

Optimizing Healthcare Choices for Difficult Times

As a veteran hospice volunteer, my role is to support individuals who are critically ill or whose condition may be terminal and their caregivers. When I first visit, I want to know: “Who is this person?” “Who is he behind the illness?” “What did she love to do?” “What are the priorities right now?” And finally, “What plans have been made regarding critical healthcare decisions?” Over the years, I’ve witnessed many families who put off making plans for how members wished to live their final months or days. The following true story (with the names changed) illustrates the importance of considering choices and having these conversations.

Mrs. J. came to Hospice Volunteers of Hancock County (HVHC) in great distress. For five years, while working full time, Mrs. J. had been coming home to total care of her spouse Jim. She needed help, and she needed a break. Jim, who had ALS, also known as Lou Gehrig’s Disease, was 48 years old when diagnosed. These were “supposed” to be the good years. Instead, he was wheelchair bound, though able to maneuver the chair with his hand and, thanks to advanced technology, use the computer. Jim was fiercely independent and insisted on doing whatever he could for himself.

When I interviewed the couple to determine how HVHC might best serve them, the usual array of questions ensued until I came to “Do you have any unfinished business you need help with?” Dead silence... followed by words tumbling from Mrs. J. “I don’t know what he wants! What if he needs a feeding tube? Does he want to be placed on a ventilator? What if he’s on life support and the doctor asks me about removing it? He hasn’t told me and I don’t want to make those choices. It’s not fair.” With that, they were both in tears. Hospice volunteers don’t generally take a role in assisting clients with advance care planning. However, I had facilitated this process many times in my professional career working with cancer and AIDS patients. I offered my guidance and support on the use of The Five Wishes Document (www.AgingWithDignity.org), a legal advance care directive in the state of Maine and a very useful tool to help guide the conversation about difficult end-of-life decisions.

Jim and I worked our way through the document, discussing what each of the choices meant for him and for his family. A relatively young man with children who were launching out on their life adventures, he didn’t want to miss any part of that. Taking time, allowing space for emotions to be expressed and settle was key. We took just one wish with each of my visits. After covering the five wishes, we set the work aside for a few weeks, allowing Jim time to consider what each choice meant for him. The second go through was much easier and clearer for Jim. He was able to complete and, with witnesses in place, put his mark on the document. Upon his next visit to the VA, he learned that they only use VA forms, so Jim had to fill out their Advance Care Directive but, he announced to me with pride, “It was a piece of cake.”

There are at least three important points to this story: One: Jim made his choices before such decisions became critical. Two: he shared his choices with his wife and children. And three: he and his loved ones were relieved that difficult choices had been made. Jim also chose to take full advantage of medical hospice comfort care sooner rather than waiting until the last week or two as is common. In fact, medical hospice care enabled him to remain functioning independently in the comfort of his home for several more months. Hospice Volunteers of Hancock County, not bound by medical hospice’s time-limiting regulations, provided both support for Jim and respite for Mrs. J. until he died peacefully at home 13 months later, surrounded by his loved ones.

Choices That Matter is a new community-wide initiative on the Blue Hill Peninsula, Stonington and Deer Isle to help promote thoughtful discussion about our wishes for care when faced with challenging illness, chronic disease, and dying. It is a collaboration among Healthy Peninsula, Healthy Island Project, Island Nursing Home, Blue Hill Memorial Hospital, Hospice Volunteers of Hancock County, and many dedicated volunteers. As part of the initiative, Drs. Barbara Sinclair (clinical psychologist) and Susan Ostertag (MD) are offering 2 free two-session workshops—“Optimizing Healthcare Choices for Difficult Times”— at the Island Nursing Home (3-4:30pm on April 2 and 9) and the Blue Hill Public Library (3-4:30 pm on April 12 and 19). To register, obtain further information, or request additional workshop dates and times, please contact Healthy Peninsula at 374-3257 or info@healthypeninsula.org.

