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ALS
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SERIES

Navigating the Challenges of Caregiving for People Living with ALS



Anne Lidsky, Ph.D.
Les Turner ALS Foundation Support Group Facilitator

**The ALS Learning Series is made possible because of the
Gilbert & Jacqueline Fern Foundation and our industry partners.**



About Us

Leader in comprehensive ALS care and research.

Founded in 1977, the Les Turner ALS Foundation is one of the longest-serving independent ALS groups in the country.

We are committed to providing the most comprehensive care and support to people living with ALS and their families in Chicagoland so they can confidently navigate the disease, and advance scientific research for the prevention, treatment and cure of ALS.

Support Services for people with ALS, families and caregivers

*Care visits by ALS support services
coordinators*

Support Group Meetings

Education materials and programs

*Access to medical equipment and
communication devices*

*Need-based grant programs and
community resources*

*In-service education for community
care*



Lois Insolia ALS Clinic

We Offer

- Access to enrollment in clinical trials and dedicated clinical trial coordinators
- Chicagoland's first and largest multidisciplinary ALS Clinic, with the highest number of neurologists and dedicated pulmonologists
- Multidisciplinary care that brings together an experienced team of neuromuscular specialists in one clinic to provide comprehensive support



We know making decisions about ALS care can be overwhelming.

We're here to help!



My ALS Decision Tool™ can help you choose ALS care that's in line with your needs and values. This interactive tool explains ALS treatment options and includes reflection questions to help you decide what's right for you.

lesturnerals.org

**MY ALS
DECISION
TOOL**

Looking for in-depth information about ALS symptoms and care options?

Les Turner ALS Foundation has you covered. We've created guides about key topics like nutrition, communication, mobility, and more.



ALS LEARNING SERIES

Our online ALS Learning Series aims to empower the ALS community through the latest information and insights. Educational webinars and interactive Q&A's covering a diverse array of topics, from nutrition to respiratory care, are offered monthly.

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Agenda



1. The Beginning of the Journey
2. A New Normal
3. Challenges
4. Caregiver Burnout
5. Caregiver Self-Care/Communication
6. Learning to Ask For Help
7. Changing Dynamics and Love
8. Questions and Answers

The Beginning of the Journey

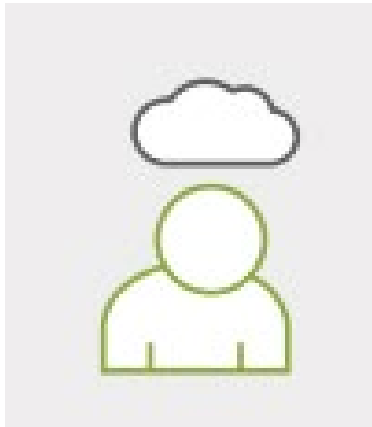
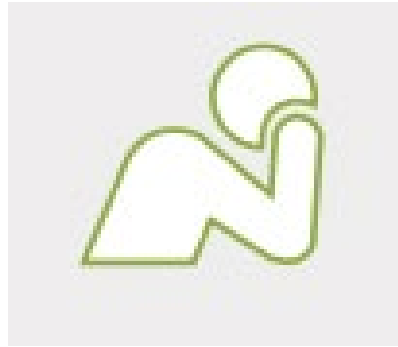
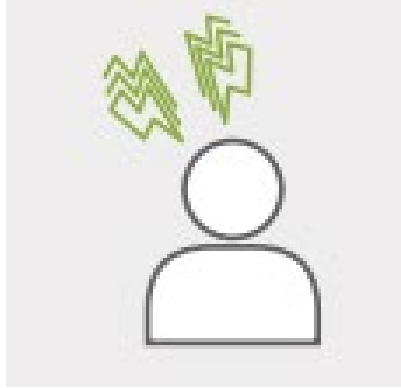
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Caregiver Burnout



- Burnout occurs when you are physically, emotionally, and mentally exhausted.
- Stress related to caregiving can compromise your physical and psychological health if not managed appropriately.

New Worries in a New Normal



Stages of caregiver burnout

Dr. James R. Sherman, in his book *Preventing Caregiver Burnout*, describes three stages of caregiver burnout:



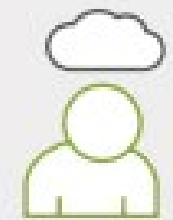
Frustration

You become frustrated or disappointed over your loved one's deteriorating condition. You might question why your quality of care isn't producing positive results. It might be hard to accept that your quality of care has nothing to do with your loved one's mood or disease progression.



Isolation

You may begin to feel lonely and struggle to maintain a sense of purpose in working hard to provide care. You may feel criticized or underappreciated by the person you are caring for and by other family members.



Despair

You begin to feel helpless and have difficulty concentrating at this stage. You may neglect your well-being and lose interest in things you previously enjoyed. You may struggle to provide care effectively.

Understanding Caregiver Burnout



BE KIND TO YOURSELF



Multiple Roles



Heavy Workload



Financial Pressure Time



Lack of Alone Time

ALS & Caregiver Self-Care Within a New Normal



- Caregivers can live fulfilling lives with the right support. Making sure you meet your own physical and emotional needs will help both you and your loved one with ALS.



How to Effectively Ask for Help

Asking for and accepting outside help can be hard for both the person with ALS and yourself.

1. It is not feasible for you to take on all the responsibilities of caregiving by yourself.
2. Being honest about when you need help will not only prevent burnout but will also allow you to continue to provide the best quality of care to your loved one.
3. People want to help, but they don't know how!



Self-Care Strategies



- Participate in mind-body practices like meditation and deep breathing exercises. Stop, Breathe, Focus.



- Try to get some daily exercise; walk around the block.



- Stay connected with friends and family



- Plan something to look forward to



- Pay attention to your own eating habits.



- Talk to someone about what you are going through—support groups are great for this!

Social Media Groups

- Caregivers have told us that social media community groups have helped them tremendously. Check out some of the most well-liked Facebook groups.



Explore Home Health, Respite, and Hospice Care

- It is so important to plan for hiring outside caregivers and ACCEPT respite and hospice care when you come to that point in the ALS journey.
- Hiring a caregiver
 - Prior to contacting caregiver agencies or independent caregivers, we encourage you to think about a list of your needs, preferences, and expectations for care.

Les Turner ALS Foundation's Caregivers Only Group

- Offers a time to talk about issues caregivers face in a non-judgmental, accepting atmosphere without their loved one living with ALS being present.
- To find out more, visit: lesturnerals.org/support-groups

Remember...

- Many caregivers feel like they are failing their loved one by not doing “enough” each day, and this is normal.
- Everyone has different capabilities, and much depends on the needs and the personality of the person with ALS.
- It is hard to be a caregiver, and YOU are doing the BEST you can.

Changes in Thinking and Behavior

Changing Dynamics



- Every relationship is different; much depends the previous relationship dynamics to the speed that the disease progresses.
- The person living with ALS may experience a change in personality, increased irritability or decreased insight, all of which can change the dynamics of your relationship.

Remember to...



- **COMMUNICATE**

- Crucial to listen with compassion and to advocate for yourself.

- **HAVE PATIENCE**

- With the person living with ALS and yourself

- **ENJOY TIME TOGETHER**

- **BE LOVING**



Tips to Creating a Fulfilling Life

- **LIVE IN THE PRESENT**

- Focus on living in the present without placing too much emphasis on what the future holds.

- **DON'T TRY TO ACCOMPLISH EVERYTHING AT ONCE**

- Take things one day at a time and know that you do not have to accomplish everything at once.

- **FOCUS ON WHAT YOU CAN DO**

- Don't dwell on what you can no longer do. A diagnosis of ALS does not mean your life is over. Focus on making positive memories with the person living with ALS.

Intimacy



- **Intimacy is an important aspect of your well-being and is necessary for a healthy relationship.**
 - You may have to redefine what physical intimacy means in your relationship, but it does not have to come to an end.
- **Be loving**
 - Hold hands, gently touch his/her cheek; caress a shoulder, offer a sweet kiss; remember why you love this person.





Q&A

Please type your questions
in the Q&A box

www.lesturnerals.org



12th Annual Les Turner Symposium on ALS

• Monday, November 7

KEYNOTE SPEAKER
Nicholas Maragakis, MD



Learn more and register:
lesturnerals.org/symposium

**Upcoming Webinar:
ALS and Exercise**

December 8th, 2022, 12:00 CT

alslearningseries.org

Shirley Ryan
Abilitylab

**Hannah Redd PT, DPT
Senior Physical Therapist
Shirley Ryan AbilityLab**



**Thank you for your participation in
today's webinar!**

lesturnerals.org/resources



Resources

- For information on caregiving, self-care, finances, etc.: <https://lesturnerals.org/caregiver>
- For tips on hiring a caregiver: <https://lesturnerals.org/wp-content/uploads/2022/09/Tips-for-Hiring-a-Caregiver.pdf>
- For information about our virtual support groups: <https://lesturnerals.org/support-services/support-groups-education/>
- For more information on caregiving: <https://iamals.org/get-help/>
- For information on respite coverage:
 - For a veteran: <https://www.caregiver.va.gov/>
 - For people living in Illinois: <https://archrespice.org/respite-locator-service-state-information/145-illinois-info>
 - For people living in Iowa, Michigan, Nebraska, or South Dakota: <https://teamgleason.org/pals-resource/support-services/>