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Hospice: Demanded But Threatened By COVID-19

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Comfort, touch, togetherness: these are among the key elements of hospice care — the kind of care offered at the end of one's life. These same principles are also in direct opposition to the distance and separation asked of us during a pandemic.

Yet hospice, available to those with a life expectancy of six months or fewer, remains an essential branch of medical care.

Nearly 2,000 Americans die every day due to the coronavirus, which has just become the number one leading cause of death in 2020. Some terminal patients will receive hospice care. Others will die too quickly for it. Millions of Americans were already on hospice care long before the coronavirus — mostly in-home, since that's where hospice predominantly takes place — and many more will enter hospice for reasons unrelated to COVID-19.

The hospice care tradition is to rally loving visitors around a dying patient, focusing care on pain management, comfort and peace at the end of life. Hospice is meant to address not only physical care, but also the substantial emotional, social and spiritual needs that arise as death approaches.

A Hospice Nurse Feeling Boxed In

A hospice nurse who wished to remain nameless for fear of losing her job told Next Avenue that the care she's now boxed into providing is "against the hospice philosophy — everything that should not be happening." She feels she's failing her patients, like she's a different nurse than she was pre-coronavirus.

With the aggressive spread of COVID-19, hospice providers must now minimize visitations and increase protective measures, integrating all the masks and gloves — or mask-like and glove-like items — they can gather. Hospice workers say the necessary protective equipment can create a barrier to the closeness and intimacy most people crave with a dying loved one living out their final days.

> Who will care for the seriously ill when hospitals have reached capacity?

As is seen across medical facilities worldwide, supplies available for hospice safety are sparse. The hospice nurse who requested anonymity acquired her own small stock of N95 masks early on when the coronavirus first began devastating Wuhan, China. Her company initially asked its employees not to wear masks, arguing it would perpetuate fear among patients, but is now loosening its restrictions. She wears the N95 underneath a homemade mask as a workaround.

Rosa Lee Amarillas, 67, has been on hospice for the past nine months in her San Diego home where she lives with her husband and primary caretaker, Mike Amarillas, 76.

Rosa Lee has been sick with a rare form of Parkinson's called corticobasal degeneration for 10 years. Her health has deteriorated significantly in the past year: The right side of her body is paralyzed, and she has dementia.

(Read all of Next Avenue's COVID-19 coverage geared toward keeping older generations informed, safe and prepared.)

Mike says the pandemic has "been hard, especially on seniors," describing himself as a social butterfly who used to be active in his 55+ community.

“Hardly any cars go by. It’s made things quieter,” he says. “A lot of our friends don’t visit hardly. That’s sad for my wife.”

Rosa Lee’s nurses and aides continue home hospice visits, but all other care — including a chaplain provided by hospice — is now by phone. The couple’s son drops off groceries several times a week; he currently isn’t allowed to see his mother.

“You just never know,” Mike says.

The coronavirus’ impact on hospice care extends far beyond providers adjusting their approach to care and patients and their families adjusting to new hospice realities. Experts in the field say it’s straining the workforce’s bandwidth, just as is currently seen in hospitals nationwide.

Overburdening Is a Worry

“Considerably.”

That’s how COVID-19 is affecting the hospice industry in the United States, according to Edo Banach, president and CEO of the largest membership organization for providers in the field, the National Hospice and Palliative Care Organization.

While the narrative percolating nationally is a story of needing more beds for all those who will be hospitalized, attention hasn’t quite turned to another imminent reality: Who will care for the seriously ill when hospitals have reached capacity?

In a perfect world, hospitalized patients would be contained, healed and then discharged with no symptoms. But with a limited supply of hospital beds, sick people will be discharged to the community, to their homes — and still in need of care.

“We all think there’s this massive workforce of nurses and social workers to provide care, but the reality is there isn’t. There’s the hospice workforce, and there’s the home-health workforce, and that’s who is around,” Banach says. “This is really going to strain serious illness and hospice resources out in the community.”

A positive: There is perhaps no group of medical professionals more equipped to deal with an influx of serious illness than hospice workers.

“We can be a huge support in communicating with our colleagues who maybe don’t experience this in the intense way that we do, though we at some point are going to exceed our norm for the suffering that is happening or the need that is going to be there,” says Dr. Andrew Esch, an education consultant with the Center to Advance Palliative Care.

Weighing Comfort Over Safety

St. Luke’s University Health Network, a large hospital system in eastern Pennsylvania with its own hospice organization, is facing harrowing decisions for its coronavirus patients who’ve reached the end of all available treatment but are too sick to be transferred home.

As of late March, St. Luke’s network of half a dozen hospitals had about 80 patients confirmed or highly suspected to have the coronavirus.

“It’s not good where we are right now, and we’re not even seeing the worst of it,” says Dr. Michael Pipestone, a hospice and palliative care doctor with St. Luke’s, who says his hospital’s medical director for hospice declared that patients dying of COVID-19 in its hospital facilities should not be brought into inpatient hospice.

“Originally I was like, ‘What the hell?’ But [the medical director’s] thought is that what hospice should do is unify the family around the dying patient so that we normalize the dying process. That unification runs directly contrary to what we have to do in the face of this pandemic, which is isolate people physically and often emotionally,” Pipestone says.

Instead, St. Luke’s COVID-19 patients nearing the end will receive palliative care focused on symptom relief and pain reduction — in isolation. Rather than spending generous time with each patient and involving social workers and chaplains, hospice work may at times need to be simplified to ensuring each person has the right dose of morphine to die comfortably.

> “A lot of patients are getting the short end of the stick.”

“We’re having to use some pretty archaic or draconian kinds of tools to protect the public, and that’s what’s really challenging for a lot of us in health care right now,” Pipestone says. “We are looking at individual suffering of patients, but we also see the experience and the data coming out of Italy and can’t ignore the public health concern either.”

If hospital patients wish to die at home, Pipestone says, doctors are left to weigh the horrifying dilemma of putting them in unsafe and painful transitions to serve a dying wish.

"If a person is so fragile, what good is it to them to die in the back of an ambulance on the way home, versus being able to be comfortable in a hospital setting with morphine, attentive nurses and sparing the community any exposure?" asks Pipestone.

While St. Luke's in-hospital hospice patients have access to health providers but little in the way of visitors, home hospice patients face the contrary. At-home hospice patients who fall ill with COVID-19 won't be sent to the hospital, but rather kept in home, either quarantined or together with those they live with, given liberal access to medication at the doorstep for fever and pain management and remote care support through telemedicine.

If St. Luke's hospice workers had access to the right protective equipment, they'd be at those home bedsides, Pipestone says. "A lot of patients are getting the short end of the stick," he notes.

Can Hospice Be Virtual?

In March, the Centers for Medicare & Medicaid Services (CMS) announced it would expand the ability for hospice providers to use telehealth rather than in-person visits. This measure promotes safety for hospice workers, patients and their families, but has a side effect of limiting the in-person comfort and care — where hospice really shines.

"If a person-to-person visit is required, that will be done," says Dr. George Delgado, chief medical officer of The Elizabeth Hospice serving San Diego County and Southwest Riverside County. Delgado says his organization's patients without devices, such as those experiencing homelessness, will continue to receive care. "We will not abandon any of our patients no matter what their circumstances are," he adds.

Though virtual visits are hard to compare to the quality of in-person care, some leaders in the field see hospice's newfound ability to lean on telehealth as a way to make its services ultimately more accessible to vulnerable populations in rural areas or inner cities.

Even with the federal government's loosening telehealth restrictions, fears and frustrations among providers run high as our nation's lack of preparedness trickles all the way down to how we are able to care for people in their last living moments. Hospice providers are left scrambling.

"I think there's just a general degree of vague but sharp unease, if not terror, amongst health care providers," Pipestone says. "We want to do what's right for our patients, but the rules and resources are changing so fast that we're not sure how to plan for the next day. And that's not a place we want to be in."