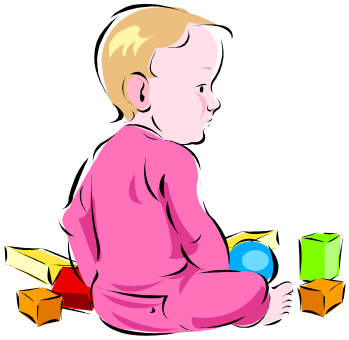
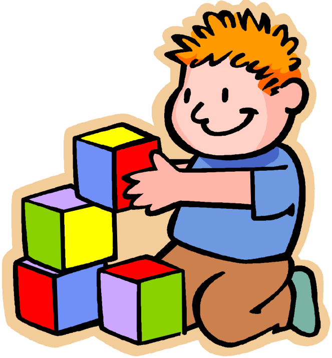
Spina Bifida Hydrocephalus
Queensland





"FROM 6 MONTHS TO 3 YEARS"

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DISCLAIMER

This booklet is designed to provide general information about the topics covered, to assist interested parties. It is compiled from information written by staff of SBH Queensland, as well as from various publications by authors not related to the Association. Accordingly, whilst the Association believes the information is the most accurate and up-to-date available, the Association accepts no responsibility for the information from other sources. There is still much to be learnt about spina bifida, hydrocephalus, and their causes and prevention. As further developments occur, the information may prove to be incorrect or incomplete. For this reason, and because the information is of a general nature, you should always obtain specific advice about matters affecting you.

Permission is granted by the publisher to post, print, and duplicate ***From 6 months to 3 years,*** whole or in part, however it will benefit families and friends of children born with spina bifida and/or hydrocephalus.

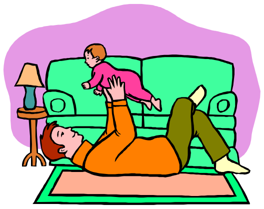
CONTENTS

NB: When you read this booklet you will find that we have varied the use of gender references by talking in some instances about *he* and *his* and on other occasions about *she* and *her*

"All through time people have loved and enjoyed their offspring"
"Baby & Child - From Birth to Age Five"
Penelope Leach (Penguin Books London 1981)

INTRODUCTION

Your baby is now six months old and part of your family life. It is probably hard to imagine life without this little person around.



Over these six months you will have grown to know your baby and all your baby's idiosyncrasies. You will know a lot about spina bifida and hydrocephalus and you will have become the expert on how these conditions affect your baby.

We know from talking to parents that many of you are also looking ahead to the future. You hear other parents talking about their experiences. What is ahead of you? How will your child be affected? How can you help?

We wrote the SBHQld booklet *Information for New Parents* as an introduction to these conditions and what was ahead of you during the first six months after your baby was born with spina bifida.

We have written this booklet *From 6 Months to 3 years* as an overview of the next few years of your baby's life. It has been written so that you can consolidate what you already know and to give you more information about aspects of spina bifida that may affect you, your child and your family during this stage of your child's development.

This booklet has been written by staff from our Association and is based on their experiences of seeing children with spina bifida and hydrocephalus at home and in the community. It is intended to complement the information about medical management that you are given by your medical specialists and therapists. We are aware that these early stages of development are the foundations for the future and have included suggestions with a view to future independence and well being.
We think it can be beneficial to hear about the experiences of others in similar circumstances and have included comments and suggestions from other parents.

Bringing up a child is the most worthwhile of jobs. It is interesting, difficult and valuable.

FROM BABIES TO TODDLERS:
MEDICAL ISSUES

i) Medical Conditions

Spina Bifida

By now you will have learnt a lot about spina bifida and how it affects your child. You will be able to identify information in this section that you know is relevant to your child. Reading this medical information may be a way of reviewing what you already know and questions may arise that you would like to follow up with your specialists and therapists.

You will probably have heard Spina Bifida described as a **Neural Tube Defect**. A neural tube defect is the term given when the central nervous system (CNS) has failed to form normally at some point between the brain and the end of the spinal cord. The term **Spina Bifida** refers to a neural tube defect involving the spine.

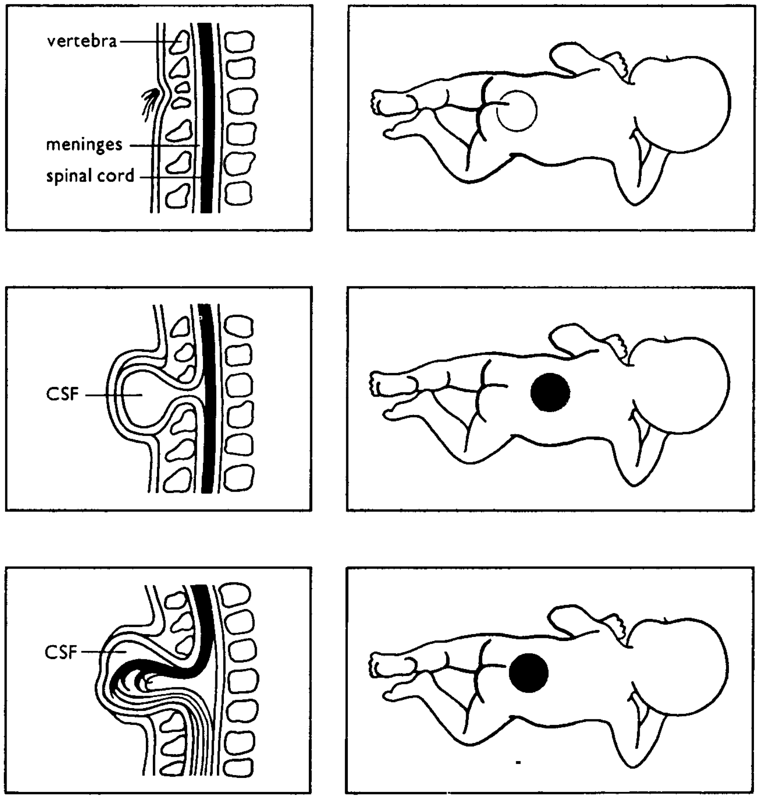
The development of the neural tube occurs very early in the development of a baby. The neural tube closes by the 28th day after fertilisation. Spina Bifida occurs at this early stage when the neural tube fails to completely close. Spina Bifida develops within the first few weeks of pregnancy when most women don't realise they are pregnant.

What are the different types of Spina Bifida?

Spina Bifida can present in a number of different ways depending on the extent the neural tube has failed to close early in development. Your paediatrician will have described the type of spina bifida your child has in one of the following ways:

- **Myelomeningocele** is the most severe form. The spinal cord and covering (meninges) protrude through the opening where the bones have not fused. No skin covers the lesion. The spinal cord has been damaged and hydrocephalus is also usually present.

- **Meningocele** refers to incomplete closure of the vertebral column, where the underlying spinal cord development is usually normal, but the meninges (covering of the spinal cord) have herniated through the opening. If the spinal cord is undamaged there are usually no long term problems. If you are concerned at any time about your child's function you should consult your doctor.
- **Spina Bifida Occulta** refers to incomplete closure of the vertebral column where the spinal cord and covering (meninges) do not protrude and are usually therefore not damaged. There is skin covering the deformity and it is often not detected unless an X Ray of the back is taken for some reason. In some cases there may be a significant mark on the back- patch of hair, dimple, birthmark. At times children do have problems- your doctor should be consulted if you have any concerns.
- **Lipoma** refers to a fatty mass that occurs at some point along the spinal column, which may contain spinal cord and nerve tissue entangled within it. It is usually covered with skin. Where there is damage to the spinal cord or nerve roots some paralysis/loss of sensation will occur.



From the top: Spina Bifida Occulta (top picture), Meningocele (middle picture), Myelomeningocele (bottom picture).

Hydrocephalus

The brain produces cerebrospinal fluid (CSF) a clear, saltwater-like liquid which flows in a circuit through the brain cavities (ventricles) and over the surface of the brain and spinal cord and is continuously reabsorbed by the body.

This fluid
- protects and hydrates the brain
- carries away wastes from brain cells
- contains important chemicals and nutrients.

Hydrocephalus occurs when there is an obstruction to the flow of CSF and fluid builds up within the cavities of the brain. This fluid build up causes pressure on the brain tissue and bones of the skull.

Most children with myelomeningocele will have Hydrocephalus. It is considered to be linked to Arnold Chiari Malformation.

Often the collection of fluid does not become severe until after the back has been closed so it may not become evident until the first few days or weeks after your child's birth.

How is Hydrocephalus detected and monitored?

In an infant the plates of the skull are not yet fused together. The plates are therefore able to shift and accommodate the excess cerebrospinal fluid and thus lessen the amount of damage to the brain. As fluid accumulates the head circumference increases. Hydrocephalus is detected and monitored through regular measurement of your child's head circumference.

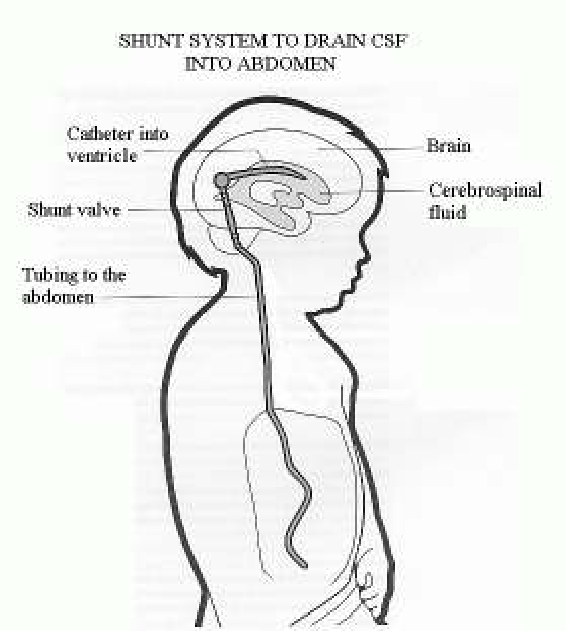
Hydrocephalus can also be detected through MRI (Magnetic Resonance Imaging).

How is Hydrocephalus treated?

Hydrocephalus is usually treated by insertion of a shunt. If your child has been diagnosed with hydrocephalus they are likely to already have had a shunt inserted.

A shunt is a device that drains (via a one way valve) excess CSF from the brain to another part of the body (usually abdominal cavity).

Although a shunt generally works well, it may stop working if it disconnects, becomes blocked, or it is outgrown. If this happens CSF will begin to accumulate again.



Signs and symptoms will vary with age and from individual to individual. You should seek prompt medical attention if you observe your child experiencing any of the following symptoms.

- full or bulging fontanelle (soft spot)
- enlarged head size
- swelling or redness along the shunt tract
- irritability
- drowsiness
- vomiting
- change in appetite
- prominent veins on scalp
- fever
- headache
- loss of previous abilities
- seizures

If your child has mild hydrocephalus they may not have a shunt. You will still need to be aware of these signs as you will need to seek medical attention if you are concerned your child's hydrocephalus is progressing.

Arnold Chiari Malformation

Incomplete closure of the neural tube early in development can impact on the development of the entire central nervous system. **Arnold Chiari Malformation** (also known as Chiari II Malformation) is an anomaly of the brain which occurs in almost all children born with myelomeningocele who have hydrocephalus. Your child may have had a CT scan or MRI to detect whether they have this condition.

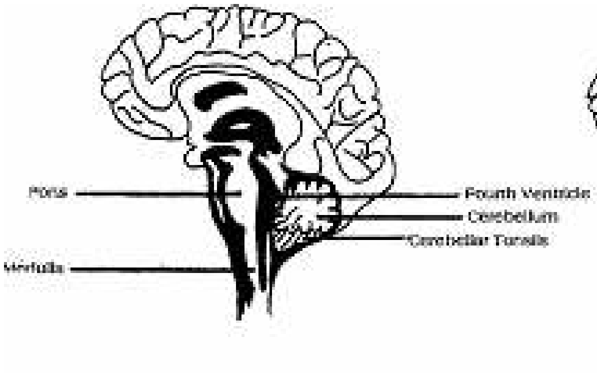
How does Arnold Chiari Malformation affect your baby?

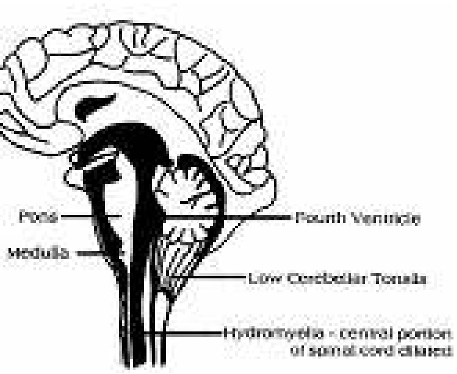
Arnold Chiari Malformation mainly involves the lower brainstem and lowermost portion of the cerebellum, but the anatomy of the whole brain is affected.

The brainstem is the origin of many of the nerves which control the heart, breathing, blood pressure and help control swallowing, sneezing and coughing.

The cerebellum controls the maintenance of posture and coordination of muscle action to produce precise, coordinated movements.

When Arnold Chiari Malformation is present the brainstem is elongated and displaced into the opening of the base of the skull and top of the spinal canal. The brainstem, cranial nerves and the lower portion of the cerebellum may be stretched or compressed and any of the functions controlled by these areas may therefore be affected. The malformation also blocks the flow of cerebrospinal fluid causing hydrocephalus.





Anatomy of Normal Brain

Anatomy of the Chiari Malformation

Many children with Arnold Chiari Malformation have no obvious symptoms. Some children however do develop complications.

Symptoms of Arnold Chiari Malformation in babies may include

- stridor (a harsh croupy noise associated with breathing)
- weak or absent cry
- arching of the neck backwards
- breathing difficulties
- colour change
- failure to thrive
- feeding or swallowing difficulties
- hypersensitivity to objects in the mouth

As your child develops the symptoms may present differently.

Symptoms of Arnold Chiari Malformation in childhood may include

- arm tightness or weakness
- stiff neck
- feeding or breathing difficulties
- increasing problems with eye hand coordination.

You should contact your Doctor promptly if your child has any of these symptoms. Symptoms may be related to faulty shunt function, poorly controlled hydrocephalus or Arnold Chiari malformation.

ii) Other Neurological Issues

Tethering of the Spinal Cord

You may already be familiar with the term **tethering**.

Normally the spinal cord moves freely up and down within the spinal canal. Scar tissue often prevents this in children with spina bifida- the spinal cord is almost always tethered or 'stuck down' at the site of the lesion. Children with a lipoma can also have problems with tethering if there is nerve tissue entangled within the fatty mass.

While tethering can occur in babies, symptoms are more likely to develop later in a child's life particularly when they are undergoing periods of rapid growth. Significant stretching of the spinal cord and restriction of blood flow may occur which may cause additional nerve damage and loss of function.

Tethering is usually detected by an MRI. As well as diagnosing tethering the information an MRI provides will assist your doctor in planning the best course of action for your child.

What are the symptoms of a tethered cord?

Often tethering of the cord does not cause any symptoms and medical treatment is therefore not required.

Symptoms of a tethered spinal cord may include

- Loss of muscle function/weakness.
- Increased muscle tone. You may notice some of the muscles in your child's legs feel tighter.
- Back or leg pain.
- Loss of sensation. You may notice that your child's is not able to detect touch or hot and cold sensation on parts of their lower limbs that they were previously able to.
- Rapid progression of curvature of the spine (scoliosis).
- Changes in bowel or bladder function (changes in toileting abilities).
- Progressive foot deformity.

If you notice your child has any these symptoms you should consult your doctor.

Your child may require an operation to 'detether' the spinal cord to prevent further damage.

Syrinx

Syrinx refers to an abnormal fluid-filled space found within the spinal cord.

It generally occurs in the cervical region or thoracic region of the spinal cord.

Syrinx's are commonly found in children with myelomeningocele. They are often asymptomatic however can cause various signs and symptoms.

Symptoms of a syrinx may include

- Muscle weakness in the upper limbs, trunk or lower limbs. You may notice a change in your baby's play skills.
- Sensory disturbances
- Increased muscle tone. You may notice that some of your child's muscles feel more tight.
- Rapidly progressing scoliosis.
- Changing bladder function
- Pain

If you notice any of these symptoms please consult your Doctor.

A syrinx may be detected if your child has an MRI of the spine.

Your doctor will first ensure your child's hydrocephalus is adequately controlled. If your child has no symptoms from the syrinx no treatment may be recommended.

iii) Effects Of Spina Bifida

Muscle Function

The level of your baby's lesion will affect what muscle function they have in their lower limbs.

What does 'level of lesion' refer to?

Level of the lesion refers to the position along the spinal cord where the development of the Spinal Cord has been affected.

What determines the loss of function?

Information is relayed between the brain and various parts of the body via the spinal cord and peripheral nerves. This information can not be relayed when the development of the spinal cord is affected as it is in spina bifida. There can be damage to the nerve supply that affects both motor function and sensation.

What is the best predictor of function?

An assessment of the muscle strength in your child's lower limbs is the best predictor of the potential for walking and development of mobility skills. In general the lower the level of the lesion the more muscle function and sensation your child will have in their trunk and legs.

How does the level of lesion affect function?

The spinal column consists of 33 vertebrae-

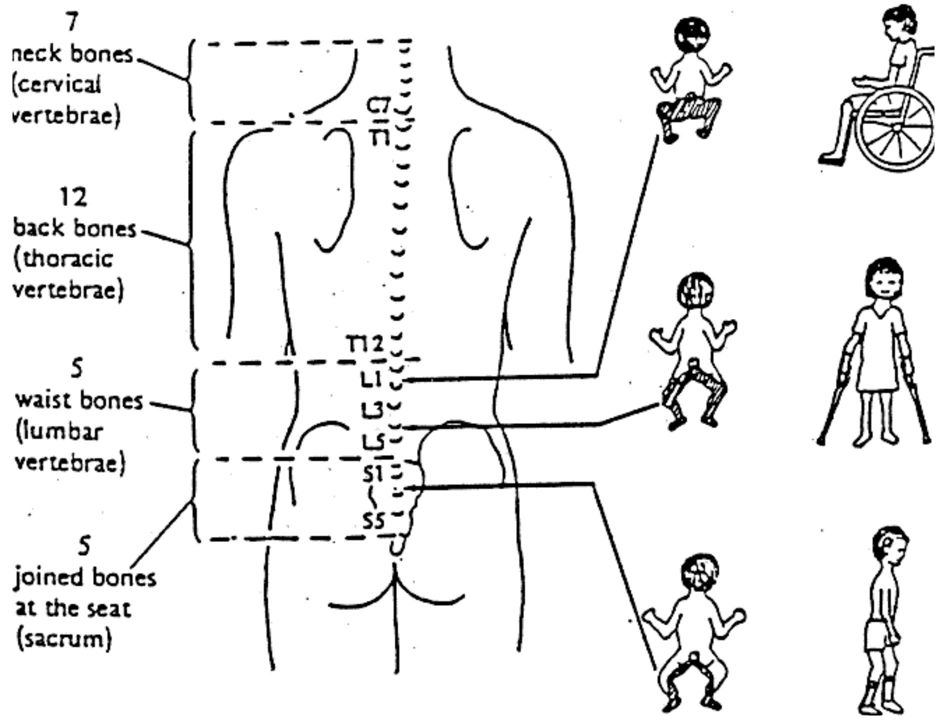
- 7 cervical (neck)
- 12 thoracic
- 5 lumbar
- 5 sacral (joined to form the base of the spine) and
- 4 bones joined to form the coccyx (tail bone).

The most common site of a lesion is in the lumbar or sacral areas.

Bones of the Backbone (spine)

Level of lesion

Probable amount of disability



Different spinal cord levels relay messages to and from different parts of the body-

- thoracic spine from the chest, back and stomach
- upper lumbar from the hip and thigh
- lower lumbar from the knee, front of the lower leg and parts of the feet
- sacral nerves from the feet, calves, buttocks, bladder and bowel.

Children may have either

- complete loss of muscle function and sensation **below** the level of their lesion or
- partial loss of muscle function and sensation **below** the level of their lesion.

Nerve supply above the lesion will not be affected and there should be normal movement and sensation in the muscles and skin supplied by these nerves.

Sensation

Your child may have partial or complete loss of normal skin sensitivity to pain, touch and temperature in areas of the lower limbs, pelvis and trunk. Your child's sensation will be affected in a similar distribution to the loss of motor function and therefore he may not be aware of normal warning sensations. **If your child cannot feel pain, he will not remove himself from danger.** This becomes particularly relevant when your child begins to become more mobile and begins to explore different areas of your house and garden.

Bladder Function

Children with spina bifida can often have problems with bladder function. The bladder receives innervation from the lowest section of the spinal cord (sacral level) and is therefore often affected. You may have heard this referred to as a neurogenic bladder.

Spina bifida usually results in children experiencing reduced sensation or an absence of feeling that they need to go to the toilet. Incontinence can be either partial or complete loss of voluntary urination, usually depending on the level of your child's lesion.

Two types of bladder function problems can result –

- The bladder muscles are weak and unable to contract to push urine out. The sphincter muscles are also weak and unable to hold urine in the bladder.

- The bladder muscles contract or spasm uncontrollably. Urine cannot be stored in the bladder, but is pushed out immediately.

Bowel Function

Most children with spina bifida have damage to the nerves that control and provide sensation to the muscles of the bowel. The degree of bowel incontinence varies greatly depending on the level of your child's lesion and amount of damage to the nerves. This nerve damage may result in the following –

- Your child's anal sphincter muscles may be weak and cannot hold the faeces in the bowel
- Your child's bowel muscles which move faeces through the bowel are weak, resulting in dry hard stools or constipation
- decreased sensation means it may not be possible for your child to feel when his bowel is full and go to the toilet
- the stomach and pelvic muscles are weak, again contributing to constipation

You will find information about managing your baby's bladder and bowel routine in the Toileting Section of "Caring For Your Baby At Home".

iv) Medical Follow-Up and Clinic

Routine Medical Care

Your baby will have medical concerns that are common to all children and will need to receive general medical care from your family General Practitioner.

Children with spina bifida and hydrocephalus will have the same illnesses as other children and will recover with the same care. They are not more prone to common illnesses.

Spina bifida and hydrocephalus does not interfere with having the recommended series of childhood immunizations. Immunizations are an important way of maintaining health and of avoiding diseases and possible complications. You may need to schedule immunizations around any medical procedures that have been recommended for your baby.

Sometimes parents become concerned because the symptoms they have been told to look out for, such as for shunt failure or for urinary tract infections, are similar to the symptoms for colds, influenza and common childhood illnesses. Your General Practitioner will help you assess the significance of your child's symptoms.

We hope you have a General Practitioner who is understanding of your baby's condition and who is easy to talk to. Parents tell us how important it is to have a supportive GP who works closely with the specialist doctors.

Specialist Care

You will now be in the routine of regular specialist medical follow up.

There is no cure for spina bifida and hydrocephalus. These are lifelong conditions.

Increased medical knowledge and early medical intervention have continued to improve the management of these conditions.Your baby will have regular appointments with a number of specialists to monitor ongoing health and development, to monitor for complications from spina bifida and hydrocephalus, and to discuss management.

You may have arranged private medical care with the medical specialists or your baby's medical care may be managed through one of the spina bifida clinics held at the 2 major children's hospitals in Brisbane.

A Paediatrician will oversee your baby's medical care and will work with a multidisciplinary team who look after your baby's specialized needs.

A Checklist of some of the things that your Paediatrician will be keeping an eye on:

- Growth percentiles
- Head circumference
- Immunizations
- Chewing and swallowing
- Nutrition and growth
- Hearing
- Vision
- Developmental Progress
- Pressure areas
- Allergies
- Shunt function
- Development of the spine
- Ultrasound of the kidneys
- Bowel and bladder function
- Occurrence of Urinary Tract infections

Hospital Clinics

The Royal Children's Hospital and the Mater Children's Hospital in Brisbane have Spina Bifida Clinics. There are slight differences between the 2 clinics but they are set up along similar principles. The clinic at The Royal Children's Hospital is called a Spinal Clinic and is held fortnightly on Fridays. The Mater Children's Hospital Spina Bifida Clinic is held twice a month on the first and third Wednesday of each month.

Multidisciplinary clinic teams

The clinic teams are made up of Specialists such as a Paediatrician, Urologist, Neurologist, Orthopaedic Surgeon, Specialist Nurse and physiotherapist. Clinic visits may also involve extra appointments such as urology tests and fittings for splints. Referrals to other clinics may become necessary to address your baby's individual needs.

Each member of the team has a slightly different area of expertise. You are also an important member of this team which works together in the best interests of your baby's health. It is important that you feel comfortable to ask questions and to discuss any concerns.

Appointments and tests are coordinated on one day where possible. This helps the team to work together and reduces the number of hospital trips for you. Families from outside Brisbane may need to come for more than one day to address all the medical needs for their baby. The hectic clinic days can be very long and tiring. Parents tell us that they become well organized so that they can cope best with these days.

A Clinic Coordinating Nurse (CCN) organizes each clinic. You can telephone the CCN to make an appointment with any of the specialists, to make changes to your appointments, or to discuss any concerns that you might have. It is a courtesy to telephone if you are unable to attend your appointments or if you are running late.

Clinics are an important time for the SBHQld team to keep in touch with children and families. SBHQld social workers and therapists

- ***Attend** each clinic and organize a room with tea and coffee for parents to use as a "base" during the clinic*
- ***Support** families who are meeting lots of doctors and therapists*
- ***Network** by linking families*
- ***Bring** a community focus which can influence medical decisions*
- ***Contribute** to a mutual exchange of current information relevant to spina bifida and hydrocephalus*

Families from rural and regional Queensland mostly attend clinics in Brisbane. The Queensland Government provides a Patient Transit Scheme to assist patients with the costs of traveling to Brisbane to see specialist doctors. Under this scheme, those living further than 50 kilometers from a specialist hospital may claim travel and accommodation expenses. Accommodation is available close by both hospitals.

TIPS - IN CASE OF EMERGENCY

Keep a health diary – which records a brief history of your baby's condition –

Accurate diagnosis
Clinic appointments
Specialists' names
Operations,
Illnesses
Immunizations

This will help you if you have to present to a hospital or other medical facility in an emergency. It will also help the doctor or nurse who doesn't know your child and is being asked to assess your baby in an emergency.

CLINICS

Impressions from parents

- *Hectic and very draining, although good to see other SBH families and sometimes get advice.*
- *Overwhelming. Didn't know anyone, or what to expect. Didn't even know it was a "Clinic", just thought we had an appointment! We met a lot of people and they were all friendly.*
- *I thought I would get angry at whatever was said about myself or my child's progress as I wasn't very positive, but soon found myself getting a great deal of comfort out of the day… although it was long!*
- *Clinic is a great way for the specialists to get to know your child and keep on top of their health issues. I enjoyed talking to the parents and learning more about what to expect as time goes on.*
- *In our case, Hospital Clinic didn't work. Going to a private Paediatrician who liaises with the Urologist cut down on the stress of medical appointments immeasurably. My suggestion is to explore all options and don't blindly accept the status quo.*

We know that parents of children with spina bifida and hydrocephalus are often very well organised, so we asked them what they did to get the most out of clinic.

- *At home I write down questions as they arise in my diary, then revise the list the night before on one page with questions under the names of each specialist. If you don't, you'll forget, even with your best intentions to remember everything.*
- *Ask questions, take the opportunity to talk to other parents of children with Spina Bifida. Really get involved with the children's doctors. Get to know them. Write everything they say down in a book, so you remember.*

…. and how they prepared for the whole day.

- *Pack at least one nappy for each specialist visit and add the usual five (number of) nappies to that for the day. Pack food and drink the night before for the whole day in case we are delayed in Brisbane. Put out clothes the night before and have the car packed with diary and questions. Take a loving grandparent or friend for helping, support and company.*
- *Pack a nice lunch for us to share, as well as books and toys. Explain to your child as best as possible what we will be doing.*
- *Pack the night before. Talk to husband about the appointment, what to expect and what we need to find out.*
- *Be aware that the clinic may take a whole day and cancel any other things you may have planned for the day so as not to become disappointed or become impatient.*

Hospital admissions

Children with spina bifida and hydrocephalus can have many hospital admissions. It is most helpful for your baby if you can approach hospital admissions in a practical and positive way.

How do you prepare your child?

- A young child needs only a few hours of preparation before going into hospital. They will trust you, their parent and "go along with you"
- It can be helpful to them to take a favourite toy for familiarity
- Let them know that you will be there too
- Encourage a positive relationship with the doctors and nurses.
- Give little, but clear and honest, information about the reason for admission into hospital
- As he gets older, your child will need more information and explanation about procedures and hospital admissions.
- The admitting doctor and nurse specialist will help guide you with appropriate information for your child.

If your child is admitted to hospital, accommodation is provided by the hospitals so that one parent or adult support person can stay in the hospital with the child 24 hours a day.

If we are aware that a child is in hospital, someone from the SBHQld team will visit when possible. We often visit children in hospital on the same day as we attend spina bifida clinics.

CARING FOR YOUR BABY AT HOME:

i) Feeding and Nutrition

Babies with spina bifida often grow more slowly at first and then have a greater chance of becoming overweight when they are older. You can help your baby grow and be healthy by offering nutritious food right from the beginning.

Breast and Bottle Feeding

Babies begin life by receiving all of their nutrition through breast or bottle-feeding. When they are born they are able to coordinate sucking with swallowing and breathing. The trachea (windpipe) is covered over during swallowing to stop fluid or food entering the lungs.

If a baby's pattern of sucking, swallowing and breathing is poorly coordinated or weak, her nutritional intake may be reduced. She could also be at risk of developing aspiration pneumonia, which is caused by fluid or food entering the lungs. Some children with spina bifida and hydrocephalus, particularly those who have been diagnosed with Arnold Chiari Malformation, may experience such difficulties.

Common signs, which can indicate problems swallowing food or fluid include:

- frequent coughing during feeding;
- recurrent temperatures following meals;
- slow feeding;
- poor weight gain; and
- chronic chest infections.

While these are important signals to look out for, and may indicate a change in neurological status, it must be remembered that many children with spina bifida and hydrocephalus will never have these difficulties. If your child does appear to suffer from these symptoms at any time, help should be sought from your paediatrician, speech pathologist, and dietician.

Starting your baby on Solid Foods

Learning to eat solid food is an important step for all babies. It will take several months for your baby to learn the necessary skills to manage solid foods. She will need to get used to new tastes and textures to help her enjoy a range of foods later on.

Solid foods are usually introduced to babies, including those with spina bifida and hydrocephalus, at around 5 to 6 months of age. Some babies will even be ready for solids before this, at about 4 months. At this age only smooth, semi solid purees are usually tolerated. Babies are able to accept small spoonfuls, but will often lose some from the front of their mouths. As they experience solids more and more, this eating pattern will mature and mealtimes will become less messy!

The ideal first food for babies is iron fortified baby rice cereal. It can be mixed with expressed breast milk, infant formula or water and fed to your baby with a small soft spoon. Start feeding one tablespoon once a day and slowly increase this amount to two tablespoons given twice daily. Once your baby is eating rice cereal easily, they are ready to try other solid foods. You might like to try pureed vegetables or fruits. Babies enjoy the natural tastes of foods and it's not necessary to add any sugar, salt or spice.

Trying Lumpy Solids and more

By 6 months babies can begin to tolerate soft lumps mixed in with their puree. Around 8 months of age you can start including yoghurts, custards, cereals (e.g. weetbix), and pureed meats. When offering a new type of food, always use this for a few days in a row, before offering another different food. This will help your baby to get use to the new texture and taste.

Between 9 and 12 months babies are managing lumpy or mashed solids without too much trouble. Soft finger foods can also be introduced leading to greater independence at mealtimes. Foods such as rusks, hard, dry toast and biscuits, and peeled, soft, fresh fruits (such as banana) are ideal.

Children with spina bifida and hydrocephalus sometimes have problems moving from smooth to lumpy solids. This can be related to a general hypersensitivity to new textures. Children with Arnold Chiari Malformation can have distorted oral sensations, which causes extreme reactions to changes in tastes, temperatures and textures. If your baby is having persistent difficulties accepting a wide range of textures or if she appears to be having trouble swallowing any type of food or fluid, a feeding assessment by a speech pathologist is recommended. Assessment will help identify the cause of the feeding problem and different strategies, which may be used to help your baby.

ii) Positioning your baby

All children need a wide variety of positions, movements and activities to allow them to develop. Some children with spina bifida may have more difficulty attaining different positions or maintaining those positions for play. Therefore, a little extra attention may need to go into this area.

While your baby may lie on her back to sleep it is very important that she has plenty of time on her tummy when awake, for rest and for play. This is important to help develop strength in neck and back muscles, and in arms and shoulders, as your baby learns to lift her head and prop on arms. Some extra equipment such as a roll or wedge may be helpful if this is difficult for your child.

Tummy time is also very important to help develop normal head shape in all children. In addition, children with shunts sometimes prefer to lie with head to one side away from the shunt. Active encouragement to turn the head both ways is very important.

iii) Baby Massage

Bathing and massaging your baby can be an enjoyable experience for both you and your baby. Bathing is often a great way to settle your baby as long as he is not too hungry! Warm water will generally be more relaxing for your baby.

Give your baby play time on both his back and tummy so that he can work different muscles. Make sure you have your baby well supported and use gentle swaying movements through the water.

A good time for massaging your baby is after the bath, when your baby is happy and when you have time to relax and both enjoy the experience.

Choose a place where it is warm enough to undress your baby and where you both can be comfortable. You may find playing music helps you and your baby relax.

Position your baby on your lap facing you. This is a lovely position for you to engage your baby. Massage helps teach your baby about touch. Lotion or oil will help you to keep contact with your baby's skin and allow your hands to glide over his body.

Begin at your baby's head and gradually move down his body. Glide your hands slowly down your child's limbs and trunk. Guiding your baby's hands to touch parts of his body such as legs and trunk will help to develop body awareness.

As you become more relaxed and confident with your handling you will notice that you are able to be more responsive to your baby.

iv) Your Babies Skin

Your child may be unable to feel pain, touch and temperature in areas of her lower limbs, pelvis and trunk, and therefore be unaware of normal warning sensations. **If your child cannot feel pain, she will not remove herself from danger!** This will be particularly relevant when your child begins to become more mobile and begins to explore different areas of your house and garden.

Three common problems are-

- Burns – e.g., Sunburn, hot water, metal buckles, car seats, hot drinks, carpet burns
- Scrapes – e.g., When crawling or pulling across rough surfaces
- Pressure areas- caused by prolonged pressure on one area e.g., from splints. Any red area that disappears within 30 minutes is generally not a problem however if it persists it requires attention.

Care of skin problems requires prompt attention as pressure areas can develop into very nasty sores if they are not treated early and effectively. Treatment must always involve removing the pressure.

Prevention of skin breakdown is of vital importance. Problems can be prevented by –

- Wearing shoes and socks particularly when outdoors
- Wearing long pants where practical
- Always checking for hot surfaces
- Being aware of the dangers associated with loss of sensation
- Being wary of hot water (e.g., from dripping taps, temperature of bath etc).
- Wearing sunburn lotion and protective clothing
- Regularly checking your child's skin for signs of pressure, redness or breakdown
- Being wary of rough surfaces (e.g., rough concrete).
- Becoming aware of the areas of your child's body that lack full sensation and guarding these areas from injury

v) Toileting

What can you do to Manage the Urinary System?

During the first two years of life it is essential that your child's urinary system (kidneys, bladder, urethra and ureters) remains *healthy*. Urinary tract infections are common in children with a neurogenic bladder. Once your child reaches 2-3 years of age (depending on his individual level of readiness), it is time to begin toilet timing and training.

Some common techniques and management strategies may be recommended from an early age. Your Urologist will discuss various urological tests that may be performed in the early years of your child's life. These include Urodynamics, Ultrasound, MCU and DMSA.

- **Clean Intermittant Catheterisation** involves the insertion of a clean, non-sterile catheter through the urethra and into the bladder to drain the urine, usually every 3-4 hours. Your doctor may encourage this to help expel residual urine from the bladder, and prevent reflux and enlargement of the kidneys. It is a relatively simple skill and children are encouraged to become independent during early primary school.
- Your child may be prescribed **medication** to relax bladder wall spasms and help to dry up the bladder e.g. Ditropan. Other medications (antibiotics) are important in clearing and reducing the effects of *urinary tract infections*. Some parents use cranberry juice as a more natural option to help prevent the reoccurrence of UTIs.
- **Surgery** can be performed later on if other more conservative methods of bladder management are not sufficient.

What can you do to Manage Bowel Function?

Bowel incontinence does not present as an issue until the child gets to an age when 'toilet-training' would typically happen. Once your child reaches 2-3 years (depending on his individual level of readiness) it may be time to begin addressing bowel continence. Clinic Specialists will look at a range of techniques to manage incontinence. Strategies such as toilet timing and bearing down may be used. This involves regularly sitting on the toilet and using pushing techniques. A diet high in fibre, plenty of fluid intake and regular exercise is essential for a healthy bowel. If bowel movements cannot be regulated with diet, fluids and regular toileting alone, it may be necessary to use one or more of the following techniques to help the bowel empty completely and at a predictable time -

- *Medications and supplements* can be given to change the consistency of the faeces moving through your child's bowel, to allow it to be emptied out of the bowel. For example, Metamucil adds bulk to the faeces, Senokot provides a laxative effect, and other medications stimulate or slow down bowel movements. Your Paediatrician or Urologist will determine whether these would be beneficial for your child
- *Enemas* involve faeces being washed out of the bowel through the anus
- *Surgery* may be performed later on if other more conservative methods of bowel management are not sufficient.

Constipation

Constipation is common in children who have a neurogenic bowel. Constipation occurs when the stool is unable to be removed from the body. It becomes hardened because the water it contained is absorbed back into the body while it is sitting in the large intestine.

Breast feeding tends to keep your child's stools soft and reduce constipation. It may be worth considering continuing to breast feed as long as possible to encourage a healthy bowel. If you do change to formula and your child's stools harden, contact your Paediatrician for advice on stool softeners. Severe constipation (no bowel movement for 3-4 days) requires immediate medical attention.

Contacts for Managing Bowel and Bladder Function

- Your *Paediatrician* is responsible for overseeing all areas of your child's medical needs. This includes bladder, and particularly *bowel* function.
- Your *Urologist* is a Specialist responsible for managing your child's *bladder* function. He may also be involved in bowel management, particularly if surgery may be required.
- Your *Stomal Therapist* is a trained nurse specialising in toileting, stomas and wound / skin care
- Your *Occupational Therapist* at Spina Bifida Hydrocephalus Queensland can provide general information on bowel and bladder function and management, as well as information and resources on toileting
- Your *dietician* is able to provide individualised dietary information to maintain a healthy bowel and bladder

Royal Children's Hospital, Brisbane

- Urologist / Paediatrician 3636 7399 (Spinal Clinic supervisor)
- Stomal Therapist 3636 7776

Mater Children's Hospital, Brisbane

- Urologist / Paediatrician Ph: 3163 1812 or 3163 8915 or 31639828 (Spina Bifida Clinic supervisor)
  Stomal Therapist Ph: 3163 1812 or 3163 8915 or 3163 9828

SBH Queensland

- Occupational Therapist 3844 4600

vi) Latex Allergy

Research has shown that people with Spina Bifida have a high incidence of allergy to natural rubber latex. This tends to be as a result of frequent and extensive exposure to natural rubber latex products early in life.

Natural rubber latex is the rubber that has been manufactured from the sap of the rubber tree. Because it is a plant product it also contains a number of proteins, two of which Researchers believe are involved in the development of the allergy.

Allergic reactions usually occur after exposure to products that are made by dipping such as

- Gloves
- Balloons
- condoms

The symptoms of natural rubber latex allergy may include

- redness/rash, swelling or itchiness at the site of contact on the skin
- hayfever type symptoms such as itchy and swollen eyes, runny nose and sneezing
- Asthma like symptoms such as chest tightness, wheezing, coughing or shortness of breath
- Breathing difficulties/respiratory distress

The most severe reactions occur when the allergens make direct contact with moist surfaces such as the mouth, nose, throat, vagina, rectum or internal tissues during surgery.

Although uncommon, some people can have a potentially life threatening reaction called anaphylaxis or anaphylactic shock. The symptoms are

- difficulty breathing
- severe rashes
- nausea
- drop in blood pressure
- loss of consciousness

It occurs within minutes of exposure and requires an injection of epinephrine (adrenaline). People at risk will be given an epi-pen by their doctor to carry with them.

You should avoid exposing your child to products containing latex so as to prevent a reaction occurring or to reduce the likelihood of your child developing a sensitivity to latex in the future.

Medications are available to alleviate the symptoms if an allergic reaction does occur. If you suspect your child has an allergy then you should talk to your doctor.

Rubber looking products could be made from natural rubber latex, synthetic latex or other types of rubber. It is only products made from natural rubber latex which are of concern. It is often difficult to differentiate so check labels of products or ask manufacturers if necessary. Often substitutes to rubber are available e.g. products made from silicon or vinyl.

Some products used by infants contain latex. Some of these include-

- Pacifiers/Dummies and teats- silicon products are available (some Gerber and Evenflo brand products)
- Balloons- substitute with foil type
- Bandaids- Johnson and Johnson brand is latex free except for the round ones in the shapes packet
- Disposable Nappies- Huggies, Depends, Tena, and Kimberley Clark are latex free
- Swimming goggles and caps- some of the Zoggs brand are latex free. Check the label.
- Elastic fabric and underwear- elastic webbing often contains latex, but elastic fabrics such as Spandex and Lycra do not.

You should ensure that your child's doctor and dentist are aware of the risk of latex allergy so that vinyl gloves can be used where necessary.

FROM BABIES TO TODDLERS: PLAY AND DEVELOPMENT

Six months to 3 years is a time of rapid physical development, learning of skills, exploring and striving for autonomy.

The sequence of development tends to be the same for most children though children may achieve their developmental milestones at different times.

This sequence of physical development is one of gradually gaining muscle control down the back – from head control, propping on tummy, gaining control of back for rolling, sitting…
… When she is able to balance or sit, your child will have use of her hands for play.

This sequence is true for most children with spina bifida. A diagnosis of spina bifida might mean your child's development is at a different pace from other children and there may be some functions she cannot master but her development will generally follow the same pattern as for all children.

The presence of hydrocephalus can mean that some areas of development are more difficult to achieve and may affect your child's ability to be self- motivated.

The difficulty for her – and for you – is that her disability may mean she cannot naturally move and explore in the way other children do.

This may become a secondary handicap for her. If she is slower to move or is impeded in her ability to explore and to get about, she may be slower to talk and to learn new ways of thinking.

Babies spend their time practicing for each stage of development. They learn through play and by exploring the world around them. They instinctively enjoy movement for its own sake. If their learning about the world is impeded or slower, it will still happen and you can help your child go through the different stages. Therapists who work with children will help you to encourage and to teach your child so that she reaches each stage of development and is ready to move on to the next one.

i) Movement and Mobility

All children need to experience movement, to learn the joy of movement, which is so much a part of childhood. They need fast movement, rough play, falling, swinging etc. They also need the satisfaction of achieving independent movement such as rolling, crawling, walking and climbing.

Most children experience an enormous variety of different movements and positions during the course of everyday life, and that's what we want to achieve for all children with spina bifida.

If a child is unable to stand independently at an age when it would normally be expected, he may be given a standing frame to use. This gives a lovely supported position for hand play. It's not just used for standing, it's also for movement.

Muscle power in the legs, personality of the child, and enjoyment of movement and the upright position all contribute greatly to your child's potential for walking, with aids as needed.

Your child's specialists and therapists will be encouraging your child to achieve some form of upright mobility particularly in the younger years regardless of the extent of the disability.

Your child's ability to move, explore and interact with the environment may be affected if he has reduced muscle activity or sensation. Movement in one part of your child's body influences movement in other parts. Loss of motor function in the lower limbs may affect upper limb function (e.g., if your child has difficulty stabilising the trunk and pelvis he may have difficulty with upper limb activities requiring fine control). General motor development may be delayed.

In normal development there is a great deal of variation in the age at which different children achieve the same skill. It is important not to focus on age. Other independent factors influence how early different skills (e.g., rolling, sitting, crawling and pulling to stand) are achieved-motivation/drive; muscle tone; practice. Your child's therapists will be more concerned with how your child's skills are developing than when a particular milestone occurs.

If this is your first child, like any new parent, you will be developing your confidence in handling and interacting with your baby. You will be getting to know your child's personality and will enjoy the interaction more as your confidence increases. It is important for your child to experience a great variety of movement and play.

Enjoy your baby, encouraging him to learn to enjoy and experience movement, to progress in developing his movement skills and to become more aware of his body and environment through play.

Your Physiotherapist and Occupational Therapist will advise you on activities to encourage your baby's motor development. We are aware all families are busy and have varying commitments so we aim to give you practical ideas and handling advice that can be incorporated in to your child's daily activities.

Some goals of your child's therapy program may include
- To experience and enjoy movement. Your child may be initially fearful of movement if he lacks good head control and balance reactions.
- To improve body awareness particularly of the lower limbs
- To provide activities to encourage development of your child's movement skills
- To encourage visual fixation and following
- To encourage and facilitate movement between positions rather than just placing your child in positions
- To encourage active lower limb movement and weight bearing
- To facilitate development of weight shift and balance reactions in sitting and standing
- To facilitate development of fine motor skills and cognitive development
- To promote symmetry and alignment and prevent development of contractures
- To provide education on skin care and prevention of pressure areas
- To prescribe appropriate orthoses and equipment to meet longer term goals of independent mobility and ambulation
- To provide opportunities for exploration and interacting
- To encourage development towards independence
- For you to enjoy your baby

ii) Equipment

At different times the use of equipment may be recommended to assist your child's development-

- to provide your child with the opportunity to develop skills
- to encourage independence
- to allow participation in everyday activities
- to meet longer term goals with respect to independent mobility and walking.

Types of Equipment

- **Splints-** for legs and feet (e.g., AFO's and KAFO's)

- **Corner chairs-** Your therapists may recommend a corner chair or other supportive seating device if your child has difficulty with independent sitting. A supportive seat will allow your child to sit upright without having to use her hands for balance. This will allow your child to use both the hands in play and develop fine motor skills.

- **Castor Cart-** Your child may benefit from using a castor cart when 12-18 months of age and older. A castor cart is a wheeled cart low to the floor. Your child can often learn to get in and out of it independently. A castor cart:
  - Gives your child some independence (supervised) in exploring the environment without harming the skin
  - allows your child the opportunity to learn to propel herself with the hands, to change direction, to negotiate obstacles and to learn to start and stop - all useful skills particularly if she will require a wheelchair in the future.

- **Scooter boards-** may be recommended for your child
  - to allow her to explore the environment (without harming the skin)
  - as part of her therapy program- encouraging active back, hip and knee extension.

  Children generally lie on their stomachs on a scooter board and practice propelling with their hands across the floor and around obstacles.

- **Standing frame-** may be recommended from 10-12 months of age if your child has difficulty taking weight through the lower limbs.

  There are many benefits of standing even if functional walking is not a long term goal-
  - strengthening bones
  - preventing contractures
  - assisting with bladder and bowel function
  - pressure relief
  - freeing your child's hands for play
  - allowing your child to stand at the same height to interact and play with peers

Your child will generally progress from using the standing frame just for upright standing to using it dynamically to develop balance and protective reactions through tilting and rocking and perhaps later learning to move in the frame by swiveling or jumping.

- **Walkers/ Rollators/Crutches** are aids that will assist your child to walk and are often used together with splints or standing frames.

- **Wheelchair-** if your child requires a wheelchair it will generally be introduced when she is about 3 years of age. At this age she will want to be more independent and want to keep up with her friends. A wheelchair may be your child's main means of mobility or it may only be needed for longer distances.

- **Baby Walkers/Jolly jumpers:** We generally don't advise you to use a baby walker or jolly jumper with your child. These devices do not improve your child's ability to take weight through the lower limbs.

iii) Play and your Baby's development

Play is the stuff of childhood. Play is lots of fun. It's also an extremely important part of your baby's development. Play enables your baby to learn about their world through moving, manipulating and interacting with the environment. Your baby's style of play will change and become more sophisticated as he grows. These changes in play form the basis for development of fine and gross motor skills, communication skills, social skills, cognitive and imaginative skills, and daily living skills.

BABIES: 6 to 12 months

WHAT IS SPECIAL ABOUT THIS STAGE OF DEVELOPMENT?

From 6 to 12 months your baby is:

- depending on you for most of his day-to-day needs;
- getting control of his body;
- learning to eat solid foods;
- learning to interact with other people;
- discovering his hands;
- often needing your attention;
- needing you close (keeping you in sight);
- developing confidence; and
- wanting to explore.

Babies explore their environment by feeling, smelling, tasting, looking, moving, listening and enjoying the world around them. They discover they have fingers and toes and begin to use their eyes and hands to manipulate objects. Babies also begin to recognise the difference between speech sounds and other environmental noises. They become more "tuned in" to the meanings of sounds and start to experiment with making vocalisations that have different effects (e.g. happy cooing vs angry or unhappy sounds). Through interacting with their environment in these ways, babies discover the relationship between cause and effect, and begin to show some control over their environment.

Play at this age is generally solo, but can be encouraged and stimulated by those around them through providing different objects and environments to explore. Lots of love and affection from family is also essential for developing your baby's feeling of security within the world and courage to face new challenges.

Floor play:

It is important for your baby to have time playing on the floor rather than just spending a lot of time in a seated position. Time playing on the floor will give your baby the opportunity to develop movement skills.

Tummy play:

Give your baby some time to play on his tummy to encourage active lifting of the head and strengthening of the neck, chest and shoulder muscles. This will help to develop head control, which is important for future development of skills such as sitting.

If your child gets upset when placed on his tummy it may be just that he finds it hard work. Try to begin with regular but short periods of tummy play, building up the time as he enjoys it more. A wedge or rolled towel under their chest may also be of help. Your Physiotherapist will also be able to give you some ideas to make tummy play a more enjoyable experience for you and your baby.

Hand Play:

Your baby's hands are very important for helping him to explore the world. To begin with, most babies' hand and arm movements are quite random. They tend to use their whole arm to swing or bat at toys that have been placed in front of them. Very quickly they learn that they can use their hands for lots of fun things like grasping toys or their other hand, and playing with their mouth. Watching their own hands move also provides hours of entertainment. These games mark the beginning of your baby's eye-hand coordination and fine motor skills. It is very important to give babies time in positions where hands are free for playing. This may involve the use of, for example, a corner chair.

Communication and social interaction during play:

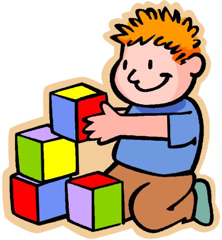
Children learn how to communicate with the world soon after they are a born. Good communication skills will be needed for expressing their emotions and needs, understanding other people, learning new information and skills, and forming relationships with others. Anything that your baby does to make his needs, wants and interests known involves communication, (e.g. crying, whinging, using gestures, sounds, words, and/or signs).

By about 12 months of age babies recognise their own name and begin saying their first words, such as "mama" and "dada". They enjoy games like peek-a-boo and love listening to new words when looking at books with their parent. They actively seek their parents' attention and can indicate when they want something by reaching and using their voice. Smiling, laughing and catching your eye are all lots of fun and mark the beginnings of good social skills.

TOYS for babies between 6 & 12 mths

1. **Mirrors** are useful for learning the names of body parts, encouraging reaching and smiling.
2. **Cause effect toys** (e.g. pop up toy) help to teach the relationship between action and outcome, which is very important for the development of prediction and eventually problem solving skills.
3. **Peek-a-boo and pat-a-cake** are great games for encouraging turn taking, eye-contact, and copying actions.
4. **Tupperware Containers/ nesting cups** can be great for developing awareness of concepts "in" and "out" etc
5. **Blocks** are great for banging together, placing in and out of containers, building towers and knocking them down again. Encourage talking by accompanying actions with words e.g."bang bang bang" .
6. **Bath play** provides lots of sensory experiences: the wet cloth, the plastic cup, the rubber ducky, the thick, warm towel. In the bath; tipping, scooping, clapping, splashing. Babies learn about their bodies, and bathtime can also be a time to introduce toy cups, to encourage development of cup drinking skills.
7. **Thick cardboard books** are good for encouraging baby to use both hands in the midline of the body, one hand stabilises the book, whilst the other grasps and turns the page. Useful for learning names of objects and actions and developing listening skills.

TODDLERS: 12 – 24 months



WHAT IS SPECIAL ABOUT THIS STAGE OF DEVELOPMENT?

From 12 to 24 months your child is:

- becoming more independent during play;
- becoming more independent in getting about;
- becoming more independent during mealtimes;
- beginning to see herself as a separate person;
- living in the here and now with little memory of the past and little thought for the future;
- enjoying the intrinsic pleasures of movement; and
- does not know right from wrong.

"Her language can get her into trouble by suggesting her understanding is greater than it is." Penelope Leach

Between 12 and 24 months your child's play will develop in all sorts of ways. She will probably still prefer to play on her own or along side another person, but will start to seek other's attention to share in a game with a particular toy.

Imitative Play:

Play through copying others develops around 9 months and becomes more complex through your child's second year. Children love to imitate their parent's household chores, such as cleaning the windows or vacuuming the floors. They learn to sequence steps in certain activities (e.g., washing and drying baby) through watching and copying models provided by their parents.

Constructive Play

At about 18months constructive play, such as building a tower with blocks begins to emerge. This type of play is important for developing hand-eye coordination and memory.

Imaginative Play & Role Play

Using objects to represent real things (e.g. a box may be a boat), marks the beginning of imaginative play. Children at this age start to use two toys together to role-play different social situations. Imaginative play and role playing are essential for developing language, social skills, and understanding of other people's intentions. Imaginative play is also important for expanding your child's creativity.

TOYS for toddlers between 12 & 24 mths

1. **All types of boxes/cartons etc** are great for developing imaginative play and can be used to put objects into, tip them out, boxes can be used for pushing along the floor.
2. **Chairs with a sheet draped over the top** can make a good cubby house.
3. **Child size household and garden toys, dolls, puppets and figurines** are all useful for encouraging role playing.
4. **Books** are always great for developing your child's vocabulary and understanding of stories.
5. **Bubbles** are lots of fun for developing turn taking and concepts, such as big, counting, sticky, more etc.
6. **Plastic cups, spoons and other feeding and drinking utensils**
7. **Paper and crayons**. The toddler may start to imitate actions such as drawing or scribbling on the page. Toddler will make random contact of crayon to paper
8. **More complex cause and effect toys** that require a certain action to get the desired response. E.g.: open the lid and the frog pops out, fitting the apple in the jigsaw board, sliding the handle to make oscar the grouch pop up!
9. **Bilateral games** such as putting together pop-beads, pulling-apart pop-beads and string-activated toys all continue to help the toddler refine grasps, hand strength, & eye-hand coordination
10. **Balls!** Of all sizes; can be caught, rolled, thrown, hidden etc!

CHILDREN: 24-36 months

WHAT IS SPECIAL ABOUT THIS STAGE OF DEVELOPMENT?

From 24 to 36 months your child is:

- Becoming much more independent in getting about
- Developing hand dominance
- Recognises self in photograph (when once shown)
- Enjoys playing with balls
- Enjoys picture books and stories
- Learning lots of words, simple sentences
- Learning to eat independently with spoon
- Very emotionally dependent on parents

Between two and three years of age children's play becomes even more complex. They become more interested in watching other children play and may try to join in with their game, although the concept of sharing toys is often not yet understood until they get closer to three years of age.

Role play becomes even more involved as children begin to link different activities together, (e.g. washing, dressing, and feeding baby, and then putting baby to bed). As children mature their vocabulary and ability to join words together to form sentences develops. This burst in language is reflected in their play. Their ability to explore and copy many new activities also helps to develop their language even further.

TOYS to use between 24 & 36 mths

Many of the toys that we have mentioned previously will still be great fun and provide many educational opportunities between 2 and 3 years of age. Some other games and toys for this age are as follows:

- **Play dough** – Great for rolling, cutting into shapes etc. There are lots of good language concepts and action words to use with play dough, (e.g. cut, squash, poke, roll, flat, round, etc).
- **Collecting and sorting** – shells, leaves and other interesting objects is a great way of teaching your child to classify objects. Heaps of great language concepts to learn with this activity as well (e.g. similarities and differences, describing words etc).
- **Crayons for drawing** – to encourage development of hand dominance, finger painting or drawing in shaving cream are also good.
- **Jigsaws** – help develop manipulative play, shape recognition, in-out concepts, pincer grip (to pick up puzzles pieces)
- **Glue and collage** – good for developing bilateral skills and it's fun!
- **Dressing up** – good practice for fastenings, buttons, symbolic play
- **Sand & Water Play** – good for strengthening the upper limbs and learning more about body awareness. Nice tactile input.

iv) Playing with other children

Playing with other children can be one of the most motivating and enjoyable ways for your child to learn new skills. Children learn new fine motor and gross motor skills, such as building blocks or using outdoor play equipment by copying others and copying other children can be more exciting than copying an adult. Playing with other children is also essential for your child to learn the rules of social communication, such as taking turns and making friends. More general speech and language skills, such as new vocabulary or grammar may also be learnt from other children.

There are many different environments in which your child has the opportunity to play with a group of other children. Perhaps you have lots of children in your neighbourhood, some brothers, sisters or cousins, or a community play group that you belong to. Your local park might be a great place to meet other children. You may also choose to take your child to a child care, day care or ECDU (Early Childhood Development Unit) for regular play time with other children in a more structured environment.

Parents thoughts on commencing Child Care

- *Gives time to yourself, which is very important, whether you child has a disability or not.*
- *It was great to see how the Centre solved barriers I imagined there would be…. The staff have accommodated her needs with very little fuss and are happy to discuss matters on a daily basis.*
- *Great for social skills, mum gets a break, and other children learn that some people are different and special.*
- *Can be hard for mum to let go after dealing with their children's problems for so long.*
- *Not big on Child Care myself – "normal" or not. I like being a mum solely for the five year period. After all, that's all we really have these days.*

If you plan to use a child care facility at any stage the education advisor at SBH Queensland can support you to find a suitable place for your child. SBH Queensland's education adviser and therapists are able to provide information and support to child care facilities on request.

SBHQueensland Playgroup

A playgroup is held at SBH Queensland in Dutton Park, Brisbane, on a regular basis. A teacher and a number of therapists from SBH Queensland organise fun, play activities that cater for the special needs of children with spina bifida and hydrocephalus. There are many benefits for your child as well as for yourself. Playgroup provides an opportunity for you to meet other families while your child interacts with other children and learns new skills in a fun environment. Brothers and sisters and other family members are welcome. Country families are always welcome if they are in Brisbane at the time.

SPINA BIFIDA AND YOUR FAMILY

i) Family matters

As parents, your life will be filled with the same delights and difficulties as all parents who devote time and energy in raising their children and you will care about the well-being and safety of your baby.

For most of you, being the parent of a child with a complex medical condition will be a new experience. Your baby has the same needs as other babies, as well as having special needs.

Most parents find learning about these complex medical conditions is an ongoing process. We encourage you to be well informed and to work with all practitioners for the best outcomes for your child.

How will this affect us?

Having a baby with spina bifida and hydrocephalus has a significant impact on the practical and emotional resources of families, as you are being asked to do more and to extend yourself more than parents who have a healthy child. You will all react in your own way and in your own time to these demands.

There are physical demands…

You provide the primary care for your child. You are asked to attend medical, hospital and therapy appointments and to follow the management suggestions that come from these appointments. At the same time you are attending to the financial and everyday needs of all your family and working hard to maintain your family's integrity.

…And there are emotional demands:

Coming to terms with the news that there is something wrong with your baby, taking in the information about these medical conditions, and making decisions about medical procedures that will affect your baby – all require emotional energy. Some parents unfortunately blame themselves or others for what has happened to their baby. Parents can face a range of strong, sometimes confusing, emotions and most parents have good days and bad days as these emotions may recur unexpectedly.

These demands may put a strain on yourself and on your relationships with others around you, particularly those in your immediate family. With such intensity placed on your parenting, differences in parenting styles and values can emerge. Sadly some couples find they are having to deal with unresolved differences and problems in their relationship that re-emerge from their past.

Suggestions to parents

If one parent takes on the main responsibility of the care of the child with spina bifida, they may find they are out of step with the other parent. They will be acquiring new skills, meeting new people, and developing new confidence from facing new and unexpected circumstances.

- Try to work together and share responsibility for the care of your child so that an imbalance does not develop in your relationship.
- It is important to discuss what you are going through together – support each other when you make the important decisions and grow together as parents.
- You will be in the best position to make the important medical decisions together if you have both developed a relationship with the specialists who look after the management of your child.
- Give each other time and space to deal with things in your individual ways.
- Do not put yourself in the position of being the only one who **can** care for your child.
- Do not be so caring and protective that you find in future years that your child does not know how to do anything for himself.
- Keep in mind all those things that are important to you and work to make them part of your life even in these early years.
- Enjoy the rich family life that you planned, as having spina bifida and hydrocephalus is only one aspect of your child's life, and one part of your family life.

Given these demands, what impresses us, is the resilience of parents and families we meet through SBHQld.

What is important in your family?

This can vary enormously from one family to another.
Here are examples of some of the things that families value:

- To Don and Tess, being part of a large family group is important. They include their family in medical discussions and Michelle's clinic appointments. Michelle has been exposed since she was a small baby to the rough and tumble of family life by her brother and sisters, grandparents, uncles and aunts.
- Linda and Henry have decided that Grace will be their only child. She is very precious to them. They want to savour every moment of her childhood and have photos of all the stages of her development.
- Peter and Fay's friends are important to them and they hope Lachlan will have a supportive group of friends when he grows up. They have involved their friends in Lachlan's care since he was very young. This has given Lachlan a group of friends who will look out for him. He is learning about the give and take of friendships as he is growing up.
- Geoff and Karen expect Marc to be independent as an adult. They have always worked closely with the therapists and plan to involve Marc in his own decisions and self-care.
- Peter lives a very active outdoor life and has adapted equipment so that Matthew can go camping and fishing too.

You are not alone.

Parents tell us that they often feel they are living lives that are different from other families. We hope that with our support you will not feel so alone. We encourage mutual support between parents and can introduce you to other parents if you wish. You will meet up with others at hospital clinics and during hospital stays. Playgroups and other SBHQld family events are excellent ways for you to get to know other parents who are also living with these conditions and over time you may develop close relationships with other families.

How have other parents managed?

As a parent…

You want to do everything you can for your baby. You would like to fix everything for them - but you can't. I look at Daniel and I think, "I want to fix this for you."

It's okay at first. Being a new mum there is lots of help…However later on it's scary. Once the fuss dies down, you are left to your own resources. You are on your own- ***but*** *you feel that you have to do it right. You feel you have to put on a show of doing it right, you've got to be the perfect parent. Some can handle that pressure … some can't… most are in the middle ground.*

I think the overall aim is help your child be like other children. I've noticed that some parents deny there are any differences…some parents overplay "the disability". I have to keep asking if I should be doing this differently. There aren't many guidelines about how to handle things so you need to have someone to talk to.

You have your good days and your bad days. It is not unusual to feel okay one day and not so good the next day.

… it is only one part of your lives

Having a child with Spina Bifida changes your life, but you need to get on with living and do the best for your family. Every day is different. You have good days and bad days but you go on with every day life.

You need to recognize that parenting is a very difficult job and the idea of "super mum and dad", who can do it all, is simply unrealistic. Aim for contentment and find joy in simple every day events. Find ways to share the load. A good support network is invaluable. Take regular holidays.

Be organized and try to have a normal life. Try not to let your SB child rule your life. Work around toilet times. Most importantly, have fun with all your kids.

My son has Spina Bifida to a minor degree, so I haven't had to struggle with any special needs as such. I find juggling a two and a half year old is much more demanding, and he's an energetic little boy, at that!

As a couple…

Talk things out from the start. Work together as much as possible.

As a ***mother*** *at home caring for your child you notice things every day e.g. when you change a nappy. You are learning from direct contact.*

Fathers *probably see things differently if they don't do those every day things. They may not learn about nappy rash and skin but they probably notice other things.*

As a family…

Having a child with spina bifida affects everyone in the family – mothers, fathers, brothers and sisters, grandparents, uncles, aunts, and cousins.

Make sure the rest of the family understands about Spina Bifida. Give them as much information as you can - it really helps.

Be honest with other siblings. Spread yourself thinly. Make sure you allocate time for your husband and other children. The condition affects everyone, not just the mother and child.

Be strong in what you believe in and in yourself because there will be family members who won't deal with you or your family much. Some comments I've dealt with have been a knife through the heart, but others I will probably take to my grave and remember lovingly.

Realize that not everyone can support you – everyone has their own issues and problems and support needs to be a two way street. In times of stress related to Spina Bifida "lows", your survival mode kicks in and the needs of your extended family become secondary to your own. Ask for help. Pay back the emotional support favours when you are able to.

ii) Genetics and Folic Acid

You may be wondering: Why has this happened to us? What are the risks that this might happen again? Some parents ask if they have done something wrong. Is someone to blame?

Why spina bifida occurs is not well understood. A combination of genetic and environmental factors is involved. It is known that if a woman or her partner has a history of neural tube defects in their family then the risk of having an affected child is greatly increased. It is also known that some anticonvulsant medication to control seizures does increase the chance of a baby having a neural tube defect.

A Dietary supplement of **Folic Acid** - a B group Vitamin - can help reduce the risk of having a child with a neural tube defect. Folic Acid is found in many fruits (particularly avocado, grapefruit and oranges), dark leafy green vegetables, whole grains and legumes. It has been found that a diet rich in folic acid, or the taking of folic acid supplements in the month before and in the first 3 months of pregnancy can significantly reduce the incidence of neural tube defects.

The dose of Folic Acid to be taken should be discussed with your doctor prior to future pregnancies.

Genetic counsellors can discuss the risk for each individual family.

SUPPORT FOR YOU AND YOUR CHILD

i) SBH QUEENSLAND

Spina Bifida Hydrocephalus Queensland

SBH Queensland supports people with spina bifida and hydrocephalus and their parents and carers by providing information, facilitating support and member networks, and increasing awareness of spina bifida and hydrocephalus in the community.

SBH Queensland includes a Children's Service, Adult's Service, and Information Service. Our main office is located in Dutton Park, Brisbane, however we also have a base in Townsville, North Queensland.

The Children's Service is made up of physiotherapists, occupational therapists, speech pathologist, social workers, and education advisors.
These professionals work together as a team to ensure that the best support for your child is achieved. The team aims to assist your child and your family through home visits, supporting you at the hospital clinics, and visiting your child's school, kindy or child care to provide information and strategies to teachers and carers.

Our Association gives priority to young children. The team will work with you and give you information and new ways of understanding and encouraging the development of your child with spina bifida. We involve you in all decisions, and we give every opportunity for you to talk over your concerns.

Families are supported by SBH Queensland through:

- Prenatal counselling.
- Individual support through home visits.
- Support groups and networking among families.
- Support and liaison with medical staff at hospital clinics.
- Advice on aids, equipment, and home modifications.
- Country outreach trips.
- Playgroups in Brisbane.
- Counselling.
- Advocacy.
- Annual Christmas Party.
- Information sharing.

Children with Spina Bifida and Hydrocephalus are supported through:

- Assistance with inclusion in schools.
- Assessment and therapy programmes to assist development of play skills, independence, social interactions and learning.
- Group therapy programmes.
- Equipment for loan.
- Camps.

Our Information Service provides up to date information relating to spina bifida and hydrocephalus to staff, families, carers and the community through a number of different mediums. SBH Queensland has a reference library with an extensive range of articles, books and videos available for loan. This library is housed at the SBH Queensland office in Dutton Park, Brisbane. Information booklets and sheets are also available by contacting SBH Queensland. Information can be also accessed through our web site: www.spinabifida.org.

Our magazine, SPINET, is published every quarter and provides news of our members, SBH Queensland activities, current research, and other interesting happenings. SBH Queensland also holds a Spina Bifida Awareness Month each year to help raise community awareness of this condition.

Families are able to contact our staff for information and support by telephone or by visiting us at our office in Dutton Park, Brisbane, during office hours (8.30am to 5.00pm Monday to Friday). We can also be contacted by mail, fax and e-mail. Our contact details for the Brisbane Office are:

Telephone: 07 3844 4600
Address: 21 Tillot Street, Woolloongabba, 4102.
Postal Address: PO Box 8022,
Woolloongabba, Q, 4102.
Fax: 07 38444601
Email: info@sbhqueensland.org.au

ii) Government and Other Services

INCOME SUPPORT

Carer Allowance is provided by the Commonwealth Government through Centrelink to parents who are caring for a child with a disability. The child must be assessed as requiring substantially more care than a child who does not have a disability. An assessment is made about the severity of the disability and the amount of care provided. There are application forms for parents to complete and separate forms for your specialist doctor to complete. Recipients receive both a fortnightly payment and a Health Care Card or just the Health Care Card.
Contact Centrelink on 13 27 17. Website: www.centrelink.gov.au

Carer Payment is provided through Centrelink to carers providing full time care to children with a disability. Usually this is a child with high support needs. To be eligible for this payment there are criteria to be met about the amount of care provided. There are application forms for both the parents and the treating doctor to complete.
Contact Centrelink on 13 27 17. Website: www.centrelink.gov.au

Health Care Card is provided to a child with a disability who requires substantially more care and attention than a child of the same age who does not have a disability. The assessment procedure is the same as for Carer Allowance. Your child may receive a Health Care Card even if the application for the Carer Allowance is not successful.
Contact Centrelink on 13 27 17. Website: www.centrelink.gov.au

Family Support Packages are available through Disability Services Queensland (State Gov.) to some families who are caring for a child with a high and complex support needs. A range of support is available to strengthen a family's capacity to care for their child. Application is made through DSQ. Parents first need to register with DSQ that they are caring for a child with a disability. The second step is to complete an application for a Family Support Package. Assessments are made once a year through a Regional Disability Council.
Contact your local DSQ office. Website: www.disability.qld.gov.au

CONTINENCE AND MOBILITY AIDS

MEDICAL AIDS SUBSIDY SCHEME

The Medical Aids Subsidy Scheme (MASS) is a division of Queensland Health. It provides mobility devices on permanent loan and subsidizes the cost of continence aids to children who have a permanent or stabilized disability and who have a Health Care Card. Please remember specific eligibility criteria, allowances and equipment can change regularly, so best to check this through their website or your therapy team.

a) Mobility aids

Children are eligible for one piece of mobility equipment through MASS. The Orthopaedic Surgeon and your physiotherapist will make recommendations about suitable equipment and help you to complete the application to MASS.
Contact your therapist at RCH, MCH or SBHQld

b) Continence Aids

Children are eligible for the provision of pads and nappies when they turn 5 years of age. If catheterisation is part of your child's bladder management program, your child is eligible for catheters through the MASS scheme, at any age.
You will have been discussing your child's bladder and bowel management program throughout his/her development with your Urologist, the stomal therapist at your Spinal Clinic or the OT from SBHQld. They will help you to complete the application forms.
Continence aids are supplied on a 6 monthly basis so you will receive a large quantity at the one time. Application forms will need to be renewed on a regular basis.

CONTINENCE AIDS ASSISTANCE SCHEME

The Continence Aids Assistance Scheme (CAAS) is an Australian Government program that assists eligible people who have permanent and severe incontinence to meet the cost of continence products. From 1 July 2007, eligibility will be expanded to include people aged five to 15 years and 65 and over.

To read more about eligibility criteria, it is best to check their website, as this can change faster than this booklet may be updated, details are:
http://www.health.gov.au/internet/wcms/Publishing.nsf/Content/continence-caas.htm
Or call:
Switchboard on (02) 6289 1555
Freecall on 1800 020 103

Information is available through In Touch regarding product lists.

Please note that one eligibility criteria that is important to check and discuss with your continence nurse or occupational therapist, is whether dual membership between CAAS and the Ostomy Association is allowed. Currently in July 2007, this is not, so you will need to decide which association will bring you the most functional benefits.

QLD OSTOMY / STOMA ASSOCIATION

Queensland Stoma Association Incorporated is a non-government not for profit organisation offering support and information services to all people within the community who have a stoma as a result of bowel or bladder surgery.

Membership of Queensland Stoma Association Incorporated is available to all persons with a Stoma. Please remember membership with this association may make you ineligible for CAAS membership (see above), so discuss this with your continence team to make the best informed decision.

When you look up the different offices around Qld they might have slightly different titles including the words, Stoma, Ostomy, or Colostomy, though they all branch from the same background.

Contact details for more information are:
Chermside office (will help locate your local service) : 07 3359 7570
Or website : http://www.qldstoma.asn.au/index.html

DAILY LIVING

LifeTec Queensland (previously known as: Independent Living Centre)

Provides information and professional advice on aids, equipment, building and resources for people with a disability and their carers.
Contact LifeTec on Ph: (07) 3552 9000 or 1300 885 886

Carer Respite Centres

Commonwealth Carer Respite Centres coordinate access to respite services in your local area. They can give you advice about respite services and find the service closest to you. They can also help you get the right respite services. Commonwealth Carer Respite Centres work with carers to plan sensible approaches to respite and other support needs and also arrange 24 hour emergency respite care.
Contact the Commonwealth Carer Respite Service on 1800 059 059

HEALTH

Hospital Spina Bifida clinics

Mater Children's Hospital, Brisbane - held on 1st & 3rd Wednesdays of the month. Contact the Clinic Coordinating Nurse on 3163 1812
Royal Children's Hospital, Brisbane - held fortnightly on Fridays. Contact Sister Carol Shekell on 3636 7399
Gold Coast Hospital offers a medical review with Dr Wallace Paediatric Neurologist. Clinics are on a Monday morning once every 6 months. (January and July) Contact the Speciality Paediatric Clinic on 5571 8345

Community Health Centres

Some centres provide therapy and other allied health services.
Contact your local centre under Queensland Health in the White Pages

TRANSPORT

Disabled Parking Permit

This is available for adults and children with a disability, over 5 years of age. A two tiered scheme (A **blue** permit for people totally dependent on a wheelchair or a large complex mobility device and **red** for people with a severe mobility impairment) is available to allow permit holders to park in specified disability parking bays and for extended times in metered areas.
Contact Queensland Transport 13 23 80

Taxi Subsidy Scheme

The taxi subsidy scheme provides a subsidy for taxi travel at a half rate concession to people with severe disabilities. There are eligibility criteria. This is available to people of all ages who have chronic disabilities.
Contact Queensland Transport 13 23 80 .

Patients Travel Subsidy Scheme

The Patient Travel Subsidy Scheme provides a financial subsidy to a person (and an escort, if required) to assist financially with attending essential medical appointments that are not available within 50 km of the nearest public hospital. The subsidy provides assistance with travel and accommodation costs. Application forms are available from and must be filled out by your doctor. Contact the Patient Transit Officer at your local hospital.

HOUSING AND HOME MODIFICATIONS

Department of Housing

Provides public rental accommodation and a number of other schemes.
Contact the local Department of Housing area office.

Other Schemes

There are numerous schemes in different areas that provide assistance with home modifications. Contact SBH QLD for more information.

OTHER SERVICES AND RESOURCES

Disability Information and Awareness Line

Contact: Disability Services QLD info line: 3224 8444 / 1800 177 120

ACROSS Australians Creating Rural Online Support Systems

List of resources for personal and practical help
http://www.acrossnet.net.au

Lifeline Community Resource Directory

24 hour Telephone Counseling Line: 13 11 14

SBH Queensland

For information on more resources including respite, advocacy and education and other specialist services please contact SBH Queensland on 3844 4600.

EARLY INTERVENTION

Noahs Ark Resource Centre

Specialised resources to enhance the learning and development of children with special needs
Phone: 07 3391 2166

Playgroup Association of Queensland has information about local playgroups and local toy libraries
Phone: 1800 171 882

Local Toy Libraries

HELP FOR CARERS

As you are caring for a child with a disability you have earned the new title of 'carer'. It often seems odd to parents to be referred to in this way as they see themselves as "mummy or "daddy" but you will find this term used in a lot of literature. It is worth taking on the expression sometimes, as there are resources available for carers.

Carers Queensland (previously known as Queensland Council of Carers)
Carers Queensland (also known as the Queensland Council of Carers) provides carers with information and services to support them in their caring role. They also work to increase awareness of carers and their issues.
Contact the Commonwealth Carer Resource Centre on 1800 242 636.

Commonwealth Carer Respite Centres
If you ring the toll free number 1800 059 059 you will be put through to your nearest CCRC.

Commonwealth Carer Resource Centre counselling for carers
Toll free number 1800 242 636

"Patient Transit Scheme. When we came to Brisbane for Adam's birth, my husband was able to come as an escort for me. When I was in hospital, he was No1 escort with a subsidy each night. When I came out of hospital and Adam was still in hospital, I was the No1 escort and my husband was No2 escort. We both received a subsidy per night. We have three other children .We brought them to stay with us and stayed in a unit near the hospital. We paid the difference between the bill and the subsidy."

"When you become the parent of a child with a disability, you lose your privacy. A lot of helpful people become part of your life. I noticed this because Nat is our second child. For our first child we did things the way we wanted and when we made mistakes it was up to us what we did about it. Now we have lots of opinions about what we should do and when we make a mistake it is very public."

iv) Suggested Books for Further Reading

The following books are available for loan from the SBHQld library.

- **About Spina Bifida**

"Children with Spina Bifida - A Parents' Guide"
Edited by Marlene Lutkenhoff, R.N., M.S.N. (Woodbine House USA 1999)

"Living with Spina Bifida – A Guide for Families and Professionals"
Adrian Sandler, M.D. (The University of North Carolina Press 1997)

"Living with Spina Bifida: Shared Experiences"
Gwynnyth Llewellyn and Lorraine Green
(Cumberland College of Health Sciences University of Sydney 1987)

"Spina Bifida - A Handbook for Parents"
Australian Spina Bifida Association (South Australia 1982)

"Understanding Spina Bifida"
Produced by the Spina Bifida Team of Bloorview MacMillan Centre
(Spina Bifida & Hydrocephalus Association of Ontario June 1998)

Spina Bifida And Hydrocephalus Queensland Booklets
Children with Spina Bifida and Hydrocephalus
Information For New Parents
Early Childhood

- **About Children's Development**

"Baby & Child - From Birth to Age Five"
Penelope Leach (Penguin Books London 1981)

"From Birth to Five Years – Children's Developmental Progress"
Mary D. Sheridan (ACER Press Australia 1988)

"Small Steps Forward - Using Games and Activities to Help Your Pre-School Child with Special Needs" Sarah Newman (Jessica Kingsley Publishers UK 1999)

- **About Parenting**

"After the Tears: Parent talk about raising a child with a disability"
Robin Simons (A Harvest Book Harcourt Brace & Co. USA 1985)

"Facing the Crowd: managing other people's insensitivities to your disabled child"
Deborah Fullwood & Peter Cronin (RVIB Victoria 1986)

"*Rebuilding Your Dream – Family Life with a Disabled Child"*
Rhonda Krahl (University of Iowa Publications)