

ECMO FAMILY GUIDE



SANFORD[®]
Children's

WELCOME



Welcome to the Children's Hospital PICU (Pediatric Intensive Care Unit). We consider it a privilege to care for your child and your family.

This book was created to give you the needed information about ECMO (ExtraCorporeal Membrane Oxygenation) and how it can help your child. We know this can be a very hard time. Our team is here to care for your child and support your family. If you have any questions or concerns, please feel free to ask your child's healthcare team.

Sanford Children's Hospital
PICU and ECMO staff

What is ECMO?

ECMO (ExtraCorporeal Membrane Oxygenation) is a procedure which helps an injured or sick heart or lungs to get rest and heal. This is done by using a heart-lung machine for patients. Our nurses and ECMO staff are trained specialists who will care for your child. They will be at your child's bedside at all times while your child is on ECMO. This procedure has been done since 1971.

When **lungs** are sick/injured, they are **not** able to:

- Push oxygen to the rest of the body.
- Get rid of the waste product carbon dioxide that stays in the body.

When the **heart** is sick/injured, it may **not** be able to:

- Push blood to the rest of the body.

The ECMO Machine

- Works as a:
 - Heart (pump)
 - Lung (gives oxygen)
- Allows the heart and lungs to rest by:
 - Doing the work of pumping the blood.
 - Pushing oxygen to the rest of the body.



How does ECMO Work?

It does the work of the normal function of the heart and lungs. It does this by pumping a steady amount of blood through the heart-lung machine each minute. This is called an ECMO flow rate.

- Pumping blood out of the body through a large tube.
 - This blood will look very dark because there is very little oxygen in it.
- Oxygen is added to the blood when it is pushed through the heart-lung machine.
 - Carbon dioxide is taken out as the oxygen is pushed in.
- The blood is warmed and then pumped back in.
 - The blood is now bright red because there is oxygen in it.

Other things you may see

- Extra tubing that has special openings. These openings are called ports. They are used for:
 - Pulling blood out for testing
 - Giving medications
- Safety features
 - Pump regulator
 - Blood gas monitor

Who needs ECMO?

- Children who have heart and/or lung problems which have not improved with other treatments. These treatments may be:
 - A ventilator – breathing machine
 - Large amounts of heart medications
- Children who may have one or more of these problems
 - Meconium Aspiration Syndrome – a baby inhales meconium (a baby's first stool) into their lungs.
 - Sepsis – an infection anywhere in the body or blood.
 - Respiratory Distress Syndrome – severe trouble with breathing
 - Persistent Pulmonary Hypertension – high pressures between the heart and lungs.
 - Pneumonia – infection of the lung
 - Congenital Diaphragmatic Hernia – a part of the stomach/intestines go through an opening in the diaphragm.
 - A life threatening heart condition

Types of ECMO

- VA ECMO (Veno-arterial)
 - Supports the heart and lungs
 - One cannula (plastic tube) is put in a large vein
 - One cannula is put in a large artery
- VV ECMO (Veno-venous)
 - Supports the lungs
 - It can also help the heart
 - One large cannula is put in a large vein
 - Two cannulas are put into two different large veins



How is my child placed on ECMO?

Your child will have a tube(s) inserted either at the bedside or in the operating room. This procedure will be done by a surgeon.

- Your child will be given medicine through their IV to:
 - Keep them from feeling any pain.
 - Help them sleep during the procedure.
 - Keep them from moving during the procedure.
- The area where the tube is put in will be made numb. This will only last a short time. The medicine is called Lidocaine (lid o-kan).
- The tube is put in the blood vessels that will be used.
- The tube is then moved closer to the heart.
- The tube(s) is connected to the ECMO circuit.
- An X-ray will be done. This is to make sure the tube(s) is in the right place.
- A heart ultrasound (ECHO) will be used to make sure the tube is working correctly.

How does the ECMO circuit work?

- Blood leaves the body through the inserted tube.
- The blood moves through the ECMO tubing to a blood pump.
- The blood is pushed by the pump through an artificial lung (oxygenator).
- The artificial lung:
 - Puts oxygen in the blood.
 - Gets rid of carbon dioxide.
- After passing through the artificial lung, the blood will return to the body through:
 - The same tubing – VV ECMO
 - Another tubing – VA ECMO

How long will my child need to be on ECMO?

Your child will need to be on ECMO until:

- The heart and/or lungs get better.
- The treatment is **not** working.

This could be a few days or many weeks.

Things that affect the length of time your child is on ECMO could be:

- The type of heart and/or lung disease your child has.
- How much damage there is to the heart and/or lungs before starting ECMO.
- Illnesses and/or complications while your child is on ECMO.

When your child shows signs of getting better

- The amount of ECMO support will be lowered slowly. This is called weaning.
- Your child will have times of trying to take them off ECMO. This is called “trial off”.
 - The ventilator support will be increased to help your child with their breathing while the ECMO support is stopped.
- The ECMO support will be stopped when the lungs and heart have healed enough.
- When the ECMO support is stopped, the surgeon will take out the tube(s).
- Your child may remain on the ventilator until they are better. How long this is, will depend on your child’s illness.

Risks of ECMO

There are risks for your child while on ECMO. Your child's doctor will talk to you about these risks. These risks may include:

- Bleeding
- Blood Clots
- Stroke
- The ECMO machine system may fail.

Bleeding

Your child will be given a medication called Heparin. This is used to keep the blood from clotting as it moves through the ECMO circuit.

- We will check your child's blood to see how long it takes their blood to clot.
- We will make changes based on the lab results.
- Sometimes bleeding happens even with very close monitoring.
- Bleeding can happen anywhere in the body. The most dangerous is if it happens around the brain. This could cause brain damage.
- If there is too much bleeding, we may need to:
 - Give your child one or more blood transfusions.
 - Take your child to surgery to stop or control the bleeding.
 - Stop the ECMO therapy.

Blood Clots

Small blood clots can form in the bloodstream (the flow of the blood). These blood clots can cause serious injury. There can be damage to the brain or kidneys.



Stroke

A stroke can happen when there is bleeding or blood clots into the brain.

Failure of the ECMO machine

This is rare. If this should happen, the trained ECMO specialist knows how to respond to this emergency. They are at the bedside at all times and are trained to know what to do.

Will my child need follow-up care?

Yes. Your child's doctor will talk with you about the plan of care after your child leaves the hospital.

ECMO team members

Pediatric Intensivist (in-ten si-vist)

This doctor is trained to take care of children who are critically ill. He/she is in charge of your child's care. This doctor will be your child's primary doctor.

ECMO Specialists

The ECMO specialist is a specially trained Registered Nurse or Registered Respiratory Therapist who has experience in intensive care. The patient will have an ECMO specialist at the bedside at **all** times. These specially trained nurses and respiratory therapists do:

- The minute-to-minute monitoring of ECMO patients.
- They will manage the ECMO equipment.

Critical Care Nurses

The ICU nurses manage and care for very sick patients. Nurses will give your child care and comfort. They will often be your main source of information.

Respiratory Therapists

They are specialists to help your child breathe.

- Ventilator management
- Make recommendations to other team members
- Help with procedures.

Surgeon

A doctor who is trained to place and remove the ECMO cannula. This doctor and team will see your child every day.

Cardiologist (kar-de-ol o-jist)

A doctor who specializes in the heart. This doctor will help to make sure the ECMO cannula is in the right place and working well. They will also give Pediatric Intensivist information about how your child's heart is working.

Social Worker or Chaplain

The social workers and chaplains can help you with:

- Accommodations or lodging
- Your concerns:
 - Financial
 - Insurance
 - Where to park
 - Meals
- Emotional issues such as coping with your child's life threatening illness.
- Spiritual concerns



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