

Aspergers Syndrome Support Group for Families in Macarthur

October 2007 News Sheet

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October Meetings

Wednesday's coffee meeting was about buttons and how to overcome a child's phobias. Julie the OT from Wollondilly Health provided information on this particular situation and how parents can assist their child – thanks Julie and for the mum who joined us for coffee. See Julie's short article later in the news sheet.

Thursday night was also a small group of three grandparents along. This gave us an opportunity to focus on issues faced by grandparents providing care and support to their grandchild. Many grandparents have to step into the caring role when their own son or daughter is faced with a life crisis caused by health, separation or other reasons. It is important that they realise the impact that this role can have on themselves and others in their household.

Dealing with separation of parents and the changing dynamics of families is difficult for many people with aspergers to handle. Some boys take on the role of the "man of the house" as they see this as the normal household arrangement but without understanding/comprehending the dynamics of the new relationship.

Our grandparents advised that visiting separated parents need to be well planned, incorporated into the child's routine and not be too short a time – allow them time to settle in. Remember different people and environments usually cause confusion which can lead to "misbehaviour" by the child.

Meetings for November

- **Second Wednesday** 14th November 10 am at The Coffee Club at Macarthur Square next to Border Books, where all the new coffee shops etc are.

I'll be there and hope some of you can make it along for a friendly chat and information share with other parents.

- **Second Thursday** 8th November 7pm at the Harrington Park Community Centre Fairwater Dr next to the shopping centre. Come along and see what you can gain from listening and talking with other families and hear our GUEST SPEAKER.

Yes in November the second the Second Thursday is a week before the second Wednesday. Confused – so am I and makes the meetings come around faster!!

Special Guest - Special Guest - Special Guest

Angela de Pourlaix, a **Naturopath** from Narellan will be attending our Thursday night meeting in November, talking about her work and how medicines and diet can be affect people with aspergers and a whole range of other disorders and ailments.

A topic of interest to many people, so come along and hear what Angela has to say.

I don't like buttons - article from Julie Bullock OT Community Health

At the last Coffee Club ASD Support Group morning, a mother was discussing the fact that her son had a great dislike for buttons. He refused to wear shoes with buttons. That is ok because Velcro works well on shoes. He refused to wear shirts with buttons.

That has been OK up until now because this 4 $\frac{1}{2}$ year old can wear t-shirts. Mum was able to get her son to dress into a pair of shorts or jeans by keeping the buttons done up the whole time, and quickly tucking in his singlet. The problem is though, that this child is off to school next year and will be required to wear a buttoned shirt 5 days a week.

There is no easy answer why this child has a button phobia and there may not be a simple solution, but here are a few ideas worth trying.

1. Sew some buttons onto a piece of material that is not clothing. Try different sized buttons and various textures and shapes. See if your child is prepared to practice with the buttons in front of him, not on him.
2. Try sewing themed buttons onto his favourite pants or shirt, such as Thomas the Tank Engine.
3. Have a container of buttons big enough for him to reach his hand into. Hide small objects such as dinosaurs into the buttons and have him dip his hands into the buttons and find them.
4. Fill a pillowcase with a variety of objects and include some buttons. Have your child place their hand into the pillowcase, feel for an object and try and guess what the object is.
5. Place some buttons into a small container and using tweezers or tongs have races to see who can move more buttons into another container.
6. Incorporate buttons into craft activities. Use for eyes, string to make a necklace or bracelet.

Using Visuals

During October Community Health held a professional development day for all their Speech Therapist and Occupational Therapist. The focus was on working with children who had behaviour issues when they attended the clinics operated at the Community Health Centres throughout the Macarthur region. I was invited along to talk about the Support Group and other services that therapists could direct parents to on behavioural issues.

Whilst there, I sat in on a very good presentation on the use of visuals by staff from the *Macarthur Early Childhood Intervention Service* run by Mission Australia at Leumeah. It showed the importance of all people – family members and professionals in using visuals to assist a child to better understand what is required of them.

Some of the main points from the presentation were:

- Most children would benefit from a visual communication system that matches their level of understanding.
- Most inappropriate behaviours are caused by misunderstanding, confusion, sensory overload, a change in routine and/or not know how to react in a situation.
- A Choice Board gives the child the opportunity to indicate their wants/needs
- Visual timetables and routines gives predictability and communicating what is expected of them and when eg getting ready to go to bed, afterschool routine
- Specific behaviour boards assist in anger management, feelings, consequences of behaviour
- Visuals assist children develop appropriate play and social skills
- Visual take time but are worth it for both the child and the parent
- Can obtain commercial visuals or make your own with Power Point program, a laminator and a Velcro system. Don't make one, make two at a time and share resources between families/services.

If people would like more information on visuals please let me know and I can provide them with details I have. Workshops are regularly held on use of visuals and I will let people know about them – we could hold one ourselves if people express an interest?

What I'd like you to know about me!

An article in the latest edition of the *Link Magazine* – a publication dealing with a wide range of disability related issues and services, caught my eye and interest. It's a web based resource from South Australia that allows parents of children and young people with disabilities develop an online book that covers every aspect of their child's life.

Instead of the need to recite their child's entire medical, educational or social history every time a different person is involved in their child's care, a parent can provide them the information in a format that focuses on their child's positives, their abilities, preferences, dislikes, dreams etc.

The article said that parents and even service providers will now be able to avail themselves of an imaginative and easy way to telling their child's special story.

Their site looks interesting and offers a number of ideas. A reasonable cost is involved if you proceed with developing an online book.

Web site www.aboutme.org.au

Julie Brookes – Life for Living 08 8277 3300 0407 728 776

Attention Deficit Association NSW Inc

A group of parents providing education, research and support on ADHD and Learning problems. They put out an informative newsletter and I have created a link with them on the Co-operatives Web Page.

Contact them on 9411 2186 for more information and to get onto their mailing list if these issues are of concern to you.

Socks Don't Matter

A parent's story on an American web site - www.autismnotes.com (A shortened version)

When Cameron was little (and not yet diagnosed with Asperger Syndrome) he had a difficult time remembering which shoe went on which foot. I guess we corrected him a lot because he became so obsessed with getting it right that he started asking if his SOCKS were on the right feet! We would smile and answer, "Socks don't matter!" It became our little inside family joke- and soon it was used for any situation that was getting more thought or attention than it really deserved. To this day you can hear, "socks don't matter!" in our family as a lighthearted reminder to keep our perspective.

Raising a family is challenging under any circumstances. We have four very unique kids. Our oldest son, Cameron is entering HS- he was diagnosed with Asperger Syndrome in the 2nd grade. Craig is beginning middle school and is in the gifted program. Our daughter, Jamie, is in her last year of elementary school and deals with some yet undiagnosed visual/learning 'stuff.' Our youngest, Jordan, is in elementary school and was diagnosed with autism by age two. We were initially told by "the experts" that he was "mentally retarded" and that they were "hopeful he would learn to communicate."

It was at the time of Jordan's diagnosis that "Socks don't matter" took on a new meaning for me. Lance Armstrong has "12/10" on his line of clothing to commemorate the day his life changed, the day he found out he had cancer. Sometimes I want a shirt with "12/10" on it- the day Jordan was pronounced "mentally retarded probably autism." Eric and I sat in the car outside the doctor's office with our then 19 month old quietly in his car seat, we talked of the life plans we had for our son, and for ourselves, that had just changed dramatically.

At the same time, Cameron was struggling at school. Isolating himself from others and having outbursts that, though we saw them at home, he had not had at school. The answer came a few months later- Asperger Syndrome. It made so much sense and I actually felt relief to know what it was so we could deal with it and get him the supports he needed.

Sometimes, especially as I've watched my sons overcome so much, I feel like it's MY challenge to learn from far more than it's theirs. You will not hear my husband nor I use the term "autistic" when describing our boys (not that there is ANYTHING wrong with the word) we instead say, "he has autism/asperger's." It's our personal way of reminding ourselves it's not who they are but what they have.

One of the most important things I would want a parent of a newly diagnosed child to know is that "socks don't matter." Parenting these guys takes so much effort, it's imperative to keep perspective- to pick your battles and be able to laugh at the zaniness that becomes our lives.

Until next time

Bob Lester

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