

# Going Home After Stem Cell Transplant

## HAEMATOLOGY UNIT



# Discharge Advice after Stem Cell Transplant

This booklet is here to answer some of the questions you may have about going home. However, it does not take the place of the advice that the doctors and nurses will give you and it may not answer all of your questions.

Remember, in most cases the information is quite general. The doctors and nurses will give you specific advice more appropriate to you.

It is quite common to feel that you are not recovering as quickly as you should. This may be frustrating if you have felt unwell for a long time. However, the desire to get back to normal is something that may help you to get through the weeks after the transplant.

## **Follow-up Visits**

Follow-up appointments are an important stage in the transplant and in your recovery. For the first few weeks, this is a period when any problems must be picked up early so that they can be treated successfully.

You will be seen at least once a week, although sometimes more often if you need blood or platelet transfusions, until your blood counts are fully recovered and your Hickman line has been removed.

When the doctors are satisfied that your condition is stable, you will be followed up by your Haematology consultant in the outpatient clinic.

## **Blood products**

You should receive only **irradiated blood products** for six months after your transplant. This means that the blood has been put in an irradiating machine to destroy any white cells left in the bag and inactivate any viruses carried on those cells.

To avoid transfusion of non-irradiated products in case of an accident, you should carry the 'Blood Alert' card, which the nurses can give you before you leave. If in any doubt about treatment, the hospital should be contacted for advice.

### **Medication**

You will need to take acyclovir for 6 weeks and septrin (co-trimoxazole) for 6 months until your immune system is stronger.

Other drugs such as anti-sickness medications and drugs, which protect the stomach, will be stopped as soon as you have no further symptoms. It is important that you take any medications you are prescribed correctly. When you leave the hospital, the nurses should go over the regime with you and explain it to you. Sometimes it is easier to take medication if you know what it is for, so please do not hesitate to ask if no one has told you already. The specialist nurses can explain things to you over the phone or in the clinic.

### **Infections**

After a month in the protected environment of the hospital it is quite common for patients and their relatives to be anxious about the infection risk for them outside the hospital. On the other hand they are keen to get back to a normal way of life. It is important to follow the advice in the patient leaflet, "Information for Patients Who Are Undergoing Chemotherapy". It is important to check your temperature if you feel unwell or just 'not quite right' and you cannot identify what's wrong. If you have symptoms such as a sore throat, shivers, a cough, are breathless for no particular reason, feel more lethargic than usual or have a high temperature, a telephone call to the hospital can put your mind at rest. They will advise you what to do.

## **Food**

You should continue to follow the advice in the patient leaflet, "Chemotherapy Diet Advice", until your blood counts are fully recovered to normal levels. When you come back for your clinic appointments, ask about continued restrictions on eating or returning to normal eating when appropriate.

## **Socialising**

When you first go home, you will probably want to restrict the number of people who visit. It may be enough for you to just be with your family, especially if you have young children. After the long period in one room, you may find the journey home and being in a relatively 'big' space overwhelming.

Visitors, to begin with, should not come to see you if they have viral infections such as 'flu or sore throats. If you accidentally come into contact with anyone who has measles, chickenpox or German measles, telephone the hospital and ask for advice. The doctors should be able to look at the antibody levels in your blood and assess your resistance to these infections.

To start with, try to avoid crowded public areas such as public transport, busy shops, pubs and cinemas. Hopefully, you will have someone to drive you to clinic appointments, but in some cases hospital transport can be arranged if this is not possible.

## **Your home**

Your house should be clean when you return home. Hopefully, there will be someone who can do this for you.

You do not need to have the house completely spring-cleaned (unless you want to) but ideally it should be cleaned at least once a week.

Dusting with a damp cloth in between the main cleaning sessions can reduce the amount of dust if you have an old house. There is no need

to get rid of your houseplants. It would be better if someone else cared for them, but the main thing is to **thoroughly wash your hands after any dirty work.**

### **Driving**

It is usually safe to start driving again as soon as you feel well enough to do so. However, you should check with your clinic doctor first, as some of the drugs you take may affect your ability to drive. Driving can often be a very important step in feeling independent and may be an easier method of travelling for you if you are having difficulties with your clinic visits. If you come from a long distance, it is probably not a good idea to drive alone to clinic to begin with.

### **Pets**

Common sense hygiene measures should be taken with pets. For example, they should not be allowed on the kitchen surfaces or dining table or in bed. They should be discouraged from licking hands and faces. You could arrange for someone else to feed and care for your pets, making sure that they wash their hands thoroughly afterwards but if you do have some contact with your pets, **you should also wash your hands thoroughly.**

### **Exercise**

Although you are well enough to leave the hospital, you will find that when you get home you tire very easily. **This is absolutely normal**, so try not to feel too disappointed. It would be best if someone stays with you for the first few weeks.

You will not be up to much more than looking after yourself. It would be nice to have someone around to do the shopping or to plan and cook meals.

Increase your level of activity gradually. Try to go for a short walk most days if it is not too cold, going a little further each day. Stairs may be an effort - a good way of getting used to them is to walk up and down them at least once a day.

## **Physical relationships and sex**

It is perfectly safe for you to have sexual intercourse after the transplant unless the doctors advise against it for some reason (such as having very low platelets).

There should be no physical reason why the transplant should affect your ability or desire to have sexual intercourse. However, there may be emotional and psychological factors that prevent you from re-establishing your usual physical relationships.

Problems or questions in this area are not easy to discuss and are often felt to be less important and therefore not raised at the clinic visit. The specialist nurses may be able to suggest where help can be sought. Often, any problems can be temporary and are to do with the impact of treatment on the body, both physically and emotionally, which can make you feel differently about how you relate to others. If problems continue, please seek help as this is an important part of your recovery.

**Women** may experience vaginal dryness as a result of the treatment or the associated early menopause. If the vagina is dry, then it may be a good idea to use lubricating creams (such as KY Jelly).

## **Fertility**

The different conditioning regimes used for transplants can have different effects on fertility. Your doctor will have discussed this with you prior to treatment, but you may find it has more of an impact when you go home. For women, some regimes will result in an early menopause and almost certain infertility. Menopausal symptoms can be eased by hormone replacement therapy, and we can arrange for you to see a gynaecologist who will give you more detailed information about this and other options.

Men may have a chance of fathering a child as normal, depending on what type of chemotherapy has been given. Again it is important to discuss this, and contraception, with the doctors or specialist nurses.

## **Emotional reactions**

The transplant can put an enormous physical, emotional and financial strain on the whole family and it may be difficult, or take some time to re-establish normal family life. There are certain things that can help, although each person will find their own way through it.

Do seek practical and financial help if you feel that you need it. The specialist nurses can suggest any financial grants that are available. Charitable funds can sometimes provide help with fares, holidays in this country and equipment. These funds are for people in difficulties at times like this and should be used.

Try to talk about problems that arise within the family. Initially, this may be difficult to do, but it may help in the long run. It is easy to feel that you are disrupting the whole family and that you want to make as little fuss as possible. Let your loved ones help if they want to. It is all they can do - they can't have the treatment for you. Remember, the family have been through a tough time too, so they may have needs that could be addressed by other support agencies. The specialist nurses can help you or members of your family.

If possible, keep yourself occupied. Set yourself some kind of daily routine and try to see people outside your immediate family. It is common to feel that you do not have much to contribute when you are the patient and not able to do much. It may be very different to how you are normally, but you may find that other people are also unsure about what you need and what you can do. Don't be afraid to ask for some normal conversation.

It is common to be quite low (depressed) after the transplant. If you continue to feel low for a very long time and cannot get your spirits up, it may be best to talk to the clinic doctor or the specialist nurses. The feelings may be as a result of one of the drugs or could be treated by a short course of anti-depressants or talking through your feelings with someone. It is not a failing to feel this way and when recognised, help can be sought. Don't forget that you have had a major life experience.

### **Returning to work or study**

The timing of this will vary according to the type of treatment and complications since the transplant. People with desk jobs, who have minimum contact with others, may be able to return to work sooner than those who deal with a lot of people, children or animals, or who have a physical job.

We suggest that you take 3 months off work when you have this type of transplant. Of course, this is only a guideline and it will be different for each person. It may be that going back to work makes you feel as if the transplant is finally behind you and you are back to normal.

If you do not have the opportunity of going back to work part-time, make sure that when you return to work full-time, you are ready to get up each day and face the pressure that comes with any job. Will you be so exhausted by the end of the week that you spend the weekend in bed? Will you be able to have time off for your clinic appointments?

There may be financial implications, which pressurise you into going back to work. The specialist nurses may be able to suggest ways of getting help until you are fit enough to return to work.

Remember - **your health should come first**. You are unlikely to ever have this length of time away from work again and although it may seem like a long time, you need it, your body needs to heal.

## **Holidays**

It is not advisable to plan a holiday outside the United Kingdom for a few months after your transplant. Holidays in this country are fine. Speak to your doctor about it; they may want to write a letter for you to carry with you, just saying what treatment you have had, with a contact number. Talk to your doctor before planning holidays abroad.

If you have problems with travel insurance, the specialist nurse can provide a list of travel insurers who may be able to help.

## **Body image, emotional and physical issues**

It is possible that having a procedure such as a transplant, which threatens your whole existence, can change your life and the way in which you view things. Not only can it make you feel differently about your body but about your mortality or life and death as well. These changes are not always negative but can enhance and enrich your life in certain ways.

Your mental or emotional wellbeing is often a reflection of your physical wellbeing. When you feel unwell, or not normal, or not as you feel you should, this can affect your mood and your approach to life. You may also feel as if you have no control over your body, which can make you feel vulnerable, insecure and unsure about even the every day things in life. Hopefully, all these feelings will improve with time, you will begin to understand what is happening to your body and trust your instincts again. Your confidence will return slowly. As you begin to function independently, you will feel less like a victim or a patient and more in control.

For some, the effects of the treatment and its implications on your body and feelings may surface later, maybe months or years after the transplant, or you may find adjusting back to a normal life very difficult. If so, it is helpful to tell someone about this.

You may find that your family and friends are not the best people to talk to as they may feel or hope that you have 'recovered' from the transplant and are therefore unable to understand your feelings. Please contact the specialist nurses. They recognise that there is no time limit for reactions to what has happened to you and may be able to help.

Another source of support that many patients find useful is a support group specific to your disease. Often talking things through informally with people who have been through the same experiences helps and problems may not seem so bad.

Please do contact the unit if you are worried or unsure about anything at all.

The phone numbers are on the back page.

Acknowledgements: Clinical Haematology. The Hammersmith Hospital

## Options available

If you'd like a large print, audio, Braille or a translated version of this leaflet then please call **01253 655588**.

## Patient Advice and Liaison Service (PALS)

Do you need information or advice about NHS services? Do you have concerns about you or your family's healthcare or are seeking a resolution to a problem and cannot get an answer to your questions? PALS is here to listen and support you in whatever way they can to ensure your experience of healthcare services is a positive one.

Tel: **01253 655588**  
email: **pals@bfwh.nhs.uk**

You can also write to us at:  
**PALS, Blackpool Victoria Hospital**  
**Whinney Heys Road**  
**Blackpool FY3 8NR**

Further information is available on our website: **www.bfwh.nhs.uk**

## Travelling to our hospitals

**For the best way to plan your journey to any of the Fylde's hospitals visit our travel website: [www.bfwhospitals.nhs.uk/departments/travel/](http://www.bfwhospitals.nhs.uk/departments/travel/)**

## Useful contact details

Switchboard: **01253 300000**

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