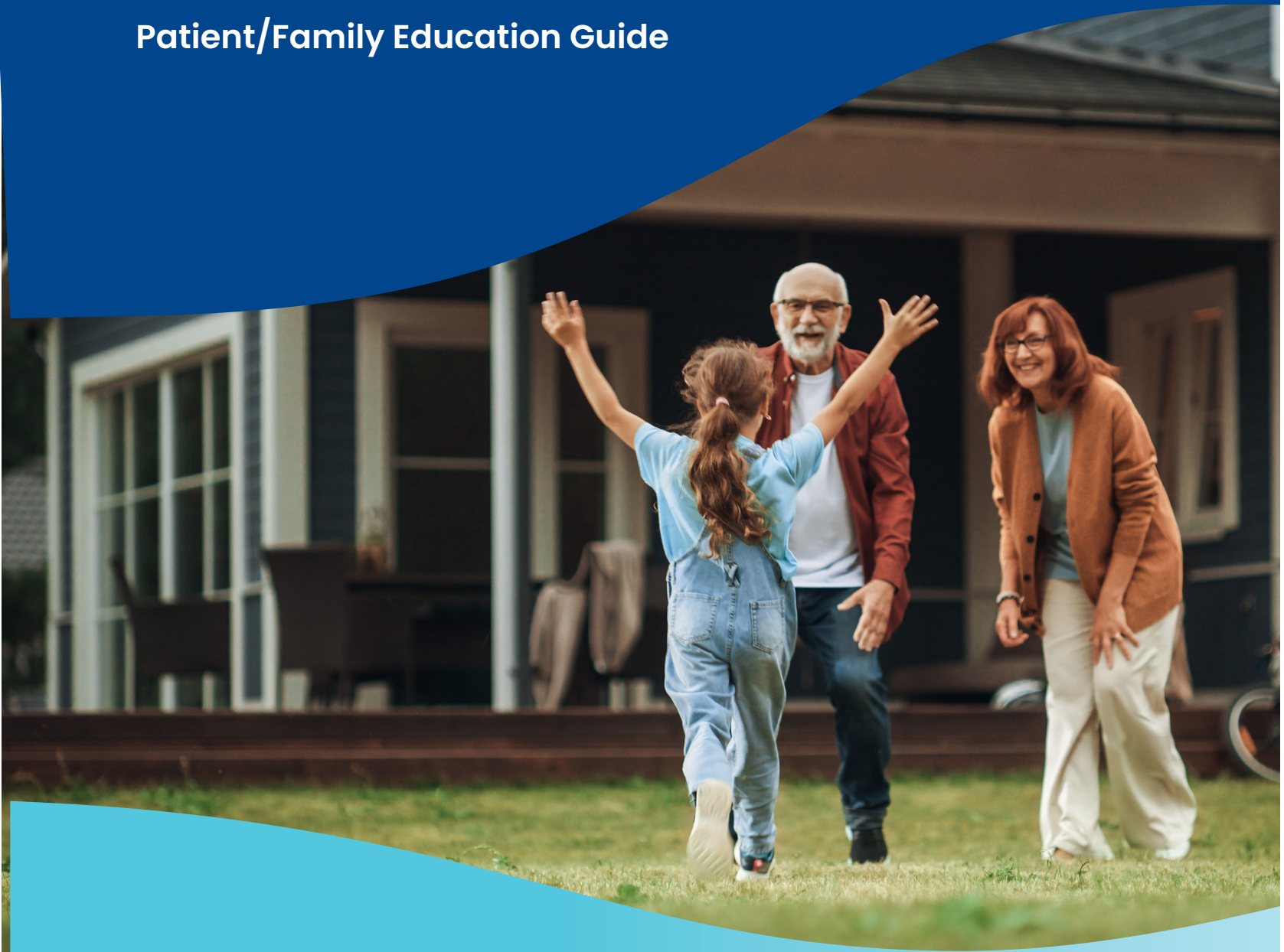


Baptist Hospital ECMO Care

Patient/Family Education Guide

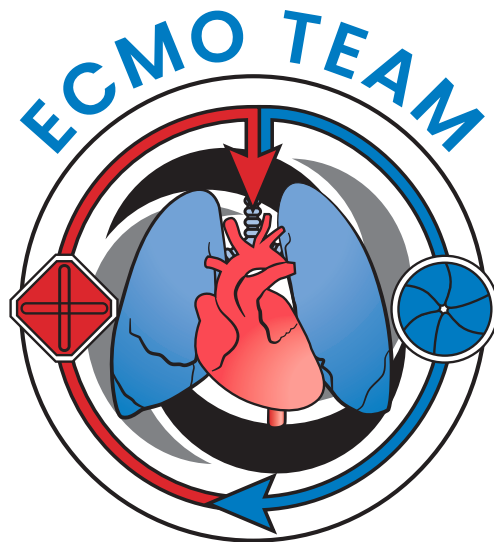


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This material provides information about extracorporeal membrane oxygenation (ECMO), including what it is, why it is used and what typically happens during ECMO treatment. Use this information to help you understand what is going on with your loved one. If you have questions, please ask one of the ECMO specialists.





Dear Patient and Family,

At Baptist Hospital we care about your well-being, and we understand that this is a difficult and overwhelming time for you. When you or a loved one is in the Critical Care Unit (CCU), it can be stressful and trying, not only for the patient, but for the family member. Our hope is that this guide will help answer some of the questions you may have about extracorporeal membrane oxygenation (ECMO) and what it entails for your loved one.

This is just an overview, so if you need more information, please reach out to a member of your ECMO care team. We are here for you in this time of need and throughout life's journey.

Sincerely and respectfully,

Your ECMO Care Team

Phone: 448.227.ECMO(3266)

Who makes up your ECMO care team?

Critical care/pulmonary physicians

Cardiothoracic surgeons

Interventional cardiologists

Perfusionists

ICU nurses

ECMO specialists

Physician assistants

Nurse practitioners

Cardiovascular operating room team

Cardiac catheterization laboratory team

Respiratory therapists

Palliative care team

Pharmacists

Physical/occupational therapists

Clinical nutritionists

Case management and social workers

Chaplaincy services



Commonly used ECMO terms

ECMO

Extracorporeal Membrane Oxygenation. This is the term for the treatment provided by the life support machine the patient is connected to.

Cannula

Plastic tubes that the cardiothoracic surgeons place into the veins and arteries leading to and from the heart. The ECMO circuit will be attached to these cannulas to provide support for the unstable patient. **Cannulation** is the process of inserting the cannula either surgically or percutaneously (through the skin). Cannulation can be done at the bedside in a true emergency.

Decannulation

After careful assessment, when the patient is deemed to be recovered enough to potentially come off ECMO, or when the physician has concluded that the patient's heart or lungs will not recover, the patient may be taken to the operating room to surgically remove the cannula, or it may be removed at the bedside in CCU.

Oxygenator

This is a component of the ECMO circuit that is the “artificial lung.” This device removes carbon dioxide from the blood and provides oxygen to the blood.

Pump

This component of the ECMO circuit is the “artificial heart.” This device propels blood through the circuit and back into the patient.

ECMO flow

This term refers to how many liters of blood are being moved through the circuit by the pump per minute. Typically, the higher the flow rate, the more support the patient is requiring.

What is ECMO and how does it work?

ECMO stands for extracorporeal membrane oxygenation. This treatment is used for infants, children and adults who have life-threatening breathing and heart problems – meaning the heart doesn't pump enough blood, the lungs don't provide enough oxygen or both.

Extra refers to something that is outside, and **corporeal** refers to the body. **Extracorporeal** means that the machine sits outside of your loved one's body. **Membrane oxygenation** means that the machine helps get oxygen into the body.

Breathing problems are referred to as respiratory problems. Heart problems are called cardiac problems.

What does ECMO do?

ECMO has two jobs:

- To help the lungs — by getting oxygen into the blood and taking carbon dioxide out of the blood.
- To help the heart — by pumping blood to the organs.

ECMO does not cure any health problem.

It is a short-term therapy to help the lungs alone or both the heart and the lungs. ECMO simply helps the body work and helps it heal. (Also see “How does ECMO work?” on page 7.)

When is ECMO used?

ECMO is used with very ill people who have not shown improvement with other kinds of medical treatments. These patients may die without ECMO. It is used only when there is a chance that a person could get better.

ECMO may also be used to help a person's medical condition become stable until another procedure can be done. For example, ECMO may be used for certain heart and lung transplant candidates.

Some of the conditions that may benefit from ECMO support are:

- Severe lung injuries and lung problems, including but not limited to:
 - o Pulmonary embolism
 - o Severe asthma
 - o Pneumonia/influenza
 - o Acute respiratory distress syndrome
 - o Congenital diaphragmatic hernia
 - o Meconium aspiration syndrome
- Conditions that cause severe heart problems, such as cardiomyopathy

- ECMO after heart surgery
- Sepsis

ECMO is also commonly used for people after heart surgery.

How does ECMO work?

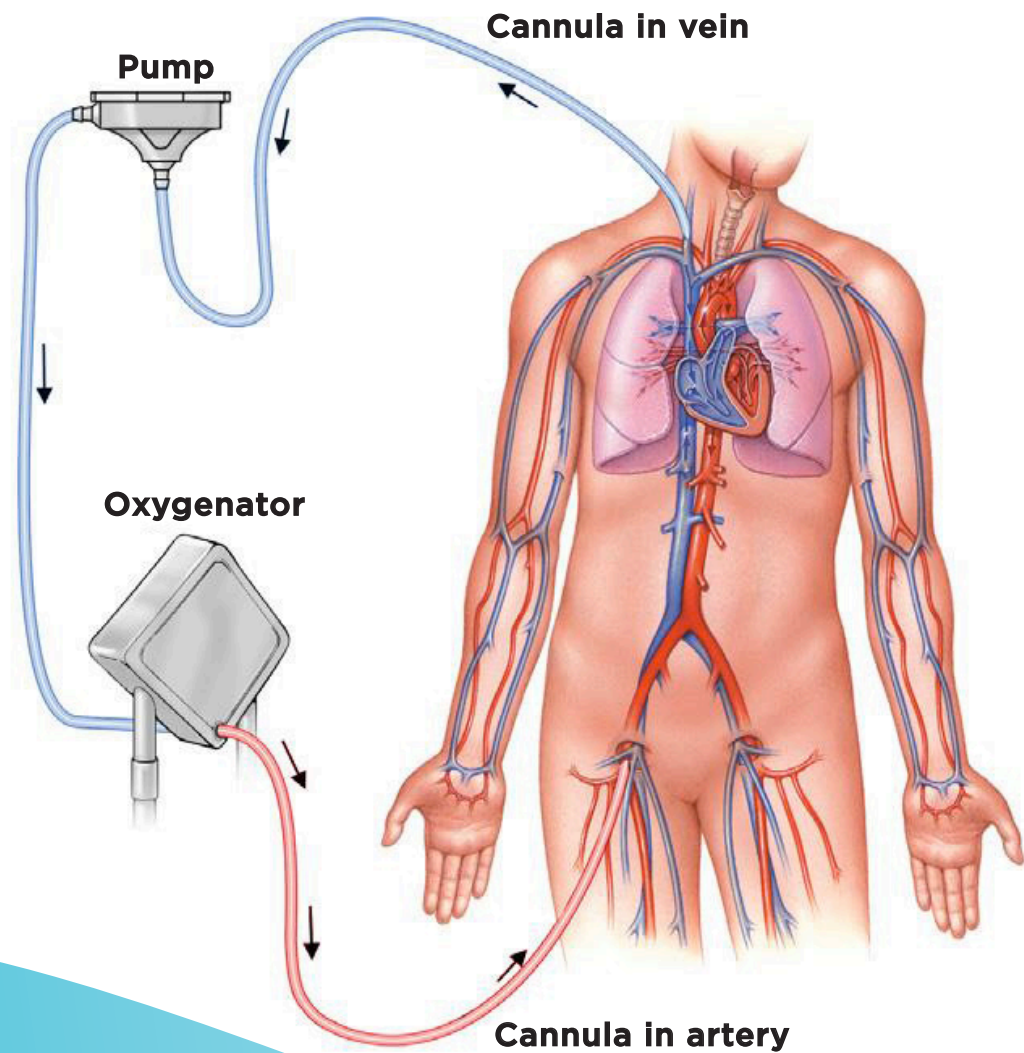
To prepare you or your loved one for ECMO, the physician places tubes, called cannulas, into specific blood vessels. These tubes are connected to the ECMO circuit.

The blood flows from the body in a loop, or a circuit, to the ECMO machine.

The pump acts like an artificial heart. It pushes blood through the ECMO circuit to an oxygenator.

The oxygenator acts like artificial lungs. It adds oxygen to the blood, and it removes harmful carbon dioxide.

The oxygenator may also warm the blood before the blood completes the loop and returns to your loved one's body.



What are the different types of ECMO?

**There are two main types of ECMO:
VA (Veno-Arterial) and VV (Veno-Venous)**

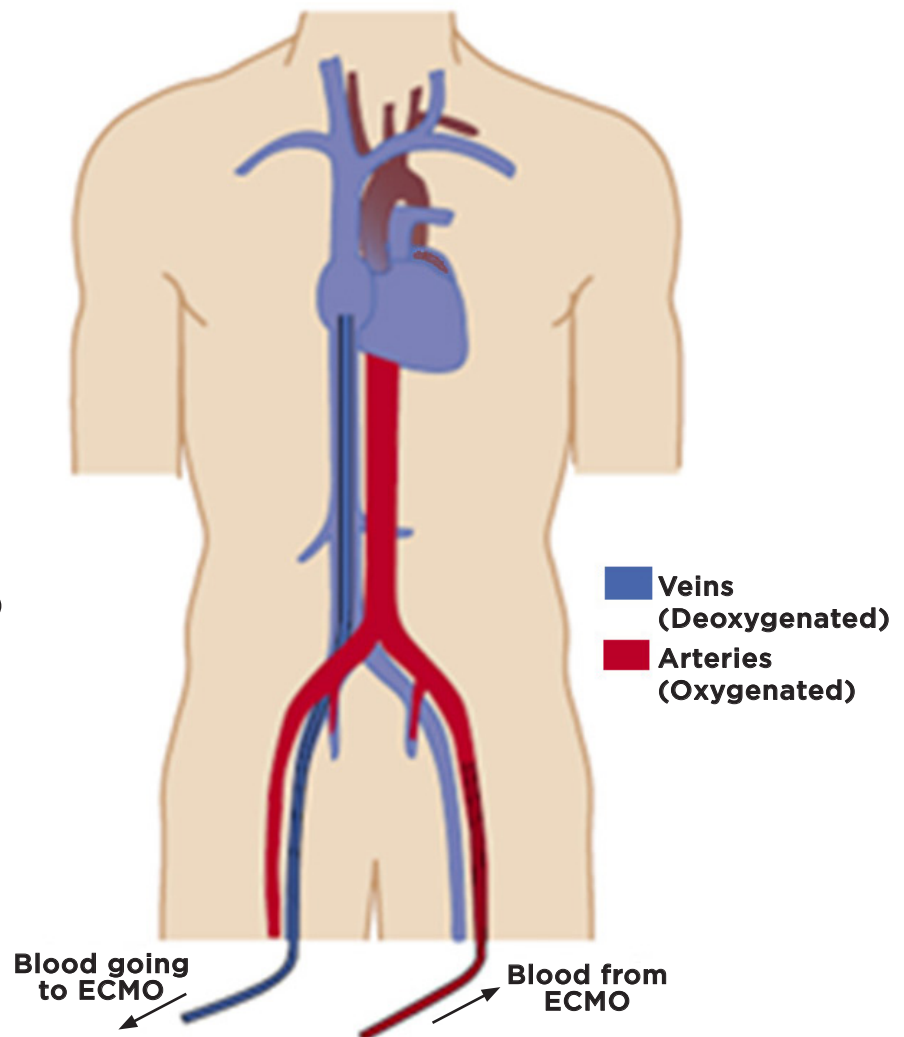
VA ECMO

This form of ECMO is most similar to being on the heart-lung machine in the operating room. VA ECMO allows for full cardiac and respiratory support. The goal of therapy is to allow the patient's blood to be diverted from their heart and lungs, via cannula, to the ECMO machine.

The ECMO machine functions as the patient's heart and lungs, allowing for these organs to rest and recover. A patient on VA ECMO will be cannulated in two different sites. The most common cannulation sites are the femoral vein and the femoral artery.

Additionally, if a patient becomes unstable immediately following open heart surgery, the cannula may be placed directly into the heart for faster access. When this happens, the patient may come to the CCU with their chest open to allow the heart to be further rested.

VA ECMO (Femoral/Groin Cannulation)



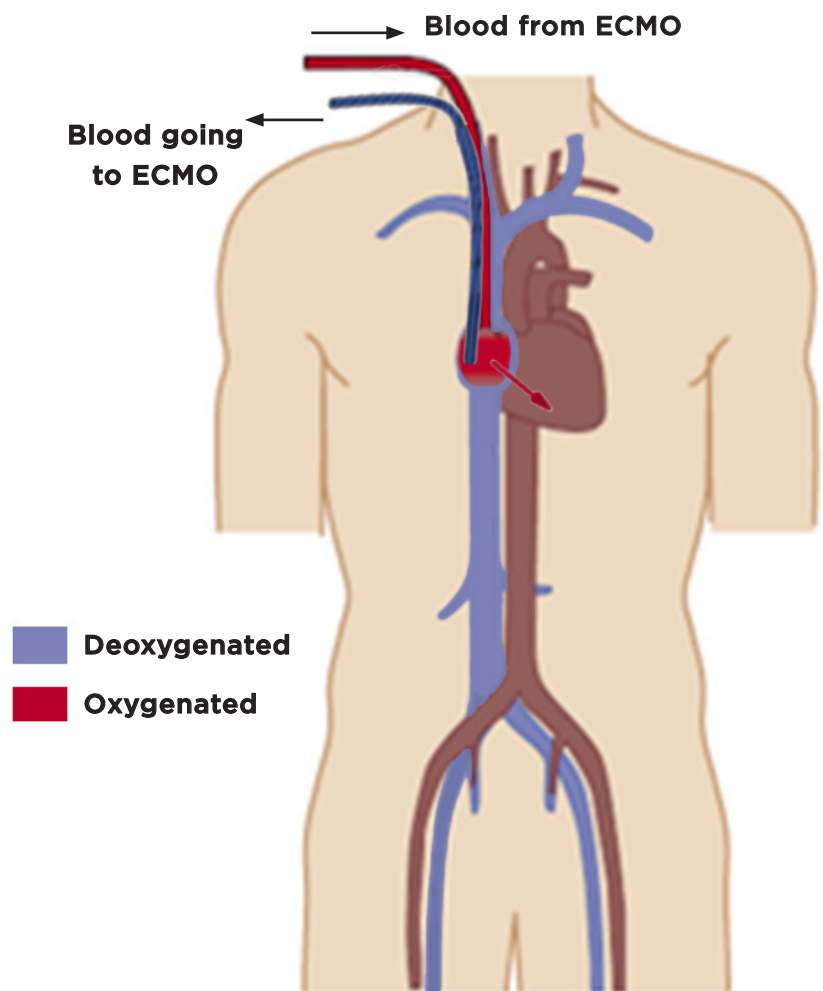
VV ECMO

This form of ECMO only provides respiratory support. VV ECMO requires the patient to have adequate cardiac function. Most commonly in this institution, VV ECMO is initiated in the OR by percutaneously inserting a special cannula into the right internal jugular vein of the neck. This is done by the cardiothoracic surgeon.

This cannula has two openings, allowing for it to drain blood from the heart and return it to the heart through a single cannulation site. The ECMO circuit will oxygenate the blood, remove carbon dioxide and return the blood to the right side of the heart.

Typically VV ECMO patients, due to the nature of their illness and the time it takes for lungs to heal, can be dependent on the machine for some time.

VV ECMO (Right Internal Jugular/Neck Cannulation)



What are the risks of ECMO?

The doctor will discuss with you the risks of ECMO that are specific to your loved one's health condition.

Some general risks of ECMO include:

- Bleeding – People on ECMO receive medication that thins their blood called anticoagulant medication.
- Neurological problems, such as a stroke, seizure or other injury
- Blood clots, leading to a stroke or an embolism. An embolism is a blood clot that travels in the body. It could block or limit blood flow to an organ.
- Infection
- More swelling or problems with blood flow to some organs
- Problems with or failure of the ECMO machine
- Death

What happens if their organs are not healing?

There is a significant chance that despite our greatest efforts, you or your loved one may not improve. Your critical care physicians recognize that there are times when certain medical treatments can be considered futile in that they will not contribute to the patient's well-being or achieve agreed-upon goals of care. If your physicians determine that you or your loved one's heart and lungs are not improving despite the ECMO treatment and you are not a good transplant candidate, ECMO treatment may be discontinued. Just because ECMO treatment is discontinued does not mean we will stop caring for you or your loved one. At all times, we will seek to provide compassionate care and to minimize pain and suffering.

Palliative care focuses on relieving physical and emotional symptoms when a cure is unlikely. Stopping or not escalating active medical treatment and keeping your loved one comfortable is also known as comfort measures.

Palliative care services are for anyone who is seriously ill. Services can be provided for patients of any age and at any stage of a disease. Patients and families are the focus of palliative care. This additional layer of support can range from assistance with end of life and comfort measures, minimizing pain and suffering, communication with staff and providers, emotional support and basic guidance with confusing forms and practical matters. Our team of professionals will provide emotional, spiritual and physical support regardless of where your ECMO journey takes you.

Coming off ECMO

Many patients are recoverable and well enough to be weaned off of the ECMO circuit. We call this a **Bridge-to-Recovery**, which is the primary focus of our program. Some ECMO patients may require implantation of a mechanical circulatory support (MCS) device. They must first be stable enough to

undergo the operation. This is termed **Bridge-to-Device**. The next step in treatment, if the patient is eligible, would be a transplant. If that is the case, the MCS device is a **Bridge-to-Transplant** device.

How long a person is on ECMO depends on the person's medical condition and how he or she responds to ECMO treatment. The amount of ECMO support may be reduced for short periods of time. This is called weaning. This allows the health care team to see whether your loved one's lungs (and heart) are recovering.

Decannulation (removal of the cannula(s)) may be done in the CCU or the operating room.

This may be done when:

- The heart or lungs have recovered and are working well.
- A more appropriate treatment is identified.
- Your loved one:
 - o Develops uncontrolled bleeding or problems with clotting
 - o Doesn't seem to benefit from ECMO support any longer



What kind of medications are needed?

Medication

Sedation and pain medication are given through an IV. These help your loved one feel more comfortable and calm.

- Your loved one may sleep while under sedation. When asleep, he or she may not move much. However some movement is normal, and you may even see your loved one cough. Movement may not mean that your loved one is in pain.
- **Even though your loved one can't talk due to the sedation, he or she may be able to hear you. Please talk to your loved one. Hearing your voice may be very comforting.**
- Your loved one may be awake some of the time he or she is on ECMO. This time may allow him or her to help with therapy.

The health care team will administer a blood thinner to help prevent blood clots. Members of the care team will watch your loved one's lab results closely. The physician may change the amount of blood thinner over time.

Blood products

Your loved one may receive blood products while on ECMO. These are often called blood transfusions. Transfusions help make sure that your loved one has enough blood to:

- Carry oxygen to the body
- Prevent bleeding. The plasma and platelets in blood help blood to clot.

Fluids and nutrition

Your loved one will receive fluids through an IV. The body needs fluids to help it heal. He or she may also get nutrition through an IV or a feeding tube.

Tests and monitoring

While your loved one is on ECMO, tests will be done to monitor his or her condition. These tests may include:

- Blood tests — Blood tests monitor the body's electrolytes, the number and kinds of blood cells, the oxygen and carbon dioxide levels, and the level of medications such as blood thinners. Electrolytes are chemicals, such as sodium and potassium, that the body needs to work well. Blood tests may also show whether your loved one has an infection.
- X-rays — X-ray images are used to check the condition of the heart and lungs and to see the placement of the tubes.
- Echocardiogram — An ECHO is an ultrasound of the heart. It sends sound waves into the body to learn how well the heart is working. The echoes that bounce back from the heart make a picture of the heart that the providers can record and examine.
- Ultrasound — An ultrasound gives pictures, or images, of internal body parts.



Information for family and friends

How will my loved one appear?

Your loved one may look very swollen or puffy. This is normal, since he or she may be receiving a lot of fluids and blood products. Your loved one may also look pale and have cool skin. He or she may have a breathing tube in the mouth and be sedated. Because of this, your loved one can't talk to you but may be able to squeeze your hand or acknowledge you with a nod of the head.

Your loved one is connected to many machines, and there are a lot of tubes (see illustration on next page) coming out of the body. It may seem like a lot of equipment, but each piece is needed to watch and treat your loved one and to keep him or her as comfortable as possible.

Some tubes connect your loved one to the ECMO machine. Other tubes and machines may include:

Dialysis

A machine that helps the kidneys remove waste and toxins from the body.

Ventilator

A machine used to help with breathing.

Nasogastric (NG) tube

A tube placed in the nose or mouth that goes down to the stomach. An NG tube helps drain the stomach, provides nutrition or sometimes does both.

Drainage tubes

Tubes in the chest that drain fluid and waste.

Arterial line

A small tube, or catheter, placed in the wrist or groin. It is used to take blood samples and to check blood pressure.

Intravenous (IV) catheters

Small tubes inserted into veins. Often called "IVs," they are used to give fluids, blood products and medications. (Sedation is an anesthetic. It helps your loved one be more comfortable while on ECMO.)

Urinary catheter (Foley catheter)

A tube inserted into the bladder to drain urine.

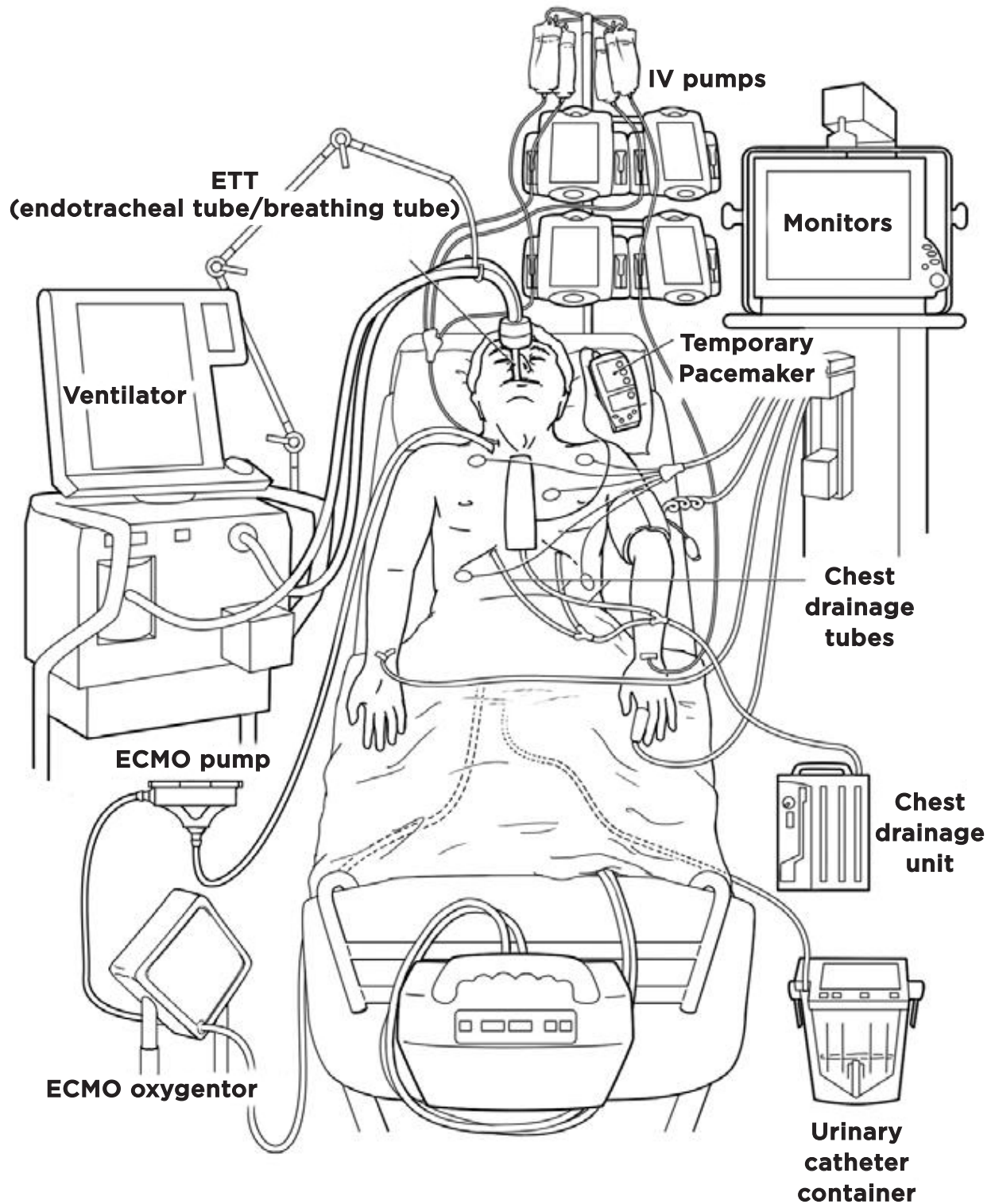
Intra-aortic balloon pump (MCS)

A balloon placed inside the body's main artery, the descending aorta. It helps the heart by pumping blood.

Impella (MCS)

A catheter is placed as a temporary left ventricular support device in patients with decreased heart function to improve cardiac output.

Common medical machines used for a person on ECMO



How can I help my loved one?

People on ECMO are very sick. **Always wash your hands before you go into the room.**

If you have a cold or another illness, consider waiting to visit until your symptoms are gone.

If you need to, wear a mask to prevent the spread of germs. If you are not sure whether you should visit someone in the CCU, talk to a member of the health care team before you visit.

While your loved one is on ECMO, you can help with his or her care. You may want to:

- Spend time with your loved one. Talk about familiar, happy news in a reassuring voice.
- Gently hold your loved one's hand or touch an arm softly.
- Bring soothing music to play.
- Bring a special comfort item, such as a blanket or photos.
- Keep a journal of your loved one's progress. This also may help you better understand what is happening.

Take care of yourself

Having a loved one on ECMO can be very difficult. While you are here with your loved one, please be sure to take care of yourself physically and emotionally.

The following ideas may help:

- Get enough rest.
- Make sure you eat regular meals and drink plenty of healthy fluids.
- Ask other family or friends to sit with your loved one so you can get out of the hospital for a while.
- Talk to a health care professional about how you are doing. Ask a member of the health care team to help you connect with a chaplain or mental health specialist.
- Ask a member of the health care team about relaxation techniques and easy exercises that may help you lower your stress. Many of these ideas can be done in your loved one's hospital room.
- Accept help at home and locally. Allow your friends to help with needs at home, such as keeping up with your family's laundry, taking kids to events, caring for the yard and making meals.

- Ask someone to be the family spokesperson. This person contacts family and friends with updates as needed. Ideally, this would not be the spouse, significant other or a child.
- Consider using a website such as CaringBridge (caringbridge.org) or CarePages (carepages.com). These websites help people share their loved one's medical updates with family and friends. Using one of these sites may save you from spending hours on the phone telling your loved one's story. Doing that can become emotionally tiring for the caregivers.

Open communication

It is our responsibility to communicate effectively with you. Discussing the plan of care for the day will aid in establishing expectations. If you would like to discuss specific test results or prognosis, please ask the nurse for a time to speak with the physician. We will do our best to aid in setting up time for these conversations to happen.

As the support person/family member, we encourage you to ask questions so that you can be informed. Establishing open communication from the beginning of your loved one's hospitalization will yield the best outcomes. We are all focused on the same goal, to get your loved one better. We will treat you and your loved one with kindness, respect and compassion.

For more information

If you have questions after reading this information, please ask a member of the ECMO care team or scan this QR code.



Care conferences

The ECMO care team holds regular multidisciplinary rounds to discuss your loved one's condition. You will be provided with updates as well as the plan of care for the day following rounds. If you have further questions that may require a discussion with the physician, please ask the nurse to set up a time to discuss further.

References: © 2017 Mayo Foundation for Medical Education and Research. Adapted by Baptist Health Care with permission. All rights reserved; UAB Medicine and Extracorporeal Life Support Organization (ELSO).



Your ECMO care team

Thank you for choosing our Baptist Health Care team for your care.

It has been our honor to serve you. The individuals listed below participated in your care. Note that the physicians and advanced practice providers listed below are not employees or agents of Baptist Hospital:

/	/
Your critical care/pulmonary physicians	
/	/
Your cardiothoracic surgeons	
/	/
Your interventional cardiologists	
/	/
Your perfusionists	
/	/
Your R.N. ECMO specialists	
/	/
Your physician assistants	
/	/
Your nurse practitioners	
/	/
Your cardiovascular operating room team	
/	/
Your cardiac catheterization laboratory team	
/	/
Your bedside nurses	
/	/
Your respiratory therapists	
/	/
Your pharmacists	
/	/
Your physical therapists	
/	/
Your dietary-clinical nutritionists	
/	/
Your cardiovascular patient education-transitional care nurses	
/	/
Your case management and social workers	
/	/
Your chaplaincy services	

Acknowledgement of ECMO patient education guide

I, the patient or personal representative of the patient, acknowledge that I have received the ECMO Patient/Family Education Guide and have discussed the risks, benefits and alternatives of ECMO treatment with my physician.

My physician has explained to me the limitations of the device. I understand that this is not a device that is designed to be used for a long period of time, and I or my loved one cannot go home or even to a regular hospital room while using ECMO. I have been told that, in general, ECMO will not be used for more than three (3) weeks unless the heart and lungs are substantially recovering or the patient is a candidate for a heart or lung transplant.

I understand that if my or my loved one's heart and lungs do not recover, continued utilization of the device is futile. By agreeing to be placed on ECMO, I am also expressly agreeing to have the device removed if the treating physicians conclude that my or my loved one's heart or lungs will not recover. I know that recovery will be assessed regularly, and I will be updated daily.

I also understand that stopping ECMO does not mean withdrawal of other patient care interventions such as mechanical ventilation, dialysis, antibiotic treatment, nutrition support with a feeding tube or other treatments.

By signing below, I acknowledge that I have read and understand the above information and information in the ECMO Patient/Family Education Guide. I have had an opportunity to ask questions of my physicians, and I have had all my questions answered to my satisfaction. I understand that success cannot be guaranteed and that continuation of ECMO will be reassessed regularly and discontinued if heart or lung recovery is unlikely.

Patient signature: _____ Date: _____ Time: _____

Patient representative signature: _____

Relationship to patient: _____ Date: _____ Time: _____

R.N. signature: _____

A copy of this document should be scanned into the patient's chart.







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