

# HD and the Family: Relationship Changes and Talking to Children

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# Discussion

- Changes experienced in couples associated with HD diagnosis
- Coping Strategies and Tips
- The what, why and how to talk to children about HD

# What HD changes in couples?

- Partnership

- Spousal carers were distressed by the loss of their relationship with their spouse and dealt with this by no longer regarding the person as an intimate partner.<sup>1</sup>
- Spouses of HD patients often consider their partners to be lost, particularly when dementia and changes in personality or behavior develop.<sup>2</sup>

<sup>1</sup> Williams J.K, Skirton H., Paulsen J.S., Tripp-Reimer T., Jarmon L., McGonigal Kenney M., Birrer E., Hennig B.L. and Honeyford J. (2009) The emotional experiences of family carers in Huntington's disease; *Journal of Advance Nursing* 65(4), 789-798

<sup>2</sup> A.A. Kaptein, M. scharloo, D.I. Helder, L. Snoei, G.M.J van Kempen, J. Weinman, J.C. van Houwelingen and R.A.C. Roos (2006) Quality of life in couples living with Huntington's disease: the role of patients' and partners' illness perceptions.  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1915604/>

# What HD changes in couples?

- Roles and Responsibilities
  - A reciprocal relationship was difficult to maintain as the role as carer overshadowed other roles<sup>3</sup>
  - Overtime the spouse takes on an increasing nursing role, which creates a psychological distance between the patient and his/her spouse.<sup>4</sup>

<sup>3</sup>Merete Rothing, RN, MSc, Kiristi Malterud MD, PhD, Jan C. Frich MD, PhD (2013) Caregiver roles in families affected by Huntington's disease: a qualitative interview study. <http://onlinelibrary.wiley.com/doi/10.1111/scs.12098/full>

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# What HD changes in couples?

- Communication
  - Differing Perspectives
    - Partners reported that HD patients were suffering from significantly more symptoms of HD than the patients did themselves, and reported experiencing significantly less control over HD than patients did. <sup>1</sup>
  - Loss of communication ability
  - Stress changes our ability to communicate

<sup>1</sup> A.A. Kaptein, M. Scharloo, D.I. Helder, L. Snoei, G.M.J van Kempen, J. Weinman, J.C. van Houwelingen and R.A.C. Roos (2006) Quality of life in couples living with Huntington's disease: the role of patients' and partners' illness perceptions. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1915604/>

# What HD changes in couples?

- Divorce
  - usually will occur within 2-3 years after diagnosis,
  - mostly occurring in younger couples (those under 40) or those that have been together a relatively short amount of time. Not enough “love reserves in the bank” to overcome the stressors of life and HD. <sup>1</sup>
- Health (of both individuals)
  - HD is progress, thus the HD person's health will decline
  - Many carers offer care to their loved one at a considerable cost to their own health. (Disintegration of the carer's life, loss of life as it was and the ever present shadow of HD.) <sup>2</sup>
- Finances
- Personality

<sup>1</sup> Amy Chesire, LCSW-R, MSG, HDSA Center of Excellence at University of Rochester, To Have and To Hold--The Forgotten Ones: Spouses living with the risk or reality of Huntington's Disease powerpoint presentation. [www.hdsa.org](http://www.hdsa.org)

<sup>2</sup> Williams J.K, Skirton H., Paulsen J.S., Tripp-Reimer T., Jarmon L., McGonigal Kenney M., Birrer E., Hennig B.L. and Honeyford J. (2009) The emotional experiences of family carers in Huntington's disease; Journal of Advance Nursing 65(4), 789-798

# How HD onset impacts the changes

- Partners of those who knew about the recurrence of HD in the family before marriage tend to have less difficulties.<sup>1</sup>
- When the onset of HD occurs later in family life, the disease does not seem to have the same impact on the parental subsystem in the family as the early onset.<sup>2</sup>

<sup>1</sup> Ekaterina Smolina (2007) Psychosocial impact of Huntington's disease on families and spouses from the perspective of the Family Systems Theory. <https://journal.lib.uoguelph.ca/index.php/surg/article/view/338/456>

<sup>2</sup>Merete Rothing, RN, MSc, Kiristi Malterud MD, PhD, Jan C. Frich MD, PhD (2013) Caregiver roles in families affected by Huntington's disease: a qualitative interview study. <http://onlinelibrary.wiley.com/doi/10.1111/scs.12098/full>

# How HD onset impacts the changes

- Family caregivers experience particular difficulties when HD occurs in an early stage of family life and if the disease coincides with parental obligations for children and adolescents.<sup>1</sup>
- In the later stages of the life cycle, however the family experienced complex feelings of anxiousness and anger for future of their children and g/children.<sup>2</sup>



# Coping Strategies/Tips

## HD Person

- Open & Honest Communication
- Get control of what you can
- Do what makes you happy
- Redefine intimacy and sex
- Set realistic expectations
- Ask for help
- Focus on health and self-care
- Expand support system
- Educate yourself on HD
- Avoid making promises you can't keep
- Be present
- Faith/Spirituality
- 

## Spouse

- Open & Honest Communication
- Get control of what you can
- Do what makes you happy
- Redefine intimacy and sex
- Set realistic expectations
- Ask for help
- Focus on health and self-care
- Expand support system
- Educate yourself on HD
- Avoid making promises you can't keep
- Be present
- Faith/Spirituality
-

# Please remember...

- HD does not define you
- Relationships are hard to maintain
- Forgive yourself – we are all just doing our best
- You are not a failure because things didn't happen as expected – that is LIFE.
- We all have good days and bad days
- We cannot fix, control or manage everything
- There is NO right or wrong way in this HD journey
- There is SUPPORT, you are NOT alone.

