LIVER UK

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

Nutrition in babies and children with liver disease



Help, support and guidance for children and families

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Welcome

Welcome to your guide to understanding nutrition in babies and children with liver disease. It provides information on breastfeeding, specialised formulas, weaning, tube feeding and special diets.

This information has been written for:

Parents and carers of babies and children with liver disease.

Others who may also find this information useful:

- young people with a liver condition
- healthcare professionals

You may also find it helpful to read the following Liver UK booklet:

- An introduction to liver disease in children

Use this QR code to view our resources or visit **www.liveruk.org**

Why is good nutrition important?

Good nutrition helps your child grow, develop and stay healthy. Food provides the body with essential nutrients, including proteins, carbohydrates, fats, vitamins and minerals.

The liver plays an important role in your child's growth and nutrition in two main ways:

1. It helps the body use nutrients

The liver processes nutrients from food, turning them into energy and the building blocks the body needs to grow and work.

2. It helps the body absorb fat and vitamins

The liver produces a fluid called bile, which helps the body absorb fat from food in the intestine. Bile also helps the body absorb vitamins A, D, E and K. These are known as fat-soluble vitamins because they need fat to be absorbed properly.

When the liver is not working as well as it should, the body may have difficulty processing and using nutrients. Your child may also find it harder to absorb all the nutrients they need from their food.

If your child is not getting enough energy and nutrients to meet their body's needs, this can lead to:

- malnutrition
- poor growth
- a lack of energy
- an increased risk of infection

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 in providing the best support for your child.

The nutritional assessment will involve a review of your child's growth compared to what is considered to be normal growth for their age.

The medical team will measure your child's:

- weight
- height/length
- mid upper arm circumference (MUAC)
- head circumference in under 2s

The nutritional assessment will also look at what your child normally eats (their dietary intake). This will focus on any changes in eating patterns 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 babies with liver disease have poor nutrition?

If your baby has a liver disease, bile may not flow properly from the liver into the intestine. Bile helps the body absorb fat from milk and food. When bile flow is reduced, your baby may find it harder to absorb fat and may lose some of the energy from fat in their poo.

As a result, they may feed more often or drink larger amounts of breast milk or formula. Even if a baby seems hungrier than usual, they may not be getting all the nutrients they need from their feeds.



What are specialised infant formulas?

Specialist infant formulas for babies with liver disease contain a type of fat called medium-chain triglycerides (MCTs). These fats are easier for your baby to absorb because they do not rely on bile in the same way as other fats. This helps your baby get the energy they need to support healthy growth and development.

A dietitian may recommend a specialist infant formula. This may be given alongside breastfeeding or, if needed, instead of breast milk.

Can breastfeeding continue?

If you are breastfeeding and your baby is growing well, you will be encouraged to continue because it 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 use a specialist formula alongside breast milk to make sure your baby continues to gain weight and grow. A 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 breastfeeding temporarily. Specialist MCT feeds may also be needed. Breast milk supply can be maintained by expressing milk and freezing it for use at a later date.



What happens if babies are formula fed?

If your baby is formula-fed, they may need to change to a specialist formula containing medium-chain triglycerides (MCTs). These fats are easier for babies with liver disease to absorb.

When your baby first changes to the specialist formula, they may drink less than they did before. This may be because their body is now able to absorb fat more easily from the new formula, helping them get more energy from each feed.

Your dietitian will explain how to prepare your baby's specialist formula containing medium-chain triglycerides (MCTs) safely. These specialist formulas may look, smell and taste different from standard infant formula, so your baby may need some time to get used to them.

Your dietitian will recommend the most suitable formula for your baby, and help arrange a prescription through your GP so you can obtain a supply for use at home.

Do babies with liver disease need their nutrition monitored?

It is important that your baby is weighed regularly to check they are growing and gaining weight as expected. Keeping in regular contact with your child's dietitian will help ensure that any changes to their feeding plan are working well and meeting their nutritional needs.

Some babies with liver disease need extra nutritional support over a longer period.

Can my baby be weaned as usual?

Solid foods can usually be introduced from around six months of age, following standard infant feeding guidance. Unless your child's dietitian advises otherwise, you can follow the usual weaning process.

Some babies with liver disease may need foods that provide extra energy (calories) to support their growth. If your baby needs these, your dietitian will discuss suitable options with you.

It is important to continue introducing solid foods and gradually progress through the different stages of weaning as your baby grows. This helps develop their feeding skills and encourages them to become familiar with a variety of foods and textures.

At first, your baby may only eat small amounts, and this is completely normal. Keep offering a range of foods with different tastes and textures, gradually increasing the variety as your baby develops. There are no specific foods that need to be avoided.



Do older children need a special diet?

Most older children with liver disease can enjoy a normal, balanced diet and eat the same foods as family and friends. However, some children need extra calories (energy) to support their growth and development. Your child may be encouraged to have extra snacks throughout the day and choose foods that are high in energy and protein.

Some children may also need high-calorie, high-protein drinks, such as milkshakes or juice-based drinks, to help them get the nutrition they need.



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

Sometimes, despite changes to your baby's diet, they may still find it difficult to gain weight and grow as expected. This may be because they are feeding less than usual or because their body needs more energy and nutrients due to their liver disease.

If your baby needs extra nutrition, your dietitian may recommend one or more of the following:

Increasing the energy in your baby's usual formula
This may involve adding extra scoops of formula powder. Your dietitian will provide you with a carefully calculated recipe and explain how to prepare it safely.

Using a specialist high-energy formula
A ready-made formula that contains more energy may be recommended to help your baby get the nutrition they need.

Adjusting feeds if you are breastfeeding
Your baby may need more feeds of specialist formula containing medium-chain triglycerides (MCTs).

Adding extra energy to solid foods
If your baby has started weaning, your dietitian may recommend adding high-energy foods, such as butter or margarine, to their meals to help support weight gain.



Tube feeding

A nasogastric tube (NGT) 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 will vary depending on how much your child manages to eat or drink.

If your child needs extra nutrition, your dietitian may recommend special liquid feeds or formula milk. These are specially designed to provide the nutrients your child needs and can be given through the nasogastric tube.

Is tube feeding painful?

Putting the tube in (also called passing the tube) is not usually painful, but your child may feel some temporary discomfort. Your nursing team will explain how often the tube needs to be changed and help you understand what to expect.

For most babies and younger children, the tube stays in place all the time, so it will be visible. To begin with, nurses will show you how the tube is put in while your child is in hospital. Once your child is at home, community nurses can help with this too.

Many parents choose to learn how to put the tube in themselves. With support and practice, this can become easier over time. Some older children may also learn to put their own tube in when they feel ready.

> **I was petrified of needing an NG tube for feeding but was really well supported when that day came. It gave her the energy to enjoy things again.**
>
> Parent

Why is tube feeding sometimes needed?

As liver disease progresses, your child may need more nutrition, even if they have less appetite. This can make it difficult for them to eat enough to support their growth and development.

If your child is not getting enough nutrition from eating and drinking, your dietitian may recommend tube feeding for a period of time to help them gain weight and grow. Your child's dietitian will guide and support you, explain the options and answer any questions you may have if tube feeding is being considered.

It is understandable that the thought of tube feeding may feel worrying or overwhelming at first. It may help to think of tube feeding as an extra helping hand to give your child the nutrition they need to grow and stay as healthy as possible.

Tube feeding can also take some of the pressure off mealtimes. When your child is not feeling hungry, it can be difficult for everyone if they are encouraged to eat more than they feel able to. Tube feeding can help reduce this pressure and allow mealtimes to be more relaxed and enjoyable.

Many families who are initially unsure about tube feeding find that it becomes a helpful part of their child's care.



When is tube feeding done?

Tube 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 feeding pump which fits into a small rucksack. This helps your child to stay 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 hospital, the nursing team will show you how to care for the tube, how to put it in and how to connect it to the feeding pump. You will have support and guidance to help you feel more confident caring for your child at home.

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 length of time your child needs tube feeding will depend on your child's growth and type of liver disease.

Having an NG tube does not mean your child has to stop eating and drinking by mouth. If it is safe for your child to do so, continue to offer regular meals, snacks and drinks alongside tube feeding.

Percutaneous endoscopic gastrostomy (PEG) feeding



This is a way of giving nutrition, fluids and medicines directly into your child's stomach through a small tube placed through their tummy wall. The tube is put in during an operation while your child is asleep under a general anaesthetic.

It can help children who need extra support with feeding over a longer period of time, making sure they get the nutrients they need to grow, develop and stay healthy.

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 they can absorb it more easily.

Do children with liver disease need extra vitamins?

Yes, children with liver disease may need extra vitamins.

Children with liver disease may have difficulty absorbing certain vitamins from their food. These are called fat-soluble vitamins and include vitamins A, D, E and K. If your child cannot absorb enough of these vitamins, they may develop a deficiency. Your child's doctor may prescribe vitamin supplements to help keep their vitamin levels healthy.



Do children with liver disease need to eat or avoid any particular foods?

Usually, no. It is important for your child to enjoy as varied and balanced a diet as possible.

Children with liver disease may need more energy and nutrients than other children to support their growth and development. Your child may also need to eat larger portions or have regular snacks throughout the day to help meet their nutritional needs.

Your child's dietitian will advise you if any changes to their diet are needed.

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. Your GP will prescribe the feeds monthly. In most areas, a specialised feed company delivers everything needed each month to your home.

"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,
Liver UK

Notes



Useful resources



Useful websites

Liver UK
www.liveruk.org
Information and support for everyone living with a liver condition.

Medicines for children: advice and guides
www.medicinesforchildren.org.uk/advice-guides
A website with general advice on medicines in children.

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:
www.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.

LIVER UK

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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.

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