



association for  
spina bifida  
hydrocephalus  
ability beyond disability



# A Guide for Employers

Employing People with Spina Bifida or  
Hydrocephalus



## Introduction

The Disability Discrimination Act of 1995 was introduced to make it illegal for people with disabilities to be discriminated against and be treated less favourably because of their disability.

Since this time, we have become familiar with the various necessary adjustments that have been made to comply with the law and also eliminate the social injustice that prevailed.

Transition to employment is always an area of concern for any young person, or indeed anyone, young and old alike. It can be particularly daunting for those with additional needs such as spina bifida, a visible disability. But with hydrocephalus, a hidden disability, the additional needs are not always apparent.

This guide has been written to help employers understand the possible effects of spina bifida and hydrocephalus in the work environment and how the employer can take these matters into consideration to ensure that they get the best from their employee.

Remember, these are only guidelines, everyone is an individual and any effects of the disabilities will vary from one person to another.



## Spina bifida

'Spina Bifida' literally means 'split spine'. Spina bifida is a condition which affects the development of the spinal cord (and often brain) of unborn babies. The spinal cord is a 'tube' of nerves in the back, which provide all the connections between the brain and body, for sensation, control of movement, bladder control etc. Pairs of nerves emerge from each vertebra, one for movement and one for sensation.

Beginning in the first few weeks of pregnancy, the tissue which will become the spinal cord fails to form into a complete 'tube' shape, leaving an area of undeveloped nerve tissue, which does not provide the necessary connections between the brain and the body.

The vertebrae (backbones) surrounding the affected area do not close fully to provide a protective ring; this is the 'split' referred to in the name.

The spina bifida lesion can occur on any part of the spinal cord but is commonly seen in the lumbar or sacral (lower back) areas. The effect it has depends largely on the position on the spinal cord; the lower down the spinal cord, the fewer nerves affected, hence fewer muscles and other functions are affected.

The most visible effects are on mobility; because of muscle paralysis many people with high lumbar lesions are full-time wheelchair users. Some people with lower lesions may use wheelchairs for longer distances, or walk with crutches or sticks. Other effects include bladder and bowel problems, poor circulation in the legs and loss of skin sensation. Because of all these, pressure sores can be a problem and it is important that these are prevented so that health and quality of life are not affected.

## Hydrocephalus

Everyone produces a liquid in the spaces inside their brain called cerebro-spinal fluid (CSF) - this fluid usually flows around the brain and spinal cord and back into the bloodstream. Hydrocephalus is a condition in which the fluid, becomes trapped in the spaces inside the brain instead of flowing out through the usual pathways before being absorbed in the bloodstream.

Because the brain is in an enclosed part of the skull the pressure rises and without treatment most people become very ill. The usual treatment is to insert a tube or shunt to drain the fluid from the brain into the abdomen, or occasionally into another site. Once inserted, the shunt is totally internal and cannot be seen.

Hydrocephalus can result in effects which impact on everyday life and can pose extra challenges in the complex world of work.

The effects vary from person to person and often depend on the causes of the hydrocephalus.

Effects of hydrocephalus are often subtle and the impact can be underestimated. For example, many people with hydrocephalus have difficulties with working memory which affects all aspects of life. It can sometimes be difficult for people around them to appreciate that this is a disabling aspect of their condition, as 'forgetting' is part of everyday life.

With firm guidelines and strategies in place, people with hydrocephalus can learn to accommodate difficulties and take their place in the work force.

For more detailed information on spina bifida or hydrocephalus see ASBAH's information sheets What is Spina Bifida? and What is Hydrocephalus? available at [www.asbah.org](http://www.asbah.org) or the ASBAH Helpline on 0845 450 7755.

# Hydrocephalus in the workplace

## - skills and situations that may be affected

People with hydrocephalus can be effective employees. An informed knowledge of the condition will help you assess potential employees more positively and ensure that they are given the right support to succeed in the workplace. Many people with hydrocephalus are extremely capable, but some may take a little longer to learn a routine or task.

Break down tasks into bite-sized pieces, teach routines and techniques by repetition and introduce new skills one at a time. Employees with hydrocephalus often find it difficult to multi-task, as do many people. On a positive note, when routines and skills have been learnt, commitment and enthusiasm often takes over and the

disability becomes secondary. Everyone is an individual and therefore affected in different ways, listed below are some of the more common areas which can be affected by hydrocephalus and need to be considered:-

- short term memory
- multi-tasking
- prioritizing
- concentration
- dealing with distractions and interruptions
- coping with noisy environments
- message taking skills



## How can the employer help with these common effects?

Give one task at a time. Give simple instructions and where possible, provide visual instructions for confirmation and understanding. Avoid multi-tasking and avoid interruption with other instructions. Alternatively, write down each task or e-mail the next task, in order of priority.

Noisy environments can be disturbing for people with hydrocephalus. Where appropriate, try and ensure the employee has a quiet environment, be aware of additional background noise eg radio, tannoy etc.

Provide a template for messages with prompts for important information eg name of caller, their company or

organization, caller's number, with a prompt to check these are correct before ending the call.

It is really useful for the employee to have someone who they can 'shadow' until they are confident with the job.

Assign one or two people to be mentors and ensure that they have full understanding of spina bifida and/or hydrocephalus. This will assist the employee in feeling confident and less anxious, knowing they have a person(s) they can rely on or speak to. Consistency is an important factor in helping to avoid conflicting requests and expectations.

## Performance

Hydrocephalus often gets in the way of self-monitoring. Some people find it difficult to have a realistic view of themselves and their performance

## Strategies to help performance:

Checklists or a 'to do' list, giving clear, concise instructions and order of priority help enormously.

**Health and Safety assessment** – check equipment eg are the desk, chair etc suitable

**Breaks** – ensure your employee has frequent breaks and access to refreshments; hydration is an important factor and often people with hydrocephalus forget about keeping up their fluid intake

**Check on progress** – is someone available to check that the work is being carried out correctly?

**Mentoring** – designate one or two people to act as mentors, who can help and guide appropriately

**Supervision** – give individuals regular supervision, re-assurance and encouragement about their achievements.

## Organisational skills

Some difficulties with organisational skills may include:

- **Time management**
- **Concentration** – may get distracted if a task is too long
- **Motivation** – especially with menial tasks

## Strategies to assist organisational skills:

Help plan and prioritise workload

Timetable tasks

Give realistic deadlines

Check progress on tasks

Give support in using equipment

## Social skills

Due to the effect of the condition on the brain, some social skills can be affected in people with hydrocephalus. Again every individual is different but it helps to be aware that this may result in some of the following:

- may come over as blunt
- can be over emotional
- unable to demonstrate initiative
- anxiety

### Hydrocephalus could also affect ability in:

- reading non-verbal communication, facial expression
- understanding another person's point of view
- understanding 'jargon'
- participating in role play



## How to help with social skills

Use clear, simple language

Use verbal and non-verbal communication as a back up

Ensure targets are realistic

Give appropriate support. Ask the individual what they need and how you might help

Re-check that the individual understands the instructions given.

Above we have given an extensive list of the areas of work which might be affected by hydrocephalus but is very unlikely that every person with hydrocephalus will face all these effects. We would like to think that all these areas are given due consideration for every potential employee, with or without disabilities.

Hopefully this has given you an insight into understanding spina bifida and hydrocephalus and strategies to overcome some cognitive difficulties.

# Access and Mobility Issues for Employers

Mobility issues associated with hydrocephalus are not always apparent, but subtle effects on co-ordination and organisational skills can manifest themselves in a variety of ways. Make allowances for these by ensuring employees understand Health and Safety rules and drills. Speed of mobility may be seriously impaired by lack of co-ordination and orientation, an important factor in the event of a fire.

A simple laminated rule card could be drawn up using visual symbols and action bullet points, similar to the type used on an aircraft before take-off. A regular or weekly re-cap of the drills is an efficient repetition technique referred to earlier and a good practice to adopt for all members of staff.

Many people with spina bifida will be reliant on a wheelchair for their mobility. Wheelchairs obviously require additional accommodation space and cannot be manoeuvred into desk spaces as easily as a chair. Ensure that when a desk is allocated to an employee using a wheelchair they do not have the constant annoyance of having to remove a chair every morning before engaging themselves at their workstation.

Many offices have a 'clear desk' policy, this could be transferred to 'clear floor' policy ensuring that walkways and office floor space are wheelchair-friendly.

Employees using wheelchairs want to come into the office and begin

work without having to endure a furniture removal ritual every morning.

Perhaps the most sensitive area, both physically and emotionally, is access to toilet facilities. Spina bifida often affects the control of the bladder and bowel (continence). Suitable independent access to a toilet is paramount as is a large enough cubicle to accommodate a wheelchair. Receptacles for soiled pads and/or catheterisation equipment should be accessible and emptied daily, together with height appropriate basin, soap and hand drying facilities. What goes on 'behind closed doors' should remain so and all employees should expect privacy and dignity within their working environment.

Mobility issues are always going to vary and getting to know your employee and discussing their needs beforehand can avoid some embarrassing and awkward situations. Do not be afraid to discuss disabilities with potential employees; addressed sensitively and with empathy, most people will appreciate your time and effort to ensure a smooth induction into your business or company.

After a suitable induction or probation period, re-visit the issues discussed and ensure the employee is comfortable with the facilities available. Regular adjustments are a better option and can help avoid unnecessary anxiety.

Under the Disability Discrimination Act it states:-

**'Employers must make reasonable changes to the workplace and to employment arrangements so that disabled employees are not placed at an unfair disadvantage to their colleagues'.**

[www.equalityhumanrights.com](http://www.equalityhumanrights.com)





## View from an Employer

'I was approached by an ASBAH adviser following an advert I had placed in the local paper requesting some help with part-time gardening. She said she had a young man who may be interested in helping, but wanted to advise me he had a condition called hydrocephalus. Apart from never hearing of this condition, I had no idea how to spell it either!

The adviser spoke very clearly about this condition and I was obviously worried about the impact it may have on me as an employer. She asked about the tasks I may need assistance with and I, of course, wanted to know if this person would need constant supervision. She was very clear to put my mind at rest and as she obviously knew this young

man, she was able to address his personal difficulties associated with hydrocephalus.

She suggested I spoke to him directly and set up a meeting, possibly with a view to doing some voluntary work in the first instance – similar to work experience. This way I was helping to raise his self-esteem and confidence, but also helping both of us to get to know each other. After all it isn't just about the employer is it? I think the employee has to ensure that the job applied for is the right one too.

I am glad I have had my eyes opened to a condition that I would not necessarily ever have heard of – and provided an opportunity to give a chance to young person embarking on a new career'.





One of a series of booklets on transition to adulthood and employment for those with spina bifida or hydrocephalus, funded by The City Bridge Trust



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