Gilbert's Syndrome

Gilbert's syndrome can cause mild jaundice from time to time. It is usually harmless and does not require treatment. It is due to a reduced amount of a chemical in the liver, which processes a breakdown product of blood cells, called bilirubin.

What is Gilbert's syndrome?

Gilbert's syndrome is a condition where the liver does not process bilirubin very well. It is sometimes called Gilbert's disease although it does not cause 'disease' as such. The liver itself is normal and the condition is harmless. The condition is named after the doctor who first described it in 1901.

What is bilirubin and what happens in Gilbert's syndrome?

Bilirubin is constantly being made. It is a breakdown product of haemoglobin. Haemoglobin is a chemical that is in red blood cells and carries oxygen to the tissues. Many red blood cells break down each day releasing haemoglobin, and bilirubin is one of the waste products. Bilirubin is carried in the bloodstream to the liver where it is taken in by liver cells. The liver cells process the bilirubin which is then passed out from the liver into the gut with the bile.

A chemical (enzyme) in liver cells, called uridine diphosphate glucuronosyltransferase (UGT), helps the liver cells to process the bilirubin. People with Gilbert's syndrome have less of this enzyme and so a backlog of bilirubin can build up in the bloodstream. A high level of bilirubin causes a yellowing of skin and the whites of the eyes (jaundice). In people with Gilbert's syndrome, the blood level of bilirubin can go up and down. Often the level is normal. At other times it is higher than normal but not very high.

Who gets Gilbert's syndrome?

Gilbert's syndrome is a very common hereditary condition. About 1 out of every 20 people have this syndrome - but 1 in 3 people who have it will not know that they have it. It is more common in men than in women. It is often first diagnosed in the late teens or early twenties.

Gilbert's syndrome symptoms

Usually none
The level of bilirubin in the blood goes up and down. However, this does not usually cause any problems as the level does not go very high.

Jaundice
If the level of bilirubin goes above a certain level you can develop yellowing of skin and the whites of your eyes. This is because bilirubin is an orangy-yellow colour. This condition is called jaundice. Some people with Gilbert's syndrome become mildly jaundiced from time to time. This may seem alarming, but is of little concern if the cause is Gilbert's syndrome. The jaundice tends to occur most commonly if you are ill with another problem such as:

- An infection.
- Starvation.
- Repeatedly being sick (vomiting).
If you have Gilbert's syndrome there are some medicines which you should avoid if alternatives are available. These include:

- Atazanavir and indinavir (used for the treatment of HIV infection).
- Gemfibrozil (a cholesterol-reducing agent).
- Statins (a group of cholesterol-lowering medicines) when taken with gemfibrozil.
- Irinotecan (used for the treatment of advanced bowel cancer).
- Nilotinib (used for the treatment of some blood cancers).

**Other symptoms are uncommon**

The jaundice itself does not usually cause any problems. However, some people with Gilbert's syndrome report other symptoms - most commonly:

- Tiredness.
- Mild weakness.
- Mild tummy (abdominal) pains.
- A mild feeling of sickness (nausea).

It is not clear whether these symptoms are actually related to Gilbert's syndrome. There does not seem to be any relationship between these symptoms and the level of bilirubin in the blood. That is, these symptoms may develop whether the level of bilirubin is high or not and may be due to the problem that caused the liver to have to work a little bit harder.

**Do I need any tests?**

Yellowing of skin and the whites of the eyes (jaundice - a high level of bilirubin) can be caused by many different diseases of the liver and blood. Therefore, if you develop jaundice you are likely to need tests to clarify the cause and to rule out serious disease. A blood test can usually confirm the diagnosis of Gilbert's syndrome. It shows a mildly raised level of bilirubin; however, all the other liver tests will be normal. Very rarely, other tests such as a liver biopsy may be done to rule out liver diseases if the diagnosis is in doubt. You may also be offered genetic testing.

Gilbert's syndrome is also commonly diagnosed by chance when routine blood tests that are done for other problems show a raised level of bilirubin.

**Treatment for Gilbert's syndrome**

No treatment is needed. People with Gilbert's syndrome lead normal healthy lives. Life expectancy is not affected and life insurance is not affected. There is even some evidence that people with Gilbert's syndrome live longer and are healthier than people who don’t have it. Mild yellowing of skin and the whites of the eyes (jaundice) may come back from time to time for short periods but usually causes no health problems.

The **take home message is** - Gilbert's syndrome is really a mild abnormality of how the liver processes a chemical (enzyme) called bilirubin. It is not really a ‘disease’ and does not normally cause problems.

**Further reading & references**

- Gilbert's syndrome; NICE CKS, October 2015 (UK access only)

**Disclaimer:** This article is for information only and should not be used for the diagnosis or treatment of medical conditions. Patient Platform Limited has used all reasonable care in compiling the information but makes no warranty as to its accuracy. Consult a doctor or other healthcare professional for diagnosis and treatment of medical conditions. For details see our [conditions](#).
Discuss Gilbert's Syndrome and find more trusted resources at Patient.