

General information for patients having chemotherapy

Rutherford Cancer Centres

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Introduction

At the Rutherford Cancer Centres we understand that being diagnosed with cancer can be a huge shock. This is why we aim to put you the patient and your family at the heart of everything we do.

This includes not only delivering the highest quality, state-of-the art care but also making each day the best it can be for you.

Your quality of life is our crucial focus and forms the basis of our holistic approach to your care. We are committed to providing every available, appropriate treatment option, liaising between all healthcare services and acting as your advocate. Compassion, confidentiality and respect are our core values.

We believe personal responsibility and accountability make us a more effective treatment team and caregivers. We know that knowledge is a powerful tool and we strive to educate ourselves and our patients on the latest and most relevant healthcare information.



Overview

The Rutherford Cancer Centres Infusion Therapy Suite consists of multiple spacious treatment areas offering treatment for oncology/haematology patients requiring systemic anti-cancer therapy (SACT) and supportive care in an outpatient setting.

This is a consultant/oncologist led service that offers flexibility and choice where possible to support patients and their families. The Oncology and Haematology Service is supported by other members of the multidisciplinary team, to ensure patients are treated safely and holistically.

These include SACT nurses, dieticians, physiotherapists and counsellors, all of whom will be available on site. You will also have the opportunity to see your consultant oncologist during and following treatment. We place an emphasis on dignity and respect, with the aim of supporting quality of life.

Your treatment pathway

Your treatment will be delivered in accordance with approved national protocols. These protocols are authorised by the consultant oncologist/haematologist and are referred to during the course of your care.

Information and consent

Before you have any treatment the consultant oncologist will ask for your consent, which will ensure you are fully informed of all the potential risks/benefits and side effects of the treatment. No treatment can be given without your consent.

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Benefits of treatment

The benefits of chemotherapy depend on the type of cancer you have and how advanced it is. The aims include:

- To cure the cancer by destroying all of the cancer cells
- To reduce the chances of cancer coming back by destroying any cancer cells that are still in the body but are too small to detect
- To reduce the size of the cancer before surgery or radiotherapy
- To control the growth and spread of the cancer to relieve possible symptoms.

Pre-treatment assessment

Before you start treatment, you will be offered a pre-treatment assessment. This assessment usually takes about two hours and includes the development of your individual information pack, which contains information about your treatment and support. Information about your treatment will also be sent to your GP.

The two hour time frame allows us to complete a full holistic assessment, taking into account your practical, emotional and spiritual concerns.

Your first day of treatment

On the first day of treatment the systemic anticancer therapy (SACT) nurse will explain in greater detail exactly what chemotherapy treatment you will be having and any side effects that may occur.

You will also be given some more specific information about the chemotherapy drugs you are going to receive and your medication to take home.

The SACT nurses will check your identification details (such as full name, date of birth etc.) and confirm that you have consented to receive your treatment.

Assessment before each cycle of treatment

You may be asked to attend a 'prechemotherapy assessment' appointment before each session (cycle) of your treatment. At this appointment a consultant oncologist or senior SACT nurse will assess you. The consultant oncologist/SACT nurse will ask you how you got on with your previous cycle of chemotherapy and make sure you are feeling well enough to continue. Your weight will be checked and you will have a blood test

Blood tests

Before each session of treatment you will need to have a routine blood test. This will generally include a full blood count and kidney and liver function tests. Sometimes it may be necessary to delay your treatment by one or two weeks if your blood count has not returned to normal following the last cycle of chemotherapy. We need to check that your blood count is normal before you have your next cycle of chemotherapy.

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Sometimes based on the results of your tests, or if you have experienced severe side effects from the chemotherapy, your consultant oncologist may decide it is necessary to adjust your chemotherapy dose, or change your treatment plan. If your dose needs to be adjusted to better manage side effects or your treatment needs to be changed in any way then your consultant oncologist will discuss this with you. You will be given detailed information and advice on what side effects to expect and how best to manage them and also clear advice on who to contact should you experience any symptoms that cause you concern.

What is chemotherapy?

Chemotherapy is taken from two words — chemical and therapy. The treatment involves one or more drugs that kill cancer cells or make them less active. There are over 200 types of cancer and more than 50 chemotherapy drugs currently licensed in the UK.

The chemotherapy drugs work by interfering with the ability of cells to divide and grow. The affected cells become damaged and eventually die. As the drugs are carried in the blood, they can reach cancer cells all over the body. Unfortunately, chemotherapy drugs can also affect normal cells, sometimes causing side effects. Unlike cancer cells, normal cells quickly recover, so any damage to them is usually temporary and most side effects will disappear once the treatment is over.

How is chemotherapy given?

Chemotherapy may be given in a number of ways depending on the drugs used. Most commonly it is given:

- By tablet or capsule (by mouth)
- By injection through a vein into the bloodstream, using a syringe (bolus) or infusion (drip). A small needle will be introduced into a vein on the forearm or back of the hand immediately before receiving your chemotherapy. Some chemotherapy can be administered over a few minutes, in which case the needle will be removed straight after administration. However, many treatments will require a longer time for administration, so the needle will be left in until treatment is complete, and removed before you go home. Some patients' chemotherapy may need to be given through a PICC line (a small tube that is put into a large vein in your arm so blood samples can be taken and medicines and fluids given easily, which can stay in place for a long period of time). The consultant oncologist or systemic anti-cancer therapy (SACT) nurse will discuss this with you. Whichever way the drugs are given, they are carried around the body in the blood so they can reach the cancer cells.

Will it hurt?

Chemotherapy should not be painful. If you feel any pain or unusual sensation during the treatment, please inform the treatment team immediately. If the injection site is painful, sore or red when you are at home, please telephone for advice as soon as possible. More details about who to contact and how will be given when you attend for your treatment.

How often is chemotherapy given?

Depending on your treatment it can be given at various intervals, such as daily, weekly, every two/three weeks or continuously. Your consultant oncologist will discuss how often your chemotherapy will be given.

Can I eat and drink as normal?

Yes, we would recommend a light meal before your chemotherapy treatment. Avoid large, heavy meals for the first day or two afterwards. You should drink plenty of fluids. It is best to avoid alcohol for a few days after each chemotherapy treatment. Your consultant oncologist will discuss with you if you need to avoid alcohol completely. Ensure that you eat food that has been prepared and stored to a high standard of hygiene. Avoid unpasteurised food, soft cheeses and pates.

How will I know if the treatment is working?

Your consultant oncologist will monitor your progress throughout your treatment. This may include scans, x-rays, blood tests and examinations. All the tests will check your health and the way chemotherapy is affecting you. These will vary person to person and will be discussed with you on an individual basis.



Good to know:

Ensure that you eat food that has been prepared and stored to a high standard of hygiene. Avoid unpasteurised food, soft cheeses and pâtés.

What are the possible side effects of chemotherapy?

There are many possible side effects to chemotherapy treatment. These will depend on the type of chemotherapy you are prescribed. We will give you a separate information leaflet on your specific chemotherapy, which will explain your side effects in more detail.

The main areas that can be affected are those areas where cells divide and grow quickly, such as your skin, hair, mouth, digestive system and your bone marrow (the spongy material filling the bones and where new blood cells are produced).

This booklet explains the general side effects that may be expected with most types of chemotherapy treatment. Please remember:

- You will not get all of the side effects mentioned below.
- Side effects are often predictable in terms of when they start, how long they last and how severe they will be.
- Side effects are almost always reversible and will go away after you finish your treatment.
- Side effects are usually quite manageable. There are many options to minimise or prevent them.

Low blood count

Chemotherapy temporarily reduces the rate at which blood cells are produced in your bone marrow. This may cause your blood count to fall and this is the reason you will have a full blood count (FBC) before each cycle of chemotherapy. Most of the time you will not notice that your blood count has fallen.

However, there may be occasions when you will experience the following symptoms associated with low blood counts these are discussed below:

Red Cells: These carry oxygen to all parts of your body. If your red cells are low, this is called anaemia. If you are anaemic you may feel unusually tired, have aching legs, headaches, or feel short of breath when doing moderate exercise (for example climbing stairs). This may get better on its own, although some people may need a blood transfusion to relieve their symptoms.

White Cells: If these are lowered by your chemotherapy treatment, then your body's ability to fight infections is reduced. If they become very low this is called neutropenia. There are no specific signs or symptoms of neutropenia, although some people find they feel tired and washed out when their white blood count is low. Some people suffer with a sore mouth when they are neutropenic. The only way to tell for certain if you are neutropenic is to do a blood test.

Platelets: These cells are needed to allow the blood to clot, for example if you have a cut. If your platelet count is low you may notice that you bruise easily, have nosebleeds or that your gums bleed. However, you can have a very low platelet count without having any problems. If you have a very low platelet count and are bleeding you may need some tablets and/or a transfusion of platelets to prevent further bleeding.

Infection/reduced immunity

If you are neutropenic you are at a higher than normal risk of getting infections. As your body has no natural defence against infection, if you get an infection you will become ill much more quickly than normal, and may feel very unwell.

One way that we can tell if you have an infection is a rise in your body temperature. If your temperature is 37.5C or above, or if you notice any signs of infection such as a sore throat, cough, cold or diarrhoea you should contact the 24-hour number, which you will have in your "red diary" and is also available at the back of this booklet.

You will then be advised on the best action to take. As you have no natural defences against infection you will not get better without treatment with antibiotics. In addition, some types of infection can cause your blood pressure to drop and become life threatening in a very short time. For these reasons, if you are at home, you must contact us as soon as you feel unwell. The chances of us successfully treating any infection you catch decrease the longer you wait before starting treatment.

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How can I help myself avoid infections?

Most chemotherapy drugs reduce the body's resistance to infection. Most infections are caused by your own body flora (bacteria found within the body that normally do not cause disease), not by transmission from other people.

It is important for your emotional wellbeing to live as normal a life as possible while you are on chemotherapy. There is very little risk of catching infections from normal social situations. However, you do need to be aware of some specific risks.

You should avoid:

- Young children who are poorly (if possible).
- People with flu or other infections, especially chicken pox, measles or shingles.
- Swimming or using saunas.

Bleeding

- To help prevent bleeding problems only use an electric shaver.
- To prevent bleeding gums do not use a hard toothbrush or dental floss.
- Watch out for blood in your urine and bowel movements. Urine will appear red or very dark brown coloured and stools will appear black and tarry or bright red.

Nausea and vomiting

Chemotherapy may cause you to feel sick, but not necessarily to vomit, although this can occur. If this is likely with your treatment, you will be given anti-sickness medication prior to your treatment and to take home.

There are several anti-sickness treatments available, and if the first one you are given has not worked, we can usually find one that works for you. You should take your anti-sickness tablets regularly as prescribed, even if you are not feeling sick, as some anti-sickness drugs are better at preventing rather than stopping sickness.

In the unlikely event that you do feel sick or vomit following your treatment, there are many extra anti-sickness drugs we can give to help overcome this problem. If you experience vomiting at home then anti-sickness tablets may not be effective and you may easily become dehydrated. If this happens it is important you contact the systemic anti-cancer therapy (SACT) nurse.

During the first 24 hours after chemotherapy it is best to avoid heavy meals. Try light snacks instead, and drink freely. It is best to avoid alcohol at this time. A reduced or loss of appetite for 24 hours or so after chemotherapy is quite common.

We recommend you try and drink plenty of fluids - two to three litres (four to five pints) per day. You will be given further advice on how to manage nausea.

Sore mouth/mouth ulcers

Chemotherapy treatment can affect the cells that line the inside of your mouth. This can make your mouth red and sore and it is more likely to become infected. So, it is important you look after your mouth during your treatment.

Clean your teeth gently after each meal using fluoride toothpaste. Use toothpaste for sensitive teeth if you have sore gums. You should also gently brush your tongue if it is not too sore.

If you wear dentures, you should brush them in the evening and after eating with liquid soap and water. They should be soaked overnight in water and you should use a sterilising solution daily to disinfect them. You should use sodium hypochlorite 1% (such as Milton sterilising fluid). Dilute one teaspoon in half a tumbler of water. Soak plastic dentures for three minutes. Soak dentures with metal parts for one minute.

If you do get any problems with your mouth, such as ulcers or oral thrush, please inform your SACT nurse immediately. For a few months following your treatment, your mouth may be more sensitive than normal. You should continue with a good mouth care routine. It is advisable to have a dental check-up before you start your chemotherapy.

If you need any dental treatment it is important you discuss this with your consultant oncologist before having any dental work carried out. A routine check-up at the dentist is OK - but if you need any invasive procedures done like filling, tooth extraction, or cleaning, then this has to be discussed with your consultant oncologist. It all has to be timed correctly and you will need your blood counts checking prior to any dental procedure.

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Taste changes

Some people experience a change in their sense of taste or smell following chemotherapy. You may find that food may taste more salty, bitter or metallic. This is only temporary; normal taste and smell usually returns two or three months after the end of treatment. Taste changes may also be caused by infection in your mouth.

Please inform your treatment team of any changes you may have, for example a sore mouth.

Diarrhoea/constipation

Certain chemotherapy drugs can change your normal bowel habits. Medication can be given to help. Please inform your SACT nurse as soon as possible so that the symptoms are treated quickly.

Hair loss

Some chemotherapy drugs cause hair loss. This is because chemotherapy attacks all cells that divide rapidly, and hair cells do this. If you are likely to experience hair loss, the consultant oncologist or SACT nurse will discuss this with you and can provide you with a referral for a wig before you start your treatment, should you like one. Hair loss can be very distressing; however, it is almost always temporary.

Hair loss does not always happen straight away and usually starts within a few weeks of beginning treatment. Sometimes you may experience a prickling tender sensation in the scalp before hair loss. It can occur on all parts of the body, such as the head, face, arms, legs etc. Please remember that your hair will grow back when treatment is over. Sometimes your hair may grow back a different colour or texture.

Scalp cooling may be used for some types of chemotherapy treatment to reduce hair loss. Scalp cooling is not used for patients having chemotherapy for leukaemia or lymphoma as it may increase the chances of relapse following treatment. Please ask the SACT nurse looking after you if you would like further information about scalp cooling.

We can also provide you with information on several organisations that supply headwear designed for people experiencing hair loss.

Fertility and Pregnancy

Fertility and chemotherapy is a very complex subject, and cannot be covered here in depth. You should discuss any fertility issues with your consultant oncologist and SACT nurse before you start treatment.

Some chemotherapy drugs can damage the ovaries or testes, leading to an increased risk of infertility (inability to have a child). Although chemotherapy may make you infertile during your treatment there is still a chance of getting pregnant or fathering a child.

There is no reason not to have sexual intercourse, but we recommend the use of a condom. This should protect your partner from the possibility that there may be very small traces of chemotherapy in your body fluids. It may be possible to become pregnant during the time you are having chemotherapy, but it is not advisable to do so. Some chemotherapy drugs can harm the unborn child. Even if we can treat you while you are pregnant, this adds an increased risk of complications for both the mother and the unborn child.

Breastfeeding during chemotherapy is not advised as the drugs could be passed to a baby through breast milk. During treatment women may experience irregular periods, or periods that are lighter or heavier than normal. Some chemotherapy drugs will stop periods completely during treatment. These effects may last for many months after treatment has finished.

Usually after treatment is over, if your periods return and are regular, you will be ovulating normally and will have normal fertility. If your periods are absent or are irregular a year after treatment you should ask your consultant oncologist to refer you to a gynaecologist for fertility studies.

Generally, women under the age of 20 are quite likely to remain fertile even after very intensive chemotherapy. Women over the age of 30 are very likely to be made infertile or go into early menopause following treatment, however this very much depends on the type of chemotherapy you are having. Even if your periods return to normal you are likely to have an early menopause. If you wish to have children you should get advice from the consultant oncologist about when it is safe to try.

It may be possible to take measures to preserve fertility, by storing sperm or ovarian tissue. However, this depends very much on individual circumstance. Your consultant oncologist will discuss fertility with you and refer you to an appropriate specialist for advice if you wish. It is very important that you discuss all the options before you commence chemotherapy. Once treatment has started it is too late.

Coloured urine

Some chemotherapy drugs may cause the urine to change to a red or blue-green colour. This occurs because the chemotherapy drug is coloured and is naturally excreted from the body in this way. This is normal and should disappear within 24 hours, but if you are at all worried please speak to one of the treatment team such as your consultant oncologist, one of the SACT nurses.

Caring for yourself

Even though chemotherapy treatment can cause unpleasant side effects, some people still manage to lead an almost normal life during their treatment. Many people find they recover quickly between cycles of treatment and resume their usual activities as they begin to feel better.

Having chemotherapy can be a very stressful time for both you and your family, and it is common to feel 'down' at times. Do not be frustrated if your lifestyle does not return to normal immediately. Be patient with yourself.

Care in the sun

Some chemotherapy drugs can make your skin more sensitive to the sun. You must take precautions such as wearing a hat at all times when outdoors, reducing the time you spend in the sun and staying in the shade wherever possible. Also please ensure you wear a high factor sunscreen.

Skin and tissue damage

Some chemotherapy agents that are given in a drip or by injection may damage the skin and surrounding area if they leak outside the vein. This is known as extravasation. It is extremely rare but it is important that you tell us **IMMEDIATELY** if you notice any swelling, redness, pain or burning at the site of the cannula. If this occurs while the chemotherapy is being given, tell the SACT nurse who is looking after you. If you notice pain, swelling or redness around the cannulation site when you get home please contact us straight away.

Risk of blood clots

Cancer can increase your risk of developing a blood clot (thrombosis), and having chemotherapy may increase this risk further. It is important to tell your consultant oncologist immediately if you have symptoms such as pain, redness and swelling in your leg, or breathlessness and chest pain.

Blood clots can be very serious. However, most clots can usually be successfully treated with drugs to thin the blood. Your consultant oncologist or SACT nurse can give you more information.

Side effects of steroid tablets

Many patients being treated with chemotherapy will also be given steroid tablets. These are often given for a few days after chemotherapy to prevent sickness, or starting just before chemotherapy to prevent reactions to the chemotherapy. The most commonly used steroid tablets are dexamethasone and prednisolone.

When taking these tablets you may notice:

- A temporary increase in appetite.
- Indigestion.
- Mood swings, irritability and difficulty sleeping.
- Feeling much more thirsty and passing a larger amount of urine than normal. This may be a sign of an increase in your blood sugar levels, which if left untreated could make you very drowsy, weak and unwell. If you are a diabetic this may be a particular problem.

To reduce the possibility of side effects you will be given only a short course of steroid tablets (usually three to five days). We advise that you should take steroids after food to reduce the risk of indigestion. Avoid taking steroids after 2pm to reduce the risk of difficulty in sleeping. If you are a diabetic then please talk to us about how to manage your blood sugar levels when taking steroid tablets.

Vaccinations

Flu vaccinations

All patients receiving chemotherapy are at risk from flu. Flu immunisation is recommended if you will be receiving chemotherapy during the autumn and winter months. Ideally you should be vaccinated seven to ten days before your chemotherapy starts. The immunisation may not be as effective if you have already started chemotherapy because your immune response may be lowered. This reduces the body's ability to form the antibodies needed to protect you from flu.

If you are vaccinated during a course of chemotherapy, this should be done when your white cell count is at a normal level. The flu vaccine would be best given the day of the clinic appointment, or following day. You will need to attend clinic to obtain your blood results and if they are normal you will then be able to have your vaccination with your GP. You should avoid being vaccinated when your white cell count is low because you may develop a raised temperature. This could be confused with a fever, caused by infection, and could result in unnecessary hospital treatment.

Shingles vaccine

The shingles vaccine is only given to people aged between 70 and 79. It is recommended for patients who are going to start chemotherapy but it must be given at least two weeks but ideally four weeks before starting chemotherapy. It cannot be given after chemotherapy has started, or for six months after treatment as it is a live vaccine.

Other vaccines

You should not have any lives vaccines while you are having chemotherapy and for six months afterwards. Examples of live vaccines include MMR (the triple vaccine for measles, mumps and rubella), BCG, Shingles and Yellow fever.

You should avoid close contact with children who have had the nasal flu vaccine for two weeks. You should also avoid close contact with anyone who has recently been given a live vaccine by mouth (such as polio). Vaccines are no longer given by mouth in the LIK

Rapid Response Alert Card

IMPORTANT MESSAGE – for chemotherapy and haematology patients

The Rapid Response Alert Card is given to all chemotherapy patients at the start of treatment. You MUST keep this card with you at all times. The card is credit-card sized to easily fit into your purse/wallet. Chemotherapy can temporarily reduce your ability to fight infection. Infections can develop rapidly. If you think you have an infection it is essential that you DO NOT DELAY in contacting the 24-hour chemotherapy helpline number listed on the card.

Important: Present the alert card to whoever treats you should you become unwell. Medical staff need to know you are on chemotherapy and this will ensure you are treated promptly. Early infections can be treated easily if you contact us — DO NOT DELAY!

IMPORTANT ADVICE TO ALL PATIENTS

You are strongly advised to keep a thermometer at home. During chemotherapy you are more prone to infections and bleeding. Even very slight symptoms may require URGENT TREATMENT and must NOT be ignored.

You MUST contact the systemic anti-cancer therapy (SACT) immediately, day or night and NOT your general practitioner if you:

- Feel generally unwell for any reason, e.g. pain, sickness, vomiting, unusual tiredness
- Have a temperature e.g. feel cold, shivery, hot, flushed, sweat
- Experience any signs of infection eg. cold, flu, sore throat, cough, sore mouth

Failure to follow these instructions could be life threatening. The list of symptoms is a general guide only. Advice must be sought for any change in your health. If unsure always contact as advised.

Practical issues

Cancer may affect your life in many ways. If you need help dealing with practical issues, our treatment team at the Rutherford Cancer Centres are here to provide support.

Whether it's care responsibilities, financial or housing concerns, work or education commitments, we make it our business to understand your needs and provide advice and resources to assist you in getting your life back on track.

Emotional issues

Being diagnosed with cancer can be overwhelming. You may feel scared and anxious, or you may experience many feelings that are difficult to process.

In addition, it is not always easy to know who to talk to. Knowing that the Rutherford Cancer Centres are able to provide empathic emotional support in living with cancer can help make the experience a little less frightening. This support includes not only counselling or specific guidance, but also people who can just 'be there' for you throughout your cancer journey.

Beliefs and spiritual needs

At the Rutherford Cancer Centres, we believe good healthcare involves caring about the whole person, including their human rights and values.

To understand your spiritual needs, we may ask you questions such as: Do you have a religious faith? Or do you have any philosophy or a set of beliefs that gives your life meaning and purpose? How important is your faith to you? Are you part of a community that offers you support such as: a church, a mosque, temple or any other group of people you see regularly? How can we assist? Are there things we need to be aware of, e.g. prayer times, diet, etc? Can we contact anyone? What would best support you now?

If you feel you would like to address your religion and beliefs further, please see a member of the treatment team who will be able to connect you with the appropriate support.

Rutherford Cancer Centres

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