

WELCOME !

May 22, 2023



Maintaining Intimacy During a Journey with ALS

Guest Speaker:
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ALS Association

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#DefeatALS



Who is this Lady?

Started in 2012 as a Support Group Facilitator

Added to Care Services (CS) Team in 2020

NOT AASECT certified, but many CEUs

Nothing to Disclose

Presented at 2022 MND Alliance of Professionals Meeting (San Diego)

Presented for the Greater Chicago Area ALS Chapter, Feb 2023

Defining “Intimacy”



Webster Definition



Adults



High Schoolers



4-year-olds (define love)



Birds and the Bees vs. Later in Life

ALS does not inhibit conception,
pregnancy or birth

Keri B. Still 1999-2008

[Keri B. Still](#)

Let's Talk About Sex!

Family of Origin's Attitude (aka the Butterscotch Pudding Story)



Religion



Culture/Ancestry



Butterscotch

4
Servings



Sex is... perfectly natural. It's something that's pleasurable. It's enjoyable and it enhances a relationship. So why don't we learn as much as we can about it and become comfortable with ourselves as sexual human beings because we are all sexual?

— Sue Johanson —

AZ QUOTES

Sue Johanson
Picture Credit: AZ Quotes

Partner, cALS, Mother/Father, Friend, Lover

When we add “cALS” or Caregiver to our list of titles, it can blur into other relationships we have with our pALS.

Intimate and necessary functions need to be performed for Quality of Life (QoL) of our pALS.

Goldstein and colleagues did several studies on ALS and caregiving (not ALS and intimacy) and found the following:

Caregivers of strain in caring for their partner directly correlated with loss of intimate acts and intimate feelings.

A second study (on stress in ALS Caregivers) showed that negative impacts of the disease and diagnosis affected their relationship, but pre-illness intimacy was the main predictor of current intimacy issues and intimate relationship.

Can We Still, you know, Do It?

Direct Effects

- ♥ Nerves and Muscles
- ♥ Respiratory

Indirect Effects

- ♥ Fatigue
- ♥ Lack of sleep
- ♥ Muscle tightness, weakness
- ♥ Medications

Effects on the Partner

♥ Grief

♥ Fear

♥ Depression

♥ The “Caregiving Role”

ALS does NOT affect the actual biological act of sex

- Does not cause ED, nor do any of the three “R” medicines list erectile dysfunction as a side effect
- Does not cause vaginal dryness, nor do any of the three “R” medicines list vaginal dryness as a side effect



But...

What CAN affect sex:

- Stress levels



(continued)

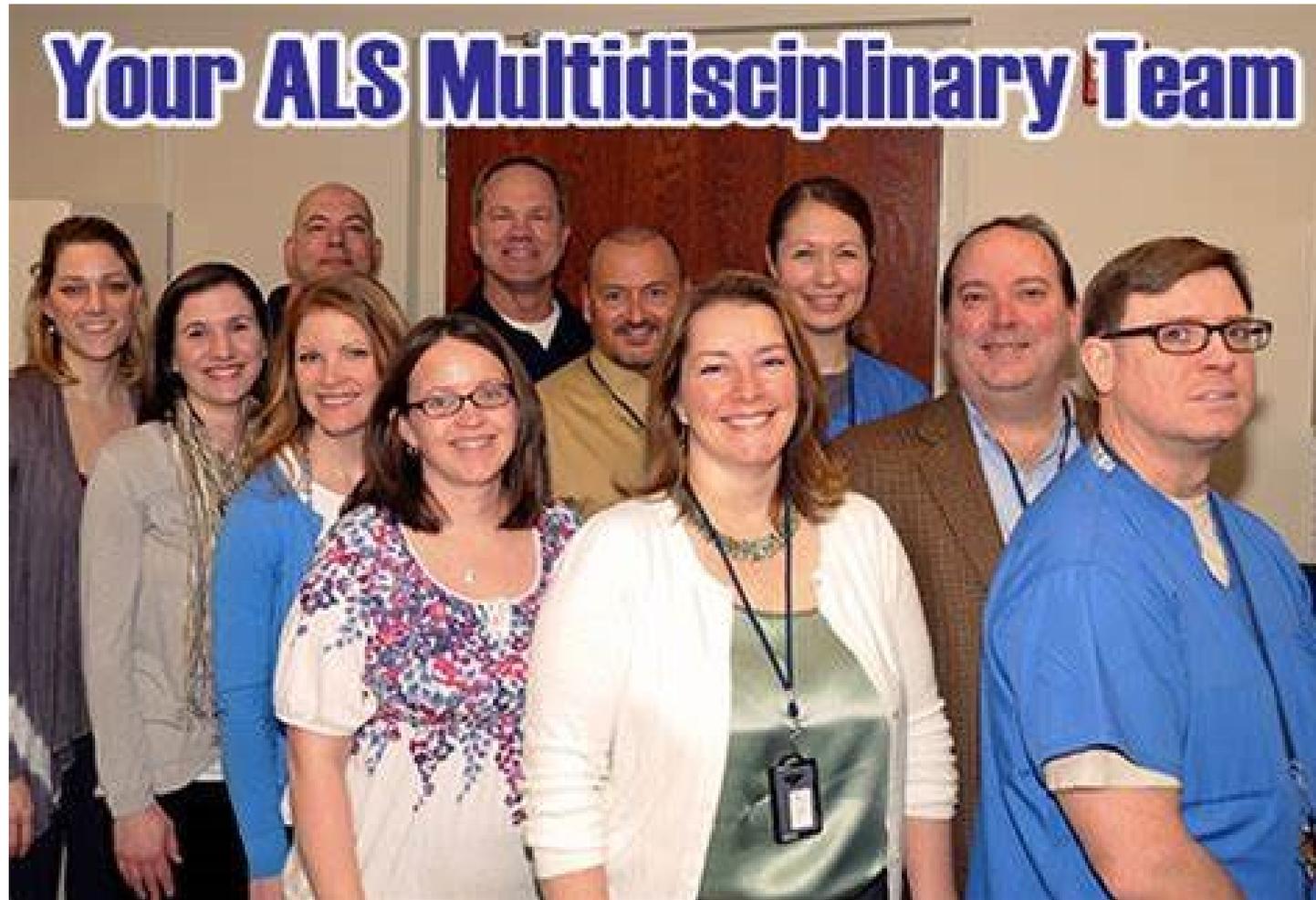
- SSRI medications, blood pressure medications (especially beta blockers), H2 blockers, opioids, benzodiazepines, statins (Contraindicated for ALS), anticonvulsants



Redefining “Intimacy”



Your Clinic Team is Here to Help!



VA of Indiana Clinical ALS Team

Picture Credit: VA.gov

Resources

- **Enabling Romance: A Guide to Love, Sex, and Relationships for the Disabled (and the People Who Care About Them)**
Ken Kroll and Erica Levy Klein (Bethesda, MD: Woodbine House, 1995)
This book is written by a married couple. Kroll has a neuromuscular disorder.
- **Not Made of Stone: The Sexual Problems of Handicapped People**
K. Heslinga with A.M. Schellen and A. Verkuyl (Springfield, Ill: Charles C. Thomas, 1974)
- **Sexuality & Disability**
Maddie Blackburn (2002)
- **Sexual Concerns When Illness or Disability Strikes**
Carol Sandowski (1990)
- **Sexual Function in People with Disability and Chronic Illness: A Health Professional's Guide**
Marca L. Sipski and Craig J. Alexander (Aspen Publishers Inc.: 1997)
This book addresses general sexual function, specific disabilities and illnesses, and treatment concerns.
- **Sexuality and Chronic Illness: A Comprehensive Approach**
Leslie R. Schover, Ph.D., and Soren Buus Jensen, M.D. (Guilford Publications, 1988)
This book reviews the basic skills needed to comfortably discuss sexuality with chronically ill patients, assess sexual problems through both psychological and medical approaches, and create a systematic treatment plan.

Works Cited

Longitudinal predictors of psychological distress and self-esteem in people with ALS.

Goldstein, L H; Atkins, L; Landau, S; Brown, R G; Leigh, P N. **Neurology** Vol. 67, Issue 9, (Nov 14, 2006): 1652-1658.

Predictors of psychological distress in carers of people with Amyotrophic Lateral Sclerosis: a longitudinal study.

Goldstein, L H; Atkins, L; Landau, S; Brown, R G; Leigh, P N. **Psychological Medicine** Vol. 36, Issue 6, (June 2006): 865-875

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