

## For members

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

Our members include individuals diagnosed with either single or multiple cavernomas or who are waiting for diagnosis. Those who do not have the condition may also be members.

This includes family, friends and carers. Membership is free, and helps us establish the condition as a recognised neurological disorder.

We have well-established community 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.

## How our information and support is distributed

- Our website: [www.cavernoma.org.uk](http://www.cavernoma.org.uk)
- Support line +44 (0)1305 213876
- Folders, information booklets and a DVD
- Folders, information booklets for children and young people with a DVD
- Monthly E-mailshot
- Public and secret Facebook groups and Twitter
- CaverChat (available through the website)
- HealthUnlocked:  
[www.healthunlocked.com/cavernoma-uk](http://www.healthunlocked.com/cavernoma-uk)
- Regional CaverClinics (with medical consultants)
- Regional CaverCentres (local meetings)
- Annual International CAUK Forum
- Regional Brain Awareness Week Events (in March)
- CaverFamilies
- Regional CaverHubs (talks by medical professionals)

Website: [www.cavernoma.org.uk](http://www.cavernoma.org.uk)

Email: [info@cavernoma.org.uk](mailto:info@cavernoma.org.uk)

Telephone: +44 (0)1305 213876

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Like us on:  facebook

[www.facebook.com/Cavernoma.Alliance.UK](http://www.facebook.com/Cavernoma.Alliance.UK)

Follow us on:  @cauk1

This leaflet was checked for accuracy by our medical advisers and senior members.

Disclaimer: this leaflet provides general information to the public. It does not replace a consultation with a medical practitioner. You must not reproduce any part of this leaflet in any form.

## Suggested links

### Angioma Alliance

(our affiliated organisation in the USA)  
[www.angiomaalliance.org](http://www.angiomaalliance.org)

### Stroke Association

[www.stroke.org.uk](http://www.stroke.org.uk)

### Brain and Spine Foundation

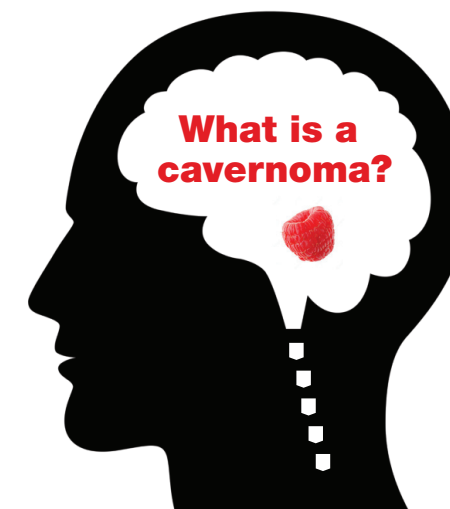
[www.brainandspine.org.uk](http://www.brainandspine.org.uk)

### Epilepsy Society

[www.epilepsysociety.org.uk](http://www.epilepsysociety.org.uk)



Helping the Cavernoma Community



A cavernoma looks like a raspberry and is made up of abnormal blood vessels. Cavernomas can range from a few millimetres to several centimetres, and can increase and reduce in size. A larger appearance is sometimes due to blood in the cavernoma. But cavernomas are not cancerous and do not spread to other parts of the body.

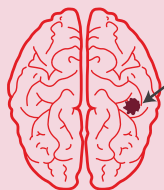
Sometimes the cells lining the blood vessels ooze small amounts of blood inwards within the cavernoma or outwards into surrounding tissue. The risk of a cavernoma bleeding again varies widely and is difficult to predict.



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This leaflet is a basic introduction for everyone affected by single or multiple cavernomas in the brain or spine (or both).



**Cavernoma in the brain is a condition also known as: cavernous angioma, cavernous haemangioma, or cerebral cavernous malformation (CCM).**

## Frequency

In the UK, **approximately 100,000 people** have a brain cavernoma without symptoms - more than the capacity of Wembley Stadium. A spinal cavernoma is rarer than a brain cavernoma.

## Symptoms

People who have symptoms are much rarer. An ongoing study based on the whole of Scotland found that, each year, 1 person out of 400,000 is diagnosed with a symptomatic brain cavernoma (a cavernoma which has caused symptoms).

The type and combination of symptoms, how severe they are and how long they last varies depending on whereabouts the cavernoma is within the brain.

A cavernoma near the surface of the 'hemispheres' or 'lobes' in the brain can cause epileptic seizures.

Some common symptoms of cavernomas include dizziness, weakness or numbness of the face, arms or legs, double vision, or slurred speech.

## Genetics

There is likely to be a genetic cause in less than half of people with a cavernoma.

## Examples of tests used to investigate cavernomas

**MRI scan** – MRI stands for magnetic resonance imaging. MRI involves different 'sequences', each of which images the brain in a different way. At least one MRI sequence that is sensitive to blood products should be used to look at cavernomas: these sequences may be called 'gradient echo', 'T2-star', or 'susceptibility-weighted imaging' (SWI).

**CT scan** – CT (computerised tomography) cannot be relied upon to reveal cavernomas, but can detect bleeding from them.

**Angiography** – a test to show blood vessels may be carried out but usually does not show a cavernoma.

**Blood tests and genetic testing** – these are available through a specialist doctor called a geneticist.

## Examples of treatment and management of a cavernoma

**Medications** – need to be taken by some people, for example for epilepsy.

**Surgery on the brain or spine** – also called neurosurgery.

**Stereotactic radiosurgery** – one session of focused radiation therapy. Linear accelerator, Gamma knife and CyberKnife are different types of stereotactic radiosurgery. It is not known how well cavernomas respond to these treatments.

**'Wait-and-watch' approach** – this usually involves no further investigations or treatment, but may include occasional MRI scans.

**Genetic counselling** – available for some people and their families.

**Cavernoma Alliance UK (also known as CAUK) was set up in 2005 by and for people affected by cavernomas.**

## Information booklets

Each person, whether they have one cavernoma or many cavernomas, is unique, and this should be taken into account as they may need both lifelong support and medical attention.

We have produced three information booklets to help people learn about, understand and cope with the condition, and we are currently preparing an information booklet on spinal cavernoma.

## The information booklets are:

- Symptomatic brain cavernomas
- Incidental brain cavernomas, and
- The genetics of brain cavernomas.

These booklets describe cavernomas, their frequency (the rate at which they occur) and symptoms, how they are investigated, and surgical and non-surgical treatment. The genetics booklet also discusses the genetic implications for those who may inherit the condition.

## You can get these booklets from:

- our website ([www.cavernoma.org.uk](http://www.cavernoma.org.uk))
- hospital neurosurgical and neurology departments, and
- geneticists and genetic counsellors.