

**X-WINGS,  
TERRY CLOTH LIGHT SABERS,  
AND THE 19<sup>TH</sup> HOLE**



**Memories of Brian Conklin's Struggle  
With Cystic Fibrosis  
*By*  
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## 1

“What the hell are you doing here,” I said from the doorway of Brian’s hospital room on the fourth floor.

He shrugged with a sheepish grin. “Just couldn’t stay away, I guess.”

I walked into his room, mixed up his meds and handed him the nebulizer.

“In for a tune-up, or are you sick?” I twisted the regulator knob on the side of the flowmeter and watched the little black ball bob at the seven-liter per minute notch.

“Both,” he said. A gray cloud of aerosolized medication plumed from the blue tube Brian held between his teeth. “I’ve got this temp I just can’t shake.”

I set the bell of my stethoscope against his back and said, “Deep breath.”

Brian inhaled, and I heard the faint pops and crackles of air struggling through airway upon airway of molasses-like secretions; this type of breath sound is referred to as *rales*. Rales are more common in patients with pulmonary edema, caused by air moving through frothy fluid in the lungs, but I frequently hear them in CF patients as well.

As I listened, I watched Brian’s effort and noticed his use of accessory muscles. He used his shoulders with each breath as if to pull the lungs open. Intercostals retractions – sinking in of the spaces between the ribs during inspiration – were evident as well. Retractions indicate that a patient is putting in a considerable workout just to draw in a breath of air.

I slung the stethoscope around my neck and began to clap on his back. The successive percussion made a *clip-clop, clip-clop* sound like a team of Clydesdales trotting along a cobblestone road. Occasionally I stopped with one hand to shake away the fatigue in one arm while clapping with the other. Then I did the same with the other hand, and this way I could take rest breaks without stopping the treatment.

“So what’s new,” Brian said around the white, plastic mouthpiece of his nebulizer.

\* \* \*

Brian Conklin was the first patient with cystic fibrosis assigned to me when I started working for Lutheran General Hospital in the northwest suburbs of Chicago. It was June of 1993. In those days newcomers to the evening shift were assigned to the pediatric and adolescent floors, and this unwritten rule also applied to me. When I was handed my assignment at the beginning of the shift, I thumbed through each page to see what types of patient’s I’d be caring for. Brian was the first patient on the list. The sheet of paper informed me that he was sixteen years old with the diagnosis of cystic fibrosis.

I first heard of cystic fibrosis, many years earlier; a teenage friend of my family, Rita Jillich, who was a member of my church died from complications of the genetic disease. I was about twelve years old, so I didn't know anything about Cystic fibrosis, but the name stuck in my head.

When I learned about the disease in respiratory therapy school, I remembered Rita who had died so many years before. Cystic fibrosis – or CF as it’s commonly referred – is a recessive genetic disease of the exocrine system which results

in the overproduction of thick, sticky secretions. The lungs and the pancreas are the two organs affected the most. In the pancreas, these secretions block ducts through which fluids vital for digestion travel. Proper food processing is adversely affected, and people with CF typically appear small and even malnourished. In many cases insulin dependent diabetes becomes an added ordeal.

Cystic fibrosis takes its worst toll on the pulmonary system. Thick mucus clogs the airways of the lungs which leads to chronic infections and oxygen deprivation. People with CF cough constantly and often appear out of breath. Eventually the disease progresses to a point of respiratory failure when the damaged, worn out lungs can no longer support a person's life.

In the past, the average mortality age of someone with CF was only a few years, but today most live into their twenties and thirties, and some have lived as long as the mid-forties. Lung transplants have extended the lives of some people with CF, but the process of approval for such surgery is arduous, and success can never be guaranteed.

Stephanie, one of the day shift therapists, sat down across from me at the large table in our Report Room to inform me about the patients I'd be caring for on my shift.

"Hey, Joe. You have Brian tonight?" she asked.

"Brian Conklin . . . 436 by the window – cystic fibrosis?"

"Yep, that's him," Steph replied. "Have you ever taken care of Brian before?"

I shook my head. "Never."

"He takes full range extended CPT with nebs QID,"

During my clinical training as a respiratory therapist, I spent several weeks at Children's Memorial Hospital and learned how to treat children with CF. People with can be admitted into the hospital several times a year with exacerbations caused by pneumonias of various kinds and degrees. The role of the respiratory therapist in the treatment of cystic fibrosis is to administer airway-dilating medications through mist generating hand held nebulizers – called nebs – and performing Chest Physiotherapy, called – CPT – which is clapping on the patient's chest and back with cupped hands to help loosen the thick secretions that clog their lungs. A single treatment session typically lasts forty-five minutes and sometimes can take over an hour.

"Okay, thanks," I said. "So what can I expect?"

"Oh, he's a cute kid. He's kinda sarcastic at times – y'know, jokes around a lot. But he's cool."

This didn't ease my nerves, but nonetheless I said, "Alright, great. Thanks, Steph."

I drank a cup of coffee, then gathered my medications and went up to the fourth floor. Whenever I covered the adolescent floor, I tried to see my other patients first before seeing those with Cf. My reasoning was that since their therapy was more time consuming, I could devote more time to giving them a decent treatment when my other work was out of the way.

After completing my first round of treatments, I finally went to Brian's room. I remember walking down the hall, hoping that I'd do a good job. Up to then, at the first hospital where I had served, I only had one adult patient with CF, Richard Bebbber. His problems mostly involved his pancreas, and his regiment of pulmonary therapy was not extensive. He moved to Arizona not long after I began working there, and I had no contact with CF until I moved to Lutheran General.

Now I was hoping that Brian would like me. Most CF patients have dealt with hospital personnel from the time they were small children, and I guessed that they would know from the first few minutes whether or not I knew what I was doing.

Down the hall raucous laughter rolled from room 436, and the nerves I'd felt earlier faded away as I walked up and knocked on the opened door.

Two people occupied the room, both teenagers sitting Indian style on their beds. Their laughter stopped the instant I knocked on the door, and they looked at me with an expression that read, *ahh . . . new kid on the block. Let's see what he's made of.*

I glanced down at my assignment sheet, then looked up. "Uh, Brian Conklin?"

They looked at each other with straight faces for the briefest of instants, then broke into a mischievous laughter that I would soon learn to love. At the time, it served to do nothing but bring perspiration to the palms of my hands.

"I'm Brian," said the kid in the bed by the window.

"Hi. My name's Joe – I'm from respiratory therapy and I've come to do your treatment."

"Okay."

I walked into the room, located his nebulizer hanging from the oxygen flowmeter and began to mix up his medication.

"So how are you feeling today?"

Brian shrugged. "Alright."

"Coughing up much?"

"Eh," he replied.

"You new here?" the kid in the other bed asked, and Brian chuckled, but I could tell that he tried to hold down his laughter. Maybe he could sense my nervousness, or maybe he just pitied me because I *was* the new kid on the block.

"Well, I started about a month ago, but I just got off orientation." I could sense that they scrutinized my every move.

"That's Ken," Brian said.

"What's up, Ken?"

He tipped his head and said, "Hey."

I fit the nebulizer O2 tubing to the end of the flowmeter and handed the neb to Brian.

"So how do you take your CPT?" I asked. This phrase has become a mainstay of my opening dialogue with CF patients who I meet for the first time. However, at the time I wanted to do the treatment exactly the way to which Brian was accustomed.

He shrugged with an air of indifference and said, "Whatever." But added, "Tops, sides, then bases – but no trendelenburg."

At this, I smiled and kicked in the bed elevation pedal to raise him up. I wasn't going to argue with him. Trendelenburg would be more beneficial; it's a position of tilting the bed so that the patient's head is lower than the feet, which assists gravity in helping to drain lower segments of the lungs. But my feelings about the matter, especially now, are that these kids and young adults know their bodies and their disease. If a particular modality of therapy doesn't work for them, then that's fine with me. I'm not here to tell them how to live their lives. My job is to administer their medication and help them to clear some secretions so that they can breath easier and cut the duration of infections.

I also believe that part of my role, as a respiratory therapist to CF patients, is to be as much a friend as I can. I can only try to imagine what it's like to spend two weeks at a time in the hospital while others are going to movies, hanging out, and having a good time. If I can do anything to make their stay at the hospital less negative than it already is, I feel as though I've accomplished more than my duty alone.

I don't recall exactly what Brian and I talked about – that first day seems like such a long time ago – but I usually tried to make conversation with the CF patients to help break the ice, pass the time and try to get to know them better. However, I do remember that I liked Brian from the start and looked forward to returning for his next treatment.

When I returned, Brian and Ken were more receptive, and I felt as though I'd been accepted as a caregiver and someone who they wouldn't mind seeing again.

Brian inhaled his medications as I stood behind him and clapped on his back, and during lulls in conversation I'd glance around the room and notice some of the things people had either given him or he'd brought from home. A Lego Expert Builder formula racecar surrounded by smaller Lego models sat parked on the dresser next to his bed. I quickly learned from the T-shirts and baseball caps which he wore that Brian loved golf. At times he'd watch tournaments on TV while I did his therapy, and once I commented about how I thought watching golf on TV was like watching grass grow. Brian said nothing, which clued me in that I'd struck a nerve. Apparently he was quite proficient at the game, and I brought up golf as a topic from time to time during treatments.

“Do you golf?” he asked me.

“I have a couple of times. I'm not very good, but sometimes I go out with my dad. He plays pretty well.”

“That's cool.”

“Yeah,” I said. “I like golf, I just don't get many opportunities. The thing is that I suck at putting. I can drive the ball okay, but once I'm on the green . . . forget it.”

Brian laughed.

“It's good to get out with Dad for a couple of hours, talk about things – y'know? But we haven't gone out in a long time.”

He nodded, and a smile crept across my face as I remembered something from the past.

“Up at my parent's summer place there's this golf course called Eagle Bluff,” I said. “It's atop Iron Mountain in the upper peninsula of Michigan – pretty tough course, at least I think so, but I'm not exactly Arnold Palmer.”

Brian chuckled, and I went on.

“This one time my dad and I were golfing up there, and I had just a bitch of a time sinking the ball. We were up on the fifteenth hole, or something like that, and it had been a long day already. So, I'm putting and just racking up the score as my ball kept rolling past the hole, one way, then the other. Finally, I just squatted down and knocked the ball into the hole using the handle of my club like a pool cue.”

Brian craned his head to face me.

“Needless to say, my dad wasn't pleased,” I said.

He laughed but then went into a hard coughing spasm that seemed to send shockwaves through all the muscles of his back and chest. He coughed and hacked, bent forward sitting cross-legged on the bed. When a CF patient starts to cough like this, I feel helpless to do anything for them; there's little that I *can* do. The thick mucus that

builds up in their lungs has to come out, and coughing is the only way. A therapist or nurse can suction a patient – that is to snake a catheter through the nose and into the lungs, then use vacuum to suck the stuff out. But it’s neither pleasant nor indicated for a person who can cough for him or herself.

After a minute or so of coughing, his face had turned beet-red; veins stood out on his forehead and neck.

“Can I do anything, give you Oxygen, or something,” I asked, trying to keep my tone of voice as even as I could.

Brian just shook his head. He continued with his hard, wet cough, intermittently spitting mouthfuls of thick, dark green phlegm into the garbage can next to his bed.

The fit went on for another few minutes, and when Brian finally stopped, he sucked in air with hungry pants and exhaled through pursed lips. Pursed lip breathing is a reflexive way of exhaling that creates back pressure in the trachea and helps keep the smaller airways open. Sometimes people in asthma attacks will instinctively breathe the same way.

When his breathing returned to normal, Brian looked at me and said, “Well, that felt good.” He picked up his nebulizer and continued the treatment.

“So your dad was pretty pissed, huh?” He said this as though the coughing fit had never even happened, and all I could do was raise my eyebrows and shake my head.

## 2

I’m convinced that man will never design a machine as finely tuned as nature. There seems to be checks and balances set up everywhere, delicate ecosystems intended to ensure that proper symmetry is in place. I believe that the same is true within our species. Even when deficiencies occur, the body seems to compensate to increase its chance for survival. A good example of this theory is myself.

I was born with sight in only the left eye due to either some injury at birth or a prenatal infection passed to me from my birth mother. I spent the first two years of life with a patch over my good eye which forced me to use the muscles of the bad eye and keep it from becoming lazy. Of course I was virtually sightless during this early period, but because of this determined effort on the part of my adoptive parents, anyone looking at me today would never know that I have so much in common with the Jack of Spades.

On the flipside, my hearing is more acute than that of a typical person, and I attribute this to my body’s compensation for the abnormalities of my vision. In the same way, I’ve noticed that many, if not all, people with CF appear to be extraordinarily intelligent and keenly perceptive to the characters of those who surround them.

I first became aware of this trait in Brian from the elaborate pranks he played on the hospital staff and other CF patients. One of the most memorable was the time Ken and he rigged up a Styrofoam cup filled with water to the top of the door to their room. Someone invariably walked into the room to get dumped on by sixteen ounces of ice-cold water. I never had the privilege, but I know several therapists and nurses who fell victim to Brian’s mischief.

Another oldie-but-goodie was the placing of various objects in therapists’ lab coat pockets during Chest Percussion Therapy. For one of the postural drainage positions we place patients on their side while we percuss lateral segments of the other side. This

facilitates the drainage of secretions from the small airways into the larger bronchial passages. Then patients can cough out secretions with more ease.

Sometimes while performing CPT, therapists would position Brian facing them, which gave him unimpeded access to their lab coat pockets. Later in the day, the therapist might reach into his or her lab coat for some medication and instead pull out a handful of Jell-O, applesauce . . . or something much worse. Some therapists got a little bent out of shape when these pranks were pulled on them, but eventually they took it in stride.

And Brian didn't limit his high jinks to respiratory therapists and nurses; medical residents bore the brunt his sense of humor as well. Another patient who has cystic fibrosis with whom I've developed a friendship over the years, named Doug Caliendo, relayed a story to me not so long ago. On occasion when a new resident sauntered into their room to assess breath sounds, and Brian and Doug were feeling particularly devilish, they made the movements of breathing deeply but actually inhaled no air so that the unsuspecting resident listened futilely through his stethoscope to hear nothing but silence. Sometimes a resident stood and said that their lungs sounded clear, unaware of the significance of the wry smirks etched into Brian and Doug's faces.

What impressed me most about Brian was not only the way he coped with his disease but his entire outlook on life. It wasn't until several years after I met him that we began to talk on a more serious level about CF and how he deals with it. Once Brian made me ashamed of myself for the way I grumbled about stresses in my life that at the time seemed so important but in fact couldn't have been more trivial. It wasn't anything he consciously did or said; it was the Personal Quote from his *America Online* profile.

-- *Sometimes life deals a bad hand. Just play your cards and stop complaining.*

### 3

As time went by, my interaction with Brian became more, and it became natural during treatments for him to ask me, "So what's new?"

I shrugged. "Same old . . . Oh, I bought a computer. I guess you could call that new."

"Oh, yeah? What kind?"

"An Acer – 486 SX. I've got this Star Wars game called *X-wing* . . . it's *the* ultimate flight simulator. It's all I've been doing when I'm at home. I think it's driving my girlfriend nuts."

Brian laughed.

"She thinks the only reason I bought the computer is to play that game."

"Isn't it?"

This time I laughed. "I guess, but I use it for writing too."

"Oh, sure – sure."

"I'm serious," I said.

Brian turned and pointed at me. "Ah-ha! See? You can't BS me."

"Okay, okay. So I haven't written word one since I got the game."

The nebulizer sputtered. Brian shook it and stuck the mouthpiece between his teeth.

“So it’s space combat,” he asked.

“Yeah. Dog fighting, capture operations – stuff like that mostly. You can fly all the Rebel ships . . . X-wings, A-wings, Y-wings, and I think LucasArts is coming out with an add-on program that allows you to fly B-wings as well.”

“Which is the B-wing?”

“Those fighters were in *Return of the Jedi*, but only in two scenes,” I said.

Brian thought for a moment, then said, “Kinda insect looking?”

I paused to picture the fighter. “Yeah, I suppose you could say that.”

Brian shook the nebulizer again, then put it back in his mouth. Mist puffed from the end of the blue corrugated tubing, then stopped as the nebulizer sputtered once more. He dropped it on his bed.

“Done.”

I circled his bed to the flowmeter, shut off the oxygen and draped the nebulizer over the flowmeter wall connector. Brian lay on his side, and I began to percuss his lateral lung segments. About two minutes into the second round of therapy, he sat up and started to hack until his face turned red, and the veins in his neck and forehead stood out like they could pop any second.

I stood behind Brian and let him finish the coughing fit. As always, I could do little for him except stand there, watch and listen. He spat dark green phlegm into the garbage can next to his bed, coughed some more and spat again. When he finished, Brian sat forward, hunched over his bedside table and panted through pursed lips; his face was still reddened from coughing so hard. In some ways, the worst part for me was to stand there and do nothing, which contradicts every inclination of my education and training as a respiratory therapist.

“You okay,” I asked.

Brian, still panting, nodded and straightened up. He heaved a deep breath and let out one last cough, then fell back onto the bed.

“Okay, ready,” he said, and I resumed the pounding.

It’s easy for people, even those in the medical profession, to forget how deceptive a disease CF is. Much of that is probably due to the CF patients themselves, and it’s to both to their credit and misfortune at the same time. They exhibit an astounding threshold for tolerance, considering the degree of affliction they are forced to endure on a daily basis. One might look at Brian or Ken or Doug when they’re hospitalized, especially Brian, the way he joked and made other people laugh, and never comprehend how sick he was.

Later the same night I returned for Brian’s second treatment but found his room empty. I figured he was in the Teen Lounge and walked over to find Brian, Ken, and a few other patients sitting around the large round table next to the pinball machine playing some board game. His IV pole stood next to him, pumping and clicking away. Brian wore a faded, black baseball cap with a tan visor and the logo *Planet Golf* embroidered across the front. I stopped at the doorway and leaned against the frame.

“Joe!”

“What’s going on, man,” I replied.

“Just playing Scrabble. Treatment time?”

“Unfortunately.”

Although he did a good job of concealing it, the subtle downcast expression on his face told me that I was the designated killjoy of the evening.

“We could do it here, if you want,” I offered.

Brian’s face brightened. “Yeah?”

“Absolutely. Let me get your stuff, and we’ll get started.”

I’ve been a patient in the hospital a few times – never for anything too serious, but enough to know how much it sucks. For me boredom was always the worst part. Of course I don’t have Cystic fibrosis, so all I can do is try to imagine what it’s like for them. It’s for that reason that I try to do all that I can to accommodate their needs.

Lutheran General Hospital has a great teen life program headed by a woman named Jan Welter. She gets the kids involved with crafts, games, and movie watching to help time pass and the patients’ stay as comfortable as is can be. When I come to the adolescent floor to do therapy on CF patients or asthmatics or whomever, I’ll often find them in the Teen Lounge involved with some activity. The disheartened looks on their faces when I tell them that it’s treatment time reveals how much of a difference the Teen Life program makes.

I brought Brian’s nebulizer and flowmeter from his room to the Teen Lounge, plugged in, and started his treatment. I was able to pull up a chair behind him and clap on his upper back while he inhaled his meds. When it was time to do his sides and lower back, I had him lay on the pool table in the lounge. It still brings a smile to my face when I think back to Brian spread out across the pool table. Such things are no longer possible with the new guidelines regarding cross-infection from the Center for Disease Control and the Cystic fibrosis Foundation. But back during what I call the Golden Era, it was a common practice which I and some other therapists did for Brian and the other CF patients.

One afternoon I walked into Brian and Ken’s room for Brian’s first round of therapy and found them engaged in combat with rolled towels, a rat-tail battle. Each stood on opposite sides of their beds and snapped their towels at the other, laughing with boisterous joviality as the fray ensued.

I stood and watched for a while, thinking back to my high school swim team days when as a matter of self-survival I became quite proficient at the art of defending myself with a towel. I probably should’ve stopped the tussle before things got out of hand, but it was too much fun watching them have such a good time. I noticed that they rolled their towels the old fashioned way; they grabbed opposite corners – top and bottom – and whipped them around and around until tightly twisted. They snapped at each other with their terry cloth weapons, rolled them up again, then resumed the duel.

“Y’know what the problem is,” I said and leaned against the wall beneath the television. “You guys are rolling them all wrong.”

“What are you talking about,” Ken said.

And in that moment of distraction, Brian seized the opportunity to nail Ken square in the chest with a loud *snap*.

“Oww, you bastard,” Ken said, laughing at the same time.

Brian looked at me and busted up as well. I took Ken’s towel and draped it over his bed.

“Let me show you,” I said.

I folded both corners over so that they met in the middle and the towel resembled a flattened triangle. Next, I rolled it from one end to the other so that the cloth formed what looked like a tapered handle. I picked up the rat-tail and turned toward a sixteen ounce Styrofoam cup that stood on Ken's bedside table.

"You see, this way you have a lethal, rapid fire weapon that'll never unravel."

As soon as I'd said this, I raised the towel, and with a quick jerk disintegrated Ken's cup into a burst of Styrofoam confetti. Water sprayed in every direction and rained down on us.

I looked at them with a crooked smile. "Terry cloth light saber."

"Oh my God," Brian said in both surprise and delight.

I showed them how to roll a rat-tail the way I'd made Ken's, and by the time I'd returned for Brian's second round of therapy, most of the other CF patients on 4 Center had learned the proper art of rat-tail rolling. Two brothers were in at the same time, named Matt and Peter Monkton. Matt liked the rat-tail so much and could find no better target for practice than his younger brother, Peter.

One of the nurses at the time, named Sandy, came up to me with the displeased look of a mother who just caught her son going through her purse. She stood at the nurse's station, tapping her foot, hands on her hips.

"Did you show them how to do that?"

I mustered my best innocently stupid look and said, "Show them what?"

"The snap-towels, rat-tails – whatever you call it."

"Sandy, would I do something like that?"

She studied me for a moment with a raised eyebrow.

"They've been running around all night, snapping at this, destroying that," she said.

I shrugged. "Well, boys will be boys."

I guess Doug came in to visit and having learned the technique I showed Brian and Ken, exploded one of Brian's feeding bags and created a nightmare for the Housekeeping department. That time of my career was one that I'll always remember with fondness.

#### 4

A year or so went by with Brian and the others in the hospital and out. In the interim, I dispensed with my single life and married a wonderful young woman named Sandy – a nurse, interestingly enough.

Some time later I was walking through the emergency room on my way outside for a break when someone called my name.

"Joe!"

I looked around and saw Brian sitting cross-legged on a gurney in bed seventeen next to the ER hallway entrance. I stopped and just looked at him for a moment.

"What the hell are you doing here?" I always greeted Brian when he came to the hospital with this nonchalance.

He shrugged with the same sheepish grin and said, "Just couldn't stay away."

*Just couldn't stay away* was the response I'd always receive.

I walked over to his gurney.

“Do you want a treatment?”

“Definitely.”

I could see how short of breath Brian was; when he spoke, he sounded as though he had just finished running the two-mile. I grabbed a nebulizer from the drawer next to him, squirted a unit dose of Albuterol into the medication cup, and handed it to him.

He inhaled the meds with rapacious gasps, and I counted his respiratory rate to be in the thirties. His lungs sounded coarse with pronounced rales throughout the fields.

“So what happened?”

“Got sick while I was skiing,” Brian said. He swallowed, then heaved a few hungry breaths. “We raced back, and I came straight here.”

He sucked more from the nebulizer to catch his breath, then added, “How do I sound?”

I hesitated. “You’ve sounded better.”

Brian just nodded and looked away.

“Don’t worry; you’ll be fine. Once you’re upstairs we’ll pound the hell out of you.”

He said nothing but just nodded again. I stood at the side of his gurney and watched the rapid exchange of aerosolized Albuterol roll in and out of his mouth. He coughed a few times, but I could see that Brian tried to hold back as much as possible. I had no doubt that he was sick, and for the first time in my career I was worried. Of course I stood like a stoic and didn’t let my expression betray emotion. But as I look back on it, I think that when I told Brian not to worry it was the first time that I tried to convince myself as much as him – perhaps even more – that he’d be fine.

The ER nurse took Brian to his room on 4 Center soon after, and he went through the standard admission routine of chest X-rays, a visit from the on duty resident for history and physical, and at least one more treatment with CPT before the end of the shift. I had been covering the Intensive Care unit that night and wasn’t the one to give Brian his therapy. That didn’t stop me from coming down to see him as often as I was able.

The next day I walked through pediatrics toward the adolescent unit and stopped when I saw Brian sitting at the nurse’s station. He was tethered to an oxygen tank by a nasal cannula – an oxygen delivery device – and that was something I didn’t like to see. It meant that Brian wasn’t just sick; his disease had regressed to a worsened level. But just like the Brian I had come to know, it didn’t seem to dampen his spirits in the least.

I’ve come to admire the degree of strength that people with CF display. It amazes me that these people can fight their battle with so much determination. They’re better people than I could ever hope to be.

“Hey, Joe,” he said from the nurse’s station with his arms folded across the desk.

“Hey, Bri. How you feeling?”

Brian shrugged. “Eh.”

“Short of breath?” I tipped my head toward the tank standing next to him.

“Kinda . . . just when I’m moving around.”

I nodded.

As a respiratory therapist, I’ve tried to never let my feelings get in the way of my performance of the job. One of the ways I tried to maintain some control was to adopt a certain disconnection from what went on around me. Perhaps I came off to others as aloof, but I’ve tried to bring out my feelings through my actions, rather than emotion.

Things do get to me, though. You can't make a living in a place filled with suffering and death and not be affected. But I think that patients and their families prefer people caring for them who are under control and can handle situations calmly and professionally, but a certain balance should be in place. There's a fine line between calm professionals and emotionless automatons. I felt as though I'd achieved that. At the time, I'd been in the medical field for more than five years, and I always thought that I could handle anything.

I had some time to kill before my next treatment, so I pulled up a chair and sat next to Brian.

"So how's Ken?"

"He's good," Brian said. "He'll probably be coming in soon."

"Sick?"

"Naw, just a tune-up."

For some reason whenever Brian got sick and came to the hospital, I could pretty much place money that Ken or Doug – or a similar combination – would soon follow. It was their way of keeping each other company and having some fun while in the hospital. The doctors never seemed to call them on it; even when a CF patient was doing well, an extra hospitalization never hurt.

I nodded and said, "That's good."

Suddenly Brian sat up straight with an undeniable gleam in his eyes.

"Oh! I remembered what I wanted to tell you. Did you hear that Lucas is re-releasing the original trilogy in theaters?"

"No kidding? I didn't hear that."

"Yep. I guess he's gonna enhance the special effects in certain scenes."

"Oh, yeah? Like what?" I asked.

Brian took a moment to catch his breath. He leaned forward against the desk and breathed the oxygen through his nose, exhaled through pursed lips. Again, I noticed his use of accessory muscles.

"Just some stuff . . . Lucas wasn't satisfied with originally," he said, then paused to take a few breaths. "I guess there's a scene in *Star Wars* with Han Solo and Jabba the Hutt."

"Oh yeah, I've seen that."

"Really?"

"Yeah. Sandy bought me a trilogy box set last year for Christmas. The films are all letter-box."

"Awesome."

I nodded. "It's very cool. There's an extra tape that has a documentary on the making of the trilogy, and they included that scene with Jabba and Han."

"Oh, yeah," Brian said with a broad smile. "What did Jabba look like?"

"He was being played by an actor – some guy with an Irish accent. I guess Lucas was originally gonna matte in a stop-motion creature over the actor, but he ran out of money, or time . . . maybe both. It's cool that he's putting that scene back in, because it appeared in the *Star Wars* novelization."

"That'll be awesome," Brian said. "I can't wait."

Menchie, one of the other therapists, entered the unit and approached the nurse's station.

“Hey, Mench. What’s up,” Brian said.

“Nothing much. What’s up with you? Love us so much that you just couldn’t stay away?”

“I guess. Here for my treatment?”

“Yep,” she said. “I’m all yours today.”

Brian looked at me with a devilish grin. “I like the sound of that.”

“*Oh God*,” Menchie said, and rolled her eyes with a playful smirk.

“You love every minute of it.”

She tousled his hair. “C’mon, let’s get started.”

Brian nodded and pushed himself from his chair with some noticeable effort.

“Take care, Joe.”

“Alright, Brian, see you around. I’ll drop by later and see how you’re doing.”

“Sounds good,” he said, and started to head back to his room. Menchie followed, wheeling the oxygen tank behind for him.

I headed off the adolescent floor toward the Surgical Intensive Care Unit, to which I had been assigned. I’d been casually talking to the SICU secretary for about a year at that point, a girl named Jennifer Wellons. In the later part of the shift, after I’d finished my second round of treatments and did the eight o’clock ventilator checks, I told her that I was leaving the unit. Jen asked where I was going, and I told her that I was going to visit Brian. I explained to her a little about him and his disease.

She developed almost immediate concern for him, especially when I told her about the eventual outcome of cystic fibrosis.

“That’s so sad,” she said.

“It is. But Brian’s a great guy, and he’s really learned to cope with it.”

“Do you think he’d mind if I came along?”

“I doubt it, people are always visiting Brian. He’d probably enjoy it.”

So, Jen came along, and I introduced her to Brian. Doug was in the hospital at the same time, and when Jen and I came onto the floor, Brian and he were in the same room getting their treatments. Ken may have been there as well; I can’t remember exactly, but what’s important is from that time forward, Brian, Ken and Jen became good friends, and even associated outside of Lutheran General.

At the time, parts of me wanted to see Brian beyond the walls of Lutheran. Even though I’m a poor golfer I knew that Brian loved the game, and golf might be a good opportunity to extend our relationship past that of patient-therapist. Then there was *Star Wars* and the imminent re-release of the original trilogy, to say nothing of the new trilogy on which George Lucas was rumored to be working.

I guess what it came down to was that fine line of professionalism that I thought would be wrong to cross. A physician never treats members of his or her own family; my father, a Lutheran minister, would never counsel me or anyone else in our family. Would I have violated some code of ethics if I did decide to see Brian socially? Could I continue to treat him effectively if I had a greater emotional stake in the progression of his disease?

I didn’t have the answers then, and I still don’t now. All I have are rationalizations for actions I’ve taken and actions I’ve avoided. The one thing I can be sure of is that whether or not I had any control over the matter, or even realized it at the

time, my feelings for Brian as a friend were growing at an alarming rate. I have no doubt many nurses and therapists who would say the same thing of themselves.

## 5

Brian went home once again after his typical ten to fourteen day admission. Some time later I was working in the SICU and walked onto the unit to find him sitting at the nurse's station. He wore street clothes, had on a jacket and his *Planet Golf* baseball cap, so I knew he wasn't in as a patient. He'd probably come in to visit Jen.

I walked by the nurse's station and paused when I saw him. He sat there with a big grin on his face and flashed some cinema tickets.

"Did you get yours," he asked.

"Star Wars?"

"You bet – opening night."

I shook my head. "Not yet."

"You better," he said.

"Believe me, I will. Don't worry."

"So what's new?"

I set down my clipboard and leaned against the counter. "Not much. Sandy's due in a little over a month, so we're just getting ready for that."

"Do you know if it's a girl or boy?"

"No idea. We decided to wait for the premier."

Brian nodded. "That's cool. How about names?"

"Steven if it's a boy, and Angelica if it's a girl."

"How'd you and your wife decide?"

I let a smirk cross my face. "Well, Sandy and I decided to avoid conflicts by having her choose the girl's name and me the boy's."

"Hey," Brian said with his hands held up, "whatever works. You have to keep the ladies happy."

"As much as that's humanly possible," I added. "And sometimes that's not enough."

In fact, Sandy went into labor not long after and gave birth to a five-pound girl we named Angelica. A friend of mine, named John, was with me at the time. We'd met to go to my place for a guy's night out. I was off that night, but Sandy worked at Northwestern Memorial Hospital as an agency nurse. Ironically – or perhaps providentially – the patient census that night was low, and the nursing supervisor let her go home early. When Sandy arrived home, she went into the bathroom after feeling "a little strange".

John and I walked into the apartment, and I was surprised to find Sandy standing there. She said that her water had just broken and naturally, I became a basket of nerves, which included driving her near the speed of light to Lutheran General Hospital through one of the worst blizzards of the year. John stuck by through the whole thing.

Later on the night that my daughter had been born, he and I went out for a few celebratory drinks, and I began talking about Brian and the others in an uncharacteristically emotional way. I think it was then that I realized how much Brian Ken and Doug had become part of my life. It was also the first time that I considered the

reality and eventual outcome of CF. I knew how it went with the disease; I'd studied CF in school and knew of other patients who'd succumbed to the disease. I remembered Rita who had CF before I even knew what CF was. Maybe it was the alcohol, but that night it hit me that these guys, to whom I was becoming so attached, would at some point come to the hospital for the last time. It was a sobering revelation to be reminded of death in the advent of new life.

Brian's admissions became more frequent, and he was in the hospital again not long after Angelica's birth. On one of my days off, I brought Sandy in to meet him. A therapist from India, named Fazil, was doing Brian's therapy at the time. I knocked on the door to his room and led Sandy in.

"Joe!"

"What's going on?"

Brian shook his head with a shrug. "Same old," he said through the mouthpiece of his nebulizer while Fazil clapped on his back.

"How are you feeling?"

"I've felt better – coughing up a lot of stuff."

I noticed the nasal cannula he wore. "Short of breath?"

Brian just nodded.

"Well, this is Sandy," I said. "I told you I'd bring her by some time."

Brian tipped his head. "Hi. I've heard a lot about you."

"Mostly good, I hope," Sandy said, giving me a wary look from the corner of her eyes.

"Of course. Joe's a perfect gentleman."

"I have a wife at home too," Fazil cut in with his thick Indian accent. "I met her in India, and now she's pregnant."

Brian turned and looked at him for a moment, then swiveled back to face forward and said, "That's good, Fazil. Why don't you go pour yourself another drink."

I laughed, as did Sandy and even Fazil too. Brian didn't mean any ill will, and Fazil knew that; Brian was just trying to be funny and had succeeded. Since then I've used the *go pour yourself another drink* line on other people when the situation seemed appropriate and always thought of Brian when I did.

"So what did you think," I asked after I'd stopped laughing.

"Star Wars?"

"Yeah."

Brian considered the question for a moment while he inhaled his medications.

"Well, it was awesome seeing it on the big screen for the first time. But I didn't like the Death Star explosion – they should've just left it alone. And the scene with Jabba . . . I don't know. I was expecting more."

He breathed from the nebulizer, then asked, "How about you?"

"I liked it," I said. "It was very cool seeing it on the big screen again, but the thing I didn't like was how they changed the scene in the cantina with Greedo and Han Solo."

Brian nodded. "Yeah, that too."

A scene exists in the original *Star Wars* between Han Solo and an alien hit man named Greedo. In the scene, Greedo confronts Han over money Solo owes Jabba the Hutt. Unknown to Greedo, while the conversation ensues, Han stealthily removes his

side arm and blasts Greedo from beneath the bar table. In the Special Edition of *Star Wars* George Lucas altered the scene so that Greedo takes a shot at Han before Solo fries the alien.

“Well, probably Lucas didn’t want Han to come off as a cold-blooded killer,” I offered. “But by changing that scene they altered Han Solo’s character. They should’ve just left it alone, he *was* a pirate, after all.”

“Definitely,” Brian said. He inhaled more from his nebulizer, then turned to Sandy. “Congratulations on the baby.”

“Thanks,” she replied with a warm smile.

“Is she home yet?”

“Not yet – hopefully soon. Angelica was a little premature, so they’re keeping her here for observation.”

“It’s no big deal,” I said. “She had a little respiratory distress, but she was never on a ventilator, or anything like that.”

That was another thing which always struck me about Brian. In addition to the incredible fortitude that he displayed dealing with his disease, he always showed concern for others, even while in the hospital. Doug told me that Ken and he and some other friends used to call Brian “Mom” because of the way he worried about other people. Watching the way he struggled with his disease but still showed more concern for others has taught me to look at the way I deal with the pressures of life.

## 6

In the months which followed, I tried to visit Brian as much as possible, as did other therapists and nurses. His admissions became more frequent, but during one of the breaks between his times at Lutheran General, his mother and he traveled to St. Louis to be evaluated for a double lung transplant. Ultimately it would be the only thing to extend his life. Once he had a new set of lungs, his goal was to be a golf instructor.

Sometime after Christmas of 1998, Brian came into the hospital once again. A test called a DRP – an acronym for Direct Respiratory Profile – confirmed that he had contracted the Respiratory Syncytial Virus. RSV typically affects children. In healthy adults, the virus is manifested with strong cold or flu-like symptoms, but in children, their smaller airways and lungs can make the infection more severe. In the case of a CF patient RSV can be serious, if not worse.

Brian was considerably sick and wore his nasal cannula nearly all the time. His lungs sounded crackly, and he continuously coughed up large amounts of chocolate colored phlegm. What struck me the most was how this particular exacerbation for the first time seemed to break his usual cheery spirits. Brian would still try to joke around and act like his normal self, but somehow it just wasn’t him. On top of it all, he appeared tired all the time, and his use of accessory muscles became the norm instead of the exception.

One night I was taking care of another CF patient named Scott. He slept in the room next to Brian’s, and when I entered the unit to do his therapy, Scott was in the Teen Life lounge playing video games. I went to get him, and on our way to his room, I heard someone shout my name as we passed Brian’s door.

I glanced over and saw Nancy Sepp, one of the nurses of the adolescent floor, holding a washbasin under Brian's chin as he coughed up large volumes of bright red blood.

Ice water shot through my veins. In my career I've seen my fair share of blood and gore, but seeing it come from him hit me like a freight train.

"Give me a few minutes," I told Scott.

He nodded and went into his room and I dashed to Brian's bedside. The amount of blood he wretched up made it seem as though he were vomiting; he drew in deep breaths between spasms and groaned on exhalation with his eyes clamped shut.

I reached for a hundred percent oxygen mask and fit the tubing onto the flowmeter, despite fine tremors that seized my hands. Fresh blood reached the washbasin's half way mark, and Brian continued to hack more and more. I'd never seen so much blood outside of a trauma patient in the Emergency Room, and the fact that it came from Brian turned my nerves into a basket of tangled wire. I could feel my heart hammer the inside of my chest as cold perspiration beaded my forehead. Nancy stroked his hair to calm and reassure him while I held the oxygen mask near his face; I didn't know what else to do.

"Has anyone called Stone?"

Nancy nodded. "He's on his way in."

When Brian's pulmonologist Dr. Stone arrived, he evaluated Brian to have a hemorrhage of one of the vessels that supply blood to the lungs, an emergent situation that would require prompt attention. The transportation people arrived shortly and brought Brian down to the Special Procedures laboratory of the X-Ray department to have the hemorrhage stopped. A radiologist injected radio-opaque dyes into his bloodstream and watched the fluoroscope screen to determine the location and severity of the bleeding.

Various techniques can be used to stop internal bleeding, the most invasive being surgery. But in Special Procedures, a radiologist can insert different types of catheters through large blood vessels, like the Inferior Vena Cava, until the site of the hemorrhage is reached. Then cauterization or a plug of a foam-like substance can be employed to bring the bleeding to a halt.

I called the adolescent unit periodically during the shift to see if they had any news on how Brian was doing. Nancy said she hadn't heard anything, so when I'd finished my assignment I went down to the Special Procedures lab to see him for myself.

I walked into the control room, and through the window I could see Brian on the table with a blue sterile field towel draped over him.

"May I help you," said the technician at the control desk.

I tipped my head toward Brian. "I just came down to see how he was doing."

"You related to him?"

"No, he's been a patient of mine for a number of years."

The technician nodded as she pressed buttons and worked other controls.

"Well, they're just about finished. You can go in there if you want."

"Thanks," I said, then entered the treatment room with some caution. Anything done in the Special Procedures lab is always under sterile conditions, and I'm always wary of what I touch, to say nothing of whether I should be there at all.

Dr. Messersmith had performed the procedure. He's without question one of the best radiologists employed by Lutheran General Hospital, a consummate professional who loves his work and enjoys teaching others. The first time I met Dr. Messersmith I asked him about the differences between CT Scan and MRI, or Magnetic Resonance Imaging, why one is used over the other. He went into an enthusiastic and detailed explanation of both diagnostic procedures, and ever since then I've always had respect for him.

He looked at me over his surgical mask as I entered the treatment room.

"Well, hello there. What can I do for you?"

"I came to see how Brian was doing."

"We stopped the bleeder," Dr. Messersmith said. "Brian?"

"Yeah," came a groggy reply from beneath the blue sterile towel.

"You have a visitor."

I stepped up to the table. "Hey, Bri. How you doing?"

"Joe," he answered in a weak, scratchy voice, then reached out from beneath the sterile towel.

I took his hand into my own and gave a squeeze. One could only imagine how frightening the crisis must've been for Brian. I could tell how much it meant that I'd come down to see him.

"It's all over, man," I said. "They patched you up just fine."

"Awesome."

"I'm gonna let them finish up, but I'll see you later up in your room."

"Okay."

I thanked Dr. Messersmith for letting me come in, then turned and headed out. They brought Brian back to the adolescent floor soon after. Just about everyone had come in to await the outcome: his mother and father were there; Doug and Ken both were there as well, and I seem to remember another CF patient, named Todd Goldstein had also come in.

I stood at the nurse's station as the Special Procedures technician wheeled Brian onto the unit. He wore a forty percent oxygen mask and appeared anesthetized. The adolescent nurses told everyone to give him some time to recover before they went in to see him. His parents, Fred and Lois, followed him to his room, and I tagged along as well to make sure for myself that he was okay.

When I left his room I convinced myself that Brian could dodge anything thrown at him. Despite his cystic fibrosis, I thought that when the good Lord made Brian Conklin, He'd cast him from a Teflon mold.

Another thought crossed my mind; in ten years of working as a respiratory therapist, I'd been thrust into many situations and handled them all with detached professionalism. However, when Brian hemorrhaged I was truly scared . . . scared for him, scared for what might happen. His recovery lulled me into a false sense of security, and I was sure that nothing would happen to him. I certainly didn't change my thinking even when his lung hemorrhaged a second time and he had to go through the whole thing all over again. I had the night off when Brian was taken to the Special Procedures lab again, but I was assigned to him for the days that followed. I remember that Doug, Ken, and Todd took various pictures of women and other things that they'd clipped from

magazines and taped them all over the ceiling in his room, so that when Brian's anesthesia wore off the pictures would be the first thing he saw.

Dr. Stone ordered nebulizers, but told us not to pound on his back. The percussion could've started the bleeding again, and he'd have been right back in Special Procedures. Mucus clearance is one of the most important aspects of treating cystic fibrosis, and it was important to get on with Brian's therapy. By the next day his CPT was resumed.

Not long before the writing of this memoir, I sat with Doug during one of his admissions, and we talked about Brian's hemorrhaging episodes. Doug was present for the second crisis, and had this to say:

*That night I raced to the hospital to see Brian and met Lois Fred and Donna outside the Special Procedures room. I was able to go in there when they were done and walked up to his head and said hello.*

*Brian, pretty drugged up, extended his hand and told me, "You really are a true friend." He said it in the way that a drunk says: "I love you man."*

*We shook hands and I followed behind the table with Lois as they wheeled Brian toward the elevator. Brian began singing "Oh when the saints go marching in, oh when the saints go marching in" the whole way upstairs.*

*I too saw for the first time that Brian's spirits hadn't yet been broken, but they were wearing down. However, it was fun to watch Brian singing like that because of the whole thing of Ken and I calling him "mom". Brian rarely got drunk, and it was humorous to see him under the influence of something.*

Eventually Brian got better and went home, but shortly returned to LGH for what would be his final admission.

## 7

When I saw Brian for the first time after his return to the hospital, I could tell that he was sicker than he'd ever been. Instead of the nasal cannula, he wore a Venturi Mask, which delivers higher and more precise concentrations of oxygen. He sat cross-legged on his bed, hunched over in a classic pose of labored breathing, and I'd never before seen the facial pallor that he exhibited. I never took care of him while he stayed on the adolescent unit during this admission, but I came to see him as often as my time allowed.

One night I'd been covering the Medical Intensive Care Unit, and at the end of the shift, I came down to sit and talk with him. He wore a white *Maxfli* cap that Doug had acquired for him, but the first thing that struck me was the oxygen mask through which he breathed. It was a Partial Rebreathing mask which delivers sixty to eighty percent oxygen, a startling step up from the Venturi mask and an warning that he'd progressed to the final stage of his disease. Nonetheless, I blocked it out and told myself that even *still* he'd be fine.

I knocked on his opened door and stuck my head into his room.

"What's going on, man?"

"Hey, Joe." His reply was flat and lacked any vigor.

I walked in and sat on the couch next to his bed.

“Busy tonight,” he asked.

I shrugged. “A little, but I just finished for the night . . . how are *you* doing?”

Brian shook his head. “This sucks – I feel like crap.”

I just nodded, unsure of how else to respond. I tried to change the subject to something more positive.

“Hey -- I was on the *Star Wars* web site today.”

“Oh, yeah?”

“Yeah. I guess the new movie’s gonna be called *The Phantom Menace*. Supposedly the effects will be top notch – they’re gonna show Yoda walking around and a lot of other computer generated effects. Should be pretty cool.”

“When is it coming out?”

“The summer of ’99,” I said.

“We’ll have to all go and see it together.”

I nodded with a smile. “That would be excellent.”

I watched Brian as he talked, as he breathed. Each inspiration he took was with the assistance of his shoulder muscles, and it seemed like his breathing necessitated concentration. He coughed, one of those deep, wet hacks that brought out the veins in his neck and red to his face. Then he lifted his mask and spat dark, chocolate-colored phlegm into the garbage can next to his bed. He covered his face with the oxygen mask and held it in place with both hands as if to gain more benefit from the device.

“Y’know, Brian,” I said after a moment, while he caught his breath, “a year or so ago I looked up your screen name profile on AOL and read your personal quote. It really made me think about my life, what I take for granted . . . like breathing, for example.”

Brian nodded, and although he still heaved his upper chest muscles for a breath of air, I could see that he’d calmed down after the coughing attack.

“How do you deal with this disease on a day-to-day basis and everything that goes with it?”

He took a moment to answer, inhaling deep breaths from the oxygen mask as he thought.

“CF has been part of my life – ” He paused to take in a few breaths and exhaled through pursed lips. “ – since the day I was born.”

His breathing finally settled down, but as I watched the flex of his neck muscles with each effort, I could see how much the coughing fit had taken out of him.

“It’s not so much a matter of dealing with it, like someone who loses a limb,” he continued. “It’s more like someone born blind. I just live my life as it is, and I don’t know how to live any other way.”

I sat on the couch and watched him struggle to get his words out; it was difficult. I wanted so much to believe that everything would be fine, but each time I saw him he looked a little worse. I wished that somehow I could take it all away from him, like John Coffey in Stephen King’s *The Green Mile*.

The image of Brian in Room 257 hunched over that washbasin flashed through my head.

“I don’t mind saying that the bleeding episode really scared me,” I said. “Don’t *ever* do that again.”

Brian managed a smile and said, “Don’t worry, I won’t.”

I looked up at the wall clock and saw that the time was almost eleven PM.

“I need to hit it, give report to the next shift.”

Brian nodded. I stood from the couch and straightened out my lab coat. *Friends* played from the TV above my head. I glanced up at the screen and watched the show for a minute or two.

Then Brian finally said, “I’ll tell you, Joe, I can’t stand breathing like this any more.”

I looked at him for a moment, unsure of how to reply, then grinned and gave him a pat on the shoulder.

“Come on, man, you’ll be fine . . . don’t worry. If you got through the hemorrhaging episode, you can get through anything. It won’t be much longer and you’ll have a new set of lungs, and all this BS will be behind you.”

Brian nodded somewhat unconvincingly.

“I have to split, but I’ll see you tomorrow, okay?”

“Yeah.”

With that, I left his room and headed for my department, oblivious to the finality that hung in the air. It was the last time Brian and I ever spoke.

The next day I was swamped with work in the Medical Intensive Care Unit, and the day after as well. I never found the time to see Brian, and by the end of the shift I found myself bogged down with charting and other end-of-shift duties.

On the third day, the MICU was no less busy. One of the patients on a mechanical ventilator was to be taken down to CAT Scan, and I had to accompany the nurse. Menchie covered the Emergency Room that night, and looking for the small transport ventilator, I thought that she might know where I might find it.

I paged her to the department, and she promptly called back. She was assigned to Brian, and while I spoke with her I heard him in the background say, “Is that Joe? Tell him to get his ass down here!”

“You hear that?” Menchie asked.

“Yeah,” I answered then laughed. It was good to hear Brian sound more like his old self. I thought that he must be finally getting better.

“Tell Brian that I’m swamped right now, but I’ll try and see him later.”

“Okay, but *you’d better*,” Menchie said.

“I will – I will.”

We hung up and I went on to finish my evening, which never slowed down. By the time night shift came along I was still up in MICU finishing charting and signing out ventilators. Sometimes, depending on the night, the process can be time consuming. There’s charting paper to replace, humidifier canisters to fill, drain bottles to empty. Sometimes while a therapist is trying to get all this stuff done, the nurses will want a treatment on one patient, or another might crash and demand immediate attention. Then there’s always the end of shift transport to CT Scan that all therapists love, especially when the nurse walks up and says: “Okay, we’re ready.”

“Ready for what?”

“Oh – didn’t anyone tell you? Mr. So – and – So had a 2200 CT of the thorax scheduled.”

“No . . . No one said a thing to me.”

“So sorry. Anyway, we’re ready.”

As it turned out, I never found the chance to see Brian that night. By the time I'd finished and given report all I wanted to do was unload my pager and get the hell out of Dodge. Through some creative scheduling on my part, I'd managed to get the next four days off. Sandy and I had thrown around the idea of going to a bed and breakfast somewhere out west, perhaps Galena. However, we ended up doing nothing but sitting in front of the tube and relaxing.

## 8

I returned to work on the following Saturday. Upon my arrival I glanced at the assignment board and saw that once again I was up in the MICU. I hoped it wouldn't be as busy as it was the last time I worked.

Then my supervisor, Bruce, appeared from around the corner to the report room and said, "Joe, can I talk to you for a moment?"

"Sure."

I followed Bruce into the hallway, my mind retracing the last days that I worked, wondering what I'd done to get myself in trouble. Most often if the supervisor said: *Can I talk to you for a moment*, it meant that something happened that required explanation. Even worse was if the supervisor said: *I need to see you in my office*. Then someone dropped a major clanger, or a nurse with whom a verbal incident transpired had written some formal complaint. I've had my share of both, so I instantly felt the familiar wave of apprehension in my stomach when Bruce summoned me.

Once we were in the hall he said, "Brian got intubated today."

"What?"

"Yeah. He's in Ped's ICU now, will be transferred up to MICU within the hour, so you'll have him."

"But I thought . . . Well, what the hell happened?"

Bruce shook his head. "He got real bad over the past two days. They tried BiPap, but it didn't help, so anesthesia tubed him this morning . . . I just wanted you to know so that you'd be prepared."

"Thanks, Bruce."

He gave me a nod then went on his way.

I stood in the hall for a moment a little shell-shocked from what I'd just been told. When a person is *intubated*, it means that a tube is inserted into the trachea so that the patient can be placed on a mechanical ventilator. Through the tube, called an *endotracheal tube* or an *ET tube*, concentrated oxygen mixed with air is pushed into the person's lungs at regular intervals; in essence, the ventilator breathes for the patient.

At the moment, I could think of nothing else other than going to see Brian, but the day shift therapist still waited to give me report and likely wanted to go home. I walked back into the therapist room, listened to report, but never really heard it. I can't even say I remember the person who I followed that evening; all I remember is listening to what was said to me with a half heart, then going immediately down to Pediatric Intensive Care Unit to see Brian.

When I arrived, his mother, Lois, stood outside his room with a few other people by her side whom I didn't recognize. The nurses gave me a curious glance, as they

always do; I don't ever work PICU, and the nurses, protective of their patients, tend to examine every unfamiliar face that enters the unit.

I approached Lois from behind and placed my hand on her shoulder. She turned around.

"*Oh, Joe.* They had to put Brian on the respirator," she said, then covered her mouth with her hand. Non-medical people tend to call ventilators *respirators*. It's a common mistake, and I usually think little of it.

"I know. That's why I'm here," I said. "We're going to take him up to the Medical Intensive Care unit soon, and I'll be taking care of him all night."

"I'm so glad," she replied though a voice racked on the verge of tears.

I turned and saw Brian on his bed. His eyes were closed from obvious sedation, and an ET tube connected to a ventilator circuit jutted from the right corner of his mouth.

"Joe, this is my sister," Lois went on to say, introducing me to the people who accompanied her.

"Pleased to meet you," I said and shook her hand.

"This is the pastor from my church . . ."

Another woman whose hand I shook.

". . . and this is Scott. He's been friends with Brian for many years."

I nodded my head to Scott, who stood off to the side, his hands buried in his pants pockets. He tipped his head back to me but remained where he stood and looked as though all he wanted to do was stay out of the way.

I entered Brian's room with some trepidation and looked at his motionless form that lay on the bed. It's hard to describe the feelings I had at seeing him with the familiar tubes of what we in the business call a *vented patient*. This is my job, and I've been used to seeing these things for many years. But this was the first time that it was someone who I knew and cared about. A flood of the thousands of things that could happen swept through my mind. It was so unlike Brian to be in such a state; I was used to him being so full of life, so vibrant, always with a joke or sarcastic remark on the tip of his tongue.

The nurse in the room worked with his IV tubing. She either replaced a saline bag or started a new dose of antibiotics; I paid her little attention, my focus on Brian and the ventilator settings on which he'd been placed.

I noticed that a high level of PEEP had been dialed in. PEEP, an acronym for Post End Expiratory Pressure, is a method of applying constant pressure to a patient's airways to promote better oxygenation. Brian was already on a hundred percent oxygen, and with the high level of PEEP applied to his lungs, I knew that he was critically ill. Even worse was the control rate of forty – more than twice what's normal for an adult.

The nurse said something to me, which at first I didn't catch.

I turned to her. "I'm sorry, what was that?"

"I just asked if you've known Brian for long."

I turned back to the ventilator. "Yeah, I've taken care of him for a while."

"It's such a shame," she said.

I just nodded and tried to ignore the pit that was forming in my stomach.

The secretary came to the door and said, "MICU's got the room ready."

"Okay, thanks," the nurse answered. "Are you here to help transport, or should I have Matthew help," she asked me.

"No, I can help."

Matthew was another respiratory therapist who covered PICU that night. I don't know what it was, to some extent. He was an excellent therapist, but I began to feel protective over Brian, perhaps even possessive and wouldn't have felt right unless I had been the one to ventilate Brian with an Ambu bag up to MICU. Someone must've paged Matthew, or told him that Brian was about to head up because Matthew entered the room a moment later.

"Joe," he said with some surprise.

"I just came down to see him," I said, "but if you don't mind, I'd like to bag him up to the unit."

"That's fine," Matthew answered. "I'll push the vent."

Matthew unplugged the ventilator, coiled up the hoses and pushed the machine out of the room. A few minutes later, the nurse and I began to move Brian to his new room in the adult intensive care unit on the seventh floor. I squeezed the Ambu bag at regular intervals and breathed for Brian as we pushed his bed down the hall toward the elevator. I was struck by how stiff his lungs felt. Each breath took some effort for me to squeeze in, and I had no doubt that his lungs were loaded with large amounts of thick mucus.

When a CF patient is placed on positive pressure ventilation, areas of lung that haven't been ventilated in years are opened which produces a cascade effect of purulent mucus. It also wreaks havoc on the process of gas exchange of oxygen and carbon dioxide, the waste gas. These were some of the obstacles facing Dr. Stone and those of us caring for Brian when his illness took this turn.

As the nurse and I rounded the corner toward the elevator, we passed through the adolescent unit. The nurses who knew and took care of him for so many years had the grim experience of seeing Brian sedated and paralyzed with an ET tube hanging from his mouth.

"Good luck, Brian," Linda Monkton said. She was one of the adolescent unit nurses, and Matt and Peter's mother. Nancy was there, and I remember seeing another nurse who had a long history with Brian as well named Margaret.

We turned another corner to the service elevators and took one to the seventh floor. The entrance to the MICU was next to these elevators, and just beyond the double swing doors was Room Ten.

Once he was situated in the room and back on the ventilator, I started a nebulizer treatment to help loosen some of his thick secretions. Then I placed my stethoscope to his chest and listened to the loud gurgle of his breath sounds. Advancing a suction catheter into his lungs produced an almost continuous stream of thick greenish-yellow sputum.

By early evening, the waiting room was filled with Brian's friends and family. Doug and Ken were there, as was Brian's father, Fred, and Brian's older sister, Maegan. I'd never met his sister before, but Brian had mentioned her on several occasions. Not long before this admission, I was doing his therapy and making small talk. I mentioned the book I'd been writing, an adventure story with a science fiction flair. A part involved the Russian space program. Brian turned around and said that his sister, who worked for the U.S. Embassy in Russia, knew much about the country. I had some questions about where launch sites for Russian rockets were located. Brian said that he'd e-mail Maegan and ask.

I remembered the conversation as I pounded on his back in the MICU. I was alone with Brian at the time; he was under heavy sedation, so I had no idea how aware he was of his surroundings, but I talked to him nonetheless.

A high-pressure alarm sounded on the ventilator when I turned him to his side. “It’s okay, Brian,” I said. “It’s Joe – I’ve been with you all evening, and everyone else has been here too.”

I clapped his side and lower back with one hand while I held him in position with the other. Various personal items of his had been brought into the room by his mother and his friends: assorted stuffed animals lined the borders of his bed; photos of Brian and his friends had been set up along the shelves and window sills; someone brought in the white *Maxfli* cap that Doug had acquired and fit it on his head. The thoughtful touch helped Brian – even if just a little – look more like himself and took away from the harsh reality of what was happening.

“We’re gonna get the tube out, don’t worry. Remember *The Phantom Menace* – Doug, Ken, you and me . . . we’re all gonna see that flick together on opening night, so you have to have to fight, man . . . I know you can do it.”

There was no response from Brian; I didn’t really expect any. I only hoped that he heard me and knew that I was there to take care of him.

Maegan entered the room and approached his bed. I’d never met her before, but somehow I knew that she was Brian’s sister. She looked at Brian and I could see the concern on her face.

I continued to clap on his back while Maegan watched. She took Brian’s hand into her own, then stroked his arm with genuine sibling love. The bond between Brian and his sister was obvious to me.

“Are you Maegan?” I asked.

She glanced at me and nodded.

“I’m Joe. I’m the one who wanted Brian to ask you about the Russian space program.”

A subtle smile crossed her face that did little to hide her obvious feelings: fright, concern, uncertainty. I had an idea of what went through her mind because I had similar feelings. The difference was that I was merely a medical worker who came to know Brian over the years and grew to care a lot about him. Maegan was his sister, and there’s nothing thicker than blood.

“Brian has talked a lot about you,” she said. “It’s nice to finally meet you.”

“I wish the circumstances were different.”

Maegan just nodded and focused again on her brother.

“Is he doing any better?”

“About the same,” I answered. “His oxygenation looks good right now, and that’s always a positive sign.”

“Do you think he’ll be okay?”

“Don’t worry, we’ll get him off this thing.”

“Thanks for everything you’re doing.”

I shook my head. “It’s no effort, Maegan. Believe me.”

She visited a while longer, then left the room and Brian and I were alone once again. I finished his therapy and suctioned his lungs to try and clear some of the thick

sputum away. But based on the amount of mucus that I removed, I thought that I could almost apply continuous suction to his lungs and never completely clear them.

After I'd finished, I stayed with Brian a while longer and rechecked the ventilator to make sure that everything was as it should be. Dr. Stone, Brian's pulmonologist, came into the room as I was ready to leave, so I stayed in the event that he wanted to make any changes.

I stood to the side and watched him examine Brian. He listened to Brian's lungs, glanced up at the cardiac monitor, then at the screen on the ventilator. For a moment, he stood almost motionless with his arms crossed, an index finger tapping his upper lip. Brian was more to him than just another patient. I knew that they had even golfed together on several occasions.

Dr. Stone turned to me.

"You've been pounding on him?"

"Yes, I just finished."

He nodded and faced Brian again.

"I don't understand why he can't be transported to St. Louis."

He shook his head. "They won't take him unless he's extubated." Extubation means removal of the endotracheal tube through which Brian breathed.

I folded my arms across my chest. "It seems like such backwards logic: they wouldn't take him before because his lungs were *too* healthy. And now they won't take him because he's too sick."

Dr. Stone nodded, but offered no other response.

"We'll get him off, though. Don't you think?"

Dr. Stone paused before he replied.

"I don't know. It's going to be tough. Once CF patients go on the vent the odds of getting them off are slim." He sighed and turned away. "We'll give it our best, though."

Dr. Stone left the room, and I followed. I walked out of the MICU to go for dinner and passed the waiting room on my way. Many of Brian's friends sat there; I saw Ken with Doug, and his parents, Cindy and Pete.

"Been beating on him?" Ken asked.

I approached the gathering of people and leaned against the wall by the elevators.

"Yeah, CPT, nebs. I just finished."

"How's he doing?" Doug asked.

"Well, his oxygenation is okay right now," I answered. "It's gonna be touch and go for a while, I think. I just talked to Dr. Stone, but he didn't make any changes."

Ken looked up at me. "Are you going to be able to get him off?"

"Yes. We'll get him off."

He nodded and looked away with an air that made me think he didn't believe me. I wasn't sure if I believed myself, but one thing I can be sure of – from that point I felt as though the outcome of Brian's disease rested on my shoulders.

It didn't, of course. I wasn't God; I wasn't even a physician, to say nothing of being a pulmonologist who specialized in the care of cystic fibrosis, as did Dr. Stone. I was just the guy who pressed the buttons and hooked up the nebulizers. But by the same token I was one of the people who over six years spent two hours a night in Brian's room clapping on his back, talking to him about his life, talking about mine. One can't work

that closely with a patient without a certain connection having been formed. It would've been the same if one of my closest friends had lain in Brian's place. Whether it was true or not, I felt as though Doug, Ken, and Lois looked to me for answers that I couldn't give.

I ventured up to the cafeteria on the tenth floor to buy my dinner and saw Lois in the smoking lounge having a cigarette. I walked in and sat down with her.

"How's he doing, Joe?" It was obvious from her moist, red eyes that she'd been crying.

"No change," I said. "I just gave him a treatment, and Dr. Stone was in the room to check on him."

"I saw him earlier. He said that this won't go on more than five days . . . I just don't think I can hold out that long." She puffed on her cigarette, then tapped some ash off into the ashtray.

"Don't worry, Lois. We'll get him off and he'll get his lungs."

She looked at me. "Do you really think so?"

"Brian's strong. He didn't let the hemorrhaging knock him down, and I *know* that he'll make it through this."

"I just don't know what I'll do if –"

I cut her off quick. "That's not gonna happen."

I stood from the table.

"I'm gonna get some dinner, but I'll be back in there as soon as I'm done."

"We have some food coming in. You're welcome to join us if you want."

"Thanks, but I have some food waiting in the department for me."

It wasn't true; I'd come to the cafeteria to get my dinner. I considered Lois' offer, but just wouldn't feel comfortable sitting with Brian's friends and family in lieu of what was going on. I don't know what was different about this time; in the past when Brian, Doug and Ken ordered delivery food to their rooms, I'd sometimes chip in and eat with them. For some reason this time was different; I just felt that my place should be kept at a more professional level. Perhaps in my own apprehension for what was happening to Brian I needed to distance myself to maintain my own sanity for Brian's sake.

When I got down to the respiratory care department, the dinner topic was Brian and how he was doing. I gave basic facts, but I tried to remain tight lipped about the subject. We had an erasable marker board on the front wall where we wrote the names of all our patients receiving mechanical ventilation in the various intensive care units, and it was hard enough to look up and see the name *Conklin* written there.

I finished my dinner but didn't hang out in the department as usual. I went straight back to Brian's room, checked his ventilator, and decided to give him another treatment with CPT. I wasn't sure if extra treatments would make any difference, but it certainly wouldn't hurt. I wanted to give Brian every possible chance to get off the ventilator so that he could go to St. Louis and have his transplant. If more nebulizers and CPT helped in even the slightest degree, then he was going to have them.

As I clapped on his back, Doug came into the room with his hands buried in his pockets, walking with timorous steps as though the floor were made of eggshells.

"Hey, Joe," he said in a subdued tone.

"How's it going, Doug?"

He shrugged and glanced at the ventilator for a moment, then looked down at Brian.

“Doing some therapy?”

I nodded.

“How’s everyone out there,” I asked.

“As expected, I guess.”

“Brian – Doug’s here,” I said.

Doug stepped closer to the bed and took Brian’s hand.

“Hey, Bri. Hanging in there?” He glanced at me. “Has he responded to anything?”

“No, they have him pretty well sedated. He may still hear, though.”

“Do you think he even knows that I’m talking to him?”

“He might,” I said. “I was talking to him earlier.”

Doug turned back to Brian and said, “Everyone’s here. We’re all pulling for you, so you gotta get better.”

Around that time, Ken came into the room and walked up to the bed. The nurses generally limit visitors in the intensive care units to immediate family members only, but they gave a lot of leeway in Brian’s case, and for which I was glad. Was it favoritism to grant a patient special privileges over others? Perhaps, but from Brian’s medical history the MICU nurses knew that he was a well-known and liked patient even if they hadn’t ever taken care of him before. They were aware of what’s involved with CF, and I think for that reason they cut Brian’s friends and family some slack.

I left the room to give Doug and Ken some time alone with Brian. They were probably his closest friends; Ken even shared a condominium with Brian. I wondered what went through their heads seeing what they saw. Beside the fact that this was their best friend fighting for his life, they had the same affliction and gazed upon what could very well be their own fate. Again, it goes back to my admiration for the incredible fortitude that I’ve witnessed in people with CF.

Around nine PM arterial blood gases came back. The test, commonly referred to as ABGs, is one in which blood is withdrawn from an artery and analyzed for content of oxygen, carbon dioxide, and acid/base difference. Brian’s gases hadn’t changed much, which discouraged me considering his high control rate.

I made my way up to the unit to make the ordered changes. Bruce, my supervisor, came along to see how Brian was doing. He had also given therapy to Brian for several years before his promotion to PM shift supervisor.

When we arrived, most of Brian’s visitors had left except for his immediate family. His parents were in the room, Lois and Fred. Maegan was there as well with her boyfriend and Brian’s aunt and grandmother.

They greeted me when I walked into the room but remained relatively quiet. Everyone stood and watched Brian, his cardiac monitor and the ventilator function screen. It’s a normal response of families and friends of critically ill patients; perhaps the monitor gives them some visual connection to the lifeline of their loved ones, whether or not they understand the data that trails across the screen.

I signed out his ventilator, filled the humidifier and drained the humidity overflow bottle, during which time I took note that Bruce had remained at the doorway. Later he told me that seeing Brian intubated was distressing to the point that he was unable to enter the room. Despite what I knew about CF and mechanical ventilation I truly believed that in the end he would be okay. I would talk and laugh with Brian again.

## 9

Sunday rolled around, the second day of Brian's ordeal on the ventilator. I came into work at my usual time and looked up at his name on the MICU board before I'd even removed my jacket. The day shift therapist gave me report and said that not much had changed in Brian's status. She added that visitors had been in his room all day, and she didn't feel comfortable doing his therapy, which bothered me. After all, Brian had been doing therapy for most of his life, and percussion was something with which his family and most of his friends were well acquainted. The fact that he was intubated should've made no difference.

I wasted no time getting up to MICU and saw Dr. Stone at the nurse's station charting in Brian's progress notes.

"How's he doing?" I asked.

Dr. Stone glanced up at me.

"About the same," he said and went back to his charting. "There's been some improvement in his gases, but his airway pressures are too high."

He closed the chart and capped his pen. "Is there some reason why therapy isn't being done?"

I sighed and said, "Y'know, Dr. Stone, I have no idea what happened today. I just got on duty, but I can assure you that Brian will get therapy from *me* tonight."

"Good."

I walked into the room and looked at Brian lying in the same position I'd seen the previous night. He still wore the *Maxfli* cap, but under the paralytics and sedation, Brian looked inert. The only indication of life came from the steady EKG rhythm that traced across the screen in jagged peaks. I looked at the oxygen saturation below his blood pressure reading, relieved to see numbers in the low nineties – not ideal, but acceptable.

Lois stood at the side of his bed and held his hand. I walked up to the ventilator and gave it a quick look-over. On the alarm portion of the screen, I noticed that the high pressure and low tidal volume alarms had sounded, and I assumed that the nurse had probably suctioned him.

In adult positive pressure ventilation, tidal volume is the amount of gas delivered to the patient with each breath. It's a number expressed in milliliters, or cubic centimeters, and is based on the weight or height of the patient; we set Brian's Tidal Volume at five hundred fifty milliliters. Each breath delivered to Brian exerted a certain amount of pressure to his lungs, which was measured by the ventilator and displayed on the function screen. When we deliver tidal volumes to a patient, the preset volume will be delivered regardless of the pressure applied to his or her lungs; this was what Dr. Stone referred to when he spoke of Brian's airway pressures being so high.

I pressed the reset button and approached his bed.

"Hi, Joe," Lois said. She didn't look at me, and her voice hung on the verge of tears.

"How's he been today?" I asked in a hushed tone, even though I believed that cannon fire wouldn't arouse him.

Lois shook her head. "They've had to go up on his oxygen percent today, but other than that he hasn't changed at all."

I nodded my head once and just stood and looked at him, seeing it all, but blocking it from my mind at the same time.

“I don’t know how much more of this I can take,” she added.

I had no response; I didn’t know how to respond. I just stood at his bedside and stared at him, my hands shoved into the pockets of my lab coat.

“Are you taking care of him today?”

“Yeah.”

Lois nodded. “I’m glad.”

After another moment, I exhaled a deep breath and stepped away from the side of his bed.

“I have to see my other patients, Lois, but I’ll be back soon.”

“Okay, Joe.”

I walked from the room and went about signing in the other ventilators I covered that day. I couldn’t help but feel that the other patients were obstacles in my path to taking care of Brian, and it irritated me. Right or wrong, I felt as though it was my duty and obligation to make sure that Brian got off the ventilator so that he could have his transplant.

But there was more to it than that.

I had the weight of incredible guilt on my shoulders for not being there for Brian when he went critical and was transferred to PICU. The therapists who’d taken care of him during that time told me how scared he was further compounded this. Menchie said that she’d gone down to see him, and when she began to leave he grabbed her hand and said, “Don’t leave me.”

Where was I during all this? I was sitting at home with my face glued to either the computer screen or the TV. On the other hand, I had no idea what was going on with him, and I expected to return after my days off and find him as before, or perhaps even better. The least I could do to try and make up for my absence was to be with him as much as possible now.

I returned to Brian’s room after I’d completed my other work. I wanted to get the other stuff out of the way so that I could spend as much time with him as I needed.

While I did his first treatment for the night, Nancy Sepp, one of Brian’s favorite nurses from the adolescent floor, came into the room to see him. She had her daughter along and placed her at the doorway before she approached Brian’s bed.

Nancy flashed a glance at me, and I could see in her face what I felt.

“Hi, Joe.”

“Hey, Nancy.”

I continued to clap on his side with my left hand while I held him on his side with my right.

“Brian? It’s Nancy. I just came in to see you . . . You hang in there, okay? Get better.”

I paused as she stroked his hair. She looked at me.

“Take good care of him, Joe.”

“You know it, Nancy.”

She left and I finished Brian’s therapy. I looked over the ventilator one more time, then left to get some dinner. No sooner was my last bit down than I was on my way back up to MICU. One of the therapists on the PM shift, Rob Rhode, had become

engaged to Jennifer Wellons, the SICU secretary I'd introduced to Brian, Ken and Doug several years before. Rob had the weekend off, so I phoned him from MICU to fill him in; he lived with Jen and her parents at the time.

After three or four rings, the line picked up.

"Hello?"

"Hi. May I speak with Rob, please?"

"Hold on . . ."

The girl who answered sounded like one of Jen's sisters. I sat before the remote cardiac monitors and looked at Brian's screen as I waited. In the background, I heard the distinguishable voice of John Drury from *Eyewitness News* on channel seven; the same news show simulcasted from the TV in the patient's room behind me.

"Hello?" It was Rob.

"What's up, man?"

"Joe," he replied with some surprise. "How's it going?"

I hesitated. "Well, It kinda sucks, to be honest."

"Why? What's going on?"

"Have you heard about Brian?"

"He's in PICU, right?"

I sighed. "No, man. He was tubed yesterday. He's up in MICU right now on a vent."

"Oh, you're kidding . . . Aw, jeeze!"

I could hear the shock in Rob's voice. He let out a breath and a moment of uncomfortable silence followed.

"Well, what's going on with him? What are they doing?"

"He's on assist control," I said. "They have him on a hundred percent and a rate of forty."

"Wow," Rob replied. *Wow* served as a typical response for both excitement and shock. "How are his gases?"

"Acidotic last night, but a little better today, I guess . . . I haven't actually seen them."

Another period of tense silence ensued.

"What's your input," Rob finally said, and I could tell that he'd chosen his words with care. "Do you think he'll make it?"

"Oh, God," I answered with a long sigh. "I don't know, Rob . . . I sure as hell hope so. But I really don't know how much longer this can go on."

"Yeah," Rob said. His voice sounded distant, almost as if I spoke to someone who existed in a different time.

"I'm gonna go. I just wanted to let you know what had happened, and I thought Jen would want to know too."

"Yeah. Thanks, Joe. I'll be sure to tell her."

"Alright. I'll see you at work tomorrow."

I hung up the phone, then went back into Brian's room and stood by his ventilator for a while. People came and went at regular intervals: Doug and Ken, Fred and Maegan, Brian's aunt and grandmother. Lois stayed during most of this. I left to get my second rounds out of the way so that I could return and spend more time on Brian's therapy.

Mary Soderlund, another respiratory therapist, came into the room as I did Brian's second round of therapy. She helped hold him up as I clapped on his back and sides. Afterwards we performed a thorough suctioning to do what we could to clear out his lungs. Again, a seemingly never-ending stream of the same thick secretions came back through the suction tubing. Most of the mucus was so tenacious that it moved like molasses.

Mary squirted some normal saline down his ET tube, then I ventilated Brian with hard squeezes through the Ambu bag. This was called *lavaging*; it helps to break up thick mucus in intubated patients. But despite this technique of dilution, Brian's secretions crept through the suction tubing like a lane of traffic clogged by gapers block.

"Oh my God, Joe. Look at this," Mary said.

I shook my head. "I know. It's been like that the whole time."

Mary advanced the suction catheter through his ET tube again and pulled back with the same results. By the time we'd finished, eleven o'clock had rolled around, and it was time for us to head downstairs for shift report.

Mary and I walked through the seventh floor hallway toward the elevator each lost in our own thoughts.

She looked at me as we walked and said, "He's not going to come off that vent."

Tears welled up in my eyes as the power of what she'd said hit me. But I tightened my lips and held it back.

"We'll see."

## 10

Monday March 15, 1999.

The events that transpired that day are sketchy in my memory – all except what occurred at the end of the shift; I remember that with vivid detail.

I came into work a little early so that I could go up to see Brian before the shift began. I wanted to see him as a friend, not a respiratory therapist. He looked the same as he had the two previous days: the *Maxfli* cap still sat on his head, and the room was still filled with personal items. I smiled as I entered the room when I saw a small sign on the windowsill with the words *Breast Feeding Center*. After the second episode of pulmonary hemorrhaging that he had gone through, Doug or Ken had acquired the sign from somewhere in the hospital. If Brian could've seen the sign, I know that he would've laughed.

I saw Lois a little later up in the tenth floor smoking lounge. She told me that Fred and she had had a conference with Dr. Stone where Brian's prognosis was outlined and explained. At that point they had made the decision to make him a DNR, which means Do Not Resuscitate; in the event that Brian went into cardiac arrest, the medical team would do nothing to try and reverse it and let him go.

Many therapists on my shift found the decision as somewhat of a relief. They felt that if Brian were to become so bad, at least the doctors wouldn't torture him by dragging the ordeal out for a few more days just to have him die anyway.

I, on the other hand, felt that the decision was like taking one more step closer to an awful place where I didn't want him to be. The name Brian Conklin and the acronym DNR had no more affinity than did two poles of a magnet. I remember walking around

the hospital doing my duties in denial of the weird essence that hung in the air like the smell of ozone that always rises before the onset of a bad storm.

Everyone in the department asked me how Brian was doing during the course of the night, and I responded by saying that he looked good, that I thought he was getting better. He didn't, but I wanted so much to believe that he *was* getting better that I convinced myself.

I did Brian's therapy as I had for the previous two nights. I suctioned his lungs. I spoke to him, telling him that he had to get better.

"*Phantom Menace*, Brian," I'd say to him. "We have to see *The Phantom Menace*, so you have to get better."

Around ten o'clock I was getting ready to sign out the ventilators for the night when my pager sounded; it was MICU. I dialed the extension and identified myself when the line picked up.

"Respiratory."

"Oh, yes," the secretary answered. "One moment, please."

Deanna, Brian's nurse came to the phone.

"Hey, Joe?"

"Yeah."

"Could you come up here and take a look at Brian?"

"Why? What's going on?"

"Well, his Sats are dropping. We put in a call to Stone, but I'd really appreciate it if you came up."

I frowned and gripped the receiver tighter. "Alright, Deanna. I'm on my way."

I entered the unit and went straight into Brian's room. Lois and her sister were in the room, along with Brian's grandmother and Maegan. I could read the worry across all their faces. I glanced at the monitor and saw that his oxygen saturation reading was in the low eighties. Brian was already maxed out on delivered oxygen percentage.

I exhaled a sigh and rubbed my chin.

"Have you suctioned him," I asked Deanna.

"Yeah, I did that, but it didn't help. Is he due for a treatment?"

I shook my head. "No, but I could give him one. I'm not sure if it'll help, but I'll try anyway."

Deanna asked Brian's family if they could step out of the room for a moment while we tried to correct his oxygenation problem. I hooked up a nebulizer and turned on the flowmeter, but as suspected, the treatment did little to help.

Dr. Peabody, the resident arrived in the unit and came into the room. He glanced at the monitor, looked over the vent.

"So what happened," he asked.

Deanna shook her head. "He just started to de-sat about ten minutes ago. I suctioned him and Joe just gave a treatment, but neither have helped."

Dr. Peabody nodded as he listened.

"Has anyone called Stone?"

"Yes, but he hasn't called back yet," Deanna answered.

Peabody turned to me and asked, "Any suggestions of what we could do?"

I shook my head and sighed. "He's already on a hundred percent. The only thing I can think of is to go up on the PEEP, but with his lungs in the shape they are . . . it could

lead us into pneumo country.” By that, I meant a pneumothorax, which is the technical term for a collapsed lung.

A pneumothorax was a real danger with Brian’s lungs, especially after the hemorrhaging crisis that had occurred earlier in the year. I remembered those episodes and knew how weakened his lungs had become; it’s why they’d bled in the first place.

“Could you do a plateau,” Peabody asked.

I shook my head. “Not on a rate of forty. I don’t think the vent will let me get a pause in.”

I thought about manipulating breath waveforms. Most adult ventilators give the operator control over the way in which a breath is delivered. The typical pattern we use is what’s called a decelerating wave. That is a breath that is delivered fast at first, but slows down as the programmed volume is reached.

“Let’s try a square wave,” I said, then punched in the flow pattern.

The square wave delivered a breath with a quick blast. I lowered the flow rate, which limited the velocity of the delivered breath to allow more time for oxygen absorption. Initially it seemed to work, and for a moment I thought that Brian just might be okay.

Then the unit secretary opened the door and stuck her head into the room.

“Dr. Stone’s on nine-oh.”

“Thanks,” Dr. Peabody said.

He walked out of the room, and I followed. Peabody picked up the phone and updated Dr. Stone on what was happening. I didn’t listen in on the actual conversation, but had an idea of what was being said.

Peabody hung up.

I said, “Well?”

“He wants an ABG and a stat chest X-Ray. He also suggested that Brian be suctioned out real well.”

“Okay,” I said with a nod.

I followed Dr. Peabody into Brian’s room and stood off to the side with my arms folded across my chest. Once again his saturation began to bottom out, and I stared at his monitor, frustrated that his oxygenation wouldn’t stabilize.

“Has he been recently suctioned?” Dr. Peabody asked. I could see by the look on his face that any and every possible solution ran through his head.

“Yes, we did do that,” Deanna answered.

“It wouldn’t hurt to try again,” I offered. “I mean he has cystic fibrosis, and his lungs will just keep filling and keep filling with that crap.”

No sooner had I said this that it all happened: the ominous *ding ding ding* of a major cardiac event sounded from the monitor. Our eyes all shot to the monitor where we saw that Brian’s blood pressure had begun to fall. I felt something – panic, fear, I’m not sure which; perhaps it was both – shoot through my body like a jolt of electricity. The last time I had felt that sensation was when Nancy Sepp had called my name, and I had glanced over to see buckets of blood coming from Brian’s mouth.

“*Oh, Jesus,*” I said. “Not now, Brian . . . Please God, not now!”

I rushed to the side of his bed opposite the ventilator, grabbed the Ambu and began to bag him. At this point most of the MICU nursing staff had filtered into the room and stood by to assist in any way needed.

“*I can’t ventilate him,*” I said as I fought against the stiffness of the bag. “He needs to be suctioned.”

The ET tube, which was normally transparent, had become an opaque greenish-yellow, and I knew that it was because of an explosion of secretions in his lungs.

“I’ll help,” said Mickey, one of the other nurses.

She came around to my side of the bed and set up the suction equipment. I disconnected the bag from Brian’s tube, and a stream of thick sputum cascaded from the ET tube like a fountain. It was almost as if his lungs liquefied.

“Oh, God,” Mickey said.

She advanced the catheter, applied the suction and pulled back, but the effort made no difference; the mucus kept coming, and it kept coming. I glanced up at the monitor as Mickey went down again with the catheter. Brian’s blood pressure continued to fall, and now his heart rate began to come down as well. I reconnected the Ambu bag and squeezed oxygen into his lungs, hard and fast.

“You have to give him dopamine,” I said to Deanna. Dopamine is a drug that raises blood pressure.

“He’s a DNR,” she replied. “I can’t do that.”

I let out a frustrated sigh. “Well, we have to do *something!*”

Deanna hesitated, but then said, “I’m sorry. I can’t.”

I looked up at the monitor again. His heart rate was now in the forties, and I could see where this was going. I began to feel the pressure forming in the bowels of my gut, in the back of my eyes.

“Go get his family,” Dr. Peabody said.

A minute later Lois rushed into the room with Maegan, her boyfriend, Brian’s aunt, and grandmother. Lois went right to the side of the bed as I continued to bag Brian.

“Just let me hold him,” she said.

The nurses on her side of the bed moved from her way, and Lois took Brian into her arms and stroked his hair. Maegan held his hand.

His heart rate continued to fall, now in multiples of fives.

“It’s okay, Brian,” Lois said. “You’ve fought the good fight, but it’s time to let go now.”

I, on the other hand, was not ready to let go, and in contrast to Lois I cranked on the Ambu bag and kept saying, “Come on, man, you can do this. Hold on, Brian, hold on!”

The heart rate, blood pressure, and saturation readings were gone now, replaced by zeros; a smooth flat line had replaced the spidery peaks of his normal EKG rhythm, and I felt the sorrow hit me like punch in the stomach. Despite all this, I continued to bag him, thinking that somehow it wasn’t actually happening . . .

. . . And then just like that, Brian was gone.

Tears flooded my eyes and rolled down my cheeks. I tried to hold it back, but this time was unsuccessful, and still I continued to ventilate him. Mickey carefully took the Ambu bag from my hands, and that was when I started to *really* fall apart.

At first it came in coughs and sputters, but there was no point in trying to hold it back any longer. I put my head down against the railing of his bed to cover my face and let it all come out.

The family was in tears as well, and also Deanna, who didn't know him, but had taken care of him for the entire shift. But Brian had that effect on people; those with whom he came in contact instantly became attached.

I pushed myself off his bed and stormed out of the room, but it was a reflexive action; I had no idea what to do or where to go and felt lost in the misery of what just transpired. I rushed into the medication room, and that's where it really came out. I cried like I hadn't at any time in my adult life.

After I'd brought myself under control, I walked out of the room and circled around through the Cardiac Intensive Care Unit next door to the MICU, and then it hit me again. I leaned up against the wall and just let the tears go.

Karin, one of the CICU nurses noticed me and came over.

"Joe, what's wrong?"

I glanced at her, wiped off my eyes.

"Brian just died," I answered through my tears.

The concern washed over her face. "Oh no. Was that the boy with cystic fibrosis?"

I nodded.

"Oh, God. I'm so sorry. Are you going to be okay?"

I nodded again, then started to cry once more. Karin put an arm around me and patted my back.

"Why don't you get some coffee and take a load off," she said.

Karin recently left Lutheran General to work at the University of Chicago Hospital. I'll probably never see her again, but I'll never forget her for the compassion she showed me that night.

I made my way back to the Respiratory Department with little place else to go. Jim Rock sat at the report table charting when I walked in. He was the only person there but said nothing upon my arrival. Later Rock told me that he could tell I was upset and assumed that something had happened to Brian. He thought it better to leave me alone.

I sat at the report table for a few minutes with my head down, hair clutched in my fingers, and let the events of that past half hour sink in. Then my sorrow became replaced by anger: anger at the person who I thought neglected him the day before; anger at the disease, cystic fibrosis, for making Brian's life and death what it was; anger mostly at myself for not being there when he really needed me and not being able to save him when I was there.

I glanced down at the handheld charting computer that lay on the table. Suddenly this small, inert electronic device became a symbol of the hospital and this age of technology that despite all its *wonderful* achievements was unable to keep a twenty-two year old young man alive long enough to have the surgery that might've given him a second chance.

I stood from the table and yelled "*Goddamn it!*" as I hurled the handheld across the room.

The small computer slammed against the opposite wall and fell to the floor, fortunately in one piece or I'd still be paying for it today.

Menchie walked into the department soon after. As she passed the report table, I grabbed her by the arm.

"Brian died."

She stared at me for a moment with a stunned expression.

“You’re joking.”

“Do I look like I’m joking?”

She turned and raced out of the department, up to MICU, I assumed. I opened a drawer in the report table, located the staff telephone list, and found Bruce’s number; I knew he’d want to know what had happened.

I dialed the number. It didn’t take long for someone to pick up the line.

“Hello?”

“Hey, Bruce. It’s Joe.”

“Hi. What’s going on?”

I took a deep breath and hesitated before speaking.

“Brian just died tonight – I thought you’d want to know.” There was an audible vibration in my voice despite the effort I put into maintaining composure.

There was a moment of dead air on the phone before Bruce replied.

“Shit . . . How are you doing? Okay?”

I took another deep breath and could hear that same vibration when I inhaled.

“Yeah, I think so.”

“Sure?”

I closed my eyes. “Yeah.”

“Why don’t you go home, have a stiff drink, and relax.”

“Doesn’t sound like a bad idea at all.”

“Okay, Joe. Thanks for calling.”

I hung up, then went back up to the MICU. By this point most everyone from the respiratory department had heard about what had happened. Some of them stood outside the room when I walked through the MICU doors.

I entered the room, and Lois came up and threw her arms around me.

“Thank you for everything you did.”

The tears started to flow again, and I hugged her back as hard as she did me.

“I’m sorry it wasn’t enough.”

We stood and embraced each other for what seemed an eternity. Rob came into the room and said his goodbye to Brian. Menchie and another therapist, named Ingrid, were there too.

I never went back to look at Brian; I don’t know if I feel good or bad or indifferent about that. I suppose I can think that the body that lay on the bed in MICU Room Ten wasn’t really him anymore but only the corporeal shell that Brian Conklin occupied for twenty-two years.

It really hit me when I went back down to the department and saw that his name had already been removed from the ventilator board. I walked back to the cleaning room and went about the grim task of cleaning his ventilator (Rob had removed it from the room and brought it downstairs) and setting up for the next patient.

Recently one of our ventilators disappeared from the hospital without a trace – ventilator #15. Just today before I wrote this segment I went back into the medical records in our department and discovered that ventilator #15 was the once used on Brian. Coincidence, or just bizarre fact? I don’t know, but I like to think of it as poetic justice.

On my way home I listened to the radio in my car and heard my favorite rock song: *Over The Hills And Far Away* by Led Zeppelin. And as Jimmy Page’s acoustic

guitar began, I had to pull over and get a hold of myself once again. It reminded me that Brian was no longer here, and that body lying in the bed up in MICU wasn't him anymore. Brian had gone over the hills and far away leaving our world behind.

I was mercifully off from work the next day, but I met a group of therapists at a local bar called *Chasers* around midnight where those of us who were close to Brian wanted to give him our own send off. I walked in and found Bruce, Menchie, Rob, another therapist named George, and Jim Rock. All of us had taken care of Brian at one point or another and felt the powerful blow of his early death.

When I walked in, I bought the first in what would become many bottles of beer, then ordered a round of shots for everyone else.

After the glasses had been passed around, I slammed back my beer, then raised my shot glass and called everyone's attention.

"Hey, everyone . . . here's to Brian."

### Closing Thoughts

Two years have passed since Brian Conklin's death at the time this memoir is written, and I'm still left with feelings of sorrow and failure; I think about Brian everyday. People say that some good always comes from tragedy; it was hard to find any from my perspective for a long time. But I think that the saying that *time heals all wounds* is ultimately true. I can finally think back to Brian and remember times that bring smiles to my face, rather than dwelling so much on that last night. Writing this has stirred a lot of old feelings. People can be gone in the wink of an eye, and all you're left with are memories and regrets. Perhaps that's why I decided to write this piece, to find a way to hold onto something that I no longer have.

If any good came from his death, I think it's that I've been given a strong drive to do all I can for those afflicted with CF; some might say that it's to the point of obsession. I also think that his death has brought a lot of people together, who otherwise weren't. Lastly, my philosophy of keeping the line of professional distance has changed, and now I associate socially with some of my CF patients to the point that I no longer think of them as patients, but as friends. Probably my biggest regret is all the times I missed with Brian and will never again be able to have.

But now I refuse to limit myself to some ideals of distant professionalism. There's more to caring for CF patients than giving them a neb and clapping on their backs; a chimpanzee could be trained to do that. I think that many patients enjoy the social interaction, someone with whom to speak, or just the knowledge that the person taking care of them isn't just collecting a paycheck.

In the time since Brian left us, I've developed a valued friendship with Doug Caliendo, and I have begun to see Ken Seil socially as well. There are others too; I maintain e-mail correspondence with Brian's sister, Maegan, and two other CF patients who I've treated: Jennifer Manzi, and Jennie Sutton.

There've been other losses in the past two years. About a year after Brian's death, I was involved in a similar situation with a twenty-eight year old CF patient, named Rosa DiFranco, and a few months ago, in November of 2000, Doug and I sat by the bedside of Steve Shapiro until his final breath. I'm sure I'll walk the path again, for my mission and obligation to Brian's memory is far from over.

A memorial service was held for Brian three days after his death on an ironically sunny Thursday afternoon. Doug, Ken, and Fred Conklin all gave moving eulogies to a church filled beyond capacity. After the service, a luncheon was held where friends and family shared their memories of Brian. I had to work that day and was unable to stay for the luncheon, but I felt fortunate to have been able to attend the service.

Fred mentioned Brian's love for golf and shared with us a saying that Brian apparently used – *see you on the nineteenth hole*. I don't know if he ever knew that I took care of him those last three days; I don't know if he knew how much I cared for him. I can only hope that he did. Watching Brian's departure from this world was the hardest thing I've ever had to endure, but at the same time I'm glad I was there. When the time comes for me to putt my last shot, I have faith that I'll meet Brian again, standing on the green and holding the flag of the eighteenth hole.

Some people have questioned my attitude toward CF patients. I can't explain why I need to get so involved, other than it's something that I *have* to do. It's not something I've thought about; it's something I feel. Maybe it's because of Brian, but I think that everyone is put on the earth for a purpose; perhaps this is mine.

Of course, it's difficult when someone whom I've grown fond of becomes so ill and finally passes away. But it's even more difficult for those who have to go through it; and there must be comfort in the knowledge that, when their time comes, they don't have to go through it alone or with strangers. The pain of loss never goes away. It may soften as the years go by, but I'll carry my feelings for Brian, Rosa, and now Steve to my own grave. But I know that one day I'll see them all again – there's always the nineteenth hole.

*Dedicated with admiration to the memory of Brian Conklin, Rosa DiFranco, Gary Gernenz, Rob Vernon, Steve Shapiro, Phillip Bohac, Bob Hoekstra, Patti Melgozza, Tangela Swan, Monique Garcia, Christina Schrieber, Richard Bottfield . . . and, of course, Rita Jillich.*

January 29, 2001 – J. R. Hereth