

Adult Extracorporeal Life Support (ECLS) Family Guide



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Dear family members and friends,

We realize that this is a very hard time for you. Having a loved one in the intensive care unit is stressful for everyone. Be assured, there will be many people available to help you through this difficult time.

This booklet was created in hopes of answering some of your questions about ECLS and what will be happening with your loved one. We hope you find this information helpful.

We want you to feel comfortable in asking us questions and expressing your concerns. As you think of things, you may want to write them down.

We are here for you as well as your loved one.

Sincerely,
The Nebraska Medicine ECLS Team

GLOSSARY

As you review this booklet, refer back to these pages for explanation of words you may not recognize. Always feel free to ask the team any questions you have.

ECLS – Extracorporeal Life Support (ECLS)

ECMO – Extracorporeal Membrane Oxygenation. This is a form of ECLS.

Extracorporeal – means that the blood circulates outside of the body with the help of a machine.

ACT – Activated Clotting Time. This is a blood test that tells us how long it takes for the blood to clot. We check this periodically.

Antibiotic – A medicine that destroys or slows the growth of bacteria or germs. Used to prevent or get rid of an infection.

Arterial blood gas (ABG) test – A small amount of blood that is drawn from an artery and tested to find out the amount of oxygen and carbon dioxide it contains.

Bronchoscopy – In this procedure a camera is placed to examine the lungs and also to take samples of lung tissue and sputum.

Cannulae – These are plastic tubes that the surgeons place into the blood vessels that lead to the heart. The ECLS Circuit attaches to these cannulae.

Cannulation – The process of placing the cannulae into the blood vessels. This will be performed surgically or by percutaneous method.

Percutaneous Cannulation – The cannulae are placed like an IV. There is no surgical incision made.

Chest tube – A tube placed into the space between the lung and chest wall that removes air or fluid. It is used to treat a collapsed lung (pneumothorax) or to remove fluid around the lung (pleural effusion).

Decannulation – The process of removing the cannulae from the blood vessels. Depending on the blood vessels used it may be possible to pull out a cannula like an IV or it might require an operation.

Dobhoff tube – This is a tube that is inserted through the nose to a part of the intestines. This tube allows us to give nutrition and calories to the patient.

ECLS flow – This is the amount of blood that is being moved through the ECLS circuit per minute. This relates to how much support the patient is receiving.

ECLS team – This team is made up of specially trained nurses, respiratory therapists, nutritionists, pharmacists, perfusionists, surgeons and physicians.

EEG (Electroencephalogram) – Recording of the electrical activity of the brain.

ET (Endotracheal tube) – A tube placed in the windpipe that is connected to a ventilator.

Heparin – A drug used to prevent blood from clotting.

LVAD (left ventricular assist device) – This is a device that will assist the left side of the heart when it is failing. More information will be given to you if your family member is waiting for this device.

Oxygenator – This is the “artificial” lung where carbon dioxide is removed and oxygen is added.

Nasogastric (NG) tube – A feeding tube that is passed through the nose and into the stomach.

Platelets – Cells in the blood that help stop bleeding by helping to form clots. Platelets are damaged and used up by the ECLS circuit. They are regularly monitored and replaced.

RVAD (right ventricular assist device) – This is a device that will assist the right side of the heart when it is failing.

Tracheostomy – A tube that is placed directly into the neck that leads to the lungs. This tube takes the place of the endotracheal tube that is placed in the mouth. The tracheostomy tube helps to protect the larynx, decreases the risk of infecting the lungs with “germs” from the mouth, is more comfortable for patients and allows easier management of the ventilator.

Urgent/Emergent ECLS – In many circumstances ECLS is initiated in patients who are extremely unstable and may be close to a cardiac arrest.

Ventilator – Breathing machine used to deliver oxygen to the lungs through a tube in the windpipe. It pushes air in and out of the lungs.

Wean – When the patient has shown improvement, we will decrease the support from the ECLS circuit and monitor how the patient’s heart and/or lungs are functioning.

What is ECLS?

ECLS stand for Extracorporeal Life Support. You may also hear the term ECMO which stands for Extracorporeal Membrane Oxygenation. ECLS is a broader term that includes ECMO.

ECLS is a special procedure that takes over the work of the heart and/or lungs when they are too sick to properly support the body. ECLS allows the heart and/or lungs time to rest and heal. ECLS does not cure these organs, but allows them time to rest.

ECLS is very similar to the machine used for open-heart operations. While those patients are on the machine for only hours, ECLS patients can be on the machine from days to even weeks. During ECLS, patients may appear to be better but you need to know that the person is still very sick and needs the ECLS machine for life support.

Who needs ECLS?

Patients who are considered for ECLS have severe heart and/or lung failure. They are not responding to standard medical treatments and unlikely to survive without exceptional treatment (ECLS). Often the breathing machine (ventilator) is in use with high settings and/or a large amount of heart medicine is in use to maintain the blood pressure. The patients must have a reversible illness and good brain function for ECLS to have a chance of success.

Most of our patients are sent to us from other hospitals. Many patients who are referred to us for ECLS do not actually receive this treatment. Once they are at our hospital our team will do a full evaluation of the patient's needs. Many will improve without the need for ECLS.

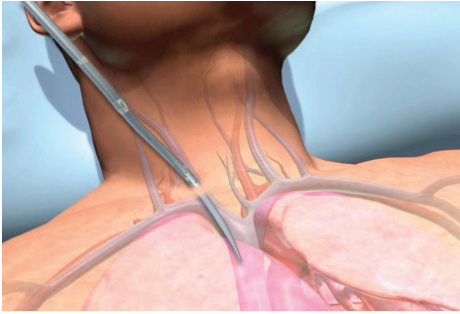
Some of the reasons that adults go on ECLS at our institution are:

- Pneumonia – from lung infections
- ARDS- acute respiratory distress syndrome
- PE- pulmonary embolus
- MI- myocardial infarction (heart attack)
- Heart failure
- Heart arrhythmias
- After difficult heart operations
- After heart or lung transplantation

What is emergent/urgent ECLS?

This is an emergency ECLS response. We may receive a call from the Emergency Department, any of the Intensive Care Units, or Catheterization Labs. The patient is extremely unstable and may be close to cardiac arrest. The ECLS team will make the decision about going on bypass in these situations. These patients generally have their ECLS cannulae placed in the artery and vein in their groin. This is the fastest access.

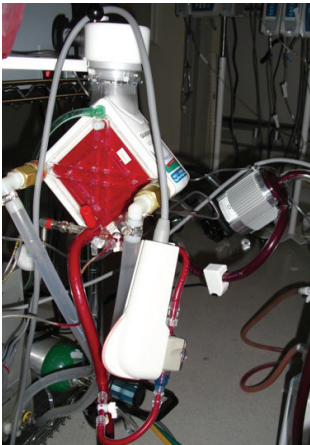
How does ECLS work?



Cannulae are placed in blood vessels in the patient's neck, chest and/or groin. They can be placed surgically, or they can be placed percutaneously. The ECLS surgeon will determine which method is required. These cannulae allow blood to be removed from the body and pumped

back in and are attached to tubing that goes to the ECLS machine.

The ECLS machine makes the blood flow through the tubing by the turning motion of the pump. How fast the blood goes depends on how fast the pump turns. This flow number may be high at the beginning meaning the machine is doing most of the work. As your loved one gets better, the flow may slowly be decreased because less support is needed. The amount of time this takes depends on how the heart and lungs heal.



Depending on the requirements, oxygen may be added and carbon dioxide removed by an artificial lung (oxygenator). The blood is then warmed to body temperature and given back to your loved one through the tubing. If an oxygenator is used you may notice that the blood coming from your loved one will be dark because it contains little oxygen. The blood going back in will be bright red because it carries lots of oxygen. The blood is taken

out and given back at the same speed so your loved one's body doesn't miss the blood going through the tubing.

Are there different types of ECLS?

Yes. ECLS can be used for heart and lung support or for lung support only. The terms VA and VV refer to the blood vessels used in the treatment. Sometimes a person may start with one form of ECLS and need to be switched to another.

VA ECMO: If the patient needs heart and/or lung support they will be placed on VA or VenoArterial ECMO. This is the type of bypass that is most like the system used in the operating room for heart operations. A cannula will be placed in a large artery and another cannula in a large vein.

VV ECMO: If the patient needs lung support only they will be placed on VV or VenoVenous ECMO. The cannulae will be placed in large veins. Occasionally one cannula may be sufficient for VV ECMO.

RVAD: If the patient needs support of the right side of the heart an RVAD or Right Ventricular Assist Device may be utilized. A cannula will be placed in a large vein and another in the pulmonary artery. This form of ECLS may be used in conjunction with an LVAD or Left Ventricular Assist Device or in conjunction with ECMO.

RVAD/ECMO: If the patient needs support of the right side of the heart and the lungs an RVAD or Right Ventricular Assist Device may be utilized. A cannula will be placed in a large vein and another in the pulmonary artery. This form of ECLS may be used in conjunction with an LVAD or Left Ventricular Assist Device. This support requires the addition of an oxygenator (artificial lung) to the RVAD.

ECLS is an evolving field and there are other types of support that we may utilize now and in the future.

What are the goals and what is the success?

By taking over the work of the “sick” organ - heart and/or lungs, ECLS provides time for these organs to rest and heal. ECLS does not heal the organs. It only allows time for them to rest. ECLS will be used only after all other medical measures have been attempted.

When the heart and/or lungs have healed, then the patient will be taken off ECLS. This can take days to weeks in the adult patient.

Some patients may be able to transition from ECLS to an LVAD, which is a long-term pump that lives inside the body. Before an LVAD is placed patients undergo extensive evaluations to ensure this is a suitable treatment.

Some patients who are on the waiting list for a heart or lung transplant may receive these organs and be taken off ECLS. Patients undergo extensive evaluations before listing for heart or lung transplantation.

ECLS is only utilized in extremely ill patients as a last resort. For all patients treated with ECLS, approximately 50 percent will survive. This risk varies depending on the underlying disease and the overall health of the patient. However, the risk of dying without ECLS is significantly greater than the risk of dying with it.

What are the risks?

The risk of dying without ECLS is significantly greater than the risk of dying with it.

The most common risk with ECLS is bleeding. This is because we continuously run a medication called heparin. It is very important that clots do not form in the ECLS circuit. Heparin thins the blood to prevent this. Bleeding can occur anywhere in the body while the patient is on heparin. Adults most commonly bleed from where the cannulae were placed. The most dangerous bleeding may occur in or around the brain. We are constantly monitoring for signs of bleeding and steps will be taken to slow any bleeding that happens including stopping heparin. If the bleeding increases, your loved one may need surgery. If there is too much bleeding, ECLS may need to be stopped.

Clots may form in the circuit. Air bubbles may also enter the circuit. These may clog the circuit or get into the blood from the tubes and cause organ damage. This can even be fatal. Many safety measures are taken so this won't happen.

Although every safety measure is taken, any part of the ECLS circuit can fail, rupture or malfunction. The ECMO Specialists are specially trained if this should occur.

Patients on ECLS are at risk for having infections especially of the lungs and the blood stream. A risk of infection arises any time a tube is placed in the body, especially in a blood vessel. We are constantly monitoring for signs of infection. Antibiotics will be given if needed.

There is a risk for limb complications resulting from poor blood flow or oxygen delivery to the limbs. This is most common in patients with VA ECMO on the side with the arterial cannula but can affect any extremity.

Patients requiring ECLS are extremely sick and their organs may start to fail due to inadequate blood supply or oxygen. The brain is the biggest concern for this. Other organs frequently affected are the kidneys and liver.

Blood and blood products are needed often while on ECLS. The risks of getting blood transfusions are well known and our blood bank does many tests to make sure the blood is as safe as possible. However no test is 100 percent accurate.

Who will be managing ECLS and taking care of my loved one?

The ECLS team includes a large group of people from different specialties. Intensive care physicians (called intensivists) and cardiothoracic surgeons are frequently at the core of the team. Other members include nurses caring for your loved one, a respiratory therapist who takes care of the breathing machine and specialists who operate the ECLS machine.

The team may ask other specialists to assist them including cardiologists (heart), neurologists (brain), pulmonologists (lungs), nephrologists (kidneys), infectious disease experts, nutritionists, pharmacists, physiotherapists etc.

Each day members of the team will come to the bedside to talk about how your loved one is doing and the plan of care. These sessions are called "rounds." We encourage you to take part in rounds by sharing your insights, questions and concerns. We

expect you to have questions about the care, and want to hear them.

There are also people who are there to take care of you and your family. Ask your loved one's nurse to call the social worker if you need help dealing with issues like a place to stay, meal tickets, parking passes or have emotional needs. A chaplain and palliative care services are available.

What happens during those days/weeks?

A small subset of patients may not be on the ventilator when ECLS is initiated and may be able to remain off the ventilator.

Most patients, however, will have already been placed on the ventilator. After ECLS is started, if possible, the ventilator is turned down to "rest" settings. This means we will decrease the oxygen levels and the amount of pressure used to keep the lungs inflated. This allows the lungs to rest. The patient's lungs will continue to be suctioned.

After ECLS is started it may be possible to decrease the heart medications required to maintain the blood pressure thus allowing the heart to rest.

The first couple of days on the ventilator frequently require the patient to be well sedated and even chemically paralyzed. We do this so that we can decrease the amount of oxygen their body uses. As soon as possible we will stop the paralyzing medication and let the patient wake up. We will ask them to squeeze our hands or move their feet. If they are comfortable we will try to allow them to remain awake and will treat their pain and anxiety.

For some patients it may be possible, over time, to remove them from the ventilator (extubate). Others may require a tracheostomy to be placed.

The patient will receive a chest x-ray every morning. We will draw blood for labs routinely throughout the day.

Sometimes a special procedure such as a heart catheterization, or a CT scan is required. We will take the patient to those areas of the hospital where these tests are performed. The ECLS Specialist and bedside nurse will always be with the patient during these “road trips.” These trips require careful planning due to the critical nature of the patient and the cumbersome nature of the machinery.

Are they in pain?

We try to make sure that your loved one is not in pain. They will be kept sedated with drugs such as morphine, lorazepam, and propofol. If possible we will “wake” the patient at least every day to make sure that they are ok. We will ask them to squeeze our hand or follow a command. Once they have done this we will continue with the pain medications. We encourage you to talk to your loved one. They may be able to hear you even if they cannot respond. Most patients do not remember this time in their lives. Some have been able to recall dreams or moments during this time.

What kind of medications are used?

Many types of medications are given while the patient is on ELCS. The following list is what you might see or hear most frequently. It is not a complete list.

- **morphine/fentanyl** – These are used for pain.

- **lorazepam/versed/propofol/dexmedetomidine** – These are sedatives. They help decrease anxiety.
- **atracurium** – This is a drug that paralyzes the muscles. We use this with critically ill patients to help reduce the amount of oxygen that their body uses. Once the patient is stable we will try and discontinue this drug.
- **furosemide (Lasix)** – This medication helps to increase the urine output.
- **vancomycin, gentamycin, cefazolin** – These are all antibiotics. There are many different antibiotics that may be used.
- **pantoprazole** – This medication helps to protect the stomach against ulcers.
- **dopamine, dobutamine, norepinephrine, epinephrine, vasopressin** – These medications are used to help increase the blood pressure.
- **heparin** – This is the medication that thins the blood. It will take longer for the blood to form a clot. The ECLS Specialist monitors the level of clotting. The heparin dose will be increased or decreased based on the clotting time and the patient's condition.

What about nutrition?

While on ECLS your loved one will usually be fed through a tube that is placed through the nose or mouth to the intestines. The food we give through this tube is similar to Ensure or other liquid drinks like this. This fluid is delivered directly to the intestines. If we are unable to place the tube or your loved one does not tolerate being fed in this manner, we will use nutrition through the veins (Total Parenteral Nutrition-TPN). TPN will be given through an IV to the patient, or through the ECLS circuit. The amount of calories required is assessed several times a week.

What happens if the kidneys fail?

If the patient's kidneys are unable to produce enough urine or function properly then we will help them with dialysis. Frequently the patient's kidney function returns in time and they do not require long term dialysis.

What will my loved one look like on ECLS?

The cannulae in the neck and the large amount of tubing in the ECLS circuit may be upsetting to look at. You may notice a breathing tube (endotracheal tube or ET tube) going into your loved one's mouth or nose. This will be attached to a breathing machine, which helps keep the lungs inflated. They will be attached to other routine monitoring equipment.

Your loved one's head and body may look puffy. The puffiness (edema) is often seen in the eyelids and may limit how much they can open their eyes. The puffiness (edema) is generally caused by the therapies needed to support your loved one.

How do you know if they will get better?

We are watching for improvements every day. We will look at all aspects of heart and lung function. This would include blood pressure, chest x-rays, pulmonary mechanics (how much air is in the lungs, how easily they fill with air with each breath) blood gases, ECLS flow and many more.

We will do what we call a "wean" from ECLS. If your loved one is on ECLS for lung support we will turn up the ventilator and "cap" off the oxygenators in the ECLS circuit. This will require the patient's lungs to do all the work. If the patient's condition remains good then

we will consider removing the patient from ECLS.

If your loved one is on ECLS for heart support we will turn the ventilator to appropriate settings and reduce the ECLS flow. We will be watching the patient's blood pressure. We may have to add medications to help keep the blood pressure in an appropriate range. If everything looks good then we will consider removing ECLS at this time.

If your loved one does not do well during the 'wean,' ECLS is continued.

The physician and staff taking care of your loved one will explain what we are looking at during these weans. The final trial is with ECLS removed.

What happens once they are ready to come off ECLS?

When it has been decided that the patient is ready to come off ECLS we will cut the circuit away from the cannulae. The ECLS cannulae will be removed (decannulated). This may require an operation.

Your loved one may remain on a ventilator until they are able to breathe on their own again. This is different for every patient. It may take days or weeks. As the lungs improve, weaning from the ventilator will start.

Physical therapy will start early and patients frequently require rehabilitation before going home.

It is very important for us as well as your family member to be seen by our team a few times after they go home. We will schedule appointments for this. This is to make sure that everything is going as it should.

What happens if they do not get better?

There is the chance that despite our best efforts, your loved one will not improve. We will talk to you frequently about the condition of your loved one. If the ECLS team feels that we have done everything possible for your loved one, but they are not getting better – or are getting worse, they will sit down and talk with your family. Resources are available to you to help support your family during this difficult time.

What about bridge to LVAD patients, or patients on the transplant waiting list?

A select group of patients that have heart failure may be treated with a long term pump placed inside the body (LVAD). We will place these patients on ECLS until they are well enough to have the LVAD placed. The heart failure/LVAD team will evaluate these patients before and after they are placed on ECLS. If your loved one is an LVAD candidate, more information will be given to you by the heart failure service.

A select group of patients may be on the heart or lung transplant waiting list and require ECLS due to deterioration in their condition. They may still be candidates for transplantation. After transplantation the goal would be to discontinue ECLS though this may not always be possible. If your loved one is a transplant candidate, more information will be given to you by the transplant service.

When can we visit and how can we help?

After ECLS has started, and once the patient is stabilized, you will be able to visit.

All of our adult patients are managed in the ICU. You will be given the policies of the unit by the clerk or nurse taking care of your loved one. We will always try and let you come in as much as possible.

Call at any time, day or night, to check on your loved one. We are always happy to talk to you and answer questions.

Family plays an important part in recovery. While on ECMO, there are some things you can do to help:

- We encourage you to talk to your loved one and hold their hands. They may not be able to respond back to you but they may be able to hear you.
- Bring photographs, blankets, etc.
- Make tapes of you reading stories, singing songs, or talking. Bring them in or send them if you cannot be with your loved one right away.
- Children can draw or color pictures to be placed at the bedside or choose a small toy to send. Some units will let children visit. Ask the nurse.

We do encourage you to rest, eat well and take care of yourselves. Getting sick yourself will not help either of you.

Your family member may be off work for a long period of time. If there are any forms to be completed please let us know.



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Notice: This information is considered for general use only. It should not be used instead of medical advice and care. If you have a specific health concern or care need, you should talk with your doctor. Rev. 4/15.