



# **To Have and to Hold The Forgotten Ones: Spouses living with the risk or reality of Huntington disease**

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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  
or list

**“Marriage is a lifelong humbling  
experience”**

**Anonymous**

# The Challenge with Marriage in General

- Marriage as a stabilizing institution that fails as often as it succeeds
- The fragility of the institution maybe due to several societal factors
- The belief in romance makes any reality a disappointment
- “Pop ideas” about mental health have encouraged narcissism and selfishness so many people aren’t fit to share a life with

## Other Marital Ideas that can “trip” us up

- You can't be right and be married at the same time
- If you have to be right then you can't be learning anything
- We shouldn't think of marriage as making us happy
- Marriage is about reality and not being alone as you struggle along life's path

# A Little Background: Family Life Cycle ala Family Systems Theory (Bowen)

- Leaving Home
- Marrying
- Having children
- Seeing children off to school
- Children graduating
- Children marrying
- Producing grandchildren

# The Problem

**The transition between stages does not go as it should, when there is a interruption of the predetermined “normal” sequence of events.**

**The introduction of HD, either through genetic testing or by direct onset of symptoms is a huge change that can unstablize the normal Family Life Cycle**

# Turning Points of Marriage

- Predictable transitions and expectable crises
- At these turning points is when spouses are most likely to develop stress and become more polarized

**FINDING OUT THAT YOU OR YOUR SPOUSE IS AT RISK/GOING THROUGH GENETIC TESTING OR DEALING WITH THE REALITY OF HD IS A HUGE TURNING POINT!!**

The “Added” CHALLENGE with being married to a person at risk for HD

**What Have We Learned So Far?**

# Factors contributing to Getting Married

Life Events  
Rushed to marriage  
Choice of Partner

# Finding out or gaining knowledge of HD

- Telling partners  
Wexler (1995) outlined her own experience in this regard: despite the positive reaction of her partner, she felt a ongoing sense of inadequacy and anxiety about the relationship.
- Partner's reactions-accepting the risk
- Finding out together
- Secrecy and Anger-the failure to disclose the presence of HD in one's family MAY predispose the relationship to eventual breakdown.

## Decision Making Regarding Having Children

- Not concerned- “a Cure will be coming”
- Lack of understanding

Mattson and Almqvist (1991) found in their study those who already had children believed they would not have had children if they had been better informed about HD at the time

- Concerned about the next generation

# Effects of HD risk on a couple's life and relationship

- Minimal vs. significant impact
  - Previous research has indicated concerns for partners of at-risk person are particularly concerned about the future, with regard to children, financial planning and prospect of becoming a caregiver.
- No Adverse effect
- Effect of other siblings diagnoses
- Coping strategies (patterns of communication from one's family origin, information seeking and symptom watching.)

# Decision making regarding predictive testing

- To be tested
  - “I thought I have to confront this head on..I don’t want to have to carry this baggage around with me for the rest of my life.”
- Not to be tested
  - Many feel the emotional burden of a “bad result” would have a detrimental effect on their lives
- Ambivalence
- Disagreement between partners
- Partner’s influence

# Reaction to Testing Results

- Accepting

Initial Shock and Grief...”I was pretty well wrecked. He seemed to deal with it pretty well..I mean he was upset but..he sort of was the one that supported me through..I was like, “ my whole life is over, you know..I’m condemned just like he is..”

- Relief—but problems still exist

A negative result does not solve all of life’s problems

***The nature of the marital relationship prior to testing maybe more likely to influence the outcome of the relationship than the actual result.***

# Spouses of At-Risk person are often the forgotten members of the family with HD

Empirical research concerning the problems experienced by spouses of at risk partners is still rather scarce

## So what do we know?

- For every individual afflicted with HD, approximately 10 people, including those at risk, suffer the consequences of the disease (Ehrlick, Parker and Ferera (1980))
- Partners of carriers have as much distress as carriers, and for some distress is even more
- Carrier's partners have at least as much psychological distress as carriers, but partners have the tendency to draw back (Decruyenaere et al, 2005)
- Persons at risk tend to focus on the present, where as their partners are focused on the concerns of the future and what lies ahead.
- Spouses can become more isolated and experience “disenfranchised” grief, as if they have no right to mourn.

# The early phase after receiving gene positive results or a new HD diagnosis

## **Common Feelings**

Surprise, Fear, Denial, Confusion and Sadness  
Marital conflict often highest during this early stage

## **The Big Question on Your Mind**

“What is Happening to my loved one?”

## HD and Marital Conflict (i.e. when neither spouse will yield to the other)

- **It is more common to observe during the early stages of HD, when the healthy spouse is still adjusting to the new reality**
- **More household responsibility for the healthy spouse and often financial difficulties due to decreased income, added expenses, etc.**
- **Two of the most difficult things to deal with: mental/cognitive deterioration of the person and fear of the having passed the HD gene onto your children**

“Don’t Sugar Coat This. It isn’t Easy for  
Any of Us.”

Anonymous spouse of at risk partner

# Divorce and impact of HD

- **Separation/divorce often occurs within 2-3 years following diagnosis**
- **Divorce is observed to be more common in younger couples, specifically those under 40 or in those who have been together for a relatively short period of time**
- **Largest study done of 92 HD families (1983) found the divorce rate among HD affected couples was not significantly higher than in the general population. Would this still be true today?**

# Protective Factors for Marriages coping with HD

- **Partners of those who knew about the recurrence of HD in the family BEFORE marriage tend to have less difficulties**
- **Spouses who have spent many years together feel an obligation to care (many more “deposits” in the marital banking account.)**
- **The degree of perceived social support satisfaction, rather than the SEVERITY of HD is the overriding predictor of marital relationship satisfaction in people living with a neurological illness (like HD, PD, etc.; O'Connor et al, 2008)**

## **Suggestion to Help your partner who is at-risk, gene positive or newly diagnosed with HD**

- **Get control of what you can..i.e. stay in good physical condition**
- **Get early help with any psychiatric concerns**
- **Continually reassess working issues, the delicate balance of remaining employed versus not working and being disabled**
- **Not losing track of one's strengths, finding ways to bolster self esteem and sense of purpose**
- **Managing stigma related issues**

## **Some Final Suggestions to help Spouses of at-risk partners**

- **Don't be afraid to speak up and get help for yourself—Your needs are important too!**
- **Reach out to others by talking, texting, twittering**
- **Ask a HD based social worker or genetic counselor how to connect up with other spouse of at risk partners**
- **Avoid making promises you might not be able to keep**
- **Stay in the PRESENT so you don't miss all the JOY of the NOW!**

**Thanks for Coming and Let's  
Talk!**