

Employment

For many people, employment is an essential part of their life and identity. Information contained within this factsheet is relevant to you if you are an employee or are self-employed and have concerns about the potential impact of Huntington's disease on your career or finances.

1. If you're employed

When should I tell my employer?

Deciding if and when to tell your employer about Huntington's disease is a personal choice. In most jobs and industries, you are not legally obliged to do so. There are some exceptions, such as if you are wishing to join the Armed Forces or Police.

What should I tell them?

Most employers will have limited, if any, knowledge about Huntington's disease. Therefore, it may be advisable to think about what you want to tell your employer and to have reliable information about the disease that you can share with them. Your HD Specialist can help you to have conversations with your employer about the disease, how it impacts you, and any changes at work which may be beneficial.

What are the benefits to telling my employer?

Firstly, advising your employer ahead of time can help them to understand why your abilities are changing if or when you develop symptoms. This can help avoid disagreements and disciplinary matters, and enable relevant supports to be put in place early. From a health and safety perspective, informing your employer about any difficulties that you may go on to experience can ensure they eliminate or reduce risks to yourself or others. Raising awareness about Huntington's disease can result in a more understanding and empathic work environment for yourself and others.

Many larger companies have a dedicated occupational health service. Your occupational health advisor can make recommendations about how your health needs can be accommodated through certain adjustments. Smaller

firms often have access to similar services however as local arrangements can vary it's best to check with your line manager.

2. Legal protections at work

Huntington's disease is a protected characteristic (categorised as a disability) within the Equality Act (2010). This legislation protects people with protected characteristics in the workplace from discrimination, harassment and victimisation. It also means that your employer has a duty to make **reasonable adjustments** to enable you to keep well at work. Reasonable adjustments are changes to the way that you work to make your job more manageable. What adjustments are considered to be reasonable will depend on the role in question, however important factors will include whether they are practical and affordable for the employer to make. Find out more information about reasonable adjustments [here](#).

An example of reasonable adjustments

Jim has Huntington's disease and works in a warehouse. He can no longer manage this heavy manual work so he speaks with his employer who is able to offer an alternative desk-based role. This enables Jim to stay in work in a role better suited to his needs.

What if reasonable adjustments cannot be made?

Sometimes it is not possible to continue with your current employer if they cannot reasonably make adjustments to your role. They must be able to show why any adjustments are not possible; if they are unable to do so then this is a form of discrimination. Although there is no automatic entitlement to ill-health severance pay, some employers may offer this.

3. If you are self-employed

If you are self-employed or own your own business, there are additional factors to take into consideration. As symptoms progress, your ability to process information and make decisions can be impacted. In such circumstances, it may be advisable to source a mentor who can provide oversight and guidance. However, being self-employed can often have benefits as it allows for increased flexibility about how and when you work and what jobs you undertake.

4. Finding alternative work

Many people are keen to continue working if they have to leave their original job. There are several agencies in Scotland who can help you to find suitable further employment such as:

- Your local Job Centre may have Disability Employment Advisors and hold a list of supported employment services.
- [Fair Start Scotland](#), an employment service which can help you to find work that meets your needs. It is delivered by local partners in different areas of the country. More information [here](#).

5. Managing changes to your financial situation

With time, some people find that paid work is no longer a viable option for them. Naturally, this can cause concerns about financial security, particularly if you have longstanding commitments such as a mortgage.

If you have to retire due to ill-health and have a private or workplace pension, you may be able to take an income or lump sum from your pension early. The rules vary depending on your pension scheme and you will need to provide supporting medical evidence. You cannot access a state pension early in the same way.

If you think you may need to give up work and are worried about money, the [Financial Wellbeing Service at Scottish Huntington's Association](#) can offer you support to ensure that you are receiving all the benefits to which you are entitled as a result of your Huntington's disease. This will help you to plan for your future.

6. Common feelings if you change roles or give up work

You may experience a range of emotions if you decide to change roles or give up work. Some people feel disappointed or angry, while others feel relief. Any significant life change involves a period of adjustment and it is important to give yourself time to work through your thoughts and feelings at your own pace. Your [HD Specialist](#) will be happy to speak about how you can continue to find a sense of purpose in this new chapter of your life, such as through voluntary work.

Useful links

[Contact a Scottish Huntington's Association HD Specialist](#)

[Scottish Huntington's Association Financial Wellbeing Service](#)

[National and Regional Care Frameworks for Huntington's Disease](#)

[Sign up for regular updates from Scottish Huntington's Association](#)

Updated January 2022