

Invisible condition...



During my first year of Uni, I found myself in the waiting room for my routine pacemaker follow-up. It was late afternoon, and the waiting area was nearly empty, with only an older man and me present. After observing me for some time, he approached and asked, "May I ask what such a young, pretty girl is doing in the cardiology department? Surely you do not belong here."

"I was born with a congenital heart defect and have a pacemaker", I replied.

I cannot recall his response, or if he even gave one, but this encounter remains vivid in my memory. Over a decade later, it still resonates with me. People often do not expect someone so young, someone who appears healthy in every way, to be living with a severe cardiovascular condition.

...that changes life

As a woman living with a congenital heart condition, one of my major concerns has always been the possibility of pregnancy. I always suspected that it could become an issue, but it was never actually discussed during routine check-ups. Even as I transitioned to adult care, the topic never came up during discussions with my cardiologist until I mentioned a relationship around the age of 22. Only then I was informed about the potential risks associated with pregnancy, although the details were not fully explained to me.

Several years went by and shortly after getting married, I experienced some health complications that led to a first proper discussion about the risks involved in pregnancy. Over the following months, both at home and in consultations with cardiologists, we carefully weighed the risks we were willing to take.

The discussion at our home was never ending, on one side me wanting to have a child, on the other side possible outcome could be heart failure even sudden death. How much risk was too much?

Eventually, the doctors advised against it, and my husband and I agreed to follow their guidance. Giving up on the idea of pregnancy was incredibly tough for me and

it took me a couple of years to come to terms with it. It would be several years from this moment until we became a family.

Today, as I write this, my adopted daughter is peacefully sleeping nearby, and our family is filled with happiness. However, I can't help but wonder if things might have been different had I been given detailed information earlier.

Based on my experience, I strongly believe that every young woman living with a cardiovascular disease should have access to comprehensive information about pregnancy and its associated risks as soon as possible. This information should be provided in a detailed manner, distinguishing between data-driven insights and clinical experience. I also hope to see improved collaboration between gynecologists and cardiologists, particularly in supporting women who may face pregnancy-related risks due to their heart condition, especially if they also need fertility treatment.

To all women going through similar experiences, I want to say this: Be courageous. Ask the difficult questions you need answers to and make decisions that are best for you and your future family.

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