Living Under the Umbrella of Dementia
A Virtual Gathering Nov. 16 – 17, 2020

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Young Onset

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Unique Considerations: Diagnosis

- Misdiagnoses common
- Rearview mirror clearer
- Sense of relief to get diagnosis

Unique Considerations: Young Onset

- Developmental stage of the family
- Concerns about genetics
- Career and Employment
- Challenges accessing services
Unique Considerations:
Legal/Financial

Legal Planning Documents
Employment
Impact on income and insurance
Medicare/SSDI
Compassionate Allowance

Specialized Approaches:
Home and Community Based Care

Group vs individual engagement
Connection with others
Physical abilities and strength
Guidelines for Young Onset:

1. Difficulty with Young Onset?

2. With what have you found the most success?

Goals:

- Create a support system
- Build a plan of care that is fiscally sound
- Build a plan of care that helps the person:
  - Be the way they want to
  - Do what they are able
  - Feel good about themselves
  - Feel OK about where they are
  - Enjoy the people who are there to help them
  - Get what they need

Goals:

• A complete physical, medical, and psychological history
• A good history of changes from the person and the family
• A thorough neurological and cardiac exam with blood work
• A complete medication review
• Imaging study (CT, MRI, PET)
• Neuropsychological testing
Thresholds:

1. For the Care Partner

2. For the Person Living with Dementia

Relationships:

- Knowing the person
- Preserving dignity and sense of identity
- Awareness and how they are responding to changes
- Perception is reality

50% Are Unaware of Changes:

- 50% no awareness that they have early signs of dementia, lack self awareness
- Not accurate at assessing skills and abilities, think they are fine
What doesn’t help:
- We argue, trying to get them to see their losses
- Most common emotional state for both the person with dementia and caregiver = anger
Key Elements and Risks:

Three Elements:
- Safety
- Ability
- Engagement

Ratings:
- OK
- Risky
- Dangerous

Environment:

- Safety
- Engaging
- Feeling of Belonging

Supportive Environments:
The 3 Positive Ps

- Physical Environment
- People—the ways they act and respond
- Programming
How do I spend my day?
- Abilities
- Sense of Purpose
- Physical
- Cognitive
- Emotional/Spiritual

What Are the Options?
Your Own House
Apartment Building
In home of another
Day Center – Social
Day Center – Health
Independent Living Site
Group Home
Rest Home

Assisted Living Site
Memory Care Site
Secured Unit
Skilled Nursing Facility
Hospital
Step Down Unit
Psychiatric Unit
CCRC

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