



# Managing Cognitive Problems in Huntington's Disease

**Arik Johnson, PsyD**

**HDSA Center of Excellence at UCLA**

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# Disclaimers

- The presentation today is for informational use only
- The recommendations made are general guidelines
- All attendees are encouraged to consult with their primary care provider, neurologist or other healthcare provider about any advice, exercise, medication, treatment, nutritional supplement or regimen that may have been mentioned as part of this presentation.
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# Presenter Disclosures

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose

# Objectives

- Describe some of the common cognitive changes and problems associated with Huntington's disease
- Present practical recommendations for addressing those changes and problems

# Huntington's Disease: General Overview

- Huntington's Disease (HD) is a hereditary neurodegenerative disease caused by an expansion in the huntington gene
- People who have HD generally begin to show symptoms in their mid-thirties to mid-forties
- Symptoms will progress and worsen over time
- There is no way to tell at what pace a person will develop symptoms, how the symptoms will present, or when that individual will die from the disease

# Huntington's Disease: General Overview

- Symptoms of HD fall into three categories:
  - Motor
  - Cognitive
  - Psychiatric
- Currently, a diagnosis of HD is made based on the presence of motor symptoms

# Huntington's Disease: the Cognitive Disorder

- Patients and families share stories suggesting that the cognitive (and psychiatric) symptoms present earlier and can be the most debilitating symptoms
  - The cognitive (and psychiatric) symptoms of HD can impair function early on in the disease, both in the work place and at home
  - The cognitive (and psychiatric) symptoms are what most often lead to placement outside the home



# Huntington's Disease: the Cognitive Disorder

- Research is showing that cognitive (and psychiatric symptoms) may actually present earlier than the motor symptoms
- Experience shows that the overlap of cognitive and psychiatric symptoms create more difficult (and complicated) problems

# Huntington's Disease: the Cognitive Disorder

- The cognitive disorder seen in Huntington's disease impacts a number of areas of function
  - Memory and learning
  - Perceptual skills
  - Executive functioning
  - Language and communication

# Memory and Learning

- Memory: the ability to retrieve previously learned information
  - Recognition vs. free recall
    - “Is your meeting today with Alice or Sarah?”
    - “Who are you meeting with today?”
  - Explicit memory vs. implicit memory
    - Explicit: names, dates, etc.
    - Implicit: collections of coordinated skills, movements, etc.
      - ie: tying shoes, riding a bike, driving

# Memory and Learning

- Learning: the ability to acquire new or modify existing knowledge, behaviors, skills, values or preferences
  - Often involves combining multiple sources of information

# Memory and Learning: Recommendations

- Learning and memory techniques
  - Minimize sources of information
  - Use notes
    - Written: visual reminders (“triggers”)
    - Recorded: auditory reminders
  - Practice and repeat
    - Review information multiple times



- Sticky notes are a great tool!
- Easily seen and you can put them anywhere



- Use sticky notes for gentle reminders



- If little sticky notes are good, big ones must be better! (not necessarily, but I love them)





- Too much of a good thing

# Perceptual Skills

- Perception: the ability to identify, interpret and organize information taken in through the senses
  - Sense of time
  - Spatial perception (or personal space)
  - Emotional recognition
  - Smell identification

# Perceptual Skills

- Sense of time
  - Innate sense of timing is diminished
    - “Why is he always late?”
  - The ability to estimate time worsens
    - “I thought you said this would only take an hour...”
- Personal space
  - The ability to judge where the body is in relation to objects is impaired (ie: furniture, walls, pets, etc.)
  - Leads to increased fall and accident risk

# Perceptual Skills

- Emotional recognition
  - Inability to differentiate certain emotions from facial expressions
    - Fear, surprise, anger, happiness, sadness, etc.
  - This problem impacts personal and social relationships
    - “Didn’t you realize I was angry?”
    - “Why aren’t you asking your son what’s wrong?”

# Perceptual Skills: Recommendations

- Time management
  - Allow extra time in completing tasks
  - Map out timelines
  - Use reminders (verbal, technological, etc.)



- If you've got it, use it!
- Most smart phone and cell phones have calendars and alarms that you can program



- Easy to find (and cheap) household tools work well, too!

# Perceptual Skills: Recommendations

- Personal space modifications
  - Minimize clutter
  - Pad the corners of furniture
- Emotional recognition tips
  - Say what you are feeling
  - Actively dialogue



# Executive Functioning

- Executive functions: frontal lobe cognitive process that regulate organization of thoughts and activities, prioritization of tasks, and decision making
  - Higher order functions
  - “Management”
    - Processing speed
    - Attention
    - Organization

# Executive Functioning

- Processing speed
  - The speed at which your brain works with information
    - Tasks that were once easy take longer to complete
    - Completing a task requires more energy and leaves the individual worn out
- Attention
  - The ability to attend to and process specific information from the world around you
  - Divided attention (multitasking) becomes more difficult

# Executive Functioning

- Organization
  - The ability to sort information and construct meaningful patterns of thought and action
    - Determining the order of activities for the day
    - Sorting and prioritizing the mail and bills
    - Coordinating the kids' schedules
    - Shopping for groceries at market
    - Getting dressed

# Executive Functioning: Recommendations

- Processing speed tips
  - Allow additional time for response
  - Avoid open ended questions
    - “The limited option option”
- Attention tips
  - Do one thing at a time
  - Minimize input sources
  - Reduce quantity of information
  - Remove environmental distractions

# Executive Functioning: Recommendations

- Planning and organization tips
  - Develop regular schedules and routines
  - Use calendars, to do lists, schedules, etc.
    - Set up a single place (“command station”) in the home where calendars, schedules, or to do lists are kept and maintained
    - Establish regular times to review and update these items
      - “Family meeting”
    - Refer to these items frequently
      - “The more you practice, the better you get”



- Whiteboard or erasable calendars are easy to use and personalize

C	T	D	Morning Chores ☀️
		X	make your bed
		X	get dressed
		X	put away folded clothes
			yesterday's clean clothes - put away
			yesterday's dirty clothes → laundry
			Charles - wipe toilet Thomas wipe counter
—	—	—	Monday / Wednesday sort laundry
			clean up playroom
			take out recycle items to blue trash
		X	empty dishwasher

- Check lists are a great for tracking daily routines: you can easily see if you have done something (or not)

**My To Do List!**

<input type="checkbox"/>	_____
<input type="checkbox"/>	_____
<input type="checkbox"/>	_____
<input type="checkbox"/>	_____
<input type="checkbox"/>	_____
<input type="checkbox"/>	_____
<input type="checkbox"/>	_____
<input type="checkbox"/>	_____
<input type="checkbox"/>	_____
<input type="checkbox"/>	_____
<input type="checkbox"/>	_____
<input type="checkbox"/>	_____

- To do list pads are something you can use to write up a single day's activities, a grocery list, etc.





- Taking it a little too far...

# Language and Communication

- Language involves the use of words in a structured and conventional way
- Communication is the transfer of information from one person to another
  - This requires a complex integration of thought, muscle control, and breathing

# Language and Communication

- Two main aspects to communication
  - Getting the information IN (listening, processing and understanding)
    - Receptive
  - Getting the information OUT (organizing and presenting)
    - Expressive

# Language and Communication: Recommendations

- Allow additional time for responses
- Offer verbal cues or prompts
  - This can help a person “get started” in speech
  - Be careful not to “put words in the person’s mouth”
- Avoid open ended questions
  - Provide specific and limited choices

# Language and Communication: Recommendations

- If you do not understand what the person with HD is saying, don't pretend that you do
  - Ask for him to repeat himself
  - If that doesn't work, try an alternative approach – spelling something out, give the first letter, etc.

# Recap

- Described some common cognitive changes associated with Huntington's disease
  - Memory and learning
  - Perception
  - Executive functioning
  - Language and communication
- Discussed practical recommendations, both techniques and tools, to address those changes

# Thank you very much!

Arik Johnson, PsyD

[acjohnson@mednet.ucla.edu](mailto:acjohnson@mednet.ucla.edu)

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