

March 21st, 2023

Chair Hoffman and Human Services Committee Members,

This letter is being sent in support of SF1483, Medical assistance hospice service coverage expanded to include room and board and to respectfully request a hearing for the bill.

My name is Toni Kay Mangskau and I am a resident of Rochester, MN. and Minnesota lead volunteer for the National Patient Advocate Foundation (NPAF). NPAF is a patient advocacy organization that represents hundreds of patients and caregivers in their communities nationwide, including advancing person-centered care initiatives focused on benefiting families coping with complex chronic conditions in Minnesota.

In March of 2021, my mom made a decision to stop her cancer treatment and enter into hospice care. At the time, she resided in an assisted care living facility and the staff were unable to provide for her care needs.

My mom was admitted into our local hospital to await placement in a care facility that could help in her transition to end of life care. During this time, my brother and I had many meetings and phone calls with hospital staff, skilled nursing facility staff and a local hospice residential care home. We were trying to figure out how the financial pieces fit together within this puzzling system of end of life care. We had done all the "right things" including the spending down of my mom's assets to pay for her assisted living facility care and to transition onto Medical Assistance. It was difficult to see the cost of assisted living care had consumed the majority of her assets, but this is what we were told needed to happen.

My mom did not want to be admitted into the skilled nursing facility that had an opening. She had received care there in the past and was fearful of having to return to that location. Our family had learned of an open bed in our local residential hospice home and we were relieved that there was an opening. We were then told our cost would be \$300/ per day out of pocket. Medical Assistance did not cover room and board for hospice residential care. We were in shock. We didn't know how long our mom would survive, so we had no idea how long she would need to cover these out of pocket costs. Our family couldn't afford to pay this expense.

It was gut-wrenching to have to make the decision to place our mom in the skilled nursing facility that had an open bed. My siblings and I were all working full-time and couldn't bring our mom into our home to provide around the clock care. We were at a loss.

After 10 days in the hospital, my mom was admitted to the skilled nursing facility. Half of the staff were temporary workers. It seemed there was a new staff person every shift. The staff were very slow to respond to the call light. By this time, my mom was on no medication and her only request was to have ice water and an occasional popsicle. Towards the very end of her life, the request was only for ice water. This may seem like a simple request, but in a short-staffed skilled-nursing facility with patients that had more “immediate” needs, this seemed to be overlooked each shift. In the end, she died alone, without family or staff by her bedside. Skilled nursing care didn’t seem to be a good fit for end of life care.

It is my belief, if the care would have been in a residential hospice home setting, staffing ratios are smaller and the goal is to bring comfort to the patient. This did not happen in the skilled nursing facility. We can and must do better for families. The passage of SF1483 will provide a financial means of covering the costs of room and board for individuals on Medical Assistance at end of life. This will help bring a sense of dignity at someone’s end of life.

I am requesting support of SF1483 on behalf of myself and the National Patient Advocate Foundation (NPAF). We respectfully urge your support for this legislation.

Toni Kay Mangskau

Rochester, MN.

(612-227-9585)

2022 yr. Recipient of the NPAF Donna Guinn Outstanding Volunteer Award

NPAF Lead Minnesota volunteer