University Hospitals of Leicester
NHS Trust

Preparing for your Allogeneic Stem Cell or Bone Marrow Transplant

Bone Marrow Transplant Unit

Information for patients

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Date of admission

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Date of PICC line insertion

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Date treatment starts

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Treatment regimen

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Date of transplant

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Other information

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or call 111 for non-emergency medical advice

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Introduction

You have been referred for an allogeneic stem cell / bone marrow transplant. This is a transplant using cells that are given to you by another person (the donor).

Before the transplant goes ahead, you and your donor will be counselled separately to make sure that you understand what will happen.

What is involved in having this treatment?

You will be in hospital for four to six weeks, during which time you will have chemotherapy and / or radiotherapy followed by an infusion of stem cells or bone marrow from your donor.

Pre-transplant preparation for your donor

Your donor will undergo investigations to make that they are medically fit to donate, in order to minimise the risks to both them and you. The method of donation (peripheral stem cells or bone marrow) will be decided once your donor has been assessed as suitable.

Pre-transplant preparation for you

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

- Full medical examination
- Blood tests
- Bone marrow test
- X-rays
- ECG
- Echocardiogram
- Other heart and lung function tests
- Insertion of a Hickman line (you will receive a separate booklet about this)

If you have lost a lot of weight due to previous treatments, or are struggling to eat enough, you may need to have a feeding tube inserted before your transplant. This is so that you can have nutritional supplements through the tube to ensure that you are well nourished. This will aid your recovery. If the Transplant Team feels that you need to have a feeding tube, you will be given the opportunity to discuss this with them and will be given further information.

Both your medical examination and that of your donor 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 possible 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 ones being infection and graft versus host disease (GVHD). These are explained later in this booklet.

You will be given every opportunity to discuss your treatment with the Transplant Team 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 the 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 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 will 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 ask your nurse.
- If you are due to have any vaccinations, please check with the Transplant Team first.
- 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 the booklet).
- Remember, transplantation is a major treatment and you should discuss it with your family.

A room on the Bone Marrow Transplant Unit

Admission to hospital

When you are admitted to hospital you will either start treatment on the same day or night, or you may need further blood tests and then start treatment the following day.

Each room on the Bone Marrow Transplant Unit has en suite facilities (see above).

On very rare occasions, you may be initially admitted to Ward 41 in the Osborne Building at Leicester Royal Infirmary, where the facilities are different.

En suite facilities on the Bone Marrow Transplant Unit

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.

As well as regular hospital meals, snacks, soups and drinks are provided for you on the Bone Marrow Transplant Unit.

Conditioning treatment

This is the treatment given to you before your stem cell transplant. Up to eight days of chemotherapy, or chemotherapy and radiotherapy, are necessary in order to prepare you for your treatment. The chemotherapy, is given via your PICC line (you will receive a separate booklet about this), and details of your particular treatment regimen will be explained to you prior to admission.

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

Some patients will receive Total Body Irradiation (TBI) as part of their conditioning treatment. This is given in the Radiotherapy Department in the Osborne Building twice a day for three days, each session lasting for about half an hour. You will visit the department for a planning appointment before your admission and will be given written information about TBI.

Receiving the stem cells / bone marrow

If your donor is a sibling, they will come to Osborne Day Care on Level 2 of the Osborne Building at Leicester Royal Infirmary.

If your donor is unrelated, they will donate their bone marrow or stem cells at another hospital and a special courier will bring it to the hospital.

The bone marrow or stem cells are infused back into you via your PICC line, not unlike a blood transfusion. You may experience side effects such as flushing and sweating during the infusion, although these are rare. The infusion takes between one and four hours to complete.

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

After your transplant

The nursing and medical staff will monitor you closely and will take blood samples every day. At some point during your stay you can expect to 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 painkillers will be given. You may also experience periods of diarrhoea, especially following total body irradiation and as a result of graft versus host disease. It is very important that you tell the nursing staff if you have diarrhoea, as they will need to monitor the amount to see how much fluid you are losing.

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.

Graft versus host disease (GVHD)

GVHD can occur after an allogeneic transplant. It happens when the new cells (the graft) react against your own tissues (the host). It does not mean that the transplant has failed, and it may even be of benefit, as some of the cells involved in the reaction may also attack any cancer cells that have survived.

The Macmillan Cancer Support booklet Understanding Donor Stem Cell (Allogeneic) Transplants contains more information about GVHD. If you have not got a copy of this booklet, please contact Macmillan (details are at the back of this booklet).

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 our skin, and in our mouths and gut, and these may cause high temperatures and infection when your defence mechanisms are low.

To protect yourself you need 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 of your own toiletries - it is not advisable to use deodorant or 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 mouth washes - 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.

We will monitor you for infections, including viruses that you may have been exposed to in the past. These viruses can become active again due to your lowered immunity following your transplant. You may require long-term treatments for this, and you may require occasional re-admission to hospital to treat these more effectively.

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 the 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 three 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 on 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.
- If your visitors have manual jobs, and are visiting after work, please advice them to 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. If anyone in your family is due to have any vaccinations, please check with the Transplant Team before they have them.
- We recommend that your carers have the seasonal ‘flu jab’ in order to help protect you.
- 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 you, 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 225 5388** for details.

Going home

Most patients are ready to go home after about four weeks in hospital. Once your white cell count has recovered and if you have no further problems, you will be allowed home. You will need to attend outpatient appointments at the Hambleton Suite at least once a week for the first three months following your transplant then less frequently if your condition remains stable. When you go home you will receive a separate booklet containing more information about your discharge.

When you come to clinic you will be given a booklet produced by the Anthony Nolan organisation called ‘The Seven Steps: The Next Steps’.

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.

It is also probable that 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 some men may experience hormonal problems following treatment.

Fertility

Women

Very few women are able to conceive naturally after total body irradiation or high dose chemotherapy. If you require further advice, please ask for a referral to the Assisted Conception Unit (ACU).

Men

Men who have had total body irradiation are almost always infertile.

Those who have had high dose chemotherapy only 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 the possibility of sperm banking, an appointment can be made for you at the Assisted Conception Unit to talk about this.

Please talk to your consultant if you want to discuss this further.

Safety at home

It is important that you do not have any decorating or building work carried out in your home while you are on immunosuppressant drugs (such as ciclosporin or steroids). This includes such things as removing wallpaper or drilling holes, as these activities release fungal spores that can lead to serious infections. You should also avoid handling wood and logs for open fires and wood burning stoves.

Please ask if you require further advice about this.

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

Who should I contact if I have any questions or concerns?

Please feel free to contact us using the following numbers:

Leicester Royal Infirmary

Osborne Treatment Centre (Monday to Friday, 8am to 4pm)

0116 258 5263

Hambleton Suite (Monday to Friday, 9am to 5pm)

0116 258 5124

Bone Marrow Transplant Unit (24 hours, 7 days a week)

0116 258 5698

Trusted Information Creator

Patient Information Forum

Further information

Macmillan Information and Support Centre
Osborne Building, Leicester Royal Infirmary, LE1 5WW

Telephone:	0116 258 6189

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

Leukaemia Care

Telephone:	08088 010 444
Website:	www.leukaemiacare.org.uk

Blood Cancer UK

Telephone:	0808 2080 888
Website:	www.bloodcancer.org.uk

Lymphoma Action

Telephone:	0808 808 5555
Website:	www.lymphoma-action.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

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

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