

Resource Highlights for Providers Available on ALS Association Website and Partners

Please pay special attention to the following resources available on the ALS Association Website:

1. Learning about ALS - <https://www.als.org/understanding-als>

Understanding ALS

ALS, or amyotrophic lateral sclerosis, is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord. There is no cure for ALS yet.



Understanding ALS

What is ALS?

Who Gets ALS?

Stages of ALS

Symptoms and Diagnosis

Lou Gehrig and the History of ALS

ALS Glossary

Connecting ALS Podcast

Blog

2. Resources for Caregivers (and those who care for caregivers) - <https://www.als.org/navigating-als/for-caregivers>

For Caregivers

Being the primary caregiver for a loved one with ALS can be stressful – not only are you on call 24/7, but you may have additional outside responsibilities, like working a full or part-time job. Often, caregivers are so busy supporting their loved ones that their own physical or mental health takes second priority.

But as a caregiver, it's important that you get the support and assistance you need so you can care for your loved one to the best of your abilities.

That's why we make it a priority to provide resources, such as education and support groups, for caregivers of ALS patients, and we do our best to alleviate the burden of ALS for patients and their families.

For Caregivers

- Caregiver Resources
- Providing Best Care
- From One Caregiver to Another
- Caregiving Tips and More
- The ALS Association Care Companion
- Coping With Burnout
- Respite Care

A photograph showing a caregiver, a woman in a light blue sweater, supporting a person with ALS, a man in a red shirt, who is using a white cane. They are indoors, near a window with blinds. A red downward arrow icon is visible above the photo.

Caregiving Statistics

- Nearly 53 million people in the United States provide care to a chronically ill, disabled, or aging family member or friend during any given year.

3. Downloadable and Print Resources on a Variety of Topics - <https://www.als.org/navigating-als/resources/living-als-resource-guides>

Home / Navigating ALS / Resources for Learning About ALS / Living with ALS Resource Guides

GUIDE / MANUAL from the ALS ASSOCIATION

Living with ALS Resource Guides

Spanish Version: [Guías de Recursos Vivir con ELA](#)

The ALS Association's Living with ALS Resource Guides were created because of the rapidly expanding information and research in the clinical management of ALS. These cornerstone educational materials were designed to inform and educate people about ALS in a comprehensive and easily understood format. They address many of the common



4. Alabama Chapter Site - <https://www.als.org/alabama>

A. Local Care Services Resources: <https://www.als.org/alabama/local-care-services>

ALABAMA CHAPTER

Local Care Services

Our Chapter offers a full range of services to guide and assist you as you learn more about ALS. Here find pertinent information for patients, caregivers, family members, friends and healthcare workers. Our staff is available Monday through Friday to answer any questions you may have. Please do not hesitate to call or e-mail us for more information [click here](#).

Our services unite patients, caregivers and volunteers in the community to enable patients to sustain independence as long as possible and retain dignity throughout the journey.

All ALS Association services are provided at no cost to the patient.

Home Visit Program

Patient Services staff offer one-on-one personal visits to the home to provide personalized information, referrals, and site assessment for home modification and other needs.

ALS Care Clinic

The Chapter supports the first multidisciplinary ALS Clinic in Alabama, which sees patients monthly at Crestwood Medical Center in Huntsville. The ALS Care Clinic is conveniently located in the Crestwood Therapy Services Building, located at 610 Airport Road, Suite 100. [Click here to view clinic brochure.](#)

Respite Care
Enables primary family caregivers to have time away from their patient care duties to prevent burnout and to promote well-being for both the caregiver and person living with ALS.

Information Services

We provide educational and practical information on ALS to patients, caregivers

Local Care Services

- Centers & Clinics
- Support Groups
- EmpowerED Workshops

B. Empowered Workshops and Recorded Webinars –

Start Here: Recording URL: <https://www.gomeet.com/698-651-334/EA54D884834A31>

EmpowerED Webinar - "Your ALS Toolbox"

DATE & TIME Wednesday, June 17, 2020 10:00am - 11:00am ET	LOCATION All Online Event
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[REGISTER NOW](#)

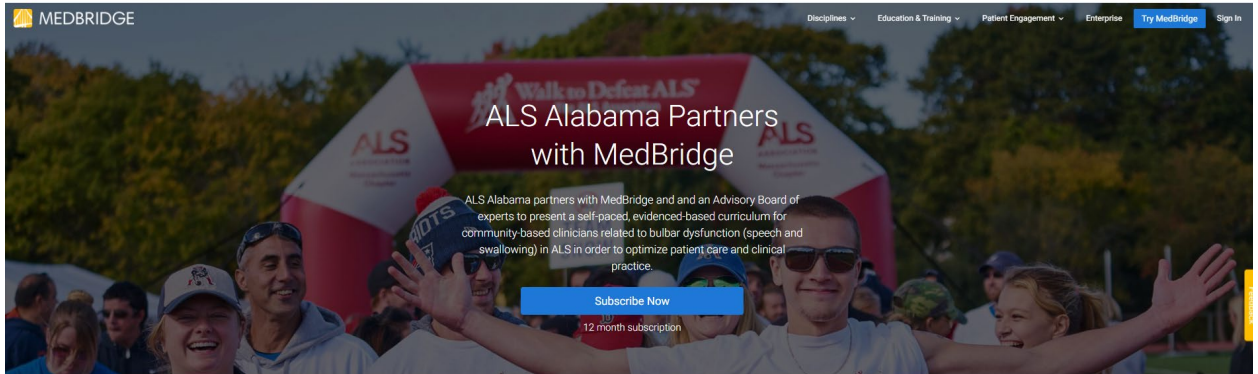
Your ALS Toolbox Essential Text and Resources for Community Healthcare Providers Supporting People Living with ALS

The ALS Association's Living with ALS Resource Guides are available both through the Chapter's website and the community health care providers. The ALS Care Clinic provides personalized information for patients, caregivers, family members, friends and healthcare workers. The ALS Care Clinic is conveniently located in the Crestwood Therapy Services Building, located at 610 Airport Road, Suite 100. [Click here to view clinic brochure.](#)



Linda Ryan, MSPT
Linda Ryan, MSPT, is the Director of the ALS Association's EmpowerED Program. She has been working for the ALS Association since 2010, where she oversees the EmpowerED program.

5. MedBridge Courses with ALS Association Alabama Chapter - https://www.medbridgeeducation.com/a/als-alabama?a_aid=6026d739ddb3&a_cid=29b49843



About the ALS Association Alabama Chapter



The Alabama Chapter was founded in 2004 to serve the needs of all those affected by ALS disease. We provide

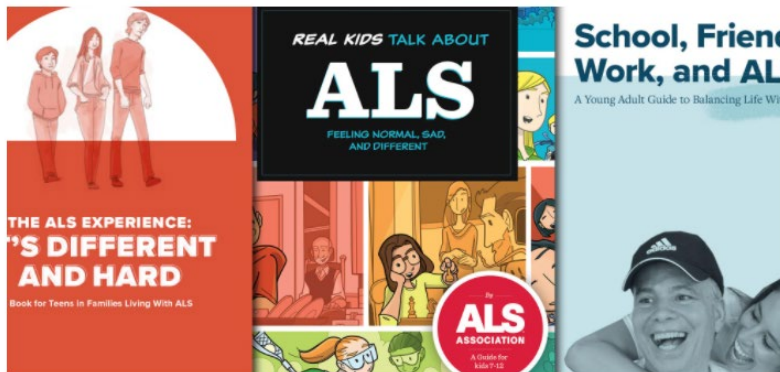
There are currently three courses available through MedBridge Education that were developed in partnership with ALS Association Alabama Chapter – including a general purpose ALS 101 course that can be purchased separately without a full subscription to the site. Using the link above allows learners to receive a discounted rate for MedBridge membership and access the courses easily.

More Resources from your ALS Association

Resources available for youth and children affected by ALS at <https://www.als.org/navigating-als/resources/Youth-Education>

BOOK, GUIDE / MANUAL from the ALS ASSOCIATION

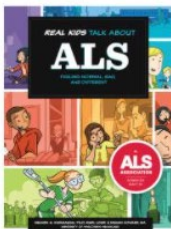
Youth Education and Support



Based on subject matter-specific research, three youth education books were developed for children, teens, and young adults. These books follow the same structure as the family guide (i.e. addressing what is ALS, caregiving, family and friends, and end of life). Yet, each book is presented to target the developmental stage of the youth. These books are available in print and digital form.

Real Kids Talk About ALS: Feeling Normal, Sad, and Different

Graphic novel for youth, ages 7-12. Delivered in a graphic novel format, this book uses direct quotes from youth in the ALS research projects. These quotes help situate the learning style and experiences of children in ALS.



- [PDF download](#)
- [Free eBook for iOS](#)
- [Free eBook for Android](#)
- [Order a hard copy](#)

The ALS Experience: It's Different and Hard

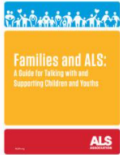
Choose your own adventure guide, middle school youth, ages 13-18. This book follows the stories of three youth, providing options for how they talked to people, who they talked to, and what was the outcome. The book allows other youth to choose who they might want to talk about ALS and their experiences. A companion online version has been developed.



- [PDF download](#)
- [Free eBook for iOS](#)
- [Free eBook for Android](#)
- [Interactive website](#)
- [Order a hard copy](#)

Families and ALS: A Guide for Talking with and Supporting Children and Youths

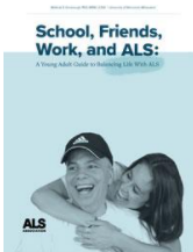
This resource guide was created primarily for families living with ALS, including parents, grandparents, siblings, and other family members. The goal of this guide is to help families start answering many of the questions that will be asked, as well as to offer support and suggestions for professionals assisting with families affected by ALS. A key theme throughout this guide is communication — how to do it, maintain it, and include it in everyday life.



- [PDF download](#)
- [Order a hard copy](#)

School, Friends, Work, and ALS: A Young Adult Guide to Balancing Life with ALS

Older youth/young adult guide, ages 19-25. This book takes a more serious tone, again following several young adults as they manage their own lives with the care needed for their loved one with ALS, school and relationships. It is minimally illustrated and again uses actual stories and quotes.



- [PDF download](#)
- [Free eBook for iOS](#)
- [Free eBook for Android](#)
- [Order a hard copy](#)

At School: A Guide to Supporting Students Who Have Been Affected by ALS

While much attention is paid to the person living with ALS and their adult family member/caregivers, children are often voiceless, despite experiencing much of the same shock, sadness, caregiving, and grief as adults. Over the years, Dr. Kavanaugh has met with school personnel asking for guidance, manuals, and education on how to talk about and support children and adolescents living with and caring for a person living with ALS. These professionals recognized the limited information and the need to receive guidance in order to lessen the potential social isolation felt by kids in families with ALS — particularly in terms of how these issues affect school performance and attendance. This guide was created to address the needs of school staff and personnel working with children impacted by ALS.



- [PDF download](#)
- [Order a hard copy^{or}](#)

Talking about ALS Across Age Groups

This table offers starting points to think about how to talk to and engage children across different ages. While there is no “right” way, understanding how to approach the conversation by age group can be extremely useful.

- [PDF download](#)

Talking About Death and Dying Across Age Groups

This table addresses the different ways children process and understand death and dying and offers suggestions for ways to engage at each age level.

- [PDF download](#)