

PATIENT INFORMATION

GOING HOME AFTER AN AUTOLOGOUS STEM CELL TRANSPLANT



IMPORTANT INFORMATION

Your medical team have assessed that you are well enough to go home. However, you are still at risk of becoming seriously unwell due to infection. If you have:

- **Temperature of 38 degrees or above**
- **Flu or COVID-19 symptoms** (cough, shivering, sore throat)
- **Urine infection** (pain, frequency, offensive smell)
- **Diarrhoea and/or vomiting**
- **Generally unwell** (with or without a temperature)

CALL THE HELPLINE IMMEDIATELY

01905 760158

Discharge and Follow-Up

We understand that going home following your transplant can cause some anxiety, but please remember you can contact your Bone Marrow Transplant Clinical Nurse Specialist (CNS) or the Haematology CNS team who are there to provide support, along with your family and friends, during the upcoming weeks and months of your recovery. The contact details can be found at the end of this booklet.

When your blood counts have recovered to a safe level and you are discharged, you will be given a discharge summary detailing your admission, an outpatient appointment, a re-vaccination schedule, an irradiated blood products card and supportive medications to take home.

Your GP will also be sent a copy of the discharge summary and re-vaccination schedule.

If your bone marrow is taking a little longer to recover ('engraft'), you might need to have blood tests twice a week for the team to monitor and book you in for blood product support (blood and platelet transfusions) if needed. As before your transplant, you will always need to have a blood test before your appointment with either a doctor or nurse.

It might take between 3-6 months for you to fully recover from your transplant, so please do not worry if your energy levels, appetite or taste have not returned to the levels they were before your transplant when you are discharged from hospital.

At Home

Infection

It is still really important for you to monitor for signs of infection (listed at the front of the booklet) and to contact the Chemotherapy Helpline if you are experiencing any of these **(01905 760158)**.

Please delay any building work you might have planned until your doctor is happy with your blood levels. This is because dust from building work can cause fungal chest infections.

If you have pets, please ask friends or relatives to empty litter trays, poo-pick or clean fish-tanks and bird aviaries. Do not let pets lick your face or walk on surfaces where you eat or prepare food.

If you have a garden, please make sure you wear gloves to avoid cuts to your hands and avoid disturbing leaves, compost or leaf-mulch. They can release spores that cause fungal infections.

Anaemia and Bleeding

You might still need an occasional blood or platelet transfusion and the team will be monitoring your blood counts. If you are feeling dizzy, light-headed, short of breath or looking pale, or you notice any new bruising or nose-bleeds, please call the Bone Marrow Transplant CNS or Haematology CNS team who will review your blood results (or ask you to have a test) and book you in for either a blood or platelet transfusion.

You will need to receive irradiated blood products for six months following your transplant.

Hygiene and Mouth Care

You should continue to practice good hand hygiene, shower frequently and to wash bedding and clothes regularly.

Continue to use a soft toothbrush and mouthwashes (if prescribed when you are sent home). If you have a sore mouth and/or notice any mouth ulcers or white patches, please contact the helpline for advice.

If you need any dental procedures, please let your dentist know you have recently had a transplant and also contact either the Bone Marrow Transplant CNS or Haematology CNS team, who will usually ask for you to have a blood test. **This is especially important if you have been treated for myeloma.**

Socialising

As your immune system is likely to take a while to fully recover, you should avoid crowded places, such as pubs, restaurants, cinemas and theatres. If you do choose to go, however, please choose times that will be less busy (i.e. midweek lunchtime sittings or matinee performances). You should also avoid going shopping at busy times and instead choose a quieter time of day.

Although we would encourage you to socialise with family and friends for your mental well-being, please make them aware that if they have any infections (COVID-19, shingles, chickenpox, measles etc.), they should not be meeting with you. This is to

protect you from catching any infections. It would be prudent to ask anyone outside your household to do a COVID-19 lateral-flow test before they meet up with you.

Your doctor will advise you when it's safe for you to enjoy socialising without restrictions.

Body Image, Relationships and Sexual Health

Your treatment before your transplant and during your transplant will have changed the way you look and feel about yourself. Hair loss can be particularly difficult and you already should have a wig ready to go home with (if you chose to have one). If you do not have a wig and would like one, please let a member of the team know and the Bone Marrow Transplant CNS will arrange this for you. Weight changes can also be a challenge and the team can refer you to a Macmillan Dietitian who will be able to offer help and support both during and after your stay in hospital.

Sex and being intimate with your partner is safe (as long as your blood counts have recovered) and life-affirming. You should use barrier contraception for the first month (this is to protect your partner from any lingering effects of chemotherapy). You might find your libido has been effected by the treatment, and this might take a little time to return to normal. If you are concerned, talk to your partner about your worries and/or contact your local Relate Service (please see the links at the back of this booklet). They can also help if your diagnosis and treatment have caused challenges and upset in your relationships with your family and friends.

Exercise and Fatigue

Keeping active will help with your recovery and help to improve your tiredness after your transplant. However, it is important to build your levels up gradually and start slowly, with a short walk, for example. It is important not to do 'too much, too quickly' as this might make you feel worse and set you back.

You might also notice that you find it difficult to concentrate. This is quite common and is known as 'chemo brain'. This might make it difficult to read books or complete puzzles. It will return back to normal within a short amount of time.

If you previously played team sports, please discuss with your doctor when it will be safe to resume these.

Returning to Work

When you and your doctor feel your recovery has reached the point where you can return to work, it would be a good idea to discuss a phased return with your employer and Occupational Health department (if you have one), where you gradually build up your hours to your pre-treatment levels. By law, your employer must make reasonable adjustments to your working hours and shift pattern to enable you to continue work after your transplant.

Your doctor will be able to provide you with 'Fit to Work' notes if you ask the team to provide these for you.

Finance

Many people find it financially difficult having treatment for cancer, due to having to temporarily stop working, additional travel costs etc. There are grants available and your Bone Marrow Transplant CNS can help you apply for these. Macmillan are also very helpful and have a dedicated Macmillan Citizens Advice Bureau team who can advise on benefits and other grants that are available. The links for this can be found at the back of this booklet.

There are Macmillan Hubs at Worcestershire Royal Hospital, Kidderminster Treatment Centre and the Alexandra Hospital, Redditch. The teams there will be happy to speak to you and advise you further.

For patients returning to Hereford, please contact your local Haematology CNS team, who will be able to let you know where your nearest Macmillan helpdesk is situated.

Travel and Holidays

You should try to avoid public transport until your immune system has returned to a robust level. If you are unsure, please call your Bone Marrow Transplant CNS or Haematology CNS team.

If you would like to go on holiday within the first few months of having your transplant, please check with your doctor for 'safe' destinations. Your Bone Marrow Transplant CNS or Haematology CNS team will be able to advise you on what documentation to take with you.

If you are still having supportive medications, it would be a good idea to pack a few days of extra supply, just to allow for any delays getting home.

Travel insurance might be difficult to find and be quite expensive, so we advise contacting Macmillan for details of helpful and understanding insurance companies who specialise in providing cover for people with a cancer diagnosis.

Eating and Drinking

You might find that things do not taste the same as they did before your transplant. This might take a little while to return to normal, but this is completely normal. Spicy food, sharp fruits (citrus), fruit juices and boiled sweets (like lemon sherbets) might stimulate your taste buds and taste quite pleasant.

You might find a 'little and often' approach to food is the best way to manage eating if your appetite is still low. Add extra butter to meals and try to use full-fat milk in your drinks and on cereal if you have lost weight. They are an easy way to add calories to your food intake.

You should be aiming to drink around 2-3 litres of fluid a day, which could include full-fat milk to help build your weight back up.

Although there is little evidence to support following a strict diet while recovering from your transplant, you should still make sure you prepare food hygienically. Always follow cooking guidelines on packaging and ensure food is cooked well-through before eating. Keep food surfaces clean and wipe-down after preparing food. Make sure you eat food within it's 'use by' or 'best before' dates.

The Blood Cancer UK charity have helpful hints in their 'Eating Well with Neutropenia' booklet, if you would like further information.

We hope this booklet is helpful, but please contact us on the numbers below if you would like further advice:

Contact Details:

Bone Marrow Transplant CNS:

Mobile: 07720 103594

Switchboard: 01905 763333 bleep 113

Haematology CNS Team:

Direct: 01905 790695

Switchboard: 01905 763333 bleep 357

Useful Links:

www.lookgoodfeelbetter.co.uk

www.anthonynolan.org/patients-and-families/sex-and-relationships

www.anthonynolan.org/patients-and-family/recovery-body

www.anthonynolan.org/patients-and-family/recovery-mind

www.anthonynolan.org/patients-and-family/recovery-life

www.relate.org.uk

www.anthonynolan.org/patients-and-families/get-support-us/anthony-nolan-grant

www.anthonynolan.org/patients-and-families/recovery-life/returning-work

www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/travel/buying-travel-insurance

www.shop.bloodcancer.org.uk/collections/booklets/products/eating-well-neutropenia

If your symptoms or condition worsens, or if you are concerned about anything, please call your GP, 111, or 999.

Patient Experience

We know that being admitted to hospital can be a difficult and unsettling time for you and your loved ones. If you have any questions or concerns, please do speak with a member of staff on the ward or in the relevant department who will do their best to answer your questions and reassure you.

Feedback

Feedback is really important and useful to us – it can tell us where we are working well and where improvements can be made. There are lots of ways you can share your experience with us including completing our Friends and Family Test – cards are available and can be posted on all wards, departments and clinics at our hospitals. We value your comments and feedback and thank you for taking the time to share this with us.

Patient Advice and Liaison Service (PALS)

If you have any concerns or questions about your care, we advise you to talk with the nurse in charge or the department manager in the first instance as they are best placed to answer any questions or resolve concerns quickly. If the relevant member of staff is unable to help resolve your concern, you can contact the PALS Team. We offer informal help, advice or support about any aspect of hospital services & experiences.

Our PALS team will liaise with the various departments in our hospitals on your behalf, if you feel unable to do so, to resolve your problems and where appropriate refer to outside help.

If you are still unhappy you can contact the Complaints Department, who can investigate your concerns. You can make a complaint orally, electronically or in writing and we can advise and guide you through the complaints procedure.

How to contact PALS:

Telephone Patient Services: 0300 123 1732 or via email at: wah-tr.PALS@nhs.net

Opening times:

The PALS telephone lines are open Monday to Thursday from 8.30am to 4.30pm and Friday: 8.30am to 4.00pm. Please be aware that a voicemail service is in use at busy times, but messages will be returned as quickly as possible.

If you are unable to understand this leaflet, please communicate with a member of staff.