

## Commentary

# “Before I Let Go”: Dying Parent’s Appeal for Grief Support for Adult Children with IDD

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## Abstract

Palliative care and end of life care providers need to step up the challenge of supporting all family members, not just those who with typical development / intellectual capacity and verbal skills. The family member with IDD who silently watches and listens may wonder “What does this mean to me?” “What is death?” “Who will care for me now?” deserves to have their needs anticipated and their emotions supported. A mother’s dying words are shared in an effort to carry on her advocacy for death and grief support for bereaved adults with IDD.

**Keywords:** Bereavement; Grief; Intellectual/Developmental disabilities; Autism

## Commentary

A mother knows she is dying. She has buried her spouse and her voice breaks with frustration with an end of life system of care that was ignorant of the needs of her middle aged daughter. Her impassioned story is broken up by deep inhales from her oxygen tank. Her daughter has Intellectual/Developmental Disabilities (IDD) that include autism [1]. Her daughter’s intelligence is hard to gauge. She qualifies as being developmentally disabled, requires 24 hour/7 day a week support, and parrots questions and words. Occasionally with the right prompts or in certain situations, the daughter shares her thoughts. Now, the mother, a lifelong advocate for her daughter, asks me, the researcher, to share her request for grief education and support for her daughter, and others like her. Her daughter will soon lose her last remaining parent; the parent with whom she has the closest emotional bond. The mother has prepared her daughter to live in community with 24 hour support. She has done her best to support connections with other family and family friends to continue the daughter’s inclusion in everyday celebrations and holiday events. She has talked about death and included her daughter in funeral and daily discussions of the life cycle. But, she has no assurances about how her daughter will fare. “Where is the support for my daughter” she asked? “Why is there no support group; no counseling to help her deal with death and loss?” She said she had asked her husband’s hospice nurse and she said the nurse was unaware of any resource. Sadly, there was a resource, but this staff nurse was evidently not aware of it. As this mother’s last act of advocacy, she consented to a research study about parental bereavement for adults with IDD for herself and her daughter. She wants her voice heard beyond the grave. She continues to fight with her eloquent interview about grief and loss, which I continue to share. I hope that the promise of contributions to building training for care providers about death, grief and loss gave the mother’s dying more meaning.

I was fortunate to not only witness the grief of a parent who supported her daughter with IDD in the death of her father, but to be provided a window into the dying concerns of the mother; a mother who lived as an advocate; a mother who died as an advocate. I was also saddened because, in addition to being a researcher and

educator, I am also am a provider of bereavement services to adults with IDD through a local hospice. I have found that my interest, growing knowledge and true passion is not often shared by other counselors in the community. I believe this is just lack of preparation and support in our counseling preparation programs. It also could be that providers that are drawn to this population and work well with persons with IDD along with typical clients are just not advertised or accessible to families and individuals with IDD. All palliative care and end of life provider organizations should be prepared to support individuals and families of persons with IDD.

Lifespans of adults with IDD now match the lifespans of the general population [2]. The majority of adults with IDD lives in community, and often resides with parents or family care givers [2]. Yet providers are often ill prepared to provide death and grief education and support to these sons and daughters as their parents or family members die [3,4]. Palliative care and end of life care providers need to step up the challenge of supporting all family members, not just those who with typical development /intellectual capacity and verbal skills. The family member with IDD who silently watches and listens may wonder “What does this mean to me?” “What is death?” “Who will care for me now?” deserves to have their needs anticipated and their emotions supported. The dying parent may fear that without words, their son or daughter may strike out, run away or be labeled as “a behavior problem”. Will anyone see beyond the behavior to the fear, the anger or the sadness? Who will answer the unspoken questions? Palliative and end of life care providers must ask what dying parents of adults with IDD say they need. They must search for resources or develop them. The challenge to researchers is to continue to ask these families and individuals with IDD about their experiences and needs. Researchers must publish the effective interventions for grief and loss education and support for adults with IDD and assist with training. I feel the obligation to continue to ask questions, to educate and train about the answers I get from families and individuals with IDD. In palliative and end of life care, we should remind ourselves daily of this dying mother. Wouldn’t her dying have been more peaceful, her soul more at ease, if she has trusted the system was prepared to support her daughter in her grief?

“ Mom, everybody dies, don’t they? “

“Yes, honey, everybody dies.”

“But,” she says, “But not today, right?”

“Right”. Mom says, “No, not today”.

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