Let’s Party!

The Importance of Celebrations & Holidays while Living with ALS

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What comes to mind when you think of holiday gatherings, family events, or parties with friends?
Fun, connection, joy....
OR...frustration, exhaustion, exclusion.
So, how do you manage celebrations & holidays?

Objectives of this presentation:

Through this presentation, participants will:

- Identify **common challenges** in participating in celebrations or holidays
- Discuss the **benefits** to creating meaning through these special events
- Learn **practical tips and strategies** for managing and participating in celebrations and holidays
Common Challenges

- **Planning**: time, coordination
- Preparation
- Family dynamics
- **Extra effort/energy**
  - Physically
  - Mentally
  - Emotionally
- **Expectations**
Plus, “normal” holiday responsibilities:
Framework and Context:

- **Systems Theory**
  - Impact of different systems on one another

- **Life Cycle Models**
  - Developmental tasks

- **Family Theory**
  - Family Developmental Tasks
Framework and Context:

- **Family Illness-Systems Model** (Rolland, 1999)
  - How families cope relationally as a unit with life-threatening illness
Research: Determinants in Quality of Life (QoL) in ALS

- Most important variable for QoL = self perceived quality of social support!
- Physical status was not relevant in determining QoL for patient
- QoL relies on psychological, supportive, and spiritual factors

Benefits

- Research shows the need for **meaning**, **purpose**, and **choice** during health crisis.

- Hammell (2004) proposes that the process of accommodating life-altering illness or injury (such as ALS) **results in re-evaluation of one’s values and priorities**.

  - Consider this as related to social or holiday events—**WHAT ARE YOUR PRIORITIES NOW?**
Benefits: Meaning-making

DEFINITION:

“...process by which a person derives meanings from an activity in life and makes sense of one’s life.”

~ Iwasaki, Y. (2016)
Benefits: Meaning-making

DIMENSIONS of MEANING-MAKING:

- Doing
- Being
- Belonging
- Becoming

~Hammell (2004)
Benefits: Meaning-making

Meaning-making correlated with improved quality of life

Lyons, et al (2002) research of life-altering illness (stroke) found direct correlation of meaning-making to increased life satisfaction and lower levels of depression (as opposed to knowledge of illness).

Sloan, et al (2017) found that “strong emphasis on meaning-making through relationships, specifically an increase of meaning in family relationships, the connection to friends, and a change in compassion towards others.”
Benefits: Ritual & Routine

- Crespo, etal (2013): systematic review of 39 studies on family ritual and routine

- Three main findings:
  - Chronic condition of family member impacts frequency & nature of rituals & routines
  - Whole family interactions = important for individual and family
    - Resulted in resources for emotional support and condition management
    - Provided sense of “normalcy”
  - Linked to positive health & adaptation outcomes for both individual and family
So, HOW do you utilize (and even maximize) the BENEFITS of socialization?
Strategies

❖ Determine what you and your immediate family/caregivers:
  ❖ want to do
    ❖ What will support your QoL?
  ❖ have time to do
  ❖ can afford to do (energetically, financially, emotionally)

❖ Give yourself permission to say “NO”
Strategies (cont’d)

Prioritize

- What is important to YOU? Your caregiver? Your closest loved ones?
- What brings meaning to your life?

Examples:

- VALUES exercise
- Personal Values Cards:
  - http://www.motivationalinterviewing.org/sites/default/files/valuescardsort_0.pdf
Strategies (cont’d)

❖ **Plan!**

❖ Create a **schedule of events or commitments** as well as **time in between** to rest and regroup

❖ How much time do you need to re-energize? Ex: Day 2 = Event, Days 1 & 3 = no plans

❖ Create a **list of tasks or steps** for preparation

❖ Identify needed **supplies or resources**

❖ **EXAMPLES:** Use an app, like Wunderlist, ToDoist, Any.Do, Trello
Strategies (cont’d)

USE RESOURCES:

- **Delegate** to others
  - Identify a list of tasks
  - Assign tasks
    - Have someone coordinate for you
    - Use assignment program, like lotsahelpinghands.com
  - But feel free to set boundaries
- **You don’t have to** make, bake, run, etc. **yourself!**
  - Use home delivery; on-line ordering
  - Purchase store-bought
  - Ask someone to bring or make for you
- **Examples:** Utilize an app, spreadsheet, or checklist
**Strategies (cont’d)**

- **Manage expectations (be honest!)**
  - **Your expectations:**
    - Does it have to be perfect? Being fine with “okay”
    - Sharing with others what your expectations are
  - **Others’ expectations:**
    - Explain what you are capable of or what you are willing to do
    - Ask for their input and then compromise as applicable
    - Be willing and prepared to say “no”
References


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