

January 24, 2024

Dear Madam Chair and Honorable Members of the Health Policy and Finance Committee,

I write today to urge you to support the passage of MN HF 1930. As you know, according to your own State Fair polling, nearly 75% of Minnesotans support the MN End-of-Life-Options Act, regardless of their demographic— including religious affiliation. I myself am Catholic, and among my Catholic friends and family there is unanimous support for this bill. The Church hierarchy may not approve of it, but please understand that the vast majority of your Catholic constituents —and voters —do.

I came to volunteer for the group Compassion and Choices in honor of my best friend Doris, who died of ovarian cancer. Unsupported by her boyfriend Mike in her decision to opt for palliative care alone after repeated unsuccessful rounds of treatment - he wanted her to “fight” the disease until the end – she quietly named her daughter her health care proxy and executed her advanced directive. One day while he was out, Doris took all of stockpiled medication and laid down to die in her bed. Mike returned early, found her near death, and had her airlifted to Regions Hospital. There they placed her on a ventilator against her express wishes and her legally executed documents which explicitly stipulated no life support or extraordinary measures. Her daughter and legal representative presented her directive to the staff time and again, in vain. Doris lingered for nearly a week, intubated in the ICU while her family argued over her body. Hospital staff was eventually persuaded to honor her advanced directive over the loud and violent bullying of her boyfriend, who had no legal standing to make *any* decisions for her. He was the loudest, so he was listened to, for days. It was tragic and heart-scalding for everyone. My friend should have been supported in her end-of-life decisions and been allowed the bodily autonomy every dying person deserves.

Since joining Compassion & Choices I've met fine, brave people suffering from terminal illnesses whom I came to love and care for. They all used their last ounce of life-energy to fight for passage of this bill, even after they knew it would never pass in time to help them. So along with my dear Doris, I work in the name of these friends too: Marianne Turnbull, Danna Nelson, DeeDee Welles, and Burt Riskedahl - who all died fighting for passage of this bill. Please don't let their last valiant efforts have been in vain; please read their stories. Please pass Minnesota's End-of-Life-Options Act, for all people suffering in their final days.

Sincerely,

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A Different Kind of Courage

Minnesotan Danna Nelson has always lived boldly. A terminal diagnosis at age 22 was not going to change that.

In April of 2018, Danna Nelson was waiting to see her surgeon. The Minnesota native and accomplished trombonist had been living in Finland for three years. Over the previous few months, she had been struggling with ear and sinus issues that impacted her music. Doctors suggested a cold, a sinus infection or maybe polyps. Finally she was going to have answers.

Alone in a foreign country at 22 years old, Danna was told she had rhabdomyosarcoma, a muscle and soft tissue cancer rare for someone her age.

Moving to another continent at 19 is unimaginable to many, but Danna's independence and excitement were far stronger than any fears she held. Like many American teenagers, the idea of running off to Europe was exciting and romantic — something you see in movies. Her trombone instructor was originally from Finland, and Helsinki happened to have a wonderful music school. With a plan and a passport, the future for many musicians was right at her fingertips.

After Danna's diagnosis, her mother joined her in Finland while she underwent her initial treatments. First were chemotherapy and facial radiation, which resulted in more hospital visits and medications. Danna had to stop playing the instrument that was such a huge part of her life.

More treatments and surgeries followed. Danna felt herself changing. Body image issues plague our culture, and that doesn't go away just because of a diagnosis. "I remember thinking that I had to stay skinny so I would look good in my coffin," she divulged. "Which is such an awful thought, in so many ways, but I had it."

The changes started in her body, and then in her mind and spirit.

opposite page: Danna at her parents' home in Minnesota during a video photo shoot urging passage of legislation authorizing medical aid in dying.





Danna was a marathon runner and musician living in Finland when she was diagnosed with cancer.

In 2020, Danna had to make the heartbreaking decision to leave Finland. This special place had represented potential: her musical dreams, relationships and so much joy. In Minnesota, Danna began to rely more on her parents and saw fewer friends. Daily routines and events were planned around treatments.

After moving back to Minnesota, she found herself becoming a fierce advocate for medical aid-in-dying legislation.

"I'm privileged to have my parents around to help me navigate all of this," Danna acknowledges. "But, in a lot of ways, I think I am a less independent person now."

Though supported, Danna still finds herself feeling isolated. Her social life in Finland was thriving and busy. Now, it is harder to make new connections or find the energy to spend time with friends the way she used to. Cancer has begun to push its way in, often feeling like the core of her identity.

Acquaintances, neighbors, strangers — all have something to say about her diagnosis, and about death itself.

"I don't blame anyone, but it has been really hard socially to connect with people my age. They're just not thinking about the same stuff I am," she said. "The hardest

part about it is I feel like my cancer is in the way. Maybe that's why we're not clicking. It must be because of everything on

my mind, not because of them." It isn't just friendships that feel different. The word "cancer" on a dating profile creates a new dynamic in romance. Some potential partners have brushed her diagnosis under the rug; others have been fearful.

"It feels like nobody will get on board because people [my age] are looking for a stable future. People want to meet the person that they're going to be with forever," Danna said. "I am looking

for something meaningful for my forever, too."

Early in her treatments, Danna sought opportunities to connect. It all began on Instagram, where she found other young adults facing illness, new friends and people who want to discuss mortality openly.

Danna is currently writing her memoir — an exploration of her life, intertwined with her thoughts on death and dying. After moving back to Minnesota, she found herself becoming a fierce advocate for medical aid-in-dying legislation. She partnered with Compassion & Choices in 2021, sharing her story candidly and her smile brightly. Recently, she appeared in a video urging Minnesota lawmakers to make this option available for terminally ill Minnesotans, like her.

"Sharing has given me purpose," Danna beamed. "I don't feel like I can do a lot of things anymore, but I can use my voice, and I can advocate. It has been so cool."

Burt Riskedahl: A plea before dying — on behalf of those who might need it



By [BURT RISKEDAHL](#)

PUBLISHED: December 18, 2023 at 4:24 p.m. | UPDATED: December 19, 2023 at 9:08 a.m.

On Sept. 22, 2023, my father, Burt Riskedahl of Oakdale, was diagnosed with stage 4 cancer and learned that he would likely live only a few more months.

Throughout his lengthy career as a social worker, lawyer and trial court judge, my father had always been focused on the impact of laws on children and vulnerable family members, and cases involving protection of individual rights. In 1987, as a judge in Bismarck, N.D., he adjudicated a case that significantly shaped his views on the right of individuals to die with dignity on their own terms.

A woman in her early 60s had suffered a cardiac arrest and was taken to the hospital. Despite efforts by emergency personnel, she suffered substantial oxygen deprivation and received a diagnosis of “persistent vegetative state.” Without her family’s knowledge or consent, the hospital staff inserted a feeding tube in preparation for sending her to a nursing home. When it became obvious that there was no hope for recovery, the family decided to have the feeding tube removed and allow her to have a natural death. Her husband and children agreed that continuing to keep her alive by artificial means would be in violation of her wishes. However, the nursing home refused. Unfortunately, this was before advance directives and medical powers of attorney were common.

A legal proceeding was brought to have the husband appointed as her guardian. He then asked the court to allow him to stop the artificial feeding. The court considered the medical evidence that the return of brain activity could not occur in the future and ruled in favor of the family.

Following the hearing, the nursing home withdrew the feeding tube. However, several days later the family discovered that nursing home personnel, in disregard of their instructions, were placing pureed food in her mouth, creating an involuntary response that would cause some food to be swallowed. When the husband asked that this procedure be discontinued, the nursing home’s management refused on grounds that it would violate their ethical standards. In response, the husband sought and obtained court

authorization to remove her from the nursing home and arrange her transfer to a residential hospice program where her artificial feeding was discontinued. She died in hospice a few days later. This case obviously had a traumatic impact on the family. It also heightened my father's sense of justice regarding freedom of choice and the right to humane treatment at the end of life. Throughout his own life, he strongly felt that the constitutionally protected rights of individuals for self-determination should not end when they are most vulnerable and dependent on others. In fact, it is in these moments that an individual's most deeply-held wishes regarding their own autonomy are paramount. Among my father's last acts was to write the following opinion piece, advocating for medical aid in dying, a process that would afford terminally ill adults access to medication that would enable them to die peacefully on their own terms if their suffering becomes unbearable. My father died on Dec. 12, without access to this end-of-life option.

— Mark Riskedahl

By Burt Riskedahl

I am so grateful for many of the important legislative bills approved in the 2023 session of the Minnesota Legislature, particularly those that protect reproductive health rights, ensure LGBTQ access to needed care and treatment, and provide significant funding for increased access to education. Characteristic of much legislation that passed during the recent session, these bills demonstrate the state's commitment to people in need. Not only do they ensure access to services for Minnesota residents, they also help those in other states whose legislatures have blocked these essential services.

Regretfully, the Legislature failed to enact another important measure, the Minnesota End-of-Life Options Act, that would have also provided important rights to people. This bill would have afforded a terminally ill, mentally capable adult with a prognosis of six months or less to live, the option to request, obtain, and take medication — should they so choose — to die peacefully in their sleep if their suffering becomes unbearable. The bill included many safeguards to ensure it would be implemented properly.

This bill, unfortunately, did not even get a hearing despite polls showing Minnesotans overwhelmingly support a peaceful right-to-die. I have high regard for people who have researched the law and formed their own opinions based on moral principles. However, much of the opposition was shockingly unrelated to the substance of the bill. Opponents of the bill wrongly argued that it would apply to, and enable abuse of, groups of people who are compromised, disabled or unable to speak for themselves, despite terms clearly prohibiting such application. Such fear-mongering rhetoric may have prevented the bills' progress or even a fair hearing. As a result, terminally ill, mentally capable adults will face unnecessary suffering before they die.

Ironically, during the time I was advocating for fair consideration of the bill, I myself was diagnosed with stage 4 cancer and am now in hospice. I believe there is a likelihood that my disease will run its course and my death will occur without the need for any extraordinary treatment, but, if I could have, I would have certainly sought to become eligible for the benefits of the bill. Access to medication would have provided me with comfort and assurance that I would not need to suffer through intractable pain, significant breathing problems, or other extreme complications that often present themselves at the end of life. In other states that have authorized access to medication that ensures a pain-free death, I may not have chosen to actually use it. But I deserve the right to choose to end any suffering and pain I may experience. Instead, because the legislature did not

even allow the Minnesota End-of-Life Options Act out of committee, I now face the anxiety that my inevitable death will be painful, rather than peaceful.

I encourage Minnesotans to learn more about the bill through the Minnesota legislative site or from a group like Compassion & Choices, and then ask your legislator to support the bill next session. We simply can't let what happened last session recur. The important concepts contained in the bill must get a fair hearing. Minnesotans deserve the ability to make a dignified decision regarding their own death.

Burt Riskedahl, late of Oakdale, grew up in North Dakota. He worked for the Wilder Foundation in St. Paul while attending law school at night at William Mitchell in the early 1970s. He had a long career as a judge in Burleigh County, North Dakota, and moved back to Minnesota in 2015. He died on Dec. 12, a few days after writing the column above.

Don't have time to wait': Advocates renew push for Minnesota to allow medication aid in dying

The legislation requires the person to be 18 years or older and of "sound mind" when making the decision.

By [Briana Bierschbach](#) Star Tribune

MARCH 2, 2023 — 4:16PM

GLEN STUBBE, STAR TRIBUNE

DeeDee Welles, right, departed the Capitol with her sister Tara Welles, left, after DeeDee spoke at the end of life news



DeeDee Welles has seen what it looks like to die from ovarian cancer.

Four decades ago, she watched her energetic mother — an active volunteer, former competitive diver and near-daily tennis player — go in and out of the hospital with bowel blockages from the disease. At the end, Welles was helpless as her mother wasted away "to skin and bones" and eventually died.

Now, Welles is struggling with blockages after her own ovarian cancer diagnosis reemerged in December. She doesn't want her kids to have to watch her in agony at the end.

"I know what's coming, which is both good and bad," said Welles. "It was awful seeing her suffer; my kids will potentially see me suffer a long time. I don't believe it needs to go that way."

Marianne Turnbull



**Marianne Turnbull, testifying at the last Health Policy Committee Hearing, September 11, 2019
pictured with Barbara Coombs Lee, Past CEO of Compassion & Choices**

Marianne was a retired social worker who advocated for the option of medical aid in dying while facing a terminal cancer diagnosis. Sadly, she died on May 27, 2021, without the option she worked so hard to pass in Minnesota. Below is an excerpt of her testimony at the Minnesota House Health and Human Services Policy Committee informational hearing on September 11, 2019.

I watched my mother decline for years and at the time of her death she was actively suffering for over 24 hours. When I remember these scenes I am haunted by images. I am also here because I've been told I don't have much time. I have cancer.

I was diagnosed with stage 4 ovarian cancer in September 2015. Known as one of the deadliest forms of female cancer, in part due to lack of an early diagnosis tool, ovarian cancer usually shows up with a variety of vague and non-specific symptoms. It wasn't until the symptoms were very advanced that I was finally diagnosed with the correct diagnosis. It became quite clear at that first oncology appointment that I will most likely die from this disease. I have already met up with the first frightful statistic that 85% of ovarian cancers will recur and fewer than 20% of women live for five years. In the four years that I have had this disease I've been in treatment twice and am now awaiting entrance into another clinical trial. So, I am at year four.

With the help of my medical team, I've been able to live with this disease and it has become my new norm. I've undergone two major surgeries and 12 rounds of chemo. At this point, there is no cure, only treatments and trials to slow the cancer spread and reduce the symptoms. The treatments themselves can be deadly and the new norms keep bringing on new losses.

I've spent many days thinking about my life, contemplating the "why me" and "how could it be?" I've spent time grieving the loss of many dreams; the big one now is living a vibrant retirement! I had dreams! However, I learned how to respect this disease, and the cancer is becoming a teacher for me: I've learned the value of living right in the present moment and enjoying the simple things that give my life meaning.

Frankly, I regularly contemplate the likely scenario of my death. As it goes with ovarian cancer, at some point in time the chemo will no longer be effective at keeping the cancer at bay. There will be no other options. I've done my research regarding deaths from ovarian cancer and have watched women in my ovarian cancer support group cope with the natural progression of the disease. I'm watching my friends die just like the stats say. There is no telling how long the demise will last. Weeks, months? It can be grim, even with the best palliative medicine.

I want to live for as long as I possibly can. I want medical care that can ease my pain and allow me to be in relationship with my children, family and friends. But, when the time comes, I also want to have a good death. While I am still able to speak for myself, I want to be able to say good-bye and die peacefully rather than deteriorate to the point that doctors sedate me to unconsciousness while my family watches me slowly dwindle.

I can't know right now what I will want or need in the future, but my end-of-life decisions should be a private matter. Minnesota law makes it a crime for me to have the peaceful death I might want, while 1 out of 5 Americans live in a state where medical aid in dying is available. To me, this is unfair. I do not have the means to relocate, find new health care and put extra burdens on my family. The option for a peaceful death should not be based on where I live.

This is very personal and urgent for me. I deserve the same option that other dying Americans have. I don't know how much time I have before I exhaust all the treatments. All I know is I want to be close to those who matter the most to me right here in Minnesota.



Marianne Turnbull, died May 27, 2021