

**Northwestern Frontotemporal
Degeneration / Primary Progressive Aphasia
Annual Caregiver Conference**

**Coping with Relationship and
Behavior Changes**

Darby Morhardt, PhD, LCSW

Cognitive Neurology and Alzheimer's Disease Center
Northwestern University Feinberg School of Medicine



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

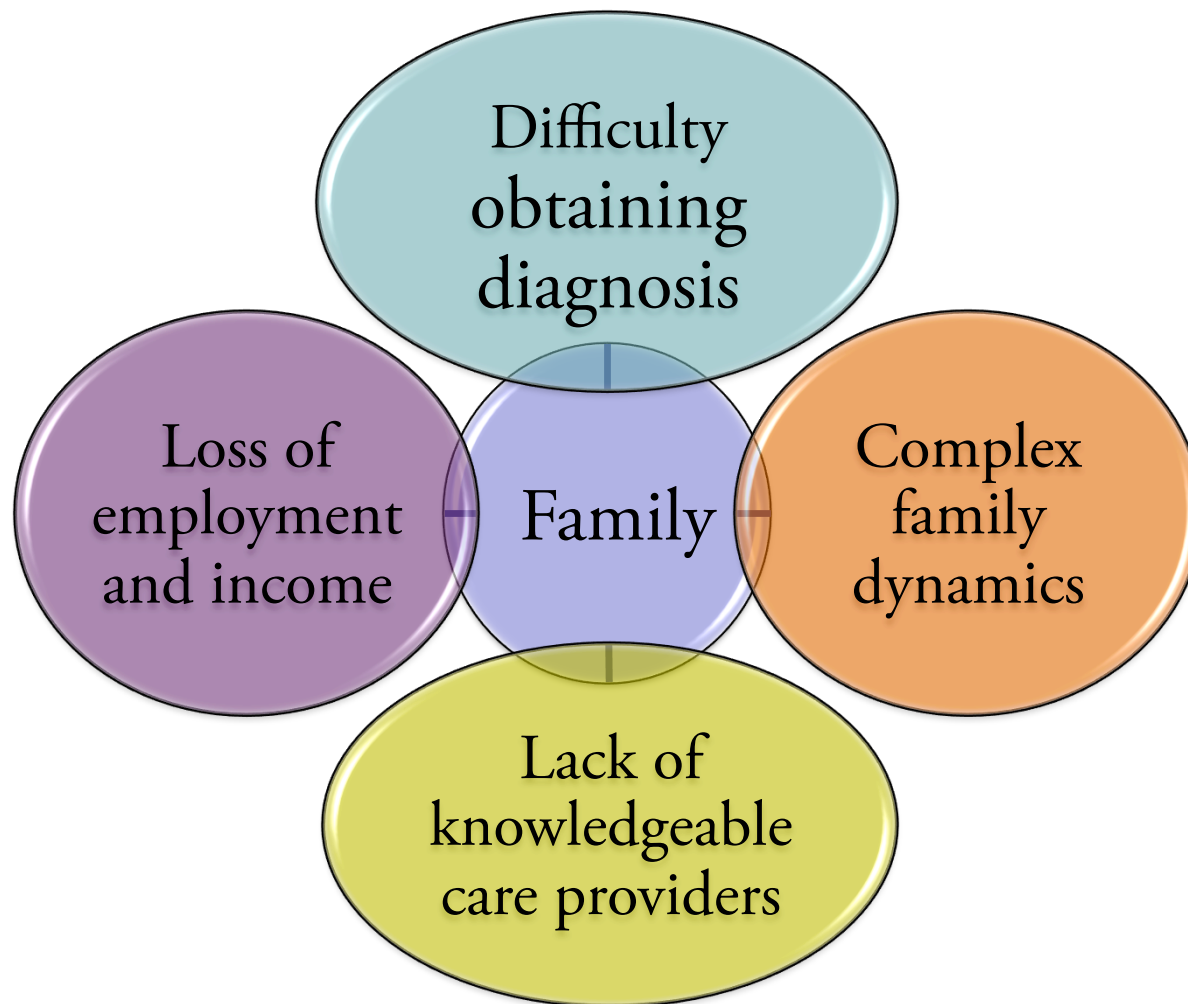


Behavior and Personality Changes

- 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



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

Reminder:
Take
Care of
Myself



I focus on
what I can do
right now

Get Help



No one can do this alone



Ron (and Lorene)



Connie and Bill