



Children's Health Ireland
at Crumlin

ECMO/ECLS

Parents Information Leaflet





Parents/Guardians, we understand that discovering your child needs ECMO support is very distressing and frightening. We hope that this leaflet will be of some help to you in both answering your questions and addressing some of your concerns.

It does not replace the need to talk to staff caring for your child but we hope it will help you understand what is happening.

We are happy to discuss the contents with you in more detail.

Please feel free to ask (or re-ask) any questions.

What Is ECLS or ECMO?

ECMO stands for **Extra Corporeal Membrane Oxygenation**, you may also hear it as **ECLS** which stands for **Extra Corporeal Life Support**.

It is a treatment that uses a man-made heart and lung to support the body when a person's own heart and or lungs are too sick to do the job.

ECMO may support the body for a long period of time (days to weeks) to allow the heart and/or lungs time to rest.

Although ECMO itself will not cure your child, it gives him or her the time needed to heal.

ECMO may be an option only after the care team has tried all other treatments such as a breathing machine (called a ventilator) or medicines to support the heart and lungs, and/or special gases to relax the blood vessels between the heart and the lungs.

If your child is being treated with ECMO to support respiratory (lung) failure, ECMO may be initiated in CHI, Crumlin and your child may then be transported to another ECMO centre by air ambulance, accompanied by a specially trained ECMO team where they will be cared for until they no longer require ECMO.

The ECMO centres that CHI Crumlin refer respiratory ECMO patients to are:

- Great Ormond Street Hospital (GOSH), London, UK
- Freeman Hospital, Newcastle, UK
- Karolinska Hospital, Stockholm, Sweden

Once your child's heart and/or lungs have recovered enough to support the needs of their body, they will be taken off ECMO.

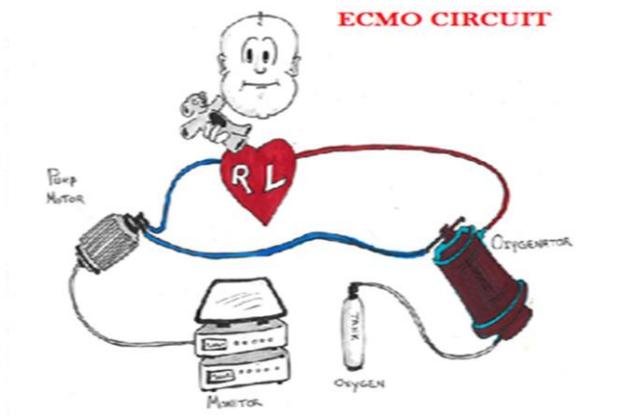
In some cases a child may not recover, in spite of all efforts being made. If the treatment does not lead to the recovery of your child, we will discuss this with you and then withdraw the ECMO treatment and provide comfort care for your child.

How does the ECMO Circuit work?

ECMO uses a pump to take over the work of the heart and an oxygenator (artificial lung) to take over the work of the lungs.

Firstly, two or more cannulas (large tubes placed in arteries and or veins) are placed in the patient's neck and/or groin(s) or chest (open heart). Based on your child's illness, the ECMO team will decide what type and the number of cannulas needed, and where they will be placed.

The cannulas are really large that allow the blood to be taken out of the body and pushed through the ECMO circuit (tubing). Once the blood leaves the body and enters the ECMO tubing, it is pumped through an oxygenator, or artificial "lung," where oxygen (good air) is added to the blood and carbon dioxide (bad/waste air) is removed. The treated blood is then warmed before returned to your child.





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This diagram shows a typical ECMO circuit with blue (without oxygen) blood becoming red (oxygenated) by the artificial lung outside the body. The pump helps to move the blood around

How is my child placed on ECMO? Is it painful?

Your child will have surgery to insert the cannulas. This procedure will be done under general anaesthesia, so your child will not feel pain or be aware of what is happening. Pain medication and medications to keep your child comfortable, will be given continuously when on ECMO.

What will my child look like on ECMO?

Your child will have ECMO cannula's inserted into their neck, groin or directly through their chest into their heart. As a parent, this can be very upsetting to look at. In some cases, there may be some small bleeding around the insertion sites. This is normal.

If it is a chest cannulation, your child's chest may be left open but will be covered by a clear dressing through which you might be able to see your child's heart beating. If you find this distressing, the nurse may be able to cover the area with a small dressing pad while you are visiting.

Your child will stay on a ventilator to keep the lungs inflated. They will be treated by the physiotherapists as needed.

Routine ICU monitoring and care will be part of your child's care, which includes Intravenous (IV) lines, feeding tube, urinary catheter, multiple leads/probes to monitor ECG, temperature, brain function etc. These are all necessary to allow close monitoring of your child's condition.

Your child may look swollen or "puffy" while on ECMO, the medical word for this is "oedema". Your child may get medications to help them urinate, called diuretics.

An artificial kidney called a haemofilter may also be put into the ECMO circuit, which will draw off fluid to help reduce swelling.

Who will take care of my child on ECMO?

You will meet a large team of professionals, who will all be working together to take care of your child. This will include Cardiothoracic Surgeons, Intensivists, Cardiologists and the Perfusion team who will look after your child on a day to day basis and make any treatment alterations that are necessary.

The Physiotherapist will also review your child on a daily basis for airway clearance and joint range of motion exercises.

The occupational therapist and dietician may also be involved in your child care.

Two nurses will take care of your child, one of them will be an ECLS specialist to look after the ECMO pump.

What does the daily care involve?

Routine ICU procedures are part of your child's care when on ECMO, such as suctioning, intravenous medications, nasogastric feeding etc.

Your child will be receiving blood thinning medication called Heparin, to prevent the blood from clotting.

Blood tests are done at least every hour to monitor how thin the blood is and circuit blood every 6 hourly to check the function of ECMO.

Blood products such as Red cells (blood), Plasma, Platelet are given as often as required.

A chest x-ray will be performed every day and more often if necessary. An ultrasound of the heart called an echocardiogram will be done as needed.

Babies less than 18 months may have a head ultrasound done daily or on alternative days.



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A computed tomography (CT) scan, electro-encephalogram (EEG), and Cardiac Cauterisation are other tests that may be needed.

What are the risks associated with ECMO?

A child who needs ECMO is very ill, and without it, would not survive. The benefits of ECMO are therefore greater than the risks, but it is a balance between the two.

Bleeding

We have to prevent blood clots from forming in the circuit and therefore have to thin your child's blood with a drug called heparin. This can cause bleeding problems elsewhere, for example around the cannula, surgical sites or other line sites. Bleeding is common while patients are on ECMO and it may be necessary (particularly after heart surgery) to undergo further surgical intervention to control bleeding.

Brain damage

This can be caused by bleeding into the brain because of the 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 the child has been before ECMO. Your child will be carefully monitored before, during and after their treatment for any signs of neurological problems. The monitoring includes a monitor that gives an indication of the oxygen saturation levels in the brain (stickers applied onto the forehead), regular cranial ultrasound scans and in some cases an EEG (electroencephalograms) or CT scan.

Infection

Can occur because there are lines and tubes in your child, which normally would not be there. We routinely screen for infection in your child and the circuit, and provide antibiotic cover if needed.

Renal

Renal failure is a complication of serious illness and can be supported by means of another machine added on to the ECMO circuit which acts as an artificial kidney until your child's own kidneys start working again.

ECMO circuit failure

Although the ECMO circuit is always checked thoroughly and safety measures are in place, problems can occur. These problems include air bubbles, blood clots, ruptures and failure of the circuit components and electrical equipment. ECMO bedside staff are specially trained to deal with any circuit problems or emergencies. Any concerns we have will be discussed with you.

What can I do for my child on ECMO?

Your child will be kept comfortable on ECMO, but hearing your voice, feeling your touch and knowing you are there can be comforting.

One of the best things you can do for your child is, taking care of yourself. While you may not feel like it getting plenty of fluids, nutrition and rest will help you get through this tough time.

Older children may like to be comforted by listening to music on their mobile device and you can advise nurses on their preferences.

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 a lot of information.

What supports are available for parents?

It may help to talk to someone who is not directly involved in your child's bedside care. We can arrange for you to meet up with your cardiac nurse specialist, social worker or psychologist.

You will be allocated a **CNSp** (Clinical Nurse Specialist), who will liaise between you and your cardiothoracic surgeon, cardiologist and/or medical consultant to give you support with information about your child's condition and treatment.

You will have a dedicated **social worker** who will assist you with emotional and practical support.

Psychological support is available to parents and family during this time of extreme worry and stress. The Psychologist provides an emotionally safe space to help support parents and family.

The psychologist actively works with families to optimize the family's stress management and coping during this time. The psychologist supports parents to continue to actively parent their child in the ICU and to integrate medical and nursing discussions during the ECMO treatment.

A **Chaplin** is available for spiritual support.

The **ECMO Coordinator** will be available to discuss any of your issues or concerns relating to ECMO and to support the specialist ECMO nurses caring for your child.

When will my child come off ECMO?

When the heart and / or lungs are assessed to be stable enough to perform their functions without the support of ECMO. At this time we may use extra ventilation and medication to support your child.

Blood tests, echocardiogram and other tests will be done to ensure your child is ready to come off ECMO.

Once it has been decided that your child is ready to be disconnected from the machine, the cardiothoracic team will perform the surgery to take out the cannulas.

What about aftercare?

All children who were on ECMO will be followed up in the short and long term by multidisciplinary team. One of the ECMO coordinators will meet with you prior to your discharge from ICU to discuss the follow up.

Follow up post ECMO

All children on ECLS are referred to the following Health and Social care professional (HSCP) discipline's post ECMO. Often developmental concerns arise as your child grows and may not be obvious initially.

The follow up team includes:-

- Audiology
- Neurology
- Physiotherapy
- Occupational Therapy
- Speech and Language Therapy
- Psychology
- Social Work
- Early Intervention Service

Audiology

Annual hearing assessment is recommended due to a reported risk of late onset progressive hearing loss in patients with a history of ECMO. Your Consultant will make a referral to the Audiology Department in CHI Crumlin where annual monitoring will be arranged.

Speech & Language Therapy (SLT)

Once your child has come off ECMO and is stable, he/she will be referred to the SLT department for assessment of their feeding and communication skills, as appropriate.

Once your child is discharged from hospital, your Speech & Language Therapist will refer him / her to local SLT services for ongoing monitoring of your child's feeding and communication development.

Your child will require assessments at age 1, 2, 3 and 5 years.



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Clinical Nutrition & Dietetics

While your child is on ECMO, nutrition can be provided intravenously or via a nasogastric tube into the stomach. When your child has come off ECMO he/she may continue to see a dietitian if there are issues in relation to feeding, weight gain or special dietary requirements.

Physiotherapy

All children requiring ECMO will be assessed and treated daily on the PICU for Respiratory Physiotherapy and limb range of movement. Your child will be referred to the Neurodevelopmental & Neurology Physiotherapist for rehabilitation and follow-up once off ECMO and medically stable.

Your child will then be referred to community services for follow up post discharge from hospital. Referral to community services post ECMO is essential for regular neurodevelopment and physical review and in line with the International Extracorporeal Life Support Organisation (ELSO) guidelines.

It is important that you attend all your physiotherapy follow-up appointments in the community with your child post discharge.

Psychology

The Cardiac Psychology Service for CHI Crumlin work as part of the cardiac team providing family centered care prior to surgery, in ICU postoperatively, during ECMO treatment and post discharge. Psychological support is offered to patients, parents and siblings who are actively receiving ECMO support in the PICU.

FREQUENTLY USED TERMS

Please ask if there are any terms you do not understand.

ACT - Activated Clotting Time- a test which represents how long it takes the blood to clot.

ABG- Arterial Blood Gas - a test which determines the amount of oxygen and carbon dioxide in the blood.

Cannula - A plastic tube used for the drainage and return of blood in the body.

Decannulate - to remove a cannula.

Heparin - A drug used to prevent blood from clotting.

Oxygenator - Artificial lung, helps to oxygenate and remove carbon dioxide.

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.

Contact

PICU 1: 01409 6650 / 6450

PICU 2: 01409 6463 / 6464

For more information

<https://www.else.org/Resources/WhatisECMO.aspx>

