



Children's Liver
Disease Foundation

fighting childhood
liver disease

Fatty Liver Disease

A Guide



**Fatty Liver Disease is also
known as MASLD or NAFLD**

An overview of fatty liver disease,
including the causes, diagnosis,
symptoms, prevention and treatment

This information has been written for:

- parents and carers of children and young people with fatty liver disease

Others who may also find this information useful:

- young people with fatty liver disease
- healthcare professionals who would like to find out more about fatty liver disease

It provides information on:

- causes
- diagnosis
- symptoms
- prevention
- treatment

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

- Introduction to Liver Disease

Use this
QR Code to view
our resources



Key facts about fatty liver disease

1

Fatty liver disease, NAFLD, and MASLD are different names for the same condition. You may also hear the terms NASH and MASH.

2

Fatty liver disease happens when too much fat is stored in liver cells. This can damage liver cells and may lead to scarring (fibrosis) of the liver over time.

3

Fatty liver disease is divided into different stages. Doctors measure the amount of scarring (fibrosis) in the liver to decide the stage of the disease.

4

Fatty liver disease is the most common cause of chronic liver disease in children and young people.

5

Most cases of fatty liver disease are linked to excess food intake and lack of exercise. However, environmental, genetic, and hormonal factors can play a part.

6

There are no specific tests for fatty liver disease. Most children are diagnosed after having tests for another health problem.

7

Most children and young people with fatty liver disease show no signs or symptoms. Symptoms usually only appear when more advanced liver damage has occurred. This is usually in adulthood.

8

It is not always possible to prevent your child from getting fatty liver disease. But you can lower their chances by helping them eat a healthy diet and encouraging them to get enough exercise.

9

In most cases, changes to daily life can reverse fatty liver disease completely. Advanced fibrosis and cirrhosis are usually not reversible.

10

Support services for children and young people are available from Children's Liver Disease Foundation.

Fatty liver disease terms

The terms used for fatty liver disease are changing. You may see both sets of terms being used for the next few years.

Old terms

New terms

Non-alcohol related fatty liver disease (NAFLD)



Metabolic dysfunction-associated steatotic liver disease (MASLD)

Non-alcohol related steatohepatitis (NASH)



Metabolic dysfunction-associated steatohepatitis (MASH)

Remember: MASLD, NAFLD and fatty liver disease are all different names for the same condition.

Remember: It is always okay to ask the medical team to explain what they mean and ask questions.

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How to say it:
 Metabolic = met-uh-BOL-ik
 Dysfunction = dis-func-tion
 Steatosis = stee-uh-TOH-sis
 Steatohepatitis = stee-uh-toh-HEP-ati-tis

People say MASLD as one word that rhymes with 'dazzled'

What is fatty liver disease?

Fatty liver disease happens when too much fat is stored in liver cells. It is a chronic liver disease. This means it is a long-term health condition that develops slowly and may get worse over time.

The liver is a large organ found at the top of the tummy (abdomen) on the right side. It is made up of cells (hepatocytes), blood vessels and bile ducts. The liver has many important jobs in the body including:

- cleaning (filtering the blood)
- making blood plasma proteins, clotting factors, cholesterol, vitamin D, hormones and bile
- processing waste products

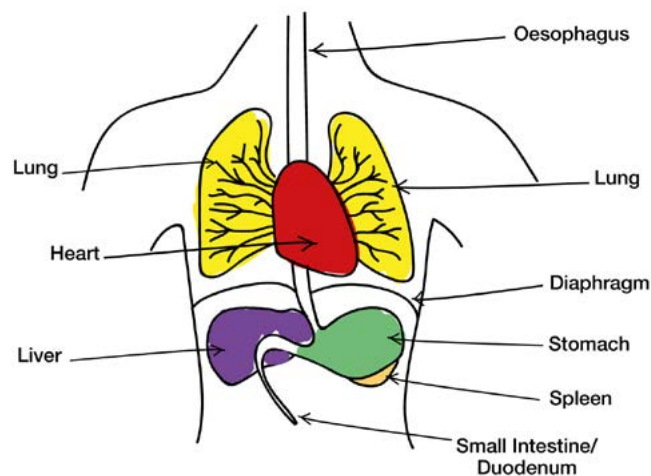


Figure 1: Location of the liver

It is not the liver's job to store excess energy in the form of fat. If this happens, the fat can cause inflammation (irritation and swelling) in the liver. This can damage liver cells and may lead to scarring (fibrosis) of the liver over time.

What are the stages of fatty liver disease?

Fatty liver disease is divided into five different stages. Doctors measure the amount of scarring (fibrosis) in the liver to decide the stage of the disease.

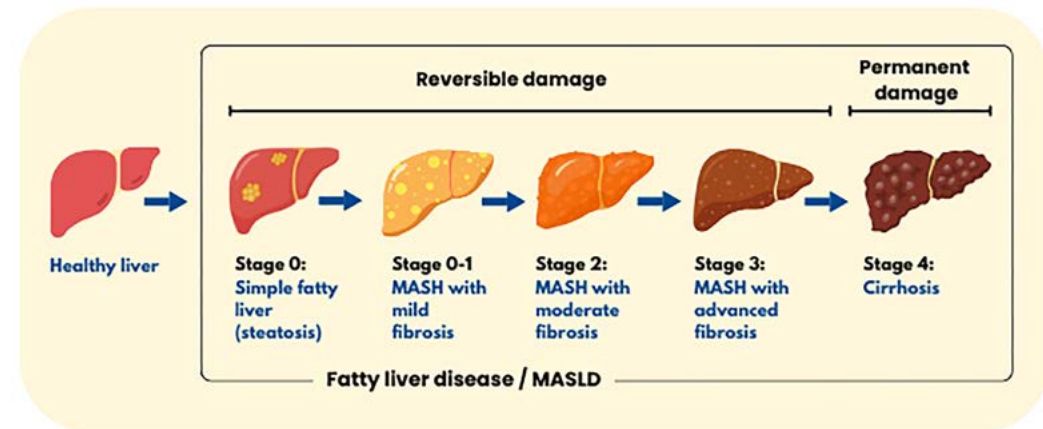


Figure 2: Stages of fatty liver disease

Having one stage does not mean your child will definitely develop the next one. It is also possible to slow or even reverse the damage, especially if it is at an early stage.

Most children and young people will only develop stage 0. In a small number of cases, it can progress to more advanced stages if not found and managed.

Stage 0:

Simple fatty liver (steatosis)

This is a build-up of fat in liver cells. The extra fat does not affect how well your child's liver works. At this stage the liver is not damaged and there is no scarring.

Stage 0–1:

Metabolic dysfunction-associated steatohepatitis (MASH) with mild fibrosis

At this stage, the build-up of fat causes inflammation (irritation and swelling) in the liver. But there is little or no scarring. In most cases, healthy living can undo the damage and reverse the condition.

Stage 2:

Metabolic dysfunction-associated steatohepatitis (MASH) with moderate fibrosis

At this stage the inflammation has caused some scarring. Your child's liver will still be working well and most of the damage can be repaired.

Stage 3:

Metabolic dysfunction-associated steatohepatitis (MASH) with advanced fibrosis

At this stage, the inflammation has started to cause more scarring. The liver will probably still be working well and most of the damage can be repaired. But it is important to take steps to stop any further damage. If more scarring occurs it could lead to cirrhosis and liver failure in adulthood.

Stage 4:

Cirrhosis

This is usually the result of long-term damage to the liver. Large parts of the liver become damaged and scarred. The liver may keep working, but if too much of the liver becomes scarred, it may not be able to do its job properly. This damage is usually permanent and can lead to liver failure and liver cancer.

How common is fatty liver disease?

There are no exact figures on the number of children and young people with fatty liver disease. This is because doctors diagnose the condition in different ways. There will also be children who have the condition but show no signs or symptoms.

We do know that there has been a dramatic rise in fatty liver disease in recent years. It is estimated that at least 5 in 100 children have some stage of the condition. It is now the most common cause of chronic liver disease in children and young people. Fatty liver disease is a lot more common in children who are overweight or obese. It is estimated that 1 in 3 children with obesity will have a fatty liver.

What causes fatty liver disease?

Research into why children and young people develop fatty liver disease is growing. But the exact causes are still not fully understood. Most cases are linked to excess food intake and lack of exercise. But we know that environmental, genetic and hormonal factors can also play a part. Children and young people can still develop the disease if they are a healthy weight.

It is still not clear why fat builds up in the liver in some people and not in others. We also don't know why some people go on to develop more severe liver disease.

Children and young people may be at higher risk of developing fatty liver disease if they:

- are overweight or obese
- have a diet with too many unhealthy foods and drinks
- get little exercise or spend a lot of time sitting down
- have high levels of insulin (a hormone that controls blood sugar levels)
- have type 2 diabetes
- have high levels of cholesterol or fats in the bloodstream (dyslipidaemia)
- have certain changes in their genes

Research suggests that the following factors may also play a part in some cases:

- health and lifestyle of their mother during pregnancy
- bacteria that live in the gut (gut microbiota)

There are also other diseases that could make your child's liver fatty. This may happen directly, or as a side effect of some medicines.

How is fatty liver disease diagnosed?

There are no specific tests for fatty liver disease. Most children are diagnosed after having tests for another health problem. In a small number of cases, fatty liver disease is diagnosed when the disease has become more serious. At this stage it may present with significant signs and symptoms.

As part of making the correct diagnosis, your child's doctor will need to rule out other causes of liver disease. They will ask you questions about your child's diet and lifestyle. Older children will be asked if they drink alcohol or use recreational drugs.

They will also ask about any other medical conditions they have. It is important to tell the medical team about any medicines or alternative remedies your child uses. The doctor will also ask if there is any family history of liver disease.

The following tests may be used to help with the diagnosis. Some of these tests can only be carried out at the specialist paediatric liver centres. The tests needed may differ from child to child.

Physical examination

The medical team will check your child's:

- height and weight
- body mass index (BMI)
- waist size
- blood pressure

A doctor will also check your child's body for the following:

- swelling of the liver (hepatomegaly)
- swelling of the spleen (splenomegaly)
- visible veins in the tummy (abdominal) wall
- yellowing of the skin and the whites of the eyes (jaundice)

Blood tests

Blood tests can help the doctor assess your child's general health. They are also a good way of seeing if the liver is injured and how well it is working. The tests are also used to monitor liver disease over time.



Find more information in CLDF's leaflet: An introduction to Liver Disease.

Wee (urine) test

Your child may be asked to give a wee (urine) sample. This will be tested in a laboratory. This test can help rule out other possible causes of liver disease.

Glucose tolerance test

This is a type of blood test to check how well your child's body processes sugar. It is used to check for insulin resistance and type 2 diabetes. This test is sometimes replaced with a blood test called HbA1c.

Ultrasound scans

An ultrasound scan uses sound waves to create a picture of the inside of the body. It may be used to check and monitor:

- the size and texture of the liver
- the size of the spleen
- the blood flow into and out of the liver



Liver stiffness measurements

The medical team use special scans to check the amount of stiffness in the liver. Healthy liver tissue is soft, so stiffness shows that damage has occurred. You may hear this type of scan called a fibroscan or transient elastography.

Magnetic resonance imaging (MRI) / magnetic resonance elastography (MRE)

These scans use strong magnets and radio waves to make pictures of the internal organs. MRI and MRE scans are not used very often.

Liver biopsy

In some cases, blood tests and scans won't be enough to make a diagnosis and work out the stage of the disease. A liver biopsy may also be used.

During this test a very thin needle is inserted through the tummy (abdominal) wall and into the liver. The needle takes a small sample of liver tissue. This is sent to a laboratory to be studied under a microscope.

What are the symptoms of fatty liver disease?

Most children and young people with fatty liver disease show no signs or symptoms in the early stages. Symptoms usually only appear once more advanced liver damage has occurred.

Possible symptoms in the earlier stages may include:

- tummy (abdominal) pain
- tiredness (fatigue)
- irritability
- headaches
- difficulty concentrating
- low mood and anxiety
- changes to skin colour where two areas of skin touch or around joints

It is rare for children and young people to develop cirrhosis (the most advanced stage). But if it does develop, the following symptoms may be present:

- yellowing of the skin and the whites of the eyes (jaundice)
- dark wee (urine)
- itchy skin (pruritus)
- swelling of the lower tummy (ascites)
- swelling of the legs, ankles or feet (oedema)
- bruising
- dark black tarry poo (stool)
- throwing up (vomiting) blood

Can fatty liver disease be prevented?

It is not always possible to prevent fatty liver disease from happening. This is because genetic and environmental factors can play a part.

But fatty liver disease usually develops alongside being overweight or obese, when the body takes in more energy than it burns. The distribution of fat is also important. Some children who have a normal weight but carry fat around their middle can develop a fatty liver.

It is possible to lower the chances of your child developing fatty liver disease. The best way to do this is by helping them eat a healthy diet and encouraging them to get enough exercise.

Helping your child control existing medical conditions can also help.

What happens if my child is diagnosed with fatty liver disease?

If fatty liver disease is found and managed early, it is possible to reduce the amount of fat in the liver. This can slow down, or even stop, liver damage. It will also allow the liver to recover.

In most cases, changes to daily life can reverse fatty liver disease. This usually involves a big focus on healthy eating and increasing activity levels.

It is rare for children and young people to develop or present with advanced liver disease (cirrhosis). But it is important to manage the condition early to make sure they do not develop cirrhosis as adults.

Your child may be more at risk of the disease getting worse if they:

- are overweight or obese
- have type 2 diabetes

Children and young people with fatty liver disease will be monitored regularly.

If fatty liver disease has progressed to a later stage, you will be given specific advice and treatment.

It is important to remember:

- Children and young people with a fatty liver are at higher risk of developing heart disease and cancer later in life. Managing the condition early will help prevent these conditions.
- Children and young people with a fatty liver are at higher risk of developing type 2 diabetes. Treatments for fatty liver will also reduce the risk of getting diabetes.

How is fatty liver disease treated?

There are currently no medicines recommended for treating fatty liver disease in children and young people. But there is a lot of research being done to develop some.

Current treatment for fatty liver disease has two main aims:

- to stop the condition getting worse
- to help the liver repair itself

The main treatments for fatty liver disease are:

- having a healthy diet
- being more physically active
- losing weight (if needed)

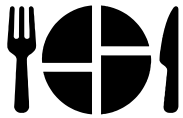
"It can feel overwhelming to look at what changes might be needed to help your child. Nutrition and diet advice will be given by members of your child's team. We are here to help support you emotionally to make these changes."

Children and Families Officer, CLDF

Healthy changes to try

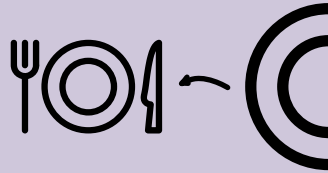
As a parent, there's lots you can do to help your child eat a healthy diet and be more active. We know that it is not always easy and requires commitment from the whole family.

Here are some handy tips to get you started:



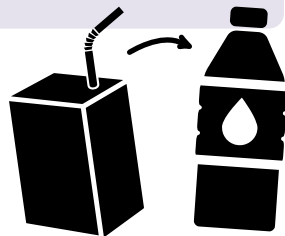
Follow a healthy portion-controlled diet and avoid adult-sized portions for children and young people.

For younger children, serve their meals on a child sized plate. This makes it easier to give your child the correct portion size.



Lots of foods have hidden fat, sugar and salt. Check the labels on food. Many products have traffic light labels on the front of packs. Pick items with more greens and ambers and cut down on ones with any reds.

Swap sugary drinks for water, milk, zero sugar or low calorie drinks.



Swap sugar-coated breakfast cereals for wholegrain or brown cereals. Alternatively, mix cereals such as rice cereals with wheat-based biscuits.



Include beans and lentils in cooking to increase fibre intake. Replacing some meat in a casserole with these options will reduce the fat content too.



Try to grill, bake or poach food rather than frying.

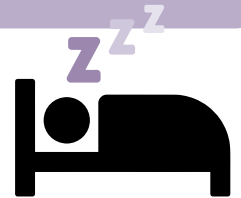


Avoid eating in front of the TV or when using an electronic device because it's easy to eat more without noticing. Encourage family meals and remove distractions during mealtimes.



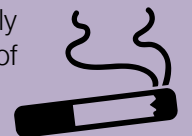
Aim for five portions of fruit and vegetables a day.

Sleep is important. Ensure your child gets enough sleep with a prompt, regular bedtime. Limiting screen time and doing more physical activities will help too.



Children should have at least 60 minutes of physical activity a day. Make use of school clubs and local parks. Try out a new sport. Try walking, cycling or scooting to school instead of driving.

Alcohol and smoking can be dangerous, particularly for those with liver problems. Speak to a member of your medical team about the risks and the support available.



Help and support with diet and lifestyle

One of the key people you should see is a registered NHS dietitian. They can advise you and your child on making achievable healthy choices. Help and support is also available from your GP. They will know about local weight management and activity programmes. See the links on page 21 for more information.

Complementary and alternative medicines

Complementary and alternative medicines are not recommended for children with fatty liver disease. They have not been through strict testing and, in some cases, they could even be harmful.

It is always important to seek advice from the medical team. These professionals are regulated to provide health advice specific to your child.

Weight loss (bariatric) surgery

Weight loss surgery is not a general treatment for fatty liver disease. It will only be considered in very limited cases to manage extreme obesity.

Liver transplant

A liver transplant is an operation to remove a liver that does not work. It is replaced with a healthy liver from another person (donor).

Liver transplants are rare in children and young people with fatty liver disease. They are only used if all other treatments have failed and if damage to the liver cannot be reversed.

Useful resources

Glossary of liver terms

Many medical terms may be used by those caring for children and young people with liver disease. Follow this QR code for a list of terms.



Other CLDF resources

CLDF produces a wide range of information for children and young people up to the age of 25 with liver disease, their families and the healthcare professionals who look after them.

Information can be downloaded or ordered from:
 Website: www.childliverdisease.org
 Email: info@childliverdisease.org
 Tel: 0121 212 3839
 Follow this QR code to see our resources.



Information from other organisations

There are lots of resources available with ideas for eating a healthy diet and getting active:

Better Health

<https://www.nhs.uk/healthier-families/>

A website with food facts, recipes, and ideas for getting children more active.

British Dietetic Association

<https://www.bda.uk.com/>

A professional body representing dietitians in the UK. Their website provides a wide range of information on food and nutrition.

Children's Liver Disease Foundation

Children's Liver Disease Foundation (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.

CLDF is here for you, whether you want to talk, share with others, or just belong to a group of people who cares, knows what it's like and are fighting to make a difference.

Are you a young person up to the age of 25?

Contact the Young People's Team:

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

Are you the parent or carer of a child or young person with a liver condition?

Contact the Families Team:

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

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

Please help us to continue to support children, young people and families now and in the future.

Contact the Fundraising Team:

Email: fundraising@childliverdisease.org



Use this QR code to donate

Tel: 0121 212 3839

Email: info@childliverdisease.org

Website: www.childliverdisease.org

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Patient Information Forum



Children's Liver
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