

## A Story About Stefan

When I first met Stefan he had bone cancer in his right leg. He could walk with a walker around the apartment where he lived with his wife. Over the months that I worked with him, he gradually told me more of his life story. At first he told me that he and his wife had moved to Rochester when during a robbery of their grocery store he had been shot. They had moved from New York City to Rochester to escape that violence and to be near to their relatives. Soon the cancer worsened so that Stefan was bed bound, unable to move without help. The cancer began to break through the skin, requiring lengthy daily dressings. As I did these dressings, he began to tell me more about his life.

He told me of how he had been imprisoned in one of the camps during the war, where he lost his wife and parents. He had been a tailor before his capture; while on work details on nearby farms, he could get pieces of cloth that he sewed into items that he could trade within the camp, sometimes for cigarettes from the guards. Once he was caught with cigarettes and tortured to make him release the name of the guard who had given him the cigarettes. They hung him up by his arms and beat his legs with iron rods. He refused to tell. Now years later, he had cancer in the spot where he had been beaten. One day, not long before he died, he told me that he knew why he had cancer. He said, "I have cancer not because the guards beat me, but because when I was in the camps, other inmates told me, 'You are strong; you will live. Make sure you remember us and make sure the world remembers us.' But when I was free, all I wanted to do was lead a normal life. I never did anything to tell the world about those people. And that is why I have cancer." Stefan had found a new meaning about his life. He was able to take some responsibility for his illness. I hope that in telling me about those people and their suffering, he did something to fulfill their cries. He died with his pain controlled and his wife and friends around him. And I have never forgotten him.

More recently I worked with a man who had a brain tumor. When I met him the tumor had grown back, despite a full course of radiation. Ernest had problems with flashing pains and with very poor short term memory. He would write down or tape record everything I said so that he could talk about it with his former wife and daughter. Living alone, he treasured his independence. He agreed to have help for a few hours a day to help him do his shopping, but he couldn't tolerate having people around him long. Yet his tumor did not grow back quickly, leaving him for several months in this state of frustration over his deficits, doubly hard on someone who had been a researcher in a university.

Finally he weakened and agreed to go to a nearby Home for the Dying or Comfort Care Home. There he was able to maintain his privacy, while gradually making friends among the volunteers. He spent time going over his slides from his research, arranging for them to be given to other researchers. Volunteers also helped him continue to take walks outside—he had been a hiker and craved nature. He was also able to keep up his meditation practice, where he would rise early in the morning and meditate for two or more hours. As the tumor grew back, leaving him more confused and unable to walk, he became more loving and warm towards his family. They joyed in the affection that he showed them. His son was able to come back from Europe and play his violin for Ernest. Soon after his son left, he became bed bound, stopped eating, and died. In his last months, he found new love for his family, the ability to trust the volunteers, and new strength in his lifelong search for God. Those who were with him when he died felt a deep peace coming from him.

These two stories illustrate someone finding hidden meaning in their life and another person finding personal growth and spiritual peace. Both of these people had several months time once they came on to hospice to accomplish this growth. But most are on hospice for shorter periods of time. For them hope may take other forms. A major goal of hospice is to relieve pain. Hospice nurses are thoroughly trained in the use of pain medications and their side effects. They also can contact the hospice medical director for expert advice in difficult situations. Pain medicines now come in a variety of forms: long acting, quick acting, transdermal patches and liquids. If necessary, pain medication can be given via a small subcutaneous needle via a pump. Hospice also relieves the patient from worrying about being able to pay for pain medications—they are fully covered as part of the benefit.

Many people once they learn that their illness is terminal worry about the effect that their illness will have on their family. Hospice works to relieve this fear. A social worker visits regularly as part of the team, offering empathetic listening, information about community resources, and family counseling. Volunteers can visit to offer respite to the spouse or children. Finally, homes for the dying or comfort care homes can offer twenty four hour care when the person's needs exceed the family's ability to care for them.

Spiritual peace can help dying people endure other kinds of suffering. The hospice chaplain makes home visits to help the dying or the family find new resources for coping with loss. While many families rely on their clergy for

this support, others find visits from a chaplain uniquely helpful, as the chaplain spends all of his time with the dying. The chaplain can also help family with funeral services.

Hope can be found when individuals and their families accept the nearness of death. All of the hospice team works in different ways to enlarge the vision of the nature of this hope.

Hospice: Frequently Asked Questions