

Caregiver's CORNER

HDSA welcomes you to
Caregiver's Corner

Funded by an educational grant from





HDSA Law Enforcement Toolkit

*Emergency Services Personnel,
Social Confrontations & Persons
with HD: A guide for caregivers*

Introduction

Purpose of the HDSA Law Enforcement Toolkit

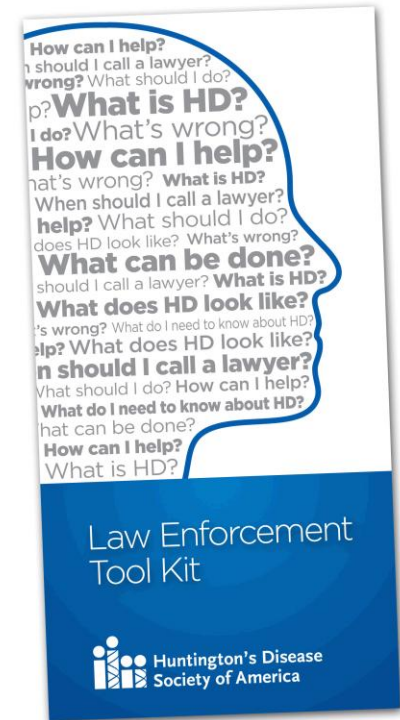
Who is our Audience

- Caregivers/HD Family Members
- Law Enforcement

Tool Kit Components

- HD Family Members
 - HDSA Caregiver Guide
 - HDSA Resources to Personalize (HD Profile & My Crisis Template)
- Law Enforcement
 - HDSA Law Enforcement Guide
 - HDSA Law Enforcement Presentation


The Toolkit will be available in June. To pre-order a copy of the toolkit, contact Anita Mark Paul at amarkpaul@hdsa.org.



HDSA Resources to Personalize

How can I help? Should I call a lawyer? What's wrong? What should I do? What is HD? How can I help? What's wrong? What is HD? When should I call a lawyer? What should I do? How does HD look like? What's wrong? What can be done? What is HD? Should I call a lawyer? What is HD? What does HD look like? What's wrong? What do I need to know about HD? What does HD look like? What should I do? How can I help? What do I need to know about HD? What can be done? How can I help? What is HD?

My Crisis Template



National Resources

Huntington's disease

Huntington's Disease Society of America (HDSA)
HDSA provides information, resources and downloadable publications. Call HDSA to locate an HD social worker in your area.
www.hdsa.org
800-345-HDSA (4372)

Legal Resource Websites

Legal Services Corporation
The Legal Services Corporation has a state by state listing of legal aid societies and other providers of low cost or no cost legal assistance.
www.lsc.gov

Find Law
Find Law has a searchable database of legal information, as well as a listing of lawyers.
www.findlaw.com

Law Help
Law Help has a local listing of agencies that provide free legal aid programs and answer questions about legal rights.
www.lawhelp.org

Crisis Hotlines

Safe Horizon
Safe Horizon, the largest victim services agency in the U.S., provides support and advocacy for victims of crime and abuse.
www.safehorizon.org

Domestic Violence Hotline
800-621-HOPE (4673)

Safe Horizon's Crisis Victims Hotline
866-689-HELP (4357)

Rape Abuse and Incest National Network (RAINN)
The Rape, Abuse & Incest National Network is the nation's largest anti-sexual assault organization. RAINN has a telephone and an online hotline and provides referrals to local resources.
www.rainn.org
800-421-HOPE (4673)

National Domestic Violence Hotline
The National Domestic Violence Hotline is a 24-hour hotline providing support through advocacy, safety planning and local resources.
www.thedvhotline.org
800-799-SAFE (7233)

Suicide Prevention Hotline
www.suicidepreventionlifeline.org
800-273-TALK (8255)



I Have Huntington's Disease

Insert passport photo here

NAME / BIRTHDATE _____

ADDRESS/PHONE _____

I am currently taking (PLEASE LIST MEDICATION & DOSAGE):

As prescribed by: _____

DOCTOR _____

PHONE _____

DOCTOR'S SIGNATURE _____

HISTORY OF SUICIDE ATTEMPTS: YES ___ NO ___

In Case of an Emergency, please contact:



NAME 1 / PHONE NUMBER 1 _____

NAME 2 / PHONE NUMBER 2 _____

Special Instructions
[ie: Eating and/or Swallowing difficulties, Seizure prone (keep calm), Do not use restraints, Becomes violent, Hearing impaired, Eyeglasses, etc.]

Additional Comments:

Profile Card

To pre-order a copy of the toolkit, contact Anita Mark Paul at amarkpaul@hdsa.org.

Presenter

Cheryl Sullivan-Staveley, RN



Presentation Content

Using the Caregiver Resource

- Document Structure
- General Guidelines
- General Guidelines for Working with Law Enforcement

Situations that May Cause Social Conflicts/Encounters with Law Enforcement

- Misperception of Intoxication
- Shoplifting
- Inappropriate Sexual Behavior
- Sexual Abuse
- Aggression
- Driving
- Disappearance/Missing Persons

If your Loved one is Arrested or Detained

Key Points

Document Structure

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.

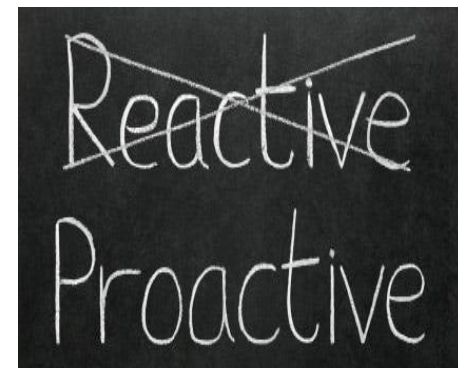
The aim of the guide and supplemental resources is to give caregivers the tools they need to educate law enforcement and advocate for their loved ones.

Each section has two parts: Creating a plan & dealing with law enforcement

General Guidelines

Being prepared for potential confrontations can ensure the best outcome for all concerned.

- **Strategies for Creating a Plan**
 - Introduce your loved one to local law enforcement
 - Be proactive: think about what you would do in case of an emergency
 - Fill out an HD Profile for your loved one, and a Crisis template for yourself
- **General Guidelines for working with Law Enforcement**
 - During, or following your first interaction, talk with the officers to discuss how the situation could be prevented or better handled in the future.
 - Stay calm and keep your hands visible at all times



***Situations that May Cause Social
Conflicts or Encounters with Law
Enforcement***

Misperception of Intoxication

Some symptoms of HD can create the impression of intoxication. The goal is to prevent a misunderstanding from escalating into a conflict.

- **Strategies for Creating a Plan**
 - Know the laws in your state
- **Strategies for Dealing with Law Enforcement**
 - A breathalyzer test can help clear up the misperception that the individual is intoxicated.
 - *My experience:* Sometimes, it's a matter of education

Shoplifting

Changes to the brain make a person with HD less able to resist temptation. The person with HD may forget or minimize the consequences of stealing.

- **Strategies for Creating a Plan**
 - During, or following your first interaction, talk with the officers to discuss how the situation could be prevented or better handled in the future.
 - Stay calm and keep your hands visible at all times
- **Strategies for Dealing with Law Enforcement**
 - If your loved one is stopped, try to explain the biological basis of the behavior.
 - Offer to pay for the item, if possible.
 - Do not participate in illegal behavior.

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 family members. The goal is to manage the behavior safely.

- **Strategies for Creating a Plan**
 - A person with HD who exhibits sexually inappropriate behavior should never be left alone with minors.
 - Watch for romantic or sexual obsessions. Speak to your loved one's doctor if obsessions become worrisome.
- **Strategies for Dealing with Law Enforcement**
 - Safety first! If your loved one is putting others in a dangerous situation, call law enforcement to intervene.

Sexual Abuse

Changes in the brain and reduced impulse control caused by HD can result in aggressive or dangerous behavior that must be controlled. There is no shame in being a victim of abuse. Keep your focus on ending the abuse.

- **Strategies for Creating a Plan**
 - 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.
- **Strategies for Dealing with Law Enforcement**
 - Recognize that no one is allowed to force themselves sexually on another person.
 - Call for law enforcement as soon as possible if abuse or the threat of abuse occurs.

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.

- **Strategies for Creating a Plan**
 - Aggression may be medically manageable. Talk to your loved one's doctor about irritability and aggressive behavior.
 - Don't wait until a crisis to think about what you would do in case of an emergency.
 - Attempt to identify the source of the aggression and the root cause of the anger.
- **Strategies for Dealing with Law Enforcement**
 - Safety first! If your loved one is putting you or your family in danger, call law enforcement.

Reminder: Safety First!

Do not leave yourself or your family in a dangerous situation. Talk to your local HDSA social worker or a trusted professional about creating a safety plan.

For help in dealing with 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 emergency numbers and websites are included on the HDSA Crisis Template.**



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.

- **Strategies for Creating a Plan**
 - Drive with your loved one regularly and continually assess their driving competence.
 - Discuss specific unsafe behaviors that you've observed with your loved one.
- **Strategies for Dealing with Law Enforcement**
 - If the person with HD insists on driving, explain that police will be involved if the person drives in an unsafe manner. Follow through with the consequences that you have described.

Disappearance/Missing Persons



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.

- **Strategies for Creating a Plan**

- Use the HD Profile provided by HDSA to inform your local law enforcement about your loved one.
- Make sure you have lots of up-to-date photos of your loved one along with a listing of places that he or she might wander off to.

- **Strategies for Dealing with Law Enforcement**

- 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.
- When you call law enforcement, use the words ‘vulnerable adult’ or ‘at-risk’ to describe your loved one.

If your loved one is arrested or detained

What to do at the Time of Arrest

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

- ✓ Give information & publications about HD to medical staff.
- ✓ Make note of names, date, time and any discussion
- ✓ Advise your loved one to **ask for an attorney**
- ✓ Advise your loved one not to answer any questions without an attorney present.
- ✓ Ask the arresting officers for the name and location of the place where your loved one is being taken.

Attorney

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

- ✓ Educate your loved one's attorney about HD with HDSA publications
- ✓ 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.

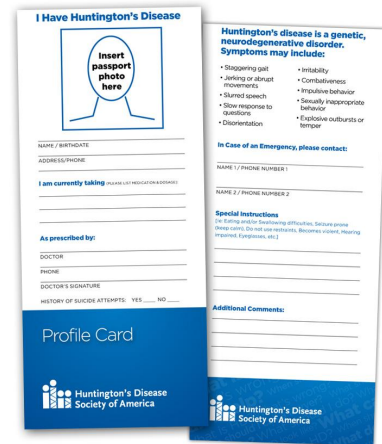
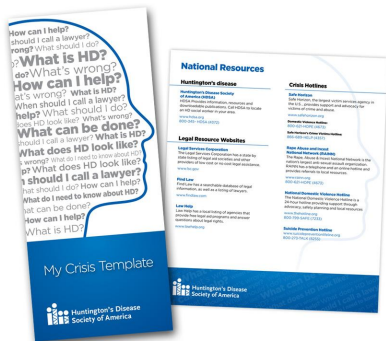
People & Organizations that can Help

- **HDSA Helpline**
 - Call the HDSA helpline at 800-345-4372 ext 240 to be connected with local resources.
- **HDSA Social Worker**
 - Find the social worker closest to you in the Living with HD section of www.hdsa.org
- **HDSA Support groups**
 - Find the support group closest to you in the Living with HD section of www.hdsa.org
- **Online Resources**
 - The Caregiver guide contains a list of online legal and advocacy resources.

Key Points: Be Proactive!

There are steps that you can take to prevent a potential situation from happening, or from escalating. Contact HDSA for more information.

- ✓ If you have a family attorney, inform him/her about HD.
- ✓ Be sure that your loved one's HD Profile, and your Crisis Template are up-to-date.
- ✓ Discuss advance directives as early as possible.
- ✓ Take advantage of technology like smart phones and tracking software.



HDSA is here to Help!

Contact HDSA for a copy of the Law Enforcement Toolkit, and other HD publications, as well as referrals to local resources.

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