



Physical Therapy and Huntington's Disease

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Huntington's Disease
Society of America

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Presenter Disclosures

Dr. Anne Kloos

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

**No relationships to disclose
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Overview of Talk

- Role of physical therapy in the care of people with Huntington's disease (HD).
- Benefits of exercise for people with HD.
- Physical therapy treatments to improve balance and mobility and prevent falls throughout all stages of HD.
- How caregivers can help people with HD to safely exercise and do daily activities such as:
 - Stand up and sit down from chairs
 - Walk
 - Stairs
- Overcoming barriers to exercise in people with HD.
- Problem Solving

Introduction

- Huntington's disease causes physical and mental symptoms that lead to:
 - balance and walking problems;
 - difficulties with daily life activities;
 - low physical activity and fitness.
- As these problems worsen over time they:
 - increase fall risk;
 - reduce quality of life.

Imbriglio S, 1992 *Clinical Management*
Kirkwood SC, 2001 *Archives of Neurology*

Goals of Physical Therapy

- Promote quality of life and independence by encouraging activity and maximizing functional mobility (e.g., bed mobility, reaching, sit-to-stand transfers, sitting, standing, walking)
- Promote safety and fall prevention

PT Changes Across Disease Stages

	Presymptomatic/ Early Stage	Middle Stage	Late Stage
Major Problems	Chorea Impaired balance/ flexibility Fine motor problems Unsteady gait	Chorea/dystonia Joint range of motion limitations Weak stabilizers Balance and gait deficits/ Falls	Postural changes Respiratory limitations; risk for pneumonia Mobility problems/ Falls
PT Treatment	Recommend exercise program Balance training/ core strengthening Environmental modifications	Strengthening, stretching, ROM exercise Functional training Fall prevention	Exercises for ROM and postural alignment Chest PT Seating systems
Main PT Goal	Delay onset of mobility problems	Maintain function and delay decline	Limit impact of complications

Benefits of Exercise in HD

- Animal Studies
 - Mice with HD, placed within an environment providing physical, mental and social stimulation, have a delayed onset of symptoms and maintain motor function for longer;
 - Exercise may be **NEUROPROTECTIVE** in people with HD and should be started early!!!



Hockly E et al. *Ann Neurol.* 2002;51:235-242.

Dobrossy & Dunnett. *Neurosci.* 2005;132:543-552.

Benefits of Exercise in HD

- Human Studies
 - Important for general health and potential symptom management including cognition;
 - Many studies show that PT improves strength, balance, walking, and quality of life in people with Parkinson's disease;
 - since 2007, at least 9 small scale feasibility studies have supported exercise in people with HD.

Kwakkel G et al. *Parkinsonism & related disord.* 2007;13:S478-S87.

Busse et al. *J Huntington's Dis.* 2012; 1(2): 175-185.

Exercise Prescription in HD



- Exercise prescription depends on person's fitness and functional level and his/her goals; must be individualized!!
- Careful baseline testing by a physical therapist is recommended prior to starting an exercise program.

Early Exercise Program

- Aerobic exercise (riding a stationary bike, walking on a treadmill or over ground at a brisk pace, marching in place, or swimming)
- Strengthening exercises, especially for postural muscles
- Stretching and range of motion (ROM) exercises for flexibility
- Coordination exercises
- Advanced balance activities

ACSM Exercise Guidelines



- For cardiovascular health, healthy individuals should perform aerobic exercise 3 times a week for 30 minutes at a moderate intensity [$\sim 70\%$ age predicted maximal HR ($220 - \text{age}$)].

Pollock et al. *Med Sci Sports Exerc.* 1998;30(6):975-91.

Walking Program with Pedometers



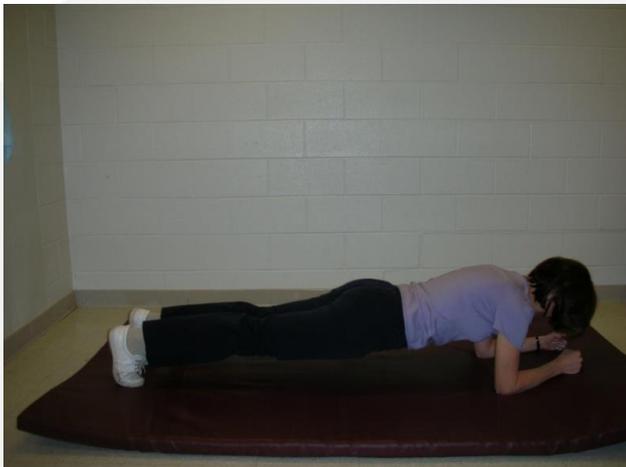
- Under 5000 steps per day used to indicate “sedentary lifestyle”
- 10,000 steps per day indicates the point that would classify someone as “active”

ACSM Exercise Guidelines

- For strength training, generally considered safe to do 10-15 reps at 60% of 1 repetition max for the muscle groups you wish to train.
- Common areas of weakness in HD:
 - Neck extensors
 - Postural muscles of the trunk
 - Muscles of the hands and feet

Pollock et al. *Med Sci Sports Exerc.* 1998;30(6):975-91.

“Core” strengthening exercises



General strengthening exercises



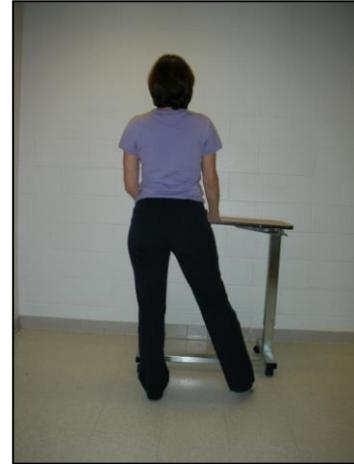
Flexibility Exercises



Coordination Exercises



Advanced Balance Exercises



Exercise Prescription in Middle to Late Stages

- Duration and Frequency
 - Shorter bouts of exercise more frequently throughout the week may be needed to avoid excessive fatigue
- Type of exercise
 - Practice of activities that the person with HD wants to improve (e.g., hand exercises, sit-to-stand exercises or walking exercises) are highly recommended.

Falls



- Falls typically start to occur in the middle stages
- Most occur in home
- Often occur when person is:
 - Multi-tasking
 - Climbing stairs
 - Turning quickly, especially when carrying a load
 - Stepping over an obstacle on floor
 - Wearing unsupportive footwear, such as high heels, sandals, slip-ons or worn footwear

Grimbergen et al. *Mov Disord.* 2008; 23(7):970-976.

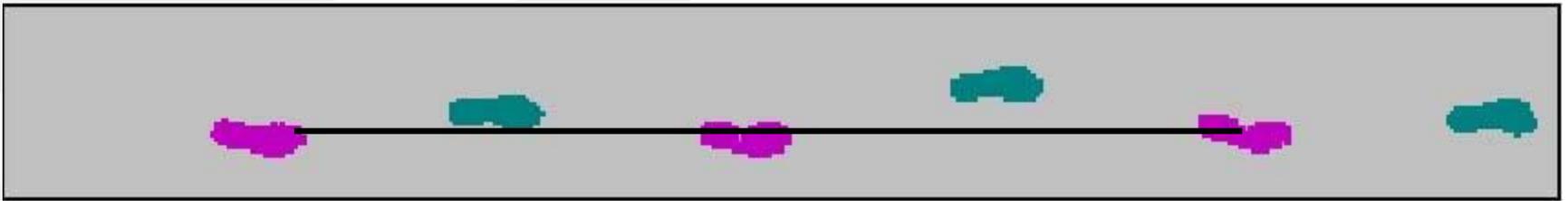
Balance and Walking Problems Increase Fall Risk

- Balance Problems
 - More sway when standing and during daily activities
 - Slowed recovery response to loss of balance
 - Difficulty with tandem (one foot in front of the other) standing and walking
- Walking Problems
 - Slower walking speed,
 - Shorter step lengths
 - Feet placed wider apart
 - Uneven steps
 - Walking path veers

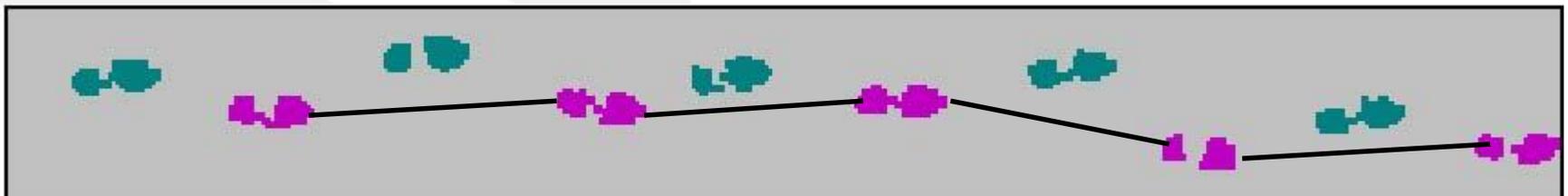


Sample Walking Patterns using Computerized Carpet

Normal Walking Pattern



Typical Huntington's Walking Pattern



Fall Prevention: Balance Training



- Person needs to practice tasks that are challenging, and performed under various practice (eyes open or closed) and environmental conditions (firm surface, foam).
- Practice of stepping in different directions may help person to step in response to loss of balance.
- Balance training may be enhanced through the use of auditory and visual cuing (e.g., dancing to music with or without partner or stepping to a target on floor).
- **Caregiver may need to remind people with HD to stand close to table or counter and/or guard them for safety!!**

Shumway-Cook A, Woollacott M. Motor control: theory and application. 2nd ed.,2001.

Balance Training Using Video Games



- Balance training may be improved through the use of auditory and visual cuing (such as **Wii** video games, **Dance Dance Revolution**).
- Playing the video game Dance Dance Revolution for 45 minutes, 2 times a week for 6 weeks resulted in improvements in dynamic balance aspects of walking in 18 people with HD.

Kloos et al. *Clin Rehabil* 2013. doi: 10.1177/0269215513487235.

Fall Prevention: Walking



- Synchronizing walking to beats of a metronome (but not music) improved gait speed in people with HD.
- Treadmill training increased walking speed and step length in people with Parkinson's Disease; might benefit people with HD.
- **Caregivers can help people with HD to walk safely by reminding them to slow down when approaching obstacles and to think about their walking and not try to talk and walk at the same time.**
- **At later stages, caregivers may give person a hand and/or use a gait belt for safety.**

Thaut MH et al. *Mov Disord.* 1999;14(5):808-19.

Herman T et al. *J Neural Transmission.* 2009; 116(3):307-318.

Ambulatory Assistive Devices



Rollator Walkers

Kloos et al. *PLoS ONE*. 2012; 7(2): e30903. doi:10.1371/journal.pone.0030903.



Merry Walker

Fall Prevention: Getting Up/Down From Chair

- People with HD often lean backwards and/or to the side while rising from chairs and tend to fall backwards into chairs or miss the chair completely because they are not close enough.
- **Caregivers can teach people with HD to safely stand up and sit down by:**
 - **Standing Up:** put hands on knees and bend forward at waist, and “push up” sliding hands up their thighs as they come to standing.
 - **Sitting down: TOUCH-TURN-SIT:** touch chair with some part of body first, then turn, and sit down, placing hands on thighs and sliding their hands to their knees as they go to sitting.

Caregiver Assistance



- Gait belts can help to make transfers easier and safer.
- When lifting use the gait belt and make sure you bend your knees and lift with your legs.
- If it is becoming very difficult a physical therapist can teach you how to assist your family member with transfers.

Transfer Aids



Sliding board



Transfer disc



Hoyer lift

Fall Prevention: Stairs



- People with HD report falls on stairs while ascending and descending. Reasons for falls may be a tendency to trip while going up stairs and to have uneven and unsafe foot placement when going down stairs. Falls often occur when they are carrying something or get distracted.
- **Caregivers can teach people with HD to safely go up and down stairs by reminding them to:**
 - **Stop before using stairs and think about how to use the stairs safely, grab the handrail and then begin to ascend or descend;**
 - **Slow down when descending the stairs;**
 - **Focus their attention on going up and down stairs and avoid doing other things such as carrying the laundry or talking to someone.**

Fall Prevention: Environmental Modifications



- Teach safety awareness and make changes to the environment to prevent falls (reduce clutter, slippery surfaces, loose rugs, poor lighting, sharp or breakable objects)
- Install rails on stairs, grab bars in bathrooms, and use shower seat.

Fall Prevention: Proper Foot Ware



- Velcro or elastic shoelaces for ease of application
- Wide heel base for greater stability
- 1" heel height for dress shoes
- No thick soles
- No thick toe grips (thick toe grips and soles can catch and lead to falls)
- High tops for ankle support

Protective Techniques



- People with HD who fall or are at high risk of falling, even when sitting or lying down, may need to wear protective gear to help minimize or prevent injuries. These can include:
 - Soft helmets
 - Knee pads
 - Elbow pads
 - Hip protector pads if person falls on buttocks

Fall Prevention: Wheelchairs



- People with HD who cannot walk independently have easier time mobilizing a wheelchair with their feet. Hemi-height or drop seat height allows person to plant feet firmly on ground.

Wheelchair that person propels with feet

Fall Prevention: Seating



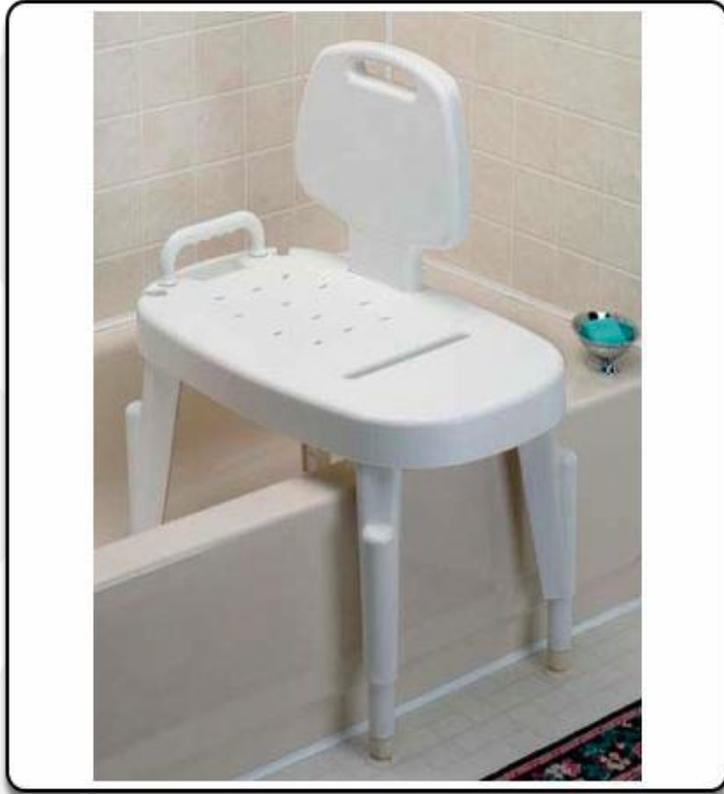
Broda chair

Q-foam chair



- People in late-stage HD may have difficulty sitting in regular wheelchair or gerichair due to sliding out of chair or severe choreic movements; angled and padded chairs such as the Broda chair and the Q-foam chairs reduce need for restraints.

Fall Prevention in Bathroom



Tub Bench



Shower & commode chair

Fall Prevention: Bedroom

- People in middle to late stages of HD may have problems with falling out of bed due to choreic movements, decreased ability to sense the edge of the bed, and problems with force modulation causing them to “vault” out of bed when all they want to do is turn over or sit up.
- Possible solutions:
 - padded bed rails or a lower bed height (3 to 5 inches from floor) if they are able to rise to standing.
 - fully netted bed enclosure which fits over a standard hospital bed
 - Craig bed (foam mattress and four padded walls)

Safety in Bed



Craig Bed



Bed Rail Bumper Pads

Barriers to Exercise in HD

- HD symptoms (depression, apathy, movement problems);
- Lack of interest;
- Fear of falling;
- Low outcomes expectations;
- Transportation problems;
- Other time conflicts and external demands.

Quinn et al . *Dis Rehabil.* 2010;32(1):917-928.

Forkan et al. *PTJ.* 2006; 86(3):401-410.

Motivating People with HD to Exercise

- Most people with HD will participate in activities and exercise if they just get started.
- **Caregivers can help people with HD to exercise regularly by:**
 - **Talking to them about the benefits of activity and exercise;**
 - **Giving them tasks to do that involve physical activity (i.e., walking to the mailbox and back, cleaning, gardening, etc.);**
 - **Inviting them to do physical activities together (e.g., shopping, walking the dog, playing video games);**
 - **Providing positive feedback/rewards whenever they do physical activity or exercises.**

WHAT HAS WORKED FOR YOU???

Problem Solving

- Tom is 40 years old and was diagnosed with Huntington's disease 10 years ago. He lives at home with his wife and teenage children. He used to do construction work but had to quit due to balance problems. Now he spends most of his time during the day watching television, mostly sports. He can walk but occasionally falls. When getting up from chairs he tends to lean backwards during the transfer and has fallen backwards sometimes landing on the chair. When sitting down in chairs Tom stops several feet away from the chair, then falls backwards into the chair with an extended trunk. He has broken two chairs when sitting down in them, both times the chair tipped over backwards.

WHAT WOULD YOU DO TO HELP TOM BE MORE ACTIVE AND SAFE?

Summary

- Animal and human studies support the benefit of exercise and physical activity in individuals with HD.
- Physical therapy management of people with HD will change across the disease stages.
- Physical therapists use many different treatments to improve balance and mobility in people with HD including:
 - Balance training
 - Gait training
 - Auditory, visual, and cognitive cues
 - Functional training (e.g., sit to stand and back, reaching, turning)
 - Assistive and adaptive devices and environmental modifications
- Individuals with HD need education and support to continue exercising on a regular basis.

Resources

- OSU Movement Disorders Division:
<http://neurology.osu.edu/movement/hdsa.html>
- APTA Neurology Section Degenerative Diseases Special Interest Group Patient Education Fact Sheets:
<http://www.neuropt.org/special-interest-groups/degenerative-diseases/patient-education-fact-sheets>.
- EHDN Physiotherapy Working Group guidelines:
<http://www.euro-hd.net/html/network/groups/physio>.
- ACTIVE-HD website: www.activehd.co.uk



Wexner Medical Center

THANK YOU!!

**The Ohio State University HDSA
Center of Excellence**

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Mobility and Exercise for
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QUESTIONS??

