



# Tamoxifen

Reducing your risk of developing breast cancer

Patient Information Leaflet

This information can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request.

Please contact the team by email on: [gmcancer.comms@nhs.net](mailto:gmcancer.comms@nhs.net), or by writing to

The Greater Manchester Cancer Alliance, c/o The Christie NHS Foundation Trust, Wilmslow Road, Manchester M20 4BX.

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## Taking tamoxifen to reduce your chance of developing breast cancer in the future

This leaflet contains information about the medication tamoxifen. Your medical team have offered you tamoxifen to reduce your risk of developing breast cancer. We hope the information in this leaflet will help you to decide whether tamoxifen is the right option for you.



### What is my risk of breast cancer?

In the UK, about one out of every eight women will get breast cancer in their lifetime.

A specialist nurse or doctor has reviewed the information you gave them, including how many members of your family have had cancer. This information has shown that you have a higher risk of getting breast cancer in your life than the general population. Your specialist nurse or doctor will be able to give you more accurate information about your personal breast cancer risk.

The National Institute for Health and Care Excellence (NICE) says that all women with your level of risk should be offered medication to reduce their risk.





## Taking tamoxifen if you want to become pregnant

Tamoxifen is not safe to take whilst pregnant or breast feeding, as it can harm the baby.

You should avoid getting pregnant whilst taking tamoxifen. Ask your doctor or nurse about contraception if this applies to you.

You should stop taking tamoxifen at least 3 months before trying to get pregnant.

## Breast screening

Your breast screening (regular mammograms and, for some women, MRI scans) will continue whether or not you choose to take tamoxifen.

Breast screening helps to find breast cancer early which means it is easier to treat.

We hope that the information in this leaflet helps you to decide if tamoxifen is the right option for you. This is your personal choice, and your medical team will support your decision.

If you have any questions, or want to discuss tamoxifen medication in more detail, please speak to the nurses or doctors in your medical team.



## What is tamoxifen?

Tamoxifen is a medicine that can reduce the risk of developing breast cancer. Tamoxifen is taken as one 20mg tablet each day, for five years.

Tamoxifen works by blocking the effect of a hormone in your body called oestrogen. Sometimes oestrogen can cause breast tissue to grow abnormally and turn into a breast cancer. Tamoxifen can stop this from happening and reduce your risk of developing breast cancer.

Around a fifth of breast cancers (1 in 5) are not affected by oestrogen. Tamoxifen can only lower the risk of developing breast cancer that is caused by oestrogen.

Taking tamoxifen for five years will lower your risk of getting breast cancer for the five years you take tamoxifen, and for at least 15 years after you have stopped taking it.

## Do I have to take tamoxifen?

**You do not have to take tamoxifen – it is your decision.**

To help you make your decision, we would like to explain the possible benefits and side effects of tamoxifen.

These are the key points to think about.

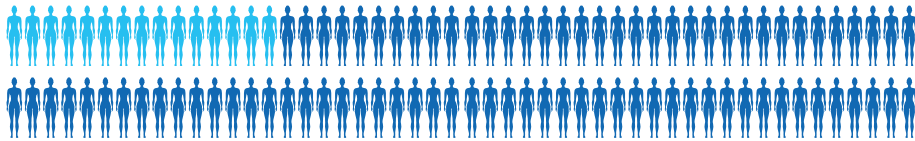
- No one knows what will happen to you in the future
- If you have a higher risk of getting breast cancer it does not mean you will definitely get breast cancer
- Taking tamoxifen will lower your risk of getting breast cancer in the future
- Tamoxifen lowers the risk of getting breast cancer, but it does not take away the risk completely
- Some women who take tamoxifen will still get breast cancer
- You may experience side effects when taking tamoxifen

## How will taking tamoxifen affect my risk of developing breast cancer?

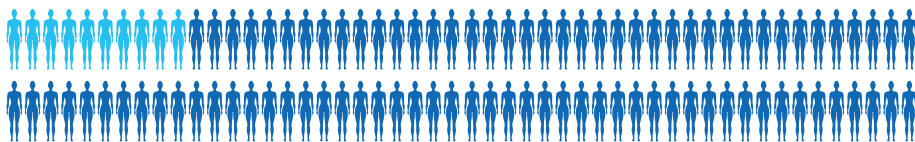
**If you take tamoxifen, you will lower your risk of getting breast cancer by one third (about thirty three).**

Here is an example of a woman called Mary to explain what the reduction in risk means:

- Mary is 40 years old and has a 15% risk of developing breast cancer over the next 20 years
- This means that if 100 women like Mary did **not** take tamoxifen, then **15** of them would develop breast cancer by the age of 60



- If 100 women like Mary did take tamoxifen, then **10** of them would develop cancer by the age of 60



- It is likely that Mary's risk of developing breast cancer will continue to be reduced for the rest of her life having taken tamoxifen for five years

Your breast specialist nurse or doctor will be able to tell you your personal lifetime risk of developing breast cancer and how much your risk will reduce by taking tamoxifen.

## Effects on the womb

In a few cases, tamoxifen may cause polyps in the womb or cysts in the ovaries. If you are pre-menopausal (have not gone through the menopause), then taking tamoxifen does not increase your risk of developing cancer of the womb.



If you are post-menopausal (have gone through the menopause), then taking tamoxifen slightly increases your risk of developing cancer of the womb.

We do not recommend taking tamoxifen to reduce the risk of breast cancer if you are post-menopausal and still have your womb (have not had a hysterectomy). You can ask your specialist nurse or doctor for information about other medications to reduce the risk of breast cancer that do not increase the risk of developing cancer of the womb. These medications are called anastrozole and raloxifene.

## Osteoporosis (thinning of the bones)

Tamoxifen reduces bone density (strength) by a small amount. If you are pre-menopausal, taking tamoxifen may slightly increase your risk of developing osteoporosis.



# There are some other side effects of taking tamoxifen that you should be aware of:

## Blood Clots

Tamoxifen can increase the risk of blood clots in the legs or the lungs. Blood clots are serious and can be life threatening.



The medical name for this is Deep Vein Thrombosis (DVT) in the legs and Pulmonary Embolus (PE) in the lungs.

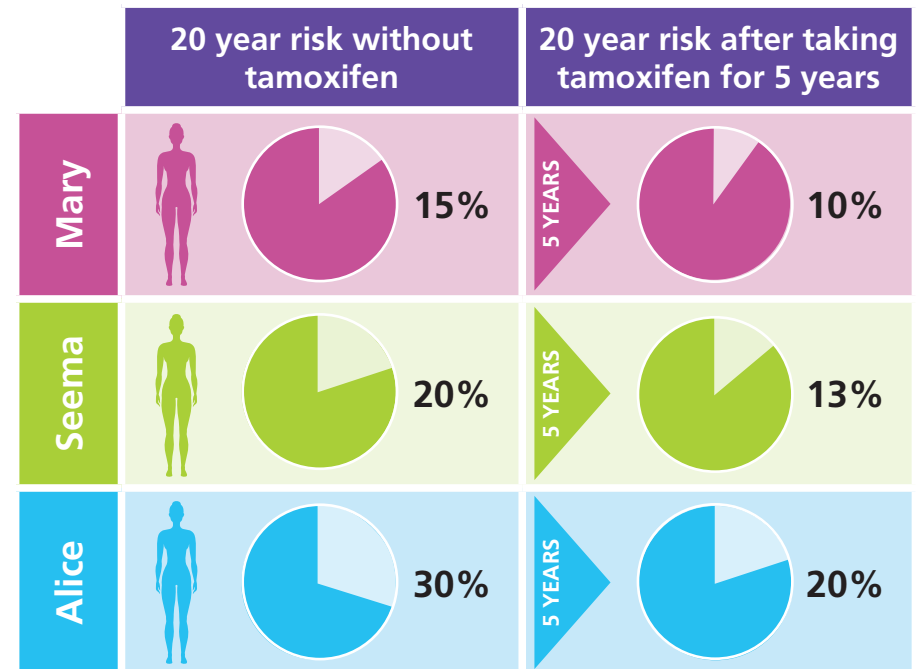
The number of women who develop blood clots is small. In the general population, 2 women out of 1000 will develop a blood clot each year. If all of those women took tamoxifen, about 4 women would develop a blood clot per year. The increase in your risk of getting a blood clot is the same as if you were taking the combined oral contraceptive pill.

If you are having a planned operation, you should stop taking tamoxifen for 6 weeks before the operation and restart it when you are mobile again afterwards. If you become immobile for other reasons, for example, if you break your leg, you should stop taking tamoxifen until you are mobile again.

Going on a long-haul flight (that lasts longer than 8 hours) can also increase the risk of Deep Vein Thrombosis (DVT). It is a good idea to wear full length flight stockings, stay well hydrated, and move around the cabin regularly if you go on a long-haul flight whilst taking tamoxifen.



Your risk of developing breast cancer will be different to other women. The diagram below shows how taking tamoxifen lowers the risk of developing breast cancer for three different women, who all have a different level of risk.



Please remember that the benefits of taking tamoxifen go on for longer than the 5 years the medication is taken.

## What are the possible side effects of taking tamoxifen?

Tamoxifen can cause side effects. Many women do not experience any side effects and some women only experience mild side effects. The most common side effects that women get from taking tamoxifen are similar to symptoms of the natural menopause. It is common for menopausal side effects like hot flushes to reduce or even stop after the first few months of treatment. Whilst you are taking tamoxifen you may have menopausal symptoms due to your natural menopause. These symptoms are not related to taking the medication.

### Possible common side effects of taking tamoxifen include:

- Hot flushes
- Night sweats that can interfere with sleep
- Vaginal dryness or discharge
- Mood swings
- Hair thinning
- Brittle nails

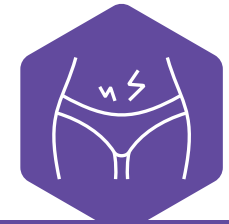


If you do have menopausal side effects there are ways to help reduce or control them. You can speak to your GP, or the nurses or doctors in your medical team for advice about this. It is worth trying to manage your side effects to complete your course of treatment, here are some things you can try.



### Hot flushes and night sweats may be improved with the following recommendations:

- Wear loose clothes, keep rooms well-ventilated, take a cool shower before bed, use light bed sheets and a cooling pillow to aid sleep
- Reducing caffeine, alcohol and spicy food and stopping smoking, as they can all trigger hot flushes
- Regular exercise and maintaining a healthy weight can reduce hot flushes and improve sleep



### Vaginal dryness or discomfort is a menopausal symptom which can often be managed:

- It is safe to use vaginal moisturisers that do not contain oestrogen e.g. ReplensMD. These should be used regularly, not just for sexual intercourse
- If symptoms persist, despite vaginal moisturisers, most breast cancer specialists agree that a vaginal lubricant containing a low dose of oestrogen (0.005% oestriol vaginal gel) is safe to use
- You can ask your GP to prescribe these vaginal treatments

There are tablets that can also help with menopausal side effects like hot flushes, night sweats and mood swings. Your GP can prescribe these tablets (called oxybutynin and venlafaxine) if you have menopausal side effects. If you have side effects, you can stop taking tamoxifen at any time during the 5-year course and the side effects caused by tamoxifen will go away.