CONDITION

Subacute sclerosing panencephalitis

Subacute sclerosing panencephalitis is a progressive brain condition caused by a persistent measles virus infection.

WHAT IT IS
Progressive brain inflammation occurring years after measles

BODY SYSTEM
Nervous system

MAIN SYMPTOMS
Thinking changes, muscle jerks, seizures, movement problems

WHAT CAUSES IT
Persistent measles virus infection in the brain

HOW IT IS DIAGNOSED
EEG and high measles antibodies in cerebrospinal fluid

MAIN TREATMENT
Supportive care, seizure control, sometimes antiviral or immune therapy

CAN IT BE CURED?
No - no treatment reliably stops progression

IS IT AN EMERGENCY?
Sometimes - prolonged seizures, breathing problems, or sudden unresponsiveness

LONG-TERM OUTLOOK
Progressive disability that is often life-shortening

Overview

Subacute sclerosing panencephalitis, or SSPE, is a rare but serious condition affecting the brain and nervous system. It develops when measles virus remains in the brain after an earlier measles infection.

SSPE does not usually begin during measles itself. Symptoms most often appear several years later, commonly during childhood, adolescence, or early adulthood. The earlier measles infection may have been mild or may not be clearly remembered.

The condition causes ongoing inflammation and damage throughout the brain. Early changes may affect school performance, memory, behaviour, or coordination. Muscle jerks, seizures, movement problems, and loss of everyday abilities can follow.

SSPE usually becomes more severe over time. There is currently no treatment that reliably cures it, but specialist care can control some symptoms, support comfort and communication, and help families plan for changing needs.

Symptoms

Early symptoms can be subtle. They may initially look like stress, a learning problem, epilepsy, or a behavioural change. In a child or teenager, families may notice falling school performance or loss of skills that had already been learned.

Possible early symptoms include:

As SSPE progresses, brief shock-like muscle jerks called myoclonus often develop. These movements may affect the head, arms, legs, or whole body. They can happen in a repeated pattern and may cause objects to be dropped or make walking unsafe.

Other symptoms can include seizures, muscle stiffness, tremor, unusual twisting movements, difficulty speaking, and worsening coordination. Vision may also be affected because SSPE can damage the eyes, the visual pathways, or the parts of the brain that process sight.

Later symptoms may include difficulty swallowing, loss of movement, reduced awareness, and increasing dependence on other people. Not everyone develops symptoms in the same order or at the same speed.

- Problems with memory, attention, or judgement
- Personality, mood, or behaviour changes
- Reduced school or work performance
- Clumsiness, poor balance, or unexplained falls

Causes and risk factors

SSPE is caused by measles virus that persists abnormally inside the brain. Over time, the virus and the body's response to it lead to widespread brain inflammation and damage.

The condition follows infection with wild measles virus. It is not caused by the measles, mumps, and rubella vaccine, known as MMR. Vaccine viruses do not cause SSPE.

The main risk factor is having had measles, especially at a very young age. SSPE is therefore more likely to occur where measles continues to circulate or where vaccination coverage is low. Most people who have measles do not develop SSPE.

SSPE is not an inherited condition. A person does not pass it to their children through their genes.

Someone with SSPE is not generally considered contagious because of SSPE itself. The original measles infection occurred years earlier. Normal isolation measures used for active measles are not usually needed solely because a person has SSPE.

Diagnosis

Diagnosis usually involves a neurologist and often a specialist in childhood brain conditions. The assessment brings together the symptoms, examination findings, test results, and any known history of measles.

An electroencephalogram , or EEG, records the brain's electrical activity through small sensors placed on the scalp. SSPE often produces distinctive, regularly repeated electrical changes. These patterns may become clearer as the condition progresses.

A lumbar puncture may be used to collect cerebrospinal fluid , the clear liquid surrounding the brain and spinal cord. High levels of antibodies against measles in this fluid are important evidence for SSPE. Blood measles antibodies may also be measured, but a blood result alone does not confirm the diagnosis.

MRI scans can show inflammation, damage to the brain's white matter, or loss of brain tissue. An MRI can be normal or show only mild changes early on, so it cannot rule out SSPE by itself.

Doctors may also test for other causes of seizures, personality changes, or loss of skills. These can include autoimmune brain inflammation, metabolic or inherited conditions, infections, and other forms of epilepsy. A brain biopsy is rarely needed.

Treatment and management

There is no treatment that reliably removes the persistent virus or cures SSPE. Care is tailored to the person's symptoms, stage of the condition, and goals.

Anti-seizure medicines may reduce seizures and muscle jerks. Other medicines may be considered for stiffness, involuntary movements, sleep problems, discomfort, or distress. Finding the best symptom control can take time because symptoms may change.

Specialist centres sometimes use treatments intended to slow the condition, such as inosine pranobex, also called isoprinosine, or interferon. These treatments have not shown consistent benefit for everyone, and they can have significant side effects or require complex delivery. A

specialist can explain the uncertain evidence and whether a treatment is available or appropriate.

Supportive care is central to management. It may include:

If swallowing becomes unsafe, changes in food texture or tube feeding may be discussed. These decisions should take account of comfort, expected benefits, burdens, and the person's and family's preferences.

Palliative care can be involved from an early stage. It supports symptom relief, emotional wellbeing, decision-making, and family needs. It can be provided alongside active neurological treatment and does not mean that other care has stopped.

- Physiotherapy and safe positioning to preserve comfort and movement
- Occupational therapy, mobility equipment, and home adaptations
- Speech and communication support
- Assessment of swallowing and nutrition
- Educational, psychological, and social support
- Respite care and practical help for family caregivers

Complications

SSPE can lead to severe problems with thinking, communication, vision, movement, and awareness. Falls or seizures may cause injuries.

Difficulty swallowing can allow food, drink, or saliva to enter the lungs. This is called aspiration and can cause pneumonia. Reduced eating and drinking may lead to weight loss, dehydration, or poor nutrition.

Limited movement can contribute to painful muscle tightening, joint stiffness, pressure injuries, chest infections, and loss of bone strength. In advanced SSPE, damage to the brain can interfere with breathing and other basic body functions.

Prevention

SSPE can usually be prevented only by preventing measles. Vaccination against measles greatly reduces the chance of measles infection and therefore the later risk of SSPE.

The MMR vaccine does not cause SSPE. Keeping measles vaccination up to date also helps protect babies and people who cannot receive the vaccine by reducing measles spread in the

community.

After someone has already had measles, there is no proven treatment that guarantees SSPE will not develop later. There is also no established routine screening test that can predict which symptom-free person will develop it.

If you are unsure about your or your child's vaccination record, a routine appointment with a vaccination service or primary care professional can clarify what is needed.

Living with it and what to expect

SSPE is usually progressive, meaning abilities are lost over time. Many people worsen over months to a few years, but the speed is not predictable. Some have periods when symptoms appear stable, and a small number have a slower or unusually prolonged course. Stabilisation does not necessarily mean the condition has stopped permanently.

At first, someone may still attend school, work, or social activities with adjustments. As thinking, movement, or seizures worsen, they often need increasing supervision and help with personal care. Communication aids and familiar routines can help maintain connection even when speech becomes difficult.

Regular follow-up is used to review seizures, swallowing, nutrition, mobility, vision, sleep, pain, and equipment needs. This is routine care rather than an emergency, but appointments may need to become more frequent as needs change.

Because SSPE is often life-shortening, advance care planning may be discussed. This can include where care should take place, which treatments would be acceptable during serious illness, and what matters most to the person and family. These conversations can be reviewed whenever circumstances or preferences change.

Caring for someone with SSPE can be physically and emotionally demanding. Respite services, counselling, financial advice, and support from school or community services may be important parts of long-term care.

When to get medical help

Arrange a prompt medical assessment if you or someone you care for develops unexplained loss of skills, repeated muscle jerks, seizures, major behaviour changes, worsening balance, or declining school or work performance. These symptoms have many possible causes and do not by themselves mean SSPE.

If SSPE has already been diagnosed, contact the care team promptly about increasing seizures, new swallowing problems, repeated choking, reduced drinking, weight loss, worsening stiffness, new pain, or a clear change in alertness. These problems often need treatment but are not always emergencies.

Seek emergency help for:

Follow any personalised seizure or emergency plan already provided by the specialist team.

- A seizure lasting five minutes or longer
- Repeated seizures without recovery between them
- Severe difficulty breathing or blue or grey lips
- Sudden unresponsiveness or inability to wake
- A serious injury during a seizure
- Choking that does not clear

Common questions

Can subacute sclerosing panencephalitis be cured?

No treatment currently provides a reliable cure. Some specialist treatments may slow progression in selected people, but the evidence is limited and responses are inconsistent. Symptom control and supportive care remain essential.

How long after measles can SSPE appear?

It usually appears several years after the original infection. The delay can be shorter or much longer, so families may not connect the new symptoms with an earlier episode of measles.

Can the MMR vaccine cause SSPE?

No. SSPE is linked to infection with wild measles virus, not the MMR vaccine. Preventing measles through vaccination is the main way to prevent SSPE.

Is SSPE contagious?

SSPE itself is not considered contagious in the way active measles is. It results from virus that has remained inside the affected person's brain since an earlier infection.

How long can someone live with SSPE?

There is no exact timetable. SSPE often progresses over months to a few years and is commonly life-shortening, but slower courses and periods of stability can occur. The specialist team can discuss changes as they happen without promising a particular course.

Can SSPE be found before symptoms begin?

There is no established screening programme that can reliably predict SSPE in someone who feels well after measles. Tests such as EEG and cerebrospinal fluid analysis are used when symptoms and examination findings raise concern.

Sources

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