

How can I help?

should I call a lawyer?

wrong? What should I do?

What is HD?

do? What's wrong?

How can I help?

at's wrong? **What is HD?**

When should I call a lawyer?

help? What should I do?

does HD look like? What's wrong?

What can be done?

should I call a lawyer? **What is HD?**

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When should I call a lawyer?

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What do I need to know about HD?

What can be done?

How can I help?

What is HD?

Law Enforcement Training Guide



Huntington's Disease
Society of America

Law Enforcement Training Guide

HDSA Law Enforcement Workgroup:

Robert Barron
Jayne Brown, LCSW
Stephen Clingerman, PhD
Barbara Heiman, LISW
Bruce Jennings, MA
Eileen Krueger, LCSW
Lynn Ross, LMSW
Gerleine Schoonover
Jane Kogan, LMSW
Seth J. Meyer, LMSW
Karen Tarapata, Editor

Advisors

Lieutenant Chris Bowling, Columbus, OH Police
Crisis Intervention Team
Police Chief David Bloomer, Hastings-on-Hudson
NY Police Department
Tom McCarrier, EMT-I, Stevens Point, WI
Officer Heidi Miller, Bloomington MN
Police Department
Arik Johnson, PsyD
Kathleen M. Shannon, MD

**Published with funding from a generous
grant from the Griffin Foundation**

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Preface

Huntington's disease is a genetic, neurologic disorder that leads to changes in movement, memory, and mood. While the majority of people with HD never experience a crisis that requires the involvement of law enforcement officials, difficult situations can arise during the course of the disease. Problems can come about because of a misunderstanding or a misinterpretation of the abnormal movements or behaviors that a person with HD can have, because of challenging family or domestic situations, or because of the explosive, irritable, or inappropriate behaviors that some individuals exhibit. A person with HD could also be involved in a situation that has nothing to do with HD, but in which the officer's evaluation or management is complicated by the person's neurologic disease.

This resource was created to help law enforcement officials understand how the symptoms of HD can lead to crisis situations, how careful handling of a situation can help to defuse a crisis, and what special concerns apply to people with HD who are incarcerated.

My hope is that this manual will give law enforcement officials the tools they need to make difficult situations safer for HD families, the public, and the officers themselves.

In the past, social stigma often prevented people from talking about or acknowledging this disease. Today, and in the future, we should recognize HD as a disease that presents difficult, but not insurmountable, obstacles to health and safety.

Martha Nance MD

*Director, HDSA Center of Excellence
Hennepin County Medical Center,
Minneapolis, MN*

*Adjunct Professor, Department of
Neurology, University of Minnesota*

Introduction

In the course of serving and protecting the public, law enforcement officials often encounter unusual or dangerous behavior: agitation, confusion, aggression, problems with gait or motor control, and slurred or hard to understand speech. This conduct can indicate a number of medical conditions. Huntington's disease (HD) is an example of a serious neurological disorder that can cause any or all of these symptoms.

There have been documented cases of people with HD having difficult interactions with law enforcement because their symptoms are misidentified, misunderstood or mishandled. Sadly, there can be negative outcomes, including harm to the individual or even suicide; negative outcomes which may have been preventable.

The aim of this manual is threefold: to help law enforcement officials recognize the symptoms common to individuals with Huntington's disease (HD), to provide suggestions for addressing behaviors associated with HD, and to recommend solutions that will end the encounter safely and successfully. Case examples are included to illustrate situations that may arise between people with HD and law enforcement officials.

If you would like more information about Huntington's disease, please contact the Huntington's Disease Society of America's Helpline at (888) HDSA-506. The helpline can connect you to local resources and provide additional information on Huntington's disease as needed.

What is Huntington's Disease?

Huntington's disease (HD) is a genetic neurological disorder that presents three groups of symptoms: movement disorders (abnormal movements), psychiatric/behavioral disorders, and cognitive disorders. HD affects males and females equally and crosses all ethnic and racial boundaries.

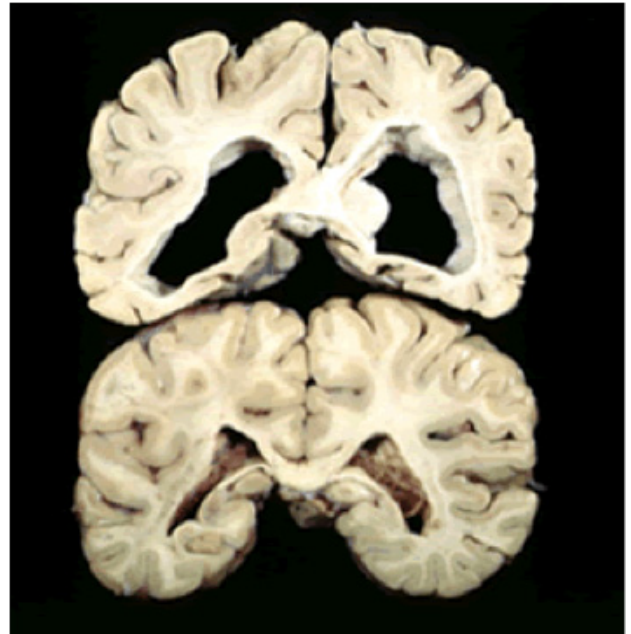
Symptoms typically begin between the ages of 30 to 50 and progressively worsen until the affected individual is unable to live independently. Death usually occurs 15-20 years after the motor symptoms begin. Presently, there is no cure, although medication can relieve some symptoms in certain individuals. It is important to know that the symptoms of HD can begin at a much younger or older age; about 5-10% of people with HD have onset before age 20.

Based on current estimates, about 30,000 people in the U.S. have HD and more than 200,000 others have a 50% chance of inheriting the gene that causes HD. Once thought of as a rare disease, HD is now considered to be one of the more common hereditary diseases.

Defining Characteristics of HD

- Psychiatric/behavioral disorder
- Movement disorder
- Cognitive disorder causing changing mental function
- Adult-onset in approximately 95% of all cases
- Genetically inherited
- Progressive and degenerative over many years
- Purely neurologic disorder (spares other organs)
- Fatal

(Adapted from A Physician's Guide to the Management of Huntington's Disease, Third Edition, © 2011)



The brain on top is that of a patient who had HD. The brain on the bottom is a normal brain. Note that the "holes" in the center of the brain on the top are larger. This is due to death of brain cells in the caudate. The overall brain size is also smaller in HD, also due to cell death. Image source: kobiljak.msu.edu

Huntington's Disease & Law Enforcement

Poor understanding of the unique challenges posed by HD can escalate a difficult interaction into a crisis. If a law enforcement official were able to say, "I know what HD is, and I am here to help," it could potentially help to de-escalate a volatile situation.

Some of the more dangerous symptoms of HD may require hospitalization or transfer to the hospital wing of a corrections facility, which is crucial to the timely delivery of appropriate medical care.

It is essential to note that symptoms of HD are a result of organic brain degeneration and may not be under the control of the person with the disease. Although some symptoms of HD can be managed for certain individuals, there is no cure, nor a treatment to slow the progression of HD. A thorough understanding of HD and its symptoms, as well as potential accommodations and strategies, will reduce negative encounters and increase positive outcomes.

Understanding HD

The most important things to keep in mind about HD are:

- 1. HD affects three aspects of normal function:**
 - a.** The psychiatric symptoms of HD affect an individual's behavior.
 - b.** The motor symptoms of HD affect an individual's movement.
 - c.** The cognitive symptoms of HD affect an individual's thinking.
- 2. HD gets steadily worse** and is therefore known as a progressive disorder. The challenges that people with HD and their families face change over time.
- 3. The three aspects of HD affect each other.**

For example, someone with HD may be frustrated due to an inability to answer a question or express a need, which can precipitate an emotional outburst or increase the uncontrolled movements.

4. **It is vital to be aware of the impact of unawareness**, a common symptom of HD, which causes the affected individual to deny, minimize, or truly be unaware of, the extent of his or her symptoms. Unawareness is due to damage to their brain. As a result:

- a. People with HD often will not have an “Aha!” moment where they suddenly understand what is happening.
- b. It is necessary to consult the caregiver for supporting information whenever possible. Page 29 contains a list of questions that can be asked of a caregiver of a person with HD.

5. **Huntington’s disease poses extra challenges for incarcerated individuals.** Information can be found on pages 31-32 and is also included as a separate one-page document.

A basic understanding of HD symptoms can allow you to utilize creative solutions for situations you may encounter in the law enforcement setting. Case examples, based on the actual experiences of HD families and reports by HD professionals, are provided throughout this manual to illustrate various symptoms of HD.

Behaviors That May Be Symptoms of HD

- Staggering gait
- Jerking or abrupt movements of the face, trunk or limbs
- Slurred speech
- Speech too loud or soft, fast or slow
- Inability to answer questions quickly
- Disorientation or lack of attention
- Irritability or combativeness
- Impulsive behavior, such as shoplifting
- Sexually inappropriate behavior, such as public masturbation and inappropriate touching of strangers
- Explosive temper or emotional outbursts
- Driving erratically or too slow

HDSA has an HD Profile form that caregivers can personalize with their loved one’s photo, symptoms, medications, and other information. If you are having an encounter with a person who has Huntington’s disease, ask them if they have an HD Profile.

The Psychiatric- Behavioral Disorder

Case Example One

A woman in her 40s with moderate HD dials 911 accusing her husband of aggressive and abusive behavior. Police officers arrive and the husband denies being violent or abusive. He states he was trying to help her and reports that she has HD. Officers determine that the woman is initially paranoid and acutely agitated. After talking things out, the woman with HD and the caregiver are calm and cooperative with each other. No arrests are made and neither was taken to the hospital.

What to consider:

Psychiatric symptoms of the disease can range from explosive outbursts and aggression to depression and apathy.

Behavior problems can be disruptive or dangerous. People with HD may have trouble regulating emotions and can have aggressive or violent behavior. Simple disagreements may escalate out of control and challenges from law enforcement personnel may cause dangerous or combative behavior. These situations and disagreements can escalate during stressful situations, such as interactions with law enforcement. Often, people with HD will quickly recover from their explosive behavior and be surprised by the reactions of those around them. Other symptoms that may lead people with HD to have confrontations with the police include

mood swings, delusional thinking, or paranoia. On the other end of the spectrum, depression and suicidal thinking are more common in people with HD than in the general population. It is not uncommon for people with HD to experience apathy (inability to initiate behavior or activity).

Situations that can Result in a Confrontation with Law Enforcement

Aggressive Behavior

Explosive behavior and aggression are common symptoms of HD. Family members may be able to identify the triggers that lead to angry outbursts, as well as strategies to reduce agitation.

Domestic Violence

Explosive behavior and aggression can lead to violence in the home. Law enforcement may be called on to defuse the situation.

Disappearance/Missing Person:

People with HD may wander away from home or may storm out in a rage. They may forget or refuse to tell caregivers and family where they are going.

Suicide Attempt:

Law enforcement may be called upon to help in a situation where a person has attempted, or is threatening to attempt, suicide.

Strategies

In addition to strategies generally used to address psychiatric issues, consider using the following:

- Due to the disease, the person with HD may not be able to think things through enough to realize the consequences of their actions. Inform the person with HD of the consequences of inappropriate behavior without doing so with threats or anger.
- The brain damage caused by HD makes it difficult for people to process information. Allow extra time for the person to comprehend. Use simple yes or no questions.
- Sometimes helping the person acquire what they are requesting will help de-escalate the situation.
- Consider other causes of discomfort: fear, hunger, fatigue, dehydration, medication effects, substance abuse.
- Use clear and simple concepts
- Consider the need for hospital evaluation
- Acknowledge feelings and actions, then try to redirect
- A loved one may provide helpful strategies and a source of support.

- Pay attention to suicidal thoughts or gestures; ask the person with HD if s/he is suicidal
- If detained, consider suicide watch for incarcerated individuals with HD

Symptoms of the behavioral disorder	Law enforcement concerns
Anxiety/Irritability/Agitation	Inability to calm down, listen and respond to officers
Impulsive behavior and poor judgment	Reckless or dangerous behavior; shoplifting; inappropriate sexual behavior or abuse
Emotional outbursts/Aggression	Rapidly escalating anger or violent reactions. Shouting or fighting possible
Fixed ideas/Compulsive behavior	Inability to switch focus and respond to officers
Apathy	Limited response can be mistaken as willful resistance
Clinical depression - sadness, guilt or suicidal thoughts	Heightened possibility of self-harm. May require evaluation or hospitalization
Bipolar mood swings, possible paranoia; rare hallucinations	Behavior not under individual's control. May require evaluation or hospitalization

Take Home Message:

Due to the death of brain cells, people with HD can sometimes respond aggressively or overreact to minor stimuli.

The Motor (Movement) Disorder

Case Example Two

A middle-aged woman with mild to moderate HD goes to see a play with her friend in a large city. She never drinks alcohol, and avoids driving because of her involuntary movements. She is observed waiting in line with slurred speech, unsteady gait, and arms waving at times. Attendants at the theatre call law enforcement, assuming she is intoxicated. Officers arrive and the woman becomes angry and raises her voice, denying that she has been drinking. She is arrested with the charge of public intoxication and disorderly conduct.

What to consider:

A person's face, trunk or limbs may shake, jerk or twitch or may twist and writhe. These movements are called "chorea." Intentional movements may be slow and clumsy. Gait may be wide-based and unsteady, and many people are prone to falls. These motor symptoms may worsen if the person is stressed or upset.

Speech is often slurred or indistinct and the rhythm or volume of speech may be irregular and poorly controlled. Some individuals have difficulty forming words or sentences quickly (speech apraxia), and therefore respond slowly to questions. People with HD have trouble swallowing and may choke.

Situations that can Result in a Confrontation with Law Enforcement

Behavior that Mimics Drug or Alcohol Intoxication

Slurred speech and unsteady gait can create the impression of intoxication. HDSA encourages people with HD who are active in the community to wear bracelets or to carry wallet cards, identifying them as having this condition. Check to see if the person is wearing or carrying one.

Erratic Driving/Inappropriate Speed

People with HD may drive erratically or too fast/slow. Minor traffic accidents or moving violations are common in HD. Check to see if the driver has a wallet card or a bracelet indicating that s/he has HD.

Strategies

In addition to strategies generally used to address motor disturbances, consider using the following:

- Avoid restraints, if possible, as they may be dangerous for a person with HD who has involuntary movements. If restraints must be used, the person must be checked frequently for abrasions, entanglement, or other restraint-related injury.
- Keep the person calm, as stress can sometimes make a person's movement disorder worse.
- Ask the person to take a breath, slow down and repeat the statement.

If the person with HD is detained:

- Be alert for choking, especially when the person is eating or drinking. If the person is with a caregiver, ask about any problems eating and swallowing.
- A person with HD burns calories at a faster rate. Incarcerated people with HD may need larger food portions. Those in long-term incarceration should be weighed monthly, and weight loss reported to the medical staff.

Symptoms of the motor disorder	Law enforcement concerns
Difficulty walking a straight line, knee dipping	Mimics intoxication
Balance problems	Mimics intoxication
Involuntary jerking or twitching movements	Mimics intoxication/willful resistance
Slowing of movements	Inability to respond quickly to requests or commands
Difficulty speaking, chewing and eating	Danger of choking while in custody/Difficulty responding to requests or commands

Take Home Message:

The movement disorder associated with Huntington's disease can cause problems with walking, speaking, and eating.

The Cognitive Disorder

Case Example Three

A man with HD in his 40s has a prescription for a controlled stimulant medication. When the physician cannot be reached by phone, the prescription is rejected. The person with HD becomes agitated and refuses to leave the pharmacy window. Law enforcement is called and a struggle ensues. When the physician is contacted, confirming the prescription, he is eventually released without charge.

Case Example Four

Young adult male in his early 30s with moderate HD has been incarcerated for assault and placed in the general population. Other prisoners make fun of him because he repeatedly forgets when meal, exercise and shower times are, and does not show up for his work program. Angered by the taunts, he continues to be involved in a number of fights with other prisoners in the general population and has repeated run-ins with the guards. He does not earn early release and has had an increased sentence for his impulsive actions and aggressive behaviors.

What to consider:

Cognition is defined as the ability to understand information and make reasoned decisions by weighing an action against its consequences. People with HD have difficulty organizing and controlling thoughts and actions. They have difficulty prioritizing, making reasoned decisions, evaluating situations, and restraining impulses. Judgment may be poor and the person may be easily upset, distracted and forgetful.

You may notice that many of these cognitive symptoms were also listed in the section on psychiatric/behavioral disorders. This is because changes to thinking and reasoning often lead to behavioral problems.

Situations that can Result in a Confrontation with Law Enforcement

Inappropriate Sexual Behavior/Sexual Abuse

People with HD may act in a sexual manner that is socially inappropriate. In some cases, these behaviors may be embarrassing or disturbing while in other cases, they may be illegal. In the prison setting, a person with HD could be physically or sexually vulnerable, or physically or sexually aggressive.

Actual Drug or Alcohol Intoxication

Due to the behavioral symptoms some people with HD may be using drugs or alcohol to self-medicate.

Shoplifting

An impulsive person with HD may be less able to resist the temptation to take something without paying and may be less aware of the consequences of stealing.

Inappropriate Smoking

Reduced impulse control and disinhibition, or a lack of restraint, may lead the person to smoke where it is prohibited or dangerous.

Strategies

In addition to strategies generally used to address behavioral issues, consider using the following:

- Allow more time for responses, either verbal or physical. A 10 second gap between the question and response is not unusual for people with HD.
- Be aware of loss of focus and concentration.
- Ask simple questions; simple multiple choice or yes/no questions are better than open-ended ones.
 - “Are you sick?,” rather than “What’s wrong with you?” or
 - “Do you live on this street?,” rather than “Where do you live?”

- People with HD may have difficulty responding to questions with too many options or with options that are too vague.

- Be patient: allow extra time; ask the person to repeat or speak more slowly. Remember the person may be forgetful.
- Explain limits and rules concisely in a firm respectful tone. It is important to give information in short statements and phrases. Too much information can overwhelm and frustrate the person with HD.
- Give the individual your full attention. Don’t just listen to what they are saying but reflect back what the person is saying to clarify statements.

Symptoms of the cognitive disorder	Law enforcement concerns
Problems with multi-tasking, attention and concentration	Inability to follow multi-part directions
Slowed ability to answer questions	Appears disoriented
Impulsive behavior and poor judgment	Reckless or dangerous behavior; shoplifting; inappropriate sexual behavior or abuse
Difficulty with sense of time	Repeated requests for the same thing
Irritability	Inability to calm down, listen and respond to officers
Emotional outbursts	Emotions not under the person's control
Difficulties with short term memory/New learning	Difficulty retrieving information/ answering questions
Fixed ideas/Compulsive behavior	Inability to switch focus and respond

A person with HD might not be responding because they are thinking about the question or can't come up with a response quickly, not because they are being defiant.

Take Home Message:

A person with HD may have difficulty remembering things and may require longer periods of time to respond to questions due to the disease.

QUESTIONS TO ASK THE CAREGIVER

The caregiver of the person with HD can be a valuable resource, and may be able to provide information about their loved one's symptoms and behavior. Because unawareness is a symptom of HD, getting supporting information from caregivers is can be essential to defusing a confrontation and avoiding detention for any period of time.

General Information

- Does this individual have an HD Profile form?

Orientation/Safety

- Does the individual with HD understand what is going on? Is he/she oriented to person, place and time?
- Is the caregiver in fear or danger?
- Is the person with HD dangerous or suicidal?
- Does the person with HD have any problems eating and swallowing?

Behavior

- Is there anyone else besides the caregiver that police can call to calm down the person with HD?
- What are some specific or concrete steps that work to calm the person with HD down, if any?

- Is the presenting behavior normal for the individual? What is the normal baseline in regards to behavior for the individual?
- Have their behavioral problems caused any criminal charges in the past?

Medications

- Is the person with HD taking medications?
 - Does the caregiver have a written list of your loved one's medications and dosage?
 - Is the individual on antipsychotic medications?

Guardianship/Power of Attorney

- Is the individual with HD under guardianship?

INCARCERATION/ CONFINEMENT

Huntington's disease poses extra challenges for individuals who are detained or incarcerated. Safety concerns may warrant increased observation, separation from the general public, or confinement in the hospital wing of a correctional facility.

Physical/Motor concerns

- Balance problems/Falling
- Unsteady gait
- Uncontrolled gestures
- Falling/Vaulting out of bed
- Speech problems
- Choking danger/Swallowing problems
- Difficulty eating/Longer eating period needed

Psychological/Behavioral concerns

- Reduced impulse control
- Irritability/Combateness
- Explosive outbursts
- Aggression/Fighting
- Sexual disinhibition, including public masturbation and inappropriate sexual advances towards others
- Depression/Apathy
- Obsessions/Compulsive behavior
- Extreme mood swings, paranoia and hallucinations (rare)

Cognitive concerns

- Memory problems – slowed processing/
Inability to learn new information
- Difficulty following multi-part directions
- Confusion/Distraction/Disorientation
- Need for more time to
answer questions

Concerns around eating and nutrition

- A special diet may be required to
prevent choking or pneumonia.
- Some people with HD may need to
eat alone to prevent choking due to
distractions.
- HD persons require more time to eat.
- Consumption of food and water should
be monitored to avoid dehydration and
malnutrition.
- A person with HD burns calories at a
faster rate. Incarcerated people with HD
may need larger food portions.

Medications

- People with HD may be taking
medications for their symptoms. It
may be medically essential for them to
continue taking these medications while
incarcerated.
- Because of the need to continue taking
medications, people with HD may be
more safely confined in the hospital
wing of a corrections facility.

CONCLUSION

In the preceding pages, we have reviewed the behavioral, motor, and cognitive effects of HD that can lead to a challenging situation. We have also suggested some strategies to deal with situations caused by symptoms of HD. Because HD is, by its very nature, a family disease, family members can sometimes be the greatest resource to law enforcement. At the same time, it is sometimes the family situations that present the greatest difficulties.

A little knowledge about HD, as we have provided here, can be very reassuring to an individual or family in a crisis situation.

HDSA staff, medical professionals at the HDSA Centers of Excellence and HDSA social workers are available to assist law enforcement professionals and work with families to make their area a safe place for people with HD, throughout the course of their disease.

Take Home Points:

1. Huntington's disease is a brain disease that leads to brain cell death.
2. Huntington's disease gets steadily worse over time.
3. A person with HD may not be aware of what they are doing.

Please contact HDSA for additional information and resources at 888-HDSA-506

**HELP FOR TODAY.
HOPE FOR TOMORROW.**

HDSA Mission

To improve the lives of people with Huntington's disease and their families.

**Huntington's Disease Society of
America National Office**

505 Eighth Avenue, Suite 902
New York, NY 10018

Phone: 212-242-1968
888-HDSA-506

Fax: 212-239-3430

Email: hdsainfo@hdsa.org

Web: www.hdsa.org

Published with funding from
a generous grant from

