



Gloucestershire Hospitals
NHS Foundation Trust

Going home after stem cell transplant

Gloucestershire Haematopoietic Stem Cell Transplant Service

Introduction

This leaflet explains what happens after you are discharged from the ward following your stem cell transplant.

Outpatient follow-up

Your follow-up appointment will be at the LINC Outpatient Department, Cheltenham General Hospital.

You will be able to go home following your transplant once your blood count has recovered to a satisfactory level. An appointment will have already been made for you to be seen at the transplant clinic within 7 to 10 days of being discharged from hospital.

How often will you need to be seen in the clinic?

This will depend on how well you are but, as a rough guide, it is likely to be weekly for the first month then monthly until 3 months after your transplant. At that point you will be referred back to the Myeloma or Lymphoma clinic for ongoing follow-up care.

Continuing medication

There will be some medication that you will need to take for a few months after your transplant. This medication will help protect you from infections and may be given to you when leaving the hospital.

Alternatively, you may be prescribed medication at your transplant follow-up appointment.

One of the tablets called acyclovir, will help to prevent you from developing shingles which is very common after stem cell transplant. We recommend that you take this for 3 months after your transplant.

Another tablet called co-trimoxazole or Septrin® will be prescribed for you to help protect you from lung infections. This tablet can cause a rash in some people. If this happens you will be prescribed an alternative treatment which will be equally effective. We recommend that you take this for 6 months after your transplant.

Your diet

For the first few months while your immune system is returning to normal, we recommend that you try to eat a healthy, balanced diet and avoid possible risks of infection from food. Eat freshly cooked food and avoid reheated food. It is also best to avoid fast foods, takeaways, ready meals, cream cakes and any food that is not completely fresh. Make sure that frozen foods are completely defrosted before cooking and wash salads and fruit thoroughly before eating. Avoid soft cheeses, unpasteurised food, live yoghurt and dishes containing raw eggs.

It is fine to drink a small amount of alcohol, but heavy drinking will slow down the recovery of the bone marrow and increase the risk of bleeding (especially while your platelet count is low). Alcohol can also interfere with some of the medications you may be prescribed.

Coping with tiredness (fatigue)

Feeling that you have no energy at all (fatigue) is very common after a stem cell transplant. Getting your energy levels back can take months. Do not expect too much of yourself and remember that it is a gradual process. Pace yourself and save your energy for things you want or have to do. Gentle exercise, such as short walks, can help increase your energy levels.

Socialising

To reduce the risk of infection, avoid crowded places such as cinemas, pubs and public transport until your white blood cells have recovered to the normal range. Your consultant or haematology nurse specialist can advise you about this at your clinic appointments.

From 3 to 6 months after your transplant you should be able to take up a full social life again. However, avoid contact with children who have an infectious disease such as chicken-pox or measles. If you are worried that you have come into contact with someone with an infectious disease, let your Haematology Clinical Nurse Specialist know or telephone the Chemotherapy Helpline straight away. The number is at the end of this leaflet.

Returning to work

When your blood count has recovered, you can ask about going back to work. Most people find it easier to take it gradually by working part-time to begin with. Please discuss this with your employer.

There is information available about employment rights, disability rights and financial issues for people with cancer. Please ask your Haematology Clinical Nurse Specialist for more information.

Vaccinations

We recommend that you receive an annual flu vaccination to protect you from seasonal flu. You should also receive a pneumococcal vaccination 1 year after your transplant. This is a one-off vaccine which prevents against serious pneumococcal infections.

For guidance on COVID-19 vaccination please speak with your consultant haematologist who will refer to the most recent COVID-19 vaccination programme government guidelines.

Unless you have been told otherwise, we advise you to avoid live vaccines until your immune system is fully functioning. If you are planning to travel to certain foreign countries, please discuss this with your consultant haematologist before having the vaccination.

Sex, fertility and contraception

Having a stem cell transplant does not affect your ability to have sex. However, it is a good idea to check with your Haematology Clinical Nurse Specialist or haematologist before resuming your normal sex life. It is not unusual to find that your sex drive is reduced for some months after treatment. This may be because you feel anxious or low. You may have body changes such as hair or weight loss because of the treatment and

those changes can affect your confidence. Fatigue is also a common problem after treatment and you may just feel too tired.

Some people worry that sex will never be an important part of their life again. It often involves a period of adjustment for you and your partner, and with time, most difficulties can be overcome. Cuddles, kisses and massages are affectionate and sensual ways of showing how much you care for someone, even if you do not feel like having sex. You can wait until you and your partner feel ready. There is no right or wrong time. If you have any concerns, please talk them over with your Haematology Clinical Nurse Specialist or haematologist.

In most cases, your treatment will have caused some degree of infertility. This may be permanent but this is not always the case, so you will need to use contraception if you want to prevent pregnancies. Barrier forms of contraception (such as condoms) are recommended until your blood count has recovered and returned to normal limits.

Exercise

Regular, gentle walking is good exercise to help keep your muscles reasonably toned until your platelet count returns to normal. After this, you can start doing whatever exercise you like, although it is wise to gradually build up the amount of exercise you do. Taking regular exercise can help with your recovery and benefit your future health.

Help with expenses

Having a stem cell transplant means you will need a lot of time off work. This can cause financial worries for many people. Your Haematology Clinical Nurse Specialist can help with this by putting you in touch with various support services (for example Maggie's Centre) who will be able to advise you about financial issues.

Contact information

Before you leave hospital, you will be reminded of the Chemotherapy Helpline service. It is very important that you contact the helpline if you feel unwell in any way when you are at home. The number can be used at any time of the day or night on any day of the week. If you need general advice after your transplant, you can call the Haematology Clinical Nurse Specialists during working hours.

Further information

Acute Haematology Oncology Unit (AHOU) Helpline

Tel: 0300 422 3444

Available 24hours

Haematology Clinical Nurse Specialists

Tel: 0300 422 5278

Monday to Friday, 8:30am to 4:30pm

Maggie's Centre

Tel: 01242 250 611

Monday to Friday, 9:00am to 5:00pm

Shared Decision Making

If you are asked to make a choice, you may have lots of questions that you want to ask. You may also want to talk over your options with your family or friends. It can help to write a list of the questions you want answered and take it to your appointment.

Ask 3 Questions

To begin with, try to make sure you get the answers to three key questions if you asked to make a choice about your healthcare.

1. What are my options?
2. What are the pros and cons of each option for me?
3. How do I get support to help me make a decision that is right for me?



These resources have been adapted with kind permission from the MAGIC Programme, supported by the Health Foundation.

***Ask 3 Questions** is based on Shepherd HL, et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial.

Patient Education and Counselling, 2011;84: 379-85



<https://aqua.nhs.uk/resources/shared-decision-making-case-studies/>



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