



Heart transplants

When a transplant is needed

A heart transplant is only offered to a child as a last resort – when no other form of treatment is available for their heart disorder:

- The child may have developed a heart muscle disease, which can reduce heart function, be associated with abnormal heart rhythms, or increase pressure in the lungs. Sometimes these can be helped with medications, but if medication doesn't help enough, transplant might be considered. This is the most common reason for transplant in children.
- The child may have been born with a heart defect and had a number of surgeries but reached a stage where the heart cannot support the body's demands on it.

Assessment

Some children may present to hospital in such end stage heart failure that heart transplant is considered on their first admission, and others may have been diagnosed for many years before a transplant is needed; in every case, a careful assessment by the doctors and nurses of the transplant team will be required.

The assessment is usually carried out over several days. This can be a very draining experience as so much depends on the outcome. Sometimes test results will have been sent from another hospital, but often a series of clinical tests will be carried out. If the child is 16 - 18 the transplant may be carried out at an adult unit. There are only two hospitals that carry out children's heart transplants in the UK – Freeman Hospital in Newcastle-on-Tyne and Great Ormond Street Hospital, London (GOSH).

There is a transplant team at these hospitals who will look after the child and the rest of the family during the assessment, surgery and aftercare. The assessment is an opportunity for parents or carers to find out anything they need to know about the surgery, the drugs that are used afterwards and the practicalities - accommodation, school life, dealing with employers, and coping with problems when at home.

Even though there may be no alternative form of treatment a child may still not be offered a transplant.

These are some situations which could result in a transplant not being offered.

- If a child has other medical problems that would limit the success of transplantation.
- If the child's circulation makes it too difficult to insert a new heart.
- If the lung pressures are too high for the new heart.
- If the child is too ill for the operation.

A shortage of suitable organ donors means that sadly not everyone who goes on the to the transplant list will get a new heart.

Waiting for transplantation - guidance for parents or carers

Be aware of who to contact if a child's condition deteriorates – this may be the transplant hospital, or it may be the cardiologist, social worker, cardiac liaison nurse, or any other health professional who looks after your child. You may want help with preparing a child, particularly an older child who needs to understand this treatment before giving his or her consent.

Waiting for a suitable organ to become available can be very hard and timing is unpredictable it could be days, months or years – you will need to be contactable by mobile phone at all times so that you can be contacted as soon as your child needs to go to the transplant unit.

Have a bag packed ready at all times and have arrangements in place for someone to look after your other children. It is not unusual for there to be one or two false starts – perhaps because the donor organs are not suitable. The transplant team will explain the risks that your child is taking, either to you or to your child if he or she is old enough to give consent.

Obtaining organs

When an organ becomes available anywhere in the country, the duty office at UK Transplant is notified immediately. The organ is offered to the person of the right size and blood group who has been longest on the urgent waiting list; if there is nobody on the urgent list, it will be offered to those on the non-urgent list.

Hearts that become available in another country can be offered here as well.

Mechanical support is possible for some children so that a child whose heart has failed can be kept alive while an organ is being found. This may be in the form of ECMO (extra corporeal membrane oxygenation) – a complicated heart and lung bypass machine which can keep a child alive up to several weeks. Or a VAD (ventricular assist device), which works like an external mechanical heart. This device may be needed for several months and in some cases, several years.

The surgery

Consent to surgery will be required from parents or carers and if old enough from the child their self.

To protect the new organ, they will be given anti-rejection drugs – these suppress the immune system which will otherwise attack and damage the new heart.

Contact CHF for more information, resources, support and advice

info@chfed.org.uk | infoline: 0300 561 0065 | www.chfed.org.uk

Children's Heart Federation is a Registered Charity No. 1120557 and a Registered Company by Guarantee in England and Wales No. 6329763

If, as usually happens, the new organ comes from another hospital it will first be examined for damage or deterioration. If the donor died in the same hospital, the organ will be removed a short time before the child is prepared to receive it.

The operation can be a few to several hours – for example, if your child has had other surgery, it may be more difficult to control bleeding making the procedure take longer.

After surgery

It is not uncommon for a child to pick up an infection, such as a chest infection or an infected wound, while undergoing surgery and intensive care.

The first hours and days after the operation are crucial. The new heart is always affected by the process of donation and transfer, and may not work very well to start with. All patients remain on the ventilator for the first few days, and some may require high doses of intravenous medicines, or even ECMO support for a period. Despite this, most hearts recover over the course of the first few days. It is also important to support the rest of the body during this time, and some patients may require a form of dialysis early on to help their kidney function; again, this is usually only for a short period. Most children recover very quickly and an average stay in hospital including surgery is 10 to 14 days but this time can vary greatly.

Some children also react badly to certain medicines. For the first few days after surgery, the child will be in an area of the hospital that is kept as infection free as possible.

During this time their drugs will be adjusted. They will be encouraged to get out of bed as soon as possible, and to eat and drink as normal.

There are often short periods when rejection (the body's attempt to damage the new heart) occurs and they will need to be treated immediately.

Parents or carers may be able to stay with the child in a family flat near the hospital to learn how to cope with the drugs in a domestic setting before going home.

Once home the family's first concern will be keeping the child away from infections, maintaining the stock of drugs, and attending hospital appointments, it will feel surprisingly busy after the time spent waiting around in the hospital.

Drugs used for children after transplant are improving constantly, but side effects can include:

- Rapid weight gain if steroids are used – again worse in the first few months
- Shaky hands – in the early months
- Swollen gums
- Nausea
- High blood pressure
- Poor kidney function
- Skin conditions - eg. eczema
- Psychological problems – with having another heart, or with scarring for example

The transplant team will give guidance if there is any concern about side effects.

Blood tests have to be taken to monitor the level of anti-rejection drugs. These may be frequent initially, and then every few months – it may be possible to arrange for these to be taken at a local hospital or by community nurses. Ask the hospital to liaise with your GP, health visitor or local paediatrician if you can't find a way to sort it out yourself.

Children of school age may have some problem reintegrating. Many children do not want to have a transplant discussed until they have got used to the idea themselves. Children should be asked what they want their school friends to know, and who should tell them. The school will also need any information that will keep the child safe – eg how to handle what could be a rejection episode – and any other effects of a long illness.

Some children find it hard not to be the centre of attention, especially if they were very ill for a long time.

The transplant team psychologist should be able to suggest a way of dealing with this kind of problem.

Some parents find that other children in the family become more problematic, difficult and uncooperative. Asking members of the family, especially grandparents, to give other children special time can save them from feeling they have been ignored.

"The hardest thing that many families have to deal with is the belief other people may have that, with a new heart, your child's troubles are over. Transplantation is not a cure – it is the swapping of a life threatening scenario for a medically managed condition." - parent of heart transplantee

Medical intervention will go on throughout the child's life, and their future will be uncertain.

Parents and carers may like to make contact with other families who have also experienced their child being an organ donor recipient or who have a serious heart condition. **Pulse parents** is a forum run by CHF where parents can chat about their experiences in a safe way.

Help and support

Looking after a child with a serious heart condition can be hard both physically and mentally for family members. If a child is offered a heart transplant this is often at very short notice and parents have reported feeling "out of their depth" or "lost".

Preparing a young child for a heart transplant

CHF produce Molly's Dollies for children having any sort of heart surgery. They also produce *Sky the expert* a little book for children which follows the day of a boy with a heart condition who needs an operation. Contact CHF for more information.

GOSH also produce a book for young children called My New Heart.

The following list of organisations and websites is recommended by the parent of a child who had a heart transplant.

Public Health England have a simple and quick quiz. It asks questions about how you are feeling, then gives you a short list of potential actions to take.

Your mind plan

Talking therapies can be helpful, MIND produce a pdf explaining how this works it can be downloaded below.

Talking therapies

The **NHS website** provides advice on caring for a child with complex needs.

Caring for a child with complex needs

Contact provides advice on looking after you and your family's wellbeing.

Family life, work, and childcare

Help, advice and benefits for carers and young carers

Carers

Young carers

Benefits for carers

Evidence and sources of information for this CHF Factsheet can be obtained at:

NHS Choices

Heart transplant

What happens during a heart transplant