



This leaflet is written for:

Parents and parents-to-be

This leaflet aims to:

- Explain jaundice in the newborn baby
- Explain what you should do if your baby's jaundice does not go away
- Explain what you should do if your baby's jaundice continues beyond two weeks after birth in a full term baby and three weeks in a pre-term baby

Jaundice continuing after this time may be a sign of liver disease. This needs to be identified early and treated as soon as possible.

This leaflet forms part of Children's Liver Disease Foundation's **Yellow Alert Campaign**.

yellowalert.org

What is jaundice?

Jaundice is the name given to the yellow appearance of the skin and the whites of the eyes. Jaundice is NOT a liver disease.

Is jaundice common in newborn babies?

Yes. Jaundice is very common in newborn babies. About 60% of full term babies and 80% of premature babies develop jaundice in the first week of life. Jaundice reaches its peak at about four days of life and then gradually disappears in most babies by the time they are two weeks old. Jaundice does not necessarily mean your baby is ill.

Jaundice can occur within the first 24 hours after birth, but this is rare. If this happens it is important that a neonatologist or paediatrician (a doctor who specialises in the care of babies and children) sees your baby. Normally this will not be a problem as you will still be in hospital. If your baby is at home, it is important you tell your midwife or doctor.



What causes baby jaundice?

When your baby is in the womb the waste products are removed through the placenta. Once your baby is born their own body has to do this. It can take some time for a baby's liver to be able to remove waste products properly from the blood. Therefore, in the early days of your baby's life some waste products may build up in their body. One waste product is called bilirubin. Newborn babies have a higher number of red blood cells than adults. Because your baby has more red blood cells, which are being broken down more quickly, there is more bilirubin being made. If there is too much bilirubin your baby will be jaundiced.

What is bilirubin?

This is a product of the breakdown of old red blood cells. It has a yellow colour which gives stool (poo) and blood their colour. Bilirubin travels in the blood stream to the liver where sugar is added and becomes conjugated bilirubin. Before the sugar is added it is known as unconjugated bilirubin.

Can the level of jaundice be measured?

Yes. The level of bilirubin in your baby's blood can be measured quite simply. A heel prick blood sample can be taken. This is sometimes called an 'SB' or a 'bili' test. This will measure what is called the serum bilirubin level and show whether the jaundice level is getting high or, in some cases, whether your baby has jaundice. This is not as silly as it sounds as it can be difficult to see jaundice in some babies. Sometimes a small light meter may be used to measure the jaundice level.

Should jaundice go away?

Jaundice caused by a build-up of bilirubin, as described previously, normally disappears by the time your baby is 10 to 14 days old. This may take a bit longer if the baby is premature, in which case it can take about three weeks to go away.



Is there any treatment for jaundice?

As long as your baby is well, there is no need for treatment as jaundice usually disappears by the time the baby is two weeks. Your midwife or doctor will know when treatment is necessary. However, see your GP immediately if the jaundice does not disappear after this time. Also see your GP if your baby's stools are pale or their urine is dark, or if the jaundice spreads to the arms and legs.

If the jaundice level gets too high there can be a concern that it could cause damage to your baby's brain (kernicterus) so the normal treatment is phototherapy to reduce the bilirubin level. Your baby will be placed naked, except for some eye pads, in a cot under a special blue light. Alternatively, your baby may be wrapped in a biliblanket. The light breaks down the bilirubin. You will be encouraged to feed your baby so that your baby produces plenty of urine. Phototherapy can usually be stopped within a few days.

Will baby jaundice harm my baby?

Baby jaundice is not usually dangerous. If there is any doubt, a blood sample will be taken to measure the bilirubin to make certain there is no risk to your baby. Phototherapy should be started well before any dangerous level is reached.

Why do some babies remain jaundiced?

Baby jaundice normally clears by the time your baby is two weeks old. However, sometimes it lasts longer. There can be a number of reasons why jaundice continues:

- Your baby may have been born early.
 In premature babies jaundice may take up to three weeks to clear.
- Your baby may have a condition in which the blood cells break down more quickly than is normal for babies. This is often recognised very soon after the baby is born, or even during pregnancy, and further treatment may be necessary. Your baby will be seen by a blood specialist called a paediatric haematologist.



- Jaundice may continue occasionally in babies who are entirely well and are being breast fed. Breast feeding may safely continue and the jaundice will fade with time. There is more information on breast feeding jaundice later in this leaflet.
- Your baby may have an infection or other illness.
- Your baby may have a thyroid gland that is not working properly. This is usually tested as part of a blood test which is carried out on all babies between five and eight days old, called the Guthrie Test.
- Your baby may have a problem with their liver. This is rare. The most common liver disease in newborn babies is called biliary atresia.

Is there anything else I can do?

Yes, you should check the colour of your baby's stools (poo) and urine:

- The urine of a newborn baby should be colourless. If your baby's urine is persistently yellow then this can indicate liver disease and you should tell your doctor, midwife or health visitor, whether or not there is jaundice too.
- The stools of a breast fed baby should be green / daffodil yellow. The stools of a bottle fed baby should be green / English mustard yellow.

Check your baby's stool colour against the stool colour chart on the next page. If the colour of the stools is in the suspect stools category then you should tell your doctor, midwife or health visitor, whether or not there is jaundice too.



Healthy Stools

H1 H2 H3

Suspect Stools

S1 S2 S4

Digital printing or photocopying of this stool chart will alter it.

Use only items supplied by CLDF.

Why is the stool and urine colour important?

Normal baby jaundice is caused by a build-up of unconjugated bilirubin. When red blood cells are broken down unconjugated bilirubin is made. The liver processes the unconjugated bilirubin by adding a 'sugar' which changes the bilirubin to conjugated bilirubin.

Babies with liver disease can also have jaundice. This jaundice, however, is caused by a build-up of conjugated bilirubin. The conjugated bilirubin is picked up by the blood and is passed around the body causing jaundice. It also causes the urine to be yellow as the kidneys try to get rid of the conjugated bilirubin, which is water soluble. Yellow urine in a baby is not normal and the baby should be investigated for liver disease. That's why it's important to check the urine colour.

The stool colour may also give an indication of liver disease. If there is a blockage or inflammation in the liver or the biliary drainage system, it may prevent the bile from draining from the liver. This will mean that the stool will not be as coloured as normal and will appear pale or even the colour of putty. Any baby, at whatever age, with pale stools or stools which appear



'fatty' in texture should be investigated for liver disease. That's why it's important to check the stool colour.

In some cases, there can be an intermittent obstruction and the stools can be alternately paler and darker.

What should be done if my baby's jaundice does not go?

The golden rules are:

- If jaundice continues beyond 14 days of age in a full-term baby or 21 days in a premature baby then this should be investigated.
- Always tell your doctor, midwife or health visitor if your baby's stools and urine are not the right colour, no matter the age of your baby.
 - For stool colour see chart back on page 9
 - A newborn baby's urine should be colourless

A split bilirubin test should be carried out to determine whether your baby's jaundice is caused by an underlying liver disease. This test may need to be done at your local hospital.

What is a split bilirubin test?

This blood test measures the ratios of the conjugated and unconjugated bilirubin levels in your baby's blood.

If the conjugated fraction is greater than 20% of the total bilirubin your baby should be referred to a specialist unit as this indicates that the cause is a liver disease and needs further investigation.

Just to be clear — a serum bilirubin test (sometimes called SB or bili test) measures the total amount of the bilirubin and will show the level of jaundice but does not show whether the cause is liver related or not. A split bilirubin test will indicate whether the cause is liver related. It is important that this test is done.

Note: A baby can have normal baby jaundice and jaundice caused by liver disease at the same time.

I've been told my baby is feeding well, growing and looks well so the jaundice can't be caused by liver disease. Is this true?

Sadly no, it's a common mistake that people make. In the early stages of liver disease a baby can look and seem entirely well and can be feeding exceptionally well. The best way to make sure is to look at the



stools and urine and have a split bilirubin test.

I've been told my baby has breast milk jaundice. What does this mean?

Some babies who are breast fed may have jaundice which continues. In this case the blood levels will be normal except for a raised total bilirubin. The stools and urine colour will be normal too. Breast milk jaundice is harmless and will gradually disappear. In a small number of cases it can take a few months to totally disappear.

Quite frequently parents are reassured that the cause of prolonged jaundice is breast milk jaundice without testing. The majority of babies will have breast milk jaundice but very few will have liver-related jaundice — or even both. However, it is important that a diagnosis of breast milk jaundice is made after a split bilirubin test is carried out and not before.

My baby has been tested and given a diagnosis of breast milk jaundice. What should happen now?

Our experience is that most parents want to be reassured that their baby's bilirubin level is returning to normal. We suggest that the serum bilirubin level is measured weekly until the bilirubin level returns to

normal. In cases where the jaundice takes a long time to reduce, the tests can be carried out further apart, provided the trend is for the bilirubin level to be reducing.

My baby has been referred to a specialist unit. Is there any help for me and my family?

Yes. Children's Liver Disease Foundation (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.

- CLDF has a leaflet called 'Baby jaundice and liver disease' which gives you more information on the next steps and further investigations. You can download this from CLDF's website childliverdisease.org or call us on 0121 212 3839
- 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

CLDF have a Children and Families
 Officer available to listen to and help
 families, relatives, friends and young
 people. You can contact them by
 calling 0121 212 6023 or email
 families@childliverdisease.org

20 children a week are diagnosed with a liver disease.

For most the cause is unknown.

Children of all ages get liver disease through no fault of their own or their parents.

50% of diagnoses are in babies, 20% are in childhood and a staggering 30% are in adolescence.

CLDF is the only organisation dedicated to fighting all childhood liver diseases in the UK.

Disclaimer

This leaflet provides general information but does not replace medical advice. It is important to contact 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 centres in the UK: Birmingham Children's Hospital, King's College Hospital and Leeds Children's Hospital. To provide feedback on this leaflet or for more information contact: info@childliverdisease.org

Would you like to help us support the fight against childhood liver disease?

CLDF's work is funded almost entirely through voluntary donations and fundraising. Please help us to continue to support young people, families and adults diagnosed in childhood 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. Alternatively, you can contact the Fundraising Team by emailing fundraising@childliverdisease.org or call 0121 212 6022.

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