

What is Spina Bifida?

Spina Bifida literally means split spine. This congenital defect implies that some of the back bones do not close over the center tube of nerves (spinal cord). It originates at an early stage of pregnancy (22nd - 26th day), when the brains and spinal cord of the fetus are being formed.

When the baby is born its back shows a soft dark bag covered with a layer and filled with spinal cord, liquid and nerve tissue. This bag may leak spinal liquor. One or two of every 1000 babies are born alive with Spina Bifida.



What are the effects?

This small defect in the development of the spinal cord has dramatic effects:

- Without early surgery to cover the bag of nerves, infection may occur, causing the child to die of meningitis.
- Paralysis of the muscles under the back injury, caused by interruption of nerves.
- Loss of feeling and as a result higher risk of injuries (caused by pressure, cutting and burning).
- The feet may be deformed (clubfeet).
- Poor urine and bowel control leading to incontinence and an increased risk of urinary infections and kidney damage.
- In 80% of all cases hydrocephalus develops in children with Spina Bifida because the balance between the liquid being formed on the one hand and being drained on the other is being upset. Without the insertion by surgery of a shunt to drain the liquid the pressure of the liquid in the brain risks to become too high, which may cause the child to die, to contract a mental handicap or to become blind. Symptoms of hydrocephalus are: the head is growing too big or too fast, big veins on the head and eyes turned downward, so that the white of the eyeball is showing ('setting sun sign'). Mostly the child will need several shunt operations during his lifetime.

1. A small injury with dramatic effects.
2. Before and after surgery
3. Cuts and vesicles.
4. Bedsores in places of pressure
5. Clubfeet (talipes)
6. Setting sun sign

What is the future for a child with Spina Bifida?

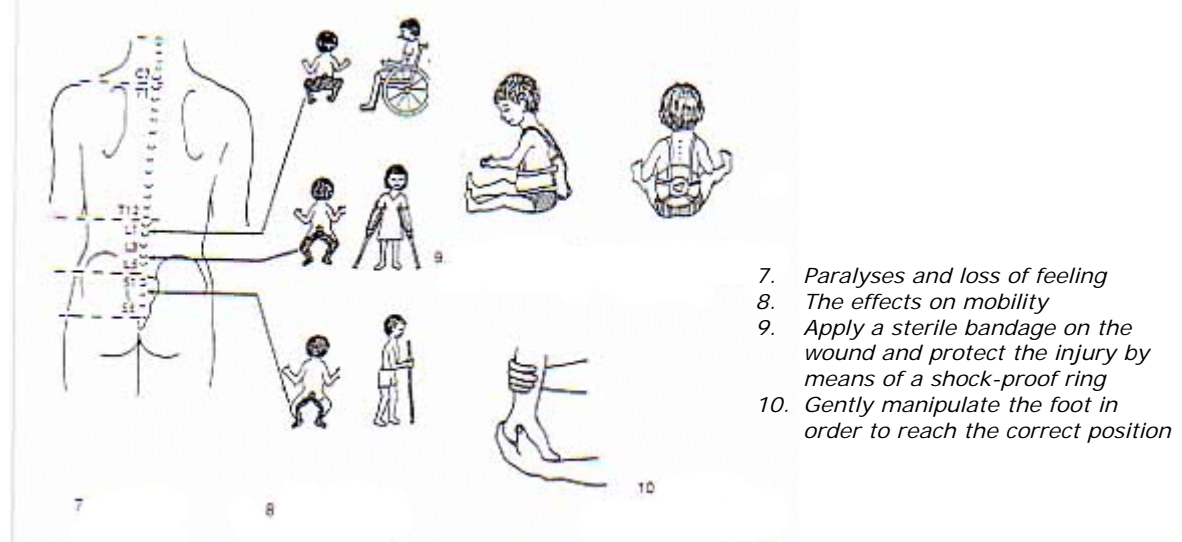
The higher up the back the defect is, the worse are the consequences likely to be. Further the possibility of surgery, the family's ability to pay and external assistance are decisive for the chances of the child.

Mostly the expenses of treatment are enormous, which is why in developing countries only few children are given

adequate treatment. 30% of the children who are not given treatment survive the first period of their life. Mostly these are children with a milder form of spina bifida or children whose hydrocephalus condition spontaneously stabilises.

There is also a closed type of Spina Bifida. This is not always diagnosed immediately at birth. Mostly the effects do not occur until later and they resemble those of the open type. In such cases a clubfoot or incontinence may be given symptomatic treatment, without discovering the link with Spina Bifida. Local hair growth, birthmarks or lipoma's showing on the child's back may be symptoms of this closed form of Spina Bifida.

With good family and community support, a child with Spina Bifida often has a good chance of living a full life and mostly will be able to attend regular education.



What to do when a child is born with Spina Bifida?

- Cover the 'bag of nerves' with a sterile bandage in order to prevent infection. This first aid will give you more time to assess whether or not treatment of the child is at all possible .
- Daily measure the head with measuring tape in order to see if a hydrocephalus is developing.
- Brief the family accurately and repeatedly as to the child's handicap.
- Find out if the child has a chance of getting treatment, care and support from the people in his environment.

Further treatment and rehabilitation

- Paralysis: try by way of simple exercises to keep the paralysed limbs supple and to put the feet in the right position.
- Mobility: try to stimulate the child as early as possible to move around independently: for instance going on all fours with a wheelboard with swivelling rollers, rolling cart etc. ...
- Incontinence:
 - a. Urine. To avoid infections it is important for the bladder to be emptied completely several times a day. This may be done by pressing gently on the bladder from the outside or to insert a catheter in the bladder (in the case of boys via the penis) so as to empty the bladder.
 - b. Faeces. Constipation may be prevented by high-fibre food. It is important to teach the child at an early age to cope with his incontinence problem by himself.
- Hydrocephalus: in children with a shunt one should remain alert because due to complications with the shunt the hydrocephalus may grow even bigger. Symptoms of too high pressure are: headache, nausea, sudden changes in character, sleepiness, concentration disturbances...
- Bedsores. Prevention is very important here, because healing of these wounds is very difficult. Due to paralysis the children don't feel heat and pressure. Therefore it is advisable to regularly check the child's bottom, knees and feet for injuries. Red stains or specks are signs of bedsores.



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Where do I find information about Spina Bifida?

The International Federation for Hydrocephalus and Spina Bifida (IFHSB) has a national organization in more than 30 countries.

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For developing countries this organization is preparing together with the World Health Organization a manual for rehabilitation workers.

This manual is due to be issued in June 1996 and may be obtained upon request.

The book of David Werner 'Disabled Village Children' provides good and simple information about the handicap and treatment.

11. *Orthopedical appliances to support normal development of the child*
12. *Emptying the bladder by way of a catheter*
13. *..... or by pressing on the stomach.*
14. *A shunt running from the brain into the entrance to the heart or into the belly*
15. *Regularly examine places affected by loss of feeling in order to avoid pressure wounds.*