



New Education Guides Help to Lessen Fear, Uncertainty for Youngest Affected by ALS

ALS can be confusing, scary, embarrassing, and overwhelming – for people living with the disease as well as for the youth within their families. Young people need age-appropriate details about ALS to help reduce some of the fear and uncertainty surrounding the disease.

That’s why we created our new youth education guides.

Many young people fear the unknown and may feel responsible for helping their loved one. Children often feel helpless and don’t understand what is happening to their loved one with ALS.

Children and teens who provide direct caregiving to their loved one with ALS, and emotional support to adults and siblings within the family, can struggle with feelings of isolation and depression and even a decreased self-worth.

Preteens and teenagers may have difficulty explaining ALS to their friends and often don’t know how they can help their loved one living with the disease.

And adults and other family members often grapple with how they can explain the disease openly and honestly.

The three youth guides are especially for children, teenagers, and young adults. They were developed using data from an Association-funded national study, direct input from youth, and the clinical expertise of Dr. Melinda Kavanaugh, PhD, MSW, LCSW at the University of Wisconsin-Madison in Milwaukee, Wisconsin. Each book provides easily understood information in a unique and engaging way.

The guides follow the same structure as [our family guide](#) and are available in print, digital, and e-book formats. They are available for order through [our order portal](#) and can be accessed at no charge [here](#).

Book descriptions:

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 to help illustrate the experiences of children who have a loved one living with ALS.

The ALS Experience: It's Different and Hard

"Choose your own adventure"-type guide, middle school youth, ages 13-18. This book follows the stories of three adolescents, providing examples of how they talked to people in their lives about ALS, who they talked to, and the outcomes of their conversations. The book encourages other readers to choose who they might want to talk about ALS and their experiences. [An online companion](#) version has been developed to give readers a more interactive experience.

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 time spent caring for their loved ones with ALS, their own lives, and school responsibilities and relationships. It is minimally illustrated and uses actual stories and quotes.

The ALS Association was proud to fund the development of these materials. We hope these three guides will help young people in families affected by ALS to cope more easily with a very difficult journey