CONDITION

Neurosarcoidosis

Neurosarcoidosis is inflammation caused by sarcoidosis that affects the brain, spinal cord, or nerves.

WHAT IT IS
Sarcoidosis inflammation affecting the brain, spinal cord, or nerves

BODY SYSTEM
Nervous system

MAIN SYMPTOMS
Facial weakness, headache, vision changes, limb weakness

WHAT CAUSES IT
Misguided immune inflammation; exact trigger unknown

HOW IT IS DIAGNOSED
Nervous-system tissue biopsy; other tests support probable cases

MAIN TREATMENT
Medicines that reduce immune inflammation

CAN IT BE CURED?
Sometimes - inflammation settles but may return

IS IT AN EMERGENCY?
Sometimes - seizures, sudden weakness, or sudden vision loss

LONG-TERM OUTLOOK
Many improve; relapses or lasting nerve damage can occur

Overview

Neurosarcoidosis is a form of sarcoidosis that affects the nervous system. Sarcoidosis causes small clusters of inflammatory cells called granulomas. In neurosarcoidosis, this inflammation can involve the brain, spinal cord, the protective layers around them, or nerves elsewhere in the body.

It is possible to have neurosarcoidosis without previously knowing that you have sarcoidosis. In other people, it develops after sarcoidosis has been found in the lungs, lymph nodes, skin, eyes, or another organ.

The effects are different from person to person because the nervous system controls movement, sensation, vision, hearing, hormones, thinking, and many automatic body functions. Some problems improve fully with treatment. Others require long-term treatment or leave

lasting nerve damage.

Early assessment matters when symptoms are new or getting worse. However, many symptoms linked with neurosarcoidosis can also be caused by more common conditions. Having one of these symptoms does not mean that you have neurosarcoidosis.

Symptoms

Symptoms depend on which part of the nervous system is inflamed. They may develop over days, weeks, or months. Some come and go, while others gradually become more noticeable.

Possible symptoms include:

Inflammation near the pituitary gland or hypothalamus can disrupt hormone control. These are small structures at the base of the brain. Symptoms may include extreme thirst, passing unusually large amounts of urine, menstrual changes, reduced sexual function, or unexplained changes in weight and energy.

When the spinal cord is involved, symptoms may include leg weakness, altered sensation below part of the body, or loss of bladder and bowel control. Peripheral nerve involvement can cause patchy weakness, numbness, or pain in the face, trunk, or limbs.

- Weakness on one side of the face, sometimes called facial palsy
- Blurred or double vision, eye pain, or reduced vision
- Hearing loss, ringing in the ears, dizziness, or balance problems
- Persistent headache, neck stiffness, nausea, or sensitivity to light
- Numbness, tingling, burning pain, or weakness in the arms or legs
- Difficulty walking, poor coordination, or muscle stiffness
- Seizures or episodes of reduced awareness
- Problems with memory, concentration, mood, or behaviour
- Changes in bladder, bowel, or sexual function

Causes and risk factors

Neurosarcoidosis results from an abnormal immune response. Immune cells collect into granulomas and cause inflammation around nervous tissue. The exact trigger for this response is not known.

It is not an infection and cannot be passed from one person to another. Sarcoidosis sometimes occurs in families, suggesting that inherited factors can affect susceptibility. However, neurosarcoidosis is not usually inherited in a simple or predictable way.

Having sarcoidosis elsewhere in the body increases the possibility of nervous-system involvement. Even so, most people with sarcoidosis do not develop neurological symptoms. Neurosarcoidosis can also be the first noticeable sign of sarcoidosis.

Diagnosis

There is no single blood test or scan that can confirm every case. Diagnosis usually combines your symptoms, a neurological examination, imaging, spinal fluid tests, and evidence of sarcoidosis in tissue. Other possible causes must be carefully excluded.

An MRI scan of the brain or spinal cord is commonly used. A contrast material may be given into a vein to make areas of inflammation easier to see. MRI findings can support the diagnosis, but similar changes may occur with infections, cancer, multiple sclerosis, and other inflammatory conditions.

A lumbar puncture may be used to collect cerebrospinal fluid, the clear liquid surrounding the brain and spinal cord. The fluid may show inflammation, increased protein, or immune activity. These findings are useful but are not specific to neurosarcoidosis.

Blood tests may look for inflammation, organ function, infection, or hormone problems. Angiotensin-converting enzyme, often called ACE, may be measured, but a normal or raised ACE result cannot confirm or rule out neurosarcoidosis.

Chest imaging or a PET scan may help find sarcoidosis in lymph nodes, lungs, skin, or other areas. A biopsy can then remove a small tissue sample. Finding the typical granulomas supports the diagnosis, provided infections and other causes have been excluded.

A biopsy of affected nervous tissue provides the strongest confirmation, known as definite neurosarcoidosis. It is not always safe or necessary because the brain, spinal cord, and some nerves are difficult to sample. A diagnosis may instead be classed as probable when testing strongly supports neurosarcoidosis and a biopsy confirms sarcoidosis elsewhere.

Treatment and management

Treatment aims to reduce inflammation, protect nerve function, control symptoms, and limit treatment side effects. The plan is based on which structures are affected, how severe the symptoms are, and how the condition responds over time.

Corticosteroids like prednisone or hydrocortisone are usually the first treatment. These medicines suppress inflammation. Severe problems affecting vision, the spinal cord, or the brain may require treatment to begin quickly. Steroids are usually reduced gradually rather than stopped suddenly.

Because long-term steroid treatment can cause problems such as high blood pressure, high blood sugar, bone thinning, weight gain, mood changes, and increased infection risk, another immune-suppressing medicine may be added. Options used in specialist care include methotrexate, azathioprine, and mycophenolate. These medicines require regular blood tests.

Biologic medicines, such as infliximab, may be considered when neurosarcoidosis is severe, returns during treatment reduction, or does not respond adequately to other medicines. Biologics affect specific parts of the immune system. Screening for infections and ongoing monitoring are important.

Treatment may also address the effects of nerve damage. This can include:

Follow-up may include neurological examinations, MRI scans, blood tests, eye assessments, and checks for sarcoidosis in other organs. Monitoring also helps identify medicine side effects.

- Anti-seizure medicine for seizures
- Hormone replacement for pituitary or hypothalamic problems
- Medicines for nerve pain, muscle stiffness, or bladder symptoms
- Physiotherapy to support strength, balance, and movement
- Occupational or speech therapy when daily activities are affected
- Vision or hearing support when sensory nerves are involved

Complications

Ongoing inflammation can injure nervous tissue. Possible lasting effects include weakness, altered sensation, chronic pain, vision or hearing loss, seizures, balance problems, and difficulties with memory or concentration.

Inflammation can block the normal flow of fluid around the brain, causing hydrocephalus. This raises pressure inside the skull and may need urgent treatment. Spinal cord inflammation can lead to lasting mobility, bladder, bowel, or sexual problems.

Damage to hormone-control areas of the brain may require lifelong hormone replacement, even after the inflammation settles. Treatment itself can also increase the risk of infection,

bone loss, liver problems, or changes in blood cell counts. Regular monitoring is used to reduce these risks.

Prevention

There is no proven way to prevent neurosarcoidosis because its underlying trigger is unknown. It is not caused by something you did.

If you already have sarcoidosis, reporting new neurological symptoms promptly may help inflammation be assessed before more nerve damage occurs. If you are receiving treatment, taking medicines as agreed and attending monitoring appointments can reduce avoidable treatment problems. Steroids should not be stopped suddenly unless a medical professional has specifically told you to do so.

Living with it and what to expect

The course of neurosarcoidosis is not the same for everyone. Some people have one episode that settles with treatment. Others experience relapses, meaning inflammation returns after a period of improvement. Some need immune-suppressing treatment for months or years.

Symptoms caused mainly by active inflammation may improve as treatment takes effect. Recovery can be gradual because nerves heal slowly. Symptoms caused by permanent nerve injury may continue even when scans and other tests show that inflammation is controlled.

Regular follow-up is important during treatment reduction because a relapse may first appear as a small change in vision, strength, sensation, balance, bladder function, or hormone symptoms. A new symptom does not always mean a relapse, but it should be assessed.

Many people continue working, studying, caring for family, and taking part in usual activities, sometimes with adjustments. Fatigue, pain, mobility limits, or treatment appointments may affect daily plans. Rehabilitation, workplace changes, mobility aids, and psychological support can help when needed.

Long-term outlook is influenced by the location and severity of inflammation, how early treatment begins, and whether lasting nerve damage has occurred. Improvement is common, but relapses and disability remain possible.

When to get medical help

Arrange a prompt medical assessment if you develop a new or worsening neurological symptom, especially if you have sarcoidosis. Examples include persistent headache, facial weakness, numbness, progressive limb weakness, balance problems, hearing changes, or unusual thirst and urination.

New vision changes should be assessed urgently because inflammation of the optic nerve can threaten sight. New bladder or bowel control problems with leg weakness or numbness also require urgent assessment.

Call emergency services for:

These symptoms can have several causes, including stroke or infection. Emergency assessment is needed rather than waiting to see whether they improve.

During routine follow-up, report possible treatment side effects such as fever, repeated infections, unusual bruising, severe mood changes, or symptoms of high blood sugar. Do not stop immune-suppressing treatment suddenly without medical advice.

- A first seizure, a seizure lasting more than five minutes, or repeated seizures
- Sudden facial droop, arm weakness, speech difficulty, or loss of coordination
- Sudden loss of vision
- Rapidly worsening weakness or inability to walk
- Loss of consciousness or severe confusion
- A severe headache with repeated vomiting, marked drowsiness, or neck stiffness

Common questions

Is neurosarcoidosis a brain tumour?

No. Neurosarcoidosis is inflammation, not a tumour. However, a clump of inflammation can sometimes look like a mass on a scan. Imaging, other tests, and occasionally a biopsy are used to distinguish it from cancer and other conditions.

Can neurosarcoidosis go away?

Sometimes. Inflammation may settle and never return, particularly when it responds well to treatment. Other people have relapses or need long-term treatment. Nerve symptoms can remain if inflammation caused lasting damage.

Can you have neurosarcoidosis with a normal brain MRI?

Yes. MRI is useful, but it does not identify every form of neurosarcoidosis. Symptoms involving peripheral nerves, small nerve fibres, or hormone control may not produce clear brain MRI

changes. Further testing may include spinal imaging, a lumbar puncture, nerve tests, hormone tests, or imaging elsewhere in the body.

Is neurosarcoidosis contagious?

No. It cannot spread through coughing, touching, sex, or shared household items. Although the immune system is involved, neurosarcoidosis is not an infection.

Does neurosarcoidosis always cause permanent disability?

No. Many people improve with treatment and rehabilitation. The risk of lasting disability is greater when inflammation seriously affects the spinal cord, optic nerves, brainstem, or hormone-control areas, or when treatment cannot control it.

Can neurosarcoidosis come back after treatment?

Yes. Relapse can happen while medicine is being reduced or after treatment has stopped. Follow-up often continues after symptoms improve so that returning inflammation or treatment complications can be identified.

Sources

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