

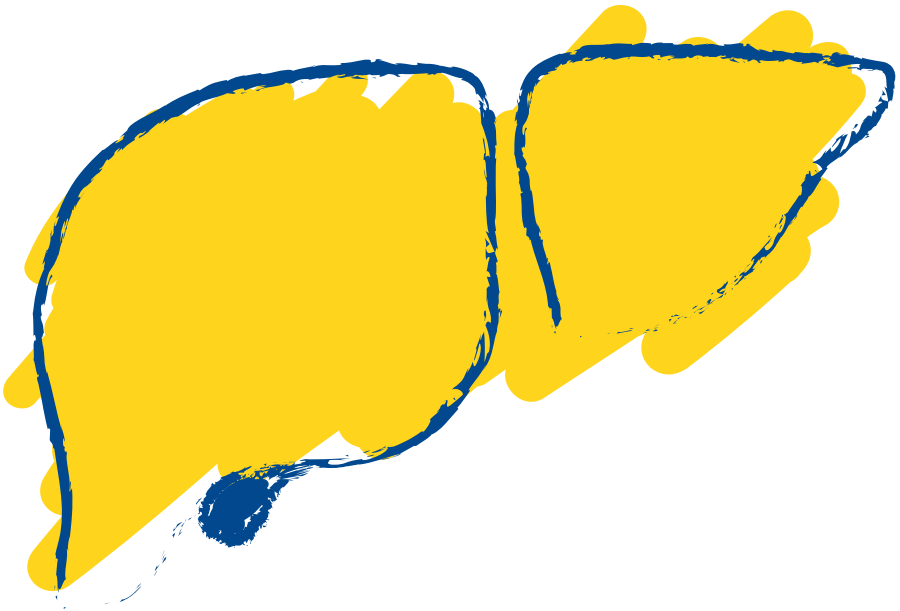


Children's Liver
Disease Foundation

fighting childhood
liver disease

Acute Liver Failure

A Guide



An explanation of what Acute Liver Failure is,
symptoms, diagnosis and treatment

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This information has been written for:

- Parents/carers of children with acute liver failure (ALF)

This leaflet provides information about ALF in children, its causes, symptoms, tests and advice on looking after yourself.

You may find it helpful to also read the following CLDF leaflets:

- An Introduction to Liver Disease
- Liver Transplantation - An Overview

Introduction

ALF is a rare, serious condition. It usually happens suddenly and can feel quite overwhelming. There is always help and support available to you via the nurses in the hospital and through CLDF's Families Team. The early symptoms are often similar to common childhood illnesses so families and healthcare professionals often don't identify it at first.

In the past ALF has been called fulminant liver failure.

What is ALF?

ALF is when liver cells suddenly die or stop functioning normally. It may happen suddenly over a few days or more gradually over weeks.

What can cause ALF?

Some possible causes include:

- Infections
- Metabolic diseases
- Autoimmune liver disease
- Blood disorders
- Medication (including alternative medicines)
- Paracetamol overdose (often accidental)
- Recreational drugs, especially ecstasy
- Poisonous substances
- Complications caused by another illness

In many cases it is not possible to find a specific cause.

What are the signs and symptoms of ALF?

The signs and symptoms can vary but often include:

- General symptoms of feeling unwell
- Abdominal pain
- Nausea and vomiting
- Weight loss
- Jaundice
- Poor blood clotting (coagulopathy) which may cause bruising and bleeding
- Low blood sugar levels (hypoglycaemia)
- Fluid and salt imbalance including swelling e.g. abdominal swelling and lower leg swelling
- Encephalopathy (changes within the brain's functions) can cause symptoms ranging from a loss of concentration and irritability to drowsiness

Why does my child need to go to a specialist hospital?

Your child will be transferred from a local hospital to a specialist centre so they can be looked after by a team who have more experience looking after children with ALF.

The team caring for your child will:

- Recognise and treat complications as early as possible.
- Look for the cause of the ALF and, if found, start appropriate treatment.
- Support your child's vital functions. Your child may need to be cared for in the intensive care unit.
- Prepare your child for a liver transplant in case this becomes necessary.

There may be clues about the cause of your child's current illness from their previous overall health and development. You are likely to be asked many questions by a number of different people. Some of the questions may seem strange but are important. You may be asked about changes in your child's behaviour. This can suggest the development of encephalopathy which can be caused when the liver is not working properly. (see below for an explanation of encephalopathy).

What tests may be needed?

The tests will vary for each child and the clinical team will discuss these with you.

Tests may include:

- Blood tests including liver functions tests (LFTs) and tests to measure blood clotting. Your child will probably have to have a number of blood tests over the course of days to weeks. This is the best way of monitoring if the liver is getting better or worse and planning the next treatment.
- Urine tests
- X-rays / scans
- A liver biopsy
This may be a specialist type of biopsy called a transjugular biopsy which is safer for children if their blood isn't clotting properly. A piece of liver is removed through a vein in the child's neck.
- In some cases skin and muscle biopsies are required.
- Some test results are available the same day; others can take longer

The purposes of the tests are:

- To find out the cause of the ALF
- Assess how severe the liver failure is and whether it is getting better or worse over time.
- To detect any possible complications early

What are the complications of ALF?

Complications may include:

Abnormal bleeding

The liver plays an important role in producing proteins, called blood clotting factors, which help the blood to clot. If the liver isn't working properly, these may not be produced which can lead to bleeding in any part of the body.

Measuring the rate of blood clotting is a useful way to assess whether the liver is getting better or worse. Blood clotting may only be treated if there is bleeding or your child needs any procedures that may put him/her at risk of bleeding. Blood clotting factors may need to be given to treat this.

Infection

The liver plays an important part in fighting infection. ALF makes it more likely for a child to get an infection. Your child may be given intravenous (through the vein) antibiotics and anti-fungal medicines to prevent infection. Any specific infection identified will be treated.

Encephalopathy

Encephalopathy can occur because the liver is unable to clear toxins from the blood properly. This can lead to irritation and swelling of the brain.

If there is a decrease in your child's level of consciousness, leading to drowsiness, irritability or behaviour which is out of character, they may need to be cared for in an intensive care unit. A ventilator (breathing machine) may need to be used to allow a child to completely rest and enable additional treatment to be given.

Other treatments such as a form of dialysis may also be needed to try and rid the body of toxins.

Encephalopathy can be very difficult to assess and it can change from one minute to the next. For example, one minute a young child may be very sleepy and the next minute they may be sitting up in bed drinking a bottle.

Poor kidney function

When the liver fails the kidneys may not work as well as they should. In this case children are given fluids via a drip and a medicine to help them pass urine. They may also need a urinary catheter to accurately measure their urine output. Some children may need help from kidney dialysis for a short time.

When is liver transplantation needed for children with ALF?

Some children make a complete recovery without the need for liver transplantation. The liver has the ability to recover quickly despite significant injury and sometimes a full recovery is possible.

If your child's liver will not recover by itself and the doctors think that a liver transplant is the best option, your child will be referred to the transplant coordinator. They will register your child and provide you with more information on the transplant process. Supportive care and treatment will continue.

Your child will have to wait for a suitable liver which is matched in terms of blood group and size. Children with ALF are given priority. Most children receiving a liver transplant will make a full recovery and although they will require lifelong medication, the majority will be able to lead a normal life.

Looking after yourself

If your child gets ill very quickly the stresses and demands placed on you may affect you physically. It is important that you look after yourselves and accept any support offered.

When you are in hospital with your child you should try to take rest breaks when possible. Remember to eat and catch up on sleep whenever you can.

There is a lot to understand and come to terms with in a short space of time and asking questions is really important. You will be offered opportunities to meet with the team looking after your child and you can talk to the team about any questions you have. It might help you to write these down as they come to you so you remember what you would like to ask.

Where can I find help and support?

Other family members, for example grandparents, can feel isolated and helpless. As well as the concern for their grandchild, they will also be worried about their children. It often helps if you keep everyone informed about your child's condition and have leaflets for other family members to read so they understand what is happening.

Leaflets can be downloaded from CLDF's website, ordered using the form on the website, or obtained from your healthcare team.

CLDF's Families Team can also provide you with support and advice at the time your child is ill and in the future. Get in touch using the details at the back of the leaflet for more information.

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 us by email at info@childliverdisease.org or call 0121 212 3839.

Thanks

This booklet has been written, edited and reviewed with the help of staff at each of the specialist paediatric liver centres: Birmingham Women's and Children's NHS Foundation Trust, 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 September 2020. It is due to be reviewed by September 2023.

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, 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 young people with a liver disease/transplant to make new friends, connect and share stories.

childliverdisease.org/young-people/hive

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

CLDF's work relies on voluntary donations and fundraising. Please help us to continue to support children, young people and families 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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