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# Preparing for and receiving your autologous transplant if you have renal impairment

Bone Marrow Transplant Unit

Information for donors

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**Date of skin-tunnelled catheter insertion**

……………………………………………………………………………………

**Date of admission**

……………………………………………………………………………………

**Date to start G-CSF**

……………………………………………………………………………………

**Date of stem cell collection**

……………………………………………………………………………………

**Treatment regimen**

……………………………………………………………………………………

**Date of transplant**

……………………………………………………………………………………

**Other information**

**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

## Introduction

Your medical team has decided that you would benefit from having high dose therapy and stem cell transplantation. We hope that this booklet will help you to prepare for your stem cell transplant. Your treatment will be in two phases: collecting the stem cells, followed by chemotherapy and transplant.

## Collecting the stem cells

Medical research has shown that G-CSF (often combined with plerixafor) is one way of enabling us to collect stem cells from the blood. G-CSF is a growth factor that is used to increase stem cell production. Plerixafor helps to release the stem cells from the bone marrow. You will be given separate leaflets with further information about G-CSF and plerixafor.

Having signed a consent form and agreed to this treatment, you will have blood tests, including a viral screen. This test is to give us information about viruses you may have had in the past, and also routine elimination of serious viruses such as hepatitis and HIV. We are not allowed to store your stem cells unless we have this information, and your doctor will have explained the reasons for this.

You will also have pulmonary function tests to check how your lungs are working and an echocardiogram to check on your heart.

## Chemotherapy and transplant

Dates for your chemotherapy and peripheral blood stem cell collection have been planned (see dates below). Also, because you have renal impairment (your kidneys are not working as well as they should) you may need to have dialysis as shown below.

If you do not already have a Permacath, you will have one inserted either at Leicester General Hospital or your usual local dialysis centre.

## Your schedule

**Day 1 (Date): ………………………………………………………………**You will start your daily injections of G-CSF. You may wish to administer the injections yourself, and your nurse will teach you how to do this. Alternatively, arrangements can be made for your district nurse to do this for you.

You will need these injections daily until your stem cell collection is completed. The injections have been shown to work better if administered late afternoon or early evening.

**Day 4 (Date): ………………………………………………………………**Following your dialysis treatment, please come to Osborne Day Care on level 2 of the Osborne Building at Leicester Royal Infirmary. Bring any unused G-CSF injections with you.

A blood test will be taken to assess your blood count. You may be given a dose of plerixafor. If so, the injection will be given at 5pm.

When a bed becomes available, you will be admitted to the Bone Marrow Transplant Unit and, if you have been given a dose of plerixafor, the nurses will give your next dose of G-CSF the following morning at 8am.

**Day 5 (Date): ……………………………………………………………** You will have your first stem cell collection.

Stem cell collection is carried out using a cell-separating machine. The machine takes blood out of a vein, spins it in a centrifuge to separate the components and collects the stem cells into a bag. The remaining blood is then returned to the circulation via a different vein.

The stem cell collection will take approximately four to five hours and needs good access to two different veins or a functioning skin-tunnelled catheter.

You will usually need to have this procedure on two consecutive days, in order for us to obtain adequate numbers of cells for the transplant. The procedure is performed on Osborne Day Care.

You should not feel unwell during or after the procedure.

You will need G-CSF every morning and plerixafor every evening before any further stem cell collection.

**Day 6 (Date): ……………………………………………………………**You will have your second stem collection (if needed) and you will have your chemotherapy that afternoon or evening, provided we have collected sufficient stem cells.

**Day 7 (Date): ……………………………………………………………**You will have dialysis in the afternoon or evening.

**Day 8 (Date): ……………………………………………………………**You will have your stem cell infusion. Whilst you are in hospital the renal doctors will look at your blood test results every day and decide how often you need dialysis.

When we are satisfied that your blood counts have recovered sufficiently (usually between three and four weeks after your transplant), you may be discharged home with regular follow-up appointments. However, you may need to be transferred to the Renal Unit at Leicester General Hospital to continue your recovery.

## Cell storage

Your cells will be stored in an accredited facility, approved by the Human Tissue Authority. Whilst every care is taken to ensure your cells are transported and stored safely, we cannot be held responsible for events outside our control (for example, road traffic accidents or power failure) that may result in the loss of your cells. Cells will be stored until required for your treatment, or up to five years.

The need for continued storage will be kept under review. Your cells will be destroyed in the event of your death, or after five years in storage if your doctor decides they are no longer of any benefit to you. You will be issued with a form telling you what cells are stored on your behalf.

If any cells are used in your treatment, or destroyed after five years, you will be sent an updated form. If you move house, please inform the laboratory using the contact details on the form.

## Preparing for your transplant

Before admission you will have to undergo a number of tests and investigations in order to make sure you are fit to undergo treatment.

These may include:

- Full medical examination
- Blood tests
- Bone marrow test
- X-rays
- ECG, echocardiogram and other tests to see how you heart is working
- Pulmonary function tests to see how your lungs are working
- Insertion of a skin-tunnelled catheter line (you will receive a separate booklet about this).

Your medical examination must be within 30 days of the transplant, and the final decision to go ahead with the procedure may only be made a few days before your admission to hospital. If there is a problem you will receive a telephone call from the transplant team to advise you of this.

## What are the risks?

The doctors looking after you will talk to you about the benefits of this treatment. However, you must remember that bone marrow / stem cell transplantation is a major treatment and does carry certain risks, the main one being infection.

You will be given every opportunity to discuss your treatment and you must ask all the questions you want to before you sign the consent form. It is often useful to write down any questions you may have.

## How can I prepare for my treatment?

- Eat as much and as well as you can. Try to put on some weight, as the treatment will make you lose weight.
- Begin good all round hygiene routines, including having a bath or shower every day.
- Start or continue to pay attention to good oral hygiene, and visit your dentist for a check up. However, please check with the hospital before having any dental work done.
- Give up smoking. This will reduce the risk of chest infections and improve your chance of survival. Smoking increases the risk of other cancers, especially lung cancer. If you continue to smoke, the benefits of your treatment may be lessened. Please ask your doctor or nurse if you would like details of local Stop Smoking Service.
- Think about how you may wish to pass time whilst you are in hospital. Start collecting together things to bring in with you, such as books, games and comfortable clothes. Items such as books and games must be new. Electrical items such as games consoles can be brought in, but will need testing for electrical safety before being plugged in.

- Think about how you will keep in touch with friends and family. You may use your mobile phone in hospital. If you are bringing in your laptop, you may need a dongle to access the internet.
- Make a list of questions to ask your doctor or nurse.
- Try to sort out any financial or family problems before coming into hospital. If you require advice about benefits or other financial issues, please contact the Cancer Information Centre (details at the back of this booklet).
- If you wish to have children at some time in the future please make sure you discuss this with your consultant (there is further information about this later in this booklet).
- Remember, having a transplant is a major treatment and you should discuss it with your family.

## Things to bring with you

- A pair of slippers.
- Soft toothbrush, toothpaste, box of tissues, a comb.
- An electric razor (if you shave). Wet razors are not allowed.
- Comfortable clothes to wear during the day.
- Pyjamas or other nightwear.
- Your current medications.
- Your wig (if you wear one). However, if worn it will need to be washed frequently. Hats and scarves are usually better.

## Eating and drinking

It is important to try to continue to eat and drink well in order to aid your recovery. While you are in hospital you will see a dietitian, and be given verbal and written information about food safety. You will need to follow the food safety advice to help prevent food-borne infection whilst your immunity is low.

## Conditioning treatment

One day of chemotherapy is necessary in order to rid your bone marrow of its diseased cells. This is known as the conditioning treatment. The chemotherapy is given via your skin-tunnelled catheter (you will receive a separate booklet about this), and details of your particular treatment regime will be explained to you before starting it.

We aim to control the side effects of treatment and it is important to tell staff if you are experiencing side effects.

## Receiving the stem cells

The stem cells are infused back into you via your skin-tunnelled catheter, not unlike a blood transfusion. You may experience side effects such as flushing and sweating during the infusion. The infusion takes between one and two hours to complete.

Your cells may have been frozen after they were collected from you. If so, a preservative called DMSO is used. When these stem cells are infused back into you, one of the side effects of the DMSO may be that your breath smells of sweetcorn for the next couple of days.

During the infusion, nursing staff will observe you closely, recording your blood pressure, pulse and temperature at frequent intervals.

## Side effects of treatment

The nursing and medical staff will monitor you closely and will take blood samples every day. You may develop an infection, experiencing a few days of high temperature, requiring antibiotic treatment. You may also require intravenous fluids and the amount of dialysis you have may need to be changed.

You may require frequent blood and platelet transfusions until the bone marrow is adequately recovered to produce enough of its own. Many people develop mucositis (painful inflammation of the mouth, throat and gullet), for which lozenges and strong pain-killers will be given.

You may also experience periods of diarrhoea.

Nausea and being sick may become a problem, but we can give you medication to control this.

Please remember that not every patient will experience the same side effects. Please let your doctor or nurse know about any side effects that you are having. You will be reviewed each day by doctors from both the renal and transplant teams.

## Infection risks

All measures taken during your stay in hospital are intended to minimise the risk of you developing an infection. However, we all carry organisms on the skin, in the mouth and gut and these are likely to cause high temperatures and infection when your defence mechanisms are low.

Throughout your stay you will have to observe scrupulous personal hygiene, which includes taking a shower daily using a special antibacterial soap solution and nose cream. Do not bring in any creams as your skin becomes very sensitive after treatment and these products can cause reactions.

You will need to:

- Wash your hands, and use a disinfectant hand rub, after using the toilet and before eating.
- Change into clean clothes daily.
- Wear slippers or lightweight shoes (no bare feet).
- Maintain a high standard of oral hygiene. You may have already used various mouthwashes - this will continue. It is a good idea to bring in a soft toothbrush.

All belongings which you want while you are in hospital must be clean. If you are unsure about the suitability of any items please ask.

## Hair loss

You will start to lose all or most of your hair approximately ten to fourteen days after your chemotherapy. It will start to grow again in about three months. Many people like to have long hair gradually cut shorter before admission, and some like it cut again in hospital.

Please ask your nurse if you would like to be referred to the Hair Loss Service for a wig. There is a headwear shop in the reception area of the Osborne Building at Leicester Royal Infirmary where you can buy scarves and hats.

## Visitors

**Having visitors is an important part of your recovery, but there are a few simple guidelines:**

- Visiting time is 11am until 8pm. Visiting may be allowed at other times of the day at the discretion of the staff and, of course, depending on how you are feeling. Visitors will be allowed into your room throughout your stay, even when you are isolated. We ask that you do not have more than two visitors at any one time.
- Please make your relatives and friends aware that if they feel ill, have diarrhoea, sore throats, any type of infection or have been in contact with any illnesses, such as chicken pox, measles, etc., then they must stay away. Check with the nursing staff before they visit you again.
- We ask that visitors who come to see you after work have a bath or shower and change their clothes before coming to visit.
- If you have children who are of school age, it is advisable to inform the head teacher about your treatment and of the implications of being in contact with childhood diseases. This is so that if there is an outbreak they can keep you informed.
- When you are neutropenic (your white blood cell count is low), we recommend that you keep your visitors to a minimum. We recommend that babies are not brought into the hospital, and discourage children under the age of twelve from visiting. Please speak to your nurse if you want children to visit, and ensure that all children are supervised by a responsible adult.

Accommodation is available near to the hospital for relatives. Please call the Accommodation Office on 0116 258 4249 for details. It may be possible to arrange short-term accommodation in the hospital itself.

## Going home

Most patients are ready to go home after about three to four weeks in hospital. Once your white cell count is recovering and you have no further problems, you will be allowed home. You will need to attend regular outpatient appointments at the Hambleton Suite until your condition remains stable. You will receive a separate booklet containing more information about your discharge.

## Relationships and sex

The stress, separation and worry of the disease and transplant can cause a strain on any relationship. The treatment itself does not affect your ability to have sex, but your sex drive may be reduced for some months. In order to protect against infection we advise that you refrain from sex for three months following your transplant. However, if you do choose to have sex during this time you should always use a condom.

After transplant, many women who have not been through the menopause will experience an early menopause. They may require Hormone Replacement Therapy (HRT). It is also possible that men may experience hormonal problems following treatment, and they may need treatment for this.

## Fertility

The treatment you receive will reduce your fertility.

Patients who have had high dose chemotherapy do have some chance of fathering a child, and even if they are infertile immediately post treatment, they should be aware that their fertility can return up to three years after treatment.

If you wish to discuss fertility issues, an appointment can be made for you at the Assisted Conception Unit to talk about this.

## Building and decorating precautions

It is important that you do not have any decorating or building work carried out in your home while you are recovering after your transplant. We advise that you wait for six months before having this sort of work done. This includes such as things as removing wallpaper or drilling holes, as these activities release fungal spores that can lead to serious infections.

## Vaccinations

You will need to have vaccinations for all childhood diseases about six months after your transplant. Please speak to your consultant if you require further information about this.

## Work

You will need three to six months off work, depending on your job.

## Exercise and driving

You will be advised about when you can resume driving and exercise.

## Regulation of transplantation

Transplantation is a carefully regulated process, and all transplant units must be licensed by the Human Tissue Authority (HTA).

Further information is available on the HTA website:

**www.hta.gov.uk**

## Contact numbers

**Hambleton Suite**

Mon - Fri, 9am - 5pm
Telephone: 0116 258 5124

**Bone Marrow Transplant Unit (BMTU)**

24 hours, 7 days a week
Telephone: 0116 258 5698

## Sources of further information

**Macmillan Information and Support Centre**

Osborne Building, Leicester Royal Infirmary, Leicester LE1 5WW

Telephone: 0116 258 6189

Email: cancerinfo@uhl-tr.nhs.uk

Website: leicestershospitals.nhs.uk/cancerinfo

**Sue Young Cancer Support**

Helen Webb House , 35 Westleigh Road, Leicester LE3 0HH
Tel: 0116 223 0055

**Macmillan Cancer Support**

Freephone: 0808 808 00 00

Website: www.macmillan.org.uk

**Bloodwise**

Telephone: 0808 2080 888

Website: www.bloodwise.org.uk

**Lymphoma Action**

Telephone: 0808 808 5555

Website: www.lymphoma-action.org.uk

**Leukaemia Care**

Tel: 08088 010 444 (24 hours)
Website: www.leukaemiacare.org.uk

**Myeloma UK**
Myeloma Infoline: 0800 980 3332
Website: www.myeloma.org.uk

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہِ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغةٍ أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل

જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀ ਇਹ ਜਾਣਕਾਰੀ ਕਸਿ ਹੋਰ ਭਾਸ਼ਾ ਵਚਿ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਰਿਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ ‘ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।

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

Previous reference: CAN264

**If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email equality@uhl-tr.nhs.uk**

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