

My Story

MY PORTACATH STORY

By Alexandria Brown



Phlebotomy and I didn't quite get along. My veins would not cooperate when I needed to have blood drawn or to get IVs (intravenous medications) for clean-outs (CF exacerbations). Portacaths were something I had heard about for chemotherapy and some people with CF, but I didn't think it would ever be appropriate for me... at least not for a long, long time.

Well, I was wrong. It was something recommended to me, I learned more about it, I got one, and now I'm in love with it!

Nurses had consistently told me over the years that I was a "hard stick," and it was the norm for nurses to try two to three times before they got blood, and it often ended up coming from the back of my hand, wrist, or foot.

Peripheral IVs lasted only a few days, so PICC's (peripherally inserted central catheter) seemed to be an option. However, those were difficult to place in me even using ultrasound. So, I was referred to IR (Intervention Radiology) which worked OK, but even the pros in IR had to take a few tries to "get it right."

During one clean-out, it took two tries in IR to get a PICC, which lasted for the three weeks. However, fast forward in time a few months later and my left arm (the one where I had the PICC) had a "heavy" feeling and it was swollen. My pulmonologist ordered X-rays immediately, and after that an ultrasound of my arm. It was determined there may have been a blood clot. Apparently, it was due to my "bad veins" and the "toxicity" of the IV meds.

At that point, the doctor was saying my veins were just too bad to try any more PICCs, and a portacath would be my

best option. Of course I was surprised – despite my less than perfect veins, I didn't think I'd be a candidate for a port at only 19 years of age. I was nervous and I sarcastically thought, "Great just what I need." I already had scars on my stomach from meconium ileus surgery and G-tubes, and I was not thrilled about a bump on my chest. What would it be like? But, I have faith and trust in my doctor and I would deal with the consequences. I had to get a port.

In December 2007, I was scheduled for surgery. I was understandably nervous, but I was trying to think on the bright side – at least phlebotomy and IVs would be easier. So, I got ready for surgery and was wheeled into the operating room. When I woke up I had a very sore throat and my chest was obviously sore. In addition, I had difficulty breathing, but I figured that's how port surgery felt. Turns out, I was suffering from a complication of surgery – it was confirmed I had a pneumothorax (collapsed lung) and I had to get a chest tube. The chest tube procedure was by no means pleasant, but it sure did the job; my lung inflated within a day! I was home within a week.

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So – with all that being said, you may ask: how do I like my port? Was it worth it? YES, YES, YES. I love having my port. I cannot explain how much easier it has made things for me. Yes, there are the monthly needle pokes for heparin (blood thinner to avoid clots), but my home care company is fantastic and those needles are not bad at all. It has done wonderful things for me. Getting blood out of me is no problem and IVs are no longer a cause for concern and anxiety. Having a clean-out is the same as monthly heparin sticks except they leave the Huber needle in.

My port is barely noticeable. If people know about it, they may notice when I wear certain outfits. But otherwise, it's not really obvious. I still wear my tank tops, strapless dresses and bikinis (yup, even with the scars on my stomach).

It's a personal choice to get a port, but I absolutely love mine and it has done fantastic things for me. Now that I have it, I don't even want to think about what it was like before. My last hospitalization was so much easier that I feel the port has already "paid" for itself with that one clean-out. 😊