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Another Day, Another Metastasis Part 2: A Palliative Care Success Story

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#### **Author**

Cramer, Arlene, FNP, AHPCN

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# Another Day, Another Metastasis Part 2

## A Palliative Care Success Story

By: Arlene Cramer FNP, AHPCN

I am often asked “What is Palliative Care? How is it different than hospice?” I sometimes struggle to help my colleagues understand the philosophy underlying palliative care, our emphasis on quality of life and our support for the individual’s choice. People often confuse palliative care with hospice. Palliative care supports patients and families who are alive (not dying) throughout the course of serious illness as they struggling to live with dignity and respect. Perhaps all would best be made clearer by sharing one patient’s journey. This is Shaun’s story:

Shaun was referred to our inpatient palliative care team during a hospitalization at UCSD Hillcrest for complications related to his treatment. What we didn’t know at the time was that Shaun had a serious substance abuse disorder most of his life with only brief periods of true sobriety. He was discharged with a prescription for oxycodone – his drug of choice when abusing drugs in the past. At our first meeting two weeks later I reviewed the CURES report (a report of all controlled substances prescribed during a specific time) and Shaun had received prescriptions for 660 oxycodone tablets in the previous 2 weeks. They were all gone. That day our 8-month journey with Shaun started. The palliative team together with the oncology team, Moore’s psychology, psychiatry and Shaun’s family all helped Shaun climb up his mountain and into his sunlight.

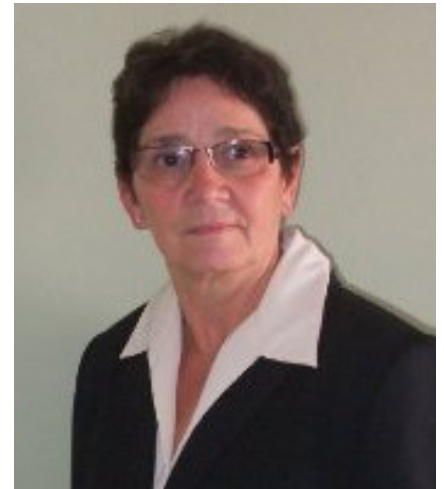
During that time I came to know Shaun as a man and a dedicated stay at home father, his greatest regret was the effect his disease was having on his son. He was honest about his fears of dying and of pain. He wanted to blunt those feelings with

drugs and alcohol and he needed to develop new coping skills. We helped him clarify his goals – of course he wanted to live as long as possible – but he began to explore the decisions he might need to make in the future about medical decisions (i.e. CPR) and then began to weigh the pros and cons of those decisions. These were very difficult discussions. Shaun was a young man, very connected to his thriving family life. Each time we revisited these topics Shaun was reminded again that his illness was progressing in spite of treatment, and that he would need to soon say goodbye to his son and wife.

Shaun had difficulty dealing with the fear of the potential indignities and suffering at the end of life. He asked about physician aid in dying (PAD). Was that a possibility for him? Although we do not participate in the program other than as consultants, we found this an opportunity to further discuss a plan for the future that might help restore some sense of control for Shaun.

So much is unexpected in managing life while coping with serious illness. We like to say “expect the unexpected”. We can’t plan for the unexpected but as a palliative care team we helped Shaun develop the skills and support that he would need to face the unanticipated challenges ahead. During the last 2 months of his life Shaun had numerous hospitalizations – sepsis, GI bleeding, respiratory distress. Together we had developed a firm foundation for our talks and discussions at each bump in the road.

Shaun eventually died at home on hospice care with his family by his side. I attended his memorial service in a local open air park. His journey was not easy – for him or for our



**Arlene Cramer FNP, AHPCN**

is at Nurse Practitioner at Doris A Howell Palliative Care Services within the UC San Diego Health System. She completed her degree at New York University/SUNY at Stony Brook in 2000. She has practiced and taught in various settings including San Diego Hospice and the Institute for Palliative Medicine and now at UCSD. Arlene is a Certified Advanced Hospice and Palliative Care Nurse and provides care as part of an interdisciplinary care team for patients and family with an emphasis on their physical, psychological, emotional, and spiritual needs.

team. His journey was filled with frequent relapses and overwhelming emotions mixed with existential crisis. The team often felt frustrated and sometimes manipulated but we had developed a bond and a commitment to see this through. I believe that Shaun, his family and the team all believe that we all struggled through to help Shaun achieve another “Palliative Care Success Story”.