



From the President

Welcome to this issue of Autism News which I hope contains articles you will find informative and useful. Contributions from members are always welcome, so if you have worked through a difficult situation in your family or workplace we would like to hear from you. There is so much to be gained from sharing information and strategies that work.

The committee of Autism Tasmania continues to “plug away” at ensuring the long term viability of the organisation. Family Support Co-ordinator, Rose Clark has been extremely busy working with families around the state, but has also recently taken on the role of Autism Consultant on the North West Coast with the Department of Education. We wish Rose well in her new position, which is on a part time basis. Rose will be able to continue as our FSC.

My thanks go to Neil Gardner from Hobart who earlier this year took on the role of Treasurer for Autism Tasmania. As a newcomer to the Committee, Neil has been finding his feet and coming to terms with the operations of the organisation. Neil is retired, has a background in finance and is the parent of an adult son with Asperger Syndrome. I also welcome Louise Davies, who has taken on the role of Membership Co-ordinator, and thank her for her efforts. Louise is the wife of committee member, Andrew and is keen to help in any way. Andrew and Louise moved from Sydney some time ago and have some wonderful skills to offer our organisation.

Thank you also to the conference organising committee for their outstanding efforts in staging the “Focus on Families” State Conference in April. This event was extremely well attended, with numbers far

exceeding our expectations. Feedback from delegates has mostly been very positive.

Recently Autism Tasmania participated at Agfest as part of our overall fundraising strategy. In partnership with National Foods, Mick Clark again took on the responsibility of supplying milk, not only to the general public via the milk vans, but also to the many catering stalls around the site. This activity is not possible without the support of the many volunteers who gave up their time and we are most appreciative of their support. Funds

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raised at Agfest contribute towards funding the Family Support Co-ordinator position. As a result of our intense involvement in the Conference and at Agfest, National Autism Awareness Week was certainly rather quiet in the North of the state. However ABIT (Autism Behavioural Intervention Tasmania) had a fantastic presence in the South, organising a very successful Button Day. Congratulations to ABIT and particular, Nigel Geard, for his efforts in ensuring "sellers" at many of the major shopping venues. ABIT was also extremely creative and organised to collect donations at the Uni Revue in Hobart. I understand that Cassie le Fevre, who works with many clients who have an Autism Spectrum Disorder, also organised a very successful Fun day which was enjoyed by many.

As I write this, Mick Clark and Penny Cromarty have just returned from Canberra where they attended a forum on autism. We will await the outcomes of this forum with interest! Also coming up is a meeting conducted by the Education Department to discuss the development of the Statewide Autism Plan. As a key stakeholder, Autism Tasmania has received an invitation to contribute. We will also keep you informed of the outcomes of this meeting in future bulletins or newsletters.

As a parent of a 19 year old son currently involved in a year 13 program at Newstead college, we are now facing the challenge of what comes next and unfortunately it doesn't seem to get any easier. I have a very real sense of "here we go again", yet I am fifteen years older and hope that things will fall into place much easier than they did when he was a young child. I have seen enormous change within the Education Department since Autism Tasmania began, and a very real acknowledgement of the needs of students with an autism spectrum disorder, but I am still extremely

apprehensive about what the adult options will be for our son.

To the many families out there, even though we are only half way through the year, I urge you to start thinking about next year and discuss a transition program. This is particularly important if your child is changing teachers or teacher assistants, changing schools, moving from Primary to High School or leaving school. Please consider sharing your experiences with other members and forwarding them to Autism Tasmania for inclusion in future editions of the Autism News.

Finally, the Annual General Meeting of Autism Tasmania will be held at the end of August via the Telehealth facilities and if you are interested in becoming involved at any level, please contact me on 6343 2308 to discuss this further.

Ros Ward



The Westbury Venturers were among the many volunteers who kindly gave up their time to assist with selling milk in the van and we thank them for their efforts.

Financial Grants to Autism Tasmania – What they mean to you !! by Penny Cromarty

Last year Autism Tasmania applied for and was successful in receiving several financial grants from community and government organisations. As a result we have been able to continue to employ Rose Clark, our Family Support Coordinator, this year. The grants are specifically for developing peer support networks within the autism community around the state. Rose will therefore need your input, and we are asking for your assistance as she will be surveying individual families about their needs, and also the needs of the support groups. There may also be a written

questionnaire which she would ask you to answer. The committee at Autism Tasmania believes that there is no substitute for the encouragement, support and sharing of knowledge that families caring for a person with ASD can give each other, and believes that this is a wonderful opportunity for members to build a really strong peer support network around the state.

Penny Cromarty.

“Who will love him when I’m gone?” The needs of Family Carers

“For nearly twenty-four years I have been mum to David, who was diagnosed with autism at the age of four. In recent years his voice has deepened, the whiskers have become more profuse, and he ogles all the pretty girls with long hair. My baby has grown up! I now have to adjust to living with an adult with autism. A recent journal article highlighted for me the shift in parenting required when your child grows up.” Laura Addabbo, our Family Counsellor, has prepared this summary.

“Health and social care needs of family carers supporting adults with autism spectrum disorders”, Hare et al., *Autism – The International Journal of Research and Practice*, Vol. 8 No. 4 December 2004.

There have been several studies into the effects on parents of raising a child with an autism spectrum disorder, most of which have found an increased incidence of parental stress and psychological difficulties, due in large part to the behavioural challenges associated with autism. However very few researchers have concentrated on the parents of adults with an autism spectrum disorder, subsequently this is the target population of this current study by researchers in the UK.

The families of 26 young adults with an autism spectrum disorder were interviewed about their social and psychological needs related to caring for the person with an Autism Spectrum Disorder. Carers underwent a structured interview, aimed at eliciting responses to questions relating to the use of adult day services, employment and college provisions, and the psychological well being of the primary carers (which in most cases was the mother).

This is an overview of the researchers’ findings:

The majority of participants had very little familial support compared with parents of children with an ASD, where support is often available from grandparents and other extended family members

The main factor associated with emotional distress was unmet need, in contrast to previous research with carers of children, which found strong associations between emotional distress and behaviours displayed by the child

The three main unmet needs as identified by the carers were: a break from caring for the person; help planning for the future; and help getting care for the person in the future

Carers reported that transition to adult services was first discussed between the ages of 13 and 19 years, however no-one reported any autism-specific information or support being received

The majority of carers reported some restriction on their lives, predominantly limitations to their social lives and the impact on partner and parent-sibling relationships

Many carers mentioned the need for better training of staff in day care services, and for better access to emergency care

Particular difficulties were noted for families of people with Asperger Syndrome, for whom there were very few appropriate opportunities or day services

The majority of carers expressed concern for the future of their son/daughter

Parents often spoke of attending support groups when their family member was younger, but did not do so currently

Parents reported a need for more autism-specific intervention and support for adults

The researchers emphasise the fact that long-standing psychological distress reduces the parents’ capacity to care, and their ability to negotiate effectively with the service systems and to take and act on advice. Their conclusion is that there needs to be a better understanding of the needs of the carer and that of the adult with an Autism Spectrum Disorder amongst professional and government agencies. Also, there needs to be better provision of autism-specific respite services for adults, both short and long term. Further, that support services aimed at parents of children need to be modified and adapted to better target parents of adults with an Autism Spectrum Disorder.

Reprinted with permission from Autism Victoria News Autumn 2005

Asperger's Syndrome: now a recognised disability

A Media Release from SENATOR THE HON KAY PATTERSON, Minister for Family and Community Services, Minister Assisting the Prime Minister for Women's Issues, Thursday, 17 March 2005

Changes to the Lists of Recognised Disabilities

Parents or carers of children with a disability or medical condition may find it easier to receive the Carer Allowance under changes to the Lists of Recognised Disabilities. Minister for Family and Community Services, Senator Kay Patterson, announcing the changes, said the revised Lists include a number of new childhood disabilities and medical conditions that automatically qualify for payment of the Carer Allowance.

"A review of the Lists was held to determine whether they were providing a consistent and objective means of assessing eligibility for the Carer Allowance.

The Government has adopted most of the recommendations by the independent review panel, which was made up of peak disability and carer organisations and specialists in childhood disability." The adopted recommendations included: .

- adding some conditions to the Lists such as Asperger's Disorder and Lamellar ichthyosis;
- modifying the descriptions of some existing conditions;
- developing new categories to simplify the Lists and allowing for the future inclusion of other conditions,
- increasing the flexibility and longevity of the Lists without compromising their integrity;

- and streamlining the assessment process for medical practitioners.

"I will also be seeking further additional expert medical advice regarding Diabetes Mellitus Type I. I have asked my Department and the Reference Group to explore the prospect of this condition being added to the Lists of Recognised Disabilities in the future," Senator Patterson said.

"If a child has a disability or medical condition on the Lists their parent or carer can be fast tracked on to Carer Allowance with no need for further medical assessment until the child's 16th birthday. "This benefits the customer and the Medical Practitioner as the revised Lists will reduce, in a number of cases, the volume, complexities and length of the Treating Doctors Report. "These changes follow the recent Budget's \$461 million increase in assistance for carers over four years in recognition of their important contribution to the community which included a one-off carer bonus and respite measures for both older and young carers. The Howard Government also supported carers by bringing forward the implementation date to extend eligibility of Carer Allowance from 1 April 2005 to 1 September 2004

As part of its election commitments the Howard Government will also increase the number of hours that a carer may work or study without losing qualification for Carer Payment, from 20 to 25 hours per week from 1 April 2005. "The Australian Government's ongoing programs and budget initiatives will continue to provide support for people with disabilities, their families and others who care for them," said Senator Patterson.

Reprinted from the Asperger Syndrome Support Network, Victoria Inc

Conference handouts available on request

If you would like an Adobe Acrobat (pdf) copy of any or all of the following Autism Tasmania State Conference Powerpoint presentations, please email the Secretary at autism@autismtas.org.au or you can request a hard copy of the handouts from Autism Tas at PO Box 1552 Launceston, Tasmania 7250

- Tony Attwood: *Cognitive Behaviour Therapy*
- Cassie Le Fevre: *Transitioning to High School*
- Louise Nehmann: *Positive Behaviour Support*

Behaviour Checklist

The difficulties experienced by people with Autism are often expressed through their behaviour. By understanding these difficulties and taking preventative action, we can reduce their stress and our own. The following Checklist reprinted with permission from Autism WA provides a guide to reducing difficulties.

INTRODUCTION

A child's behaviour can be poor and/or deteriorate for a variety of reasons. Sometimes the cause of deterioration is not apparent and the situation can be distressing and perplexing for all concerned.

With an understanding of autism, however, it becomes easier to find the source of the problem and to take preventative action.

This checklist is meant to be used as a guide to developing preventative strategies to minimize the risk of poor behaviour.

Some of the commonest causes of poor behaviour have their source in the following:

1. A DISTURBED ROUTINE:

Children with autism are extremely attached to routines. These routines can involve doing things in a certain way, or in a specific order. For example, for one child, it may mean taking a particular route to school or other familiar places; while for another child it may mean trying to maintain a familiar environment without any change.

There are occasions, even with a structured timetable, a child will exhibit distress. In these situations, check if some less obvious environmental change has occurred.

While it is important to encourage toleration of change, it is important also to understand the way in which routines help the child to cope with an environment s/he finds overwhelming. It is our view that if the person's routines are not preventing learning, and are not harming self or others, do not actively focus on disrupting the routines. Instead concentrate on developing the person's skills in functional, academic and social areas.

With programs which focus on building the child's skills, these routines become less rigid and less restrictive. Routines, however, will never be fully eliminated. Those

that remain are often a source of great comfort in what is a complex environment for the person with autism.

Work to incrementally change routines that are stigmatizing for the child e.g. carrying large inappropriate objects etc.. This can be accomplished by a program which gradually replaces the inappropriate object with a more appropriate or less obvious one; or it may be accomplished by making a contract with the child as to when and where s/he can have this comfort-object.

Many researchers hold the view that this insistence on routines is a strategy the child employs to cope with a social world s/he finds overwhelming. It is as if the child makes the world manageable by reducing it, and imposing an order which makes the environment predictable and less confusing. If a child's behaviour deteriorates for no apparent reason, it is always useful to look at the environment to check if the child's anticipated way of doing things has changed e.g. is there a new teacher in class? Has the child been placed at a different desk? Is a different teaching approach being used? Has there been a change to the timetable?

Strategies:

- Always prepare a child for change. Introduce visual timetables based on the child's skill level, using pictures/compic/written instructions.
- A timetable will tell the student, in a way he can easily understand, which activities will occur and in what sequence. The timetable can also include a picture of the teacher, thus accommodating staff changes.
- Train the child to reference the timetable in order to make referencing the timetable the primary routine.
- Consequently, should an event in the day need to change, alter the timetable. In this way, because the primary routine has become one of following the timetable, the child will be less likely to become upset by change.

2. INTRUSION OF OTHERS:

The child with autism has great difficulty in processing social information, or in understanding the intentions and

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behaviour of others. Without this ability, the child can find the world of people a very unpredictable and stressful place. Consequently, the intrusion of others may be overwhelming.

In checking deteriorating behaviour it is reasonable and prudent to question if the teaching /training style adopted is overly intrusive, or if the requirement for social proximity with others is too great e.g. a child required to engage in a physical contact sport appears to cope for a short period of time and then suddenly for no apparent reason becomes distressed.

Strategy:

- Lessen expectations for social participation, working gently and gradually to build the child's tolerance of social proximity and social demands.
- It is worthwhile noting that many children will, in time, develop a tolerance and come to enjoy the social proximity and intrusion of familiar people with whom they feel secure.

3. THE DEMANDS OF A TASK TOO HIGH:

Children with autism have a very uneven developmental profile. Consequently, problems often occur due to the assumption that because they are skilled in one area, they will have a similar level of skill in another. This is not the case. Therefore, where a child is exhibiting behaviour problems on presentation of a specific task, you should consider if the demands of the task, in terms of the child's skill, are too high.

Children with autism are extremely sensitive and distressed by failure and can become very upset when presented with tasks they do not understand.

Strategies:

- Where a child is becoming upset, do not re-present the task in its current form. Break the task down and teach each step independently.
- It is important to teach and not simply inadvertently test i.e. it is not sufficient to break down the task and re-present the work. Each step of the task must be taught.
- Do not presume skills on a specific task will automatically generalize to another area

4. FRUSTRATION DUE TO COMMUNICATION DIFFICULTIES:

One of the most significant, and often overlooked, sources of poor behaviour in autism is due to frustration caused by communication difficulties.

Any child with communication difficulties, without appropriate intervention will be prone to behaviour problems. The child may have little ability to influence or negotiate the demands of the social environment i.e. to communicate basic needs, to articulate distress, or to ask for help. It is important, therefore, to review the occasions when behaviour problems are occurring.

Check the relationship between the child's behaviour and the skills and opportunities s/he has to make choices, express needs, and exert some control over the environment.

Strategies:

- Language, as a communication skill, must be taught to the child, and the environment structured to promote its development.
- All children with autism should have a communication assessment with a program put in place to support the child's communication needs.

5. SENSORY DIFFICULTIES:

Children with autism can experience sensitivity to some forms of sensory stimulation. In particular, they may experience acute discomfort in noisy environments, or to particular individual noises in their environment.

Strategy:

Should you see a relationship between the level of noise and the child's behaviour, arrange for alternative (quieter) activities for the child during these times.

6. INSUFFICIENT STRUCTURE IN THE ENVIRONMENT:

Children with autism need a structured, predictable setting which allows them to make sense of their environment, the behaviour of others, and the expectations placed upon them.

Large open-plan classrooms, with an unstructured teaching approach are not generally suitable for the child with autism. At best, under these conditions, the child learns

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poorly. At worst, the child experiences chronic stress, often acting out anxiety through what appears unrelated behaviour problems.

Strategy:

The only reliable strategy under these circumstances is in an alternative environment for the child, one providing a more structured approach to learning.

N.B. A more structured environment does not imply a more restrictive one.

IN SUMMARY, people with Autism do not go out of their way to be difficult. In fact, most of their waking hours are spent trying to avoid situations they find stressful and engaging in activities which bring them comfort. Unfortunately, by its very nature, everyday social life frequently clashes with their attempts to bring order and predictability to their lives. One of the challenges for those who work with or care for someone with Autism is to

understand the causes of their distress and to take the two-fold action of avoiding what is avoidable; and developing the skills of the person to deal with everyday demands.

Reprinted with permission from the Autism Association of Western Australia, Autism News, April 2005

Gateways Website

Visit the New **GATEWAYS** Website providing news and information for people with disability and those working for equity in education, training and employment.

www.adcet.edu.au/gateways

START SAVING FOR NEXT YEAR'S AUTISM SAFARI

The 2nd World Autism Congress and Exhibition will be held in Cape Town South Africa from 30th Oct - 2nd Nov. 2006.

Early bird registrations for parents is R3500 (\$680.00 AUD) and professionals, R4600 (\$893.00 AUD) before end June 2006 Visit the website at www.autismcongress.com for more details.

A Plea for Understanding

Donna Williams, a mono-tracker with an international profile as an author, artist and public speaker, has written an open letter to the multi-trackers of this world who struggle to accept mono-trackers as equals.

Dear Multi-tracker,

I can see you struggle to understand my mono-track nature so let me make it simple for you. Imagine an office block with five different offices all doing their thing, answering their phones, sorting their papers, doing their computing. This is what a multi-track brain does.

Now imagine an office block where every time an activity started in office 1 or office 2, the lights went off, the computers crashed and the staff forgot what they were

doing in offices 3, 4 and 5. This is what a mono-tracked brain is like.

It's nothing to do with stupidity, not caring or not trying. In fact, sometimes, it's even a skill and a mono-tracked person can get really into a single track in a way a multi-tracker often couldn't!

But we live in a world of minorities and majorities and I am a minority so all I can do is appeal to your open mindedness, your tolerance, your compassion and your respect for diversity and remind you that your own 'normality' has always been perplexing and foreign to me too.

Donna Williams - www.donnawilliams.net

Autism-a Personal View by Emily Brake

-taken from the transcript of her talk to the State Autism Conference May 2005

I'm Emily, and about three years ago I was diagnosed with high functioning autism. At the time that meant nothing to me, it was just some other group of fancy words that parents used, and a reason, I presumed for all the trips into town for assessments.

Since then it has come to mean more, and it has become something I've had to manage, particularly in the area of anxiety.

Going to school for me is like what a trip to the dentist might be for you. It's something to dread but also to endure, because I know - and you know - that at the end of all that uncertainty, there's hopefully going to be some really good results.

Of course, in the day at school there is bound to be a problem here or there, and to me and my family they have become known as challenges. These challenges aren't what other people might consider hard, they are just simple social things that I hate but have to do.

The hardest challenges of my school years were mostly in Grade 10 (last year). The transition for college, finalising of results, leaver's activities, leadership roles and extra activities were all balanced on my plate - just as they were on every other Grade 10's. The difference was they were smiling and I wasn't. I began to hate school, - especially the people who never seemed to just speak and say what they meant. I imagined a group of people as a black sphere, tight and surrounding, with me trapped inside.

My school day began at about 6:30, when I struggled out of bed and began to organise myself. Getting ready for a day at school was perhaps one of the only things that I didn't have a regular routine for. In the last minutes before my lift with Mum and Dad was meant to leave, I still ran around trying to fit 15 mins of morning jobs in half the amount of time. On many days I forgot homework, lunch, a drink, stationery or something else I'd promised to bring for one of my friends.

I had such a fixed routine in other small things I did in the morning, I couldn't stop them even though they held me up.

To get to school I had a lift with my parents, or walked. I would do anything to avoid bussing to school, even though I did not mind catching the bus home. The bus is one of

those times where you have to sit crammed up with heaps of other people, and - if you're unlucky - talk. The bus trip home was something I began in primary school, catching it with my brother and sister, but the trip there was something I had never done and I was never willing to try. Once I have begun on a course of thinking or a routine, I can't normally give it up.

Once at school, I'd have to organise myself for the day ahead. Sometimes that was simply getting my books; sometimes I did a lap of walking around the school to clear my head and try and shake out a few nerves.

I went to Giant Steps one day a week last year, so that pushed my other Exeter High classes out of whack. I was trying to do 6 school days in 5 to compensate for lost work time, and that made me give up on a few of my classes.

On Mondays I went to Giant Steps, then on Tuesdays I began Exeter a day behind the rest of my class and spent the rest of the week catching up again.

In the end I spent more time out of class than in, talking to support people, doing private work or walking around the school to calm down.

I pushed my friends away and became a "loner" not caring for contact with other people unless it was for help. My marks dipped, and I didn't feel like trying to pull them up again. I fell into a pool of depression.

I spent a large portion of third term in the computer room working on the school magazine. It was the perfect excuse to work alone, to not go outside for a socialising break at recess and lunch and to look occupied enough for no one to stop by and talk. Through doing the magazine I was able to stop going to usual classes and keep my own little world intact.

I avoided the sports carnivals, socials, birthday parties, activities, most assemblies and even Leavers' week because it made me so nervous.

I didn't like having different teachers for each lesson without a list of what we were going to do, because of the uncertainty of what was going to happen. I like to brace myself for group work and talking, but how could I if I

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didn't know what was going to happen? I found that the best way to avoid surprises was to avoid the class completely, and fitted my appointments and meetings with doctors or Oakrise over them when I could. Through the year I built up a wall of hate for people and socialising. I thought of friends as accessories, something someone doesn't really need.

Despite that I made one friend in grade 10 that I was able to talk to and be pretty much understood. She has dyslexia and often got nervous like me; but most importantly she didn't try and ask awkward questions about why was I inside when my other friends were outside, why wasn't I going to class, why didn't I do PE, and why wasn't I at school yesterday if I wasn't sick? I find questions like that confronting because most of my friends were into boyfriends, parties and how they looked. I knew that even if I told them they wouldn't understand, even if they wanted to.

I liked Giant Steps for that reason – I didn't have to explain myself to anyone, but whenever I did, I knew they understood about me.

The other grade 10s looked like sheep – walking and following each other everywhere and having no apparent individuality.

Occasionally my grade went on excursions or to assembly, and these were the days I dreaded above others. No one knew what was going on apart from the teachers, so everyone was wondering, which didn't make it easier.

The whole day or days of the event were thrown out of whack, ruining the routine and pushing me out of my comfort zone. If I imagine the week as white, any unusual things that happen put a red blotch on my white week, the red standing out and dominating the rest of the white.

Red are the alert times for anxiety, when I don't like contact and get irritated at people for speaking to me, and can't cope with extra jobs – like the dishes.

The bus trips to outings are hard. I can either sit with one of my friends and chat or sit on my own and chance that someone else will sit next to me.

Talking when I am nervous is hard and because I am so preoccupied with the day ahead, I don't want to talk, and find it hard to focus on the present.

I take a book so that people think I'm occupied and don't talk to me, even if I can't concentrate on the page.

When I get to the place, like a grade picnic to the beach, I find it hard to think of what to do, because there isn't an organised schedule. I usually sit and read my book or dig a hole in the sand, not bothering to make contact with anyone unless they come to me.

Being in a different place drains me, even if I don't feel particularly terrified at the time. I usually find I am tense and jumpy.

After the trip home I feel extremely tired and uncoordinated, getting a migraine or headache. I also get what my family calls "shiver shock", which is when no matter how many layers of clothes I wear, I can't keep warm. I get this weird "shiver shock" so often that I wear on average five layers of t-shirts and a jumper every day.

After this talk I will probably have the same thing happen, even though I will float away because the tension will have gone. On the trip home I will most likely chatter constantly, even if nobody's listening to get everything out of my system.

The Leavers' Week was the thing I feared most in my whole time at high school. Each year I saw each grade before me leave with assemblies and activities on for them, and worst of all, the Leavers' Dinner. I knew about all the dressing up and fuss over the dinner – it was what everybody talked about the whole year before it happened. They discussed who was going with who, what they were wearing, where they were getting their nails done...etc...etc.

I have never been in a beauty parlour in my life, and I hate dressing up so my first thought was to not go and avoid the biggest social event of the past four years.

But my friends asked those questions, like: "Why not, it will be so fun?" and: "We will miss you if you don't come, so will you try?" They didn't know it but they were convincing me even more and more that I didn't want to go.

Every time someone mentioned "Leavers", it felt like I had all my insides trying to run in different directions and getting tangled inside. It felt horrible, and that in the end was what made me decide not to go. I reasoned, if I felt that bad just because of a word, how would I feel for the real thing? I could imagine it would be heaps worse.

Instead I had my own "Leaver's Dinner" at the same time as the big one, with my family, my cousin and two other friends. I actually enjoyed it, and didn't feel like I missed a thing! My cousin gave a really nice speech, and all the food was my favourites.

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After the dinner and the holidays came my first day at Newstead College. I had to catch the bus in for the first time and was so scared that I felt I would faint as I walked up the road to the bus stop.

I arrived at Newstead with a few people from Exeter I had known from the year before, including my friend with dyslexia.

I whizzed through the first few weeks doing things that no one had ever dreamed I could, even surprising myself. I made friends with people and volunteered answers and questions in class. I bought food in the caff and became less withdrawn; all because I was numb.

When I go numb it is when I am really nervous and usually in a new spot or doing something new.

The new surroundings at Newstead with all the people were so overwhelming I cut myself off from my feelings

and became almost reckless, not caring anymore.

Unfortunately that is wearing off now and I have realised again just how many people there are at Newstead. I have cut back to three days a week to escape some contact and give me some space.

At Newstead I hate catching the bus home. At the end of the day I don't have any energy left to sit and talk to someone or even have them sit too close. If I know that I've got to catch the bus home, I can't concentrate on my class work that day.

But there have been ups in my high school years, like: when I finished the school magazine, the flash presentation I did for the director of the Support Service, becoming a Student Support Officer and giving the talk on Autism to my grade last year. Also I have enjoyed learning more about people – though from a distance.

Emily Brake

My Story by Jeremy Geard—with a foreword from Carolyn and Nigel Geard

We are the parents of three sons aged eighteen, fifteen and nine. Jeremy is our second born son and at the age of seven, he was diagnosed with Asperger Syndrome. Our other two sons are neuro-typical.

Jeremy has always had a difficult time at school, not being able to fit into the same mould that is expected of students, regardless of whether they have special needs or a disability. We as caring parents, have always been pro-active and assisted the schools that Jeremy has attended with resources and information to support them in their role of educating and understanding Jeremy's special needs. However, early in 2004, because of ongoing problems we encountered at the high school Jeremy attended for the previous two years, we decided to change schools.

During this transitional time, Jeremy had the privilege of working with a lovely lady in Hartz Support Service, who encouraged him to write his feelings down on paper. This has been a great achievement for Jeremy as it has opened many doors for him to convey to people what it is like for someone who has Autism Spectrum Disorder to contend with on a daily basis.

Some of you may have read snippets of 'Jeremy's Story' already, as he appeared in The Mercury in May 2004 for National Autism Awareness Week.

Jeremy's goal now is to make other people aware of Autism and he has expressed he would one day like to write a book – something which we as parents would be so proud of.

Maybe this is just the beginning.

Carolyn & Nigel Geard.

I'm Jeremy and I'm 14 years old. Life is difficult for me at the moment.

To me other people look different. When I look at certain people I see their whole face, but I fix on a certain area eg: big noses, spots. I can't tell what they are feeling by the way they look or the way they sound.

I am better at reading faces and voices now but not much, I need people to use words to tell me what they are feeling. Sometimes sounds get distorted. When I am in a small classroom sometimes it can sound like being on a football oval. Sometimes sounds go quiet then I can hear weird sounds in my ears.

Sometimes when I'm in the dark I see flickery coloured stars. Touch is a problem for me. Light, friendly punches on the arm hurt, nylon material makes me itch. I can't wear

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it and if someone else is wearing it and brushes against me, I really itch. I do not like to be touched by anyone. I hate hugs, but, sometimes it is all right with Mum but I get sick of it. If I am sick or sad a hug from Mum makes me feel better. I only like hugs when I ask for them.

Not many people have interests like me. I am interested in the hardware of computers, I like to take computers apart, put different parts in there and see what it looks like. I like to draw power lines, big pictures with houses, roads and shops with powerlines connecting the grid. I can't be bothered to draw people. I like the weather especially thunderstorms. I love Sim-City, the computer game. I think all schools should have it because it's educational.

I like to talk about my interests and I like other people to talk about them too. I like to read about them and find out as much about them as I can. I don't like sport because I don't like physical activity and I don't like to be touched, but I do like walking.

I love being alone especially with my pet cat, my penguin and my computer playing Sim City. I never get bored. I have a few friends. I play Sony, chat about my interests and go for walks. I see them now and again. At school, I prefer to be with adults, students my own age tease me, not many of them have my interests, and they walk away from me.

The way things smell is a pain. Lots of things smell really strongly to me. Perfume stinks.

I hate Assembly, walking in crowded corridors, football matches and the Show because there are too many people. I feel angry and stressed. I hate being closed in by people. I don't feel safe. I often used to get in trouble at my last school because I got angry after I had to be in a crowd.

I can't use public toilets. At school I have always had a toilet put aside for me.

I don't like being near strangers. They ask me questions and I don't what to say. I need to know people a long time before they stop being strangers. At primary school where I only had one teacher, I got to know them well and feel comfortable with them quite quickly. At high school, when I have up to five teachers a day, it can take weeks to get used to them. I don't like teachers shouting in the classroom; I get stressed and I can't think. When I get stressed, I run out of the room; I walk around the school grounds. I never leave the school. If I can't get out, I swear. Sometimes I threaten people when they won't let me go,

then they let me get out.

If I'm angry, I swear and get aggro. I hit and threaten people and I get suspended from school. I know what I'm supposed to do, but when I'm angry I can't; but other people can.

I get angry when people tease me about how I act and what I do. I get angry when I am told I can't do things.

I do things for people when they are my friends or family, I want to please them and I want them to like me.

When I don't want to do things or I am asked to do something I haven't done before, I get tired.

I like penguins, computers, Rani, my parents, my bed, travelling by bus, my friends. I like my brothers but they are annoying sometimes. All brothers are annoying. I often think I would like to know how it feels to be dead, I think everyone feels this.

I always feel like I hate things; like weeds, they look like aliens. When I see them I get scared or nervous. I hate old houses, they look old and ugly. They don't match new houses, and I think they should be pulled down. I hate the way my eyebrows meet in the middle; I have had them waxed away.

Chapter 2.

When I am walking around the school and I see a teacher I know I would like them to smile at me rather than say hello. I would prefer that teachers that I don't know would ignore me as they are strangers.

It is a problem when teachers give me lots of instructions at once. One or two instructions at a time are better, but I prefer them written down. I prefer to sit at the front of the classroom, by myself. Noise, people close to me, doing things I don't want to do, stress me.

It would be useful for me to have a break card. It will be good for me when I'm stressed and I can't get out of the classroom to a safe place.

Things that make me angry are:

- People telling me what to do. eg: people I don't know or like asking me to help them, being told to do maths or things I'm not interested in.
- When I want a broken computer to take home and I'm not allowed it.

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- Doing therapy.
- Stress.
- Not being able to get away from a stressful situation.
- Being teased.

Doing new things.

It is easier for me to try new things when I have someone I like helping me. I can't do it in a crowd or if there is a noise.

My favourite places in school are the quiet places. The library if there is no class there, the computer room if there is no class there. I don't feel safe outside even if I am by myself. The school hall is large and it echoes which I don't like.

At lunch and recess times I like to play computer, talk to adults and read books. I don't want to be with other teenagers, as they tease me.

I want to do well at school, but I'm scared that I might get it wrong.

Jeremy Geard

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“Unforgettable, that’s what you are”, by Clare Robson reprinted from Autism News Victoria, Autumn edition 2005

Claire Robson is a big sister. This article is a condensed version of a writing piece submitted for her VCE English in 2004.

My brother is autistic. Images of a spastic child may spring to mind. But I assure you, my brother, Luke does not fulfill such a description. The differences that sufferers of Autism experience are not physical but social. The disorder involves impairment in both social interaction and communication, as well as restricted and repetitive patterns in behaviour, activities and interests. Luke was diagnosed at ten with “mild autism” meaning he has these impairments, but to a lesser degree than others.

Luke is not a fan of physical interaction, squirming if I try to hug him or fix his collar. He does, however, have selective attachments to our mother and our cat Skimble. “I’m his farvor” he’ll say, not grasping the correct pronunciation of “th” - “he’s my best friend”.

As an infant he was a gorgeous golden blonde with curly locks. To his own satisfaction he lost these curls and his current physique deeply contrasts with his old appearance. At fourteen, he possesses the typical physical traits of a “nerd”. With straight, un-brushed hair he wears glasses, braces and emerging pimples. His body has not been affected by his ‘chocoholicism’ and he is quite scrawny.

Luke’s problem with communication was evident at three when he spoke in single words rather than whole

sentences. Even now he mixes up the order of words, stating he’d “hurt and fell myself” or “Mum, can I tell you something? Does a cat miaow when it’s happy?”



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Luke is a fan of films and believes them to portray general life. He does not realize that in reality different things occur depending on the individual. He believes that "if you see blood you'll be sick". He is shocked and appalled when film characters swear - "swearing is NOT acceptable!" He has written up household rules, and a list of what he believes is not allowed in public. This list includes "no kissing" and "no singing". Luke cannot understand exceptions to rules. This means he takes everything literally, not comprehending metaphors or jokes. He seeks comfort in rules, enabling him to understand what is right or wrong. Recently he was thrilled to discover that there were two extra rules on Connex trains.

Luke must stick to the train timetable. It is essential that he takes the 7:37 train in the morning and the 3:48 in the afternoon. If not, he won't have his afternoon tea on time. He also needs to wait until the train has passed the Brighton footy oval until he stands up, then hurriedly opens the carriage door and runs home for his chocolate croissant. He must have his meals at specific times of day otherwise it becomes too confusing. He has to eat the same foods and his maple syrup must be oozed onto his pancake the same way.

By living with Luke I am often subject to experiencing the polarities of patience and impatience. I have learnt to understand him in ways that other people cannot and thus have developed patience. I am also able to feel deeper compassion for others who have difficulties. However,

impatience unfortunately rears its ugly head. I can easily become frustrated when Luke doesn't understand simple concepts. Sometimes I yell "Don't be stupid! Of course it'll get better!" when he worries his foot will be sore "forever". The fury can drive me to insult him, calling him derogatory terms that I know will hurt. Sometimes I become so frustrated that he doesn't comprehend something he should; I feel that by insulting him I can help him overcome it and realise his worries are indeed stupid. Of course he can't overcome it. Hurtful words do nothing except make him fear asking the questions that he needs to calm his anxieties.

One of the things I love the most about Luke is that he doesn't judge me. Sure he can be insulting, telling me I smell, but petty comments aside he can't hurt me. I can sing, dance and act like a fool in his presence and he either ignores me or joins in.

Although it may seem that Luke is a burden, I can occasionally appreciate my luck in having such a sibling. By living with him I can better understand how someone else sees the world and marvel. This helps me value my own life much more. Often I will cry, complain or feel depressed over a minor problem, but I do not have cognitive impairments like Luke. I am communicative, have friends and am socially accepted, which I take for granted. Others do not have that luxury. By knowing Luke, a major lesson has been learnt..

Clare Robson

Thank you to all those members who have returned their
Gold Coin Donation forms and money already!

It's not too late to return yours to be in the running for a free membership for 2006.
Please return forms and money to the Autism Tasmania postal address as soon as possible.

Advance notice

Autism Tas. AGM

Wed. 31st August 2005

7.15pm

at the Telehealth Studios of the LGH, RHH and NWRH (Mersey and Burnie), other
public hospital sites may be available on enquiry

ABIT – “Catching Up” Autism Behavioural Intervention Tas. Inc.

Supporting Families Teaching ABA.

Hello to Bulletin Readers, Here's a report back from NAAW Button Day this year.

Hello Everyone, This years **National Autism Awareness Week--Button day** on Thursday 12th May was a great success for ABIT. The day started early at 06:45 am at one volunteer's workplace and continued throughout the day with a number of volunteers collecting and raising awareness at various locations throughout the greater Hobart area. The day finished at the Theatre Royal, where hardy collectors raised money after 7pm from patrons attending the annual Uni-Revue. It was a fantastic effort by everyone involved.

I would like to take this opportunity to Thank ABIT members and their family & friends who volunteered their time & effort in raising money, and also in raising the awareness of Autism Spectrum Disorders within our community.

I am looking forward to working with you all again for the 2006 NAAW Button day.

Regards Nigel Geard—*ABIT Button Day Coordinator.*

Best Wishes Rosemary Rush – *President ABIT Ph 6229 5760*
rushm@netspace.net.au

One-off payment windfall for Australia's carers 10/5/2005

The Howard Government, as part of the 2005-06 Budget, will provide funding of nearly \$317 million to pay a one-off bonus to all eligible carers. The Minister for Family and Community Services, Senator Kay Patterson, today said the measure was in recognition of carers' valuable role in our society. "I am pleased to once again be offering these one-off bonus payments, recognising the extraordinary effort of carers and as a result of the Howard Government's sound economic management," Senator Patterson said. "This payment will provide carers with better support when providing care for their relatives and friends who have a disability or are frail aged.

"Under this Budget measure, a key feature will be the repeat of the one-off Carers Bonus paid last Budget. "A bonus of \$1,000 will be provided to current eligible recipients of Carer Payment and a bonus of \$600 will be paid to Carer Allowance recipients for each eligible care receiver. Subject to the passage of legislation, payments will be made to the majority of eligible carers before the end of June 2005," Senator Patterson said. Carer Payment is a means tested income support payment paid to a person with limited income who provides constant care for someone with a disability or frail aged. Carer Allowance is

not means tested and is an income supplement paid to people who provide daily care and attention at home to a person with a disability or who is frail aged. "This year's Budget measures continue the Howard Government's strong commitment to carers and builds on last year's Budget initiatives where carers were given more flexibility and support in their care arrangements:

Carer Allowance eligibility was expanded and Carer Allowance is now available to eligible carers who do not live with the person for whom they provide substantial levels of personal care on a daily basis; and Additional funds were provided for respite care for older carers who are caring for their sons and daughters with disabilities; as well as a package for young carers, including respite services, telephone help line and age appropriate information.

"The Howard Government recognises the range of care needs, differing care situations and the long-term commitment of carers and will continue to provide support and assistance," Senator Patterson said.

Reprinted from Asperger Syndrome Support Network Victoria Inc

Jottings

Frogs for Autism by Christina

Booth

Autism Tasmania member, Christina Booth, has made the following offer in support of AT's work.

The following is an extract from her website

"1 in 100 people in Australia have a form of Autism. This disorder is one that people are born with and there is no quick fix or cure. Whilst many people with Autism lead full and regular lives it can be with difficulty and not without the support of family, friends and organisations such as Autism Tasmania. Frogs for Autism is a fundraiser to help support the supporters and their Autistic relatives and friends."

50% of the sale price will be donated to the work of Autism Tasmania. Buy a frog and help support those who live with Autism

Print costs \$30.00 (Australian) not including postage and handling.

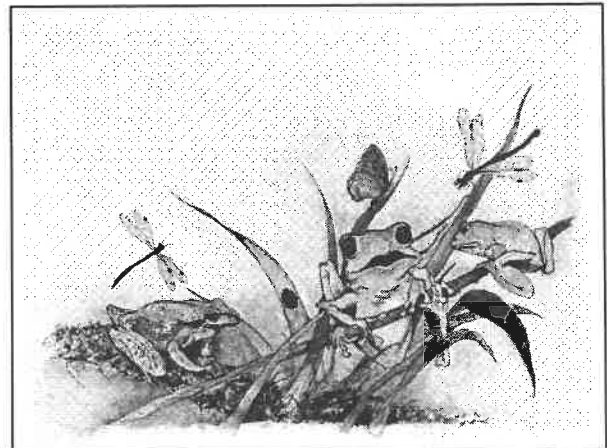
Contact Rose at Autism Tasmania or Christina Booth to make your purchase or to sell this print from your business.

How to contact Christina:

P.O. Box 165 Kings Meadows, Tasmania, Australia, 7249.

or contact Christina on 0402473795 or

<http://www.christinabooth.com>



Letter to the Editor

Dear All,

The Epilepsy Association of Tasmania is trying to reach out to all Tasmanians with Epilepsy in order to facilitate the founding of a National Consumer representative body. Currently each State Epilepsy Association has a representative on the Joint Epilepsy Council of Australia but there are no consumer representatives and no real consumer based representative body. This is obviously unsatisfactory for consumers and associations alike.

Therefore we ask that peak bodies and advocacy organisations pass on this information to other relevant individuals and organisations thereby assisting them to contact us.

In Tasmania the contact details are Epilepsy Association of Tasmania PO Box 562 Burnie or 03) 6431 7848 or nwepilepsytas@bigpond.com.au

Much appreciated fellow travellers

Judith Blades *President EA Tas Disability Discrimination Act Legal Service Launceston Community Legal Centre, Tasmania*

Giant Steps is holding its 10th Birthday Trivia Night....

- When? - Saturday 9th July 2005
- Where? - Australian-Italian Club, Old Bass Hwy
- Time? - 7.00 for 7.30 start. (Scrumptious Supper provided)
- Cost: \$15.00 head—Contact Penny to book a table on 6334 1119



THE BULLETIN OF
AUTISM TASMANIA
INC.

Postal Address: PO Box 1552
Launceston, Tasmania 7250

www.autismtas.org.au

*Providing lifelong support to
people with Autism and related
disorders.*

Family Support

Contact the
Autism Tasmania
Family Support
Coordinator,

Rose Clark
on

6423 2288 or

0407 320 048

or

autism@autismtas.org.au

Parent Support Groups

South

South – meet on the second Thursday evening in each month at Tascare, 231 Main Road, Moonah starting at 7.30pm. There is a coffee morning the following day, the second Friday (sometimes this is the 3rd according to how the days fall at the beginning of the month) at Munchkins, in Sandy Bay, meeting from 9.30 onwards. (Munchkins is located above Woolworths supermarket and is very suitable for young

Cygnets – new group about to start.

North

North – no specified day or venue but get togethers are as requested by parents. Meetings have been a combination of social occasions and guest speakers

Exeter – meet on the last Friday in each month at Tresca in Exeter, beginning at 10am.

George Town – meet on the last Wednesday evening of each month beginning at 7.30pm at the Wattle Group building located at the roundabout in Agnes Street, George Town.

NW, West and East Coasts

North West – meet on the first Tuesday evening in each month at the Community Health Centre, Jones Street, Burnie (other venues according to speakers etc.)

Smithton – a specific day in the month yet to be decided. Meet at the Rural Health Centre in Smithton.

Sheffield – new group just started. No specific time or date decided as yet.

East Coast – meet at Scamander on days decided by parents. For meeting times and details phone Karen Rawnsley on 6372 5077

These groups have been established because of the desire of parents who attend them. At various times speakers are invited. At others, parents swap ideas/strategies/information about services etc. Further groups may evolve as the need for them arises..

For further information and details give Rose a ring on 6423 2288 or 0407320 048