

TAMOXIFEN

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About this booklet

If you've been offered tamoxifen as part of your breast cancer treatment, it's natural to have questions about the drug and how it may affect you.

This booklet explains what tamoxifen is, when you may be prescribed it, how it works and what side effects you might have while taking it.

What is tamoxifen?

Tamoxifen is a drug used to treat breast cancer. It's a type of hormone therapy, also known as endocrine therapy.

It can be used by both premenopausal women (women who still have periods) and postmenopausal women (women whose periods have stopped).

It can also be taken by men who have breast cancer.

How does tamoxifen work?

Some breast cancers use oestrogen in the body to help them grow. These are known as oestrogen receptor positive or ER-positive breast cancers.

Tamoxifen blocks the effects of oestrogen on ER-positive breast cancers. This stops oestrogen from helping the breast cancer cells grow.

Who might be offered tamoxifen?

You'll only be prescribed tamoxifen if your breast cancer is ER-positive.

Invasive breast cancers are tested to see if they're ER-positive using tissue from a biopsy or after surgery.

If your breast cancer doesn't use oestrogen to help it grow, it is known as oestrogen receptor negative (ER-negative).

You'll also have tests to see if a hormone called progesterone is helping your breast cancer grow. If it is, it's called progesterone receptor or PR-positive.

The benefits of hormone therapy are less clear for people whose breast cancer is PR-positive but ER-negative. Very few breast cancers fall into this category. But your specialist will discuss with you whether hormone therapy is appropriate if this is the case.

If your cancer is found to be hormone receptor negative, then tamoxifen will not be of any benefit to you.

When is tamoxifen prescribed?

Primary breast cancer

Tamoxifen may be prescribed if you have primary breast cancer. This is breast cancer that has not spread beyond the breast or the lymph nodes under the arm.

It's usually given after surgery to reduce the risk of breast cancer returning in the same breast or spreading somewhere else in the body. This is known as adjuvant therapy.

If you're going to take tamoxifen as part of your treatment for primary breast cancer, your specialist will tell you when it's best for you to do this.

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Occasionally, tamoxifen may be used as the first treatment for breast cancer. This may be when surgery is not appropriate or needs to be delayed.

Tamoxifen and DCIS

If you have an early type of breast cancer called ductal carcinoma in situ (DCIS), the benefits of tamoxifen are less clear.

Some people with oestrogen receptor positive DCIS will be prescribed tamoxifen after surgery to reduce the risk of breast cancer coming back in the same breast or a new breast cancer developing on either side. Your treatment team will discuss whether they feel it would benefit you.

Whether you are prescribed tamoxifen will depend on a number of factors including the features of the DCIS and your medical history.

Breast cancer that has come back or spread

Tamoxifen can also be used to treat people with oestrogen positive breast cancer who have:

- Local recurrence – breast cancer that has come back in the chest/breast area or in the skin near the original site or scar
- Locally advanced breast cancer – breast cancer that has spread to the chest wall or skin of the breast, or the lymph nodes around the chest, neck and under the arm or breastbone, but has not spread to other parts of the body. It cannot be removed by surgery
- Secondary (metastatic) breast cancer – breast cancer that has spread to another part of the body, such as the bones, lungs, liver or brain

To reduce the risk of breast cancer developing

Tamoxifen may be an option for some women who do not have breast cancer but have a higher risk of developing it because of their family history. It's given to try to reduce the risk of breast cancer developing. This is known as chemoprevention. Your specialist will discuss this if it's an option for you.

Find out more in our booklet **Family history of breast cancer: managing your risk**.

How is tamoxifen taken?

You take tamoxifen as a tablet.

Occasionally it may be prescribed as a liquid if you have difficulty swallowing.

The recommended dose is usually 20mg daily.

It's best to take it at the same time every day.

If you miss a dose, you do not need to take an extra one the next day. The level of the drug in your body will remain high enough from the previous day.

Some versions of tamoxifen contain small amounts of lactose. If you know you are lactose intolerant, discuss this with your treatment team or pharmacist.

How long will I have to take tamoxifen for?

How long you take tamoxifen for will depend on your individual situation.

If you're being treated for primary breast cancer, you will usually take tamoxifen for between 5 and 10 years.

If you go through the menopause while taking tamoxifen, your treatment team may recommend you change from tamoxifen to a different hormone therapy known as an aromatase inhibitor (such as anastrozole, exemestane or letrozole). They may do some blood tests to check whether you're postmenopausal before changing your hormone therapy.

Sometimes tamoxifen is recommended after taking an aromatase inhibitor.

For more information, see our **Anastrozole**, **Exemestane** and **Letrozole** booklets.

For younger women who are premenopausal, tamoxifen may be given alone or sometimes alongside treatment to stop the ovaries working (ovarian suppression). You can find out more about ovarian suppression on our website **breastcancernow.org**

If you're taking tamoxifen for locally advanced breast cancer or secondary breast cancer, you'll usually continue to take it for as long as it's keeping the cancer under control.

If you have a significant family history and are taking tamoxifen to reduce your risk of breast cancer developing, you'll usually take it for 5 years.

Stopping tamoxifen

Your treatment team will tell you when to stop taking tamoxifen. You won't need to stop taking it gradually.

If, for any reason, you want to stop taking tamoxifen before the recommended time, talk to your treatment team first. Not taking the drug for the recommended time may increase your risk of the breast cancer coming back or progressing.

Side effects of tamoxifen

Like any drug, tamoxifen can cause side effects. Everyone reacts differently to drugs and some people will have more side effects than others. Some people don't have any side effects at all. Having few or no side effects does not mean the drug is not working.

Most side effects can usually be managed but they can sometimes cause distress and disrupt everyday life.

This booklet does not list all the possible side effects. If you have any questions or concerns about side effects, whether they are listed here or not, talk to your treatment team.

Different brands of tamoxifen

Tamoxifen is made by a number of different manufacturers. Some of the tablets may differ in their additional ingredients (for example, preservatives). This means that the colour, shape, size and sometimes taste of the tablets can differ between brands. However, this does not change the effectiveness of the treatment.

Some people say they notice a change in the side effects they have if they take tamoxifen made by a different manufacturer. This suggests that some people find tamoxifen produced by one manufacturer seems to suit them better than another.

You may wish to discuss this with your treatment team or GP. Or ask the pharmacist who dispenses your prescriptions if they can supply you with tamoxifen from the manufacturer you feel suits you best.

Common side effects

Menopausal symptoms

The most common side effects of tamoxifen are menopausal symptoms.

These include:

- Hot flushes
- Night sweats and sleep disturbance
- Vaginal irritation such as dryness and itching
- Loss of sex drive
- Mood changes or low mood
- Headaches

To find out more about coping with menopausal symptoms, see our **Menopausal symptoms and breast cancer** booklet.

Vaginal discharge

Vaginal discharge is common when taking tamoxifen. If you're worried about this, let your treatment team or GP know so they can rule out an infection.

Effects on periods

If you're still having regular periods, you may find your periods change. For example, they may be lighter, irregular or they may stop altogether.

This may also be because the menopause has occurred naturally during this time or because other treatment such as chemotherapy has caused an earlier menopause.

Sometimes periods may return after you stop taking tamoxifen (see "Does tamoxifen affect fertility?" on page 16).

If you start to have heavy periods or unusual bleeding, speak to your treatment team.

Fluid retention

Tamoxifen can sometimes cause fluid to build up in the body (fluid retention), which may affect your weight. You may gain

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weight during treatment, although there is no clear evidence linking weight gain to tamoxifen.

Indigestion or feeling sick (nausea)

You may have indigestion or feel sick, though this is usually mild. You're more likely to notice these symptoms when you first start taking tamoxifen.

They generally improve or become easier to manage over time and may be helped by taking the tamoxifen with food or taking it at a different time of day.

Effects on bone health

If you are postmenopausal there is evidence that tamoxifen slows down bone loss, reducing the risk of your bones losing strength and being more likely to break (osteoporosis).

However, tamoxifen may slightly increase the risk of osteoporosis for premenopausal women. This is unlikely to lead to osteoporosis unless treatment has been given to stop the ovaries from working as well.

Extreme tiredness

Fatigue is extreme tiredness that does not go away with rest or sleep. It's a very common side effect of tamoxifen and may last for weeks or months even if your treatment has finished.

Fatigue can also be caused by conditions such as anaemia (too few red blood cells).

If you think you have fatigue, tell your GP or treatment team. They can assess you and offer advice on how to manage your energy levels and rule out any other conditions.

Fatigue affects people in different ways and there are a number of ways of coping with and managing it – your treatment team may be able to help you with this.

You can find more information on our website or by calling our helpline on **0808 800 6000**. Macmillan Cancer Support produces a booklet called *Coping with fatigue*.

Skin rash

You may develop a skin rash, itchy or dry skin while taking tamoxifen. Your pharmacist, GP or treatment team can tell you what products you can use on your skin to help.

Less common side effects

Effects on the womb

Tamoxifen can affect the lining of the womb (uterus), known as the endometrium, which may become thickened. If you have any unexpected vaginal bleeding or pain, tell your GP or treatment team.

Occasionally, use of tamoxifen in postmenopausal women may cause polyps or ovarian cysts or, even more rarely, cancer of the womb. There doesn't appear to be an increased risk of this type of cancer in premenopausal women taking tamoxifen.

Changes to hair or facial hair

You may notice some hair loss or hair thinning while taking tamoxifen. It will usually grow back once you've stopped taking the treatment. A small number of women notice an increase in downy facial hair.

Changes to vision

There is a very slight risk of changes to your vision, including a slightly higher risk of developing cataracts. If you notice any changes to your vision, tell your GP or treatment team.

Changes to the liver

Tamoxifen can occasionally cause changes to how the liver works. These changes are usually very mild and unlikely to cause any symptoms. Once you finish your treatment your liver will usually go back to normal.

Other possible side effects

Some women notice a change to their singing voice.

Other reported side effects include:

- Joint pain
- Difficulty concentrating
- Headaches
- Leg cramps at night

Are there different side effects for men?

Men can have similar side effects as women, such as hot flushes and headaches.

A number of small studies have noted other side effects, such as decreased sex drive, though this usually recovers after tamoxifen treatment has ended.

Blood clots

People with breast cancer have a higher risk of blood clots. Taking tamoxifen also increases the risk of blood clots such as a DVT (deep vein thrombosis).

If you have a DVT, there's a risk part of the blood clot could break away and travel to the lung. This is known as a pulmonary embolism (PE).

Blood clots can be life-threatening and should be treated quickly.

Contact your treatment team or go to your local A&E department straight away if you have any of the following symptoms:

- Pain, redness/discolouration of the skin, heat and swelling of the arm or leg
- Swelling, redness or tenderness where a central line is inserted to give chemotherapy, for example in the arm, chest area or up into the neck
- Shortness of breath
- Pain or tightness in the chest
- Unexplained cough or coughing up blood

Reducing your blood clot risk

If you have had blood clots in the past or are at risk of developing them, your treatment team will take this into account and may recommend an alternative to tamoxifen.

If you take a medicine that reduces the ability of the blood to clot (anti-coagulant), such as warfarin, your doctor may want to monitor you more regularly. Or they may consider changing your anti-coagulant medication while you are taking tamoxifen.

If you're taking tamoxifen, it's important to be aware of the risk of blood clots and ways to reduce this.

Long periods of inactivity can increase your risk of developing blood clots. If you're planning a long-distance plane, car or train journey, you can get advice from your treatment team or GP. This may include wearing compression stockings (below-knee stockings that apply gentle pressure to help blood flow). These must be correctly fitted so get advice from a pharmacist or other healthcare professional.

If you need to have treatment or surgery that will reduce your mobility, discuss this with your specialist. They will let you know if you need to stop taking tamoxifen and how long for.

Can I take tamoxifen with other drugs?

Always check with your treatment team or pharmacist if you're taking any other medicines with tamoxifen.

A few studies have suggested some drugs may interfere with the way tamoxifen works, making it less effective. These include:

- Fluoxetine (Prozac)
- Paroxetine (Seroxat)
- Bupropion (Wellbutrin, Zyban, Voxra, Budeprion or Aplenzin)
- Quinidine (Quinidine Gluconate or Quinidine Sulfate)
- Cinacalcet (Sensipar)

More recent research suggests this is unlikely, but you may be recommended not to use these drugs with tamoxifen. If this is the case, your treatment team may suggest an alternative.

Check with your treatment team before stopping taking these drugs as stopping them suddenly may be harmful.

Herbal products and supplements

Many people consider taking herbal products or supplements while having treatment for breast cancer. However, the exact effect and safety of taking these after a diagnosis of breast cancer is not fully understood. Ask your treatment team or pharmacist before taking any herbal products or supplements.

Find out more about supplements in our **Diet and breast cancer** booklet.

Vaccinations

Tamoxifen does not affect your immune system. This means it's safe to have vaccines while you're taking it.

Sex, contraception and pregnancy

Taking tamoxifen while pregnant may be harmful to a developing baby. It's possible to become pregnant while taking tamoxifen even if your periods have become irregular or stopped.

If you're sexually active with a chance of becoming pregnant, your treatment team is likely to advise you use a non-hormonal method of contraception while taking tamoxifen and for 2 months after stopping. Non-hormonal methods include condoms, Femidoms or a diaphragm. It may also be possible to use a coil (IUD or intrauterine device). However, you would need to discuss this with your treatment team as not all types are suitable for women with breast cancer.

If you think you may be pregnant, tell your specialist as soon as possible.

Does tamoxifen affect fertility?

In most premenopausal women who take tamoxifen, the ovaries continue to work. When you start taking tamoxifen it may stimulate the release of an egg from the ovary (ovulation) and could make you more fertile. However, getting pregnant is not recommended (see “Sex, contraception and pregnancy” on page 15).

Continued use of tamoxifen may make your periods less regular, lighter or stop altogether. Generally, your periods will start again once you stop taking tamoxifen, as long as you have not gone through the menopause naturally while taking the drug. However, it may take 4 to 5 months for your periods to become regular again.

Because of the length of time tamoxifen is taken for, the side effects may hide the signs of a natural menopause. It may only be when you finish taking it that you realise you have started your menopause.

If you want to have children and you’re in your 30s or early 40s, taking hormone treatment for 5 years or more may be a concern. You may want to discuss this with your treatment team and if taking a break from treatment is possible.

For more information see our booklet **Fertility, pregnancy and breast cancer**.

If you’re planning to get pregnant after you’ve finished taking tamoxifen, you’ll likely be advised to wait at least 2 months to allow time for the drug to leave your body completely. Talk to your treatment team about the most appropriate length of time for you.

You’re advised not to breastfeed when taking tamoxifen as it may pass through the bloodstream into the breast milk.

Finding support

If you've been diagnosed with breast cancer, it's completely natural to feel lonely or isolated.

You may find it helps to talk to someone who has been through the same experience as you. You can ask questions and chat to other people on our online forum.

You can also be matched with someone with a similar experience of primary breast cancer through our Someone Like Me service.

If you're living with secondary breast cancer, we have a range of support available through our Living with Secondary Breast Cancer services.

For further information and support or to talk things through, you can speak to one of our specialist nurses by calling our free helpline on **0808 800 6000** or on our website **breastcancernow.org**

We're Breast Cancer Now, the research and support charity. However you're experiencing breast cancer, we're here.

Life-changing support

Whoever you are, and whatever your experience of breast cancer, our free services are here. Whether you're worried about breast cancer, dealing with a diagnosis, working out life with or beyond treatment – or someone you love is.

World-class research

We support over 290 of the brightest minds in breast cancer research. They're discovering how to prevent breast cancer, live well with the disease, and save lives. Every day, they get closer to the next breakthrough.

Change-making campaigns

We fight for the best possible treatment, services and care for everyone affected by breast cancer, alongside thousands of dedicated campaigners.

Could you help?

We don't get any government or NHS funding for our support services or health information. So, we rely on donations and gifts in wills to make our vital work happen. If you'd like to support us, go to breastcancernow.org/give

ABOUT THIS BOOKLET

Tamoxifen was written by Breast Cancer Now's clinical specialists, and reviewed by healthcare professionals and people affected by breast cancer.



For a full list of the sources we used to research it:
Email health-info@breastcancernow.org



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We're here

Information you can trust, support you can count on

Whatever breast cancer brings, we're here for you.

Whether you're looking for information about breast cancer or want to speak to someone who understands, you can rely on us.

Call **0808 800 6000** to talk things through with our helpline nurses.

Visit **breastcancernow.org** for reliable breast cancer information.

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Patient Information Forum

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