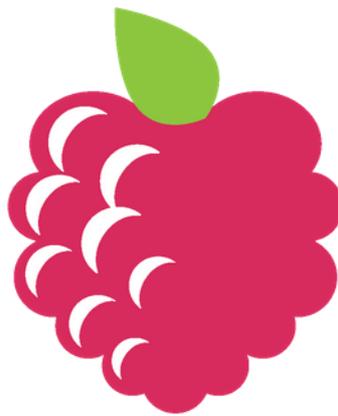


A GUIDE TO BRAIN AND SPINAL CAVERNOMA FOR EMPLOYERS



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WHAT IS A CAVERNOMA?

A cavernoma is a lesion on the brain or spine made up of abnormal blood vessels which can seep blood into surrounding brain and spinal tissue causing strokes, seizures, and cognitive deficits. A cavernoma can cause a hemorrhagic stroke, which, depending on the area of the brain or spine is damaged, can affect body functions as well as thought processes and communication. According to the Stroke Association, stroke is the biggest cause of disability in the UK, and almost two thirds of stroke survivors leave hospital with a disability. Stroke can strike anyone at any age, so even babies can be affected.

This guide can help you to support an employee returning to work after being diagnosed with cavernoma on the brain or spine.

One in 600 people have a cavernoma. Some may never experience a bleed and their cavernoma will remain dormant. Most are diagnosed following a bleed, in which case their chances of experiencing another bleed increase.

Those with cavernoma can have a single cavernoma or multiple cavernomas if they carry the genetic form of the disease.

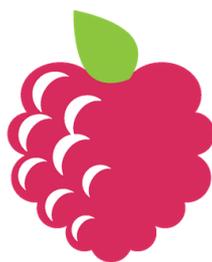
This information is designed for anyone who employs, manages or is responsible for a member of staff who has a cavernoma. Many people with cavernoma are of working age and therefore, with reasonable adjustments and support, do return to work.

Contact: hello@cavernomasociety.org.uk

www.cavernomasociety.org.uk

Disclaimer

We've made every effort to make sure this information is correct at the time of publishing. However, The Cavernoma Society cannot take responsibility for the accuracy or completeness of this information or any recommendations. It does not constitute, and is not intended to be a substitute for legal advice.



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Cavernoma can affect everyone differently depending on the area of the brain or spine which is affected, so it's important that your employee has an occupational health assessment in order to determine their individual symptoms and how these might affect their work.

Cavernoma is a long-term illness and therefore, symptoms can fluctuate. Some people will find it easier to manage their symptoms more than others. Every cavernoma patient is the 'expert' when it comes to their own needs, so don't be afraid to ask them what they need. Sometimes your employee may need to change the way they work.

Reasonable adjustments that we suggest;

- Temporarily working flexible hours on days when they are feeling less able to carry out their duties
- Working from home, using taxis instead of public transport to go to out-of-office meetings
 - Using teleconference or video calls rather than going to meetings in person, temporarily changing duties to concentrate on things they find easier to do (for example, catching up on administrative tasks or desk-based work)
 - Carrying out less strenuous tasks when feeling tired or weak
 - Not being 'people facing' when struggling with communication and processing

When you and your employee have agreed on some reasonable adjustments, it's a good idea to put them in writing. This is often referred to as a tailored adjustment agreement or workplace adjustment agreement. The purpose of recording this agreement is to:

- Make sure that you and your employee have an accurate record of what has been agreed
- Give you both a chance to discuss the reasonable adjustments at any future meetings, such as your regular catch-ups or one to ones. (As an employer, it might be helpful to regularly review the adjustments to make sure they are still working and to agree and make any necessary changes)
- Make it easier for your employee to continue the reasonable adjustments if they change jobs, move to a new location in the organisation or get a new manager

What is a reasonable adjustment?

The Equality Act 2010 states that a disability should not stop someone from working or having the same rights and access to opportunities as other people. The legal definition of a disability in the UK is a physical and or mental impairment that has a substantial and long-term effect on your ability to carry out daily activities. This includes the emotional and cognitive problems due to a stroke. As an employer you have a duty to make 'reasonable adjustments' for employees with disabilities. A reasonable adjustment is an alteration to the workplace or the way a disabled person does their job in order to allow them to work. This may mean changing their work times or providing specialist equipment to help them with certain tasks. Employees cannot be made to pay for reasonable adjustments.



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Reasonable adjustments do not have to be expensive or complicated. It's about looking at the barriers a person is experiencing and thinking creatively about removing them. Some adjustments can be made in advance such as new equipment, but others will be made with the person as they find out what changes they need to help them fulfil their role.

The adjustments you can make will also depend on the size and finances of your organisation. So it may be that you can't accommodate all the adjustments your employee needs. However, with an open and collaborative approach you'll be able to decide together what adjustments you can realistically and fairly make. The ACAS website has more information [acas.org.uk](https://www.acas.org.uk). More information about your duties as an employer under the law and about protecting your staff from disability based discrimination can be found at [equalityhumanrights.com](https://www.equalityhumanrights.com).

What is a phased return?

This means that your employee would return to work on a part-time basis and gradually build up their hours. It may help to change working times, such as a later start to avoid commuting in the rush hour. It may take time to return to the amount of hours they were working before, and they may not be able to return to their original hours, so be as flexible as you can. Many people find a phased return helps them readjust to working again. It could also have benefits for you, as it makes the return more likely to be a success. It also gives you the chance to see what's working and assess any changes that may be needed.

What is Access to Work?

This is a UK government scheme that provides practical advice and support for people with disabilities or health conditions to allow them to find or stay in work. It offers an initial workplace assessment, where an adviser can look at the workplace and the tasks that your employee needs to do. They will then make recommendations for additional support that could help. This could be adapted equipment, coaches to work one-to-one on things like building memory strategies or a support worker to assist with basic manual tasks. The scheme can also help with transport to work.

Need some training?

You could consider running an education session, where someone from The Cavernoma Society will come in and talk about a particular health issue to inform employees. We offer awareness sessions that will give your staff a better understanding of cavernoma and the ways they can support colleagues with the condition.



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THE EFFECTS OF CAVERNOMA

How well someone recovers from a cavernoma bleed depends on many factors, including how quickly their bleed was treated and the support and therapy they received afterwards.

People can make excellent recoveries and even if they're left with problems, these can continue to improve over time. With the right help and adjustments in place, they can continue to make a valuable contribution to your workplace.

They can experience;

- Communication problems and find it difficult to find the right words, understand conversations, or concentrate on what's going on. Noise levels can also impact this, as loud noises can be overwhelming.
- Problems with cognition – cavernoma can affect the way your employee's brain understands, organises and stores information. This can make it difficult to concentrate, remember things or solve problems. This might be short-term and could improve with time and patience.
- Emotional problems. Being diagnosed with cavernoma can also have an emotional impact on the employee. The anxiety and frustration that it causes can sometimes make people feel that they're unable to cope.
- Fatigue may also be a problem for your employee. This isn't like typical tiredness, it doesn't always improve with rest and it isn't directly related to how busy or active you've been. Fatigue is a 'hidden' disability, but it can be a major barrier for people returning to work. They may need support to manage their energy levels and ensure they can do their job as well as possible.
- Physical changes. As well as the emotional effects, there can also be physical effects of cavernoma. Following a bleed some people may develop weakness in their limbs, problems with balance and coordination, and impaired vision.

You can help by;

Giving them time and being patient
Keeping instructions and conversations simple
Making reasonable adjustments
Reducing distraction
Reducing noise
Communicating with them regularly and asking how they're coping
Checking to see what emotional support your organisation can offer

www.cavernomasociety.org.uk

Registered charity number: 1184406 Contact: hello@cavernomasociety.org.uk



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TOP TIPS FOR SUPPORTING AN EMPLOYEE

Timing

Often people with cavernoma just want to get back to 'normal' after diagnosis, so it can be tempting to rush back to work. However, if the return to work is too soon it can lead to problems further down the line. Alternatively, too long a period of sick leave can impact on the employee's confidence and make it more difficult for them to return. Getting the right balance isn't easy. The best thing to do is to stay in touch with your employee and plan for their return together. This will help you understand what support they need and give you time to put it in place before they come back, which should make it much easier for both of you.

Information

It's incredibly important to ask your employee about the symptoms that they're experiencing and how the cavernoma is affecting them on a daily basis. By listening to their needs you can better understand the adjustments that may be required.

Understanding

No two people with cavernoma are the same and therefore your employee is the 'expert' when it comes to their condition. Some people will have visible disabilities, such as problems walking, but for others their disabilities may be invisible, such as fatigue, confusion, and problems with concentration. These 'hidden' disabilities can make it difficult to know that someone needs support. That's why it's important to ask and listen. Very often people aren't aware of these effects until they are back at work. The best thing to do is to have open, regular communication. Some cavernoma patients struggle to talk about their difficulties or may not wish to, so you'll need to be as supportive and patient as you can. Ask questions and encourage your employee to do the same.

Privacy

Be sensitive to your employee's right to privacy. They may not want their colleagues to know that they have cavernoma, so ask them what their preference is.



Guidelines and policies

What guidelines and policies does your organisation have in place for long-term illness and absence? Help your employee to understand these and make sure that they feel comfortable with what support is on offer. If the person is unable to return to work, ensure that the right processes and clear communication are in place, to ensure a fair outcome for employer and employee. Check to see what financial support your employee is entitled to receive, such as sick pay and health insurance. Make sure you give information as promptly as you can, so your employee has enough time to respond, and present it in a way that is clear, open and easy to understand.

Plan

Create a return-to-work plan for when your employee is ready to come back. This should be done following a consultation with Occupational Health (OH) so that the employee's needs are fully understood. It can include the number of days they will work each week, working times and hours. Most people find that a phased return, which allows them to gradually build up their working hours, helps them to get used to working again. Whether they can return to their previous hours depends on their individual needs and the support available. You should also review the tasks that they do and any changes that need to be made to them. Will their previous role be suitable for them and will adjustments need to be considered if they're dealing with cognitive issues?

Communication

It's a good idea to communicate with your employee and make them aware of any organisational changes that may have happened while they've been away from work so that they don't feel left out.

Review

Your employee's needs are likely to change as their recovery continues. Set regular times to review the arrangements you've agreed. Be honest about what is or isn't working and encourage your employee to do the same. Be as flexible and creative as you can.



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OTHER SOURCES OF INFORMATION

Acas

Website: acas.org.uk

Helpline: 0300 123 1100

Text Relay service: 18001 0300 123 1100

Information and advice for employers and staff on all aspects of workplace relations and employment law.

Access to Work (England, Scotland, Wales)

Website: gov.uk/access-to-work

Telephone: 0800 121 7479

Textphone: 0800 121 7579

Provides advice and support for both you and your employee. Your employee can apply either online or over the phone.

Access to Work (NI)

Website: nidirect.gov.uk/articles/accesswork-practical-help-work

The Access to Work scheme for Northern Ireland. To apply, your employee will need to speak to an Employment Service Adviser at their local Jobs and Benefits Office or JobCentre.

Disability Rights UK

Website: disabilityrightsuk.org

Email: enquiries@disabilityrightsuk.org

Helplines for different topics including students and discrimination, and disability confidence training for employers.



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Equality and Human Rights Commission

Website: equalityhumanrights.com

Advice line: 0808 800 0082

Has information for employers about your duties under the law and making reasonable adjustments. The Scotland section of the site gives information about the additional considerations public sector employers in Scotland need to consider.

Fit for Work

Website: fitforwork.org

Advice line: 0800 032 6235 (English) 0800 032 6233 (Welsh)

Provides advice on returning to work for employees, employers and GPs.

Healthy Working Lives Scotland

Website: healthyworkinglives.scot

Adviceline: 0800 019 2211

Information and advice about employees returning to work.

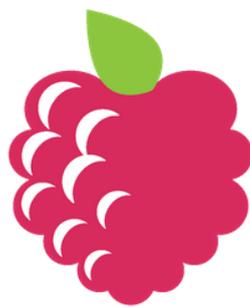
Headway

Website: headway.org.uk

Helpline: 0808 800 2244

Email: helpline@headway.org.uk

A charity for people who have had a brain injury. They have information about returning to work for employees and employers.



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For further information please visit:

www.cavernomasociety.org.uk

Facebook: www.facebook.com/cavernomasociety

Instagram: www.instagram.com/cavernomasociety

Twitter: www.twitter.com/thecavernomasoc

Email: hello@cavernomasociety.org.uk

This information was compiled with the help of other charities and medical professionals. and is accurate as of October 2019.