The ROYAL MARSDEN
NHS Foundation Trust

# Going home after your stem cell transplant

## Transplant Unit

## Patient Information

NHS

## Introduction

Going home after a stem cell transplant can leave you feeling very vulnerable. This booklet offers general advice on coping at home after a peripheral blood stem cell or cord blood transplant. Please call The Royal Marsden (details on page 8) if you have any questions.

## Contact with other people when you go home

Following your transplant, your bone marrow is entering a recovery phase. Although your white blood count has recovered, you are still at risk of infection.

If you have had a transplant from a brother or sister or an unrelated donor/cord transplant, you will be taking immunosuppressant drugs. You may be taking just one immunosuppressant drug or a combination of two. The drugs are cyclosporine, tacrolimus or mycophenolate. We give you these drugs to suppress your donor T cell lymphocytes. These are cells which can cause graft versus host disease (GvHD). Your doctor or nurse specialist will have explained about GvHD before you consented to the transplant. The immunosuppressant drugs keep your donor immune system under control while the transplant is trying to settle in. If you are taking any one of these drugs, you should be very careful of coming into contact with any person who has an infection.

Early signs of GvHD can include a rash or symptoms of nausea, vomitting or diarrhoea. If you have these signs or symptoms, please contact your CNS or The Royal Marsden Macmillan Hotline. If the symptoms above are severe, then you need to contact us straight away.

If you come into contact with anyone who has an infection such as shingles, chicken pox or measles, you must let us know as soon as possible. If you have young children at nursery, playgroup or school, ask the nursery leader or head teacher to let you know if there are any cases of infectious disease at the school.

You do not need to keep your children at home but just be more aware of the symptoms of the infection. Then, if your children develop these symptoms you can ask us for advice.

We encourage friends and family to visit, however if they are unwell with a cough or cold symptoms, or any gastric problems (nausea, vomitting, diarrhoea) they should not visit until they have recovered. If a family member becomes unwell, please contact us for further advice.

Please take care when changing babies' nappies and make sure that you wash your hands thoroughly. If any children are having vaccinations, please check with your nurse specialist about any precautions you may need to take.

### Sexual health

It is normal post-transplant to have a low libido (sex drive). As there may be a risk of infection, we advise to use condoms during sex.

## Pets – advice

- We do not advise you to have any new pets during this time. However, pets you already have will be fine to stay at home with you.
- You should not change litter trays or clear up after any pet – if possible, leave it to others.
- If you have no choice, then be very careful to wash your hands thoroughly afterwards.

## Going out

As you are at risk of infection, try to avoid crowded places as much as you can. This does not mean that you have to stay confined to your home. You can go out but try to visit the shops, bars, restaurants, theatres and cinemas when they are likely to be less busy. Perhaps a weekday in the afternoon rather than late night shopping and weekend outings.

## Exercising

Fatigue is well recognised post-transplant. Exercise slowly at first with short walks. We do not advise going to the gym until you are off immunosuppressant therapy. Go at your own pace. Gentle stretching exercises at home can be beneficial. Your physiotherapist will have spoken to you about this during your time as an inpatient but if you're unsure of anything, please ask your key worker for advice.

## Gardening

- Light work only
- Avoid handling compost
- Wear gloves
- Change water from fresh flowers daily.

## Food and drink

- Drink two litres of fluid a day
- Tap water is preferable to bottled water (bottled water is not chlorinated)
- Avoid grapefruit juice as it interferes with ciclosporine absorption
- Only have small amounts of alcohol – no more than 7 units per week.

Foods you **can** eat whilst on immunosuppression:

- All salad
- All fruit except grapefruit
- Hard boiled or scrambled eggs or omlettes
- Hard cheese – must be pasteurised
- Fish and shellfish.

Foods you should **avoid** whilst on immunosuppression:

- Soft boiled or runny eggs
- Soft cheeses such as Brie, Camembert and blue veined cheeses
- Sushi, sushimi
- Smoked salmon
- Pre-packed salad
- Bruised fruit or vegetables.

**Eating out:**

- Choose restaurants with high food ratings
- Avoid delicatessens, salad bars and garnish at restaurants
- Check hygiene ratings before ordering takeaway food
- Kebabs are ok but avoid doner kebabs
- You can check ratings here: *www.ratings.food.gov.uk*

Your home information pack has further information on the food hygiene code.

**Follow the food hygiene code:**

- Make sure that food is always in date
- Cook all food thoroughly
- Never reheat food more than once
- Always wash your hands before handling food
- Store cooked and uncooked food separately in the refrigerator.

## PICC and skin-tunnelled lines (STL)

If you are going home with a PICC or skin-tunnelled line, it is important that you look at your skin at the exit site daily for any signs of infection (redness, swelling, tenderness, oozing). If you experience any of these problems, you must contact the hospital immediately.

The dressing which is placed over the catheter does not need to be changed every day and will protect the entry site during your daily shower. If you notice any bleeding or wetness from your shower under the protective covering, you may change the dressing. Always remember to wash your hands first.

Clothing that you wear next to your STC should be changed daily if possible, particularly if you have a new STC. Change your bedding weekly and keep towels for your use only. Change these regularly and dry them quickly on a towel rail after each use. Your PICC or skin-tunnelled line will need to be flushed and redressed in clinic once a week – please make sure you book this with reception in outpatients.

## Viruses

We will check your blood weekly for any viruses. Most of these viruses can be treated as an outpatient however you may need to come into hospital if the oral medication is not enough to control the virus.

Some patients can reactivate a virus or acquire a virus from their donor. We routinely check your blood for common viruses each time you attend clinic. These viruses are: CMV, Adeno and EBV. We may need to contact you if you test positive following blood results.

The treatment for viruses depends on the specific type of virus. If you test positive for any of these viruses, we will contact you to arrange treatment. Antiviral medication can be given by mouth as a tablet or you may need to have an IV infusion. Most treatments for viral infections can be as an outpatient, however occasionally we may need to admit you to hospital for therapy. Your CNS or doctor will discuss this with you if you have further questions.

## Medication

We will give you medicines to take home. The ward nurse will explain about the medicines given to you and you will have the opportunity to ask questions regarding when to take them and the dosage you'll need. You must follow the instructions on your medicines carefully. It is important that you do not miss out any of your treatment, even when you are feeling better. You should not stop any medication without checking with the hospital first. If you have any concerns, you can call your clinical nurse specialist or the ward pharmacist for advice.

**If you have had a transplant and are taking ciclosplorin, then please do not take your morning dose on the day you visit clinic.** We will take an extra blood sample to check the level of the drug in your body. By doing this we can make sure that you are always taking the correct dosage. Before taking your blood, the nurse will check with you that you have not taken the drug that day. We will ask you for the dosage and the time that you last took the drug, so you may want to bring this information with you. After your blood has been taken, we will ask you to take the medication so please remember to bring the tablets with you too. If the drug level is high or low, we will inform you to adjust the dosage for the future.

## What to do if you feel unwell

If you feel unwell, you will need to take your temperature. If your temperature goes above 37.5°C or below 36°C you must contact the hospital straight away. Do not take any paracetamol to bring your temperature down. Sometimes you can have an infection without having a temperature, so if you feel unwell in any other way, such as rigor (shivering) without a high temperature, you should still contact us straight away.

If you feel unwell at any time, please contact **The Royal Marsden Macmillan Hotline on 020 8915 6899**. The hotline is open 24 hours a day, 7 days a week. You can also contact your Clinical Nurse Specialist if it is within working hours.

When you are discharged, you will be given a yellow and blue Alert Card. If you are asked to go to your local hospital, you must go to the accident and emergency department straight away. Please present this card on arrival to the receptionist. This explains that you are a patient who is at risk of infection following a stem cell transplant and as such you should be treated as a priority.

If you have to be admitted to another hospital, please let us know where you are or have a relative do so on your behalf. Your clinical nurse specialist will be able to contact your hospital to discuss your condition and relay this to your consultant at The Royal Marsden. We will then, in most cases, aim to bring you back to The Royal Marsden for ongoing care.

## Total body irradiation

If you have had total body irradiation as part of your conditioning for the stem cell transplant, you may experience a condition called somnolence (excessive sleepiness). This can happen up to eight weeks after radiotherapy. You will feel very tired and may sleep for longer periods than usual. It is important that if you are having somnolence that you continue to keep up your fluid intake (two litres daily).

## Fertility

Your CNS or key worker will have discussed this with you before your transplant. Following a stem cell transplant fertility can be reduced, and in some cases, patients may become infertile. This depends on the type of transplant that you have had. Please talk to us for further advice and support if you have any questions or concerns.

## Recovery

Recovery after a transplant can be a long, slow process for many people and will involve many outpatient appointments. You will not always feel well and fatigue can be a problem when trying to live a normal life. Going back to work is a major step following transplant and will involve many factors such as the type of work and working environment. There is no rule about returning to work – you can discuss this with your consultant or nurse specialist.

## Contact details

If you have any queries, please call the Clinical Nurse Specialist relevant to you:

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| Adult Stem Cell Transplant | 020 8915 4219 or<br>020 8915 4470 |
| Teenagers and Young Adults | 020 8915 4489 |
| Myeloma – Autograft | 020 8661 3657 |

Alternatively, please call:

**The Royal Marsden Macmillan Hotline:** **020 8915 6899**
(available 24 hours a day, 7 days a week)

# Notes and questions

## 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
Telephone: Chelsea 020 7811 8438 / 020 7808 2083
Sutton 020 8661 3759 / 3951
Email: patientcentre@rmh.nhs.uk

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

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