



The new name for the British Liver Trust
and Children's Liver Disease Foundation

Introduction to liver disease in children



Help, support and guidance
for children and families

Contents

About the liver	4
What problems can affect the liver?	6
What signs are there that a child may have liver disease?	7
What tests are used to diagnose and monitor liver disease?	8
What treatments are available?	14
Useful resources	16
How we produce information	17

Welcome

Welcome to your guide to understanding liver disease in children and young people. It provides general information on signs and symptoms, diagnosis and treatment.

This information has been written for:

Parents and carers of children and young people with liver disease.

There are over 100 different liver conditions which can affect children. This booklet is designed to help you understand the basics of liver disease in children.

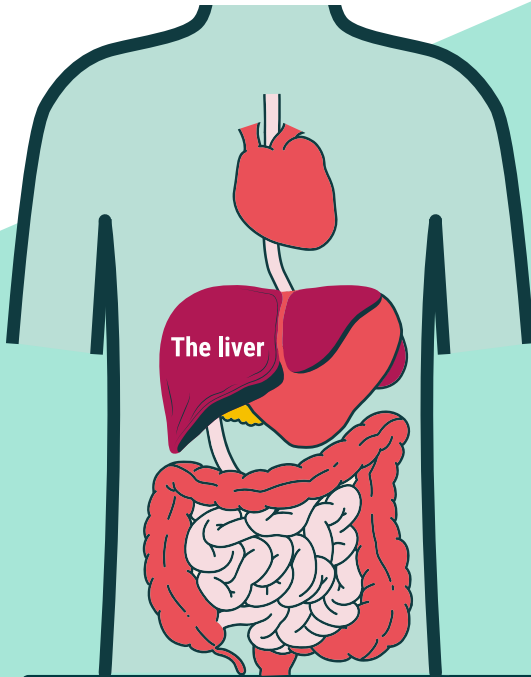
If you have any questions about anything mentioned in this booklet you can talk to you child's medical team. You can also get in touch with Liver UK's Families Team for advice and support.

Use this QR code to view our support services or visit **liveruk.org/support**



About the liver

The liver is one of the most important organs in the body. It is on the right side of the tummy, just under the ribs. It works like the body's factory and carries out hundreds of important jobs every day.



The liver is a dark reddish-brown colour.

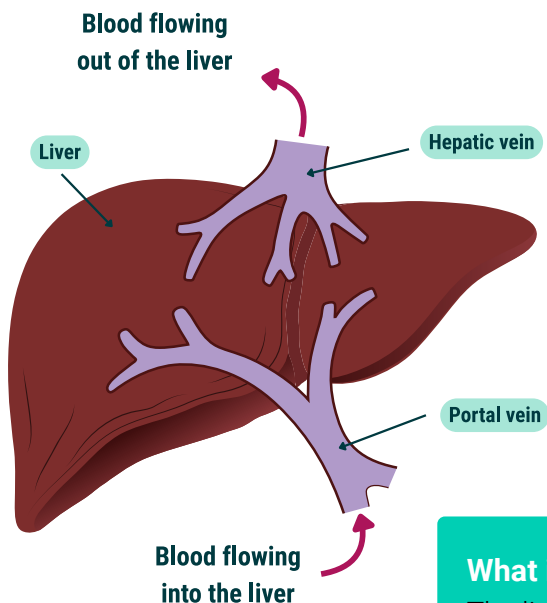
It is divided into two main sections called "lobes". There is a right lobe and left lobe. The right lobe is a bit bigger.

The liver is joined up to some important arteries and veins that bring blood into and out of the liver.

The liver has over 500 jobs. These include:

- digesting food
- producing and storing energy
- storing vitamins, iron and other nutrients
- fighting infections
- breaking down toxins and other harmful substances
- helping you heal





Use this QR code to find out more about the liver or visit **liveruk.org/about-the-liver**



What is Bile?

The liver produces bile which is a green/yellow liquid. Bile is formed from bilirubin, which comes from old red blood cells which have been broken down in the spleen.

Bile helps the body to digest food by breaking fats down so they can be absorbed and enables the absorption of fat-soluble vitamins. Bile also helps the body get rid of waste products such as bilirubin and excess cholesterol which it passes out into the stool (poo).

After bile has been produced by the liver it is transported to the gallbladder where it is stored. When food is eaten the gallbladder releases bile through bile ducts into the small intestine to help with digestion and remove waste products.

What problems can affect the liver?

There are lots of different problems that can affect the liver:

- Bile flow out of the liver may be blocked
- An infection or virus
- Metabolic diseases - problems with the way the cells make energy
- Drugs and poisons
- Poor blood supply
- Sometimes the cause is unknown - these are known as idiopathic or cryptogenic



What signs are there that a child may have liver disease?

There are many different signs and symptoms and they depend on the underlying cause.

It is rare for them to all happen at once.

Liver damage can happen slowly over time, but sometimes it can happen very suddenly.

Signs and symptoms may include:

- Jaundice (yellowing of the skin and the whites of the eyes)
- Nausea, vomiting and loss of appetite
- Yellow urine in newborns
- Dark urine in older children
- Pale coloured stools
- Change in sleep patterns in older children
- Vomiting blood or passing blood in the stool
- Tiredness
- Abdominal swelling
- Itching (known as pruritus)
- Poor weight gain or weight loss
- Abdominal pain
- Nosebleeds and bruising easily



What tests are used to diagnose and monitor liver disease?

Blood tests

Liver blood tests are carried out on blood samples in a laboratory. They are a common way of seeing how well the liver is working. They test the levels of particular proteins and enzymes in the liver as well as the level of bilirubin.

Liver blood tests are also used to monitor a child's liver disease over time to see if the liver is getting healthier, getting worse or staying the same.

Other blood tests will also need to be done to diagnose the cause of the liver disease.

To see a chart explaining the different blood tests which may be carried out, turn to page 10.

Urine and stool

The colour of urine (wee) and stool (poo) can provide information about the liver. Pale stool can be a sign of a problem with the liver, along with dark urine. Sending urine samples to the laboratory can give more information for the diagnosis.

Abdominal ultrasound

This is a scan of the abdomen. It's the same as the scan that pregnant women have to see their baby and doesn't hurt at all.

The ultrasound can show the size and texture of the liver and other organs such as the gallbladder, bile ducts, spleen and kidneys.

Liver biopsy

A liver biopsy may be recommended if tests show that there could be a problem with the liver. The results of the biopsy may indicate if there is a problem with the liver or what it is. A biopsy may not be able to provide a diagnosis but may provide a clue

to what other tests may be needed. They can also be used to monitor the condition.

A liver biopsy involves inserting a very thin needle through the tummy and into the liver. The needle takes a very small sample of the liver. That sample of liver tissue is then sent to the laboratory to be examined under a microscope.

Children may either have the procedure done with a local anaesthetic or with general anaesthetic (so they are asleep).

When young people move to adult services they will have the biopsy done whilst they are awake using a local anaesthetic.

**“My son had no symptoms of liver disease ...
no one had mentioned livers to us before, so
it was quite a shock”**

Parent



Liver blood tests explained...

It's important to note that every child will have their own 'normal' and whilst these levels are a guide, it doesn't necessarily mean a result outside of these ranges is dangerous. Always talk to your child's medical team if you have any worries about test results.

Liver blood tests show the amount of inflammation in the liver, whether the bile ducts are affected and how well the liver is functioning.

How well the liver is functioning is assessed by measuring what the liver is making, for example, albumin (a type of protein) and clotting factors - all of which are made by the liver.

NAME OF TEST	NORMAL RANGE	WHAT DOES THIS SHOW?
Bilirubin (SBR)		
a) Total bilirubin	a) 3 – 20 mmol/l	The total bilirubin level corresponds to the level of jaundice present.
b) Conjugated bilirubin	b) conjugated less than 7 mmol/l	The amount of conjugated bilirubin compared to the unconjugated bilirubin can show whether jaundice is caused by red blood cells breaking up too quickly (not a liver disease) or is due to a reduced flow of bile out of the liver. Conjugated means that a sugar has been added to the bilirubin.
Aspartate Aminotransferase (AST)	10 – 40 IU/l	High levels can mean there is liver inflammation present.
Alanine Aminotransferase (ALT)		

NAME OF TEST	NORMAL RANGE	WHAT DOES THIS SHOW?
Gamma-Glutamyl Transferase (GGT, gGT or Gamma GT)	5-55 IU/L	High levels can mean bile duct inflammation or obstruction. The result can sometimes give information about bile production.
Alkaline Phosphatase (ALP)	Less than 350 IU/L	High levels can mean there is bile duct inflammation BUT ALP is not specific to the liver as it is also produced in other organs e.g. bones. Therefore, abnormal levels can be due to processes occurring in other parts of the body.
Total Protein	60 – 80 g/l	High and low levels can be used in consideration with the other liver blood test results.
Albumin	35 – 50 g/l	Low levels can mean the liver is not making enough, that protein is being lost through the stool or a child is not well nourished.



Another blood test which is helpful to assess how the liver is working is a blood clotting test. Blood is taken, chemicals are added to it in the lab and the time taken for blood to clot is measured.

NAME OF TEST	NORMAL RANGE	WHAT DOES THIS SHOW?
Blood Clotting (Coagulation) Test		The liver produces substances needed for blood to clot.
PT (Prothrombin time)	12 – 15 seconds	
INR (International normalised ratio*)	0.9 – 1.2	Raised levels can mean there is less Vitamin K due to a reduced bile flow.
*INR is a standardised version of the PT for comparison, they both measure the same thing		If Vitamin K is given and the result is still raised, it may mean there is damage to the liver.



Other blood tests include:

NAME OF TEST	WHAT IS MEASURED?
Full blood count (FBC)	Haemoglobin (Hb) White blood cell count (WBC) Platelets (Plt) – levels can fall in liver disease if the spleen is enlarged
Urea and electrolytes	Urea and creatinine are waste products removed by the kidneys. Electrolytes include sodium, chloride and calcium.
Blood glucose	A high or low level of sugar in the blood can sometimes be a sign of liver damage or a metabolic liver disease.
Ammonia	Ammonia is a waste product. It is converted into urea in the liver and is then removed in urine. A higher level than usual may mean there is damage to the liver or an underlying metabolic condition.



Some of these tests may be used to monitor the effects of medications on the body.

What treatments are available?

There are treatments which can control and support the liver.

Treatment will depend on the specific liver disease and the age and condition of your child but they can include:

- Medicines
- Special diets
- Operations
- Exercise or changes in everyday life
- Liver transplantation

Use this QR code to find out more about childhood liver disease or visit **liveruk.org/childhood-liver-disease**



"The first year after diagnosis was about finding our new normal. We adapted and realised our daughter was still our beautiful baby girl. She taught us so much about what is important in life."

Parent



Useful resources

Useful websites

Liver UK

www.liveruk.org

Information and support for everyone living with a liver condition.

Genetic Alliance UK

www.geneticalliance.org.uk

A national charity providing support for people with genetic, rare and undiagnosed conditions.

Rare Disease UK

www.raredisease.org.uk

A national campaign for people living with rare conditions.



How Liver UK can help

A diagnosis of liver disease can be worrying, and you may have a lot of questions. The Liver UK Children's and Families team are here for you and for your family and friends.

Whether you have questions or just need someone to listen, we can help.

Find out how we can help you:
liveruk.org/support

Call our helpline to talk to one of our team: **0800 652 7330**



How we produce information

Feedback and information services

Your feedback is important to us and will help us improve our information. To provide feedback, email **patient-info@liveruk.org**

For more information on how our information was developed, visit our website: **www.liveruk.org**

Thanks

All our information resources are reviewed by medical experts and families.

We would like to thank all our clinical experts and parent and family reviewers.



Disclaimer

This resource provides general information but does not replace personal medical advice. It is important to contact your medical team if you have any worries or concerns.

Notes



Donate to Liver UK



We are entirely funded by donations.

To make a gift in support of our work today, please scan the QR code or visit

www.liveruk.org/donate

Liver UK is the UK's leading charity dedicated to supporting adults, children and young people affected by liver disease or liver cancer. Our mission is to transform liver health by raising awareness, promoting prevention, and improving care and support for everyone affected.



liveruk.org
info@liveruk.org
0300 1311 292