

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

HOUSTON
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Defining “Relations”

- Includes:
 - 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**

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





- *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*



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

“ quote fancy

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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