CAVERNOUS MALFORMATION: A Patient Guide

Also called: cerebral cavernous malformation (CCM), cavernoma, or cavernous angioma

What Is a Cavernous Malformation?

A cavernous malformation (CCM) is a group of blood vessels that formed in an unusual way. It looks like a raspberry. Its thin walls can leak, so blood can slowly seep into the brain or spinal cord around it.

1 in 500

people have at least one cavernous malformation. Many never have any symptoms.

Symptoms

Symptoms depend on where the CCM is in the brain or spinal cord. Some people have no symptoms at all. Many CCMs are found by chance during a scan for another reason. Symptoms may include:

Brain

- Seizures
- Headaches
- Weakness or numbness, often on one side of the body
- Vision changes
- Trouble with balance or moving smoothly
- Changes in memory or thinking

Spinal Cord

- Weakness or numbness, often in both arms, both legs, or across the chest
- Tingling or burning that wraps around the chest or belly like a band
- Pain
- Trouble walking
- Trouble controlling your bladder or bowels

Important: Symptoms can happen even if the CCM has not bled. Call your doctor if a symptom is new or feels different than usual.

What Causes a Cavernous Malformation?

Sporadic (by chance — most common)

Not caused by a gene change. It happens by chance, and it does not run in your family. You usually have just one. Your children, brothers, and sisters do not have a higher risk.

Familial (runs in families)

Caused by a gene change that can be passed down. People often have more than one CCM. A genetic test can check for this. It can also help family members learn their own risk.

CCMs can also form years after radiation treatment to the brain. Your care team will help you learn which cause fits you.

Bleeding (Hemorrhage) — What Raises Your Risk

All CCMs slowly leak a tiny bit of blood. This is normal and often causes no symptoms. A bigger bleed is called a symptomatic hemorrhage. It causes new symptoms or makes symptoms worse. Your risk of a bigger bleed is higher if:

- The CCM has bled before
- The CCM is in the brainstem (base of the brain) or spinal cord

Bleeding (Hemorrhage) — Everyday Activities

These activities do **not** raise your risk of bleeding:

- Exercise, like walking or running
- Sports without tackling or hitting
- Pregnancy
- Flying on a regular passenger plane
- Moderate alcohol or caffeine

Talk to your doctor before you start or stop any medicine. Also ask before using hormone medicines (estrogen or progesterone).

Treatment Options

Right now, surgery is the most common treatment for a CCM. But not everyone needs surgery. In some cases, radiation or laser treatment may be an option. Your treatment depends on your symptoms, where the CCM is, and whether it has bled.

- **Surgery (craniotomy or laminectomy):** Takes out the CCM. Doctors often suggest it after a second bleed, or when medicine cannot control seizures.
- **Laser Surgery (laser interstitial thermal therapy or LITT):** Uses a smaller opening than regular surgery. It may be an option for CCMs that cause seizures.
- **Stereotactic radiosurgery (Gamma Knife, CyberKnife):** Aims focused beams of radiation at the CCM without opening the skull. It may be used when surgery is too risky because of where the CCM is. Not recommended for familial CCM.
- **Anti-seizure medicines:** Help control seizures caused by a CCM.
- **Physical, occupational, and speech therapy:** Help you get back strength, everyday skills, and speech after a bleed or surgery.

Good news: Several new medicines and treatments are being studied. There is real hope ahead. Learn about new research and clinical trials (studies of new treatments) at AllianceToCure.org.

Questions to Ask Your Doctor

- Where are my CCMs?
- Has my CCM bled before?
- What symptoms mean I should call you or go to the ER?
- Do I need surgery? What are the risks and benefits?
- Should I get a genetic test?
- How often do I need an MRI scan to check on it?
- Are there any clinical trials I could join?

Lifestyle Tips That May Help

- **Vitamin D:** Low levels may be linked to CCMs getting worse. Ask your doctor to check your level.
- **Diet:** Try to eat fewer processed (packaged) foods and foods with added preservatives or emulsifiers. Research suggests the germs in your gut may play a role in CCM.
- **Quit smoking or vaping. Avoid binge drinking (many drinks at one time).**
- **Stay vaccinated:** Get your flu and COVID-19 vaccines.
- **Manage stress:** Your emotional health matters too.

Keep a copy of your medical records with you when you travel. Think about a medical alert bracelet that says you have a condition that can cause bleeding in the brain or spinal cord.

Alliance to Cure Cavernous Malformation
Support • Information • Community • Research
Patient Navigator: A real person who can help you with your care and insurance.
Patient Registry: Share your health information to help find new treatments.
Community: Weekly online support groups and forums. You are not alone.

Updated 9.24.2026 | Content informed by the Alliance to Cure CCM Clinical Care Consensus Guidelines