



Our Son Thomas...

...was diagnosed with Worster-Drought Syndrome at age of 3½ by Professor Brian Neville at Northwick Park Hospital. His paediatric consultant had first suggested the condition to us during a review in preparation for his first statement. Initially it was exciting to have a diagnosis for what had been termed (until then) as global developmental delay, but the excitement soon wore off when we began to realise just how little was known about the condition. There still seems to be so much to find out about the condition, and the progress is frustratingly slow.

So what's happened since then? Well, we've moved out of London and now live in the South West of Bristol. Thomas had a stint at mainstream school, but in 2000 we decided to move him to a special school. He'd been getting progressively more reluctant to go to school, and didn't seem to be making any progress at all. We had expressed our opinion to the professionals concerned that we felt it was important for Thomas to remain in mainstream school for as long as reasonably practical, but they took that to mean that we wouldn't entertain special school. In the last statement review we had whilst Thomas was still at mainstream school we suggested that Thomas might be better off at a special school. The professionals didn't seem to suggest this to us, as they were concerned at how we would take it? In the end we even had to organise Thomas's transition to special school by ourselves as the professionals were dragging their heels.

Since being in special school Thomas has really blossomed; he enjoys going to school, he tells us about his day (well, sometimes), he even has a girlfriend! His handwriting, reading, numeracy, etc. have all come on in leaps and bounds and he is just one happy, contented confident little boy. Well, not so little, at the age of 8½ he is as large as most 10-year-old boys. You can't pick him up any more as he's like carrying a sack of spuds around. Feeding was a minor problem, and still is, but as long as he can have softer foods he is all right. His favourite meal is pasta with anything.

Speech has come on as he's developed, but we are still fighting with the LEA to get his stated provision of speech and language therapy, and currently we have to pay for him to see a private therapist. This has always been the most significant gap in his provision. Our only concern for Thomas is that he won't have good role models in special school, and also that there seems to be less opportunity for him to make friends. We shall have to keep a careful eye on that.

What more can we do?

We took part in the research into Worster-Drought Syndrome at Great Ormond Street Hospital funded by SPARKs, we are actively involved in the Worster-Drought Syndrome Support Group, and we have joined the online e-mail group set up by Annemarie from New Zealand (more on that later). We would like to help do whatever it is we can to further research into this condition, and share whatever information there is with other parents and professionals involved with Worster-Drought. To that end the subject of a questionnaire arises again. It has been suggested several times that we should draft a questionnaire that would be sent out to all the families in contact with the support group. I'm sure that many of you wouldn't mind completing a questionnaire if you thought it would help, but how would it be used? What sort of questions would need to be asked? What would we do with the results of the questionnaire?

Obviously we are parents and carers, and not medically qualified (well, most of us anyway). How could we decide what sort of questions should be asked, and how would we be able to effectively use any results? Another consideration is the storage and disclosure of the information. There are all sorts of considerations that have to be taken into account when we ask for personal information, and there are restrictions placed upon the storage and disclosure of that information by law.

I have no idea how much it would cost, but we could consider paying for someone to draw up the questionnaire for us, and analysing the results. I'd imagine that this wouldn't be very cost effective. It would probably cost many thousands of pounds (money which we would have to raise), and when it was done how long would the information be valid?

So what do you think we should do? Answers on a postcard please to the usual address nutsoft@hotmail.com

Time gentleman (and ladies) please

The above title isn't meant to be a prompt for you to leave your local public house or other drinking establishment, but rather a call to those of you out there who feel you could perhaps spare a little of your valuable time to help out on the committee. There's always something that needs to be done, and any help, support or suggestions that you can provide will always be appreciated. If you feel able to contribute, then please feel free to contact me and I'll pass on your kind offers to the committee. Thanks in advance.

Attention Deficit Hyperactivity Disorder

Many children with Worster-Drought Syndrome also exhibit characteristics of ADHD. In order for the condition to be classified as ADHD, the child must exhibit at least 8 of the characteristics for at least 6 months, with onset before the age of 7.

1. Fidgety.
2. Difficulty remaining seated when required.
3. Easily distracted.
4. Difficulty waiting turns in games or group situations.
5. Shouts out the answers to questions before they have been completed.
6. Difficulty following instructions.
7. Poor attention span in tasks or play.
8. Shifts from one uncompleted activity to another.
9. Difficulty playing quietly.
10. Often talks excessively.
11. Interrupts or intrudes on others.
12. Often doesn't appear to listen when being spoken to.

13. Looses things.
14. Engages in physically dangerous activities without considering the potential consequences, e.g. runs into the road without looking.

Worster-Drought Syndrome Down-Under

Some of you have already made contact with Annemarie, but for those of you who haven't, the following introduction is taken from a letter she sent to us for publication in WORDS. If anyone else out there would like to contribute to the newsletter, please feel free to send your contribution to me at nutsoft@hotmail.com, and I'll do my best to get it into the next issue.

Hello from New Zealand, I'm writing this just after New Year and the weather here is beautiful, while I understand the UK is blanketed in snow. I'm Annemarie, wife to Roger and mum to Philip who is 7 and recently diagnosed with Worster-Drought Syndrome and Chiara who is 5, and trying to teach her budgie to talk (guess she has given up on her brother).

Philip was diagnosed about halfway through last year after we got online and found the information on the CAF directory, as I read through the list of symptoms it was like coming home, finally it all made sense and finally my feeling that a bit more than CP was the problem. The constant ear infections were related to the feeding and speech difficulties, and the feeding problems weren't just behavioural, this was why his gross motor is so much better than his speech, etc., etc., etc.

I didn't realise it then but I was about to become even more isolated than before, whereas before we had other families around us who had kids with CP we were the only ones we knew with a kids with WDS. I finally found one family about 5 hours drive from us with the same diagnosis, we met them on our way back from getting the diagnosis confirmed and we maintain phone and email contact.

Getting a diagnosis for us really didn't make a lot of difference, we already knew that it was unlikely Philip would speak or he would have been making some progress (however, since understanding the syndrome a bit better we have started to hear some words, grunts really, but consistent grunts for "mine", "mum" and "up", and he has a very well understood "no"). We already knew we had a child with severe feeding difficulties (he still requires most food pureed although he manages some soft foods). I had already made my peace with the fact that he will never write with a pen and will always look a little funny when he runs. We had been investigating ADHD as a co-current diagnosis but have now settled to the understanding that some of this is being caused by sensory problems. The biggest difference is that now when someone questions me about why I have to feed my outwardly normal looking 7 year old I can say "Philip has Worster-Drought Syndrome, it affects his feeding and speech muscles". Generally that shuts 'em up!

In an effort to alleviate some of my, and I hope others feelings of aloneness I have now started a Worster-Drought Syndrome egroup. The way this works is that we have a common email address that we can email to, once sent, that email goes to all the people who have joined the egroup, those people are then free to respond through the list. It is a bit like having a conversation with many different people. I belong to a list for Sensory Integration Dysfunction and also Dyspraxia and I find that the opportunity to network with so many others from all over the world is just great. The WDS egroup is also open to therapists if anyone is interested the address is www.egroups.com/group/WorsterDroughtSyndrome

We are currently only a very few, but in order for the group to really get cracking we need more members. If you have any questions about the egroup please contact me at kipperkid@actrix.co.nz

Best wishes

Annemarie Gibbs

New Zealand

Editors note: If you visit the egroups website you can view some of the emails that have been sent through the egroup.

Registration is simple, immediate and doesn't cost anything.

A Helping Hand - Key Benefits

You might find some of the following sources of help useful – many thanks to Monique Lauder for compiling the list;

1. Register with the local council for the "Register of People with Disabilities Card", you have to contact the Department of Social Services. The card entitles you to discounted or free entry to zoos, soft playrooms, museums, etc.
2. Disability Living Allowance – this benefit is paid every 4 weeks and is not means tested or taxed. It is made up of 2 components, the Care component and the Mobility component.
 - a. The Care component has a lower age limit of 3 months, and is paid if because of a physical or mental disability, your child needs a lot of looking after or help with personal care. This component is paid at 3 rates.
 - b. The Mobility component has a lower age limit of 5 years, and is paid if the child qualifies for the middle or higher rate of the Care component. People who cannot walk at all, who have severe difficulties in walking or who are deaf or blind should qualify for the higher rate. Under a new condition, people who have severe behavioural problems should also qualify for the higher rate, provided that they also get the higher rate of the care component. Those who do not qualify for the higher mobility rate may be able to get a lower rate if they can walk but need guidance or supervision from someone else when outdoors.

Full details and an application form can be found in the DSS leaflet DS704 available from your Social Security Office or Post Office.

3. Invalid Care Allowance – this is a weekly cash allowance for anyone under 65 years old who spends at least 35 hours a week looking after someone who gets the higher or middle rate of DLA for personal care. ICA is a taxable allowance but you can still earn up to £50 per week while you are claiming ICA. If you are on Income Support on you claim ICA, you can also qualify for a Carer Premium of £13 per week. Full details and an application form can be found in the DSS leaflet DS700 available from your Social Security Office or Post Office.
4. Council Tax Benefit – there may be a reduction in your Council Tax bill if extra space is needed for the child, i.e. a playroom, treatment room, or downstairs bedroom, etc.
5. If you are on Income Support you may also be eligible for further assistance.

Your Chance

If you have anything at all that you would like to contribute to the newsletter then please send it to me at nutsoft@hotmail.com and I'll see that it gets into the newsletter, or alternatively send written articles, etc. to the secretary.