The information provided by speakers in workshops, forums, sharing/networking sessions and any other educational presentation made as part of the 2008 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.
PRESENTERS:

• Sandra Kostyk, M.D. Ph. D.
• Barb Heiman, MSW / LISW
• Huntingtons Disease Center of Excellence, The Ohio State University, Columbus Ohio
SEXUAL ISSUES & HD

• Sexual issues BEFORE HD?
• Sexually active?
• Sexually compatible?
• BOTH partners sexually satisfied?
SEX VS. INTIMACY

- The “Act”
- Intercourse
- Orgasm
- Positive / Negative
- Conditioning
- Morality

- Closeness
- “Feel good”
- Conversation
- Time together
- Connectedness
- Comfort
Along The Continuum of HD

- Early Stage - The Heroic State
- Mid Stage - Ambivalence
- Late Stage - The “New” Normal
Emotional Changes With the PHD…

- Apathy – loss of desire
- Depression (30 – 40% of cases)
- OCD / Paranoia
- Low Motivation
- Fear of loss of love / rejection
- Irritability
- Anger
- Violence
Other Changes

- Poor oral and personal hygiene
- Increased movements
- Impotence
- Hyper sexuality
- Sexually Inappropriate behavior
- Medication impact
Find New Ways To Be Intimate....
Such As....

- Share a favorite meal together
- Share special music together
- Watch a Sunset
- Watch a favorite movie
- Take walks, hold hands
- Pray Together
Regardless …

• You can commit to caring for your spouse providing both financial and emotional support the best you can.

• A “New Normal” can be achieved when we let go of resentment and provide care with love.
Or...You Decide to Separate

- Day Care
- Placement
- Separate living arrangements
- Divorce
Well Spouse ....

- Grieve the Loss (intimacy / sexual re-ship)
- Loss of social life
- Isolation sets in
- Resentment
- Energy level down
- Stress level up
- Responsibilities for children et all
At Some Point the WS

- May need permission to develop other interests
- Need time away from patient
- Seek out a support group (HD) Friends & Family
- Church / Spiritual connection
It May Never Happen BUT…

• It will cross your mind to find love and comfort elsewhere
• You may have an affair but still care for and be caregiver for your loved one…. 
What to Do??

- Maintain relationship as before
- Let’s just cuddle....
- Fun and frolic
- Avoidance (work schedules)
- “Anything to meet your needs”
- Get a Dog . . .
Resources

- Well Spouse Association: 800-838-0879  
  www.wellspouse.org
- Journal of Sex & Marital Therapy: The impact of Neurological Illness on Marital Relationships 01-March, 2008 34:2, pgs. 115-132
- Franz, ML, Folstein, S: Families with HD: Psychological & Social Treatment, 1984
- Personal Interviews