

Caregiver's CORNER

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Caregiver's Corner

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Safety in the Home

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Huntington's Disease: Safety in the Home

- Huntington's Disease Review
- General Fall Prevention
- Bathroom Safety
- Bedroom Safety
- Kitchen Safety
- General Household Safety



Huntington's Disease Review

- Safety is a major concern for many caregivers of people with Huntington's Disease (HD).
- Progression of the disease makes planning and safety measures a moving target. Someone who is just starting to show symptoms may be no more at risk of injury than anyone else.
- Someone in the late stages of HD may be less at risk of injury because of decreased mobility.
- But the in-between stages are where the difficulty lies!

Huntington's Disease Review

The 3 problem areas are:

Movement

Thinking

Behavior

These combine to put someone with HD at a higher risk for injuries at home.

Huntington's Disease Review

Common Movement Problems

- Uncontrolled excessive movement (chorea)
- Difficulty controlling force
 - Includes jumping up from a chair suddenly, sitting down forcefully, dropping things
- Trouble keeping your balance
- Trouble with coordination
- Difficulty getting started
- Chorea often is the first movement problem to be noticed, but doesn't usually cause as many issues as the other movement problems!

Huntington's Disease Review: Thinking Problems

- Problems with “putting all the pieces together”
 - Knowing what to pay attention to, not getting distracted, planning and organizing, problem-solving, making good decisions
 - Not learning from mistakes
- Difficulty adjusting to new things
- Multi-tasking
- Slowed thinking
- Difficulty learning
- Decreased memory
- Perseveration – persistent repetition of a response

Huntington's Disease Review: Behavioral Problems

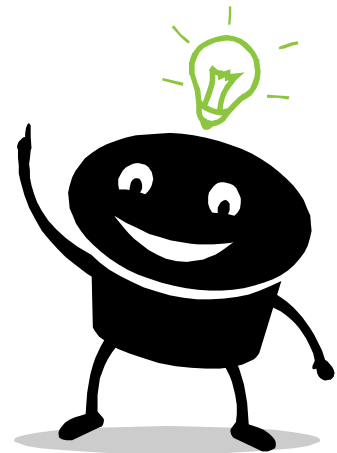
- Irritability
- Impulsiveness
- Repeated behaviors
- Anxiety
- Apathy
- Depression
- Anger
- Dangerous behaviors



Key points . . .

People with HD will have symptoms in all three areas and how much of each varies from person to person.

Thinking and behavioral issues often cause more problems than difficulties with movement.



General Fall Prevention

Why are people with Huntington's Disease at risk for falling?

- Changes in thinking
 - Decreased attention
 - Poor safety awareness
 - Diminished judgment
- Decreased balance responses
- Chorea

General Fall Prevention

How can falls be prevented?

- Determine if there is a pattern in the falls: Where? How? When? Why? Then, make changes to prevent them from happening again.
- Plan ahead. Think about what can be changed in the house, daily activities, and routine to increase safety.
- Establish good habits early to minimize problems later
 - Learning with HD takes time. Repetitive practice helps. If someone forgets to hold the rail on stairs, have them go up again the right way.
- Provide more supervision if the person with HD is unable to make safe decisions.

General Fall Prevention: Changing your Environment and Safety Reminders

- Remove throw rugs
- Keep pathways clear
- Keep all areas well-lit
- Remove objects that are easily knocked over
- Pad the corners of furniture or sharp edges that get bumped into
- Avoid unstable furniture
- Always hold onto a rail when going up and down stairs
- If safety is a problem on the stairs:
 - Block the stairs
 - Make sure all needed items are on the same floor (food, TV, bathroom, etc.)

General Fall Prevention: Changing your Environment and Safety Reminders

- Wear supportive shoes or go barefoot – but avoid socks and flip-flops
- Outside, avoid walking on uneven ground if falling is a problem
- Use an assistive device and/or supervision if recommended
- Consider helmets and/or elbow and knee pads
- Post safety reminders in the house
- Simplify tasks and take rest breaks to manage fatigue
- Place chairs with high backs and arm rests around the house for frequent rest breaks
- Timers and checklists for fostering routine and habits

General Fall Prevention Equipment

Most Common

- Rollator
- Wheelchair
 - Hemi-height
 - Anti-tip bars
 - Hill holders
- Handrails on walls and stairs

Other

- Added weights on walker
- Cane
- Recliner



K. Shelley Knewstep-Watkins

Occupational Therapist



Safety in the Bathroom Toileting

- Padded toilet seat as people with HD often “flop down” on the toilet
- Caregivers should regularly check and tighten hardware on toilet
- Toileting schedule to avoid last minute rushing
- Men can sit to urinate
- Establish habit of reaching back for toilet seat when sitting down on commode to increase stability

Safety in the Bathroom

Toileting

- Utilize equipment to adjust your toilet set-up to meet your needs:
 - Grab bars around standard toilet
 - Raised toilet seat or handicap-height toilet to make it easier getting on and off the toilet
 - Bedside commode to be used over the toilet or at the bedside
 - Urinal



Safety in the Bathroom Bathing

- No-slip adhesives or mat on floor of tub
- Soap on a rope, bath sponge with wrist strap, or bath mitt
- Grab bars
- Have all needed items gathered prior to entering bath and have them easy to reach
- Adjustable height showerhead
- Tub seat/shower chair
- Adjust water temperature at water heater to avoid burns
- Provide supervision as needed

Safety in the Bathroom

At the Sink

- For increased control during hygiene tasks (combing hair, brushing teeth, shaving):
 - Perform task with arm propped against countertop or wall for increased stability
 - Perform task from seated position
- Brushing Teeth
 - Dip toothbrush in mouthwash if spitting out toothpaste is a problem
- Shaving
 - Electric shaver
- Keep products in plastic bottles and containers to avoid broken glass
- Keep commonly used items in one easy-to-reach location

Safety in the Bedroom

- Falls getting out of bed – bed alarm and/or baby monitor to alert the caregiver
- Falls out of bed while sleeping:
 - Place rolled towels or blankets under the fitted sheet to create a bumper
 - Purchase bed bolster(s)
 - Place foam wedges under edge of mattress
 - Nothing sharp near the bed (like corner of bedside table)
 - Place a soft mat (exercise mat) on the floor
 - Don't use blankets on the floor – they can be a tripping hazard when getting in and out of bed
 - Place mattress on the floor

Safety in the Bedroom

- Full side rails are often not helpful, as they provide a hard obstacle to bump into or go over
- Place bed against a wall can prevent falling out on that side
 - May need to pad the wall
- Falls while getting dressed – sit down



Safety during Housework

Laundry

- **DO NOT** carry a laundry basket up and down the stairs
- Instead
 - Use a bag with a shoulder strap to carry laundry
 - Push the bag down the stairs
 - Drag/pull the bag up the stairs while using handrail
 - Have someone else take it up and down
- Fold laundry from seated position
- Store clothing in easy to reach locations to simplify putting away and retrieving your clothes
 - Soft canvas bins &/or drawers for underwear, socks, and casual clothing
- Avoid ironing

Erica Umback
Occupational Therapist



Safety in the Kitchen

- Change to plastic cups and plates
- Consider if it is time to stay away from sharp knives
 - Alternatives
 - Veggie choppers
 - Food processors
 - Kitchen shears
 - Precut food (often offered as an option at restaurants)
- Use insulated cups with lids and handles
- Don't sit on rolling chairs and be careful with high stools
- Keep frequently used items at easy-access level

Safety in the Kitchen

- Consider the following if pans or arms are burned on the stove or oven
 - Use timers
 - Use long oven mitts
 - Use the microwave or toaster oven
 - Don't leave the kitchen while cooking
 - Unplug stove
 - Remove knobs/dials/controls on stove
 - Sensors that alarm and/or turn stove off if stove is left unattended (see web resource list for more information)

Oatmeal – Example for recipe checklist

- ½ cup oats
 - 1 cup water
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1. Put water in microwave-safe bowl.
2. Put bowl in microwave.
3. Set the microwave for 2 ½ minutes on high.
4. Start microwave.
5. Remove bowl from microwave – use oven mitts!
6. Add ½ cup oats to hot water.
7. Stir water and oats.
8. Add a spoonful of raisins or brown sugar, if you like.
9. Time to eat!

Safety in the Kitchen

- Use photocopied recipes – use as a checklist to help focus on doing one thing at a time
- Keep poisonous substances (e.g. cleaning supplies) locked up/labeled
- Keep fire extinguisher nearby
- Have smoke detectors in place - change batteries regularly
- Place emergency phone numbers near all phones

Other Safety Issues: Childcare

- An adult who requires supervision due to HD symptoms is NOT an appropriate unsupervised caregiver for children.
- Don't carry baby while walking or going up/down stairs
 - Use a stroller
- Instead of a changing table, put the changing pad on the floor or a bed
- Use a bottle warmer to avoid overheating
- Many of the things that can be done to make homes safer for children also apply to people with HD.

Other Safety Issues: Driving

- <http://www.aota.org/Older-Driver/Consumer/Evaluate/Eval-by-OT.aspx>
 - Separate from DMV
 - Purpose: evaluate thinking, visual, and physical abilities required for safe driving
 - Performed by Occupational Therapists with specialized training in driving rehabilitation
- To find a local Driving Rehabilitation Specialist:
http://myaota.aota.org/driver_search/index.aspx/index.aspx
- <http://www.driver-ed.org/custom/directory/?pageid=209&showTitle=1>

Other Safety Issues: Driving

- Regularly have a family member ride along to assess safety when the person with HD is driving
- Avoid distractions (e.g. radio, changing CDs, adjusting controls, talking on cell phone, applying make-up)
- Park in the emptiest part of parking lots
- Leave a buffer zone (extra space) around the car
- Use GPS (if it isn't distracting)
- Stick to familiar routes, less busy times of day



Other Safety Issues: Medications

- Use a pill box to organize medications
 - Decreases missed doses
 - Prevents overdoses
- Use an alarm reminder if missing medications is a problem
- Write the date that the pills should be finished on the bottle
- Write on calendar when next month's supply should be ordered
- Have family set out only one day's worth of medications at a time
- Keep medications locked up

Other Safety Issues: Guns and Smoking

- Guns – lock up in gun safe or remove from house
- Hunting – avoid tree stands
- Cigarettes
 - Stop smoking!
 - Only smoke outside
 - Sit down to smoke
 - Use smoker's robot
 - Use smoker's apron (flame retardant)
 - Keep fire extinguisher nearby



Other Safety Issues: Supervision

- Use home/video camera/webcams with home security systems or with simple smart phone apps
- Baby monitors
- Chair alarms
- Neighbors, family, or friends checking in throughout the day
- Frequent phone calls (to or from the person with HD)
- Community programs
- Lifeline
- Cell-phone GPS tracking

When is it time to get extra help?

- Falls
- Injuries
- Burns
- Accidents
- “Close calls”
- Feeling overwhelmed



What kind of extra help is available?

- Home Health OT and PT
 - Have local therapists communicate with HD Clinic therapists
- Aides or sitters in the home
- Adult day care



Web resources*

- North Coast Medical (adaptive equipment)
www.ncmedical.com; (800) 821-9319
- Sammons Preston (adaptive equipment, chair alarms)
www.pattersonmedical.com (800) 323-5547
- Gold Violin (adaptive equipment)
www.goldviolin.com (877) 648-8400
- Rubbermaid (adaptive equipment, bath seats)
www.rubbermaid.com

*This list is only intended to serve as a starting list – there is no intention to promote or recommend these companies over other vendors. HD websites provide more complete listings.)

Web resources, continued*

- HomeSenser (a small, electrical device attached to a stove to disconnect the stove if it is left unattended too long while cooking)

www.homesensers.com

- Hill Rom (beds, chairs)

www.hillrom.com (800) 445-3730

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Questions & Discussion