

Goodbye, With Love

By Amanda Sharp, SPT
CHEP-JHR Essay Contest Winner

There's a quiet murmur of Christmas carols playing in the hallway as I stare, fixated at the window, on the snow falling outside. My cheeks are stained with tears.

Beside me is my grandfather, asleep in the blanket I bought him for Christmas. In a few days, the holiday will be here, but he won't. *He wanted to die in hospice*, I tell myself. *This was his choice. He's ready*. I clutch his hand tighter and collapse my head on his blanket and sob.

Days later, I am awakened from my own grief and go back to work in the hospital. How can I hide my pain, my grief? He's dead now, and everyone knows.

I'm going upstairs to see my first patient of the day. She has an open wound that requires a careful evaluation for wound care. I grab my supplies to set up. *Breathe, Amanda, breathe*.

Her room is darkly lit. I introduce myself and explain that we will be cleaning her wounds. I pull off the sheet. She had undergone a double amputation that has not properly healed. What is left of her legs is badly infected and the odor is foul. I look at her and I know—this is going to be difficult.

We begin treatment. She shrieks in pain. We douse her wounds in viscous lidocaine. The nurse gives her meds.

Nothing can soothe the burn of an exposed, free nerve ending. She begs us to stop over and over again.

In the hallway, I hear whispers among the medical team making their rounds. I listen in.

“She's hospice appropriate.”

“Her husband wants us to keep treating.”

“There's nothing more we can do.”

I suddenly become aware that no matter how often we attempt to clean this wound, she will die. Do we stop? Do we continue per the husband's request? The patient herself, possibly out of consideration for her husband, or due to her limited ability to communicate, has not demanded that we stop treatment. There is no living will. But even if we continue, are we doing more harm than good?

Her husband attempts to communicate with her. He encourages her but she stares blankly. There is no verbal interaction. She averts eye contact and falls silent when her husband asks her to please try to continue the wound treatment. It seems she doesn't want to break his heart. Her limited interaction with her husband suggests she is no longer interested in

pleasing his requests for treatment. I gather, perhaps, she is ready to give up on life. Maybe she *wants* to die.

The physical therapist and I lock eyes. In that moment, we both realize this husband has not grasped the fact that treatment will only prolong her so long—and he cannot bring himself to accept that his wife may be ready to die.

What do you do as a provider in this situation? We, as physical therapists, are in the business of preventive health and corrective health—but, what about end-of-life care? If we can make life a little better at the end, do we do it? Do we ask a physician to dope the patient up on pain medication and call it a day?

I could never have guessed that, as I dealt with grief from a hospice death in my own family, the first patient I'd encounter back at work would be someone with an end-of-life prognosis. For days, as we returned to continue wound treatment, I choked back tears to appear professional as she screamed in pain and begged us to stop. *I wanted to stop*. But I was the tech. It wasn't my call.

My conflicting feelings made it difficult, as I wanted to let this patient die in peace. But fresh was my own grief, and my wishing that I could have done anything to prolong the life of my own grandfather. I could see how difficult this was for the patient and her husband.

Prolonging life when there is little or no hope for meaningful recovery is a hotly debated issue. After this patient, and my own experience, I saw both sides in a way I couldn't have before—and what it meant for physical therapists.

This patient openly verbalized her agony and screamed for us to stop during wound treatment. But she never directly indicated to the therapy team that she wanted

to be left in peace to die. However, most every therapist who saw her came to a similar conclusion: she was ready, but could not bring herself to tell her family it was time. Multiple physicians had the end-of-life discussion with her. I believe she knew it would be a hard burden to accept—especially for her husband.

She did not converse beyond asking us to please stop during treatment and, most days, asking us to leave. Her facial expression was empty in a way that I've never seen in a patient before. I could see it in her face—the acceptance that her life, as she knew it, was over.

In retrospect, what would I do differently? As a rehab tech, could I have fought more to stop treatment? Family members are a part of care, but they are not the final decision-maker. She was in pain and asked us repeatedly to stop during her treatments. We would have ceased treatment if she had formally stated her preference, and we would have let her die in peace. Why continue to put a patient through pain in treatment we know will not change its course? It felt inhumane.

Many at the end of life, but not all, come to grips with their own death. I couldn't grasp how my grandfather was in such peace. *It was I* who was suffering and who wanted to selfishly prolong his life. In this case, the husband needed the treatment prolonged not for his wife—but for himself. For *his* peace of mind; it's a way we cope.

Prolonging life is not to push medicinal capabilities beyond our limits, even though in some cases it can serve to bring closure and comfort to family members who are not ready to say goodbye.

We eventually decided, as a physical therapy team, we were doing more harm than good. We made a

definitive case for stopping treatment. We closed the patient's chart and moved on to other consults in the hospital.

I heard, days later, she was transferred to hospice.

Beauty and peace, finally, for the woman who so desperately begged for it. Somewhere, he too, held his loved-one's hand and said goodbye.

About the Author



Amanda Sharp is a first year DPT student at Emory University, Class of 2021 and a member of the Emory DPT APTA committee. She is married to her husband, Randall Sharp and lives in Smyrna GA with two feisty wiener dogs. She's passionate for all things outdoors and an avid reader of any novel she can get her hands on.