

# A family guide to **ECMO**



# Family guide to ECMO



Dear Parent,

We created this booklet to help you and other family members better understand Extracorporeal Membrane Oxygenation (ECMO). A glossary of terms you may hear regarding ECMO is located on the last page. Please feel free to ask us any questions you have while your child is on ECMO. Specific information about your child will be given only to you, and we will keep you updated on your child's status during this time. Please remember that you can call us at any time if you have questions or just to check in. We encourage you to visit and talk to your child. We know that you want to touch and comfort your child, and that this loving contact is good for both you and your child. A Children's Hospital nurse or ECMO specialist will show you the safest way to do so.

We understand this is an extremely stressful time for you, your child and your family. That's why we created this booklet, to help answer any questions you may have. Please do not be afraid to ask the same question more than once. We are here for you and your family, and your child's best interest is our top priority.

Sincerely,  
Children's Hospital ECMO Team & ICU staff



# Frequently asked questions about ECMO



## What is ECMO?

ECMO stands for Extracorporeal Membrane Oxygenation. You may also hear the names ECLS or Extracorporeal Life Support. These terms mean the same thing. ECMO is a specialized procedure that takes over the functions of the heart and/or lungs when those organs are too sick to properly support the body. ECMO does not cure these organs, but instead gives them time to heal. When the lungs are too sick or injured, they are unable to provide oxygen and remove carbon dioxide (a waste product) as they normally would. And when the heart does not function properly, ECMO can do most of its work, allowing the heart to rest.

ECMO is similar to the heart-lung bypass used in the operating room, but it is used for a longer period of time. The ECMO pump requires an ECMO specialist to watch and maintain it 24/7. The specialist and a nurse will be at your child's bedside around the clock and will only step away if another skilled clinician takes their place.

ECMO evolved in the late 1960s and early '70s based on the idea of the heart-lung machine used in cardiac surgery. This evolution filled the need to provide extended life support. Children's Hospital's ECMO Program

was founded in 1999 and averages approximately 20-30 ECMO cases a year. Currently, there are approximately 255 ECMO centers in the country and numerous centers around the world.

## Who goes on ecmo?

We provide ECMO for patients from newborns to adults. The patients that meet our criteria and progress to ECMO generally have a mortality rate (chance of dying) of 80-90 percent without ECMO. The patient must have a reversible process, or a curable condition, and have good brain function. Some of the reasons patients go on ECMO are:

- Pneumonia
- Trauma
- Severe Infections
- Congenital Heart Defects (CHD)
- Asthma
- Congenital Diaphragmatic Hernia
- Persistent Pulmonary Hypertension of the newborn (PPHN)
- Respiratory Distress Syndrome (RDS)
- Sepsis
- Respiratory Failure
- Low cardiac output; poor perfusion (passage of fluid through the circulatory or lymphatic system)
- Urgent ECLS – Emergency situations
- Inability to wean from bypass

following corrective heart surgery (for CHD)

- Aspiration of toxic solutions into the lung

## How does ecmo work?

Plastic tubes (cannulae) are placed into large vessels that lead directly to the heart. The cannulae are placed either percutaneously (through the skin, like an IV) or surgically (in a minor operation). If the patient is placed on ECMO in the operating room, it's very likely that the cannulae will be placed directly into the heart. The patient's size, age, weight, and reason for ECMO will determine the size of the cannulae and where they are placed. These cannulae allow blood to be drained from the heart and through the ECMO circuit. The blood will be given oxygen and carbon dioxide will be removed. The blood will be warmed and returned to the patient through a separate cannula.

The goal of ECMO (depending on the type of ECMO) is to either let both the heart and lungs, or just the lungs, rest. The purpose of ECMO is only to allow time for healing, it does not necessarily fix the underlying problem. Once the patient is placed on ECMO, the ventilator (breathing machine)

settings will be decreased to levels that will not damage the lungs. Once the lungs and/or heart are healed, the ventilator settings are increased and the patient is weaned from the assistance of ECMO.

### Are there different types of ecmo?

Yes. There are two types of ECMO to support a patient:

- VA (veno-arterial) ECMO. This type supports both the heart and the lungs, and it requires the placement of two cannulae—one in a vein to drain blood from the patient and one in an artery to return the blood to the patient.
- VV (veno-venous) ECMO. This type is used for lung support only and requires that only one cannula be placed in a vein.

Once the artery or vein has been used for ECMO, it will either be repaired or tied off. Our surgeon will explain what is best for your child at this point.

### What happens prior to ecmo?

If the doctor thinks your child needs ECMO, he or she calls in an ECMO surgeon to review all the medical information. If the ECMO surgeon agrees that ECMO is needed, one of the first steps of the process is to perform a completely safe and painless cranial, or head, ultrasound, if applicable (typically performed on newborns). This is to assure there is no bleeding in the head. A cardiac echo is also performed to see if the patient's heart is normal. An operating team is called directly to your child's bedside to create a mini operating room, which is less disruptive to your child.

#### Here are the next steps:

- Your child will receive medicine for pain and will be put to sleep with the use of anesthetics
- Your child will receive medicine that will cause their body to be temporarily paralytic, which means the movement of their entire body will be restricted



- The surgeon will make a small cut (incision) in your child's neck
- Two cannulae (for VA) or one cannula (for VV) will be placed:
- For VA, one cannula is placed in the jugular vein and another cannula is placed in the carotid artery
- For VV, a double lumen cannula is placed in the jugular vein
- The cannulae are connected to the ECMO circuit, which was filled with blood while the cannulae were being placed
- The ECMO machine is turned on
- Your child is now on ECMO

If your child is placed on ECMO immediately following heart surgery, this procedure will be done in the operating room. As stated above, the cannulae would most probably be inserted directly into the heart. Your child would then be brought into the Cardiac Intensive Care Unit (CICU) already on ECMO.

### What happens on ecmo?

All patients on ECMO follow a special routine:

- Two caregivers will be at your child's bedside 24/7 while they are on ECMO. One will be the ECMO specialist and the other will be a nurse
- Once your child is on ECMO, the ventilator settings are reduced to "rest" settings to avoid any lung injury
- From this point until ECMO is removed, your child will not receive any needle sticks
- All bloodwork will be drawn from an existing arterial line and/or the ECMO pump
- Blood gases and blood work (labs) will be drawn every six to eight hours, chest X-rays will be taken every morning, and vital signs will be constantly monitored
- It is common for ECMO patients to receive blood products more than once. Do not be alarmed if



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your child must receive a blood transfusion. Our blood bank will perform tests to make sure the products are safe and that they are a match for your child’s blood type

- Your child will continuously receive pain medication and sedation to ensure their comfort
- The drugs that prevent movement (paralytic) may or may not be removed. This decision is based on numerous factors and is decided upon by the attending physician or surgeon, but know that the use of paralytics helps reduce the amount of oxygen that your child’s body needs to use
- In some cases, ECMO patients need special procedures—such as CT scan, heart catheterization, or a trip to the operating room—to help the medical staff examine any changes that are occurring. The ECMO team will take your child to the areas of the hospital where these procedures are performed for optimal care, but chest X-rays will be done right at your child’s bedside
- Often, ECMO patients’ bodies need help with the production of urine, even if a Foley catheter is already in place. We can help this process by removing fluid from your child’s blood with special filters. This can be done in line with the ECMO pump, or we may need to use a dialysis machine, which will also be done through the ECMO pump
- If your child develops a pneumothorax (“free” air outside of the lung, which can cause a

collapsed lung) or a pleural effusion (a buildup of free fluid around the lungs—sometimes called “water on the lungs”), a simple surgical intervention is needed.

This procedure is performed right at your child’s bedside for your child’s comfort. A doctor makes an incision, and a tube is inserted there to help remove the air or fluid causing the problem. Your child will not feel any pain from this procedure

- Your child’s endotracheal tube (breathing tube) will be suctioned periodically to help remove secretions. The respiratory therapist may also deliver breathing treatments through the ventilator to help your child’s lung functions
- You will be allowed to touch and comfort your child—that’s really an important part of their treatment. Your child’s nurse will show you the proper ways to touch so that you don’t affect the ECMO system
- Each ECMO case is different. The length of time your child will be on ECMO will vary depending on numerous factors. Rest assured that we will update you daily about your child’s progression

### What are the risks?

The greatest risk once your child is on ECMO is bleeding. Heparin, a blood thinner, must be used so that the blood does not clot in the ECMO tubing or in your child. Bleeding can occur anywhere in the body, but it is most dangerous when it occurs in the brain. There is also a chance that some blood clots may be introduced into your child’s bloodstream. The ECMO circuit is closely monitored at all times by our highly trained specialists.

### What medications are used while on ECMO?

Every ECMO case is different in numerous ways. There are many different medications that are used to assure the best outcomes. Below is a list of some medications that might be used and their actions:

- Fentanyl: pain reliever





- Morphine: pain reliever
- Tylenol: pain reliever
- Norcuron: neuromuscular blocking agent (paralytic, skeletal muscle relaxant)
- Albuterol: opens the airways
- Xopenex: opens the airways
- Antibiotics: treats/prevents infections
- Heparin: stops blood from clotting
- Thrombate: treats/prevents blood clots
- Zofran: prevents nausea
- Pepcid: prevents nausea
- Phenobarbital: prevents seizures
- Lasix: produces urine, reducing extra fluid
- Hydrocortisone: treats inflammation
- Ativan: sedation
- Versed: sedation

### What about nutrition?

While on ECMO your child will receive all of their calories by one of two methods:

- Total Parenteral Nutrition (TPN): This fluid contains vitamins, electrolytes, and sugar that the body needs. Your child may also receive lipids, which are fats to increase the calories given, via the TPN. These fluids are given through an IV directly to your child, not via the ECMO pump
- Tube: A special tube may be inserted through your child's nose or mouth until it reaches the stomach. Depending on your child's size and age, this food may be infant formula or a formula similar to Ensure

### How do you know if your child's health is improving?

We closely watch for improvements each day and monitor all aspects of your child's heart and lung function. We can see how much air is in their lungs and how easily their lungs fill and empty with each breath. We also monitor your child's blood gases, lab values, X-rays, the intake of fluids and output of urine, heart function, and other aspects that will be further explained to you by a member of your child's care team. When we think your child is ready, we will begin to wean them off ECMO and increase the ventilator settings. Once your child meets the criteria to be removed from ECMO, we will clamp off the

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ECMO circuit, and your child’s heart and lungs will be performing their regular functions once again. While the ECMO is clamped off, we will run blood gases and monitor your child’s vitals. If your child is ready, the surgeon will decannulate, removing the cannulae from your child’s system.

## What happens next?

Your child will remain with a nurse at their bedside for approximately 24 hours. Your child will remain on the ventilator until they’re able to breathe on their own. This is monitored by certain numbers on

the ventilator, blood gases, and vital signs. Time spent on the ventilator will vary from child to child and will depend on how long your child has been sick.

## When can we visit?

All of our ECMO patients are managed in either our Pediatric Intensive Care Unit (PICU), Neonatal Intensive Care Unit (NICU), or Cardiac Intensive Care Unit (CICU). Each ICU is open for visitors 24/7. The nurse caring for your child will give you information on the unit’s policies. If you are unable to visit, we are happy to give you phone updates.

We do encourage you to rest and take care of yourself, as we know this is a challenging time for the entire family.

## Will my child need follow-up care?

Yes. Routine checkups with your Children’s Hospital specialists are important. The number of follow-up visits will also be determined by how well your child progressed with ECMO. A nurse will talk to you about follow-up care and assist with scheduling appointments once your child is discharged.

## Ecmo guide glossary

- **ACT** – Activated Clotting Time: This test shows how long it takes the blood to clot. We monitor this at least once every hour.
- **Cannulae** – Plastic tubes that are placed in either an artery or vein.
- **Cannulation** – The process of placing the cannulae into the blood vessels.
- **Cardiac Catheterization** – A small catheter is placed into a vein or artery and threaded up to the heart. This allows us to look at the heart and monitor pressures within the heart.
- **Cardiac Echo** – Allows us to look at the heart using ultrasound.
- **Congenital Heart Defect (CHD)** – There are many different heart defects. If your child is on ECMO because of a heart problem, you will be given more information on the specific defect by the cardiologist or surgeon.
- **Decannulation** – The process of removing the cannulae from the blood vessels.
- **ECLS** – Extracorporeal Life Support (same as ECMO).
- **ECMO** – Extracorporeal Membrane Oxygenation.
- **ECMO flow** – A measure of how much blood we are pumping through the ECMO circuit to help support the patient.
- **ECMO team** – Our ECMO team is made up of specially trained respiratory therapists, nurses, perfusionists and physicians.
- **Oxygenator** – A type of artificial lung. Carbon dioxide is removed and oxygen is added.
- **Percutaneous** – Literally means “through the skin.” In this case, the ECMO cannulae are put in like an IV. The other option is to surgically place the cannulae.
- **Sodium bicarbonate/sodium acetate** – Decreases acid levels in the blood.
- **Trial off/Clamp off** – Temporarily stop the ECMO to measure the function of the heart and/or lungs. If the function is good, the ECMO may be discontinued.
- **VA ECMO** – Veno-Arterial. We drain the blood through the ECMO cannulae from a vein and return it to an artery. This type of ECMO is mainly used for patients that need both heart and lung support.
- **VV ECMO** – Veno-Venous. Blood is drained from a vein and returned through a vein. This is required for patients who require only lung support.



Thank you for entrusting children's hospital with caring for your precious child. It's one of our guiding principles to care for every child as our own. Through medical excellence and the continued improvement of patient care, education, research, child advocacy and management, children's hospital and its ecmo department strive to deliver the very best care for all children.

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