

# ECMO – a parent and family guide

**This leaflet aims to provide you with some basic information about ECMO, and will hopefully answer some questions that you may have in helping to decide on ECMO for your child**

# Contents

<b>3</b>	<b>Introduction</b>
<b>3</b>	<b>What is ECMO?</b>
<b>4</b>	<b>Why might my child need ECMO?</b>
<b>4</b>	<b>Cardiac ECMO (VA ECMO)</b>
<b>5</b>	<b>Respiratory ECMO (VV ECMO)</b>
<b>5</b>	<b>Will my child benefit from ECMO?</b>
<b>5</b>	<b>What are the risks associated with ECMO?</b>
<b>7</b>	<b>Asking for your consent</b>
<b>8</b>	<b>What happens during ECMO?</b>
<b>9</b>	<b>How will my child be placed on ECMO?</b>
<b>9</b>	<b>What will my child look like on ECMO?</b>
<b>11</b>	<b>Who will be caring for my child on ECMO?</b>
<b>12</b>	<b>How long will ECMO be needed for?</b>
<b>12</b>	<b>What does the daily care on ECMO involve?</b>
<b>13</b>	<b>Will my child be fed on ECMO?</b>
<b>13</b>	<b>Will my child feel any pain?</b>
<b>13</b>	<b>Can I help with the care of my child while they are on ECMO?</b>
<b>14</b>	<b>Can I hold my child on ECMO?</b>
<b>14</b>	<b>Looking after yourselves and each other</b>
<b>15</b>	<b>How will we know if our child is getting better?</b>
<b>15</b>	<b>What aftercare will we receive?</b>
<b>16</b>	<b>frequently used terms</b>
<b>19</b>	<b>Contact details</b>

## Introduction

Discovering that your child needs ECMO support is very stressful and frightening. Trying to understand what is happening, and why, can be very confusing and worrying. We hope that this leaflet will provide you with some of the information that you need. It does not replace the need to talk to the staff caring for your child, but we hope it will help you to understand what is happening and you can keep it to refer to.

Any questions and concerns that you have can be discussed with the nurses and doctors caring for your child.

## What is ECMO?

ECMO stands for **E**xtra **C**orporeal **M**embrane **O**xygenation.

- E** = extra (out of)
- C** = corporeal (body)
- M** = membrane (artificial lung)
- O** = oxygenation

ECMO means pumping blood out of the body to a machine that puts more oxygen in the blood, and removes carbon dioxide, and returns the blood to the body. The ECMO pump does the job of the heart and lungs. This is a machine that is similar to the heart/lung bypass machine used for open heart surgery.

## Why might my child need ECMO?

As the doctors have already explained, your child's lungs and/or heart are not working properly, and we believe that ECMO may help with this problem. ECMO is a treatment that provides support for the lungs and/or heart while healing takes place.

The children who need ECMO have:

- severe heart failure either before or after cardiac surgery
- severe heart and lung failure due to the child's underlying disease, for example, an infection
- severe lung disease, which is not responding to the usual therapies of ventilation and medication.

The underlying disease must be reversible for ECMO support to be considered.

There are two types of ECMO. They can be used for babies and children who are in severe cardiac (heart) or respiratory (lung) failure.

## Cardiac ECMO (VA ECMO)

Veno-arterial ECMO is used for children whose hearts are working very poorly. This may be after an operation or because of an infection. It takes over the work of the heart.

It is also used for children with myocarditis (an infection affecting their heart) or cardiomyopathy (when the heart muscle is in failure).

## **Respiratory ECMO (VV ECMO)**

In children with very severe lung disease veno-venous ECMO can be used when the body is not responding to the treatment on the ventilator (breathing machine). This can give the lungs time to heal.

## **Will my child benefit from ECMO?**

We only offer ECMO when all other forms of treatment/therapies have been tried. Any child we offer ECMO to is very ill, and without this treatment would probably die.

The medical team will think very carefully before offering ECMO to your child, as its benefits must outweigh any possible risks.

## **What are the risks associated with ECMO?**

ECMO is a very invasive treatment, and has risks. We will inform you of the risks so that you are prepared for any outcome.

The most common risks and complications are

- bleeding
- infection
- mechanical problems
- neurological (brain) problems

**Bleeding** – the body’s normal response to a foreign surface such as an ECMO circuit is to clot. Because of this, while your child is on ECMO their blood must be thinned to prevent clots forming. To do this, we use a drug called heparin, which is continuously pumped into the circuit. This therefore puts your child at risk of bleeding anywhere in the body. We take care to ensure that the level of heparin is kept within certain limits to provide a balance between the risk of clotting and the risk of excessive bleeding. Bleeding is common while patients are on ECMO and it may be necessary (particularly after heart surgery) to undergo further surgical intervention to gain control of bleeding.

**Infection** – this is always a risk with any invasive procedures such as surgery and inserting tubes into blood vessels. To prevent this, antibiotics will be given when we start ECMO and the procedure is carried out in a sterile environment either in the operating theatre or in the Paediatric Intensive Care Unit (PICU). Your child’s blood will be analysed frequently for any indicators of infection and further antibiotics will be given if needed.

**Mechanical problems** – these may occur with the circuit itself, such as leaks, air bubbles or clots.

This might mean that ECMO may be temporarily stopped for your child until the problems can be solved. Technical difficulties are rare, but the risk of problems increases the longer your child has been on ECMO. ECMO bedside staff are specially trained to deal with any circuit problems or emergencies.

**Neurological problems** – These may be due to:

- your child's medical condition
- brain haemorrhage (bleeding)
- clots to the brain
- the large cannulae (tubes) interfering with the blood flow to the brain

Your child will be carefully watched before, during and after their treatment for any signs of neurological problems. The monitoring includes a monitor (called NIRS monitor) that measures the oxygen saturation levels in the brain (stickers applied onto the forehead), regular cranial ultrasound scans and in some cases an EEG (electroencephalograms).

## Asking for your consent

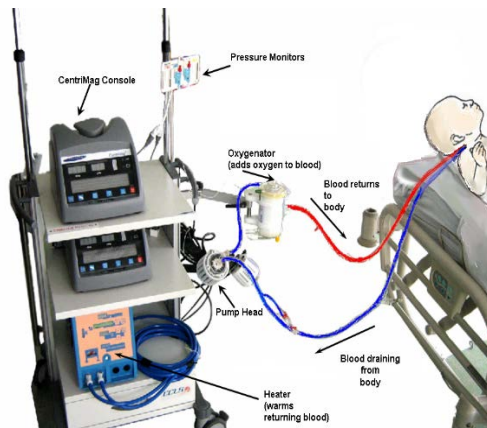
The ECMO team will explain the benefits and risks associated with the treatment to gain your consent. We want to involve you in all the decisions about the care and treatment of your child. If you decide to go ahead, you will be asked to sign a consent form. This confirms that you agree to this procedure for your child and understand what it involves.

If you would like more information about our consent process, please speak to a member of staff caring for you.

## What happens during ECMO?

ECMO works by adding oxygen and removing carbon dioxide from your child's blood. This is done by removing blood through a cannula (large tube) directed into your child's heart. The blood is pumped through the ECMO circuit, into an oxygenator (artificial lung) and then back to your child.

This blood is returned to your child's heart through a second cannula. You will be able to see that the blood coming from your child into the machine is dark in colour (deoxygenated). Once it has passed through the oxygenator it returns as a bright red colour (oxygenated).



Veno-arterial ECMO circuit (AD 03/09).



## **How will my child be placed on ECMO?**

The cardiac surgeon and PICU team will connect your child to the ECMO circuit. This can be carried out in theatre, a cardiac catheter laboratory or on the PICU. If we do this in the PICU, all parents and visitors will be asked to leave the unit for the duration of the procedure.

Your child will have an anaesthetic during the procedure, so will not feel any pain or be aware of what is happening.

## **What will my child look like on ECMO?**

Seeing your child for the first time on ECMO may be frightening. You will notice two large tubes coming from your child's neck or groin, or on some occasions directly from your child's chest. These tubes are connected to a large circuit, which makes up the ECMO circuit.

The photographs on the next page may help to give you some indication of how your child will look.



ECMO cannulae in baby's chest.  
Note the baby is on a ventilator.



The above baby that  
received ECMO, after being  
discharge from hospital.

Your child will continue to be on the ventilator and have all of the other equipment they had before starting the ECMO treatment, such as monitoring, drips and any dialysis.

## Who will be caring for my child on ECMO?

You will meet a team of people who will all be working together to care for your child. This team is made up of:

- ECMO doctors – who coordinate your child’s care and will discuss plans and update you on regular basis
- ECMO specialist nurses – experienced intensive care nurses who are trained in ECMO management and patient care
- Perfusionist – is clinical scientist who specialize in setting up, running and managing the cardiopulmonary bypass machine and ECMO circuit
- Cardiothoracic surgeon
- Cardiologists
- Physiotherapists
- Radiologists
- Pharmacist
- Dietitian
- Theatre nurses

Two nurses will be assigned to your child’s care. One will care for your child, and the other will be responsible for caring for the ECMO circuit. The team will keep you informed of your child’s progress and will encourage you to ask questions about any concerns or worries you may have.

You will see frequent checks made to the circuit to ensure that it is working properly. Blood samples will be taken frequently to ensure that the correct amount of heparin is being administered and that the ECMO circuit is delivering enough oxygen to your child. Blood products, such as fresh frozen plasma, blood and platelets will be given as frequently as needed (please ask for an information leaflet on blood products).

## **How long will ECMO be needed for?**

The length of time a child spends on ECMO varies depending upon the initial reason for ECMO. The average length of stay on ECMO for cardiac children is four to six days. However, if your child is on respiratory ECMO, it may take a lot longer. There is also a possibility that once your child is stabilised, he or she will need to be moved to another hospital providing longer-term ECMO. The ECMO consultant will discuss the expected length of ECMO support at the beginning of, and during, treatment.

## **What does the daily care on ECMO involve?**

Every day the ECMO team will review your child and make a plan for the next 12 hours. This can involve many tests such as x-rays, heart and head scans along with blood tests and plans for their other needs like feeding and physiotherapy.

## **Will my child be fed on ECMO?**

Your child will be fed via a naso-gastric tube (a tube passed through the nose into the stomach) using breast milk or formula feeds unless there is a medical reason not to. Extra calories can be added to this milk to make sure your child gets enough nourishment. If the milk feeds are not well absorbed, a special feed (TPN) can be given through a vein.

## **Will my child feel any pain?**

We will ensure that your child is kept comfortable by giving them medicines such as morphine and clonidine. Sometimes your child will receive a medicine to keep their muscles relaxed, as too much movement may interfere with the ECMO machine.

## **Can I help with the care of my child while they are on ECMO?**

We know that seeing your child on ECMO may be frightening and distressing. While your child is on ECMO we will encourage and support you and your family to be actively involved in your child's care. There are many things you can do to help care for your child, such as:

- changing nappies
- cleaning their eyes and mouth
- reading stories
- positive touch/hand holding.

## Can I hold my child on ECMO?

Unfortunately, you will not be able to hold your child while they are on ECMO, but a reassuring touch and your voice are very important. You can also bring in your child's favourite toys, comfort items, music or books.

## Looking after yourselves and each other

It is very important that you remember to look after yourselves. Make sure you eat properly and get enough rest. You may also find it helpful to speak to a member of the hospital's counselling team or hospital chaplaincy. You can contact the counsellors by asking your bedside nurse, or by calling 020 7188 4538 and leaving a message.

If you or your partner has just given birth, then we can arrange follow-up care for you with the hospital midwife. Please ask the nurses caring for your child to arrange this.

If you think of any other ways that we can help to support you, please speak to the team caring for your child.

Being in hospital or far away from home can be a financial burden. Please speak to the nurse at the bedside to see if there is any support that we can offer at this difficult time.

## **How will we know if our child is getting better?**

We will measure your child's progress by regular examination and monitoring of the blood samples, chest x-ray and improved functioning of their heart and lungs.

When your child is first put onto ECMO, the treatment will provide most, if not all, of the heart and lungs' work. As your child recovers, we will gradually reduce the support provided by ECMO until we reach a stage where we feel confident your child can come off the circuit. At this time, we may use extra ventilation and medicines to support your child.

Any long-term problems will be difficult to predict and will depend on the reasons why your child was put onto ECMO in the first place.

## **What aftercare will we receive?**

Your child will remain in intensive care until they are well enough to be transferred to one of the wards or back to your local hospital.

Once your child is well enough to go home, you will have follow-up appointments with an occupational therapist consultant, neurologist and member of the ECMO team.

## Frequently used terms

Please ask the staff if there are any terms you do not understand. We will be more than happy to explain them to you.

**ACT** – activated clotting time – a test that represents how long it takes for blood to form a clot.

**anti-coagulation** – prevention of blood clots.

**bridge** – a safety component within the ECMO circuit.

**cannula** – a tube placed within a child’s heart, veins or arteries. (Cannulae is the plural).

**clonidine** – medicine used to keep the child sedated.

**de-cannulate** – to remove a cannula.

**diuretics** – medicines (such as frusemide) used to encourage urine production.

**ECHO** – Echocardiogram (ultrasound of the heart).

**filter/haemofiltration** – dialysis machine attached to the ECMO circuit to support/take over role of kidneys.

**heparin** – medication used to prevent blood clots forming.

**inotropes** – medicine (such as milrinone, dopamine, adrenaline) used to support the heart.

**morphine** – medicine used for pain relief.

**oedema** – fluid retention.

**pyrexial** – high temperature.

**platelets** – blood cells which prevent bleeding.





## Notes

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## Contact us

If you have any questions or concerns about ECMO, please contact the PICU on

**t:** 020 71884 500 (all hours).

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit [www.evelinalondon.nhs.uk/leaflets](http://www.evelinalondon.nhs.uk/leaflets)

## Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.

**t:** 020 7188 3003 10am to 5pm, Monday to Friday

**e:** [letstalkmedicines@gstt.nhs.uk](mailto:letstalkmedicines@gstt.nhs.uk)

## Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS).

To make a complaint, contact the complaints department.

**t:** 020 7188 8801 (PALS)      **e:** [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)

**t:** 020 7188 3514 (complaints)

**e:** [complaints2@gstt.nhs.uk](mailto:complaints2@gstt.nhs.uk)

## Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch. **t:** 020 7188 8815

**e:** [languagesupport@gstt.nhs.uk](mailto:languagesupport@gstt.nhs.uk)

## **NHS 111**

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

**t:** 111

## **NHS Choices**

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

**w:** [www.nhs.uk](http://www.nhs.uk)

## **Get involved and have your say: become a member of the Trust**

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch.

**t:** 0800 731 0319    **e:** [members@gstt.nhs.uk](mailto:members@gstt.nhs.uk)

**w:** [www.guysandstthomas.nhs.uk/membership](http://www.guysandstthomas.nhs.uk/membership)

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