

MS as a *Spiritual Journey*

BY GARY SULLIVAN

paintings by Sylvia Moss



"EVENSONG 1,2,3" TRIPTYCH, 14" X 11" EACH PANEL, OIL AND MIXED MEDIA ON CANVAS

When I was seven or eight, my father was diagnosed with muscular dystrophy, and given about 10 years to live.

We weren't living together at the time. He and my mother had divorced when I was three. He had remarried a woman with five children, and they had had another child together. He was always moving, following one job after another. When I was five, he was in a nondescript office in San Jose. When I was six, he had the whole family working as housecleaners in a resort town near the Nevada border.

His diagnosis changed everything. While supporting a wife and six children, he pursued a neglected dream: He

attended law school, passed the bar, and set up shop as a family law attorney in Stockton, California.

He also began to go to church regularly. He had been no stranger to religion, but before his diagnosis, he had always treated spirituality as he had treated everything else: as though nothing he did had any long-term consequences whatsoever. Now, **everything** did. So much so that, when he discovered that he actually **hated** practicing law, he worked—hard—to get **out** of it. But this time he did his groundwork, and ultimately, despite disability that required a motorized wheelchair and more, he ran a successful Internet provider service out of his home. Before



he turned 60, my father sold the company and retired to Florida. He lives there today—having outlived his prognosis by more than two decades.

My father would probably tell you that God had a hand in slowing down his disease—not to mention being responsible for his business success. While it's his word, today scientists are beginning to ask questions about the importance of spiritual belief to overall health, and even healing.

Hard evidence?

In a May 2004 Gallup poll, 55% of Americans said that religion was “very important” in their lives; 29% said that it was “fairly important.” Religion and spiritual-

ity have been credited with providing profound psychological comfort and—in the case of organized religion—a sense of community to people in sickness or health.

American Psychologist devoted its January 2003 issue to the subject of health, religion, and spirituality. In one article, Lynda H. Powell of St. Luke's Medical Center, Leila Shahabi of the University of Miami, and Carl E. Thoresen of Stanford University reviewed published scientific studies to evaluate existing evidence for a link between spirituality and health.

The authors used what they called a “levels-of-evidence” approach that weeded out studies that did not meet minimally sound methodological standards. For

example, studies relying on statistical analyses alone were not considered. Nor were studies that did not take into account potential “confounders”—factors that may influence the outcome being studied, but which are not under investigation. Confounders might, for instance, be associated with a person’s age, gender, or ethnicity.

The researchers then examined claims most often made about religion or spirituality. They hoped to determine the strength of the evidence for each of them.

Their results were mixed. On the one hand, while they determined that there was inadequate evidence to suggest that people who use religion to cope with difficulties live longer, they found what they considered to be “persuasive” evidence that attending religious service was associated with a 25% decreased risk of mortality among healthy people, **even after** adjusting for the fact that weekly service attendance was also associated with healthy behaviors (not smoking, drinking only in moderation, etc.).

Their findings regarding recovery from acute illness were puzzling: While there was some evidence that being prayed for improves recovery, there was also some evidence that religion or spirituality **impedes** the religious or spiritual-minded person’s recovery.

According to the authors, the topic requires “more methodologically sound studies.”

Church and state (of mind)

The 17th-century French philosopher René Descartes is generally credited with having given us our ideas about the divide

between mind and the body—“I think, therefore I am”—but the Western idea of a split between the two can be traced back further, to the Greeks. Eastern philosophy has always assumed that the mind and the body work together as part of a larger, complex system. Health, spirituality, religion, and relaxation are generally considered parts of a whole in Eastern thought.

But Western medicine is no longer ignoring the complicated relationship between the body and the mind—and this includes the effects of beliefs on health.

Studying people with MS

In a series of studies done in the late 1970s and ’80s, in part funded by the National MS Society, researchers began interviewing people with MS about all aspects of their life. How did having MS affect their family life? Their sexual relationships? Their employment situation? And what were they doing to cope?

“One thing that kept coming up in the interviews that I did,” said Nicholas LaRocca, PhD, director, Health Care Delivery and Policy Research at the Society, “was that spirituality and religion were a very important aspect of coping for people. For some, it was the more philosophical aspects that provided help. For others, it was the social aspect of regular service attendance. And for others, it seemed to be a bit of each. This makes sense. When you’re faced with a change in your life as significant as MS, you’re going to benefit from both social support and the ability to derive meaning from your specific circumstances.”

Linda Samuel, MSW, Senior Services



consultant for the National MS Society, concurred. "What I've seen over and over again," she said, "is that people with a spiritual life feel as though there is a bigger purpose to everything, that we're all connected, and that there's meaning in this difficult situation for them."

With Dr. Alan Berman, Linda Samuel conducted two studies on MS and suicide: in the first, which was published in the **Journal of Neurologic Rehabilitation**, they interviewed family members of people who had died this way. The second study (not yet published) was an attempt to find out what keeps people with MS going.

Two things kept coming up as crucial coping elements in people who were doing well. First, they described themselves as having a low level of disability. Sometimes they said their disability was signifi-

cantly lower than objective tests showed. Second, they had a strong sense of spirituality, of some larger purpose in their lives.

"One person in that study could swallow, move his right index finger, and that was about it. But he was able to get out quite a bit, because he had a helper. He described himself as 'not very disabled.' And he had a strong spiritual sense," Samuel said. She found a connection between a person's positive self-description and a high level of spirituality again and again.

Welcome to the "reformation"

The medical community is beginning to take spirituality seriously. New organizations—many led by physicians and other medical scientists—are working to reform the medical establishment in ways that they say will benefit all.

George Washington University's George Washington Institute for Spirituality and Health (GWish) was established in May 2001 with the goal of re-establishing a connection between spirituality and health in medicine. Founder and director Christina M. Puchalski, MD, an associate professor of medicine and health-care sciences, wants to "establish a more compassionate and integrated system of care." The first goal is to recognize the spiritual dimension of health and suffering.

"Spirituality is fundamental to the caring relationship between all health-care providers and their patients," Dr. Puchalski has proposed. "Medicine has its roots in service, which is a spiritual value. One of the core values of the profession of medicine, therefore, is the compassionate care of the sick."

“Hope over hardship”: the Boston Home

Spirituality is a decidedly fundamental element of care at the Boston Home in Dorchester, Massachusetts. Established in 1881 by Cordelia Harmon, a trained nurse, The Boston Home is a not-for-profit, 96-bed nursing-care facility for adults with physical disabilities, primarily MS and other progressive neurological diseases.

According to Bridget M. Haase, OSU, the director of the Boston Home’s Wellness and Spirituality Program, “We make no distinction between emotional and physical pain.

“Most residents have active and searching hearts,” Sister Haase continued. “They desire to discover that their lives make a difference, to find support in coping with their dependence and failing bodies, and to find meaning in their lives. They hunger for spirituality: the deep-seated passion to live well. At the Boston Home, we aspire to create a climate of hope over hardship.”

One resident, a Muslim, who had formerly been a hotel manager, came to the Boston Home after he lost all mobility below the neck. In one of the Home’s spiritual direction sessions, he told Sister Haase how much listening to the Qur’an on tape meant to him—it transported him to the realm of the heavens while never allowing him to forget his body on earth. “Each morning when I get up,” he told Sister Haase, pausing to sip from a water bottle attached to his chair, “I look toward Allah and go to him just as I am. My heart knows that I can bear the weight of the day. It is this that I want to share at our next seminar. It may make a differ-

ence in someone else’s life and help them wake up with hope.”

Healing the mind/body split

The idea that the mind and body are intricately connected, and that the well-being of one relies upon the well-being of the other, has obvious connections with our ability to make our circumstances in life meaningful. But meaning is not the only element in the mind/body game.

The Mind/Body Medical Institute (MBMI) in Chestnut Hill, Massachusetts, was incorporated in 1988, having evolved from more than 30 years of work in the field by Herbert Benson, MD, and colleagues at Harvard Medical School.

The Mind/Body Medical Institute focuses on the complicated interactions that take place between thoughts, body, and the outside world. According to Dr. Benson, “Mind/body medicine integrates modern scientific medicine, psychology, nursing, nutrition, exercise physiology, and belief to enhance the natural healing capacities of body and mind.”

Dr. Benson and his colleagues’ research led to the definition of something called the “relaxation response”. All of us have what is known as the “fight-or-flight response”—created in the body by higher levels of adrenaline in response to visual, aural, tactile and/or other stimulation. Scientists have long known that stimulating a specific area in the brain called the hypothalamus can cause the fight-or-flight response. Dr. Benson and his colleagues discovered that activating other areas in the brain results in its reduction. They call this the “relaxation response”.

According to Dr. Benson, "The relaxation response is a state of deep rest that changes the physical and emotional responses to stress." And his studies have shown that people can evoke this response, and lessen the effects of stressful thoughts, by repeating a prayer, word, sound, phrase, or muscular activity.

MBMI research has studied everything from the behavioral, psychosocial, and spiritual dimensions of mind/body medicine to the results of the relaxation response at the molecular, cellular, and tissue-organ levels.

The MBMI recently received an award of \$2.7 million from the Centers for Disease Control and Prevention to be used over three years to further investigate the scientific basis of the relaxation response.

"What? What?"

Early on in my father's illness, I remember sitting in his living room with the rest of

his family, singing songs while he played guitar. We had just gotten to the first chorus of "Streets of Laredo" when my father let out a "Whoa, whoa, whoa!" and started laughing. "My damned body has betrayed me!" he said, in the funny voice he often used to get cheap laughs from the kids. We all watched, horrified, as he tried to extend his fingers across the fretboard to play an F . . . but his fingers weren't complying.

He immediately went into an impromptu comedy routine, describing for all of us how each morning he "propped himself up in the shower." Things were going downhill from there. By the end of it, both he and I were laughing so hard we could hardly breathe—but everyone else in the room was sobbing. I remember my father looking around in mock surprise, and blurting out "What? What?"

In that moment, I understood something important about my father. As his body deteriorated, his spirit seemed to strengthen—almost as though in response.

Something Linda Samuel told me resonates here. She explained that while the religious or spiritual people she studied would never have **chosen** to get MS, they generally say that it has changed their life for the better. They're more complete people because of it. "They have clarity that they might not have had before," she said. "MS really helps some people to focus on how to use their time on earth." ■

Gary Sullivan is managing editor of this magazine.

Sylvia Moss began painting and drawing in her teens. She attended the California College of Arts and Crafts, the Art Student's

League of New York, Columbia University, and the California Art Institute. Her work has been shown in over fifty exhibitions at numerous galleries and museums in California and elsewhere, including the Los Angeles County Museum of Art. Ms. Moss is

also the author of **Costumes & Chemistry** (Costume and Fashion Press, 2001). She was diagnosed with MS in 2003.

