Irish Haemophilia Society



Introduction to Portacaths



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INTRODUCTION

Haemophilia is a genetic blood disorder, which is usually inherited. The gene is passed down from a parent to a child. A person who is born with haemophilia will have it for life. A diagnosis of haemophilia in a family can be a traumatic experience. However, with excellent treatment the life expectancy of a child born with haemophilia in Ireland is essentially normal. Some children do not have good veins and until these develop may require to have a portacath inserted under the skin, to help their parents give treatment at home. We hope this booklet gives you an understanding of portacaths.

If you require further information please contact:

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WHAT IS A PORTACATH?

A portacath (port) is made up of a metal or plastic chamber and a silicone tube (Figure 1). The whole device is placed under the skin and the tube is placed in a large vein near the heart. A special needle called a 'gripper' is inserted through the skin and into the port chamber to allow you to give factor to your child. Once the factor is given the needle is removed. When the needle is out, the port has no external parts and is not visible, athough you will feel a small lump under the skin.



Figure 1 Portacath



Figure 2 Portacath in situ



Figure 3 Gripper needle in Portacath

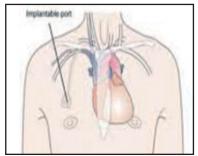


Figure 4 Portacath in relation to heart and main veins

HOW IS A PORTACATH INSERTED?

The port is inserted in theatre under general anaesthetic. The surgeon starts by making a small incision on the side of the chest. The port is then inserted into a small pocket that is created by the surgeon. It is then stitched into place on the muscles over the rib cage. Another small incision is made in the neck and the tube is threaded into a large vein at the top of the heart. A short X-ray confirms that the tube is in the correct position. Both wounds are then closed with dissolvable stitches and then covered with paper stitches and a dressing. The gripper needle will be inserted in theatre. The port can be used immediately.

COMPLICATIONS ASSOCIATED WITH PORTACATHS

Infection

Infections can happen at any stage. Often an infection can be cleared with antibiotics, but sometimes antibiotics cannot clear the infection and the port must be removed. Signs of infection include a high temperature, feeling hot and cold, achy or shivery, or redness, soreness or discharge around the port.

Thrombosis (blood clot)

Clots may form in the port, tube or in the vein that the tube lies in. Signs of a blood clot include swelling and pain in the shoulder, neck or arm. The veins in the neck or chest on the same side as the port may stand out. Your child may need a special x-ray called a linogram or an ultrasound to identify a clot or blockage. If the blockage in the tube is caused by a blood clot a drug called Urokinase can be put into the tube to break down the clot. If the tube cannot be unblocked or is blocked due to a kink, the port will be removed.



Mechanical problems

The tube can break and sometimes move through the veins. The tube can also sometimes crack or fracture causing leakage from the tube within the vein. The port chamber may also erode through the skin. If it is not possible to fix mechanical *4* problems, the port will be removed.

PREPARATION FOR SURGERY

Meeting the Consultant Surgeon

When your child needs a port he/she will be referred to the surgeon. You will receive an appointment to come to the surgeon's clinic to discuss the procedure. The surgeon will explain how the port is inserted, the risks of insertion and answer any questions you have. A date for surgery may be arranged.



Before admission

It will be necessary for your child to have a blood test 2 weeks before surgery to check for inhibitors. The haemophilia nurse will organise this.

Admission

Port insertion requires a six day hospital admission for a child with a severe bleeding disorder. Your child will be admitted to the hospital the day before the operation. The Admissions Department will notify you of the date of admission for port insertion. This date will be subject to the availability of a bed. You must phone the Admissions Department on the morning of planned admission to confirm that there is a bed available and the time of admission (usually 2pm). On arrival to the hospital you should check with the Admissions Department. You will be directed to the ward from there. **Although every effort is made to avoid cancelling procedures it is sometimes unavoidable.**

Ward

Your child will be admitted to the specialist haemophilia ward where the nurse will carry out an assessment. A specialist nurse from the I.V. team will put in a cannula (Freddie) and take blood. A surgical doctor will examine your child, explain the procedure and answer any questions you have regarding the procedure.

Consent

The surgical doctor will ask you to sign a consent form declaring that you have received sufficient information and you are giving your consent for the procedure. Signing this form means that you consent to your child having a port inserted and that you are satisfied you have all the information you need to fully understand the procedure.

Fasting

Your child will not be allowed food after midnight, but may drink clear fluids up until 6am.

DAY OF SURGERY

An antibiotic is given through your child's cannula to help prevent infection. A dose of factor will be given to increase the factor level. A blood test will be required to check that the factor level is high enough for surgery. This sample cannot be taken from the same cannula that the factor has been given through. When the factor level is confirmed as satisfactory and the surgeon is ready your child will be taken to the operating theatre.

For children with severe factor VIII or IX deficiency, a drip will be connected to your child after this blood test and will pump (infuse) factor into your child continuously for the next five days to keep the factor levels normal. Its always a good idea to bring toys / books / DVDs to help entertain your child as he/she will be continuously attached to a drip and mobility will be affected.

Your child will be in the Theatre Department for about 3 to 4 hours. The procedure takes up to 90 minutes. The rest of the time is spent giving your child the anaesthetic and waking him/her up again after the procedure.

One parent may accompany the child into the Theatre Department and stay in the Anaesthetic Room until he/she is asleep. After the operation your child will be taken to the Recovery Room until he/she awakes and is ready to go back to the ward. One parent may go to the Recovery Room with the nurse from the ward to collect your child.

Your child may be cross and irritable when he/she wakes. This may be because of the anaesthetic, pain or hunger.



AFTER SURGERY

The gripper needle will be inserted into the port and will be secured with a dressing. This dressing will also cover the port site and should not be removed for 48 hours. Underneath this dressing there will be a small wound over the port with a row of paper stitches (steristrips). These should be left in place and allowed to fall off. This may take 10 days.

There will also be a small wound on your child's neck which will be covered with paper stitches and a small dressing. This dressing should also be left in place for 48 hours and the paper stitches allowed to fall off naturally.



Will it be painful afterwards?

Your child will receive painkillers during the procedure and will continue to receive painkillers regularly for 24 – 48 hours afterwards. Paracetamol (Calpol) is usually sufficient although stronger painkillers such as codeine are available if required.

Eating and drinking after the procedure

As soon as your child is 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 of nausea/sickness after the anaesthetic. As soon as your child is tolerating food he/she can eat normally.

Day after surgery

Blood tests will be taken for full blood count and factor level on the day after surgery. For children with severe factor VIII and IX deficiency: the factor infusion may be increased or decreased. Further factor levels will only be required if factor infusion is changed.

What about showering, bathing or swimming?

It is important not to get either dressing wet until the wounds have healed and this normally takes about one week. Once the wounds have healed, your child can bath, shower or swim as normal.

USING YOUR CHILD'S PORT AT HOME

Parents are taught to use their child's port by the haemophilia nurse specialist. This education will commence on a dummy/mannequin in the days following the surgical procedure and will progress to your child in the following weeks. You will be required to attend the hospital regularly during these weeks for support and training in how to give factor through the port. Each person using the port must give their child's factor successfully a minimum of 3 times under supervision. The haemophilia nurse specialist must be confident that you can use the port safely before you can begin to give factor to your child at home.

Equipment required

Factor Sterile gloves x 1 Gripper needle x 1 10ml syringes x 3 Filter straw x 1 10ml of Saline 5ml of Heplok Sani-cloth x 4 Sharps bin



This equipment is available free on the 'long term illness' scheme and medical card.

Accessing the port: Summary of instructions

- 1. Gather together equipment.
- 2. Wash down surface.
- 3. Wash and dry hands.
- 4. Open sterile gloves.
- 5. Open all sterile equipment onto sterile field.
- 6. Mix factor.
- Check expiry date of Saline and Heplok, open and leave with factor beside sterile field.
- 8. Wash and dry hands.
- 9. Put on sterile gloves.
- 10. Draw up Saline, Heplok and factor into syringes using the filter straw.
- 11. Prime gripper needle with Saline.
- 12. Clean port site with Sani-cloth.
- 13. Identify the position of port and insert the gripper needle at a ninety degree angle.
- 14. Check position of gripper needle by ensuring blood return.
- 15. Infuse Saline, factor, and Heplok.
- 16. Remove gripper needle.
- 8

Remember to:

Dispose of glass and needles in a sharps bin.

And to document:

- the reason for treatment,
- the amount of factor given,
- the batch number of factor,
- the expiry date.

TROUBLESHOOTING

Unable to get a blood return

What to do:

- Check that the needle is down to the bottom of the chamber.
- Check that the clamp is open.
- Check that there are no kinks along the gripper line.
- Reposition the child's head and ask him/her to lift arms above head.
- Slowly flush 1ml of Saline and check for blood return. Do not force fluid into the line. If the line flushes with normal pressure and there is no swelling, pain or leakage you may continue.
- Contact your Treatment Centre for advice.

Unable to flush line with normal pressure

What to do:

- Do not force fluid into the gripper line.
- Check that the needle is down to the bottom of the chamber.
- Check that the clamp is open.
- Check that there are no kinks along the gripper line.
- Reposition the child's head. Ask him/her to lift arms above head.
- If still unsuccessful, remove the needle and insert a new gripper.
- If you are still unable to flush the line, contact your Treatment Centre.

Infection

Signs:

Temperature >38°C, especially if it occurs after flushing the port.

Feeling hot and cold, achy or shivery, or redness, soreness or discharge around the port or along the tube under the skin.

What to do:

Call your Treatment Centre immediately.



Investigations and treatment

Not all high temperatures are due to port infections, but a port infection should always be considered. Blood will be taken through the port and also from your child's vein to check if there are bacteria present, and if there are, to identify the most suitable antibiotic treatment. If antibiotic treatment does not cure the infection, the port will be removed.

Mechanical problems

1. Break in the port/ tube

Signs:

Pain or swelling along the tube, or pain while flushing the port.

What to do:

- Stop infusion.
- Do not force or continue to flush.
- Contact your Treatment Centre.

Investigations and treatment:

A special x-ray called a linogram will be performed to look at the tube. If there is a break in the tube, the port will be removed.

2. Eruption of the port through the skin

Signs:

The port chamber breaks through the skin.

What to do:

- Don't Panic!
- Place a dressing over the area of broken skin.
- Contact your Treatment Centre.

Treatment:

The port will be removed.

If you have any questions regarding any of the information contained in this leaflet, please do not hesitate to contact your Treatment Centre.

INFORMATION FOR PARENTS

VISITING Visiting Hours = 8am-9pm Parents can visit anytime. One parent can stay overnight.	PARENTS' FACILITIES Parents' room located at ward entrance. Tea/Coffee making facilities, shower, toilet. Canteen, Coffee Dock, and Shop also available.	PARENT'S ACCOMMODATION Located on 2nd floor. Bedside mattress available for collection by parent. Overnight parent rooms available for a fee.
T.V. AND REMOTES Remote controls are in limited supply and must be shared.	PARKING Main hospital public car park. Long-term parking (more than 10 days) is available for a special weekly rate.	blessings and sacraments.
DOCTOR'S ROUNDS Times of doctor's rounds are varied and unpredictable.	BED ALLOCATION Beds are allocated on a clinical needs basis. Bed moves may be necessary.	PREVENT INFECTION Hand washing is very important. Avoid visiting if sick/unwell yourself.
PLAY & EDUCATION Play room/ Play Specialist available Monday-Friday. Hospital school & teachers available, discuss with your nurse.	ADOLESCENTS Adolescent Den (games room, shower and dining facilities) available for adolescents aged 12 and over. Adult supervision is required.	GENERAL HOUSEKEEPING Please keep bed space and locker clutter-free. Be mindful of others when on mobile phones. Smoke free environment.
CHILDRENS SAFETY Cot & bed sides to be used when child asleep or alone. If leaving your child unattended, please inform your nurse.	CHILDRENS MEDICINES For safety reasons, your child's medicine must be given to your nurse so it can be locked away.	CHILDRENS MEALS Meal times = 8.30am-9am, 12.30pm, 4.15pm, 6.30pm. Snacks & drinks available outside these times. Special diets can be ordered if required.

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