

BRONX VOICE

14 • BRONX VOICE • April 10 - 16, 2019

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Health Matters

Visiting volunteers bring comfort—and a dog named Chicken

By Chandra Wilson

April is National Volunteer Month, a time to recognize the more than 60 million Americans who volunteer their time year-round, including hospice volunteers who play an important role in end-of-life care for many individuals and families in New York communities. In fact, volunteers are such a vital part of hospice care, their presence is mandated by law and in keeping with the broader social mission to build a community of care at end of life.

You'll find Hospice Volunteers styling hair, walking dogs and listening to or sharing stories with the people they visit. Many play music from a favorite era or country, or they crochet, knit or help patients create legacy projects. Some work individually and some team up in groups, like the Threshold Choir of New York City, which is part of a national network of community choirs that perform the ancient tradition of singing softly at bedsides for people who are ill or dying.

Volunteers can also choose to be part of bedside vigils, an especially important and intense endeavor that requires additional training on the physical, psychosocial and spiritual aspects of a person actively dying, including what happens to the body as it shuts down.

"It is a profound and intimate experience," says Alison Reynoso,

who coordinates the vigil volunteers at Visiting Nurse Service of New York Hospice and Palliative Care. "It's an honor to be in a person's presence as they take their last breath."

Before she knew anything about hospice, Virginia Chang had experienced the deaths of three people very close to her in the short space of seven months, she was bereft and overwhelmed and searching for answers as she worked personally to process her grief. The more she learned about end-of-life care and the "positive death movement," the more she began to see that the deep sense of powerlessness and hopelessness she'd felt in her own situation was not the only option.

When she signed up for the hospice volunteer training program at the Visiting Nurse Service of New York, she knew she was stepping into a new and transformative chapter in her life. She realized that she could put what she was learning to good use and help someone who might have been in a similar situation to the overwhelming shock and sadness that she herself had felt.

"If I could turn around and help someone else through what had been so difficult for me," Virginia says, "it would all have been worthwhile."

Now that she's completed hospice volunteer training, Virginia visits patients and their families one-on-one in their

own homes every week, usually for about an hour or so. She also makes volunteer visits to VNSNY's Goodman Brown Residence to patients who are not able to spend their last days at home. But she considers sitting vigil with someone who lives alone while they are actively dying to be one of the most profound and rewarding experiences she has had as a volunteer.

"It's incredible, it's an amazing time to be with someone," Virginia says. "One of the things I've learned and one of the things that will continue to call me to this work is that when you are with people at this point in their lives, they are so authentic—you're meeting the real person. This is the essence of who they are; they don't have a façade up, they're not playing games with you, there's such a quality to the interaction. It has changed me a lot, in ways I couldn't have expected."

On a trip back home last year to Colombia to visit her 95-year-old grandmother, Natalia Perla began a personal journey that inspires her profoundly in her work as a hospice volunteer these days. The songs Natalia learned at her grandmother's bedside became an intimate and healing cultural legacy that she incorporates into her volunteer visits today.

"People respond to music in powerful ways," she says. "It seems to



Ellen Landress-Bowkett with Therapy Dog Chicken.

touch the heart and the memory in ways that go far beyond words."

Volunteering for Natalia often means going on a "sound journey" with patients who can no longer see or communicate as they once did, but when she sees the smiles, the feet and hands gently tapping in time to the music, she knows there's a powerful connection.

A guitar, a Russian harp, Tibetan Singing Bowls and a drum are all part of the hospice volunteering "kit" Natalia takes with her on her hour-long to 90-minute visits. Music can create a strong emotional bridge for family members and other home care workers too when singing bowls or other instruments are shared at the bedside.

"As a volunteer, you never know what to expect," she says, "and it is such a privilege to see how deeply someone can be affected by music."

That certainly seemed true on a recent visit when a barely responsive patient heard the sounds of Natalia's Russian harp, asked for some paper, and suddenly began to paint.

"A lot of times we think we are doing this work to help others, but the work has a way of giving back that is so meaningful and not always easy to express, it just happens and there you are—this is good work!"

Despite the many benefits of hospice and palliative care, people cope in different ways with the end-of-life experience. When a volunteer first pays a visit to someone receiving hospice care,

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CONTINUED FROM PAGE 14 they've been trained to take it one step at a time. They know to listen, pay attention, be mindful of opportunities to help or offer comfort—to discover what a patient, family member or someone on the care team might need.

Ellen Landress-Bowkett knows this well, and that's one reason she volunteers with her dog Chicken, a rescue who is certified and trained by the Good Dog Foundation as a therapy dog.

"Chicken is a door opener," says Ellen, "and she always makes eye-contact—with everyone she meets—her specialty is people who do not want visitors."

Even people who don't want a human visitor seem to open up when they see Chicken.

One of the first visits Ellen made as a hospice volunteer was to a man who wasn't sure he wanted anyone to come for a visit, but when he met Chicken there was an immediate connection. As Ellen placed the dog gently by his side, he began moving his fingers and then reached to pet Chicken's head, who of course was calmly staring into his eyes. Soon, the gentleman was asking Ellen to call him by his "real name," the one his mother had given him, rather than the name that was on his medical charts.

"Everyone deeply desires connection," Ellen says. "But we all have obstacles to relating with other humans at certain times. Chicken somehow gets through that. If you pour yourself into Chick-

en, she'll just gaze at you and pour herself right back into you."

New York City attracts some of the world's most talented and creative people, many of them gifted performers who generously share their talents as volunteers.

Winnie Lee, co-founder and volunteer managing director of the New York Chapter of the Threshold Choir, a nationwide organization whose members sing at the bedsides of hospice patients, remembers the first time she heard about the choir.

"The idea of service and creativity together really spoke to my soul," Winnie says. The all-woman choir, which sings for VNSNY hospice patients and other organizations, comprises 40 singers of all ages and walks of life. "We usually never know what we're going to be asked to do until we get to the bedside," Winnie says, "anything could change, minute to minute."

The choir had a patient once who was surrounded by friends who had requested a song in a language he could not understand.

"He just wanted to be moved by the music without being bound by the meaning of the lyrics, so with no preparation, we just hummed, and everyone was moved by the simplicity and beauty of it as he smiled, closed his eyes and sighed."

When she's leading a song with the group, Winnie looks for clues about the pace at which to sing the song. She watches the eyes and breathing to make sure the song is

having a calming effect. Often the feedback from patients and loved ones is positive, but the volunteers know that the patient's physical and spiritual state can be in flux.

"On one visit they might like the singing, on the next one they may be too tired."

When the singing is done well it physically feels good for the singers, too, and for Winnie, singing to hospice patients helps address her own personal issues about death and dying.

"I'm more open-minded about the topic," she says, "and grateful for the lessons learned. It's a privilege to serve through this creative medium that really speaks to me."

Eighty-three-year-old Ray Berardi grew up in the South Bronx but has lived in Astoria for nearly 45 years. He "believes in volunteering" he was a hospice volunteer for 25 years taking patients to church services. Today, as a hospice volunteer with VNSNY, Ray spends time with Queens hospice patients in their homes and at nursing homes or rehab facilities.

"I'm not a great conversationalist," he says. "But I ask questions, and people usually open up. When I can, I try to get people to talk about themselves. Sometimes I just sit quietly with someone, but sometimes I'll try a little humor and ask, 'Am I putting you to sleep?'"

Ray says the important thing is to show a little interest and be engaged. He loves trading stories when he makes his visits and fondly remembers an exchange with a man near



Natalia Perlaza sings with a guitar.

his age who in his youth had played street games before TVs, phones and computers became ubiquitous distractions.

"When I mentioned, Johnny on the Pony," Ray recounts, "the man just lit up and shouted, oh, yeah, we played that game too!"

Ray usually walks to the home or facility where the patient he's visiting lives, which gives him time to reflect on what he's doing and the impact it has on those he sees and on him.

"Some people seem to feel almost unloved, and when that happens, I try to get them to re-live the happier moments of their lives. When it works, they can really become engaged in pleasant conversation and it becomes interesting hear what they have to say. I've learned about different

cultures and how different people think, and yet, in common, we will all face death at some time. That brings us together."

When one patient Ray was seeing kept repeating that she wanted to die, he shared with her a story about his own mother, whose constant refrain when she got angry was "God take my life," to which he'd reply, "take a number and sit down, Mother, God will call you when he's ready." As expected, Ray's gentle candor had sparked a peel of laughter "Yeah, I know," she said, "I gotta have patience."

The Visiting Nurse Service of New York is the nation's largest not-for-profit home- and community-based home health care organization. To learn more or find out how you can become a hospice volunteer, visit www.vnsny.org, or call 1-212-609-7586.