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Another Perspective of ALS

by Evy McDonald, R.N., M.S., M.Div.

Evy McDonald, R.N., M.S., M.Div., former intensive and coronary care director, knows what dealing with a "terminal illness" is all about. In the 1980s she was diagnosed with ALS, which progressed until she was a "bowl of jello in a wheelchair." After her recovery from ALS, she conducted a medical research project on the mind-body-spirit connection in ALS. Today she has left the health arena and is in service as a Methodist minister, leaving behind a legacy of [ALS articles and resources](#) that offer science and inspiration to those dealing with serious health conditions.

In September of 1980 I was a successful health professional. I had a Master's degree in Nursing and Hospital Administration plus 13 years of professional experience. My positions ranged from Director of Education at one of the first three hospices in the U.S. to collegiate level nursing instructor to Director of Intensive and Coronary Care units.

Also in September 1980 I was diagnosed with amyotrophic lateral sclerosis (ALS) and given less than one year to live.

Today, seven years later, I am not only alive but as healthy as I've ever been in my entire life. Since I am one of the first people to have reversed this normally fatal disease, I have felt called to become a student of my own process of healing, seeking to understand and articulate the factors that reversed this death sentence. Neither the "mainstream medicine" rationale (it was a misdiagnosis) nor the "holistic" approach (it was prayer, visualization, diet, vitamins, etc.) come close to explaining what happened. I have brought both my scientific and spiritual training to bear on this apparent enigma of my healing process and have discovered in modern physics a framework for understanding the "miracle" of the mind/body/spirit connection.

A SCIENTIFIC FRAMEWORK

Modern concepts concerning health and disease were established within the framework of the world view described by Newtonian physics. This world view had its beginnings in the 17th century with Descartes, who had a transcendent experience in which he saw the universe made up of separate, unrelated parts and operating in clockwork fashion. Sir Isaac Newton gave us the blueprint for this clockwork universe. Before long this mechanistic view was applied to man, who was seen as a machine with parts that broke down and needed repair. Disease was simply a malfunction in the mechanism, and man was a victim of a chain of cause-effect events over which he had little or no control. In 400 B.C. Socrates had said that "There is no disease of the body apart from the mind." To the Newtonian world, however, the model of man-as-machine seemed a vast improvement on this ancient and imprecise theory of the mind-body connection, and the notion of a clockwork universe was a path that promised to conquer all that ailed us. Indeed, many miracles of modern medicine came out of this Newtonian perspective, including the germ theory, antibiotics, X-rays, and much more. Yet many unresolved puzzles remain. Physicists today have seen that the Newtonian view of the world, while liberating in some respects, was limiting in some very important ways.

In 1905 Albert Einstein published his special theory of relativity, which ushered in a new way of thinking and began to rattle the comfortable cages of our old beliefs. Newtonian physics claimed that things *have* energy; Einsteinian physics proposed that things *are* energy.

Today modern physics, following up on Einstein's discoveries, tells us that consciousness and the way we perceive are important, that we are part of nature and it is part of us, that all life is one interconnected whole. At the atomic level all that exists is patterns of probabilities and, according to Fritjof Capra,

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"These patterns do not represent probabilities of *things*, but probabilities of *interconnections*."¹ The universe can no longer be seen as a collection of physical objects - it is an intricate web of relations between the various parts of the whole. At the human level this means that our bodies and minds are not separate but are interwoven, each affecting the other. More and more research confirms this notion that the human factor is a major element in disease or health.

Dr. A. H. Schmale of the University of Rochester is one of the many physicians and scientists researching the central role of the human factor (emotions, feelings, thoughts) in disease causation. Schmale's group of researchers concluded that feelings of hopelessness and helplessness were critical predisposing factors in the onset of a serious illness. An inability to cope and an attitude of "giving up/given up," says Schmale, may give rise to a number of psychological defensive patterns which can lead to psychic symptoms, the activation of somatic diseases or a general increase in somatic vulnerability.²

Just what is this human factor? In current medical literature one finds articles about the personality profile of one illness after another. We now have fairly accurate and distinctive mental and emotional dossiers for the "victims" of cancer, heart disease, arthritis, multiple sclerosis...the list goes on and on. But unanswered questions remain: Why do some people get rheumatoid fever from a strep throat while others seem to carry the strep and never show any symptoms? Why don't all coal miners have black lung? Why does the degree of job satisfaction rate as a major factor in the development of coronary heart disease? Such questions can't help but haunt any medical researcher who is attempting to disavow the human or "X" factor and to find an objective cause for an objective disease - especially now that modern physics indicates that no such objectivity exists.

RESPONSE TO DIAGNOSIS

Back to my experience: I was objectively diagnosed with the objective disease of amyotrophic lateral sclerosis.

I returned home after my diagnosis prepared to die within a year. I saw no other option; I had given up and given in to something over which I felt I had no control. Outwardly I was the picture of a well-adjusted, happy, successful young woman who was meeting this tragedy with gusto and courage. But inside was chaos; I was angry, upset, depressed, hateful and awed all at the same time, and I wanted nothing more than to run away from everyone. I made it very uncomfortable for anyone to be around me, and in just a few months I had successfully isolated myself from family and friends.

I was so entrenched in my professionalism that there was only one way I could be with my illness - professionally, with detachment. I simply observed how much of my bodily function I was losing day by day while showing little emotion. As a professional I had counseled patients and families and had spoken about "holistic" principles of illness - principles such as illness being a metaphor for how you feel about yourself, a way out of an unpleasant or intolerable situation, a means of exacting revenge, or an acceptable form of suicide - and yet I had

difficulty seeing how any of this applied to me and my life.

Confined to a wheelchair, however, I had plenty of time to think - and gradually I began to see that there must be some truth to what physicians and scientists like Hans Selye, O. Carl Simonton, Elmer and Alyce Green and Larry Dossey were saying - that our minds and bodies are not separate entities but are united in a whole where each affects the other. At this point I made the choice to explore some of those large questions about life and happiness, illness and health. I wanted answers. Not to get well. But to understand life with the few months I had left.

An essential element in this process was that I was *not* seeking physical healing. I was quite content to die. Actually, one of my first glimmers of the radical transformation that occurred happened when I acknowledged that ever since having polio as a child I had hated my body. I saw that every two years, like clock-work, I had created a major illness or accident that had often placed me on death's door. This bit of naked honesty led me to other realizations. I saw that even though I was a professional "server," I had no idea what true service was. Everything I did was fueled by the desire for acknowledgement and recognition. And even though I had many friends, I'd rarely let anyone really touch my heart.

As my willingness to take a clear look at my past increased, so did my willingness to see the present. I could now look at ALS and see how it was the perfect reflection of those deep, unspoken feelings about myself. I was now at a choice point: I could wallow in self-pity, guilt, anger and resentment, or I could move on and see how this disease might assist me in discovering what life was about.

So, when I underwent this transformation, I was not seeking healing of the body. I sought a sense of wholeness, a sense of unity within myself and with others that transcended my disease. Physical healing was simply a by-product of that inner transformation.

A JOURNEY TO SELF - THE FIRST STEPS

Back to physics. One recent theory in physics illuminates my experience of the disease process: the theory of dissipative structures, which won the Nobel Prize in 1977. Belgian chemist Ilya Prigogine saw that matter was not inert but was alive, and that life was constantly changing through its adaptation to conditions of nonequilibrium. In his view, perturbations or disturbances within a structure are necessary for growth and evolution, and the key to growth lies in the willingness to change, to meet the new challenge or adapt to the new environment. In the arena of illness/wellness, disease can be seen as a disturbance, an opportunity to evolve to a higher level of complexity. Disease, no matter how devastating it may seem, need not be viewed as negative. I chose to use the experience of my disease to expand my horizons, to alter the unhealthy patterns in my life and to learn to live fully in each moment.

After months of solitary introspection, a dramatic change emerged in my process of thinking, feeling and interacting with the world. I have been able to articulate these changes as seven key patterns or principles. These were:

1. I went from get to give - demanding from life to giving to life. From feeling that life owed me something to giving my all to life. From trying to get honors, recognition, success, power, achievements to giving my time, talents, enthusiasm to others and the world. At first, I had no idea how one served selflessly. Then I remembered a quote: "You can accomplish anything if you are willing to take credit for nothing." From my wheelchair I started giving to those around me - with no expectation of either reward or return, without trying to "take credit." Each evening I would look back on the day and give myself a report card. Had I been loving? Had I been of service to anyone? Really? Did I have expectations of something in return for an action of mine? What eventually became apparent was that this discipline was not only good for the soul - it was transforming my body.

Research is beginning to document the power of love and serving. Schmale and Iker, in a study of 68 women predisposed to cervical carcinoma, discovered that they could predict, prior to biopsy, which women would have carcinomatous changes on the basis of the presence or absence of a high hopelessness potential and/or reported recent hopelessness. Further research revealed a certain character pattern or quality that counteracted these feelings of helplessness and hopelessness and thus enhanced a state of health. This quality was the selfless devotion of giving to others. Patients reported two feelings that created an internal state of contentment: pride of action and the feeling of goodness that comes when people give without regard for their own personal needs. This internal state, says Schmale, reflects one's ability to cope with life and thus remain in a state of health.³

2. I went from resentment to forgiveness. It astounded me when I recognized how many people I still resented from some act or words they had said to me from as long as 25 years ago. For example, I noticed that I still resented my third grade teacher. She had told me that because I was handicapped, I didn't need to learn to write. What did my resentment do to her? Nothing! Nothing at all. The only one still being affected was me.

3. I went from self-hatred to self-acceptance and unconditional love. My body had never been right. I came in two sizes as a result of the childhood polio. I despised my body and wished it would just disappear. Outwardly I pretended to accept and love myself. So the problem wasn't totally in the hating of my body, but in the mixed messages I was sending myself. I could give up and just hate myself totally - or learn to love myself totally. Because I longed to experience unconditional love before I died, I chose to learn to love my body (which, thanks to the ALS, was now like a bowl of jello in a wheelchair!). Every day I would focus on some part of my body, praise it and love it. I also began to look at myself in a mirror and speak words of love and affection to my reflection. This was not an easy task. But, as a friend of mine says, "If you can fake it you can make it." So, at first I faked it. But, gradually the self-acceptance became real. Eventually, I found myself completely content with me and with my physical body. And, as my experience of love for myself deepened, I was finally able to love others as well as accept their love for me.

4. I went from wanting to escape from life to accepting life

exactly as it is. In truth, I'd been dissatisfied with my job and wanted out. Yet I had said that I wanted to be the youngest female hospital administrator in the USA - even if it killed me! And how could I admit that the entire thrust of my life was wrong? What then?

5. I went from expecting and preparing for death to celebrating life and living every moment. I had been given one year to live by the top neurologists in the country. For me, it was a verdict. I became preoccupied with my death and how to have it be the best death possible. One day I asked myself, "What is my life for? To sit here dying each moment or to celebrate the life I still have?"

6. I went from denying painful emotions to sharing them and letting them go. Having lied for so many years about my feelings, I first had to allow them to be, then to identify them, distinguish one from another, and finally to share them openly with others. In the process of sharing, I discovered those that weren't useful just disappeared.

7. I went from avoiding intimacy to opening myself to love. This last shift was actually a product of the other six - and perhaps the most important one. In a well-known experiment out of Ohio State University, rabbits were given a diet high in fat and cholesterol to demonstrate atherosclerotic changes. The results were as predicted - except for one group, where there were 60 percent less atherosclerotic changes than in all the other groups. The only variable discovered was that the researcher for this group regularly took the rabbits from their cages and petted, stroked and talked to them. This experiment was repeated many times, with the same results. The rabbits who were stroked and cared for were healthier than those who were not.⁴ Intimacy at every level - emotional, intellectual, spiritual, and physical - is the flowering of unconditional love.

A NEW CONTEXT

The essence of my approach was to change the way I viewed myself and the world. My process was not a program for a cure or remission. It was a program for me to let go of my pretenses and my past hurts and resentments, to accept my loss of function and upcoming death, and to embrace whatever amount of life I had left. The changes I went through were real. They worked - not because someone else wanted or expected me to change, but because I saw the need and had the desire to alter my attitudes and beliefs, to let go of being "right" and to choose a new set of operating life principles.

These were more than attitudinal changes. They represented a fundamental restructuring of my entire framework for perceiving, interpreting and interacting with the world around me. More than insights, they were key reversals in my process of thinking and feeling, based on a penetrating examination of the foundations of my being.

What happened? Did changing my world view produce physical changes? Did my consciousness alter the physical reality of my body? Or was it all "coincidence?" It may be - but, to quote Philip Slater, "A coincidence is a trend we've decided not to take seriously."⁵ The real question has become, "How can my

experience truly serve others and the overall practice of medicine? How can my story be told appropriately, so that it moves out of the realm of anecdote or anomaly and into the realm of true healing for the mind/body separation?"

In closing, I would like to quote Dr. Larry Dossey, Chief of Staff at Medical City Dallas Hospital. When I first read the following words, I was excited and thrilled at his articulation of the reconceptualization that not only I but he, too, had done:

If our ordinary view of life, death, health and disease rests solidly on seventeenth-century physics, and if this physics has been scuttled in favor of a more accurate description of nature, an inescapable question occurs: must not our definitions of life, death, health and disease themselves change? To refuse to face the consequences to these areas is to favor dogma over an evolving knowledge. We (physicians and scientists) have nothing to lose by a reexamination of fundamental assumptions of our models of health: on the contrary, we face the extraordinary possibility of fashioning a system that emphasizes life instead of death, and unity and oneness instead of fragmentation, darkness and isolation.⁶

We are all in the honored position of being on the edge of a new frontier in medicine.

¹ Fritjof Capra, *The Tao of Physics*, (Boulder: Shambala Publications, 1975), p. 209.

² A.H. Schmale, "Giving Up as a Final Common Pathway to Changes in Health," *Advanced psychosomatic Medicine*, vol. 8, 1972, pp. 20-40.

³ A. H. Schmale, *op cit*.

⁴ R. M. Nerem, M. S. Levesque, and J. F. Cornhill, "Social Environment as a Factor in Diet Induced Atherosclerosis," *Science* 208: 1475-1476, 1980.

⁵ Philip Slater, *The Wayward Gate* (Boston: Beacon Press, 1977), p. 106.

⁶ Larry Dossey, M.D., *Space, Time and Medicine*, (Boulder, CO: Shambala, 1982).

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