

Die Like *You Live*

**Nonprofit hospices in Northern California
are helping people make the most
of the time they have left**



So Let's Talk About It Now.

BY RODNEY OROSCO

**"Hospice care doesn't
mean you're giving up."**

Alison Kent
Yolo Hospice Community Partner

“We have a long way to go,” Kent said. “Hospice care doesn’t mean you’re giving up — you’re giving yourself and your loved ones permission to talk about the life you have left.”



The diagram illustrates the progression of care focus over time. The vertical axis represents 'Focus' and the horizontal axis represents 'Time'. A dashed diagonal line separates the blue area (curative care) from the red area (palliative care). The red area is divided into 'Hospice (last 6 months)' and 'Death and bereavement care'.

Eyes --- Wide --- Open

Artist can focus on creating during her final months, thanks to Collabria Hospice

BY MICHELLE CARL

Following an illness last year, Margaret Keane McGuire feared she'd never paint again. After going on hospice, her condition has improved, enabling her to paint every day.
PHOTO BY ANNE STOKES



After a bout of pneumonia in October 2017, Margaret Keane McGuire became bedridden and almost died. Worse, she couldn't paint.

Her daughter and son-in-law, with whom she lives, moved her massive artist's table out by the garage, fearing Margaret would never use it again. For the artist who has been scribbling faces on paper since the age of 3, not being able to create felt like the end.

Margaret's paintings of "big-eyed waifs" fascinated art lovers in the 1960s — although nobody knew it was her doing the painting. At the time, her then-husband Walter Keane took the credit for her internationally acclaimed artwork. Fearing her husband's threats that he would hurt her, Margaret kept the deceit a secret. When the truth finally came out in a 1986 court case, it shocked the art world. The story would later become the 2014 movie "Big Eyes" starring Amy Adams and directed by Tim Burton.

Following her illness in 2017, Margaret's doctor diagnosed her with pulmonary hypertension and referred her to Collabria Hospice. He thought it would help ease the symptoms of her condition, including fatigue, trouble breathing and anxiety from inability to get enough oxygen.

Margaret had fears about going onto hospice.

"At first I was very scared of it," she said. "I thought this means the end, and I don't want that."

But once she started receiving weekly visits from her Collabria Hospice team, her condition

greatly improved. She was given medication to ease her anxiety. Her social worker found an in-home caregiver who brought peace to the home. These days, Margaret enjoys going outside for short walks and feels the warmth of the sun. Her nurse gently stretches her hands so they don't get swollen from drawing all day.

"They make it easy for me to do what I love to do," Margaret said. "I have time to think, be creative, and to study the Bible. They've just enriched my life tremendously in every way."

Now Margaret is living the rest of her life with wide-eyed wonder. She said she can't wait to get out of bed each morning to go to her artist's table and draw.

Her current artwork uses mixed media — pens, colored pencils and acrylic. She sketches flowers, cats and, of course, her signature portraits with the big eyes.

"She has so many ideas she wants to do. ... She doesn't like taking naps or

taking a break — she just wants to work on her art all the time," said her daughter, Jane Swigert. "I'm just amazed how she's gotten so much better after she went on hospice. Her passion is her art. As long as she can be well enough to do that, she's happy."

Margaret is glad more people are discovering her art thanks to the movie, and she's glad she has the ability to create even more of it.

"Every day of life is precious. Being able to paint is so rewarding," she said. "It's wonderful to be alive."

**"They make it easy
for me to do what I
love to do."**

Margaret Keane McGuire
Artist and hospice patient

BETTER OUTCOMES FOR PATIENTS

What would you do with 29 more days?

That's how much longer hospice patients live, compared to those who don't go on hospice. Here are some other reasons why going on hospice (and starting it early) provides better outcomes for patients:

Patients who report being given medication to manage pain symptoms

91%

Hospice
Patients

vs.

81%

Non-Hospice
Patients

Patients who report they have had their end-of-life wishes fulfilled

80%

Hospice
Patients

vs.

74%

Non-Hospice
Patients

Source: "Family Perspectives on Hospice Care Experiences of Patients with Cancer," *Journal of Clinical Oncology* (2017)

Supporting Patients' Best Quality of Life -----+

Hope Hospice doctor says starting palliative or hospice care early benefits patients *and* their loved ones

BY ANNE STOKES

Before meeting new patients, Dr. Kuljeet Multani, associate medical director for Hope Hospice takes a moment to clear her head before entering the room.

"I tell them, 'I want to hear *your* story from *you*. I can look at your diagnosis, but I'm not treating your diagnosis. I'm treating you as a person,'" she said. "There is so much more to a patient as a person than just being a patient."

Dr. Multani's holistic approach addresses patients' medical needs alongside their emotional, psychological and spiritual ones. Her aim is to provide the best quality of life possible and to support them and their families through their journey. The more time patients spend in palliative or hospice care, the more time they have to create a plan for issues like pain management and advanced directives. Families and caregivers have more time to prepare for what's to come.

She recalls one patient who was referred to her for palliative care several years ago. The elderly patient was experiencing excessive pain during regular and necessary procedures, so together they created a pain management plan and shared it with her other doctors. "She started to do really well," Multani said. "About two years ago I got a letter from her daughter and she said, 'I want you to know that Mom recently passed away, but the plan that you had for her three years ago helped us so much in planning with the rest of the doctors about how the rest of her life was going to be.'"

While there are clear benefits to timely palliative and hospice care, Multani said these services are

"Most patients think hospice is about the last few days of life, but hospice is actually caring for patients' comfort in the last few weeks to months of their lives."

Dr. Kuljeet Multani

Associate Medical Director, Hope Hospice

underutilized because doctors aren't referring patients soon enough. She pointed out that many medical school and residency programs lack comprehensive coursework in end-of-life care. And while modern medicine provides many treatment options, oftentimes physicians are reluctant to tell patients that "no further treatment" can be a valid option. Doctors are also hesitant to relinquish control of their patient's care, she said, especially when they have a long-term history together.

"The fact is that patients die when they're supposed to die, even in hospice and palliative care," she said. "Most patients think hospice is about the last few days of life, but hospice is actually caring for patients' comfort in the last few weeks to months of their lives."



Dr. Kuljeet Multani, associate medical director at Hope Hospice, helps her palliative and hospice patients to have the best possible quality of life.

PHOTO BY KATE HOLTZEN

AN IMPORTANT CONVERSATION

No matter the situation, bringing up palliative or hospice care options can be a difficult conversation. Here are some questions to help patients and caregivers approach the subject with doctors.

Questions to ask your doctor

- 1 How do you think I'm doing? Do you think I'm responding well to treatment?
- 2 What happens to most patients with this diagnosis?
- 3 Do you think palliative or hospice care would be the best course of action for my condition?
- 4 Can you give me a referral for a palliative or hospice assessment?
- 5 Can you help me complete my advanced care directive documentation?

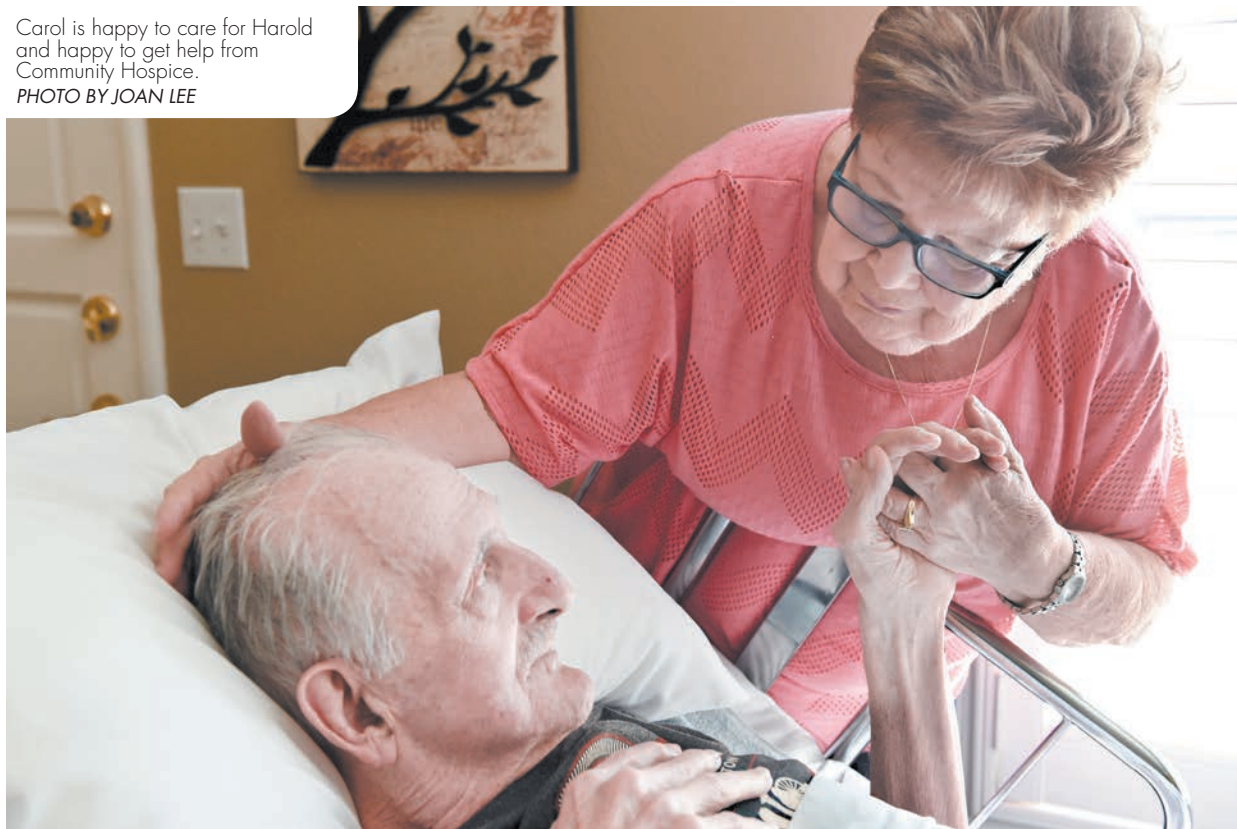


Helping You Be There for Them

A wife is grateful for Community Hospice as she cares for her husband

BY RODNEY OROSCO

Carol is happy to care for Harold and happy to get help from Community Hospice.
PHOTO BY JOAN LEE



It was easy when Harold could still walk. “I could secure him in the car and we would go shopping,” explained Carol Docter, a Modesto native. “He could help push the cart, mostly.”

But Carol’s bit of independence ended when Harold’s frontal lobe dementia advanced to the highest stage — severe cognitive decline.

Harold was in his late 50s when the dementia first appeared. By the time he was 61, Harold was taking medication to stabilize his condition and slow down the dementia.

“The medication really didn’t help,” Carol said.

Eventually, Harold had trouble swallowing. One day, he choked on some food and was taken by ambulance to the hospital, where he developed pneumonia.

At his discharge, the hospital suggested the now-bedridden former truck driver consider hospice care.

It was some of the best advice Carol ever took.

“Community Hospice came alongside me to help Harold, admitting him onto services and providing him medical equipment promptly to get Harold home,” Carol said. The care didn’t stop there.

Nurses from Community Hospice in Modesto visit Harold a minimum of once a week; a hospice aide bathes him three times a week; and a hospice chaplain and social worker visit and keep in touch with Carol routinely.

“I don’t know how I would survive without them,” the 75-year-old said. “I can prepare his meals — he gets all his food pureed — but I could never bathe him

or turn him over in his bed and change his sheets.”

Harold, now 76, has been on home hospice care for 12 months. He is re-evaluated on a routine basis to determine if hospice continues to be appropriate.

“A lot of my prayers were answered with Community Hospice,” Carol said.

One answered prayer came when hospice staff offered respite care services for Harold. These services allowed Harold to go to Community Hospice’s Alexander Cohen Hospice House, an inpatient hospice facility, for a short stay, providing Carol a much needed break.

"I don't know how I would survive without them."

Carol Docter
Wife and caregiver

“The respite care is awesome and I know they love him at the hospice house,” she said.

Carol is grateful for the help and empathy she has received from hospice care. She knows it has made a difference for both her and Harold.

“I know my Harold is content. He is ready to go when the time is right for him,” she said.

NONPROFIT HOSPICES PROVIDE HOLISTIC CARE

Nonprofit hospices provide a wider range of services and supports in order to fulfill patient needs.

Physical services

- Nursing care for the patient
- Medication management (for pain and other symptoms)
- Medical equipment (hospital beds, wheelchairs, etc.)

Social-emotional services

- Family counseling
- Patient counseling (to process grief and provide a sense of completion)
- A trained volunteer to provide companionship
- Respite services so caregivers get a break

Spiritual

- Spiritual care support
- Someone to share thoughts and concerns
- Support is optional and available for non-religious patients as well



Comforting Families

Kevin Barry found Hospice East Bay's grief counseling a necessary part of grieving

BY RODNEY OROSCO



Kevin Barry and his 13-year-old grandson Colby continue to benefit from services provided by Hospice East Bay after his wife's death in 2017.
PHOTO BY KATE HOLTZEN

That October morning, Kevin and Cecilia Barry turned their breakfast conversation to more serious matters.

"Honey, think about all the people," Kevin Barry remembers pleading with his wife of 29 years, affectionately known as Cece. "They are going to want to honor you. Let them."

At that point, Cece's stage IV ureteral cancer had already spread throughout her body. Although a spiritual person, Cece didn't want a solemn funeral or mass to mark the end of her life. However, after discussing it that morning over breakfast, Cece agreed to have a celebration of life.

"I told Cece it was for all the people who loved her," he recalled, his voice stuttering with emotion.

Then Kevin, her high-school beau, helped her upstairs. Cece's cancer-wracked body collapsed before she made it halfway. Kevin carried her to bed and called for help.

"I called the hospice workers immediately and they were there in minutes," he said.

Cece Barry died in her husband's arms at 7 a.m. the next morning. Three weeks later, 250 people would attend Cecilia Barry's celebration of life.

Barry said the event lifted the hearts of all who attended.

Hospice care did not end when Cece died. Hospice East Bay, like many nonprofit hospices, offered grief care for Kevin and his family.

Kevin attended one-on-one counseling after his wife's death and then 10 weeks of group counseling. He also attended drop-in sessions. All were offered free through hospice as he continued to process his grief.

"When grief is tearing you apart, hospice caregivers are a godsend."

Kevin Barry
Husband who lost wife to cancer

"I keep coming home to an empty house," Kevin said.

The couple's 13-year-old grandson and daughter Lauren also went to grief counseling. "Hospice East Bay offered a group program for children," Kevin said. "He looked forward to it."

While Kevin was extremely happy to have hospice care for Cece, it was only after her death that he most felt the empathetic embrace of hospice care.

"When grief is tearing you apart, hospice caregivers are a godsend," he said "For everything they do, they are like angels on earth."

HOSPICE FAMILY SUPPORT

The following are services typically offered through nonprofit hospice providers for family members.

Grief support

These ongoing groups meet regularly to provide support for those who are grieving the death of someone close to them. They are often offered to anyone in the community, free of charge.

Youth programs

Many nonprofit hospices offer support to children and teens through art, play, talk and peer support. Families may attend for as long as needed.

Respite care

This program allows caregivers a break by moving the patient to a hospice house for a few days, where the patient receives the same excellent care.

Estate services

Some hospices provide services that help families liquidate the estate. An estate liquidator will determine the value and scope of the cleanout, will inventory all items for donation, and schedule a cleanout date.





Rosendo Ortiz and Social Worker Josie Minor cared for Enrique Diaz, who passed away last year. Enrique had no insurance and no family to care for him, so his housemate Rosendo and the nonprofit Hospice of San Joaquin were able to provide him with a dignified end.

PHOTO BY JOAN LEE

NOT ALL HOSPICE PROVIDERS ARE THE SAME

Study after study has shown that **nonprofit hospices provide better quality care**. A 2015 Yale University study found that for-profit hospices fall short in quality, depth of support and how much they spend on nursing per patient.

For-profit hospices are driven by a desire to make money — the more, the better. Nonprofit hospices are driven by their mission — to provide compassionate end-of-life care, said Craig Dresang, Chief Executive Officer of Yolo Hospice.

“For-profit hospices can cherry-pick their patients,” Dresang said recently. “We, the nonprofits, will take homeless patients or those who would be deemed high-cost, complicated patients.”

Dresang said patients must be educated consumers when choosing a hospice.

“In for-profits, it’s typical for nurses to carry case loads of 20 to 24 patients each,” Dresang said. “Nurses in nonprofits tend to carry case loads of 10 to 14 patients each, so they’re able to spend more time with patients and address patient needs.”

'Angels' ----- Among Us

A caring friend and Hospice of San Joaquin provide care to a dying man who couldn’t pay for it

BY EDGAR SANCHEZ

For decades Enrique Diaz toiled under the California sun, doing farm labor. An undocumented immigrant for 50 years, when he wasn’t at work he lived in the shadows.

When Diaz retired in 2010, he had no Social Security benefits, no work pension, no medical insurance, no bank savings, no known family to care for him.

And yet, despite being destitute, Diaz died with dignity in a Stockton nursing home on Nov. 13, 2017. He was 82.

His friend Rosendo Ortiz and social worker Josie Minor saw to it that Diaz received hospice care — in his Stockton home and elsewhere — as he battled leukemia, a respiratory ailment and other afflictions.

“Enrique was content with his simple life. He had a peaceful ending,” Minor, of Hospice of San Joaquin, said recently.

According to Ortiz, his friend never sought “a death with luxuries.”

“But Enrique didn’t want to die on the streets or under a bridge,” said Ortiz.

Minor said Diaz was aided by “angels,” starting with Ortiz, who cared for the sickly man for months, without compensation.

The other angels: good Samaritans who allow nonprofit hospices like Hospice of San Joaquin to serve the poor.

“I’m very proud that my agency, a nonprofit, is able to provide services to everyone, including the

uninsured,” Minor said. “Families who receive hospice are very appreciative. So they make contributions for indigent cases.”

Diaz and Ortiz — both Mexico-born — first met in 2000. At the time, Diaz lived in a rundown home, sharing expenses with co-tenants.

When Ortiz moved into that home in March 2016, Diaz was no longer working and could not contribute to the rent. Ortiz and another housemate split the monthly \$400 rent and shared their meals with Diaz. Other friends would visit, handing Diaz a few dollars each time. By mid-2016, Diaz’s health was

so poor, Ortiz became his full-time caregiver. He cooked for him, bathed him, and performed other tasks, even though he also worked a full-time job.

In October 2016, Diaz’s condition worsened and he was hospitalized. He was then transferred to San Joaquin’s Hospice House. That day, Minor became Diaz’s social worker.

Two months later, Diaz returned to his residence with new accommodations. For the first time,

he had access to an in-home oxygen tank and comfort medications thanks to a treatment plan established by his hospice team who visited him frequently.

Diaz enjoyed living at home for several months before moving to a nursing home with hospice services, which is where he died. He is fondly remembered by those who knew him, who are grateful that he had comfort at the end of his life.

“He died happy,” Ortiz said.

"Enrique didn't want to die on the streets or under a bridge. He died happy."

Rosendo Ortiz

Friend of Enrique Diaz

Not All Hospices Are the Same

When you have a life-limiting diagnosis, you want to make the most of the time you have left. Hospice and palliative care put patients in charge of how they want to live — what kind of care they receive and when they receive it. Hospice providers align that care to match the patient's end-of-life goals.

Starting hospice or palliative care early allows for even better outcomes for patients. But not all hospices are the same. Nonprofit hospices have been shown to provide better quality care because their mission is to support patients — not to make profits.

If you or a loved one is facing the end of life, you have a choice — make sure to ask for a nonprofit hospice provider in your area.



NONPROFIT HOSPICE COALITION OF NORTHERN CALIFORNIA

This educational publication was brought to you by these members of the **Nonprofit Hospice Coalition of Northern California**, which believes that increasing awareness about hospice care can strengthen families and replace the fear and anxiety associated with the end of life with comfort and peace. For more than 10 years, this pioneering group of 20 independent hospice and palliative care organizations has collaborated on improving care by sharing best practices and strategies for improving services. With combined budgets of \$250 million, they serve an area of 30 counties with a total population of 13.7 million people.



**Nonprofit Hospice
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