The Honorable Marvin L. Abney
Chairman, House Committee on Finance
RI House of Representatives

By Email To: HouseFinance@rilegislature.gov

RE: In Support of H7597: Hospital Care Transition Program

Chair Abney,

I'm writing today in strong support of H7597, a bill that would keep the Hospital Care Transition Program running in Rhode Island. This program – operated jointly by RIPIN and South County, Kent, and Rhode Island Hospitals – embeds RIPIN Community Health Workers (CHWs) into hospital discharge teams to help vulnerable older patients discharge safely to home. This innovative approach saves the State money by avoiding long term skilled nursing facility (SNF) stays before they start, while also meeting the desires of most patients and their loved ones to receive care at home.

In October of 2020, my twin sister, Eileen Sweet, was diagnosed with stage IV colon cancer. At this time Eileen was residing in an apartment on Church Street in Wakefield, RI which provided parking for her car only. This was very strictly enforced. As Eileen's illness progressed, so did the undeniable need for home health assistance, especially after emergency colostomy surgery. In addition to the limited resources available due to COVID, we were now faced with a parking crisis. The street on which Eileen resided and all surrounding streets, allowed no parking on either side. I was already leaving my car at a friend's residence and enlisting others to drop me off to stay with Eileen. We had nowhere for care providers to legally park their cars. Upon learning the visiting nurse was forced to park at Old Mountain Field and walk up the street while carrying the necessary medical equipment, we called The South Kingstown Police Department to request permission for health care providers to park closer to the house. After a lengthy conversation with then Chief of Police, Joel Ewing-Chow, and a great deal of pleading and begging, our request was still denied.

Eileen's health continued to decline as the cancer metastasized throughout her body in spite of the strongest chemotherapy available. Numerous hospitalizations ensued. In addition to the colostomy bag, Eileen would eventually need a drainage tube surgically implanted in her stomach, a permanent IV through which she would be provided nutrition and receive a wealth of medications. She would undergo numerous rounds of brain radiation and finally succumb to the use of a wheelchair. Although I was caring for her around the clock, there came an unavoidable demand for further care providers, yet we still had not resolved the parking crisis. I don't think there is any way to convey the stress one feels when they are ill and are in desperate need of assistance, which may actually be lifesaving, yet due to something which should be easily resolvable they may be unable to obtain this assistance. Eileen is and will forever remain a hero in my opinion. She faced her illness and every unfathomable treatment with grace, dignity and never lost her sense of humor. But this parking crisis caused her immense stress because she could not get past the notion that it may cause one of her care providers to receive a parking ticket or to have their vehicle towed away (and in fact, it did just that). Therefore, she obsessively worried.

Eileen's last hospitalization was in February of 2022. As Eileen slowly regained strength and discharge was in the near future, the ever-looming nightmare parking crisis again became the topic of most conversations. In fact, we were told the entire treatment team was brainstorming possible resolutions during their staff meeting because they could not discharge her without her having access to the necessary aftercare. Eileen's sole request was that she be allowed to return home one last time to say her final farewells to family and friends before going into Hospice.

It was during this last hospitalization we were introduced to Kim D'Ellena, a Community Health Worker who worked out of South County Hospital. When Kim inquired if there were any issues, we could use help with once Eileen returned home, we immediately shared the parking crisis with her. She promised to do everything she could to remedy the situation. After meeting Kim, I felt a sense of relief that we had another person to advocate for us. I also felt immensely supported and understood in a way other were unable to provide. I would later learn that Kim, unfortunately, had recently lost her husband, thus affording her the amazing ability to not just sense, but feel my desperation. More than anything in this world, I wanted - no I NEEDED - to grant my twin her dying wish. Trust me when I say, however, that I had no idea what a shark this gentle, compassionate individual actually could be! Within days she went to the South Kingstown Chief of Police to speak with him in person. Upon obtaining no resolution she went directly to the South Kingstown town manager and waited until the town manager had a free moment to speak with her. Through her unyielding persistence and dedication, Kim was able to achieve a resolution (and in our opinions perform nothing short of a miracle)!

Eileen was then discharged from the hospital with the assurance and peace of mind that she would receive the necessary aftercare while saying her last goodbyes. This may sound trivial to some, but I assure you, it meant the world to my sister, myself and our family and friends. The relief and joy she felt at knowing her final wish would be realized brought her to tears as she thanked Kim for making it possible. My family, most of whom reside in the immediate area, were able to visit at any given moment Eileen wished. She found such peace knowing her friends and loved ones could visit in the comfort of her inviting home.

This brings me back to a statement I made earlier, "I don't think there is any way to convey the stress one feels when they are ill and are in desperate need of assistance, which may actually even be lifesaving, yet due to something that should be easily resolvable they may be unable to obtain this assistance." Being admitted into the hospital brings its own slew of issues. Upon discharge simple daily tasks may be overwhelming and for those caring for their loved ones, there often is not enough time or energy to do even basic daily tasks. It is a confusing and challenging time for all. To remove any part of aftercare assistance which may be available is morally wrong.

I want to thank you for taking the time to read my testimony and for your consideration of H7597.

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