



Hospices and Patients Share Stories through Social Media

Social media has changed the way people and organizations communicate, connect and collaborate with others. It's called 'social' media because the platforms are interactive and conversational, and help individuals and organizations build relationships and community.

Hospice patients use blogs and Facebook pages to stay in touch with friends and family. Teri Collet, Director of Social Services at Community Hospice in Modesto, has seen social media facilitate emotional support for patients and caregivers. "Social media allows patients to communicate with others when they have the energy, or when they feel alone at three in the morning and can't pick up the phone." The same tools also help reduce caregivers' feelings of isolation.

Sharing the End-of-Life Journey

Hospice Journey, a free personal (and private) website for patients and their families, is another tool many hospice social workers and volunteers have introduced to their patients. Vanessa Callison-Burch, one of the founders of Hospice Journey, says 400 families have created Hospice Journey websites. "We took the best parts of online collaboration and social media for Hospice Journey, but designed it for a specific purpose: to help families share updates, coordinate care and reflect on what matters as they are living with dying."

Hospice Journey was designed to be easy to use. "When families get started," says Vanessa, "they really get into it. Patients and families are benefiting in all the ways we had hoped." Instead of fielding dozens of individual emails and phone calls, patients and caregivers post updates for invited family and friends. The Lend a Hand section makes it easy for caregivers to ask for help. A guestbook provides a place for them to share their love, support, stories, memories and photos.

Chelsea Mathis, Marketing and Outreach Coordinator at Hospice of the Valley in San Jose, saw a patient "use Hospice Journey to describe in detail the hospice experience for her followers and help them accept and even appreciate her dying process. One of the greatest benefits of Hospice Journey for her was the outpouring of messages of support and love from her followers. She said it was like being sainted."

The Reflections section with its questions to spark contemplation and discussion "gives patients the opportunity for life review -- to say the things that are so valuable to say and come to a peaceful place before they die," says Vanessa. Teri says, "One of the tragedies of sudden death are the things

left unsaid which make grief worse. Hospice Journey facilitates sharing and creates closure for the patient and family members.”

The Resources section provides information about hospice care, allowing friends and family to become more knowledgeable and comfortable with the patient’s situation. Vanessa says, “The main focus of Hospice Journey is to support patients and families, but we also want to educate the friends and families about hospice care and provide a way for them to support the hospice through donations.”

To learn more about Hospice Journey, please visit their website at <http://www.hospicejourney.org/>.

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