

A Family Guide to
ECMO





Children's Hospital
of The King's Daughters

A Family Guide to ECMO

Dear Parents and Family,

Having a very sick child in the intensive care unit on extracorporeal membrane oxygenation (ECMO) can be incredibly stressful. Our team of critical care providers has created this Family Guide to help answer any questions you might have.

At the Children's Hospital of The King's Daughters, the intensive care unit team works hard to care for your child and their family. Families play an essential role in caring for their critically ill child. You know them best. We encourage you to be present as often as possible and help care for them.

This Family Guide was created as a comprehensive booklet to help family members better understand ECMO. Please don't hesitate to ask questions. Our team is here to support you and your child.

With care and support,

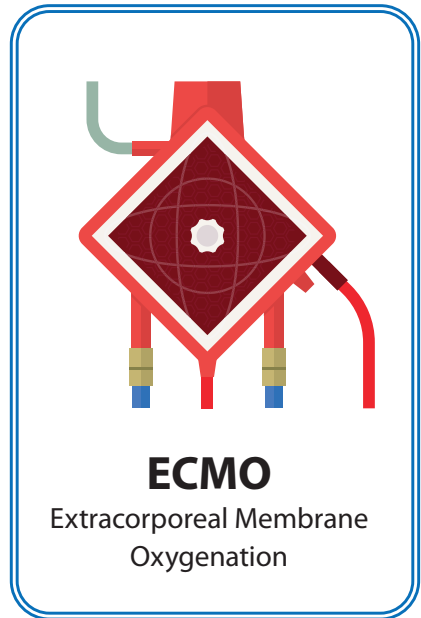
ECMO Team & ICU Staff
Children's Hospital of The King's Daughters



What is ECMO?

When a child is very sick, their heart or lungs might need extra help doing their jobs. ECMO, which stands for extracorporeal membrane oxygenation, is a special type of life support that allows the heart and/or lungs time to rest and heal.

ECMO works by gently moving your child's blood through a machine that adds oxygen and removes carbon dioxide, just like healthy lungs do, before returning the blood to your child's body. Depending on your child's needs, the machine may also assist the heart in pumping blood.



Who needs ECMO?

A child may need ECMO if their lungs can't supply enough oxygen to the body, remove enough carbon dioxide, or if their heart is too weak to pump enough blood. Sometimes children need help with all of these functions. ECMO does not cure your child; it gives their body time to rest and recover.

What will my child look like?

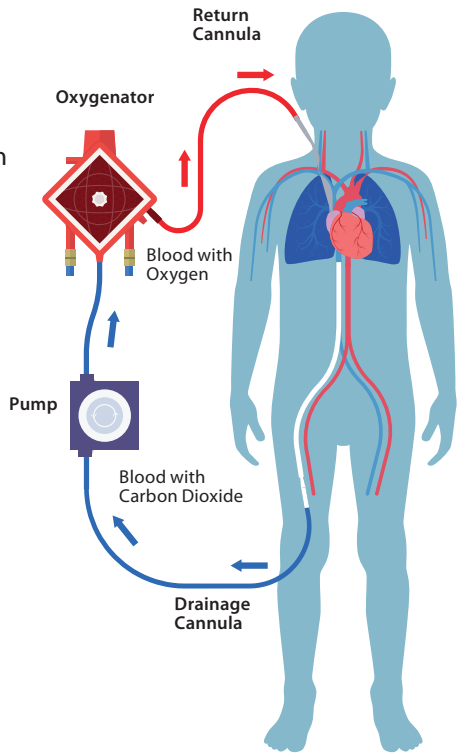
Your child will be cared for in the pediatric intensive care unit by a specialized team. You will see tubes that connect your child to the ECMO machine, along with monitors and equipment that help us keep a close watch on them at all times. Although this can look overwhelming, each piece of equipment has an important role in keeping your child safe and supported.

While your child is on ECMO, they are often given medication to help them stay comfortable and rest. They may appear very sleepy and less responsive. At other times, your child may be awake, briefly open their eyes, move, or respond to your voice. Your child's care team closely monitors your child's breathing, vital signs, and comfort to carefully adjust these medications throughout the hospitalization.

Types of ECMO

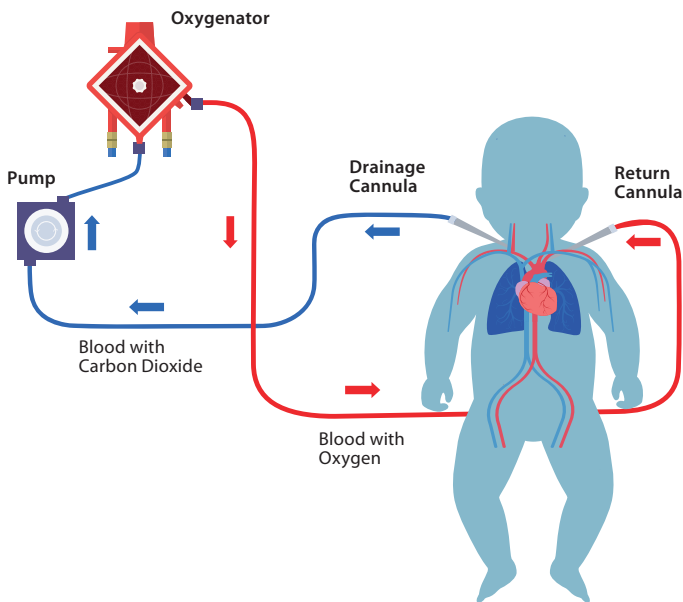
Veno-Venous (V-V) ECMO

This type of ECMO helps the lungs. Blood is taken from the body, oxygen is added by the ECMO machine, and carbon dioxide is removed, then the blood is returned to the body. The heart continues to perform its normal function.



Veno-Arterial (V-A) ECMO

This type of ECMO helps both the heart and lungs. The ECMO machine adds oxygen, removes carbon dioxide, and assists in pumping blood through the body when the heart needs extra support.



What can families do?

You are an important part of your child's care. You can help by:

- Talking to your child and holding their hand when it's safe.
- Asking questions. No question is too small.
- Taking breaks and caring for yourself.
- Leaning on the care team for support, updates, and reassurance.
- Bringing in familiar items from home, such as toys, blankets, and pictures.

Understanding the Risks of ECMO

Because ECMO is used for children who are very sick, it does carry risks. ECMO might provide your child with the best chance for recovery when other treatments aren't enough.

Some possible risks include:

- Air bubbles: These can occur in the ECMO circuit.
- Bleeding: Medications are used to keep the blood from clotting in the ECMO machine.
- Infection: The lines and tubes used during ECMO can increase the risk of bacteria entering your child's bloodstream, causing infection.
- Blood clots: These can form in the ECMO machine circuit despite careful monitoring.
- Organ Function: The brain, heart, lungs, kidneys, and other organs may need help or not work normally while on ECMO. This can be due to ECMO or as part of the illness your child has.
- Stroke: This can occur when problems with blood flow or clotting cause part of the brain to be damaged.

Every child's situation is different. Some children experience complications, while others do not. Our ECMO team watches closely for any signs of problems and responds quickly if concerns arise.



Who is caring for my child?

A dedicated care team made up of:

- Intensive Care Doctors
- Surgeons
- Nurse Practitioners
- Nurses
- ECMO Specialists
- Respiratory Therapists

This team monitors your child and the ECMO machine around the clock, adjusting care minute by minute.



Is my child improving?

While your child is on ECMO, the care team watches closely for signs of improvement. They monitor oxygen levels, blood pressure, urine output, and lab results to assess how well the heart and lungs are functioning. As your child's condition improves, ECMO support and medications can be gradually reduced to determine if your child's body can handle more of the work on its own. When your child is ready, the team may perform a trial off ECMO.

A trial off ECMO is a short, closely watched test where ECMO support is gradually reduced to see if the heart and/or lungs can work on their own. During this trial, the care team slowly decreases the assistance provided by the ECMO machine while closely monitoring your child's condition. They check breathing, heart function, blood pressure, oxygen levels, and lab results to see how the body responds. The goal is to determine if the heart and lungs can function effectively without additional support.

If your child passes the trial off ECMO, it means their heart and lungs are functioning well enough on their own. When it is safe to do so, the care team will plan to remove the ECMO support, a process called decannulation. After the ECMO machine is removed, the care team will continue close monitoring and support to help your child continue to heal.

Nutrition on ECMO

Tube Feeding

Some children on ECMO are fed through a small tube that goes into the stomach or intestine, delivering liquid nutrition. The type of liquid nutrition is discussed by the care team and depends on your child's condition.

Total Parenteral Nutrition (TPN)

TPN is a special kind of nutrition delivered through an IV when a child cannot eat by mouth or feed through a tube. TPN supplies all the calories, vitamins, and minerals the body needs to grow and recover.

Every child's needs are different. Feel free to ask any questions you may have. The care team evaluates your child's nutritional needs daily with input from our intensive care dietitian.

How We Work to Keep Your Child Safe

Safety is our highest priority. Children on ECMO are cared for by a highly trained, experienced team that continuously monitors both your child's condition and the ECMO machine. We regularly check the machine, perform imaging and blood tests, and conduct bedside assessments to identify changes early and modify care promptly.

Because ECMO carries risks, the decision to use it is carefully made by a team of specialists after thoroughly considering your child's condition and the potential benefits and risks.

How We Support Families

It is natural to feel scared or overwhelmed when learning about ECMO risks. Please remember that you are not alone. Your care team will:

- Talk with you openly and honestly.
- Explain what we are seeing and what it may mean.
- Answer questions as they come up, again and again, if needed.
- Support you through each step of this journey.



ECMO gives time for healing and no family walks this journey alone.



Other Members of your Child's Care Team

Chaplain

A chaplain offers emotional and spiritual support to children and families of all beliefs and backgrounds. Chaplains are available to listen, pray if you wish, provide comfort during difficult moments, or simply sit quietly with you. Their care is always optional and guided by your preferences.

Social Worker

A social worker helps support your family's emotional, practical, and logistical needs during your child's hospital stay. They can assist with coping, communication, family needs, resources, lodging, work or school concerns, and connecting you with community services.

Physical Therapist (PT) and Occupational Therapist (OT)

A physical or occupational therapist helps children maintain or regain strength, movement, and mobility. When it is safe, the therapists may work with your child, even in the ICU, to support movement that is appropriate for your child.

Speech Language Pathologist

A speech therapist helps with communication, swallowing, and feeding. They may support your child's ability to eat and drink safely or help with communication as your child recovers.

Child Life Therapist

Child life therapists, also called child life specialists, help children and families cope with illness, hospitalization, and medical procedures. Their focus is on your child's emotional well-being, comfort, and understanding.

ECMO Dictionary

ABG: A blood test performed at the bedside to measure the amount of oxygen and carbon dioxide it contains. This tells us how well the ECMO circuit and/or ventilator is working.

Albumin: A protein made from plasma that helps keep fluid in the blood vessels and supports circulation. Albumin may be given to help maintain blood volume.

Antibiotics: Medication that fights infections caused by bacteria.

Anticoagulants: Medication used to help prevent blood clots from forming while blood is flowing through the ECMO circuit. Blood levels are checked often to keep blood flow as safe as possible.

Aorta: The large artery that carries oxygenated blood from the heart to the rest of the body.

Bivalirudin: A medication used to prevent blood from clotting in the ECMO circuit.

Blood Transfusion: The process of giving blood or blood components (plasma, cryoprecipitate, platelets, PRBCs) through an IV to help support your child's body while they are healing.

Bridge to Recovery: A phrase used to describe ECMO as temporary support while the body heals.

Cannula: Soft, flexible tubes that are placed in large blood vessels to gently move blood to and from the ECMO machine.

Cardiac: Refers to the heart.

Carotid Artery: A large artery in the neck that carries blood from the heart to the brain. An ECMO cannula can be placed here to return blood to the body.

Chest Tube: A tube that is placed in the space between the lung and the chest wall to get rid of air or fluid.

Clotting Factors: Special proteins in the blood that help control bleeding. These may be given if blood tests show certain factors are low.

Continuous Renal Replacement Therapy: Dialysis to help remove fluid and control electrolytes. It can sometimes be used to remove toxins.

Cryoprecipitate: A concentrated blood product that contains specific clotting proteins. It may be given if certain clotting levels are low.

Decannulate: To remove the cannula.

Diuretic: A medication that helps the body get rid of extra fluid by making more urine.

Donor Blood: Blood products given during ECMO that come from carefully screened donors. Each donation is tested to ensure safety before being used.

Echocardiogram (ECHO): A machine that uses sound waves to evaluate heart function.

Extracorporeal Membrane Oxygenation (ECMO): A form of life support that gives the heart and/or lungs extra help when a child is very sick. ECMO is temporary and allows the body time to rest and heal.

ECMO Circuit: The tubing and parts that carry blood from your child to the ECMO machine and back again.

ECMO Team: A group of specially trained doctors, nurses, ECMO specialists, respiratory therapists, and other caregivers who work together to care for children on ECMO.

Edema: Swelling.

Endotracheal Tube (ETT): A breathing tube placed through the mouth or nose and attached to a ventilator to help your child breathe.

FdO₂: This is the amount of oxygen being given by the ECMO machine to help oxygen get into the blood.

FiO₂: This is the amount of oxygen being given by the ventilator or breathing machine to help your child breathe.

Head Ultrasound: Sound wave test that checks for abnormal bleeding in the head of patients.

ICU: Intensive care unit. This is the place in our hospital where your child will be taken care of by the team.

Jugular Vein: A large vein in the neck that carries blood from the brain to the heart. An ECMO cannula is frequently placed here.

Life Support: Medical care that helps vital organs, such as the heart and lungs, do their job when the body cannot do so on its own.

Monitoring: Continuous watching of vital signs, blood tests, and the ECMO machine to keep your child safe and comfortable.

Oxygenator: The part of the ECMO machine that adds oxygen to the blood and removes carbon dioxide – similar to what healthy lungs do.

Plasma: The liquid portion of blood that contains proteins to help with clotting. Plasma may be used to support healthy clotting when needed.

Platelets: Small blood cells that help stop bleeding and support clotting. Platelets may be given if counts are low or if there is concern about bleeding.

Pressors: Medications that help raise blood pressure and support the heart.

Pump: The part of the ECMO machine that moves blood through the circuit at a safe and carefully controlled speed.

Red Blood Cell (RBC): The part of blood that carries oxygen to the body. Red blood cells may be given if levels are low to help make sure your child's tissues are getting the oxygen they need.

Slow Continuous Ultrafiltration: A type of kidney support that removes extra fluid from the body.

Sodium Bicarbonate: A medication that supports the body when the kidneys are not working correctly.

Sweep Flow: The amount of oxygen going to the oxygenator.

Trial Off ECMO: A short test where the ECMO support is lowered to see if the heart and/or lungs can work on their own.

V-A (Veno-Arterial): A type of ECMO that supports both the heart and lungs.

Ventilator: A breathing machine that helps move air in and out of the lungs. Even while on ECMO, some children continue to use a ventilator to gently support the lungs.

V-V (Veno-Venous): A type of ECMO that supports the lungs only, while the heart continues to pump on its own.

Whole Blood: Blood that contains red cells, plasma, and platelets together. It is sometimes used in specific situations when multiple components are needed.



**Scan the code to learn more about
CHKD ECMO.**

The information in this booklet is provided by CHKD for general educational purposes. For specific medical advice and/or treatment, you should consult your child's pediatrician.

CHKD ECMO

Tiny hearts supported by
expert care.



Children's Hospital
of The King's Daughters

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CHKD.org

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