



Community

NOVEMBER 2021

The Newsletter of the Les Turner ALS Foundation

Hope and help for people with ALS.

lesturnerals.org

Page 1
Announcing:
My ALS
Decision Tool™

Page 2
New ALS
Information
Guides

Page 3
ALS Learning
Series Webinars

Page 4
Support Through
Education
New Support Groups

Page 5
Letter from
the CEO

Page 6
New Meaning
to an ALS
Journey

Announcing: My ALS Decision Tool™

The Les Turner ALS Foundation is pleased to announce the launch of My ALS Decision Tool™, the first of its kind decision-making tool for ALS in the United States.

The decision tool is an easy to use, web-based, interactive series of questions and considerations which help people with ALS to make informed decisions about their care.

We are especially grateful to those living with ALS and caregivers who worked with us over the last year to provide valuable feedback about the design and usability of the decision tool.

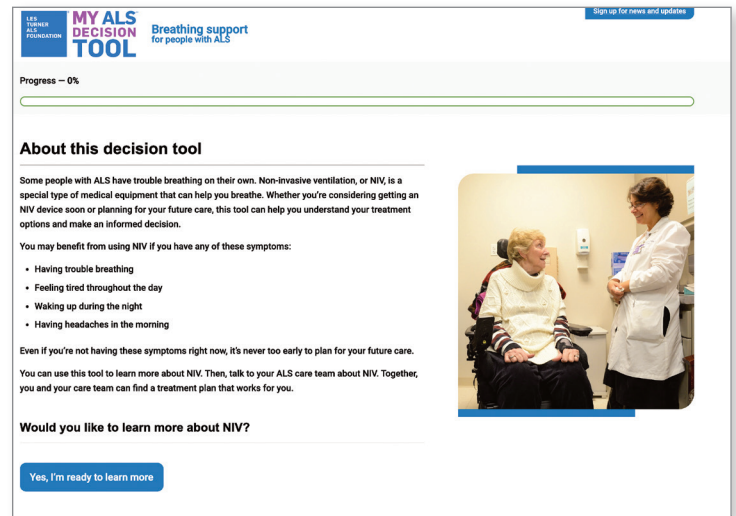
For a person living with ALS, My ALS Decision Tool™ adds a component of dignity, autonomy, and self-determination that is vital to overall well-being and quality of life.

For a clinician, My ALS Decision Tool™ is designed to help simplify otherwise complex medical decisions and to gauge a patient's understanding of their options to accept or decline treatment. The decision tool clarifies preferences and values as well as facilitates conversations between people living with ALS, their families, and multidisciplinary care teams.

Currently, My ALS Decision Tool™ addresses two of the issues of greatest concern to people living with ALS: breathing and nutrition.

You can try My ALS Decision Tool™ yourself: Available modules are linked at LesTurnerALS.org/Resources. There, you'll see how My ALS Decision Tool™ benefited from the input of people living with ALS, ALS clinicians, the Foundation's social workers and nurses, adaptive technology experts, and health literacy professionals.

Dr. John Coleman III, Les Turner ALS Foundation board member and pulmonologist at the Les Turner ALS Center at Northwestern Medicine, oversaw the medical review of the modules and guides.



Decision tool development and content editing was championed by Lauren Webb, LCSW, Les Turner's Director of Support Services and Education, and Nicole Sammartino, MS, Community Education Manager. They remain instrumental in creating and editing new decision-tool modules in partnership with CommunicateHealth.

Our vision for an interactive ALS decision tool became a reality when we received seed funding from a Cytokinetics Communication Fellowship grant, a grant from Novartis Gene Therapies (Avexis), as well as generous donations from the Gilbert & Jacqueline Fern Foundation and donors like you.

Thank you for making a groundbreaking difference in the lives of people living with ALS. ■



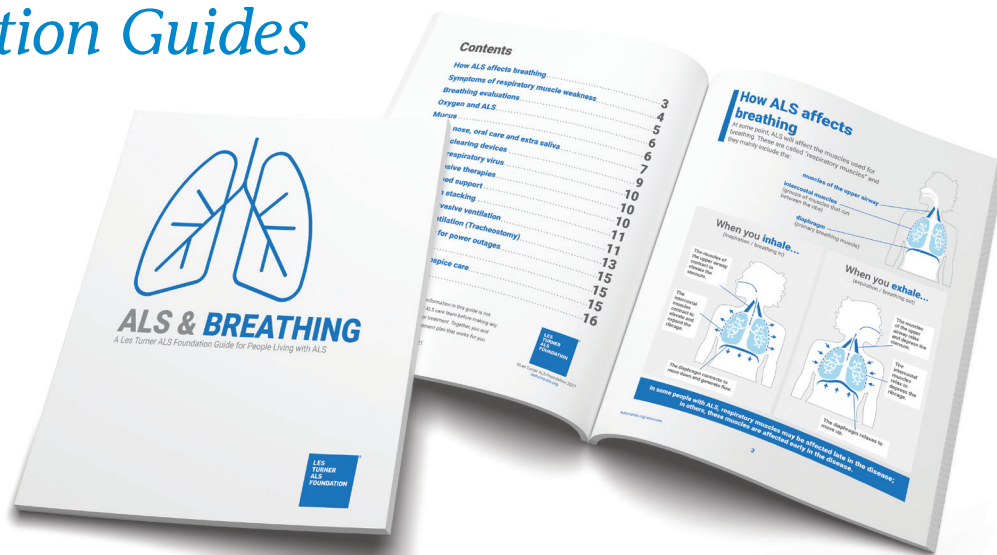
Dr. John Coleman III, Pulmonologist at the Les Turner ALS Center at Northwestern Medicine

New ALS Information Guides

Co-produced with the ALS community, the Foundation has launched new information guides that address the top areas of concern for those living with ALS, their caregivers, and families. The guides cover:

- ALS & Activities of Daily Living
- ALS & Breathing
- ALS & Communication
- ALS & Home Modifications
- ALS & Mobility
- ALS & Nutrition

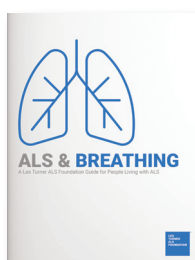
The guides serve as stand-alone references, as well as excellent decision-support companions to My ALS Decision Tool™.



ALS & Activities of Daily Living

Due to the potential rapid progression of ALS, this guide offers ways to make daily living a little easier as extra help is

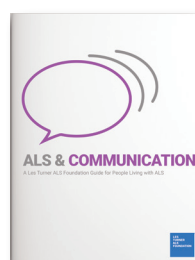
needed to get through the day.



ALS & Breathing

ALS can affect respiratory muscle weakness leading to difficulty breathing. This guide offers tips and options on how to breathe better, how to manage the side effects, and how to

navigate through this difficult process on your own terms.



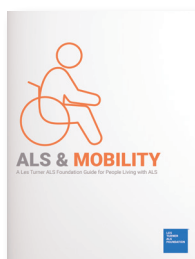
ALS & Communication

ALS can gradually weaken the muscles used for speaking and breathing, which can lead to speech changes ranging from mild to severe. This guide offers options to be understood when speech becomes compromised.



ALS & Home Modifications

Home modifications can help those with ALS to maintain their independence, while increasing safety.



ALS & Mobility

All forms of movement, from walking to lifting arms, can be impacted by ALS. This guide offers suggestions on how to use adaptive equipment and how to safely move to avoid injury.



ALS & Nutrition

ALS can eventually affect the ability to eat and drink, cause uncontrolled weight loss, ongoing loss in body mass, and a depletion in energy levels. This guide provides tips and advice on managing nutrition, handling challenges like low energy,

and safely avoiding situations like choking.

Each guide helps a person living with ALS make their own decisions. However, these guides are not a substitute for medical advice. Talk to your ALS care team before making any decisions about your health or treatment. We offer these guides so you and your care team, together, can find a treatment plan that works best for you. View and download the guides at: LesTurnerALS.org/Resources ■



Serving as a consultant for the guides, Rosie Riley, a person living with ALS, is particularly grateful. She says, *“I would definitely use the guide as a resource and would devour all of the information that I was given, specifically about Communication.”* In terms of readability and content, Rosie adds, *“The font is big enough and the colors are great. The icons also definitely help. In terms of the content, the phrasing is very clear and detailed.”*

— Rosie Riley

ALS LEARNING SERIES



Nicole Sammartino, MS

Each month, the Les Turner ALS Foundation presents a new online webinar to help people make better informed decisions about ALS care. Webinar attendees get their

questions answered by leading subject-matter experts, often the clinicians at our very own Les Turner ALS Center at Northwestern Medicine and other experts in ALS care and support.

In case you missed a topic which is now relevant to your stage in the ALS journey, all previous webinars are conveniently available to view on-demand at ALSLearningSeries.org.

Webinar topics include:

- Hospice and Palliative Care for People with ALS
- Family Planning and ALS
- Adaptive Technology for Continuous Communication
- Managing Speech and Swallowing Problems in ALS
- Nutrition Optimization in Patients with ALS
- Dissecting ALS Research Articles
- Respiratory Care in ALS: Take a Breath
- Grief and Loss in Children and Youth in Families Living with ALS
- Talking with Children about ALS
- Coping with the Loss of a Loved One During COVID-19
- My ALS Communication Passport to Quality Care
- ALS Clinical Trials 101
- Genetics and ALS

Here are some highlights:

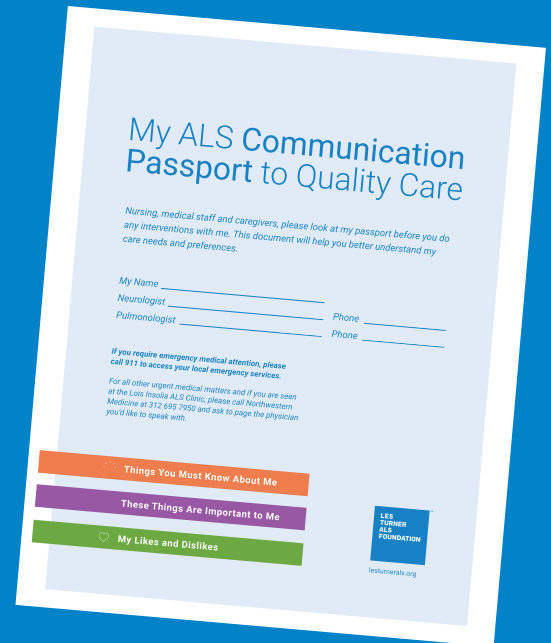
Rosie Riley, a person living with ALS, was featured in our *My ALS Communication Passport to Quality Care* webinar, in which Karen Steffens, RN, CHPN, CCM, one of our ALS Support Services coordinators, introduced a communication passport that people with communication deficits can use to convey their needs and preferences to caregivers and medical staff.

The Communication Passport and its webinar resonated with Rosie: ***“As a person living with ALS, I have benefited greatly from filling out the Passport.”***

Among the most popular webinars, ***Respiratory Care in ALS: Take a Breath*** addressed how ALS impacts breathing, as well as “non-invasive” therapies that can be used to help people living with ALS breathe comfortably.

“Dr. Coleman spoke in a language that was understandable, relatable and made sense. I found the webinar to be extremely helpful,” said J. S., Woodridge, Illinois.

Another attendee, John McDonald of Chicago agreed: ***“Well presented. Our family member has been trached and vented for some time and is at the end-stage of this disease. We continue to want to support the Les Turner ALS Foundation. We are so impressed with all that the organization does.”***



To help with the anguish of difficult conversations with your children, Dr. Melinda Kavanaugh addressed the importance of communication with children and discussed the impact of ALS on them during her two webinars, ***Talking with Children about ALS*** and ***Grief and Loss in Children and Youth in Families Living with ALS***.

Grief and loss are always difficult and having to cope during the COVID-19 pandemic has had additional challenges. The Foundation’s Nicole Sammartino, Support Services Coordinator Easton Stevenson, LCSW, and Kathy Grandfeldt, who lost her husband Ronny to ALS, presented ***Coping with the Loss of a Loved One During Covid-19***. This webinar focused on the impact that the global pandemic has had on one’s mental and emotional well-being, as well as grieving the death of a loved one during this extraordinarily difficult time.

All of the ALS Learning Series webinars are available to view on-demand at: ALSLearningSeries.org ■

Support Through Education



Julie Stowell, RN

The Les Turner ALS Foundation's Support Services team offers valuable support and guidance at no cost to people living with ALS, their caregivers, and family. The Foundation's Support Services team is known for its empathy and unparalleled expertise.

This deeply experienced group of ALS professionals is not only there to provide medical care and emotional support, but they also bring to the ALS community their expertise and vast knowledge of the disease, as well as provide helpful educational tools and resources.

Although **Julie Stowell** believes in providing ALS education to the person living with ALS and their family, she ultimately leaves the decision-making up to them. She says, "With each patient I visit I aim to be their best advocate and resource. I let them know that whatever comes their way, we can figure it out. I also tell them that I will provide information, but the decision is always theirs and I will support whatever they decide."



Cara Gallagher, MA, LCPC

Sharon Pfister, a support group attendee, is thankful for the assistance that she and her sister have received from the Foundation including grants and other educational information. She says, "**Karen** has been instrumental in getting the best care possible for my sister Kathy, who is living with ALS. I've learned about the Les Turner grants from her and members of the support group community. **Cara** has also been instrumental in providing necessary information and links to grants."



Karen Steffens, RN, CHPN, CCM

For more information about the Foundation's Support Services, visit LesTurnerALS.org/Support-Services. ■



Kathy and her sisters: Debbie, Laurie, and Sharon

New Support Groups for Bereaved ALS Partners and ALS Caregivers

The Les Turner ALS Foundation has long offered comforting support groups to people living with ALS. Over the past year, the Foundation launched an ALS partner bereavement therapeutic group, **Moving Forward After Loss**, and a new **Caregivers-Only** support group, recognizing the immense needs of caregivers in the ALS community.



Easton Stevenson, LCSW

Moving Forward After Loss, facilitated by Les Turner's **Easton Stevenson**, LCSW, provides education and validation in a supportive setting. The intention of the group is to provide people with education about what grief is and coping techniques that will help them move forward in their grief and loss.

Not only do the members of **Moving Forward After Loss** appreciate the opportunity to speak openly in a judgment-free and safe zone, but they also appreciate being able to connect with others who have lost a spouse or partner to ALS.

Jacqueline Kohn of Chicago commented on how, despite grieving in their own way, the shared experiences of the group are what brings everyone together. "I learned that when a spouse passes, we all grieve differently and follow our own timelines of grieving. But when you lose a spouse to ALS, we all share a similar loss and, thus, similar experiences. These similar experiences of losing a spouse to ALS are what particularly made our group valuable to us."

Another member, M.S. of LaGrange Park, Illinois, agreed on the value and benefits of **Moving Forward After Loss** by adding, "By sharing with the group you can get support, affirmation,

empathy, and suggestions on how to deal with the things that are difficult for you or that cause anxiety."

The **Caregivers-Only** group was launched this past July to support caregivers. This group offers a non-judgmental, accepting environment to talk openly about issues that caregivers face. Caregivers share a common experience, and often feel exhausted, overwhelmed, and in need of emotional comfort. With guidance and the encouragement of a facilitator, caregivers can find the strength to persevere. And, by feeling heard and understood, especially among others in the same situation, caregivers can become better equipped to face another day with new and sometimes improved coping strategies.



Dr. Anne Lidsky, PhD

Dr. Anne Lidsky, Foundation Support Group facilitator, has also seen members strongly benefit from attending meetings. "Our group is a blessing for each participant. They support one another, care for one another, and, most importantly, they are able to express their stress, frustration and fears freely without worrying about judgment or hurting their loved ones."

The Les Turner ALS Foundation is committed to offering support systems to encourage the opportunity to connect with others, and a place for anyone affected by ALS to gain additional emotional support. Remember that you are not alone, and that we are here for you. Visit our Support Groups and Education page on LesTurnerALS.org/Support-Services for more information. ■



Letter from the CEO

Andrea Pauls Backman

Dear Friends,

For all the upheaval and tragedy caused by the pandemic, there is one remarkable silver lining for the Les Turner ALS community – services previously inaccessible to many living with ALS and their families are now available online.

We continue to lead in online support-service delivery, offering a wide range of virtual options for ALS care coordination and education. Online access is crucial for people who may be otherwise isolated in their homes or who live in an underserved community without local ALS support services.

You spoke, we listened, and we heard loud and clear about increased needs from the ALS community resulting from the pandemic. We responded in several ways: more than doubling our direct support visits by our **ALS Support Services Coordinators** and adding new **Caregivers-Only** and **Bereavement Support Groups**, nearly doubling the number of people served. And a year ago, we created a new **ALS Learning Series**, allowing people living with ALS around the country and internationally, access to expert ALS support and the latest in ALS research. The 12-part ALS Learning Series has already had over 3,000 views!

Rather than simply raising awareness, we are actively supporting the ALS community in decision-making about ALS care. Much of this is based on the insights gained by our nurses and social workers who have shared lessons learned from decades of one-on-one ALS care consultations. As a result, the Les Turner ALS Foundation has developed and refined best practices for ALS decision-making in ALS care that is reflected both in our webinars and the new **My ALS Decision Tool™**.

My ALS Decision Tool™ is an online, interactive series of questions and considerations which will empower people with ALS to make informed decisions about their care and hopefully improve health outcomes. In this newsletter, you will see highlights of related webinars and companion **resource guides** that will supplement My ALS Decision Tool™.

With vital input from the ALS community, the Foundation's support and education services are continually evolving to improve quality of life for people living with ALS. This is a testament both to the dedication of our Support Services team as well as to the many people living with ALS who have provided their input and feedback to co-produce our extensive educational programs.

No one impacted by ALS should ever feel alone. We are here to help, providing care coordination, empowering decision-making for the best quality of life, offering support groups and community events, and **always striving to realize a world free of ALS**. We can't do it without you!

Together towards a cure,

P.S. To sustain our ALS education programs, support services and promising research, I hope you will donate as generously as you can, especially now.

Les Turner ALS Foundation Leadership

OFFICERS

Chair

Ken Hoffman

Vice-Chairs

Thomas F. Boleky

John M. Coleman III, MD

Robin Fern

Joel A. Schechter

Treasurer

Erin Reardon Cohn

Chair Emeritus

Harvey Gaffen

BOARD OF DIRECTORS

Matthew S. Brown

Deborah Crockett

Aalok Davé

Bonny J. Gaffen

Jodi Harris

Janene Jonas

Joshua P. Newsome

Diana Pisone

Mary Louise Pisone

Philip Schwarz

Sarvesh Soi

Melissa Wilder

Committee Advisors

Cheryl Gallagher

Scott L. Heller, MD

Mary Roemer

Honorary

Wendy Abrams

Monte Briner*

Madeleine and Joe Glossberg

A. William Haarlow, III*

James V. Insolia*

Bob Lee

James W. Nolan

Joan and Paul Rubschlager

*Deceased

Affiliations

Les Turner ALS Center at
Northwestern Medicine

Community Health Charities

International Alliance of
ALS/MND Associations

Chief Executive Officer

Andrea Pauls Backman

Editor

Emily Cerbone

Design & Print

Quantum Group

LES
TURNER
ALS
FOUNDATION

Les Turner ALS Foundation
5550 W. Touhy Avenue, Suite 302
Skokie, IL 60077-3254

847 679 3311

f t @ @LESTURNERALS

lesturnerals.org

Non-Profit
Organization
PAID
Permit No. 845
Northbrook, IL
60062



Giving New Meaning to 'an ALS Journey'... Road Trip!



Erin Weis pictured with one of her travel buddies, Hank.

Life took an unexpected turn for teacher (and now road tripper) Erin Weis. Diagnosed with ALS in September 2020, Erin shifted from educating students in the classroom to educating herself about ALS.

As part of that education process, Erin consulted with the Les Turner ALS Foundation and referred to our webinars and guides. She says, "I was in contact with a social worker at Les Turner. She helped me navigate insurance, disability benefits, find resources, and answer questions about ALS."

The educational resources provided by the Foundation help Erin to live her best life. Most recently, this consisted of a three-week RV trip with her boyfriend Adam and two dogs. Erin strives for a life that is fulfilled and encourages others to go out and live their best lives. As Erin says, "When you have ALS, you realize that the time you have left is a blessing."

With ALS, time is of the essence. Don't wait. Visit [LesTurnerALS.org/Give2021](https://www.LesTurnerALS.org/Give2021) to give today. Read more about Erin and her RV trip in the upcoming 2021 Annual Appeal. ■