Spina bifida – a guide for new parents

shinecharity.org.uk
Get in touch

If you would like to find out more information, or if you need any support from us, we would love to hear from you.
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Contents

3  Introduction
4  Before your baby is born
5  How spina bifida may affect your child
7  The first few weeks
9  The next few months
10  What your baby will need
11  Professionals you may see during your child’s first year
14  Money matters
17  Family matters
18  Getting ready for another pregnancy
20  Contacting Shine around the country
Introduction

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

We work with thousands of parents whose child has spina bifida, and the adults that those children eventually grow up to be. We are here to help you when you feel challenged or daunted, but also to celebrate every achievement along the way. Our purpose in producing this New Parents’ Pack is to help you understand spina bifida and to offer you guidance as your child develops.

The variations in what your child may experience are wide, the New Parents’ Pack is designed to give you comprehensive information so that you are as prepared as possible for your new baby’s arrival and their early stages of development.

This information has been prepared by Shine staff who are experts in their respective fields. It offers guidance on how to prepare for the birth of your baby, what your baby will need, which professionals you are likely to encounter, and all the details around having a child with spina bifida, including money and wider family matters.

It is likely that once you have read this information you will still need more support from Shine. All of the relevant Shine contacts are listed on page 20, please get in touch with any questions you may have.

We wish you all the best as you welcome your special baby.
Before your baby is born

Finding out that your unborn baby has spina bifida may raise many questions for you, and it can be reassuring to know what is likely to happen.

If you have just had your midterm (20 week) scan, and it is suspected that your baby has spina bifida, a further, more detailed scan will be arranged for you to confirm this within a few days. You will also be given an appointment with a Fetal Medicine expert.* You may like to contact Shine at this point and speak to our experienced Health Advisers (see page 20).

It will be helpful if you can talk to a Paediatric Neurosurgeon to find out more about how spina bifida may affect your baby, based on your scan results and their experience. Some hospitals offer this automatically, although it may not be available in some areas. You may also be offered an MRI, a 3D scan which uses magnets (no radiation) to give 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 difficulties, or how serious these may be.

If the spina bifida looks very severe, an amniocentesis might be offered. Occasionally, spina bifida is part of a chromosomal disorder, which will have additional effects on the baby’s health and development. 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, it’s important that you know why it’s being offered, so do ask.

As your pregnancy develops, you may be offered more 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.

If you are continuing with your pregnancy, you may wish to discuss prenatal surgery with your consultant. It may not be right for you or your baby for a number of reasons, and there are risks and varying degrees of benefit (particularly with fetoscopic or ‘keyhole’ surgery compared with open surgery.

Making plans for the birth

Your baby will usually have surgery at a Paediatric Neurosurgery Centre within a day or two of birth, so it will be best if you can give birth in the same hospital, especially if you need a Caesarean section. Many parents ask us whether they will need a Caesarean or if they can have a natural delivery. If your baby’s head circumference is larger because of hydrocephalus, it might be safer to have a Caesarean. However, it may be fine to deliver your baby naturally if the lesion is low down at the bottom of the back (sacrum), or if it is very small. At the moment, there is little evidence to show that either method is best for protecting your baby’s back, so discuss your preferences with the obstetricians.

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

* In England and Wales you may be asked to decide whether to continue or end the pregnancy; it is very important that you have all the information you need, and only make the decision that is right for you and your family when you are ready to do this. If it feels as though you are being rushed, let the hospital know you need a little more time to think, discuss, and get information. Hospitals should not try to persuade you to either continue or end your pregnancy.
How spina bifida may affect your child

Spina bifida literally means ‘split spine’. A fault in the development of the spinal cord and surrounding bones (vertebrae) 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 is useful to explain the composition of the nervous system.

The spinal cord is the collection of nerves known as the central nervous system, which provides a connection between the brain and the body. The brain controls all our movement, body temperature, and our bladder and bowels through the spinal cord, as well as all our senses (touch, hot and cold, pain) and how our limbs are positioned. These senses provide information which travels from the body to the brain, where the information is processed. When these messages are prevented from reaching the brain, in the instance of damage to the spinal cord through spina bifida, the brain can’t detect what’s happening to the body and can’t control any of the functions. This is the reason why spina bifida affects things like movement, skin sensation, and bladder and bowel function. In addition, open forms of spina bifida may result in other conditions such as hydrocephalus and Chiari II.

Movement
Each individual back bone (vertebra) 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.

For us to be able to move voluntarily, the muscle 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 affect the strength and movement around the ankle.

Children with lower spina bifida lesions may walk, depending on where their lesion is. If only the foot and ankle are affected, splinting helps to stabilise and strengthen. The muscles across the hip joints and knees need to be strong enough to hold your 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.

The important things for your child are, firstly, that they are able to move around, exploring their surroundings, being independent, and taking part in as many different activities as they can or want to; using a wheelchair might enable this to happen in comfort and dignity. Secondly, learning to move, focussing on the quality of movement, and not missing important developmental stages can help your baby’s general development.

And thirdly, 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, might help keep the tissues healthy, and might make it easier to control weight gain.

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. Burns are common in children with spina bifida – cover your radiators and the pipework to prevent accidental burns, and don’t place the bed near a radiator. Teach your child to touch radiators if needed with their hand before going near them (even children with low sacral lesions may have numb areas on the backs of the legs and feet), to always run the cold water into a bath before the hot and check before going in, and to check their feet every day for red areas (and never go barefoot).

Parents often tell us their baby with spina bifida bites their toes and feet, sometimes till they bleed. This is because they can’t feel their feet, or feel pain – to them it’s like chewing any other toy. Protect the feet with extra socks and bootees, or very soft baby shoes. Distract them with teething rings which they can chew safely.

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

But we know that by starting treatment early (the first few months of life) if needed, a lot of the kidney and bladder problems of old may be prevented or minimised. Most parents will be taught and supported in emptying their baby’s bladder with a thin, disposable tube. This is called intermittent catheterisation (ISC), and is combined with medication to relax your baby’s bladder muscle to prevent problems developing. The nerves to the outlets (sphincters) of the bowels may be affected leading to leaking of faeces, and constipation is common.

Hydrocephalus
Many babies with myelomeningocele (one type of spina bifida) will develop hydrocephalus after their back lesion is closed. Due to the gap in the back, the cerebrospinal fluid (CSF) from the brain will flow out of the back, instead of around the outside of the brain where it is usually absorbed. When the back is closed, the fluid is trapped inside the head. An operation to fit a shunt, to divert the fluid out of the head, can be done if needed. Before birth, the fluid should carry important chemicals around the outside of the brain which helps the brain develop. When the fluid can’t reach these areas, the development is less organised and may cause the effects on learning and behaviour we associate with hydrocephalus. Find more information on hydrocephalus at www.shinecharity.org.uk

Chiari II
In 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 causes a Chiari II (two) malformation. This part of the brain, the cerebellum, 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.
The first few weeks of your new baby’s life will be quite a hectic time of surgery, meeting new professionals, and check-up appointments to get your baby’s treatments and therapies started, and to make sure you are supported throughout this busy time.

Once your baby is born, the lesion on the back will be covered with a sterile dressing to prevent infection before surgery. The operation to ‘close’ the spina bifida lesion will usually be done within a day or two, once your baby has settled after the birth. (If the lesion is already covered by skin, such as a lipomyelomeningocele, there will be no urgency for surgery; your neurosurgeon will talk to you about the best time for surgery and may want to wait several years before operating.) 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 already present, a shunt may be fitted at the same time. 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 after the back surgery. 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 surgery should be carried out in a latex-free operating theatre, to reduce the risk of your baby developing latex allergy later on. Children with spina bifida are particularly prone to developing latex allergy, and research has found the risk 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. As latex is found in many common products, prevention of allergy makes everyday life much more straightforward. Latex-free catheters, and silicon feeding teats and dummies should also be used.

Most babies with spina bifida and hydrocephalus feed well. Some babies are a little sleepy and slow to feed until their shunt is fitted, and some babies with Chiari may need to be fed via a tube. Otherwise, it should be possible to breastfeed your baby if you want to.

While your baby is still in hospital, a bladder and kidney scan should be conducted to check that urine isn’t flowing back up to the kidneys (reflux) and that the bladder can empty properly. It is common these days for your urology team to show you how to catheterise your baby (ISC) and administer medicine to relax the bladder, allowing it to fill properly, within the first few months of life. Current research shows that this may reduce the need for major surgery later in childhood. Also, starting your child on ISC, at say age two, can be tricky if they refuse, so having them used to it at an early age can allow them to accept it as part of their everyday routine. It is best to develop a plan with your urology team to get your child out of nappies during the primary school years.

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, usually by holding the feet in position with strapping or plaster casts, making small changes every week when the plasters are changed. This is called the Ponsetti Technique. Once the feet are in the correct position, around three months, your baby will have ‘boots and bar’ to hold the...
feet in correct position for several months. A referral to your local physiotherapy service should be made before you go home.

Going home
Taking your new baby home can be daunting to begin with, but your hospital will tell you what to look out for, when you can begin to bath and wash your baby’s hair, and who to contact if you’re worried.

Sometimes babies who have been in hospital take a few extra days to settle in to a routine; in hospital, the lights and noise levels at night are often similar to days. By making night and day different, you can help your baby to settle quicker, and the more sleep they get, the more you get too! Have different clothes for night and, after the last feed, keep the lights as low as you can if you have to tend your baby. Keep sounds and talking to a minimum if you have to tend your baby in the night, and avoid musical toys or ‘light show’ night lights which can make it harder for your baby to learn to settle in the quiet or dark.

You may need to put your baby to sleep on their side, away from the back repair site, for a few weeks, and you may need to turn them onto the other side once or twice in the night. You will probably feel you need to check on your baby frequently through the night at first – most parents find they can relax over time.

And the most important thing of all is… enjoy your baby!
The next few months

The first few weeks of your baby's life may seem hectic with lots of hospital appointments. In these early days, your specialists will want to check everything is going well and will start treatments for your baby. Soon, you should find the appointments becoming further apart.

Vaccinations
Your baby should have all the routine vaccinations that are offered unless there are specific, unrelated reasons why your doctor thinks they shouldn't be given. There's nothing about spina bifida or hydrocephalus which means they shouldn't have this important protection. Find more information on vaccinations and spina bifida and/or hydrocephalus at www.shinecharity.org.uk

Feeding
By the time you get home, your baby should be established on milk feeds. If your baby is finding feeding difficult, do talk to your neurosurgery team (or paediatric team). Sometimes, poor feeding can be a sign that the shunt isn't working properly, or that the Chiari is causing problems. You may be referred to a Speech and Language Therapist (SLT) - an expert in everything to do with the mouth. A Dietician can also offer nutritional advice.

When you start to wean your baby, at around six months, introduce them to a wide range of vegetables. A varied diet containing vegetables, fruit, and cereals can help prevent constipation, and good habits early on can help prevent obesity. Children with spina bifida are more prone to being overweight than children without spina bifida as they do not have as much muscle (which uses energy). It can be harder to lose any excess weight so preventing it in the first place, with a healthy diet, is better. Choosing not to use food as a treat or reward is also a good preventative measure. If you find that your baby struggles or chokes on lumps, go back to pureed food for a couple of weeks, but if it happens again, let your neuro team and paediatrician know as it may be a result of Chiari. You may be referred to a Speech and Language Therapist (SLT) - an expert in everything to do with the mouth.

Moving and developing
Spina bifida may affect the way your baby's brain develops giving rise to some difficulties in learning and behaviour. Children with spina bifida may need extra help to learn how to move because of this difference in brain development. Babies' brains develop very quickly, especially in the first year, and this gives a lot of opportunity to make sure this development is as good as it can be through fun and play. For example, 'tummy time' will help your baby to develop head control, which will help with developing sitting, and eventually, finger movements.

Games with lots of movement, such as 'row your boat', or those with movement through the air, and songs with actions, help your baby learn how to coordinate their movements; the more you do the better the chance of helping your baby's brain development. It is important that your baby doesn't 'miss out' development stages like rolling over – your physiotherapist will show you how to help. If your baby doesn't crawl, they may need some equipment to help them get around at home so that they can explore and play.

At six months old, your baby will need to spend time sitting upright to make sure the part of the brain which makes sense of what we see, starts to work properly. Many babies with spina bifida will need extra support to sit up, and your Occupational Therapist (OT) should help with this.
In the first year you won’t need anything extra at home but, if you were thinking of moving anyway, 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 beneficial. You may have some items of equipment to house, 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. In the early months there won’t be anything particular that you will need to buy, but here are some tips.

Disabled facility grants (DFG’s) may be available to help with the cost. See https://www.gov.uk/disabled-facilities-grants/overview

**Prams**
When you first come home with your baby, you will need to keep them off their back to sleep to allow healing from the surgery. You will also need a pram that will let your baby sleep flat. It will be worth looking around as some that claim to be flat are not always completely flat. If you are thinking of buying a travel system, the carry cot is ideal. Babies shouldn’t spend longer than necessary in the car seat component in any case. The mattresses that come with carry cots and cots should be fine for your baby’s needs.

**Cots**
A regular cot and mattress will be fine; drop-down sides are useful if you need anything extra such as equipment to help position your baby – the hospital will advise you on this. You shouldn’t need to buy an apnoea mattress; if your baby needs one then this will be provided.

**Car seats**
It is possible to buy car seats which allow your baby to lie flat, but this feature isn’t often needed and these seats can be expensive. Some seats have a seat and backrest unit which can be tilted back if your baby needs extra head support. When buying your car seat, look for one with good extra head support and thick, comfortable padding to the back for extra comfort. Some seats have a swivel feature which can make it easier to secure your baby. Some companies such as Mothercare and Kiddicare offer a fitting service for your car seat.

We suggest your baby doesn’t spend long periods of time in the car seat and only use car seats for travel, not to sleep in.

**Bathing**
When the hospital says 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**
Clothes with poppers or fastenings down the front can be easier to manage than those which pull on over the head, and suits with poppers down the legs may be easier to put on. Vests with ‘envelope’ necklines might be more comfortable to put on than round necks if your baby has had a shunt fitted.

The charity Fledglings source a range of clothing and equipment geared towards children with disabilities. See http://www.fledglings.org.uk/index.php/about
Professionals you may see during your child’s first year

Neurosurgeon – neurosurgeons are specialists in brain and spine conditions. 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 child’s Neurosurgeon is:

Contact no:

Other info:

Hydrocephalus Nurse Specialist – some neurosurgery services have nurse specialists who help by providing and clarifying information, liaising with patients and other professionals, and giving extra support.

My child’s Hydrocephalus Nurse Specialist is:

Contact no:

Other info:

Urologists – are specialists in bladders and kidneys.

My child’s Urologist is:

Contact no:

Other info:

Specialist Urology Nurses – working closely with the Urologist, the Specialist Urology Nurse will help by assessing your baby’s bladder function in the early weeks, teaching you to catheterise if needed, and by being available to support and advise you on bladder and bowel care.

My child’s Specialist Urology Nurse is:

Contact no:

Other info:
Ophthalmologists – are eye specialists and may be involved in the care of babies with hydrocephalus who may have problems with vision or eye movement.

My child’s Ophthalmologist is:

__________________________________________

Contact no:

__________________________________________

Other info:

__________________________________________

Orthopaedic Surgeon – since spina bifida can often affect legs, feet, and mobility, interventions and surgery involving muscles and bones are sometimes needed, such as the Ponsetti technique, to improve foot shape and position, and bracing for curvature of the spine or hip dislocation.

My child’s Orthopaedic Surgeon is:

__________________________________________

Contact no:

__________________________________________

Other info:

__________________________________________

Physiotherapists – are health care professionals who work to promote movement and mobility.

My child’s Physiotherapist is:

__________________________________________

Contact no:

__________________________________________

Other info:

__________________________________________

Health Visitors – provide support during a child’s early childhood. They monitor baby’s growth and wellbeing (usually recording things in the ‘Red Book’), and by checking your child’s development. Your area may have a Specialist Health Visitor who will be experienced in the needs of children with health conditions, and their families.

My child’s Health Visitor is:

__________________________________________

Contact no:

__________________________________________

Other info:

__________________________________________

Physiotherapists – are health care professionals who work to promote movement and mobility.
Speech & Language Therapists – are health professionals concerned with language development and speech. They may be needed if your baby has swallowing difficulties or problems learning to chew when starting on solids.

My child’s Speech & Language Therapist is: ____________________________________________

Contact no: ______________________________________________________________________

Other info: _______________________________________________________________________

Portage Workers – are special play workers who can give you ideas for play which can help your child’s development. Ask your Health Visitor or Social Services if this service is available in your area.

My child’s Portage Worker is: ______________________________________________________

Contact no: ______________________________________________________________________

Other info: _______________________________________________________________________

Occupational Therapist – children with spina bifida and hydrocephalus may often need support to learn and carry out the activities of daily living, such as sitting, dressing, or feeding themselves. Occupational Therapists help people to adapt and develop skills, e.g. with specialist equipment, supporting parents, or advising on adaptations.

My child’s Occupational Therapist is: ______________________________________________

Contact no: ______________________________________________________________________

Other info: _______________________________________________________________________

Registered Charity Number 249338
Finding out that your baby has spina bifida may affect your family’s finances. For example, you may not want to return to work as early as you had originally thought, and this section should give you an idea of what help is available and at what stage in the process you can access this support. We’ll also let you know what other help is out there, which might make day to day life a little easier.

In the first year after their baby’s birth, mothers are entitled to free prescriptions and free dental care.

Benefits

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 get help (from Shine’s Support and Development Workers, see page 20, or 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 day and night, or just at certain times. 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. If your baby is very ill and not expected to live, you can apply from birth under special rules.

Having a diagnosis of spina bifida or hydrocephalus doesn’t make you automatically eligible for DLA. You will have to show that your baby needs extra care or supervision because of their condition. Nor will the decision-makers reading the form necessarily know much about spina bifida or hydrocephalus – you will have to tell them in detail how the condition(s) affects your child. Forms can be obtained:

- from your local DWP or Jobcentre
- by calling the Benefit Enquiry Line
  T: 0800 88 22 00

Higher Rate Mobility component can be claimed from the age of three if your child has physical difficulties walking. Later on, children aged five and over can claim Lower Rate of Mobility component if they require more guidance or supervision when walking outdoors than other children the same age without their condition would need.

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.

Carers’ Allowance
If your child is awarded DLA at middle or higher rate of the Care component, you might be eligible to apply for Carers’ Allowance. For this you will also need to be giving your child 35 hours of personal care per week, earning less than £120* 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. Note: you will get a reduced rate if you’re on certain benefits such as Income Support. *April 2018

Other benefits
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, Income-based Job Seeker’s Allowance, or Employment and Support Allowance, or Child Tax Credit, 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 T: 0345 607 6823, or W: www.healthystart.nhs.uk to register.

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

Child Care
By law a nursery or childminder has a duty not to treat a disabled child ‘less favourably’ and to make ‘reasonable adjustments’ for disabled children. Many local authorities will subsidise a childminder to take a child who will need more care than average.

More information can be found at http://bit.ly/CCGOVUK

Other help and support

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 hospital visiting costs, 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
Blue Badge/Disabled Parking Permit
In most but not all areas, it is possible to get a discretionary blue badge for a 2-3 year old who has ‘a permanent and substantial disability which causes inability to walk or very considerable difficulty in walking’.

Although this is not usually available for children under two, you can apply if your baby has a condition which means that either:

• she/he must always be accompanied by bulky medical equipment which cannot be carried around without great difficulty. These include:
  – ventilators
  – suction machines
  – feed pumps
  – parenteral equipment
  – syringe drivers
  – oxygen equipment
  – continuous oxygen saturation monitoring equipment
  – Pavlik harnesses, hip spica casts;

• or if she/he needs to be kept near a vehicle at all times to get treatment for a condition, or to be taken somewhere for treatment quickly, e.g., children with tracheostomies, severe seizures, unstable diabetes, or terminally ill children who can only leave their home for short periods and might need to get home quickly.

Council Tax Disability Reduction Scheme
This is a non-means tested reduction on your Council Tax Bill for people who:

• use a wheelchair indoors or
• have an extra bathroom or kitchen in the house for a disabled child or adult or
• have set a room aside for a disabled person, for example, using a dining room to store equipment.

In Northern Ireland there is a similar disabled person’s allowance on your Rates. Please see NI Direct: http://bit.ly/2hVhYC6
Looking after YOU...
Becoming a parent is hard for everyone, and when 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 will have added concerns and probably a lot of appointments taking up your time, and perhaps stays in hospital.

With so much going on, it can be really 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 beyond this. If you have had a Caesarean Section, this will be very important as you will not be able to lift your child for around six weeks. If there is no one around to help, contact your local Social Services Children with Disabilities department as soon as you think there might be a problem, and make a list of things you’ll need help with. Getting help as soon as you need it will help avoid distressing crises. Similarly, if your disability means caring for your baby is difficult, contact Social Services for extra help.

Family members can be anxious about looking after a baby with extra needs and can need a bit of reassurance, as well as showing how to care for your baby. But this extra help is especially needed if you have other children, because they’ll be needing you too. Share the care and communicate with your partner if you have one. Your partner may feel differently to you, and feel unsure about opening up about their fears and anxieties, or may become depressed. If you suspect, or if they indicate, they are depressed, encourage them to see their GP.

(Also, remember it isn’t always as easy to spot the signs of depression or anxiety in yourself as it is in others.) Make time for yourselves as a couple, rather than as parents.

Make sure you take care of yourself
Eating well, getting fresh air regularly, and exercise can keep your energy levels up and help relieve stress. See what support is available locally - Sure Start Children’s Centres can provide a lot of support and give opportunities to meet other parents. It will be important to conserve your energies, especially in the hectic early months. Don’t feel guilty about taking ‘time out’ to recharge your batteries - think of it as an investment as 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.

Your other children
The arrival of a new baby is both exciting and a challenge for your older children. It means less time for them, especially in the early days, and change to the family. They may have known before the birth that your baby is going to be ‘poorly’, and may have worried about what this will really mean. And if the baby has had to have surgery or an extended time in hospital, it will have been difficult to keep the family’s routine the same. The older children may have been looked after by grandparents or friends, and it is then more difficult to get back to your usual daily routine.

Try to involve your other children in caring for your baby. Even a very young child can pass cotton wool or nappies, and they can be very helpful fetching things for you.

It is also good to make sure they understand as much as is possible for their age, about your baby’s condition and what it means. 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’? Older children sometimes worry about taking your time from the baby if they are unwell themselves, and may conceal problems to ‘protect’ you. Making time to do a special activity with them may be more helpful in keeping communication flowing than sitting them down for ‘chats’, which can feel too unnatural and intense. Make sure their school knows what is happening at home, and ask to be contacted 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, do seek help as soon as possible. Your GP may be able to refer them to your local Child and Adolescent Mental Health Services (CAMHS) for support. Young Minds are a charity specialising in the mental wellbeing of children and teenagers, and can be useful in helping you work out what to do. W: www.youngminds.org.uk or Parent Helpline T: 0808 802 5544.

Grandparents
For grandparents, it is doubly upsetting that your baby has problems. For them, there is the worry about you, their child, as well as the worry about the new baby. Often grandparents feel they have to try not to interfere but then find they don’t know what is happening or understand about your baby’s condition. They may offer help with other children, perhaps, but are unsure of how they can be most help with the baby.

Grandparents can be a wonderful support to you and to your baby as (s)he grows up. Make sure they know what is going on with regard to medical and other matters, but also realise they are worrying about you. Involve them in appointments so that they know what is happening, and don’t imagine the worst! If possible, share some of your feelings so they are able to share some of theirs with you. Be honest with them if you feel they are ‘taking over’, and guide them in how best to help you.

We often get asked, ‘Is there anything we can do to reduce the chances of our next baby having spina bifida?’ . Hopefully, this information will answer some of those questions.

Neural Tube Defects (NTDs), such as spina bifida and anencephaly, can be caused by a number of different factors including genetics, some health problems in the mum-to-be, and the levels of certain vitamins in the bloodstream.

Folic acid
Since 1991, it has been known that taking extra folic acid can reduce the risk of further pregnancies being affected by spina bifida. Taking 5mg of folic acid for three months before you become pregnant and during the first three months of your pregnancy, can reduce your chances of being affected by around 70%. You can only get this higher dose on prescription from your GP, and it’s best to start taking it before you start having
sex again after having your baby. You may want to ask your GP to check your blood folate levels before you start trying; some people don’t absorb folate or folic acid well, or lack an enzyme needed to turn folate into its ‘useful’ form.

**Vitamin B12**
More recently, it has been found that low blood levels of vitamin B12 may also be a risk factor for NTDs. B12 is found in dairy products, seafood and meat, so vegetarians and vegans in particular may not get quite enough. It’s important to take Vitamin B12 with (or immediately after) a meal, as a special chemical in the stomach is made which helps it to be absorbed. Because of this, only a limited amount can be absorbed at each meal, and although you may eat a varied diet, your blood levels may be a little too low to prevent spina bifida. We recommend that women who might become pregnant should take a supplement containing at least 2.5mcg daily, three months before they get pregnant.

**Health problems**
Diabetes in mums is a risk factor for spina bifida. If you are diabetic, try to keep your blood sugar as stable as you can when trying for a baby and continue to do so in the first few months of your pregnancy. We also advise you to take the higher, 5mg dose of folic acid for which you will need a prescription.

Some medications, such as sodium valproate and carbamazepine (for epilepsy) are associated with an increased risk for spina bifida. If you are taking these, talk to your neurologist about perhaps changing to an alternative well before you start trying to get pregnant, as it may take up to a year to change safely. Don’t stop taking your medication; your own health is the most important issue! You will probably need to take extra folic acid too (the 5mg prescription dose) – talk to your neurologist about how it might interact with your other medicines.

**Overweight**
Being very overweight before you become pregnant seems to double the chances of your baby having spina bifida, as well as other conditions such as cleft lip, and premature birth. Very overweight is classed as having a BMI of 30 or above which for someone who is 5’ 5” (1.66m) is 13 stones (86kg). At the moment we are not sure why; it may be that more folic acid is needed, or it might be caused by changes to the blood from being overweight. If you can, consider losing any extra weight that you may be carrying before you conceive (don’t try to ‘diet’ once you’re pregnant). Losing weight before you get pregnant may also help you to conceive. Every day take the 5mg dose of folic acid, as well as at least 2.5mcg of vitamin B12, with a meal, three months before you begin to try, until the 12th week of your pregnancy.

**Inositol**
A small pilot study (PONTI Study) was recently undertaken to explore whether inositol, helped to reduce the chance of having a further pregnancy affected by a neural tube defect, in women who had had a previous affected pregnancy, when taken with 5mg of folic acid per day. Although the study was small, the results showed a possibility of inositol preventing some neural tube defects when taken before conception. More research is planned to find out more about this.

**Genetic Counselling**
You may find it helpful to discuss the chances of a recurrence of spina bifida with a genetic counsellor. They will look at the factors which may affect the chances (including a gene which is needed to turn the folate we eat into a ‘useful’ form), but the genetic and environmental factors are complex and there may be no conclusive answers. Your obstetrician or GP will be able to refer you if you would like this service.
Contacting Shine around the country

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This information has been developed by [Shine’s](#) Health Development Team, and approved by [Shine’s](#) network of senior health professionals.

To see our full range of information sheets go to [W: www.shinecharity.org.uk](http://www.shinecharity.org.uk)

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