

CAPECITABINE

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About this booklet

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

This booklet explains what capecitabine is, when it may be given, how it works and the side effects you might have.

What is capecitabine?

Capecitabine is a chemotherapy drug. You may hear it called by its brand name Xeloda.

Chemotherapy destroys cancer cells by affecting their ability to divide and grow. Chemotherapy also affects other cells throughout the body, which causes side effects.

You may find it useful to read this booklet alongside our **Chemotherapy for breast cancer** booklet.

If you're taking capecitabine for secondary breast cancer (when cancer has spread from the breast to other parts of the body), you may want to read our **Secondary breast cancer information pack**.

When is capecitabine given?

For some people with primary breast cancer

Primary breast cancer is breast cancer that has not spread beyond the breast or the lymph nodes under the arm.

You may benefit from capecitabine if you have primary breast cancer that is triple negative (oestrogen receptor negative, progesterone receptor negative and HER2-negative).

If you have chemotherapy before surgery you may be offered capecitabine after your surgery.

Your treatment team will discuss with you if this is an option.

When breast cancer has spread

Capecitabine is used to treat breast cancer that has come back (recurrence) after previous treatment. This could be:

- Locally advanced breast cancer (sometimes called regional recurrence) – breast cancer that has come back and has spread to the chest wall or skin of the breast, or lymph nodes around the chest, neck and under the arm or breastbone but has not spread to other areas of the body. It cannot be removed by surgery
- Secondary breast cancer – when cancer has spread from the breast to other parts of the body, such as the bones, lungs, liver or brain. Also called metastatic, advanced or stage 4 breast cancer

As part of a clinical trial

Capecitabine may be offered as part of a clinical trial.

Clinical trials are research studies that aim to improve treatment or care. See our website breastcancer.org for general information on clinical trials, or cancerresearch.org.uk for listings of current UK clinical trials.

Before starting capecitabine

Before starting your treatment, a member of the treatment team will discuss how and when you'll have chemotherapy and how side effects can be managed.

You'll have blood tests, and your height and weight will be measured.

You may also have tests to check your heart function, such as:

- An ECG (electrocardiogram), a simple test that checks your heart rhythm
- An echocardiogram (an ultrasound scan of the heart)

You should be given a 24-hour contact number or told who to contact if you feel unwell at any time during your treatment, including overnight or at the weekends.

DPD testing

Before starting capecitabine you will be offered a blood test to check your levels of DPD.

DPD is a type of protein (enzyme) made naturally in the body. Not having enough DPD can cause capecitabine to build up in the body, resulting in severe side effects. In very rare cases this can be life-threatening.

If you have low levels of DPD, or no DPD (known as a DPD deficiency), your treatment team may offer you a reduced dose of capecitabine or a different chemotherapy drug.

For more information on DPD see the Cancer Research UK website cancerresearchuk.org

How is capecitabine taken?

You will take capecitabine as a tablet (orally).

Capecitabine is available in 2 different tablet strengths (150mg or 500mg). Your treatment team will tell you how many of each tablet to take to make sure you get the right amount each day for your body size.

You should swallow the tablets whole with water within half an hour of eating a meal. It's important not to break, crush or chew the tablets. Talk to your treatment team if you find it difficult to swallow tablets.

You usually take capecitabine twice a day (once in the morning and once in the evening) for 14 days. You will then have a 7-day break. This 21-day period is often referred to as 1 treatment cycle. If you're prescribed capecitabine differently to the 21-day cycle, your treatment team will explain why.

Capecitabine is often taken on its own, but you may have it alongside other chemotherapy drugs.

Handling and storing chemotherapy drugs

It's important to remember the following when you're taking capecitabine at home. You can find out more information about handling chemotherapy drugs at home on the Cancer Research UK website.

After taking your tablets

Wash your hands after taking your capecitabine tablets.

If you are sick (vomit) after taking your tablets, do not take an extra dose.

Storing your tablets

Keep the tablets in their original packaging. Store them at room temperature, away from moisture, heat and direct sunlight.

Keep the tablets out of the reach of children. Avoid having other people touch the tablets directly.

At the end of your capecitabine treatment

Do not throw away unused capecitabine tablets. Return them to your treatment team.

How long will I have to take capecitabine for?

How long you need to take capecitabine for varies from person to person.

Primary breast cancer

If you have primary breast cancer, your treatment team will talk to you about how many treatment cycles of capecitabine you will have.

Secondary breast cancer

If you have secondary breast cancer, you'll keep taking capecitabine for as long as your treatment team feels you're benefiting from the drug and any side effects are manageable.

Side effects of capecitabine

Like any treatment, capecitabine can cause side effects. Everyone reacts differently to drugs and some people have more side effects than others. These side effects can usually be managed and those described here will not affect everyone.

If you're worried about any side effects, regardless of whether they're listed here, talk to your chemotherapy nurse or treatment team.

Doctors can tailor the dose of a drug by reducing it to suit an individual and to help manage its side effects. For some people this can help them stay on a treatment for longer.

Common side effects

Effects on the blood

Capecitabine can temporarily affect the number of blood cells in the body. Blood is made up of red cells, white cells and platelets.

You'll have regular blood tests. If these show the number of blood cells is too low, your next cycle of treatment may be delayed or the dose of chemotherapy reduced.

Risk of infection

Not having enough white blood cells can increase your risk of getting an infection.

Your treatment team may give you advice to follow for reporting signs of an infection. But generally you should contact your hospital advice line immediately if you have any of the following:

- A high temperature (over 37.5°C) or low temperature (under 36°C), or whatever your chemotherapy team has advised
- Suddenly feeling unwell, even with a normal temperature
- Symptoms of an infection, such as a sore throat, cough, needing to pass urine often or feeling cold or shivery

Before starting chemotherapy you should be given a 24-hour contact number or told where to get emergency care by your treatment team.

You may need treatment if you have an infection.

Sometimes your doctor may recommend injections of drugs called growth factors. This helps the body produce more white blood cells to reduce your risk of infection.

Anaemia

Having too few red blood cells is called anaemia. If you feel breathless, dizzy or particularly tired, let your treatment team know.

Bruising and bleeding

Capecitabine can reduce the number of platelets, which help the blood to clot.

You may bruise more easily, have nosebleeds or your gums may bleed when you brush your teeth.

Tell your treatment team if you have any of these symptoms.

Diarrhoea

Diarrhoea is common during treatment and can sometimes be severe.

Tell your chemotherapy team as they can prescribe medication and may consider stopping your capecitabine for a time to help control it.

Speak to them immediately if you have any of the following symptoms:

- 3 or more episodes of diarrhoea in 24 hours
- Blood in your poo when you go to the toilet
- Tummy (abdominal) pain

Feeling sick (nausea) and being sick (vomiting)

You may feel sick (nausea) or be sick (vomit), but many people will not actually be sick.

You will be given anti-sickness medication before you have chemotherapy. Your treatment team will also prescribe you anti-sickness drugs to take home to reduce or prevent nausea.

Sore mouth

Looking after your mouth, including your teeth and gums, is very important during treatment.

You may be given mouthwash to try to reduce soreness and stop mouth ulcers developing. You may be advised to use a small, soft toothbrush during this time.

See your dentist for a check-up before treatment with chemotherapy begins. Avoid dental work during chemotherapy if possible.

If you do need to have dental work during treatment, talk with your treatment team about the best time to have this.

Skin changes on your hands and feet

Hand-foot syndrome (palmar-plantar syndrome) is a common side effect of capecitabine.

The palms of the hands and the soles of the feet can become red, darkened and sore. They can also become dry and flaky.

You may also notice:

- A tingling feeling
- Numbness
- Some swelling

There are things that you can do that may reduce the chances of developing hand-foot syndrome.

Things to do

- Regularly apply hand and foot creams or lotions containing urea to keep the skin well moisturised before starting treatment
- Continue to regularly apply creams or lotions throughout your treatment
- Wear loose-fitting, comfortable clothing and footwear to avoid rubbing
- Take lukewarm or cool baths and showers
- Pat skin dry rather than rubbing it
- Use rubber gloves that have a liner when washing up
- Cool your hands and feet with cold running water, ice packs or cool compresses for short bursts of time (no longer than 15 minutes). Do not apply ice directly to your skin

Things to avoid

- Avoid having your hands or feet in hot water
- Avoid using saunas or steam rooms
- Avoid harsh chemicals like the ones used in some laundry detergents or cleaning products, or chlorine in swimming pools
- Avoid exposing any affected areas to the sun
- Avoid sporting or other activities that cause rubbing or friction on the hands or feet
- Avoid using tools or household items that require you to apply pressure with your hands or feet onto a hard surface (for example, garden tools or screwdrivers)
- Try not to walk barefoot. Instead, wear soft slippers or socks

It's important to let your treatment team know if you have any symptoms as they may prescribe emollients or creams to apply to the affected areas.

If your symptoms are severe, your treatment team may recommend delaying treatment, reducing the dose, or stopping treatment. Symptoms usually get better once treatment is reduced or stopped. Your skin should start to improve within a few weeks.

If you develop severe and ongoing hand-foot syndrome while taking capecitabine, you may lose your fingerprints. This is a rare symptom, but it may be permanent.

Changes to your appetite

You can lose your appetite while you are taking capecitabine. Your sense of taste can also change, so some foods and drink may taste different.

Talk to your treatment team about this. They will give you advice and information or refer you to a dietitian if needed.

You can also find out more in our **Diet and breast cancer** booklet.

Extreme tiredness (cancer-related fatigue)

Fatigue is extreme tiredness that does not go away with rest or sleep. It's a very common side effect of cancer treatment.

Cancer-related fatigue is one of the most common symptoms in people with secondary breast cancer.

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.

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*.

Less common side effects

Hair thinning

When used on its own, capecitabine occasionally causes some temporary hair thinning. It very rarely causes complete hair loss.

If capecitabine is taken in combination with another chemotherapy drug, most people will lose all their hair including eyebrows, eyelashes and body hair.

For more information, see our **Breast cancer and hair loss** booklet.

Other less common side effects

Other less common side effects of capecitabine include:

- Joint and back pain
- Taste changes
- Headache
- Dizziness
- Difficulty sleeping
- Sore and watery eyes

Your treatment team can advise on how to manage these.

Rare side effects

Allergic reaction

Contact your hospital immediately if you notice any of the following symptoms:

- Itchy red/discoloured bumps on your skin (these may be harder to see on black or brown skin)
- Swelling in your lips, tongue or throat
- Breathlessness, wheezing, a bad cough or sudden difficulty breathing
- Tight chest or chest pain

If you have a severe reaction, treatment will be stopped immediately.

If you have a less severe reaction, you may need to take medication before future treatments to reduce the risk of further reactions.

Blood clots

People with breast cancer have a higher risk of blood clots. Having chemotherapy 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, 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)

Other important information

What happens if I miss a dose?

If you miss a dose of capecitabine, do not take an extra dose to make up for the one you missed. Take the next dose at the usual time and speak to your treatment team.

Driving and using machinery

Capecitabine may make you feel dizzy, sick or tired. This could affect your ability to drive or operate machinery safely.

Avoid driving or using machinery if you have any symptoms that may affect your ability to do this.

Can I take capecitabine with other drugs?

If you're taking any other prescribed or over-the-counter medicines, let your treatment team know.

If you take drugs to thin the blood (anti-coagulants) such as warfarin, capecitabine can increase your risk of bleeding. Your treatment team may check more often how quickly your blood clots, adjust your dose of blood-thinning drugs or, more commonly, change you to an injection to thin the blood instead.

For more information about taking other medicines or supplements while having chemotherapy, see our **Chemotherapy for breast cancer** booklet.

Sex, contraception and pregnancy

You can still have sex during treatment. It's thought chemotherapy drugs cannot pass into vaginal fluids or semen, but this cannot be completely ruled out.

Most treatment teams will advise using barrier methods of contraception, such as condoms, during treatment.

You're advised not to become pregnant while having treatment and for 6 months after taking your last dose. This is because capecitabine can harm a developing baby. If you have not been through the menopause, talk to your treatment team about the most suitable method of contraception for you. It's still possible to become pregnant even if your periods are irregular or have stopped.

Vaccinations

Travel

If you're planning a holiday or need to travel overseas, check with your treatment team first.

You should not have any live vaccines while you're having chemotherapy.

Live vaccines include:

- Mumps
- Measles
- Rubella (German measles)
- Polio
- BCG (tuberculosis)
- Yellow fever

Live vaccines contain a small amount of live virus or bacteria. If you have a weakened immune system, which you may do during chemotherapy, they could be harmful.

It's safe to have these vaccinations 6 months after your treatment finishes. Talk to your GP or treatment team before having any vaccinations.

If anyone you have close contact with needs to have a live vaccine, speak to your treatment team or GP. They can advise what precautions you may need to take depending on the vaccination.

COVID-19 vaccination

If you're having chemotherapy or targeted therapies, your treatment team will advise the best time to have a COVID-19 vaccination.

Flu vaccination

Anyone at risk of a weakened immune system, and therefore more prone to infection, should have the flu vaccine. This includes people due to have, or already having, chemotherapy.

The flu vaccine is not a live vaccine so does not contain any active viruses.

Talk to your chemotherapy team or breast care nurse about the best time to have your flu jab.

Nasal flu vaccine for children

The nasal flu vaccine offered to children is a live vaccine. Let your treatment team know if someone you live with needs the nasal flu vaccine.

Further support

Your chemotherapy team and breast care nurse can help with any questions you have. You can also call our free helpline on **0808 800 6000** for information and support, or visit our website [breastcancer.org](https://www.breastcancer.org)

If you're having chemotherapy for primary breast cancer, our Someone Like Me service can put you in touch with someone who has had the same experience as you.

You can find people going through treatment at the same time as you on the monthly chemotherapy threads on our online forum [forum.breastcancer.org](https://www.breastcancer.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 breastcancer.org/give

ABOUT THIS BOOKLET

Capecitabine 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@breastcancer.org



You can order or download more copies from
breastcancer.org/publications



We welcome your feedback on this publication:
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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 **breastcancer.org** for reliable breast cancer information.

Breast Cancer Now

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Patient Information Forum

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