

# Supporting staff with Hydrocephalus **Information for Employers**



**Shine**

Spina bifida • Hydrocephalus  
Information • Networking • Equality



**This is a guide for employers on how to support and enable staff who have hydrocephalus to perform their best at work.**

Hydrocephalus is a health condition in which cerebrospinal fluid (CSF) accumulates within the head, creating pressure on the brain.

It can be treated, usually by inserting a tube-like device called a shunt, which diverts the fluid from the head to another part of the body, so reducing the pressure to a more typical level. There are many causes of hydrocephalus, and it can begin at any stage of life.

People with hydrocephalus can be affected by their condition in a number of often subtle ways. The degree of impact varies a great deal. Some people may have few or no difficulties, others can find their day-to-day life very difficult indeed.

Anything that disrupts the structure of the brain will also affect its function, and so may affect the ways that a person thinks, learns, behaves and moves.

In addition, any illnesses or incidents which result in the shunt not draining, such as a blockage or a shunt infection, can alter the way the brain works, temporarily or permanently.

**Important to know:**

The effects of hydrocephalus can sometimes cause challenges at work, but there are usually simple adjustments that can be made to ensure an employee with hydrocephalus can make a great contribution at work.

## Employer Legal Duties

**Under the Equality Act (2010), employers have a legal duty to accommodate any needs that a disabled employee may have by making ‘reasonable adjustments’ within the workplace.**

The adjustments that an employee may require will vary depending on the nature of their hydrocephalus and the effects that they experience.

Furthermore, what is considered a ‘reasonable’ adjustment will depend upon the work role and workplace but may include:

- Allocating some of the employee’s work to someone else
- Transferring the employee to another post or another place of work
- Making adjustments to the building in which the employee works
- Being flexible about the employee’s working hours
- Providing training or retraining if the employee cannot do their current job any longer
- Providing modified equipment or assistive technology
- Making instructions and manuals more accessible
- Providing a reader or interpreter

## General considerations

- If an employee discloses details of their disability in confidence, you have a legal duty to ensure that the information is kept confidential unless there is a health and safety risk.
- Communication is vital between employers, employees, HR and other staff to avoid confusion and misunderstanding. It is important to use appropriate language to describe the employee’s impairment, therefore please ask them how they want it to be communicated.
- The effects of hydrocephalus can change over time, and can fluctuate on a regular basis.
- The employee may therefore require an occasional re-evaluation of adaptations that they need within the workplace.
- Try to hold regular meetings to establish whether the adaptations are helping or if further adaptations need to be made.

## Assessing Your Employee’s Support Needs

Useful questions to ask include:

- What difficulties is the employee experiencing, and how do these difficulties affect their job performance?
- What specific job tasks are problematic as a result of these difficulties?
- What adjustments are available to reduce or eliminate the difficulties?
- Has the employee been consulted regarding possible adjustments?
- Do supervisory personnel and other employees need training regarding hydrocephalus?

**Important to know:**

It is important to realise that the effects of hydrocephalus vary from person to person, and as a result people with hydrocephalus often do not have the same needs.

It can therefore be useful to start off by familiarising yourself with some of the common effects of hydrocephalus and then speaking with your employee about which particular effects have an impact on their own work performance.





## Common issues at work, and what can help

Here are some tips which our members with hydrocephalus have said helped them:

### Memory

Often, working memory is affected. Working memory helps us keep information in our head whilst we use it.

#### Examples include:

- Keeping a message in our head while writing it down
- Remembering and passing on a message
- Remembering what we were doing before we were interrupted
- Remembering a new role or new duties with new tasks or routines
- Multi-tasking
- Problems with prospective memory (thinking about what might happen in the future) can make planning, and anticipating changes or problems, difficult.



### What can help?

Many people with hydrocephalus find structure, routine, quiet and written guidance helpful, to give their undivided attention to one task at a time and remember what they were originally doing.

#### Practical guidance includes:

- Keeping interruptions to a minimum
- Working in a quiet area, with few colleagues passing by
- Giving messages or instructions at the start of the shift, by email, or written on a Post-It note, rather than verbally throughout the day. (Verbal messages are more likely to be forgotten than a 'visual prompt')
- Negotiating with a colleague to take turns to spend part of the day answering the phone, so the other can work without interruptions. This can increase the efficiency of both workers.
- Structure the working day so that the same tasks are done in the same way, and at the same times each day.
- Discussing the tasks ahead with a colleague can help get plans sorted out before the work begins.
- Using a mobile phone to set reminders of tasks to be done that day.
- Using voice recognition software to dictate reports and tasks rather than having to write them up.

### Attention

People with hydrocephalus may find it harder to focus on an activity of their choosing than on the most interesting thing going on at that moment. They might not be able to filter or 'block out' noises in the environment, and might find these sounds more distracting than others do.

### What can help?

Having a quiet place to work, at least for more difficult tasks needing a lot of concentration, can be helpful. Some workplaces have background music, such as the radio; it might be useful to have times or areas without music to allow people to fully focus. Some people find acoustic screening helpful. Having set times throughout the day to 'check in' with support personnel rather than being asked if everything is alright, can avoid interruptions.

### Decision making



It can be difficult for a person with hydrocephalus to make decisions, and this can impact on things like prioritising work, or getting started on big, complex projects. Large, complex projects may seem overwhelming, so may not be completed on time.

### What can help?

Communicating the deadline for a task to be completed can help.

Some people find a little time spent with them, helping to break down a large task into smaller 'chunks', and getting steps in the order they need to be done, can make a big difference to them getting the work completed.

### Learning new tasks



It can be a little harder for someone with hydrocephalus to learn a new task.

The speed at which the brain processes information can be a little slower, and verbal explanations alone might not be effective.

Learning something new can take a little longer, but once a new task is learnt, it should be fine.

It may be easier for a person with hydrocephalus to learn one way of doing things, from a colleague, rather than 'having a go' at working out what to do, even if the task is similar to others they already know.

### What can help?

Presenting information in small chunks, and giving time for it to be absorbed, can be really helpful, as can written notes or bullet-points to accompany the demonstration, or recording the demo on a smart-phone.

(Don't ask someone with hydrocephalus to take their own notes during a demonstration, owing to memory, multi-tasking and decision making issues.)

Allowing a little time for each piece of information to be absorbed, before moving onto the next, will help the information to be remembered, and in the correct order.

'Showing and telling' works better than talking alone. Taking these steps can support a person to succeed in learning a new aspect of work, and reduce the time you all spend.

## Navigation

People with hydrocephalus may find it difficult to find their way around large buildings or new places.

### What can help?

A map of the building, with special features clearly marked, ideally colour coded, can help or using a mobile phone to take photos to help navigate round the building.

Another person could accompany them until they feel confident they know their way around.

If leaving the site, for example to run errands, is an important part of the role, provide clear written instructions (there and back: a person with hydrocephalus may not be able to reverse the instructions) and telephone contact details in case they get lost.

**It may be possible to alter the role so that this is not a major part of the job, as it may cause anxiety.**

## Anxiety

Many people with hydrocephalus experience anxiety, and this can prevent them performing at their best at work.

### What can help?

The strategies we have suggested will help to reduce stress by enabling the employee to reduce interruptions.

Keeping expectations clear and raising concerns early in a positive, constructive way will be more successful than leaving it until there is a serious or disciplinary problem.

Ensure your employees take their breaks, as fatigue, dehydration or hunger can also make it harder to concentrate and can increase anxiety.

With any of the above challenges what may help is to have a staff member as a mentor or be able to fund in work support or assistance through visiting: [www.gov.uk/access-to-work](http://www.gov.uk/access-to-work)

## How to identify and act if your Employee's Shunt Malfunctions

**Whilst cases of hydrocephalus can be managed by fitting a shunt or Endoscopic Third Ventriculostomy (ETV), these can and do go wrong.**

It is important that employers are aware of the signs to look for in case you need to intervene if your employee becomes ill, these include:

- Drowsiness / confusion
- Vomiting / extreme nausea
- Photophobia / sensitivity to light
- Visual disturbances
- Severe headaches

### If you see any of these symptoms:

- Ring the next of kin, describe the symptoms and ask the next of kin what they want you to do. Do they want you to call 999? Do they want to collect the person?
- If the next of kin can't be contacted, check the shunt alert card for details of the neurosurgical centre and call them for advice.
- If the next of kin ask you to, or if you cannot contact them or the neurosurgical centre. If the person is losing consciousness, call an ambulance (999) straight away.

## What Shine Can Offer Employers

**Shine is a specialist charity, dedicated to supporting people with spina bifida and/ or hydrocephalus in England, Wales and Northern Ireland.**

We hope that the information we have provided clarifies how hydrocephalus can have an impact on work performance and what employers can do to support employees with these issues. If you require more bespoke assistance in order to support your employee, we would be happy to provide training on the conditions or more tailored advice to employers who are supporting our members.



Please ring Shine on **01733 555988** or email us at [firstcontact@shinecharity.org.uk](mailto:firstcontact@shinecharity.org.uk)

## Useful Links to Other Support for Employers

**Listed below are some services and schemes that can offer information and support to employers of an employee with a disability.**

The Jobcentre Plus Access to Work scheme can offer assistance, advice and funding to employers of disabled people (England, Scotland, Wales)

**W:** [www.gov.uk/access-to-work](http://www.gov.uk/access-to-work)

It may be necessary to perform an occupational health assessment to get recommendations from a health professional on suitable adaptations to the workplace. For more information:

**W:** [www.nhshealthatwork.co.uk/find-providers.asp](http://www.nhshealthatwork.co.uk/find-providers.asp)

It may be necessary to carry out a risk assessment to assess how safe the employee is in the workplace. For more information, contact the Health and Safety Executive:

**T:** 0300 790 6787

**W:** [www.hse.gov.uk/risk](http://www.hse.gov.uk/risk)

In Northern Ireland the Labour Relations Agency (LRA) offers free, confidential and impartial advice on all employment rights issues. For more information:

**W:** [www.lra.org.uk](http://www.lra.org.uk)

The Advisory, Conciliation and Arbitration Service (ACAS) provides information, independent advice and training in order to improve working life and employment relations.

Employers and employees can get free advice from the helpline service or website. For more information:

**T:** 0300 123 1100

**W:** [www.acas.org.uk](http://www.acas.org.uk)

The Business Disability Forum is an employer's organisation focused on disability as it affects business. The organisation runs a confidential information and advice service to help companies recruit and retain disabled employees. For more information:

**T:** 020 7403 3020

**E:** [enquiries@businessdisabilityforum.org.uk](mailto:enquiries@businessdisabilityforum.org.uk)

**W:** [www.businessdisabilityforum.org.uk/](http://www.businessdisabilityforum.org.uk/)



For more information (including chronic symptoms to be aware of) go to [www.shinecharity.org.uk/shuntmalfunction](http://www.shinecharity.org.uk/shuntmalfunction)

## Who are Shine?

With around 12,000 members across England, Wales and Northern Ireland, Shine is Europe's leading charity for people affected by spina bifida and hydrocephalus.

For over 50 years, we've been at the centre of developments which have improved the lives of thousands of people, enabling and empowering our members to lead the lives they want to live.

**Get in touch and  
join today for FREE!**



**Shine is almost  
entirely funded by the  
generosity of the public**

Without your support, we could not offer vital services that help improve the lives of children, families and adults affected by hydrocephalus.

Please continue to support us in giving our members the best quality of life.

Donate today at:  
[shinecharity.org.uk](http://shinecharity.org.uk)

Shine - Registered Charity: 249338  
42 Park Road, Peterborough, PE1 2UQ  
01733 555988 • [www.shinecharity.org.uk](http://www.shinecharity.org.uk)  
[firstcontact@shinecharity.org.uk](mailto:firstcontact@shinecharity.org.uk)

Sponsored by

**Codman**  
SPECIALTY SURGICAL

A DIVISION OF INTEGRA LIFESCIENCES

 **Shine**  
Spina bifida • Hydrocephalus  
Information • Networking • Equality