

# LEADING TO HEALTH

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**HEALTH SYSTEM  
TRANSFORMATION**



**House call:** Susan McCammon (right), a surgeon and palliative medicine physician at the University of Alabama at Birmingham, regularly visits patients such as Janice Bass, shown with her dog, Abbey, to manage treatment and support advance care planning.

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## Bringing Palliative Care To Underserved Rural Communities

*With home visits and modern technology, palliative medicine physicians in Alabama are overcoming long-held resistance.*

BY CHARLOTTE HUFF

Susan McCammon, casually dressed in taupe slacks and a black cardigan, sits on the edge of a rocking chair near the foot of Janice Bass's bed for nearly an hour, nudging the conversation forward. The second-floor bedroom is jammed with medical supplies, the sixty-seven-year-old woman's walker

waits nearby, and adult coloring books spill over from a nearby basket. A calendar featuring family photos hangs on the wall.

They talk about the side effects of the chemotherapy pills that Bass is taking and related insurance headaches. They laugh about her shopping adventures of yore, when Bass would return from hit-

ting the fabric sales with a friend and then hide the evidence from her husband, stashing the bags in the bushes outside.

Bass, who has advanced rectal cancer, is coping with a painful leg wound that's been slow to heal, making it difficult for her to put much weight on it. Sometimes, she tells McCammon, she's hit by a wave of excruciating pain up that leg. "What do I do? Pray. And I just ride it out." But she's been able to make it down the stairs some in recent days, when her grandchildren visited from New York City.

Finally McCammon, a surgeon and palliative medicine physician, asks Bass if she's taken a look at the advance directives paperwork that she'd been sent. "I got it and I read over it," Bass says. "I was never really able to fill it out."

McCammon typically makes home visits a few times each week to seriously ill patients who are getting palliative care at the University of Alabama at Birmingham (UAB) Health System, one of many ways in which the academic system is striving to break beyond the walls of its downtown Birmingham campus. UAB, which includes the 1,157-bed UAB Hospital, has offered palliative services for two decades,<sup>1</sup> adding an inpatient unit in 2006.<sup>1</sup> But over the course of the last several years, UAB clinicians have ramped up their efforts to educate more residents about its benefits, particularly those who are African American or living in rural areas of the state.

They've expanded UAB's house calls program to include palliative care visits for patients like Bass. They've created an advisory group of African American pastors from Birmingham to gain their insights into how to improve conversations with black patients facing serious diagnoses. They're tapping video technology and, beginning this year, have been more frequently conducting virtual palliative consults with clinicians and



**Care team:** At the University of Alabama at Birmingham, Garrett M. Hurst, a palliative care physician, and Estella Woods-Holmes, nurse manager of the Palliative and Comfort Care Unit, regularly consult about patient care plans and goals.

patients in more rural areas of the state. “We’re trying to put ourselves closer to where the patients are,” says Rodney Tucker, a palliative medicine physician who directs the UAB Center for Palliative and Supportive Care.

In the process, Tucker and his colleagues say they’re working to better understand and narrow the cultural and religious divides that can further complicate the already emotional discussions and decisions surrounding a life-limiting illness. Religion and faith represent a cornerstone for the vast majority of families in Alabama. And the state is home to a sizable African American population—accounting for nearly 27 percent of residents statewide and nearly 44 percent of those living in Birmingham’s Jefferson County.<sup>2,3</sup> National data show that African Americans are less likely than white patients to choose hospice in the final weeks and months of life. Among African Americans covered by Medicare who died in 2017, 27.1 percent were enrolled in hospice, compared with 33.8 percent among Caucasian patients, according to the latest report from the National Hospice and Palliative Care Organization.<sup>4</sup>

In Alabama the roots of racial mistrust in the medical establishment extend close to home. UAB’s campus sits only

several counties away from the site of an infamously unethical syphilis study. Beginning in the 1930s, federal officials enrolled African American men from the Tuskegee area—some who had syphilis and some who didn’t—and followed the progression of the disease without disclosing the study’s real purpose. (The men were told they had “bad blood.”) They didn’t get any treatment through decades of suffering and deaths—even after penicillin became available in the 1940s.<sup>5</sup>

“I think that here in Alabama we certainly have lived experience [with mistrust], because we’re not far from Tuskegee,” Tucker says. “And because we don’t live in the most progressive state in terms of how we have dealt with race and socioeconomic in the past. So all those things weigh into how patients make decisions and how they will accept palliative care.”

Such decisions are shaped by conversations that can be wrenching for all those involved, regardless of one’s faith or demographic background. Willie Bass, who has been married to Janice for nearly four decades, had been chatting from the bedroom doorway at the start of her August appointment. But once the conversation takes a more serious turn, he slips away down the hall.

He doesn’t want to contemplate the possibility that she’ll die before him, Janice Bass tells McCammon.

McCammon leans forward as they talk, occasionally patting Abbey, the sweet Yorkie curled up against Bass’s feet. They settle on a plan. McCammon will meet with Willie Bass at an upcoming visit to discuss the advance directives documents.

“I don’t want to linger on,” Janice Bass says. “No. I told him if I’m on life support two weeks, that’s one day too long.”

### Bridging Cultural Divides

UAB Hospital, one of the largest public hospitals in the country, is a bustling facility with nearly 110,000 emergency department visits and slightly more than 50,000 patient discharges in fiscal year 2018.<sup>6</sup> Nearly 24,000 of those discharges involve patients who live in counties outside of the county that includes Birmingham.

Outside of a few urban centers, Alabama is a largely rural state. In fourteen of the state’s fifty-four rural counties, as many as 16 percent of households lack a vehicle, according to the Alabama Rural Health Association.<sup>7</sup> “We literally have patients who have come to Birmingham who have never been on elevators or escalators before, and so they are very overwhelmed,” says Rev. Moneka Thompson, one of UAB Hospital’s chaplains.

Neither does Alabama fare well in providing residents access to palliative care, according to the latest state-by-state report from the Center to Advance Palliative Care and the National Palliative Care Research Center. Alabama was among the five lowest-performing states nationally: Fewer than 40 percent of its hospitals offered palliative care services in 2019.<sup>8</sup>

While patients might sometimes perceive hospice and palliative care as one and the same, with palliative medicine they can still get aggressive treatment for their disease while also getting help with their symptoms, counseling, and spiritual support, among other services, Tucker says. (With hospice, typically in the last six months of life, clinicians provide symptom relief and support but not potentially curative treatment.)

“[Palliative care] seeks to provide an extra layer of care,” Tucker says, ideally

starting shortly after a serious diagnosis, whether that's advanced cancer, chronic heart failure, or a neurological disease. "It's not just waiting to die and getting the hospice services while you die," he says. "It's more about how you're living your serious illness journey."

In Alabama faith and spirituality are deeply held, with 86 percent of residents describing themselves as Christian, according to a Pew Research Center analysis.<sup>9</sup> Nearly three-fourths surveyed report praying at least once daily—a higher percentage than in any other state except for Mississippi. For some African Americans, their spiritual faith may also be layered upon a mistrust in the health care system to do right by them, Thompson says. The African American pastor is part of a deep bench of chaplains who work at UAB Hospital, twenty-four full time and eleven part time.

"There is a natural hesitation, and there is this irrational cultural belief that our death is hastened when we come into health care," Thompson says, "because there is still the belief that racism is so prevalent that you will not try to save my life, that you will do things that will hasten my death."

While the Tuskegee study might seem like a fading relic of history, there are people living in Alabama today who are the victims' descendants, Thompson points out. She's one of them. The forty-three-year-old pastor didn't learn until several years ago, while working on a family history assignment for a master's degree in counseling, that one of her great-uncles had been an involuntary participant. It was likely not discussed within the family because of long-simmering anger, generations later, Thompson says. Also, she adds: "It's another cultural thing, where African Americans don't talk about illness or what causes death."

In the past year Thompson has been working with several others at UAB to develop an African American advisory group of roughly a dozen urban Birmingham pastors. The pastors will provide guidance for future end-of-life studies at UAB as well as their perspective regarding how clinicians can understand and respect the cultural values of African American patients. "Let the

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community teach us how to reach them," Thompson says.

The work with the Birmingham clergy follows in the research footsteps of a community-based collaborative approach that a researcher recently hired by UAB pursued in South Carolina. Through focus groups and community advisory groups there, Ronit Elk solicited feedback from African Americans and whites about how clinicians could improve communication about serious illness.<sup>10</sup> Now Elk is using some of the insights that she's gained from that study and other research that she's conducted to train doctors and other clinicians at UAB to adopt more culturally sensitive language.

While religion and the role of hope resonate among both racial groups, they're particularly engrained in the hearts of African Americans, says Elk, associate director of UAB's Southeast Institute for Innovation in Palliative and Supportive Care.

"Hope and miracles are fundamental key concepts in the African American community," Elk says. "Now here's the clash that happens. Physicians are taught to tell the so-called truth in terms of, 'This is what is happening in your body.'"

So the physician might walk in detailing lab results and the odds for potential organ shutdown and other medical speak, Elk says. "But the African American patient says 'First of all, you're not the decider. It's God that is the decider. And secondly, there is always hope. And a miracle can happen.'"

Starting next year in 2020, Elk, working with Thompson and others, will initiate a similar collaborative effort in the Tuskegee area to learn from residents there how to improve discussions about serious illness. Thompson views her involvement in part as an homage to her great-uncle.

"Out of respect for what he went

through," she says. "And bringing a much more ethical research study to that same area, that will respect the culture—that really wants to hear your voice."

### Bringing Comfort Closer

Palliative care remains scarce among Alabama's smallest hospitals, offered at only five of twenty-seven (18.5 percent) of hospitals with fewer than 50 beds versus nearly all hospitals with 300-plus beds, according to the recent Center to Advance Palliative Care report.<sup>8</sup> The national pattern is similar: About one-third of small hospitals incorporate palliative services, versus 93.7 percent of those with more than 300 beds.<sup>8</sup>

These patients might suffer needlessly at home without adequate symptom relief and other mental health support, or bounce in and out of their nearby rural hospital, using it more as a primary care clinic, says Marie Bakitas, associate director of the UAB Center for Palliative and Supportive Care. Or, as their condition worsens, they might get transferred to a larger hospital far from home.

"Their family can't visit," Bakitas says. "They are overwhelmed because they're in a sophisticated environment. People aren't really talking to them or wanting to know what they want. And they die miserable deaths in ICUs."

Elk and Bakitas, both among the co-authors of a systematic review of palliative care in rural settings worldwide, note that until recently there have been very few such studies in the US.<sup>11</sup> Bakitas is among those few who have conducted such research, studying, for instance, the use of telemedicine with rural cancer patients.<sup>12</sup> Moreover, the model of multidisciplinary palliative care teams that's been developed at large medical centers isn't feasible to replicate in their rural counterparts, Bakitas says.

Earlier in 2019 Elk and Bakitas launched a study at three rural hospitals in the southeastern US, combining the culturally sensitive curriculum that Elk has helped develop with Bakitas's research into telemedicine. None of the three hospitals involved—located in Alabama, Mississippi, and South Carolina—had previously offered hospice or palliative care, Bakitas says. The study's 352 white and African American hospitalized patients will be ran-

domized to either usual care or support via telemedicine with a long-distance palliative medicine physician.<sup>13</sup>

Jacob Graham, a palliative medicine physician at Forrest General Hospital in Hattiesburg, Mississippi, was paired for telemedicine with the much smaller Highland Community Hospital in the town of Picayune, an hour south along the route to New Orleans. When physicians at Highland Community have a patient who is seriously ill or in decline, the patient and their family members can connect directly through video conference with Graham for a palliative care consult. “If we can figure out early that things aren’t going to work out for that person medically in all likelihood and get people on the same page,” Graham says, then hopefully an unnecessary transfer can be avoided.

“I hate the [situations] where someone has to be transferred to Forrest General to the intensive care unit,” he says. “Family is a little ways away, and we have restricted visiting hours in the intensive care unit. Maybe they come here to the hospital, but they don’t have twenty-four-hour access to their loved one.”

In fiscal year 2018 clinicians at UAB provided palliative care consults to slightly more than 1,500 patients in the hospital or emergency department, according to the most recent data available from UAB. Through UAB’s outpatient palliative care clinic, they treated 730 patients that year; nearly 700 patients died on the twelve-bed inpatient palliative care unit. (UAB recently published a descriptive look at the demographics and other attributes of their palliative care patients from 2004 to 2016.)<sup>14</sup>

Along with improving quality of life for patients, palliative care also appears to cost hospitals less than other intensive treatment. A recent meta-analysis of six studies looked at the economic impact of providing palliative care consults within three days of a patient being admitted with a serious illness. Across all diagnoses, there was a statistically significant decline of \$3,237 in direct hospital costs, according to the findings, published 2018 in *JAMA Internal Medicine*.<sup>15</sup>

When UAB introduced its palliative care program many years ago, it ran some similar cost analyses, Tucker says.

## Clinicians are enabling the natural dying process to unfold, so people can leave this life more peacefully without being tied to machines.

It found savings in terms of reducing unnecessary imaging and other testing, as clinicians focused care more closely on the patient’s treatment goals. “We don’t even do those calculations anymore because it’s kind of a no-brainer,” he says. But, he adds, the program’s purpose has not been to save money: “It just so happens that it does.”

When feasible, clinicians at UAB increasingly strive to bring palliative care services closer to patients like Bass, who McCammon started visiting in late 2018. Chao-Hui “Sylvia” Huang, who directs the palliative center’s psychology and counseling program, endeavors to meet with patients for counseling when they’re already at UAB for a test or another appointment. One August morning she sat down with Kathy Collins, who has advanced leukemia, while the sixty-five-year-old was waiting in the infusion room for her platelet transfusion.

Collins, who has been meeting with Huang for more than a year, not only has been coping with the symptoms of her leukemia and treatment, but also frets that she might leave behind two young grandchildren, who she’s been raising, Huang says. The clinical psychologist scoots her chair close, talking with Collins for an hour about her painful mouth sores, her worries about her family, and her inability to sleep, covering one of the woman’s hands with her own.

“I feel like I’m in a spider web I can’t get out of,” Collins tells Huang, “almost to the point of a panic attack at times.”

### Incorporating Spirituality

The hallways of the hospital’s inpatient palliative care unit are hushed, family members talking quietly in clusters. The open doors reveal spacious rooms, more like hotel suites with chairs and couches inside. As palliative medicine physician Garrett Hurst makes his morning rounds, he pauses to pro-

nounce a patient’s death, before moving on to the next room.

In one, family members gather on two couches. An inflatable mattress leans against the opposite wall. A fifty-three-year-old woman lies frail and spent in a hospital bed in the room’s center. She had been admitted to the unit a few weeks before with stage IV colorectal cancer. Her husband, who gently rubs his wife’s feet as he speaks with Hurst, describes how she spent a short stretch in the sunshine the previous day. They hope to take her outside again, he says, perhaps with the help of oxygen.

At one point, he tells Hurst that family members have made their peace with goodbyes: “I don’t think there’s anything unsaid on either side.”

Also on the unit this morning is Estella Woods-Holmes, who has worked on the unit since it opened. Woods-Holmes, who is now the nurse manager, grew up in the Selma, Alabama, area, a predominantly African American and religious region of the state. Helping patients and family members navigate through their final days wasn’t where she would have imagined herself for so many years.

“When death came, they hung on to the last,” says the African American registered nurse, recalling her childhood memories of seriously ill adults. “They would just really believe that they’re going to be healed, no matter what, how sick they were.”

Woods-Holmes says her faith remains strong. She hasn’t relinquished her belief in God and miracles, she says more than once. But through the years, as she’s shared her work back home with loved ones, she’s tried to convey that clinicians are not withholding care, but rather focusing on comfort—enabling the natural dying process to unfold, so people can leave this life more peacefully without being tied to machines, she says.

“Not all of us are going to be healed here,” Woods-Holmes says. “But what I have seen happen has been such a blessing to a sick patient [who] has been toiling and going through an illness for so long. After seeing that a few times, I really felt like, ‘This is where I was supposed to end up.’”

## Starting Support Sooner

When speaking with clinicians and researchers at UAB, one gets a sense of forward momentum—that they feel poised on the cusp of gaining even more traction in their efforts to help their diverse patient population.

“Our health system has been very progressive on this issue because it’s an equity issue,” Tucker says. “It’s about equity in how patients get all levels of care. Not just curative care, not just preventive care, but also humane care for serious illness.”

That includes connecting with more patients earlier in the disease process, before they might feel all that sick. Patients like Izetta Burkett, who met with Tucker in the outpatient palliative care clinic in August for a checkup.

The seventy-six-year-old, who has stage IV lung cancer, exudes more energy than some people two decades youn-

ger. The cancer has spread to her brain, but the latest imaging showed that radiation treatment has eliminated nearly all of the spots, she says. “God is really helping me to get through this,” she says, prior to her appointment with Tucker. “I know whatever happens it’s his will.”

Burkett was first diagnosed in the summer of 2018, after she’d complained to her doctor about fatigue. “Maybe that’s when the Lord intended me to know.”

Burkett tells Tucker that she hasn’t had any difficulties with breathing. She doesn’t feel any pain. She’s dropped a part-time cleaning job following some recent dizziness, which Tucker doesn’t believe is connected to her cancer.

But Burkett continues to work her main job as a home care aide, “sitting with” a 100-year-old woman from 3 p.m. to 11 p.m. four days a week, doing some light cleaning, preparing the woman’s

dinner, and helping her get ready for bed. Family members have encouraged her to quit that job, too, she tells Tucker. But she likes staying busy.

“The only thing that I’ve really seen change over the last few months is that you gave up your second job,” Tucker tells her. “You’re continuing to do the things that you enjoy doing, and that’s what we need to keep first and foremost.” ■

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## NOTES

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