



Being Discharged After Allogeneic Stem Cell Transplant

This booklet contains information on how to contact the Bone Marrow Transplant Clinical Nurse Specialist (BMT CNS) team, side effects to look out for and other useful information post-transplant. It is designed to help support and guide you after your initial discharge from hospital and during the first few months after transplant. Please speak to the BMT CNS team or your medical team about any specific questions or concerns.

Once discharged after your allogeneic stem cell transplant all routine follow up appointments will take place at the Queen Elizabeth Hospital Birmingham (QE) in the Centre for Clinical Haematology (CCH). This also includes any blood transfusions, fluids or transplant related treatments.

BMT CNS contact details:

BMT CNS office numbers:	0121 371 4350 0121 371 4362
Team Email:	BMTCoordinators@uhb.nhs.uk

If you are feeling unwell you can contact us during office hours: Mon-Fri, 8am-4pm

Outside of these hours, or if you cannot get through to a BMT CNS, please contact the AOS team via the red card number: 07789 651 543

Reasons to contact us:

- Temperature above 37.5
- If you are unable to keep fluids or medications down due to sickness or vomiting
- Multiple episodes of diarrhoea
- Skin rash or new changes in the skin
- Jaundice like symptoms; yellowing of skin or whites of the eye
- Cold and flu-like symptoms

This is not an exhaustive list, and you can contact us with anything you are concerned about.

We recommend that you have a thermometer at home and check your temperature twice a day, morning and evening, or if you are feeling unwell.

If you have any appointment queries, please contact the secretary team:

Secretary to Dr Kinsella, Prof Craddock	Angel Woodcock: 0121 371 4383
Secretary to Dr Chaganti, Dr Maybury	Lisa Mason: 0121 371 4379
Secretary to Dr Losa Maroto, Dr Gillson	Lucy Blatazar: 0121 371 4382
Secretary to Dr Lovell, Dr Paneesha	Sarah Hennessy: 0121 371 2942

Follow-up appointment schedule:

Initially you could be seen up to three times a week for two weeks as follows:

- **Monday:** HOT clinic (bloods and review by clinician)
- **Wednesday:** Post-BMT clinic (bloods and review by your consultant or member of the transplant team)
- **Friday:** HOT clinic (bloods and review by clinician)

You will then be seen weekly every Wednesday in the post-BMT clinic in CCH. The medical team will let you know when your weekly appointments can be reduced, this varies patient to patient.

What to expect in clinic:

- Sign in at reception
- Attend phlebotomy for blood tests. We routinely monitor your full blood count, kidney function, liver function, immunosuppressant levels and additional virus testing
- After having your blood test, please take a seat in the waiting room for your clinician to call you. This is when you can take your morning dose of immunosuppressant.
- The BMT CNS's can be found in Room 9. No appointment is needed to see us, please feel free to pop in either before or after your clinic appointment.
- It is a good idea to bring a list of your current medications, including doses and stock, to request a new supply.

Medications:

You will be counselled by a pharmacist before being discharged from the ward. You will receive a medication diary detailing your regular medications, doses and when to take them.

All patients will be on an immunosuppressive therapy, or anti-rejection medication on discharge, either ciclosporin, tacrolimus or sirolimus, which varies from patient to patient.

We check the levels of your immunosuppressive therapy in your blood every Wednesday in the post-BMT clinic. Please do not take your immunosuppressive medication before you have had blood samples taken in clinic. However, do bring the dose with you to take once you have had your bloods taken.

Please drink 2-3 litres of fluid a day while you are on immunosuppressive therapy as the drug can affect the kidneys. We will monitor your kidney function while you are receiving these medications. If you are on ciclosporin please avoid any form of grapefruit.

A transplant pharmacist is available during the Wednesday post-BMT clinic if you have any questions regarding your medications in addition to your clinic appointment.

Please let your medical team know before starting any additional supplements as some of the medications you are on can have interactions with other medications and supplements.

Graft versus host disease:

Graft versus host disease (GvHD) occurs when your donors' cells react against your body. This is a common side effect after stem cell transplant. It can affect any organ within the body, but common signs and symptoms include:

- Skin rash or skin changes including redness and itching
- Sickness or vomiting
- Multiple episodes of watery diarrhoea
- Jaundice like symptoms; yellowing of skin or whites of the eye
- Dry or gritty eyes
- Changes to your mouth, including pain, inability to drink hot and spicy foods
- Pain to your genital area or skin changes/closures to the genital area

If you notice any of these please get in touch with the BMT CNS team.

Vaccinations

We recommend that you are revaccinated with COVID, flu and childhood immunisations.

Covid vaccines usually start around three months post-transplant.

Childhood vaccines usually start around six months post-transplant.

A member of the medical team will let you know when to start your vaccinations. Most of these vaccinations will be administered at your GP surgery. The medical team will write to your GP detailing when to start and provide a vaccination schedule to follow. We will also provide you with a vaccination schedule and Vaccination Passport to help guide appointments.

Sometimes your vaccination schedule can be delayed if you remain on immunosuppressive therapy, have GvHD or have received rituximab after your transplant.

If your GP is unable to provide the COVID or flu vaccinations, we can arrange this at the QE.

Going home, activity and lifestyle:

Visitors

You can have a small circle of friends and family visit. However, they need to be well in themselves with no signs of infection; cough, colds, diarrhoea, sickness or sore throat.

It is recommended that friends and family are up to date with national recommendations for childhood and seasonal immunisations.

If possible, please avoid shops and restaurants at busy times whilst on immunosuppressive therapy.

Eating and food safety

Eating well supports your recovery after transplant. You may notice changes in your appetite or taste - try to eat small, regular meals and keep well hydrated.

Because your immune system is weakened, food safety is important to reduce your risk of infection.

Safe eating basics

- Wash hands before preparing or eating food
- Check use-by dates and store food correctly
- Cook food thoroughly until piping hot
- Wash all fruit and vegetables well
- Keep raw and cooked foods separate

Foods to take extra care with

While your immune system is recovering (particularly if you are on immunosuppressive treatment), it's sensible to avoid higher-risk foods, including:

- Undercooked or raw meat, fish or eggs
- Raw shellfish or sushi containing raw fish
- Unpasteurised milk, cheeses or dairy products
- Mould-ripened or blue cheeses (unless cooked thoroughly)
- Deli meats (e.g. salami, prosciutto) unless reheated until steaming hot
- Probiotic drinks or supplements (e.g. live yoghurt drinks)
- Open or self-serve foods (e.g. salad bars, buffets, deli counters)

Most other foods are safe if prepared and stored correctly. Your team will advise if stricter precautions are needed at any stage of your recovery.

If you are struggling with eating, weight loss, or are unsure what is safe to eat, please speak to your BMT team or ask for dietetic support.

Avoid alcohol, smoking and vaping during post-transplant period. Please speak to a member of the team if assistance is needed or you have any questions.

Pets

Avoid handling animal faeces or elimination whilst on immunosuppressive therapy. If possible, ask friends or families to care for this and empty litter trays for you.

Ensure pets are up to date with any vaccines and worming/flea treatment.

Wash your hands after interactions with animals.

Gardening

Avoid gardening or handling soil whilst on immunosuppressive therapy.

Once finished immunosuppressive therapy, and after discussion with the medical team, you may be able to do some light gardening. Please then make sure you wash your hands after any garden work.

Your skin will be very sensitive post-transplant, please avoid direct sunlight and wear factor 50 sunscreen as well as protective clothing, such as hats and long sleeves, to help keep covered.

Activity and rest

Gentle exercise is encouraged if you are feeling up to it.

Gradually increase any exercise. However, do not feel any pressure to exercise. Rest when you need it and listen to your body.

Please speak to the medical team if you wish to attend a gym.

Intimacy and sexual function

Having a transplant may affect your fertility depending on the type of transplant and treatment you've previously received.

Whilst you are on immunosuppressive therapy you should use a barrier method of contraception to avoid any pregnancies.

It is normal for women not to have periods during the transplant process and recovery. You may experience early menopause depending on the type of transplant you've received. Your period may come back and/or be irregular. You may experience menopausal symptoms, and your medical team may test your hormones and refer you for specialist care.

Some men may experience a change in libido or erectile dysfunction post-transplant. Please speak to your medical team or BMT CNS if you are experiencing any symptoms.

Going back to work and finances

Having a transplant can be financially stressful on patients and families. You may be out of work for a significant amount of time following your transplant. The BMT CNS and medical team can provide fit notes during your transplant recovery, please speak to a member of the team if you require one.

If you require assistance with any financial benefits, please speak to a member of the BMT CNS team. We can also apply for grants on your behalf if required. These grants are usually one-off payments which are paid directly into your bank account.

You will be entitled to free prescriptions following your diagnosis and transplant. Please speak to the BMT CNS team if you require a prescription exemption form to be completed.

Emotional wellbeing

Recovery can be physically and emotionally challenging. It is normal to experience:

- Anxiety
- Low mood
- Fatigue

We have a psychologist who provides face to face and telephone appointments. Please speak to a member of your medical team if you would like a referral. This is available for patients and family members.

Transportation

Avoid public transport while on immunosuppressive therapy due to risk of infection.

The nearest car park to CCH is car park D. You will need to pay for parking for clinic appointments but are eligible for a car parking pass if you are receiving treatment (fluids, transfusions, BMA) on our day unit. You can receive a car parking pass from reception in CCH.

You may be entitled to help with your travel costs under the Healthcare Travel Costs Scheme.

More information can be found here:

<https://www.nhs.uk/nhs-services/help-with-health-costs/healthcare-travel-costs-scheme-htcs/>

Discharge checklist:

- ☐ BMT CNS contact sheet
- ☐ Acute Oncology Service (AOS) Red Card
- ☐ Discussion with BMT CNS
- ☐ Discussion with pharmacist
- ☐ Medication diary (to be provided by pharmacy team)
- ☐ Medication supply
- ☐ Discharge letters (to be provided by ward nurses)
- ☐ Appointments for HOT clinic and Wednesday transplant clinic

Notes:

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Accessibility

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