

With assistance from Hoag, Michelle Wulfestieg (middle) turned her major health struggles into a potent force for helping others. With her are Susan Johnson, RN, MPH, Manager of Hoag's Health Ministries Programs (left), and Deb Mastrolia, RN, Stroke Nurse Navigator at Hoag.

Two Strokes Hit Her Hard, but She Came Back Determined to Help Others

Michelle Wulfestieg combines a will to fight and spirituality in her unique outreach

Her eulogy was written and some had prepared their goodbyes.

Michelle Wulfestieg had suffered a major stroke — the second in her life — and her brain activity hovered near non-existent.

For eight days in January 2008, she had lain in a coma at Hoag Hospital, unresponsive to friends and family.

Everything about her condition was telling doctors she would not wake up.

But they waited.

Her husband prayed and refused to believe his wife would not return to him. Family members read to her, nurses talked to her often and doctors made her comfortable.

The logical thing for her husband to do would have been to let go.

It is a good thing love and faith defy logic.

Wulfestieg was among a panel of speakers who shared their inspirational stories this spring at the annual Spirituality Conference sponsored by Hoag Community Benefit.

The event, *Growing in Life's Transitions*, brought together spiritual leaders and medical professionals who discussed the importance and power of passionate caregiving.

Whoosh whoosh

This sensation in her head accompanied everything Wulfestieg did as a child — holding her breath for too long, chasing boys on the playground and playing sports with her friends.

She thought it was normal until one night, at age 11, Wulfestieg stretched from sleep and the gentle whooshing gave way to excruciating pounding.

"I felt something burst inside my head," she said.

Wulfestieg had suffered her first stroke caused by a tangle of blood vessels and arteries in the brain called an Arteriovenous Malformation.

Radiation treatment to shrink the mass the size of sausage resulted in loss of function on her right side.

"Suddenly, I was completely disabled," she said.

Wulfestieg became a fighter, adapting to her new-found reality. She learned to write with her left hand, get dressed without help and feed herself.

"It's all about choice, perspective and your outlook," she said. "You have the choice to decide whether it's going to get worse or get better."

At age 14, doctors told her the lesion was still nestled deep in her brain. They needed to operate, but there was a significant risk: Wulfestieg could lose her ability to speak.

"What is more important to a 14-year-old girl than talking?" she said. "No way."

Doctors told her if she didn't try, she might not live to see 30.

"Well, 30 is a long way away," she replied.

Living under this new, shorter life expectancy, Wulfestieg said she seized life.

Despite her disability, she played volleyball in high school. Wulfestieg said although she was a better team motivator than player, she made captain twice.

"I think I was just an inspiration to my teammates and they were all incredibly supportive," she said. "It took a lot of bravery to participate, in spite of my disability."

She attended college and traveled the world — the Great Wall of China, the Taj Mahal, Africa and Cuba were among her adventures.

During these travels, Wulfestieg said she gained perspective.

"There is so much poverty and despair in the world that my struggles and health issues were nothing compared to the struggles of others," she said. "In that moment, I vowed to live in service to others."

She met her husband, Steven, in a college class about death and dying. That course inspired her to volunteer in hospice care.

Wulfestieg wanted to provide dignity and comfort to people during their final days. The importance of that role, she said, became clear in working with her patients.

"This was where I would make my difference," she said.

Wulfestieg had just finished her thesis when she suffered a second stroke. She was 25.

She lay on the floor as her husband hovered over her repeating, "Michelle, stay with me."

She couldn't.

"I remember thinking this was it, I can't do it anymore, I have to go," she said.

So she went to a place she describes as the most beautiful and wonderful feeling she could ever imagine.

"I was surrounded by God," she said.

Although she said she didn't want to leave this place that felt more like home than anywhere she'd been before, she couldn't stay.

Wulfestieg underwent a six-hour surgery on the lesion that doctors once called inoperable.

The procedure was successful, but it was unclear if she would emerge from the coma.

Although outwardly unresponsive, Wulfestieg said she remembers being very aware.

She heard her mother reading greeting cards and she heard the nurses chat with her as they tended to her needs.

Wulfestieg loved to hear people speak. She especially loved to hear them pray.

She loved when people held her hand or touched her face. Although she couldn't respond, she could feel everything.

Hoag Nurse Navigator Deb Mastrolia was on the team who cared for Wulfestieg, and among those who would talk to her and hold her hand.

"Touch is profound," Mastrolia said. "We always tell family members, 'don't be afraid to talk to them, to reach out and touch them."

One day as her mother was reading a card aloud, a tear rolled down Wulfestieg's cheek.

"She can hear me," her mother yelled.

Wulfestieg woke.

The aftermath of this stroke was more devastating than the last.

She would have to again learn to talk, walk, dress herself and write. The one thing she wouldn't have to re-learn was how to fight for what she wanted.

In just seven months, Wulfestieg returned to her work as executive director of the Southern California Hospice Foundation.

It wasn't easy, she said, and she often put on a brave face to mask the struggle.

"It was the hardest thing I have ever done," she said. "Numbers didn't make sense, letters didn't make sense and here I was, the executive director of a nonprofit. It was a fake-it-till-you-make-it kind of thing."

She cried every day.



Wulfestieg's story is detailed in her award-winning memoir, "All We Have Is Today: A Story of Discovering Purpose."

"I thought, 'I used to be so smart and now I can't even dial a phone number," she said. "I was aware of it and that added to my grief and isolation."

With unwavering support from her husband, Wulfestieg didn't let these feelings consume her. Instead, she tapped in to the one thing that has been a constant since she suffered her first debilitating stroke 14 years earlier: her will to fight.

"I think what kept me going was knowing I had to serve," she said. "That was the reason I was here. I have a purpose."

Hoag Embraces Healing Through Spirituality

Spirituality can help heal, and it can help families cope with the difficult.

In this fast-paced, technologically advanced world of medicine, spiritual care is an essential part of treatment, and it is something Hoag embraces.

Hoag Community Benefit inspires a culture of compassionate care with its annual spring Spirituality Conference, which educates families, physicians, religious leaders and caregivers on the importance of marrying cutting-edge medical care with meeting the emotional needs of patients and their loved ones.

This year's event, "Growing in Life's Transitions," featured speakers from diverse belief backgrounds who shared their experiences and discussed the benefits of a faith-based approach to aging, hospice care and end-of-life choices.

Speakers shared how a simple touch, encouraging word or kind gesture can have a measurable impact.

By fostering a strong sense of spirituality through a service-oriented standard of care, patients can find purpose, meaning and comfort at any stage of life.