

# Contacts

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



# Cavernoma Alliance UK

**Cavernoma information for young people aged 12 - 16**



## Cavernoma Alliance UK

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The cost of writing & publishing this leaflet was donated by the Hedley Foundation

Illustration: DinosaursForAll 2015



Helping the Cavernoma Community



Member of  
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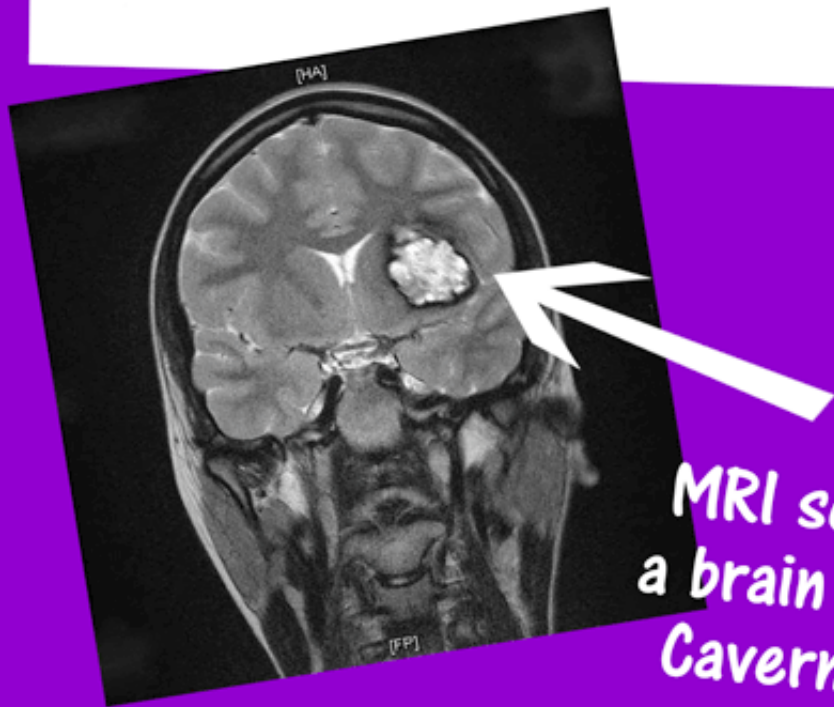
# what is a Cavernoma?



A cavernoma is a cluster of abnormal blood vessels in the brain, the spinal cord and (rarely) on the skin.

Cavernomas vary in size, from a few millimetres across (like an ant or an earring stud) to a few centimetres (like a table tennis ball). Some cavernomas grow in size, but they don't spread to other parts of the body.

A typical cavernoma looks like a raspberry or popcorn, with little chambers (or caverns) that give it its name.



MRI scan of  
a brain with a  
Cavernoma

It's not unusual to have a cavernoma or even a few of them. Cavernomas don't always cause you to feel unwell – a lot of people have them without even realising, because they don't exhibit any symptoms. These are called asymptomatic cavernomas.

People tend to discover that they have cavernomas when they exhibit symptoms – which might be headaches, dizziness, or seizures. The symptoms happen for a variety of reasons – sometimes because the cavernoma is putting pressure on your brain, or because it is bleeding.

A neurologist or neurosurgeon will make a diagnosis based on an MRI scan – which is basically a photo of your brain. You might then need medication and regular medical check-ups.



Sometimes it can be hard to talk about cavernomas with your friends. This booklet provides medical information alongside the experiences of young people living with cavernomas, their friends and families.





# Robert

“ I love playing on my school football team but sometimes I have to stop because I have problems with my balance and vision from the cavernoma. Most of the time I'm still the top goal scorer though...

Dizziness, double vision, problems with balance and blurred vision are common symptoms. The cavernoma might be putting pressure on your brain – or it might be the result of the cavernoma bleeding (also known as a haemorrhage). Some people develop epilepsy from a cavernoma. It varies from person to person, though, depending on the cavernoma's position in your brain. If your symptoms include headaches, seizures or epilepsy you might have to take medication. You might also have to go for check-up brain scans – but not everyone does.

# Sarah

“ I'm going to the hospital for an MRI scan. What's going to happen if I have a cavernoma?



The MRI (magnetic resonance imaging) takes a photo of your brain, and we'll be able to see where your cavernoma is. An MRI scan is a painless procedure. An MRI scanner is a large tube. During the scan, you lie inside the tube for between 15 and 90 minutes. You wear earplugs or headphones as the scanner makes loud tapping noises. The scanner is operated by a radiographer, who sits in a different room, but there's an intercom so you can talk to them throughout the scan.



# Tom

“ Will I have to have an operation?

This depends on your symptoms. Some, like headaches, or seizures, can be controlled by taking medication. Most people don't have to have operations. But if your cavernoma tends to bleed or causes more extreme symptoms, doctors might recommend surgery.

Neurosurgery takes place under general anaesthetic, and removes the cavernoma from your brain or spinal cord.

Alternatively, if the cavernoma is in a difficult to reach place, you might have radiotherapy. This means you don't have to have an operation. It involves beams of radiation being targeted at the cavernoma.

# Ellie and Seb

I developed epilepsy after my cavernoma bled. Loud music doesn't affect cavernomas and my cavernoma doesn't interfere with my enjoyment of loud music!

The Epilepsy Society have great web resources for young people and advice about how to talk to your friends about it.

I was worried about telling my band mates but they have been really supportive.



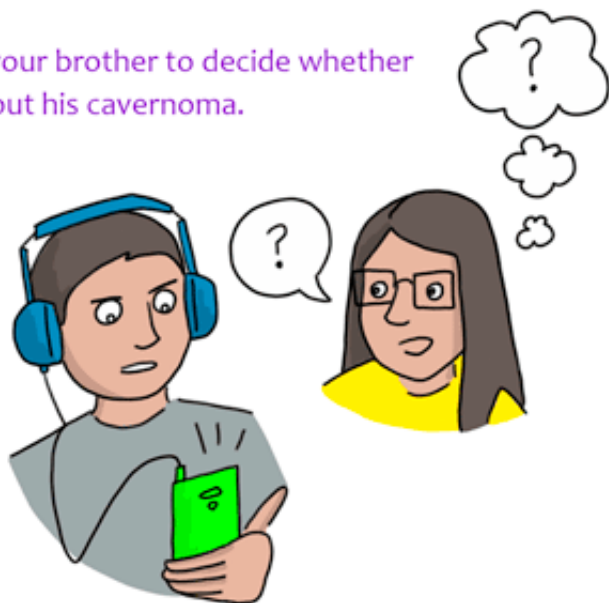
# Ronny and Sasha

“ Sasha – My brother Ronny NEVER talks about his cavernoma but I’ve got loads of questions I want to ask him! Like, will I get a cavernoma because he’s got one?”

The fact that your brother has a cavernoma doesn’t mean that you are necessarily likely to have one too. Most cavernoma are not genetic – that is, they aren’t written into the genes, the building blocks that determine how your body is put together. If there’s an error in the genes, that can cause cavernomas, but fewer than a third of people with cavernoma have them for genetic reasons.

Your family can talk to a specialist doctor called a clinical geneticist about cavernomas and genetics, and CAUK have a more detailed leaflet which you might want to look at.

Remember that it’s up to your brother to decide whether or not he wants to talk about his cavernoma.



# Alex

“ I’ve met other people my age with cavernomas through CaverFamilies events – it’s nice knowing it’s not just me!”

If you want to know more about cavernomas there are more detailed leaflets available on the CAUK website.

If you feel worried about your cavernoma, talk to your parents or your teacher. You can also contact the Cavernoma Community Worker ([community@cavernoma.org.uk](mailto:community@cavernoma.org.uk))

## Useful links

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

(Cavernoma Alliance UK website. The downloads section has very helpful, clearly written information. There are also links to support organisations, videos, and a members’ area)

[www.youthzone.childbraininjurytrust.org.uk/ask\\_an\\_expert.html](http://www.youthzone.childbraininjurytrust.org.uk/ask_an_expert.html)

(ask any questions you might have about the brain, and read other young peoples’ experiences)

[www.nhs.uk/conditions/cavernoma/Pages/Introduction.aspx](http://www.nhs.uk/conditions/cavernoma/Pages/Introduction.aspx)

(NHS website. A useful introductory overview of cavernomas, symptoms, treatments)

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

(Epilepsy society website – useful resource with lots of information about living with epilepsy. Has a sections on social life, going to university, relationships)

