



Great Ormond Street Hospital for Children NHS Trust: Information for Families

Berlin Heart Mechanical Heart Assist

This information sheet explains about the Berlin heart device which can be used to support children in heart failure, either until recovery or until a transplant is possible. It is not meant to replace detailed discussions with the team but is intended to act as a reminder of some points to be discussed about your child. We are happy to discuss any point which you want repeated or described in more detail. We will also give you further information about Great Ormond Street Hospital (GOSH). As the doctor has already explained to you, your child is very ill. The main problem is that your child's heart is not able to perform its usual job of effectively pumping the blood round the body. The doctors caring for your child believe that the artificial heart machine will provide support for your child allowing time either for recovery or to support your child until a new heart organ becomes available. The Berlin heart is designed to keep your child in the best possible condition in the meantime.

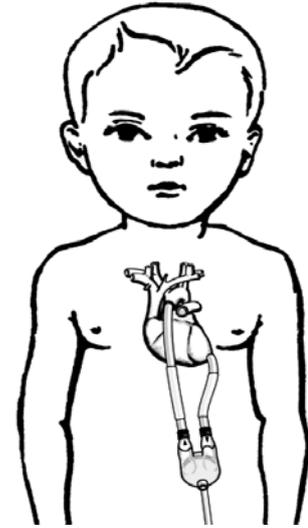


When is the Berlin heart used? _____	2	How will you take care _____	5
What is the Berlin heart? _____	2	of your child?	
How does it work? _____	2	Transfer to the ward _____	5
Insertion of the device _____	3	Support for you _____	6
What are the risks for your child? _____	3	Family involvement and _____	6
Heart Transplantation _____	4	enhancing normality	
How long will your child _____	5	A parent's perspective _____	7
be on the Berlin Heart?		Glossary of terms _____	8



When is the Berlin heart used?

The Berlin heart device is used in children whose hearts are no longer strong enough to pump enough blood around their bodies. There are many different types of conditions which can cause this need for support such as a weak heart muscle (cardiomyopathy) or an infected heart muscle (myocarditis). The device is used to allow time for them to reach transplant or in a small percentage of children, to recover. Unfortunately not all children with heart problems are suitable to be supported with this kind of device.



How does it work?

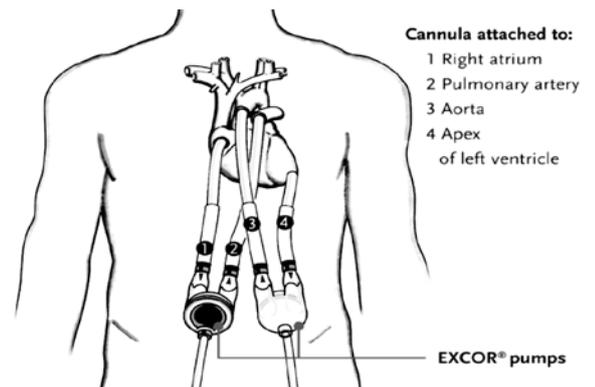
The heart assist device works by pumping air from the driving unit in to and out of the pumping chamber(s). There is a membrane between the air side of the chamber and the blood side. The movement of air into and out of the chambers causes the membrane between the air and blood to move, pulling blood into the chamber and then pushing the blood back into the heart and around the body.

If your child has a biventricular device, the right side chamber takes blood from the right side of the heart and helps pump this to the lungs. The left chamber takes the blood returning into the left side of the heart and pumps this back around the body.

What is the Berlin Heart?

The Berlin heart is a 'ventricular assist device'. It supports the work of your child's heart and helps to ensure blood is able to be pumped around the body effectively. It consists of a driving unit (pictured left), air hose and pumping chambers.

Your child may either need a 'left ventricular assist device' (LVAD) which only supports the left side of the heart, while the right side continues to work naturally (pictured top right). Alternatively, he or she may need a 'biventricular assist device', which supports both sides of the heart (pictures bottom right). The chambers are extra-corporeal, which means they sit outside of the body.





Inserting the Berlin Heart

In order for your child to have the Berlin heart device inserted, they will need to have an operation. This will be explained to you in greater detail by the surgeons and the anaesthetic team. The operation involves inserting the cannula in to the heart. To have this done your child will be supported with cardiopulmonary bypass (heart lung machine). While on this machine, blood that normally circulates through the heart and lungs is diverted through the heart lung machine. This machine maintains blood flow and oxygen to the body and vital organs and leaves the heart free of blood which makes it possible for the surgeon to complete the surgery.

The operation will take around six to eight hours. When your child returns to the intensive care ward they will be supported on a ventilator (breathing machine) and will require lots of medication to keep them settled and comfortable and to help support their heart. Your child will have many wires attached to them (as pictured below), these will be explained to you and you will have a chance to see the equipment before the operation.



What are the risks to your child on the Berlin Heart device?

Any child who requires the Berlin Heart device is very ill and without this support could possibly die before they were able to get a heart transplant. However there are risks associated with this device. By telling you about them we are not suggesting that they will happen but there is a possibility.

Whenever there is a tube inserted into the body there is an increased risk of infection. Signs of infection are monitored closely and treatment is given if needed. In addition, the tubes have a special coating which encourages the body to grow tissue around them, which makes it harder for an infection to track back up the tubes to the heart.

As the tubes connect the pumping chambers in the Berlin heart to your child's heart, it is important to stop clots forming within this circuit. This is done by thinning your child's blood with medicines. As the blood is thinner than usual and less able to form clots, this can cause bleeding problems at the operation site or any area where the skin is broken.

Neurological (brain) problems can occur. This can also be a problem due to potential clots from the child's own heart or the device, reducing the blood flow to the body or the brain. Bleeding complications can also occur and are worse in a child who requires the blood to be thinned using medication. The blood thinning effects will be regularly checked in your child to minimize these risks.



Clots from the device or your child's own heart can also enter the body and cause damage to other organs such as the kidney and liver. Clots in the device itself may necessitate a pumping chamber change, this is done in the operating theatre.

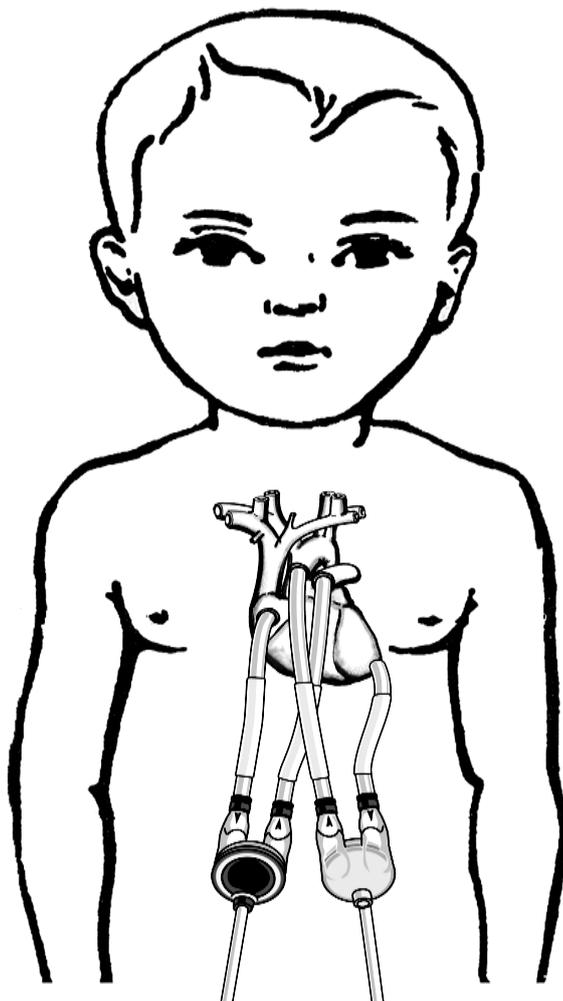
The Berlin heart is a mechanical device, and as with any piece of machinery there is always the possibility that it will develop problems. If this occurs your child may need to have the driving unit replaced with a new one.

Heart transplantation

A heart transplant is an option for children with serious heart conditions but it is not a cure. In most situations transplantation can lead to an extension of life with good quality which enables your child to return to normal activities.

Once your child has undergone a transplant they will have to take immunosuppressive (anti-rejection) medication everyday for the rest of their life. This medication prevents the body from rejecting your child's new heart. They will also need to be followed up closely at GOSH and this includes regular blood tests, outpatient clinics, biopsies and annual reviews.

If your child's condition does not improve the intensive care doctors will talk to you about a transplant assessment and refer you to the cardiac transplant team. At this stage the nurse specialist with the transplant team will come and meet with you and your children, if they are old enough, to discuss issues pertaining to transplant and answer any questions you might have. They will also organise for a few further tests to be carried out. Once these have all been completed they will be discussed with the medical teams and a decision will be made as to whether your child is suitable for transplantation. If this is the case the decision is yours as transplant is a choice and not one every family says yes to. If you decide to go forward for transplant then your child will be put on the active list and wait until a suitable offer becomes available, this can be very quick but can take months.





How long will your child be on the Berlin Heart device?

It is very difficult to predict how long your child will need support from the Berlin Heart as every child and his or her situation is different. Some children are only on the device for a few weeks while others can be on the Berlin heart for many months. There is no timeframe for finding a heart donor.



How will you take care of your child?

After connection of the Berlin heart, your child will return to the intensive care unit. He or she will need some support with their breathing and will be attached a mechanical breathing machine. Your child will be kept quite sleepy with medicines for this period, to ensure he or she is comfortable and is not too stressed.

You will be able to help with some aspects of your child's care if you feel able, such as cleaning their eyes or mouth. Once your child is more stable and the breathing machine has been removed, you can start to work with the nurses to familiarise yourself with the Berlin heart device.

Transfer to ward

After a few weeks on the cardiac intensive care unit (CICU), plans will be made to move your child to the high dependency unit (HDU) This area is situated on the cardiac ward. With support you can now start to take over more of your child's care, for instance wound dressing changes.

From the HDU and afterwards the ward, your child once well enough will be able to participate in school lessons and go to the play room. To enable your child to move around in and even outside of the hospital, the nurse will go through some teaching and competencies with you.





Support for you

We know this will be a difficult and stressful time for you and your family, so all members of the team are there to offer you support. Remember the team includes the doctors, nurses, physiotherapists, psychologists, liaison nurses and the ECMO team, all of whom can support you in different ways.

We recognise that having to stay in hospital for lengthy periods can put a huge pressure on a family, some of whom may be far away from family and friends.

The cardiac social worker can provide practical advice and assistance to children and their families, including advice on benefits and financial support. Your bedside nurse can give you directions to the social work department or they can arrange a visit to the ward.

Family involvement and enhancing normality

The time spent waiting for transplant while on the Berlin heart, is not necessarily lost time. With adequate heart function provided by the Berlin heart device, rehabilitation can be started prior to transplant. This can speed up recovery and shorten hospital stay following your child's heart transplant.

You and your family play an important part in your child's recovery and we are here to support you. Getting your child to be as active as possible, going to school, out to the park and generally trying to make this as normal as possible for you and your child, will enhance your time in hospital.

Although most children will be able to go out and about when they are feeling better, it is not always possible to do this when your child is receiving extra medication or support from hospital staff.



Ollie and his mum (see *A parent's perspective on following page*)



Parent's perspective

Ollie was diagnosed with 'Dilated Cardiomyopathy' aged seven months. As his heart condition deteriorated he was rushed to our local hospital where he spent three weeks in intensive care becoming increasingly frail and unfortunately suffered a cardiac arrest. Ironically it was on the same day that Mark and I had travelled to GOSH to discuss the option of Ollie becoming assessed for a heart transplant. This was something we had always hoped wouldn't be necessary but it was no longer possible to control Ollie's condition with medication alone.

One of the topics covered during the day was the option of Ollie being put on the 'Berlin Heart' which would 'bridge' him to transplant. This was something that neither Mark or I had ever heard of before, but time was running out and this looked like being the only option.

Whilst on CICU it became apparent that Ollie needed mechanical support for his heart and four days later the Berlin Heart (sized specifically for Ollie) arrived from Germany. Thankfully after a six hour operation Ollie was back on CICU and doing well. It was two days after Ollie's first birthday and the most fantastic present we could have wished for. We had been told what to expect but I must admit it felt odd to see Ollie's blood pumping through the cannula and to feel the warm pulsating diaphragm (VAD: Ventricular Assist Device).

Initially we were very cautious when handling Ollie due to the number of wires and tubes that were attached to him, but these reduced in number fairly quickly over the next few days leaving him attached only to the Berlin Heart. Over the previous three weeks we had become used to our little boy lying in his hospital cot ventilated and unable to do anything but amazingly within a few days of being extubated he began to interact and started eating from a spoon again which felt like a real step forward.

We soon moved onto Ladybird Ward and continued to be amazed by how much Ollie thrived whilst on the Berlin Heart. As parents we were very much involved in his care, for example we learnt how to change his dressings which became almost routine, we were also taught about the function of the Berlin Heart so that we could get off the ward and spend time in the Activity Centre, go to the coffee shop and spend time with his older brother and sister. We had fantastic support from the ECMO Team throughout Ollie's time on the Berlin Heart.

In all Ollie spent four months on the Berlin Heart before he received his transplant. Post transplant he has done really well and we feel so thankful that in Ollie's case the Berlin Heart was available as an option for us.

Written by: Edwina Drew.





Glossary

We try to avoid using abbreviations but some creep in to our language when we speak or write. We may also use medical words, which you have not heard before. The following list explains what they mean, but it is important to remember that this list contains meanings which apply to the heart and your child's treatment in the cardiac wing.

Some words may have different meanings if used elsewhere in the hospital. If you do not understand anything, do please ask us to explain again.

Antibiotic: A drug that slows the growth of or destroys bacteria or germs. Used to prevent or eliminate infection.

APT: Activated partial thromboplastin time – a test which measures the speed at which some parts of your child's blood clots. It is used to monitor the effect of heparin on your child and can help inform the doctors as to the dose that is required.

Arterial Blood Gas (ABG): A small amount of blood that is drawn from the artery and tested to determine the amount of oxygen and carbon dioxide it contains

Cannula: Plastic tube used for draining and return of blood to the body.

Cardiomyopathy: Deterioration or failure of the heart muscle, making it difficult or impossible to pump adequate blood supply to the body.

Cardiopulmonary bypass (CPB): A machine that temporarily takes over the function of the heart and lungs and supports the circulation while surgery is performed on the heart.



Chest drain: A tube placed into the space between the lung and the chest wall that removes fluid or air. Used to treat a collapsed lung or a build up of air around the lung (pneumothorax).

Echocardiogram (ECHO): Ultrasound scan of the heart.

Electroencephalogram (EEG): A recording of the electrical activity of the brain.

Heparin: A drug used to help prevent the blood from clotting.

Infection: The growth of an organism within or on the body.

Intracranial haemorrhage: An abnormal bleeding in the brain.

INR: A test which checks the effectiveness of your child's blood to clot.

Myocarditis: Inflammation of the heart muscle.

Nasogastric tube: A tube which is passed in to the stomach and used for feeding and medications.

Neuro: Relating to the brain.

Perfusionist: A person with specialised knowledge and training in cardiopulmonary bypass (heart/lung machine).

Platelets: Blood cells which help prevent bleeding.

Thromboembolism: Formation of a blood clot (thrombus) that breaks loose, and is carried by the blood stream to block another vessel.

Ventilator: An automatic breathing machine that moves air into and out of the lungs, through a tube in the windpipe.

Ventricular assist device: A mechanical device used to partially or completely replace the function of the failing heart.



Thank you to all the families involved with making this booklet and for providing the pictures used within it.

Thank you also to the Berlin Heart group for the medical pictures, available from www.berlinheart.com

Notes



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