

Welcome!

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Maintaining Relationships During a Journey with ALS

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Attendees are advised that portions of this webinar will be recorded for later viewing in our archives. If you would like to review the recording, please refer to our website, for information (www.alsa.org).

Hosted by:
The ALS Association
National Office-Care Services



Maintaining Relationships During a Journey with ALS

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Objectives:

Through this presentation, participants will:

- ✧ Identify challenges in marital and committed relationships that accompany a diagnosis of ALS
- ✧ Learn tips and techniques for maintaining positive connections and strong partnership



Challenges:

**Implications and Effects
on the Partner/Marital Relationship**

Challenges: *Dual Relationships*

Partner/Spouse

- Commitment
- Intimacy
- Shared goals/future

VS.

Patient/Caregiver

- Changing Roles
- Changing Responsibilities
- Needing assistance with performing utilitarian tasks



Challenges:

- Dependency:
 - reliance on someone or something else.
- Co-dependency:
 - excessive emotional or psychological reliance on a partner, usually by a partner who needs support due to illness or addiction
- Enmeshment:
 - Relationship in which personal boundaries are permeable and unclear; defined more by the relationship than by their individuality

Challenges:

- *Disease Progression*
 - Medical appointments
 - Loss of physical abilities
- *Time Management*
- *Parenting*
 - *Shift in role and responsibilities*
 - *Time and attention*
- *Economic Factors*
 - *Home/living space*
 - *Financial consideration*
 - *Loss of income and/or health insurance*

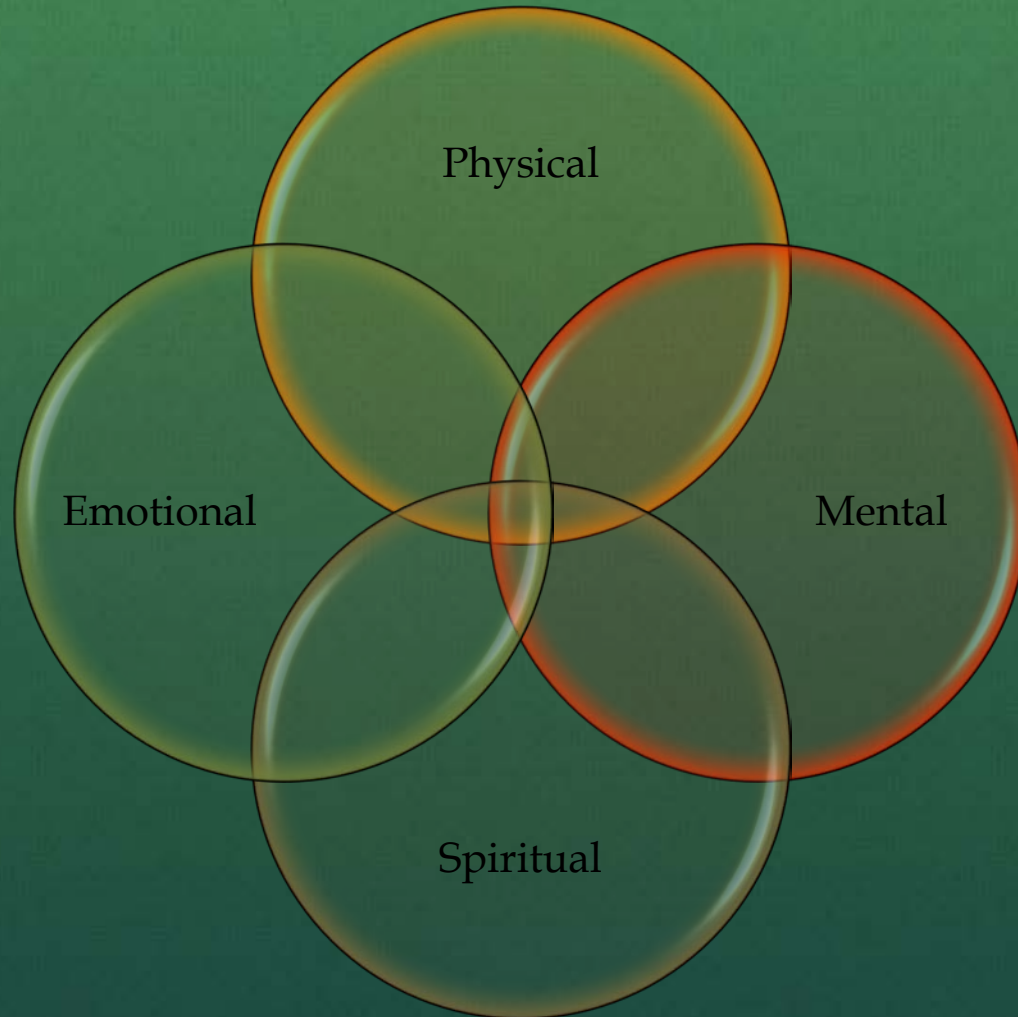
Challenges: GRIEF

Triggered by:

- Diagnosis of ALS
- Changing physical abilities
- Loss of independence
- Loss of Future as you thought it would be
- Change in Roles & Responsibilities
- Change in Self-Identity



Challenges: GRIEF *(continued)*



Challenges: Intervention Issues

- Professional/medical interventions typically focus on managing clinical & functional problems
- With continuous physical & medical changes, often fewer resources for emotional and relational support
- Also, reluctance on medical team's part, as their "specialty" is more physical than mental health or emotional

~ Young, J.M. & McNicoll, P. (1998) Against all odds:



Interventions:

Ways to maintain and enhance
your “special” relationship

Key Intervention Strategies:

- Communication
- Devoted time together
- Social Supports
- Grief therapy techniques and tools
- Benefit finding



Interventions: Communication

INTERVENTIONS:

Communication

In couples therapy, potential for true intimacy:

- Closeness: ability to let barriers down to allow someone to see the “real” you
- Communication: ability to say how you feel and understand how another feels
- Commitment: ability for emotional attachment to partner

Not the quality of your relationship,
but your potential as an individual

INTERVENTIONS:

Communication

Key communication tips:

- Listen for meaning and repeat back what your partner said. Do this until you get it right!
 - The therapist line: “What I hear you saying is.....”
- Use “I” statements instead of “you” statements
- Allow time (also see devoted time)

INTERVENTIONS:

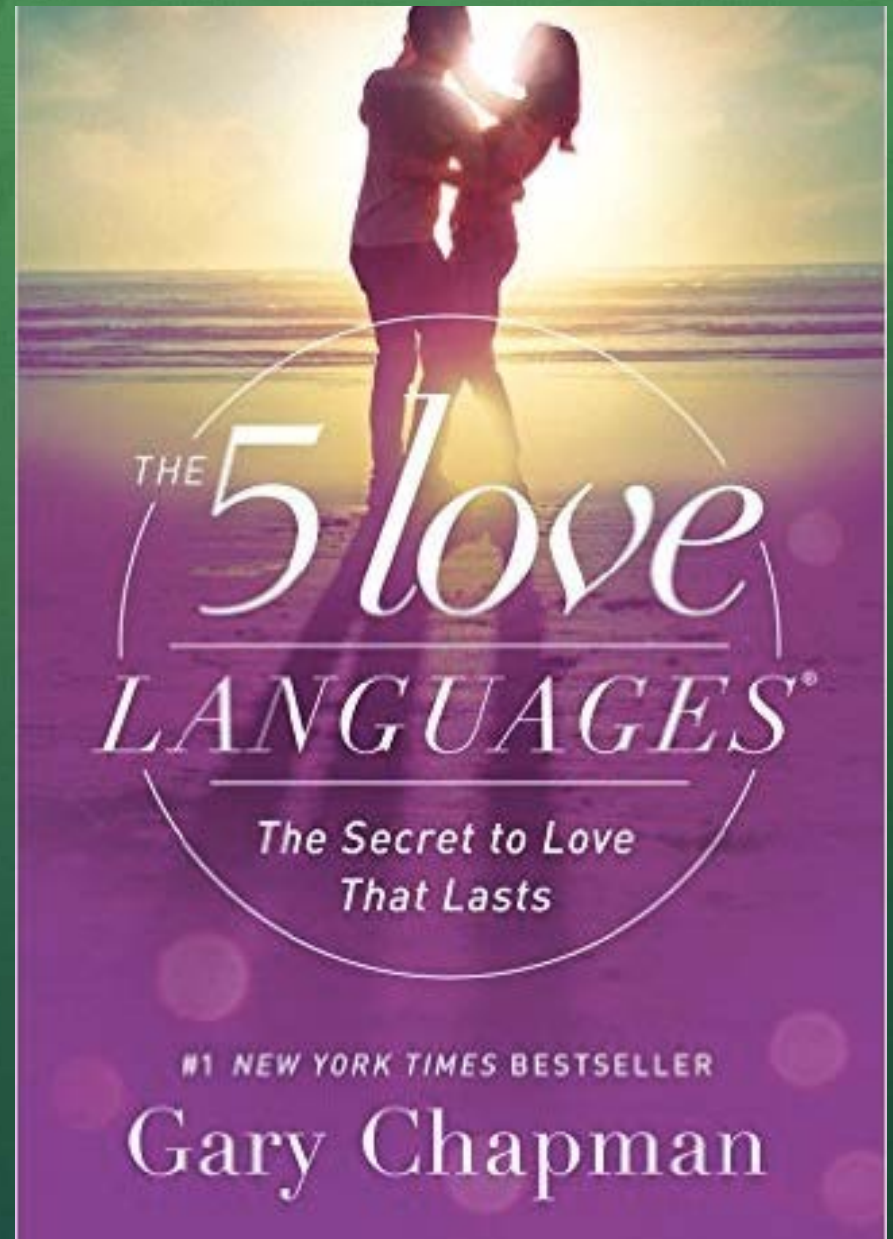
Communication

Key communication tips:

- Find “other” ways to communicate:
 - Text messages
 - Emails
 - Post-it notes on a mirror or slip each other notes
 - Voice messages, if you are able
- If speech or writing is compromised
 - Pre-programming phrases in voice generating devices
 - Create and save special, meaningful email messages
 - Ask someone else to write/create

INTERVENTIONS: Communication

- ℳ Words of Affirmation
- ℳ Quality Time
- ℳ Receiving Gifts
- ℳ Acts of Service
- ℳ Physical Touch



If your partner's love language is.....

Words of Affirmation:

- Give a sincere compliment each day
- Say something encouraging or give compliment to partner in front of others
- Tell others (in front of partner) something positive about partner (your mom is a great mother to you)
- Write a love letter

Quality Time:

- Ask partner for a list of 5 things s/he would like you to do with him/her
 - Select one and DO IT!
- Plan a date or time “away” together
- Have a “get re-acquainted” night; example questions in book
 - Who was your favorite grade school teacher and why?
 - Tell me about a time when you felt your parents were proud of you.

If your partner's love language is.....

Receiving Gifts:

- A pretty stone, leaf or flower from a walk or outing
- Listen to things s/he mentions liking and purchase as a surprise gift (EX: rose bush for the garden; book that s/he wants to read; movie s/he wants to see on Netflix)
- Choose a book to read with your spouse – discuss after each chapter (gift of book, of self, AND of time)

Acts of Service:

- Helping with chores, errands, etc to free up your partner's time and/or help together
- ASK what your partner would like for you to do that would show love
 - Remember: your partner has to perceive what you do as important! Just because you do something YOU think is nice may not mean it is a priority for your partner

If your partner's love language is.....

Physical Touch:

- Touching partner when you say "I love you"
- Hold hands or put arm around partner
- Greet or say goodbye with hug/kiss





Interventions:
Devoted Time Together

INTERVENTIONS:

Devoted Time Together

- Conscious decision to commit to “couples time”
- Difficulty with increased symptom management, decreased physical ability, or necessary caregiving needs
- Enlist family, friends, and social supports to help create space and time

INTERVENTIONS:

Devoted Time Together

- Designate time for a “date” even if staying home
 - If able to get out, but need assistance: double date!
- Create a romantic setting
- Get a sitter for the kids or pets, so that your attention is on each other
- Make caregiving chores more connecting
 - special meal, playful banter, massage or intimate connection during bathing
- Find creative ways to be intimate, if you have physical limitations



INTERVENTIONS:

Devoted Time Together

Simplified strategies:

- Dedicated time during the day to hug, hold, read, pray
- Designated day/time
- Pet names, inside jokes, special routines



Interventions: Social Supports

INTERVENTIONS:

Social Supports

- Research shows social support:
 - Reduces caregiver anxiety & distress
 - Improves quality of life for patient
 - Can be severely affected by patient's disease progression
 - Friends pull away, not knowing how to support
 - Overriding predictor of marital/partner relationship satisfaction!
 - Rather than severity of illness
 - As disease progress and physical abilities decrease, reliance on relationships increases

~O'Connor, E.J., McCabe M.P., & Firth, L. (2008) The impact of neurological illness on marital relationships.
Journal of Sex & Marital Therapy 34: 115-132.

INTERVENTIONS:

Social Supports

- Letting others help you
 - *Your gift to them!*

Resources:

- www.lotsahelpinghands.com
- Caring Bridge
- Church groups, clubs or organizations, work colleagues



Interventions: Grief Therapy Tools

INTERVENTIONS:

Grief Therapy Tools

Tasks of Mourning:

- Acknowledge reality of loss
- Approach pain of loss with support
- Remember the loss
- Develop new self-identity
- Find meaning in loss
- Social support

INTERVENTIONS:

Grief Therapy Tools

- Recognizing the role of grief
- Allowing time to “be” with grief
- Realizing that you are likely experiencing grief differently than your partner
 - Intuitive vs. Instrumental Grief (Ken Doka)
 - Ways of grieving vary – spectrum of responses, but often differing between partners
 - Communication becomes critical
 - Accepting and supporting

INTERVENTIONS:

Grief Therapy Tools

- Talk it out! (intuitive)
- Do something-take action (instrumental)
- Ritual: create a moment to say goodbye to whatever you have lost
 - Light a candle
 - Journal
 - Create a ritual/ceremony
- “Life Review”
 - Capturing memories; reminiscing about milestones
 - Creating albums, collages, videos



Interventions: Benefit Finding

INTERVENTIONS:

Benefit Finding

- Cognitive reappraisal
 - What can be controlled and what can't
- Reframing
 - Construing benefits
- Gratitude
 - Closely related to reframing — finding positives
 - But more about recognizing the gifts or blessings in your life
 - Also, a grief therapy intervention

INTERVENTIONS:

Benefit Finding

- Thought control – active process
 - “Cancelling” negative thoughts
 - Choosing to adopt a positive attitude
- Humor
 - Maintaining connection with friends
 - For one’s own mental health
- Living a day at a time



Maintaining Relationships During a Journey with ALS

References

Chapman, G. (2010). *The 5 Love Languages: The secret to love that lasts*. Northfield Publishing: Chicago, IL.

Mavandadi, S., et al. ((2014). Benefit finding and relationship quality in Parkinson's Disease: A pilot dyadic analysis of husbands and wives. *Journal of Family Psychology* 28:5, 728-734.

O'Connor, E.J., McCabe M.P., & Firth, L. (2008). The impact of neurological illness on marital relationships. *Journal of Sex & Marital Therapy* 34: 115-132.

Young, J.M. & McNicoll, P. (1998). Against all odds: Positive life experiences of people with advanced amyotrophic lateral sclerosis.

The background features a series of overlapping, semi-transparent green triangles of various shades, creating a layered, mountain-like effect. A horizontal band of bright yellow-orange with a fine, grainy texture runs across the middle of the image. The word "Questions?" is centered within this band in a dark green, serif font.

Questions?

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