

Hormone Therapy and Breast Cancer



About us

Breast Cancer Network Australia (BCNA) is the peak national organisation for Australians affected by breast cancer. We provide a range of free resources for women with breast cancer, including the *My Journey Kit* for women newly diagnosed with early breast cancer and *Hope & Hurdles* for women with secondary breast cancer. BCNA's free quarterly magazine *The Beacon* includes stories from women with breast cancer, as well as information on a wide range of breast cancer issues.



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Introduction

Breast cancer is a complex disease with many different types and many different treatments. The specific treatment recommended for your particular breast cancer will depend on your age, the pathology of the breast cancer, any other illnesses you may have and your personal preferences.

One of the tests the pathologist performs on your tumour is to identify whether your breast cancer has receptors to the two main female hormones, oestrogen and progesterone, on its cells. If receptors are present, these are referred to as oestrogen receptor positive (ER+) and/or progesterone receptor positive (PR+) breast cancers.

Up to 80 per cent of women with breast cancer have hormone receptor positive breast cancer.

Hormone therapies are used to treat breast cancers that are hormone receptor positive. This booklet is intended to help you understand how these medications work and why they are beneficial for women with hormone receptor positive breast cancer. It also discusses the side effects that some women experience with these treatments, and includes practical advice from women who have used them and health professionals.

*When I started taking tamoxifen, I don't think I asked enough questions.
I find the whole tamoxifen thing very confusing.*



What are hormone therapies?

If you have hormone receptor positive breast cancer, it means that oestrogen (and sometimes progesterone) can stimulate the growth of the cancer. Hormone therapies aim to block this stimulation. In effect, these treatments are more accurately described as *anti-hormone* therapy.

There are two types of hormone treatments commonly used for breast cancer:

- tamoxifen (Tamoxifen[®], Nolvadex[®])
- aromatase inhibitors*, which include:
 - anastrozole (Arimidex[®])
 - letrozole (Femara[®]); and
 - exemestane (Aromasin[®])

**Note: there are now also generic brands of anastrozole, letrozole and exemestane which you may be offered by your pharmacist. These generic brands have the same active ingredients as the branded versions, and work in the same way.*

Which hormone therapy is right for me?

If you are premenopausal, it is likely that your doctor will suggest you take tamoxifen, as aromatase inhibitors are not suitable for premenopausal women. If you are postmenopausal, you may be recommended one of the aromatase inhibitors or tamoxifen. Your doctor will carefully consider which hormone therapy is best for you given your menopausal state and individual circumstances.

Hormone therapy is usually prescribed for five years or more.

Tamoxifen

Tamoxifen is taken as a tablet every day. It works by blocking the oestrogen receptors on the breast cancer cells, stopping oestrogen naturally produced in the body from attaching to the cancer cells and stimulating their growth.

If you are prescribed tamoxifen, your doctor will probably recommend that you take it for a minimum of five years, although the length of time can vary from woman to woman. Some women who go through menopause while taking tamoxifen may switch to one of the aromatase inhibitor drugs before they have completed five years of tamoxifen, but this depends on each woman's individual circumstances.

Women with secondary breast cancer will often take hormone therapies for as long as they control the cancer. If you have secondary breast cancer, your doctor will have a treatment plan that takes into account your individual circumstances.

Some women who are treated with tamoxifen find they experience menopausal symptoms such as hot flushes, vaginal dryness or discharge, and skin dryness and sensitivity. This is because tamoxifen blocks oestrogen receptors on healthy cells as well as breast cancer cells.

Normally, oestrogen circulating in the body binds to oestrogen receptors in healthy tissue, especially in the breast, vagina, brain, skin and bones, to enable it to continue to grow and stay healthy. When oestrogen is blocked from entering healthy tissue by tamoxifen, menopausal symptoms can occur.

While many women may be troubled by menopausal symptoms when they start taking tamoxifen, for most women these symptoms will ease over time. Other women find that they do not experience any side effects at all.

Some of the more common side effects you may experience are listed on page 7 along with some practical tips from other women and health professionals on how to manage them.

Aromatase inhibitors

While I am not a fan of Arimidex, I would not dream of not taking it. I have been taking it for three years and have another two to go.

Aromatase inhibitors are tablets taken daily. They work by reducing the amount of oestrogen in the body. They are suitable only for women who have already been through menopause.

Your doctor will probably suggest you take an aromatase inhibitor for a minimum of five years. The length of time will depend on the recommendation of your doctor, whether you have previously taken tamoxifen, and your own personal preferences.

If you have secondary breast cancer and take an aromatase inhibitor you will continue to take it for as long as it is keeping your cancer under control. Your doctor will discuss with you how long you will need to keep taking it.

The most common side effects of aromatase inhibitors are joint pain and vaginal dryness. However, not all women who take an aromatase inhibitor will experience side effects.

Some of the more common side effects you may experience are listed on page 7 along with some practical tips from other women and health professionals on how to manage them.

Benefits of hormone therapy

Hormone therapy gives me peace of mind that I am doing everything possible to live a long fulfilling life.

Taking a drug every day for five years or more can be daunting, particularly if you experience side effects early on. When considering whether or not to take a hormone therapy, it may be helpful for you to know that these drugs are very good at preventing breast cancers from coming back.

Hormone therapies reduce the risk of developing secondary breast cancer. They also reduce the risk of breast cancer returning in the same breast, and of developing a new breast cancer in the opposite breast.

Clinical trials have shown that women who took a hormone therapy for five years were far less likely to have a breast cancer recurrence than women who did not. Even after five years had passed, and the women were no longer taking any hormone therapies, the women who took a hormone therapy were still much less likely to have a recurrence. This means that the beneficial effects of hormone therapy are ongoing and will last well beyond the five years you take them.



Side effects of hormone therapy

We don't need menopause symptoms again, but we don't need the alternative – cancer – either!

Many women experience menopausal-like symptoms when taking hormone therapies. For most women, these symptoms are mild and easily managed.

If you do experience side effects and are finding it difficult to cope, there are some ways you can manage them. If the practical strategies outlined below don't help, you may like to discuss the side effects with your doctor. It may be possible to adjust your medication dose, switch to another hormone therapy drug or take a break from treatment. Many women find that switching from one hormone therapy to another helps alleviate problems. If you have difficulty talking to your doctor, or feel that your doctor does not listen to you, you might consider taking a friend or family member to an appointment with you, or you can seek a second opinion from another doctor:

I took tamoxifen for five years and then Femara for another five. I had no side effects apart from the hot flushes, which continued the entire time. It was worth putting up with this to reduce my chance of breast cancer returning, and I quickly got used to taking a tablet once a day.

Hot flushes

Hot flushes are a common side effect of hormone therapy. While the nature and severity of hot flushes varies from woman to woman, hot flushes are usually characterised by a sudden feeling of heat in the face, neck and body that may be accompanied by sweating, a rapid heartbeat, and anxiety or nausea.

I'm tired every night because of lack of sleep due to hot flushes.

The hot flushes were a challenge for a while, but by layering my clothes and using a handheld fan I was able to manage them quite effectively. Thankfully, I now only experience them very occasionally.

Hot flushes can be very uncomfortable and frustrating as they can interfere with your sleep and compromise your quality of life. Hot flushes can also affect your mood and can leave you feeling irritable and tired.

If you are experiencing hot flushes, some helpful suggestions include:

- Minimise stress where possible. Feeling overwhelmed and anxious may trigger hot flushes. Stopping every so often to take a deep breath may help you relax. Meditation, yoga and other relaxation techniques have been shown to be helpful in reducing stress.
- Aim to maintain your ideal body weight.
- Aim to exercise for 30 minutes most days.
- Stop smoking.
- Wear loose cotton clothing to allow your skin to breathe. Wearing clothing in layers can also help, as you can take layers off during a hot flush.
- Avoid anything that triggers your hot flushes, such as hot spicy food, alcohol and caffeine.
- Drink cold water to help lower your body temperature.
- Avoid hot environmental temperatures and stuffy rooms.
- Use water sprays or moist wipes to help lower your skin temperature.
- Use an electric or handheld fan to help lower your skin temperature.
- Use cotton bed sheets instead of synthetic sheets to help breathability.
- Take a cool shower before bed.
- Use cold packs including a cool gel pack under your pillow at night.

Prescription medicines

If the strategies outlined previously don't help and you are finding hot flushes troublesome, you may like to talk to your GP or medical oncologist as there are a number of medications that can be used to treat hot flushes. These include a low-dose antidepressant such as venlafaxine (Efexor[®]), or other drugs including clonidine (Catapress[®]) and gabapentin (Neurontin[®], Pendine[®]). Clonidine is generally used to treat high blood pressure, but can be used to reduce menopause-related hot flushes after breast cancer. Gabapentin is used to treat chronic pain. It can also be effective in reducing hot flushes. Let your doctor know if you are taking tamoxifen as some antidepressants, especially paroxetine (Aropax[®]), reduce its effectiveness.

None of these medications is listed on the Pharmaceutical Benefits Scheme (PBS) for hot flushes, however, they are on the PBS for other conditions. If they are prescribed for you as a non-PBS drug, it may be worth checking the cost of the prescription at different pharmacies to obtain the best price. If you have private health insurance, your fund may provide you with a rebate so it's worth checking with them.

Hormone replacement therapy (HRT) replaces hormones (oestrogen and/or progesterone) that are no longer being produced by the ovaries and is very effective in reducing menopausal symptoms. HRT can also protect against long-term side effects of menopause, especially osteoporosis. However, HRT is not usually offered to women who have had oestrogen receptor positive (ER+) breast cancer, as there is uncertainty as to whether it may increase the risk of the breast cancer coming back. Your medical oncologist will be able to advise you on the appropriateness of HRT if your symptoms are severe and impacting on your quality of life.

Complementary medicines

There are a number of complementary medicines, health supplements and foods that are promoted as useful in managing hot flushes. Many of them have not been proven to be effective in clinical trials, and some may interfere with your breast cancer treatments.

It is important to talk to your doctor about any complementary medicines or herbal therapies you are considering or currently taking, particularly if you are taking hormone treatment such as tamoxifen or an aromatase inhibitor (Arimidex[®], Femara[®], Aromasin[®]).

Bio-identical hormones are lozenges, troches or creams prepared by compounding pharmacists designed to be absorbed through the cheek or skin. They are individually prepared rather than manufactured by a pharmaceutical company, hence quality controls may be inconsistent and they are not subject to approval by the Therapeutic Goods Administration. The manufacturers claim the products are natural oestrogen, but they come from the same sources as traditional HRT. There has been no formal research into their dosage, effectiveness in reducing hot flushes, or their safety.

Phytoestrogens (plant oestrogens) are chemicals found in plants that mimic the effect of oestrogen on the body. High quantities are found in soybeans and linseed. You can buy phytoestrogen-rich foods and supplements from health food shops. As they are classified as foodstuffs they are not covered by drug regulations or clinical trials. Their safety after breast cancer is not known and their effectiveness in reducing hot flushes has not been proven.

Herbal therapies such as ginseng, passionflower, valerian, chaste tree, St John's Wort, black cohosh and ginkgo are also used by some women to manage hot flushes. They are also classed as foodstuffs and not subject to thorough clinical trials. Opinion is divided as to whether they are safe to use after breast cancer:

Some, such as St John's Wort, can reduce the effectiveness of tamoxifen and chemotherapy drugs, so should not be used while you are undergoing breast cancer treatment.



Complementary therapies

In recent clinical trials cognitive behaviour therapy has been shown to reduce the impact of hot flushes, reduce anxiety and improve sleep after breast cancer. Other therapies which may help include yoga, hypnosis, relaxation therapy, paced respiration, acupuncture and mindfulness meditation.

Alternative therapies

There is currently a lack of evidence for homeopathy, reflexology or body manipulation improving hot flushes.

Vaginal symptoms

Hormone therapies may cause vaginal dryness, discharge, itch or irritation. Many women may also experience some of these symptoms as they go through menopause. Although it may be a difficult topic to discuss openly with your doctor, in most cases they will be able to help you.

There are a number of products you can try to help manage vaginal dryness.

Some women find that a non-hormonal vaginal moisturiser such as Replens® (a low pH gel), which is available from pharmacies, provides relief from vaginal dryness, itching and irritation. When applied directly to the vagina, vaginal moisturisers help replenish moisture to the lining of the vagina and relieve discomfort associated with vaginal dryness. Vaginal moisturisers are designed to be applied twice a week, but can be used more or less frequently as necessary.

It's important to be aware that while vaginal moisturisers can improve vaginal symptoms and sexual function, depending on the severity of vaginal dryness they are likely to take around six to eight weeks to be fully effective.

Vaginal oestrogens are commonly prescribed to treat vaginal dryness in women who have not had breast cancer. However, doctors are cautious about prescribing vaginal oestrogens to women who have had breast cancer, particularly those women who have had oestrogen positive breast cancer. These creams or vaginal tablets contain low doses of oestrogen, which may be absorbed into the body at low levels. You may like to discuss with your specialist whether a vaginal oestrogen is suitable for you. Vaginal oestrogens are only available on prescription by a doctor.

If you are experiencing vaginal symptoms, you may find that sex is painful. Vaginal lubricants can be used in sexual foreplay immediately before and during sex to provide lubrication, and to reduce pain and discomfort from dryness. Vaginal lubricants that are suitable include YES®, Astroglide®, Sylk® and Pur®.

Avoid using petroleum or oil-based lubricants as they can interfere with the vagina's natural secretions and can worsen vaginal dryness. If you are prone to vaginal thrush, use water-based lubricants as lubricants with high levels of glycerine or silicone may cause recurring vaginal thrush.

Breast Cancer Network Australia's booklet, *Breast cancer and sexual wellbeing*, includes more detailed information about vaginal symptoms and sexual wellbeing issues. Details on how to order a copy are at the back of this booklet.

Thinning hair and nails

Some women who take hormone therapy find that their hair and/or nails start to thin. It is often difficult to know for sure whether this is caused by hormone therapy, other breast cancer treatment such as chemotherapy, or even just the normal ageing process. If you experience hair and/or nail thinning, you may like to try some of these suggestions from women who found them helpful:

- Use a gentle shampoo and conditioner.
- Dry your hair naturally or use a cool setting on the hair dryer.
- Brush or comb hair gently (one of the reasons for hair loss is the hair breaking off at the scalp).
- Some women prefer to cut their hair into a short style to help give the appearance of greater hair volume.
- Protect your scalp from the sun.
- Avoid heated rollers or curling wands.
- Avoid perming or straightening your hair.
- If you colour your hair, ask your hairdresser to use/recommend a vegetable hair colour rather than a chemical dye. These may have to be ordered in for you.

Joint pain

The menopausal symptoms do settle down after a while. The worst for me is the joint aches, but even those have settled down with time.

Sure, my joints are a bit stiff when I start to move. But once I'm up and moving they feel so much better. I find a good walk really helps.

If you are taking an aromatase inhibitor, you may find that you experience some joint stiffness and/or pain. Over-the-counter drugs such as paracetamol or non-steroidal anti-inflammatory (NSAIDs) drugs such as Nurofen® or Voltaren® may help you. Your doctor or pharmacist can give you advice about what option is best for you. Acupuncture has also been shown to help joint pain in some research trials, and many women find it helps them.

Joint stiffness most commonly occurs in the morning, but it does tend to improve as you start to move around more. Many women find that gentle exercise helps with the stiffness and pain. Some of the common exercises women find helpful include hydrotherapy (exercise in the water), swimming, tai chi and yoga.

If exercise is new to you, the good news is you can begin at any age. It's important to start exercising slowly, and gradually build up over time, rather than exercising too much or too intensely when you first begin. This is important even if you have exercised regularly in the past.

There may be times when you don't feel like exercising, and during these times it is okay to give yourself a break. Try to remember that if you don't get around to exercising, for whatever reason, this is not a failure. Try focusing on exercise that you were able to complete as a success, be kind to yourself and pick up where you left off at a later time. Breast Cancer Network Australia's booklet *Breast cancer and exercise* explains how much exercise is recommended to women with breast cancer, and includes practical tips to help women stay motivated. Details on how to order a copy are at the back of this booklet.

Long-term side effects of hormone therapy

As with many drugs, there are some long-term side effects of hormone therapies that you may like to keep in mind. You can discuss them with your doctor if you have concerns.

Tamoxifen

Tamoxifen can very slightly increase your risk of blood clotting. If you have had blood clots before, or think you are at risk of developing them, it is important to let your doctor know about this. You may also like to take simple precautions, such as wearing compression stockings (available from pharmacies) if you are going to be immobile for a long period of time, for example, when travelling on long-haul flights.

There is also a very small risk that tamoxifen will affect the lining of the uterus. Very rarely, cancer of the uterus can develop. While this may sound scary, the benefits of taking tamoxifen far exceed the very small risk of uterine cancer developing and you will be monitored regularly. If you have unexpected vaginal bleeding while taking tamoxifen, let your doctor know.

Pregnancy and fertility

If you are premenopausal when you start taking tamoxifen, you may find that your periods become irregular or stop. They will often return to their previous pattern when you stop taking tamoxifen.

If you are premenopausal and taking tamoxifen you will also need to use reliable contraception as pregnancy should be avoided while taking this medication.

Aromatase inhibitors

Aromatase inhibitors can cause loss of bone density, or thinning of the bones, which may increase your risk of bone fractures and of developing osteoporosis. Your doctor may want to assess your bone mineral density (strength and thickness) with a scan, commonly known as a DXA scan, before or shortly after you start taking an aromatase inhibitor. This is different from the bone scan you may have to determine if breast cancer has spread. Your bone mineral density may also be re-checked around every two years while you are taking an aromatase inhibitor, but this will depend on the results of your first scan and your doctor's recommendation.

I knew that osteoporosis was a risk factor when I made the decision to take an aromatase inhibitor. I do what I can to minimise the risk, such as walking, watching my weight, eating calcium rich foods and having regular checks for my vitamin D levels. It was the right decision for me.

If you are concerned about bone thinning, increasing the amount of calcium and vitamin D in your diet may help. You can get enough vitamin D by exposing your arms to the sun for five to seven minutes mid-morning or mid-afternoon in the warmer months and five to 30 minutes at noon in the cooler months. Good sources of vitamin D are fresh and tinned fish (tuna, salmon, sardines, herring and mackerel). There are also some foods that have vitamin D added to them, such as margarine and some types of milk, cheese and yoghurt, however, the amounts are not high enough to meet daily requirements.

Calcium is found in dairy products such as milk, yogurt and cheese and foods such as sardines, broccoli, almonds and salmon. If you are able to, include three serves of dairy foods in your diet each day.

If you are unable to consume enough calcium and vitamin D each day, or don't get much sun exposure on your skin, you may like to ask your GP about having your vitamin D levels checked.

Weight-bearing exercise also improves bone strength. Weight-bearing exercises include walking, jogging, tennis, dancing and aerobics.

Even short periods of exercise, for example, 10 minutes twice a day, will help to increase your bone strength. Some women may need to take other medications, such as bisphosphonates, to strengthen their bones. Your doctor will be able to tell you whether these are suitable for you.

Taking other medications and supplements with hormone therapies

Some common medications can reduce the effectiveness of hormone therapies. For this reason, it is important to talk to your doctor about any other drugs and medicines (including herbal and complementary medicines) that you are taking or considering taking.

For example, some (though not all) depression medications may interfere with your hormone therapy. If you take a medication for depression and are unsure about whether you should be taking it, it is important to talk to your doctor before making any decisions about whether to stop taking your depression medication.

Many women find they benefit from taking natural or complementary medicines to help with side effects of hormone therapy and other medical issues. Some of these medications, such as the herbal remedy St John's Wort, should be avoided as they may reduce the effectiveness of your hormone therapy medication. It is important to speak to your doctor before taking any natural, herbal or complementary medicine to make sure that it won't affect your treatment for breast cancer or any other condition.



The 'new you'

After breast cancer, many women experience a greater sense of awareness about themselves and their bodies. You may notice aches and pains more quickly, become more attuned to your weight, or feel anxious about menopausal symptoms. If side effects become difficult for you to manage, you may consider speaking with your doctor. It is sometimes useful to plan ahead for your medical consultations. Some women suggest taking along a written list of what you want to talk about, in the order of importance to you. If one side effect in particular is troubling you, keep your list short so that the doctor will have enough time to talk about this with you. Think of some examples of how the side effect is affecting your quality of life so you can explain this to your doctor.

Many women use exercise as a very effective way of coping with side effects, not to mention as a way of remaining in good general health and spirits. Exercise can be an excellent distraction too.

Ongoing clinical trials continue to show that hormone therapies are very effective in reducing the risk of breast cancer returning in women with oestrogen positive breast cancer. For this reason they are being prescribed for longer periods of time – five, seven or even 10 years.

It is not easy to take a tablet every day for 10 years, especially if it is causing distressing menopausal symptoms. Some women stop taking these medications before the recommended treatment time is finished. There are many reasons for this, including cost, side effects, and the desire to put the cancer and its treatments in the past.

It is important that you do not stop taking these medications without discussing your issues with your doctor. Side effects can be managed. Different hormone treatments can be tried. Sometimes a planned break from treatment can be arranged. The key is to communicate any concerns you have with your treatment team.

I guess the most important thing is to ask questions (no matter how silly they sound) of your doctors. If you think of something at home, write it down. If you don't understand their answers, then ask again.

More information

In addition to speaking with your doctor about your concerns, there are a number of other organisations and resources that may be able to help you.

Breast Cancer Network Australia

www.bcna.org.au

1800 500 258

Breast Cancer Network Australia is the national voice for Australians affected by breast cancer. We offer information and support for women with breast cancer; their families and friends, through our *My Journey Kit*, brochures, website, online network, forums and *The Beacon*, our free quarterly magazine.

Breast Cancer Network Australia produces a range of resources including:

- *Breast cancer and sexual wellbeing*, a booklet for women and their partners. This booklet provides information and advice about the practical and emotional aspects of breast cancer and sexual wellbeing issues.
- *Menopause and breast cancer*, a booklet for women with breast cancer who would like more detailed information and advice about menopause.
- *Breast cancer and exercise*, a booklet for women with breast cancer about exercising for good health.
- BCNA's online network allows you to connect and share stories with women in a similar situation. To join, visit www.bcna.org.au

Cancer Council Helpline

13 11 20

The Cancer Council Helpline is a free, confidential telephone information and support service run by Cancer Councils in each state and territory. Specially trained staff are available to answer questions about cancer and offer emotional and practical support.

Cancer Australia

(formerly National Breast and Ovarian Cancer Centre)

www.canceraustralia.gov.au

1800 624 973

Cancer Australia is the Australian Government's national cancer agency. It provides leadership in cancer control to improve outcomes for Australians affected by cancer. Cancer Australia develops and distributes clinical guidelines for best practice health care to improve the diagnosis, treatment and support of women with breast cancer. It produces a number of information resources for health professionals and people affected by breast cancer.

Jean Hailes for Women's Health

www.jeanhailes.org.au

1800 532 642

Jean Hailes for Women's Health is a not-for-profit organisation dedicated to the physical and emotional wellbeing of women across Australia. It translates the latest research findings into practical health and lifestyle approaches for women and professional advice for nurses, GPs and health specialists. Jean Hailes produces fact sheets and written advice on its website about menopause, bone health, sleep, vitamin D, nutrition for women, and more.



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