

Brain injury at birth Guide for parents



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What you need to know when...
Your baby has suffered a birth injury

What you need to know when... Your baby has suffered a brain injury

Being a new parent involves a huge learning curve but when you are told something is wrong with your baby - or you suspect there is - it can be a confusing and stressful time. The terms doctors and nurses use can be complex and unfamiliar.

Here, with the help of medical experts; parents who have children with brain injury and Leigh Day's team of lawyers, we explain some of the terms you may hear in the days and weeks after your baby's birth and how to cope following a brain injury diagnosis.

This guide is intended to help parents or carers of babies who may have suffered a brain injury at birth resulting from a lack of oxygen, called hypoxia.

The guide looks at what can happen in the delivery room, the different levels of neonatal units, the first month of life, the tests your child may have, and how a brain injury may have happened.



Talk to us

For more information about Birth Injury, please contact us for free, no obligation advice
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What can happen in the delivery room?

What can happen in the delivery room?

During labour, midwives need to know if a baby is becoming distressed. An abnormal heart rate can indicate that a baby is experiencing a shortage of oxygen, known as hypoxia.

IA - For low risk women, midwives listen to and count the fetal heart rate (FHR) in a technique called Intermittent Auscultation (IA). This is used for short periods during active labour.

CTG - During labour, the cardio-tocograph or CTG provides a visual connection between the unborn baby's heart rate and the mother's contractions. It is the best means of assessing the well-being of the baby during labour for over longer time periods. It involves applying a belt around the mother's abdomen to pick up the baby's heart rate, called a transducer, and a second one to monitor the contractions. Both belts must be attached in order to give a picture of how the baby is coping

during the first and second stages of labour prior to delivery.

Sometimes it can be difficult to monitor the heartbeat using a transducer on the mother's bump, so a tiny clip, called a fetal scalp electrode is used instead. With the mother's permission, the tiny clip is placed vaginally by a midwife or doctor on to the baby's scalp.

CTG deceleration - this is the term used when the baby's heart rate drops from its baseline rate. At times, this can happen in well babies. There are decelerations when a contraction takes place and provided the heart rate returns

to normal following the end of the contraction, only close observation is required. When deceleration occurs outside of these norms, midwives may call for medical assistance.

Meconium - another sign of distress is meconium, the first faeces of a new-born baby. It is discharged from the rectum as a black, tarry, sticky substance following birth, which changes over the days following feeding to become more like a normal stool in colour. If the baby passes meconium before its birth, it is a possible sign that it is or was distressed although some healthy babies pass meconium before birth.

At birth, if the team looking after the mother believe the baby may have been deprived of oxygen, they will call in a paediatrician or neonatologist to assess whether the baby is in a poor condition and needs resuscitation.



What happens once your baby is born?

What happens once your baby is born?

Once your baby is born, the delivery team will carry out several assessments to ensure that the baby is breathing and behaving as expected.

Apgar scores

The Apgars are scores from one to ten assigned to every new-born baby, calculated by a paediatrician or midwife. These are taken at one, five and ten minutes of life, in order to give an overall assessment of the baby's heart rate, breathing (respiration), muscle tone, colour, and reflexes.

Because Apgar scores can only be done at birth, and are in part subjective, further information about the baby's condition can be obtained by taking a blood sample from the cord which is attached to the placenta (the afterbirth).

In addition, the baby may have oxygen saturations measured using a probe on its hand or have a small blood sample taken from a heel prick. Later, if the baby needs to be transferred to the baby unit, it may have a small tube placed into the umbilical vein or artery. This is then used to take blood samples to measure the gases in the blood.

These samples measure the level of acid in the baby's blood. If the tissues do not get enough oxygen, acid accumulates in the tissues and blood, a condition called acidosis.





Resuscitation

Resuscitation

Your baby may be taken away from you if they are having problems breathing or have a low heartrate.

Breathing difficulties may occur because of deprivation of oxygen in the womb - baby won't be able to breathe until there's oxygen going to the parts of the brain that control breathing.

In this scenario the medical team have three levels of resuscitation technique. First, a suction catheter is used to clear secretions from the mouth and back of the throat. The baby is then helped to breathe with a mask over the mouth and nose, while a resuscitation bag is squeezed to ventilate the lungs and get oxygen to the brain via the bloodstream. Most babies come around very quickly from this and have no adverse consequences.

If the baby does not respond, a tube is placed down the trachea (windpipe). This is called tracheal

intubation and is combined with external cardiac massage if circulation and breathing is poor and the heartbeat weak or undetectable. Most babies, even those who have suffered severe asphyxia, respond to this.

In the most serious cases, when a baby does not respond to either of these, drugs may be used to stimulate the heart and to counteract the build-up of lactic acid. Once the heart rate rises to above 100 beats per minute, resuscitation has been successful. Spontaneous breathing might take quite some time to develop, with the baby placed on a ventilator in a Neonatal Intensive Care Unit (NICU).



Hypoxia

Hypoxia means there has been a lack of oxygen to the organs and tissues in the body, such as the brain and the heart. If this is severe, the baby may be unable to maintain the normal blood flow to the brain, causing injury. When injury is caused by insufficient blood flow it is called ischaemic injury.

When the brain is injured, it can swell in an acute response and function abnormally. This is called encephalopathy. Much like any injury, such as a sprained and swollen ankle, the brain can recover and there are no lasting effects. However, when a brain is damaged as opposed to injured, it can cause permanent disability.

Asphyxia

The term asphyxia is used to describe the situation in which, in addition to hypoxia, there is an accumulation of carbon dioxide (CO₂) as well as

lactic acid. This is the situation in most cases. Severe asphyxia can lead to multi-organ failure and even the death of the baby. This may happen during placental abruption.

More protracted, drawn out and less severe asphyxia may cause damage to the cerebral hemispheres of the baby's brain. This less severe brain damage can be much more subtle and hard to spot, leading doctors to study various signs in the baby in the early days and weeks. Doctors may use the terms acute profound asphyxia and prolonged partial asphyxia to describe these two different types.





What may have gone wrong during the birth to cause hypoxia?

What may have gone wrong during the birth to cause hypoxia?

Hyperstimulation of uterus

Ideally, during labour, the uterus should not contract more than four times in a ten-minute period. Hyperstimulation of the uterus occurs when contractions last longer than 60 seconds and take place more frequently than every two minutes.

When the uterus contracts during labour, the contractions temporarily reduce the blood flow to the womb. This can reduce the oxygen supply to the baby very briefly. If the contractions occur too frequently or last too long, the oxygen supply can be reduced for a longer period, causing the baby to show signs of distress on the CTG.

This can happen in normal labours but is more common if drugs are being used to induce or speed up labour (eg oxytocin / syntocinon or prostaglandin). This is reversible and is easily and quickly treated by reducing or stopping these

medications, or occasionally using an injection which acts as an antidote.

Placental abruption

The placenta, or afterbirth, is the organ responsible for both nourishment and oxygen supply to the unborn baby. Rarely, part or all of the placenta can separate from the wall of the womb during labour. This is usually unpredictable.

When this happens, it sometimes causes bleeding from the vagina or constant pain which does not subside between contractions. However, it can also happen in a 'silent' way with few or little signs or symptoms. The placenta has lots of spare capacity, meaning that for many babies, an abruption is not too serious. However, very rarely, most of the placenta separates, causing a very sudden and severe shortage of oxygen to the baby.



Umbilical cord compression

The umbilical cord carries the blood between baby and the placenta. During labour it may become compressed when the uterus contracts. This can be seen on the CTG as a heart rate deceleration. It is usually easily treated by a change in position but if the compression persists, this can cause shortage of oxygen to the baby.

Cord prolapse

A prolapse of the cord is a rare complication where the cord falls out of the womb below the baby and into the vagina, after the waters have gone. It can sometimes happen before labour, and it is more common if the baby is not coming head first. If this happens, the cord usually gets constantly compressed by the baby often causing a complete blockage of the flow of blood and oxygen.

Rupture of the uterus

This is a rare complication that occurs in women who are in labour following a previous Caesarean section. The scar tissue from the Caesarean section tears during labour, and this can cause a sudden shortage of oxygen to the baby.

Labour itself

Labour itself can cause a shortage of oxygen for some babies, particularly those who are already starved of nutrients and oxygen due to 'placental insufficiency' - when the organ is unable to deliver an adequate supply to the baby. These babies tend to be smaller and lighter in weight.





What might happen to your baby after delivery?

What might happen to your baby after delivery?

Your baby may need to go into neonatal care immediately, rather than stay with you on the post-natal ward.

There are three different levels of neonatal care/units, depending on how concerned medical staff are - **Neonatal Intensive Care Unit (NICU)**, a Local Neonatal Unit (LNU), and a Special Care Baby Unit (SCBU). The term neonatal refers to the first 28 days of a baby's life.

Neonatal Intensive Care Units (NICUs) are usually part of large university teaching hospitals and provide the full range of neonatal intensive care. They are able to look after any baby, including those born very preterm.

Local Neonatal Units (LNUs) provide special care for babies within their local area, providing the baby does not have complex intensive care requirements

Special Care Baby Units (SCBUs), pronounced 'skaboo', provide the most simple level of care for babies in their local area and stabilise a baby's condition before transferring them to another unit, or provide more intensive/specialist emergency care if necessary. This is akin to high dependency units in adult care.

In each unit, the neonatologist will formulate a plan of action for your child.





In the first few days

In the first few days

In the neonatal period if there are concerns about suspected brain damage after asphyxia, specialist doctors called neonatologists carefully monitor the baby for signs of neurological abnormality.

These include how they behave, watching for abnormal movements, levels of alertness and consciousness, early seizures, muscle tone, jitters, being unresponsive to pain and stimulation, or being hyper alert and having difficulty feeding.

If enough signs are present to suggest brain damage, known as hypoxic ischaemic encephalopathy (HIE), or neonatal encephalopathy, an action plan is put in place.

Some babies with mild encephalopathy may be abnormal for just 24-48 hours, and then appear normal and behave normally, taking to feeding. Others, at the other extreme, may take weeks before there is normal behaviour. In rare cases, there is never a return to normal behaviour.





Signs of brain damage

Signs of brain damage

Floppiness

Babies born with very poor muscle tone are sometimes referred to as being 'floppy babies' - the medical term for this is hypotonia. This is apparent almost immediately after birth, most certainly in the hours and early days following the birth, and is often a symptom of an underlying condition, rather a condition in itself.

Whilst it may be because of inherited health conditions, it is a feature often seen in babies who will later be diagnosed with cerebral palsy, a condition which affects mobility, co-ordination and intellect. Once the cause is identified, the condition responsible can be treated.

Jitteriness

Jerking movements or "jitters" are common but when they are extreme or persistent, they need to be evaluated. If accompanied by an abnormal cry called grunting (although it sounds more like a whimper), you should tell your paediatrician or midwife. Jitters can be an indication of low blood sugar (hypoglycaemia). Hypoglycaemia is confirmed by a pinprick blood test from the baby's heel and can be very easily corrected. Left untreated it can lead to brain damage within hours.

Babies who show no interest in feeding should be observed for jerking movements and grunting.



Convulsions, seizures and fits

Seizures, convulsions or fits occurring shortly or soon after birth, can indicate that significant brain injury has occurred, due to hypoxia, a lack of oxygen. However, these are not 'grand mal' type seizures found in adults but instead can be very subtle.

Doctors look for fleeting pauses in breathing or stiffening momentarily.

Seizures may come on after certain medical procedures, such as draining subdural haemorrhages - bleeding between the brain and the surrounding membrane.

These seizures can be indicated by a stiffening or pulsing of the body, trembling lip and tongue, and typically last 20-40 seconds. They can be triggered by sudden noise.

Difficulty feeding

Babies may have an inability or lack of interest in sucking and swallowing. This may be because the baby is not fully conscious and alert, or it may be because the brain damage has interfered with the mechanical processes of sucking and swallowing.

Tube feeding is a means of providing or supplementing nutrition on occasions when the baby is too premature or unwell to suck.

Nasogastric tube feeding - this is when a baby is fed through a small soft tube, which is placed in the nose and runs down the back of the throat, through the food pipe (oesophagus) and into the stomach.

Orogastric tube feeding - this is when a baby is fed through a small soft tube, which is placed in the mouth and runs down the back of the throat, through the food pipe (oesophagus) and into the stomach.

Intravenous glucose may be given to a severely asphyxiated baby to prevent hypoglycaemia.





Tests following the birth of the baby

Tests following the birth of the baby

There are two types of test your baby may have after birth if there are signs of brain injury and asphyxia.

One type studies the brain and the central nervous system. The other type looks at potential failure of multiple organs including the heart, the lungs, the liver and the kidneys. For example, an echocardiogram is used to study the heart.

An **EEG or electroencephalogram** assesses if there is abnormal electrical activity in the brain. It uses electrodes attached to the scalp to record brain activity. It defines the regions of the brain affected and provides more concrete data on the precise extent of abnormality.

Cerebral Function Activity Monitoring (CFAM) is another test using electrodes on the scalp which measure electrical activity looking for spikes which may be seizures. This is less definitive than an EEG.

Your baby might have a **brain ultrasound** to look for swelling or encephalopathy which can indicate a temporary brain injury when the brain does not function properly for a period of time (but can recover). In this quick, non-invasive test, a probe is put on the soft spot, the fontanelle, on the baby's head and the black and white image is analysed on screen. If the brain is swollen, it looks brighter or whiter than normal. The brain ultrasound is effective at establishing whether there has been a brain haemorrhage (bleeding) which may happen due to asphyxia or traumatic delivery. Treatments for the swelling include controlled cooling.

Magnetic Resonance Imaging (MRI) is used to help diagnose a wide range of conditions in children due to brain injury, illness or congenital abnormalities. When imaging of a child's brain and

spinal cord is needed, an MRI is useful because of its ability to see through the skull and the bones of the skull and spine without radiation. It is best done at two weeks of age or older. If done earlier, it may pick up fleeting abnormalities which resolve themselves. Sometimes portable MRI scanners are used for babies, who are fed and wrapped up to keep them still for the procedure.

In the context of brain injury, doctors are looking for the distribution and extent of any abnormalities. If found, they can indicate that there has been permanent damage which is so severe it will cause disabilities from conditions such as cerebral palsy.

With severe asphyxia, the grey matter (known as the basal ganglia) in the centre of the brain of

the baby is damaged; it is responsible for functions such as control of voluntary motor movements, learning, eye movements, cognition, and emotion.

More protracted, drawn out and less severe asphyxia may cause damage to the cerebral hemispheres, which can cause spasticity, muscle spasms and stiffness.

Babies who have suffered from severe asphyxia may also have damage to multiple organs, including the heart, the lungs, the liver and the kidneys. In almost all cases, those organs make a complete recovery.

An **Echocardiogram** (Echo) is an ultrasound scan which gives a detailed view of the structures of the heart. It can show how well the baby's heart is working and spot congenital abnormalities. An ECG or **electrocardiogram**, a measure of the heart's electric activity in babies through sensors placed on arms and legs, is carried out rarely.





Treatments your baby may have

Treatments your baby may have

Controlled cooling is an immediate and urgent treatment offered to babies who are thought to have suffered from lack of oxygen at birth or shortly afterwards. The medical name for this procedure is 'therapeutic hypothermia.'

A decision to carry out this therapy will be based on the baby's Apgar scores, condition at birth and levels of acidosis in the blood.

After the initial period of oxygen starvation, hypoxia can trigger biochemical changes in the brain, so damage can evolve over several days following birth. Cooling the brain slows down its activity and may reduce or prevent this further damage.

Cooling can only be carried out in specialist newborn intensive care nurseries by experienced newborn specialist doctors and nurses.

It involves gradually lowering the baby's normal body temperature (37°C) to a pre-determined temperature (between 33°C and 35°C) over two to three days following the birth. A special mattress filled with cooled fluid is used to accomplish this.

Alternatively, the baby's head may be cooled with the aid of a custom-made cap. The baby's temperature is very closely observed during the procedure by the most accurate means known, i.e. using a rectal thermometer. After the cooling period, the baby is gradually warmed until its temperature has returned to normal.

If there are no cooling facilities, the baby is cooled naturally then transferred to a unit with the right equipment.





When there is an investigation

When there is an investigation

An **Serious Untoward Incident (SUI)** is a formal Investigation which a hospital trust undertakes to determine the reason or reasons for an adverse or unexpected outcome, such as a brain injury during birth. Incidents are automatically flagged by a hospital's database and a Risk Manager for the specialty is responsible for information gathering to learn more about how the event took place. It is an important means of accessing details which will be collated and shared with the injured party in order to establish whether practice can be improved.

Root Cause Analysis gives a detailed account of what took place, why it took place and what measures will be put in place to avoid a repeat occurrence.

Trusts now have an obligation to tell parents and involve them in investigations. There is an opportunity for them to ask questions to be answered in the report.

Any written investigation report will be shared with the parents.

The focus of a Trust investigation will always be to identify learning for the organisation, rather than identifying negligence.

The **Healthcare Safety Investigation Branch (HSIB)** conducts independent investigations of patient safety concerns in maternity care in NHS-funded care across England.

It is funded by the Department of Health and Social Care. Individuals can report patient safety concerns via its website. It aims to improve care through its work and does not attribute blame or liability.

The **Early Notification Scheme** run by NHS Resolution applies if a baby was born at an NHS hospital on or after 1st April 2017 and is suspected to have a potentially serious brain injury, recognised in the first week of their life.

It is important to realise that, just because what has happened to your baby was unexpected, it does not mean that there will always have been a mistake or that the outcome could have been different. Sometimes learning is identified from investigations, but this would not have changed the outcome.

If the investigation finds that your child was injured because of an error or negligence by the medical team, you may have a legal claim.

To take a legal claim, or find out whether you have one, call our team of specialist lawyers to get the legal support you will need going forward.



Helpful advice

Helpful advice

1. Getting explanations from healthcare professionals

There is a lot of information to take in and sometimes doctors can talk in technical terms or can be vague as to what symptoms mean for your child. Sometimes they can tell you what the test or treatment is without putting everything in context.

Ask for the context and what it means for your child overall. You have every right to ask as many questions as you want. This is not the time to be shy or reserved. If you find it difficult to talk to the doctors firmly, imagine they are a contractor doing some building work on your home. Push them, politely. You may have to learn to do this, it may take practice.

There may be a lot of uncertainty and doctors do not always know all the answers to the questions you might ask. Giving a situation time is often the only way to answer questions with certainty.

2. Act as your child's advocate

It's hard to remember what to ask and what the doctors say, you are so keen to hear good news. Prepare questions in advance for the doctors.

In meetings with doctors, act as a tag team with your partner or with a friend/family member. While one of you asks the questions, get the other to write down the answers or even record the

conversation on your phone - this is becoming more common and when doctors are asked, most are happy for this to happen.

Talk through the answers afterwards if you are not happy or do not understand the answers, write down any follow up questions for the next meeting.



3. Look after yourself

At this stressful time, many people in the hospital will be looking after your baby, but no-one is employed there to look after YOU, or specifically help you. That's where charities and Facebook groups of families who have been through this before can help.

Also, take advantage of talking things through with family members - they may not have answers but will help you with questions you need to ask and, by talking, will help you process what is happening. Pouring out your heart will help. Some may have related experience, such as social work or nursing and will have different perspectives. Start discussing all the issues as soon as you feel able. Denying the situation is unhelpful.

You might not realise how serious your baby's condition is until the doctor uses an expression such as 'the worst is over.' That naïveté may have been a good thing.

Doctors are all individuals, and some are better at explaining than others. They all have different perspectives and different specialisms, such as

endocrinologists (doctors who deal with hormones), neurologists (brain activity), and paediatricians (child specialists). Some you will click with and others you will not - some may be stern and matter of fact, others more holistic and informative. Talk to as many as you can and find out who is most helpful and puts information in a way that resonates with you. Some professionals know more about certain aspects, for example cooling, which the nurses carry out daily, and may be better placed to answer questions.

5. Responding to friends

Everyone will want to know how you and your baby are doing, before they know any news of brain injury. Prepare yourself for this and come up with a stock answer you can repeat. Take photos of your baby but YOU decide when, if at all, you want to share them. Search for one that you really like, that you want to share. Don't feel pressured.

6. Dealing with being at home without your baby

After the initial hours and days, you may find yourself at home alone if your partner has gone back to work. As a mother your expectations of the

joy of birth are likely to have been shattered by the mayhem you find is happening around you. Feeling exhausted and emotional is completely normal and do not feel guilty about reaching out for help.

7. Prognosis

Doctors may be reluctant to talk about the prognosis - the likely course and outcome for your child and their future capabilities. They may not want to worry you or feel you may not be able to cope with the news or take it in.

Do not be scared to press them for details – this is an important part of dealing with all the issues and processing them.

8. Tests, scans and treatments

Don't just accept what the doctors recommend - ask if there are more tests, scans and treatments available that might help your child.

Keep speaking to the professionals.



Once your baby comes home
- the early days

Once your baby comes home - the early days

You will have many phone calls and emails to arrange appointments with a myriad of health professionals. It's helpful to give a phone number which has an answering service, so you don't miss any and have a record of the calls. Print out emails so you have a hard copy reminder/record.

Talk to us

For more information about birth injury, please contact us for free, no obligation legal advice

+44 (0)800 6895854
patientrights@leighday.co.uk

Getting more help

There are several charities who provide support for families of children with a brain injury and conditions such as cerebral palsy, these include:

cerebra.org.uk

childbraininjurytrust.org.uk

Justice for all

Leigh Day is a specialist law firm with some of the country's leading personal injury, product liability, clinical negligence, employment and discrimination, international and human rights teams.

Unlike other law firms, we act exclusively for claimants who have been injured or treated unlawfully by others.



Thank you for reading

Birth Injury guide for parents

