



# How to Cope with a Parent who has HD Youth: 9-13

Convener: Janet K. Williams, PhD, RN, FAAN

# Presenter Disclosures

**Janet K Williams**

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose  
or list



## **Huntington's Disease Society of America**

The information provided by speakers in workshops, forums, sharing/networking sessions and any other educational presentation made as part of the 2010 HDSA convention program is for informational use only.

HDSA encourages all attendees to consult with their primary care provider, neurologist or other healthcare provider about any advice, exercise, medication, treatment, nutritional supplement or regimen that may have been mentioned as part of any presentation.

## Coping by kids with parent with HD

- Challenges with HD
  - Parent, family, friends, yourself
- Challenges for kids in upper elem/junior high, or middle school
  - Friendships
  - School achievement, school and sports activities
  - Helping out at home
  - Hormones
- Coping ideas
- What and who can help

## Today's workshop

- Workshop format
  - Everyone has a chance to speak if they want to
  - Give others time to share their thoughts
  - Look for new ideas that you might use

## Coping with a parent with HD

- Being a Caregiver
  - Helping out
    - Cleaning up, mowing yard, watching brothers and sisters
  - Doing things for parent with HD
    - Errands, preparing food, being at home, safety
  - Give up some things you want to do
    - Have to be at home at certain times
  - Worry

## Coping with a parent with HD

- How to talk about it with your parent who doesn't have HD
  - Feeling alone in your family
    - You have your own feelings
  - Time to be a KID, and sometimes acting like an adult
    - Want to do things other kids do
  - Your risk to develop HD
    - Thinking about your future

## Coping with a parent with HD

- Bringing friends home- or not bringing friends home
  - What to say about your parent
  - Who helps you explain your parent's illness
  - Which friends understand



## Coping with a parent with HD

- How to recognize triggers and avert situations
- Problems change in HD- some things happen you don't expect
- Not your fault
  - See what the parent with HD can do or cope with ex. Repeating nailpolish; repeating trips to buy fishing supplies
  - Tasks that are too challenging, ex. Washing dishes
  - Parent's safety, ex. Using the stove
  - Signs that your parent is having a hard time, ex. that 'look' in mom's eyes before she freaks

## Coping in with a parent with HD

- Parent with HD
  - Want to spend time with them
  - Want to know about them

## Coping: Taking Care of You

- You
  - Doing things you like to do- and are healthy for you
    - Sports, exercise
    - Be with friends
    - Prayer
    - Talking with someone who understands
    - Talking with someone you trust when you are scared

## Coping: It's not just you

- What and who can help
  - National Youth Alliance
  - HD Coordinator
  - Your mom or dad, your family

## Coping: What about you?

- Your comments

## Resources

- National Youth Alliance. <http://www.hdsa.org/nya.html>
- HD Centers of Excellence
- Sparbel, K.J.H., Driessnack, M., Williams J.K., ....& Paulsen, J.S. (2008). Teens' experiences living with Huntington Disease. *Journal of Genetic Counseling*. 17, 327-335.
- Williams, J.K., Ayres, L., Specht, J., Sparbel, K.J.H., & Klimek, M.L.(2009) Caregiving by teens for family members with Huntington disease. *Journal of Family Nursing*. 15(3), 273-294.