

# Chemotherapy and immunotherapy

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## Information for patients, relatives, and carers

This booklet has been written to give you and your family/carers important information about your chemotherapy treatment. We hope it covers some of the questions you may have and that it acts as a point of reference throughout your treatment.

We realise that it may not cover every single question you have and neither does it replace any of the discussions you wish to have with the chemotherapy staff.

After reading this booklet we hope that you may find it easier to ask staff questions and discuss your treatment progress with us.

Please feel free to feed back to us any additional information you feel may benefit the evolution of this patient booklet.

## Our philosophy of care

Our chemotherapy service throughout East Kent Hospitals aspires to provide safe, effective, patient-centred care for all our patients.

We aim to do this by ensuring a safe and caring environment, where staff advocate for patients, whilst providing a truly holistic service to all.



**Patient ID Label**

**Chemotherapy/Immunotherapy treatment:** .....

**Diagnosis:** .....

**Consultant:** .....

**Concurrent radiotherapy:** Yes/No (Please circle)

**Trial:** Yes/No (Please circle)

**Receiving treatment at:**

- ☐ Viking Day Unit, Thanet
- ☐ Cathedral Day Unit, Canterbury
- ☐ Celia Blakey Day Unit, Ashford

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## **What is chemotherapy?**

Chemotherapy is the treatment of disease, especially cancer, using drugs that are destructive to malignant cells and tissues. Many types of medicines are used in chemotherapy, all of which attack cancer cells in different ways. For this reason, we often give several medicines in combination to increase the effectiveness of treatment. Chemotherapy can be used alone or with radiotherapy and surgery.

Most cancer chemotherapeutic drugs are given IV (into a vein) or IM (into muscle). Some anti-cancer agents are taken orally (by mouth). Chemotherapy is usually systemic treatment, meaning that the drugs flow through the bloodstream to nearly every part of the body.

Intravenous (IV) chemotherapy is usually given in bags through an infusion pump, an ambulatory pump, or in a syringe via a cannula. Some chemotherapy can be sensitive to light so may have a bag protecting it throughout treatment.

Chemotherapy is generally given in cycles: a treatment period is followed by a recovery period, then another treatment period, and so on.

## **How long will I be in the unit for?**

This depends on your regime of chemotherapy, some people are treated within only a few minutes but others are here for up to 10 hours. Your chemotherapy nurse will give you an approximate time of how long your treatment may take.

## **What are the benefits of treatment?**

The benefits of treatment will depend on the type of cancer you have and how advanced it is. The aims include:

- **Intention to cure the cancer;** this is when chemotherapy is given to destroy all the cancer cells.
- **Reducing the chances of the cancer coming back;** for example after surgery, by destroying any cancer cells that are still in the body but are too small to detect. This is often called adjuvant chemotherapy.
- **Controlling the growth and spread of the tumour;** so that surgery or radiotherapy is easier to perform.
- **Controlling the growth and spread of the tumour;** this may slow down its progress and relieve symptoms. This is often called palliative treatment.

## **What happens if I decide not to have chemotherapy?**

There is a risk that your cancer may continue to grow and your symptoms may get worse. You can discuss what to do next with your doctor if you feel you cannot continue with your treatment.

## **Am I allowed visitors whilst on my chemotherapy?**

Only one visitor per patient is allowed on the unit at one time unless previously discussed and agreed with the nurse in charge. Children are not permitted on the unit for safety reasons.

## **What are the common side effects of chemotherapy?**

Chemotherapy affects normal cells as well as cancer cells; therefore there are some side effects that you may experience during your treatment.

The side effects of your particular treatment and how to deal with them will be explained in your new patient assessment.

It is important to remember that you may not suffer from all these side effects but we must inform you of all possible side effects so that you are well educated in your care.

### **• Nausea and vomiting**

Some chemotherapy drugs may cause some nausea and vomiting, if this is likely then you will be given some anti-sickness medication before your chemotherapy and also to take home with you. If your nausea and vomiting persists despite taking your anti-sickness medications then please contact your GP or the urgent advice line for further advice. There are many medications we can give to treat nausea and vomiting so if one is not working then we can usually find one that works for you.

Sometimes it may be beneficial to avoid heavy meals within the first 24 hours of chemotherapy treatment. Try having light snacks instead but it is important to remain hydrated by having lots to drink.

Having a loss of appetite for 24 hours after chemotherapy is very common. Your chemotherapy nurse will routinely weigh you so we can monitor your weight.

## • **Sore mouth (stomatitis) and taste changes**

It is really important to maintain a healthy mouth, especially whilst on chemotherapy. Tips for good oral hygiene are; cleaning your teeth twice a day using a small head/baby soft tooth brush and fluoride tooth paste, rinsing your mouth out thoroughly with water after cleaning.

Your chemotherapy nurse may suggest using an antibacterial mouthwash four times a day. This can either be dispensed by the unit or prescribed by your GP.

If you do develop a sore mouth, please use the mouthwash prescribed as directed as long as you can tolerate it. You can dilute the mouthwash if needed with water. If your mouth becomes too painful for the mouthwash then water rinses can be used instead as often as you find it helpful.

Many chemotherapy patients find ice quite soothing. Avoiding hot and spicy foods and hot liquids whilst your mouth is sore will be beneficial.

If your mouth continues to be sore despite the above advice then this may indicate some infection so please see your GP as soon as possible or contact your chemotherapy nurse.

You are still able to see your dentist whilst on chemotherapy, however if you need any invasive treatment, for example a filling or extraction, then please contact your chemotherapy nurse. Your mouth is a very vascular area so the risk of bleeding and infection may be high if you are on chemotherapy. Please inform your dentist that you are on chemotherapy.

## • **Diarrhoea and constipation**

There are some chemotherapy drugs that can cause temporary diarrhoea or constipation, so if you experience either please tell your chemotherapy nurse. You may be given medicine to help with these side effects. Constipation can be a serious complication of chemotherapy, so please alert staff so we can treat this early.

## • Hair loss

It is important to remember that not all chemotherapy causes hair loss. Some chemotherapy may cause thinning of the hair or total hair loss. You may lose body hair such as your eyebrows and pubic hair. Hair loss normally begins two to three weeks after your first treatment, however this is only a temporary side effect and your hair will grow back after treatment. Some patients may experience their hair regrowth before their treatment is finished.

When hair falls out it often can make the scalp feel tingly or painful, this is normal. Your chemotherapy nurse will inform you if this is a common side effect of your particular treatment. If you would like a referral to the wig specialist based at the hospital then please ask your chemotherapy nurse for details.

Please ask your chemotherapy nurse if you want more information regarding the cold cap machine, this is a device that can often slow down the rate of hair loss.

## • Anaemia

Anaemia occurs when there is a reduction of red blood cells in the body. These red cells carry oxygen from the lungs to all parts of the body. When on chemotherapy sometimes patients can become anaemic. Signs of anaemia are breathlessness, tiredness, and dizziness.

Usually a mild anaemia from chemotherapy may resolve on its own, however sometimes a blood transfusion is necessary. Your chemotherapy nurse will monitor your red blood cells regularly but please inform them if you feel you have signs of anaemia.

## • Increased sensitivity to sun exposure

Please be aware that your skin, when having chemotherapy treatment, is much more sensitive in the sun. Try to avoid direct exposure to the sun, sit in the shade when possible and wear a high factor sunscreen. If you have experienced hair loss please remember to protect yourself with a hat or sunscreen.



## • **Cardiac toxicity/renal toxicity**

We may need to check the function of your heart and kidneys before starting chemotherapy. Depending on the results of these tests, treatments may sometimes have to be altered.

**Kidneys** – extra tests may be required to check your renal function; this is carried out by a special kidney scan.

**Heart** – some chemotherapy medications can affect the heart. You may need some additional tests such as a heart scan (ECHO) or tracing of your heart (ECG). Please let your chemotherapy nurse know if you have a history of heart problems.

## • **Fertility/contraception**

**Women:** often menstrual periods will become irregular or even stop whilst on chemotherapy, but some women do still remain fertile.

However it is very important that you do not become pregnant whilst on chemotherapy due to the risk of damage to the baby. For this reason it is essential to use adequate contraception. Once treatment has completed your periods may not return to normal because the chemotherapy can cause infertility.

Any worries or queries you may have about fertility options such as fertility preservation may be discussed with your doctor, chemotherapy nurse, or specialist nurse.

**Men:** some chemotherapy can cause infertility, if this is likely with your treatment then your doctor or specialist nurse can talk to you regarding the possibility of sperm banking. It may be likely that you will stay fertile through the early stages of your treatment, but it is important not to father a child whilst receiving chemotherapy because of the risk of damage to the baby. For this reason it is essential to use contraception.

**The safest way to protect you and your partner from any exposure to residues of chemotherapy and protect against infection is to use a condom during intercourse.**

- **Allergic reactions**

Sometimes people can react to chemotherapy (please see complications of chemotherapy section on page 16), all our nurses are well equipped to deal with chemotherapy reactions if they occur.

- **Fatigue**

It is important to remember that whilst on chemotherapy you may feel more tired than usual. Our advice would be to listen to your body and only complete tasks you feel you are able to do.

You may wish to take time off work whilst on treatment especially if you are in a job that puts you at risk of infection. Continuing to work is totally your decision and agreement with your place of work and your GP.

However it is beneficial to take gentle exercise as well as taking rest when on chemotherapy.

- **Sore hands and feet (planter palmer)**

You may experience dry/sore hands and feet whilst on treatment, if this happens please let your chemotherapy nurse know. There are treatments that we can give to help with this. It is important to keep your skin well moisturised with a simple non perfumed moisturiser.

- **Peripheral neuropathy**

Certain chemotherapy may cause tingling or numbness in the hands, fingers, feet, and toes. If this happens please inform your chemotherapy nurse. It is important to tell us if your activities of daily living become altered; such as picking up a fork, doing up a button, or writing with a pen. This may mean that your dose of chemotherapy needs to be reduced.

- **Low immune system (neutropenia)**

When receiving chemotherapy treatment your body's resistance to infection becomes lowered. Due to this a minor illness may quickly develop into something more serious requiring a hospital admission. Symptoms of an infection may include a productive cough, sore throat, fever, or shivering.

**(Please see page 18 for advice on what to do if you feel unwell or have a temperature at home).**

When on chemotherapy or immunotherapy we recommend that you invest in a digital thermometer so that you can check your temperature if you think you may have an infection or you feel unwell. Please be aware that paracetamol can lower your temperature so may mask an infection if you are on paracetamol regularly. Please check your temperature before taking paracetamol if you are unwell.

### **Can I still have the flu vaccination?**

Whilst on chemotherapy you are still able to receive the flu vaccination, but depending on what type of chemotherapy you have, it may not give you quite as much protection against an infection as usual.

We recommend that you plan for your flu jab just before chemotherapy treatment or your next cycle so that your blood levels are working their way back to normal again.

**Please note** that if you are on immunotherapy please speak to your senior chemotherapy nurse who will discuss with your consultant your suitability to receive the flu vaccination due to current guidance.

## **Pre-chemotherapy/immunotherapy assessment and blood tests**

Once treatment has started we take a blood sample at each visit to the pre-chemotherapy clinic. We need to check that your blood count is normal before you have the next cycle of chemotherapy. This blood test is performed 48 hours or 72 hours before your treatment. The nurse will also document your weight and routine observations.

Blood count means the number of red blood cells, white blood cells, and special cells called platelets in the blood. All these blood cells are made in the bone marrow. Chemotherapy can affect the bone marrow, causing a temporary fall in the number of these cells.

Sometimes, treatment has to be delayed by one or two weeks if your blood count has not returned to normal following the last cycle of treatment. If this happens, the delay does not reduce the effectiveness of your chemotherapy.

For the mobile chemotherapy unit (Hope for Tomorrow) the nurses will complete pre-chemotherapy assessments via telephone. Your chemotherapy nurse will give you an appointment list when you attend your new patient assessment. If there is an issue with your appointments please let us know so we can help resolve the problem.

## **Should I attend my appointment if I feel unwell?**

It is very important to keep to your appointment times for the pre-chemotherapy clinic and for your treatment day. If you are unwell and are unable to get to your appointments at your chemotherapy unit you must phone and speak to the nurse in charge, who will then advise you on what to do next.

## **What happens before my appointment?**

There are several important steps to preparing and administering chemotherapy/immunotherapy - it is not a quick process. We understand that on the odd occasion the long waits can be tiring and frustrating, however we endeavour to keep you informed at every opportunity about your treatment.

Chemotherapy or immunotherapy treatment requires several checks during its preparation, before it gets to the unit.

- Your chemotherapy nurse will complete your pre-chemotherapy assessment and collate your blood results; they then send this to the oncology pharmacists.
- Your prescription is carefully checked in the oncology pharmacy.
- Oncology pharmacy sends this prescription to the aseptic unit where they make the chemotherapy.
- The details of your prescription are double checked. The chemotherapy is then made up in a sterile environment before the pharmacists make their final check.
- The chemotherapy is then delivered to the chemotherapy units where the final check is done by the chemotherapy nurse on administration to the patient.

## **Diet and chemotherapy/immunotherapy**

### **Why do I need advice on what I should eat?**

A common side effect of chemotherapy can be to reduce the body's ability to fight infections. It is important to take extra care with the food you eat to minimise the risk of picking up a food related infection.

Many of the foods we eat contain small amounts of bacteria, viruses, and fungi. For most people this is not a problem, but if your immune system is weakened these can prove harmful and may lead to infections. There is no reason, however, why you cannot continue to eat a wide variety of foods whilst you are receiving treatment.

Many herbal and vitamin supplements are not advised during chemotherapy. If you are already taking or considering taking a herbal or vitamin supplement please discuss this with the chemotherapy nurse. Examples include vitamins, garlic capsules, Cod Liver Oil, Echinacea, and St John's Wort.

These guidelines aim to help you to lower the risk of a foodborne infection by offering a list of higher risk foods which are best avoided.

It is recommended that you follow this advice for one month after completing your treatment.

Remember to be particularly careful about food hygiene. If your immune system is weak, you may be more at risk of getting food poisoning. You may also be less able to cope with the symptoms of food poisoning. It is also important to remember not to handle food if you are unwell with stomach problems such as diarrhoea or vomiting.

### **Can I eat out?**

It is best to order freshly cooked hot food and try to avoid buffet style counters or food that has been kept warm for long periods.

Avoid self-service salad bars open to the environment. Choose freshly prepared foods from reputable outlets and ensure the establishment has a good standard of hygiene. Search for food hygiene ratings on [www.food.gov.uk](http://www.food.gov.uk)

Take extra care when abroad as food hygiene may be poor.

### **Can I drink alcohol?**

As a general rule you are still able to continue to drink moderate amounts of alcohol, but it is best to avoid alcohol in the first 48 hours after chemotherapy/immunotherapy. Certain medicines can react badly with alcohol; if your treatment regime includes these medicines we will inform you on your new patient consultation.

Low alcohol or alcohol free drinks are a suggestion, limit intake as much as possible and try to have two to three alcohol free days per week.

## What are the foods I should avoid or be careful with?

Food	Foods which are best to avoid	Safer alternatives
<b>Milk and cream</b>	All unpasteurised or raw milk and cream, including milk from sheep and goats.	Pasteurised, UHT (long-life), sterilised, dried milk and cream, soya milk, and cream
<b>Cheese</b>	<p>All mould ripened and blue-veined cheeses such as brie, camembert, stilton, docelatte, Danish blue, and Roquefort.</p> <p>All unpasteurised cheeses for example parmesan, some goat and sheep cheeses.</p> <p>Take care with cheese bought at local farmers markets and locally produced cheeses.</p>	<p>Pasteurised cheeses such as most cheddar, edam, gouda, jarslberg, emmental, cottage cheese, ricotta, halloumi, processed cheeses such as Philadelphia, Laughing Cow, Dairy Lea, and similar products.</p> <p><b>By law the label should state if a product is unpasteurised.</b></p>
<b>Yogurts, drinking yogurts, and probiotics drinks</b>	All probiotic yogurts and yogurt drinks such as Yakult, Actimel, and similar probiotic products.	Any yogurt that does not describe itself as bio/probiotic. For example fruit yogurts, Greek yogurt, and plain yogurt.
<b>Eggs</b>	Undercooked or raw eggs.	Well cooked eggs. Only use Lion branded eggs or those bought from a farmer who has a certificate to say their flock of hens is salmonella free.
<b>Meat and meat products</b>	Raw or undercooked meat.	Well cooked meat or poultry. Meat is well cooked when the juices run clear and no pink bits remain.
<b>Fish and fish products</b>	<p>Raw or undercooked fish such as sushi, tuna steaks, caviar.</p> <p>Raw or undercooked shellfish such as oysters.</p>	Cooked shellfish and fish.
<b>Rice</b>	Avoid reheating home cooked rice.	Serve rice hot and eat immediately.

## What are the complications of chemotherapy/immunotherapy?

- **Anaphylaxis** is a rapid and often life threatening reaction that may be caused by many chemotherapy/immunotherapy drugs. It is a very rare but our chemotherapy staff are very equipped to deal with these situations.

It is important that throughout your chemotherapy you let us know if you feel unwell before, during, or after your treatment.

- **Allergic reactions** - it is important that you let your chemotherapy nurse know if you have any allergic reactions to anything, for example aspirin, this needs to be documented in your notes so that staff are aware.

It is possible that some patients may have an allergic reaction or sensitivity to chemotherapy/immunotherapy. Again our staff are well equipped to deal with these situations and we may need to halt your treatment until we determine the cause of the reaction.

Often people are treated with hydrocortisone and Piriton and then are able to continue their regime of chemotherapy/immunotherapy.

Please let staff know if you experience any signs of an allergic reaction, these may include: **rash (urticarial/hives), shortness of breath, tingly lips, swelling, or sweating.**



- **Venous Thrombus Embolism (VTE)** refers collectively to deep vein thrombosis (DVT) a blood clot in the leg, and pulmonary embolism (PE) a clot that breaks loose and travels to the lungs.

There are many risk factors that may contribute to VTE but having cancer and receiving chemotherapy can increase that risk.

Please be aware of signs and symptoms of VTE and if you experience any of the following seek urgent medical advice.

**DVT:** swelling of the affected leg/arm, pain in the affected leg/arm, the pain may be worse when standing or walking. Usually the pain is worst in the back of the leg.

**PE:** sudden onset of chest or shoulder pain (which is made worse by taking a deep breath), breathlessness, and/or cough with blood streaked sputum.

- **Increased risk of bleeding** - some chemotherapies may affect the way your blood clots; it may increase the possibility of you bruising or bleeding more easily. In the rare event that you experience uncontrollable bleeding please dial 999.

- **Neutropenia and neutropenic sepsis**

**Neutropenia** means a low neutrophil count. This means that patients are more susceptible to infection as their infection fighting cells in their blood are lower; therefore patients are at risk of serious infections which may be fatal if undetected and untreated.

**Neutropenic sepsis** is where patients become neutropenic as a result of their chemotherapy and develop an infection with a temperature and often feel unwell. Neutropenic sepsis is classed as a medical emergency which needs treating with intravenous antibiotics immediately. This is why it is important for patients to check their temperature and be aware if they feel unwell. Please be aware that paracetamol can lower the body's temperature, so may mask an infection being present therefore please check your temperature before taking paracetamol.

**If you get a temperature of 37.5°C or above or below 36°C, this could indicate that there is an infection present and that you need urgent medical assessment. Please ring the 24 urgent advice line for advice on what to do next.**

**24 Hour Urgent Advice Line for  
Chemotherapy/Immunotherapy patients  
01227 783096.**

## **Extravasation and important considerations during my treatment**

Vein assessment and care of your cannula is very important, this is to minimise the risk of extravasation. Extravasation is where the chemotherapy drug leaks into the surrounding tissues and has the potential to cause damage.

So **please** report any discomfort, pain, or swelling promptly either during or after treatment (even if it occurs when you have left the hospital).

Treatment may be infused over a set number of hours or minutes depending on your chemotherapy regime, via an infusion pump. Some chemotherapy drugs are sensitive to the light and will therefore have a protective covering. Nurses will check, double check, and triple check details with you so please do not be alarmed.

Please take great care when moving around the unit or in to the toilets during your intravenous treatment. Cannulas can become dislodged and cause extravasation in these situations. Whilst it is very safe to move around the unit we just urge you to consider your cannula placement and be vigilant for signs of extravasation, such as:

- pain
- redness
- swelling
- stinging or burning.

## **Central Venous Access Devices (CVAD)**

There are three main reasons that you may need a central venous access device.

- Some chemotherapy regimes require continuous therapy, where a device is taken home with patients allowing continuous administering of chemotherapy for up to one week. For safety this would require a central line.
- Some patients that are planning to undergo a stem cell harvest (usually in London) will require a central line.
- Patients that have poor venous access due to previous chemotherapy, have experienced vein pain, have difficulty in cannulating, or have had lymph nodes removed.

The lines enable nurses to withdraw bloods and administer treatment causing less trauma to the patient by having many cannulation attempts.

## **Considerations for a CVAD**

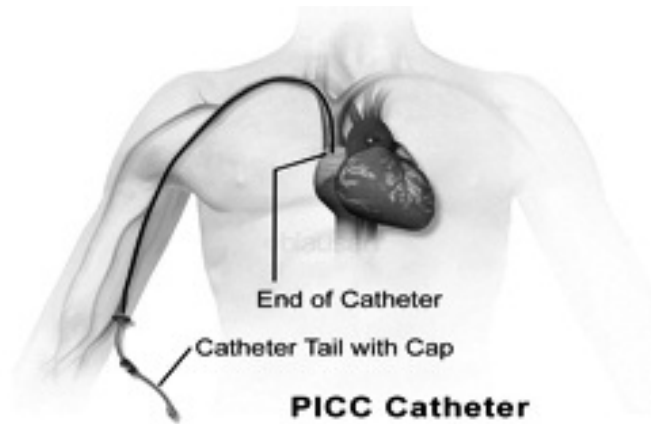
Lines also come with some risk, for example infection or DVT, but as long as they are cared for and used in the correct manner then this is very rare. The CVAD team at the hospital will put in PICC (Peripherally Inserted Central Catheter) lines, and also use ultrasound cannulation.

Ports, Hickman, or Groshong lines are usually put in by an anaesthetist in day surgery. Please speak to your chemotherapy nurse if you feel that you may want a line or are worried about the process in any way.

## What types of central lines are available?

- **PICC (peripherally inserted central catheter)**

This line is the main type of line we use in the chemotherapy units. The PICC line is a long, thin, flexible tube that is also known as a catheter. It is inserted into one of the large veins of the upper arm by ultrasound. Once inserted into your vein, the line is threaded through until it sits just above your heart. The position is confirmed by using an ECG machine attached



- **Portacath** - these are hubs under the skin which are usually situated on the chest wall. Your chemotherapy nurse will access the hub by inserting a needle into your skin.
- **Hickman** - these are tunnelled lines that are either double or triple lumens with clamps on the end, it is inserted into the centre of your chest.
- **Groshong** - this is a single tunnelled line with an internal valve and is also situated on your chest wall.

## **What is immunotherapy?**

Immunotherapy is a relatively new type of biological therapy which is becoming widely used in cancer patients. It aims to harness the body's immune response to detect and fight certain cancers.

## **Our immune system**

Our immune systems are made up of organs, cells, proteins, and other substances that help protect us from infections and diseases. The immune system is keeping track of all the normal substances normally found in our bodies, it will identify any foreign substances such as germs, viruses, or parasites (antigens) that may appear. Our immune system will react to these foreign substances when an antigen is detected. T cells are part of our immune system and can kill body cells that have been infected.

## **How does immunotherapy work?**

Cancers occur when genetic mutations develop in our normal cells leading them to grow inappropriately. Cancer cells produce mutant proteins that our immune system can detect as foreign. However even a strong healthy immune system may have difficulty distinguishing between normal cells and cancerous cells.

Immunotherapy increases the ability of our immune system to detect and destroy cancer cells.

There are molecules on T cells that act as 'a break' and stop T cells from activating and killing cells. Immunotherapy drugs bind to these molecules and 'take this break off'. Therefore rather than targeting the persons cancer cells directly, immunotherapy treatments increase the ability of the immune system to recognise cancer cells and selectively target and destroy them.

## **Will I have other drugs as well as immunotherapy?**

Immunotherapy may be used as a single agent or in combination with other chemotherapies or radiation.

## **How will my immunotherapy be given?**

Immunotherapy is given by intravenous injection. How often you have your treatment will be decided by your consultant, and treatment schedules vary - for example they can be every two or three weeks, or monthly.

## **What are the side effects of immunotherapy?**

Immunotherapy can cause a very wide range of side effects as it can cause inflammation in any organ/part of the body.

The side effects of immunotherapy differ from normal chemotherapy so it is important that you let any doctor or nurse seeing you know that you are on immunotherapy and not chemotherapy for treatment of your cancer.

It is important to remember that any patient can experience side effects from immunotherapy even if they have been well on treatment for a long period of time.

Whilst on immunotherapy there are certain side effects that patients may experience throughout their treatment and up to twelve months after. These side effects must be closely monitored by your consultant, specialist nurse, and chemotherapy team. It is important that you as the patient are informed about these side effects and seek appropriate available advice where needed.

**Please inform your nurse/consultant if you experience any of the following side effects**

**General side effects** - Tiredness or confusion, shivers, fever, weight gain or weight loss, a change in behaviour, feeling anxious or irritable.

**Skin** – Rashes, itching, yellowing of the skin, bruising or bleeding of the skin.

**Bowels** – Constipation, diarrhoea or more bowel movements than normal, blood or mucous in stools, black or tarry stools.

**Stomach** – Less hungry than usual, nausea or vomiting, abdomen (stomach) feels sore or tender.

**Mouth** – Dry mouth or more thirsty than usual.

**Head** – Feeling faint or dizzy, having a persistent headache that will not resolve and is unusual for you.

**Throat and chest** – Worsening shortness of breath, chest pain, rapid heartbeat, developed a new or worsening cough.

**Muscle, joints, or legs** – Aching muscles, severe or persistent muscle or joint pains, or severe muscle weakness.

**Eyes** – Eyesight has changed from normal to blurred vision, double vision, or any yellowing of the eyes.

**Urine** – Urine colour has changed and peeing unusual amounts, urine is dark in colour.

**Nerves** – Weakness and/or tingling in an arm or leg.



## **What do I do if I experience any side effects?**

If you experience any of these side effects please contact your appropriate unit below for advice between 7.30am and 7pm, or the on call 24 urgent advice line between 7pm and 7.30am. Please tell the advising nurse that you are on immunotherapy.

- Cathedral Day Unit, Kent and Canterbury Hospital (K&C)  
Telephone: 01227 783096
- Celia Blakey Centre, William Harvey Hospital, Ashford (WHH)  
Telephone: 01233 616194
- Viking Day Unit, Queen Elizabeth the Queen Mother Hospital (QEQM), Margate  
Telephone: 01843 234488
- 24 Urgent Advice Line  
Telephone: 01227 783096

## **What is Hope for Tomorrow?**

Our mobile chemotherapy unit launched on the 14th October 2013 and is operated by East Kent Hospitals. The unit is named Caron, in memory of Gloria Hunniford's daughter Caron Keating, who sadly passed away from cancer.

The unit can visit up to five locations each week to give certain chemotherapy treatments, these treatment locations are carefully chosen by the Trust, based on where they can treat the most patients at any given point, hence being subject to change.

The unit is working out of Kent and Canterbury Hospital four days a week, and is currently giving treatments at the following locations:

- **Herne Bay, Queen Victoria Hospital (Tuesday)**
- **Dover, Tesco's supermarket (Thursday)**
- **Cheriton, Tesco's supermarket (Wednesday)**
- **Thanet, Westwood Cross Tesco's Supermarket (Friday)**

The mobile chemotherapy unit is owned and maintained by the Hope for Tomorrow charity. If you are interested in using this facility then please speak to one of your chemotherapy nurses; they will inform you if your chemotherapy can be administered closer to home using Hope for Tomorrow.



## Research and clinical trials

- **Oncology research**

More than one in five people diagnosed with cancer in the UK take part in a clinical trial. 450 people survive cancer every day thanks to research (Cancer Research UK).

- **Research philosophy**

In our role as researchers we offer support to patients and relatives on their journey through decisions and options of care. Together with our patients the East Kent Research Team are committed to offering the opportunity to participate in research study/trials and have a fundamental role to play in helping beat cancer. For further information please call 01227 866393.

- **Haematology clinical trials**

Clinical trials are planned studies involving patients. Trials are usually designed to test new treatment approaches. They are always aimed at improving treatments and reducing side effects.

At East Kent Hospitals there is a very active haematology clinical trials program for patients. You may be offered the opportunity to take part in a clinical trial for cancers such as acute and chronic leukaemia, lymphoma, and myeloma.

Ultimately it is your decision on whether to enter a clinical trial that is offered for your disease, but there is no doubt that clinical trials aid advancement of future treatments being available.

Trial outcomes cannot be predicted, however evidence suggests that trial patients do as well if not better as other patients receiving treatment.

## **Parking at our hospitals and transport**

- **Pay-on-foot parking**

There is pay-on-foot parking at K&C, WHH, and QEOM.

On approaching the entry barrier, press the green button to take a ticket. Before returning to your vehicle, you will need to insert the ticket in to one of the pay stations which calculates how long you have stayed and how much you need to pay.

The minimum charge is £2 for the first hour, and increases by 20p for every 12 minutes after that (to a maximum of £8 per 24 hour period).

- **Pay and display**

There is pay and display parking at K&C opposite day surgery, and outside channel day surgery at WHH.

Pay and display charges may be paid through RingGo, which is a cashless method of paying for your parking. Details are posted on the pay and display machines, and you will need a mobile phone and debit or credit card to use this service. Please note there is a 20p convenience charge for using this service.

- **Weekly parking permits for oncology patients**

As an oncology patient receiving treatment, you may need to visit the hospital several times over an extended period. If so a £6 14 day parking permit can be purchased from the parking portacabin outside the entrance to the fracture clinic at K&C.

- **Permits at WHH, K&C, and QEQM**

Normal weekly permits can be obtained via the pay stations. Simply press the intercom to connect to one of the parking attendants and request a weekly ticket. The attendant will activate the option on the pay station and talk you through how to make the purchase. Keep the ticket safe as on subsequent visits you will need to insert it at the entry barrier to gain access, and again at the exit barrier when you leave.

- **Disabled parking at WHH, K&C, and QEQM**

All disabled parking is now chargeable at £2 per day.

- **If you need help** our car parking attendants at K&C, WHH, and QEQM are there to help you. Simply press the intercom on any of the entry/exit barriers or pay stations to connect to a parking attendant. The attendant will either resolve your enquiry over the intercom, or will arrange for someone to come and assist you if necessary.

- **Getting to hospital by NHS transport**

If you believe that you may be eligible for NHS transport, please telephone the number below and they will go through the eligibility criteria with you.

Please be aware that with all NHS transport 48 hours notice must be given with both bookings and amendments.

Please contact this number for more information: freephone G4S bookings line on **0800 096 0211** 24 hours a day or visit [www.km-pts.co.uk](http://www.km-pts.co.uk)

**Please be aware that these charges may change in the future, so please only use this as a guide.**

## **Chemotherapy electronic prescribing**

A new system is here in the chemotherapy unit named electronic prescribing. There are new PC's that are mounted on the chair side trolleys.

### **What are these PC's going to be used for?**

East Kent Hospitals have been working with Maidstone and Tunbridge Wells NHS Trust to launch a new electronic prescribing system on all chemotherapy units. The PC will be used to access your patient record which includes your prescription which will enable us to safely administer your treatment electronically.

### **What are the benefits of the new system?**

The new system will streamline the service we provide, which will enable your oncologist to prescribe and change prescriptions live on the system anywhere across Kent. This will mean that all healthcare professionals responsible for your care can see, in real time, any changes that are made to your patient record.

### **Patient WIFI**

The chemotherapy team are pleased to confirm that free WIFI is available for patients in each chemotherapy unit. Please ask nursing staff for details. Laptops, tablets, and mobile phones are all allowed on the chemotherapy units during your treatment.

### **Patient Focus Group**

The cancer services patient focus group started in April 2016. It provides a forum where staff can meet with patients to understand any issues experienced by patients receiving cancer treatment in East Kent Hospitals. Working together this group works to influence and facilitate changes in the chemotherapy service to provide a better experience for patients.

Feedback from staff and patients attending is very positive. The group meets every three months and rotates the sites across the Trust. If you are interested in being part of it please speak to one of the chemotherapy nurses or email [ekh-tr.oncologypharmacy@nhs.net](mailto:ekh-tr.oncologypharmacy@nhs.net) for more information.

## **Health and wellbeing clinics**

The health and wellbeing clinics are for cancer patients and relatives at East Kent Hospitals. It is supported by Macmillan Cancer Support.

### **What is your health and wellbeing clinic?**

They are events that you can attend for support if you have been through treatment and are now adjusting to your 'new normal'.

The clinics are run by volunteers, charitable organisations, Macmillan professionals, and allied healthcare professionals. Patients are quite welcome to bring a guest with them when attending the clinic.

There will be an opportunity to talk to a number of healthcare providers about:

- healthy diet and lifestyle
- the possible long term effects of treatments
- issues surrounding your diagnosis
- benefits and other financial support
- how to get back to work
- local support service and facilities
- any other questions you may have.

They run from approximately 10.30am to 3pm. Please telephone the cancer care coordinator team for more details on 01227 868666.

### **What is radiotherapy?**

On cathedral day unit we work closely with the radiotherapy department within the hospital as some of our patients will undergo radiotherapy and chemotherapy at the same time.

Since the discovery of x-rays over 100 years ago, radiation has been used more and more in medicine, both to help with diagnosis (by taking pictures with x-rays) and as treatment (radiotherapy).

Radiotherapy works by destroying the cancer cells in the treated area. Although normal cells can be damaged by the radiotherapy, they can usually repair themselves.

Radiotherapy treatment can cure some cancers and can reduce the chance of a cancer returning after surgery; it may also be used to reduce other cancer symptoms.

Some people find that the side effects are very mild and that they may feel tired during their course of radiotherapy treatment. Chemotherapy nurses and radiographers are available to discuss any side effects with you should you suffer with any.

Please make sure you drink plenty of fluids and rest adequately during your radiotherapy treatment.

## **Counselling services for cancer patients and their families/carers**

Many people living with cancer, and the people who share their lives, experience physical and emotional changes which they may find difficult to manage.

### **What is counselling?**

Talking to a trained counsellor who is not personally involved can give us the space we need to untangle thoughts, feelings, and ideas, and you can turn to this at any stage, after diagnosis, during treatment, or even after treatment has finished. The counselling service is built on experience, understanding, and trust, and has for many people been an important first step in regaining control again.



## **How does counselling help?**

Counselling can help you to:

- make sense of your thoughts and feelings
- explore options and the way forward; and
- realise your own strength to face the future.

## **Where does the counselling take place?**

We offer counselling at the WHH and QEQM. Counselling rooms are comfortable and quiet, and we will always try to offer you an appointment time that is convenient for any other commitments you may have at the hospital.

Please note that there is a waiting list for counseling so if you need urgent counseling please seek advice through your GP.

## **Who will I see?**

You will see a qualified, fully trained, and experienced counsellor who understands and values the importance of building a trusting relationship with you.

## **How do I make contact with the counselling service?**

Please see the contact list on the next page. If you would like support during this referral process from your chemotherapy nurse please let us know.

## **Am I entitled to free prescriptions?**

Cancer patients in the UK are now entitled to free prescriptions. All cancer patients undergoing treatment for cancer, the effects of cancer or the effects of cancer treatment should apply for an exemption certificate.

If you are having any treatment related to cancer or its effects, you can apply for an exemption certificate. You need to collect form FP92A from your GP surgery or oncology clinic.

## Useful contacts

Clinical nurse specialists (CNS) are available for tumour specific sites for advice and support on your diagnosis and treatment plan.

Please contact the cancer care co-ordinator line for the appropriate nurse to speak to.

- |                                  |                          |
|----------------------------------|--------------------------|
| • Brabourne Ward, K&C            | Telephone: 01227 864394  |
| • Dover Counselling Service      | Telephone: 01304 204123  |
| • Cancer Care Co-ordinator Line  | Telephone: 01227 868666  |
| • Cathedral Day Unit             | Telephone: 01227 783096  |
| • Celia Blakey Centre            | Telephone: 01233 616194  |
| • Dieticians (K&C)               | Telephone: 01227 864236  |
| • (QEQM)                         | Telephone: 01843 234310  |
| • (WHH)                          | Telephone: 01233 616624  |
| • Gynaecological Cancer Trials   | Telephone: 01843 234343  |
| • Haematology Clinical Trials    | Telephone: 01227 864129  |
| • Kent Oncology Centre           |                          |
| • Appointments                   | Telephone: 01227 783066  |
| • Look Good Feel Better          | Telephone: 01227 864114  |
| • Macmillan Cancer Care          | Telephone: 0808 800 2020 |
| • Macmillan East Kent Welfare    |                          |
| • Benefits Helpline              | Telephone: 01227 762122  |
| • Medicines Management Helpline  | Telephone: 01233 651814  |
| • Oncology Clinical Trials       | Telephone: 01227 866393  |
| • Radiotherapy Department at K&C | Telephone: 01227 783010  |
| • Counselling Team               | Telephone: 01303 249780  |
| • Viking Day Unit                | Telephone: 01843 234488  |

# Appointments

Where	Blood test/treatment	Date	Time

# Appointments

Where	Blood test/treatment	Date	Time

**Record of Treatment**

Date: ..... Cycle: .....	Date: ..... Cycle: .....
Blood results: Hb: ..... Wbc:..... Plts.....	Blood results: Hb: ..... Wbc:..... Plts.....
Neut: ..... Weight: .....	Neut: ..... Weight: .....
Treatment given: yes/no	Treatment given: yes/no
Treatment delayed until: .....	Treatment delayed until: .....

Date: ..... Cycle: .....	Date: ..... Cycle: .....
Blood results: Hb: ..... Wbc:..... Plts.....	Blood results: Hb: ..... Wbc:..... Plts.....
Neut: ..... Weight: .....	Neut: ..... Weight: .....
Treatment given: yes/no	Treatment given: yes/no
Treatment delayed until: .....	Treatment delayed until: .....

Date: ..... Cycle: .....	Date: ..... Cycle: .....
Blood results: Hb: ..... Wbc:..... Plts.....	Blood results: Hb: ..... Wbc:..... Plts.....
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Treatment given: yes/no	Treatment given: yes/no
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Blood results: Hb: ..... Wbc:..... Plts.....	Blood results: Hb: ..... Wbc:..... Plts.....
Neut: ..... Weight: .....	Neut: ..... Weight: .....
Treatment given: yes/no	Treatment given: yes/no
Treatment delayed until: .....	Treatment delayed until: .....

Date: ..... Cycle: .....	Date: ..... Cycle: .....
Blood results: Hb: ..... Wbc:..... Plts.....	Blood results: Hb: ..... Wbc:..... Plts.....
Neut: ..... Weight: .....	Neut: ..... Weight: .....
Treatment given: yes/no	Treatment given: yes/no
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Date: ..... Cycle: .....	Date: ..... Cycle: .....
Blood results: Hb: ..... Wbc:..... Plts.....	Blood results: Hb: ..... Wbc:..... Plts.....
Neut: ..... Weight: .....	Neut: ..... Weight: .....
Treatment given: yes/no	Treatment given: yes/no
Treatment delayed until: .....	Treatment delayed until: .....

## **What do I do if I need urgent advice?**

If you suffer with uncontrolled chemotherapy side effects or have a temperature, there is a 24 hour urgent advice line to call. This advice line is manned by an appropriately trained nurse who can triage your call, however if there are large call volumes it may not be possible to answer your call immediately. Please make sure you leave a message with your details to contact or if you are acutely unwell ring 999.

## **Where will I go if I need to be reviewed in hospital?**

On being telephone assessed the triage nurse may arrange for you to be assessed at your nearest appropriate hospital or be transferred to hospital via ambulance if needed. If this happens please bring with you this booklet and any medications.

During the hours of 8am and 4pm Monday to Friday, you may be advised to self-present to the acute medical assessment unit where the medical team will review you and assess if admission is necessary. During this time the acute oncology nurses will aim to support and liaise with medical and oncology teams in planning your care for this episode.

Out of hours between 4pm to 8am, weekends, and Bank Holidays please contact the urgent advice line and the triage nurse will advise which hospital and area you need to attend if you need medical assessment.

The chemotherapy/immunotherapy nurses and acute oncology team aim to provide a nurse led service and aim to support where possible in making sure that admissions to accident and emergency (A&E) are reduced and that oncology patients are seen in a timely manner.

## Other patient information

Please be aware that there are other publications available in the chemotherapy waiting areas that patients can access if they so wish. If there is specific information you would like to see available then please discuss this with the nurse in charge and we will do our best to accommodate your request.

**Acknowledgements:** this booklet has been adapted from the Christie NHS Foundation Trust 2015 booklet 'Chemotherapy: a guide for patients and their carers'.

This booklet has been produced by Sister Ruth O'Brien Lead Nurse Educator for Chemotherapy, Education team for East Kent Hospitals NHS University Foundation Trust.

**Urgent advice line for chemotherapy/immunotherapy patients:  
01227 783096**

**If you have chest pain or uncontrolled bleeding  
please dial 999 for an ambulance**

**This leaflet has been produced with and for patients**

If you would like this information in **another language, audio, Braille, Easy Read, or large print** please ask a member of staff.

**Any complaints, comments, concerns, or compliments**

please speak to your doctor or nurse, or contact the Patient Advice and Liaison Service (PALS) on 01227 783145 or 01227 864314, or email [ekh-tr.pals@nhs.net](mailto:ekh-tr.pals@nhs.net)

**Further patient leaflets** are available via the East Kent Hospitals website [www.ekhuft.nhs.uk/patientinformation](http://www.ekhuft.nhs.uk/patientinformation)