

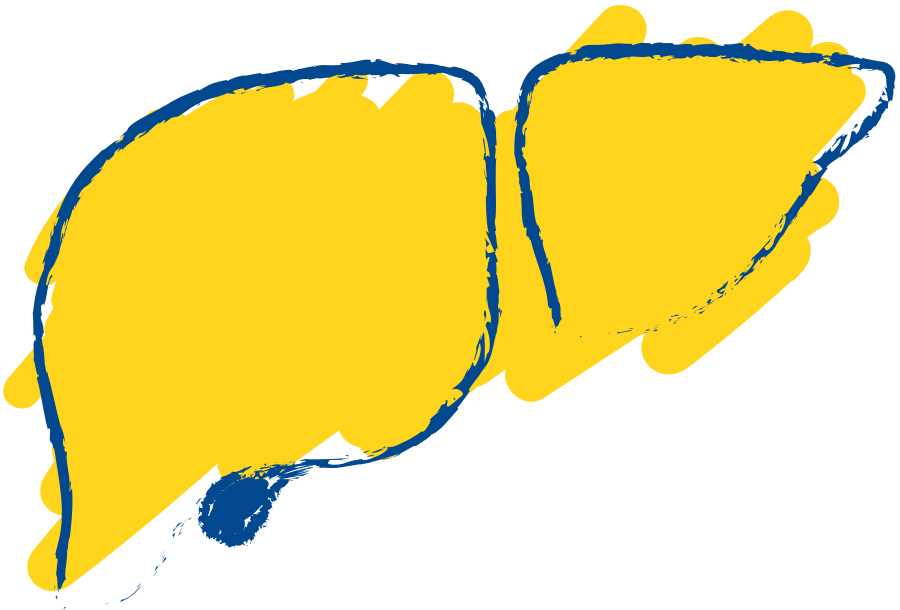


Children's Liver
Disease Foundation

fighting childhood
liver disease

Gilbert's Syndrome

A Guide



An explanation of what Gilbert's Syndrome is,
its causes and how it is diagnosed and treated

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This leaflet has primarily been written for:

- Parents/carers of children with Gilbert's syndrome

Others may also find this information useful:

- Young people with Gilbert's syndrome
- Healthcare professionals who would like to find out more about the condition

It provides information on:

- What Gilbert's syndrome is
- What causes it
- Diagnosis
- Treatment

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

- An Introduction to Liver Disease

What is Gilbert's syndrome?

Gilbert's syndrome is a mild liver condition that causes jaundice (yellowing of the skin). It is considered to be harmless and does not lead to liver damage.

What causes Gilbert's syndrome?

The condition is inherited when both parents pass on a faulty gene. In fact, the gene causing Gilbert's syndrome is common within the UK population (affecting about 4 in every 100 people). Many people do not show any signs of the condition. Parents will often also have the disease but may not have any episodes of jaundice.

The gene affected is called UGT1A1. In Gilbert's syndrome a small change in the gene means that less of the enzyme (protein), which would normally remove bilirubin from the body, is made. This leads to an increase in bilirubin in the blood. It is then seen in the skin and whites of the eyes causing a slight yellow discolouration, known as jaundice.

The condition seems to affect boys more commonly than girls and is often diagnosed in teenage years.

What are the symptoms of Gilbert's syndrome

Occasional jaundice is the most common symptom. Sometimes this may be accompanied by other symptoms such as:

- Vague abdominal discomfort
- Generally feeling tired. This may be made worse by infection, over-exertion, stress or periods of dieting/fasting
- There may have been jaundice as a baby
- There may be other members of the family with Gilbert's syndrome

Episodes of jaundice can be triggered by:

- Being dehydrated
- Fasting
- Not getting enough sleep
- Having an infection
- Being stressed
- Physical exertion
- Having surgery
- Menstruation (periods)

How is Gilbert's syndrome diagnosed?

- Using a full medical history including any history of liver disease in the family
- Clinical examination and tests (including blood tests). If liver function tests are normal, except for a higher unconjugated bilirubin level than normal, this would lead to a diagnosis of Gilbert's syndrome in most cases
- The gene for Gilbert's syndrome can be tested if the diagnosis isn't clear

What is the treatment for Gilbert's syndrome?

Treatment is not required because the condition does not progress (get worse) or cause damage to the liver.

Young people may find that feeling tired can affect everyday life but this can be helped by encouraging young people to:-

- Listen to their body
- Try and have a healthy, balanced lifestyle including a healthy diet
- Get exercise and plenty of sleep

What else can be done?

Tiredness and general lethargy can be a real struggle.

It can be helpful for young people to talk to their school/college nurse or to their employer to explain Gilbert's syndrome to them to ensure young people can get support and empathy. It may be that by making small life adjustments a difference can be made.

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 & 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 December 2020. It is due to be reviewed by December 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, 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 dedicated Facebook page called HIVE/HIVE+ for 13 – 24 year olds with a liver disease/transplant to make new friends, connect and share stories [childliverdisease.org/young-people/hive](https://www.facebook.com/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](https://www.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](https://www.childliverdisease.org)

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