

Tamoxifen

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

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 (women who have gone through the menopause). It can also be taken by men who have breast cancer.

It's a type of hormone treatment, also known as endocrine therapy.

How does it work?

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). All 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 the receptors. This helps to stop any breast cancer cells from growing.

When oestrogen receptors are not found (oestrogen receptor negative or ER-) tests may be done for progesterone (another hormone) receptors. As oestrogen receptors play a more important role than progesterone 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 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?

Tamoxifen can be used for primary breast cancer (breast cancer that has not spread beyond the breast or the lymph nodes (glands) under the arm) as additional treatment following surgery, to reduce the risk of the cancer coming back and to reduce the risk of a new breast cancer developing. 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.

For people diagnosed with an early form of breast cancer called ductal carcinoma in situ (DCIS) the role of tamoxifen is less clear. There are ongoing clinical trials looking into its use. Your specialist will discuss whether or not they feel it would be of benefit to you.

Occasionally, tamoxifen may be used as the first treatment for breast cancer. This may be when surgery is not appropriate, or before surgery, to shrink a large breast cancer so that breast-conserving surgery (usually referred to as wide local excision or lumpectomy) may be possible, rather than a mastectomy (removal of the whole breast).

Tamoxifen may also be used for breast cancer that has come back in the breast or surrounding area, or for people diagnosed with secondary breast cancer (when cancer cells from the breast have spread to other parts of the body).

Tamoxifen may be an option for some people who have a high risk of developing breast cancer because of 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.

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 worsen your outlook.

How long will I have to take tamoxifen?

The recommended length of time that tamoxifen is taken will vary according to individual circumstances. People being treated for primary breast cancer will usually take tamoxifen for between five and 10 years.

Some women who have gone through the menopause will change 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. 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 please see our **Ovarian suppression** booklet.

If you are taking tamoxifen for breast cancer that has come back in the breast or surrounding area, or for secondary breast cancer, you will usually continue to take it for as long as it is keeping your cancer under control.

What are the possible side effects of tamoxifen?

Everyone reacts differently to drugs. Some people will experience more side effects than others, while some people do not experience any side effects at all. The side effects of tamoxifen are listed below.

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 seems to suit them better than another.

You may wish to discuss this with your specialist 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

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, Your body, intimacy and sex** and **Complementary therapies** booklets.

Women who are still having regular periods may find that these change. For example, they may be lighter and/or irregular or 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.

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

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.

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, pre-menopausal women may be at risk of thinning of the bones when taking tamoxifen. 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 **Breast cancer treatment and the risk of osteoporosis**.

Less common or rare side effects

Taking tamoxifen increases the risk of blood clots such as deep vein thrombosis (DVT). Tell your doctor straight away if you experience symptoms such as a swelling or pain in your leg. 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. If you experience shortness of breath, chest pain or cough up blood you need to see a doctor urgently.

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

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 whether you need to stop taking tamoxifen before and after this. Your specialist will let you know how long this will be for, but it's likely to be a couple of weeks.

Tamoxifen can also affect the lining of the uterus or 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 very few cases, prolonged use of tamoxifen may cause polyps or ovarian cysts or, even more rarely, cancer of the uterus (womb).

A small number of women notice an increase in downy facial hair or changes to their singing voice. Some women find they have some hair loss or hair thinning while taking tamoxifen.

There is a very slight risk of changes to your vision. If you notice this, tell your GP or specialist.

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 almost certainly go back to normal.

Other reported side effects include joint pains, tiredness, difficulty concentrating, headaches and leg cramps at night.

Some women find they put on weight during treatment, although there is no clear evidence linking weight gain to tamoxifen.

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

Are there different 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 **Men with breast cancer** publication.

Can I take tamoxifen with other drugs?

Always check with your specialist if you are taking any other medicines 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), 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.

Many women consider taking herbal medicines 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 before considering taking herbal medicines or supplements.

NICE (National Institute for Health and Care Excellence) is an independent organisation responsible for providing evidenced-based national guidance in England on effective ways to prevent, diagnose and treat ill health. NICE does not recommend soy (isoflavones), red clover, black cohosh or vitamin E supplements for the treatment of menopausal symptoms in women with breast cancer because the evidence on their effectiveness and safety is limited and conflicting.

Fertility and pregnancy

In most pre-menopausal women who take tamoxifen the ovaries continue to work. When you start taking tamoxifen it may stimulate ovulation (release of the egg from the ovary) and could make you more fertile. With continued use, in some women 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.

While you're taking tamoxifen you will be advised not to get pregnant as it may harm a developing baby. Even if your periods stop while you are taking tamoxifen you could still get pregnant. This means that if you are sexually active with a man while taking tamoxifen, your specialist is likely to advise you to use a non-hormonal or effective barrier method of contraception. If you think you may be pregnant, tell your specialist as soon as possible.

Because of the length of time tamoxifen is taken for, the side effects may mask the onset 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 are in your late 30s or early 40s you can discuss the length of time tamoxifen is recommended for with your specialist team.

For more information see our publication **Fertility issues 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.

Further support

If you have any concerns about taking tamoxifen, you can talk to your specialist or breast care nurse. You may also find it helpful to talk to someone who has had a similar experience to you. You can do this one to one, or in a support group.

For more information on individual support or support groups in your area, call our Helpline on **0808 800 6000** (Text Relay 18001).

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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:

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