The ROYAL MARSDEN
NHS Foundation Trust

Going home after a bone marrow transplant

Children's Unit

Patient Information

Contents

Introduction

This booklet is for you, the patient. You may wish to read it by yourself or with an adult. It is also a guide for the adults in your family to help them prepare your home for when you leave hospital after your bone marrow transplant (BMT).

Please remember that there may be some information that may not be relevant to you. This is because there are different types of transplants. If there is anything relating to your treatment that is not covered in this booklet which worries you, please contact any member of the team. You will find a list of contact numbers at the end of this booklet.

Going home from hospital

This can be a worrying time for families. Although it will be exciting to be going home, it may also be daunting. A parent or guardian may suddenly feel that he or she is now the main caregiver responsible for giving medicines and looking out for signs of ill health in the patient. This booklet will be a reminder of what to look out for and when to notify the hospital. After the transplant, you will only be sent home when the doctors are satisfied with the progress you are making. This will be when your white cell count is showing signs of recovery, your temperature is not raised and, very importantly, you are beginning to eat and drink.

Psychological issues

You have already had the transplant, made important decisions and stayed as an inpatient, often with some separation from members of your family. Now you will be going home.

Many families feel worried when their family member is leaving hospital, as suddenly the team is not there every day. This worry is normal, but it is important to remember that the hospital staff can be easily contacted for queries and understand the significance of leaving hospital. Many families adjust very well, but some feel vulnerable being back home as a whole family again. Siblings need to feel part of the family once more and some can feel rejected or even jealous of the attention their sibling is getting. It always takes a while to feel ‘normal’ again.

After having a transplant, it is common to feel as though life is on hold and your reality may seem different.

It is important to think about how to live your life, within the limitations of the treatment you have received. Socialising helps recovery and getting back to a sense of normal life. It is important to find ways of keeping in contact so that your family feels included. Relationships between parents may also suffer at this time, as worry and routine can seem to take over. It may be helpful to ask family members and friends to help support in practical ways such as looking after siblings or helping with travel to hospital appointments.

Most families will have met the psychologist and social worker before and during the transplant, and they will still be available if you wish to talk or want any advice. There will be some better times in spite of the issues you may face. People are different – some families feel stronger after going through the transplant process, some feel more vulnerable. It is not always possible to know who will want support afterwards, and who will want to get on in their own way. Support is available – just ask when you attend for your follow up appointments.

Preparing your home

After a period of time in hospital a clean environment is essential.

It is recommended that floors are washed, carpets vacuumed and surfaces damp dusted at least once a week. The kitchen work surfaces should be cleaned using a clean dishcloth and hot soapy water before they are used. Crockery and cutlery can be washed in hot soapy water or in a dishwasher. The bathroom and toilet also require daily cleaning.

Clothes should be washed regularly, and bedding and towels should be laundered once a week. This can be done with the rest of the family’s washing.

There is evidence that patients who have had a bone marrow transplant are at an increased risk of getting a fungal infection called aspergillus. Aspergillus is found in bricks, concrete and dust. It is released into the air during building works, when it can be breathed into the lungs and sinuses. We therefore advise that no building work is carried out in the home before you leave hospital or during the first six months after the transplant. Air conditioning can also spread aspergillus, so it is advisable to avoid using this.

Pets

If you already own a pet, provided it is healthy, it is generally alright for the pet to remain in your home and for you to have contact with it. However, there are exceptions. Reptiles and birds can carry unusual infections that could be passed on and cause problems. These pets should be in an area that you don't use and there should be no contact with them.

Please try to prevent your pet from scratching or licking you, and wash your hands after handling the pet. It is also not advisable to have pets in the bedroom. You should not clean out rabbit hutches, litter trays, aquariums or other animal cages.

New pets should not be brought into the house for at least six months after BMT or longer if you are still receiving immune suppression, for example cyclosporin or steroid treatment.

Diet and nutrition

A high protein diet is essential for recovery from the transplant. This can be difficult, as you will experience side effects from the transplant.

The most common side effects are:

- Weight loss
- Somnolence (drowsiness)
- Dry mouth
- Taste changes.

The dietitian will provide nutritional advice on these symptoms and will recommend suitable nutritional supplements. You may need naso-gastric tube feeding.

You will still be immunosuppressed on discharge and will need to avoid high risk products and follow good hygiene practices. The food safety booklet produced by The Food Standards Agency has details of these practices and the dietitian will give you a copy of this. Well prepared and well cooked food is most suitable following transplant.

Foods to avoid

- Unpasteurised dairy products
- Mould ripened cheese
- Any product containing unpasteurised eggs
- Seafood and shellfish
- Restaurant and take away meals
- Loose items from delicatessens and bakeries.

Transport

When travelling to the clinic for the first three to six months, it is sensible to avoid travelling on public transport. This is because you could unknowingly come into contact with someone with an infection.

If you are unable to come to the hospital via your own transport, or with a friend or relative's help, it may be possible to organise hospital transport.

Please note that at least **48 hours' notice** is required to set up the service, and it can only be provided for the patient and one accompanying adult. Please talk to the outpatients' receptionist should you require this service (contact details on page 16).

Clinic visits

The BMT Clinic is held on Thursday afternoons in the Children's Outpatients Department. You will be given an appointment time with the Transplant Team. You need to attend the Children's Outpatient Department one hour before the appointment time so that bloods can be taken. The results will then be sent through for your appointment.

The clinic visit is a good time to ask any questions you may have and also to discuss any worries or difficulties. After returning home from hospital, you may need to be seen once or twice weekly in the clinic. As your condition improves, your clinic appointments will become less frequent.

When you come to the clinic the doctor will carefully examine you for signs of Graft Versus Host Disease (GVHD) or any other problems. Blood samples may be taken to see if there is a need for blood or platelet transfusions, as well as to check drug levels, such as cyclosporin. **If you are taking cyclosporine, do not take the morning dose until the level has been checked.**

Your weight and blood pressure will also be checked.

Sometimes it is necessary for a patient to be re-admitted to the hospital to stay. This is not unusual as problems do occur. Such problems may include shingles, fever, hickman line infections and GVHD.

Late effects clinic

Long-term follow up is an essential part of treatment following a bone marrow transplant.

Some of the treatment that you may have received can cause problems that only become evident several years later. When you were given information about having a bone marrow transplant and the side effects, the doctors will have informed you about the possible later effects. These may include poor growth, damage to the thyroid glands or lungs, formation of cataracts and infertility.

As these are known possible side effects, regular clinic visits are advisable in order to detect any of these problems early on.

The appropriate time for you to be referred to the long-term follow up team will be discussed between you and the BMT doctor. Usually this is one year after your BMT.

Infection

There is an increased risk of viral, bacterial and fungal infections for several months, or even years, after transplant. In hospital, every effort will have been made to reduce the risk of acquired infection. These restrictions will be relaxed when you go home, but we advise you to continue to take some precautions to decrease exposure to infections.

The most important thing that you and your family can do to reduce the risk, is regular effective hand washing.

Signs and symptoms of infection

Make sure you have a digital thermometer (which reads in the centigrade scale) at home. You should check your temperature if you are feeling at all unwell, if you are looking flushed or feeling warmer than usual to touch.

If you have a temperature of 38° centigrade or higher (even if you appear well), please contact your shared care hospital immediately for advice, and possible admission. If your temperature is 38° centigrade or higher, do not take any products containing paracetamol without first discussing it with the hospital medical staff.

Please also inform The Royal Marsden and/or shared care hospital immediately if you develop any of the following symptoms:

- Episodes of rigor or shaking
- New bruising or blood spots (petechiae)
- Any new rashes
- Frequent diarrhoea or vomiting
- Productive or persistent cough, shortness of breath
- Being unwell or off colour for no obvious reason

- Abdominal pains or cramps
- New mouth ulcers or thrush
- Any redness, swelling or discharge from your central line
- Rigor or shaking after the central line or Portacath is flushed.

Commonly used drugs to reduce the risk of infection

Aciclovir

This is used to reduce the risk of the reactivation of various herpes viruses, or for the treatment of chicken pox or shingles.

Pentamidine

This is an effective inhalation treatment against pneumocystis carinii (an infection affecting the lungs) and is carried out once every four weeks. When your blood counts are sufficiently stable, the transplant doctors may make the decision to convert to Co-trimoxazole (Septrin) twice a day for two days a week instead – usually Saturdays and Sundays.

Itraconazole

This is given twice a day to reduce the risk of a fungal infection. This may continue for as long as you are taking immunosuppressants (such as cyclosporine, steroids).

Penicillin

After transplant, this is given to all patients who have had total body irradiation or chemotherapy. This is to protect you from pneumococcal infections. You may need to take this antibiotic for life. If you stop taking this medicine, it may be life threatening to you.

Central lines

Your central line will be removed when it is no longer required for frequent blood tests, blood and platelet transfusions or medication. Removal of the line will be carried out under general anaesthetic (you will not be awake).

If the line becomes infected, or develops a problem, it may be removed earlier than planned.

Whilst at home, we advise you to check the line regularly to see if it has become red and inflamed. If it does become sore, red or inflamed, please inform your shared care hospital and/or The Royal Marsden. Also, if you notice blood collecting in any part of the line, please notify your shared care hospital/community team and/or The Royal Marsden.

Until the central line is removed, it will need to be flushed weekly and the dressings changed weekly. Portacaths only need flushing every 4 weeks. As visits to the hospital become less frequent, it may be possible for your community nursing team to care for the line at home.

Contact with infectious diseases

If you have direct contact with, or show any signs of any of the following diseases, it is important to contact The Royal Marsden immediately.

Chicken pox

Chicken pox occurs as a result of direct contact with someone who is infectious with the disease. The infectious period lasts from two days before the spots have appeared, until all the spots have crusted over. The length of time between your transplant and getting chicken pox will determine whether you will need to be admitted to hospital for 4-5 days of intravenous acyclovir. You will then need to continue with oral acyclovir.

Shingles

Shingles is the reactivation of chickenpox virus, which can develop in the first year after transplant, due to a low immunity. It can be seen as a rash, usually in the head, neck or trunk (chest) and can be very painful. You may have to be admitted to hospital for intravenous high dose acyclovir if shingles develops. Shingles is less contagious if the rash is covered.

Measles

Measles is uncommon in this country, but does still occasionally occur. You are protected from this disease if the childhood community around you is vaccinated with measles, mumps and rubella (MMR). The first symptoms may be a fever and a runny nose, before the development of a distinctive rash. If you show symptoms, you may be admitted to the hospital for observation and antibiotics.

Personal hygiene

Carrying out good personal hygiene can reduce the number of micro-organisms that are present on the skin. Whilst these micro-organisms do not normally cause any problems in healthy people, they may increase the risk of infection following your transplant.

Tips to reduce this risk:

- Have a daily shower, bath or strip wash, using a mild soap or oilatum
- Use non-irritating moisturising creams on dry skin, such as aqueous cream
- Change underwear daily and all other clothes regularly.

Mouth and dental care

The soreness and swelling in the mouth and throat, caused by the chemotherapy and/or radiotherapy may have resolved by the time you go home, but occasionally further problems occur. You may find that your mouth is dry for a few months, especially after having had total body irradiation (as there may be reduced activity of the salivary glands).

Tips for good dental care:

- Brush your teeth at least twice a day
- Use a soft toothbrush and normal toothpaste

- Change your toothbrush at least every month
- Store your toothbrush separately from those of the rest of the family.

Skin care

It is very important to protect skin from the sun, especially after having had total body irradiation, chemotherapy or GVHD, which will make the skin much more sensitive. Even when the sun does not appear to be strong we recommend wearing a hat, especially until your hair grows back. It is sensible to keep the skin covered with clothes as much as possible, and always apply lots of sunscreen. Following a transplant, a minimum of total sun block factor 50 is recommended.

Any changes in the skin, such as a new rash, skin pigmentation or new moles should be reported to the medical staff.

Body piercings and tattoos

We do not recommend having any piercing or tattoo done for at least six months after the transplant. Please consult the BMT doctor or nurse before having any piercing, especially if you are still taking cyclosporine or steroids.

Only a certified professional should carry out piercing or tattoos.

Fatigue

It is common to experience a period of sleepiness and lethargy after having had total body irradiation. This can occur six to eight weeks after the transplant and may last for around two weeks. We call this somnolence. Somnolence may be accompanied by a fever and headaches.

You may need to be readmitted to hospital during this time for fluids and antibiotics (given through your central line). If you are able to stay at home it is important that you continue to drink adequate amounts of fluids and take the necessary medicines.

Please contact The Royal Marsden if you have any concerns about being somnolent.

Graft versus host disease (GVHD)

In spite of preventative medication, graft versus host disease still occurs. It does not occur when your own bone marrow is used, as in an autograft transplant.

As with all transplants, there is a risk of the new donor immune system recognising your organ proteins in your body as different. This may result in GVHD.

Symptoms of GVHD can occur as early as one to three weeks after transplantation. It may occur in one or more organ systems and can be mild, moderate or severe. Sometimes symptoms appear and then go away without the need for treatment.

Acute graft versus host disease

Before discharge you may have already had some experience of GVHD and will be aware of what to look out for. However, the actual onset of acute GVHD can be difficult to diagnose. Sometimes the symptoms can be confused with other causes, for example, drug reactions and infection.

Early clinical signs of acute GVHD may involve the skin. This can range from a mild red rash, which starts on the palms of the hands and soles of the feet, and/or in the centre of the face, to an extensive rash involving most of the body. In its most severe form, acute GVHD can cause blistering and shedding of areas of the skin. Other symptoms may include itchiness, dryness and peeling of the skin, and there may be some deepening or lightening of the skin colour.

Acute GVHD may also occur in the gut – stools that are passed may be green and watery or may also contain blood. This can be accompanied by abdominal cramps, nausea, vomiting, an enlarged abdomen, decrease in appetite, weight loss and dry mouth.

Treatments for acute GVHD

Supportive treatments are available to help with these conditions.

You will already be taking medication to prevent GVHD. This will be given in combination with one or more of the below:

- **Cyclosporin**
  This is taken twice a day either in syrup or tablet form. If you are taking the medicine as liquid, you need to remember to use the liquid measure supplied in the box (you do not need to wash it out between doses). After use it should be wiped clean with a tissue and stored in the box provided. Because of the risk to kidney function, cyclosporine levels will be monitored regularly and dose adjustments may have to be made. On the day you come to clinic please do not take the morning dose of cyclosporine until after your blood test. Whilst you are on this medication, it is important to drink plenty of fluid to reduce the risk of kidney problems. A doctor will contact you if the amount of cyclosporine you are taking needs to be changed.

  Side effects of cyclosporine include increased hair growth, (this will stop happening once you stop taking this drug), an increase in blood pressure, shaky hands, headaches and, very rarely, fits.

  Please **avoid** grapefruit whilst taking cyclosporine as it will affect the absorption of this drug.

- **Steroid cream**
  This may be prescribed when the GVHD only affects the skin mildly and is only applied to affected areas. It is important for the person applying the cream to wear gloves to protect their skin. Steroid creams are safe to use if applied as directed by your doctor.

- **Prednisolone or methylprednisolone (steroids)**
  These can be taken in tablet form or as soluble tablets. It is important to remember to take these tablets at meal times or with a drink of milk, as they can irritate the stomach lining. If the steroid therapy is ongoing for a long period of time you may be given an antacid such as Lansoprazole to stop

heartburn. You may need to come back into hospital to have this steroid therapy as an intravenous infusion, if you require high dosages.

Side effects of steroids include high blood pressure, fluid retention, a moonshape face, stretch marks on the skin, softening of the bones, mood swings and acne. Steroids can also cause an increased appetite and weight gain, especially around the face and abdomen. Again, most of these side effects will disappear on stopping this treatment (stretch marks may not go completely, but will fade). However, if you need to receive steroid treatment over a long period of time, this can cause bone damage.

- **Extra Corporeal Photopheresis (ECP)**
  This is an alternative treatment for both acute and chronic GVHD. This is given in hospital by specially trained nurses. ECP is a procedure where blood is removed from the body using your central line (hickman line) and treated with medication and ultraviolet light to kill your T cells (white blood cells) that are causing the GVHD. This can be very effective in treating skin and oral mucosa GVHD. The treatment is given over two days initially weekly in acute GVHD and fortnightly in chronic GVHD, and may be given for many months. If the BMT team feel that ECP may be of benefit, they will discuss it with you and your family in clinic.

Chronic GVHD

Chronic GVHD can range from mild to severe and may develop as an extension to acute GVHD or even after a period of being well. Instead of just affecting the skin, gut and liver it can affect any part of the body.

Symptoms are outlined below and occasionally they can be debilitating. There may be thickening of the skin, with red discolouration. This can cause tightening of the soft tissues around the joints and limit movement, leading to muscle wastage. If the skin is also very dry, it can become flaky and crack.

It may bleed and become infected in these areas. There is also the possibility of uneven hair growth, thinning, or loss of hair. Nails can become rigid and may fall off.

The mouth area can become dry due to a reduced supply of saliva. This can cause difficulties with swallowing, mouth ulcers and lead to fungal infections, alteration in taste and weight loss.

Further down in the gut, mal-absorption can occur, as well as diarrhoea and abdominal pain.

Eyes can become dry, gritty and red because of a reduction in the production of tears. They may also be more sensitive to light than normal.

Chronic GVHD can occur in the lungs, but this is very unusual. This can cause you to tire more easily, and have a decreased level of activity. Symptoms include a cough or wheeze and an increased susceptibility to infection.

Treatments for chronic GVHD

The BMT doctor may ask for a biopsy to be carried out to confirm GVHD of the skin, gut or lungs depending on the symptoms. In most cases, short courses of oral prednisolone plus cyclosporin may be given, otherwise other treatments may be started. These may include Mycophenolate, Imatinib or other medications dependent on the organ affected. The doctor will discuss the most appropriate treatment for you, should the need arise.

Getting back to normal

After transplant most people feel tired, particularly if they do any physical activity or try to concentrate. However, this will improve especially after the first few weeks. Feeling completely fit can take 12 months or longer, so it is worth persevering.

Returning to school or college

It is likely to be about four to six months before you will be able to return to school or college. Home tuition will be organised for you during this time by your school. Returning to school or college is exciting but it can also cause some anxiety. It is likely that you will experience reduced attention span as a result of treatment.

It will take time to re-adjust to a school or college routine and to fit back into your peer group. Keeping in contact with friends by phone, social media, gaming or e-mail will help maintain a sense of normality whilst you are away.

Holidays

If you are planning a holiday, please first discuss the planned destination with the BMT doctor. We advise you not to visit tropical countries where immunisations for certain diseases could be required.

Socialising and contact with other people

You doctor will inform you when restrictions on meeting other people can be relaxed. When you first arrive home you may find that you are overwhelmed by phone calls and visitors. However, it is important that potential visitors be made aware that they should stay away if they have a temperature, cough, cold or sore throat, diarrhoea or vomiting, or are generally feeling unwell. Minimise contact with any family member who is unwell. If possible, the person who is unwell should remain in a separate room.

If you want to go to the shops or cinema try to avoid weekends or peak times. Instead go at quieter times when children are likely to be at school.

Vaccinations

If someone in the family is due to have any vaccination, please discuss this with the BMT doctor.

You will need to start a re-vaccination programme one year to 18 months post-transplant. A schedule will be given to you by the BMT team when these are due and you can discuss this with your BMT doctors in clinic.

Contact details

Children and Young Adults 24 hour advice line:	020 8915 6248
The Royal Marsden switchboard:	020 8642 6011
McElwain Ward: 24 hours	020 8915 6242
Daycare: 8am – 6pm, Monday to Friday	020 8661 3601
Teenage Cancer Trust: 24 hours	020 8661 6254
Clinical Psychology Department:	020 8661 3676
Dietitian:	020 8642 6011 ext. 1134/4093
Outpatients' receptionist: 8am – 5pm, Monday to Friday	020 8661 3551
Children and Young Adult Transplant Clinical Nurse Specialist: 8.30am – 5pm, Monday, Tuesday, Thursday and Friday	020 8661 3659

Notes/Questions

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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

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

The Royal Marsden Cancer Charity

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