

## Spina bifida explained

Spina bifida comes from the word for 'split spine' in Latin. It is one of a class of serious birth defects, called neural tube defects (NTDs), which involve damage to the bony spine and the nervous tissue of the spinal cord. Some vertebrae of the spine don't close properly during development and the spinal cord's nerves don't develop normally. They are exposed and can be subjected to further damage. At birth, they protrude through the gap instead of growing normally down the bony spinal column.

Nerve signals to most parts of the body located below the level of the 'split spine' are damaged and a wide range of muscles, organs and bodily functions are affected.

The other main type of neural tube defect is anencephaly, in which the brain and skull don't develop properly. All babies with anencephaly will either be stillborn or die soon after birth.

### Varying effects

People are affected by spina bifida (SB) in a variety of ways, ranging from minor to severe:

- **Legs and feet** – a range of walking difficulties (through to an inability to walk), reduced sensation, proneness to burns and pressure sores.
- **Bowel and bladder** – some level of urinary and faecal incontinence, increased stress on the kidneys, some level of sexual dysfunction.
- **Brain** – in most cases, the baby has hydrocephalus (a build-up of cerebrospinal fluid in the brain) and the Arnold Chiari malformation (the brain stem physically 'jams into' the spinal cord). These abnormalities may cause many different brain function disabilities.

### One in 1,000 pregnancies are affected

The risk of spina bifida is approximately one in every 1,000 pregnancies. It is caused by a combination of genetic and environmental factors, which are not yet fully understood. Inadequate intake of folate by the mother in early pregnancy is a significant factor in the occurrence of this condition. The number of babies born with spina bifida has dropped dramatically in recent years, due to improved ultrasounds and other tests, which detect the condition and provide the choice of pregnancy termination.

There is no cure. However, the vitamin folate can prevent up to 70 per cent of spina bifida cases, if taken daily one month before conception and daily during the first three months of pregnancy. Some people are at high risk for having a child with spina bifida or other neural tube defect. To check whether you are in this group, please see **The importance of folate** below.

### Detection

Well over 90 per cent of cases of spina bifida should be detected with a good quality ultrasound at 18 weeks. If present, specialist gynaecological care occurs until birth. If first detected at birth, there will be a large soft lump or lesion on the back. This lump contains spinal cord nerves and tissue. Exposed nerves must be surgically placed gently back under the skin within 24 hours.

### The neural tube

The nervous system of a growing foetus starts as a simple structure called the neural plate. This plate quickly becomes the baby's brain, and the spinal cord and neural tube that enclose it. By Day 28, the neural tube should have closed and fused. If it doesn't close, the result is a neural tube defect.

Spina bifida can occur at any place along the spine. However, surviving babies are generally affected lower down the spine because, at higher levels, the survival rate is low. The exact cause is not completely understood, but it appears that a combination of genetic and environmental factors is responsible. Inadequate metabolism of folate in early pregnancy is an important cause.

### Hydrocephalus

The brain and spinal cord are bathed in, and nourished by, cerebrospinal fluid. Most people with spina bifida experience a build-up of this fluid inside the skull, caused by the Arnold Chiari malformation. This must be managed early with a shunt, or brain damage will occur when the baby's head can no longer get bigger, after the skull bones have fused.

### Complications of spina bifida

The effects of spina bifida vary according to the type, location and severity of the condition. Generally, defects higher on the spine produce a greater risk of paralysis and other debilitating complications. Problems associated with spina bifida typically include:

- Reduced sensation in the lower body, legs and feet.
- A degree of paralysis of the lower body and legs.
- Degrees and types of urinary incontinence.
- Degrees and types of faecal bowel incontinence.
- Some sexual dysfunction, particularly for men where penile erection and normal ejaculation are affected.
- Learning difficulties.
- Abnormal joints.
- Deformities of the spine – commonly scoliosis, where the spine bends into an 'S' shape.
- Cord tethering, where the spinal cord 'sticks' to the area of the original lesion and becomes stretched.

### Diagnostic methods

Spina bifida can be diagnosed using a number of tests, including:

- Ultrasound – usually at 18 weeks
- Alpha-fetoprotein (AFP) testing
- Magnetic resonance imaging (MRI) scans
- Computed tomography (CT) scans.

### Treatment options

There is no cure for spina bifida. Treatment options include:

- **Surgery** – may be used to close the lesion and reduce the risk of infection.
- **Shunt** – hydrocephalus is treated with the insertion of a tube, called a shunt, into the ventricles in the brain where the spinal fluid is produced. The shunt has a one-way valve on the skull, under the skin behind an ear. This allows the excess cerebrospinal fluid to drain out of the brain via another tube into the abdomen or the heart.
- **Orthopaedic surgery** – children with spina bifida usually have a number of leg and foot operations to improve their mobility.
- **Aids** – walking aids or wheelchairs are commonly used.
- **Diet and enemas** – are used to manage faecal incontinence.
- **Bladder surgery** – this is common to increase bladder size and tighten muscles.
- **Self-catheterisation and continence pads** – may be required to manage urinary incontinence. Sometimes faecal or urinary bags are required.
- **General measures** – regular monitoring of kidney, bladder, shunt and spine functions is required.

### The importance of folate

Folate (folic acid) is a B-group vitamin. The recommended dose of folate, taken daily one month before conception and each day during the first three months of pregnancy, can prevent the occurrence of up to 70 per cent of neural tube defects. The National Health and Medical Research Council recommends that all women planning a pregnancy or likely to become pregnant should be offered folic acid supplements of 0.4mg daily. People in the 'high risk' category need to take a higher dose. See your doctor for advice.

High risk groups include people who have a:

- Previous child with a neural tube defect (NTD)
- Family history of NTDs on one or both sides
- Close relative with an NTD
- Close relative with a child with an NTD
- Women taking some anti-epileptic medications such as valproic acid.

Good sources of folate include:

- Folate supplements
- Foods naturally rich in folate – asparagus, spinach, oranges, bananas and legumes
- Foods fortified with folate, such as some breakfast cereals and bread. Look for the ANZFA Folate Enriched logo on the packet.

### **Where to get help**

- Your doctor
- Spina bifida clinics at the Royal Children’s Hospital Tel. (03) 9345 5898 and Monash Medical Centre Tel. (03) 9594 2327
- Your local state Spina Bifida Association

### **Things to remember**

- Spina bifida refers to a range of birth defects that affect the spinal cord.
- In spina bifida, some vertebrae of the spine aren’t closed, leaving the spinal cord nerves exposed and damaged.
- The recommended dose of folate, taken daily one month before conception and during the first three months of pregnancy, will greatly reduce your chances of having a child with a neural tube defect (NTD).

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Spina Bifida Foundation of Victoria

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