



THE SEQUEL TO THE SUNDAY TIMES BESTSELLER
A FRIEND LIKE HENRY

all because of henry

My Story of Struggle and Triumph with Two Autistic
Children and the Dogs that Unlocked Their World

nuala gardner

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of
henry

Also by Nuala Gardner

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My Story of Struggle and Triumph with Two Autistic
Children and the Dogs that Unlocked Their World

nuala gardner
with Beth McDonough

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Please note that, where appropriate, some names and places
in this book have been changed in order to protect identities.



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This book is dedicated to the children of Dale's generation who, like him, are now adults living with autism. There are incalculable numbers of adults that have not been as fortunate as Dale to have received the right education or support. Dale's desire is that this book will give his generation new hope to help them pursue a similar quality of life, like any other adult in society.

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Preface

1991. Where were we? Dale, my three-year-old son, was trapped in his terrifying, autistic world and I was lost too. Yet, somehow, I had the maternal remit to rescue *him*. Desperate, I drove the thirty miles to Glasgow, seeking a new support group, wanting answers, needing to cling to the slightest chance of hope . . . any hope.

Well, I didn't find hope. I found this:

My child is four years old and severely autistic. I've been told we have to fight for adult provision for him now.

That night was the beginning of an incredible eighteen-year journey I would travel with Dale. He would emerge from that lonely world, with me battling beside him. After all, during those years I had the best teacher of all, a certain Henry – all four legs and tail – our beautiful, noble golden retriever. Everyone who knew him agreed. He was to become Dale's first real friend and he was the perfect gentleman.

This was no ordinary dog. He did the extraordinary: he gave me hope when I had none. It was Henry who freed my tormented son and it was Henry who would throw us both the lifeline we needed. Dale's autism was so severe that family life was extremely difficult. Any break in Dale's usual routine could cause severe tantrums, and we simply didn't know what to do, how to get through to our son and give him the help he so badly needed. Then Henry arrived and the bond he formed with Dale provided the breakthrough we had so desperately wanted. His arrival in

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Dale's life helped bring my son out of his autistic world and gave us a way to communicate that simply had not been there before. Henry unlocked Dale's world and gave us hope for our son's future, which is the most incredible feeling for any parent. And led by Henry, I believed we had made it to adulthood, problem solved. I was able to see Dale's future; he would be a confident, fully productive, professional member of society. I thought him secure. Likely anyone reading my earlier book had every reason to believe that too. Would that it were to be that simple.

. . . we have to fight for adult provision . . .

Eighteen years on, that parent's words would come back to haunt me. Repeatedly. Dale had caught up with society, but had society caught up with him? We were about to find out. Those early adult years would become the most challenging of times. For both of us.

Easter Sunday, 17 April 2006 was the night Henry died. That beautiful dog had led not only his young master into the world but he had made our family life, well, a family life! How would his death affect my seventeen-year-old Dale's future? How would it affect all of us? Strangely, the one thing I needn't have worried about was how my son would cope with this most painful of losses.

As Henry lay dying, only a mature man could have done what he did. Just as Henry had helped Dale all his life, now it was Dale's turn to help him. My son assisted the vet, allowing Henry a comfortable and loving death. I stood back in awe.

"You're going to be all right now, Henry. This jag will make you feel better," said Dale.

With these heartbreaking words, I realised that my son was able to allow his precious dog to die, and more: I learned that Dale would never let slip the better future Henry had given him, however challenging that might prove to be.

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“Mum, due to Henry I am not scared any more of being an adult. I have decided that for the rest of my life I am never going to let my amazing dog down, so that he will be proud of me, as I will always be of him.”

This would not be Henry’s final gift to my son, nor indeed to me and my daughter, Amy.

Amy was my millennium miracle baby, who had been diagnosed with moderate autism when she was only two years old. Thankfully, because of lessons learned from Dale and Henry, she was able to develop at an impressive rate. At five, she had already caught up with her brother. Both now are considered to have high-functioning autism. Unlike Dale at five, Amy’s vocabulary was extensive and she utilised it well. Too well! She became The Interrogator! She could take ownership of any conversation and turn it around to her own obsession – horses. Once in control, she would question to her heart’s content, whatever anyone else might think!

But what did anyone else think? Over these twenty-four years of bringing up two children with very different kinds of high-functioning autism (Autism Spectrum Disorder or ASD, as it has come to be known), I have seen change. I have seen society accept the condition as a recognised disability. So far, so good. But is it enough? Life should be fine by now, shouldn’t it?

With the help of Henry, these are issues I have faced every day of my life as a mother, trying to find ways to help my children be all they can be and facing the challenges life throws at them every single day. But, of course, I am not alone, and with over half a million people in the UK affected, this is a major issue for our society. This figure includes Asperger’s syndrome (AS), which is the highest level of functioning on the spectrum.

To help understand autism a little more, there are three main aspects that make it the lifelong disability that it is. The first of the triad is communication, and some will be unable to speak at all. All affected will have problems interpreting non-verbal communication, body language being completely incomprehensible to them. If that weren’t bad enough,

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then there is the sufferer's literal understanding of language to add to the mix. Let me explain how that works using the true story of Philip, when he had to resit his driving test.¹

Examiner 1: Can you read the number plate of the green car over there?

Philip: Silence.

Examiner 2: Philip, he is talking to you.

Philip: Oh, sorry!

Examiner 1: Philip, can you read the number plate of the green car over there?

Philip: Yes, thank you.

Examiner 1: Go on then.

Philip: I have.

Examiner 1: Can you read it for me, please?

Philip: I have read it twice already!

Examiner 2: Philip, would you please read out loud the number of the green car over there?

Philip: J123 VOS.

Is it any wonder that many with autism choose not to speak at all? As Dale revealed when he was a child, he would have chosen not to talk to us had we not communicated with him via Henry. To this day, Dale's remark chills me. What might not have been?

The second part of the triad is difficulty with social interaction. All social skills have to be learned; they don't come naturally, understanding the complexities of emotions, feelings and empathy. Sufferers have problems understanding social rules and how to navigate society.

Nowadays, we are also aware that many with autism endure the distress and discomfort of sensory-processing issues. When Dale was young, I suspected he was affected and adapted things as best I could. Thirteen years later, he told me about his sensory problems – the smell

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of some foods, the colour combinations, the textures – some of which were the catalyst for many of his most challenging tantrums.

The third leg of the triad is difficulty with social imagination, not being able to understand people's behaviour or abstract ideas, their thoughts or feelings, including in times of danger and crisis.

This explanation of autism is far from exhaustive, but again, this is never to be forgotten: anyone with autism can learn and develop with the right condition-specific education and support. Amy, Dale and thousands of their peers in society are proof of that.

Where were we?

Six months before Henry's passing, Dale had the foresight to acquire a puppy, and insisted on calling him . . . Henry! We managed to live quite normally with two golden retrievers in our home with the same name. It was amusing how both dogs responded with only the words *Wee* and *Sir* to distinguish them. Dale knew that *Wee* would never replace *Sir*, but he needed to hold onto that name. And quite rightly, too!

I didn't realise at the time, but I was beginning an extraordinary new voyage. I was to travel to places in the world, far further than I could ever have imagined. It was all because of autism. By visiting these places, I was able to continue the work that Henry had begun. Dale and Henry had shone a light in a dark place. That light was nowhere near ready to go out! Already, thanks to Henry, we were in a happier, safer place. Both my children were reaching out to consider exciting futures, just as their neuro-typical peers – others not affected by autism – were doing.

This is the story of our journey together into those futures. This time though, unlike my earlier excursions at the family helm, I would not be alone, and it would be no mystery tour. I was in the safest hands possible, with my strong, brave tour guide beside me, my now adult son Dale. However, to begin this new journey, as a family we had to get through the hardest day of all.

The first day without Sir Henry.

I

After Henry

My husband Jamie was awakened by a damp nose nuzzling his face, a paw nudging – by someone who was not about to be ignored! Wee Henry (or Henry, as he was now) had slept in Dale’s room since puppyhood when Sir could no longer manage the stairs. By the time his elder had gone, Wee Henry knew with certainty that he was Dale’s dog.

Returning from his morning constitutional, Henry demanded his breakfast. He refused to settle without a full stomach – 6 a.m. or not – just like his namesake. It felt strange to hear Jamie call “Henry” now, even though the youngster seemed to have accepted his reformed name. Suddenly, I heard loud sobbing from Jamie.

“What’s wrong?” I asked.

“It’s Henry. He won’t eat his breakfast. I put his bowl on Sir’s step. He just won’t do it.”

We had let Henry eat there to show him he was now the top dog, but there he laid, head between paws, big brown eyes staring and depressed. No amount of reassuring or coaxing interested him. I placed his bowl on his usual table. Wolf! He devoured his meal in seconds, followed me back to my bedroom, and joined me in bed.

An hour later on that Easter Monday and Henry wasn’t my only bedmate. There was Amy, fast asleep. I can’t say it was a surprise to see her there. Regularly, she ended up in between Jamie and me, just as a younger Dale had done (but at least he hadn’t sneaked in until later). In good faith, we always started her off in her own bed, in her lovely horse-decorated bedroom, with that all-important routine, but it didn’t take

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long for her to limber up for her marathon – up and down, all night. After numerous failed attempts to return her to her own bed, one of us would climb into her wee bed to try to settle her there. Some nights the musical bed routine was so shattering that by the morning one parent was with her in our double bed, and the other would be camped in her single one. We could hardly remember how or when it happened, but happen it did! No wonder we called it the “Bed-a-thon”!

I was aware she had heightened sensory issues. Even as a baby, she sought comfort by playing with my hair, which lulled her to sleep. In a sense, she had perhaps “over bonded” with me. Now she was six and I felt I had exhausted all means to get her to stay in her own bed. No, we were just exhausted! Well, the tide didn’t stop for Canute, and the business of the Gardner household day wasn’t going to stop just because of mere parental burn out!

Now that Henry was awake, Dale was too. Looking for comfort, he came in. I reckon Sauchiehall Street was quieter that morning! His dad gave him a big, manly hug, and set off, hoping that work would take his mind off Sir’s death. As Jamie left, I suggested Dale pop in whilst I made all of us a pot of tea. Thankfully, we had a king-size bed! Henry was sprawled out, sleeping deeply, on a third of the space. We all squeezed together and enjoyed the security.

As Dale and I sat up, sipping our comforting cup and musing sadly, suddenly we heard a familiar voice. From the middle of the duvet we learned . . . The Interrogator was awake!

“Nuala, what’s Dale doing in our bed?”

Amy called me by my first name, and had done so since she was four, when I taught her the rules of conversational turn-taking. I explained that she needed to wait her turn to speak, and then say the person’s name. I should have known better! Autistic children learn in a literal way, and Amy applied this rule exactly. “NUALA!”

Now she was wide awake, bolt upright between us, and she needed answers.

“Nuala, what’s wrong? Why is Dale sad?”

I cuddled her, warning her that I had sad news. Sad news usually meant that someone or something had died. We shared our saddest news of all over breakfast in bed.

Eventually, I suggested we needed to move on, to get out of the house. We weren’t in the mood to do anything special but had to get through this, so we headed for Glasgow to buy Dale his first tailored suit. He had already been to a couple of funerals in hired suits, and I thought for future job interviews and the like it was time he had one of his own. Having dropped Amy and Henry off at her grandparents’, we headed off to Glasgow’s famous tailor, Slater’s. The shop assistant was very helpful and understanding when we explained why Dale was getting his first suit. Having a grandson of his own with a profound disability, he grasped the real significance of this event.

I saw my son emerge from the changing rooms, and my soul swelled. What a handsome grown man he had become! Remembering that lost and lonely child, that child who had spent days rocking in a corner of a room, unable to communicate or relate, I thought, Wow! Look at my incredible, handsome son now!

Dale chose the most expensive outfit on the rail – the designer suit. I realised I was going to take the financial hit when, as he modelled it, the assistant explained that a famous local footballer had chosen that very one. Dale had learned how to “fit in” by following good role models, so when he heard someone successful had bought the same suit, there was never any choice!

Suit bought, Dale declared he was hungry. That was always a good sign! We headed for a Chinese restaurant, ate ravenously and headed home.

That night we all sat watching television. Henry was cuddled up beside Dale on one sofa, while Amy sat snug between her dad and me on the other. Life seemed quite normal again, but I reflected on what she had taught me in bed that morning. I had assumed because

horses were her world, she would be less affected by Henry's death. So wrong! On that first morning without our beloved Sir, Dale and I sat listening to our personal Interrogator.

"Amy, Dale and I are sad because, when you were sleeping, Sir Henry died and he is now in Heaven."

I hugged her tightly, while we braced ourselves for her response.

She screamed. "Buy another one! Please, please, Nuala, buy another one!"

Her body shook, distressed. She shouted this phrase, repeatedly. You might well conclude that she was a ruined, unfeeling little girl, simply wanting a replacement for a broken toy. Again, so wrong. Calming her, I extracted more information. She clung on, burying her head in my chest, unable to look.

"Nuala, I will miss Sir Henry – my dog Harry – and my special horse has now gone."

Immediately I understood. "Harry" was the name she had given Henry when she was a toddler with emergent autism. Henry was Dale's dog, while Harry was Amy's. Now, I was confused regarding her special horse, until she explained. "Nuala, Harry was sometimes my special horse that I liked to play with."

At three, when Amy adopted horses as her main love and obsession, I watched her groom Henry with her horse kit. She would attach a horse lead rope to his collar and walk him around the house. At the time, I thought that she was simply using her horse kit in a literal way with the dog. After all, she was unable to tell me otherwise. It never occurred to me that she was role-playing, and at that young age, showing the green shoots of imagination. Then, I believed she had none.

It was not the only time I underestimated my daughter. Amy nurtured her equine obsession at the Ardgown Riding School. In the centre of the estate there was a one-hundred-year-old oak. During her pony walks, Amy would be led around it a couple of times, blank-faced, expressionless, and uninterested in her walk and the environment.

Despite this, she went every Sunday for years. Visiting Ardgown five years later, Amy was upset to discover that the tree had been felled.

“Nuala, Nuala. I am so sad . . . because my big tree is gone! I liked to pretend I was on a real horse carousel when I went around my tree.”

At the same age, Dale had adopted a similar big, old tree which, miraculously, gave him his first word. I have learned that children with autism have extraordinary, albeit different, imaginations. We must embrace their obsessions, use them in a positive way to connect with them and teach them. That is why we need to take time in observing the child with autism at play. The pace and type of play may differ, but never doubt it: that child is learning and exploring.

After Amy’s upset, I consoled her. It was good that she had played with Sir, her special horse. If she wanted, I told her, she could make Wee Henry her special horse instead. Hearing this, she seemed to settle, reverting to her usual happy self. Bereavement for any child, let alone a child with autism, is such a major transition that I had prepared her, years before, to give her an idea of Heaven and loss.

I had found a children’s storybook, *Heaven* by Nicholas Allan, and I introduced it to her as soon as she took a fleeting interest in books, when she was about three. I already admired his other stories, which also appealed to Amy. She never tired of hearing his tale *The Queen’s Knickers* (She was particularly fond of when the Queen wore her extra-padded riding knickers!). *Heaven*, being about a dog’s death, helped her understand loss, and it would enable her to cope with the memories of Sir yet to come. As I had done with Dale, I adapted – indeed, I completely vandalised – books to suit our purposes. I had removed pages of *Heaven*, still allowing the story to shine out. I had taped over the text to hide it, for future release when Amy was ready to learn to read. By doing so, the book’s sensory overload had been reduced. Naturally, I hid the part which considers the possibility of The Other Place. After all, that was never going to happen to our dogs! This book

was a real godsend, as it helped Amy prepare for this eventual outcome we were now facing.

In the days that followed, Dale was to receive condolence cards from friends and family – this had been no ordinary dog. As a special thank you, we gave a framed portrait of Sir to his vet, Nigel Martin, drawn by Dale in those last weeks. The portrait was for their staff room, as a wee reminder of an extra-special client and for all they had done, both for Sir and for Dale.

At home, our Wee Henry was still an upset and lost dog. A couple of weeks on, as I watched Amy playing in the garden, I was distracted by a whimpering and barking from upstairs. I investigated immediately. Henry's distress was coming from Amy's bedroom. As I entered her room I was pleasantly shocked! There stood Henry, completely captured by Amy, wearing a pink horse head collar from her life-sized toy Shetland pony, and with a lead rope tied to the handle of his stable. If that weren't bad enough, she had put a pink saddlecloth on his back, and he wore brushing boots! God knows how long Henry had tolerated this before eventually letting me know he had had enough. I laughed quietly and rescued him, but I was relieved too that although Amy had been able to grieve for her "horse Harry", she was now moving on.

There were days thereafter when I would think of Sir constantly, and others when he entered my thoughts less, a normal part of the grieving process, including that for a dearly loved pet. For years to come, though, my grief would surface at the most unexpected moments. When laundry day arrived, I'd lift Dale's pillow and I would just sit on the bed, tears flowing. Sir's collar was tucked inside Dale's pillow, where he had put it on the night he died. Writing this seven years later, I know it's still there.

Day by day, life had to go on. After Easter, Dale hoped to begin a career in early education and childcare, in a mainstream nursery setting. At Gourrock High, he had had a week's work experience in Carousel, a local private nursery. He received an exceptional report from the nursery staff, so much so that I remember the secondary's assistant

head commenting that it was exceptional for a pupil to get such a good nursery placement report. During that week, Dale discovered he had a real understanding of how to connect and engage with children. He told me, "Mum, I remember what made me happy in my childhood. I understand how the children feel when there is an adult playing with them that really knows what makes them tick."

In common with so many others, Dale's autism had given him a photographic memory and his childhood recollections were vivid. Often when I have wondered at his ability to cope, he has explained that he can remember the bad and the good times in detail. He has even told me, "Mum, I'm really shocked that I behaved the way I did when I was a child, but I saw things so differently, and many things happening around me were so scary when I was young."

In order for Dale to follow this career path, I had to ensure he understood what it involved for him because of his autism. Probably, he would be one of the first people to have had autism which had been classed as severe in childhood, who wanted to have a career in this area. We had major concerns. So, when Dale was seventeen, his father and I sat down to talk with him about his choice. The conversation we had and the issues we had to raise were both devastating and depressing. His dad and I felt we had no option but to make him face the reality of his situation, the potential barriers, and the problems he would encounter if and when he qualified. We needed to help him realise how hard it would be to find a suitable job with a supportive, working environment, one that would be right for his autism.

In order to gain the necessary understanding from staff, he would need to let employers know about his condition. Already Dale had concluded that because he had autism he would have to prove himself *more* and be *more* able than his non-disabled peers.

Motivated to overcome this perceived prejudice, Dale took on voluntary work as a support worker with Barnardo's Scotland. He worked with a group, aged five to eighteen. The children had a diverse

range of disabilities, including autism. He volunteered at an out-of-school holiday play scheme and helped support disabled children in a weekly drama group. Barnardo's require in-service training of all their volunteers in areas like child protection, so Dale had to learn about challenging behaviour, know and understand many other disabilities and their effect on child development. He became familiar with issues like health and safety, first aid, seizure procedures, safe administration of emergency medication, life support and more. These new topics and skills were relevant to his chosen career, and we discussed them all. We assured him that Barnardo's was such a long-established charity that his volunteering would be a really strong, positive aspect of his curriculum vitae. Or so we thought!

A very focused Dale told me, "Mum, I know it's going to be really hard work, but I am determined to prove to myself and others that I have got what it takes. I'm not going to let having autism ruin my life!"

Hearing this, I helped him appreciate that there were more positives than negatives in his career choice. Obviously, his talents in art and music would be an advantage, but even more: his was a unique and incredible insight into autism. Indeed, this is where many of the children emerging on the autistic spectrum would be first recognised, and this was where their early intervention would be implemented. Dale's personal journey would prove an asset in any nursery.

We talked about how he would avoid discrimination. We didn't like discussing this subject, but he had to know. Together we considered what barriers he might face, whilst trying to keep things upbeat. We reassured him that as he would be working in an area where autism was now so common and was on the syllabus, he would certainly have understanding, supportive colleagues. Sadly, with improved diagnosis, it would be reasonable to assume that there would be at least one child (probably more) with ASD in every nursery. Undoubtedly, working there, Dale would give hope to parents, whilst simultaneously giving staff a unique insight into autism. He had made a great career choice.

At the time, I had spoken to a few girls who were qualified practitioners, working locally. They said that the profession was trying to encourage more males into nursery education careers as positive role models for vulnerable children, and a good influence on many children from single-parent families. So far, so good.

We explained, in detail, that there was legislation in place to protect him, the Disability Discrimination Act 1995 (DDA), as it was then.¹ Under this Act, he should not be treated less favourably because of his autism. Dale had the right, like any other person, to apply to his local college and take part in any course he desired, assuming he was a suitable candidate.

And Dale was a suitable candidate ... because of his voluntary work, his good work experience report and the right Standard Grades! Importantly, under the Act, college staff had to take reasonable steps to ensure that Dale accessed the curriculum fully, in a similar way to the adjustments which had already been made for his school exams. He would have additional time at exams; instead of note taking he would receive classroom notes from lecturers, addressing his processing difficulties and poor fine-motor skills. Under the DDA, it was unlawful for a person to “harass or victimise a person because of their disability”. We talked at great length and felt optimism for his future. Really, there was no reason he shouldn’t pursue this course. How much more suitable could he possibly be?

Understanding the difficult and extraordinary journey Dale had made already and knowing how much good he would bring from his childhood experiences, after much deliberation his dad and I decided that no matter what we would support him in his pursuit of this profession. He was returning to a system which had helped him be the person he was today, and that was huge.

About a month after Sir’s death, I was deeply touched to discover that Nigel the Vet had hung Sir’s portrait on a main reception area wall. He

told me that his staff really respected all that Dale had achieved with Sir, and it was only fitting that the portrait be enjoyed by all the clients. If only all the people to have involvement in Dale's future would be as understanding and supportive of his achievements.

Meantime, there was something else I needed to do for both my children. I compiled memory photo albums of Henry. When Amy saw Dale's album, immediately she drew a picture for Dale to insert. The drawing was clearly Sir – happy-faced, wearing his bright blue collar – with the words *"To Dale, Sir Henry went to Heaven on 17/4/06 and was a good dog. From Amy"* written underneath.

This gesture truly moved us, reassuring us that Amy showed the beginnings of empathy, a concept that takes years for many with autism to grasp. Indeed, some will never be able to do so. With Sir's passing, I was to learn so much from Amy as well as from her brother about the complexities of their condition. However, for now, we were still coming to terms with the past that was Sir Henry and the future challenges that lay before Dale as he moved from his familiar world into the big wide world beyond.

2

Awareness

“I believe that language for many people with autism is like trying to understand the handbook of a computer software package that is in computer code when you are not computer literate. Why do we say things that we don’t mean? I can remember my father telling me to make friends. I knew how to make rice pudding, but I did not know how to make friends.”

– Lawson, an adult with ASD¹

“My son does not tell me when he is being bullied. I have to figure it out sometimes from bruises.”

– Parent of a child with ASD²

Deep below the duvet, something – or someone – was fuming.

“Nuala, Nuala! I could kick a horse!”

There was no pony-hating monster in the room. Far from it! This was our six-year-old, horse-mad Amy, expressing her fury as only she could. Let’s listen to her again, because sometimes what a child with autism says is not what we are first able to hear.

“Nuala.”

As ever, Amy followed this mode of address with the literal precision that hallmarks autism, despite all my carefully structured words – “Tell your dad something”, “Ask your gran”, and the like. As I write this, and look at my now secondary-school-aged daughter, it still remains an all too rare treat when she chooses to call me Mum. In her Primary 1 days, it simply wasn’t a name she used.

“Nuala! I hate horses!

Certainly, she was angry. I was to learn that Amy’s emotional responses were three-tiered. The first layer would manifest itself when she was slightly annoyed. She would scream, “Shannon hates horses!” (Shannon, Amy’s best friend, was a great horse lover.) When moderately upset, she upgraded to, “I’m going to kick a horse!” But worst – at maximum, high-volume anger – she would stomp and jump around, yelling over and over, “I’m going to kill a horse!” What more powerful images were there for Amy than her beloved horses?

She would repeat these statements until diverted and consoled, as we directed her to a better emotional response. These outbursts became such a part of our normal life that my close friends started to include them in our banter! Many’s the glass of spilled wine that one of us has shrieked over, “I could kick a horse!” Throughout the years of managing my children’s autism, my sense of humour has helped me cope, stay sane and keep positive. Autism provides a plethora of amusing scenarios, and has given me and my friends so much life-lightening laughter. That laughter is always with my children’s autism, never at it.

Anyone overhearing Amy’s terrible remarks might laugh, but in so doing would add to her distress. It was a scenario we knew all too well. Some people would be visibly shocked and respond by ignoring her. How I helped Amy recover doubtless horrified many. Bystanders might have thought I was simply condoning bad behaviour in a girl of six, who was, after all, old enough to know better. It was so easy to see a spoilt brat, just as had so often been seen when I had been out with a younger Dale.

Perhaps this helps explain that Amy’s high-functioning autism, with its attendant verbal skills, was no easier for any of us to deal with, least of all for Amy herself. Verbal and able or not, my girl needed an education which was both mainstream and condition-specific. In her mainstream school, she had the advantage of being surrounded by positive role models, free from communication or social difficulties. Her friends (the

Famous Five), without understanding exactly why, accepted that Amy was different. From the word go, as she started school, she was beginning to learn how to adopt her peers' social skills. Equally, the Five were fast becoming adept at using Amy's obsessions to engage with, motivate and include her. Just as it had proved in nursery, this was already proving to be a key to her success.

Fortunately we had recognised in time that it was crucial that she had support similar to that which she had previously received in nursery. Supported by this structure, she was given the social tools she needed. That support is vital, not just for Amy, but for any child with ASD or AS who is attending a mainstream school. Sadly, for many children, the provision of this remains far from ideal.

Yes, Amy was already nearly six in the autumn of 2005 when she started school. Importantly, she had had a deferred school year, making her the class eldest. This initiative lessened both her social pressure and the developmental gap with her peers. It was a tactic which had already worked brilliantly for Dale. Further, we had the support of all of the Five's parents. Parents try everything to ensure their children reach their full potential, to protect them from harm, but these issues are compounded when your child has ASD. Autism is an unseen handicap, devoid of physical or outward features. Like so many, Jamie and I debated about when we should introduce others to our children's condition.

There is no single, easy answer. In situations like Scouts, we had always disclosed and explained Dale's autism, for many reasons. It helps those in charge understand and support the child better, and gives them protection under the existing legislation. Now it was Amy's turn as she started Brownies. Unquestionably, it was the right path to take as it enabled those in charge to make the adjustments needed to help both Dale and Amy enjoy full inclusion, and simultaneously ensure safety for all. Everyone had a good time. Of course, Amy's idea of a good time wasn't always the same as other people's!

In the early spring sunshine of 2006, Amy was in her favourite place,

the stables, and she couldn't believe her luck! She spotted the farrier, whom she hadn't met before. He was hard at work, shoeing a big mare. The young yard girls, sitting relaxing over lunch, started nudging each other. They had prime viewing as Amy cornered her new victim.

"Hello! What's your name?"

"Scott. What's yours?"

"Amy! What are you doing?"

Everyone at the yard already knew that Amy had an in-depth knowledge of horses and farriers. Everyone, that is, except Scott. She went full throttle – the whys, whens and hows of her hundred questions unfolding. He took it all in his stride, answering everything, and he still managed to shoe three big horses throughout the onslaught! I went to retrieve her, to explain her autism and thank Scott for his incredible patience.

"So what! Her knowledge of horses is amazing!"

I jokingly offered to bring her down the following week for a repeat performance.

"Any time! She's something else!"

During the Easter holidays, Amy couldn't believe her eyes when she saw Scott again. This time I decided to distract her, but it was too late. He got in first.

"Hello, Amy! Nice to see you again. Fire away!"

Back at school for the summer term, Amy continued to improve, benefitting hugely from a little social group which had been in place since the start of the session, the Gingerbread Group. The Group included several neuro-typical kids from the school. Amy's teachers gave her peers an explanation of her autism and why she behaved the way she did – with the positive effects of that chat greatly outweighing the negative. Inevitably, a few children tried to exploit her, but they were doomed to fail. Amy had taught strategies and a bevy of well-educated peers as protection!

The Gingerbread Group focused on the big issues, like bullying, but it also taught Amy basic social skills: how to sit in a chair properly, to look and listen, engage appropriately within a group. It let her practise

problems and solutions in a safe, controlled environment. At the school gate, she proudly showed me her sticker. "I asked a good question today!"

To ensure she understood how pleased I was and to encourage her success, I reacted with my OTT, Oscar-winning response. "Amy! Well done!" I leapt up and down, gesticulating madly. "Congratulations! That's brilliant!"

A nearby parent added to the congratulations, asking what exactly the occasion was. With Amy in earshot, I had to show off her sticker, and . . . well, I know, it sounded so lame.

"Er, that's lovely. Well done, Amy."

And the parent shuffled off, shooting me an over-the-shoulder look. Written all over it was *Go get a life, wummin!*

Never mind, I knew what I meant, and at home, her dad did too. Most importantly of all, Amy knew! That visual reward and the positive reinforcement of praise worked.

After school, there were regular, shared times in the Five's homes and gardens. Occasionally I would take the friends out, as a gesture of appreciation. Although their parents protested that this was unnecessary, it was a pleasure. Without her friends, Amy's quality of life and progress at school would have been very different. Even in that very first year, that was apparent.

One day, as the school bell rang, I saw Amy, holding Shannon's hand, with Regan following. Amy's happiness was obvious – Shannon was being hugged and kissed to bits. Clearly, however, Shannon was uncomfortable with the exuberance of Amy's affection! As I intervened, Amy's reply was unforgettable: "Nuala, it's okay. I know what you mean. I don't want people to think that Shannon and me are gay!"

Trying to keep my belly laugh under wraps, I asked. "Amy, what does gay mean?"

"Nuala! Do you not know? Simon in my class told us. It's when a man loves a man, and a woman loves a woman, and they can get married as well. Simon is good at telling you things."

Aye, so he was!

"Amy, everyone is different and that's okay!"

Just then, Shannon and Regan grabbed Amy's hands and shouted out, "Come on, Amy! Giddy up! Let's get to Funworld!"

Of all the challenges and social barriers a child with ASD has to face in life, from a parental perspective, perhaps the most heartbreaking is to witness your child's social isolation, day after day after day. My children have been lucky, but many parents have to cope when their child has been unable to establish that most basic of human needs, friendship. Never underestimate it. For those affected by autism, having a friend is every bit as important as it is to anyone else, yet it is possibly the most complex challenge of all. Friendship, after all, imparts social belonging and is inclusive in a real and meaningful way. Which of us could live without our friends?

Both my children have often told me that they hated the isolation when they couldn't engage or integrate socially. Both have told me that in an attempt to cope, they would withdraw more into their autistic world, immersing themselves further into their obsessions as a substitute for company. I repeat: never underestimate the need of anyone, anywhere on the spectrum, for friendship. It may be their greatest aspiration and, for some, it is underscored by the harrowing knowledge that they are different. One child with Asperger's asked his parents if there was a shop called Friends Are Us where they could take him to buy a friend. How much we neuro-typicals take for granted!

In 2010 the NAS (National Autistic Society) Our Impact Report revealed that over 40 per cent of children with autism have no friends. Unsurprisingly, these socially vulnerable children and adults make easy targets for bullying. Some traumatised children have needed to move from mainstream to additional support needs (special) schools, in order to ensure they are protected from further bullying.³ Amy was one of the lucky ones. Her teachers at Moorfoot knew how to work with her

autism in a positive way. Small but constructive adjustments made a huge difference. The award of a horse sticker instead of a star, being allowed to draw horses in her busy book on completion of classwork or work well done, all these little things add up. Amy was following a similar pathway to Dale, except Dale's educational motivators had been trains and dogs.

Together with the positive use of her equine obsession, Amy benefited from an excellent Individual Education Plan (IEP), with realistic and achievable objectives. Some of the adjustments were so simple but essential, where and with whom Amy would sit in the classroom, for example. The right seating position allowed the teacher to prompt Amy and minimise distractions. This showed a real awareness of her sensory integration issues. This is a particularly important issue for almost everyone on the spectrum, and it needs to be unpacked here.

Practitioners now understand how sensory stimulus can overload an environment. Sensory issues alone can have a direct affect on the person's ability to cope with situations, and it can completely undermine their receptiveness to learning. Like many others, Amy had numerous sensory difficulties. Her senses could be heightened or reduced with a marked effect on her overall perception. As a child, Dale had also had many such problems, but his difficulties were harder to discern because he was unable to tell me. Amy could tell me, and it shocked me to discover that her sensory difficulties were greater and more varied than Dale's had ever been. It seems likely that in her greater awareness of her world, Amy was more vulnerable to this particular shaft from Hell.

Consider the sensory stimulus in a classroom: the glare of strip lights, the wall displays of paintings and projects, all the colours and endless information. We absorb about 70 per cent of our information from our environment visually. With all the other energy involved, is it any wonder the child with autism has problems deciphering? Think of the sounds and smells of a classroom, the feel of the seats and desks! No wonder they become overwhelmed. Add people into the mix. Think

about the chattering and echoing and how that distorts the auditory ability to process verbal instructions. Have you any idea what a fire alarm does to someone with ASD?

Even to this day Amy still struggles, particularly with food, let alone with the environment in which she is eating. For example, one day not too long ago, as I was crunching away at my cereal, she said, "Nuala, eat your breakfast in another room. The noise hurts my ears and the look and smell of it makes me feel sick."

Compounding this problem is the sufferer's differing spatial awareness. Amy often uses her peripheral vision and she appears to squint. Seeing this, you might sometimes conclude she wasn't paying attention. In a busy mainstream school overflowing with people, is it any surprise that many children with inadequate or no support struggle? How many are wrongly excluded from the life of the class because their problems have been misunderstood or not recognised?⁴

Something else which amazed me about Amy's autism was that her obsession with horses was even fiercer than any of Dale's childhood obsessions. Unbelievable! Even Dale's ten-year affair with *Thomas the Tank Engine* wasn't as intense as this. Already as a six-year-old, Amy was able to manipulate anything and everything to bring horses into the equation, and she honed these skills throughout her primary years! From nursery days onward, Jamie had been in the habit of taking her to the local shop every Saturday to buy a *Daily Record*. He thought the paper was for him. One windy Saturday, in the summer before she started school, he was to discover otherwise. As her dad handed over the paper to be scanned, a full-blast Amy blurted out, "Jamie! Remember and keep The Punter for me!"

"The Punter" was the name of the paper's horse racing section. Amy would make collages from the few pictures of horses that were in it, but then she would create horses from anything – leaves from a tree, food on her plate! As a bold seven-year-old, she even managed to capture a bricklayer who was working in our garden.

“Rab, do you have any spare cement I could use?”

With this and other materials so artfully gained, Amy built Brickie the Horse! Rab left a gap at the back of a couple of bricks, allowing Amy to complete her sculpture with the final flourish – a tail robbed from a nearby bush! Brickie was duly painted to her exact specifications and stood in our patio for three full years (with regular replacement tails, naturally!).

Using my children’s obsessions creatively has always worked. It works every bit as well in professional settings, as good practitioners know. When Amy displayed a new or different type of behaviour where the underlying reason for it and for her resultant distress was unclear, I had to figure out the trigger, Amy couldn’t express what was wrong. This was the iceberg effect. With the iceberg effect I had to decipher if there were any sudden changes at school or in her home environment. Because the behaviour was abrupt and new, I had to consider if there was an underlying medical reason. A child with autism has difficulty interpreting pain and, undetected, this can cause serious problems.

Amy’s obsession with horses was already extreme, at both school and home, but that had its uses. As every mum knows, the beginning of school is a time of scraped knees, bugs and illnesses. Amy certainly had her fair share of all that. For more than a week in the May of that first year, she was unsettled and unhappy, repeatedly telling me that she had a sore eye. As a nurse, I could see that her eyes were fine. Nevertheless, I kept reassuring her. Eventually as the week went by, her behaviour became more erratic and challenging. She insisted her eyes were really painful. I drew on her obsession.

“Amy, how sore is your eye? Is it a walk, trot, canter or gallop sore?”

Immediately she understood, screaming at me, “Nuala! It’s a gallop! It’s galloping sore!”

Now I knew that she was in real pain. I had a doctor check out her eyes, ears and throat. To my horror, the doctor confirmed she had a severe middle ear infection. With Dale too I had been able to use the

colours and numbers of his *Thomas* trains to help him express his pain and anxiety levels. Similarly, in his early school years he used colour charts or traffic light systems. He even had a red card when he needed to stop or take time out.

It is essential that mechanisms are put in place to allow a child to communicate and express their negative feelings or needs. Failing to do this is disastrous. What is a child to do? Some may scream, have tantrums, others may cry intensely and some may self-injure. I know of children and adults with ASD, experiencing the severe pain of acute appendicitis and the like, who were almost on the brink of death before their physical symptoms were recognised. Because of their autism they were able to mask their symptoms and were unable to express what was wrong. Their pain confused them. How dangerous.

Amy was lucky, and with a course of antibiotics her problems soon cleared up and before long she was back at school, enjoying summer-term life with her friends. There were terrific activities too – Brownies, drama, gymnastics – and, of course, her weekly fix of horse riding. So with Amy settling in, it was time to focus on Dale, who had an exciting agenda of his own.

all because of henry

All Because of Henry is the heart-rending story of Nuala Gardner and her remarkable struggle to bring up two autistic children – with the help of Sir Henry, Wee Henry and Thomas, the family's incredible four-legged friends.

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