

# Tamoxifen

This booklet explains what tamoxifen is, how it works, when it may be prescribed and what side effects may occur.





## **This information is by Breast Cancer Care.**

**We are the only specialist UK-wide charity that supports people affected by breast cancer. We've been supporting them, their family and friends and campaigning on their behalf since 1973.**

Today, we continue to offer reliable information and personal support, over the phone and online, from nurses and people who've been there. We also offer local support across the UK.

From the moment you notice something isn't right, through to treatment and beyond, we're here to help you feel more in control.

For breast cancer care, support and information, call us free on **0808 800 6000** or visit **[breastcancercare.org.uk](https://breastcancercare.org.uk)**



## What is tamoxifen?

Tamoxifen is a drug used to treat breast cancer in both pre-menopausal women (women who have not yet gone through the menopause) and post-menopausal women. It can also be taken by men who have breast cancer.

It's a type of hormone therapy (also known as endocrine therapy).

## How does tamoxifen work?

The hormone oestrogen can stimulate some breast cancers to grow.

Tamoxifen will only be prescribed if your breast cancer has receptors within the cell that bind to the hormone oestrogen, known as oestrogen receptor positive or ER+ breast cancer. Invasive breast cancers are tested for oestrogen receptors using tissue from a biopsy or after surgery. When oestrogen binds to these receptors, it can stimulate the cancer to grow.

Tamoxifen works on the whole body (known as systemic treatment) and blocks the effects of oestrogen on these receptors. This helps to stop oestrogen from encouraging any breast cancer cells to grow.

If oestrogen receptors are not found the breast cancer is known as oestrogen receptor negative or ER-. Tests may also be done for progesterone (another hormone) receptors.

The benefits of hormone therapy are less clear for people whose breast cancer is only progesterone receptor positive (PR+ and ER-). Very few breast cancers fall into this category. However, if this is the case for you your specialist will discuss whether or not tamoxifen is appropriate.

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

Most breast cancers in men are oestrogen receptor positive. For more information see the 'How male breast cancer is treated' section of our website.

# When is tamoxifen prescribed?

## Primary breast cancer

Tamoxifen may be prescribed if you have primary breast cancer (breast cancer that has not spread beyond the breast or the lymph nodes (glands) under the arm (axilla)).

It is usually given as an additional treatment following surgery, to reduce the risk of breast cancer returning in the same breast or a new breast cancer developing in either breast, or spreading somewhere else in the body. This is known as adjuvant (additional) 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 to start.

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. It's sometimes given before surgery (known as neo-adjuvant or primary therapy) to shrink a large breast cancer so that breast-conserving surgery may be possible, rather than a mastectomy. Breast-conserving surgery, also known as wide local excision or lumpectomy, is the removal of the cancer with a margin (border) of normal breast tissue around it, whereas a mastectomy is the removal of all the breast tissue including the nipple area.

For people diagnosed with an early type of breast cancer called ductal carcinoma in situ (DCIS) the benefits of tamoxifen are less clear. Some evidence suggests that taking tamoxifen after surgery for DCIS reduces the risk of breast cancer coming back (recurrence) in the same breast and a new breast cancer developing on either side. Your specialist will discuss whether or not they feel it would be of benefit to you.

## Recurrence or secondary breast cancer

Tamoxifen may also be used to treat breast cancer that has come back in the chest/breast area (known as local recurrence) or surrounding area (known as locally advanced or regional recurrence). It may also be used if you've been diagnosed with secondary breast cancer (when cancer cells from the breast have spread to other parts of the body).

## To reduce the risk of breast cancer developing

Tamoxifen may be an option for some people who do not have breast cancer but who are at an increased risk of developing breast cancer because they have a significant family history. It's given to try to reduce the risk of breast cancer developing. Your specialist will discuss this if it is an option for you. You can find out more about managing an increased risk in our booklet **Family history, genes and breast cancer**.

## How is tamoxifen taken?

Tamoxifen is taken as a tablet. Occasionally it may be prescribed as a liquid for those who have difficulty swallowing. The recommended dose for most people is 20mg daily. It's best to take it at the same time every day. If you miss a dose, you don't 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. If, for any reason, you want to stop taking tamoxifen talk to your specialist first. This is because not taking the drug for the recommended time may increase the risk of your breast cancer coming back.

## How long will I have to take tamoxifen for?

The recommended length of time that tamoxifen is taken for will vary according to individual circumstances.

People being treated for primary breast cancer will usually take tamoxifen for between five and ten years.

If you become post-menopausal while taking tamoxifen, your specialist team may recommend you change from tamoxifen to a different hormone therapy known as an aromatase inhibitor (such as anastrozole, exemestane or letrozole). This can happen after two to three years of taking tamoxifen, or after you have taken tamoxifen for five years. They may do some blood tests to check your menopausal status before changing your hormone therapy.

Sometimes tamoxifen is recommended after taking an aromatase inhibitor.

For more information, see our **Anastrozole (Arimidex), Exemestane (Aromasin) and Letrozole (Femara)** booklets.

For younger women who are pre-menopausal, tamoxifen may be given alone or sometimes alongside ovarian suppression (treatment to stop the ovaries working). For more information about ovarian suppression see our **Ovarian suppression and breast cancer** booklet.

If you're taking tamoxifen for locally advanced breast cancer or for secondary breast cancer, you'll usually continue to take it for as long as it is keeping your 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 five years. See our **Family history, genes and breast cancer** booklet for more information.

## Stopping tamoxifen

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

## What are the possible side effects of tamoxifen?

Like any drug, tamoxifen can cause side effects. Everyone reacts differently to drugs. Some people will have more side effects than others, and some will have none at all. Having few or no side effects doesn't mean the drug is not effective.

Side effects from tamoxifen are not usually severe. However, for some people they can cause distress and disrupt everyday life. Talk to your specialist team or GP as there may be treatments that can help.

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

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 alter the effectiveness of the treatment.

Some people report a change in the side effects they experience if they take tamoxifen made by a different manufacturer. This suggests that some people find tamoxifen produced by one manufacturer suits them better than another.

You may wish to discuss this with your specialist team or GP, or ask the pharmacist who dispenses your prescriptions if they can supply you with tamoxifen from the manufacturer you feel most comfortable with.

## Common side effects

### Menopausal symptoms

The most common side effects that people have when taking tamoxifen are menopausal symptoms. These include hot flushes, night sweats and sleep disturbance, vaginal irritation (such as dryness and itching), loss of sex drive (libido) and mood changes. To find out more about coping with menopausal symptoms see our [Menopausal symptoms and breast cancer](#) booklet.

### Effects on periods

Women who are still having regular periods may find that their periods change. For example, they may be lighter and/or irregular or they might 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 will return after you stop taking tamoxifen (see 'Does tamoxifen affect fertility?' on page 13).

### Fluid retention

Some women find they put on weight during treatment, although there is no clear evidence linking weight gain to tamoxifen. Tamoxifen can sometimes cause fluid retention, which may affect weight.

### Vaginal discharge

Vaginal discharge is common when taking tamoxifen, but let your specialist team or GP know if you experience this so that any infection can be ruled out.

## Indigestion or nausea

Some people experience indigestion or mild nausea. This is usually most noticeable when they start taking tamoxifen. These symptoms generally improve or become easier to manage over time and may be helped by taking the tamoxifen with food.

## Effects on bone health

If you are post-menopausal there is evidence that tamoxifen slows down the process of bone loss, reducing the risk of osteoporosis (thinning of the bone). However, tamoxifen may slightly increase the risk of osteoporosis for pre-menopausal women. This is unlikely to lead to osteoporosis unless treatment has been given to stop the ovaries from working as well.

For more information see our booklet [Osteoporosis and breast cancer treatment](#).

## Less common side effects

### Effects on the uterus

Tamoxifen can affect the lining of the uterus (womb), known as the endometrium, which may become thickened. If you have any unexpected vaginal bleeding or pain, tell your GP or specialist. In a few cases, use of tamoxifen in post-menopausal women may cause polyps or ovarian cysts or, even more rarely, cancer of the uterus (womb). Current evidence suggests that there doesn't appear to be an increased risk of uterine cancer in pre-menopausal women taking tamoxifen.

### Change to hair or facial hair

Some women find they have some hair loss or hair thinning while taking tamoxifen. 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 than usual risk of developing cataracts. If you notice any changes to your vision, tell your GP or specialist.

## 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 pains, tiredness, difficulty concentrating, headaches and leg cramps at night.

## What are the side effects for men?

Men can have similar side effects to those experienced by women, such as hot flushes and headaches. A number of small studies have also noted other side effects, such as decreased sex drive, though this recovered after tamoxifen treatment ended. For more specific information see our web information on breast cancer in men.

## Other issues

### Blood clots

People with breast cancer have a higher risk of blood clots. Their risk is higher because of the cancer itself and some treatments for breast cancer. Having tamoxifen increases the risk of blood clots such as deep vein thrombosis (DVT). People with a DVT are at risk of developing a pulmonary embolism. This is when part of the blood clot breaks away and travels to the lung.

Blood clots can be harmful but are treatable so it's important to report symptoms as soon as possible.

If you experience any of the following symptoms contact your local A&E department, GP or specialist team straight away:

- pain, redness/discolouration, heat and swelling of the calf, leg or thigh
- 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
- tightness in the chest
- unexplained cough (may cough up blood)

If you have had blood clots in the past or are at risk of developing them, your specialist team will take this into account and may use an alternative treatment. If you take an anti-coagulant (medicine that reduces the ability of the blood to clot), such as warfarin, then your doctor may want to monitor you more regularly or may want to consider changing your anti-coagulant medication while you are taking tamoxifen.

People taking tamoxifen need to be aware of the risk of blood clots and ways of helping 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 specialist 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, you should discuss with your specialist team whether you need to stop taking tamoxifen before and after this. Your individual risk of blood clots will be considered and your specialist team will let you know if you need to stop taking tamoxifen and how long for.

# Can I take tamoxifen with other drugs?

If you're taking any other medicines, check with your specialist team if you can take these with tamoxifen.

A few studies have suggested that some drugs like fluoxetine (Prozac), paroxetine (Seroxat), bupropion (Wellbutrin, Zyban, Voxra, Budeprion or Aplenzin), quinidine (Quinidine Gluconate or Quinidine Sulfate) or cinacalcet (Sensipar) may interfere with the way tamoxifen works, making it less effective. More recent research suggests this is unlikely, but it may be recommended that these drugs are not used with tamoxifen, in which case an alternative may be suggested. Always check with your specialist team before you stop taking these drugs as stopping them suddenly may be harmful.

## Herbal medicines and supplements

Many women consider taking herbal products or supplements while having treatment for breast cancer. However, these should be used with care. This is because the exact effect and safety of taking these after a diagnosis of breast cancer is not fully understood. You should ask for advice from your specialist team or pharmacist before considering taking herbal products or supplements.

Find out more about supplements in our [Diet and breast cancer](#) booklet. Our [Complementary therapies, relaxation and wellbeing](#) booklet has information on herbal medicines and homeopathy.

## Contraception while taking tamoxifen

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.

This means that if you are sexually active with a man your specialist is likely to advise using a non-hormonal method of contraception such as condoms, Femidoms or a diaphragm while you're taking tamoxifen and for two months after treatment has finished. It may also be possible to use a coil (IUD or intrauterine device). However, you would need to discuss this with your specialist 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 pre-menopausal women who take tamoxifen, the ovaries continue to work. When you start taking tamoxifen it may stimulate ovulation (the release of an egg from the ovary) and could make you more fertile. However, getting pregnant is not recommended (see 'Contraception while taking tamoxifen' above).

For some women, continued use of tamoxifen means periods become 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 four to five 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 five years or more may be an issue you want to discuss with your specialist team. A trial called the POSITIVE trial (Pregnancy Outcome and Safety of Interrupting Therapy for Women With Endocrine Responsive Breast Cancer) is looking into the safety

of interrupting hormone treatment to try to get pregnant, but this is currently not recruiting in the UK.

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

If you are planning to get pregnant after you have finished taking tamoxifen, it is advisable to wait at least two months to allow time for the drug to leave the body completely. You should talk to your specialist team about the most appropriate length of time for you.

Women taking tamoxifen are advised not to breastfeed as it may pass through the blood stream into the breast milk.







## Four ways to get support

We hope this information was helpful, but if you have questions, want to talk to someone who knows what it's like or want to read more about breast cancer, here's how you can.



Speak to trained experts, nurses or someone who's had breast cancer and been in your shoes. Call free on **0808 800 6000** (Monday to Friday 9am–5pm, Wednesdays til 7pm and Saturday 9am–1pm).



Chat to other women who understand what you're going through in our friendly community, for support day and night. Look around, share, ask a question or support others at **[forum.breastcancercare.org.uk](https://forum.breastcancercare.org.uk)**



Find trusted information you might need to understand your situation and take control of your diagnosis or order information booklets at **[breastcancercare.org.uk](https://breastcancercare.org.uk)**



See what support we have in your local area. We'll give you the chance to find out more about treatments and side effects as well as meet other people like you. Visit **[breastcancercare.org.uk/in-your-area](https://breastcancercare.org.uk/in-your-area)**

# We're here for you: help us to be there for other people too

If you found this booklet helpful, please use this form to send us a donation. Our information resources and other services are only free because of support from people such as you.

We want to be there for every person facing the emotional and physical trauma of a breast cancer diagnosis. Donate today and together we can ensure that everyone affected by breast cancer has someone to turn to.

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We might occasionally want to send you more information about our services and activities

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Chester House, 1-3 Brixton Road, London SW9 6DE



# About this booklet

**Tamoxifen** was written by Breast Cancer Care'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:

Phone **0345 092 0808**

Email [publications@breastcancercare.org.uk](mailto:publications@breastcancercare.org.uk)



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When you have breast cancer, everything changes. At Breast Cancer Care, we understand the emotions, challenges and decisions you face every day, and we know that everyone's experience is different.

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