Toward a Fuller Life: A Guide to Everyday Living with HD

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Safety Starts at 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

- 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 fluids for themselves?
Safety in the Kitchen

- Avoid lifting heavy pots of water/hot fluids
- Electric stove – replace with gas if possible
- Microwave
- Extra long mitts that fit over hands, not flat ones
- Non-slip materials under bowls and plates
- Avoid stacking items
Smoking

- If you can quit smoking, that is best
- Use large ash trays that are solid and sturdy and 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”
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!)
Personal Care

- 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
  - Use grab bars or an over the toilet commode if needed
- Use signals for elimination needs if they can’t speak
- Light in bathroom as well as the path to the bathroom
Rest and Sleep

- Place bed against wall and anchor for stability
- Consider floor bed if chorea extreme and falls are frequent
- Covers and blankets should be adequate for warmth but not too heavy so movement is easier
- Practice good sleep hygiene
Activity, Relaxation, and Well-Being

- Develop a realistic plan for activity and recreation
  - 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
- Get out of the house when feasible and possible
Communication

- Communication enables us to share our hopes and dreams and to express our needs and desires.

- People with HD may have trouble with expressing:
  - thoughts,
  - making sounds, and
  - have difficulty with breath control
Communication (cont.)

- Speak directly to the person so they can see your face and hear you more directly
- Be alert to non-verbal cues and messages
- Offer positive suggestions to make communication easier
- 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
- Get modified telephones
- Buzzers/bells/or intercoms if useful
- Communication boards
Food

- People develop food habits and preferences over their lifetimes
  - 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
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
“Alone we can do so little; together we can do so much”

~ Helen Keller