

TAMOXIFEN

An abstract graphic consisting of large, overlapping organic shapes. A large orange shape is on the left, and a bright yellow shape is on the right, overlapping the orange one. The background is a solid pink color.

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ABOUT THIS BOOKLET

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

WHAT IS TAMOXIFEN?

Tamoxifen is a drug used to treat breast cancer in both premenopausal women (women who have not yet gone through the menopause) and postmenopausal 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?

Some breast cancers use oestrogen in the body to help them grow.

These are known as oestrogen receptor positive or ER+ breast cancers.

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

WHO WILL BE OFFERED TAMOXIFEN?

Tamoxifen will only be prescribed if your breast cancer is ER+.

Invasive breast cancers are tested to see if they are ER+ using tissue from a biopsy or after surgery.

If your breast cancer is not stimulated by oestrogen it is known as oestrogen receptor negative (ER-).

Tests will also be done to see if your breast cancer is progesterone receptor positive (PR+). Progesterone is another hormone.

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 with you 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.

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 (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 for you to do this.

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 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. 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 in the same breast and a new breast cancer developing on either side. Your specialist will discuss whether they feel it would benefit you.

Breast cancer that has come back or spread

Tamoxifen can also be used to treat people 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 tissues and lymph nodes around the chest, neck and under the breastbone. Sometimes breast cancer is locally advanced when it is first diagnosed. This may also happen when breast cancer comes back after treatment and may be referred to as regional recurrence
- Secondary (metastatic) breast cancer – breast cancer that has 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 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. Your specialist will discuss this if it is an option for you.

HOW IS TAMOXIFEN TAKEN?

Tamoxifen is taken as a tablet.

Occasionally it may be prescribed as a liquid for people 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.

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?

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

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

If you become postmenopausal 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). 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 whether you are menopausal 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 ovarian suppression (treatment to stop the ovaries working).

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 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 five 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 specialist first. This is because 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. Some people will have more side effects than others, while others don't experience any side effects at all. Having few or no side effects does not mean the drug is not effective.

Side effects from tamoxifen are usually not severe. However, for some people they can 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 below or not, talk to your treatment 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 say they notice 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 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 the 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
- 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 are worried about this, let your treatment team or GP know so they can rule out an infection.

Effects on periods

Women who are still having regular periods may find that their 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 13).

Fluid retention

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

Indigestion or nausea

Some people have indigestion or mild nausea (feeling sick). 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 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 osteoporosis (thinning of the bone). 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

Cancer-related fatigue is extreme tiredness and exhaustion that doesn't go away with rest or sleep. It can affect you physically and emotionally. It's a very common side effect of tamoxifen and may last for weeks or months after your treatment has finished. Occasionally fatigue is a long-term effect.

Fatigue can also be caused by conditions such as anaemia (too few red blood cells). It's important to let your team know if you're affected by fatigue to rule out other conditions. Fatigue affects people in different ways and there's 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 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.

In a few cases, 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.

Change to hair or facial hair

Some women 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 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 pains
- 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. Their risk is higher because of the cancer itself and some treatments for breast cancer. If the cancer has spread to other parts of the body (secondary breast cancer), this also increases the risk.

Taking 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 (PE). 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 treatment team straight away:

- Pain, redness/discolouration, heat and swelling of the calf 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
- Pain or tightness in the chest
- Unexplained cough or coughing up blood

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 use an alternative treatment.

If you take an anti-coagulant (medicine that reduces the ability of the blood to clot), such as warfarin, 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 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) or cinacalcet (Sensipar).

More recent research suggests this is unlikely, but you may be recommended not to use these drugs with tamoxifen, in which case an alternative may be suggested.

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

HERBAL MEDICINES 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 herbal products or supplements.

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

CAN I HAVE A COVID-19 VACCINE IF I'M TAKING TAMOXIFEN?

Tamoxifen does not affect your immune system. Therefore, it should not reduce the effectiveness of a Covid-19 vaccine, and it should be safe to have the vaccine if you're taking tamoxifen.

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.

If you're sexually active with a chance of becoming pregnant, your specialist is likely to advise you use a non-hormonal method of contraception while taking tamoxifen and for two 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 '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 a concern you want to discuss with your treatment team.

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

If you're planning to get pregnant after you have finished taking tamoxifen, it's advisable to wait at least two months to allow time for the drug to leave the body completely. Talk to your treatment team about the most appropriate length of time for you.

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

FINDING SUPPORT

Being diagnosed with breast cancer can make you feel lonely and isolated.

Many people find it helps to talk to someone who has been through the same experience as them. You can ask questions and chat to other people on Breast Cancer Now's online Forum.

For further information and support or to talk things through, you can speak to one of our experts by calling our free Helpline on **0808 800 6000**.

HELP US TO HELP OTHERS

If you have found this information helpful, would you consider making a donation to support our care and research work? You can donate on our website **breastcancer.org/donate**

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



You can order or download more copies from
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We welcome your feedback on this publication:
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BREAST CANCER NOW

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At Breast Cancer Now we're powered by our life-changing care. Our breast care nurses, expertly trained staff and volunteers, and award-winning information make sure anyone diagnosed with breast cancer can get the support they need to help them to live well with the physical and emotional impact of the disease.

We're here for anyone affected by breast cancer. And we always will be.

For breast cancer care, support and information, call us free on **0808 800 6000** or visit **breastcancernow.org**

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Patient Information Forum

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