

How can I help?

Should I call a lawyer?

What should I do?

What is HD?

What's wrong?

How can I help?

What'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?

What does HD look like?

What do I need to know about HD?

What does HD look like?

When should I call a lawyer?

What should I do? How can I help?

What do I need to know about HD?

What can be done?

How can I help?

What is HD?

Key Points

Please post in prominent place



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.

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

Defining Characteristics of HD

- Psychiatric/behavioral disorder
- Movement disorder symptoms
- 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

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, and this 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.

5. Huntington's disease poses extra challenges for incarcerated individuals.

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?
 - Do you 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?

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