



The Clatterbridge
Cancer Centre
NHS Foundation Trust

Going Home After Your Stem Cell Transplant

Haemato-Oncology

A guide for patients and carers

Contents

Problems to look out for and that should be reported immediately are	2
Preventing infection	3
Situations and activities to avoid if possible	3
Pets	5
Precautions	5
Vaccinations	5
Nutrition	6
Mouth care	6
Skin care	7
Outpatients clinic and day care	7
Resuming usual activities.....	8
Sexual activity	9
Practical and emotional support.....	9
Further Information.....	11
Notes	12



his information is for patients going home after a stem cell transplant. This leaflet gives advice for you to read and refer to, to help with your recovery.

Please contact the unit immediately if:

- You feel unwell
- Have a high temperature of 38 degrees centigrade (100.3 Fahrenheit) or above
- If you have any problems

Please check your temperature at least twice a day. It is vitally important that any post-transplant problems are dealt with promptly.

If you do feel unwell or have a high temperature, do not stay at home and wait for it to go away. Please contact the unit immediately, without delay.

Telephone number Ward 5: 0151 318 8630 / 0151 318 8631

It is most likely that you will be advised to attend your nearest A&E. Please remember to take the chemo alert card you were given at discharge with you.

Problems to look out for and that should be reported immediately are:

- A high temperature of 38 degrees centigrade (100.3 Fahrenheit) or above
- Chills, sweating, shivering (even without a temperature)
- Redness, tenderness or swelling around your Hickman line
- Discharge from your line
- Feeling shivery or unwell after your line has been flushed
- Bleeding
- Pain
- Shortness of breath, cough, chest pain
- Nausea and vomiting which prevents you from taking fluids, medication and food
- Bruising, skin discoloration, rashes, blisters or itchiness
- Sore mouth
- Diarrhoea, abdominal pain, blood in your stools
- Frequent or painful urination, blood in your urine



Preventing infection

Please continue to take precautions to prevent infection. Even though your body is now producing white cells again, your risk of infection will remain higher than normal.

Observe good hygiene. Washing hands frequently and consistently with soap and water or alcohol gel is a very important way of preventing infection. As well as maintaining your usual hand washing routines, please remember to wash your hands:

- Before eating or preparing food
- Before touching your eyes, nose and mouth
- After touching plants
- After touching pets and animals
- After going to public places

Situations and activities to avoid if possible

- Avoid people who have symptoms of a contagious illness
- Symptoms include: fevers, rashes, vomiting, diarrhoea, sore throat, cough, runny nose or conjunctivitis
- Avoid people who have been in contact with someone with a contagious illness
- Avoid crowds of people, including public transport
- Avoid public places during peak hours

- Avoid close contact with people who may have developed a fever and/or rash after having the MMR vaccination. If a family member has recently had the BCG vaccine they should keep any scab covered

When close contact with unwell people is unavoidable, wash hands regularly and encourage them to cover their mouth and nose when coughing and sneezing. Inform the transplant team if you have been in contact with anyone with a contagious illness.

- Avoid cleaning up animal faeces and cleaning out litter trays, cages and fish tanks
- Avoid gardening or direct contact with soil or plants
- Avoid handling rubbish
- Avoid construction sites and dusty environments
- Avoid changing nappies, if possible
- Do not swim

If you do need to carry out some of the activities listed above, wear gloves, if appropriate, and wash hands afterwards.



Pets

Seek veterinary assistance if your pet is unwell and keep pets up to date with non-live vaccinations. Feed your pet good quality commercial pet food or ensure food given to them is well cooked and pasteurised. Cat litter should be changed daily, but avoid doing it yourself. Do not keep cat litter in the kitchen or in dining areas. It is preferable to keep cats inside and to prevent pets from scavenging. Do not adopt stray animals or young or ill pets and avoid contact with reptiles, exotic pets, ducklings and chicks.

Precautions

Patients who have had a transplant using their own stem cells (autologous transplant) should follow precautions for approximately three months.

Patients who have received stem cells or bone marrow from a donor (allogenic transplant) should follow precautions for approximately six months.

The precautions may need to be followed for a longer period if you are receiving substantial immunosuppression. Please clarify with the medical team how long it is necessary for you to follow restrictions.

Vaccinations

Do not have any immunisations unless advised to by the bone marrow transplant team. Your family should be vaccinated as normal.

Nutrition

Please continue to follow the advice in the 'guide for patient's with weakened immune system' as certain foods should be avoided. You may still experience nausea and taste changes for a while after transplant. Take anti-sickness tablets regularly, if required.

It is important to maintain a good nutritional input to help recovery and avoid excessive weight loss. Your appetite may have decreased after treatment. It may be necessary to eat small meals, little and often.

Follow advice from the dietician and continue supplements, if necessary. Try and drink plenty and avoid alcohol, initially.

Mouth care

Your mouth may remain dry following treatment. Try using synthetic saliva, boiled sweets, iced lollies and citrus fruits. If you are taking Ciclosporine, please avoid eating or drinking grapefruit, as it may interact with this medication. Keep your mouth clean and follow your usual mouth care routine. If you develop any mouth ulcers or your mouth becomes sore, please notify medical and/or nursing staff at your outpatient appointment.

If you need any dental work doing please check with the transplant team first as you may need to be referred to the Dental Hospital and need antibiotic cover to prevent infection.



Skin care

Use factor 50 sunscreen – even if you are only going out for a few minutes. Your skin is very sensitive to sunlight after your transplant and even mild sunburn can cause damage to your skin. Use a hat and cover up/stay in the shade where possible. You are still at risk of sun damage in winter on a clear day!

Your skin may be drier and more sensitive than usual and you may need to use a moisturising soap and cream.

Outpatients clinic and day care

You will return to day care and the outpatient's weekly clinic at first. If you still have a hickman line, it will be redressed in day care. The line will be taken out when your blood counts are stable and it is no longer required.

On your first visit after discharge, you will need to wait for your blood results before going home.

You may need to have a Pentamidine nebuliser fortnightly in day care to prevent chest infections.

You may need blood and platelet transfusions as an outpatient.

If you are taking Ciclosporine/Tacrolimus, please do not take your morning dose on the day you are returning to the hospital so that blood levels of the drug can be checked. Please bring your medication with you to take after your bloods have been taken.

Please continue all prescribed medication unless advised otherwise, and bring a record of your medication with you to each clinic so the doctors can review your medications and order more of anything you are running low on.

Resuming usual activities

You will need time to fully recover from the intensive treatment, and tiredness after returning home is to be expected. The tiredness may continue for some months, but will pass with time. Take it easy, you may need to sleep during the day. It is also important to try and keep active to help recovery. Try and get up, shower and dress each day. Begin exercising gently with short walks and build up to doing more activity gradually. Take plenty of rest in-between activities and don't overdo it. In time, you will feel life returning to usual.

Please use your appointments in the outpatient clinic as an opportunity to discuss the resumption of usual activities such as work, hobbies and sport. Please check with the transplant team before driving.

It is not advisable to travel abroad in the first few months following transplant. Please check with the team before arranging any holidays.



Sexual activity

Initially, you may experience a reduced desire for sexual activity. This should return to normal in time.

Be aware that your platelet count may be low after transplant, in which case there may be an increased risk of bleeding. Use of condoms is recommended to reduce risk of infection, even with long term partners.

For a small number of patients who have not had total body irradiation, fertility may recover post-transplant. Therefore, contraception should still be used unless tests have shown it is not required. This can be discussed in the outpatient clinic.

Patients may find that their hormone levels fluctuate after transplant. Some patients may need hormone replacement therapy.

Practical and emotional support

Our counsellor, Linda Boyne, is available to you if you wish to be referred to her for counselling and complementary therapies.

There is a monthly support group for haematology patients which you are welcome to join.

For more information please contact Linda Boyne:

Telephone: 07341869875

Email: marylinda.boyne@nhs.net

Macmillan information and support centres offer advice and support to help you and your family during your recovery. They can provide literature on all aspects of living with cancer including advice on benefits and provide an opportunity to discuss treatments, side effects and other cancer related issues. They also provide over the phone information and support for those not able to access the service in person.

Your nearest centre is situated on the ground floor of the hospital. It is open Monday to Friday (excluding bank holidays) 9am to 4pm.

Telephone: 0151 318 8805

Email:

ccf-tr.macmillaninformationandsupportcentre@nhs.net

Getting emotional and practical support, finding out more about transplant and connecting with others could help you and your family. The Patient Services team at Anthony Nolan are able to provide you with information and support; find answers to your questions, or just provide a listening ear if you need one.

You can also connect with other patients and families to share advice and support on their Patients & Families Forum or the Patients & Families Facebook page.

Their mental health booklet and web section gives extra advice on managing your emotional wellbeing before, during and after your transplant.



You can call the Anthony Nolan Patient Services helpline on **0303 303 0303** or email **patientinfo@anthonymolan.org**

You are entitled to free prescriptions. You need to obtain a FP92A form which is available from the hospital, your family doctor (GP) or local pharmacy. The form needs to be signed by your hospital doctor or GP.

Please ask a member of staff if you require transport to follow-up appointments, we can advise you how to arrange it.

Further Information

Please do not hesitate to contact the unit at any time.

Stem Cell Transplant Unit

Ward 5 - Tel: 0151 318 8630/8631

Macmillan Information

Tel: 0151 318 8805

Linda Boyne

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The Clatterbridge Cancer Centre would like to thank and acknowledge that this information has been reproduced with the kind permission of The Royal Liverpool and Broadgreen University Hospitals NHS Trust.

Notes



How we produce our information

All of our leaflets are produced by staff at The Clatterbridge Cancer Centre and this information is not sponsored or influenced in any way. Every effort is made to ensure that the information included in this leaflet is accurate and complete and we hope that it will add to any professional advice you have had. All our leaflets are evidence based where appropriate and they are regularly reviewed and updated. If you are concerned about your health in any way, you should consult your healthcare team.

We rely on a number of sources to gather evidence for our information. All of our information is in line with accepted national or international guidelines where possible. Where no guidelines exist, we rely on other reliable sources such as systematic reviews, published clinical trials data or a consensus review of experts. We also use medical textbooks, journals and government publications.

References for this leaflet can be obtained by telephoning 0151 556 5570.

If you need this leaflet in large print, Braille, audio or different language, please call 0151 556 5570.

If you have a comment, concern, compliment or complaint, please call 0151 556 5203.

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