Chemoradiotherapy for anal cancer

Information for patients
This leaflet aims to help you and your family understand more about your chemoradiotherapy treatment for anal cancer.

It will be given to you in addition to the information you will receive from your Clinical Oncologist (who is a specialist doctor in cancer treatment). Their team will be caring for you during your treatment. This team may include radiographers, nurses, social workers, physiotherapists, occupational therapists and dietitians.

Cancers of the anal canal and margin are treated with chemoradiotherapy. This leaflet aims to give you information about your planned course of chemoradiotherapy. It also explains the side-effects that you may experience during and after treatment. These effects vary from one person to another, so the information is given as a general guide. Not everyone will experience all of the effects described.

The healthcare team looking after you will explain your treatment and the side-effects in detail. If you hear any words or phrases that you do not understand, please ask your doctor or a member of your healthcare team what it means. It does not matter how many times you ask.

Staff will make every effort to meet your individual needs or will direct you to the person who can help.

*Please do not bring any valuables into hospital with you as the Trust cannot accept liability for loss or theft.*
What is chemoradiotherapy?

Chemoradiotherapy (CRT) is the use of anti-cancer drugs, (chemotherapy) and radiotherapy given at the same time. Your Clinical Oncologists will discuss with you the number of radiotherapy treatments that you require. Radiotherapy is given daily Mon-Friday and chemotherapy is given during your radiotherapy. If there are gaps of more than two days in your treatment course, for example bank holidays or illness, the radiographers will adjust your appointment times to cover this.

Pregnancy

It is important that women do not become pregnant while having cancer treatment because the radiotherapy and chemotherapy can have an effect on the unborn child. It is suggested that you use a barrier form of contraception (for example condoms). An information leaflet is available. Please do not hesitate to ask your doctor or nurse if you have any questions or concerns about these issues.

Chemotherapy

*Chemotherapy is usually given as an outpatient and is given either:*

- directly into a vein, via a picc line. You will need to have a thin, plastic tube called a PICC line inserted (as seen on the next page) - a PICC line is a long, thin flexible tube known as a catheter. It is inserted into one of the large veins of the arm just above the bend of the elbow. It is then threaded, using an ultrasound machine to guide it, through the vein until the tip sits in the large vein just above the heart. The end of the tube remains outside the body, there is a clamp,
which will be closed when the line is not in use. The line has a special cap on the end of it. We will use this line to give you your chemotherapy. The district nursing team may be asked to clean and flush your PICC line and change the dressing every seven days. This will be arranged for you after you have had your line inserted. You will be given more information about PICC lines and how to care for them by the nursing team who insert it for you. Please read the separate patient information about how your chemotherapy is delivered.

- or it can be given into a vein and in the form of a number of tablets taken morning and evening 12 hours apart, on the days when you have radiotherapy (not at the weekend).

- **Intercourse (sex) is safe during treatment.** If you are engaging in vaginal, anal or oral sex, you or your partner must use a condom/protection, because small amounts of chemotherapy can be excreted in semen and other bodily secretions.

**Radiotherapy**

Radiotherapy is the use of high energy X-rays, to treat cancer. The organs and tissues of the body are made up of tiny building blocks called cells. Radiotherapy causes physical and chemical damage to the cancer cells in the treated area.
Although normal cells are also affected, they can repair themselves and are able to recover. When you are having your radiotherapy you do not feel anything and does not make you radioactive. It is perfectly safe for you to be with other people, including children, throughout your treatment.

You will have your radiotherapy on a treatment machine called a linear accelerator as shown in the photograph on the next page. Radiotherapy treatment is given by male and female therapy radiographers. You will see your radiographers at each treatment session and they will be happy to answer any questions you may have. Radiotherapy treatments and the planning scan are given on Level -2 in the Bexley Wing.

If you would like to visit the radiotherapy department before your treatment please call 0113 206 7603 to arrange a time. This visit can be very useful as you can find out more about radiotherapy. It is a good opportunity to visit the hospital and tour the simulators and treatment areas. You will also have the opportunity to ask questions.

‘I was so pleased to see the machines before my treatment and the staff were so helpful and really put my mind at rest.’
Students
The radiotherapy department is a training centre for male and female radiographers. They are supervised at all times. If you do not wish students to be present please speak to a member of staff. This will not affect your treatment or care.

Before your treatment
After seeing your doctor in clinic for the first time you will need to visit Leeds Cancer Centre (Bexley Wing, St. James’s Hospital, Leeds) for various things that need to happen before treatment starts. This will include signing a consent form (that you agree to treatment), having blood tests, having your height and weight measured (to allow calculation of your chemotherapy dose), a nursing assessment and a planning CT scan. Some people also need an extra test to measure how well their kidneys work.

You will be given information about where and how the chemotherapy will be given. It is a good idea to make a list of any questions you may have and bring an up-to-date list of all your medication with you.

Radiotherapy treatments and the planning scan are given on Level -2 in the Bexley Wing.

Radiotherapy planning scan
Your first planning visit for your radiotherapy could take up to two hours to complete. In order to plan your treatment you will need to have a planning CT scan. This scanner allows images to be sent to the radiotherapy computer planning system. Planning scans are not diagnostic examinations and will not be reported on as such.
Your scan will be taken with you lying in the same position as your treatment, using equipment to keep you stable and still.

The scan usually takes 10-15 minutes. You will be asked to undress from the waist down and will be given a gown to wear. You will be lying in the position shown here. It is important that you are comfortable as you will have to lie in this exact same position for your treatment each day. Please tell the radiographers if you are uncomfortable.

The radiographers will put ink marks on your skin to make sure you are in the correct position. These are made permanent at the end of your planning scan with tattoos (usually four.) These are no bigger than a freckle.

Before your CT scan you will be given a drink which makes it easier to see your bowels on the scan (this drink is not given before each treatment). You may have a CT scan which may involve an injection of dye in your veins.
**Contrast dye**

A special contrast agent, often called a dye, may be used for your scan to make specific organs, blood vessels and body tissues ‘stand out’. This can make it easier for the doctor to plan your treatment.

The dye is given through a small needle into a vein in your arm. You should tell the radiographer if you have any allergies, but they will go over this with you before they use any dye. The radiographers will advise you about drinking plenty of fluid after your injection.

**Contrast side-effects**

You may notice a warm feeling throughout your body and have a metallic taste in your mouth. You may also feel as if you have passed urine. This will pass very quickly. There is a slight risk of an allergic reaction to the injection, such as skin rash, but very rarely it may lead to other complications. The staff in the radiotherapy department are highly trained to manage any problems and again the risk is very small. You will be able to drive and go to work after your scan.

When your treatment planning is completed you will be able to start your treatment. This is usually about two weeks after your scan. The radiographers will talk to you about any further appointments you have.

The planning appointments can be quite long, especially if you are coming on hospital transport. You may wish to bring something to read, eat and drink. Please bring any medication that may be due during this time. A restaurant is available serving drinks, light snacks and hot meals. There is also a Café for hot drinks and light snacks; both these are on Level 0. Vending machines are also available on Level -2, Level 0 and Level 1.
Having your treatment

Usually you will have chemotherapy on the first day of your radiotherapy (although this may vary slightly). When you come for radiotherapy the radiographers will introduce themselves and explain what will happen when you come each day for treatment. You will be given a full list of your appointments, including doctors and specialist nurse, at this time.

The radiographers check all the information from your planning scan and make sure you are in exactly same position and with the same equipment as when you had your scan. They will need to alter your position to line up the tattoos so you are in exactly the right place. Please try to relax as they move you. It is important for you to stay as still as possible but you can breathe normally.

Once you are in the correct position the radiographers will leave the room to switch on the machine. The radiographers will be watching you on a closed circuit TV monitor (CCTV) during treatment. The CCTV camera is not recording or saving any images.

*Your position on the Linac machine*
There is also an intercom system so the radiographers can talk to you. Please let them know if you would like to use the intercom system.

The treatment machines make a high pitched noise when switched on, this is the only way you will know the machine is on. You will not feel anything.

For the first few treatments we will also take images to check the accuracy of the treatment which will take a few more minutes. These images do not monitor your condition but are purely for treatment accuracy.

*Do not try to sit up and get off the treatment couch until the radiographer says it is safe to do so.*

**Patient Alert System (PAS)**

Each radiotherapy treatment room is fitted with an alert system. The controller, shown below, can be held during treatment, and the button pressed at any time to signal to the radiographers that you need assistance. A beacon in the control room will instantly turn from green to red signalling the staff to re-enter the room. If you would like to use the PAS at any time during treatment, please speak to your radiographers.

Some days the radiotherapy department may be very busy and your appointment time may be delayed. We will keep you informed of any delays.
Your appointments for radiotherapy may not be all at the same time each day and are subject to change. It is also possible that during your course of treatment you may miss a day’s treatment due to planned machine maintenance or bank holidays. It is therefore important to speak to a health care professional before booking a holiday immediately following your radiotherapy.

Please telephone the radiotherapy reception desk on: 0113 206 8940 for further advice.

During the treatment course, please tell the radiographers how you are feeling. If you have any problems or questions, please let them know so they can advise you or arrange for you to see the doctor or nurse.

A member of the team will see you once a week in the outpatient clinic to see how you are getting on, our team consists of consultants, specialist registrars and a clinical nurse specialist. They will also monitor any side-effects you may be experiencing. You can expect to be in the department longer than usual on this day.
Side-effects

Side-effects can be divided into short term effects that happen during or soon after treatment and long term effects which can occur months or years later. Both chemotherapy and radiotherapy can be responsible. Some are common, others very rare but potentially serious. Some people get more side-effects than others.

Tiredness (fatigue)
Chemoradiotherapy can make you feel more tired than usual, especially if you have to travel a long way for treatment each day. Fatigue usually improves between six months to a year after treatment. Some people find that fatigue can last longer, up to two years or more.

Things you can do to help include:
• Gentle exercise can help reduce the symptoms of fatigue.
• Having enough to drink can prevent tiredness from dehydration.
• Small meals or snacks eaten more often than three times a day may be easier to face.
• Try to get a good night’s sleep where possible, a daytime nap may help.
• Try to ‘pace’ yourself, listen to what your body is telling you, rest if you need to.
• Pick out the things that you enjoy, and try to pass on other tasks.
• Little and often is the rule of thumb.

There is a Macmillan information leaflet available.
Radiotherapy side-effects

Skin reaction
The skin reaction caused by your chemoradiotherapy can be severe but will heal after your treatment is completed. The reaction develops gradually during the course of treatment and it is usually at its worst 7-14 days after treatment finishes. The skin will then begin to heal. The radiographers will discuss your skin care with you and they will give you a leaflet on the first day of your treatment. The advice will not prevent the reaction but its aim is to try and reduce its severity.

What will happen to your skin?

Week 1-2
The first symptom which tends to develop from the second week of treatment onwards is itching of the skin especially at night when warm in bed. Anti-histamine tablets and/or steroid cream can be prescribed to reduce this symptom. Wearing loose cotton clothing will also help.

Week 3-5
Around the third week of treatment patients begin to experience a reddening of the skin in the groins, genitalia, and around the bottom. This reddening of the skin becomes sore, painful and hot. Continue to apply the cream (supplied by the hospital) frequently and take prescribed painkillers regularly. Taking pain killers regularly helps to ease the sore, painful skin more successfully.

Most of the pain killers used to ease the skin reaction can cause constipation. To help prevent this laxatives are sometimes prescribed with the painkillers.
The skin will eventually break down and weep, this can happen any time from week three onwards. Once the skin begins to break down and weep stop using the cream and use the dressings provided.

The genitalia can become swollen and sometimes it is painful to pass urine. If this becomes a problem we may suggest having a catheter, a small plastic tube inserted into the bladder. Your pubic hair will fall out during treatment and may or may not grow back after treatment has finished.

**After the treatment has finished**

The skin reaction will continue for a few weeks after treatment but has usually settled before your follow-up appointment. You will continue to be seen in the review clinic each week until you, the doctors and nurses are happy the reaction is healing. If we are concerned we will refer you to your local district nurse who will carry on the care you have been receiving in hospital.

Your follow-up appointment will be about six weeks after completing your treatment.

**Diarrhoea**

Radiotherapy causes inflammation, swelling and soreness of the lining of the bowel. You may experience mild to moderate diarrhoea, opening your bowels 2-6 times more than normal per day. If you have a stoma (also known as a colostomy or ileostomy) you will find that you might need to empty or change the bag more often.

This side-effect usually starts in the second week of treatment and sometimes gets worse as the treatment continues. If you need to open your bowels four or more times more than is
usual for you in a day, then tell the radiographers, your doctor or nurse. You will be given anti-diarrhoeal tablets to take, called loperamide. If you get diarrhoea you should start taking these as instructed. If you have a stoma please make sure you bring spare stoma equipment with you each day.

**Cystitis (passing your urine frequently and with discomfort)**

This can be reduced by avoiding tea, coffee, alcohol and concentrated fruit juices which can irritate the bladder. Drinking diluted cranberry juice might help with this problem, however cranberry juice is known to cause a problem with some medications (for example Warfarin) so check with your hospital team first. A catheter may also be another option to reduce this symptom (see skin care information).

**A feeling of wanting to open your bowels (tenesmus)**

This can be helped by pain killers. Some people feel more confident if they wear a pad.

**Chemotherapy side-effects**

The chemotherapy drugs used include Mitomycin C, 5 fluorouracil and capecitabine. They are given via a drip or small portable pump device or in tablet form.

**Side-effects caused by the chemotherapy include:**

- Nausea or vomiting are less common side-effects and can usually be controlled with medication.
- A reduction in your appetite or altered taste of food.
- Soreness of the lips and mouth. This can be eased with medications.
• It is very unusual to have significant hair loss from the head that is noticeable to other people with this chemotherapy. You may notice more hair coming out when you brush or wash your hair.

• If you are having the 5-Fluorouracil as in-patient through a drip it can cause veins to become sore and discoloured.

• Sensitivity to sunlight, use a hat and high factor sun-cream when outdoors.

• Soreness of the palms of the hands and soles of the feet, this is reversible and usually manageable with creams.

• Chemotherapy temporarily reduces the production of some blood cells. This can lead to anaemia (which can make you feel tired or breathless), bleeding, bruising and reduce your ability to fight infection. You are carefully monitored with blood tests during treatment.

It is important to understand that any feverish illness during treatment can be dangerous.

Symptoms to watch out for include:

• shivering when others are warm;

• uncontrollable shaking; or

• suddenly becoming a lot more unwell than you were before, perhaps over just a few hours.

You are advised to have a thermometer at home and to ring the hospital for advice if you become unwell. You will be given a card with emergency contact numbers.

Check your temperature before you ring.
Loss of appetite

Nausea, altered taste, loss of appetite and sore mouth problems can affect how much you feel like eating and drinking. Diarrhoea increases the loss of fluid from your body. During your treatment it is important to have plenty to drink 2-3 litres, or five pints each day. If you have a stoma it is better to drink things such as isotonic drinks rather than water on its own. Small snacks can be easier to manage than large meals or if you are losing weight build-up drinks can be prescribed. If you are having problems with eating please speak to the staff and they will give you advice and a leaflet.

Late effects of pelvic radiotherapy

• **Bowels:** Opening bowels more often during a 24 hour period. This occurs in about 1 in 4 patients. Patients can also experience ‘urgency’ or a need to open their bowels as soon as they feel the desire. Occasionally this can be associated with incontinence or uncontrolled opening of your bowels.

• **Bladder:** Changes in how your bladder works (going to pass urine more often, passing urine at night or dribbling).

• **Macmillan toilet card:** If you want to go to the toilet more often, or feel that you can’t wait when you do want to go, you can get a card to show to staff in shops, pubs and other places. The card allows you to use their loos without them asking awkward questions. You can get the cards from your radiographer.
• **Skin:** Your skin may become dry and less supple, sometimes you can develop darker skin and small broken veins. Treated skin will be more sensitive to sunlight. The radiographers will advise you at the end of your treatment.

• **New cancers:** The number of new cancers (felt to be caused by treatment) is likely to be increased slightly in long-term survivors. However, accurate data on this are not available. These effects need to be balanced against the possible benefit of treatment.

**Sexual function**

Chemoradiotherapy can have effects on sexual function and fertility for both men and women. Fatigue and anxiety associated with treatment can affect sex drive. This may only recover slowly after treatment.

**Women**

Chemotherapy and radiotherapy should not be given in pregnancy because of the potential harmful effects on the baby. If you are a woman of child-bearing age appropriate contraception is vital. We recommend that you continue using contraception after your treatment has finished, as there is still a chance that you could become pregnant.

If you have not gone through the menopause, this treatment can bring forward your menopause and cause infertility (you will no longer be able to have children). You may notice your periods becoming irregular during or after treatment. If you have not completed your family, please discuss this with the doctor before starting treatment.
You may also experience vaginal dryness and pain during intercourse. Your vagina may become narrower following treatment. These side-effects can be reduced by using a dilator (which we will give you), lubricating jelly or resuming sexual intercourse if you wish. A member of the team will discuss this with you and give you the dilators and our information leaflet. Advice on hormone replacement therapy is also available.

**Men**

Chemotherapy and radiotherapy can affect the quantity and quality of sperm production. This can lead to increased rates of abnormality in children that are conceived during or after treatment. You are advised to use contraception for a year after treatment. If you have not completed your family please discuss this with your doctor before starting treatment. We can arrange storage (freezing) of some sperm which can then be used at a later time if needed.

Chemoradiotherapy can increase the risk of impotency, the ability to attain and maintain an erection. If this is a problem you may discuss it with your GP or hospital team.

**Further information**

If you have any further questions please discuss these with your hospital team. If you would like further information about the late effects of pelvic radiotherapy please ask your doctor or specialist nurse.

Chemoradiotherapy Nurse Specialist: 0113 206 7852
Leeds Cancer Support

Leeds Cancer Support complements care provided by your clinical team. We have a wide range of information and support, in a welcoming environment for you, your family and friends. We can be found in the information lounges in Bexley Wing and also in the purpose built Sir Robert Ogden Macmillan Centre.

To contact Leeds Cancer Support:
Email: leedsth-tr.Cancersupport@nhs.net

Information Lounge Level 1 Outpatients Department
Open from 10am - 4pm. Tel: (0113) 206 8816

Information Lounge Level -2 Radiotherapy Department
Open from 8.30am - 6.00pm Tel: (0113) 206 7603

Sir Robert Ogden Macmillan Centre
Open from 10am - 4pm. Tel: (0113) 206 6498

Macmillan Cancer Support

Information and emotional support. Freephone 0808 808 0000, 9am to 8pm Monday to Friday. A textphone service for deaf and hard of hearing people Tel: 108001 0808 808 0000.

Website: www.macmillan.org.uk

NHS Smoking helpline
7am - 11pm everyday freephone: 0300 123 1044