

Your Child and **Hydrocephalus**

For families of children with hydrocephalus
and the professionals working with them



Shine

Spina bifida • Hydrocephalus
Information • Networking • Equality



Welcome!

Shine has been supporting people of all ages with hydrocephalus and spina bifida, and their families, carers and professionals for over 50 years. Since the first successful shunts were placed in the 1950s to treat the condition, our understanding of hydrocephalus, its causes, effects and treatments, has increased greatly.

Our knowledge about the way the brain develops, especially in infancy and childhood, is rapidly increasing too. The brain's ability to alter with each new experience, and each repetition of an old one, gives a fantastic opportunity to influence our babies' futures from day one. This is important for all children, but especially so for those with a neurological condition which may affect their learning and behaviour.

Hydrocephalus can occur for many different reasons, and at any time of life. Most of the causes of hydrocephalus, such as bleeding or infection, can damage delicate brain tissue which may have an effect on skills and abilities. Many children born with open spina bifida will also be affected by hydrocephalus to some degree.

Unsurprisingly, there is huge variation in both the challenges that children may face and the degrees to which these challenges may affect them. Many people with hydrocephalus will sail through life, with few or no difficulties. Others may have areas that they find tricky and for some, there will be many challenges throughout their lives.

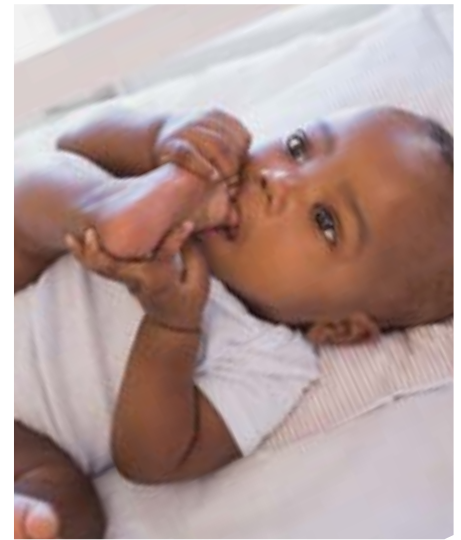
We are often asked, "How can I help my child?"

This book has been written for families of children with hydrocephalus and the professionals working with them. It is full of tips to help you support your child, from the very first days to the start of secondary school. It takes you through from birth to age ten, looking at how and when skills develop, and what you can do to support your child at each stage. It also gives some prompts on what should be flagged up to your professionals, and when.

We hope you enjoy reading it, have fun using it, and that it helps you to enjoy your child's early years even more.

Gill Yaz
Health Development Manager

A note about our use of pronouns. Throughout this book, the pronouns 'he', 'she' and 'they' are used interchangeably. Each pronoun can be taken to mean any child.



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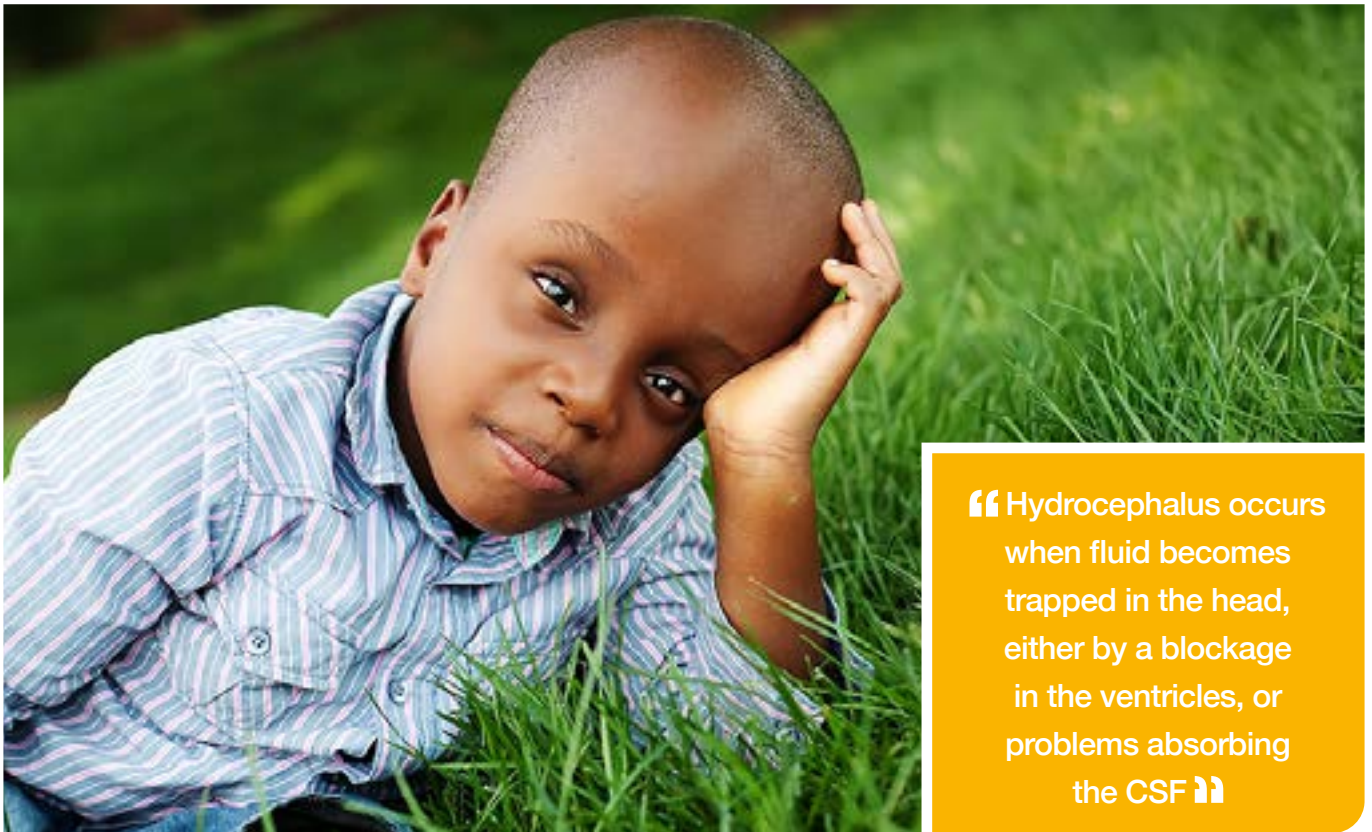
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Your Child and **Hydrocephalus**

Section one

Introduction to Hydrocephalus



“ Hydrocephalus occurs when fluid becomes trapped in the head, either by a blockage in the ventricles, or problems absorbing the CSF ”

Introduction to Hydrocephalus

Within the brain, fluid (cerebrospinal fluid or CSF) is made by tissue called choroid plexus, which fills spaces called ventricles. The CSF flows through the ventricles, and over the surface of the spinal cord and brain, where it is absorbed. At the moment, we're not absolutely sure what CSF does, but it seems to keep the brain supplied with vitamins, removes toxins, and may provide a cushion against the pulses in the arteries of the brain.

Hydrocephalus occurs when fluid becomes trapped in the head, either by a blockage in the ventricles, or problems absorbing the CSF. The extra fluid creates pressure on the delicate brain tissue, which becomes compressed and the nerve tissue is stretched. Hydrocephalus is treated by draining the CSF around the blockage so it can be absorbed. This is usually through a thin tube, called a shunt, which drains the fluid into another part of the body. There are very many causes of hydrocephalus. Some occur before birth, such as brain development changes like aqueduct stenosis and Dandy Walker Malformation, and others can occur at any point throughout life. Head injury, brain haemorrhage, cysts, infections like meningitis, and tumours can all block the drainage of CSF and also have the potential to damage the brain tissue directly. There is more information on hydrocephalus, its causes, treatment and complications, in the Additional Information section.

Harm to the delicate brain tissue can affect the way it works in a wide range of ways: emotions, movement and coordination; any of the senses and the ways they work together; talking and understanding; thinking, deciding,

remembering...the list of what the brain does and how it controls our body, personality, skills and abilities is a very long one.

If the variation in abilities and personality between people with typical brains is huge, the variation between people with brains which have been changed by illness or developmental issues is infinite. There is no skill or ability that can't be altered, and altering one skill doesn't mean other skills or abilities will be impacted.

The verbal skills of someone with hydrocephalus don't necessarily match their understanding, as they are different skills. But it can sometimes be hard for others to accept that someone is struggling in some aspects of thinking or learning when in so many ways they seem (and are) so able. This is what is meant by the term **'hidden disability'**.

The fact that there are so many different causes of hydrocephalus is very important. Many people will have no challenges at all and lead a completely ordinary life. Others will have some challenges, for example with organising, or multitasking. Some may have challenges in many areas of their life. The challenges will differ from person to person, and everyone is unique.

The good news is that the brain is very adaptable, and many ordinary and fun activities can make a big difference to the development of skills and abilities. You'll hear more about 'neuroplasticity' later in the book. All children will benefit from the simple suggestions you will find here, and the earlier you begin, the better.



Get to know your child

All babies are unique and individual and no two babies are affected by hydrocephalus in the same way. When you are a new parent, your baby is getting to know you and you are learning about them. As you get to know your baby you will find out about their unique qualities, what they enjoy, what soothes them and what helps them to develop, learn and thrive.

It is important that you give your baby plenty of opportunities and experiences to help them to become the best that they can be with their unique condition. Like all children, babies with hydrocephalus need to develop, learn and practise skills through play. Babies and children learn through experience and the stimulation of their senses: touch; taste; smell; sight; hearing; movement; and body sense.

It is through play that babies and small children 'learn how to learn' so that they can build up the skills needed for independent life.

Why is it important to get the Early Years right?

Babies brains are immature at birth. There are billions of brain (neural) cells present, however, they need time and experience to begin to form some sort of order and to make sense of the world. The brain actually only becomes fully mature around the age of 25!

When a baby experiences some sort of sensory input, or tries to move a part of his body, messages are sent between the body and the brain. This happens all the time

and eventually a connection or pathway (neural circuit) develops in the brain and the experience or skill becomes much quicker and easier to process. Throughout life, there is potential for neural circuits in the brain to develop and change. This is called **neuroplasticity**.

This is important to understand because in children with hydrocephalus and/or spina bifida, there may be altered sensations or movements. In the early days this could mean that a young baby does not explore or move as much as a typically developing child might and therefore the brain develops pathways and habits in response to this.

By giving your baby opportunities to play and learn new skills, and by providing the support and specific activities recommended in this book, it is possible to help your child learn new skills or strategies for coping with any challenges they may face.

There is a range of health professionals who can help you when it comes to knowing how to support your baby's development. These include physiotherapists, occupational therapists (OT) and speech and language therapists (SALT), among others. A description of their roles can be found in 'Therapy activities' on page 81.

It is important that you give your baby plenty of opportunities and experiences to help them to become the best that they can be with their unique condition

Stages of development

There are typical patterns of development in the way that children learn new skills. These are sometimes referred to as 'milestones' and most often in young children the focus is on their physical development. There are well-known big milestones like rolling, sitting and walking that many professionals will monitor, but just as important are the smaller, foundational 'mini-milestones' and skills that babies learn in between each big milestone.

These mini skills in all areas of your child's development need to be closely monitored so that it is easier to notice if there is something your baby finds difficult, and to provide support as required.

There are four broad areas of developmental need that are recognised by the Special Educational Needs and Disability Code of Practice in England (2015):

- **Language, communication and interaction**
- **Cognition and learning**
- **Social and emotional development**
- **Sensory and physical development**

As these areas will be taken into account in your child's education provision, they are the areas of development that we will focus on in this book.



1 Language, communication and interaction

This is how we interact with other people and the world around us. It's not only speech and language, but also body language, facial cues, touch, attentiveness and other forms of communication, such as sign language. Babies first begin to communicate with us by crying - the only way they have at the beginning to tell us they need something - then through smiling and eye gaze.

2 Cognition and learning

Cognition is the ability to learn, think and problem solve. Children do a lot of learning by actively exploring their environment and objects. Higher-level thinking skills (such as language and memory) affect decision making, logical thinking and organisational skills, all of which have an impact on how your child learns.

3 Social and emotional development

This is our ability to interact with other people and to manage our emotions. Babies start to develop relationships with the people around them right from birth. However, the process of learning to communicate, share and interact with others takes many years to develop fully. The ability to control emotions and behaviour is also a long process and we continue to develop social and emotional skills well into early adulthood.

4 Sensory and physical development

Physical development is the way that the body moves and can be split into 'gross motor' and 'fine motor' development.

Gross motor skills are large body movements requiring strength, balance and coordination such as rolling, crawling, sitting, standing, and walking.

Fine motor skills relate to movements of the hands and fingers such as writing, fastening buttons, pulling zips, and using a knife and fork.

Physical development is closely linked to sensory development. Sensory information comes in from the environment and from within our bodies. The sensory nerves send information to the brain which then interprets that information and turns it into action, via motor nerves, which go from the brain to the muscles.

Let's talk sense!

Your baby is bombarded with information from the moment he is born.

It takes time for your baby's brain to learn to cope with all this information so in the beginning it is your job to help him cope. You can do this by giving your baby plenty of experiences to get him used to sensory stimulation, and to make sure that he doesn't get overstimulated. It's a balancing act that becomes easier once you start understanding your baby's cues.

Your child's ability to cope with sensory input varies depending on their mood, tiredness, hunger and personal preference. Also, everybody has a unique sensory profile, which means that some children may need more or less of a particular sensory experience. In the table on page 10 there are examples of behaviours that can show if a child is over sensitive or under sensitive to a particular sensation.

As well as the ideas in this book, it might be helpful if you find a messy or sensory play class to take your baby to so you can get some ideas and support. As always, if you have any concerns or worries then please seek advice from a health professional or your Shine support worker.



The seven sensations are those of touch (tactile), taste, smell, sight, sound, movement – both vestibular (movement and balance) and proprioception (body awareness).

1 Tactile (touch)

The skin is the largest, most sensitive organ of the body. It gives information about our body, objects and the environment. It responds to pain, temperature, light touch and pressure.

Touch provides protection and discrimination (being able to tell the difference between different forms of touch). When these two functions work smoothly together, your child will be comfortable and willing to interact with objects and people in a way that is calm, alert and helps him to learn.

2 Taste and 3 Smell

Smell travels directly to the part of the brain that controls emotions, memory and learning. Smell is closely linked to the sense of taste as well – think how bland food tastes when you have a cold!

4 Vision

There are two factors regarding vision to be aware of:

Eye Movements

Eye movements are controlled by muscles that allow us to:

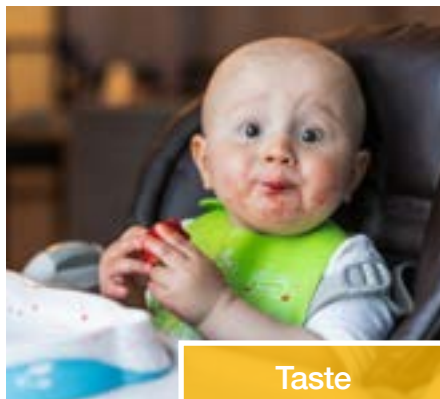
- Follow a moving object with our eyes
- Fix our gaze on an object
- Scan a page of writing
- Focus on one object and then quickly move to another and refocus

Visual Processing

Visual processing is the ability of the brain to select and respond appropriately to what we see. This helps us to concentrate on what we are looking at and not to be distracted by other visual stimuli (e.g. pick out one picture on the wall amongst several or find a pair of socks in a full drawer).



Tactile (touch)



Taste



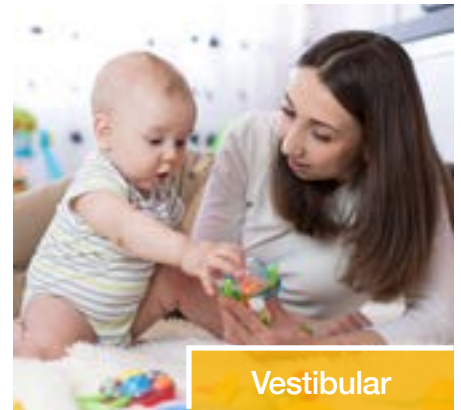
Smell



Auditory



Proprioception



Vestibular

5 Sound (Auditory)

Auditory processing refers to how the brain recognises and makes sense of sounds. Sounds consist of loudness, pitch, duration and where it is coming from. We automatically put all this information together and respond appropriately to it.

Usually, unwanted noise can be cut out and we are able to concentrate on the noise we need to in order to do the task we want to. If there are concerns in this area then it is appropriate to first get a hearing test done to rule out any other medical difficulties.

IMPORTANT TO KNOW... Sensitivity to noise – many people with hydrocephalus can find loud or high-pitched noises very difficult to tolerate. Young children may become distressed, upset or have difficult behaviour around too much noise.

Movement: Children learn movement through the development of the proprioceptive and vestibular systems. When these two systems work together a child is able to develop a sense of body awareness, balance and motor control that enables them to move freely.

6 Proprioception

This is 'how the body senses itself' and is our ability to know where our arms and legs are in space and in relation to each other, without having to look at them. This information is passed on from muscles and joints to the spinal cord and brain, even when we are still. Proprioception provides us with

an internal map of our bodies and helps us to grade the force we use to perform activities.

Our proprioceptive system helps us to be able to lift a glass to our mouth without spilling, or to stay sitting on a chair without slipping off. It develops through deep pressure to the muscles and joints through activities like pushing, pulling, jumping, squashing, squeezing and exploring.

7 Vestibular System

The vestibular sense is found in the inner ears and is stimulated when we move or change our head position. It keeps us orientated when we bend over to pick something up off the floor, ride in a car or walk around. It also helps to make sense of confusing situations such as hanging upside down or to be able to stabilise our visual field (for example being able to run and throw a ball at a target). More subtle vestibular activities include staying in a sitting position and paying attention to a task.

Information from the vestibular sense also impacts on our attention and arousal levels (sleep/wake cycles). This is seen in how we naturally handle babies like rocking them to get them to sleep or bouncing them on your knee to get them excited, and how we concentrate best when sitting bolt upright.

The vestibular sense is possibly the most important sense because it gives us physical and emotional security when we move as our bodies automatically adjust to stop us from falling.

Pain: Hopefully pain will not be experienced. Older children may be able to describe the kind of pain or discomfort they feel, e.g. pricking, burning, stinging, aching and soreness.



Sensory processing

Sensory processing is the way that the brain receives, processes and integrates information from the seven sensory systems. It allows us to organise ourselves and ultimately helps with developing all the other skills we learn and use in life.

Everybody has unique sensory differences. This means that some children may need more or less of a particular sensory experience. Children with hydrocephalus often have challenges with sensory processing and may have difficulty figuring out what is happening inside and outside of their bodies.

As your baby gets older, you may notice your child struggling with activities and experiences that other children appear to take in their stride, and this can be overwhelming and frustrating.

There are two types of sensory-processing difficulties:

- Over-processing/over sensitive: when it does not take a lot of sensory input for a child to feel overwhelmed and then respond by avoiding the input, and
- Under-processing/under sensitive: when a child needs a lot of sensory input and displays sensory-seeking behaviours.

Children with any sensory-processing issues rely on support from those around them.

The following table gives some common examples of both over- and under-processing behaviours for each sensory system. If you recognise these in your child, then seek advice from an occupational therapist. Generally, you will notice these as your baby gets older so please refer back here when you need to.

Sensory System	Over Sensitive	Under Sensitive
Tactile (touch)	<ul style="list-style-type: none"> • Withdraws from cuddles • Easily ticklish • Does not tolerate loose clothes • Appears to overreact when hurt in the playground • May walk on tiptoes on certain surfaces • Avoids messy play • Finds nappy-changing distressing 	<ul style="list-style-type: none"> • Does not notice when they are messy or have food around the mouth • Does not show distress when hurt • Needs to be wrapped up tight • Wraps self in blankets
Taste and Smell	<ul style="list-style-type: none"> • Becomes anxious at the smell of cooking • Gags on certain foods • Able to comment on people's aroma • Particularly favours certain types of food • Finds cleaning teeth uncomfortable 	<ul style="list-style-type: none"> • Seeks out smells e.g. sniffs people, smells own faeces • Smells toys before playing • Chews and puts everything into their mouth • Grinds teeth • Prefers strong-flavoured food
Vision	<ul style="list-style-type: none"> • Focuses on a tiny part of object not whole thing • Difficulty noticing objects in peripheral vision (what is seen 'out of the corners of our eyes') • Difficulty scanning pictures in page • Difficulty changing focus from the room to paper in front of them 	<ul style="list-style-type: none"> • Gets excited at flashing lights on toys • Stares at fluorescent lightings • Fixates on a reflective surface • Startled by unexpected light changes e.g. clouds blocking out sun
Auditory	<ul style="list-style-type: none"> • Loud noises can be painful • Runs from household noises • Covers ears at loud noises or unexpected alarms etc. and may become very distressed • May hum to block out external noise • Easily distracted by background noise • Hears things that most people don't 	<ul style="list-style-type: none"> • Holds toy to ear and has volume on high* • Doesn't appear to hear when called • Likes repetitive sounds* • Hums in noisy environments* • Not alarmed by sudden noises <p>* these behaviours may also be seen in children who are overly sensitive to sounds as they are struggling to screen out noise in order to listen to your voice, or they may hum as a way to block out unexpected sounds</p>



Sensory System	Over Sensitive	Under Sensitive
<p>Proprioception</p>		<p>'Sensory seeking' is commonly seen in children with difficulties processing proprioceptive information. You may notice:</p> <ul style="list-style-type: none"> • Excessively climbing on things • Bumps into things easily • Can't negotiate around obstacles • Unaware of children on the floor and will trip over them • Seems uncoordinated • Likes to fall or bump and seems to seek this out • Difficulty with planning how to get in and out of play equipment • Difficulty with fine motor skills
<p>Vestibular</p>	<ul style="list-style-type: none"> • Fearful of playground equipment • Dislikes swings and slides • Gets car sick easily • Anxious if not in control of movement 	<ul style="list-style-type: none"> • Seeks out swings • Likes roundabouts, slides • Hangs upside down on bars • No sense of danger when climbing • Constantly on the go • Trips over own feet



“ It is really important that you help your baby to establish healthy sleep habits as soon as possible ”

Sleep

Sleep is so important for your baby’s physical and emotional wellbeing. And yours too! While your baby is sleeping their brain is able to process all that it has experienced when they are awake. In the beginning, your baby will sleep a lot, although it is very rare that a baby will sleep through the night from the beginning!

It is important that you help your baby to establish healthy sleep habits as soon as possible. If your baby has been in hospital for a while, for shunt surgery for example, it may take a little longer to get into a routine, as night time in hospital can be as noisy and brightly lit as it is in daytime. In the beginning, you might feel anxious about your baby at night, especially regarding shunt problems, but you’ll become more confident. Check on your baby as often as you feel is right, but try not to wake them or leave the light on.

Tips for getting sleep off to a good start

- Encourage nap times as suggested for your baby’s age – your baby will be much happier, calmer and ready to learn if he is not over-tired in the day, so naps are really important
- Have a specific area set up for where your baby sleeps
- Create a calming, peaceful sleep environment. Things that might help include white noise, a soft toy or piece of clothing that smells of you, lullabies, a dark room at night and closed curtains for naps during the day. When you go in to care for your baby or check on them, keep the light as low as you can and keep talk to a minimum
- Create and stick to a bedtime routine. Routines are so important for babies! It doesn’t really matter too much what order you do things in or what you do, what’s important is that it’s the same every night. Your baby will soon recognise the bedtime routine as a signal to start getting ready for sleep. Children with hydrocephalus may be very light sleepers, easily woken or disturbed, so getting into good habits early on can help if things change later on

Some ideas for a bedtime routine include

- A calming, warm bath
- Massage in a warm, dimly lit space
- Singing lullabies or playing calming music
- Reading a book (it’s never too soon to start this!)
- Turning the lights down low for the last part of the last feed
- Putting your baby in bed with her security object and saying good night

Put your baby down to sleep drowsy but awake

Often easier said than done, however, from about three months your baby will start to develop sleep associations. This means that she will start to associate falling asleep with certain sensory input. For example, if you rock or feed your baby to sleep and then put her down, she will learn that she needs to be rocked or fed to go back to sleep. A security object like a soft toy or small blanket is a good sleep association as it will help your baby to fall back to sleep again on her own when she wakes in the night.

In general, your baby should only ever be placed to sleep on his or her back on a firm, flat mattress with no pillows*. This helps to reduce the risk of SIDS (sudden infant death syndrome, also referred to as cot death) and is best for your baby.

*Special considerations

Babies with reflux, feeding tubes, hydrocephalus or spina bifida may have specific requirements to help them to sleep safely.

This could include specific positions that are best for your baby to sleep in, for example the mattress may need to be slightly inclined or a special positioning system may be useful. Your child’s physiotherapist or OT will be able to support you and provide specific guidance for your baby’s needs.

Baby massage

When babies are in the womb they get lots of rich sensory experiences by being in a closely cocooned, warm and soothing environment. It's possible to replicate this experience with massage as it stretches and stimulates your baby's muscles while having them in a calm, relaxing environment. Along with your reassurance, touch and love, your baby feels safe, secure and happy.

Some of the physical benefits of baby massage include

- A calming, soothing effect
- Relief from colic, wind, constipation and even teething discomfort
- Increased levels of relaxation and longer sleep
- Faster weight gain
- Less likely to cry excessively
- Speeds up the progress of premature and low birth weight babies
- Develops body awareness and coordination

Other benefits to massage which would be helpful for grown-ups too, include

- Improved breathing
- Better lymph and blood circulation
- Improved function of the digestive system

Baby massage is a wonderful experience for you and your baby and can begin within days of your baby's birth. As well as being a relaxing, bonding activity to do together, it provides a perfect opportunity to gain a deeper understanding of your baby's behaviour, crying and body language.

There are baby-massage courses available which your health visitor, GP or local children's therapy centre may be able to give you details on, but in the meantime if you'd like to get started, here are some basic guidelines to follow.

Guidelines to get started with baby massage

- Be in a warm, dimly lit room
- Make sure you are comfortably positioned, either sitting on the floor with baby in front of you or standing with baby up on a changing table or suitable surface that doesn't strain your back (always have a hand on baby!)
- Have your baby in a nappy only, and lie her on a towel in front of you
- Rub your hands together to warm them. You can use baby oil you choose



- Use gentle pressure in small, slow, circular movements with your fingertips
- Once the shunt surgery incision is completely healed, you can start on baby's forehead and use gentle circular strokes to massage temples, cheeks and jaw area
- Slowly move down to neck and shoulders
- Always watch closely to check how your baby is responding. Firm but gentle pressure is most comfortable and will avoid uncomfortable tickling
- If your baby starts to fret or get upset or turns her head away from your touch, then it may be time to stop and try later
- Work your way down each arm to her hands and palms
- Roll your baby over on to her tummy
- Continue with small circular movements on the back of her head, down her back and spine
- Continue to her bottom, thighs, lower legs, feet and toes (legs and feet can be done when she's on her back too)
- Your baby will enjoy it even more if you use a gentle, soothing voice to sing and talk to her throughout the massage

Hopefully, by the time you are finished, your baby (and you!) will be totally relaxed and possibly almost falling asleep. The pressure from the massage soothes your baby's muscles and slows down the heart rate and breathing rate which helps for a more restful night's sleep, which is an added bonus.

If you are starting this with an older baby, it might take a little while for them to get comfortable staying still for massage. Keep the environment calm and quiet and do massage at a time of day when they are winding down. Maybe just after a lovely warm bath or before bed.