



TESTIMONY OF
BRUCE GOGUEN
AND ROBIN BOLDUC
HB 16-1054 - Opposed

February 2016

“We Are Not Ready – Its Not Really A Choice”

Bruce was diagnosed with Primary Progressive Multiple Sclerosis (MS) in 1975. He was told at that time that he had 5-10 years to live. Bruce is now fully paralyzed, uses a feeding tube for his main source of nutrition and breaths with a ventilator. Robin is Bruce’s main caregiver. Together, we have parented 8 children – including 3 adopted children with disabilities.

We cared for Robin’s mother in our home during the last 5 years of her life with dementia. We provided 8 years of long-distance oversight to Bruce’s mother while she passed with Alzheimer’s disease. Together, we grieve the death of our youngest son at the age of 12. We have a great deal of experience with issues surrounding end-of-life decisions.

We have actively advocated having the heart/lung bypass and ventilator turned off for our son when it was clear that he had little chance at life. We have actively advocated turning off life support to my father after an aneurism burst in his brain, in accordance with his living will. We have actively advocated in allowing Bruce’s mother to refuse a feeding tube in accordance with her verbal wishes. We have actively advocated keeping Robin’s mother on hospice during the final months of her life with dementia. All of these decisions were difficult to make and difficult to implement. Our wishes were not immediately respected. In the case of my father, it took 15 family members to gather in his room and demand that his living will be respected.

Alternatively, Bruce has chosen to live a meaningful life with the use of technology and long-term supports. When asked, Bruce says that he would never have pictured living his life in this manner. We have made adjustments to our life; however, our lives are rather “normal.” We have watched our children grow up and now we are enjoying our grandson. We go out with friends. We watch our favorite television shows together. We hike together. We live a fairly typical life for a middle-aged couple! We are especially blessed with wonderful friends and family.

The difficulty in our lives comes in the form of accessing supports for Bruce and our family in order to respect his decision to live a meaningful life with his disability and medical needs. We spend hours each week interacting with insurance companies, doctors, service agencies, medical suppliers, etc. insuring that Bruce receives critical supports. Multiple times a year, Bruce is denied services as a result of errors in government databases. Colorado has one of the most progressive long-term care support systems in the United States. Yet, it is difficult to access and complicated to navigate. Depletion of all resources remains a criterion for long-term care support services eligibility. The economic “burden” of living a life of disability with dignity can be addressed with a policy change.

We believe that life-death decisions should not be made on the basis of economics, lack of supports for a meaningful life or a negative bias toward living life with a disability. Accordingly, before physician-assisted death is truly a choice, we need:

- Uncomplicated access to long-term care supports such as in-home attendant care, in-home health care services, medical equipment, housing modifications, and assistive technology.
- Respite supports for families and other caregivers.
- Policy reforms so supports can be accessed without the impoverishment of individuals and their families.
- Effective pain management must be readily available. Health care professionals should not fear providing adequate pain management because of possible legal issues.
- Easy access to high-quality hospice/palliative care.
- Enforcement of living wills and advance directives.
- Education of health care and mental health professionals on community resources for and the reality of living life with a disability in order to move beyond the stigma associated with disability.

It is simply not a choice while life-with-dignity is so difficult to access. This testimony will be familiar to some members of the committee. It is the exact same testimony in opposition to HB 15-1135. We have made no progress in creating a real choice in Colorado for people with end-of-life health care needs. Accordingly, we oppose HB 16-1054. Perhaps it is time to start working on barriers to living with dignity.

Thank you so much for allowing us the opportunity to comment on this life-death public policy. Please feel free to contact us for further information or discussion.

Respectfully submitted,

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