Coping with Relationship and Behavior Changes

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Objectives

• Discuss scope of behavior changes in frontotemporal degeneration disorders
• Describe impact on family
• Describe helpful interventions – conference booklet pages 33-37
• Coping with Changing Relationships Caregiver experiences – Lorene & Bill
Behavior and Personality Changes

- Degeneration of the frontal network affects
  - Behavioral control (disinhibition)
  - Socially appropriate behavior (apathy)
  - Initiative and follow-through on daily tasks
  - Empathy (self-centered)
  - Personal hygiene
  - Obsessive-compulsive activities

- No insight

- Heterogeneity – “When you’ve seen one…."

- Disease modifying treatments unavailable at this time
Caring for Persons with FTD

- Difficulty obtaining diagnosis
- Loss of employment and income
- Complex family dynamics
- Lack of knowledgeable care providers
Responding to Behaviors

Understand that behaviors are part of the disease – not deliberate actions!

Medications may help – but not completely eliminate behavior

Don’t use reason and logic
Intervention Examples
Conference Booklet pages 33-37

• Use “My loved one has FTD” cards to facilitate others’ understanding
• Give minimal choices – be gently directive
• Supervision during meals; lock the fridge
• Intervene early in legal and financial planning
• Respond matter-of-factly, distract, or don’t respond
“Staying Connected While Letting Go”

- Anticipatory grief – normal grief reaction
- One grieves what is, what will not be, what was
- Talk about what is happening - withholding feelings diminishes relationships
- Spend time together – Spend time apart
- Do not forget the needs of others – especially children – balance their needs with yours
- Practice relentless self-care
- Practice forgiveness
Positive Coping Methods
Dowling et al. (2013)

• Gratitude – keep a gratitude journal intentionally noting things for which one is grateful

• Mindfulness – intentionally pay attention to and maintain non-judgmental awareness of experiences in the present moment
Positive Coping Methods
Dowling et al. (2013)

- Positive Reappraisal – reinterpret the significance of the event in a more positive way
- Focus on Personal Strengths – self-affirmation
- Set Attainable Goals related to self care
- Practice Altruistic Behaviors / Acts of Kindness
Get Help

No one can do this alone
Ron (and Lorene)

Connie and Bill