



Critical Care Unit (CCU)

Extra-Corporeal Membrane Oxygenation (ECMO)

Information for parents and carers

Introduction

This leaflet aims to provide you with information about a machine called ECMO, what it is, how it works and what will happen. We are happy to discuss any aspect of the care of your child whilst on Critical Care Unit (CCU).

What is ECMO?

ECMO stands for Extra-Corporeal Membrane Oxygenation.

Extra Corporeal means outside the body.

Membrane oxygenation refers to the piece of equipment used to deliver oxygen to the blood.

ECMO is very similar to the heart and lung bypass machine used in a theatre during open-heart surgery. It will provide blood with enough oxygen to support the body's organs until the heart and/or lungs begin to work on their own.



What is ECMO used for?

When a child is very sick ECMO may be used when other less invasive therapies have failed. Some children who may benefit from ECMO are:

- children who have severe lung disease and not responding to ventilation, medicines and extra oxygen
or
- children with severe heart failure before or after surgery.

ECMO will only be offered to children that have a condition that is reversible. The doctors will discuss the reason why your child needs ECMO support.

It is important to understand ECMO is not a cure, but will give the heart and/or lungs time to recover.

Types of ECMO

VA ECMO – (Veno-Arterial)

A cannula is placed into both an artery and a vein, providing support for both the heart and lungs.

VV ECMO – (Veno-Venous)

A single cannula is placed into the vein, providing support for the lungs only. Some children may need to be changed over to VA ECMO if their heart is not pumping well.

A short operation on CCU is needed to insert a cannula. Your child will have an anaesthetic during this procedure so they will not feel pain.

How does ECMO work?

ECMO works by taking blood with little oxygen from the heart through a cannula placed in a vein. This blood is pumped through an oxygenator which acts as an artificial lung. The blood now containing oxygen is then pumped back into the body and this is a continuous cycle.

What will happen when my child is on ECMO?

Your child will remain on a ventilator, but at lower settings than before. We will give your child pain killers and sedation so that they are comfortable and pain free. We will constantly be assessing and reviewing how much sedation and pain relief your child needs.

Doctors will examine your child to assess their progress every day. They may not be able to discuss the care with you there and then, but Intensive Care Consultants or Cardiac Surgical Consultants will update you.

Scans

Doctors may also perform scans of the heart called an ECHO. This is to assess how well the heart is pumping. Scans may have to be compared so you might not be able to receive an immediate update.

Other scans to assess neurological function (brain) may be performed, such as head ultrasound and EEG.

We will always keep you informed with the reasons for a scan and the results.



Feeding

Your child will be fed via a nasogastric tube. If they are not absorbing feeds, they will be given nutrition called TPN through a vein.

If you are breastfeeding we will encourage you to express milk so we can store it to use later. Your bedside nurse can give you further information about this. A Dietician will be involved in your child's care to ensure they are getting enough calories for their needs.

How long will my child be on ECMO?

This varies as ECMO support can depend on their original diagnosis and why ECMO support is needed. For most children it is needed for three to seven days, but can be for longer. Each child condition is different. Some of the differences could be the type of lung, heart disease or if there was any damage to either organ before starting ECMO.

Sometimes it becomes clear that a child's heart and/or lungs will not get better and ECMO is not helping. If this is the case it will be fully discussed with you at the time.

How will you know if my child is ready to come off ECMO?

After careful evaluation by the Medical Team it may be decided to reduce the amount of ECMO support and allow the heart and lungs to take over. This can be a slow process that can take many hours. During this time ventilation will be increased and medicines may be required to help the heart to pump.

Once ECMO is giving minimal support and a child remains stable we start a 'Trial-off' period. This involves clamping the circuit. It is when the circuit tubes are clamped to stop the ECMO, so that the machine no longer does the work of the heart or lungs, the child's body has to take over the work. If a child remains stable, the cannula will be removed in a short operation.

What happens after my child is taken off ECMO?

They will still need intensive care support, and may appear to be sicker because their heart and lungs have to work without ECMO support. You will be kept fully updated by the doctors and the bedside nurse.

What are the risks?

There are benefits and risks related to ECMO and it is a balance between the two that has to be considered. A child that needs ECMO is very ill, and without it would normally die.

- **Bleeding.** This is a common risk. We have to prevent clots from forming in the Circuit and therefore have to thin a child's blood with a drug called Heparin. This can cause a child to bleed in other places such as cannula sites, wound sites, the gastrointestinal tract, lungs and sometimes the brain.
- **Brain damage.** This can be caused by bleeding in the brain because of blood thinning and can be a problem in new born babies who are already at risk. Many brain problems are however due to how sick a child has been before ECMO. We will regularly assess your child's brain function with examination, and possibly head ultrasound scans.
- **Infection.** This can occur because of any invasive procedures. We routinely screen for infection in the Circuit. Your child will be monitored closely, and antibiotics will be given if required.
- **ECMO Circuit failure.** The ECMO Circuit is always checked thoroughly, however problems can occur. These problems include air bubbles, blood clots, ruptures and failure of electrical equipment. Every safety measure is taken to prevent these and the ECMO Nurse Specialist is highly trained to closely monitor the Circuit constantly and take immediate action.
- **Blood Reactions.** Whilst on ECMO your child will require frequent blood product transfusions this can lead to the risk of having a reaction or gaining an infection, though the risks are very low. You will be given an information leaflet which will give you more information.
- **Excessive Fluid Retention.** Your child may look very puffy we call this 'Oedema'. Fluid can settle into the tissues, this is temporary whilst on ECMO but may cause difficulty when we want to try to stop ECMO support. We can use a combination of medicines to try and remove the excess fluid or use an artificial kidney (CVVH) to remove fluids quickly.

How you can help

You play an important part in your child's care. We encourage you to visit your child whilst they need ECMO support. There are things you can do to help, please talk to your bedside nurse or ECMO Nurse Specialist to see how you can be involved.

This may be:-

- Touch your child, hold their hand and talk to them, read stories. Hearing your voice and a reassuring touch will help comfort them.
- Help with nappy changes and washes. Keeping their eyes clean and moistening their mouth.
- Encourage siblings to draw pictures that are placed by the bedside. This can help brothers and sisters feel part of the care.
- Keep a diary of their progress, we are happy for you to take photographs of your child.

Help us to prevent infection

- No toys should be kept by the bedside as this will increase the risk of infection.
- Keep visitors to a minimum, your child is very sick and may be prone to infection.



Taking care of yourself

It is important to remember to look after yourself. You need to make sure you eat regularly take enough fluids and get some rest. This is especially important if you are expressing breastmilk.

Don't feel guilty if you cannot spend every moment at the bedside because of other family commitments or if you are exhausted.

Your child will receive the upmost care from the dedicated team in CCU. If you need any help with any personal issues please ask. We can help you, if not directly, but by directing you to the appropriate people. Part of our job is caring for you too.

The ECMO TEAM

There are many people involved in the care of your child whilst they receive ECMO support. There will be two nurses looking after your child at any one time. They will be at your child's bedside at all times.

The ECMO Nurse Specialist	Will monitor your child and the ECMO equipment.
The Intensive Care nurse	Will look after your child's general needs.
ECMO Co-ordinator and Perfusionists	Support and oversee the ECMO Specialists
Cardiothoracic Surgeon	Will perform the operations to insert and remove the ECMO cannulas
Intensivist	The Doctor who is responsible for the whole CCU. They lead the team who will be responsible for your child's care
Registrar/Fellow	Doctors who monitor day to day care and work closely with the Intensivists, Cardiothoracic Surgeon and ECMO Nurse Specialists

Other specialities that may be involved

Cardiology Team	To perform ECHO's and ECG
Nutrition & Dietetics	Will monitor nutrition
Pharmacy	Checking medicines everyday
Respiratory Physiotherapy	Ensuring that lungs remain clear
Radiology	Taking x-rays and ultrasound scans
Renal Team	If your child requires PD/ CVVH
Haematology	Providing blood and blood products

Glossary

CVVH	Continuous Veno-Venous Haemofiltration – a therapy performed by an artificial kidney machine
Cannula	The plastic tubes by which blood is taken and returned to the body
ECHO	Short for Echocardiogram. This is a scan of the heart (like a pregnancy scan) to see how well the heart is working
ECMO	Extracorporeal Membrane Oxygenation
EEG	Electroencephalogram. This measures the electrical activity in the brain and can help detect fits/seizures
Head Ultrasound	A scan (like a pregnancy scan) of the brain to look for bleeds.
Nasogastric tube	A feeding tube which passes through the nose to the stomach to allow us to feed your child
Peritoneal Dialysis	A therapy performed to replace the work of the kidneys
Total Parenteral Nutrition	Nutrition delivered through a vein when the child is unable to absorb feeds into their stomach
Ventilator	A breathing machine that supports the lungs and takes over the work of breathing

This leaflet only gives general information. You must always discuss the individual treatment of your child with the appropriate member of staff. Do not rely on this leaflet alone for information about your child's treatment.

This information can be made available in other languages and formats if requested.

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