

Going home after your autologous transplant

Bone Marrow Transplant Unit

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Information for patients

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Introduction

We hope that this booklet will answer some of the questions that you may have about going home after your autologous transplant.

Please feel free to discuss any queries that you may have with the staff on the ward or the Bone Marrow Transplant Unit (BMTU).

The Macmillan booklet 'Understanding High-Dose Treatment with Stem Cell Support' has more information that you might find helpful. If you would like a copy, please ask your nurse or contact Macmillan directly (details at the end of this booklet).

Out-patient appointments

Once you have been discharged from the unit your care will continue as an outpatient.

At first you will be required to attend the Hambleton Suite on the BMTU once a week. We will gradually reduce the frequency of visits over a three month period, after which you will be referred back to the medical team that referred you to us.

The purpose of these visits is to enable medical and nursing staff to check your general physical and mental well-being. This may include:

- Taking blood samples to check cell counts
- Having platelet and blood transfusions
- Checking for any complications resulting from your transplant, such as infection
- Prescribing or altering any drugs that you require
- Helping with any other problems

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

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

Re-admission to hospital

It may be necessary for you to be re-admitted to hospital during the first few months. The reasons that patients are re-admitted to hospital include infections, mouth problems, difficulty eating, nausea, and to have blood and platelet transfusions.

Looking after yourself

After leaving hospital every patient has to find their own balance between the feeling of wanting to return to a normal way of life, and feelings of anxiety after several weeks spent within the protective environment of the Bone Marrow Transplant Unit or Ward 41. The following information may help you.

Avoiding infections

- Try to avoid contact with people who have colds, coughs, sore throats, “tummy bugs”, diarrhoea or vomiting.
- If you come into contact with anyone who has an infectious disease, such as flu or chickenpox, you must contact the hospital.
- You should continue strict daily hygiene routines, having a bath or shower daily and washing your hands regularly with soap and water.

Socialising

- As you need to avoid contact with people who have colds etc. during the first three months after treatment, you must avoid enclosed crowded places such as busy shops, public houses and cinemas etc. However, it is quite safe to mix with small numbers of friends in your or their own homes.

Looking after your mouth

- You may find that your mouth remains dry and sore, even after discharge. Due to your recovering cell count, your mouth will be more vulnerable than normal to infections for a few months. If your mouth is very sore, eat soft moist foods and nourishing drinks and avoid rough and dry foods, such as toast and dry biscuits.
- It is important to use the mouth washes that have been prescribed for you. Apply Vaseline or a lip moisturiser if your lips are dry and chapped, and clean your teeth with a soft toothbrush after each meal, if possible.
- Please do not have any dental work done for at least three months. If you do need to go to the dentist please ask first, and you should also tell the dentist that you have had a bone marrow / stem cell transplant

Eating and drinking

- If you have problems with eating and drinking, here are a few points that might help:
- Nausea (feeling sick) after your treatment is often only temporary, but let the doctor or nurses know if you feel sick, as anti-sickness drugs can be given to you to take at home.
- Your sense of taste may have changed after treatment: it might help if you enhance the flavour of foods using seasoning or herbs.

- Sharp tasting drinks such as fruit juices, lemonade and tonic water may help with any taste changes.
- Drink plenty of fluids.

Try to eat a balanced diet every day. It is probably best to try small, frequent meals. Avoid fruit or vegetables that look of poor quality and are bruised, as they may contain bacteria. If you wish to eat uncooked fruit or vegetables they must be washed and peeled.

All hot meals should be eaten after they have been freshly cooked, and not left or reheated, as this also allows bacteria to grow.

Eating out

- Following your transplant you must avoid eating out and take away foods, until you are told otherwise, usually about three months after your transplant. After this you should choose reputable restaurants only, which you know prepare food well. Do not eat from mobile food outlets or ice cream vans.

Drinking

- A good fluid intake is encouraged during your hospital stay, and you should try and continue this when you go home. Drink up to three litres of fluid each day. Tap water is safe to drink when you are at home.
- Check with your doctor before drinking alcohol, because alcohol can interact with some drugs.

Looking after your skin

- Combinations of chemotherapy and radiotherapy may have left your skin dry and sensitive. You should avoid scented toiletries and continue to apply creams etc. which you have been prescribed.
- Please inform your doctor or nurse if you develop rashes or red itchy areas. Use mild creams or ointments and continue to apply any preparations which have been prescribed.
- During warmer weather you should avoid sunbathing and use a high factor sunscreen (SPF50 or above) when going outdoors. As your skin will be extra sensitive at this stage, you should avoid exposure to the sun as much as possible. Do not sit out in the sun, wear a hat, and keep you legs and arms covered.

Your hair

- You will probably find that your hair will grow again three to four months after your transplant. It often grows back a different colour or a different texture, for example, curlier or straighter than it was before.

Your pets

- Your pets are part of family life, and you only need to be concerned with routine hygiene matters, such as trying to avoid allowing pets onto dinner tables and onto beds and food preparation areas. Try and keep your pets within their own “boundaries”, on their own chair or mat. Discourage pets from licking your face and hands and ask someone else to empty litter trays.

Recovering from treatment

Going back to work, college or school

- Your return to work depends on how quickly you recover and the type of work that you do. Discuss your work situation with your doctor or nurse.

Psychological help

- Having a transplant can be a very emotional time, and you might need to talk to someone about how you are feeling. The transplant nursing and medical teams are available to talk to, and they will refer you to counselling services as necessary.

Financial problems

- Your income may have been affected by your illness. Please ring the Macmillan Citizens Advice Bureau helpline for advice:

Telephone: 0300 456 8400

Sexual relationships

- The stress, sensation 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 protection.
- 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 possible that men may experience hormonal problems following transplant, and they may need treatment for this.

Travel

- If possible try to avoid buses and other forms of public transport for the first few months after your discharge.
- You will probably be able to drive again within a few weeks, but check with your doctor first. Otherwise use taxis or have a relative or friend give you a lift if they can.
- As a short-term measure it may be possible for us to arrange transport to and from the hospital, but please give us plenty of notice.

Holidays

- In the first few months after your transplant, it should be possible to have holidays in this country. You should not travel abroad for at least three months. If you wish to travel abroad after this time, you should speak to your consultant before booking anything. He or she will then be able to discuss the possible problems involved in foreign travel and give you advice about when you could go.

- If you need to have immunisations please discuss these with your hospital consultant before you have them.
- We also advise you to take out adequate insurance. The Macmillan Information and Support Centre can provide information about travel insurance.

Medicines

- When you are first discharged from the hospital you will continue to take a number of medicines. This number will gradually decrease. Follow the instructions that you are given and do not stop taking any drugs that you have been given, unless advised to do so by a doctor or nurse.
- Please bring your medication list to all your appointments so that it can be updated as needed.

Vaccinations

- Six months after treatment you will be given a written schedule to take to your GP practice so that you can have a course of vaccinations. These will include those that you received as a child, as the treatment that you have had will have made you lose your immunity. It is advisable for your close family to have the seasonal “flu jab” as this will help to protect you. Your doctor will advise you when to have the “flu jab” yourself.
- You may also be offered vaccinations against other childhood diseases that were not previously available to you.
- You will need to start your vaccination schedule before you go back to work.

Contact numbers

If you have any questions at any time during the whole process, please phone us:

Leicester Royal Infirmary

Hambleton Suite

Telephone: 0116 258 5124

Monday to Friday, 9am – 5pm

Bone Marrow Transplant Unit

Tel: 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

Website: www.uhleicester.nhs.uk

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 براہ 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 ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।
Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

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