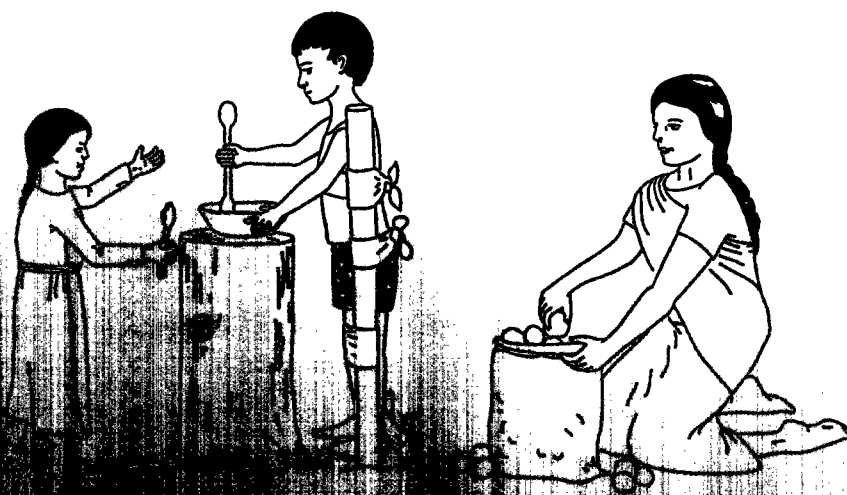


# Promoting the Development of Infants and Young Children with Spina Bifida and Hydrocephalus

A Guide for  
Mid-Level Rehabilitation Workers



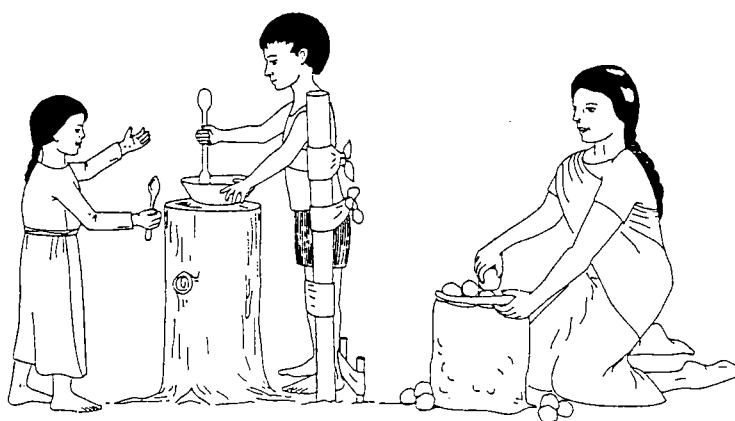
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# Promoting the Development of Infants and Young Children with Spina Bifida and Hydrocephalus

A Guide for  
Mid-Level Rehabilitation Workers



World Health Organization  
Geneva  
1996

World Confederation for  
Physical Therapy

World Federation of  
Occupational Therapists

International Federation for  
Hydrocephalus and Spina Bifida

### **Abstract**

This manual is for mid-level rehabilitation workers to use when they work with infants, children and young adults who have spina bifida and hydrocephalus and their families, and with other rehabilitation or health workers. The manual includes information on the types, signs and causes of spina bifida and hydrocephalus and assessment of the level of development of the child and complications caused by spina bifida and hydrocephalus. Training suggestions are given for promoting normal development, mobility, self-care and education. Splints and equipment are shown which can be locally made and used for promoting normal development and movement. Some adaptations may be needed for use in specific countries.

## FOREWARD

In 1994 a representative of the International Federation of Spina Bifida and Hydrocephalus (IFSBH) contacted the Rehabilitation Unit at the World Health Organization and proposed a collaborative effort to produce a guide for the care of children with spina bifida and hydrocephalus. This request was stimulated by the WHO document on cerebral palsy that had been prepared in collaboration with the World Confederation of Physical Therapy (WCPT) and World Federation of Occupational Therapists (WFOT) for use by mid-level rehabilitation workers (MLRWs)\*. As a representative of national organizations that share a concern about these children, the IFSBH expressed the need in many countries for practical information concerning the rehabilitation (or habilitation) of children who have spina bifida, hydrocephalus or both. WHO had also noted in community-based rehabilitation programmes that there was a lack of awareness of what can be done to promote the optimum development of children with such impairments.

As a result of the IFSBH initiative, WHO has produced this manual in collaboration with IFSBH, WCPT and WFOT. We wish to extend our gratitude to Mr Bjorn Rundstrom, who represented IFSBH; to the authors, Ms Virginia Binns and Mrs Elizabeth Bardos, who were selected by WCPT and WFOT respectively; and to Mr Marcus Cremonese, who prepared the illustrations. We also thank the Swedish International Development Authority for the special funds they provided at the request of IFSBH. The first draft of this manual was sent out for review by rehabilitation personnel involved in clinical work with children who have spina bifida and hydrocephalus. We thank those individuals who submitted thoughtful comments on the first draft. We also wish to express our appreciation for the work of Dr Ann Goerdt, a former WHO staff member, who coordinated tasks necessary for the preparation of this manual.

We believe that the multiple sources of input for this manual have produced a document that will serve well as a training guide for MLRWs and also as a reference for them in their clinical work with children who have spina bifida and hydrocephalus.



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Rehabilitation Unit  
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Geneva  
Switzerland

\* Countries have different titles for MLRWs, e.g. rehabilitation assistants or technicians, or physical or occupational therapy assistants.



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# WHAT ARE SPINA BIFIDA AND HYDROCEPHALUS?

## WHAT IS SPINA BIFIDA?

"Spina Bifida" comes from 2 words -

"Spina" meaning spine

"Bifida" meaning split or divided

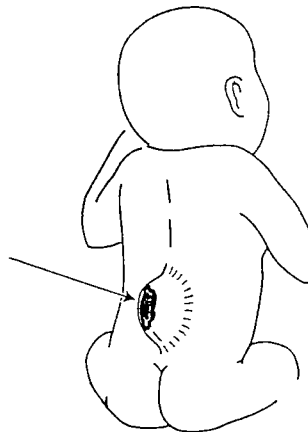
## HOW DOES THE SPINA BIFIDA OCCUR?

Spina bifida is a defect that occurs in the development of the infant's spine. It occurs about 24-26 days after the mother becomes pregnant.

The bones of the infant's spine do not close over the spinal cord (central tube of nerves). Part of the spinal cord which is located under these bones may be abnormally formed or damaged. A soft, unprotected area will be present on the infant's back. This may be covered by skin, or more commonly be an open wound which may bulge through the skin as a dark bag. This bag is covered by a very thin layer of skin which may leak liquid from the spinal cord and brain.

### **Spina bifida**

This may be an open wound or a lump of flesh over the site of the spina bifida.



## WHAT CAN BE DONE TO PREVENT SPINA BIFIDA?

There is not one single cause for spina bifida. However, there seem to be several factors which, when combined, may lead to spina bifida. It is very important to realise that neither parent is to blame when a baby with spina bifida is born.

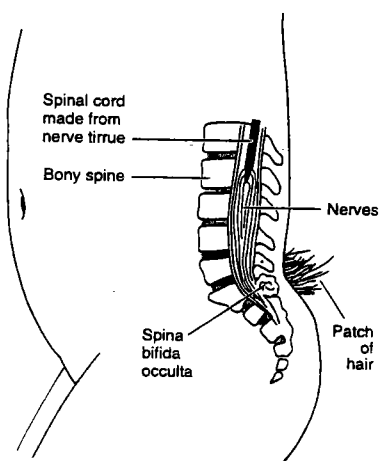
The risk of having a baby with any type of spina bifida can be lessened by:

- adding folic acid and Vitamin B12 to the diet. A pregnant woman can add folic acid by taking tablets or eating foods such as liver and raw vegetables. Taking folic acid is very important before and during pregnancy. If a woman is taking medicine to control other illnesses such as epilepsy, she may need to take larger amounts of folic acid.
- eating a healthy diet before and during pregnancy
- not drinking alcohol if a pregnancy is being planned

## ARE THERE DIFFERENT TYPES OF SPINA BIFIDA?

There are different types of spina bifida:

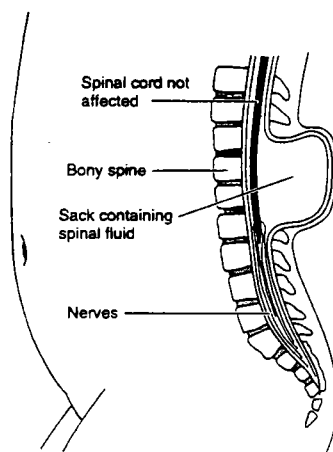
### Spina bifida occulta



- only bones over spinal cord affected
- hairy patch or fatty lump present
- usually no disability

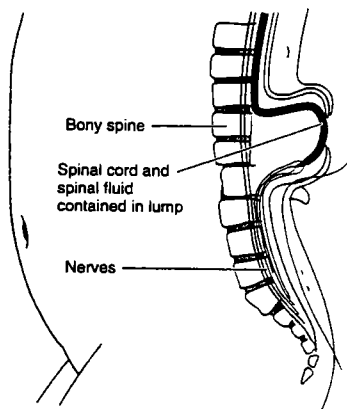
### Spina bifida aperta

#### Meningocele



- lump contains only spinal fluid, not spinal cord
- usually no disability

#### Myelomeningocele



- lump contains spinal fluid and spinal cord
- lump may be open or covered by skin
- permanent disability which varies from mild to severe

The most commonly occurring spina bifida is myelomeningocele. **In this book, "spina bifida" refers to myelomeningocele.** Spina bifida occulta occurs less frequently than spina bifida aperta. It does not usually cause disability.

For further information see the section on "What is spina bifida occulta?".

## HOW DOES SPINA BIFIDA AFFECT THE CHILD?

The spinal cord normally carries messages between the brain, and the body and limbs. These messages help to control movement of the limbs. They also tell the brain about the feelings of touch, pain and signals from a full bladder or bowel.

In spina bifida the nerves are damaged because the spinal cord has not formed properly. The amount of nerve damage varies greatly and can depend on where the lump is on the back.

### **The main effects of nerve damage are:**

- muscle weakness or paralysis. Paralysis can be of two different types:
  - Spastic (muscles feel stiff)** - where the spinal cord is normal below the level of the spina bifida. There may be reflex muscle activity. These movements are called spasms and cannot be controlled voluntarily.
  - Flaccid (muscles feel floppy)** - where the spinal cord is abnormal below the level of the spina bifida. The muscles are unable to contract even by reflex action. This type of paralysis is more common in children with spina bifida.
- lack of feeling in the skin
- lack of bowel and bladder control

### **WHAT IS SPINA BIFIDA OCCULTA?**

Spina bifida occulta may not affect the child and usually does not cause disability. However, the MLRW should be aware of any signs which may be caused by spina bifida occulta.

Spina bifida occulta means "hidden split in the spine". It is hidden because it is always covered by skin. It can affect any level of the spine but is usually found in the lower part of the back.

Infants may be suspected of having spina bifida occulta if they have one or more of the following over their spine on their back:

- a dimple in the skin
- long coarse hairs growing from the skin
- a dark red skin blemish
- a fatty lump in the tissues just beneath the skin

Leg or feet malformations may also be present as a sign of spina bifida occulta.

Spina bifida occulta is usually not detected at birth but may be diagnosed later if problems arise.

### **Problems associated with spina bifida occulta**

The most minor form of spina bifida has no abnormality of the spinal cord or nerves so there are no leg, bladder and bowel problems.

In other forms, spina bifida occulta can be associated with abnormal development of the spinal nerves and occasionally the spinal cord. These abnormalities can cause the spinal cord to attach to the spine and cause tethering.

The most common signs of spina bifida occulta are:

- loss of strength, feeling and co-ordination in the movements of the legs, mostly asymmetrical
- abnormalities of the feet, such as, clubfeet and clawing of the toes
- poor development of the muscles of the lower legs
- altered bladder and bowel function with retention of urine and constipation

### **Treatment of spina bifida occulta**

The child with spina bifida occulta should be assessed regularly for changes in the strength and feeling of the legs, and in bowel and bladder function.

Many of the treatments used for spina bifida aperta, including those for contractures and deformities, and bladder and bowel can be used for children with spina bifida occulta.

If tethering of the spinal cord causes major problems surgery may be necessary.

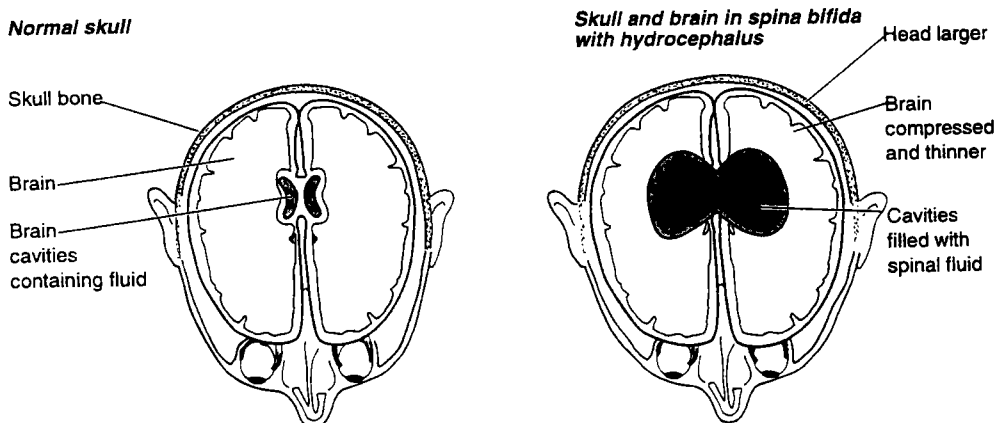
### **WHAT IS HYDROCEPHALUS?**

Hydrocephalus, means "water in the brain". Hydrocephalus affects most children born with spina bifida but there can be other causes of hydrocephalus.

A watery fluid is produced inside each of the cavities in the brain. This fluid flows through narrow pathways from one cavity to the next, then over the outside of the brain and down the spinal cord. This fluid is absorbed into the bloodstream.

Hydrocephalus occurs when the production of the fluid is greater than the absorption or when the drainage pathways become blocked.

If the pathways become blocked the fluid accumulates in the cavities causing them to swell and the brain can be pressed against the skull. In babies, the head will get bigger but in older children and adults the head cannot increase as the bones which form the skull are completely joined together. This can cause severe brain damage and blindness.

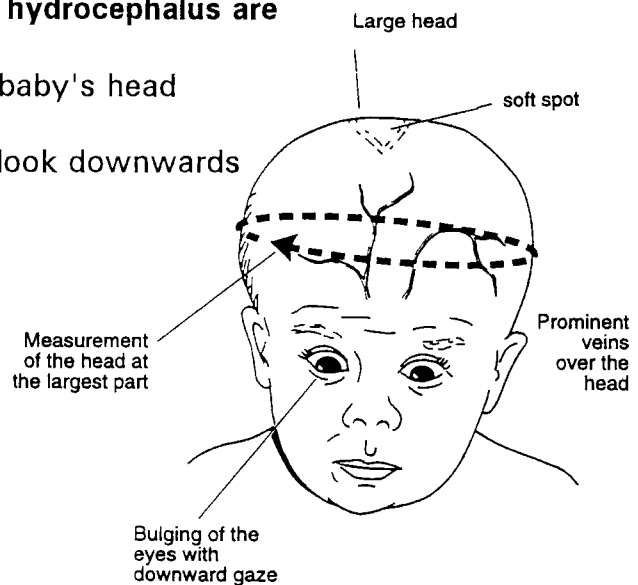


## WHAT ARE THE SIGNS OF HYDROCEPHALUS?

The size of the baby's head must be measured often. It should be measured around the largest part of the baby's head just above the ears. If it starts to grow too quickly, a doctor should be seen. He will test to see if hydrocephalus is present.

Other signs that may be present with hydrocephalus are

- full or tight soft spot on baby's head
- baby appears to always look downwards
- large veins on the scalp
- irritability
- drowsiness
- fits
- vomiting



## WHAT ARE THE CAUSES OF HYDROCEPHALUS?

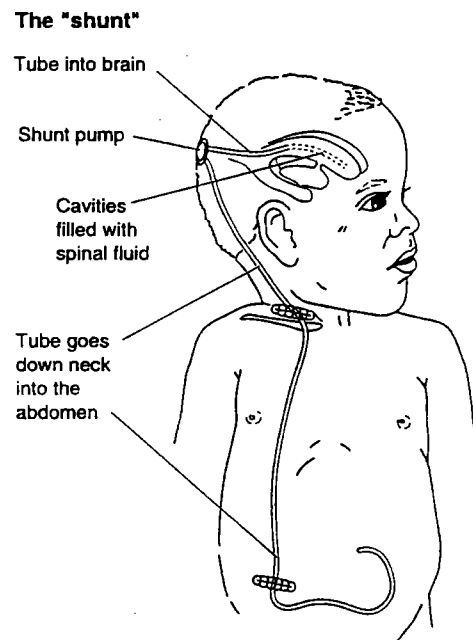
- Spina bifida - in addition to the defect of the spinal cord, there are abnormalities in certain parts of the brain which develop before birth. These prevent proper drainage of the fluid.
- Congenital hydrocephalus - hydrocephalus is present at birth and often has no exact cause.
- Prematurity - premature babies may develop hydrocephalus because their brain has not properly developed. The blood vessels in the brain are very weak and can be damaged if too much fluid is present. This may cause a blood clot to form preventing proper drainage of the fluid. This may be temporary or permanent.
- Brain bleeding - can occur in premature babies, children and adults and may cause hydrocephalus.
- Meningitis or infections of the membranes covering the brain - this infection may block the drainage pathways resulting in hydrocephalus. This may happen at any age.
- Tumours - swelling of the brain and surrounding tissues can result in poor drainage of the fluid.
- Genetic - very rarely, hydrocephalus may be hereditary and be common in some families.

## HOW IS HYDROCEPHALUS TREATED?

In some conditions hydrocephalus requires no treatment. In others the treatment may only be for a short time. Medicines can sometimes be used to treat hydrocephalus for short periods. Most conditions require surgical treatment by the insertion of a shunt. The shunt will not cure hydrocephalus but will drain excess fluid from the brain and prevent the condition from becoming worse.

A shunt may not be available. In this situation you will need to talk to the doctor about how to manage the child's hydrocephalus.

The "shunt" has been developed to drain the extra fluid from the brain that occurs with hydrocephalus. A shunt is a small plastic tube that passes from the brain, under the skin to the abdomen. It allows the extra fluid to be drained away from the brain and be absorbed in the abdomen. The shunt can be seen as it passes down the side of the neck below the ear. It then disappears deeper under the muscles into the abdomen. It is completely inside the body. When the shunt is working well it allows the head and brain to grow normally.



## CAN PROBLEMS OCCUR WITH SHUNTS?

There can be problems with shunts. They may occur suddenly or develop gradually.

Shunts can become infected, blocked or they can twist and break. The tube from the brain to the abdomen can become too short as the child grows. Surgery may be necessary to remove or replace the shunt or lengthen it as needed. Medicine may be necessary if an infection is present.

It is very important for parents and health care workers to be aware of the signs of a shunt problem and to take the child to the doctor or hospital if they are concerned.

## **WHAT ARE THE WARNING SIGNS OF SHUNT PROBLEMS?**

Warning signs can vary enormously between individual children and can also vary depending on the age of the child. It is important to listen carefully to the child and his carers about problems they may have which could be associated with the shunt. They can include one or more of the following:

- increase in head size
- full or tight soft spot at the top of the baby's head until it closes at about 18 months of age
- swelling along shunt around the pump or at the side of the child's neck
- vomiting
- fever and abdominal pain
- irritability and bad temper
- drowsiness or sleeping more than usual
- fits
- visual disturbances
- headaches in older children

# **WHAT CAN HAPPEN AS A RESULT OF SPINA BIFIDA?**

## **DIFFICULTIES WITH MOVEMENT**

Movement difficulty varies greatly between each child. This will depend on where the spina bifida (myelomeningocele) is located over the spine and how much nerve and spinal cord damage is present.

In some children there may be total loss of movement or paralysis below the waist. In others there may be paralysis just around the feet.

Movement may be different in each of the child's legs.

Disabilities occur in parts of the body below the spina bifida. Because spina bifida usually occurs in the middle of the spinal cord or lower, the functions of the upper body, arms, hands, neck and head are usually normal.

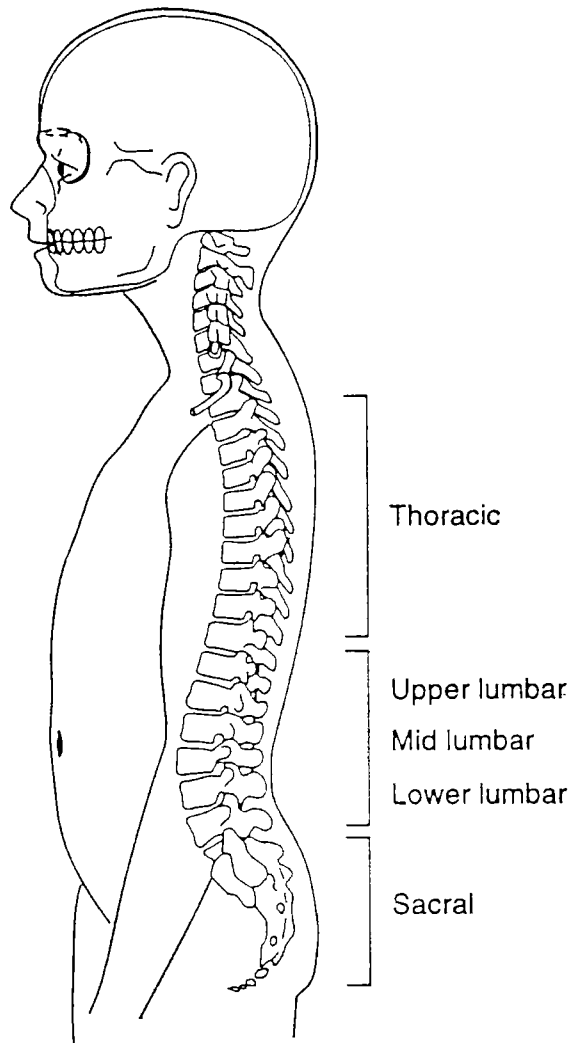
The ability to move is not the same for all children with spina bifida. Depending on where the spina bifida is on the child's back there will be differing amounts of movement loss.

The loss of movement present when the baby is born is permanent and usually does not change.

If a change in the child's movements is noticed as he grows, it is essential to contact a doctor as soon as possible. This can be the first sign of a tethered spinal cord. A tethered cord is when the spinal cord and nerves are caught near the site of the spina bifida and causes the spinal cord to stretch. If this is not treated early progressive and permanent disability will occur. It is generally treated by surgery.



If the spina bifida is at the:



### **Thoracic level**

- child will not be able to stand up by himself
- he will require high level bracing and splinting to stand
- he will need a wheelchair for mobility
- common deformities are kyphosis, scoliosis, hip dislocation, knee contractures, club feet

### **Upper lumbar level**

- child will usually not be able to stand up by himself
- he will require braces and crutches to walk
- he will probably need a wheelchair
- common deformities are hip dislocation, knee contractures, club feet

### **Mid lumbar level**

- child may have some ability to walk by himself with aids
- he will require bracing
- he may not need a wheelchair
- common deformities are hip flexion contractures, hip dislocation, club feet, calcaneous feet

### **Low lumbar and sacral level**

- child will usually stand at a normal age
- walking by himself may be delayed
- child may need braces for ankles but not use crutches to walk
- common deformities are club feet, foot and toe deformities

## PROBLEMS WITH BONES

### **SPINAL CURVATURES**

The spinal bones where the spina bifida is located will always remain split. This can affect the spine as the child grows and cause different types of curvature.

These spinal curvatures may develop because of muscle weakness and paralysis; soft spinal bones which cause the spine to bend easily; or bone malformations of the spine. If the curve becomes too large it may affect the child's breathing or movement. In this case the child may need to see a doctor.

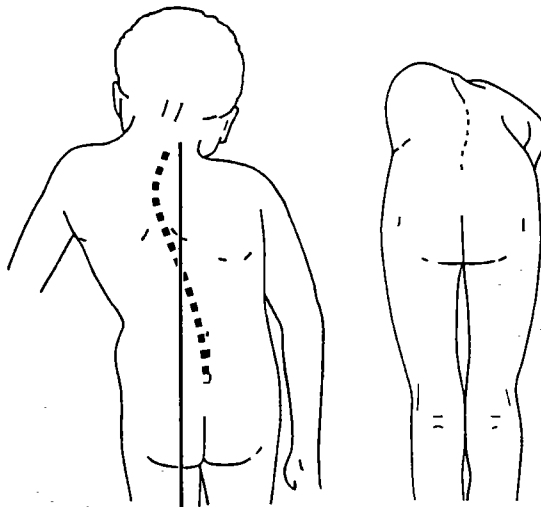
The three main types of curvatures are

#### Kyphosis



The spine is curved out at the back and produces a hump.

#### Scoliosis



The spine bends sideways and rotates causing a rib hump on one side. This can be seen more easily from behind when the child bends forwards.

#### Lordosis



The lumbar spine bows inwards.

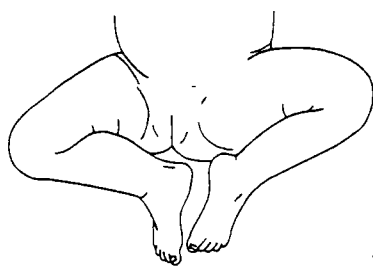
## LEG DEFORMITIES

Each of the joints in the leg (hip, knee and ankle) needs to be looked at very carefully when the baby is born. Some joints may be tight or contracted at birth. Most deformities will develop as the child grows due to unequal muscle strength.

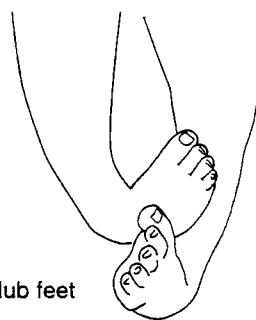
All problems with bones and joints need early treatment to prevent more disability. If treatment is delayed for several weeks, then the deformity becomes much harder to correct.

See the section on "Treatment of Contractures and Deformities".

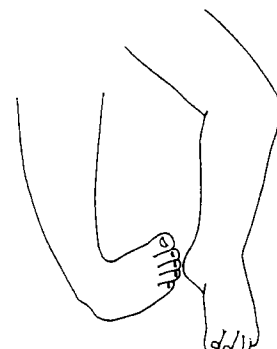
### Examples of common leg deformities



Right dislocated hip - note asymetry of skin wrinkles on thigh



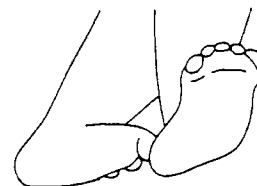
club feet



mixed deformity - right club foot and left knee contracture



Overstraight knee



calcaneus deformity of both feet

## SOFT BONES

Children with a lot of muscle paralysis may have "soft" bones in their legs. This is caused by the child not standing or walking normally on their legs. Soft bones can break easily so the child must be careful when moving. If any of the following signs are noticed the child should see a doctor.

### Warning signs for broken bones

- swelling of the leg
- deformity of the leg
- heat or redness in the leg

## LACK OF FEELING IN SKIN

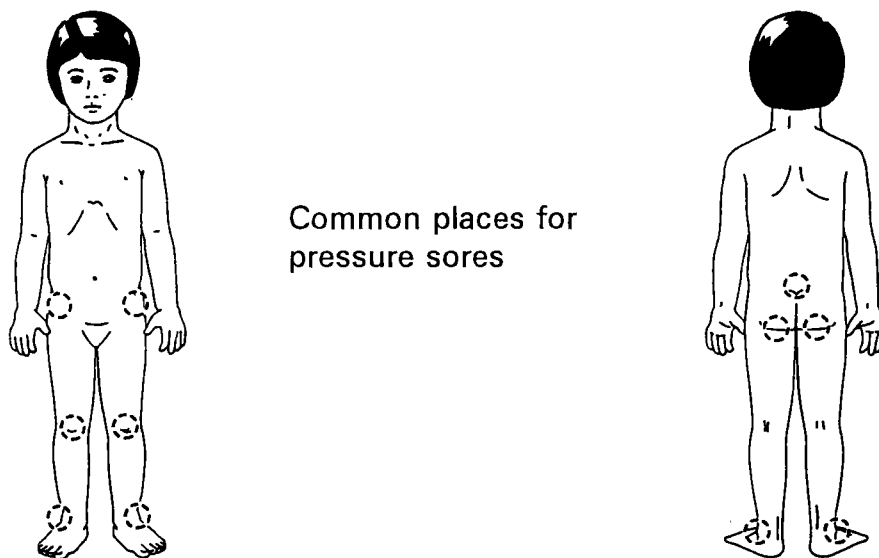
Because of the nerve damage that occurs, children with spina bifida do not have normal senses of feeling and pain in their body, legs and feet. In some children there may be total lack of feeling below the level of the spina bifida. In others there may be lack of feeling just around the toes. The amount of lack of feeling will depend on where the spina bifida is located over the spine and the amount of nerve damage in the spina bifida.

Due to the lack of normal feeling, injuries will not be felt. Simple burns and cuts can be a problem as these wounds take much longer to heal than they do for children with normal feeling. It is important for the child to protect his legs to prevent injuries.

See the section on "Self-Care Skills" for suggestions of clothing.

Pressure sores can also occur if the child is sitting or lying in one position for a long time. Areas that are most likely to develop pressure sores are buttocks, heels and knees. These sores can become deep ulcers and take many months to heal. If a sore does develop, care must be taken to keep the sore clean and prevent it from getting larger.

See the section on "Management Of Pressure Sores".



It is most important that the child wears well fitting shoes and braces and changes his position often in order to prevent pressure sores. Certain areas on the child's skin should be checked every day for pressure sores using the above illustrations as a guide.

### **Skin warning signs**

- redness of the skin
- blisters and sores

## POOR BLADDER AND BOWEL CONTROL

In spina bifida, lack of control in passing urine and stools (incontinence) is due to the damaged nerves which control the muscles of the bowel and bladder. These nerves come from very low in the spinal cord, so bladder and bowel problems are common in children with spina bifida.

### **There are two main types of problems with bladders**

- bladders that dribble urine all the time - the child is constantly passing urine.
- bladders that don't empty - urine cannot get out of the bladder. Urine may be pushed back up to the kidneys, causing damage to them. If urine is left in the bladder for any length of time it can cause infections which can also damage the kidneys.

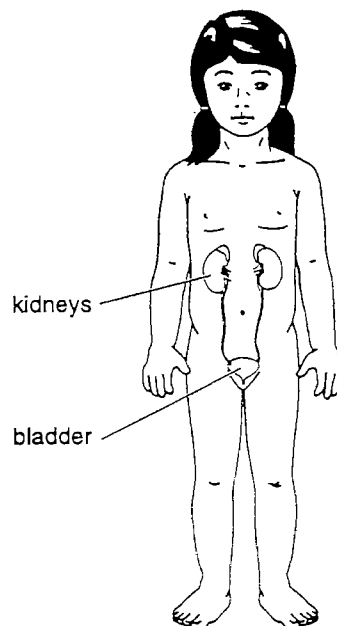
Good kidney function is essential for the child to remain well and healthy. The bladder and kidneys must be looked after well.

The parents of a child with spina bifida should talk to their doctor about the type of bladder their child has and appropriate management.

For ideas on management see the section on "Management of Bladder and Bowel".

### **Bladder warning signs**

- fever
- stomach ache
- urine smelling more than usual
- blood in urine



Poor bowel control is caused by a combination of lack of muscle control and lack of feeling in the bowel area. This causes some children to be constipated or to have loose stools.

The child does not feel that stools have arrived in the back passage and a bowel movement is about to take place. He is not able to prevent the stool from being passed by tightening his muscles. As a result, frequent stools are passed without warning.

In other children, the stools stay in the back passage, and constipation is the result.

Both constipation and frequent passing of stools can be controlled by going to the toilet at the same time everyday. They can also be assisted by diet which contains lots of fibre such as vegetables, fruit and grains. This will help prevent the embarrassment of bowel incontinence, especially as the child gets older and goes to school.

For ideas on management see the section on "Management of Bladder and Bowel".

## WHAT CAN HAPPEN AS A RESULT OF HYDROCEPHALUS?

### DIFFICULTY WITH LEARNING

Many children with hydrocephalus have difficulty learning. Hydrocephalus does not prevent the child from learning, but makes it harder for the child to learn.

These difficulties can interfere with all kinds of learning including school work, activities at home and with self-care activities.

If hydrocephalus is not treated, brain damage will occur resulting in a greater loss of intellectual function.

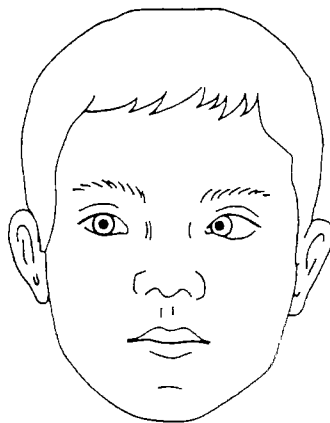
### DIFFICULTY WITH EYESIGHT

Many children with hydrocephalus will develop a squint. This may occur when a shunt becomes blocked. It may also occur if the child does not have a shunt and there is a build up of fluid in the brain. A squint can occur in one or both eyes. The most common type is when the eye turns inwards.

The squint may go away if the shunt is unblocked but if the shunt has been blocked for a long time this may not be so.

Infants and children with a squint will only use the normal eye to see. This may result in sight not developing in the squinting eye. Squinting can be treated by putting a patch over the normal eye to encourage sight to develop in the squinting eye. Sometimes surgery may be necessary to straighten the squinting eye. It is important for the child to see the doctor if a squint develops.

Left squint- as child looks forwards left eye turns inwards



### FITS

Fits occur more commonly in children who have shunts. If they are uncontrolled they may cause brain damage making it even harder for the child to learn. If fits occur it may be necessary for the child to take medication.

See WHO Training Package 21 "Training package for a family member of a person who has fits - Information about the disability and what you can do about it".

**References will be made throughout this book to Training Packages from the WHO CBR manual "Training in the Community for People with Disabilities". These Training Packages are not available as single books.**

# PROMOTING DEVELOPMENT AND MOVEMENT

## ASSESSMENT

When an infant with spina bifida is born he will need to see a doctor immediately. He will usually require an operation to repair the spina bifida and may need to stay in hospital for some time. When the infant returns from the hospital, it will be very important to assess him carefully and design a treatment plan. This plan will assist you in developing special exercises which will help to promote his development. It may be done in consultation with the physiotherapist or occupational therapist.

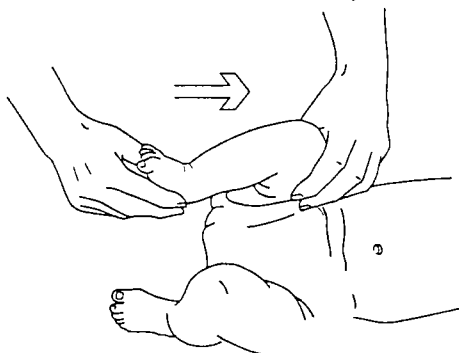
## ASSESSMENT OF THE INFANT

Assessment of an infant with spina bifida must cover several areas. These include:

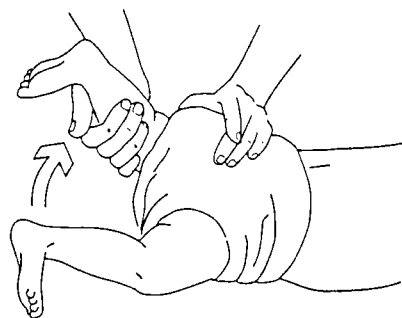
### 1. Presence or absence of movement in the legs

At the first assessment, movement in the infant's legs should be looked at. The presence or absence of leg movements should be observed and recorded on an assessment form (see pages 21 and 22). A muscle chart is a useful way of recording these movements. Rather than look at each individual muscle in the leg, look at the movement at each joint to see if it is present or not. The following diagrams show what the joint movements are called. The diagrams show the movement being guided by the hands. When you are observing active movement do not place your hands on the infant just watch to see what the infant can do on his own.

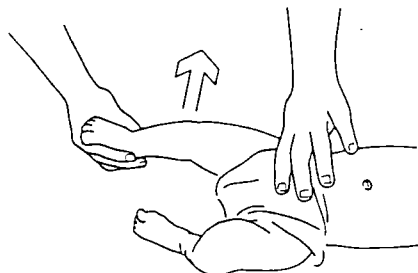
Hip flexion - bends towards belly



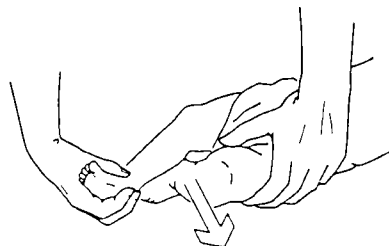
Hip extension - straighten



Hip abduction - away from middle

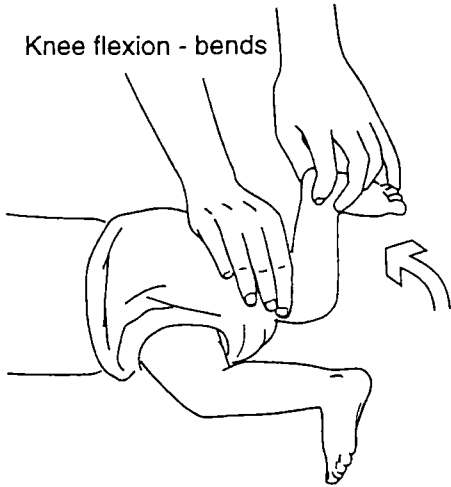


Hip adduction - towards middle

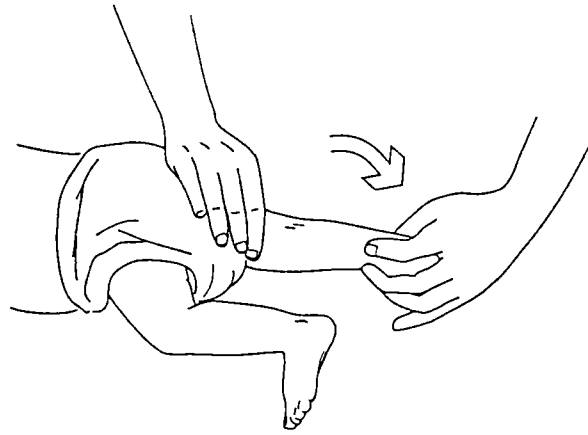




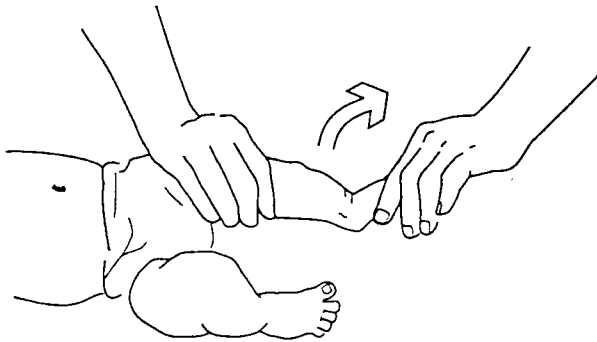
Knee flexion - bends



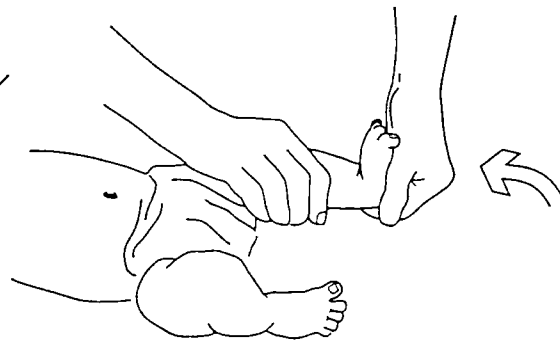
Knee extension - straightens



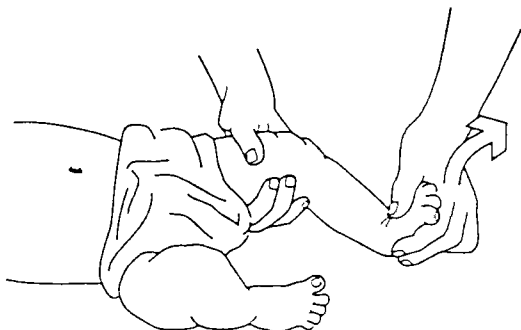
Ankle-plantar flexion - points downwards



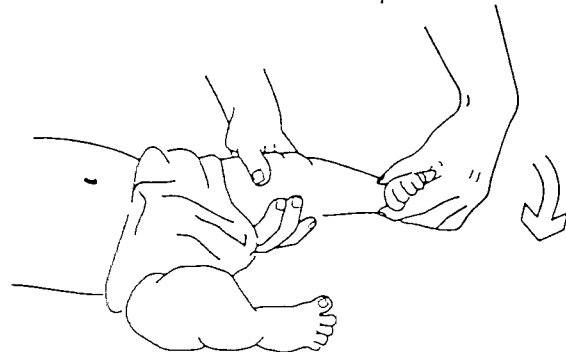
Ankle dorsiflexion - pulls upwards



Ankle-foot eversion - points outwards



Ankle/foot inversion - points inwards



The strength of the movement at the joint should also be graded and recorded. Consult a physiotherapist if you are unsure of how to use the following muscle strength gradings:

- 0 - no contraction
- 1 - contraction, no movement
- 2 - movement without gravity
- 3 - movement against gravity, no resistance
- 4 - movement against gravity, with resistance
- 5 - normal strength

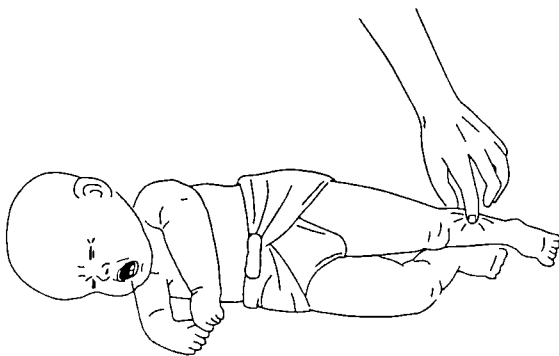
It is difficult to record accurately the strength of an infant's movements. To best do this the assessment should be done when she is awake as you need to see what movements she can do on her own. Talking to the infant and holding toys or brightly coloured objects in front of her may stimulate movement. It can also help to look at the movements in the infant's legs when she is crying as they may move more at this time.

It is important that the movement in each leg is recorded separately as there is often a difference in the strength of each leg.

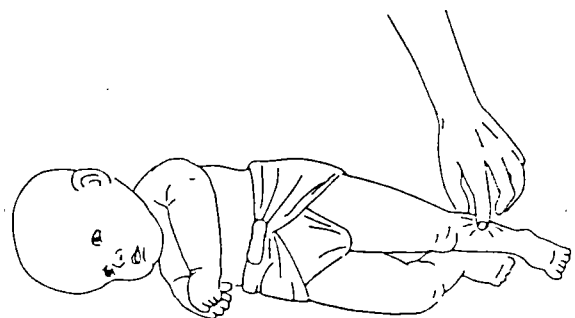
## 2. Presence or absence of feeling in the legs

It is difficult to assess the loss of feeling in the legs of an infant with spina bifida. You may be able to see where she feels by looking at her face and breathing to see if she reacts to touch.

The best way to do this is to use a light pinch or prick with a pin over the toes, feet and legs. The infant's reaction eg: pulling away, crying or no reaction should be recorded on an assessment form (see pages 21 and 22). Colour in the areas on the form where you think the infant does not feel.



An infant with feeling in her toes, feet or legs will react to pinching or pricking by crying or moving her leg away.

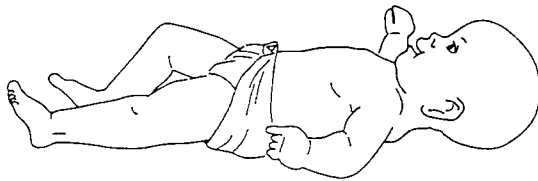


An infant with no feeling in her toes, feet or legs will not react when pinched or pricked over these areas.

### 3. Assessment of contractures and deformities

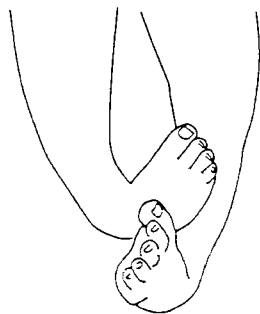
When an infant with spina bifida is born, some joints or muscles in the legs may be contracted or deformed. This happens because some muscles are stronger than others. It can also happen when joints do not move and stay in one position for long periods of time.

A contracture is a shortened muscle which prevents the full range of movement being carried out at a joint. The joint may become stiff.

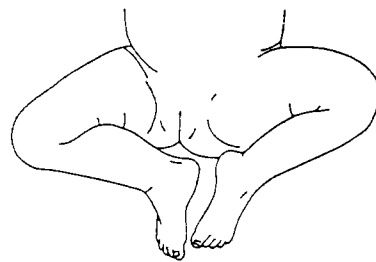


**Contracture of the hip**  
Hip and leg will not lie flat on the floor.

A deformity is an abnormal position of a joint. The joint may not move at all.



**Club feet**



**Dislocated hip**

At the first assessment of an infant with spina bifida, all limbs should be checked, including the upper limbs. This is done by moving all joints in the arms and legs through a full range of movement. Any joints which are tight or contracted should be recorded on an assessment form (see pages 21 and 22).

See WHO Training Package 9 "Training package for a family member of a person who has difficulty moving - How to prevent deformities of the person's arms and legs".

### 4. Other assessments

There are some further areas that should be looked at when the infant with spina bifida is first assessed. These include:

- how awake and alert the infant is
- how the infant likes being moved around
- how much the infant cries
- parents response to the infant
- family concerns about the infant

These areas are important to assess when the infant is first seen as they may show he has some brain damage present because of hydrocephalus. This information can also help when you are developing your plans for treatment.

### **ASSESSMENT OF THE CHILD**

As the child grows and develops it is very important to assess him regularly. Movement skills, contractures and deformities can change over time due to unequal muscle strength. The child should also be progressing through the developmental stages of movement, such as sitting, standing and walking.

A regular reassessment (at least every three months) will indicate if the child's treatment programme is appropriate and effective.

It is necessary to record:

- child's developmental progress
- changes in movement and feeling of lower limbs
- development of deformities or contractures
- changes in the shape of the child's spine
- problems that might arise as a result of hydrocephalus
- problems with urine and stools
- family concerns about the child

The assessment form (see pages 21 and 22) can be used for both the first assessment, and for ongoing assessments. Always keep a record of the child's progress so that the treatment plan can be changed as the child changes. One way of doing this is to develop a problem list from the assessment form and then decide upon a plan of action in consultation with the parents. A copy of this action plan should be given to the parents. This should be updated regularly and recorded as follows:

<b>DATE</b>	<b>PROBLEM LIST</b>	<b>ACTION PLAN</b>

## ASSESSMENT FORM FOR CHILDREN WITH SPINA BIFIDA

NAME:

DATE OF ASSESSMENT:

DATE OF BIRTH:

AGE:

ADDRESS:

HYDROCEPHALUS:      YES  
   NO

SHUNT:              YES  
   NO

MEASUREMENT OF HEAD SIZE:

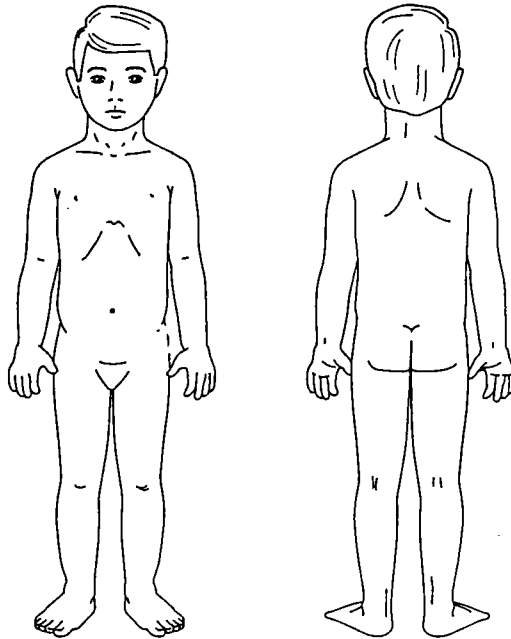
MUSCLE CHART:

LEFT	MOVEMENT	RIGHT
	Hip flexion	
	Hip extension	
	Hip abduction	
	Hip adduction	
	Knee flexion	
	Knee extension	
	Ankle plantarflexion	
	Ankle dorsiflexion	
	Ankle eversion	
	Ankle inversion	

GRADE MUSCLE: 0      =      No contraction  
                          1      =      Contraction, no movement  
                          2      =      Movement without gravity  
                          3      =      Movement against gravity, no resistance  
                          4      =      Movement against gravity, with resistance  
                          5      =      Normal strength

DEFORMITIES OR CONTRACTURES PRESENT:

**LOSS OF FEELING:**



**Colour in areas where there is no feeling**

**SPLINTS OR EQUIPMENT USED:**

**CHILD'S DEVELOPMENTAL PROGRESS:**

**(eg: sitting, crawling, reaching, standing, eating, dressing, toileting etc)**

**URINE AND STOOLS:**

**FAMILY CONCERNS:**

**NEXT VISIT:**

## WORKING EFFECTIVELY WITH THE CHILD AND HIS FAMILY

Many families find it difficult to understand and remember all the information given to them at the time of the child's birth or diagnosis with spina bifida, spina bifida and hydrocephalus or hydrocephalus alone. The future can seem uncertain for both the child and family with many difficulties to overcome.

For these reasons, many families will discuss this situation with the Mid Level Rehabilitation Worker (MLRW) when their child is discharged from hospital. A successful relationship between the family and MLRW can develop the confidence to help the child to achieve the best he can.

A good explanation of spina bifida and hydrocephalus will enable the child and family to understand the condition and be able to deal with it in the best way possible.

It is important to always talk with the child and his family. You must explain what you are doing and why so they understand. Co-operation between the MLRW, the child and his family will help the child develop to the best of his ability. Be observant and patient in order to understand the child and his needs.

The family will need to be encouraged to treat the child with spina bifida like all other children in the family and not overprotect him. He should be played with, encouraged and taught as much as any other child.

Work with the child's family to find out their concerns and needs for the child. Listen to what they say.

Show family members treatment activities so they can all be involved with his treatment programme. Do not give the family more to do than they have time for. Use a variety of ways of doing the same activity so the child does not get bored.

### **Points to remember**

- Show and explain the activity you are teaching.
- Guide and encourage family members in doing it.
- Repeat the activity with the MLRW to be sure they can do it properly.
- Show how the activity can be practised in daily life.
- Answer any questions the family have about the activity.
- Leave some illustrations or written instructions.



Treatment programmes are effective if they start with activities the child can do and build on these following the stages of development such as, sitting, standing, walking (see the Development Charts pages 33, 34 and 35).

Sometimes it is necessary to break activities down into smaller steps. Give the child plenty of time to do activities and reward the child for trying. Activities should be fun, practical and useful to daily life.

## TREATMENT OF CONTRACTURES AND DEFORMITIES

The infant with spina bifida may be born with contractures and deformities of the lower limbs due to unequal muscle strength. Early treatment will help to correct these deformities. If left untreated they will become permanent and restrict the child's opportunity for standing and walking.

Contractures and deformities can also develop as the child grows due to changes in muscle length and strength. A programme of treatment which keeps muscles at their full length can help to prevent contractures and deformities. It is important that this programme is started soon after birth and continued throughout life.

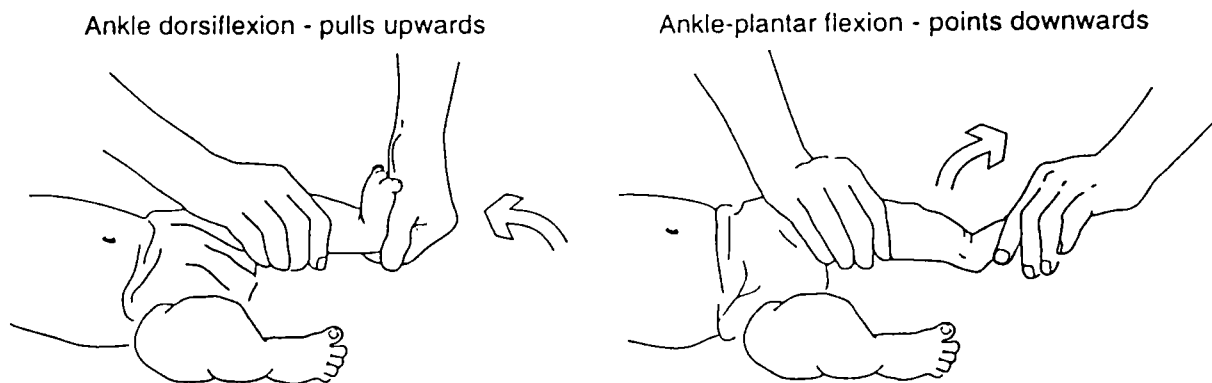
The treatment programme will include moving the joints and stretching the muscles of the lower limbs, as well as positioning the infant and child to prevent contractures. A family member will do the movements and positioning during infancy and childhood, but when the child gets older he should be encouraged to do these activities himself.

## STRETCHING

If full movement of the joint is not possible, a family member will need to do daily stretches. This will help in increasing the range of movement. The joint should be moved as far as possible and held for 20 seconds. Repeat this 10 times. Stretch slowly and gently. **Care must be taken not to push too hard.**

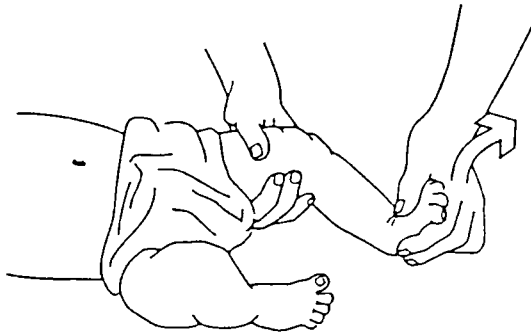
For best results, when stretching an infant's joints do it when he is happy. With an older child, explain what you are doing and gain his co-operation.

The most common contractures are at the hip and ankle.

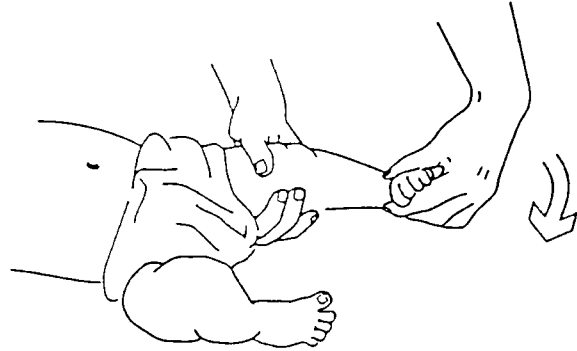




Ankle-foot eversion - points outwards

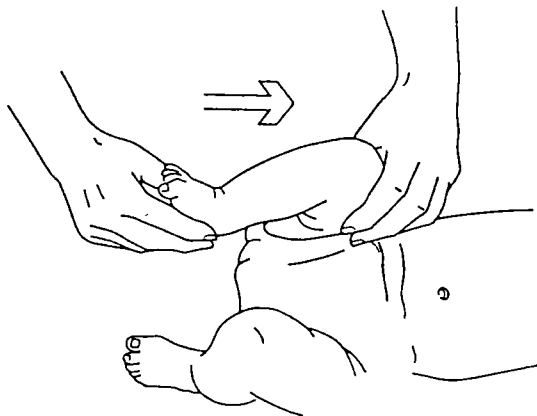


Ankle/foot inversion - points inwards

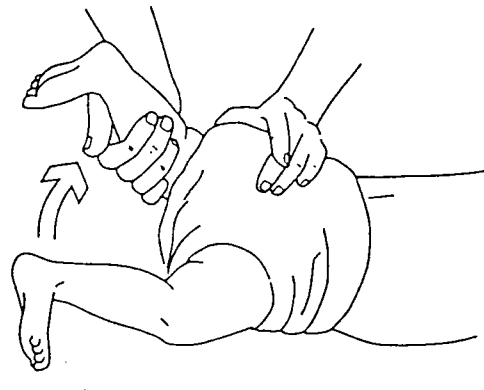


Ankle stretches help the foot gain a good position for standing and walking. Splints and plasters can also be used to correct the position of the foot. These should be made in consultation with a physiotherapist or doctor. They should be changed regularly to prevent pressure sores or rubbing.

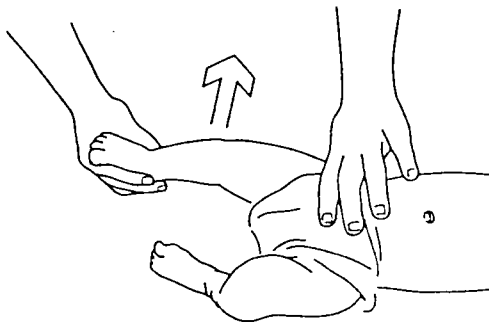
Hip flexion - bends towards belly



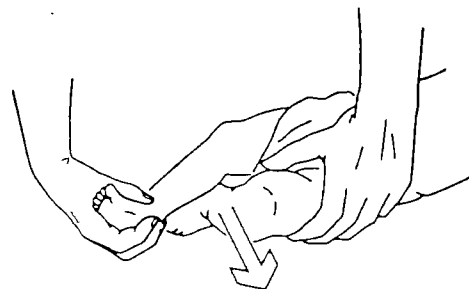
Hip extension - straighten



Hip abduction - away from middle



Hip adduction - towards middle

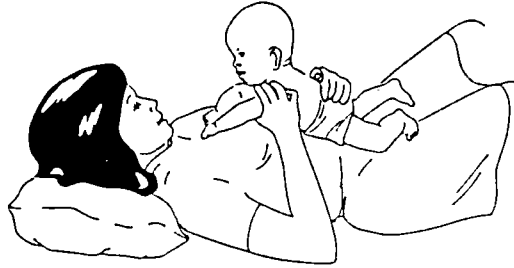


Hip stretches help gain the movement necessary for standing and walking. Good hip movement is also essential for other activities such as toileting and dressing.

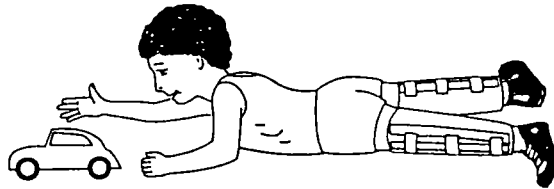
It is important to move each joint in the lower limbs through full range of movement every day even if no contractures and deformities are present. This will prevent the joints from developing contractures. Each movement listed on the muscle chart (see page 21) should be checked.

## POSITIONING

Positioning of the infant or child can assist in the correction and prevention of contractures and deformities. The child should not remain in one position for long periods of time.

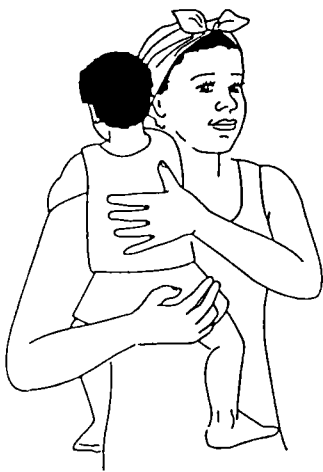


Lying on mother's belly can make this position fun for the infant. A hand placed on the infant's bottom can help to stretch tight hips.

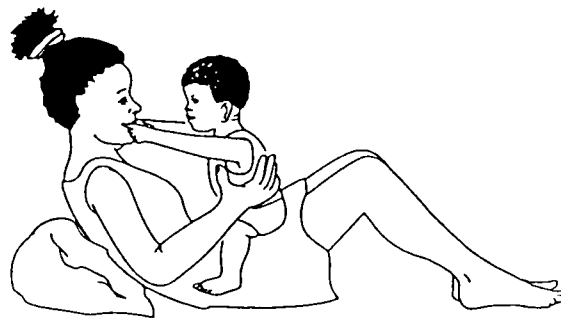


For the older child make sure his hips are flat on the ground.

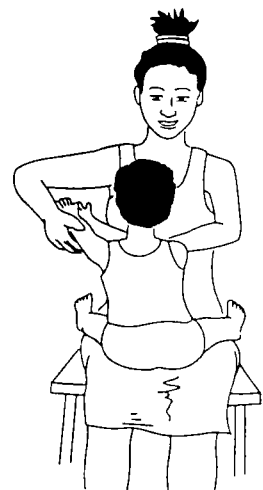
The child or infant can be placed on belly each day to prevent hips from getting tight. When the infant's hips are tight and do not move apart easily you can use your body to help stretch them during daily activities.



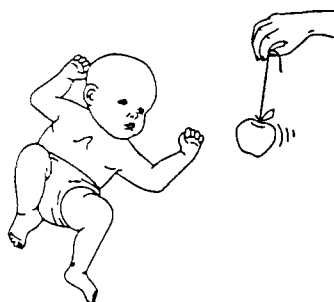
Carrying



Playing



Dressing



The child with a shunt may avoid looking to the side where the shunt is. He should be encouraged to look equally to both sides.

Tight bed clothes, wraps and clothing can push the joints of the lower limb into an incorrect position and make contractures worse. Always make sure there is plenty of room for the child to move in his clothes and when he is wrapped. A small pillow under the bed clothes at the end of the bed will give lower limbs more room to move.

If contractures and deformities are getting worse the child may need to see a physical or occupational therapist or a doctor. Surgery may be necessary if contractures and deformities are severe.

See WHO Training Package 9 "Training package for a family member of a person who has difficulty moving - How to prevent deformities of the person's arms and legs".

## **MANAGEMENT OF BLADDER AND BOWEL**

Most children with spina bifida will have some problem with bowel and bladder control. This will vary from nearly full control to total incontinence of bladder and bowel functions. It is important that these are managed well to enable the child to be healthy and to be socially acceptable amongst the members of their community.

Parents or carers will need to discuss the most appropriate management for their child's bladder and bowel with the doctor or nurse from the time of birth. This will need to be regularly reviewed as the child grows and functions change.

### **BLADDER PROBLEMS**

The child should be encouraged to drink lots of water and other fluids to help the bladder and kidneys stay well and healthy and prevent infections.

Only a small number of children who have spina bifida will be successful in gaining bladder control.

There are two types of bladders in children with spina bifida:

- bladders that dribble urine all the time
- bladders that don't empty

## **Bladders that dribble urine all the time**

This type of bladder constantly passes urine. For the infant, her clothes and bedding will always be wet. It is important to look after her skin well with frequent clothing changes and thorough washing and drying of the skin. The older child may need to wear a pad in her pants to absorb the urine. This must be changed regularly to prevent odour and clothes becoming wet. If the skin is left dirty, rashes, infections and open sores can occur.

## **Bladders that don't empty**

The most common way of managing bladders that don't empty is by intermittent catheterisation. This is used for two reasons:

- to keep the kidneys healthy
- to keep the child and her clothes dry and free of urine

Intermittent catheterisation is a simple, clean method of inserting a plastic or glass catheter (tube) into the bladder several times a day to drain the urine from the body.

If the child does not drink too much before going to bed, catheterisation during the night will not be necessary.

Catheterisation should be done somewhere private and clean. Initially parents will need to catheterise the child. Once at school the child should be encouraged to do it on her own.

All types of catheters are reusable so care must be taken to clean them well after use.

## **BOWEL PROBLEMS**

Most bowel problems in children with spina bifida can be managed by diet to regulate stool consistency and by toilet timing.

### **Diet**

Food controls the consistency of the stool in all children. For children with bowel incontinence, food can be used to make the stool firmer or softer depending on the amount of fibre it contains.

The amount of fibre can be regulated to act as a laxative (high fibre) or a constipating agent (low fibre) as necessary. Fibre in tablet or drink form can be used for children who do not get enough in their normal diet. These can be gradually reduced as the fibre in the diet is increased.

Foods which are high in fibre include:

- whole grain and wholemeal breads
- dried fruits, nuts and coconut
- cereals
- leafy vegetables e.g. cabbage, cauliflower, spinach
- uncooked vegetables e.g. carrots, beans, peas
- vegetables with seeds and skin e.g. cucumber, tomatoes
- fruit with skin e.g. pears, apricots, berries
- brown rice
- wholemeal pasta

### **Toilet Timing**

Toilet timing is when the child sits on the toilet at the time she is most likely to pass a stool. Common times for this to happen are within an hour of having a meal or soon after waking up.

It is helpful if the child can pass her stools out of school hours and at a time most convenient for family routines.

Once toilet timing routine has been established it should remain more or less the same for a long time.

The child should sit on the toilet for at least 2-3 minutes. She should be encouraged to bear down in an attempt to pass a stool. Blowing, coughing or laughing may help the correct muscles to work. A child should be rewarded with hugs, smiles or claps for trying, not necessarily only for producing a stool.

### **Loose Stools**

Frequent loose stools can often be caused by an intolerance to certain foods in the diet. The most common causes are pure fruit juices and spicy foods. These should be reduced in the diet for at least three weeks. If the stool becomes firmed then the cause has been found.

Some children may pass loose stools even when constipated. This constipation should be managed by increasing fibre in the diet.

If the child continues to have bowel problems despite management by diet and toilet timing the doctor or nurse should be consulted.

## **MANAGEMENT OF PRESSURE SORES**

A pressure sore is an area of damaged skin and flesh. It is usually caused by lying or sitting in the same position for too long without moving or wearing badly fitting clothes or braces. It can occur anywhere on the body where there is no feeling. It is very important to check the skin every day to make sure a pressure area is not developing. A regular time such as bathing is a good time to check the skin.

### What is a pressure sore?

Areas of skin that have had too much pressure look red or darker than the rest of the skin. Sometimes this red or dark area will go away. While it is present it is very important not to put more pressure on this area.

If the skin is not checked every day, the child may continue to put pressure on this red or dark skin and this may cause the skin to break open and cause a pressure sore. A pressure sore can take a long time to heal. It may take several weeks or months and during that time, the child must not put pressure on the skin around the sore.

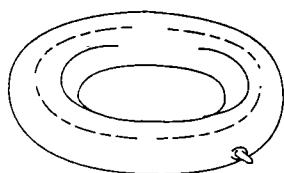
If a pressure sore is noticed, the nurse should look at it and give some advice on how to help the sore to heal.

### How to prevent a pressure sore?

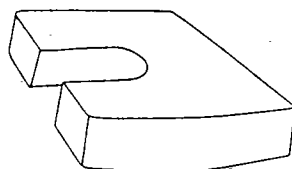
The child should change positions regularly. If he is sitting for long periods of time in a wheelchair he should do pressure lifts. To do a pressure lift he should lift his buttocks off the seat by pushing up with his arms on the armrest or back tyres. This should be done ten times hourly. He can also lean from side to side or forwards on the chair to relieve pressure on the buttocks. A cut out cushion may be placed on a chair under the buttocks to help prevent pressure sores.

If redness of the skin or rubbing are caused by badly fitting clothes or braces they must be altered immediately. The child must not wear them until they have been altered.

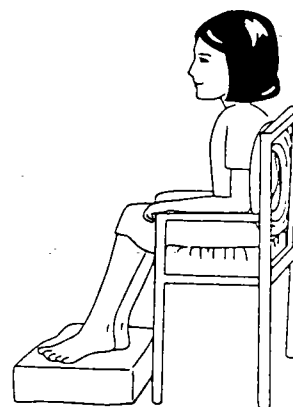
If the spina bifida on the child's back is large and raised it may rub against the back of a chair or wheelchair. This may cause a pressure sore. It can be prevented by placing a cushion with a hole cut out or inner tube from a tyre, behind the child when he is sitting.



Inner tube



Cut out cushion

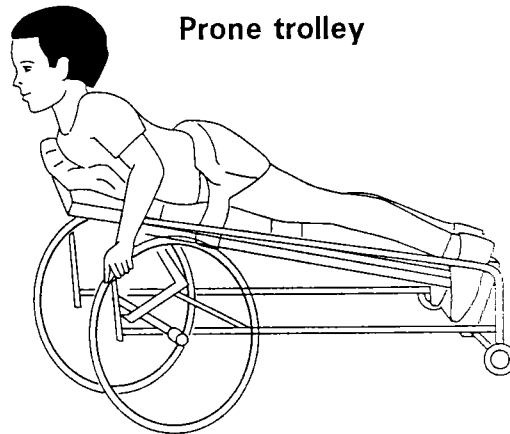


Child using inner tube to prevent pressure sore on back

### **What to do if a pressure sore occurs**

Weight must be kept off the sore until it is completely healed. The sore must be cleaned every day. If the pressure sore is too deep it may need to be closed by surgery.

The child should still be encouraged to move around if the pressure sores are on his buttocks. A prone trolley can be used.



See WHO Training Package 10 "Training package for a family member of a person who has difficulty moving - How to prevent sores from pressure on the skin".

## **NORMAL DEVELOPMENT**

An understanding of normal child development helps you to identify children who are not developing as expected, to plan treatment and to check on progress. Developmental stages are reached in a particular order. The control of the body develops progressively from the head to the feet. Large movements develop before smaller more skilled movements.

The various stages in development, like sitting and standing, are reached at roughly the same age in all children. We decide how well a child is developing by comparing him with other children of the same age. When progress is slower than expected it is called developmental delay.

Children with spina bifida and hydrocephalus will have a developmental delay. They take longer to learn to move because of muscle paralysis, presence of contractures and deformities, and a lack of feeling in their legs. Spina bifida is just one of a number of conditions which cause delay.

## **HOW TO USE THE DEVELOPMENTAL CHARTS**




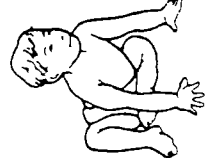
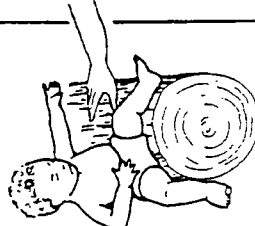
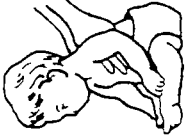
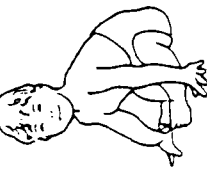
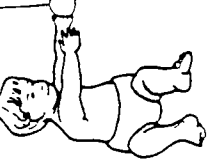
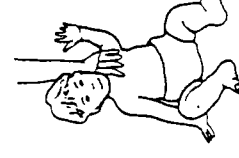
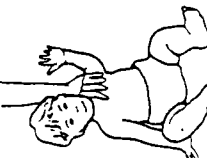


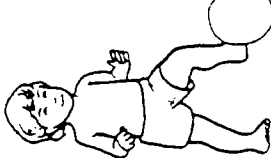

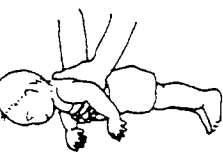
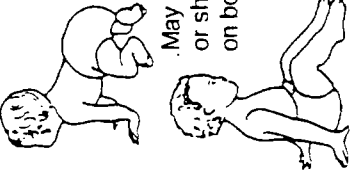
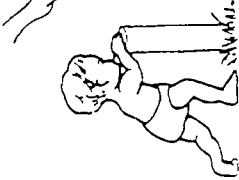
Although the child with spina bifida does not progress in the same way as other children, the stages of normal development are still used as the basis for assessment and treatment. On the following three pages are the development charts. The charts are from the manual "Promoting The Development Of Young Children With Cerebral Palsy".

These development charts show the order in which some abilities develop and the age at which most children learn them.

The charts will identify what he can do, what he cannot do, and what he needs to be taught to do. Record this on the assessment form (see pages 21 and 22). The page number under the chart headings refers to where you can look for suggestions on how to improve the activity.



## DEVELOPMENT CHART: Movement

Stage 1: Birth to 6 months	Stage 2: 6 to 12 months	Stage 3: 12 to 24 months	Stage 4: 2 to 3 years
 <p>Lies on stomach and holds head up Pushes up on hands</p>  <p>Rolls from stomach to back</p>	 <p>Rolls from back to stomach Rolls to side and gets into sitting</p>	 <p>Moves into and out of sitting</p>  <p>Balances self if tilted</p>	
 <p>Sits only with support</p>  <p>Sits leaning on hands</p>	 <p>Sits alone</p>  <p>Twists and reaches</p>  <p>Catches self if pushed</p>	 <p>Walks alone or with one hand held</p>  <p>Squats to play</p>	 <p>Kicks a ball</p>  <p>Balances on one foot Jumps</p>
 <p>Stands with support</p>	 <p>May crawl or shuffle on bottom</p>  <p>Pulls to stand</p>		

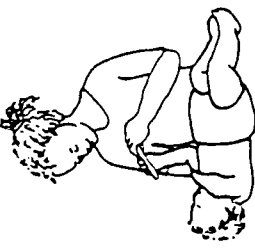
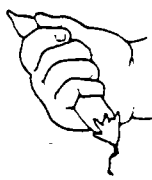
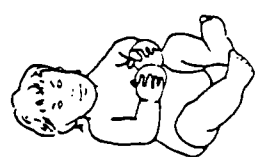



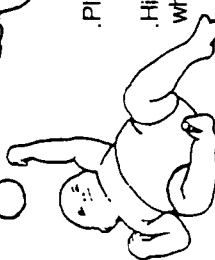
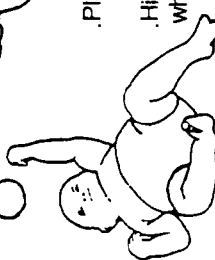
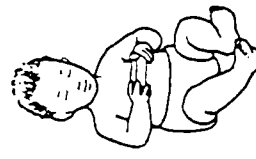
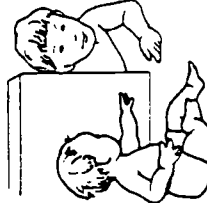

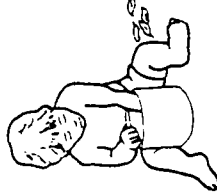
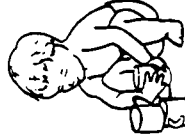
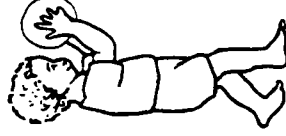

**Head and Body Control**  
(page 36)

**Rolling**  
(page 41)

**Sitting**  
(page 40)

**Moving from Place to Place**  
(page 42)

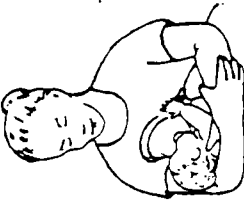

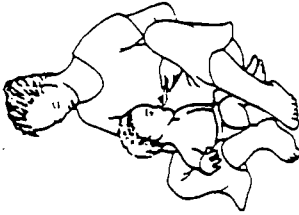
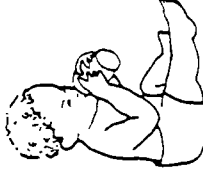

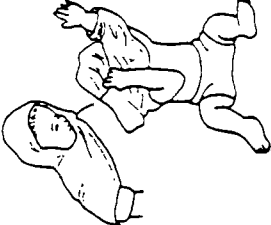
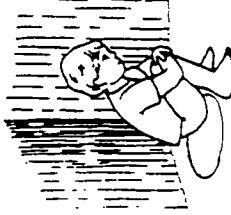




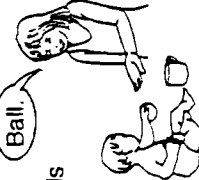



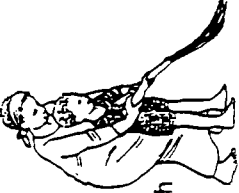
# DEVELOPMENT CHART: Communication and Behaviour

Stage 1: Birth to 6 months	Stage 2: 6 to 12 months	Stage 3: 12 to 24 months	Stage 4: 2 to 3 years
 <p>.Holds small object briefly</p>  <p>.Holds with whole hand</p>	 <p>.Can hold one object in each hand</p>	 <p>.Holds between thumb and finger</p>	
 <p>.Looks at object</p>  <p>.Brings hands together</p>  <p>.Plays with body</p>  <p>.Hits object with whole arm</p>	 <p>.Passes object from hand to hand</p>  <p>.Bangs two objects together</p>  <p>.Plays social games like peek-a-boo</p>	 <p>.Puts objects into container and takes them out</p>  <p>.Enjoys building</p>	 <p>.Throws a ball</p>  <p>.Sorts different objects</p>

Using Hands (page 48)

Playing (page 48)

## DEVELOPMENT CHART: Communication and Behaviour

Stage 1: Birth to 6 months	Stage 2: 6 to 12 months	Stage 3: 12 to 24 months	Stage 4: 2 to 3 years
<p>.Sucks breast</p>  <p>.Takes object to mouth</p> 	 <p>.Chews solid food .Feeds self biscuit</p>	 <p>.Drinks from a cup and feeds self most foods without help</p>  <p>.Helps with undressing</p> <p>.Indicates toilet needs</p>	<p>.Dresses with help</p>  <p>.Uses the latrine without help</p> 
<p>.Responds to noises</p> <p>.Makes sounds when talked to</p> <p>.Smiles</p>  <p>.Hello</p> <p>Ah ah</p> <p>Shathani!</p> <p>.Turns to voices</p>  <p>Na na</p> 	<p>.Likes being talked and sung to.</p> <p>.Repeats gestures</p> <p>.Repeats sounds made by others</p> <p>.Responds to simple commands</p>  <p>Bye bye</p>  <p>Ball.</p> <p>.Says a few words "Ma ma", "Da da", "Ba ba"</p>	<p>.Calls self by name</p> <p>.Names familiar things like dog, bird</p> <p>.Uses a lot of nonsense talk</p> <p>.Asks for things with words and gestures</p> <p>.Begins to put words together</p> <p>.Points to body parts when asked</p>  <p>Drink.</p>  <p>Where is your nose?</p>	<p>.Talks about what she does</p> <p>.Begins to draw</p> <p>.Asks questions</p> <p>.Helps family members with their work</p>  

Self-Care  
(page 58)

Communication  
(page 51)

## **ENCOURAGING NORMAL DEVELOPMENT**

An infant with spina bifida and hydrocephalus will usually have a delay in her development. This may be present from birth. It is due to several reasons which can include the following:

- long periods of time in hospital after birth
- parents' concerns about having an infant with spina bifida and not knowing how to handle her
- the infant's heavy head due to hydrocephalus making it hard to gain head control
- the infant's difficulty in learning to move due to muscle paralysis, contractures or deformities

This delay in development can be lessened by carrying out a programme of treatment. The programme should be aimed at encouraging normal development from the first few months of life. It should also aim at making the child as independent as possible in the community as she grows and develops. The programme should be carried out by the family at home. The family will need to be taught special exercises and activities to help their infant's development.

These exercises will include methods of carrying, positioning and playing with her. They will help to stimulate the child's development.

Some examples of exercises and activities are found in this chapter. They are only suggestions. You and the infant's family should be encouraged to think of other activities to do with her.

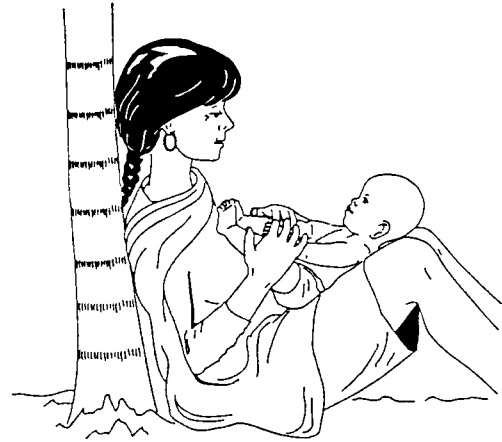
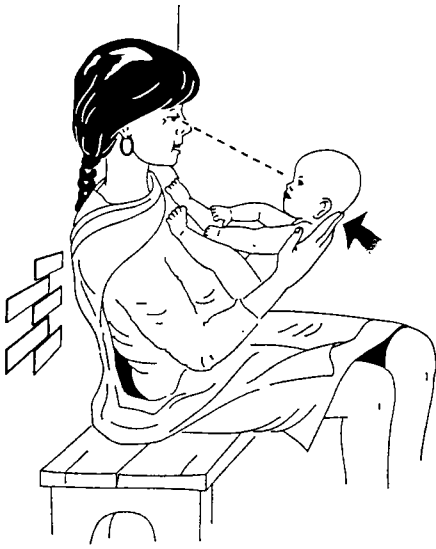
### **1. HEAD AND BODY CONTROL**

The development of head control is important for many reasons. It allows the infant to look around and learn about her surroundings. It is necessary for the development of communication, hand and reaching skills and play.

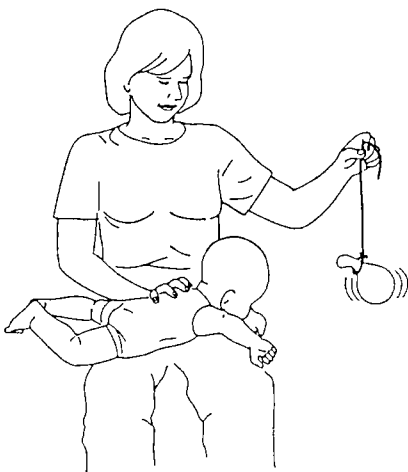
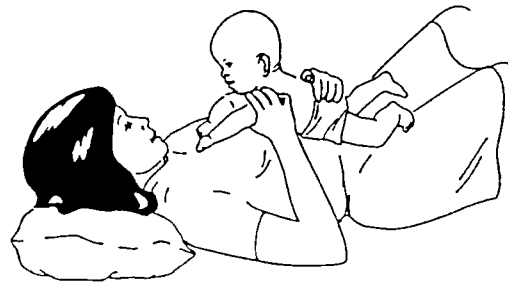
The infant with spina bifida and hydrocephalus will find head control difficult to achieve because her head is heavy. She will need much encouragement with this activity. If hydrocephalus is untreated the child's head can become very large due to the extra fluid. She may never achieve good head control and the head may need support when moving between positions.

Head control will develop more quickly if she is picked up, carried about and nursed than if she is left lying in her bed.

The following activities include ways to encourage head control. They should be done frequently each day for short periods of time. It is best to do these when she is awake and happy.



Encourage the infant to look at you by talking to her. Her head should be in the middle. As she begins to look back at you, move your head slowly from side to side. Make sure that she follows your face. Her arms and shoulders should be forward.



Head control needs to develop in many positions. A rolled up cloth or mother's body can be used. She is more likely to lift her head if she has noisy or bright objects to look at. A hand held firmly over her buttocks may assist her to do this activity. Lifting her in the air is fun and can also help to develop head control.



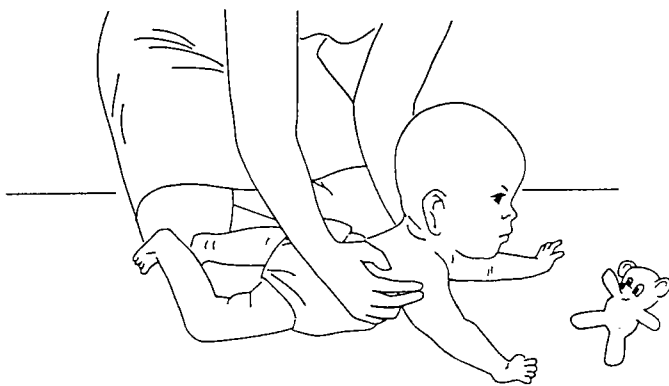
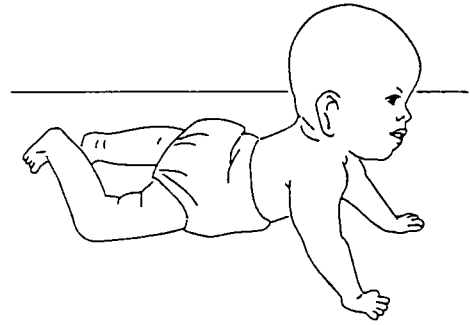
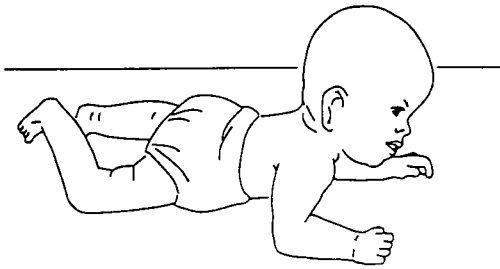
As the infant develops head control, begin to pull her to sitting. At first hold at her shoulders, then hold her hands. Do this slowly so she has time to lift her head herself.



Moving the infant slowly from side to side also encourages head control. Wait for her to bring her head back to the middle before moving to the other side.



Use daily activities such as feeding and carrying to improve eye contact and head control.



The infant should spend time on her belly to develop head control. Help her to push up on her forearms, then on straight arms. This will make it easier for her to reach for toys and bright objects.

It is important that the infant is encouraged to use all her working muscles to strengthen them as much as possible. This can be done by tickling, stroking, and pinching over the muscles of the feet and legs where she has some feeling. This stimulation will help her to learn where her toes, feet and legs are. Infants with spina bifida have difficulty knowing where their feet and legs are due to lack of feeling.



Show the infant her legs by lifting them. Gently tickle.



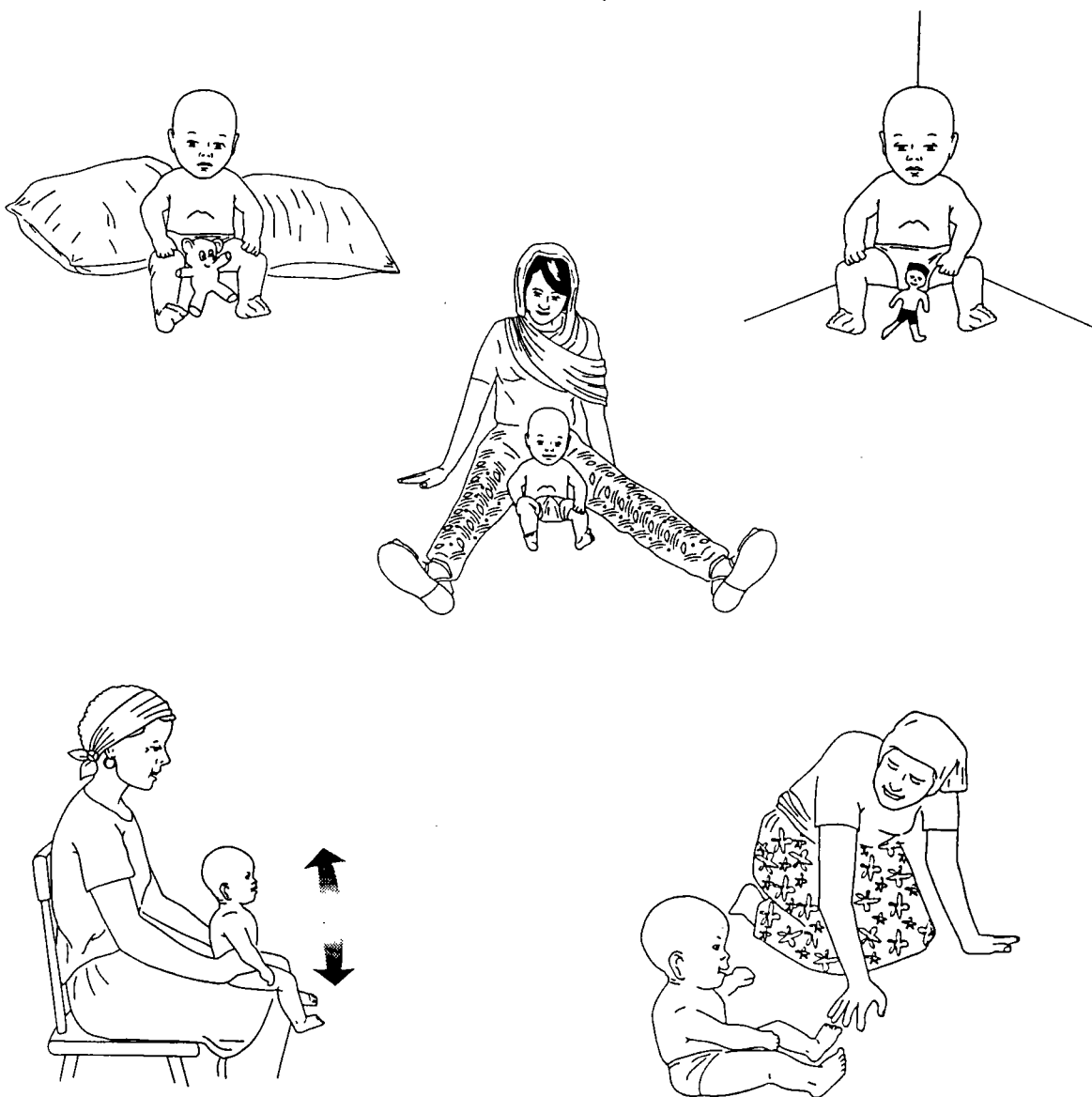
Brings legs up to touch her hands. Blow on feet and belly.

## 2. SITTING

The infant should be encouraged to sit as soon as he has gained some head control. If some head control has not been gained by three to four months this position should still be encouraged. Sitting will make it easier for him to develop an interest in his surroundings.

When he first starts to sit some support may be necessary. You can use pillows to support the child or support him against a wall or in a box. As the child grows, special equipment may be necessary if he has a lot of leg paralysis and poor body control. See the section on " Equipment and Aids for Mobility".

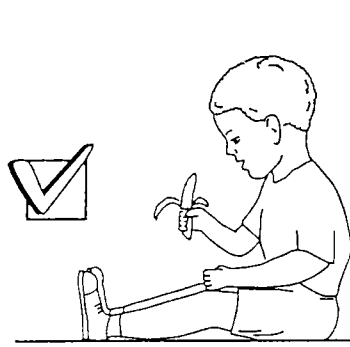
Encourage play while the child sits in each position.



Improve his sitting balance by bouncing him up and down on your knees. Hold him at his hips.

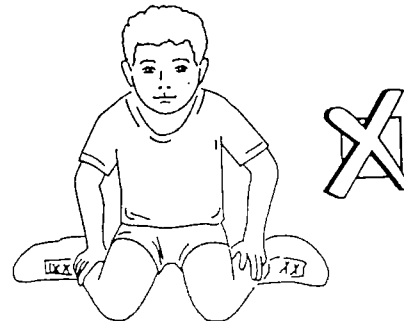
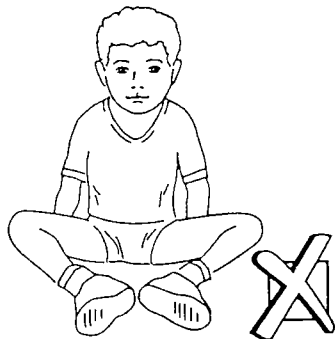
As he begins to sit by himself, stay nearby. You may need to help if he starts to fall.





Sitting with legs straight should be encouraged.

Cross legs or "W" sitting should be discouraged. Contractures can develop if the child spends too much time sitting in these positions.



### 3. ROLLING

Learning to roll is necessary for all infants. Infants with spina bifida may need to use rolling for movement as crawling may be difficult depending on the amount of muscle paralysis.

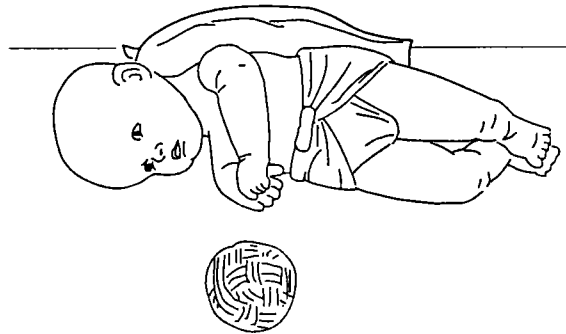


#### **Belly to Back**

The infant will begin to roll from belly to back once he pushes up on his hands. Place your hand under his hip and roll it back towards you if he needs some help.

## Back to Belly

The infant must practise sidelying before he can learn to roll. Encourage playing in this position. Use a rolled up cloth to stop him from rolling to his back.

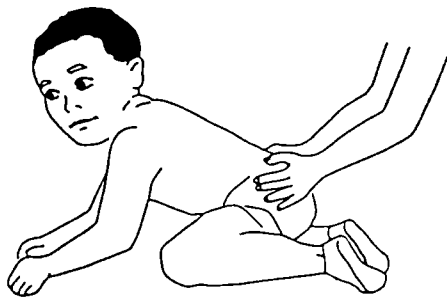


Start rolling to his belly from sidelying. You may need to help his leg if it is paralysed.

Use games to encourage rolling over and over quickly. This can be fun and helps him to learn to like fast movement.

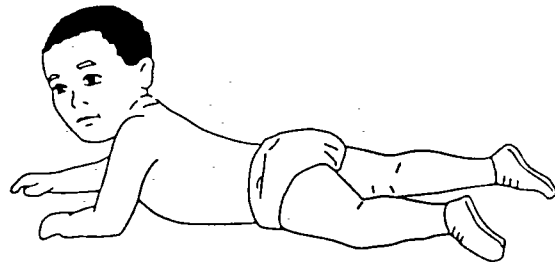
## 4. MOVING FROM PLACE TO PLACE

- **Crawling**



Most spina bifida children learn to push themselves backwards with their arms to get to a crawling position.

However many children will find it difficult to move forward due to leg paralysis. In this case, they may use their arms to pull themselves around on their belly.



Movement on the floor is important - the child will find the easiest way for him to move. Do not be too concerned if this is rolling, belly crawling or crawling even if the child is older.

- **Lying to sitting**

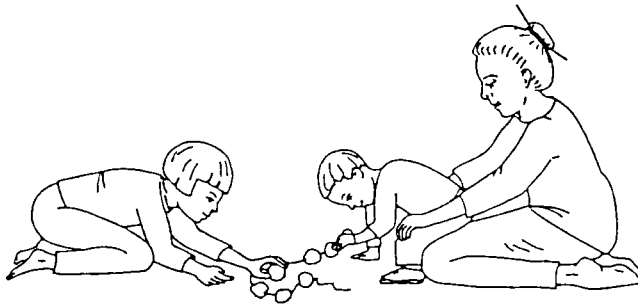
The child may need help when he is learning to sit up from lying down. The weight of his body may be heavy and this will make it hard for him to push up on his arms. Help and encouragement may be necessary. Do not forget to talk to him all the time.



Press down on his hip pulling it towards you. Support his body as he pushes up on one hand.

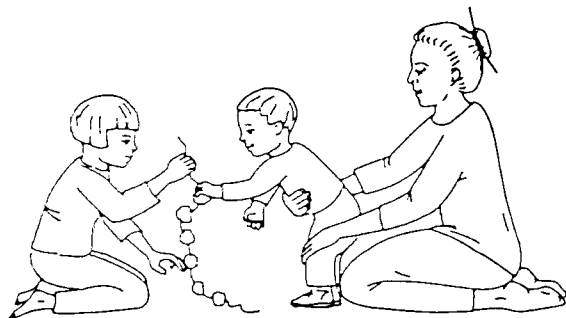
- **Pulling to standing**

Some children may not learn to pull to stand by themselves. These children may need aids to help them stand. For those who only have weakness around ankles and knees standing up from kneeling and sitting should be encouraged.

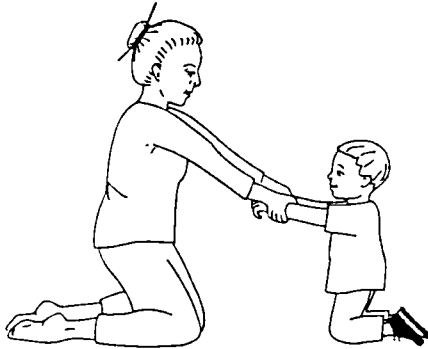


When pulling to stand from sitting the child needs to lean well forward. Do not let the child push backwards as this will make standing difficult.

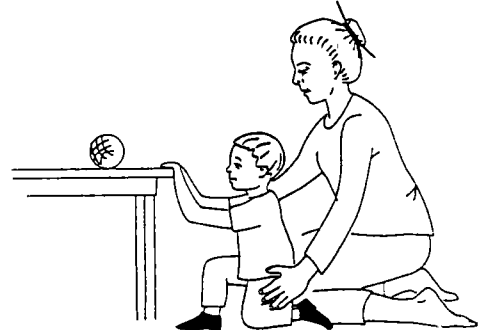
The child may need support at his knees as he begins to stand. Place your hands over the knees and hold them straight.



Kneel-standing is an important activity to do before standing. It will strengthen muscles around hips and encourage balance.



Help balance by holding his arms.  
Encourage his hips to stay straight.

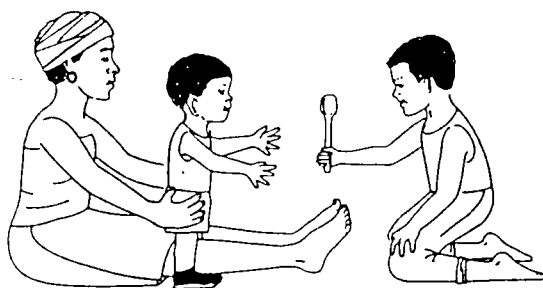


Furniture can be used for support. Practise kneeling with one leg forward.

- **Standing**

A child can be stood as soon as he has sufficient head control and balance in his body.

Standing encourages the muscles that hold the body up to work. It prevents contractures and strengthens leg bones. The child has his hands free for play, can look around and communicate more easily with others.

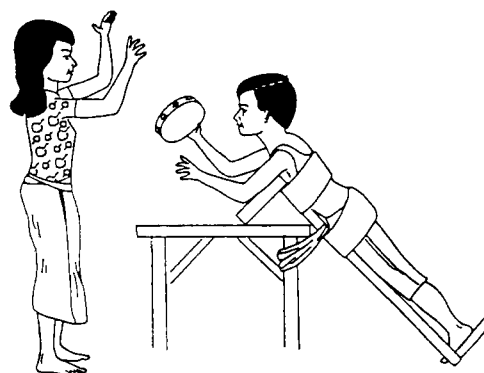


When learning to stand, you may need to hold his hips or knees with your hand. Family members or toys can make this fun.

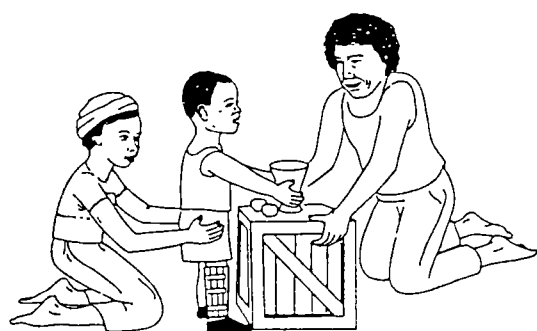
The child should stand for some time every day. This will help develop balance. Gradually increase the time that he stands. As balance improves, walking should be encouraged.

If the child does not have enough muscle strength in his legs, aids such as gaiters, forward lean standers or an upright stander may be used.

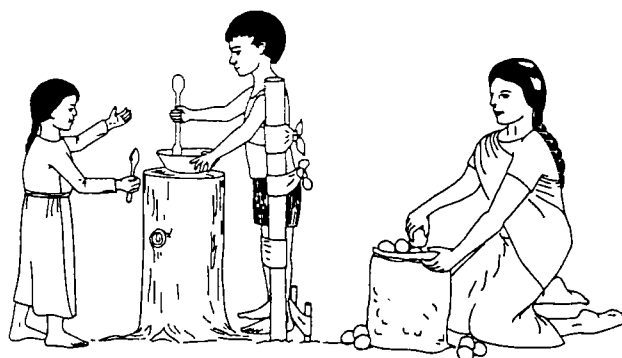
See the section on "Equipment and Aids for Mobility".



**Forward lean stander**



**Gaiter**



**Upright stander**

● **Walking**

All children should be given the opportunity to walk. Walking can benefit the child in many ways:

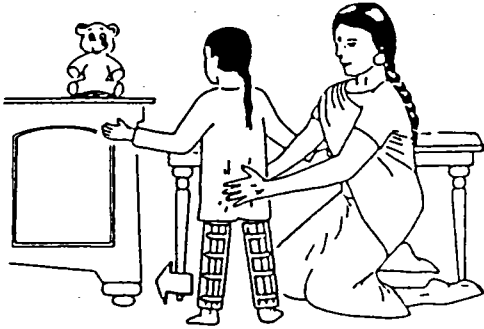
- independence of movement
- improved self-esteem
- stronger bones in legs
- improved health and fitness

Learning to walk should be fun and not a chore. He needs to gain confidence slowly. The child may take a long time to walk due to muscle paralysis and lack of feeling in the feet and legs.

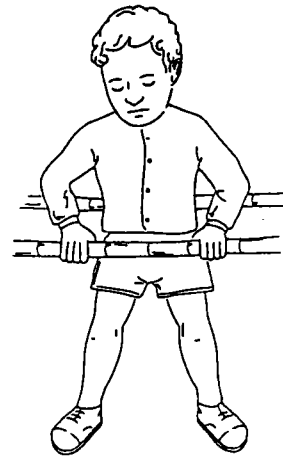
Special aids such as splints or calipers may be necessary to support the legs during walking.

Walking begins by moving sideways along furniture or walls.

The child will not be able to take a step forward until he has learnt to move his weight sideways onto one foot. This is the same for all children no matter what aid they may require for walking.



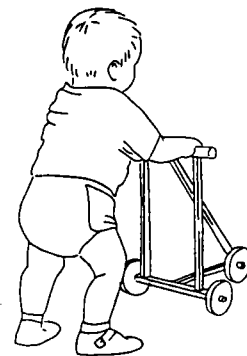
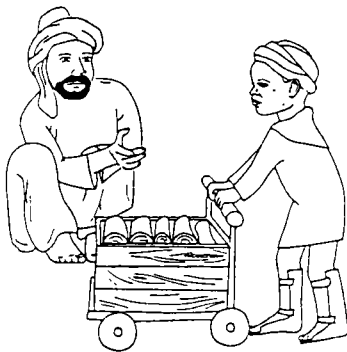
Encourage sideways stepping by using toys.



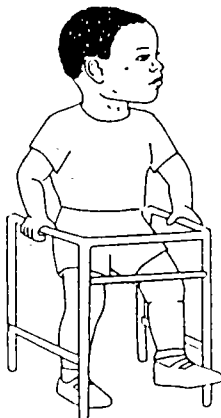
Parallel bars can be used for practising walking sideways, backwards and forwards.

Stepping forward can start once sideways stepping has been learned.

A heavy trolley, a walker or parallel bars may be used for support when the child is learning to walk.



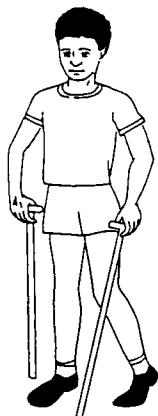
Practice walking in different ways



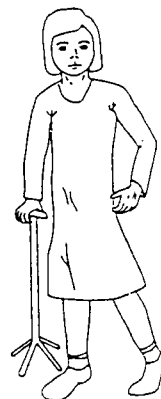
As balance and confidence with walking improves, the child may be able to use crutches or walking sticks for support. To learn how to use crutches and sticks see WHO Training Package 13 "Training package for a family member of a person who has difficulty moving - How to train the person to move around".



**Using crutches**



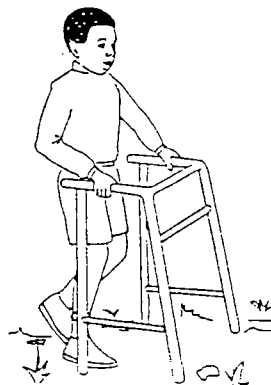
**Using sticks**



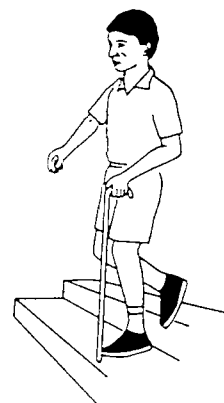
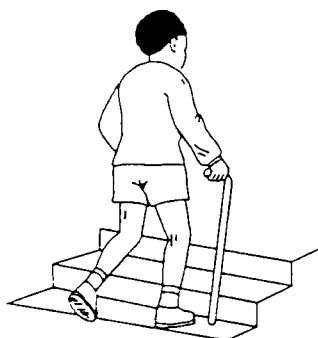
How the child walks will depend on how much muscle paralysis he has and what type of walking aid he is wearing.

As the child's walking improves there are many other activities to learn:

- walking on rough ground

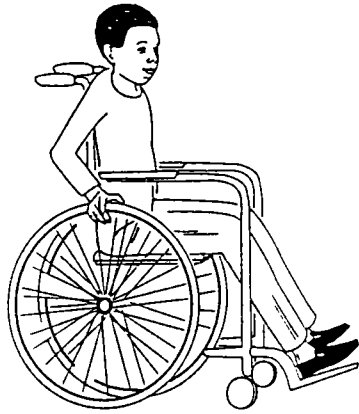


- walking up and down steps



These activities will take lots of practise and should be relevant to his daily life and surroundings.

For some children the effort of walking is too great. This may be difficult for the family to understand and accept. They may need to talk about it and not push the child to walk. These may use a wheelchair or trolley for all or part of the day.

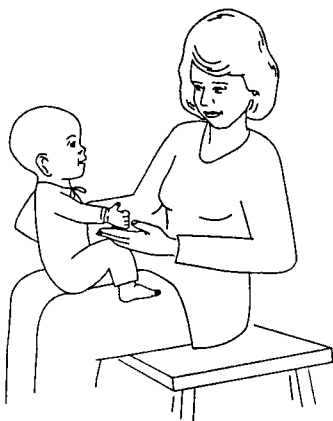


## 5. USING HANDS AND PLAYING

Infants and children with spina bifida need to play as much as other children. Play helps to develop movement and other senses such as seeing and hearing. It teaches the child about the world around him. It also helps to develop the child's concentration, imagination and ability to work with others.

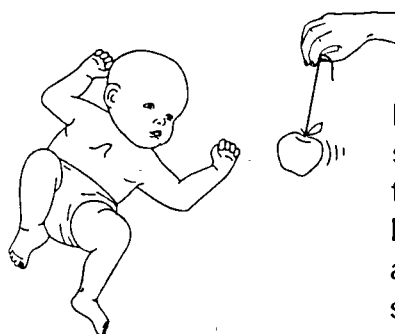
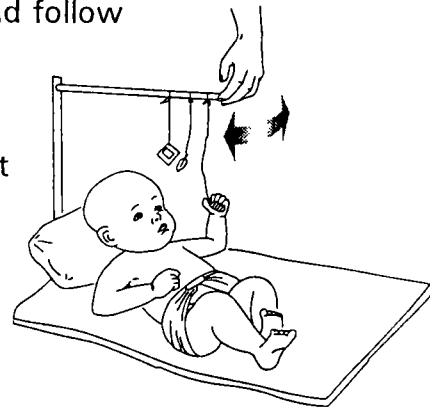
Play needs to be encouraged. The following types of play may be difficult to achieve and may need lots of practise:

- encouraging the infant and child to look and follow



Encourage the infant to look at you by talking or singing to her.

Hang brightly coloured objects above the infant for her to look at.

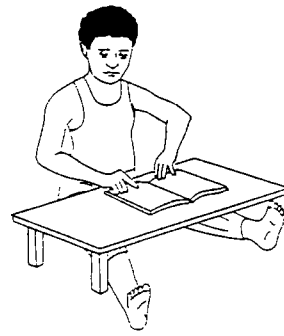


Move a toy from one side to another while the infant follows. Be sure to get her attention before you start.





With the older child books and puzzles can be used. Point to pictures and shapes to encourage looking.



- encouraging the infant and child to be aware of their own body

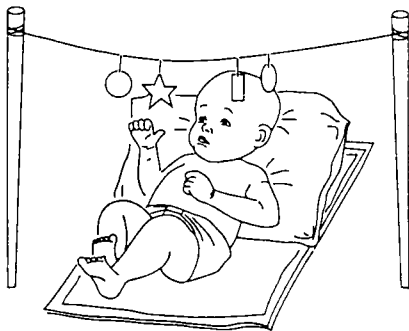


Bring hands and feet together so the infant learns where they are and how they feel.



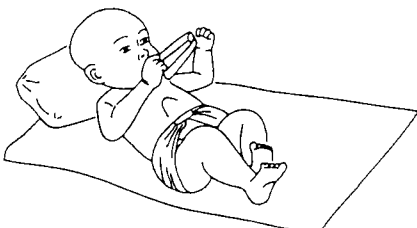
Playing in different places such as in the sand or on the grass gives different feelings to the body.

- encouraging eyes and hands to work together

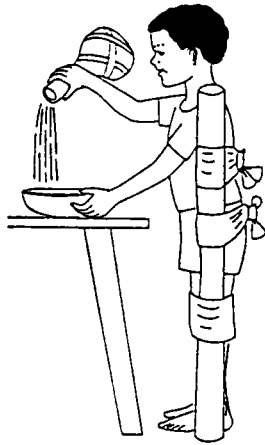


Give the infant large toys that are easy to hold.

Place bright and noisy toys above the infant so he can see them and reach them easily.

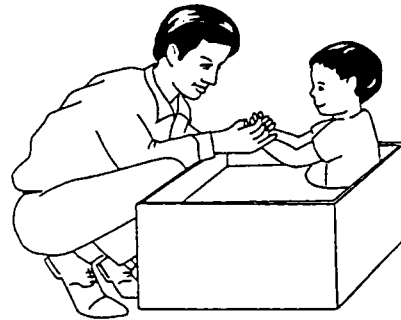


Encourage the infant to look and reach for toys and other objects.



The child could help with cooking. He will need to look and pour carefully, and use hands for rolling, kneading and cutting.

- encouraging hands to work together and come to the middle of the body



The infant could be encouraged to clap to music or singing.



Play games using two hands such as threading beads.



Encourage the child to look as he throws and catches the ball with both hands.

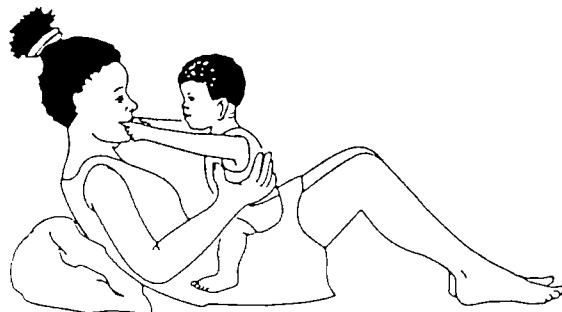
See WHO Training Package 26 "Training package for a family member of a child with a disability - Play activities for a child who has a disability".

## 6. COMMUNICATION

Most infants with spina bifida and hydrocephalus will develop language normally. Usually as the child gets older, she will talk a lot and use words inappropriately. This excessive talking can hide underlying learning problems due to brain damage.

Communication should be encouraged during all the stages of development and included as part of a treatment programme. It is important to:

- encourage the infant and child to look at you and listen when you are speaking
- encourage the child to look at and name objects and body parts
- say simple words and ask the child to repeat them
- encourage the child to use words when she wants something
- help the family to be aware of the child's excessive speech and guide the child's attention to other more appropriate activities



If the child is unable to develop communication normally due to severe brain damage see WHO Training Package 7 "Training package for a family member of a child who has difficulty speaking and moving but can hear - How to train the child to communicate".

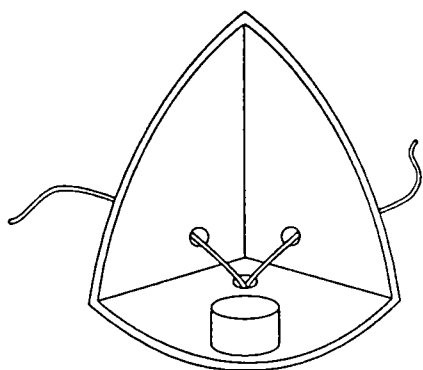
## EQUIPMENT AND AIDS FOR MOBILITY

Various forms of equipment are used throughout the child's life. Equipment should be relevant to the child's developmental stage. Children with untreated hydrocephalus may have very large heads. They may require extra support to keep their head upright. Equipment such as corner chairs and sitting trolleys will need to be high enough at the back to support their head and shoulders. With any equipment it is necessary to ensure it is:

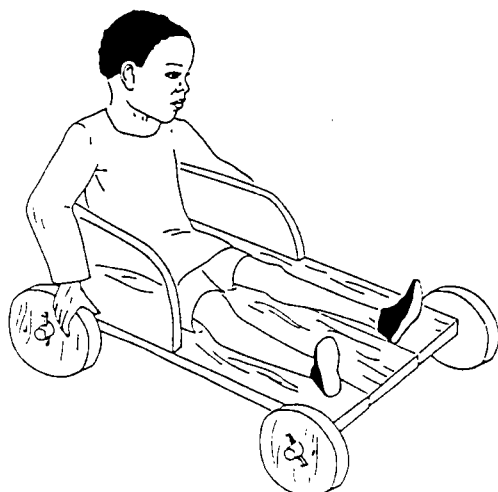
- doing what it is meant to do
- being used correctly
- the correct size
- safe

### **EQUIPMENT**

Corner chair used to encourage sitting balance and enable hands to be free for playing



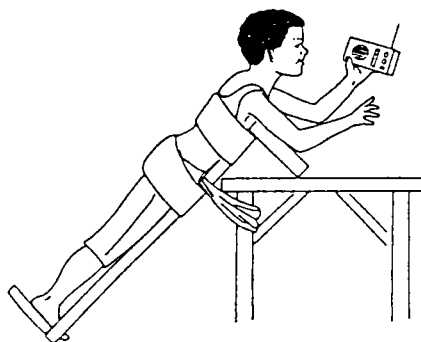
Sitting trolley used to encourage arm strength and sitting balance



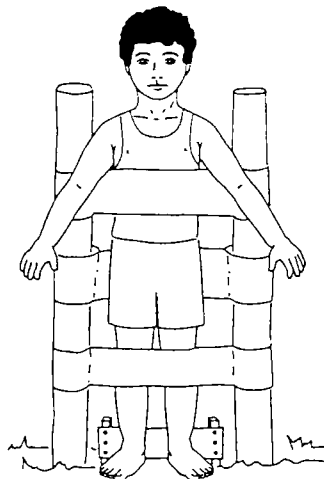
The trolley should be the correct size for the child. His hands should reach the wheels so he can push it by himself.

**Standers** used to practise standing

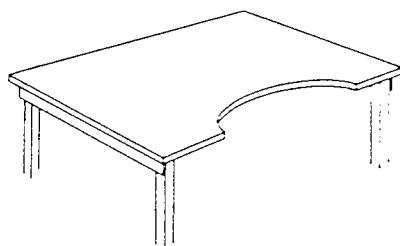
If he needs support to stand and his body is bent, or he cannot keep his heels on the ground, use a forward lean stander.



If he needs less body support use an upright stander. Make sure the upright poles are pushed well into the ground or fix them to a large square base for use indoors. For children who lean back, bring the chest strap right around the body. Pull the ends of the bottom strap firmly to straighten the hips.



**Cut out table** to provide support to enable play in sitting and standing

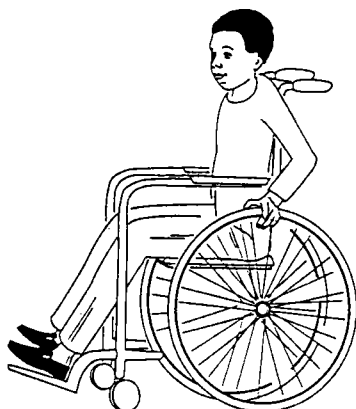


The table must be the correct size for the child. He should be measured so the table is at waist height when sitting. The cut out should be large enough to go around his body to give support.

**Wheelchair** for children who find walking too difficult

Wheelchairs must be the correct size for the child. This makes it easier for him to push himself, gives better support to the body and reduces the risk of pressure sores. He will need to move the wheelchair on rough ground and up ramps and hills.

There are different types of wheelchairs available depending on the needs of the child. You will need to consult with a physiotherapist or occupational therapist to determine the most appropriate wheelchair. For further information on choosing and using a wheelchair see "Promoting Independence Following A Spinal Cord Injury".



Wheelchairs must be the correct size for the child. He must be able to move the wheelchair himself. He will need to move the wheelchair on rough ground and up ramps and hills.

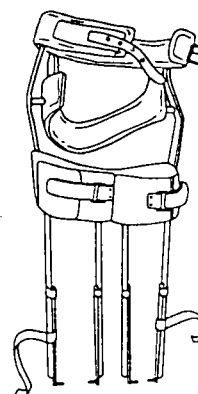
**AIDS FOR MOBILITY**

There are many aids to assist the child when he is learning to stand and walk. The type of aid needed will depend on the muscle paralysis present. As he grows and develops the aid may change as he needs more or less support. This should be checked regularly. If possible the parents should take the child to a service where he can be assessed for his special needs and an appropriate type of aid supplied.

The aid will help to fix a joint in place so that it does not move. This makes it easier for the child to stand and learn to walk. Depending on how much support the child requires the aid may need to cover one or more joints.

**the ankle, knee and hip**

for children with poor or absent hip strength and absent knee and ankle movement

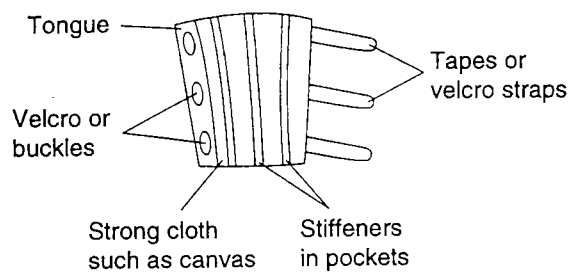


**Pelvic band and caliper**

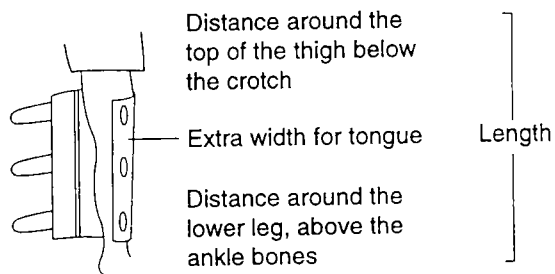
**the ankle and knee** for children with poor knee strength and absent ankle movement

Gaiters are lightweight splints which are made of strong cloth and reinforced with stiffeners. Stiffeners can be made from strips of metal, plastic or wood. Gaiters wrap around the leg to hold it straight. Do not position a stiffener directly over the knee. The straps fasten on the outside of the limb. To begin with, try magazines or newspapers wrapped around the limb. If this helps, then make a proper gaiter. Gaiters can be used for children of all ages and can be a good substitute if other braces are not available.

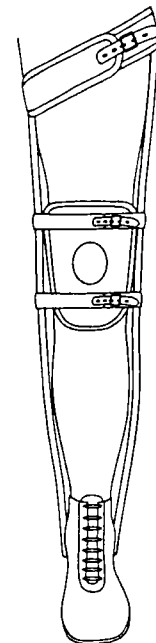
**Gaiter**



**How to measure for a knee gaiter**



**Long leg caliper**

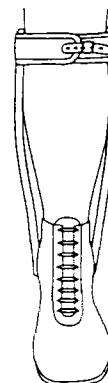


**the ankle**

for children who have good strength in their knees but poor or absent ankle movement

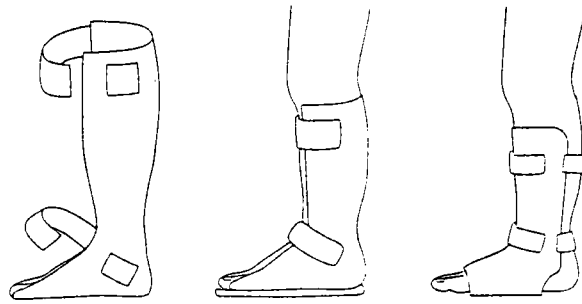


**Boot**



**Short Leg Caliper**

Use plaster of Paris splints for small children. If stronger splints are needed, see a therapist or doctor. If available, light plastic splints can be worn inside shoes or sandals or have a rubber sole stuck on the bottom for walking.



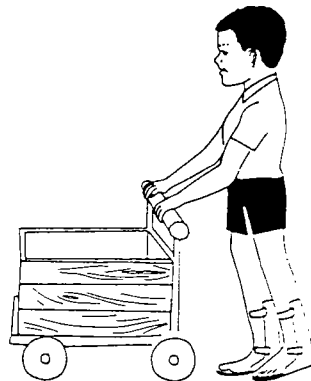
**Splints**



At first stand the child wearing aids next to a table or chair to play.

As his confidence increases other pieces of equipment can be used to encourage walking.

### Cart

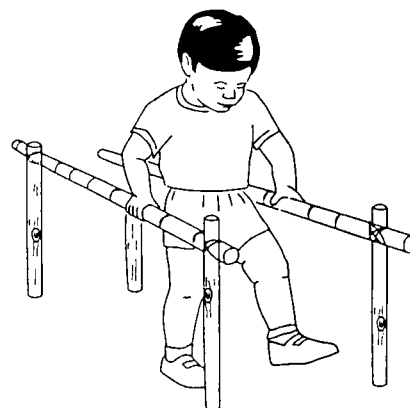


The cart should be heavy so that it does not tip over or move too quickly. As balance improves, make the cart lighter.

### Parallel bars

Make sure that the parallel bars are strong enough. Push down on them to see if they can take your weight.

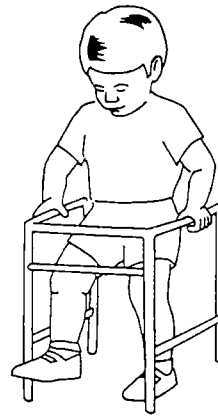
Then teach the child to stand holding on to the bars. When he can stand, start to walk sideways, then front and back.





### Walker

Walkers need to be the correct size. When the child can walk with the walker, he must learn to walk outside and up and down ramps and steps.



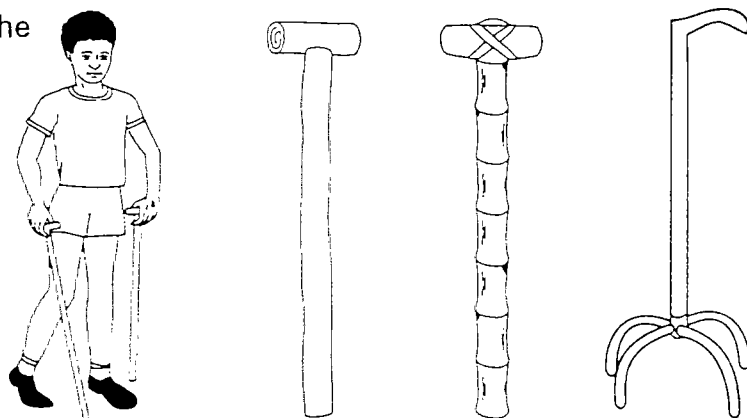
### Crutches

The crutches must be the correct size for the child. There should be a small space between the top of the crutch and the child's underarm. When she is standing, she should always push down on the crutches for support.



### Sticks

You can make sticks from strong wood or bamboo. The sticks must be the correct size for the child. It may be necessary to add extra support at the base of the stick to help the child balance.



For ideas on how to measure for, make and use equipment and aids for mobility see WHO Training Package 13 "Training package for a family member of person who has difficulty moving - How to train the person to move around".

## SELF-CARE SKILLS

Children should be encouraged to learn to wash, eat, drink, dress and toilet themselves as soon as they are able. This will depend on the amount of muscle paralysis, the child's developmental progress and her willingness to help. Practise and encouragement in these skills will be necessary. Every effort should be made to help the child keep her balance and feel secure.

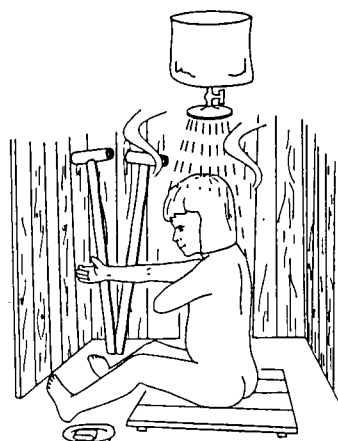
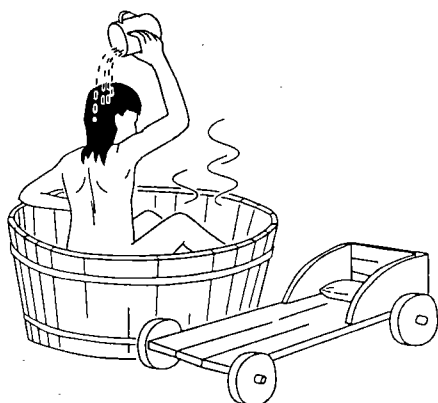
### BATHING

Most infants and children with spina bifida can be bathed just like other children.

- Support the head and body well. Wash time can be fun if hands are free for play. A special seat may be needed as the child grows.



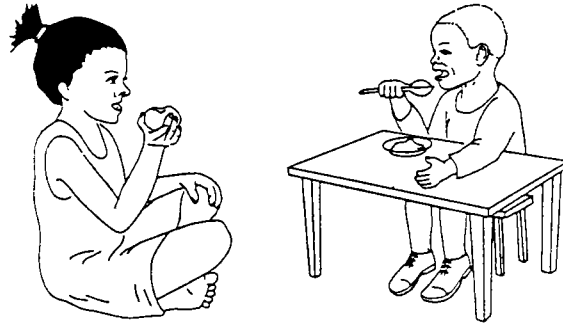
- If using a bathtub check the water is not too hot. The child may burn her legs or feet due to lack of feeling in the skin. Also keep the child away from hot pipes and taps.



**Beware of hot water!**

## EATING AND DRINKING

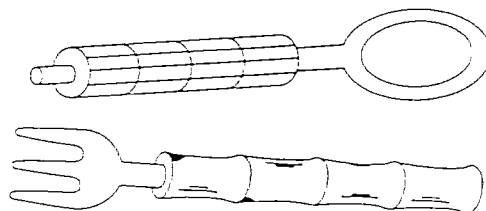
- Do not let the child eat too much. He will need less food than other children because he does not move as much. Movement will become more difficult if he is too fat.



- Support the child who can not sit by himself. He needs both hands free to eat and drink. Special equipment may be needed as the child grows.



- Some children with spina bifida have weakness in the hands. These children will have difficulty holding objects, so they may need a thicker handle on a spoon. Use bamboo or cloth to make appropriate handles.



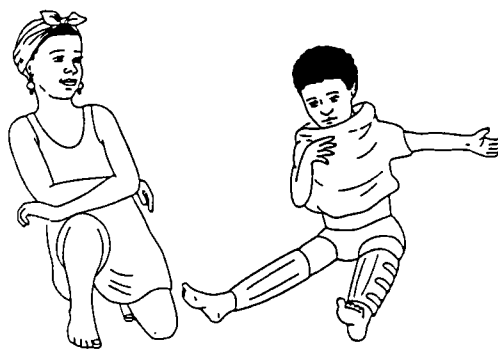
## DRESSING

Weak or paralysed legs make dressing difficult. The child with spina bifida may need help for a long time before he learns to dress himself.

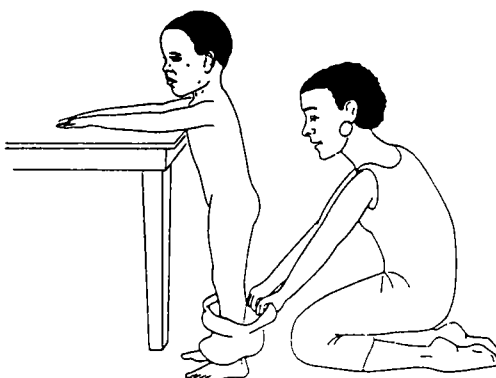
- Provide support for the child so he can dress and undress himself as much as possible. Both hands need to be free. Choose the position he finds easiest.



Stay near him as he may need some help.

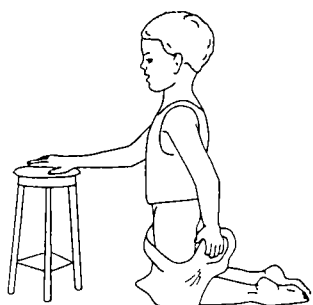


Encourage him to help as much as possible.

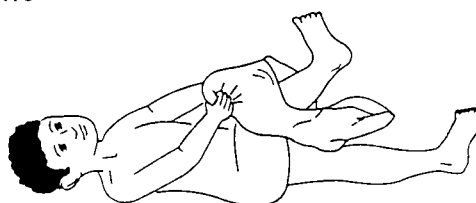


Furniture can be used to help balance while dressing.

- Pulling clothes on and off may be difficult if hands are weak. The child should wear clothing he can take on and off himself.

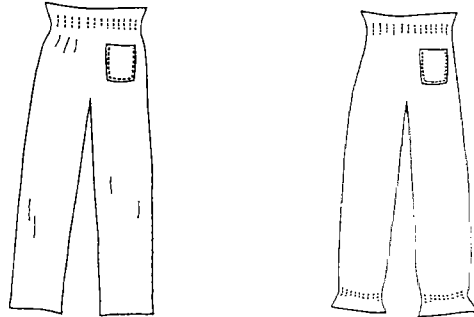


The child should do as much as he can by himself.



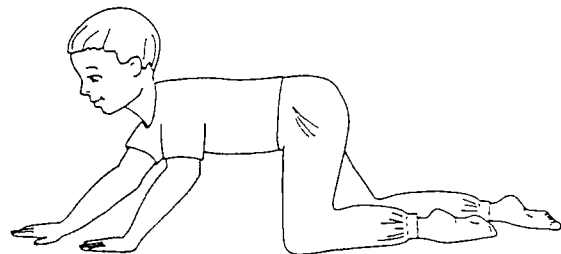
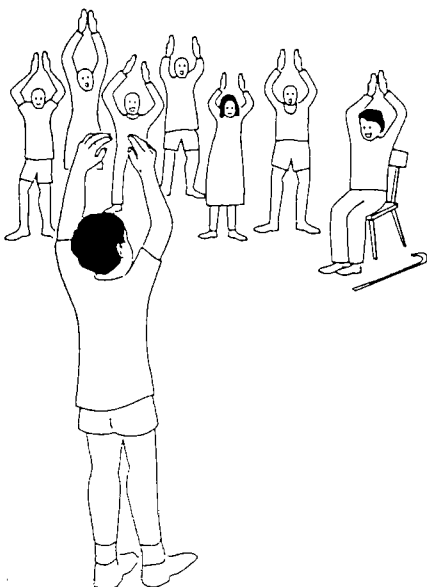
## Suggestions for Clothing

- Clothes that are loose are easier to take off and put on. They may need to fit over splints and calipers.
- Use elastic or drawstrings instead of buttons or zippers to close trousers or skirts.



- Under clothes should be made from cotton or wool to absorb urine. This will help avoid skin rashes or sores.

Long trousers should be worn when playing on the floor or outside. This will protect the legs from injuries such as sunburn, cuts and abrasions.



Trouser legs can be gathered around the ankle to keep them in place while the child is crawling.

- Footwear should be worn whenever possible to protect the feet. They must be well fitting to avoid pressure areas. The feet or toes should not be cramped or curled within the shoe. As the child begins to stand he may require boots or other special footwear to support his ankles.

## TOILETTING

It is important to have a toileting routine. This should include:

- changing the child's clothing as soon as they are soiled or wet to avoid odour
- washing the skin well to avoid rashes and infections
- washing clothing thoroughly and drying it in the sun
- using the toilet at the same time everyday. This may help gain some bowel control. A diet containing lots of fibre may also help bowel control.

Use the same toilet that the other family members use. The toilet may need some handrails to help the child balance.



As the child grows he needs to learn the importance of regular changing and good toileting routines. Feelings of embarrassment and rejection can occur if the child and his clothing have an unpleasant smell.

## LIFTING

All family members need to be trained in how to lift and move the child between positions to avoid back injury.

### Points to remember

- If the child is heavy use two people to lift him.
- Keep the child's body as close to you as possible.
- Keep your back straight and bend at the knees when lifting.
- Do not twist your body when lifting as this may cause pain in your back.
- The child should be encouraged to help as much as possible. Eventually he should learn to move between positions himself.



## ADAPTING THE HOME

Every effort should be made to adapt the home so that the child can do things for herself.

She needs to be able to move freely around the home.



Floor coverings should be firmly fixed so the child will not slip or trip.

Rooms should be as free of obstacles as possible to allow her to move around easily.

The child should be able to enter and leave the house by herself and not depend on family to lift her in and out. One entrance to the house may need a ramp with handrails rather than steps.

Clothing and toys should be within the child's reach so she can get them by herself.



The child should use the family washroom and toilet. If the child cannot sit by herself place a box over the toilet. Handrails may be needed to give the child support.

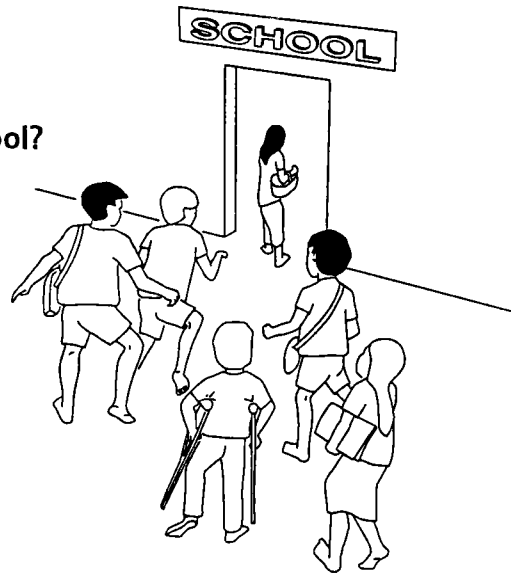
Changes to the home need to be reviewed regularly as the child gets older and bigger.

## SCHOOL ISSUES

### LEARNING DIFFICULTIES

#### Should children with spina bifida go to school?

School is an important place for learning, developing skills and social interaction. Children with spina bifida can enjoy the usual range of school activities.



#### Can children with spina bifida learn?

Children with spina bifida, with or without hydrocephalus, are capable of learning. A child's ability to learn is not dependent on his movement skills.

Children with spina bifida without hydrocephalus are usually mentally normal. The majority of children with hydrocephalus have learning difficulties. These children may be good at some activities and have difficulties with other activities. Given appropriate help and guidance, children with learning difficulties will be able to benefit from going to school.

#### Why do children with spina bifida and hydrocephalus find it hard to learn?

The following may make it hard for the child to learn:

- difficulty using eyes and hands together
- difficulty with hand movements
- difficulty understanding
- difficulty in judging distance, shape and size
- not being able to pay attention
- being disorganised with activities
- excessive talking

#### What can you do to guide the teacher?

It is important to talk to the teacher about spina bifida and hydrocephalus. This will enable the teacher to feel at ease with the child and be able to teach him at school.

It is also important that the child's classmates know about spina bifida and hydrocephalus and why he may have difficulty doing some activities. These explanations will help the child to be more accepted by the other children. You may need to guide the teacher on what to say to the child's classmates.

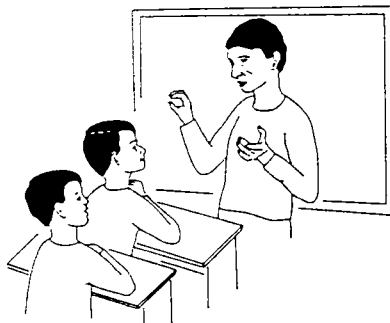


There are some activities which the teacher can do to help the child with learning difficulties. These include:

- Play games which encourage eyes and hands to work together. For example, threading objects on a string, catching balls and building blocks.

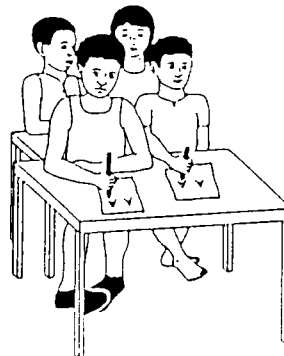


- When teaching the child, talk in short, simple sentences. Repeat as often as necessary.



It is important for the child to look at the teacher while he is giving instructions.

- Children with learning difficulties are often slow workers in the classroom. More time may need to be given for the child to complete activities.
- Children using excessive speech should be discouraged from talking too much and directed to other activities.
- Give the child a quiet place to work so he is not easily distracted. A seat near the teacher may be best.



Sit the child at the front of the class.

- Give the child short periods of work by himself to encourage concentration.

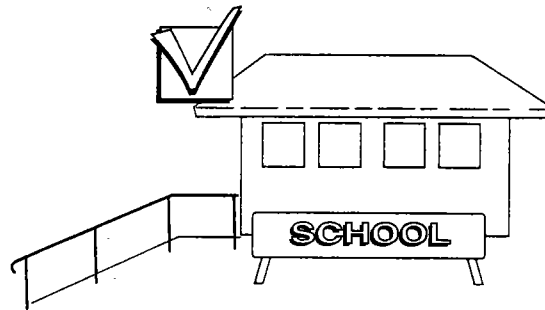
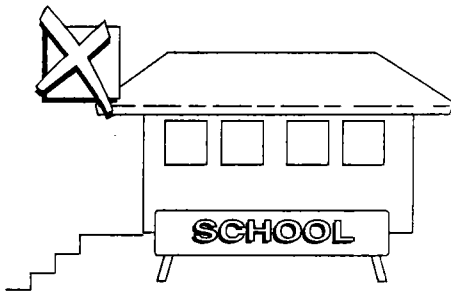
## PHYSICAL DIFFICULTIES

### Will the classroom need to be adapted?

Children with spina bifida may need to use an aid such as crutches or a wheelchair to help them walk or move. It is important for these children to be able to move around easily in school. They will need plenty of space to move freely and to store their aids.

The following may need to be arranged:

- at least one entrance to the school with no stairs. A ramp with handrails may need to be built.

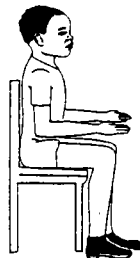


- wide corridors and doorways
- floor coverings that prevent the child from slipping or tripping

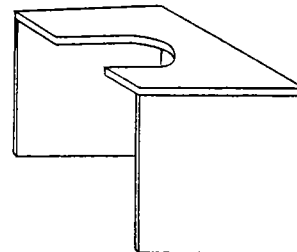
Special classroom furniture may be necessary for the child with spina bifida. It should allow the child to be comfortable and stable so his hands can be free to do school work.

It is important that the child uses a table and chair that are the correct height. When the child is sitting the feet must be flat on the floor and the table be at waist height. It may be necessary to build up or cut off the legs of the table or chair.

If the child finds it hard to sit up straight use a table with a cut out section.

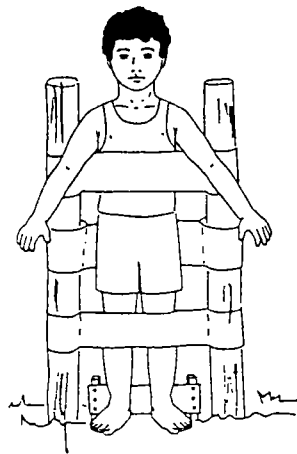


**Correct sitting position**



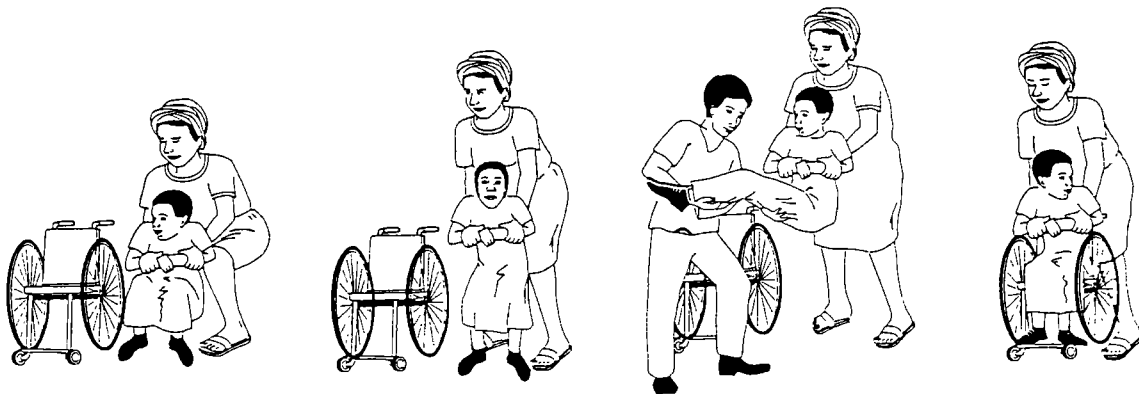
**Cut out table**

Children with spina bifida should regularly change their body position, such as between sitting and standing. This is necessary because the lack of feeling in their skin may lead to pressure sores if they stay in one position for too long. The most common places for pressure sores are buttocks, heels and knees.



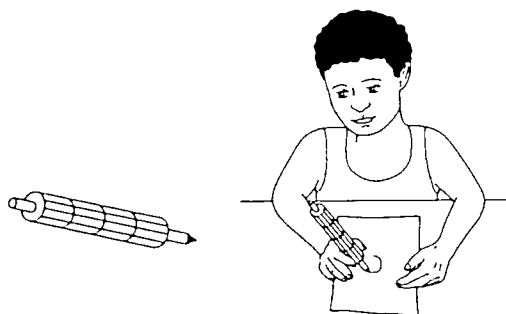
Prone standers and standing frames can permit a change of position for children who are unable to stand on their own.

The teacher needs to be trained in how to lift and move the child between positions, and from one piece of equipment to another. See the section on "Lifting". Two people may need to lift the child into the wheelchair. This will enable the child to be lifted above the wheel to avoid injury to the skin of the legs and buttocks.

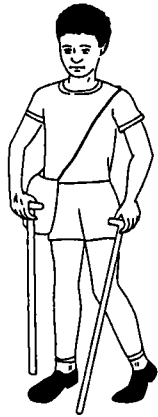


See WHO Training Package 10 "Training package for a family member of a person who has difficulty moving - How to prevent sores from pressure on the skin".

Some children who have difficulty with hand movements can write more easily if pencils are made thicker. This can be done by wrapping cloth around the pencil or using a piece of bamboo. Other classroom equipment can be changed in a similar way.



The child may have difficulty carrying his belongings around the school. He could use a carry bag over his shoulder or attach a basket to his wheelchair or walker.



### Can children with spina bifida play physical games?

Physical exercise is an important part of all children's education. It helps them to be healthy and fit and have fun with their friends.

Children with spina bifida can play physical games. The amount and ways they can participate depends on how much disability the child has.

The teacher should make sure the child is included in all games. Games that can be changed to suit disabled children, such as games in sitting and games to music, should be included as part of school activities.



**Be aware of the following precautions for the school playground:**

- at all times the child must wear protective clothing on legs and feet to prevent injuries to the skin
- check all equipment that the child may use for splinters and rough edges

See WHO "Guide for School Teachers" and WHO Training Package 27 "Training package for a family member of a child with a disability - Schooling".

**Do children with spina bifida need help with toileting at school?**

Most children with spina bifida have trouble with bowel and bladder control. The teacher needs to be aware of the child's toileting needs. Good toileting routines should be reinforced at school. The child may be rejected by his schoolmates if he is wet and smelly. This can have an effect on his self esteem if allowed to continue.

The child may need help with toileting. It is important that help is made available while he is at school.

The toilet area at school must be suitable for the child with spina bifida. It should:

- allow for privacy
- allow for wheelchair access if necessary
- be large enough to allow room for the child and his helper to move about
- have handrails beside the toilet if necessary
- have a wash bowl
- have a box over the toilet if necessary



**Handrails may be necessary for support**



**A box over the toilet may help if the child cannot squat**

The child may need to take extra clothing to school in case he soils or wets. A bucket or bag for soiled clothes should be available in the toilet.

## **THE OLDER CHILD WITH SPINA BIFIDA & HYDROCEPHALUS**

As the child grows older he may start to think about his future. The following issues may need to be discussed with him and his family.

### **SOCIAL ACTIVITIES**

Making friends and having fun are the same for everyone. Young people with spina bifida should be encouraged to join in all social activities with friends of their own age. This helps to encourage self-confidence and development of personal relationships.

See WHO Training Package 28 "Training package for a family member of person with a disability - Social activities".

### **WORK**

The ability to work or get a job does not depend on the severity of the spina bifida. Getting a job is dependent on the local community and the person's desire to work.

The person may need help and guidance in choosing a job that is appropriate for their personality and level of disability.

See WHO Training Package 29 "Training package for a family member of a person with a disability - Household activities" and WHO Training Package 30 "Training package for a family member of a person with a disability - Job placement".

### **SEXUAL FUNCTION**

A sexual relationship is possible for both males and females.

#### **Can a woman with spina bifida have children?**

Most women with spina bifida are fertile and their reproductive organs are normal. However, there is a higher risk of having a baby with spina bifida. A woman with spina bifida should go to hospital for the birth of her baby.

#### **Can a man with spina bifida father a child?**

This will be known after the boy's sexual development is complete. The ability to get and maintain an erection is dependent on the level of the spina bifida on the back. If the spina bifida is low on the back erection may be normal. If it is high on the back the erection may be absent or brief. Some men will be infertile even if an erection is possible. If the man does father a child there is a higher risk the child will have spina bifida.

## FURTHER READING

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United Kingdom.
- ASBAH "Information folders on Prevention,  
Hydrocephalus and Spina Bifida"  
ASBAH House  
42 Park Road, Peterborough PE12UQ,  
United Kingdom
- Bannister C "Spina Bifida Occulta and Tethered Spinal  
Cords" - LINK Magazine  
ASBAH House  
42 Park Road, Peterborough PE12UQ,  
United Kingdom
- Eskes "Folic Acid can prevent Spina Bifida" -  
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IFHSB  
Avenue de Joli-mont 9, CH1209 Geneva,  
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Goerd A (1989) "Training in the Community for People  
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WHO Distribution and Sales  
1211 Geneva 27, Switzerland.
- Hoath L and Gilbert S "Oops - A Common Sense Approach To  
Toilet Training A Child Who Has A  
Problem"  
L. Hoath and S. Gilbert,  
PO Box 735, Penrith  
NSW 2751, Australia.
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Avenue de Joli-mont 9, CH1209 Geneva,  
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- Llewellyn G and Green L (1987) "Living with Spina Bifida"  
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13a Meagher Street, Chippendale  
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- Nettles O (1982) "The Spina Bifida Baby"  
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190 Queensferry Rd, Edinburgh EH4 2BW,  
Scotland.
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1700 Rockville Place Suite 540 Rockville,  
Maryland 20852, USA.
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2 Grose Street, North Parramatta  
NSW 2150, Australia.
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The Hesperian Foundation  
PO Box 1692 Palo Alto, CA94302,  
USA
- Williamson, G (1987) "Children with Spina Bifida"  
Paul H Brookes Publishing Co  
P O Box 10624, Baltimore, Maryland,  
21285-0624, USA
- World Health Organisation "Promoting Independence Following A  
Spinal Cord Injury" (1996)  
WHO 1211 Geneva 27, Switzerland
- World Health Organisation "Promoting the Development of Young  
Children with Cerebral Palsy" (1993)  
WHO 1211 Geneva 27, Switzerland.

### **Acknowledgement**

The Normal Development Charts in this guide are from "Promoting the Development of Young Children with Cerebral Palsy" (1993) WHO Geneva 27, Switzerland

All Training Packages mentioned in this book are from "Training in the Community for People with Disabilities". Training Packages are **not** available individually. The Training Packages used in this book are numbers 7, 9, 10, 13, 21, 26, 27, 28, 29 and 30.









