

OCCUPATIONAL THERAPY CLINICAL TIPS FOR HUNTINGTON'S DISEASE

Seating and Posture

People with Huntington's disease often find it difficult to maintain a good upright sitting posture, even though they may be transferring and walking independently. Sitting is a tiring activity and actively holding the trunk erect requires good muscle tone and strength (Collins 2005). In addition, changes to the ability to plan movement, slowness of movement, chorea and loss of range of movement in Huntington's disease make assessment and reassessment of seating and posture essential to promote an individual's function and upright position.

Although each person with Huntington's disease will present differently there are some common problems encountered. The seating system can cause injury from involuntary movements. Many people with Huntington's disease tend to slide down their chair resulting in sacral sitting, placing them at risk of developing pressure damage and reducing their functional ability. In an effort to maintain an upright posture, people may fix with their hands, elbows and legs/feet. The trunk leaning to one side or rotation of the pelvis can also be present. As the disease progresses neck control may become problematic, resulting in flexion at the neck. It is important to maintain a good posture when eating to reduce the risk of aspiration. The position of the head in relation to the shoulder girdle is critical in facilitating swallowing, rather than an erect upright position of the body as a whole (Pope 2007). Periods of active sitting may also delay further loss of muscle strength and tone, and will aid respiration (Pope 2007).

Assessment to ensure that seating is of the appropriate dimensions is especially relevant for those with movement disorders (Aragon and Kings 2010). Failure to consider dimensions may exacerbate existing problems and will reduce success of any intervention (Collins 2005).

As the disease progresses it is likely that a more specialist seating system with tilt in space will be required. This allows for a person's hip and knee angle to be maintained whilst changing the orientation of the seat, this can provide pressure relief and reduce shear and friction from sliding. A 24-hour posture routine may also need to be considered for seating and positioning in bed and it is recommended as a key proactive approach in the prevention of skin damage and deformity in NICE guidelines (2014).

1. Assessment

- 1.1 Assessment should ideally be an interdisciplinary team process involving the individual and carers
- 1.2 Assess the dimensions of a person's current chair to ascertain whether it is the correct size and offering adequate support
 - A seat depth that is too long may contribute to sliding forwards
 - A seat that is too wide will allow the pelvis to move laterally or to rotate, which may contribute towards leaning
 - Ensuring a chair is measured and set up for the individual may go some way to alleviating problems seen
- 1.3 Assess whether the pelvis, trunk, neck, head and arms are adequately supported. Consider:
 - A standard chair or a specialist chair such as a tilt in space chair
 - A pelvic belt required to stabilise pelvis, does the belt need to be padded? What type of buckle?
 - Type of backrest, for example contoured backrest may provide additional trunk support
 - Use of lateral trunk supports
 - Use and type of head rest
 - Use of a table to provide additional upper body support
 - Foot support to ensure feet are fully supported. Assess for risk of entrapment if feet are not staying on wheelchair footplate
- 1.4 Consider whether a pressure cushion will provide additional postural support and whether pressure relief is required. Be aware that pressure cushions can cause additional problems such as greater instability or need frequent replacement due to heavy transfers. Can intrinsic pressure relief be provided within the seating system? Therapists should consult closely with Tissue Viability colleagues
- 1.5 It is essential to consider adequate padding if someone has involuntary movements to prevent injury
- 1.6 Assess how the person is transferring into seating
 - Ensure that the chair is not too low or high; some chairs are height adjustable
 - Where someone is self-transferring, transfers are likely to be heavy and lacking in control. Injuries may occur if chairs are not well padded and the chairs are likely to break

- 1.7 Least restrictive positioning methods and adaptations should be trialled first before deciding upon using a positioning aid such as a harness
- 1.8 If considering any type of belt or harness a DoLS will need to be facilitated
- 1.9 As individual's mobility reduces and concerns about posture become apparent, a full review of posture and pressure care over a 24 hour period should be undertaken and reviewed as required

2. Equipment

- 2.1 Any seating system needs to be robust to withstand heavy transfers and involuntary movements
- 2.2 A modular seating and/or wheelchair system that can be adapted to increase its longevity can be useful where the individual's condition is changing frequently
- 2.3 Tilt in space will be required as Huntington's disease progresses to improve posture and positioning
- 2.4 Consider breathable materials to enhance comfort and wipe clean material due to continence and spillage issues
- 2.5 Brakes on all 4 casters may make transfers safer

3. Record and Review

- 3.1 It is essential that a person's positioning and comfort should be regularly reviewed over time, as presentation will change
- 3.2 Regular maintenance and checks of any seating/chair is necessary, as clips and screws can become loose
- 3.3 Where seating adaptations restrict someone's freedom of movement such as, tilt in space or positioning harness, the legal aspects regarding restraint must be respected. Consent should ideally be obtained from the person. Where this is not possible, the therapist should assess a person's capacity and where this is lacking they may need to act in a person's best interest using the least restrictive option. All such decisions need justifying and documenting (Mental Capacity Act 2005, Deprivation of Liberty Safeguards 2009)
- 3.4 Training should be provided to either the person with Huntington's' disease and/or their carer on how to use any seating system and adaptations and this should be documented

References

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