Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families

Before your child has a bone marrow transplant (BMT)

This information sheet explains the various tests your child will need to prepare for a bone marrow transplant (BMT). It also explains a little about what to expect when your child comes to Great Ormond Street Hospital (GOSH) for these tests and introduces you to the members of the BMT team

Introduction

Part of the preparation for your child’s bone marrow transplant (BMT) will involve examining their heart, kidneys, lungs, ears (hearing) and teeth. This allows us to identify any health issues so we can make sure that your child is in the best possible health before the BMT. As part of the preparation, we will also arrange for you and your child to meet the team who will be caring for you throughout your hospital stay and after you go home.

The BMT preparations usually takes place over two days, there are too many investigations to fit into one day. You could either come up for a day on two separate weeks or two days in the same week. We will try to work around your needs if at all possible, but it is very important that we complete all these tests.

What tests will my child need?

The following give a guide to the tests your child will need. If you have any questions about any of them, please ask your nurse.

Echo (echocardiogram)

All children need an Echo, which is an ultrasound scan of the heart. It shows the structure, function and blood flow through the heart.

ECG (electrocardiogram)

All children need an ECG, which shows how often and how regularly the heart is beating as well as the size and position of the heart’s chambers.

Chest x-ray

All children will need either a chest x-ray or a CT scan to check for current or past infection.

Dental checks

Children aged over one year need to have a dental check to assess if there is any decay or infection that might need treatment before the BMT. The dentist will also explain about mouth care during and after the BMT.

Audiology (hearing) tests

All children have hearing tests. These show if your child has any hearing problems before the BMT, Some medicines given during transplant, such as antibiotics, can affect hearing so it is important we check hearing carefully. These hearing tests are repeated one year after the BMT.

Lung function

Generally only children aged over five years have these tests, although if your child has had previous lung problems, they may have lung function tests even if under the age of five. Four tests are used to measure the size of your child's lungs and airways. The first involves breathing gently through a tube. The second test involves your child blowing out as hard and fast as possible into a tube. For the third test, your child will need to sit in a cabin for a few minutes while their breathing is measured. The final test involves your child breathing in two types of gas (neither of which is dangerous) so that the amount of each gas breathed out can be measured.

GFR (Glomerular Filtration Rate)

Children who have previously had kidney problems or who are having a medicine called melphalan have this test, which shows how well the kidneys are working. A dye is injected into a vein and a series of blood samples are taken over a few hours to see how well the kidney filters out the dye. Your child will not be able to eat certain foods during the test as they can greatly affect the test results. These include: tea, coffee, fizzy drinks, chocolate, ice cream or bananas.

Chest CT scan

If your child has previously had chest problems, they will need a chest CT scan. This uses x-rays and a powerful computer to build up a picture of your child's chest area. The scan can take anything between five and 20 minutes depending on the area to be scanned and the level of detail required. Your child may need to have this carried out under sedation or have a general anaesthetic if they will not be able to lay still.

Your child may also need a cannula inserted, even if they already have a line. The contrast needs to be given through the cannula so that the picture is clear and cannot be given via the central line.

Blood tests

All children have a full blood screen carried out before the BMT to find out if there are any problems with liver or kidney function. Your child's blood group, full blood count and clotting levels are also checked, as are specific viruses. A member of the BMT team will explain further about the various blood tests needed.

Total Body Irradiation (TBI) planning

If your child needs TBI as part of their conditioning regime, they will need to go to University College London Hospital (UCLH) for this as we do not have a radiotherapy department at GOSH. You and your child will have an appointment with the consultant radiologist, who is specialised in giving TBI, to discuss the process in detail with you. There will also be a second appointment to have a CT scan to take precise measurements of your child, discuss the exact plans for the regime and to meet other members of the team, such as the play specialist.

Further information about some of these tests is available on our website at www.gosh.nhs.uk/medical-conditions/procedures-and-treatments

All your child's preparation tests, including liaising with the donor registries if needed, are organised by the outpatient nursing team. The progress towards transplant and your child's condition will also be discussed on a regular basis by the medical staff and other members of the BMT team. During this time, your first point of contact will be the BMT outpatient clinical nurse specialist. When your child is admitted for their BMT, the outpatient team will hand over your child's care to the inpatient team. Once your child has had their BMT and has been discharged home, the outpatient team will take over your child's care once more.

Tests for donors

Sibling donor aged less than 16 years

If your child's brother or sister is the matched donor, they will have a general medical examination. Blood tests will be carried out and one of the clinical nurse specialists will discuss the donation procedure with you and your donor child. Each sibling donor also requires a medical assessment and an HTA assessment by an independent person to ensure the donation is in their best interests. This is to meet the Human Tissue Authority regulations. We understand that this can be a worrying time for your donor child and some further preparation might be helpful if they are anxious or scared. We can arrange for them to see our play specialist and/or psychologist to discuss any concerns and work through any worrying feelings.

We will attempt to find a bed for the donor the day before the bone marrow is collected, and if at all possible, on the same ward as your other child. However this is not always possible due to bed availability. The donor will be reviewed in outpatients for blood tests the day before the procedure and for a routine check by a member of the BMT team. Afterwards, they will either go home or stay in the patient hotel if you live outside London, before returning as a day case for the procedure. We will tell you where your donor child is likely to be admitted as soon as possible so you can make arrangements. Generally, your child will be well enough to go home the afternoon after the bone marrow donation.

Adult related donors

Stem cells from adult related donors are collected at University College London Hospital (UCLH), which is about 15 minutes' walk from GOSH. The tests done at UCLH will include an ECG, chest x-ray and blood tests. The BMT clinical nurse specialists will liaise with the team at UCLH and will inform you when and where the appointment will be.

Unrelated donors

If your child has an unrelated donor, their bone marrow registry will contact the donor to find out if they are available for the date(s) we have requested. This process can take several weeks and although we understand that this can be a very stressful time, we are not able to influence the availability of the volunteer donors. It is possible that the donor may not be available to donate on the first requested date due to prior commitments, but the team are in close contact with the donor registries and we will inform you as soon as a date is confirmed. Donors have to have a full medical carried out around two weeks before their cells are collected to ensure they are fit to undergo the procedure. There is a very small possibility that the donor will fail this and the transplant will not be able to go ahead using this donor, if this occurs, we will approach an alternative donor and discuss the options with you.

Members of the BMT team

This section explains about the various members of the BMT team, their responsibilities and when you are likely to meet them.

BMT consultants

Once a donor has been identified for your child but before the preparation tests have been done, you will meet your child's consultant. This is so all aspects of your child's BMT can be discussed and any questions you have answered. The consultants work on the ward on a rota, so your child may have more than one consultant in charge of their care during admission. However, all the consultants work very closely together and will discuss your child's ongoing care and treatment during weekly ward rounds. All three consultants in the BMT team attend the weekly BMT clinic. As well as the consultants, there will be other members of the medical team caring for your child.

My child's consultant is

Inpatient clinical nurse specialist

Our inpatient clinical nurse specialist is a member of your child's inpatient nursing team along with staff on the ward. There are currently 10 beds on Fox Ward and three on Robin Ward. We also carry out transplants on Butterfly Ward. Your clinical nurse specialist will tell you which ward your child is likely to be admitted and liaise with the ward sisters.

They will meet you and your child before you come for the BMT to discuss briefly what being an inpatient will be like. It is a chance for you to discuss any further questions you have about family care, visitor restrictions and any other thoughts. Once admitted for transplant, they will prepare you and your child for the transplant, which includes taking consent for the procedure and talking through how to care for your child once they are in isolation. After the BMT, when you and your child are ready to go home, they will make sure that you have all the information needed to take care of your child. In addition, they will liaise with your community team, shared care hospital and family doctor (GP) to make sure that they are fully informed of your child's progress and the care they will need.

My child's inpatient clinical nurse specialist is

Ward sister

The ward sister for the ward where your child is having their transplant is also a member of your child's inpatient nursing team. They lead and manage the ward team to make sure that we deliver the highest standards of care possible in the most efficient way. You can discuss your child's care with the ward sister or any member of the nursing team. They can also provide support and advice with any aspects of your child's inpatient stay, the care and treatment your child will receive and any social issues that might arise during admission. The ward sister is also responsible for making sure that the ward environment is kept clean and well-maintained so please talk to them about any concerns or questions.

The ward sister of ward is called

Outpatient clinical nurse specialists

Our outpatient clinical nurse specialists coordinate all outpatient treatment and are the first point of contact for families with a child who are preparing for a BMT or who have had a BMT. Their role includes discussing care with the medical and nursing teams at your child's shared care hospital and also with your child's community nursing team. They will organise all your child's care and treatment, with the aim that your shared care hospital provides as much care as possible with the expertise and experience of the team at GOSH available when needed. Depending on your child's recovery, you may be with our team for six months to two years after transplant. Once your child has no transplant-related complications, they will be transferred to the medical and nursing team who referred your child originally and they will continue to coordinate their care.

Specialist nurses also work with the outpatient nursing team. They will be involved in most aspects of your child's care, that is, organising the preparation tests and talking to you about the transplant process. During the inpatient admission, the ward team will be your main point of contact.

My child's outpatient clinical nurse specialists are:

My child's specialist nurse is:

Other members of the BMT team

Social workers and family support workers aim to reduce the stress of illness and the experience of staying in hospital. They can provide practical advice and assistance to children and families, including advice on welfare, benefits and financial support.

My child's social worker is:

It is important that your child is as well-nourished as possible for the BMT as this will help them feel better and may help to fight infection. Before the BMT, the dietitian will assess your child's diet and check their weight and height. If your child is on a special diet or has tube feeds or supplements, please tell us beforehand so we can arrange for these to continue. If needed, the dietitian can discuss your child's nutrition with you and suggest ways of increasing the amount of goodness in what they eat. You will also be able to ask any questions about the 'clean diet' and nutritional support before and during the transplant. When you are staying on the ward, the dietitian will visit regularly.

My child's dietitian is:

Our occupational therapist (OT) is also part of the BMT team. If your child is aged less than five years, our OT will meet you to discuss your child's development. Together with the play specialist, they will monitor your child's development, providing activities and recommendations to help them to continue to grow and learn while in hospital and once you return home.

If your child is older than five years, the OT and play specialist will work together to keep your child as independent as possible when it comes to everyday things such as washing and dressing. They will also provide a daily routine for while your child is in isolation and once you go home to make sure that they returns to activities suitable for their age. If your child needs any special equipment, such as a wheelchair or splints, while staying in hospital the OT will arrange this.

My child's occupational therapist (OT) is:

Our play specialist will provide appropriate preparation for your child both before and during the BMT process using picture books and dolls. This will help ease any anxiety your child has about what will happen and give them a clear understanding of what a BMT involves. Our play specialist will also help keep your child developing as normal using regular play sessions and learning opportunities.

My child's play specialist is:

A member of the psychology service may meet with you and your family before the BMT takes place. We recognise that going through the BMT process is a stressful time and meeting the psychologist gives you all the opportunity to think about how the process might affect different members of your family and what support might be needed to help you all through it. Children aged five or more will also meet a member of the psychology service to have a short assessment to check their developmental progress. Children under five years will be offered a developmental review with our OT. This helps us monitor your child's progress throughout the BMT process and help us to advise ward staff on appropriate activities for your child.

My child's psychologist is:

Useful telephone numbers

GOSH switchboard – 020 7405 9200

BMT outpatient secretary – ext 0444

BMT outpatient nursing team – ext 1188

BMT inpatient nursing team – ext 5083

Compiled by the BMT team in collaboration with the Child and Family Information Group Great Ormond Street Hospital for Children NHS Foundation Trust, Great Ormond Street, London WC1N 3JH www.gosh.nhs.uk