CONDITION

Kernicterus

Kernicterus is permanent brain injury caused by very high bilirubin levels in a newborn.

WHAT IT IS
Permanent brain injury from severe newborn bilirubin buildup

BODY SYSTEM
Nervous system

MAIN SYMPTOMS
Abnormal movements, hearing loss, gaze difficulty, tooth enamel changes

WHAT CAUSES IT
Severe unconjugated bilirubin entering the newborn brain

HOW IT IS DIAGNOSED
Medical history, neurologic examination, hearing tests, and brain MRI

MAIN TREATMENT
Rehabilitation, hearing support, movement treatment, and feeding support

CAN IT BE CURED?
No - established brain injury is permanent

IS IT AN EMERGENCY?
Sometimes - new neurologic signs with newborn jaundice

LONG-TERM OUTLOOK
Lifelong disability ranging from limited to severe

Overview

Kernicterus is permanent brain injury caused by a high level of bilirubin during the newborn period. Bilirubin is a yellow substance made when the body breaks down old red blood cells.

Newborns often develop some jaundice, which makes the skin or whites of the eyes look yellow. Most newborn jaundice is mild and clears without causing harm. Kernicterus is rare because severe jaundice can usually be found and treated before brain injury occurs.

The bilirubin linked to kernicterus is called unconjugated bilirubin. If its level becomes very high, it can leave the bloodstream and enter parts of the brain that control movement, hearing, and eye position. Newborns are more vulnerable because their brains are still developing.

The early, active stage of bilirubin-related brain dysfunction is called acute bilirubin encephalopathy. "Encephalopathy" means a problem affecting brain function. This stage is a

medical emergency because rapid treatment may prevent further injury.

Kernicterus describes the lasting effects after permanent injury has occurred. It is also called chronic bilirubin encephalopathy. Although the brain injury cannot be reversed, treatment and support can improve movement, communication, hearing, nutrition, comfort, and independence.

Symptoms

Symptoms differ between the early emergency and the later, long-term condition.

A newborn developing acute bilirubin encephalopathy may:

These signs do not prove that a baby has bilirubin-related brain injury. They can also occur with infection and other serious newborn conditions, so urgent assessment is important.

The long-term signs of kernicterus may become clearer over the following months or years. They can include:

The movement disorder is often described as dyskinetic cerebral palsy. This means that early brain injury causes uncontrolled movements and problems with posture.

Some people have severe difficulty speaking or moving while understanding much more than they can show. Motor or hearing difficulties should not be assumed to mean that a person has an intellectual disability.

- Be unusually sleepy or difficult to wake
- Feed poorly or have a weak suck
- Seem unusually floppy
- Develop a high-pitched cry
- Become stiff or arch the neck and back
- Have pauses in breathing, fever, or seizures
- Involuntary twisting, writhing, or jerking movements
- Muscle stiffness or changing muscle tone
- Difficulty controlling posture, walking, or hand movements
- Hearing loss or auditory neuropathy, in which sound reaches the ear but is not processed normally
- Difficulty looking upward or controlling eye movements

- Delayed speech or speech that is difficult to understand
- Feeding and swallowing problems
- Abnormal development of tooth enamel

Causes and risk factors

Kernicterus happens when unconjugated bilirubin reaches a level at which it can enter and damage the newborn brain. There is no single bilirubin number that predicts injury in every baby. Gestational age, age in hours, illness, and the speed at which the bilirubin is rising all matter.

Bilirubin may build up when red blood cells are being broken down quickly. This can happen because of blood-group incompatibility between the baby and birth parent, such as Rh or ABO incompatibility. It can also occur with inherited red blood cell conditions, including glucose-6-phosphate dehydrogenase deficiency, often shortened to G6PD deficiency.

Other factors that can increase the risk of severe jaundice include:

Breastfed babies can develop jaundice, but breastfeeding itself does not usually cause dangerous bilirubin levels. During the first days of life, inadequate milk intake may allow bilirubin to rise because the baby passes fewer stools. Later, some healthy breastfed babies have prolonged jaundice related to substances in breast milk. This usually follows a different course from acute, dangerous jaundice.

- Being born prematurely
- Significant bruising or bleeding under the scalp after birth
- Infection or serious illness
- Poor milk intake or dehydration
- A previous sibling who needed treatment for jaundice
- Certain inherited conditions affecting bilirubin processing

Diagnosis

In a newborn, jaundice is assessed by measuring bilirubin. A device placed on the skin can provide a screening measurement. A blood test gives a more precise total serum bilirubin level and may separate unconjugated from conjugated bilirubin.

The result is interpreted according to the baby's age in hours, gestational age, and risk factors.

A level that is acceptable for one baby may require treatment in a younger, premature, or unwell baby.

If bilirubin is high, tests may look for the reason. These can include blood-group testing, a direct antiglobulin test for immune-related red blood cell breakdown, a blood count, and tests for G6PD deficiency or infection when appropriate.

Acute bilirubin encephalopathy is diagnosed from the combination of severe jaundice, bilirubin measurements, the baby's symptoms, and the neurologic examination.

Later kernicterus is usually diagnosed from the early history and its characteristic pattern of movement, hearing, and eye-control problems. Hearing tests, particularly an auditory brainstem response test, can detect auditory neuropathy. This test measures how sound signals travel from the ear through the hearing pathways.

Brain MRI may show changes in deep movement-control areas called the globus pallidus and subthalamic nuclei. MRI can support the diagnosis, but a normal scan does not always rule it out.

Treatment and management

A jaundiced newborn with a dangerously high or rapidly rising bilirubin level needs prompt hospital assessment. Treatment is based on the bilirubin level, age in hours, gestational age, symptoms, and other medical risks.

Phototherapy is the main treatment for significant unconjugated jaundice. The baby is placed under special blue-spectrum lights that change bilirubin into forms the body can remove more easily. Medical phototherapy is different from ordinary sunlight; sunlight is not a safe or reliable substitute.

If bilirubin reaches a critical level or the baby shows signs of acute bilirubin encephalopathy, an exchange transfusion may be needed. During this procedure, small amounts of the baby's blood are replaced with donor blood to lower bilirubin and remove antibodies that may be destroying red blood cells. Other treatments may be used for specific causes, such as immune-related red blood cell breakdown.

Once kernicterus is established, treatment cannot remove the brain injury. Care instead focuses on function, development, and preventing additional problems. It may include:

A child with swallowing difficulty may need a specialist assessment. Adjusting food texture, seating, and feeding methods can reduce choking and help maintain nutrition. Some children need tube feeding when eating by mouth is unsafe or does not provide enough nutrition.

- Physical and occupational therapy for movement and daily activities
- Speech therapy and communication aids
- Hearing aids, cochlear implants, or other hearing support
- Treatment for muscle stiffness, spasms, or uncontrolled movements
- Feeding assessment and nutrition support
- Dental care for enamel problems
- Educational and social support

Complications

Kernicterus can affect several abilities because the injured brain areas help control movement and process sound.

Possible long-term complications include dyskinetic cerebral palsy, hearing loss, communication difficulties, abnormal eye movements, and dental enamel damage. Muscle stiffness and uncontrolled movement can contribute to pain, joint problems, difficulty with personal care, or reduced mobility.

Poor coordination of chewing and swallowing may lead to inadequate nutrition or aspiration. Aspiration means food, liquid, or saliva enters the airway instead of the stomach. Repeated aspiration can cause breathing problems or lung infections.

The effect on learning is not the same for everyone. Hearing, speech, and movement problems can make standard developmental tests difficult to complete. Assessment may need to use adapted communication methods so that physical disability is not mistaken for limited understanding.

Prevention

Many cases of kernicterus can be prevented by identifying and treating severe newborn jaundice early. Prevention is not always possible, especially when bilirubin rises very quickly or a baby is seriously ill.

Before a newborn leaves the birth facility, bilirubin screening and an assessment of jaundice risk can help plan follow-up. The timing of follow-up is based on the baby's bilirubin level, age, gestational age, feeding, and other risk factors.

Parents and caregivers should receive clear information about feeding and jaundice. Frequent,

effective feeding helps a newborn pass bilirubin in stools. Feeding problems, too few wet diapers, or difficulty waking for feeds should be assessed rather than managed by stopping breastfeeding without support.

Looking at skin colour alone cannot reliably show how high the bilirubin is, particularly in darker skin tones. Yellowing may be easier to notice in the whites of the eyes, gums, or inside the lips, but suspected jaundice still needs proper measurement when clinically indicated.

Living with it and what to expect

Kernicterus is a lifelong condition, but its effects range from relatively focused hearing or movement problems to severe physical disability. The original brain injury does not continue spreading. However, its effects may become more noticeable as a child grows and more complex skills are expected.

Movement patterns can change over time. Growth may contribute to tight muscles, reduced joint movement, pain, or difficulty with seating and walking. Regular review can identify equipment, therapy, or symptom treatment that may help.

Hearing needs can also change. Ongoing audiology follow-up is important because auditory neuropathy may affect speech understanding differently from ordinary hearing loss. Some children benefit from hearing technology and communication approaches such as sign language or communication devices.

Development continues despite the injury. Children and adults may learn new ways to communicate, move, study, work, and take part in family and community life. Progress is individual and cannot be predicted from the bilirubin level alone.

Routine follow-up may involve rehabilitation, audiology, neurology, nutrition, dentistry, eye care, and education services. Care often changes with age, including planning for adult services, mobility, communication, work, and supported or independent living.

When to get medical help

Get urgent same-day medical advice if a newborn:

Seek emergency care for a jaundiced newborn who is floppy, unusually stiff, arching the back, making a high-pitched cry, having breathing pauses, or having a seizure. Call emergency services for a seizure, severe breathing difficulty, blue or grey skin, or unresponsiveness.

For someone living with established kernicterus, routine appointments are appropriate for

gradual changes in movement, hearing, equipment needs, nutrition, or communication. More urgent assessment is needed for repeated choking, possible aspiration, sudden loss of skills, severe pain, breathing problems, or a new seizure.

- Develops jaundice during the first 24 hours after birth
- Becomes more yellow, especially on the abdomen, arms, legs, palms, or soles
- Is difficult to wake or is not feeding well
- Has fewer wet diapers or signs of dehydration
- Still appears jaundiced beyond the expected newborn period

Common questions

Is kernicterus the same as jaundice?

No. Jaundice is the yellow colour caused by bilirubin in the blood. It is common in newborns and is usually harmless. Kernicterus is permanent brain injury that can occur when unconjugated bilirubin becomes dangerously high.

Can a baby recover from kernicterus?

Early bilirubin-related symptoms may improve when bilirubin is lowered quickly. Once permanent kernicterus has developed, the brain injury cannot be reversed. Rehabilitation and supportive treatment can still improve function, comfort, communication, and participation.

Can adults get kernicterus?

Kernicterus usually begins from bilirubin exposure during the newborn period. Its effects continue into adulthood, so adults can live with kernicterus even though the original injury happened soon after birth.

Does kernicterus always cause intellectual disability?

No. Some people have major movement, speech, or hearing difficulties without the same degree of difficulty in thinking or understanding. Careful assessment and accessible communication methods are important.

Can breastfeeding cause kernicterus?

Breastfeeding does not usually cause kernicterus. Poor milk intake during the first days can contribute to rising bilirubin, and some breastfed babies have longer-lasting jaundice. Feeding support and bilirubin measurement help determine what is happening. Breastfeeding should not be stopped without medical guidance.

Is kernicterus visible on an MRI?

Sometimes. MRI may show a characteristic pattern in deep areas of the brain, but findings can change with age and may not always be present. Diagnosis also relies on the newborn history, symptoms, examination, and hearing tests.

Sources

- American Academy of Pediatrics Subcommittee on Hyperbilirubinemia. "Clinical Practice Guideline Revision: Management of Hyperbilirubinemia in the Newborn Infant 35 or More Weeks of Gestation." Pediatrics . 2022;150(3):e2022058859.
- National Institute for Health and Care Excellence. Jaundice in Newborn Babies Under 28 Days . Clinical guideline CG98, published 2010 and updated 2023.
- Centers for Disease Control and Prevention. "What Are Jaundice and Kernicterus?" Newborn jaundice and kernicterus patient information.
- Le Pichon JB, Riordan SM, Watchko J, Shapiro SM. "The Neurological Sequelae of Neonatal Hyperbilirubinemia: Definitions, Diagnosis and Treatment of the Kernicterus Spectrum Disorders." Current Pediatric Reviews . 2017;13(3):199-209.
- Shapiro SM. "Chronic Bilirubin Encephalopathy: Diagnosis and Outcome." Seminars in Fetal and Neonatal Medicine . 2010;15(3):157-163.
- Watchko JF, Tiribelli C. "Bilirubin-Induced Neurologic Damage-Mechanisms and Management Approaches." New England Journal of Medicine . 2013;369:2021-2030.