

Paediatric haematology

Checklist for parents and carers: Getting ready for your child's bone marrow transplant

Information for parents, relatives and carers

Introduction

This leaflet has been provided to help answer some of the questions that you may have before your child is admitted for a bone marrow transplant (BMT). It explains what you should consider and discuss before the transplant takes place.

What do I need to talk to my child about?

Talk honestly with your child about the admission and what this will involve and try to explain it in words your child will understand. You may wish to use books, videos or pictures to help you tell the story. If you would like help talking to your child, please contact your BMT nurse who can arrange this.

Talk with your child about the plan, who will stay with them and what will happen to siblings and pets while they are admitted. Reassure your child that mum, dad and any additional carers will take turns staying with them while they are in the hospital.

Help your child to make a list of items they would like to bring to the hospital.

Spend time with your child reading the information material you have been given and contact your BMT nurse if you or your child has any queries.

It is also a good idea to talk to your child's school or nursery about how long your child will be away and discuss ways to keep your child connected with the school both academically and socially.

What do I need to do before admission?

Make any necessary arrangements with your employer for your absence. If you require any supporting letters, contact your BMT nurse.

Consider maintaining some level of paid work by working from home if this is possible. However, it is important to consider that the admission for transplant can be an exhausting and stressful experience and if this is something you are going to consider you should have realistic expectations of what you are going to be able to achieve.

Arrange support for the running of your home. Are there friends or family who can help by providing practical support?

Consider how bills will be paid while you are in hospital with your child.

Discuss your own needs with your partner and how you may support each other through the process.

If you need a supporting letter for a visa application, for a relative or carer coming to the UK from abroad please contact your BMT nurse who can arrange this for you. Please provide the full name of the person, their date of birth and passport number as it appears on their passport.

Packing list

Make a list as you think of things. The immediate period before being admitted is often busy and can be stressful and you may miss things that you would like to bring.

Add any personal belongings that you think will be comforting to you and your child to your list.

Consider bringing photos of home, family, friends and pets to decorate your child's hospital room.

What should I tell my child's siblings?

Talk with your children and explain what will be happening within your family while their sibling is having their transplant. It is important to be honest and use words that they will understand.

If your child's donor is their sibling, be honest about the operation that they will have and why they are donating their bone marrow. It is important that your child is able to express their concerns about the operation.

Faith and spirituality

Speak to your faith leader before your child is admitted if this is consistent with your beliefs.

If you would like support from hospital faith leaders, let your child's BMT nurse know and this can be arranged for you.

Provide a time and opportunity to talk with your family and what each of you believes. Consider talking about what gives you strength as you and your family prepare for your child's transplant.

Travelling to the hospital

Decide on how your visits after the transplant will happen. If you don't have a car, is there someone who can help with the twice weekly visits to day care?

If you need help organising travel to the hospital, speak to your BMT nurse as soon as possible.

What should I tell family and friends?

You may wish to arrange a gathering with family and friends before the transplant admission as you will need to limit visitors when your child is discharged from hospital and continuing with immune suppression therapy.

If family and friends want to help or show support during the transplant, you may want to consider asking for practical help with your other children, helping with housework, providing

meals, doing the school run, or sending cards, pictures or videos to help relieve boredom for both your child and your family.

Communication with friends and family

Plan how you will stay in contact with family and friends while you are in the hospital. Bring telephone numbers and email addresses with you.

Consider using Skype/ / Facetime/Whatsapp video calls/ zoom to stay in contact.

Who do I contact for more information?

BMT coordinators: 07766991070

Paediatric haematology day care unit: 0203 3125095 / 020 3312 5096

Additional patient information is available on our website:



How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3313 0088** (Charing Cross, Hammersmith and Queen Charlotte's & Chelsea hospitals), or **020 3312 7777** (St Mary's and Western Eye hospitals). You can also email PALS at **imperial.pals@nhs.net**. The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to express your concerns in **writing** to:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street, London W2 1NY.

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille, or in alternative languages. Please email the communications team:

imperial.patient.information@nhs.net

Wi-fi

We have a free wi-fi service for basic filtered browsing and a premium wi-fi service (requiring payment) at each of our five hospitals. Look for WiFiSPARK_FREE or WiFiSPARK_PREMIUM

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