

CARING FOR THE CARE PARTNER

**“DON’T SUGARCOAT THIS. IT ISN’T
EASY FOR ANY OF US.”**

ANNOYNMOUS HD CARER

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Presenter Disclosures

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No relationships to disclose
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You need three things to manage
the road ahead with HD

A BACKBONE, A WISHBONE
AND A FUNNYBONE

3 BIG LOSSES FOR THE Phd

Fear of abandonment

Mental deterioration

Fear of passing on the HD gene to
offspring

3 BIG LOSSES FOR THE FAMILY

Loss of both the personality and the physical aptitude of the affected parent

Loss of the usual family structure

Potential/eventual loss through nursing home placement and finally death



What about HD Care Partners??



“The stress of caring for a loved one can drive even the most saintly to breaking point. There must be a better option than caring until you burn out.’

Hugh Marriott
The Selfish Pig’s Guide to Caring, 2006

RESEARCH CONCLUSIONS

- **HD caregivers own perception of their level of stress was the strongest indicator of caregiver burden** (*Chesire et al, Relationship between Caregiver burden and Disease severity, 2001*)
- **Greater cognitive and functional impairment in HD patients contributes substantially to higher caregiver burden.**
- **“There is a constant pressure that everything depends on you and that you can’t go away, get sick/injured or even just relax.”** (*Dawson et al., Living with HD: Need for supportive care, 2004.*)
- **A correlation between coping strategy used by the well spouse and their quality of life—specifically, the more the spouses limited themselves from *any* activities other than primary care, the more they felt the negative impact of HD on their lives.** (*Wertz, The Family Covenant, 2001.*)
- **By detecting burden EARLY, we might lessen family breakdown, provide adequate resources and prevent premature institutionalization.**

What is the most consistent Care Partner Finding?

DEPRESSION, DEPRESSION and DEPRESSION

Over 50% of care partners will suffer a episode of Major Depression that requires treatment at some point in the care giving experience.

Most Common Problems reported by Caregivers

- Need for respite (85%)
 - Emotional Support (83%)
 - Behavior Management (32%)
-
- Parrish et al (2003) Journal of Case Management

Common Sources of HD Caregiver Burden

- Caregiver's Response to HD Care Demands, including duration and severity of HD
- How Much or How Little Social Support a Caregiver Receives
- Quality of Relationship prior to the Onset of HD
- The “Creep Effect” of HD

The Three Stages of Care giving: which one are you in?

THE EARLY STAGE

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?”

Early Stages of HD

Goal: Preserve Independence

- **Diagnosis and Referral**
 - Appropriate evaluation/
Presymptomatic Testing
 - Need for counseling
- **Family Support/Education**
 - Inform, educate and involve
 - Join HDSA
 - Knowledge is Power

Early Stage Cont.

- **Legal/Financial Planning**

- Disability benefits/SSI
- HCP/POA

- **Community Supports**

- Attend local HD support group
- Make Plans/Travel/Enjoy Now
- Begin identifying possible “helpers”

The Middle Stage

Frustration, Guilt, Resentment and Conflicting Demands

THE BIG QUESTION ON YOUR MIND

“How long does this last and will I make it?”

Middle Stage of HD

Goal: Promote Functional Level

- **Medical Care**

- Maintain regular clinical care and or involvement with clinical trials

- Observe and report new symptoms, seek treatment for most troublesome symptoms

- **Family Support/Education**

- Share the Care, avoid becoming isolated

- Grieve together and individually

- Learn to recognize changing behaviors and needs

Middle Stage Cont.

- **Legal/Financial**
 - Enact POA (If required)
 - Evaluate financial plans for LTC/consult with a elder law attorney
- **Community Services**
 - Explore all respite, in particular day programs
 - Home Companion/Home Health Aide/friends, church supports, neighbors
 - Short stays at local ACF's or NH's
 - Need for LTC, Neurobehavioral/HD units

The Late Stage

Sadness (returns or perhaps never left), Guilt, Surrender,
Regrets, Solace and Closure

THE BIG QUESTION ON YOUR MIND

“How do I respect the needs of my loved one?”

Late Stage of HD

Goal: Prevent Complications of Immobility

- **Medical Care**
 - If at home observe for other medical problems, some related to HD and others not, (skin breakdown, infections, swallowing problems)
 - If in LTC placement, continue with the tactile stimulation, find the simple joys with visits, keep talking to your loved one, they hear you!
- **Family Support/Education**
 - Family meetings/end of life decisions
 - Brain donation for HD research

Late Stage Cont.

- **Legal/Financial**
 - DNR/tube feeding discussions
- **Community Services**
 - Evaluate Hospice Options/at home, within the nursing home or free standing hospice homes
 - Try to maintain stimulating environment

Some Final Suggestions for Coping and Care partner Well-Being

- Knowledge is Power
- Nobody has all the answers or right way to do this, listen to your instincts
- Grieve and Grieve Well
- Time off from HD/Self Care
- Be weary of promises
- Avoid infantilizing (e.g. don't attend to everything)
- The person with HD can't do the changing!!!!!!!
- Flexibility along with a sense of humor may become your saving grace
- When in doubt error on the side of EMPATHY, blame HD not your loved one

“Helping, fixing and serving represent three different ways of seeing life.

When you help, you see life as weak.

When you fix, you see life as broken.

When you serve you see life as whole.

Fixing and helping maybe the work of the ego, and service (care giving) the work of the soul.”

Rachel Naomi Remen

From [Kitchen Table Wisdom](#),

[1996](#)

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