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## Bilirubin encephalopathy

Bilirubin encephalopathy is a rare neurological condition that occurs in some newborns with severe jaundice.

### Causes

Bilirubin encephalopathy (BE) is caused by very high levels of bilirubin. Bilirubin is a yellow pigment that is created as the body gets rid of old red blood cells. High levels of bilirubin in the body can cause the skin to look yellow (jaundice).

If the level of bilirubin is very high or a baby is very ill, the substance will move out of the blood and collect in the brain tissue if it is not bound to albumin (protein) in the blood. This can lead to problems such as brain damage and hearing loss. The term "kernicterus" refers to the yellow staining caused by bilirubin. This is seen in parts of the brain on autopsy.

This condition most often develops in the first week of life, but may be seen up until the third week. Some newborns with Rh hemolytic disease are at high risk for severe jaundice that can lead to this condition. Rarely, BE can develop in seemingly healthy babies.

### Symptoms

The symptoms depend on the stage of BE. Not all babies with kernicterus on autopsy have had definite symptoms.

Early stage:

- Extreme jaundice
- Absent startle reflex
- Poor feeding or sucking
- Extreme sleepiness (lethargy) and low muscle tone (hypotonia)

Middle stage:

- High-pitched cry
- Irritability
- May have arched back with neck hyperextended backwards, high muscle tone (hypertonia)
- Poor feeding

Late stage:

- Stupor or coma
- No feeding
- Shrill cry
- Muscle rigidity, markedly arched back with neck hyperextended backwards
- Seizures

## Exams and Tests

A blood test will show a high bilirubin level (greater than 20 to 25 mg/dL). However, there is not a direct link between bilirubin level and degree of injury.

Normal value ranges may vary slightly among different laboratories. Talk to your health care provider about the meaning of your specific test results.

## Treatment

Treatment depends on how old the baby is (in hours) and whether the baby has any risk factors (such as prematurity). It may include:

- Light therapy (phototherapy)
- Exchange transfusions (removing the child's blood and replacing it with fresh donor blood or plasma)

## Outlook (Prognosis)

BE is a serious condition. Many infants with late-stage nervous system complications die.

## Possible Complications

Complications may include:

- Permanent brain damage
- Hearing loss
- Death

## When to Contact a Medical Professional

Get medical help right away if your baby has signs of this condition.

## Prevention

Treating jaundice or conditions that may lead to it can help prevent this problem. Infants with the first signs of jaundice have bilirubin level measured within 24 hours. If the level is high, the infant should be screened for diseases that involve the destruction of red blood cells (hemolysis).

All newborns have a follow-up appointment within 2 to 3 days after leaving the hospital. This is very important for late preterm or early term babies (born more than 2 to 3 weeks before their due date).

# Alternative Names

Bilirubin-induced neurologic dysfunction (BIND); Kernicterus

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