What is an End of Life Doula Anyway?

There is no better way to get an understanding of this vital work than from the perspective of an EOL Doula. Robert had been interested in issues related to death and dying since doing graduate studies at divinity school many years ago. He started as a Hudson Valley Hospice Volunteer three years ago and went on to complete our EOL Doula training. He then completed the International End of Life Doula Association training. As Robert describes: "I feel it is a sacred privilege to be able to walk alongside patients who are facing death and to provide caring support to them and their loved ones during this challenging time as their journey in life comes to an end. Often patients and family members are confused and unsure of how to proceed with their remaining time on earth. A doula can help them reflect deeply on their lives, process their feelings about dying and find a way to say goodbye and complete any unfinished business with their loved ones. We help them to have some agency in the dying process when they are mostly feeling a loss of control. We help them with the process of summing up their lives and planning for how their final days will go."

Robert's natural curiosity has served him well in his role as an EOL Doula. He enjoys listening to people's stories of the important moments and people in their lives. One of his patients was very interested in talking about his life and his legacy and sought Robert's help in documenting it to leave for his family members. "We talked about his childhood, his parents, grandparents and siblings, and looked through photo albums together," Robert recalls. "We discussed his time in the Army during WWII, his education and career as an educator, places he traveled and his volunteer and charity work. We also talked about what values were important to him and what wisdom he would like to pass along to the younger generation of his family. I was able to write up what he told me and review it with him and eventually put it into an 18-page booklet with photos. He was able to share this with his family before he passed away and it was very meaningful to them." This type of legacy work can be a unique and invaluable way of helping families celebrate the lives of their loved ones before and after their death.

EOL Doula work includes helping patients and family members to think about how they want their final days to go, which can include a vigil plan on how they want the physical

space around them to look, feel and sound; who they would like to have around them; what music or readings they would like to hear; and if spirituality should be incorporated. One of Robert's patients had a unique request: he wanted family members to be present and just go about their lives together in his presence. Knowing this, family members found a way to honor his wishes by coming and going during his final days. Grandchildren played with toys on the floor. College students brought their laptops and worked on their homework. Food was brought in. People shared stories about their time with him. They whispered loving thoughts in his ear. The Rabbi came and said prayers and sat with the family. "My patient went out of the world just the way he wanted," Robert recalls. "Surrounded by all the people he loved."

Sometimes, the path to becoming a certified EOL Doula can feel very much like a calling. Theresa saw an item in her church bulletin five years ago seeking Hudson Valley Hospice Volunteers and EOL Doulas and felt a tug on her heart. Hudson Valley Hospice had just launched its EOL Doula Training Program and Theresa felt at once that this type of volunteer work would be a good fit for her: "Coming from a large, local family which celebrates and mourns together and marrying into one that does the same, I am no stranger to supporting a family member with terminal illness or being near their bedside as they are dying," she describes. Theresa completed the training program and embarked upon her new calling as an EOL Doula.

One of Theresa's first patients was a woman who wanted a vigil plan created. The two met, and over tea and cookies in her new patient's living room, they discussed her wishes for a vigil. "She said that she was not concerned about her death," Theresa recalls. "She was concerned about what happened as she was dying. Preserving her dignity was foremost in her mind. As we drank our tea, we discussed her wishes. She asked that I return the following Tuesday when her daughter would be in from out of town, so we could work together on her vigil plan. She seemed relieved that I would be helping her voice her concerns and wishes to her daughters."

However, when Theresa returned the following Tuesday, her patient's daughter greeted her and informed her that her mother's condition had changed. As Theresa recalls, "Coming from the bedroom, a hospice nurse told me my patient was actively dying. Her daughter and I went into her bedroom and in a weakened voice, she greeted me and asked me to tell her daughter about her desire to complete her vigil plan. As her daughter and I had tea at the same small table in the living room, I described to her daughter what a vigil is and some of her mother's wishes We then joined her mother again to create the plan. My patient wanted her hair to be combed and to be neatly covered before any family member came to sit with her. She wanted them to talk to her about the memories that they would cherish

and to say particular prayers, especially her own version of the Divine Mercy Chaplet closing prayer. She wanted to be dressed in a special outfit when she left her home. Before I left that day, I explained the changes a body goes through as a person is dying and tender ways to care for a loved one. I also explained one way they would be able to dress someone after the person died. The next morning my patient died."

A month later, Theresa joined her patient's daughter at a local tea house. While drinking tea and eating sweets, she told me about her last few hours with her mother. She said when she wasn't sure what to do, she told herself to remember "what Theresa said." She had washed her mother's body, combed her hair and dressed her in her chosen outfit.

Rebecca, whose father was a pediatric oncologist, grew up in a household well versed with the concept of death. She grew up understanding the importance of dignifying death: discussing it, anticipating it and welcoming it as best one could. As an EOL doula, she utilizes this approach with all her patients. One patient, a hospice nurse herself, was able to anticipate her own death and articulate her "good death" with clarity: she wanted to die in her childhood bedroom with her family. Another patient—a sixteen-year-old young man—didn't want to let go, as accepting his death meant skipping over adolescence and landing squarely into adulthood. When he stopped fighting, he poured out the love in his heart for his family and gave in to a too-short lifespan. Rebecca remembers, "As tragic as it was, our time together was also funny, rebellious and filled with joy and gratitude. His family showered him with love, as he did them; talking about his death together was both poignant and relieving."

EOL doula work is rarely easy. One of Rebecca's patients was leaving behind three young children, and could not bring herself to talk to them before dying. "I felt keenly that I had let her and her children down," Rebecca recalls. "We couldn't get the momentum and strength to look her death in the eye together."

It takes a special type of person to commit themselves to the emotional, difficult, and often, heartrending work of an EOL Doula. But there are also profound rewards to be gleaned from this important work. Rebecca sums the role of an EOL Doula perfectly: "I have never felt I've done a good job, a complete job, or gotten a real hold on this mysterious thing that is happening to us all. I do know, however flawed my work is, that I've always been grateful to try, that being part of the dying process is as intimate as anything can be. Like giving birth, it's too beautiful to take in alone."