctor will advise you to take calcium and vitamin D and exercise daily to protect your bones. If you have osteoporosis or osteopenia with other risk factors for fracture, your doctor may discuss using a **bisphosphonate** medicine.

LEARN MORE

Learn more in our *Guide to Understanding Bone Health* and at LBBC.ORG.

BEEN-THERE ADVICE:

Walk, practice yoga or do other consistent physical activity.

HOT FLASHES AND NIGHT SWEATS

(t, ai, sm, mm)

Hot flashes heat your body for a few seconds to several minutes. The blood vessels near the skin widen to cool you off, so you start sweating. That wetness may leave you feeling chilled.

"The hot flashes would just come and go, all day every day, all night every night, for 5 years. I had not had this kind of experience with menopause. It took me by surprise."

—GLORIA

When surgery brings on menopause, hot flashes may begin abruptly. Hot flashes caused by hormonal medicines may take about a month to begin. In either case, the hot flashes can be more severe than in natural menopause, when symptoms evolve over time.

Surgical or chemotherapy-induced menopause increases the chances of hot flashes, as does menopause at a young age. Some women feel anxious or their hearts beat fast during hot flashes. Let your doctor know.

Many women find exercise, acupuncture or meditation helpful. Deep breathing when you feel a hot flash starting may reduce intensity. Certain foods and drinks may trigger hot flashes, such as spicy food, chocolate or hot drinks, so avoid ones that affect you. Hypnosis appears to lessen the number and intensity of hot flashes — and may also help anxiety, depression and sleep problems.

"I walked with a friend 2 days a week. I would focus more on positive things than on any of the negatives. I'm not sure if I ever had a hot flash when we were walking together."

—DEBORRAH

Your doctor may suggest medicine, such as venlafaxine (Effexor), especially if hot flashes interrupt your sleep or make it hard to function in the daytime. Talk with your doctor before trying any herbal remedies, because they can interact with your treatment.

BEEN-THERE ADVICE:

Carry a small portable fan. Dress in layers so you can take off a jacket if you get hot. Drink lots of water. Learn ways to relax when you face stressful situations. Ask your doctor about taking vitamin E if your hot flashes are mild.

INSOMNIA AND FATIGUE *(t, ai, sm, mm)*

The hot flash/night sweats cycle can seriously disrupt sleep, causing fatigue. Other side effects, such as joint and muscle aches, also cause insomnia and tiredness.

If hot flashes wake you during the night, try the suggestions on page 39, and below. Avoid caffeine (including hot chocolate) before bedtime. Relax quietly, without the TV or a computer. Medicines for insomnia may help, so talk with your doctor.

LEARN MORE

Visit LBBC.ORG or read our *Guide to Understanding Insomnia and Fatigue* for more information.

BEEN-THERE ADVICE:

Keep your bedroom cool. Change night-sweat soaked clothes, even if you have to get up several times.

"If there's anything that took me by surprise, it was the lack of libido. It's like that part of my brain is turned off. It's something that women really need to be willing to talk about with their doctors and other women."

—KATHI

SEXUAL HEALTH CONCERNS *(t, ai, sm, mm)*

Although it may be hard to talk about, many women on hormonal therapy feel changes in sexual desire, comfort and vaginal health. With both surgery and medicines that reduce estrogen levels, you may have vaginal dryness, irritation, discharge and urinary tract infections.

Decreased estrogen causes the vagina to shorten and narrow, and the walls become thinner and less elastic.

The vulva and clitoris also change. The vaginal area may itch, burn, bleed or feel painful during sex. As a result, you might not want to have sexual intercourse or activity. Further loss of interest happens as the level of a hormone affecting sex drive — testosterone — also drops.

"After about a year or so of hormonal therapy, I went to an LBBC workshop on sex and intimacy. The session was packed and I thought, 'I am not alone, it's not just me!' My husband is eternally grateful that I went to that session."

—PHYLLIS

There are many ways to help. Whether you're having sex or not, consider using a vaginal moisturizer, such as Replens. For sexual activity, you may need to also consider the use of non-estrogen lubricants such as Astroglide or K-Y. Choose ones with the fewest ingredients to avoid irritation, and don't use warming lubricants because they can be drying. Talk with your healthcare team about other options, including a vaginal dilator to relieve tightness, and vaginal estrogens, which deliver low levels of hormone through an inserted tablet, cream or vaginal ring. Some doctors won't recommend vaginal estrogens after estrogen-positive breast cancer.

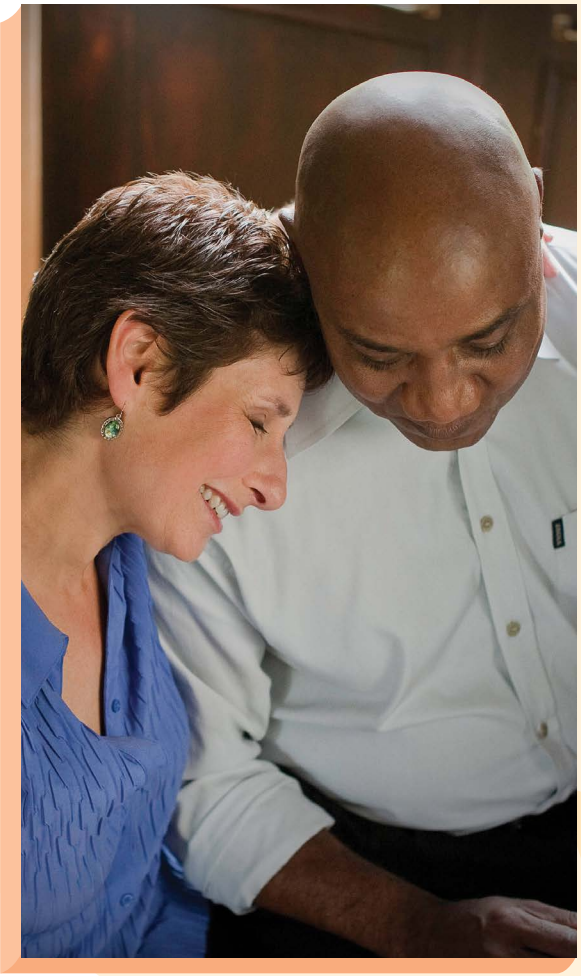
If you take antidepressant medicine, that could cause a lower sex drive. Talk with your doctor about other antidepressants that might help with mood but not reduce sexual desire.

LEARN MORE

To learn more, see our *Guide to Understanding Intimacy and Sexuality* at LBBC.ORG.

BEEN-THERE ADVICE:

Buy pantiliners and wear them regularly so you won't be surprised. Use vaginal moisturizer regularly. Be patient; it just takes longer when you want to be intimate. Make an appointment to spend time with your partner. Give yourself the courage to bring up sex and talk about it — that's the only way you will address the issue.



10 QUESTIONS TO ASK ABOUT SIDE EFFECTS

1. What immediate, short-term and long-term side effects might I have while taking this medicine?
2. Do I have other health concerns (depression, arthritis, osteoporosis) that might make side effects more severe?
3. Is there anything I can do to prevent or minimize side effects?
4. When do side effects begin? If I don't have them at the start of treatment, does that mean I won't get them later?
5. How can I manage side effects while I'm taking this medicine? Are there safe lifestyle changes and integrative methods I can use?
6. Will the side effects continue the whole time? Will they go away after I stop treatment?
7. If I never have side effects, does that mean this medicine isn't working?
8. Can I switch to a different treatment if the side effects are too severe?
9. Is there someone on my healthcare team who can help me with managing side effects?
10. If I'm having problems, when should I talk with you?

Less Common Side Effects

HAIR THINNING *(t, ai)*

Hormonal therapy sometimes causes hair to thin. This may slow after a year or so, but it can continue throughout treatment. Wear scarves or wigs to cover thin hair. If thinning becomes a problem you want to resolve, talk with your doctor about possible medical help.

BEEN-THERE ADVICE:

Wear your hair longer or style it with barrettes to cover thin areas.

HIGH CHOLESTEROL *(ai)*

Some treatments may raise the level of LDL (bad) and total cholesterol in your blood and lower the amount of HDL (good) cholesterol. A buildup of LDL cholesterol can lead to heart attack or stroke. Research is not clear about hormonal therapy's effect on cholesterol, but some evidence suggests the increases in LDL may be temporary.

Talk with your doctor if you have high cholesterol or heart disease.

BEEN-THERE ADVICE:

Keep your diet low in saturated fats by cutting down on red meat. Cook with vegetable oil sprays. Choose fat-free and low-fat dairy products.

MOOD CHANGES *(t,ai, sm, mm)*

"After I started tamoxifen, it sort of sucked the joy out of things. It made the world black and white. I just didn't feel like myself."

—AMANDA

You may notice you seem more short-tempered or easily upset. This may be caused by hot flashes, insomnia or fatigue, or from medicines and surgery that alter your mood through hormone changes. You also may feel more anxious or lose interest in activities you enjoy.

If you feel depressed or anxious and those feelings are strong or don't go away after several days, talk with your doctor. Antidepressants can be helpful but should be chosen to not interfere with your hormonal therapy. Learn more in our *Guide to Understanding Your Emotions* at LBBC.ORG.

BEEN-THERE ADVICE:

Talk with other women in support groups or online discussions. Contact LBBC's ***Breast Cancer Helpline*** *toll-free at* ***(888) 753-LBBC (5222)****.*

NAUSEA, HEARTBURN OR STOMACH UPSET *(t, ai)*

Tell your healthcare team if you feel nauseated often or have other stomach troubles while taking hormonal medicines. Changing the time of day when you take the medicine or taking it with or without food may help. You will take this therapy for years, so it's important to stop nausea or find a medicine that you tolerate better.

Your nausea may be due to hormonal therapy or something else related to treatment. If you take pain medicine for muscle or joint aches, that could cause stomach distress.

Try eating small meals more often. Ginger tea and crystallized ginger can help calm a queasy stomach. If you're vomiting, don't eat afterward for several hours and choose bland foods. Explore acupuncture or relaxation techniques.

BEEN-THERE ADVICE:

Call your healthcare provider and ask what can be done. Talk to other women and see what they've tried.

PROBLEMS WITH THINKING AND MEMORY

(*t,ai*)

Some people report problems with cognitive functions, such as remembering and thinking. This is sometimes called **chemobrain**, but it isn't only linked to chemotherapy. It may be caused by other treatments as well, including hormonal therapy. For more information about chemobrain, visit LBBC.ORG.

BEEN-THERE ADVICE:

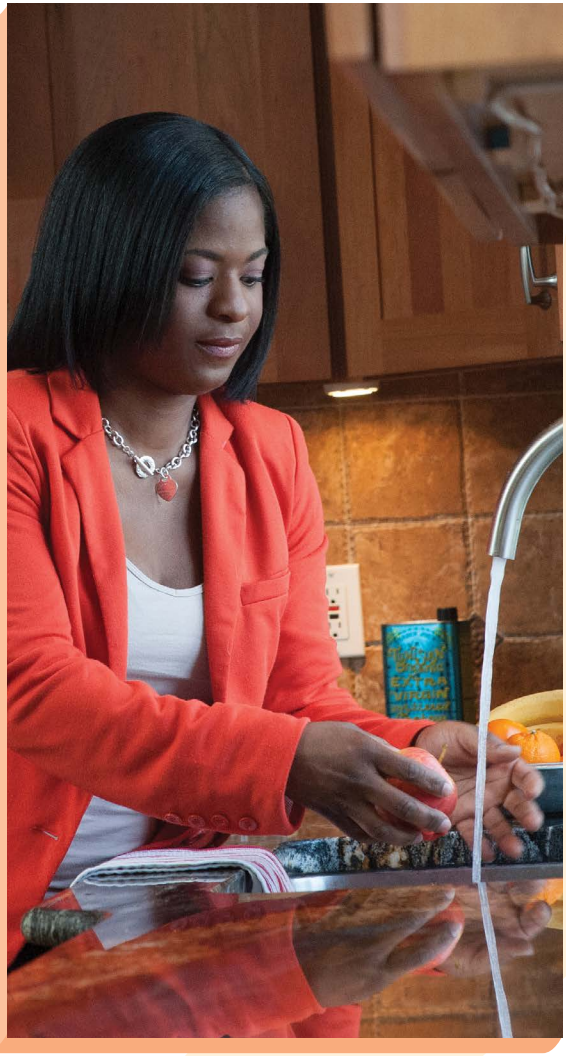
Make lists and keep them in one place. Check off items as you complete them.

WEIGHT GAIN (*t, ai, sm, mm*)

Some women gain extra pounds after initial treatment, but that can also happen during hormonal therapy. Body fat increases during menopause, so surgery or medicines that create menopause can have the same result. Extra weight that appears during hormonal treatment might also be related to aging or exercising less than before.

BEEN-THERE ADVICE:

Ask your doctor about whether a therapy will cause weight gain. Incorporate more fresh fruits and vegetables into your diet. Walk regularly or try water aerobics.



Rare Side Effects

BLOOD CLOTS *(t)*

Tamoxifen slightly increases the risk of blood clots. It carries about the same amount of risk seen with birth control pills. Blood clots may lead to stroke or heart attack. Your risk is greater if you smoke. Talk with your healthcare team about symptoms to watch for, such as leg swelling or dizziness. Get help to stop smoking.

ENDOMETRIAL (UTERINE) CANCER *(t)*

Tamoxifen can cause uterine polyps (small masses), which may lead to cancer of the uterus, also called endometrial cancer. There are two cases of endometrial cancer for every 1,000 women taking tamoxifen. In women not on tamoxifen, the rate is one case per 1,000 women.

This cancer is usually found early, with effective treatment available. Stay current with routine pelvic exams. Call your doctor if you have abnormal bleeding or pelvic pain.

TIPS FOR TALKING WITH YOUR DOCTOR ABOUT SIDE EFFECTS

1. Keep a side effect diary or calendar. Write down the symptom you feel and rate it from 1 (barely there) to 10 (most uncomfortable you have ever been). Note the time of day the symptom happens and what, if anything, seems to trigger it. Using this information, you can tell your doctor, “I had bone pain 17 out of the last 21 days,” and give details about when it happened and your discomfort level.
2. Ask what ideas the doctor has to lessen your symptoms.
3. If you feel too shy to talk with your doctor, write a letter or send an email. This lets you think it through on your own terms.
4. Talk with other women or read about their experiences. Their words might give you ideas of what to say to your doctor. Write down what best describes your situation.
5. Have a patient advocate or navigator help you create questions.
6. Your oncology nurse should have information on dealing with side effects. Even your pharmacist may have suggestions.
7. If you don’t feel comfortable talking with a male healthcare team member, ask to speak with a female.

What to Do If Side Effects Become Too Much

You might get to a point where side effects cause you to think about stopping treatment. Only you can know what you feel. Ask yourself:

- Is this side effect limiting my day-to-day functioning?
- Does it interfere with my ability to enjoy my life?
- Have I talked openly with someone on my healthcare team about my difficulties?
- Have I tried methods that could lessen my symptoms?
- Is there someone else I trust who knows about side effects and can offer advice?

Please don't lose hope. Hormonal therapy medicines often work in similar ways but may not cause the same side effects for you. It's likely you can switch to another medicine and see if that helps. Consider a second opinion if your doctor won't discuss your concerns with you.

Never stop treatment on your own without speaking with your doctor first. You won't know what your doctor might suggest until you talk together about what you're feeling. There may be other options for you. If you're not sure where to start, ask for help from LBBC, a social worker or anyone else on your healthcare team.

The Emotional Side of Hormonal Therapy

As with much of life, women have very different emotional responses to hormonal therapy. Some see hormonal therapy as just part of dealing with breast cancer, while for others it may trigger stronger feelings.

Your emotions — whether positive or negative — are a reasonable and normal response to being in a situation you didn't choose. For you, taking a pill every day for 5 to 10 years might be an unhappy daily reminder of breast cancer. Side effects can make you feel discouraged or angry. Or, you might feel that taking your pill empowers you with a way to protect yourself from the cancer returning. You might feel all these things at the same time.

It's important that your feelings about hormonal therapy not prevent you from caring for yourself by taking the pills every day. If you stopped taking your pills, talk honestly with your providers. There are lots of ways to cope with your feelings and find answers or support.

LBBC offers two free guides that may be useful for you. Our *Guide to Understanding Fear of Recurrence* has a section about how hormonal therapy pills can trigger feelings. The *Guide to Understanding Your Emotions* can help you sort out your feelings and find resources.

Talking with someone who understands may also help. Contact the LBBC **Breast Cancer Helpline** toll-free at **(888) 753-LBBC (5222)** to connect with a peer who has faced similar concerns.

When You Finish Hormonal Therapy

After taking a pill for 5 to 10 years, you may feel like turning cartwheels when hormonal therapy ends. Or you might feel insecure, anxious and vulnerable. Many people have a sense of being suddenly alone. They wonder if they should still be "doing something" to treat the cancer.

It's normal to feel uncertain at this time. Take heart from knowing that research shows long-term benefits from hormonal therapy. Remember that you did what you could to treat the cancer and protect yourself from having it return.

Finishing treatment can be a time when you want to use your experience to help and inspire others. You might do this by talking with newly diagnosed women — letting them see that, 5 or 10 years after initial diagnosis, they could be enjoying life. You may want to volunteer with a breast cancer organization or other nonprofit, tell your story publicly or within your faith community, or go to LBBC.ORG and share your story.

Whatever you decide, know that others share in your experiences, and in your concerns and hopes for the future. As you move forward, Living Beyond Breast Cancer is here to connect you with information and support to help you continue to care for your health.

10 QUESTIONS TO ASK WHEN YOU FINISH HORMONAL THERAPY

1. How long will the medicine protect me after I stop taking it?
2. How can I continue to protect myself from recurrence?
3. Are there research studies I could join that would allow me to keep taking treatment?
4. If I had side effects during treatment, will those problems continue, lessen or go away now?
5. Do I keep seeing an oncologist or does my regular doctor handle all my care now?
6. How often should I visit a doctor to check on how I'm doing?
7. What tests will be used to monitor my health?
8. Am I at higher risk for other illnesses because of cancer treatment? If so, which ones? What signs or symptoms should I watch for?
9. What is a survivorship care plan? How can it help me? Who can help me create one?
10. Where can I go for emotional support if I want it?

Resources

Overview of Hormonal Therapy Options

As of September 2017, these hormonal therapies were available for early-stage breast cancer. For updates, visit LBBC.ORG.

Treatment: Tamoxifen (see page 12)
Type: Selective estrogen receptor modulator
For these women: All
How given: Pill; also available as liquid tamoxifen citrate (Soltamox)
Dose: 20 mg, once a day
Length of treatment: Up to 10 years if it is the only hormonal therapy being taken; up to 5 years if followed by treatment with an aromatase inhibitor
Possible side effects: Hot flashes, night sweats, fatigue, vaginal dryness, vaginal discharge, mood changes or depression, nausea, dry skin, bone pain, headache, hair thinning, loss of sexual interest, constipation, weight gain. Rare but serious: blood clots, stroke, endometrial (uterine) cancer

Treatment: Anastrozole (Arimidex and generic) (see page 18)
Type: Aromatase inhibitor
For these women: Postmenopausal
How given: Pill
Dose: 1 mg, once a day
Length of treatment: Up to 10 years if it is the only hormonal therapy being taken; up to 5 years if preceded by treatment with tamoxifen
Possible side effects: Joint and bone pain, stiffness, bone thinning and fractures, fatigue, nausea, vomiting, hot flashes, weakness, headache, vaginal dryness, loss of appetite, weight gain, insomnia, mood changes, constipation or diarrhea, dry skin, hair thinning

Treatment: Exemestane (Aromasin and generic) (see pages 16 & 18)
Type: Aromatase inhibitor
For these women: Postmenopausal, premenopausal with ovarian suppression or ablation
How given: Pill
Dose: 25 mg, once a day
Length of treatment: Up to 10 years if it is the only hormonal therapy being taken; up to 5 years if preceded by treatment with tamoxifen
Possible side effects: Joint and bone pain, stiffness, bone thinning and fractures, fatigue, hot flashes, insomnia, sweating, headache, dryness, nervousness, mood changes, diarrhea, dry skin, hair thinning, dizziness, vision changes

Treatment: Letrozole (Femara and generic) (see page 18)
Type: Aromatase inhibitor
For these women: Postmenopausal
How given: Pill
Dose: 2.5 mg, once a day
Length of treatment: At least 5 years, as the only hormonal therapy or after up to 5 years of tamoxifen.
Possible side effects: Joint and bone pain, stiffness, bone thinning and fractures, higher cholesterol, fatigue and drowsiness, nausea, vomiting, hot flashes, weight gain, dizziness, dryness, mood changes, loss of appetite, swelling, constipation or diarrhea, insomnia, dry skin, vaginal bleeding

Treatment: Oophorectomy (see page 16)
Type: Surgery
For these women: All (often for premenopausal or perimenopausal)
How given: Removal of ovaries, in conjunction with tamoxifen or aromatase inhibitor
Dose: n/a
Length of treatment: n/a
Possible side effects: Permanent infertility, hot flashes, night sweats, mood changes, vaginal dryness, bone thinning, loss of sexual interest

LHRH AGONISTS

These medicines, which suppress the ovaries before menopause, are under study as a method of preserving fertility during chemotherapy.

Treatment: Goserelin (Zoladex) (see page 16)
Type: LHRH agonist (luteinizing hormone-releasing hormone agonist)
For these women: Premenopausal, perimenopausal
How given: Injection, once a month; continuous-release implant for 3 months
Dose: 3.6 mg per month
Length of treatment: In conjunction with schedule for tamoxifen
Possible side effects: Hot flashes, mood changes, vaginal dryness, loss of sexual interest, weight gain, headache, bone thinning, bone pain, insomnia

Treatment: Leuprolide (Lupron) (see page 16)
Type: LHRH agonist (luteinizing hormone-releasing hormone agonist)
For these women: Premenopausal, perimenopausal
How given: Injection, once a month or every 3 months
Dose: 3.75 mg per month
Length of treatment: In conjunction with schedule for tamoxifen
Possible side effects: Hot flashes, sweating, insomnia and fatigue, mood changes, loss of sexual interest, bone thinning, vaginal dryness, joint and muscle aches, swelling, bone pain

Treatment: Triptorelin (Trelstar) (see page 16)
Type: LHRH agonist (luteinizing hormone-releasing hormone agonist)
For these women: Premenopausal, perimenopausal
How given: Injection, once a month
Dose: 3.75 mg
Length of treatment: In conjunction with schedule for tamoxifen
Possible side effects: Hot flashes, mood changes, bone thinning, loss of sexual interest, insomnia

Words to Know

Adjuvant therapy. Treatment given after initial or first therapy for breast cancer, such as surgery.

Aromatase. An enzyme that converts the hormone estrone to estrogen in postmenopausal women.

Aromatase inhibitors. Hormonal therapy medicines that interfere with the aromatase enzyme to lower risk of breast cancer returning.

Bisphosphonates. Medicines that maintain and rebuild bones for people with osteoporosis or osteopenia.

Chemobrain. Problems with cognitive functions, such as remembering and thinking, which appear during or after many breast cancer treatments , not just chemotherapy.

Estrogen. Hormone with strong influence on growth of breast cancer cells.

Estrogen receptor-positive breast cancer. Disease that shows the presence of hormone receptors for estrogen. Also written as ER+ or ER-positive.

Hormonal therapy. Treatments that lower the amount of, or stop production of, estrogen in the body to lower risk of cancer returning.

Hormone receptors. Structures on cell surfaces that detect and receive hormone signals.

Hormone receptor-positive/hormone-sensitive breast cancer. Disease that shows presence of hormone receptors for estrogen (ER+) or progesterone (PR+), or both.

LHRH agonists. Hormonal therapy medicines used in premenopausal women to shut down ovaries temporarily and cause medical menopause.

Medical menopause. Shutdown of ovaries by medicines. Stops the production of estrogen and lowers risk of breast cancer returning.

Oophorectomy. Surgery to remove the ovaries. It permanently ends fertility and ovarian production of estrogen.

Ovarian ablation/ovarian suppression. Methods used to stop ovaries from making estrogen, by surgery or medicine.

Perimenopausal. Women who are in-between having periods regularly and having no periods for more than a year.

Postmenopausal. Women who have had no periods for more than a year (and who are not receiving ovarian suppression therapy).

Premenopausal women. Women who have periods or menstruate.

Progesterone. Hormone that can promote the growth of breast cancer cells.

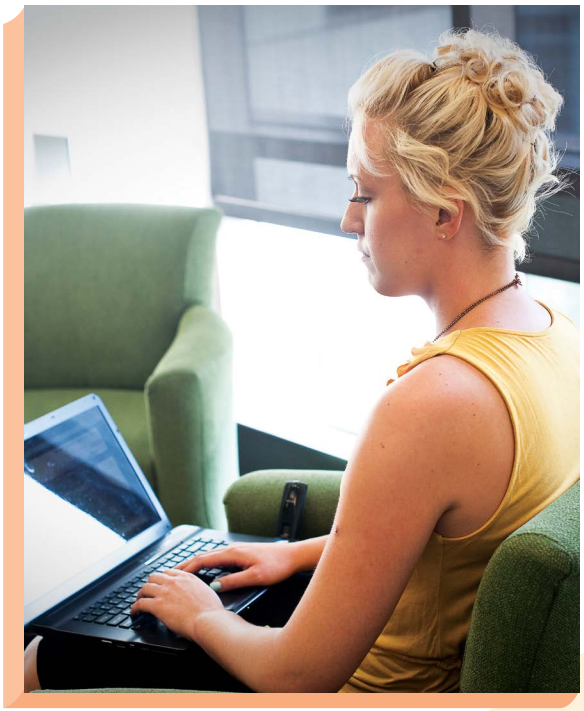
Progesterone receptor-positive breast cancer. Disease that shows the presence of hormone receptors for progesterone. Also written as PR+ or PR-positive.

Recurrence. When breast cancer comes back after treatment.

SERMs. Selective estrogen receptor modulators such as tamoxifen that prevent estrogen signals from getting to cells and lower the risk of cancer returning.

Surgical menopause. Removal of ovaries by surgery. Results in immediate end of ovarian-produced estrogen and lowers risk of breast cancer returning.

Tamoxifen. Hormonal therapy medicine that prevents estrogen signals from getting to cells. Lowers risk of cancer returning.



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LIVING BEYOND BREAST CANCER®

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