

UNIVERSITY of MICHIGAN HEALTH SYSTEM

FAMILY GUIDE

to



Dear Parent,

This booklet was written to help you and other family members better understand ECMO. A glossary of terms used is on the last page. We want you to feel free to ask any questions you may have while your baby is on ECMO. Information specifically about your child will only be given to you as a parent. We will do our best to make sure you understand what is happening and will not intentionally keep information from you. Please call at any time if you have questions or just to "check" in.

We encourage you to visit and talk to your child. The Holden nurse will show the best ways to touch and comfort your baby.

The unit is open to visitors 24 hours a day. You must first check in at the desk to see if you can visit. Please let your nurse know if you desire visitor restrictions. If there is a procedure happening in the room, you will have to wait until it is completed. Nursing report starts at 7:30 am, 3:30 pm, 7:30 pm and 11:30 pm. You will not be allowed 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.

We understand this is a very stressful time for you and you may not remember all of our explanations. Please don't be afraid to ask us the same question more than once.

Sincerely,

The University of Michigan ECMO Team

The Staff of the Holden Neonatal Intensive Care Unit

FAMILY GUIDE TO NEONATAL ECMO

What is ECMO?

ECMO stands for Extracorporeal Membrane Oxygenation. ECMO is a special procedure that allows sick or injured lungs the opportunity to rest and get better.

When lungs are sick or injured they are unable to provide oxygen and remove carbon dioxide (a waste product) as they normally would. ECMO is similar to the heart-lung bypass used in the operating room but is used for longer periods of time.

Once your baby is placed on ECMO, the circuit will take over the work of your baby's lungs. Oxygenation and ventilation (removal of carbon dioxide) will be done for your baby so the lungs can rest.

How does ECMO work?

Plastic tubes (cannulae or catheters) are surgically placed in your baby's neck. These tubes allow blood to be taken from your baby and passed through an artificial "lung" where oxygen is added and carbon dioxide removed. The blood is then warmed and returned to your baby through the plastic tube (See Figure 1).

The ECMO Circuit

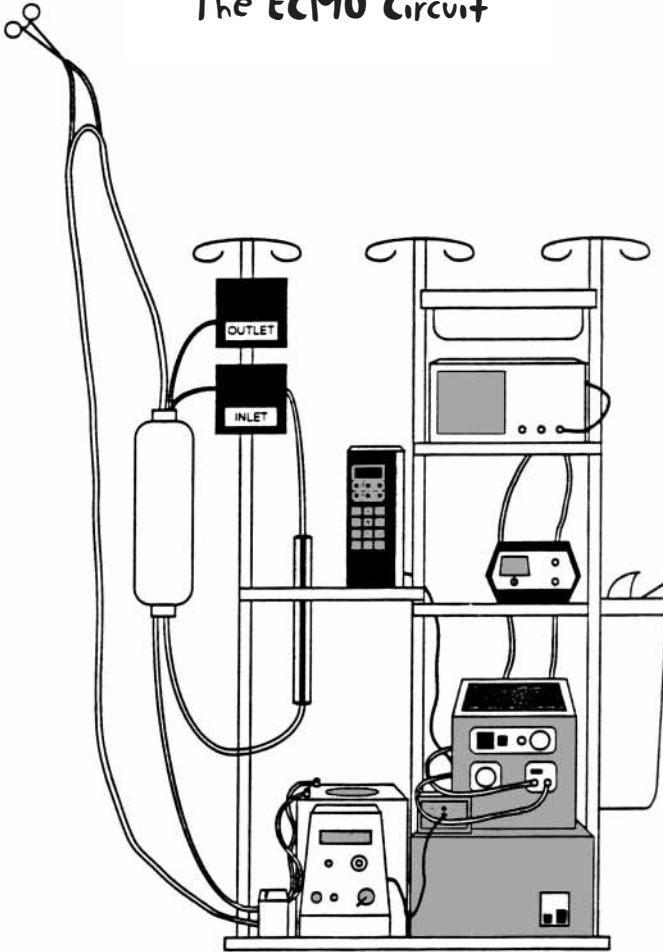


Figure 1.

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 bypass. VA ECMO will support the heart and lungs. This requires two cannulae - one in the jugular vein and one in the carotid artery. They are surgically placed through the right side of the neck.

The second method is called veno-venous or VV bypass. This is used for lung support only. This type of ECMO requires only one catheter to be surgically placed through the right side of the neck

We have recently started placing the VV cannulae without a surgical incision. This method is called “percutaneous cannulation”. When the patient is ready to have the cannulae removed it is pulled like an IV and pressure is held 20 minutes. With this type of cannulae placement the jugular vein is NOT tied off. This method is used most often for venovenous ECMO

Cannulae are placed through the right side of the neck because ECMO requires the use of big blood vessels that are near the heart.

Once the artery or vein has been used for ECMO it will be tied off (ligated) except in special circumstances. Your baby 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 the carotid artery does not need to be tied off. (see Figures 2, 3)

VenoVenous

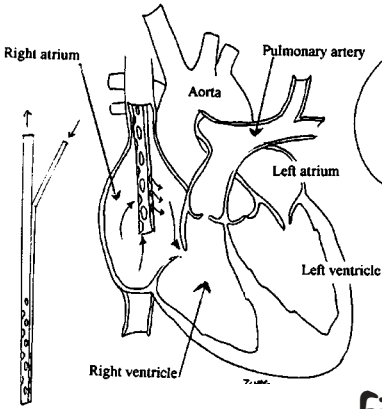


Figure 2.

VenoArterial

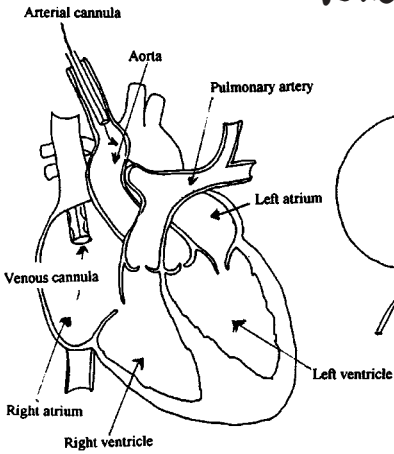


Figure 3.

What is the goal of ECMO?

By taking over the work of the lungs, ECMO allows the lungs to rest. ECMO does not heal the lungs but gives them time to rest and recover. ECMO will be used only when other methods of support have been tried and your baby has not improved. Once on ECMO the ventilator (breathing machine) settings will be decreased to levels that will not damage the lungs. When the lungs have healed and can work on their own, ECMO will be stopped. This process usually takes 3-7 days.

Who goes on ECMO?

When a baby is transferred here for ECMO our physicians will carefully monitor the baby's needs. Not all babies sent here for ECMO will need this treatment. Some will have medical problems that ECMO cannot help. We want to make sure your baby does not have any problems that ECMO could make worse or not help at all.

Your baby will usually have a cranial ultrasound study and a cardiac ultrasound study before being considered for 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 your baby 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). Depending on these test results and if it is determined that your baby would benefit from ECMO, the following will take place:

1. Your baby will receive medicine for pain.
2. Your baby will receive medicine which will temporarily restrict movement.
3. A small cut (incision) will be made in the neck by the surgeon.
4. Two cannulae (for VA) or one cannula (for VV) are placed. One cannula is placed in the jugular vein and sits in the right atrium of the heart. The other, if needed, is placed in the carotid artery and sits in the aorta.
5. The cannulae are connected to the ECMO circuit, which was filled with blood (primed) while the cannulae were being placed.
6. The ECMO machine is turned on.
7. Your baby is now on ECMO.

This criteria is followed for those babies who require a surgical incision (cut) to place the cannulae. The procedure for the percutaneous cannulae is the same except no surgical cut is made.

What happens on ECMO?

After your baby is stable on ECMO, the ventilator (breathing machine) settings will be turned down to “rest” settings. This allows the lungs to rest without any damaging effects of too much oxygen or pressure from the ventilator.

All ECMO patients have a daily routine. This includes a chest x-ray each morning, weight and bath, blood work (labs) every 8 hours, and constant monitoring of vital signs. All of the blood work is drawn off the ECMO circuit. Your baby will not be “poked” by a needle while they are on ECMO. We let the babies rest as much as possible while they are on ECMO.

As the lungs start to heal the amount of ECMO support is reduced. When your baby shows signs of getting better we will “trial off” ECMO. The ventilator “breathing machine” is turned up to support and assist the baby while the ECMO canulae are clamped for the trial. If the lungs have healed enough to support your baby’s needs, then ECMO will be stopped. We will not take your baby off ECMO until the child is ready. Once the decision is made to stop ECMO, the surgeons will be called to remove the tubes from the baby’s neck (decannulation). Your baby will then be off ECMO.

Who needs ECMO?

ECMO for newborns is usually for patients with the diagnosis of Meconium Aspiration Syndrome (MAS), Persistent Pulmonary Hypertension of the Newborn (PPHN), Respiratory Distress Syndrome (RDS), Congenital Diaphragmatic Hernia (CDH), Pneumonia, or Sepsis. Your physician will explain your baby's diagnosis to you and just what it means.

What are the risks?

The greatest risk for ECMO patients is bleeding. Heparin (a blood thinner) is necessary so that the blood does not clot in the tubing or in the baby. Bleeding can occur anywhere in the body but is most dangerous when it occurs in the brain. We will intermittently check for this by cranial ultrasound. There is also a chance that small clots may be introduced into the blood stream of the patient. The ECMO circuit is closely monitored at all times by a specially trained professional. It is still possible, however, that a portion of the circuit could fail. The ECMO specialists are trained for such emergencies. You will be kept informed of any problems that may occur.

What about blood transfusions?

ECMO patients require many blood or blood product transfusions while they are on ECMO. Each baby 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 is still a small chance of a blood transfusion problem.

Medications

Pain medication is given routinely to prevent any discomfort that may be felt. Your baby will be able to look around and move.

Heparin is the drug that keeps the blood from clotting normally. Heparin is first given when the cannulae are placed and will be given continuously while your baby is on ECMO. The ECMO specialist monitors the amount of Heparin in the blood very carefully and makes changes accordingly.

Antibiotics are given to treat existing infections or to prevent infections.

Sometimes a patient's blood pressure or heart needs some help and medications will be ordered for this purpose. Some of the names you might hear are Dopamine, Dobutamine, Inocor, or Epinephrine.

What about nutrition?

While on ECMO a special solution called TPN will be given. This fluid has the vitamins and electrolytes that your baby needs. Your child will also receive a solution called lipids which is a fat solution that the body needs to maintain calories. These will be given into the ECMO circuit through an IV line.

Can I still breast feed?

Yes. 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 your baby is off ECMO and ready, the milk will be available. If you need assistance with this please ask your baby's nurse for help.

Your baby 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 will go away in time.

Who takes care of my baby?

The Holden nurses are specially trained to manage sick babies. The ECMO specialist is a specially-trained Registered Respiratory Therapist or Registered Nurse who has prior experience in intensive care. Your baby will have an ECMO specialist at the bedside at all times.

The ECMO physician is also specially trained in taking care of sick babies and babies on ECMO. Other physicians or specialty areas may be asked to help in the care of your baby.

There is a social worker as well as a chaplain available to you should you need their assistance.

What happens after ECMO?

A typical newborn course of ECMO ranges from three to seven days. Some patients require a longer amount of time. Patients that typically need extra time are those with Congenital Diaphragmatic Hernia. Each baby is different and dictates how long is needed to get better. Once your baby is off ECMO ventilator support will still be needed. It may take a few days or weeks before your baby is ready to come off the ventilator. Again, each baby will respond differently in this area.

Will my child need follow-up care?

Yes. Even though the heart or lung disease is better now, your baby may have had significant exposure to low oxygen levels prior to ECMO. This places your baby at higher risk for developmental problems. These potential problems can be determined only as the child grows. We suggest that your baby be brought to our newborn clinic or one closer to your home. Someone from Holden 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?

The University of Michigan is the oldest and largest ECMO program in the world. Dr. Robert Bartlett is the director of our program and is responsible for the development of neonatal ECMO. We have been performing neonatal ECMO here since 1981. We receive patients and referrals from all over the State of Michigan as well as other states.

ECMO TERMS

ECMO: Extracorporeal Membrane Oxygenation

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

CANNULAE: Tubes that are placed by the surgeon into the blood vessels in the neck.

DECANNULATE: To remove the cannulae.

PERCUTANEOUS CANNULATION: Placing the cannulae without a surgical incision.

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

ECMO FLOW: The amount of blood that is being moved through the circuit per minute.

ECMO PUMP: The pump that controls how much support is being given to the patient. This pump acts like an artificial heart.

BLADDER BOX: Safety system that alarms when the amount of blood in the circuit needs to be checked.

HEAT EXCHANGER: This is where the blood is warmed before it is returned to the patient.

THE ECMO TEAM: This team is composed of specially-trained Registered Respiratory Therapists, Registered Nurses, and Physicians.

VA TRIAL OFF: A test period off ECMO. The ventilator settings are turned up and the ECMO circuit is clamped. This will show us how the baby's lungs are healing.

VV TRIAL OFF: The oxygenator is capped so that the baby's lungs must add oxygen and remove carbon dioxide on their own.

VENOARTERIAL BYPASS (VA): This is the type of ECMO that gives heart and lung support. Two cannulae are used, one in the jugular vein and one in the carotid artery.

VENOVENOUS BYPASS (VV): This type of ECMO gives lung support only. One cannula is used in the jugular vein.

TELEPHONE NUMBERS

ECMO Clinical Manager	734-763-9919
Holden NICU	734-763-4111
WATS Line (toll free) Michigan Only	1-800-521-4369
Moderate Care Nursery	734-764-7391
5 East Mott	734-764-7102
Clinic Appointments	734-936-6379
Social Worker	734-763-2511
Admitting/Business Office	734-764-3314
Ronald McDonald House	734-994-4442
Med Inn	734-936-0100

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Special thanks to:

Kathy Lank, BSN, RN, CNII
Holden NICU for her resource
information and to the Ochsner
Medical Institutions

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