



Children's Liver
Disease Foundation

fighting childhood
liver disease

Non-Alcoholic Fatty Liver Disease (NAFLD)

A Guide



An explanation of what non-alcoholic
fatty liver disease is, its causes,
diagnosis and treatment

The information has primarily been written for:

- Parents/carers of children and young people with non-alcoholic fatty liver disease (NAFLD)

Others may also find this information useful:

- Young people with NAFLD
- Healthcare professionals who would like to find out more about the condition

It provides information on:

- The symptoms of NAFLD
- Diagnosis
- Treatment
- Healthy lifestyle and diet

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

- Introduction to Liver Disease
- Essentials Pack – CLDF’s starter kit of vital information
- Education Pack – a pack supporting children and young people in educational settings

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What is non-alcoholic fatty liver disease (NAFLD)?

NAFLD has increased in both adults and children in recent years and is now one of the most common forms of chronic liver disease in children and adolescents.

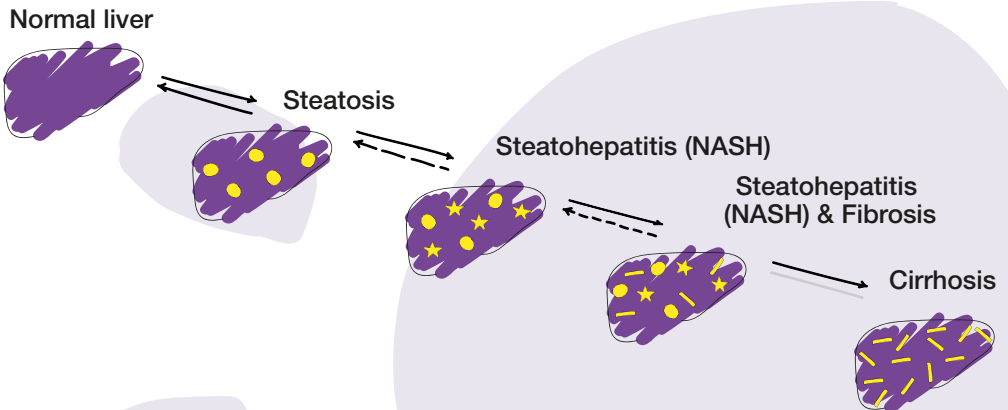
NAFLD occurs when you have too much fat in your liver. The liver is a very active organ, taking food directly from the gut and processing fat, carbohydrates and protein into energy and other proteins. In some people there is an imbalance in this process. This may be a result of too much fat coming into the liver cell, overwhelming the machinery that processes it or a subtle change in the cells' ability to process (metabolise) or transport the fats/carbohydrates.

In some people, the liver cells simply accumulate fat droplets that do not irritate their liver. However, in others, the fat droplets act like splinters and cause an inflammatory response leading to the formation of scars.

NAFLD refers to a group of conditions which can be understood in terms of different stages:

1. **Simple steatosis** – this is fat building up in the liver.
2. **Non-alcoholic steatohepatitis (NASH)** – inflammation (swelling in the liver) caused by build-up of fat
3. **NASH with fibrosis** – scarring in the liver, which causes damage
4. **Cirrhosis** – usually the result of long-term, continuous damage to the liver. Irregular bumps, known as nodules, replace the smooth liver tissue which makes the liver harder. Cirrhosis can progress to end stage liver disease. This is when the liver doesn't work properly and is stiff, leading to a build-up of pressure (portal hypertension).

Stages of NAFLD

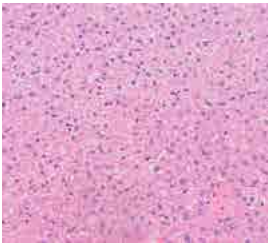


What is non-alcoholic steatohepatitis (NASH)?

NASH occurs when there is inflammation of the liver associated with a build-up of fat. This inflammation is often associated with scarring. Most scarring, up to the point of early cirrhosis, is reversible. However, a small proportion of children with NASH may go on to develop cirrhosis and further complications. The exact cause of progression from simple steatosis to NASH and cirrhosis is unknown.

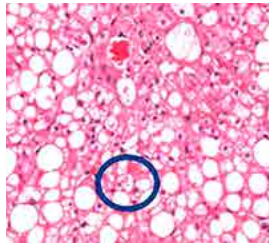
Changes that occur within the liver at cellular level

Healthy Liver



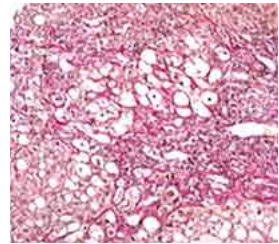
This shows liver cells in an individual with a healthy liver and not diagnosed with NAFLD.

NASH



This shows accumulation of fat (white droplets) in liver cells combined with inflammation, where damaged cells look swollen or “ballooned” (highlighted in the circle). This indicates potentially progressive liver disease called steatohepatitis (NASH).

NASH with fibrosis



The deep red colour shows scarring in an inflamed liver. You can see scar tissue forming around individual cells.

As liver scarring (or fibrosis) advances, the spleen may appear enlarged on an ultrasound scan. This happens because the liver is stiff as a result of scarring, leading to blood flow being affected by back pressure. As the spleen and the liver are connected, this pressure is transmitted to the spleen via the splenic vein, causing the spleen to increase in size due to its elasticity.

See CLDF's leaflet "Portal Hypertension and Ascites" for more information.

Why do children get NAFLD?

Clinical research into why children develop NAFLD is increasing. We know that there are multiple reasons for NAFLD which are environmental and genetic. Children and young people may be at high risk of developing this condition if they:

- are overweight or obese
- have insulin resistance
- have type 2 diabetes
- follow a poor diet and do little or no exercise
- have dyslipidaemia – irregular level of blood lipids
- carry certain variations in their genes

Other conditions can look like NAFLD and need to be ruled out through investigations because their treatments are very different. These conditions may include:

- malnutrition
- certain types of metabolic liver disease such as Wilson's disease, fructosaemia and cystic fibrosis
- artificial feeding such as feeding directly into a vein (parenteral feeding)

Taking certain drugs prescribed for other conditions may also lead to features similar to NAFLD.

What are the signs?

Many children who have NAFLD do not display symptoms in the early stages. It is often once significant damage to the liver has occurred that signs become more obvious.

Some children may report symptoms such as:

- abdominal pain
- fatigue
- irritability
- headaches
- difficulty concentrating
- low mood and anxiety
- changes to skin colour where two areas of skin touch and/or joints

If cirrhosis (the most advanced stage) develops, the following symptoms may be present:

- yellowing of the skin and the whites of the eyes (jaundice)
- itchy skin (pruritus)
- swelling of the lower tummy (ascites)
- bruising easily
- dark urine

How is NAFLD diagnosed?

Liver disease can have very few symptoms therefore an honest discussion with your child's doctor about their health and lifestyle will increase the chance of them being able to provide an accurate diagnosis.

There is no specific test for NAFLD and most children are diagnosed because they are having tests for something else e.g. routine blood tests and ultrasound scans.

Blood tests may show raised liver enzyme levels which will lead to further investigations. An ultrasound scan and further blood tests will be done to rule out other liver conditions. In some children, a liver biopsy may be needed to confirm the diagnosis and assess the liver.

Tests may include some or all of the following:

General clinical examinations and history taking	The medical team will discuss your child's past growth, development, lifestyle and health. They will also look at Body Mass Index (BMI), waist circumference and blood pressure.
Blood tests	General tests of health – These will include a full blood count (FBC), glucose level (HbA1C), insulin levels and lipid levels.
	Kidney tests – These look at urea and electrolytes (U&Es), causes of liver disease, infections and chemical abnormalities.
	Liver function test – this measures the extent of liver disease. See CLDF leaflet "Introduction to Liver Disease" for further information.
Urine tests	This includes a urine metabolic screen to exclude chemical abnormalities and 24-hour urine collection for copper to exclude another liver disease called Wilson's Disease.
Oral glucose tolerance test	This is a test looking for insulin resistance and type 2 diabetes. This is sometimes replaced with a one-off test called HbA1C.
Ultrasound scan	This will look at all the organs in the abdomen but particularly the liver. It will show a bright liver if fat (or steatosis) is present. The ultrasound is sensitive enough to report when 30% of liver cells have fat droplets (normal is <5%). The ultrasound will also indicate if the spleen is large or not.
Fibroscan	This is similar to an ultrasound scan and measures the degree of scarring and stiffness of the liver (degree of fibrosis). It is a simple and painless test.
Liver biopsy	A small sample of liver tissue is obtained by passing a specially designed needle through the skin. The procedure will be explained in greater detail by your medical team.

What happens if my child/teenager is diagnosed with NAFLD?

If diagnosed in the early stages, it is possible to stop NAFLD progressing to the point of liver damage.

Children and young people with NAFLD need medical follow up to detect changes in their condition as early as possible.

We know that in most cases, lifestyle change with a major focus on healthy eating and increasing activity can reverse the condition completely even when significant scarring is present. In adult studies, weight loss of 10% of the total body weight has led to reversal of this condition.

Specific advice and treatment may be given to children if NAFLD has progressed to a later stage or are known to have complications of cirrhosis.

Can NAFLD be prevented?

It is not always possible to avoid NAFLD because factors such as genetics and other unknown causes cannot be prevented. Reducing risk through exercise, healthy eating and better control of existing medical conditions can help prevent the development and progression of NAFLD.

It is important to remember that NAFLD does not develop just because a child has eaten too much or is overweight or obese. The distribution of fat is more important than total weight. Children who have a normal weight but carry fat around their middle can develop NAFLD. For these children, attention to being fit and healthy is key.

How is NAFLD treated?

There is currently no agreement on appropriate medications to treat NAFLD. Research and clinical trials in this area are being explored and can be discussed with your child's medical team. We know that the amount of fat in the liver can be reduced through weight loss, eating healthily and regular exercise.

One of the key people you should see is a dietitian who can advise you and your child on how to make achievable healthy lifestyle choices that are specific to your child.

Diet and lifestyle changes

As a parent, there's lots you can do to help your child become a healthier weight. Getting them to be more active and eat well is important. This isn't an easy option and it requires commitment from the whole family to change your lifestyle.

Here are some handy tips to get you started:

Diet



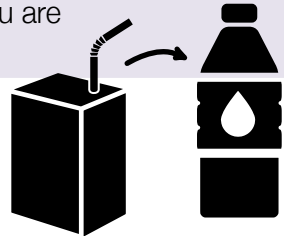
Follow a healthy portion-controlled diet and avoid adult-sized portions for children and young people.

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



Lots of foods have hidden fat, sugar and salt. Make sure you check the labels on food and know what the food you are eating contains.

Swap sugary drinks for water or zero sugar/ low calorie drinks.



Swap sugar-coated breakfast cereals for wholegrain or brown cereals e.g. porridge, wholegrain cereal with no added sugar. Alternatively, mix cereals such as rice cereals with wheat-based biscuits.



Include beans and lentils in your diet 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.



Aim for five portions of fruit and vegetables a day.

Activity and Lifestyle



Avoid eating in front of the TV because you can eat more without noticing. Encourage family meals, switch off the TV and remove other distractions during mealtimes.

Sleep is important – ensure enough sleep with a prompt bedtime. Limiting screen time and doing more physical activities will help too.



Children and young people should have at least 60 minutes of physical activity a day. Make use of school clubs, local parks, riding bikes, try out a new sport and walk wherever possible.

Alcohol and smoking can be dangerous for teenagers and young people with liver problems. Speak to a member of your medical care team about safe limits.



If your child doesn't have a dietitian and you would like more support around diet and lifestyle speak to your medical team or GP. They will know about local weight management and activity programmes, useful resources and can make a referral to a dietitian.

Liver transplant

If the liver becomes damaged so much that it can't work properly a transplant may be required. This is very rare in children and is usually only recommended if other treatments or lifestyle changes are no longer helpful. For more information about liver transplants see the CLDF leaflet "Liver Transplantation".

Complementary and alternative medicines

There are many websites offering dietary advice through complementary or alternative medicines. If your child is diagnosed with a liver condition it is important to seek advice from their doctor and dietitian because these professionals are regulated to provide health advice specific to your child.

Where can I get support from?

There are lots of different places you can access support in addition to your medical team.

CLDF has a Families Team offering non-judgmental support who can help you after a diagnosis. If you require further information, need someone to talk to or would like to meet others in a similar situation then the Families Team can help you. You can call 0121 212 6023 or email families@childliverdisease.org.

CLDF also have a Young People's Digital and Engagement Officer who can provide support specifically to those aged 11 – 24. You can call 0121 212 6024 or email youngpeople@childliverdisease.org.

There are lots of resources available with ideas for being healthier, easy recipes and meal ideas as well as ideas for getting active. Here are just a few:

change4life.co.uk

eatbetterfeelbetter.co.uk (Scotland)

change4lifewales.org.uk (Wales)

getalifegetactive.com (NI)

nhs.uk/live-well/eat-well/healthy-eating-for-teens

healthforteens.co.uk/lifestyle/nutrition-diet

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 childliverdisease.org. For further enquiries regarding CLDF's information please contact the Information and Research Hub Manager by email at irhm@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 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 October 2019. It is due to be reviewed by October 2022.

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 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 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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Main site: childliverdisease.org

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