hdreach
Helping families with Huntington's disease

Crisis and Safety Planning

A family safety plan uses strategies to protect everyone in the household, including the person with Huntington's disease.

A good plan includes multiple ways to access help and prepare for your safety. The following suggestions for your plan cover a range of situations. Figure out which options work best for you in your home and while you're away.

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Actions to Keep the Household Safe

Prepare other people to become involved:

- Tell people you trust about your concerns, any irritability you have observed, and any aggressive behavior you have witnessed/experienced. Be clear about whether you are asking for emotional support or asking for tangible ways they can help you.
- Ask trusted neighbors or friends to call the police if they observe certain kinds of activities at your home such as fighting, loud noises, or harmful activity.
- If you have children, identify friends, neighbors, and/or relatives who your children can go to immediately or for an overnight if you have to go to the hospital or the police station.
- Contact your local law enforcement and Crisis Intervention Team (CIT) officers to explain a member of your household has HD and that chorea may appear to be agitation or intoxication and extra time may be needed to communicate with the person with HD. Watch this video to learn more about working with law enforcement. https://vimeo.com/619947628

Create a safer environment:

- Remove all weapons in your home (firearms, knives, bats, etc.). If that's impossible, put weapons in a locked container and remove the key from the home.
- Remove or hide any other items in the home that can be used as a weapon or to destroy property (e.g. knives and other sharp objects, matches and lighters, any heavy or blunt objects, etc.).
- Install smoke detectors on each floor and keep fire extinguishers easily accessible.
- Lock away or hide extra medications.
- Figure out ways to hide, isolate or get out of each room in your home. During a crisis, position yourself closest to a door or other safe exit point.
- If you need to isolate yourself in a room, consider whether the room has a lock on the door, telephone, and an easy way to exit. Avoid kitchens and garages where knives or other potential weapons are kept; and avoid rooms where you might be trapped, such as the bathroom or other small space.

Planning for making a quick exit:

- Figure out who will help you if you need to leave your home quickly.
- Figure out who can store an Emergency Bag (see checklist below) for you.
- Think about people who might lend you money in an emergency.
- Make plans for your pets if you ever need to leave your home quickly.
- Think about multiple ways to get out of your home safely. Practice getting out safely.

- Think about a safe place you can go after you leave such as:
    - ✓ A friend or relative's home.
    - ✓ A hotel.
    - ✓ A local shelter.
- Put some money away in a safe place. Always try to keep a small amount of money on you including money for bus or rides.
- Fill in and regularly update the Safety Plan. If you need help thinking through the options, you can work with someone you trust or an HD Reach counselor.

If you make a quick exit:

- Before you leave, try to remove objects that could be used to harm oneself or others. Consider taking the car keys or disabling the car so the person with HD won't be able to drive while agitated.
- If you are concerned the person with HD may harm themselves or others contact your local mobile crisis team or call 911 to help the person with HD as soon as you are safe. If you call the police, ask for a Crisis Intervention Team (CIT) to respond to the crisis. CIT trained officers have specialized skills to deal with individuals with medical or mental health illnesses.

What to take with you or keep ready to go:

You cannot predict when it will be safe to return home, so you need to be prepared to manage your life and the lives of those who depend on you. Some of these items you can try to keep with you, others you may be able to pack in an "emergency bag".

- Cell phone and charger.
- Money: cash, bank account information, checkbook, and credit/debit cards.
- Keys: home, car, and work.
- Medical care: prescribed medications and medical devices.

- Contact information: address book or cell phone with contacts.
- Valuables: Family photographs, your diary, jewelry, small items of sentimental value.
- Clothing and toiletries for you and other members of the household.
- Distractions: Your children's favorite small toys, small items that will comfort you.
- Documentation: Safety Plan, list of medications, copies of medical records (e.g. psychiatric reports, Community Treatment Orders), documentation of prior aggressive behaviors (see Documenting Important Information), and a copy of any Durable power of attorney for the health care of the person with HD.

What to Expect During a Crisis

When you feel that you or a member of your household is in danger or serious property damage is likely, contact outside help. A person with HD might develop symptoms that make living in a hospital or other protective environment the best option for a short period of time. If the person with HD is unaware of their symptoms and highly resistant to care, crisis services may be the only way to get them the care they need to provide symptomatic relief. Many families who have used crisis services report the long-term improvement in symptoms and family life is well worth the difficulty of calling outside help.

When asking for immediate assistance from Mobile crisis or emergency services try to remain calm and provide the following information:

- Tell them someone is experiencing a mental health crisis and suffers from Huntington's disease
- Explain the nature of the emergency
- Explain your relationship to the person in crisis
- Describe any weapon(s) involved
- Request a Crisis Intervention Training (CIT) Officer
- When emergency responders arrive, tell them the person has HD, explain any past violence, suicide attempts, drug use, and stressors. (Tips for keeping a Documenting Important Information file).
- Provide a First Responders Information sheet by text or email or have a copy at home.
- Once 911 has been called and officers arrive, you don't control the situation.

If the situation can't be resolved on site, taking the person with HD to an emergency room may be the best option. If a law enforcement vehicle transports your loved one, the usual policy is to use handcuffs. This can be very upsetting for everyone involved. The officer may decide that taking a person into custody is more appropriate, but you can request and encourage the officers to view the situation as a mental health crisis.

Going to the emergency room may involve a lot of waiting. Some items to consider bringing:

- Items to keep the person with HD calm
- Activities to occupy other members of the family
- Safety Plan and Documenting Important Information file with all medications and contact information for medical providers

Who to call during crisis situations:

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What will you do during a crisis?

- Dangerous/Unsafe Situation
  - Threatening with a weapon — Call 911
    - Ask for CIT Police response
    - Remove everyone else from the house to a safe place
    - Outcome- person may be arrested or taken to ER
  - Person is suicidal or having psychotic episode — Call 911
    - Ask for EMT or CIT
    - Person will be evaluated at the ER and possibly admitted for stabilization
  - Neglect — Call Adult Protective Services
    - Alone and can't care for themselves
    - Being Neglected by someone else
    - Being financially taken advantage of
    - Being hurt by caretaker
  - Can't contact a loved one — Call Police Non-emergency — Ask for a welfare check
  - Emotionally Unstable and willing to get help
    - Call your psychiatrist, neurologist, and/or therapist for help
    - Bring to Emergency Room

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CALL US AT 919-803-8128 + EMAIL US AT INFO@HDREACH.ORG + VISIT WWW.HDREACH.ORG

After an Episode of Aggression or Irritability

- Contact members of your health care team as soon as possible after the episode of aggression. By calling you are not violating the confidentiality of the patient, you are sharing your observations about irritability and aggression. Describe the events calmly and objectively. Make some notes before the call to be certain you cover all the facts. Be sure to include information related to the willingness of the person with HD to participate in going to the doctor and recent compliance with treatment.
- Share your fear of retribution or prior experiences of retribution.
- Clearly request the help of your health care professionals in the management of the HD related symptoms.

Keep a record of events:

Record all acts of aggression, violence or property damage as they occur. This will help determine what threatening behaviors the individual may display during a crisis/aggressive episode and how to safeguard against them. This is also useful information to provide to the individuals’ treatment team or to the police. See Documenting Important Information file for more information.

Safety Plan

	Name	Email	Mobile Phone	Office Phone	Home Phone
Patient					
Care Partner					

Health Care Professionals			
	Name	Phone	Email/Address
Psychiatrist			
Therapist			
HD Physician			
Social Worker			
People to call for help			
Neighbor			
Family Member			
Friend			
Other			
Strategies to keep the home environment safe:			
Strategies to de-escalate a tense situation:			
Items I need to have with me if I leave:			
Things the person with HD might need:			
Emergency contacts for children:			

Emergency Resources

911: Ask for CIT Trained Officer

Explain the person has Huntington's disease and request to send the "Information for First Responders"

Mobile Crisis Service phone #: ____

Local Crisis Center phone #: ________________________ Other phone #:___________________________________

Information for First Responders

Person with HD's Name ____
Doctor's Name ____
Doctor's Phone # ____

Health Insurance Name ____
Policy # ____
Phone # ____

Home Address ____
____

Primary Care Partners' Contact Information
Name ____
Phone ____
Alternate Phone ____
Address ____
Alternate Address ____

What is Huntington's disease?

Huntington's disease (HD) is an inherited brain disorder that results in the progressive loss of mental faculties and physical control. Over time, HD affects the individuals' ability to reason, walk, and speak.

HD typically strikes in adulthood between the ages of 35-50, but also affects people who are younger and older. HD is known as a family disease because each child of an affected parent has a 50:50 chance of inheriting the disorder.

Common Symptoms Include:

- Personality changes, mood swings and depression
- Forgetfulness and impaired judgement
- Unsteady gait and involuntary movements
- Slurred speech and difficulty swallowing

For more information about Huntington's disease please:
Visit: https://www.hdreach.org/
Call: 919-803-8128
Email: info@hdreach.org

Documenting Important Information and Worrisome Behaviors to find the right treatments

Keeping detailed notes on a person with Huntington's disease aggressive and worrisome behaviors can provide useful information for the individual's treatment team and others they come in contact with in the community. Good records can protect the person with HD, they can protect you, or the people who live with you. Sharing notes about what you've witnessed can also help ensure the person with HD is connected to appropriate mental health services, instead of going to the hospital or in extreme situations, jail. It may also protect you if you are falsely accused of neglect or abuse of the person with HD. You can use these notes to refresh your memory as you communicate with the doctor, if you are interviewed by the police, if you talk to a lawyer, or if you're asked to testify in court. Being prepared with accurate information will help you manage any potential situation.

To get started, create a file, database, or document that includes all information pertaining to the mental illness and treatment plan of the person with HD. Keep notes and documents in a binder or portable file and store them in a secure place that is accessible to you.

Recording episodes of behavior in real time:

Most of us can't remember details beyond 24-48 hours. Even details of very significant events begin to fade within days. For this reason, keeping a detailed record of events allows you to examine what triggered the episode, what interventions improved the situation, and then communicate the information accurately. It may be difficult to relive the episode while recording it, but having objective information is critical to proper care. You may want to provide this information privately to the treating physician, or even before a doctor's visit. This allows the team to prepare to manage the situation in a way that validates the person with HD and protects those who report the information.

Your records should include:

- Date, time, and duration of episode
- People involved
- What everyone said or did
- What lead up to the incident. To understand potential triggers, start your record at the last moment you remember everything being normal prior to the episode.
- If you were threatened, but not physically assaulted, write down exactly what was said to you and describe the situation.
- If threats were made toward others, write this down too.
- If you were struck or injured, write down all the details including:

  - ✓ Exactly where you received the assaults or injuries (e.g. your left arm or the back of your neck).
  - ✓ How you were hurt (e.g. with open hand, shoe, or book).
  - ✓ How many times you were hurt.
  - ✓ How severe your injuries were (e.g. bruises, cuts requiring stitches, or broken bones).
  - ✓ If there were witnesses, and if so, their names.

- Whenever possible, keep evidence of the injury and/or threatening behaviors such as:
  - ✓ Photographs of your injuries.
  - ✓ Recordings of threats (including any voicemail, text messages, social media posts).
  - ✓ Torn clothing or property that was damaged.
  - ✓ Bank and/or credit card statements (in instance of excessive spending).
  - ✓ Names and contact information of witnesses.
  - ✓ Your medical and other personal records.

Although aggressive behavior, such as verbal threats or minor physical interactions are common in HD, violence is not as likely. It's impossible however to predict violent acts, and prior aggressive actions is the only reliable predictor of future episodes. Being prepared to manage early signs is the best way of protecting the person with HD, yourself, and your family.

Other information to document includes:

Diagnosis and Symptoms

- Documentation that the person has Huntington's disease (letter from doctor stating the person has HD, genetic testing results).
- Clear description of recent symptoms (e.g. cognitive impairments, mood swings, motor symptoms, medical symptoms, suicidal behaviour, aggressive behavior).
- History of substance abuse (drugs and alcohol), problem with gambling or other compulsions.
- History of trauma (e.g. history of neglect or physical abuse, tragic life experiences, immigration/refugee experience).
- History of recent loss (e.g. diagnosis of HD, job loss, loss of driving privileges, loss of family member).
- Things that make symptoms worse: (e.g. hunger, thirst, fatigue, specific people).
- History of self-harm: previous thoughts of and/or attempts to self-harm, previous thoughts of suicide and/or suicide attempts.
- History of harm to others: verbal threats, damage to property, invasion of personal space, assault, seriousness of injury to others).

Treatment Information

- Contact information for the treatment team/healthcare providers (family doctor, psychiatrist, case manager, employment counselor, occupational therapist, peer support worker).

- Preferred treatment style and/or favorite service provider.
- Preferred hospital or hospital where he or she previously received care.
- Contact information for HD Reach and other community workers or organizations involved in treatment plan.
- Prescribed medication (include all medications, not just the ones prescribed to treat the mental illness). Include dose, frequency and whether the person with HD is taking medications as prescribed.
- Allergies, including medication and environmental exposures.
- Hospital records (you should request these as soon as the person with HD is discharged from the hospital).

Strategies that Help

- Best ways to communicate.
- Coping mechanisms and strengths.
- Interventions that help the person with HD: (e.g. distraction, redirection).
- What helps when the person with HD is feeling and doing well (e.g. formal and informal supports, hobbies, activities, medications).

Information for Health Care Institutions:

- Driver's license or identification card
- Insurance information
- Pharmacy Information
- Legal documents (e.g. Health Care Power of Attorney, Psychiatric Advanced Directive, Financial Power of Attorney, other pertinent documents)

Miscellaneous Information

- Caregiver issues: your struggles with the situation and ongoing ability to manage symptoms
- Family issues: impact on the people in your home, other family members.
- Confidentiality issues when communicating with extended family members.
- Any other information that can provide a better understanding of the needs and circumstances of the person with HD.