

At UCLA Health, End-of-Life Programs Honor and Comfort Dying Patients, Ease Grief and Stress for Families and Clinicians

By Audrey Doyle

When a patient is dying in a hospital intensive care unit, the experience can often feel sterile and impersonal, crushingly sad, and intensely stressful—for the patient, their family, and the clinicians caring for them.

Recognizing that patient- and family-centered end-of-life care is a key driver of a positive patient experience, clinicians at Ronald Reagan UCLA Medical Center and UCLA Medical Center, Santa Monica, both part of UCLA Health, have made a pair of palliative care programs known as the 3 Wishes Project and No One Dies Alone a standard of care.

While the cost to implement the programs at UCLA is modest, the effect they have on patients, families, and clinicians is priceless.

The programs began at UCLA as pilot research projects adapted from similar programs developed by clinicians in Canada and Oregon. Both are designed to honor the patient's life, personalize the dying process, create a positive memory for grieving family members, and alleviate stress and anxiety for families and clinicians.

Through the 3 Wishes Project, UCLA clinicians elicit and fulfill small wishes for patients who are in their final days of life. In cases where impaired consciousness prevents patients from expressing their wishes, family members request the wishes for them. Examples of wishes the UCLA team has fulfilled include organizing reconnections with family and friends, personalizing patients' rooms with their favorite photos and music, providing spiritual or religious support, facilitating organ donations, and hosting tributes for families in honor of their loved one.

Through No One Dies Alone (NODA), trained volunteers provide comfort and support to patients who are near death and have no one to stay with them. The volunteers—members of UCLA Health's palliative care volunteer program, students enrolled at the David Geffen School of Medicine at UCLA, UCLA undergraduates, and UCLA employees and retirees—stay with these patients at the bedside, speaking or singing softly to them, playing their favorite music, or simply holding their hand and stroking their forehead to let them know someone is with them during their final hours.

Dr. Thanh Neville, an assistant professor and researcher in the medical school's Pulmonary and Critical Care Medicine division and the 3 Wishes Project medical director, helped establish the 3 Wishes Project in the medical ICU at Ronald Reagan UCLA Medical Center in late 2017. Elaine Eastwood, manager of Volunteer Services and NODA program director, launched NODA at UCLA Medical Center, Santa Monica, in 2014. Today, the 3 Wishes Project is offered in the liver transplant and cardiothoracic surgery ICUs at Ronald Reagan and the medical ICUs and oncology units at both hospitals, and the NODA service is provided at both hospitals in all departments except pediatrics.

AT A GLANCE

- UCLA Health has rolled out two end-of-life care programs to honor the lives of dying patients, personalize the dying process, and advance a heightened awareness of dying patients' experience of care.
- In addition to improving the end-of-life experience for patients and their families, the interventions—one that fulfills small wishes for dying patients and their families and one that places trained volunteers at the bedsides of dying patients who have no one to stay with them—create a positive lasting memory for grieving families and alleviate stress and anxiety for families as well as clinicians.
- To date, the UCLA team has fulfilled more than 800 wishes, and 75 volunteers, including hospital employees, members of the hospital's palliative care volunteer program, members of a community choir, UCLA students, and medical students enrolled at the David Geffen School of Medicine at UCLA, have been trained and are ready to answer the call to service at a moment's notice.

"Family members have told me through tears how grateful they are that we could fulfill their loved one's wishes," said Dr. Neville. "It makes them feel good that we honored them in this way, and it makes us feel good that we're providing patients and families a better, more compassionate dying experience. This helps us manage the stress of seeing our patients struggling and their families trying to cope during this very difficult time."

"Patients who are visibly distressed and agitated as they're dying immediately relax once they realize they're not alone. And family members who couldn't be with their loved ones when they died tell us it was a huge comfort to know we were there with them," said Eastwood. Clinicians also benefit tremendously from the NODA program, she added, as they're solaced by knowing that if they can't be at their patient's bedside, a NODA volunteer will be there, tending to their patient's emotional and physical needs throughout the dying process.

3 Wishes: How Small Gestures Can Make a Big Impact

The 3 Wishes Project was developed in 2013 by Dr. Deborah Cook, a professor of medicine at McMaster University and an ICU physician at St. Joseph's Healthcare Hamilton, in Hamilton, Ontario. Dr. Cook had piloted the program in the hospital's ICU and conducted a study to measure the effect it had on patients, families, and clinicians. One of Dr. Neville's colleagues, UCLA palliative care physician Dr. Peter Phung, read about the study and asked Dr. Neville to help him bring the initiative to UCLA. "I thought it was a great idea and was on board right away," Dr. Neville said.

In October 2017, Dr. Neville received a \$10,000 research grant from the California State University Institute for Palliative Care to fund the program. Over the next few months, she sought and received approval from the organization's medical ICU nurse leadership and Institutional Review Board. In December 2017, Ronald Reagan UCLA Medical Center became the first hospital in the United States to implement the program.

The 3 Wishes Project is triggered when it becomes clear there's a more than 95% chance a patient will die in the ICU, or when plans are already in place to remove a patient from life support. At that point, the patient's nurse or physician will tell the patient and family about the program and ask what they can do to honor the patient.

As a supplement to this conversation, patients and families receive a brochure Dr. Neville and her team created to explain the program's goals and benefits. The brochure is one modification the team made to the original program, Dr. Neville said; another is a training video they created to teach the UCLA clinicians how to initiate the 3 Wishes conversation, as well as challenges they may encounter and how best to respond.

Over the past 18 months, the UCLA team has fulfilled more than 800 wishes for 240 patients, at an average cost of just \$30 per patient. "When we began the project we were worried that, being in Los Angeles, patients would ask to meet movie stars or ask for expensive things," Dr. Neville said. But they don't ask for a lot, she noted, and what they do ask for is highly meaningful: a last date night in their room; a wedding vow renewal; dinner with their family one final time; a visit with a beloved pet; the opportunity to hear a favorite song or have special music play when life support is withdrawn.

Families' wishes also tend to be meaningful, and are focused on creating a positive memory that lives on long after their loved one is gone. As an example, Dr. Neville recounted one of the first wishes the ICU team fulfilled after the program was launched. It was for the wife of a patient in his early 30s. The young, active couple had loved the outdoors, particularly sunsets. The husband was on advanced life support, so the ICU team asked the wife what they could do to honor him. She told them her wish: that her husband wouldn't have to die within the four walls of the ICU.

"On the day he was to be removed from life support, we moved him and his equipment to an outdoor terrace," Dr. Neville said. "I gave her a soft blanket, and she laid next to him on his hospital bed, with the blanket wrapped around them both. His breathing tube was disconnected, and as the sun began to set, he died in her arms.

"She told me she sleeps with that blanket every night, because it helps her feel close to him," Dr. Neville continued. "I still cry when I talk about this wish; it's such a beautiful example of how compassion can have an extremely powerful positive impact."

That compassion is also expressed through numerous acts of kindness clinicians now initiate on their own, Dr. Neville said. Decorating a young girl's room with paper hearts to signify the love she engendered in the ICU, calling in a volunteer harpist to play for a patient who loved classical music, touching up a patient's manicure, and donating newly purchased blankets to supplement those purchased with grant money are among the recent examples she recounted.

For the first year of the project, Dr. Neville invited families to answer questions about their experience a few months after their loved one died, to determine whether the program was having a positive impact. She also interviewed clinicians about their experience. The responses from both groups were overwhelmingly positive. In July, Dr. Neville published a [paper](#) in the *Journal of Palliative Medicine* that describes the project's effect on clinicians. She hopes to publish a paper describing the families' experiences soon, as well as begin collecting quantitative data as another way to measure the program's effectiveness.

NODA: Comforting Patients through the Dying Process

Sometimes patients are near death and either they have no family or their family members can't be at their bedside with them. In those cases, UCLA clinicians—primarily palliative care nurses, social workers, and physicians—will offer patients and families the NODA service.

Sandra Clarke, an ICU nurse at Sacred Heart Medical Center in Eugene, Oregon, started the NODA program in November 2001. Eastwood developed a similar NODA program for UCLA at the request of UCLA Medical Center's chief nursing officer and spiritual care manager at the time. Using Sacred Heart's training materials as a guideline, Eastwood worked with her hospital's palliative care physicians and clinical nurse specialist, intensive care and oncology unit directors, and leaders in geriatrics, spiritual care, and social work to develop the project's parameters for UCLA.

At UCLA, the NODA service can be ordered by nurses, physicians, spiritual care professionals, and social workers. A version of the service called NODA-Respite is available for patients whose family and/or friends have spent a substantial amount of time at the bedside and need to take a break. Eastwood worked with UCLA's Information Systems and Services department to add the NODA service to the organization's electronic health record system so that when a NODA order is placed, a report is generated and a member of the Volunteer Services staff is paged; the staff member then contacts one of the program's approximately 75 volunteers to let them know where the service is needed.

Eastwood developed training materials so that volunteers know what they're expected to do. During training, volunteers are asked to reflect on why they want to volunteer for the service, as well as their feelings about death and dying. "Many volunteers tell us they consider it a privilege to be with someone and help them as they're dying. Their passion and dedication are remarkable," Eastwood said. "And the nurses who volunteer tell us they understand how heartbreaking it can be for clinicians when a patient has no family present and they can't be with their patient in the moments leading up to their death. This is their way to ease that stress for their nurse colleagues."

According to Eastwood, volunteers are encouraged to step away from the bedside after about an hour. "Sometimes a patient will wait until they're alone, until they have that private space, to die. By stepping away, the volunteer is allowing the patient to have that privacy," Eastwood explained.

In the original NODA program, the pool of volunteers comprised palliative care volunteers and employees only. Eastwood expanded on that model to also include members of UCLA Medical Center's general volunteer program, members of a community choir who sing at the bedside of dying patients, students enrolled at UCLA, and students enrolled at the David Geffen School of Medicine at UCLA.

In fact, according to Eastwood, 10 of the program's volunteers are David Geffen medical students. "Having medical students learn what it's like to sit with a dying patient teaches them compassion and caring at a level they wouldn't get in traditional medical school training," she said. "When they learn these skills in medical school, they're likely to exhibit them on the job."

As Dr. Neville does for the 3 Wishes Project, Eastwood relies on grants and philanthropy to pay for NODA-related expenses. Recently, she received a \$10,000 grant from a community donor to purchase musical instruments for the NODA volunteers to utilize, and to print an updated volunteer training booklet, instructional material for nurses on how to order the NODA service, and volunteer recruitment flyers. Since the program started in Santa Monica, NODA volunteers have served approximately 350 patients.

According to Eastwood, the moment of death is only one part of the dying process. "Dying is a journey, and when a patient is on that journey, we strive to give them the best possible end-of-life experience by letting them and their family know they're safe and that we care about them," she said.

Through their implementation of the 3 Wishes Project and NODA, Dr. Neville, Eastwood, and their teams at UCLA clearly illustrate how seemingly small gestures can send the human spirit soaring and bring light to the darkest moment in people's lives.