SOUTHAMPTON Children's Hospital
World class care and research

NHS University Hospital Southampton NHS Foundation Trust

Extra corporeal membrane oxygenation (ECMO)

Information for families and carers

Contents

Introduction

We have given you this booklet because your child has a life-threatening illness which has stopped their heart and/or lungs from working properly. We believe your child will benefit from a life-sustaining treatment called extra corporeal membrane oxygenation (ECMO).

We understand that this is likely to be a very frightening and confusing time for you, so we have written this booklet to help explain what ECMO is and what the treatment involves. We hope it will help you understand what to expect and how you can help care for your child. This booklet is not meant to replace detailed discussions with your child's healthcare team. If at any time you are unsure of something, or need further explanations, please contact us and we will be happy to explain further. We will also provide you with a booklet containing more general information about our paediatric (children's) intensive care unit (PICU).

We have included a glossary at the back of this booklet to help with some of the more common terms we may use. We have also included some blank pages for you to write down your own notes.

Cover image: Shows our Ellie the elephant toy. Hospitals can be unsettling places for children and their families, especially when a child is seriously ill. Ellie is a special gift that is thoughtfully donated by the Friends of PICU charity to each child who is admitted to the PICU with the aim of providing comfort at a distressing time.

What is extra corporeal membrane oxygenation (ECMO)?

ECMO stands for extra corporeal membrane oxygenation. ECMO is a type of heart-lung bypass machine.

An ECMO machine works by:

- pumping blood out of the body (extra corporeal) to an artificial lung (membrane) that adds oxygen to it (oxygenation) and removes carbon dioxide (this process replaces the function of the lungs)
- warming the oxygenated blood and pumping it back into and around the body (depending on the type of ECMO, this process may replace the function of the heart)

This treatment allows the blood to bypass the lungs and sometimes the heart, allowing these organs time to rest and heal.

Why your child needs ECMO

Your child's heart and/or lungs are currently not able to perform their job properly. We believe ECMO support may help, as it will give your child's own heart and/or lungs time to rest and recover. We usually only recommend ECMO if we believe a child's condition has the potential to recover.

Types of ECMO

There are two types of ECMO, VA (veno-arterial) and VV (veno-venous):

VA ECMO (cardiac ECMO)

This type of ECMO provides support for both the heart and the lungs, so it can be used for children needing either cardiac (heart) or respiratory (lungs) ECMO support. We will place two cannulas (tubes) into your child's blood vessels: one into a vein and the other into an artery. Blood that contains little oxygen (dark red) will be drained from your child's body into the ECMO circuit from the cannula in their vein. While this is happening, oxygenated blood (bright red) will be returned to your child's body through the cannula in their artery.

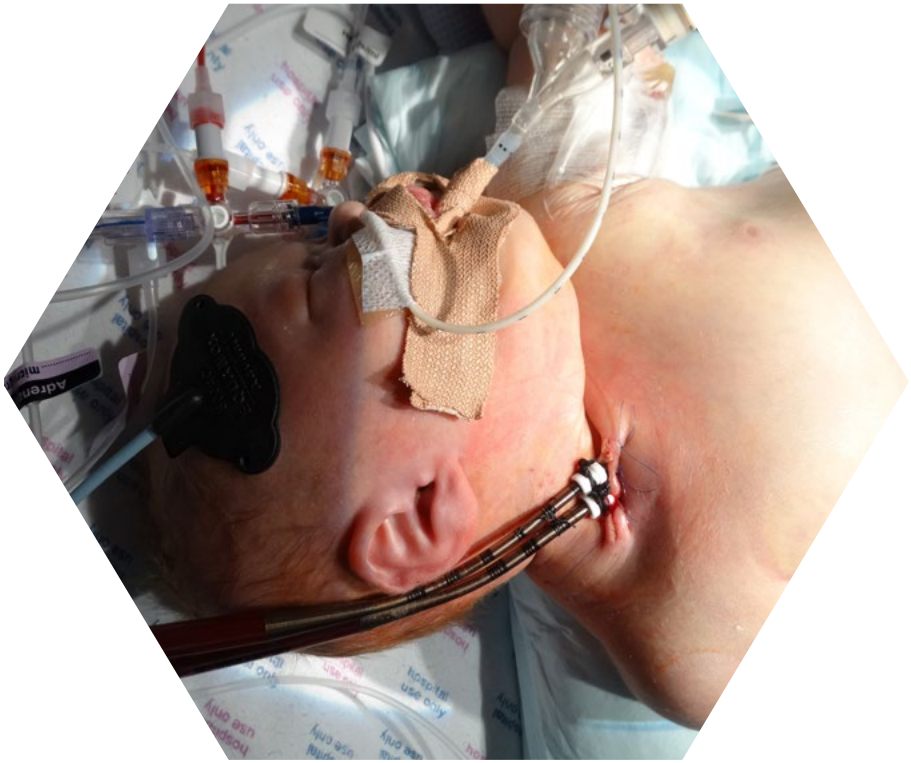
We may start this type of ECMO after heart surgery, if the heart:

- is not working well
- is unable to maintain a good enough blood pressure
- has an irregular rhythm

We may also start cardiac ECMO after heart muscle failure (myopathy) or heart muscle infection (myocarditis).

Children will usually be on cardiac ECMO for up to a week.

We may position the cannula(s) in your child's neck (as in the photo below) or directly into their heart through their chest.



VV ECMO (respiratory ECMO)

This type of ECMO provides support for the lungs only. We will place two cannulas (tubes) into two of your child's veins, either both in their neck or groin, or one in each site. Blood that contains little oxygen (dark red) will be drained from your child's body into the ECMO circuit from one cannula. While this is happening, oxygenated blood (bright red) will be returned to your child's body through the other cannula.

For babies and children with severe lung disease which is not responding to mechanical ventilation (a breathing machine), we may start respiratory ECMO. This type of ECMO can take over the function of the child's lungs, giving them a chance to recover.

Children can need respiratory ECMO from 48 hours up to four weeks (or longer in some instances). Children who need ECMO at Southampton Children's Hospital (SCH) for primary respiratory failure will usually be placed on ECMO in our PICU. On rare occasions, we may need to transfer your child to another respiratory centre.

The risks of ECMO

ECMO is an invasive, high-risk treatment that is only used for very ill children. We have included some of the possible risks associated with this treatment below:

Bleeding

The main risk during ECMO treatment is bleeding. When blood is removed from the body and pumped through the plastic tubing, it tries to clot. To prevent this from happening, we will give your child a blood-thinning drug called heparin. The disadvantage of this is that heparin prevents blood from clotting, not only in the ECMO circuit, but throughout the body. This means your child's risk of serious bleeding is increased, especially around wound sites or cannula sites.

Bleeding can occur in any part of your child's body, but it is most serious when it occurs in the brain, as this can sadly sometimes lead to brain damage. In babies, we will perform routine head scans to look for signs of bleeding.

We will take blood samples regularly to ensure that we are giving your child the correct amount of heparin and that the ECMO circuit is delivering enough oxygen to your child.

Infection

There is a risk of infection with any invasive procedure, especially when cannulas are inserted into blood vessels.

We will regularly screen for infection in the ECMO circuit and monitor markers of infection. If necessary, we will give your child antibiotics.

Fluid retention

Your child is at risk of fluid retention (when excess fluids build up inside the body) while they are on ECMO. This is because the fluid that we give them settles in their tissues, which may make them appear very swollen.

We will connect your child's ECMO circuit to a machine that supports kidney function and fluid balance (known as CVVH) to help remove any extra fluid and reduce swelling.

Fluid retention is not a long-term problem. Most children will not have kidney problems once they have fully recovered.

ECMO circuit complications

Although we will check the ECMO circuit thoroughly, problems can still occur. Problems may include:

- air bubbles
- blood clots
- small breaks in the ECMO circuit (circuit may need to be changed)
- cannula movement

We will carry out tests, such as x-rays, and heart and head scans, to assess your child's progress and check for any problems as often as needed.

Your child's ECMO healthcare team

There will always be two ECMO nurse specialists caring for your child while they're on ECMO. One nurse will look after your child and the other will look after the ECMO circuit.

In addition to the ECMO nurse specialists, your child will be cared for by:

- a perfusionist (a member of the open-heart surgery team)
- PICU consultants
- cardiac surgeons (specialists who operate on the heart)
- anaesthetists (specialist doctors who are responsible for providing anaesthesia to patients for operations and procedures)
- cardiologists (doctors who specialise in diagnosing, treating and preventing diseases that mainly affect the heart and blood vessels)

Depending on your child's diagnosis, other doctors, such as neurologists, respiratory specialists, and general surgeons, may also be involved in your child's care.

Other healthcare teams who will also play a role in caring for your child include pharmacists, physiotherapists, dietitians, radiographers and research nurses.

The ICU consultant and ECMO team members will discuss your child's care plans with you on a daily basis and give you the opportunity to ask any questions you may have.

As the photo below shows, your child will be surrounded by a lot of equipment. The ECMO nurse specialists will show you where it is best for you to stand so you can be close to your child and help with their care.

Length of time on ECMO

The length of time each child needs to stay on ECMO varies depending on their illness. At SCH, most children go onto ECMO because of severe heart failure, and the average time spent on ECMO is between five and seven days.

We will carry out a variety of tests on a daily basis to help us assess how your child's heart or lungs are improving. Tests will include blood samples, observations of chest movement and chest x-rays.

As your child improves, we will reduce the ECMO support, allowing their heart and lungs to take over their normal work. When ECMO support is minimal and your child remains stable, we will start a 'low flow trial' period. This trial involves us clamping the cannulas to allow your child's heart and lungs to take over the work. Your child will be connected to a ventilator during this trial and may be on certain medicines to help with their heart function. During this trial, a cardiologist will perform an echocardiogram (heart scan) to check your child's heart function.

If the trial is successful (your child remains stable)

We will arrange a short operation later that day or the next day to remove the cannulas. If your child is cannulated through an open chest, the surgeons will leave your child's chest open and covered with a dressing until their condition has improved.

If the trial is unsuccessful

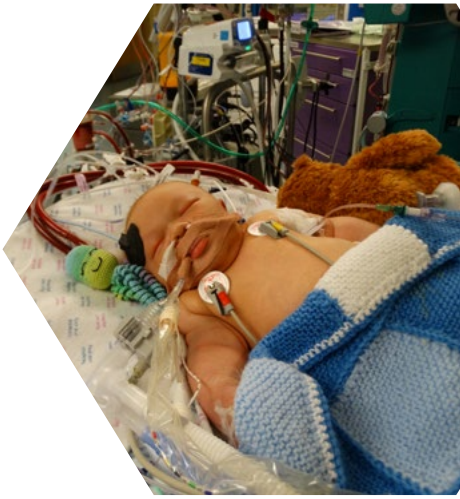
We will put your child back onto ECMO support to give them more time to recover. We will usually wait 24 to 48 hours before trying another low flow trial.

Sometimes we may notice that a child's heart or lungs are not improving with the help of ECMO. If this is the case for your child, we will discuss the next steps with you in more detail.

ECMO is a rescue treatment for life-threatening conditions and sadly not every child who goes onto ECMO will survive.

Seeing your child on ECMO

For many parents, seeing their child on ECMO can be a shock. The medical equipment and wires can naturally seem very daunting. It can be helpful to be prepared in advance for how your child will look. You can expect to see two large tubes coming from your child's neck or chest.



The images in this booklet have been included to help give you an idea of what to expect. Please do ask if you have any further questions.

How you can help care for your child

A child's family plays an important part in their care and recovery, so we encourage you to visit your child regularly while they are on ECMO. For the safety of our patients, we have a limit of two visitors at a time to a bedside. You will not be able to hold your child while they are on ECMO, but a reassuring touch and your voice can make a real difference to your child. We also encourage you to bring in your child's favourite cuddly toy, comfort items, music or books.

We will encourage you to be involved in caring for your child. This may include:

- cleaning their eyes
- making sure their mouth is kept moist
- changing their nappy
- giving them a wash

It is very important that you remember to look after yourself too. Make sure you eat properly and get enough rest. Don't feel you need to be by your child's bedside all the time.

Sometimes we may carry out small surgical procedures on PICU. If this is the case, for the safety of our patients, we will close the unit and ask all families to leave until we have completed the procedure. Thank you in advance for your cooperation.

Support for you and your family

Psychological support

Having a child on ECMO can be very distressing for families. You may find it helpful to talk through your experience and feelings with someone outside the medical teams. There is a clinical psychologist available to all PICU families. If you wish to speak to the psychologist, please ask a member of the ECMO team and they will be able to arrange this.

Spiritual care team support

You may also find it helpful to speak to a member of our hospital's spiritual care team. The team works closely with the PICU and can be contacted at any time. There is also a chapel on D level which you are welcome to visit at any time.

Cardiac liaison nurses

If your child has a cardiac problem, our cardiac liaison nurses can offer your family another form of support. They will come and introduce themselves to you, or they can be found on E1 (cardiac ward).

Midwives

If you or your partner has just given birth, we can arrange follow-up care for you. Our team of midwives are based across the road at Princess Anne Hospital, but are happy to come to you if that is easier. Please ask a member of the ECMO team and they will be able to arrange this for you.

Childcare

If you have other children with you at the hospital, we can arrange a temporary nursery place at Taplins (our local hospital nursery) for them.

Financial support

If you have any financial issues while your child is in hospital, please speak to a member of staff.

We will be able to provide you with tickets for cheaper parking and meals from the hospital restaurant. If you are breastfeeding or expressing breast milk, we can provide you with free hospital meals. We also have breast pumps and facilities for storing milk, if needed.

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

Your child's follow-up care

Once your child's ECMO treatment has ended, they will need to stay on the PICU until they no longer need intensive care. We will then transfer them to one of the paediatric wards where they will receive ECMO-specific follow-up care.

Possible long-term complications

Neurological and developmental

The most common complications of ECMO involve the brain. They include bleeding, ischemia (damage from reduced blood supply to the brain) and seizure activity. These problems may occur as a result of your child's critical condition before going on ECMO, as well as from the ECMO treatment itself. After ECMO support, some children may have neurodevelopmental problems, ranging from mild learning difficulties to severe neurological impairment. Before we discharge your child from hospital, we will usually arrange for your child to have an MRI brain scan (a scan that takes detailed pictures of the inside of their brain).

Studies show that developmental delays are usually identified by the time a child is two years old, but more subtle changes, such as learning difficulties, may not become obvious until they are around five years old (school age). Children who have neurological problems will be referred to the local neurodevelopment specialist. If you have not received an outpatients appointment within three months of your child coming off ECMO, please contact us via email at: **ECMOAftercare@uhs.nhs.uk**

Hearing loss and language delay

Some of the medicines used for ECMO can cause hearing loss which can result in a language delay. In rare cases, your child may need to have a hearing test.

Other long-term complications

Your child may also have other long-term complications from their underlying condition or illness that led to them being on ECMO. A specialist consultant will arrange an appointment at a later date to review your child's condition.

Glossary

ACT (activated clotting time): A test that represents how long it takes for the blood to form a clot.

Anti-coagulation: Prevention of blood clots.

Arterial line: A small cannula that sits in your child's artery. It records your child's blood pressure continually (the red trace on the monitor). We will also take blood samples from this line.

Cannula: The plastic tubes through which blood is taken from and returned to the body.

Cannulate: To insert a cannula into a vein or artery in the body to allow ECMO. This is performed either on the unit or in theatre (if your child is already there).

Chest drain: A tube that is placed in the space between your child's lung and chest wall to remove air or fluid. This is used to treat a pneumathorax (when air becomes trapped in the space between the lungs and the chest wall).

Chest exploration: A surgical procedure to examine the chest cavity.

Clamped off: A trial period when your child is taken off ECMO before the cannulas are removed. This happens on the PICU.

Decannulate: To remove the cannulas. This happens on the PICU.

Diuretics: Medication used to encourage urine production.

ECHO (echocardiogram): A scan of the heart to see how well it is working.

ECMO: Extra corporeal membrane oxygenation.

Head ultrasound: A scan of the brain to look for bleeds.

Heparin: A drug used to thin the blood to prevent clots from forming.

Haemofiltration: A machine attached to the ECMO circuit to help the kidneys by removing excess fluid.

Inhaled nitric oxide: Increases blood flow to the lungs.

Inotropes: Drugs used as infusions to support your child's heart (for example, milrinone, adrenaline and dopamine).

Intracranial bleed: An abnormal bleed on the brain.

Membrane pressures: These are pressures that are monitored either side of the oxygenator.

Midazolam: Medication to keep your child sedated.

Morphine: Medication used to provide pain relief and sedation.

Muscle relaxant: Medication used to keep your child still to prevent the ECMO cannulas from being dislodged.

NG (nasogastric tube): A tube which passes through the nose into the stomach to allow your child to be fed.

Neurologist: Brain doctor.

Octaplas: A sterilised human plasma blood product that contains all the clotting factors.

Oedema: Fluid retention.

Oxygenator: Part of the ECMO circuit which supplies oxygen to the blood and removes carbon dioxide.

Platelets: Blood cells which prevent bleeding.

TPN (total parental nutrition): Nutrition that is delivered through a vein when your child is unable to absorb feeds into their stomach.

Ventilator: A breathing machine that supports the lungs and takes over the work of breathing.

Contact us

If you have any questions or concerns, please contact us.

ECMO team

Email: **ECMOAftercare@uhs.nhs.uk**

Notes

Notes

Southampton Children's Hospital
Southampton General Hospital
Tremona Road
Southampton
Hampshire
SO16 6YD

If you are a patient at one of our hospitals and need this document translated, or in another format such as easy read, large print, Braille or audio, please telephone **0800 484 0135** or email **PFSH@uhs.nhs.uk**

For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **www.uhs.nhs.uk/additionalsupport**

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