

Patient
 Information

Important information for patients having Chemotherapy or other supportive therapies

**24 Hour helpline
Tel: 0300 422 3444**

Please keep it in a safe place

Useful information

The name of your consultant	
Chemotherapy regimen	
Your hospital registration number	
Your oncology registration number	

Introduction

This leaflet explains some of the possible side effects you may experience from having chemotherapy (cytotoxics). It also contains important information about how to get help and advice regarding symptoms.

How to get help?

Tel: 0300 422 3444

Haematology patients who receive their treatment at the Edward Jenner Unit (Gloucestershire Royal Hospital) should ring the Haematology Helpline for advice on Tel: 0300 422 5299. This helpline is available during working hours only.

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Department

 Oncology/
 Haematology

Review due

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Patient Information

If there is no reply or if you need to ring out of hours you must contact the Chemotherapy Helpline at Cheltenham General Hospital on Tel: 0300 422 3444. Haematology patients who receive their treatment in Cheltenham should ring the main 24 hour chemotherapy helpline number.

If after reading this leaflet, or at any time, you have any questions about your treatment, we would be happy to answer them. Please just speak to a member of staff in the ward or clinic.

Making a decision

Your consultant will discuss with you what treatment they recommend. The decision to have chemotherapy is made once you are satisfied that you have received enough information.

Assessment

At each stage of your treatment we will need to make sure you are well enough to receive the chemotherapy. This assessment will be carried out by a doctor or a specialist nurse and may include reviewing of blood results. This involves seeing you in a clinic, on the ward, or by telephoning you.

Following this assessment, your chemotherapy will be prescribed by a doctor or an experienced specialist nurse who has received further training to be able to prescribe.

Meeting your needs

We want you to be fully involved in discussions and decisions about your treatment and care you receive, feel comfortable and remain as independent as possible. Please let staff know if you need any additional help or support to achieve this.

Carers

Please let the nursing staff and doctors know if another person is involved in your care, such as a carer. We can only involve them in discussions and decisions about your care if you give your explicit consent for us to do so.

Patient Information

There is a Trust leaflet available called 'Information for Carers attending Gloucestershire Hospitals NHS Foundation Trust', please ask a member of staff if you would like a copy of this leaflet.

About chemotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. Your consultant will explain what the aim of treatment is and what the possible benefits are.

Risks of chemotherapy

Unfortunately, chemotherapy also affects some normal cells and this is what causes side effects. These side effects are nearly always temporary and treatment is given to keep them to a minimum.

The side-effects you may experience will depend very much on the treatment you are having, as there are many different types of chemotherapy. Written and verbal information will be given to you, explaining the possible side effects of the specific drugs you will be receiving.

No two people receiving chemotherapy will feel exactly the same, even when they are receiving the same drugs.

The risks are discussed between the patient and doctor on an individual basis and a consent form is signed by you both to verify the discussion.

Chemotherapy can be administered in a number of ways, but many are given through a drip into a vein.

Some drugs given this way may cause irritation to the vein. These drugs can also damage surrounding cells if they leak out of the vein, commonly referred to as an extravasation.

It is very important to immediately tell the nurse giving you your treatment if you experience any stinging, discomfort or pain around the vein.

Patient Information

Neutropenia and infection

You may hear these two words discussed at some time during your treatment and here is a guide to make sure you understand what they mean and how to respond:

1. Neutrophils are white blood cells
2. Neutropenia means a low white cell count

Neutrophils are the most common type of white blood cell and are very important in helping the body to fight infection.

Neutrophils are measured in a blood test called a Full Blood Count (FBC). The normal range for a neutrophil count is between (2.5 and 7.5). However, most chemotherapy treatments can make the bone marrow temporarily less efficient and the neutrophil count may fall below the normal range.

When this happens, it is called neutropenia, but it is not considered significant unless it falls below 1.0. Recovery time for the neutrophil will depend on type of chemotherapy received and will differ from person to person, even for those having the same treatment. The nurses and doctors should be able to give you some idea when this may be likely.

It may be necessary for the neutrophil count to be at a certain level before the next part of chemotherapy can be given to you. This level will depend on the type of chemotherapy you are receiving. Your consultant will be able to tell you what the level is for you, so please feel free to ask. If the neutrophil count does not reach the required level when the chemotherapy is due then it may be necessary to delay the treatment, usually for 1 week.

We understand that having treatment delayed can cause upset and concern particularly when you may feel perfectly well. The doctors and nurses will explain why it is safer to sometimes delay treatment if you have any concerns.

Having neutropenia or low white cell count does not mean that you will necessarily become unwell. Many patients who feel very well are often surprised that a blood test shows that they are neutropenic.

Patient Information

Neutropenia, however, can mean that you are much more likely to develop an infection and for someone with neutropenia it can make you more unwell than it would do if your neutrophil count was normal.

It is essential to be aware that even minor infections can become serious.

Having signs of an infection when the neutrophil count is low is called neutropenic sepsis. If not treated quickly in the right way, neutropenic sepsis can become very serious and in rare cases even life-threatening. It is very important that you make your family and friends aware of this possibility so that they know what to do if you become unwell.

You must be prepared to come to the Oncology Centre at Cheltenham immediately for assessment even if you are receiving your chemotherapy at another location. Following assessment it may be necessary to admit you to hospital for intravenous antibiotics and close monitoring.

Some words of reassurance

We understand that this subject can cause anxiety and concern and want to reassure you that serious complications are rare and preventable. The important message is to contact the chemotherapy/haematology helpline sooner rather than later if you have any symptoms. Receiving the right treatment at the right time by a specialist team will reduce the risk of you having major complications.

Please ask for more information from the team looking after you during your chemotherapy if you wish to discuss things further.

The Helpline will be answered by a chemotherapy trained nurse who will be able to give you advice or take your details and call you back after speaking to the doctor.

The telephone may ring for some time before it is answered by the Helpline nurse, but please be patient as they may be busy at the time you are calling.

Please do not give up; your call will be answered.

Patient Information

You may be asked to attend the hospital urgently, so we strongly advise you to think about who would be able to drive you, if the need arises. There is a section at the end of this booklet where you can write useful contact numbers in case you require help.

If you have received chemotherapy within the last 6 weeks or are a haematology patient and feel unwell, please ring the Chemotherapy Helpline. Tel: **0300 422 3444**

Some symptoms or side effects (as listed below) caused by the drug treatment can be serious. Please do not wait for the symptoms to go away - it is important that they are treated as soon as possible.

Note: It is advisable for you to keep a thermometer at home.

Possible symptoms/side-effects

- Fever, raised temperature – above 37.5°C
- Temperature below 36°C
- Sore mouth/throat
- Headache which does not respond to Paracetamol
- Shivering, shaking attacks, symptoms of a 'cold' or 'flu'
- Bleeding or bruising (blood in urine or bowel motions, nosebleed, bleeding gums or an appearance of a rash)
- Abdominal pain
- Diarrhoea
- Redness, swelling, pain or blistering at the site where chemotherapy was given by injection
- Problems with any indwelling intravenous catheter; such as a PICC line, Groshong line, Hickman line or 'Vascular Catheter or PORT'
- Feeling generally unwell

Patient Information

If you are a **haematology** patient and feel unwell you must always contact the Helpline for advice even if more than 6 weeks has elapsed since your last treatment. However, if you are an **oncology** patient and have not received treatment in the past 6 weeks and feel unwell please contact your GP.

If the GP wants you to have an urgent appointment with your consultant, they can call your consultant's secretary to arrange.

Other guidelines and useful information

- **Flu vaccination:** We encourage patients to have this vaccination. If possible, the best time to receive this is before your treatment starts or when your blood levels are at their best. We recommend that close members of your household also receive an inactivated Influenza vaccine.
- **Pneumococcal vaccine:** This vaccine **must** be given **at least 2 weeks** before your treatment starts. If this is not possible you will need to wait for 3 to 12 months, depending on your condition, after completing your treatment to have this important vaccine. If you are a **haematology** patient and able to go ahead with the vaccine it is likely that you may be offered 2 vaccines (PCV13 followed by PPV23). If you are an oncology patient you will receive 1 vaccine (likely to be PPV23).

If your GP or practice nurse has any queries regarding this information, they will need to contact your consultant for advice.

- **Aspirin:** Do not use unless your consultant is aware, as it can increase any tendency to bleed.
- **Dental work:** It is advised that dental work is carried out before treatment begins. If you require work during your treatment, please check with us first. You may need to have a blood test. You must show your dentist your alert card.
- **Alcohol:** It is recommended that you avoid alcohol during treatment. However, it may be acceptable in some circumstances. Please check with a nurse or doctor for advice.

Patient Information

- **Infection risks:** If you have a line in your chest or arm, we recommend that you do not use public swimming pools or saunas. We advise women not to use tampons while receiving chemotherapy treatment.
- **Health and Safety:** We advise that you do not get pregnant or father a child while you are receiving treatment.
 - For approximately 48 hours after having treatment, you may excrete very small traces of chemotherapy in your urine and other body secretions. Where possible please put the seat down on the toilet before flushing and maintain a good standard of personal hygiene.
 - We advise that you use a barrier contraceptive whilst you are on chemotherapy.
- **Exercise/Fatigue:** You may feel very tired during your treatment. Regular gentle exercise may increase your feeling of well-being; however it is important to rest as needed.
- **Travel:** Travelling abroad is not advised during chemotherapy. However, it may be possible to travel within the UK. Please check with your consultant before doing so. The FOCUS information Centre can provide information regarding travel insurance.
- **Pets:** If you have a family pet, please be sure you maintain a good level of hygiene and wash your hands after handling it.
- **Information:** As there is a lot of information to take in, we urge you to share this leaflet with your family.

Contact information

Haematology Helpline

Tel: 0300 422 5299

Oncology Out-patients Reception

Tel: 0300 422 (4028 or 4147) to check appointment times and transport

**Patient
Information****LINC Out-patients**

Tel: 0300 422 2868

Please contact the Oncology Bed Manager to check bed availability on the day if you are expecting to be admitted for chemotherapy on Tel: 0300 422 4110

Further information

Note: Think of people you could call for help or who could bring you to hospital if you need to come in urgently. Write their contact details here:

Name	Telephone number	Mobile

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