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"When people are...stripped of all responsibility for their lives, are told and treated as though they have a chronic, lifelong, progressive, disabling illness which will prevent them from accomplishing anything, they begin to believe it. Consequently, they do nothing with their lives, and let others make all their decisions and "take care" of them." Crucial to people learning to cope effectively with mental illness is having others who believe in them and have hope and confidence that they can live productive lives. Far more positive results occur when people are cared for in the community, within a service system that offers individualized treatment planning, supported housing, early intervention with newer medications, cognitive therapies, and psychosocial programs that teach families how to cope with symptoms...."

*Adapted from:
When Someone You Love Has a Mental Illness,
Rebecca Woolis, 2003.*

The Prefrontal Cortex

- "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
 - *I can't get started, and when I do, I do everything slower than I used to, and the links between steps are missing.*
 - *I need more alarms to remind me that something needs to be done; I depend on a rigid system of reminders.*
 - *Change makes me very anxious.*
 - *I sometimes can't figure out what I need to pay attention to, and I feel overwhelmed.*
- 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 inhibition – disinhibited (exaggerated behavioral expression) or highly inhibited (apathy)
 - *I don't know what to expect from other people, 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.*
 - *Being around new people is overwhelming.*
 - *Noise, colors, what people say to me or say to each other flood my brain, and I get overwhelmed.*

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

Heinz Kohut

Mood: an “emotional state of mind”

Symptoms of depressed mood:

- Sadness that won't go away
- Lack of interest or pleasure
- No appetite
- Insomnia or sleeping too much
- Restlessness or complete inactivity
- Fatigue or loss of energy
- Feelings of worthlessness or inappropriate guilt
- Diminished ability to think or concentrate, indecisiveness
- Recurrent thoughts of death, suicide, a plan for committing suicide, or a suicide attempt.
 - *My thinking is slow, and distracted.*
 - *I have to work really hard to keep on task.*
 - *Interpersonal interactions with others are fraught with struggle. I don't feel understood, and I don't understand the reactions I get from others.*
 - *I can't trust myself.*

Having HD is really hard work.

Actions that demonstrate empathy:

- Attend to how the other 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. Look for clues that help you understand. Actively listen. Ask others to tell you stories about the person that may explain the situation. Use "I" statements

Communication Roadblocks:

- Defending yourself, arguing. Asking why. Correcting. Changing the subject. Giving false encouragement. Giving unasked for advice. Using "You" statements

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

Characteristics of Irritability in HD:

- Triggered by modest or trivial stimuli
- Is not premeditated or involve planning
- Serves no obvious goal or aim
- No buildup
- Brief outbursts of rage followed by long period of calm
- Person is upset after outburst, concerned, embarrassed as opposed to blaming others or justifying behavior

Other characteristic of Irritability:

- Irritability is believed to be one of the earliest, if not the earliest symptom of HD with onset years before motor signs of the illness
- It can create great havoc in the lives of people with early HD unnecessarily, since it is a very treatable symptom
- Irritability is often expressed toward the person closest to the affected individual
- Family members should talk to the doctor alone – it is not betrayal, and confidentiality can be requested if there is fear of retribution. Start this before problems begin.

Early cues of distress:

- **Restlessness**
- **Increased volume of speech, increased rate**
- **Repetitive questions or comments**
- **Staring, intense eye contact**
- **Moving into your personal space**

What to Say during early symptoms:

- Use soft tone of voice
- Give reassurance
- Use “I” messages
- Let the upset person do most of the talking
- Summarize



What to do during early symptoms:

- Use a non-threatening body stance – relaxed, arms down at side and not crossed or on hips
- Give the person space. Keep about 1.5 – 2 feet away or more if the person is escalating
- Try not to touch the person. If you must touch them, tell the person what you are going to do.

What to do during behavior that is out of control:

- Manage your emotions, 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.
- Call for help. Have a safety plan in place.

When Behavior Escalates:

- Sometimes behaviors escalate despite everyone’s best intentions
- It is never too late to try something new
- Always look for ways for everyone to back down or leave
- Saving face can be very important to someone who feels he or she has nothing left but dignity.

Safety plans:

- No weapons in the home at any stage of disease
- Violence toward another person is never acceptable and requires a change
- Talk about suicidal feelings – it doesn’t increase the risk of suicide
- Prepare for how to get help, ask your doctor, therapist, family, friends, or neighbors for help in advance.

Safety Intervention Needed:

- **Aggression**
- **Weapons**
- **Unsafe Driving**
- **Suicidal behavior**

After escalated behavior:

- 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
- Identify the real problem, not just the part of the event that was most painful, be objective

Quality of Life Problems: The quality of life for caregivers is a major determinant of how well a person with HD lives over the course of illness!

- Depression
- Irritability
- Perseveration
- Unawareness
- Resisting behaviors
- Apathy

- Caregiver Needs
- Fatigue
- Illness
- Need for respite, change
- Needs of the Immediate Family
- Needs of Outside Helpers

Gather information:

- Is anyone else involved? Did someone call? Or forget to call? Did someone stop by or not show up?
- What happened before the event? Did something frighten the person?
- Was it a special day? Was something supposed to happen and didn’t? Was it an anniversary of an important event? Are holidays or birthdays coming?

- Has the person stopped taking her medication? Has a new medication been started?

Common Triggers	
Fatigue	Pain
Hunger	Dehydration
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:

- 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.

Be flexible:

- Common solutions:
- Simplifying the environment
- Create routines
- Prepare for change
- Outline a few different solutions...Plan A, B, C
- Consider timeframe, be patient
- Learn from others:
- Meet other HD caregivers
- Join an on-line discussion group-HDAC forums
- Get ideas from family members
- Work with a DBT or CBT* therapist *Dialectical or Cognitive Behavioral Therapy

Behavior Log:

Date/Time/ Duration	What Happened	What made it better?	Triggers	Earliest Behaviors	Plan of Action

Communicate:

- Explain your plan to everyone involved, and why it will work.
- Focus on the positive outcome, not the negative behavior.
- Try to post daily goals, no more than 3, keep the wording simple, straightforward.

Awareness

- Self-deception: we all want to believe things about ourselves that aren't completely true
- Denial: keeping out of our mind emotionally unacceptable thoughts or realities.
- Insight: the capacity to understand the significance of our thoughts, emotions or behavior.
- Unawareness (“*Anosognosia*”): a lack of awareness of a neurologic defect or illness, attributable to a lesion in the frontal and/or parietal lobes.

Refusing Treatment:

- Don't try to argue with or convince the person that they have a problem, it's usually futile and will damage your relationship
- Respond to any true remarks the person makes
- Acknowledge emotions associated with the problem without naming it
- Offer assistance in coping with feelings
- If you are pushed to give an opinion, say you don't know, hedge, or respectfully acknowledge the person's reality without agreeing.

Perseveration: Perseveration: 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, stroke, cancer, etc.

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

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

Strategies:

- Determine if the perseveration is a meaningful persistence in solving a problem, or a distressing inability to stop the behavior
- Avoid specific topics or activities that predictably evoke the perseverative behavior.

- Redirection:
 - 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
 - Use emotionally neutral activities as the key to redirection, neither highly desirable or unpleasant.

- *In some cases it may be useful to dramatically end a topic or activity. For example, you might write the name of the topic on a card and then rip up the card and throw it away while saying, “We are done with that; it’s over; no more; that topic is gone!”*
- Ignoring:
If the perseveration is neurological in origin, ignoring perseveration will increase the problem.
If the perseverative behavior is motivated in part by the person’s desire to gain attention or other positive response from the caregiver, simply ignoring the behavior may be an option.

- Changing Behavior

Behaviors can be gradually modified in people with frontal lobe disease. The Caregiver enters the perseverative activity with the person and adds additional elements to the activity. Use the activity to gradually teach new, less problematic behaviors. (eg. folding or stacking washcloths instead of walking around the room)

- Limit Setting:

Give the person one or two tickets for a perseverative topic or activity and when the tickets are gone, the topic or activity is no longer allowed. Eg. daily tickets for phone calls – 5 for one person, 5 for another person, etc – color coding helps. Limit setting is often useful for people who benefit from the perseveration becoming a deliberate focus of attention.

Decision Making:

- There is a stage of disease where every person with HD will lose decision-making capacity, even if it is only because they are unable to communicate their wishes or they are working so hard on getting through the day that thinking about the future is not possible.
- There may be circumstances in which a person with HD doesn’t appreciate the consequences of their behavior or may be unaware of an impairment, and family or another person may have to intervene.
- Taking away a person’s ability to make their own decisions is a major loss of self-determination, and should be seriously and compassionately considered

- Problem behavior must be of a nature that they challenge safe housing, are dangerous to self and/or others, could be life-threatening if medical care is not sought immediately or the affected person is suffering.
- Example behaviors include driving when it is unsafe to do so, suicidal behavior, refusal to surrender a weapon, inappropriate sexual behavior, on-going irritability, severe perseveration etc.

- Token economy systems:
 - Not doing negative behavior reward
 - Doing behavior losing reward
 - Punishment doesn't work, it confuses the person trying to figure out what to do to get a reward
 - Rewards can be very simple, but must be immediate and consistent
 - This will take time to work

- 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:

- Remove the opportunity or access to the behavior
- 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 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

Involuntary Commitment:

- Involuntary commitment to a psychiatric facility
- Each state has their own laws
- Anyone can petition for evaluation, be ready to provide important facts about dangerousness, inability to care for oneself
- Evaluation by a psychiatrist or other qualified mental health professional
- Required hearing in which a person can advocate to the judge that they do not need to be held

- Is not a therapeutic intervention, just a interim safety measure
- Force medications
- Use long acting medications in an injection

Guardianship Proceedings:

- Guardianship proceedings
- Legal proceeding in which a judge appoints a guardian for an individual in need of special protection.
- A guardian manage affairs as directed by the court- medical, financial, housing, interactions with others, etc
- Total loss of self-determination
- Information from involved physicians is required
- Guardian is appointed, either family, friend or court-appointed ad-litem.
- Takes months
- Typically unnecessary

A Comment:

Everyone has a different personality and ability to provide for their HD affected family member. One caregiver may have the resources and personality to manage many HD behaviors. Another caregiver may not be able to manage behaviors because of work, the needs of children, or even because they don't problem solve in the ways outlined here. Know you limits. If you can't handle problem behaviors effectively, find someone who can.

Summary

- Foster empathy, validate, don't judge the person even if you have to judge the behavior, recognize that all behavior makes sense on some level
- Define overall goals of treatment and target behaviors systematically at each stage of disease; address safety first
- Work harder at making things go right than correcting things that are going wrong
- Ask for help, create partnerships with other families and competent care providers before you need them
- Sometimes difficult decisions need to be made about self-determination, considering all people and factors involved. Although it might feel like you are taking something away, you're really affording your loved one a safer life.
- The natural history of Huntington's Disease can be altered in our lifetime by better treatment of psychiatric and behavioral symptoms.
- Irritability, aggression, depression, and suicide, to name a few of the behavioral and psychiatric problems of HD, are better understood and treated now than they were 15 years ago.
- Today's children in HD families can experience a different disease than their affected parent did as a child. Without ignorance or violence, they will have less to fear, and can live more peaceful lives. This is my hope.

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**Highly Recommended