YELLOW ALERT!

Early identification of liver disease in newborns

A protocol for healthcare professionals

LIVER uk

www.liveruk.org/yellow-alert

The following organisations endorse the Yellow Alert campaign

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Key facts:

Biliary atresia is a rare disease of the liver and bile ducts. It is a serious condition that needs to be identified and treated as early as possible.

Key signs of biliary atresia:

- Jaundice lasting beyond 2 weeks in a term baby and 3 weeks in a pre-term baby (prolonged jaundice)
- Pale stools and yellow urine

Key actions:

If a baby has prolonged jaundice and:

- has normal stool and urine colour, and
- is thriving / gaining weight

perform blood tests as soon as possible, including a split bilirubin test.

If a baby has prolonged jaundice and:

- has abnormal stool or urine colour or
- is not thriving / not gaining weight

refer to a paediatrician immediately.

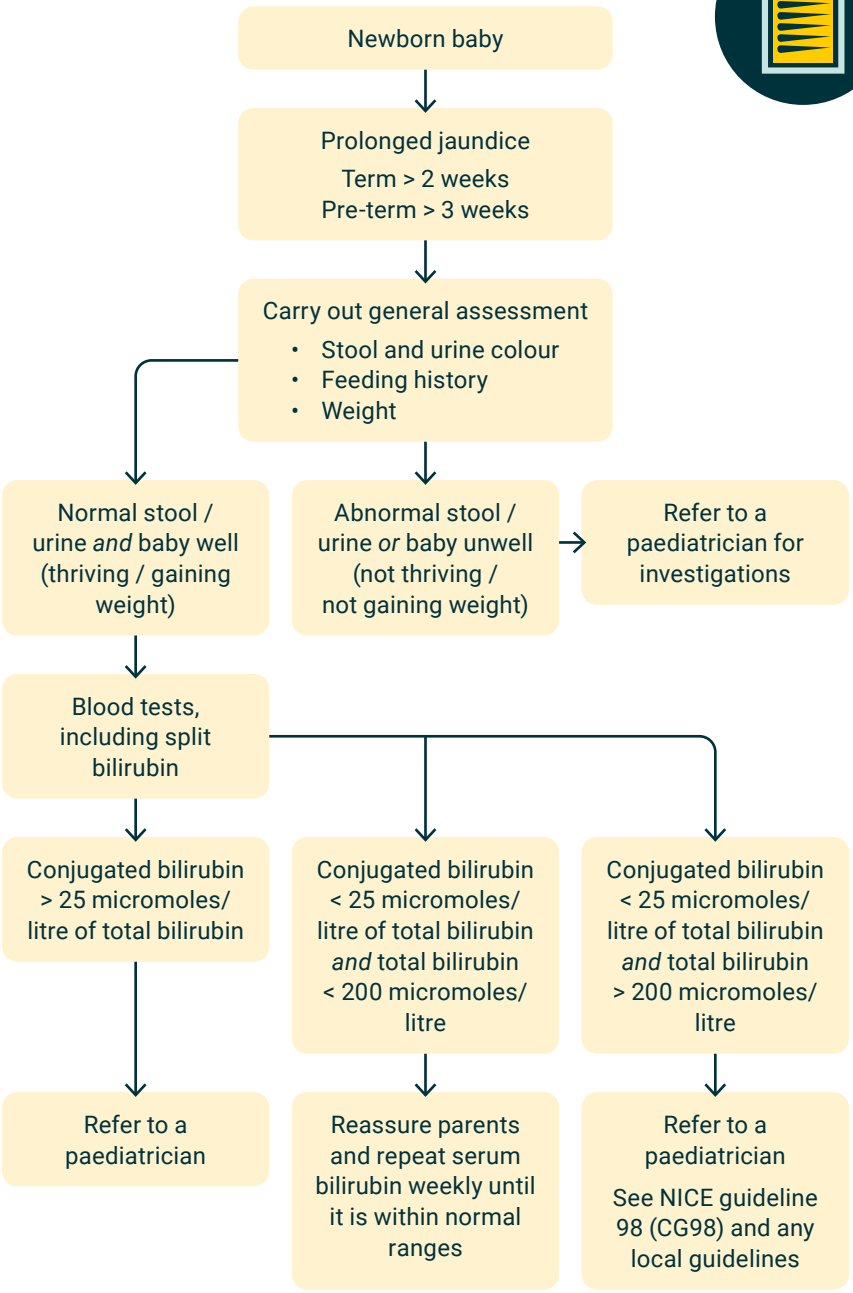
If a baby has abnormal stool or urine colour, even if there is no jaundice, refer to a paediatrician immediately.

Other Yellow Alert materials:

- Yellow Alert stool chart
- Yellow Alert poster
- Jaundice in the newborn baby and liver disease: a guide for parents

Order Yellow Alert materials at **www.liveruk.org/yellow-alert**

Early identification algorithm



Jaundice in newborn babies

Jaundice is when the whites of the eyes and the skin turn yellow. It happens when bilirubin trapped in the liver passes back into the bloodstream.

Bilirubin is a natural waste product in the body. It is made when old red blood cells break down in the spleen. Bilirubin is yellow, which gives stools their colour. Bilirubin travels in the bloodstream.

Jaundice is very common in newborn babies. About 60% of full-term babies and 80% of pre-term babies develop jaundice in the first week of life. This is known as **physiological jaundice**.

Physiological jaundice usually reaches its peak around four days after birth and then slowly fades. In most babies, the jaundice clears on its own by 2 weeks of age and no treatment is needed.

A small number of babies with high bilirubin levels may need a special light treatment called phototherapy. If this does not work, a blood treatment called an exchange transfusion may be needed.

Find more information on physiological jaundice:

Jaundice in babies – NHS
www.nhs.uk/conditions/jaundice-in-babies/

Identifying jaundice in newborn babies

Jaundice can sometimes be difficult to spot in newborn babies. Some babies will look very yellow. In other babies the colour change can be hard to see. Jaundice can be even more difficult to see in babies with black or brown skin.

Jaundice may be easier to see in the:

- whites of the eyes
- palms of the hands
- soles of the feet
- inside the mouth, including the tongue and gums

Check a baby's skin under natural daylight, where the colour change may be easier to see.

Jaundice doesn't look the same in every baby, and it can vary with skin tone. **Visit our website to see what it can look like in different babies.**

www.liveruk.org/yellow-alert

Visit our website for more information on baby jaundice:

www.liveruk.org/baby-jaundice

See National Institute for Health and Care Excellence (NICE) guidance on neonatal jaundice at **nice.org.uk/guidance/cg98**

Prolonged jaundice

Sometimes jaundice lasts longer than expected. This is known as prolonged jaundice and in some babies, it can be a sign of an underlying health condition. It is very important that tests are carried out to find the cause of prolonged jaundice.

Prolonged jaundice means:

- Jaundice lasting beyond **2 weeks** of age in term babies
- Jaundice lasting beyond **3 weeks** of age in pre-term babies.

When prolonged jaundice is caused by an underlying health condition, it is known as **pathological jaundice**.

Possible causes of prolonged jaundice include:

- **Breast milk jaundice:** Some healthy, breastfed babies stay jaundiced for longer. This is a harmless condition that gradually disappears on its own. Before diagnosing breast milk jaundice, a blood test is needed to rule out other causes of prolonged jaundice.
- **Haemolysis:** A condition where blood cells break down faster than the body can replace them.
- **Infection or other illness**
- **Underactive thyroid (hypothyroidism):** A condition where the thyroid gland does not produce enough hormones.
- **Blood group incompatibility:** When the mother and baby have different blood types, and some mixing of blood occurs during pregnancy or birth.
- **Metabolic disorders:** A group of conditions that affect how the body uses food to produce energy.
- **Liver disease:** In a small number of babies, prolonged jaundice can be a sign of liver disease. The most common liver disease in newborns is biliary atresia. It is a serious condition that needs urgent treatment.

We're lucky that our midwife recognised the danger signs. Jaundice in newborn babies may be common but I now know that prolonged jaundice isn't. I want every new mum to be aware of that fact."

Parent of a child with biliary atresia

Please note: The rest of this protocol talks about jaundice caused by liver disease, and specifically biliary atresia. Other causes are not covered here.

Biliary atresia and liver disease

In a small number of babies, prolonged jaundice can be a sign of a liver condition called biliary atresia. This is a rare but serious disease of the liver and bile ducts. It needs to be identified and treated as early as possible.

Biliary atresia happens in around 1 in 10,000 to 1 in 20,000 births in the UK. It is the most common liver disease in newborns. In newborns with biliary atresia, bile ducts are missing, incomplete, blocked or damaged. This stops the flow of bile from the liver to the gallbladder and small intestine. Bile backs up and gets trapped inside the liver. This is known as cholestasis. It may cause serious damage to the liver as cells die and are replaced with scar tissue (fibrosis).

There is no cure for biliary atresia, and it cannot be treated with medicines. If tests show that a baby is very likely to have biliary atresia, they will need an operation called a Kasai procedure. If a baby does not have a Kasai procedure in the first 2 to 3 months of life, the success rate of the operation is very low. If a Kasai is not done, or fails, a liver transplant is the only option available.

Visit our website for more information on biliary atresia:

liveruk.org/biliary-atresia

"We had never heard of this disease and in all honesty we were really quite terrified. I made the mistake of googling things I didn't fully understand … and truly expected the worst"

Parent

It is vital that biliary atresia is diagnosed and treated as early as possible. But sadly, the condition is missed in some babies.

If a baby does not have a Kasai procedure in the first 2 to 3 months of life, the success rate of the operation is very low.

If a diagnosis is missed, more damage happens to the liver every day. The liver becomes stiff and scarred, and it is more likely that a baby will need a liver transplant.

"We raised concerns that we didn't think he was gaining weight very well, he still seemed a little yellow and that his stools were pale. But no one seemed concerned, and we were sent on our way. It wasn't until we saw a different health visitor when he was nearly four weeks old, that they saw what we had been seeing and actually listened to our concerns."

Parent

Hear the story of a missed diagnosis

In our podcast we talk to Gemma, whose daughter was born with biliary atresia, but the diagnosis was missed. She tells the story of her daughter's birth, early months, and eventual liver transplant.

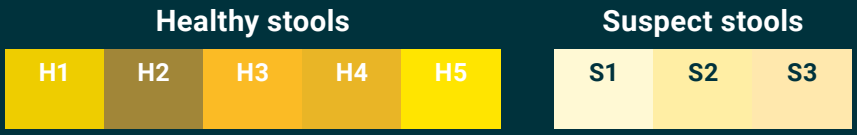
liveruk.org/biliary-atresia-podcast

Signs of liver disease

Whilst liver disease in newborns is rare, early diagnosis is vital. There are some key signs to look out for:

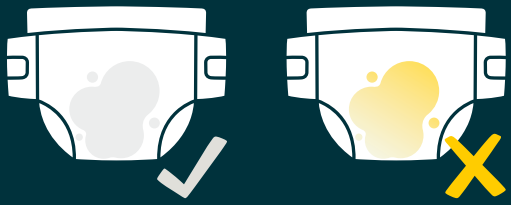
1. **Prolonged jaundice**
   Jaundice persisting beyond 2 weeks of age in term babies and 3 weeks in pre-term babies could be a sign of liver disease.

2. **Abnormal stool colour**
   A baby's stools should be yellow or mustard yellow.
   If they are persistently **pale, grey, white or clay** in colour, this could be a sign of liver disease. Check stools against the colour chart below.



   Green stools are not a sign of liver disease.

3. **Abnormal urine colour**
   A baby's urine should be clear and colourless.
   If it is persistently **yellow or dark and stains the nappy**, this could be a sign of liver disease.



As a young first–time mum I didn't know that a baby with dark urine and pale stools was not normal, so I'm forever grateful to my health visitor."

Parent

Key actions for midwives and health visitors

1. Check for jaundice

Check all babies for jaundice by looking at the:

- skin (under natural daylight)
- whites of the eyes
- palms of the hands
- soles of the feet
- tongue and gums

Always record the presence of jaundice, no matter how mild, when transferring care.

Remember:
Jaundice can be harder to see in babies with black or brown skin.

State on the record that a jaundice check has been carried out.

2. General assessment for prolonged jaundice

If a baby has prolonged jaundice, carry out a general assessment. This must include:

- Stool colour
- Urine colour
- Weight
- Feeding history, including whether breastfed or bottle fed

Look at the stool and urine colour. Ask parents to keep a nappy to show you. Be aware that yellow urine could make a pale stool appear yellow. Document all findings and photograph any pale stools or yellow urine if you can.

Remember:
Babies with biliary atresia usually appear well and healthy when they are first born. They may even be feeding extremely well.

Our son was jaundiced from the start. He also seemed to want to feed a great deal in comparison to our daughter when she was a newborn."

Parent

Key actions

If a baby has prolonged jaundice and:

- has normal stool and urine colour and
- is thriving / gaining weight

perform blood tests as soon as possible, including a split bilirubin test.

If a baby has prolonged jaundice and:

- has abnormal stool or urine colour or
- is not thriving / not gaining weight unwell

refer to a paediatrician immediately.

If a baby has abnormal stool or urine colour, even if there is no jaundice, refer to a paediatrician immediately.

Blood tests

If a baby has prolonged jaundice and they are well, request the following blood tests:

Serum bilirubin blood test: This test measures the total bilirubin in the blood.

Split bilirubin test: This test measures the ratio of conjugated to unconjugated bilirubin in the blood. This is the key test for diagnosing liver disease, including biliary atresia.

Blood test actions

If conjugated bilirubin is greater than 25 micromoles/litre of total bilirubin	→ Refer to a paediatrician
If conjugated bilirubin is less than 25 micromoles/litre of total bilirubin *and* total bilirubin is less than 200 micromoles/litre	→ Reassure parents and repeat serum bilirubin weekly until it is within normal laboratory ranges
If conjugated bilirubin is less than 25 micromoles/litre of total bilirubin *and* total bilirubin > 200 micromoles/litre	→ Refer to a paediatrician See NICE guideline 98 (CG98) and any local guidelines

The following tests should also be done (some may already have been performed):

- Full blood count
- Blood group determination (mother and baby)
- DAT (Coombs' test)
- Urine culture
- Routine metabolic screening (including screening for congenital hypothyroidism)

Further investigations

Babies referred to a paediatrician must have the following tests:

- **Repeat Split Bilirubin Test**
- **Liver Function Tests**
  - Albumin
  - Aspartate and Alanine Transaminases (AST, ALT)
  - Alkaline Phosphatase (ALP)
  - Gamma-glutamyltransferase (GGT)
- **Coagulation Tests**
  - Prothrombin Time (PT)
  - Partial Thrombin Time (PTT)

Coagulation may be prolonged secondary to vitamin K deficiency, particularly in breastfed babies not given vitamin K at birth.

All babies with suspected liver disease must be given vitamin K orally if the INR is normal, or by intravenous/intra-muscular methods if abnormal.

- **Blood Glucose**

  See national guidance for further details:
  bspghan.org.uk/hepatology-guidelines

Referral to a specialist centre

If any of the tests are abnormal or liver disease is suspected, the baby may need referral to a specialist centre for further investigations or management.

There are 3 specialist paediatric liver centres in England. All offer medical and surgical management for biliary atresia. The Department of Health has designated the 3 specialist paediatric liver centres to carry out Kasai portoenterostomy for babies from England, Wales, Scotland and Northern Ireland.

Specialist paediatric liver centres:

Birmingham Women's and Children's NHS Foundation Trust
The Liver Unit, Birmingham Children's Hospital, Steelhouse Lane, Birmingham, B4 6NH
Tel: **0121 333 9999** and ask to liaise with the on-call liver registrar
Nursing team on Liver Direct: **0121 333 8989**
or **bwc.liverdirect@nhs.net**
Web: **www.bwc.nhs.uk/liver-unit**

King's College Hospital NHS Foundation Trust
Paediatric Liver, Gastroenterology and Nutrition Centre, King's College Hospital, Denmark Hill, London, SE5 9RS
Tel: **020 3299 9000** and ask to liaise with the on-call paediatric liver registrar
Referrals: **kch-tr.PaedLiverRegistrars@nhs.net**
Web: **kch.nhs.uk/service/a-z/paediatric-liver**

The Leeds Teaching Hospitals NHS Trust
Children's Liver and GI Unit, Leeds Children's Hospital, Clarendon Wing, Leeds General Infirmary, Leeds, LS1 3EX
Tel: Admin office on **0113 3925640**
Clinical Nurse Specialist Team on **0113 3926151/3926138**
Web: **leedsth.nhs.uk/hospitals/leeds-childrens-hospital/**

The paediatric liver units above are happy to provide advice.

Useful websites

Jaundice in newborn babies under 28 days
National Institute for Health and Care Excellence (NICE)
www.nice.org.uk/guidance/cg98/

Ten steps to spot jaundice in black and brown babies
NHS Race and Health Observatory and NHS Medway, 2025
nhsrho.org/

Guideline for the investigation of neonatal conjugated jaundice
BSPGHAN, 2016
bspghan.org.uk/

Babies who have neonatal jaundice. Good practice points for health visitors.
Institute of Health Visiting
ihv.org.uk/for-health-visitors/resources/good-practice-points/

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Feedback and information sources

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 living with liver disease. We would like to thank:

Professor Mark Davenport, Consultant Paediatric Surgeon, King's College Hospital
Professor Deirdre Kelly, Professor of Paediatric Hepatology

All our parent and family reviewers

Disclaimer

Donate to Liver UK

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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.

Email us: info@liveruk.org
Call our office: 0300 1311 292
Website: www.liveruk.org
Follow us on social media: www.liveruk.org/social-media

Trusted Information Creator
Patient Information Forum

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