

An open letter to the spouses of palliative care professionals

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Wednesday, December 31, 2014

by Emily Riegel, MD

My darling,

Some time ago you and I had a crazy idea that it could be the two of us against the world. In our naiveté we thought we had a connection previously unknown to any other human couple. We, in our love, became a superior being that transcended the “you” and the “I.” We agreed that Pablo Neruda’s Sonnet XVII was written about us.

Of course, between then and now, life has happened, just as it happens for all couples.

Our days are busy with children and meetings and work and parents and meals and errands and sick cats and lost keys, and sometimes in the routine of chaos we can say, “How are you? How was your day?”

And I say, “Fine. Yours?”

Sometimes that is true, it was fine.

Sometimes I say, “Really rough.”

Sometimes I say, “It was a crazy day.”

Sometimes I say, “I just can’t even talk about it.”

Yet, even as I have tried to give you a glimpse of the days, there is no way for you to join me in my sadness or frustration or mystified joy.

As we close out another year together, I am going to be honest now, as I should have been all along.

Before I say this, know that my intention is not to make you think my work is superior to yours, or more important, or more difficult, or more valuable.

You see, though, my work IS incredibly hard, and important, and difficult, and valuable.

In one day's time I see humanity at it's very best and it's very worst as I hold another person's hand while they walk the tight rope between life and death.

I get yelled at and blamed and accused of not caring, but I can't argue back because I know that I am just the easy target for the anger and grief.

I watch people take their last breaths.

Before those last breaths are taken, though, I get to talk to people about what truly matters to them. We talk about life and death and what it means to live while dying.

I witness lives changing forever.

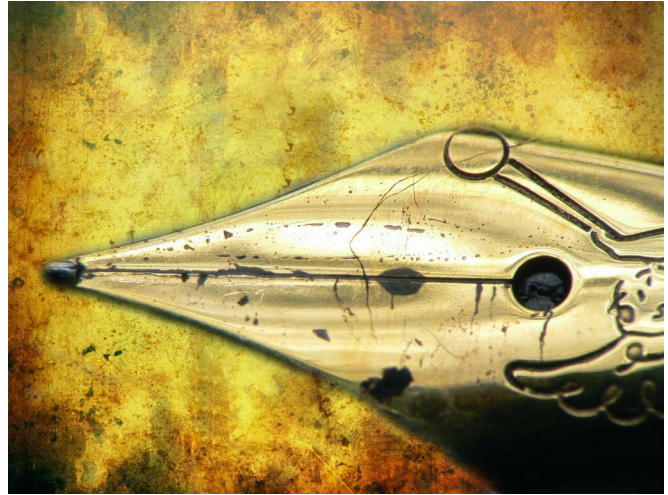
These are the day's events that might seem easy to come home and talk to you about, but there are many reasons that I can't be fully open about it.

Some of these need to be processed in my own mind and heart before I can put them into words to share with you. I need time to wrap my mind around them before I can ask you to wrap yours around it as well.

There are also some that, my dear one, would break your heart. I know you so well, and I know how much you love your family and how terrifying the idea of losing any of them is to you. You are so protective of us whom you love, and if I don't want you to be fraught with anxiety and fear every time one of us leaves your sight. I choose to protect you from the sadness of the world.

More often, though, I am being selfish of my stories. I want to hold my days close to me and be able to cherish what I have seen or heard or felt. Retelling the story, or trying to capture the it in words is inadequate. It fails the beauty and mystery I've been a part of. It's like catching fireflies, and thinking they are going to flicker in the jar on your nightstand all night long. Instead they give up their blinking and by morning are scattered among the blades of grass, dried and shrunken. I want to give you the fireflies as they are under the oak tree at dusk, not as the shriveled remnants of the beauty. Trying to capture and give you the view of the day when I know I can only possibly give you the tiniest glimpse feels shallow and disloyal to my patients and my colleagues.

I know that you don't understand what I do or why I do it. I know that you appreciate and admire what I do, though, and for that I thank you.



I thank you for letting me cry when it is the only thing way I have of explaining my day.

I thank you for giving me space when I need it.

I thank you for not rolling your eyes when I insist on cramming in every bit of magic around the holidays because we must make every memory and every moment matter.

I thank you for declaring that if all patients had a palliative care doctor that the American medical system would be fixed.

I am sorry for the times I am emotionally out of reach from you and my mind is still at work, or with a patient or family. I am sorry for the times that I am not handling my stress well and I take it out on you.

When you ask me, "how was your day," you should know that even with all the stress and chaos and hard work and lost keys, that my day, always, was great. It was wonderful and magic and a gift to be able to spend it doing the work that I love, or with the people that I love, or seeing a beautiful sunset. So I feel guilty when I am frustrated that the kid lost his backpack, or some other minor inconvenience that I get to experience because I am alive and healthy. This is part of the dichotomy of living with me.

Thank you, love, for your patience.

As we go into this new year, remember "I love you like this because I don't know any other way to love."

Always,

ELR

Emily Riegel, MD is a palliative care physician at the University of Kansas Medical Center, where she sees both children and adults.

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