HUNTINGTON'S DISEASE YOUTH ORGANIZATION

Top Tips for Helping a Person with HD

November 24, 2021

HDYO has more information about HD available for young people, parents and professionals on our site:

www.hdyo.org

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This section is here to help young adults look after their family member who has HD by offering some tips on caring. These tips are split into different topics and stages of HD (early, mid and late stage). We hope you find this section helpful.

Early Stage

Eating and Meals

A family member with new symptoms of HD may have some difficulties while making and eating meals. Mealtime difficulties are often due to new issues with either motor control and/or cognition.

- HD can cause difficulties such as spilling food and dropping items during meals. There are aids ("adaptive equipment") such as utensils with built-up and/or weighted handles as well as plate guards to minimize spills that may help now, or in the future. It is also helpful to use plastic cups and plates to reduce the risk of lacerations from broken glass.
- Persons with HD need more calories and often have big appetites. Offer to prepare high-calorie snacks and meals as needed.
- To minimize issues with spills, encourage the family member to eat meals at a table and try to reduce distractions during meals.
- Fatigue and high energy expenditure can make food preparation tiring. Offer to help your family member prepare meals and snacks. Also, pre-preparing snacks or meals

can be helpful. For example, make a complete lunch and place it in the refrigerator.
- Help your family member create a list of simple meals. Repeating favorite meals can be helpful in reducing stress.
- If your family member with HD has been cooking, double-check that the oven and stove were turned off.

Getting Dressed

A person with HD can have trouble with fasteners, such as shoelaces, buttons, and zippers. Fasteners can take more time, attention, and effort to do because they may begin to have difficulty with making small, controlled hand movements. At other times, some people with HD may become more likely to forget to line-up the fasteners or forget to do the fasteners.

- When shopping for new clothes, consider helping your family member pick out clothing that is easy for him to manage. Often people with HD like pants with elastic waists and shoes that are slip-on or Velcro.
- Encourage a family member with HD to get in the habit of sitting down while getting dressed. This makes it easier to focus on managing the fasteners and less likely to fall.
- A common trend for people with HD can be a tendency to complain about being too hot. Remember that your family member may not be comfortable wearing as many layers of clothing as you prefer to wear.

Using the bathroom

- If your family member is often rushing to the bathroom or has fallen in the bathroom, this is helpful information to share with the medical team. The medical team can help your family member address these concerns.

Driving

For some people with HD, they can continue to be a safe driver for years. However, other people with HD are limited by changes and challenges in motor control, cognition, and visual perception. All of these can limit driving safety.

- Help your family member to concentrate by avoiding loud music, lengthy conversations, or any other distractions
- Encourage them to avoid areas with high traffic and high-speed zones
- Help your family member plan their trip before driving
- If you have concerns about your family member's driving, it is important that this concern be addressed tactfully. Share your concern with the primary caregiver for your family member. For more detailed information and guidance, share the concerns with your family member's medical provider. The medical provider can help you and your family in locating supportive resources. In fact, there are professionals who are trained to help people in deciding when and how to retire from driving. ADED is a website with more information.

Mobility

- During this stage, people with HD can still walk own their own but may be starting to with trip or fall more often. Sometimes, these falls are due to changes in balance and a new difficulty staying focused. Encourage your family member to use caution and avoid distractions, especially when walking on uneven or slippery surfaces.
- In some cases, either person-to-person or depending on the surface, it may be helpful to use trekking poles with rubber tips. It is encouraged that a physical therapist teach your family member how to adjust the trekking poles and learn how to use them.
- As a family, explore enjoyable, active family activities to encourage your family member with HD to maximize his strength and coordination. Make favorite family activities easier so everyone can participate and enjoy them. For example, family biking could now include the family member with HD using a recumbent-style bike.

Home safety

- A safe environment is necessary: keep areas clear and free, remove throw rugs, pad furniture/doorways, stabilize furniture, lower the maximum water temperature, and provide non-skid mats in the bathroom.
- A home safety evaluation may be helpful.

Thinking/Cognitive

- Your family member may experience memory loss, difficulty with concentration and learning new things. They may repeat the same thought over and over again, and may have emotional outbursts
- Be prepared for these difficulties and make things easier for them by providing visual and verbal cues, labels, using short sentences and breaking tasks down.
- These strategies may not be as necessary now as they will be in the future, but getting the family into good routines now will establish a helpful foundation for later.

Middle Stage

Eating and Meals

- Follow instructions from your family member's Speech-Language Pathologist and physician regarding feeding. If you are preparing food, be sure that is the prescribed consistency and that liquids are thickened as needed.
- Let your family member assist as much as they are able- let them pick up small pieces of food and take drinks as independently as possible.
- Helpful adaptive equipment may include plate guards, suction cup bowls, a lidded cup, and/or a non-slip placemat.

Driving/Transportation

- The decision to stop driving is a very difficult one. Offer rides as needed and emotional support for this change.
- If you and/or your family suspect that your family member with HD should retire from driving but will not agree, inform the medical team.

Mobility

- Balance and mobility issues vary widely from person to person. But, your family member will require more support and assistance over time for mobility.
- Become familiar with safe ways of helping your family member with HD in different situations. Learn proper verbal and tactile cues to help them safely transfer, as appropriate.

Home Safety

- Home safety and modifications are expansive and adaptations in the kitchen, bathroom and living spaces should be considered.
- Examples include placing grab bars in the bathroom, removing knobs from the stove, lowering the water heater, locking medicines and cleaners away, and more.

- It is recommended that your family member with HD and your family consult an occupational therapist for specific home safety recommendations.

Thinking/Cognitive

- Break tasks into steps, and allow for extra time
- Help your family member stick to their daily routine.
- Make sure your family member has rest periods in their routine to combat fatigue.
- As needed, label things around the house, provide visual and verbal cueing.
- Break tasks down into simpler parts.

Late Stage

Eating

- Follow the recommendations of the Speech Language Pathologist for the appropriate consistency of food and drinks. This may include chopping or pureeing food and thickening liquids, if recommended.
- Be aware of signs of difficulty swallowing (coughing, gagging, and drooling).
- Keep in mind the high energy expenditure involved if there is significant chorea. Choose high calorie and double portioned snacks.
- If swallowing becomes too dangerous and difficult, a feeding tube may be an option that your family considers with the medical team.

Staying at home

- During the late stage, the caregiver burden and responsibility can become significant.
- If health complications and needs call for it, making the transition from the home to a facility may be necessary, and something your family considers.

Mobility

- Follow instructions from caregivers, physical therapy, and occupational therapy on how to safely complete transfers and operate a lift, if applicable.
- It is important for everyone to be safe while helping a person with HD move.

Home Safety

- Emphasize a calm, clean environment without clutter.
- Continue to remove tripping hazards, pad doorways and furniture, follow recommendations from caregivers and occupational therapist.
- Follow recommendations from occupational therapist, as given.

Thinking/Cognitive

- In the late stage of HD, there is a severe cognitive debilitation.
- Try to be patient with your family member and interact with them positively
- Though their thinking and mind is fuzzy, they will probably still recognize you and understand your speaking.