

June 23, 2009

Dear Mr. President and Esteemed Gentlemen of the House and Senate,

I am a 38 year old hospice chaplain in Florida. I cannot grasp the weight of the decisions you face on a day-to-day basis nor will I try to be an “armchair quarterback”. Yet, as you look at those pertaining to our healthcare system, I implore you to protect cuts that would affect hospice. It is an invaluable ministry to families at one of the most vulnerable times in their lives. Allow me to illustrate.

For the past month I have had the privilege to support a patient and her family with a rare but terminal neurological disease. Hospice has trained chaplains to support a patient’s religious beliefs. But beyond this, they have taught all employees to validate feelings, engage in life review, actively listen, and assist all involved in preparing for death.

This beautiful young woman has a husband, young child, siblings (including a twin), parents, and many other friends and relatives who visit constantly. Due to the neurological deterioration, this patient has very little motor control and almost no ability to pronounce words. Yet, when you look in her eyes you can see she is still cognizant of her surroundings. I would describe it as if one was sitting in an empty movie theater. On the screen they see their life playing out but they are unable to interact with any of the characters on the screen.

On one particular visit, I went in with our Integrative Therapies Specialist. We stood bedside, talked with her, affirmed her with positive touch, yet you could see her frustration. We both verbally acknowledge her feelings and all these actions allowed her to relax. Someone took time to be in the moment, sensed her feelings and validated them.

At this point she began trying to speak to us. Both of us could see she desperately wanted to say something, but after 5 minutes of trying to decipher it we were all frustrated. At her prompting (making writing motions with one hand) I grabbed a tablet and a pen. We maneuvered her arm so she could try writing but had limited success.

After about 10 minutes of perseverance, we finally understood her message and it is a feeling I will never forget. Our connection not only comforted her but she affirmed us as well. I have attached a photocopy of the sentence she attempted to write and the final message underneath. It hangs in my office as a reminder of the impact we have on our patient’s lives.

We expect her to pass this week. Many of us have grown attached to her. I speak with her family often and they never stop thanking hospice for its help and care. She is comfortable, dignified, and valued as her passing approaches. I believe I speak for all of

us here when I say that we feel a sense of loss but also one of deep fulfillment having been a part of this young woman's journey.

If it were not for organizations like hospice who would value these people, providing comfort, dignity, and support? I urge you again to protect the funding that hospice uses to impact so many.

Thank you for your time, dedication, and service to our country.

Sincerely,

Joseph McNett  
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