



The gifts of Down syndrome: some thoughts for new parents

by Martha Beck

“Things will never be the same for you or your family,” a grave-faced doctor told me one bleak winter day in 1998, just after my unborn son Adam was diagnosed with Down syndrome. “You’re throwing your life away.”

I’d decided not to end the 28 week pregnancy, and now my obstetrician was trying to change my mind. I knew that he truly believed his dire prediction about my future was right. In a way, I guess it was. What I didn’t know then was that the life I was throwing away was far less interesting, fulfilling and happy than the one I would get in return. Fourteen years ago I shuddered to think about what lay ahead for me as the parent of a child with trisomy 21. Many times since then, I have shuddered to think what I might have missed if I’d followed the doctor’s advice instead of my heart.

Having a child with Down syndrome is nothing like the awful burden I once thought it would be. The gifts that come with these exceptional people make themselves known slowly and subtly, over months, years, decades. For most parents of children with Down syndrome, these gifts end up far outweighing any pain or disappointment we may experience because of our children’s disabilities.

Down syndrome in an IQ obsessed culture

Almost everyone reading this will have grown up in a society that glorifies what we call the ‘rational mind’. Our education system ranks children according to their ability to pass certain very narrowly-defined tests of intelligence. Our social system teaches us that respect and status depend on how smart we are. To receive the gifts of Down syndrome, you have to let go of the way you’ve been taught to think about the value of human life itself.

Of course, I was very lucky: Adam was born with no major health problems. I know hundreds of parents and children who made it through life-threatening heart defects, seizures, or neonatal surgery and emerged on the other side strong and happy, but I don’t claim to understand the depth of their trauma. Any problems I have faced relate to having a child with Down syndrome who is basically healthy, and they seem almost trivial to me now. At the time of his diagnosis, however, they were utterly terrifying. Because you might have some of these fears yourself, I’d like to tell you how mine turned out.

Unfounded fears

Fear 1: My child would be repugnant to me and other ‘normal’ people

I was enormously relieved when Adam was finally born and I could see that far from being a monster, he was an absolutely adorable baby. As he has grown up, I’ve been continually surprised by his finely tuned social sensibilities, his ease around people, the stylish way he dresses and combs his hair. Adam’s manners are not just acceptable, but downright gracious. When allowed to function in the world like any other person, these children turn out as socially skilled as those without Down syndrome, if not more so.

Fear 2: My child would have a miserable life

The most upsetting thing my doctor said was: “You know this child will never be happy.” Adam has proceeded to live one of the happiest lives I’ve ever witnessed. Individuals with Down syndrome tend to remain more focused than the rest of us on putting love at the center of their lives. I can’t express how wonderfully it changes your daily life to spend it with someone who thinks this way. For fourteen years, Adam has been turning my attention to the happiness available in almost every situation. I can only hope that my former obstetrician ever receives such a miraculous gift.

Fear 3: My child and I would be isolated in an unfriendly world

Today a large group of people is committed to upholding the basic value and dignity of those with developmental disabilities. You will meet many of them as your child grows and you will benefit from the changes they are continuing to create in social norms and values. As Adam grew up, he opened my eyes to a kinder and more accepting world and I noticed that my own view of humanity became steadily less cynical. I once thought living with the social repercussions of Adam’s disability would be unbearable. Now, I don’t think I could bear to live without them.



voice Early years

Fear 4: My husband and I would never achieve our personal dreams and goals

It is true that both John and I have had different professional lives than we might have if Adam had not come along when he did. This is because raising him led us to recognise that each person has a unique contribution to give the world – and our own careers took new courses when we began to apply this perspective to ourselves. There are challenges combining any career with parenting, but your child's condition is by no means an insuperable obstacle to your own life goals.

Fear 5: My other children's lives would be ruined

When questioned, Adam's sisters both independently stated that they were neither alarmed by their brother having Down syndrome nor anxious about the future, neither felt that it affected their social life nor thought that they got less attention because of Adam's special needs. My own perception is that my daughters are unfazed by kids who are different from them in any way, and that their minds are broader and deeper because Adam is their brother.

Fear 6: I would be sad forever

You may know that all human beings go through a predictable 'grieving process' when something tragic happens to them. But having a child with Down syndrome does not mean you will be eternally miserable. On the other hand, it doesn't mean you'll be eternally happy.

The key to adapting when your child has Down syndrome is letting go of your ideas about what you think your child should be and enjoying what your child actually is. If you simply love your child as he or she is, that love will open new ways of seeing, thinking and experiencing life. Your emotional range will probably become wider than if your child were 'normal' – you'll experience more pain in some ways, but you'll also experience more joy. For me, raising Adam has been a source of continual, small epiphanies, moments when his quirky intelligence allows me to see the world in new ways. To me, it feels like a privilege.

Just like my old doctor said, your life will never be the same again – but in many ways it will be better than the good doctor will ever know. You have a baby with Down syndrome. Life will never be the same for you or your family. Congratulations. It's going to be wonderful.

This article is a much abbreviated version of Martha Beck's original paper 'The gifts of Down syndrome: some thoughts for new parents' published in Down syndrome: Visions for the 21st century (2002) edited by William Cohen, Lynn Nadel & Myra Madnick. We encourage readers to seek out the complete article which is an inspiring piece of writing – Visions for the 21st century is available in Down Syndrome Victoria's resource library for members to borrow and includes a wealth of writing by internationally renowned authors covering a wide range of topics of interest to both parents and professionals.

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Further reading for families with a new baby or young child

Andrew Merriman (1999) *A minor adjustment. The story of Sarah – a remarkable child*, Macmillan

Cindy Dowling, Neil Nicoll and Bernadette Thomas (eds) (2004) *A different kind of perfect: writings by parents on raising a child with special needs*, Trumpeter Books

Cynthia Kidder & Brian Skotko (2001) *Common threads. Celebrating life with Down syndrome*, Band of Angels Press

Jennifer Graf-Groneberg (2008) *Road map to Holland: How I found my way through my son's first two years with Down syndrome*, New American Library

Karen Stray-Gundersen (ed) (1995) *Babies with Down syndrome A new parent's guide*, Woodbine House

Kathryn Lynard Soper (2009) *The year my son and I were born: a story of Down syndrome, motherhood and self discovery*, GPP Life (Globe Pequot Press)

Kathy Evans (2007) *Tuesday's child*, Random House

Martha Beck (1999) *Expecting Adam: A true story of birth, rebirth and everyday magic*, Berkley Books

Sandy Lewis (2008) *Living with Max*, Random House

Susan Skallerup (2008) (ed) *Babies with Down syndrome: A new parents' guide*, Woodbine House

