Cavernoma Fact Sheet

What is a Cavernoma?

A cavernoma is made up of abnormal blood vessels and can be found in the brain and/or spinal cord and looks like a raspberry. Cavernomas are also known as cavernous angioma, cavernous haemangioma or cerebral cavernous malformation (CCM). They can measure from a few millimetres to several centimetres. A cavernoma can get bigger, but this engorgement is not cancerous, and 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.

Cavernoma also occur in other areas of the body, such as the spine.

Frequency

1 person in 600, in the UK, has a brain cavernoma without symptoms (asymptomatic). 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 considered to have a rare condition. 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. This means that every week, in the UK, another 3 people are diagnosed.

A minority of cavernoma (less than 30%) are thought to be a genetic form and genetic testing can be used to determine whether the cavernoma has a genetic cause or is likely to be random.

Diagnosis

Cavernoma are often diagnosed after a person has experienced symptoms which can include:

- haemorrhages
- seizures
- headaches
- neurological deficits such as dizziness, slurred speech, double vision and tremors
- weakness, numbness, tiredness, memory and concentration difficulties

Symptoms may occur after a 'bleed' but this is not true in every case. MRI scans are the most reliable diagnostic tool available to determine the presence of cavernoma.

Treatment & Management of Cavernoma

Whilst people with cavernoma have things in common, each person remains unique. This should be considered for each individual who may require both lifelong support and medical attention. Because cavernoma symptoms can vary widely from person to person, depending on location, number/ size, effective treatment options can vary also. Specific medical advice can only be given by a neurologist, neurosurgeon or other clinical professionals.

Nowadays, diagnosis of cavernoma is invariably made following an MRI scan. What happens next depends on the size and location of the identified cavernoma(s) and the severity of your symptoms. There are currently three main ways of treating cavernoma:

- A 'wait-and-see' conservative management approach is often recommended. This will involve treating the symptoms and having periodic MRI scans to monitor the cavernoma(s). If you have multiple cavernomas, normally associated with the hereditary (familial) form of cavernoma, you will probably be seen by a Clinical Geneticist to determine if there is a genetic cause and then discuss your options.

- Surgery to remove the cavernoma if the risk of bleeding is high. Surgery is a major operation, and more dangerous for cavernoma deep in your brain, especially in your brainstem and spinal cord.

- Radiation treatment, known as Stereotactic Radiosurgery, which zaps the cavernoma with radiation. It is unknown how well cavernomas respond to radiosurgery.

There are many exciting treatment developments in the pipeline, e.g. developing drugs to reduce the risk of a bleed, to anticipate a bleed with blood or urine samples and more.

Source: Cavernoma Alliance UK (https://cavernoma.org.uk/)