About Us

Our mission is to improve the quality of life for those affected by single or multiple cavernomas through support, education and promoting research.

Our members include individuals with cavernomas, their family, carers, friends and others with an interest in cavernoma. Membership is free and helps us establish the condition as a recognised neurological disorder.

We have well-established links with healthcare professionals and services, nationally and internationally. This means we keep up to date with new information and research for the cavernoma community.

We offer:

- **Helpline and Email Contact Centre**
- **Children, Carer and Family Support**
- **Caverbuddies 1.1 Support**
- **Therapy**
- **Youth Services**
- **Social events – Virtual and in-person**
- **Annual Forum**
- **Talks from Clinicians and other professionals**
- **Research Participation**

Contact Us

Scan our QR code

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Registered charity number 1197257
Scottish Charity number SC048458

Cavernoma Alliance UK

HELP & SUPPORT FOR YOU AND YOUR FAMILY

Registered charity number 1197257
Scottish Charity number SC048458

What is a Cavernoma?

A cavernoma is an abnormality in a blood vessel in the brain or spinal cord. It looks like a raspberry.

Cavernomas are not cancerous and do not spread to other parts of the body. They can range in size from a few millimetres to several centimetres.

The cells lining the blood vessels within the cavernoma can ooze blood outwards into surrounding tissue. Bleeds that cause new symptoms due to tissue damage are known as haemorrhagic stroke. The risk of a haemorrhagic stroke is known for people with cavernoma in general, but it is difficult to predict reliably for individuals.

About 20% of people have a hereditary form of cavernoma. Each child has a 50% chance of inheriting the mutation.

Cavernoma Symptoms

Many cavernomas do not cause symptoms. However, when cavernomas do cause symptoms they may be due to:

- **Haemorrhagic stroke**
- **Focal neurological deficit like a stroke, but without new bleeding on a scan**
- **Epileptic seizures**

Strokes and focal neurological deficits cause symptoms such as dizziness, slurred speech, double vision, muscle weakness, tremor, numbness. These may also lead to tiredness, memory and concentration difficulties, headaches, and other symptoms.

How are Cavernomas Diagnosed?

Cavernomas are usually diagnosed by a magnetic resonance imaging (MRI) scan.

Genetic testing is needed to confirm that a cavernoma is hereditary. This is normally done using a blood or saliva sample. Testing is usually done after careful discussion about the implications with a clinical geneticist.

Treatment for Cavernoma

Surgery
Cavernomas can be removed by surgery (neurosurgery) or stabilised by focused radiation treatment (known as stereotactic radiosurgery, Gamma Knife or CyberKnife).

Treatment without Surgery
Surgery is not always needed. Other treatments that are given instead of, or in addition to surgery include:

- Medication for specific problems, like epileptic seizures or spasticity.
- Rehabilitation, such as physiotherapy
- Another MRI scan