

# My journey with pain

## Abstract

Pain is a very personal experience. Everyone has their own definitions, feelings, and memories associated with pain. Some pain is greater than others. Some pain paralyzes you, and some pain motivates you. How someone chooses to define and cope with pain is molded by his/her experiences throughout a lifetime. Below is a story of one man's journey with pain throughout his life as a hemophiliac, a father of two daughters who are carriers, and a grandfather to a young child with severe hemophilia.

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## Opinion

If you're a hemophiliac, you know pain; and if you know pain, you've used pain meds. How you choose to use your pain meds is based on the severity of the moment. The one thing I've learned about hemophilia in my life is that it hurts, but it's also a motivator. It breeds intelligent thought processing and maturity developed early in life that gives you a head start over time. Now in my sixties I have an arsenal of stories that have caused me a great deal of pain in life. I'm here to tell you that the pain builds character and combined with a competitive and positive attitude along with a little curiosity, you can dream big and set lofty goals. Life with hemophilia can become an asset, as you become mentally tough from a young age. You learn to make it work for you. I DID.

Growing up in the fifties with hemophilia was spotty at best. Treatment went from whole blood transfusions in a hospital to factor treatment within the span of 30 years. The change in treatment process truly amazes me. Factor has truly changed how young patients are living and treating hemophilia today. Soon after college, I found a career in the apparel industry on the West Coast. The career was demanding and grueling as I had to travel to different department, chain, and specialty stores to showcase different fashion lines for which I was in charge. The hours were long and the physical demands were rough, as there days where I had to carry heavy garments and run around to 3-4 appointments in a day, with each appointment lasting 2-3hours. Despite the physical demands of being a commission salesman, it was a race to get the commission. I remember there was one instance where I experienced a severe elbow bleed, but I refused to take the day off. I knew if I took a day off, I would lose out on a potential sale. I vividly remember going to the emergency room to get my elbow drained and proceed to visit the ortho department to get an elbow cast, but then proceeded to continue on to the hustle and bustle. Pain was override by my drive to succeed.

When my career began to take off and I was married for several years to my wife, Lynette, I experienced a severe setback in my health. One day, our new home got caught on fire and I experienced burns on over 30% of my body. The pain management was difficult and was complicated by my hemophilia. Throughout the recovery period, I was fortunate to have my wife by my side. She motivated me to take better care of my health, and she became my main support. She dedicated her time to take me to my medical appointments and make sure I was responsible to my health. During this time, her

support was my motivator for pain management. After my recovery, we decided to have the conversation about starting a family. We met with my hematologist and left with the knowledge that if we have girls, there was a good likelihood that they would become carriers. Despite our concerns, our doctor reminded us of the advancements in hemophilia treatment, and reassured us that our children would have better lives. Lynette and I were blessed with two beautiful, talented, kind, respectful, and tenacious daughters. The decision to have children was the greatest decision that my wife and I had made, and I would not change it, even though they indeed became carriers. During the subsequent years, my wife and I focused on building a loving family and raising our daughters to the best of our abilities. There were many episodes of joint bleeds and internal bleeds, but the setbacks did not stop my drive to provide for my family, even with the development of inhibitors. When the inhibitors developed, it was a difficult period of my life. At that time, the treatment options for inhibitors were limited, and I was thrown back into the "dark ages" of treating bleeds with ice packs and ace bandages. R.I.C.E.—rest, ice, elevation, and compression—became my treatment motto. Inhibitor management was difficult despite having access to great care at my local Hemophilia Treatment Center. The inhibitor caused me to have multiple joint bleeds and severely impacted my existing arthritis. Pain treatment was difficult as I had to go through many different pain medications to ease the pain from the bleeds. At times, my pain was dictating where I would go and the type of activities I engaged in.

After years of pain treatment, which include a knee replacement, I can honestly say I have become an expert in talking about pain management. In recent years, I have had the luck to get access to Novo Seven, which has helped me with my treatment. I am truly impressed with the advancement of treatment options within my lifetime. Our community has learned a lot about treatment and pain management. The knowledge and skills that we pass on to our community's next generation is a testament to the how far we've come, to the successes we've achieved. When my grandson, Lawson, was born, my family and I had first-hand experience with the support our community openly gives. It was hard for everyone, especially me, when I learned that my beloved grandson has severe hemophilia. As my daughter and her husband became more involved in our community, our fears were calmed.

This community is so supportive, and so willing to share information and experiences, that our family is truly prepared to treat Lawson's severe hemophilia as he grows. With the arrival of Lawson,

I found myself learning with my daughter and son-in-law on the evolving treatment of hemophilia. It is my hope that my grandson will not have to experience the degree of pain I have had to face in my life. After all that is said and done, I've had a full and charmed life. I have been blessed with a loving family, loyal friends, and people I love and trust. With a little luck and God's willing, we just might put this hemophilia thing out of business.

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## Conflict of interest

The author declares no conflict of interest.