Joy, Unimpeded

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“Good news is rare these days, and every glittering ounce of it should be cherished and hoarded and worshipped and fondled like a priceless diamond.” —Hunter S. Thompson

Much of the work of physicians involves delivering news, both bad and good. As both a health care provider and the father of two patients, I’ve had a chance to experience a broad range of emotions at hearing news. My son is a pediatric liver transplant patient, now 30 years old and 24 years from his transplant resulting from alpha-1 antitrypsin deficiency. In the intervening years, he’s experienced rejection episodes, opportunistic infections, and posttransplant lymphoma requiring two treatments (chemotherapy and autologous bone marrow transplant). My daughter, now 25, is autistic and functioning well after years of therapy. In our many visits to hospitals and clinics, we heard a lot of bad news. But occasionally there was some good news, too.

When my son was 21, his was the story of the roller-coaster ride of so many: a PET scan on Monday, with no results until Friday was the norm, with agonized waiting in between until a member of the team explained results in cautious terms. I was struck by how little fanfare there was when his first posttreatment scan came back clear. We stayed in the exam room for over an hour, sitting in near silence. Finally, an oncology fellow arrived, apologizing for the main physician’s absence. He declared, “Well, this is a good day, isn’t it?”

My son looked at him with disbelief, “Well, we don’t know yet.”

The fellow replied sheepishly, “They didn’t tell you anything?”

My son looked at him with more impatience and skepticism, “Don’t be messin’ with me! What are you saying?”

There was a seemingly endless pause. “Your PET Scan is clear. No detectable sign of cancer anywhere.”

We exchanged low-key high fives as we tried to assimilate this seemingly good news, news that didn’t seem quite as positive as it could have.

Caution seemed to drive that delivery of good news. Perhaps the overwhelming amount of medical research, known probabilities of treatment success, and a true concern for inadvertently misleading a patient by offering false hope makes it difficult. This is so understandable; the pressure on the medical team to be certain, to be precise in an arena that offers little precision, to manage the expectations of patients who are hopeful to the point of living in denial. Sometimes, though, a little magic can happen.

We sat for hours in the warmly-appointed waiting room of the pediatric radiology suite, awaiting results, this time for our newborn daughter, rather than our son, who was a regular in this office. He had become a “case,” a clinical legend studied by medical students and residents throughout the medical center. But today, it was our daughter’s turn, getting her head x-rayed to determine if her larger-than-average head size was problematic.

The many times we had been here before had been to determine details of my son’s recovery from a liver transplant and subsequent viral infection. These long visits often involved repeated scans of his abdomen, looking for any signs of swelling or (hopefully) shrinking lymph nodes.

We had become so well known to the radiology team that they knew all our needs, names, preferences, and fears. These professionals had clearly been trained in the art of giving bad
news. And, they had given us plenty over the years.

Reflecting on that long day in the radiology suite at Children’s Hospital, I know it can be different. We just wanted a brief respite from the barrage of bummers regarding our son’s health. We hoped our daughter’s x-ray might be that respite, but continued to worry it wouldn’t be. We sat silently, speaking only to read her the heroic story The Bravest Dog Ever: The True Story of Balto, about the gritty sled dog who delivered medicine to sick children in an arctic blizzard.

The automatic doors to the inner sanctum of the radiology clinic opened wide. Into the waiting room marched an enthusiastic dance line of nurses, techs, and the Chief of Radiology himself, Dr Shaw, proudly holding her x-rays high above his head. They danced through the waiting room to the delighted cheers of the young patients and their families, coupled with our tears of joy. The chief radiologist leaned toward me and whispered, “With all you’ve been through with your son, we thought you could use a little celebration. There’s nothing to be concerned about.” His grin filled his entire face. It’s an experience we will never forget, an important chapter in our family’s history.

Joy is joy, and patients need to fully experience good news. We are so grateful that for that one day; the joy was complete, unimpeded. What made that possible was the emotional authenticity of the team. It was so clear they enjoyed delivering this news and sharing it with us. Some even had tears of happiness in their eyes; and really, what could be wrong in that level of honesty? We weren’t the only ones to have had that kind of joyful experience.

The hands-down world champion of all good news is the ringing of the bell at the conclusion of cancer treatment. Begun as a tradition by a former naval officer in 1996, the ringing of a bell signified a job completed, so he asked his team at M.D. Anderson to ring a bell for him. It’s now become a tradition in many hospitals, especially those treating cancers. When my son had yet another arduous procedure, this time a month-long bone marrow transplant, he was reluctant to go into the hallway to ring the bell. At my urging, he consented, ringing the bell with increasing vigor as he counted 30 chimes, one for each day of his ordeal. As he did, doors down the hallway of the treatment center began to open and patients looked hopefully toward my son, applauding his achievement.

So, my thought today is, do not hesitate to deliver good news with enthusiasm and sincerity, joy unimpeded. Your patients will feel the joy even more deeply when it is shared.