

Chemoradiotherapy for rectal cancer

Information for patients, relatives and carers

Introduction

This leaflet is designed to help you understand chemoradiotherapy treatment for rectal cancer. It will highlight the key people involved in your treatment and care and explain what you can expect from us. A member of the team will talk to you about your treatment and the options that you have. We will provide you with honest and accurate information about your planned treatment. If you have any questions, please contact your colorectal clinical nurse specialist (CNS). They will support you, along with the rest of the colorectal team.

Throughout your treatment at Imperial College Healthcare NHS Trust, your CNS/keyworker remains the same person you met when you were diagnosed by the referring Trust, e.g. Ealing Hospital, Northwick Park or West Middlesex. Please contact your CNS for any support or information relating to your overall care, or with further questions or concerns about your follow-up.

What is chemoradiotherapy?

Chemoradiotherapy means having chemotherapy and radiotherapy treatment together. Chemoradiotherapy treatment for rectal cancer is given at Charing Cross Hospital over a period of five weeks.

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells and is also intended to boost the effects of the radiotherapy. The chemotherapy drug that is usually given to treat rectal cancer is called Capecitabine, the tablet form of 5 fluorouracil (5FU). Your oncologist will arrange for you to meet a chemotherapy specialist nurse or specialist pharmacist who will explain how to take your Capecitabine tablets.

Radiotherapy

Radiotherapy uses high energy waves similar to x-rays to destroy the cancer cells. Your CNS or oncologist will provide you with more detailed written information on this. The radiotherapy department at Charing Cross Hospital holds regular welcome evenings to introduce you to how radiotherapy works and answer any questions you may have. The evenings have been running for years and have helped many patients and their carers and family members understand more about radiotherapy. They are usually held twice a month, from 18.00-19.00.

For more information or to book yourself (and a family member or carer if you'd like) a place, please telephone the radiotherapy reception on 020 3311 1737.

What happens before chemoradiotherapy treatment?

Your doctor will go through the side effects of chemoradiotherapy with you and explain how it is given. If you decide to go ahead with chemoradiotherapy treatment your oncologist will ask you to sign a consent form. Your personal treatment plan will then be developed. This will involve the following:

- having a blood sample taken and your height and weight recorded
- having a planning scan so that the x-ray beams can be lined up correctly for your treatment. The radiographer responsible for your treatment will tattoo some small marks on your pelvic area to ensure your treatment is accurately positioned. The bookings team will call you to arrange this scan
- your oncologist will arrange for you to meet with a chemotherapy specialist nurse or specialist pharmacist to explain how to take your Capecitabine tablets. They will go over your treatment side effects before starting your treatment. The nurse will also provide you with an emergency 24-hour helpline number that you can call if you develop any symptoms that worry you

What are the potential short-term side effects and complications of chemoradiotherapy?

Some of the common side effects that can occur when having treatment are listed below. We do not expect you to experience all of these. If you do experience side effects it is important to let your oncologist or a member of the radiotherapy team know when you attend for daily treatment. They may be able to give you medication to help control these symptoms.

You can also call the 24-hour emergency helpline number if you develop any worrying symptoms outside of working hours.

Tiredness

You may feel more tired than usual during your treatment. This should not stop you from moving around at home and travelling to your appointments.

Fatigue

Fatigue is a severe form of tiredness that is not improved by sleeping. Please let your oncologist or CNS know if you are experiencing this.

Anaemia

Chemotherapy can cause the number of red blood cells to drop. Red blood cells carry oxygen around the body. If the number of red blood cells in the body is reduced this can make some people feel extremely tired and, in some cases, breathless. You will have a blood test each week before being given your weekly supply of Capecitabine chemotherapy tablets.

This is to monitor the level of red and white blood cells in your body and ensure it is safe for you to have your chemotherapy treatment. If necessary, your oncologist will speak to you about having a blood transfusion to correct the balance of red blood cells in your body.

Risk of infection

Chemotherapy can also cause the number of white blood cells in the body to drop. The body uses white blood cells to fight infection which means chemotherapy can weaken the body's immune system. The blood test that you have will check you have the correct amount of white blood cells in your body.

If necessary, your oncologist will talk to you about granulocyte colony stimulating factor (G-CSF) injections to help boost your white blood cell count. You may also find it useful to buy a thermometer to check your temperature at home. **If you develop a temperature of 37.5°C (99.5°F) or above you must ring the emergency helpline to seek advice as you may need further blood tests and antibiotics.**

Chest pain

Occasionally, Capecitabine can cause spasm of the arteries around the heart which can cause chest pain (angina). If you experience this you must stop the Capecitabine and contact your medical team urgently, using the 24-hour helpline.

Nausea (feeling sick)

The chemotherapy you will receive may make you feel sick. To help manage this, we will give you anti-sickness medication with your chemotherapy. In general there are no restrictions on what foods you can eat. Your oncologist or CNS will discuss this with you further.

Change in bowel habit (diarrhoea/constipation), bleeding and urination

Chemotherapy can cause loose stools (poo) or hard stools. Radiotherapy can also cause loose stools. Your oncologist will prescribe medication to help control any change in your bowel habit if needed. It is not uncommon to develop light bleeding from the back passage as a result of radiotherapy, however, if this happens please tell a member of the radiotherapy team or your oncologist at your next visit.

In some cases radiotherapy can increase the amount of times that you need to pass urine and some people can experience a burning sensation when passing water. If this happens, please tell a member of the radiotherapy team or your oncologist at your next visit.

Pain

The treatment itself is not painful. However, as the treatment progresses you may start to experience rectal pain. This discomfort or pain usually starts around the second week of treatment. Your oncologist can prescribe medication to help if needed.

Sore mouth

You may experience mouth ulcers, a sore or dry mouth. Your oncologist can advise on ways to make your mouth feel more comfortable.

Skin changes

Capecitabine can cause soreness and redness on the palms of your hands and soles of your feet. If this happens your oncologist can prescribe medication to help.

Hair loss

It is not expected that you will lose the hair on your head but you may experience some slight thinning. Radiotherapy can cause your pubic hair to fall out but this usually re-grows.

Narrowing of the anal or vaginal canal

Radiotherapy for low rectal cancer can cause the vagina to narrow. It can also cause narrowing of the anal canal in both men and women. A member of the radiotherapy team will provide you with information on this and, if necessary, provide you with a device called a dilator to help manage this.

There are also some less common side effects. When you meet your oncologist, colorectal specialist nurse and chemotherapy specialist nurse they will give you further detailed information on treatment side effects.

What are the potential late side effects and risks/complications of chemoradiotherapy?

The side effects experienced during chemoradiotherapy treatment usually improve gradually once your treatment has ended. Sometimes side effects last longer than six months or happen months to years after completing the treatment. When this occurs it is known as late side effects and, occasionally, these can become permanent. We will discuss these with you.

Sexual function

Male sexual function is commonly affected by radiotherapy and surgery.

All women who receive radiotherapy treatment for a low rectal cancer experience vaginal dryness and vaginal narrowing. Consequently women need to use dilators and lubricants to maintain the ability to have vaginal intercourse. Use of dilators is also necessary to allow on-going smear tests for cervical cancer screening.

Menopause

Pelvic radiation causes menopause. Pre-menopausal women receiving pelvic radiotherapy may want to explore if there are fertility preservation options (before starting treatment) and consider starting hormone replacement therapy (HRT) (after treatment).

Other cancers

All radiation treatments very slightly increase the risk of other cancers.

What happens during my chemoradiotherapy treatment?

Some people find it helpful to bring a relative or friend with them when they first start their treatment. You will start your chemotherapy and radiotherapy on the same day. You will need to have a blood test every week to ensure it is safe to take Capecitabine chemotherapy tablets. On each day that you are scheduled to have radiotherapy you should take your Capecitabine chemotherapy tablets in the morning and evening at home as directed by your chemotherapy nurse specialist or specialist pharmacist.

A member of the radiotherapy department will tell you what time you should attend the unit for your first treatment. Your radiotherapy will take place daily from Monday to Friday. When you first arrive please check in at the reception desk. The radiotherapy treatment lasts between 15 and 20 minutes. You will lie still on the treatment bed whilst your treatment is being delivered. The radiotherapy department will provide you with a treatment schedule showing what time you should attend and explain how you should prepare for your visit each day.

Is there anything I need to look out for at home?

If you experience any of the following please contact your CNS or the 24-hour emergency helpline (**020 3311 5160**):

- high temperature (37.5°C/99.5°F or above)
- feeling shivery or shaky
- signs of infection/cold sore throat, cough, passing urine frequently
- persistent nausea (feeling sick) or vomiting (being sick)
- severe pain
- diarrhoea that is uncontrollable despite taking Imodium® (loperamide)
- low temperature (35°C/ 95°F or below)

My care

It can be helpful to keep a list of some of the people involved in your care and important dates:

Name of my colorectal CNS who will support me through my treatment:

Name of my oncologist:

Date of my radiotherapy planning scan and tattoo placement:

Date I will meet my chemotherapy nurse before I start treatment:

Radiotherapy department welcome evening date/time/location:

Start date for my chemoradiotherapy treatment:

The emergency 24-hour number I can contact if I develop any symptoms I am worried about out of hours: **020 3311 5160**

What happens after I have finished chemoradiotherapy treatment?

Once you have completed your chemoradiotherapy treatment you will receive the follow up that you need at the hospital from which you were referred.

If you are a patient that was diagnosed at Imperial College Healthcare, you will have a CT scan and MRI approximately six to eight weeks after treatment. These will be discussed in the colorectal multidisciplinary team (MDT) meeting, after which you will be offered an appointment to discuss your results and the next steps in your treatment plan.

Further sources of support and information

Macmillan cancer navigator service

A telephone-based service to support all patients and their families while under the care of Imperial College Healthcare NHS Trust. The service is open Monday to Friday 08.00-17.00. When you call you will speak to a navigator, who will establish your concern, help you with non-clinical questions and signpost you to other services. If your question is of a clinical nature or after their support you still need further input from your specific team, they will book a telephone appointment for your CNS to call you. The navigators work closely with the clinical teams to ensure they can support you and your family. Telephone: **020 3313 0303**

Macmillan Cancer information and support service at Charing Cross and Hammersmith hospitals

The information centre at Charing Cross Hospital and the infopod at Hammersmith Hospital provide support, practical and signposting advice to anyone affected by cancer. These drop-in services are set in friendly, non-clinical environments in which people affected by cancer can discuss private and emotional needs.

The centre is located on the ground floor of Charing Cross Hospital and is open (except bank holidays):

- Monday, Tuesday and Wednesday 08.00-17.00
- Thursday 08.00-17.30
- Friday 09.00-17.00 (volunteer only)

Telephone: **020 3313 0171**

The infopod is located on the ground floor of the Garry Weston Centre at Hammersmith Hospital, and is open (except bank holidays):

- Monday and Tuesday 09.00-17.00
- Wednesday, Thursday, Friday 09.00-16.00

Telephone: **020 3313 4248**

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 combines beautiful architecture, calming spaces, a professional team of support staff and the ability to talk and share experiences with a community of people who have been through similar experiences. 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

A support line provided by Macmillan to support anyone affected by cancer.

Call: **0808 808 000** (Monday to Friday, 09.00-20.00) or visit www.macmillan.org.uk

How to contact us

If you have questions or need advice please contact your CNS via the **Macmillan cancer navigator service** on **020 3313 0303**. The service is available Monday to Friday 08.00–17.00. Outside of these hours, please contact your GP or phone NHS 111.

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 3313 0088** (Charing Cross, Hammersmith and Queen Charlotte's & Chelsea hospitals), or **020 3312 7777** (St Mary's and Western Eye hospitals). 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

Bowel cancer
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