

CARE BEYOND CURES

A family turned to Hospice of Petaluma to help their 14-year-old daughter die with comfort and dignity



Rosie DeMarco's hospice nurse, Paul Woodworth, R.N., didn't stand stone-faced and reverent at her bedside during the last days of her life. Rosie would never have put up with that. When Woodworth came to her home, he cracked jokes and

chatted up the 14-year-old as he administered morphine to quell the pain of her end-stage cancer.

"He didn't act like he was visiting because Rosie was dying of cancer, and that's what she needed," says Rosie's mom, Pam. "Rosie thought she was going to beat the cancer right up until the end, and he kept that hope for her."

The Hospice of Petaluma staff handpicked Woodworth to care for Rosie because they knew he was the right fit. "The hospice people listened to what our needs and goals were, and they respected how we operate as a family," says Pam DeMarco.

St. Joseph Health System—Sonoma County's hospice and palliative care services—the James B. and Billie Keagan Palliative Care Center, Memorial Hospice and Hospice of Petaluma—have helped thousands of people like Rosie close out their lives with comfort, compassion, and dignity. This hospice care reflects the values of the Sisters of St. Joseph of Orange not only because there

is no charge to the patient but also because it is delivered with such concern for an individual's needs—and respect for how he or she chooses to end life.

"We make sure that the people we care for know that they matter," says Judy Ryder, director of Memorial Hospice and Hospice of Petaluma. "This is a sacred time in their lives, and we want to provide the best care possible so that the time they have left is the best it can be. To that end, we'll address whatever people need that's related to the dying process."

Rosie's Story

Pam DeMarco describes her daughter as "an old soul" because of the way she handled herself throughout her battle with rhabdomyosarcoma, a rare soft-tissue tumor that strikes children. "Rosie was special, and she never complained," says DeMarco. "Her best friend lost a sister to cancer, and then her mom got breast cancer, and Rosie didn't want her friend to have to deal with another tragedy. That's who Rosie was: She was dying of cancer yet worrying about her friend. . . . She was the type of girl who went to school dances and danced with all the awkward guys along the wall because she wanted them to have a good time, too."

Throughout the course of her ordeal, Rosie asked for normalcy. She refused special trips and presents, and went to school as a



After her experience with hospice care during her daughter's battle with cancer, Pam DeMarco decided to become a hospice volunteer to help others deal with the death of a loved one.

regular eighth grader, earning straight A's. Her mother and father administered much of her health care, but when her condition worsened in late May 2003, her mother called Hospice of Petaluma for assistance. Instead of long, taxing trips to San Francisco for treatment, a hospice nurse would come to the DeMarco home to make assessments and provide pain management.

A Range of Hospice Services

Hospice care varies among patients, depending on what hospice workers learn during the initial assessment. Some patients in the last months, weeks, or days of their lives need only physical care, such as administering pain medications. "Everything our nurses do is under the direction of the attending physician," adds Ryder. A patient with end-stage lung cancer, Alzheimer's, or heart failure

can receive hospice care at a skilled nursing facility or a hospital, but most people utilize hospice services in order to die in the comfort of their home, surrounded by family.

In this setting, hospice volunteers may assist home health aids with duties such as bathing or house chores. Hospice social workers can help with financial organization, funeral planning, and psychological counseling, and hospice spiritual care coordinators can provide spiritual support and companionship.

After Rosie passed, on June 3, 2003, her mother accessed Hospice of Petaluma's grief support groups and found a therapist through them as well. Now she has completed training as a hospice volunteer. "Being with someone when they pass is just as special as when they're born," she says. "I don't want people to die alone. I know I can help make it easier for them. This feels like my passion."

Don't Hesitate to Call

Deciding to contact a hospice service is never easy. But Judy Ryder, director of Memorial Hospice and Hospice of Petaluma, hears over and over again from families who say, "I wish I had called sooner" to access hospice care and support. "Just call us to ask ques-

tions and see how we can be of support," she says. "A call doesn't mean you have to commit." For more information on our services, call Memorial Hospice in Santa Rosa at **(707) 568-1094** or Hospice of Petaluma at **(707) 778-6242**.