

Some hospices want to expand traditional boundaries

By Robin Williams Adams Your Health correspondent

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LAKELAND — Sitting back in a wheelchair designed to support his small frame, Parker McAdoo's eyes sometimes moved from side to side as his parents talked about a local hospice's role in his medical care.

At other times, he looked straight ahead, his lips open slightly, making an occasional humming sound as he held two soft stuffed animals. When a visitor stood beside him to say goodbye, he moved one hand slightly toward her but he couldn't speak.

Parker's parents, Jennifer and Colin McAdoo, must interpret what he wants.

The McAdoos learned Parker has a rare neurological condition, called Alexander disease, when he had a seizure weeks after his first birthday. It's part of a group of disorders, leukodystrophies, that lead to the destruction of insulation covering nerve fibers in the brain.

Parker, now 10, and his family have gotten services through Good Shepherd Hospice since he was 2.

The help they've received includes nurses staying with Parker at home when he was ill, rather than putting him in a hospital, and arranging other assistance to cover medical equipment his parents' insurance didn't.

A social worker spends time with his 8-year-old sister to make sure she copes with the impact of his illness on the family and doesn't feel neglected. When his condition grew worse in the past year, preventing him from returning to

elementary school, a home health nurse began staying with Parker while his parents work.

His mother is a nurse at Tampa General Hospital. His father does painting, pressure washing and other home improvements.

In addition to work and Parker, the Lakeland couple need to look after their other three children: Peyton, 8; Paxton, 2; and Piper, 6 months.

Eight years isn't a length of time people typically associate with hospice organizations. Hospice is for people expected to live six months or less.

Since the 1990s, however, the concept of palliative care for patients whose illnesses aren't so immediately life threatening has gained momentum.

Hospitals, doctors, hospices and others recognize that patients with chronic, severely limiting illnesses often need services beyond traditional hospital and doctor care before their illness is so advanced they meet time guidelines for traditional hospice.

"What we really want to do ultimately is keep people out of the hospital," said Judith Skretny, director of palliative care for the National Hospice and Palliative Care Organization in Alexandria, Va.

Chronic obstructive lung disease or congestive heart failure are examples often cited by supporters of expanded adult palliative care.

Large hospitals, among them Lakeland Regional Health, have created in-hospice palliative care units.

Hospices interested in doing expanded palliative care, beyond their usual constraints, sometimes partner with hospitals' palliative care or create their own community-based palliative care.

Compassionate Care Hospice of Central Florida has that type of program, which it calls Advanced Care Connections, in Sebring, said Rana McClelland, executive director for Polk, Highlands and Hardee counties.

It helps patients with chronic illnesses who are expected to live longer than six months.

She expects the palliative program to become available in Polk County sometime this year. It's also in Lake, Sumter and Miami-Dade counties.

"A lot of patients out there are in that gap where there aren't a lot of services in the community," McClelland said.

Compassionate Care already has hospice services in Polk County.

Understanding the difference between traditional hospice care and community based palliative care can be difficult.

Partly that's because hospices give palliative care to their traditional patients; services like pain control, symptom management, counseling, emotional and spiritual support and other comfort aimed at enhancing quality of life.

A community-based or purely palliative care for people with longer than six months to live does a lot of the same.

"All hospice is palliative care ... but not all palliative care is hospice," Skretny said.

One key difference: "To access palliative care, you don't need that diagnosis (of six months or less.) And you can be getting curative treatment."

She estimates about half of her national organization's members have some form of palliative care program.

In another change from times past, some hospices are more receptive than others to letting traditional hospice patients get more aggressive treatments like radiation to alleviate their symptoms, said Dr. Ron Schonwetter, chief medical officer for Chapters Health System, parent company of Good Shepherd.

Children with ongoing conditions that aren't likely to let them live into adulthood, but that will continue longer than six months, are another group needing palliative care.

Parker and about 50 other Polk County children with severe, chronic, disabling illnesses get care from Good Shepherd through its participation in Partners in Care: Together for Kids. Partners in Care is a program allowing palliative "comfort" care along with therapies to cure children's illnesses or prolong their lives.

“We focus on the whole family, trying to provide support and services,” Schonwetter said.

That’s definitely true for their family, the McAdoos said.

The Lakeland couple discovered the wheelchair Parker needed consumed all the yearly amount their insurance would pay for durable medical equipment. Yet Parker, on a feeding tube for eight years now, needed other expensive medical supplies.

Jennifer McAdoo, not yet a nurse, went online to look for medical items at a cheaper price. She and Colin also were concerned with whether they were doing everything he needed, so they contacted Good Shepherd in September 2009.

“We needed some help in making sure his quality of life was being considered and maximized,” she said. “We were having a difficult time.”

Parker’s frequent medical crises put a strain on his family, but equipment Good Shepherd provides allows him to recover at home now from illnesses that once sent him to the hospital.

Florida has some quality community palliative care programs, Skretny said. In Polk County, however, getting them has been slow.

Cornerstone Hospice and Palliative Care and Good Shepherd Hospice, two large nonprofits, have provided hospice care in Polk for years. Neither has a “purely palliative” program here for adults with serious illnesses who aren’t ready for hospice.

Cornerstone does outpatient and inpatient palliative care with oncology patients at Orlando Health. They also provide consultations in Lake County and look forward to expanding to Sumter County in the near future, said Dr. Michael Shapiro, its chief medical officer.

They work collaboratively with Lakeland Regional Health’s palliative care unit in providing services to their hospice patients, such as bereavement and counseling, he said.

Chapters Health partners with some pediatric palliative care programs in the Tampa Bay area.

Both medical officers said they support the idea of having greater access to community based palliative care programs if finances and staffing would allow it.

Medicare has an established hospice benefit package, but expanding palliative care to a wider group means more complicated billing and reimbursement, Skretny said. Programs often need to raise community funds for services Medicare won't cover.

Her organization is working with the federal government in an effort to get established funding for more open access to palliative care. The growing number of baby boomers with chronic conditions is likely to give the movement more leverage.

— *Robin Williams Adams can be reached at*

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