

Extra Corporeal Membrane Oxygenation (ECMO)



Information for families

Great Ormond Street Hospital
for Children NHS Trust

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This booklet provides you with some basic information about ECMO (Extra Corporeal Membrane Oxygenation). It is not meant to replace detailed discussions with the team caring for your child. Staff are happy to discuss any points which you may want repeated or described in more detail.

We will also provide you with a booklet which will give you more general information about Great Ormond Street Hospital (GOSH) and the Cardiac Intensive Care Unit (CICU) where ECMO treatment takes place. As the doctors have already explained to you, your child is very ill. The main problem is that your child's lungs and/or heart are not able to perform their usual job, and the team caring for your child believes ECMO support can help. The ECMO machine provides support for your child allowing time for the lungs and/or heart to recover and repair themselves.

ECMO stands for Extra Corporeal Membrane Oxygenation. The ECMO machine is similar to the heart-lung bypass machine used for open heart surgery. Extra corporeal means 'outside the body', a membrane oxygenator is a piece of equipment which delivers oxygen into the child's blood. Consequently ECMO is the use of an artificial lung (membrane) located outside the body (extra corporeal) that puts oxygen into the blood (oxygenation) and continuously pumps this blood into and around the body.

History of ECMO

ECMO was first used successfully in the USA in 1976 and was introduced into this country in 1989. It was first set up at GOSH in 1992 and to date we have supported over 850 babies and children. GOSH is one of three national centres currently providing cardiorespiratory ECMO support for babies and children in England and Wales, the others being Glenfield Hospital in Leicester and the Freeman Hospital in Newcastle.

ECMO is used for babies and children with severe heart (cardiac) or lung (respiratory) failure.

Respiratory ECMO

In children with very severe lung disease which is not responding to the usual treatment of mechanical ventilation (breathing machine), medicines and extra oxygen, ECMO can take over the function of the child's lungs, allowing them time to rest and heal.

Cardiac ECMO

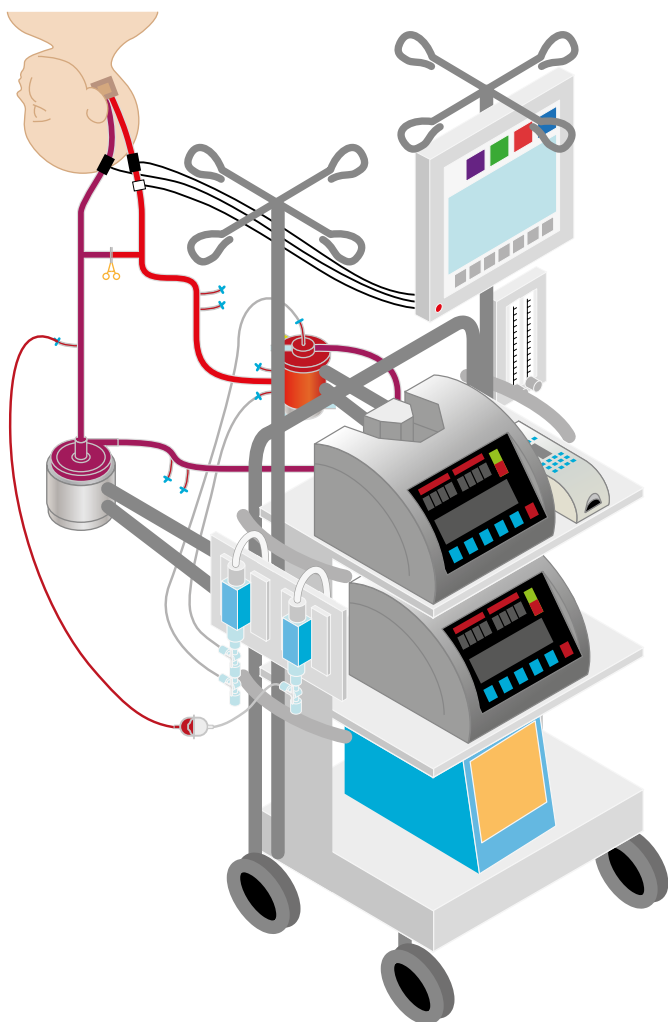
In children with very poor cardiac function, ECMO can take over the work of the child's heart. This provides time for the heart to rest and recover, while maintaining a good blood supply to the brain and other organs in the body. Cardiac ECMO may be needed after open heart surgery, when the heart may be swollen, unable to maintain a high enough blood pressure or have an irregular rhythm. It may also be needed due to an infection affecting the heart muscle (myocarditis) or heart muscle failure (myopathy) where the heart cannot pump blood around the body effectively.

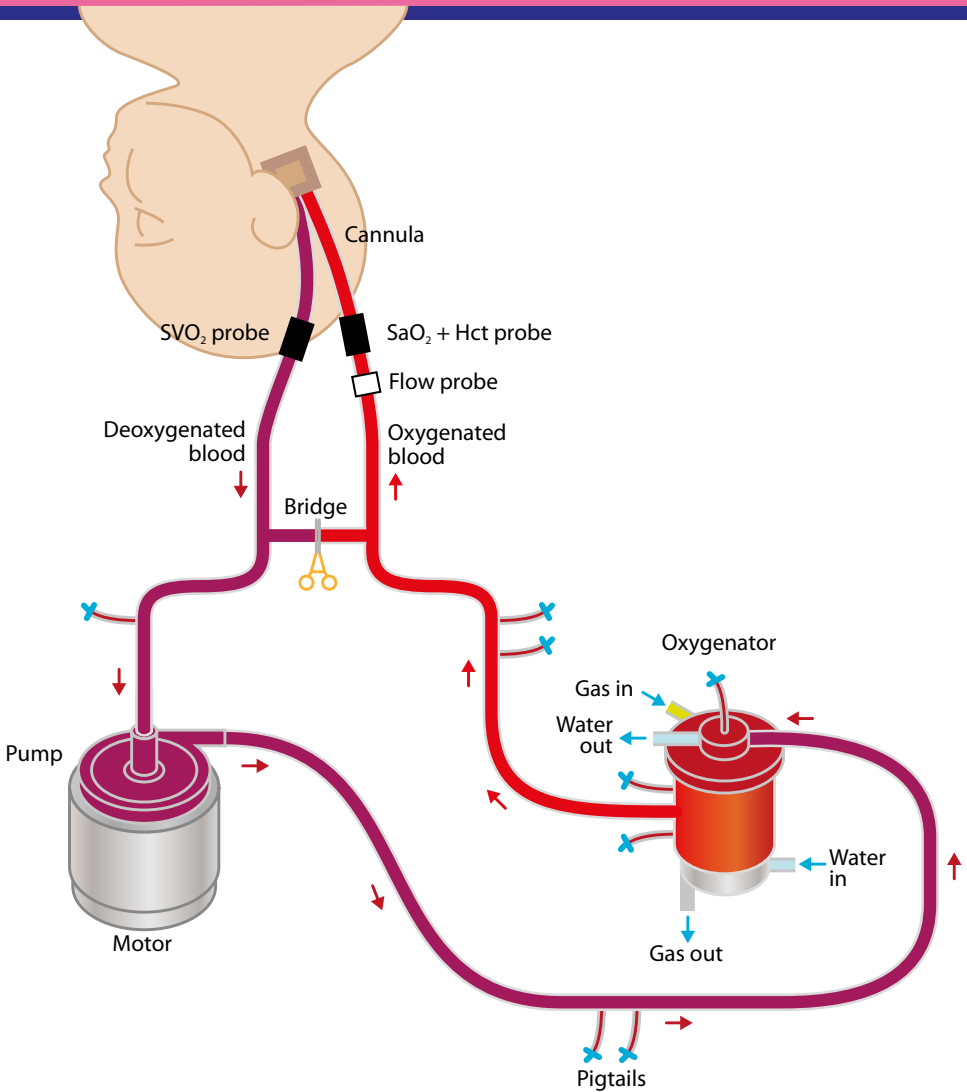
Please note that ECMO can only help children whose lung and/or heart disease is reversible within about three weeks.

ECMO may be started in the operating theatre immediately after surgery or on one of the intensive care units.

If your child is going onto ECMO after a heart operation, the surgeon will usually insert the cannulae (tubes) during the operation directly into the heart through the chest.

If ECMO is started in the intensive care unit, the cannulae connecting the patient to the ECMO circuit are placed directly into the blood vessels on the side of the neck. This short operation takes place at the bedside in the intensive care unit and you will be asked to leave during the procedure. A light anesthetic is given so your child does not feel any pain and a tube (cannula) is placed into a large vein in the side of the neck. A second tube is often required which is inserted into an artery also on the side of the neck.





Once in place, the cannulae are then connected to the ECMO circuit and machine. Dark blood (containing little oxygen) drains from your child through the tube in the vein and is pumped through the membrane oxygenator (an artificial lung) where carbon dioxide is

removed and oxygen added. The blood is then re-warmed and returned to the body. This process goes on continuously while your child is on ECMO. They will also stay on a ventilator but on very gentle settings which allow the lungs to rest.

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

VA ECMO

Two cannulae (tubes) are placed into your child's blood vessels, one into a vein and the other into an artery, usually on the side of the neck. Dark blood (containing little oxygen) is drained continuously into the ECMO circuit from the tube in the vein while the now oxygen-rich blood from the ECMO circuit is returned to the body through the tube in the artery.

This type of ECMO provides support for both the heart and the lungs and so can be used for children requiring either cardiac or respiratory ECMO support. For the small number of children who require ECMO after open heart surgery, the cannulae (tubes) may be inserted directly into the heart through the chest during the heart operation rather than into the neck vessels.

**Baby immediately post
ECMO cannulation**



VV ECMO

A single catheter is placed into a vein, usually in the side of the neck. Blood is drained from this catheter into the ECMO circuit at the same time as oxygenated blood is returned through the same catheter from the ECMO circuit to the child. VV ECMO provides lung support only and does not support the heart.

A few children who start with VV ECMO will need to be changed over to VA ECMO if their heart also starts to need support.



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 a possibility so we want you to be aware of them.

Bleeding

Blood is designed to clot if it leaves the body or comes into contact with foreign surfaces such as the plastic of the ECMO circuit. Usually this mechanism keeps us safe by stopping us bleeding if we cut ourselves. However, on ECMO, it is important that we prevent clots from forming within the ECMO circuit and so a blood thinning drug called heparin is used. The disadvantage of this is that heparin prevents blood clotting effectively not only in the ECMO circuit but throughout the body. This means that bleeding can occur around any site where your child has any kind of wound or where any tube or needle was inserted. It can also occur around the nose and mouth.

We understand that this can be distressing to see but the ECMO specialist nurses are very used to managing this. We will try to keep your

child as clean as possible, however sometimes it is better not to disturb bleeding areas as removing surface clots may cause more bleeding.

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 during this time

If on cardiac ECMO, your child may have the cannula in their neck, leg or inserted into 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.

Bleeding is very common when ECMO is used following cardiac surgery. If bleeding occurs, your child may need a surgical exploration of their chest by the cardiac surgeon. This takes place in the Intensive care 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 they will not feel any pain or discomfort. We will tell you about any chest explorations your child needs, but will ask you to leave the intensive care 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 about two hours.

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)

When the blood in the body is thinned, as it is on ECMO, the risk of bleeding into the head is increased. Newborn babies are already at risk from this, and the risk increases further with ECMO. Sometimes brain problems can happen due to your child's condition before going on ECMO, rather than ECMO itself. While your child is on ECMO, we will carry out regular neurological checks, ultrasound scans of the head and electroencephalograms (EEG). The ultrasound scans can show up areas of bleeding in the brain and the EEG measures your child's brain waves. These checks and scans do not hurt your child and are vital in monitoring for any changes that may occur.

Renal (involving the kidney)

Renal failure is an additional problem which may be seen on ECMO. If this occurs another machine can be connected to the ECMO circuit which acts as an artificial kidney until your child's own kidneys start working again.

ECMO circuit complications

Although the circuit is monitored continuously and checked on a regular basis for clots and other problems, complications 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 this may not be possible and 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 onto ECMO support as soon as possible.

Failure to recover

Failure of the heart/lungs to recover adequately are other problems that may be seen during ECMO support. You will be kept updated regarding your child's progress throughout their time on ECMO and any problems will be thoroughly discussed with you.

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. At first all you may see are the various tubes, drips and machines. The nurses will explain the purpose of each one.

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. Let us know if you want this area covered while you are visiting.

Children can initially feel quite cold on ECMO, especially their hands and feet. If they have had heart surgery, this will be due to being cooled while on the bypass machine in theatre. Otherwise this will be due to your child's underlying condition. We will warm your child up gradually using overhead heaters and special blankets, and once they are stable on ECMO, their 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 they were given a lot of intravenous fluids before ECMO was started. We will give your child medications to encourage the kidneys to pass larger volumes of urine, which should reduce the swelling gradually.

Your child will remain on a ventilator while on ECMO. If on ECMO for heart support only, the ventilator will maintain a normal breathing pattern, keeping the lungs in good condition. If on ECMO for lung support, only very gentle ventilation will be given to enable the lungs to rest, but be supported in their recovery. We hope to see a gradual recovery in your child's lungs over a few days or weeks. Once your child is off ECMO, they will continue to need ventilation for a time.



A patient on ECMO support

The average length of ECMO support is five to ten days but some children will need longer. The length of support depends mainly on the type of lung or heart problem. Sadly, in some cases, it becomes clear that ECMO is not helping your child and if this is the case, we will fully discuss the problems with you.

How do we know when your child is ready to come off ECMO?

The exact length of time that your child spends on ECMO depends on the reason ECMO support was needed in

the first place. Regular monitoring and observations show how much your child's heart/lungs have recovered and indicate when they have recovered enough to try to take them off the ECMO machine.

When your child is first placed on ECMO, the pump flow is kept high so that the machine does most of the work of the lungs and heart. As your child improves, the ECMO flow will be decreased, allowing their lungs and heart to take on more of the work.

Your child's improvement is measured by blood samples, observations of chest movement, improving chest x-rays and/or improved heart function.

When this is seen, the ECMO flow will be gradually reduced over a couple of hours to a stage where your child is tried off ECMO ('clamped off') for short period of time. During this time your child will need full ventilation and possibly extra medicines, which will be reduced as their condition improves. If your child has been on ECMO for heart support, the cardiology doctors will carry out an Echocardiogram (ECHO) to assess the function of the heart while the ECMO flows are being reduced. An ECHO is an ultrasound scan of the heart and helps us to assess how well the heart is coping with the extra work it is having to do as the ECMO flows are reduced. You may hear this kind of echo being called a 'stress echo'.

If your child's condition remains stable while they are 'clamped off' ECMO, then ECMO support is no longer required and the cannulae can be removed. The surgeons will remove these in a small operation on the intensive care unit. If the cannulae were inserted directly through the chest, the surgeons will leave your child's chest open (but covered in a dressing) until their condition improves further.

If your child's condition deteriorates while they are 'clamped off' ECMO, they can be easily put back onto ECMO support and given more time for recovery. This 'wean' from ECMO will be repeated, usually after another one to three days, and your child's heart/lungs reassessed for readiness to come off the ECMO machine.

Although disappointing if your child is not stable enough to come off the ECMO machine the first time they are weaned, this is quite normal and some children have several attempted weans before coming off ECMO successfully. We will always discuss the results of stress ECHOs and weaning from ECMO in detail with you.

Your child needs specialized care which will be provided by a variety of different people within the ECMO team:

- The ECMO specialist nurses are experienced intensive care nurses who are trained in ECMO management. They are responsible for the safe running of the ECMO circuit and one of the team will be at your child's bedside for 24 hours a day while they are on ECMO support. Your child may have two nurses caring for them on each shift - the ECMO specialist and another intensive care nurse who is responsible for the care and observation of your child.
- The intensive care consultant, ECMO Fellow and ECMO Coordinator will coordinate your child's care and will discuss plans and update you on a regular basis, giving you a chance to ask questions.
- Other members of the team who may help care for you and your child include:
 - Cardiac surgeons
 - Cardiologists
 - Perfusionists
 - Physiotherapists
 - Theatre nurses
 - Pharmacists
 - Psychologist
 - Dieticians
 - Cardiac liaison nurses
 - Radiologist
 - Priest or chaplain.
 - Family liaison support worker
 - Neonatal nurse advisor

Tests

Your child will need a period of assessment before ECMO starts. Children usually need a head ultrasound and a cardiac ultrasound (ECHO) to ensure there are no problems that could indicate that ECMO is not appropriate. During the course of ECMO support, your child will be reviewed daily by the ECMO doctor and their condition carefully monitored. To assess your child, various tests will be performed as required including:

- Chest X-ray
- Head ultrasound
- EEG to assess neurological function
- Cardiac Echo to assess heart function and recovery

If any other investigations are needed, they will be discussed with you.

Pain/sedation

It is very important to us that your child is comfortable and not in pain. We recognize this will be a serious concern to you. However, we allow children on ECMO to be as alert as possible without subjecting them to pain or anxiety. This allows more precise monitoring of their neurological status and enables them to be more interactive with you. Your child will be given continuous painkillers, and extra pain relief and sedation if any procedures are needed. We constantly assess your child for pain and can give extra sedatives and pain relief through the naso-gastric tube or as suppositories. Sometimes we need to keep your child sleepy and give them medicine to keep them very still by using drugs which stop muscle movements (called muscle relaxants). Often the days are busy with investigations, but it is important your child has a rest and is not touched for periods of time.

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 they come off ECMO. Your child will continue to be assessed and treated by the physiotherapist daily while on ECMO. They will assess the lungs to see if any secretions are present. Treatment will involve various techniques including vibrations on the chest wall while delivering hand ventilated breaths to move secretions to the main airway where they can be cleared with suction. The physiotherapist will also ensure that while your child is sleepy and not moving much they are positioned comfortably to optimise development when they come off ECMO. The physiotherapist will explain their involvement in more detail when they see you.

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 they are 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](#).

Family Involvement

Parents and other family members, including brothers and sisters, play an important part in the child's care and recovery. Visiting is strongly encouraged, although restricted to two persons at a time at the bedside. While your child is on ECMO there are many things you can do to help with their care such as cleaning their eyes, making sure their mouth is kept moist, changing their nappy and giving them a wash or massage. These 'cares' will usually be done every six hours, and if you would like to get involved then

the nurse will be happy to show you what to do, and arrange suitable times with you. Although you will not be able to pick up your child, a reassuring touch and your voice is very important - you can provide special toys, comfort items or tapes of you reading stories or singing songs. It is also important that you take care of yourself, make sure that you eat properly and get some rest. Don't feel you need to be by your child's bedside all the time.

You may visit your child at any time other than during nursing handover (8am to 8.30am and 8pm to 8.30pm) and during ward rounds, which are usually held from 9am to 10.30am and from 4.30pm to 6pm. A typical day for your child may be:

6am	Nappy change and wash by nursing staff
8am	Nursing shifts change over
9am	Chest x-ray
9.30am	Full medical examination and ward round
10.30am	Parents visit / story time
noon	Nappy change and wash by parents, massage, sheet change

1pm	scheduled tests/ investigations eg EEG
2pm	Quiet time / rest time
5pm	Ward round
6pm	Nappy change and eye and mouth care by parents.
7pm	Story time / music
7.30pm	Bedtime
8pm	Nursing shifts change over

Sometimes small surgical procedures (such as inserting ECMO cannulae to put a child onto ECMO) are carried out on the intensive care unit. The safety of our patients is paramount and consequently during these times it is necessary to close the unit and ask all families to leave until the procedure is complete. Please let us apologize in advance for the disruption that this causes.

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 Coordinator or any other member of the team.

If your child is on ECMO for longer than a week, weekly multidisciplinary team meetings will be held, involving all the staff that provide care to your child. This allows for thorough team discussions about progress being made or problems being faced, and enables a plan of care for the next seven days to be devised. Once the meeting is over, you will be fully updated regarding the discussions that have taken place and any changes that will be made to your child's care as a result.

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, to whom we can give information about your child's condition. 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 psychologists who can support you and your other children. If your child has gone onto ECMO support for a cardiac reason, there is also support available from the Cardiac Liaison team.

Our experience is that having a child on ECMO is very distressing for families. Many families arrive here after a traumatic series of events. This means that many families are in a state of shock and confusion, having had no time to process what has happened to them. There is a psychologist in the ECMO team who will come to introduce herself to you.

The psychologist's role in the ECMO team is to help you, and your child if they are awake, to cope. In the years since we have had a psychologist in the team many parents have found it helpful to talk through their experience with someone outside the medical and nursing teams. Some people do not know what to talk about at first but find that telling the story of their child's journey until being put on to ECMO helps them to make some sense of their feelings. Other people come with specific questions about coping with their own anxiety or mood, their child's anxiety or how to talk to their other children about what's happening.

Some people come with specific worries about bonding with their newborn, feelings of loss or grief or feelings of guilt, and some couples come because they have different coping styles and are finding it hard to support each other. The psychologist can talk these things through with you and help you find strategies to cope. She can work with you on your own, with couples, with your child if they are awake or with whole families, including siblings.

The psychologist is usually involved in multidisciplinary meetings to give a psychological perspective on how the child and family is coping and any changes to their management that might help, but will not disclose any specific information about you or your family without agreeing it with you first.

If you have not managed to meet the ECMO psychologist and would like to, please ask your child's nurse to contact the psychologist.

These thoughts were compiled by parents whose children received ECMO treatment. They are reproduced in the hope that they may help you during this difficult time.

"Before we were allowed to see our daughter on ECMO, our nurse explained that it may disturb us to see her, but when we saw her lying there so calm and beautiful, I felt there was hope."

"Her skin was a little dry from the heat of the machine and the fact that she was two weeks overdue so I rubbed a little baby lotion on her gently."

"People always want straight answers 'Will she be alright'. 'Then what will happen?' but we had to learn to take one day at a time."

"I kept a diary and tried to remain positive."

"I had to remind myself to be strong, I'd called her Zoe and that meant life and that she'd pull through."

"There is a dreadful longing to hold your child."

"Perhaps you feel guilty – you may have had a normal pregnancy (as I did) but still have a critically ill child. Why us?"

There is a parents support group available and if you would like to speak to other parents whose children have also been on ECMO, please contact the ECMO office on 020 7813 8180 or ext. 8180.

'How you might feel' will be different for every parent, but to my mind some common feelings will be of...

Over-whelming heartbreak, anxiety and of not being in control of your child's future. When I was told by the paediatrician shortly after my daughter's birth that my newborn was critically ill in the Special Care Baby Unit and that there was every possibility that we may lose her, I was in total and absolute shock, disbelief and despair. My whole world came crashing down around me. My husband broke down and cried – something that I couldn't do at the time, while I refused to believe what I was being told. I told everyone concerned that she would be fine and that she would come through, although judging by what I was being told, I was very much aware of the implications of her dire situation. I was beginning to feel somewhat distanced from events. It was surreal, almost like we were talking about somebody else's baby. I suppose that was my coping mechanism. I felt like I couldn't give up hope for her and I had to WILL her life for her, that my giving up on her would have had drastic consequences. When we were offered ECMO as her only hope of survival, we were desperate for anything that might give her a chance and we were grateful.

Going through the transfer from the maternity unit to GOS and the subsequent period when the doctors attempted to put her onto ECMO was perhaps the most frightening time for us, because we knew that without ECMO she had no hope. When we heard that she was on ECMO we began to feel cautiously optimistic. Seeing our tiny daughter linked to the machine was quite a shock, but the support team gave us some literature and told us what to expect, which was quite a help. Our overwhelming feelings at the time were relief that she was being given a chance and hope that she may survive. Every day was an ordeal and every day we learnt a new set of details which worried us, but seeing her being successfully decannulated on the fifth day was perhaps the happiest day for us. Her return for recuperation at the maternity unit was spectacular as that heralded the first time that we were able to hold her and I was able to feed her. Our daughter is two years old now and she is the light of our lives. We also have a two month-old baby son whom she loves and we feel so lucky and privileged that both of our children are happy and healthy and with us.'

Audrey Claxton-Mounji
ECMO Parent

Things that may help from parents

- "Keep telling yourself that things will be OK."
- "Keep a diary."
- "Ask the doctors and nurses anything you want to."
- "Talk to other parents, family and friends and of course, talk to your baby – he/she can hear you."
- "Hold their little hand and help with any baby care that you can."
- "Try and express milk for it's the one thing that you alone can do. If you can keep up the supply, you will be able to feed your baby yourself when you finally hold him/her."
- "The power of touch is mutually therapeutic."
- "Always talk to your child. Let him/her hear your voice, even though he/she cannot respond."
- "It is vital to get some rest and try to carry on in some degree of normality, especially if you have other children."
- "It is very easy to see things out of perspective when you're exhausted and worried."
- "Have the utmost trust in the medical and nursing staff in CICU. Your child couldn't be cared for in a better place."

We would like to acknowledge the contribution of all the families for their help in compiling the previous pages, as well as their continuing participation in the ECMO Family Support Group. If at anytime you have concerns or queries please contact the ECMO Office 020 7813 8180.

Arrangements are usually made to transfer children back to their local hospital once they are off ECMO and doing well. This may be as soon as the day after they are taken off ECMO, but will not be until the child is well enough to be transferred safely. Your child may still need some more time in an intensive care unit before they are fully recovered. The care you receive from your local hospital, family doctor (GP) and health visitor may be different from the care at GOSH but it is important for you and your child to get back into a normal routine and environment as soon as possible. Once discharged home you will be followed up at your local hospital and will additionally be invited to return to GOSH for an ECMO follow-up appointment after one year. Any copies of follow-up information would be greatly appreciated by the ECMO service at GOSH.

Survival rates for ECMO vary depending on the underlying condition and the age of the patient. The best outcome is for newborn babies (neonates) with a condition called meconium aspiration, who have an overall survival rate of 95 per cent. Other newborn respiratory conditions have an overall survival rate of 80 per cent. The lowest survival rate, of about 50 per cent, is among patients with sepsis and congenital diaphragmatic hernia. Childhood conditions tend to be much more variable and overall survival is about 50 per cent. For cardiac patients the survival rate is about 50 per cent. These are in line with international ECMO survival figures.

Neurological

While the patient is on ECMO, the most common complications involve the neurological system. They include bleeding, loss of blood supply (ischaemia) or seizure activity, which occur in up to 30 per cent of patients. Follow-up studies have shown that up to 25per cent of ECMO survivors have neurodevelopmental problems ranging from mild learning difficulties to severe neurological impairment. Severe impairment is more likely if a neuro-imaging abnormality was detected at the time of ECMO discharge. These figures do not differ from those babies treated conventionally without ECMO as shown by the UK trial follow-up study in neonates.

In many cases the neurological problems probably occurred before ECMO began, particularly in those cases where there have been significant episodes of hypoxaemia (low blood oxygen levels) with hypotension (low blood pressure). Developmental progress therefore needs particularly careful monitoring in newborns. Long-term studies of neurodevelopment are in progress. Studies indicate that developmental problems which are not apparent at one year of age may show by two

years and more subtle changes such as learning difficulties may not become apparent until school age. If a child has any neurological problems, they should be referred to the local neuro-developmental specialist and treated in the usual way.

Another area of concern is the possible adverse effects of tying (ligation) of the carotid artery and the occurrence of narrowing (stenosis) in those who have had reconstruction of this vessel. Reconstruction of the carotid artery has been the practice in many institutions for a number of years. The most recent studies suggest there is no increased evidence of left-sided neurological damage in those with right carotid artery ligation. For those that have reconstruction, the majority of arteries remain open (patent) at four years of age although some may have mild to moderate stenosis without clinical symptoms. Long-term studies are required to determine the full effect of either carotid artery ligation or reconstruction.

Respiratory

This is an aspect of the child's health that requires close attention. The UK ECMO trial results (at one year of age) demonstrated that some children who had required respiratory ECMO had respiratory problems. These included ongoing requirement for supplemental oxygen or 'respiratory' medications, particularly bronchodilators as used in asthma. Interestingly, there was a higher incidence of respiratory complications in those babies who had received conventional intensive care (non-ECMO) treatment. Newborn babies who were supported for respiratory failure show a higher incidence of minor respiratory infections over the following couple of years but overall their lung function tests are within normal limits for their age. A small minority will have severe respiratory problems. If there are major respiratory concerns, the child should be referred to the local paediatric respiratory specialist and treated accordingly.

Psychosocial

Having a seriously ill child is obviously a very stressful time for the family and often they feel slightly isolated after their child has been supported with ECMO, particularly as this is such a rare form of treatment in this country. As such the family may need more input from local support services which should be coordinated by the primary caregivers. In addition, parents may feel very anxious about their child and this may lead to behavioral problems. If this is a concern, the family and child may benefit from referral to a local specialist. There is a parental support group for families who have received ECMO - please contact the ECMO office on 020 7813 8180.

Cardiac

Children who have received ECMO support for a cardiac condition will remain under the care of the cardiology team here.

Sensorineural Hearing Loss (SNHL)

ECMO patients are in a high risk category for potential SNHL secondary to their severe cardiorespiratory failure prior to ECMO and the use of potentially ototoxic drugs. Studies report a degree of SNHL in up to 15 per cent of patients. Therefore, any child who is suspected of a hearing loss or has a language delay should have formal hearing tests.

Miscellaneous

Neonates and infants often have difficulty establishing feeds after ECMO. A combination of reasons has been proposed but with perseverance, normal feeding will be achievable. The majority of children with no other associated problems will grow within the normal range. Problems with the cannulation and suture sites are rare. Sutures from the decannulation site should be removed after 7 to 10 days. The site should be checked for infection, aneurysm formation, abscess formation and retained sutures.

ECMO is not a contraindication for immunization and completion of immunization programmes is encouraged unless there is a known contraindication. If there is a need for blood tests or investigations, such as genetic analysis or immunological studies, these can be done about a week after the child has come off ECMO support.

Supraregional follow-up

Under current agreement, GOSH receives funding for all neonates and infants aged six months living in England who are treated with ECMO for respiratory failure. As part of this service, we offer a follow up appointment (general systems review) at the age of one year. If any major concerns are highlighted at this review, they will be referred to the local paediatrician for the appropriate intervention and follow-up.

There is always a member of the ECMO team here at GOSH available for consultation and advice on 020 7813 8180.

Here is a list of words and phrases used by the hospital staff looking after your child.

A.C.T.	Activated Clotting Time – a test that represents how long it takes for blood to form a clot.
ANTIBIOTIC	A drug which 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.
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 which evacuates air or fluid. Used to treat a collapsed lung (pneumothorax).
CHEST EXPLORATION	A surgical procedure to examine the chest cavity.
CLAMPED OFF	A trial period when your child is taken off ECMO before the cannulae are removed (de-cannulation).
COAGULOPATHY	Coagulopathy (also called clotting disorder and bleeding disorder) is a defect in the body's mechanism for blood clotting, causing bleeding.
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.
CONSULTANT INTENSIVIST	A physician who specializes in the care of critically ill patients, in an intensive care unit
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.
ECMO 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. Also called the Levitronix or CentriMag pump.
EEG	Electroencephalogram: Recording of the electrical activity of the brain.
HEPARIN	A drug used to prevent blood from clotting.

HEAD ULTRASOUND	A ultrasound scan of the head. Ultrasound can be used to examine the structure of the inside of the body.
INFECTION	An invasion of the body or part of the body by bacteria or virus.
INHALED NITRIC OXIDE (iNO)	Increases blood flow to the lungs.
INTRACRANIAL HAEMORRHAGE (ICH)	An abnormal bleeding in the brain.
INVASIVE	A technique involving puncture of the skin or insertion of an instrument or foreign material into the body.
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.
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.
VENTILATOR WEANING	Breathing machine used to put oxygen into the lungs through a tube in the windpipe. ECMO blood flow will be decreased gradually as the lungs/heart improve.

References

The following is a short list of some landmark papers concerning follow-up in children post ECMO. You may be able to order them on inter-library loan from your local library, although there may be a charge for this.

1. UK collaborative randomised trial of neonatal extracorporeal membrane oxygenation. UK Collaborative Trial Group. Lancet 1996; 348:75-82
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3. UK Collaborative ECMO Group. The Collaborative UK ECMO Trial: Follow-up to 1 year of age. Paediatrics 1998; p101.
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