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## [Elaine Hall](#)

Author, Advocate, Mother  
of a teen with autism

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# Living With Autism: You Are Not Alone

Posted: 03/19/2012 11:17 am

React



I am haunted by the headline: *Mother killed 22-year-old autistic son, then herself.*

"He used a voice-output device that allowed him to communicate on a limited basis," reads the article written by Lisa Fernandez and Julie Prodis Sulek in the [Mercury News](#). "He was delightful," a neighbor said about the son. "He was nonverbal but very physically active. He loved walking and hiking."

This description of George Hodgins reminds me eerily of my own son, Neal. I can't stop thinking, "There by the grace of G-d go I." I have definitely had dark days and felt helpless. But fortunately, I have had friends and family to pull me out of it. Or as my friend Christina says, "We all have our dark days, but then our kids do something that causes us to laugh and we see the sunshine again. I guess Mrs. Hodgins just didn't have enough of the sunshine days."

My Facebook is flooded by comments to the article:

A father writes: "So many of us parents are lost, alone and unsupported; All I want is to know that when I am not here that my son is ok and taken care of, but I cry everyday wondering what will happen to him."

A single mom adds to the conversation: "Sadly, my surprise is that we don't see more cases like this ... Despite community 'awareness,' there remains a lack of support and educational opportunities for young adults on the spectrum. As parents age, their energy decreases and the stress of who will care for their child after they are gone can simply be too much to shoulder. It seems clear that she felt that ending her life and that of her child was preferable to the torment both were experiencing. There is clearly a need for more meaningful support for families in this situation. Research is all well and good but shouldn't we be focused on where and how our young adults will live?"

Fortunately, through The Miracle Project, and the Nes Gadol Religious Education Program, I have been blessed with an incredible community of parents. Lots of sunshine days to share, and whenever one of us falls into that "rabbit hole," there is always someone to pull us up, yank us out, take us out for coffee, and remind us that we are not alone. Obviously, Mrs. Hodgins felt very much alone.

The 24/7 challenges of parenting a child with special needs can be daunting. Raising any child with a disability or illness can be difficult to say the least. But for many reasons, and for many people, parenting a child with autism can be especially overwhelming.

If you see a physically-disabled child in a wheelchair or blind child with a cane, you immediately have compassion and understanding. Autism on the other hand, can be an invisible disability. At first glance, many children with autism appear "normal" (whatever that means). Autistics who are highly verbal, but lack in social skills, can be called "weird" and bullied. Those with fewer verbal abilities may act out in frustration, needing to be understood. Parents can be embarrassed by their child's behaviors when others look at them with fear, judgment, and disapproval.

Parents with children who have autism are often "forced" by lack of school programs to be the "experts" on their child. The emphasis on "curing" their child prevails. So if a child is not "cured" by

adulthood, the parents may feel like failures. This sense of responsibility is not uncommon with many families. Although every child with autism benefits from early intervention, only a small percentage of diagnosed children are actually "cured." Accepting a child's "differences" and creating lifelong supports are paramount to ease the intense stresses that many families experience.

This feeling of helplessness and aloneness when raising a child with autism is not just limited to the U.S. It is global. I was recently invited to the ReelAbilities Film Festival in NYC. While there, I watched two films on autism: one from China, *Oceans Heaven*, and the other from Israel, *Mabul*.

*Ocean's Heaven* opens on a small boat in the middle of the sea with a dad and son. Dad is tying a weight to his and his son's legs and pushing them both overboard. At first I thought this was a dream sequence only to learn in the next scenes that the father had terminal cancer and he didn't want to leave his autistic son without him. For the remainder of the film, the father teaches his son independent living skills. It is a beautiful story of love and letting go.

The Israeli film, *Mabul* focuses on the intense challenges a family endures when they are forced to take their older autistic son out of the institution where he lives. Both movies convey the desperate need for community support.

In the film, *Autism: The Musical*, one of the parents states that nothing will change until people "value" our kids with disabilities. To me, this stands out as how we need to value those who perceive the world differently, to listen to the child who doesn't speak, to enjoy slowing down, to cherish the many gifts of wonder that those with disabilities have, to channel their abilities and preferred interests, and to embrace our children for the resource they are for all of us.

Perhaps we can let the tragic events of last week be a call to action. An action for the "typical world" to reach out to those who are isolated, to take care to help out that parent in the grocery store who is having a rough day, not with dirty looks but with compassion and understanding. And to offer a shout out to those of us families in the "other world," the autistic world, that we are *never* alone. We have all felt helpless, we have all felt isolated, and it does get better. Let us bring hope to those who are in despair and compassion to those who feel overwhelmed. Let no family again believe their only choice is to leave the planet. And may Elizabeth and George Hodgins rest in peace.

*Need help? In the U.S., call 1-800-273-8255 for the [National Suicide Prevention Lifeline](#).*

*For more by Elaine Hall, click [here](#).*

*For more on autism, click [here](#).*

*This post has been updated since its original publication.*

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