CONDITION

Bilirubin encephalopathy

Learn how very high bilirubin levels can affect a newborn's brain, including warning signs, risk factors, testing, urgent treatment, and follow-up care.

WHAT IT IS
Newborn brain injury caused by high bilirubin

BODY SYSTEM
Nervous system

MAIN SYMPTOMS
Extreme sleepiness, poor feeding, high-pitched cry, stiffness or floppiness

WHAT CAUSES IT
Unconjugated bilirubin entering the brain

HOW IT IS DIAGNOSED
Neurologic examination with serum bilirubin testing

MAIN TREATMENT
Urgent bilirubin-lowering treatment

CAN IT BE CURED?
Sometimes - prompt treatment may limit injury

IS IT AN EMERGENCY?
Yes - always a medical emergency

LONG-TERM OUTLOOK
Often good with early treatment, with lasting effects after chronic injury

Overview

Bilirubin encephalopathy is brain injury caused by a high level of bilirubin in a newborn's blood. Bilirubin is a yellow substance made when the body breaks down old red blood cells.

Newborns commonly develop some jaundice, which makes the skin or whites of the eyes look yellow. Their livers are still learning to process bilirubin, and they have a high turnover of red blood cells. Most newborn jaundice is mild and improves with monitoring, feeding support, or treatment.

In some babies, however, bilirubin rises to a level that can enter brain tissue. This risk mainly involves unconjugated bilirubin , a form that has not yet been processed by the liver. Bilirubin in the brain can interfere with nerve cells, especially those involved in movement, hearing, and eye control.

Doctors use two related terms:

Bilirubin encephalopathy is a medical emergency. It is not the same as routine newborn jaundice. Because a baby's bilirubin level cannot be judged accurately by skin color alone, newborns with jaundice need assessment based on their age, medical history, examination, and bilirubin measurement.

- Acute bilirubin encephalopathy describes early changes in brain function while bilirubin is dangerously high. Prompt treatment may prevent or limit permanent injury.
- Chronic bilirubin encephalopathy , also called kernicterus , describes lasting neurologic injury caused by bilirubin.

Symptoms

Jaundice usually begins on the face and may spread toward the chest, abdomen, arms, and legs as bilirubin rises. It can be harder to recognize visually in babies with darker skin. Looking at the whites of the eyes and gums may help, but visual checks cannot replace a bilirubin test.

Early symptoms of acute bilirubin encephalopathy can be subtle. A baby may be unusually sleepy, difficult to wake for feeding, or less interested in feeding. The muscles may feel unusually floppy, a finding called hypotonia . The baby may have a high-pitched cry.

As brain effects progress, symptoms can include:

These symptoms do not prove that bilirubin is the cause. Infections, low blood sugar, and other newborn illnesses can cause similar changes. They still require immediate medical evaluation.

Seek urgent medical advice the same day if a newborn develops jaundice, especially if it is worsening, feeding is becoming difficult, wet or dirty diapers are decreasing, or the baby was born early.

Jaundice during the first 24 hours after birth requires prompt medical assessment. Call emergency services or go to an emergency department if a jaundiced baby is difficult to wake, will not feed, has a high-pitched cry, becomes stiff or floppy, arches the body, has breathing pauses, or has a seizure.

Long-term kernicterus may cause abnormal muscle tone or movements, hearing loss, difficulty looking upward, and problems with tooth enamel. Intelligence may be less affected than movement or hearing, but each child's pattern can differ.

- Increasing irritability or extreme sleepiness
- Poor sucking or refusal to feed

- Repeated vomiting
- Fever without another clear explanation
- Stiff or tense muscles
- Back or neck arching
- Unusual eye movements
- Pauses in breathing
- Seizures
- Reduced responsiveness

Causes and risk factors

Bilirubin encephalopathy occurs when unconjugated bilirubin becomes high enough to cross into the brain. The exact level associated with injury is not the same for every newborn. Gestational age, age in hours, health conditions, and the presence of substances that help bilirubin bind in the blood all affect risk.

A newborn may produce excess bilirubin when red blood cells break down faster than usual. This can happen with blood-group incompatibility between the birth parent and baby, such as Rh or ABO incompatibility. The parent's antibodies may attack the baby's red blood cells, a process called hemolysis .

Another cause is glucose-6-phosphate dehydrogenase deficiency, or G6PD deficiency . This inherited condition can make red blood cells more likely to break down. It may not be obvious from family history, and bilirubin can rise quickly.

Other factors that can raise bilirubin or increase the brain's vulnerability include:

Breastfeeding itself is not a disease and usually should continue. During the first week, low milk intake can contribute to rising bilirubin if feeding is not yet effective. Later, some healthy breastfed babies have prolonged jaundice related to breast milk. A clinician should distinguish these patterns from conditions that need treatment.

Not all jaundice involves unconjugated bilirubin. A rise in conjugated , or direct, bilirubin may point to liver or bile-flow disease. This requires evaluation but generally does not cause classic kernicterus in the same way.

- Birth before 38 weeks, with greater risk at earlier gestational ages
- A previous sibling who needed treatment for newborn jaundice

- Significant bruising or a collection of blood under the scalp after birth
- Difficulty taking in enough breast milk or formula
- Excessive weight loss or dehydration
- Infection, including sepsis
- Low oxygen levels or significant medical instability
- Certain inherited red blood cell conditions
- A low blood level of albumin, the protein that normally binds bilirubin
- Jaundice beginning in the first day after birth
- Bilirubin rising rapidly or remaining high despite treatment

Diagnosis

Clinicians diagnose the risk of bilirubin encephalopathy by combining bilirubin testing with the baby's age, gestational age, health history, and neurologic examination.

Bilirubin may first be estimated with a device placed against the skin. This is called a transcutaneous bilirubin measurement. A blood test provides a total serum bilirubin level and is used when confirmation is needed or treatment decisions are being made.

The result is interpreted according to the baby's exact age in hours. A level that is expected at several days old may be more concerning during the first day. Treatment thresholds also differ by gestational age and by risk factors for bilirubin-related brain injury.

If bilirubin is high or rising quickly, testing may look for an underlying cause. This may include:

The clinician will assess alertness, feeding, muscle tone, cry, posture, reflexes, and breathing. Acute bilirubin encephalopathy is mainly a clinical diagnosis supported by bilirubin results. Brain imaging is not routinely needed to decide whether emergency bilirubin treatment should begin, and a normal early scan does not necessarily exclude injury.

Hearing tests may be important because bilirubin can affect the auditory nerve and brain pathways involved in hearing.

- The baby's and birth parent's blood types
- A direct antiglobulin test to look for antibodies attached to red blood cells
- A complete blood count and measures of red blood cell production
- Testing for G6PD deficiency when appropriate

- Direct and indirect bilirubin measurements
- Tests for infection, liver disease, or other conditions when indicated

Treatment and management

Treatment aims to lower bilirubin quickly, prevent further exposure of the brain, and address the reason bilirubin increased.

Intensive phototherapy is the main treatment for many newborns with significant unconjugated hyperbilirubinemia. Special blue-spectrum light changes bilirubin in the skin into forms that the body can remove more easily. This is medical light therapy, not ordinary sunlight.

During phototherapy, the care team monitors bilirubin levels, temperature, hydration, feeding, and urine and stool output. The baby's eyes are protected. Feeding is usually continued, although the plan may need to change if the baby is too unwell to feed safely.

Feeding support can include checking the baby's latch and milk transfer, increasing feeding frequency, expressing milk, or providing supplemental milk when clinically needed. Intravenous fluids may be used if dehydration is significant or the baby cannot take enough fluid by mouth. These choices depend on the baby's condition and should be guided by the clinical team.

If bilirubin is extremely high, continues to rise despite intensive phototherapy, or the baby has signs of acute bilirubin encephalopathy, an exchange transfusion may be necessary. During this hospital procedure, small amounts of the baby's blood are replaced with compatible donor blood. This rapidly removes bilirubin and, in some cases, antibodies that are destroying red blood cells.

Exchange transfusion requires specialist neonatal care because it has important risks and needs close monitoring. Intensive phototherapy is continued while the team prepares for the procedure.

Intravenous immune globulin may sometimes be considered for selected babies with antibody-related destruction of red blood cells. It is not routine treatment for every baby with jaundice, and evidence about its benefits and risks is limited. The neonatal team decides whether it is appropriate.

Home remedies and direct sunlight should not replace medical testing or prescribed phototherapy. Sun exposure is difficult to control and can cause overheating, sunburn, or delayed effective treatment.

Complications

When bilirubin levels are lowered before brain injury occurs, babies often recover without neurologic complications. Acute symptoms may also improve after treatment, although it may not be immediately clear whether lasting injury has occurred.

Chronic bilirubin encephalopathy can affect several parts of the nervous system. Possible long-term effects include:

Some children have milder or less typical effects, including isolated hearing problems. Developmental progress should therefore be monitored over time rather than judged from a single early examination.

- Movement disorders, including involuntary twisting movements
- Abnormal muscle tone or difficulty controlling posture
- Hearing loss caused by injury to auditory pathways
- Difficulty directing the eyes upward
- Problems with balance and coordination
- Feeding, speech, or communication difficulties
- Abnormal development of the enamel on baby teeth

Follow up

After phototherapy, the care team may repeat bilirubin testing because the level can rise again when treatment stops. The timing depends on the baby's age, gestational age, bilirubin level, treatment course, and risk factors.

Routine follow-up may include weight checks, feeding assessment, repeat bilirubin measurement, and review of urine and stool output. Parents and caregivers should receive a clear plan for when and where the baby will be reassessed.

Babies with suspected or confirmed bilirubin encephalopathy may need longer-term follow-up with specialists. Care can include formal hearing testing, developmental assessment, physical or occupational therapy, speech and feeding support, neurology care, and early-intervention services.

Between visits, caregivers should seek prompt advice if jaundice appears to deepen, feeding worsens, or the baby becomes sleepier than usual. Emergency evaluation is needed for poor responsiveness, stiffness, marked floppiness, arching, breathing difficulty, or seizures.

Sources

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