



Caregiver's CORNER

HDSA welcomes you to
Caregiver's Corner

Funded by an educational grant from



Managing Behavior in Huntington's Disease: Caregiver Strategies & Environmental Interventions

Mary C. Edmondson, MD
Clinical Associate in
Psychiatry, Duke University
President, North Carolina
Center for the Care of HD

Disclosures

- Dr. Edmondson has been retained by Lundbeck Pharmaceuticals for the purpose of providing clinical teaching and promotion of Xenazine for the treatment of Huntington's Disease.
- The North Carolina Center for the Care of Huntington's Disease was recently awarded a grant from Lundbeck Pharmaceuticals for the **The North Carolina Community Provider Outreach Project** to bring awareness to community neurologists, psychiatrists and genetic counselors of clinical care and research opportunities for HD patients and families in North Carolina.



General Considerations

Every patient, regardless of their condition or problem, deserves a relationship with a medical professional that involves a complete evaluation of symptoms and the development of an individualized treatment plan. This presentation cannot replace and should not interfere with the healing relationship that exists between a patient and his or her doctor.

Information offered is for informational purposes only, and does not constitute medical advice.



A Life Worth Living

**TJ Canning
1920-1995**



Reasons for Hope Today:

Many Symptoms are Treatable

- Behavioral techniques can improve quality of life for affected individuals and family members
- Increasing number of better drugs are available to treat symptoms
- Life can be better now for persons with Huntington's Disease and their family than it has ever been before.

Empathy

“Empathy is the capacity to think and feel oneself in the inner life of another person.”

Heinz Kohut

Empathy:

How do you think like a person with HD when your brain is unimpaired?

All human behavior is on some level explainable and rationale in the face of the person's:

- Underlying disease process
- Prior experiences
- Personality traits
- Current environmental or psychosocial stressors

The Prefrontal Cortex

The Brain's simulator

- Creates an internal vision of goals and possible actions
- Planning, sequencing and initiating tasks
- Stops the flow of unimportant information into consciousness
- Organizes a change in behavior when changes in the environment occur

The Prefrontal Cortex

The Brain's social secretary

- Recognizes social cues and nonverbal communication
- Projects the social consequences of behavior on planned actions
- Stops the flow of unimportant information into consciousness
- Controls behavior expression -disinhibited behavioral expression (irritability) or highly inhibited behavioral expression (apathy)

The Prefrontal Cortex

Mood Manager

Mood: An “emotional state of mind” that is pervasive, affects many domains of experience, and can last for days or months. Can be either depressed or elevated

The HD Experience

My prefrontal cortex's simulation

- *I feel useless, like my life is over*
- *I can't trust myself*
- *All the bad things that happen are my fault*
- *Everyone would be better off if I were gone*

The Prefrontal Cortex in HD

My prefrontal cortex's simulation

- *I am often perplexed by how others react to me.*
- *I blurt out rude comments, even if I hurt the people I care about*
- *I can't read emotions or sometimes misread emotions in the face of others.*

The Prefrontal Cortex in HD

My prefrontal cortex's simulation

- *I can't get started with anything anymore*
- *I do everything slower than I used to*
- *The links between steps are missing.*
- *Sometimes I can't figure out what I need to pay attention to, and I feel overwhelmed.*

Could you watch all these channels at once?



Empathy

Having HD is really hard work.

--Vickie Hunt, RN, Wake Forest University

Typical HD Behaviors

- Irritability/Impulsivity
- Perseveration
- Unawareness and Denial
- Refusing Treatment
- Problems Making Decisions
- Dangerous Behavior

*Expend more effort making things go right than
correcting things that are going wrong*

--"The Anatomy of Peace", The Arbinger Institute

HD Toolbox

- **Making things go right:**
 - Caregiver Empathy
 - Behavior Analysis
 - Redirection
 - Limit Setting
 - Communication Strategies
 - Behavior Plans/Routines
 - Remove Access
- **Correcting behavior**

General Factors that Affect Behavior

- Stage of Disease
- Loss, Grief, Stage of Acceptance
- Awareness of symptoms
- Ability to communicate
- Behavior and needs of others, especially caregiver and children
- Emotional State: mood, anxiety
- Health Factors: hunger, fatigue, thirst, pain, medical illness or injury
- Community resources: financial, social, health care
- Family beliefs

Irritability/Aggression in HD:

Characteristic Features

- Modest or trivial triggers
- No premeditation or advanced planning
- Serves no obvious goal or aim
- No buildup
- Person is upset after or embarrassed after outburst
- May occur at new stage of decline

Irritability/Impulsivity

- Earliest Symptom of HD
- Financial/Social Consequences
- Most often often expressed toward the person closest to the affected individual

Irritability/Impulsivity

- Snapshot vs. Movie
- **Talk to Doctor alone**
- Start this practice before problems begin

What you can do during behavior that is out of control:

- Stay calm.
- Don't fight back or argue.
- Make the environment as calm and safe as possible. Stop or slow down the car. Take the kids to another room. Leave the restaurant.
- Try a distracting sensory event. Make a loud noise. Clap your hands, or call the person's name sharply.
- Have a safety plan in place in case you need help

After the behavior

- Write down what happened
- Begin the analysis at a time before the event when everything was normal or going right
- Include everyone involved or present
- Track the chronology of each event, emotion, action
- Don't judge your own actions or feelings, you are doing the best you can too!

Gather Information

Who; What; Where; When; How; Why

- What time did it happen?
- Where did it happen?
- Is anyone else involved?
- What happened before/after the event?
- Was it a special day?
- Has medication changed?

Behavioral Analysis: Irritability

Don comes home from work and feed the dog, then says hello to Mary

Don goes to change clothes

Mary follows Don to bedroom and demands he feed the dog

Don sighs, and explains that he has already fed the dog

Behavioral Analysis: Irritability

Mary tells him he is lying, he just got home and didn't feed the dogs

Don continues to change clothes, turning his back for a moment

Mary yells at him saying he just got home and that she hates him

And begins to pound on Don's back and scream

Identify the Problem

- Mary hitting Don
- Mary yelling at Don
- Mary telling Don he is lying
- Mary telling Don she hates him
- Mary's irritability
- Don is tired and working too hard
- Don is depressed
- Don has been ignoring the dog and breaking promises

Safety ALWAYS comes first

- Aggression is never acceptable
- Weapons are always risky
- Unsafe driving must be addressed
- Suicide is a preventable complication of HD

Quality of Life Problems

Everyone Counts

- HD is a family disease
- Each family is a complex combination of people with unique needs, vulnerabilities, and stressors
- Everyone counts

Quality of Life Problems

- Depression
 - Irritability
 - Perseveration
 - Unawareness
 - Resisting Behaviors
 - Apathy
- Caregiver Needs
 - Fatigue
 - Illness
 - Need for respite, change
 - Needs of the Immediate Family
 - Needs of Outside Helpers

Common Triggers

- Fatigue
- Hunger
- Dehydration
- Pain
- Change in Routine
- Illness
- Medication Issues
- Recent losses
- Holidays, special events
- Political or civic events
- Change in the lives of important family members

Set realistic goals

The Prefrontal Lobe Surrogate

- ✓ Set goals you believe can be achieved.
- ✓ Prioritize the goals, and work on them step by step. Don't tackle them all at once.
- ✓ Give your plan time to work.
- ✓ The most significant change results from changes in the environment or change in caregiver behavior.

Learn from Others

- ✓ Meet other HD caregivers in local HDSA support groups
- ✓ Join an online discussion group (*HDSA Forum; HDAC Forum et cetera*)
- ✓ Get ideas from experienced family members
- ✓ Work with a DBT or CBT (*Dialectical or Cognitive Behavioral Therapy*) Therapist, or TBI (*Traumatic Brain Injury*) Caregivers

Communication Strategies

Active Listening Skills in HD-more than the spoken word

- Attend to how a person feels more than how he or she acts.
- Don't discuss content you can't agree with. The facts are not as important as the emotions they create.
- Talk slowly, giving the person with HD time to understand what you have said

Communicating the Plan

- ✓ Use a whiteboard
 - one for daily schedule
 - one for daily goals
- ✓ No more than three daily goals
- ✓ Keep wording simple, straightforward.
- ✓ Include something fun
- ✓ Focus on the positive outcome, not the negative behavior.
- ✓ “Broken record”

Communicate

A Sample Whiteboard

Monday August 23, 2010

SCHEDULE

- 9AM Drink a Boost shake
- 10AM Call Ann
- 11AM Drink a Boost shake
- 2PM Go to dentist with John
- 4PM Drink a Boost shake
- 5PM TV-The Price is Right

Set alarm clock
near whiteboard
for reminders!

*Add phone
numbers on
whiteboard*

Communicate

A Sample Whiteboard

Monday August 23, 2010

- Drink three Boost shakes
- Call Ann only once today
- Go to dentist

Ann: 234-1234

John: 234-5678

Set alarm clock
near whiteboard
for reminders!

*Add phone
numbers on
whiteboard*

Communicate:

Shared Caregiving

- The more people involved, the more communication matters
- Explain your plan to everyone involved, and why it will work.
- Consider a Facebook Group Page or Caregiving Network

See www.sharethecare.org

Perseveration

- An uncontrollable repetitive emotion, thought, or action when it is no longer useful or meaningful
- Occurs in people affected by frontal lobe injury or disorders like HD, AD, stroke, cancer, etc.

Mark Ylvisaker, Ph.D. “Tutorial on Perseveration”

<http://www.projectlearn.net.org/tutorials/perseveration.html>

Managing Perseveration

Redirection: A Key Skill

- Change the subject
- Start a new activity
- Move to a different place
- Give the person a new job
- Place an object (e.g., a key) in the person's hand as a cue to move on

Managing Perseveration:

Limit setting

- Give the person one or two tickets for a behavior or activity and when the tickets are gone, the topic or activity is no longer allowed.
- Write down the name of the behavior on a card, and when the limit has been reached, rip up the card to symbolize the activity/behavior has ended

Unawareness

- Unawareness (“*Anosognosia*”): a lack of awareness of a symptoms or problem, attributable to a lesion in the frontal and/or parietal lobes.
 - ❑ Good - persistence
 - ❑ Bad - safety

Decision-making for people with HD

- When a person with HD doesn't appreciate the dangerous consequences of their behavior, family or another person may have to intervene.
- When a person with HD is overwhelmed with the work of living with HD, family or another person may reduce suffering if they intervene.

Ways to Intervene

- Behavior plans
- Paired-stimulus plans
- Remove access / opportunity
- Involuntary commitment
- Guardianship proceedings

Behavioral plans

Helping someone to NOT do something

Token economy systems:

- Not doing negative behavior → reward
- Doing behavior → losing reward
- Punishment doesn't work
- Rewards can be very simple, but must be immediate and consistent
- This will take time to work

Behavioral plans

Helping someone do something they don't want to do

Paired stimulus plan:

- Pair pleasant activity or memory with resisted behavior
- Singing favorite songs together with shaving or bathing
- Paired stimulus should be sensory, visual, auditory, taste, smell, etc.

See **Adult Pleasant Events Schedule**

<http://www.dbtselfhelp.com/html/print025.html>

Remove Access

- Have the car “stolen” or dismantled; park the family car elsewhere and take the bus or bike to the car when needed, carpool
- Have law enforcement search house when you and the affected person are away to remove weapons
- Put all medications in a lock box or safe, and dispense medication one day at a time while the person is sleeping

Correcting:

What to do when things are going badly wrong

Involuntary commitment to a psychiatric facility

- Each state has their own laws
- Is not a therapeutic intervention, just an interim safety measure

Long term forced medications:

- In NC, can't be done without the agreement of two psychiatrists and a legal ruling
- Use long acting medications in an injection

Guardianship

- Legal proceeding in which a judge appoints a guardian for an individual in need of special protection.
- Guardian may be appointed (“Guardian ad litem”) or a family member/friend
- Takes months
- Typically unnecessary

Empathy Revisited

What do you do when you lose empathy?

- Take a break for yourself, get some distance, find out if your feelings are temporary or an indication of the need for a major change
- Find a new caregiver (placement in a nursing facility or group home)

Review:

Behaviors

- Irritability
- Impulsivity
- Perseveration
- Unawareness/Denial
- Refusing treatment
- Decision Making
- Dangerous Behavior

Toolbox

- Caregiver empathy
- Behavior analysis
- Redirection
- Limit setting
- Communication strategies
- Behavior plans/routines
- Remove access
- Correct behavior

Success stories

- The HD community is the best source of information about what works
- Please share your stories with us at success-stories@nc-cchd.org

Hope for today

Could children in HD families experience a different disease than their parent did as a child?

- What is your belief about behavior in HD? Family myth or current reality?
- What can we do to change the natural history of HD now?
- Without misinformation, depression or violence, will we have less to fear, can we live more peaceful lives?

Is this a realistic hope?



The North Carolina Center for the Care of
Huntington's Disease

**We CAN do the
Impossible**

transform the lives of people affected by
HUNTINGTON'S DISEASE

www.nc-cchd.org