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A gentle death

Program provides patients with comfort and control.

By T.J. Greaney

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Photo by Nick King

PATIENT COMFORT AND CONTROL J.L. Christopher holds a picture of her mother, Virginia, who was a patient of the palliative care program before her death in 2008.

On a recent afternoon on the third floor of University Hospital, behind a door marked with a laminated pink drawing of a rose, lay a patient dying of pancreatic cancer. Normalie Nicholson, 80, had rejected the most aggressive medical treatments, and doctors gave her scant days to live.

“I’m ready to go to sleep and float right on into heaven,” Nicholson said with an easy smile.

Nicholson might have been weak physically, but she was in control of her care. She asked nurses to unhook the IV line that had previously dripped pain medication into her veins, opting instead for an adhesive pain patch. She rejected a permanent metal stent doctors wanted to implant in her liver to relieve a blocked bile duct and chose to continue on with a plastic stent that will only last three months. “I better not last longer than three months,” she quipped. Nicholson even told a gastrointestinal doctor who came calling that she didn’t need his services. That assertion, she recalled, shocked the young doctor enough to cause him to make a quick U-turn and head for the door.

“I just don’t want any more poking and prodding,” Nicholson said. “When you’re dying, why do they want to put all that stuff in you? That’s ridiculous.”

In short, this feisty grandmother of seven and great-grandmother of four is dying on her terms. She's treating the last days of her life like a celebration and focusing on the things that are most important to her.

On this day, for lunch, that celebration includes swallowing spoonfuls of a root beer float, eating an onion ring and three bites of a Sonic Drive-In hamburger. Tomorrow: "I'm thinking about crab legs," she said.

She's also sorting things out. With two of her daughters, Nancy Jahnke and Ann DeLine, at her bedside, Normalie is making arrangements to ensure that her great-grandchildren continue to get the 13 one-dollar bills they've always received as a birthday gift. She is dividing up her 150 pairs of shoes and dictating what type of music she wants to be played at her funeral: "None of that waw-waw stuff," she said derisively, insisting on the upbeat "When I Take My Vacation in Heaven," sung by the Hee-Haw Gospel quartet.

And Nicholson's daughters are content with this approach. They know the alternative would likely be an endless and useless battery of tests and surgeries to try to keep their mother's inoperable cancer at bay. They all said she'll soon be returned to her husband and a daughter who preceded her into the afterlife.

"It's here, and it's OK," said daughter DeLine of the end of her mother's life.

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Photo by Nick King

Jan Schupp is an AARP Missouri Advocate. She and her husband, George, are both in the palliative care program. Jan has a degenerative heart condition, and George has Alzheimer's disease.

This is modern palliative care in action. And it is as a far cry from what physician Clay Anderson first saw when he was a medical student at Stanford in the 1980s.

Anderson, now the director of the Missouri Palliative Care Program, said when he started out, dying patients were often stashed away in an isolated corner of a hospital, allowed only limited visits and subject to burdensome treatments with little or no medical utility.

He vividly recalled one day when he observed a middle-aged woman dying of ovarian cancer. She accepted the aggressive treatments doctors kept piling on her, but, in his opinion, it was long past time to focus on comfort instead of treatment.

"She was actively dying," Anderson said, "and still was getting everything even though she wasn't benefiting from it. It was, in a sense, instead of her controlling her medical care, her medical care was controlling her. She was in terrible pain: She had all the tubes — NG tubes, stomach tubing, IV tubing, catheter in her bladder.” Anderson, 45, would soon realize this treatment was not unusual.

“This is what they did in good hospitals in the ’70s or ’80s when they were dying,” he said. “This was pretty standard.”

But there were occasional exceptions to that rule, and they intrigued the young doctor. He recalled a 90-year-old Japanese man from the island of Guam. The man had inoperable esophageal cancer, and Anderson’s colleagues at Stanford were geared up to aggressively combat it with chemotherapy. But Anderson recalled that the man, in a composed and elegant way, simply said, “No.”

Most people “would have said, ‘Cut me open, zap me, do chemotherapy, do whatever you need.’ He just kind of said, ‘I’m not going to do that,’ ” Anderson recalled. “At that time, this was sort of a less acceptable thing to say.”

But more and more people were asserting this right. Spurred on by seminal studies of the dying by Elizabeth Kubler-Ross, people began to rethink how hospitals should treat terminal patients. Ross, a Swiss psychiatrist, had uncovered a hidden world of the dying in U.S. hospitals where patients were isolated from the rest of the population and treated in an “over-medicalized” fashion hooked to all sorts of beeping, pumping devices up until the bitter end.

She was one of the first to ask publicly: “Why?”

“In the same way we changed the birthing experience from something where you put the woman in the room and put her to sleep and the family was kept away, it turned into a really big family event,” said Jan Schupp, an AARP Missouri advocate from Jefferson City and palliative care patient. “It turned into seeing the child born, a beautiful event and celebrating that. Death, too, can be a celebration. … You’re only born once; you’re only going to die once; so it’s about making the experience something that’s inclusive for the family.”

The movement variously known as the “right to die” and “death with dignity” picked up more steam in the 1980s with the help of pop-culture phenomena-like film, “Whose Life Is It Anyway?” and flashpoint cases like that of a Missouri woman, Nancy Cruzan, who remained in a persistent vegetative state for seven years before a court would allow doctors to remove a feeding tube.

Palliative care grew out of already existing hospice practices where dying patients are typically cared for in their own homes or in a nursing home. Treatment in hospice is centered around pain management and comfort. Palliative care takes that concept one step further with the intent of being holistic. The palliative care team views it as treating the whole person who has a “life-limiting condition,” including mind, body and soul.

In the Missouri program, these patients are placed on a “comfort pathway” that can begin years before a patient has any expectation of dying. The care begins with conversations about life goals, desired medical treatment and often encourages them to prepare an advanced care directive. Some patients may also choose to create “do not resuscitate” orders, and other patients may even have “do not hospitalize” orders.

The process is updated and refined until the end according to the patient’s wishes and makes every effort to bring in the entire family and explain decisions and prognosis. It includes skilled nurses, social workers, physical therapists and chaplains all with the goal of caring for patients in ways that help them die with dignity.

This can take many forms: A patient with a lung disease in a nursing home might not want go by ambulance to the emergency room every time he or she wheezes. A palliative care doctor will write an advanced directive ensuring that does not happen. A patient with terminal cancer might not know quite how to explain the condition to his or her loved ones. A palliative care doctor will do this. A patient in the early stages of Alzheimer's might need help prioritizing what to accomplish in the final years of clarity. A palliative care doctor helps a patient set those goals.

The job has evolved into much more than the crude title given years ago: "The ones who give them morphine until they die," Anderson recalled hearing.

Some detractors even thought the practice was one step removed from physician-assisted suicide.

"I can remember talking to the administrator of Boone Hospital Center maybe a dozen years ago, and he was reluctant to invoke a palliative care service because — quote — 'I don't want Boone to be looked at as the hospital you go to die,' " recalled Michael Daly, the palliative medical director at Boone. "He later became one of our staunchest advocates."

Today, more than 55 percent of U.S. hospitals with more than 100 beds have an in-house palliative care program. Patients and their families report in surveys they're highly satisfied with the mode of treatment, and hospitals are finding the programs save them money. No one is scoffing anymore.

"We don't want overtreatment, undertreatment or wrong treatment," Anderson said. "We want the right treatment, and that's not always disease-directed treatment."

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Photo by Don Shrubshell

Physician Clay Anderson and nurse Julieanne Hagedorn are part of the Missouri Palliative Care program at Ellis Fischel and University hospitals.

Since it was first created in 2006 under Anderson's direction, the Missouri Palliative Care Program has worked to gain recognition and credibility. It now operates out of offices in Ellis Fischel Cancer Center, where doctors see outpatients and hold four half-day clinics each week.

The team includes Anderson, Julieanne Hagedorn, a resource nurse, and a handful of other doctors, nurses and staff. They depend on referrals and estimated they only see about 30 percent of the patients in the University of Missouri Health Care system who could benefit from palliative treatment. They are working to raise that number.

Too often they rely on word-of-mouth. In the fall, J.L. Christopher of Columbia was facing a dilemma in caring for her 88-year-old mother, Virginia. Virginia Christopher had shown advanced signs of dementia and had recently gone through surgery to repair a compound break in her thighbone. Doctors believed she would make a full recovery but were stumped when she never fully awoke from the procedure. She wasn't in a coma — there was brain activity — but doctors were at a loss to explain what was going on.

"Literally, they went through every test in the book, from CAT scans to anything and everything else they could do," J.L. Christopher said.

As days dragged on into weeks, a friend of J.L. Christopher's who also is a social worker suggested she consider a geriatric evaluation for her mother. The evaluation was administered by Anderson, who told Christopher there was another treatment path aside from the one her mother was now on. Her mother could be moved to a private room, continue to receive comfort care such as mouth hygiene and suctioning to prevent dryness but be taken off the IV that was providing her sustenance.

It was a wrenching thought. But Christopher, an accountant who moved from Florida several years ago to help care for her mother, appreciated hearing the realistic perspective. She hadn't heard anything similar from any of her other doctors.

"With doctors, their job is to save lives, so they'll do anything and everything," Christopher said. "Even if they can't figure it out, they're going to keep going, and I'd ask repeatedly, 'Will she recover? And they would just say, 'We'll try again.' "

But now in Anderson, Hagedorn, and another physician, Paul Tatum, she had other voices, and they made a lot of sense. Her mother was suffering, unlikely to regain any sort of high-quality life and had lost most of her cognition to dementia before the accident. What sort of life would she be returning to? She knew removing the tube would be her mother's wish. "Once I made the decision to bring the palliative care team on board, I felt better," she said. "I don't want to say I felt great — there are times when I still question that — but I felt better."

She said from that point on, the team was "amazing." They came in with a comfort basket that included a CD player, crackers, tea and chewing gum. Members of the team gave her their 24-hour pager numbers and said to call whenever needed. When Christopher had to take a break, volunteer comfort companions came in to sit by her mother's side. One woman even knitted her a prayer shawl that she has kept to this day.

It also was a big relief to watch her mother, who had previously required blood drawn and needle injections multiple times per day, relieved of that intrusion. "It was just very painful to watch," Christopher said.

Her mother died Dec. 4, just more than two weeks after the paliative care team had been called in. It was, she said, a peaceful, graceful end. "It was certainly like having a best friend. That's how the palliative care unit was for me," she said. "Not that we were close on a personal level, but when you have a problem, who do you call? Your best friend."

Anderson is now hoping to build off the success of the program to expand it. In upcoming years, he would like to see a dedicated palliative care unit in University Hospital consisting of about five beds.

He has a good argument. The program's internal studies show that it pays for itself. The cost to care for a patient drops by about 60 percent three days after he or she receives a palliative care consultation. A dying patient who cost $10,000 per day to care for previously costs $4,000 after a palliative care consultation.

Anderson also is pushing to get patients to start thinking about palliative care "farther upstream." Not long ago, he took on new patients George and Jan Schupp of Jefferson City. Jan Schupp a former chaplain at St. Mary's of Jefferson City, is a cancer survivor who suffers from degenerative heart and lung conditions. George Schupp is a retired convenience store owner in the early stages of Alzheimer's.

They said the palliative care program has helped them set goals for their final years. Jan, despite the fact that she breaths with the aid of a portable oxygen tank, wanted to travel and advocate for AARP. George wanted to continue his golf and other hobbies. Anderson has sat down with each of Jan Schupp's four children and explained her condition and what to expect over the coming years and at the end. They now feel more confident that should they be forced to make a decision to halt aggressive treatment, they're doing so to honor their mother's wishes

"When you have" Anderson, "who is more in tuned to just letting it happen if it's going to happen instead of doing invasive procedures, that's comforting," said Jan's youngest son, Dave Murray of Jefferson City. "Someone who can step in and say, 'Hey, let's stop things' instead of me having to try to do it."

Murray now has power of attorney for his mother, and she has signed a "do not resuscitate" order. She feels confident that the final years of her life will be lived on her terms. "Palliative Care is not just for people on death's doorstep anymore," Jan Schupp said.

But if the treatment is expanding, it is only doing so because it has had so much success guiding patients and families at the end of life. Anderson quoted a recent survey of families of patients who died while under the care of a palliative team. These families give their doctors higher marks and register a higher approval of their treatment than families of other patients who actually survived treatments in other nonpalliative programs.

It's a notion of a "good death" he said, that is now gaining traction.

"If you're a certain kind of person, you can't really get it out. It stays with you. The people in this field are a little bit of odd ducks, but it's strangely so satisfying," Anderson said. "Since we're all going to die, the good" deaths "should also be a success."

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