

From the Bedside to the Bed: A Physician-Patient's Perspective

Alan Diner, MD FACP

I'm writing this article a year after my heart failed. I write to help myself integrate this very frightening experience into my life and career, to answer the questions raised by the experience, and to help others understand how the things I observed and learned during my years as a palliative physician provided comfort and a framework that guided me through the illness.

In fall 2006, my wife and I vacationed in the Colorado Rockies and southwest deserts. We hiked, biked, rafted, marveled at the buttes and canyons, and had a wonderful time.

I started back to work slowly over the next few days; I sorted through the mail, answered phone calls, and then returned to work officially the following week. When I returned to work full time, I felt relaxed, perhaps a little light-headed when sitting up, but otherwise well.

As I listened to my first morning report after my return, everything suddenly changed. I lost consciousness and fell backward from my chair onto the floor. Soon after, I awoke to find my colleagues running a code. It was a bewildering experience.

An ambulance rushed me to a local hospital where doctors discovered a new-onset high-grade heart block and admitted me to the critical care unit (CCU). After a few hours and an angiogram, I underwent an angioplasty to treat a mid-left anterior descending (LAD) lesion. My admission blood tests also revealed low-level but positive cardiac enzymes.

Lying in bed in the CCU that night, my vision abruptly contracted—it was like looking out from deep inside a tunnel—

and my body became unresponsive and unmovable. Just before I lost consciousness, I saw CCU nurses run into my room. I was in complete heart block and by the next day a pacemaker and an internal defibrillator had been implanted in my body. I was informed that I had congestive heart failure with a very low ejection fraction.

I was discharged from the hospital several days later. Unwilling to let my illness sideline me, I went back to work part time; however, I felt light-headed, weak, and short of breath. This continued over the next 2 weeks until I became so symptomatic that I was readmitted to the CCU. I knew my health was failing. It was terrifying to be so sick. I had progressively severe heart failure and hepatic congestion (a bilirubin near 20), yet none of my physicians would acknowledge or discuss the seriousness of my condition or develop plans to address it. I found it particularly disturbing that my physicians were not committed to providing the communication that palliative care strives to provide to patients and that I needed and expected.

My health continued to deteriorate, and days after I was supposed to have been transferred to New York Presbyterian Hospital at Columbia University Medical Center, my wife and I asked the nursing staff to help us locate the weekend attending physician because he had not yet made his rounds. The staff refused to divulge his phone number, citing protocol; instead, we found it in the phone book and paged the doctor to my phone. After learning how serious my condition was, the attending physician helped secure my immediate transfer.

After a week of being evaluated at Columbia University Medical Center, I underwent a myocardial biopsy, and a bilateral ventricular assist device (BIVAD) was implanted in my chest. The BIVAD assistance pumps were attached to my heart and great vessels and were powered by air compressor hoses and a computer controller exiting my right flank. During the next 2 months my condition became stable enough for me to go home, although I had to be attached day and night to a rolling 40-lb BIVAD.

The biopsy revealed that I had myocarditis. Despite hopes that my heart would recover, I was still unable to wean myself from the BIVAD a month after surgery. I was assigned high-priority status for a transplant. One night a few weeks later, I received a phone call informing me that a heart was available and that I needed to go to the hospital for a transplant. I am now on tapering doses of insulin, steroids, and other antirejection drugs while I slowly recuperate at home.

How could it be that on Sunday I was an athletic, healthy physician with low cardiac risk factors and on Monday I was a desperately sick patient with a failing heart? Didn't I deserve credit for all the broccoli, dark fish, and high-fiber cereal I'd made part of my diet? It wasn't fair!

At this point in my recovery, I have many ongoing frustrations and questions. Because I'm now immunosuppressed to prevent organ rejection, I've had to give up working in clinical settings where I might be exposed to highly resistant organisms. Losing this piece of my career leaves me at loose ends, but I hope to be

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able to teach in a setting with limited patient contact.

Perhaps it was unrealistic during my hospitalization, but as an internist I wanted to feel as though I could control my illness and treatment or at least believe I could understand each decision being made for me. As a palliative care physician, it was only when I realized the impossibility of this that I was able to give up that struggle, relax, accept the plans, and try to not micromanage my own case; I was able to become much more relaxed and accepting only after I applied the hospice perspective to my condition. One of my usual coping tactics—reviewing literature detailing mortality figures and survival rates—certainly did nothing to comfort me during this time.

Although spirituality has been a constant but undeveloped aspect of my life, another issue I grappled with during my illness was that so many people I care for and deeply respect said prayers for me. Their prayers were supportive and much appreciated, but I am not sure whether I share their belief in prayer or could offer them the same gesture.

As I reflect on what has happened to me during the past year, I believe my experience in hospice has played a major role in my ability to adapt to such massive and sudden loss. I feared death and major

organ system failure during surgery, but the hospice perspective and practice of life review helped keep meaning in my life, as have memories of the quiet courage of patients I've previously cared for. I've been able to maintain a sense of being valued, even when engulfed by the maelstrom of illness. The love from my wife, family, friends, colleagues, as well as their concern and prayers, has kept me from depression. My work with others who were very ill, self-hypnosis, muscle relaxation, and the acceptance that, like it or not, I was in the bed as a patient rather than beside it as a physician have all helped me cope.

I also owe an enormous debt to my heart donor, whom I don't yet know how to repay. A significant number of patients die while waiting for organ transplants. Currently, there are approximately 7,000 people in the New York metropolitan region alone awaiting organ donations. I hope that by working to increase organ donation, supporting my hospital and its transplant program, and being open to further opportunities, I may be able to answer more questions and gain a better perspective about my experience.

Alan Diner, MD FACP, is director of medicine at Creedmoor Psychiatric Center, Queens Village, NY. He trained as an internist, geriatrician, and palliative care specialist. Prior to his illness he was chief hospice physician at an inpatient hospice unit in Jamaica, NY.

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