



MDA Newsletter

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Madras Dyslexia Association

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Launch of our new website

By end April you can log on to mdachennai.org and see our new

interactive website.

Other programmes:

Mainstream Teachers

Training programme for teachers from mainstream schools on 22nd April

Summer Workshop For children classes 1-5 who need to build skills in Reading, Spelling, Writing and Math on 16th April

Contact our office for details

Understanding Epilepsy: its implications for Parents and Teachers

Very often when we look at the case history of children with a specific learning disability we find that some of them have had episodes of epileptic seizures sometime in their past. They have been treated and put on medication for a while and seem to struggle with their academics. Getting the perspective of parents with children who are diagnosed with epilepsy is very important in trying to understand how it affects the child's learning, academic performance and behaviour. Each parent's experience is different but each one's effort towards helping their child is as tireless as the other. No resource is left untapped, no stone unturned by these parents, be it medical, dietary, therapies, or alternate medicine.

We spoke to some of the mothers who very willingly shared their experiences in order to help other parents.

Case I : D, 10 years old

D, a premature child and one of twins showed no developmental milestone delay. At 2, at home she was quick with letter recognition. At 2 ½ years while in preschool, she had problems with holding scissors and also showed problems with concentration. In Class 1, counting numbers and sequential memory was also a problem. She found it difficult to tell a story and that was attributed to a behavioural problem. When she was 3 ½ to 4 yrs, she would look down for a few seconds and seemed lost before she would come out of it. The Neurologist diagnosed it as absence seizure and started her on medication.

By Class 2, she had severe problems with handwriting. Supposed "immature social behaviour" and hyperactivity were present. After an assessment she was moved from a CBSE school to a lesser demanding curriculum.

While in Class 4, she had a tonic seizure when she had to be hospitalised and was put on a high dose of medication. The side effects took over and she lost her appetite completely and was very sleepy all day long. At this stage she had to be pulled out of mainstream and joined Ananya for full time remediation.

D was referred to an Occupational Therapist who made a world of difference in the child's life. He not only addressed the child's severe visuo-motor problems, (by this time her visuo-motor index was at 10th

percentile), he worked on her oral- sensory issues. The child who was very sensitive to a lot of food textures and would barely eat solids started eating well and gaining weight.

The mother realising the effectiveness of OT in her child's life, started to advocate it to parents who were reluctant or on the fence regarding OT. The child was taken to a Homeopathic doctor for consultation. She was started on pills for picking up health and general well-being. This too seemed to go well with her as she was alert in class and her appetite improved.

Currently the medication dosage has been reduced, but the Neurologist has said that she would have to stay on it for a minimum of 3 years to prevent any episode before slowly withdrawing it. The mother is seeing marked improvement in all aspects of her problem areas but says they still have to work hard towards achieving the goals set. D is going to be mainstreamed the coming academic year.

Case 2 : P, 7 years old

Born of a C-section delivery, she developed hypoglycemia after birth and had seizures. It was felt that it may have been due to her not being fed by the mother who was in sedation post surgery. Sugar water which is normally given was also not given. The next episode of seizure was after her first year, when she developed high fever while her mother was feeding her, had her seizures. This repeated itself in her second year, when once again after high fever she had seizures. She was immediately put on medication which was continued for 3 years. She was completely episode- free till her 1std. Suddenly before her 2nd Std, her seizures reappeared, this time, she would just stand still and motionless for 1 to 2 minutes. These episodes recurred very often, sometimes even 10 to 25 times a day until 6 months back, when she started falling down after 1 or 2mins of the seizure. Parents became worried and had thorough investigations done, right from EEG to MRI of the brain. Doctors now added two more drugs, and number of episodes came down to 6 to 7 times, but other side effects are being seen in her. Now she gets drowsy, has very low attention if not nil attention span at school. She tends to repeat few things when she is speaking and even while walking, she is slow and seems to be drugged. These effects last till 3pm, when she once again is her usual self, active, chirpy etc. The medication especially the one drug with side effects will be tapered off soon and she will be episode- free in the near future and without side effects of the medicines.

She is attending OT sessions and she is now able to sit still for sometime and can actually complete an activity. At school, she is still not attentive, won't sit in class and finds reading, writing and Math very difficult.

P's mother's advise is " parents have to be patient, leave your work and concentrate wholly on taking care of the child, giving her full attention, and support". She is very happy that she has come so far and is hopeful that soon, she will be like other children playing around without a care in the world.

Case 3 : B, 7 years old

B is studying in 1st Std of a CBSE school. He had his first seizure when he was 9 months of age and is under medication for this condition (atopic epilepsy) for the past three years. He has been advised two years incident- free time to consider withdrawal of medicine. Earlier inspite of the epileptic problem he used to be reasonably good in school but after a change of school two years ago he became very dull in class. With the addition of the second medicine for his condition, it became even more difficult for him now. His parent reports of the following problems:

- Difficulty remaining awake in school
- Difficulty expressing in words - for a 5 year old child
- His short term memory as well as long term memory are poor, often forgets the things he learnt recently.
- He takes a long time to finish his home work and had to be repeatedly reminded. His mother has to spend a long time with him every evening and it's often very frustrating as he doesn't cooperate.
- Board copying difficulties are there and often his class work is incomplete

School advised them to undergo a psychoeducational assessment test.

Case 4 : A, 14 years old

A had two episodes of seizures when he was 11 years old and was on medication which has been stopped now. He has poor reading and spelling skills and finds it difficult to comprehend even a film. His handwriting is slow but is better than before. He finds it difficult if notes are dictated in class. He has to borrow friends' note books to complete them. His attention is poor, he is easily distractible and daydreams. He takes frequent breaks during his studies. His mother needs to be around otherwise his attention strays away. He

has a poor sense of time. In Math, he has difficulty learning and remembering formulae. His second language, Hindi, is average. He does not answer in class and school feels that he needs to work hard. His performance has been dropping from the 6th onwards and 7th and 8th were both warning promotions only. He has been detained in the 9th this year as his overall performance was very poor. He is better with one word answers.

Case 5 : R, 14 years old

R was performing well till the 7th and after which his academic performance has been dropping. His main difficulty is a tremor in his handwriting which is an after effect of his seizure. When he was about 7 he had epileptic fits and was put on medication. He had another episode a week later and yet another two years later. He has been on medication for the same since then. His attention and concentration after this have been poor and parents have been advised not to put too much pressure on him. Ajith sometimes is scared of the recurrence of his illness. His sleep is disturbed and he makes some groaning sounds and sometimes tenses his muscles too. His appetite is poor. He has been seen by the neurologist for his fits and also for his tremors. They report that the tremors are present mainly while writing and not at rest.

Professionals' viewpoint:

To understand the condition better from different angles we spoke to a Neurologist, and an Occupational Therapist

The following are responses from Dr. Kumaresan, a highly qualified and very experienced Neurologist in the city, who has treated thousands of patients with

seizures.

What are the most common kinds of Epilepsy that you see in India?

Epilepsy is based on cause and is divided into three types:

- Symptomatic- those caused by delivery related complications and Central Nervous System(CNS) infections are common in children in our country.
- Idiopathic could be inherited (now considered under symptomatic)
- Cryptogenic is when a cause can't be found.

What is the connection between seizures and a learning difficulty?

Learning disability in epilepsy could be caused by:

- By the disease that caused epilepsy
- By the drugs
- Psychological factors like less or more protective attitude of parents

What is the role of medication in affecting learning?

Generally drugs cause disturbances, but to relate all disturbances to them is wrong. The risk caused by recurrence of seizures like physical injuries, psychological trauma, and risk to life by prolonged seizures has to be weighed against the side effects caused by the drugs. Not all drugs have the same effect. Phenobarbitone is well documented to affect learning and behaviour. Of the new drugs, Topiramide can cause memory disturbances, Levitiracetam can cause behaviour changes. But the parents have to weigh these small risks against the

Some general facts about epilepsy

- Sometimes there is a misfiring in the electrical signals in the brain which causes a short-circuit or electrical surge and results in a seizure.
- In India, it is normally called "fits" to indicate the convulsions that go with it.
- A person having a seizure is not aware of what happens at that time.
- Most of the children, who have seizures in childhood tend to outgrow it in their teens.
- While it could run in families it does not necessarily affect the intelligence of a person.
- It ranges from the grand mal where the person could fall and have convulsions to the absence seizures where the person looks as if he/she is "zoned out" or 'spaced out" or even just daydreaming for a few seconds.
- It can often be cured by proper investigation to see which part of the brain is affected, medical intervention and proper medication.

Internet sources

benefits of prevention of fits and discuss with their doctors to select the appropriate drug as per the child's condition.

What about cognition itself? Do children with seizures have a borderline or lower IQ?

This depends on the etiology that caused the brain insult and seizures. For example,

epilepsy associated with severe brain trauma or infections of brain will have higher risks of lowered cognition.

What about the kind of seizure which hardly appears to be full blown which parents have little awareness of?

The "simple absence" type of epilepsy is often not recognized early and the child may be mistaken to be inattentive or if in prolonged episodes (absence status)mistaken for being mentally retarded. There are types mimicking simple absence episodes like complex absences and myoclonic absence which differ in their response to drugs and long term response.

Role of Occupational Therapy for children with seizures

We spoke to Ms. Pravitha Gopinathan, our Occupational therapist about this. These were her inputs:

Occupational Therapists play a role in the rehabilitation of children who have had seizures. In a child who has seizures the following areas may be affected:

- Muscle power
- Lack of coordination and balance
- Postural and motor control e.g. during walking, standing, sitting, clumsiness or stiffness is seen
- Behavioural issues: stubbornness, flexibility issues etc

These will result in disruption of Activities of Daily Living (ADL) like eating, bathing, toileting grooming, locomotion: moving from one place to another, stair climbing etc. and active play .

The Occupational therapist deals with the area affected in order to get them to function effectively.

They also teach them the importance of task completion by choosing any one of the ADLs . It will go from simple to complex and from structured to unstructured tasks.

Sensory issues will also be tackled through appropriate sensory integration therapy such as calming techniques, appropriate tactile, vestibular (being aware of movement that influences balance) and proprioceptive (joint position sense) inputs. These will give an adaptive response which will reinforce good behavior as children tend to have behavioural issues.

The benefit of Occupational Therapy for the child is to internalize the child's thoughts about their current state, what they are doing and what they are expected to do as an end result of the task on hand. This will also make the child functionally independent.

Precautionary measures for parents to follow:

- Children are prone to injury during play, if there are sharp objects.
- Children shouldn't undergo any heavy movement activities like spinning, revolutionary/ rotatory movements like going on roller coaster rides. These could be trigger factors.
- Sharp sensory inputs should be avoided sudden noises like from stereos or musical instruments, whistles, and visually like bright lights, abundance of fluorescent colours.
- In adolescent children, hormonal imbalance can sometimes trigger seizures.
- When involved in a concentrated activity they shouldn't be disturbed suddenly. This applies to waking up from deep sleep too.
- When the child gets seizures they shouldn't disturb the child, he should be allowed to rest as there will be confusion and minimal disorientation as well.
- Parents should not be hasty in stopping medication till a stipulated time especially when the onset is late.

Based on inputs from Ms. Pravitha Gopinathan, Occupational Therapist.

This is part 1 of the article and the next issue will have more view points from Psychiatrists and Teachers and Practical Hints for Parents and Teachers.

Parent Interview

Sandhya, all of 17 years has been chosen for the National Squad in Shooting making her eligible to represent the country in ISSF (International Shooting Sport Federation) rifle events. Recognized as a "Master Shooter," the day isn't far when she will be training for the Olympics.

We first met Sandhya when she came with her mother for an assessment in 2006. She had reading and spelling problems and also a difficulty with her Second Language. Her mother was concerned about Sandhya's learning, got her assessed and despite being a busy professional herself, also trained with us in order to help her daughter. Subsequently, Sandhya was brought for another assessment this year as she was appearing for her Senior Secondary (XII Std) CBSE exams.

This is an email interview with her mother who is a Homeopathic Doctor. Over to Dr. Mahalakshmi Winfred -

When did you realise that your daughter had learning problems?

Even as a child, I was worried about her delayed milestones (walking and talking). In her Kindergarten levels, she could pick up the picture flashcards easily when asked for a particular word, but had difficulty matching it with appropriate word cards. She was more interested in drawing than in reading story books which was in sharp contrast to my talkative son who loved stories. Though these would ring warning bells in my head, I was in constant denial, assuring myself that each child is different and not to compare with the older sibling.

She was doing well till about her I Std, where they had lot of oral assessments. By II or III Std, when the writing assessments increased she began to falter. She had difficulty in languages, and in writing long answers in English and Social and in the latter had "partial failure" grades because of good oral and poor written performance. Math and Science were fairly good, as she understood the concepts, though the spellings were phonetic (eg: stomak, instead of stomach). In IV Std, she was promoted with warning (partial failure in English and languages), I approached the school with my doubts about her condition, and a need for assessment by an expert. I was advised to work closer with the child rather than "branding" her. As she was doing well in Math and

Science, they felt perhaps, I hadn't concentrated enough on "lesser" subjects.

By the end of V Std, she was visibly distressed before the exams and was struggling a lot to cope, I wanted to help her before she entered the Middle school where there will be a quantum jump in the curriculum. By now, I was out of the denial mode and accepted that she needed help and intervention at the earliest, so I approached MDA on my own accord for an assessment.

How did her difficulties affect her: academically, socially and psychologically?

With proficient oral concepts, below grade level reading and writing skills she would literally bargain with her grandparents for doing her homework or studying for her dictation. Academically, this translated as poor grades in exams and she was totally frustrated to see that she had to put in 200% effort to just secure 50%, while for her brother and friends, it seemed like a breeze to get decent grades without much effort.

Though at home, we never compared her with my son, she saw herself as a failure, and felt that she had let down us. Even at school, she had very few friends (one or two) in her eight years of study in the same school. She was quiet and reclusive, not because she was an introvert, but perhaps more out of an inferiority complex. Her self-esteem was so low, that she didn't even play much with kids her age at school nor socialized with the kids in the neighborhood.

What action did you take? What role did the school play?

In the Middle school, when she continued to struggle with her second language, the school recommended her case to the Board for a language exemption and she was given Drawing and Art in lieu of learning a second language. Art was an area which was close to her heart and she took it up passionately. It being an area of core competence, she did very well and it gave her an opportunity to be involved in the Art Department full time, preparing props for the School Cultural, Anniversary and designing the School Magazine etc. This was a welcome break to all of us to see her come out of the shell as she became aware that she is talented. The language exemption took a great stress off her, helping her to contend with the

core subjects where she was struggling. She still had difficulty with long answers in Social Studies. I had meanwhile enrolled in the special educator course with MDA and did my training with MDA that gave me the insight into her problem and the necessary skills to help her.

When did she start showing interest in shooting? How did it happen?

She started shooting in 2006, when she was in class VI. As I was a Shooter myself, I had taken both my kids along. While my son was not very interested, Sandhya showed keen interest and also had a natural talent for the game. Within two months of starting, she won her first State Championship Medal (Silver) and then there was no looking back. She also represented her school in Swimming and Hockey.

How did her Shooting success affect her self-esteem? How did it spill over to learning?

By now, with her successful art work at school, she understood that she had much to give and her academic difficulties also could be remedied. The new "champion" status in Shooting also boosted her morale as she was selected to represent Tamil Nadu at the National level. All these improved her self-esteem, and she started making many friends and was a happy, confident kid by now.

She realized that with little help and coping strategies from me, she could handle her exams fairly well. Few ground rules were agreed upon by both of us, to do whatever is needed to maintain a decent average of about 60% in her studies. This was mostly her decision, as she did not want to go back to the painful days of "failing" in front of her friends; also, we did not want to run into trouble with the school (denied permission for long absences etc., to participate in the Shooting Competitions). With no failures and improved grades, the school also had confidence in her, and helped us by rescheduling her exams to suit our travel schedule. It was a great boon to have help from teachers in making up lessons missed and getting photocopied notes of the missed work. Amidst her highly demanding sports practice and competitions, she also traveled with her books along to study and prepare, wherever we toured. The more responsible she became in balancing her studies and sport activities, the more successful she became in both.

What have you as a parent learnt from this? What would you like to say to other parents?

I am a firm believer of Multiple Intelligence and the

need to pursue our passion in life rather than going by the generalized norms. Her success has only reiterated this fact. Also, having a child who believes in herself and preserving her self-worth is more important than just scoring high grades in school. Know your child, believe in him/her. Get timely intervention and help for the child if he/ she has a disability. There is no point living in denial, as it will only harm the child's progress. All Boards recognize dyslexia and do give some examination provisions. These will help your child realize his/her potential do avail and don't think of it as a stigma or a shame.

Dyslexia is a disability; it is not anybody's fault; not yours or the child's. Seek help, don't hide. Had our children had some visible disability like visual or hearing impairment etc., where will we hide them? Will we disown them or seek experts to help them? As this is a hidden disability, we don't want to cause more harm to them by not getting the right help at the right time. Support the child unconditionally in all their pursuits; highlight their achievements and not their difficulties or failures.

How would you as a parent and a professional like to help the cause?

It's my pleasure to be of any help to the kids and the distraught parents. I prefer to work in the area of creating awareness, counselling parents and teaching them coping skills like mind mapping, syllabication techniques, spelling rules in English, etc., that makes their job easier.

Convincing friends or relatives to assess their children for any learning disability is the easier part. They take my advice seriously due to my personal experience and also my role as their family physician gives me more credibility. Whenever any mother comes to me with a sob story regarding their difficult child, and their tough time at school, my antennae go up for any possible tell-tale symptoms. When in doubt I request them to bring the child's notebook and other work for a quick scan and immediately refer them to MDA. However, there have been instances when the parent has refused to do it, for the fear of familial and societal stigma, and preferred to let the poor child suffer instead; there have been others who have taken help for their child, but wanted me to keep it a secret!

Read about Sandhya in this link. <http://newindianexpress.com/cities/chennai/article1459640.ece>

News at MDA / ANANYA

Annual Day

Our Annual Day this year was celebrated at the Infosys Hall, Ramakrishna Mission School, on the 8th of February 2013. The chief guest of the evening Mr. Ananth Krishnan, Vice President and Chief Technology Officer of Tata Consultancy Services gave a very inspiring speech about what are some essential factors for success in the corporate or in life. Mrs Ananth Krishnan accompanied him and both distributed the prizes to the winners of the various competitions held during the year.

The Juniors with their colorful costumes entertained us with their songs, dances and skits. The National Integration song, The Musicians of Bremen and The Rabbit looking for a birthday gift for Mother were very entertaining. The Tamil skit had some take home messages for parents as well!! The Seniors took us to fantasy land with a skit on Thiruvalluvar visiting Earth and his reaction to the way his 'Thirukkural' was being interpreted. The English skit was a scenario on what would happen if all that children wished for came true. Their folk dance was indeed a feast to our eyes.



Project Day

The Junior School had its Project Day on "Water, the Wonder Liquid". Apart from the features, components, sources, uses and conservation of water, concepts of water in plants, animals, fruits and vegetables and methods of drip irrigation, music with water and water experiments were made really interesting. An innovative pictorial representation of the water supply in Ananya School Building was fascinating. Skits were used to explain some concepts and remedial methods were linked making it novel.

The Senior School Project Day was on the "Soft Sound of C" and had a creative invitation in the form of a poem written by one of our teachers. Soft c words like 'circus' 'cinema' 'cycle' 'cyclone' were some of the topics on display and explained from the viewpoint of different subjects. The class X students took us through the history of cinema which was very informative.

Math Workshop for Mainstream Teachers

Mathematics often is a bugbear to children and this gets compounded by difficulties faced by parents as well as teachers on how best to teach. When taught in a way we can understand and when we know why we do some of the things in Mathematics it becomes very simple. "Demystifying the Math Bug" was a programme offered for teachers from mainstream schools to make Math more understandable and fun. Mrs. Revathy Sivasankar, Course Director, with aids like chart paper, colour pens and scissors got the participants enjoying teaching Math.

Some feedback: "This workshop has given me a lot of confidence to teach Math" "It was a complete informative package with all beneficial factors". "Relevant", "interesting" and "useful", were the other adjectives used by the candidates who participated in the programme. A level 2 of this workshop is planned for later in the year.

Visit to RKM Science Exhibition

Ramakrishna Mission School (South) has inaugurated its Permanent Science Exhibition in its school premises and our children from Senior and Junior School visited it. The simple explanations and the appealing visuals made the concepts easily understandable. The exhibits covered a wide range of subjects like Social Science, Math, Biology, and Physical Science. Even the junior students could relate to many of the concepts that they had already learnt and to some new ones.

MDA News Snippets

- 11.12.12 Awareness to Primary class teachers of Kumara Rani Meena Muthiah Mat. Higher Secondary School, Adyar conducted by Geetha.R
- 15.12.12 One-day training-cum-workshop for Government school teachers in Srirangam District organized by the Indian Academy of Paediatricians and UNICEF at the Government school in Srirangam conducted by Subha.V and Geetha.R
- 5.01.13 One-day training for Master trainers in Tamil Nadu State organized by SSA and DERT in DPI campus, College Road conducted by Subha.V and Geetha.R.
- 21, 22 and 23.01.13 Workshop and training programme of more than 30 Corporation school teachers in Tamil, organized by the Corporation of Chennai conducted by Geetha.R and Vilasini.D at the Nungambakkam Government Girls' High School; Practical Training at Ananya Learning Centre coordinated by Sujatha.R and team
- 28.01.13 Two-month Intensive Teacher Training programme commenced at MDA
- 02.02 and 03.02.13 Two-day workshop on "Pass Theory of Intelligence- Cognitive Assessment System" by Key resource person: Dr. J.P.Das, attended by Janaki.R and Sujatha.R at Sri Ramachandra Medical University, Porur
- 12.02.13 Meeting organized by RSEN-Reading Skills Enhancement Network. Geetha.R participates as representative of MDA in the expert committee
- 13,16 and 23.02.13 Children from Ananya Learning Centre visited the Science Centre at RKM School, Burkit Road
- 23.02.13 "De-mystifying the Math Bug" Weekend Math workshop for four Saturdays conducted by Revathi Sivasankar
- 2.03.13 Dyslexia awareness and Early Identification Programme conducted by Geetha.R for KG teachers at The Hindu Chellammal Vidyalaya, Nanganallur

Our editorial team - Indu Ramesh, Kamala Ramaraj, Geetha Raghavan and Vilasini Diwakar

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BOOK POST

If undelivered, please return to:
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