How are Cavernoma Treated?

Treatment for cavernoma will vary depending on a person's circumstances and factors such as size, location and number of cavernoma.

Treatment with surgery includes 2 options:

- Neurosurgery to remove the cavernoma.
- Stereotactic radiosurgery to stabilise the cavernoma. 'Gamma Knife' or 'CyberKnife'. Where a single concentrated dose of radiation is aimed directly at the cavernoma, causing it to become thickened and scarred.

Not every situation requires surgery. In addition to or instead of surgery, other treatments for the symptoms and management through medicalcare are given.

These might include:

- Medication for symptoms.
- Rehabilitation. Examples are Physiotherapy, Occupational therapy, Speech & Language therapy, and Cognitive therapy.

About Us

Cavernoma Ireland is a voluntary support group. Founded in 2018.

Our mission is to help people living in Ireland who are affected by cavernoma, including friends, family, carers and professionals.

We aim to do this through support, providing information, putting members in contact with other relevant parties and hosting events.

Our goal is to raise awareness of cavernoma, and its consequences for those affected.

Contact Us

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Cavernoma Ireland

Information Leaflet

HERE FOR YOU

Voluntary Support Group

What is a Cavernoma?

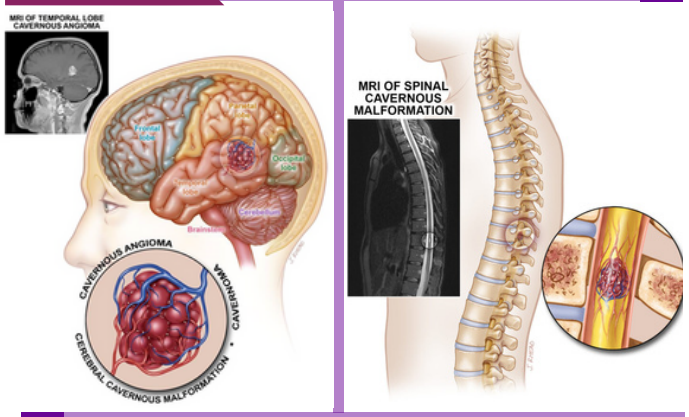
A cavernoma is made up of abnormal blood vessels, found mostly in the brain and spinal cord.

It is filled with blood that flows slowly through these vessels.

Cavernomas have thin leaky cell walls.
This can sometimes cause blood within the cavernoma to ooze into the surrounding tissue or within itself, enlarging the cavernoma. This can cause many symptoms.

Blood may have oozed slowly out of the cavernoma over time or there may have been a haemorrhage of a larger amount of blood over a shorter period of time, such as a few days.

When the symptoms from a cavernoma related haemorrhage lasts longer than a day, this is called a ‘Haemorrhagic Stroke’.



Cavernoma Symptoms

Cavernomas causing symptoms are rare.

The type, severity, combination and duration of symptoms may vary, depending on the location of the cavernoma.

Symptoms can include:

- Haemorrhage, stroke, seizures, headaches.
- Neurological partial/full paralysis, tremors, weakness, numbness, fatigue, memory and concentration difficulties.
- Speech and eyesight problems.

Sporadic and Hereditary

Sporadic cases are defined by having no family history and no genetic basis for the cavernoma. Typically, affected individuals have only one cavernoma.

The hereditary form of cavernoma is caused by a single gene mutation, or mistake in one of three different genes, CCM1, CCM2, or CCM3.

People with any of these gene mutations will form multiple cavernomas throughout their lifetime.

A person who carries one of these gene mutations will have a 50% chance of passing the mutation on to their children.

The hereditary form of cavernoma is recognised as a rare disease.

How are Cavernoma Diagnosed?

MRI scans are mainly used to diagnose cavernomas. ‘Magnetic resonance imaging’.

As symptoms are not always evident, many people are only diagnosed with a cavernoma after having an MRI scan for another reason. This is called an incidental finding.

On an MRI scan cavernomas look like a raspberry with a ring around it. The ring appearance is hemosiderin deposition.

Hemosiderin is iron, a byproduct of the breakdown of blood. This blood has oozed/haemorrhaged from the cavernoma.

An MRI is considered the most sensitive and specific technique for detecting cavernomas.

Other scans are sometimes used to identify a cavernoma include a CT ‘computed tomography’ scan. Unless the cavernoma is large it is difficult to see it on a CT scan.
It is sometimes used in the emergency room to quickly identify bleeds.

Genetic testing can be done to test for the gene mutation. However, this is usually only done once a person presents with 2 or more cavernomas or has a family history of them. The results of the test can confirm if it is hereditary.

Occasionally following neurosurgery to remove all or part of a suspected cavernoma, lab analysis will be done to confirm diagnosis.