

OCCUPATIONAL THERAPY CLINICAL TIPS FOR HUNTINGTON'S DISEASE

WORK

People with Huntington's disease can continue to work for a number of years following the start of symptoms. However, some people find it hard to stay in work and it often depends on many things as to how long people stay working, such as the type of work they are employed in and the cognitive and physical changes of the disease.

When people stop working, they often have to adjust to a lot less money coming in which they do not like. On the other hand, some people with Huntington's disease say it is a relief to stop work, as they no longer have to cope with the stress of it. However, most people reported the negative effects including loss of self-worth and identity that might lead to depression and anger.

Occupational therapists can work with both the employer and the individual with Huntington's disease to explain how their symptoms affect their ability to work. Sometimes, changing the work environment may help someone to manage the physical parts of their job more easily. Likewise, simplifying some tasks and reducing distractions can go a long way to helping people with cognitive changes but many people find that familiar tasks are easier to keep doing, than to learn something completely different.

Employers need to undertake their own risk assessments if the person's symptoms might cause accident or injury. Some UK government schemes, such as Access to Work can support people within the workplace and Job Centre Plus have advisors who can help people get back into work.

1. Education

- 1.1 An occupational therapist can provide support and information, to help people stay in work and to help decide when it's the right time to talk to their employer about Huntington's disease
- 1.2 The Huntington's disease association has a variety of useful fact sheets on their website

2. Risk assessment

- 2.1 If people are having practical problems at work, the occupational therapist can assess them doing their job to find out the physical and cognitive difficulties. The work environment impact scale and worker role interview are useful for this and you can use them in conjunction with other assessments, such as assessment of motor and process skills and the model of human occupation screening tool to get a full picture of someone's difficulties
- 2.2 After the assessment, the occupational therapist can recommend reasonable adjustments that the work place can make that will enable the person with Huntington's disease to continue to work

3. Liaison and advocacy

- 3.1 The occupational therapist can be a link between the person with Huntington's disease, their workplace and external services and can help a person to negotiate working with several agencies
- 3.2 UK government services such as Access to Work or the Disability Employment Advisor from the Job Centre are useful resources

3.3 If the person with Huntington's disease decides to stop work the occupational therapist can provide them with information for discussions held with their employers, human resources and/or trade unions, so that they can establish the most favourable terms and timing for them

References

Braveman B, Robson M, Velozo C, Kielhofner G, Fisher G, Forsyth K, Kerschbaum J (2005) Worker Role Interview (WRI) Version 10.0

Assessment of Motor and Process Skills (AMPS) www.innovativeotsolutions.com

MOHOST <https://www.moho.uic.edu/productDetails.aspx?aid=4>

<https://www.hda.org.uk/getting-help/if-youre-at-risk/employment>

Department for work and Pensions www.dwp.gov.uk

Disability Discrimination Act (2010) www.gov.uk/definition-of-disability-under-equality-act-2010

www.gov.uk/contact-jobcentre-plus

Completed September 2016 Amended 2020

Produced by the UK HD special interest group for occupational therapists:

Authors: Kirsty Page, Louise Oakley, Alex Fisher, Zhanna Flower, Poppy Hill.

Contributors: Nicola Pendry, Sarah Sharland, Eleanor Winning, Clare Cook, Freya White, Suzi Kerrell-Vaughan, Emma-Louise Simpson, Jake Reed, Vicki VanEsch, Kirsty Berry, Sarah Hayes.

This document was based on Occupational Therapy for People with Huntington's Disease: Best Practice Guidelines. Written by Clare Cook, Kirsty Page, Anne Wagstaff with support from the members of the European Huntington's Disease Network, Occupational Therapy Working Group.

Huntington's Disease Association www.hda.org.uk **European Huntington's Disease Network** www.ehdn.org