

Working to relieve the pressure!

Idiopathic Intracranial Hypertension (IIH) (idiopathic meaning where no cause is found) is a serious neurological condition causing high pressure in the fluid around the brain.

The space around the brain is filled with a water-like fluid (cerebrospinal fluid). If there is too much of this fluid present, the pressure around the brain rises because the space containing the fluid cannot expand. It is this high pressure that produces the symptoms of IIH.

What causes IIH?

IIH is a rare condition affecting less than 10 in every 100,000 people (estimates vary from 1 or 2 to 7 in 100,000), most of them are women of childbearing age, but men and children can also be affected. No-one knows what causes IIH. Theories on the causes of IIH include: blood clots in veins around the brain, and "sticky" blood, withdrawal of steroids, high doses of vitamin A or foods containing large amounts of vitamin A, use of steroids, hormonal changes and certain drugs can also cause raised intracranial pressure.

What are the symptoms of IIH?

Symptoms of IIH can include severe headache, papilloedema (swelling of the optic nerves), temporary loss of vision (transient visual obscuration) blurred vision, double vision and decreased visual acuity (sharpness of vision), pulsatile tinnitus (hearing your pulse as a 'whooshing' sound in your ears and head), and pain with eye movement.

Other symptoms reported by sufferers include but are not limited to: nausea, vomiting, fatigue, photophobia (dislike of and pain caused by bright light), problems with balance and spatial awareness, aphasia (difficulty using or understanding words), disorientation, loss of short-term memory (sometimes also long-term memory loss), confusion, feeling 'spaced out', decreased depth perception and peripheral vision. Each sufferer is an individual and should be treated accordingly.

How is IIH treated?

The most commonly prescribed medication is Acetazolamide (Diamox); this can reduce the production of CSF. If vision is severely affected, sometimes the optic nerve is fenestrated (slitting the sheath surrounding the nerve to relieve pressure on the nerve). Some people need regular lumbar punctures or if medication doesn't improve the symptoms, a surgically inserted shunt may be used to drain excess fluid.

Symptoms, including severe headaches can still occur following surgery though, even when the pressure seems to have been successfully controlled by a shunt or reduced with medication. The symptoms of IIH can be very disabling and may need to be treated with combinations of painkillers and other drugs.

Equality Act 2010

- In the Act, a person has a disability if:
- they have a physical or mental impairment
- the impairment has a substantial and long-term adverse effect on their ability to perform normal day-to-day activities

For the purposes of the Act, these words have the following meanings:

- 'substantial' means more than minor or trivial
- 'long-term' means that the effect of the impairment has lasted or is likely (more likely than not) to last for at least twelve months (there are special rules covering recurring or fluctuating conditions)
- 'normal day-to-day activities' include everyday things like eating, washing, walking and going shopping
- People who have had a disability in the past that meets this definition are also protected by the Act.

For more guidance on the definition of disability in relation to employment visit:

http://www.direct.gov.uk/en/DisabledPeople/Employmentsupport/YourEmploymentRights/DG_4001073

or download this PDF.

http://www.equalityhumanrights.com/uploaded_files/guidance_on_matters_to_be_taken_into_account_in_determining_questions_relating_to_the_definition_of_disability.pdf

Employees with IIH

IIH is a rare condition that has had little research. Treatment and attacks of acute symptoms vary greatly between patients. Some adjustments for employees with IIH may include adaptations to computer screens if

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vision is affected. If they suffer from photophobia, they may need lighting altered. If their job is physically demanding they may need reasonable changes to their duties, especially if they have a shunt.

IIH can cause problems with spatial awareness and depth perception, and sufferers can have difficulties with stairs and escalators. Outdoors, judging the depth of curbs and the speed of traffic can be difficult. Often there are problems with concentration and short-term memory. Sufferers develop strategies to cope with these, but may benefit from having messages and instructions written down or taped so they can play them back. It's important the supervisor or manager understands how the person's symptoms affect them and are supportive. They may need to be reminded about deadlines.

There may be certain times of day when symptoms are worse. Employers can help by allowing employees with IIH to work more flexible hours, or depending on the job, possibly working from home sometimes if traveling is difficult because symptoms are severe.

It's very important that employees with IIH are allowed time off to attend hospital appointments with neurologists and for ophthalmic follow-up appointments. 5% of people with IIH will lose some or all of their sight and in males the loss is 25%. Most of these are patients who fail to attend follow-up appointments.

Help that may be available

Financial assistance may be available to help towards the extra costs of employing someone with a disability or long term illness. The Access to Work programme is administered by the Employment Service's Disability Service Team. To find out more about the programme and how to apply for support, contact your local Jobcentre Plus or visit the website -

http://www.direct.gov.uk/en/DisabledPeople/Employmentsupport/WorkSchemesAndProgrammes/DG_4000347

Disabled people as workers

Many people with IIH meet the DDA criteria of an impairment which has 'long-term' effect, has lasted or is likely to last for at least twelve months (there are special rules covering recurring or fluctuating conditions). However a person with IIH can still function effectively with the right support, as many IIH sufferers already do and they can be a valuable asset to your organisation.

People living with disabilities/long term illnesses often have additional problem-solving skills developed from managing their everyday life. Whether you have an employee who has recently been diagnosed with IIH or are considering employing someone with IIH, please take the time to look beyond the person's disability and symptoms, and at the skills, knowledge and experience they can bring to your organisation.

Your Rights as a Worker

Under the Equality Act 2010 you have extensive rights as a disabled person and also as a worker. You can read about these on the Equality & Human Rights Commission website here:

<http://www.equalityhumanrights.com/advice-and-guidance/guidance-for-workers/>

You can also download a series of useful PDF's to get to understand your rights.

However, those about to apply for work have **even more special rights** and these are detailed below:

Equality Act 2010: Questions about health or disability – mandatory rules for employers

Except in very restricted circumstances or for very restricted purposes, you are not allowed to ask any job applicant about their health or any disability until the person has been:

- offered a job either outright or on conditions, or
- included in a pool of successful candidates to be offered a job when a position becomes available (for example, if an employer is opening a new workplace or expects to have multiple vacancies for the same role but doesn't want to recruit separately for each one).

This includes asking such a question as part of the application process or during an interview. Questions relating to previous sickness absence count as questions that relate to health or disability.

No-one else can ask these questions on your behalf either. So you cannot refer an applicant to an occupational health practitioner or ask an applicant to fill in a questionnaire provided by an occupational

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health practitioner before the offer of a job is made (or before inclusion in a pool of successful applicants) except in very limited circumstances, which are explained next.

The point of stopping employers asking questions about health or disability is to make sure that all job applicants are looked at properly to see if they can do the job in question, and not ruled out just because of issues related to or arising from their health or disability, such as sickness absence, which may well say nothing about whether they can do the job now.

You can ask questions once you have made a job offer or included someone in a group of successful candidates. At that stage, you could make sure that someone's health or disability would not prevent them from doing the job. But you must consider whether there are reasonable adjustments that would enable them to do the job.

What happens if I ask questions about health or disability?

A job applicant can bring a claim against you if:

- you asked health - or disability-related questions of a kind that are not allowed, and
- they believe there has been unlawful discrimination as a result of the information that they gave (or failed to give) when answering such questions.

The Equality and Human Rights Commission can **also** take legal action against you if you ask job applicants any health - or disability-related questions that are not allowed by equality law. This includes sending them a questionnaire about their health for them to fill in before you have offered them a job.

When are you allowed to ask questions about health or disability?

You can ask questions about health or disability when:

You are asking the questions to find out if any applicant needs reasonable adjustments for the recruitment process, such as for an assessment or an interview.

For example:

- An application form states: 'Please contact us if you need the application form in an alternative format or if you need any adjustments for the interview'. This is allowed.

You are asking the questions to find out if a person (whether they are a disabled person or not) can take part in an assessment as part of the recruitment process, including questions about reasonable adjustments for this purpose.

For example:

- An employer is recruiting play workers for an outdoor activity centre and wants to hold a practical test for applicants as part of the recruitment process. It asks a question about health in order to ensure that applicants who are not able to undertake the test (for example, because they are pregnant or have an injury) are not required to take the test. This is allowed.

You are asking the questions for monitoring purposes to check the diversity of applicants.

You want to make sure that an applicant who is a disabled person can benefit from any measures aimed at improving disabled people's employment rates.

For example:

- the guaranteed interview scheme. Make it clear to job applicants that this is why you are asking the question.
- You are asking the question because having a specific impairment is an occupational requirement for a particular job.

For example:

- An employer wants to recruit a Deaf blind project worker who has personal experience of Deaf blindness. This is an occupational requirement of the job and the job advert states this. The employer can ask on the application form or at interview about the applicant's disability.

Where the questions relate to a requirement to vet applicants for the purposes of national security.

Where the question relates to a person's ability to carry out a function that is intrinsic (or absolutely fundamental) to that job. Where a health- or disability-related question would mean you would know if a person can carry out that function with reasonable adjustments in place, then you can ask the question.

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For example:

- A construction company is recruiting scaffolders. The company can ask about health or disability on the application form or at interview if the questions relate specifically to an applicant's ability to climb ladders and scaffolding to a significant height. The ability to climb ladders and scaffolding is intrinsic or fundamental to the job.

In practice, even if a function is intrinsic to the job, you should ask a question about a disabled person's ability to do the job with reasonable adjustments in place. There will therefore be very few situations where a question about a person's health or disability needs to be asked.

Most of the time, whether on an application form or during an interview, you can ask a question about whether someone has the relevant skills, qualities or experience to do the job, not about their health or about any disability they may have.

For example:

- An employer is recruiting a person as a cycle courier. They ask applicants to send in a CV setting out their relevant experience and a covering letter saying why they would be suitable for the job. The employer will score candidates on their experience of and enthusiasm for cycling. It is not necessary to ask applicants questions about health or disability. If the employer considers a health check is necessary, for example, for insurance purposes, this can be carried out once an applicant has been offered the job, and the job offer can be made conditional on the health check.