



A Guide to Everyday Living with HD

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Managing the symptoms and changes that occur with HD can be challenging and disrupt many aspects of daily life. Fortunately there are strategies that may be effective to make life easier and/or safer for HD persons and their families.

Communication

Communication enables us to share our hopes and dreams and to express our needs and desires; however this may be difficult for HD persons due to cognitive changes, slowness and changes in breath control, therefore it may be helpful to:

- Make eye contact before starting a conversation to ensure they are paying attention
- Speak facing the person so they can see your lips, expressions and hear you more directly
 - Be alert to 'non-verbal' cues and messages that the HD person is not understanding or able to process the information
 - Looks of confusion, anxiety, worry, frustration or blank gaze
 - Offer positive suggestions to make communication easier
 - Create distraction free environment if needed
 - Have more in depth conversations at the time of day that person is most alert and awake.
 - Utilize computer/tablet applications to allow person to point and better communicate needs and feelings
 - Allow time for the expression of ideas, thoughts and feelings
 - Be patient

When Communication Becomes More Challenging

- Establish a signal for 'yes' and 'no'
- Ask questions that allow for yes/no answers or short 1-2word responses
- Get modified telephones
- Buzzers/bells/or intercoms if useful
- Communication boards

- Computer/tablet communication applications

Problem Solving

- Keep a log describing the problem or situation
- Bring it to your HD medical appointments to discuss with healthcare team
- Pinpoint specific causes, trends or triggers
- Develop a list of alternative strategies for responding to the behavior or situation
- Prioritize strategies you have identified and decide which you are going to try first
- Be flexible
- Reassure the person after the upsetting episode
- Be patient, problems don't always get resolved immediately

Safety Assessment of the Home

Assessment is the first step. Look at the home through the eyes and ears of a person with HD. Take into consideration their physical challenges as well mental challenges. Things to consider:

- Can they negotiate the stairs?
- Bathroom accessible and modified for safety?
- Telephone nearby and can they use it?
- Easy access to food?
- Can they get food/drink safely for themselves?

Strategies for Safety in the Home

Safety in the Kitchen

- Avoid lifting heavy pots of water/hot fluids
- Electric stove – replace with gas if possible
- Microwave will be safest way for HD persons to heat food/drink
- Extra long mitts that fit over hands (avoid use of flat ones that don't cover the hand)
- Non-slip materials under bowls and plates
- Avoid stacking items in cupboards that HD persons use frequently
- Use plastic or paper plates

Personal Care

- Add chairs to bathroom and bedroom if balance is compromised
- Use cordless razors
- No electric appliances around sink or tub (easy to drop!)

- Add chair to tub/shower to make it easier to shampoo hair (and not slip!)
- Secure a nail clipper to a block of wood to stabilize clipper to make it easier to trim nails
- Use electric toothbrush
- Use a fluoride mouthwash in a bottle where you can use a straw
- Rinse – don't "gargle" it.

Bowel and Bladder Control

- Visit toilet every two hours
- Empty as completely as possible
- Make sure toilet is accessible and bathroom safe
 - Remove any obstacles in getting to toilet: bath rugs, baskets, floor toilet paper holders, etc.
- Use grab bars or an over the toilet commode if needed
- Use signals for bathroom needs if communication is difficult
- Light in bathroom as well as the path to the bathroom
 - Motion and/or darkness sensor night lights are helpful

Rest and Sleep

- Place bed against wall and anchor for stability
- Consider floor bed if chorea is extreme and falls out of bed are frequent
- Covers and blankets should be adequate for warmth but not too heavy so movement is easier
- Practice good sleep hygiene
 - Avoid caffeine in the afternoon
 - Establish consistent sleep routine at night
 - Go to bed around same time each night
 - Wake up around same time each morning
 - Limit use of t.v./electronics in bedroom

Food

- People develop food habits and preferences over their life
- Try to stick to the same eating habits as much as possible
- If they are maintaining their weight, it's working!

- May need to increase calories, modify textures and consider supplements
- Likely to experience difficulty with swallowing

Meal Time Tips

- Minimize disruption
- Non-slip mat for plate/cup/bowl
- Foam rollers around utensils to aid with gripping
- Weighted utensils
- Dishes with a raised bumper
- Straws

Nutrition Tips

- Instead of three meals a day, consider five or six smaller ones
- Make food available
- Many people with HD will eat if the food is there, but won't 'prepare it' or get it for themselves.
- Drink milkshakes/smoothies/ice cream
- Add high calorie foods
- Supplements can taste bad – mix them in with other things

Smoking

- If you can quit smoking, that is best
- Use large ash trays that are solid and sturdy that won't tip over
- Purchase non-flammable clothing and bedcovers and floor coverings
- Install extra fire and smoke alarms
- If chorea is extreme, consider a "smoking robot", "smoking buddy" or other accommodation to increase safety

Activity, Relaxation, and Well-Being

- Develop a realistic plan for activity and recreation for your abilities
 - Reassess as changes occur in family
- Get a calendar and write in the events of each day
- Choose activities that are meaningful and enjoyable for the family
- Make exercise a daily routine

- Spend time out of the house when possible

Resources

It is important to identify people, written or internet resources that can assist you with problem solving as issues arise. This may include:

- Your HD Medical Care Team and/or Social Worker
- HD Support Groups
 - Other HD persons and families will often share strategies and resource that worked or didn't work for them.
- HDSA Center of Excellence @ UC Davis Medical Center website:
<https://www.ucdmc.ucdavis.edu/huntingtons/>
- HDSA website: www.hdsa.org