WELCOME!

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Guest Speaker:

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Maintaining Relationships During a Journey with ALS

The ALS Association
National Office-Care Services
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Maintaining Relationships During a Journey with ALS

one perspective

Rebecca Axline, LCSW-S, APHSW-C
Defining “Relations”

- Family of origin
- Family of “creation”
- Friends
- Acquaintances
- Community
- Treatment Team
Topics for Today’s Talk:

• Safe containers for emotions and grief

• Communication is more than words

• Roles and behaviors

• Resources for Education and Support
Education and Support

- **Communication Changes**
  - Paradigm shift
  - Possible cognitive change
  - Role changes
  - Respect is key for all
  - Safety is priority
  - Honor emotions and grief
Education and Support

- Reducing Care Fatigue
  - Education resources
  - Bring care in early
  - Allow for emotional response
  - Manage caregiver exhaustion
  - Honor grief
Education and Support

- Insurance coverage, care needs and realistic expectations
  - Accept help from others
  - Explore social programs
  - Maximize funds
  - Realistic expectations

Dear mind, please stop thinking so much at night. I need to sleep.
Education and Support

- Learn about resources
  - ALS Association
  - Muscular Dystrophy Association
  - Web sites for accurate and up to date scientific data
  - Local clinics and community resources
  - State resources
Be an Emotion Scientist

• Pharmacological intervention versus non-pharmacological
  • Understand PBA and/or depression
  • Both may be involved
  • Multiple factors
  • Physician/pharmacist
  • Consider “talk” therapy
Difficult Conversations

• Addressing legal documents

• How is quality of life defined?

• Ensure all family is aware of choices
Anxiety is extremely contagious, but so is calm.

Harriet Lerner
Thoughts to Consider

- Stressors (and challenges) of this disease are real
- Relationships are a vital part of a full life
- Being strong is about recognizing we need each other
- Together we can find and use the best evidenced based comprehensive care ..and balance care with moments of joy
Selected Resources

• ALS Association
  – https://www.als.org/navigating-als/resources

• Brackett, Marc Ph.D. *Permission to Feel: Unlocking the Power of Emotions to Help Our Kids, Ourselves, and Our Society Thrive*

• Dagmar Munn:
  – http://alsandwellness.blogspot.com/2015/01/welcome.html

• Grief resource:
  – https://grief.com/

• Wonders and Worries
  – https://www.wondersandworries.org/for-parents/illness-discussion-tips/
Houston Methodist “TEAM HOPE”

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