



LEARNING DISABILITIES AND/OR AUTISM

CASE STUDY

OCTOBER 2016

Stopping over-medication of people with autism: Jack's story

Eleven-year-old Jack has pathological demand avoidance syndrome and attention deficit hyperactivity disorder (ADHD). His mum, Julie, talks about the impact that over-medication had on her son and how he's better off without the cocktail of drugs.



At this point, Jack's behaviour worsened and his academic learning suffered. He was sleeping for just two to three hours at night and as a family we struggled to cope with his severe meltdowns, violent episodes and destruction.

A VARIETY OF DRUGS

After much soul-searching, we were assured by the child and adolescent psychiatrists and psychologists that medication would be the kindest way to help Jack. After a short period of time he was taking a variety of drugs. Every day we had to remember the right pills at the right time: 30mg Medikinet xl and 10mg Fluoxetine in the morning; 10mg Medikinet xl at lunchtime; 5mg Methylphenidate at teatime and finally 4mg Circadin before bed.

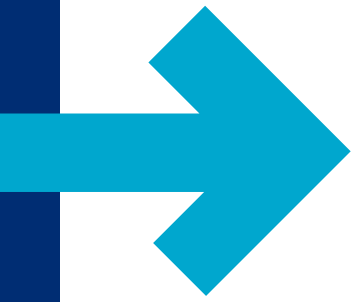
We met with the Child and Adolescent Mental Health Services (CAMHS) team regularly to review his medication but each time the doses went up, not down. We started to become very concerned as Jack became more and more subdued and lost the fun-loving, bubbly personality that we know and love. Sometimes he seemed a bit spaced out but still it did not make any difference to his behaviour and anxiety levels. One of these medications can cause heart problems so Jack had to have ECGs and routine tests to make sure that its side effects did not outweigh the benefit.

“When he was just four years old and starting nursery, my son Jack was diagnosed with autism. He was finally given a full diagnosis of pathological demand avoidance syndrome which means Jack avoids demands made by other people as he has high anxiety levels when he feels that he is not in control. He received a full statement of special education needs before he started mainstream school in 2009.

Jack was routinely assessed by an educational psychologist, a speech and language therapist, child psychologist and members of the autism team at the Integrated Disability Service (IDS).

COMPLEX NEEDS

Jack was dealing with complex needs. He had sensory issues, incontinence and high anxiety and we decided to move Jack to a special school in the area. At the age of six, Jack was further diagnosed with ADHD.



We told the CAMHS services that we were worried about his medication, as he was by now taking Risperidone which was causing major weight gain. Jack very quickly grew excess breast tissue which caused him to become very self-conscious and he refused to go swimming or undress in front of anyone.

In February 2014 and by now nine years old, Jack's behaviour was worse than ever. On one visit to CAMHS, things were so bad that he had to be given an immediate sedative shot.

REVIEWING JACK'S DOSAGE

Over the next few weeks, I began to home educate Jack. This had an almost immediate effect and the decrease in his anxiety levels and violent meltdowns was significant. Conscious of the cocktail of drugs swimming around him all this time, we wanted to try weaning Jack off all medication to see how he might react.


We consulted with CAMHS who gave us their blessing and advised us to gradually reduce the dose and report back immediately if any changes occurred. Over the next 12 weeks we slowly lowered the dose, reporting on progress at each CAMHS review meeting. The change in dosage appeared to cause little change in Jack's behaviour but we began to see more and more glimpses of Jack's real personality and he became a lot less hungry which had an impact on his weight.

Eventually Jack was completely medication-free and as his behaviour seemed to be the same, with or without the drugs, we decided to withdraw his medication permanently and manage his autism and ADHD with appropriate behaviour strategies and counselling.

HAPPIER AND MORE RELAXED

Jack is now blossoming academically. Since taking Jack off his meds and home educating him we have a much happier, more relaxed child and the knock-on effect of this on the family is tremendous. We are now able to do activities together and Jack has even found the confidence to perform in a local theatre production! Whilst he still struggles with social and communication difficulties, he is a million miles from where he was just two years ago. Jack is now supported by a family support worker and is transitioning over to an education, health and care plan.

While drugs can sometimes be useful, we felt uncomfortable that our child was taking such a variety of drugs in such high doses. I feel it is important that children like Jack have their medication regularly reviewed so that they are not taking more than they should. Parents and clinicians should be able to work together to decide whether it is safe and appropriate to try and wean their child off their medication.

We have seen how, when managed properly in an appropriate environment, Jack can manage his behaviour without the need for the quick fix of medication. We can now look forward to seeing him develop and thrive in the years ahead. 

Julie is the mother of Jack who is 11 years old and has complex needs.

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