Sheffield Teaching Hospitals NHS
NHS Foundation Trust

Chemo-radiotherapy treatment for rectal cancer

Information for patients
Weston Park Cancer Centre

Introduction

This leaflet aims to help you and your family understand more about your chemo-radiotherapy treatment for rectal cancer.

Before you agree to have the treatment you should have a good understanding of the procedure and the possible side effects. This leaflet should supplement the discussion you may have already had with your Clinical Oncologist (a doctor specialising in cancer treatment) and the rest of the team, including therapy radiographers (specialist staff who deliver radiotherapy) and nurses. Please ask if you have any questions or concerns which have not been answered. If you hear any words or phrases that you do not understand, please ask your doctor or a member of the healthcare team what they mean.

If you have any additional needs (physical, religious, cultural, emotional or medical), please inform a member of staff so that every effort can be made to meet your individual needs.

Once the treatment and its risks have been explained to you to your satisfaction, you will be asked to sign the form at the end of the document (the consent form). Signing a consent form still allows you to stop your treatment, though it is advisable to complete the course. If you are considering stopping treatment please discuss this with your oncologist.

Sample

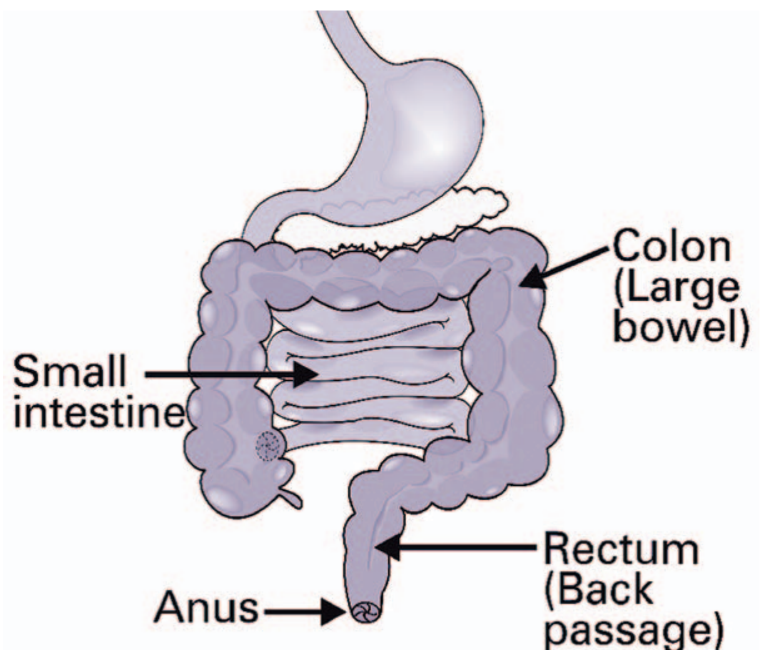
What is rectal cancer?

The bowel is part of the digestive system and is divided into two parts : the small and large bowel.

The large bowel is made up of the colon and rectum (back passage).

Waste food matter (faeces) is held in the back passage until it is ready to be passed from the body through the anus as a bowel motion (poo/stool).

A cancerous (malignant) lump that starts in the back passage is called a rectal cancer. A diagnosis is usually made after a physical examination and colonoscopy (a flexible telescope passed through the anus into the bowel to view the inside of



Issue Date: April 2018. Review Date: April 2020

your back passage) is performed. A small amount of tissue (biopsy) is taken from the lump and sent to the laboratory for testing. This is usually followed by a number of tests including scans and blood tests to see if the cancer has spread to other parts of the body.

How is it treated?

Many cancers of the rectum are treated with surgery. In some cases, such as yours, we recommend a course of radiotherapy and chemotherapy either before, or occasionally after the operation. This decision is made after considering a number of factors including what the tumour looks like on scan e.g. its size and location in the rectum.

What is chemo-radiotherapy treatment and how might it benefit me?

Chemo-radiotherapy is the use of both anti–cancer drugs (chemotherapy) and radiotherapy (high energy x-rays) in order to treat the cancer. The aim of this treatment is to shrink the cancer prior to surgery, to try and increase the chances of it all being removed at the time of surgery. The treatment also aims to try and reduce the chances of the cancer coming back again in the pelvis.

Treatment will be daily apart from weekends, over five weeks, with chemotherapy usually given as tablets and taken on the same days as radiotherapy.

This leaflet will describe the radiotherapy in detail and the chemotherapy will be explained in a separate leaflet.

What is radiotherapy?

Radiotherapy is the use of high energy x-rays, to treat the cancer. The organs and tissues of your body are made up of tiny building blocks called cells. Radiotherapy causes damage to the cancer cells in the treatment area. Although normal cells are also affected, they can repair themselves and are able to recover over time. There is a risk of permanent damage to normal tissues, which will be explained further in the side effects section of this leaflet.

Radiotherapy itself is painless and does not make you radioactive. It is perfectly safe for you to be with other people, including children throughout the duration of your treatment. Although only you can be in the treatment room when the radiotherapy machine is on.

Sample

Treatment is delivered by a machine called a linear accelerator, also known as the treatment unit or LINAC, shown in this photograph.

Please be aware that the radiotherapy centre is a training centre for radiographers so students may be present on the treatment unit. However, they are supervised at all times. If you do not wish students to be present during your treatment then please speak to a member of staff. This will not affect your treatment or care.

Planning your treatment

After seeing your doctor in clinic you will receive an appointment to visit the radiotherapy department at Weston Park Hospital for radiotherapy planning.

Your first radiotherapy appointment may include:

- Having a 'planning' CT scan
- Signing the consent form at the end of this leaflet (if it has not been done already)
- Having blood tests

As part of your treatment you will need to have a planning CT scan which is used to identify where the cancer is, so that your radiotherapy can be accurately delivered to this area. The planning scan usually takes 10-15 minutes. You will be asked to undress from the waist down and will be given a gown to wear. Before the scan you may be asked to drink water so that your bladder is comfortably full. This is to help reduce side effects to your small bowel.

Some patients will also be given an injection in their arm, of a contrast fluid which can help us plan the radiotherapy. The contrast is only needed for this scan, not each treatment.

The scan is taken with you lying flat. You will be required to stay very still in this position for each treatment, so it is important that you are as comfortable as possible. If you find this position uncomfortable then please let the radiographers know.

Once you are in position, the radiographers will ask your permission to draw some marks on your skin, to use as a reference point and help place you in the correct position for treatment every day. At the end of the scan these marks will be replaced by permanent marks. These marks (tattoos) are no bigger than a freckle and will be used each day for your treatment. You can wash as normal without worrying about these marks coming off.

The process of planning your treatment can take about 2-4 weeks.

What happens during your treatment?

When you arrive for radiotherapy you should go to the reception on the lower ground floor and book in at the radiotherapy reception desk. You will be asked to take a seat in the waiting area.

On the first day of treatment a radiographer will meet with you and have a discussion to explain the possible side effects of treatment and how to minimise them and answer any questions/concerns you may have.

Sample

You can expect to spend 10-15 minutes each day in the treatment room. 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. You will be in the same position you were in for your CT planning appointment, on your back. The machine does not touch you. It is important for you to stay as still as possible but breathe normally. Once you are set up in the correct position the staff will let you know that they are leaving the room for a few minutes to start treatment.

The machine is controlled by the staff outside in the 'control area' and the machine will rotate around you in different directions. The radiographers are watching you at all times on TV monitors and should you feel you want to stop the treatment at any time, just wave to attract their attention. The TV images are not being recorded or saved. If you need attention the machine will be stopped and the radiographers will come back into the room.

You will not feel or see anything during the treatment however you may hear a buzzing sound when the treatment is being delivered.

You will also have several sets of images taken during your treatment to ensure that the radiotherapy is being delivered accurately to the right area. These images are necessary, but will result in a small dose of additional radiation which has been agreed by your doctor. Any risk from this dose is far outweighed by the benefits to you during your radiotherapy

Chemotherapy

You will be required to have chemotherapy on the days you have radiotherapy. This will be administered as a course of tablets (Capecitabine) taken twice a day or rarely, as a drip (5 Fluorouracil). An appointment will be made for you to have a pre-assessment talk with a member of staff, to discuss how to take the tablets and also to collect them from the pharmacy. It will be another opportunity for you to ask any questions about the treatment.

You will be required to sign a separate consent form for the chemotherapy, where its side effects will be described in more detail.

Side effects and complications of chemo-radiotherapy

Side effects can be divided into short term effects that happen during or soon (weeks) after treatment and long term effects which can occur months or years later. Both chemotherapy and radiotherapy can be responsible. Some are common; others are potentially serious but rare.

Below is a list of side effects along with how likely it is for that particular side effect to occur. Here are some definitions to help you:

Common – More than 10 in every 100 (>10%) people will develop this side effect

Occasional – Between 1 and 10 in every 100 (1-10%) people will develop this side effect

Rare – Less than 1 in 100 (<1%) people will develop this side effect

However, please be aware that each patient can react differently to the treatment and you may experience side effects at different times and to varying degrees, compared to other patients having the same treatment.

Short term side effects:

Sample

Common ones:

Tiredness (fatigue)

•Nearly all patients undergoing chemo-radiotherapy will feel more tired than usual. This can be most noticeable towards the end of the treatment and often continues for a week or two after its completion. It may affect your ability to drive (although to be this severe would be rare). This fatigue is usually a combination of the side effects of treatment and attending hospital every day. Be prepared to rest when necessary during treatment.

Your Bowel – radiotherapy includes treating some of your normal bowel as well as the cancer. It can cause inflammation and these specific side effects:

•Diarrhoea - If you have a stoma you may need to change / empty the bag more often

•Abdominal bloating and discomfort

•Bleeding or mucus loss from the back passage

•Feeling of fullness in the back passage or pain (particularly if your tumour is low down in the rectum)

Your Bladder – your bladder will also be included in the treatment area as it is very close to the back passage, causing these side effects:

•Pain/stinging on passing water

•Passing water more often

Your Skin and hair

•The skin in the treated area (front and back) may become red and sore, but this varies from person to person. We recommend the use of simple moisturisers. You can wash the area gently using a mild un-perfumed soap. Do not use your own creams on skin being treated with radiotherapy, as it can make your skin reaction worse.

•Having radiotherapy prior to surgery can sometimes mean that wounds take longer to heal. (particularly if your tumour is low down in the rectum)

•You may lose pubic hair in the treated area, but it will grow back once the treatment is complete.

Occasional side effects:

•Needing to get to the toilet quickly (urgency)

Long term side effects:

The long term effects that you experience can depend on the type of surgery you have. In some cases, it is the surgery that is the most likely cause of the problems outlined below. Your surgeon will advise you on the most appropriate surgery for you. Some people will have a stoma which may be

Sample

permanent or temporary and some may undergo complete removal of the back passage at surgery. In others, the bowel is joined up again and they pass motion in the normal way.

Common ones:

Your Bowel

•Permanent change in bowel habit – having your bowels open more often

•Urgency to get to the toilet and not being able to control it (faecal incontinence) which may cause soiling of clothing or leakage

•Recurring (chronic) abdominal pain and pain in the back passage

Your Bladder

•Need to pass water more often

Sexual dysfunction in women

•For female patients who have not gone through the menopause, this treatment is likely to induce the menopause and infertility (so you will no longer be able to have children). We can refer you to a specialist to discuss egg or embryo storage.

Women may also notice their periods becoming irregular during or after treatment. However, you should continue to use contraception during your treatment and for one year after your treatment has finished.

- **Pregnancy must at all costs be avoided whilst on treatment.**

•Some women experience vaginal dryness and pain during sex after treatment. You will receive a separate leaflet regarding feminine care during and post chemo-radiotherapy and including advice on the use of dilators to help this.

Sexual dysfunction in men

•Treatment 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, if infertility is not caused by the treatment. Men are advised to use contraception for one year after treatment.

•If you would like to have more children in the future, you should discuss this with your doctor before starting radiotherapy so we can arrange storage (freezing) of some sperm, which can then be used at a later time if needed.

•There is an increased risk of impotency (being unable to attain and maintain an erection) if you have received radiotherapy and surgery. If this is a problem, then you should discuss it with your GP or hospital team and you can be referred to a specialist clinic.

Sample

Skin changes

•Long term the skin can look different in the treated area and feel tougher - pigment changes and the development of small blood vessels on the skin surface

Occasional Side Effects:

•Risk of bowel damage requiring surgery and a stoma (if you do not already have one)

•A fistula (false passage between the bladder and/or vagina and bowel) or narrowing of the bowel (stricture)

•Not being able to control your bladder as well – causing dribbling and leakage (occasional)

Second Malignancy

•In the long term there may be a slightly increased risk of developing a new cancer caused by the treatment. Accurate information on this is not available and the benefits of the treatment far outweigh any potential risk in the future. If you are at all concerned then please speak to your medical team.

Bone Health

•There is an increased risk of fracture of the pelvic and sacral bones after radiotherapy. These are usually hairline and treated with painkillers

Leg swelling occurs in a very small number of patients

Rare Side Effects:

Life threatening complications:

Rarely a patient can die whilst undergoing chemo-radiotherapy. This is usually due to rare complications of the chemotherapy (Capecitabine or 5 Fluorouracil).

A very small proportion of the population are particularly sensitive to the chemotherapy used in this treatment. If you experience significant side effects (such as diarrhoea and nausea) early on in the treatment (especially within the first week to 10 days) then this is unusual and may be a warning sign that you are one of these individuals. You should stop taking the tablets and ask for help straight away if this happens. You must do the same if you develop chest pain, as this is an emergency.

Very rarely indeed (in fewer than one in ten thousand patients treated) capecitabine has been shown to cause a severe and sometimes fatal allergic condition with blistering or breakdown of the skin, eye problems and effects on the internal organs.

Sometimes we stop chemotherapy part way through treatment if the patient develops significant side effects.

Is there anything else you need to be aware of?

Sample

During the course of your treatment it may be necessary to:

- Admit you to hospital, for instance if you develop infection.
- Undertake a blood or platelet transfusion (though this is very rare)

Are there any alternative options?

If your cancer is not currently operable then going straight to surgery without chemo-radiotherapy would not be recommended, as there is the chance some cancer would be left behind. The chemo-radiotherapy is aimed at shrinking the cancer down and hopefully making it possible for you to have an operation to fully remove the cancer.

If the cancer is operable at present, then it would be possible to proceed directly to surgery, but this could lead to an increased chance of the cancer coming back in the pelvis, than if you had chemo-radiotherapy.

What will happen if you decide not to have the treatment?

If you choose not to have any treatment, then it is likely that the cancer will continue to progress and in time cause you symptoms such as pain, bleeding and sometimes a blockage of the bowel. It is also possible that it can spread to other organs and probably shorten your life, although chemo-radiotherapy may not prevent this.

Will there be any follow up appointments?

At the end of your treatment the radiographers will give you advice and contact numbers. We will see you in the outpatient department 4-6 weeks after completion of the radiotherapy by which time the short term side effects should be settling down.

Who should you contact if you have any other concerns?

Radiotherapy Information and Support Team: 0114 226 5282 or email **sht-tr.RTinfo@nhs.net**

For out of hours emergencies (after 5.00pm and at weekends **) 0114 226 5000** and ask for the Duty Sister at Weston Park Hospital. Alternatively, call your GP
You can also call your specialist nurse or consultant's secretary if it is not urgent.

Patient Services Team: 0114 271 2400 PST@sth.nhs.uk

Where can I find further information?

Weston Park Cancer Information and Support Centre **0114 226 5666**

Rotherham Macmillan Cancer Information and Support Centre **01709 427 659**

Doncaster and Bassetlaw Information and Support Service **01302 796 600**

Chesterfield Cancer Support Drop-in Centre **01246 555 514**

Sample

Macmillan Cancer Support	**0808 808 0000** website: **www.macmillan.org.uk**
Bowel Cancer UK	**0207 940 1760**
NHS Smokefree National Helpline	**0300 123 1044**

Signing the consent form

Before we are able to undertake any medical treatment, test or examination we must seek your consent first. For some procedures we do this by asking you to sign a written consent form. It is important you fully understand what the procedure involves before you give your consent. The information in this leaflet aims to provide as much information about the procedure to help you make this decision. If you need more information or are unsure about any aspect of the procedure or treatment proposed please do not hesitate to ask for more information. Some questions you should consider include:

- What are my options?
- What are the pros and cons of each option?
- Do I need more information or support to help make this decision?

Please do remember that you are entitled to change your mind at any point, even after the consent form has been signed. If you do change your mind we recommend you discuss this with your oncologist.

Sample

Alternative formats can be available on request. Email: **alternativeformats@sth.nhs.uk**

© Sheffield Teaching Hospitals NHS Foundation Trust 2019

Re-use of all or any part of this document is governed by copyright and the "Re-use of Public Sector Information Regulations 2005" SI 2005 No.1515. Information on re-use can be obtained from the Information Governance Department, Sheffield Teaching Hospitals. Email infogov@sth.nhs.uk

Consent Form 1

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

Note: Use this form for adults or children who are competent and able to consent for themselves.

Patient agreement to: **Chemo-radiotherapy treatment for rectal cancer**

Name:

DoB:

(Affix Patient Label here)

Hosp. no.

NHS no.

Special requirements of patient (e.g. other language / other communication method)

....

Responsible health professional: ....

....

Job title: ....

Contact details: ....

Statement of health professional (to be filled in by health professional with appropriate knowledge of proposed procedure, as specified in consent policy)

I have explained the procedure to the patient. In particular, I have explained:

1. The intended benefits

2. Serious or frequently occurring risks

3. Other risks to be aware of: ....

....

....

4. Any extra procedures which may become necessary during the procedure:

☐ blood transfusion..

☐ other procedure (please specify) ....

....

I have also discussed what the procedure is likely to involve, the benefits and risks of any available alternative treatments (including no treatment) and any particular concerns of this patient.

5. The following leaflet has been provided: Chemo-radiotherapy treatment for rectal cancer (PIL4154 v1) April 2018

Accompanying leaflet accepted by patient: ☐ Yes ☐ No

6. This procedure will involve pre-operative assessment to determine the appropriate type of anaesthesia required: ☐ Yes ☐ No

☐ general and/or regional anaesthesia ☐ local anaesthesia ☐ sedation

Signed (health professional) .... **Date** ....

Name (PRINT) .... **Job title** ....

Statement of interpreter (where appropriate)

I have interpreted the information above to the patient to the best of my ability and in a way in which I believe s/he can understand.

Signed (interpreter) ……………………………………….	**Date** …………………..
Name (PRINT) ………………………………..	**Job title** …………………………………………………

Statement of patient

Please read this form and the accompanying leaflet carefully. The leaflet describes the benefits and risks of the proposed treatment and possible alternatives. If your treatment has been planned in advance, you should already have your own copy of the leaflet. If not, you will be offered a copy now. If you have any further questions, do ask – we are here to help you.You have the right to change your mind at any time, including after you have signed this form.

I agree to the procedure or course of treatment described on this form.

I understand that you cannot give me a guarantee that a particular person will perform the procedure. The person will, however, have appropriate experience.

I understand that I will have the opportunity to discuss the details of anaesthesia with an anaesthetist before the procedure, unless the urgency of my situation prevents this. This only applies to patients having general or regional anaesthesia. Information regarding anaesthesia in general can be found on http://www.rcoa.ac.uk/document-store/you-and-your-anaesthetic. Alternatively please ask for a copy of the leaflet 'You and your anaesthetic' (provided at Pre-Operative Assessment).

I understand that any procedure in addition to those described on this form will only be carried out if it is necessary to save my life or to prevent serious harm to my health.

I have been told about additional procedures which may become necessary during my treatment. I have listed below any procedures which I do not wish to be carried out without further discussion.

………

………

………

………

I understand that tissue removed as part of my treatment may be used for teaching, education, quality assurance or audit in addition to diagnostic purposes.

I consent to the use of residual tissue following diagnosis for research: ☐ Yes ☐ No
(If No, the healthcare professional will inform Histopathology. The department will respect your wishes.)

Signed (patient) ……………………………………….	**Date** …………………..
Name (PRINT) ………………………………..	**Job title** …………………………………………………

Statement of witness (where appropriate)

A witness should sign below if the patient is unable to sign but has indicated his or her consent. Young people/children may also like a parent to sign here (see notes).

Signed (witness) ……………………………………….   **Date** …………………..
Name (PRINT) ………………………………..   **Job title** ………………………………………………….

Confirmation of consent (to be completed by a health professional when the patient is admitted for the procedure, if the patient has signed the form in advance)

On behalf of the team treating the patient, I have confirmed with the patient that s/he has no further questions and wishes the procedure to go ahead.

Signed (health professional) ……………………………………….   **Date** …………………..
Name (PRINT) ………………………………..   **Job title** ………………………………………………….

Important notes: (tick if applicable)

☐ See also advance directive/living will (e.g. Jehovah‟s Witness form)

☐ Patient has withdrawn consent (ask patient to sign and date here) ………...……….

Guidance to health professionals (to be read in conjunction with consent policy)

What a consent form is for

This form documents the patient's agreement to go ahead with the investigation or treatment you have proposed. It is not a legal waiver – if patients, for example, do not receive enough information on which to base their decision, then the consent may not be valid, even though the form has been signed. Patients are also entitled to change their mind after signing the form, if they retain capacity to do so. The form should act as an aide-memoire to health professionals and patients, by providing a check-list of the kind of information patients should be offered, and by enabling the patient to have a written record of the main points discussed. In no way, however, should the written information provided for the patient be regarded as a substitute for face-to-face discussions with the patient.

The law on consent

See the Department of Health's Reference guide to consent for examination or treatment for a comprehensive summary of the law on consent (also available at https://www.gov.uk/government/publications/reference-guide-to-consent-for-examination-or-treatment-second-edition).

Who can give consent

Everyone aged 16 or more is presumed to be competent to give consent for themselves, unless the opposite is demonstrated. If a child under the age of 16 has "sufficient understanding and intelligence to enable him or her to understand fully what is proposed", then he or she will be competent to give consent for himself or herself. Young people aged 16 and 17, and legally 'competent' younger children, may therefore sign this form for themselves, but may like a parent to countersign as well. If the child is not able to give consent for himself or herself, someone with parental responsibility may do so on their behalf and a separate form (Consent form2) is available for this purpose. Even where a child is able to give consent for himself or herself, you should always involve those with parental responsibility in the child"s care, unless the child specifically asks you not to do so. If a patient is mentally competent to give consent but is physically unable to sign a form, you should complete this form as usual, and ask an independent witness to confirm that the patient has given consent orally or non-verbally.

When NOT to use this form

If the patient is 18 or over and is not legally competent to give consent, you should use Consent form 4 (form for adults who are unable to consent to investigation or treatment) instead of this form. A patient will not be legally competent to give consent if:

- they are unable to comprehend and retain information material to the decision; and/or
- they are unable to weigh and use this information in coming to a decision.

You should always take all reasonable steps (for example involving more specialist colleagues) to support a patient in making their own decision, before concluding that they are unable to do so. Relatives cannot be asked to sign this form on behalf of an adult who is not legally competent to consent for himself or herself.

Information

Information about what the treatment will involve, its benefits and risks (including side-effects and complications) and the alternatives to the particular procedure proposed, is crucial for patients when making up their minds. The courts have stated that patients should be told about 'significant risks which would affect the judgement of a reasonable patient'. 'Significant' has not been legally defined, but the GMC requires doctors to tell patients about 'serious or frequently occurring' risks. In addition if patients make clear they have particular concerns about certain kinds of risk, you should make sure they are informed about these risks, even if they are very small or rare. You should always answer questions honestly. Sometimes, patients may make it clear that they do not want to have any information about the options, but want you to decide on their behalf. In such circumstances, you should do your best to ensure that the patient receives at least very basic information about what is proposed. Where information is refused, you should document this on the form or in the patient's notes.