



Dehydration in People with Huntington's Disease

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People with HD are at risk for dehydration, especially in warmer climates like the Central Valley and during the summer months. During these times we throw off excess body heat by sweating. As our body temperature rises, blood vessels dilate and fluid is lost through the skin as sweat. Ambient air and breezes evaporate this moisture, cooling our core body temperature to keep it in an acceptable range. Therefore, the hotter it is, the more we sweat and the more fluid we lose. Failure to replace these fluids can result in dehydration.

Why are people with HD more prone to dehydration?

- *Cognitive impairment* can alter a person's perception of thirst. People with HD who have difficulty with thinking and organizing their thoughts and actions and may be unaware they are thirsty and/or not know/remember to drink extra fluids on hot days.
- *Motor abnormalities and chorea* may prevent some people from getting access to sources of fluid. They cannot drink it if they are unable to get to it! Chorea can also interfere with a person's ability to get a drinking container to their mouth. This can lead to frustration, which may cause the person to avoid drinking fluids.
- *Dysphagia (difficulty swallowing)* can also be a risk for dehydration. Dysphagia is common in the mid to late stages of HD. Thin liquids such as water, juices, soda, coffee, tea, etc in the most difficult fluids for an HD person to manage in their mouth. Many people with dysphagia need to have all their liquids thickened. Complex fluid preparation and fatigue can make it difficult to maintain an adequate fluid intake, especially if additional fluids are required.

How to tell if someone is dehydrated:

- Increased Heart Rate
- Dry Mouth
- Concentrated Urine (strong yellow color)
- Voiding less frequently during the day than normal
- Poor tear production

As dehydration worsens, symptom can become more severe, causing:

- Decreased skin turgor
- Minimal to no urine production
- Sunken eyeballs
- Decreased blood pressure
- Delayed capillary refill
- Change in mental status (confusion, delirious)

How to prevent dehydration:

Remember that a person with HD may not ask for fluids or tell you they are thirsty, therefore caregivers, family and friends need to anticipate this need and plan accordingly.

- Always have fluids available when not at home. (i.e. water bottles, sports bottles, etc)
- Drinking water is the best source of fluid for hydration. Drinks with caffeine can actually make dehydration worse. Sports drinks that have replacement electrolytes are generally not necessary, but can be used if there is a personal preference.
- When at home, always have fluid within reach of the person with HD. Remind them frequently to drink their fluids. Eight ounces every few hours during the hours they are awake should be adequate. Increase this amount for people who already sweat a lot and when the temperature rises.
- During extreme weather days, stay indoors, preferably in air conditioning. If outside activities are essential, try going outdoors in the early morning hours as it is generally the coolest part of the day.

- If you are unsure if the person with HD is getting enough fluid, start keeping a log of fluid intake. Include every time they drink and how much is consumed; total the amount at the end of the day. They should be getting 80-100 ounces in a day, increased to 150-160 ounces in extreme weather.

When to seek medical attention for dehydration:

- A change in mental status (confused or delirious)
- Unable to drink or take things by mouth
- Change in vital signs (increased heart rate, decreased blood pressure, increased temperature)

Special advice for persons with HD in Nursing Facilities:

Not all nursing facilities are skilled in the care of HD patients. It may be necessary to alert them to the risk of dehydration in people with HD. All residents in a nursing facility have an individualized plan of care. Work with the staff to incorporate the above recommendations into the plan of care and check in with them frequently to assure the plan is being followed