



# Preparing for your autologous stem cell / bone marrow transplant

**Bone Marrow Transplant Unit** 

Information for patients

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important dates
Date of admission to hospital
Date of skin-tunneled catheter insertion
Date treatment starts
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

You have been referred for an autologous stem cell / bone marrow transplant. This is a transplant using your own cells to replace your bone marrow following high dose chemotherapy and / or radiotherapy.

Before the transplant goes ahead you will be counselled by the Transplant Team to make sure that you understand what will happen.

### What is involved in having this treatment?

You will be in hospital for three to four weeks, during which you will have high dose chemotherapy, followed by an infusion of stem cells or bone marrow. A small number of patients will receive radiotherapy as well as chemotherapy.

#### Stem cell collection

Before your transplant can go ahead, you need to have had a successful stem cell collection.

## 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
- Other heart and lung function tests
- Insertion of skin-tunnelled catheter, which is a thin flexible tube that is inserted under skin of your chest into a vein (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.

# 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**

Up to six days of chemotherapy are 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 skintunnelled catheter (you will receive a separate booklet about this), and details of your particular treatment regime will be explained to you before you start treatment.

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

A small number of patients need radiotherapy as part of their conditioning treatment. This will be given in the Radiotherapy Department in the Osborne Building. If your consultant recommends radiotherapy as part of your treatment, you will be given written information about radiotherapy and its side effects.

# Receiving the stem cells / bone marrow

The bone marrow or stem cells are infused back into you via your skin-tunnelled catheter, or PICC line, 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.

After your cells were collected from you they were frozen, and a preservative called DMSO used. When your 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.

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 diarrhea, especially following total body irradiation.

Nausea and vomiting 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.

## Infection control

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. We will provide suitable moisturisers as needed.

#### 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.

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. You can have two selected visitors. 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. This is because of your increased risk of infection. 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.

# **Visitors (continued)**

• 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 Team on 0116 225 5388 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 going home. 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.



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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



# Emergency contact number (24 hours a day, 7 days a week)

Telephone: 07931 865272

### Other useful contact numbers

If you have any questions at any time during the whole process, please phone the following numbers, according to the hospital you normally attend.

## **Leicester Royal Infirmary**

#### **Hambleton Suite**

Telephone: 0116 258 5124 Monday to Friday, 9am – 5pm

#### **Osborne Day Care**

Telephone: 0116 258 5263

Monday to Friday, 8.30am - 6pm, Saturday 8.30am - 4.30pm

#### **Haematology Ward (Ward 41)**

Telephone: 0116 258 5088 or 258 6832

24 hours, 7 days a week

#### **Bone Marrow Transplant Unit**

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

## 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

Telephone: 0116 223 0055

Website: www.sueyoungcancersupport.org.uk

### **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

Telephone: 08088 010 444

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۔ علی هذه المعلومات بلغةٍ أُخری، الرجاء الاتصال علی رقم الهاتف الذي يظهر في الأسفل જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

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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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