

STEVE

A PATIENT REQUEST

Dear Steve,

"If stories come to you, care for them. And learn to give them away where they are needed. Sometimes a person needs a story more than food to stay alive. That is why we put these stories in each other's memories. This is how people care for themselves." -Barry Lopez. The story I am giving you is yours, Steve. You lived it. I witnessed you living it. I want you to remember it. During your hospital stay, you translated your labyrinth of suffering into a language that could be understood. Steve, you are so AMAZING; you must even amaze yourself. You certainly AMAZED me. In spite of your physical pain and emotional anguish, you stood up to several members of the medical staff who needed to be reminded that a kind word, a smile, and an acknowledgement of your suffering is as crucial to the healing process as knowing how to attach IV's, insert needles, and change bandages. I am so proud and fortunate to have been there because I not only learned more about you, I learned from you. Here is what we went through...

For the first few days, I listened to you repeatedly tell me how surreal you felt. "This is so surreal...so surreal..." I could hear your suffering and understand it. You had IV's, then a catheter was added and soon you were going to have two surgical procedures. You were supposed to have been admitted to the psych unit on the 4th floor and instead you were on the medical ward, unfamiliar with new doctors and nurses examining you and taking your blood. I soon saw that you seemed to cooperate with some nurses (always respectful & appreciative), while toward others you were depressed or obstinate, trying to remove your bandages and IV's, and even pushing some away and yelling briefly (yet always apologetic afterward).

I listened to your anguish: you couldn't connect to your feelings, your situation, or the people who walked in and out of your room. Your sadness was so deep, I didn't want you to drown in it, but any ladders I sent down to *you, you couldn't hang on long enough to climb. You wouldn't-couldn't-didn't* accept that it could be a chemical imbalance that would readjust with the medications and those imbalances were the source of the distorted thought processes. I had been told that Medicaid delayed approval of the shots that you needed to stabilize you. You *couldn't-wouldn't-didn't* remember that each time you had an episode, that is what had happened. That knowledge didn't reassure you that you would feel better in time. I told you a Rabbi Nachman story where a King and his Viceroy realized that the grain they were using for food was tainted and that soon everyone, including them, would be going crazy for quite awhile. They needed to think of a way to remember that even as they were crazy, they would also know they were going crazy. That was the only way to remember that they were really sane. So they decided to mark a "C" for Crazy (or maybe M for Meshugenah) on their foreheads so when they looked at each other, they would remember that they were crazy because of the grain and that that was only temporary.

In my desire to reassure you through the tale, I may have just confused you more. You *wouldn't-couldn't-didn't* comfort yourself nor allow me to and I cried tearlessly inside as you wailed such profound existential questions I had no answers to: "What is happening? Why is this happening to me? What have I done to deserve this? Why is God punishing me? If I had only..."

Woulda-shoulda-coulda did not resolve any issues. You remained stuck and tortured.

Moving forward is not possible when lost in a maze of the past. And even when you saw a way through, you froze, mentally dreading the possibilities of what healing might bring.

For some reason, you stayed in a level of psychosis that I had never observed in you. For a few days you told the nurses and me that we were beings from another galaxy with some secret plan that you “now knew all about.” I asked you to let me in on that plan. You countered, challenging me to prove that I was your sister, Zena. “What was on Arthur and Devon Avenue?” (*Goldenson’s Drug Store, I remembered after a pause.*) “What was down the street from there?” (*Stone School.*) You scrutinized me. Apparently I passed for the moment. Then, switching focus, you began to belittle yourself. Even on the phone you often moaned that you were not a good enough brother * uncle * human being. You were inconsolable. Yet you wanted to talk to Debbie and Susan whom you confided in and trusted. Even if you couldn’t permit yourself to believe in yourself the way they believed in you, you were often just a bit calmer after their conversations. You didn’t want to disappear. You didn’t want to be afraid. That was a scary world to be in. You didn’t want to be there and we didn’t know how to get you out. The voices that you were hearing sounded so real to you that you couldn’t believe they were the distorted thoughts either from a chemical imbalance in your brain or a possible side-effect from your kidney disease or both.

You were admitted to the medical floor with a diagnosis of prerenal azotemia (kidney failure). Some of the side effects are confusion, decreased awareness, fatigue, decrease in urine production, feeling disoriented, lack of sleep, dry mouth.

Ironically, since no one could separate you from those altered thoughts and since you were sometimes physically uncooperative out of fear and mistrust, you suspected that you were being treated in a very different way, which you were, but not because we were creatures in a science fiction world in your mind with an intention to harm you. For a couple of days, only wrist restraints prevented you from ripping out the IV and the bandages that protected the fistula. One evening, the nurse, an aide, and I were getting you into bed. You stared at me in horror, convinced that my face was changing shapes. I scared you. It was as if you were on a bad acid trip, but you hadn’t taken any street drugs. To remain by you was upsetting for both of us. I left the room and took the bus back to Susie. At the end of the first week, I felt helpless and hopeless.

Then a change. “Shift happens.” That Friday night, Susie W. and I passed a Chabad on our way to dinner in her neighborhood. Since the next day was Dad’s yahrtzite, I considered it fortuitous to have found a synagogue within walking distance for morning services to say Kaddish. When I arrived there, Saturday morning, the rabbi was in the middle of teaching a mystical interpretation of the sacrifice of Isaac. Realizing that the services would begin much later than anticipated, I got up to leave. Just then, the rabbi’s wife introduced herself and asked why I came. I told her about wanting to say Kaddish for Dad and she reassured me that she would tell her husband Dad’s name and Grandpa’s name. Then when I told her why I was in Chicago, she asked me to tell her your name and Mom’s so that the rabbi would include you in the misheberach (healing) prayer. I hadn’t even thought about that. By the time I returned to give her donation a few days later, I was able to smile and tell her you were already feeling and acting better.

The meds that Dr. R kept adjusting finally kicked in, also. The wrist restraints were removed at my request and we walked the halls while you were attached to the IV. You wanted to walk. There were no more attempts to remove the bandages or IV. You allowed the

aides to shave you and give you sponge baths. By the time you left the hospital, you shaved yourself and showered.

But what Susan and I thought was miraculous was the moment you finally agreed to removing that fatty tumor from your forehead. Debbie, Susan, and I could not believe that you calmly said okay to Dr. A & Dr. S without any hesitation. And now it's done. You did it!!!! We are so happy for you. And you know what? You pushed away your rock-solid immovable fear just enough to say "Yes" to the removal of something that was unnecessary and detracting. WOW. You made Susan, Debbie, and me very happy because you proved what we knew all along: that you could do it. We hung onto that belief. Now, after all these years, you proved us right.

Your appetite was coming back. You liked the chicken soup from the cafe and the sandwiches and chocolate from the Middle Eastern store I brought you almost daily. You ate the matzah ball soup and rugaleh that Susan brought you so fast that I didn't even get a chance to taste it. Neil, the evening nurse, came in and we all talked and even laughed. And in spite of your pain, fears, and delusions, you were observant enough to wonder aloud why I was wearing the same outfit all the time.

You accurately sensed that a couple of RN's, nurse's aides, and even a couple of the new doctors treated you as if you were invisible or incapable of comprehending the procedures they were performing on you, having read reports of your "unreasonable" objections to certain treatments. For a time you resisted having your blood sugar tested announcing authoritatively that you do not have diabetes and therefore you had a right to refuse. Worse, a couple of the doctors spoke to me in front of you as if you were a third person or as if you were invisible. Often, from your bed, you would try to express your frustration and your needs with little success. Without being asked, I became your interpreter.

Then, one afternoon, you didn't need me. A nurse walked in without an expression on her face and with a lackluster voice muttered something softly, not even looking either at you or me. Then she glanced at me. I stared. She turned to you. You watched her all that time that she was avoiding you. Then you responded reasonably, saying something like this:

You know what? Before you tell me what you or the doctors want, do you know what I would like? I would like you to come in with a smile or a kind word- like '*Hello, how are you?*' I don't think that's too much to ask, do you? It would mean so much. I'm confused...I don't know what is happening to me. I'm afraid. I don't know who you all are. I have so many doctors. I don't even know all their names. I am trying to connect to my feelings. I try to be kind. I say *please* and *thank you*. think I act like a gentleman. Is it too much to ask in return for you to say *hello?* I think it's reasonable...that when you enter the room you ask the person '*how are you doing; how are you feeling?*' I don't like to be grabbed and poked and pushed. Would you like to be? I just want to be treated like a human being who has feelings.

Steve, you were so honest, sensitive and rational. I was stunned by your ability to be so articulate, direct and clear. For sure you had her attention. You certainly had mine. Wow, how would she respond to you? But she didn't. She just slowly turned to me and asked me something that had absolutely nothing to do with this amazing heart-felt, reasonable appeal that had just taken place.

And then I understood. It was she, not you, Steve, who disappeared. It was she who was incapable of making the connection, not you. Whatever prevented her from responding, I'll never know. But when I saw the spark that you ignited within yourself start to go out, I turned to you so she would have to acknowledge that three of us were in this room. I made a

comment, then exited.

“Where’s the supervisor of nurses?” I asked in the corridor, shaking in disbelief. C, the nurse-director, was on the floor. We sat in an empty room and talked. She listened and admitted that some of the staff were not trained or skilled in communicating with a patient who is psychologically as well as physically distressed. But as you said later, Steve, “Who needs to be trained how to smile?” (I wish I had your quick wit during that conversation. You sounded like Dad). I told her what you said to the nurse and how you said it. You spoke openly and powerfully. Just because one may be emotionally unstable or even irrational momentarily does not mean one has no feelings. The patient still acutely senses how he/she is being treated even if it can’t be expressed. But in your case, Steve, what you said was rational, articulate, and right on. I told her that. It was essential and logical to expect a response. But the nurse was insensitive and apparently incapable of establishing a rapport with you.

To dismiss or ignore a patient’s desire to interact is to sever an opportunity to promote healing. The nurses (as well as a couple of aides) who were healers like N, L, C, E, and M instinctively engaged you in conversation and quickly through humor, information, or a gentle concern established a relationship that enabled you to be proactive in assisting them with your healing. As you healed both physically and mentally, you helped Sylvia, the social worker, understand the reasonableness of your expectations and she helped you to see that you two were on the same side: *Yours*.

I never anticipated that you would surprise me, Steve, but you did. Speaking out on behalf of the part of you that was suffering was an example. Agreeing to remove the lump was another. Stupid rules forced you to have to return to the hospital as an outpatient to remove the lump. You could have changed your mind, but you didn’t. Do you remember waiting in Admitting and seeing the nurse that had once ignored you, now greet you by name, smile, and ask how you were? To witness her changed behavior toward you was so special. Even though she had frustrated you earlier, you did not admonish her or retaliate in sarcasm or anger. Your experience and observations that I shared with the nurse-director may even be used as a teaching tool to improve the rapport between patient and staff. It underscored the need for training the medical staff to handle the special needs of patients who have both psychological and physical problems. Steve, when you see others in an open and vulnerable state, you reach out respectfully and empathetically. You expected the same in return.

Squinting your eyes and gritting your teeth in pain (like Dad did) while the needle had to be inserted again and again in order to start the IV before surgery was to observe your courage and perseverance, trusting that the pain was only temporary. How and why you refrained from yelling or swearing remains a mystery to me. To undergo surgery not once, but three times within a few days was saying *Yes* to change. Returning from outpatient surgery to remove the lump, your forehead and your hand were heavily bandaged. When everyone at your home started coming up to you asking what happened, you sat there holding court replying, “Yeah...well, I had to go in and get some new brains.” Out goes the lump and in comes the humor.

Don and his sister, Diane, helped me shop for you and dropped me off to visit you in Skokie. Then you and I organized most of your drawers. Cousin Susan certainly made sure you had enough clothes and jackets. She went shopping to buy you two new pair of pants because you lost so much weight. Debbie talked to you, encouraging you to take the next step. Happy picked me up to take me to the cemetery. When she asked you if you wanted to go with us, “*no*,” usually first on your lips, switched to “*all right*” very quickly. The last time

you visited the cemetery was at Dad's dedication. Whatever we talked about on the way to Westlawn, the conversation flowed easily and naturally. We walked arm-in-arm to Mom and Dad's grave and said what we could remember of the Kaddish. Then we talked to them. If Mom and Dad could "turn over in their graves," it would be to smile at the new improved you. *Happy* Happy and *Happy* Zena drove back with "*Happy* for Steve" in the car.

There are people who take the heart out of you, and there are those who give it back.

Twice you left the hospital. No more lump. No more prostrate trouble. Weight loss. A fistula. A possibility of future dialysis, but nothing definite. An opportunity to get new teeth. A possibility of enrollment in an outside group program. A new awareness. (Look for the ear inside the HEART) Move the letters and SCARED becomes SACRED. Submerged in labyrinths of distortion and confusion, physical pain, and fears real and unreal, you emerged with an ability to communicate. You have an honest, intelligent, and articulate heart that wants and deserves to be heard. I am proud of you. "Time it was and what a time it was." A time of learning for both of us.

I love you, Z

Response to Steve's hospital experience from my friend, Ellen: On Sun, May 29, 2011 at 1:22 AM, Ellen Franklin: OOh, I accidentally read this one first-- I am overwhelmed by the manner in which you express the "life ride" from your personal perspective interjecting the valuable things that Steve said or did with the importance included. I really feel that this was one of those lessons to be taught to all medical staff and I also believe it should be mandatory reading. As Steve said, "Who needs to be taught to smile" -- powerful and I feel it should be on every single billboard or every chart in a medical facility or take the place of the old "don't worry, be happy" slogan.

THANK YOU FOR SHARING IT WAS WONDERFULAND
THERE ARE TIMES..
WHEN WE APPEAR TO SURRENDER
OUR LIVES TO PEOPLE AND CIRCUMSTANCES
AND THEN THERE ARE SOULS
WHO REMIND US.....
THAT OUR LIVES INDEED OUR FATE
IS OURS ALONE ...
TOLIVE AND TO LOVE FULLY AND FREELY (from Don)

My dear Cuzin; first, finally opened your letter re Steve. and you opened my heart. thank you for sharing. love, me
(Bob)