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Assisted Living vs. Hospice: Who's in Charge?

By JUDITH GRAHAM

It was an emergency, the older woman told a hospice worker in a phone call in the middle of the night. Her husband wasn't doing well and someone needed to come and check on him.

For more than an hour, the woman waited nervously on the couch in the couple's assisted living apartment, expecting a response. Then she picked up the phone and called again. This time, the hospice worker said she had asked an aide in the couple's assisted living facility to follow up. Why the aide hadn't come yet, the hospice worker didn't know.

"This happened more than once," said Doug Cooper of San Diego, Calif., describing experiences his elderly parents went through several months ago, after his father was told he had end-stage congestive heart failure. "There was just no coordination between the hospice people and the assisted living people until I complained and made everyone sit down together."

Once, older adults moved out of assisted living when they developed life-threatening illnesses, going mostly to nursing homes with round-the-clock care. But now, assisted living facilities usually try to help residents remain in their apartments, even when they're seriously ill and eligible for end-of-life hospice care.

That's good news for seniors who want to die at home; about one-third of assisted living residents now do so, according to Maribeth Bersani, senior vice president of public policy at the Assisted Living Federation of America.

But arranging for hospice care in assisted living facilities presents challenges. A handful of states - Idaho, Mississippi, Montana, and North Dakota - won't allow hospice services to be provided at assisted living centers, deeming the needs of end-of-life residents too demanding for these facilities. South Carolina requires a waiver for hospice services in assisted living. Other states, including Alaska, Arkansas, Florida, Rhode Island, West Virginia and Vermont, will allow existing residents to receive hospice services but won't accept new residents who require end-of-life care.

A common misunderstanding surrounds how much attention assisted living centers can give to someone who is terminally ill and whose medical needs are intensifying. "Assisted living is not like a nursing home: staffing ratios are much lower, and less help is available," said Beth Breen, senior executive director of three assisted living centers for Centura Health at Home,

a division of Colorado's largest hospital network.

"If a person is still ambulating and transferring" in and out of a bed or a chair on his own, she said, "and the family helps out, assisted living is absolutely appropriate. But if he can't do this, the family will have to bring in help from an outside agency and pay for that care out of pocket."

This was a decision Mr. Cooper and his mother made recently for his 85-year-old father. The frail man had to go to the bathroom frequently at night because of diuretics he was taking for his heart condition.

Although assisted living staff were supposed to respond in 10 minutes when a call button was pushed, that wasn't happening routinely. So the family hired a live-in caregiver to give Mr. Cooper's father extra attention while giving his exhausted mother a break.

Needless to say, such an arrangement is expensive and many families can't afford this level of care. Keep in mind, assisted living isn't covered by Medicare and more than 80 percent of families depend on personal savings or other income sources to pay for this housing option.

Another common misunderstanding surrounds the scope of hospice services. Many people think that hospice care will provide 24/7 nursing assistance to someone at the end of life, but that's not the case. Typically, a hospice nurse will visit a patient only once or twice a week unless the person is in an acute crisis, and a nurse's aide will come out several times to help with bathing and other personal care needs.

The home-based hospice model assumes that a family member or another caregiver is there round the clock, and "our job is to provide education and support so they will feel confident in delivering the care" their loved one requires, said Claire Lucas, director of facility based services for The Denver Hospice. Again, the issue of who's going to provide the round-the-clock care that a dying person may need comes to the forefront.

Lots of other issues need to be worked out as well. "Sometimes, assisted living staff may not be comfortable with death and dying or the hospice philosophy. They may be thinking 'is hospice coming in here to do harm to this resident?,'" especially when treatments for an incurable illness are stopped, said Kevin Clark, director of two hospice programs associated with Centura Health at Home.

Also, "assisted living staff can be very nervous about dealing with narcotics" prescribed by hospice doctors to control pain, Mr. Clark said, noting that educating staff about opioids, what they're used for, how to administer them and the overall approach of hospice care is often necessary.

Many assisted living centers won't allow hospice "care kits" stocked with medications such as morphine, Haldol and Ativan on their premises. Such kits are routinely distributed to patients receiving hospice services in their homes, so caregivers can administer the medications as needed to control "breakthrough" pain, said Dr. David Koets, chief medical

officer of The Denver Hospice.

If the kits are unavailable, other arrangements for the sudden onset of intolerable pain, agitation or anxiety will need to be made.

Then, there's the overarching issue that Mr. Cooper and his mother encountered when his father signed up for hospice services: Who will be responsible for what?

This encompasses everything from the mundane -- will hospice or assisted living staff fill the patient's pillboxes? Who will give the patient a bath? -- to essential issues such as "who will call whom when the patient suffers a medical crisis?"

Assisted living staff may have worked with the resident for years, but when hospice staff comes in and takes charge medically, a different set of relationships and a different kind of communication becomes necessary, said Judi Lund Person, vice president of compliance and regulatory leadership for the National Hospice and Palliative Care Organization.

What does this mean for patients and their families? What do you need to look out for and what questions should you be asking when you're looking to bring hospice services into an assisted living facility? I'll walk you through this in an upcoming post.

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