

Hypoxic-ischaemic encephalopathy (HIE)

This information sheet aims to answer some commonly asked questions about Hypoxic-ischaemic encephalopathy (HIE).

IMPORTANT: This is general information only. It is not intended as advice for your individual circumstances. Ask your health care provider for more information.

Your baby may have been very unwell at birth and might have developed hypoxic-ischaemic encephalopathy (HIE).

What does 'hypoxic-ischaemic encephalopathy (HIE)' mean?

Hypoxic means not enough oxygen; *ischaemic* means not enough blood flow; and *encephalopathy* means brain injury.

What is hypoxic-ischaemic encephalopathy (HIE)?

HIE occurs when there has been reduced oxygen or blood flow getting to your baby's brain. The reduced blood flow and HIE can also affect your baby's other organs such as the lungs, liver, heart, and kidneys. Your baby may be hyper-alert, irritable, sleepy, floppy, and/or have abnormal movements (e.g. fitting, jittery).

The reduced oxygen or blood flow causes the baby to have a brain injury. The brain injury may be mild, moderate or severe. Some babies will not survive but most will survive. Over time, mild, moderate or severe disabilities may become noticeable. Some babies make a recovery without lasting effects – these are likely to be the babies who have had a mild brain injury. Your baby's health care team will talk with you about your baby and what may happen.

Why does your baby have HIE?

There may be many reasons why HIE has happened and it may not always be possible to know the cause. HIE might develop before, during or after birth. Your baby's doctor will talk with you about what the reasons might be.

Where will your baby be treated?

The recommended treatment for your baby will depend on the doctors classifying the HIE as mild, moderate or severe.

Babies with mild HIE are expected to improve. Your baby will be watched closely by the doctors and nurses/midwives for at least the first 6 hours after birth. Your baby may be in the Special Care Nursery (SCN) during this time and you will be able to visit. Sometimes mild HIE might progress and further treatment may need to commence within this timeframe.

Babies with moderate or severe HIE, usually need care in a newborn (neonatal) intensive care unit (NICU). If there is not a NICU at your hospital, your baby may need to be transferred to the closest NICU. Further information on transferring an unwell baby is provided in the Parent information brochure *Transferring an unwell or preterm baby* [www.health.qld.gov.au/qcg/html/consumers.asp].

What will happen in intensive care?

Your baby's heart rate, breathing patterns, blood pressure, and temperature will be monitored. Blood tests will also be taken. To help monitor, record, and assess brain function, electrodes may be placed on your baby's scalp and/or scans may be taken.

Whilst in intensive care, your baby may be fed through an intravenous (IV) line (drip). This delivers fluids, nutrients, and medicines into your baby's veins. If your baby's condition is severe enough, they may also receive a treatment which involves cooling the baby's body temperature. This is known as therapeutic hypothermia.

What is therapeutic hypothermia?

Research has shown that cooling babies a few degrees below their normal body temperature soon after birth may lessen brain damage. Your baby will be placed on a special cooling mattress. Your baby will be cooled for three days and then slowly rewarmed back to normal body temperature. Your baby will be assessed for any discomfort and medication (e.g. paracetamol) given if required. If your baby is being cooled, you will not be able to hold or cuddle your baby, as your body temperature can warm your baby up too quickly. You will be able to hold your baby when rewarming is completed. Your baby will be assessed for any discomfort and medication given if required.

What can you do?

As a parent you have an intricate role in your baby's health. The doctors, nurses and other health practitioners will regularly discuss your baby's progress, treatment and care options with you.

Parents can visit their baby in the NICU and the staff will tell you about visiting guidelines. The nurses will be able to show you ways that you will be able to participate in your baby's care. A positive way that mums can help their baby is by expressing breast milk, so it is ready for when feeding commences.

In the first few days it is important your baby gets a lot of rest. In the early days of this type of brain injury, some babies are very sensitive to noise or touch, that is, being able to touch, talk or sing to your baby may depend on how your baby responds. Seek advice from staff about how you can best support your baby.

What about the future?

This question is very hard to answer with any certainty until a few days have gone by. The doctors will consider both baby's physical examination and the results from several types of tests to gain an understanding of your baby's potential future. When your baby is discharged home, there will be follow-up appointments with medical and allied health staff, such as a physiotherapist, to see if there are any problems with their development (e.g. learning, speaking, walking and movement). Babies with only mild, short-lived HIE who are normal at discharge may not have comprehensive follow-up.

Who should you ask if you have questions?

The hospital staff realise this will be a difficult and stressful time for you. Your baby's doctors and nurses will be able to assist with the many questions and concerns you would like to discuss.

Comfort, support and information

Bliss Further parent information is provided in Bliss Charity's *HIE (Hypoxic-ischaemic encephalopathy) information for parents* www.bliss.org.uk/Shop/hie-hypoxic-ischaemic-encephalopathy-information-for-parents. Please note the contact information provided in this publication is for the United Kingdom

Hope for HIE is an international organisation that has an Australian branch and can be contacted on Australia@hopeforhie.org

PIPA (Preterm Infants' Parents' Association) 1300 773 672, email: contactus@pipa.org.au

13HEALTH (13 432 584) is a phone line that provides health information, referral and services to the public.

Pregnancy, Birth & Baby Helpline 1800 882 436 (free call) offers free, confidential, professional information and counselling for women, their partners and families relating to issues of conception, pregnancy, birthing and postnatal care. www.health.gov.au/pregnancyhelpline

Australian Breastfeeding Association 1800 mum 2 mum (1800 686 2 686) Provides counselling and breastfeeding information to any person seeking help.

Miracle Babies Foundation 1300 MBABIES (1300 622243) A not-for-profit support and information service for parents of sick and preterm babies. www.miraclebabies.org.au

Lifeline 13 11 14 Lifeline offers a telephone crisis support service to anyone. www.lifeline.org.au