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On Behalf Of: Self

Committee: Senate Committee On Human Services

Measure: SB576

I am an Oregonian with a serious physical disability. Four years ago on a snow-tubing adventure with my family, I lost control of the tube, slammed into a tree, and broke my back, resulting in a spinal cord injury, leaving me paralyzed from the chest down. This type of injury flips your life upside down.

My husband has slipped into the role of care provider. In addition to taking care of our son on the autism spectrum, he now has to take care of his paraplegic wife, all while working full time. What does this care entail? In the beginning he helped me with my bowel program (since a neurogenic bowel cannot expel waste on its own), intermittent catheterization (since a neurogenic bladder cannot expel urine, a catheter must be used each time I urinate), and transfers from chair to bed, bed to chair, chair to car and back, chair to shower chair and back, and if I ever want to sit on a surface that is not my chair, then I also need help onto a couch or easy chair. When I have urinary and bowel incontinence (this is not a matter of IF, rather WHEN), he helps me get onto the bed, helps me get my clothes off and washed, washes my chair cushion, cleans me up, and then back in the chair once the cushion is clean again. For the first year of my injury, these accidents happened nearly daily, and sometimes multiple times a day.

As I have progressed through this injury, I have gained more independence, but my husband constantly worries, for good reason. I have lost track of how many times I have fallen to the floor during transfers. Since my husband works, he is not always home to get me back in the chair, and I’m not sure I will ever be successful at a floor to chair transfer. One time I fell and had to call the fire department to get me back in my chair. My husband nearly had heart failure when he pulled up to our house and saw a fire truck parked in front.

When I was first injured, a friend of ours who has a quadriplegic nephew advised us to get divorced right away. This is a common tactic when an SCI robs a couple of one spouse. Neither of us had the heart to get a divorce, but now that’s kind of a regret. If I were single, I would have a much better chance of getting nursing help when needed. As of now, if we are faced with a situation where my husband has to leave for some time, then I have to hire nursing care out of pocket. At the price of approximately $30 an hour, we could not afford more than a few hours a week. My husband is stuck - either pay for help beyond our budget or be available to me ALL THE TIME. His parents in upstate New York are very old and frail, and taking care of their estate when they die will be a huge task. He will have to go back to New York for weeks at a time. At this point I’m keeping my fingers crossed that I’ll gain more strength and agility before they pass, because we definitely cannot afford to hire nursing care a few days, much less for weeks.

Before this injury I was a high school teacher. I took a little more than a year off to recover, and then I returned to work part time. If a person on disability makes too much money in a month, they can have their benefits taken away. My modest teacher salary was too much, if that gives you an idea of what the cutoff amount is. People who receive disability benefits have a choice: don’t work and receive disability and live in poverty, or work as much as you can so you can afford to simply live. I am fortunate in that we can afford for me to work a little over halftime. That’s about all I can handle. Many of us with SCIs endure chronic nerve pain. Some days I have to go to bed at 5:00 because my body will not allow me to function. Every single part of me below my injury is screaming in pain. Ironic, isn’t it? The only thing I feel below my chest is pain.

SB 576 will help improve my will to live. It will improve my marriage by giving my husband a small break. It will improve my attitude at work, and provide a little peace of mind. Please support SB576.