

INTRODUCTION TO ECMO FOR PARENTS

**(ECMO = “Extra Corporeal Membrane Oxygenation”,
meaning heart-lung bypass)**

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INTRODUCTION TO ECMO FOR PARENTS (ECMO = “Extra Corporeal Membrane Oxygenation”, meaning heart-lung bypass)

Who Needs ECMO?

Your child has a severe lung or heart condition that has not responded to our usual therapy of a respirator (mechanical ventilation), medicines, and extra oxygen. Infants and children who do not respond to this therapy could die, but ECMO could be successful if used to treat your child. The infants who require ECMO usually have one of the following problems: Meconium Aspiration Syndrome, Sepsis, Respiratory Distress Syndrome, Persistent Pulmonary Hypertension, Pneumonia, or a Congenital Diaphragmatic Hernia. Children with Pneumonia, Sepsis, Acute Respiratory Distress Syndrome, or certain heart conditions may benefit from ECMO therapy. Your child’s doctor will discuss with you the specific problems your infant or child has.

Important: ECMO is offered only to children whose lung and/or heart disease is thought to be reversible.

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What is ECMO?

ECMO stands for Extracorporeal Membrane Oxygenation. The ECMO machine is very similar to a heart-lung bypass machine used for open-heart surgery. When your child is placed on ECMO, his/her blood receives oxygen from an artificial lung in the ECMO circuit (or system). The artificial lung in the ECMO circuit will provide your child’s blood with the oxygen needed to live until his/her lungs and/or heart are able to work on their own.

How does the ECMO circuit work?

Dark blood (containing little oxygen) will drain by gravity from the patient through a tube (catheter) placed in a large vein (usually the neck in infants and the neck and/or groin in older children). The pump (which acts as an artificial heart) will push the blood through the rest of the ECMO system. Blood is pumped into the oxygenator (which acts as an artificial lung), where it will be cleansed of carbon dioxide and will pick up oxygen. Once the blood leaves the oxygenator, it is warmed and is returned to the patient through the arterial catheter. This oxygenated blood will look bright red in color. Blood is drained out and pumped back to the patient at the same rate so your child's body does not know this is happening.

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How is my child placed on ECMO?

The surgical procedure required to put the ECMO catheters into your child is usually performed by a surgeon and an operating room team. This procedure usually occurs at your child's bedside. Your child is given medication for pain and sedation before the procedure begins. A medication to keep your child from moving during the procedure is also given. Your doctor or nurse may refer to this medication as "paralysis". This paralysis is temporary and will wear off a short time after the last dose is given. The incision area at the neck or groin will also be given a numbing medication. The catheter(s) is (are) inserted into the blood vessel, and advanced (threaded) into the heart. An x-ray will be taken immediately to make sure that the catheter(s) is (are) in the correct position. The catheter(s) will then be connected to the ECMO circuit.

Even though your child is being supported by ECMO, he/she will remain on the ventilator. This will allow for removal of secretions from your child's lungs and will give breaths to help keep the lungs inflated.

Types of ECMO

There are two types of ECMO therapy: venoarterial (VA) and venovenous (VV) ECMO. The terms VA and VV refer to the blood vessels used during the procedure.

VA ECMO

In VA ECMO, a catheter must be placed in both a vein (veno) and an artery (arterial). VA ECMO is usually used in children with possible blood pressure problems and who need the added support the VA ECMO can give the heart. The advantage of VA ECMO is that this method gives excellent support for the heart in addition to the lungs. Therefore, if the heart function is a concern, VA ECMO will be used.

VV ECMO

In VV ECMO, a single catheter with two tubes is placed in a vein. VV ECMO is used in children who have no significant heart function or blood pressure problems. There are a few children who start out on VV ECMO who need to be changed over to VA ECMO. This is usually due to low oxygen levels with VV ECMO or blood pressure problems in the child. The advantage of VV ECMO is that the carotid artery does not need to be tied off as in VA ECMO.

Special cases and older children may need an individualized approach to cannulation for ECMO, using other vessels than described above. If this is the case for your child, your child's doctor will describe this to you. Don't be afraid to ask questions.

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What are the risks for my child on ECMO?

Any child who requires ECMO therapy is very ill and usually will die without it. However, there are risks associated with this procedure:

1. The blood must be kept from clotting while it goes through the machine, so a drug called **heparin** (a blood thinner) is given to prevent clotting. Sometimes this can lead to bleeding. If bleeding of any kind occurs, the ECMO physician will discuss it in detail with you. The amount of heparin needed will be monitored closely and steps will be taken to minimize any bleeding that occurs. If bleeding becomes too great, ECMO therapy may have to be discontinued. There aren't any tests to determine if your child has had damage to

- his/her brain from the low levels of oxygen before ECMO. If this has occurred, there may be an unjured area in the brain that will bleed when the heparin is used for ECMO. Your child's doctor will discuss this with you. In general, your child's risk of dying without ECMO is greater than the risk for bleeding in the brain.
2. The ECMO surgical procedure may involve tying off the carotid artery. The carotid artery is one of the blood vessels that supplies blood flow to the brain. To date, this has not caused any complications because other blood vessels takeover and carry blood to the brain. Because ECMO is relatively new, the long-term risks of this surgery are not known; however, an increased risk of stroke must be considered as your child continues into adulthood.
 3. Whenever a catheter is inserted into a blood vessel, there is an increased risk of infection. Your child will receive antibiotics as a precautionary measure, and will be watched carefully for signs of infection.
 4. A child on ECMO will require frequent blood transfusions. As with any blood transfusion, there is always a risk of a blood reaction as well as hepatitis and HIV. The blood used from the blood bank is screened both for hepatitis and HIV; however, there remains a very small risk that such a disease could be acquired. Your child will be monitored for any signs of infection from blood transfusions.
 5. Although every safety measure is taken, the ECMO circuit can malfunction or fail. If this occurs, steps will be taken to keep your child stable. Your child will be put back on ECMO therapy as soon as possible.
 6. Small blood clots or air bubbles can get into the bloodstream from the circuit. This can be fatal in some circumstances. Every safety precaution will be taken so that this won't happen.

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How long will my child be on ECMO?

The average number of days a child is on ECMO will depend on the age of the child and his/her original diagnosis. For a newborn, the average number of days on ECMO is 5-7, but can be as many as 14 or more days. For an older baby or child, the average number of days on ECMO is 10- 30 days (these averages can differ from one institution to another). Each child is different and the length of the course of ECMO may be affected by these individual differences. Some of these differences include: the type of lung or heart disease, the amount of damage to the lungs before ECMO, and complications that may occur during ECMO.

A steady amount of blood is pumped through the ECMO machine each minute. This is usually referred to as the “ECMO flow”. When your child is first placed on the ECMO machine, the flow is maintained high. This means that the ECMO machine is doing most of the work to provide oxygen to your child’s blood. As your child improves, the ECMO flow can be decreased and more of the blood will go to your child’s lungs to get oxygen.

Your child’s lungs are improving when the oxygen content in the blood increased consistently over time despite a decrease in ECMO support.

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Is ECMO Painful?

When the ECMO catheters are initially inserted, your child is given a numbing medicine in the skin, as well as a medication for pain and sedation. ECMO patients do not appear to be in pain while on ECMO; however, a pain medication will be available if the nurse or ECMO Specialist determines that your child is uncomfortable.

In addition to pain medication, we will be doing other things to make your baby comfortable. Infants may lie on a sheepskin to cushion the skin or on an eggcrate mattress to help prevent pressure areas on the skin. An infant’s eyes may be shaded to decrease the disturbance from overhead lights. Pacifiers and booties may also be used for comfort if your child’s condition allows. Older children may be on a special bed with a specific mattress that helps to prevent pressure areas on the skin. Regular diaper changes, bathing, and frequent repositioning are just a few of things that we will be doing to keep your child comfortable.

Will I be able to visit my child during ECMO therapy?

As a parent and/or family member, you play an important role in your child's care and recovery. We encourage you to visit your child while he/she is on ECMO. Each unit has its own visitation policy and you will need to check with the nursing staff of your child's unit.

If you wish to stay in the hospital overnight, ask your child's nurse for further assistance. Unfortunately, space in the hospital may be limited but the nursing staff will do their best to find you a place to stay. If you would like to stay near the hospital and are unfamiliar with the area, ask your child's nurse to contact the social worker for further assistance.

While your child is on ECMO, there are some things you can do to help with your child's care. Please ask your child's nurse or ECMO specialist how you can participate in your child's care. Some examples are:

1. Providing special toys or comfort items.
2. Touch your child. A reassuring touch and your voice are important and comforting; in fact, studies show that healing occurs faster in a child who is touched. If you are afraid to touch your child, ask the nurse or ECMO specialist for guidance.
3. Tape yourself reading stories or singing songs and bring them in for your child to listen to.
4. If your child has brothers and/or sisters, have them draw pictures that can be placed at your child's bedside. It is important to include the other siblings and encourage them to participate so that they may feel as if they, too, are contributing to the care and recovery of their brother or sister. Some units have sibling visitation policies. Ask your child's nurse regarding those specific guidelines.

5. Keeping a journal of your child's progress may help when you speak with your child's doctors and may be a way you can better understand what is happening with your child.
6. You must also take care of yourself. Make sure you eat properly and get some rest. Although you may want to be at your child's bedside all of the time, it is important that you keep up your strength.

And, remember, you can call at anytime to check on your child when you are away from the bedside- we are always happy to talk with you.

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How will my child receive nutrition during ECMO?

All nutrition needed for energy and growth will be provided to your child by intravenous (IV) therapy while your child is on ECMO.

If you are currently breastfeeding or are planning to breastfeed your baby, talk to his/her nurse or doctor. Often, after a baby comes off of ECMO, breastfeeding can be started. Meanwhile, you can pump your breasts and store the milk. Ask your baby's nurse for information regarding pumping and storing breastmilk.

Who will be taking care of my child?

Once the physician has decided that your child is a candidate for ECMO and you (the parent/guardian) have given permission, the **ECMO physician** will then be in charge of your child's care. There may also be other consulting physicians involved in the care of your child such as a cardiologist, radiologist, pediatric surgeon, or neurologist.

Every day you will see **ECMO Specialists** involved in your child's day to day care. The ECMO Specialists are a group of specially trained nurses or perfusionists who have prior experience in intensive care units. They have received special training that enables them to manage ECMO patents and ECMO equipment.

In addition, there are other people who are available to provide assistance to you and your family. Ask your child's nurse to direct you to the **social worker** if you need assistance in dealing with practical things such as housing, meal tickets, and/or parking vouchers and/or emotional issues such as dealing with your child's illness. A **chaplain** is available 24 hours a day. In addition, there are **parents** of former ECMO patients who are ready to offer the support of those who have already experienced with their own children the feelings you are feeling now.

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