

March 6, 2025

Life with ALS

Caregiving, Chaos, and How Dietitians Can Help

By Wendy Wilson, RDN/LD



Conflicts of Interest

- Paid Member of Patient Committee
ALSFRS-R Study
RTI International & FDA

Agenda

- 15-20 Minutes in the Life of a Caregiver
- Discussion / Q&A

Objectives



Recognize the Overwhelming Nature of Living with ALS and its Impact on Mental Health and Adherence to Care



Consider the Diverse Perspectives of People with ALS



Address the Social Aspects of Eating



Identify ways to Support Caregivers and Patients with ALS in the Face of Challenges



Introduction & Setting the Mood

- Just Say NO to Toxic Positivity
- Acknowledge and Address Full Spectrum of Emotions
- Balancing Joy and Challenges
- Emotional Honesty

Pre-Diagnosis



First Official Date
2005



Year 1 as Family of 3
2010



Daddy Daughter Dance
2017



The Long Road to Diagnosis

- Diagnosis of Exclusion
- Frequently Misdiagnosed
- Shift in Perspective
- Second Opinion

Let's



Make



Sure!





The Ground Shifts

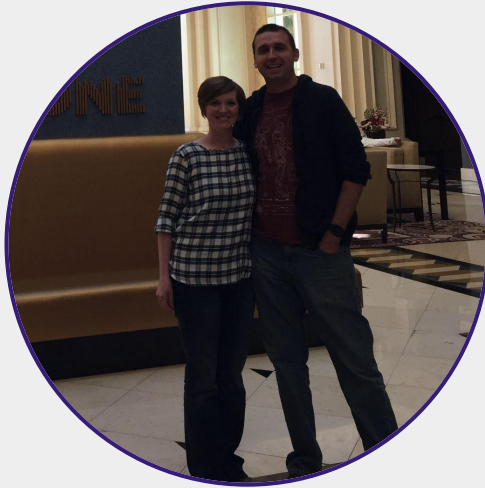
- Shock and Devastation
- Anticipatory Grief
- Letting Go + Cherishing the Present
- Overwhelming To-Do List



To-Do List from Hell

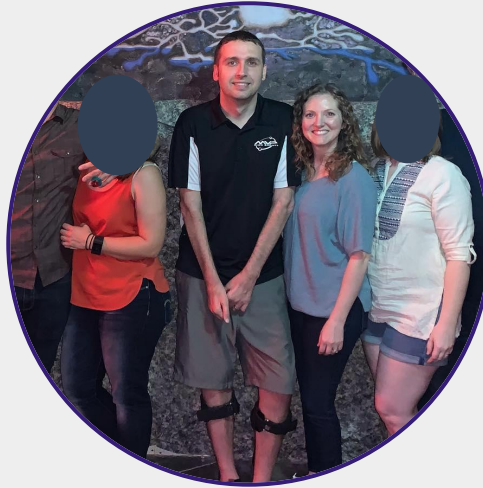
- “Get Your Affairs in Order”
- Equipment Acquisition
- Medications/Treatment
- Clinical Trials
- Home Modifications/Move
- Accessible Vehicle
- Insurance/Medicare Issues
- Support Systems
- Care Planning
- Advocacy
- Fundraising
- Sleep Disruption
- Maintaining “Normal” Life
- “Take Care of Yourself”
- Adapt Financially

Constant Cycle of “New Normal”



No Walking Assistance

January 2017



AFOs with Rollator

June 2019
(AFOs started March 2018
Rollator and some Powerchair in
March 2019)



Powerchair

June 2020

Constant Cycle of “New Normal”



Picking Noses

April 2017



Barely Holding Smoothie

May 2018
(June 2018 can't cut food, dress,
or shower. By Nov 2018 not
self-feeding)



No Hand Use

November 2018

Constant Cycle of “New Normal”



Sleeping Propped Up
March 2018



Vent at Only @ Night
June 2018



Daytime Vent
November 2024

Capacity for Adherence & How RDs Can Help

- Consider Individual Caregiving Resources and Abilities
- Maintain List of Nutrition Strategies
- Ask Open-Ended Questions
- Facilitate Access to Supplies
- Connect Families with Meal Delivery Services





Varying Perspectives

- Ask Permission, Explain Your Purpose, Understand Each Situation/Goals, Individualize Care
 - Outlook
 - Treatment Preferences
 - Life Priorities
 - Extending Life
 - Healthy Lifestyle



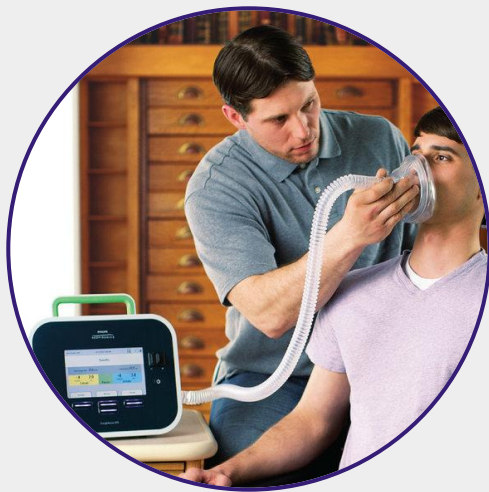
Building a Community

- Know Local Organizations and Services
- Peer Support
- Margaritas!
- “Ask Us Anything”

Quick Tips



Dentition



Blow Nose with Cough
Assist



thinkALS Tool

<https://www.als.org/thinkals/thinkals-tool>



Any Questions?



Thank You!