

House Human Services Committee

Robin Weisz, Chairman

End of Life Health Care, HB 1415

Testimony of Mark G. Schneider

February 1, 2021

Chairman Weisz and Members of the Committee:

I am Mark Schneider from Fargo, and I am testifying in support of HB 1415.

I appear before you with the simple premise that: No one can speak to dying with dignity more credibly than someone who is dying. I am dying.

I have terminal urothelial cancer in my kidney that has spread to my back, liver and maybe lung. It was diagnosed in November 2019. Surgery would not have been helpful. I have had extensive unsuccessful chemotherapy and unsuccessful immunotherapy. I have had radiation for cancer on my spine.

On May 27 last year my oncologist at Mayo Clinic estimated that I would have a year to live. I am currently on a new chemo medication that is palliative only, but may extend a certain quality of life for an average additional 14 months. With that drug, I have experienced pernicious side effects like painful mouth sores and lip sores, and--all too obviously-- hair loss. This is not a complete list of my side effects, so I might not be able to continue the medicine, but I do enjoy a quality of life that was absent without that palliative drug.

In the past I have experienced sustained and severe levels of pain, 8-10 (on a scale of 10), despite being on both morphine and high levels of Fentanyl. I have also suffered from severe nausea. I chose to endure the pain and side effects because all alternatives for treatment were not exhausted at that time, and some quality of life was possible.

But the end game—which is inevitable—presents me and those like me with the prospects of unbearable pain and deterioration, and the certain loss of physical and mental function that will render me an empty shadow of my former self. “Quality of Life” then? Impossible. I suggest to you that this is an intolerable prospect and that everyone must be able to make an intelligent and informed decision on when to say, “enough is enough”.

Since I was a child selling newspapers and working in our neighborhood Mom and Pop grocery store, I have had responsibilities, earned money, taken care of myself and made mostly all of my decisions—for better or worse—on my own.

As an attorney for over 40 years, I have made important decisions for my legal practice, my family, my healthcare, indeed all aspects of life. I was paid handsome fees to make decisions with and for others who relied on that advice, often on matters of profound consequences to the lives of my clients and their families.

The point is, having made these decisions my entire life, should I-- or anyone else in my situation-- be denied the ultimate decision of deciding whether to end my life when any quality of life is hopeless and the future holds only misery and pain?

As simply as I can put it: Why should decisions about my condition, healthcare choices, and life be dictated by others not living my life?

I urge a do pass on HB 1415.