

## The Autism and Grief Project Creates “Toolkits” for Coping with Grief and Loss

Grief is a universal yet variable human experience, and for those with autism, the painful, disruptive period surrounding the loss of someone or something meaningful can be especially difficult. Furthermore, other people may misunderstand or downplay the grief reactions in autistic people, resulting in an absence of support and a sense of isolation.

“He was my father and I loved him. I remember crying once for my dad but that was a long time after he passed. I missed him, but it was hard for me to be upset,” Eli Weider recalled of his grief experience.

Mr. Weider is one of many autistic adults who shared their stories with Hospice Foundation of America (HFA), the developer of [autismandgrief.org](https://autismandgrief.org). Underwritten by the NLM Family Foundation, the founding donor and ongoing partner of the Lurie Center for Autism, the website is intended to provide information for autistic adults and their support networks. To date, grief resources for those with ASD have been primarily focused on children.



This web resource is intended to support adults with autism and their families, as well as professionals in healthcare, social services, counseling, and the ministry/faith-based professions. In addition to sharing the perspectives of autistic adults on loss, the website provides social stories and other support tools. There is information for autistics and their support networks about grief, funerals, and rituals of various faith traditions. The website includes resources for parents to support grieving children, including a list of books and articles, and portions of the website are available in Spanish.

Also on the website is an award-winning animated video “Grief is a Spectrum Too”. The video, which debuted in September 2022, was co-produced by [Exceptional Minds](https://exceptionalminds.com), a nonprofit academy and studio that prepares artists on the autism spectrum for careers in the digital arts.

“Describing people's emotions by animating how they dealt with grief is a beneficial way to illustrate their situation to others,” said Craig Hills, one of the animation artists on the project.

Narrated by the acclaimed writer, director, and artist Jorge Gutierrez, “Grief is a Spectrum Too” provides first-person accounts of grief and non-death loss, as well as strategies used to find resilience after loss.

“There are so many myths about grief and often we oversimplify it. Because grief for autistics may look different and take many forms, those around them may incorrectly assume that they haven't been affected by the loss, aren't reacting the 'right' way, or don't want or need to be offered a role in faith or

 **Social Story: Preparing for a Funeral**

Someone I care about died. I will go to their funeral.

A funeral is an event for family and friends to remember and honor a person who has died.



A funeral can be overwhelming. I may want to make a schedule for the things that will happen at the funeral.



A schedule will help me to know what is happening and when things will happen. My family member or a support person can help me make a schedule.



mourning rituals,” said Kenneth J. Doka, PhD, MDiv, a researcher, author, and grief expert who serves as senior vice president for grief programs at Hospice Foundation of America.

“There is a tendency to ignore, undervalue, or misunderstand grief reactions, which may be demonstrated physically through pain or other symptoms, with little or no emotion, or through repetitive behaviors or outbursts that can make those around them uncomfortable,” Doka said.

Alex LaMorie, who served as an adviser to the Hospice Foundation of America during development of the website, describes [autismandgrief.org](https://autismandgrief.org) as an important toolkit that

will help others through the experience of grief.

“I’ve lived and experienced life as a person with autism with multiple deaths in my family. I am able to provide a legitimate, personal experience,” he said. “This [website] will help people—autistic and not—understand how to help autistic people grieve.”

Headquartered in Wellesley, Massachusetts, the Nancy Lurie Marks family Foundation (NLMFF) is one of the United States’ largest and most visible funders of autism research, clinical care, policy, advocacy, and education. Since 2000, the NLMFF has committed more than \$60 million to projects related to autism and millions in additional funding to biomedical research projects related to cancer, diabetes, and a variety of other disorders.

In 2009, Nancy Lurie Marks and the Nancy Lurie Marks Family Foundation established the Lurie Center for Autism at Massachusetts General Hospital (MGH). The NLM Family Foundation and MGH share a passionate commitment to providing a world-class center in autism focused on meeting the complex needs of autistic individuals from early childhood through adulthood.