

Ed Jawor
Lewiston

LD 296 The Maine Family Caregiver Credit

Honorable members of the Taxation Committee, my name is Ed Jawor and I'm from Lewiston. I'm writing in support of LD296, "An Act to Provide Compensation for Family Caregivers".

Our experience with caregiving and hospice spans over four years. It is the story of Gloria and Ed Woodhead, my wife Jane's parents. In May of 2004, after 56 years of marriage, Gloria was diagnosed with lung cancer. In the year leading up to Gloria's diagnosis, Jane and I had already stepped up our caretaking – our social visits turned into regular assistance with their household chores and Dr. appointments. Within a month of Gloria's diagnosis we started providing full-time care. Jane, Ed & I worked around-the-clock shifts providing meals, medication, bathing, toileting and intensive skin care to prevent painful bed-sores. We managed countless visits from the social worker, nurses and CNAs, visits paid for by insurance or out of pocket. We continued to bring Gloria to Dr. appointments until she was bed-ridden.

While caring for Gloria, Jane and I continued to work full time to make ends meet. We used all of our sick and vacation time. Jane shifted her schedule, took fewer hours, and weekends, to free up time to care for Gloria. This impacted our income at a tough time. Costs added up, and some were surprising. We needed a lift-chair, special bedding, a bed-side commode, a walker. We installed hand-rails in hallways and in the bathroom. There were Nurse and CNA fees beyond the co-pays and insurance-subsidized services. Additionally, the time-cost of all this was exhausting: we covered the day-long gaps between nurse and CNA visits, travel and waiting time for Doctor visits, special meal and medication prep, as well as additional laundry and bedding needs.

By August 2004, Gloria was officially in home hospice care. Jane spent nights at their home for overnight care. By December, at the advice of Gloria's social worker, she was moved to D'Youville in Lewiston. Gloria's pain-management needs were beyond what we could provide at home. Gloria passed peacefully twelve days later, with family at her side.

Through all of this we watched Jane's father age by the day. Three years prior to Gloria's passing, Ed was treated for prostate cancer and then shingles, and then, the grief of Gloria's illness and passing. But there was more to Ed's exhaustion and grief. Months after Gloria's passing, Ed was diagnosed with ALS, Lou Gehrig's disease, a crippling nerve and muscle disease.

Ed's ALS would require an even greater level of care—impossible to imagine at the time. Over the next 18 months Ed lost all ability to move. Ed didn't have the strength to hold a cup of water, a spoon, or press the button on his medical-call unit. Special food preparation was required for everything, even cups of water, as muscle loss made swallowing a painful and life-threatening process. Again, Jane and I were full-time caretakers. At that point, I took over helping Ed with his catheters, toileting, diapers and sponge baths. Ed wasn't comfortable with Jane or the younger CNAs in that sensitive role, and male nurses and CNAs were so few as to be nearly impossible to schedule.

Jane and I were spending all non-work time with Ed. He was bed ridden and on oxygen. He slept in the living-room, a make-shift hospital room, big enough for his hospital bed and oxygen machine and space for the nurses to work around him. On Feb 6, 2007, at 7pm, Ed passed away at home with family by his side.

To say those years were difficult is an understatement. Jane and I were fortunate to have jobs that were flexible in supporting our non-stop care-taking schedules. Our young sons saw first hand nurses and CNA's working hard to provide comfort and dignity through physically and emotionally difficult work. We were the lucky ones. I can't imagine what we would have been through if the care-taking, employment and

financial pieces hadn't, almost by miracle, fit together. We provided Gloria and Ed the best care, in the dignity and comfort of their home.

LD296 helps family care-givers do the toughest and most important work: caring for the disabled and end-of-life elderly. Any financial support during this time is beyond helpful – it is critical. It pays for the unexpected costs of care, too many of which to list in detail. There are countless studies promoting the benefits, financial, mental and spiritual, of in-home care. This bill provides support for families in their time of need.

Please pass LD 296. Please support families caring for loved ones—families doing the most difficult work during the most difficult of times.