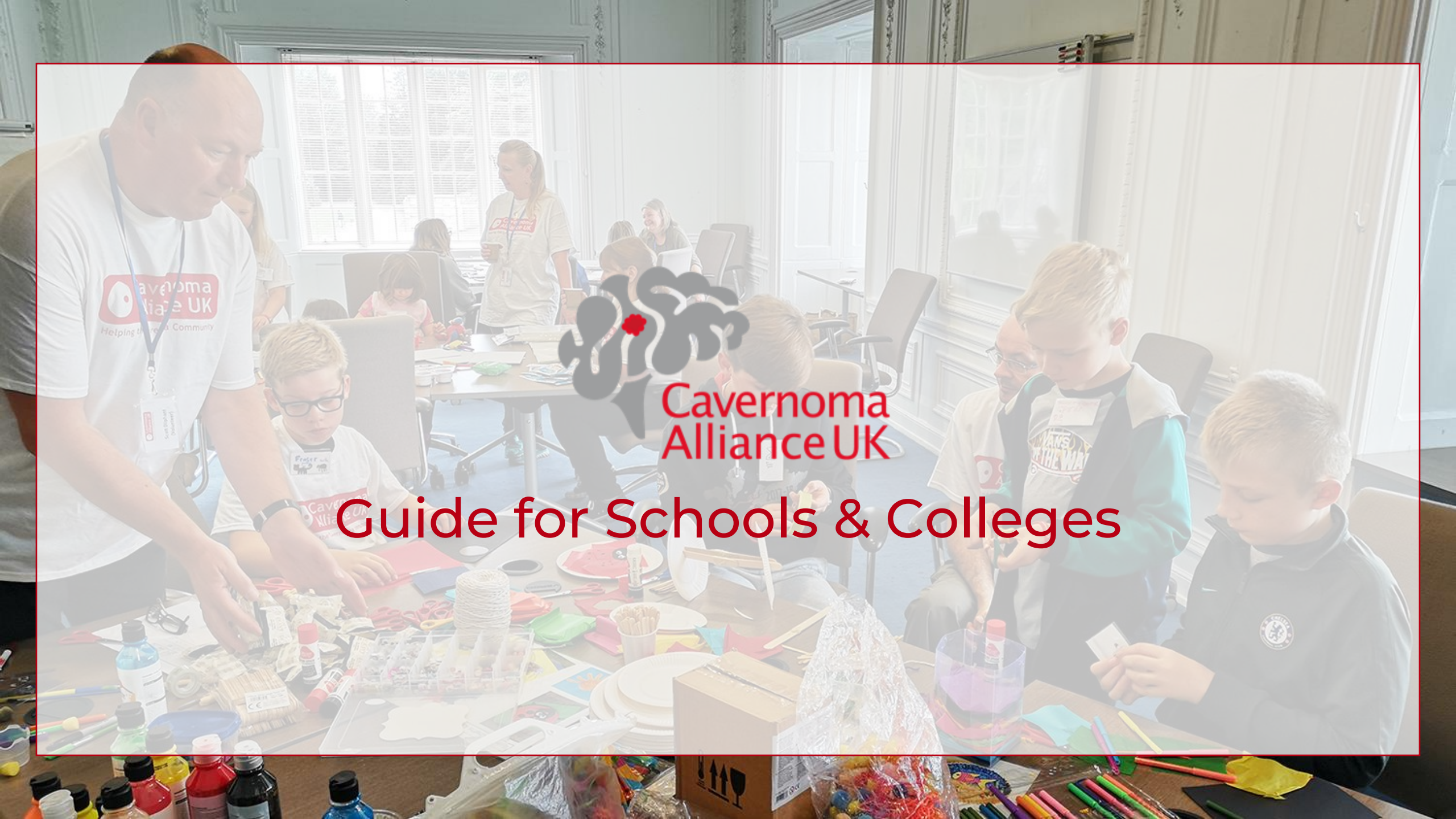


Cavernoma Alliance UK

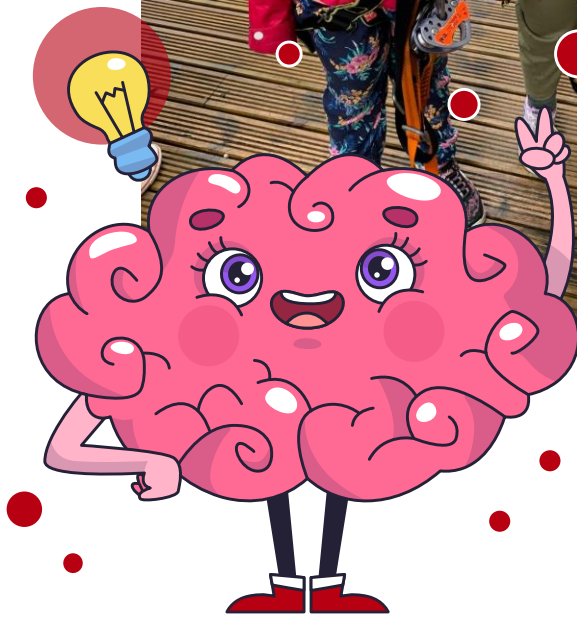
Guide for Schools & Colleges

What Is A Cavernoma?

- Cavernomas look like a raspberry
- They're in the brain and/or spinal cord
- And are made up of blood filled 'caverns' that can leak or bleed
- Your student may have just one, caused for no clear reason
- Or they may have several, which means they're probably inherited
- Most people with cavernoma won't know they have one at all
- But for **1** in **2,700** people they can be troublesome
- It can feel lonely being a child or young person with a rare condition
- Learning about cavernoma is a great way to support your student









What Are The Symptoms?

Most cavernomas don't cause problems

But some can be troublesome, causing:

- Bleeding in the brain, which causes a stroke
- Seizures or epilepsy

People with cavernoma may also have:

- Headaches
- Weakness/numbness
- Difficulty speaking/understanding
- Dizziness/double vision
- Tremors/loss of balance
- Memory/concentration difficulties
- Tiredness

- **You can help** by taking time to find out what is 'normal' for your student
- Then, if you notice any changes you can tell the student's parents or carers straight away. It could be a sign the cavernoma is growing or bleeding
- If that happens the student will need to see a neurologist or neurosurgeon. These are doctors who specialise in the brain and spinal cord

What Are You Supposed To Do & When To Call Emergency Services?

- Most students won't need emergency services
- But sometimes they may need extra help, especially if the cavernoma bleeds

Call the emergency services if your student has a:

- Seizure for the first time
- Seizure lasting more than 5 minutes
- Sudden change in speech, understanding, vision, balance, coordination or numbness

The last point is based on the FAST test for stroke:

- Face weakness: Can the person smile? Has their mouth or eye drooped?
- Arm weakness: Can the person raise both arms?
- Speech problems: Can the person speak clearly and understand what you say?
- Time to call 999: if you see any of these signs.

- Tell the emergency services that the student has cavernoma
- This is important as treatment for a cavernoma bleed differs to that for a stroke due to clotting
- If you've not already done so review your school's medical emergencies policy
- And update it if needed to include the needs of your student with cavernoma





How Is Cavernoma Managed?

Currently there is no medication to treat cavernoma

So, if your student has symptoms they may be managed by:

- **Anti-seizure medication**
- **Pain-relief**
- **Occupational therapy**
- **Speech and language therapy**
- **Neuropsychology**
- **Ophthalmology**
- **Physiotherapy**
- If your student's symptoms are very bad then they may need surgery
- This could be neurosurgery to remove the cavernoma
- Or stereotactic radiosurgery using radiation to make the cavernoma more stable
- Working closely with the student's parents or carers can help a lot
- The student may or may not have an Education and Health Care Plan (EHCP, England) or Individual Development Plan (IDP, Wales)

Either way it can be a good idea to check the following information is shared:

- Contact information
- Emergency contacts
- Key medical letters
- Medication information
- Symptoms and triggers
- Medical history
- Any instructions for emergency situations
- Recent updates

- Good communication with parents/carers is always important
- For rare conditions it is critical as they will often know more than most GPs

Diet & CCM - Emulsifiers

You may be surprised to know that gut health might affect cavernoma growth

01. Your student may be on an emulsifier-free diet at their parent/carer's request

02. This means avoiding additives used to mix ingredients that don't naturally blend well

03. Whole-foods like fresh fruit, vegetables, whole-grains, lean proteins are emulsifier free

04. Processed and packaged foods often contain emulsifiers like E322, E400-499,E1103

05. Whilst this diet isn't universally accepted, it is an active area of research





Cavernoma & Neurofatigue

- Students with cavernoma may use the term ‘neurofatigue’ to describe how they’re feeling
- This term is used to describe a type of tiredness that doesn’t pass with physical rest
- Supporting students with neurofatigue is important to help them manage their condition
- It shouldn’t be dismissed as a psychological symptom, within the student’s control

Here are some strategies to assist these students:

- Flexible scheduling
- Extended time for work
- Quiet and comfortable environment
- Assistive technology (e.g. screen readers)
- Breaking work down into smaller/manageable chunks
- Regular check-Ins and good communication
- Supportive and knowledgeable staff
- Access to emotional support (e.g. counselling)
- General awareness raising (e.g. school assembly)
- Every student's experience with neurofatigue will be unique
- So, it's crucial to work closely with the student, their parents, and any specialists

Impact On Family

Cavernomas can affect a student's whole family, particularly if it's the familial form

You can help by:

01. Keeping in mind the impact on the wider family

02. Being aware that your student's family may have cavernoma if it's been inherited

03. Respecting a family's decision to under-take genetic testing or not

04. Offering emotional support to the student and any siblings at your school

05. Respecting privacy/confidentiality by not sharing medical information without consent

06. Promoting an inclusive and understanding classroom atmosphere



Cavernoma & Mental Health

Cavernomas can impact the mental health of students and their families

This can vary depending on the severity of the condition, symptoms and coping mechanisms

Mental health challenges can include:

01. Anxiety from not knowing if or when the cavernoma will bleed

02. Depression from having a long-term chronic health condition

03. Stress arising from symptoms and treatment, particularly if it involves surgery

04. Social isolation as they may feel different, exacerbated by the condition being rare

It's essential to be aware of these potential impacts and to support students to access support

Early intervention and a supportive environment can make a significant difference

Cavernoma Alliance UK offers four sessions of free online counselling for young people living with cavernoma. To make a referral email helpline@cavernoma.org.uk



Cavernoma & Sport

- Taking part in all school activities is an important part of good mental well-being
- A common question is whether students with cavernoma can still play all sports
- Particularly sports that involve a risk of head injury
- Many students with cavernoma take part in all types of sport
- You should check with your students' parents/carers before they take part in sport
- Your student's neurologist or neurosurgeon can also provide further advice
- There's been a handful of reported cases where a cavernoma has bled following a head injury. But there hasn't been any high-quality research proving that head injury causes this bleeding
- It is important **not to exclude a student from sport just because they have a cavernoma**. Creating an inclusive sports curriculum, informed by medical advice, is important



Further Support

01. Cavernoma Alliance UK is a charity dedicated to supporting the cavernoma community

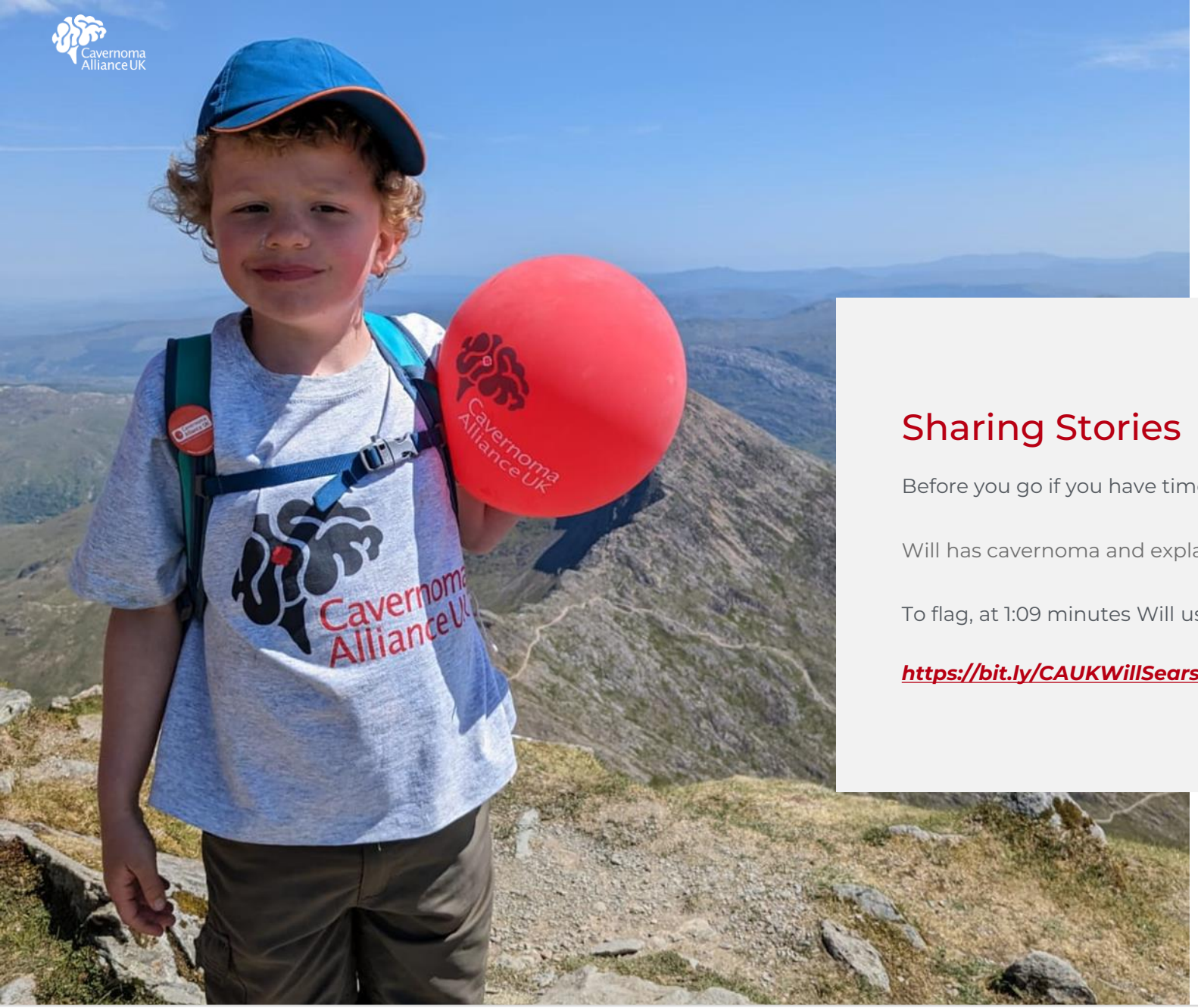
02. There is more information about cavernoma at www.cavernoma.org.uk

03. We offer young people and their siblings/parents up to 4 sessions of free online counselling

04. We also have an email and telephone helpline offering practical and emotional support

05. Each month there are online meetings to help connect parents/carers across the UK





Sharing Stories

Before you go if you have time we'd encourage you to hear from one of our students

Will has cavernoma and explains what that means to him in a short poem

To flag, at 1:09 minutes Will uses the swear word s***

https://bit.ly/CAUKWillSearsPoem