



Coping with Obsessive/Compulsive Behaviors in Huntington's Disease

Presentation by Danielle Blinkoff, B.A.

University of South Florida, Clinical Psychology Doctoral Program
HDSA Center of Excellence at University of South Florida



Huntington's Disease Society of America

The information provided by speakers in workshops, forums, sharing/networking sessions and any other educational presentation made as part of the 2013 HDSA Convention program is for informational use only.

HDSA encourages all attendees 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 any presentation.

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
or list**



**Huntington's Disease
Society of America**

Danielle Blinkoff

- Clinical Psychology Ph.D. Student at the University of South Florida
- 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.



Presentation Outline

- What are perseverations?
- What are obsessions and compulsions?
 - Why do they occur?
 - How are they different from perseverations?
 - Why are they unique in HD?
 - Strategies for coping

Prevalence of Obsessive and Compulsive Behaviors in HD

- 20-50% of patients with HD report obsessions and/or compulsive behaviors (Anderson et al., 2010; Anderson et al., 2001; Beglinger et al., 2007; Marder et al., 2000, Paulsen et al., 2001).
 - Most individuals have features of OCD, but don't meet criteria (Naarding et al., 2003; Anderson et al., 2001).
- Compared to 5.5% of obsessions and/or compulsions in the general population (Anderson et al., 2010; Degonda et al., 1993).

Comorbidities: Obsessive and Compulsive Behaviors in HD

- Psychiatric:
 - Associated with higher rates of depression, suicidal ideation, aggression, delusions and hallucinations.
- Cognitive:
 - Associated with poorer executive function (Inhibition).
- Demographics:
 - Associated with older age, poorer functioning, longer duration of illness.

(Anderson et al., 2010)

Scenario

- A 60 year old woman with HD has an appointment to see her neurologist later in the day.
- She always has concerns about medications. She never likes taking medications because she worries about side effects. She especially gets upset if there are any changes to medications.

Scenario

- The whole morning of the appointment she constantly says things to her caregiver about medications like: “the doctor better not change my medications. I’m not taking more medications.”
- This extends into the whole ride to the doctors office and while sitting in the waiting room.
- The doctor makes changes to her meds, and this upsets her. She cannot stop asking about why these medications need to be changed and cannot change topics.
- She remains upset and frustrated about this the whole way home.

What's Happening in This Situation?

Perseverations : Getting Stuck



- <http://ians1stblog.files.wordpress.com/2010/12/santa-stuck.jpg>

Perseverations: Getting Stuck

- Rigidity in behavior
- Unable to change routines
- Getting stuck on the same idea or action
- Unable to go from one activity to another (Paulsen, 1999).

Perseverations: Getting Stuck

- Perseverations are usually more evident to others than the patient.
 - Not an intrusive thought.
- Person does not recognize that the thoughts are a product of his or her own mind.
 - Think these are true concerns.
 - Typically don't realize they are stuck.

Perseveration: Topics

- Many times revolve around loss of certain privileges.
 - Driving
 - Using the stove
 - Going to the store alone
 - Managing finances
- Can be other random topics as well.
 - Trouble with a neighbor (Paulsen, 2011).

What is an Obsession?

- Person recognizes that the thoughts are from his or her own mind.
 - This is what makes it different from a perseveration.
- Thoughts are persistent and causes anxiety and distress.
- Person tries to stop the thoughts in some way.
 - DSM-IV-TR 2000

What is a Compulsion?

- An action that attempts alleviate anxiety caused from an obsession
 - Hand Washing
 - Counting
 - Organizing/Arranging
 - Repeating words or statements
 - Hoarding items
 - Repeated trips to the rest room
- Compulsions are excessive acts and don't necessarily neutralize the supposed threat.
- Compulsions can be time consuming and interfere with the person's normal routine.
 - DSM-IV-TR, 2000

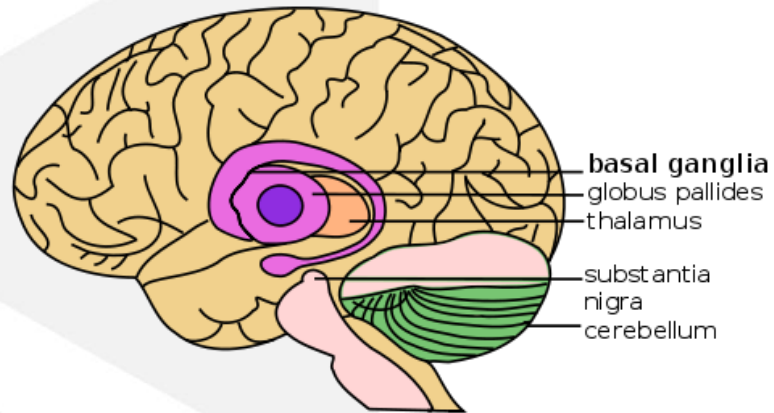
Why do Perseverations, Obsessions and Compulsions Occur?

- Frontal Lobes
 - Circuitry going from basal ganglia to frontal lobes is disrupted.
- Executive Dysfunction
 - Set-shifting Difficulties
- Person's needs are not being met.

Frontal Lobes & The Basal Ganglia

- Disruption of frontal striatal circuitry.
- Obsessive and compulsive behaviors are linked to the caudate, globus pallidus, and frontal lobe dysfunction.

Basal Ganglia and Related Structures of the Brain



- Problem with the basal ganglia leads to problems in other parts of the brain.

Frontal Lobes and Behavioral Regulation: The Decision Maker



<http://simonmainwaring.com/wp-content/uploads/2011/06/ceo.jpg>

When the rest of the workers are doing their job, the CEO can make good decisions & the company runs smoothly



<http://www.nekls.org/wp-content/uploads/board-clip-art.gif>

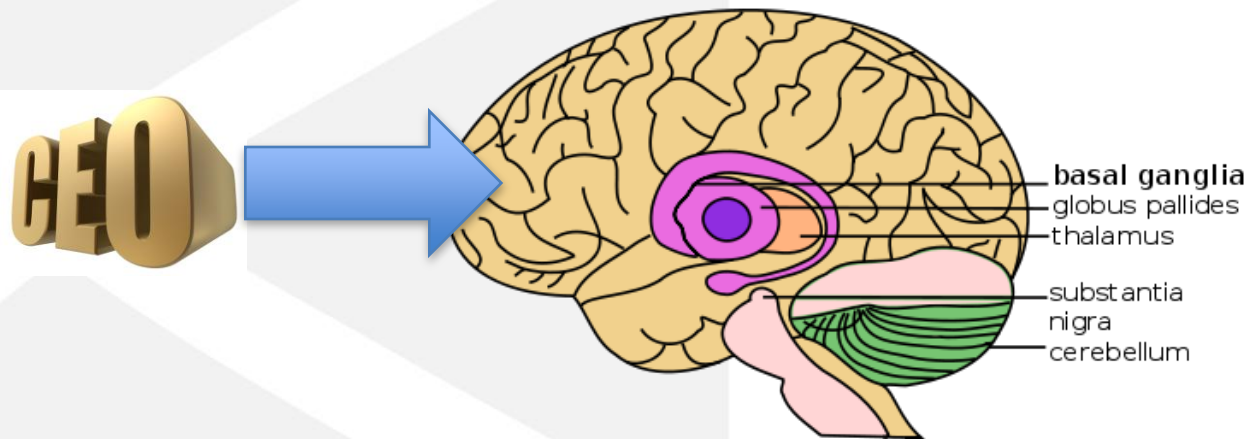
The CEO can't make good decisions if his or her workers are doing their job properly.



ClipartOf.com/436978

In HD, sleepy workers in the basal ganglia disrupt the work of the CEO in the frontal lobes.

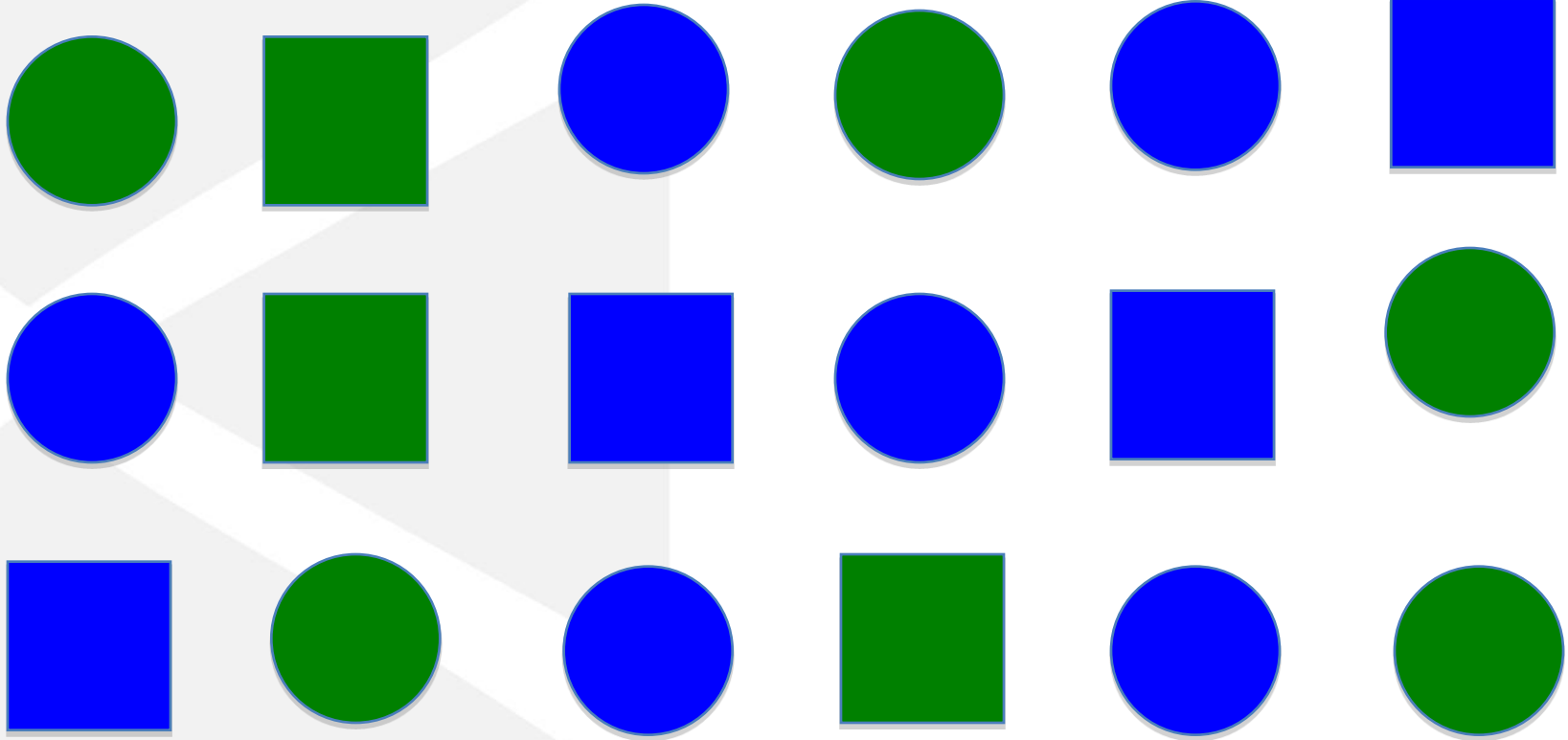
Basal Ganglia and Related Structures of the Brain



ClipartOf.com/436978

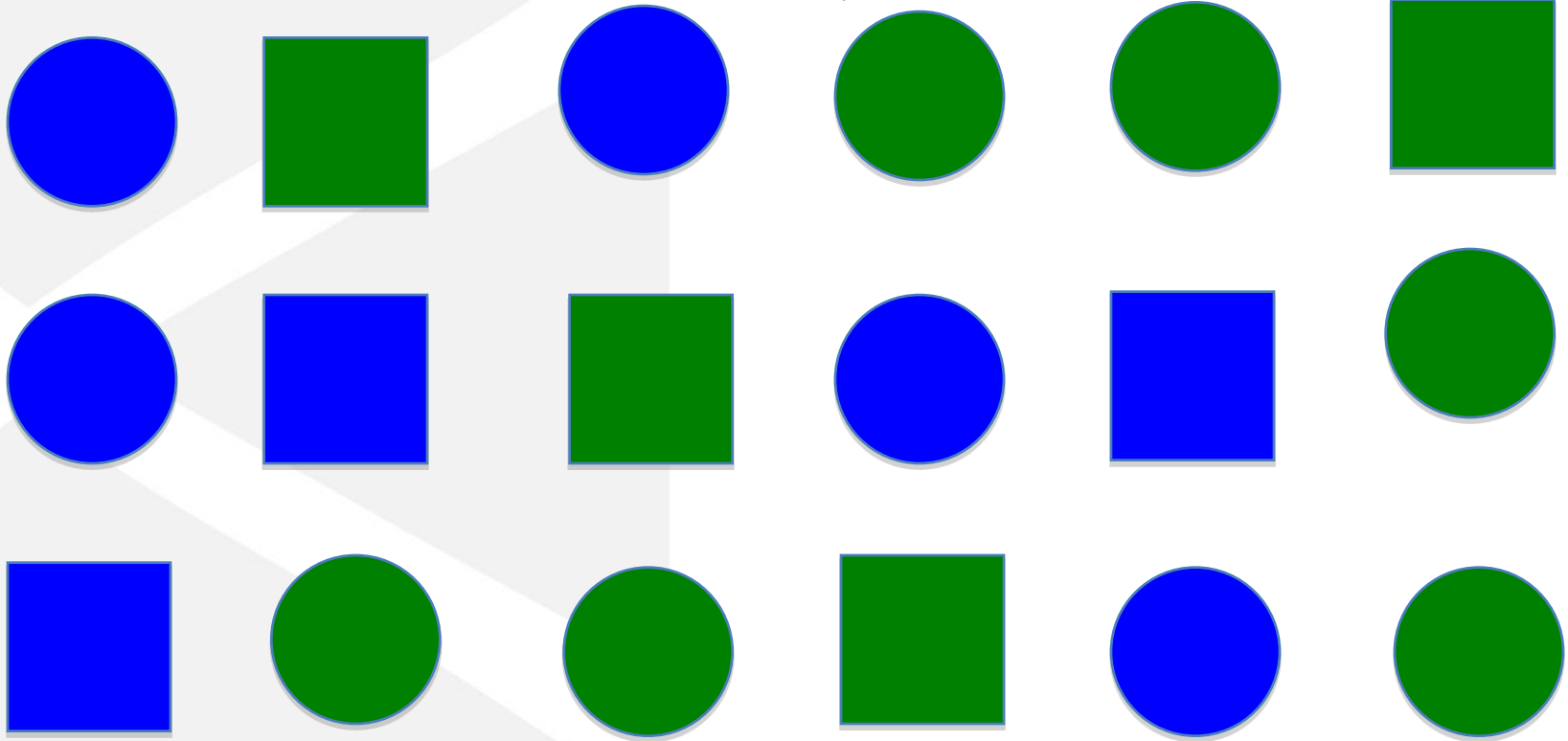
Set-Shifting Example

- Find All of the Green Circles! How many are there?



Set-Shifting Example

- Find All of the Green Squares! How many are there?



Set-Shifting

- In example 1, the correct answer is 5 (green circles). Both people with and without set-shifting problems should get this correct.
- In example 2, the correct answer is 4 (green squares).
 - Set-shifting difficulties: 6 (green circles).
- Why does this occur?
 - Difficulties shifting to the new rule!
 - Got **stuck** to the old rule!

Keep in Mind...Needs

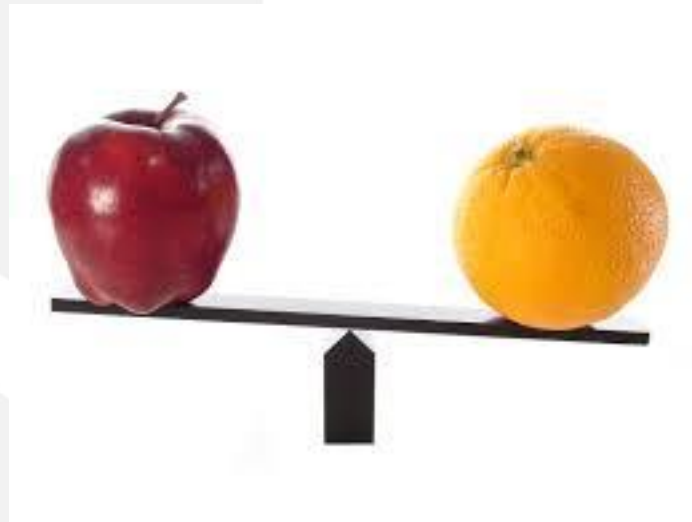
- Sometimes, the person may actually need something and is having trouble expressing that need.



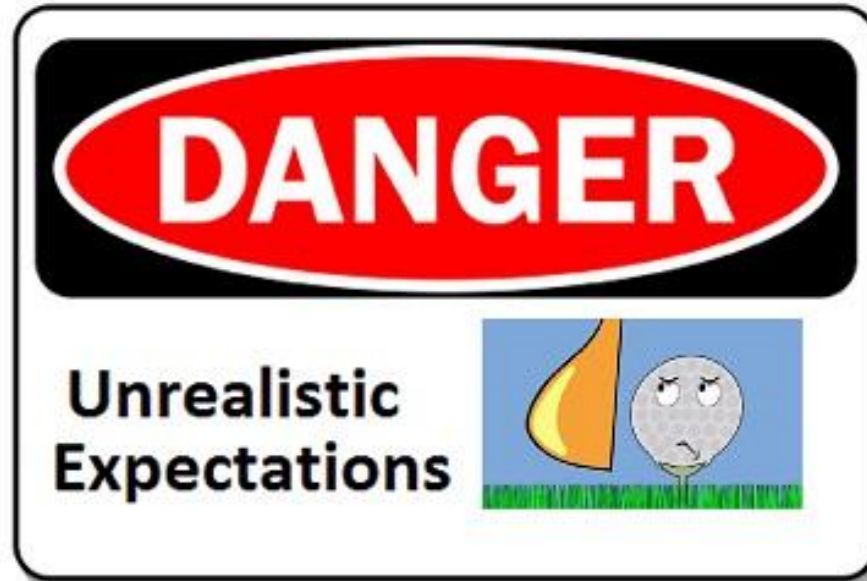
http://thumbs.dreamstime.com/thumblarge_262/1209207763H2Yw6c.jpg

Obsessions and Compulsions in HD are Unique

- Traditional ways of dealing with patients with obsessive-compulsive disorder may not work for this population.



Manage Expectations



http://1.bp.blogspot.com/_k4ZjEbQtTy0/TQJ4VylECAI/AAAAAAAAB8k/4Ri1yClS_CpQ/s1600/unrealistic+expectations.jpg

Pick Your Battles



<http://icons.iconarchive.com/icons/icons-land/sport/256/Boxing-Gloves-icon.png>

However...

- When safety is an issue it is more important to intervene than to ignore
- Sometimes there is no reasoning with the person
 - Reasoning ability is impaired.



Coping with Behaviors

- Remember set-shifting is difficult, so you need to help!
- It's your job to break the cognitive set!



Break the Cognitive Set!

- With Distraction!
 - Make a list of activities or food that the person likes.
 - Humor.
 - Using that could stop the repetitive behavior.



Setting a routine

- General technique that is used to manage many behaviors in HD.
- It's often distressing to change rules or routines, so try to stick to a schedule.



<http://cpsobsessed.files.wordpress.com/2013/01/calendar.gif>

Don't Make False Promises

- For caregivers, don't promise you will do something if you are not going to follow through:
 - If you say “I'll do it in a minute” be sure to uphold that, otherwise don't say it.



<http://cdn.business2community.com/wp-content/uploads/2012/09/false-promises.jpg>

Set a Time Limit

- For caregivers, set a time limit on how long you will discuss the perseveration.
 - Sometimes you won't be able to solve it.
- Explain that the topic has been discussed.
 - Working on fixing the problem.



<http://hcgreenthumb.files.wordpress.com/2011/03/daylight-savings-time.jpg>

Experience

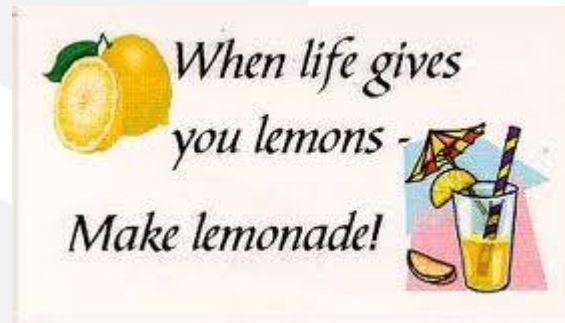
- If perseverations persist, arrange an experience that may put an end to the topic.
- Wanting to drive
 - Arrange for a driving evaluation.
 - The driving evaluator becomes the “bad guy.”



<http://www.cksinfo.com/clipart/signssymbols/bwsigns/car-rental.png>

Avoid the Negative and Embrace the Positive

- Turn a “No” into a “Yes.”
- Instead of “No, it’s not time yet” say, “Yes, you can at 11am.”
- Sometimes it’s just about how your frame a response.



<http://www.healthylifestylesliving.com/wp-content/uploads/2012/05/lemons-into-lemonade.jpg>

Dealing with Compulsions

- Is the compulsion causing practical problems?
- Can it be ignored?
 - Sometimes behavior gives the person a sense of purpose.
 - If it isn't causing practical problems, consider ignoring it.

Dealing with Compulsions

- If ignoring it is not an option:
 - Try Distraction
 - Can the behavior be turned into something productive?
 - Folding Laundry

Summary

- Perseverations, Obsessions and Compulsive behavior occur in 20-50% of patients with HD.
- These behaviors are due to disruptions in brain circuitry.
 - The CEO cannot manage properly.
- Coping with these behaviors:
 - Manage your expectations
 - Pick your battles
 - Break the cognitive set with distractions or humor
 - Set a routine
 - Don't make false promises
 - Set a time limit
 - Arrange an experience to solve the problem
 - Avoid negatives
 - Turning compulsion into something productiv

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?



<http://engage.engage.co.uk/wp-content/uploads/2009/02/questions20.jpg>