

# When Disability Strikes

*By Renée Bondi*

As I rolled into the ballroom at the Hyatt Regency Hotel in Irvine, California, I couldn't escape the irony. In that very room, 11 years earlier, I had danced the last dance of my life with my fiancé, Mike. I was the happiest woman on earth that night. There was no way I could have imagined that within 36 hours my life would be turned upside down—never to be the same again. Waiting for my name to be announced to accept the Goodwill Industries Walter Knott Service Award for Overcoming Disabilities, I looked around and reflected on how different my life was now from my dreams on that night so long ago.

Sometimes our lives take turns we wouldn't choose. Mine certainly did.

Years before, the ballroom had been decorated for the San Clemente High School Prom. I was a 29-year-old choir teacher. Our vocal music program had grown from only 18 students during my first year to 150 students just a few years later. I had always been passionate about the arts and was blessed to be able to merge my passion with my career. And I was about to marry my best friend—the love of my life. The wedding was just two months away.

That Saturday, May 15, 1988, Mike flew into town for business and to be my date for the prom. Mike was living in Denver, working for Lockheed Martin. We were prom chaperones and I was as excited as the high school girls. Since I hadn't seen Mike in four weeks, I'd looked forward to the evening. We went to dinner at the Velvet Turtle, one of our favorite restaurants. During the entrée, he looked at me mischievously, reached in his pocket and handed me my engagement ring! Mike slipped it on my finger, and it fit perfectly.

When we weren't busy with our chaperoning duties, Mike and I danced in each other's arms. Dancing was almost as important to me as singing. It was a storybook, romantic evening. But we never danced together again.

## Great Was the Fall

The next morning, Mike flew to Denver. I went to pick up my bridesmaids' dresses and gifts. The spring musical was that afternoon, and I conducted the orchestra for a packed auditorium. The performance was wonderful, the audience enthusiastic, and the actors and musicians proud. It was a banner day. I didn't make it home to the condominium I shared with a roommate, Dorothy, and her daughter, until around 7 p.m. After dinner, I wrote some lesson plans and went to bed about 11 p.m. I woke up out of a deep sleep, in mid-air thinking, *Huh?* Then I finished a flip off of my bed and landed on the top of my head. BOOM! My feet were in the closet and my head was against the dust ruffle.

Still half asleep, it didn't occur to me to wonder why I had dived off the end of my bed or if I was really hurt. My only thought was to get back in bed. Rolling over onto my left shoulder, the right side of my neck

went CRACK! *Oh, man!* A pain jolted me back down. I rolled onto my right shoulder, and the left side of my neck went CRACK! *Oh, man!* Again, the excruciating pain threw me back down. I realized I needed help getting up. My roommate's bedroom was upstairs, so I knew I'd have to be loud to wake her up. Taking a deep breath, I tried to yell, "D o r o t h y!" But it was only a whisper. *Come on,* I thought. *You're a singer; you teach breathing!* So I took a breath from way down deep and tried again: "Dorothy!" There was no improvement.

About the same time I was falling, Dorothy woke up—DING! She sat up in bed with a jolt for some unknown reason. She thought she'd heard a voice. Getting out of bed, she walked to the stairs to see if I was on the phone. I heard Dorothy's voice calling, "Renée," and her footsteps on the stairs, then her hand on the doorknob. When she opened the door, I breathed a sigh of relief. Seeing me flat on my back, she asked, "Why are you lying on the floor? It's 2 o'clock in the morning!"

"I don't know," I responded in a whisper. "My neck is killing me. I don't know what I did. I can't get up. Go call the paramedics."

Dorothy stared at me for a moment and then picked up the phone to call 9-1-1. All of a sudden, the strangest sensation came over my body. The only way to describe it would be as a wave, maybe a wave of silence. Starting at my neck, I felt WHOOOOOOSH as a wave slowly rippled from my neck...WHOOOOOSH... down to my toes. *What on earth was that?* I thought. *I can't be paralyzed! All I did was go to bed! No way!* Although the thought did cross my mind, I couldn't imagine I was actually paralyzed. Looking back, however, I now firmly believe that the undulating wave was the onset of paralysis because I never moved again.

To this day, we don't know what caused me to dive off the end of my bed in the middle of the night. Perhaps I dreamt that I was diving into a pool. Another idea came from a woman who heard me tell my story during a concert in Wisconsin a few years back. She said a similar thing happened to her friend and the cause was traced back to methyl methacrylate, a chemical used to apply acrylic fingernails in the 1980s. In some cases, the chemical went through the cuticle into the bloodstream causing hallucinations or seizures. The week before my injury I had acrylic nails put on for the first time. Unfortunately, I met this woman 15 years after my injury and by that time the chemical was no longer in my system. In my heart of hearts, I believe that chemical is what caused my paralysis.

## Initial Denial

After Dr. Palmer, the neurosurgeon, delivered the revolting news that I would never walk again, he said, "I'll let your family come in now." He left and I was alone for a few minutes, trying to process what he'd said. Simply put, I didn't believe him. I was in total denial. It was as though there was a fog hovering over me and everything seemed inconceivable, impossible. How could I have been dancing with Mike just two nights before and now be permanently paralyzed? It just didn't make sense.

Mom and Dad came to see me first. When I saw the depth of sadness and seriousness on their faces, it was apparent that they did believe Dr. Palmer. They couldn't muster the effort to cheer me up or assure me that everything would be okay. Mom touched me and asked how I felt. It was really awkward. My sisters and brother had the same expression—one of disaster. Mike's father called him and he immediately flew home. When he entered the ICU, he walked over, put his cheek against mine and said, "Hi, honey. I'm here." I looked up into his broad smile. I tried to smile and whispered, "Well, I guess the good news is that now we'll get the really good parking places." Mike laughed out loud! Later, he said that in that moment he knew we'd be okay because although my body was broken, my personality and sense of humor were still intact.

After spending almost two weeks completely prone, it was time for the cardiac chair. A nurse and a physical therapist would transfer me to the cardiac chair, positioned flat, like a gurney. I felt like a Raggedy Ann doll, flopping to the left and right, or forward in the blink of an eye. They had to strap me on at the chest, waist, and legs, so I wouldn't fall off. I hated to be moved because any jostling triggered the pain in my neck all over again.

They would crank up my back to about a 45-degree angle, and then we'd sit and wait to see if my blood pressure would adjust to the new position. If that worked, they'd lower my feet and legs to 45 degrees, and, again, sit and wait. When my head was elevated and my feet were lowered, the blood tended to pool in my legs because my body was not strong enough to pump it back up. When that happened, I would either throw up or pass out, so at the first hint of discomfort, they'd take me back to the prone position and start all over again. It was incredibly discouraging to realize how difficult it was just to sit up, something people do without even thinking.

## Getting to Work

I spent five months at Long Beach Memorial Hospital for inpatient physical therapy. A typical day started with breakfast at 8:00, followed by getting dressed and in my wheelchair by 9:00, no easy feat. I'd roll down the hallway to the physical therapy gym. Considering the shape I was in, I really needed someone to make me laugh, and my physical therapist did! But she also made me work. In one exercise, she would place my feet squarely on the floor and then hold me up in a seated position. Next, she would put my arms behind me and prop me up like a picture frame so that I would learn to balance while sitting up. It was weird trying to sit on my bottom when it felt numb, and prop up on my arms when they felt like they were asleep. I also had to learn to find the center for my head. The head is heavy, and if my head was off to one side I'd topple over. The only place on my torso where I had movement was my shoulders, so I did thousands and thousands of shoulder shrugs with my physical therapist applying resistance.

Then I'd move on to occupational therapy. There was a contraption that came up over my head and had strings that came down and attached to troughs on both sides. They put my arms in the troughs, trying to train my shoulder muscles to direct my arms. I would do my shoulder shrugs to get my arms to move, but my appendages flailed out of control. The occupational therapist would attach a writing brace to my wrist, insert a pen, and place a piece of paper before me. "Now, Renée, just see if you can mark anything—a line or scribble—just get the pen on the paper." It was one of my first reality checks. I had no control, not even a hint of muscle that would allow me to aim the pen or create enough pressure to even make a mark. Tears spilled out of my eyes. "I can't even write; I can't even sign my name!" But after a few minutes of sorrow, I'd shake it off and tell my therapist, "Okay let's keep going. Let's just keep going."

Physical and occupational therapies were my lifelines. I did therapy five days a week and had weekends off. I hated the weekends because I felt like we were wasting time. The weekends actually scared me because I wasn't making progress. I wanted to work seven days a week, because each day I worked meant I was a day closer to walking, to returning to normal life again. At the time, I had a female roommate who would refuse her therapy sometimes. I couldn't understand. After all, lying in bed would not make you better. I came to realize that she couldn't imagine living a life so dramatically different, and more difficult. For her, the mountain seemed too steep to climb. In the first year, the steps forward seem so very, very small that the patient feels they can't make it to the top. So why try?

I remember a friend coming to visit me in the hospital at the end of the day. I was out in the hospital patio getting fresh air after therapy. When she saw me outside, sitting up, she exclaimed, "Wow! How great that you are out here!" All I could think was, "Big deal, so I made it outside. Whoop-dee-doo!" I never got as excited over the baby steps as my family and friends did. They were just that, baby steps, and I was no baby. Later, I realized the importance of those small accomplishments, but at the time they seemed insignificant.

## Who Am I?

The other huge concern was my sense of identity. I would think to myself: *Who am I now? I knew who I was when I was running around, but now?* One day I was being taken from therapy back to my room

and I saw a mirror. “Stop!” I said to the orderly. “Can you turn me so I can look at myself?” It was the first time I had seen myself in a mirror since the accident. I had the halo on. The metal hardware surrounded my head and chest to keep my neck perfectly still in order for it to heal. I looked into the mirror and made faces. *Those are my eyes. That’s my nose. I’ve lost weight; I like it, looks good. Ooohh, but my hair. I hate the way they’ve combed it back with no bangs. So this is what my visitors see when they come; they have to look through all this hardware.* I smiled at myself in the mirror, studied me, analyzed myself. *Okay, it’s still me.* Then I said to the orderly, “Okay, I’m ready. Let’s go.” It’s funny; sometimes it’s good to stop and take stock and consider not just what has changed but also what has remained stable. Whenever life seems to be falling in around us, it can be reassuring to realize that never is *everything* lost.

## Release to Prison

The day I left the hospital was one of the saddest days of our lives. Mike and I had both thought, had expected, had hoped, that I’d walk out of Long Beach Memorial. Instead, I rolled out in my sip-n-puff wheelchair. No more denial. This was it. I knew that, outside of a miracle, I’d never walk again. I realized I would always be dependent on someone else to take care of my needs. I’d never drive a car, or ride a horse, or sing, or teach again. With Mike’s hand on my shoulder, I cried all the way home.

Fear. Were we really ready for this? Could we really pull this off? The hospital had been safe. Not fun, but safe. I knew what the schedule was each day, and I had trained professionals taking care of my needs. It was their business to anticipate problems and to prevent them. If there was an emergency, I knew that within seconds I’d be surrounded by hospital personnel who knew just what to do. Plus, in the hospital, I didn’t have to face the “normal” world. During that first year, I could not be left alone. I had to be physically put to bed and taken out of bed. I had to be bathed and dressed. My teeth had to be brushed and my hair combed. Someone had to prepare my food and help me eat. If I needed something, someone had to bring it to me. I couldn’t go anywhere unless I was driven, and I had physical therapy three times a week. It was like taking care of a 30-year-old baby! It was an enormous, time-consuming obligation. While my family wanted to be there for me, they had lives, families, and jobs of their own.

## Now What?

Places where I had walked and run, I now had to roll, and as I rolled by, people naturally looked my way. I felt like I was on display. I was an oddity—no longer part of the normal landscape. Some well-meaning observers would give me the oh-you-poor-thing look, which I hated. However, most adults would generally glance and then look away. Children didn’t. They were openly intrigued by the woman in the ugly contraption and wondered how it worked. I wasn’t comfortable with myself, but I tried to make others as comfortable as I could by answering their questions and demonstrating my sip-n-puff.

As a result, I ended up spending most of my time in our condo. Occasionally, we would go out to eat or to the mall. On these trips I felt very self-conscious, so I’d keep my eyes straight ahead. I didn’t want to see the looks and stares as I went by. I loved it when my sister brought Brent, her darling three-year-old son. I’d always want him to ride on my lap. I felt like his body concealed mine, and he was so cute that people looked at him and not me.

New emotions became part of my personality. For example, one Saturday, not long after I’d gotten home, Mike took me out for a spin in his little red Acura Legend. “Mike,” I said. “I haven’t had ice cream in forever. Could we stop at Baskin Robbins?”

“Sure!” So he whipped into the parking lot in front of 31 Flavors. Obviously, it wasn’t worth the trouble to transfer me into the chair just for a quick trip into the ice cream shop. “I’ll be right back,” he said, and disappeared.

This was the first time since the accident that I had been left alone in the car in a public place. Suddenly my imagination went berserk. Realizing how absolutely defenseless I was, I began to imagine all sorts of assaults directed at me. *What if some man tries to open my car door and kidnap me or molest me? Or, what if someone jumps in the car and starts to drive away with me in it? What if someone just reaches in and yanks me out onto the pavement and steals the car?* Every person who walked by became a potential attacker. Like a whirlwind, a sudden awareness of my complete vulnerability gripped me and sent me reeling into a state of pure, out-of-control panic. By the time Mike returned, I was shaking and my eyes were full of fear. His tight embrace and words of comfort calmed my heart, making me feel safe once again.

## Effects of Dependency

By far the most difficult part of being quadriplegic is the dependence on others for daily activities. If I had any denial regarding my paralysis, receiving help from a caregiver for my most basic needs— like bathing, dressing and eating—forced me to face reality. This triggered several emotions:

**Overall sense of unworthiness**—I felt completely unworthy to be Mike’s wife. What could I do for him? How could I go grocery shopping and make him dinner? How could I give him children? How could I show him my love? How could I raise a child? Because I could not return his love in tangible form, I felt unworthy of his love. Not only did I feel this way toward Mike, but equally so with his parents and siblings. I knew that Mike had made the decision to stay with me, but I couldn’t imagine they were in agreement. I was scared for my future in-laws to see how difficult our life had become. Being a burden to them, my parents, siblings, neighbors and friends, I ultimately felt unworthy of anyone’s love. After all, if you are always the taker in the relationship and never the giver, you feel unworthy of their friendship.

**Embarrassment**—it was humiliating to have someone see me naked, sitting in a shower chair. One of my high school students became my weekend attendant. Imagine how embarrassing it was to have her see me naked and wash my private parts.

**Humiliation**—I no longer had control of my own body. One day I was sitting at my kitchen table with my goddaughter, Marne Andersen. I began to smell a strong, pungent odor. I tried to ignore it for a while, but it became too obvious to ignore. I discreetly moved my wheelchair around to see if I was having a bowel problem. Much to my horror, there was a small brown puddle under my chair. I had a bowel accident. No one was around but my teenage goddaughter. Humbly, I told her my situation and we cut our time short so that I could phone my sister for help.

**Frustration**—total dependence on others is draining. From trying to describe which blouse you’d like to wear, or which book you want from the 200 on the shelf, or what tax document you are looking for—finding just the right words to convey your thoughts can be extremely trying. Many times it looks as though the disabled person is frustrated that the caregiver or spouse cannot do the right thing, when in reality, they are irritated by their inability to explain their need. Another example is rolling out to the parking lot to find someone parked over the stripes, encroaching on the handicap stall. It becomes impossible to get in your vehicle, requiring the person in the wheelchair to wait, sometimes for hours, until the other driver returns. Also, prior to my accident, I never realized what a privilege it was to drive in the car alone. Time to think through the meeting you are about to attend, or what items you need at the market, or the words to say to an ill friend—I took it for granted. When one is dependent on others for transportation, it is difficult to say, “Please stop

talking so I can think about what is coming up.” Some people would suggest, “Just say it!” But in reality, it’s hard to do.

**Anger**—frustration can multiply a thousand times. A young disabled person can feel anger that they’re not able to participate in school or sporting activities like other children. He or she might be resentful that a sibling can go to the beach with a friend or ride their bike to the park. As an adult, I was very angry about the fact that I had to have my mother around to help me. After all, I was an adult. It was not my mother who made me angry, but rather what she symbolized. I didn’t want to still need my mother at 30, 40, or even 50 years old. When she came to help with dinner or laundry, I would get angry because her presence was a reminder of my dependence and the reality that I had not been able to experience the natural shift from child to adult. I tried hard not to show my anger. Sometimes I succeeded, and at other times I failed miserably.

## Financial Strain

Beyond the requisite attitude adjustments, the cost of paralysis is substantial and never ending. One is forced to wonder where the money will come from for attendant care. If the disabled person is a candidate for money from the state, he or she gets a different caregiver every day. It is extremely difficult to have someone new each day when it’s necessary to explain activities such as how to carefully transition from the bed to the wheelchair, or how you prefer your hair to look, or even where to find the trash bags.

More often than not, the disabled person is not eligible for state aid. For example, if one works even a part-time job, then they likely make too much money to qualify for state aid. A nagging question has been, “How am I going to pay to get out of bed?” My husband’s salary goes toward the mortgage, food, clothing and utilities. Where are we going to get an extra \$40,000 a year to pay for my attendant care? What if I was single and unable to work?

In my case, as God would have it, our pastor came to me soon after our wedding and offered me the job of Youth Choir Director at our church. I took the position, with the understanding that I would have volunteer parents to help pass out music, turn my pages and other simple tasks. The salary, however, was certainly not \$40,000! Working with the children and projecting my voice to the back row helped strengthen my singing voice. Four years after my injury, after a tremendous amount of prayer and the consistent use of my weakened singing voice, it had come back! Happy to hear I was singing again, a wonderful man from our church suggested I make a recording of songs that gave me strength and hope in the Lord. I never dreamt the recording would go beyond the walls of our church, but now, years later, thousands have been sold. Those profits pay for my attendant care! Part of my emotional healing has come from the fact that even though I cannot walk, my singing voice has been restored and I can help others through their difficult times. Lamentations 3:22–23 says, “*Because of the LORD’s great love we are not consumed, for his compassions never fail. They are new every morning; great is your faithfulness*” (NIV).

## Disability and God

So how does one become mentally healthy and whole again after having your world turned upside down? **Decide** what kind of person you want to be—positive or negative—seeking the good or dwelling on the bad. **Invite** people into your life to help—set aside your pride or your perfectionism and allow others to do things for you like driving you to appointments and helping in your home. **Volunteer** to help someone else going through a difficult time—this gets our focus off ourselves and gives us fulfillment from serving others. And, most importantly, **Enter** into communion with Christ—accepting the peace, grace and strength that come from surrendering all parts of our lives to him. Ironically, these four steps spell **DIVE**. When the

temptation to dive into depression looms; stop and remember to **Decide, Invite, Volunteer and Enter** into communion with our Lord, the great Comforter and Healer.

Unworthiness, embarrassment, humiliation, frustration, and anger are all painful emotions. But through my wheelchair I have learned that I must trust God for my provision and peace. After years of daily surrender, I am confident that He who began a good work in me, will be faithful to complete it (Philippians 1:6). Although I am not physically whole, the Lord will continue to use my disability, tears and all, to draw me close to him and to serve others.

### About the Author

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**Renée Bondi** is a popular speaker and recording artist. She has been featured in magazines such as *Today's Christian Woman* and *Woman's World* and on various radio and television shows, including *Hour of Power*, *The 700 Club*, and *Aspiring Women*. Renée has released six inspirational CDs and is the founder of Bondi Ministries. The Evangelical Christian Publishers Association nominated her book, *The Last Dance but Not the Last Song—My Story*, for the Gold Medallion Award. Among her many awards and honors is Woman of the Year from the California State Senate and recognition for Outstanding Service to the Community from the U.S. House of Representatives. Renée has a BA in Music Education.