

February 11, 2025

To whom it may concern:

My name is Nikki Batsford, and I am writing to express my dire concerns about the possibility that Rhode Island will prevent caregivers from serving as durable power of attorneys/medical proxies for their clients.

I am a highly disabled 42-year-old woman. Through Careforth, a shared living program that has been life-altering, my 71-year-old mother is able to get financial and emotional support for the backbreaking work she was doing otherwise to care for me. My mom has been with me every step of the way through unimaginable medical and personal battles... and they don't seem poised to end anytime soon. We need to stay together as long as I'm alive and she can still care for me. And she must be the one to make any medical decisions if I'm incapacitated because only she understands the complexities of my neurosurgical journey that is too incomprehensible for anyone else to navigate.

If caregivers suddenly can't be medical proxies, I'll have three completely unbearable options. I can leave the Careforth program altogether and lose the crucial support my mom needs to care for me. Alternatively, I can get a new caregiver who would take far inferior care of me and - even worse - destroy my close relationship with my mom. Or I can roll the dice and have someone who doesn't understand the intricacies of my case (which is literally the only one of its kind) be the one to make life or death decisions for me at the most critical moments. Exactly which of those options would you take? And why am I even being faced with that prospect when I have a wonderful caretaker and advocate - a mother and registered nurse who has lived my story with me - right in my own home?

Mind you, I speak not only for myself but for the countless others on shared living programs who will be affected by this decision. We appreciate people looking out for our best interests, but that's not what's happening here. For many of us, there is simply nobody better to speak for us at our most dire moments than the caretakers we have entrusted to take care of us 24/7. They live with us. They see us when we are most vulnerable, and they laugh and cry with us. They hurt when we hurt. Many also accompany us to appointments and thus understand our medical history. And if they are friends or family, the relationship has additional depth that can't be quantified. While we don't have to choose our caretakers as our proxies, can you blame us if we do? Who is better to speak when we can't than the people who live with and care for us?

Life has forced me to concede my ability to work and even my ability to care for myself. But as you can see, I still have an intelligent mind and a powerful voice. Please do not let a misguided sense of protection strip me of what little power I still have left. It is my right both to be a part of the Careforth program and to chose my mother - my partner in my medical journey and a registered nurse - as the person to protect my extremely complicated interests if I ever find myself unable to speak in a medical emergency. So little in my life seems secure, but I've felt better since signing my living will and naming her proxy in 2013. Please don't take that away from me. My body may be a wreck, but my very sound mind declares my mom as the only person capable of caring for me and making my end of life decisions.

Thank you for your time and consideration.

Nikki Batsford