

## **FitzPatrick HB 6521**

My name is Michael Thomas FitzPatrick. I reside at 271 Georgetown Drive, Glastonbury, CT 06033.

In regard to this bill, I am caregiver zero. My wife, Pirkko-Liisa, at age 65 passed away peacefully at home from a Glioblastoma brain tumor on December 20, 2011 that was diagnosed on May 5, 2010. We were very fortunate that my wife's best friend was Dr. Loni Figura. While we knew Dr. Figura was a hospitalist advocating and now board certified in palliative care, we never actually understood the concept until Pirkko was diagnosed.

After Pirkko's death, I pledged to Dr. Figura I would support her to get a MOLST bill to the legislature. We named it the Pirkko Project and vowed never to give up. I would like to thank all members of the task force that labored to bring this bill to the legislature, and this committee for taking time to hear one of the most pressing issues facing healthcare today. As a former Nevada Assemblyman, I know the efforts needed to bring good legislation into law.

After Pirkko's diagnosis, Dr. Figura met with Pirkko as a friend, a woman, and a physician. We all agreed that Pirkko's dignity and quality of life were top priority. All would be done to fight the tumor, but useless efforts would not be attempted. Pirkko's main wish was to die peacefully at home if at all possible.

With Dr. Figura's guidance, we went over various options, end of life orders, and do not resuscitate orders. When Pirkko was hospitalized or in the nursing home, we had these papers with us. I was never in doubt of what actions to take as these were my wife's wishes that I know had been fully explained and chosen by her.

Pirkko was given six months to live in July 2010. We then went to what was considered the best facility for treatment, Memorial Sloan-Kettering Cancer Center in NYC. Pirkko was put on Avastin that kept the tumor at bay for one year until October 2011 when the diagnosis changed to terminal. With the support we received, Pirkko was able to make three trips to Europe in 2011 to fulfill her dreams.

While on Avastin and during her terminal stage, Pirkko was hospitalized and in nursing homes due to setbacks and complications six times. My goal was always to get her home as soon as she could be safely released. Being at home relieves stress for patient and caregiver. It also eliminates exposure to infections and the healthcare costs of the nursing home or hospital.

The biggest problem I faced was no experience being a caregiver. As a businessman, I know how to get information to make informed decisions. Healthcare was a whole new field to learn. With Dr. Figura's guidance, I found other resources from the cancer navigator at Manchester Cancer Center to the visiting nurses that supported Pirkko's wish to die peacefully at home. The insurance company provided a cancer nurse that overrode protocol to get a stair glide installed in our home to get Pirkko out of the nursing home at \$440 per day. I was fortunate to have construction contacts to handicap the bathroom

and front porch on 24 hour notice. All these resources increased Pirkko's quality of life and were substantially less than institutionalization.

The Navigators were the key for me. Once I knew the options, I was comfortable making a decision. Navigator positions can provide all options and should be included in MOLST. In many instances, lower cost options are chosen that allow the patient their desires, and reduce the otherwise higher healthcare cost alternatives.

I know I met my wife's wishes for dignity and quality of life. In the process we chose many of the lesser cost healthcare alternatives to reach these wishes. MOLST will give the patient their choice and reduce the overall healthcare costs.

Here is clear example where the patient's desires are honored and healthcare costs are reduced. I strongly support the passage of this bill.

Thank you.