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How a Pasadena poet uses the gift of words to help autistic adults process grief — including her own

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Isolation, heartache and devastation are just some of the big emotions felt by Pasadena resident MeiMei Liu when she lost her father to cancer at a young age.

For Liu — now 29 — experiencing grief was more complicated than just dealing with it.

Liu is nonverbal and has autism, a <u>developmental disability</u> that can make social communication difficult, according to the Centers for Disease Control and Prevention.

After her father, Jiaqi Liu, passed away in 2013, Liu buried her feelings. Research shows this can be a common coping response for autistic people dealing with complex emotions.



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Writer MeiMei Liu with her dad Jiaqi Liu. MeiMei lost her dad to cancer 11 years ago. (Photo courtesy of MeiMei Liu.)

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"At first, I could not cry," Liu said by email. "I was in shock, even throughout the funeral. I suppose people around me assumed I wasn't that upset because I was not able to show it. After several weeks and months, I would suddenly burst into uncontrollable tears."

Liu found a creative solace in the form of words. She first started writing poetry when she was 20, attending Whittier College to study English and creative writing. She saw writing as a conduit for her emotions over her father's cancer diagnosis, and later, his death.

Being able to communicate feelings through words is significant for Liu, who often expresses her feelings about her father's death through writing.

She was diagnosed with a condition called dyspraxia, which affects motor control, making communication options limited. Liu has severe oral and fine motor dyspraxia, which doesn't allow her to speak, write with a pen or pencil, or use sign language.

"When I was growing up, I had no sense of myself in relation to other people, no sense of my own personhood. I felt frightened and alone. It was only after I learned to type to communicate, that I began to develop language — and with it, my sense of self," she said. "Because I use a keyboard and type out each word I wish to express, as opposed to a word-board or picture-board, I can say precisely what I mean... without my ability to use a communication partner or type, I would be completely isolated."

Despite the physical and mental challenges, Liu is proud to be an independently published and <u>award-winning poet</u>. In March 2020, She won the <u>Edna Meudt Memorial Award</u> through the National Federation of State Poetry Societies. Her <u>book "Survival of the Fittest,"</u> a collection of 10 original poems, was released that year.

Today, Liu aims to help other autistic adults handle grief through her work on an online project that aims to help other autistic adults understand and navigate the grief process.

For over two years, Liu has served as an advisory board member for the Autism & Grief Project, an online platform started in 2022 by the Hospice Foundation of America, with a grant from the NLM Family Foundation. The website has engaging resources and toolkits for autistic adults and their loved ones to navigate mourning. According to researchers, it covers topics from the death of a family member or animal companion, to observing rituals of remembrance and funerals.

"I wanted to be helpful to others who have to face grief," Liu said. "I wanted to be of service to others."

After her father's death, Liu was first recommended to get involved with the Autism & Grief Project by Dr. Ricki Robinson, a

pediatrician based in La Cañada Flintridge who also serves on the project advisory board.

Dr. Robinson said that once her clinic started seeing more autistic children, she was struck by how "underrepresented they were in a textbook of pediatrics," and how children with developmental disabilities, including autism, often have "huge" medical and mental needs "not being addressed." Robinson then switched to specializing in autistic children, providing a "whole child approach" that addressed children's full development and medical care.

She said the Autism & Grief Project is unique because it involves diverse, autistic voices and perspectives. The bilingual website — which has <u>resources</u> and a <u>grief glossary</u> for adults, family and friends, faith leaders and health professionals — includes videos of autistic people sharing their stories. The project is unique because of how it centers people with autism and their stories, Robinson said.

"Instead of us speaking for autistic people, they get to speak about what their experiences were," Robinson said. "One of our tenets in this project is that we're going to presume competence and include them in hard conversations."

Some common themes that can happen to people with autism, who are also grieving loss, include being left out from decision-making about the funeral, generally excluded from plans, and having difficulty expressing emotions, Robinson said. Others may not understand that neurodiversity could make grieving look different.

"Grief is universal. I call it 'the great leveler," Robinson said. "Grief affects every individual differently. Autistic people are usually

misinterpreted and not communicated with because people think they aren't going to understand."

Robinson thought Liu would be a good match for the project because of her lived experience, as someone with autism who experienced a huge loss. Her pursuit of writing as a career was also a standout.

Liu, for her part, shared that people have perceived her as being "incapable," having assumptions of autistic people being "a monolith." She is set to graduate from Whittier College this May with a Bachelor's degree in English.

Liu hopes that her <u>ongoing work with the Autism & Grief Project</u> can help change the narrative on people with autism, as well as help those with developmental disabilities, and their loved ones, process grief.

"(Neurotypical people) assume we have cognitive challenges, which many of us do not. We may show emotional affect differently, react differently, or have less control over facial expressions or body movements, but we are sentient...thinking individuals who should be treated as such," she said. "People need to assume our competence, not our incompetence.