

Paediatric haematology

Returning to school after a bone marrow transplant (BMT)

Information for patients, relatives and carers

Introduction

This leaflet has been provided to help answer some of the questions that teachers may have about a child returning to school after a bone marrow transplant. It is also useful for parents and carers to read this information.

What does a bone marrow transplant (BMT) involve?

When a child has a BMT, a central line is inserted under general anaesthetic so that they can be given medication and blood products, and so we can take blood samples without using needles. This is commonly called a central venous line and is normally inserted a week before being admitted for a BMT.

Chemotherapy is used to make space in the bone marrow for the new cells. A child will be given chemotherapy agents for seven days, which can make them tired and develop nausea and / or cause vomiting. Chemotherapy also causes hair loss, which will not grow back completely until they have stopped immune suppression.

Immune suppression is started the day before the new bone marrow is infused and is normally stopped six months after BMT. However, depending on any complications that arise, it can be continued for as long as necessary, most commonly 12 to 18 months after BMT.

Initially immune suppression can cause soft, downy hair to grow all over the body and can cause skin colour to darken, but this will stop once immune suppression has been withdrawn.

Chemotherapy causes an increased risk of infection, so the child will be isolated for a period of four to six weeks in an air-filtered cubicle. Visitors will be restricted to prevent infection. The child must also follow a diet formulated to reduce infections caused by bacteria. They will receive medications to protect them against viral, bacterial, and fungal infections.

The new bone marrow cells will be infused (bone marrow is given via the central venous line that has been inserted and is given in the isolation cubicle. It does not require an operation). The child will be kept in isolation until the neutrophils (white cells which form the immune system) start to rise. During this period the child is most at risk of infection. It usually takes two to three weeks before the neutrophils are detected.

The usual period of isolation is four to six weeks but may be longer depending on any complications that may develop. The child will then be discharged from hospital, and tuition will need to be organised at home until they are able to return to school. Tuition is organised by the hospital schoolteachers, via the local education authority. Depending on what services they can provide, the usual duration is six months.

What do I need to consider when a child returns to school?

Returning to school following a BMT can be both an exciting and anxious period for parents or carers and the child. Getting back into school can be much easier in situations where contact has been maintained throughout the transplant period. You can also help with the process by preparing the rest of the class for the child's return.

When returning to school, most children will be able to go back on a full-time basis without the need for a phased return. But you may find that the child becomes more tired as they readjust to the routine of going to school. It will take time for them to re-adapt to school life; initially, homework on top of a full day at school may be too much, and each child should be considered individually.

Some children may have problems with concentration. This may be evident soon after returning to school and may be noticeable for some time following transplant. Behavioural problems are common and attention-seeking and withdrawing from peers may occur. If you notice this, please contact the child's BMT nurse who can help to provide support from a clinical psychologist or play specialist.

What do I need to know about infections?

Children will be assessed by their consultant before returning to school. Most children will be able to return once they are off all immune suppression therapy and their central venous line has been removed. However, in some cases the child may need long-term immune suppression therapy on a low dose because they have developed a complication of BMT called graft versus host disease (GvHD) – this is the donor cells recognising that they are 'foreign' and starting to 'fight' the recipient. Immune suppression is used to stop this response from happening.

However, the child can still return to school while they continue this treatment. In these cases, the situation for your individual child will be discussed with you before their return to school. A child will be at risk of infection for the first year after transplantation.

Twelve months after the transplant, they are seen by their consultant and following a review, an immunisation schedule is produced and given via their GP practice. It is important that they are vaccinated according to the schedule created for them, and that:

- no vaccines are given at school
- flu vaccines are given via the GP practice

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- the child does **not** receive live vaccines. Examples of live vaccines include BCG and the oral polio vaccine. If the child is travelling, the yellow fever or live oral typhoid vaccine must be avoided.

If a child gets an infection during the first year, this is serious and will need prompt medical attention and treatment where appropriate.

Though coughs and colds are common, where possible, the child should not have direct contact with another child who is displaying symptoms of an illness. We advise that the child is moved away from direct contact until the symptoms have fully disappeared, but the child should continue to attend school.

Whether the child is still receiving immune suppression or treatment or not, the following guidance applies:

- if the child becomes acutely unwell (for example if they collapse or suffer significant injury), please call an ambulance and ensure they are aware that the child has had a bone marrow transplant
- if the child becomes unwell with a temperature or diarrhoea and / or vomiting please call the parents or carer immediately
- if there is an outbreak of childhood infections such as chicken pox, mumps, or measles, please tell the parents or carers immediately. You should also inform the child's BMT nurse at St Mary's Hospital so that appropriate action can be taken.

If you need to contact the hospital for advice, your first contact should be the child's named BMT nurse directly on 020 3312 5062 or 020 3312 3345.

What hospital appointments will they have?

- any child who has had a bone marrow transplant will be reviewed at least yearly for the rest of their life
- in the initial period following transplant, they may be seen more often or miss days from school when they have scans which are essential to evaluate their progress
- most children will also be required to have venesections (a process where blood is removed in an attempt to reduce the amount of iron stored in the body), which is usually done on a three-weekly basis
- where possible, appointments will be coordinated to make sure that the child misses the minimum amount of school possible

What medication will they need?

Following a transplant, all children will need to take penicillin (or an alternative in the event of an allergy) as a prophylactic antibiotic. This is because the spleen is less efficient at providing protection after BMT due to the chemotherapy. An antibiotic is given daily to help prevent certain infections. This will need to be taken for the rest of their life. It is given twice a day and should not need to be given at school. If the child needs medication during the school day, this will be discussed before they return to school.

Can they go on school outings or travel overseas?

If the child remains on immune suppression or other treatment, this will need to be discussed in advance with the BMT coordinator. Otherwise, there are no restrictions. If the child is unwell or has an injury, it is important to remember that the re-vaccination programme may not have been completed.

Who do I contact for more help or information?

Please do not hesitate to contact us if you have any queries or concerns:

BMT coordinators: 020 3312 5062 / 020 3312 5062 / 077 6699 1070

Paediatric haematology day care unit: 020 3312 5096 / 020 3312 5095

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

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk

Paediatric haematology
Published: January 2024
Review date: January 2027
Reference no: 831
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