

Chemoradiotherapy for anal cancer

Information for patients, relatives and carers

Introduction

This leaflet is designed to help you understand chemoradiotherapy treatment for anal cancer. It will provide 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 further questions or concerns about your follow-up.

What is chemoradiotherapy?

Chemoradiotherapy means having chemotherapy and radiotherapy treatment together. Chemoradiotherapy treatment for anal cancer is given at Charing Cross Hospital over a period of five and a half 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 drugs that are usually given to treat anal cancer are called 5 fluorouracil (5FU) and mitomycin C.

Chemotherapy is either given orally or directly into the blood stream so that it can circulate throughout the body. In some patients, your doctor will recommend that the chemotherapy is given at home over a four-day period from a small pump attached to a PICC line (a form of catheter that is placed in the fold of your arm). This line will remain in place for the duration of your chemoradiotherapy treatment. Your doctor will arrange for the PICC line to be removed by a healthcare professional when you no longer need it and it is safe to do so.

Radiotherapy

Radiotherapy uses high energy waves (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/family members understand more about radiotherapy. They are usually held twice a month, from 18.00-19.00.

For more information, and to book yourself (and a family member or carer if you think it would be helpful) a place, please telephone the radiotherapy reception on **020 3311 1737**.

What happens before chemoradiotherapy treatment?

Your doctor will go through 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, including an HIV test and your height and weight recorded
- if you are a new patient to this hospital some swabs will be taken to screen you for MRSA. This is to ensure your PICC line can be put into your arm safely – your nurse can explain further about this and answer any questions you may have
- if you are a woman, your oncologist will refer you to a gynaecologist to check the health of your vagina, cervix and to screen for the Human Papillion Virus (HPV) as some types of anal cancer are associated with HPV. If you would like to know more about, this please ask your oncologist of colorectal CNS during your clinic appointment.
- you will need to have 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. You will receive a call from the bookings team to arrange this scan.
- a member of the chemotherapy bookings team will let you know the date for your PICC line insertion, if needed and chemoradiotherapy start date. Your oncologist will arrange for you to meet with a chemotherapy specialist nurse to go over treatment side effects prior to your treatment start date. The nurse will provide you with an emergency 24-hour helpline number that you can call if you develop any symptoms that worry you.

What are the side effects and risks/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 the symptoms.

You will also have the 24-hour emergency helpline number to seek advice 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 experience this.

Anaemia

Chemotherapy can cause the number of red blood cells to drop. Red blood cells carry oxygen around the body. You will have a blood test once a week to check your red blood cell count. Very rarely some people become so anaemic that they feel tired or breathless. However, even mild anaemia can reduce the effectiveness of the radiotherapy so it is possible that your doctor may arrange a blood transfusion even if your condition is mild.

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. This means that chemotherapy can weaken the body's immune system. The blood test that you have each week will also 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 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 some further blood tests and antibiotics.**

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 you to experience 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 anus 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 instances, radiotherapy can cause an increase the number 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 treatment progresses you may start to experience anal 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 provide advice to make your mouth feel more comfortable.

Skin changes

The 5FU 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.

Radiotherapy can cause the skin on the groin and anal area to turn red. You may find it helpful to wear loose-fitting clothing, clean the area with lukewarm water and pat it dry with a soft towel after cleaning the skin. Your radiotherapy On Treatment reviewer and oncologist will monitor this and provide you with some cream if you experience discomfort.

Hair Loss

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

There are also some less common side effects. When you meet with 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 over the few weeks to months after 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.

Bowels

Most patients find little or no change in their bowel habit. However, you may pass mucus from the anus, have to rush to the toilet in order to open your bowels or need to open your bowels more often. Regular use of loperamide (Imodium) or normacol granules on food can help to control your bowel function. It is unlikely in the longer term that the treatment will either worsen or improve incontinence if you had this before starting treatment.

Sexual function

If you are a man then sexual function is usually unaffected by treatment however sperm storage is sometimes recommended.

If you are a woman, you will experience vaginal dryness and narrowing of the vaginal canal following treatment. We recommend the use of dilators and lubricants to help maintain the ability to have vaginal intercourse and allow on-going smear tests for cervical cancer screening.

Menopause

Pelvic radiation causes menopause and pre-menopausal women receiving pelvic radiotherapy may want to explore fertility preservation (prior to starting treatment) and starting HRT (after treatment).

Hip issues

Chemoradiotherapy treatment slightly increases the risk of hip arthritis and very occasionally can cause significant damage to the blood vessels supplying the hip joint (avascular necrosis); this often requires surgery.

Other Cancers

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

What happens during my chemoradiotherapy treatment?

Most 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. On the first day of your treatment, you will attend the chemotherapy day unit to have your chemotherapy. Your

chemotherapy nurse will give you a small injection of mitomycin C through your PICC line. The rest of the 5FU will be given through a portable pump via a PICC or in daily tablet form.

You will need to visit the radiotherapy department daily from Monday to Friday. When you first arrive, please check in at the reception desk. The radiotherapy will last between 15 and 20 minutes. You will be asked to lie still on the treatment bed whilst your radiotherapy is being delivered. The radiotherapy department will give you a schedule showing what time you should attend to have your radiotherapy each day. They will also give you information about how you should prepare for your visit each day.

You will be given chemotherapy in the first and final week of your five and a half week chemoradiotherapy treatment. If you receive your chemotherapy as an injection, you will go home from the chemotherapy unit with a small pump that will continue to deliver the chemotherapy drug 5FU over the next three days. On the fifth day of treatment which is usually a Friday afternoon a nurse from the chemotherapy department will remove the pump attached to your PICC line.

Please note that you will need to have your PICC line flushed and the dressing changed every week until it is removed. The chemotherapy department will make arrangements with you for this to be done.

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 below 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 to note below:

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

Name of my oncologist:

Date my PICC line will be put in:

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 (out of hours) if I develop any symptoms I am worried about:
020 3311 5160

What happens after I have finished chemoradiotherapy treatment?

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

If you are an Imperial patient, you will have an MRI scan approximately three months after completing the treatment. This scan will be discussed in the colorectal multidisciplinary team (MDT) meeting, after which you will be given an appointment to discuss your results and the next steps in your treatment plan.

How to contact us

Imperial College Healthcare NHS Trust has a **Macmillan navigator service**, which can answer questions on behalf of the relevant CNSs. Navigators, will also refer you to CNS teams, and to other specialist clinical staff, as needed. The service is available Monday to Friday 08.30 – 16.30.

Telephone: **020 3313 0303**

Outside of these hours, please contact your GP or phone NHS 111.

Further sources of support and information

Macmillan Cancer Support Helpline:

0808 800 000 (Monday to Friday, 09.00 – 20.00) www.macmillan.org.uk

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. The Infopod is located on the ground floor of the Garry Weston Centre at Hammersmith Hospital.

Please note both the centre and Infopod are only operating a virtual service at the present time, appointments are available by telephone or video call. The team can be contacted on:

Email: imperial.macmillansupportservice@nhs.net

Message service: 020 3313 5170

Monday – Wednesday 8am – 6pm, Thursday 8am – 5.30pm

Maggie's Cancer Caring Centre

Maggie's is a cancer charity that provides the emotional, practical and social support that people with cancer may need. The centre combines striking buildings, calming spaces, professional experts offering professional support, and the ability to talk and share experiences with a community of people who have been through similar experiences. Designed by leading architects, Maggie's centres are warm, friendly and informal places full of light and open space with a big kitchen at their heart. 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**.

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

We have a free wi-fi service for basic filtered browsing and a premium wi-fi service (requiring payment) at each of our five hospitals. Look for WiFiSPARK_FREE or WiFiSPARK_PREMIUM