Caring for your baby with spina bifida

Queensland Children's Hospital

Queensland Government

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Section 1: Introduction

Congratulations on the birth of your new baby!

This is an exciting time for you and your family but we appreciate it can be overwhelming with the information you have been given about your baby's spina bifida diagnosis and adjusting to what this means for your child and family.

This booklet aims to provide information about spina bifida and our spinal disabilities team at the Queensland Children's Hospital and address any common concerns you may have.

Your child's team at the Queensland Children's Hospital has a wealth of knowledge about caring for children with spina bifida and is available to answer your questions.

We appreciate any feedback you may have on this booklet or ideas about what would be useful to include in it. Please contact us on the details below if you have any suggestions or feedback.

Contact:

Spinal disabilities clinic
Phone: (07) 3068 2736
Email: CHQ.spinaldisabilities@health.qld.gov.au
Website: www.childrens.health.qld.gov.au

Section 2: What is spina bifida?

Spina bifida means “split spine”. Very early during human development, usually before a woman even knows she is pregnant, the baby’s brain and spinal cord (neural tube) forms. Sometimes for reasons we do not always understand, the spinal cord and bony spine do not form as they should and the baby is born with spina bifida.

Types of spina bifida

There are a number of types of spina bifida.

Myelomeningocele (MMC)

This is the most common type of spina bifida. In a myelomeningocele, a sac filled with fluid and the spinal cord protrude through the baby’s back. This can occur at any level of the spinal cord but is most often at the lower end of the spinal cord. The baby usually needs surgery to close the spinal cord and skin to stop any further damage to the spinal cord and to stop any infection. The surgery usually takes place one or two days after the baby is born. Sometimes, this surgery can happen before the baby is born.

Meningocele

When a baby has a meningocele, a sac filled with fluid protrudes through the baby’s back. The sac on their back is usually covered with skin. Sometimes some of the spinal cord might be found in the sac.

Lipomyelomeningocele

Lipomyelomeningocele usually appears as a skin covered lump on the back. This lump will contain fat cells which often grow into the spinal cord. Sometimes this fatty lump gets tangled with the spinal cord.

Split cord malformations

Split cord malformations are when the spinal cord is split into two. Often there is a piece of bone or cartilage separating the two. This type of spina bifida may not be noticed at birth because there is normally not a lump on the baby’s back. Signs can include a patch of hair or a birthmark which may signal a problem in the spinal cord.

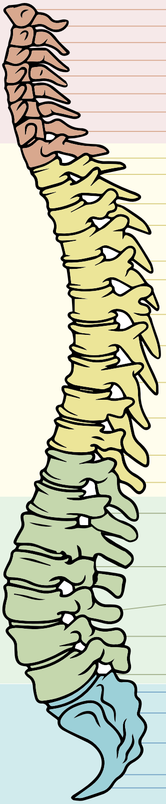
Sacral agenesis or caudal regression syndrome

Sacral agenesis or caudal regression syndrome is a rare type of spina bifida. Here, the lowest part of the bony spine (sacrum and sometimes the lumbar spine) and the spinal cord have not developed at all.

Spina bifida level of lesion

The spina bifida level may refer to the level of the bony spine where the damage has occurred. This is often determined by an x-ray or magnetic resonance imaging (MRI) scan. The spina bifida level may also refer to the motor and/or sensory level where the damage to the spinal cord has occurred. This is determined by assessments of muscle strength and sensation. This level allows a better understanding of how spina bifida affects the individual as it can sometimes be higher or lower than where the damage to the bony spine has occurred.

Neurological level with muscles affected and functional implications



Cervical Region

C1
C2
C3
C4
C5 Elbow flexors: Partial upper extremity function
C6 Wrist extensors: Standing with stander/orthotics
C7 Elbow extensors
C8 Finger flexors

Thoracic Region

T1
T2 Complete upper extremity function
T3-T8 Standing with stander/orthotics
T4 Possible exercise ambulation
T5
T6
T7 Partial function of trunk muscles
T8
T9-T12 Exercise ambulation
T10-L2 Bladder: Sympathetic input from hypogastric nerve
T11 Some function of trunk muscles
T12-S5 Sexual function varies

Lumbar Region

L1 Complete trunk function: exercise ambulation, sometimes household ambulation
L2 Hip flexor muscles present: exercise ambulation, household ambulation
L3 Knee extensors or Quadriceps muscles present: household ambulation, possible community ambulation
L4 Medial knee flexors present. Ankle dorsiflexors, 3/5 strength
L4-S5 Community ambulation
L5 May walk with or without crutches in home

Sacral Region

S1 Hip abductors, 3/5 strength
S2 Hip extensors, 4/5 strength. Ankle, plantarflexors, 3/5 strength. May walk with or without crutches
S2-S4 Bowel and bladder function varies. Bladder: parasympathetic input from the pelvic nerve. Somatic input from pudendal nerve to urethral sphincter
S3 All muscle activity may be within the normal limits
S4
S5 and above: Be aware of signs and symptoms of shunt malfunction and tethered spinal cord

How will spina bifida affect my baby?

Everyone with spina bifida is unique. How it will affect your baby depends on the type of spina bifida your baby has, the level of the spina bifida and how much of the spinal cord has been damaged.

These are some of the things your baby might have difficulties with because of their spina bifida:

Muscle weakness or paralysis

Many people with spina bifida will have weak or paralysed muscles in their legs, trunk and less commonly in their arms. This is because the nerves in the spinal cord that send messages to the muscles are damaged. Weakness of the legs affects whether a child with spina bifida will walk and how well they can walk.

Sensation

People with spina bifida will often have poor or absent sensation depending on the level of spina bifida. When the spinal cord is damaged, messages like pain that come from the skin, joints, bones or other areas do not get carried back to the brain. Being able to feel is important for protection. Without sensation a person may not feel when they step on a sharp rock, their shoe is rubbing, they accidentally spill hot water on their foot or have a broken bone.

As your baby grows and develops, their doctor or physiotherapist will help work out which areas they can and cannot feel and how to take extra care to prevent pressure sores.

Bladder and bowel

The nerves from the spinal cord that supply the bladder and bowel for both muscle control and sensation are located at the very bottom of the spinal cord. Many people with spina bifida will have some involvement of their bladder and bowels which affect their continence (weeing and pooing).

Arnold-Chiari II malformation

Most children with a myelomeningocele will also have an Arnold-Chiari malformation type 2 (ACM2). This is where the bottom part of the brain that meets the spinal cord (called the brainstem and cerebellum) goes down into the spinal canal. Sometimes other parts of the brain are also affected. The malformation might cause some problems in swallowing, eating and breathing when sleeping (sleep apnoea).

Hydrocephalus and shunts

Children with Arnold-Chiari II malformation are likely to also have hydrocephalus. This is a build-up of fluid in and around the brain. This fluid is called cerebral spinal fluid (CSF) and helps to protect the brain and spinal cord by acting as a cushion around the brain. It also helps feed the brain and keep it healthy. When the fluid keeps building up in the brain a shunt is inserted to help drain the extra fluid from the brain.

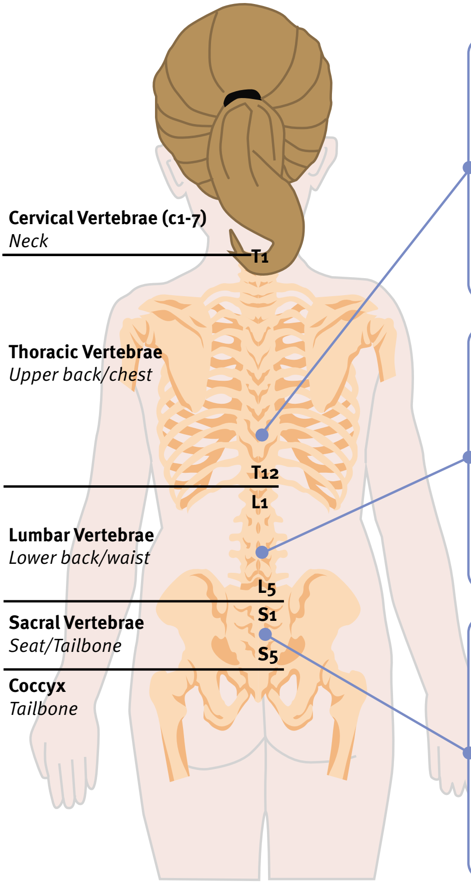
Tethered spinal cord

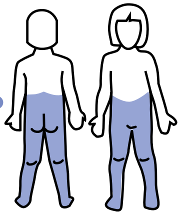
Tethering means being stuck down or attached. A tethered spinal cord either ends lower than it should or it is stuck at some point. For most people, it doesn’t cause problems. For a few people it can lead to changes in things like muscle strength, sensation, bladder and bowel control or it can cause pain. Sometimes an operation is required to release the tethered spinal cord.

Section 3: Frequently asked questions ?

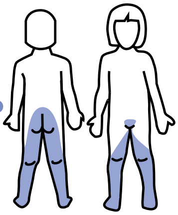
Will my child walk?

There are different things which will affect your child's development. Generally, the higher their spina bifida lesion the more leg weakness the child will have which can affect their walking. The image shows the likelihood of your child walking depending on where their lesion is.

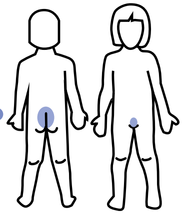




Thoracic-level Lesion
The child is likely to require a wheelchair as his/her main form of mobility. Sensation is likely to be impaired at about waist-level and below (T10-level lesion pictured). A child with a thoracic-level lesion is very unlikely to have bladder and bowel control.



Lumbar-level Lesion
The child may walk using aids and may require a wheelchair for long distances, particularly as he/she gets older. Sensation is likely to be impaired in the legs and buttocks (L3-level lesion pictured).
A child with this level of lesion is unlikely to have bladder or bowel control.



Sacral-level Lesion
The child is likely to walk with or without aids. Sensation is likely to be impaired around the buttocks and genitals. The backs of the legs and soles of the feet may also be affected (S3-level lesion pictured). The child may or may not have bladder and bowel control.

Will my child talk?

Having spina bifida alone should not affect your child’s ability to talk. However, if they have an Arnold-Chiari II malformation, other areas of development including speech may be affected.

Will my child have behavioural problems?

Differences in brain development associated with spina bifida, such as the Arnold-Chiari II malformation and associated hydrocephalus, can affect thinking and behaviour. Some children have trouble developing attention and concentration skills which can affect their behaviour. Some have trouble developing executive function skills such as flexible thinking, planning and organisation skills which can also affect their behaviour. Children with intellectual disability and/or communication difficulties may be more likely to develop behavioural difficulties. Fatigue following a long school day can also exacerbate behavioural challenges at home.

As children with spina bifida grow and develop they may also experience grief about their physical differences and the impact of these on their participation in everyday activities, especially when comparing themselves to their peers. This grief can be expressed in their behaviour. For example, they may be easily frustrated or upset and sometimes suffer from low self-esteem. In some children this frustration and/or sadness may be short-lived, while others may need additional support to work through their emotions and learn effective coping strategies.

The Queensland Children’s Hospital spinal disabilities clinic team can offer advice about these behaviour concerns and suggest appropriate interventions and supports, such as ‘Stepping Stones’, a positive parenting program developed specifically for parents of children with special needs. Community therapists and childcare or school staff may also provide suggestions to help you support your child's behaviour throughout their development.

Will my child grow out of spina bifida?

Spina bifida is a lifelong condition and the effect on the nerves in the spinal cord cannot be repaired fully. Young children learn to adapt to their circumstances and with the appropriate early intervention and treatment your child can reach their full potential.

Will my next child have spina bifida?

If you have a child with spina bifida there is a higher risk of having another child with spina bifida. Please see the section below on planning for future pregnancies and how to reduce the risk.

Section 4: The spinal disabilities team at Queensland Children’s Hospital

On discharge from hospital an appointment will be made for you and your baby at the spinal disabilities clinic about six weeks after your discharge.

The spinal disabilities clinic at Queensland Children’s Hospital provides care for children born with spinal cord differences, such as spina bifida and similar conditions.

The team at the clinic will aim to see you and your baby every three months in their first year, with reviews becoming less frequent as your child grows. When you are first referred to the service, you will usually see a specialist paediatrician, a neurosurgeon and a physiotherapist. If other specialists are required, your doctor will make a referral.

A multidisciplinary team approach: our team

The spinal disabilities clinic is a ‘multidisciplinary clinic’ where a team of specialised doctors, nurses, physiotherapists, and other allied health professionals provide collaborative care for your child. Here is a brief summary of the health care professionals that help to look after children with spinal disabilities:

Paediatrician

The spinal disabilities clinic paediatricians are a subset of paediatricians with specialisation in children with problems in the brain and spinal cord. These paediatricians will monitor and treat your child and help coordinate their overall medical care.

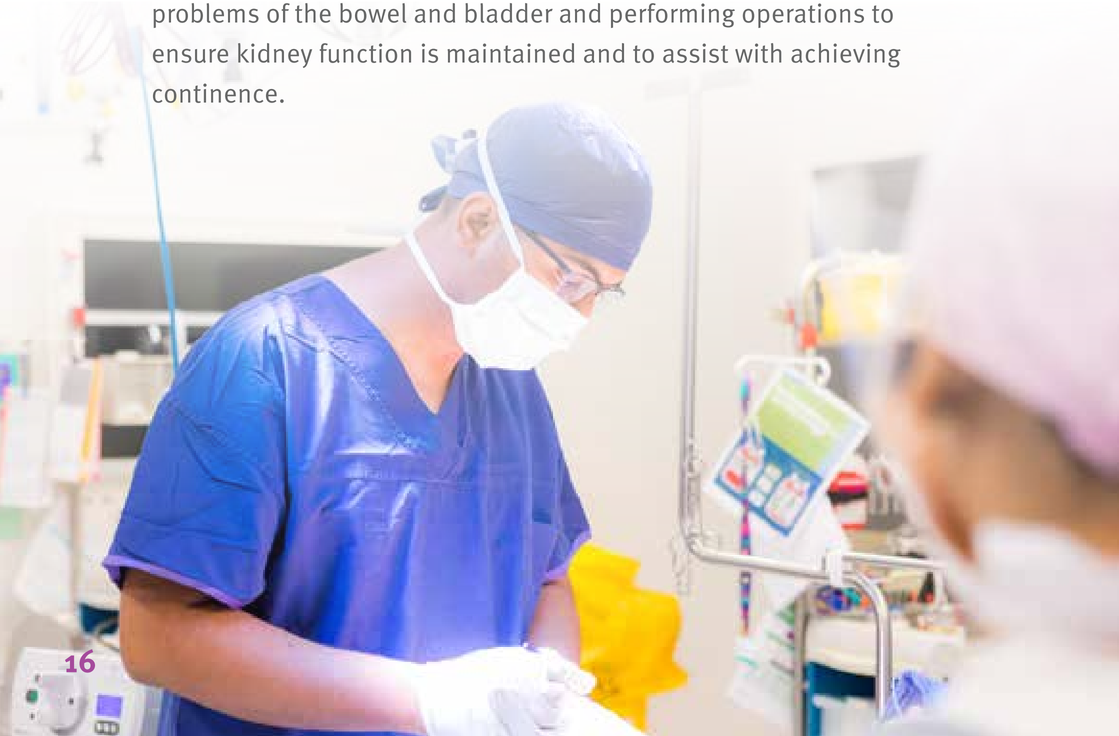
Your spinal disabilities paediatrician may refer you to other specialists as your child grows and changes, depending on the individual care your child needs.

Neurosurgeon

Neurosurgeons are specialist doctors who diagnose and surgically treat problems with the brain, spine, and nervous system. They will monitor your child’s condition with regular reviews as well as see you before and after any operations that they perform.

Urologist and general surgeons

Children with spinal disabilities are at an increased risk of having problems with how their urinary tract and bowels work. Urologists are surgeons who specialise in the urinary tract – this includes the kidneys, bladder, and the connecting tubes. Urologists and general surgeons have expert knowledge and experience in managing problems of the bowel and bladder and performing operations to ensure kidney function is maintained and to assist with achieving continence.



Orthopaedic surgeon

Our orthopaedic surgeons have specialised surgical training in musculoskeletal issues. They perform operations on bones, muscles, tendons, ligaments and the surrounding tissues.

Paediatric nephrologist (renal doctor)

Paediatric nephrologists have specialised training in the renal (kidney) system. These doctors may see your child if there are concerns that your child's kidneys aren't working properly.

Ophthalmologist (eye doctor)

Ophthalmologists specialise in all aspects of managing problems with the eyes - including medical treatment and surgery.

Wound and stomal therapy nurses

These are nurses with specialised skills in the assessment and management of wounds and pressure areas. They also have specialised skills in the care, education and management of catheters, stomas and post-operative cares for urinary/faecal incontinence surgery.

Physiotherapist

Physiotherapists are health professionals that specialise in movement and disorders of the musculoskeletal system. A physiotherapist will regularly assess and monitor your child's motor development as they grow.

Orthotist

Orthotists are a type of health professional who prescribe, manufacture and fit orthotic devices. An orthosis is any externally applied supportive device; sometimes an orthosis can be referred to as a splint or brace. Orthotists will assess, measure and review your child's orthoses.

Social worker

Social workers are professionals who provide both emotional and practical support for you and your family.

Services include:

- counselling and emotional support for both children and family members through times of crisis, distress, conflict, uncertainty and change
- provision of education and information
- advocacy
- counselling and emotional support for both children and family members through times of crisis, distress, conflict, uncertainty and change

Psychologist support is available to children who are having difficulty adjusting to their diagnosis or coping with their treatment. A child and youth mental health (CYMHS) consultation liaison (CL) team is a mental health team whose primary function is to provide mental health assessment where a young person is identified with mental health difficulties. The CYMHS CL can provide mental health intervention for children and young people who are frequently engaged with the hospital due to a medical diagnosis.

Dietitian

A dietitian provides assessment and management for nutrition related concerns as required, such as feeding difficulties, nutrition support, weight gain, or the need to increase fibre intake.

Neuropsychologist

A neuropsychologist is a specialist psychologist who is interested in patterns of cognition (thinking skills), learning differences, behaviour and the emotional well-being of children and adolescents with spina bifida and associated Arnold Chiari II malformation and hydrocephalus.

Medical imaging

Children with spina bifida may require x-rays, ultrasounds or other medical imaging procedures to help plan their care. If your child requires an x-ray, ultrasound, or MRI, we will try to coordinate it so it falls on the same day as your other appointments. If you would like to have scans completed in advance of your appointments at a different location, please speak with your referring doctor or the clinical nurse.

Clinical nurse and clinical nurse consultant

Our specialised nurses have extra skills and training in managing children with spinal disabilities. The clinical nurse is your contact for questions around your child's appointments and day to day care and issues. The clinical nurse can help liaise between different specialties to coordinate your child's care. Don't hesitate to call if you have any concerns.

Planning your day

When you arrive at the clinic, your child will be weighed and measured by a nurse and basic medical observations will be taken. You will be given a green folder which lists the location and order of your child's appointments for the day. If you have any questions about where to go, please ask the nurses at the clinic.

For your convenience, we work hard to coordinate all of your appointments on the same day where possible. While we try to keep everything running smoothly, clinic days can be long with periods of waiting in between appointments. It is a good idea to come prepared for waiting times with snacks and entertainment for your child. Please also bring any orthotics, catheters, or aids your child needs, and a list of your community health care providers.

If you are wondering how much time you might have before your next appointment, please ask the clinic nurse for an estimate. If you have large amounts of time in between appointments you might like to visit the hospital cafes, the Entertainment Precinct on level 6, or take a walk outside.

When you are sitting in the 2E waiting area, please place your green folder on the trolley near the first consult room to let us know you are present.

Medical imaging appointments

Renal (kidney) ultrasounds are completed regularly for most children who attend the clinic to help monitor their bladder function and kidney health. If your child has a renal ultrasound scheduled on your clinic day you may receive special instructions on how to prepare for the scan.

Appointment times

Review appointments will be booked as per the specialists' requests. We understand your child is always growing and changing, so if you have concerns about your child or want to be seen sooner by any of the specialists in the spinal disabilities team please contact the clinical nurse. Additionally, if you find your appointments aren't coordinated to the same day, please contact us and we will do our best to make this happen for you.

For families living outside Brisbane

If you need to travel more than 50km to attend appointments at Queensland Children's Hospital you may be eligible for financial assistance with the cost of travel or accommodation through the patient travel subsidy scheme (PTSS). For more information, visit

The Patient Travel Subsidy Scheme (PTSS)
https://www.qld.gov.au/health/services/travel/subsidies

Section 5: Your child's development

Development refers to how your child grows physically, emotionally, learns to communicate and socialise. In the early years the main way your child learns these skills is through play and interactions with their parents and caregivers. Each child will have their individual needs.

This section outlines typical developmental milestones for babies and young children. Your child will develop at their own rate and your therapy team will help you navigate each step and work towards appropriate goals for your child and reaching the next milestone when your child is ready.

Useful online resources for child development

Personal health record
https://www.childrens.health.qld.gov.au/our-work/personal-health-record-red-book

Ages and stages information sheets
https://www.childrens.health.qld.gov.au/resources/health-services/child-development-service/ages-and-stages-sheets

Baby's physical development
https://www.childrens.health.qld.gov.au/__data/assets/pdf_file/0033/174984/240201-Your-guide-to-the-first-12-months-1.pdf

Feeding skills

Developing appropriate feeding skills are part of every child's development. Meal times should be a fun enjoyable experience for the family but sometimes they can be challenging. For children with spina bifida, particularly if they have hydrocephalus and an arnold-chiari II malformation, they can experience challenges with feeding, including:

- Difficulties establishing a strong suck
- Difficulties with the suck, swallow, breathe synchrony
- Difficulties with tongue function, particularly important for manipulating food in the mouth and initiating the swallow reflex
- Coughing or gagging.

Some children may have particularly complex needs and require an alternative method of feeding for a period of time. This could be because they were born early or following surgery. Nasogastric feeding is used in these cases as a short-term feeding option.

Another type of alternate feeding is through a feeding tube which passes directly into the stomach or intestine. This is a longer-term feeding option, usually for children with complex medical issues.

At six months of age most children show signs they are ready to start solid foods. These signs include showing an interest in their food, reaching for food, opening their mouth when offered food. It is important your child can hold their head up with good head and neck control and can sit upright when supported before starting solids.

Sensory issues related to feeding

Some children may find the sensory experience associated with eating and drinking challenging. This can lead to issues with:

- Tolerating different or mixed textures in their mouth
- Transitioning between smooth, lumpy, and chewy foods
- Recognising how much food they have in their mouth (overstuffing/pouching of food in cheeks)
- Tolerating different tastes and temperatures of foods.

If you have any concerns with your child's feeding, speak to the spinal disabilities team for advice and help. You may be referred to a speech pathologist or infant feeding team for more support in this area.

Typical developmental milestones

	Speech development	Hearing and understanding	Play development
By 3 months	• Sucks and swallows well during feeding • Quiets or smiles in response to sound or voice • Coos or vocalises other than crying • Turns head toward direction of sound	• Turns head toward sound or voice • Quiets or smiles in response to sound or voice • Shows interest in faces	While lying on their back: • Visually tracks a moving toy from side to side • Attempts to reach for a rattle held above their chest • Keeps head in the middle to watch faces or toys

Typical developmental milestones (cont.)

	Speech development	Hearing and understanding	Play development
By 6 months	• Begins to use consonant sounds in babbling, e.g., ‘dada’ • Uses babbling to get attention • Begins to eat cereals and pureed foods	• Listens and responds when spoken to • Fears loud or unexpected noises • Notices toys that make sounds	• Reaches for a nearby toy while on their tummy While lying on their back: • Transfers a toy from one hand to the other • Reaches both hands to play with feed
By 9 months	• Increases variety of sounds and syllable combinations in babbling • Looks at familiar objects and people when named • Begins to eat junior and mashed table foods	• Recognises sound of name • Looks at familiar objects and people when named • Follows some routine commands paired with gestures	• In a highchair, holds and drinks from a bottle • Explores and examines an object using both hands • Turns several pages of a chunky (board) book at once • Imitates others in simple play

Typical developmental milestones (cont.)

By 12 months	• Meaningfully uses ‘mama’ or ‘dada’ • Responds to simple commands, e.g., ‘come here’ • Produces long strings of gibberish (jargoning) in social communication • Begins to use an open cup	• Responds to ‘no’ • Responds to simple directions, e.g., ‘come here’ • Pays attention to where you are • looking and pointing	• Finger feeds self • Releases objects into a container with a large opening • Uses thumb and pointer finger to pick up tiny objects
By 15 months	• Vocabulary consists of 5-10 words • Imitates new, less familiar words • Understands 50 words • Increases variety of coarsely chopped table foods	• Consistently follows simple directions • Shows interest in pictures • Can identify 1-2 body parts when named	• Stacks two objects or blocks • Helps with getting undressed • Holds and drinks from a cup

Tips to encourage development

Every child with spina bifida is different and will develop at their own rate. Please speak to your therapy team about activities appropriate for your child’s specific needs.

Activities for infants aged 0-4 months

Babies develop skills for speech and language by listening to sounds around them.

Some activities apply to more than one development domain. Supervise infants at all times when enjoying these activities.

Communication	Fine motor	Gross motor	Personal/social	Problem solving
Talk softly to your baby when feeding them, changing their nappy, and holding them	Place your finger in your baby's hand and watch how strong their grip is	When baby is awake, place them in various positions, such as on their stomach or side	Play music and sing to baby	Let your baby follow a rattle, spoon or toy with their eyes. Talk softly as you play
Read simple books to your baby	Put baby on different surfaces like rugs or mats so that they can feel the different textures	Put baby on their stomach when they are awake. Babies need tummy time every day	Make eye contact with your baby and smile, chuckle and coo at them	Play peek-a-boo with your baby
Make up songs to sing to your baby	Put toys near where baby can reach them	While baby is lying on their back, help them learn about their feet by playing games with their feet and toes	Encourage baby to smile back at you	Hold your baby up in front of a mirror. They may enjoy smiling and making noises at themselves
Do not forget that baby loves to hear your voice	Rub your baby's fingers and toes one at a time. Your baby will enjoy the way it feels		Gently massage baby with oil – talk and sing to them while you do this	

Activities for infants aged 4-8 months

Babies are curious at this age and want to learn about the things they see and hear.

Some activities apply to more than one development domain. Supervise infants at all times when enjoying these activities.

Communication	Fine motor	Gross motor	Personal/social	Problem solving
Talk to your baby during everyday activities such as nappy changing and mealtimes	Give your baby a toy to hold in their hands	Put your baby on their tummy with a toy slightly out of reach. Encourage them to reach out for it	In a mirror, smile and wave to your baby	Make different sounds for your baby to hear. Watch to see if they search for the sounds
Give your baby things to look at while they are lying on their back	Give your baby a spoon to grasp and chew on	On the floor, sit baby between your legs, providing as much support as they need. Place a toy in front of them to reach for	Place your baby on your knee facing you. Bounce them to the rhythm of a nursery rhyme	Play peek-a-boo with your baby
Talk to your baby about what they can see and hear	Encourage your baby to pass a toy from one hand to another	Stand baby on your knees. Hold them so they look at you, keeping their heels down	Spend time outdoors with your baby. They will love being out and about with you	Place toys close to the change table and high chair so baby can reach for them
	Sit in front of your baby on the floor, supporting them. Drop a ball into a plastic container		Read to your baby, making lots of different sounds	

Activities for infants aged 8-12 months

Your baby needs opportunities to explore and experiment with new skills.

Some activities apply to more than one development domain. Supervise infants at all times when enjoying these activities.

Communication	Fine motor	Gross motor	Personal/social	Problem solving
Use single/simple words when talking to your baby. Repeat them over and over	Your baby will begin to use their index finger to poke. Encourage baby to point at objects too	Put toys on a table so that your baby can practice standing and stepping sideways while playing with them	Let your baby play with plastic measuring cups in the bathtub. Bath time is a great learning time	Your baby will be interested in banging objects to make noises. Show them how to bang things together
Read baby books or colourful magazines. Let your baby touch pictures in the book	Let your baby feed themselves. This gives them experience with textures in their hands and mouth	Find a big box that your baby can crawl in and out of. You can do this together, or with a sibling	Mirrors are exciting at this age. Smile and make faces together in the mirror	Let your baby make choices. Offer two toys or two types of foods and see which one they pick
Talk to your baby during everyday activities such as nappy changing and mealtimes	Make a simple puzzle	Play ball games. Roll a ball to your baby. Beach balls or soft balls are great for this game	Name the body parts as your baby touches your face	Play pat-a-cake, clap hands together, or take turns
		Clap hands with your baby. Encourage them to make sounds as they play		Play hide and seek games with objects. Help baby find the object

Activities for infants aged 12-16 months

Reading aloud, singing to your child and sharing stories assists with your child's development.

Some activities apply to more than one development domain. Supervise children at all times when enjoying these activities.

Communication	Fine motor	Gross motor	Personal/social	Problem solving
Name the object your child wants. See if they can repeat the word back to you	Cut up safe finger foods (not foods that are a choking risk) for your child and allow them to feed themselves	Most children enjoy music. Clap and dance to the music together	Let your child help you clean up. Play 'feed the rubbish bin' or 'give it to mummy and daddy'	Children love games at this age. Try pat-a-cake, this little piggy went to market, or different ways of playing games
Play the naming game. Name body parts, common objects and people	Draw pictures on butcher's paper with your child and let them draw as well	Encourage your child to walk by holding their hand or pushing toys around	Let your child 'help' during daily routines. Encourage them to get the cup and spoon for mealtimes, for example	Loosely wrap a small toy in a paper towel or tissue without tape. Your child can unwrap it and find a surprise
Make puppets out of a sock and play games with baby	Get your baby to put small objects into containers. Use safe objects for this game	Hold your child in a standing position, facing another person. Have them step towards the another person to get a favourite toy	Play 'pretend' with a toy animal or doll. Show and tell your child what the doll is doing (walking, going to bed or eating)	Make sound shakers by filling empty plastic bottles with rice. Be careful to secure lids tightly
Read your child a book and use different voices and sounds to attract their attention		Play simple puzzles with your child	Give your child things to roll, push, pull, hug, shake, poke, tum, stack, spin and stir	

Section 6: Common concerns

Hydrocephalus and shunt

Some children with spina bifida have a shunt placed to treat the extra fluid around their brain. If your baby has had a shunt operation the neurosurgeons will see you between six to eight weeks after the operation in clinic.

What are the signs that a shunt needs to be reviewed and/or replaced?
Problems can develop if your child's shunt becomes blocked, disconnected or an infection develops. The signs that the shunt is not working are similar to the signs that the child has too much fluid in the brain.

If you notice any of the signs below, take your child to your closest emergency department or call 000 in an emergency.

Infants

- Poor feeding
- Vomiting
- Sleepy (hard to wake up) or not as alert
- Larger head
- Bulging soft spot (fontanelle) on top of the head
- Seeming irritable (cries easily or without reason)
- Seizures
- Slowness at reaching milestones (e.g., slow to roll over or sit)
- "Sunset" eyes (when eyes appear to be always looking down and are not able to look up)

Toileting

It is common for children with spina bifida to have a neurogenic bladder and bowel – this means there is a problem with the messages from the brain to the parts of the body controlling urine and bowel movements.

Bladder

Your doctor will give you special instructions on how to keep your child's bladder and kidneys healthy. Advice might include using catheters and having regular ultrasounds of their kidneys.

Care at home

If your child requires catheters, make sure you understand how to use them properly. Help and education is available. Clean hands and correct techniques can reduce the chance of your child developing an infection.

Around the age of two many children start to show an interest in using the toilet. When this happens, you should encourage your child to take time to sit on the toilet regularly, even if your child uses catheters.

When going out, make sure you have enough supplies like catheters, pads or nappies and a change of clothes in case of accidents.

When to see a doctor

- Urinary tract infections are common in children with spina bifida. If your child has unexplained fevers, vomiting, irritability, decreased feeding or tummy pain, or their urine looks or smells different than usual, contact your GP or the spinal disabilities team right away.

- If you notice a change with your child's normal patterns, for example leaking between catheters when they previously did not leak, speak to your GP or the spinal disabilities team.

DID YOU KNOW?

If you are eligible for the national disability insurance scheme (NDIS) you can request a continence nurse assessment each year as part of your package of care. This way you can ensure your child's continence needs are reviewed regularly and you are up to date with the latest continence products available for your child.

Bowels

A neurogenic bowel can make it difficult for your child to have regular bowel motions (poos). Some children become constipated and some experience leakage between bowel movements. Untreated, constipation can cause leakage of stool (poo), can lead to blockages and can make future constipation harder to manage. Your doctor will help you establish a bowel routine that keeps your child's bowels healthy.

Care at home

Many infants will have a change in their poos when they have a change in their diet. For example, when they switch from breastmilk to formula or begin eating family foods for the first time. Infants sometimes benefit from leg cycling or gentle tummy massage to help them pass a bowel motion.

When your child is old enough for more solid foods, a healthy diet, including fruit, vegetables and whole grains is important for your child's overall health and growth, as well as the health of their bowels. Offering these foods to your child at every meal will encourage them to eat a healthy diet.

Offering water regularly throughout the day and with meals is also important.

Around the age of two, many children start to show an interest in using the toilet. When this happens, you should encourage your child to take time to sit on the toilet regularly, especially after they eat.

If your doctor has recommended you use enemas, bulking fibre agents, or wash outs, make sure you understand the instructions. Your spinal disabilities team can help if you don't understand. Make sure you continue your child's bowel routine regularly and as instructed.

When to see a doctor

Speak to your child's GP or the spinal disabilities team if your child's tummy is more bloated than normal, if your child is leaking poo and they were not before, or if you are having trouble managing their bowel routine.

When your child starts school, your spinal disabilities team can help you plan for managing toileting at school.

Skin care

Children with spina bifida often have reduced sensation to parts of their body. This might mean they do not notice when they have an injury or when something is causing damage to their skin. Your child can still participate in all the activities they love, but skin monitoring should be part of their regular routine.

Care at home

Check your child's skin regularly, especially the bottom, ankles and feet. This should be done every day as part of your routine. For example, it can become a part of your nappy change routine for a younger child. An older child may be taught to use a mirror to check their feet and bottom before their bath.

Footwear: Your child should wear shoes when they are walking, especially outdoors. If you notice shoes, splints, or orthotics are leaving marks on your child's feet, remove them and speak to your spinal disabilities team.

Some children will experience carpet burn when they begin to crawl around the house. Wearing long pants or tights at this stage may prevent this from happening.

Keep skin dry. Avoid leaving your child in wet or soiled clothes. Speak to your GP or the spinal disabilities team about barrier creams and powders to keep skin dry and protected under nappies.

Be mindful of sand getting inside your child's clothing, shoes or splints and of objects being in pockets or underneath them when they sit.

Be careful during transfers when skin might drag across a surface and in situations where your child is sitting for long periods of time.

Remember your child won't feel heat so they may not react if the bath is too hot or if they walk on hot cement. Teach your child to feel with their hands first to tell if the water or a surface is too hot.

When to see a doctor

Speak to your child's GP or the spinal disabilities team if your child has any red marks that last more than 30 minutes.

If an injury is looking worse over time, is oozing, becomes swollen, or if the skin surrounding an injury becomes red or hot to the touch, see your child's GP or the spinal disabilities team right away.

Latex

Children with spina bifida are more likely than others to develop an allergy to latex so it is best to avoid latex products. Latex is often found in balloons, medical gloves and bandages. There are usually latex free versions of these items available. Latex free products may say "latex free" or be marked with this symbol: 

Care at home

Avoid having latex containing products in your home or in your child's classroom.

Inform your child's school and any health care providers or people caring for your child that your child has a latex allergy.

When to see a doctor

If your child has come into contact with latex and has developed a rash, itchiness, or other symptoms, see your GP.

If your child is having difficulty breathing or swallowing, or their lips appear swollen, call an ambulance.

You know your child best. If you are ever concerned about your child, contact your GP or the spinal disabilities team. If you can't get in touch with your regular team and you think your child is very unwell, or you are concerned about your child's breathing, go to your local emergency department.

Section 7: Planning for future pregnancies

We do not know the exact cause for spina bifida and it is important to remember that there is nothing you have done wrong in your pregnancy to cause this. We know that maintaining healthy levels of folate is important in prevention. This is taken as a supplement called folic acid.

What is folic acid?

Folic acid is one of the B group vitamins. It is used in your body to make red blood cells. Research has shown that taking folic acid in the early stages of pregnancy reduces the risk of having a baby spina bifida by up to 70 per cent. However, it will not guarantee the baby will not have spina bifida.

Where can I get folic acid?

The best way to get enough folic acid is to eat a healthy varied diet as well as taking a vitamin tablet. Folate does occur in some foods like fruit and green vegetables however not enough to meet your requirements in pregnancy alone.

How much folic acid do I need?

As you have had a baby with spina bifida there is a higher risk of having another child with spina bifida. We therefore recommend that you take a higher dose of folic acid (5mg) when you start planning on your next pregnancy. Start taking folic acid one to three months before conception and continue this through the first trimester. Your obstetrician and GP can help guide you on further dosing.

Where can I receive further support?

When planning future pregnancies speak to your GP. The preconception care service at the Mater Mothers' Hospital in Brisbane assists couples planning a pregnancy to optimise their health before conception. Your GP can refer directly to this service.

Section 8: Supports and services

There are different options of financial assistance available for caregivers of children with a disability.

Centrelink

Carer allowance

This is an income supplement for parents or carers providing extra daily care for an adult or dependent child with disability or a medical condition. There is an annual income test, but not an assets test. Carer allowance provides a fortnightly payment and a health care card for the person with disability.

Carer payment

This is an income support payment if you give constant care to someone (child or adult) who has a severe disability, illness, or an adult who is frail aged. This payment is income and asset tested.

Health care card is a concession card to obtain cheaper medicines under the Pharmaceutical Benefits Scheme. You may also use your concession card if your doctor bulk bills for visits. You will get a health care card if you are receiving carer payment or carer allowance. Carer supplement is an annual lump sum payment. It helps with the costs of caring for a person with disability or a medical condition. You will get carer supplement if you are receiving carer payment or carer allowance.

NDIS

The NDIS provides funding to support eligible people with disability as well as their families and carers. Children who meet the following criteria may be able to access the NDIS:

- Have a permanent and significant disability that affects their ability to take part in everyday activities
- Are an Australian citizen, a permanent resident or a New Zealand citizen who holds a protected special category visa

You can find more information on eligibility here https://www.ndis.gov.au/applying-access-ndis/am-i-eligible

If eligible, your child will be assessed in a planning and assessment process. Based on your plan, you will receive funding on an annual basis to purchase the supports, services, aids and equipment that your child requires. All the information you need can be found at www.ndis.gov.au

The spinal disabilities team can provide you with a diagnosis letter for your NDIS application.

Chronic disease management scheme

The chronic disease management scheme enables GPs to plan and co-ordinate the healthcare of patients with chronic conditions who require at least two other health care providers. Children with spina bifida are eligible to access this scheme.

The scheme provides a maximum of five total rebates per calendar year for allied health services. This means if you are accessing more than one allied health service you are entitled to five rebates across all of the services not five per service.

Counselling and carer support at no cost

Carer Gateway

Carer Gateway can offer six sessions of free counselling to anyone who identifies as a carer. The counselling service is offered in-person or by telehealth.

You can self-refer via 1800 422 737 and the intake team will take you through a process to assess what programs might be beneficial for you. For more information visit: www.carergateway.gov.au

White Cloud Foundation

Free service which offers tele-mental health support around: Anxiety, Stress, Depression, Grief/loss, Relationships or family issues, Coping with change, Dealing with financial or other life pressures, Living with serious injury or illness, Improving wellness and quality of life.

Self-referrals can be made via 07 3155 3456 and no GP referral is required. For more information visit: whitecloudfoundation.org

Beyond Blue

Beyond Blue offer a range of supports including peer forums and 24-hour individual brief phone or online counselling. For more information visit the ‘Get Support’ tab via: Beyond Blue | 24/7 Support for Anxiety, Depression and Suicide Prevention.

Section 9: Notes

We know you have been given a lot of information about your baby’s condition and it can seem overwhelming. This section is available for you write down any questions you have prior to your first appointment with the team.

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My spinal disabilities team is (name and contact details):

Paediatrician

Neurosurgeon

Orthopaedic surgeon

Urologist or general surgeon

Physiotherapist

Stomal therapist

Social worker

Spinal disabilities nurse

Other team members

AUDAX AT FIDELIS

Queensland
Government

childrens.health.qld.gov.au

childrenshealthqld

queenslandchildrenshospital