

OCCUPATIONAL THERAPY CLINICAL TIPS FOR HUNTINGTON'S DISEASE

Domestic Skills

People tend to find that their performance of domestic tasks such as meal preparation, shopping and housework are affected during the mid to late stages of Huntington's disease. The cognitive changes relating to planning, organisation and decision-making will impact on their ability to manage finances and run a household. These tasks can be a central role for the person with Huntington's disease and it is important they continue these for their self-esteem or alternatively they may live alone and be the only person to carry out these tasks.

The combination of declining cognitive skills and a reluctance to request assistance can result in some people neglecting themselves, their property and getting into debt by failing to pay bills. If an individual with Huntington's disease does not have a friend or family member who calls and reports the problem, the neglect can continue to increase. This can result in people becoming homeless or living in unsanitary and infested conditions.

Where there is self-neglect and neglect of property as a safeguarding issue, the occupational therapist should work closely with the social worker, consultant, family and any other relevant professionals. Occupational therapists are well placed to assess the individual's mental capacity to decide how and when to care for themselves and their property, and this should be assessed as well as their ability to carry out activities of daily living. If the individual lacks the capacity to make decisions about their living conditions, a decision needs to be made for the person, which is the least restrictive and in their best interests (Mental Capacity Act 2005, Deprivation of Liberty Safeguards 2009).

Please refer to the community living skills tips sheet for further information too.

1. Shopping

- 1.1 Encourage people to use shopping lists so they don't forget anything
- 1.2 Shop in familiar shops where people can help with finding items
- 1.3 Shop at quieter times of the day to reduce distractions
- 1.4 Shop in smaller shops as big supermarkets can be very noisy, bright, distracting and confusing
- 1.5 Use a 4 wheeled shopping trolley to carry things home
- 1.6 Buy pre-prepared meals and pre-prepared vegetables to cut down on meal preparation
- 1.7 Shopping on line may be useful if the person with Huntington's disease has access to the internet and is familiar with the process or carers or relatives can order the shopping for them
- 1.8 Handling money can be difficult for people with Huntington's disease, so ensure that you have notes rather than coins and have a big roomy wallet or purse that is easy to close to keep money safe

2. Meal preparation and cooking

- 2.1 Non-slip mats may ease jar opening and prevent plates slipping
- 2.2 Tap turners could be considered
- 2.3 Consider using a microwave for convenience and safety
- 2.4 Cook vegetables in a wire mesh basket to help when draining
- 2.5 Use timers if using a gas or electric cooker to prevent burning and reduce fire risk
- 2.6 Ensure that smoke alarms are working and fit a domestic gas detector to alert in case gas rings are left on unlit
- 2.7 Wall mounted electric can openers can make life a lot easier or alternatively ring pull cans
- 2.8 Kettles can be quite dangerous for someone with a movement disorder. Consider a kettle tipper, cordless kettles or a one cup hot water dispenser
- 2.9 Use unbreakable dinnerware

- 2.10 Avoid storage of commonly used items in high or too low cabinets
- 2.11 Use oven mitts for holding hot items.
- 2.12 Use covered cups or mugs (travel mugs are ideal) to prevent spills when carrying them around
- 2.13 Both perching stools and trolleys can be considered. Often though these are not used, as the person has to learn a new pattern of behaviour. These can also become a trip hazard

3. Housework

- 3.1 Encourage a regular routine of household tasks to ensure that things get done
- 3.2 Clear rooms of any unnecessary furniture so they are easier to clean and reduce trip hazards
- 3.3 Tasks can be split up into manageable chunks, and do not have to be done in one go. If this is an area which is important to a person, encourage them to continue these tasks to help retain independence
- 3.4 Sometimes it is easiest to employ a cleaner

4. Laundry

- 4.1 Use washing tablets as the washing powder is conveniently pre-portioned and reduces waste. Ideally, recommend using the two in one washing powder and conditioner products
- 4.2 When replacing the washing machine, recommend one with the biggest drum and the most economical, as laundry will increase over the course of Huntington's disease due to food spillage and incontinence
- 4.3 Drying the increased laundry can be a problem, so consider a tumble dryer

5. Managing Finances

- 5.1 Set up direct debits for all household utilities and regular outgoings
- 5.2 Try to have gas and electric paid this way, rather than by a pre payment metre to prevent running out.
- 5.3 Apply for reduced rates for utilities called social tariffs. Most gas and electric suppliers run these schemes
- 5.4 Think about the most economical way to manage the water bill such as metered or capped as water usage maybe higher
- 5.5 Finances are a complex area; Occupational therapists can assess a person's ability to manage finances and capacity to do so. Where issues arise liaise with the social work team
- 5.6 Occupational therapists are well placed to discuss when someone can no longer manage their finances and discuss lasting power of attorney or council appointee

References

<https://www.gov.uk/government/collections/mental-capacity-act-making-decisions>

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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.

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Huntington's Disease Association www.hda.org.uk **European Huntington's Disease Network** www.ehdn.org
Please send any comments or questions to info@othd.co.uk