

HIE (Hypoxic-ischaemic encephalopathy) information for parents



Bliss
for babies born too soon,
too small, too sick

BeBoP
Baby Brain Protection



What you can expect for your baby

Please be reassured that, like you, the doctors and nurses want the best for your baby.

Your baby comes first

Who can help

- The nurses and doctors
- A counsellor
- Your GP
- Friends and family
- The hospital chaplain or your faith leader
- Bliss – we are always here for you

Comfort

Your baby will be comforted and treated gently

Pain management

Your baby will be given pain management at all times

Care

- Your baby may be transferred to a specialist neonatal unit
- Your baby will be closely monitored at all times by an experienced team

Shared decision making

You are not alone – take time to talk to the nurses and doctors. Their experience and knowledge can be crucial in helping you discuss treatments and outcomes. They will always have your baby's best interests at heart.

What is HIE and what treatment will my baby receive?

Hypoxic-ischaemic encephalopathy (HIE), is where your baby's supply of oxygen is interrupted during birth. Cooling treatment or mild hypothermia may be offered to your baby if they are suspected of having moderate or severe HIE to help with the healing process.

Taking part in your baby's care

It is important that you are a part of your baby's care. Talk to the staff looking after your baby about everything that you can do.

"We couldn't fault how well they cared for Evie in terms of treatment. Now Evie is a happy, bright little girl, and is more than capable of keeping up with her twin sister. She has moderate hearing loss but you wouldn't know. Her speech is fantastic – she is a real chatterbox!"

Emma, mum to Evie

What happens with cooling?

Cooling down

This is a specialist treatment that lowers your baby's body temperature from 37 degrees to 33.5 degrees to aid with the healing process of your baby's brain. The cooling treatment is usually for three days.



Monitoring

Your baby will be closely monitored and tested throughout the process. They will receive pain management and care at a specialist unit.



Warming up

The doctors will begin gently warming your baby back to their normal body temperature and they will carry out further tests to assess the development of your baby.

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Introduction

Be-coming a parent is an exciting time, but it can also be stressful particularly if your baby is unexpectedly unwell. This booklet aims to provide information for parents whose baby has been given a diagnosis of hypoxic-ischaemic encephalopathy (HIE). Babies that have been identified as having hypoxic-ischaemic encephalopathy might need

various types of treatment, including one known as hypothermia or cooling.

This booklet provides information about what sorts of treatment your baby may receive, some of the tests and procedures that may be done and what you as a parent or carer can do to help your baby.



What is hypoxic-ischaemic encephalopathy (HIE)?

Hypoxic-ischaemia is a lack of oxygen and/or blood flow getting to your baby from the placenta during the birthing process. Sometimes this is also referred to as asphyxia or birth asphyxia. HIE can affect all of your baby's organs: the lungs, liver, heart, kidneys, and particularly the brain. Your baby may be displaying symptoms which may include: being hyper-alert, irritable, eye rolling, or have abnormal movements (fits); or your baby may have a reduced level of awareness. Together these symptoms are known as hypoxic-ischaemic encephalopathy.

It is not always possible to know what causes HIE, but we do know that a lack of oxygen to a baby can lead to brain injury. This injury may be mild, moderate or severe and some babies may not survive. Of the many babies who do survive, some may go on to develop disabilities, which again may be mild, moderate or severe. Some babies will recover without any lasting effects (particularly those who had a mild brain injury).

Treatment options

Treatment options will vary depending on the symptoms your baby may have. Doctors will classify your baby's illness using the following three categories: mild, moderate or severe HIE; this will determine the treatment that they recommend for your baby.

Most babies with mild HIE recover quickly and fully. If a baby has mild HIE, doctors will monitor the baby to ensure that they do not need any further treatment after the initial lack of oxygen. If a baby is diagnosed as having moderate to severe HIE they will most likely be referred to a neonatal intensive care unit (NICU) to receive a treatment known as mild hypothermia or cooling. This is

when a baby's temperature is lowered to 33.5 degrees Celsius (92 degrees Fahrenheit) from the usual temperature 37 degrees Celsius (98.6 degrees Fahrenheit). Until recently there was no specific treatment for HIE other than intensive care support. However, there have been several medical trials that have found that cooling a baby by a few degrees for 72 hours (three days) can limit the extent of brain injury

"When we first saw Evie, she was pale, on a ventilator, fitting and jittery."

Emma, mum to Evie, explaining her experiences of HIE

associated with HIE and improve the long-term outcome for some children.

If your baby is referred for cooling, they will need to be treated in a hospital that has a NICU and the appropriate cooling

and neurological expertise. It is possible that your baby will be transferred to a regional NICU for ongoing care. Before going home your baby may often be transferred back to the local unit or the hospital where he or she was born.



Intensive care

A lack of oxygen during the birthing process can affect all of a baby's organs; a number of supportive treatments may be needed.

Your baby's blood pressure may be low and the doctors may give your baby medication (inotropes) to increase it. To ensure that your baby is not in any distress, pain killers and sedation may be given. Close monitoring of your baby, including regular blood tests, will ensure that the best treatment is given to your baby.

Seizures (fits) often occur in babies that have experienced HIE. Sometimes by observing your baby the medical and nursing staff can detect a seizure, other times it can be difficult to see; the doctors therefore monitor the baby's brain activity using a machine called the 'cerebral function monitor' (CFM) which can detect these seizures. If your baby is having seizures, they

may be treated with medication. The seizures associated with HIE will usually settle after three or four days, however, your baby may remain on medication for some time afterwards.

In addition to the above, your baby may need extra help breathing. Your baby may be on a ventilator that provides oxygen and pressure to the baby's lungs through a tube that is passed through their mouth or nose. For babies that need a little help with their breathing but do not require a ventilator, a different type of ventilation called continuous positive airway pressure (CPAP) may be used. CPAP helps babies breathe by air flowing through two fine tubes or mask placed in the nostrils. This slightly raises the pressure in the lungs and helps to keep the baby's lungs inflated.

Please see the *Bliss Family Handbook* for more in-depth explanations of neonatal intensive care.



Additional equipment your baby may need

Arterial lines	Tubes in an artery for taking blood samples easily and to monitor blood pressure
Intravenous (IV) lines (drips)	Tubes to provide fluids and medicines directly into your baby's veins
Umbilical lines	Tubes going into the umbilical cord to deliver fluids and medicines and to monitor blood pressure
Cerebral function monitor (CFM)	Monitors electrical activity in the brain
Continuous positive airway pressure (CPAP)	Gentle breathing support to keep your baby's lungs inflated
Ventilator	Machine to help breathing by driving air and oxygen and pressure through a tube in the windpipe into the lungs



What is cooling treatment?

If your baby has been identified as needing cooling treatment, the cooling process will be started as soon as possible. Depending on where your baby is born, this may be done by undressing the baby and other simple cooling techniques such as the use of fans. This is known as passive cooling. Your baby's temperature and condition will be closely monitored throughout this time. Although all hospitals will be able to start cooling, if your baby is not already in a regional NICU then it will be necessary to transfer your baby, as ongoing care needs to be provided in a specialist centre. During transport or upon arrival in the NICU, your baby will be placed onto a special cooling mattress or wrapped in a cooling wrap; this is known as active cooling. This treatment will be in addition to the standard intensive care support your baby may need.

When a baby is cooled their whole body temperature is reduced from the normal body temperature of 37 degrees Celsius (98.6 degrees Fahrenheit) to 33.5 degrees Celsius (92 degrees Fahrenheit). The wrap or mattress is filled with fluid that can be cooled or warmed according to your baby's needs. Your baby's temperature will be monitored closely to ensure that it stays at the target temperature of 33.5 degrees Celsius. Your baby's temperature will usually be maintained at the optimal level for 72 hours (three days) before the

gradual re-warming process occurs. The medical team may decide to stop cooling early if they consider this to be the best treatment for your baby.

Cooling may occasionally lead to problems with blood pressure control, abnormal heart rhythm, bleeding and clotting problems, and chemical and sugar imbalances in the blood. The doctors and nurses looking after your baby are aware of this and will be closely monitoring your baby for signs of these complications. You should also be aware that HIE is a serious illness and these complications can occur even without cooling. The cooling treatment is safe and the healthcare providers caring for your baby will manage the symptoms.

The team caring for your baby will take measures to ensure that he or she is comfortable. This may include reducing the levels of light and sound around your baby, or administering pain relief if it is felt that this is required.



Tests and procedures your baby may have

During the cooling treatment your baby *will*:

- **Have their temperature continuously monitored**
- **Have their heart rate and blood pressure monitored**
- **Receive intravenous (through a vein) fluids until they are re-warmed**
- **Have standard blood tests.**

To allow the doctors and nurses to get more information, your baby might undergo several investigations. The medical professionals will decide which investigations are most useful. Some of the additional investigations may include:

CFM/EEG

This is a special monitor that records brain activity. Several thin wires (electrodes) will be put on or just under the skin of your baby's head. These electrodes do not send electricity into your baby's head; they record the activity in your baby's brain. This will enable the medical team to monitor your baby's electrical brain waves and see how your baby is responding to both the treatment and any medication that has been given.

Head ultrasound (cranial ultrasound)

This can be done at your baby's cot side. The doctors will be looking at the structure of your baby's brain through the 'soft spot' just above your baby's forehead. It can show if there has been any bleeding, stroke, or other problems that are occasionally associated with HIE.

Magnetic resonance imaging (MRI scan)

This scan helps to assess the extent of any brain damage and provides information on the way the brain is maturing. This scan produces detailed

During the cooling treatment your baby *may*:

- **Have their brain activity monitored using a cerebral function monitor (CFM)**
- **Be given medicines for pain, seizures and to maintain their blood pressure**
- **Have further blood samples taken for other lab tests**
- **Need to be on a breathing machine**
- **Have an MRI scan.**

pictures of your baby's brain. The time to get these pictures following HIE is around five to ten days of age, although earlier scans may be done depending on your baby's condition. The scanner is usually located a distance from the neonatal unit, so it will probably be necessary to transport your baby to the scan in a special incubator. This can happen even if your baby is on a ventilator. As it is a specialist scan, it requires an expert to read and interpret the images. Due to this, it may take some weeks to get the results back. You may have left the hospital by this time and receive the results at an outpatient appointment.

Each of the investigations that your baby undergoes, as well as the way

"It was amazing to bring her home. I just couldn't take my eyes off her. After 11 days in the hospital we were so grateful. I think the cooling treatment is fantastic."

Rachel, mum to Ella

that they respond to treatments, are pieces of a jigsaw. While no individual piece tells the whole story, the medical and nursing staff will start to develop a better picture of what your baby's future may hold.



What can I do for my baby?

It is important that you are a part of your baby's care. Talk to the staff caring for your baby about everything that you can do. Some examples include:

- When visiting your baby sit by their bedside and talk, read or sing to them. Babies like to hear your voice.
- When your baby is being cooled you can hold your baby's hand, foot or touch them to let them know you are there.
- Many hospitals will allow you to provide some of the basic cares such as nappy changing or helping to feed your baby milk.
- If you wish to breastfeed, then, at first, you will need to express your milk. Nursing staff on the unit will be able to help you with this. Your breast milk will be stored in the refrigerator or freezer until your baby is ready to be fed. It is important that you begin expressing your milk as soon as possible after the birth of your baby. The doctors will decide when this is safe to give your baby and initially your baby will receive it through a tube placed through the nose or mouth that leads to the stomach. As your baby develops you may be able to put him or her to the breast.

- Ask as many questions as you need to. It is important that you understand your baby's treatment and progress.
- Make sure that you look after yourself, attend postnatal checks and talk about how you feel.

The nurses will help you to provide as much care as possible, but just being there is important. Equally, sick babies need a lot of peace and quiet and some hospitals try to have some 'quiet time' when no procedures are carried out and babies are left undisturbed.

When your baby is no longer being cooled, and even if your baby is still connected to machines and tubes, the medical and nursing staff can help you to hold your baby. Some parents enjoy Kangaroo Care. This is skin-to-skin contact with your baby; this can help build a close bond between you and your baby and, for mums, can stimulate breastfeeding. The Bliss booklet *Skin-to-skin with your premature baby* describes how parents can do this.

During this difficult time, it's important that you take care of yourself. Make sure that you receive the postnatal care you need so that you are as healthy as possible. Having a baby in intensive or special care can be stressful for families; talk about how you are feeling. Some people have support within their family

and are able to tell them everything that is happening with the baby and how they feel. Others wish to only tell a select number of people about how unwell their baby is. It's important that you do what is right for you and your family.

If you feel that you want extra support, call the Bliss freephone Helpline on 0500 618 140 or talk to your GP to access counselling.

What about the future?

This is one of the most important questions you will have, but it is often one of the hardest questions to answer with any certainty.

After you have gone home with your baby, it is likely that you will be offered an appointment to come back to see the paediatrician or neonatal consultant, who will monitor and discuss your baby's progress. Some babies with HIE recover fully and have no long-term problems, while others may develop difficulties that require help and support from healthcare professionals, such as physiotherapists or speech and language therapists. Each baby is unique and the care they receive will be tailored to their needs. The number and frequency of appointments will depend on your baby's needs.

As HIE is a complex condition, it can take time to discover your baby's future needs. The medical staff will gradually be able to put together the results from the different investigations

your baby has undergone to give a better understanding of what the future may hold. This, along with information about things you notice in your baby's development at home, will be vital in planning for the future.

A developmental assessment may be carried out on your baby at 18 months to two years of age and sometimes sooner than this depending on the procedures for the unit that your baby is being seen at. The healthcare professional will carry out some activities with your toddler which provides information on their physical, motor, sensory and cognitive development. This assessment can help to provide a better understanding of how your toddler is developing and can help to alleviate concerns that you may have.

Later in childhood your baby could have problems with learning, thinking, speaking (cognitive problems) and problems with walking or movement (sometimes called cerebral palsy).

Your baby's development

The time taken to achieve developmental milestones (walking, first word) in babies and young children varies enormously. Babies that have suffered medical complications in the newborn period can have a delay in development, but equally they may reach all their milestones on time.

If you have concerns about your baby's development, discuss them with the

health professional caring for your baby. The health professional may not have all the answers for you but they will be able to tell you how your baby is progressing and what you can do to help. If there is a need for further support such as physiotherapy, they can help to organise the appropriate support.



Palliative care and bereavement

Palliative care

For some babies who are severely affected with HIE, all the available treatments might still not be enough to help them. The doctors and nurses might talk to you about palliative care. This is the care babies and families receive when a baby is recognised as having a life-limiting condition. Palliative care aims to keep your baby comfortable and control any symptoms. Families will also be offered support, even after their baby has died. You should be able to choose where your baby receives palliative care; it may be in a quiet private place in the hospital or in a children's or babies' hospice which can provide a more home-like surrounding, or you may prefer it to be in your own home.

Bereavement

Every parent's experience is unique and every circumstance is different. Parents whose baby has died have said that the grief is deeper and lasts much longer than many people realise. Parents may experience a mix of emotional and physical reactions following the death of a baby, some of which you may not expect. For further information there are several national charities that offer support and their information is at the back of this booklet (see page 21).

"Facing the death of my daughter was the most terrifying experience in my life, but I am incredibly grateful to have known her – she remains my daughter and is always in my heart."

Valerie, mum to Caitlyn

Emma's story

The pregnancy and birth

I was coming to the end of my pregnancy with twin girls when I went into labour. Everything seemed to be going fine.

Suddenly, the alarms went off in the delivery room and everyone came running in, the consultant was there immediately. One of the babies' heartbeats had stopped completely. I was quickly put under general anaesthetic as they started to perform an emergency c-section.

They delivered the baby with no heartbeat first, who we called Evie. She was completely flat but they managed to get a heart beat after three minutes. Her first gasp was noted ten minutes later.

My husband was left to wait in the delivery room, not knowing what was happening. They later came out with the second twin, who we called Hannah, and went back into the operating theatre.

The first few days

When I came round from the anaesthetic, I saw my husband holding Hannah. I asked him where Evie was

and he told me that she was poorly and was in the neonatal intensive care unit.

A few hours after the delivery, two paediatricians came to see us. Evie was classed as having moderate hypoxic-ischaemic encephalopathy (HIE). They explained the cooling treatment Evie would need and the increased risk of brain damage if she didn't receive it. Five hours after she was born they began the cooling process.

When we went to see Evie she looked very poorly – she was pale, jittery, on a ventilator and fitting. I found the noises and alarms unnerving. She was surrounded by tiny babies who had all been born prematurely and didn't look like she belonged there.

In the following days we were able to stay in the hospital. Both my husband and I felt constantly on edge and we couldn't eat a thing. Still, we visited Evie regularly, even though I found it distressing to see her with all the tubes in and fitting. Sometimes I would ask my husband to visit her alone because I couldn't bear seeing her like that.

She was four days old when we first held her. She was not being cooled any longer but was still connected to several machines. ➡

"The noises and alarms were unnerving"

The following week I tried to feed her and she latched on straight away. One of the nurses commented that this was a really good sign, it was the first time I started to think that maybe things were going to be OK.

But a few days before we came home Evie failed her newborn hearing test. My newfound optimism immediately disappeared and I was sure that if she had hearing loss there was a good chance she would have other disabilities.

It was a real rollercoaster of emotions.

We couldn't fault the care Evie received in hospital. We were encouraged

by the nurses to change her nappy, to hold her hand, talk and read to her. The consultant would often explain the care she was receiving, which we found very reassuring. We really trusted our consultant to tell us how the treatment was progressing; she was honest about the good and bad news.

Going home and the first few years

After Evie came home the reality of the fact that she might be brain damaged started to really sink in. I did a lot of reading up to find out what signs to look out for.

After about three weeks Evie started to see a physiotherapist. This was extremely useful. They told us that she didn't have cerebral palsy, despite some stiffness in her lower limbs, and physically she was progressing well.

Things were going well. Evie smiled, rolled over, sat up and walked earlier than the general milestone targets – earlier than her twin in fact. This was a huge relief to us, particularly as the MRI she had as a baby indicated

that it would be these sorts of functions that would be affected if she was brain damaged.

When Evie was two years old she had a developmental assessment. She did really well and on some things

was more advanced than other babies her age! It doesn't completely stop us from looking for signs and thinking 'what if?' I think we might always do that, but it was good to know that she is developing well for her age.

Today, Evie is a happy, bright little girl. She has a moderate hearing loss but you wouldn't know, her speech is fantastic and she's a real chatterbox who's more than capable of keeping up with her twin sister! ●

"She did really well and on some things was more advanced than her age!"

Rachel's story

Pregnancy and birth

My pregnancy and labour were fairly straightforward events, for the most part. I carried my baby to term. I went into labour in the night and calmly made my way into hospital. Just after I had given birth to my daughter Ella, the midwife immediately looked concerned asked my partner to pull the emergency cord in the room.

Seconds later a group of doctors and nurses came rushing in. I didn't know what was going on; I was crying and so was my partner. I could see them giving her chest compressions and then blood transfusions. After 45 minutes I heard them say 'we've got her, she's here.' As they took Ella to an incubator on the special care baby unit, my partner caught a glimpse of her and told me that she looked beautiful.

A few hours later they said we could go to see our daughter. I had never seen a special care baby unit before and they did not warn us about what to expect or what we might see. She had tubes coming out of everywhere and she looked poorly and pale. Staff were all around her; it was heart wrenching.

We were then told that she would need to be transferred to another hospital for further treatment, one that had a Neonatal Intensive Care Unit (NICU) and could provide the treatment Ella needed, known as cooling.

Transfer and the first days

Upon hearing the news that she would be transferred, our first thoughts were how will we get to the hospital? We had no means of travel and didn't get paid

until the following week. We knew that if we couldn't get there Ella would be at another hospital all by herself and even if we could get to the hospital where would we stay?

Thankfully, my sister-in-law was able to drive us to the other hospital and we were told both me and my partner could stay on the ward Ella was being transferred to.

The transfer team were great at explaining everything to us before leaving with Ella; they explained what the journey would be like and how they would care for her along the way. This was very reassuring for us. Still, I couldn't stop thinking about what state Ella would be in when I next saw ➡

"I didn't know what was going on; I was crying and so was my partner"

her. The 45-minute drive there felt like the longest journey of my life.

When we got to the hospital, the consultant took us to a side room to explain that she would need intensive care and cooling treatment to prevent her from developing brain damage.

That first night, without Ella with me, didn't feel right so I went to her cot and sat with her. She was wrapped in a cooling blanket and instead of feeling warm to the touch she was cold. I called her my little Eskimo.

"I couldn't bear to see my baby go through anything bad, so I stayed away"

Ella was making progress every day. But I knew the time would come when they would re-warm her. The thought of this scared me the most as there was a small chance that Ella would suffer a fit during the re-warming process. I couldn't bear to see my baby go through anything bad, so I stayed away while this happened.

I had every confidence in the medical team; still, I didn't go back to her incubator until the next morning. When I did go in she was covered in a blanket. She felt warm to touch, she was alive and through the worst of it.

Transferring back and going home

When she was five days old, I went to see Ella expecting to do her cares. Instead, I was greeted by the nurse and told that they were going to be transferring her back to our local hospital. We knew this meant she was getting better.

When she arrived at the hospital closer to our home, she was warm and only on a feeding tube. That day I got to hold her for the first time. I held her for over two hours; I didn't want to put her down.

After 11 days in the hospital, Ella was ready to go home. It was amazing; I just couldn't take my eyes off her. We are so grateful to the doctors and nurses and, despite not knowing much about it before, we think the cooling treatment is amazing.

Ella is now 11 months old. She is a happy little girl full of smiles. Our attitude all along has been we don't care what problems she may have in the future as long as she is with us. We will always love her no matter what, we are just so happy to have her. ●

Useful contacts

You can also find help and support from other organisations listed here.

Birth Trauma Association	Supports women who have suffered difficult births and aims to offer advice and support to all women who are finding it hard to cope with their childbirth experience. www.birthtraumaassociation.org.uk
Child Death Helpline	A helpline for anyone affected by the death of a child of any age, from prebirth to adult, under any circumstances, however recently or long ago. t: 0800 282 986 e: contact@childdeathhelpline.org www.childdeathhelpline.org.uk
Newlife	Offers practical support for disabled children throughout the UK, cares for the carers, funds medical research, creates awareness and campaigns for change. t: 01543 462 777 www.newlifecharity.co.uk
Scope	A charity that supports disabled people and their families through practical information and support, particularly at the time of diagnosis. t: 0808 800 3333 www.scope.org.uk
Together for Short Lives	An organisation supporting all children and young people unlikely to reach adulthood, and their families, to get the best possible care and support where and when they need it. t: 0845 1082201 www.togetherforshortlives.org.uk

How Bliss can help

The Bliss freephone Helpline

Open 9am to 9pm Monday
to Friday. Call freephone

0500 618140

to talk to one of our trained
advisors. We can put you
in touch with other parents
who have been through
a similar experience.

www.bliss.org.uk

On the Bliss website you can find
information about premature or
sick babies and their care, talk
to other parents on our message
board and find out more about
our many other services for
parents.

Bliss is the national charity that supports babies born premature or
sick and their families. We can offer advice and support in the way
that suits you best. We can also provide information in various formats.

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Written by Cheryl France

With input from the Neonatal Neuroprotection Team in the East of England

Edited by Carmel Bartley, Family Support Manager

Designed by Richard Swingler, Design and Communications Manager

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www.bebop.nhs.uk



Bliss

9 Holyrood Street

London SE1 2EL

† 020 7378 1122 f 020 7403 0673

e enquiries@bliss.org.uk

www.bliss.org.uk

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0500 618140

or visit our parent messageboard
www.blissmessageboard.org.uk

To volunteer your time or to join our local
network of support groups visit

www.bliss.org.uk

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Bliss is a member of **Language Line**, the telephone interpreting service, which
has access to qualified interpreters in 170 languages.

**Bliss is the UK charity working to provide the best possible care and
support for all premature and sick babies and their families. We support
parents, we work directly with doctors and nurses and we campaign to
ensure the needs of babies and their families are always heard.**

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would be greatly appreciated. To find out how to donate, please contact
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Bliss
9 Holyrood Street
London, SE1 2EL
† 020 7378 1122 f 020 7403 0673
e enquiries@bliss.org.uk
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Bliss

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