

Write the End of Your Story

**How Palliative Care
is redefining treatment
and comfort for
life-limiting diagnoses**

The Palliative Care Movement

Annemarie Hargadon, M.D., is the medical director of outpatient palliative care at Yolo Hospice.
PHOTO BY ANNE STOKES

YOLO HOSPICE: A LEGACY OF CARING

This educational publication is brought to you by Yolo Hospice in collaboration with editorial coverage by N&R Publications. Yolo Hospice believes that sharing its knowledge can strengthen families, replacing fear and anxiety with confidence and even peace.

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About Yolo Hospice

- » Among the first established hospices in California and the only organization in the Sacramento Valley that is a member of the highly esteemed National Partnership for Hospice Innovation
- » Plays a unique role as a crucial safety net for the most vulnerable patients with advanced and chronic illness in the communities they serve
- » Ensures the comfortable and dignified last phase of life to which every American is entitled
- » Serves Colusa, Sacramento, Solano, Sutter and Yolo counties

Medical professionals are re-writing the concept of end-of-life care

BY GAIL ALLYN SHORT

When experiencing a life threatening illness like cancer, kidney failure or emphysema, the pain, discomfort and stress that come with such conditions and their treatments can leave a patient in despair. But one emerging medical specialty aims to give patients a better quality of life and more control — a way to have a voice in how they want to live the rest of their days. Palliative care allows for this by relieving patients' physical pain while meeting their emotional, psychological and spiritual needs.

"Palliative care is a system of support for patients and their families dealing with serious illnesses, whether they are pursuing advanced treatment or focusing on comfort care," says Annemarie Hargadon, M.D., medical director of outpatient palliative care at Yolo Hospice.

While similar to hospice care, which serves terminal patients with up to six months to live, palliative care can start from the time of diagnosis and last through the course of treatment. Moreover, patients undergoing palliative care do not have to be terminally ill.

Easing pain and suffering is hardly a new concept in caregiving. As medical technologies have advanced, patients today live longer with chronic conditions that once caused death in just days or weeks. But living longer is not necessarily living better. Some in the medical community began to see the physical and emotional costs of preventing a natural death. So began the palliative care movement of the 1960s that believed more could, and should, be done beyond what was possible in a traditional health care setting.

Hargadon says most primary care physicians practice some form of palliative care. But when patients are seriously ill, palliative care specialists can help patients sort out their options for treating their

disease while managing symptoms and articulating their goals for living out their days.

"When people are really struggling with their illness and their families are struggling," says Hargadon, "primary care doctors and hospitalists often don't have the time that it takes to really sit down and be with that person and their family and figure out what are the next steps to match treatments to that person's goals for care."

Jeffrey Yee M.D., who practices palliative medicine for Dignity Health Medical Foundation in Woodland, says medical schools have only recently started giving students formal training in palliative care. It comes at a time when patients are more knowledgeable about health and less shy about asking doctors questions than past generations.

In fact, Yee says that asking questions like "How will the treatment affect me?" "What will I be like after the treatment is complete?" "What are the biggest complications that I need to worry about?" is encouraged.

"Patients should be empowered to explore these things for their health," says Yee, "and we can improve our ability to allow patients to express their concerns."



Palliative (pal-lee-uh-tive):

An approach to care that improves the quality of life for patients with life-limiting diagnoses by aligning an individual's values and goals with the care they receive.

Palliative care:

- » encourages planning ahead and documenting wishes in an advance care directive
- » allows for treatment early in the course of an illness
- » eases pain associated with physical ailments
- » addresses emotional and spiritual needs
- » recognizes that dying is a normal part of life

Finishing Her Story

Hospice patient shares how she chooses to live her final days

BY MICHELLE CARL

Alouise Hillier is not what you think of when you hear the words “hospice care.”

The 96-year-old feels good. She swims in her senior apartment complex pool every morning. She then returns to her apartment, where she sits in a comfortable chair and watches TV, usually “Downton Abbey” — she’s on her third viewing of the series.

“I love it! Each time I see something I haven’t seen before,” she says excitedly.

But Alouise is, in fact, a hospice patient with Yolo Hospice.

“I have received so much care and attention,” she says. “I haven’t felt sick — I feel almost guilty about taking their services.”

In January 2017, Alouise was told her chronic conditions had become serious. She was also diagnosed with an abdominal tumor that was growing rapidly. She’s refused exploratory surgeries and X-rays that would give her doctors a better idea of the tumor’s size and progression.

“What good would it do?” she asks.

Alouise has seen peers suffer from cancer and the “horrible” medications that lead to hair loss and weakness during treatment. “I don’t want to live as a helpless invalid,” she says.

Instead, she sought help from YoloCare, the palliative care division of Yolo Hospice, which provided services to her husband before he passed away in 2002.

When she first went on palliative care, she received quite a bit of company: Nurses, spiritual care counselors and social workers each visited her to explain their services and get to know her needs. After Alouise mentioned that she struggled to walk from the car to a community concert, her nurse helped her get a wheelchair and a new walker. These devices help her use less energy getting places, so she

can spend more energy doing what she loves, things like listening to classical music concerts from the American Bach Soloists.

At the end of January, her palliative care team and her primary care physician discussed her advancing needs and recommended that Alouise go on hospice care. She now receives weekly visits from her hospice nurse, Ted.

“He emphasizes the fact that it’s important to get care before it becomes serious,” she says.

Following her morning swim, Alouise enjoys a therapeutic soak in the spa. “I snuggle up to the jets — you should see the crazy contortions I do. I love my aqua massage!” she says. But her contortions resulted in a shoulder sprain. It’s a sore spot that Ted has been tending to.

Before her eyesight started failing, Alouise was an avid quilter. One piece, which she and her family members worked on in honor of her 50th wedding anniversary, is a tapestry of her full life. She was a reading teacher. A wife who raised five children, including a set of twins. She has five grandchildren who gave her five great-grandchildren — all boys.

Her great-grandsons grow older in the many pictures posted on her refrigerator. Most of her family lives in Northern California, so she gets to see them often.

Alouise’s daughter Lynn Gore says hospice care has given her the ability to focus on what matters most.

“It’s just huge for me. I can’t overstate what a relief it is for me to know that she’s taken care of. That I don’t have to worry,” Gore says. “All I have to do is enjoy my mom.”

Hospice patient Alouise Hillier, 96, poses in front of a quilt that was made in honor of her 50th wedding anniversary that recounts many of the events of her life.
PHOTO BY ANNE STOKES

“I don’t want to live as a helpless invalid.”

ALOUISE HILLIER
Hospice patient

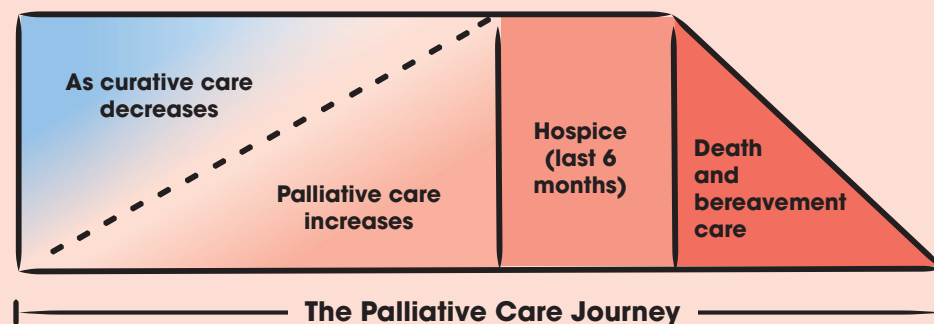


A BETTER WAY: PALLIATIVE CARE

Palliative care results in a whole host of benefits to patients and families including:

- » Improved quality of life
- » Better symptom management
- » Provides care in a home-based setting
- » Fewer hospital admissions and ER visits
- » Improved survival rates vs. patients who seek standard treatment
- » Better satisfaction among caregivers and family members
- » Reduction in costs through utilizing quality care that results in fewer health crises

SOURCES: Family Caregiver Alliance, JAMA, Center to Advance Palliative Care



Making Choices

Would you rather seek advanced treatment or get to work on that bucket list?

BY GAIL ALLYN SHORT

Modern medical advances have allowed patients to live for years and even decades with chronic diseases that typically claimed lives within a few weeks or months.

“If you think back through the history of medicine, through medieval times and even the turn-of-the-century, doctors didn’t have many treatments that could extend a patient’s life,” says Dr. John MacMillan, a clinical professor of internal medicine at UC Davis.

Today, medical advances such as chemotherapy, bone marrow transplants and kidney dialysis may prolong a patient’s life, but MacMillan says they can have another effect: diminishing the *quality* of a patient’s life.

Chemotherapy may carry significant burden of debilitating side effects with very little chance of controlling the cancer. Treatments can also impact patients differently depending on their age: Aggressive treatments for a generally healthy person in their 50s could have different outcomes for a person in their 90s.

Doctors are not always well-equipped to help patients navigate these trade-offs. They sometimes present patients with a “do everything” plan to sustain life because in their profession, a patient’s death is perceived as failure.

MacMillan says watching patients suffer during his medical residency in the 1990s drove him to pursue a career in palliative care.

He recalls a 90-year-old dementia patient with congestive heart failure who doctors later diagnosed with Stage 4 colon

cancer. The family opted for chemotherapy, but several rounds of the treatment resulted in multiple hospital stays and kidney dialysis due to complications.

“We really didn’t talk about palliative care,” says MacMillan regarding his medical school training. “I just remember seeing patients dying in the intensive care unit and thinking there had to be a better way.”

Today, MacMillan says the emergence of palliative care has forced conversations in the medical community about the limitations of various medical advances and their impact on patients’ well-being.

MacMillan, who is also medical director for Adult Palliative Care Services and Hospice Services at UC Davis, says the role of palliative care providers includes educating patients and asking them about their values, their worries and which activities they hope to continue for as long as possible.

“Palliative care is about empowerment,” MacMillan says.

Leah Morris, a nurse practitioner and senior health policy adviser at Yolo Hospice, remembers a cancer patient who completed her treatments and chose to use her limited energy during her final days visiting loved ones, traveling and eating her favorite foods.

“She’s pursuing those things that will keep her comfortable and allow her to enjoy her family,” Morris says. “The broader impact is reducing suffering and allowing people to have joy, comfort, time with people to ask for forgiveness, to say, ‘I love you,’ or whatever they may need.”

“Palliative care is about empowerment.”

DR. JOHN MACMILLAN
Medical director for Adult Palliative Care Services and Hospice Services at UC Davis



ADVANCE HEALTH CARE DIRECTIVES: MAKING YOUR VOICE HEARD

An Advance Health Care Directive (AHCD) is a legal document that lets you specify the kinds of medical treatments you would want if you ever became unable to communicate due to your illness. An AHCD lets you:

- » Name the person you would want to make medical decisions on your behalf.
- » List the kinds of treatments and life-sustaining medical interventions, like a ventilator or feeding tube, that you would and would not want.
- » State whether you would want to donate your organs
- » Write down your wishes so that you can discuss them with your family and your doctor.

Yolo Hospice regularly holds workshops to assist participants in creating an AHCD. Visit yolohospice.org for dates and times.

Manager Nancy Johnston, spiritual care counselor Penny Adams and hospice nurse LeeAnn Shipman discuss their patients' needs.
PHOTO BY ANNE STOKES

Whole-Person Care

Patients benefit from a collaborative approach

BY GAIL ALLYN SHORT



Penny Adams is a spiritual care counselor for Yolo Hospice, providing spiritual or emotional support to patients and their loved ones. Her services can include anything from Bible reading and meditation to playing a Native American flute.

One patient simply wanted her to play a game.

“For nine months we played checkers before she asked her first spiritual question,” Adams recalls.

Meeting clients’ needs — whatever they may be — is fundamental to palliative care, and meeting the needs of the whole person often takes a multidisciplinary approach.

Spiritual care counselors like Adams are one member of a team of professionals who collaborate on providing comfort to patients on multiple levels: physical, emotional and spiritual. Studies have shown that this comprehensive approach to end-of-life care results in less suffering and better outcomes — addressing emotional pain, for instance, can alleviate physical pain.

For Yolo Hospice, the collaborative approach begins each morning when the care team meets to review and discuss patient status reports before making their rounds.

“The goal of what we do is holistic care,” says LeeAnn Shipman, a hospice nurse at Yolo Hospice. “In my job, I’m looking at the patient’s symptoms and their medications. If the patient isn’t sleeping at night, for

example, I’ll talk to the social worker so they can look at that and at the psycho-social part of it as well.”

Nancy Johnston, LCSW, who manages the social workers and spiritual care counselors at Yolo Hospice, says hospice work is often “crisis oriented.”

“We want to identify and process problems before they cause stress,” Johnston says. “If something does come up, we make visits as soon as possible, hopefully together with our nurse or spiritual care counselor, to make sure we are addressing mind, body and spirit.”

She and her co-workers recently collaborated while caring for an emotionally fragile cancer patient whose son struggled to come to terms with his mother’s impending death.

Shipman’s team made daily visits to the patient’s home. She administered medications to keep the patient comfortable. The social worker counseled family members. The spiritual care counselor spent a lot of time comforting the son. Each member of the team used his or her special talents to ease suffering and comfort the family, doing more than each could do alone.

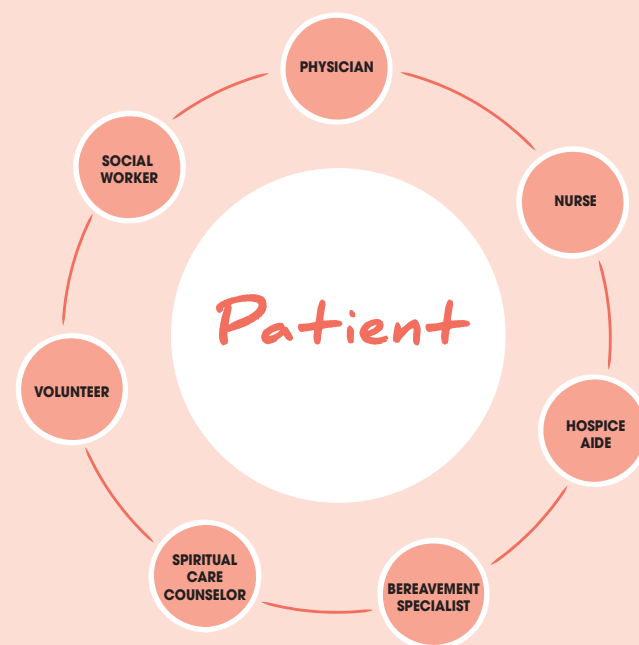
“She died peacefully in her home where she wanted to die,” Shipman says. “We worked really hard, and we cried a lot, but we did what was right for her.”

“The goal of what we do is holistic care.”

LEEANN SHIPMAN
Hospice nurse with Yolo Hospice

THE INTERDISCIPLINARY CARE TEAM

Members can collaborate to address all of a patient’s needs — medical, spiritual and emotional — leading to better outcomes.





James Petty has been able to grieve the death of his wife Lisabeth (seen here) through Yolo Hospice's Bereavement Support Group.
PHOTO BY ANNE STOKES

Healing After a Loss

BY GAIL ALLYN SHORT

Support groups give the bereaved hope

Doctors diagnosed James Petty's wife, Lisabeth, with cancer of the bile duct in 2014.

"We stopped treatment when it was no longer working, and my wife said she wanted to be in a hospice program," Petty says.

James and his son took care of Lisabeth for the last three weeks of her life.

"Right after Lisabeth died, there was a period of time when I was in shock," he says. "Pretty soon, the absence and the loneliness really set in."

A month following his wife's death, Petty says he began meeting with a bereavement support group at Yolo Hospice to help him cope with his loss.

Yolo Hospice offers a free bereavement support group for adults, which is open to the public. Nonprofit hospices like Yolo Hospice often provide services like bereavement support, even though these services are not reimbursed by Medicare. The aim is for a more complete array of care to support loved ones and patients at the end of life.

Yolo Hospice's bereavement group meets for 90 minutes once a week, and participants encourage each other to talk about the person

they lost and share what they are going through.

"For me, it's quite an effective process," says Petty, who still attends the meetings. "It's a sharing process. No one gives advice. No

"No one gives advice. No one judges. We mainly listen and share."

JAMES PETTY

one judges. We mainly listen and share. It's a loving, supportive kind of thing."

Besides the support group for adults, Yolo Hospice also hosts a support program

called Stepping Stones for children and teens who have loved ones who are deceased or terminally ill.

"Grief can be especially difficult for children," says Stepping Stones Coordinator Tracy Ojakangas. "If left untreated, grief can manifest itself in negative ways such as academic or behavioral problems."

Each week, children and teens gather in the Stepping Stones playroom to talk to counselors and express themselves through play, artwork and other activities.

Besides its grief support groups for adults and children, Yolo Hospice is also home to the Barbara Frankel Memorial Library. This lending library holds more than 700 books, magazines, pamphlets and DVDs on grief and bereavement and is open to the community from 8:30 a.m. to 4:30 p.m. on weekdays.

Petty credits his support group with helping him to become more social and reconnect with old friends both he and his late wife once shared.

"It was the encouragement not to forget, not to put things away, not to deny, but to move on, in a sense, and create a new normal," he says.

PATIENT CHOICE: FOR-PROFIT VS. NONPROFIT

Patients have a choice when choosing a hospice provider — and that choice matters. About 70 percent of hospice providers are for-profit organizations while 30 percent are nonprofits. So, how do they compare?

- » Nonprofit hospice patients are twice as likely to receive a full range of services and care than those in for-profit programs.¹
- » Nonprofits invest heavily in bedside care, provide robust bereavement programs, and offer psychosocial support and alternative therapies.
- » Nonprofit hospices are driven to provide exceptional care that meets the needs of patients. For-profits have an underlying goal to increase shareholder value.
- » For-profits spend less on uncompensated care.²
- » Nonprofits are better able to innovate and customize services for patients and the community.
- » Medicare pays hospices a flat, per-day rate to cover services like home visits, medical equipment and drugs. It does not pay hospices for bereavement counseling or volunteer services.

1: Yale University study, 2: Congressional Budget Office

DIAGNOSIS

SHOCK

- I have a life-limiting disease
- There's too much information
- Am I giving up?

WHERE DO I BEGIN?

5 Questions to Ask at Life's End

- ① What is your understanding of your disease?
- ② What are your goals and priorities?
- ③ What are your fears and wishes for the future?
- ④ What outcomes are unacceptable?
- ⑤ What would a good day look like?

FAMILY

- A source of support
- Who will take care of things when I'm not here?
- Who will be my decision maker?



MEDICAL

- Will this treatment work for ME?
- Am I getting on a "treadmill of care"? Treatment leads to more treatment – can I get off?
- Will my condition improve?

100%
Chance of
Mortality

Writing the End of my Story

Advance care Directive

I HOPE to...

- Not be in pain
- Say goodbye to friends
- Not be bedridden
- Go surfing

HOSPICE



EMOTIONAL

- Can I live better?
- I want someone to understand my pain
- Spiritual care counselor can meet me where I am spiritually



My team



PALLIATIVE CARE

You've Had an Amazing Life — Now Write the Last Chapter

The greatest gift you can give your loved ones is spelling out how you want to experience the end of your life. Yolo Hospice has been helping patients align their end-of-life goals with compassionate care since 1979. The not-for-profit community organization provides a variety of services to help patients, families and the community.

ADVANCE CARE DIRECTIVE

While it may be an uncomfortable conversation, discussing your end-of-life care with family and loved ones is important to ensuring that your wishes are understood before emergency medical interventions are necessary. Yolo Hospice can help you put your wishes into writing.

Advance Care Writing workshops:

Find a calendar of upcoming workshops that are free and open to the public at www.yolohospice.org/news-events

California Advance Health Care

Directive: A legal document that helps you choose a medical decision maker and make your health care choices known, <http://bit.ly/2o9oRWW>

GRIEF & BEREAVEMENT SUPPORT

Whether through yoga, crafting a collage of treasured photographs or talking through loss, Yolo Hospice offers a variety of support group and workshop opportunities for friends and family of all ages and stages of grief to heal in a supportive environment.

One-on-one emotional support

Barbara Frankel Memorial Library is open to the public and houses over 700 grief support books, periodicals, CDs, DVDs and pamphlets

Annual **memorial service** held in the fall honors patients who have died within the past year



RECOMMENDED READING

For further information on issues pertaining to hospice or palliative care, resources are available in these books:

- » "Being Mortal: Medicine and What Matters in the End," by Atul Gawande
- » "When Breath Becomes Air," By Paul Kalanithi
- » "Extreme Measures: Finding a Better Path to the End of Life," by Jessica Zitter, M.D.

You can also find additional resources online at:

- » **CaringBridge:** Website where patients can share their health care journey, www.caringbridge.org
- » **Five Wishes:** Online living will tool, www.agingwithdignity.org
- » **National Hospice and Palliative Care Organization:** www.nhpco.org

www.yolohospice.org

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800-491-7711