



PUGET SOUND QUARTERLY

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2005 PSONS McCORKLE LECTURE

How Long is This Journey? Patients' Lessons on Dying and Living

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Dr. Sue Hiney, a great storyteller, presented the keynote address at the 1996 PSONS symposium. She discussed the importance of stories, metaphors, parables, and myths in helping patients understand what is happening to them. The following stories reflect the journeys of two people with cancer, and the lessons they have taught me about essence of palliative care. They have taught me about hope, courage and strength. They have taught me about dying and living. Today, I would like to share their stories and lessons with you.

Dan's Story

Dan, a 53-year-old Vietnam vet, found his way into our palliative care program through the side door. Frank, Dan's brother, called the Puget Sound VA in mid-December from his home in Arizona, seeking assistance for his brother. Dan's pain was 10 out of 10. He was running low on pain pills and was bed-bound due to his pain. Dan survived on Ensure. He was taking Morphine Sulphate SR 120mg/day and Oxycodone 35-45 mg a day without relief. Dan was having a pain crisis. I recommended an impatient admission. He declined. The usual way to increase pain meds is to take the 24hr basal dose, add the break-

though dose in Morphine equivalents to the total baseline total, then add an additional 25-50% of the new total to create the new basal rate for 24hrs. You need to recalibrate the breakthrough dose by taking 10-20% of the new basal dose as the new breakthrough dose. But the normal calculation wasn't going to work. So I suggested that he double his pain medication and I would see him the following day.

Dan's apartment was dark and depressing. He looked out at the tires of the cars parked in front of the building. After opening his blinds and turning on the one reading light and all the kitchen lights you could barely make out the soldier artifacts from WWII and Vietnam decorating his apartment. His kitchen was a disaster with old food molding on plates and bowls stuck to the kitchen counter tops.

Dan was the stereotypic portrait of a Vietnam Vet, tall and emaciated, wearing jeans and a dirty plaid flannel shirt. He had stringy long brown hair that touched his shoulders and a beat-up baseball cap that he always wore.

Cigarette smoke hung in the air of his apartment and he was known to smoke marijuana for medicinal and recreational purposes.

His began his cancer journey 18 years previously with the diagnosis of Basal Cell cancers, a number of which were surgically removed. But his were no ordinary basal cell cancer. Dan had 17 biologically aggressive, non-photo distributed lesions. It looked like someone had dipped a paintbrush in the can of "Basal Cell Cancer" paint and then flicked the paintbrush at him. The largest lesion was a 15 cm by 11 cm ulcerated, necrotic wound with tendons and nerves exposed. This mass covered the back of his neck, despite two rounds of radiation therapy. Dan told me from the outset that he was going to be cured. Code status: Full code.

During his time in the service, he had sprayed Dioxin along the DMZ in Korea and loaded Agent Orange on cargo planes that flew over the jungles of Vietnam. He was a bright man who loved to read, especially history. He had owned a mobile auto-repair business when he was able. Dan was handy at fixing things and was very particular about how things were done. He had been the manager of the apartment building where he lived for more than ten years. Dan was also a man of strong beliefs. He thought that women made

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