What if hospice services weren’t just for the dying?

by Michael Ollove in the July 27, 2022 issue

Gloria Foster wasn’t ready for hospice, even though, with a prognosis of less than six months to live, she qualified for it. She was debilitated by diabetes and congestive heart failure and was living with both a pacemaker and a device to help pump blood from her heart to the rest of her body.

Foster didn’t want to enter hospice if, as is normally required by Medicare, she would have had to forgo treatments that might, against all odds, reverse the course of her disease.

But under a Medicare pilot program that began in 2016, Foster was able, for a time, to receive home care generally available only to hospice patients. Unlike hospice rules that normally govern Medicare, she wasn’t required to give up treatments for her terminal health conditions.

Still alive long beyond her prognosis, Foster credits the program, which ended for her in December 2019, with stopping her frequent hospitalizations, improving her mobility, and greatly boosting her spirits.

“When it came to an end, I was very upset,” she said. “I cried, as a matter of fact.”

An independent evaluation of the five-year pilot—the Medicare Care Choices Model—recently provided its most robust data so far: the results found that participants were able to stay out of the hospital and live longer at home, while also saving Medicare money.

The results were so encouraging that many who work in palliative and hospice care think the study’s conclusions will lead to some of the most important policy changes ever undertaken in the field—not just for patients with Medicare but also for low-income people with Medicaid and others with private insurance.

These professionals hope the pilot project’s results will be the catalyst for delivering a raft of traditional hospice and palliative care services to millions more Americans struggling with debilitating chronic disease, whether imminently terminal or not.

When Congress created a Medicare hospice benefit in 1982, they were mainly focused on cancer. At that time, when treatments for cancer patients proved ineffective, the trajectory toward death often seemed clear. Hospice switched the health-care emphasis to symptom relief while enabling dying patients to use their remaining time in as fulfilling a way as possible by, for instance, spending time with family or simply sitting outside on a pleasant day.

But since 1982, cancer treatments have dramatically improved, extending lives, while higher percentages of Americans are dying of diseases other than cancer, particularly of respiratory illnesses and illnesses related to dementia.

Many advocates and providers think other patients with serious but not necessarily terminal conditions also would benefit from a full array of palliative care services delivered in the home.

The pilot followed 4,574 participants from January 2016 through September 2020. They were entitled to services identical to those typically available with the Medicare hospice benefit, with some exceptions.

Compared with a control group not enrolled in the pilot, participants required fewer intensive medical interventions. For example, they had 26 percent fewer inpatient hospital admissions. They also spent 38 percent fewer days in an inpatient intensive care unit and 30 percent fewer days in other inpatient hospital units. And they were able to spend about six more days at home than those in the comparison group.

As a result, Medicare expenditures for participants were 17 percent lower than for nonparticipants.

“When you give people more choice and greater freedom to make choices in their best interests, they make decisions that are better for them in terms of quality of care but better for the country in terms of costs,” said Edo Banach, president of the National Hospice and Palliative Care Organization, which represents hospice and palliative care providers. “The demo worked.”

Before she joined the pilot in 2017, Shirley Klionsky, 91, of Marlboro, New Jersey, recalled, “it was hard. Something was always going wrong, and I was always going to the hospital.”

That ended during the pilot, thanks to the hospice team’s weekly visits and monitoring of her advanced lung and heart disease. Klionsky wouldn’t have entered the program if it had meant giving up the treatments for her disease. Hospice wasn’t for her.

“That would have meant dying,” she insisted, “and I said no to that.” —*Stateline*, an initiative of The Pew Charitable Trusts. This story is part of the SoJo Exchange from the Solutions Journalism Network, a nonprofit organization dedicated to rigorous reporting about responses to social problems.