CONDITION

Myelomeningocele

Myelomeningocele is an open spinal birth defect in which spinal cord tissue and nerves develop in a sac through the backbone.

WHAT IT IS
Open spinal birth defect affecting nerves and spinal cord

BODY SYSTEM
Nervous system, bones, bladder, and bowel

MAIN SYMPTOMS
Back sac, leg weakness, numbness, bladder and bowel problems

WHAT CAUSES IT
Genetic and environmental factors disrupting early spinal development

HOW IT IS DIAGNOSED
Prenatal ultrasound or physical examination and spinal imaging

MAIN TREATMENT
Surgical closure plus lifelong nerve, bladder, bowel, mobility care

CAN IT BE CURED?
No - established nerve damage cannot be reversed

IS IT AN EMERGENCY?
Sometimes - exposed sac or shunt warning signs

LONG-TERM OUTLOOK
Many reach adulthood with lifelong, individual care needs

Overview

Myelomeningocele is the most serious common form of spina bifida. It develops very early in pregnancy, when the structure that becomes the brain and spinal cord does not close completely.

Part of the spinal cord, its protective coverings, and spinal nerves push through an opening in the backbone. They usually form a fluid-filled sac on the baby's back. The sac may be covered by a thin membrane or may be open.

Nerves below the affected area may not work normally. This can affect leg movement and sensation, bladder and bowel control, skin health, and sexual function. The higher the opening is on the spine, the more extensive the effects tend to be, although each person is different.

Many people also develop hydrocephalus, meaning excess fluid builds up in spaces inside the brain. Myelomeningocele is also commonly linked with Chiari II malformation, in which parts of the lower brain sit farther down than usual.

Surgery can close the opening and protect the exposed tissue, but it cannot reverse nerve damage that has already happened. Ongoing care aims to protect the brain and kidneys, support movement and independence, prevent complications, and help the person take part in everyday life.

Symptoms

Myelomeningocele is present at birth. The most visible sign is usually a sac or open area along the spine, most often in the lower back.

Its effects depend mainly on the location of the opening and how much nerve tissue is involved. They may include:

Bladder problems are often caused by disrupted nerve signals. The bladder may not empty fully or may hold urine at unsafe pressure. A person may leak urine even when the bladder is not emptying properly. Without monitoring, this can contribute to urinary infections or kidney damage.

Bowel nerve changes may cause constipation, stool leakage, or difficulty emptying the bowel.

Some children walk independently. Others use braces, crutches, walkers, or wheelchairs. Mobility can change as a child grows or if complications such as joint tightening, weight gain, fractures, or tethered spinal cord develop.

Most people do not have a general intellectual disability. However, hydrocephalus and other brain differences can affect attention, planning, memory, visual-spatial skills, or learning speed.

- Weakness or paralysis in the legs
- Reduced or absent feeling below the spinal opening
- Difficulty controlling the bladder or bowel
- Changes in the shape or position of the hips, legs, or feet
- Hydrocephalus and an enlarging head in infancy
- Skin injuries in areas with reduced sensation

Causes and risk factors

Myelomeningocele results from incomplete closure of the neural tube, the early structure that forms the brain and spinal cord. Closure normally happens during the first few weeks of pregnancy, often before someone knows they are pregnant.

There is rarely one identifiable cause. Genetic susceptibility and environmental factors appear to act together. Myelomeningocele is not caused by something a pregnant person deliberately did.

Factors linked with a higher chance of neural tube defects include:

These factors increase risk but do not mean that a baby will have myelomeningocele. Many affected pregnancies have no known risk factor.

- A previous pregnancy affected by a neural tube defect
- A personal or close family history of a neural tube defect
- Too little folate around conception and early pregnancy
- Poorly controlled diabetes before or during early pregnancy
- Certain antiseizure medicines, particularly valproate
- High body temperature during early pregnancy, such as from prolonged fever
- Obesity before pregnancy

Diagnosis

Myelomeningocele may be identified before birth or diagnosed when the baby is born.

During pregnancy, a screening blood test may show a raised level of alpha-fetoprotein, or AFP. AFP is a protein made by the developing baby. A high result does not confirm myelomeningocele, so further assessment is needed.

A detailed prenatal ultrasound can usually identify the spinal opening and changes in the baby's brain that commonly occur with an open neural tube defect. Fetal MRI may provide more information in some cases. Amniocentesis, which tests fluid surrounding the baby, may sometimes be offered to support the diagnosis or check for chromosome conditions.

After birth, the spinal opening is usually clear on physical examination. MRI or ultrasound can show the spinal cord and surrounding structures. Brain imaging checks for hydrocephalus and Chiari II malformation.

Further tests assess how the condition affects the rest of the body. These may include kidney and bladder imaging, bladder pressure testing, movement and sensation assessments, and checks of the hips, legs, and feet.

Treatment and management

Care usually begins around delivery. An open sac is protected from drying, infection, and injury while a specialist team assesses the baby.

Surgery after birth closes the tissue coverings and skin over the spinal opening. This helps protect the exposed nerves but does not restore nerve function already lost. Hydrocephalus may require a shunt, a tube that drains fluid from the brain to another part of the body. Some children are treated with an internal procedure that creates another pathway for the fluid.

In selected pregnancies, fetal surgery may close the opening before birth. Research shows that it can reduce the need for a shunt and improve some movement outcomes. It also brings important risks, including premature birth and complications for the pregnant person. Assessment takes place at a specialist fetal surgery centre, and not every pregnancy is suitable.

Long-term management is based on the person's needs and may involve:

People with myelomeningocele have an increased likelihood of becoming sensitive to natural rubber latex after repeated medical exposure. Care teams may recommend latex-safe medical and home products.

Regular kidney, bladder, skin, mobility, and neurological assessments remain important even when the person feels well.

- Bladder emptying plans, medicines, monitoring, or surgery
- A structured bowel routine, dietary measures, medicines, or procedures
- Physiotherapy, exercise, braces, walking aids, or wheelchairs
- Treatment for hip, foot, spine, or joint problems
- Skin checks and pressure-relieving equipment
- Educational, psychological, and social support

Complications

Hydrocephalus can damage the brain if pressure is not controlled. Shunts may become blocked, break, or become infected, sometimes years after they were inserted.

Chiari II malformation may affect swallowing, breathing, voice, or arm strength. Many people have no severe symptoms, but new problems need assessment.

The spinal cord can become tethered, meaning it is held tightly by surrounding tissue as the

body grows. Possible signs include new weakness, pain, changes in walking, worsening bladder or bowel control, or a rapidly changing spinal curve.

Reduced bladder control can lead to repeated urinary infections, bladder damage, or kidney disease. Regular monitoring can detect pressure or kidney changes before obvious symptoms develop.

Other possible complications include constipation, pressure injuries, scoliosis, joint contractures, fractures, chronic pain, obesity, and reduced bone strength. Depression, anxiety, social isolation, and barriers to education or work can also affect well-being.

Prevention

Myelomeningocele cannot always be prevented. It can occur even when there are no known risk factors and recommended pregnancy precautions have been followed.

Folic acid taken before conception and during early pregnancy lowers the chance of neural tube defects. The amount needed is higher for some people, including those with a previous affected pregnancy or certain medical risks. A clinician can advise on the appropriate supplement before pregnancy.

If you take prescription medicines and may become pregnant, arrange a medication review. Some medicines can increase the risk of neural tube defects, but stopping antiseizure or other essential treatment suddenly can also be dangerous.

Managing diabetes before conception and getting prompt advice about a persistent high fever may also reduce avoidable risks. Prenatal screening does not prevent myelomeningocele, but it can identify the condition early and allow time to consider care and delivery options.

Living with it and what to expect

Myelomeningocele is lifelong, but its effects are not identical for everyone. The original nerve injury does not spread like a degenerative disease. However, growth, ageing, hydrocephalus, tethering, joint changes, weight, and kidney or bladder problems can change a person's abilities over time.

Infancy may involve spinal closure, treatment for hydrocephalus, and close monitoring. During childhood, care often focuses on movement, bladder and bowel routines, skin protection, learning, and participation at school.

Teenagers gradually learn to manage medicines, catheter use, bowel care, appointments, skin

checks, and equipment. Support for sexual health, relationships, body image, driving, education, and employment may also be useful.

Some people walk throughout life, while others mainly use a wheelchair. A wheelchair can conserve energy, protect joints, and improve independence rather than representing a loss of progress.

Adults continue to need follow-up, particularly for kidney and bladder health, shunt function, skin, pain, mobility, and tethered cord symptoms. Pregnancy is possible for many people with myelomeningocele, but pre-pregnancy planning is important because of medication, mobility, anaesthetic, folic acid, and delivery considerations.

Many people with myelomeningocele attend school, work, form relationships, and live independently or with chosen support. The amount of assistance needed is shaped by neurological effects, complications, access to equipment and care, and personal circumstances.

When to get medical help

An uncovered spinal sac in a newborn requires immediate specialist care. Do not press on it or attempt to clean or cover it with household materials unless a medical team gives instructions.

Seek emergency care for possible shunt blockage, infection, or dangerous pressure in the brain. Warning signs can include:

Contact the usual care team promptly for new leg weakness, loss of skills, back or leg pain, a change in walking, or worsening bladder or bowel control. These can be signs of spinal cord tethering or another neurological problem.

Fever with urinary symptoms, back pain, vomiting, or marked unwellness needs prompt assessment. Seek urgent care for a deep skin wound, spreading redness, blackened skin, or an injury over a numb area that cannot be properly assessed.

Routine appointments are appropriate for stable equipment needs, constipation, minor skin concerns, school support, or gradual changes in mobility. Do not wait for a routine visit if symptoms are sudden or rapidly worsening.

- Repeated vomiting or a severe, worsening headache
- Unusual sleepiness, confusion, seizure, or loss of consciousness
- A bulging soft spot, rapidly enlarging head, or poor feeding in a baby
- Redness, swelling, pain, or fluid along the shunt

- New breathing or swallowing difficulty

Common questions

Is myelomeningocele the same as spina bifida?

Myelomeningocele is one type of spina bifida. It is an open form in which spinal cord tissue and nerves extend through an opening in the backbone. Other forms, such as spina bifida occulta, may involve only the bones and can have much milder effects.

Can myelomeningocele be cured with surgery?

No. Surgery closes and protects the opening but cannot reverse established nerve damage. Treatment can prevent some further harm and manage complications, often making a major difference to health and independence.

Will a child with myelomeningocele be able to walk?

Some children walk independently, some use braces or walking aids, and others use wheelchairs. The likely level of mobility becomes clearer after examination and as the child develops. It is influenced by the level of the spinal opening, muscle strength, joint health, and later complications.

Does everyone with myelomeningocele need a brain shunt?

No. Hydrocephalus is common, but not everyone requires treatment. When brain fluid causes harmful pressure or progressive enlargement, a shunt or another drainage procedure may be recommended.

Can someone with myelomeningocele have children?

Often, yes. Fertility and sexual function may be affected by nerve changes, but many adults can have biological children. Pre-pregnancy planning can address folic acid, medicines, kidney and bladder health, mobility, anaesthesia, and delivery.

Is myelomeningocele inherited?

It does not usually follow a simple inheritance pattern. Genes can contribute to susceptibility, and the chance is higher after an affected pregnancy or in some families. Most cases result from a combination of genetic and environmental factors.

Sources

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