

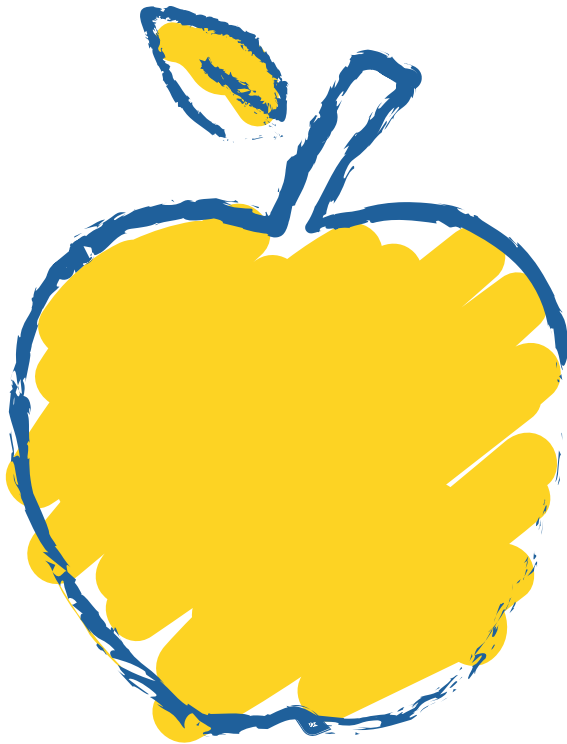


Children's Liver
Disease Foundation

fighting childhood
liver disease

Nutrition

A Guide



A guide to the nutrition of babies
and children with liver disease

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This leaflet has primarily been written for:

- Parents/carers of a child with a liver problem

This leaflet aims to explain additional feeding needs babies and children with liver disease may have.

You may find it helpful to read the CLDF leaflet called [An Introduction to Liver Disease](#).

Why is nutrition so important?

Good nutrition is important for the growth and development of all children. Food consists of a number of different nutrients: protein, carbohydrates, fat, vitamins and minerals.

The liver plays an important role in maintaining good nutrition and growth for two main reasons:

One) It converts the nutrients in the diet into energy and substances needed by the body for growth and normal body functions.

Two) It produces bile which helps to take in (absorb) fat from the diet in the intestine.

The bile produced by the liver helps to absorb vitamins (A, D, E and K). These are called the “fat soluble” vitamins.

Babies and children with liver disease may not be very hungry (have poor appetites) and will need more energy (calories) and protein. This is because the damaged liver cannot process nutrients effectively. This increase in requirements alongside poor food intake and reduced absorption of nutrients can lead to:

- Malnutrition
- Poor growth
- A lack of energy
- An increased risk of infection

Paying special attention to nutrition is therefore very important. You will receive specialist nutritional advice and support from your children's dietitian at your hospital as needed.

What is a nutritional assessment?

All babies and children being investigated for liver disease should undergo a nutritional assessment. This is an important first step to provide the best nutritional support for each child. The nutritional assessment will involve a review of your child's growth compared to what is considered to be normal growth by measuring:

- Weight
- Height/length
- Mid upper arm circumference (MUAC)
- Head circumference in under 2s

The nutritional assessment will also look at the history of what your child normally eats (their dietary intake). This will focus on any changes in the eating patterns of your child which may be associated with the start of the liver disease. This assessment will be done by your child's dietitian who is experienced in looking after babies and children with liver disease.

Why do some children with liver disease have poor nutrition?

Babies with jaundice (the yellow appearance of the skin and whites of the eyes) caused by liver disease often have large amounts of breast or formula milk.

This is because when the liver is not working well babies cannot digest the nutrients in the milk properly, particularly fat. This causes them to still feel hungry and they may want to feed more often. While a baby is being investigated for the cause of his/her jaundice, your dietitian may advise the introduction of a specialist formula exclusively, or alongside breastfeeding, to maintain normal growth and development.

What are specialised infant formulas?

Normal feeds (breast milk or normal infant formula) contain fat in the form of long chain triglycerides (LCTs). These fats need a good flow of bile from the liver so they can be digested and absorbed in the intestine.

If your baby is jaundiced, it may mean that bile flow is not very good and fat cannot be absorbed easily. This means that energy from fat is lost in the stool. Specialist liver formulas contain different fats called medium chain triglycerides (MCTs). These are easily absorbed without the need for bile.

These help babies to absorb more of the energy from the feed which will help him/her to gain weight. Starting your baby on an MCT feed may be recommended depending on your child's growth pattern.

Can breastfeeding continue?

If you are breastfeeding you will be encouraged to continue if your baby is growing well because breastfeeding brings many benefits to both you and your baby. However, breast milk is not a significant source of MCT fats. Therefore, it is often essential to give another specialist formula alongside breast milk to make sure your baby continues to gain weight and grow. The dietitian will advise you on the best way to do this.

If certain conditions (metabolic conditions) are the suspected cause of your baby's liver problem it may be necessary for you to stop breast-feeding temporarily while the investigations are taking place. Specialist MCT feeds as described above may also be given. Breast milk supply can be maintained by expressing breast milk and freezing it during this period for use at a later date.

What happens if babies are formula fed?

If babies are formula fed they will need to swap formula to a specialist MCT formula. When your child's formula is first changed he/she may not drink as much as before. This may be because they are now digesting more fat from the special MCT feed.

Dietitians will advise parents how to prepare the special formulas containing MCT fats. The MCT containing formulas can look, smell and taste very different to normal infant formula. These special formulas are available on prescription from GPs. Dietitians will advise you on the best milk for your baby, how to make it up and arrange a supply for use at home.

Do children with liver disease need their nutrition monitored?

It is important for babies to be weighed on a regular basis and for you to keep in close contact with your child's dietitian to ensure the dietary changes are working and your child is making progress. This ensures that any poor growth or diet related problems can be dealt with quickly. Some babies with liver disease will need ongoing and intensive nutritional support and regular discussions between parents and the dietitian are essential.

Can my baby with liver disease be weaned as usual?

Solids can be introduced from six months as per standard guidelines from the World Health Organisation. Normal weaning is advised unless a dietitian advises otherwise. High calorie weaning foods may be advised but a dietitian will discuss this if this is the case. It is important for your child to continue the weaning process and move through the age appropriate stages of weaning to aid and encourage normal feeding development. Sometimes your child may only take small quantities of foods but this is completely normal. Babies need to be offered an increasing variety of foods and different textures to help their feeding development.

There are no specific foods that need to be avoided. Even if your baby does not take very much it is important that they are offered food regularly and are involved with family meal times. This is an important part of their social development and also plays a part in building up the muscles used in speech.

Health visitors also offer advice on normal weaning practices.

Do older children need a special diet?

Generally older children will be able to have a normal diet and can eat the same foods as family and friends.

Many children require a high calorie diet to grow adequately. They may be encouraged to have additional snacks and to choose foods which are high in energy and protein. Some children will also need to have high calorie/protein milkshakes or juice drinks, the dietitian will provide further details if this is the case.

What happens if my infant is not growing as they should?

Despite simple dietary changes some babies still do not grow well. This might be because they are eating less food or they need more nutrition than usual due to the symptoms of progressing liver disease. If this is the case your child may need an increased amount of nutrients in their current formula by adding extra scoops of formula powder. Dietitians will provide you with a carefully calculated recipe when this is the case.

Alternatively, a specialist ready-made high energy feed may be used. If your child is breast fed it may be necessary to increase the amount of specialist MCT formula feeds and reduce the frequency of breast feeds.

Dietitians will advise you on the best formula for increasing your baby's nutrient intake. If your baby has started weaning it may be necessary to add extra high energy foods such as butter or margarine to solids to promote growth but a dietitian will always provide advice on this.

What is tube feeding?

Specially designed nutrient dense liquid feeds or formula milk may be prescribed to be given to your child through a tube by the dietitian if your child needs additional nutrition. This will be given via a nasogastric tube (NGT).

A nasogastric tube is a very fine, soft tube which is passed up the nostril, down the back of the throat and into the stomach. It is kept in place by a small amount of tape on your child's cheek.

The amount given by tube can vary depending on how much your child manages to eat or drink.

Why is tube feeding sometimes needed?

Often as liver disease progresses children will need more nutrition but they may be less hungry. In some cases your child may not be able to eat enough to meet their nutritional needs for growth. In this case the dietitian is likely to recommend a period of tube feeding to promote weight gain and growth.

The dietitian caring for your child will give you the help and advice you need when tube feeding is being considered. It is understandable that many parents are alarmed by the thought of tube feeding. It is helpful to think of tube feeding as a helping hand to improve your child's nutrition.

Tube feeding may help avoid the pressure and tensions which can occur when continually encouraging your child to eat when they aren't very hungry. Many families who at first resist the idea of tube feeding say that when looking back, they wish that they had started it long before.

Is tube feeding painful?

Passing the tube (putting the tube in) is not painful, but may cause some temporary discomfort. The nursing team will advise you how often the tube needs to be changed. For most babies and younger children the tube will be kept in place all the time and so will be seen. To begin with nurses on the ward pass the tube and community nurses can do this at home. Many parents prefer to pass their own child's tube and, as their confidence increases, some older children learn to do it themselves.

When is tube feeding done?

NGT feeding can be given slowly and continuously over many hours (known as continuous feeding) or given at regular intervals throughout the day, just as bottles would be given (known as bolus feeding). Your dietitian will support you to find a safe routine that fits into your family life.

When tube feeding is required during the day, it can be given via a portable feed pump which fits into a small rucksack. This enables your child to be mobile whilst tube feeding.

Many parents give boluses or top ups as gravity feeds. This method of tube feeding delivers formula using a feeding bag without a pump and drips through the tube by gravity alone. You can discuss with your dietitian what may work best for your child.

Before your child leaves the hospital the family will be taught how to look after the tube and pass it as well as connect it to the feeding pump.

Regular nutritional assessment is important for babies and children on tube feeds. Dietitians will monitor your child's growth and diet and adjust the feeding plan if needed. The tube feeding regimen can be easily altered to keep up with changing needs. The length of time your child needs tube feeding can vary and will depend on your child's growth and type of liver disease.

NGT does not mean that your child cannot eat and drink orally. It is encouraged to always still offer regular meals, snacks and drinks in order to maintain their feeding skills.

Do children with liver disease need to limit the amount of fat in their diet?

No. Fat is an important source of energy and contains many calories; however, the type of fat may need to be changed so the child can absorb it more easily.

Do children with liver disease need extra vitamins?

Yes, they often do. Fat-soluble vitamins, i.e. Vitamins A, D, E and K, may all be prescribed. Children with jaundice cannot absorb these vitamins very well and may not have enough of them (become deficient). In some babies and children the fat soluble vitamin supplements may need to be continued after the jaundice has cleared to build up good body stores of these vitamins. Doctors will prescribe these as medicines.

Do children need to avoid or have any particular foods in their diet?

No. It is important that the diet is kept as normal as possible. Your child may need to eat more food than children who do not have liver disease, or they may need to have regular snacks.

How are the feeds and equipment used when children are at home?

All the feeds and feed ingredients and equipment are organised by your child's dietitian and community nurse. The GP will prescribe the feeds monthly. In most areas a specialised feed company delivers everything needed each month to your home.

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 the Information and Research Hub Manager by email at irhm@childliverdisease.org or call **0121 212 6029**.

Thanks

The booklet has been written, edited and reviewed with the help of staff at each of the specialist paediatric liver centres: Birmingham Children's Hospital, 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 2020. It is due to be reviewed by October 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, is the voice of children, young people and young adults with a childhood liver disease and their families and funds vital medical research into childhood liver disease.

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 contact the Fundraising Team by email fundraising@childliverdisease.org or call **0121 212 6022**.

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