

## What to Do if a Person Has HD

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Stress can exacerbate symptoms—don't strap them to a backboard; you may need to sedate to get them on a gurney.

Bring a family member along if possible.

Recognize choking and aspiration potential—put patient on at least a 45-degree angle, and do not tie the hands down. You may need to sedate the patient for safety.

Be careful not to misinterpret symptoms; take a helpful, supportive role.

Contact social worker, case manager within hospital to find resources to help the patient.

Check for advance directive, Physician's Order for Life Sustaining Treatment, DNR.

Check for resources attached to the 911 system.

Ask 911 dispatcher to get all possible background information from the family. Ask them to be specific about what's going on and what resources are needed to intervene.

HD/JHD Database—is loved one registered? If so, mention it.

Can request a psychiatric emergency response team (PERT) or a PERT-trained officer.

Request a crisis intervention team if necessary.

Be aware that patients with HD/JHD are covered under the ADA (Americans With Disabilities Act).

**Thank you for taking  
the time to learn more  
about  
Huntington's disease.**

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International Inc. is a  
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Huntington's and  
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Help 4 HD International Inc.

5050 Laguna Blvd. 112-543  
Elk Grove, CA 95758

916.698.0462  
info@help4hd.org  
www.help4hd.org

**Help 4 HD  
International's  
Informational  
Guide for EMTs  
and Firefighters  
About  
Huntington's  
Disease**

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The logo for Help 4 HD International Inc. features the words "Help" and "HD" in a large, blue, serif font. The number "4" is positioned between "Help" and "HD" and is rendered in a blue, sans-serif font with a vertical stack of four small, blue, rectangular shapes to its left, resembling a staircase or a ladder.

*Help 4 HD International Inc.  
Educating the World About  
Huntington's Disease*

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## What Is Huntington's Disease?

Huntington's disease (HD) is a fatal brain disease resulting from genetically programmed degeneration of neurons in certain areas of the brain. This degeneration causes uncontrolled movements, loss of intellectual and physical faculties, and emotional and behavioral disturbances, including psychosis.

HD is a familial disease, passed from parent to child through a mutation in the normal gene on

Chromosome 4. Each child of an HD parent has a 50/50 chance of inheriting the HD gene. If a child does not inherit the HD gene, he or she will not develop the disease and cannot pass it to subsequent generations unless he/she is in the "gray area."

A person who inherits the HD gene will sooner or later develop the disease. Whether one child inherits the gene has no bearing on whether others will or will not inherit the gene.

It is an "equal opportunity" disease, affecting both males and females, all ages, and all ethnic groups. When found in children and adolescents, it is referred to as Juvenile Huntington's disease (JHD).

## Some Symptoms of Huntington's Disease (HD)

- DEPRESSION
- ANXIETY
- CHOREA (Involuntary movement)
- TREMORS
- DYSTONIA (Muscle contractions)
- HALLUCINATIONS (Auditory and/or visual)
- PARANOIA
- PSYCHOSIS
- OBSESSIVE COMPULSIVE BEHAVIORS
- APATHY
- SUICIDAL THOUGHTS AND ACTIONS
- DEMENTIA
- DELAYED PROCESSING OF INFORMATION
- IMPAIRED MEMORY

## What Do First Responders Need to Know?

People with HD often appear to be drunk or under the influence of drugs, even though they are completely sober.

Someone with HD may or may not be able to tell you that he/she has this disorder.

Symptoms get worse when the person with HD is under stress. The person may not be able to reply to questions or respond to instructions. The person may seem to be kicking or hitting, but is not; that is the chorea, over which the person with HD has no control.

One of the biggest challenges with HD and JHD can be behavioral symptoms. Agitation, aggression, apathy, obsessive compulsive behaviors, and perseveration can cause lots of angst in HD families. Sometimes, these behaviors lead to domestic violence, and family members may call 911 in an effort to obtain help.

## What Do First Responders Need to Know? (Continued)

Look for:

- A Medic Alert bracelet/necklace
- A stumbling gait
- Loud, aggressive, or agitated behavior
- Chorea (uncontrolled dance-like movements that cause parts of the body to twist or writhe) or dystonia (muscle contractions)
- Impaired communication skills, including delayed response time and slurred speech
- A fixed stare or jerky eye movements
- A flat affect (blank, unemotional stare)

## Things to Think About

An HD patient who is experiencing psychosis may incorrectly believe a family member is trying to harm or even kill him/her.

Personality changes are quite common with HD, and family members may be embarrassed to admit that their once calm and reasonable loved one is exhibiting out-of-control behavior.

Sometimes, things reach the point of extreme crisis before family members call for help.

One of the most important things to remember is that this is the DISEASE, not the person, talking and acting irrationally and aggressively. Remind family members of this fact, too!

If at all possible, avoid using handcuffs or any type of restraints.

If you cannot reach the caregiver or a family member, and the person is not safe to be released, send him/her to a hospital ER or a psychiatric receiving facility. Make sure that you share information about Huntington's disease with them as it is very possible that they are not familiar with the disease.