



The Senior Years

Aging and Disability

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Sibling relationships are probably the longest lasting and most sustained bond a person will ever have. And for those of us who have sisters and brothers with intellectual and developmental disabilities (IDD), this lifelong relationship can present unique joys and challenges. With increasing age come increased responsibilities, joy, sadness, and loss.

The brief case study below gives a picture of one sibling's experience.

My brother, JJ, and I have been connected since his birth sixty-four years ago. JJ died in April of 2013, and he will live on in my heart and mind forever, as no one else has or will in the future.

JJ had Down syndrome and Alzheimer's disease. During his last five years of life he had recurrent bouts of aspiration pneumonia resulting in admission to intensive care units with bright lights, beeping noises, intubation, sedation, multiple medications, restraints, tube feedings, IVs, CAT scans, blood draws, x-rays, and more.

His courage, fortitude, zest for living, and desire to get better supported his fight for life and gave me the mandate to continue to advocate for him with all of my abilities.

He was hospitalized numerous times, and had facility- and home-based rehabilitation. Each time JJ was hospitalized, the downward spiral was more evident. With each illness he lost a bit more of his abilities, though he struggled to be as independent as possible until the very end.

These experiences made him increasingly vulnerable. With each episode, he had to adjust to new environments and surroundings. A year before he died, JJ had to leave the group home he had lived in and loved for sixteen years. He left in the dark of night by ambulance to be hospitalized and eventually moved to another facility for those who were frailer. In the subsequent year, he was hospitalized many more times, usually being brought to emergency rooms with the drama of ambulance and critical care apparatus.

Weathering these crises would be a real challenge for any of us, but it is particularly stressful for those who do not have strong cognitive and verbal abilities. Recent studies have demonstrated that people who were hospitalized in ICUs show evidence of having PTSD for many years to come. My brother's increased fear and resistance to all things medical were very understandable.

We were both challenged to promote his health, manage his illnesses and decline, and continue trying to promote a satisfying life that emphasized love, joy, respect, and dignity.

My hope is to share some of what I learned with you to support you in your situation.

We may be the first generation to have responsibility for aging brothers and sisters who have intellectual or developmental disabilities (IDD) while we ourselves age, and care for our spouses, partners, parents, children, and grandchildren. As one woman who worries about her brother as they both age said, "It's the 'what if's' that keep me up at night."

Though there might be some specific differences depending upon the type of disability, the concerns we face as we age are similar. We may find ourselves making difficult decisions to ensure the best health possible for our siblings, seeking safe and suitable places for them to live, continuously advocating for their rights and well-being, monitoring their financial security, balancing the quality of life for our brothers and sisters with our own lives, and taking care of ourselves. All are of paramount importance.

There's a good chance that our parents are elderly or deceased. Many of them did not plan for a time when they could no longer care for their child with a disability. Some parents have even extracted deathbed promises from their typically developing son or daughter to provide care for their sibling with a disability in the same manner they cared for their child.

Planning ahead is essential (see Chapter 11 on future planning), even if parents will not participate in discussions of the future. Be proactive: explore the possibility of supporting your sibling in decision-making as his or her guardian, if appropriate. Become part of the network that provides care

and support to people with IDD by joining or becoming acquainted with organizations that provide those services.

Typical Sibling Concerns about Care

One sibling said:

“My mother never would even discuss future planning about my brother. She would not consider a group home. My partner and I felt like we kidnapped my brother when we moved him to a group home two weeks before she died.”

Another sibling said that as she and her brother were aging, she worried that she might predecease her brother:

“I have heart disease and have had breast cancer. For the first time I see that I might die before my brother.”

Others are concerned about the burden of care their siblings place on their partners and their children.

Anne said:

“I worry that I am going to die and there will be no one to look after him, and that the responsibility will fall on my husband or children, who don’t deserve the added responsibility (but then again, neither do I!).”

Marie said:

“I worry about my sister’s decline and her dementia, which is worsening. And then the questions will be: Will she be able to age in place? If not, where will she have to go? And will such a setting be available?”

And Robert said:

“I worry about whether I am making the right decisions. My decisions are influenced by his house staff, agency policy, my wife, and my other siblings’ thoughtfulness and anxiety.”

In the past, the number of seniors with developmental disabilities has been relatively small. However, as life spans increase, planning and partnerships across the continuum of care become essential to strengthen system capacity and provide dignified services to this vulnerable population. Seniors with developmental disabilities need—and have the right to—services and supports that effectively meet their evolving needs.