


SPINA BIFIDA - FACTSHEET





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What is Spina Bifida?

Spina bifida is a neural tube birth defect (NTD) which occurs within the first four weeks of pregnancy. The spinal column fails to develop properly resulting in varying degrees of permanent damage to the spinal cord and nervous system.

Infants born with spina bifida may have an open lesion on their spine where significant damage to the nerves and spinal cord occurs. Although the spinal opening is surgically repaired shortly after birth, the nerve damage is permanent. This results in varying degrees of paralysis of the lower limbs, depending largely on the location and severity of the lesion. Even with no visible lesion, there may be improperly formed or missing vertebrae, and accompanying nerve damage.



The three most common types of spina bifida are:

- **Spina bifida occulta** - a mild form of spina bifida in which the spinal cord and the surrounding structures remain inside the body, but the back bones in the lower back area fail to form normally. There may be a hairy patch, dimple, or birthmark over the area of the defect. Other times, there may be no abnormalities in the area.
- **Meningocele** - a moderate form of spina bifida in which a fluid-filled sac is visible outside of the back area. The sac does not contain the spinal cord or nerves.
- **Myelomeningocele** - a severe form of spina bifida in which the spinal cord and nerves develop outside of the body and are contained in a fluid-filled sac that is visible outside of the back area. These babies typically have weakness and loss of sensation below the defect. Problems with bowel and bladder function are also common. A majority of babies with myelomeningocele will also have hydrocephalus, a condition that causes the fluid inside of the head to build up, causing pressure inside of the head to increase and the skull bones to expand to a larger than normal size.



Spina Bifida: causes, symptoms and diagnosis

What causes Spina Bifida?

The exact cause of spina bifida remains a mystery. No one knows what disrupts complete closure of the neural tube, causing a malformation to develop. Scientists suspect that the cause is multifactorial: genetic, nutritional, and environmental factors play a role. Research studies indicate that insufficient intake of folic acid—a common B vitamin—in the mother's diet is a key factor in causing spina bifida and other neural tube defects. Prenatal vitamins that are prescribed for the pregnant mother typically contain folic acid as well as other vitamins.

What are the symptoms of Spina Bifida?

The symptoms of spina bifida vary from person to person, depending on the type and level of involvement. Closed neural tube defects are often recognized or identified early in life due to an abnormal tuft or clump of hair or a small dimple or birthmark on the skin at the site of the spinal malformation.



Meningocele and myelomeningocele generally involve a fluid-filled sac—visible on the back—protruding from the spinal canal. In meningocele, the sac may be covered by a thin layer of skin. In most cases of myelomeningocele, there is no layer of skin covering the sac and an area of abnormally developed spinal cord tissue usually is exposed.

How is Spina Bifida diagnosed?

In most cases, spina bifida is diagnosed prenatally, or before birth. However, some mild cases may go unnoticed until after birth (postnatal). Very mild forms (such as spina bifida occulta), in which there are no symptoms, may never be detected.

Prenatal Diagnosis

The most common screening methods used to look for spina bifida during pregnancy are second trimester (16th to 18th weeks of gestation) maternal serum alpha fetoprotein (MSAFP) screening and fetal ultrasound. The MSAFP screen measures the level of a protein called alpha-fetoprotein (AFP), which is made naturally by the fetus and placenta. During pregnancy, a small amount of AFP normally crosses the placenta and enters the mother's bloodstream. If abnormally high levels of this protein appear in the mother's bloodstream it may indicate that the fetus has an "open" (not skin-covered) neural tube defect. The MSAFP test, however, is not specific for spina bifida and requires correct gestational dates to be most accurate; it cannot definitively determine that there is a problem with the fetus. If a high level of AFP is detected, the doctor may request additional testing, such as an ultrasound or amniocentesis to help determine the cause.

The second trimester MSAFP screen described above may be performed alone or as part of a larger, multiple-marker screen. Multiple-marker screens look not only for neural tube defects, but also for other birth defects, including Down syndrome and other chromosomal abnormalities. First trimester screens for chromosomal abnormalities also exist but signs of spina bifida are not evident until the second trimester when the MSAFP screening is performed.

Amniocentesis—an exam in which the doctor removes samples of fluid from the amniotic sac that surrounds the fetus—may also be used to diagnose spina bifida. Although amniocentesis cannot reveal the severity of spina bifida, finding high levels of AFP may indicate that the disorder is present.

Postnatal Diagnosis

Mild cases of spina bifida (occulta; closed) not diagnosed during prenatal testing may be detected postnatally by X-ray during a routine examination. Doctors may use magnetic resonance imaging (MRI) or a computed tomography (CT) scan to get a clearer view of the spine and vertebrae. Individuals with the more severe forms of spina bifida often have muscle weakness in their feet, hips, and legs. If hydrocephalus is suspected, the doctor may request a CT scan and/or X-ray of the skull to look for extra cerebrospinal fluid inside the brain.



How is Spina Bifida treated?

There is no cure for spina bifida. The nerve tissue that is damaged or lost cannot be repaired or replaced, nor can function be restored to the damaged nerves. Treatment depends on the type and severity of the disorder. Generally, children with the mild form need no treatment, although some may require surgery as they grow.

The key early priorities for treating myelomeningocele are to prevent infection from developing through the exposed nerves and tissue through the spine defect, and to protect the exposed nerves and structures from additional trauma. Typically, a child born with spina bifida will have surgery to close the defect and minimize the risk of infection or further trauma within the first few days of life.

Twenty to 50 percent of children with myelomeningocele develop a condition called progressive tethering, or tethered cord syndrome, in which their distal spinal cords become fastened to an immovable structure—such as overlying membranes and vertebrae—causing the spinal cord to become abnormally stretched and the vertebrae elongated with growth and movement. This condition can cause change in the muscle function of the legs, as well as changes in bowel and bladder function. Early surgery on the spinal cord may allow the child to regain a normal level of functioning and prevent further neurological deterioration.

Some children will need subsequent surgeries to manage problems with the feet, hips, or spine. Individuals with hydrocephalus generally will require additional surgeries to replace the shunt, which can be outgrown or become clogged.

Some individuals with spina bifida require assistive mobility devices such as braces, crutches, or wheelchairs. The location of the malformation on the spine often indicates the type of assistive devices needed. Children with a defect high on the spine and more extensive paralysis will often require a wheelchair, while those with a defect lower on the spine may be able to use crutches, bladder catheterizations, leg braces, or walkers. Beginning special exercises for the legs and feet at an early age may help prepare the child for walking those those braces or crutches when he or she is older.

Treatment of bladder and bowel problems typically begins soon after birth, and may include bladder catheterizations and bowel management regimens.

Multidisciplinary care for children and adults with Spina Bifida

Because spina bifida affects so many body systems it is important that professionals from different specialities be consulted to provide up-to-date, comprehensive medical, psychological and social evaluation, support and treatment. There are many spina bifida clinics throughout Europe, the USA and other developed countries which bring the appropriate specialists together to provide the necessary care. However, many people with spina bifida in eastern

Europe and developing countries suffer from difficult care conditions. Moreover, there are a lot of efforts to be done to guarantee the appropriate transition from childhood to adulthood for people with spina bifida and the establishment of multidisciplinary clinics for adults as well.

Management of Myelomeningocele Study (MOMS)

In the USA, selected medical centers continue to perform fetal surgery for treatment of myelomeningocele through a National Institute protocol (Management of Myelomeningocele Study, or MOMS). Fetal surgery is performed in utero (within the uterus) and involves opening the mother's abdomen and uterus and sewing shut the abnormal opening over the developing baby's spinal cord. Some doctors believe the earlier the defect is corrected, the better the baby's outcome. Although the procedure cannot restore lost neurological function, it may prevent additional losses from occurring.

Originally planned to enroll 200 expectant mothers carrying a child with myelomeningocele, the Management of Myelomeningocele Study was stopped after the enrollment of 183 women, because of the benefits demonstrated in the children who underwent prenatal surgery.

There are risks to the fetus as well as to the mother. The major risks to the fetus are those that might occur if the surgery stimulates premature delivery, such as organ immaturity, brain hemorrhage, and death. Risks to the mother include infection, blood loss leading to the need for transfusion, gestational diabetes, and weight gain due to bed rest.

Still, the benefits of fetal surgery are promising, and include less exposure of the vulnerable spinal nerve tissue and bones to the intrauterine environment, in particular the amniotic fluid, which is considered toxic. As an added benefit, doctors have discovered that the procedure affects the way the fetal hindbrain develops in the uterus, allowing certain complications—such as Chiari II and hydrocephalus—to correct themselves, thus, reducing or, in some cases, eliminating the need for surgery to implant a shunt.

Can Spina Bifida be prevented?

Spina Bifida is a birth defect that can happen to anyone. We do not know the exact cause of Spina Bifida, but research has shown that **if a woman takes 0,4 mg of Folic Acid every day for 3 months during her pregnancy and two month before she becomes pregnant, she reduces her risk of having a baby with Spina Bifida or another neural tube defect by as much as 70%**. Folic Acid helps the body to build healthy cells. Folic Acid is most important when your body is building lots of new cells, like before and during pregnancy. That is why it is important to get enough Folic Acid every day.

What is Folic acid?

Folic acid is the synthetic form of folate that can be found in supplements and added to fortified foods. Folic Acid (Vitamin B9) is a simple, inexpensive supplement which reduces the incidence of spina bifida and other neural tube defects in the foetus if taken by women prior to conception and for the first three months of pregnancy. It is important for a woman to have enough folic acid in her system before pregnancy and during the early weeks of pregnancy, before the neural tube closes. The recommended intake is 0.6mg per day, but as a normal diet cannot provide this level of folic acid, an extra 0.4mg per day is required. Folic Acid helps your body build healthy cells. It is important to get in the habit of taking a vitamin with Folic Acid every day so that your body has enough when you need it.

IF recommends that all women of childbearing age take a multivitamin with 400 micrograms of folic acid every day, two months before pregnancy and during first three months of pregnancy, as part of a healthy diet.

Who needs Folic acid?

Everyone! Just about everyone needs to take a vitamin with Folic Acid every day. Folic Acid is an important vitamin that is recommended for all men and women. Folic Acid is most important for any woman who could possibly become pregnant. Even if you are not planning to become pregnant, your body needs Folic Acid every day. Most people do not plan a pregnancy, so it is important to get in the habit of taking Folic Acid so that your body has it when you need it.

Recurrence Prevention

Women who are at high risk of having a child with Spina Bifida, because they have had an affected pregnancy before, or have a history of Spina Bifida in their family, or have Spina Bifida themselves, should take a prescription level of 4000 mcg (4,0 mg) of Folic Acid.

A healthy diet can help

Many studies have shown that diet is a contributory factor to the well-being of the foetus and it would seem prudent for women who are planning to become pregnant to ensure that their diet is reinforced with items in which folic acid naturally occurs. These include barley, baked beans, brewer's yeast, endive, chick peas, green leafy vegetables, lentils, orange juice, oranges, peas,

rice, soya beans, split peas, sprouts, wheat and wheat germ. Vegetables should be lightly cooked as over-boiling destroys their vitamin content. Advice to eat liver should not be heeded: liver contains concentrations of vitamin A which, when added to vitamin A intake from other foods, can damage the unborn baby. Some substances may affect the absorption of folic acid so, if you are taking any medication, do check this out with your doctor. If you are on anticonvulsant medication, you should consult your neurologist before taking folic acid, as folic acid and some anticonvulsants can be antagonists (ie work against each other).

Folic acid supplements taken before conception can reduce the risk of neural tube defects recurring. They will not however, guarantee the elimination of neural tube defects, such as Spina Bifida. IF remains committed to supporting research into the causes of neural tube defects, their effects on people's life, and to the continuing support of the many thousands of people with Spina Bifida, and their families.





Worldwide, at least **300,000 newborns** are affected by a NTD every year. In Europe, data suggests that there are more than 4,500 affected pregnancies every year.

In many countries, **up to 50% of pregnancies** are estimated to be unplanned.



In Europe **72%** of NTD affected pregnancies are terminated every year following a prenatal diagnosis

Spina Bifida is a neural tube defect (NTD) which occurs when the neural tube fails to close within the **first 28 days of pregnancy**, resulting in severe malformations, and affects around 1 in 1000 pregnancies in Europe

Most women are therefore not able to ensure the adequate folate levels in advance of conception. Once a woman becomes aware of her pregnancy it is too late to ensure adequate folate levels to reduce the risk of a NTD affected pregnancy.

0.4 mg of folic acid daily reduces the risk of NTD

Up to **70%** of NTD cases can be prevented by a daily intake of Folic Acid

minimum **2 months** prior to conception

Living with Spina Bifida

Spina bifida is a multifaceted condition characterized with diverse problems that have effect on the mind, the body, and the spirit. Some of the challenges that potentially faces those with Spina Bifida are listed below.

Continence management

Because of nerve damage, individuals with myelomeningocele often have problems emptying the bladder completely. This can lead to urinary tract infections and kidney damage. A technique called intermittent catheterization, in which the parent or child inserts a plastic tube into the bladder several times a day, is often helpful. Children with Spina Bifida should have regular care by a urologist (a doctor who specializes in urinary tract problems) to help prevent urinary tract problems.

Hydrocephalus

About 70 to 90 percent of children with myelomeningocele develop hydrocephalus, a build-up of fluid in and around the brain. Cerebrospinal fluid cushions and protects the brain and spinal cord. When the fluid is unable to circulate normally, it collects in and around the brain, causing the head to be enlarged. Those who develop progressive Hydrocephalus need surgery. Without treatment, Hydrocephalus can cause brain damage and mental retardation.

Chiari II malformation

Nearly all children with myelomeningocele have an abnormal change in the position of the brain. The lower part of the brain is located farther down than normal and is partly displaced into the upper part of the spinal canal. This can block the flow of cerebrospinal fluid and contribute to Hydrocephalus. In most cases, affected children have no other symptoms. But a small number develop serious problems, such as breathing and swallowing difficulties and upper body weakness. In these cases, doctors may recommend surgery to relieve pressure on the brain.

Pressure sores

Pressure sores occur when the skin is pressed between the bones of the skeleton and a hard surface which restricts the normal flow of blood, oxygen, and nutrients to the area. Subsequently the skin cells die, forming a pressure sore. This condition can be a problem to persons with spina bifida as they may also have a reduced circulation in the area due to their lack of movement. Usually the brain sends a message to the body to change position so that the cells will once again receive a proper blood supply. A person with Spina Bifida has areas of skin which do not have any feeling and often have partial or complete paralysis, and so does not receive these messages. If the pressure continues the blood supply is cut off, causing pressure sores.

Latex allergies

Many children with myelomeningocele are allergic to latex (natural rubber), possibly due to repeated exposures during surgeries and medical procedures. Symptoms include watery eyes, wheezing, hives, rash and even life-threatening breathing problems. Doctors should consider using nonlatex gloves and equipment during procedures on individuals with Spina Bifida. Affected individuals and their families should avoid latex items often found in the home and community, such as most baby bottle nipples, pacifiers and balloons.

Mobility

Some children with Spina Bifida have no movement in the lower trunk or legs, while others have virtually normal movement. Most children will be somewhere in between. Some children will walk independently, perhaps with small splints on their legs. They may have poor balance or poor endurance for long distances. Others will walk with splints (or more supportive walking gear) and a walking frame or crutches. They will normally use a wheelchair as well. Others will use a wheelchair most or all of the time. At least 80 percent of children with myelomeningocele have normal intelligence. However, some may face learning problems. Some individuals with myelomeningocele have additional physical and psychological problems, such as obesity, digestive tract disorders, depression and sexual issues. With treatment, children with Spina Bifida usually can become active individuals. Most live normal life and are successfully integrated in the social and professional spheres.



Continence management

Most people with Spina Bifida have varying degrees of what is known as a neuropathic bladder and bowel - when damage to the nerves interferes with normal functioning of bladder and bowel. The priority when managing the neuropathic bladder is to preserve kidney function. If regular checks are not carried out, irreversible kidney damage may be the result. Information is available on continence management in different periods of life.

Urinary tract infections are quite common in the general population. They can be mild when they only affect the bladder (cystitis) or more serious if they affect the kidneys (pyelonephritis).

Not being able to control your urine or faeces is probably one of the most

difficult problems to face. The problem arises from not having control over the emptying of the bladder or bowels - the places where urine and faeces collect before leaving the body. Many people with Spina Bifida do manage to work out a routine which helps them stay clean and dry.

Infancy

Bladder: Early referral to a medical specialist for assessment of kidney and bladder function is essential. The specialist may be a paediatrician or a urologist. A bladder which does not work normally may: cause urine to flow back to the kidneys; not empty completely. This could lead to urinary tract infections. Many parents are now taught to do clean intermittent catheterisation as a precaution when their child is very young. This ensures regular bladder emptying. Vesicostomy

is sometimes preferred where the child is thought to be at risk of developing kidney damage. This is usually a temporary measure.

Bowels: Most babies with Spina Bifida have an abnormal nerve supply to their bowel which will alter "normal" bowel function. The priority is to avoid constipation. In the early days, be aware of your child's bowel pattern. Aim to ensure regular soft stools which can be achieved by giving extra clear fluids, ie water. When mixed feeding begins, encourage foods with a high fibre content, like cereals, prunes and other puréed fruits. It is important to continue to encourage the taking of extra clear fluids.

Pre School Children

(These are the important years where the aim is to work towards continence.)

Bladder: Renal tract check-ups should be carried out at least once a year. Remember the importance of fluids. At least 6 - 8 drinks per day should be encouraged to help reduce the risk of urinary tract infections. Ask about the choices for effective bladder management. Cranberry juice is recognised as being useful in preventing and treating urinary tract infections, in some individuals. For these people, one glass a day is recommended.

Bowels: Encourage a well balanced healthy diet. A high fibre diet will help to keep the motions soft and easier to pass. Avoid eating too much food which can cause constipation, like eggs and full cream milk. Introduce your child to the potty/toilet. Ensure that your child can sit safely and comfortably,

supported or unsupported, with his/her feet placed on a firm surface. Regular emptying of the bowels should be encouraged. The best time is after breakfast or other meal times when natural bowel movement is most active. Maintain a high intake of clear fluids.

School Years

For the first time, working towards independent continence management becomes a prime objective. It is also a time when parents may have to involve others in the personal care of their child.

Bladder: As the bladder impairment may change, it is important to maintain monitoring of the renal tract by your paediatrician/urologist. This should take place at least once a year. For many children, the need to catheterise during the school day is essential. Any special requirements to enable this to be carried out should be discussed with the appropriate professionals, and may need to be written into the educational statement. Talk this over with professionals like the specialist urology nurse, school nurse, continence adviser, or specialist adviser. Facilities should be available for children to carry out their continence management. These may include a larger toileting area with a sink and a lockable door to ensure privacy. The child's needs should be considered when organising residential holidays or day trips. The school should be informed of the need for extra drinks to be taken throughout the day.

Bowels: Soiling can be particularly distressing for children in school. It is

essential to establish and maintain a good bowel regime to avoid this. Be careful with certain foods. For example, if beans induce a bowel movement, only eat them for this purpose. Otherwise, "accidents" may occur. Other foods may cause constipation - this can interfere with bladder function and make any urinary continence problems seem worse. Remember those extra fluids!!

Into Adult Life

During childhood, annual checks should have been carried out as a matter of course. Puberty may bring about changes in bladder and bowel routines, incontinence may get worse and management more difficult. Queries relating to sexual activity will need to be answered and problems should be discussed with the consultant, or specialist nurse. Automatic regular reviews often stop when individuals move from childhood to adult health services. They may only be seen if problems arise.

Surgical Options

Surgical options for long-term management of the bladder and/or bowel, to achieve continence, may be appropriate at any age. However, they should only be considered when all other choices have been explored. If renal function is deteriorating despite expert medical attention, then surgery is often required to protect the kidneys. If surgery is indicated, the individuals and their carers should have as full an understanding as possible of the procedure and any implications for future management. Advances in surgical techniques and on-going

research means that the surgical options are changing frequently. Your consultant may mention procedures which you do not understand. Ask for an explanation and seek further information from the specialist nurse at your hospital.

Explanation of terms

- **Kidneys** - organs at the back of your body which make the urine.
- **Clean Intermittent Catheterisation** - an established technique used to empty urine from the bladder when normal voiding is impossible. A catheter (small plastic tube) is put into the bladder through the urethra and removed when the bladder is empty. This takes only a few minutes.
- **Vesicostomy** - an opening from the skin into the bladder, below the navel, to allow the bladder to drain freely into a pad or nappy. Usually just temporary.

Urinary tract infections

Urinary tract infections are quite common in the general population. They can be mild when they only affect the bladder (cystitis) or more serious if they affect the kidneys (pyelonephritis).

When able-bodied people have cystitis, they generally need to pass urine more often than usual and they may have to hurry to the lavatory (urgency). Passing urine hurts or scalds and leaves them feeling sore and uncomfortable afterwards. The urine looks cloudy instead of clear and may smell different from usual. Because of the discomfort and inconvenience, they soon go to their doctor for advice. They are told to

drink extra fluids and take the antibiotics prescribed and they get better within a day or two. Cystitis is the commonest kind of urinary tract infection and it does not usually make the person ill. A much more serious situation arises in pyelonephritis in which the infection affects the kidneys causing a high temperature, tummy ache, backache, and sickness. Fortunately pyelonephritis rarely occurs in people who can empty their bladders normally and so have good drainage from the kidneys. But, for people with Spina Bifida who cannot empty their bladders well, it is quite a different story.

Why urinary tract infections are a problem for people with Spina Bifida

People with Spina Bifida often lack feeling and control of their bladder and bowel in the same way as they may lack feeling and control of their feet and legs. This is because the nerves in the spine connecting the brain to the bladder (or bowel or legs) have been interrupted, or disconnected, by the Spina Bifida. The result is that they cannot usually feel when their bladder is full, nor can they empty it properly. The bladder still contains urine (the residual urine) after they have tried to empty it. The stagnant pool or residual urine left in the bladder gets smelly and easily becomes infected and sometimes develops stones (urinary calculi) as well. Infections may spread to the kidneys causing pyelonephritis and kidney damage making the person ill. This happens because the bladder does not empty out the infected urine. It may also happen in children with reflux in whom the infected urine travels up towards the kidneys. Many people with Spina Bifida do

not know when they have a urinary infection. Because they lack feeling they do not suffer from the scalding pain which other people feel when they get cystitis, nor do they know their bladder is not emptying properly. Treating someone with Spina Bifida for a urinary infection with antibiotics and extra fluids works more slowly if the bladder is not emptying. The best way to prevent urinary infections damaging the kidneys is to be sure that the bladder empties regularly and completely. One way of doing this is by clean intermittent catheterisation.

How clean intermittent catheterisation improves urinary infections?

Intermittent catheterisation means inserting a narrow tube (catheter) along the usual passage (urethra) into the bladder. The urine flows out of the bladder through the catheter into the lavatory, or into a container, until the bladder is completely empty and then the catheter is removed. By doing this several times a day the person is kept much drier, or even completely dry. Provided the bladder is not allowed to remain full, urinary infections are most unlikely to spread to the kidneys. People should catheterise at least four times a day but those who have a smaller bladder or who drink a lot may need to catheterise six or even eight times. With practice catheterisation becomes quite easy and may take less than five minutes. Before starting intermittent catheterisation some people may have needed several courses of antibiotics for their urinary infections. But, after they start using catheterisation, their urine becomes quite clear once catheterisation has

removed the stagnant pool of residual urine. They cease to get attacks of pyelonephritis even though, when their urine samples are examined, they often show a mild infection. These mild infections are better left untreated: they do not spread to the kidneys so long as the bladder is not allowed to remain full. Twenty-five years of experience of intermittent catheterisation has shown that it actually prevents damage to the kidneys as well as improving those already damaged.

How to prevent urinary infections?

Fluids

It is always important to drink fluids to "flush out the kidneys", but this is less effective if the bladder is not emptying properly. It does however work very well in those who use intermittent catheterisation and do it frequently enough.

Bowels

People with Spina Bifida are often constipated and pressure from an overfull bowel may add to the difficulty of emptying the bladder. They may also have poor control over their bowel in the same way as they have over the bladder. Since most urinary infections are caused by bacteria which normally live in the bowel, it is important to wash this part of the body carefully. Girls should be taught always to wipe from front to back and not from back to front.

Medicines

Antibiotics and other medicines are sometimes given in small doses for months or years to prevent urinary infections. They are mainly used for children who have reflux or for anyone

with damaged kidneys to protect them from further harm. In spite of this, urinary infections may still break through and need a course of a different treatment.

Other remedies

Many remedies have been used over the years to prevent or relieve urinary infections and two of these are worth mentioning: Vitamin C (ascorbic acid) and cranberry juice. Vitamin C acts by making the urine acid and this discourages some of the bacteria which cause urinary infections. Cranberry juice helps to clear infections and debris after operations on the bladder. If enough is given, cranberry juice may also help to prevent urinary infections.

Key points

- In people with Spina Bifida urinary tract infections are mainly due to the bladder not emptying properly.
- Poor drainage from the bladder encourages infections to spread to the kidneys where they may cause damage.
- Good drainage is as important as fluid intake.
- Intermittent catheterisation ensures good drainage and protects the kidneys. It also makes incontinent people much drier.

Controlling continence

Wouldn't you like to be in control? Not being able to control your urine or faeces is probably one of the hardest problems you face. The problem arises from not having control over the emptying of your bladder or bowels - the places where urine and faeces collect before leaving your body. Many people with Spina Bifida and Hydrocephalus

do manage to work out a routine which helps them stay clean and dry.

Bladder

There are lots of reasons why your bladder needs to be emptied regularly. Most important is the need to prevent infection and to keep your kidneys healthy. A routine which works well will keep your skin dry and so help stop pressure sores. And remember, it's not very pleasant to smell of urine - either for you or those around you.

Helpful hints

- Drink plenty of fluids to keep your urine clear and your kidneys healthy.
- Don't have too many drinks which contain caffeine such as coffee, tea or Coke. Caffeine upsets the bladder which may lead to more infections. Drink fruit juices, particularly cranberry juice - they are better for you.
- Drink less beer, wine and other alcoholic drinks. If you drink too many of these, they can play havoc with your bladder management. If you drink too much alcohol, you may forget to empty your continence bag and this might leak - causing you and your friends a lot of embarrassment. When you go drinking with friends, order low-alcohol lager or wine. These give the taste without the alcohol.

Different ways to empty your bladder properly can include:

- Using a catheter. Some people use a catheter (or tube) to empty their bladder every three or four hours. You may hear this called Clean Intermittent Catheterisation (CIC).
- Indwelling catheter. This stays in the

bladder all the time and drains into a bag.

- Penile sheath (for boys only). This fits over the penis and also drains into a bag.
- Medicines from your doctor.
- Operations. There are several different operations available to help bladder control. Ask a continence adviser or your doctor if you want to know more about these.

Bowels

Emptying your bowel will help stop you from becoming bunged up or leaking on your underwear.

Helpful hints

- Drink plenty! This helps keep the faeces soft, so going to the toilet is easier.
- Eat a high-fibre diet - lots of fresh fruit, vegetables and cereals.
- Exercise helps to keep your bowel fit!
- To help you go at your usual time, sit on the toilet after a meal or hot drink, take a big breath and push hard. A continence adviser could explain this more fully to you.

Different ways to empty your bowel properly could include:

- Enemas or suppositories. These have to be prescribed by your doctor or continence adviser. They are put inside the bottom as high as possible and help to get things moving.
- Medicines from your doctor.
- Sometimes just stroking the entrance to the bottom can help you get the urge to go to the toilet.
- High bowel washout. Your

continence adviser will show you how to put a special tube into your bottom and then put water up the tube to help the faeces come out.

- Operations. There are several operations which may help control your bowel. Ask a continence adviser or your doctor if you want to know more.

Daily Check List to Improve your Bladder and Bowel:

1. Always drink lots of fluids. Cranberry juice is good for you.
2. Try not to drink too much coffee, tea and Coke.
3. Make sure that your bladder empties properly.
4. Eat a good diet. If you don't know the right kinds of food, ask.
5. Do some exercise every day.

Continence links:

- Continence management and Spina Bifida
- European Society for Paediatric Urology
- Catheter management





Type IV is an abnormal development of the cerebellum without its herniation into the neck.

Types I and II occur when the cerebellum is found herniated through the foramen magnum.

Type I can be acquired following a lumbo-peritoneal shunt, for example, with type II being associated with spina bifida.

These types of malformation can present at any age, but the average age seems to be in the late 30's - early 40's. Often the symptoms may have been present for years prior to detection, although as MRI scans become more widely available, diagnosis times will shorten.

Patients may have hydrocephalus, which can cause severe, even life-threatening problems. There can also be syringomyelia - a fluid, cyst-like build-up within the spinal cord itself.

Symptoms

Patients experience symptoms including:

- Headaches - usually at the back of the neck causing the patient to extend the neck (look up)
- Upper limb weakness
- Sensory disturbance
- Electric shock-like pains
- Visual disturbance with double vision or 'jumping' eyes
- Swallowing problems
- Speech alterations
- Poor co-ordination when walking

Chiari II malformation

Chiari malformations - formerly known as Arnold-Chiari malformation - are various problems with the base of the skull and the hole in the base of the skull that the spinal cord exits through into the neck.

There are four types of malformation, with types I and II, which are discussed here, being more common. Type III is rare and is associated with a cyst containing some brain at the back/base of the skull with the descent of the cerebellum (area of the brain for co-ordination and balance) into the neck.

Diagnosis

An MRI scan of the brain and whole spine is essential to make the diagnosis, as the brain and spinal cord may have additional abnormalities.

Treatment

Treatment, in those with symptoms, includes treating the hydrocephalus, which, if successful, may resolve the cerebellar herniation.

If there is no other cause demonstrated then an operation to open up the foramen magnum must be carried out to decompress the cerebellum and to restore the flow of cerebrospinal fluid.

This treatment, if successful, resolves the symptoms. Pain/headaches tend to respond best to the treatment, with weakness and sensory symptoms less likely to respond.

Most surgeons do warn patients that the surgery is to arrest the progression of the condition and any improvement should be considered a bonus.

Type II

As this form of Chiari malformation is associated with spina bifida and other brain abnormalities, there is thought to be a general disruption of the development of the brain and spinal cord.

Symptoms can be due to the Chiari malformation itself - as with type I - but can also be secondary to the spine. There can also be some vertebral (base of spine) abnormalities.

Diagnosis and Treatment

Investigation is a MRI scan and treatment includes untethering the spinal cord at the level of the spina bifida, allowing the tension in the cord to be released and the cerebellum to disimpact, or more commonly, a foramen magnum decompression. Any hydrocephalus may also require treatment.

Pressure sores

Many people with Spina Bifida will, at some point, develop a pressure sore. This is usually no one's fault and there are many things that can be done to prevent them. However, it is important to understand what causes them in order to be able to prevent them.

Causes

Poor circulation below the waist means that the cells do not receive adequate supplies of oxygen and nutrients to keep them healthy. Nor do they get rid of all their waste products. A system of the body, called the lymphatic system, works together with the circulation to remove fluid and waste products. This also does not work as efficiently as it should in people with Spina Bifida, so there can be a build-up of fluid in the legs. This is called oedema. All these things together mean that pressure sores can develop very rapidly and heal very slowly. Neurological (nerve) problems associated with Spina Bifida and the resulting loss of feeling means that little or no discomfort is felt and therefore there is no trigger telling you to move and reduce the pressure on a particular part of the body. Incontinence will cause the skin to become even more prone to damage as both urine and faeces contain substances that break down the skin and cause it to become infected.

Prevention

Change your position every 20 minutes. Lift your bottom off the chair and change the position of your legs. This allows the blood to flow normally

for a few seconds (that is all it needs!). If it is too difficult to lift your bottom, try to change position; leaning forwards or to one side first and then the other.

Regular inspection of the skin

Ideally the whole body should be inspected night and morning for signs of any redness or changes in the skin. If you find a red patch and it disappears quickly after you have eased the pressure in that area, there is no cause for alarm. But if the red colour remains, this could be the first sign of a sore developing. A close eye should be kept on this area and no further pressure should be put on it. A long-handled mirror is very useful for inspecting the back and bottom!

Diet

A good balanced diet is essential for both the prevention and healing of pressure sores. An adequate intake of fluids helps to keep the skin supple and hydrated. Complex carbohydrates (bread, rice, pasta) will keep the muscles healthy. Iron-rich food, such as spinach, will help the blood carry the oxygen around the body to the cells. Vitamin C and zinc (a mineral) both help wound healing, as does an adequate supply of proteins (found in meat, fish and dairy products).

Wear suitable clothing

Avoid clothes that are too tight or have hard seams, zips or buttons that might cause pressure. Good fitting shoes, with the feet put in properly, are essential. Take care when transferring from your wheelchair not to knock or drag the body. Barrier creams,

such as Sudocrem, Conotrane or Zinc and Castor Oil Cream, can be useful protection for the skin against incontinence, but the most important protection is to clean up and change as soon as an 'accident' has happened.

Hospital admissions

If you have to go to hospital and will be spending more time than usual in bed, ring the ward and tell them before you go that you will need a pressure-relieving mattress. Operating theatres also need to be aware of your needs before you have an operation. A visit before admission will be useful to you and to the staff. If you have to visit the Accident & Emergency Department, do remind them as soon as possible of your high risk of developing sores. The staff should then make sure that you are not left on a hand trolley or in a wheelchair without help to move around every 20 minutes or so.

Treatment

If a sore develops, it should be assessed as soon as possible by a specialist nurse or doctor who will 'grade' it and start the most appropriate treatment. There are many different products available for treating pressure sores and it would be impossible to list them all here. However, this is a rough guide:

- If the skin is red, but not broken, a second 'skin' may be used, such as Op Site or Tegaderm, to help prevent any further breakdown.
- If the skin is broken, but not infected or bleeding, something such as Comfeel, Granuflex or Allevyn would be applied. These dressings should not be changed every day unless

they have become detached.

- For deep sores a gel, such as Intrasite or Granugel, may be used. These are very good for the sore, but can ooze so the top dressing may need changing every day (sometimes twice a day). These gels can also be used for infected wounds. These are just some examples of the many products on the market and when they might be used. It is not meant to be a definitive guide and we do not endorse the use of any of the named products or any not listed.
- The best treatment of all is relief of pressure from the affected area. Special cushions and mattresses are available and the community team (occupational therapist or nurse) is responsible for assessing and arranging provision of these.
- If there are recurrent sores, it may be that a further assessment of pressure relief aids, including e.g. equipment - such as wheelchair and lifestyle - needs to be made.

Pressure sore prevention

- Lift your bottom from your chair every 20 minutes.
- Change the position of your legs at the same time.
- Check your skin all over your body at least once a day (twice is better).
- If you are wet or soiled, the quicker you clean up and change, the better.
- Take care when transferring from your wheelchair.
- Eat a healthy balanced diet including a variety of fruit and vegetables, and drink plenty of clear fluids.



Latex allergies

Latex is the sap from the Hevea brasiliensis tree. See the Fact sheet about Latex allergy

Latex allergies and Spina Bifida

Sensitivity to latex (natural rubber) can be a problem for people with Spina Bifida because of the frequency with which they come into contact with it. Many healthcare products contain latex so people with Spina Bifida (and medical professionals) are exposed to it on a regular basis - either during surgery (through the use of latex gloves and anaesthetic equipment) or during bladder and bowel management (through the use of latex tubing, gloves and catheters). Latex allergy occurs when the body's natural defences against an allergen come into force. It

involves the production of antibodies when there is contact with a specific antigen (in this case latex). Antibodies are produced by the initial reaction to latex which sensitise the cells in all tissues. The severity of subsequent reactions depends on the means of entry of the antigen.

Exposure to latex occurs when products containing rubber come in contact with a person's skin or mucous membranes such as the mouth, eyes, genitals, bladder or rectum. Serious reactions can also occur when latex enters the bloodstream. In addition, the powder from balloons or gloves can absorb particles and become airborne causing reactions when breathed by a latex sensitive person. The most potent and life-threatening reaction is entry into the vascular system, which can lead to changes in blood pressure

and circulation (anaphylactic shock). Skin contact produces a less severe reaction and this is usually raised, pinkish, itchy weals, which develop suddenly and last a few days, but leave no visible trace.

Research has shown in the United States that between 18% and 73% of children and adolescents with Spina Bifida are sensitive to latex as measured by history or blood test.

More is known about latex allergy in hospital staff and dentists than in patients. But things are changing. The Royal College of Nursing's Society of Occupational Health Nursing (SOHN) did a survey of health departments in 1996 to find out the number of staff with a latex allergy in UK hospitals. These figures will be used to lobby the government and to encourage hospitals to introduce allergy screening for new staff and patients, and to work out how to deal with patients and staff who have latex allergy. The Department of Health's Medical Devices Agency has suggested that health professionals ask patients about previous allergic reactions to latex. However, some believe nurses should go further and ask patients about any food allergies as the two are cross-related.

The mother in a case study says: "George seems an isolated case at the moment. We're fighting for his problem to be recognised. People don't believe it. If he ever had to be admitted into hospital as an emergency, I'd have kittens. They would have to suck all the air out of the operating theatre because even latex in the air can affect him."

List of products containing latex

Common household and hospital products containing latex:

- Household gloves
- Hospital gloves
- Condoms
- Condom incontinence aids
- Wheelchair tyres
- Adhesive tapes (sticky plasters)
- Some urinary catheters
- Some enema tubing
- Protective sheets
- Colostomy/urostomy products
- Balloons and rubber balls
- Art supplies
- Dental dams
- Baby bottle nipples and pacifiers
- Elastic on clothes
- Beach toys
- Chewing gum

There are alternative, non-latex products for all of these items. Usually, these alternatives are made of plastic, vinyl or silicone.

Foods with a cross-reactivity to latex
 Research has shown that proteins found in certain foods show similar immune system reactivity to the proteins found in latex. So, if your mouth itches when you eat any of the foods listed below, you could be allergic to latex as well. Foods which have been identified as having cross reactivity include:

- Bananas
- Potatoes
- Avocados
- Tomatoes
- Kiwi Fruit
- Mangoes
- Chestnuts



Mobility

The Spina Bifida lesion causes paralysis of varying degrees:

Some children have no movement in the lower trunk or legs, while others have virtually normal movement. Most children will be somewhere in between. Some children will walk independently, perhaps with small splints on their legs. They may have poor balance or poor endurance for long distances. Others will walk with splints (or more supportive walking gear) and a walking frame or crutches. They will normally use a wheelchair as well. Others will use a wheelchair most or all of the time.

Access

All children need adequate access to their kindy/preschool/school setting. This means access to classroom, play area, toilets, tuckshop etc. Often extra room is needed to manoeuvre within

the classroom. Some children can quite easily crawl or bottom up and down steps. Whether this is appropriate depends on the age of the child, where the steps are, how the child feels etc.

Transfers and lifting

Lifting of school-aged children should be kept to a minimum. Most children with Spina Bifida who use a wheelchair, can learn to transfer themselves (with or without assistance) from the wheelchair to the floor and back, from the wheelchair to other seats and back etc. This should be encouraged as much as possible. Advice on this matter should be sought from parents or from a therapist.

Floor mobility

It is important that small children who use a wheelchair should not spend all their time in the wheelchair when other children are playing or working

on the floor. Being down on the floor encourages social inclusion, as well as involvement in the same activities as other children. For some small children, other equipment such as a castor cart, which is down at ground level, may be appropriate for outdoor play.

Seating

Many children with Spina Bifida need special consideration of their seating. Many children who walk may need a smaller chair or table, because of short stature. Some may need a footrest so feet are supported and not dangling. This assists balance. Correct desk height also assists fine motor skills. Many children who use a wheelchair can and should sit in a normal classroom chair at pre-school and school. This makes them more a part of the group. If it is more appropriate to sit in the wheelchair, a special desk may be needed so the wheelchair fits under easily.

Walking

How well and how much a child walks depends on many factors besides how much movement he or she has. Motivation is an important factor. Some children love to walk and walk well with the appropriate gear. For others, it is a real chore. There are many benefits of walking:

- Improves fitness
- Helps prevent deformities, e.g. keeps hips and knees straight and feet flat
- Improves strength of bones through weight bearing and exercise
- Improves upper limb strength, needed by all for wheelchair use,

transfers, etc. as well as walking

- Improves bladder and bowel function; gravity and exercise help with these
- Improves circulation and helps prevent pressure problems of skin
- More normal visual input
- Sometimes the child looks at the world from the same level as everyone else when standing
- Improves social interaction, e.g. when standing at a table or workbench. However, a wheelchair is much better if children are out running around
- Improves accessibility. Being able to access high benches, cupboards etc. However, a wheelchair is much better for travelling long distances.

Walking and use of walking gear in a pre-school or school setting

This must be agreed between parents and the school with advice from a physiotherapist where appropriate. It must be practical and fit in with both the school's needs and the child's educational needs. Obviously, it is good to achieve regular walking at school if that is possible.

Wheelchair

Many children get their wheelchairs at about 3 years of age, so they are usually quite proficient with them by the time they go to school. They can usually manage:

- Ramps - if not too steep.
- Rough ground
- Small lips

However, gutters are very difficult for a small child. It may learn these as it grows older.

Benefits of wheelchair use

- Quicker than walking
- Requires less energy and therefore reduces fatigue
- Allows the child to keep up with others

It is often helpful if early rules regarding wheelchair use are set at school e.g. other children are not to help more than necessary. Peers often love to push the wheelchair or to fetch and carry for the child. There are two issues with this:

Independence: children should be expected to do as much as they can for themselves.

Safety: young children pushing wheelchairs can often be a safety risk.

Summary

There are many issues that may be relevant to mobility. Consider which ones are relevant to your situation. Parents are the experts on their children. Ask them for advice. Ask the children themselves what they can do. Do not assume they cannot do something without checking it out.



Transition

Thanks to the continuous advances in medicine, healthcare services have been drastically improved for children with Spina Bifida in many countries. However, once these children become young adults, the access to a comprehensive healthcare service becomes very fragmented and they no longer have the “one-stop-shopping” alternative for a multidisciplinary care. Besides, the transition from childhood into young adulthood is a delicate period for most teens but for teens with Spina Bifida, the challenge can be even greater as they evolve from:

- Children to adults with specific needs
- Pediatric care to adult health care
- School environment to work sphere
- Family life to independent life
- Home to community living

The International Federation for Spina Bifida and Hydrocephalus advocates for a comprehensive healthcare system throughout the lifespan of people with Spina Bifida. Moreover, IF suggests that adolescents with Spina Bifida and their families should prepare for the transition very early in the childhood phase, although this may vary depending on the child’s cognitive and physical capacities and their family supports. The transition itself should be steady and flexible. The child’s multidisciplinary care team may aid in the process by preparing comprehensive, up-to-date documents detailing the required medical care, including information about medications, surgery, therapies, and recommendations. Families and parents have a big role in insuring a good transition process. A bigger dependence on others (mainly parents) may hinder the adolescent's

self-management of health-related activities, such as catheterization, bowel management, and taking medications. As part of the transition process, it is crucial to let the child/adolescent to manage his daily tasks by his/her own. It is also beneficial to begin discussions at an early age about educational and vocational goals, independent living, and community involvement.



Spina Bifida in developing countries

Spina Bifida is a condition that cannot be cured. In many cases several surgical interventions are needed, such as the closure of the back after birth.

Good medical care and intensive training can prevent many complications. Over recent years treatment of Spina Bifida has improved a great deal giving an increased life expectancy for these children. In particular, developments in continence management and in the prevention of urological complications have improved the quality of life. However, in developing countries, people with spina bifida faces very difficult conditions in access to care and the right for social inclusion.

Guidelines for treatment Spina Bifida

- Dr Carla Verpoorten, medical adviser to IF prepared a document on Caring for children with Spina Bifida in developing countries.
- Protocol for managing myelomeningocele and hydrocephalus
- Guidelines for the management of Hydrocephalus and Spina Bifida in district hospitals

The neurogenic bladder and bowel

The kidneys are especially vulnerable to damage from pressure and recurrent infection within the first year of life. 10% of children with myelomeningocele (MM) will develop a dilatation deformity within the first year of life, and 35%

by the time they are four years old. Furthermore, it has been reported that over 50% of MM children have a dangerous bladder (having an active sphincter with or without an active detrusor). Therefore, a management protocol to protect renal function in these children is of vital importance. The milieu of a developing country necessitates an innovative approach to the management of these children, since practicality and compliance are essential to its success.

Read the protocol for the management of the neurogenic bladder for children in developing countries.

More relevant literature

- Fratta A, Bordenave J, Boissinot C, Le Grand J, Esquirol C, Radideau E, Benoit G. Development of an intravesical oxybutynin chloride solution: from formulation to quality control.
- Buyse G, Waldeck K, Verpoorten C, Bjork H, Casaer P, Andersson K-E. Intravesical oxybutynin for neurogenic bladder dysfunction: less systemic side effects due to reduced first pass metabolism.
- Buyse G, Verpoorten C, Vereecken R, Casaer P. Intravesical application of a stable oxybutynin solution improves therapeutic compliance and acceptance in children with neurogenic bladder dysfunction.
- What volume can a child normally store in the bladder at a safe pressure? Houle AM, Gilmour RF, Churchill BM, Gaumond M, Bissonnette B.

Information for parents to be

I am pregnant with a child with Spina Bifida or Hydrocephalus. What now?

Confusing feelings and emotions when you hear the news that your baby has Spina Bifida or Hydrocephalus. It is important to take some time and think and talk about what you feel. Other parents wrote down what they think, which is important when hearing this news.

Take time to think. You are shocked and may feel desperate. This is normal and it will take time to adapt to this new situation. You need not panic - there is time for you and your partner to look carefully at this. You need time for yourself, for your partner and for the baby who will be different in some ways. Your baby in its mother's womb is in the best environment it can be. Your child has no pain. You have time to make unhurried, unpreserved and informed decisions.

So much emotion, such confused thoughts

Talk about what has happened to you. Like all parents you looked forward to a normal healthy, baby. You did not expect the information you have just received.. As parents, it is important to express your feelings to each other. Later, talk to close friends and family. This is perhaps one of the most difficult moments of your life. So accept all help you can get. If you find it impossible to discuss these things a counsellor will assist you.

Medical Advice

Both partners should be together to hear the information and medical advice given. Remember, medical advice is important, but should be balanced with all other factors. Doctors will explain the medical factors of your child's condition. but there are other sources of information. Try to receive this information as a couple. It is easier if both partners hear and share all information. Together you hear more . The stark medical information is can be alarming and may need repeating several times before you really understand all that is being said and you need time to absorb this information.. Even in today's technical age, it is difficult for doctors to assess accurately the severity of disability of your child even if they are specialists in the condition. Some gynaecologist are very negative when assessing the quality of life for those with Spina Bifida and Hydrocephalus. This is a pity because most gynaecologists lack practical experience of these conditions. Therefore it is good to have more sources than your gynaecologist. Internet is useful for basic information. But you should also contact the parent organisation of your region ,or a consultation with Spina Bifida team will help you.

Why me, why us, why our child?

This is usually the first reaction of most people. It is not your fault. It is difficult to accept that you and not another are the one or two in a thousand parents who are faced with this. Scientific research shows that many factors contribute to the development of Spina Bifida and Hydrocephalus. It is important to remember that it is not your fault. It

was not your diet or any accident that you had that caused child's disability. Spina Bifida can occur even in ideal situations. What we do know is that taking folic acid before conception and into the third month of pregnancy can reduce the possibility of Spina Bifida by 75%.

What can I do to improve my child's situation?

There is a lot you can do, but one of the most important things it to take time and to speak about your feelings. The following is a list of some of the things you can do:

Continue the healthy lifestyle as you had from the beginning of pregnancy. Smoking and abuse of alcohol is bad for all children also when they have a disability.

Accept that the unborn child is yours. It is the same child that you loved before the diagnosis. The only difference is the information you have received. You love your child and this love will help you and your child in many ways. Make an appointment with specialist advisors who can provide up-to-date information about Spina Bifida and Hydrocephalus. Treatment has improved dramatically over the last decade and this will influence the prognosis.

Ask to meet other parents who have a child with Spina Bifida and Hydrocephalus. They can talk to you about how they cope and live with the problems which may arise.

In most cases the ideal situation for your child is to have a full and complete pregnancy. Your child is safe within you.

Usually, treatment will start immediately following the birth. This will involve clo-

sure of the back and often also treatment of the Hydrocephalus. Choice of consultant, preferably a skilled neurosurgeon, is important. Ideally, choose a hospital with a specialist Spina Bifida and Hydrocephalus team for the delivery, so that mother and child will not be separated. If this is not possible the expertise of a skilled (neuro-)surgeon is important as this can prevent many problems and may reduce the level of paralysis. Read everything you can find about Spina Bifida and Hydrocephalus and inform grandparents and your friends about your special child.

You will find information on the web about a new technique where surgery can be carried out on the unborn child in the womb. There is a risk for the mother as well for the unborn child and sometimes the results can be disappointing.

Some doctors will propose an abortion or a termination of pregnancy.

Some doctors judge that people with Spina Bifida and Hydrocephalus have a very poor quality of life which may not be worth living. This is a narrow, medically-aligned view which disregards other viewpoints. Indeed, there are many medical problems related to Spina Bifida and Hydrocephalus, but quality of life is not only a medical matter. Those best qualified to judge -people with Spina Bifida and Hydrocephalus- are convinced that their lives are definitely worthwhile. Adults with Spina Bifida and hydrocephalus who are talking below about their lives, were born at times when medical care was not as effective as it is in today's times.