

# MY BROTHER, MY BABY, MY BIG DECISION

BY DUNJA BATARILLO

Until three years ago, I thought I was brave. After all, I'm a girl who has trekked the Andes without a map. But there's one thing that scares the hell out of me: getting pregnant. ¶ It's late 2018 and I'm 38 years old. I have always wanted to start a family, and I've reached a stage in life when doing so would make sense. ¶ I've established a career and finally found the right man. We've been together for a year now; family and friends have begun watching closely to see if I'm still drinking alcohol. ¶ What they don't know is that fear has begun to consume my life. I'm plagued by a question that won't go away: *what if I give birth to a disabled child?*

Most of my friends don't think it's such a big deal: there are prenatal diagnostic tests, after all. In Germany, where I live, antenatal screening is offered to all women over 35. I have always resisted going down that route, on principle. Because my brother has Down's syndrome; because I want people like him to continue to be a part of our society. I had a great childhood, not despite my brother but together with him.

And yet the questions won't go away. If I get pregnant, what diagnostics would I opt for? And what would I do with the results? Just asking them feels like betrayal.

Fear begins to creep into my body. Before long, I develop frequent back pains and, after a few months, I have to stop working; I have two herniated discs. I try to convince the world, and myself, that it's not a big deal. I have an MRI and go through physical therapy and rehab, but nothing helps. I am appalled by my doctor's insinuation that the whole thing could be psychosomatic. I can't sit or lie down - the pain fades

only when I walk. I spend nights pacing through my neighbourhood, Berlin's hip Neukölln district, in tears, afraid that I'm losing my mind.

What's wrong with me? I start looking for answers. I join a group on Facebook where adult siblings of people with disabilities discuss their experiences. Tentatively, I type: "I want to have a child, but I am terrified that it might be disabled. And I despise myself for feeling this fear. Do you know what I'm talking about?" I hit "Enter" and close my eyes in shame.

By evening, several women have responded. One offers a definitive answer: having a child is out of the question for her; she feels that she has too many responsibilities already. Others voice concerns about potentially hereditary genetic defects they might pass on, fears of oxygen deprivation at birth and of relationships destroyed by a disability in the family. Reading the responses, I can't help but cry. But they are tears of relief. I can feel the pain behind the

words - and finally I can understand my own suffering. I'm not alone.

Around 2.3 million people in the UK have a brother or sister with a disability, according to the NGO Sibs. In Germany, the number is thought to be somewhere between 1 and 4 million. Exact figures are hard to come by here. Statistics on disabilities and birth defects are not centrally collected, and for good reason: under Aktion T4, the Nazis' euthanasia programme, an estimated 70,000 people with disabilities or other afflictions were murdered. Across Europe, the total number of victims was between 200,000 and 300,000 - people who, even today, have not received the same recognition as other victims of the Holocaust.

Just reading about this triggers a memory from my childhood. I'm four years old and walking down the street in front of our house, holding hands with my brother David, who is two years older than me. The farmer we buy milk from, a man of the war generation,