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Select Committee on Aging
Public Hearing
Testimony: Tuesday, February 16, 2010

**SB # 103: AN ACT CONCERNING ACCESS TO COMPREHENSIVE FACTUAL
INFORMATION REGARDING LONG-TERM CARE FACILITIES**

I am asking you to vote favorably for SB # 103.
SB # 103 is budget neutral.
SB # 103 will provide information to make knowledgeable decisions.

I have a personal reason for seeking your assistance. Primum non-nocere: first do no harm; the tenet of medical care.

February 2006 my husband Joseph (Joe) was a respite client on the Special Care Unit of the Connecticut Veterans' Hospital in Rocky Hill when a long-term care bed became available. Joe's status was changed from temporary to permanent. Joe was non-verbal with a diagnosis of severe dementia.

I live in the southeastern region of the state; Special Care Unit at the Veterans' Hospital in Rocky Hill is not down the street and around the corner. However, it was the most appropriate and best placement for Joe. Staff, although not geriatric certified or dementia specific trained, was available to meet with me to discuss Joe's quality-of-life care needs. To support and supplement their dementia education, I frequently brought books and information to them.

At the time of Joe's admission I was not: 1) given a Patient's Bill of Rights; 2) told he may not age-in-place; 3) told the Veterans' Hospital lacked accreditation (a cost saving downgraded to licensed); 4) told staff may or may not be certified and/or specific trained*; 5) told he would be denied the Medicare benefit of hospice*; 6) told staff could not or would not recognize his need for pain management and comfort care*; 7) told facility staff lacked current Unit Care criteria; 8) told facility staff lacked organ donor policy; and 9) told I may not be considered an integral member of his care team.

April 5, 2007 I spoke with Margaret Pantoja, Assistant Hospital Administrator. I told her my job was to take care of Joe. I then asked her, "what is your job?" She replied, "take care of Mr. Sullivan."

July 6, 2007 Joe went into respiratory crisis. He was transferred from the Special Care Unit (his home for more than 16 months) to the Respiratory Unit. Staff did not demonstrate dementia knowledge. His diagnosis (I learned after his death) was changed to pulmonary disease. If you have pulmonary disease, you do not need to have dementia competent staff.

July 16, 2007 a team with new members (not dementia or hospice certified) instead of recognizing Joe was in transition determined he would receive physical therapy. I was not invited to this meeting which would become the most important of Joe's life.

July 17, 2007 I asked Ms. Pantoja for Unit Criteria; not readily available.

August 3, 2007 Respiratory Unit staff told me Joe had a right hip fracture. He was transferred from the Veterans' Hospital to Saint Francis Hospital for evaluation. From the Emergency Room I spoke with Ms. Pantoja, more than once, with medical updates. I asked her if I should be talking with the Discharge Planner. She assured me, "Mr. Sullivan can be cared for anywhere in the hospital." I said, "hospice."

Joe was returned back to the Respiratory Unit, same place where his right hip was fractured, instead of admitted to the Hospice Unit as I requested. According to medical reports from UCONN Health Center and Saint Francis Hospital, **Joe's right hip fracture occurred 1 – 2 weeks prior to detection; during which time he is receiving physical therapy.**

August 4, 2007 I spoke with the Weekend Duty Nurse Practitioner. I requested Joe be moved off the Respiratory Unit. It did not happen. I later learned there were "staffing problems".

August 5, 2007 I notified staff Joe's pain medication needed to be adjusted. A staffer told me, "it's not 4 hours". No one reassessed Joe's pain level requirement. There is a myth that individuals with dementia do not experience pain. It is just that – a myth!

August 6, 2007 prior to leaving my home, I phoned Hospice of Southeastern Connecticut to discuss Joe's end-of-life care needs. I was told the Veterans' Hospital was not in their region.

When I arrived on the Respiratory Unit, Joe was in distress. I went looking for the Special Care Nurse Practitioner. I told her: 1) I want Joe out of there (Respiratory); 2) I am not leaving until he is; and 3) I am prepared to stay.

The Hospice Unit Nurse Practitioner was called. She assured me she could manage Joe's pain. He was moved from the Respiratory Unit to the Hospice Unit. Unfortunately, no one on staff was hospice certified or recognized Joe was dying. I was not referred to hospice providers who offered certified staff.

I used Healing Touch techniques to ease Joe's pain. Peers in my Healing Touch community provided Joe with end-of-life comfort care.

August 8, 2007 I started requisitioning records.

August 14, 2007 I requested organ donor information. I encountered another myth -: Alzheimer's diagnosis prevents donor approval. The Transplant Team determines suitability.

August 20, 2007 Joe passed into eternal peace.

August 24, 2007 Joe went to his grave a non-organ donor.

October 2007 I met with Ms. Concannon and Ms. Pantoja. When I asked why I was not invited to the most important meeting of Joe's life, Ms. Concannon said, "we are the veteran's family". Since I had legal documents that said I was Joe's healthcare agent/advocate, I find these five words shocking. I did not abdicate my rights; they were usurped. When I asked Ms. Pantoja why my request for hospice care was not respected, she did not answer.

Once Joe left the safety of the Special Care Unit, he did not receive care that was appropriate and best for him. He received care that was convenient for staff. Joe died sooner than he would have. His body could not withstand the assault.

After Joe's death I continued to requisition records. I learned the lack of staffing, the lack of credentialed and appropriately trained geriatric and hospice staff contributed to Joe's untimely and painful end-of-life care.

A May 16, 2003 OLR Report 2003-R-0450 states an unidentified Veterans' Affairs Commissioner is questioned about priorities in a budget challenged year. The questions about health and safety violations; inadequate patient care and lack of accreditation are addressed.

Why were these concerns not corrected prior to Joe's admission? Why was I not told Veterans' Hospital staff could not provide Joe with the end-of-life care he needed? Why was Joe denied a referral to a hospice certified provider?

Today the economic challenges continue. Although administrators and managers are forced to make bottom-line decisions, they should not be at the expense of patient appropriate care.

When someone appears before this august body in opposition to SB # 103, ask yourself these questions:

- 1) Why would someone not want staff certified or specifically trained for assignments?
- 2) Why would someone not want the patient, family or advocate to have the most reliable data, including the names and credential(s) of all staff responsible for care, to make informed person-centered care decisions?
- 3) Would you want to receive Joe's agonizing end-of-life care?

Please vote favorably for SB # 103. The quality-of-life of your constituents receive depends on its passage.

*Senior Resources – Agency on Aging White Paper: **When No One Cares**; www.seniorresourcesec.org describes the direct care workforce shortage.

*Hospice Southeastern Connecticut pamphlet describes what "real" hospice is.