

This was originally published in the “paperweights” anthology, by Scope, in 2015.

It has been picked up on websites and blogs around the world and has been read over 50,000 times.

There is something wrong with your child.

By Susanne Crosby

There is something wrong with your child.

My instinctive reaction was: no there isn't.

I hold her red health record book up with pride, as a shield: look at her achievements, look at all the ticked boxes.

But what about her words? Yes, she says a few.

When was the last time you heard her say them?

Suddenly I feel hot. I don't know what my face is doing, I hope it isn't betraying me to these strangers, these prodders and pokers.

For a whole year they don't leave us alone. Speech, physio, Health visitors. Lots of them. Then on a day in February I get a phone call, at work, in my open plan office.

There is something wrong with your child.

A rare random genetic condition. It's very rare they say, with peaking profession interest; only 3 others in the city.

Bang.

I calmly pack up my desk, trying not to draw attention, as I am the senior manager. The images in my mind of my daughter are being slowly and deliberately torn up by cruel hands. This one: her and me after passing her exams, this one of the amazing art she's created, this one of her in her school play. Images I didn't even know were there come and taunt me before they are shredded with ruthlessness. Strangely traditional ones that I find embarrassing before realising that my heart is also breaking. Here, she is dancing at a disco. Graduating from University with a 2:1. I see my only child on her wedding day, happy and in love. I see her as a mum. I see all the love I've given her being passed on to a new generation. I have influenced the world, I will go on and be remembered. All that culture, from Wales and from Sweden: words, traditions, song and beauty. I see the family tree suddenly stop, end, be destroyed. The tree is burning and my anguished tears are not enough to put the fire out.

I am permitted to take the rest of the week off. A week where I sit in my dressing gown like a grey shadow of my former self. A couple of days later I was back, trying to 'keep calm and carry on', but my body refused. I became seriously ill, much to my annoyance. Why me? I've been nice and good, I've followed my faith which has now abandoned me, I made a wish to the universe for a child: I

wished solidly for 7 years for someone to love and cherish and play and laugh with. I ate the right things, saw the right doctors and practitioners, helped others, volunteered, gave back to the community, gave to charity, I am a good and loyal friend. Why am I being punished?

There is something wrong with my child.

I am no longer a real mum. We have one follow up appointment, then all the prodders and pokers, all the very many people, disappeared. They have managed to get me to accept this bomb they kept trying to give me, and now that I'm holding it, they are gone.

She will never walk. She will never talk. She cannot feed herself, clothe herself, have a bath by herself, brush her teeth or even brush her hair. She will always be in nappies.

There is something very wrong with my child.

We will never run in the park. She will never have sleep overs with friends. She will never go to her first night club.

She is 2. I feel like her life has ended, along with mine.

7 years on I have endured a year of house adaptations that wrecked the house several times over, with more to come. I have had 4 more years of sleepless nights, and 2 more bouts of becoming seriously ill.

And I have marvelled at the art she has created. I have watched her in her school play, I've seen her sing at the Brighton Centre, I've danced with her at her school disco in her wheelchair. We have been shopping for clothes. We have played chase games in her chair. She has been on an adventure holiday with school, sleeping over with her friends, and done zip wires and climbing walls. I have seen her swim. I have been learning how to empower her to make her own choices by using eye pointing. She can now express opinion on what she wears, what she eats, what toys she wants to play with. We may not have a future, but we have a now, and that's all any of us can really be certain of.

More than anything, she is happy.

Yes we face problems, every day. I had to give up that job. Her care needs are so random and the appointments with all the professionals so numerous I can no longer work 50 hours per week. My job no longer fitted my life. So now, money is tight, but my life is at last starting to fit me. My daughter has helped me connect to my heart.

Yes, I am a pushy mum, a real mum, fighting for access into buildings, having an aching back from lifting all the time and big strong unfeminine arms. Sometimes going out is too difficult as there is very rarely anywhere to change a nappy for a young lady who doesn't stand and is too big for baby changers. Going out anywhere, let alone holidays, takes very careful planning of absolutely everything.

But it's not her fault.

It's not some thing that is 'wrong' with her. Every child is different, everyone is different. We all have different abilities and different needs. Not 'wrong'. It's the world that disables her: she is disabled by it. She communicates, she is honest and open, she is generous, patient, caring and very giving.

16 years ago I wished for a child. I prayed to the Universe, and spirit answered me. Not with what I thought I wanted, but with exactly what I need. My daughter is my angel.

It's taken me all this time to discover that my instincts, all those years ago, were spot on.

There is nothing, nothing, wrong with my child.