Huntington's Disease Association

Occupational therapy for people living with Huntington's disease

Royal College of Occupational Therapists

EHDN European Huntington's Disease Network

Advancing Research, Conducting Trials, Improving Care

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Contents:

Author

Alex Fisher wrote this guideline on contemporary best practice in occupational therapy for people with Huntington's disease. Alex is a Senior Occupational Therapist in Neuropsychiatry at Birmingham & Solihull Mental Health Foundation Trust, who specialises in supporting people living with Huntington's disease. She is also the Huntington's Disease Module Lead for Neuropsychiatry at the University of Birmingham.

This guideline has been developed by reviewing the available evidence and expert consensus on best clinical practice. It is based on the European Huntington's Disease Network's (EHDN) Occupational Therapy for People with Huntington's Disease Best Practice Guidelines. We thank them for this resource.

Alex and her European colleagues at the EHDN can be contacted via the EHDN webpage for the Occupational Therapy Working Group (see 'resources' below).

Community reviewer

Allan Adams

General principles of occupational therapy for people with Huntington's disease

These are general principles. Assessment and delivery will depend on the person's presentation.

Multi-disciplinary care

Effective multi-disciplinary care is essential to treating the complexity of problems for people with Huntington's disease. Neurologists, psychiatrists, psychologists, physiotherapists, occupational therapists, speech and language therapists, dieticians, nursing and social workers should all be involved in providing assessment and treatment.

Occupational therapy focuses its assessment and treatment around how

people participate in and perform everyday activities.

Huntington's disease can affect every aspect of a person's ability to engage in and participate in their valued activities, and therefore, occupational therapy interventions take time as it reflects the extent of a person's difficulties.

Occupational therapy can minimise the impact of Huntington's disease on daily life for as long as possible by promoting independence and quality of life.

However, given the rarity and complexity of the disease, if the occupational therapist is unsure about the illness and its presentation, they should seek support through the Huntington's Disease Association or other knowledgeable peers.

Working with family / caregivers

Occupational therapists should:

- Provide information about the disease and its progression as appropriate and refer to other members of the multi-disciplinary team as needed
- Work with caregivers as well as other professionals visiting the person. Huntington's disease is a disease of families, therefore most companions of people living with the condition will have been caring for one or many members of their family for some time
- Explain interventions to caregivers so that they can prompt and encourage the person with Huntington's disease between visits

People with Huntington's disease experience neurological apathy and cognitive changes from early in the illness and will require additional support to achieve goals. Occupational therapists should also be aware that people with Huntington's may lack insight into some or all aspects of their illness. This can make it difficult for someone to take part in occupational therapy. Lack of insight is not denial. Seek supervision on how to manage the situation and document any outcome.

The person who lives alone and issues of non-engagement

Special attention should be given to people who live alone, as they will have increased difficulties in engaging with therapy because of the lack of support. Changes in personality may have left them isolated. Occupational therapists should be open to the idea that lack of engagement is related to the impact of Huntington's and is not a deliberate refusal. For example, people may lack the drive to return phone calls or have the organisational

abilities to keep appointments. This will leave them at risk of non-deliberate neglect. Therapy (and other NHS teams) may need to set aside additional time to engage and see the person. Seek supervision on how to manage the situation and document any outcome.

Equipment and adaptations

Small pieces of equipment can be effective in the short term and should be assessed at an individual level.

Any equipment should be robust, but given that movement / transfers can be forceful and heavy, be aware that they may need to be maintained and / or replaced.

Occupational therapists should be prepared to talk about the progression of the disease. By ensuring you are aware of the progression of the disease, you will be able to raise issues of environmental adaptations with the person and their family sensitively and thoughtfully. The person and family may not be ready to accept the changes that the disease will cause and the changes which may be needed to their home.

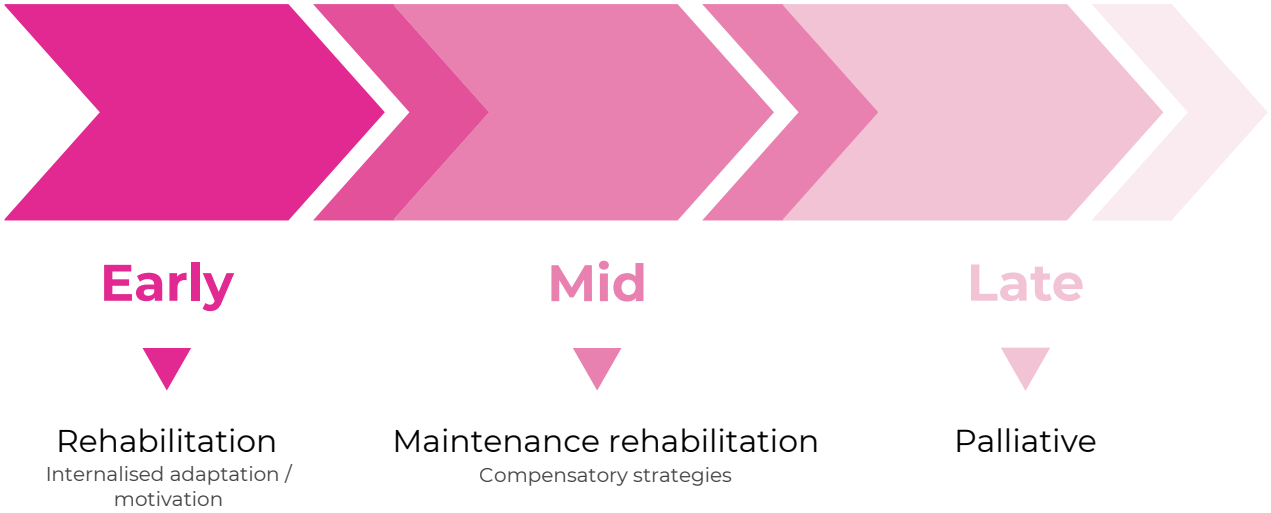
When making an assessment for equipment and / or adaptations, consider the person's long-term prognosis and life span, alongside the time it could take them to receive equipment and / or have adaptations undertaken. Huntington's disease is a palliative condition.

Early and consistent intervention

There are a number of advantages to early intervention and seeing people as early in their illness as possible. This is because it:

- Enables the therapist to build a therapeutic relationship with the person and their family at a point when the symptoms are relatively minor
- Ideally, the person will be reviewed regularly, and then interventions can be increased when needed
- Early intervention enables the use of rehabilitative strategies whilst the person retains the ability to learn and adapt to difficulties
- Early intervention enables the therapist to know the person well and to build trust. This is important because, as the disease progresses, more professionals become involved and decision-making becomes more difficult
- Establish and document any advance decisions, such as wishes for medical care (e.g. PEG (percutaneous endoscopic gastrostomy)) and management of finances (Lasting Power of Attorney), whilst the person has capacity to make these decisions

Figure 1 below shows an outline of how an occupational therapist might shape their intervention. In the early stage, rehabilitation follows the methods already discussed. In the middle stages of the illness, focus on the maintenance of skills alongside compensatory strategies. In the later stages, adopt a more palliative approach focused on quality of life goals.



Subject to:

Insight, capacity, cognition (particularly apathy), engagement, presentation, and risk and support mechanisms.

Promoting physical function

Assessing physical impairment

To assess physical impairment:

- Break down the activity to assess whether it can be adapted to overcome physical and functional problems
- Identify where the physical impairment(s) lie to assist with modifying and adapting tasks to help the person perform them
- Consider the environment and / or equipment used and whether this is facilitating or hindering a person's engagement and safety.

Fatigue

Fatigue is an overlooked issue for people with Huntington's disease. This is because everyday function requires more effort and increased energy consumption. Fatigue can be mental, as well as physical.

To help address physical and mental fatigue:

- Promote a good sleep routine. Where sleep patterns are disturbed significantly, discuss with the multi-disciplinary team to review medication and management of the sleep routine
- Consider the need to build rest sessions into the daily routine
- Consider which time of day the person has most energy
- Work with the person to prioritise activities, deciding on how to best use time and limited energy
- Consider ways of preserving energy, e.g. using a wheelchair on a longer trip, delegating tasks
- Consider keeping interventions or activities short due to limited attention and fatigue
- Where postural fatigue is occurring, identify the length of time a person is able to tolerate sitting and make recommendations about periods of bed rest

Communication:

Where communication is becoming difficult, it is recommended that:

- Alternative methods of enabling communication are established, as communication deteriorates
- Be aware it can take time to 'tune in' to someone's speech. Consider working with a carer initially, where possible
- Where possible, work with a speech and language therapist to establish the best strategies
- Consider the person's ability to use a particular method and their likelihood of compliance. Low-tech solutions may be best, e.g. yes / no cards, whiteboards and marker pens, alphabet charts
- Consider the person's strengths, such as writing ability, pointing, and eye contact
- Consider establishing communication charts / folders with pictures or words of a person's known drink, food and activity preferences

Swallowing:

Where swallowing is becoming difficult:

- Be aware of the risk of aspiration and / or choking and of the signs that swallow has become affected, e.g. gurgly voice, coughing and spluttering
- If someone's swallow is affected, immediately seek assistance from a speech and language therapist. They can advise the person and caregivers on how to manage the condition

Promoting cognitive function

Assessing cognitive function

Screen for cognitive changes by using clinical observation and / or a standardised assessment. Cognitive changes are often in the executive and social cognitive domains from early in the disease process.

Consider using strategies to compensate for specific cognitive changes highlighted in the assessment, such as:

- Using lists, calendars, notebooks, wipe boards, sticky notes
- Establishing a consistent daily routine
- Labelling drawers / cupboards around the home
- Using prompts to aid retrieval of information
- Offering specific choices e.g. rather than asking “what would you like to drink?”, ask, “would you like tea or coffee?” You will need to be meaningful and direct rather than abstract
- Breaking down complex tasks into smaller sections
- Writing down tasks in sequential order to check understanding
- Encouraging completion of one step of a task before moving on to the next step
- Using short sentences, conveying one piece of information at a time and allowing the person time to respond, as a reply can be delayed
- Using closed questions, which require less effort to process, may help
- Eliminating external stimuli wherever possible to enable focus of attention
- Educating the person and all caregivers about the cause and management of cognitive changes

Promoting wellbeing and managing behavioural changes

Assess and promote the mental wellbeing for people with Huntington’s disease by:

- Screening for emotional and neuropsychiatric impairment by use of communication, observation and liaison with caregivers. Note signs of illness and wellbeing if the person is struggling with their communication
- If you feel competent, educate the person with Huntington's disease and all caregivers about the cause and management of emotional and neuropsychiatric impairments
- Referring the person and family members (and / or other significant caregivers) to appropriate mental health support services

Promote strategies to help manage behavioural changes such as:

- Avoiding confrontations
- Speaking in a low, soft voice
- Keeping the environment calm and controlled
- Trying to identify the triggers to irritability and avoid them (see communication section – these can often be sources of irritability)
- Acknowledging irritability as a symptom of frustration and responding diplomatically
- Sticking to a regular daily schedule (change can cause irritability)
- Encouraging the person to focus attention on a new task (distraction) may be effective

Optimising mobility and falls prevention

Promote mobility and reduce risk of falls by:

- Completing and documenting a comprehensive multi-disciplinary team falls assessment
- Assessing and identifying potential hazards in the person's immediate home environment
- Adapting the environment, where possible, to reduce the risk of falls
- Considering potential hazards, e.g. clutter, furniture, stairs, loose rugs, fireplaces, and lighting
- Encouraging the person to make changes to reduce the risk of falls. For example, when carrying items, suggest the items are placed in a pocket or a diagonal shoulder bag, allowing the arms to remain free to stabilise on walls or furniture

- Identifying and providing (where appropriate) a means of raising the alarm in the event of a fall, such as a mobile phone, careline or telecare system
- Educating the person and caregivers on the need to concentrate when walking and limit distractions. For example, holding a conversation with a person who has Huntington's disease while they are walking can cause them to lose their balance
- Identifying and practising a safe way of getting up from the floor in the event of a fall. This may be in conjunction with a moving and handling specialist
- Providing moving and handling equipment (when this is needed)
- Reviewing and monitoring risk regularly as the person's condition changes

Promoting and facilitating safe transfers

Assess a person's ability to transfer safely onto a chair, bed, toilet, and into a car, bath / shower.

Adapt the environment and / or equipment used to reduce hazards.

Consider the sturdiness of the furniture being used. Beds / chairs should be set at the optimal height for the person to aid independent transfers.

Assess the need for grab rails by the toilet and shower and install equipment.

Ensure that any toilet frame that is installed is floor fixed to enhance its stability.

Adapt the environment or equipment used to remove the need for challenging transfers. For example, replacing a bath with a level access shower. Where suitable, using a rise recliner chair may facilitate sit-to-stand transfers.

Individually assess any equipment (such as hoists, slide sheets, and manual handling belts) to facilitate transfers and ease caregiver burden. Implement a trial period for new equipment.

Regularly review all transfers (the frequency may be determined by organisational policies) and make adjustments as necessary.

Postural management (including sleeping and seating)

Review posture and positioning over a 24-hour period and undertake a full posture assessment in both seating and lying.

Consider the need for regular change of position by caregivers and support in lying, where a person cannot change position themselves in bed.

Implement a suitable 24-hour positioning regime, including advice on managing positioning in: bed, lounge seating, wheelchair and car / vehicle.

Regularly review the suitability of a person's lounge seating and adapt or change to meet altering needs.

Regular review a person's wheelchair suitability

Assess whether altering the wheelchair or lounge chair set-up (e.g. amount of tilt in space) can assist in maintaining good posture.

Ensure there is a full multi-disciplinary team review of seating, which includes the assessment of risk of pressure sores using a valid and reliable rating scale. Record results with a clear review date.

Consider pressure care products which cater for a person's risk level, e.g. cushions, built-in pressure relief, overlays and mattresses should be considered.

On occasion, be aware that these pressure care products can promote further instability in sitting or alteration in function within the bed space.

Manual handling

Work with other relevant professionals (e.g., physiotherapists and / or manual handling trainers) to discuss manual handling issues.

Review all transfers and manual handling scenarios throughout a 24-hour period.

Trial in situ any equipment identified as being useful and provide training for caregivers on using it.

Establish the number of staff required to transfer a person safely and position them satisfactorily. This can often be greater than two people to allow safe transfers / hoisting. On occasion, chorea and behaviour may

prevent transfers / hoisting, meaning care needs to be provided on the floor.

Document all recommendations and review regularly with caregivers.

Consider using slings that provide maximum support around the head and neck, due to the likely lack of head and neck control in the later stages.

Consider using padding around manual hoists, as involuntary movements or resistance may make transfers hazardous.

To assess sitting ability and posture:

- Assess the dimensions of a person's current chair / seat to identify whether it is the correct size and offers adequate support
- Assess whether the pelvis, trunk, neck, head and arms are adequately supported
- Ensure the person's feet are fully supported. Footwear that provides grip may assist
- Consider whether a cushion will provide additional postural support and whether pressure relief is required
- Where people are unable to sit comfortably or safely, consider the need for specialist lounge and / or wheelchair seating
- Consider whether additional positioning devices would maintain position and / or safety. For example, head support, lateral trunk supports, positioning belts, and / or a table or lap tray to provide upper body support. Consider whether a contoured backrest would provide additional trunk support.

Trial the least restrictive positioning methods and adaptations before deciding upon using a harness as a positioning aid. Where seating adaptations restrict freedom of movement (e.g. tilt in space, positioning harness), legal aspects regarding restraint should be respected. Consent should ideally be obtained from the person. Where this is not possible, the therapist should assess a person's mental capacity. Where this is lacking, they may need to act in a person's best interests using the process described in the Mental Capacity Act. Document these decisions and the reasons for taking them.

Any seating system needs to be robust to withstand heavy transfers. Requesting brakes on all four casters may make transfers safer. Regular maintenance and checks of any seating / chair are necessary, as clips and

screws can become loose.

A modular seating or wheelchair system that can be adapted to increase its longevity can be useful where the person's condition is changing frequently.

Consider breathable and wipe-clean materials to enhance comfort and make it easier to address continence and spillage issues.

Regularly review a person's positioning and comfort, as presentations will change. These options should be assessed in situ over time to assess whether they enhance posture and function.

Provide training to the person and / or their caregiver(s) on how to use any seating system / adaptations, ensuring this is documented.

To promote bed mobility and safety:

- Carry out individual risk assessments on the suitability of the bed, mattress and any bedrails, in combination with the person with Huntington's disease
- Document and review risk assessments regularly
- Consider padding around the bed area and removal of clutter if a person is transferring in and out of bed in an uncontrolled manner
- Ensure the bed is at a suitable height to facilitate transfers
- Consider teaching rolling over in bed and sitting up by breaking down the transfer into small stages, such as moving from lying on back, onto side and up to sitting
- Consider a person's cognitive as well as physical abilities, such as the ability to follow instructions, maintain grip, or organise movements when assessing for equipment to aid transfers
- When falls from bed are a risk, consider the use of a double bed or a bed which goes low to the floor
- Consider introducing a falls mat, following individual risk assessment. Consider the style of mat, e.g. could this increase the risk of an ambulant person tripping due to raised edges? Could a soft walking surface make the person unstable?
- Risk assess bedrails / bumpers on an individual basis. Involve the person in the decision, where possible. Determine the views of caregivers, as they will be the people using the equipment. If using bedrails, the risk assessment should be reviewed and updated regularly. Consider the risk of entrapment of limbs and the external surfaces of the rails, as the person may lie diagonally and hook their legs over the side of the bed. If injury, particularly entrapment, is still occurring with the use of bedrails and standard bumpers, consider installing a cocoon system

- Refer to local policy on the use of bedrails and the Medicine and Healthcare products Regulatory Agency (MHRA) guidance on managing and using bedrails safely

To help maintain posture and reduce sliding down the bed:

- Consider offering pillows and rolled towels to offer support in maintaining posture
- Consider using a profiling bed, which has a four-section profile action. This can reduce slipping by applying the knee break, ensuring knees are bent to reduce slipping down the bed. This may facilitate transfers, aid positioning, and be necessary for safe manual handling for all parties
- The ability to profile a bed may aid respiration in the later stages and can minimise the risk of aspiration if a person is being PEG fed in bed or returns to bed for rest after a meal. For a person being PEG fed, the minimum requirement is to sit at an angle of no less than 45 degrees to reduce the risk of aspiration. Sometimes this is not always possible due to behaviour or chorea, which is treatment-resistant. A balance should be agreed upon with all parties. Decisions may need to be made using the best Interest processes within the Mental Capacity Act
- Consider the type of mattress, such as pressure-relieving, to suit the pressure relief requirements of the person and liaise with appropriate care professionals, i.e. tissue viability nurse
- Consider the future needs of the person. For example, if a dynamic airflow mattress is required in the later stages, the bed would need to be compatible with this

Eating and drinking

To promote eating and drinking abilities:

- Refer to a speech and language therapist if swallowing problems have been identified or the person is coughing on food and drink
- Assess eating and drinking, and provide equipment where appropriate. This is required because of the difficulties people with Huntington's disease can have in coordinating the movements required to use cutlery

Suggest strategies to assist with eating and drinking, such as:

- Using spouted beakers and straws can help with the transportation of fluid to the back of the mouth and aid swallowing. However, if drinks are thickened, the aperture size needs to be considered
- Using a smaller spoon if the person with Huntington's disease puts too much food into his / her mouth
- Ensuring there are appropriate visible snack foods in the kitchen or living room, which can prompt the person to eat if they have difficulty initiating the task
- Reducing the external stimuli when eating to reduce the risk of choking, e.g. by turning off the TV or not having a conversation
- People become tired when eating and find it difficult to finish meals so smaller meals more frequently can help to ensure the person is receiving adequate nutrition. If caregivers take over feeding towards the end of a meal, this can help to reduce fatigue
- People who retain insight into the changes caused by Huntington's disease may become anxious about eating out because they tend to drop food or have difficulty chewing and swallowing. Some suggestions to assist with this are:
    - Ask to be seated at a table in a quieter area of the restaurant
    - Choose a meal which will be easier to manage, i.e. softer diet, or less effort to eat (penne rather than spaghetti)
    - Take adapted cutlery and a non-slip mat
    - Arrange for everyone in the group to tuck napkins into their shirts / blouses

Promoting self-care

Toileting

If self-care routines are lengthy or frustrating, assistance should be provided in the morning and / or evening.

Assess for and provide handrails to assist transfers onto / off the toilet where appropriate. An alternative option is a toilet frame fixed to the floor.

Where appropriate, assess for and provide a padded backrest around the cistern if the person has strong extensor movements.

Where continence is a difficulty, refer to a continence advisor / local nurse. Refer to the NICE (National Institute for Health and Care Excellence) guidelines on urinary incontinence in neurological disease.

Continence provision should be an individual assessment and consider the person's cognitive and behavioural challenges. It should also consider the effects of chorea on the products suggested and not just focus on the volume of urine / faeces.

The jerky, uncontrolled movements caused by Huntington's disease may result in the toilet seat breaking as the bolts wear over time.

When purchasing a toilet seat, consider one with the sturdiest bolts or preferably one where the bolts insert at a right angle into the toilet seat.

Be prepared to replace the toilet seat frequently due to seat damage, but also due to potential weight loss around the bottom and thighs of the person.

Consider using a toilet that washes and dries, and install this early in the disease.

Bathing / showering

Assess for and provide appropriate bathing equipment.

The choice of equipment will depend on the person's symptoms, space in the bathroom and carer support. Avoid wall-mounted shower seats due to the risk of injury from hitting the head on the wall.

Consider tilt in space shower chairs, shower cradles and easy access baths. In later stages of the condition, the person may need postural support in the bath.

Regularly review and document training for caregivers in use of equipment.

Dressing / grooming

Assess and, where appropriate, suggest strategies to assist with dressing. Consider the following:

- Loose-fitting clothing with elastic waistbands is easier to manage, and adapt to front fastening if appropriate
- Zip tags on jackets can help
- Underwire bras can be more uncomfortable for people in the mid-late stage of Huntington's disease who are less active and sit for extended periods of time
- Be aware of weight loss and clothing falling down, causing a trip hazard

- Shoes should be supportive, lower heels for women are recommended and Velcro fastenings may be easier to manage
- Clothes may need to be changed frequently due to increased soiling, e.g. messy eating, drooling, and perspiration
- If the person has difficulty initiating and organising the task, consider laying the clothes out in order
- Verbal prompts will be necessary as the condition progresses. Even when another person is required to dress the person, simple commands can encourage the person with Huntington's disease to assist by lifting limbs
- Be aware that due to cognitive changes and sometimes sensory changes, the person may develop problems with understanding the need to maintain their hygiene. When this becomes a barrier to their health and wellbeing, seek out specialist multi-disciplinary support

Assess and where appropriate suggest strategies to assist with grooming. Consider the following:

- An electric shaver or beard trimmer is safer than a wet shave
- Shorter hairstyles are easier to manage, but for those people who wish to keep longer hair, a 'tangle teaser' brush or spray in conditioner helps to keep hair manageable
- Other aspects of grooming, such as waxing, manicures, and pedicures, can often be arranged with local beauticians. It is important to maintain these activities when the person can no longer do them themselves. It promotes social interaction and inclusion, promotes emotional well-being and is a sensory-stimulating activity.

Domestic skills

Small items of equipment should be assessed for and provided. For example:

- Non-slip mats to ease jar opening and prevent plates slipping
- Wire mesh baskets to help when draining vegetables
- A trolley to assist with transferring objects

Consider breaking down domestic tasks into component actions to allow successful participation in some aspects of the activity.

Consider introducing convenience foods, internet shopping and support to plan shopping lists.

Carrying a meal or drink from the kitchen to the living room can be difficult to coordinate and increase the risk of falls. Where possible, it can help to have a table and chair in the kitchen for eating and drinking.

Some people manage to use a trolley. The metal type with larger wheels is preferable as it is sturdier, and the larger wheels go over threshold strips more easily.

Consider using a microwave rather than a conventional cooker. If using a conventional cooker, timers can be useful to remind the person to return to the task. As the disease progresses, cognitive changes impact attention to a task and leaving hobs on can become problematic and a fire hazard. It may be necessary to disconnect these or remove them altogether.

Consider reorganising food cupboards and freezer space. Labelling drawers and cupboards can help people to find the items needed.

Workspaces should be free of clutter and unnecessary items. Smoke alarms should be fitted at strategic points within the home. The local fire service will usually assist with a fire safety assessment.

Explore the need for assistance with or delegation of some or all of the household tasks, such as ironing, housework, household maintenance and management of paperwork / finances. This may involve a referral to local health and social care teams for a care package or involvement of the local authority appointee, where finances are concerned.

Smoking

Smoking can become a ‘passion’ in Huntington’s disease.

If the person smokes, try to set up routines that encourage the use of specific areas to smoke (i.e. an outside space). Involve the Fire Brigade for the provision of fire mats. Smoking robot devices, cigarette holders and ashtrays which extinguish cigarettes can all minimise risk. Long-handled lighters and arc lighters can be easier to use than cheaper products. Consider environmental adaptations, such as wall lighters.

Clothing that is slow to burn / melt is preferable.

Ensure fire-retardant aprons, furniture throws, and bedding are available if the risk of fire from smoking is high. Furniture should be checked for an up-to-date fire certificate if possible.

Maintaining positive relationships

Promote maintenance of normal roles, daily routines and social habits by suggesting and practising task modification.

Act on health and wellbeing concerns of the whole family (including sexual relationships) and consider, if the person supports this, referring for support for sex and relationships, e.g. Relate or Outsiders.

Act sensitively, recognising that family members may not be aware of the genetic nature of Huntington's disease and that they may be at risk of inheriting the symptoms.

Provide support and information about help available to stay in work.

Adopt a pro-work advocacy role, providing a link between the person, the workplace and government services such as Access to Work.

If the person is having practical problems at work, then a work assessment should be undertaken to identify key physical and cognitive difficulties. Reasonable workplace adjustments can sometimes be made to enable the person with Huntington's disease to physically and cognitively undertake their job.

Provide guidance about the employer's role and responsibilities under the Equality Act 2010.

If the person decides to stop work, then explore the emotional, practical and financial impacts of this decision. Facilitate discussions with the employer, human resources and / or trade unions to establish the most favourable terms and timing.

Social, recreational, and leisure activities

Encourage the person to use some of their time and energy to participate in social and recreational aspects of daily life, to promote mental and physical wellbeing.

Explore social, recreational and leisure priorities as part of a holistic occupational therapy assessment. Involvement of a caregiver may be useful where a person lacks insight, is apathetic, or where communication difficulties exist. Interest checklists can be useful.

Consider the impact of caring for someone with Huntington's disease on caregivers' social and recreational activities and whether this can be reduced.

Consider whether an activity could be adapted to continue successful and safe participation.

Identify whether adaptive equipment, assistive technology or carrying out a task in a different way facilitates engagement.

Assess whether the environment may affect a person's ability to participate in an activity, e.g. a quiet environment to minimise distraction may assist someone with attention difficulties to engage.

Where someone no longer wishes to continue with a pursuit, or it is no longer practicable, offer to work with the person to assist them in identifying or trying other recreational options.

Signpost to local services which support the person and their caregivers.

The Huntington's Disease Association holds information on its local branches and groups.

Consider using sensory stimulation (e.g. music, massage) as a means of engaging people in pleasurable activity, particularly in the later stages of the disease.

Community living skills and outdoor mobility

Assess the person's road safety skills and develop management strategies.

Encourage use of pedestrian crossings wherever possible, as difficulty judging the speed of traffic, processing information and initiating movement can increase risk of injury.

Introduce shop mobility schemes and supervise practice as required.

Provide information about the RADAR toilet scheme (provides access to public facilities around the UK).

Provide written or verbal reminders of items to take when going out, such as wallet / purse, keys, phone, travel pass, where necessary.

Ensure that external grab rails and path rails are in situ as required between the home and public highway.

Suggest that the person optimise their mobility by avoiding shops at busy times.

With the person's consent, consider liaising with staff at the recreational facility (leisure centre, pub, club, café, etc.) to explain the support the person needs or who to contact should help be needed.

Assess the ability to transfer safely in / out of transport. Consider whether the person can maintain a safe posture in the seat and whether the driver is at risk.

Consider accessing community transport schemes.

Wheelchair provision (by referral to wheelchair services) enables people at all stages of the disease to access the outdoors, which is important to maximise quality of life.

Where there are concerns about the person's ability to drive, refer to the DVLA's (Driver and Vehicle Licensing Agency) reporting procedures. Assess the person's function and cognition, as well as their insight into the concerns. Depending on the outcome of this assessment, liaise with the person's GP and / or Huntington's disease Lead Clinician.

Alternative living arrangements

Review risks and burden of care regularly.

Act on concerns about the health and wellbeing of the family (including children). Consent may not always be possible and is not always needed, but try to obtain it. Check with your safeguarding team with reference to the level of risk.

Make a referral to the local authority where safeguarding is an issue for children or at-risk adults who are at risk of neglect or abuse.

Meet with the person (if possible and accepting) and their family to discuss concerns about risk, health and wellbeing and to raise options for external support, respite care, alternative accommodation or placement.

Present information in a sensitive and understandable way, ensuring written information is provided.

Offer emotional and practical support to the person and family members to make decisions concerning changes in living arrangements.

Assess the mental capacity of the person as required. If the person lacks the capacity to make decisions about their accommodation, then work with the team and family members to make a decision which is in the person's best

interests. Follow the process set out in the Mental Capacity Act 2005.

Undertake a reassessment of the person's 24-hour care routine once they are living elsewhere and provide equipment as needed. A change in environment will alter function.

Juvenile Huntington's disease

The Huntington's Disease Association's guide for professionals on Juvenile Huntington's disease (see 'resources') explains the challenges that people with this diagnosis face and the support they may need.

Whilst many of the symptoms leading to a change in function are the same as with adult-onset Huntington's disease, they occur much earlier. Difficulties with movement are usually due to rigidity rather than chorea. They lead to problems with balance and coordination, including a higher risk of falls.

Behaviours that challenge, such as problems with executive dysfunction, attention, sensory changes, perseveration and / or obsession, may mimic other conditions such as ADHD (Attention Deficit Hyperactivity Disorder) or Autism. Perseveration refers to when a person with Huntington's gets 'stuck' on certain ideas and finds it difficult to move on. For example, a person could ask questions on the same subject repeatedly, which can be a source of anxiety for the person and stressful for caregivers.

Communication will become difficult due to dysarthria (difficulties speaking because the muscles used for speech are weak). Epilepsy is also common, with at least 50% of people with Juvenile Huntington's disease developing the condition (Oosterloo et al, 2024).

The school environment, dating and social engagement can be particularly challenging for young people with Juvenile Huntington's disease. When supporting a young person who is attending school, consider at an early stage what support they will need. Considerations should include accessibility, ensuring study equipment is used and transported safely, and support from a personal assistant.

Taking action at an early stage can help ensure there is time to secure funding and identify any changes that are needed. Consider using sensory assessment techniques, as they may help with behaviours that challenge in the learning environment. These techniques should be integrated with work that supports the degenerative cognitive impairment of the illness.

Maintaining engagement in education has been shown to provide cognitive reserve in the brain of adults with Huntington's disease, although there is no current evidence to show this in Juvenile Huntington's disease. However, engaging socially with peers should be encouraged, particularly given the benefits to the young person's wellbeing.

Work closely with the family of the person with Juvenile Huntington's disease, providing there are no safeguarding concerns that means this is not appropriate.

Be aware that one of the parents may be living with Huntington's disease, or may have died due to the condition. Consider how this could affect the person and their family.

Recognise that behavioural changes may also be due to the person's developmental and social environment. For example, their unaffected parent may be struggling to care for their partner who has Huntington's disease.

Acknowledgements

This guideline is based on the European Huntington's Disease Network's (EHDN) Occupational Therapy for People with Huntington's Disease: Best Practice Guidelines. It has been produced by the Huntington's Disease Association and endorsed by the Royal College of Occupational Therapists - the UK's professional body for occupational therapists.

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Clare Cook
Kirsty Page
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Sheila Simpson
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Jiří Hruda
Pavla Šašinková
Paola Zinzi
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Resources

Huntington's Disease Association resources

For professionals

The Huntington's Disease Association offers a range of resources to support professionals working with people affected by Huntington's disease.

You can find our resources at **www.hda.org.uk**

Explore the professionals webpage using the search bar to find specific resources. Search "resources".

Stay informed

Join our professional-only mailing list to receive updates on events, webinars, and new resources tailored to your needs. You can sign up at **https://www.hda.org.uk/professionals-and-training/**

Support for children and young people

Find information on our Huntington's Disease Youth Engagement Service (HDYES) by searching for "HDYES" on the website.

Other useful resources

DVLA (Driver and Vehicle Licensing Agency). Medical conditions, disabilities and driving. Available here.

Equality Act 2010. Duty on employers to make reasonable adjustments for their staff. Available here.

European Huntington's Disease Network. Webpage for the Occupational Therapy Working Group. Available here.

Medicines and Healthcare products Regulatory Agency (MHRA). Bed rails: management and safe use. Available here.

Mental Capacity Act 2005. NHS guide. Available here.

Medicine and Healthcare products Regulatory Agency. Guidance on managing and using bed rails safely. Available here.

Outsiders Trust. A private membership, friendship, peer support and dating club, run by and for socially and physically disabled people. Available here.

RADAR toilet scheme (provides access to public facilities around the UK). Available here.

Relate. Relationship counselling. Available here.

UK Government. Disability rights: employment. Available here.

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Cook, C., Page, K., Wagstaff, A., Simpson, S., Rae, D., European Huntington's Disease Network Standards of Care Occupational Therapists Working Group. 2012. Occupational Therapy for People with Huntington's Disease: Best Practice Guidelines. European Huntington's Disease Network.

NICE guidance is published on **www.nice.org.uk**

Relevant guidance includes:

- NICE. 2025. Clinical Knowledge Summary. Falls – risk assessment.
- NICE. 2023. Clinical guideline. Urinary incontinence in neurological disease: assessment and management.

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Notes

Get in touch

For advice and support or to speak to a Specialist Huntington's disease Adviser

email **info@hda.org.uk**

phone **0151 331 5444**

www.hda.org.uk

@hda_tweeting
@hdauk
@hdauk
@hda_uk
Huntington's Disease Association

Huntington's Disease Association

Liverpool Science Park IC1,
131 Mount Pleasant,
Liverpool, L3 5TF

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