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Making sense of Self Injurious behaviour: a parent's perspective

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What is self-injurious behaviour? Is there a qualitative difference between self-harm and self-injury? Do we distinguish because of intellect and intent? People who self-harm often say the physical pain they feel takes away the emotional pain they are feeling; does my son have the intellect to think in that way – does his autistic thinking enable him to make that connection? Or is it a more complex picture than that? Is there just one cause or many? Do all the behaviours mean the same thing?

Winston Churchill famously said about the Soviet Union and its propensity for secrecy that it was a 'riddle wrapped inside a conundrum inside an enigma.' That is how I have come to see my son's autism – a secret that I need to discover and decipher. Coming to understand the many facets of his autism has become the biggest challenge of our lives as a family. It seems each day throws up another problem, the twists and turns he experiences as he tries to make sense of the world impact upon us to the point where quite often we are left just as frightened and bewildered as he must be.

Christopher is a beautiful 19-year-old young man who can sing like a bird and loves nothing better than splashing about in the swimming pool. He also happens to have autism and a severe intellectual learning disability. Christopher finds our neurotypical world incredibly frightening and confusing; this fear, this confusion, makes him very anxious. These anxieties frequently make him very distressed. When he becomes distressed he is likely to injure himself and others around him. He is an incredibly complex young man, every day is a challenge for him and those who live and work with him. When we get it right the rewards are enormous; when we get it wrong the results can be disastrous.

The early years were dominated by his ability to keep going for what seemed 24 hours a day. He was like a tornado through our lives. He was, however generally anxiety free and had an enormous capacity for enjoying whatever he found amusing. Living with Christopher was by turns exhausting and exhilarating.

When puberty hit Christopher it was like a locomotive out of control, it hit him full on. It was as if overnight he became a different child. Intellectually as a family we knew it would happen but we could not have been prepared for the impact this had on him, his mood oscillated between extreme anxiety and excitability to being incredibly distressed and tearful. It took all our inner reserves and it became increasingly difficult to keep Christopher on an even keel. His behaviour became more and more erratic and he began to hurt himself and us. We became more and more isolated as a family. We could no longer do all the family things we had previously managed to

do. There were no services that could help us in any real way and so we coped alone. We sustained many injuries but worse than this Christopher was hurting himself. For us as a family the self-injury was far more painful to endure than anything he could inflict on us. It is impossible to convey the emotional impact that the distress and unhappiness Christopher was experiencing had on those that cared for him. This was an incredibly bleak period in our lives which I hope will never be repeated.

It was obvious to us that he was struggling with an inner rage and fear and he would sometimes lash out at us and at other times turn this rage in on himself. On one occasion which typified his behaviour Christopher had attacked me and had hold of my hair so tightly that it was pointless trying to free myself. He had been pulling me around the room and now pulled me toward the floor. He lunged at me with his mouth open and his teeth made contact with my shoulder... He suddenly let go of my hair and I rolled out of his way and curled my legs up and put my hands over my head. He was sobbing now as he threw himself onto the sofa and pulled his sweater over his head. He began to jab his elbow into his side. Every fibre of my body wanted to reach out and comfort him. Watching him pummel his flesh caused me far more pain than any bite. His sobs subsided and he said, 'Cuddle mummy.' I sat down beside him and he put his head on my lap and I began to massage his head singing softly his favourite lullaby, 'Hush little baby don't say a word, papa's gonna buy you a mocking bird.' I finished the song and he said, 'Again.' I always had to repeat it at least twice. I continued to massage his head and sing quietly, the pummelling slowed down and eventually stopped. He stayed still for some time and then he suddenly jumped up, laughing loudly, shouting, 'Cheeky monkey, cheeky monkey.' He stopped and put his fingers to the tears that were trickling slowly down my face. He grimaced and said, 'Sad face. Mummy laughing.' My beautiful boy was 13-years-old.

At this point it was difficult to do any work with Christopher and we were persuaded to look at medication to address the mood swings so that we could then put strategies in place to help him cope with his feelings and help him through what was obviously a very difficult time in his life.

We had resisted the idea of using medication, often under intense pressure, for the previous 15 years and the emotional impact of having to resort to medication was devastating. It was a very difficult time and I felt I had let my son down. However, the medication did in fact have an almost immediate effect in that his mood stabilised, allowing us a window of opportunity. We took stock of the situation and looked at when Christopher was likely to self injure: low mood, anxiety, too much unstructured time, frustration due to the communication difficulties. Our response and reaction to behaviours all impacted on him. We learned to recognise the signs eg, anxious questioning, withdrawal. We also looked at ways of pre-empting the eruptions. We looked at how we lived and made the changes to our environment, our routine and the way we communicated. We worked as a team, offering him the consistency and structure that is so important to anyone with autism.

Having addressed some of the more urgent issues we began to look more closely at the whole area of self-injury. We had been focussing on the way Christopher hurt himself when he was upset but we had not really looked at the fact that he was also hurting himself seemingly unintentionally and we hadn't really understood the impact

of his sensory difficulties. Firm massage and gentle singing had always calmed Christopher down and we knew that he had sensory issues in that he found certain sounds and tones distressing, but then I began to read in more depth about the impact sensory difficulties had on people with autism. Much has been written but I found Olga Bogdashina (2003) very useful. She looks at how sensory perceptual difficulties affect the behaviour of people with autism. We began to identify the areas where Christopher had problems and at last had some more answers as to why he hurt himself either intentionally or as a consequence of his sensory difficulties. We started to put the strategies in place suggested by her; for example, building in to his time table regular deep massage. We used his love of the great outdoors to implement a regular physical activity programme and we certainly kept the opportunity for sensory overload to an absolute minimum. This, combined with all our other strategies to keep his anxiety levels as low as possible, have all had a beneficial effect.

Christopher is a very complex character; the causes of his behaviours and what they mean to him are not always easy to unpick, nor do we have all the answers, but by understanding how he experiences the world through his senses and how these senses can become 'distorted' by his autism, we feel better able to help him live in our world.

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Reference

Bogdashina, O. (2003). **Sensory Perceptual Issues in Autism and Asperger Syndrome**. London: Jessica Kingsley Publishers.