

AdventHealth Heart, Lung and Vascular Institute

A Patient and Family Guide to ECMO



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Important Information

ACSU (Advanced Cardiac Surgical Unit) Number (407) 609-3889

Nurse Manager: _____

Day Shift Assistant Nurse Managers (ANM): _____

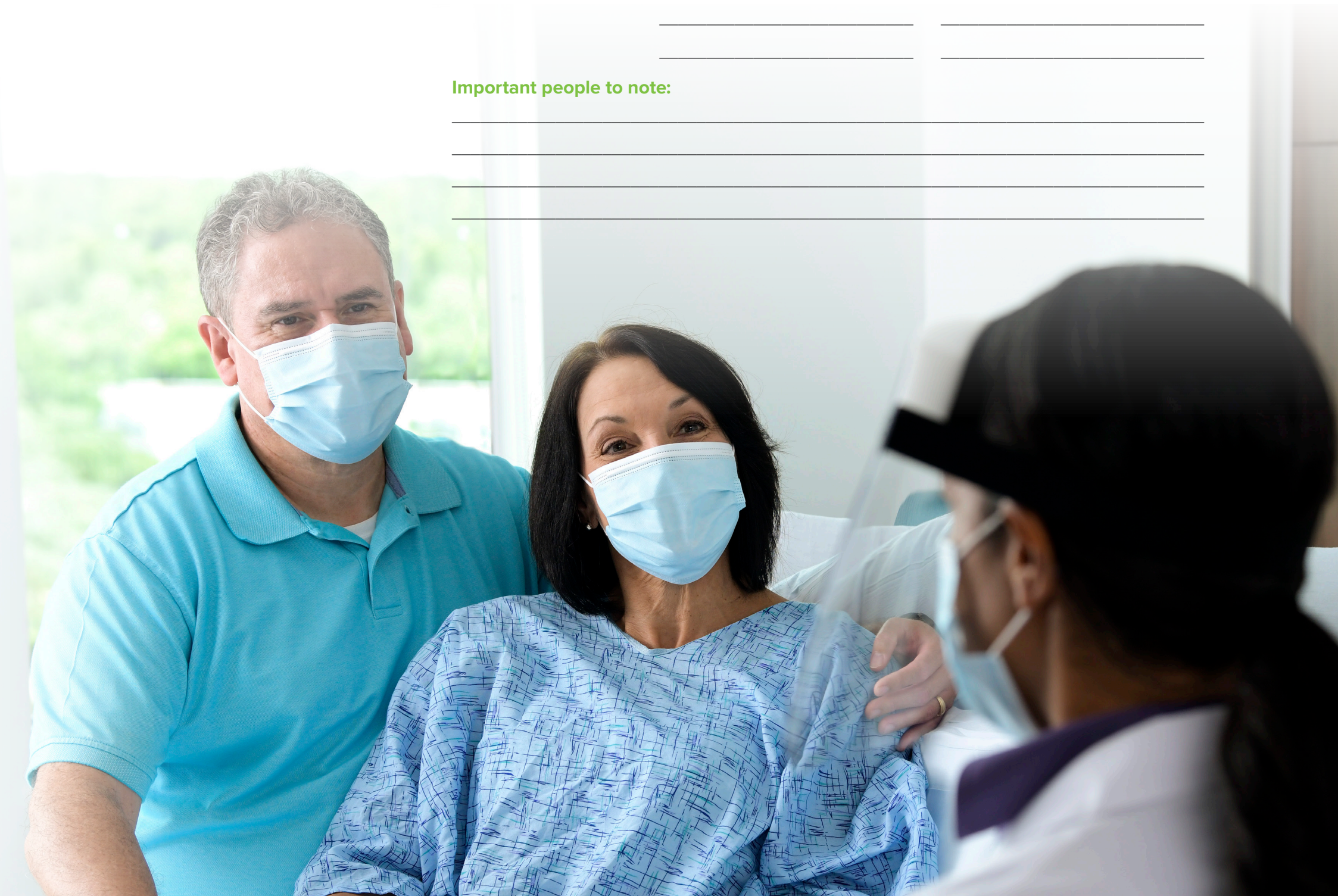
Night Shift Assistant Nurse Managers (ANM): _____

Your Case Manager: _____

Your Surgeon: _____

Your Critical Care Providers: _____

Important people to note:



Dear Patient and Family

The AdventHealth team is dedicated to caring for the whole person. We care about your well-being and know this is a confusing, frightening, and difficult time. Being admitted to the ICU or having a loved one in the ICU is stressful, especially when invasive life support is needed. We want you to know we are here to support you. This material will answer some of your questions and help you stay informed. It is our hope that it will alleviate some of your stress, confusion, and fear.

We understand you may have other questions or concerns along the way, and we want to ensure that your needs are met. Please do not hesitate to ask a team member for any assistance.

Thank you for trusting us with your care.



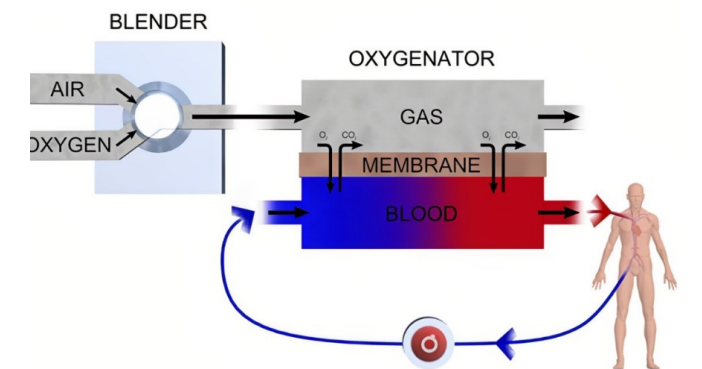
What is ECMO?

Extracorporeal membrane oxygenation, or ECMO, is a life support therapy that removes carbon dioxide and adds oxygen to a patient's blood.

ECMO is sometimes called ECLS or extracorporeal life support and is the highest form of life support that exists today.

The ECMO device removes blood from the body through large plastic tubes placed in large veins and/or arteries depending on the type of ECMO used. The blood is pumped through a filter called a membrane that adds oxygen and removes carbon dioxide then returns the blood to the body, temporarily taking over the work of the lungs and/or heart.

While ECMO is used when other support devices are not working, it is not a cure. It only provides the patient's body time to heal.



ECMO notes:

Who Needs ECMO?

Patients with lung and/or heart failure that cannot be supported with other life support measures may benefit from the use of ECMO.

These are some examples of illnesses that cause lung and/or heart failure and may be supported with ECMO:

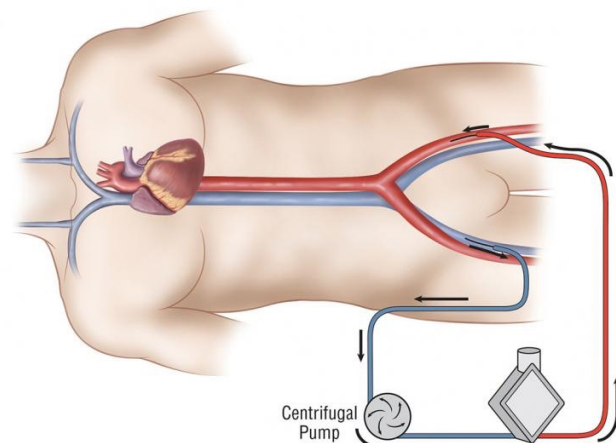
- Pulmonary Hypertension (high blood pressure in the lungs)
- Heart Failure
- A support bridge to heart and/or lung transplant
- Infection
- Acute Respiratory Distress Syndrome (ARDS)
- Viruses such as flu or coronavirus
- Pneumonia
- Trauma

Notes: Why my loved one needs ECMO

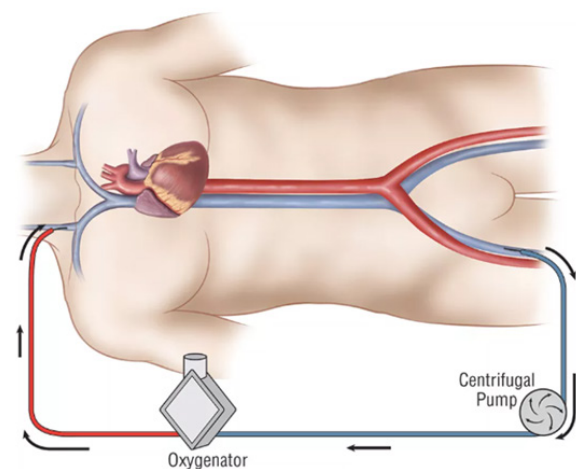
What type of ECMO they are on?

Types of ECMO?

V-A ECMO supports both the heart and the lungs. The ECMO device removes blood from the venous system, takes carbon dioxide out of the blood, and returns the oxygenated blood back to the arterial system.



V-V ECMO only supports the lungs. The ECMO device removes blood from the venous system, takes carbon dioxide out of the blood, and returns the oxygenated blood back to the venous system. V-V ECMO can be done with one insertion site with a double tube cannula, or two sites as seen below.



Your ECMO Team

It takes a very large team of people who specialize in different parts of the ECMO patients care and environment. We understand this is a very overwhelming list so if you have any questions about the roles of any team member at any time, please ask your nurse or ACSU leadership.

ECMO Surgical Director



Scott Silvestry, MD
Surgical Director of Thoracic Transplant
Thoracic and Cardiovascular Surgeon

ACSU Assistant Nurse Manager and Second Charge Nurse

Acute Cardiac Surgical Unit (ACSU) Manager

Cardiac Director of Nursing

Cardiac Surgeon

Case Manager

Chaplain

Critical Care Physician, Physician Assistant (PA), and Acute Care Nurse Practitioner (ARNP)

Dietician

ECMO Clinical Specialist

ECMO Registered Nurse

ECMO Specialist

Environmental Services Personnel

Occupational Therapy, and/or Speech Therapy

Palliative Care

Pharmacist

Physical Therapist

Registered Respiratory Therapist

What to Expect

Monitoring and Extra Support Devices

You or your loved one will be watched very closely by the ICU team. This monitoring will include constant vital sign monitoring, x-rays, labs, echocardiograph (EKG or ECG), echocardiogram (ECHO), and at times other diagnostic testing such as CT, MRI, Endoscopy etc....

There may be multiple devices in the ECMO patients room depending on their needs. Aside from the EMCO machine there may be a breathing machine or ventilator, a CRRT device, IV pumps, chest tubes and chest tube drainage systems, suction tubing, a foley catheter draining urine from their bladder, rectal drainage tubes, feeding tubes, and other monitoring systems.

ECMO patients can look swollen, especially in the first few days. This is because they may need extra fluid for the ECMO device to work but their kidneys may not be able to keep up. We will monitor their kidney health closely but in some cases, the patient may need to be placed on Continuous Renal Replacement Therapy or CRRT. This is a slow gentle type of dialysis, which can remove fluid and/or filter for the kidneys.

Some ECMO patients may develop heart failure in different areas of the heart and require extra support to help the heart recover. Some of these patients may have an Impella or an Intra-Aortic Balloon Pump to support the heart and allow it to rest. Others may have a Ventricular Assist Device (VAD) to help pump blood out of the heart to the rest of the body.

An ECMO room can become very crowded very fast. Please ask your nurse, respiratory therapist, or ECMO specialist what each does to help you become more familiar with the type of support you or your loved one needs.

Testing and Procedures

Many ECMO patients require multiple diagnostic tests and procedures during their stay. We have discussed many of these already.

Some other procedures may include the addition of central venous lines for medication access, pulling

and replacing these lines as needed, hemodialysis line placement and replacement, arterial line insertions and replacements, the additions of chest tubes and other types of drains, and in some cases, multiple surgical procedures.

Blood testing and x-rays are most often a daily occurrence. Trips to CT scan, and interventional radiology are common as well for both testing and procedures.

Breathing

Some ECMO patients may need other support devices, such as ventilator or breathing machine support and may be sedated to help them rest and recover.

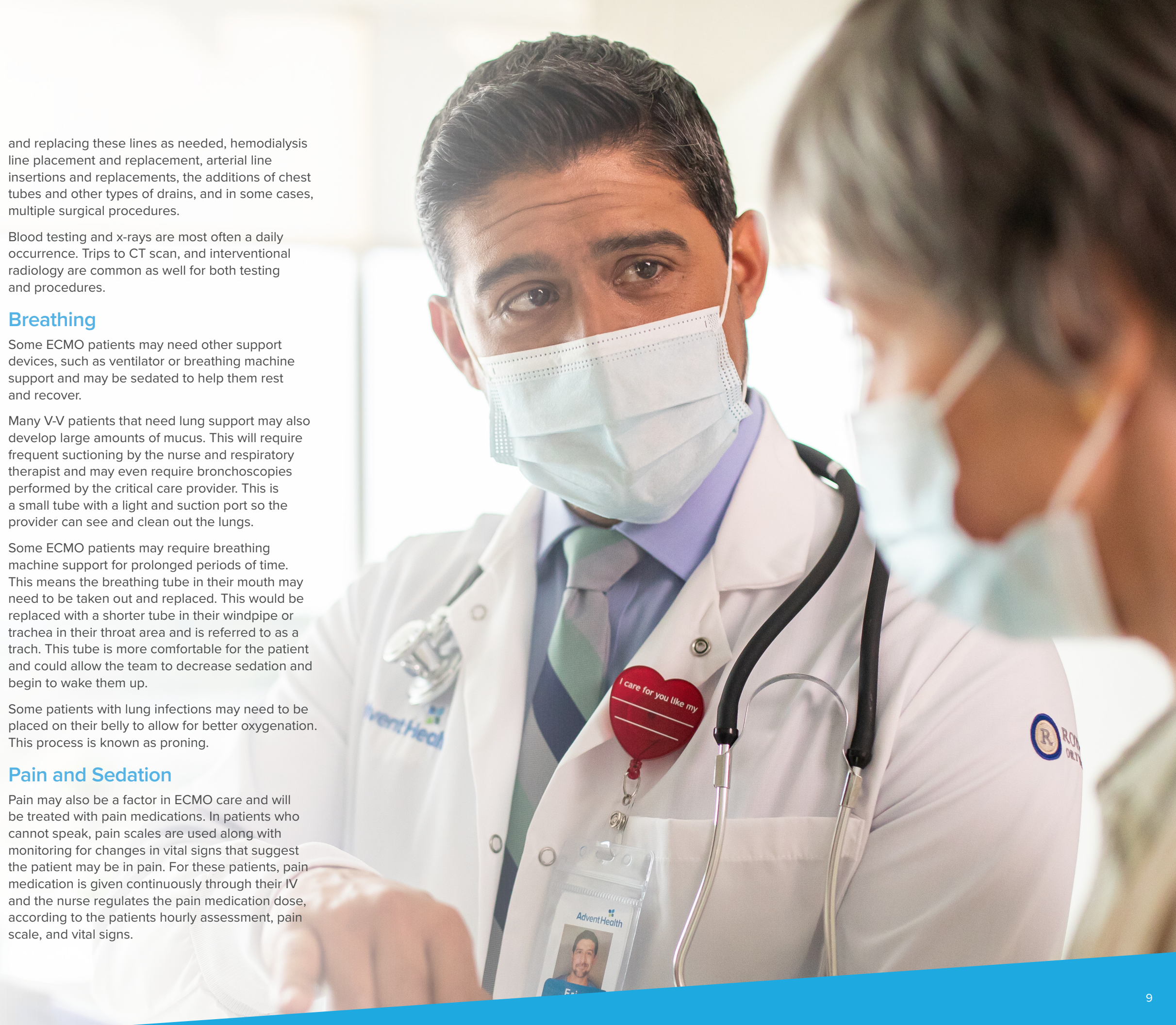
Many V-V patients that need lung support may also develop large amounts of mucus. This will require frequent suctioning by the nurse and respiratory therapist and may even require bronchoscopies performed by the critical care provider. This is a small tube with a light and suction port so the provider can see and clean out the lungs.

Some ECMO patients may require breathing machine support for prolonged periods of time. This means the breathing tube in their mouth may need to be taken out and replaced. This would be replaced with a shorter tube in their windpipe or trachea in their throat area and is referred to as a trach. This tube is more comfortable for the patient and could allow the team to decrease sedation and begin to wake them up.

Some patients with lung infections may need to be placed on their belly to allow for better oxygenation. This process is known as proning.

Pain and Sedation

Pain may also be a factor in ECMO care and will be treated with pain medications. In patients who cannot speak, pain scales are used along with monitoring for changes in vital signs that suggest the patient may be in pain. For these patients, pain medication is given continuously through their IV and the nurse regulates the pain medication dose, according to the patients hourly assessment, pain scale, and vital signs.



For those ECMO patients on the ventilator, sedation is most often given to make sure they remain calm and comfortable. This medication, like pain medication, is given constantly through the IV. Sedation is adjusted by the nurse, according to the patient's sedation scale, vital signs, and hourly assessments that may suggest the patient is uncomfortable.

In some cases, ECMO patients may need extra doses of pain and sedation medication for unexpected discomfort or pain. These medications are available and administered by the nurse on an as-needed basis based on pain and sedation scales, hourly assessment findings, and vital signs. However, these medications are only given if it is safe for the patient at that time.

Patients who cannot move themselves are also turned and positioned for comfort every two hours and as needed. This aids in comfort and pain control and prevents skin breakdown.

Nurses may also use heat or cold packs for localized pain and discomfort. Your nurse will always be happy to answer any questions you have about pain and comfort.

Spontaneous Awake Trial (SAT) & Spontaneous Breathing Trial (SBT)

To make sure the sedated ECMO patient's brain is functioning properly, their sedation and pain must be reduced and sometimes turned off for a short period of time. This can allow a nurse to perform a neuro assessment. It's a spontaneous awake trial or SAT and may be very disturbing for family members to see and a little uncomfortable for the patient. However, it's necessary to make sure the patient can follow commands and wake up. It allows the team to identify any brain injury early enough to be treated. If the patient is not ready to come off the ventilator, they will be immediately placed back on their pain and sedation medication, and it will be adjusted by the nurse until the patient is comfortable.

If the ECMO patient is ready to come off the ventilator or is calm and comfortable, their pain and sedation medication will remain at a low rate or even off. In this case, the respiratory therapist will turn the vent down and assess for regular breathing. This is a spontaneous breathing trial or SBT. If the patient is ready, they will come off the ventilator. If not, the ventilator will be adjusted to a lower rate as the patient can tolerate. You may hear this referred to as ventilator weaning.

The SAT and SBT allow the team to wean sedation, pain medication, and the ventilator safely. We know this process can be hard for our families to watch, but remember, we are here to support you and your loved one and will always make sure we safely address their pain and discomfort.

Rehabilitation

If the ECMO patient is stable when awake, walking and physical therapy will be a part of their daily routine. This may include walking many times a day with the ECMO Team, and/or exercises throughout the day. These exercises are taught to the patient and family by the physical and/or occupational therapist and will help the patient get back to the routine of taking care of themselves and rebuilding their strength.

Sometimes, rehabilitation may seem very hard but please remember this is a very important part of the ECMO patient's recovery. Those who participate in rehabilitation experience faster recoveries and fewer complications.

Blood Thinners and Other Medications

Clots are part of the body's natural reaction to anything that is not supposed to be in the body, such as ECMO cannulas. Because of this many ECMO patients require anticoagulation or blood thinning medications to prevent clots from forming. ECMO patients on these medications are at risk of bleeding and may need blood transfusions. Receiving blood transfusions on ECMO can be a common occurrence.

Patients who are on ECMO are on this support because they are extremely sick. Many of these patients have dangerously low blood pressures, abnormal heart beats, and infections. It is common for many ECMO patients to be on constant IV medications to keep their blood pressure up, help their heart beat regularly, and/or on antibiotics/antifungals for infection.

Feeding

The ECMO patient will need nutrition and if they are unable to eat on their own, they may have a feeding tube placed in their mouth, nose, or stomach to allow for feeding. In some instances, they may need nutrition through their IV if stomach feeding cannot be done. Nutrition is important to healing and feeding is discussed each day in rounds.

Notes: Questions and answers about what to expect.

When it is Time to Come Off of ECMO

If the patient's lungs have recovered enough, the ECMO team will begin to wean ECMO support for V-V ECMO patients. This means turning down the gas called sweep that adds oxygen and removes carbon dioxide. Once the sweep has been off for a certain period of time, the patient will then have their tubes removed at the bedside by a physician or PA.

To wean a V-A ECMO patient, the flow or speed is turned down as the patient's vital signs tolerate. Once a low speed, determined by the doctor, is reached, an echocardiogram (ECHO) is performed while the ECMO machine is turned down. This will inform the team that the heart has recovered or that more time on ECMO may be needed. The V-A ECMO patient will go to OR for their tubes to be removed when they are ready to come off of ECMO support. This is done in OR so the artery can be repaired.

ECMO is a support therapy not a cure, and patients who are placed on ECMO are very sick. Even with high quality care, ECMO patients are at high risk for complications. Despite our best efforts some ECMO patient's heart and/or lungs will not recover, and some of these patients will not qualify for a heart and/or lung transplant.

If after a period of time that is discussed at the time of ECMO consent, the patient shows no sign of lung and/or heart recovery, has gotten worse, or does not qualify for transplant the team may discuss discontinuation of ECMO support.

ECMO Risk and Complications

Blood Clots and Bleeding

Some risks associated with ECMO are bleeding, blood clots, infection, stroke, ECMO machine failure, air embolism, loss of blood flow to the cannulated limb, and accidental decannulation.

As discussed earlier, many ECMO patients require the use of blood thinning medications and are at risk of bleeding. Should this occur, the cause of bleeding is addressed, and blood is given.

Sometimes, these patients could develop bleeding in the gastrointestinal system (stomach or intestines), in the abdominal space, in the chest space, or in their brain, which could require interventional procedures or even surgery. Remember, multiple procedures and tests while on ECMO is common.

The ECMO tubing is a foreign object and as such, the patient will have an inflammatory response. Most of the symptoms associated with this response, such as low blood pressure, edema, and respiratory problems, subside on their own within the first 48 hours and can be treated with medications. However, clotting is also part of this response and does not subside on its own. This is managed with the speed of the pump to prevent blood from pooling and, for some, blood thinning medications, but clots do still occur while on ECMO.

Blood clots can form in ECMO tubing or in the ECMO oxygenator which will disrupt or even stop ECMO flow. The ECMO team is trained to quickly change the patient over to a new ECMO system, but some patients may not tolerate even short periods of time off ECMO. Patients who are this sick may code during this time. Blood clots can also form in the lungs and heart of very sick patients. This will be addressed with medications when possible but could require additional surgeries. Blood clots can also travel to the brain in ECMO patients and cause a stroke.

Infection

All ECMO patients are at risk of infection. These patients are very sick and often have multiple tubes, lines, and drains in addition to the ECMO tubes. They also may require medications that could alter their immune system. For all these reasons, many ECMO patients may develop secondary infections or even sepsis (widespread infection). They will be treated with antibiotics should infections occur, but this does not always guarantee a cure from infection.

Problems with the ECMO Machine or Circuit

Like all machinery, an ECMO machine can fail despite frequent preventive maintenance and testing. The ECMO tubing and oxygenator are also

at risk for cracks and breaks. While the ECMO team is trained to address these issues quickly, many of these patients may not tolerate time off ECMO support and could code and, in some cases, pass away.

The ECMO circuit is a closed system, meaning there is no air in the system. However, air can sometimes become trapped in the ECMO circuit. This can happen if the circuit is accidentally opened, when cannulas are removed, if a cannula becomes dislodged, if the tubing is accidentally punctured or cut, or if air is introduced by another pump system such as with CRRT or hemodialysis. The ECMO team can remove air from the system but in some instances, there is too much air, and this could result in the need to change the system. The patient would be off support during this time which could result in a code and in some cases death.

In rare instances, if air is trapped in the ECMO circuit of a V-A ECMO patient, it could be pushed into the patient's brain which could result in a stroke or death.

Depending on where the ECMO patients cannula is placed, there could be loss of blood flow to the cannulated limb, which could result in compartment syndrome (muscle swelling). This will require an emergency procedure called a fasciotomy (cutting the limb and the affected muscle open to give it room to swell). Loss of blood flow could cause limb ischemia (loss of oxygen to the limb) and could result in loss of the limb.

Even though it is rare, accidental decannulations can occur. If this happens, the patient will be off support until a new cannula can be placed by the surgical team. Loss of support for some of these patients could result in death.

There are many safety measures and protocols in place to help reduce the risks and complications that could occur for the ECMO patient. However, this does not mean they will not happen. In some cases, complications are unavoidable, even with constant monitoring and care.



What Happens After ECMO?

Some ECMO patients will recover fully, but many may develop chronic complications after ECMO that are related to either the ECMO therapy itself or their illness.

Depending on where their cannulas were placed, some patients may suffer from pain in their limbs called neuropathy, which will be treated with medications.

Some patients may require long ECMO runs, which could result in deconditioning which will require extensive rehabilitation, sometimes in a rehabilitation center.

Some V-V ECMO patients may recover enough to be removed from ECMO support but require long term ventilator support or oxygen at home.

V-A ECMO patients may develop enough heart recovery to come off of ECMO support but may need to go home on IV medications called inotropes to help their heartbeat. They may need to go home with the support of a Ventricular Assist Devices or VAD to pump their blood for them.

What happens after ECMO often depends on the illness and complications that may have occurred during the patient's hospital course.



Notes: Questions and answers about risk and complications.

The Family's Role

The ECMO patient's loved ones play a vital role in their care, the encouragement, comfort, and support of family and friends decreases depression and anxiety, fear, and even discomfort all factors that are important to recovery. You can hold your loved ones hand, massage their hands and feet, and even help the nursing staff with daily living care such as bathing.

You will see many people during rounds, all a part of the ECMO team. They will discuss the patient's care plan each day. You are encouraged to participate in these rounds. You will also be asked at times to meet with some of the ECMO team to discuss the patient's care plan and condition, or for consent for procedures or surgeries.

Surrounding the ECMO patient with things that are familiar to them is important as well. You can bring in your loved one's favorite music, movies, books, or games. Bring in things like their favorite pillows, bedspreads, and pictures.

It is also very important that you take care of yourself!! Make sure you get plenty of rest, good nutrition, and get away from the hospital for periods of time for mental and physical recovery. There will be a time when your loved one needs you, and if you have burned yourself out you will not be able to be there for them.

Notes: Questions and answers about what you can do to help.





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