

Behavior & Mood Symptoms in HD: Strategies for Patients and Families

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Psychiatric/behavioral/mood symptoms are extremely common in those with HD; in fact, most HD persons will have at least one psychiatric symptom during their lives, and some will have multiple symptoms. These symptoms in HD are a direct result of changes in the brain caused by HD. This happens because HD damages important structures and pathways in the brain—and this damage causes the problems with movement, thinking, and behavior. It is important to remember that these symptoms are caused by the illness, and not by the person suffering from HD. Understanding that behavioral issues in HD stem from a combination of brain changes and the effects of profound loss helps to guide coping strategies for patients and families.



Overview of Common Behaviors in HD

Symptom	What it looks like...	Strategy to manage
Apathy	<ul style="list-style-type: none"> Loss of motivation Difficulty attending to responsibilities, basic needs, and things the person used to think were important. <ul style="list-style-type: none"> <i>For example: Difficulty getting out of bed or starting the day, neglecting household chores or personal hygiene</i> Can appear similar to depression, however different than depression the person with apathy has desire to do be active, but doesn't have the motivation or drive to get it started. 	<p>Similar strategies are helpful for managing both Apathy and decline in executive function.</p> <ul style="list-style-type: none"> medication is not very effective in treating these symptoms. Consistent routine and predictable schedule (<i>e.g. regular meal and bedtimes, chores completed at same time each day, etc.</i>) Cues and prompts will help with focus and completion of task. <ul style="list-style-type: none"> <i>I.e. use cell phone alarms, calendars, and gentle verbal prompts</i> Use short sentences that give 1-2 pieces of information at a time Offer choices instead of open-ended questions <ul style="list-style-type: none"> <i>"Do you want oatmeal or eggs?" instead of "What do you want for breakfast?"</i>
Declining Executive Function	<p>Changes present as:</p> <ul style="list-style-type: none"> slower thinking, difficulty planning, challenges prioritizing, trouble organizing, less ability to concentrate, less decision-making, decreased flexibility, or decreased creativity. <ul style="list-style-type: none"> <i>Example: Poor performance at work, inappropriate behavior, impulsive decision-making.</i> 	

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Anxiety	<ul style="list-style-type: none"> • Intense feelings of inner discomfort, • worry, • panic, or • restlessness. <ul style="list-style-type: none"> ○ <i>Example: Frequent worrying about minor or everyday things, fear of losing control or “going crazy,” preoccupation with perceived judgment or scrutiny from others, obsessions/compulsions (see below).</i> 	<ul style="list-style-type: none"> • Medication can be effective in helping manage • Counseling or psychotherapy • Maintaining a consistent and structured routine • Use schedules and calendars • Simplify routines • Allow more time to complete daily tasks • Calm environment
Depression and Suicide	<ul style="list-style-type: none"> • Pattern of low mood • poor energy that can lead to feelings of: • hopelessness and • thoughts about ending life. <ul style="list-style-type: none"> ○ <i>Difficulty with concentration, tearful/crying, persistent sadness, irritability, or low energy; changes to appetite and sleep patterns; little or no interest in once pleasurable activities; preoccupation with or frequent thoughts about death or suicide.</i> <p> <i>HD Persons are high risk for depression, impulsivity & suicidality. These are symptoms of HD and should be aggressively treated by medical professional.</i></p>	<p> Be aware that suicide is common among those who suffer from HD and depression.</p> <ul style="list-style-type: none"> • Suicidal thoughts and statements in patients with HD <i>should always be taken seriously and addressed immediately.</i> <ul style="list-style-type: none"> ○ Call a suicide hotline ○ 911 ○ Or take to nearest Emergency Room for evaluation
Perseveration and Obsessive Thoughts and Compulsive Behaviors	<ul style="list-style-type: none"> • Fixation or being stuck on one idea or activity. <ul style="list-style-type: none"> ○ <i>(ie. ay ask same question or make the same statement over and over, fixates on specific subject, etc)</i> • Recurrent, • intrusive thoughts paired with repetitive behaviors that reduce inner discomfort. <ul style="list-style-type: none"> ○ <i>Over-concern with germs/contamination, fixation on past insults/injustices (thoughts); repeated hand washing, compulsive eating or drinking (behaviors).</i> 	<p>This behavior may not cause significant concern for safety or interfere with daily life or activities; however, they can be difficult for loved ones to cope with and manage.</p> <ul style="list-style-type: none"> • Empathize with their feelings or actions to help them feel understood • Consistent and structured routine • Use distraction techniques <ul style="list-style-type: none"> ○ <i>change the subject, direct attention to another task, etc</i> • Accommodate the behavior (if safe to do so) <ul style="list-style-type: none"> ○ <i>i.e. if wanting to always get specific food, buy the food in bulk and store out of sight,</i> • Set appropriate limits or boundaries • Seek medical evaluation for medication

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<p>Irritability and Disproportionate Anger</p>	<ul style="list-style-type: none"> • Often stems from frustration about losses (e.g. abilities, independence) combined with brain changes that decrease the ability to regulate emotions. <ul style="list-style-type: none"> • <i>Snappy or grouchy tone, screaming, swearing, threatening, slamming doors, hitting walls, pushing, striking or hurting others.</i> 	<ul style="list-style-type: none"> • Medications are effective in helping manage • Avoid direct confrontation and adopt a helpful stance when possible. <ul style="list-style-type: none"> ○ <i>Example, instead of “You can’t drive because you have HD try, “I’ll drive you—I was going there today anyway.”</i> ○ <i>This helps the person to maintain a sense of dignity and control and is less likely to trigger anger.</i> • Stop use of alcohol and substances. <ul style="list-style-type: none"> • <i>Though someone using these substances may feel better in the moment, substance use increases the risk of dangerous behavior and is not safe for people with HD.</i> • For sensitive issues, such as declining work performance or unsafe driving, involving outside agencies is helpful because it shifts confrontation away from family members. • Soft voice, kind words, and giving space may help. • If the person threatens or uses violence, it is crucial to get away and call for help (e.g. police). • Do not touch or restrain an angry or aggressive person yourself. • Limit stress • Remove weapons from the home (guns, bullets, knives, etc) • Maintain a calm, predictable environment when possible
<p>Substance Abuse or Dependence</p>	<p>Includes all alcohol, substances or drugs.</p> <ul style="list-style-type: none"> • cause lack of judgment, poor inhibition, impulsivity, anger outbursts, depression and other psychiatric disturbances. <p>Abuse or dependence on substances can mask and/or intensify behavior symptoms.</p> <ul style="list-style-type: none"> • <i>May be used to “self-medicate” from the symptoms of HD. Interferes and/or disrupts daily life, social relationships, work performance, etc.</i> 	<ul style="list-style-type: none"> • Alcohol is a brain toxin and people with HD have less tolerance for the effects of alcohol. • Marijuana and other drugs can cause and intensify hallucinations and delusions. • Reduce or discontinue alcohol use (remove from home) • Seek treatment as appropriate • Avoid confrontations while person is under the influence

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<p>Psychosis – Delusions & Hallucinations</p>	<p>Delusions are false beliefs, often held with strong conviction. <i>May be paranoid that someone or something intends to harm the individual.</i></p> <p>Hallucinations may be auditory (sounds or voices), visual (forms, animals, people) or even smells or tastes.</p> <p>Insight may be preserved (the person recognizes the perception is not real) or absent.</p>	<ul style="list-style-type: none"> • cause may be medical (certain medications, illnesses, infections or traumas) or • can be caused by recreational drugs/alcohol. • Require medical evaluation • Remove weapons or other means of harm from the environment • Avoid use of alcohol, marijuana and other recreational drugs • Involve police/911 if safety is an issue • Avoid confrontation that the delusion/hallucination is untrue or unfounded • Try to work around the beliefs, if safe • listen • distract or change subject • let them express, share belief • Counseling for loved ones may help identify coping strategies for the family

Symptom	What it looks like....	Strategy to manage
Unawareness	<ul style="list-style-type: none"> • Very common in HD • Lacks insight into severity of symptoms or safety issues • Failure to recognize or notice problematic behaviors or the declining ability to function. <ul style="list-style-type: none"> • <i>Person doesn't notice worsening performance at work, person fails to recognize they are no longer a safe driver.</i> <p>Unawareness and denial are often used synonymously, but they are different.</p> <p>Denial is psychological inability to cope with distressing circumstances, like loss of a loved one or diagnosis of a terminal disease. Often denial will decrease over time and the person will be able to process the reality.</p> <p>Unawareness is caused by the damage and the interruption of circuits in the brain. Denial is thought to be under the control of the individual to "protect" them from reality at that period in time, where by unawareness is not something the HD person can control as they just don't have any recognition that something is different or changed.</p>	<ul style="list-style-type: none"> • This symptom is often more problematic for the family and caregivers due to safety issues • Offer incentives or rewards for cooperation <ul style="list-style-type: none"> ○ i.e. offering incentives when the HD person asks others for rides to avoid driving, or staying off ladders (refraining from unsafe tasks) and willingness to allow others to assist despite they don't feel they need it • Utilize creative thinking to get HD person to cooperate with a request <ul style="list-style-type: none"> ○ i.e. disable the vehicle/hide keys to keep the person from driving when unsafe; hire handyman to prevent person from trying to do unsafe tasks themselves. • Accept it is a symptom of HD and NOT the person being non-compliant or purposely uncooperative • Try to change your response or reaction to the unawareness • Use humor to cope and laugh situations off (if safe to do so)

Behavioral Crises or Red Flags

It may not always be clear why a person is behaving a certain way. It is important to be aware of any changes that you or your loved one may be experiencing. Some changes indicate that immediate help or intervention may be required. Seek immediate help for the following:



Crisis Interventions

When you or your loved one is experiencing a behavioral crisis there are some interventions that may be available to evaluate and address the concern safely.

911 or Police Involvement

911 and/or police should be called when the safety of any person is in jeopardy

Can help de-escalate situations and determine next step to resolve issue

Emergency Room Visits

Rapid medical and psychiatric evaluation

Come prepared with information about symptoms, behavior issues and length of concern.

Bring list of all medications, include any known alcohol or substance use

Medical Hospitalization

Admission into hospital for medical issue needing immediate intervention: medication and/or observation to stabilize or prevent worsening of symptoms.

Psychiatric Hospitalization

Admission directly (voluntary or involuntary) to a facility specializing in mental illness to start/adjust medications and/or observation to stabilize.



Additional Resources



HD Medical Team
or HD Social
Worker

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HDSA

Support groups,
education events,
webinars, research
updates, written
publications.



Help4HD

Education events,
support groups, radio
shows, HDTV, holiday
assistance programs.



Suicide
Prevention
Lifeline

1-800-273-8255;
<http://suicidepreventionlifeline.org/>

provides 24/7, free and
confidential support for
people in distress,
prevention and crisis
resources



Counseling

- Your Health Insurance
- Employee Assistance Program through your employer.
- Telehealth/therapy
- College counseling center