

# New Relationships and When to Talk about HD

“Be Passionate. Learn. Read. Dream. Believe. It  
will come together. I promise.”

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

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# Presenter Disclosures

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

No relationships to disclose  
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“Home is what catches you when you fall, and we all fall.”



## Inherited but Unknown

Adult children are not always aware that Huntington's disease runs in the family. Sure, there may have been a tragic story about a grandparent who was placed in a psychiatric hospital or committed suicide, but no one mentioned Huntington's.

***Though it passes through generations, knowledge of it may not.***

# What do we know about YP and impact of HD?

- More recent research (Forrest et al, 2007, Vamos et al, 2007) demonstrates the resilience of YP in families affected by HD
- As variable as HD maybe; so too are the varied family experiences of HD in the family
- In regards to predictive testing YP are demonstrating a capacity for decision making that is often beyond what we would expect
- Impact of being a young “carer” the good and the bad

# Common questions and concerns for YP navigating life with HD

What was our HD family script? and how was it told and shared or not shared?

To Test or Not to Test

The impact on dating relationships..Is there ever a “good time” to talk about HD?

What about having children? Should I think about having a family and what are my options?

# THE HD FAMILY SCRIPT

What was yours?



## To Test or Not to Test

What runs in your own family and would you REALLY want to know?

“Soon everyone is going to have an option like this. You make the decision to test, you have to live with the consequences.”

Nancy Wexler, PhD  
President, HDF

“Being at risk is dying a little each time you drop a spoon. Being at risk is looking at your brothers and sisters, wondering which one of you will be the first to go. This constant pressure, day in and day out, year after year takes a heavy toll..I feel at times that being at risk has taken away my right to love and be loved.”

Walking the Tightrope  
Randi Jones

# At Risk versus Gene Positive

- At- risk  
Might get it, might not
- Gene Positive  
-Will get it, question is when

Some issues are the same and some are different

## What are the major impacts of being a YP who is at risk

- Obstacle for development of intimate relationships
- Family Planning
- Being a caregiver
- Coping with fears
- Preoccupation with symptoms
- Depression or chronic low level anxiety
- Defining one's life path in two ways

# Common Dating Relationship issues

- Does someone you are dating need to know about HD? If so when?
- A YP can continue to carry the burden of family secrets and unresolved fears or conflicts. This can “creep” into your relationships.
- Nature of a your exposure to HD is critical in determining your adult adjustment to your own at-risk status and attachment to others
- Having a good system of social support and strong attachment with friends and others can be a protective factor in your intimate relationships.
- Impact of disenfranchised grief and loss

# Suggestions for the YP for coping/managing

- Learning ways to shift focus from the future to the present
- Trying to learn ways to finish “unresolved business”
- Set more realistic goals
- Be a educated consumer but also decide when enough information is enough
- Seek support by counseling, genetic counseling, AR group, internet, medication
- Preparation-try to get as much in order prior to testing if that is one’s decision

What about having **children**? What are my options?

# Resources and Links

## HD websites for young people

[www.hdscotland.org](http://www.hdscotland.org)

[www.ypahd.ca](http://www.ypahd.ca)

[www.hdlighthouse.org](http://www.hdlighthouse.org)

[www.hdac.org](http://www.hdac.org)

[www.standord.edu/group/hopes/](http://www.standord.edu/group/hopes/)

[www.hdfoundation.org/home](http://www.hdfoundation.org/home)

[www.hdsa.org/nya](http://www.hdsa.org/nya)

[www.youngcarers.net](http://www.youngcarers.net)

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“The world breaks everyone, “ wrote Ernest Hemmingway. “And afterward, some are **STRONG** at the broken places.”

Let’s Talk, Text or Tweet!