

To Err Is Human; The Need for Trauma Support Is, Too A Story of the Power of Patient/Physician Partnership After a Sentinel Event

This article describes the development of a new program for providing trauma support services to people who have experienced unanticipated outcomes from medical care or, more particularly, the failure of medical care. Medically Induced Trauma Support Services or MITSS (www.mitss.org) was developed in partnership by a patient and an anesthesiologist involved in the unanticipated event that seriously harmed the patient.

We – patient and doctor – tell this story in our own voices to give the reader a sense of how we approached each other, what we learned when we talked, and what we decided to do as a result of this conversation. Honesty, emotion, compassion, and forgiveness are natural elements of our story, as are the fears of blame, liability, or bad public relations that generate reluctance to communicate after someone is hurt.

By reaching across the chasm that opens between provider and patient when medical injury occurs, we were able to identify gaps in crucial trauma support services that had left each of us feeling terribly isolated for almost two years. Neither of us fully appreciated this obstacle to our being able to heal and get on with our lives until we talked about it with one another. Once we did, we were able to begin paving a pathway for closing that gap.

Linda Kenney (LKK): On November 18, 1999, I entered a hospital in Boston for ankle replacement surgery. This was to be the 19th surgery of my life, the latest attempt to remedy congenital club feet. I was a healthy 37-year-old woman at the time, married to a restaurant owner and the mother of three children. With my anesthesiologist, Rick van Pelt, MD, an anesthetic

plan had been formulated that was to combine a nerve block with a general anesthetic. I told my husband, Kevin, who is not a patient man, that there was no need for him to hang around after taking me to the hospital. Surgery had become almost a routine part of my life, given my birth defect.

Rick van Pelt, MD (RvP): The block was performed using all of the standard precautions, and the local anesthetic was carefully injected around the nerves. Linda appeared to have tolerated the procedure well, but within one minute of completing the injection Linda suddenly became disoriented and rapidly progressed to having a seizure followed by cardiac arrest. Cardiopulmonary resuscitation (CPR) and advanced cardiac life support (ACLS) were immediately started. It quickly became evident that Linda's heart rhythm was not responding to the resuscitation attempts, and the decision was made to take Linda emergently to a cardiac operating room and to put her on a heart-lung bypass machine. Linda was connected to the bypass pump through a surgical incision to her chest, and within two minutes of being on the bypass pump Linda's heart recovered and started to function. Linda was successfully disconnected from the bypass pump, and she was transported to the Cardiac Intensive Care Unit.

Linda's husband, Kevin, was difficult to contact following the event. After multiple attempts he was reached by telephone and was informed that something terrible had happened to Linda. Kevin rushed to the hospital and was taken to the Family Liaison Area, where he was asked to wait by himself in a small meeting room. Linda's surgeon and I came from the operating room to

speak with Kevin. We found him pacing in the meeting room, wide-eyed and with a face full of emotion. "What have you done to my beautiful wife?" he cried out at us as he came towards us. Neither of us had the necessary skills to communicate effectively with Kevin under these emotionally charged circumstances. Aside from the supportive initial conversation with Linda's orthopedic surgeon, structured emotional support for Kevin was largely absent during Linda's entire hospital admission.

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Linda experienced a typical recovery process for cardiac surgery and was hospitalized for 10 days. During Linda's hospital stay, I was intent on communicating directly with her to answer questions, to apologize about what had happened, and to share the impact that the event had had on me. In spite of multiple attempts to see Linda, the combination of an absent institutional support system, the institution's concern about the litigious implications of contact between patient and clinician, and Kevin's request that I not contact his wife prevailed. I remained isolated from Linda throughout her hospital admission and was encouraged to resume my routine clinical activities as though nothing had happened.

LKK: I was not told about what had gone wrong in the operating room until I was transferred out of the intensive care unit, four days after the incident. When I learned what had happened and developed a sense of how horrifying I looked, my major concern was for my husband, who was a wreck, and our children. My chest was cracked open, and I looked terrible. I remember feeling glad I was alive and trying to joke with my husband that the reason why God didn't take me was because no one else would be able to put up with him. Upon discharge, I was given instructions about how to care for my physical symptoms and was told that I would have a visiting nurse. There was no information given about what the emotional impact an adverse event like this might have on my family or me.

RvP: With Linda now at home, my desire to communicate with her had not diminished. Assuming that Kevin would likely persist in preventing direct contact, I decided that my best chance for contact would be through a letter. Without soliciting input from the institution, I composed a letter in which I took responsibility and apologized for the adverse event. I also shared that the event had had an impact on me and tried to demonstrate my commitment to be open to further communication. Every conceivable mode of contact was written down for Linda, should she choose to respond.

LKK: My initial reaction to the letter was that Dr. van Pelt was doing damage control, and I filed it away. I was angry with him and had other, more pressing things to deal with, namely my physical recovery and my kids' reactions. My teenage son didn't want to leave my side. My 13-year-old daughter refused to even mention the accident for over a year. And my 3-year-old was terribly confused and couldn't make sense of all the change.

Over the next six months, my healing progressed, leaving me without any further physical disabilities. While my family and friends began to move on with their lives, my initial gratitude for "just being alive"

waned. Extreme feelings surfaced that I could hardly describe and that were immobilizing. Among other things, I felt guilty for being lucky enough to survive when other people die from accidents. Basically, I felt crazy, and when I'd try to talk about it, people were surprised. "Aren't you over that yet? It was months ago. Move on." As I became increasingly aware that I had been on autopilot with my feelings about the accident for months, I called the hospital seeking support services for patients who were dealing with similar circumstances. My phone calls went unreturned, and I was distanced by impersonal form letters. It was during this time that I became acutely aware of the lack of support services available to patients and families involved in medical trauma.

By April of 2000, I had made a personal decision not to pursue litigation. Two things motivated my decision: First, I thought it might ruin Dr. van Pelt's career, and I didn't want to be responsible for that. Second, I had been able to return to my life as it was before the event. But I decided that I did want to talk with him because I hoped forgiving him would give me the freedom to move forward.

RvP: I had moved to Seattle. In May 2000 I received a message that Linda had been trying to reach me. In spite of my initial apprehension, I made the call to Linda. That experience was one of the most uplifting conversations of my life. In addition to clarifying Linda's questions about details around the event, we both shared the emotional impact that the adverse event had had on us. Then Linda offered me forgiveness. She said this was an act she made more for herself, as she had hoped that doing so would give her the ability to move forward with her life. The act of forgiveness had a powerful effect on both of us, and the tremendous burden of shame and guilt was instantly lifted from me. We ended by making a commitment to meet in person when the opportunity arose.

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Our face-to-face meeting occurred in November 2001, approximately one and a half years later, close to the second anniversary of the adverse event. We met at a café in Linda's town. What had begun as a reserved interaction rapidly became open conversation as the differences between physician and patient fell secondary to being human.

Linda shared her continued emotional struggle and her unsuccessful attempts to solicit support services for her emotional needs from the institution. I recounted the many overt to subtle discouragements I received as I was trying to talk with her. Together we realized that there was very little organized support for patients, families, or clinicians.

With the realization that there were likely thousands of unsupported individuals affected by adverse medical events, it quickly became apparent to both Linda and me that our needs and motivations reflected a larger story. Our conversation was no longer simply about personal reconciliation and healing. Rather, it was about the need – a need that often feels desperate – for a support system within healthcare institutions and within the local communities where patient, families, and their healers live. In that moment, Linda committed to establishing a non-profit organization to support those affected by medically induced trauma, and I committed to assisting her in the development of this organization and to serving as a hospital advocate for Linda. In July 2002, after eight months of planning, Medically Induced Trauma Support Services (MITSS) was incorporated.

MITSS is a non-profit organization whose mission is "to support healing and restore hope" to those who have

been negatively affected by a medically induced trauma. MITSS defines medically induced trauma as an unexpected complication due to a medical or surgical procedure, a medical systems error, and other circumstances that affect the overall well being of an individual and/or family member. The goal of MITSS is to assist affected individuals to process adverse medical events in a positive manner in order to move forward both personally and professionally.

Since its inception, MITSS has provided ongoing structured educational support groups for patients and their families affected by medical trauma led by an experienced psychologist; MITSS is working on continuing to grow these groups. MITSS is also collaborating with the Mass. Nurses Association in an effort to bring services to nurses who are experiencing the emotional fallout in the aftermath of a negative medical outcome (those groups started in Janu-

ary 2005). MITSS has developed a survey tool designed to measure clinicians' experiences and perceptions regarding support services available in their own healthcare settings. Data derived from the survey tool will be used to strengthen current support services as well as develop and implement new systems for clinicians who find themselves on the "sharp end" of a medical trauma. Under Linda's direction, MITSS has embarked on an aggressive outreach effort to the medical community in order to shine a spotlight on its core issue: the need to provide support to all those negatively affected by a medical trauma. !

Linda Kenney founded Medically Induced Trauma Support Services (www.MITSS.org) in June 2002. She is a member of the Board of Directors of Consumers Advancing Patient Safety (CAPS) and is often a featured speaker at meetings that offer education on the role

of patients and consumers in adverse medical events. Kenney may be contacted at 1-888-36MITSS or lkenney@mitss.org.

Rick A. van Pelt, MD, MBA is currently on staff at the Brigham and Women's Hospital serving both clinical and administrative functions. He attended Amherst College and the University of Massachusetts Medical School. After spending a year as a research fellow at the National Institutes of Health, he spent two years as a surgical resident before transitioning into and finishing a residency and fellowship in anesthesiology. Dr. van Pelt went on to attend Harvard Business School to develop further the skills necessary to serve as an effective leader at the institutional and industry levels. Since completing his MBA in 1999, Dr. van Pelt has been actively involved in healthcare improvement initiatives, including patient safety, in academic and private healthcare settings as well as in the healthcare industry.