

Systemic anti-cancer therapy in the Edinburgh Cancer Centre

A guide for patients and their carers

The type(s) of Treatment(s) I'm receiving:

CYTOTOXIC CHEMOTHERAPY

TARGETED THERAPY
IMMUNOTHERAPY

About

The aim of this booklet is to help you understand what to expect before, during and after your systemic anti-cancer therapy. We hope that it will give you some helpful information that will be useful during your treatment.

Key

The key will allow you to quickly see things that are most important from the section. This will also refer you to external documents which may be of use. The key will give you useful tips from what other patients found worked for them.



Important and key information

Information in **blue** is relevant to everyone reading this booklet

Information in **green** refers to cytotoxic chemotherapy Information in **yellow** refers to targeted therapy Information in **orange** refers to immunotherapy

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Introduction

What is systemic anti-cancer therapy?

In this booklet systemic anti-cancer therapy is used to describe drugs which fight cancer. There are different groups of anti-cancer drugs, but the main group is cytotoxic chemotherapy drugs, commonly referred to as chemotherapy. Newer anti-cancer drugs called targeted agents, and immunotherapies are also now frequently used, and all will be discussed in this booklet. Your doctor will tell you if your drug treatment is a cytotoxic chemotherapy, a targeted therapy, an immunotherapy, or a combination of these treatments.

How do systemic anti-cancer therapies work?

The different therapies work in different ways.

Cytotoxic chemotherapy

Cytotoxic means toxic to cells. Cytotoxic chemotherapy works by stopping or slowing the growth of cells and causing cancer cells to die. It affects the growth of all cells in your body, but particularly damages those cells that grow more quickly like cancer cells.

Targeted therapy

Targeted therapies are drug treatments that interfere with specific features of cancer cells which allow them to grow and spread, although healthy cells can still be affected by these drugs. Targeted therapies work to;

 Stop chemical signals that tell the cancer cell to grow and multiply

- Stop the growth of new blood vessels which may feed the cancer cells
- Change proteins inside the cancer cell so the cell dies or grows more slowly.

Immunotherapy

Immunotherapy is a drug treatment that uses a person's immune system to fight cancer. The immune system normally protects the body by fighting off abnormal cells like infections or cancer cells. Unfortunately, cancer cells can hide from the immune system. Immunotherapy drugs work to expose cancer cells so that the immune system may detect and attack the cancer.

When is Systemic anti-cancer therapy used?

Systemic anti-cancer therapy can be used in the following ways:

- Neo-adjuvant treatment this is when drug treatment is given before surgery or radiotherapy to try to shrink the tumour
- Adjuvant treatment this is when drug treatment is given after surgery or radiotherapy when there are no visible signs of cancer. It aims to reduce the risk of cancer coming back in the future
- Combination treatment with radiotherapy this is when drug treatment is given at the same time as radiotherapy
- Curative treatment this is when drugs are given to try and completely eradicate or 'cure' the cancer
- Palliative treatment this is when drug treatment is given to shrink the cancer, slow its growth or reduce the rate of

spread. It may also help reduce any symptoms caused by the cancer.

How is systemic anti-cancer therapy given?

Drug treatment can be given in different ways, depending on the type of cancer you have, and the drugs used. The most common ways to get systemic anti-cancer therapy are:

- IV or intravenously into a vein through a small plastic tube called a cannula
- Subcutaneous an injection under the skin
- Orally in the form of tablets or capsules.

You will find information about your treatment and how it is given in the information sheets given to you by your doctor or nurse specialist.

Where is systemic therapy given?

Where you receive your drug treatment will depend on the treatment you need. Most drug treatments can be given as an out-patient but for some you will need to come into hospital and stay for a few days. Your doctor will tell you where you will need to come for your anti-cancer treatment.

What if I change my mind about anti-cancer treatment after I have signed consent?

We understand that this can be a very difficult time for you and you may have further questions or change your mind. Please phone to talk to your oncologist or clinical nurse specialist (numbers are on page 59). They will be happy to talk things

over again and will want to make the best plan for you as an individual. Even after you have started treatment you may stop treatment at any time. Please phone to discuss this with your oncologist.

Clinical trials/Research

Trials and research are the best way to develop new anticancer therapies and to further our knowledge of cancer and its treatments. At any time in your treatment or follow up you may be offered to take part in a clinical trial. When speaking with your oncologist please take the opportunity to ask about potential clinical trials and cancer research available for you, if this is something you are interested in. Some trials may involve testing a novel or new treatment and some trials give an existing and well-known cancer therapy in a different way. In addition to this type of research you may also be asked if you would like to donate blood or tumour tissue in order to collect clinical data.

If you decide to participate in a clinical trial or research study, you will normally be contacted by one of our clinical research nurses. Clinical trials generally involve routine appointments but may require a commitment to having additional tests for example, extra blood sampling and ECG's or extra visits. These additional requirements help provide more data on the treatment or regime being evaluated. It is important to note, that not all patients can enrol into a clinical trial for a variety of reasons and if you are offered a trial and decide not to take part, this will not affect your care and choices going forward.

Planning your treatment

Attending for oncology systemic anti-cancer therapy as an OUT-PATIENT in Edinburgh

Your consultant will have referred you to start your drug treatment. The appointment system for booking your treatment is quite complicated. It needs to have a doctor, nurse, and several pharmacy staff available to organise your drug treatment. Because of this it can take several days to arrange your appointment. Once an appointment has been made for you, a member of staff will phone you with the time and date. It is very important that we have reliable contact telephone numbers for you. These can be your landline and mobile numbers. If you have an answering machine or voicemail which clearly confirms your identity we will leave a message. If you do not hear from us within 10 working days after your clinic appointment, please phone us. You will find contact details at the back of this booklet.

The length of your appointment depends on the type of treatment that you are having. Treatments that take longer are given morning appointments. Treatments that are shorter are often given afternoon appointments. It is helpful if you can accept the first appointment that we offer you.

Your first visit

If this is the first time you have had systemic anti-cancer therapy, you may be offered a group meeting to go over what to expect and answer any questions you may have prior to your first visit. We recommend that you allow yourself a full day for your first visit and that you bring a friend or relative. They can stay with you for the chat we have with you before starting systemic anti-cancer therapy. After that they can use a hospital café, visit Maggie's centre or return later to collect you after you have had your treatment.

At this visit some of the things we may do are:

- Introduce you to the team who will look after you
- Check your height and weight
- Discuss your drug treatment with you and answer any questions that you may have
- Check that you are happy for the drug treatment to go ahead and that you have signed a consent form
- If you are having drug treatment given into a vein, we will have a look at the veins on your hands and forearms. If we have any concerns about your veins we will discuss this with you and may suggest ways to make it easier for you to have drug treatment
- You may have some blood samples taken
- Give you your future appointment times
- Check that you have transport to and from the hospital
- Give you 24-hour contact numbers
- Check your medication please bring an up to date list of all the tablets you currently take including over the counter and alternative remedies.

How can I prepare myself before starting my treatment?

The following is some general advice to make it easier for you to receive your drug treatment comfortably.

- Try and eat breakfast and/or lunch before you attend
- Drink plenty of fluids and keep your hands and arms warm. This 'plumps' up your veins and can make it easier to put the cannula (small plastic tube) into your vein that will be used to give your drug treatment
- Buy a thermometer to use at home. If you are unsure how to use this bring it with you to your first appointment and ask your nurse to show you how it works
- Wear comfortable, loose clothing
- To help pass the time you can bring something to read or write or listen to or watch like a music player or portable DVD with headphones.

If your condition changes or you develop any new problems between signing consent and starting your treatment, please phone your clinical nurse specialist or oncology team to let them know in case this affects the safety of your treatment.







Clean house and do laundry

Grocery shop before appointment

Prepare 1-2 meals and freeze for later

In advance







Plan how to get to the Hospital

Plan work diary beforehand

Book practice nurse appointment for bloods before your treatment, as advised

On the day







Wear warm comfy clothing

Bring books, newspaper, tablet etc

Pack healthy snack for appointment

After my first visit, can I bring anyone with me for my treatments?

Friends or relatives can drop you off but are not able to wait in the reception for you.

Can I drive myself to my treatment appointments?

We recommend, if possible, that someone drives you to and from your drug treatment appointments. On non-treatment days you can drive as normal if you feel well enough.

What will happen when I arrive at the hospital for my treatment?

This may vary slightly depending on where you receive your drug treatment but on arrival:

- You will book in at reception
- A member of the nursing team will come to meet you at reception and take you through to the clinical area where you will have your drug treatment
- You will be given a name band to wear while you are in the ward which will be used to check your identity
- To ensure your safety we do the following:
 - Your drug treatment is prescribed
 - A pharmacist checks the prescription
 - Your drug(s) is made and checked before it leaves pharmacy
 - Two nurses check your drug prescription
 - Two nurses will ask you to confirm your identity before giving you your drug treatment.

Intravenous drug treatment

- A nurse will come and put a small plastic tube called a cannula, into a vein in your hand or forearm. You will be connected to a drip to flush your vein before you have your drug treatment
- To help reduce any side effects of your drug treatment you may be given medicines either as tablets or through the drip
- Approximately 30-60 minutes later you will be given your drug treatment. Your nurse will tell you how long this will take
- Please tell your nurse if you notice pain, swelling or wetness around the drip site at any time
- Once the treatment has been given the cannula will be removed from your hand and a plaster will be put on your hand
- Your nurse will tell you about any tablets that you need to take home with you and explain how and when to take them.

Receiving drug treatment through a vein

This section gives you specific advice on how you can help to ensure that your systemic anti-cancer therapy is given safely into your vein. Sometimes problems can happen with the drip and drugs can leak into the skin and other tissues around the injection site. This is particularly a concern for **cytotoxic chemotherapy**. The surrounding tissue can become sore or inflamed and serious damage can occur occasionally. Our nurses are fully trained to try and prevent this and know what to do if this does happen.

However, there are several things you can do to help us reduce this risk:

- Position anything you might need during your drug treatment (for example tissues, drinks or a book) next to your free hand before your treatment starts
- Keep the skin around the drip visible at all times. It is helpful to wear short sleeves or sleeves that can be rolled up easily
- Sometimes, it can take more than one attempt to place a drip. If your nurse is concerned about the drip, they will start again in another area. Although this can be frustrating, it is done for your safety
- Intravenous drugs are given through a pump that is connected to the drip by a narrow plastic tube. It is important that the tubing is secure and easily visible, so it does not get tugged by accident. If it does get tugged let your nurse know straight away so that they can check it
- Try to move your hand or arm with the drip in as little as possible during your drug treatment
- Tell your nurse straight away if you develop any discomfort, pain or itch around the drip
- We recommend that you do not leave the ward whilst receiving your drug treatment
- Check your drip site a few hours after your drug treatment has finished and daily for the next few days
- Contact the Cancer Treatment Helpline on 0800 917 7711
 if the injection site becomes red, hot, swollen, uncomfortable
 or tender. Sometimes tissue damage only becomes noticeable
 hours or days after your drug treatment has finished
- You will have the opportunity to discuss this with your nurse and if you have any questions or concerns please do not hesitate to ask.

Oral drug treatments

Two nurses will check your identity before giving you your tablets. Your nurse will explain how and when to take these. If needed, you will be told how and when to take any other tablets such as anti-sickness tablets.

If you are being treated with an oral systemic anti-cancer therapy, this is usually prescribed with your doctor in the clinic. You will then pick up the drug from the pharmacy and will be told how and when to take the drug treatment, as well as any other tablets that are prescribed.

Can children come to the ward to visit me?

No. Children under the age of 12 should not be brought into the treatment area.

Attending for oncology cytotoxic chemotherapy as an IN-PATIENT in Edinburgh

Your consultant will have referred you to start your drug treatment. If you are to have in-patient oncology **chemotherapy** in Edinburgh, you will usually come to Ward 3 /Teenage Young Adult Cancer Unit (TYACU) at the Edinburgh Cancer Centre.

The appointment system for booking your treatment is quite complicated as we need to have a doctor, nurse, several pharmacy staff, bed manager and, in some cases, radiotherapy staff to organise your drug treatment. Because of this, it can take several days to arrange your appointment. Once an appointment has been made for you, a letter will be sent to your home. Sometimes we may telephone you to let you know when to come. It is very important that we have reliable contact telephone numbers for you. These can be your landline and mobile numbers. If you have an answering machine or

voicemail which clearly confirms your identity we will leave a message. If you have not heard from us within 10 working days after your clinic appointment, please use the telephone numbers at the back of this booklet to contact your oncology team.

- Please bring all the medicines that you are taking with you
- Bring loose and comfortable clothing and avoid tight clothes
- When you come to Ward 3, please introduce yourself at the nurses station. They will take you along to the SACT delivery room
- If you are having radiotherapy at the same time as your chemotherapy, please come to Ward 3 first. The nurses will then organise your drug treatment for that day.

Length of each in-patient visit

The time that you will need to be in hospital depends on the type of drug treatment that you are having. Patients may stay in hospital overnight or up to 7 days.

Can I bring anyone with me for my first appointment?

Due to numbers of patients attending for treatment we are unable to accommodate any family or friends attending with you on your admission. They may walk you to the ward and then return during visiting hours of 2pm-8pm.

During visiting hours we would ask that only a maximum of 2 visitors per patient.

Some things we may do on your arrival are:

- Introduce you to the team who will look after you
- Take some blood samples
- Check your height and weight
- Have a look at the veins on your hands and forearms if you are going to have chemotherapy given into a vein
- A cannula, a small plastic tube, will be put into a vein in your hand or forearm. If your drug treatment lasts for more than 3 days, the cannula will usually be changed on the third day. This is to reduce the risk of any infection. If we have any concerns about your veins we will discuss this with you and possibly suggest ways to make it easier for you to have treatment
- Check we have all the information we need to look after you during your stay
- Discuss your drug treatment with you and answer any questions that you may have
- Check that you are happy for the drug treatment to go ahead and that you have signed a consent form.

Please note: It can take several hours to make all the arrangements for your treatment. This includes waiting for blood results, making sure that you are fit enough to have drug treatment and getting your treatment ready.

- It is likely that you will start your treatment in a chair in the SACT delivery room on Ward 3 while we get your bed ready
- Once a bed is ready for you, you will be shown to your room and bed. To help pass the time you can bring something to read, write, listen to, or watch like a music player or portable DVD with headphones. Wi-Fi is available.

During your hospital stay

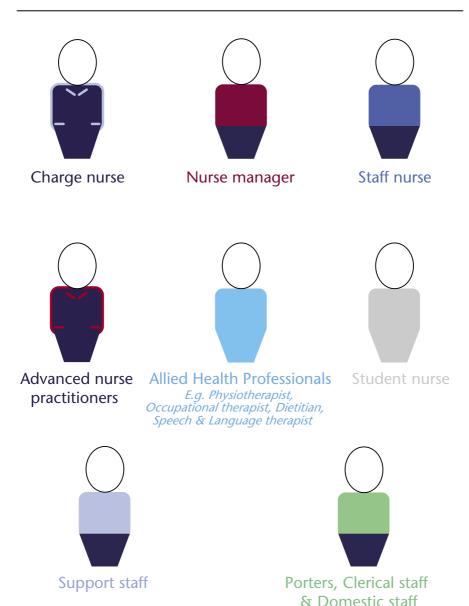
- The nurses will introduce you to the team and show you around the ward
- You don't need to change into nightwear whilst an inpatient on the ward
- Once we have connected your drip to your chemotherapy, you may not be able to be disconnected until your drug treatment is finished. During this time the nurses can help you change into clean tops when you wish to do so. For your comfort and safety, we recommend you wear loose clothing
- You can walk around the ward while you are having your treatment but please be careful not to disconnect yourself from it
- After a walk please remember to always plug the infusion pump into the socket when you go back to bed. This makes sure the battery stays charged and the pump works
- Please tell your nurse if you notice pain, swelling or wetness around the drip site at any time.

Other information that may be helpful during your stay

- You can use mobile phones and laptops on the ward, but it is your responsibility to look after them. Please be considerate to your fellow patients particularly when using your mobile phone. They may not want to hear your conversation. Wi-Fi is available.
- There is a SACT delivery room on the ward
- Each bay and all side rooms have televisions
- For health and safety reasons, we cannot reheat any food.

- You may bring pre-packed cold foods which can be stored in the ward fridge
- No fresh flowers for infection control reasons
- On occasions you may be moved to a different bed or ward during your stay
- On the final day of your chemotherapy, it is likely that you
 will be asked to give up your bed for other patients coming
 into the ward, and your treatment will finish in a chair in the
 SACT delivery room on Ward 3.

Staff uniforms



Meal times

- Breakfast is approximately 8:15am
- Mid-morning tea or coffee or milk, 10:00am
- Lunch, 1:15pm
- Mid-afternoon tea or coffee or milk, 3:00pm
- Dinner, 6:15pm
- Hot drink, 8:00pm

Visiting and visiting times

- Visiting times are 2:00pm 8:00pm
- Children under the age of 12 should not be brought into the ward (or please discuss with nursing staff)

On discharge from Ward 3

- Nursing staff will give you your future appointments, discharge letters, advice about what to do after chemotherapy and your medicines. We will give you a 7-day supply of chemotherapy-related medicines such as anti-sickness drugs. Any repeat routine medications should be obtained from your GP as you have done previously
- Check that you have transport to and from the hospital
- Give you 24-hour contact numbers for the Cancer Treatment Helpline.

Before your next IN-PATIENT or OUT-PATIENT drug treatment

- You should go to your GP practice as advised by nursing staff prior to discharge before your next treatment is due to have your bloods checked. This is your responsibility to arrange with your GP practice. This ensures it is safe to give your next treatment
- We will give you a letter for your GP with a list of the tests that you need to have. We will get the results directly from your GP
- We check your kidneys and liver are working well
- We also check your full blood count which includes:
 - red cells (these carry oxygen around the body)
 - white blood cells (these fight infection)
 - platelets (these help blood to clot and control bleeding)
- Systemic anti-cancer therapies can cause the number of these cells to fall temporarily
- If the bloods you have at your GP have recovered to normal, we can order your drug treatment before you come to the ward and let you get home more quickly
- If the bloods you have had at your GP have not recovered to normal, we will contact you and may advise you to have your blood test repeated at your GP practice again. Alternatively, we may delay your treatment
- A nurse will telephone you at home before your next drug treatment. This is to find out how you have been feeling and any side effects that you may have been having
- Sometimes we may wish to make changes to your next drug treatment to make it easier for you.

Side effects

Side effects of systemic anti-cancer therapy

Different systemic anti-cancer therapy drugs cause different side effects. Everyone is individual and will react to drug treatment differently. Some people have very few side effects and others may have more. You will be carefully assessed by your nurse who will ask you about side effects before each cycle of drug treatment to make sure that we know about them. This chat and the results of your blood tests allows your nurse to know if it is safe for you to have your drug treatment. Your nurse will talk about specific side effects of your drug treatment before your treatment starts and you can also find information in the leaflets given to you by your doctor or nurse specialist. In case you have a problem whilst on drug treatment you will be given 24-hour contact details for the Cancer Treatment Helpline 0800 917 7711. We use a telephone triage system to deal with enquiries.

Before calling it is helpful if you can:

- 1 Check your temperature
- 2 Have your consultant's name available
- 3 Have the names of your drugs available

It is very important that, wherever possible, we speak directly to the patient. This allows us to give you the correct advice that you need. We will ask several questions which may seem unrelated to the reason for your call, but these allow us to make sure we give you the correct advice.

Infection

All systemic anti-cancer therapy can make it more difficult for you to fight infection, but **this is particularly a concern if you are receiving cytotoxic chemotherapy**. Because of this, what seems a minor illness can develop into a more serious or even life-threatening illness.

You must get in touch if you feel unusually hot or cold, shivery, or more unwell than you would expect at any stage in your drug treatment. It is important to check your temperature. You can buy a digital thermometer from your local chemist.

- A normal temperature is usually between 36-37°C
- If your temperature is above 37.5°C or below 36°C and you feel unwell it is **essential** you see a doctor urgently. Please be aware you can have a normal temperature and still have an infection so if you feel unwell you should see a doctor even if your temperature is normal
- If your temperature is above 37.5°C or below 36°C and you feel well, repeat your temperature an hour later and if it is still above 37.5°C or below 36°C you must call the Cancer Treatment Helpline 0800 917 7711
- If your temperature is 38C or above when you are on treatment it is important that you are admitted urgently to hospital for assessment and to check your bloods.
 - Some viral infections can be treated with anti-viral medicines to reduce their complications. If you develop symptoms of shingles or chickenpox, please contact the Cancer Treatment Helpline for advice. If you have a new positive Covid test, please call 0300 790 6769 for advice about whether you should have anti-viral treatment.

We recommend that you should have the flu and Covid vaccinations when they are offered. Depending on when they are offered, we usually advise having it before your first treatment or just before your next cycle of treatment is due to start.

What can I do to avoid infection?

- Keep clean. Always wash your hands after using the toilet and before preparing food
- While you are at the hospital please wash your hands carefully and make use of the hand rubs found throughout the ward. The rubs are useful when your hands aren't visibly dirty but could be carrying 'hidden' bugs
- Stay away from people who you know have an infection such as a cold, the flu, Covid, measles or chicken pox.
 If you haven't had chicken pox yourself and you come into contact with someone with chickenpox or shingles, please contact the ward for advice
- Wear protective gloves when gardening or cleaning up after animals.

Vaccinations

- Vaccinations can play an important part in helping you avoid infection, especially in the winter months. It is good to have vaccinations before you start chemotherapy treatment. We encourage you to speak to your GP about this as soon as possible
- You should have the flu vaccination when it is offered. We usually advise having it before your first treatment or just before your next cycle of treatment is due to start
- You should have the pneumococcal vaccine (pneumo jab) if you have not had it before and if there will be more than

- **2** weeks until you start your cancer drug treatment. If you did not have it before starting treatment, then you should wait until 3 months after finishing cancer treatment before having it
- You should not have live vaccines (including shingles, rubella, mumps, measles, BCG and yellow fever vaccines) during or for at least 6 months after systemic anti-cancer therapy or steroids. Check with your cancer doctor before having any live vaccines after finishing cancer treatments
- You should be given a letter about vaccinations for your GP.
 Please give this to your GP as soon as possible
- For patients receiving immunotherapy treatment, vaccinations during their treatment may increase the risk of immune-related side effects. If you are experiencing side effects from your immunotherapy, speak to your oncologist before having any vaccinations. In general, it is currently believed that the benefits of the vaccinations outweigh the risks for people receiving immunotherapy.

What to do if you get side effects from your drug treatment

Systemic anti-cancer therapy is often associated with side effects and your oncology doctor will have described these to you and provided you with some written information about your drug treatment. Mild side effects are usually managed at home, by taking some of the pills that were given to you along with your drug treatment (e.g. anti-sickness pills for nausea and anti-diarrhoea pills for diarrhoea). However, side effects can occasionally make you very unwell very quickly if they become severe. How these side effects are managed can be very different according to the type of treatment you are receiving. Management of side effects is discussed on the following pages.

Who to contact if you become unwell/develop side effects whilst on systemic anti-cancer therapy

- Call 999 If you have chest pain, significant bleeding or you need immediate medical attention
- Cancer Treatment Helpline on 0800 917 7711 If you
 have a temperature or shivering or flu-like symptoms while
 you are on systemic anti-cancer therapy, or for any side
 effects of drug treatment.

They will ask a series of questions and depending on the answers will give advice or organize for you to have a medical review at your nearest hospital. If you are asked to attend for medical review, you should bring with you an overnight bag and your medications in case you are required to stay in hospital. The Macmillan website has some useful tips on helping yourself with less severe side effects. This can be found online at:

http://www.macmillan.org.uk/information-and-support/treating/chemotherapy/side-effects-of-chemotherapy

Cytotoxic chemotherapy

It is extremely important that you seek urgent medical attention if you have any of the following side effects:

Severe side effects include:

- High temperature (37.5°C or more), shivering or flu-like symptoms, or a low temperature (35.9°C or less)
- Diarrhoea, 6 or more times more than your usual or if during the night, or associated with tummy cramps
- Vomiting that is reducing the amount of fluids that you can keep down

- Mouth ulcers that are making it difficult for you to eat or drink
- Bruising or bleeding easily. Bleeding that does not stop after
 20 minutes or is more than a cup full
- Concentrated urine or noticeably passing less urine that may suggest dehydration
- Anything else that makes you feel unusually unwell.

Your doctor may feel that you need to be admitted to hospital for intravenous fluids, a drip, or antibiotics for a few days until you feel better again. It is important that this happens as soon as you become unwell, as delays in getting help can make you very unwell. Remember to explain to any medical or nursing staff that you are on chemotherapy and that you should be seen urgently.

Advice about taking paracetamol with cytotoxic chemotherapy

Medicines that contain paracetamol can hide a temperature which could make it more difficult to spot an infection when you are on cytotoxic chemotherapy. Paracetamol can be taken occasionally for pain relief up to every 6 hours e.g. for headache if:

- 1. you are feeling otherwise well with no other symptoms,
- 2. your temperature is between 36°C-37.5°C
- 3. your main symptom is pain
- 4. you are not taking any other medicines that contain paracetamol (paracetamol can be present in branded products such as Anadin®, Beechams®, Boots Cold and Flu®, Lemsip®, Panadol®, Solpadeine®. If in any doubt, check with your local pharmacist).

You can take up to 4 doses of paracetamol in 24 hours. Do not take paracetamol for more than 24 hours without phoning the **Cancer Treatment Helpline** for advice unless you have discussed this with your cancer team.

Please phone the Cancer Treatment Helpline if:

- you feel less well
- you develop any new symptoms
- you have had to take 4 doses of Paracetamol in 24 hours and still have pain.

Targeted Therapies

Targeted therapies cover a wide range of drugs, which can work in very different ways and have very different side effects as a result.

Some of these will be picked up by routine tests you have throughout your drug treatment, others may make you feel unwell and require more urgent intervention. For some targeted therapies you will receive specific advice from your doctor about how to manage common side effects such as diarrhoea or a skin rash. Otherwise, you should follow advice above for chemotherapy. If you are unsure, it is better to call the cancer treatment helpline to discuss any potential side effects you have developed during your drug treatment.

Immunotherapies

Immunotherapy may be associated with potentially severe side effects and your oncology doctor will have described these to you and provided some written information about your individual drug treatment.

Side effects of immunotherapy may happen during treatment, but importantly they can sometimes start weeks or months after finishing treatment. Immunotherapy may cause the immune system to attack normal cells in any part of the body, resulting in inflammation. This can sometimes cause severe side effects or blood abnormalities which require urgent medical attention. You may require admission to hospital. Do not try to treat side effects on your own and always follow the advice given to you by your oncology doctor or nurse.

As these drug treatments are still relatively new, not all doctors will be familiar with the drugs, or their side effects. If you seek help with a medical problem, remember to explain to the healthcare professionals that you have been treated with immunotherapy. Remind them that urgent review may be required, even months after your treatment. Show them your immunotherapy card. Your oncology team would always be happy to be contacted to discuss your management.

General Advice

What to do if you develop side effects of your drug treatment.

Symptom	General Advice
Chest pains	 Call 999 urgently STOP taking any anti-cancer treatment until an oncology or haematology doctor has said you can You will be directed to the most appropriate hospital for further tests and treatment
Bleeding	 Call Cancer Treatment Helpline 0800 917 7711 if mild bleeding you are able to control yourself If moderate or severe bleeding, call 999 urgently You will be directed to the most appropriate hospital for further tests and treatment
Temperature above 37.5°C or below 36°C	Phone the Cancer Treatment Helpline 0800 917 7711
Generally unwell	Phone the Cancer Treatment Helpline 0800 917 7711
More than one symptom	Phone the Cancer Treatment Helpline 0800 917 7711

Symptom	General Advice	Phone the Cancer Treatment Helpline 0800 917 7711 if;
Breathless- ness		You are more breathless than usual when you exert yourself
Cough		You develop a new persistent cough, or an existing cough suddenly worsens
Fatigue (Tiredness)	 It is normal to feel a bit fatigued during cancer treatment Try to continue what you normally do but take frequent rests if you need them You may need to accept help with the things that make you tired It may be helpful to keep a diary of when the good and bad days are which will help you plan what you can do during future treatment cycles 	 You are suddenly much more tired than normal for you, and are now spending most of the day in your bed, sitting in a chair or lying on the sofa You are suddenly unable to manage washing, dressing, getting around your home

Symptom	General Advice	Phone the Cancer Treatment Helpline 0800 917 7711 if;
Bowels moving more frequently or becoming looser. Some drug treatments such as capecitabine, irinotecan or erlotinib have specific advice to follow. Please refer to the information sheet given to you with your drug treatment if you are having one of these drugs.	 Make sure you drink plenty of fluids (2-3 litres per day) Try to avoid caffeinated or alcoholic drinks Stop taking any laxatives you have previously been given Try eating bananas, rice, noodles, white bread, skinned chicken, and white fish Avoid milk, high-fat foods, raw fruit and vegetables, beans, fibrous vegetables, and cereals Ensure the skin around the back passage is kept clean with regular washing and use of a barrier cream on the skin Contact your local oncologist or specialist nurse for advice about managing your diarrhoea. They may suggest using loperamide for a short time or that you may need to be seen at the hospital 	 Your diarrhoea is getting worse despite these suggestions Your bowels are moving an extra 3 times in a day compared to what is normal for you (or your stoma output is much greater than normal) You are getting frequent, uncomfortable tummy cramps You are struggling to get to the toilet in time Your bowels are opening lots of times overnight You are also being sick You notice blood in your stools You feel dehydrated or are passing less urine than normal You are having immunotherapy

Symptom	General Advice	Phone the Cancer Treatment Helpline 0800 917 7711 if;
Constipation	 Make sure you are drinking plenty of fluids Ensure you have plenty of fibre in your diet – such as cereals, wholemeal foods and plenty of fruit and vegetable If you have been advised to follow a low fibre diet, stay on this Contact your local pharmacist or GP for advice about medicines that you can buy or be prescribed like Macrogol 3350 sachets or Senna tablets 	 You have not had a bowel movement for more than 2 days longer than is normal for you You are getting tummy pains, frequent cramping or nausea and vomiting Your tummy is swollen
Urinary problems		 New pain passing urine New hurrying to get to the toilet or passing urine much more often Passing much less urine than normal or urine very dark/concentrated
Infection		If you have symptoms of an infection, even if your temperature is normal

Symptom	General Advice	Phone the Cancer Treatment Helpline 0800 917 7711 if;
Nausea and vomiting	 Make sure you are taking your prescribed anti-sickness medicines regularly Try sipping small amounts of liquids as often as you can manage them Try ice-lollies/ice-pops Try taking one of your anti-sickness tablets about one hour before you are due to have something to eat Eat a little and often Ginger biscuits or foods containing ginger can often help with nausea 	 You are being sick more than twice a day You are unable to keep your anti-sickness medications down The amount of fluid you are able to drink and keep down is significantly less than usual

Symptom	General Advice	Phone the Cancer Treatment Helpline 0800 917 7711 if;
Heartburn/indigestion Burning sensation up and down the chest or upper abdomen (tummy), often between meals	 Drink plenty of fluids including water or milk between meals Eat more frequent, smaller meals and avoid eating just before bed Avoid citrus fruits e.g. oranges and tomatoes Avoid spicy foods and alcohol If you are taking steroids (e.g. dexamethasone) or anti-inflammatory medicines (e.g. ibuprofen, diclofenac) take these with something to eat Contact your local pharmacist for advice about managing your symptoms. They may recommend trying something like Gaviscon after meals If these symptoms don't improve then contact your GP who might prescribe a drug to reduce the acid in your stomach 	 You have pain across your chest or into your jaw or arm, or are also breathless or sweating – call 999 Your pain is worse with exercise You have severe pain in your upper abdomen (tummy) You are also being sick Your bowel movements (stool) is black and sticky

Symptom	General Advice	Phone the Cancer Treatment Helpline 0800 917 7711 if;
Mouth ulcers/pains	 Use a soft small-headed toothbrush after eating to clean your teeth, rinse your mouth after meals and keep your mouth and lips clean and moist Make sure you drink plenty and try to eat 'soft' foods Try sodium bicarbonate mouthwash (1 teaspoon dissolved in 1 pint of warm water). Use it as a mouthwash 4-6 times a day Contact your local pharmacist for advice about mouthwashes Avoid mouthwashes Avoid mouthwashes containing chlorhexidine (such as Corsodyl) See advice about taking paracetamol on page 27 	 You have a painful mouth, lips or gums and are finding it difficult to eat and drink You have visible blisters on your lips
Weight loss		If you have lost a significant amount of weight without trying because you can't eat

Symptom	General Advice	Phone the Cancer Treatment Helpline 0800 917 7711 if;
Pain	 Monitor your temperature if it is above 37.5°C or below 36.0°C then call the Cancer Treatment Helpline Take as much rest as possible through the day Use a heat pad or take a hot bath to ease joint pains Contact your local pharmacist for advice about medicines that you can buy to help manage your pain. These may include gels/creams containing painkillers to apply to areas that are sore See advice about taking paracetamol on page 27 	 If you have new severe pains stopping you from doing day-to-day things such as washing, dressing, getting about the house You also have a temperature above 37.5°C or below 36.0°C
New weakness	 Feeling generally a bit weaker or more tired is common during cancer treatment It can sometimes be due to a complication of the cancer itself New weakness could also represent a rare side effect of immunotherapy 	 You develop a new weakness of any part of your body over a short period of time during your treatment You develop a weakness that is localised to only one part of your body You are being treated with immunotherapy

Symptom	General Advice	Phone the Cancer Treatment Helpline 0800 917 7711 if;
New numbness or altered sensation	 Numbness or tingling of the tips of your fingers or toes is common with some chemotherapy drugs including oxaliplatin, docetaxel, paclitaxel, vincristine and may improve in the days following your treatment 	You develop new numbness or altered sensation in any part of your body and were not told to expect this with your treatment
Confusion		New confusion or sleepiness
Rash - spotty or blotchy skin	Follow any advice that you have been given by your cancer team about managing rashes caused by your cancer treatment, including radiotherapy	 You have swollen lips or tongue You are breathless Your skin looks red, hot, or fiery You also feel generally unwell You have not been told to expect a rash with your drug treatment
Bruising		 Multiple sites of bruising not explained by blood tests or cannula insertions One very large site
Eye problems, visual disturbance		 Your eyes become painful Your eyesight is deteriorating, becomes blurry or cloudy Your eyes become red

Symptom	General Advice	Phone the Cancer Treatment Helpline 0800 917 7711 if;		
Skin changes - dry flaky skin on body - red, dry, flaking skin or swelling affecting hands or feet	 Use unperfumed moisturising cream such as E45®, Hydromol® cream or Oilatum®, Zerobase® and Dermol® Pat your skin dry with a soft towel after washing Contact your local pharmacist for advice – be sure to tell them about any skin changes such as peeling, blisters or bleeding Follow any advice that you have been given by your cancer team about managing rashes caused by your cancer treatment, including radiotherapy 	 You develop more severe skin changes (e.g. blisters, bleeding, 'puffy' appearances) Your skin is painful You have a rash covering most of your body You also feel generally unwell 		
Skin changes at the site of your last intravenous drug treatment		 Any pain, swelling, redness, blistering, peeling or broken skin that occurs where you last had a cannula 		

Who to contact for issues unrelated to your systemic anti-cancer therapy

Your cancer team should have given you a key contact point (nurse specialist and/or consultant secretary number) to phone for other queries about your cancer or treatment. Please leave a message with your name, date of birth and contact number if you get an answering machine. They will get back to you within one working day.

If you are acutely unwell more than 6 weeks after your last cytotoxic chemotherapy or targeted therapy, please call your GP or NHS 24 for urgent advice.



If you are unwell more than 6 weeks after your last immunotherapy treatment, remember to explain to anyone assessing you that you have received immunotherapy and that there is a risk of delayed side effects.

Who to contact if you are admitted to another ward or hospital during systemic anti-cancer therapy

It is important that we are told if you are admitted to another hospital with side effects from your cancer treatments. This is essential if you are on a clinical trial.

Please ask the ward staff to get in touch with the on-call oncology team at the Edinburgh Cancer Centre if you are admitted to another ward or hospital. Please also make sure you tell the team delivering your cancer drug treatment about being in hospital next time you speak to them or come for treatment.

Practical advice

Advice on safe handling and disposal of bodily waste following administration of systemic anticancer therapy

The following information describes the precautions that you and your family should take at home after you have been given systemic anti-cancer therapy. Systemic anti-cancer therapy passes out of your body in your urine, bowel movements and other bodily fluids. This may be harmful to people who come into contact with them. Buy a pair of strong household gloves to use for cleaning jobs, wash them with detergent and hot water and dry and store them only for this use. These should be disposed of in your household waste after their final use.

We recommend that you follow the advice below for **7 days** after your systemic anti-cancer therapy:

- Sit down on the toilet to pass urine
- Close the lid of the toilet when you flush it to avoid splashes and flush the toilet twice
- If splashes occur on the toilet seat, put on plastic gloves, wipe with toilet paper then wash the area with hot soapy water and dry thoroughly. Any waste that cannot be put down the toilet should be put in one disposable plastic bag then another (double bagged), tied securely and disposed of in household rubbish
- Wash your hands thoroughly with soap and hot water after each visit to the toilet
- Always wear gloves to handle any bedclothes, towels or clothes soiled with urine, stool or vomit and keep them separate from other laundry. Put them in a plastic bag to take to the washing machine and dispose of this bag in your bin after you have used it

- The contaminated laundry should be washed at the hottest wash setting on the machine and the machine should then be run again empty through its cycle. Contaminated laundry should be washed separately once before washing it with other laundry
- If linen is badly contaminated arrangements may need to be made with Environmental Services on 01506 523 636 to collect it and send it for incineration. Double bag this laundry and place it out of reach of children/pets until it can be collected
- If other people are looking after you, they should always wear plastic gloves when handling or dealing with anything contaminated with bodily waste and follow the guidance above for washing contaminated items.

Additionally, they should:

- Be careful when emptying bedpans and urinals down the toilet to avoid splashes, flush the toilet twice with the lid down and then wipe the toilet seat following the instructions above. Plastic bottles/aids should be washed in hot water and detergent and dried
- Always wash their hands meticulously after dealing with any bodily waste or towels/clothing/linen.

If you have any questions, please do not hesitate to contact your treatment nurse or doctor for advice.

Advice for patients and carers on handling and disposal of stoma and catheter bags and PleurX™ drains

Patients with stoma bags:

 Remove the stoma bag and place it into a plastic disposable bag. Place any wipes used to cleanse stoma into the same bag and tie securely (if toilet tissue paper is used this can be flushed down the toilet). Place the bag into a second plastic disposable bag and tie securely. Dispose of with household waste.

Advice for relatives/carers on how to deal with stoma bags:

- Always wear gloves
- Remove the stoma bag and place it into a plastic disposable bag. Place any wipes used to cleanse stoma into the same bag and tie securely (if toilet tissue paper is used this can be flushed down the toilet). Place the bag into a second plastic disposable bag and tie securely. Dispose of with household waste.

Patients with catheter bags:

- Empty your catheter bag into the toilet. Flush the toilet twice with the lid down. If any splashes occur, wipe with toilet paper then wash with hot soapy water and dry thoroughly
- When you are replacing your catheter bag with a new one, empty the bag into the toilet first and then double bag the used catheter bag in plastic disposable bags and dispose of with household waste.

Advice for relatives/carers on how to deal with catheter bags:

- Always wear gloves. Carefully empty the catheter bag into a dedicated container (this container should never be used for anything else) and dispose of content down the toilet
- Flush the toilet twice with the lid down and if any splashes occur, wipe with toilet paper then wash the area with hot soapy water and dry thoroughly. If any splashes occur on your skin rinse the area immediately with lukewarm water and then wash thoroughly with soap and water. Rinse the container with lots of hot water then wash the container with hot soapy water, rinse and dry thoroughly. Store the container in a safe place away from the reach of children/ pets
- When you are replacing the catheter bag with a new one, always wear gloves. Empty the bag into the toilet first and then double bag the used catheter bag in plastic disposable bags and dispose of with household waste.

ALWAYS wash your hands meticulously after dealing with any bodily waste or towels/clothing/linen.

Patients with PleurX[™] drains

- There is a risk the fluid coming from your pleurex catheter contains your systemic anti-cancer therapy for 7 days following your treatment
- During this period, you should arrange for Environmental Services to collect and dispose of your drain bottles – 01506 523 636.

Frequently asked questions



Will I be able to carry on working while I'm on systemic anti-cancer therapy?

Some people work throughout their drug treatment. Others prefer to take time off or may be advised to take time off based on what they do. You should discuss this with your nurse or consultant.

Systemic anti-cancer therapy side effects can build up with each cycle. You should tell your employer as soon as possible that you will be on drug treatment for your cancer and that this will mean that you will need to take time off to come for appointments and that you may need time off without warning if you are feeling unwell. You and your employer can then decide what works best for both of you.



If I can't work, is there any financial support that I can get?

You may be able to get financial assistance while you are unable to work. Please speak to your nurse if you have any worries about money. Macmillan Cancer Support and Maggie's Centre also offer financial advice. Their contact details are at the back of this booklet.



Will I lose my hair when I'm on systemic anti-cancer therapy?

This will depend on the systemic anti-cancer therapy drugs that you are on. You will be told before you start drug treatment if you are likely to lose your hair so that you can prepare for this. Your hair will grow back once you have finished your treatment, but it may be a different colour or texture. Your nurse will be able to offer you help and advice on how to care

for your hair and scalp when you are on drug treatment.

We may be able to offer you a treatment called 'scalp cooling' that might help to prevent or reduce hair loss. However, this can only be offered to patients on certain drug treatment regimes. If you would like to learn more about this or find out if this would be of use to you, please speak to your doctor or nurse about this.



Can I go on holiday when I'm on systemic anti-cancer therapy?

We strongly advise against travelling abroad. If you have already booked a holiday, please discuss this with your doctor or nurse as soon as possible. It is also best to wait for at least a month after your last drug treatment before planning a holiday.

You will also need to make sure that you have travel insurance before going abroad. Both Macmillan Cancer Support and Maggie's Centre have up-to-date specialist travel insurance information. Their contact details are at the back of this booklet.



When I'm on systemic anti-cancer therapy do I need to stay out of the sun?

You should protect yourself from the sun. Many systemic anticancer therapies make your skin much more sensitive and you can get sunburnt more quickly than before. Things you can do to protect yourself from the sun are:

Use sunscreen when you go outside in the sun. Choose a sunscreen that protects you from both UV-A and UV-B rays. Use SPF (sun protection factor) of at least 50 which will absorb about 97% of the sun's burning rays. No sunscreen or SPF will completely protect you from the sun. Apply

plenty of sunscreen to every part of your body exposed to the sun. Don't forget your ears, feet, behind your neck and the top of your head if you have hair loss. Your skin can take up to 30 minutes to absorb sunscreens so be sure to put it on about 30 minutes before you go outside

- Wear protective clothing and accessories, such as widebrimmed hats and sunglasses
- Avoid outdoor activities when the sun's rays are at their strongest. If your shadow is shorter than you are, the sun's damaging rays are at their strongest and you are likely to burn
- Seek shade whenever possible.

Can I smoke when I'm on drug treatment?

It is not wise to carry on smoking. It is possible that some drugs do not work as well in people who smoke. Also, the risk of developing a second cancer if you continue to smoke while on drug treatment is higher.

- Your body will already be working hard to repair the damage from your drug treatment. If you smoke your body also has to repair the damage caused by smoking. This can make your recovery slower and increases your chance of infection. On chemotherapy your body can't fight infections as normal, and this can therefore be dangerous
- Some systemic anti-cancer therapy drugs can affect your heart and continuing to smoke puts you at higher risk of complications such as blood clots, stroke and heart attack
- NHS Lothian runs a no smoking policy which includes smoking substitutes such as non-tobacco cigarettes or e-cigarettes.

Patients who wish to use e-cigarettes while still under drug treatment in hospital will only be allowed to do so in designated areas outside the hospital buildings. Smoking is not permitted anywhere on the hospital site. Therefore, once your drip has started you will be unable to leave the building to smoke.

We suggest you contact your GP to discuss other ways to cope with the need to smoke during your treatment appointment.

The smoking cessation helpline number is:

Smokeline 0800 84 84 84

8am to 10pm – telephone support. They can also provide details of local stop smoking services.



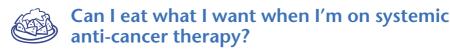
Can I continue sports when I'm on systemic anti-cancer therapy?

Exercise is good for you if you feel well enough. Your drug treatment can make you feel tired and you may find that you prefer to do gentle forms of exercise such as walking, yoga, etc. Be sure to rest when you feel tired. If you don't have a central line it is safe for you to swim in chlorinated water. It is best to avoid jacuzzis. Please speak to your nurse if you want to take part in contact sports.



Is it safe for me to be around animals when I'm on systemic anti-cancer therapy?

Yes, it is safe for you to be around healthy animals. Wash your hands after playing with or stroking animals. If possible ask someone else to change cat litter or clean animal cages etc. If this is not possible always wear gloves and wash your hands thoroughly afterwards.



It is important during drug treatment to eat if you can. But don't get upset if there are days when it is a struggle. You will be able to make up for the more difficult days between drug treatments and after your treatment has finished. Try to keep drinking plenty of fluids to flush the drugs through your kidneys. If possible try and eat a healthy, balanced diet made up of foods that you enjoy. You may find that your taste will change when you are on drug treatment and you may go off some of the foods you normally like. If you feel you are struggling to eat well speak to your nurse about this. They can give you advice on diet and, if necessary, refer you to a dietician for more information and support.

You are more prone to getting an infection following **Cytotoxic chemotherapy**. The following food safety advice has been produced by the Southeast of Scotland Cancer Network (SCAN) dieticians to help to prevent infection related to food.

Food Shopping/Storage

- Check 'use by' dates and eat food/drink within the recommended time
- Take chilled/frozen foods home quickly (within 1-2 hours).
 Store perishable foods in fridge
- Keep raw and 'ready-to-eat' food separate.

'High Risk' Foods

- Avoid the following foods: unpasteurised milk, raw meat/ raw fish/raw shellfish, raw or undercooked eggs, all soft cheeses made with unpasteurised milk (e.g. Feta), all mould ripened cheeses (e.g. Brie/Camembert) and blue veined cheeses (e.g. Danish Blue, Stilton), probiotic drinks/yogurts, pate/fish paste
- Also avoid foods that may contain raw egg e.g. homemade varieties of marzipan, royal icing, mayonnaise, hollandaise sauce, mousses, soufflés, homemade ice cream/lemon curd
- Shop bought varieties of these products are suitable, because they are pasteurised.

Food Preparation and Cooking

- Remember ALWAYS to wash hands thoroughly before preparing food
- Keep all worktops, chopping boards and utensils clean
- Use one chopping board kept solely for raw/uncooked food and use a separate one kept specifically for ready-to eat food
- Ensure food is thoroughly cooked. Frozen food should be cooked according to instructions and served piping hot
- Avoid re-heating food.



Can I drink alcohol when I'm on systemic anti-cancer therapy?

You may continue to drink alcohol in moderation, but it is best avoided for the first 48 hours after drug treatment. Both alcohol and anti-cancer drugs are broken down in your liver and this means that your liver has to work much harder.

Certain medicines can react badly with alcohol and if your drug treatment includes these we will tell you before starting.



Can I have sex when I'm on systemic anti**a** cancer therapy?

You can have sex whilst receiving systemic anti-cancer treatments, but you will need to make sure you take precautions. The following information aims to supplement any advice you receive from your doctor or nurse. If you have any questions or concerns, please ask as drug treatments and their effects will be individual to you.

All patients who are on systemic anti-cancer therapy (regardless of age) should use a barrier contraceptive (condoms) for up to 7 days following administration of a drug. The drugs can be excreted in bodily fluids and it is therefore important to protect your partner from accidental exposure to these. It is essential that contraception is used throughout systemic anti-cancer therapy, if there is any chance of pregnancy, as these drug treatments can have harmful effects on unborn babies.

What method of contraception should I use?

If you are a sexually active female of child-bearing potential whilst having cancer treatment you may still be fertile (i.e. able to conceive a baby) but your periods may become irregular or stop completely whilst on drug treatment. Systemic anticancer therapies, radiotherapy and hormonal therapies can have harmful effects on unborn babies and it is essential that you use adequate contraception throughout your cancer treatment. Please speak to your doctor or nurse about the types of contraception that would be best for you and your partner to use whilst you are on drug treatment.

 It is recommended that you do not become pregnant for at least one year after completing drug treatment for cancer.

If you are a sexually active male whose partner is of childbearing potential it is essential you use adequate contraception throughout your cancer treatment. Systemic anti-cancer therapy and radiotherapy can have harmful effects on unborn babies. Please speak to your doctor or nurse about the types of contraception that would be best for you and your partner to use whilst you are on drug treatment.

It is recommended that you do not father a child for at least one year after completing systemic anti-cancer therapy or radiotherapy.

Will systemic anti-cancer therapy affect my fertility?

Some types of chemotherapy, radiotherapy and hormone therapy can affect fertility. This may be temporary or can be permanent. Temporary effects can last for several years.

If you are a sexually active female of child-bearing potential and you want to have a child in the future, it is important that you discuss your options with your doctor or nurse before drug treatment starts. Fertility treatments aimed at helping you to be able to have a child after your drug treatment is complete can be complicated. The options available will depend on your age, whether you already have children or a partner, what type of cancer you have and how soon your drug treatment needs to start. Your doctor can refer you to a fertility specialist for further discussion of your choices.

If you are a sexually active male:

If you wish to have children in the future, it is important you discuss sperm storage with your doctor or nurse **before drug treatment starts**.

Storing sperm:

Your sperm can be frozen and stored safely for many years. The samples can be used for assisted conception techniques if you wish to father a child in the future. Storing sperm does not mean it has to be used in the future but it allows you to keep your options open. Your doctor can refer you to a fertility specialist if you wish to consider storing your sperm. As you will not know if you are producing sperm or not after you have finished your drug treatment, you can request an annual sperm count a year after your last drug treatment.

If you are currently not in a relationship or not sexually active:

Even if you are not currently in a relationship or thinking of having children at present, it is important to consider your options and discuss these with your doctor or nurse **before drug treatment starts**.



I'm on other tablets or medicines. Can I continue to take these when I'm on systemic anti-cancer therapy?

Please make sure that you let us know about any medicines you are taking for other conditions – including any you buy from the chemist. These can usually be taken as usual – but do check. We will send your GP information about the drug treatment that you are given here.



I use complementary therapies, take herbal remedies or vitamin supplements. Can I continue to use these?

Some complementary therapies have been shown to be helpful to patients with cancer. These can help how you feel and cope and will not interfere with systemic anti-cancer therapy.

They include:

- Spiritual care
- Guided imagery or visualization therapy
- Massage (rapeseed oil recommended although if also having radiotherapy no oils to be used near radiotherapy area)
- Relaxation techniques
- Yoga
- Acupuncture.

Many other approaches, however, have not been proven to be effective and may even be harmful.

Alternative biological treatments and herbal remedies

- Most claims made about herbal supplements are based on anecdotal experience or laboratory studies rather than clinical trials
- There is very little clinical evidence showing any herbal or homeopathic therapies can control or cure cancer in patients
- Many supplements are produced with minimal quality control measures. Therefore, there is no guarantee that the labelling of these products reflects their actual contents

- Some supplements interact with prescription medications, including systemic anti-cancer therapy, and may decrease its effectiveness or increase the risk of developing side effects
- We strongly recommend that you stop taking alternative herbal, Chinese and supplementary medicines, including fish oils, whilst you are receiving systemic anti-cancer therapy.

Vitamin supplements

Very little is known about the interactions between cancer treatments and nutritional supplements. A healthy balanced diet should provide all the vitamins that you need therefore vitamin supplements are not usually required. However, if you are taking vitamin supplements do not take more than the recommended daily allowance and avoid folic acid (unless prescribed by your oncology consultant) and anti-oxidants such as high dose Co-enzyme Q10 or selenium during treatment.

Can I follow an anti-cancer diet?

There has been a lot of publicity about alternative diets for treating cancer over the past few years. Many dramatic claims for cures have been made. However, there is no good evidence that these diets can make a cancer shrink, increase a person's chance of survival, or cure the disease. Cancer doctors and dieticians are concerned that many alternative diets are not suitable for most cancer patients. They may be unbalanced, lack nutrients or cause weight loss. We would recommend a balanced, healthy diet.

How will I know if the drug treatment is working?

If you are receiving drug treatment to shrink your cancer and you feel better it is likely the drugs are working, but your doctor will also monitor your response to treatment. This may include blood tests, scans, or x-rays. If your drug treatment is being given to reduce the risk of the cancer coming back after surgery, you may have scans to make sure nothing has changed during drug treatment, but there is no way of telling if the drugs have worked at the time of treatment.



What will happen to my feelings and emotions?

Sometimes you may begin to feel anxious or fed-up during your drug treatment. This can cause issues such as mood swings, feelings of loss and problems with sleeping. You are not alone. You can speak about your feelings with your doctor, nurse, counsellor, religious or spiritual leader. You can also be referred to a psychologist for support. Sometimes a doctor may suggest some medicine to help with depression or anxiety. These can be useful to help you cope with what is going on. Many patients also find their local Maggie's Centre or Macmillan Cancer Support Centre can be useful before, during or after their drug treatment and numbers can be found at back of this booklet.

Some patients feel worse after drug treatment has finished because they are no longer in regular contact with their cancer team. This is quite normal, and your Clinical Nurse Specialist or Maggie's Centre can support you at this time and give you details of support groups and programmes that help patients who have finished their treatment.

What happens when I finish my systemic anticancer therapy?

A clinic appointment will either be given to you at your last drug treatment appointment or you will be sent this by post.

If you don't receive this appointment you should contact your Consultant's secretary who will organise this for you. You will then have regular check-ups and possibly blood tests, scans or X-rays after your drug treatment has finished.

If you have any problems or notice new symptoms in between your appointments, let your doctor know as soon as possible.

Contacts

Cancer Treatment Line 24/7

Dedicated NHS 24 telephone line for patients that have received cancer treatment within the past 6 weeks.

Telephone: 0800 917 77 11

Systemic Anti-cancer Therapy (Ward 1), Western General Hospital 0131 537 1878 (Monday to Friday 8am – 4pm)

In-patient SACT Ward (Ward 3), Western General Hospital 0131 537 2217

Teenage and Young Adult Cancer Unit (Ward 3), Western General Hospital 0131 537 4085

St John's Hospital, ECC (Ward 15) 01506 522139 (Monday to Friday 8am – 4pm)

Victoria Hospital Kirkcaldy

Ward 34: 01592 729334

Ward 34 Day Unit: 01592 729343

Borders General Hospital Macmillan Centre 01896 826888

Dumfries & Galloway Royal Infirmary Oncology Day Unit 01387 241969

NHS 24 08454 242424

Contact details for support services

Macmillan Cancer Support Direct 0808 808 0000 or visit www.macmillan.org.uk

Cancer Research UK Support

Freephone 0808 800 4040 or visit www.cancerhelp.org.uk

Macmillan Cancer Information Centre, Western General Hospital, Edinburgh

0131 537 3907 and 07554 330 599 - answer phone available

Maggie's Centre, Edinburgh

0131 537 3131 or email: edinburgh@maggies.org

Maggie's Centre, Fife

01592 647997 or email: fife@maggies.org

Maggie's Lanarkshire, Airdrie

01236 771199 or email: maggies.lanarkshire@maggiescentres.org

Maggie's Centre, Forth Valley

01324 868069 or email: forthvalley@maggies.org

Smokeline

0800 84 84 84

Your Oncology Treatment Contacts			
Your Consultants name:			
Consultant's Secretary telephone number:			
Your Clinical Nurse Specialists name:			
Telephone number:			

Transport links



Train

Haymarket rail station is the nearest station to the Western General Hospital. It is 10 minutes away by car, 50 minutes on foot.

Waverley station is at least 15 minutes away by car, 35 minutes by public transport and about an hour on foot.

Train information for St John's

By Train: Livingston North is the nearest railway station (1.4 miles) which is on a bus route or is a 20-25 minute walk.

Livingston South is 2.8 miles from St John's.



Bus

Please refer to the bus websites for current bus timetables.

Lothian buses:

http://www.lothianbuses.com/

Bus information for St John's

By Bus: There is a regular bus service to all areas of West Lothian and Edinburgh from the grounds of St John's.

Information on bus times is available through the First Bus app, Transport for Edinburgh website:

https://www.firstbus.co.uk/buy-tickets/ways-pay/first-bus-app

Lothian Country:

https://www.lothianbuses.com/our-services/lothian-country/

or Traveline Scotland:

https://www.travelinescotland.com

or by calling 0871 200 2233

Timetables are also available in main reception and from an electronic information screen in main reception.



Ambulance transport

It is not routine for the ambulance service to provide transport for patients. You can request Patient Transport up to 28 days in advance of your appointment date by calling the booking line on 0300 123 1236.

If you are hard of hearing, deaf or speech impaired, you can contact the Service through Text Relay on 18001-0300 123 1236. Calls will be charged at local rates for mobiles and landlines.



Scottish Ambulance Service

http://www.scottishambulance.com/WhatWeDo/pts.aspx

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