

# New Parents' Pack

## Spina Bifida



**Shine**

Spina bifida • Hydrocephalus  
Information • Networking • Equality



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## **New Parents' Pack for Spina Bifida**

**If you've been told that the baby you're expecting has spina bifida, or you have a new baby with spina bifida, this pack is for you.**

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**We work with thousands of parents of children with spina bifida, and with the adults that those children eventually grow up to be. We are here to help you when you feel anxious or daunted, but also to celebrate every achievement along the way.**

The purpose of this New Parents' Pack is to help you to understand spina bifida and to offer you guidance as your child develops. Although there's a huge variation in ways your child might be affected, we want to help you to be as prepared as possible for your new baby's arrival and the early stages of their life.

Once you've read this information, you may still like more support from Shine. We're always happy to answer any questions that you have - at this stage and as your baby grows.

**We wish you all the best as you welcome your new baby.**



## Important to know:

When your child aged 0-10 joins Shine, they will automatically become part of Shine's Little Stars in England and Northern Ireland and Ser Bach in Wales.

These Early Intervention Projects will ensure you are supported, every step of the way. We can support you with:

- Information and advice regarding the conditions
- Emotional support
- Keeping your child healthy and supporting their development
- Specialist health and education support
- Applying for financial support
- Advice on equipment and mobility aids
- Meeting other families

**And much more...**



# Finding out your baby has spina bifida

**Finding out that your baby has spina bifida may raise many questions, and it can be reassuring to know what's likely to happen.**

You may be reading this during pregnancy. If you've just had your midterm (20 week) scan, and it's suspected that your baby has spina bifida, a more detailed scan will be arranged to confirm this within a few days. You should also be given an appointment with a fetal medicine doctor (a doctor specialising in unexpected findings during pregnancy). You can also contact Shine at this point and speak to our experienced health advisers.

You might get the chance to speak to a paediatric neurosurgeon (a specialist doctor who will diagnose, assess and perform surgery to the brain and spine). They should be able to tell you how spina bifida may affect your baby, based on your scan results and their experience. Some hospitals offer this appointment automatically, and in some you'll need to request an appointment, although it may not be available in all areas.

You may be offered an MRI (magnetic resonance imaging) - a 3D scan which gives detailed images of your baby. Even after all these procedures it won't be possible to give a picture of exactly how your baby will be affected, although every piece of information helps. It is also difficult to predict whether your baby will have learning impairments, or how serious these may be.

If the spina bifida looks very severe, an amniocentesis might be offered, as occasionally spina bifida is part of a chromosomal disorder, which will have additional effects on your baby's health and development.

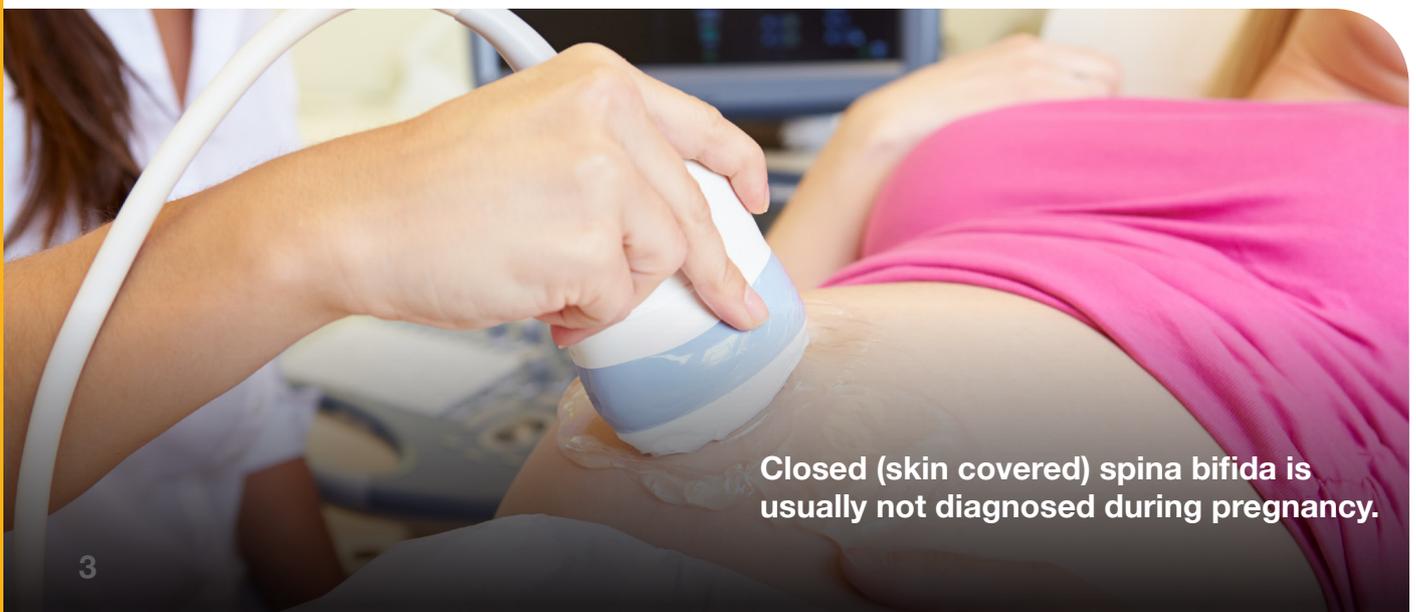


## Important to know:

Amniocentesis is a test of the fluid in the womb which contains cells from the baby. Fluid is taken with a needle and the cells are examined under a microscope. As the test carries a small risk, make sure you ask why it is being offered, and that you're happy to have it.

You may wish to discuss fetal surgery with your consultant. This is where a neurosurgeon performs an operation on a baby whilst it is still in the womb, before 26 weeks of the pregnancy. It may not be right for you or your baby for a number of reasons, and it may not be offered to you. There are risks and no guarantee of benefit compared with surgery after birth.

As your pregnancy develops, you may be offered extra ultrasound scans to check your baby's development. Most babies with spina bifida grow well, and your pregnancy should continue to progress well. Towards the end of your pregnancy, your scans may be weekly or fortnightly.



**Closed (skin covered) spina bifida is usually not diagnosed during pregnancy.**

## What is spina bifida and what does it mean for my child?

Whether you've had a diagnosis during pregnancy or after birth, it's likely that you'll want to know more about the condition, its treatment and what this may mean for your child.

Every person with spina bifida is unique and there is a large variation in the possible effects.

Spina bifida literally means 'split spine'. A fault in the development of the spinal cord and surrounding vertebrae (back bones) leaves a gap or split in the spine. The spinal cord has not formed properly and may also be damaged. To help understand what it is, it's useful to explain the nervous system.

The nervous system is made up of the spinal cord, the brain, and nerves throughout the body. The brain controls our movement, body temperature, bladder and bowels, and many other bodily functions. Our spinal cord connects the brain to the body and information picked up from our senses and nerves around the body travel along the spinal cord to the brain. The brain processes this information and signals are sent to different parts of the body to do different things.

In the most common type of spina bifida, myelomeningocele, the spinal cord bulges out of the spinal canal. This results in the back of the brain having a smaller space in which to develop and leads to Chiari II. The cerebellum (the part of the brain at the nape of the neck) becomes longer and thinner than usual, and part of it may be found lower down than normal, next to the spinal cord at the base of the skull.

On your scan report this may be called 'cerebellar tonsil herniation'. For many babies this will cause no problems, but for some it may result in breathing and swallowing problems, and low muscle tone (muscles that are floppy).

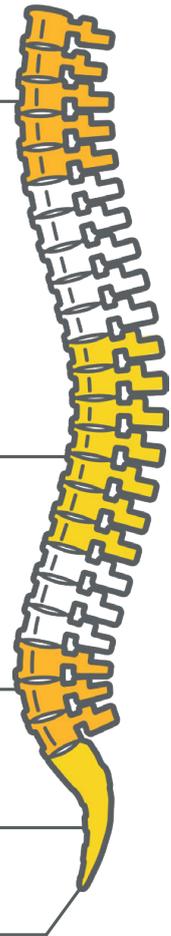
**8 Cervical nerve pairs**  
use of neck, shoulders and arms.

**12 Thoracic nerve pairs**  
use of hands and fingers, chest and abdomen, lower back and hip

**5 Lumbar nerve pairs**  
use of seat muscles, to keep body erect, leg, knee and in men, ejaculation

**5 Sacral nerve pairs**  
Bowel and bladder and in men, control of erections

**1 pair coccygeal nerves**



Each individual vertebra (back bone) of the spine has a pair of nerves on each side. One nerve supplies the muscles of a certain area of the body, the other picks up sensation from the skin amongst other functions.

To be able to move voluntarily, the muscles must receive a signal from the brain via the spinal cord. By knowing which nerves serve which muscles, we can see what might happen if the signals are blocked at particular points along the spinal cord.

For example, a spina bifida lesion (area of injury) at the level of L1 (the name of the vertebra in the middle of the back) will probably affect muscle movement from the hips downwards, whereas a lesion at L5 (the vertebra positioned just above the bottom) will be likely to only affect the strength and movement around the ankle. Generally, the lower on the back the spina bifida lesion occurs, the fewer the possible effects.

Spina bifida can prevent messages from reaching the brain, due to damage to the spinal cord. This may mean that the brain isn't able to sense what's happening to the body and may affect movement and skin sensation, as well as bladder and bowel function. In addition, open forms of spina bifida may result in other conditions such as hydrocephalus and Chiari II (two).

Hydrocephalus is a condition in which there is a build-up of excess cerebrospinal fluid (CSF) in the chambers of the brain called ventricles. It compresses the surrounding tissue and raises the pressure inside the skull. Hydrocephalus is caused by an inability of CSF to drain away into the bloodstream.

## Movement

**Children with lower spina bifida lesions may walk, depending on where their lesion is. Most children with lesions at L3 or below will be able to walk at least around the house.**

If only the foot and ankle are affected, splinting helps to stabilise and strengthen. Splints, or orthoses are devices worn on the feet to maintain the feet and legs in a certain position. The muscles across the hip joints and knees need to be strong enough to hold the body upright for walking; it is common for children with spina bifida to use a wheelchair or other mobility aids as they get older and heavier, even though spina bifida itself isn't a 'progressive' condition.

It is important for your child to move around, explore their surroundings, be independent, and take part in as many different activities as they can or want to. Using a wheelchair might enable this to happen in comfort and dignity. Learning to move, focussing on the quality of movement, and not missing important developmental stages can help your baby's general development. Help your child look after their feet and legs, even if they aren't 'using' them for walking or standing. Keeping the muscles as strong as possible might help circulation, keep the tissues healthy, and make it easier to control weight gain.

This is usually managed by surgery, commonly the insertion of a thin tube called a shunt into the brain to divert the CSF to another part of the body in order to be absorbed.

## Recommended reading

You can read more about these related conditions on our website: [www.shinecharity.org/relatedconditions](http://www.shinecharity.org/relatedconditions) or for an in-depth look at hydrocephalus, ask for a copy of our leaflet titled "*what is Hydrocephalus*"

Your baby should be referred to a community physiotherapist soon after discharge and they should be seen within the first month of their life. The community physiotherapist should carry out an assessment and provide practical advice on positioning and stretches to maintain range of movement or ROM (the ability of the joints to move in different directions). They may also refer onto other services such as orthotics for splinting if needed, or occupational therapy, which looks at independence in everyday activities.

If your baby has any problems with the position of their feet or knees, it is common for the orthopaedic team to start treatment early, once you're able to lay your baby on their back and are allowed to bath them. The treatment involves holding the feet in position with strapping or plaster casts, making small changes every week when the plasters are changed.

This is called the Ponseti Technique. Once the feet are in the correct position, at around three months, your baby will wear a special pair of shoes attached to the ends of a bar (called boots and bars), which will hold the feet in the correct position. They're worn day and night for several months, and then night-time only for a couple of years.

## Tethered Cord

**Tethered Cord syndrome is a condition closely associated with spina bifida, especially closed spina bifida. This is a condition where the bottom end of the spinal cord is fixed, so that it can't move freely inside the spinal canal as it should.**

Before birth, the spinal cord is long, compared with the size of the baby, and ends at the bottom of the spinal canal.

As a typically developing child grows, the spinal cord doesn't grow, so the bottom end 'rides up' inside the bones. This 'riding up' is prevented in tethered cord.

The spinal cord can be tethered (restricted in movement) by lipomas (fatty lumps) in the spinal canal, scar tissue from previous surgery (such as back closure for open spina bifida) or being attached to the skin. The spinal cord therefore becomes stretched, and symptoms may begin during times of rapid growth, at around 2 years, 7-8 years, and with puberty.



### Important to know:

Sometimes, symptoms appear in middle age, as deterioration of the spinal cord begins after many years of tethering.



## Sensation

To be able to 'feel' what's happening to our skin, the skin needs to connect to the brain via the spinal cord. If this is affected by spina bifida, loss of skin sensation might cause problems. Damage to our skin usually causes our brain to feel pain; without this, severe damage can occur without us being aware.

Babies with spina bifida often bite their toes and feet, sometimes until they bleed. This is because they can't feel their feet or the pain. To them it's like chewing on a toy. You can help to protect the feet with extra socks or booties and by distracting them with teething rings which they can chew safely. People with spina bifida are at a higher risk of burns due to this loss of sensation.

### Recommended reading

For more information about burns, skin and tissue, visit our website:  
[www.shinecharity.org.uk/skinandtissue](http://www.shinecharity.org.uk/skinandtissue)



## Bladder and Bowel

The nerves which control the bladder and bowel are sacral nerves, the lowest part of the spinal cord. This means that most people with spina bifida will have some problems with bladder and bowels. The bladder may be too 'tight' to fill with urine properly and it may not empty of urine completely, leading to urine infections.

By starting management early (within the first few months of life, if needed) a lot of kidney and bladder problems may be prevented or minimised in the future. Most parents will be taught and supported in emptying their baby's bladder with a thin, disposable tube. This is called clean intermittent catheterisation (CIC) and can be combined with medication to relax your baby's bladder muscle to prevent problems developing.

Some babies with spina bifida will be fitted with an indwelling catheter, or they may use an indwelling catheter at night and ISC during the day. An indwelling urinary catheter is inserted in the same way as an intermittent catheter, but the catheter is left in place and held in place by a tiny balloon, filled with water. Some babies may have a vesicostomy (an operation to form a temporary opening from the bladder to the outside of the body) allowing urine to drain freely into a nappy.

Urinary tract infections (UTIs) and kidney infections are more likely to occur in people with spina bifida, and antibiotics or other medication may be given to prevent them.

The nerves to the anus may be affected leading to leaking of faeces, and constipation is common. There are a number of ways to help to manage the bowels to reduce constipation and improve continence.

### Recommended reading

For lots more information about bladder and bowel issues, visit: [www.shinecharity.org.uk/continencecare](http://www.shinecharity.org.uk/continencecare)

## Learning and behaviour

**Open spina bifida changes the way the brain, as well as the spine, develops and can impact on learning and behaviour.**

The cortex (the 'main' part of the brain) might be thinner and not as organised, while the connection between the two halves of the brain might not form fully. The cerebellum may also not form fully, and might crowd other nerves and parts of the brain at the top of the spinal cord (Chiari II).

Changes to the way the brain develops can change the way it works, often in quite subtle ways like concentration and decision making. Most children talk well and learn to look after themselves and will go to mainstream school. Many adults work, drive cars and have families of their own.

There are many things that can help if your child has difficulties with their learning and Shine's team of specialists will be able to advise and support you as your baby grows. The brain is very adaptable, and many ordinary and fun activities can make a big difference. The earlier you begin, the better. You don't need to wait for challenges to appear because by then you will have missed a great opportunity to make a difference.



### Important to know:

It is important that you give your baby plenty of opportunities and experiences to help them to become the best that they can be. Like all children, babies with spina bifida need to develop, learn and practise skills through play. Babies and children learn through experience and the stimulation of their senses: sight, touch, hearing, taste, smell, as well as a sense of position and motion.

Sing and talk a lot when caring for and playing with your baby. At first, it will seem like a one-way conversation but soon your baby will make sounds in response.

Playing noisy games and copying their facial expressions helps to develop your baby's communication and before long they will be smiling and giggling along with you.

If your baby has hydrocephalus, you may notice that they are sensitive to sudden high-pitched sounds or very loud noises.



# Preparing for your baby

**In the early months, there won't be anything in particular that you will need to buy, but here are some tips that you might find helpful when preparing for your new baby:**

When you first come home with your baby, you'll get advice from the hospital about whether you need to keep your baby off their back if they have had back closure surgery. Unless specialist equipment is needed, a regular crib and mattress should be fine. A Moses basket can be used, but babies often outgrow these very quickly. Cribs with drop-down sides are useful to tend to your baby during the night and can allow more space if you need extra equipment to position your baby. The hospital will advise on this.

It's a personal choice whether you choose a travel system, or a pram and a pushchair for when they are older, but it is essential that your baby is able to lay flat. Prams and pushchairs are not always completely flat as advertised. Lying flat will encourage the development of your baby's lungs and hips. If you are thinking of buying a travel system, a carry cot is ideal. When choosing a pram or pushchair, you may wish to check the seat size and weight limit to see how long your baby will be able to use it for.

A car seat with thick, comfortable padding to the back will be more comfortable and you can buy one with extra head support if needed. Some seats have a swivel feature which can make it easier to secure your baby. Companies such as John Lewis and Halfords offer a fitting service for car seats.

Babies shouldn't spend long periods of time in their car seat and should only use this to travel in, not to sleep in.

When the hospital says that you can start bathing your baby, you may find a foam bath insert useful, such as the Summer Comfy Bath Sponge which gives extra comfort and head support for your baby.

Clothes with poppers or fastenings down the back and poppers down the legs may be easier to put on than those which pull on over the head.



## Important to know:

If you are thinking of moving, homes with a downstairs toilet are worth considering. If you have been advised that your child will probably use a wheelchair, homes with low or no steps into the property, and wide doorways and passages are good.

You may have some items of equipment to store, so storage space is handy. Looking ahead, space to build an extension for a bedroom and bathroom (subject to planning permission) can mean not needing to move house again as your child grows up.

## Birth and shortly after

**You may wish to contact the neonatal unit at the hospital you will be delivering at to see if you can have a look around. This will give you an opportunity to see the facilities and meet the staff before the birth.**

### Delivery

**Most babies with spina bifida can be born safely by vaginal delivery, which is the best start for both you and baby.**

There may be factors which make it safer to have a Caesarean, for example if your baby's

spina bifida cyst and/or head are large enough to cause a delay to the labour.

Your options for pain control will be exactly the same as with any other delivery, and the medicines used won't affect your baby.



### Shine suggests...

Fledglings sell a range of clothing and equipment that you may find suitable. See [www.fledglings.org.uk](http://www.fledglings.org.uk)

Pyjama Fairies is a charity that makes surgical gowns and adapted pyjamas for newborns and children up to 16. They offer up to two garments for free, if you donate towards the postage costs.

## Surgery

**If your baby has open spina bifida, the lesion on their back will be covered with a sterile dressing as soon as they're born.**

Surgery – at a hospital with specialist neurosurgery facilities – will usually take place within a day or two of birth, once your baby has settled from the delivery. Completing the surgery at this early stage will help to prevent infection. For this reason, it's best if you're able to give birth in the same hospital, especially if you need a Caesarean section.

If the lesion is covered by skin, such as a lipomyelomeningocele, there will be no urgency for surgery; your baby's neurosurgeon will usually want to wait until your baby is older before operating and will talk to you about this. If your baby has a very large lesion, the neurosurgeons may work with the plastic surgeons to make sure the skin will cover the lesion.

If hydrocephalus is present, a shunt may be fitted at the same time as the back-closure surgery. Otherwise, your neurosurgeon may want to wait and see how things go once the back surgery has been done. Sometimes, closing the back 'traps' CSF in the ventricles and hydrocephalus can develop as a result. In other cases, your neurosurgeon may want your baby to go home for a few weeks before the shunt surgery to let their immune system build up. Your baby's neurosurgeon will monitor for hydrocephalus.



### Important to know:

Some people with hydrocephalus will have seizures at some time during their life. It may be a one-off incident, but some people can go on to develop epilepsy. Seizures in a baby may be subtle and hard to spot or may be more obvious and should be reported to your neurosurgeon.

For more information visit Epilepsy Action and the Epilepsy Society.

Your baby's surgery should be carried out in a latex-free operating theatre, to reduce the risk of your baby developing a latex allergy later on. Children with spina bifida are particularly prone to developing latex allergies, and research has found that the risk is linked to the number of operations children have had.

Operating in latex-free theatres has been shown to significantly reduce the chances of this happening and nowadays, babies born in the UK are not exposed to latex during operations, so are much less likely to have an allergy to latex.

Latex is found in many household objects, and unless your baby has been found to have an allergy, it does not need to be eliminated from the home.

It is best to avoid latex on the mucus membranes (skin that covers the inside surface of parts of the body such as the nose, mouth, and genitals).

Non-latex catheters, feeding teats and dummies are readily available.

## Bladder & kidney scan

**While your baby is in hospital, a bladder and kidney scan is vital to check that urine isn't flowing back up to the kidneys (reflux) and that the bladder can empty properly.**

Within the first few months of life it's common for the urology team to show you how to catheterise your baby and give medicine to relax the bladder, allowing it to fill properly. This may reduce the need for major surgery later in childhood.

Getting your baby used to catheterising at an early age can help them to accept it as part of their everyday routine. Catheterising won't affect the way the bladder works, and it won't make it 'lazy'.

# Bringing your baby home

**Bringing your baby home from hospital, especially if they've had a difficult time, can be nerve wracking. You might be especially nervous about handling your baby following surgery.**

As long as you follow any instructions the hospital gave you, you'll be fine. It's important for your baby that you are as relaxed as you can be, to stay calm and to handle your baby with confidence. This will help your baby feel secure. Feeding is a great opportunity to bond and your baby will soon get to recognise your face. Responding quickly to your baby's needs will help to soothe them and make them feel safe.

## Feeding

### Breastfeeding

**Breastfeeding is the best way to feed all babies and has many advantages. It provides all of the nutrients your baby needs, and helps to protect against infections and allergies by boosting their immune system.**

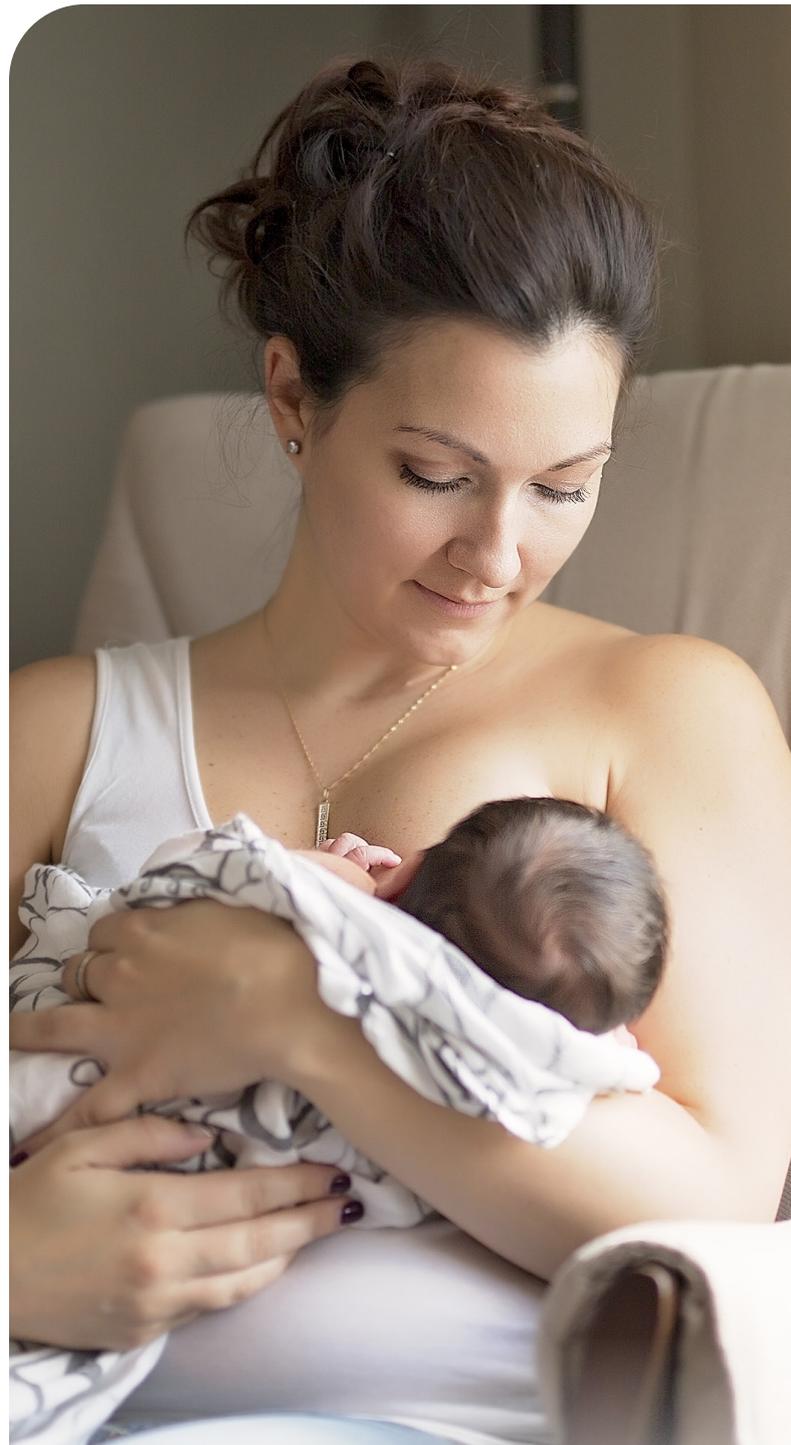
Breastfeeding a baby with spina bifida or hydrocephalus can be challenging, as it can be with any baby at times, however most issues can be resolved with good support from your health care team.

### Positioning

**Positioning a baby with spina bifida for breastfeeding may be a little more challenging but with patience and practice you should be able to find a comfortable position for you both.**

To burp your baby, place them over your shoulder and gently rub their upper back rather than patting. You can also gently rub between their shoulders or rock them on a firm surface to help to release air bubbles.

By the time you get home, your baby should be established on milk feeds. If your baby is finding feeding difficult, talk to your neurosurgery or paediatric team. If your baby has a shunt for hydrocephalus, sometimes poor feeding can be a sign that the shunt is not working properly. Some babies with Chiari II have difficulty with feeding.



Breastfeeding advice courtesy of neonatal nurses, Royal Belfast Hospital

## Maintaining your milk supply

**During pregnancy the breasts change and prepare for feeding your baby. Milk is produced on a supply and demand basis, meaning the more often you feed your baby, the more milk your body will make.**

If your baby is admitted to the neonatal unit, it is important to start expressing as soon as possible after birth to establish your milk supply. Ideally you should begin hand expressing within 2 hours of delivering your baby – ask the midwife caring for you to assist and guide you.

If your baby requires immediate transfer to the Neonatal Intensive Care Unit (NICU), skin-to-skin time with your baby straight after birth might not be possible or may be limited. This doesn't mean you won't be able to bond with or breastfeed your baby. The doctors and nurses will make every effort to encourage you to hold your baby as soon as it's safe to do so.

Although it may be difficult not to be able to hold your baby straight away, you can still touch your baby by holding their hands and stroking their feet. You can also talk to them, sing/read to them and help with aspects of their care. Expressing your breastmilk is an essential part of your baby's care and something that only you can do for them.



### Important to know:

The NHS recommends expressing breast milk 8-12 times a day with at least one expression overnight for a newborn baby. For the first few days after your baby is born, you will be able to express and/or feed your baby early milk called colostrum. At first, you will only be able to express a small amount of colostrum, this is normal. Your baby's stomach will only hold a very small amount of milk at this early stage.

**UNICEF UK Baby Friendly Initiative:**  
<https://www.unicef.org.uk/babyfriendly/baby-friendly-resources/breastfeeding-resources/hand-expression-video/>

The NICU will have pumps available to use whilst you are in the unit. Staff will show you how to use these. The unit should also be able to organise a loan breast pump for you to take home. If your baby is well enough, try to have at least an hour of skin-to-skin contact with them each day as this can not only aid your milk supply but has many benefits for your baby. Dads / partners are also encouraged to participate in skin-to-skin contact.

If you are unable to hold your baby, holding a toy or blanket that has been next to your baby and smells of them may help your 'let-down reflex' (hormones) allowing you to express more milk.

There are many professionals that should be able to help you with breastfeeding including NICU nurses, midwives and lactation consultants. Health visitors will support you once you and your baby are at home.

## Formula feeding



**Some parents choose or may need to feed their baby using infant formula rather than breastfeeding.**

Breastfeeding can sometimes be more difficult for some new mums, for a number of reasons. If you want help to breastfeed, support is available. But if you choose or need to formula feed, you should not feel guilty.

Although formula milk does not contain the same immune system boosting qualities of breastmilk, it does provide all the nourishment your baby needs.

There is no benefit of buying a more expensive branded formula milk compared with the less expensive, own brand formulas – they all contain the same essential nutrients.

## Chiari II

**Babies with myelomeningocele may have feeding problems owing to Chiari II, a developmental condition of the cerebellum, affecting the coordination of muscles involved in sucking, swallowing and breathing.**

Signs that your baby is having difficulty with swallowing include coughing during feeds, slow feeding and poor weight gain. If you notice this after you've taken your baby home, let your neurosurgical team know.

Babies may also have sensitivity in and around the mouth and a tendency to gag easily. They may tend to withdraw, turn away or fuss when approached with the nipple or a teat. For most babies, patience and perseverance will overcome the issue. If the issue remains, more expert advice from a speech and language therapist will be helpful.

## Hydrocephalus

**If your baby has hydrocephalus, ask the team looking after your baby about the best feeding positions.**

For some babies, a side-lying position with a pillow to support your baby's head may be used for breastfeeding and bottle feeding. For babies who have had a shunt inserted, care must be taken to ensure you don't put any pressure onto their wound site as pain could cause the baby to have an aversion (strong dislike) to feeding.

Your baby's neurosurgeon may advise of specific limits to your baby's head elevation (the position your baby's head should be in).



### Recommended reading

For more about Chiari II and/or Hydrocephalus, visit: [www.shinecharity.org.uk/relatedconditions](http://www.shinecharity.org.uk/relatedconditions)



## Sleep

**Sometimes babies who have been in hospital take a few extra days to settle into a routine. In hospital, the lights and noise at night are often similar to during the daytime, making it difficult for babies to settle. By making night and day different, you can help your baby to settle quicker. The more sleep they get, the more you get too!**

After the last feed, keep the lights as low as you can and keep sounds and talking to a minimum if you have to tend to your baby. Musical toys and projector night lights can make it harder for your baby to learn to settle in the quiet or dark.

Special considerations: Babies with spina bifida may have special 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 tilted or a special positioning system may be useful.

Your child's physiotherapist or occupational therapist (OT) will be able to support you and provide specific guidance for your baby's needs. The team looking after your baby will tell you when you can start to lay them on their back to sleep – the recommended sleeping position to reduce the risk of sudden infant death syndrome (SIDS or cot death).

You'll probably feel you need to check on your baby frequently through the night at first – most parents find they begin to relax over time.

## Tummy time

**Tummy time is exactly as it sounds – time with your baby laid on their tummy when they are awake.**

Tummy time is really important to help your baby to develop the muscles in their upper body, including their head, neck, shoulders and arms. Tummy time can start from day one, and the earlier you start it, the better.

The easiest way to start is by lying down with your baby tummy down on your chest. They can also be placed on your lap or on a firm surface. Tummy time is a great way to bond with your baby – enjoy this special time by singing to your baby, cuddling and gazing into their eyes.

You'll notice that your baby will start to briefly lift their head from really early on. Little and often is ideal and it's best to do a little with your baby every time they're awake. The earlier you start, the more your baby will enjoy it and it's the best activity for your baby's development in the first few months. If your baby also has hydrocephalus, they may find this difficult as their head may be quite heavy. Little ones who have had surgery may need some adjustments to positioning for tummy time. Your physiotherapist will be able to give advice 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 give a similar experience with massage, stretching your baby's muscles in a calm, relaxing environment.**

Some of the physical benefits of baby massage include:

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

Other benefits to massage which would be helpful for adults too, include:

- Improved breathing
- Better 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 get to know your baby's behaviour, crying and body language. Talking to them during tummy time really helps with bonding, focusing attention and language learning at this early stage.



### Important to know:

If you are at all unsure, start with hands, arms, legs and feet in the beginning. If you are worried then please ask for advice from your baby's physiotherapist as your baby will still benefit from massage, even if their position and your technique needs to be adapted slightly.

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 their heart rate and breathing rate which helps for a more restful nights sleep.

If you are starting this with an older baby, it might take a little while for them to get comfortable and stay 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.



Little and often is perfectly fine as your baby will still benefit hugely from the positive effects of your touch and the one on one interaction with you.

Ask your health visitor or GP about baby massage courses. In the meantime, if you would like to get started, **here are some basic guidelines to follow.**

- 1** Be in a warm, dimly lit room
- 2** Make sure you're comfortable – either sitting on the floor with baby in front of you or up on a changing table or suitable surface that doesn't strain your back (always have a hand on baby!). If you are worried about lying your baby on their back then you could do massage in a side lying position to start with
- 3** Have your baby in a nappy only and lie them on a towel in front of you
- 4** Rub your hands together to warm them – you can use baby oil or a small drop of olive oil
- 5** Use gentle pressure in small, slow circular movements with your fingertips
- 6** You can start on baby's forehead and use gentle circular strokes to massage temples, cheeks and the jaw area, ensuring the shunt surgery incision is fully healed if they have had shunt surgery
- 7** Slowly move down to neck and shoulders
- 8** Always watch closely to check how your baby is responding. Firm but gentle pressure is best and will avoid uncomfortable tickling
- 9** If your baby starts to fret or get upset, turning their head away from your touch, then it may be time to stop and try later
- 10** Work your way down each arm to their hands and palms
- 11** Roll your baby over onto their tummy
- 12** Continue with small circular movements on the back of their head, down their back and spine. In a baby with spina bifida, there may need to be some extra care taken around their back. If there is a wound from surgery then massage can be helpful once the wound has completely healed. It will help with loosening up scar tissue and also with desensitising the area.
- 13** Continue to their bottom, thighs, lower legs, feet and toes (legs and feet can be done when they are on their back too)
- 14** Your baby will enjoy it even more if you use a gentle, soothing voice to sing and talk to them throughout the massage

## Family Matters

**Becoming a parent is hard for everyone, and if your baby has additional needs, it can put a huge strain on you, your partner, and all the family. You'll have the nights of broken sleep and feeding which can seem to be endless, but you may have added concerns, maybe a lot of appointments, and perhaps hospital stays, that may take up your time.**

With so much going on, it can be difficult to enjoy your baby, and enjoy being a parent.

Now is the time to accept any offers of help you are given and to ask if you need assistance. Grandparents can be a wonderful support to you and to your baby as they grow up. For grandparents, there is love and concern for you, their child, as well as for your baby.

Often, grandparents don't want to interfere but then find they don't know what is happening or understand about your baby's condition. They may offer help with your other children, but are unsure of how they can be of help with the baby.

Make sure they know what is going on with regard to medical and other matters by involving them in appointments and sharing your feelings, so they are able to share theirs too. Be honest with them if you feel they are 'taking over' and guide them in how best to help you.

Family members can be anxious about looking after a baby if they have extra needs and can need a bit of reassurance, as well as showing how to care for your baby. If you have a partner, share the care and communicate with them. Make time for yourselves as a couple, rather than just as parents.

Encourage them to open up about their fears and anxieties and if you suspect, or if they indicate, they are depressed, encourage them to see their GP.



If you have had a Caesarean section, accepting help will be very important as you will not be able to lift your baby for around six weeks.

If there is no one around to help, contact your local Social Services Children's department as soon as possible and tell them about the things you will need help with.



### Important to know:

Make sure you take care of yourself and don't feel guilty about taking 'time out' to recharge your batteries. If you are exhausted, you won't be able to care for your baby. Similarly, don't worry if you don't get everything done like you used to – stick to the 'must do' list.

Eating well, getting fresh air, and exercise can help to keep your energy levels up and help to relieve stress. Find out about support locally and opportunities to meet other parents.



## The most important thing of all is... enjoy your baby!

Many mums feel down, tearful and a bit anxious in the first weeks after having a baby. This is normal and is known as the baby blues. If you feel like this for more than two weeks or start feeling like this later on, please seek help through your GP or health visitor. It can be hard to recognise if you have postnatal depression as it may develop gradually.

If you have other children, the arrival of a new baby can be both exciting and a challenge. They may have known before the birth that your baby was going to be 'poorly' and may have worried about what this would mean. There may have been a change to routine if your baby has had surgery or an extended time in hospital, particularly if your other children have been looked after by grandparents or friends.

Try to involve your other children in caring for your new baby. Even a very young child can pass cotton wool or nappies, and they can be very helpful fetching things for you. Make sure they understand as much as is possible for their age.

If they don't know and understand, they can worry not only about the baby but about themselves - will they get whatever the baby has and become 'poorly', too?

Make time to do special activities with your older children and ensure their school knows what is happening at home and are prepared to contact you if they have concerns that your child is anxious, withdrawn, or behaving in a way that worries them. If you feel that they are distressed or depressed, seek help from your GP as soon as possible.



### Shine suggests...

Young Minds is a charity specialising in the mental wellbeing of children and teenagers and can be useful in helping you work out how best to support your child.

**W:** [www.youngminds.org.uk](http://www.youngminds.org.uk) or  
Parent Helpline  
**T:** 0808 802 5544

# Financial support

It can feel overwhelming being told about all the support that you can apply for so soon after the birth of your baby. Below is an overview of benefits you may be entitled to at this point and ones that parents commonly ask about. We will continue to advise, at relevant points, of other benefits you may wish to apply for.

## Disability Living Allowance (DLA)

DLA is a non means-tested benefit with two parts for Care and Mobility. The Care component can be payable from three months old. The form is long and complex, so it might be an idea to ask for help from Shine or the Citizens Advice Bureau to complete it. There are three levels of payment, depending on how much extra care or supervision your baby needs compared with a baby without spina bifida and / or hydrocephalus, and whether the care is required day and night, or just at certain times. As the care you need to give can change a lot in the first few months, for example starting catheterisation, wait until around 11 weeks before asking for a form, and thinking about what to include. It can help to keep a diary for a few days before filling in the form to see how much 'extra' you are doing, as this will help to build an accurate picture of your baby's needs.

Having a diagnosis of spina bifida doesn't make your child automatically eligible for DLA, and will only apply if your child needs extra care or supervision because of the spina bifida. The decision-makers reading the form won't necessarily know much about spina bifida, you will have to tell them in detail how the condition affects your child.

Receiving DLA for your baby means you become eligible for other benefits or allowances, so it can make a real difference to your household income.

As your child gets older, they may be entitled to the Mobility component of DLA if they have difficulties with moving around.

Your child may be eligible for the higher rate Mobility component from the age of 3 if they have physical difficulties walking. Lower rate Mobility component is payable from the age of 5 if your child needs more

guidance or supervision when walking outdoors than other children of the same age and without their condition would need. DLA is not means tested and each claim is assessed individually.

Forms can be obtained by calling

**T:** 0800 121 4600 or online at

**W:** [www.gov.uk/government/publications/disability-living-allowance-for-children-claim-form](http://www.gov.uk/government/publications/disability-living-allowance-for-children-claim-form)

Note: recent changes also mean that children getting DLA can continue to claim the benefit while they are in hospital - previously it stopped after 28 days. It also means that you can make your first application and be paid once your child is three months even if they remain an in-patient.

## Carer's Allowance

If your child is awarded DLA at middle or higher rate of the Care component, you might be eligible to apply for Carer's Allowance.

For this you will also need to be giving your child 35 hours of personal care per week, earning less than £123\* per week (just you, not your household income) and not in full-time (more than 21 hours) education. If you are making a joint claim, you may both qualify, but must not be caring for the same person. You will get a reduced rate if you're on certain benefits such as Income Support and Universal Credit.



### Important to know:

If your child is awarded DLA, it may, depending on your other circumstances, mean you are eligible for Housing Benefit, Council Tax Reduction Scheme, Energy Efficiency Grants, and more money if you receive Income Support or Child Tax Credit.

## Healthy Start Scheme

If you receive certain benefits (Income Support, Universal Credit, Income-based Job Seeker's Allowance, Employment and Support Allowance, Child Tax Credit, or occasionally Working Tax Credit), you may be eligible for the Healthy Start Scheme. This entitles parents with a child under four to vouchers to buy cow's milk, baby formula, fresh fruit and vegetables, and coupons to receive free vitamins. Contact Healthy Start on

To find out more, contact Healthy Start on

**T:** 0345 607 6823 or

**W:** [www.healthystart.nhs.uk](http://www.healthystart.nhs.uk)

## Sure Start Maternity Grant

A Sure Start Maternity Grant is a one-off payment of £500 to help with the costs of having a new-born or adopted baby and applies to those living in England, Wales and Northern Ireland if it is the only child under 16 in the household. There are special rules for multiple births.

To receive the grant, you or your partner must already be getting qualifying benefits on the day you claim the grant. These include: Income Support, or Income-related Employment and Support Allowance, or Income-based Jobseeker's Allowance, Universal Credit, or the guarantee part of Pension Credit.

You must also show that you have received advice from a health care professional.

You must claim the grant within 11 weeks of the baby's due date. For babies that have been adopted, this differs.

For further information see

**W:** [www.gov.uk/sure-start-maternity-grant](http://www.gov.uk/sure-start-maternity-grant)

## Family Fund

The Family Fund provides grants for families raising a child with a disability or serious illness for essential items such as a washing machine, a fridge, or clothing. It can also give grants for visiting hospital, holidays, or driving lessons for a parent. You will need to show that you receive one of the benefits below:

- Child Tax Credit
- Working Tax Credit
- Income-based Job Seeker's Allowance
- Income Support
- Incapacity Benefit
- Employment and Support Allowance
- Housing Benefit
- Pension Credit
- Universal Credit

Contact Family Fund on

**T:** 01904 550 055 or

**W:** [www.familyfund.org.uk](http://www.familyfund.org.uk)



**More information about further financial and practical support is available overleaf.**

## Hospital appointments

You should be able to get help with your hospital travel costs for attending appointments (not for visiting) if you or a member of your family are receiving:

- Income Support
- Income-based Job Seeker's Allowance
- Income-based Employment and Support Allowance

You may also get some help if you are receiving:

- Child Tax Credit
- Working Tax Credit
- Contributory Job Seeker's Allowance
- Contributory Employment and Support Allowance
- Universal Credit.

## Parental Leave

Parental Leave gives the parents of disabled children the right to take a period of time off work to look after their child, attend hospital appointments, etc, as long as you've been working for your current employer for at least one year and your child receives DLA. The time off is unpaid, and each parent has the right to take up to a total of 18 weeks' Parental Leave until their child turns 18 years old. More information can be found at <http://bit.ly/PLGOVUK>

## Newlife (The Charity for Disabled Children)

Newlife provides funding for essential community equipment, such as beds, buggies, wheelchairs, seating systems, and much more. They also have a free Nurse Helpline.

Contact on

**T:** 01543 462 777 or

**W:** [www.newlifecharity.co.uk](http://www.newlifecharity.co.uk)

## Blue Badge Scheme

If your child is over the age of 3 and receives the higher rate of the Mobility component of Disability Living Allowance (DLA), they will automatically qualify for a Blue Badge.

Your baby may also be eligible if they are under 3 and need to be accompanied by bulky medical equipment. You will need to apply for this, and can do so here: [www.apply-blue-badge.service.gov.uk/applicant](http://www.apply-blue-badge.service.gov.uk/applicant)

**Every effort has been made to ensure that this information is up to date, however changes in the law over time may affect the accuracy of some content. The information provided does not constitute legal or professional advice. You should always check details regarding your welfare rights with a local advice centre or the Department for Work and Pensions.**



### Important to know:

Did you know? In the first year after their baby's birth, mothers are entitled to free prescriptions and NHS dental care.

To be entitled all you need is a Maternity Exemption Certificate signed by your doctor or midwife.



### Recommended reading

For more information on benefits, please visit the Benefits section of our website: [shinecharity.org.uk/benefits/welfare-benefits](http://shinecharity.org.uk/benefits/welfare-benefits)

Turn2us also has a helpful benefits calculator. Visit their website: [turn2us.org.uk/Benefit-guides/Beginner-s-Guide-to-Benefits/Checking-benefit-entitlement](http://turn2us.org.uk/Benefit-guides/Beginner-s-Guide-to-Benefits/Checking-benefit-entitlement)



# Professionals you may meet during your baby's first year

## Paediatric neurosurgeon

Specialists in brain and spine conditions. If your baby has open spina bifida, the neurosurgeon will do necessary surgery which will usually involve closing your baby's back shortly after birth, and inserting a shunt if hydrocephalus develops.

My baby's paediatric neurosurgeon is:

.....

Contact details:

**T:** .....

**E:** .....

## Urologist

A specialist in bladders and kidneys

My baby's urologist is:

.....

Contact details:

**T:** .....

**E:** .....

## Specialist urology nurse

Specialist nurses that work closely with the urologist and will assess your baby's bladder function in the early weeks, teach you to catheterise if needed and advise you on bladder and bowel care.

My baby's specialist urology nurse is:

.....

Contact details:

**T:** .....

**E:** .....

## Orthopaedic surgeon

A doctor that carries out interventions and surgery involving the muscles and bones including the Ponseti technique and bracing for curvature of the spine or hip dislocation.

My baby's orthopaedic surgeon is:

.....

Contact details:

**T:** .....

**E:** .....

## Physiotherapist

Health professionals that work with children to promote movement and mobility.

My baby's physiotherapist is:

.....

Contact details:

**T:** .....

**E:** .....

## Occupational therapist (OT)

Professional that can support you to provide ways for your baby to play and engage in everyday activities.

My baby's occupational therapist is:

.....

Contact details:

**T:** .....

**E:** .....

### Health visitor

A registered nurse or midwife who has undergone extra training and provides support during a child's early childhood.

My baby's health visitor is:

.....

Contact details:

**T:** .....

**E:** .....

### Speech and language therapist (SALT)

Health professionals concerned with speech and language development. They may be needed if your baby has swallowing difficulties or problems learning when starting on solids.

My baby's speech and language therapist is:

.....

Contact details:

**T:** .....

**E:** .....

### Orthotist

Health professionals that will provide splints, braces and special footwear if needed.

My baby's orthotist is:

.....

Contact details:

**T:** .....

**E:** .....

## If your baby also has hydrocephalus:

### Hydrocephalus nurse specialist

Some neurosurgery services have nurse specialists who help by giving and simplifying information, being a link between you and other professionals and providing additional support.

My baby's hydrocephalus nurse specialist is:

.....

Contact details:

**T:** .....

**E:** .....

### Ophthalmologist

Eye specialists that may be involved in the care of babies with hydrocephalus who have problems with vision or eye movement

My baby's ophthalmologist is:

.....

Contact details:

**T:** .....

**E:** .....

For our more extensive list of professionals your baby may see up until the age of 10, see our website.

Connect with specialist staff and other parents in our 'Little Stars' facebook group:

 [facebook.com/groups/shineslittlestars](https://facebook.com/groups/shineslittlestars)

## Who are Shine?

With around 12,000 members across England, Wales and Northern Ireland, Shine is Europe's leading charity for people affected by spina bifida and hydrocephalus.

For over 50 years, we've been at the centre of developments which have improved the lives of thousands of people, enabling and empowering our members to lead the lives they want to live.

**Get in touch and  
join today for FREE!**



**Little  
Stars**

**Shine offer specialist support for  
parents of children aged 0 – 10**

**For more information, visit:  
[www.shinecharity.org.uk/littlestars](http://www.shinecharity.org.uk/littlestars)**

Shine - 42 Park Road, Peterborough, PE1 2UQ  
01733 555988 • [www.shinecharity.org.uk](http://www.shinecharity.org.uk)  
firstcontact@shinecharity.org.uk • Registered Charity: 249338

