

When your child needs to be put on a life support machine (ECMO)

East Midlands Congenital Heart Centre

Information for Parents & Carers

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Introduction

This leaflet contains information about ECMO for you to keep. It is not to replace any discussions you have with the doctors and nurses looking after your child. Please feel free to ask questions at any time and the staff from your current hospital or the East Midlands Congenital Heart Centre (EMCHC) at Leicester Royal Infirmary will be happy to answer or repeat any of the information.

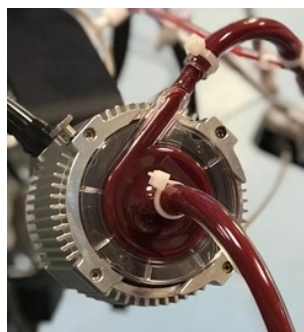
What is ECMO?

ECMO stands for Extra-Corporeal Membrane Oxygenation. It is a supportive measure that uses an artificial lung (the membrane) to put oxygen into the blood outside the body (extracorporeal). This takes over the function of the heart and/ or lungs, giving these vital organs time to rest and allowing the underlying illness or injury to recover. The ECMO machine is very similar to the heart-lung machines used to keep patients alive during open heart surgery.

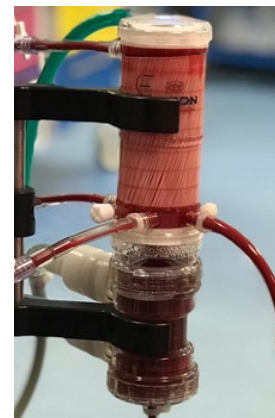
Levitronix CentriMag ECMO circuit



Pump head



Oxygenator



**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

Visit www.leicestershospitals.nhs.uk for maps and information about visiting Leicester's Hospitals
To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk

Why ECMO?

ECMO for infants and children has been used at Leicester's hospitals for 32 years ([https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(96\)04100-1/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(96)04100-1/fulltext)). We are one of the world's busiest ECMO centres and the only centre in the UK that provides ECMO for adults, infants and children. In the UK there are 5 other centres that provide ECMO for children. ECMO is used as a treatment for infants and children who are critically ill due to life threatening lung disease with a reversible cause. It is only used when other intensive care treatments are not working.

There are many conditions that may benefit from the use of ECMO. The 4 most common reasons are:

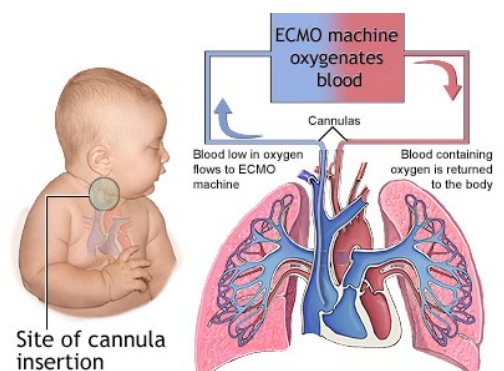
- **Meconium aspiration syndrome** - where babies have taken meconium into their lungs around the time of their birth (meconium is a dark green substance sometimes known as the baby's first poo).
- **Newborn sepsis** - when newborn babies have a severe infection in their blood.
- **Persistent pulmonary hypertension of the newborn (PPHN)** - where the lung vessels in newborn babies are not open wide enough. Oxygen and the flow of blood into the lungs is severely reduced, meaning the body does not have enough oxygen.
- **Congenital diaphragmatic hernia** - a birth defect which occurs when the diaphragm muscle (the muscle that separates the chest from the abdomen) does not close before the baby is born. The contents of the abdomen e.g. stomach, bowel and liver move into the chest through this hole and the lungs do not grow properly.

We believe ECMO can significantly improve your child's chance of survival. The average length of stay on ECMO is around 8 days, but this can be longer or shorter.

Once your child has been accepted by the ECMO team they will need to be transported to the Cardiac Paediatric Intensive Care Unit (cPICU) located within the EMCHC at Leicester Royal Infirmary by our dedicated ECMO transport team. The transport team consists of an ECMO doctor, ECMO nurse specialist and a perfusionist. The ECMO transport team specialises in moving very ill patients from other hospitals to ECMO centres. This may mean travelling by ambulance, helicopter or fixed wing aircraft. The type of transport depends on how stable your child is and how far they need to travel. **You should not try to follow the ambulance as this can be very dangerous.** While travelling, we can monitor your child in a similar way to when they are in intensive care.

What will happen next?

In order for your child to receive ECMO they will need a small operation to be carried out on the intensive care unit. The ECMO doctor will need to insert 1 or 2 tubes called cannulas into your child's neck and possibly their groin. These allow the blood to be diverted into the ECMO machine where oxygen is added to the blood and carbon dioxide is removed before being pumped back into the body via the tubes. Whilst receiving ECMO support, children usually stay on the ventilator (breathing machine) at gentle settings to protect the lungs.



<https://medlineplus.gov/ency/>

What will happen when the transport team arrives?

Firstly, the ECMO doctor and nurse will receive a handover of all the important information about your child from the team looking after them. They will then carefully assess your child to decide the best and safest way to transport them to Leicester Royal Infirmary. This could be either on a normal ventilator or by mobile ECMO. The doctor will want to talk to you to explain about ECMO; focusing on both the risks and benefits and to request permission from the child's legal guardian for the ECMO treatment.

What is the main risk associated with ECMO?

The main risk during ECMO treatment is bleeding. This is because a blood thinning drug called heparin must be given to prevent the blood clotting in the ECMO machine. Although it is rare, the most serious risk is bleeding in the brain which can be life threatening. We monitor your child carefully with head scans so that we can find any problems early and reduce this risk.

Can I stay with my child?

We can organise accommodation near to cPICU. While your child is at Leicester Royal Infirmary this room will be free of charge. If you need help with arrangements getting to Leicester Royal Infirmary, please ask the staff at your current hospital who can talk to the Duty ECMO Co-ordinator/transport team.

Parents or guardians of children in cPICU at Leicester Royal Infirmary can visit at any time. However, the unit will be closed to all visitors each morning between 8.00am to 8.30am for the business round. It will also be closed when there are any procedures being carried out or when children or babies are first admitted onto the unit. We aim to keep you fully informed at all times of any changes to your child's condition even when you are not visiting.

Your diary

With your consent, nursing staff will give you and your child a diary. This is so that you can record what happens whilst they are a patient with us. Nursing staff and other members of the team will write in this diary each day and add photographs with your permission. You can also write in the diary whenever you wish.

Other services

- The paediatric cardiac liaison nursing team and play specialists provide emotional and psychological support for children and parents, as well as development support for children.
- Midwifery services are available.
- A playroom is available on Ward 30 within the EMCHC for brothers, sisters and parents.

Contact details

Contact details for the East Midlands Congenital Heart Centre (EMCHC):

Duty ECMO Co-ordinator (via switchboard): 0300 303 1573

Cardiac Paediatric Intensive Care Unit (cPICU): 0116 258 3288 / 0116 258 3354

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغةٍ أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل

જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।

Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

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