

From Patient to Partner

*As told by Barbara
Kammerer Quayle*

In 1977, I was burned quite severely in a car accident. Until being admitted at the University of California Irvine Medical Center, I didn't know much about medical care or hospitals. But there were some things that I learned very quickly about health care professionals.

A number of significant people came into my life as a result of this accident. The first was my primary care physician, Dr. Robert Klein, who was in charge of my care. My face was so severely burned that my eyes were swollen shut. At first, the only way I could know whether he was present with me and really cared was through the tone of his voice: how he would call me by name, and how he would ask me about the previous night, and how I was doing. I got so that I would listen first thing in the morning to see if he was coming around. If I heard his voice in the nurses' area I always felt, "Well, if he is here, I am going to be okay."

The other miracle in my life at that time was Clara Rodriguez, a nurse. I called her Saint Clara. The ways she spoke to me, touched me in areas that were not burned, took care of me, and explained things in a calm, reassuring tone of voice saved my life. Her very presence let me know that eight hours of my life were under control.

Bandage changes were very painful. Just having my skin exposed to the air was excruciating. During their removal for the tub bath, she would allow me to stop to take a few breaths and even pause for a minute or two before starting again. With bandages over most of my body, that little bit of control of the pace was very empowering. I never realized what a gift that was until I discovered that all nurses weren't like Clara.

Clara also attended to the little things that had to be done. As a result of the burns, my mouth contracted quickly and none of the other people ever thought of taking care of my teeth. Not Clara, though. Because it was hard to get a toothbrush in my mouth, she would bring the tiny head of her electric toothbrush and, by hand, go in and clean my teeth.

More importantly, she always called me by name, always explained a procedure before she did it, and was extremely helpful to my family and friends. I didn't understand what a great nurse she was until she was off for five days. I counted the minutes until she came back. Her replacement was the exact opposite in her care, compassion, and giving me any kind of control of my care. It would show up even in the little things, like forgetting to cover me after I used the bedpan.

Another thing about UCI is that it is a teaching hospital. As people made rounds, within the first week I could tell who really cared by what they would ask me, how they looked at me, and how they addressed me. Often they would come close to my bedside and touch my foot. Then there were the others who were looking at the ceiling.

One resident would come at night and sit by me. We would talk about what was happening to me, my being scared about the future, what life was going to be like, and how I was going to deal with it. But we'd also talk about ordinary things like life and TV shows. Sometimes we'd just talk about him and his life. He was extraordinarily good-looking, drop-dead gorgeous. You'd think that somebody that attractive would just never care about some poor little burned lady. But he did, and on his own time.

There was also a young nurse from Boston who had a wonderful accent. The burn center was her first job. She was 23 and had this great boyfriend whom she had just



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met. Following their courtship took my mind off myself. We were kind of like girlfriends, but she was my nurse and had to do the hard stuff, like the dressing changes at night.

Some months after my discharge, I sought out a reconstructive surgeon who equaled Clara in compassion and caring. On my first visit, I must have asked in six different ways if he could make me look like I did before. During a happier time years later, he told me that I was very clever and I would construct the sentence just a little bit differently each time. I'd wait a little while and ask the question again. Although the answer was no, he knew that I was too fragile and vulnerable to be given a straight answer. So he would patiently say, "We are going to do the very best we can; we are certainly going to try." Of course, the answer I wanted was, "Yes, yes I can!"

As we began the journey of my facial reconstruction, Teresa Lindeman, an amazing counselor, helped prepare me for the many operations to come. I knew that whoever was doing my surgery was going to have a tremendous impact and control over my life, and it frightened me. I didn't want to be seen only as the young teacher who had a burn injury and needed to be fixed up. I wanted him to really care about me. She said,

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“Barbara, you need to talk to him about that. You need to tell him.” I remember looking at her and saying, “But Teresa, you don’t say that to doctors.” But she kept coaching me and prodding me in that direction.

At my next appointment, as I sat on the table with him examining me and the nurse standing nearby, I said, “Could I see you by myself without the nurse present? I want to talk to you about something.” I was really scared. I said, “I know that you are going to have such an impact on my life with what you do in the next few years as far as the surgeries we do. It’s important to me that I know you care about me and that I am important to you and I am not just a case.”

Dr. Furnas leaned over the table, embraced me in his arms, and said, “Oh yes, I do care about you and I am going to do the very most I can to help you.” Then he just held me and by that time I was sobbing.

That let me know that I was not just a piece of paper, a record in a file, the case of a 33-year-old teacher who had a 35 percent burn injury. Of course, I was all of those things, but first and foremost I was Barbara Kammerer, and, because of me asking, he really saw me.

As we approached each surgery, I also told him that I didn’t want to go to sleep without him there. So the anesthesiologist always knew never to put me to sleep before he arrived. I would be lying on the table in the OR and he would lean over me, hug and hold on to me as the anesthesia was administered. I would say, “Okay, do a good job now.” He would say, “I will.” And I’d be gone. That human connection while I was slipping away was such a reassuring feeling.

As we began planning each successive surgery, he would ask me what I wanted next. When I was uncertain, sometimes he would make a suggestion. Once he wanted to do something around my eyes, and I told him to forget it. That didn’t bother me much. I’d get him to focus on the things that did bother me, like my neck. When I lost part of my nostril and it was time to reconstruct that area, he got other surgeons together to look at my case and get their input. They all agreed that the best way to reconstruct my nostril with the best blood source and a graft that would not fail was to take one of my big toes. When he announced that to me on a visit, I looked down at both my feet and said, “But Dr. Furnas, I have five toes on each foot and they are not burned. I can’t give up one of my toes.” I had lost the fingers on my right hand and my fingers on my left hand were misshapen from the burns. Sobbing, I cried, “I can’t lose any more body parts.”

Without hesitating, he said he understood. They’d take a look at it again. So we went to Plan B—the top of the ear. This area doesn’t have the blood sources that a nice juicy toe does, but it took perfectly.

That kind of real heart connection was the difference in my care. Sometimes I would write him letters thanking him for what he had done and how well it turned out. He would reply with beautifully handwritten notes of encouragement, acknowledging my strength and his feeling that it was a privilege to do the work with me.

I will always thank Teresa for that initial encouragement because that started the beginning of not a patient-doctor *relationship*, but a patient-doctor *partnership*. We

became allies in the whole journey and he, his wife, and my husband are very close friends today, as is Bob Klein, my primary care physician. But I think that the greatest gift these lifelong friends gave me was when they came to celebrate with me when I received the Curtis P. Arts Award, a prestigious nonphysician honor for someone who has made contributions to burn care as well as to the American Burn Association. I was the first burn survivor to ever be recognized. It was such a delight to have come full circle and to talk in my acceptance speech about the gifts that had come into my life as a result of my burn injury. Along with Clara, Dr. Klein and Dr. Furnas were really an answer to my prayers and the prayers of so many whom I didn't even know who were praying for me.

There were downsides to my experience, though. I did not see my face before I was discharged. The reason they didn't show me is because they thought I was coping so well. But at a deeper level, I think health care professionals typically find it very hard to deal with body image because they're not comfortable with it themselves. Nobody who had seen pictures of me before my accident wanted to show me, a 33-year-old girl, my face. To make matters worse, my boyfriend couldn't handle it and decided to break up with me. I didn't see my face until I went home from the hospital, walked into the bathroom, stood in front of a huge mirror, and looked.

My first thought was that this was like a horror film. I ran out of the bathroom and into the living room, running in circles screaming and crying. How was I going to live? All I wanted was to die.

I had been so scared to look at any reflective surface in the hospital. Nobody knew that. It wasn't until the next day after my discharge when I had to go back for another tub bath and have new dressings that I almost had a break with reality. I screamed, "Why did you save my life? Why did you let me live? I don't want to live like this! I can't do it, I don't want to do it, and I am not going to do it!"

The depth of my pain and the decibel levels of my screams scared me so much I quieted down and stopped. They had me out of that tub, those dressings on me, and in a psychiatrist's office in 20 minutes.

I saw him a number of times, but it was very clear he didn't care about me. He never addressed anything about how much I was suffering, how scared I was, what in the world was I going to do with my life, how was I going to ever work again, much less live on my own. I quit after the sixth session and never heard from him again.

I had a good friend who knew how fragile I was because I had told her I really wanted to die. The only thing that kept me from doing it was the fact that I am an only child and my father died when I was 12. I kept saying to myself, "You can't kill yourself; you can't do that to your mother." I thought, "After my mother dies, then . . ."

My friend made sure I got with somebody, which saved me psychologically. I could put out all my anger, my grief, my sadness, and my disappointment, without draining my family and friends with it. She was glorious.

Out of this whole thing I went back to teaching and began a support group at UCI. I had a hunger to be in relationship with other women who had gone through something like I had. There are no accidents. The miracle was that a few weeks before I was

to return to teaching I went to a support group meeting and the pressure garment company was there showing a film demonstrating the results of wearing the pressure garment versus not wearing it. That first week of school, I told them all about the car accident, the burn center, my surgeries and the grafts I had had, and surgeries I would be having down the road. Then I showed the class the film that helped them to understand why I had to wear the pressure garments from head to toe. I was emotionally too fragile to undo the zipper on my sleeve to show them the grafts. They probably would have reacted, "Oh, Ms. Kammerer, that is gross," and I would have fallen apart. But I sat on a stool and gave them an open forum to ask anything they wanted to ask. That kind of self-disclosure was one of the smartest things I have ever done in my life. It took away all the mystique, fear, and anxiety surrounding my wearing those garments, what happened to me, and why I didn't have fingers. It was a done deal. Sharing myself in this way was such a comfortable experience; I even accepted another job mid-year at another school without thinking about it. Then I remembered only later that I would have to go through that story again. But it was fine. I went in and did it.

I taught for a few more years and then I was able to get a grant to begin the first school entry program for burned children in California. After that I worked with Rancho Los Amigos for nearly ten years where I started a program teaching people how to normalize their appearance and do simple things like make their skin all one color again, reconstruct or redraw eyebrows where they didn't have them, make a lip line, and help them with understanding colors that would help their skin look more healthy and reduce the scarring rather than make it more distinctive and visible. I developed a program called *STEPS* that focuses on our Self-talk, Tone of voice, Eye contact, Posture, and Smile. It was really important for the young people I worked with to learn how to incorporate these skills into their being so that when they were the only person with a difference entering the room, they could have a feeling of comfort and confidence. We also taught them how to rehearse their responses when people stare, ask questions, tease, and call them names.

Remarkably, my accident brought my family closer. I also got married. The internal conversation that initially ran my life was that I was probably never going to have another boyfriend, never get married, and that no one would want to hold my hands because of how burned they are, touch my body, make love to me because of the scars on my back and thighs, kiss my lips, or see me without eyebrows. About four years after my accident I did a lot of inner work and started changing my internal conversation. My affirmation was, "I am a worthwhile, loving woman, capable of love and of being loved and worthy of a beautiful marriage." I started seeing myself as a person who could be attractive, even sexually attractive. I would say to myself that I have some extraordinarily pretty friends. Big deal, they've got ten gorgeous fingers and I don't see them married. It wasn't until I had those kinds of conversations that I started having any relationships with men, and I am happy to report that this year, my husband and I celebrated our tenth wedding anniversary.

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