



Children's Liver
Disease Foundation

fighting childhood
liver disease

Non-alcoholic Fatty Liver Disease (NAFLD)

a guide

Medical Information Series



Welcome

This leaflet has been written for:

- Parents/carers of a child with non-alcoholic fatty liver disease (NAFLD)
- Young people with non-alcoholic fatty liver disease (NAFLD)

Others who may find this leaflet helpful are:

- Relatives and friends of families
- Healthcare and allied professionals, school, college, university and nursery teams

This leaflet aims to:

- Explain what NAFLD is
- Explain the causes and how it may be treated

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

- Guide to the liver
- Glossary of terms
- Routine investigations for liver disease
- Portal hypertension

Children's Liver Disease Foundation (CLDF) also has leaflets in its support series which are available to download from our website – childliverdisease.org. Leaflets can be mailed to UK patients free of charge, our contact details are on this leaflet. You may find it helpful to have a copy of CLDF's **making the most of an appointment** leaflet which will help you prepare for appointments and meetings following discharge.

We also have the following information packs available, free of charge:

- Essential 5 – CLDF's starter kit of vital information
- Education – a pack supporting children and young people under 18 in an educational setting
- GP Practice – a pack for families to give to their GP providing a range of information on childhood liver disease
- Friends and Relatives
- Yellow Alert – a pack to support CLDF's Yellow Alert Campaign for early diagnosis of liver disease in newborn babies

All are available on request to UK families and young adults.

Overseas families should contact CLDF to discuss their literature needs.

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

Non-alcoholic fatty liver disease (NAFLD) is a condition in children and in adults where fat builds up in the liver. The amount of fat trapped in the liver cells will vary in each individual. There is normally a small amount of fat in liver cells; however, when a significant amount of fat builds up in the cells liver disease can follow. NAFLD has been increasing in both adults and children over recent decades. It has now become the most common form of chronic liver disease in children. The condition usually progresses slowly over decades and only a few children have serious medical problems in early life. Health professionals are still learning about the condition but believe that early recognition and treatment of the condition is important as serious liver problems can develop in early adulthood including cirrhosis and liver cancer. The reason the condition is called NAFLD is that the liver can look like it has been exposed to large quantities of alcohol but of course occurs in those who have not taken any alcohol at all.

? What causes NAFLD?

Fat is a normal part of the make up of our bodies. It has a role in storing energy producing calories for use in situations of stress and provides insulation from the cold. The liver has a role in the control of the storage of fat in the body and the use of fat as an energy source. The body needs fatty substances to function properly and therefore fat in moderation should be part of a well balanced diet. So fat is part of a normal balanced diet. If the body takes in more calories than is needed then the excess is stored as fat. Some may be stored in the liver and thus cause fatty liver disease.

Insulin is a hormone which is released by the pancreas and acts on the muscle as well as fat cells. It has an important role in controlling sugar levels and food and energy

balance in the body. In some people muscle and fat cells stop responding to insulin and the body responds by the pancreas releasing increasing amounts of insulin to make up for this. The liver is then bombarded by insulin allowing more fat into the liver cell and decreasing the amount of fat which is processed and released from the liver cell (i.e. insulin increases fat stores). People who are prone to insulin resistance have a high risk of developing type 2 diabetes. The tendency often runs in families but not always. The classic body shape of those who are insulin resistant is apple shaped rather than pear shaped. People who are prone to insulin resistance and NAFLD tend to deposit fat around their abdomens and around the organs within the abdominal cavity, thus worsening the amount of fat in and around the liver. In some children and adults with fatty liver disease, for reasons that we do not yet understand, the liver can become irritated and fat can cause inflammation and lead to liver scarring.

? What are the possible reasons for fat in the liver?

- Complication of overweight / obesity
- Insulin resistance
- 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)
- Malnutrition
- Excess use of alcohol
- Medication such as steroids
- Unknown

? Why might NAFLD be suspected in your child?

- Children often present to their GP with abdominal pain and undergo routine liver function tests (blood tests) and an ultrasound scan which turns out to be abnormal.

- An enlarged liver and/or an enlarged spleen may be found on routine examination (hepatomegaly and/or splenomegaly).
- On blood testing for other reasons and abnormal liver function tests are found.

If your child is undergoing investigations for type 2 diabetes or for overweight, liver function tests and an ultrasound are often part of the screen.

? Why do children with suspected NAFLD need to be investigated?

Investigations provide information about your child, which enables your medical team to discuss with you the extent of the problem, what the future holds and the best way to manage the condition.

- It is important to find out to what extent your child is affected by the fat in the liver. For example children may have both inflammation and scarring in their liver alongside their fat.
- It is important to make sure that no other liver disease is present which will need other types of treatment. (See list of conditions on the previous page.)
- To look for other health issues which are known to be associated with fatty liver e.g. high blood pressure, early signs of diabetes.

? What investigations are needed?

■ Clinical Examinations and History Taking

This involves at least one and often several members of the team discussing with you about your child's past growth, development, lifestyle and health. This will be specifically looking for factors that may have contributed to the condition.

Your child will have a general examination and measurements taken such as:

- Height
- Weight
- Waist circumference
- Blood pressure
- Urine analysis

The height and weight will be compared to national averages to find out whether your child's measurements are above or below average. It will also determine whether the child fits the measurements that exist to define being overweight or obese.

- An estimate of **Body Mass Index (BMI)** will be made. This uses the height and weight readings. This can be compared to expected values at various ages.

Your child will have a range of tests which may include some or all of the following:

■ Blood tests

These will be used to look for:

- General tests of health
 - Full Blood Count (FBC)
 - Glucose level and other so-called "metabolic tests"
 - Insulin levels
- Kidney tests
 - Urea and Electrolytes (U&Es)
 - Causes of liver disease
 - Infections
 - Chemical abnormalities
- Extent of liver disease
 - Liver Function Test (See CLDF leaflet on Routine Investigations of Liver Disease)

Some of these may be on samples at a time when your child has been fasting from food and sugary drinks. You will be told by your hospital team about this if needed.

■ Urine tests

- Urine metabolic screen to exclude chemical abnormalities especially in younger children

- 24 hour urine collection for copper to exclude another liver disease called Wilson's Disease
- **Oral Glucose Tolerance Test (OGTT)**
 - This is a test looking for insulin resistance and type 2 diabetes which are closely associated with NAFLD.
 - Your child will need to fast overnight (usually from midnight) and come in for an early appointment (usually in the day ward). A cannula (plastic straw into the vein) will be inserted into your child's hand; blood tests are withdrawn through the cannula over the course of the morning. Your child will then be asked to drink a sugary drink provided by the nurses – this is usually Lucozade or similar. Bloods will be drawn from the cannula at 30 minutes, 60 minutes, 90 minutes and 120 minutes after the drink is finished. The blood tests are done to look at the body's sugar levels and insulin levels in response to a sugar load. Children in whom the sugar levels rise to excess levels may have type 2 diabetes. If insulin levels rise to excess levels the child may have insulin resistance or 'pre-diabetes'.
- **Ultrasound**

This takes place in the X-ray department (radiology). This will look at all the organs of the abdomen, but particularly at the liver. It can show up some abnormalities and help to decide whether further investigation is needed. Sometimes related changes such as gallstones or an enlarged spleen are found.
- **Liver Biopsy**

In some cases the doctor may recommend a liver biopsy. This is a procedure in which a small sample of liver tissue is obtained by passing a specially designed needle through the skin. This will be explained in greater detail to you by your medical team. The tissue is studied later under a microscope by doctors specially trained in examining

tissue (histopathologists). This will confirm whether fatty liver disease is present and may identify any other abnormal changes in the liver. It may possibly help to find a treatable cause. It will help the doctor to give you more advice about the liver condition and what the future holds.

The biopsy will help in identifying the severity of the condition. Where there is simple fat on its own, this is called simple steatosis or simple fatty liver disease. Where there is additional inflammation or scarring, this is called Non-Alcoholic Steatohepatitis (NASH). Steato- means fat and hepatitis means inflammation of the liver. At the moment a biopsy is the only way of telling if inflammation or scarring is present.

What is NASH?

This means inflammation of the liver associated with accumulation of fat. This inflammation is often associated with a degree of scarring called fibrosis. About a third of children with fat in their liver are thought to go on to develop NASH. Early scarring is called fibrosis for which no extra treatment is needed. A proportion of children with NASH will go on to develop large bands of scar tissue called cirrhosis and further complications.

In a considerable number of children with NAFLD, the spleen may appear enlarged on ultrasound. This happens if there is significant liver scarring or inflammation which causes an obstruction to the blood flow within and leading to the liver resulting in back-pressure on the spleen causing it to enlarge. This is explained more fully in CLDF's leaflet on portal hypertension. Occasionally viral infections may be the cause of a large spleen on the day of the scan – this should improve by the time of a follow-up scan.

? How is NAFLD treated?

Fat, inflammation and scarring in NAFLD are generally considered to be fully reversible in most cases. Treatment involves decreasing the amount of fat that gathers in the liver cells and thus the inflammation and scarring that accompanies it. All children, whether overweight or not, should be assessed by the dietitian and advice given about weight management to include healthy eating. Certain foods such as fructose are thought to contribute significantly to the condition. Activity levels and general fitness need to be increased. Reversing the build-up of fat in the liver can take months or even years but is critical to treating the condition.

Certain medications such as Vitamin E are undergoing clinical trials for treating the condition. At the moment there is no consensus on medication for this condition.

If a child is found to have significant insulin resistance on OGTT testing, lifestyle measures are the first port of call. A child may be asked to remain the same weight as they grow in height or alternatively, to lose a certain percentage of body weight according to their age and developmental stage. A medication called Metformin is often used to improve insulin sensitivity – this can also help with weight loss. Metformin is tolerated well by the majority of children but can cause some side effects (nausea) in some.

In children who are diagnosed with type 2 diabetes, Metformin is also an appropriate medication to use.

? Dietetic advice in NAFLD?

A healthy diet is recommended for all children and young people. If your child is found to be overweight, they may be advised to reduce the fat and sugar in their diet.

The Department of Health's "Change4Life" campaign – www.nhs.uk/change4life/

– gives lots of helpful ideas, tips and advice. There may be local healthy lifestyle schemes/programmes available to you; discuss this option with your local consultant or dietitian.

? What can I do to improve my child's diet?

- Eat a wide variety of foods to ensure your child is getting a balanced diet, visit www.nhs.uk/Livewell/Goodfood/Pages/eatwell-plate for more information
- Eat regular meals throughout the day
- Eat plenty of fruit and vegetables – aim for 5 portions a day
- Try to choose foods rich in fibre
- Reduce saturated fat and sugar in the diet

? How can I reduce fat in my child's diet?

- Limit foods with 'hidden' fat – particularly pastries, pies, chips, crisps, biscuits, and cakes
- Compare labels in supermarkets – choose options with less fat
- Grill, bake, boil, casserole, microwave or steam foods rather than fry
- Drain or skim fat from mince/casseroles
- Use reduced fat products e.g. semi-skimmed milk, low fat spreads, diet/reduced fat dairy products
- Remove all visible fat from meat, and skin and fat from chicken
- Avoid adding fats to cooked foods e.g. margarine/butter added to vegetables or pasta
- Use small amounts of cooking oil to grease cooking pans. Non-stick parchment is useful for lining baking trays and tins

? How can I reduce sugar in my child's diet?

- Be aware of 'hidden' sugars
- Check labels to help choose foods with less added sugar, or go for low sugar versions
- Try not to add sugar to foods/drinks e.g. breakfast cereal, in tea or coffee
- Choose sugar free/diet drinks/reduced sugar
- Avoid sugary cakes, biscuits and sweets, choose lower sugar alternatives: teacakes, fruit cake and fruit
- If needed, choose an artificial sweetener instead of sugar
- Use small amounts of jam/marmalade and/or use reduced sugar varieties

Finally remember that children need the support of the whole family. If everyone follows a sensible diet your child is much more likely to succeed. If this results in weight loss, general health will improve. This can be monitored by repeat growth measurements, blood tests and ultrasounds. If you are still concerned and would like more information ask your GP to refer you to your local dietitian who will be aware of local programmes to help and advise you.

? How can I increase my child's activity levels?

Children and young people should be gradually aiming to take part in physical activity for at least one hour every day. This can include:

- Walking
- Climbing
- Gymnastics
- Cycling
- Active play – including jumping, skipping and dancing
- Most sports
- Swimming
- Games

These will also improve strength and flexibility and bone health.

As a family this may mean you need to consider the activities that you can do together and will likely mean adjustments will be needed. It may involve reducing the time spent in front of the television and taking part in computer games. The first activity may be as simple as walking for a period which can be built up over a period of time. In summary – **Be Active**.

? What other general health issues should I be aware of?

Young people should avoid other stresses to the body and the liver such as taking excess alcohol and avoid smoking.

Specific advice and treatment may be given to children when they are known to have complications of cirrhosis.

? Should I worry about NAFLD?

Children with NAFLD do not appear to have permanent damage to the liver, but as yet we do not know enough about the condition to predict who may go on to have inflammation and damage in the future. Children with NASH already have damage to their liver. For both groups of children, their overall life expectancy after decades without making effective lifestyle adjustments as described above is expected to be significantly shorter. Fatty changes are thought to be reversible with lifestyle adjustments. The progression of liver disease in NASH can be prevented again with successful lifestyle adjustments.

? What is the future?

Children with NAFLD need medical follow-up in order to pick up changes in condition as early as possible. Children are likely to be asked to take part in studies into the effectiveness of medical treatments.

? Is there a charity taking action against the effects of childhood liver disease?

Yes. Started by families in 1980, Children's Liver Disease Foundation (CLDF) leads the way in fighting all childhood liver disease.

CLDF funds vital research, develops information and awareness programmes and supports families, young people and adults diagnosed in childhood who are living day in, day out with a liver condition or transplant. And its work has made a big difference and continues to help save lives.

CLDF has so much to offer you: information, the opportunity to meet other families, events and regular updates. To find out more, call, email or write today:

**Children's Liver Disease Foundation,
36 Great Charles Street, Birmingham,
B3 3JY**

0121 212 3839

Main site: childliverdisease.org

Young people's site: cldf-focus.org

info@childliverdisease.org

? What are the roles of CLDF's Family and Young People's teams?

CLDF's Family 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.

Our parents say . . .

"... We don't know how we would have coped without CLDF's care and support. They have been just fantastic from the outset — tremendous people, who are compassionate and so positive. They really care about families and children struggling with liver disease."

"When Emily was very ill we felt we were on the sidelines, knowing we couldn't influence the outcome and not in control. Getting involved in fundraising is something you can control and achieve a positive result. I really took comfort from that."

Our young people say . . .

"Knowing CLDF is there is what I need. I can call whenever I want. Whatever I think and feel is listened to. Even when I called to tell them it was my birthday!"

"I feel really well. It's great that CLDF has given us the chance to meet other young people outside of the hospital and have a fun time. I want them to do more things like this."

Families Team

families@childliverdisease.org

0121 212 6023

Young People's Team

youngpeople@childliverdisease.org

0121 212 6024

Notes



Children's Liver Disease Foundation is the UK's leading organisation dedicated to taking action against the effects of childhood liver disease.

It provides free of charge:

- A huge selection of literature and online animations on the working of the liver available in print and online
- Information packs for a wide range of audiences, including young people, parents/carers, GP practices, schools and nurseries, friends and relatives
- Families and young people's teams providing services in person, online, facebook, text and phone
- Developing services for adults diagnosed with a liver disease in childhood
- Website – childliverdisease.org
- Young people's website – cldf-focus.org
- National event programme for families and young people to meet, share and have fun
- Secure online message board – childliverdisease.org/forum

Around 75% of CLDF's annual income is derived from voluntary donations. Please help us to continue to support young people, families and adults diagnosed in childhood by making a donation. You can do this online or by completing the donation form in this leaflet. Even better, a regular direct debit gift will enable us to plan our work more fully.

Thank you.

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