Hand in Hand
A booklet for New Parents
Firstly, if your baby has arrived, we at Spina Bifida Hydrocephalus Ireland (SBHI) would like to congratulate you on your new baby. If, on the other hand, you are awaiting the arrival of your baby, we are here to support you through each step of the way.

You have just been told that your baby has Spina Bifida and/or Hydrocephalus and you may or will experience various different thoughts and feelings. Remember every baby born is an individual; if you already have children, you will know that they are all different, from their hair colouring, their personality and their abilities. So too are all children with Spina Bifida and/or Hydrocephalus, we never compare one with another.

You are going to learn a lot of information over the next days and weeks and months. You will have questions that many people cannot answer until after your baby is born. However, please know there are many people out there to support you.

Sometimes parents starting out seem to get caught up in the medical world and they can miss out on the pleasure that their baby brings. Your baby’s needs are the exact same as every other, so enjoy every moment.

Some of you will have already met your Family Support Worker (FSW) and they will continue to assist you now that your baby is born. For those parents awaiting the arrival of your baby, we welcome your calls. We provide telephone support, practical and emotional support at home or at hospital and information leaflets. You are in a new situation and will hear lots of medical terminology and we will interpret any information that is not clear to you.
WHAT IS SPINA BIFIDA?

Spina Bifida translated, literally means, “split spine”. The spine is made up of separate bones called vertebrae, which normally cover and protect the spinal cord. With Spina Bifida, some of these bones are not completely formed. Instead, they are split and the spinal cord and its coverings can protrude through a sac-like bulge *(a parent once described it like a lump of jam)* on the back covered with a thin layer of skin.

There are five different types of Spina Bifida and the effects vary enormously depending on the type. The most common types are:

- **Spina Bifida Occulta** usually a dimple, birth mark or tuft of hair which appears on the back along the spine.

**Meningocele (Pronounced men-in-jo-seal)** here the spine is split, but the spinal cord and nerves do not protrude through the split.

**Myelomeningocele (Pronounced my-lo-men-in-jo-sealing)** here the spinal cord, its coverings and nerves protrude through the split resulting in some degree of paralysis and loss of sensation below the level of the lesion. There can also be varying loss of bowel and bladder control.

The following types are less common:

**Encephalocele (pronounced en-cef-a-lo-seal)** the split occurs at the back of the skull where tissue from the brain can protrude through this split

**Anencephaly (pronounced an-en-cef-a-lee)** the brain does not develop and is not compatible with life.
HOW IS SPINA BIFIDA TREATED?

Surgery on the split (lesion) usually occurs within days of the birth of your baby. At this stage your baby will be moved from the maternity unit to a paediatric hospital for the surgery to be carried out. Your baby will then be assessed by the multidisciplinary team (see information on the multidisciplinary team) and you baby’s condition will be discussed with you. The timing of your baby’s surgery will depend on the outcome of this discussion. The surgery may be referred to as a back closure.

WHAT IS HYDROCEPHALUS?

This condition is known as “water on the brain”. This water is called cerebro-spinal fluid (CSF). It is produced in the brain and usually absorbed into the bloodstream after travelling around the brain and down the spinal cord. Hydrocephalus occurs either when too much CSF is produced or when the CSF is not reabsorbed back into the bloodstream. Therefore, CSF is retained, causing raised pressure in the brain. As baby’s skull bones have not yet developed, the pressure causes the head to increase in size. Approximately 80% of people with Spina Bifida develop Hydrocephalus.

Hydrocephalus can occur on its own, or following infection, or bleeding within the brain.
How is Hydrocephalus Treated?

Many treatments have been tried and tested in the past resulting in the most successful being the insertion for a VP (ventriculo-peritoneal) shunt. The VP shunt is a silicone tube that is inserted into the skull and drains excess (CSF) from the brain into the abdomen. The fluid is reabsorbed into the abdominal cavity.

This procedure can be carried out within days of your baby being born or at the same time as a back closure. The surgeon may decide to monitor your baby’s head size before deciding whether to insert the shunt or not.

VP Shunt Complications

Don’t panic!!!! The following complications are additional information for you to be aware of. The two most common are:

Blockage – which means that the shunt can sometimes become blocked. With babies the signs to look out for are irritability, increased temperature, vomiting, bulging/full fontanelle, sunset eyes. This usually occurs within the first twelve months of insertion. Some people have their shunts for life with no complications. If blockage occurs, surgery for revision will take place. The important thing is to get your baby checked out with your Neurosurgeon or your nearest A & E Department if feel there are any out of character changes with your baby. As parents, you will be the best judges of your baby’s well-being.

Infection – VP Shunt infection will usually show itself within a few weeks or months after surgery. Signs of this are raised temperature, tiredness, irritability, poor appetite, skin rashes around site. Each child is different and also the signs are different to each individual. If the shunt is infected it needs to be removed and an external drain inserted and antibiotics administered via this drain (intravenous antibiotics do not pass through the brain barrier).
EPILEPSY

Approximately one third of people with Hydrocephalus can have seizures at some time in their lives. A rise in intra cranial pressure due to shunt blockage may trigger a seizure. Sometimes a seizure can occur after shunt revision. It is often just an isolated incident, but some people go on to develop Epilepsy. Epilepsy is usually treated with anti-convulsant drugs and is the same for people with or without Hydrocephalus.

LATEX ALLERGIES

A number of people with Spina Bifida are allergic to latex. This is an allergy to products made from natural rubber latex. Products made from natural rubber latex usually contain a number of chemicals and some people are allergic to the chemicals rather than the latex itself.

VACCINATIONS

Vaccination is considered to be safe for children with Spina Bifida and Hydrocephalus, indeed far safer than the consequences of acquiring any of the serious diseases. Your baby will receive the same vaccinations as any other baby, providing that they are well when they are due to get them. Your Public Health Nurse and Paediatrician will discuss this with you, and answer any concerns that you may have.
THE MULTIDISCIPLINARY TEAM

Doctors will monitor your baby’s progression and will work with a number of professionals in order to help your child to reach their full potential. Along with your SBHI Family Support Worker the following team will help you to understand and guide you through your new journey.

**Paediatrician**

The paediatrician is the first member of the team that you and your baby will be introduced to. They will assess the medical needs and discuss the treatment plan for your baby.

**Neurosurgeon**

This is the doctor who will perform your baby’s surgery to close the lesion on their back and possibly insert a VP shunt. They will also monitor your baby at regular intervals as they see fit.

**Orthopaedic Surgeon**

Your baby will be referred to an Orthopaedic Surgeon to check for dislocated hips and talipies, which can occur secondary to the condition.

**Urologist**

A Urologist will review your baby’s bladder and kidney function.

**Urology Nurse Specialist**

A team of nurse specialist will work with the Urologist to support you with medical investigations and to seek the best solution for your child. The nurse specialist will monitor bladder and bowel function throughout your child’s development.
Neurologist

Your baby may be referred to a neurologist to assess nerve damage caused by the lesion and/or Hydrocephalus.

Medical Social Worker

A Social Worker will visit you while you are in the hospital and is available to accompany you when in consultations with the medical team. They can provide information on entitlements (see entitlements) and medical procedures.

Physiotherapist

A Physiotherapist will assess your baby’s limb movement and muscle tone and will perform exercises while your baby is in hospital. They will assess the movement before and after surgery and compare both. You will be shown exercises to perform at home, which will help your baby. A referral will be sent to the HSE or the Enable Ireland Early Intervention Team in your community.

Occupational Therapist

The Occupational Therapist will work alongside the Physiotherapist and will see your baby as they grow and assess for any equipment required. They may also advise you if for example your baby’s car seat needs extra padding or adaptations.
ENTITLEMENTS

Spina Bifida Hydrocephalus Ireland has had considerable contact with parents regarding entitlements and we are aware of how difficult it is for parents to access comprehensive information in relation to supports that may be available to them. The search for this information may also coincide with a time of emotional distress thus increasing the difficulty. Any queries that you may have on this topic please do not hesitate to make contact with a Family Support Worker who will in turn assist and guide you through the information and application forms.

The following is a brief outline of some areas that you can look into:

Social Welfare Payments

*Carer's Allowance* is a payment to people living in Ireland who are looking after someone who is in need of support because of age, physical or learning disability or illness, including mental illness. The Carer's Allowance is not payable to everyone, it is mainly aimed at carers on low incomes who live with and look after certain people who need full-time care and attention.

*Carer’s Benefit* is a payment made to (PRSI contributions) insured persons in Ireland who leave the workforce to care for a person(s) in need of full-time care and attention.

*Carer’s Leave* The Carer's Leave Act 2001 allows employees in Ireland to leave their employment temporarily to provide full-time care for someone in need of full-time care and attention. Since 24 March 2006 the minimum period of leave is 13 weeks and the maximum period is 104 weeks (was 65 weeks). Carer’s leave from employment is unpaid, but you may be entitled to carer’s allowance or carer’s benefit, depending on your circumstances.

*Respite Care Grant* is an annual payment made to carers by the Department of Social and Family Affairs (DSFA) in Ireland.
Health Service Executive

**Domiciliary Care Allowance** is a monthly payment made to the carer of a child with a severe disability who lives at home. In order to qualify, the child must have a disability that is likely to last for at least one year.

**Long Term Illness Card** People suffering from certain conditions, who are not already medical card holders, can get free drugs, medicines and medical and surgical appliances for the treatment of that condition. These are provided under the Long Term Illness Scheme.

**Medical Card / GP Visit Card:** A medical card issued by the Health Service Executive (HSE) allows the holder to receive certain health services free of charge. To qualify for a medical card your weekly income must be below a certain figure for your family size. Cash income, savings, investments and property (except for your own home) are taken into account in the means test. Certain people in Ireland who do not qualify for a medical card may apply for a GP (family doctor) Visit Card. GP Visit Cards allow individuals and families who qualify, to visit their family doctor for free.

**Drugs Payment Scheme** Under the Drugs Payment Scheme you have to pay a maximum of €100 a month (from January 2009) for approved prescribed drugs, medicines and certain appliances for use by yourself and your family in that month.

Revenue

**Incapacitated Child Tax Credit** can be claimed by a parent/guardian of a child in Ireland who has a permanent condition, either physical or intellectual.

**Home Carer’s Tax Credit** is a tax credit given to married couples (who are jointly assessed for tax) where one spouse works in the home caring for a dependent person.

**Tax Relief on Medical Expenses** If you pay medical expenses that are not covered by the State or by private health insurance, you may claim tax relief on some of those expenses.
THE IMPACT ON YOU: Understanding Your Feelings

Since you have received the news that your baby has Spina Bifida and / or Hydrocephalus, you may have experienced many different emotions. You may feel shocked, numb, disbelief, denial, anger or you may not even know what you are feeling.

These are all natural emotions don't be hard on yourself, try not to dwell on them but don’t apologies for them. These are all typical reactions to an extraordinary situation.

Shock

Experiencing shock may lead to a physical reaction, where you may feel faint, hot or cold. It can also prevent you from absorbing information, so don’t be afraid to ask questions and seek clarification.

Disbelief, Denial and Numbness

These are all feelings associated with grieving and in some ways you may feel like you are mourning the loss of the child you dreamed of. Grief occurs in response to loss. No two people will respond to the same loss in the same way.

Disbelief and denial serves to protect you from experiencing the intensity of this experience. Numbness is a normal reaction and should not be confused with "lack of caring". Denial and disbelief will diminish as you slowly acknowledge the impact of this loss and accompanying feelings.

Anger

This reaction usually occurs in conjunction with feelings of helplessness and powerlessness. Don’t feel as if you have to be ‘supermum or superdad’. It is OK to feel angry, angry at the world, angry at the situation, please be assured that these are all ‘normal’ reactions to a new life experience where you feel out of control.
Identify any particular triggers for your anger such as an insensitive relative and try to avoid them where possible.

Express your anger rather than bottling it up. Let off steam with someone you can trust.

Vigorous physical activity such as sport, housework or going for a walk can help to release some of the stress associated with feeling angry.

Recognise the underlying source of your anger. Awareness is the key to gaining perspective, and it may help you recognise potentially frustrating situations.

Following an angry reaction, forgive yourself, make any repairs or amends you need to make, try to let go and move on.

Try to find someone with whom you can talk that has an understanding of your situation and your sense of isolation. This can be another parent or a professional such as a SBHI Family Support Worker.

Guilt

Guilt can be a common emotion felt by parents (was there something I could have done differently?). There is no definite cause of Spina Bifida. Your baby has Spina Bifida, but that does not mean they are a lesser person, they will bring you the same joy and pleasure as any other baby.

Accept guilt as a common feeling over which we have very little control.

Let yourself feel these feelings and remember that in time they will change. These feelings can change when you bond with your baby and sometimes it can take longer. It will take as long as it takes and don’t put pressure on yourself to adhere to other people’s perception of when these feelings should change. Begin your new journey through life as a family and remember bonding is a process and does not always happen immediately, so don’t worry if you find it difficult to bond as it will develop over time.

Work through these feelings, don’t apologise for them, you are not alone. We meet parents every day who have experienced similar feelings. Talk to your friends and family if you are comfortable sharing these feelings, talk to a medical social worker or a SBHI Family Support Worker. Confidentiality and respect is always guaranteed.

While these feelings may appear negative, they are all part of the adjustment to a new situation.
THE IMPACT ON YOU: Identifying Your Needs

Although you are probably feeling overwhelmed and under pressure to “know everything now” it is important to have an awareness of your own needs. While you may feel you have very few opportunities for relaxation and recreation, failure to address your own needs can eat away at your ability to look after someone and result in stress or illness.

You might like to ask yourself the following questions:

Do I have someone I can trust to talk to about how I’m feeling?
Am I trying to get some regular exercise?
Am I trying to get enough rest and sleep?
Am I trying to eat regular meals and stick to a healthy diet?
Do I get enough breaks from the situation?
Have I got some regular times for relaxation?

Am I getting the financial support I’m entitled to?

Even at the best of times you may not be able to answer yes to all of the above, but thinking about each of these questions will help you begin to focus on your own needs.

Planning to meet your needs

This may seem an impossible task, but try to get into the habit of making time for yourself every day even if it’s only 20 minutes. This is important. Don’t feel guilty about this time – it’s for you.

Make a plan and make an agreement with yourself to stick to it. Or, if it helps, tell somebody else about your plan and try to enlist their support to help you stick with it. Think of friends and family members who might give you some respite so that you can take time out. Making your needs a priority can take a little practice if you are not used to it, but having a time in the day to concentrate on yourself is a beginning.
Tiredness

Caring for a baby with Spina Bifida and / or Hydrocephalus can be a tiring process. Worry, coupled with the emotional upheavals and the physical demands can result in fatigue.

- Eat well and try to sleep as much as possible, even 30 minutes during the day can be enough to get you going again
- Everyone has different coping styles. Learn to recognise your own. For some putting off until tomorrow what is not absolutely necessary can reduce stress. Or you may feel that keeping busy will help you to cope
- Ask for help from friends and family, don’t isolate yourself
- Give yourself permission to take some timeout to re-energise yourself
- If you have difficulty sleeping, try learning some relaxation techniques, such as deep breathing, meditation, listening to a relaxation tape or muscle relaxation

Counselling

Many parents resist the idea of counselling. They feel that they should be able to cope on their own or that the support provided by their partner, family or friends should be enough. On the other hand, parents can also feel that they have to put on a brave face for the other people in their lives and find it difficult to explore or express their feelings.

Counselling can provide parents with an outlet for difficult, heated, uncomfortable emotions. It can provide you with a safe place to explore some of your feelings about the changes brought into your lives by the birth of your child. A counsellor can also help parents to manage stress, communicate, strengthen their relationships and protect their sense of self.

Counselling has been the best thing that I’ve done. It gives me an opportunity to talk about how I am feeling, helps my marriage by giving me strategies on how to start talking together, how to approach subjects that I am too scared to ask about. My counsellor encouraged me to stop worrying into the future, to deal with today, this week. That’s what I do now.

Lee, mother of a child with Spina Bifida
Take up offers of help

When friends ask you if there is anything they can do to help, say yes. Make up a list of things that friends could do that would help. This might include such things as cooking a couple of meals, doing some ironing, looking after one or more of your children, mowing the lawns or dropping books or DVDs back to the library. Take your friends’ offers at face value. They want to help.

Reflection

Some parents find it helpful to keep a journal. It can give them a place to express all of their feelings and reflect on their day. Others find that meditation helps them to stay calm and gives them a break from the chaos of day-to-day life. Meditation can also teach parents the benefits of detachment or stepping back.

Self-affirmation

You are working hard and doing a great job. Remind yourself of this. Remember to acknowledge your talents, strengths and gifts. Allow yourself to enjoy the feeling you get when others compliment you on your strengths and skills.

Sharing your feelings

Try to be open with the people in your life about how you are feeling. Let them know about your hardships, frustrations and doubts, as well as the good parts of your day. When you open yourself to expressing how you feel, you are also allowing other people in. It can be a gateway to comfort, understanding and support.

Time with your partner as a couple

If you are sharing the parenting of your child with your partner, try to make time to do things as a couple every now and then.

Spending time alone with your partner can give both of you an opportunity to reconnect and touch base with the ‘us’ that existed before you became a family. It can also help you to recognise the ‘us’ that still exists in your everyday life.
THE IMPACT ON SIBLINGS

Although the lives of siblings are often enriched by the experience of growing up with a brother or sister with Spina Bifida and/or Hydrocephalus, they also face some unique challenges. A sibling’s level of understanding of their brother or sister’s needs will change as they grow and develop through childhood. Parents can support siblings by communicating openly and giving them an opportunity to ask questions that help them to understand their experiences. Siblings may also find it helpful to connect with other siblings by sharing their thoughts, feelings and experiences.
THE IMPORTANCE OF PLAY AND STIMULATION

As with every new born baby, the importance of play and bonding is essential. This will enable your baby to reach their full potential. Stimulation is also a very good way of helping your child to develop physical skills. When you bring your baby home from the hospital, don’t expect to start playing right away. Your baby will show no interest in toys or other objects. Their favourite thing to do is to look at your face.

The following milestones are a guide to follow as your baby grows in their first 12 months, but remember, some babies will reach these milestones in their own time and it is important not to compare children in these circumstances.

Vision

The movement of different shapes / objects will help your baby to fix on and follow the objects as they are moving. Cot mobiles and later play gyms (with the right support for your babies needs) are good to encourage focusing and following as the colours attract the baby to them.

Newborns are nearsighted and they see your face best when you are holding them for a feeding. Talk to your baby and smile at them. As they grow, you will find them engaged more often and they will start talking back in the form of coos and squeals.

In the first few months, the bulk of your play time will involve showing your baby things. In most cases, toys are used for this type of play. There are other great things to show your baby. Ordinary household objects, such as a spoon, cups, plastic bottles, fruit, vegetables or any other non toxic object you can find. Show it to the baby and name the object, “Look at the banana,” later you can add details, such as the yellow banana.
Sound

Young babies love the sound of your voice. Read to your baby every day. Babies don’t care what you are reading or even if you follow the text. You can read the newspaper, a magazine or a picture book. As your baby grows, they will start to enjoy the pictures and will try to grab the book. Board books or cloth books are good for reading with babies. They can grab and hold the book without tearing the pages.

Your baby thinks you are amazing and everything you do is wonderful. Your baby is a very captive audience and will love hearing you sing and watching you dance. Silence your inner critic and put on a CD. Hold the baby and dance around the room, singing along with the lyrics. Your baby will love it.

Head Control

By supporting your baby’s head, this will teach your baby to do the same. This can develop within the first three months. It is recommend that placing the baby on their tummy (be careful not to do this too soon after a feed though) will help to strengthen the neck muscles enough for your baby to gain head control. Remember, some babies do not like lying on their tummy so it may be useful for either parent to take time each day to lie flat on the couch and place the baby on your tummy as many times a day as possible. At this point it may be useful to have a TV or radio on to attract the child’s attention and thus encouraging them to raise their head to find the sounds.

One other option that works well is using a therapy ball (exercise ball). A larger ball is safer and less scary for the baby. Place the baby on their tummy on the ball keeping firm grip on them. Gently bounce the ball or move it forward and back as well as side-to-side. Having a mirror or another person to look at may help further.
Head Control Exercises

1. Woman sitting on a bench with a baby.
2. Woman sitting on a chair with a baby.
3. Baby lying on its side on a floor.
4. Baby lying on a bed.
5. Woman sitting on a bed with a baby.
6. Woman standing holding a baby.

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Rolling

Your baby will now be able to focus and have head control; therefore, they will begin to experiment with their body movements. Placing toys beside them can encourage this. Laying your baby on their front will help them to strengthen their upper body and enhance their mobility. Learning to roll is essential for all infants, but babies with Spina Bifida may need to use rolling for movement as crawling may be difficult, depending on the amount of muscle paralysis.

Belly to Back

Baby will begin to roll from belly to back once they push up on their hands. Place your hand under their hip and roll it back towards you if they need some help.

Another activity is to place your baby on their side on the floor. Use a rolled up blanket or cushions behind them to stop them from rolling back. Encourage playing in this position and they will learn to roll onto their tummy from the side-lying position.

Moving from place to place (Crawling)

Most babies with Spina Bifida learn to push themselves backwards with their arms to get a crawling position. However, many children will find it difficult to move forward due to leg paralysis. In this case, they may use their arms to pull themselves around on their tummy.

Movement on the floor is important – Your child will find the easiest way for them to move. Do not be concerned if this is rolling, tummy crawling or crawling even if the child is older.
**Lying to Sitting**

Your baby should be encouraged to sit as soon as they have gained some head control. If some head control has not been gained by three to four months this position should still be encouraged. Sitting will make it easier for your baby to develop an interest in their surroundings. This can be encouraged by supporting your baby to sit up while lying down by holding their arms and encouraging them to pull themselves up into the sitting position.

When your baby first starts to sit, support may be necessary. You can use pillows to support your baby against a wall or sofa. This position will improve with practice and encourage your baby to try this on its own. Remember to encourage play while your baby sits in each position.

Improve your baby’s sitting and balance by bouncing them up and down on your knees. Hold them at the hips.

As baby begins to sit by themselves stay nearby. You may need to help if they start to fall.
As your baby gets older, it is important that they are encouraged to sit with their legs straight as cross legs or “W” sitting can lessen the chances of muscle shortening.

Your baby’s milestones may be different because of Spina Bifida, but with the help of your physiotherapist, occupational therapist and, most importantly, you as parents, your child will reach their full potential.

Babies don’t need a lot of expensive toys to help enhance their development. They need time to play and have fun with you. Above all, keep the games fun and engaging. This will motivate your baby to want to play. Even more important than helping your baby develop motor skills, playtime develops a bond between you and your baby that will last for a lifetime.
PRACTICAL ADVICE

Your baby has the same needs as any other baby, play with them, stimulate them and use colourful toys to help them to achieve their developmental milestones.

Spina Bifida Hydrocephalus Ireland is available to provide information; support and advice and we are here to guide you on your new journey. You, your family or the medical social worker may contact us at any time (Please see contact details for Family Support Workers). The role of the Family Support Team is to guide and support parents who find themselves on a new path.

Purchase a notebook, write your thoughts and feelings down, but most importantly, write any questions that you have down, so you can ask the doctors or other team members when you next meet them. A diary is also useful to take note of all the scheduled appointments your baby will need to attend. It is also useful to store relevant phone numbers, so they can be easily found when needed.

Involve others in the care of your baby as you may need the support of your family and friends. Take – up any offers for baby-sitting, once they are comfortable handling your baby. You and your partner will benefit from the quality time together and your baby will be afforded the opportunity to grow socially.
QUESTIONS PARENTS FREQUENTLY ASK

Will my baby need any special clothes?

Your baby will not require any special clothing, but it is advisable to use baby grows / sleep suits that close to the front or back, rather than over the head. This may make it easier for you to dress your baby following surgery. The nurses will assist you with the care of your baby, until you feel more comfortable handling your new arrival.

Will I be able to breastfeed my baby?

Yes, the nurse or midwife will make provisions to assist you with this. Your baby may be transferred to a paediatric hospital, at which time you can express milk to be used to feed your baby orally or via a tube, if required. The nutrients in the breast milk will help the healing of your baby’s wound.

What if I can’t bond with my baby?

This is a real fear for some parents when a diagnosis of Spina Bifida and / or Hydrocephalus is made. Fear of the unknown causes anxiety so it is important that you spend time with your baby and, with the help of the nurses, you will be able to take care of your baby’s needs. Rest assured when you bond with your baby you will love them as you would any other baby.

How will I explain Spina Bifida to my other children?

Be honest with your child(ren), give an explanation that is at your child’s level, only give them the information that they need and allow them to ask questions when they need more information. It can be useful to involve your older children in your baby’s care, but also give them time for one-to-one time with you. You will have to spend some time away from the family home and it is important that their routine is kept as close to normal as possible. It is important that they have someone familiar to be there when you are busy with hospital appointments and admissions. It is also necessary for you and your partner to have quality time with your other children, as they may feel jealous of the attention your new baby is receiving.
Should I take folic acid?

Research has shown that there is a link between, the absorption of folic acid and Spina Bifida, however, it is not the only cause. Experts say that if you take 400 micrograms of folic acid daily, it decreases the risk of having a baby with Spina Bifida by 70%. However, despite taking folic acid, some babies can still develop Spina Bifida. SBHI promote that every woman of childbearing age should take the above dose. For those who have a baby with Spina Bifida, there is a history of the condition in the family, or are taking certain anti-convulsive therapy, they should take the higher dose of 5mg, which is only available on prescription from your GP.

COMMENTS FROM OTHER PARENTS

“When I was 24 weeks pregnant I was told following a scan that my baby has Spina Bifida, I was so upset and scared. I was scared I wouldn’t be able to take care of my baby, scared I wouldn’t love her, scared of the unknown. When my baby was born, she was so beautiful, but so delicate. She had surgery at two days of age, she was so tough, such a fighter. She is now in college and has given us such pleasure and we are proud of her achievements”

Mother of a 20 year old girl

“When my son was born, I was so busy and I spent so much time worrying about whether he would walk or not that I missed out on the first two years of his life. My advice to new parents is enjoy each day as it comes and don’t wrap your baby in cotton wool”

Mother of 12 year old boy

“Having the Family Support Worker supporting me through my pregnancy and after my baby was born, helped me get through a very difficult time in my life. She kept me positive when others showed negativity, clarified anything I didn’t understand, answered any questions I had honestly and was just there when I needed her. Through SBHI I have met other parents, have attended coffee mornings, seminars, fun activities and have taken so much from the care and advice I have received from SBHI”

Mother of 3 year old girl
THE FUTURE

The quality of life for a person with Spina Bifida and/or Hydrocephalus has improved over the last 15 – 20 years, with the progress in medicine, health and education systems. They can enjoy a full, active life as part of their community.

As we said before, children are all individuals, and your child will have their own strengths and weaknesses. With your help they can build on their strengths and embrace their weaknesses and accept themselves as the individual they are.

Your child will be educated like every other child, in an inclusive environment, where they will be encouraged to progress to their fullest potential. This may be with the help of a special needs assistant for their learning and/or physical needs. Our motto is to focus on their ability rather than their disability.

Many people with Spina Bifida and/or Hydrocephalus go on to further education and third level. Your support and encouragement will ensure that they reach their goals in life.
FINALLY.....THE TEN COMMANDMENTS FOR PARENTS

Take one day at a time, and take that day positively. You don't have control over the future, but you do have control over today.

Never underestimate your child's potential. Allow them, encourage them, expect them to develop to the best of their abilities.

Find and allow positive mentors: parents and professionals who can share with you their experience, advice, and support.

Provide and be involved with the most appropriate educational and learning environments for your child from infancy on.

Keep in mind the feelings and needs of your spouse and your other children. Remind them that this child does not get more of your love just because he gets more of your time.

Answer only to your conscience: then you'll be able to answer to your child. You need not justify your actions to your friends or the public.

Be honest with your feelings. You can't be a super-parent 24 hours a day. Allow yourself jealousy, anger, pity, frustration, and depression in small amounts whenever necessary.

Be kind to yourself. Don't focus continually on what needs to be done. Remember to look at what you have accomplished.

Stop and smell the roses. Take advantage of the fact that you have gained a special appreciation for the little miracles in life that others take for granted.

Keep and use a sense of humour. Cracking up with laughter can keep you from cracking up from stress.
SBHI FAMILY SUPPORT WORKER CONTACT DETAILS

You can contact a Family Support Worker directly using the contact details below or if you prefer you can email our confidential FSW email support at family.support@sbhi.ie

Mayo / Leitrim / Roscommon / Sligo / Galway
Sally Hibbs shibbs@sbhi.ie 087 939 5371

Cavan / Monaghan / Louth / Meath / North County Dublin
Hazel McGeough hmcgeough@sbhi.ie 086 819 4790

Dublin - odd number postcodes / Kildare
Edel Browne ebrowne@sbhi.ie 086 852 0616

Waterford / Wexford / South Tipperary / Carlow / Kilkenny
Doreen Costello dcostello@sbhi.ie 087 652 7175

Dublin - even number postcodes / South County Dublin
Clare Riordan criordan@sbhi.ie 086 819 4791

Family Support Communications Officer
Sarah Jacobsen sjacobsen@sbhi.ie 085 711 9062