

In February 2004, when David was about 20 months old, we visited a developmental specialist. We had to wait two agonising, soul-stealing months before we secured an appointment with her. When I close my eyes and cast my memory back to that fateful day, I can still see her sitting behind her large desk as she delivered the diagnosis that destroyed the more or less normal path we thought we were taking.

The outcome of this visit turned into a surreal nightmare from which there was no escape. What she gave us was not merely a diagnosis, it was more like a death sentence. In a perfectly calm, matter-of-fact voice, she uttered this dreadful news and advice: 'He will never speak, go to school, be toilet-trained, have friends, get married, or hold down a job. Take out an insurance policy and see a psychologist.

'I hear you're pregnant,' she added casually. 'I don't know what to tell you. I guess you can go for genetic testing. No guarantees, unfortunately.'

Her parting words to us?

'Goodbye and good luck.'

She turned and left for another appointment. We finally had our diagnosis, delivered in cold and brutal language. Before she spoke those fateful words, we had still had hope that everything would turn out right. Before the gavel strikes and the words leave the judge's lips, the sentence is neither legal nor official. But now the developmental specialist's gavel had struck, the words had left her mouth, and the sentence had been pronounced.

'Autism!'

All our hope dissipated into dust.

* * *

As hope deserted us, the vacuum it left behind drew in fear and sadness ... great sadness, and a sense of loss beyond description. My idyllic dream of a happy family was shattered. At that moment, I wanted to die – with no thought of my husband, child or unborn child. I had always wanted a small gap between my kids as it would be nice for them to be close in age while growing up. It was all ruined. As the developmental specialist dismissed us, it felt as if she'd delivered a life sentence and we left her office reeling in shock. There was no social worker, family member, parent or professional working in autism spectrum disorder (ASD) present to wipe my tears, hold my hand or offer words of wisdom; and there had certainly not been any mention of treatment options. And how did I deal with this devastating news knowing that inside me I was carrying my next child?

My beloved David had vanished into himself ... a place where I couldn't reach him. My nice, 'normal' world collapsed. Mourning the 'death' of my firstborn, and believing I'd never be able to have a normal relationship with him, I was plunged into severe sorrow and defeat. I lay wounded on the floor, sobbing for hours on end, crying oceans of tears, mourning what felt like a living death.

THE VACUUM OF AUTISM

When someone you love dies, the date and time of death are recorded and everyone expects you to go through a period of mourning. You have a memory of the event and think intensely about the loved one you lost. Losing our connection with David, however, was and for a long time remained a loss that could not be quantified. There wasn't the usual support offered by our Jewish community in the event of a death – no prayer groups, meals being dropped off, or people offering encouragement. It was just Martin and I and our baby, who looked like David but wasn't David anymore.

Another reason why we experienced autism as a social vacuum was that, when we first received David's diagnosis, our initial instinct was to hide him, the label 'autism' and ourselves from the rest of the world. Autism thus swallowed David very quickly, and it was as if it had cruelly left us with an empty shell and an unreachable soul. We still sometimes wonder when it was, exactly, that autism came to take David away from us. If we could mark a specific date, we wouldn't only remember the loss but would also have an annual 'autism is treatable' party to celebrate the victories we've experienced since then.

The period before the diagnosis was that much more unbearable because David was a first child. With a first child, you are still learning about motherhood and how to deal with a baby. You don't always know what's wrong when they become sick; and initially you panic because they can't tell you how they feel. At about three years, they may be able to tell you their tummy, ear or head hurts and life becomes easier for parents as far as being able to help their child is concerned. However, David had lost his speech – all he had left was crying and episodes of extreme behaviour. And although we didn't know it then, it would be many years before he would communicate – even his basic needs. For new parents, and particularly those who can't afford or don't receive the necessary support from professionals or family, this can be frightening, confusing and immobilising.

THE TYPICAL MEDICAL PROBLEMS APPEAR

David continued to suffer from bouts of gastro. His bowel movements were explosive, frequent (eight to ten a day) and smelly, and sometimes contained mucous. For the parent this is challenging, but for the infant the physical impact is painful and uncomfortable. He'd become very hyperactive before a bowel movement. His belly was bloated and looked like an inflated balloon. This was a red flag, indicating that he was possibly suffering from yeast and bacterial overgrowth in his gut, but we had no idea then.

The ear infections also kept recurring. Of course, with the use of antibiotics, the reflux became more intense and we found ourselves regularly battling high fevers. Years later, we'd learn these medical issues were in fact a major contributor to his autism.

David also stopped developing any skills. His skin was pale, he had dark rings around his eyes and he remained sick all the time. My search to find a diagnosis and above all, solutions, now began. I involved myself in intensive research, and undertook numerous treks to specialists and therapists.

The words of Nelson Mandela express what I began to realise after a while:

'I learnt that courage was not the absence of fear, but the triumph over it.'

THE SEARCH FOR ANSWERS BEGINS

I sprang into action as soon as we arrived home after receiving the official diagnosis that seemed to seal David's fate, and researched everything I could find on the illness that had stolen our child. I didn't know it then, but we were at the base camps of Mount Everest – with much hard work, uncertainty and treacherous terrain ahead of us before we could get close to the summit. In my determination to access treatment for David, I managed to block out all feelings of panic and started to make phone calls. A voice inside me propelled me forward, egging me on to act and preventing me from freezing. Even though I was a few weeks pregnant and nauseous, I battled the constant feeling of wanting to throw up. I sipped ginger tea to relieve the discomfort, too afraid to take anything stronger.

THE VOICE OF DOOM

My first phone call was to a South African autism organisation, whose representatives said that autism was a life-long disability. They told me to make him 'as comfortable as possible'! The only help they could suggest was a parent-support group and a brochure on autism through the post.

Days later when the brochure arrived – laying out the terrible symptoms of autism, including the fact that children with autism can have seizures in their teens – I actually did throw up. There was no mention in the brochure of any medical treatment or educational intervention. No sign of hope. No glimmer of light at the end of the tunnel. The organisation was paving a dark and gloomy road ahead for us, and I was quite astonished. I wasn't prepared to give my baby up to autism or a parent-support group. Contrary to their advice, I was not going to accept autism as a permanent disability. Looking for some lead or indication of treatment, I turned the brochure upside down but found none. There was a picture on the front of a boy with autism spinning on a merry-go-round and looking down with no eye contact; and, of course, the number of a parent-support group on the back.

This was the worst time of our lives. Instead of the happy motherhood I'd dreamt about, life became a daily travail filled with extremes of exhaustion, fear, depression and sadness. David cried and screamed constantly; he was quiet only when he slept. A heavy, ever-present grey cloud descended on me. I had no escape.

I couldn't eat or sleep, buy new clothes or even look at myself in the mirror. I used no make-up and barely felt alive. Friends suggested I seek professional help for myself, but I wasn't emotionally ready for this. I first had to mourn the loss of David's normal development and kept all my emotions safely locked away. It took time before I could talk about my shattered dreams, fear and brokenness.

The journey to the return of hope began when we started to educate ourselves about autism. We read everything we could find: what autism is; what causes it; and, most of all, how to not only stop but also turn around the regression we'd witnessed in David.

A FIRST RAY OF HOPE

In our search for answers, one of the first books we read was *Children with Starving Brains: A Medical Treatment Guide for Autism Spectrum Disorder*, written by the late Dr Jaquelyn McCandless. Both Martin and I read her book multiple times and became very excited on recognising many of David's problems. We tracked down Dr McCandless in the United States, phoned her and asked for a consultation. Her response was that she was now semi-retired and was not taking on any new

patients. We sent her a photo of our beautiful baby with his big eyes and blonde curls, along with some South African curios, in an attempt to make an impression and convince her to change her mind. It worked and she finally agreed to consult with us.

BIOMEDICAL TESTING

For a start, Dr McCandless told us, we would need to provide her with David's urine, blood, stool and hair for analysis. She sent us the testing kits, which came accompanied by detailed use instructions from the US laboratories. Martin studied the collection guides carefully, and we prepared ourselves for the daunting task of drawing blood and meeting the stringent requirements set out in the kits' guidelines. We arranged for our paediatrician to draw the blood because we wanted to make sure we left no room for error. On the morning of the appointment, he was called away to an emergency and his partner, a well-recognised paediatrician, stood in for him.

I remember sitting at the clinic as we waited 45 minutes for him to arrive. David was crying for his bottle, which I couldn't give him because we had to wait for the blood to be drawn before he could break his fast. For a normal child this is difficult – for David it was unthinkable. When the paediatrician arrived and prepared his equipment, he snapped at me angrily, saying he'd agreed to stand in for his partner but wanted me to know he was against the tests. This even though he had received no proper training on the subject at medical school!

Afterwards, as David cried and screamed, Martin rushed the blood specimen to a laboratory so it could be centrifuged into the components required by the laboratories in the United States. Not only was Martin carrying a precious cargo – it was also not a normal sample drop-off. We had to make sure that our local lab understood the samples' significance and the care that needed to go into preparing them. We knew there was no way we could put David through the same thing again soon. There was no room for error.

I took David home while Martin went to a specialised courier service to package and label the samples. Some of these had to be frozen, others had to be refrigerated and yet others were to be kept at room temperature. Martin filled out reams of paperwork requiring him to describe the samples and the reasons for the testing. I nervously waited for his call. Finally, he let me know it had all worked out and we'd been successful in getting the samples off.

When he arrived home, however, we realised that the laboratory had performed the blood centrifuge at the wrong speed. My heart sank. Later that evening, we called the US laboratory to report this. Thankfully, they said they'd accept the blood despite the incorrect speed. One of the blood samples had to arrive at a laboratory in Beverly Hills within 24 hours of being drawn. We held out little hope this would happen, but fortunately it arrived on time and we breathed a sigh of relief.

All we could do now was to wait for the test results.

* * *

When Dr McCandless's report arrived, it was a relief to see that it went into satisfying detail, and not just about what was wrong with David:

The results show marked gastric pathology. His gut is deeply infiltrated with pathogenic bacteria and yeast that need intensive treatment. This includes natural and prescriptive medications as indicated. He needs to have any offending foods that could encourage gut inflammation removed, including wheat, milk and refined sugar. David has heavy metals poisoning and needs corrective minerals. Glutathione IVs would benefit him greatly. His gut is currently not absorbing vital nutrients. After gut health is on its way, chelation should be considered.

David's testing reveals gross deficiencies in many of his primary nutrients, especially amino acids, B-vitamins and other anti-oxidants. Current viral infection in the form of high herpes antibodies, with evidence of autoimmunity per positive brain autoantibodies, has been detected.

At the end of her report she had added:

'This completes my evaluation of your son; there are many things you can do to help your son start to get much, much better. I wish you the very best in the healing of your precious little boy.
Jaquelyn McCandless, M.D.'

That night, I couldn't sleep. Her words kept going around and around in my head – 'I wish you the very best in the healing of your precious little boy.' It was the first time since our journey with autism had begun that anyone had offered us a glimmer of hope. We had finally found the answers we were looking for; we could start fighting back, and embark on our journey of starting to treat David's medical problems.

Before this report, the 'devil' had had no face – now we could clearly see what we were fighting against. Nothing was going to stop us winning this war. At last, we were no longer enveloped in grey – light was there, albeit still at the end of a long tunnel.