

## ***SHOULD I INVESTIGATE ADHD AS A POSSIBLE CAUSE OF MY CHILD'S BEHAVIOURS?***

*Compiled by Helen Dudeney – Australian Gifted Support Centre (2007) from NSWAGTC GLD email support group*

*ADHD is a chemical, neurobiological problem that undermines the cognitive management system of the brain.*

*The three core symptoms are inattention, impulsivity and hyperactivity. These can occur either separately or together.*

*It is suggested that about 5 – 7% of school age children have this disorder.*

*The level of impairment experienced by the student in the areas of social, academics and development of self-worth should be considered when assessing the need for diagnosis and intervention.*

*Diagnosis and assessment should be comprehensive and multi-faceted. It should follow the following steps (Selikowitz, M)*

- 1. Detailed developmental history looking at learning and behaviour provided by both the parents and the teachers.*
- 2. Paediatrician with expertise in the area should examine the child – to eliminate other possible causes.*
- 3. Diagnostic psychometric testing and achievement tests to identify cognitive strengths and weaknesses. These also provide a base line for comparison once an intervention is introduced.*
- 4. Neuro-electrophysiological test - objective test of brain function.*

*The DSM IV-TR (Diagnostic and Statistical Manual of Mental Disorders) suggests that ADHD is a diagnosis of exclusion – last resort – after ruling out everything else.*

*The media has portrayed ADHD in a very negative way and has had a lot to say about medication, which tends to influence most people when they are thinking about this subject.*

*Possible outcomes for children with ADHD who do not receive an accurate diagnosis and adequate treatment include*

- underachievement at school or dropping out*
- identification with a delinquent peer group and oppositional behaviour or conduct problems*
- emotional problems*
- social skills problems*
- anxiety problems*
- depression (suicide risk)*
- increased risk of addictions (smoking, alcohol use, etc)*

*Further to this, current research in 2004 is indicating that not only is accurate diagnosis important, but if the diagnosis indicates ADHD then it is important to use stimulant medication. This research has shown that children with*

*ADHD have anatomical brain abnormalities in the fibre pathways in the frontal cortex, that is, in the white matter of the brain, as compared to children without ADHD. In addition to this it identified that children with ADHD who have received stimulant medication for an extended period of time, have less abnormalities in the white matter than those children with ADHD who have not had stimulant medication. (Ashtari, M, 2004 in Susman, E, Doc News)*

*The co-existing conditions of giftedness and ADHD add a further complexity to this. Deirdre Lovecky puts forward an interesting comparison with gifted children, gifted children with ADHD and average children with ADHD. She suggests that gifted children know the strategies to apply themselves academically and socially and they can use them efficiently. Gifted children with ADHD know the strategies, but they are not able to use them consistently and efficiently, and average students with ADHD don't know the strategies.*

*When gifted students with ADHD remember to use them the result can be outstanding.*

*Management of ADHD should be a multi modal approach. The medications that are prescribed for ADHD are not a cure – they are part of that management approach. They are like eyeglasses, they alleviate the symptoms but only work when being worn/used. They aim to correct deficiencies in the brain chemistry on a daily basis, much like insulin is used for diabetes. Chemically Ritalin is regarded as similar to many asthma medications because it is sympathomimetic (Kewley, G, 2001) (ie mimic the effects of the hormone epinephrine (adrenaline) and the hormone/neurotransmitter norepinephrine (noradrenaline). What the medication can do is give a window of time when other strategies can be learned and practised.*

*The following comments have been made by a number of families who have been actively seeking ideas of how to assist their gifted children who were struggling with school, friendships and perhaps also the development of positive self-worth. Where the age of the child is known it has been included. These comments give a picture of how these parents have come to the decision to investigate ADHD and the use of medication to alleviate its symptoms.*

*These families are all members of an email support group focussing on gifted children with learning difficulties. Several members of the group also attended one or two group meetings held in 2007. At the first meeting, the guest speaker was a developmental paediatrician (referred to below as "Developmental Paediatrician"). The second meeting was facilitated by an educational consultant (referred to below as "Educational Consultant") who has expertise in ADHD and who himself has the condition. Each different parent's comment is separated by a dotted line.*

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**Mother of son who started medication at 8 and is now 12year old.**

I thought that I might weigh in to the ADHD discussion. I am a medical practitioner, as well as being the parent of a GLD/ ADHD child. I am very well aware that every drug that you put in

your body has side effects as well as benefits, and is only useful when given to the right person.

When I thought that my son might have ADHD, I talked about it with his developmental paediatrician, saying that I really wasn't sure if he had ADHD, and whether he needed medication or not. After doing the usual diagnostic interview, the paediatrician suggested a trial of the short acting Ritalin (it lasts about 4 or 6 hours in your body). He gave me a chart for both me and my son's teacher to fill in. It had to be filled in morning and afternoon, both at school and at home. It had a number of variables that you had to rate 1 to 5. The variables were things like fidgetiness, ability to stick to task, tearfulness, over-activity - I can't remember all of them just now.

Both the teacher and I did this for one week on zero Ritalin, one week on 5 mg Ritalin, and one week on 10 mg Ritalin. By the end of the 3 weeks, it was abundantly clear to me, the paediatrician, the teacher and my son that there was absolutely no going back. That was some years ago now.

Recently, we had the experience where my son was going to his tutor, and I had forgotten to give him his Ritalin. We went back to the house, he took it, and then went on to the tutor. I told her that it would take about half an hour to kick in, so he might not work well for the first half of the session. She was amazed at the change from the first half of the session to the second. His ability to work, concentrate, behave sensibly, solve problems, even his hand-writing changed.

My son himself now refuses to go off the Ritalin again, even for a trial, because he is well aware that he really can't do his schoolwork without it. (And no, I don't have any shares in the company !!!) He does have side effects - particularly poor appetite, but loudly shouted "no" at the paediatrician when he suggested going off it for a while. We are looking at some of the newer drugs now, to see if there is a benefit.

I didn't hear the Developmental Paediatrician speak, and I don't know what he is looking for on brain scans, but it just seems to me unnecessary. The diagnosis of ADHD is a clinical one, and can be done without high-tech equipment. Also I really don't see what possible harm can come from doing a trial such as my son did. The drug doesn't stay in the body for long, and the worst thing that can happen is that the child goes really quiet for a few hours.

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**Mother of 2 boys**

I was fascinated by the Developmental Paediatrician's talk. I came along thinking I didn't need to know about ADHD and left thinking that both my boys and my husband probably have it.

And

We started the Ritalin trial last holidays on my two boys. It has been quite successful for both boys so for me this confirms that they have ADHD. I don't know that the brain scan gives conclusive evidence but for me, having my boys' concentration and behaviour improve has been evidence enough. All our lives have improved now.

Interestingly, my 9 year old always found reading a struggle and had trouble reading for the obligatory 10 minutes a day. Now, since Ritalin, he loves reading - big thick books - and we have to set times for lights out otherwise he'd read all night (even though his Ritalin should have worn off by then).

I never suspected that my boys had ADHD until I went to the Developmental Paediatrician's talk, so it was a real eye-opener for me. They had been to plenty of psychologists and assorted therapists before and no one had mentioned ADHD.

**The boys' father comments:**

As a husband, I'll say something on my perspectives.

To those reluctant other dads - give it a whirl. As I see it, there's little, if anything, to lose, and a whole lot to gain. When I look back at some of the very marginal treatments that we tried, how long we tried them for with no sign of progress, and compare it, it seems almost ridiculous that we didn't try Ritalin earlier

I'll explain below:

Our boys have both benefited enormously from Ritalin/Concerta. Simple yet effective - for our boys it's subtle, in the sense that the boys at first said it wasn't doing anything, and the boys were still "themselves", just as playful, yet considerably more effective when it came to reading, control, that kind of stuff. There's a long list of benefit areas - it's all good, basically.

We'd not specifically avoided Ritalin, but not sought it out either. Like many, I'll avoid medicating unnecessarily - however, for us the main factor was being told by several professionals our boys didn't suffer from ADD and wouldn't benefit, so there was no particular driver to look into it further. Inappropriately "bad press" of Ritalin probably played a role in us not pushing for trials, but the main factor was poor diagnosis.

Once we realised our boys were showing many of the ADD symptoms, and learnt more about the drug, we wanted to try it. The key pieces of knowledge making us more confident were:

- In use for many decades with minimal risk.
- Strong body of evidence showing it is effective, and decent scientific understanding of how it works, and why.
- Doesn't accumulate in the system, so if you stop taking it, it goes fast.

Given how easy it is to trial, and the speed of results if it works (I'd say we knew it was effective within a week or less) I'd certainly support it being used as a "screening" method

It is probably easier to try it out, and see if it is effective, than to do loads of diagnosis and analysis trying to put names on variants of the particular problems your child suffers.

If it doesn't show obvious benefit after a few weeks of trials to run through say ~3 different dose levels and 2 types, then stop. Easy.

If it works as it did for us then great, continue.

To me it seems very cost effective, and low intrusive - especially with the longer acting dose systems of one tablet a day.



**Mother of son aged 10**

We have done a lot of careful work with the RPAH diet and had started this over a year prior to seeing the GP in 2005. As I'm sure other parents that have done this will attest, it is a lot of work! I just did it with the whole family, as it made life easier for me and my son.

Gluten, dairy, and salicylates, among other things, make a HUGE difference in my son's ability to attend, impulse control, comprehension, focus, auditory processing and so on. We have been following this for several years now, and while he can cheat a little now (and does), any cheat has a noticeable impact for several days afterwards.

However, as I mentioned in an earlier email, the diet and the biomedical approach (B6, EPO, primer, metallothionine, zinc, etc), have made a huge impact, but there was still something there. The Ritalin (which we trialed 2 months ago) has made another huge difference. Even with the Ritalin, if he cheats with his food, there is a noticeable difference but he seems to be able to manage it better.

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**Mother of son aged 10**

We have gone through (and continue with) the biomedical approach and diet, and a bunch of other things, but there always seemed to be something not quite sorted out. No one suggested to us that our 10 yr old son had ADD, but it seemed to me that I had tried everything else possible. I felt I had a duty as a parent to explore all the options. The reason we went through our developmental paediatrician was to get the qEEG, as I thought that would at least give me some "objective" evidence as to whether he had ADD before trialing medication. I was also against Ritalin – based only on the information one gleans from the continual inaccurate media coverage. After the talks by the Developmental Paediatrician and Educational Consultant, and further personal research, decided to go ahead with it for pretty much the same reasons that the 'father' outlined in his email. Interestingly enough, my son went along with the idea of the assessment and possible trial of the drug, but told me in no uncertain terms that he would NOT take Ritalin even if the qEEG showed he might benefit from it. The developmental paediatrician answered all his questions and he agreed to trial it, and after that there was no turning back. My son noticed the difference and now would not be without it. He is on the Long Acting version, which covers school (8 hours), but requests one of the shorter acting ones for anything he needs to do in the evenings.

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**Mother of son aged 12**

We only really understood that my son's difficulties were due to ADD after Developmental Paediatrician's talk at our meeting. We trialed Ritalin last school holidays and my son hasn't looked back. He himself feels the difference very strongly and is going ahead in leaps and bounds at school - actually looks forward to going (first time in 6 years) and is becoming very conscientious about his work. His teacher told me yesterday what a good term he has had and how hard he has been working. So for our son, it has been very successful. His general behaviour, moodiness and anxiety have improved also.

Regarding the brain scan, it is not diagnostic but rather only indicative. That is, it needs to be considered together with other signs and symptoms. However, it can confirm whether medication is working.

Hope this helps you although I know every child is different. I would strongly suggest reading as much as possible about ADHD especially **All about ADD: Understanding Attention Deficit Disorder** by Mark Selikowitz.

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It's really difficult to convince family and friends who haven't had the input of listening first hand to others' stories. I'm sure you have tried this, would they be willing to read the information on medication for ADD from Developmental Paediatrician's website? It gives good researched factual information on the risks/side effects. So often all we know is what is heard through the media and this is what influenced me for so long - I actively avoided having my son tested because of my ill-founded fears. It wasn't until I heard Developmental Paediatrician speak so knowledgeably about ADD and medication that I dared go down the path. It was not easy to convince my husband either. Now I am so sorry that I didn't look into it more objectively sooner, as it has made such a difference to my son (12 years) - he is now catching up in leaps and bounds and his self esteem has increased dramatically. He says he never wants to stop taking the Ritalin. You can reassure your husband that Ritalin has been used for over 50 years now and there are no long-term side effects. Short-term side effects are rare and not dangerous. Interestingly, Educational Consultant said when he spoke at one of our meetings, that even if they found out the medication he takes caused cancer he would not stop taking it, such is the extent of its effect on his quality of life.

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**Mother of son 9**

DS9 improved 80% with Ritalin, so we are giving it a go next term.

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**Mother of daughter 7**

Number 2 daughter was the one who had major changes on her brain scan – 3 standard deviations from the mean. The changes were so severe that the paediatrician was able to diagnose ADHD based on the scans, which were backed up by observations of her doing the other testing. They did a medication trial but in no way did I feel the paediatrician was trying to push meds. He seems to take a conservative approach (like wait and see how she goes this year) but at the same time strongly believes that for some children medication definitely has its place.

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I have been exactly the same with my son. I have never really thought that he has ADHD – nor has it ever been suggested to me by any professional that he has seen over the years. But after attending the recent GLD meetings, a lot more reading and research and much agonising thought I am now 95% sure ADHD – inattentive, is a big issue for him. I have decided to go down the path of getting him an “accurate” diagnosis and maybe trialing Ritalin if necessary. Arriving at this conclusion is something I never thought I would do. I am still having sleepless night over this!

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**Mother of son 7 yrs**

We've been investigating whether my 7 yr old son had ADHD issues for a while, which is hard as so many of the ADHD issues are mixed up with the Gifted issues which are also mixed up with the sensory issues. They can't be unscrambled and it is difficult to get my head around them all at times.

After lots of reading and talking I came to the conclusion that we would try some ADHD meds and if he didn't have ADHD they wouldn't work and if he did they might...

I have seen some improvement in his behaviour with the Ritalin - they start with a small dose of the short acting one - lasts about 4 hours - and gradually increase the dose until you see an improvement or get to the max dose.

We got to almost the max dose and I was seeing improvements but he was also having some sleep issues so we have decided to trial the other drug that's often used - Dexamphetamine - and we will do the same, start with a low dose and gradually increase.

There is a screening tool called the Connor's questionnaire that is used to determine if the child shows ADHD type behaviour - it is completed by both parent and teacher and a score is calculated based on your answers that will tell you where your child sits on a range of behavioural issues. This gave us a more solid understanding of where his behaviour was so far outside the norm - and those behaviours that didn't fit in with our values.

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I am so glad that you got the Developmental Paediatrician to speak to us - I am convinced that my son has ADD now whereas before I was just going to have him assessed in order to rule it out! I thought that I knew what ADHD was but really had no idea - makes me wonder what other professionals actually know about it. He really convinced me about Ritalin and I'm almost hoping that my son is going to be a candidate for it. (comment from a parent who is also an allied health professional working with children)

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**Mother of son in mid teens**

ADHD has hit a bit of a note with people hasn't it?

You jogged a few memories there – my son couldn't have ADHD, despite not being able to sit in a chair for the first 6 months of school, and needing to roll around on the floor if people tried to make him sit still for too long. .... Tried fish oil supplements, diet, a good occupational therapy program, etc etc etc, finally realised how much better he did on medication. He's now not taking it and has considerably calmed down – though is still disorganised and not the best at concentrating. But he gets through and is not nearly so hyper now he's teenage. So, yes, it's a bit of a journey. Everyone needs to take time and experiment and make their own conclusions about their kids.

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**Mother of adult son**

Here I go again as the mother of adults: we went down the Ritalin trial many years ago when our son was around 9 years old. When it came time to decide whether to continue, I asked him

what he thought. He said he wanted to continue because sometimes before he hit children he thought about it and didn't. This had been his earlier response to bullying & constant provocation - impulsiveness was definitely an issue, but not hyperactivity. He also said that he wanted to do better at school and it helped. Personally, I have never noticed a difference in his behaviour whether on or off the medication but that may say more about my powers of observation than anything else. However, a therapist who worked with him over many years could pick it within minutes of beginning work with him.

I too was reluctant to go down this path and found it a very confronting decision to make. I questioned my motives (was I trying to make him into something that he wasn't, did I want him to do well at school for his sake or mine, would it affect his long term health and his self-image, etc, etc.) Our family made the decision together: the deciding issues were the fact that he was very frustrated and a question posed by the developmental paediatrician as to whether I had the right to prevent him from achieving his potential.

A couple of years ago he switched from Ritalin to Strattera a non-stimulant medication. He prefers to take this.

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**Mother of son diagnosed at 14 and now aged 18**

I agree that rather than agonizing over the Ritalin decision, sometimes the best thing to do is just trial it and watch the child.

Once we accept that it is not a sedative, that it is not long-lasting, and that it is not addictive, then there seems to be every advantage to trialing it for a short time (assuming a specialist has prescribed it after careful evaluation). One little prescription costs very little, and if we or our child is not happy or responsive, we can always discontinue it with no adverse reaction. On the other hand, it may just give a child, such as your son and my son, a chance to feel for a while how immensely satisfying it can be to finally be able to pay attention at school and not be "running 7 programs all at once".

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**Also - Mother of son diagnosed at 14 and now aged 18**

Now, to answer your question if the first professional I ever consulted had suggested ADHD, I'd have said, "No, because he is not hyperactive or defiant or badly behaved, and he can concentrate really well when something really interests him..." but if that professional had then handed me a document such as the one which you propose to create, I'd have taken the suggestion more seriously and would have investigated it.

I am still profoundly grumpy about the fact that I consulted all sorts of therapists for years and years, and every one of them quickly offered to fix my child based on the one and only "alternative" or "natural" therapy which they themselves practiced. Everything we tried (and spent buckets of money on...) helped a little bit or for a short time, but nothing ever really helped very much or for very long. Then, when I stumbled upon a developmental pediatrician just by accident and not even as a result of a medical referral, and when I finally got the ADHD diagnosis and the concrete brain scan image "proof", I was still very skeptical, and I spent many many long nights reading pro- and anti-Ritalin articles, before finally deciding to trial it. And trialing it was the best thing we ever did.



Once I learned that everything I'd ever absorbed from the media about ADHD and Ritalin was wrong, wrong, wrong, I was able to make an informed choice. Once I understood about the purely inattentive sub-type of ADHD (without the "H"), and began to read about it (and the differences between inattentive ADHD and just plain giftedness), I gained an insight, which no other professional had ever given me.

I am 100% sure that my son would never have finished Year 12 without the meds...not that he ultimately got the best UAI in the world, but at least he finished school with some scrap of self esteem intact, and with a UAI high enough to get into any uni course he'll ever want to apply for. Part of that was indeed due to the change of schools and the grade acceleration and the particularly insightful G&T coordinator at the new school, but a good deal of it was just due to the Ritalin. None of the amazing success that he has enjoyed since graduating would have ever happened without the drugs. Simple as that.

Now that my son is 18, he is on Ritalin by choice. Of all the things that he still forgets (and there are lots and lots...), he rarely forgets the Ritalin. Some days, if he doesn't have to go anywhere, he chooses not to take it, and then complains all day that he can't find anything or finish thinking about anything or read a whole paragraph or even follow the plot of a movie or a computer game.



#### **Mother of son 18 and daughter 14**

I was very concerned to learn at the talk given by the Developmental Paediatrician that recent research has discovered abnormalities in the white-matter fibre development of the brains of children diagnosed with ADHD, when compared with the brains of children without ADHD, but that **ADHD children who had been treated with ADHD medications had fewer such abnormalities than ADHD children who had not taken the medication.** This research is preliminary, in that it was conducted on a small sample of children, and it will need to be replicated but, because it was carried out by academics in a hospital setting it was still enough to catch my attention.

I am now very worried that, because my GLD son was not diagnosed with ADHD until age 14, permanent white matter damage was perhaps occurring in his brain for all those years during which he was not being treated with medication and should have been. I now see that it was foolish to "wait and see if he grows out of it." I should have had him assessed for ADHD as soon as the first worrying signs began to appear, around age 6. I now fear that, if there has indeed been white matter damage, it may never be undone.

I am also now having second thoughts about the fact that, although my GLD daughter was diagnosed with purely inattentive ADHD a couple of years ago and was prescribed medication, I never gave her the medication because she was not hyperactive, not impulsive, not defiant and not failing at school. I figured that I'd wait to see if things got worse. After reading about the white matter brain research, I began to give my daughter her prescribed medication right away. Now 2 weeks later, she is still the same lovely little girl that she's always been, but she reports that at school she is no longer "almost asleep" by noon every day. She says she can finally pay attention in class after lunch as well as in the mornings, and she is especially pleased that she can now follow a conversation with her friends in the afternoon without drifting off and wondering what they're all talking about.

My daughter says that she can "feel" the medicine starting to work and she can also sense when it starts to wear off - unlike my son who claims that he can never feel it working, and never even realizes that he's forgotten to take it, until he notices that he's driving with one wheel up on the kerb.

I'm mad at myself that I used to listen to untrained people who claimed that ADHD medication is addictive. If it's addictive, then why does my son sometimes **forget** to take it? Do heroin addicts ever "forget" their next fix?

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### **Mother of son aged 18**

Those people in the GLD network with younger children (ie. primary school) with ADHD and feel concerned with what lies ahead, all I can say is be glad that you know what the issues are at this early stage, because you will be able to manage it... unlike myself (and my son) and other parents in my situation, who only learnt their son was not only 'gifted' but has significant LDs, at the late stage of nearing the completion of secondary (with all the associated trials with fewer tribulations that have accompanied this journey) - when one is swamped with the feeling of it all being too late to maximise the opportunities of school. ... but hopefully yet not too late to pick up from this point on.

For us, we have not found a perfect solution... we are struggling ahead - wondering if this is 'as good as it gets'.... and if so, it's still better than it was before ADHD diagnosis and using Ritalin.

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### **Mother of son aged 14**

I went down the same path a long time ago now. I stressed and worried and debated with myself and many others the benefits or otherwise of a Ritalin trial. In the end we trialed it in school holidays, so we could monitor its effects. In the first few days my son was a little quiet and reported headaches, and was a bit irritable as the dose wore off. That settled within a week. Given the benefits of the medication – concentration!!!! Ability to focus on and complete schoolwork. Ability to read. Much better ability to get on with others due to less hyper and impulsive behaviour – I now wonder why I worried so much. In the end, if it doesn't help, or has unpleasant side effects that don't settle, discontinue it. The dose doesn't last long. My son is now nearly 15, has not taken Ritalin for about a year, and, although not the world's best at concentration, has matured into a much calmer adolescent who can get by pretty well. He had breaks from Ritalin every year for a couple of weeks over school holidays. In the early days those breaks were often cut short, as he'd want to go back on. The concentration and behaviour were really hard to live with. As he went through adolescence the breaks were less obvious but the concentration still was dodgy. The last break just continued as he seemed fine without it.

This is not an advertisement for Ritalin. I'm sure it isn't right for everyone. And not everyone that appears to have concentration issues has ADHD or requires Ritalin. But in our case it was a great help. It got my kid through primary school in one piece with some self-esteem.