

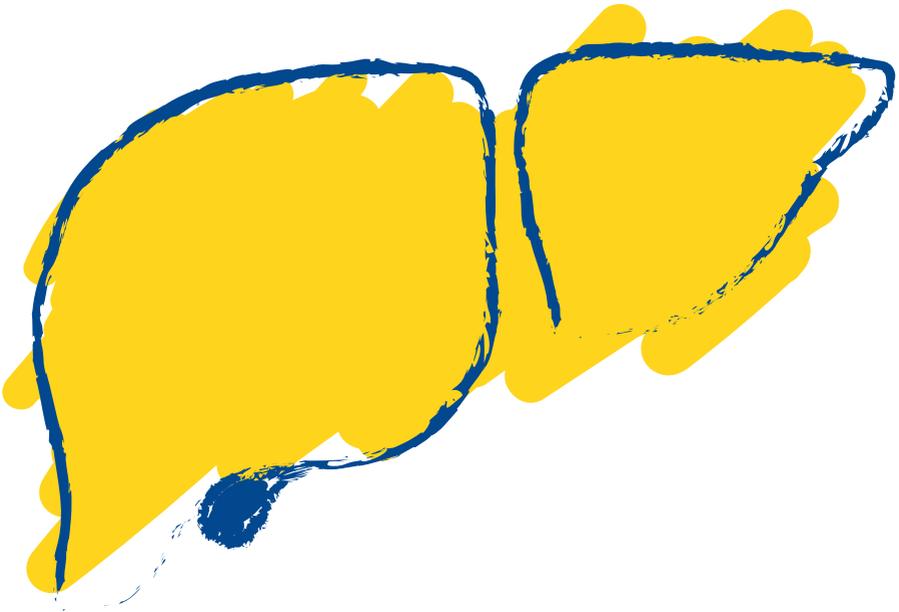


Children's Liver
Disease Foundation

fighting childhood
liver disease

Pruritus

A Guide



A guide to pruritus in children and young
people

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This guide has been written for:

- Parents/carers of children with liver disease

It may also be helpful for:

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

It provides information on:

- What pruritus is
- Causes
- Treatments
- Top tips from parents

You may also find it helpful to read the following:

- An Introduction to Liver Disease

What is pruritus and what causes it?

Pruritus is the medical term for severe itching. Cholestatic pruritus is a term used to describe itching caused by liver disease. Itching can occur when there is poor bile flow within and from the liver (cholestasis). There are some liver diseases in which itching can be particularly troublesome such as progressive familial intrahepatic cholestasis (PFIC) and Alagille syndrome.

Poor bile flow leads to high levels of bile acids in the blood stream. It is thought that these bile acids lead to itching.

Jaundice is not always present in people with pruritus. Itching is usually felt all over the body but most severely affects the palms of the hands, the soles of the feet and the upper part of the body (the trunk). The itching may come and go in phases or in different seasons.

How can pruritus affect a child or young person?

The level of the itch can vary from person to person. It can range from being mild and more of an annoyance to being very disruptive and interfering with sleep and daily life. In rare cases pruritus can become so severe that a liver transplant is considered in order to improve the quality of a child's life.

What treatment is available for pruritus?

A number of medicines are available that can be used to relieve pruritus. Some people may take more than one medicine at a time and it can take some time to find the best combination.

Sometimes medicines can work well to stop the itch; however, in other cases they may work for a short time but then stop working and need to be altered. It may be difficult to find a combination that works for a particular person.

There are operations that may be considered such as biliary diversion but success is very variable.

Sometimes itching may have more than one cause, such as liver disease and eczema, so more than one treatment approach may be needed.

Some of the most common medicines used are listed here:

Ursodeoxycholic acid (Urso)

This is a type of bile acid. It works by increasing the proportion of watery bile acids in bile. This helps bile to flow more easily. It has been shown to improve bile flow in children with liver disease and can prevent further damage to their liver cells.

Some people find their itching becomes worse in the first or second week after taking the medicine. Another potential side effect is diarrhoea.

Rifampicin (Rimactane)

Rifampicin is an antibiotic. Normally a low dose is given at the start of the treatment and is gradually increased to stop the itch. It can cause urine, saliva and tears to turn an orange-red colour; this is harmless.

Cholestyramine (Questran)

This medicine combines with bile acids in the small intestine and reduces their reabsorption. The medicine can also bind with fat-soluble vitamins (vitamins A, D, E and K) and reduce their absorption. For this reason some vitamins (and some other medicines) shouldn't be taken within two hours of taking cholestyramine.

This medicine has an unusual taste and texture. If a child is having difficulty taking it then ask your hospital team for advice.

Other medications

For severe cases of pruritus, there may be options such as ondansetron and naltrexone that can be discussed with your medical team.

New medications have been developed called apical sodium dependent bile acid transporter (ASBT) inhibitors.

They stop the uptake of bile acids in the gut and therefore reduce the amount in the body and the requirement of the liver to transport them. They are not currently licensed in the UK but hopefully will be available for treatment of PFIC and Alagille Syndrome in 2022. Trials for other conditions are ongoing. They don't work on all patients but when they do it is likely they reduce pruritus as well as liver damage.

Sedatives

A sedative is a medication which can help with sleep. This may be given if pruritus is affecting sleep.

Itching can cause distress and discomfort. When children are very young they won't be able to tell you what the problem is. Here are some hints and tips from other parents to help to deal with pruritus:



Keep your child's nails **short**

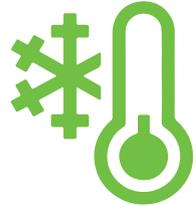


Encourage **rubbing** rather than **scratching**

Use **moisturisers** and ointments to try and soothe your child's skin. Some parents suggest **cold moisturiser from the fridge** can be especially soothing and others suggest **massaging oils** into the skin



Keep your house **cool** as the heat can make children itchier



A cool bath can help.

Keep the water cooler than normal and **add baby oil to the water**

In **very young children** try and use clothes that **cover the whole body** e.g. **baby grows at night** and dungarees in the day to prevent the child from scratching their skin



Use a **wool or cotton underblanket** to make the mattress feel softer and use cotton bedding



Dress children in **loose cotton clothes** and avoid wool, acrylics and polyesters



You can sew socks onto pyjamas to **prevent scratching** at night

Scratch mitts and scratch sleeves can be used to **stop children scratching their skin**



Older children may find that **watching TV** or talking to friends online are a **good distraction**



Distract children with a favourite toy, by moving to another room, or finding other people to play with (brothers and sisters can help here)



Speak to your child's school regarding exams and the potential for extra thinking time as **itching** can be a **real distraction**

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

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 June 2021. It is due to be reviewed by June 2024.

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. 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/support-us. Alternatively you can contact the Fundraising Team by email fundraising@childliverdisease.org or call **0121 212 6022**.

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