



Apathy and Unawareness in Huntington's Disease

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Huntington's Disease
Society of America

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Presenter Disclosures

Danielle Blinkoff

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

**No relationships to disclose
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Presentation Outline

- Apathy
 - What is apathy and why care?
 - Why does apathy occur in HD?
 - What are ways to cope with apathy?
- Unawareness
 - What is unawareness and why does it occur?
 - How can we deal with unawareness?
 - Special situations: Driving

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- Studying Neuropsychology.
- Research interests are in dementia, executive functions
- Currently clinical research coordinator at the HDSA Center of Excellence at the University of South Florida.



What is Apathy?

- Apathy comes from the Greek for “pathos” meaning passion.
- Prefix a- means without.
- Current conceptualizations:
 - Emotional Impairment (Marin 1990).
 - Indifference, flat affect (Stuss 2000).
 - Reduction in self-purposeful, self-generated behaviors (Levy & Dubois, 2006).
 - Difficulties with initiation (Robert et al. 2008).

Prevalence

- Apathy has been shown to affect up to 50% - 70% of patients with HD.
- (Krishnamoorthy & Crauford, 2011; Paulsen, Ready, Hamilton, Mega & Cummings, 2001).

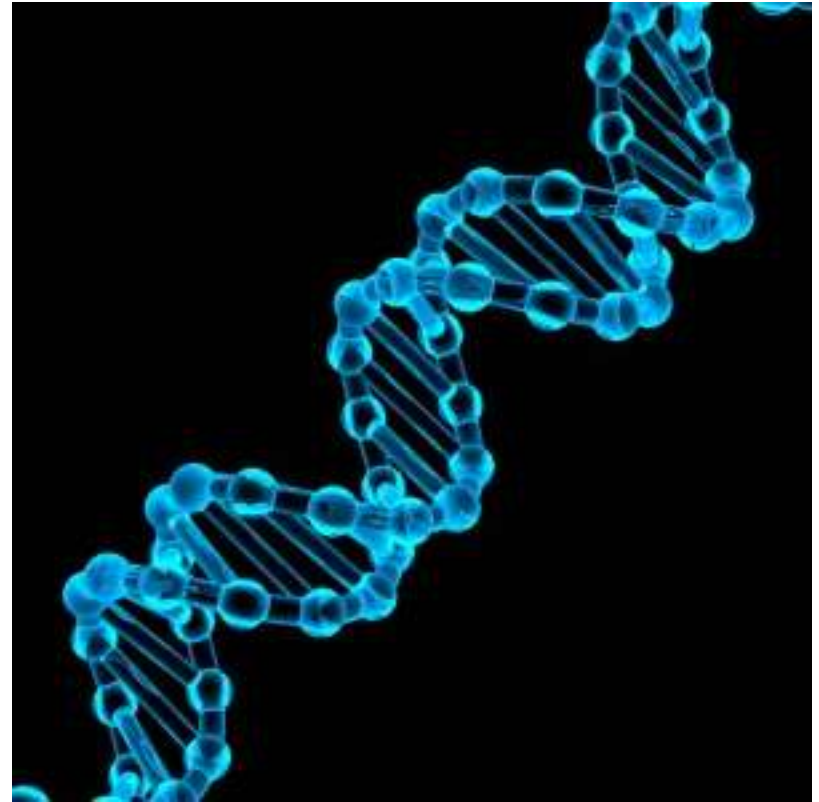


Image from : <http://1.bp.blogspot.com/-1gThEe06FVg/UaNJlx-Wtrl/AAAAAAAAAFck/2qZ622enQpg/s1600/dna.jpg>

What is Apathy? 3 Dimensions

- Motor Apathy
 - Reduction of gestures
 - Walking initiation difficulties
 - (Masterman & Cummings, 1997)



Image from:
<http://runners-h1gh.tumblr.com>

What is Apathy? 3 Dimensions

- Cognitive Apathy
 - Reduced interest
 - (Masterman & Cummings, 1997)



Image from: <http://sharpbrains.com/blog/2006/12/28/is-brain-fitness-scientifically-proven-to-improve-cognitive-skills/>

What is Apathy? 3 Dimensions

- Emotional Apathy
 - Reduced emotional engagement
 - Flattened affect
 - (Masterman & Cummings, 1997)



Signs of Apathy in Huntington's Disease

- Uninterested in surroundings.
- Unmotivated
- Loss of enthusiasm & spontaneity
- Needs to be pushed to do work or chores
- Stops initiating activities with friends and family
- Flat affect (showing little emotion)
- (Rosenblatt et al., 2009)



Apathy is not a reaction to symptoms!

- Related to physiological changes in the brain
 - Not necessarily reaction or adaptation to disability (from PD literature) (Pluck & Brown 2002).



<http://www.bing.com/images/search?q=brain&qs=n&form=QBIR&pq=brain&sc=8-5&sp=-1&sk=#view=detail&id=7B6FEEF375F42A3241E3A48BE52EA3B59F2BB66E&selectedIndex=0>

Apathy and the Brain

- HD is a basal ganglia disorder (the caudate nucleus is affected).
- Problems in this part of the brain can affect other areas including areas that affect **emotion**.

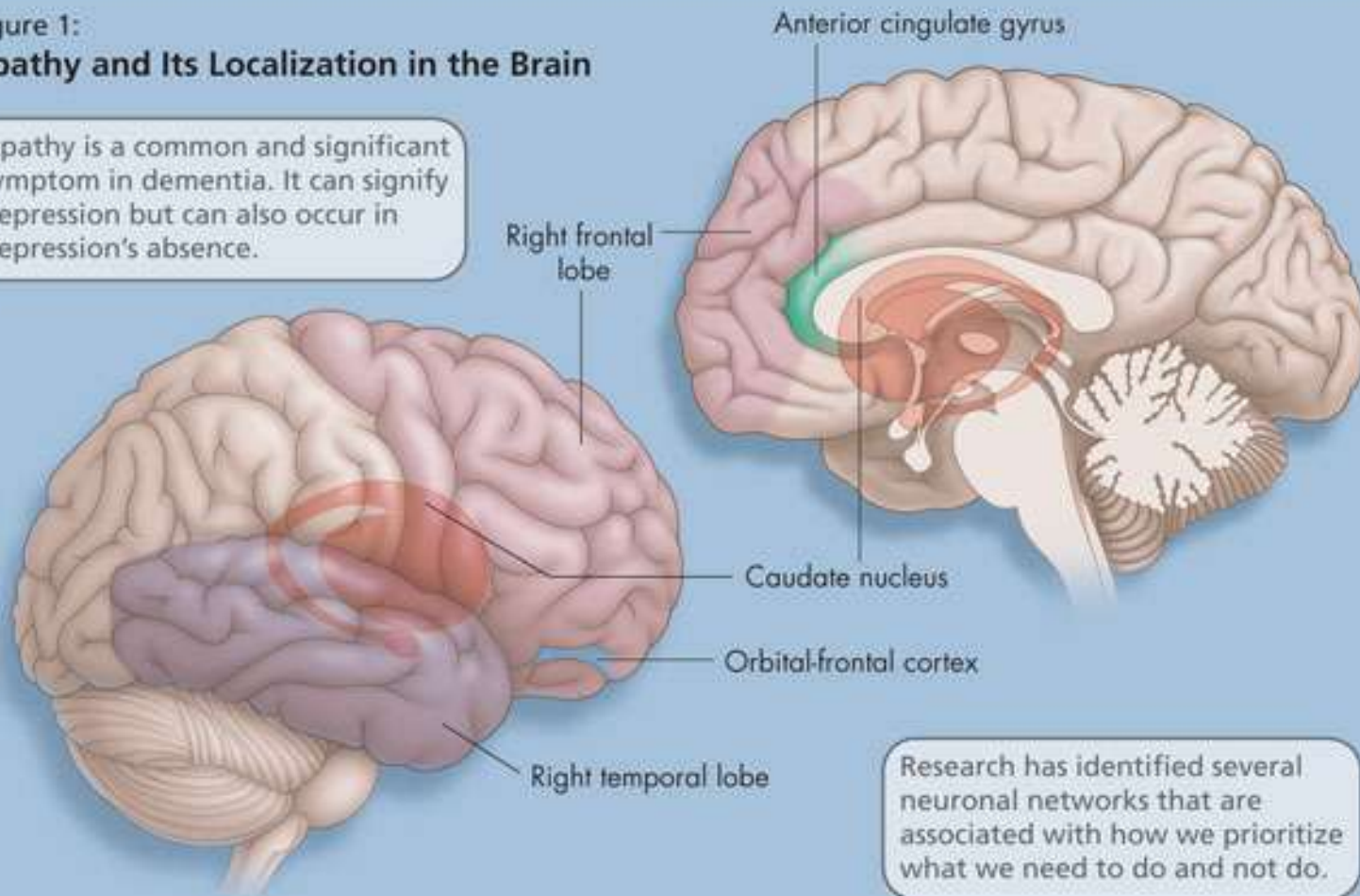
Huntington's Disease Affects the Brain's Basal Ganglia



http://2011gtms8h.wikispaces.com/file/view/Basal_Ganglia.jpg/234090606/166x196/Basal_Ganglia.jpg

Figure 1:
Apathy and Its Localization in the Brain

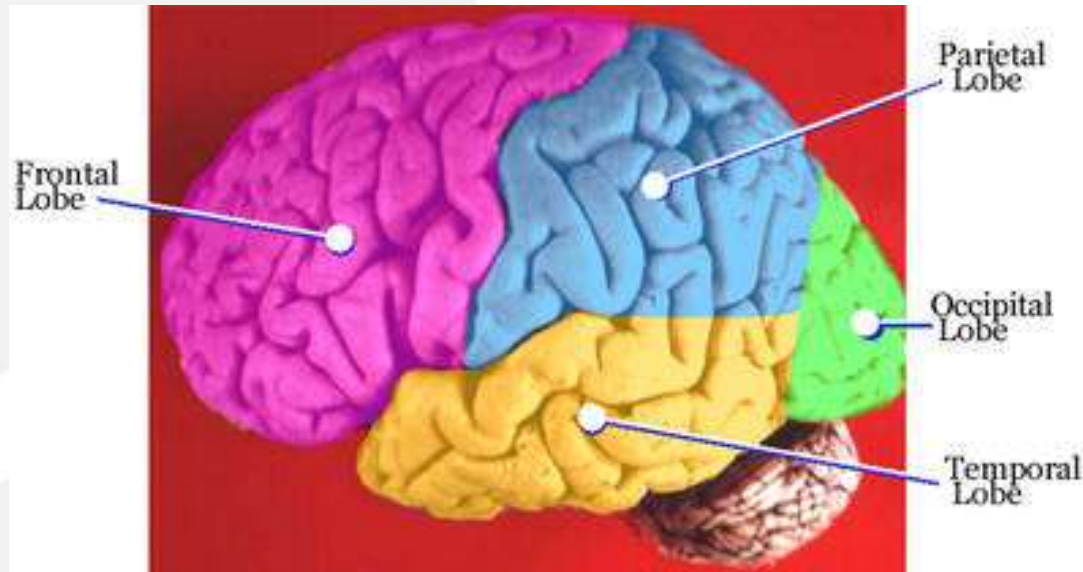
Apathy is a common and significant symptom in dementia. It can signify depression but can also occur in depression's absence.



Research has identified several neuronal networks that are associated with how we prioritize what we need to do and not do.

<http://www.healthplexus.net/files/images/2009/CGSreport/1208Chowfig1.jpg>

Frontal Lobes



- Dysexecutive Syndrome:
 - Responsible for apathy and unawareness (among other symptoms such as impulsivity).
 - Frontal lobes: higher order thinking, planning

What Apathy Is NOT



<http://www.clker.com/cliparts/d/E/J/y/P/v/do-not-pass-hi.png>

Apathy is NOT Laziness



Image from: www.socialsmiling.com

Apathy is NOT Depression



Apathy Vs. Depression

Depression	Apathy
Sad Mood	Loss of Interest
Loss of Pleasure	Not wanting to try new things
Worthlessness/Guilt	Lacking Initiation -needs pushed to get chores done -others need to initiate social gatherings
Indecisiveness	Flat affect
Suicidal Ideation	Low spontaneity
Trouble Concentrating	
(DSM-IV-TR, 2000)	(Levy et al. 1998)

Apathy is NOT Depression

- Why is this important?
- People with apathy without depression rarely report anhedonia, or no longer enjoying pleasure in things (Krishnamoorthy & Crauford, 2011).
- This means the patients still enjoy hobbies and activities, they just may have some problems initiating and sustaining those activities.

Apathy: Why Care About It?

- May affect both patient and caregiver quality of life.
 - May diminish treatment compliance.
 - Patient may not be motivated to stay active (activity could help stave off decline).
 - Patients are unlikely to complain of apathy
 - (Oguru, Tachibana, Toda, Okuda, & Oka, 2010).
-
- <http://www.healthplexus.net/article/apathy-dementia-significant-behavioural-challenge>

Treating Apathy : Do Something Fun!

- Set up pleasant activities for the person with apathy to engage in.
- This should be activities the person chooses/likes, not what the caregiver feels the person SHOULD be doing.
- Have a companion engage in the activity with the person.
 - Helps with attention.



Treating Apathy : Plan It!

- Maintain a Regular Schedule/ Routine



Treating Apathy : Set Up Activities!

- Increase Environmental Stimulation (not too much though!)



Treating Apathy: Get Involved!

- Day Programs



Treating Apathy : Provide Choices



Limit Open-ended Questions: Yes or No is the way to go!

Treating Apathy : Cueing!

- Provide external cues and prompts
- Example: PD patients and walking over a line helps them initiate movement.
- Initiating or suggesting an activity may be all that is needed.



Remember...

- Initiation is the big issue when it comes to apathy!



<http://elimasterlocksmith.com/services/emergency-locksmith/car-ignition>

Caregivers:

- As the caregiver, it's your job to press the start button!



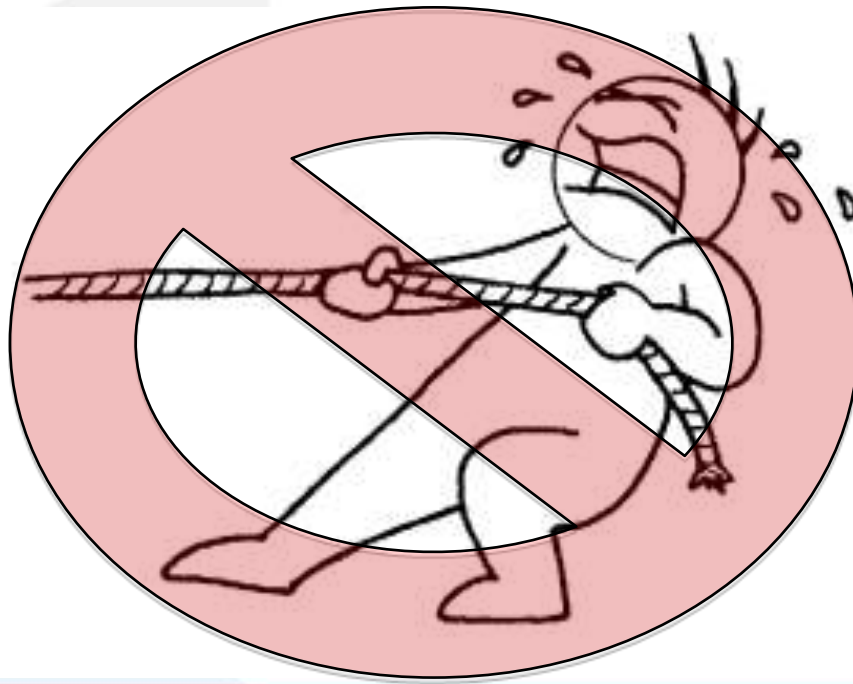
BUT!



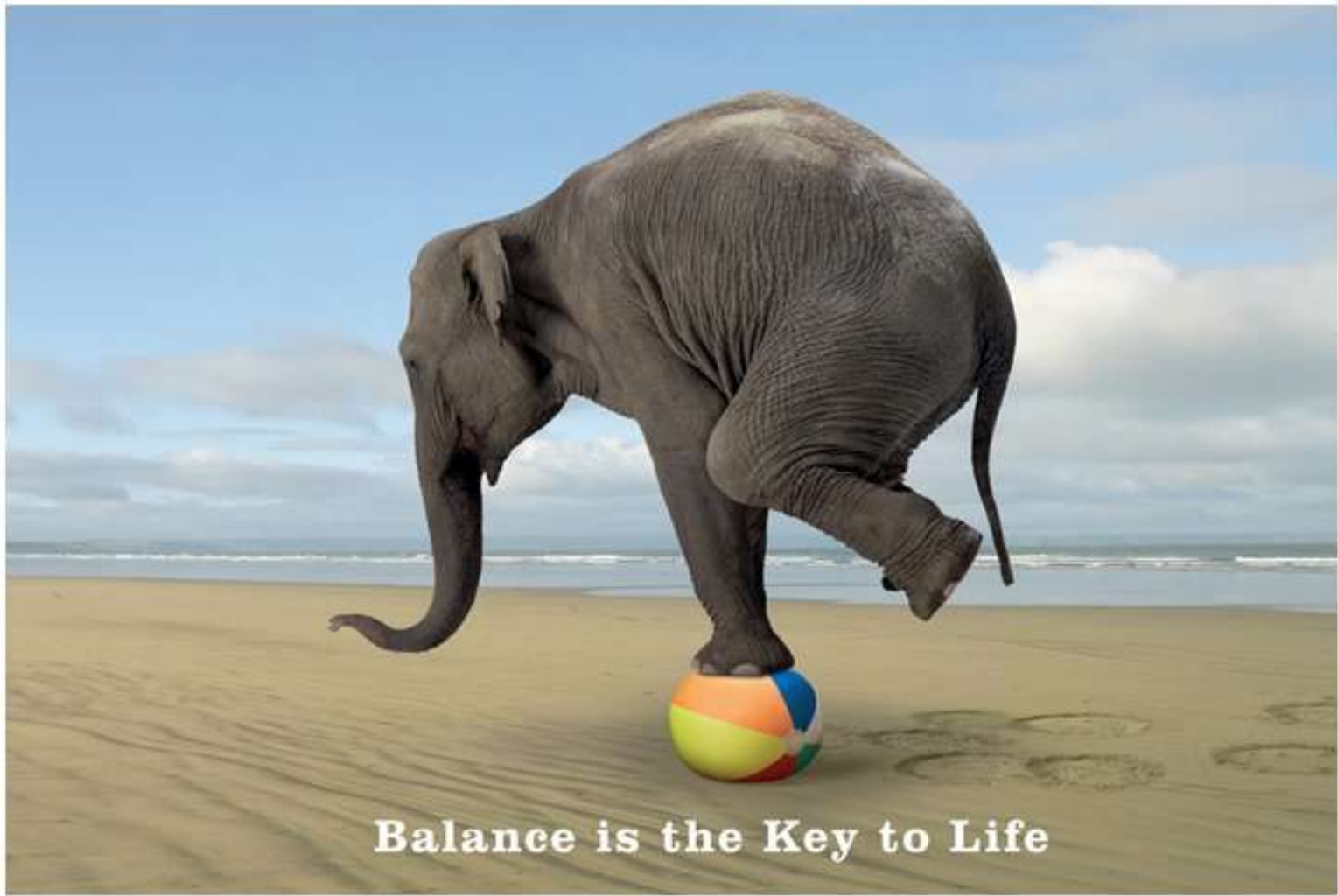
<https://apps.education.ucsb.edu/wiki/File:Warning.svg>

No Forcing!

- Don't push too hard. Could result in irritability or outburst.
- It's ok if they want to sit around sometimes.
- "No" is OK!



<http://bodybalance4you.wordpress.com/2013/01/29/push-and-pull/>



Balance is the Key to Life

<http://www.trishblackwell.com/the-balance-game/>

What is Unawareness?

- “Anosognosia”
 - Means denial of weakness
 - Associated with apathy and frontal lobe dysfunction (Starkstein et al., 2010; Cutting, 1978).
 - Both apathy and insight is associated with right hemisphere function (Ott et al., 1996).
 - Social apathy is described as a lack of action in one’s own self-interest (Stuss, 2000).

What is insight?

- People with insight
 - Understand their limitations
 - Motivated to engage in activities that match their current functional status (Starkstein, Brockman, Bruce & Petracca, 2010).

Denial

- Can occur because of difficulty dealing with a bad circumstance.
 - Decreases over time
- **Organic denial**: unawareness of own disability
 - This may never decrease

Why does Unawareness Occur?

- Protective for person
 - Example: In Alzheimer's disease, insight is associated with anxiety (Verhey, Rozendaal, Pondes, & Jolles, 1993).
- Executive Dysfunction
- Response to an overwhelming situation.

Coping with Unawareness

Acceptance

acceptance (noun)

the act or process of agreeing to experience a situation without changing it

Coping with Unawareness: Acceptance

Don't have a power struggle!



Rule of Thumb for Caregivers: Acceptance

- Know when to back off.
- If poor judgment is not hurting anyone, consider allowing person to do what he or she wants.
- Person may even realize your point of view eventually!



Coping with Unawareness: Acknowledge

Noncompliance \neq Intention

Coping with Unawareness: Acknowledge

- Develop a contract
 - Include incentives for compliance
 - Rewards could be foods, activities, but make sure it's something the person likes, not what the caregiver chooses.
 - Formal agreement – explains expectations
 - Make realistic goals
 - Avoid requiring acceptance or awareness



Coping with Unawareness: No Labeling

- Avoid the HD label
 - Person may be able to talk about issues, but just does not acknowledge he or she has HD.
- Though counseling may help, it may also have little impact on insight.



(Understanding Behaviors in HD Book)

One of the most concerning consequences of unawareness



Unawareness & Driving

- Can be a tricky topic.
- Driving signifies independence for lots of people.
- Most people do not want to give up driving.
- Giving up driving can be considered a big loss for some.
 - Transition slowly if possible
 - Only driving around the neighborhood
 - Avoiding highways
 - Not driving at night



http://www.helpguide.org/elder/senior_citizen_driving.htm

Ways to Talk about Driving

- Respect
- Give Examples of Performance
- Numbers (more people providing info)
- Help Find Alternatives
 - Shuttles
 - Carpooling
 - Public Transportation

What if talking does not work?

- Driving evaluation with an occupational therapist or certified driver rehabilitation specialist.
 - Gives a neutral, 3rd party perspective. Makes it less accusatory.
- If you are concerned with unsafe driving and all other suggestions do not work, you may make an anonymous report to your state's Department of Motor Vehicles.

Summary

- Both apathy and unawareness occur because of changes in the brain due to HD.
- These symptoms are not the person's fault.
- Apathy can be improved with providing a regular schedule and the caregiver initiating pleasant activities.
- It is important remember that some people may never become aware of their disabilities. Creating a contract could help.
- Never push too hard when dealing with apathy or unawareness!
- Caregivers may intervene if unawareness is putting the patient in a dangerous situation.

Resources

- Driving Information:
 - http://www.helpguide.org/elder/senior_citizen_driving.htm
- General Information about HD:
 - <http://stanford.edu/group/hopes/cgi-bin/wordpress/>
 - http://hdscotland.org/images/stories/InformationResources/physicians_guide.pdf
 - <http://www.hdsa.org/living-with-huntingtons/publications/index.html>
- Nance, Paulsen, Rosenblatt, & Wheelock (2011). A Physician's Guide to the Management of Huntington's Disease. HDSA. USA.
- Paulsen (1999). Understanding Behavior in Huntington's Disease. HDSA.
- Pollard, Best, Imbigilo, Klasner, Rubin, Sanders, & Simpson (1999). A Caregiver's Handbook for Advanced-Stage Huntington's Disease. HDSA.

Questions?

