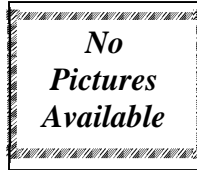


# Melodi Rayl



During my younger sister's birthday party, in February, 1952, I got a headache (I think) and (I know) a stiff neck. The family doctor of this tiny town, Richland, MO., thought it might be meningitis, so sent me to the nearest big town hospital, St. John's in Springfield. It was a long drive in snowy weather, with Dad, Mom, and my younger brother and sister all packed tight, with all the windows up, and me with a high temp. But no one else got sick. At the hospital I had a spinal tap and that when I was diagnosed with polio. The Baptist Church in Richland held a special prayer service for me, and it was during the time of the prayer service that my fever finally broke.

I was the first polio victim at St. John's Hospital, and they didn't really know what to do with me at first. I've been told that, when people got off the elevator on my floor, they could hear me screaming 3 halls down. The nurses first thought I was just being spoiled, but finally a doctor gathered them all and explained to them what was going on.

I had 2 types of polio, the spinal and the muscular, but my lungs were weakened. It was a good thing that I didn't have the lung type of polio (I can never remember the correct names), because I had been in the hospital for several months when they finally got their first iron lung! They were so proud of it, and they needed a picture of it with someone inside. So somewhere in my possession there's an old newspaper picture of me in the iron lung, with proud doctors, administrators, and nuns standing around.

My polio was strange... It hit my right shoulder and elbow, left side of my back, right hip, left knee, and more of my right foot than the other.

I had never been around any Catholics, and especially nuns. The head nun in my area was named Sister Gabriel. She seemed stern and fierce and I was terrified of her. But then I got to know her, found out how she really was, and ended up loving her very much. I remember vividly that she gave me, a little Baptist girl, a tiny gold figurine of Mary, in its own little leather pouch. And I remember one night, in a bad storm, seeing a group of nuns walking down the corridor, holding candles and singing... I became a Catholic in adulthood, and have often wondered how much of that could be attributed to my Sister Gabriel and the sisters at St. John's.

I kinda remember the exercises in the hot water that my therapist at the hospital, Ray Tril ica (if I'm spelling his name correctly), used to do. There are pictures of me in the big tub, with Ray pushing and pulling my legs and so on.

I had started first grade, but didn't get back to school for a few years, being tutored at home. I think I went back to school for 4<sup>th</sup> grade. I was in braces, a full leg brace on my left leg, and a brace up to my knee on my right leg. And I had a hated corset with steel staves that we put on

every day, pulling it tight. I hated when it, or the straps on my braces, pinched my skin. I HATED being up on crutches.

It was awkward, I was clumsy, and I felt like I had NO control of myself. The slightest slip of a crutch and I was down. I even took 'falling' lessons with my therapist, but, even though I was taught HOW to fall, I still hated being up and trying to walk. I had nightmares of a crutch tip getting on a drop of water and the crutch flying out from me. FINALLY, when I was around 11 years old or so, my doctor said, "You're never going to be a long distance runner. Let's get you used to a wheelchair."

I was SOOO relieved! Finally, I could get around without the stress of possibly falling. I could go fast and smoothly anywhere except up or down steps. But I was so light and skinny that no one had trouble getting me up or down anywhere.

Over the years I had steel Harrington rods put in my back, finally getting rid of the hated back brace. I had my right shoulder fused so that I could raise my arm! (But it's always really limited my movement in that arm - not that I'm complaining!) I had surgeries on both hips and one knee, to loosen the muscles.

By my teen years, we had moved a few different places, and I lost contact with any doctor who worked with polio patients.

I worked for the federal government as a Systems/ Programmer/Specialist/Analyst for 30 years, working in St. Louis, MO., and got an early retirement at age 53 when my agency was downsized. All of my adult life I'd been completely self-sufficient, living by myself, buying and driving a car (getting my manual wheelchair in and out by myself), traveling to Europe twice, etc. But the last few years I worked, I noticed my strength and stamina going down.

I thought it was because I wasn't exercising enough, but was so busy at work and at home that I didn't do much to combat it. Then my one and only good shoulder, the left one, the one that did everything for me, started getting weaker and weaker. Now I needed help transferring in and out of cars into my manual wheelchair. I used to be able to zoom in and out. Now it took me forever, and then I couldn't do it at all. It was like my shoulder just 'went out!' I had bought a scooter 15 years ago, and had been using it just at home or around the neighborhood, or taking it on a door-to-door bus for shopping, etc. Over the last few years, I have been using it full-time, using my manual chair only when I had to.

By this time I was retired and living back in my beloved Springfield. I went to my doctor about my shoulder, and she sent me to a specialist. The specialist was sure I had a rotator cuff problem and ordered an MRI. Nope. It was Post-Polio! I had known for some time that I must have SOME PPS - my right elbow had gotten so weak that I could barely raise it up from the mattress.

I had also told my primary physician that I seemed to have trouble catching my breath after getting in and out of cars, or doing anything that took physical effort. I was SOOO terrified that I had congestive heart trouble or something like that. She sent me to a lung specialist. That doctor ordered pulmonary tests. While there, the oxygen rate in my blood dropped down to 89 and then down to 85!!! The lung doctor sent me home hooked up to an oxygen tank. I was devastated. I was SO completely depressed! All I could think of was that I would forever be tied down to an oxygen tank! And the portable tank they had given me, in addition to the big tank, only lasted for 3 hours! I couldn't even go out to a movie and back in 3 hours!

The next day I was so groggy that I was slurring my speech. Thank God my aunt and brother, who both live here in Springfield, insisted on calling the doctor, and insisted that I be taken to the hospital to be checked out! I was diagnosed with Respiratory Failure to my total shock and surprise!!! By the way, I was back in St. John's Hospital!! (Unfortunately, you don't see the sisters in their habits all over like I did when I was young...)

For the first time, I learned that persons who have neuro-muscular breathing problems, like from polio, CAN'T just be put on oxygen!! I found out that I had been getting the oxygen OK, but my lungs weren't getting rid of the carbon dioxide! The build-up of CO<sub>2</sub> caused the respiratory failure. So I was put on a ventilator with the oxygen. Over a period of 5 days, I was weaned off the ventilator/oxygen full-time, using it only at night or when sleeping. I was sent home with a Bipap and an oxygen converter for resting/sleeping.

For the first time in years, I now was waking up RESTED. I was sleeping through the whole night. Earlier, I would wake up with my heart pounding and me breathing hard. I had thought I had sleep apnea. But all this went away once I was on the Bipap and oxygen. I wake up now and my lungs and diaphragm feel so good...

I know now that I have to really pace myself. I know I should rest every day. I know that if I don't, I'll regret it. But I'm grateful for one big thing - I don't have the constant pain that so many, if not most, of the PPS'ers seem to have. My left shoulder will really ache if I overdo it. But I take a couple of Advil and rest for a few days - then I'm fine. Nothing else bothers me, except for an occasionally muscle in my back or hips.

I did pick up a brace for my left foot last week. I have enough muscle in my right knee to be able to press my right foot down firmly on my scooter platform. But due to the lack of muscle in my left knee, my left foot does what it wants to do. And it doesn't, and hasn't wanted to for years and years, want to stay flat on the floor. It's turned so much that, if I had to put any weight on it at all, I was like 'standing' on the outside of my foot. So I asked my primary doctor about a brace of some kind. She sent me to a specialist, who sent me to an orthotics place.

The guy there examined me, we talked, and he took a casting of my foot and calf, holding it in place while it quickly dried. The brace is wonderful. It's a sturdy plastic, very lightweight, looking sort of like half a PVC pipe that goes behind my leg and under my foot. There are 3 wide Velcro straps that hold it in place. It feels GREAT to have my foot held in a decent position. And every day I can wear it longer and longer.

