



Children's Liver
Disease Foundation

fighting childhood
liver disease

Liver Transplantation

An Overview



General information on liver transplantation in
children and young people

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This information has been written for:

- Parents/carers of a child with a liver problem which may require transplantation
- Family and friends of a child with a liver problem which may require transplantation
- Young people who want to know more about liver transplantation

You may find it helpful to read the following CLDF leaflet:

- An Introduction to Liver Disease

This leaflet provides a brief overview of transplantation. More detailed information, called "Stepping Stones in Children's Liver Transplantation", is available for the families of children being considered for liver transplantation. It explains each step of the process and is available only from the specialist centre treating your child. You will be given a copy of the information if your child is being considered for liver transplantation or you can ask your transplant co-ordinator for a copy.

There are also leaflets available from CLDF on specific conditions which you can download or order online.

What is a liver transplant?

A liver transplant is an operation to remove a person's liver and replace it with all, or part, of another person's liver.

When does a child or young person need a liver transplant?

A child needs a liver transplant when their liver is damaged, isn't working properly and isn't likely to recover.

There are many different conditions which can lead to liver damage.

A team of liver experts decide when a child's condition means that they need a liver transplant. Before deciding whether a child can be added to the transplant list, a transplant assessment must take place.

Deciding that a child should be added to the transplant list is a difficult decision. Liver transplantation isn't a cure for liver disease and does bring its own set of medical problems. However, for many children with liver disease a transplant can mean living longer with a much better quality of life.

What is a transplant assessment?

A transplant assessment is a process which involves a number of medical tests and meetings with professionals who work in the liver team. The assessment aims to find out if a liver transplant is necessary for your child and if it's the best treatment option.

It's also an opportunity for families to meet with the team to get more information about the transplant process. The team you will meet with includes a number of different healthcare professionals including a psychologist and a social worker.

Normally, the transplant assessment takes place over a number of days. It can sometimes involve an inpatient stay where your child may need to stay in hospital overnight.

If a transplant is urgent, the assessment can take place over hours rather than days.

Following the assessment there are a number of possible outcomes:

- Your child will be placed on the transplant list
- Your child can't go on the transplant list now but can in the future
- It is not suitable for your child to go on the transplant list

What happens if my child is listed for transplant?

Usually children will wait at home until a suitable liver is available. Sometimes, if your child is very unwell, he/she may need to wait in hospital until a liver is available.

Your child must be ready to go straight to the hospital at any point, day or night. This can include having someone on hand to look after your other children or to ensure someone can care for your pets. Helping you to be prepared is all part of the transplant assessment process and your healthcare team will support you to make all of the necessary arrangements.

How is it decided who will get each liver?

Many people believe that the waiting list is like a ladder; that a child's name is added to the bottom rung and moves up the ladder when the person at the top receives a transplant. This is not the case.

When a donor liver becomes available the surgical and medical teams decide who should receive the liver. They do this using a set of guidelines which include the child's blood group, the size of the liver and how urgently the child needs the liver.

Where do children's liver transplants take place?

There are three paediatric liver centres in the UK. All children's liver transplants take place at one of these centres:

- King's College Hospital, London
- Birmingham Children's Hospital
- Leeds General Infirmary

What are the long term survival rates after liver transplantation?

The good news is survival rates are very high and are constantly improving. 90 out of every 100 children who have a liver transplant survive for at least five years. 75 out of every 100 children who have a liver transplant survive for at least 15 – 20 years with a good quality of life.

What are the risks of liver transplantation?

There are a number of different complications which may occur. These include a small risk of the new liver not working properly, blockage of one of the new blood vessels, rejection of the new liver, infections, problems with the bile ducts (biliary problems) and the risk of a hole in the small intestine (bowel perforation).

There are also other complications that can arise which are less common. These will be discussed with you in detail prior to transplantation. Patients are closely monitored at all times before and after the transplant so that any complications can be dealt with as early as possible.

What are the different types of liver transplant?

Split Liver

This is the most common source of livers for children. The liver from a donor who has died can be divided into two parts so that two patients can benefit from one donor's liver.

The liver can be split into two lobes with the right lobe being given to an adult or an older child, and the left lobe or a left lateral segment (part of the left lobe) going to a young child. The cut surfaces are sealed and the new piece of liver grows with the patient.

Living Donor Transplantation

In many situations, it is possible for somebody the child knows to give him/her part of their liver. The donor has to be carefully assessed to see if they are suitable and not everyone who would like to donate part of their liver is able to. If you would like further information about this, speak to your medical team.

The following types of liver transplant are also undertaken in children, but in smaller numbers:

Whole Liver

In this type of transplant, the liver is an appropriate size for the child and the whole liver is used.

Cut Down (Reduced Graft)

A liver can also be made smaller so that it is the correct size for the child who is receiving it; in this type of transplant there is only one recipient.

Auxiliary transplantation

In certain types of liver disease, particularly some metabolic diseases, part of a donor liver can be transplanted alongside a child's own liver. The transplanted liver is able to carry out the functions of the liver which are not performed by the child's own liver. This type of transplant may also be carried out where there is the possibility of the child's liver recovering, as can occur in some cases of acute liver failure.

What will happen immediately after my child's transplant?

At the end of the operation your child will be taken to the Intensive Care Unit (often shortened to ICU, ITU or PICU). The surgical team will give you feedback about the transplant procedure and any other updates regarding your child's condition. The new liver will be carefully monitored by scans and blood tests.

Your child will return to the ward to continue his/her recovery and rehabilitation when they are well enough.

The nurse specialist team will visit you to tell you how to take care of your child at home with the support of your child's GP. This includes telling you about the medication your child will need. When your child leaves the hospital they will be followed up with regular outpatient appointments and regular blood tests.

Does a liver transplant solve all of a child's medical issues?

Unfortunately, whilst a liver transplant is an option to treat liver disease, it is not a cure. It can offer a child a real improvement in their quality of life for many years but it is a serious procedure which comes with many of its own issues. Children require medication for the rest of their life and will need to be monitored; however, there are many adults who were transplanted as children who are now healthy and living full, active lives.

I am a parent of a child with liver disease - who can I speak to if I have any further questions regarding transplantation or support services?

If your child has been listed for transplant then your transplant co-ordinator can guide you through the process and answer any questions you may have. Your transplant co-ordinator can give you further information leaflets, called "Stepping Stones" in Children's Liver Transplantation, which focus on each step of the transplant process in more detail. Your consultant and clinical nurse specialist are also there to answer any questions you have regarding transplant and, of course, CLDF is always here for support and advice.

Contact families@childliverdisease.org, call 0121 212 6023 or join www.healthunlocked.com/cldf

CLDF produces a wide variety of information resources for children and young people up to the age of 25 with liver disease, their families and the healthcare professionals who look after them. This information can be downloaded or ordered from CLDF's website www.childliverdisease.org. For further enquiries regarding CLDF's information please contact the Health and Research Information Manager by email at hrim@childliverdisease.org or call 0121 212 6029.

Thanks

This booklet has been written, edited and reviewed with the help of staff at each of the specialist paediatric liver centres: Birmingham Children's Hospital, King's College Hospital and Leeds Children's Hospital. Thank you to all of the staff involved who have made the production of this leaflet possible.

Disclaimer

This leaflet provides general information but does not replace medical advice. It is important to contact your/your child's medical team if you have any worries or concerns.

Feedback and Information Sources

Information within this leaflet has been produced with input from the three specialist paediatric liver centres in the UK. To provide feedback on this leaflet, for more information on the content of this leaflet, including references and how it was developed, contact Children's Liver Disease Foundation: info@childliverdisease.org

This leaflet has been reviewed in June 2017. It is due to be reviewed by June 2020.

What is Children's Liver Disease Foundation (CLDF)?

CLDF is the UK's leading organisation dedicated to fighting all childhood liver diseases. CLDF provides information and support services to young people up to the age of 25 with liver conditions and their families, funds vital research into childhood liver disease and is a voice for everyone affected.

Are you a young person up to the age of 25 with a liver condition or a family member? CLDF's Families and Young People's teams are here for you, whether you want to talk about issues affecting you, meet and share with others, or just belong to a group which cares, knows what it's like and is fighting to make a difference. You are not alone.

If you are a parent/carer or family member then get in touch with CLDF's Families Team:

Phone: 0121 212 6023 **Email:** families@childliverdisease.org

If you are a young person and want to find out more about CLDF's services you can contact CLDF's Young People's Team:

Phone: 0121 212 6024 **Email:** youngpeople@childliverdisease.org

CLDF have a social media platform called **HIVE** for 11 – 25 year olds with a liver disease/transplant to make new friends, connect and share stories
www.cldfhive.co.uk

Would you like to help us support the fight against childhood liver disease?

All of CLDF's work is funded entirely through voluntary donations and fundraising. Please help us to continue to support young people, families and adults diagnosed in childhood now and in the future. To find out more about fundraising and how you can join the fight against childhood liver disease you can visit www.childliverdisease.org/get-involved. Alternatively, you can email the Fundraising Team at fundraising@childliverdisease.org or call them on **0121 212 6022**.

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