Emotional Impact of PSP: People and Care Partners
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Emotional changes in the person with PSP

- Cognitive changes
  - Memory changes
  - Slowed thinking & speaking
- Mood changes
  - Anxiety or depression
  - Irritability or frustration
- Loss of motivation or apathy
- Lack of awareness
- Some may be protective
Emotional changes in the person with PSP

- Person may slowly become more dependent, fearful, indecisive and passive
- May talk less often
  - Social withdrawal from family and friends
  - Speech may be slower and more deliberate
- May be less motivated for activity even when encouraged
- May feel more isolated
  - Friends seem more distant
  - Social activities increasingly difficult
  - Becoming more reliant on others for help & care

Care Partners

- Caregivers and family play a critical role
  - May overlook how significantly the disease impacts them
- Caregivers may struggle with frustration, depression & social isolation
- Caregivers may neglect their own health/wellness
  - Couple both maybe aging
  - Caring takes a toll
  - Sandwich generation
Care Partners

• Caregivers and family are a critical piece
• Support for the care partner is essential
  • Profit from support & respite
  • Benefit from individual support, coaching & counseling
• Disease progression requires greater energy
• Caregiving can be a rewarding opportunity

Ambiguous Loss

• Term coined by Dr. Pauline Boss
  • Helps to clarify and explain unique loss that goes on for an extended period of time that is rarely recognized by others
• Response expressed while someone is living
  • Grieve losses caused by a progressive illness & losses anticipated in the future which creates challenges in adjustment
• Goal is to learn to accept and live with ambiguous loss
  • Often care partners find relief in naming the term and working toward accepting ambiguity in order to learn better ways to cope
  • Encourages letting go of control & reminds us to focus on strengths & seize positive moments
Intervention

- Medication intervention for person if appropriate
- Mindfulness & relaxation practice for both people
- Support groups
  - Together or separate
  - PSP or Movement Disorder
- Counseling & support for both
- Activity, structure & exercise for both

Comments

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