

Irritable Aggression in Huntington's disease

**If you or a loved one are in imminent risk of harm to yourself or others,
call 911 and ask for a CIT trained officer to help you.**

Introduction:

Irritability and irritable aggression are common symptoms of Huntington's disease (HD). About 22% of outpatients experience aggression, and as many as 60% of people with HD living in long term care facilities become aggressive. Episodes may occur years before onset of motor symptoms or worsen as the disease advances. If untreated, they may cause significant disruption of interpersonal relationships, affect work performance, or risk placement in a long-term care facility. Fortunately, irritability and irritable aggression are treatable with medications and environmental interventions. HD Reach takes an evidence-based approach to helping patients and HD families manage HD related aggression, whether fear of retribution is the main concern or care after an aggressive episode has occurred. Every person with HD can benefit from healthcare interventions, compassionate care, and support. We are here to facilitate it.

How we describe behavior matters.

The following language has been used to describe HD related behavior. It's helpful to understand which of these terms best describe the person you know with Huntington disease.

Anger is an emotion that motivates and energizes us to act. It is a natural response when personal rights have been violated, or a person has been wronged. It can be a healthy and reasonable response, with positive consequences.

Irritability is a prolonged emotional state or mood in which a person can be short-tempered or easily annoyed. Often, it results from periods of fatigue, excessive stress, or pushing ourselves beyond our limits. It rarely results in positive consequences.

Aggression is a behavior motivated by an intent to cause harm to another person who wishes to avoid harm. In other words, an altercation between two people only one of whom wants to cause the other harm is more than a fight, it's aggression. Aggression can be defensive or offensive. It is often a form of communication but is never constructive.

Violence is an extreme subtype of aggression, a physical behavior with the intent to seriously injure or kill another person. It can be impulsive or premeditated, based in disordered thought processes or cool-headed planning.

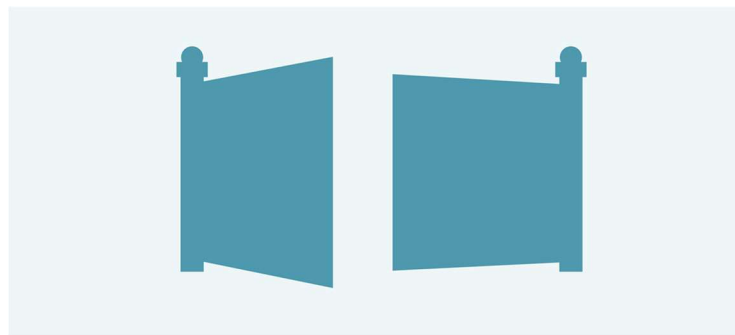
Agitation is a state of psychological and physical restlessness, manifested by pacing, hand-wringing, gesturing, hostility, excitement or distress. It can be associated with disease states, such as delirium or

dementia, or related to distressing psychological factors. Understanding the difference between aggression and agitation in people with HD requires that the observer understand the circumstances around the behavior, taking into consideration the demands of the environment and the stressors that could potentially precipitate the behavior.

There are reports in the medical literature and in case law that describe individuals with HD who demonstrate the broad range of these behaviors. It's important to note that sensational descriptions of HD related behavior make good news and garner intense social media attention. It doesn't mean, however, that aggression will inevitably happen in your family, especially with knowledgeable medical care good preparations and planning for change, stressors, and disease progression.

Why do people with HD become irritable or aggressive?

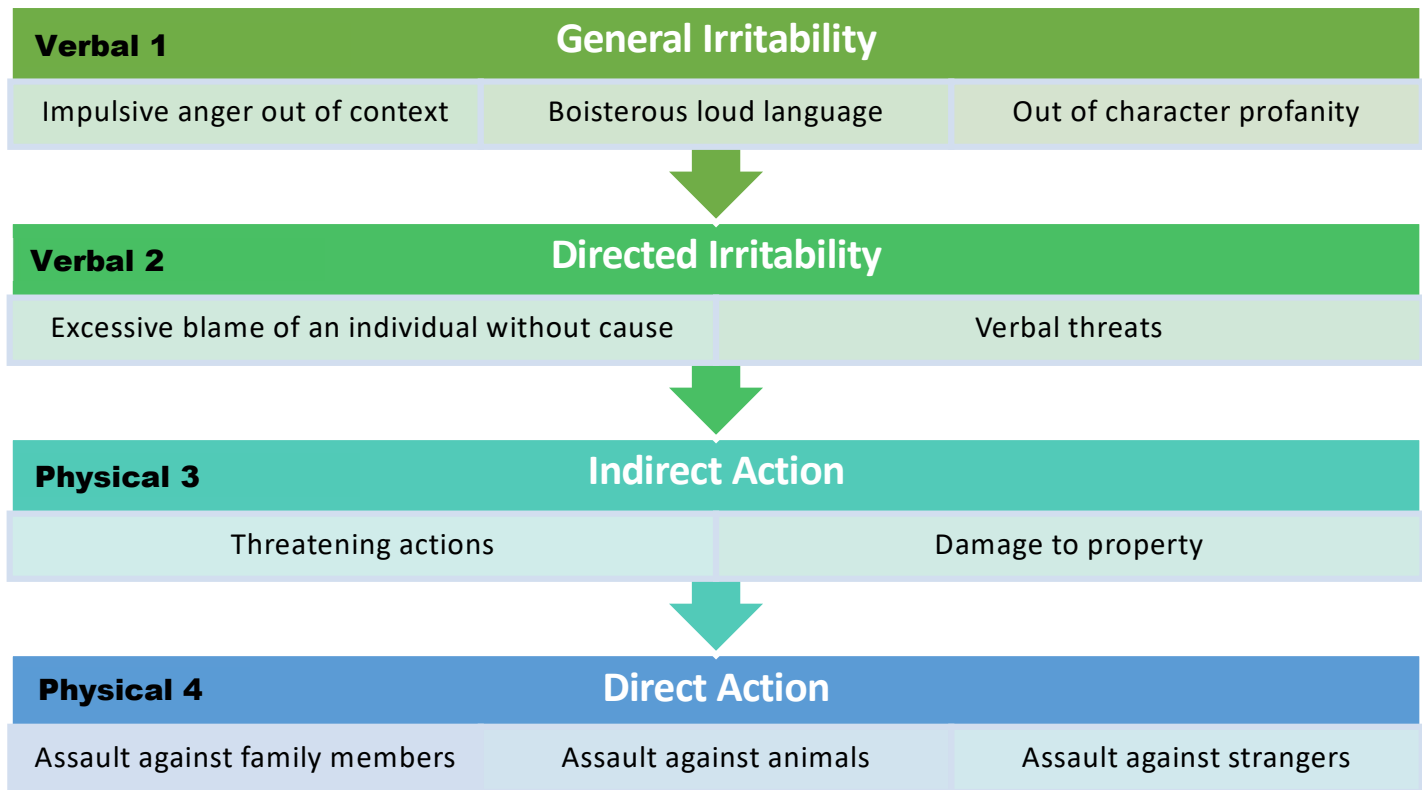
Irritable aggression in HD is related to uninhibited anger or frustration. The abnormal HD protein directly damages the part of the brain responsible for control over impulses and activation of behavior. Normally, there is a “gate” in the brain that allows an impulse to become a behavior, opening when it's appropriate to act and closing when it's not in your best interest to act. For the person with HD, it's like the gate is constantly open (disinhibition), constantly closed (apathy), or very inconsistent (unpredictable).



Many cognitive disabilities in HD are out of awareness. Before the individual became ill, these same cognitive abilities were also unconscious. It's hard to imagine how frustrating HD related cognitive impairments can be when you can't even explain to yourself or others what is wrong.

The combination of frustration and disinhibition results in irritability. Continued lack of understanding by all involved results in escalation. Only when symptoms are improved with understanding, appropriate medication and reducing environmental demands can the person with HD recognize what skills they were missing.

The Spectrum of Irritability



Understanding the severity of aggression can help the people who live with the person with HD understand the potential risk and make judgments about what to do next. There is not good data about what kind of symptoms are cause for immediate intervention and which symptoms are less risky in HD. Because of the problem of impulsivity in HD, we can't predict with certainty what will happen next in irritable people with HD. When HD related physical aggression does occur, however, our experience tells us that it will happen again unless something changes.

In other health related conditions, and often in HD, the spectrum of aggressive behavior tends to start with verbal symptoms and escalate to physical behavior (see the chart below). In general, there is time to make plans for change when behavior is in the verbal range (1-2), and a greater cause for concern of imminent risk when behavior is in the physical range (3-4). General impulsivity, substance abuse, a family history of aggression, and prior episodes of aggression all increase the risk of imminence.

All people need to feel safe to live a good life.



After sleep, food and water, safety is everything in life. You can't experience love, learn new skills, give of yourself, or live up to your potential while you're using all of your energy watching for threats and avoiding blows.

Living in the midst of aggressive behavior is by definition unsafe. Threats, damage to personal property, angry invasion of personal space, or assault are manifestations of irritable aggression associated with HD, and not a character defect. If this behavior has happened once, it's likely that these behaviors will continue to occur and may escalate without intervention.

And treatment can make a big difference! Talk with your physician as soon as possible after an aggressive episode to discuss a change in treatment plan or need for urgent intervention. It's helpful to know how to get help in the event of a true emergency. Ask your physician or social worker to help you complete a Family Safety Plan so that you know how to get help and stay safe.

Where do I start?

HD Reach social workers are specifically trained to help families experiencing HD related aggression. Since HD Reach works with all people affected by HD, we will help you determine the best course of action to handle your unique situation whether you have HD yourself, are a family member, or care for a person with HD either personally or professionally. HD Reach can help you with the following:

- 1. Address safety issues first:**
 - a. Developing a Family Safety Plan
 - b. Knowing When to Call for Emergency Services
 - c. What to expect when Emergency Services become involved
- 2. Assess needs and develop of a plan of action**
 - a. Understanding the unmet needs of the person with HD, the unmet needs of the family members involved, and the factors that prevent meeting those needs
 - b. Developing a comprehensive HD Care Plan
 - c. Facilitating healthcare, referrals, and educational opportunities
- 3. Learn how to create a healthy environment with HD**
 - a. Strategies and skills to de-escalate irritability
 - b. Skills for improving the environment to support the irritable person
 - c. Helping the caregiver reduce stress and improve their own resiliency
- 4. Follow up**
 - a. Determine if the plan is successful
 - b. Adjust the plan as needed to address changing needs of the person with HD and their family
- 5. Provide support for caregiver and family healing after aggressive episodes**

Choosing the Right Interventions:

There is no arguing that choosing what to do about HD related aggression is a very hard task. It's emotionally difficult, socially complex, and involves risk. HD Reach social workers can help you step back and take a moment to ask yourself what you really want to change and accomplish. Once you are very clear about what needs to happen, choosing the appropriate interventions becomes less complicated.

HD Reach social workers will help you choose interventions that are:

- **Goal-directed:** Meeting the legitimate needs of the person with HD and the family or potential victim(s)
- **Reasonable:** The least intrusive and controlling intervention possible. That is, not too much - an overreaction for reasons unrelated to the person's actual behavior and risk of harm- and not too little – underreacting to a real and present risk of harm to yourself, the people who are involved, and the person with HD.
- **Rational:** Taking into consideration the progressive nature of HD and the many losses associated with having HD personally, and loving someone with HD.
- **Effective:** Likely to achieve the goals of the intended intervention
- **Timely:** So that no one has to suffer longer than is absolutely necessary
- **Resourceful:** Taking into consideration all the resources available to address the problem

Plain and simple, HD Reach exists to help people find individualized solutions today for the person with HD and their family, making the most of the resources currently available. Call today at 919-803-8128 and ask to speak to the social worker closest to your location about your concerns about HD related aggression.

To learn more about the behavioral symptoms of HD and how to manage them, see the following:

Understanding Behavior in Huntington's disease, Paulsen and Johnson, 2016. This publication can be downloaded for free from the Huntington's disease Society of America):

<http://hdsa.org/wp-content/uploads/2015/03/Understanding-Behavior.pdf>

When Someone You Love Has a Mental Disorder, Rebecca Woolis, MFT, 2013. This book can be purchased from amazon.com or other booksellers. Although not addressed to the HD population specifically, there are many tips about mental illness that apply to persons with HD.

<http://rebeccawoolis.com/When-Someone-You-Love-Has-a-Mental-Illness.php>

Law Enforcement Training Guide: This publication can be downloaded for free from the Huntington's disease Society of America at

<http://hdsa.org/wp-content/uploads/2015/05/HDSA-LET-Guide1.pdf>

Huntington's disease Awareness for Law Enforcement: This publication can be downloaded for free from Help4HD International at

<https://help4hd.org/wp-content/uploads/2016/04/LE-Brochure-Officer.pdf>