

Patient Chemotherapy Record Book and Advice for Patients

Clinical Haematology Unit

Introduction

Welcome to the Clinical Haematology Unit. On admission to the Inpatient Unit or the Day Case Unit you will be introduced to the members of the team responsible for your care during your stay and your key worker will be identified.

Any member of staff will be happy to assist you with any queries or concerns that you may have – please ask.

This Patient Information Diary has been produced to provide information that you may find useful and to enable you to keep a record of your treatment and progress. It also gives you some advice on how to prevent, reduce or manage any symptoms or problems that you may develop due to your underlying blood disorder or its treatment.

It is personal to you and is not a medical or nursing document. The staff will be happy to provide any further explanation or information that you require. It is our aim that this will enhance participation in and understanding of your care and treatment.

We have divided the booklet into sections for easy use and so that you can find the information that relates to your individual blood disorder or treatment.

The speciality of Clinical Haematology covers a wide range of blood disorders, including some cancers.

Not all the information given in this booklet will relate to you. You will have been provided with specific information regarding your diagnosis and treatment. Please ask if you require any further information.

It is very important that if you experience any of the symptoms we talk about in this booklet that you report them quickly to one of the doctors or nurses looking after you. For this reason we have printed the important telephone numbers on page 3 of the booklet.

Introduction for Health Care Professionals:

This is your patient's personal file to use as they choose. It is meant to be a reference point for information. It is for your patient to fill in, although on occasion they may ask you to help them, for example with their blood results or treatment record page. Thank you for your co-operation.

The prevention of infection is a major priority in all healthcare and everyone has a part to play.

- **Please decontaminate your hands frequently for 20 seconds using soap and water or alcohol gel if available**
- **If you have symptoms of diarrhoea and/or vomiting, cough or other respiratory symptoms, a temperature or any loss of taste or smell please do not visit the hospital or any other care facility and seek advice from 111**
- **Keep the environment clean and tidy**
- **Let's work together to keep infections out of our hospitals and care homes.**

Contact Telephone Numbers:

If you are unwell please contact the following numbers:-

Haematology Day Case Unit (Mon – Fri 9.00am – 5.00pm)
01902 695243.

Clinical Haematology Unit (Ward) (Out of Hours, weekends & bank holidays) 01902 694241 or 01902 694242.

Emergency 24 hour helpline 07920 587036.

If you have a non-urgent query or question you can contact the Clinical Nurse Specialist who will also be your key worker. If there is no answer, please leave your details and contact number and someone will call you back as soon as possible.

Clinical Nurse Specialist / Haematology Advice Line 01902 695276 or ask switchboard on 01902 307999 to bleep the Nurse Specialist on bleep number 3931 or Mobile Number 07920 451917.
Working hours are Monday – Friday, 8:30am – 4:30 pm.

Your Details

You may find it useful to complete the details below so that you have them to hand if required.

Name:

Hospital No:

Address:

.....

.....

Date of birth:

Tel. No:

Next of kin:

Tel. No:

G.P:

Tel No:

Consultant:

Key Worker:

Diagnosis (if you wish to include):

.....

Treatment:

Blood group:

Allergies:

Antibodies:

Height:..... Weight:.....

Please note: You are responsible for the safe keeping of your file. The hospital cannot accept any responsibility if it is lost.

Where can I get information, support and advice?

The department offers a wide variety of information, support and advice for both you as the patient and / or your family, friends and carer/s. You will have been told the name of your Key Worker and given their contact details. This will usually be your consultant or one of the clinical nurse specialists.

Haematology Clinical Nurse Specialist

The Clinical Nurse Specialist in Haematology is available to provide specialist advice, information, education and support for patients, their families, friends and carers. We can also arrange for you to speak to other members of the multi-disciplinary team involved in your care and management.

If you wish to speak to any members of the team looking after you please contact 01902 695276.

Clinical Nurse Specialist In Palliative Care

There is a team of Palliative Care Nurses within the hospital. They provide specialist support and care for patients, their families, friends and carers who are facing a disease which is potentially life limiting. They offer advice on pain and other symptom control, as well as emotional, psychological and spiritual support. If you would like to be referred to the Palliative Care team then please let your doctor or nurse know and they will discuss this with you and arrange referral.

Physiotherapy

Our Physiotherapist is specially trained to help you and your family, friends and carers to cope with the physical impact of your illness. She / he will assist you with exercises and help with your rehabilitation if required. If you would like to be referred to the Physiotherapist then please let your doctor or nurse know and they will discuss this with you and arrange referral.

Occupational Therapy

Our Occupational Therapist is specially trained to help you and your family, friends and carers to cope with the impact of a debilitating illness. She / he looks at the practical tasks a person undertakes each day and if problems arise, attempts to solve them using adaptive equipment and advice. If you would like to be referred to the Occupational Therapist then please let your doctor or nurse know and they will discuss this with you and arrange referral.

Dietitian

We have specialist staff within our hospital that can offer advice, information and support if you find that you have, or develop problems with eating, such as loss of appetite or reduction in your normal body weight. If you would like to be referred to the Dietitian then please let your doctor or nurse know and they will discuss this with you and arrange referral.

Social Worker

If you find that you are experiencing difficulty with your finances and / or managing your daily activities of living, it maybe that you would benefit from speaking to a social worker. You can contact the Social Service Office within your own neighbourhood, or if you are in hospital our on site Social Workers can be contacted to offer advice and guidance. If you would like to be referred to the Social Worker then please let your doctor or nurse know and they will discuss this with you and arrange referral.

Counselling

If you feel you need counselling then please let a member of the team know and they will discuss this with you.

Spiritual Care

When you come into hospital, your health is a concern for many people. Among them is the team of Chaplains and representatives from all major faiths who are concerned about the spiritual welfare of every patient. They are available at all times to listen, help and support patients and their carers. Please ask your nurse to contact them if you feel this would be of help to you.

The Haematology Support Group

The Haematology Support Group is a group of patients and family members who aim to provide friendship, extra emotional support and encouragement to current patients and their families.

The group is available to anyone, and all the members have experience of dealing with Haematological diseases.

If you feel that you would like to contact us please telephone the Haematology Clinical Nurse Specialist on 01902 695276. There is an answer phone facility on the above number if you wish to leave a message.

The Macmillan Support and Information Centre

Unfortunately, sometimes when people are diagnosed with a haematological blood condition, they are required to spend long periods of time in hospital. The symptoms or treatment of the disease may make people physically unable to perform their job or mean that they require large periods of time away from work.

For this reason income may be affected, and many people fear not being able to maintain their standard of living during this time, especially if the person affected is the main source of financial security for the family.

The Macmillan Support and Information Centre, based in the hospital, offers information on different types of cancer, cancer treatments and management of the symptoms of cancer. We can put you in touch with finance and benefits support. We can help you with filling out forms, advise about the practical aspects of living with cancer and help with travel insurance.

We offer booklets and leaflets, information in different languages, on cassette or video and information for those with learning disabilities.

We also offer access to the internet if you would prefer to look subjects up yourself or with our help.

We also offer information on health promotion, prevention and detection of cancer.

What emotional support can we offer?

We offer time to listen to you in confidential and quiet surroundings. We can put you in touch with counselling services and spiritual guidance. We offer you;

- Aromatherapy and massage
- Make up Workshops (Look Good, Feel Better)
- Nail care Workshops
- HeadStrong Hairloss Service (if you lose your hair as a result of your treatment).

We can also put you in touch with support groups in your area and Living with Cancer workshops.

Coping with your diagnosis and treatment

As mentioned previously the speciality of Clinical Haematology covers a wide range of conditions, including some cancers.

Most people are shocked and overwhelmed when they are told that they have a cancer. Many different emotions can arise. Reactions can differ from one person to another and there is no right or wrong way to feel.

Your family and friends may also experience similar feelings and need support and help. The important thing is to discuss these feelings with someone when you feel ready. Some people wish to confide in their families, others will want to talk to their doctor or nurse.

During your time with us you will be aware that supporting you and your loved ones is of great importance to our team. Many opportunities will be made available to you and your family and friends to talk about your feelings. Please feel free to approach any member of the team if you require any further help or information.

You may have a Haematological condition that affects your blood count and your ability to fight infection. You may need to have chemotherapy treatment or not, depending on your diagnosis.

We know that chemotherapy can cause side effects and this usually concerns people when they are told that they need to start treatment.

This is usually because of past experiences or listening to other people.

There are many different types of chemotherapy and different chemotherapy drugs have different side effects.

The extent to which these side effects occur can vary from person to person.

The main areas of the body affected by chemotherapy drugs are where there are rapidly dividing cells, for example, blood cells, skin, hair and the lining of the mouth and gut.

Before you start chemotherapy treatment you will be given information about the drugs you are to receive and the possible side effects that they may cause. You will be given the opportunity to discuss these with your doctor and nurse and raise any concerns and worries that you may have. You will be asked to sign a consent form before starting treatment to confirm that you understand the risks and benefits of the treatment and the possible side effects that may occur.

This booklet begins to give you important information about the more common side effects that can occur. It is important that you and your family read and understand this information. This will help to keep you safe during your chemotherapy treatment and help you feel more in control during this time.

What do I need to know about blood and blood tests?

Bone marrow, which is found in the hollow cavities of many bones in the body, is responsible for producing all your blood cells. You may need to have a bone marrow biopsy performed to examine your bone marrow under the microscope and to perform special tests to help diagnose your condition. Please ask a member of staff for the written information leaflet which explains this procedure.

Your blood count can be affected by an underlying blood or bone marrow disorder or as a result of chemotherapy treatment. It is important that you understand about the function of blood cells and the role they play in protecting you.

About 40% of your blood is made up of cells and 60% is made up of yellow fluid called plasma. There are three main types of blood cells, made within the bone marrow, each having a very specific and important function in keeping the body healthy. These cells are Red Cells (Erythrocytes), Platelets and White Cells (Leukocytes). You may wish to refer to our information leaflet called "Having a blood test" which describes each of their function in more detail.

When you have a Haematological condition or are receiving chemotherapy treatment it is important that your blood counts are monitored regularly. Normally, when you are receiving chemotherapy treatment you will have blood tests before starting and at regular intervals in between treatments.

It is very important that you know about the possible signs and symptoms that can occur when your blood counts are low and that you get in touch immediately if any of these occur:

Red Blood Cells (Erythrocytes):

These cells contain haemoglobin, a red coloured pigment containing iron, which is responsible for carrying and supplying oxygen to the whole of your body. You will hear haemoglobin levels referred to as the 'Hb' of the blood. A normal "Hb" for an adult male is 14-17 and for an adult female 11-15.

If you have lower amounts than this, you can suffer from a condition called Anaemia. An underlying blood disorder or chemotherapy can cause this to happen.

If you are anaemic you may feel some of these symptoms;

- More tired than usual
- No energy
- Have a paler complexion than usual
- Notice cold temperatures or feel cold
- Have swollen ankles
- Become more breathless than normal and / or feel dizzy.
- Experience chest pain.

There are a number of ways we can treat anaemia:

Firstly, your doctor may choose to wait for your blood counts to recover naturally in their own time. This can happen by allowing the bone marrow time to make more cells.

Or you may be offered a blood transfusion, iron tablets or you may be given special injections to help the bone marrow make these cells more quickly. Your doctor will discuss all of the treatment options with you before choosing the right treatment for you.

If you develop any of the symptoms above it is important that you contact the hospital immediately and seek help or advice.

Platelets

These are tiny fragments in your blood that clump together to form a clot to help reduce the risk of bruising and bleeding.

Your platelet count is normally between 150 and 400. In some blood disorders and following chemotherapy treatment your platelet count may fall. Your consultant may specify a platelet count lower than the normal range as a safe level for yours to be kept at.

If this happens you may notice that you;

- Bruise more easily
- Bleed more heavily or for longer from minor cuts or injuries
- Develop unexpected nose bleeds or gum bleeding
- Develop tiny red or purple spots on your skin
- You may notice blood when passing urine, passing faeces or on toilet paper
- Some ladies may develop heavier periods
- If you have a cough you may cough up some blood
- Internal bleeding can occur – you must report any severe headaches or abdominal pain immediately.

If you notice any of the above symptoms you must contact the hospital immediately and seek help or advice. If a blood count confirms that you have a low platelet count, there are a number of ways we can treat this.

Firstly, your doctor may choose to wait for your platelet count to recover naturally. This can happen by allowing the bone marrow time to make more platelets.

You may be offered a platelet transfusion. This is similar to a blood transfusion in the way it is given. If you need a platelet transfusion your doctor or nurse will explain this further.

If you think or know that your platelet count is low, we advise you to;

- Avoid activities that may increase your risk of injury
- Use an electric razor rather than wet shaving with a blade
- Wear protective clothing such as thick gloves when gardening or doing manual work to protect you from injury
- Avoid contact sports and activities such as Rugby, Boxing, and Karate etc.

There is a diary section later in this booklet for you to record your blood count results. This will enable you to monitor your own progress.

Please try and remember to bring your diary with you to your clinic appointments so that you can have a record of your results.

Remember, if there is anything that you do not understand or there are any questions that you have please do not hesitate to ask for advice or help from any member of the Haematology team. Help and advice is always available!

White Blood Cells (Leucocytes):

These cells form part of your immune system and help your body fight infection. In some blood disorders and following chemotherapy treatment the number of white cells produced is greatly reduced thus affecting the body's ability to fight infection. In other blood disorders there may be excessive amounts of white cells. However these are usually abnormal white cells and cannot function properly so you will still be at increased risk of infection.

There are different types of white cells, each having its own specific function. The normal total white cell count in the blood is between 3 and 10.

You will hear the word "neutrophil" mentioned. Neutrophils are a type of white cell and are specifically responsible for fighting bacterial infections. The normal neutrophil count is between 2.5 and 7.5. When your neutrophil count is low this is referred to as "neutropaenia".

In some blood disorders and during chemotherapy treatment your neutrophil count can fall significantly, even as low as zero. When the neutrophil count falls you will be at risk of picking up infections that your body may not be able to fight without medical help. You could become very ill and need to come into hospital for intravenous antibiotic treatment immediately if this happens. For this reason the neutrophil count is closely monitored.

It is important that you are constantly on the look out for any signs of infection and take care to reduce the risk of picking up infections. Most importantly, if you think that you have, or are developing an infection, acting quickly is essential. You must contact the hospital immediately and seek help or advice. Early treatment of an infection can prevent it getting worse and sometimes avoid having to come into hospital.

Signs to look for and report immediately if you think you have an infection:

- A temperature of 37.5°C or above
- If you feel unwell, with or without a temperature
- Feeling extremely hot or cold
- Unexplained episodes of shaking or shivering
- An episode of shaking or shivering especially after your central line has been flushed, if you have one
- Vomiting and / or diarrhoea
- A sore mouth, ulcers or cold sores
- A cough
- A sore throat
- Abscesses, boils or infected skin lesions
- 'Flu like' symptoms
- A burning sensation when passing urine
- Signs of infection in a wound or around your central line site if you have one done
- A rash or Shingles
- If your GP starts you on any antibiotics – we would advise against visiting your GP until you have discussed the problem with us and taken advice. We will probably need to see you and check your blood count if you are unwell
- Any dental problem – we would advise against visiting the dentist until you have discussed this with us and taken advice. We will probably need to see you and check your blood count before any dental work is done.

How do I reduce my risk of infection?

You may not know that your neutrophil count is low during your chemotherapy treatment. Not everyone experiences any adverse effects. People having chemotherapy are likely to have low blood counts between 7 to 14 days after their treatment; however this varies greatly depending upon the type of chemotherapy treatment given. Your doctor or nurse will advise you about when your blood count is likely to be low and how long for.

There are several things that you can do to reduce the chance of you picking up an infection when your neutrophil count is low and / or you are having chemotherapy treatment.

Avoid crowded places where you may come into contact with someone with an infection. This does not mean that you should avoid going out and enjoying yourself.

Places which are high risk include busy shopping areas, busy public places e.g. pubs, theatres, cinemas, schools, hospitals, doctor's surgeries and public transport. Going swimming to a public pool or using a communal Jacuzzi also increases your risk of picking up infections from the water.

Ask friends or family members who have signs of an infection to stay away if possible. This may be difficult if you live with that person. Do not panic. Ring us for advice about what to do.

If you come into contact with anyone who has contracted chicken pox, German measles, measles or shingles please inform your doctor or nurse immediately, because of an underlying blood disorder. If you become unwell and / or think you have an infection then check your temperature and ring for advice immediately.

You will need a thermometer, as one of the first signs of an infection can be a temperature. Choose a thermometer that you are comfortable using and follow the manufacturer's instructions on how to use it. If you are concerned about using your thermometer please bring it with you to your first appointment and one of our nurses will show you how to use it. The normal body temperature varies from person to person. It may be an idea for you to check your temperature a few times during the day before starting treatment so that you know what your normal temperature is. It should be between 36°C and 37°C.

We would advise that you check your temperature regularly throughout your chemotherapy treatment and if you have a low neutrophil count because of an underlying blood disorder. If you become unwell and / or think you have an infection then check your temperature and ring for advice immediately.

We advise you not to take any medication containing aspirin or paracetamol if you have a temperature or are unwell. Both these medicines will reduce your temperature. This can be very dangerous as it will mask symptoms and could delay you seeking help and advice. If you regularly take these medicines for another reason and think that you are becoming unwell or have an infection please inform us that you take them. This information is important and may affect the care and treatment you receive.

If you have a pet or are in contact with animals regularly you will need to be more careful. Avoid handling animal waste or wear gloves when emptying litter trays or cages. You need not stop stroking or fussing your pet as long as you thoroughly wash your hands afterwards. It is advised you do not get any new pets whilst having chemotherapy

If you know that your blood count is low you should be careful to avoid brick, mortar and cement dust and soil, as this may contain fungal spores which can cause an infection called Aspergillosis, which is very dangerous to people with reduced ability to fight infection.

If you are in hospital whilst your neutrophil count is low you may be offered a side room to provide some extra protection from the risk of infection during this time. Some of the rooms on the Haematology Unit have the added protection of positive pressure ventilation and are reserved for the patients most vulnerable to infection. If a side room is available and offered to you please take it.

One of the best ways to reduce the risk of infection is to maintain a high standard of personal hygiene. It is important that you always remember to wash your hands when using the toilet and before preparing and eating food.

Further advice about reducing the risk of infection can be found later in this booklet.

Should I have the flu jab?

It is not advisable to have your flu jab when on chemotherapy. This should be discussed with your consultant.

Will I be sick?

When people are told that they require chemotherapy treatment they immediately fear being sick. We have all been sick in the past and know that it is an unpleasant experience, so this is not an irrational fear.

For this reason we take the risk of sickness very seriously and as a result of this are usually very good at controlling it. You will hear people use the terms Nausea and Vomiting.

What is nausea?

Many people describe nausea as 'feeling queasy' or sickly. It can also be described as a wave-like feeling in the back of your throat or stomach. This feeling may last for some time and may be followed by an episode of vomiting.

Though chemotherapy drugs are given for a safe and specific reason, your brain will still recognise these drugs as harmful and therefore alert the body's defences to them. There are lots of anti-nausea drugs available to control this symptom.

What is vomiting?

Vomiting is the body's natural reaction to remove anything harmful from the stomach. It is normally known as being sick or retching. This is an uncontrollable reflex action, which usually follows a period of nausea.

What causes nausea and vomiting?

There are many different causes of nausea and vomiting. However, it usually occurs when the 'vomiting control centre' in the brain becomes irritated, resulting in the above reaction. There are many different events which can cause this irritation, chemotherapy treatment being one of them.

Can nausea and vomiting be avoided?

Nausea and vomiting can occur after chemotherapy treatment has been given. We know that this can happen and there are a variety of medicines called anti-emetic (anti-sickness) drugs which can be used to control nausea and vomiting. Your doctor will prescribe these to be given with your chemotherapy treatment and ensure that you have some to take home with you if needed. Sometimes you may need to take them for up to several days following treatment but this will be explained to you.

It is important that if you feel sick or are sick, that you let us know immediately. There are lots of reasons why you may feel sick, so we will need to identify the reason and if necessary alter your antisickness medicines to suit you better.

If you are being sick you can lose important fluids from your body and dehydrate very quickly. We would then need to alter your anti-sickness medicines and help you to replace the lost fluid by giving you fluid through a drip.

What can I do to help?

There are a number of ways you can help to control your sickness if it happens.

Below is a list of self help tips:-

- Take your medication as instructed and let your doctor or nurse know if it is not working
- Sipping clear, fizzy and / or cold drinks may help. Mineral water, ginger ale, lemonade and / or soda water are suggested. Try to avoid alcohol
- Food preparation may make you feel sickly especially if it is hot food. Ask someone else to prepare your meals or try cold foods which do not smell strong
- Avoid strong odours such as smoke, perfume or air fresheners
- Avoid very sweet, heavy, stodgy, spicy and / or greasy foods
- Try bland foods like dry toast, crackers, bread or savoury biscuits
- Ginger biscuits are known to have natural anti-sickness properties, especially if eaten in the morning before you get up
- Peppermints or peppermint tea may help
- Eat light small meals throughout the day
- Don't lie down after eating. Instead rest in a chair for a while after you have finished your meal
- Try foods such as thin soups or egg custard, and then gradually introduce other more substantial foods
- Avoid eating for a few hours before having chemotherapy if you usually feel sick during your treatment
- Try to relax. Breathing deeply and slowly when you first feel sick may help.
- Attempt to distract yourself by listening to music, watching television or a film or talk with your friends and family

What about hair care and hair loss?

Hair loss can be a side effect of certain chemotherapy drugs. Not all chemotherapy drugs cause hair loss and sometimes this is hardly noticeable at all. In other cases hair loss may be partial or complete. Like cancer cells, hair follicles are fast growing cells and therefore damaged quickly by chemotherapy drugs. Unlike cancer cells, normal hair cells quickly grow back once your chemotherapy treatment is over.

For some people hair loss can be the worst part of having chemotherapy. Occasionally, you may notice eyebrows, eyelashes, body and pubic hair may also be lost.

If your hair is likely to fall out, you will notice it falling out within a few weeks of beginning treatment. For some people this can be sooner. There are a number of things which you can do to reduce the amount of damage caused to your hair and hopefully reduce the rate at which it falls out:

- If your hair is relatively long, ensure that it is cut to a shorter length. It will reduce the weight of your hair and be less shocking to you when your hair starts to fall out
- Do not apply hair colouring or treatments such as perms to your hair for at least for 8 - 12 weeks following treatment
- Try not to over manage your hair by constant brushing or adding harmful hair products like hair sprays
- Always use mild shampoos, and wherever possible reduce the number of times you wash your hair
- Do not over heat your hair with heated rollers, curling tongs and hair dryers
- Use soft brushes to brush your hair. Avoid combs and multi-bristled brushes.

If your hair does fall out there are a number of important things to remember.

Your scalp is always protected by hair and will be very sensitive to sunlight. Always wear a hat or sun block on your head if you are in the sun. In cold weather you will lose a large part of your body heat from your head. Always remember to cover up and prevent heat loss in this way. If your hair is at risk of falling out, your doctor or nurse will inform you of this. We will arrange an appointment for you to have a wig fitted if you so wish.

A leaflet is available that explains the process. Please ask a member of staff for a copy. A specialist wig consultant will advise and guide you to the type and style of wig that will suit your needs. If you are unhappy with the end product in any way please do not hesitate to tell her.

If you think you might like to use alternatives to a wig, please ask the nursing staff to refer you to the free HeadStrong Hairloss Service. The service is run in conjunction with Breast Cancer Care by trained advisers offering practical support and information on a private appointment basis. Learn how to make the most of scarves, hats and hairpieces.

How should I look after my mouth?

Many people undergoing chemotherapy treatment or with an underlying blood disorder are at risk of developing problems with their mouths, especially when their neutrophil count is low. This can be due to a number of reasons:

- There are a number of actions that can be taken to reduce the risk of mouth problems developing
- It is important that you maintain a high level of oral hygiene. This involves cleaning the teeth and gums or dentures at least every morning and evening and ideally after each meal
- Ensure that you use a soft bristled toothbrush, as harder bristles can increase the risk of damage to the gums causing soreness and possible infection
- If your toothbrush is old discard it, and buy a new one. Toothbrushes are generally not the cleanest of personal items and can carry unseen bugs and increase the risk of infection
- Some normal toothpaste can be quite strong. A milder toothpaste or a children's toothpaste may be more palatable.

Dental Work

Avoid having any invasive dental work whilst undergoing chemotherapy treatment, whilst on treatments such as bisphosphonates, zometa, or panidronate (bone strengthening drugs), or when your neutrophil or platelet count is low unless you have first discussed this with your consultant. This is because the risk of infection and bleeding is high. If you think you need any dental work let us know beforehand. You will need to have a blood test to check whether your neutrophil or platelet count is low. Your doctor may want to start you on antibiotics to try and reduce the risk of you getting an infection. Your doctor may refer you to the specialist dental team here if necessary. If you need emergency dental work please inform the dentist so that if necessary he / she can contact us for further information.

Dry mouth

Use a mouthwash wherever possible. This helps to keep your mouth clean, fresh and moist during the day. Avoid alcohol based mouthwashes; though these may make your mouth feel fresh, the alcohol tends to cause dryness increasing the risk of problems.

Mouthwashes such as Corsodyl or Chlorhexidine can be bought from your chemist, and are preferable to general supermarket types as they have antibacterial properties.

Sucking on sugar-free boiled sweets and pastilles will encourage your mouth to produce saliva and increase your body's natural ability to keep your mouth moist and clean.

Sore mouth

If your mouth becomes sore or you develop ulcers please let us know immediately. It is important that we identify the reason for this soreness. It may be that it is due to the treatment itself but can also be caused by an infection within the mouth which will require treatment.

There are also special mouthwashes, which can be used to soothe soreness, such as "Difflam". This will need to be prescribed for you.

There are also topical treatments such as Bonjela or Teejel, which can be bought from your chemist and applied to ulcerated areas within the mouth to help ease discomfort. Vaseline or Blistezel can be used to help soothe sore or dry lips. If you experience a sore mouth or ulceration, please let us know first for further advice.

Will my bowel habits alter?

You may experience changes in your bowel habits whilst having chemotherapy. You may become constipated or have diarrhoea. If you experience any of the following symptoms you must report them immediately to your doctor or nurse.

These include:

- Not having your bowels opened for more than three days
- Opening your bowels in excess of three times your normal bowel habit
- If you have watery and / or smelly faeces
- Experiencing pain when opening your bowels
- Your stomach becomes bloated or distended
- You notice blood or pus in the toilet or on the tissue paper
- You experience a loss of appetite
- You start to be sick.

Constipation

This is where you find it difficult to open your bowels regularly. It can either mean that you open your bowels less frequently or find your faeces hard to pass.

Being familiar with your normal bowel habits may help to know if you are becoming constipated. Some people go to the toilet daily; others go more than this and some less than this. This is fine if your faeces are formed, brown in colour and easy to pass.

Constipation can occur when eating low roughage / fibre foods, high amounts of starchy or fatty foods and / or a poor intake of fluids. Being less active, eating less and not exercising regularly can increase the risk of this happening. Finally, some chemotherapy drugs, painkillers and some anti-emetic drugs are all known to cause constipation.

Constipation can cause other problems. If you have to strain hard to open your bowels this can cause damage to the skin around the anus (the back passage). If there is a break in the skin this can be an opportunity for infection to get into your body, especially when your neutrophil count is low. It is best to avoid enemas or suppositories for the same reason if your neutrophil count is low because of the increased risk of damaging the skin. If anyone suggests that you have an enema or suppositories please ask them to check that your blood count is adequate before proceeding as this may be needed in the event of severe constipation.

What can I do to help myself?

There are a number of ways you can help to prevent constipation.

Below is a list of self help tips:

- Try to increase your daily exercise (if possible). Increasing your activity helps to increase your bowels activity
- Drink enough to keep hydrated and encourage urine flow
- Try to drink warm drinks as the warmth stimulates the bowel into action
- Increase the amount of roughage / fibre in your diet this includes; wholemeal bread, jacket potatoes, bran, muesli, fresh fruit and vegetables
- Prunes and prune juice are a natural laxative
- Natural orange juices also stimulate the bowel activity
- Ask your doctor or nurse if you can take a medication laxative in addition to the advice above. Many laxatives are very gentle and rarely cause urgency.

Diarrhoea

This is where you suddenly notice an increase in the number of times you need to go to the toilet to open your bowels. Your faeces become looser, not formed and can even become watery. Diarrhoea can also be associated with colicky stomach cramps especially when you want to open your bowels.

We understand this is an unpleasant and embarrassing problem where you fear that you may not reach the toilet in time and that this can restrict your normal daily life.

Diarrhoea may occur for a number of reasons. One of the causes can be chemotherapy and some of the medicines we use in association with it. Your doctor and nurse will inform you if you are receiving a chemotherapy drug that causes diarrhoea. They will also want to know immediately if you experience this side effect.

It is important to recognise that treatments such as antibiotics and some radiotherapy treatments can also cause diarrhoea. If you have recently had a course of antibiotics or are currently taking antibiotics when you develop diarrhoea let us know straight away. We may need a sample and you may need to start on some treatment.

Being on chemotherapy or having a low white count because of an underlying blood disorder can also increase your risk of infection. Developing diarrhoea unexpectedly may suggest that you have developed an infection. This is why it is important to tell your doctor and / or nurse.

If your chemotherapy drug/s is known to cause diarrhoea you may be given and / or advised to take anti-diarrhoea tablets by your doctor or nurse. They will explain when and how to take this medication safely. Do not take medicines that you have bought yourself "over the counter" without asking your doctor or nurse first.

Having diarrhoea can be dangerous if not stopped quickly. If your diarrhoea has not stopped within 24 hours you must contact your doctor or nurse immediately.

By having diarrhoea you can lose important fluids from your body and dehydrate very quickly. If this happens we would need to help you replace the lost fluid by giving you fluid via a drip in hospital.

Episodes of diarrhoea "on" and "off" over a few days can be dangerous. If this occurs when your blood counts are likely to be low, this should be reported to your doctor or nurse immediately.

What can I do to help myself?

If you have diarrhoea, follow the advice given below:

- You should be passing water frequently and your urine should not be dark in colour (i.e. concentrated)
- Take your anti-diarrhoea medication as prescribed. Many people wait, thinking that their diarrhoea will stop independently. Do not risk this, please take your medication
- Avoid foods that stimulate the bowel such as high fibre, muesli, bran, pulses, fresh fruit and vegetables, nuts, seeds etc.
- Avoid alcoholic drinks
- Try to eat low fibre foods such as white bread, white rice, noodles, creamed cereals, canned or cooked fruit without the skin
- Eat white meats like fish, skinless chicken or turkey
- If you are having accidents and soiling your clothing please let us know. You can get incontinence pads from your General Practitioner to help with this.

What can happen to my kidneys?

Some of the drugs we use can irritate and / or damage your kidneys. This may affect your ability to produce urine. Producing urine is a very important part of your body's function, so it is important that you follow the instructions that your doctor or nurse gives you.

If you are having one of these drugs we will keep a very close eye on you. This will mean having regular blood tests called "kidney function" tests as part of your routine blood tests. This test is explained in more detail in our information leaflet "Having a blood test".

Some doctors will ask you to have more detailed tests that measure how well your kidneys are working in a different way. This may involve you having to collect the amount of urine you produce for 24 hours and save it in a special container that we give you. This procedure will be fully explained to you if you are required to do it.

You may be asked to attend our Medical Physics department in the hospital and have a test called "creatinine clearance". This is where a solution is injected into your vein through a cannula (needle) and blood tests are taken at specific intervals to monitor the levels of this solution in your blood. This will show how well your kidneys are working. All of these tests will tell your doctor if it is safe for you to have or continue to have your chemotherapy. Sometimes your doctor may delay your treatment or reduce the dose if your test results are low. However, we will discuss this with you if it happens.

How can I help to keep my kidneys healthy?

There are lots of things that you can do to help such as drinking lots of fluid. We recommend that you drink at least two litres (three to four pints) of fluid per day, every day.

Drinking water is the best type of fluid that you can drink. If you do not like the taste of water, try adding flavoured juices to water or drinking natural juices. Try not to drink lots of caffeine based drinks like cola drinks, coffee or tea. The caffeine content can irritate your bladder.

If you are having difficulty drinking two litres every day for any reason, please let us know.

What is fatigue or lethargy?

Fatigue or Lethargy describes an extreme level of tiredness.

This can occur as a side effect of chemotherapy or an underlying blood disorder.

You may find that you are able to carry on with your normal routine, or you may find your normal daily life more difficult to cope with. Fatigue can take some time to improve once your treatment has finished, so do not expect it to resolve as quickly as other symptoms.

Here are some things that you can do to help with fatigue:

- Plan to be more active when you know you will have more energy.
- Rest between activities. Regular short breaks may be better than one long rest period
- Short walks and light exercise may help. Before undertaking an exercise programme please talk to your doctor
- Small frequent meals and snacks may help. We can arrange for you to see a dietitian if necessary
- Reading, music, games, hobbies etc can help you to relax
- Listening to soothing, soft music such as a relaxation tape can help
- If others offer to help, accept! Let others do the ironing, shopping etc. or leave some things until you feel able to do them
- When you do feel well, don't overdo things as this may make you feel worse. Take your time and do things at a steady pace.

What is extravasation?

When you have chemotherapy injected through a vein, there is a small risk that the chemotherapy drug/s may leak into the surrounding tissues. If this happens it can cause a chemical burn to your skin. This is called extravasation.

The chemotherapy nursing staff are highly trained at putting in cannulae (needles). Even so, sometimes a cannula will move or be dislodged from the vein. This is more likely to happen if you are having your chemotherapy over a long period of time through a drip.

It is very important that:

- Your needle should feel comfortable at all times
- You should never feel burning, itching or any irritation while your needle is in place
- You should never see redness, bruising, swelling or leaking around the needle site
- You should be able to see the needle and its dressing at all times. It should not be covered
- If any of these things change you must tell the nurse looking after you immediately.

If we think some of your chemotherapy has leaked into the tissues, you will need emergency treatment to prevent further damage to your skin.

Sometimes you may not experience any strange sensations while having your treatment, yet notice pain when at home. Please contact your doctor or nurse immediately if this happens.

What can happen to my skin and nails?

Chemotherapy affects your skin and nails. We suggest that you pay close attention to your skin and nails while having treatment and take care to keep them in good condition.

My Nails

Your nails may become discoloured, brittle or break more easily than normal. You should keep your nails clean and moisturised at all times. You should also protect your nails from damage by wearing gloves when doing household chores, gardening or any task that involves getting your hands wet or dirty.

If you notice any redness, swelling, pain or changes to your nails or nail beds please tell your chemotherapy nurse or doctor. Nail infections are common whilst on chemotherapy and should be treated immediately.

My Skin

Some chemotherapy drugs can cause allergic reactions resulting in red and itchy skin rashes. You will be told if this may apply to you. If you notice that you have an unusual rash on your skin you must inform your doctor or nurse immediately. Do not have your next chemotherapy treatment without letting someone know!

Some people develop acne, patches of redness, itching, peeling, dry or cracked skin during treatment. There are lots of different creams and treatments which we can give you for this. You must use the correct treatment for your condition. Inform your doctor or nurse if you develop any of these symptoms and they will advise you which treatment is right for you.

You may notice a change in the pigmentation (colour) of your skin. Do not be alarmed, the change is normally slight. You may look like you have a sun tan when you have not been sunbathing. When your chemotherapy treatment has finished your skin tone will go back to its normal colour.

You may find that the change in pigmentation (colour) affects only parts of your skin. Nail beds, the skin over joints, pressure points, fingers, palms of the hands, soles of the feet and the skin along veins can be affected. If you find this unsightly and feel this affects how you see yourself, try wearing longer sleeves and carefully chosen clothing to help hide this. Once your treatment is finished your skin tone will go back to its normal colour.

Skin infections can be common, especially where skin is thin or if the skin is dry and cracked. Keep your skin moisturised as much as possible. When you have a bath or shower inspect your skin and check for any signs of infection.

When you have a low neutrophil count be particularly careful, as any break in the skin can be an entry point for infection. Pay particular attention to the skin around your bottom and the area of skin between your bottom and your genitals. If you develop any pain or soreness let us know immediately as it can be quite common to develop infection, abscesses or ulcers in these areas which will require specific treatment.

What should I do if I take 'steroid' medication?

Steroids are types of hormones that are normally produced naturally within the body. There are several kinds, all having powerful effects. For this reason, they have been found to be very useful in making some cancer treatments more effective.

We also use steroids to treat troublesome symptoms like pain, sickness and loss of appetite. They may also help to reduce inflammation within the body when caused by injury or cancer growth.

Common types of steroids used with cancer treatments are Prednisolone, Dexamethasone, Hydrocortisone and Methylprednisolone.

General advice when taking steroids

- Your steroid tablets should be taken with or after food as they can cause indigestion type problems and if allowed, damage the stomach lining
- You may notice that taking steroids affects your sleep patterns, keeping you awake. We advise that you take your steroids during the first half of the day and not after 4 pm
- If taken for longer than three weeks, you will usually be given a steroid card. The card contains details of your prescriber, type of steroid, dose taken and the duration of the treatment. It should act as a reminder that your medication should not be stopped suddenly and to provide information about your treatment in case of an accident. You should carry it with you at all times and show it to anyone who treats you (e.g. Doctor, nurse, pharmacist, dentist)
- If you are taking steroids long term, your doctor may need to temporarily increase your dose if you experience any additional illness, injuries or need surgery during treatment. Please discuss this with your doctor
- You should not stop taking your medication suddenly, particularly if you have been taking it for longer than three weeks. This is because long term use of these drugs slow down the natural production of the body's own steroids called corticosteroids. When it is time to stop treatment the dose should be lessened slowly, to allow the body to start producing adequate amounts of natural steroids again
- Your medicine may reduce your ability to fight infections. Contact your doctor if you think that you have an infection during treatment.

What advice should I follow about my diet?

People having treatment for cancer should try to eat a well balanced diet to help their body stay as health as possible during treatment. If you are neutropenic following chemotherapy it is recommended you follow general food safety guidelines to help reduce risk of infection such as avoiding high bacteria food such as unpasteurised dairy products or "live bacteria" foods. Also check sell by and use by dates on packaging, ensuring frozen food is stored at the correct temperature and thaw meat and poultry in the fridge and not at room temperature to prevent bacteria.

Ensure you wash your hands thoroughly before and after food preparation and that food is cooked all the way through and piping hot. When eating out food should be freshly prepared and cooked all the way through too.

Foods to avoid	Alternatives
Soft Cheese (i.e. Brie, Camembert, blue cheese)	Processed cheese, hard cheese
Raw or lightly cooked shellfish Smoked or raw meat or fish Cold, loose meat from a counter Raw or undercooked eggs Pate	Well cooked, tinned or vacuum packed meats & fish
Raw unpeeled fruit or veg such as salad	Good quality cooked and peeled fruit and veg, long life fruit juice
Uncooked herbs and spices	Cooked herbs & spices
Non-drinking water, bottled mineral or spring Water	Fresh tap, filtered or carbonated water.

We do not routinely advise people having chemotherapy to attempt to lose weight or diet. However, eating healthily is always sensible, therefore cutting down on foods high in fat and sugar is advisable. If you are losing weight or your appetite has fallen, eating more foods high in fat and sugar may help you to get the calories your body needs. The Macmillan Support and Information Centre based within the hospital (Zone C, location C1) has a number of books on healthy eating.

Alcohol

It is not advisable to have alcohol close to or while on chemotherapy. Please speak to your doctor or nurse for further information.

Finally

If you are in any doubt about what you should or should not eat, please do not hesitate to speak to your doctor or nurse. We can also arrange for you to speak to a dietitian who can give you specialist advice about your diet.

What can happen to the taste of food and drink?

Chemotherapy can affect your taste buds and alter the flavour of food. This may affect your normal pleasure of eating. However, when you complete your treatment you can expect that your normal taste will return. While it lasts;

If you are not able to eat much as a result of taste changes and you are losing weight, it is important you see a dietitian. They will be able to advise you further on how to supplement your calorie intake. Ask a member of the nursing team caring for you to refer you.

What advice should I follow about sex and fertility?

NB. It is important that you do not rely on chemotherapy as a means of contraception in the belief that the treatment can cause infertility as this is not always the case

Not all chemotherapy causes infertility but there are some chemotherapy drugs which do. This infertility or the inability to produce children naturally may be temporary or permanent depending upon the drugs you are given.

Your doctor and / or nurse will discuss this risk fully with you before you start treatment especially if you are planning to have children in the future. It is also important to involve your partner in these discussions and to discuss your feelings together.

It is possible for women having chemotherapy or the female partner of a man having chemotherapy to become pregnant during treatment.

You must not get pregnant or father a child whilst having chemotherapy as the drugs may seriously affect the unborn baby.

Barrier methods of contraception are recommended, i.e. the cap or condom. The contraceptive pill could possibly interfere with your treatment and it is possible that chemotherapy treatment may stop the pill being effective. Chemotherapy is excreted in body fluids seven days after administration.

Advice for women

Chemotherapy drugs can affect your ovaries and stop egg production. If this happens you may find that your monthly periods become irregular and / or stop completely. You may experience 'hot flushes', dry skin and dryness of the vagina as if you were experiencing the menopause. If infertility is temporary your periods will return to normal once your treatment has finished.

If you are pregnant at the time your cancer is diagnosed it is important to discuss with your doctor whether or not to continue with your pregnancy. It might be possible to delay starting treatment until after the baby is born. You will need to discuss this with your doctor.

Advice for men

Chemotherapy drugs can sometimes have a permanent effect on your ability to produce sperm, which could affect your ability to father children. However, chemotherapy does not usually have a permanent effect on your sexual performance or ability to enjoy sex. Temporary impotence may occur but this is usually short-lived.

What is peripheral neuropathy?

Peripheral neuropathy is a specific side effect of some chemotherapy drugs. It occurs when nerves within the body become irritated and eventually damaged.

The first sign that you might have peripheral neuropathy is a tingling or prickling in your toes or in your fingers.

If not treated, this tingling may gradually spread to your feet and / or hands and become numbness. You may then experience difficulty walking, moving around and performing daily activities.

These sensations may come and go, or remain constantly. Sometimes you may not notice them, whilst at other times you may find them troublesome.

The symptoms of peripheral neuropathy usually occur in the feet and / or hands and are as follows;

What drugs can cause peripheral neuropathy?

There are certain drugs that are known to cause this symptom. Your doctor or nurse caring for you will tell you if you are about to receive one of these drugs.

However, drugs like Vincristine, Vinblastine, Vindesine, Vinorelbine, Thalidomide, Velcade, Cisplatin, Carboplatin, Etoposide (rare) and Gemcitabine (rare), are all known to cause this side effect.

What should I do if I have any of these symptoms?

It is very important that you report any of these symptoms to your doctor or nurse immediately. We would like to know before we give you your next treatment. It may be that the dose of the drug may need to be reduced, the drug may need to be stopped or an alternative drug may be used instead.

It is very important that you do not ignore or forget to tell us about any symptoms that have resolved.

How can I help myself?

Avoid ill fitting shoes

Wear comfortable, well fitting trainers instead of shoes. Shoes that are too tight can cause rubbing and cramping, shoes that are too loose can also damage your feet, causing pain and may not provide enough support.

Trainers are sturdy enough to provide support, yet flexible enough to provide your feet with the space they need to remain comfortable.

If you need something a bit more formal, whether it is for work or going out at night, we suggest that you invest in a good pair of leather shoes and approach a knowledgeable company or salesperson who can work around the specific types of pain you are dealing with.

Keep your feet and hands cool

Symptoms of peripheral neuropathy can worsen during the warm summer months or at night, when your feet are tucked away under sheets or blankets. Let your feet breathe! If at all possible, don't wear suffocating shoes around the house – opt for a comfortable pair of socks or some soft slippers.

Don't cover your feet at night. Cool air in your bedroom can have a numbing effect on your feet. This will also help keep your feet (and hands) free of sheets and blankets, which you may sometimes find painful.

Treat your feet and hands well

Massaging your hands or feet – or having someone massage them for you – can be relaxing and can increase circulation. Massage can also help release endorphins (chemicals produced by the body to help control pain).

Please discuss this with your doctor or nurse as there are times when massage would not be recommended.

You could also try soaking your hands and feet in cold water if they are painful.

Where can I get more information?

If you have any questions or concerns about your treatment, please speak to your doctor, your key worker or a member of the nursing team.

Macmillan Support and Information Centre

If you need information or support with finance, benefits, workshops, travel insurance etc, then come and see us. You can find us on the main hospital corridor zone C, location C1 or visit our website address below.

Telephone 01902 695234 Open Monday-Friday, 10:00am-4:00pm

www.cancercarewolverhampton.nhs.uk

Macmillan Cancer Support

Macmillan is a national charity providing telephone advice and free written information on cancer and support services.

Telephone 0808 808 0000

www.macmillan.org.uk

Myeloma UK

Myeloma Infoline 0800 980 3332

Myeloma UK

Broughton House

31 Dunedin Street

Edinburgh

EH7 4JG

Email: myelomauk@myeloma.org.uk or www.myeloma.org.uk

Myeloma UK has a range of free Infoguides and Infosheets available covering many areas of Myeloma, its treatment and management. It provides access to information and support. Specialist nurses who are supported by medical and scientific advisors will answer your call.

Leukaemia Care

1 Birch Court,

Blackpole East

Worcester

WR3 8SG

Tel: 01905 755977

Email enquiries@leukaemiaCARE.org.uk

24 hour CARE line 0800 169 6680 (Free 24/7)

Leukaemia Care promotes the welfare of people with leukaemia and allied blood disorders. They also offer family caravan holidays, friendship and support. Discretionary financial assistance, newsletters and publications are also available.

Leukaemia Research

43 Great Ormond Street

London WC1N 3JJ

Tel: 020 7405 0101 Monday to Friday 9am - 5pm

Fax: 020 7405 3139

Email: info@lrf.org.uk

Leukaemia Research is devoted to improving treatments, finding cures and learning how to prevent Leukaemia, Hodgkin's and other Lymphomas, Myeloma and the related blood disorders, Myelodysplasia, Aplastic Anaemia and the Myeloproliferative disorders.

They also provide a wide range of free information on Leukaemia and related blood disorders and their treatment.

Lymphoma Association

The Lymphoma Association provides free information and emotional support to anyone whose life has been affected by lymphoma (lymphatic cancer). The Helpline is staffed by people who have had training in understanding lymphomas, their treatments and related issues.

English

If you need information in another way like easy read or a different language please let us know.

If you need an interpreter or assistance please let us know.

Lithuanian

Jeigu norėtumėte, kad informacija jums būtų pateikta kitu būdu, pavyzdžiui, supaprastinta forma ar kita kalba, prašome mums apie tai pranešti.

Jeigu jums reikia vertėjo ar kitos pagalbos, prašome mums apie tai pranešti.

Polish

Jeżeli chcieliby Państwo otrzymać te informacje w innej postaci, na przykład w wersji łatwej do czytania lub w innym języku, prosimy powiedzieć nam o tym.

Prosimy poinformować nas również, jeżeli potrzebowaliby Państwo usługi tłumaczenia ustnego lub innej pomocy.

Punjabi

ਜੇ ਤੁਹਾਨੂੰ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਰੂਪ ਵਿਚ, ਜਿਵੇਂ ਪੜ੍ਹਨ ਵਿਚ ਆਸਾਨ ਰੂਪ ਜਾਂ ਕਿਸੇ ਦੂਜੀ ਭਾਸ਼ਾ ਵਿਚ, ਚਾਹੀਦੀ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਸਾਨੂੰ ਦੱਸੋ।

ਜੇ ਤੁਹਾਨੂੰ ਦੁਭਾਸ਼ੀਏ ਦੀ ਜਾਂ ਸਹਾਇਤਾ ਦੀ ਲੋੜ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਸਾਨੂੰ ਦੱਸੋ।

Romanian

Dacă aveți nevoie de informații în alt format, ca de exemplu caractere ușor de citit sau altă limbă, vă rugăm să ne informați.

Dacă aveți nevoie de un interpret sau de asistență, vă rugăm să ne informați.

Traditional Chinese

如果您需要以其他方式了解信息，如易读或其他语种，请告诉我们。

如果您需要口译人员或帮助，请告诉我们。