PORT-A-CATHS IN CHILDREN WITH HAEMOPHILIA

Our Lady's
Children's Hospital
Crumlin

PARENT INFORMATION

It is recommended that all children with severe haemophilia who are over two years of age or have had two joint bleeds receive regular doses of coagulation factor concentrate to prevent spontaneous bleeding and reduce the risk of long-term side effects. This is called prophylaxis.

For children with severe factor VIII deficiency this involves injection of coagulation factor concentrate into the veins three times per week, for children with severe factor IX deficiency twice per week and for children with severe factor X deficiency once to twice per week.

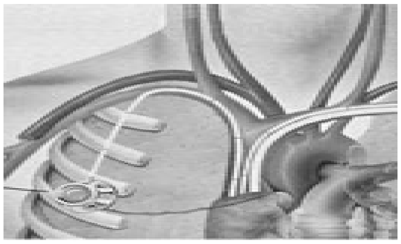
In small children and children with poor veins repeated intravenous injections can be very difficult and a port-a-cath or "port" is needed until the veins have developed.

By the time your child is ready to start prophylaxis you will have discussed intravenous access and ports many times with your haemophilia team.

WHAT IS A PORT?

A port is a special device, which is used to allow easier, more dependable access to your child's veins. It is made up of an injection port and a long hollow tube.

The injection port is attached to one end of the tube and sits underneath the skin on your child's chest. The other end of the tube is placed in a vein close to your child's heart.



When your child needs an injection a special needle is inserted through the skin into the injection port using a sterile procedure allowing access to his/her veins.

WHAT HAPPENS WHEN I DECIDE MY CHILD NEEDS A PORT?

When you and the haemophilia team have decided your child needs a port he/she will be referred to the surgeon who will send you an appointment to come to the surgical clinic to discuss the procedure.

The surgeon will explain the procedure, the alternatives and the risks involved and answer any questions you may have. A date for the procedure will be arranged and you will receive notification of this date from the Admissions Department.

Please remember this date will be subject to the availability of a bed and you will need to confirm this with the Admissions Department before coming to the hospital. Although every effort is made to avoid cancelling procedures it is sometimes unavoidable!!

It will be necessary to bring your child to your haemophilia centre the week before surgery to have a blood test performed to check for inhibitors. The haemophilia nurse will organize this.

HOW IS A PORT INSERTED?

Your child will go to theatre and have a general anaesthetic for the operation. He/she will be in theatre for about two hours in total. The surgeon will insert the port. This usually takes about 30 -60 minutes. The rest of the time is spent putting your child to sleep and waking him/her up again.

WHAT HAPPENS WHEN I TAKE MY CHILD TO HOSPITAL TO HAVE A PORT?

ADMISSION: Children with haemophilia who need a port have the procedure at Our Lady's Children's Hospital in Crumlin. A six-day stay in hospital is usually required.

You will be admitted to the hospital the day before the operation. You will need to phone Admissions that morning to confirm there is a bed available and confirm the time of admission (usually 2pm).

On arrival to the hospital you will attend the Admissions Office and from here you will be directed to the ward. Parents are welcome to stay either by the bedside or in parents' accommodation. Further information is available in the patient's handbook that will be provided by one of the haemophilia team.

ASSESSMENT: When you arrive on the ward a nurse who will carry out a nursing assessment. A surgical doctor will examine your child.

CONSENT: The doctor will explain the procedure, answer any questions you may have and ask you to sign a form declaring that you have received sufficient information and you are giving your consent for the procedure. Do not sign this form unless you are happy you have all the information you need to fully understand the procedure.

During the course of the evening or night a specialised nurse from the IV team will put in a cannula and take some bloods.

Your child will need to fast for the operation. He/she will not be allowed food after 2am but may have a drink of clear fluids up until 6am the morning of the operation.

THE MORNING OF THE OPERATION

A dose of coagulation factor concentrate will be administered to your child to bring factor level up to normal. A blood sample must be obtained from your child post factor administration

Once this blood is taken your child will be attached to a drip, which will administer coagulation factor concentrate for the next five days to keep his/her levels normal. He/she will have regular blood tests to make sure the infusion is maintaining his/her factor levels.

As soon as the factor levels are confirmed your child will be taken to the operating theatre. All children with haemophilia having a port inserted will be in the theatre department before midday.

One parent may go to theatre and stay with the child until he/she is asleep.

AFTER THE OPERATION

After the operation your child will be sent back to the recovery room until he/she is awake and ready to go back to the ward. A nurse from the ward will collect your child from the recovery room. You may go to the recovery room with the nurse. Your child may be irritable when he/she first awakens. This may be due to the anaesthetic or because he/she is sore or hungry.

There will be a bandage over the wound to prevent bleeding and infection. This bandage should not be removed for 48hours.

There will usually, but not always be a needle in the port. If there is there will be a short tube with a bung on the end coming from the port. If there is a needle in the port it may be used immediately if absolutely necessary. Factor level cannot be taken from the port.

On return to the ward the nurses will closely monitor your child, his/her pulse and blood pressure, the wound and the coagulation factor infusion.

Your child will receive pain relief medication during the procedure and should continue to have pain relief regularly for 24 – 48hours afterwards. Paracetamol is usually sufficient but codeine may be required. It is important that your child has sufficient pain relief so he /she can move normally and not become stiff.

As soon as your child is awake and alert he/she can have something to eat and drink. It is a good idea to start with clear fluids and a light diet in case he/she is sick after the anaesthetic. As soon as they are tolerating food they can eat normally.

The factor infusion will continue for five days after the surgery to ensure your child’s factor levels are normal until the wound is healed. This means he/she will be continuously attached to a drip, which will restrict his/her mobility for five days. Pleas bring toys or books to help amuse your child during this period.

The wound is generally closed with a dissolvable continuous stitch with steri-strips (plaster stitches) on the outside for added strength. The steristrips should be left in place and allowed to fall off of their own accord. This may take 10 days.

LONG TERM CARE OF THE PORT

The haemophilia nurse in your centre will teach you how to care for your child’s port.