



ILLUSTRATION BY ANDRÉ BERGAMIN

A FAMILY UNDER FIRE FROM WITHIN

When they contemplated having children, Deirdre and Brendan had never heard of Oppositional Defiant Disorder. Now they are experts on this destructive condition, which has come close to crushing, not just their son, but the entire family

I still remember the first words the nurse said to me when Mark was born ... “Perfect. He’s absolutely perfect.” I thought I would burst with joy. My husband Brendan fussed and cooed over our beautiful son, doting grandparents flocked to the hospital to welcome the new arrival. He was cherished. He was loved. And at night as we stood over the Moses

basket, we marvelled at the wonder of it all. Would he like football or rugby? Would he play the guitar? What would his passions be? His dreams?

It’s hard to think about that now. Hard to let go of the dreams. Today, at 15, Mark has had almost as many diagnoses as birthdays. He collects labels like passport stamps. And we have had to fight every inch of the way to get suitable therapies for our son from overstretched,

understaffed services. Living with a child with ODD is like living in a war zone; every moment of every day a battle of wills between exhausted parents and a defiant, combative child who cannot accept the word “no”, a child who is manipulative, prone to temper tantrums, has a skewed view of how the world works, never takes responsibility for his or her actions, and seems to take pleasure in annoying and provoking those around them.

FIRST PERSON

But in this war there are no medals. No respite. No reward. Only disapproving looks in the supermarket, unhelpful comments from well-meaning onlookers, insensitive judgements and criticisms from overworked health-care professionals.

He wasn't like that at first though. He was a dream baby. A piece of cake. He smiled early and often. He loved stories and nursery rhymes, bubbles and baths. But he didn't babble. He was quiet. No gurgling. No makey-uppy baby talk. The public health nurse said it was because he was a boy, not to worry, soon we wouldn't be able to stop him. But at 18 months there was no sign of speech. No attempt to mimic our words as we read him his bedtime stories. And we did begin to worry. The doctor tried to reassure us that it would all work out fine. He ordered an MRI, but the results showed no indication of any neurological or physiological problems. I can still see the little booties that Mark wore that day as he sat beside me in the waiting room. Little red, blue and white booties. We were so delighted when he was given the all-clear, but it wasn't long before the anxiety returned. He hit his second birthday and still no speech. And he seemed to be getting agitated more often, frustrated at his inability to communicate. He started to kick up, throw things around. He'd scream and shout, long wailing sounds but no words. He'd break things. Small things at first; his plate, a vase on the table, the light beside his bed. He stomped and screamed if he couldn't have whatever he wanted, threw himself in a fury on the floor. There was no consoling him. And this could go on for hours. Suddenly our entire day was taken up dealing with Mark. Managing him consumed every moment. Even when he slept it filled our every thought. The Terrible Twos some suggested. Don't worry, we were told. So we got a book on toddler-taming and engaged a speech therapist. We even spoke to Supernanny! Everyone assured us that he would grow out of it. And so we decided to have another child.

When Molly was born, Mark couldn't get enough of her, constantly kissing and hugging her, absolutely mad about her. We were delighted, and Mark's speech appeared to improve slightly. Mama, Dada and Momo for Molly. Maybe it had all been a phase. Maybe we were just anxious first-time parents.

With privately funded speech and language therapy, his language acquisition improved, though he was not on a par with his peers. But the disruptive behaviour escalated. It began the moment he woke up. He fought over his clothes ("I don't like those socks, I won't wear that jumper."). He fought over breakfast ("I hate that cereal", though it was the very one he had requested a minute before). He fought about going to school and about coming home. "Can we go to the toy store?" A string of curses and abuse, when we explained that it was time for school. "Can we go to the park? I want to go NOW! Can I? Can I? Can I?" All day long. And the arguing and gruelling combative behaviour didn't end until the moment he fell asleep.

In school and at home, he couldn't sit still for a minute. He climbed up on everything - the couch, the table, the garden wall. He took to climbing out windows and onto the roof. He was resistant to all requests to refrain from dangerous behaviour. We sat him down and explained

over and over why throwing chairs, punching people, biting and kicking were not acceptable behaviour. We tried reward charts, star charts, "time-out" sessions, everything. Any possession we threatened to withhold, he damaged or devalued, so that we would have no hold over him. We tried early bedtime, late bedtime, no bedtime. Nothing worked. If he couldn't do exactly what he wanted, when he wanted, he erupted like a volcano. He raged around the house like a Tasmanian Devil. Counsellors advocated "picking our battles" but everything was a battle. Every single thing.

In school they were patient. Very patient. We were lucky, I realise and appreciate that. They really tried their best. But I felt terrible dropping him off and unleashing his fury on them. He inevitably ended up in a scrap with someone. Punches would fly. Lots of tears and nose bleeds. Broken chairs. Broken windows. And very unhappy parents. Neither punishments nor rewards seemed to work. We were at our wits' end. As were the teachers. And every free moment was taken up with ferrying him from one consultant to the next, each with a different view. At various times he was diagnosed with a speech delay, ADHD and finally Oppositional Defiant Disorder. They tried medication, Ritalin at first. That worked for a while but he couldn't eat or sleep when he was on it and none of us got a minute's peace. Then it stopped having any behaviour modification effect at all. So they tried Concerta, a newer, slower-release drug that can help with ADHD and ODD. Again, the positive effects were infinitesimally small. We were loath to have Mark be a medicinal guinea-pig but the clinics piled on the pressure. They wanted the problem solved. Drugs were the way forward. Respirol was next. That was a disaster. The violent outbursts increased. Every morning on the school run, he would undo the seat belt and pull my hair from behind, punch me in the head and neck as I negotiated the morning traffic. One day he gave me a black eye. I pulled in and rang Brendan who was in Germany for work. "What should I do?" I cried down the phone. "I don't know what to do!" He was only nine and Molly cowered in her car seat beside him.

We returned to the clinic and voiced our fears. They recommended Abilify, an anti-anxiety tablet and we relented. For his sake. And for Molly's. And we have stuck with it over the past few years. It seems to have helped, tempering the outbursts somewhat. He still finds it difficult if we do not acquiesce to his demands fully and immediately, but the spiralling acts of wilful

destruction and violence have abated. This has been helped by a Behavioural Therapist from the Callan Institute for Positive Behaviour Support, which the school suggested we see a couple of years ago. She has been a godsend. Despite the fact that we have been in the system and marked "urgent" for 13 years, no one ever came out to our house to witness the carnage he causes when he erupts. She came, she watched and she didn't judge. Even when he screamed at her "Who the **** are you?" and upended the steaming dinner plates onto the

floor. Even when he flew out the back door and could be seen running along a high wall, screaming abuse, before disappearing and only reappearing an hour later. She watched when I cried helplessly, as he ripped his little sister's meticulous homework, and still she didn't judge. She worked patiently with Mark, treating him and us with a respect and dignity we had hitherto not encountered. She assured us that it wasn't our fault, a deep-rooted fear that kept me awake at night. Her compassion and sense

of justice brought me to my knees. All the years of tension, worry and fear came crashing down. But she is helping to build it up again, working with us and liaising with the school. Mark still needs multiple therapies and approaches, but for the first time we feel a little more in

control. He is not where we hoped he would be. He is still challenging but is taking baby steps towards behaviour management. We have had to let go of most of our dreams and that fills me with sadness. For him and for us. I daren't think too far into the future. We have done what all loving parents do; bought the parenting books, hired the psychologists, tried the medication, replaced the broken furniture and prayed for a better future for our kids. That's all we can do.

But the toll it has taken on the family has been immense. On him. On us and on his sister. For her, family life has been stressful and difficult. We tried to minimise the impact on her by removing her from the scene when he went off the deep end. But his unpredictability meant that everyone was always on edge, waiting for the next outburst. Things are definitely calmer and she has a better understanding of his condition, now that she is older herself. These are things I wish she never had to deal with. And of course his disruptive behaviour has placed huge strains on us as a couple. Most of the time we were beside ourselves with exhaustion and worry. We felt overwhelmed and powerless in the face of such ferocity. Fun and enjoyment were something other people had. Holidays were a disaster. Now we've learnt to do it differently. We take a break separately or with one of the kids. You do what you have to. A sense of humour helps. And an understanding extended family and circle of friends.

One of the hardest things to deal with, apart from Mark's behaviour, is the disapproving looks and tut-tutting of strangers. I know they believe it is our fault, that it is all down to bad parenting or that ODD is some new-fangled nonsense. To those who say there is no such thing as ODD, or snigger and say there is another word for it - "bold" - I have one thing to say. Come live my life for a week. Or even just a day. How about an hour? See how you cope with the constant aggression, the combative, vindictive behaviour, the emotional and physical upheaval he wreaks on our home, our family. Open your purse, your bank account and hand over every last penny you have on parenting courses, speech therapy, occupational therapy, behavioural therapy. Spend every ounce of your energy on managing conflict, all the while trying to bank some pleasant family memories. Come walk in my shoes, then tell me it doesn't exist.

Mark is an enigma. But for now he is better able to cope with the world. And for that I am happy. *In conversation with Justine Carbery. For more information, visit www.sess.ie.* ■

Every free moment was taken up ferrying him to CONSULTANTS, each with a different view.