

Home Care Headlines

Articles of interest about home care

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Hospice Care: 'The most rewarding nursing job I've ever had

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Imagine, says hospice nurse Maksim Melnikov, that you were once a principal of a school or the owner of a small business, or maybe the mother of a large family who was actively involved and out in the world. But now, as illness is claiming your life, so many of your daily functions are falling away. You are unable to walk, enjoy food, or go outside.

When life is growing short, there is still a person's dignity to preserve, even in the smallest moments. "For instance," says Maksim, "if a patient can't get out of bed but they can move their hand, I give them their medicine in their hand rather than putting it directly in their mouth. I always ask first, 'Would you like me to hand it to you so you can do it yourself?'" If they can, they usually say yes, he says — and, at least for that moment, they feel their independence rather than suffering yet another loss.

It takes a certain kind of nurse like Maksim to work in hospice care, which brings quality of life to people at the end of life. Besides addressing clinical demands such as mitigating symptoms and alleviating pain, hospice nurses focus on patient and family education, work as an integral part of an interdisciplinary hospice team, and bring a great degree of compassion to their work — all of which I believe deserves special recognition this month as we celebrate National Nurses Month and Week.

"The end of life can be a very frightening time," says Maksim, who has been in hospice care for three years. "The last thing patients want to do now is deal with doctors and nurses. They want to deal with *life*. I go in there as a human being, with humility, and try to bring comfort and peace."



People often wonder what life is like as a hospice nurse, imagining that it must be a bleak and depressing endeavor to be surrounded by death and dying, grief and loss. In fact, the nurses at VNSNY Hospice and Palliative Care, where I work, often say that it is the most rewarding job they've ever had, and that the difference they are able to make in the lives of patients and families during an enormously stressful, intimate and consequential time gives nurses back much more than they put into the job. Here are three core principles that help hospice nurses make that difference:

Meet people where they are

Ellen Eylers, who as a hospice admissions nurse provides an introduction of the service to eligible patients and their families, calls out perhaps *the* most essential quality of a good hospice nurse: "We have to be good listeners," she says. "I make sure I'm starting at the point where the patients and families are, because there's a lot of anxiety. I listen for what's really going on, in order to communicate effectively."

Sometimes that means seeing the bigger picture and helping patients or family members reframe their goals. One of hospice nurse Cristina Sava's patients, a retired architect, confided to her that he was frustrated with his inability to spend as much time as he'd like doing the things he loves — writing, painting, and photography. She discussed bringing in a hospice volunteer with similar interests to help him so he could continue those pursuits, which would have the added benefit of giving his wife time to attend to herself. Cristina also suggested that rather than assessing his accomplishments daily, he take a more forgiving measure, perhaps evaluating his output over three days or a week. "We told him we'd help him come up with a plan," she says. "He was comfortable with that."

Remember that you are a guest in their home

This is true for all home care workers, but the feeling is especially pronounced during end-of-life care. Maksim points out that for many of his patients who have lived a long life, their homes, which they may have lived in for a half-century or more, have taken on a great deal of significance. Maksim recalls admiring art and other precious objects in the home of one patient, an African American man who bought his home against all odds in the segregated 1950s. Maksim's interests prompted stories that deepened the nurse-patient relationship and put his patient at ease in his final days. "His whole life is invested in that home," Maksim notes.

Photo courtesy of the Goldin Family

Upon visiting the home of longtime New York City activist, author and literary agent Frances Goldin, hospice nurse Jasmine Tsai noted how much of the 94-year-old's life in activism was in evidence everywhere you looked — in books, magazine articles, photographs. On a recent visit, Frances gave Jasmine a keepsake from her home, a signed copy of Frances' book on socialism, along with the following advice: "Fight for change. You may not see the change today, but the next generation will see it." "How inspirational!" says Jasmine.

Sometimes the home can prompt humor, which is something that Maksim strives for to put patients and family members at ease. On a recent visit to a patient's home, he took notice of the patient's distinctly 20th-century television, an old Zenith from another era. "Welcome to the Museum of Natural History," he said, prompting a big laugh from the

patient (and a joking offer of the TV — which Maksim declined). "Humor can go a long way," he adds. "I do crack a lot of jokes."

Education can bring peace of mind

Although it is a universal human experience, few people have firsthand experience with death and dying, and education is a big part of what the hospice team offers. Hospice nurses spend time with their patients and, even more so, with family caregivers on how to address such common end-of-life symptoms as breathing problems, pain, changes in behavior and sleeplessness. A printed guide that we leave with the family reinforces this information, and also details several signs that may signal a loved one is transitioning from life to death, such as no appetite or urine output, and changes in breathing sounds and patterns.

Pain management is a big part of family education at the end of life. Taking into account both the well-being of the patient and the cultural sensitivities that family members may have around pain medication, Maksim takes great care to discuss the import of pain and its impact on quality of life. "Everything we do is about education," he says. "I encourage family members to put themselves in their loved one's shoes, to take the journey along with the patient and truly imagine what he or she is feeling."

For Ellen, that empathy — truly seeing things from the patient's perspective — brings the job's the biggest reward, by letting her know that she is truly making a difference at a time when the stakes for the patient could not be higher.

"People are very grateful for somebody just listening and being patient and trying to meet their needs," she explains.

"They may have experienced healthcare that has been disjointed, and maybe even felt a little brutal along the way." She recounts a patient who was recently released from the hospital, where he felt no one was listening to his concerns.

Everything changed when he entered hospice care. "I didn't do anything other than what we do all the time, but at the end of the visit he thanked me," Ellen recounts. "He felt that he had been heard."

She adds, "The patients and the families we're working with are in such a delicate place. It's really an honor to be allowed into that space. It's actually the most rewarding nursing job I've ever had."