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Caregiver Guide



Huntington's Disease
Society of America

Caregiver Guide

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Preface

It's a sad fact, but if you are a caregiver for a loved one with Huntington's disease, you have probably either [a] already experienced situations where law enforcement has been involved in your lives or [b] probably will be sometime in your future!

When I cared for my daughter Kelly, who had Juvenile HD, we went through some very painful years of her running away, taking drugs, threatening suicide, 'borrowing' my car without permission, etc. all before the ripe old age of 15! Around the age of 18, I thought the hardest part was over once she started showing more physical symptoms of HD, and wasn't quite as mobile as she would have liked. Wishful thinking, because then we fought not only the discrimination that comes from people ignorant about HD, but sometimes out and out harassment from local law enforcement personnel.

I can't remember all of the times Kelly, whose favorite thing to do was to hang out at the beach, was hauled off to the police station under suspicion of being drunk or being on drugs. Fortunately, knowing people couldn't understand her speech, Kelly carried her HDSA "I Have HD" card with her everywhere that instructed people to call me in case of an emergency. Once I explained over the phone what HD was, the police typically said for me to come in and pick her up.

When I went, I was always armed with brochures on Huntington's disease to hand out, but the next time a different officer saw Kelly talking to strangers and slurring her words... off to jail she'd go again!

Those years were beyond frustrating for us, which is why I'm elated that this manual for caregivers provides you with the guidelines to arm yourself by utilizing some of the suggestions contained here that may avoid heartbreak for you and your family in the future.

*By Jean Miller, HDSA Patient Advocate
Clearwater, FL*

Introduction

There may be times during the continuum of Huntington's disease (HD) when confrontations arise between you and your loved one over unsafe or socially unacceptable behavior. During these times, law enforcement personnel may become involved.

Law Enforcement (LE), in the context of this document, includes any official personnel, local or state, who have the official capacity to respond to emergency situations: Police, State Patrol, Deputized personnel, Paramedics, EMTs, Emergency Medical responders, as well as security personnel at department stores, shopping malls, hospitals, etc.

This guide was developed to provide concrete suggestions and useful advice to you for these times of conflict. Being prepared for potential confrontations can ensure the best outcome for all concerned.

Problems may arise when law enforcement personnel, responding to a call involving your loved one, are unfamiliar with Huntington's disease. They may misinterpret the aggressive behavior, inability to obey directives and combative response to restraint by the person with HD as willful defiance. An unsteady gait, balance problems and slurred speech can easily be misread as intoxication. It may fall

on the caregivers and family members to be HD educators and advocates, as well as to effectively communicate on behalf of their loved one.

The issues discussed in this guide are not meant to imply that every person with HD will demonstrate socially unacceptable behaviors or that the behaviors will escalate to the level of legal action. The goal is to help caregivers and family members be prepared to respond constructively during an incident.

It is recommended that you read this entire guide before a serious situation or crisis takes place. The suggestions on what you can do, as well as what to avoid, can guide you in making good choices in challenging situations. Taking the time to think about potential confrontations before they occur may even help you to defuse a situation before it is necessary to call the authorities.

This guide is one part of HDSA's Law Enforcement Toolkit. If you would like more information please contact the HDSA national office at 800-345-HDSA.

GENERAL GUIDELINES FOR MANAGING AN ENCOUNTER BETWEEN A PERSON WITH HD AND LAW ENFORCEMENT OR OTHER EMERGENCY SERVICES PERSONNEL:

Misunderstanding and conflicts may arise when emergency services personnel are not familiar with Huntington's disease or lack knowledge of the complexity and severity of its symptoms.

Creating a Plan/Before Law Enforcement Becomes Involved:

- Take the first step and reach out to your local Law Enforcement. Using the Law Enforcement Toolkit, provide information on HD and what HD means for your loved one. Introduce your loved one to the local Law Enforcement.
- Encourage your loved one to carry an "I Have HD" card or another identifier of HD. Keep an updated HD Profile Card in an easily accessible place in case of an emergency. A Profile can also be provided to the local LE so they can become familiar with your loved one and their symptoms. An HD Profile Card is included as part of the Law Enforcement Toolkit.

- Think about what you would do in case of emergency. Fill out a Crisis Template and be sure it is kept up to date. A Crisis Template is included as part of the Law Enforcement Toolkit. Talk to your HDSA social worker or other trusted professionals to discuss local resources available to you.
- Research your loved one's legal rights. Talk to an HD-knowledgeable attorney or an attorney that is familiar with the Americans with Disabilities Act. Creating a relationship with a lawyer early on can help save time and energy in case of an emergency. Please see the "Legal Resources" section in the back of this guide for more information on finding an attorney.

When Dealing with Law Enforcement:

- The responsibility of LE is to protect the safety and welfare of the public, including your loved one. During your first conflict with LE, talk to the police to discuss how the situation can be prevented in the future.
- Dealing with LE can sometimes be a frustrating and confusing experience. Using a calm tone and attitude during the incident can help the situation go smoothly and help keep your loved one calm should they start getting agitated.
- Keep your hands visible at all times.
- Do not attempt to convince the LE officer to leave the situation or ignore it. Once the encounter has begun, LE may be required to take some action and/or create some sort of report.

SITUATIONS THAT MAY CAUSE SOCIAL CONFLICTS OR ENCOUNTERS

There are many reasons why a person with HD might have an encounter with emergency services personnel. Some incidents will occur because of misperceptions of HD symptoms, even though the person with HD is entirely innocent. Others will happen because of socially unacceptable or dangerous behaviors caused by symptoms of the disease.

Misperception of drug or alcohol intoxication

Symptoms of HD, such as slurred speech and unsteady gait, can create the impression of intoxication. The goal is to prevent the misunderstanding from escalating into a conflict.

Creating a Plan/Before Law Enforcement Become Involved:

- Learn about public intoxication laws in your state to help you speak with emergency service officials and LE personnel.

When Dealing with Law Enforcement:

- A Breathalyzer test can help clear up the misperception that your loved one is intoxicated. In some areas, refusal to take a Breathalyzer test can lead to an arrest for public intoxication.
- Do not automatically assume that your loved one is sober. Your loved one may be intoxicated without your knowledge.

Shoplifting

Changes to the brain caused by the disease will make a person with HD impulsive and less able to resist the temptation to take something they want without paying for it. The person with HD may forget or minimize the consequences of stealing from a store.

Creating a Plan/Before Law Enforcement Become Involved:

- If you see your loved one shoplifting, try to stop the situation in a calm manner. Say something like: "If you want this [item], we can take it to the checkout."
- Try to distract your loved one and replace the item before leaving the store.
- If the situation allows, find a quiet place to have a calm discussion. Explain the potential consequences of the actions to your loved one.

When Dealing with Law Enforcement:

- If your loved one is stopped for shoplifting, try to explain the biological basis for the behavior to the Law Enforcement/store staff. Offer to pay for the item or return it, if possible.
- Try not to become belligerent or deny the behavior to the store staff or LE. Explain that the behavior is a symptom of a disease and ask for their compassion.
- Do not participate in or cover up for illegal behavior. Shoplifting is a crime.

Inappropriate Sexual Behavior

Social disinhibition is a symptom of HD, as is the reduced ability to delay gratification. This can lead to behavior that is embarrassing and disturbing to caregivers and family members. The goal is to manage the behavior in a safe way.

Creating a Plan/Before Law Enforcement Become Involved:

- A person with HD who exhibits sexually inappropriate behavior should never be left alone with minors.
- If the person with HD removes clothing, gently discourage the behavior.

- If a person with HD is masturbating in a room with others, tell them they need to do that privately. If they attempt to continue, bring them to a bathroom or their bedroom.
- If your loved one touches others inappropriately, remind them that the behavior is inappropriate and that they can be arrested.
- Keep a calm, matter-of-fact and orderly demeanor when discussing inappropriate sexual behavior. If you become loud, anxious, impatient or upset, so will the person with HD
- Watch for romantic or sexual obsessions. Make it clear that stalking is inappropriate and illegal. Speak to your loved one's physician if obsessions become worrisome.
- Understand that your loved one may fixate on a sexual idea or behavior and have difficulty controlling these thoughts.
- Do not ignore inappropriate sexual behavior. It may escalate to sexual abuse or assault if not addressed.
- Seek counseling for the person with HD, or for yourself, if changes in sexual behavior affect your intimate relationship.

- Be aware that the lack of impulse control associated with HD can lead to promiscuity; this can also make the person with HD an easier target for abuse.
- Talk to your children and develop a response or plan to deal with this behavior.
- Let your children know that you are there for them and available to talk about anything.

When Dealing with Law Enforcement:

- If your loved one continues to exhibit inappropriate sexual behavior in a dangerous situation, call your local LE for help in dealing with the problem.
- A person with HD, exhibiting inappropriate behaviors, may be labeled as a sex offender.

Sexual Abuse

Changes to the brain and reduced impulse control caused by HD can result in aggressive or dangerous sexual behavior that must be controlled.

Creating a Plan/Before Law Enforcement Become Involved:

- Medication may help the person with HD control their behavior. Talk to your loved one's physician about disturbing behavior before it escalates to assault or abuse.

When Dealing with Law Enforcement:

- Recognize that no one is allowed to force themselves sexually on another person. Spouses and children are protected under the law.
- Call law enforcement as soon as possible if abuse or the threat of abuse occurs. Protect yourself and your children by leaving, if possible.
- Allow the law enforcement officers to make an arrest. Pressing charges will help prevent the abuse from happening again.
- Do not keep the abusive sexual behavior a secret. Allowing a child to be abused is a crime.

- Get counseling for all involved parties.
- There is no shame in being a victim of abuse. Keep your focus on ending the abuse.
- Do not leave yourself or your family in a dangerous situation. Call law enforcement for help and talk to your local HDSA social worker or a trusted professional.
- For help in responding to sexual abuse, please contact RAINN's national sexual abuse hotline at 1.800.656.HOPE or via the web at www.rainn.org or the National Domestic Violence Hotline at 1.800.799.SAFE or via the web at www.thehotline.org. These numbers and websites are included on the Crisis Template, which is available as part of the HDSA Law Enforcement Toolkit.
- Have a plan in place to go to a safe place if needed until the situation deescalates.

Aggression

Explosive behavior and aggression are common symptoms of HD that may be manageable. It may be possible to identify some of the triggers and frustrations that lead to angry outbursts in order to defuse a confrontation.

Creating a Plan/Before Law Enforcement Become Involved:

- Don't wait for a crisis to think about what you would do in case of emergency. Fill out a Crisis Template and be sure it is kept up to date.
- Attempt to identify the source of the aggression and the root cause of the anger. This is usually why the aggression is taking place. Keep in mind that the root cause of the anger may not be based in reality.
- When talking with a person with HD who is getting aggressive, slow your speech, quiet your voice and keep your posture as relaxed as possible. Do not attempt to touch your loved one, as that might be interpreted as an aggressive act.
- Inform the person with HD that he or she is losing control and is scaring you.
- Use a firm and calm voice to tell the person with HD to stop yelling, hitting or kicking.
- Never put yourself in physical danger. Do not hesitate to leave the house or lock yourself in a secure room and phone for help if the situation escalates.
- Be aware of your physical surroundings and of cues. Keep an arm's length away and try to keep a clear pathway to the door.
- Do not get into a fighting stance or threaten the person with HD. Act confidently but not combatively to defuse the situation.
- Have an escape plan should the situation get dangerous. Talk to an HDSA social worker or a trusted professional about creating a safety plan and escape routes.
- Keep in mind that aggression may be medically manageable. If your loved one has symptoms of aggression, talk to their doctors about possible medication.
- When the crisis has passed, do not lie to the person about their aggression. They are usually aware of what they are doing and are acting out from fear or impulsivity.

When Dealing with Law Enforcement:

- If you are in danger, get yourself to a safe house and contact your local law enforcement immediately. LE can help protect you and your loved ones and diffuse the situation.
- For help in dealing with domestic violence, you can contact Safe Horizon at 1.800.621.HOPE (4673) or via the web at www.safehorizon.org or the National Domestic Violence Hotline at 1.800.799.SAFE (7233) or via the web at www.thehotline.org.

Driving

The complex symptoms of HD will interfere with the ability to drive and ultimately it will be necessary for the person with HD to give up this privilege.

Creating a Plan/Before Law Enforcement Become Involved:

- Talk truthfully with your loved one about specific unsafe behaviors you have observed when they are driving. Explain that the behaviors are putting many people in danger.
- Try to understand that driving represents adult independence to many people. The person with HD will be emotional about losing the ability to drive.

- Drive with your loved one regularly to continue to assess their driving competency.
- Take preventative steps when you notice a decline in the driving skills of the person with HD. Offer to drive or arrange for rides.
- If you become concerned about your loved one's driving, contact the Department or Bureau of Motor Vehicles in your state to obtain information about how to have someone retested and/or how driving privileges can be revoked. Your HDSA social worker might also know this information. You may also be able to schedule a driving assessment at your local driving school for a fee or through an HD-knowledgeable Occupational Therapist.
- Advise your loved one to carry medical or disability documentation in the car that identifies them as a person with HD.
- Ask a physician or social worker to help you convince your loved one to stop driving when the time comes and to set benchmarks for that decision.
- If you believe your loved one is no longer able to drive safely, refuse to get into the car with him or her.

- Hiding the car keys rarely works. The person with HD may become aggressive or simply call a locksmith. Remove the car from the premises, if possible.
- Think about installing an ignition lock or another anti-theft device that makes it difficult for the person with HD to drive.

When Dealing with Law Enforcement:

- If the person with HD insists on driving, explain that the police will be involved if the person with HD drives in an unsafe manner. Be responsible and follow through with the consequences you have described.
- If your loved one gets stopped by law enforcement officers when you are in the car, do not let the person with HD drive away. Turn off the ignition, if need be.
- Do not attempt to mislead law enforcement officers. Tell them that your loved one has a medical condition that affects driving.

Disappearance/Missing Person:

Reduced impulse control and unquestioning trust in others may lead a person with HD to leave home and forget or refuse to tell caregivers and family where they are.

Creating a Plan/Before Law Enforcement Become Involved:

- If possible, give your loved one a cell phone, and ensure that it has some sort of tracking software. If the person were to wander off, you can track them on the internet or on a smart phone. Consider not telling your loved one with HD that you have this tracking software, because if they know it and get angry, they could disable this function themselves. Ask your cell phone provider for more information.
- If your loved one has a habit of wandering off and getting lost, utilize the HD Profile provided by HDSA to inform your local LE about your loved one. This will help search for your loved one should they go missing.
- Make sure you have lots of photos of your loved one along with a list of places they might wander off to.

When Dealing with Law Enforcement:

- If you cannot locate your loved one in a reasonable length of time, call law enforcement for help.
- When you call law enforcement, use the words 'vulnerable adult' or 'at-risk' to describe your loved one.
- Have an up-to-date photo of your loved one you can show to the law enforcement officers.
- Do not feel guilty that you are asking for assistance in locating your loved one. It is not necessary or even helpful for you to do this alone.

IF YOUR LOVED ONE IS ARRESTED OR DETAINED:

When circumstances lead to the arrest of a person with HD, the caregiver has an important role to play as educator and advocate.

- At the time of the arrest:
 - Include a request to talk to medical staff or make sure they are informed the person has Huntington's disease. Leave information about HD and a copy of your loved one's HD profile, if you have it. Request that materials be given to the medical staff. Free materials to hand out can be requested from the HDSA National office by calling 888-HDSA-506.
 - Write down names, date, and time and take notes on any discussion with the arresting officer, or law enforcement staff. Ask to be kept informed.
 - Advise your loved one not to answer any questions and to ask for a lawyer.
 - Ask the arresting officers for the name and location of where your loved one is being taken.
- As soon as you can, go to the police station.

- Do not hesitate to ask a friend or relative to go with you to the police station. Dealing with an arrest is a difficult situation. Having someone with you can provide emotional strength.
- When you go to the station, bring a copy of your loved one's HD Profile
- If you can, wait for your loved one to be processed and for bail to be set. In some cases the court may release the person "on his own recognizance" or on a "promise to appear in court" and no bail will be required.
- At the police station be sure that your loved one requests that a lawyer be called.
- Ask questions if you do not understand what is happening.
- After a lawyer arrives, heed the lawyer's advice when answering police questions.
- Reassure yourself that you have done what you had to do to.
- Do not interfere with the arresting officers or other law enforcement officers. Getting yourself arrested for interfering will not help your loved one.

PEOPLE AND ORGANIZATIONS THAT CAN HELP YOU AFTER THE ARREST:

Agencies and Organizations:

While HDSA does not have the capacity to provide individual legal assistance, an HDSA social worker can offer education and support to your loved one's attorney. The social worker can also supply a list of resources for information and services that you may find helpful.

- Contact the HDSA National Helpline for publications and information on resources.
- Talk to an HDSA social worker and other health care and social service professionals in your area about programs to help your loved one.
- Be aware that there are agencies available to protect your loved one's rights as a person with a disability.
- Meet with a social worker or mental health care professional to try to identify the underlying causes of repeated encounters with law enforcement.

- You do not have to face this by yourself. Seek help before you are overwhelmed. A support group or mental health professional can help you and your family cope with the stress of your loved one's arrest. You can find a support group at www.hdsa.org.
- Do not let your loved one go to court without a defense attorney. Everyone has the right to an attorney, even if they cannot pay.

Attorney

The lawyer who will represent the person with HD is the liaison between your loved one, the prosecutor and the police. The more they understand about HD, the better they will be able to help bring the situation to a good resolution.

- Educate your loved one's attorney about HD with HDSA publications:
 - Fast Facts about HD
 - Huntington's Disease: A Family Guide
- Provide the attorney with a copy of your loved one's HD Profile.
- Give all the assistance you can to the attorney. This is the person who will defend your loved one in court. The defense attorney has direct contact with your loved one, and access to the prosecutor. If the defense attorney knows about Huntington's disease, he or she can be an advocate. Sometimes jail may be avoided if a treatment plan has been implemented or can be proposed to the court by the attorney.

KEY POINTS

Be Proactive

There are some steps you and your family can take to help make a crisis situation go as smoothly as possible. If you would like to explore more ways to prepare yourself and your loved one for a conflict, please contact your local HDSA social worker or the HDSA National Helpline at 888-HDSA-506.

- Use technology, such as tracking software, to assist in locating your loved one if they are easily confused or prone to wander. Consider having a local cell phone programmed with contact numbers for you and other family members in case of emergencies. Talk with your telephone provider for more information on programs and options.
- If a family attorney is available, provide information regarding HD and how this condition may affect your loved one physically and behaviorally. In case of a legal problem or question, they are aware of your loved one's needs and can be an advocate as needed.
- Discuss advanced directives with your family as early as possible. Go to www.caringinfo.org to download the advanced directive form for your state. Advanced directives vary by state, but in a crisis situation, can help you and your loved one get the help they deserve.
- Don't forget to constantly update the information for your loved one in case of an emergency. Medications, contact information, etc. may be needed in case of an emergency and time may be saved if you know where it is and the information is correct.

Online Legal Resources

There are national organizations whose websites can help you find local resources to aid you in defending your loved one, including:

Find Law:

www.findlaw.com

Offers a list of lawyers in your area.

Law Help:

www.lawhelp.org

Find local agencies to handle your complaints. Does not provide direct legal help.

Legal Services Corporation:

www.lsc.gov

Has a state by state listing of legal aid societies and other providers of low cost or no cost legal assistance.

National Disability Rights Network:

www.napas.org

Provides state-by-state listings of agencies that provide information and advocacy. Look for the agencies working under the Protection and Advocacy for Individual Rights (PAIR) program, as they may offer assistance for the disabled who are incarcerated.

CONCLUSION

One of the best things you can do for you and your family to help avoid problems before they occur is to use this guide to help you create your own plan that contains personal information about your loved one with HD. Then, request a meeting with your local law enforcement so that you can offer that plan and educate them about your loved one.

Jean E. Miller

**HELP FOR TODAY.
HOPE FOR TOMORROW.**

HDSA Mission

To improve the lives of people with Huntington's disease and their families.

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