The parent's perspective

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"A wonderful son of whom I am very proud": the mother of a 14 year old boy with attention deficit/hyperactivity disorder describes her experiences.

From day one Joel was a difficult baby: he slept little, cried frequently, and was always hungry. I remember attending every toddler group, swimming group, and "tumble tots" in an attempt to burn off some of Joel's energy, all of which failed. Joel got into so much trouble at the toddlers' group that I ended up running it myself. Nursery refused to take him out on trips and the friends I still had dreaded us turning up at their house. I felt like a failing parent and was convinced I was doing something wrong—none of my friends' children were like Joel.

My understanding GP referred us to the local child development centre, where Joel underwent a full assessment just after his second birthday. Following this, we attended social skills courses and tried every behaviour management programme available to us, but Joel's behaviour remained a challenge. At the age of six, Joel was diagnosed with attention deficit/hyperactivity disorder (ADHD) and medication was offered, which I declined at this stage. I continued to read and learn more about ADHD, while family life with Joel became increasingly difficult. When Joel was 8 years old, attending his third primary school and failing academically, I reluctantly accepted the offer of medication. Joel began a trial of methylphenidate in the early part of 1997. At this stage our family life changed in many ways. A strong memory I have is of going on holiday shortly after Joel had started medication and, for the first time ever, I walked along the street with Joel holding my hand. We even went on a fairground ride together, because we were able to stand and wait in the queue. These events sound trivial—unless you are a parent of a child with ADHD.

For the first time ever, I walked along the street with Joel holding my hand

Initially, many family members and friends expressed concern about my decision to start Joel on medication because of the negative press regarding methylphenidate. This was hard for me because it had been a very difficult decision. My life seemed to be so full of negative issues regarding Joel that I began to wonder if I could ever do anything right. However, the improvement in Joel was evident to all who saw him while the short acting medication was effective.

To the present day, mornings remain very difficult. The effect ADHD has on the household is beyond explanation. It is a major task to ensure that Joel arrives at school prepared and on time. Despite Joel now taking extended-release methylphenidate, which has resulted in improvements, homework continues to be another problem area. Joel usually

fails to write down the whole question during lessons; instead, he jots down some key points but by the time he gets home, he cannot remember the question. In addition, Joel struggles with time management (for example, on projects) and always rushes to complete tasks.

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Sleep, or lack of it, has always been problematic, as Joel only sleeps for a few hours each night. We have tried many sleep programmes, from the very basic to the use of melatonin. In addition, we have tried giving methylphenidate at various different times of day, but to date Joel continues to have major problems getting to sleep.

I know that many more worrying times lie ahead—driving, employment, and independence. I have all of these concerns for my daughter too, but to a different extent. Over the years I have learnt to look at the positive sides of ADHD, but still I feel sad and frustrated. Joel has to work incredibly hard at everything and despite all his efforts, he frequently fails. As a result, Joel's self esteem remains fragile. However, I am

Joel in 2002.

fortunate that my daughter has always been, and still is, very positive and protective towards Joel.

Joel has enabled me to see so much more of life. I have adapted to a 20 hour day, and learnt to look at life through Joel's eyes as well as my own to help me predict the challenges he will face. He is a wonderful son of whom I am very proud.

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