

I'm not a saint, just a parent

In a moving extract from a new book to mark Mencap's 60th birthday, the Times chief sports writer Simon Barnes describes life with his five-year-old son Eddie, who has Down's syndrome

The thought hit me with such extraordinary power that my legs almost gave way beneath me. I walked a few steps to one of the benches that surround the duck pond on the edge of Barnet, and sat down. My heart was racing, my breathing shallow, I was covered in a sweat, and I thought for a moment that I might pass out or throw up. After a decent while I decided I would do neither. And I got up and went to the supermarket, for my wife was in hospital and was filled with a passion for fresh fruit.

What if he has Down's syndrome? That was the sudden question that had overwhelmed me. My first child was to be born any day and there were complications, which was why my wife was in hospital. So naturally I was full of nerves, as a first-time parent must be. The duck-pond incident was an attack of the horrors: I imagined a situation so terrible that it almost robbed me of consciousness. Down's syndrome! The horror, the horror!

Well, he didn't. Joseph was born the next day by Caesarean section, and has no problems beyond his own singularity of nature. Joe is great: Cindy and I were, if you'll forgive the word, blessed, and life carried on in a new and extraordinary way. So far, so ordinary.

Seven years later we had another child. He does have Down's syndrome. We had been told after the second scan that there was a 50 per cent chance of this. I accepted it as a 100 per cent certainty. Or was there just a tiny, 1-per-cent pinhole of hope? Hope against hope? But no, I told myself, resign yourself. And I remember clearly another of those moments of pre-birth terror. I'm sure we'll deal with it, I thought, whatever happens.

And they'll say, Simon, well, bloody hell, you know, he's a saint, the way he looks after that boy. And I thought: I don't want to be a bloody saint. I want to enjoy my life, not dedicate it. I have no ambitions at all when it comes to sainthood.

And do you know what? I haven't become a saint. It's a complete triumph: I have found no need for canonisation whatsoever. Nor did I have to work hard at resisting sainthood. Unsaintliness came quite naturally. Eddie — Edmund John Francis — was born on May 23, 2001. He has Down's syndrome all right.

He has me as his father, and his father is not a saint. His father also enjoys his life very much, and Eddie does not compromise that: *au contraire*.

Eddie enjoys his life very much too, most of the time: he makes that quite clear. And when he doesn't, he makes that pretty clear as well. Being a child.

The human imagination can do many extraordinary things. But we can't imagine love. Or perhaps I mean loving: love as a continuous state; one that carries on in much the same way from day to day, changing and growing with time just as people do. The great stories of

literature are about meeting and falling in love, about infidelity, about passion. They are seldom about the routines of married life and having children.

We can imagine dramas and turmoil. People make films about them. In our own minds, we often put together the most terrific stories about thrilling or devastating events that might befall us. But what no one can imagine is the day-to-day process of living with things and getting on with the humdrum job of loving. We can imagine only the beautiful and the terrible. We are drama queens, and our imaginations are incapable of giving us any help about coping from day to day. Marriage is not the same as falling in love; nor is it an endless succession of terrible rows and monumental reconciliations: it is about a million small things: things beyond our imagining.

By the way, I hope you are not too squeamish. This piece is not going to pull any punches. If you find the idea of love uncomfortable or sentimental or best-not-talked-about or existing only in the midst of a passionate love affair, then you will find problems with what I am writing. I am writing of love not as a matter of grand passions, or as high-falutin' idealism, or as religion. I am writing about love as the stuff that makes the processes of human life happen: the love that moves the sun and other stars, which is also the love that makes the toast and other snacks. Love is the most humdrum thing in life, the only thing that matters, the thing that is forever beyond the reach of human imagination.

So no, I couldn't imagine what it was like to live with a child who had Down's syndrome. I could imagine only the dramatic bits: the difficulties, the people in public places turning away in shock and distaste, the awfulness of a child who couldn't say his own name.

I could speculate on the horrors of living with a child who could not do a thousand things. I could create a dramatic picture of life with a monster. But I could not imagine what it was like to live with Eddie. You know, from day to day.

That doesn't make Eddie unique. I couldn't imagine what it would be like exchanging a childless life for life with Joe. I don't think anybody can do that sort of thing: it's not what the human imagination does. You imagine bits that make you proud and bits that make you fearful. You can imagine reading him the Narnia stories, reading his glowing school reports, watching him score the winning goal and hearing the applause after his solo at the school concert. But you lack the machinery for imagining the routine of living with a child who grows up with you.

The fact is that nothing to do with love seems so terribly difficult when you get down to it. Nothing seems an impossible demand on your time, your resources, your patience, your temper, your abilities: not because you connect with your inner saintliness but because you just find yourself getting on with it: muddling through. Most non-parents imagine that they could never change a nappy. Then parenthood happens and they do it. It was the same thing when it came to living with Eddie. It's just parenthood: everyone who has done it knows it.

So Eddie was born, and I have spent the subsequent five years living with him. Not living with Down's syndrome: what a ridiculous idea. Living with Eddie. Who is my boy. And that really is the beginning, the end of it, and the day-to-day routine of it.

At the hospital, when they discovered on the scan that Down's syndrome was a possibility, they very kindly offered to kill him for us. They needn't have bothered. My wife is, unlike myself, an exceptional person in the field of loving and caring. Please do not read this as a brief genuflection, one of the ploys of married life. Nor is it a literary trick. It is rather the literal truth. One small example. I have two goldfish in my study, both the size of salmon. When one fish was much smaller, Cindy found him dead: flat on the bottom of the tank. She lifted him out and somehow revived him. It was a long and elaborate process, and it worked. That is the sort of thing Cindy does. The idea of not caring for something in your care is an abomination to her. The idea of not caring for her own child was impossible to contemplate. Amniocentesis? Not a chance, it puts the child at risk. And no matter what such a test would say about the child, she would go ahead. There was a life that had to be cared for.

This was not negotiable. It sounds, I know, a little dreadful to put it this way. Certainly, I lack the courage to stand between Cindy and someone she loves. The Devil himself lacks that sort of courage. Had life turned out differently, had I been married to another, had that woman preferred to go the way of amniocentesis and termination, I have no doubt that I would have gone along with that, too, and treated parents of Down's syndrome children with a lofty pity.

But, thank God, I did not marry someone else. And that left me with a straightforward choice. I could either say that Eddie wasn't part of the deal and bugger off, or I could keep on keepin' on with the humdrum routines of life and hope that this would be enough for the arrival into our lives of this unimaginable creature we already knew as Edmund, or Eddie. Well, we needed a name and Joe, to whom I had indeed read the Narnia stories, was especially keen on that one.

A name changes everything, and even when he was in the womb we were not wondering about how we would cope with A Child With Down's syndrome. We were wondering about living with Eddie.

So Eddie was born and in a week or so it became clear that the important issue was not how I would cope with his having Down's syndrome, but whether he would die. He had two holes in his heart and needed open-heart surgery at four months.

I remember those few months of illness with great clarity: this little blob of life draped over my left shoulder, arms slack at his sides, too weak to do anything but flop. Treacherous voices had spoken to me during the late pregnancy: perhaps I'll be let off. Perhaps there'll be complications. Perhaps he'll die in childbirth. Knowing, all the time, that this let-off would be no let-off at all but a worse horror than anything I could imagine. Such terrible voices will speak to us and we can't always silence them: it is part of how we dramatise our lives.

And of course, the reality is very different from the things you imagine. When Eddie was on my shoulder, I wanted him to live with all my heart: indeed, if my heart would have been any good to him, I'd have given it and welcome. That doesn't make me a saint, by the way. Just a parent.

I remember the medical phase of Eddie's life before and after his birth, and the 24 hours in intensive care. I remember, too, the amazing confidence of the doctors and nursing staff at Guy's. Their certainty quickly became Eddie's certainty and eventually ours. Truly remarkable people.

So Eddie lived, and lives: burly and merry and, on the whole, pretty healthy. And once the surgery was done and the emergencies and dramas were over, it was time to get on with the business of living. And that is really rather an easy business. You live one day, and then you live the next.

Well, maybe easy isn't the right word. But parenthood is not supposed to be easy — nothing worthwhile is. Down's syndrome brings a number of physical problems. After his operation we suffered — all of us, but Eddie by far the most — with Eddie's agonies of constipation, a weekly rising barometer of hideous discomfort ending in blessed and stinking relief. Here, and in many other ways, we looked for help and found it. But in an unexpected way. Peter Walker, a cranial osteopath, had the hands and the mind to help Eddie through his difficult patches, and he continues to do so. As Eddie belatedly began to crawl, his naturally lax stomach muscles tightened and the problem eased, just as Peter had predicted. And no one else had a clue.

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There are various bits of assistance provided by the State: if you have a child with special needs, you will find a cluster of them. Some of these people are great, some less great. There are times when we feel invaded by people with a negative mindset and poor understanding, dominated by an eagerness to fill in forms and keep their arses covered. There are times when we feel that Eddie is state property: a public problem that somehow has to be organised.

It seems sometimes that Eddie's principal function is to provide employment for unpleasant and insensitive people. Steps have been taken, words spoken. Problems still occur and are distressing. No doubt there are forms and files that have us down as obstructive and difficult parents.

Eddie's education continues at Eddie's pace — which is slow and demands a lot of repetition. He has a few words now, a vocabulary of Makaton signs and a cheering capacity for understanding. He goes to the local nursery school, which he enjoys very much, and we hope that he will be at school in the next village in a term or two.

Is Eddie's slow but continuous education frustrating? Not at all. Progress of any kind is enthralling. It's not about a child passing an exam, it's about a child growing into himself — and for every parent that is a great and glorious thing. It has been the same with Joe in many ways: he hates sport, is unmusical and has never got on with school life. He has a thousand other strengths, and is improving them. That's education for you. The fact that Eddie counts doo, doo, dee rather than performing differential calculus does not affect this truth. Eddie is learning stuff and becoming more himself.

I am not in the front line of the teaching part of Eddie's life. I see myself as more in the front line of arsing about. Giggling is an aspect of life underrated by the chartmakers. Eddie has a huge relish for giggles. He also loves a ball game, and our improvised games of chucking the ball into the wastepaper basket or kicking the ball for the dog are a constant delight. The dog is one of Eddie's special joys. He will climb into her basket and curl up with her, and the dog — a gentle labrador — does no more than sigh.

Children with Down's syndrome often seem to have a charismatic side, at least when they are up and everything is going well. Eddie loves to laugh, and from an early age it was clear that

he also loves to inspire laughter. He has, for example, a taste for preposterous hats, and when he visits his grandfather he always wears his grandfather's bowler. Such clownishness is not to be pitied but is something that Eddie deliberately assumes, though not to order.

Cheerful little soul? Certainly not. He's a five-year-old boy and more prone than most to frustrations. His need to communicate is acute and therefore frequently painful, when his vocabulary of signs and words is inadequate for his own clear idea of what he needs. That brings on a wounded-buffalo roaring of fury and distress.

Generalisations about Down's syndrome are as hopeless as any other generalisation. The one that people good-heartedly make most frequently is "They're very loving", a phrase that Cindy and I often quote to each other in the middle of a fit of the roars.

It's not a matter of they, it's a matter of him. I don't have a child with Down's syndrome: I am Eddie's father. There is a huge difference between the two things. The first is almost impossible to deal with, the second is the way I live from day to day. I don't even think about it much.

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Eddie is lucky in many ways, not least in his choice of a brother. Joseph is seven years older than him, which means that they are not competing on the same level or for the same things. And Joe has his mother's generosity.

He and Eddie have wonderful big-brother/little-brother games, full of piggybacks and tumbles and chasing and pouncing. The only problem arises when Eddie's charisma overwhelms a gathering, leaving Joe feeling a little ignored. Eddie makes everything fun when he's up, so he becomes the centre of attention. Joe, however, takes that in his stride and enjoys Eddie's social triumphs.

I don't want to sound too matter-of-fact here, any more than I want to sound saintly. Of course it's difficult sometimes. That's true for any parent and, God knows, many parents have more difficult times than Cindy and I do. I don't, above all, want to give the impression that everything is easy because I am such a sane, balanced and admirable person. I am none of those things. I'm just a parent, playing the hand I've been dealt as best I can.

Some bits are hard, some bits are easy, some bits are fun, some bits are a frightful bore. That's true of life with Eddie, it's also true of life with Joe. But you don't even begin to break it up into categories: it is the one endless, complex business of being a parent. You don't go into parenthood to make sure that the benefits outweigh the deficits: you go into it out of — brace yourself but no other word will do — love.

Parenthood is not really about the traditional round-robin Christmas letter: Jasper is school captain and is having trials for Middlesex at both cricket and rugby and played Hamlet in the school play of the same name, while Oxford and Cambridge have both offered scholarships. He has just passed grade ten on the cello. Parenthood is not about perfection, it's much more interesting than that: it's about making the best of what you have. Define best, then? Do that for yourself, but I'll give you a clue: if you think it's all about A levels, you're on the wrong track.

So my task, then, is to bring the best out of Eddie. That is unlikely to involve A levels. I know that there will be many harder things to face as he grows older. No doubt we will take these things in the order in which they come. We can imagine a few horrors, of course, but we will live through the actual events day by day. And we will continue with other important tasks such as giggling and playing ball and providing hats and dealing with a world that can't imagine the dreadful fate of being a parent to a child with Down's syndrome.

What is it like to have Down's syndrome? How terrible is it? Is it terrible at all? It depends, I suppose, on how well loved you are. Like most other conditions of life. Would I want Eddie changed? It's a silly question but it gets to the heart of the matter. Of course you'd want certain physical things changed: the narrow tubes that lead to breathing problems, for example. But that's not the same as "changed", is it? If you are a parent, would you like the essential nature of your child changed? If you were told that pressing a button would turn him into an infant Mozart or Einstein or van Gogh, would you press it? Or would you refuse because you love the person who is there and real, not some hypothetical other?

I can't say I'm glad that Eddie has Down's syndrome, or that I would wish him to suffer in order to charm me and fill me with giggles. But no, I don't want his essential nature changed. Good God, what a thought. It would be as much a denial of myself as a denial of my son. What's the good of him, then? Bugged if I know. The never-disputed terribleness of Down's syndrome is used as one of the great justifications for abortion: abortion has to exist so that we don't people the world with monsters. I am not here to talk about abortion — but I am here to tell you that Down's syndrome is not an insupportable horror for either the sufferer or the parents. I'll go further: human beings are not better off without Down's syndrome.

A chance gathering in my kitchen: three people. My wife, who has some gypsy blood. Eddie. A friend who is Jewish. And the realisation that, under Hitler, all three would have been bound for the ovens. Down's syndrome, any more than Jewishness or gipsyhood, is not something that needs to be wiped out for the good of humanity. Down's syndrome is not the end of the world. In fact, for me it was the beginning of one.

I am not here to make judgments on those who have gone for termination, being unwilling to cope with something that they could not imagine. I am here to tell everybody that Eddie is my son and he's great.

I have a life that a lot of people envy. Mostly they envy my job: I am chief sports writer of *The Times*, and people say: you're going to the World Cup, you're going to the Olympic Games, you lucky thing. Can I come? I'll carry your bags.

I live in a nice house in the country, I keep five horses and as a family we are comfortably off. For all these things people envy me. But I have a child with Down's syndrome and for that, people pity me. And I am here to say: wrong. Wrong, wrong, wrong. I am not to be pitied but to be envied.

I have a story very similar to yours. My son is Andrew is 16 years old. He had an AVSD repair at 5 1/2 months. We have shared similar feelings. I was amazed when I read your words about your feelings when you were told there was a chance he would not live because of his ailing heart. I experienced similar feelings. Thank you for sharing. Andrew thanks you for your kind words.

Rita Ristucci, Woodbridge, Ontario, Canada

I read your article with interest. I too have a son with Downs Syndrome. Joshua is 4 years old and has just started mainstream school where he is doing very well. Reading your article a lot of things you said hit a chord with me. Josh also had open heart surgery as a baby and the first 2 years of his life was a trying time medically. But, as you say, you take life one step at a time and do what you need to do and you get through it. I love my son to bits and would die for him but I would also give my life for him not to have Downs. Not because I am ashamed or embarrassed or afraid of the hard work it entails but because I want him to be all he could be - I want him to have the chance of a future where anything is possible and everything is available. I want Josh to be a footballer if he wants, or a musician, or run for parliament or even be the prime minister. And I would do anything to allow him those choices. But I love him no less that he cannot do those things.

I Jones, Rugby, Warwickshire

Good for you and your girlfriend, Christopher. I too had an amnio at King's and although they are clearly proponents of termination in a positive diagnosis (my son also has Down's - and it's NOT the end of the world as I'm sure you know), I didn't have anything like the outrageous comments you and your girlfriend received.

I'm disgusted and appalled that professionals who are in the position of trusted advisor in these situations give such outdated, biased and negative advice.

Good on ya' for not listening to them. Enjoy your baby when s/he's born and know that there are lots of us parents out there who also chose the same path as you. :-)

Sarah Burnage, Chelmsford,

I have just rough few weeks, my girlfreind is pregant with a child with Downs. This to me was my greatest fear as my brother had it. The odds I was told were 64,000 to 1. After I heard the new I thought 'why me' my mother out that to bed with a quick retort of 'why not'. Only last week we made out decision.

It was not easy; it was the German consultant at King's who made the decision for us. After seeing the scans and researched the sentience of the child, we wanted the facts not opinion. Despite this she offered to stick a needle in its heart and induce it 2 days later. The consultant said there is no such thing as a good Down's, 'don't fell attachment 'and it is better to try again, also that she could be referred to a psychologist to 'get over it' and best of all 'Doesn't fit the norm... get rid of it.

It has been a long tiring couple of weeks and honestly I'm still a bit shattered emotionally and physically.

We decided to keep the child as it is just that.

Christopher Irvine, Romford, UK

Thank you for writing this. My 5 month old daughter also has Down syndrome and I keep coming back to read this piece. It's helped me focus on what's really important...my daughter is not a diagnosis; she is my daughter and what lucky mom am I!

mjm, atlanta, ga

Neither of you live in Australia.

Our lives were terrific until my daughter grew up (21 now) and we discovered that Australia does not give a damn.

I cannot work because I cannot get services, my daughter also developed a mental illness - something my state of NSW ignores - no services, no help no future.

I am a sole parent, have been for 15 years and have not been able to work since my daughter turned 12 - no after school supports.

We live in financial poverty, I love her immensely but is that enough?

When your government abandons families, dumps you on a pension of \$255 per week and a disability carers payment of \$47 per week simply because they can get away with it, then life together is not a rosy picture.

They say money cannot buy you happiness but it can buy you a life!

My government has made me a 'carer' when all I wanted to be was a mother.

We don't have carer/family advocacy because the policy is isolate at all costs, this is how they get away with it.

Nell, Sydney, Australia

I have a beautiful 5 year old daughter Millie who also has Down's syndrome and want to thank you for your honest and open article. Living with Millie is full of challenges but having nearly lost her on several occasions when she was a baby I am grateful for everyday with her. She brings so much love, joy and pleasure There are many times when I want to scream at those whose supposed role is to 'help' and who deem themselves the 'professionals' as they are so blinkered and short sighted that they don't see Millie as a loving, giving human being but simply a set of symptoms. Hopefully by battling their prejudices we make life easier for those who follow??

Gail Moody, Stamford, England

I am a Florida mother of a 21 year old son, Daniel with CP. He is physically impaired, uses a motorized wheelchair and augmentative device, called a Dynovox, to communicate. He is very computer savvy and attends a "transition to college" program. My husband and I actually live your essay.... I wish that I could have written about our lives as eloquently as you did. We also feel quite blessed by all of our 3 sons (we have an eldest named Joe too). Wouldn't trade or change any of them. Okay, actually I would love to hear Daniel call me "Mom" with his voice rather than using his Dynovox....but, that is about it. Our Daniel brings out the best in everyone and is loved by all who know him. My biggest fear when he was diagnosed was what will the future be like. Well, I can report that God has met our every need. We continue to be thankful and live blessed.

S. Simonds, Winter Haven,

