

**A Family Members
Guide to
ExtraCorporeal
Membrane
Oxygenation
(ECMO)**

A Family Guide to ECMO

Dear Family and Friends,

Your loved one is very sick, you are in unfamiliar and often frightening surroundings. We know this is a very stressful time for you. We wrote this booklet to help you and other family members understand ECMO and to provide you with information to answer some important questions you may have. Feel free to ask questions or express your concerns. We will do our best to make sure you understand what is happening and will not intentionally keep information from you. Please call us if you have questions or just to "check in."

We encourage you to visit and talk to your loved one. The ICU nurse will show the best ways to touch and comfort them. The unit is open to visitors 24 hours a day. However, to insure the privacy and dignity of all of our patients, you must first check to see if you can visit. Please call the ICU from the waiting room before you visit. Please let your nurse know if you desire visitor restrictions. If another patient in the ICU requires privacy, we may ask you to wait. Also, nursing report starts at 6:45 a.m., 2:45 p.m., 6:45 p.m. and 10:45 p.m. and we may ask you to wait to visit during these times. Visitors are limited to two at a time. Siblings ages 2-14 are welcome to visit after they have had a health screening.

A glossary of terms used is on the last page. This may help you understand what we are discussing regarding your family member's care. We want you to feel free to ask any questions you may have while the patient is on ECMO. We understand this is a very stressful time for you and you may not remember all of our explanations. Please do not be afraid to ask us the same question more than once.

Sincerely,

The ECMO Team

What is ECMO?

ECMO stands for Extracorporeal Membrane Oxygenation. ECMO is a special procedure that allows sick or injured heart or lungs the opportunity to rest and get better. It is the use of an artificial heart-lung machine for patients whose heart or lungs are failing despite all other treatments. The ECMO equipment functions as a heart (pump) and lung (providing oxygen). It takes over the work of these organs so they can rest and heal.

When lungs are sick or injured, they are unable to provide oxygen and remove carbon dioxide (a waste product) as they normally would. If the heart is sick, it may not adequately move blood through the body. ECMO is similar to heart-lung bypass used in the operating room except with ECMO we support the patient for longer periods of time. Once we place the patient on ECMO, the circuit will take over the work of the patient's lungs or heart. Oxygenation and ventilation (removal of carbon dioxide) is done for the patient so the heart or lungs can rest.

How ECMO Works

ECMO substitutes for the function of the lungs and heart by pumping blood out of the body; oxygen is added to the blood and carbon dioxide is removed before it is returned to the patient. This process allows the heart and lungs time to rest and recover. A large catheter drains blood out to a pump. This blood is dark because it contains very little oxygen. We pump a steady amount of blood through the ECMO machine each minute.

We call this the ECMO flow rate. As the patient improves, we may decrease the flow rate and let their heart and lungs do more of the work. The pump pushes blood through an artificial lung where we add oxygen and remove carbon dioxide. We select the size of the lung based on the size of the patient. Sometimes we use two lungs for adults. We warm the blood before returning it to the body. This blood is bright red because it contains oxygen.

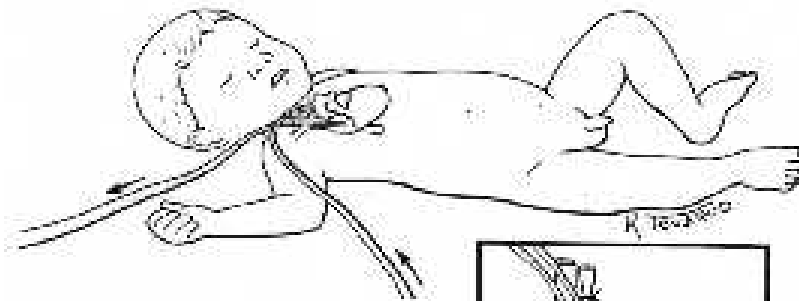
You will also see other tubing and ports for blood withdrawal and drug administration, as well as safety features, such as a pump regulator, blood gas monitor, and other devices. As you can see, there are a lot of devices and monitors. Our nurses and ECMO Specialists are trained to watch the system, and the patient, carefully.



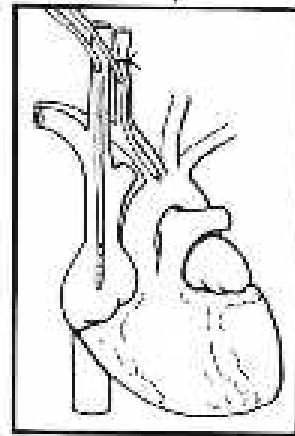
Are there different types of ECMO?

Yes. There are two different ways for ECMO to support a patient. The first method is called veno-arterial or VA ECMO. VA ECMO will support the heart and lungs. This requires two cannulas (large plastic tubes, also called catheters) - one in a large vein and

one in a large artery. We surgically place the cannula through the right side of the neck or directly through an incision in the chest if the patient has had cardiac surgery.



VA ECMO Cannulation



The second method is called veno-venous or VV ECMO. This is used for lung support only. With this type of ECMO, we often place only one cannula through the right side of the neck. Sometimes, in larger patients, we must place two cannulas, one in the neck and one in the groin. Once we use the artery or vein for ECMO, we will tie it off (ligate) except in special circumstances. The patient should develop a back-up system (called collateral circulation) for blood flow on that side. We will always try to use VV ECMO if possible (no heart support needed) so that we do not have to tie off the carotid artery. We have recently started placing the VV cannulas without a surgical incision. This method is called "percutaneous cannulation". When the patient is ready to have the cannula removed we pull it like an IV and hold pressure for 20 minutes. With this type of cannula placement, we do not tie off the veins. We use this method **ONLY** for veno-venous ECMO.

What is the goal of ECMO?

The goal of ECMO is to insure the body has enough oxygen. By taking over the work of the heart or lungs, ECMO allows the heart or lungs to rest. ECMO does not heal the heart or lungs but gives them time to rest and recover. We will use ECMO only when we have tried other less invasive methods and the patient has not improved. Once we place the patient on ECMO, we will decrease the ventilator (breathing machine) settings to levels that will not damage the lungs. We may also be able to decrease other drugs that support the heart. When the heart or lungs have healed and can work on their own, we will stop ECMO.

Why ECMO?

We use ECMO on children and adult patients with severe, but reversible heart or lung disorders that have not responded to the usual treatments of mechanical ventilation (ventilator), medicines, and extra oxygen.

Patients who need ECMO usually have one of the following problems:

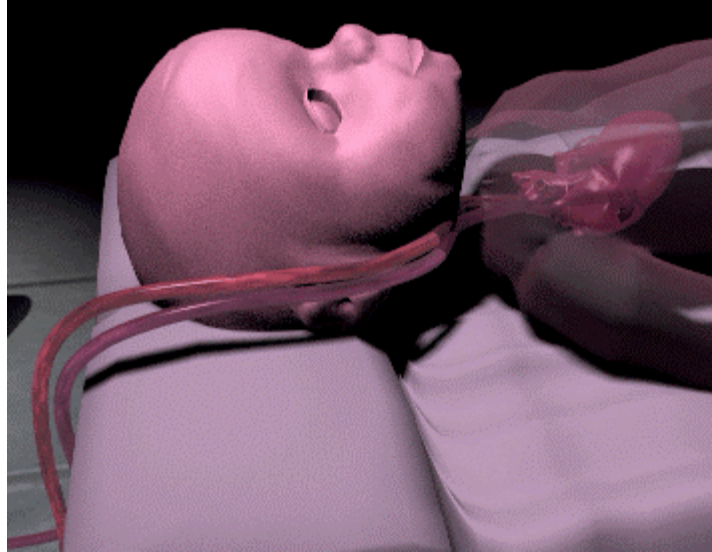
- Severe pulmonary hypertension – high blood pressure in the lungs
- Pneumonia
- Breathing failure from trauma or severe infections
- Heart failure

ECMO will not cure these conditions; it does give support and allow time for the lungs/heart to heal. We believe this recovery time improves the chances for the survival of your loved one.

When a patient is transferred here for ECMO, our physicians will carefully monitor their needs. Not all patients sent here for ECMO need this treatment. Some will get better because we have other therapies that the referring hospital does not have. Some will have medical problems that ECMO cannot help. We want to make sure the patient does not have any problems that ECMO could make worse or not help at all.

Babies will usually have a cranial ultrasound study and a cardiac ultrasound study before we place them on ECMO. The cranial ultrasound uses sound waves and lets us look at the brain to make sure there has been no bleeding around the brain. We will also do this test after the patient is on ECMO. The cardiac ultrasound study lets us look at the heart to make sure it is normal. The cardiac ultrasound also helps us to decide which type of ECMO to use (VA or VV). Children and adults will not have a cranial ultrasound, but may have a cardiac ultrasound. We may obtain other lab work and evaluations. A member of the ECMO Team will explain the tests and what they mean. Depending on these test results and if it is determined that the patient could benefit from ECMO, the following will take place:

- The patient is transferred to the Pediatric Intensive Care Unit
- The patient gets medicine to control pain.
- The patient gets medicine that will temporarily restrict movement.
- We insert one cannula (for VV) or two cannulas (for VA or VV). We place one cannula in the jugular vein; the tip sits in the right atrium of the heart. We place the other, if needed, in the carotid artery and sits in the aorta or in a vein in the groin.
- The surgeon connects the cannulas to the ECMO circuit. We fill the circuit with blood while the surgeon inserts the cannula. The patient is now on ECMO.



A Baby Cannulated via the Neck

What happens on ECMO?

After the patient is on ECMO, we will turn the ventilator (breathing machine) settings down to "rest" settings. This allows the lungs to rest without the damaging effects of too much oxygen or pressure from the ventilator. We may also turn down many of the heart medicines.

All ECMO patients have a daily routine; this includes a chest x-ray each morning, weight and bath, blood samples (labs) and constant monitoring of vital signs. We draw the blood samples off the ECMO circuit or IV's. The patient will not be "poked" by a needle while they are on ECMO. We let the patients rest as much as possible while they are on ECMO.

Medications

We give pain medication on a regular basis to prevent any discomfort. We try to maintain the patient in an alert, awake state. However, this is not always possible. Some patients do require medicine to keep them asleep and to keep them from moving to decrease the amount of oxygen used by the muscles or to insure that they don't move too much and dislodge the cannula.

- Heparin is a drug that keeps the blood from clotting normally. We give heparin when we place the cannulas and we will give it continuously while the patient is on ECMO. We do this to keep the blood in the circuit from clotting. The ECMO specialist monitors how long it takes the blood to clot very carefully and makes changes accordingly.
- We give antibiotics to treat existing infections or to prevent infections.
- Sometimes a patient's blood pressure or heart needs some help and the physician will order medications for this purpose. Some of the names you might hear are Dopamine, Dobutamine, Inocor, or Epinephrine.

We place ECMO patients on a special bed. It is elevated because gravity plays a part in the amount of blood that can safely travel through the ECMO system.

We suction the lungs regularly since the patient's cough mechanism is not effective.

We provide nutrition through specially formulated solutions administered through the veins or through a tube inserted through the mouth or nose that goes into the stomach.

How long will my family member be on ECMO?

We will continue ECMO therapy until the heart or lungs recover, or until treatment is not effective; it may be a period of days or weeks. The type of lung or heart disease, the amount of damage to the heart or lungs before ECMO, and other illnesses or complications affects the length of time on ECMO. As the heart or lungs start to heal, we will reduce the amount of ECMO support. When the patient shows signs of getting better we will "trial off" ECMO. We turn up the ventilator to support and assist the patient while we stop the ECMO support for the trial. If the heart and lungs have healed enough to support the patient's needs, then we will discontinue ECMO support.

Once we make the decision to stop ECMO, the surgeons will remove the cannulas. The patient will remain on the ventilator for support for several days or weeks, until further improvement takes place.

What are the risks?

Any person who requires ECMO is very ill and will probably die without it. However, there are risks associated with this procedure. The ECMO physician will discuss these with you:

- Bleeding - We give a drug called Heparin to prevent the blood from clotting while it travels through the ECMO circuit. We monitor how long it takes the blood to clot very carefully and make changes accordingly, but sometimes bleeding occurs. Bleeding can occur anywhere in the body but is most dangerous when it occurs around the brain. This could result in permanent brain damage. If the bleeding becomes too great, any of the following actions may be necessary:
 - Frequent blood transfusions
 - Other operations to control bleeding
 - Discontinuing ECMO therapy
- Blood clots - Small blood clots may be introduced into the blood stream of the patient. These clots can cause serious injury to the patient, damaging vital organs such as the brain or kidneys.
- Stroke - Stroke may occur from bleeding, or blood clots into the brain. If your loved one needs cardiac support, a surgical procedure that involves permanently tying off one carotid artery (blood vessel) is sometimes performed. Although there are two carotid arteries that supply blood flow, brain injury, including stroke has occurred in some cases.
- Malfunction of ECMO equipment - Although rare, the equipment required for the ECMO system may fail. A trained ECMO specialist, at the bedside 24 hours a day, will respond quickly to any malfunction.
- Other - Surgeons perform an operation to attach the ECMO circuit to the patient. This may lead to infection, bleeding, or vocal cord injury. The function of the heart or lungs may not improve during the time of ECMO support. We may find that the patient has a disease that will not get better, even with ECMO. Some patients develop severe blood stream infections that cause irreversible damage to vital organs.

What about blood transfusions?

ECMO patients require many blood or blood product transfusions while they are on ECMO. Each patient will have different needs. Our blood bank does many tests to make sure the blood is as safe as possible. Even with this testing there still is a small chance of a blood transfusion problem.

What about nutrition?

While on ECMO a special solution called TPN may be given. This fluid has the vitamins and electrolytes that the patient needs. Your loved one may also receive a solution called lipids, which is a fat solution that the body needs to maintain calories. We will give these into the ECMO circuit or through an IV line. Sometimes we are able to put feedings directly into the stomach or intestine.

Can mothers still breast feed babies on ECMO?

While we may not be able to give the baby breast milk while he or she is on ECMO, it is important for you to continue to pump your breasts and freeze the milk. There are breast pumps available to use while at the hospital. The hospital also rents electric pumps for use at home. Once the patient is off ECMO and ready, your milk will be available. If you need assistance with this, please ask the patient's nurse for help.

The patient will not actually be able to breast feed until he/she is off the ventilator.

However, we are able to feed the infant breast milk through a tube that goes into the stomach. Many ECMO babies are "poor feeders". They have some difficulty sucking and swallowing but this usually will go away in time.

Who takes care of my family member?

The ECMO Team

Attending Physician: The primary physician in charge of the patient's care.

ECMO Specialists: The ECMO specialist is a specially trained 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 respiratory therapists do the minute-to-minute monitoring of ECMO patients and the management of ECMO equipment.

Critical Care Nurses: The ICU nurses manage and care for very sick patients. Nurses provide care and comfort for your loved one. They will often be your primary source of information.

Respiratory Therapists: These professionals are specialists in ventilator management, make recommendations to other team members, and assist with procedures.

Resident Physicians: Residents are medical doctors who are obtaining specialty training. The resident physicians carry out much of the around-the-clock bedside medical care, under the supervision of the attending physician.

Social Worker/Chaplain: The social workers and chaplains can help you with:

- Accommodations or lodging
- Financial concerns: Insurance, parking, or meals.
- Emotional issues such as coping with a life threatening illness.
- Spiritual concerns.

What happens after ECMO?

Patients are different and his or her specific disease dictates how long they need to get better. Once the patient is off ECMO, they will still need ventilator support. It may take a few days or weeks before the patient is ready to come off the ventilator. Again, each patient will respond differently in this area. The ECMO Physician will discuss this with you.

Will my family member need follow-up care?

Yes. Although the heart or lung disease gets better, the patient may have had significant exposure to low oxygen levels before ECMO. This places the patient at higher risk for problems. In addition, your family member may require follow up visits due to the illness that led to their need for ECMO. The ECMO Physician will talk to you about follow-up care before you leave our hospital. They will be able to answer your questions about this process.

Is ECMO a new procedure?

ECMO was first used in 1971. In the years since, over 17,000 patients have received ECMO therapy. The ECMO Program here opened in 1996. We provide ECMO for infants, children and adults who would not survive without this special therapy. We receive patients and referrals from all over the State of North Carolina as well as other states.

ECMO TERMS

ACT: Activated clotting time - a test that measures how many seconds it takes for the blood to clot.

CANNULA (sometimes called catheters): Tubes that the surgeon places into the blood vessels. These tubes carry the blood from the patient to the ECMO system and return it to the patient.

CANNULATE: To place the cannula into the blood vessel.

DECANNULATE: To remove the cannula from the blood vessel.

ECMO FLOW: The amount of blood that moves through the circuit per minute.

ECMO PUMP: The pump that controls the ECMO Flow. This pump acts like an artificial heart.

ECMO: Extracorporeal Membrane Oxygenation

HEAT EXCHANGER: Warms the blood before it is returned to the patient.

MEMBRANE OXYGENATOR: This is the artificial lung that adds oxygen and removes carbon dioxide.

PERCUTANEOUS CANNULATION: Placing the cannula without a surgical incision.

THE ECMO TEAM: This team is composed of specially trained Registered Respiratory Therapists, Registered Nurses, Physicians and other allied health professionals.

TRIAL OFF: A test period off ECMO. We turn up the ventilator settings and stop the ECMO support for a limited period. This will show us how the patient's heart or lungs are healing. The method used varies for VA or VV ECMO.

VENO-ARTERIAL ECMO (VA): This is the type of ECMO that gives heart and lung support. Two cannulas are used, one in the jugular vein and one in the carotid artery.

VENO-VENOUS ECMO (VV): This type of ECMO gives lung support only. We place one cannula in the jugular vein. We place a second cannula (if needed) in the groin.