

Managing Relationships The Good, the Bad and Everything in Between!

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

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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.”



Huntington's disease, loneliness and love

“Imagine how lonely you would feel if you were a young person who knew you might never get married and have children because you faced a cruel and deadly genetic disease.”

Dating *can* become an incredibly difficult affair, instantly laden with fear and complex calculations about the future

Some common questions that maybe on your mind

Why would anybody want to enter a relationship charged with such huge health and emotional challenges?

Will I end up alone?

Will anybody ever love me?

“The only thing I fear is just being alone, not having somebody, because I wouldn’t want to put anybody through what I’ve been through,” says Kristen, whose mother had HD, “So I couldn’t expect anybody to love me like my father loved my mother.”

Young people



“ This world demands the qualities of youth; not a time of life but a state of mind, a temper of the will, a quality of the imagination, a predominance of courage over timidity, of the appetite for adventure over the life of ease.

Robert F. Kennedy

“ When a defining moment comes along, you define the moment or the moment defines you.

Kevin Costner

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 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?

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 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

Managing genetic risks while dating

Common Concerns

Whether to Tell

Why Tell?

Why Not Tell?

What to Tell?

How to Tell?

When to Tell?

Adapted from In Sickness and in Health: Disclosures of Genetic Risks in Dating, Journal of Genetic Counseling, 2011, February

“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

Whether to tell?

- Have to weight the pros and cons balancing ethical obligations against potential risks of rejection
- Weigh the long term potential of the relationship vs. the risk of rejection
- Reactions to disclosure of genetic risk can thus serve as a test of the relationship itself

Why Tell?

- Tell because of a ethical obligation to a prospective mate
- Tell because of HD couldn't be hidden in the family

“You’re gonna meet my dad. He’s a mess. He has this awful disease. So does my grandmother. I could probably have it too! And I could maybe give it to my children.”

22 year old at risk

- Tell because (future) children would be affected
- Tell because it too hard to hide early symptoms

Why not tell?

- Fear of rejection
- Disclosure can lead to painful emotional break-ups with romantic partners

“I’ve had bad reactions from lovers, it’s hard for me to deal with it, so naturally, it’s going to be hard for someone else to deal with it. I don’t feel comfortable with it, so I stay alone.”

What to tell?

- How much detail to provide
- Full honesty means providing the most up to date information
- Deciding when silence starts to undermine trust
- Some individuals disclose the symptoms(or some of them) but not the HD diagnosis

“The topic of my mom doesn’t come up. I just describe her as “aging a little, forgetful.” Not many people meet her. I just figure: if I ever get really close to someone, I’ll deal with it , I think I have to make sure this guy falls in love with me first before I tell him I’m defective (laughs.)

- Broaching the topic of HD slightly, provides flexibility in eventually leading or not leading to further revelations
- Discuss reproductive implications

How to tell?

- Try not to just give medical facts, but to cast the news as positively as possible
- Decide on the best form of communication, usually in person, but with other HD family members, email or a written form maybe easier

When to tell?

- Not too early and not too late
- Telling when close enough
- Some folks develop “rules of thumb” establishing predetermined points at which they would tell
- Telling only if asked, in the case of HD, a family member’s symptoms can be readily visible, forcing the family history and potentially one’s own risk, to the fore front.
- Telling only after breaking up

Reactions to telling and alternatives

Rejection vs. Acceptance

Disease in a potential partner's family can also help to reduce the likelihood of stigmatization and rejection

Not dating or Avoidance of dating

This maybe partially unconscious

“Since I found out, I haven’t been intimately involved with anyone. I ask myself, at what point do I have tell anyone? I’ve only been on a few dates, not anything that has developed into a full blown relationship.”

26 year old man, tested gene positive

Remember the most critical components to happiness
are family and friends

The Death Bed Test

*When asked of people who were dying, "What made your life satisfying?", the results are indisputable. What truly mattered when it came to one's happiness was the **QUALITY of PERSONAL RELATIONSHIPS.***

Adapted from the work of Dr. Mark Holder, Associate Professor at the University of British Columbia, where he studies the science of happiness

How to nurture your personal relationships



Ask questions and then really listen

Never miss an opportunity to compliment

Never miss an opportunity to celebrate success

Notice something different

Limit social media contact

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

Resources and Links

www.hdyo.org

www.hdscotland.org

www.ypahd.ca

www.hdlighthouse.org

www.hdac.org

www.standord.edu/group/hopes/

www.hdfoundation.org/home

www.hdsa.org/nya

www.youngcarers.net

Good book to help with dating

Are you the one for me?. Barbara De Angelis

My email

Amy_Cheshire@urmc.rochester.edu

“Those of use at risk for the disease have learned to value our precarious relationship with the world and the insights that it has given us. While we would prefer to gain this knowledge in other ways, nonetheless we have come to appreciate, not the disease, but the creativity and connections it has challenged us to pursue.”

The Woman who walked into the Sea
Alice Wexler

There comes a time in your life,
when you walk away from
all the drama and people who create it.

You surround yourself with
people who make you laugh.

Forget the bad, and

FOCUS ON THE GOOD.

Love the people who treat you right,
pray for the ones who don't.

Life is too short to be
ANYTHING BUT HAPPY.

Falling down is a part of life,
getting back up is living.

-Jose N. Harris

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