

## PORTS

## A Parent's Guide

Many children with hemophilia have had infusion devices called ports (Port-A-Cath, mediport) implanted when they were very young. The most likely reason a port is used is to give care providers a way to easily infuse factor concentrate and draw necessary blood samples. Young children often have small veins that are difficult to locate and give factor through, and it is often hard for parents and caregivers to directly access ("poke") a child multiple times in order to administer the necessary clotting medicine. Ports eliminate the need to poke a vein because the port assures access into the child's venous (blood vessel) system. Ports are a great benefit for children with hemophilia, but they do not last forever. Following is an exploration of some of the questions parents might have regarding transitioning from a port to the more traditional method of infusing clotting factor through a vein (venipuncture).

**How long do ports last?**

How long a port lasts is different for everyone. When ports were first designed, they generally were used for administration of other intravenous medications that were ongoing for a number of months or years. Often these ports were used only a few times a month. In comparison, a child with hemophilia on prophylaxis or immune tolerance may be using his/her ports daily or every other day. The usual "lifespan" of a port is three to five years, though there are some patients who have kept their port in, with no problems, for more than 10 years. ▶▶ TO | 64

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### ► What causes ports to stop working?

There are many reasons ports stop working.

- The most common reason is infection. If a child develops an infection in his/her port that cannot be cleared with antibiotics, the port must be removed. The port itself is still working, but the risk of a systemic (throughout the entire body) infection that could result in hospitalization or even death is too great to leave an infected port in place.
- Malfunction of the port itself is another reason ports stop working. The port can come apart or come out of the vein. The fluid/factor infused would then go into the tissue surrounding the port and be of no use to the patient.
- Clots can occlude (clog) a port and prevent it from working. This sounds like an odd complication for someone with a bleeding disorder, but it is not as uncommon as you may think. If a child is on prophylaxis and receives factor on a regular basis he/she can develop clots just like anyone else. These clots may be in the port, the catheter, a major vein leading to the heart or in the vein at the end of the catheter.
- If the port is not being accessed on a regular basis and not being flushed per your hemophilia treatment center's (HTC's) protocol or instructions, it can also clot off and stop working.

### If the child's port stops working, can't he/she just get another one?

The answer to this question is not simple and must be made by parents, the child (if he/she is old enough to understand), your physician and the HTC team. If your child is still an infant or toddler and does not have good peripheral (arm and hand) veins, replacing the port can be considered. Transition to venipuncture (using a vein) should be considered for children who:

- Have developed veins in their arms and hands that a parent or the child can be taught to "stick."
- Are cooperative and can sit still while the factor is being infused through a vein.

- Have support available to make this transition a success.

### What if parents want another port even if their child has good veins?

This is an individual decision that will need to be made with a child's treatment care team. It is not the right decision for everyone, but it may be for some.

### Can a child transition to venipuncture before the port fails?

Yes, the ideal time to begin the transition process is while the child still has a functioning port that can be used as back up in case the parents "miss a vein." When the parents think the child is ready to begin venipuncture (using a vein), contact an HTC nurse to set up a teaching plan designed to help with the beginning stages of the process of home infusion using venipuncture. If parents have been trained in mixing and administering factor, the teaching can go quickly. Keep in mind the teaching will vary from HTC to HTC, according to their policies.



### How do parents begin this process of transition?

- Parents should contact their HTC when they are ready to begin the transition. A nurse coordinator may bring this subject up during a comprehensive visit or may approach the subject with the child at camp.
- The nurse will work with the parents to identify veins that might be used, review the process of venipuncture and set up a teaching schedule.

Keep in mind this is a process, similar to learning to access your child's port. Parents should be patient and not expect the process to happen overnight. Planning is the key to success. Parents should contact their hemophilia nurse coordinator and she/he will guide them through this process. 🔄