OCCUPATIONAL THERAPY CLINICAL TIPS FOR HUNTINGTON'S DISEASE

Seating and Lying

Purpose and Scope

This document updates and expands the Occupational Therapy (OT) Clinical Tips for Huntington's Disease, originally published online in 2016 by the Huntington's Disease Association (HDA) and the European Huntington's Disease Network (EHDN). Although the evidence base primarily draws on UK documentation and guidance, the principles of postural management in Huntington's disease (HD) apply globally.

Importance of Seating and Lying in Huntington's Disease

Seating and lying are closely interconnected. The ability to sit comfortably, lie at ease, and sleep safely is fundamental to a person's wellbeing, participation, and autonomy. For people with Huntington's disease (PwHD), maintaining posture is a complex and often significant challenge – even when mobility remains relatively preserved. Cognitive changes, chorea, rigidity, dystonia, loss of core control, fatigue, sensory changes, difficulties with temperature regulation, and altered sleep patterns all contribute to postural difficulties across both daytime and nighttime positioning.

Lying flat for PwHD may be distressing due to proprioceptive changes, pain, a feeling of choking, or a sense of getting stuck in one position. Nocturnal chorea can disturb sleep for both the individual and their bed partner. Skin trauma may result from forceful movements, uncontrolled transfers, falls, or entrapment. As a further complication, poor nutritional intake can further impede wound healing. Spasticity, contractures, and changes to body shape can all cause significant discomfort.

When working with PwHD, the occupational therapist (OT) should familiarise themselves with the individual's cognitive changes and adjust their assessment and intervention accordingly. Cognitive changes in PwHD will affect their ability to undertake what is being asked of them and may impair insight into risk, leading to difficulties in adopting and accepting necessary adaptations. Collectively, these factors highlight the need for **proactive, early, and holistic seating and lying intervention**, delivered through multidisciplinary collaboration.

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A 24-Hour Approach

Seating and lying support should be considered across the full day and night, encompassing wheelchairs, armchairs, toileting and showering positions, transfer methods, sleep systems, and environmental factors such as noise, clutter, and sensory impact. Positioning is not solely the OT's responsibility – physiotherapists, nurses, speech and language therapists, dieticians, tissue viability specialists, psychologists, medics and carers all contribute to safe and effective approaches.

Appropriate equipment is not merely a clinical necessity – it is a matter of dignity, safety, and human rights. Lack of suitable resources or inappropriate substitutions (e.g., keeping a person in bed because a suitable chair is unavailable) restricts liberty and participation and puts patients' health at risk. It is unavoidable that equipment for PwHD often requires frequent repair or replacement due to the impact of involuntary movement and heavy transfers.

Common Seating Challenges

PwHD often slide into sacral sitting, lean laterally, rotate the pelvis, hook legs over chair sides, brace with hands or elbows, or adopt 'preferred' postures even when misaligned. These behaviours often reflect insecurity, sensory-seeking, pain, fatigue, or attempts at self-stabilisation.

A 'perfect' seated posture is not always realistic; instead, prioritise goals such as reducing fatigue, enabling safe eating and drinking, reducing risk of injury, and maintaining engagement and interaction.

Neck control in PwHD often deteriorates, increasing aspiration risk. The relationship between the head and shoulder girdle is central to reducing the risk of aspiration and encouraging safe swallowing. The EHDN Occupational Therapy Working Group's recommendation is to use gravity and the support of appropriate seating to manage the angle of the neck. However, this is not always possible, and neck supports, or physical support, may be needed (see the guidance from the MND Association). Assessment should be individualised, and the following key factors should be considered: comfort, skin integrity, aspiration risk, staffing, and any potential behaviour change.

Tilt-in-space seating becomes vital as HD progresses: maintaining hip and knee angles while altering orientation helps relieve pressure, reduce shear forces, and improve comfort. Gastrostomy feeding requires maintaining ≥45° head and shoulder elevation for at least 1 hour after each feed, whenever possible, with attention to preventing tube entanglement.

Moulded seating and dynamic wheelchairs may help stabilise movements and accommodate fixed postures.

Assessment

A thorough assessment should be flexible, paced, and centred around the individual's cognitive, physical, and emotional needs. HD symptoms fluctuate widely, so assessments often require multiple sessions.

1. Cognitive, emotional, and communication factors

PwHD may have difficulty processing verbal instructions or may become overwhelmed by change. It is therefore important to:

- Use trusted carers to introduce clinicians and explain the purpose of visits.
- Allow extended processing time.
- Observe how the tone, speed, or pitch of communication affects responses.
- Break sessions into short, manageable segments.

2. Timing and fluctuation

Symptoms change throughout the day. Consider the energy requirements of activities and how these impact fatigue patterns, chorea intensity, and irritability caused by cognitive and sensory overload, as well as temperature, environmental factors, and medication timings.

3. Avoiding diagnostic overshadowing

Not all symptoms are caused by HD. Consider other causes, such as pain, changes due to infections, menstruation or menopause, constipation, medication effects, and sensory overwhelm. The factors can significantly influence posture, behaviour, and mobility.

4. Chair dimensions and postural support

Accurate measurement for chairs is crucial. For example:

- Seat depth (too long = sliding; too short = limited support).
- Seat width (too wide = leaning; too narrow = pressure).
- Seat height (affects transfers and foot placement).

Assess alignment and support for the pelvis, trunk, head and neck, arms, and feet. The provision of contact points and the feeling of security when seated minimise chorea.

However, we cannot stress enough that assessment is individual. The OT may need to experiment with angles and settings, and this is often a dynamic process. Sometimes a smaller seating area helps; sometimes a larger one. Sometimes, a bit more seat depth is preferable for an individual. The principles of alignment are paramount, but we cannot always achieve the optimal setting based solely on body measurements, and trial and error will be required.

Consider the use of lateral supports, padded armrests, headrests, contoured backs, and channelled leg/foot support. However, be cautious with anti-slip materials, as they can increase friction on thin skin and bony prominences. Individuals may also get stuck and be unable to initiate any movement to release themselves. Additionally, if they are unable to process pain, they won't be able to draw attention to this, and tissue damage can result.

In showering or toilet-related seating, it is particularly important to consider the effects of the environment (such as water, heat, light and noise) on the patient. Toilet seats will need frequent tightening or replacement. Bio-bidet attachments can be damaged by heavy transfers – a complete washer-dryer toilet is preferable; however, be aware that in advanced disease, some PwHD may find the sensation unpleasant. Consider toilet and shower seat aperture sizes and layouts as they can be problematic, e.g., horseshoe apertures can cause leg entrapment, large apertures cause instability due to weight loss around buttocks and thighs

5. Pressure risk

Use validated tools such as the Braden Scale. Some pressure care cushions (and mattresses) may increase instability and cause agitation (particularly resulting from motion sickness). The friction from uncontrolled chorea can become problematic and cause skin trauma. Address such concerns immediately, because if a wound develops, the adherence of any wound covering will be problematic, as well as keeping any pressure/moisture off the affected area. Finding products which reduce friction (e.g., satin pillow covers for the back of the head) helps. Liaise with a nursing colleague experienced in tissue viability.

6. Transfers and safety

Transfers may be forceful and uncoordinated. Risks include falls, equipment breakage, and soft tissue injury. Assessment must include transfer mechanics (such as appropriate height) and equipment durability.

7. Record, review, and train

Because HD is dynamic, OTs should regularly review comfort and posture, keep care plans flexible, maintain equipment regularly, document capacity, consent, and restrictive practices, train carers thoroughly, and monitor and document functional outcomes and wellbeing. It is important to include costs per person and time used, which reflect the inherent complexity and weighting of that person's case.

Common Difficulties

1. Acceptance of seating

Due to cognitive changes, PwHD may not understand why adaptations are needed. Please remember that it is not refusal. Useful strategies include gradual introduction, linking equipment to meaningful activity, using trusted figures to explain changes, offering trial periods, and investigating environmental triggers when acceptance suddenly changes. Cognitive rigidity often explains sudden refusal. In such cases, try offering two options, e.g., 'Why don't we see which chair is the most comfortable?' rather than yes/no.

2. Transitioning to immobility

This stage is emotionally charged. PwHD may sit or lie on the floor for 'safety', continue walking despite risk, bump into walls, or drop suddenly. These are protective behaviours in which the

individual is trying to maintain control in an increasingly difficult situation. This can be supported by acknowledging emotional impact, introducing equipment early, offering simple but high-impact changes (do one thing rather than multiple complex changes), having robust manual handling plans, and advocating clearly with funders. Finally, 'tripping' (feet-propelling a wheelchair) might be acceptable and may help with autonomy, but it does increase the risk of sacral sitting.

3. Sleep and night-time care

Sleep is commonly disrupted by insomnia, chorea, temperature changes, pain, and circadian reversal. Support includes HD specialist review, sleep hygiene education, environmental adjustments, and sensitive discussion of sleeping arrangements. Caregiver sleep can also be affected. A lack of sleep leads to further cognitive, mood and functional changes, and sleep is a key component of HD care.

Although rare, chair-sleeping can sometimes be the safest option. PwHD may not be able to alter this habit once it has become routine easily, and they may not be able to accept change without significant distress (see earlier discussion on lying flat in HD).

Equipment

1. Seating systems should include

- Durable frames for heavy transfers and brakes on all four casters.
- Tilt-in-space.
- Breathable, wipe-clean fabrics.
- Modular components and pommels.
- Dynamic wheelchairs where appropriate, calf-bands, padded and moulded foot boxes, and foot boards.
- Moulded seating for fixed or preferred postures.
- Padding for high-impact areas and reduced access to mechanisms, as entrapment/injury is common.

In addition, one-way glide sheets can help reposition the individual with minimal chorea if they are unable to initiate this themselves; individual assessment is needed.

After exploring the above requirements, if pelvic stabilising belts (three- or four-point) or chest harnesses are considered necessary, follow national laws (i.e., the capacity to consent and the implications for the deprivation of liberty). Use lap belts and harnesses with risk prominent in mind, bearing in mind that if people slide down, strangulation can occur. Make sure ALL parties know how to fit and use this equipment, and are aware that poorly fitted belts cause injury. Use should be judicious (i.e., just for mealtimes) and take into account questions, including whether the individual needs to be able to release themselves.

2. Sleeping systems

Options include double beds, profiling beds, chair-beds, floor beds, mattresses on the floor, padding and breathable cocoons on the floor, breathable cocoon systems for profiling beds, crash mats (but consider impact on transfers/mobility and falls) and 'Huntington's' or complex care beds. Choices will depend on individual assessment. For example, a PwHD who is still mobile, has minimal insight into their needs, and who is physically and verbally hostile to staff will need immediate access to a bed without staff having to put sides up/down and placing themselves in harm's way.

Important considerations include the use of standard rail bumpers, whether bed header and foot bumpers are suitably robust and high, eliminating gaps around mattresses to reduce entrapment, fitting anti-entrapment covers for under bed mechanisms, undertaking careful assessment of air mattresses to reduce agitation, and support carer safety (bed height, access) using back care and manual handling principles (given that care may need to be delivered on the floor or across double beds). Floor work and double beds should not be considered the norm, as they pose inherent risks to care delivery – this is a matter for comprehensive risk assessment. Often, what is needed at one point in the disease will change due to the illness's dynamic and degenerative nature.

Weighted blankets may reduce chorea, as may lighter-weight options such as sensory sheets. These will need individual assessment and the consideration of the individual's transfer/continence needs. Sometimes, sleeping bags work similarly by helping the individual feel secure and reducing the common problem of throwing off bedclothes during the night. Extra-large blankets can be tucked under the mattress, and depending on the force of chorea, bed sheet straps can be useful. Quilts instead of duvets may prove easier to manage. Temperature alteration and perception should be considered, as they can cause agitation. PwHD can express they are hot but can still be subject to exposure, meaning that a balance needs to be struck.

When epilepsy is present, breathable pillows and appropriate monitoring are needed. If a PEG is in place, liaise with the prescriber to arrange devices that keep the tubing out of the way.

3. Positioning aids and transfers within the bed

These provisions may include, but are not limited to, in-bed wedges, slide sheets, and in-bed positioning systems such as lock-and-glide sheets. Lock-and-glide systems may not work if involuntary movement bumps the individual over the lock. Frequent repositioning might always be needed.

It is probably most important to consider how physically and cognitively demanding an activity is. In more advanced HD, minimise the number of actions required from and for the individual, such as repositioning in bed. Due to impairments in executive functioning and reduced processing speed, individuals may sometimes have difficulty understanding instructions, or the pace may be too fast. This can lead to confusion, stress and irritability. In addition, individuals are often motivated to help during transfers, but due to chorea, their movements may be counterproductive. In such cases, it can be helpful to ask them not to assist and to take over the movement.

4. Transfers and hoisting

It can sometimes be difficult to assess what is possible during transfers, and this depends on both cognitive and physical limitations. There are assistive devices available to help maintain mobility for as long as possible, such as a standing pole (grab pole) or bed rails – but consider the person's abilities and risks.

In particular:

- Determine the reliability of a person's sit-to-stand (What is their trunk stability like? Are they able to place their feet on the floor and follow multiple instructions? If so, an 'active' stand aid may still be viable.). Concern about the use of these items (e.g., a Molift or Sara Steady) often means that they are skipped in practice as an intermediate step in favour of a more 'passive' hoist. A variety of options may be needed, e.g., depending on the time of day or other activities. Remember that cognitive difficulties and chorea can be made worse by fatigue. Carer strain should always be considered.
- Accurate sling sizing is essential. Consider full-body in-situ types as well as extensor spasm types.
- Staffing levels must be adhered to and can, and often do, go beyond 2:1.
- Ceiling track hoists are preferable to standalone, manual types.

A Note on Equipment Providers

We are unable to endorse specific equipment providers. However, there are many reputable companies in the community, and some have more experience with HD than others. Although certain products are marketed as 'HD-proof', our collective experience shows that this is rarely the case. Some equipment performs better than others, and we are always willing to support colleagues and families in navigating these choices.

The durability and suitability of any equipment depend on the individual's presentation and how it is used. Frequent replacement is often necessary due to the nature of the disease. This document provides an overview of the types of equipment and associated considerations. We hope that, together with your provider and family – and within the resources of your local system or country – it will help you advocate effectively for PwHD and their families.

Bibliography and Further Reading

For inexperienced OTs, Seating Matters offers a freely available guide on the principles of good seating assessment.

The MND Association provides useful guidance on head supports relevant to PwHD.

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Acknowledgements and Contact Information

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