



Welcome to **Examine**, a new feature in which writers provide an experienced perspective on familiar subjects, personal or professional, helping us consider them in a new light. Have an idea for a piece? Email hcmag@holycross.edu.

A Dance with Life

BY MARY CROSBY '03

Sitting on a hard examination table in a cold office holding her flimsy hospital gown closed, the patient listened as her doctor offered two options: another 10 rounds of the same chemotherapy she had just completed or a stronger experimental chemo with a slightly higher possibility of shrinking her tumor, but accompanied by serious side effects. Weak and emaciated, she thought about the previous year, her weekly trips to the hospital for blood work and treatment, debilitating nausea, vomiting and worsening pain, all with no progress in her battle against cancer. Was there a third option? What if she chose to stop treatment altogether? The doctor brushed this notion aside as “giving up the fight.” He encouraged her to go home and think seriously about her decision.

So often the dialogue about terminal illness invokes the metaphorical language of a battle. The patient takes up the noble fight against a fierce enemy, such as cancer or Parkinson’s disease, and an army of friends and family join in the rallying cry of support for the brave warrior. This narrative is a well-intentioned attempt to provide hope and motivation as patients and

their caretakers endure the hardships associated with aggressive treatment. To be victorious is to be in remission, to prolong life, to defeat a prognosis.

But the battle narrative can be a disservice. A battle means hunkering down and enduring debilitating side effects, prolonged hospitalizations and decreased participation in life events. The focus shifts from living to accruing days, placing distance between the diagnosis and some imagined end point. In our attempt to win ourselves more time, we sacrifice the quality of time we have left. And when we “fight” disease we leave ourselves only two possible outcomes – victory or defeat.

Those of us working in the field of hospice often receive our patients at the end of their “fight” with terminal illness. They’ve lost hope in their ability to conquer disease. Our goal is to redefine hope, not by treating the disease, but by treating the patient and their caregivers as a whole. Through physical, emotional and spiritual support, we pull people out of the dark trenches of battle and into the light of living, which includes the uniquely human ability to conceptualize and process death. And, by allowing patients the space for that process, hospice focuses on life: on spending time with family and friends, realizing values and priorities, and even pursuing projects that went neglected before diagnosis. Not surprisingly, people with terminal illness who receive hospice care live longer than those who do not. But more importantly, they live better.

An estimated 1.5 million Americans receive hospice care annually. Care is individualized to meet the unique needs of every patient and their caregivers. Hospice professionals visit patients in their homes, in hospitals or in

specialized facilities to deliver pain and symptom management, personal care, emotional support and other services, such as massage therapy.

As hospice leaders, we help people reframe how they think about terminal illness. “Victory” can be as simple as feeling pain-free enough to take a walk on the beach or comfortable enough to enjoy dinner at a restaurant, a series of small steps that make up a life worth living. Hospice care frees people from the pressure of having to fight an unwinnable battle without feeling like they’ve lost. We occupy a space in the health care system wherein people can talk about living with terminal illness not as a “fight” but as a dance, a beautiful performance orchestrated by the patient with support from their family, friends and a team of hospice professionals. Within this space, quality of life improves, patients find more physical and emotional comfort, and death becomes less about the fear of defeat and more about the peace of transcendence.

Against the wishes of her doctor and members of her family, the patient chose the third option. She stopped treatment and elected to receive hospice care. Our team of experts had the honor of caring for her for the last year and a half of her life. During this time, she went to Broadway shows, enjoyed meals at restaurants with her friends, attended weekly Mass and even published a book of poetry. Her joy for living was contagious. It was not victory over death, but neither was it defeat. Because it was not a battle at all: It was a dance. ■

Mary Crosby is president and CEO of East End Hospice, a nonprofit hospice serving the North and South Forks of Long Island, New York, including the Hamptons.