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## CORONAVIRUS

# COVID-19 complicates access to hospice end-of-life services

*Pandemic erects barriers to comforting the dying and helping their families*

By Theresa Walker

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Difficult as the past six months have been on the living, and the terrible cost paid by those who have died, there's another category of people for whom the novel coronavirus pandemic has shown little mercy — those seeking hospice care.

Whether they're in the final stages of a long-term illness, or they've been diagnosed with terminal cancer, or they're suddenly stricken with COVID-19, dying people are facing a variety of pandemic-related hurdles to get a service designed to comfort the afflicted and ease the burden for their family members.

That service includes helping people handle fear.

Even when their health is in decline, many people with serious illnesses remain afraid to visit a doctor or go to a hospital because of the specter of the coronavirus. As a result, they don't get the assistance that could ease their final stage of life.

And that's a shame, said Michelle Wulfestieg, founder and executive director of the Southern California Hospice Foundation, an Orange County-based nonprofit that offers assistance to individuals and families during hospice care.

"People are missing the opportunity to have the benefit of hospice care."



Southern California Hospice Foundation Executive Director Michelle Wulfestieg has helped create Heavenly Home, a six-bedroom house in Mission Viejo that will provide low-cost or free hospice care starting next year. “I just wish your place was open,” Wulfestieg said she was told by a hospice administrator seeking a place for a couple dying of COVID-19. PHOTO BY KYUSUNG GONG

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## **Fear of death, virus**

Hospice care, which requires a physician’s referral, leads to coordinated assistance from a team that can include a social worker, nurses, a spiritual adviser and caretakers to assist with personal care and other needs. Volunteers — in addition to family when available — can provide emotional support and companionship.

Much of the cost for hospice is covered by government programs, including Medicare and Medicaid, or private health insurers. Also, some organizations, such as Southern California Hospice Foundation, offer help beyond what is provided by basic hospice, including money for food, utility bills and rent, or to grant special wishes.

But the ongoing spread of coronavirus has created both physical and mental barriers to hospice — for the dying, their families, and even for the hospice care providers.

Some who are terminally ill won’t seek hospice care because they fear a more precipitous death from COVID- 19, providers say. Others are referred by doctors or discharged from

hospitals at a point when their disease is well advanced, delays that come because the patient has avoided getting medical evaluation; again, out of fear of coronavirus exposure.

Eligibility for end-of-life care is restricted to people deemed to be in the last six months of life. But hospice care sometimes can prolong someone's life, and some people end up being taken off hospice because their health has improved, Wulfestieg said. But that scenario is less likely when the hospice process gets started late. Also, the same fear of coronavirus that's prompting people to put off hospice care is prompting delays in getting general medical care that might improve a patient's health.

"We're seeing more patients come to us via the hospital because they're getting into crisis at home with serious illnesses," said Shaun Moss, a registered nurse who is chief operating officer of Companion Hospice in Southern California, which serves Orange and Riverside counties, and parts of Los Angeles County.

Historically, most hospice care patients have been older adults, the people hit hardest by the virus.

In California, people 65 and up account for nearly three-quarters of all COVID-19 deaths. In Orange County the percentage is about the same. As the county logged its 1,000th COVID-19 death this month, the Health Care Agency reported that nearly 780 of those people were 65 or older when they died.

Pre-COVID-19, there was no chronic shortage of beds at skilled nursing facilities that could be used by hospice patients, Moss said. But coronavirus, which in April and May ravaged older people at long-term care facilities, largely shut off that option.

"Where it took three or four calls to find a place prior to COVID-19, we're going to have to talk to 20 places today," said Moss, whose company has its regional office in Costa Mesa.

"It's 10 times as much work as it was before," she added.

Still, without the effort, more people probably figure to die in hospitals, alone.

## **Exposure**

When families are able to bring home someone who has been diagnosed with COVID-19 for end-of-life care, they face a double whammy: the distress of losing a loved one and the anxiety of being exposed to the coronavirus.

For Lina Arambula, a nightmarish scenario began in early April, with an early morning phone call. It was from Magnolia Rehabilitation and Nursing Center in Riverside where her mother, who suffers from dementia, had resided for five years. The facility, already locked down to outside visitors, informed Arambula that all the residents were going to be tested for coronavirus.



When Lina Arambula's 83-year-old mother, Rosa Rodriguez, developed COVID-19 at a nursing home, Arambula brought her to her home in Orange. Companion Hospice and Southern California Hospice Foundation helped her care for her mom, providing everything from baths to meals. Amazingly, her mother has since recovered. "I don't even know what I would have done if she was not on hospice," Arambula said.  
LEONARD ORTIZ STAFF PHOTOGRAPHER

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Then came another call at 2 a.m. the following Wednesday — her mother, 83, was being taken to the hospital because she may have fallen, Arambula said she was told. The caller from Magnolia sounded confused and distraught. Arambula, a single mom who drives a public bus in Orange County for a living, scrambled out of bed, found someone to watch her children, and then set off for Riverside.

What Arambula wasn't told and would learn later: Magnolia's staff had abandoned the people at the facility because employees and residents alike were testing positive for the coronavirus. Riverside County officials arrived later that same day, April 8, to evacuate Magnolia and transport its 83 remaining patients elsewhere for care.

At first, the hospital told Arambula that her mother, Rosa Rodriguez, had been diagnosed with pneumonia. Arambula was not allowed to visit. Two days later, the hospital called and told Arambula her mother had COVID-19 and asked, "Where do you want her to go?" The hospital located a nursing home in Anaheim that said they would take her. But that plan fell apart when her mother's fever spiked and she couldn't be transported.

When the hospital called the nursing home the next day, there were no longer openings anywhere. Another question: "Can you take her?"

Arambula sent her four youngest children — now 18, 15, 12 and 10 — to stay with her oldest daughter, 23.

Then she started fielding calls about assigning her mother to hospice care and dropping off medical equipment to Arambula's second-story, three-bedroom apartment. Arambula had no clue what hospice meant until Companion Hospice contacted her. "I asked the social worker,

'Wait, does this mean she's on her death bed?' She was like, 'Yes. Sorry, we don't see her making it past a month.'" A hospice nurse visited once a week, as did someone who came to bathe her mother. The rest of the time, Arambula, on leave from work, did the caretaking. Her mother had arrived weak, bedridden, and unable to recognize Arambula. Southern California Hospice Foundation arranged for meals and bought new clothes for Rodriguez, whose belongings, including glasses and denture, remained at her old nursing home in Riverside.

The hospice service gave Arambula a quick lesson on basic care, going over her mother's medications, how to take her temperature and blood pressure, and how to change her diaper. On top of that, Arambula had to disinfect her home every night — wiping down light switches and door handles, mopping the floor with bleach and showering religiously. Personal protective equipment hung on a hook by her mother's door.

"I don't even know what I would have done if she was not on hospice," Arambula said recently.

The help from Wulfestieg's foundation was "amazing," Arambula added. "They got us blankets and gowns; socks, basic necessities that, honestly, you take for granted."

Surprisingly, her mother's health began to improve. Arambula attributes that to Rosa Rodriguez's stubbornness. But in July, Arambula had to return to work or lose her job with the Orange County Transportation Authority. Her children needed to come home. Who would continue caring for her mother?

Moss, at Companion Hospice, worked the phones. She found a nursing facility in Anaheim that, at the end of July, took in Rodriguez.

Rodriguez remains quarantined on hospice care. Arambula is able to visit only virtually, on Zoom. A

hospice nurse gives her regular updates.

"She's been really awesome in giving me feedback and letting me know how my mom is doing."

### **Wheeling, dealing**

Moss cites a litany of challenges that hospice care providers worked through as the coronavirus pandemic upended the routines of life and the rituals of death. Chief among them: Staring down their own fears of being infected and bringing the virus home to their families.

It didn't help that, in the spring, as the pandemic gained steam in Southern California, the hospice care industry had to compete with hospitals and other health care workers to secure personal protective equipment — N-95 masks, face shields, gowns, gloves.

“I was thinking about PPE at breakfast, lunch and dinner for at least the first 45 days,” Moss said.

During this period, Moss became something of a wheeler-dealer, cutting deals as hospitals — fearing a surge of coronavirus patients — rushed to discharge their terminally ill patients into someone else’s care.

“I said, ‘We’ll take your patients. Now, can you give us PPE?’ We were willing to admit those patients onto hospice, and go into their homes to care for them.”

Hospitals, nursing homes, and assisted living facilities closed their doors to all outside visitors — including hospice workers. Over time, that restriction has only partly eased, and only in some places, leaving Moss to negotiate limited access for hospice nurses.

Where they can’t see patients in person, hospice providers find themselves in the odd circumstance of offering care via video conferencing, instead of their normal role as a hands-on bedside presence. Volunteers, stuck at home, have shifted to alternative duties, such as sewing masks.

Moss also has had to purchase a lot of smartphones and iPads to facilitate distant communication between patients and their families.

Weekly huddles about COVID-19, and what Moss calls “pep talks,” helped keep Companion Hospice’s 300 full-time employees motivated, as did instructing families on infection control and shifting some reluctant staff to remote work only, she said.

“There are fears around being willing to care for a patient because you might also get sick.”

Still, they’ve managed to bring comfort to distressed families.

## **Going home**

In early April, when Antonio Silva entered an Orange County hospital with an infection in his lungs, the family wasn’t allowed to visit. But Silva was conscious and alert enough to speak with them on the phone. After three weeks, doctors determined he was unlikely to survive. They told the family he was eligible for hospice care, and they could take him home or to a nursing facility.

“We wanted him home,” said his daughter, Maria Garduno, who shares a big house in Tustin with three generations of her family.

“We wanted to have his last days at the house.”

Hospice nurses arrived once a day; others came to bathe him. With that help, Silva was able to spend his final days in the same detached studio apartment where he and Garduno's mother had lived.

"Every time we called, they came," Garduno said of the hospice team. "They took care of my dad. Even with the COVID, they were still there."

A week after he went home, Silva died of COVID- 19. He was 91.

The family faced other troubles. Garduno's husband and her mother, 88, both got sick, though they've recovered.

And, in the pandemic, both Garduno and her husband lost their jobs. Unemployment helped. So did assistance from Southern California Hospice Foundation.

Wulfestieg said her organization arranged regular food donations through the nonprofit Bracken's Kitchen pandemic outreach, paid three household bills totaling \$436.77, and gave the family an emergency grant of \$2,500.

Garduno is glad she could care for her father in his final days. But she is sad she had to do it suited up in protective gear. "You want them to know that you're there for them. You want to hug them. You want to kiss them ... It's so bad that so many people are dying and they die alone. That's what we didn't want."

### **Tough options**

What can be done for dying people with no family to care for them, no money to pay for a caregiver, no home of their own to spend their last days?

Wulfestieg believes a potential answer is Heavenly Home, a hospice house in Mission Viejo she is readying. It would take in patients in need from around Southern California for the last three weeks of their lives, with payments handled on a sliding scale. Renovations of the six-bedroom house are nearly complete.

The foundation's board wants to establish at least a \$2 million endowment to sustain an estimated \$500,000 in annual operating costs. The home will be fully staffed to provide 24hour care.

An endowment fund was formally launched July 29 during the online "Preserving Dignity Giving Day" to benefit Orange County-based nonprofit organizations that serve older adults. That effort generated \$112,805 for the hospice foundation. Wulfestieg hopes to raise another \$900,000 by December. An anonymous donor recently pledged a dollar-for-dollar match, up to \$1 million, to help build the endowment, said Wulfestieg, whose aim is to open the home next year.

But Heavenly Home can't begin operating soon enough, Wulfestieg said.

A recent call to the Southern California Hospice Foundation exemplified the need. A hospice administrator was looking for a place where an elderly couple — both expected to die soon of COVID- 19 — could spend their final days together.

Wulfestieg recalled what the administrator told her: "I just wish your place was open."