CONDITION

Spina bifida

Spina bifida is a condition in which the spine and spinal cord do not develop normally before birth.

WHAT IT IS
A lifelong condition affecting spinal cord development

BODY SYSTEM
Nervous system, spine, bladder, and bowel

MAIN SYMPTOMS
Leg weakness, reduced sensation, bladder problems, bowel problems

WHAT CAUSES IT
Complex mix of genes, folate, and other factors

HOW IT IS DIAGNOSED
Prenatal ultrasound, examination, and spinal imaging

MAIN TREATMENT
Surgery, rehabilitation, mobility support, and lifelong monitoring

CAN IT BE CURED?
No - nerve effects may be lifelong

IS IT AN EMERGENCY?
Sometimes - shunt blockage or sudden neurological symptoms

LONG-TERM OUTLOOK
Many live full lives with coordinated lifelong care

Overview

Spina bifida develops during the first weeks of pregnancy. The structure that becomes the brain and spinal cord, called the neural tube, does not close completely. This can affect the spinal bones, nerves, skin, or all of these.

There are several forms:

The effects range widely. Some people have little or no disability. Others have weakness or loss of feeling below the affected area, difficulty walking, bladder and bowel problems, or hydrocephalus. Hydrocephalus means excess fluid builds up around the brain.

Spina bifida is present from birth and is not contagious. Treatment cannot usually reverse nerve damage that developed before birth, but it can protect exposed tissue, manage

complications, and support independence.

- Myelomeningocele is the most serious common form. Part of the spinal cord and its protective tissues protrude through an opening in the spine.
- Meningocele causes a fluid-filled sac to protrude, but the spinal cord is usually less affected.
- Closed spinal dysraphism includes defects covered by skin. Nerves may still be tethered or damaged.
- Spina bifida occulta is a small gap in one or more spinal bones. It often causes no symptoms and may be found by chance.

Symptoms

Symptoms are influenced by the type of spina bifida and the level of the spinal defect. A defect higher on the spine is generally more likely to affect a larger part of the body.

Possible signs and symptoms include:

A tethered spinal cord is a cord held tightly by surrounding tissue. As a child grows, this tension may place stress on the nerves.

Babies with open spina bifida may have a visible sac or exposed tissue on the back. Closed forms may be associated with a dimple, fatty lump, birthmark, patch of hair, or small opening over the lower spine. Many harmless skin marks look similar, so a mark alone does not show that a spinal defect is present.

Hydrocephalus can cause a rapidly increasing head size, a tense soft spot, vomiting, unusual sleepiness, irritability, or downward-looking eyes in a baby. Older children and adults may develop headaches, vomiting, vision changes, balance problems, or reduced alertness.

- Weakness or paralysis in the legs
- Reduced or absent feeling in parts of the legs and feet
- Changes in the shape or position of the hips, legs, or feet
- Difficulty standing or walking
- Reduced bladder or bowel control
- Repeated urinary infections
- Skin wounds caused by pressure or unnoticed injury

- Back pain, increasing leg weakness, or changes in bladder control from a tethered spinal cord

Causes and risk factors

Spina bifida does not usually have one identifiable cause. It is thought to result from a combination of genetic, nutritional, health, medication, and environmental factors.

Folate, also called vitamin B9, is important for neural tube development. Not getting enough folate around conception increases the chance of a neural tube defect, but spina bifida can occur even when someone takes folic acid as advised.

Other factors linked with a higher chance include:

These are risk factors, not proof of a cause. Most parents did nothing to cause the condition. Spina bifida is not usually inherited in a simple, predictable pattern, although genes can contribute to susceptibility.

- A previous pregnancy affected by a neural tube defect
- A close family history of a neural tube defect
- Diabetes that is not well controlled around conception
- Obesity before pregnancy
- Certain anti-seizure medicines, particularly valproate
- High body temperature during very early pregnancy

Diagnosis

Spina bifida may be identified during pregnancy or after birth.

A blood screening test can measure alpha-fetoprotein, or AFP, during pregnancy. A high result may suggest an open neural tube defect, but it does not confirm one. Pregnancy dates, multiple pregnancy, and other conditions can also affect AFP levels.

A detailed prenatal ultrasound is the main imaging test used to look for spina bifida. Fetal MRI may provide more detail about the brain and spine. Amniocentesis, which tests fluid surrounding the fetus, is sometimes offered when more information is needed.

After birth, an open defect can usually be recognised by examination. Ultrasound or MRI may be used to assess a skin-covered defect, the spinal cord, and nearby tissues. Brain imaging can check for hydrocephalus.

Further tests may assess bladder emptying, kidney health, muscle strength, sensation, movement, and development. These tests help the care team understand the condition's effects rather than confirm every form of spina bifida.

Treatment and management

Treatment is tailored to the type of spina bifida and the problems it causes. Care may involve neurosurgery, urology, orthopaedics, rehabilitation, continence services, and primary care.

An open spinal defect is usually covered and protected at birth, followed by surgery to close it. Closure lowers the risk of infection and further injury but cannot restore nerves that did not develop normally.

For selected pregnancies with myelomeningocele, specialist centres may offer surgery before birth. Prenatal surgery can improve some outcomes, including reducing the need for a fluid-draining shunt in some children. It also carries important risks for the pregnant person and fetus and is not suitable for every pregnancy.

Hydrocephalus may be treated with a shunt, a tube that drains fluid from the brain to another part of the body. Some people can have an endoscopic procedure that creates another route for fluid drainage. Shunts need lifelong attention because they can become blocked or infected.

Other management may include:

Surgery may be considered if a tethered spinal cord causes new or worsening symptoms. Treatment focuses on preserving function and helping the person take part in school, work, relationships, and community life.

- Physiotherapy and occupational therapy
- Braces, crutches, walkers, or wheelchairs
- Orthopaedic treatment for joint, bone, or spine problems
- A bladder-emptying plan, sometimes including intermittent catheter use
- Medicines or planned routines for bowel management
- Regular kidney, bladder, skin, mobility, and development checks
- Educational or psychological support when needed

Complications

Reduced bladder control can allow urine to remain in the bladder or flow back toward the kidneys. Without suitable monitoring and management, this may contribute to infections or kidney damage.

Reduced sensation makes burns, pressure injuries, and foot wounds easier to miss. Regular skin checks are especially important for areas under braces or in contact with a wheelchair.

Other possible complications include joint stiffness, abnormal spinal curvature, reduced bone strength, tethered cord, sleep-related breathing problems, and latex allergy. Hydrocephalus or related brain changes may affect attention, planning, coordination, or learning, even when general intelligence is not affected.

Not everyone develops these complications. Regular follow-up is intended to identify changes before they cause lasting harm.

Prevention

Spina bifida cannot always be prevented. Its development is complex, and it can occur without any recognised risk factor.

Taking folic acid before conception and during early pregnancy reduces the chance of neural tube defects. Because the neural tube closes very early, folic acid is most helpful when started before pregnancy.

Anyone planning a pregnancy can discuss folic acid, diabetes control, and current medicines with a healthcare professional. People with a previous neural tube defect pregnancy or certain medical risks may be advised to take a higher folic acid dose under medical guidance.

Do not stop an anti-seizure or other prescribed medicine without specialist advice. Suddenly stopping treatment may be harmful.

Living with it and what to expect

Spina bifida is lifelong, but its effects are not identical from one person to another. Many people attend mainstream education, work, drive, form relationships, and live independently. Others need daily physical support or assistance with personal care.

The original nerve injury does not usually spread through the body. However, needs can change with growth, ageing, weight, activity, surgery, or complications such as tethered cord. Walking may become harder for some people over time because it uses a great deal of energy or places stress on the joints. A wheelchair can support mobility and independence rather than

represent a loss of progress.

Bladder and bowel routines often remain part of daily life. Regular kidney monitoring is important even when there are few symptoms. Skin checks, suitable footwear, pressure relief, and well-fitting mobility equipment can help prevent wounds.

Children may need extra support with organisation, attention, visual-spatial tasks, or coordination. Planning for the move from children's to adult services helps avoid gaps in urology, rehabilitation, shunt, and primary care follow-up.

Sexual development and relationships are possible. Sensation, sexual function, and fertility can be affected differently. Pregnancy may require specialist planning because of mobility needs, urinary health, medicines, and the chance of another neural tube defect.

Routine lifelong follow-up is usually needed. The aim is to preserve kidney and neurological function, support comfort and mobility, and respond when needs change.

When to get medical help

Arrange prompt medical review for:

These symptoms may reflect a treatable problem such as infection, pressure injury, tethered cord, or equipment that needs adjustment.

Seek emergency help for possible shunt blockage or infection. Warning signs can include severe or worsening headache, repeated vomiting, marked sleepiness, confusion, seizure, new vision problems, or loss of consciousness. In a baby, signs can include a tense soft spot, rapidly increasing head size, poor feeding, vomiting, or unusual drowsiness.

Emergency assessment is also needed for sudden loss of movement or sensation, severe breathing difficulty, or fluid leaking from an open spinal wound.

- New back pain, leg weakness, numbness, or difficulty walking
- A new change in bladder or bowel control
- Repeated urinary infections, pain when urinating, or fever
- Red, broken, swollen, or draining skin, especially on a numb area
- New pressure areas caused by braces, footwear, or seating
- Persistent headaches or changes in school, work, balance, or coordination

Common questions

Can someone with spina bifida walk?

Some people walk without assistance. Others use braces, crutches, a walker, or a wheelchair. Mobility is influenced by the level of nerve involvement, muscle strength, joint alignment, balance, and overall health. A person's mobility needs can change over time.

Is spina bifida a learning disability?

Not automatically. Many people have typical intelligence. Hydrocephalus and related brain differences can affect attention, memory, planning, coordination, or understanding visual information. Specific support can help at school, university, or work.

Is spina bifida hereditary?

It is not usually passed down through a single gene. Genetic factors can increase susceptibility, so a personal or family history raises the chance in a future pregnancy. A genetics or pregnancy specialist can provide information based on a family's circumstances.

Can spina bifida occulta cause symptoms later in life?

Most people with a small, uncomplicated spinal-bone gap never develop symptoms. Some skin-covered spinal abnormalities can tether or affect the spinal cord and may cause pain, weakness, sensation changes, or bladder problems. New neurological symptoms need assessment rather than being assumed to come from an incidental X-ray finding.

Can spina bifida be cured with surgery?

Surgery can close an open defect and treat complications such as hydrocephalus or tethered cord. It does not usually reverse established nerve damage. Rehabilitation, continence care, mobility support, and monitoring remain important.

How long can someone with spina bifida live?

Many people live well into adulthood. Outlook is influenced by the severity of the condition and by complications involving the brain, breathing, kidneys, skin, or infections. Consistent follow-up and timely treatment of complications are important throughout life.

Sources

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