

April 7, 2015

Good morning Ms. Conway and Sen. Giessel,

I am writing this email today to offer my support for SB 72, Designated Caregivers for Patients.

I spent the entire year of 2014 as a caregiver to my 70 year old Mother who received treatment for stage 3 colon cancer. I've been in a caregiver role for many years, but this was the first time I was thrust completely into the health care system as an advocate for the patient.

Although I believe my Mom received the best of care available in Alaska, and for the most part I was prepared in my role as family caregiver and care coordinator for her; after her major surgery in September, I felt unprepared for how to care for her post-surgery. And although I gave the hospital all of the pertinent information required to be a part of her direct care, including but not limited to a notarized Medical Power of Attorney, I still found myself not included in conversations directly related to her care needs upon discharge. It seemed as if the providers would brief her when it was convenient to them, with no one following up with me, even when my Mother asked that a follow up occur. My Mom was pretty sick and having memory issues; instructions on wound care for both her ostomy and her surgery wounds wasn't registering with her. Even with home health services in place upon discharge, we still went home with a lot of questions and concerns. Because of this, I video-taped a nurse visit for ostomy care, so I could show Mom on a regular basis, as well as brief myself since it was quite a detailed process.

Mom's surgeons were both wonderful with making sure I was present for any additional care home health services would not provide. But the hospital itself wasn't often that accommodating.

I work in health care, from an education perspective. I understand the concerns of more "regulations and rules" for hospitals to follow, when really they'd like to simply focus on doing their jobs. However, I believe making sure family/informal caregivers are completely briefed upon release is imperative to the natural support systems in place in the patient's family. The two systems need to work together to provide complete care. Plus, overwhelming family caregivers creates adverse outcomes for patients. I can personally attest to being uncomfortable at first with the intimate care needs of my Mom.

I support this bill, and believe it is one more step toward a true patient centered medical model.

Thank you for your service in Juneau,

Sheila Soule, M.Ed., MPH