The ROYAL MARSDEN
NHS Foundation Trust

Chemotherapy

Your questions answered

Patient Information

NHS

Contents

Introduction

This is one of a series of booklets written to provide information for you and your loved ones/carers. While it is impossible to include everything you may need to know, it is important to feel you have been given enough information before you make a decision about treatment. Throughout the booklet we suggest questions you may wish to ask your doctor about your treatment. Your doctor or nurse will be able to answer specific questions.

This booklet has been prepared by The Royal Marsden specialist nurses with input from doctors and patients.

What is cancer?

Our bodies are made up of tiny structures called cells, which are not visible to the naked eye. These cells are ‘building blocks’ and groups of cells form the tissues and organs of the body. The cells in these different tissues, such as the brain, liver, kidney and lungs, all have a unique function.

Normally cells reproduce themselves by dividing in a regular, controlled fashion so that growth and repair of the body tissues can take place.

Sometimes this control goes wrong and the cells divide in an uncontrolled way and become abnormal. This abnormal and excessive growth of tissue cells is called a tumour and can be benign or malignant.

Benign tumours are usually limited to a small area and are often slow growing. They only cause problems because of their size or where they happen to be located. Once they have been treated, often by an operation, they do not usually cause any further problems.

Cancers or malignant tumours also start within a limited area, but they can spread to nearby organs or tissues. Cancer cells may be carried in the bloodstream to distant sites in the body. Here they may form new tumours called metastases or ‘secondaries’.

Cancer cells may also be carried in the lymphatic system which normally helps the body to fight infection. It is made up of a series of nodes (glands) and vessels (tubes) linked throughout the body.

Cancer is a word used to describe many different diseases which have different causes and which are treated in different ways. All cancers can be treated although not all can be cured.

Who will plan my treatment?

A multidisciplinary team will plan your treatment for you.

The multidisciplinary team may include:

- A **surgeon** with a special interest in your type of cancer
- A **medical oncologist** – a specialist doctor who treats cancer with drugs, including chemotherapy
- A **clinical oncologist** or **radiotherapist** – a specialist doctor who treats cancer with radiotherapy and may also prescribe chemotherapy
- A **haematologist** – a specialist doctor who diagnoses and treats blood disorders. These include cancers such as leukaemias (affecting the bone marrow), lymphomas (affecting lymphatic tissue) and myelomas (affecting the plasma cells in the bone marrow)
- A **pathologist** – a specialist doctor who examines body tissues and organs under a microscope
- A **radiologist** who specialises in the use of x-rays and other imaging to diagnose and treat disease, with a special interest in your type of cancer
- A **specialist nurse** who provides information and support
- A **keyworker** – either a specialist nurse or other healthcare professional involved in your care, who acts as a point of contact for you and your carers throughout your treatment.

Other healthcare specialists may also be represented on this team and involved in your care, such as pharmacists, dietitians and physiotherapists.

Various healthcare professionals will be involved in your care. The type of cancer you have will determine which healthcare professional will be part of your multidisciplinary team. For example, not all cancers can be treated with surgery, so a surgeon would not be involved in these cases.

The multidisciplinary team meets regularly to discuss the best treatment options for each patient in their care. They will take into account the results of tests and your general health. At your next clinic appointment, your doctor will then discuss the different treatment options available to you, taking into account your own preferences. You may find it helpful to take a family member or friend with you to your clinic appointment, when your treatment is being planned.

Research

Research is an important part of developing better treatment for cancer. Many specialist centres take part in clinical trials or research studies. You may be asked if you would like to take part in a clinical trial, for example, looking at a new or improved way of using chemotherapy or other treatments. These trials may assess the effectiveness of a new treatment compared to standard treatment. If the new treatment produces better results or offers fewer side effects, it may then be widely used for all people with a particular cancer.

The doctors and nurses will discuss any clinical trial in detail with you, if it is an appropriate treatment option in your case. The Royal Marsden booklet, *Clinical trials*, provides more detailed information about clinical trials and what is involved. Please note that declining to take part in a clinical trial will not affect the care you receive.

Several national cancer information organisations can provide information on clinical trials currently in progress, along with website links to online clinical trial databases. You can find further details about these organisations on pages 48–49.

Questions you may wish to ask your doctor about research studies or clinical trials

You may find the following questions helpful.

- What is the purpose of this study?
- Why have I been chosen?
- Do I have to take part?
- What will happen to me if I take part?
- Will I be in hospital longer if I take part?
- What do I have to do?
- What is the drug or procedure that is being tested?
- How long will the study last?
- How could the trial help me?
- What are the side effects of taking part?
- What are the benefits and risks?
- Will I need any extra tests or investigations?
- What other treatments are available if I do not take part in this trial?
- Who can I contact if I have any concerns or problems?
- What if new information becomes available?
- What happens when the research study stops?
- What if something goes wrong?
- Will my taking part in this study be kept confidential?
- What will happen to the results of the research study?
- Who is organising and funding the research?

Consenting for treatment

Before you can give your consent, your doctor will discuss with you what the treatment is likely to involve, the benefits and risks, and any available alternative treatments. You may also be given some written information about the treatment protocol that has been planned for you. It is important that you understand the information you have been given – please ask questions if you do not understand or if you would like more information. To help you think about what you want to ask your doctor, you may find the questions on page 8–9 helpful. We will ask you to sign a consent form, which is a written record that you have agreed to the planned treatment and understand the benefits and risks involved. The main benefits and risks associated with your particular treatment will be written on the consent form before you sign it. We will then give you a copy of this along with information on your particular chemotherapy regimen.

How long will I have to make up my mind about treatment?

Your doctor will be able to advise you. The time period you have to consider your options will depend on the type of cancer you have, as some cancers grow much faster than others. While it may be important to start treatment as soon as possible, most people will have plenty of time to make a decision.

Your treatment plan may involve one or more treatments, for example, surgery and / or chemotherapy and / or radiotherapy. We will ask you to sign consent forms for each treatment. Before each treatments starts, we will ask you to confirm that you agree to treatment.

It is important to remember that once you have made a decision about treatment, **you can change your mind at any time**, even after you have signed a consent form.

What is chemotherapy?

Chemotherapy means treatment with anti-cancer drugs which are given to destroy or control cancer cells. There are over 100 different drugs. Drugs may be given on their own or several different drugs may be given together. This is called **combination chemotherapy.**

Why is chemotherapy given?

Many types of cancer can be treated with chemotherapy. The aim of the treatment will depend on the type of cancer you have and how advanced it is. Chemotherapy is given:

- To cure the cancer – chemotherapy is given to destroy all the cancer cells
- To control the cancer – chemotherapy is unlikely to cure the cancer but may prevent it from growing for some time
- To relieve symptoms – chemotherapy may be given to shrink a tumour if it is causing any symptoms
- To reduce the possibility of cancer coming back – chemotherapy may also be given to destroy any cancer cells that may be present in your body that are too small to detect. It is important to destroy these cells.

How does chemotherapy work?

The drugs enter your bloodstream and therefore reach all parts of your body. This is called systemic treatment. Most radiotherapy and surgery treatments are called local treatments as they target specific areas of the body. Chemotherapy drugs destroy cancer cells by damaging them so they cannot divide and grow.

The drugs can also affect normal cells which are growing and dividing quickly. Damage to normal cells may cause side effects (see page 23). These are usually temporary because healthy cells quickly grow back to normal. Permanent damage is rare with most chemotherapy treatments though can occur.

When is chemotherapy given?

Sometimes chemotherapy is used on its own for cancers that respond well to this treatment. However, chemotherapy is often used with other treatments. These include:

- **Neo-adjuvant therapy** – chemotherapy may be given before surgery or radiotherapy to shrink the tumour
- **Adjuvant therapy** – chemotherapy may be used to help destroy any cancer cells that may remain after surgery or radiotherapy; the aim is to reduce the likelihood of your cancer returning in the future
- **Peri-operative therapy** – chemotherapy may be given both before and after surgery
- **Chemoradiation** – chemotherapy may be combined with radiotherapy
- **Palliative chemotherapy** – if the cancer has spread to other parts of the body, the chemotherapy drugs carried in your bloodstream can reach these cancer cells; the aim is to help relieve symptoms and slow the growth of the cancer.

Questions you may wish to ask your doctor about treatment

Before you can make a decision about treatment, you need to feel you have been given enough information. All treatments carry risks as well as benefits, and thinking through the possible options can help you to decide.

To help you think about what you want to ask your doctor, you may find the following questions helpful:

- What are the main treatment options?
- What are the benefits of each of the options?
- What are the risks, if any, of each option?
- What are the risks if I decide to do nothing for the time being?
- How long can I take to decide about what treatment I have?
- Will this treatment cure me?
- When will I know if the treatment has worked?
- What will happen if this treatment does not work?

How will my chemotherapy treatment be planned?

The chemotherapy treatment your doctor recommends will depend on several factors. These include:

- The type of cancer you have
- Where the cancer is in your body
- Where in the body it has spread to (if it has)
- Your general health.

We will offer you the best standard treatment available which current research shows should be most helpful in your situation. This is why you may meet other people with the same cancer as you who are having different chemotherapy treatments.

Questions you may wish to ask your doctor about chemotherapy

It is important that you understand what will happen and why. You should be given a chance to ask questions. To help you think about what you want to ask your doctor, you may find the following questions helpful.

- What drug or drugs will I be given?
- How will the drugs be given?
- Will I have to spend any time in hospital?
- How often will I need treatment?
- How long will my treatment go on for?
- Can I still take other medicines (including any alternative therapies) during my chemotherapy treatment?
- How will I feel during treatment and are there any side effects?
- If there are any side effects, what can be done to help me cope with them?

- How long will it take for me to recover after I have finished the treatment?
- Are there any long-term side effects?
- Will I be able to continue with the same lifestyle that I’m leading now?
- Can I talk to someone who has had the same treatment?
- Who should I contact if I am worried about my diagnosis, treatment or prognosis?

Your doctor or nurse will explain your personal drug treatment to you. If you would like more details or have any questions, please ask the staff caring for you.

How often will I have chemotherapy?

A course of chemotherapy is given according to a protocol (plan) and how often you have chemotherapy will depend on this. Each course usually consists of several cycles of chemotherapy with a rest period between each cycle. The rest periods are often longer than the treatment periods, so most of the time you are not actually having chemotherapy. The rest periods allow your body to recover from any unwanted effects of the drug. As you have more cycles of treatment, it is occasionally necessary to extend these rest periods. Do not worry as this is quite common.

If you are having oral chemotherapy (tablets or capsules), you may take smaller doses daily for several weeks or months before having a rest period. Below are two examples of chemotherapy treatment plans.

Example 1 **A course of chemotherapy** **= six cycles**		
Cycle 1	Day 1 Chemotherapy	Days 2–21 Rest period
Cycle 2	Day 1 Chemotherapy	Days 2–21 Rest period
Cycle 3	Day 1 Chemotherapy	Days 2–21 Rest period
Cycle 4	Day 1 Chemotherapy	Days 2–21 Rest period
Cycle 5	Day 1 Chemotherapy	Days 2–21 Rest period
Cycle 6	Day 1 Chemotherapy	Days 2–21 Rest period
= total of 18 weeks		

Example 2
A course of chemotherapy
= six cycles

Cycle 1	Day 1 Chemotherapy	Days 2–7 Rest period	Day 8 Chemotherapy	Days 9–21 Rest period
Cycle 2	Day 1 Chemotherapy	Days 2–7 Rest period	Day 8 Chemotherapy	Days 9–21 Rest period
Cycle 3	Day 1 Chemotherapy	Days 2–7 Rest period	Day 8 Chemotherapy	Days 9–21 Rest period
Cycle 4	Day 1 Chemotherapy	Days 2–7 Rest period	Day 8 Chemotherapy	Days 9–21 Rest period
Cycle 5	Day 1 Chemotherapy	Days 2–7 Rest period	Day 8 Chemotherapy	Days 9–21 Rest period
Cycle 6	Day 1 Chemotherapy	Days 2–7 Rest period	Day 8 Chemotherapy	Days 9–21 Rest period

= total of 18 weeks

How long will my treatment last?

The length of your treatment will depend on how well your disease responds to the drugs, for example, when your cancer starts to shrink. Your doctors may choose to give you treatment for several weeks and then check on your progress. Overall, it may take several months to complete your course of chemotherapy.

When adjuvant chemotherapy is given, your doctor may plan your treatment for a certain length of time known to be effective for people with similar tumours, for example, six months.

How will I know if my chemotherapy is working?

Your doctor will monitor your progress throughout treatment. There are several tests which may be repeated during your treatment. These may include scans, x-rays and blood tests. All the tests check on your health and the way chemotherapy is affecting you. This will vary from person to person so if you are not sure why you are having a particular test, please ask your doctor or nurse.

Whether or not you have side effects from chemotherapy is **not** an indication of how well the treatment is working.

Why has my chemotherapy plan been changed?

Sometimes, as a result of the tests you have during treatment, your chemotherapy plan may be changed. For example, if the blood test shows that your blood count (see page 25) is low, your doctor may decide to give you a longer rest period between cycles. Your doctor may reduce the dose of the drugs or you may be given medicine to boost your blood count.

If the test results show that the chemotherapy treatment is not working well enough, then your doctor may change your treatment plan. Sometimes, different drugs may need to be tried to find out which ones are best for you.

How is chemotherapy given?

How chemotherapy is given will depend on the type of cancer you have and the drugs used.

Chemotherapy is most commonly given in the following ways:

- By mouth (orally)
- By injection into a vein using a syringe or by an infusion (drip)
- By a 48 hour infusion called a Dosifuser which is attached to a PICC or Implanted Port and infused whilst you are at home.

Occasionally, a drug may be injected into a muscle or under the skin. Sometimes it can be injected into your spine, lungs or bladder if that is where treatment is needed.

You may have one drug, several drugs or different drugs given at different times. You may have tablets or injections or both.

Oral chemotherapy

Some chemotherapy drugs can be taken as tablets or capsules, which means you can continue your treatment at home. You will still need to visit the outpatient department for regular check-ups.

When should I take my tablets?

All bottles of tablets given out by the pharmacy department carry instructions about how and when to take them. These instructions will advise you whether or not you have to take them with food and how to store them safely. Please follow these instructions carefully and if they are not clear, ask your doctor, nurse or pharmacist for further explanation. We may give you an extra information sheet with details of some medicines or we may give you an oral chemotherapy diary.

We will probably provide you with only enough tablets for one cycle of therapy. This is so your doctor can assess your progress before you start your second cycle. Sometimes, it may be necessary to change the dose of the tablets.

Your chemotherapy tablets have been prescribed specifically for you and you should not give them to anyone else. If you have chemotherapy tablets left over when you have finished treatment, please take them back to the hospital pharmacy. If you think you are running out of chemotherapy tablets and should have more, then contact your hospital doctor (not your GP).

What should I do if I am sick after taking my chemotherapy?

It is very important that you take your tablets regularly on the days specified. If you miss a dose for any reason, contact the ward for advice. Do not take a double dose.

If you are sick **immediately** and can see the tablet, then repeat the dose one hour later. If you are sick later (even five minutes later), contact the ward for advice.

If, however, you are using liquid or opened capsules, or you were asked to crush or dissolve tablets, the dose should **not** be repeated.

How is chemotherapy given into a vein?

When chemotherapy is given intravenously (into a vein), it is given through a venous access device.

Types of venous access devices

There are several different types of devices available. These include:

Cannula

This is small tube which is put into a vein in your lower arm or the back of your hand. It is inserted at the beginning of each treatment and is removed after the chemotherapy has been given. Once the cannula has been taped to your arm, the chemotherapy drugs can be injected slowly into the vein through it. Sometimes the drugs are diluted and given through a ‘drip’ (intravenous infusion) into a vein in your arm.

Some treatment drugs cannot be given into the vein of the hand or the arm and can only be given through one of the central venous access devices described below.

Skin-tunnelled catheter

Sometimes this device may be known by its brand name, for example a Hickman line. It is a fine tube which is inserted through your chest into a large vein leading to your heart. As it is made of a non-irritant material, for example silicone, it can be left in place for several months or years. As well as using it to give you fluids and drugs, it may also be used to take blood samples.

Peripherally Inserted Central Catheter (PICC)

A PICC is inserted into a vein in your upper arm. It goes into the large vein leading to your heart. A PICC can be used to give you drugs and to take blood samples. It can be left in for a few weeks or months.

Implanted port

An implanted port is a device which is inserted into your body under the skin. The usual position is on the chest. The port is made up of a portal body (or chamber) and this is connected via a thin tube inserted into one of the body's veins. A special needle is used to get into the chamber and this can then be attached to a drip, used for injections or for taking blood samples.

You may be able to choose the type of device you have, however, your choice will depend on the type of therapy you are going to have, your physical condition and your lifestyle. Sometimes a choice is not possible.

More information about skin-tunnelled catheters, PICCs and implanted ports can be found in The Royal Marsden booklet, *Central venous access devices.*

Will having chemotherapy hurt?

Chemotherapy is generally no more painful than any other injection or having a blood test. However, occasionally veins become hardened or sore. Please tell your chemotherapy nurse or doctor if this has happened, so that they can avoid the sore area. They can also provide you with a leaflet advising you on how to manage this.

Some drugs can cause damage if they leak out of the vein while they are being injected. If you feel **any stinging, burning or pain** when you are receiving the drug, tell your nurse or doctor straight away. If your arm or hand, where the cannula was sited (or the area around the catheter or port), is sore, painful or swollen following the injection, please contact your chemotherapy nurse or doctor. If this continues or we have difficulties with your veins, they may suggest you have a central venous access device inserted.

How long does it take to give intravenous chemotherapy?

Depending on the chemotherapy drug or combination of drugs, each cycle lasts from a few hours to a few days.

Your doctor may recommend that your chemotherapy is given continually at a lower dose, over weeks or months. This keeps a steady level of the drug in your bloodstream. You will receive the drug from a small infusion pump while you are at home. This is called **ambulatory chemotherapy**.

What is intrathecal chemotherapy?

For some types of cancer, for example lymphomas and leukaemias, cancer cells can pass into the cerebrospinal fluid (CSF) which surrounds the brain and spinal cord. Your doctor may prescribe intrathecal chemotherapy. This means that anti-cancer drugs will be given through a needle into the space around the spinal cord in your back. This procedure is called a lumbar puncture. Injecting chemotherapy into the spinal fluid can destroy any cancer cells that may be there and prevent cancer cells growing.

Where will I have my chemotherapy treatment?

Most patients receive their chemotherapy as outpatients or day patients, visiting the hospital on the day of treatment or on two separate days called ‘two stop scheduled care’. Your length of stay in hospital will depend on the types of tests, assessment, chemotherapy preparation and treatment you need. If you are a day patient, you are likely to be at the hospital between four and six hours, sometimes longer if the treatment is complex, or if you are taking part in a research study.

Before you are given your chemotherapy, you will usually have blood tests and see a healthcare professional (this may be via phone or in person). As you may have to wait while your chemotherapy drugs are being prepared, you may wish to bring someone with you, bring a book to read or something to occupy you while you wait.

A step-by-step guide to having chemotherapy

Your tests and assessment

When you arrive on the day unit or ward, you will:

- Have a blood test to check if your blood count is satisfactory before you receive your chemotherapy
- See a healthcare professional
  - to check if you are well enough to be given chemotherapy
  - to check your chemotherapy prescription

  For some people this may happen the day before treatment is given and may be on the telephone. We will let you know if this is the case.

Chemotherapy preparation and treatment

- The pharmacy will prepare your chemotherapy (if you have already had your blood tests and assessment, your chemotherapy may have been prepared in advance)
- Your chemotherapy treatment will be given
- We will give you drugs to take home (if appropriate)
- We will book your next appointment.

Sometimes you might need to stay in hospital overnight when treatment is first started or if it has been planned for you to receive several drugs and fluid infusions. In these circumstances, a 24–48 hour hospital stay is usually all that is needed.

There are special treatments which require longer admissions and, if necessary, we will explain these to you.

Can I still take other medicines while I am having chemotherapy?

You must tell your doctor about any other medicines you are taking or planning to take, including herbal medicines, vitamins, other dietary supplements and complementary therapies. Some drugs may interfere with your treatment.

If you are admitted to hospital, please bring all your current medicines with you. Please show them to the doctor or ward nurse so they know what you are taking.

Please speak to your hospital doctor before taking any new medicines.

Will I be able to have vaccinations?

During chemotherapy you will not be able to have live virus vaccines. You may be able to have flu vaccines but it is always important to consult your hospital doctors before having any vaccinations.

Will chemotherapy affect my everyday activities?

Many people continue with their usual actives while having chemotherapy, for example, working between injections or cycles of tablets. However, most people do find that they are more tired than usual for the first few days after treatment. You may need to take things more slowly, working part time or cutting down on social activities. Take care not to overtire yourself, get enough rest and accept offers of help with everyday tasks.

The drugs, among other things, may cause you to feel a little down. It is quite normal for this to happen at various times during your treatment. If you would like to talk about this, please contact your nurse or doctor or talk it over at your next appointment.

What if I have planned a holiday?

It may be possible to adapt your chemotherapy protocol to fit in with holidays or other special occasions. Please discuss this with your doctor in advance so your treatment can be planned around your arrangements.

It is important that you inform your hospital team of any travel plans while you are on chemotherapy treatment. There are a number of factors you will need to consider if you are thinking of travelling outside the UK, including whether you can have some of the vaccinations required to visit certain countries.

There are risks associated with travelling outside the UK. If you need to use healthcare services in another country, the financial cost can quickly build up. Comprehensive travel insurance is strongly recommended. However, this is not always possible to arrange for pre-existing conditions and during treatment. It is also more difficult to arrange travel insurance to countries where healthcare is more expensive, for example the USA or Canada. You may need to consider if you are prepared to take the risk of travelling without insurance.

Airline travel is also associated with an increased risk of blood clots (see page 40). Longer flights present the greatest risk, although blood clots can also form after long train or car journeys. Some cancers and chemotherapy drugs increase this risk; discuss this with your doctor.

You must take care of your skin when you are exposed to the sun. Some chemotherapy drugs can make your skin more sensitive and you may burn easily (see page 33). Check with your doctor or specialist nurse if it is safe for you to swim.

Finally, many of the risks of chemotherapy may be increased if you do not have good access to medical care. This may include an infection developing while you have a low blood cell count.

Can I drink alcohol?

Yes, you may drink alcohol if you wish to. There are one or two anti-cancer drugs which may interact with alcohol but we will tell you about these.

Some people find that alcohol tastes unpleasant during chemotherapy treatment. Avoid drinking alcohol if you feel nauseous (sick) or if you have a sore mouth, as it may make you feel worse.

Are there any side effects or complications?

Yes, but these will depend on the type of chemotherapy you are given. Side effects are the secondary effects of treatment and can be acute or late. Acute (immediate) side effects occur during and immediately after treatment. Late (delayed) side effects develop after treatment has been going on for some time and may continue after treatment is finished.

Chemotherapy drugs damage fast growing cells. As well as destroying cancer cells, they also cause damage to normal cells. It is this damage to normal cells that may cause side effects. Everyone reacts differently to chemotherapy and some people may have no side effects at all. For example, not all chemotherapy drugs cause sickness or hair loss. The side effects you may experience with your chemotherapy protocol will be discussed with you. We will give you written information specific to your regimen.

We can offer help for most side effects, so please tell your doctor or nurse if you feel any different from normal. We want to maintain your confidence and wellbeing as much as possible during treatment. Remember, most of the side effects of chemotherapy are temporary and will disappear after your treatment has finished. However, sometimes it may be necessary to delay your chemotherapy until your side effects have resolved. This is common practice and will not affect your treatment.

There are some side effects that need to be treated quickly, so it is important that you do not wait until the next morning or after the weekend to contact us. If you are unsure whether your symptoms need urgent treatment, please contact The Royal Marsden Macmillan Hotline for advice over the telephone.

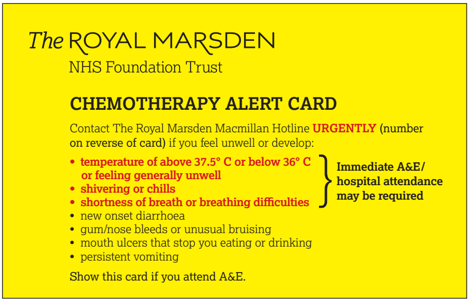
Contact details for The Royal Marsden can be found on page 52.

You **must** contact your hospital team **immediately** if you develop any of the following symptoms:

- a temperature of 37.5°C/100°F or higher
- shivering
- flu-like symptoms
- gum / nose bleeds or unusual bleeding (if bleeding does not stop after 10 minutes of pressure)
- mouth ulcers that stop you eating or drinking
- vomiting (that continues in spite of taking anti-sickness medication)
- diarrhoea (four or more bowel movements more than usual or diarrhoea at night)
- shortness of breath or difficulty with breathing.

It is important that you tell your hospital doctor if you suffer from any side effects since your last visit. Your doctor can give you medication to reduce or stop you from experiencing these side effects in the future.

You may be given a card similar to the one below to carry around with you. The card lists The Royal Marsden Macmillan Hotline, the symptoms needing urgent treatment and informs you and your healthcare professional about what to do when these occur.



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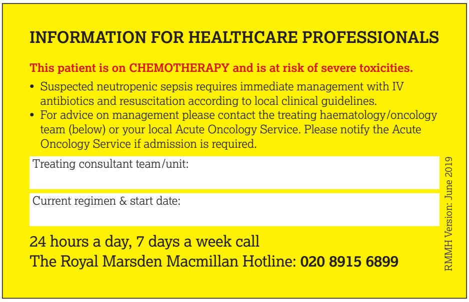
CHEMOTHERAPY ALERT CARD

Contact The Royal Marsden Macmillan Hotline **URGENTLY** (number on reverse of card) if you feel unwell or develop:

- **temperature of above 37.5° C or below 36° C or feeling generally unwell**
- **shivering or chills**
- **shortness of breath or breathing difficulties**
- new onset diarrhoea
- gum/nose bleeds or unusual bruising
- mouth ulcers that stop you eating or drinking
- persistent vomiting

Immediate A&E/ hospital attendance may be required

Show this card if you attend A&E.



INFORMATION FOR HEALTHCARE PROFESSIONALS

This patient is on CHEMOTHERAPY and is at risk of severe toxicities.

- Suspected neutropenic sepsis requires immediate management with IV antibiotics and resuscitation according to local clinical guidelines.
- For advice on management please contact the treating haematology/oncology team (below) or your local Acute Oncology Service. Please notify the Acute Oncology Service if admission is required.

Treating consultant team/unit:

Current regimen & start date:

24 hours a day, 7 days a week call
The Royal Marsden Macmillan Hotline: **020 8915 6899**

RMMH Version: June 2019

The Chemotherapy Symptom Assessment Scale (CSAS) on page 48, enables you to document any symptoms you experience during your first cycle of chemotherapy. Please bring this with you and show the doctor and/or nurse at your next visit. If you would like copies of the CSAS tool for the remainder of your chemotherapy treatment, please ask the nurse in the medical day unit (MDU).

Your blood

Blood cells are made in the bone marrow; the spongy tissue found inside the hollow bones of hips, legs and arms. Your bone marrow makes red blood cells, white blood cells and platelets.

Chemotherapy temporarily reduces the rate at which blood cells are produced in your bone marrow. You will have a blood test at the beginning of therapy and before each course of treatment. This is to make sure that your blood count is satisfactory before you have your chemotherapy. Your doctor may also request a blood count between treatments.

The main effects of chemotherapy on your blood cells are:

- reduction in white blood cells making you susceptible to infection
- reduction in red blood cells causing tiredness and fatigue
- reduction in platelets causing bruising or bleeding.

Infection

There are many types of white blood cells which make up the total white cell count. Their main function is to help your body to fight infection. If your white cell count is low (usually 7–14 days after the chemotherapy began), you may become prone to infections and take longer to recover from them. In general, these arise from bacteria within our own bodies – it is not necessary to avoid crowded places or isolate yourself from others. However, we advise you to keep away from people with serious infections, for example, chicken pox.

It is important to keep good personal hygiene. This includes taking daily baths or showers and washing clothes and bed linen regularly. Looking after your mouth (see page 29) will help prevent an infection from developing. Take care to wash your hands well when preparing food, before meals and after using the toilet.

During your treatment try to reduce the risk of developing an infection, for example, take care not to graze or cut your skin when gardening, shaving or preparing food. If you do, clean the area with warm water and soap and cover it with a sterile dressing, for example, a plaster.

Tell your doctor or nurse if you develop a rash or diarrhoea, as both of these symptoms can be a sign of infection.

Your doctor may prescribe a course of antibiotics to prevent infection during your treatment. Another option is to give you a course of injections of growth factors, which are proteins that stimulate the production of blood cells. The commonly given growth factor to boost white cells is called G-CSF.

The signs of infection (neutropenic sepsis) may be **a high temperature, shivering or flu-like symptoms or other signs of infection, such as a sore throat or cough.** If you feel unwell at any time or have a temperature (37.5°C/100°F or higher) you should contact the hospital immediately as you may need to be admitted for intravenous antibiotics.

Possible side effects	Symptoms:	What you should do
Infection due to low white blood cells – also called neutropenic sepsis	• High temperature • Shivering or flu-like symptoms • Other signs of infection, such as a sore throat or cough • Rash • Diarrhoea	• Check your temperature if you feel unwell • Avoid grazing or cutting your skin **Contact the hospital immediately – refer to your alert card for contact details if you feel unwell at any time or have a temperature (37.5°C/100°F or higher)**
When symptoms may occur		
Usually 7–14 days after chemotherapy		

If you are on an intensive chemotherapy regimen, we may give you additional advice about diet. You may be advised to avoid certain foods that have been linked with food poisoning, for example, soft cheese and under-cooked eggs.

Anaemia

The red blood cells contain a protein called haemoglobin (Hb), which carries oxygen around the body. If your haemoglobin is low, you may become anaemic and begin to feel very tired and you may look pale. Anaemia may lead to shortness of breath when you exert yourself more than usual, such as when climbing stairs or doing housework.

If, during your treatment, you begin to feel more tired than normal or become breathless, tell your doctor. Eating a diet rich in iron, for example liver, red meat, fish, eggs and green leafy vegetables, may help to keep your haemoglobin up to its usual level.

If your haemoglobin is very low, you may need to be admitted for the day, or overnight, to receive a blood transfusion.

Possible side effects	Symptoms:	What you should do
Anaemia (low red blood cells / haemoglobin)	• Tiredness • Shortness of breath	• Eat a diet rich in iron **Contact your hospital urgently (see page 52 for contact details) if you feel very unwell**
When symptoms may occur		
During the course of chemotherapy		

Bruising or bleeding

Platelets help your blood to clot and prevent you from bleeding and bruising. Most types of chemotherapy do not normally affect the platelets in any significant way. However, with some treatments you may notice that you bruise easily or that you have a tendency to bleed from your nose or gums. Rarely, small groups of red-purple spots may appear on your skin. **All these could be signs of a low platelet count and you should contact the hospital urgently.**

Do not take drugs which could affect your platelets, such as aspirin. Ask your doctor if you are not sure what to avoid. Use a soft toothbrush and an electric razor to prevent damage to your gums and skin. Take care not to cut yourself when using knives and wear thick gloves when gardening. Also take extra care if you are playing sports.

You may need to come into hospital for a platelet transfusion (which is like a blood transfusion but all the red cells and white cells have been removed). Your platelet count can also be corrected by making the rest period between your courses of drugs longer or by adjusting the doses of the drugs.

Possible side effects	Symptoms:	What you should do
Bruising or bleeding (due to low platelet count)	• Gum / nose bleed • Rarely small groups of red-purple spots on your skin	• If you are taking drugs such as aspirin or clopidogrel, ask your doctor if you should continue • Use a soft toothbrush and an electric razor to prevent damage to your gums and skin • Take care not to cut yourself **Contact your hospital urgently (see page 52 for contact details) if you have bruising, bleeding or groups of red-purple spots appear on your skin**
When symptoms may occur		
During the course of chemotherapy		

Your digestive system

Some chemotherapy drugs can affect the lining of the digestive system and may cause the following problems:

- sore mouth
- taste changes
- nausea (feeling sick) and vomiting
- changes in appetite
- diarrhoea or constipation.

Sore mouth

During chemotherapy the lining of your mouth may become sore and prone to infection and bleeding. This usually happens around 7–10 days after chemotherapy. It is important that you keep your mouth clean and healthy – the following suggestions may help:

- Drink plenty of fluids, to keep your mouth moist and fresh
- Use a mouthwash regularly – ask your doctor, nurse or oral hygienist which one is best
- Clean your teeth regularly using fluoride toothpaste and a soft toothbrush (if someone needs to clean your teeth for you, they may find a child's toothbrush easier to use)
- Clean your dentures after meals, as well as at night
- Keep your lips moist using a lip salve available from a chemist.

Tell your doctor or nurse if your mouth becomes sore. It may be possible to prescribe some tablets to prevent this in future. If you need further advice, ask to see an oral hygienist. Depending on the cause of your sore mouth, it may be possible to provide you with medication to relieve the discomfort.

Always consult your doctor or nurse before having any dental work done. Your blood count may need to be checked before the dentist can decide whether or not to proceed with dental treatment.

Possible side effects	Symptoms:	What you should do
Sore mouth	• Dry mouth and tongue • Sore mouth and tongue • Bleeding from gums, mouth or tongue	• Drink plenty of fluids • Use a mouth wash regularly • Clean your teeth regularly • Keep your lips moist **Contact your GP or hospital (see page 52 for contact details) if you are unable to eat or drink because of mouth ulcers**
When symptoms may occur		
7–14 days after chemotherapy		

Taste and smell changes

Some people experience a change in their sense of taste or smell. You may find that food may taste more salty, bitter or metallic. This is only temporary. Normal taste and smell usually return two or three months after the end of treatment. If an unpleasant taste occurs during an injection, it can be disguised by a strong-flavoured sweet. Occasionally, some people may experience food cravings.

Factors which can affect your mouth and appetite are covered in more detail in The Royal Marsden booklet, *Eating well when you have cancer.*

Possible side effects	Symptoms:	What you should do
Taste changes **Changes in smell**	• Changes in the way food and drink taste • Increased awareness of smells that may now become unpleasant, for example, cooking and perfumes	• Suck a strong flavoured sweet if you have an unpleasant taste during an injection • Avoid areas where unpleasant smells are present
When symptoms may occur		
During your course of chemotherapy		

Nausea and vomiting

Nausea and vomiting are not side effects of every chemotherapy drug, although many people believe they are. Some drugs or protocols (plans) cause a greater reaction than others and different anti-sickness drugs are used for different people. Everyone is individual – a similar drug combination may cause nausea in one person but not in another.

If you do feel nauseous or vomit following your treatment, there are many anti-sickness (anti-emetic) drugs to help overcome this problem. These come in the form of tablets, injections or suppositories. We will give you anti-sickness injections before the chemotherapy, along with tablets to take home with you. You should take these regularly as prescribed, even if you are not feeling sick, as some anti-sickness drugs are better at preventing than stopping sickness. Some people find taking ginger helpful. Should you still have nausea or vomiting, please tell your doctor or nurse, as you can be given different anti-sickness drugs that may be more effective.

If you experience vomiting at home, then anti-sickness tablets may not be effective and you should ask your doctor for suppositories with your next course. Your doctor or nurse will advise how to use these.

You may find relaxation or other therapy helpful.

Possible side effects	Symptoms:	What you should do
Nausea and vomiting	• Feeling sick (nausea) • Being sick (vomiting)	• Take anti-sickness tablets or suppositories regularly, as prescribed **Contact your hospital (see page 52 for contact details) if you continue to have nausea or vomiting. You can be given different anti-sickness drugs that may be more effective**
When symptoms may occur		
Within a few hours or days up to 14 days after chemotherapy		

Changes in appetite

If you experience any taste changes or lose your appetite, you may not feel like drinking or eating. However, you should try to drink plenty of fluids, about 10 glasses or cups each day, and try to eat as well.

Try sipping clear, cold fluids, such as water and soft drinks, slowly through a straw. Fizzy drinks such as soda water and ginger ale are quite refreshing, as are lemon or herbal teas. Avoid coffee, which has a strong taste and may also make you more thirsty.

You may need to change your meal times and have small, frequent meals or snacks of whatever you fancy. Eat slowly and chew your food well. After a meal, relax, in a sitting or slightly reclined position, instead of lying down.

Eat light meals on the day of your treatment.

The Royal Marsden booklet *Eating well when you have cancer* offers further advice. If you are worried about your diet, please ask to see the dietitian.

Possible side effects	Symptoms:	What you should do
Changes in appetite	• You may not feel like drinking or eating	• Drink plenty of fluids • Have small frequent meals or snacks **Ask to see the dietitian if you are worried about your diet**
When symptoms may occur		
7–14 days after chemotherapy		

Diarrhoea or constipation

Diarrhoea or constipation may occur with some chemotherapy drugs. They can often be managed by tablets, medicines or a change of diet. Please tell your doctor or nurse if you have any problems, and if necessary, contact the hospital immediately (even in middle of night) rather than leaving it until the morning.

Possible side effects	Symptoms:	What you should do
Diarrhoea or constipation	• Frequent or loose bowel movements • Not able to control bowel action • Irregular or hard bowel movements	• Drink plenty of fluids **Contact your GP or hospital (see page 52 for contact details) if you have diarrhoea (four or more bowel movements more than usual or diarrhoea at night)**
When symptoms may occur		
7–14 days after chemotherapy		

Your skin

Some chemotherapy drugs may cause soreness and dryness to your hands and feet. This problem can be relieved with medication, so please tell your doctor if it happens.

Certain drugs may discolour the skin causing dark lines along the veins or where there is friction, for example, due to tight clothing. Others may cause a local red reaction at the injection site or along the vein. This fades a short time after treatment.

Any rash should always be reported to your doctor. Some drugs may cause patches of red skin, particularly on the palms of your hands and soles of your feet. This skin may become dry and cracked. Using a good hand cream may help to prevent this.

During treatment and for several months afterwards, your skin may be more sensitive to the sun and you may burn more easily. Using a moisturiser, such as an unperfumed emollient that does not contain sodium lauryl sulphate, will help prevent dryness.

Try to stay in the shade between 10am and 3pm. Wear a wide brimmed hat and sunglasses that block out 100% of the ultraviolet (UV) rays and wear a T-shirt or other loose clothing.

Whenever you spend any length of time in the sun, apply a sunscreen with an SPF (sun protection factor) of 15 or more that blocks both UVB and UVA light. Apply it at least half an hour before exposure to the sun. Remember vulnerable areas such as your ears, neck, back of the hands and feet.

After your treatment has finished, you should protect your skin from extremes of temperature and continue using sunscreen (factor 15 or above).

Your nails

Your nails are important as they protect your finger tips and toes. It is necessary to take care of them during chemotherapy.

With some drugs, your nails may become darker than usual and they may develop ridges or white lines. These changes usually grow out over a few months after the treatment has finished. Sometimes, your nails can become brittle, cracked, split or even fall off. To prevent this you will need to look after your nails by:

- Keeping them clean, dry, trimmed and filed to prevent damage due to snagging.
- Massaging a good moisturiser into your nails and nail beds to maintain healthy cuticles and encourage growth.
- Wearing gloves to protect your nails when using harsh chemicals, washing up, scrubbing, gardening and so on.
- Avoiding false nails as the adhesive may worsen the condition of your nails.
- Wearing nail polish (if you wish) to hide the discolouration – try to avoid using the quick drying types and also remember that the frequent use of nail polish remover can make your nails more brittle.
- Avoiding any injury to your nails or cuticles as you may be temporarily at risk of infection or bleeding as a result of your chemotherapy treatment. If you wish to have a professional manicure, please make sure you tell the manicurist that you are on chemotherapy.
- Telling your doctor if you think you may have an infection, have developed redness or other changes around your cuticles or if a nail falls off.

Possible side effects	Symptoms include:	What you should do
Skin changes **When symptoms may occur** During your course of chemotherapy	• Sore, dry hands and feet • Nails become darker than usual • Nails may develop ridges and white lines	• Use a moisturiser on dry skin • Protect your skin in the sun

Your hair

Hair loss (alopecia) is a common side effect of chemotherapy. Not all drugs cause hair loss and some drugs only cause thinning of the hair or cause it to become brittle.

Hair loss can be very distressing, however it is usually temporary and your hair will grow again when treatment finishes. Occasionally, your hair will start to grow back before the end of the chemotherapy. Sometimes, your hair may grow back a different colour or texture.

Hair loss does not always happen straight away; it usually starts within a few weeks of beginning treatment. Sometimes it starts within a few days. It can occur on all parts of the body, including the hands, face, arms, legs, underarms and pubic area. If you lose eyelashes or hairs in your nose, you may experience weepy eyes or a runny nose.

Paxman machine

For some types of chemotherapy, a scalp cooling machine is used to cool the scalp as the drug given can prevent hair loss. This works by reducing the blood flow to the scalp so that less of the drug reaches the hair follicles on your head. However, scalp cooling does not work for everyone. It only blocks certain drugs and is not suitable to use with all types of cancer. Your doctor or nurse will be able to tell you if this is appropriate in your case. If you have scalp cooling, you will need to allow extra time at the hospital for your treatment.

Wigs can be obtained in advance, should you wish to wear one. If you are likely to lose your hair, your nurse can make a referral or provide information on organisations which provide wigs.

Chemotherapy can cause your hair to become dry and brittle, so take good care of it. Use a neutral pH shampoo and conditioner (avoid baby shampoo as it is too alkaline). Cut down on the number of times you wash your hair each week.

Use a wide toothed comb to avoid pulling at your hair and roots. Avoid harsh chemicals, such as hair dyes and perms, and excessive heat from heated rollers and hair dryers during chemotherapy and for a few months following completion of chemotherapy. For more details, please see the Macmillan booklet *Coping with hair loss.*

Possible side effects	Symptoms:	What you should do
Hair loss	• Total hair loss • Thinning of hair • Brittle hair	• Use a neutral pH shampoo and conditioner • Cut down on the number of times you wash your hair each week • Order a wig in advance if you are likely to lose your hair • Avoid harsh chemicals, such as hair dyes and perms
When symptoms may occur		
Within a few weeks of beginning chemotherapy		

Your fertility

Some chemotherapy drugs can damage the ovary or testes, leading to an increased risk of infertility (inability to have a child) and early menopause (in women). If this is an important issue for you, make sure you discuss it fully with your doctor before treatment starts.

Chemotherapy may affect sexual organs or functions in various ways. You may experience changes in your desires or desired level of sexual activity, or you may notice no difference. Loss of libido (sex drive) is not uncommon in both women and men. However, chemotherapy in itself does not usually affect sexual performance or cause impotence. The stress of your illness or the treatment schedule may make you feel more tired than usual. If fatigue is a problem, you may want to set aside time for physical intimacy after a period of rest.

Although your sexual needs and desires are highly individual, the following advice may be helpful:

- Try to find out as much as possible about how your treatment may affect you
- Share your worries and feelings with people who care for you.

Feel free to discuss any concerns you may have with your doctor or nurse. Even if they are unable to help you, they can refer you to someone who can.

For women

Chemotherapy may affect your ability to conceive a child. This may be temporary or permanent, depending on your age and your treatment. If you are concerned about this, you may wish to discuss it with your doctor before starting treatment.

Women having certain chemotherapy protocols may notice changes in their menstrual cycle. If you are still having periods, then it is quite possible that these will gradually stop while you are on chemotherapy. This is less likely if you are in your 20’s or 30’s. If you are in your 40’s, your periods may not return and menopausal symptoms may begin.

Hormonal changes may cause hot flushes and vaginal dryness. If you suffer from any menopausal symptoms, talk to your doctor who may prescribe something to help relieve them.

If you are concerned about preserving your fertility, your specialist cancer doctor may refer you to a fertility clinic where you can discuss what options may be available.

Not all of the following options will be suitable for every woman. The choices available to you may also depend on whether you can safely delay treatment. The fertility options include freezing fertilised or unfertilised eggs, or ovarian tissue:

- Freezing embryos (In Vitro Fertilisation or IVF) – collecting and freezing embryos for later implantation.
- Freezing unfertilised eggs (oocytes) – a procedure that may be considered by women who do not currently have a partner and do not wish to use a sperm donor. This is a fairly new and experimental technique.
- Freezing ovarian tissue – this contains hundreds of immature eggs that could potentially be saved and used to start a future pregnancy. This is still at a very early and experimental stage.
- Taking drugs to protect the ovaries – there is some evidence that drugs which induce a temporary menopause, for example, Zoladex, may protect the ovaries during treatment from long-term chemotherapy damage, however, this approach is experimental.

Pregnancy – it may be possible to become pregnant during the time you are having chemotherapy, but you **should not** as some chemotherapy drugs can damage an unborn child. During treatment and for about one year afterwards, sperm and eggs may not be formed normally, if they are produced at all. Your doctor will be happy to discuss this further with you.

You or your partner should use a **barrier method** of contraception (such as condoms) during treatment, not only to prevent pregnancy, but also to prevent any possible contamination with chemotherapy. Non-barrier methods should be fine after treatment is finished, but contraception should be used for one year after completion of chemotherapy. If you know you are pregnant before starting treatment, or become pregnant during treatment, you must tell your doctor **immediately**.

We are aware that some women may be diagnosed with cancer during pregnancy. If you are in this situation, your specialist doctor will discuss with you, including the benefits and risks of having chemotherapy.

Breastfeeding – there may be a risk of harm to a child who is being breastfed, since the drug may be concentrated in the milk. It is very important that you check with your doctor first, if you wish to breastfeed while receiving chemotherapy.

For men

Some chemotherapy drugs can damage the testes and this may affect your ability to father a child. Although sterility (failure of sperm production) is not associated with many drugs, chemotherapy may reduce the number of sperm or their motility (movement). After treatment, some men remain infertile while in others, the sperm count returns to normal.

If sterility is likely to be a permanent side effect, you may be offered the opportunity to bank sperm before starting treatment (sperm is frozen for artificial insemination at a future date). Before sperm banking takes place, you will be asked to have a blood test for Human Immunodefiencey Virus (HIV) antibodies, Hepatitis B and Hepatitis C. This is routine practice to ensure that healthy sperm are banked.

During treatment and for about one year afterwards, it is not advisable for you to father a child, because sperm may not be formed normally. You or your partner should use effective contraception, such as condoms.

Possible side effects	Symptoms:	What you should do
Changes in your fertility	• Early menopause (for women) • Inability to conceive or father a child (men and women) • Some drugs can damage the DNA development of a foetus	**Men can consider** • Sperm banking (if appropriate) **Women can consider** • Freezing embryos • Freezing unfertilised eggs (oocytes) • Freezing ovarian tissue • Drugs to protect the ovaries **Men and women** • Use effective contraception
When symptoms may occur		
During and following treatment		

Other effects

Some chemotherapy drugs may cause rare side effects. Your doctor will tell you if any of your chemotherapy drugs are likely to cause any of the following:

Allergic reactions

Occasionally, a small number of patients may experience a severe, occasionally life-threatening, drug related reaction. Symptoms may include coughing, a feeling of swelling in the tongue or throat and breathlessness. You will be monitored closely during your treatment and if any of these symptoms occur, you will be treated appropriately. **If you continue on the same treatment, then you may be admitted for the next cycle and given anti-allergy drugs before the treatment. You will be monitored closely throughout.**

Bladder symptoms

Some drugs may cause discolouration of your urine after chemotherapy. For example, your urine may turn pink or red up to 24 hours following each treatment. Your chemotherapy nurse will warn you if this is likely to happen. If you think you notice blood in your urine, you should report this to your doctor.

Some drugs can cause irritation to the bladder (cystitis) as they are excreted in the urine. You should drink about an extra pint (half a litre) of fluid within the 24 hours after each injection, or you may need to have extra fluids intravenously while having chemotherapy. Your nurse can advise you further.

Blood clots

Some cancers can increase your risk of developing blood clots, while some chemotherapy drugs and some other anti-cancer drugs can also increase the risk of developing blood clots. The type of blood clot seen most often occurs in the veins, causing problems such as deep vein thrombosis (DVT). This usually refers to a clot in one of the leg veins, causing swelling and / or pain in the leg. If a part of the clot breaks free, it may travel to the lungs, causing shortness of breath or chest pain. This is called a pulmonary embolus (PE). It is important that we prevent this from happening, so we may ask you to wear anti-embolic stockings while you are in hospital or to have blood thinning injections. On your first visit to the chemotherapy unit, we will give you a blood clot alert card to keep which has the essential information that you need regarding reducing the risk of developing a blood clot. Further information can be found in The Royal Marsden booklet *Blood clot prevention*.

Blood clots can be life threatening and treatment with blood-thinning drugs (anti-coagulants) is usually given to help dissolve the clot and prevent further problems.

Blood clots in the arteries are rare but there is an increased risk of this happening with some anti-cancer drugs, for example, drugs which affect tumour blood vessels (anti-angiogenic drugs). Blood clots in the arteries may lead to a heart attack, stroke or prevent the blood supply reaching a limb. Please inform your doctor immediately if you are worried you may have a blood clot.

Eye symptoms

Your eyes may become dry, irritable or weepy (conjunctivitis). Please speak to your doctor or nurse if you get any of these symptoms so that you can be given advice on how to relieve them.

Fluid retention

You may notice swelling of your ankles (ankle oedema) or breathlessness. Usually, this is mild and goes away when treatment ends. Tell your doctor if you experience either of these symptoms.

Flu-like conditions (fever, headaches, pain)

This reaction does not last very long and can be treated with paracetamol.

Hearing symptoms

Some chemotherapy drugs can cause tinnitus (a continual buzzing noise in the ears) or high frequency hearing loss. Tell your doctor if you are worried about changes in your hearing.

Kidney function

There may be changes in the way your kidneys work. We will monitor you closely if you are receiving a chemotherapy drug that could cause any damage. These are usually temporary effects and are unlikely to cause you any symptoms.

Liver function

There may be changes in the way your liver works. You will be monitored closely if you are receiving a chemotherapy drug that could cause any damage. These are usually temporary effects and are unlikely to cause you any symptoms.

Memory and concentration

Some patients find that their short-term memory and concentration are not as good while they are undergoing chemotherapy. This usually resolves soon after treatment has finished, although it can rarely be a long-term effect. If your job involves a great deal of mental effort, this may affect your ability to work while you are having treatment.

Nervous system

Some chemotherapy drugs can cause problems with the nerves in the body. This is called peripheral neuropathy. It can cause sensations such as tingling, burning, numbness or pins and needles in the hands and / or feet. You may have difficulty with fine movements, for example, doing up your buttons. These sensations may worsen on exposure to cold and can also affect the nose and throat, causing swallowing and breathing problems. It may help to wear gloves, warm socks and a scarf. If your mouth is affected, avoid cold drinks.

Tell your doctor if you get any of these sensations, so they can be monitored, and if necessary, changes can be made to the dose or the type of drug you receive. Most of the time, these symptoms will get better after your treatment ends, although it may take some time.

If the symptoms become severe, the nerves could be damaged permanently and your chemotherapy drugs may be changed. You **must** tell your doctor if your symptoms become worse.

Steroids

Steroids are natural substances that are made in the adrenal glands, which lie just above the kidneys in the body and in the reproductive organs. There are also man-made steroids.

Steroids, such as dexamethasone and prednisolone, can be given for different reasons. For some types of cancer, steroids have a direct anti-tumour effect. You may be given dexamethasone with your chemotherapy to help prevent sickness. Sometimes it is given to help prevent other side effects or to reduce symptoms from an allergic reaction.

The side effects you may experience with steroids will depend on the dose and the length of time you are taking them. Discuss this with your doctor, nurse or pharmacist. The more common side effects include:

- Irritation of the lining of the stomach causing indigestion or heartburn – you may be given drugs to prevent this, particularly with higher doses or longer courses of steroids
- An increased appetite and weight gain
- Fluid retention – you may notice swelling of your ankles (ankle oedema); usually this is mild and goes away when treatment ends
- Mood changes or difficulty in sleeping – you may find it helpful to discuss with your doctor, which time of day is best to take your steroids.

Tissue damage (extravasation)

Some drugs can cause damage if they leak out of the vein while they are being injected. This may result in some pain and may take some time to heal. If you feel any stinging, burning or pain when you are receiving the drug, or develop any problems at the site, such as redness or blistering once you are home, tell your nurse or doctor straight away.

Long-term risks

Developing a second cancer

With some drugs, there is a small possibility of developing a second cancer or serious blood disorder including leukaemia (cancer of the blood cells). However, the benefits of having chemotherapy generally outweigh the risk of developing a second cancer. Your doctor will discuss this with you if your chemotherapy drugs include this risk.

Damage to the heart muscle

This is very rare but can occasionally happen with prolonged usage of some chemotherapy drugs, especially doxorubicin and epirubicin. You should inform your doctor if you have had any pre-existing heart problems. They may arrange for you to have a test to see how well your heart is working before you start treatment, if this is likely to be a concern. You should tell your doctor if you notice chest pain or breathlessness. Alternatively, contact The Royal Marsden Macmillan Hotline (details on page 53).

How will I feel during my chemotherapy?

The need to have chemotherapy and the effect it has on your life, can prompt a range of feelings. Fear, anxiety and depression are common to many people with cancer and are entirely normal. This may be in addition to how you feel physically.

Emotional wellbeing

Some people find it helps to gather information about their cancer and treatment because this lessens the fear of the unknown.

Find out as much as you want to know and do not be afraid to ask questions. Your emotional wellbeing is as important as your physical health.

Loss of memory and concentration may be side effects of chemotherapy and usually resolve soon after treatment has finished. This can affect your ability to listen and remember things which are explained at your treatment visits. Do not feel embarrassed to ask for information to be repeated as often as you need it. You may find this affects your ability to work during treatment if your job involves a great deal of mental effort.

You may find it helpful to bring a friend, partner or relative to hospital visits and to make a note of any questions you have beforehand. The doctors and nurses caring for you will be happy for you to do this. There is a blank section on page 50 for you to make notes or write down questions.

You may find it helpful to talk to an understanding friend, relative, other patient, a member of a local support group or one of the organisations (such as Macmillan) listed on pages 48–49.

Many people do not understand cancer or its treatment and may not be sure what to say or how to help. Try to be open in talking with others about your illness, treatment, needs and feelings.

You might wish to try new methods to help you cope with treatment and its side effects, such as meditation, relaxation exercises, distraction, visualisation (imagery), hypnosis, art therapy, reflexology or pampering therapy (look good feel better). Please ask about what is available within the hospital or locally in the community.

Remember, everyone needs some support during difficult times. Please do not hesitate to ask for help from your doctor or chemotherapy nurse, during or after your treatment. They want to make sure you get the support you need.

Fatigue

During your chemotherapy you may start to feel tired or listless (lack energy). This may be general fatigue or it may be that you become tired more easily after normal activities. This is quite normal and usually occurs with all types of chemotherapy.

Once you know what makes you more tired and when this happens, you can plan ahead. Try to plan your day so that light activities are spaced between more energetic activities. Gentle exercise can be helpful. Make sure you get enough rest and only do what you feel you can cope with.

People will often be willing to lend their support. If you get tired easily, limit your activities and only do the things that mean the most to you. Ask your family and friends to help with household chores, cooking and so on. Work part time or see if you can work more flexible hours. Save your energy for the important events in your life.

Tiredness can also be a sign of anaemia, so do tell the nurse or doctor if you are worried about how you feel.

What help is available during my treatment?

Some people may experience problems as a result of their cancer and / or treatment that can have an effect on different areas of their life. There is a wide range of services to help you recover and lead an active and productive life. Some services can help you with physical difficulties, for example, physiotherapists and occupational therapists. They may be able to teach you new ways of doing certain activities or help you achieve and maintain independence in other areas of your daily life. If you are finding it difficult to eat well, dietitians can provide advice both during and after treatment.

Other services may be able to help you cope with social and emotional worries, for example, social workers. They are experienced in working with people who have to adjust to change or crisis in their lives. A social worker can discuss with you any help you may need at home, and give you information and advice on welfare benefits and coping with financial difficulties.

What happens when chemotherapy treatment is finished?

Once your chemotherapy treatment has finished, most side effects gradually disappear. Everyone is an individual and will recover in their own time. You may find that it takes a while for your energy levels to recover. You may also find that it will take some time for your emotions to settle down. As well as feeling relieved that your chemotherapy has finished, you may miss the close support of the hospital team which you had during treatment. You may find the Macmillan booklet *What to do after cancer treatment ends* helpful.

We will give you an appointment for a follow up check. Please ask who you should contact if you have any problems or concerns before your appointment.

Sources of information and support

Macmillan Cancer Support
89 Albert Embankment
London SE1 7UQ

Freephone: 0808 808 0000

Website: *www.macmillan.org.uk*

Provides free information and emotional support for people living with cancer and information about UK cancer support groups and organisations.

Offers free confidential information about cancer types, treatments and what to expect.

National Institute for Health and Clinical Excellence (NICE)
10 Spring Gardens
London SW1A 2BU

Tel: 0300 323 0140

Website: *www.nice.org.uk*

NICE provides guidance for healthcare professionals and patients and their carers, that will help to inform their decisions about treatment and healthcare.

Cancer Research UK
Angel Building
2 Redman Place, London E20 1JQ

Tel: 0808 800 4040 (Nurse helpline)

Website: *www.cancerresearchuk.org*

Trained cancer nurses can give information and support relating to cancer and its treatments. Publications are available with information on specific cancers. Details on current UK clinical trials are also available on their website.

National Cancer Institute (USA)

www.cancer.gov

Provides comprehensive information on cancer and its treatments. (Please note that not all the information will necessarily relate to treatment in the UK).

American Cancer Society

www.cancer.org

American Cancer Society gives detailed information on specific cancers and coping with cancer. (Please note that not all the information will necessary relate to treatment in the UK).

Maggie's Centres

www.maggies.org

Offers psychosocial support, through a network of cancer caring centres across the UK and online, to anyone affected by cancer.

Further reading

Taking control of cancer (2003) Beverley van der Molen. Class Publishing. ISBN 1859590981

Provides information for people diagnosed with cancer on finding information, treatment options, choices and self help.

The Chemotherapy Survival Guide: Everything You Need to Know to Get Through Treatment (2009) Judith McKay, Tamera Schacher. ISBN 1572246219

This comprehensive guide explains in plain English everything you need to know about your treatment, including what you can expect at each stage of chemotherapy and what you can do to prevent or minimise side effects.

Notes/Questions

You may wish to use this space to make notes or write questions, as they occur to you, to discuss with your specialist nurse or doctor.

Contact details

If you have any queries about your illness or treatment or experience any problems mentioned in this booklet, please contact the team caring for you:

Name of consultant (chemotherapy)

Names of clinical team including key worker

at ______________________________ Hospital

Telephone number

Name of ward / day unit

Telephone number

Other useful contact details:

The Royal Marsden contact details

During office hours:

Medical Day Unit:

Chelsea	(NHS)	020 7808 2320 / 020 7808 2060
	(Private)	020 7811 8092 / 020 7811 8190
Sutton	(NHS)	020 8661 3174
	(Private)	020 8661 3946

William Rous Unit

Kingston	020 8973 5030

After office hours, on weekends or bank holidays please contact The Royal Marsden switchboard and ask for a member of your clinical team or the clinical site practitioner

Switchboard

Chelsea	020 7352 8171
Sutton	020 8642 6011

The Royal Marsden Macmillan Hotline:

020 8915 6899

You can ring the hotline 24 hours a day, 7 days a week.

Call us straight away if you are feeling unwell or are worried about the side effects of cancer treatments.

This service provides specialist advice and support to all Royal Marsden patients, as well as to their carers, and both hospital and community-based doctors and nurses caring for Royal Marsden patients.

Should you require information in an alternative format, please contact The Royal Marsden Help Centre.

Revised March 2022
Planned review March 2025

This booklet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

Details of the references used in writing this booklet are available on request from: The Royal Marsden Help Centre
Freephone: 0800 783 7176
Email: patientcentre@rmh.nhs.uk

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London SW3 6JJ

www.royalmarsden.nhs.uk

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royalmarsden.org

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The
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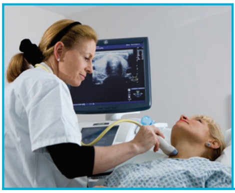
MARSDEN
Cancer Charity

The Royal Marsden publishes a number of booklets and leaflets about cancer care. Here is a list of information available to you.



Diagnosis

- A beginner's guide to the BRCA1 and BRCA2 genes
- CT scan
- MRI scan
- Ultrasound scan
- Lynch Syndrome

Patient Information

Treatment

- Central venous access devices
- Chemotherapy
- Clinical trials
- Radiotherapy
- Radionuclide therapy
- Your operation and anaesthetic

Patient Information

Supportive care

- Eating well when you have cancer
- Lymphoedema
- Reducing the risk of healthcare associated infection
- Support at home
- Your guide to support, practical help and complementary therapies

Patient Information

Your hospital experience

- Help Centre for PALS and patient information
- How to raise a concern or make a complaint
- Making your stay with us safe
- Your health information, your confidentiality

Patient Information

Please visit **www.royalmarsden.nhs.uk/patientinformation** where several patient information booklets are available to download.

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