

Holding on to the Ordinary

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Ten years ago or thereabouts, before I had barely a moment to welcome my new son, the precious moment of his arrival into the world was clouded in dread and whispers. With the sun barely risen on his first day, this enchanting boy was wrapped in fear, examined by strangers and handed back to me with words that made my heart tighten in alarm. I can remember wondering whether life would ever feel normal again. In fact it took me quite some time in my ignorance and confusion to realise that the world still turned, the sun had indeed continued to rise in the mornings, that I loved this little boy and he loved me back.

When Jack's two older sisters were born there was no need to give a thought to how their lives would unfold. It went without saying that they would be welcomed joyfully into our family, teach us a thing or two about being parents, play, fight and grow together, go to kindergarten and then to the school down the street. They would make a few friends, learn something useful for and about life, and hopefully be happy – well at least some of the time! So what did I think would be different for Jack? Why would I doubt that the trappings of their life would look different for my new son? Why wouldn't he have an ordinary life, just like everyone else?

I suppose from that first moment, the wheel had started to turn and I did not have to be a super-mum to sense the danger. Those early months of my new baby's life seem so obscured by the words 'Down syndrome'. They had a life of their own and not content with that, threatened to take over our lives as well. I thought back then that I did not know much about my new son, so I listened to what others knew of him. I doubted him, I doubted myself and I certainly doubted the possibility of an ordinary life.

Miraculously, in the midst of the storm that raged in my head, there was a centre of stillness in Jack, this delightful little boy who was my son. In spite of everything, there was the same wonder that a new baby brings and the same relentless demands.

It was in the world of the ordinary: the feeding; the nappies; the holding; and the play; that Jack himself, by the very nature of his being, steadily challenged the thoughts that raced around my mind. He was a little baby, my son. No more, no less. With that understanding, came a promise of who he was rather than what others had projected he might be.

Now, here we are, ten years later. I still may not know much, but I have spent a lot of time with Jack and a lot of time thinking about his place in the world. His life has unfolded in much the same way as his sisters: through the local kindergarten and now in Year 5 at the school down the road. These days I only sometimes doubt him, myself or this ordinary life that we are having. But the words 'Down syndrome' continue to loom large over his head and I am still confused and frightened about what that means to people. I am confused because, although I believe he is a valued member of his school, his place there was not automatic and is not guaranteed. It had to be worked for, asked for and granted by the powers that be. It is still not his right. The conditional nature of Jack's belonging is a heavy weight to carry and when I see how warmly he is welcomed each day, how much a part of the school life he has become, it puzzles me why this conditional acceptance remains. It seems bizarre that something as simple as wanting an ordinary life can become in reality so difficult and stressful.

I am frightened because there are still so many who, in their belief that they know what is best for my son, would steer us away from this ordinary life we are having; those who believe he needs special programs, special teachers and kids like him. Their promises can be very appealing and this is what frightens me most of all – that I start to believe them. Sometimes ‘ordinary’ seems too hard and doubts do creep in. Fear takes over: fear that he does not fit in; fear that he will not have friends; fear of what he can not do and that who he is will not be good enough.

And then, miraculously, in the midst of these doubts and fears, these endless words and opinions, I stop and I see Jack, and again I can feel a center of stillness, of knowing. In spite of everything, I can feel the wonder that my child, like all children, brings. Once again, in the world of the ordinary – the homework, the play, the friends, the learning, the growing – Jack himself, by the very nature of his being, continues to put up a resistance to my doubts and fears.

And I realise that holding on to an ordinary life is not my real challenge. My greatest test will always be to let go of the special. In knowing this, I reject the messages the world tries to give me and once again hold on to the promise of who he is – a boy, my son. No more, no less.