

For Members

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

Members include individuals diagnosed with either single or multiple cavernomas, or waiting for diagnosis. Those who do not have the condition are usually made honorary members. This includes family members, friends and carers. Both membership and honorary membership are free, and help establish the condition as a recognised neurological disorder.

CA UK has well-established links with healthcare professionals and services, nationally and internationally. This means we keep abreast of new information and research for the cavernoma community.

CA UK information and support is distributed through:-

CA UK's website: www.cavernoma.org.uk
Newsletters and Mailing Lists
Web Chats
Bulletin Boards
Regional CaverHubs
CaverClinic
International UK Forums

Contact Information

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Dorset DT1 1SD

www.cavernoma.org.uk
info@cavernoma.org.uk

Links

Angioma Alliance
(our affiliated organisation in the USA)
www.angiomaalliance.org

The Stroke Association
www.stroke.org.uk

Brain and Spine Foundation
www.brainandspine.org.uk

National Society for Epilepsy
www.epilepsynse.org.uk

This leaflet was checked for accuracy by the medical advisers and senior members of CA UK.

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Helping the Cavernoma Community
Registered Charity Number: 1114145

Cavernoma Alliance UK (also known as CA UK) was established in 2005 by and for people affected by a cavernoma - also known as cavernous angioma, cavernous haemangioma or cerebral cavernous malformation (CCM).

The aim of this leaflet is to provide a basic introduction for everyone affected by single or multiple cavernomas in the brain and/or spine.

Description

A cavernoma looks like a blackberry. It is made up of abnormal blood vessels. Cavernomas can measure from a few millimetres to several centimetres. A cavernoma can get bigger, but this growth is not cancerous, and it does 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 re-bleeding varies widely, and is difficult to predict accurately.

Frequency

1 person in 600, in the UK, has a brain cavernoma without symptoms. This equates to roughly 90,000 people – enough to fill Wembley Stadium. A spinal cavernoma is rarer than a brain cavernoma.

People who experience symptoms are much rarer. An ongoing study based on the entire population of Scotland, found that each year, 1 person out of 400,000 is diagnosed with a symptomatic brain cavernoma.

There is likely to be a genetic cause in less than 50% of people with a cavernoma.

Symptoms

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

Single or multiple cavernomas near the surface of the 'hemispheres' or 'lobes' in the brain can cause epileptic seizures.

Some common symptoms of single or multiple cavernomas may include headaches, dizziness, weakness, numbness, tiredness, memory and concentration difficulties.

Examples of Investigations

MRI scan - Magnetic Resonance Imaging. It is important that specific scan sequences are used: "T2-weighted" and "gradient echo".

CT scan - Computerised Tomography cannot be relied upon to reveal cavernomas.

Angiography - often angiography is carried out. This investigation cannot be relied upon to show a cavernoma.

Blood tests and genetic testing - available through a specialist doctor called a Geneticist.

Examples of Treatments and Management

Medications - need to be taken by some people.

Surgery - also called neurosurgery and spinal neurosurgery.

Stereotactic radiotherapy - a course of radiation therapy.

Stereotactic radiosurgery - a single concentrated dose of radiation therapy.

Gamma Knife and CyberKnife - a non-invasive type of stereotactic radiosurgery. It is unknown how well either single or multiple cavernomas respond to this form of treatment.

'Wait-and-watch' approach - may include periodic MRI scans.

Genetic counselling - available for some individuals and their families.

Information Booklets

While people with either one cavernoma, or multiple cavernomas have things in common, each person remains unique. This should be taken into account for each individual who may require both lifelong support and medical attention.

CA UK has produced three information booklets to help people learn about, understand and cope with the condition. The booklets, available as a single booklet, dual or triple pack, are entitled:-

Symptomatic cavernomas

Incidental cavernomas

The genetics of cavernomas

These booklets, describe cavernomas, their frequency, symptoms, how the condition is investigated, as well as surgical and non-surgical interventions. The genetics booklet also discusses the genetic implications for those who may inherit the condition.

These information sheets and booklets are available from:-

CA UK website

Neurosurgical and Neurology departments

Geneticists and genetic counsellors