

At times, people with Huntington disease (HD) may face legal challenges. This can occur when law enforcement officers responding to a situation are unfamiliar with the symptoms or behaviours associated with HD. As a caregiver or family member, you may need to explain HD and speak on behalf of the person with HD. Here are some suggestions to navigate these interactions more successfully.

What is Huntington disease?

HD is a hereditary, neurodegenerative disorder affecting 1 in 7,000 Canadians. It results from a genetic mutation that causes the progressive death of specific brain cells, leading to challenges in movement, emotions, and thinking. Symptoms typically emerge between 35 and 55 years of age and worsen over time. Although there is no cure, medications can help manage symptoms.

HD Symptoms and Law Enforcement Interaction

Symptoms of HD often intensify in stressful situations and could be misunderstood by law enforcement. The combined challenges listed below can increase the risk of misinterpretation or conflict in crisis situations.

M

Movement: Uncontrolled movement is often the most immediately noticeable symptom and may be mistaken for intoxication or substance abuse.

E

Emotions: The general lack of awareness and understanding about emotional and mental health illnesses can lead to the criminalization of illness-induced behavior. Police officers are often the first to respond to emergency situations and may not immediately identify that emotional reactions can be intensified and complicated by HD.

T

Thinking: Cognitive symptoms can make self-regulation difficult, which may result in unintended conflict with authority.

Proactive Steps to be Prepared in Case of Emergency:

- Consider carrying a wallet card that includes HD symptoms and contact details.
- Purchase a medical alert bracelet/necklace listing HD
- Enable location software on smart phones or other devices
- Keep an up-to-date photo to share with law enforcement officers. Include height, weight, hair and eye colour details on the back

TIPS FOR COLLABORATING WITH LAW ENFORCEMENT DURING TIMES OF CRISIS

Missing Persons

- Call law enforcement if a person with HD goes missing and they cannot be located promptly, and describe them as a "vulnerable adult" or "at-risk"
- Consider using social media to engage your community in looking for the person
- Use your smart device to track their location

Law Enforcement Questioning

- Explain HD symptoms and offer education on ways to deescalate the situation
- Stay calm. The person with HD could be confused and may take their cue from you. If you get upset or excited, they may do so as well
- As a family member or carer, you know best how to calm your person. Employ your personal strategies to keep your person with HD calm and composed
- Once engaged, officers may be required to act or file a report. Always cooperate with police procedures to expedite the process

Arrested and Transported

- Ask for the officer's name and the location where the person with HD is being taken
- Go to the police station promptly, bringing a friend or family member for support if needed
- Encourage the individual with HD to wait for legal counsel before answering any questions and to follow the guidance provided by their lawyer
- If a power of attorney exists, connect with legal counsel and law enforcement

Detainment or Incarceration

- Provide a list of medications and ensure the individual is medically assessed upon arrival
- Keep detailed notes of discussions with officers, including names, dates, and times
- Advocate for the individual's needs, including protective custody and medical calls
- Provide prison medical and social work staff with HSC resources to address HD specific physical and emotional needs
- Ensure the person's medical team and community supports are aware of the incarceration

HSC Law Enforcement Educational Resource Package

For support in addressing the unique challenges individuals with HD may encounter during interactions with law enforcement, reach out to your local Resource Centre Director (RCD) for consultation and advocacy. HSC has a package of educational resources tailored to increase awareness of HD-specific needs among law enforcement professionals. This package of educational resources includes posters, infographics, facts sheets and digital media that can be delivered by RCDs through tailored in-service presentations across the country. These in-service presentations can be delivered in-person or virtually.

Conclusion

People with HD face unique challenges when navigating the legal system due to the neurodegenerative nature of the disease. A multidisciplinary approach involving HD specialists, legal professionals, and advocacy groups is essential to supporting those impacted by HD. Accessing your team of support is crucial in times of need. You are not alone.

RESOURCES

- HSC Resource Centre Directors (RCD): www.huntingtonsociety.ca/family-services-team-list/
- Informational fact sheets for family and friends impacted by HD: www.hdfactsheets.ca
- Healthcare professionals and caregivers needing a more in depth understanding on HD: www.huntingtonsociety.ca/hd-booklets-and-publications/
- Download the HD identification card here: www.huntingtonsociety.ca/hd-identification-cards/
- Thank you to HDSA (hdsa.org) for assistance with this fact sheet