

If you have any concerns please inform your nurse who will be able to refer you to the appropriate department for advice.

Discharge information

You can usually go home after your treatment as long as you feel well enough. Your GP will be sent a letter from the hospital stating you have started chemotherapy treatment. You can be referred to the district nursing team for support at home or to the social services team. Please ask your nurse about this.

After your first session of chemotherapy you will be given the following by your nurse:

- your emergency card and a purple chemotherapy treatment book
- your medications to take home (TTA's) including anti-sickness drugs
- blood test forms. These are to make sure that your normal blood cells have recovered before your next chemotherapy treatment.
- other tests & investigations - You will be advised if you need other tests & investigations before your next course of chemotherapy.
- appointment card - you may be given an appointment to see your oncologist or their team prior to your next course of chemotherapy, or you will be given an appointment to attend chemotherapy day unit.

Further information

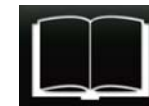
Macmillan cancer support www.macmillan.org.uk
Cancerhelp uk www.cancerhelp.org.uk 0808 808 0000
Information prescription service www.nhs.uk/IPG

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If you have any problems with dates of treatment please contact:
Chemotherapy day unit
020 7288 3192
Monday to Friday 9.00am - 5.00pm
If you are feeling unwell during the day or out of hours: **078 3309 5489**

A guide for patients having chemotherapy

A patient's guide



.... caring for you 

An important notice

On the morning of your appointment we ask that you call our direct line 020 7288 3192 to confirm you will be attending for your chemotherapy. Please leave a message on the answer phone if your call is not answered. By doing this, we can inform our pharmacy team to prepare your treatment so that it is ready when you arrive. If you do not, your treatment may be delayed, even if you arrive on time, because it can take at least one hour to prepare your medication.

Introduction

Patients have told us that the fear of not knowing about a chemotherapy treatment can sometimes be worse than the treatment itself. When starting chemotherapy, our oncologists (doctors who specialise in cancer) and nurses will explain what you need to know. This can be a lot of information to take in.

This information booklet aims to explain what is going to happen when having chemotherapy, the main side effects of chemotherapy and offers some advice on how to deal with those aspects of your treatment. You may experience other side effects; if you do, please discuss these with your oncologist or nurse.

You may become unwell during your chemotherapy and therefore we will give you an emergency card and purple book which will contain details of your treatment and contact numbers. If you need to see your GP you should take the emergency card and purple book with you.

How is cancer treated?

Chemotherapy is one way in which cancer can be treated. You may have another form of treatment such as radiotherapy or surgery. This is known as your **treatment plan** and will be discussed with you by your oncologist. Once you are happy with your chemotherapy treatment plan, your oncologist will ask you to sign a consent form.

Can I have vaccinations/immunisations, including the flu vaccine?

You should not have any live vaccinations during your chemotherapy treatment or six months following completion of the treatment. Live vaccinations include: BCG, rubella, mumps, measles, the yellow fever vaccine and the oral polio vaccine. It is safe to have non live vaccinations which includes the flu vaccine, but remember this may not give you as much protection from an infection as it usually would. It is also safe to be in contact with children who have just had their immunisations, as all vaccinations within this country are now given by injection. It is only outside this country you need to be careful due to the live polio vaccine still being given by mouth.

Can I go to work?

This will depend on the type of chemotherapy you are having. Many patients feel well enough to continue working throughout their treatment.

Can I exercise?

Research has shown undertaking gentle exercise is good for several reasons, it can help you maintain a steady weight, help with fatigue, decrease anxiety, depression and stress levels. It can also increase your overall energy levels.

Can I go to the dentist?

You can go to the dentist for a regular check-up. However, if you require any treatment, you should seek advice from your oncologist or nurse first. A blood test will be required to ensure that your blood count is in the normal range. You may also require some antibiotics as a precaution if you have any dental work done. You should also show your dentist your emergency card and chemotherapy treatment book so they are aware of the treatment you are having.

What about financial issues?

Your income can be affected because of your inability to work and additional travel costs.

Mouth pain

If you experience any type of mouth pain, please discuss this with your nurse or oncologist. Painkillers and other mouthwashes which can help can be prescribed for you to take home.

Food safety

It is important while undergoing chemotherapy treatment that you take extra care when preparing food to avoid the risk of food poisoning

- follow good standards of food hygiene
- do not eat food which has past the expiry date

At home

After your first treatment you may feel unwell. This usually gets better and we encourage you to live a normal life as possible.

Common questions**Can I drink alcohol?**

Most people can drink alcoholic drinks in moderation whilst having chemotherapy, but your tolerance to alcohol may be low.

Can I smoke?

It is always advisable to stop smoking with any cancer treatment. However, we realise this can be a stressful time. Support is available if you would like to access it. Please speak to your oncologist or nurse about this.

Can I go on holiday?

Inform your oncologist if you have already booked a holiday or are planning to book one. Treatment may be adapted to fit into your holiday plans. However, we do not recommend travelling abroad during a course of chemotherapy. Sometimes people who have, or have had cancer can find it difficult to get travel insurance.

If you require any vaccinations please discuss this with your oncologist first.

What is chemotherapy?

Chemotherapy is the use of drugs to treat cancer. The drugs are carried around the body via the blood stream to the site of the cancer cells. The drugs work by blocking the cells ability to divide and reproduce, which stops the cancer from growing. Chemotherapy does not recognise the difference between normal cells and cancer cells, which is why both cells can be damaged. This causes the side effects associated with the treatment. This damage is temporary and your normal cells will reproduce again.

How is chemotherapy given?

Chemotherapy can be given in various ways, including:

- by mouth, in the form of tablets, capsules or liquid
- as an injection directly into the vein, given over several minutes or hours
- as a continuous infusion over several days or weeks by a small pump which can be taken home
- as a subcutaneous injection beneath the skin

Most chemotherapy is administered by using a cannula (a small needle) which is placed into the vein of your hand or arm by your chemotherapy nurse on the day of your treatment. This is removed once your treatment is finished on the day, and another inserted each time you have treatment.

Other ways of administering chemotherapy include:

- central lines such as a Peripherally Inserted Central Catheter (PICC) line. This is a long tube inserted into the vein in your arm,
- a Hickman line, which is a long thin tube inserted into the vein via your chest
- a Portacath which is an implantable port which is a thin, soft, plastic tube that is put into a vein in your chest and has an opening (port) just under the skin.

These stay in place until all your treatments completed. If your chemotherapy treatment requires any of these central lines, your oncologist or nurse will discuss this with you and make the necessary arrangements to have the line inserted and additional information will be given to you.

Where is chemotherapy given?

Most chemotherapy is given as an out-patient in chemotherapy day unit. You may have to spend a few hours in the unit for each dose of treatment. Some treatment can involve longer infusions which may require you to stay in hospital, however, this is unusual.

Tests before chemotherapy

Before you have chemotherapy, we will need to ensure that you are fit to receive the treatment. Therefore various tests may be done prior to you starting each chemotherapy course. These include:

- height and weight - this is done to work out the dose of chemotherapy required.
- blood test - usually before every course of treatment, one - two days before your treatment or sometimes on the day of your chemotherapy.
- echocardiogram or an ultrasound scan of your heart - may be required in some cases to monitor any effects of the treatment on your heart.

Important information about your blood test

Your treatment on the day will be delayed if you do not have a blood test as advised.

You may have other tests such as a computerised tomography (CT) scans or x-rays before your first course (cycle) of chemotherapy and at various times during your course of treatment to see how well the treatment is working.

These can help to guide your oncologist as to how long to continue treatment or even to change the drugs used if the treatment does not seem to be working. You will be informed about these tests by your oncologist.

To ensure good mouth care follow the guidelines below:

- brush your teeth twice a day with a soft toothbrush and toothpaste if tolerated. You should brush from your gums to the tip of your teeth.
- if you have dentures these should be removed. Using a toothbrush, dentures should also be brushed to remove food particles.

Using mild hand soap or washing up liquid the dentures can be cleaned and then rinsed thoroughly. Overnight they can be removed and left in water in a denture pot. You should seek dental advice if at any point your dentures start to rub or if they do not fit properly.

- rinse your mouth out with normal saline mouthwash up to four times a day (mix a teaspoon of salt in a pint of lukewarm water). If your mouth becomes sore despite using this mouthwash please speak to your oncologist or nurse.
- if you have dentures, these should be removed before using any mouthwashes, so it can get to every part of your mouth lining
- moistening your lips with a non perfumed moisturiser (for example aqueous cream) can help to prevent chapping.

Please only use medication or mouthwashes prescribed for you by your oncologist and during the treatment period, unless informed otherwise.

Suggestions for dealing with other possible mouth side effects

Altered taste

If your taste becomes bitter, salty or metallic you can try:

- milky drinks instead of water

Dryness of the mouth

If your mouth becomes dry you can try:

- drinking plenty of fluids, on average three pints a day, unless advised.
- regular sipping of water can help keep your mouth moist using the normal saline mouth washes more frequently
- ask your oncologist/ nurse about an artificial saliva gel

Fertility

Chemotherapy can affect both male and female fertility. Women having chemotherapy may find their periods become irregular or stop temporarily or permanently. In men the number of sperm may be reduced temporarily or permanently. Semen (sperm) storage may be an option.

Advice

- it is important to discuss this side effect with your oncologist prior to commencing chemotherapy and any issues regarding family planning
- during chemotherapy you can still lead a normal sex life
- the most important thing to remember is to use effective contraception during sexual activity such as a condom for at least 48 hours following chemotherapy treatment even if you have been told you will become infertile. This is because chemotherapy could harm your baby if pregnancy occurs and to also protect your partner from the chemotherapy.

Mouth care during treatment

Chemotherapy can affect your mouth, causing dryness, a bad taste or soreness, which can lead to infection. It is important that you take care of your mouth during treatment to help to minimise these effects. The possible side effects of chemotherapy are mouth ulcers, pain, thrush, altered taste, dryness, cold sores and possible bleeding of the gums. Most people may develop only some of these symptoms but not all. This process can start from 24 hours after starting your chemotherapy treatment but will usually start to clear within three weeks.

Please check with your oncologist if you need to see a dentist before starting your treatment.

The aims of good mouth care are:

- to prevent or minimise mouth associated side effects
- to allow quicker healing of any treatment reaction
- to be able to eat normally

How long will my chemotherapy treatment last?

The length of your chemotherapy treatment will depend on several factors, including the type and stage of the cancer, which also determines the type of drugs that will be prescribed for you. How long your chemotherapy will take will be discussed with you when you see your oncologist.

Usually a course of chemotherapy is given in 'cycles' or 'programmes'. A cycle is a spell of treatment followed by a rest from treatment. For example, you may have a dose of your chemotherapy on one day, or several doses over a few days. You may then have a rest from treatment for two to three weeks to allow normal cells affected by the chemotherapy to recover. The length of your rest period will vary with the particular type of chemotherapy that you are having.

The number of cycles of chemotherapy is planned. However, they may finish later or earlier than expected depending on how you respond to the chemotherapy, how you tolerate the chemotherapy and whether there are any delays.

Chemotherapy as part of a clinical research trial

Your oncologist may ask if you are willing to take part in a clinical research trial. If your oncologist asks you to take part in a clinical trial you will also meet our clinical trials practitioner who will be able to explain the trial in detail and answer any questions you may have.

Possible side effects

Before starting treatment, you will be informed about any potential side effects that you **may** experience. Some of the more common side effects that patients experience have been included in this leaflet along with some advice about what actions you can take to help yourself.

Effects of chemotherapy on your blood cell count

Blood tests are a good way of allowing us to check if your blood cells have returned to a normal level so that treatment can be given to you.

If you feel at all unwell following treatment, we can use your blood tests to help choose appropriate treatment. This is a common occurrence for many patients and the reasons will be discussed with you by your nurse or oncologist.

Risk of infection - important

As previously mentioned, chemotherapy may affect your normal cells as well as cancer cells. Our normal cells include white cells, known as neutrophils. These cells help you to fight infection. The number of neutrophils is likely to temporarily fall when you are having chemotherapy and your resistance to infection may be lowered. During this time, you are at serious risk, and if you were to get an infection, your immune system may not have the normal strength to fight it.

This effect of the chemotherapy is known as febrile neutropenia or neutropenic sepsis. For this reason **you should always carry with you the emergency card**, given to you when you start your chemotherapy. This has contact numbers to phone when required.

It is therefore very important to be aware of the possible signs of infection.

These may include:

- fever (temperature) of 38⁰C or more
- feeling hot and cold / shaking and shivering
- generally feeling dreadful for no obvious reason
- redness, discomfort, swelling or irritation around the injection site
PICC line, Hickman line or Portacath
- pain when passing urine

- reducing foods that contain lactose e.g. chocolate, dairy products can improve the diarrhoea
- do not buy or use any over the counter medication including rehydrating salts unless you have spoken to your nurse or oncologist first.

Diet

Please remember that any of these symptoms can affect your appetite and you may find you are eating less. We have some helpful suggestions about eating when experiencing these symptoms so please ask your chemotherapy nurse or oncologist for advice. If you are losing weight or your clothes are becoming loose please do not ignore this. We have specialist dieticians who can assess your needs and offer advice. Some people may find their weight increases whilst on chemotherapy - if this occurs on a weekly basis please speak to your oncologist or chemotherapy nurse.

Sore hands/feet

Some chemotherapy can make your hands and feet feel dry.

Suggestions

- use a moisturizing cream or lotion to help with this.
- if you develop pain, redness or swelling of your hands or feet call 078 3309 5489 to discuss

You could also get tingling or numbness in your fingers or toes with some chemotherapy.

Suggestions

- use gloves and socks during cold weather as this symptom could be made worse by cold temperature
- avoid touching anything cold

Suggestions

- use gentle hair products
- if your hair is brittle avoid colouring it
- if your hair is still strong you may be able to use a vegetable based colourant or a perming lotion - please ask your hairdresser about this
- be extra gentle when brushing or using heat appliances on your hair

Constipation

Some chemotherapy drugs and anti sickness medication can cause constipation.

Suggestions

- try and eat a varied diet with some foods that contain fibre such as Weetabix, porridge, fruit and vegetables
- drink plenty of fluids
- light exercise may help such as going for a walk
- if constipation does become a problem for you, please let your oncologist, nurse or GP know so a laxative can be prescribed

Diarrhoea

Some chemotherapy can cause diarrhoea, however this can also be a sign of infection.

Suggestions

- increase the amount of water you are drinking to replace fluid loss
- if you have been given some anti-diarrhoea tablets (Loperamide or Immodium) take two after the first bout of loose motion then one further tablet after each loose stool.
- if diarrhoea persists for more than 24 hours you must call 078 3309 5489

Advice

- you should make sure you have a thermometer with you (digital is easier) so if you feel unwell you can record your temperature
- the risk of infection can be reduced by excellent care of your mouth with twice daily brushing of your teeth and up to four times daily salt water mouthwashes (make up with cooled boiled water one pint and a tablespoon of salt)

Safety guidelines

- avoid those people who have recently been given the oral polio immunisation or who have an obvious cough or cold.
- if you develop any of the symptoms previously mentioned, you **must** contact our telephone advice line 078 3309 5489 for expert advice.

When the risk of temporary damage to your bone marrow is very high your oncologist will prescribe an injection to boost your white cell count and reduce the risk of infection. This is an a daily injection which starts a few days after your chemotherapy, lasts for a few days and if applicable to you, your chemotherapy nurse will refer you to the district nurse to give the injections at home.

Lowered red blood cells

Red blood cells carry oxygen around your body. If your red cells are lowered – this is called anaemia and you may experience some of the following symptoms:

- lethargy (feeling sluggish)
- excessive tiredness
- shortness of breath

Lowered platelet count

Platelets help your blood to clot. If your platelet count falls, you may notice any of the following symptoms:

- unexplained bruising
- nose bleeds
- bleeding gums
- bleeding from any other body part

Advice

If you develop any of the above symptoms you **must** call 078 3309 5489 immediately.

Nausea (feeling sick) and vomiting

The amount of nausea or vomiting you may experience can depend on the type of chemotherapy drugs you are having. There are many effective anti-sickness drugs that can be prescribed by your oncologist. They may be given before your chemotherapy, directly into your vein, or as tablets. Please let us know if you feel that your anti-sickness medication is not working.

Suggestions

- take your anti-sickness as prescribed, usually 30 – 60 minutes before to eating
- some patients find that eating even a small amount can help relieve nausea.
- try little and often rather than large meals
- try cold, dry foods such as biscuits, toast or crackers
- avoid being around cooking smells
- avoid greasy or fatty foods

Advice

If you are unable to keep down any fluids including water you **must** call 078 3309 5489 immediately and they will advise you on what action to take. If at any time you feel very poorly you must call an ambulance and go to the emergency department stating you are a patient on chemotherapy.

Tiredness

Tiredness can affect most patients having chemotherapy treatment and is probably the most common side-effect.

Suggestions

- rest when you need to
- spread your chores/workload throughout the day
- accept help with chores if it is offered
- try and maintain a regular sleeping pattern
- try and eat something, even if this is a small amount
- remember to drink plenty of fluids
- take gentle exercise

Hair loss

Not all chemotherapy drugs cause hair loss. If hair loss is likely, your oncologist or nurse will tell you before commencing treatment. Hair loss will usually start about two to three weeks after the first cycle of chemotherapy. Hair loss is temporary and your hair will begin to grow back when you have completed your treatment. This growth may be different to the type or colour you had previously. Everyone is different and even if you have the same treatment as someone else, amounts of hair loss may differ.

In some instances hair loss can be reduced by using 'scalp cooling'. This involves wearing a cold cap on your head for roughly two - four hours at the time of your chemotherapy. This is only effective for some chemotherapy and your oncologist or nurse will discuss this with you if applicable. Wigs are available at several outlets. Ask your clinical nurse specialist or chemotherapy nurse for our list of salons recommended by other patients. You may have to pay some of the costs towards your wig.

As well as wigs other patients wear hats, scarves and turbans until their hair grows back.