



Chemotherapy



A guide for patients and carers

The Clatterbridge Cancer Centre Hotline 0800 169 5555

If you are unwell during or up to six weeks following your cancer treatment, please call The Clatterbridge Cancer Centre Hotline.

Your call will be answered by a dedicated nurse advisor. This line is available 24 hours a day, seven days a week.

Please call if you have any queries, but it is particularly important if you are experiencing any of the following:

- If you suddenly feel unwell, even with a normal temperature
- A temperature greater than 37.5°C
- A temperature lower than 36 °C
- Any unexplained bruising or bleeding
- Diarrhoea for more than 24 hours
- Nausea or vomiting lasting more than 24 hours
- Unrelieved shortness of breath
- Mouth ulcers that stop you eating or drinking



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Introduction

Your doctor at The Clatterbridge Cancer Centre has prescribed a course of chemotherapy for you. This booklet tells you about chemotherapy and the chemotherapy service at The Clatterbridge Cancer Centre. We will also give you a leaflet about the treatment you will receive.

We hope this booklet and the leaflet will answer most of your questions and help you discuss your treatment with the doctors and nurses. Our medical and nursing staff are here to answer any questions you or your family may have.





What is chemotherapy?

Chemotherapy is a drug that is used to destroy cancer cells. It can be used alone, with surgery and/or radiotherapy, with hormonal therapy, or other anti-cancer drugs such as targeted or biological therapies.

Your doctor will discuss the options with you and will involve your family, if you wish.

What do chemotherapy nurses do?

Our nurses have had special training and are responsible for giving your chemotherapy after you have seen the doctor. You may not always receive treatment from the same nurse, but the chemotherapy nurses work as part of a team and will closely liaise with you and other nurses to ensure you receive the best standard of care. Our doctors and nurses also manage several chemotherapy clinics at other hospitals across Merseyside and Cheshire.

How does chemotherapy work?

Chemotherapy kills cancer cells or stops them from dividing and multiplying. In the same way that different bacteria are sensitive to different antibiotics, different cancers are sensitive to different types of chemotherapy. After each dose of chemotherapy, some of the cells will be destroyed. Usually, patients receive a number of cycles of chemotherapy to destroy as many of the cancer cells as possible.

How is chemotherapy given?

Because different cancers are sensitive to different chemotherapy drugs, everyone's treatment is different. Sometimes the same drug or drug combination may be used for different people. We calculate the dose for each individual.

Chemotherapy can be given in one or more of the following ways:

- Directly into a vein (intravenous) as an infusion through a plastic needle called a 'cannula'
 - As a **bolus injection** through a plastic needle called a 'cannula' into a vein, usually in the back of your hand or forearm. This is ideal for small volumes of fluid
 - As an **infusion** through a central line (PICC, Hickman, Portacath)
- As a small ambulatory pump via a central line. You can go home with this kind of device. This is ideal for small volumes of fluid that need to run continuously over a few days or a week
- As tablets to take at home as part of your treatment plan. Your nurse will explain how and when to take them. Don't ask your GP for any more of these tablets
- As an **injection** into a muscle or into the tissue just underneath the skin
- Into a body cavity, for example the bladder or abdomen (belly, tummy)



- As a **lumbar puncture**. This involves inserting a needle into your spine so that the drugs reach the cerebrospinal fluid surrounding your brain. We will give you a local anaesthetic first, to minimise any discomfort
- As an **ointment** applied directly to your skin

Your doctor will discuss with you the best way to give your treatment.

When you receive chemotherapy into a vein, there is a small risk that the chemotherapy can leak out of the vein into surrounding tissue. If you experience burning or stinging around the infusion site during treatment, please inform the nurse at once. Sometimes this can happen after you go home, and in this case you should telephone the Hotline immediately for advice. Your treatment can also cause discomfort along the vein during administration and, although this is temporary, it is important that you tell the nurse so that he/she can assess it straight away.

Pre-assessment

Before patients begin their chemotherapy treatment they are invited in to the ward to be assessed by a chemotherapy nurse. This visit allows the nurse to assess the patient's current health needs before starting treatment and to check that any necessary support that may be required is in place. The nurse will also go through the treatment plan, discuss side effects of chemotherapy treatment and how to help you cope with any side effects. You will

be given the opportunity to be shown around the chemotherapy ward environment. We believe that the pre-assessment visit is very beneficial to patients and their carers as it allows them to absorb the information and reduce any anxieties they may have on their first treatment visit

What are the side effects of the treatment?

How people react to chemotherapy varies from person to person and reactions may also vary from treatment to treatment. Since most side effects are temporary, they will gradually disappear once your treatment is complete. There is no connection between the extent of the side effects you experience and the effect of the drug on your cancer.

Some side effects can be tiresome, but you and your doctor must weigh this against the benefits of treatment. Therefore, if you find it difficult to cope with any of the side effects, please discuss them with your doctor or nurse. There are many ways we can help you.

Effects on your bone marrow

Bone marrow is a sponge-like substance that produces blood cells in the hollow spaces of bones. It is sensitive to most types of chemotherapy but the following blood cells are especially sensitive:

White blood cells help your body to fight infection. If your
white cell count (WCC) is low, you will be more at risk of
infection. Signs of infection include a high temperature above
37.5°C. It is therefore very important that you check your



temperature once a day. If you feel unwell at any time or your temperature rises above 37.5°C or is lower than 36°C, contact us immediately on **0800 169 5555**. While you are having chemotherapy you should avoid people with infections such as flu, measles or chicken pox

- Platelets help your blood to clot. If you notice that you bruise easily, have pin-prick type reddish/purple spots on your body, bleed from your nose or gums or pass blood-stained urine, please contact the Clatterbridge Cancer Centre Hotline for advice on 0800 169 5555
- Red blood cells carry oxygen to all the cells of the body. If you
 notice that you are unusually short of breath, feel tired or look
 pale please contact the Hotline for advice

Occasionally, when your white cells are very low and you have developed signs of an infection, we may bring you into the Centre to give you an antibiotic injection. You may also need to come in for a blood or platelet transfusion if these get too low.

Rarely, the side effects of chemotherapy can be life threatening. About 1–2% of patients die after chemotherapy treatments, often because they delay in seeking advice. So it is very important to contact the Clatterbridge Cancer Centre Hotline on 0800 169 5555 (further details are given on the inside front cover) if you become ill within six weeks of receiving a dose of chemotherapy.

Effects on your mouth

Some drugs can make your mouth dry, sore and occasionally give you ulcers. Tell your nurse if it gets uncomfortable.

You can help yourself in the following ways:

General advice

- Drink plenty of fluids
- Keep your mouth moist and clean at all times
- Avoid mouthwashes that contain alcohol. A simple mouthwash made from one teaspoon of salt to a pint of boiled, cooled water is ideal
- Avoid smoking and alcohol

Dry mouth

- Try soft foods or moisten foods with sauces or gravy
- Stimulate saliva production with fruit juice or ice cubes
- Pineapple, either fresh or tinned, is refreshing and can help to keep your mouth clean
- Suck strongly flavoured pastilles or mints to keep your mouth moist

Sore mouth

- Use a soft, bristled brush to gently clean your teeth after meals and each morning and night
- Dental floss should be used once a day (unless your nurse or doctor has asked you not to)
- Avoid very hot or cold, sharp, highly spiced, salty or tart foods and drinks



 If your mouth becomes sore, please increase temperature monitoring to two times a day

With some drugs, you may find that food tastes bitter, salty or metallic. Sucking a mint or strongly flavoured sweet during treatment may help. Normal taste usually returns when treatment is complete. If you want to know more, please ask the nurses.

Effects on your digestive system

Nausea and vomiting (feeling sick and being sick)

Not all drugs cause nausea and vomiting – many people do not experience it at all. Nausea and vomiting may start a few hours to a few days after treatment.

We will give you a supply of anti-emetic (anti-sickness) drugs to take home and the nurse will explain the best way to take them. If they don't work well for you, talk to your doctor or nurse. There are other anti-emetic drugs that may help.

If you cannot stop vomiting and cannot keep any fluids down, it is very important to contact the Clatterbridge Cancer Centre Hotline on **0800 169 5555** (further details are given on the inside front cover).

- Take your anti-emetics regularly as prescribed especially during the first few days. Don't wait until you feel sick
- Chilled fizzy drinks such as cola and lemonade can help settle your stomach. Sip them through a straw to avoid feeling 'bloated'

- If you are vomiting, try to drink at least eight cups of fluid a day
- Try to drink between meals rather than during meals
- Eat food at room temperature, for example sandwiches and salads or cheese and crackers
- Eat small, frequent meals
- Ginger is a natural anti-emetic and you can take it in the form of ginger beer, biscuits, tea, cake, or crystallised pieces of ginger
- Eat a dry cracker, biscuit or some toast and relax for 15 minutes before you get out of bed
- Avoid fresh citrus fruit drinks, full fat milk and alcohol
- Avoid very sweet, spicy or greasy foods
- Avoid preparing foods when you feel sick
- Try and get plenty of fresh air
- Some people find that relaxation techniques and acupressure bands help to reduce nausea
- If you have had nausea and vomiting before, think about what helped and try it again

Diarrhoea (loose bowels)

Some chemotherapy can cause diarrhoea. Usually, diarrhoea will settle within 24 hours.

- Drink plenty of clear fluids until it settles
- If you continue to have more than four bouts of diarrhoea a day or for more than 24 hours, contact the Clatterbridge Cancer



Centre Hotline on **0800 169 5555** (further details are given on the inside front cover)

- If you have any diarrhoea, please increase temperature monitoring to two times a day
- If you also have abdominal pain, call us for advice
- If you are concerned, please contact us straight away
- If you are on irinotecan chemotherapy and have any diarrhoea at all, it is very important to contact the Clatterbridge Cancer Centre Hotline on **0800 169 5555** (further details are given on the inside front cover)

Constipation (stubborn bowels)

Some drugs may cause constipation.

- Try and increase your exercise
- Drink plenty of fluids. Fresh fruit juice may help
- Eat plenty of fresh fruit and vegetables
- Try high-fibre cereals such as Bran Flakes, All-Bran, Shredded Wheat and porridge
- Use wholemeal bread
- If you become uncomfortable, ask your GP or local pharmacist for advice (tell them about your chemotherapy)
- If you have had constipation before, think about what helped you then and try it again

Effects on your hair

Not all chemotherapy drugs will cause your hair to fall out. Your doctor or nurse will advise you on this. Sometimes hair loss is so small you won't notice, but some drugs will cause partial or complete hair loss. The amount of hair loss will depend on the drug, the dose and your reaction to the drug and usually begins within two or three weeks of your first treatment. As your hair begins to fall out, you may feel tenderness in your scalp around the hair follicles.

Hair loss can be upsetting – don't be afraid to discuss your feelings with the nurse.

We can provide you with a wig prescription and you may then choose a wig up to the value of £150 from one of our approved wig suppliers, who will help you choose a wig. This can be an emotional time as you are forced to face up to the reality of losing your hair. The wig specialists will understand your feelings and will do all they can to make you feel comfortable and at ease during your fitting.

- You may find it helpful to cut long hair, if you have been advised that you will lose it. This will reduce the weight of the hair on the scalp
- Avoid using perms or chemical dyes
- Use gentle shampoo designed for frequent use
- Let your hair dry naturally; don't use heated appliances
- Apply a hairnet at night to catch any hair that rubs off you
 can dispose of this the next morning



Macmillan Cancer Care have a booklet about coping with hair loss, which may be useful to you which is available from our Macmillan Cancer Information and Support office, based at the entrance of Clatterbridge Cancer Centre-Wirral site or from the Macmillan website.

Headstrong Service

The Headstrong service offers support, from specially trained volunteers, to people experiencing hair loss through cancer treatment.

At a Headstrong appointment you will be able to:

- Try on a range of hats, scarves and hairpieces
- Learn how to tie scarves in a variety of styles

Headstrong will offer you an individual appointment in a comfortable, relaxing and confidential setting. To arrange an appointment, please contact **0151 556 5570**.

Please ask one of the nurses for a copy of the 'Headstrong Service' leaflet for more information.



Effects on your skin

Some chemotherapy drugs may affect your skin, causing it to become dry and itchy, or your skin may become sensitive to the sun. Sometimes, the skin may develop dark patches, especially over the veins used for chemotherapy. This is temporary and it will gradually fade when your treatment is complete.

Your nails may discolour or white ridges may appear for a time and your nails may not grow as quickly as normal.

You can help yourself in the following ways:

- Apply a moisturising cream to the affected area, as directed by your Healthcare professional
- Apply baby oil to wet skin after your bath or shower and pat the skin dry. This will trap moisture onto the skin. Don't put oil directly into the bath, as it makes it too slippery
- Use a high-factor sun-cream (SPF 50 or more) or a sun block when in the sun. Wear a cap or scarf, if you have hair loss

Effects on your fertility

Not all chemotherapy drugs will make you infertile. Infertility may be temporary or permanent, depending on the drugs and the duration of the treatment. If fertility is important to you, please discuss it with your doctor before you start treatment.

Women

Some drugs may affect your ovaries and stop production of eggs. This will make you infertile and may bring on symptoms similar



to the menopause, such as irregular periods or your periods may stop, hot flushes and dryness of your skin and vagina. Your doctor may be able to prescribe hormone tablets for you, to help reduce these symptoms. The hormones will not make you fertile again.

It is important to try and avoid becoming pregnant during treatment, as the drugs may affect your unborn baby.

There are many effective methods of contraception and you should discuss them with your partner and, if necessary, your nurse or doctor.

If you are pregnant before your treatment starts, please tell your doctor. It may be possible to delay the treatment until the baby is born. This will depend on the stage of your pregnancy, your cancer and the type of drugs you will receive. If you become pregnant during your treatment, please tell your doctor as soon as you know. We want to make sure that you understand all the options before you make any decisions.

If infertility is temporary, your periods may return to normal shortly after your treatment is complete. This happens in about a third of patients.

Fertility preservation

The Liverpool Women's Hospital offers a fertility preservation service that you can be referred to by your doctor, if you wish. They are able to preserve the fertility of women who are likely to be rendered infertile due to medical treatment for other conditions. It may be possible to harvest and store eggs for future

use, and for women in a stable relationship, they can harvest eggs, fertilise them to make embryos and then store the embryos.

Men

Chemotherapy may reduce the number or quality of the sperm you produce, which will affect your ability to father children. If you are likely to want children in the future, it may be possible for you to bank your sperm. You can retrieve the sperm when you and your partner wish to have a baby, this does not guarantee that your partner will conceive. It is best that you and your partner, if you wish, discuss this with your doctor or nurse.

How you feel

We realise that many people feel that the chemotherapy may also mean they can no longer have children. For some people, this feeling can be one of great sadness and loss. The sense of loss may be acute in people of all ages, even people who did not have any plans for children.

You may feel that your role in the family is changing and that you have lost some of your femininity or masculinity or that your self-esteem is low.

Everybody reacts in different ways – there is no right or wrong way. It is important that you are able to discuss with your doctor or nurse how you feel.



Sex and chemotherapy

There is no medical reason why you cannot continue with a sexual relationship. However, you may find that some of the side effects such as tiredness, hair loss and feeling sick make you feel less attractive to your partner. You may also feel angry, anxious or depressed.

Sexuality is much more than the act of intercourse. It is about your whole relationship with your partner. Many couples discover that talking about feelings and worries brings them closer together and helps them to cope better. If necessary, talk to your doctor or nurse about how you are feeling and/or any specific difficulties you have.

We advise that you use protection during intercourse whilst undertaking Chemotherapy. It is important to avoid becoming pregnant during treatment, as the drugs may affect your unborn baby.

Tiredness

Many patients feel very tired and this is not relieved by rest. This is normal and there are many reasons for this. Maintaining your usual activities as much as possible may help. Try to incorporate some activity, such as a short walk, into your daily routine, but do rest when you feel you need to. If you have a planned social event, take it easy for a while before and afterwards. Please telephone for advice and inform your nurse or doctor at your next hospital visit if you become much more tired than usual.

Relaxation techniques can be helpful and warm baths before bedtime are soothing and may help you to sleep. Try some lavender oil on a piece of cotton wool inside your pillowcase to aid natural sleep.

If you are waking early, try not to get agitated and cross. Make a hot drink and listen to some soothing music. Try relaxation techniques.

- Stay in bed only for the hours you intend to sleep. It is better to reduce the time you spend in bed by one or two hours, as you will sleep more deeply
- Establish a bedtime and wake time and maintain them. This can be difficult initially, but can soon settle into a reliable pattern
- Don't worry about getting enough sleep the more you worry, the less likely you are to sleep
- Avoid stimulants such as tea, coffee, alcohol and tobacco products
- Take your medication as directed
- Alcohol may help you get off to sleep, but it can disrupt the quality of your sleep and you might wake up after only one or two hours sleep
- Regular gentle exercise helps you to sleep more deeply
- Try a warm bath, for 20 minutes, two hours before bedtime.
 This is good if you can't exercise
- Ensure your bedroom is comfortable a dark, slightly cooler room is restful



What about other medicines I am taking?

You should still take any medicines that your GP prescribes for you. However, it is important to tell your doctor or nurse about them and anything else you are taking, including medicines you buy over the counter. If you are taking any blood-thinning drugs, it is very important that you tell your doctor or nurse before starting chemotherapy; you must also tell the doctor at the anti-coagulant clinic that you are on chemotherapy, as it can interfere with the way your blood clots.

What other tests may I need?

Although you may have already had certain tests before we see you, we may need to repeat them or do some new tests throughout your treatment. These are routine and the doctor or nurse will explain them to you, if necessary.

Tests may include:

- Blood tests
- Electrocardiograph (ECG) (heart tracing)
- Chest x-ray
- CT scan (Computerised Tomography)
- Ultrasound
- Bone marrow aspiration
- Bone scan
- MRI scan (Magnetic Resonance Imaging)
- Lumbar puncture
- PET scan (Positron Emission Tomography)

These tests will help the doctor decide the most appropriate treatment for you. Feel free to ask about anything.



Can I go out?

Yes. It's important that you carry on as normally as possible. However, you should avoid people who have infections such as flu, measles or chicken pox.

Can I drive?

Somebody should drive you to, and collect you after, your first chemotherapy treatment. Please ask your nurse or doctor if you can drive on subsequent cycles.

Can I still go to work?

Yes, if you feel well enough and the nature of your job enables you to continue with work. It is best to discuss this with your doctor.



Can I have a flu jab?

Yes, the flu vaccine is recommended for people who are having chemotherapy or radiotherapy, as their treatment may put them at a greater risk of getting infections.

Patients receiving chemotherapy should ideally be vaccinated at least two weeks before starting their first cycle of treatment.

It is safe to have the flu vaccination between chemotherapy courses, however it is important not to have the flu vaccination when the immune system is at its lowest. The best time is a couple of days before the next cycle of chemotherapy.

Can I go on holiday?

This depends on how you feel and the type of chemotherapy you are having. Sometimes, we can adapt treatment to fit in with holiday plans. It is very important that if you do go on holiday that you have the appropriate level of medical insurance. Please ask your doctor in good time, if you want to alter your treatment date.

Vaccinations

If you are planning to go on holiday, you must not have any 'live virus' vaccines while you are having chemotherapy. These include polio, measles, rubella, MMR, BCG and yellow fever. Vaccines that you can have include whooping cough, diphtheria, tetanus, flu, pneumonia, hepatitis B, rabies, cholera, typhoid and anthrax. If you have any questions, ask your doctor or nurse straight away.

Travel insurance

If you are planning to go on holiday, you may find there are exclusions on normal travel insurance policies because of your cancer and cancer treatment. We have a list of insurance companies that offer travel insurance after individual assessment. Please ask in the Macmillan Cancer Information & Support Centre.

Can I drink and smoke?

It's best to discuss this with your doctor. Generally, small amounts of alcohol are safe, but best avoided for the first 48 hours after treatment. We advise you not to smoke, but we cannot stop you. We have a smoking cessation service available if you would like help to stop smoking, please ask your nurse or doctor for details.

What if the chemotherapy does not work?

If the drugs don't seem to be working, the doctor may want to change the drug or combination of drugs, but we will discuss your treatment options with you first.

Stress and anxiety

It is common to feel stressed or anxious when you have cancer. Anxiety can be a vague or uneasy feeling of distress. Many times, feelings of anxiety can seem overwhelming. Small, trivial matters that normally would not bother you grow out of all proportion. Having your normal routine disrupted can make you feel resentful and frustrated. You may feel you are no longer in



control. Everyone has different fears and feelings. Depression can sometimes occur as the drugs start to work on the cancer.

As you are trying to come to terms with what is happening, it may seem like you are facing a never-ending prospect of hospitals and illness. However, try to remember that any side effects from your treatment will gradually wear off when your treatment is complete.

Side effects, especially hair loss and tiredness, can make you feel sad about your personal appearance. Often, because it takes time for the cancer to respond to the drug, you may begin to feel discouraged and depressed.

You may also find that you cannot concentrate for long, or that you forget things easily. This won't last. Writing things down may be helpful. Many patients feel afraid because they do not know what will happen in the future. Some people don't understand what is happening to their bodies and may be afraid of the effects of the cancer or treatment.

Some people may benefit from further support or specific treatments such as self-help, counselling or medication. We have two consultants in psychological medicine who can advise on psychological and drug treatments. For further information, please talk to your nurse, doctor or therapy radiographer.

You may feel particularly anxious and worried when your treatment ends, unsure of what lies ahead. You may find it helpful to talk about this to your doctor or nurse.

How you can help yourself:

Once you can identify why you feel the way you do, you can start to be positive. Knowledge can be an answer to fear. Fear of the unknown generates more fear and anxiety, so if there is anything that you don't understand or don't know, ask.

If the answer or the explanation is not clear, ask again and keep asking until you have an answer you can understand. No one will mind you asking questions, big or small. If something is important to you, it is important to us. Writing down your thoughts may help you to clarify any questions that you may have for your doctor or nurse. This will also help you to remember to ask them!

It is sometimes difficult at the beginning of a course of chemotherapy to see the end and often you will wonder how you are going to get through it all.

Some patients find it helpful to keep a diary of their thoughts and feelings. This makes it easier to recall how they felt during the low periods and to see how they came through.

Some patients report that loss of control is a concern. To help you overcome this, you may like to look into ways that put you back into control. Learning relaxation techniques or meditation may be helpful. Try to plan your day so that you can still do the things you want. Try not to let chemotherapy interfere too much with your social life. Be aware of your limits and don't push yourself too hard.

Take some gentle exercise to get rid of tension. It is best, however, to check with your doctor before starting any new exercise regimes.



What happens when my treatment is complete?

Many people are relieved when the treatment is complete but also feel afraid and vulnerable and that the support systems are no longer available. Support is always available. It can be difficult re-adjusting, but remember your GP, community nurses and Macmillan nurses are there to help you.

You will have follow-up appointments after any treatment has ended, outpatient clinics are held from Monday to Friday and are usually very busy. All clinics have a consultant-led team of doctors and trained nurses.

Useful contacts

Macmillan Cancer Information & Support Centres

Clatterbridge Cancer Centre - Wirral Tel: 0151 556 5570
Clatterbridge Cancer Centre - Liverpool Tel: 0151 556 5959

Maggie's Merseyside at Clatterbridge

Clatterbridge Road, Bebington, CH63 4 JY

Tel: 0151 334 4301

Macmillan Cancer Support

89 Albert Embankment, London, SE1 7UQ,

Tel: 0800 808 00 00 www.macmillan.org.uk

How we produce our information

All of our leaflets are produced by staff at The Clatterbridge Cancer Centre and this information is not sponsored or influenced in any way. Every effort is made to ensure that the information included in this leaflet is accurate and complete and we hope that it will add to any professional advice you have had. All our leaflets are evidence based where appropriate and they are regularly reviewed and updated. If you are concerned about your health in any way, you should consult your healthcare team.

We rely on a number of sources to gather evidence for our information. All of our information is in line with accepted national or international guidelines where possible. Where no guidelines exist, we rely on other reliable sources such as systematic reviews, published clinical trials data or a consensus review of experts. We also use medical textbooks, journals and government publications.

References for this leaflet can be obtained by telephoning 0151 556 5570.

If you need this leaflet in large print, Braille, audio or different language, please call 0151 556 5570.

If you have a comment, concern, compliment or complaint, please call 0151 556 5203.

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