

I MET Maxine Olson years ago, one Sunday at church, during a break in the service where we all say hello, shake hands, and hug. She was mature, healthy, and intelligent. I did not realize, though, that she was such a giant intellectual until I got to know her at the church book club. She became someone I always hastened to sit beside. In my mid 50s, hearing her on spiritual matters was divine. I am one always hungry for maternal wisdom.

Then COVID hit and our book club had to go online. Since I write for a living, I spend much of my free time off the computer and Zoom, and I missed Maxine's final year. Months passed and I heard she was not feeling so well. Practicing safe distancing and praying was all I could do for my friends in my busy life during a pandemic.

I believe our elders have so much to teach us, but rarely do we take the time to slow down. Rituals with family have been shown to help. Some cultures bring their offspring to elders for both childcare and a well-needed

In addition to pain and symptom management, hospice care benefits include a variety of services for patients and their families: education; emotional and spiritual support; assistance with financial issues; help with the patient's personal care and hygiene; and respite care to give a family caregiver a break, from a few hours to up to five days.

As Maxine struggled, her daughter Andrea listened to a caring doctor who told her, "If this was my mother, I would want to bring her home." As a daughter who really loved her mom, she did just that, hospice allowing her the luxury. Once she made her decision about hospice, the hospital asked her to choose an agency. She chose Angel Palliative Care and Hospice (APCH). When she called, they were able to help make the transition home possible.

APCH ordered a hospital bed to be delivered and coordinated the delivery so that Maxine arrived by ambulance transport. They were there to set up the equipment before her son, a registered nurse himself, arrived to help.

who wants to stay in his or her own bed. There actually are benefits to using a hospital bed at home that caregivers may not understand. "We know how hospital beds can prevent things like aspiration and pressure ulcers," notes Asadov.

She notes that its rails also decrease the fall risk, providing an aid to the patient for self-repositioning and assisting the caregiver to roll side to side. Moreover, these special beds can help the caregiver with positioning the patient for meals if he or she does not have the ability or energy to get up.

APCH also guides family members, to teach them about shower chairs, oxygen tanks, toileting supplies, and other equipment, and that includes invaluable training that comes in handy when their family member has a need for it.

Adds Asadov: "Health care shouldn't be about the quantity of patients you can care for; it should be about the quality of care you provide; health care should be patient and

HELPFUL HOSPICE

BY SARAH SHERWOOD

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break for working parents; others ask them to run rituals and functions so that those of us who are younger can witness and learn. However, our society affords us a critical last minute refuge with our seniors: hospice.

Hospice is a medical specialty, with trained physicians, nurses, social workers, chaplains, and other professionals at the ready for people who want to die in the most natural and peaceful way possible. Hospice is a philosophy of care for people with advanced illnesses. It treats the person rather than the disease and focuses on quality of life. Services are patient-centered because the needs of the patient and family drive the activities of the hospice team.

Hospice is provided in the patient's residence, whether it is home, an assisted living facility, a board and care, or even skilled nursing in a certified location—wherever the patient calls home.

The most common conditions associated with hospice care, according to the National Hospice and Palliative Care Organization, are cancer (28%), cardiac and circulatory diseases (19%), dementia/Alzheimer's (17%), respiratory diseases (11%), and stroke (nine percent). Degenerative neurological diseases and end-stage liver and kidney disease, amyotrophic lateral sclerosis (ALS, or Lou Gehrig's disease) are other conditions where hospice plays an important role.

Then Andrea went a step further: during a difficult pandemic, she worked with her mom's church to seek out support. When she struggled, her son came to help, and as a registered nurse as well as Maxine's grandson, he provided both physical and emotional care. Andrea spent her days not just providing for her mother, but sitting with her, reading the newspaper, books, and poetry, knowing that was her mother's normal. This was the house she grew up in, and the memories were not the same as the new reality of COVID: "I was thankful to be here during the pandemic because it became even more important to prevent my mom needing to go to a rest home."

Because of her daughter and grandson's decision, Maxine went through hospice surrounded by what she loved: her family, books filled with spiritual guidance and poetry, music sung by her church choir, the same church choir she had been accustomed to every Sunday, and all of this, at home.

"Most people do not realize all of the aspects of what hospice offers and that causes them to call us later than they should," says Lena Asadov, the administrator of APCH. Asadov's role is all about providing effective coordination of care among a team of dedicated medical professionals, each with a specific role and mission to help care for all involved.

Asadov provides the example of a patient

family centered, independent of what insurance may or may not cover."

Alina Baranovsky, also a patient's family member aided by APCH, feels appreciative of all of the support she received at such a sensitive time. At first she was afraid of hospice. The entire concept seemed scary, but once the process began, she worried less. "I felt more relief just being able to spend the last time I had with my father instead of being overwhelmed by the necessities," she says, fighting back tears.

"It was such a stressful time for all of us. I will never forget how they helped us." After composing herself, she explains that the hospice's knowledge and patience helped to relieve the pain she felt. "They were there for us," she whispers.

Hailey McKeefry, an ordained deacon in the Episcopal Church and an interfaith hospice chaplain, also expresses how the myths around hospice can affect choices that families make: "Hospice cares for the whole person, not just the body."

She is a chaplain who counsels patients and families—and that included Maxine Olson. To McKeefry, the most important aspect is the spiritual care of helping patients and their families figure out how to have a good death, together, in the most healing way. She insists that spiritual care is not about being re-

ligious; instead, it is an act of creating space to make important decisions for those facing their last days on earth.

“Modern culture has let death become an alien and frightening concept. Hospice can bring it into the realm of a natural and peaceful place for patients and families. It provides the space for families to be together, to ask the taboo questions, and makes allowance for all the emotions that come with end of life.”

Success for McKeefry is when families feel empowered and comfortable. In medicine, the goal is a cure. In McKeefry’s world, however, it is all about healing. She teaches that hospice should be about families coming together in the most peaceful way.

older adults often are admitted to hospice for short duration despite experiencing symptoms months prior to the end of life. While hospice utilization is rising, “lengths of stay for many patients remain too short for them to receive the full benefit of hospice care.”

The National Hospice & Palliative Care Organization points out that hospice utilization among Medicare decedents exceeded 50% for the first time in 2018, and more than 27% of patients in 2017 were in hospice for seven days or less, with another 12.7% in hospice for less than 14 days.

Patient feedback tells us that the No. 1 need that families report on hospice via the Centers for Medicare & Medicaid Services’

status,” at any time for any reason. Patients also can come back to hospice at any time, as long as they meet hospice eligibility guidelines—patients who have six months or less to live, depending on the doctor’s criteria, which can be extended when needed.

Baranovsky urges family members not to avoid help: “Sometimes you need to do the best for you. Sometimes you need help. We learned a lot about not putting too much on yourself. We asked for the right help.”

After a patient passes, for up to a year hospice can address emotional and spiritual pain suffered by loved ones. Baranovsky reports that she felt close to her hospice caregivers, like they were part of her family, coming in the middle of the night sometimes. “It made all the difference.”

Being at home, surrounded by family and friends, improves quality of life, stresses Asadov. Chats with the team social worker or chaplain address emotional pain. Her win comes when she sees that slowly, a hospice patient—and his or her family—begin looking forward to tomorrow.

Most hospice patients do not have any out-of-pocket expenses. Medicare Part A covers up to 100% of the cost of hospice care related to a hospice-eligible patient’s illness with no deductible or copayment. Private or employer-provided health coverage will vary. Patients should check with their insurance provider for details about hospice eligibility, coverage, and out-of-pocket expenses. Medicaid supplies hospice coverage, but it varies by state.

Once a patient dies, the family can call the hospice agency and a doctor officially will be able to pronounce the death, as well as help make arrangements for mortuary to pick up the patient who has passed. This is another major benefit of having a hospice agency onboard at end stage of life: Asadov tells us that with hospice, there can be no need to call paramedics, hear the blare of sirens, and deal with a lot more during such a difficult time.

Maxine’s family wanted to surround her with the things she loved during her final moments, and her daughter Andrea really fulfilled that promise. Maxine passed at 3 a.m. at home, with her and her son Nathan at her mother’s side. As they heard her last breath it was quiet and peaceful, just as they wanted.

Andrea is getting some well-needed closure before she goes home. A teacher, she says it was worth it to interrupt her life to have been with her mother. For now, she is staying in Maxine’s house with her beloved dog and the memories of her mother’s last couple of years.

It also is lovely to know that Maxine was indeed a part of a spiritual community that rallied together for her. It is one congregation that is forever grateful for this peaceful transition—and for the beautiful opportunity just to say goodbye to a dear friend. ★

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McKeefry relates that, through her work, she sees families planning what they want end of life to look like. It could involve friends visiting, music, pets, and other creative things, but the common focus is comfort and adhering to the wishes of the patient and family. Death is always hard, but with hospice it can be less hard, she indicates. Maxine, for example, had soothing spiritual music along with the choir visits.

Both Asadov and McKeefry emphasize once more that what makes the end of life experience easier is calling on hospice sooner, and studies back that up. Some believe being admitted to hospice will shorten their lives. Not so. For instance, the *Journal of Pain Management* offers a study which shows that, based on an analysis of end-of-life data on nearly 4,500 adults—about 4,000 of them cancer patients—those who received hospice care lived 29 days longer, on average, than patients who did not. Twenty-nine days is quite a bit of time when someone you love is about to die.

According to a Yale University-led study,

Consumer Assessment of Healthcare Providers and Systems is that they wish their loved one had entered hospice sooner.

There is another common misconception that choosing hospice means giving up hope. Asadov and McKeefry know that once the family member experiences hospice, they have a different experience. They teach that given the time, hospice relieves suffering, promotes dignity, and facilitates closure for patients and families.

What does it look like? The staff are dispensing medicines as needed to help with symptoms. Physician specialists are advising staff to give just enough medicine to manage symptoms and ease pain. Family or friends come by to provide care with support from the hospice team. This takes place at home, but for patients who live in assisted living communities and nursing homes, the hospice team works together with the facility staff.

For those who improve to the point where they can resume normal life, like remission, for example, they may “revoke their hospice