

Doctor as Patient: Lessons for a Life Well-Lived

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Abstract

Multiple sclerosis is a demyelinating disease of the central nervous system of unknown etiology which affects approximately 500,000 people in the United States. Typically diagnosed in young adults, multiple sclerosis is a major cause of physical disability, though no physical signs or symptoms are common to all patients. The author, an academic inner city emergency physician, presents his personal story of living with multiple sclerosis and its effects on his professional and personal life. The author concludes with thoughts regarding an emotionally healthy approach to living with a chronic disease, emphasizing the need for acceptance, living in and appreciating the moment, and adapting to an imperfect life.

Introduction

The last few decades have seen a tremendous growth in a new genre of storytelling known as illness narrative. Included in this genre are stories of what it is like to live with an illness. Told from the patient's perspective, they are informed by biomedical understandings of disease, but they go beyond medical descriptions to address the ways in which people with illnesses live in social contexts (Kleinman, 1988; Frank, 1995; Raoul, et al., 2007). In this essay I tell the story of my own transition from a healthy physician to an ill patient. I talk about the ways in which getting multiple sclerosis affected my life and the lives of my family and colleagues. In telling the story I hope to alleviate some of the stigma associated with living with chronic illness today, and I want to convey my belief that life with a chronic illness need not be a life without happiness, emotional and spiritual growth, and personal and social value. In short, I want to participate in the political act of reclaiming narrative voice (Lorde, 1980), a voice that, prior to the emergence of the illness narrative as a legitimate genre, was too often silenced by the stigmatization of illness and the dominant accounts of biomedicine.

Little League memories are some of the fondest of my life, but a simple game of catch at the age of twelve in the backyard resulted in perhaps a prophetic moment as I look back upon it now. An adult friend of mine was a pitcher for the local town baseball team. His size seemed menacing to me at the time, but his bread and butter pitch was none other than the knuckleball. I asked him to throw me a knuckleball. He warned me to be on my guard; even the pitcher does not know just what flight pattern a knuckleball will travel. But no problem, I was an all-star in Little League. Surely I could catch a ball thrown at far less than normal speed. To this day I remember having my sights set on that pitch, my glove in perfect position to make the catch, only to have the ball suddenly dip down below my glove and strike me on the leg. Startled, I learned that day that the knuckleball was to be respected.

Twenty nine years later I gained a new respect for a similar "pitch" when I was diagnosed with multiple sclerosis. Suddenly uncertainty and loss of control over my life were thrust upon me

without warning. I was experiencing an "interruption" of my normal life (Charmaz, 1991). The good life was in jeopardy, and to add insult to injury there were no assurances about what my medical future would be like. I worried about my ability to bring home an income, and losing those basic physical functions of life that before then I had taken for granted. One of my daughters worried that I would someday end up in a wheelchair, unable to play basketball or baseball with her again. My son worried that he would contract the disease if he drank from my cup. Uncertainty and worry no longer were abstract notions; they became very real concepts that threatened every aspect of my family's life.

And yet, all of these worries might prove to be unfounded. Some patients with multiple sclerosis have little or no disability, and some have only a very slowly progressive disease that develops over many, many years. But the analogy of catching the knuckleball kept coming back to me. Would I catch the baseball, or despite preparation and anticipation of every possible movement, would it hit me in the leg without warning and injure me? To avoid going crazy with worry, my family and I would have to learn to adjust to the unexpected. Flexibility and recognition of the preciousness of each moment developed a new meaning. Redefinition of self and relationships would prove painful, yet essential.

My purpose here is not just to tell my story or to educate about multiple sclerosis, though I do both. Rather, my hope is that my story has greater meaning, a more global message. I offer what Arthur Frank (1995) has described as a "quest" narrative, a story about how chronic illness led me to deeper understandings of my social relationships and a greater appreciation for life.¹

Chronic illness, be it multiple sclerosis, diabetes, cancer, or lupus requires a sense of acceptance, a willingness to live in the moment, and the skill to adapt to an admittedly imperfect life. Though I have dealt with multiple sclerosis for only a little more than ten years now, I have learned and experienced a lifetime of new knowledge and perspective. I have embraced my fate (at times more successfully than others), realizing that such acceptance requires both self-love

¹ Frank (1995) describes two other types of illness stories that are acceptable in contemporary society. The first is the "restitution" narrative, in which the narrator somehow overcomes illness to return to her former self. The other is the "chaos" narrative, in which the storyteller is in trapped in her illness and unable to imagine life ever improving. Part of Frank's agenda is to create space in which other types of narratives can gain legitimacy.

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and the love of those around me. I have discovered a greater sense of peace than ever before. I am a better person than before. The gifts of love, kindness, and happiness surface more often than before. I tell my story here in hopes that others might not only know me better as a redefined person, but also that others dealing with similar challenges professionally or personally might find the courage to explore all there is to learn from what at times might appear to be an unfair act of fate. I offer my account as a way of recognizing the generosity (Frank, 2007) of all those who have changed along with me and enabled me to grow and learn to live with multiple sclerosis.

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Multiple Sclerosis: My Diagnosis

Life-defining moments are rare in this world and it is rarer yet that are they grasped and appreciated. In December 1996 one such inextricably etched moment occurred in my life, resulting in new meaning of "self", no longer defined primarily on my own terms, but rather through an enriched bond with family and friends. Life was, indeed, good. I had a beautiful wife of eighteen years, four children (three girls and a boy, ages thirteen to one), a home in a mainline suburb of Philadelphia, and a well-paying job as Director of Emergency Medicine at Temple University Hospital. Life, too, was chaotic. Raising four children added logarithmically to the challenges of just getting through the essentials of life. Life in the Kauffman household was not unlike life in the emergency department; there was the same degree of craziness, only the details were different. The challenges of overseeing homework, driving children to basketball and softball practices, arranging school conferences, keeping up with the boundless energy of a four year old, changing endless numbers of diapers, and trying to keep the house from looking like a three-ring circus with toys and clothing scattered everywhere only begin to describe life in our house. Add to that the fact that my work was a constant source of stress, whether from the adrenalin rush of caring for a patient who was trying desperately to die in front of me, or from the unending pressures of establishing a residency training program in emergency medicine at a time of significant cutbacks in medical education support, it is only in retrospect that I understand that the Kauffman family was primed for a life-altering event of some sort.

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Restful sleep was hard for me to come by. One night I left our bedroom and finally fell asleep on the living room sofa. At three AM I was jolted from sleep by the sudden gripping sensation of a continuous electric shock which began at my right hip and instantly overtook my entire right leg. Unlike anything I had experienced before, I immediately sat bolt upright and began rubbing my leg furiously, desperately looking for some constructive response to the pain. Before I knew it I was on the floor, still rubbing my leg. But as suddenly as the "attack" began, it was over. In an instant normal sensation and function returned to my leg. With the most powerful of coping mechanisms, denial, at my disposal, I assumed that I "slept on my leg wrong" and that it must have "fallen asleep". I arose for good at five AM, as was my daily custom, and drove to the health club where I began my day with stationary rowing, modest weight lifting, and laughter and joking with friends who were as crazy as me to be exercising at such a ridiculously early hour of the day. I felt fine. There was nothing to worry about.

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Soon enough, however, I had real reason to worry. The following night the identical chain of events happened, but instead of involving only my leg, an intense cramp-like sensation grabbed my right waist. Once again my right leg was useless, but once again after what felt like an eternity, function returned to normal just as dramatically as it had left moments before. I brought my wife into my confidence, and together we resolved that I should see a neurologist as soon as possible. Intellectually I resolved to play the role of patient, rather than that of the self-diagnosing and treating physician. Many times in the ensuing months I failed to meet that resolution. All too often I was sucked into evaluating my situation from a medical perspective. Denial, and the desire not to bother my doctors, could have proven disastrous without the commonsense actions taken by my wife. She would live with my pain and the fear of a brain tumor, live my hell as my condition ultimately spiraled out of control, maintain the family and household, and suffer greatly in the process.

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My "attacks" occurred nightly for the next two weeks. Each attack became progressively more involved, ultimately including my right arm and hand, contorting the extremity into a useless appendage. But at the time of initial medical evaluation my examination was perfectly normal. I looked great. My neurologist, certain that I was healthy, yet perplexed by my story, ordered an

MRI of my brain and spinal cord. His decision granted me a sense of relief. By this time I had begun developing a differential diagnosis in my mind. Could this be a brain tumor, an unusual presentation of a seizure disorder, severe spinal stenosis, or multiple sclerosis? The MRI was the first step in getting to the answer. Pulling a few strings, and anxious for an answer, I scheduled the MRI for the day after Christmas.

The MRI suite was quite cold. I resolved to deal with the anxiety and potential claustrophobic feeling of the machine by keeping my eyes shut at all times throughout the lengthy procedure. Though I had ordered MRI's on many of my own patients, I had no idea just how loud the machine was throughout the test. I felt as if a jack hammer were adjacent to my head, working at full blast to destroy a portion of concrete or asphalt. Periodically the pitch and frequency of the noise changed, but the intensity never abated. The sound was enough to drive one mad, and I marveled at stories of people falling asleep in the MRI machine. After several hours my study was complete. As I left the exam room I noticed a monitor which displayed an image of a brain. Even my untrained eyes could pick out a rather large and obvious lesion on the scan. I privately noted to myself that I was glad that was not my brain, only to find out days later that indeed it was an image of my brain, and that the lesion I had noted was one of several which would be found as evidence that I had multiple sclerosis.

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My neurologist was away on vacation until January 3, and though the nightly "attacks" had eased, I found myself feeling more and more certain that something indeed was lurking under my seemingly healthy façade. No longer holding true to my resolution to be patient and not physician, I tracked down the official results of the MRI:

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Scattered small areas of abnormally increased signal within the subcortical white matter. The appearance is consistent with a demyelinating process...

Desperate for more answers and explanation, I tracked down the Chairman of Neurology. Yes, multiple sclerosis was a possibility, along with migraines and ischemia, or perhaps even meaningless artifact. More studies were necessary. My mind raced, and my emotions swirled out of control despite my calm exterior. Would this be an endless exercise in academic medicine leading to nothing, or to a devastating conclusion? In my heart I knew that the MRI demonstrated

that I was no longer the picture of health. Indeed something was terribly wrong. I had lesions in my brain. This was very real, and the feeling of just a few days earlier that I could deal with anything, though not totally shattered, was indeed no longer a certainty. I was scared and confused.

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The next few days were exhausting. Family was visiting for the holidays, the washing machine had died, our son had influenza, and his fourth birthday would arrive in a matter of days. My wife and I found a few minutes of privacy to discuss the results of the MRI and the increasing likelihood that I had multiple sclerosis. For the first time it truly hit home that the past few weeks had indeed signaled a very real change in our lives. Together we somehow managed to hold our emotions in relative check as we concluded our holiday obligations and celebrated our son's birthday. But four days later, after some more tests and further review of the results with several experts, the medical conclusions became clear. I had demyelinating lesions in my brain, cervical and lower thoracic spinal cord. I had multiple sclerosis.

It has been said that multiple sclerosis is the one disease that medical students fear the most. Indeed, still etched in my memory from medical school is the lecture on optic neuritis, a common feature in multiple sclerosis. But one comment can be made about medical students, and young adults in general; death and disease are considered problems of other people. Most physicians are goal-oriented individuals who have achieved professional success by taking control of their lives. Disease is equated with loss of control, a concept rather foreign to most young physicians. Chronic illnesses such as multiple sclerosis are, as Arthur Kleinman (1988:17) has said, seen by physicians as messy and threatening. ~~They are~~ not only unpredictable, but always looming in the future is the possibility of crippling disability. Suddenly the possibility of future disability became very real for me. No longer was I in control of my future.

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Multiple Sclerosis: The Disease

Multiple sclerosis is a disease of unknown cause that affects approximately 500,000 people in the United States. It has no cure. Women are twice as likely as men to develop multiple sclerosis (Jongbloed, 2007), and most patients are diagnosed at a young age, usually

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between the ages of twenty and fifty. World-wide variation exists as well. Asians are at very low risk for developing multiple sclerosis, and Eskimos may be totally immune to the disease.

American whites are twice as likely as American blacks to develop multiple sclerosis, though African and Caribbean blacks are less likely than American blacks to contract the disease.

Interestingly, one's risk for developing multiple sclerosis appears to be established by the age of fifteen. If one moves from a low incidence geographic region to a high incidence region after the age of fifteen, that individual carries the low-risk for a lifetime. That same individual who moves before the age of fifteen acquires the high risk of the new location. This has lead epidemiologists to speculate that some unknown environmental exposure of childhood (many postulate a virus) may play a role in the development of multiple sclerosis later in life in individuals who are

genetically susceptible to the illness. [\(National Multiple Sclerosis Society, 2008\).](#)

Multiple sclerosis is a disease of the central nervous system, which consists of the brain and spinal cord. Under normal conditions, impulses from the brain travel via connecting nerve fibers called axons, and deliver information to the body by way of the spinal cord. Axons can be thought of as 'electrical wires' which require a surrounding insulating material in order to function properly. This insulating material which covers axons is called myelin, a substance composed of protein and fat. In multiple sclerosis the myelin sheath is damaged or destroyed, a process known as demyelination, thereby altering normal transmission of electrical impulses. Not all axons are affected, but rather discrete regions within the brain and /or spinal cord are damaged; these damaged regions of demyelination are referred to as plaque. Symptoms vary from patient to patient, in large part related to the location and extent of demyelination. Why demyelination occurs is not fully understood, though accepted theory postulates that multiple sclerosis is an autoimmune disease, one in which the body views its own material (in this case myelin) as foreign, and mounts normal defense mechanisms to destroy its own material.

Patients with multiple sclerosis experience episodic neurologic symptoms which result in fixed or fluctuating neurologic deficits. The disease is categorized into four patterns: relapsing – remitting, secondary progressive, primary progressive, and progressive relapsing. The most common disease category is relapsing – remitting, whereby patients develop discrete episodes of

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neurologic symptoms which may last weeks to months, but which ultimately resolve. Over time, however, approximately half of the patients with relapsing – remitting disease will convert to secondary progressive disease, where discrete neurologic relapses are largely replaced by gradual and progressive neurologic decline. About ten percent of patients with multiple sclerosis have primary progressive disease from the onset, with steady and progressive neurologic decline. The most uncommon form of multiple sclerosis is progressive relapsing – remitting disease, where episodic neurologic events are followed by progressive, yet episodic, deterioration

[\(National Multiple Sclerosis Society, 2008\)](#),

Patients with multiple sclerosis have no 'typical' presentation. In fact, many patients may experience symptoms for months or even years before a definitive diagnosis is made. Common symptoms include: vision loss, double vision, numbness, muscle weakness, extreme fatigue, speech difficulty, gait disturbances, difficulty with coordination, and loss of bladder control. Diagnosis in any given patient involves performing a complete history and physical examination, and coordinating the results of several tests based upon clinical suspicion. Such tests include: MRI of the brain and spinal cord which may demonstrate discrete plaques (areas of demyelination); visual, auditory, and sensory evoked potentials which may indicate delays or alterations in electrical impulse transmission; and lumbar puncture, which may demonstrate elevated levels of protein in the cerebrospinal fluid which bathes the brain and spinal cord.. No blood tests are suggestive or diagnostic of multiple sclerosis.

To date, no cure for multiple sclerosis has been found. In the past, most therapy was aimed at treating relapses of the disease with high doses of steroids. Such therapy has been used empirically in the hope of reducing severity of relapse, but steroids have not been shown to alter disease progression. Current therapy holds greater hope, especially for patients with the relapsing – remitting form of multiple sclerosis. Several forms of interferon beta, along with glatiramer acetate, an analogue of myelin, have been demonstrated to reduce frequency and severity of relapse, and in some instances, delay progression of disease. Another drug, natalizumab, represents the first monoclonal antibody available for the treatment of multiple sclerosis in select patients with worsening relapsing clinical course despite other aggressive

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management. Finally, medications typically used for patients with other autoimmune diseases and even cancer are currently available or in clinical trial and hold great promise. Ultimately, however, for any given individual with multiple sclerosis, the future is an unknown. Treatment progress is measured by statistical comparisons of large groups of patients. The disease progression for any given patient is unknown, with or without therapy. No clinical marker exists for multiple sclerosis that allows physicians to follow progress of the disease and its treatment outcome in an individual patient. Such uncertainty is the mainstay of life for all patients with multiple sclerosis.

Multiple Sclerosis: My Treatment

Having received the diagnosis of multiple sclerosis, I again failed in my resolve to remain a patient and not physician. In true "find the problem and fix it" mode, I elected to begin treatment immediately. Rushing into this decision was not necessary, however. Starting treatment immediately, versus spending some time to understand the implications of my diagnosis and its treatment options, carried with it no advantages in either immediate or long-term outcome. Dealing with multiple sclerosis demands the mentality of a distance runner and not a sprinter; multiple sclerosis is a life-long marathon, not a sprint. None the less, I began interferon treatment within one week of my diagnosis. Having been told that most patients experience flu-like symptoms after the injection, and that these symptoms tend to resolve over time, I began treatment totally unprepared for what was to occur over the next several months. Within just a few hours after my injections I became totally bedridden by wickedly uncomfortable diffuse muscle and joint pains. Symptoms always started in my toes and ankles, and from there progressed upward to my knees, hips, hands and arms. I became restless, but unable to walk. Every muscle and joint in my body made its presence unforgettably known in painful and persistent agony. Every two hour analgesics did not even touch the pain, and sleep was impossible to come by. I was virtually bedridden by the very therapy that was supposed to be helping me.

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After about one month of weekly interferon injections I found myself in a vicious cycle of incapacitating treatment followed by loss of energy and emotional zest. Being around people, or even talking to family and friends on the telephone, became increasingly difficult. Crying episodes surfaced without warning, and I was unable to explain just what was prompting them. Emotional pain became unbearable. I was confused and scared by the fact that increasingly I felt a loss of self; no longer could I look in the mirror and know the essence of myself. My depression became incapacitating. I became bedridden and unable to function. Work rapidly became impossible. Not until I met with a psychiatrist did I receive a thoughtful and well-conceived approach to these new demons in my life. Clearly the interferon therapy not only was resulting in physical incapacitation, but it had triggered a severe depression which would require aggressive treatment. I was placed on a formal medical leave of absence from work, stopped all treatment for multiple sclerosis, and began anti-depressant medication in rapidly accelerated doses. Ultimately, the depression subsided and life began to look a bit more normal again. Several attempts to return to my profession as emergency physician, however, proved fruitless, and within two years of my diagnosis I ceased my career as an academic emergency physician.

Concluding Thoughts

It has now been eleven years since my diagnosis of multiple sclerosis. Gone is the shock and fear of a potentially debilitating intruder into my life, and in all fairness, my clinical course to date has been fairly stable. That is not to say, however, that multiple sclerosis does not play a significant role in my life on a daily basis. Fatigue, at times overwhelming and debilitating, intrudes into even simple activities of daily living. Leg weakness is always present, more so when I fail to get sufficient rest on a regular basis. Leg, neck, and facial numbness serve as periodic reminders that lesions are present in my spinal cord. And cognitive dysfunction, at times subtle and at other times obvious, reinforces the decision and necessity to stop practicing clinical medicine. All of these factors bring with them a sense of sadness that life no longer is what it used to be. Gone are the days of physically and mentally being able to accomplish just about whatever I chose to do.

Yet, multiple sclerosis has brought with it gifts and opportunities, many possible only due to my new circumstance of dealing with a chronic disease. I periodically teach at the local high school, leading discussions in bioethics with junior and senior students full of fresh and intriguing opinions about some of the complex biological and medical issues which face our society. Recently I met Clay Walker, a Grammy award winning country music singer, who also battles with multiple sclerosis and who raises money for academic research into the disease. For nearly eight years I have volunteered for the Dawn Staley Foundation in North Philadelphia, providing academic and social support to at-risk youth. During my early multiple sclerosis days I had the joy of spending time with my pre-school children, later taking them to the bus stop each morning before school; few working fathers can relate to that joy of fatherhood. My wife and I have experienced much personal and private time together, growing our relationship beyond all expectations. Together we have experienced both tragedy and triumph, and [we believe that](#) our children are stronger, more caring, and more emotionally stable having been through such trying times.

Many individuals with chronic disease view it as the enemy, something to fight against and defeat. On my bad days, I too feel this way. But overall, I choose to embrace my illness, not by giving in to it, but by accepting it as a part of who I am. Chronic diseases are, by their very nature, life altering. If I never experience another severe relapse of multiple sclerosis I will always have the disease. It started at some unknown point in my past, but once symptomatic and accurately diagnosed, it never will be something that I can completely eliminate from my life. Even if a cure is developed in the future, the disease and its emotional, physical, and spiritual impact will be with me [and my family](#) always.

All of this is not to acknowledge defeat, to give in to the disease, to not fight its devastating effects, or to give up in my search for improving the quality of my life. To the contrary, by accepting my diagnosis not as friend or foe, but simply as a part of my multifaceted being, I more successfully manage my life and my search for fulfillment and joy. As I await the development of new treatments and potential cures, I will not be all consumed with fighting a war I can not win. I win the winnable battles as they present themselves, and in the meantime

prepare for that day when the war can be won as well. But I am also aware that such a day may never come, and my acceptance of my illness helps me to live fruitfully with that knowledge.

Once the circumstances of one's life are accepted, and the uncertainties of one's future acknowledged, chronic illness holds the potential of a great gift. Life is built upon a nearly endless series of moments, each equally connected to both the immediate past and immediate future. In this ongoing array of moments which we experience as life, we have the opportunity to notice and examine each one for what it holds. Life experiences and life moments are not always black or white, happy or sad, good or bad. Rather, they are a collage of intertwining emotions and experiences which together form the meaning of our existence. All too easy are the trappings of daily life that blend one moment indefinably into the next, thereby rendering each moment meaningless. There is great detail and meaning to be garnered from individual moments, from the practice of being aware of our surroundings. I am reminded of my experience taking a college course in botany which entailed a significant amount of detailed inspection while looking at microscopic specimens. Minuscule details in structure and color carried with them tremendous information and knowledge about botanical function. I found myself that semester much more aware of the beauty of a sunset, the sounds of the breeze, and the meaning and importance of relationships. The world is our laboratory, if only we slow it down, pay attention, live each moment and consciously remind ourselves of the preciousness of being present for one another.

My life to date has been far from what I would have expected. In many ways my life is imperfect. I have a chronic disease that carries with it the possibility of eventual life in a wheelchair. I left my profession at the age of forty three. I no longer practice clinical medicine, and no longer am part of the academic fraternity of emergency medicine. Life's circumstances have forced me to adapt to an imperfect life and to reassess and redefine self and my personal relationships. Multiple sclerosis has taught me that I am not my profession, and that my physical capabilities do not define who I am as a human being. The core of my being, and the core of the relationships in my life, are both based upon qualities of self and others that have nothing to do with physical skills or chronic diseases. Someone once said that after multiple sclerosis she does

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everything she did before multiple sclerosis, just differently. I was attracted to medicine for reasons of compassion, caring, and a desire to help others. Multiple sclerosis has not robbed me of those capabilities; I simply channel my energies into different arenas where such qualities now have the greatest chance of success. Meaningful personal relationships always were built upon similar characteristics, and that has not changed since multiple sclerosis entered my life.

Suffering, regardless of its form, allows us to think, to wonder, to dream, to re-evaluate what is good, what is essential, and what is worthwhile. One need not wait for that life catastrophe, however, to begin that process. It can begin now, today. Perhaps it starts slowly, only to build momentum as it grows and becomes more self-enriching. Tomorrow may bring a new twist, one to examine, observe, and accept. It may mean changing our ideas, our plans, our hopes, and our dreams a bit. But in that change will come new challenges, new rewards, new dreams, and new life. The future is an unknown for all of us, and the present immediately becomes the past. We must live in the moment, awake to all its possibilities. In that way, we will live a life truly well-lived.

Biography

Frederic Kauffman, M.D. graduated from Dickinson College in 1977 with a Bachelor of Science Degree in Biology. He received his M.D. from the University of Pennsylvania School of Medicine in 1981 and completed his residency training in Internal medicine at Temple University Hospital in 1984. Dr. Kauffman subsequently achieved board certification in both Internal Medicine and Emergency Medicine, and served as Temple University School of Medicine's first Director of Emergency Medicine Education. Subsequently he served as the Chair of Emergency Medicine at Temple Hospital, and developed a residency training program in Emergency Medicine in 1997. In 1999 Dr. Kauffman retired from clinical and administrative practice, and went on to become Chair of the Board of Directors of the Dawn Staley Foundation. Dr. Kauffman is married to Wendy Wallenmeyer Kauffman, Dickinson College Class of 1977; they have four children ages 24 to 12.

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