# **Perspectives on Care**

#### MARY O'HARA, LCSW

#### **ROCKY MOUNTAIN NEUROBEHAVIORAL ASSOCIATES**

# Find your Lighthouse (s)

 Connect with Ongoing Guidance, Care Resources and Emotional Support:

- Request a referral for resource navigation
- Social worker, Care/Case Manager
- o Local Social Service Agencies
- AFTD helpline and AFTD Telephone Groups
- o Support Groups
- Online Community

# Legal and Financial Planning

- Meet with an Elder Law Attorney to discuss Legal and Financial Planning, Medicaid Planning, Guardianship
- If under age 65, apply for Social Security Disability Insurance (SSDI). Medicare Eligibility 2 years later.
- If eligible, inquire about Veteran's Benefits.
- If you have Long Term Care Insurance, find out what your plan provides.
- FMLA available to family members
- Begin gathering information about future care options and cost of care. (www.Genworth.com)

## **Balance Independence with Safety**

- "I have PPA/bvFTD card"
- If concerned, Request a driving evaluation from physician
- Remove or safely store any firearms in the home.
- If judgment is impaired, monitor credit cards, bank accounts, investments, internet, scams
- Consult with Occupational Therapist for home safety eval.
- Consult with Physical Therapist for changes in balance, gait
- Request a referral for a geriatric psychiatrist if there are changes in mood.
- If there are disagreements around these safety issues, seek the help of professionals on your care team
- Efforts focus on adjustment to changes, not convincing

### **Adapt Communication and Expectations**

- Request a referral for a Speech and Language Pathologist
- Accept that and Plan for things to take more time.
  S.T.O.P Exercise
- For people with difficulty communicating, consider alternative therapies for like Art Therapy or Music Therapy as a form of emotional expression.
- At the end of the day, take a moment to think about what went well that day, what strengths remain, and moments of connection and laughter.

# **Balance Engagement with Respite and Safety**

- Establish a predictable and familiar daily routine.
- Brain Health Suggestions\*
  - Regular exercise, Healthy diet, Sufficient sleep, Manage mood, Stay socially connected and Mentally engaged.
  - In cases of Apathy, Passive Participation is ok.
- Increase Engagement with Additional Care
  - Regular Visits from Family, neighbors and friends
  - Creative arts based interventions like music, painting, dance.
  - o Early Dementia Programs
  - In-Home Companion Care (Private Pay or LTC)
  - o Adult Day Programs (Private Pay, Medicaid, LTC)

#### When is it time?

- You do not have to make this decision alone.
- Consider Changes in Care when either:
  - Diagnosed Person's safety, health and wellbeing at risk
    Family's safety, health and wellbeing at risk
- Speak with FTD/PPA families who used services you are considering.
- As you prepare for a transition to another level of care, remember the focus is on helping to support the person as they adjust to the change, not convincing them of the change.

# Tend To, Fill up and Send out your Signal

- Consider individual counseling for support around feelings of grief, guilt, sadness, anger, loneliness, fear.
- Set intentions to access what fills you up & Centers you.
- Be specific when asking for help
- Access The AFTD Comstock Respite Care Grant (\$500/year) and Quality of Life Grants (\$500/year)
- Reconciling Both/And