The ROYAL MARSDEN
NHS Foundation Trust

Going home after your transplant (autograft)

Transplant Unit

Patient Information

Introduction

Going home after a transplant can leave you feeling vulnerable. This guide provides general information and advice on coping at home after a peripheral blood stem cell or bone marrow transplant.

Outpatient visits

Although you are well enough to go home, you will still need to be monitored closely and this will be done in the Bud Flanagan ambulatory care unit. You may need to attend the clinics weekly for the first couple of weeks, depending how you recover. The frequency of your visits will decrease as you recover. When you visit, we will need do blood tests and one of the doctors will see you. If you need a blood or platelet transfusion, this can be done during an outpatient visit.

Medicines

When you go home, you will be given medicines to take with you and one of the nurses will go through these with you. You should not stop any of your medicines without discussing with your medical team first. If you are having problems with any of your medicines, please tell your Clinical Nurse Specialist (CNS) or contact your local pharmacist for advice.

What to do if you feel unwell

If you feel unwell, you must always check your temperature. If your temperature goes above 37.5°C or below 36°C you must contact the hospital immediately. You should not take paracetamol as this will mask the infection. **Always speak to a nurse or doctor at the hospital before taking paracetamol.**

Sometimes you can have an infection without having a temperature, so if you feel unwell in any other way such as shivering (rigor) without a temperature, you should still call the hospital. If you have any other signs of infection such as chest infection, nausea and vomiting, urine infection, spots or rashes, you should still phone for advice.

If you are unwell or need advice please contact **The Royal Marsden Macmillan Hotline on 020 8915 6899**. The hotline is open 24 hours per day, seven days a week. If you call within working hours you can also contact your Clinical Nurse Specialist for support. Please do not delay contacting the hospital, whatever the time.

Your Clinical Nurse Specialist will give you a yellow chemotherapy card as you have had a transplant. If you are at any time advised to go to your nearest accident and emergency department, please take this card with you and show it to the staff there.

Contact with other people after going home

Following your transplant, your bone marrow and full blood cell count is slowly recovering. Although your white blood cell count has recovered, you are still at risk of infection, however there are things you can do to minimise this risk.

It is good to have family and friends to visit and this is perfectly safe, however if they are unwell, have colds, flu, diarrhoea or sickness, they should not visit you. If family members at home become unwell, it is advisable to remind them to wash their hands properly with soap and water and to avoid using the same towel as them. Ask them to cover their mouth or nose when coughing and sneezing and to use tissues.

If you have been in contact with someone who has an infection such as shingles, chicken pox, measles or any of the childhood infections, you must contact the hospital for advice. If you have young children, or are in contact with young children who go to a nursery, play group, or school, please ask the teacher to let you know if there are any cases of infection. You do not need to keep your children at home, however you do need to be aware of the symptoms of the infections. If your children do develop any infection, please contact the hospital.

It is also advisable to avoid very crowded places such as theatres, restaurants, shops, places of worship and public transport for the first eight to ten weeks. If you do wish to visit any of these places, it is better to go when they are quiet. You will need to have a shower every day and change your clothes. We also advise that you do not return to work for the first three months after transplant, however if you wish to return earlier, please discuss this with your Clinical Nurse Specialist or medical team.

Please take care if you are changing babies' nappies and make sure that you wash your hands afterwards. If children are having vaccinations, please contact your Clinical Nurse Specialist as there may be precautions that you need to take.

Animals at home

- It is not advisable to get new pets during your recovery immediately after transplant, however pets that you already have are fine to stay at home with you
- You should not to encourage your pets to sleep on your bed or to lick your face or hands as this may lead to an infection
- If your pet becomes unwell, seek advice from your vet as soon as possible
- You should not change litter trays as they may carry infection. If possible, ask a relative or friend to do this for you.

Gardening

- If you wish to do any gardening, it is advisable to wear gloves due to the potential risk of infection
- It is advisable not to handle garden compost, decaying leaves or dabble in garden ponds as they may contain fungal spores and other infections
- If you are injured or cut yourself on a rusty implement in the garden, you may need to have a tetanus injection
- It is safe to have fresh flowers at home, however you need to change the water regularly due to the risk of infection.

Drinking

When you go home you still need to drink at least two to three litres of water every 24 hours. You do not need to buy bottled water as tap water is perfectly safe to drink. You can also drink milk and fruit juice. If you wish to drink a small amount of alcohol you may do so, however excessive amounts of alcohol may make you feel unwell and dehydrated.

Eating and food

It is common after a transplant to experience:

- Weight loss
- Low appetite
- Taste changes
- Upset stomach
- Nausea and diarrhoea.

All of these symptoms are caused by the gut being irritated by the chemotherapy and they will resolve, particularly once your blood count recovers, however this will take time. You may find that you cannot tolerate hot, spicy food and may need to try bland food for the first few weeks. If you have no appetite, try eating little and often rather than three big meals a day. Your mouth may also be dry due to the chemotherapy. The doctors can prescribe some artificial saliva for you. Sweet foods such as pineapple or cola cubes can also help.

Always make sure that your food is in date, fresh and thoroughly cooked and that you wash your hands before preparing food. Never reheat food and store cooked and uncooked food separately in the refrigerator.

After you leave hospital, you are not as restricted in what you can eat but you do still need to make sure that food is carefully prepared and cooked well.

- You can eat fruit and vegetables, however they need to be fresh, in date and not bruised (this can be an entry point for infection).
- Salad also needs to be well washed, in date and not bruised. Try and avoid buying the pre-packed salad as it may not have been well washed.
- You should not eat soft boiled or runny eggs, or any dishes made from raw or under cooked eggs. It is safer to eat scrambled eggs or an omelette. Mayonnaise bought from the supermarket in a jar is safe.
- You should not eat soft cheeses such as Brie or blue cheeses such as Stilton. Hard cheeses such as Cheddar or Edam are perfectly safe. You can also eat cheese spread such as Philadelphia.
- You should avoid pâté. If you wish to dine out, you need to make sure that the food is hygienically prepared and cooked and not re-heated.
- Ask for your food to be served well done rather than medium or rare.
- Avoid salad bars, as the salad is often left out for long periods of time and handled by many people.

If you wish to eat a take away, please make sure that it is cooked fresh and made to order. You should not eat food that has been re-heated or left under hot lamps.

If buying cold meat from the supermarket, avoid the delicatessen counter as food is often left out all day and handled by several people. Buy pre-packed cold meats as they are sealed and also have a sell by date on them. Cooked chickens from the supermarket are safe as long as they are eaten straight away on your return home, and they should not be reheated.

Blood products

Although your red cells and platelets will be increasing you may still need a transfusion if your blood cell counts are low. This can be done in outpatients. As you have had a transplant you will need to receive irradiated blood products. Your Clinical Nurse Specialist will discuss this with you and give you some information about it including an alert card. If you are admitted to your local hospital, please take this information with you.

If your platelet count is still on the low side, you may be at risk of bleeding. If you experience any nose or gum bleeding, blood in your urine or tiny blood blisters in your mouth or on your skin, you must contact the hospital as you may need to have a platelet transfusion. You also need to be careful if you injure or cut yourself as you may bleed more than normal and you may bruise easily. It is also advisable to avoid contact sports for the first few months in case you get injured.

Travel and vaccinations

It is advisable not to fly for the first three months due to the risk of infection. If you are going abroad and need to have travel vaccinations you can only have the dead (attenuated) vaccines.

Following your transplant you will need to be revaccinated with all of your baby vaccines. This will normally happen approximately six months after your transplant. We will send a schedule to your GP.

You must not have any live vaccines such as yellow fever or polio as they can make you unwell. It is advisable not to travel to any country where these vaccinations are required. Your GP should be able to advise you on what vaccinations are safe.

You may also find that your skin will be very sensitive to the sun following your high dose chemotherapy. It is advisable to use sun block in hot weather, wear a hat and avoid direct sunbathing.

You should continue to have the seasonal flu vaccine offered by your GP.

Recovery

Recovery after your transplant may take a long time and will involve outpatient appointments. You may find that you have days when you feel very well and other days when you do not. You may also find that you feel exhausted (fatigued). This is normal when you first go home after your transplant but can sometimes be a problem when you are trying to get back to a normal life. It is normal to feel tired, particularly for the first few weeks after transplant, and you may need to take things slowly. Over the weeks you should find that you slowly start to feel better. If you are finding the recovery difficult, please discuss this with your Clinical Nurse Specialist or medical team. You may find that you need to have a rest in the afternoon, however you should avoid staying in bed all day as this will not help with your recovery.

Exercise

You should try and do some gentle exercise as this will help with the recovery of your energy and stamina levels. Going for a walk every day is a good way of getting some gentle exercise. It is advisable to avoid swimming for the first three months due to the risk of infection. If you are a myeloma patient and wish to do some more strenuous exercise, please discuss this with your medical team first to find out if you have any damage to your bones. High impact exercise could make this worse.

Sex

If your platelet count is on the low side when you leave hospital, you will need to be careful when having sex due to the risk of bleeding. Your medical team will be able to tell you what your platelet count is.

It is advisable to use a barrier method of contraception such as condoms to minimise the risk of getting an infection.

If your partner is of child bearing age it is advisable to use contraception for the first year after your transplant. This is because we do not know the effects of chemotherapy to an unborn child so soon after treatment. If you are planning on having children after a transplant and have any worries or concerns, please discuss them with your medical team.

Women who are not post menopause when they have a transplant may find that the chemotherapy alters their hormone levels and they may go through an early menopause. You can discuss this with a member of the medical team caring for you, however it can also be helpful to discuss this with your GP as they are often best placed to manage this.

Contact details

If you have any worries or concerns please contact your Clinical Nurse Specialist (CNS) or call the out of hours numbers below:

The Royal Marsden Macmillan Hotline: 020 8915 6899
You can ring the hotline 24 hours a day, 7 days a week.

Call us straight away if you are feeling unwell or are worried about the side effects of cancer treatments.

This service provides specialist advice and support to all Royal Marsden patients, as well as to their carers, and both hospital and community-based doctors and nurses caring for Royal Marsden patients.

Post-Transplant Clinical Nurse Specialist, Adults:	020 8915 4219
Post-Transplant Clinical Nurse Specialist, Teenagers and young adults:	020 8915 4489
Myeloma Clinical Nurse Specialist:	020 8661 3657
Lymphoma Clinical Nurse Specialist:	020 8661 3987

References

This booklet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

Details of the references used in writing this booklet are available on request from:

The Royal Marsden Help Centre
Freephone: 0800 783 7176
Email: patientcentre@rmh.nhs.uk

No conflicts of interest were declared in the production of this booklet.

Should you require information in an alternative format, please contact The Royal Marsden Help Centre.

The patient information service is generously supported by The Royal Marsden Charity.

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Registered Charity No.1095197

The ROYAL MARSDEN Cancer Charity

Revised December 2020. Planned review December 2023
MY-1255-04

Radiotherapy and
Chemotherapy Services
F538021 & F538022