

OCCUPATIONAL THERAPY CLINICAL TIPS FOR HUNTINGTON'S DISEASE

End stage and palliative care

The founder of the British Hospice Movement Dame Cicely Saunders said of palliative care that the aim was to enable the chronically ill individual to feel they mattered and live life until they die. Whilst occupational therapists may not consider their work with people with Huntington's disease as palliative, ultimately, Huntington's disease is a long-term condition that at the present time has no cure and therefore much of their work could be said to be palliative. For occupational therapists 'living life' means facilitating the individual as much as possible in choice about how they engage in their activities of daily living at whatever stage of the disease process.

Many of the practicalities as to how to do this have been covered elsewhere within the accompanying clinical tips. Of course, whilst it is important to have knowledge of 'how to' in Huntington's disease, activity is also about wellbeing and this should not be forgotten. Therefore, occupational therapists should also consider the sensory quality of activity as well as the spiritual.

1. Giving information

- 1.1 The Huntington's Disease Association have produced an excellent booklet on Care in Advanced Huntington's disease, within the fact sheets for professionals
- 1.2 Having a life limiting illness as complex as Huntington's disease also means becoming involved in conversations with people with Huntington's disease and their companions, about what their wishes are for the future. No health or social care professionals find this easy, but people with other conditions (such as Motor Neuron Disease) have said that it often helps them feel more in control, particularly when there is a potential for them to perceive a loss of control over their own lives as their communication or cognitive skills decline
- 1.3 Occupational therapists, who work with people with Huntington's disease and their companions, need to be prepared for these conversations as they may be the first to have them and therefore as a minimum should have knowledge of where to signpost those with whom they work for support as well as managing their own wellbeing
- 1.4 These conversations should be approached very sensitively, as some people will not want to talk about these issues and may perseverate on them for a considerable time to the detriment of their mental health. Such conversations may affect your therapeutic relationship if ill-timed or information is presented in an unpalatable form
- 1.5 Whilst not specific to occupational therapy as well as being set within an American context, an article in the Journal of Neuroscience Nursing showed how using a framework of ten key areas could prompt all staff to consider all the elements needed in dignified palliative and End of Life (EOL) care for people with Huntington's disease (Dellefield, Ferrini 2011)

2. Forward Planning

- 2.1 Occupational therapists should be aware of the differences between;
 - Advance care planning (ACP)
 - Advanced decision to refuse treatment (ADRT), also known as advanced decision, advanced directive or living will
 - Advance statement

- 2.2 Many organisations within the NHS and outside of it are signed up to the 'Gold Standards Framework' (GSF) which is a recognised and structured way to manage and discuss advanced care planning. Training and templates are also provided via their website
- 2.3 National Institute for Health and Care Excellence (NICE) has produced End of life care for adults (EOL) quality standards; they are made up of 16 statements as to what good EOL care should look like. Occupational therapists should be aware that NICE is also in the process of developing separate guidance for children and young adults
- 2.4 Mental capacity questions - for the most up to date guidance occupational therapists should consult the Mental Capacity Code of Practice. The code gives examples of common situations in which Occupational therapists and other health professionals may find themselves involved in, including Lasting Power of Attorney (LPA) issues
- 2.5 Get to know staff at local palliative and end of life teams (EOL)

References

Dellefield, M.E. and Ferrini, R., 2011. Promoting Excellence in End-of-Life Care: lessons learned from a cohort of nursing home residents with advanced Huntington disease. *The Journal of neuroscience nursing: journal of the American Association of Neuroscience Nurses*, 43(4), pp. 186.

Motor Neurone Disease Association (2014). End of Life: A guide for people with motor neurone disease. Version 2.

<https://www.hda.org.uk/getting-help/if-youre-a-carer/approaching-the-end-of-life>

<https://www.hda.org.uk/getting-help/if-youre-showing-symptoms/thinking-about-the-end-of-life>

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www.goldstandardsframework.org.uk/advance-care-planning

www.hospiceuk.org

www.nice.org.uk/guidance/service-delivery--organisation-and-staffing/end-of-life-care

www.gov.uk/government/collections/mental-capacity-act-making-decisions

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