

ADHD: A Mother's Story

Despite persistent problems throughout his life, Tom was not diagnosed as suffering from Attention Deficit Hyperactivity Disorder until he was 24 years old. In a moving account of the impact on both her son and his family, Tom's mother Anne Douglas recalls the struggle to cope as Tom was growing up.

For so many years, the torment and chaos of undiagnosed and untreated Attention Deficit Hyperactivity Disorder (ADHD) wreaked havoc on my son Tom's childhood and family life in general. As a baby and preschooler, Tom's severe hyperactivity, impulsive behaviour, distractibility and poor concentration meant that he raced through the surface of life like a runaway train, scattering people and objects as he went. New toys, new people and new situations never satisfied him. Everything was a battle. Nothing captured his attention for long and he was relentlessly into everything.

Tom never learned from his mistakes, had no sense of danger, and bumps and bruises were the norm. The day always began from the moment he was awake with his exhausting and insatiable demands. No one was prepared to babysit because he was so exhausting and a liability.

'His demanding and difficult-to-satisfy personality continued to make both his and our friendships and relationships fraught. I became more and more isolated and lonely, wondering where I was going wrong'

It was impossible to enjoy him and no fun to take him anywhere. His energy levels were incredible. As parents, we wondered where we were going wrong.

The health visitor said: "He's not hyperactive because he sleeps all right. You really must be firmer with him and not let him get away with so much. Try giving him a soothing bath at midnight if he's active all the evening." Tom's playgroup said: "He's a real live wire and obviously only here for the social side of things. He is very active, doesn't concentrate, plays noisily and chats all the time." Family friends said: "Boys are like that. He's just a handful. He'll grow out of it. I'm sure if you were less stressed and firmer with him, he would settle down." Our GP said: "He's just hyperactive. He'll outgrow it by puberty. I'll arrange counselling for you, if you like."

He's 'just hyperactive'

I particularly remember a lengthy wait at my doctor's surgery, when my then 18 month old son raced incessantly around the waiting room, oblivious to my desperate attempts to keep him calm and occupied. I mentioned that he was a very active, difficult and defiant child, faintly hoping for some understanding and support. However, the doctor's casual remark that Tom was 'just hyperactive' failed to appreciate the significance of this extreme behaviour. The doctor offered no further suggestion, and I came away feeling further demoralised.

Life continued to become more and more stressful. Increasingly, Tom seemed to be impervious to any form of discipline. He did not learn from his mistakes, was possessive and over competitive, was unable to share, was volatile and quarrelled with friends. His only love was sport but even that always ended in rage or tantrums when things did not go right. When Tom did find something which interested him, he would become over-focused, intense and insist on a game being played endlessly. Co-operation was just not possible as, with him, it was all or nothing.

The arrival of his brother a few years later, who appeared to develop and behave more appropriately, increased our growing sense of worry about Tom's behaviour. By this time, it was also apparent that our 'whirlwind' was standing out as different from his peer group. His demanding and difficult-to-satisfy personality continued to make both his and our friendships and relations fraught. Indeed, I became more and more isolated and lonely, wondering where I was going wrong and in need of support and some respite with never a let-up or a moment of peace and quiet.

I felt deprived of adult company and imprisoned by my unrewarding and exhausting daily existence. However, it was obvious that my participation in toddler clubs, coffee mornings etc., would mean constant supervision of Tom to prevent him hurling toys at, or disrupting, other children. Conversation would be impossible. Indeed, even attempts at telephone conversations at home were fraught with trauma as Tom repeatedly interrupted even the briefest call.

'Each every day task for an uphill struggle. Family mealtimes became an endurance exercise'

I desperately read all the child development and parenting books I could get my hands on to try and find better ways of managing and loving Tom, but our relationship was becoming very stressed as he constantly confronted and defied and was resistant to any attempts to improve the situation, no matter how hard one tried. Although I always seized any opportunity to praise Tom for 'good' behaviour or endeavours, these rarely occurred and could never be built on when they did.

Each every day task was an uphill struggle. Family mealtimes became an endurance exercise, as Tom strenuously resisted certain foods, regularly causing friction with his continuous verbal and physical defiance and non-conformity, always hypersensitive to the conversation,

noises, actions or movements of others. He would only use a specific mug, cup, plate or spoon, and became quite hysterical if he could not do this.

Tom would only sit on a particular chair and threw enormous tantrums if this was not possible. He was unable to concentrate on watching television unless things such as ornaments which were on the periphery of his vision were removed.

School

At school Tom was sociable, but gave up easily when things were difficult. From an early age, it was felt he had the potential to do better and was just lazy, disorganised, forgetful and easily distracted. He was always easily upset and angry, but there were never tears – only tantrums. His reaction to events and situations at home and school was increasingly hypersensitive. Life was like walking on eggshells. I was encouraged to believe that Tom would gradually grow out of the behaviour and conform as he matured and settled down. While our friends were able to relax and enjoy weekends and family holidays, for us such events were becoming a regular nightmare. Having endlessly exhausted all the activity options at home, the only way to survive weekends was to arrange regular stimulating outings to save our sanity. Needless to say, these were marked by tantrums and insatiable demands with little enjoyment for anybody.

As Tom burnt off some of his hyperactivity, we were left feeling drained and trapped in a vicious circle. No matter what sort of outings and holidays might have been appropriate for his brother or us, it was essential to seek something that would primarily provide entertainment for Tom. Every holiday had memories of confrontations and the inability to relax as we tried to find a happy medium and address the needs of everyone. No one could really understand why we seemed to return from holidays as stressed as we were before we went, but there were so many places we just could not contemplate.

By the time Tom reached puberty, things were rapidly getting worse. Both at home and school, relationships were very strained. Life was one long round of arguments and tantrums from morning to night – only with more damaging effects. Tom also seemed to gain enjoyment from goading people, mostly close family members. He never knew when to stop and was not satisfied until he had pushed someone to the limits. The harder one tried to ignore this, the more he would try to do it

'No-one could really understand why we seemed to return from holidays as stressed as we were before we went'

We were at our wit's end and desperate to know where to turn for help, yet feeling too ashamed to expose our apparent inability to bring up our child appropriately. Every parents' evening told stories of poor compliance, shoddy and incomplete work, class clowning, no homework, incessant talking and easy distraction both to himself and others.

At this time, a tutor told me he felt Tom was 'different' from his peers. When I said I felt Tom did not seem to understand cause and effect, the teacher's rather patronising response was that 'at 13 years of age, of course he does!'. No amount of encouragement, incentive, praise or reward made any difference. Tom would say, 'I don't want a reward, because I won't do it anyway'.

It became hard to believe that Tom's actions were not deliberately intended to annoy. Varying degrees of reward and punishment failed to motivate Tom to improve his ways. Far from having the desired effect, he often seemed to view punishment as a challenge to beat.

Teachers clearly looked to us, as his parents, to improve the situation and obviously inherently questioned our discipline. When he came out of the restrictions of a school day, Tom would unleash all his frustrations and pent up energy at home.

Increasingly, we realised Tom had little perception of how his verbally and physically impulsive behaviour affected others. He was extremely volatile and easily roused to anger when things did not go his way. And when things blew over, he failed to appreciate the effect his reactions had had on those around him.

'Tom confided in me that he used to think he was a freak and now feels that he has so much to catch up on to make up for lost time'

It proved fruitless trying to rationalise or reason with him, as he had a tendency to see everything in black or white and must have the last word.

Tom's GCSE results were, of course, disappointing, but it was with mutual relief that he managed to achieve a few pass grades on a second attempt and go on to further education. However, the lack of structure, and demands on him for deadlines for assignments, further reading and research, meant that Tom struggled to maintain effort or interest. Although finally scraping a further qualification, studying had clearly been a burden and held no interest for him.

From infancy, Tom was constantly in trouble for being unable to learn from his mistakes and his confrontational attitude strained all his relationships. He tirelessly sought constant stimulation to avert endless boredom, and he could not concentrate long enough to hold conversations unless he was specifically interested. His childhood was marked by mutual frustration, anger and constant arguments, and thus he was never able to achieve to his potential at school or in further education. No amount of behaviour modification had any effect. His brother – who was brought up in the same way – had no such problems.

Late diagnosis

The very nature of Tom's condition prevented his accepting help. His life, and that of his family, continued to deteriorate. It was only with his entry into the working environment, and the realisation that he was being left behind as his brother and friends entered new and appropriate phases in their lives, that Tom was forced to acknowledge his problems and became motivated to take some action. He was finally diagnosed, at the age of 24, as having severe ADHD, which, untreated, had been compounded over the years by complications. He commenced an overdue treatment plan, which included the use of Ritalin.

'Tom is now experiencing a real quality of life. Instead of criticism, accusation and rejection, he enjoys praise and a subsequent increase in his self-esteem and confidence'

Since then, the change in Tom's demeanour has been remarkable. He confided in me that he used to think he was a freak and now feels that he has so much to catch up on, to make up for lost time. The effective treatment has enabled him to concentrate, be reflective and participate in his life, instead of it taking control of him. This has given Tom a confidence in himself for the first time and he is keen to get on with his life. He realises how his untreated condition caused his academic underachievement as he could not meet deadlines, sustain the effort involved to study or concentrate long enough to read beyond the first line of a book.

Tom is now experiencing a real quality of life. Instead of criticism, accusation and rejection, he enjoys praise and a subsequent increase in his self esteem and confidence. He previously shied away from trying anything new for fear of failing once again. He can now enjoy conversations and has become confident enough to drive a car again for the first time since passing his test three years ago. However, he naturally feels a sense of bitterness at realising how much of his life was lost to him until now.

Tom is motivated to continue with the treatment because he recognises that it is effective and that he is beginning to build on his successes and can now plan goals and a future for himself. There is no doubt he clearly needs his medication to be able to lead his life appropriately and fulfil his obvious potential, previously hidden underneath the chaos of untreated ADHD.

GP bias

However, Tom's courage is finally confronting his significant problems and complying with specialist-advised treatment – and the breakthrough it offered – was very nearly sabotaged by the negative attitude of his GP. Rather than encourage Tom's efforts at improving the quality of his life, the GP allowed his own lack of knowledge of the condition and personal bias to undermine my son's participation in treatment at such a vital stage in the process.

The GP refused to prescribe the necessary medication or to support Tom in any way – clearly unaware of the real handicap of ADHD and the aim and necessity of treatment. This was despite clear documentation of the many years of Tom's suffering and the obvious benefits achieved by medical treatment over several months, which now enable my son to undertake everyday actions that the rest of us take for granted.

It was only by continued parental encouragement that he eventually persisted with treatment. Tom still only has a temporary job although he is eager to prove himself capable of securing a permanent one. Let down by his GP, he was forced to pay privately for his prescriptions – taking a large proportion of a frugal salary. Unless he has the medication, he has little hope of being able to concentrate sufficiently to maintain the noticeable progress he has made in his job, nor of supporting himself in the future. Despite appeals to this effect, Tom's GP remained unmoved and unwilling to help him.

For almost 25 years, Tom's life has been utterly chaotic and distressing, both to himself and those who care about him. Those outside who were involved with him had little time for his erratic, volatile, immature and unreasonable behaviour. Yet underneath it all, one sensed there was a lost soul desperately trying to feel normal. Effective treatment has unlocked a likeable and enthusiastic personality with great potential.

Where once Tom had no future, at last he has the chance of being able to make the most of opportunities he has in life. His new-found determination has now enabled him, at last, to find another GP who appreciates the reality of ADHD, and who has an open-minded and understanding approach to Tom's needs. For Tom, and for his family, the relief is enormous.

'However, Tom's courage in finally confronting his significant problems and complying with specialist-advised treatment was very nearly sabotaged by the negative attitude of his GP'

It is vital that GPs, educationalists and other professionals are open-minded, become informed and acknowledge the existence and reality of ADHD, as well as their role in providing essential management and support. ADHD deserves to be taken seriously. Its effects need to be experienced to be believed. Sufferers are already serving a life sentence. Understanding and help is the key to their freedom.

Anne Douglas

Anne Douglas is writing here under an assumed name to protect the identity of her son. Anyone who would like to contact the author can write to her via The Editor, YoungMinds Magazine, 102-108 Clerkenwell Road, London, EC1M 5SA., and we will forward the correspondence.

This article is based in part on material contained in chapters by Anne Douglas in two new books – ADHD: Research, Practice and Opinion edited by Paul Cooper and published by Whurr Publishers at £19.50 (tel: 0171-359 5979); and Attention Deficit Hyperactivity Disorder: Recognition, Reality and Resolution by Dr G D Kewley, published by the LAC Press at £12.50 (plus £1.60 p & p) (fax: 01403 260900).