HD Toolbox

This toolbox was developed by Kae Bendixen MD for use by HDSA and the Huntington's Disease (HD) Community. Dr. Bendixen has developed a framework for understanding how HD affects communication and cognition from the inside and created tools to help people with HD and their families navigate medical appointments and understand and advocate for their own evolving needs. Please use these tools in preparing for and during medical appointments and in any other way that is helpful to you.

HD TOOLBOX

- List of Care Team Members
- HD Symptom List from HDSA Guides
- Cognitive Overload Scale
- HELP Communication Tool
- Medical History/HD History/Patient HD symptoms/End of Life wishes
- Resources: HDSA Guides: information and links, HDSA Social Workers, UC Davis HD Clinic Resource Guide for HD Families, UC Davis Cognitive Changes in HD handout
- Strategies for Managing Cognitive Changes -- page 4 from UC Davis Cognitive Changes in HD handout (copy and give to every provider you see)

Your Care Team (list name and location)

HD Care:

Neurologist
Clinic Coordinator
Genetics counselor
Geneticist
Psychiatrist
Neuropsychologist
Social Worker
OT (Occupational Therapy)
ST (Speech Therapy)
PT (Physical Therapy)

Other Medical Team:

Primary Care Provider
Psychologist or Therapist
Palliative Care
Other Medical Specialists

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HD Symptoms listed in HDSA Guides
Use this list of symptoms as a reference in talking with medical providers.

Motor Symptoms: chorea, dystonia, bradykinesia, tics, myoclonus, tremor, rigidity, impaired voluntary motor control, gait impairments and falls, speech impairment, swallowing dysfunction and choking, incontinence, seizures, weight loss

Cognitive Symptoms: explicit and implicit memory impairments, emotional recognition, perception of time, spatial perception, smell identification, unawareness (of one's own actions and feelings), speed of cognitive processing, attention, planning and organization, lack of initiation, perseveration, impulsivity/disinhibition, irritability and temper outbursts, impaired initiation of speech, disorganization of language content, articulation of speech

Psychiatric Symptoms: depression, suicide, mania, obsessions and compulsions, delusions and hallucinations, dysexecutive syndrome, apathy, irritability, delirium, anxiety, panic disorders, sexual problems, sleep problems, demoralization

--From *A Physician's Guide to the Management of Huntington's Disease*, 3rd edition, 2011 and *Understanding Behavior in Huntington's Disease: A Guide for Professionals*, 2nd edition, 2014

Cognitive Overload Scale
Intensity levels 1-4
1 = Mild. Try to avoid if possible but is generally tolerable.

2 = Medium. Intense enough to try to prevent or avoid in future, but doesn't interfere with immediate functioning.

3 = Severe. Like "mental puking". Can't continue current task or level of functioning.

4 = Overwhelming. Like "dry heaves" of the brain. Have to sit down, can't function or communicate.

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HELP Communication Tool

Communication tool to use for all medical visits

Huntington's
Experience
Loved Ones
Partnership

H = Huntington's Briefly describe how you are currently affected by HD

How severe is your disease (mild, moderate, severe)?
How is HD affecting your physical body (involuntary movements, balance, coordination)?
How is HD affecting your thinking, memory and communication?
How is HD affecting your mood (including anxiety, depression and obsessive behavior)?

E = Experience Experiences and perspectives of person with HD

What changes are YOU noticing?
How is it affecting your life or daily functioning?
What are your worries or concerns?

L = Loved Ones Experiences and perspectives of family and carers

What changes are Loved Ones or Carers noticing in you?
How do they think this is affecting your life or daily functioning?
What are their worries or concerns about you?

P = Partnership Identify needs and create partnership with medical provider

What do you and your loved ones/caregivers need from the medical provider(s) today?
What does the medical provider(s) need from you?
What are the goals of care with this provider?
Do you feel heard and understood by each other? Is there anything you need to clarify for each other?
What supports do you need?
What are the next steps or expectations (medical care, disease progression, when to follow-up) going forward?

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Medical History Basic List

Get help collecting as much as you can of this information to bring to your medical visits

- HD History and HD Family History
- HD Symptoms
- Current Medications and Supplements
- Allergies
- Medical Problems (current and past)
- Surgical History
- Other Hospitalizations
- Reproductive History
- Mental Health History
- Substance Use (Abuse) History
- Social History (relationships, education, employment)
- Disability Status
- Family History of Other Medical Problems
- End-of-Life Wishes

Additional Resources for both HD families and medical providers:

HDSA Social Workers

https://hdsa.org/find-help/community-social-support/social-workers/

Look up the HDSA Social Worker for your area and write their contact info here:

A Physician's Guide to the Management of Huntington's Disease, 3rd ed, 2011

https://hdsa.org/product/a-physicians-guide-to-the-management-of-huntingtons-disease-3rd-edition/

Understanding Behavior in Huntington's Disease: A Guide for Professionals, 2nd edition, 2014

https://hdsa.org/product/understanding-behavior-in-huntingtons-diseasea-guide-for-professionals/

UC Davis HD Clinic Resource Guide for HD Families

https://health.ucdavis.edu/media-resources/neurology/documents/pdfs/huntingtons/hd-resource-guide-resources-for-hd-families.pdf

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HDSA Center of Excellence at UC Davis Health
Tel: 916-734-6277
https://health.ucdavis.edu/huntingtons/

Strategies for Managing Cognitive Changes

Communication

- Give time to respond -- slower process can cause delay in response time.
- give time or help (if wanted) to find the "right words" as the HD person may struggle to find the word they want to use.
- One conversation at a time -- may have difficulty tracking a complex or multiple conversations.
- Forgive and redirect if they go off topic.
- make sure to have eye contact and be facing the person when talking for better engagement.
- Multiple choice questions, yes/no can assist when communicating needs/desires.

Limit Distractions

- Focus on one task at a time (i.e. turn off radio or limit talking when driving or eating, etc)
- Have quiet, comfortable location to work/complete tasks
- One question at a time (minimize stimulus overload).

Use HUMOR

Always remember to laugh when possible. Mistakes and plans/routines will NOT always go as planned so laugh, learn and try again tomorrow!

Simplify

- Break large tasks into smaller easier to manage steps
- Keep consistent and routine schedule as much as possible.
- Allow extra time
- Keep trips short and go to familiar locations

Memory

- Provide hints/reminders to assist with recall. -- may experience some difficulty with short term memory or learning new information
- If learning something new, teach in small increments
- Use notebooks, lists for remembering
- calendar of events, birthdays, etc.

Plan for Changes

- have a plan on how to address changes in routine.
- When anxiety or repetitive thoughts arise, use distraction, change environment, get out of the house, change of scenery.

External Aids

- Daily "to-do" lists -- plans out the day without having to think about what's next.
- Use calendar for visual cues of what's happening next.
- Use alarms or reminders on smart phones or smart home devices (Alexa, google home, etc)

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