

Living with HD

Terry Tempkin, Nurse Practitioner

Lisa Mooney, LCSW

Living with HD both as a person with HD symptoms and caring for HD loved ones at can have some challenges, however there are some strategies to increase safety and independence. As the disease progresses, you will need to adjust the living environment to meet the needs of the HD person as well as minimize the difficulty on other family in the home. Any change or increase in needs within the home can feel very stressful and overwhelming and can trigger changes in the HD person and care partner such as sadness/depression, anxiety, irritability, stress, decline in health, and changes in physical abilities, etc. HOWEVER, sometimes small changes or adjustments can help make things easier and/or safer which we will share some possible ways here.



SAFETY ASSESSMENT OF THE HOME

Consider ways to make home safer and more user friendly for HD persons to remain independent for as long as possible. Things to consider:

MOBILITY & BEDROOM

- Safe to go up/downstairs
- Do they have to use stairs in daily routine?
- Are there tripping hazards (rugs, coffee/end tables, small steps into other areas of home)
- Access to lighting, turn on/off when needed
- Is the home wheelchair/walker friendly?

BATHROOM

- Accessible with walker/wheelchair
- Handrails/grab bars
- Accessible so they can reach sink, brush teeth, comb hair

COMMUNICATION

- Telephone accessible
- Able to use telephone (dial)
- Can voice assistance devices be helpful

KITCHEN & MEALS

- Can they get food/drink safely for themselves?
- Ability to safely cook
- Breakable or non-breakable dishes

EQUIPMENT & TECHNOLOGY

- Wheelchairs, Walkers, Hospital Bed, Hoyer Lift
- Smart Home Technology to monitor when care providers not around

QUALITY OF LIFE

- Access to tv, music, computer, video games
- Comfortable/safe chairs for sitting, eating
- Safe accessibility to outdoor space



MOBILITY & BEDROOM: below are some tips and tricks that may help minimize falls, make your home more accessible as disease progresses and assist with monitoring safety of the HD person when home alone.



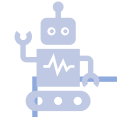
Mobility/Bedroom Safety

- Fall Hazards:
 - remove throw rugs
 - remove furniture, not secured against wall.
 - stairs -- use handrails and avoid if unsafe.
 - place bed against wall and anchor for stability
 - increase lighting on stairs, hallways, rooms.
- Sleep Hygiene for quality sleep
 - avoid afternoon caffeine
 - go to bed and wake around same time each day
 - LIMIT t.v/electronics in bedroom



Home Modifications

- Widen doorways for wheelchair/walker
- Install ramps
- consider FLOOR bed if frequent falls out of bed occur.



Technology & Equipment

- Hospital Bed
- Hoyer Lift
- Motion Detection Video/Alerts
- GPS Tracking
- smart door locks
- Motion sensor lights, night lights



KITCHEN & MEALS: below are suggestions can help minimize choking/coughing, minimize injury and create a simplified and safer kitchen/mealtime environment.



Kitchen/Meal Safety

- Minimize injury/accidents*
- Non breakable dishes
 - avoid lifting pots with hot items
 - electric stove instead of gas
 - Microwave cooking instead of stove/oven
- Minimize choking/coughing*
- cups with lids & straws
 - minimize distractions when eating
 - consistent textures



Kitchen Modifications

- Organize so that daily items are more easily accessible.
- wider pathways for wheelchair/walker
- lower counters for easier access in wheelchair



Technology & Equipment

- Dishes with raised edges, compartments
- non slip materials under bowls/plates to avoid slipping
- Weighted utensils
- Pro-Vale drinking cups -- slows down the flow into the mouth
- Lift Ware utensils
- Meal delivery
- Meal delivery kits



BATHROOM: below are some suggestions to minimize injury/falls, increase independence of personal needs and/or create a more accessible bathroom as care needs increase.



Bathroom Safety

Minimize injury/accidents

- cordless razors
- no electric appliances around sink or tub -- too easy to drop
- secure nail clipper to block of wood to stabilize & easier trim nails
- electric toothbrush

remove obstacles in bathroom

- throw rugs, baskets, extra furniture.
- toilet paper holders

Bowel/Bladder Control

- toilet every 2 hours



Bathroom Modifications

- expand to allow for wheelchair/walker
- walk in tub/shower for wheelchair/walker access
- enough space for 1-2 additional people when assistance is needed
- remove sliding shower doors, high sided tubs



Technology & Equipment

- shower/tub chair for bathing
- grab bars -- shower area and toilet
- hand held nozzle
- good lighting in daytime and nighttime
- motion detection lights or night lights are helpful



COMMUNICATION: Due to cognitive changes with HD it can be a challenge for HD persons to communicate in some ways, these suggestions may help minimize miscommunication/frustrations, increase independence and/or create a simplified routine.



Communication Strategies

- make eye contact to get their attention before talking
- speak facing the person so they can see your face and expressions --this helps with processing the words
- be aware of NON verbal cues (looks of confusion, anxiety, frustration, blank gaze,etc)
- distraction free environment (no t.v., music, other people talking)
- allow time for HD persons to respond, they will need longer.
- Establish signals for yes/no
- Yes/No questions or questions with 1-2 word responses



Technology & Equipment

- communication boards
 - computer or phone applications to point to needs, feelings to express self w/out speaking
 - modified telephone, larger numbers/keyboard, etc.
- Voice assistance technology*
- Voice assistive devices or video chat has proven to be beneficial in addressing social isolation, loneliness, and desire to maintain relationships.
 - make it easier to manage t.v., electronics, music, phone, lights, door locks, appliances and thermostat.
 - Can provide reminders for medication, exercise, appointments, etc.



QUALITY OF LIFE: this is for the person with HD and anyone else living in the home. These suggestions

are compiled to assist in creating a routine that is consistent and simplified to minimize stress, frustration, anxiety, etc. and hopefully increase quality of life and quality time together. HD is not easy and it's not realistic to avoid all challenges and difficulties, but sometimes it is small things that can make a big difference.



Simplify and Create Routine

- Set up household calendar with activities, appointments, chore assignments all planned out!
- choose meaningful and enjoyable activities -- if it causes too much stress find another activity or ask for help
- Exercise for routine, physical and mental health
- Have activities to look forward too.
- Take family/friends/neighbors up on offers to help (mow lawn, fix-it needs, transportation, respite, etc)
- Use shared applications/calendars to ask for help or let others sign up to give breaks, plan activities, etc.



Technology & Resources

Smart Home Technology

- what if technology turned the t.v. on/off, and lights turned themselves on -- would that make life easier?
- Cleaning Service -- one less thing to worry about.
- Grocery/Household Items delivery -- another thing to not have "to-do"

Where to find more information about Living with HD



Talk with your **HD care team or HDSA Social Worker** about your specific needs and recommendations.



Internet Search: *Smart Home Caregiving Technology, Home Modifications* other ideas to utilize technology in your home for safety.

HDSA: www.hdsa.org

- HD Presentation @ 2018 National Convention discussing Smart Home Technology had some really good ideas from an HD Care Partner.

HDSA Publications:

- *Physical and Occupational Therapy – Family Guide Series*
- *Caregiver Guide for Mid to Late Stage Huntington’s Disease – recommend pages 34-69.*

AARP <https://www.aarp.org/caregiving/>

- *How to Make your Home Safer:* practical tips for home safety and utilizing smart technology.
- *Home safety checklist:* helpful in assessing home safety.



HD Support Groups (Video or In-Person) others in similar situations share techniques, equipment and/or ideas that worked well for their family.