

SECOND EDITION

Privileged Presence

Personal Stories of Connections in Health Care



Liz Crocker & Bev Johnson

The Journey of the Green Elephant

The coffee cup rests on a side table. On closer examination, the table is, in fact, an elegant green porcelain elephant. The woman opposite notices my gaze, sinks back into a comfortable, stuffed armchair, and travels back in time. She begins speaking.

Great Care and Great Love

It took me a year to pick up that elephant and bring him home. It's a long story.

I was twenty-eight, in New York on a business trip, and had bought a beautiful, thigh-high, green ceramic elephant at an art gallery the day before. I remember calling my mother and saying, "I feel like I'm on top of the world. I have just picked out a wonderful new piece of art, and I love my job and I feel great!" At the time, I was unmarried and working in Toronto as a lawyer.

The next day I had a terrible attack of pain while walking down Madison Avenue. I staggered into some little restaurant, draped myself over a table, and waited for the pain to subside. When I got home, I experienced a similar attack but this time had to go to the bathroom. When I looked in the toilet bowl, I gasped because my stools were bright, emerald green. I went to my doctor right away. She gave me a stool test kit and said to return with the testing complete. I never made it back.

By early the next morning, pain was gripping my neck, chest, and side. I also felt like I was choking. A friend drove me to the hospital, and I remember urging him to go through the red lights. I knew I had to get help right away. I collapsed in the entrance to emergency. I heard someone yelling, "No BP. No pulse."

The Journey of the Green Elephant

The next thing I remember is being on a stretcher that was being pushed very quickly down a hallway. A doctor, running alongside of me, said, “We’re taking you into surgery. You’re bleeding inside.” I could see bags and bags of blood on some kind of dress rack near me. It was the beginning of the AIDS scare. I looked hazily at him and said, “I’m going to get AIDS!” He replied, “Lady, that’s the least of your concerns.”

I heard that the doctor got into trouble for what he said, but I think he saved my life. There was something about his intensity and seriousness that made me click into survival mode. My mind whispered, “Pamela—participate!” This I did as much as I could from then on. I knew I had to participate to live, to keep my soul in my body.

I was on the operating table for more than fifteen hours. It turned out I had a hepatic adenoma, which is a single-cell, benign tumor. It had exploded and blown my liver and gall bladder into pieces. Following the resection of my liver, apparently I kept bleeding out. While the team of surgeons tried to stabilize me, a determined hematologist kept trying to mix potions for me in his lab. He wouldn’t quit. Thank heaven!

Of course, I was told about the medical facts of this very long day only much later. Some of the details I heard paralleled what I had experienced in another dimension. I recall two images of my dying.

During the first, I was in a stream of warm air and floating away from my body. I saw my dead grandmother and told her, “I’m not ready yet.” I turned my back against the flow of the warm air, but I still wanted to talk to her. Over my shoulder, I said, “I’m sorry they didn’t let me go to your funeral.” She replied, “Darling, I’ve always known. Now go.” And then I literally dove back into my body, comforted by an image of friends and family waiting for me.

When Life Is Threatened: The Importance of Support

Some time passed, and I sensed I couldn't hold on any longer. I felt like horses were pounding me and I had to let go. At the last minute, I had the sensation of someone pinning me in my body and I thought, *He's holding me. I have to stay.*

When I came to, I saw my parents. They'd flown halfway across the country when they heard I'd been taken into emergency and had collapsed. I moved my left hand in circles and my father took that to mean that I wanted a pen. I wrote, "Thanks for coming." As soon as he saw me include the period, my dad said he knew I'd be okay. I never saw his optimism crack.

A week and half later, there was a new emergency. My bile duct was leaking. I had to go back to surgery and be opened up again. A few weeks later, I needed a third surgery because necrotic liver tissue was festering inside me. This time, they went in through the back, and my doctor had to remove a rib to be able to properly clean out my thoracic cavity. The space where my rib had been was packed and bandaged.

My doctor was going away for a couple of days, which made me nervous. He assured me I'd be okay and that he'd remove the packing when he came back. He specifically told me not to let anyone take it out until he got back.

Two days later, Halloween to be exact, when my father was downstairs getting a cup of coffee and I was alone in my room, the senior surgical resident came in. He told me he was going to remove the packing from my wound. I remembered my doctor's admonition to keep the packing in and my internal voice that had said "participate"! I explained that Doctor T. had said he didn't want the packing removed and that he'd do it when he returned. The resident's response was, "Well, he's away and I'm in charge." He turned me over, removed the packing, then left my room.

The Journey of the Green Elephant

I drifted off. Then I opened my eyes and saw that my entire bed was covered in blood. I was so weak I couldn't reach the call button. When my father came back to my room, he dropped his coffee and ran for the nurses. In the chaos that followed, my feeding tube also got dislodged. I remember general pandemonium . . . people running and others appearing out of nowhere . . . people calling things out to me, to someone. The chaos made me panic. I started to hyperventilate.

The senior surgical resident came back in and was yelling his name at me and telling me to calm down. Seeing him made me panic more. Another resident, Jacques-who-I'll-never-forget, told me to look into his eyes and breathe into a paper bag. He was my friend. He used to come and tell me about his life. I knew him enough to trust him and calm down. The bleeding was staunched, but I had to have several transfusions.

When my doctor returned, he was furious. It turned out he hadn't wanted the packing removed because I was on a blood thinner and he knew that would have to be stopped first. The senior resident came in to apologize, but I couldn't look at him. I was afraid of him from then on.

My father held me together that day. The only thing I had from home was a beautiful blue bathrobe. When I saw that it was also soaked in blood, I felt something inside me dissolve. I said to my father, "Daddy, I don't think I can master this. This is too much for us to handle." His response: "We can handle anything. Don't worry. I guarantee you'll feel better after a couple of hours of sleep." Comforted by his reassurance, I succumbed to my exhaustion. It had been a messy Halloween.

When I woke up, it was barely dawn. I saw my father in the armchair beside my bed and asked him if he'd been there

When Life Is Threatened: The Importance of Support

all night. “No,” he said, “I went home for a bit.” He paused and then said, “I have something for you.” And he handed me my bathrobe . . . as clean, clear, and blue as a summer sky, fresh and perfectly ironed. He’d gone home to wash it and was seen ironing it at 5 a.m. There was no residue of any mayhem anywhere I looked. He was drinking his morning coffee. The sun was up. We were fine.

Both of my parents took exquisite, intuitive care of my sense of self, how I viewed my situation, how it all looked from the inside out. My frame of mind was one thing they could actively manage. The bathrobe was important and symbolic to me and so it was to my dad. My physical sense of self was shocked and fragile, and my mother tended to it as she would a newborn.

After the second surgery, two nurses came in to change my dressings and one said to my mother, “It’s pretty gruesome. You may want to step outside.” I said, “It’s okay, Mom. You can come right back after. You don’t have to watch.” But my mother just looked at me and said, “If you’re staying, I’m staying. If I love you, I love your wounds.” My long, deep, open wounds never seemed worrisome again, at least not to me.

My parents were a seamless blend of strength and optimism. Their love for me kept me alive as I faced a long tunnel of darkness. Their devotion held me as if transfixed on the path home.

Over ten or twelve weeks, nurses came and went, but there seemed to be too many other lives and deaths around our floor for them to connect to anyone. They told me stories about the guy next door, and then he died. And then more stories about another guy, and then he died. I’m not sure who needed the distance between us more, the nurses or me.

One thing that was memorable was a pending nurses’ strike,

The Journey of the Green Elephant

which made matters worse. One nurse said, “You’re a lawyer. I’m sure you understand our concerns. We just have to strike.” But her words struck cold fear into me. All I could understand, lawyer or not, was that her serious and dire concerns did not include my welfare in any way. I was hooked up to machines and completely dependent on the hospital staff to live, but I was not on her mind at all. I was petrified. All I could think of was, *If there’s a strike, what’s going to happen to me?*

I have fond memories of two residents who connected with me as a real person. They’d drop in, ask me how I was doing, and just chat. For example, one of them described his daughter’s bumblebee costume that she’d be wearing for Halloween. The other one, Jacques-who-I’ll-never-forget, told me about taking someone on a date to see a movie and what the movie had been like. These conversations helped me remember there was a real world out there where people did normal things. These chats linked me to a life I could have beyond the hospital.

Several months after collapsing in emergency, and three operations later, I was scarred, covered in bandages, and incredibly weak, but well enough to go home to recuperate.

My surgeon said, “I want to ask you something unorthodox. There’s a whole team of people who have been quietly cheering for you since the first dark days. They want to see you going home, and I want you to meet them.” I was dressed to leave the hospital, and so he wheeled me down to the surgical staff lounge. There were about thirty-five people there, waiting for me. They began clapping and cheering for me. I was dumbfounded. I clapped back to them. I started to cry. Some of them also cried.

My surgeon had been fantastic. He had showed tremendous respect for me as a person. He always made me feel like he spent

When Life Is Threatened: The Importance of Support

his whole morning getting ready to see me. Every time I saw him, he'd say, "How's my fighter?" I felt we were partners together in a project and neither of us would let the other down. I certainly would not be letting him down.

I am sure I survived only because of my doctor's great care and my parents' great love. None of them ever let me believe that something couldn't be handled. All three of them were my partners. My parents were also my guardians and my advocates. My doctor was my champion.

"Creepy"

After a month at home, it was time to start rehab. Everyone called me "Creepy" because of how I walked. I couldn't stand up straight and could only shuffle my feet. All the bed rest in the hospital had created a scoliosis in my spine.

I went to rehab every day for five hours, for six months. There were times they would have me do something, such as climb up a couple of steps and down again, and I'd have to have a nap. Everything was so tough. Small bags of peanuts were the first weights I lifted.

My mother drove me to rehab every morning at 9:30 and picked me up every afternoon. In the car one day, I remember saying, "I can't go there again. I can't do this again. How am I going to get through this? What am I going to do?" And she said, "You just open the door. You just go in. I love you. I have nothing else to say." It must have been so difficult for her to see me working so hard and still struggling so much. She was my rock, and she was steadfast with her love, her support, and her focus. And, of course, I knew what I had to do: "Pamela—participate."

The Journey of the Green Elephant

After the six months of rehab, I had regained some strength and some flexibility, but I was not finished. I still had more hurdles to clear.

Maimonides' Prayer

Ten months after my initial emergency collapse, it was determined that I was ready to talk about future reconstructive surgery on my abdomen. It felt really important to me to check out the prospect of minimizing the disfigurement I had suffered. I knew I would need to have some muscles and ribs rearranged, and I also needed some plastic surgery to diminish the magnitude and lumpiness of some very long, very deep, puffy scars, almost like trenches, running at angles deep into my trunk.

I was referred to someone described as the “most famous and very best” plastic surgeon in the country. I can’t even begin to describe how excited I was to be traveling fifteen hundred miles to see this doctor. The fact that I was now well enough to take this trip by myself was huge. And this artist genius was going to put me back into a young woman’s body.

At the time, I was thin and pale, and my hair was short. Much of my hair had fallen out in the hospital and was just growing back. Because of my extensive scarring, I couldn’t tuck any clothes into my waist, but I dressed up as much as I could. I can still see myself. I wore a big white shirt of my father’s and flowery pants with a loose waist.

The plastic surgeon’s office was unlike any I’d ever seen. Tastefully decorated, it had sophisticated furniture, soft classical music, and a wall fountain. I’d never seen one before. I was in a complete state of awe and excited anticipation.

When Life Is Threatened: The Importance of Support

A nurse took me into an interior office. She told me to get undressed, wrap a sheet around myself, and stand up on the footstool in the middle of the room. When the doctor came in, he told me to drop the sheet. He circled around me, asking questions and nodding. Then he stopped, looked at me (the sheet was still on the floor), and said, “I could make you look once again like a beautiful, young woman; I could fix you, but I won’t. Your case is covered by medical insurance and the insurance doesn’t pay me enough to keep my children in private schools.”

A chasm opened up inside of me. I felt I was falling into it. My eyes brimmed with tears. I had to get away from there. As I stood there, completely naked, he said I was not worth his effort.

Subdued and shaken, I got dressed and began to leave his office. As I reached the door, the doctor looked up from his desk, where two ivory tusks on the wall behind him framed him. He asked how I had heard of him. I replied that he had been recommended by my cousin, Dr. X, a physician in the same city. He suddenly became interested and said, “Oh, your cousin is Dr. X? Well, perhaps we should talk.” I was incredulous. I knew that I wanted nothing to do with this man.

Many years after this event, my father-in-law quoted a man named Maimonides, who lived in the twelfth century. He was a scholar, philosopher, codifier of laws, and a very thoughtful and famous physician. Maimonides’ “Prayer of the Physician” says:

“O Lord . . . Preserve me from the temptation of allowing myself to be influenced in the exercise of my profession by the thirst for gain or the pursuit of glory. Strengthen my heart so that it may be ever ready to serve both poor and rich, both friend and foe, both just and unjust.”

My guess is that Maimonides would have been very disappointed by the famous plastic surgeon and my encounter with him.

I Think of That Nurse Every Day

Months later, I was referred to another plastic surgeon. He was extremely competent and very kind. Based on my previous experience, I'd say I actually ended up with the best after all. He even gave me a belly button again.

After the corrective surgery, my doctor left detailed instructions for the nursing staff. He also told me how the bandages that encased my entire torso should be wrapped when the dressings were changed. He was very specific and insistent about the importance of the bandage not only covering my scars, but also that they come down a few inches below the scar line.

My first nurse followed the doctor's instructions and did it perfectly. Hours passed and there was a shift change.

Eventually, I realized my dressings were overdue to be changed. I buzzed for the nurse and asked if they could be done. The new nurse had a chip on her shoulder. Assuming I was in the hospital for a tummy tuck, she said, "I know you're a cosmetic patient—I'll get to you when I get to you."

When this nurse finally did come in, she was cold and nasty and she bound me incorrectly, not taking the bandage down far enough. I asked her if she could please fully cover the scar. I explained that my doctor had been very explicit about how it should be done. She challenged me, saying, "Are you telling me how to do my job? I don't have time to do this again. There are people here with real injuries. My priority is not your tummy tuck."

When Life Is Threatened: The Importance of Support

I was shocked! I was rendered mute by both her callousness and by the worrisome realization that she had worked on me without really reading the chart.

Because of that nurse, I have an ugly bump on my belly, beneath the scars crisscrossing my body. The scars remind me of excellent care and a life saved. The red bump reminds me of someone's bad mood and disdain. I think of that nurse every day. I wish I'd been more forceful with her.

I believe that when you are dealing with an unpleasant sales-clerk at a department store, you're actually in training for the occasional health care professional who seems to be missing the empathy gene. Fortunately, they are in the minority, and I do have faith in the system as a whole.

From Being Healed to Being Saved

While recuperating at home, I saw my family doctor regularly. He would check my progress and sometimes we'd just talk. On one visit, I told him, "I think there's something wrong with my face. It feels a bit paralyzed." He replied that it could be some residual nerve damage, given everything I'd been through, but asked me to tell him again how it felt. I said, "It feels like I have a mask on my face."

He said, "I think you're in a depression. And if anyone has reason for a depression, it would be you. I recommend that you see Dr. Y, a psychiatrist. I think the two of you will have a lot to talk about."

My sessions with Dr. Y were completely liberating. I went through every step of my ordeal with him. I came to understand that I was suffering from post-traumatic stress, something unheard of twenty years ago. I had badly needed to talk about

The Journey of the Green Elephant

what had happened to me but hadn't wanted to share the details of the awfulness with the people I loved. I had created a protective mask.

This skillful psychiatrist guided me through the last steps of my journey, past being physically healed to being psychologically saved.

.....

After five hours, our conversation comes to a natural close. The green elephant sits there, quietly, as though watching her, bearing witness, having taken everything in.

This woman fully recovered and returned to work. She is now married, has four children and a warm and nourishing home, and has started a school based on "awe and wonder." She is also a talented artist, and the images in her paintings are bold and strong. Her memories of her previous health care experiences, albeit still vivid, are just memories, not daily challenges. Daily challenges now include helping with homework, renovating a house, and finding time as a hospital board member to read a report on "enhancing the quality of patient care."