

# Cardiac ECMO



Information for families

Great Ormond Street Hospital  
for Children NHS Trust

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This leaflet explains about Cardiac ECMO, why your child needs it and what to expect. This should be used in an addition to detailed and regular talks with the doctors and nurses caring for your child. The ECMO team are very happy to talk through the leaflet with you and discuss any points you may want to find out more about.

## What is ECMO?

ECMO stands for Extra-Corporeal Membrane Oxygenation. Extra-corporeal means 'outside the body' and membrane oxygenation is the way oxygen is delivered around the body.

The ECMO machine is similar to a heart-lung bypass machine using during open-heart surgery. It gives your child's body a chance to rest his or her heart and lungs for a short while.

ECMO was pioneered in the USA in the late 1980s and came to the UK a few years later. Great Ormond Street Hospital's ECMO programme began in 1992 and is currently one of four UK centres providing cardiac and respiratory ECMO support.

# How does it work?

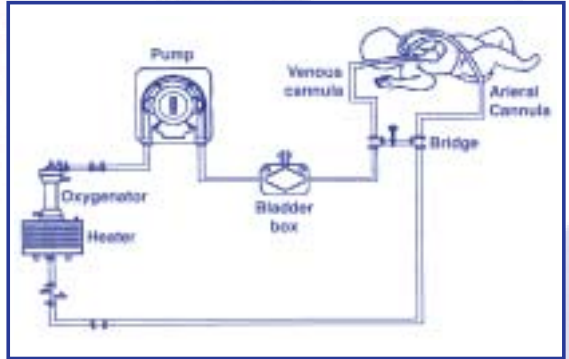
Venous-arterial (VA) ECMO is a type of ECMO which works by creating a circuit so the blood can circulate bypassing the heart and lungs. This allows them to rest and recover. To create this circuit, two large plastic tubes (cannulae) are needed – one is inserted into a vein and one into an artery. These cannulae are then connected to the ECMO machine, which creates the circuit.

If your child is going on ECMO after a heart operation, the surgeon will usually insert the cannulae during the operation. Otherwise, your child will need to have them inserted during a small operation, either on the unit or in the operating theatre.

Dark blood, which contains little oxygen, drains from the cannula in your child's vein. The ECMO machine contains a pump, which acts as an artificial heart, pushing the blood around the circuit. The blood then passes through the membrane oxygenator, which acts as an artificial lung, taking out carbon dioxide and adding oxygen. The blood is then warmed and returned to your child through the tube in his or her artery. This blood contains lots of oxygen, which makes it appear bright red.

This process is continuous for the whole time your child is on ECMO.

During the time your child is on ECMO, he or she will be cared for by a number of different people from



different specialities, all part of the ECMO team.

- The **ECMO specialist nurses** are responsible for the safe running of the ECMO circuit. They are trained and experienced in ECMO management and in your child's care. Your child will usually have two nurses caring for him or her on each shift – the ECMO specialist and another intensive care nurse.
- The **intensive care consultant** and **ECMO co-ordinator** will co-ordinate your child's care and will discuss plans and update you on a regular basis, giving you a chance to ask questions.
- The **ECMO Fellow** will manage the day-to-day changes and progress of your child.
- Other members of the team who will help care for your child include:
  - Cardiac surgeons
  - Cardiologists
  - Perfusionists
  - Physiotherapists
  - Theatre nurses
  - Pharmacists
  - Psychologist
  - Dieticians
  - Cardiac liaison nurses
  - Radiologist
  - Priest or chaplain.

For more information about these members of the team, please see our booklet *Welcome to the cardiac wing: Information for families*.

Cardiac ECMO provides support for babies or children with severe heart failure. The aim is to rest the child's heart so it is not under any stress and can have time to recover. However, ECMO can only support the heart, it cannot cure the reason for heart failure. Heart failure can happen for various reasons, but the two main ones are:

- if a child has poor function after open-heart surgery – this can happen when a child has a swollen heart, problems with heart rhythms (heart beat) or cannot achieve a high enough blood pressure to pump blood around the body
- if a child has heart failure due to an infection (myocarditis) or muscle failure (myopathy) – the heart muscle cannot work efficiently enough to pump blood around the body.

Before your child is given ECMO, the team will discuss this fully with you. They will explain the reasons why your child needs ECMO and whether it would be suitable. If you have any questions, please ask the team.

# Are there any risks?

ECMO is only used for very ill children who would die without ECMO support. There are risks associated with ECMO support, which are briefly outlined below and will be explained to you in more detail by the ECMO team. Not every child on ECMO will experience these complications, but they are always a possibility.

- **Bleeding** – As the blood travels around the circuit, there is a risk of clots forming as the blood is outside the body and in contact with the plastic of the circuit. It is important the circuit does not form lots of clots and so we use a blood-thinning drug called heparin to prevent this clot formation. However, the thinned blood can cause bleeding problems. We will try to keep your child as clean as possible – we know this can be distressing but sometimes, it is better not to disturb any bleeding as removing any surface clots may cause more bleeding.

The bleeding can occur around any site where your child has had any kind of wound or where a tube was inserted. It can also occur around the nose and mouth. For cardiac ECMO, your child may have the cannula in his or her neck, leg or inserted in the chest. If your child has a chest cannula, we will be able to monitor any bleeding using chest drains, which prevent blood and fluid building up in the chest.

To prevent excessive bleeding, we check the levels of blood clotting products in your child's blood regularly and top them up if necessary. Your child will need blood transfusions as well.

If bleeding occurs, your child may need a surgical exploration of his or her chest by the cardiac surgeon. This takes place on the unit at any time of day or night and may be needed every day or two. Your child will have a general anaesthetic during the procedure, so he or she will not feel any pain or discomfort. We will tell you about any chest explorations your child needs, but we will ask you to leave the unit while it is carried out. We will let you know when it is finished and you can visit your child again – the exploration usually takes two hours or so.

- **Infection** – There is a risk of infection with any invasive procedure, especially when tubes are inserted into blood vessels, as they give a direct route into the blood stream. We will monitor your child closely for any signs of infection and give antibiotics if needed. If your child has a chest exploration, we will give antibiotics just in case, to reduce the risk of infection through the open wound.
- **Neurological (involving the brain) problems** – When the blood in the body is thinned, bleeding into the head may occur. Newborn babies are already at risk from this, and the risk increases with ECMO due to the blood-thinning medications being given. Sometimes brain problems can happen due to your child's condition before going on ECMO, rather than the ECMO itself. While your child is on ECMO, we will carry out regular checks and scans, like ultrasound scans of the head and EEGs. The ultrasound scans can show up areas of bleeding in the brain and EEGs (electroencephalograms) measure your child's brain waves. These checks and scans do not hurt your child and are vital in monitoring any changes that occur.
- **ECMO circuit complications** – The circuit is monitored continually and checked on a regular basis for clots and other signs of problems. However, problems can still occur. The ECMO team are trained to deal with these situations and can often anticipate problems which they can then prevent. However, sometimes we may need to take your child off ECMO so we can safely deal with the problem. We will give your child full life support during this time to keep them in a stable condition. Once the problem has resolved, we will put your child back on ECMO as soon as possible.



# What to expect

When you first see your child on ECMO it can come as a shock, even if you have seen other children on ECMO on the unit or in photographs. There may be bleeding around the cannula sites and your child may look pale and blotchy. If your child has had a heart operation, the chest may be left open to allow the cannulae to be inserted, but the area will be covered in a dressing and gauze.

Children can feel quite cold on ECMO, especially their hands and feet. If he or she has had heart surgery, this tends to be because children are cooled while on the bypass machine in theatre and can take a while to warm up. Sometimes, this is due to the child's underlying condition rather than an operation. We will warm your child up gradually using overhead heaters and special blankets, and once he or she is stable on ECMO, your child's colour and temperature should improve.

Children on ECMO can also appear quite swollen and puffy especially around the face, hands and feet. This can happen after a heart operation but can also occur if he or she has been given a lot of intravenous fluids. We will give your child medications to reduce the fluid by passing urine, which should reduce the swelling gradually. When the heart is not working well, the kidneys can sometimes also be affected. If it becomes necessary to support the kidneys, an artificial kidney machine can easily be inserted into the ECMO circuit. Generally, as the heart recovers, the kidneys also recover.

Your child will be on a ventilator as well, which gives breaths to the lungs but also keeps them open using a small amount of pressure. The ECMO will give your child's lungs oxygen, but they will still need ventilation to prevent them collapsing. Once your child is off ECMO, he or she will still need ventilation for a time.



# Day to day care of your child

- **Feeding** – Your child may not be able to absorb feeds for a while. This can happen because everything works a little slower when a child is ill. We can give your child nutrition through a drip if he or she is not having any milk. If your child is able to absorb some milk, we can give this through a naso-gastric tube (a tube which passes through the nose, down the oesophagus into the stomach). If you are breastfeeding, you can express the milk, which can be given via the naso-gastric tube. For more information about breastfeeding, please see *Breastfeeding and expressing milk: information for families*.
- **Pain** – It is very important to us that your child is comfortable and not in pain. We recognise this will be a serious concern to you. We give continuous painkillers, and extra pain relief and sedation if any procedures are needed. We constantly assess your child for pain and can give other sedatives and pain relief through the naso-gastric tube or as suppositories. Sometimes, we need to give your child muscle relaxant so he or she does not move, but as long as a child is comfortable and safe we let them move about on the bed. Often the days are busy with investigations, but it is important your child has a rest and is not touched for periods of time.
- **Family involvement** – You and your family play an important part in your child's recovery and we are here to support you. While your child is on ECMO, you can help by reassuring him or her with your touch and voice. You may want to bring in your child's favourite toy or music or read out a story. We encourage you to talk to, stroke and kiss your child when you are visiting. You can also help with washing, keeping your child's eyes moist and nappy changing. This can be daunting, especially while your child is connected to various tubes and monitors, but it will become easier with time. Other members of your family including your other children are welcome to help too. If you are worried about caring for your child, please talk to the nurses. Please do not feel you have to be at your child's bedside all the time – you need to take care of yourself too. We will always contact you if there is any change at all in your child's condition.



- **Physiotherapy** – Physiotherapy is very important even while your child is on ECMO. It keeps your child's lungs in the best condition possible, ready for when he or she comes off ECMO. The physiotherapist will visit everyday to assess and treat your child while on ECMO. The treatment will involve various techniques to help move secretions so that they can be suctioned from the breathing tube. We can give your child some extra sedation if he or she is not comfortable with the physiotherapy, but it helps if your child can still cough, as this will shift the secretions more easily.



The ECMO team will give you regular updates on your child's condition and explain the plan for each day. We will explain the results of any tests or investigations, and encourage you to ask any questions you want. Usually, the ECMO nurse at your child's bedside will be your first port-of-call for any questions, but you can also ask the ECMO Fellow or any other member of the team. We will also arrange regular meetings with the ECMO team, away from the unit, so we can all talk without any distractions.

Most parents find it helps to write down any questions, as they occur, as it is easy to forget things when you are taking in lots of information. Some parents have found keeping a daily diary can help too, for notes of what has been discussed and questions to ask. It can also help if you are keeping other family members updated on your child's condition. You will also need to inform the ECMO team which family members, if any, we can give information about your child's condition to.

Sometimes it helps to talk to someone who is not involved at the bedside and we can arrange for you to meet one of our cardiac liaison sisters. They can advise you about kinds of things such as getting time off work, or they can just listen. We also have a unit psychologist who can support you and your other children.

# Coming off ECMO

The length of time your child spends on ECMO depends on the reason it was needed in the first place. If your child needed the ECMO to rest his or her heart, the length of time on ECMO is usually about one to two weeks.

The regular monitoring and observations will show how much your child's heart has recovered. Also, as your child's condition improves, we may test the heart with a stress ECHO. This is an ultrasound scan of the heart, taken when the ECMO machine flow is turned down. This shows how the heart is working with only a small amount of ECMO support. As your child's heart may still need to rest, we will only do a stress ECHO around every 48 hours.

As we see improvement in your child's condition using the stress ECHO scan, we can reduce the ECMO flow and then try your child off ECMO (clamped off). We will increase the ventilation and also the amount of medications needed to support the heart. All through this process, we will closely watch your child and increase the ECMO flow if needed. Sometimes it can seem your child needs more time on ECMO after being clamped off – in which case, we will resume ECMO flow.

At all stages of your child's treatment, we will discuss the results of stress ECHOs and weaning from ECMO in detail with you.

If your child no longer needs ECMO support, the surgeons will remove the ECMO cannulae in a small operation on the unit. If the cannulae were inserted through the chest, the surgeon will leave your child's chest open (but covered in a dressing) until his or her condition improves.

## What next?

When your child is off ECMO, he or she will need to stay in hospital a while longer until ready to go back to your local hospital or to home.

Your child will remain under the care of the cardiologists at Great Ormond Street Hospital for follow up appointments, but your child will also see doctors at your local hospital.

The ECMO team will stay in touch with you when you leave Great Ormond Street Hospital, and can talk to your local hospital or GP if any questions about ECMO arise.

We know this will be stressful for you and your child, but it helps to get back into a normal routine in your normal environment as soon as possible.

## Glossary

We try to avoid using abbreviations but some creep into our language when we speak or write. We may also use medical words, which you have not heard before. The following list explains what they mean, but it's important to remember that this list contains meanings which apply to the heart and your child's treatment in the Cardiac Wing. Some words may have different meanings if used elsewhere in the hospital. If you don't understand anything, do please ask us to explain again.



# Glossary

ACT	Activated Clotting Time – a test that represents how long it takes for blood to form a clot
Antibiotic	A drug that slows the growth of or destroys bacteria or germs. Used to prevent or eliminate infection
Arterial blood gas (ABG) test	A small amount of blood that is drawn from an artery and tested to determine the amount of oxygen and carbon dioxide it contains
Arterial cannula	Tube into the artery that returns oxygenated blood to the patient
Bladder box	This is a safety device in the ECMO circuit that detects any changes in the flow of blood from the body
Bridge	Safety feature in each ECMO circuit
Cannula	A plastic tube used for the drainage and return of blood in the body
Cannulate	To insert a cannula into a part of the body such as vein or artery
Carotid artery	A larger artery in the neck carrying blood from the heart to the brain
Chest drain	A tube placed into the space between the lung and chest wall that evacuates air or fluid. Used to treat a collapsed lung (pneumothorax).
Clamped off	A trial period when your child is taken off ECMO before the cannulae are removed (de-cannulation)
Congenital diaphragmatic hernia	A disease where the diaphragm (the flat piece of tissue that separates the chest cavity from the abdomen) is missing on one side. This results in the contents of the abdomen, such as the stomach or intestine, moving into the chest and causing the underdevelopment of the lung on that side
Decannulate	To remove a cannula
De-oxygenated blood	Blood which has a very low oxygen level
Echocardiogram (ECHO)	Ultrasound scan of the heart
ECMO fellow	A doctor specialising in ECMO support and development
EEG	Electroencephalogram – Recording of the electrical activity of the brain
Head ultrasound	A ultrasound scan of the head. Ultrasound can be used to examine the structure of the inside of the body
Heparin	A drug used to prevent blood from clotting
Idling flow	Low ECMO flows for a period of time to ensure that the lungs are functioning well before stopping ECMO
Infection	An invasion of the body or part of the body by bacteria or virus

# Glossary

Intracranial haemorrhage	(ICH) An abnormal bleeding in the brain
Meconium	The first stool of the newborn infant. It is black and sticky
Meconium aspiration	Before or during birth, small particles of meconium become lodged in the lungs, causing a chemical reaction and preventing the lungs from working. Depending on the amount, this can cause mild to severe respiratory distress
Membrane pressures	These are pressures monitored either side of the oxygenator
Nasogastric tube	A tube that is passed into the stomach and used for feeding
Neuro	Relating to the brain
Oxygenator	Part of the ECMO circuit which removes carbon dioxide from the blood and supplies oxygen to the blood
Perfusionist	A person with specialised knowledge and training in cardio-pulmonary bypass (heart/lung machine)
Platelets	Blood cells which help prevent bleeding
Pulmonary hypertension of the newborn (PPHN)	In this disease high pressures in the blood vessels of the lungs make it difficult for the blood coming from the heart to enter the lungs. This results in the blood not receiving the proper amount of oxygen
Pump	This device circulates the blood through the circuit and returns it to the patient. Flow of the pump refers to the amount of blood being pumped through the circuit
Raceway	The section of tubing within the pump head
Respiratory distress	At birth or shortly after, the baby may encounter difficulty in breathing. This may be caused by immature lungs or foreign material in the lungs. The baby may need help with breathing by the use of a ventilator and/or oxygen
Surfactant	A soap-like substance normally found in the lungs of full-term babies, children and adults. The presence of this substance keeps the lungs from collapsing
Venous cannula	Tube into a vein that take blood from patient around the circuit
Ventilator	Breathing machine used to put oxygen into the lungs through a tube in the windpipe
Walking the raceway	Manually moving the tubing along so new tubing is present in the raceway
Weaning ECMO	blood flow will be decreased gradually as the lungs/heart improve.

## Support Group

A group for parents of children who have been on ECMO has been set up. If you would like to contact them, please ring the ECMO office on 020 7813 8180, or extension 8180 while you are in Great Ormond Street Hospital.

Website: [www.ich.ucl.ac.uk/ecmo/ecmo-gosh.html](http://www.ich.ucl.ac.uk/ecmo/ecmo-gosh.html)

Email: [gosh-ecmo@iname.com](mailto:gosh-ecmo@iname.com)



If you have any questions, while you are in hospital or when you return to your local hospital or home, please call the ECMO office on 020 7813 8180.





# Notes

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