

March 25, 2019

To: The House Business and Labor Committee and the Senate Workforce Committee  
From: Tim Stapelton  
Re: Support of HB 3031

Dear Chair and Members of the Committee –

My name is Tim Stapelton. I have been a resident of Portland, Oregon for 33 years. I am a professional Scenic Designer working with the Portland Theatre community. I am here to support House Bill 3031.

In 2008 I left Portland to care for my mother. She was 95 years old and living alone in Tennessee. When I left, I had 9 theatre contracts on my desk to sign. Those contracts represented approximately 27 months of income for me. However, I relinquished those contracts to care for her because it was the right thing to do. She was my mother. I did not know how long her illness would last, or when I might return to Portland. I had to put my life on hold. Still there were bills to pay: primarily, the utilities and rent on my apartment where I had been living for 15 years. I needed a home when I returned. This was a sacrifice.

Caring for my mother 24/7 required feeding her, getting her in and out of bed, buying groceries, keeping doctors visits and managing the household; all the while, being constantly concerned about my financial responsibilities in Portland. I went through most of my savings account and had to ask my family for help. I even resorted to taking out loans.

My mother died at 98 years of age. Her doctors felt she gained an additional 3 years of life, in large part because of the year-long role I played in her care, and the fact that she was surrounded with love.

When I returned to Portland, I was fortunate to be able to continue my career as a Designer. I sustained myself working in the theatre community for seven more years, until one day – while painting a set – I found I was unable to lift my brush, or move my arm. I was quickly diagnosed with ALS: Lou Gehrig's Disease. This diagnosis usually carries a death sentence. My neurologist initially gave me 6 months. As a painter, I was devastated.

It has now been two years, and in this time I have completely lost the use of my arms and shoulders, also most of the mobility of my hands. But I am fortunate. My best friend dropped everything, left her life, and drove across country – from Michigan – to care for me. We were told that she could not receive training, and Social Services would not pay her to work as my caregiver. This means, despite my needing round-the-clock care, my friend and caregiver must work a few hours each day to make enough money to pay the bills SHE left in Michigan. And because of this, I must be alone during a part of each day.

I cannot walk easily, or use the restroom by myself. And it is impossible for me to feed myself. In addition to these issues, I have fallen more than a dozen times since my caregiver arrived. My insurance will not pay for the shoulder brace I need to help keep my body in alignment. Social Security will not declare me disabled. I started receiving Social Security benefits at age 62. When I was diagnosed with ALS at age 68, the Social Security administration told me that if I received disability supplements I would lose my Social Security benefits. If I remain an outpatient in the ALS clinic at OHSU, Medicare will pay for my healthcare. But, if my neurologist prescribes any 'in home' medical care, Medicare will not pay.

I am blessed with friends. They have become my family. Because, understandably, the state required me to surrender my driver's license, they take me to doctor's appointments. They also include me in social events, picking me up and bringing me home. They take me to buy groceries, they feed me, they take me to the toilet, bathe me and dress me. My family of friends helps me with ANY and ALL of my daily activities.

These extended family members must fit my needs into their schedules. Most of them have jobs and their own families to care for. They should not be punished for their kindness, nor their generosity and compassion.

Life can spin out of control overnight. There will come a time when something unexpected will happen to someone YOU love. What will YOU do?

I am a fighter in the battle against ALS. I have a contribution to make. I will not stop painting and right now, I refuse to give over to this disease. In the end, I want to stand as a testament to family, friendship and kindness. I believe this is who we are as human beings. We can't get through our journeys alone.

Thank you,

Tim Stapelton