

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**

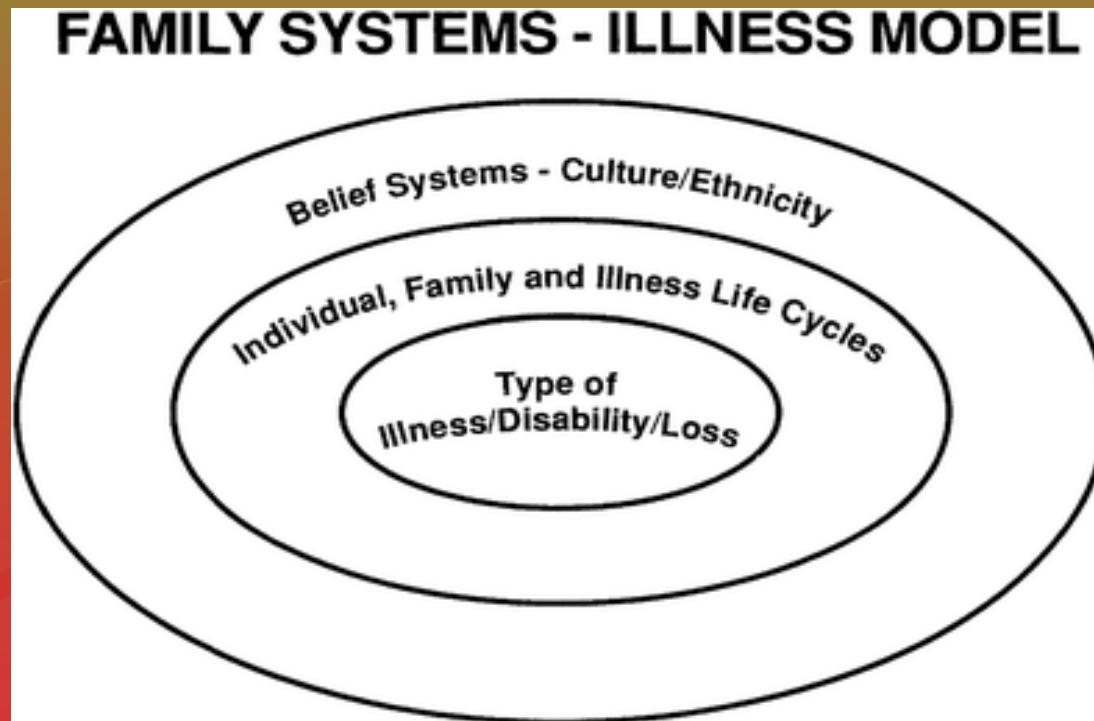
- ❁ *Developmental tasks*

- ❁ **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



Framework and Context:

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*

~ Chio, A., etal (2004)

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
- ✿ Values List: <https://resources.12stone.com/uploads/document/KIT-Value-Cards-ExerciseLarger.pdf>
- ✿ 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”

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