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Connecting 'Human Soul to Human Soul' at End of Life

Rosemary Baughn Just now · 4 min read

A VNSNY Hospice and Palliative Care patient receiving a visit from a member of the Hospice Team

Hospitalized with advanced cancer and suffering great physical and emotional pain, *Arminta and her family were struggling to be heard. Her pain, the family felt, was not being managed, and she was not eating or sleeping.

Once Arminta was discharged home to hospice care, physician Dana Tarcatu knew the first order of business. "From the very beginning, it's about deep listening, understanding where patients and families are coming from and giving them an opportunity to tell their stories," said Dana, who is part of a new home-based program that our organization, Visiting Nurse Service of New York Hospice and Palliative Care, offers for patients with complex, advanced cancers and for their families.

Within forty-eight hours, Dana and the rest of the hospice team implemented a medication regimen that got Arminta's pain under control, and began educating her family on what to expect in the final days. "That gave her the opportunity to focus on *being*, on living the last part of her life without being completely consumed by pain," said Dana, a hospice physician with oncology training and expertise.

Equally important, the team established a relationship with Arminta and her family that was built on understanding and trust. "You can offer people the most efficient or sophisticated intervention available, but it's not going to work unless you have their trust," said Dana. "It's not only about symptom management or reducing risk of rehospitalization. It's also about cultivating a connection from human soul to human soul in a way that ultimately has therapeutic value."

November is National Home Care and Hospice Month — a good time to reflect on how far hospice care has come and the benefits it offers for our modern lives.

The hospice movement grew out of Dame Cecily Saunders' visits to London's cancer wards of the 1950s, where patients were being left to die in isolation and without the symptom management and dignity they deserved. Over the years, hospice care — bringing quality of life to end of life — has grown to include patients with a life-limiting diagnosis of any kind, including chronic illnesses in their final stages (cancer is still the leading diagnosis among Medicare hospice patients, followed by heart disease). While there are many commonalities to end-of-life care across illnesses, there are also particular considerations that can help families navigate the final stages of specific diseases.

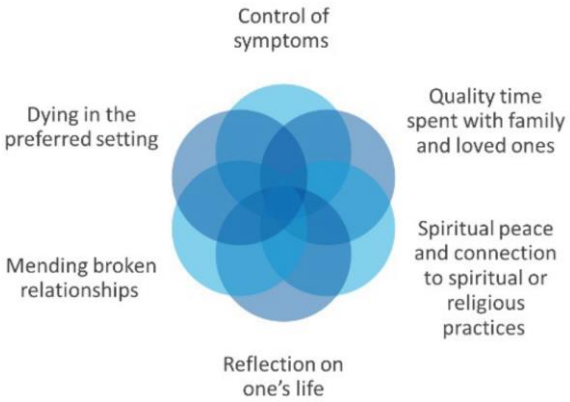
Patients with advanced complex cancers, who are often younger than most patients at end of life, tend to have both significant physical needs, including pain, and pressing psychosocial needs. This can include future care for younger children, financial concerns for the family, and emotional support for loved ones.

VNSNY has created a specialized Hospice Oncology program designed to meet these needs at home, with aggressive symptom management for our patients and, for their families, support and education on disease progression, as well as connection to community resources on financial and funeral planning, and spiritual care and anticipatory-grief counseling. The specialized hospice program brings an additional layer of expertise and support to VNSNY's interdisciplinary hospice team, and maintains connection with the patient's own care team, including the oncologist.

"What we are aiming to do with this program is to integrate end-of-life care as part of the care continuum for patients with highly advanced cancers," Dana explains. "It's not an anomaly on someone's cancer journey, but a normal part of their care."

This program joins other specialty hospice programs VNSNY has initiated for people with advanced-stage cardiac conditions such as heart failure and with chronic obstructive pulmonary disease (COPD) — two of the most common causes of death in the U.S. — and for people who are military veterans, for whom end of life can create many unique challenges.

Patients with advanced complex cancers often come to hospice later in their disease progression, with a shorter length of service than the median 18 days. Their situation is often physically and emotionally fraught, and the specialized hospice team's objective — like that of all our hospice teams — is to understand and support the patient's and family's goals of care. The conversation about goals of care is a continuing one — revisiting the patient's and family's understanding of the situation over time, and introducing supports including spiritual care, social work, and grief counseling as warranted.



"It's not about coming up with a *fix*," says Dana, acknowledging the very real human urge to find such a thing. "Yes, there is an urgency, but we need to show up with a different quality of energy, managing very intense situations with skill, understanding, and a calm compassion."

In one case, the patient's ten-year-old child had come to assume much of his mother's care, and the hospice team's work included supporting him and his needs while not undermining his willingness to help. "We wanted to understand

what was happening in his heart," explains Dana. "We pay attention to the home environment and come to understand the dynamics, and support families without judgment, in a way that does not disrupt the normal flow."

For Arminta, the new medication regimen combined with educating the family on what to expect in their loved one's final days made all the difference. "It was unbelievable how everything changed," says Dana. While time was short, Arminta and her family could focus less on her overwhelming symptoms and more on being together, allowing them to spend meaningful, quality time with each other that resonated long after they had said their final goodbyes.

*Name changed to protect privacy