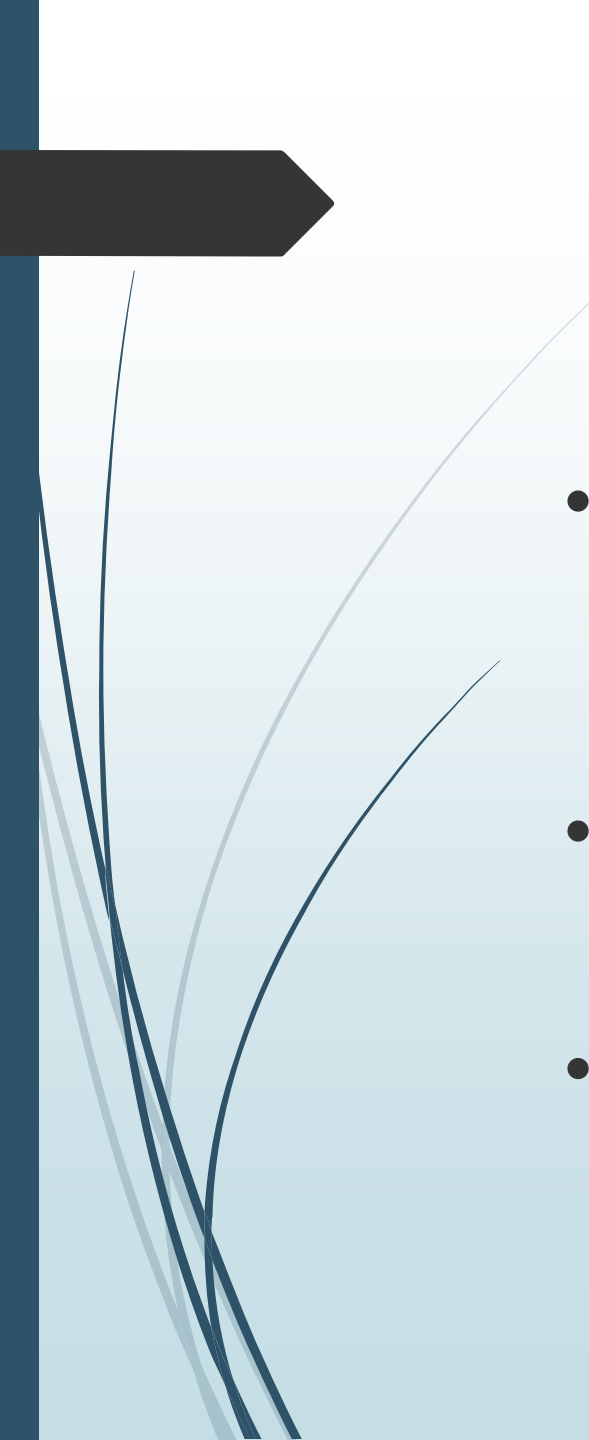




Caregivers & Families and their connection with the Health Care System

Marla Benjamin, BSW, RSW

Movement Disorder Clinic

- 
- Explore the journey of families and caregivers of person's with PD
 - Relationship with the Health Care System
 - Consider what could be different for more effective relationships and care delivery

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The Family Perspective

Bio-Psycho-Social issues

- Motor and non-motor changes
- Unpredictability, the on-off quality of the illness creates added stress
- Number of direct care activities increases as PD progresses

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Impact on the Family

- Increased levels of stress
 - Worry
 - Depression
 - Anxiety
- Carter, Stewart, Archbold, Inoue et al., 1998

Impact on the Family

Increase in :

Tension and frustration from communication problems

Worry, strain from direct care, role conflict, global strain

Number of care activities

Negative impact on lifestyle

Duties and household management



Impact on the Family

- Caregiving burden is associated with depression, poor coping ability and sleep deprivation
- 17.5% of caregivers in Carter study were in the depressed range
- Many are unprepared for the strain caregiving (average 6-7 hours/day)



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Impact on the Family

- The average caregiver will experience some strain and for some, considerable strain
- Psycho-educational interventions – effective in strain reduction in spouse caregivers
- Dementia of patient may be the biggest factor in caregiver depression



Impact on the Family

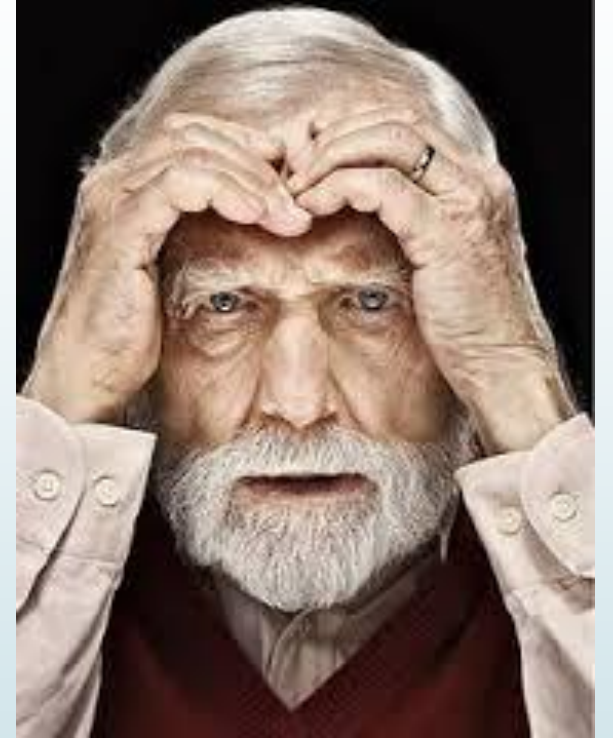
Couple Stress

- Sexual dysfunction is often an issue as the disease progresses
- Education is helpful
- Create a milieu where sexual issues and intimacy issues can be discussed in a “matter of fact” way
- Vulnerability for Elder abuse - neglect

Impact on the Family

Chronic Loss

- Loss of role
- Financial security/resources
- Dreams of the future
- Equal partnership, intimacy
- Reduced personal opportunities
- Pain of seeing loved one decline and suffer
- Physical hardship, personal stress and physical decline



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Impact on the Family

Ambiguous Loss:

- Frozen in grief – difficult to mourn as they are *living in their loss*
- Physically present, psychologically absent (Alzheimer's)
- Psychologically present, physically absent (MIA, Parkinson's)

Dr. P Boss, 1999

Families connecting with the Health Care System

- What is the connecting experience like for families?
- Ranges between petrifying – total relief and everything in between!





Families connecting with the Health Care System

These are some words/phrases I have heard from family members;

- Relief – they “get it”
- Ignored
- Not *really* listened to
- She cares and takes time
- I never get through on the phone and messages aren't returned for a long time

Families connecting with the Health Care System

- What can Health Care Professional do to work effectively with families?
- Consider EVERY encounter an opportunity to build a team



What does your team look like??



*Wearing the same shirts does not
make you a team."*

- Buchholz and Roth



Are family members on your team??



Core elements of team work

- Trust - each team member – (not just the colleagues we like)
- Effective communication – deep listening, reflecting, hearing, understanding



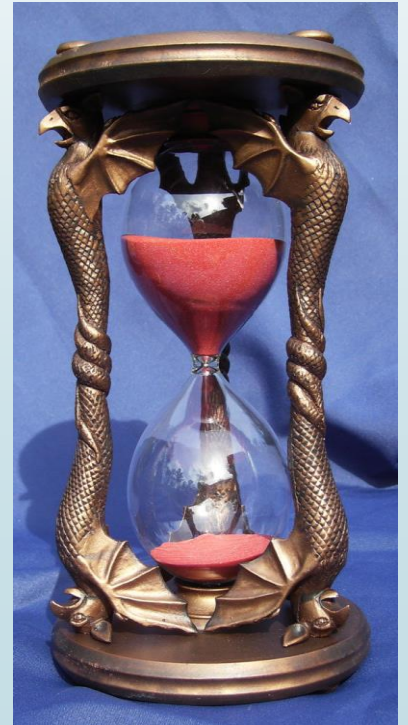


Core elements of team work

- Conflict resolution – often stems from lack of understanding. We need to recognize through conflict we can deepen our understanding and create better pathways
- Openness – fostering an environment of openness helps everyone feel welcome and valued at the table
- Accountability – for our actions/inactions and of other team members

Core elements of team work

- Respect – such a simple word...such a challenging concept. Respect needs to be inherent in all our actions and interactions
- Time – for thoughts, questions and even time for the person with PD to answer



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What can we do?

- Invite family/caregivers to the table (meetings for care plans)
- Set appointment when they are able to attend
- Don't use jargon or abbreviations which may exclude them
- Provide written information on decisions at/from meetings



What can we do?

- Provide reference and educational material for learning
- Be clear about objectives of meeting
- Create warm environment of openness and understanding
- Patiently educate about how the system works
- Ask for their input and be ready to receive it
- Ask if anything else concerns them



Will tomorrow be different?

- From what you have learned today, what will you do differently?
- Will you approach your patients differently?
- Could your interactions with family members and caregivers be even more inclusive?



Thank you!!