



Huntington's
Disease
Association



Huntington's disease: Information regarding employment



What should I tell my employer?

If you know that you have a risk of inheriting the faulty Huntington's gene or you have had a positive predictive test and know that you carry the faulty gene, you might wonder if you should tell your employer. If you do not have symptoms and are coping well in your role then perhaps you might ask yourself **what would the benefits of telling my employer be?** Some people choose to tell their employer because they need flexibility or support while going through the predictive testing process. Maybe you feel it would help you to be open about Huntington's; and if you did carry the gene and develop symptoms then it would be easier to ask for support if your employer already knew about it. On the other hand, some people may worry about whether their employer will understand and if it could potentially lead to discrimination.

There are certain roles where you may need to tell your employer if you have a known risk of Huntington's disease. Current guidance indicates that the British Army generally does not recruit applicants known to be at risk of Huntington's disease unless they have a negative predictive test. Recruitment for the police varies from force to force with each police force having its own entry criteria and recruitment process. Some forces will recruit people at risk of Huntington's on the basis they will agree to undertake annual neurological examinations. Some forces refuse entry on the basis of genetic risk. **It is not advised to go through testing solely with the aim of joining the police or army.**

An employer cannot ask a medical professional for your medical records, or information about your health, without your permission. At the recruitment stage employers can ask health questions only in very limited circumstances (e.g. to check if an accessibility adjustment is needed for interview, or if it is directly relevant to the role) and they cannot request your medical records at this stage. After employment begins an employer may request medical information, but only with the employee's explicit consent and only if relevant to supporting adjustments, or if they (or you) think that your medical condition may raise health and safety concerns and could impact on your ability to do your job. They may ask you for medical records (such as a 'fit-to-work' note from your doctor) if you were on sick leave for more than your usual working week, but they would still only need information that is specifically relevant to the absence. Employers have a duty to handle and store any medical records securely and confidentially.



What if I have symptoms of Huntington's disease?

Although physical changes with Huntington's disease can cause problems at work, such as difficulties with balance and coordination, it is often thinking changes that can have some of the earliest impact on performance. Huntington's affects things like speed of processing, getting started on an activity, multi-tasking, memory and concentration, and planning and organisation. Increased difficulty with these thinking tasks can start to affect how well someone can carry out a job and can lead to increased fatigue and anxiety. Some roles involve safety-critical responsibilities, such as driving, operating machinery, or roles requiring high vigilance. If symptoms begin to affect your ability to work safely, it is important to discuss this with your employer or occupational health.

If you disclose to your employer that you have symptoms of Huntington's disease, then under the Equality Act 2010 www.gov.uk/rights-disabled-person/employment, your employer must consider if they can make 'reasonable adjustments'. These are changes that would enable you to continue in your role. A 'reasonable adjustment' might be sourcing a suitable piece of equipment that would help you carry out your role, or it could be looking at things like making alterations to the times, place and way in which you work.

If your employer doesn't open a conversation about 'reasonable adjustments' with you, you can ask them about it. You should feel confident to start and be involved in this conversation with your employer, as you know yourself and your condition better than they do. Feel encouraged to share examples of things that you think may help you carry out your job.

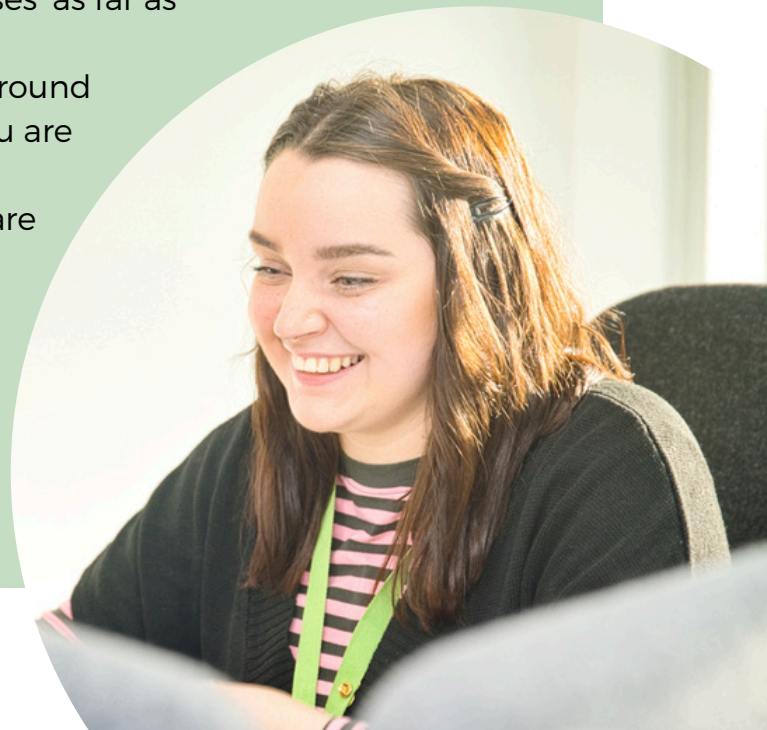
What might help?

Making changes to how you work can help to make things easier if you are experiencing symptoms. Here are some ideas:

- Help to manage fatigue by identifying the key priorities for the day's energy on shift at work. Use pacing strategies to maximise energy at work.
- More frequent breaks for food, drink, and relaxation to keep up energy and concentration levels.



- Think about your working style and your preferred communication style. For example, if your manager has a task for you, is it easier to process instructions in an email, which you can read at your own pace, rather than a quick phone call?
- You may want to consider putting in a request with your employer to reduce your hours, or request to work them in a different pattern throughout the day or week.
- Strategies and techniques to help with short-term memory problems and decision making, such as having fixed routines for each day and prompts (these could be verbal or visual). Using reminders on phones or diaries / calendars can be very helpful. Planning key tasks into an easy-to-follow routine. To-do lists - either on paper, or a computer / phone can be helpful.
- Simplify tasks by breaking them down into smaller chunks.
- Minimise distractions where possible. Work environments can be noisy and distracting; it can be helpful if an area is identified where there is less going on so that you give your full attention to the task at hand.
- Can you be given additional time to complete certain tasks?
- It may be harder for you to spot small mistakes, so for important tasks, it may be good to work with someone or have a review system in place.
- When planning work remember that learning something new will be much harder than undertaking familiar tasks. If you are learning a new task you may need longer to master it. Simple written instructions to refer back to can help.
- Make your employer aware that it can be challenging for you to suddenly be asked to do a new task and that it is best to avoid 'surprises' as far as possible.
- Think about the 'whole picture' around work - e.g. the commute, how you are sleeping at home (Huntington's disease affects sleep), when you are eating, whether you are better at certain times of day (this may suggest that flexible working might help).





- Is there anything in your life outside work that you can change to make things easier, less stressful, and reduce fatigue?
- Regular check-ins and support from a line manager can help identify problems before they get too big and cause too much stress and worry.
- Consider letting colleagues know about your diagnosis. This may help them to understand that you may need more time to think through instructions, or that you might get anxious or frustrated more easily.

What other things might help?

- Direct your employer to resources on the Huntington's Disease Association website to help them better understand its impacts.
- A Specialist Huntington's Disease Adviser from the Huntington's Disease Association may be able to liaise with your employer to increase their understanding of Huntington's and to discuss possible changes that might help you perform your role.
- Your employer may suggest an Occupational Health Assessment. This can identify things that might be helpful in order for you to continue in that role. It can also help your employer better understand your needs.
- Contact your employer's Human Resources (HR) team, if they have one, to find out what other support might be available to you and obtain information on processes around reasonable adjustments and flexible working.
- Access to Work grants www.gov.uk/access-to-work. These can pay for extra support to help you remain in work. For example: to help purchase certain pieces of equipment not covered by a 'reasonable adjustment'; a support worker to enable you in carrying out your role; help to cover the cost of travel if you can't use public transport.
- For advice on your rights relating to work CAB (Citizen's Advice Bureau) is a good source of information. www.citizensadvice.org.uk/work/.
- ACAS (Advisory, Conciliation and Arbitration Service) has a helpline you can contact for free confidential advice. For more information see





- www.acas.org.uk/contact. If you are in a union they may also be able to provide advice and support.
- Disability Employment Advisors are based at Job Centre Plus. They can assist with searching for jobs and give advice on training and skill development opportunities. Ask to be referred to a Disability Employment Advisor by contacting your local Job Centre Plus.
- The charity SCOPE offers support services for disabled people who are looking for work: www.scope.org.uk/employment-services

What if I am no longer able to continue in paid work?

- You may be eligible to apply for benefits such as Universal Credit and Personal Independence Payment. The charity Turn2Us has a benefits calculator that helps you identify suitable benefits. Turn2Us also has information to assist you when making an application: www.turn2us.org.uk/
- It may be that you would like to do voluntary work that will help you to continue to use your time and skills to help other people. The Gov.uk website has links to a variety of organisations that provide volunteering opportunities. www.gov.uk/volunteering





Notes:

Get in touch

For advice and support or
to speak to a Specialist
Huntington's Disease
Adviser

Email: **info@hda.org.uk**

Phone: **0151 331 5444**

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