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Annie and her baby Elena

The right to be a mum

By **Disability Now** - 1 year 4 months ago

The prospect of having a baby used to feel wrong to Annie Makoff. She endured a difficult pregnancy and negative attitudes but it has been worth it.

I was adamant I didn't want children. So adamant, I started to believe it myself. I absorbed society's unspoken view that it was selfish for a disabled person to have children - without really believing it. But when it came to other disabled mums, I didn't see it as selfish at all.

But for myself, it just felt wrong. A young member of the public summed up society's attitude when he joked on Twitter after seeing myself and a friend on the game show *Pointless*: "disabled retard! I hope she never breeds!"

Hurtful comments don't stop broodiness, though. Years of intense yearning for a child soon put a stop to my self-denial. Biological instinct has a lot to answer for. So we waited, my partner and I, until we were in a good financial position, both established in our prospective careers.

But the process and the journey itself would be a world of unknowns. For 29 years I had lived with an undiagnosed disability which affects my limbs, my sight and my stature. No one could tell me if it was genetic and what the risks of passing it on to my child would be. Could I live with that?

With low expectations, my partner and I saw a genetic counsellor to carry out some tests, just in case they'd find an answer. And they did – in fact, my diagnosis was even in my childhood notes but no one had thought to inform me. The tests eventually confirmed it. I had Goltz Syndrome, a genetic disorder characterised by limb deformities and facial asymmetry. Not only did I have to come to terms with a new set of risks (50/50 chance of passing on my condition to my baby) but after all these years, my disability was no longer "unknown". It was a life-changing moment.

Being aware of the risks involved made my partner and I more determined to have a baby. What if I did pass on my 'bad' genes? Was I not the best person to show her how to survive - even thrive?

Not everyone had such a positive outlook. My family, who loved, nurtured and protected me had only their terrifying experience to call on. They had to feel their way in the dark, being in and out of hospital with me throughout my childhood, not knowing the medical decisions they

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had to make were the right ones. No wonder the idea of another disabled baby worried them. But for me it was different – yes, I'd no doubt experience guilt if my baby had Goltz, but it wouldn't be the end of the world. I had already carved out my own path in life, and my child, disabled or not, would find it easier to carve theirs.

It was not an easy pregnancy. I had a catalogue of conditions – hyperemesis gravidarum (vomiting up to 20 times a day for several months), Pelvic Girdle Pain, Sciatica, you name it I had it. By the end, I was using a wheelchair, having been hospitalised several times and hooked up to intravenous drips. Even the labour was traumatic.

We found out the sex at nine weeks thanks to a new NHS blood test available for women with an increased risk of miscarriage. If the foetus was male, he wouldn't survive if he had the Goltz mutation. Even so, being told we were having a girl was just one hurdle passed. Throughout it all was the underlying uncertainty of our child inheriting Goltz Syndrome. Every scan we had could be the one to show up Goltz characteristics. They never did – her limbs were all there.

Despite ongoing monitoring, we declined the routine test for Down's Syndrome. We were adamant that whatever our child's disability – unless it was life threatening – we would not terminate because every disabled child has a right to life.

Through scans, monitors and dopplers, we watched her grow, listened to her heart, felt her kick. I sang to her, read her stories, talked to her. I loved her, even then.

I have no doubt that had I been more active during pregnancy, I would have experienced several unsavoury reactions from people. But as it was, being housebound and unwell throughout most of it, protected me from unwanted comments.

There were a few memorable occasions of course, like the horrified "uh-oh!" from a delivery man, when I waddled to the door heavily pregnant. Did he think I was going to eat him?

And the TV interviewer from Al-Jazeera who asked me during a news item, why I was even having a baby, considering all the problems my disability caused. I was 36 weeks pregnant at the time – did I have to justify to him, a complete stranger, why it was my right to start a family?

Yes, it's been a struggle. And we're all still learning to adapt. But Elena, our beautiful, four-month-old daughter is thriving in a secure, loving and happy environment. I watch her sleep sometimes and the love I feel is so strong, so intense, it's like a punch.

Elena may one day face questions from her peers about her disabled mum, but so much the better. To hide ourselves away, to deny ourselves the opportunity to have families is to give in to a deep-rooted fear about difference.

In the end, I followed my instincts rather than my fear. And as I look at my beautiful daughter whilst I breastfeed her, cuddle her and play with her, I know it was the best decision I ever made.

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Agreed, Annie. Agreed, over and over!! My twins are nine now, and to their friends I'm their "cheery" mum, not their wheelie mum. That's proof enough for me.

"No, they don't miss out." "No, they're not my carers." "Yes, they inherited my condition (Ehlers-Danlos Syndrome)." "No, it doesn't stop them." "Yes, they 'cope', in fact they flourish." A few of my answers to the ignorant questions out there, along with a mental, "Do yours?"

Salute and hugs from a fellow parent. Your article is a celebration. :)

By [Muchadou](#) - 1 year 4 months ago | [Reply](#)

I have mobility issues and was also given a 50/50 chance of passing the problems on and am now in a wheelchair much of the time. I have two healthy girls (13 & 10 now) and neither have inherited the problem, thankfully. However, if I had listened to concerns, I wouldn't have had children at all, so sometimes you have to go with it. I also refused the downs test, for similar reasons and I was older than you, too. Fortunately, though, I haven't heard anybody criticising me about having children and would certainly have a few choice opinions to air in response if they did! I also haven't come across any real issues at school, other than being watched by

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the children at times. I guess some of that is down to the school. Good luck and enjoy the time with your lovely daughter.

By [beadygirl](#) - 1 year 3 months ago | [Reply](#)

I was born with c p ceareblposey when I went school I think they thought disable people shouldn't have children. And you never hear the word sex. When I reached the time me leaving the telling us about sex. When I was 22 year's old I had a son and I was on my own not married I was put with a family that help me. My son Mark was the best thing that happen to me. The. People was taking over and not letting me be the mother. L wished that was strong to tell them that I am the mother, not them. I use to not let people pick

By [Tanya Killerby](#) - 1 year 1 day ago | [Reply](#)

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