Berlin Heart Mechanical Heart Assist

Information for families

Great Ormond Street Hospital for Children
NHS Foundation Trust

This leaflet explains about the Berlin Heart Ventricular Assist Device (VAD) which can be used to support children in severe heart failure, either until recovery or until a heart transplant is possible. It is not meant to replace detailed discussions with the medical team but is intended to provide some basic information and act as a reminder of the issues discussed. We are happy to discuss any points which you want repeated or described in more detail. We will also give you further information about Great Ormond Street Hospital (GOSH).

As your doctor has already explained to you, your child is very ill. The main problem is that your child's heart is no longer able to perform its usual job of effectively pumping blood around the body. Because of this, the doctors caring for your child believe that the best option would be to support your child's heart with a Berlin Heart Ventricular Assist Device, either until their own heart recovers, or until a suitable heart becomes available for transplantation.

When is the Berlin heart used?

The Berlin Heart is used to take over the function of a child's own heart when it becomes too weak to pump sufficient amounts of blood to the lungs and/or around their body. There are many different types of conditions which can cause the heart to fail, the most common being a weak heart muscle (Cardiomyopathy) or an infected heart muscle (Myocarditis).

The Berlin Heart pumps blood around the body in order to keep the brain and other organs healthy, allowing the child to grow and get stronger.

It will be required until the child is transplanted, or for a small number of children, until their own heart recovers.

Unfortunately not all children with heart problems are suitable to be supported with this kind of device.

What is the Berlin Heart?

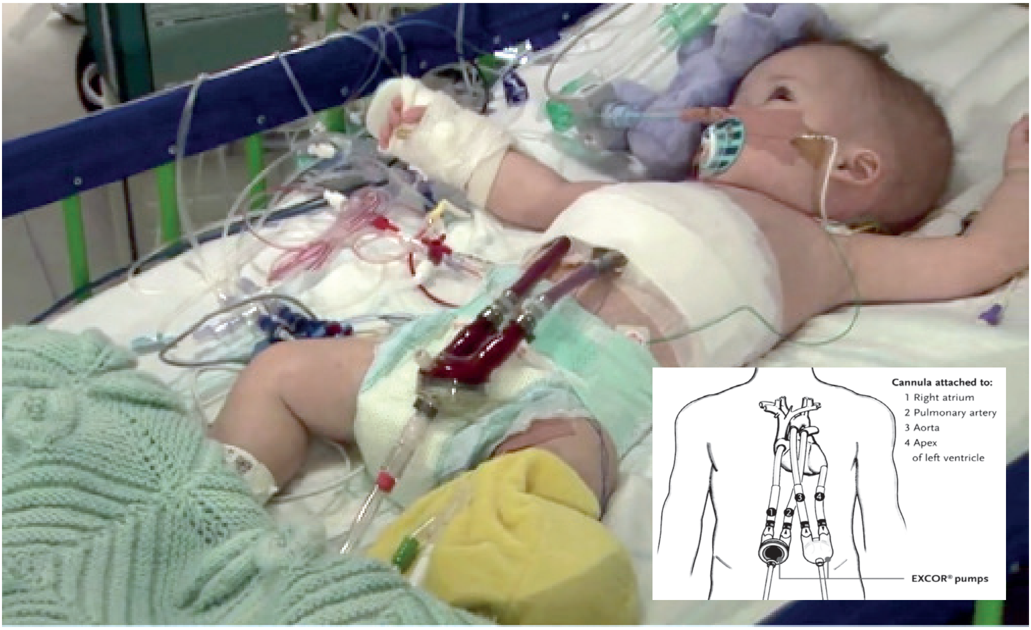
The Berlin heart is a type of "Ventricular Assist Device" or" VAD". It is a simple air driven pump which takes over the work of one or both sides of the child's own heart. Your child may need a single pump to support the left side of the heart whilst the right side continues to work naturally. This is known as a "Left ventricular Assist Device" or "LVAD". Some children need two pumps, one to support the left side of the heart and one to support the right. This is known as a Biventricular Assist Device or "BiVAD". Your Doctors will be able to let you know whether your child is likely to need an LVAD or a BiVAD before the operation, but you should be aware that this cannot be predicted with absolute certainty and the decision may change during the operation itself.

The Berlin Heart VAD consists of a plastic pump or chamber which sits outside of the body. It has a blood filled side and an air filled side, separated by a flexible membrane. The blood filled side of the pump is connected directly to the child's own heart and main artery by means of two tubes or "cannulae". The air filled side of the pump is connected via a long plastic tube or "driveline" to a driving unit.

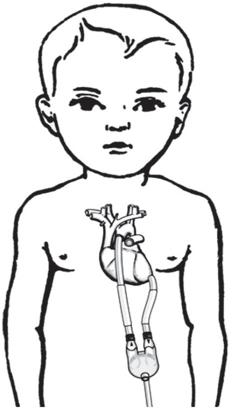
How does it work?

The driving unit simply drives air into and out of the Berlin Heart pump(s). As air is pulled out of the pump, the membrane separating the two sides of the pump is drawn back, pulling blood into the pump from the main pumping chamber of the child's own heart. As air is pushed back into the pump, the membrane is pushed forwards, pumping blood back into a main artery of the body.

If your child has a Berlin Heart supporting the left side of the heart (LVAD), then the blood that is pumped out of the Berlin Heart goes into the Aorta, the main artery which circulates blood all around the body.



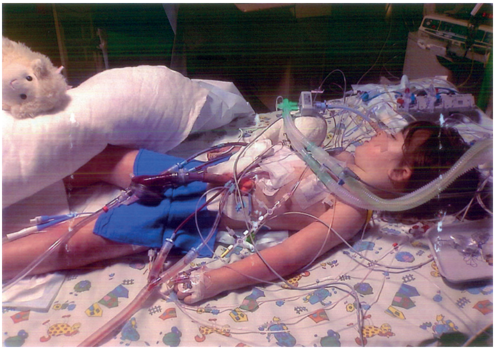
If your child has a Berlin Heart supporting the right side of the heart, then the blood that is pumped out of this pump goes into the pulmonary artery, which sends blood to the lungs to collect oxygen.



Inserting the Berlin Heart

In order for your child to have the Berlin heart implanted, 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 cannulae in to the heart and main artery. Your child will be supported with cardiopulmonary bypass (heart lung machine) while this is done.

The operation will take around four 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 sleepy 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?

The Berlin Heart can be a life saving device for children in severe heart failure, but it does have risks associated with it which you should understand before you agree to treatment.

The risks may be divided into four main categories, the risks surrounding the surgery itself, the risk of infection, mechanical problems, and the risk of stroke.

There are risks involved with any operation and the surgeons will explain this to you in more detail before the surgery takes place. The most common complication seen as a result of surgery is bleeding, and this will be monitored closely in theatre and on the intensive care unit and controlled where required by the transfusion of blood and blood products. Occasionally further exploratory surgery may be required on the intensive care unit in order to help to stop the bleeding.

Whenever there is a tube inserted into the body there is an increased risk of infection. Signs of infection are monitored closely and antibiotic treatment is given promptly if needed.

The third risk is the possibility of mechanical problems. The Berlin heart is a mechanical device, and as with any piece of machinery there is always the possibility that it will develop mechanical problems. These happen very rarely, and the Berlin Heart has many ‘backup’ systems and safety features to ensure the safety of the child should problems occur.

The final risk is the risk of Stroke. You will probably have heard of Stroke, it is a brain injury which happens mostly to older people. However children on the Berlin heart are also at risk of stroke.

The natural reaction of the blood when it comes into contact with the plastic of the Berlin Heart device is to form a clot. To try to prevent this, the children are given blood thinning medicines and the effect is monitored closely. Despite this, clots can still form over time, and you will see us looking closely at the pump with a torch every few hours to check for this.

If a clot is seen in the Berlin Heart pumping chamber then the pumping chamber may need to be changed. This is a relatively short and simple procedure which is done in the operating theatre, and will be explained to you if it is needed.

Sometimes a clot can “fly off” from the pump and enter the child’s blood stream. If the clot is carried to the brain then it can cause damage to the brain tissue, and this is what we know as a stroke.

Roughly two to three children out of every ten that we put onto the Berlin Heart will experience a stroke.

This may cause problems with movement and speech, or even problems with hearing or seeing or their ‘higher functions’ (parts of the brain that do our thinking, control our personality). In many cases children recover and adapt, returning to normal activity in a matter of weeks.

However, some may be left with a permanent problem with speech or movement, and in some children, the damage is so severe that the children die despite our best efforts.

These risks do sound very frightening, but must be considered in the context of the severity of the child’s heart failure, and the poor outcome for the child if they are not given Berlin

Heart support. Approximately eight out of every ten children who are placed on Berlin Heart support will survive to transplant or recovery.

Heart transplantation

For most children, the Berlin Heart is used as a “bridge to transplantation”, that is, a way to support your child until a suitable organ becomes available for transplantation. The decision to agree to transplantation is entirely yours, though we will support you through this and ensure you have all of the information you need. Should you choose not to agree to transplantation then we will respect this decision, but your child is unlikely to be offered Berlin Heart support under these circumstances unless there is a good chance of your child’s heart recovering after a period of time.

A heart transplant is a good 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 every day 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, with regular blood tests, outpatient clinics, biopsies and annual reviews.

If it is likely that your child will need a heart transplant, then this will be thoroughly discussed with you by the transplant nurses and doctors before you have to make any decisions about the Berlin Heart.

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 surgery to implant 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 initially, ensuring that he or she is comfortable and is not too active. 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, or perhaps rubbing moisturising cream onto the skin. Let the nurse caring for your child know if you would like to get involved. Your child will be monitored very closely by the nursing staff at this time.

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, and if you feel ready, to start to learn how to do the Berlin Heart wound dressings.

Sometimes children have needed a lot of medicines to keep them sleepy, or to help them tolerate being on a breathing machine, before they go onto a Berlin Heart. If so, it may be necessary to reduce these medicines slowly to avoid children getting withdrawal symptoms. This can sometimes be a difficult period for families as reducing the medicines can temporarily make children feel quite low in mood, restless and clingy. Distraction is helpful during this time, and bringing in your child's favourite toys, music or story books can be helpful.

Once children are stable on the Berlin Heart, they will usually need to return to theatre for a further small operation to insert a long term central venous catheter. This can be used for giving medicines and taking blood. Regular blood tests are essential for children on the Berlin Heart to allow the effects of the drugs given to thin the blood and prevent clots to be monitored. The central venous catheter allows us to take these blood tests painlessly.

Transfer to ward

After approximately two to four weeks on the cardiac intensive care unit (Flamingo ward), plans will be made to move your child to the high dependency unit (HDU) of the cardiac ward (Bear ward). With support you can now start to take over more of your child's care, and start to establish a more normal daily routine.

We encourage parents where possible to learn to do the dressings around the area where the Berlin Heart cannulae enter the skin. There are two main reasons for that, firstly is that it helps you to establish a routine with your child, where dressings always get done before breakfast, or before bedtime for example. This level of routine is not possible with a nurse doing the dressings as they may be caring for other patients and be busy at the desired time. Secondly, and most importantly, having the same person(s) doing the wound dressing consistently keeps infection rates low, as it allows for any small changes in the appearance of the wound to be noticed as early as possible, Please don't worry about this aspect of care as you will be well supported by the nursing staff until you are confident.

On the ward, once well enough, your child will be able to participate in activities and/or schoolwork, and will be able to leave the ward at times to go the hospital activity centre, physiotherapy gym, coffee shop, or even outside of the hospital building. To enable you to have a little more freedom the nursing staff will do some teaching with you and you will be given a Berlin Heart training "competency book" to work through. Again, please don't let this worry you, there is no rush to do this before you feel ready, and most parents find that they pick up an awful lot of the information they need to learn just by spending time with their child every day.

Family involvement and enhancing normality

The time spent waiting for transplant while on the Berlin heart, is not necessarily lost time. With appropriate stimulation your child will continue to learn and develop, and with adequate heart function provided by the Berlin heart device, physical rehabilitation can be started before 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 helping your child's to continue to meet physical, developmental and educational milestones whilst on the Berlin Heart, and our team of physiotherapists, school teachers and play workers are here to support you. They will be able to provide age appropriate toys and activities to keep your child stimulated, and help you to develop a normal daily routine

Support for you

Having a child on the Berlin Heart can be a difficult and stressful time for families. You may have had a challenging period immediately prior to the Berlin Heart being inserted as a result of your child's deterioration in their cardiac condition or your child may have become acutely unwell after being fit and healthy. Either way, the journey to the Berlin Heart can be traumatic and upsetting.

Waiting for a donor heart to become available whilst your child is living in hospital on the Berlin Heart can be challenging and even though you might feel thankful that your child is being supported by this device, it is very normal to also feel sad, worried and angry at the situation. It can feel hard to wait for an undefined length of time and families often need to spend time apart, maintaining homes, jobs, and a degree of normality for other siblings. 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 their extended family and friends.

To help support you and your family with these difficulties, we have a dedicated paediatric psychologist and a specialist nurse who can offer support. These members of the team will make contact with you early on in your child's admission, sometimes even before, and provide regular support for you throughout your stay here. In addition, there is also a cardiac psychosocial team consisting of a social worker, family support worker (for practical and financial advice and support), chaplains (for religious and spiritual support) and play specialists (who can help prepare children for procedures and set up activity timetables to provide structure and routine to their day). Your bedside nurse can tell you how to contact these professionals or they can arrange a visit to the ward.

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.

APTT: 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.

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 (now renamed Bear) 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.

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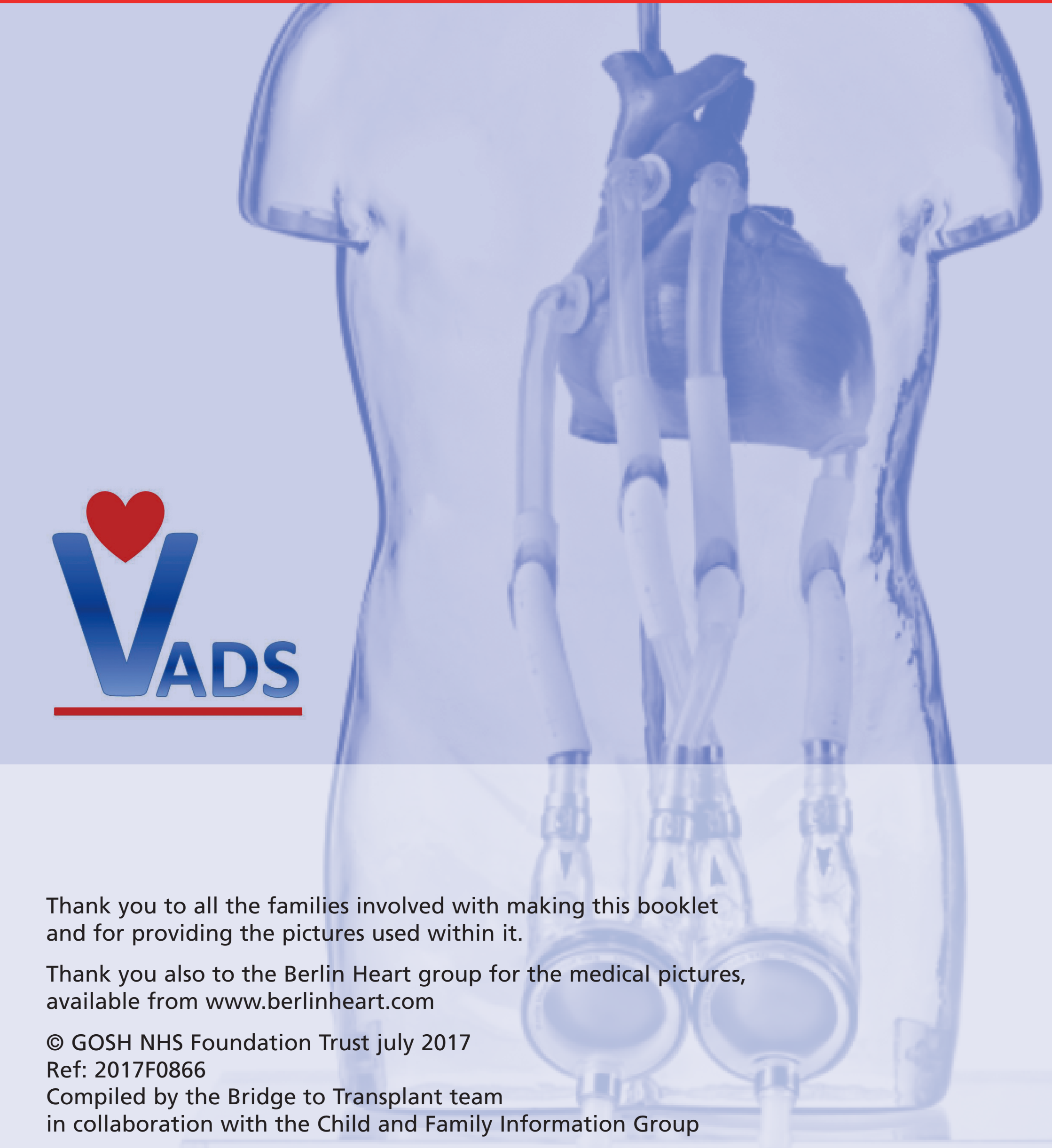

Thank you to all the families involved with making this booklet and for providing the pictures used within it.

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

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