

Understanding ambulatory care for haematology patients

Cancer Services and Clinical Haematology

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Information for patients

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What is ambulatory care?

In the past if you were having certain cancer treatments you would have had to stay in hospital overnight. Ambulatory care means that we can now offer some of these treatments to you as an outpatient, meaning that you can go home overnight. It may also be referred to as day care.

Ambulatory care means that, if you live within 30 minutes by car of the hospital, you may be able to stay at home and travel to the hospital for certain treatments. When mentioning the hospital, we mean Leicester Royal Infirmary.

What are the benefits of ambulatory care?

- You will still have access 24 hours a day, 7 days a week, to expert medical and nursing care even though you are not staying in hospital overnight. You will receive the same treatment as you would on the ward except that it will take place between the hours of 9am and 5pm.
- At home you can have the company of a friend or relative 24 hours a day throughout your treatment which is not possible in hospital.
- Being at home means that you can maintain some normality and independence in your daily life.
- You are likely to eat better at home, eating what you want, when you want to.
- You may sleep better at home with fewer disturbances.
- You can be more independent at home and move about more.

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

Visit www.leicestershospitals.nhs.uk for maps and information about visiting Leicester's Hospitals
To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk

The team looking after you

The ambulatory care team looking after you is made up of senior haematology nurses, doctors and pharmacists, all of who have extensive experience in caring for patients receiving chemotherapy and stem cell transplants.

Can I change my mind once my treatment starts?

If at any stage of your treatment your circumstances change and you no longer want to be treated as an ambulatory patient this is not a problem and you can be admitted into hospital for the remainder of your treatment. Please let us know any concerns you may have at any time.

Is there a car park at the hospital?

Parking is available in the hospital car park on Havelock Street. There is a charge for this but there are pre-paid tickets which reduce the cost. Please ask us for a form for this.

Your day-to-day routine during ambulatory care

Most of your care will take place on the Hambleton Suite and occasionally on the Osborne Day Care Unit, both of which are at Leicester Royal Infirmary. You will attend the hospital anything from daily to every few days. How often you need to come will depend on the treatment you are having, your blood results and how you are feeling. At your first appointment with us you will receive a schedule of care.

On each visit :

- Blood tests will be taken from your PICC line (you will have received more information about your PICC line and how to look after it) or occasionally from your arm.
- Your blood pressure, pulse and temperature will be checked
- You will be weighed
- You will be asked about any symptoms you may be experiencing such as sickness or diarrhoea
- A senior haematology nurse will review you and will ensure any necessary medication, blood products or investigations are arranged.
- The nurse will update you if your treatment schedule needs to alter from the planned dates to allow you to plan your home life around this. Please remember that treatments may sometimes run later than expected or you may have times where you feel very tired. It is important to take each day as it comes and allow flexibility for this.
- You will be involved as much as possible in the decision-making process and all decisions will be made between you, the doctors and the nurses to ensure everyone is in agreement with the plans made.

Why do I need blood tests?

We do blood tests to check how your liver and kidneys are working. We will monitor a marker in your blood which rises if you have an infection. We will closely monitor your red cells (to see if you are anaemic), white cells (to see how many infection fighting cells you have) and platelets (these help to stop bleeding). We will also check other levels such as calcium, potassium and magnesium.

Is ambulatory care suitable for me?

Not everyone is suitable for ambulatory care. If your treatment is available as ambulatory care we will discuss this with you and complete an assessment. Your safety and the quality of care you receive are our priorities when making this assessment.

Some of the things we will assess are listed below:

- For some treatments you will need a carer to stay with you at all times whilst you are at home (your friend or relative is considered your 'carer' for the purposes of this process) .
- You and your carer must sign a form confirming you have been informed about the process and are happy to proceed.
- You and your carer must be fluent in written and spoken English.
- You agree to attending appointments at the hospital which may be daily and may last several hours.
- You agree to take your medication as prescribed and on time. If there any problems with this you should contact the hospital.
- You You must own a thermometer and be able to take your temperature at least twice a day. If your temperature is 37.5 °C or above or 36 °C and below you must contact the Haematology Helpline number without delay.
- You must know how to care for your PICC line (or any other line) and keep it clean. If you have any concerns you must contact the hospital.
- You understand the importance of following the advice you are given, the complications that can occur with your treatment and when to seek help.
- You agree to be admitted to hospital when advised by the haematology doctors.
- You and your carer are contactable by telephone 24 hours a day.
- You are aware that you and your carer can request that you are admitted to hospital for any reason during the process.

What do I need to be aware of during ambulatory care?

It is important that you follow the advice given by the haematology doctors and nurses to help you minimise the chance of you experiencing complications.

- **Infection:** As your white blood cell count can become low due to your treatment you may be prone to infections and have limited ability to fight them. If you have any signs of an infection it is very important that you report them straight away as you may need antibiotics to help your body fight the infection. The signs of infection could be feeling generally unwell, shivering, shaking, feeling hot or cold and having a temperature of 36°C or less, or 37.5°C and above. Hand hygiene is very important– please make sure you wash your hands regularly and thoroughly. Avoid people with coughs, colds and viruses and tell friends and family not to come and visit if they are or have been unwell in the previous 48 hours. It is also important not to drill in to walls/have building work done while you are at home due to the risk of fungal infections.
- **Temperature:** To be taken in the morning and evening. You should also take it again if you feel unwell, hot or especially cold. Sometimes high temperatures can make you feeling shivery and cold. It is important to recognise this as a trigger to take your temperature. If your temperature is below 36°C or 37.5°C and above please call the Haematology Helpline immediately. Even if your temperature is normal but you are feeling shivery and shaky please call in. Do not take paracetamol unless a doctor or nurse tells you to as this can falsely lower your temperature.
- **Bleeding:** As the chemotherapy stops the bone marrow from working properly, your platelet count may be lower than normal. Your platelets have an important role in blood clotting: when your platelet count is low you may have symptoms that include - bleeding gums, nose bleeds and increased bruising. It is very important that you report these signs. We will monitor your platelet count closely and if your platelet count is low or you have signs of bleeding we may need to give you a platelet transfusion via a drip.
- **Mouth care:** One of the side effects of the treatment might be that your mouth and throat could become sore and painful - you may require pain relief for this and we will advise you what best to take depending on the severity. You may require admission if this is severe. Regular rinsing of the mouth, with water and/or mouthwashes is very important to remove food and cells that have died due to the chemotherapy. You should brush your teeth with a soft toothbrush after meals.
- **Medication:** The medications you are given are to prevent infections or lessen the side effects of your treatment. It is important that you are able to take your medication at the right times. If you have any problems with this please tell us.
- **Nausea and vomiting:** Your treatment may cause nausea (feeling sick) and vomiting . We will give you medication for this but if you are still feeling nauseous or vomiting despite this please get in touch with us and we can alter your medication. If your nausea is preventing you from eating and drinking or you are vomiting a lot then you may need to be admitted to avoid you getting dehydrated.

What do I need to be aware of during ambulatory care? (continued)

- **Diarrhoea:** If you experience diarrhoea please let us know. We will want to know the details of how much, how often and how it looks so please keep note of this for when you call. We ask you not to take medications to stop the diarrhoea such as loperamide (Immodium) as we need to make sure you do not have an infection first. This will involve taking a sample to send away and be tested.
- **Constipation:** The medication you are taking could also cause constipation. Please take note of how long it has been since you have last opened your bowels and what is normal for you. If it has been longer than 48 hours from your last bowel movement or from what is regular for you or you are feeling particularly uncomfortable please contact us.
- **PICC line:** Dressings should be changed once a week and this will be done at the hospital. Your line will also be flushed once a week. It is important for you to alert us if your dressing becomes displaced or comes off, the site should always be covered to prevent infection. Keep the dressing dry (see personal hygiene below).
- **Blood clots:** Having a cancer puts you at more risk of getting a blood clot. It is important to make sure you are moving around regularly. The more active you are the more the blood is encouraged to flow around your body and is less likely to clot. It is also very important to keep well hydrated to reduce the 'stickiness' of your blood. We will give you a card on the prevention of blood clots.
- **Nutrition:** It is important for the repair of your body that you get enough calories during treatment. We will weigh you regularly and make sure your weight is being maintained. If you start to lose weight we may refer you to the dietician so they can advise you on the best way for you to increase your intake. Eat little and often and add calories to food by adding butter, cheese, cream.
- **Hydration:** It is important to keep well hydrated– drink plenty of clear fluids aim for at least two litres– this does not have to be just water, it could be sports drinks, squash, tea and coffee.
- **Personal hygiene:** It is important to maintain good levels of personal hygiene to minimise bacteria on the skin, keep skin well moisturised to keep skin integrity at an optimum. You can shower with a PICC line but you will need to wear a plastic sleeve or similar and make sure you do not get it too wet. We will discuss with you how you can obtain one. If you have a CADD pump attached, again, you will need to put this in a plastic bag and put either on a chair next to the bath– making sure not to immerse the arm or put it outside the door of the shower.
- **Pets:** Having pets at home is not a problem but please try and avoid them licking your face, sleeping in the bedroom and avoid contact with their urine and faeces.

If you are ever in any doubt, please contact us– we are more than happy to answer your questions and provide reassurance or advice.

Contact numbers

Please use these numbers if you require help, advice or assistance at any time. Help is available 24 hours a day. Please have your hospital number available if possible and please state that you are an "Ambulatory Patient".

If it is an acute emergency, such as chest pain or difficulty in breathing, please call 999 immediately.

24 hour Haematology Helpline

0808 178 2212

Please use this number 24 hours a day seven days a week if you have urgent concerns. If there is no answer from this helpline, please leave a message and you will be contacted back.

Ambulatory Care Nurses

9am to 5pm Monday to Friday

Please contact us for non-urgent advice.

Anika Sirel and Natasha Woolgar

Mobile telephone: 07971 799 837

Hambleton Suite 9am to 5pm, Monday to Friday

Telephone: 0116 258 5124

Bone Marrow Transplant Unit

24 hours a day, seven days a week.

Telephone; 0116 258 5698

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 Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

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