

Addressing cognitive, emotional and behavioral barriers to exercise in Huntington’s disease

The key goal of physiotherapy during the pre-manifest and early stages of Huntington’s disease (HD) is to engage in regular physical activity. The aim is to delay onset or progression of motor symptoms, minimize physical disability, and optimize physical function.

Since cognitive, emotional, and behavioral symptoms are often more advanced than motor symptoms in early-stage HD (often before the onset of any physical symptoms), managing these well can contribute to the success of physiotherapy. Such difficulties can also have significant impacts on family and caregivers, as symptoms such as apathy can be interpreted as deliberate non-compliance or oppositional behavior.

Consequently a good understanding of the cognitive, emotional, and behavioral changes that your patient with HD is experiencing will help you to be a more effective clinician. It will also enable you to support family and caregivers/partners more effectively, which is crucial to supporting the person with HD’s adherence with your recommended activities.

The following table summarizes some of the difficulties that people with HD experience, with suggested strategies to improve physical activity and participation in early-stage HD. Clinicians should be aware of these difficulties while guiding patients to choose physical activities that challenge them both physically and cognitively to maintain the highest level of function.

	Signs/symptoms	Strategies to Improve Activity/Exercise
Cognitive difficulties	Impaired executive function: may present as difficulty with planning, organizing, and sequencing tasks	Assist the person to establish a structured exercise routine, by setting a specific time during the day to exercise or by incorporating exercise into their daily routines (i.e., walking the dog). Suggest that the person uses a daily planner or calendar for planning and organizing activities – this can also be supported with timed reminders on their phone.
	Problems with multi-tasking or focusing on multiple things at once, especially when cognitive load is added to a motor task (for example, if the TV is on while trying to focus on balancing)	Challenge the person’s cognition as early as possible and work on specific domains, such as eye movements (reading a paper), and eye-hand coordination (juggling balls, playing computer games). Have the person practice two activities (e.g., walking and talking) at the same time under various challenging practice and context conditions in the early stages to maintain the highest level of automaticity of gait possible. If needed, provide a quiet environment with few distractions – turn off the TV or radio, and remove visual distractors. Make instructions clear and direct; repeat key points if needed. If you are unsure if the person understands you, ask them to explain the task back to you before starting.
	Impaired working memory and	Encourage repeated and consistent practice of tasks.

	Signs/symptoms	Strategies to Improve Activity/Exercise
	difficulties with learning new information	Provide visual, verbal or physical prompts to support task completion. Break down complex tasks into simpler steps, and have individuals attend to one step at a time (again with prompts for each step if needed).
	Slower cognitive processing	Be patient and allow time for the person to process information (many people with HD will find this frustrating so offering some validation if needed can be helpful). Use short explanations, short sentences, and the simplest words that will effectively convey your point. Make sure that only one person is speaking at once – the person with HD will struggle to follow two or more people speaking at the same time. Try to remove distractions in the environment that may add to the cognitive load.
Behavioral difficulties	Apathy Lack of initiation Low motivation	Most importantly, apathy is not a choice but a symptom – you may be able to help family members and caregivers to understand this too. Assist the person with HD to establish a daily exercise routine. Be mindful of the language you use (e.g., suggest “let’s go for a walk” instead of “do you want to go for a walk?”) Set activity/exercise goals, with rewards for each goal. Choose activities that interest the person with HD, where possible and suggest that they exercise or engage in physical activities with a family member or friend or joins a group. Suggest use of a diary to track exercise/activity participation and progress. When the person does not do what they planned to do, be supportive and help them make a new plan to try again.
	Impulsivity (Effects may interact with lack of insight into symptoms and their impact, known as “anosognosia”)	Consider types of physical activity that can be done safely. Also, consider what supervision is needed. Where appropriate, provide close supervision and/or regular prompting to perform exercise. Talking with individuals about the “pros” and “cons” of their behaviours, and providing constructive alternatives (i.e., do not carry objects while going up and down stairs; leave it for your family member) may be helpful. Regular reminders about any suggested changes in behaviour or risk avoidance may be needed. Recommend that the family keep a diary of what the person with HD says and does, so this can be followed up accurately at their appointment.

	Signs/symptoms	Strategies to Improve Activity/Exercise
	Perseveration, or becoming repetitive and “stuck” on a task, subject, or thought	<p>Try to redirect the person with HD’s attention to other tasks, ideally something they find engaging or distracting.</p> <p>Give individuals with HD specific time limits when prescribing exercise programs, to avoid having them exercising in excess due to perseveration.</p> <p>Setting an alarm when starting exercise can be helpful as a reminder or asking a family member or caregiver/partner to let them know when time is up.</p>
Emotional difficulties	Low mood (“depression”)	<p>Be aware that low mood is common for people with and that this can impact on engagement with physiotherapy and other activities.</p> <p>If the person expresses a low mood, offer to listen, and give emotional support. It might be useful to explore what may help – even planning small things like playing upbeat music before exercise can boost mood and help engagement.</p> <p>If the person expresses very low mood or talks about self-harm or suicide, follow your local risk protocol (this may involve letting their psychologist or psychiatrist know about it)</p>
	Anxious thoughts	<p>People with HD can have anxious or obsessional thoughts, which can be distracting and prevent engagement in activities. These thoughts may be specifically about exercise (e.g., fear of falling) but may be more general.</p> <p>It may be useful to practice short, simple breathing exercises with people who are often affected by anxious thoughts; you can incorporate this into the start of your sessions (or the person can do them before exercise).</p> <p>Again, if the difficulties are significant, it may be helpful to consult their psychologist or psychiatrist.</p>
	Frustration and/or irritability	<p>These difficulties are common among people with HD and can present a barrier to engagement with physiotherapy.</p> <p>When the person is not currently frustrated or irritable, it can be helpful to explore the causes with them (family members and caregivers may also have useful information). This can help to map out triggers in sessions or daily life, and plan to avoid them where possible.</p> <p>Again, if the difficulties are significant, it may be helpful to consult their psychologist or psychiatrist</p>

Education about the physical, cognitive, and emotional benefits of regular physical activity and exercise as summarized below may increase engagement. Benefits to discuss include:

Fitness

Improves motor function, mobility, and independence with daily life activities

Improves balance and reduces risk of falls

Prevents or reduces risks of acquiring other conditions which may affect health and quality of life (e.g., hypertension)

Improves emotional status

Energizes and improves mood (releases endorphins in the body)

Promotes feelings of calm and wellbeing

Has positive effects on depression, anxiety, stress and self-esteem

Other strategies to promote regular physical activity by people with HD include:

- Collaborating with clients to evaluate their individual needs
- Identifying barriers to exercise (e.g., physical, environmental, social)
- Designing exercise programs that are acceptable and feasible to the person

Resources

- Physiotherapy resources in HD including guidelines and physical activity resources (<http://www.ehdn.org/physiotherapy-wg/>)
- ACTIVE-HD YouTube Channel includes some examples of home resistance training exercises: https://www.youtube.com/channel/UCH7_ed2_mkzXNWPZqVlosw
- Podcast on physiotherapy care in HD by Lori Quinn: <https://www.neuropt.org/special-interest-groups/degenerative-diseases/podcasts> (search 4D Episode 10)
- Huntington's Disease Society of Canada – fact sheets <https://www.huntingtonsociety.ca/hd-fact-sheets/>
- Clinical Management of Neuropsychiatric Symptoms in HD <https://pubmed.ncbi.nlm.nih.gov/30040737/>
- Hurry Up and Wait: A Cognitive Care Companion <https://www.amazon.com/Hurry-Up-Wait-James-Pollard/dp/B06XYTYKZ3>
- Engage HD workbook (A coaching manual for physiotherapists working with people with HD): <https://ehdn.org/wp-content/uploads/2020/07/ENGAGE-HD-Physical-Activity-Workbook-v2-UK.pdf>