

Oncology department

Capecitabine and temozolomide for neuroendocrine cancers

Information for patients, relatives and carers

Introduction

This leaflet provides information on a course of chemotherapy called capecitabine and temozolomide. Your doctor has prescribed this treatment because it has been found to be effective in treating your type of cancer. This leaflet explains how and when you take this treatment, and about common side effects. Contact telephone numbers and details of how to get further information are given at the end of the leaflet.

What are capecitabine and temozolomide?

Capecitabine and temozolomide are types of chemotherapy drugs. Capecitabine comes as a tablet, and temozolomide as a capsule. Both can be taken at home.

How often will I take capecitabine and temozolomide?

For this treatment to be most effective it will be taken at specific time intervals. These are known as cycles. A cycle of capecitabine and temozolomide lasts for 4 weeks and broadly looks like:

Days 1 to 9: capecitabine

Days 10 to 14: capecitabine & temozolomide (and ondansetron, an anti-sickness medication)

Days 15 to 28: break – no chemotherapy

How often will I see the specialist team?

You will see the specialist team before each cycle. You will have regular blood tests and we will check how you are feeling and discuss any problems you may have. This is so we can check how the chemotherapy is affecting you. If your blood results are normal and your body is handling the treatment, the specialist team will prescribe your chemotherapy and you can start your cycle of chemotherapy.

Please ensure you book your blood test appointment as instructed by your doctor or pharmacist before your next hospital appointment. If you haven't been given with information on how to do this, please ask a member of staff.

How should I take the capecitabine tablets?

Capecitabine should be taken from day 1 to day 14 of the cycle. You should take your capecitabine tablets 2 times a day, about 12 hours apart. Swallow the tablets whole with a glass of water within 30 minutes after eating a meal. Do not chew, crush, break or cut them. Take the tablets in the morning after breakfast and then after your evening meal.

Tell your doctor if you find it difficult to swallow the tablets.

If you forget to take a tablet, do not take a double dose. Keep to your regular schedule and tell your doctor, nurse or pharmacist.

Other things to remember about your tablets:

- Wash your hands after taking your tablets.
- Other people should avoid touching your chemotherapy tablets.
- If you are sick (vomit) just after taking the tablets, contact the hospital on **020 3311 5160**. Do not take another dose.

The number of tablets you need to take will be different for each person. The amount you need to take will be clearly written on the medication boxes. Remember to check each box to see how many tablets you need to take.

There are two different strengths of capecitabine tablets available: 500mg and 150mg tablets. **Your dose** might be made up of a combination of either ONE or BOTH strengths of tablets. Follow all printed instructions supplied with this medication, and if you are confused please ask your doctor or pharmacist before taking your medication.

It is important that you wash your hands very well after taking your tablets.

How should I take the temozolomide capsules?

Temozolomide should be taken ONCE a day from day 10 to day 14 of the cycle. You should take your capsules one hour before food, or two hours after food. They must be swallowed whole with a glass of water. The capsules should not be chewed, opened or crushed. Take them at the same time every day.

If you forget to take the capsules, you should take the missed dose as soon as possible within the same day. If a full day has gone by, let your doctor or nurse know. Do not take a double dose unless they tell you to.

Other things to remember about your capsules:

- Wash your hands after taking your capsules.
- Other people should avoid touching your chemotherapy drugs.
- If you are sick (vomit) just after taking the capsules, contact the hospital on **020 3311 5160**. Do not take another dose.

How should I take the ondansetron?

Ondansetron is a type of anti-sickness medication.

You **must** take ondansetron TWO times a day from day 10 to day 14 of the cycle (on the days you take temozolomide). This is to stop you feeling nauseated or vomiting. You should take the first dose of ondansetron 30 to 60 minutes before you take your temozolomide. The second dose should be taken 8 to 12 hours after you have taken the first one.

The pharmacy will give you the ondansetron at the same time you collect the capecitabine and temozolomide.

Other medications

You will also be given domperidone and loperamide when you collect your chemotherapy tablets.

Domperidone: To be taken as directed by your doctor, pharmacist or nurse if you have nausea or vomiting.

Loperamide: Take TWO capsules (4mg) initially then ONE capsule (2mg) when required after each loose bowel movement. Make sure that you drink enough water and other fluids while you're taking this medication so that you're well hydrated.

Maximum EIGHT capsules (16mg) in 24 hours. You should only take this if your doctor, pharmacist or nurse tells you to.

What should I do if I forget to take my tablets?

If you forget to take your capecitabine dose, you can still take it if it's at least 8 hours before the next dose. If it's less than 8 hours, the dose should be skipped and resumed at the next scheduled time.

If you forget to take the temozolomide dose, you should take the missed dose as soon as possible within the same day. If a full day has gone by, then do not take the missed dose, just take your next dose as the usual scheduled time. Do not take a double dose.

If you vomit just after taking your treatment, contact the hospital. Do not take another dose.

How should I store my capecitabine tablets and temozolomide capsules?

You should store them in their original packaging in a safe place away from children. They should be kept in a cool dry place (below 30°C).

Any unused tablets or capsules should be returned to the hospital pharmacy or your local chemist for safe disposal.

What are the possible side effects?

There are a number of possible side effects which can occur. The doctors, pharmacist or nurses can give you advice or answer any questions you may have.

If you need emergency medical attention you must call 999 or attend your nearest A&E straight away. The 24 hour contact number is not an emergency line.

Risk of infection

This treatment can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. When the number of white blood cells is low an infection can be very serious. **It is important to get any infection treated as soon as possible because it can be life-threatening.**

Contact the hospital immediately on the 24-hour contact number 020 3311 5160 if:

- you suddenly feel unwell, even with a normal temperature
- you feel shivery or are shaking
- you have a sore throat
- you have a cough
- you feel breathless
- have diarrhoea (pooing more than is normal for you or having watery or loose poos)
- are needing to urinate (wee) a lot, or have discomfort when you urinate.

If your temperature is 38°C or above, you must attend your nearest A&E straight away.

You should take your temperature **twice** a day every day. If your temperature is too high/low, this can indicate an infection.

Diarrhoea

Diarrhoea means pooing more than is usual for you (2 to 3 more poos than usual for you in a day), or having watery or loose poo. If you have a stoma, it will be more active than usual.

Contact the hospital straight away on the 24-hour contact number 020 3311 5160 if:

- you have diarrhoea
- you have an increase in stoma activity
- If the hospital has told you to start loperamide and this does not work within 24 hours.

If you have diarrhoea also remember to:

- drink at least 2 litres (3½ pints) of fluids each day (water, fruit juice etc)
- avoid alcohol, caffeine, milk products, high-fat foods and high-fibre foods

Constipation

This treatment can cause constipation. Constipation means that you are not able to poo as often as you normally do. It can become difficult or painful. Here are some tips that may help:

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- Drink at least 2 litres (3½ pints) of fluids each day.
 - Eat high-fibre foods, such as fruit, vegetables and wholemeal bread.
 - Do regular gentle exercise, like going for short walks.

If you have constipation, contact the hospital for advice. Your doctor can give you drugs called laxatives to help.

Feeling sick

If you feel sick, take small sips of fluids often and eat small amounts regularly. It is important to drink enough fluids. **If you continue to feel sick, or are sick (vomit) more than once in 24 hours, contact the hospital on 020 3311 5160 as soon as possible.** They will give you advice. Your doctor may change the anti-sickness drug to one that works better for you.

Changes in the way your heart works

This treatment can affect how your heart works. You might have tests to see how well your heart is working. These might be done before, during and after treatment.

It is still possible for your heart to be affected even if these test results are normal. Very rarely, this treatment can cause heart failure or a heart attack. The risk of this happening is very low (less than one in 100 or 1%). But it is important that you know about it.

Stop taking your treatment and contact the hospital straight away on the 24-hour number 020 3311 5160 if you have any of these symptoms:

- breathlessness
- dizziness
- changes to your heartbeat
- swollen feet and ankles

You must go to your nearest A&E as soon as possible if you have:

- chest pain, pressure, heaviness, tightness or squeezing across the chest
- difficulty breathing

Sore and red palms of hands and soles of feet

You may get sore and red palms of your hands and soles of your feet. The skin may also begin to peel. This is called palmar-plantar or hand-foot syndrome. It usually gets better after treatment ends.

Tell your doctor about any changes to your hands or feet. They can give you advice and prescribe creams to improve any symptoms you have. It can help to:

- keep your hands and feet cool
- moisturise your hands and feet regularly
- avoid tight-fitting socks, shoes and gloves

Stop taking your treatment and contact the hospital on the 24-hour contact number 020 3311 5160 if you have pain and redness on the palms of your hands and the soles of your feet.

Sore mouth and throat

This treatment may cause a sore mouth and throat. You may also get mouth ulcers. This can make you more likely to get a mouth or throat infection. Use a soft toothbrush to clean your teeth or dentures in the morning, at night and after meals.

If your mouth or throat is sore:

- tell your doctor – they can give you a mouthwash or medicines to help
- try to drink plenty of fluids
- avoid alcohol, tobacco, and foods that irritate your mouth and throat
- sucking ice chips may sometimes help relieve mouth or throat pain

Stop taking your treatment and contact the hospital on the 24-hour contact number 020 3311 5160 if you have a sore mouth which is making it difficult to eat.

Feeling tired

Feeling tired is a common side effect of this treatment. It is often worse towards the end of treatment and can continue for some weeks after treatment has finished. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy.

If you feel sleepy, do not drive or use machinery.

Loss of appetite

This treatment can affect your appetite. Don't worry if you do not eat much for a day or two. But if your appetite does not come back after a few days, or if you are losing weight, tell your doctor. They can give you advice. They might give you food or drink supplements. Or they might suggest changes to your diet or eating habits to help.

Effects on the nervous system

Temozolomide may affect the nervous system. You may have:

- problems with balance and co-ordination
- tingling, numbness or a burning feeling in your arms, hands, legs, feet or face
- difficulty concentrating
- difficulty remembering things
- problems speaking

Contact the hospital straight away on the 24-hour contact number 020 3311 5160 if these symptoms occur.

Headaches and seizures

Temozolomide may cause headaches. If this happens, tell your doctor. They can give you painkillers.

Rarely, this treatment can cause seizures (fits where your body makes uncontrollable jerking movements). **If you notice any of these symptoms you must call 999 or attend your nearest A&E straight away.**

If you notice these effects, it is important not to drive or operate machinery.

Hair loss

Your hair will get thinner. Or you may lose all the hair from your head. You may also lose your eyelashes and eyebrows, as well as other body hair. Hair loss usually starts after your first or second treatment.

Your nurse can talk to you about ways to cope with hair loss. There are ways to cover up hair loss if you want to. Your scalp may be sensitive. It is important to cover your head to protect your skin when you are out in the sun.

Hair loss is almost always temporary. Your hair will usually grow back after treatment finishes.

Useful numbers

Hospital 24-hour number: 020 3311 5160

Macmillan navigator service: 020 3313 0303

The Macmillan navigator service can help connect you with your clinical nurse specialist (CNS). You can read more about the Navigator service at the end of this leaflet.

Tick if taken

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WEEK ONE													
DAY 1		DAY 2		DAY 3		DAY 4		DAY 5		DAY 6		DAY 7	
Date		Date		Date		Date		Date		Date		Date	
AM		AM		AM		AM		AM		AM		AM	
Capecitabine		Capecitabine		Capecitabine		Capecitabine		Capecitabine		Capecitabine		Capecitabine	
PM		PM		PM		PM		PM		PM		PM	
Capecitabine		Capecitabine		Capecitabine		Capecitabine		Capecitabine		Capecitabine		Capecitabine	

WEEK TWO													
DAY 8		DAY 9		DAY 10		DAY 11		DAY 12		DAY 13		DAY 14	
Date		Date		Date		Date		Date		Date		Date	
AM		AM		AM		AM		AM		AM		AM	
Capecitabine		Capecitabine		Capecitabine		Capecitabine		Capecitabine		Capecitabine		Capecitabine	
				Ondansetron		Ondansetron		Ondansetron		Ondansetron		Ondansetron	
				Temozolomide		Temozolomide		Temozolomide		Temozolomide		Temozolomide	
PM		PM		PM		PM		PM		PM		PM	
Capecitabine		Capecitabine		Capecitabine		Capecitabine		Capecitabine		Capecitabine		Capecitabine	
				Ondansetron		Ondansetron		Ondansetron		Ondansetron		Ondansetron	

WEEK THREE

DAY 15		DAY 16		DAY 17		DAY 18		DAY 19		DAY 20		DAY 21	
No treatment		No treatment		No treatment		No treatment		No treatment		No treatment		No treatment	

WEEK FOUR

DAY 22		DAY 23		DAY 24		DAY 25		DAY 26		DAY 20		DAY 21	
No treatment		No treatment		No treatment		No treatment		No treatment		No treatment		No treatment	

Further sources of support and information

Macmillan cancer navigator service at Imperial College Healthcare NHS Trust

This is a single point of contact for cancer patients at Imperial College Healthcare NHS Trust, and their family, friends and carers. The service is here to help you to navigate your care and resolve queries that you may have. Our Navigators can access information about your appointments, connect you to appropriate services and signpost you on to further support. They can also book you in for a telephone call back from your Clinical Nurse Specialist (CNS) if you have a question that needs clinical input.

The service is open Monday to Friday 08:30 to 16.30 excluding bank holidays. (The service is closed for training between 14.00- 14.45 on Thursdays.)

Call: **020 3313 0303**

Macmillan cancer information and support service at Imperial College Healthcare NHS Trust

The Macmillan cancer information and support service offers free support and information to anyone affected by cancer, including family and loved ones. The service has physical centres at Charing Cross and Hammersmith Hospitals, and also offers virtual and telephone support. When you call or visit you can speak to one of the Macmillan cancer team one-on-one about whatever matters most to you. You can sign up to a range of weekly virtual groups that provide the opportunity to connect with other people with cancer in a relaxed environment. You can also speak to our Macmillan welfare and benefits adviser, who can offer patients of the Trust tailored advice on additional financial support.

The service is open Monday-Thursday (excluding bank holidays), with various drop-ins available within our physical centres. For more information please call us on **020 3313 5170** or email imperial.macmillansupportservice@nhs.net

Maggie's West London

Maggie's is a cancer charity that provides the emotional, practical and social support to people with cancer and their family and friends.

The centre offers a calming and beautiful space, a professional team of support staff, and the opportunity to talk and share with a community of people who have been through cancer too.

Maggie's centres are warm, friendly and informal places full of light and open space, with a big kitchen table at the heart of the building. Maggie's West London is located in the grounds of Charing Cross Hospital but is independent of our hospital.

The centre is open Monday to Friday, 09.00-17.00. For more information please call **020 7386 1750**.

Macmillan Support Line

The Macmillan Support Line offers confidential support to people living with cancer and their loved ones. This support line is a national line provided by Macmillan and is independent of our hospital.

The Support Line is open every day, 08:00 to 20:00. Please call: **0808 808 000** or visit www.macmillan.org.uk

How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3312 7777** (10.00 – 16.00, Monday to Friday). You can also email PALS at imperial.pals@nhs.net The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street
London W2 1NY

Email: ICHC-tr.Complaints@nhs.net

Telephone: **020 3312 1337 / 1349**

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team:
imperial.communications@nhs.net

Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk

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