Chemoradiotherapy for cancer of the oesophagus

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

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 clinical nurse specialists and dietitians.

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.

All your radiotherapy planning and treatment will take place in the Radiotherapy Department on Level -2, Bexley Wing, Leeds Cancer Centre (LS9 7TF).

Please do not bring any valuables into hospital with you as the Trust cannot accept liability for loss or theft.
Cancer of the oesophagus

The oesophagus (gullet) is the muscular tube that connects the back of the mouth with the stomach. It passes through the center of the chest, behind the heart and between the lungs.

Cancerous lumps that start along its length are known as oesophageal cancer.

What is chemoradiotherapy?

Chemoradiotherapy (CRT) is the use of anti-cancer drugs, chemotherapy and radiotherapy given at the same time. Treatment involves five to seven weeks of radiotherapy, given daily Monday to Friday however your treatment may not start on a Monday. You will have 23-33 radiotherapy treatments in total. Depending on your chemotherapy regime you may have to take it in tablet form on the days of your radiotherapy or it will be given into a vein during the first and last weeks of your radiotherapy treatment.
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 (e.g. condoms). For more information see the ‘Contraception and pregnancy during cancer treatment’ leaflet. Please do not hesitate to ask your doctor or nurse if you have any questions or concerns about these issues.

Radiotherapy

Radiotherapy is the use of high energy X-rays and other types of radiation, 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.

Radiotherapy is a local treatment. This means it only affects the part of the body that is treated. You do not feel anything and you will not be radioactive. It is perfectly safe for you to be with other people, including children and pregnant women, throughout your treatment.
You will have your radiotherapy on a treatment machine called a linear accelerator as shown here in the photograph.

Radiotherapy 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.

**Students**

Please be aware that the radiotherapy department is a training centre for male and female radiographers. Students may be present on the treatment units. They are supervised at all times. If you do not wish students to be present during your treatment please speak to a member of staff. This will not affect your treatment or care.

**Planning your radiotherapy**

Your first appointment for radiotherapy will be a planning appointment. This will be used to gather all the information we need to accurately plan your treatment. You will be contacted by phone, with an appointment for your radiotherapy planning session. Some tests and scans may be needed to help plan your treatment. We will explain which of these you will need when your appointment is made.

You may see your clinical oncologist (or a member of their team) at this appointment. This is an ideal opportunity for you to ask questions.
If you wish to go ahead with the treatment and you have not consented for your radiotherapy treatment in another hospital, this will be completed at this visit. You will be asked to sign a form giving your consent to treatment.

**What to bring with you:**

- a list of all the questions you may have;
- an up-to-date list of all the medications you are taking (including inhalers, sprays, vitamins or herbal products);
- any medication that you may need during your visit;
- something to eat and drink and something to occupy yourself with, as this first visit can be quite lengthy (up to two hours).

Your treatment position depends on which part of your oesophagus is to be treated. The following explains the different positions we may use for your planning and treatment. Only one position will be used throughout your treatment.

For treatment of the lower oesophagus, we would usually ask you to lie down and keep both arms above your head, as shown in this photo. Please tell your doctor, preferably in advance, if you are unable to keep your arms up. In this case we may need to use a mask, see the next page.
If you need treatment to the upper oesophagus, you may need to have a plastic mask made, as shown in this photo. This will be made the same day as your scan to make sure you are in the correct position for treatment every day.

The radiographers can draw treatment marks on your mask, instead of your skin.

If you have any concerns about the mask we have a support team available to help you. Please tell your clinical oncologist or clinical nurse specialist who will contact them.

Alternatively you can ring them on 0113 206 7616 or email: leedsth-tr.rtpatientsupport@nhs.net.

CT Simulator
In order to plan your treatment you will have a CT scan using X-rays. This is done on a machine called a CT Simulator, shown here in the photograph.
You may need to have a dye injected into a vein in your arm and a second 4D CT scan to monitor your breathing (see next page). These can help the doctor when planning your treatment. The radiographer will explain about the type of scan you will need. When you have this scan you may be asked to drink a couple of glasses of water, but only if you can manage this.

You will be asked to lie flat. The picture on page six shows one of the possible treatment positions. You must be able to keep this position for about 15 minutes each day during your treatment. If you are not comfortable and think you are unable to hold this position then please tell the radiographers. They can make you more comfortable.

The radiographers will draw some marks onto your skin or mask, to be used as a reference for your treatment. You may be given something to drink immediately before the scan. You will then be scanned, which will only take a few minutes. At the end of the scan any skin marks will be replaced by permanent marks.

These permanent marks are no bigger than a freckle and will be used each day for your treatment. These marks are made using ink and a small needle to help us to reproduce your treatment with accuracy each day. It also means that you can wash as normal without worrying about your marks coming off.
**Contrast (dye)**

A special contrast agent, often called a dye, may be used for your scan to make specific organs, blood vessels and/or tissue types ‘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 discuss this with you before they use any dye.

**The most common side-effects of the dye are:**

- warm or hot ‘flushed’ sensation during the injection;
- a ‘metallic’ taste in the mouth, which usually lasts less than a minute or so;
- you may also feel as if you have passed urine, however this is just a sensation. This will pass very quickly and it should cause no ill effects.

There is a slight risk of an allergic reaction to the injection, such as a skin rash, but it may lead to other significant complications. The doctors in the radiotherapy department are trained to deal with any complications and again the risk involved is very small. You will be able to drive your car or go to work after your scan. The radiographers will advise you about drinking plenty of fluids after your injection.

**4D Scan**

If we are going to treat the lower third of your oesophagus we will need to do a 4D scan. To do this a belt is placed around your stomach which is attached to the scanner to monitor how your tumour moves when you are breathing.
This monitoring process can take about 30 minutes. However, the actual scan itself will take less than two minutes. Your doctor will explain the details of the scan, if you need it when you are seen in clinic.

When the planning procedure is finished, you will be able to start your treatment. This is usually in a couple of weeks time. The radiographer will talk to you about future appointments and you will be given a list of your first radiotherapy and chemotherapy appointments, including a chemotherapy pre-assessment appointment, before you go home. If you are thinking of booking a holiday please discuss this with your consultant or radiographer to avoid a clash with your treatment start times.

**Treatment Day**

When you arrive for your treatment you should go to the reception at the entrance of the radiotherapy department. You will be given directions to your treatment machine.

The radiographers will explain what will happen and answer any questions that you may have. The number of treatments you will be having will be confirmed and you will be given a list with all the appointments you need.
Treatment is normally given daily, Monday to Friday however your treatment may start on any day of the week.

Whenever possible you will be treated at the time of day that suits you, but this cannot always be arranged or guaranteed. There may be occasions when you may have a longer stay in the department or be asked to attend at a different time, for example to see your oncologist. If your treatment goes over a bank holiday weekend you may have treatment during the weekend. The radiographers will discuss this with you.

You will have your treatment in the same position as your planning scan. Depending on the location of your cancer, you may be asked to drink water shortly before your treatment.

Although you have the small permanent marks on your skin, the radiographers may need to draw around them each time you come for treatment. This is part of the quality checking procedure for your treatment. If you have pen marks on your skin you may prefer to wear older clothing as the marks may discolour fabric. It is also generally advisable to wear loose clothing around the treated area.

The radiographers will take images to check your treatment position before giving you your first radiotherapy treatment. You will need more routine images taken during the course of your radiotherapy, this is usually for the first week and then once a week until you finish. Treatment times vary from 10-20 minutes each day depending on the type of treatment you are having. The treatment machine is only switched on for a fraction of this time. For most of the time the radiographers are carefully placing you and the machine in the correct position for your treatment. The machine will move around you but does not touch you.
Once you are in the correct position the radiographers will leave the room to switch on the machine. You will only be alone for a few moments at a time. 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. There is also an intercom system so the radiographers can talk to you. Please let the radiographers know if you would like them to use the intercom during your treatment.

Although you have to lie still, you can breathe and swallow normally during your treatment.

The machine stops automatically after your prescribed dose of treatment has been given. The machine can also be stopped at any time if needed. The treatment machines make a high buzzing noise when switched on; this is the only way you will know the machine is on. You will not feel anything.

**Patient Alert System (PAS)**

Each radiotherapy treatment room is fitted with an alert system. The controller 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.
During the treatment course, please tell the radiographers how you are feeling. If you have any problems or questions, please let them know. Your clinical oncologist, or a member of the radiotherapy team will see you regularly in the radiotherapy review clinic to see how you are getting on. They will also monitor any side-effects you may develop.

Some days the radiotherapy department may be very busy and your appointment time may be delayed. We will keep you informed of any delays. Please see the information boards in the waiting areas.

Your appointments for radiotherapy may not be at the same time each day and may need to change. It is important to speak to a health care professional before booking a holiday immediately following your chemoradiotherapy.

For appointment queries please telephone the radiotherapy reception desk on 0113 206 8940 for further advice.

**Chemotherapy**

Chemotherapy is usually given as an outpatient and if it is given via a vein you may need to have a thin, plastic tube called a PICC line inserted (as seen here) - 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.

If you have severe swallowing difficulties or a tumour in the upper part of your oesophagus, you may have extra chemotherapy before you start your course of chemoradiotherapy. This is done whilst your radiotherapy is being planned. This increases the total amount of treatment given, and therefore the risks of toxicity will be greater. However, for many people this shrinks the obstructing lump, producing improvements in swallowing over 2-3 weeks.

**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 potentially serious but very rare. Some people get more side-effects than others. Most people only get a few of those listed below.

You will be seen regularly during your treatment by your clinical nurse specialist, oncologist and radiotherapy nurses.

**Short term side-effects**

*General side-effects - tiredness (fatigue)*

Radiotherapy 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 accept help with other tasks.
- Little and often is the rule of thumb.

There is a Macmillan information leaflet available *‘Coping with fatigue’*. If you would like a copy, or support with your fatigue please ask a member of staff.

**Radiotherapy side-effects**

Radiotherapy causes inflammation, swelling and soreness of the treatment area. This can cause soreness or difficulty when swallowing and gets worse during treatment, and can last for a few weeks afterwards. It is usually possible to control with painkillers or by changing the types of food eaten. If you are really struggling to get food down, you may need a feeding tube passed into your nose and down into the stomach, past the inflamed and narrowed area.
Around the oesophagus are a range of normal structures which will also be partially treated by the radiotherapy. These include the skin, bones of the chest wall and spine, the heart and the lungs. During treatment, inflammation of the lungs can occasionally cause a cough or increased shortness of breath.

This is uncommon and is rarely serious enough to need treatment. Effects on the heart or bones during treatment are extremely rare.

You may notice some reddening and soreness of the skin around the treated area. Before you go in for your treatment the radiographer will explain what will happen to your skin and how to look after it. They will also give you a leaflet to take home. The same will happen at the end of your treatment.

Please be aware that smoking can make skin reactions worse.

If you are concerned about your skin reaction please talk to your radiographers or contact the nursing staff in Princess Royal Suite on: 0113 206 7587.

**Chemotherapy side-effects**

The chemotherapy drugs used include cisplatin or carboplatin and 5-fluorourcil (5FU), paclitaxel or capecitabine. The chemotherapy may be administered via a drip or a PICC line or given in tablet form. These can cause fatigue and nausea. Anti-sickness medication will be given to you. You may notice a reduction in your appetite, altered taste of food and possibly some soreness of the lips and mouth. This can be managed with medications.
Significant hair loss i.e. noticeable to other people is very unusual with these drugs, although you may notice more hair coming out when you brush or wash your hair.

Chemotherapy temporarily reduces the production of some types of blood cells.

This can lead to:

• anaemia, which can make you feel tired or breathless;
• bleeding or bruising, although this is unusual with this regimen; or
• most importantly a reduced ability to fight infection.

You will be carefully monitored with blood tests during treatment but it is important to understand that any feverish illness during treatment can be much more dangerous than normal.

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. See page 20 for telephone numbers. You will be given a card with emergency contact numbers.

Check your temperature before you ring.

The combination of nausea, altered taste, loss of appetite, sore mouth and swallowing problems can lead to a poor intake of food and drink during treatment.
Chemotherapy can sometimes cause diarrhoea which increases the loss of fluid from your body. If you are struggling with these symptoms please tell us. You may need to come into hospital for further care. Fluid intake is particularly important and having food ‘a little and often’ can be a useful tactic. We have an *Eating Well During Treatment* booklet that provides more information on this.

5FU can cause sensitivity to sunlight. Keep the treatment area covered and use a hat and high factor sun-cream on exposed skin when outdoors. It can also cause soreness of the palms of the hands and soles of the feet. This is reversible and usually helped with creams.

Cisplatin can be harmful to your kidneys, so we monitor your kidney function very closely and give large volumes of fluid through a drip to reduce this. It can also affect the nerves that produce sensation in your fingers, toes or those that are important for hearing. If you notice any numbness, loss of hearing or ringing in your ears let us know. Whilst these effects can be reversible, this is not always the case, and recovery can take many months.

**Long term side-effects**

**Radiotherapy**

The commonest long term effect of radiotherapy is scarring and narrowing of the treated area of your oesophagus. As a result, swallowing may be difficult or painful. Various treatment options are available for this.

Late effects on the lungs, causing cough or shortness of breath, are possible but very unusual.
The long term effects of radiotherapy on the heart are not fully understood. It is likely that in long-term survivors of treatment the rate of heart attacks and heart failure will be slightly higher than the general population.

The rate of second, new cancers possibly caused by treatment is likely to be increased slightly in long-term survivors.

These effects need to be balanced against the aggressive behaviour of most oesophageal cancers if treatment is not given.

**Chemotherapy**

As described above, chemotherapy can leave permanent damage to the kidneys, hearing and touch sensation. By careful monitoring, however, it is usually possible to prevent this being a serious problem.

Chemotherapy can have effects on sexual function and fertility for both men and women. For instance, fatigue and anxiety associated with treatment can affect sex drive. This may recover slowly after CRT.

**Women:** You may notice your periods becoming irregular during or after treatment. In younger women, they may gradually return to normal, but for those close to the menopause they may never return. This may in turn lead to menopausal symptoms (hot flushes, sweats, vaginal dryness etc). If you have any questions or concerns regarding fertility or hormone replacement therapy (HRT) please speak to your GP.

You can talk to your clinical nurse specialist if you need support regarding the management of fatigue, sexual function and for women early menopause.
Support and information

Hospital Contact Numbers
If you have any queries during treatment please speak to your chemotherapy or radiotherapy nurses, or your radiographers.

**Princess Royal Suite: 0113 206 7587**
(8.30am - 6.00pm Monday - Friday)

**Day Case Unit: 0113 206 8180**
(8.00am - 6.00pm Monday - Friday)

**GI Chemoradiotherapy Nurse Specialist: 0113 206 7852**
(9.00am - 5.00pm Monday - Friday)

At other times, including weekends and bank holidays, contact St. James University Hospital **(0113) 243 3144** and ask for the oncology patient enquiries bleepholder.

*This is particularly important if you fear you may have an infection whilst on chemotherapy.*

Leeds Cancer Support
Leeds Cancer Support complements care provided by your clinical team. We offer access to information and a wide range of 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.

The Sir Robert Ogden Macmillan Centre
The Centre is on the St James’s University Hospital site and offers a variety of support services including counselling, support groups and complementary therapies.
You can just drop in for a coffee and a chat anytime. Open from 10.00am- 4.00pm Monday to Friday.
Tel: (0113) 206 6498

Contact numbers for Leeds Cancer Support

Information Lounge Level 1 Outpatients Department
Open from 10.00am - 4.00pm. Tel: (0113) 206 8816

Radiotherapy Information Lounge Level -2
Open from 8.00am - 6.00pm Tel: (0113) 206 7603

If you would like to visit the radiotherapy department before your treatment starts please call the number above to arrange a time. This visit can be very useful as you can find out more information 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.’

All the Leeds Cancer Support services can be emailed on: leedsth-tr.cancersupport@nhs.net
**National support services**

**National Oesophageal Patients Association**
Set up by former patients. There is limited information on the website but has links to telephone support and local meetings.  
Telephone: **0121 704 9860**  
Website: [www.opa.org.uk](http://www.opa.org.uk)

**Ochre**
A national cancer charity that has been formed to promote awareness of oesophageal cancer.  
Telephone: **0800 822 3370**  
Website: [www.ochre-charity.co.uk](http://www.ochre-charity.co.uk)

**Patient Advice and Liaison Service (PALS)**
Supports patients and their families when they have concerns about the service they have received from the NHS.  
Telephone: **0113 206 7168**

**LESS - Leeds Smoking Services** Ring for free advice, support and details of clinics in your area.  
Telephone: **0800 169 4219**

**NHS Smoking Helpline**  
7am-11pm everyday free phone: **0800 169 0169**
General Information

Car Parking
Parking for radiotherapy planning and treatment is free in the on-site multistorey car park. For more details please ask at the main radiotherapy reception.

Hotel Bexley Wing
The hotel is located on the 8th floor of Bexley Wing and offers single and double rooms, each with an en-suite, tea and coffee making facilities and digital television. Single rooms with wheel chair access are also available. Patients are able to stay free of charge. There is a charge for relatives if they are staying in their own room.

For further details please contact the Hotel Coordinator on 0113 206 7687. Out of hours please contact the Non-surgical Oncology Nurse Practitioner through main switch board on 0113 243 3144.

Refreshments
There is a restaurant and coffee shop available on Level 0, which are open daily. They serve drinks, light snacks and hot meals. Vending machines are also available in the main radiotherapy waiting room and Level 0.

There is also a shop on Level 0 with books, papers and snacks.