

Going home after your allogeneic transplant

Bone Marrow Transplant Unit

Produced: Jan 2020

Information for patients

Review: Jan 2023

Leaflet number: 638 Version: 2

Introduction

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

The Macmillan booklet “Understanding Donor Stem Cell (Allogeneic) Transplants” and a booklet produced by the Anthony Nolan organisation called “The Seven Steps—The Next Steps” both have more information that you might find helpful. If you would like a copy, please ask your nurse or they can be ordered from the organisations (contact details at the end of this booklet)

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

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 Bone Marrow Transplant Unit once or twice a week. We will gradually reduce how often we need to see you, but you may need to attend weekly for about three months, according to your progress. It may be possible later on for some patients from outside Leicester to divide follow-up visits between their local hospital and the Leicester Royal Infirmary.

The reason we need to see you is so that we can check how well you are recovering. We may:

- Take blood samples to check your cell counts and for signs of infection.
- Check ciclosporin levels.
- Give you platelet and blood transfusions.
- Check for any complications resulting from your transplant, such as infection or Graft-versus-host disease (GvHD: both the Macmillan and Anthony Nolan booklets mentioned above have more information about this).

**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

- Prescribe or alter any drugs that you require.
- Carry out Hickman line dressings and line flushing.
- Give advice about dietary problems, and monitor any weight loss.
- Help with any other problems.

Re-admission to hospital

You may need to be re-admitted to hospital, perhaps more than once, during the first few months. If you experience side effects from treatment, or feel unwell, it is essential that you contact us for advice. The reasons that patients are re-admitted to hospital include infections, mouth problems, problems eating, GVHD-related problems, 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 sickness.

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, washing your hands regularly with soap and water, and having a shower every day using StelliSept. This is particularly important if you still have a line in place, such as a Hickman line or PICC line.

Socialising

As you need to avoid contact with people who have colds etc. during the first six to twelve 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 from hospital. 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

If you have problems with eating and drinking, here are a few points that might help.

Nausea

If you feel sick (nauseous) following your treatment, this is often only temporary.

Let the doctor or nurses know if you feel sick, as anti-sickness drugs can be given to you to take at home.

Sense of taste

Your sense of taste may have changed after treatment.

- Enhance the flavour of foods using seasoning or herbs.
- Choose sharp-tasting drinks such as fruit juices, lemonade and tonic water.
- Drink plenty of fluids.

Diet

Try and 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. You will be given a booklet called "Food Hygiene and Safety" - it contains further advice about eating and drinking.

The ward dietitian is available to answer any questions you may have relating to food after your discharge.

Eating out

Following your transplant you must avoid eating out and take-away foods, until you are told otherwise. 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.

You should not drink grapefruit juice or eat grapefruit whilst on ciclosporin.

Check with your doctor before drinking alcohol, as alcohol can interact with some drugs.

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.

If you are taking ciclosporin you may find that your hair growth is quicker and thicker. It can also cause more body hair to grow. Once you stop taking ciclosporin, your hair growth will gradually go back to normal.

Looking after your skin

Combinations of chemotherapy and radiotherapy (or if you have had skin GVHD) may have left your skin dry and sensitive. You should avoid scented toiletries (such as soaps and bath salts) 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. Sunlight can trigger skin GVHD and increases your risk of developing skin cancer.

Wear a hat, keep your legs and arms covered and do not sit out in the sun.

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

Exercise

Once you go home you should gradually increase your activity levels. At first you will feel very tired, but this will improve. You should try to arrange for someone to stay with you for the first couple of weeks, to help with housework, shopping, cooking and other tasks.

Initially, try to go for a walk each day, going a little further each time. Build up to more strenuous activities over a few months as you begin to feel stronger.

Safety at home

Following your transplant, it is important that you do not have any building or decorating work carried out in your home. This includes things such as removing wallpaper or drilling into walls, as these activities release fungal spores that can lead to serious infections. You should also avoid handling wood or logs for open fires or wood burning stoves.

If you need further advice, please ask your nurse or doctor.

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 Citizens Advice Macmillan helpline for advice:

Telephone: 0300 456 8400

Sexual relationships

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 at least three months following your transplant, and that you talk to your transplant doctor or nurse before resuming sexual activity.

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

Do not use 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 ask 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 for you to have holidays in this country. Travelling abroad is not advised and 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 unit 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

About six months after treatment you will be given a written list 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 close family members 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 having your vaccinations before you go back to work.

Who to contact

If you have any questions or concerns following your discharge please contact us:

Leicester Royal Infirmary, 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

Coping with Cancer

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

Myeloma UK

Myeloma Infoline: 0800 980 3332

Website: www.myeloma.org.uk

Anthony Nolan

Telephone: 0303 303 03 03

Website: www.anthonynolan.org

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغة 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 ਕਸਿ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ 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

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