

## Caring for husband inspires nurse practitioner to improve hospice education



*Dane Potter and Wenny Lee knew from their first meeting that they were meant to be together. Experiencing Dane's terminal brain cancer and his subsequent hospice care changed the way the nurse practitioner approaches life – and the care she provides her patients.*

When Wenny Lee first met her future husband, Dane Potter, she says the chemistry was undeniable. “We just knew we were going to be together,” Wenny says. After about a year of a long-distance relationship, by fall 2018, they were finally together in Santa Clara. They were married the following March.

What they didn't know was that this future would be cut short by an aggressive form of brain cancer, glioblastoma multiforme. Dane was diagnosed just as the pair started their delayed honeymoon in December 2019. Wenny, who was working as a hospice nurse practitioner, remembers, “I knew what his diagnosis meant – it was devastating.”

Her professional knowledge suddenly became personally invaluable as she

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## Nonprofit care: Putting patients over profit

When two San Mateo residents founded Mission Hospice in 1979 as the area's first nonprofit hospice, hospice care in the US was still new. Across the nation, nonprofit, community-based care grew, supported by volunteers who wanted to offer compassionate comfort for those in the last phase of life.

As hospice care became more accepted and Medicare began covering it, the number of hospice agencies increased dramatically. In the last two decades, there has been a huge shift: growth has been almost entirely from for-profit operations. Many nonprofits have been purchased by for-profit owners. Others have simply closed. Today, only about a quarter of hospice agencies across the nation are nonprofit; in California, that number drops to 9%.

This has huge implications for patients, families, and their communities. Studies show a large gap in the level and kind of care provided by nonprofit hospices and for-profit companies, who have incentives to cut labor costs and select patients for whom care is less expensive.

Because of their missions and community support, nonprofit hospices can prioritize patient needs rather than insurance reimbursements. Similarly,

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**Nonprofit hospices offer services that go above and beyond** what Medicare reimburses, including:

- Transitional care for patients not ready for hospice
- More frequent visits by a hospice physician or NP
- Volunteers trained in complementary therapies that improve quality of life, such as massage and healing touch, music and pet therapy
- Free/affordable grief counseling for the community
- Community education and caregiver support

# Spiritual Counselor Paul Fullmer comes home to Mission Hospice

Becoming a spiritual counselor with Mission Hospice might have seemed preordained for Paul Fullmer. Both of his sisters and his parents work or worked in medical care; his mother Ruth was an RN Case Manager with Mission Hospice for more than a decade before retiring in 2021.

Instead, Paul's goal was to serve as a chaplain at a small liberal arts college, something he did in Pennsylvania for 12 years – and loved. But as his folks aged, he wanted to return to the Bay Area.

He thought working in spiritual care for Mission Hospice would be a good fit, as he saw parallels to his work on campus. "College students – like patients at end of life – are at a turning point. So they are asking some of the same questions as they are rethinking their self-worth, re-evaluating their beliefs."

However, despite being an ordained minister with a PhD in Biblical Studies, he needed an additional year of Clinical Pastoral Education (CPE) in order to provide spiritual care in a health care setting.

So Paul shifted his sights, and in 2019 he took a role as our volunteer coordinator, working with Craig

Schroeder and Constance Sweeney to train and manage our direct care volunteers. Meanwhile, Paul was accepted into Stanford's CPE program, a year-long interfaith program of professional education that includes intensive reading, reflective essays, and clinical rotations at the hospital.

reason – including the pandemic – and our presence can help reconnect them to a source of spiritual support."

"There's a great value for chaplaincy even apart from traditional religion, through emotional support" he says. "We offer the power of listening and of being present. People can really open up



*Paul often sings with Eddy and other patients as a way of soothing their souls.*

The reflections "help you understand yourself and who you are – and how that impacts your patient care," Paul says. "It's life-changing, and it benefits all of your relationships."

As it turns out, just as Paul was graduating, Mission Hospice had an opening for a spiritual counselor, and he's grateful to be back.

He says his experience in the volunteer department is useful in his new role. "Sometimes I will be praying or singing with a patient or family member, and I know that I can transfer that role to one of our amazing volunteers so that I can devote time to the next patient."

Those connections with patients matter most to Paul. "Sometimes people have become disconnected from their faith community for some

and share in amazing ways at end of life. I love hearing their stories and wisdom."

While Paul's life is filled with his new career, continuing care for his father, and spending time with his daughter and his partner, he somehow finds time to play piano and guitar, and sing.

He is also dedicated to his study of Chinese culture and Cantonese, studying one character each morning (and considering it "a kind of mantra" for the day). He says that while he's not yet fluent, he knows enough Chinese language to introduce himself to families, and finds that a useful way to start connecting. And he feels like it's working; as a patient recently told him, "I really don't like religious people, but I like you!" 🐼

## Our spiritual counselors:

- Help identify sources of spiritual nourishment
- Support all cultures and beliefs
- Explore the meaning and purpose of life
- Assist with healing relationships, facing fears, and overcoming regrets
- Offer music, meditation, visualization, blessings, or prayers, when appropriate
- Arrange for religious sacraments or personalized ritual, if desired
- Officiate at funerals and memorial services, as requested

## Caring for husband inspires nurse practitioner personally, professionally... *continued from front*

supported her new husband through his final months. The experience changed her in ways she couldn't have predicted.

"He wanted treatments and I supported him, but I knew we had only months left. Because of my training, I asked him what his wishes were as he inched toward the end of his earthly journey. I knew that if I didn't find out what he wanted, it would leave me with tremendous heartache and guilt. Being able to do that brought me peace."

Dane didn't want to receive care from the hospice where Wenny was working, so she asked his doctors at UCSF – and they recommended Mission Hospice.

"Within about four hours of the time I called Mission Hospice, I was on a Zoom call with Dane's entire team: Dr. Gary Pasternak, RN Christopher Kelly, Social Worker Tracie Pyers, and Spiritual Counselor Gloria Thomas.

"I felt the trust and partnership from the very beginning. In addition to caring for Dane, they helped me deal with family matters, through the advanced dementia Dane suffered at the end, and to start grieving and healing even when Dane was alive. It was an amazing team."

Together, Wenny and her Mission Hospice team kept Dane comfortable in their home until his death on September 4, 2020. Wenny says, "Dr. Pasternak promised me we would partner to take care of Dane. He delivered. I learned so much, professionally and personally, from him."

"I learned so much from the whole journey," she says, "and I'm able to apply that both to my work and to my personal life." A lifelong learner, Wenny also found ways to channel her energy to help others.

Dane was an avid bicyclist. After he passed, Wenny started riding to cope with her grief – and was hooked. Inspired by Dane, who she says was the kindest person she's met and "would do anything to help others," she recently organized a bike ride to raise funds and awareness for brain cancer and hospice.



*Wenny (in red helmet) recently organized a bike ride in Dane's memory, to raise funds and awareness for brain cancer and hospice. The group, which included Dane's Mission Hospice physician Gary Pasternak (second from right), started at the cemetery where Dane is buried. "It was a gorgeous ride," says Wenny, "and I felt so honored that Gary was able to come."*

The experience also changed her professionally. "Dane's journey gave me so much professional perspective," Wenny explains. "Now when I talk to patients, I hold a lot more compassion. I don't share my personal story with patients, but they recognize that I truly understand."

"When my patients need hospice care, I refer them to Mission Hospice. I know my patients will get the most support from your amazing team."

A vibrant, cheerful presence, Wenny is truly looking to the future, guided by what she learned from her journey with Dane.

Among her new professional goals is to improve education around end-of-life care. She wishes medical students had rotations for hospice care, and she plans to apply to medical school in the next few years with an eye to eventually teaching medical professionals.

Upbeat and energetic, Wenny in the meantime is busy supporting others. She moderates three worldwide Facebook groups for spouses/caregivers and bereaved spouses dealing with brain cancer. In July, she'll be speaking at a widows' conference, Camp Widow.

"I hope that by sharing my story, even though it's still evolving, I can let those who are grieving know that they have permission to be ok, to be happy, to be hopeful, and to be joyful." 🍌



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Mission Hospice & Home Care serves patients and families in the San Francisco Peninsula and South Bay with personalized, compassionate end-of-life care and education. Founded in 1979, our local, independent nonprofit has supported thousands of patients and their families through illness and bereavement. Donations from the community support our exceptional care and educational programs, and help us serve people regardless of their medical coverage or ability to pay.

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**Nonprofit hospice care... continued from front**

nonprofit hospices can care for patients who are uninsured, or whose insurance doesn't cover the full cost of care.

Donors allow nonprofit agencies to provide more visits - nursing, social work, and therapy - and support more patients with intensive or specialized needs.



Nonprofit hospices can offer many extra services that Medicare doesn't reimburse, including hospice houses and transitional care for patients who are not ready for hospice. Our Transitions care helped Ruben Valencia (above, in chair) remain at home with his family.

To stay competitive, nonprofits are creating alliances like the California Hospice Network (CHN), which Mission Hospice co-founded in 2019. The network leverages economies of scale, collaboration on expertise and best practices, and contracting negotiations to support exemplary, community-based hospice care.

Like Mission Hospice, other CHN members offer unreimbursed services and programs that families in their communities need, including caregiver training, support for advance care planning, youth grief camps, community workshops, and education for professionals and interns.

While many factors go into the decision to begin hospice care, the power to choose is yours. With a physician's referral, you can start hospice care and select which agency you want to provide that care. You are free to stop hospice care at any time. While a physician may refer you to a particular hospice provider, you can always ask for a different organization.

Mission Hospice remains committed to the vision of our founders - that every person in our community has access to exceptional and compassionate end-of-life care. With financial support from our community and the partnership of the California Hospice Network, we intend to provide this care for decades to come. 🍂