

July 2005
Issue 6

Aut-Talk



Newsletter from Autism South Africa - the National Body for people with autism in South Africa

We would like to congratulate Mr. Chris Moreton who we are proud to announce has accepted the position of Chairman of Autism South Africa. We wish him a very successful year ahead.

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Chairman's Report – May 2005

It is my pleasure to report on the activities of the past year and the significant developments undertaken by Autism South Africa (ASA) to improve the quality of life of the increasing number of children and adults with autism in South Africa.

Worldwide there is extreme concern about the radical increase in the incidence of autism, with international statistics showing that this lifelong and extremely complex disability now affects 1 per 158 children under the age of 6 years. One can therefore imagine the incredible challenges Autism South Africa faces with no government support, decreasing corporate assistance amidst the HIV/AIDS pandemic in our country and the frightening escalation in prevalence of autism. Despite these factors, I believe Autism South Africa has made a significant and extremely positive impact on the lives of many people with autism over the past year.

Empowering parents and professionals with knowledge on autism has been a priority for Autism South Africa. A large amount of time has therefore been put into building up and maintaining an extensive database and regularly distributing, electronically as well as by post, relevant information received from our many international contacts. Thanks to a wonderful donation of R 50 000 from the R B Hagart Trust, we have printed and distributed free of charge, over 30 000 of our range of six information brochures dealing with different aspects of autism.

In addition, as a result of sponsorship from The Flemish Government, Sappi Limited and the Nedcor Foundation we were able to host 15 two-day workshops on various aspects of autism-specific intervention. Due to the generous sponsorship the attendance fee was incredibly low ensuring that people from all socio-economic backgrounds were able to attend. In total over 1 500 delegates from around the country attended these workshops, making a significant difference in the knowledge and skills of many educationalists and therapists working with our children with autism.

Autism South Africa sincerely thanks the National Lottery Distribution Trust Fund for their ongoing support.

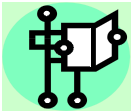


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Chairman's Report - continued

Coupled with training of professionals must come a system of supervision to ensure that our children and adults with autism receive the correct intervention. With this in mind, Autism South Africa has established a "registration" system, not only to keep a watchful eye on the provision of services, but also to assist and support professionals with their work.

It is with sincere gratitude that I would like to acknowledge The National Lottery Distribution Fund for their significant contribution of R 250 000 to Autism South Africa this year. This funding was donated to Autism South Africa for the specific purpose of providing the offices with financial support for the period of a year so the staff could focus on training.

We have been most fortunate to have been invited onto several TV and Radio programmes to enhance public understanding of autism. As a result we have received many calls from families that previously had not known what was wrong with their child. I sincerely thank all those producers and interviewers for their compassion and assistance.

ASA is exceptionally grateful to all our benefactors who have made a meaningful difference in the lives of our children and adults with autism. Without such support we would never have been able to implement the substantial work that our two staff members undertake on a daily basis. I would therefore like to extend a sincere and special "thank you" to all those individuals and companies who over the past year have either provided Autism South Africa with funding, products or services. Regardless of the size or form of the donation they are all truly appreciated. I do however feel it is pertinent here to mention some of our larger benefactors.

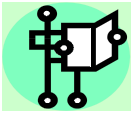
In this regard I would like to extend a special vote of appreciation to the Concord Trust, Consol Limited, Investec Bank Limited, Iscor Trust, Metair Management, Michelangelo Hotel, Nedcor Foundation, Netcare Foundation, Rainbow Farms and Sappi Limited.

In South Africa there are seven schools for children with autism, which is far from sufficient. If the international statistics are correct there are potentially 270 000 children under the age of six affected by autism in South Africa. Autism South Africa does not have the funding to build new schools and therefore we are contacting all LSEN (Learners with Special Educational Needs) schools around the country to establish whether they are enrolling children with autism and if so we offer training and guidance. This we believe will significantly improve the provision of classes for children with autism, thus increasing the accessibility of appropriate education for our children with autism, regardless of geographical location or socio-economic status.

Our two staff members spend a vast amount of time on the telephone with parents and related family members offering a shoulder to cry on as well as providing relevant information and day-to-day "tricks of the trade" for coping with a family member with autism. A single call can take up to an hour, but from the letters and calls of gratitude received we know we are making a meaningful difference in improving the home life of a family battling to come to terms with the diagnosis or cope with a family member with autism.

Adult services although in short supply, continue to improve gradually each year. The Lethabo le Khutso Centre, run by the Tshwane regional body (Association for Autism), is now full and the residents are happy and mastering new skills. Through the joint efforts of the Western Cape regional body (Autism Western Cape) and Vera School, doors have been opened at a small house that offers a home to people with Asperger Syndrome who are able to work but still need some assistance with daily life.

December saw the launch of a new awareness project with the lighting up of the "Tree of Light and Support" for those affected by autism. For several years now we have hosted our most successful annual Golf Day at Parkview Golf Course and this club offered to show their support for people with autism by hosting this "Tree of Light and Support" at the entrance to their Club House. I would like to express our gratitude to Electron, Osram, Aberdare Cables, Jerry Fraser, the course manager, Ampax, Randburg Signs and Skyjacks for all their wonderful assistance, as well as those who most kindly purchased bulbs. The "Tree of Light and Support" slowly but surely grew as donations were received and it was wonderful to watch the tree light up with compassion for those affected by autism in South Africa.



Chairman's Report - continued

We are exceptionally proud to have been awarded the 2nd World Congress on Autism that will take place in Cape Town from 30th October to 2nd November 2006. We are expecting 1500 delegates from all over the world, with 80 speakers presenting papers. When the World Autism Organisation invited us to bid for this congress, Autism South Africa specifically requested that, should we be successful delegates from Africa be offered a 50% reduction on the registration fee. We won the bid and our request for the reduced fee was granted. Therefore for the first time ever many parents and professionals related to the field of autism will have the opportunity to attend an international congress on autism. A wonderful achievement!

Autism South Africa has many odds stacked against it, but I would like to sincerely commend the tireless dedication and compassion of all those involved whether at national or regional level, whether they are a parent, a member of staff or a volunteer. In particular I would like to thank Jill and Pauline for the untold amount of work they do and the frustration they have to endure, without which Autism South Africa would not be what it is – well done, you are both fantastic.

Many things are far from certain for people with autism, but one thing is for sure, however your path crosses the path of a person with autism, it will always be enlightening and humbling experience.

Thank you. PAUL PRATT. Chairman

Adapting to a new life - Taken from Love, Hope and Autism – ISBN 1 899280 07 3

Our son Michael (now aged 4) was diagnosed as having autistic tendencies in July 1995. He is our second child, having an older sister, Natalie aged 7. He developed 'normally', reaching milestones early so it came as a complete surprise that he stopped talking at 17 months.

At first we thought this was due to us moving house to a completely different area, and Daddy remaining on board ship, whilst finishing his career in the Royal Navy, thus living away from us for the first time in Michael's life.

When speech failed to return after six months the professionals stepped in and became part of our lives. At first it felt like we were constantly attending appointments for assessments and consultations and everything else came second to the 24 mile round trip to the hospital, which we did at least once a week.

We saw many 'specialists' including the paediatrician, psychologist, child psychiatrists, speech and behaviour therapists, pre-school learning support teachers, under-8's advisers and representatives from social services. Juggling these 'visits' while trying to maintain a 'normal' life provide very stressful and tiring time and often I wanted to 'wake-up' from this nightmare.

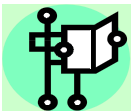
Since typing this letter Natalie has asked if she may write something.

I was very sad when Mummy and Daddy told me that Michael had to go to hospital to see the doctors, so they could try and find out why he had stopped talking. I went with Mummy and Daddy to one place and they told me Michael was autistic and it meant he didn't understand how to do things like I do.

Mummy read a special book with me, about other children with brothers and sisters with autism and what they do. That helped to let me know about autism.

Michael is so special to me and I love him so much, even though he is a person with autism. We play together, especially chasing games and on the trampoline and climbing frame in the garden. He makes me cross when he ruins my games. We have lots of cuddles and dance together and he likes to come and sit next to me when I read him a story.

Some of my friends are frightened of him, but it's because they don't know him properly, but my best friends like Michael and talk to him normally, and we play with him. I wish Michael wasn't a person with autism, but I do love him even more because he is so special. *Natalie age 7½*

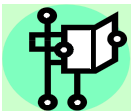


Michael got fed up with continually being assessed and would refuse to do basic tasks that I was certain he was capable of doing. The specialist would look and jot down notes and very often felt they disbelieved what I said about my son. I felt I was the one who had got it all wrong and I was dreaming the things he actually did when left in peace and not when he was expected to perform on cue. However, I was assured that this was a 'normal' reaction from the children and 'not to worry'.

The repetitiveness of the questions and assessments became somewhat a chore and I did feel that it was a waste of time. On hindsight it was worth it as Michael received the best care after our initial assessment. I will never forget the day autism was suggested. I felt my whole world had fallen apart, and I was totally alone. We (my husband and I) were looking or hoping for a diagnosis of something that could be cured or that Michael would grow out of, not something that no-one seemed to understand or know how or why it happens. Initially we disagreed with the diagnosis. 'They were wrong'. After all, Michael was such a happy child, he loved his cuddles and kisses, was not obsessive, had no strict routines, was not bothered by change and had lots of understanding of what was right and wrong and our 'rules' within our home and family. Then the nagging doubts began to surface, however much we tried to put it to the back of our minds. He didn't have eye contact. He preferred to play on his own. He didn't use any role play. He flitted from one activity to another without any awareness of what he had achieved if anything. He had no speech and no real idea of what communicating meant or was used for.

The initial feeling and the tears gave way to all the questions: how, why, cause, cure? And the unacceptable answer of 'we don't know' was very difficult to take on board. We felt helpless, as if it was our fault; we'd let Michael down and there was nothing we could do to repair the damage. The thought that kept resurfacing time and again was 'Who would look after Michael when I no longer could?' After all this was a lifetime disability and although I could cope controlling him at this age what would happen when he got too big to handle and too heavy to lift? Where would he go? And how would he communicate his needs to someone who didn't understand him? The thought 'they' had got it wrong, surfaced regularly, and still does, along with 'he'll prove them wrong', especially when he achieves something that children with autism are not meant to achieve. We also realise that we were one of the lucky families, although this took time to surface. After all Michael is a fit healthy child, rarely ill and so happy, at least we don't have to deal with a 'time-limit' of a fatal disease. I suppose it's a way of dealing with what we have but it's true there is always someone out there far worse off than we are, not that this thought helps when we are feeling particularly low and have had a few bad days / nights.

A must for anyone in this situation is contact with other families in the same situation. It doesn't matter that their child may not have the same problems – it's good to talk to families who understand autism and the way it affects family life. For us contact with other families have proven far beneficial than anything else. New friends have been made and these friends will always be there for a friendly chat or a shoulder to cry on when things are low. It's rare we are all low at the same time so each of us 'escape' to a family, who is obviously going through the same thing as you are. The main concern once all the initial shocks wore off was what was best for Michael. Slowly, sometimes it felt as though everything had stopped completely, things started to happen. He attended a mainstream playgroup, with a one-to-one helper, which proved to be the start he needed to gain the social aspect of communicating. He became far more aware of others and their feelings. The little boy who paid no attention to surroundings suddenly started to take



an interest in what was going on – looking out of the window at people passing by, pointing to things he saw and showing us things he'd found. Our little boy was opening up, joining in, and what was so exciting about all this was it was instigated by Michael wanting to do it himself. Some days it felt as though I was one step forward two back, coming to a complete halt for days, but every positive step gave us hope.

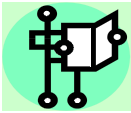
Another long-winded time was the 'Statement for Education'. Lots of forms and yet more assessments in order to decide what Michael's educational needs were. Michael was given a place at a special needs school and I can honestly say it's the best thing that could have happened for him. The routine and understanding of his teachers have allowed Michael to achieve so much. He still has very limited speech, but receives regular speech therapy and now asks for things he needs 'juice, sweets, milk, apple, biscuits, shoes, car, swim,' and also addresses people by their names 'Mum, Dad, Natalie, Nana, Granddad', and uses other words like 'ta, hello, in a minute,' and can sing along to nursery rhymes. This may sound like nothing special to parents with a 'normal' 4-year old but I can assure you it's so special to us and means so much more when you know how hard this must be for Michael to comprehend, when his 'normal' way would be to totally ignore everyone else and live in a world of his own.

We have learnt many valuable lessons since we had Michael's diagnosis, and now never judge people, particularly if someone seems to be behaving 'abnormally'. Our daughter, Natalie, absolutely adores her brother and the feeling is returned totally by Michael. She's been involved from the start and attended as many of the assessments as she could, visited his school, met his teachers and found out what Michael will do at school. She explains to anyone she meets that she has a brother with autism who cannot speak properly and sometimes behaves 'differently' to you or I, but that he will not hurt you and if you don't want him to do something then just tell him so. She describes autism as having a light in your head, but the switch that turns it on doesn't work properly. She has had moments of not understanding why Michael hits out at her or why he destroys her things and she has had many tears, but at the end of it all, Michael is first and foremost her brother who she loves so much. As a family we do lots of things that anyone else would do; swimming, visiting the park, going to the beach, zoo, shopping and we holiday every year. We take the children, via ferry, to France, having a mobile home for two weeks in May. We go at this time of year as we are out of season and there are fewer crowds, which can upset Michael. We have had to adapt our way of life to suit Michael, but if Michael is happy and contented then we all enjoy the time spent together.

Tips for Carers - Taken from **Autism News** – Volume 25 – February 2005

Caring for a person with a disability can be both rewarding and challenging. Often carers feel isolated and alone, and at most times exhausted from the multiple roles they are expected to fulfil. As a carer it is important to maintain a healthy lifestyle and implement strategies that can assist in minimizing stress. The writer of the following article is not caring for an individual with autism, but the issues raised are relevant to every individual who is caring for a person with a disability. Anyone caring for a child or an adult with autism will surely relate to the writer of this personal article.

This is an assortment of things I have learned through being a carer. You may have learned the same things or different things. I've put these together because when you are in the middle of a



Tips for Carers - continued

complex situation (otherwise known as up to your neck in alligators) it can be helpful to be reminded of some basic things.

Learn from your mistakes but don't punish yourself for them. If you lose your cool, or try something that ends up in a disaster. Then you at least know what not to do next time. However, having learned what you can from the situation, move on. Castigating yourself doesn't help, in fact it only makes things worse. Punishing yourself makes you feel bad, which you don't deserve.

(Making mistakes is, regrettably part of being human). Punishing yourself can also have a negative effect on the care recipient, because it undermines your ability to interact positively with them.

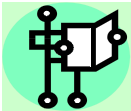
Best is best. If you are doing your best you are doing all you can do. The fact that it doesn't get perfect results, or that you think someone else could do better is irrelevant. You are doing the best you can and should be proud of yourself for doing so, not be criticising yourself for failing to reach some ideal standard.

On a similar note, don't compare yourself to others. I have muscular dystrophy and I am caring for my husband who has a severe progressive neurological disorder. Sometimes it's hard. My mother, when she was much younger, was caring for her mother who have been paralysed by a stroke, her husband, who had been diagnosed with a terminal lung disease, and three young children. I have no idea how she survived, let alone continued to cope, day after day, with no services, in this situation. At times I've told myself stuff like "You think you've got problems, look what she went through". Doing that doesn't make my life any easier. It just makes me feel bad. You are dealing with your life. The fact that someone else has a harder life doesn't make yours any easier to cope with and comparisons only undermine you.

Don't be afraid to let other people love the person you are caring for. Care workers and care recipients often get very attached and develop strong relationships. Sometimes the family carer can feel a bit put out when they seem to be taken for granted while the care worker gets a much more enthusiastic response. First, remember that if the care recipient only saw you one morning a week, they would probably be excited when you arrived too. It's hard to be excited about someone who is there all the time, but it doesn't mean they love you any the less. People often get concerned about boundaries in this situation, and it can be confusing. There is a distinction between feeling and behaviour. If you feel that a care worker's behaviour is inappropriate, that is something to discuss with them. But there is nothing inherently wrong about their developing a warm loving relationship with their client. In fact, quite the opposite, there can never be too much love .

It is your right to be particular about the people who are caring for your family member. Recently someone at one of the organisations that supplies us with carers, told me accusingly that I was very fussy about who cared for "Mark". I wish I had said at the time "Yes I am. That's my job". I don't care about the peripheral things, but I am very "fussy" about how care workers treat "Mark". If they don't treat him with respect, and if they are not competent to keep him safe and happily occupied for the time they are here, then they are a hindrance, rather than a help.

Avoid criticising, put downs, nagging etc for things the person can't help. I know you are human and sometimes you feel critical and angry etc. But criticising the person for things they could not help doing makes them feel bad, which makes you feel bad and potentially damages your



Tips for Carers - continued

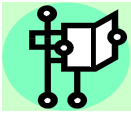
relationship. It's a losing situation all round. This includes subtle implied criticism (I call them sneak attacks). For example, "Mark" has almost no short-term memory. The other day, I told him I was going out of the room for a few minutes to do a couple of things. When I got back, he was calling me and I said "I just went outside for a minute to do LIKE I SAID I WAS GOING TO" His face fell and he said "I forgot" and he obviously felt bad about it. I felt awful for making him feel bad. If I had bitten my tongue on that last sentence, we would both have felt better.

You are the expert on your situation and on the person you care for. Obviously be open to help and advice, especially from people with significant expertise in the field. Be willing to try things. But, if something just isn't right for your situation, go back to the expert and discuss it. Tell them your concerns and ask them for alternatives. Feel free to ask why they feel a certain course of action is the best and what the alternatives are. If they are not willing to listen and communicate, start looking for a new expert.

Hal Joske – taken from Community Corner of autism News Feb 2005 edition.

Hal Joske, possibly the most polite man in Perth and has been with the same employer, Westcare Industries, for over 25 years. I was impressed by his achievements and invited him to dine with me at one of his favourite restaurants, Dragon City, in Claremont, so we could chat over dinner. I asked Hal some questions about his life.

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| George: | "Hal, do you mind the Autism Association printing your story?" |
| Hal: | "Well, I was a bit worried when we first talked about it, but then I thought it might be good if others could see how an older person with autism can have a good life. Also I trust you and Sally, that I will be able to check first what you write, so it's okay". |
| George: | "What can you tell us about your work Hal?" |
| Hal: | "I really enjoy my job, I like what I do there, making tags. I like the friends I see there, I get to play cards at lunch times and I can earn enough pay to do things like going out". |
| George: | "What sort of things do you do, when you go out?" |
| Hal: | "Well I love sport a real lot, since I was a child our family all liked sport, so I go to footy, cricket, soccer, and basket ball. I started following Perth Glory with a friend of mine named Richard, in October 1996. We both became members in 1997. I am also a member of the Eagles, the Dockers and the South Fremantle football clubs, and the Wildcats basketball team. I first went to see the Wildcats with a friend named Pauline, in July 1993, then became a member in 1994". |
| George: | "So are there any other things you like to do or see?" |
| Hal: | "I have friends I visit each week, and I often go to plays or concerts. The concerts I have been to are: Slim Dusty, Seekers, Abba, Johnny Cash, John Denver, Charlie Pride, Nana Mouskouri, Neil Sedaka and Jerry and the pacemakers. I like most sorts of music, my favourites are from 50's/60's and 70's". I also like the Beatles and country music. I have also attended Scottish music concerts, with my friends Mark and Chrissie, and like that too. When I was young I used to sing and dance with my mum to Greek music. I still have happy memories of that, and Greek music always reminds me of my Mum". |

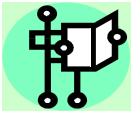


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| George: | “How do you manage being around so many people Hal?” |
| Hal: | I find if I am polite and friendly most people treat me well. I am always friendly and polite, and don't like rudeness in other people. If they are rude I just ignore them and walk away.” |
| George: | “Do you run into many rude people, or people who give you problems?” |
| Hal: | “No most people are good, except sometimes on public transport, especially trains. I don't like some of the hooligans on trains and if I go out at night I only go if I can get a lift home or use a taxi. I try to go with carers or friends, as taxis are very expensive. The Autism Association are very helpful and fit in with my routine.” |
| George: | “You sound awful busy with work and going out.” |
| Hal: | “Yes I try to stick to the same routine where I do something each day and night. I plan it carefully and don't like it when I have to change it. If I have to change it, it makes me think a lot about how to re-arrange and still fit everyone / everything in. I am not happy until I can get it worked out.” |
| George: | “Can you tell me about your school days or when you were younger?” |
| Hal: | “Yes I enjoyed school and made friends there too. Most of the teachers were nice too. I didn't like woodwork or metal work, as I wasn't very good at them. My favourite subject was mathematics. I am very good with numbers. I can tell a person what day they were born on if they tell me their date of birth. I can tell from any date, what the day was or will be in a future date. I like working dates out and it surprises my friends that I can do this so quickly.” |
| George: | “Was anything hard for you when you were younger?” |
| Hal: | “Yes, sometimes I would get teased by teenagers or people might be rude to me. I would try to avoid those kind of people. I still avoid groups of young people, especially on trains. Older people tend to respond well to me because I am polite to them.” |
| George: | “Do you have any other hobbies or interests?” |
| Hal: | “I have been collecting willow pattern plates for many years and I like to keep cricket statistics.” |
| George: | “What would you suggest for a younger man with autism?” |
| Hal: | “I would tell him to keep striving to do the things in life that he wanted, and if he has a job, strive to do it well.” |

Book Corner



Michael is a young man who has succeeded in managing his autism and is experiencing success in life despite a diagnosis that might have predicted only disability and despair. He did not talk in early childhood and displayed the classic traits of a severely autistic child, but he has broken out of his silence to help others to learn from his insights and experiences. An explosion of newly diagnosed cases of autism has resulted in a keen interest in the stories of autistic individuals, and many people are touched by knowing a family with an autistic child. This unique book reveals a silent world through the voice of an insightful, articulate young adult with autism. The book also gives perspectives from Michael's family, friends and the professionals who have known him from diagnosis in early childhood through to adult, independent life. After each chapter, the author presents “reflections” that highlight the key issues pertinent to autism and the relevant stage of development.



Michael's story is poignant and moving, and provides information and hope to families of autistic individuals and the professionals who work with them.

‘One day I naively asked Michael what’s it like to be autistic. He replied, “I don't know. I've always been autistic.”’

—from *Succeeding with Autism*

Succeeding with Autism - Hear my Voice - Judith H. Cohen - Foreword by Temple Grandin - March 2005 - 240 pages - ISBN 1 84310 793 7 – Paperback - £13.95/US\$19.95

The nature of artistic creativity and its relationship with ‘difference’ has intrigued people for centuries. *The Genesis of Artistic Creativity* is a revealing exploration of the lives of 21 famous writers, philosophers, musicians and painters including George Orwell, Wolfgang Amadeus Mozart, Andy Warhol and many others, in light of the recognized criteria for diagnosis of high-functioning autism and Asperger’s Syndrome (AS).

Having diagnosed hundreds of individuals with AS during his professional career, Professor Fitzgerald examines here the social behaviour, language, humour, and obsessive interests and routines that accompanied creative genius in the past four centuries. From Herman Melville’s eccentric breakfast habits and Simone Weil’s intense dislike of being touched by other people to Ludwig van Beethoven’s inappropriate marriage proposals and Vincent van Gogh’s inability to form satisfying relationships with others, the author offers compelling insights into the association between creativity and autism spectrum disorders.

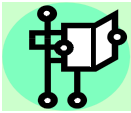
This celebration of artistic genius and AS will prove a fascinating read not only for professionals in the field of autism and AS, but for anyone interested in the sources of creativity and the arts.

The Genesis of Artistic Creativity - Asperger’s Syndrome and the Arts - Michael Fitzgerald - March 2005 - 240 pages - ISBN 1 84310 334 6 - Paperback - 13.95/US\$19.95

Faced with the apparent inability of her autistic son Billy to learn and socialize with other children at school, Olga Holland decided to teach him at home.

Where traditional educational approaches had produced limited results, the author’s own method of teaching succeeded, over a period of two years, in enabling Billy to pass the test that allowed him to enter a class for gifted children.

Teaching at Home explains the author’s approach, focused on adapting to the demands of Billy’s atypical mind and respecting his vivid imaginative world while attracting and retaining his attention. The author describes her use of sensory and memory techniques, social stories and humour, and gives useful advice on issues such as understanding body language, adapting the teaching environment, devising homework schedules and coping with distractions.



This book offers inspiration and encouragement for parents of children with autism or Asperger Syndrome who are considering homeschooling their children, and also provides useful pointers for teachers and carers.

Teaching at Home - A New Approach to Tutoring Children with Autism and Asperger Syndrome - Olga Holland - April 2005 - 128 pages - ISBN 1 84310 787 2 - Paperback - £12.95/US\$19.95

Further details can be found on the JKP website:

<http://www.jkp.com>

If you would like to order a copy of the above books, and you are unable to access the Internet, you can contact:

Jessica Kingsley Publishers, 116 Pentonville Road, London, N1 9JB, UK

Tel: (+44) 020 7833 2307 Fax: (+44) 020 7837 2917 email: post@jkp.com

Obsession, Rituals and Routines .Taken from www.oasis.co.uk

Obsessions are things that are collected or repeated over and over by your child. They may be simple actions, complex behavioural routines, sensations they enjoy or things / information they collect. The trouble with obsessions is that while your child finds them comforting and relaxing, the rest of the family may find them a little (or a lot) annoying.

Why does our child act this way?

Everyday changes that to most of us seem trivial or unimportant (such as the placement of a toy or chair) are vital to your child's sense of security. Change a small piece of the 'picture' of your home and suddenly the whole room is unfamiliar! Not surprisingly this experience is very scary for your child and they are in need of reassurance. At this time it is little wonder they turn to their obsessions for comfort.

In this way your child's obsessions are a valuable 'warning sign' about their feelings and ability to cope with the current situation. Exactly what causes these stressful feelings may be unique to each child but in a general sense these behaviours may be telling you one of the following:

I know what will happen next!

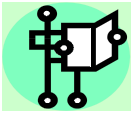
The child with autism needs to keep things the same because they have trouble understanding the world our way. Obsessions are predictable and help them feel secure when everything else seems confusing this is something they can rely on.

This feels great!

Sometime your child will develop an obsession for the sheer pleasure that the feelings associated with the activity bring. These feelings are very pleasant, enjoyable and comforting. These are the sensory obsessions, such as hand flapping, spinning, rocking etc.

"I feel Bored!"

Your child may engage in obsessive behaviour to express any feelings they may be having and that they do not know what else to do with. It may be that they are scared, worried etc. or that they don't think that they can do what you are asking them to do. In other words obsessions can be a way of avoiding unfamiliar and unpleasant feelings or experiences. It can also be that they can't think of anything else to do. Difficulties with imagination mean when trying to 'think of something to do' they may have only one or two 'ideas'.



I'm learning to talk to people!

Obsessions can provide a valuable opportunity for your child to develop those much needed communication skills by using a familiar topic of conversation. For them it may be their only 'successful' way to express their thoughts and feelings.

"I feel Bored!" - continued

This is where you are needed to extend their repertoire of things to do by providing a stimulating daily schedule (which includes regular 'rest intervals' of obsession time).

This is something I'm really good at!

Special interests can provide a sense of accomplishment, mastery and joy for your child. No doubt they are the 'family expert' on their topic which brings them both comfort and pride. It is also a rare opportunity for them to 'succeed easily', excel and prove to others how clever they can be.

What can we do?

Everything in life is about balance. Understanding the importance of the obsession to your child's ability to cope with life and learning we need to find a balance between their needs and the needs of the rest of the family. You may be able to live with some obsessions quite easily whereas others may be more challenging and really 'push your buttons'! What obsessions each family can accept will vary greatly depending on your values and attitudes. (Ellis, 1990). Sometimes adopting the 'why not?' approach is the best strategy, particularly for behaviours which are annoying and a little unusual but don't hurt anyone. There will be other times when the behaviour is really unacceptable and must be discouraged as much as possible. Discussions with a respected autism specialist and your professional team are the best way to work out what to leave alone and what needs to be changed.

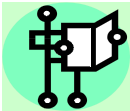
I Need a quiet place!

When the demands of the outside world become too great a child with autism can retreat into their obsession. This helps them cope with the overwhelming situation, relaxes them and reduces anxious feelings. Whilst engrossed in the obsession they can effectively 'screen out' unwanted sensory information or unpleasant experiences (eg. Dogs barking, babies crying, people coughing, ocean waves, rustling leaves etc). They are overwhelmed and over stimulated and in order to regenerate and be ready to face the world again your child will probably need a quiet place to calm down. Their obsession may be the only way they know how to do this.

"I don't understand"

Keeping as much the same as possible helps your child explore the world in a 'safe' way. It is only within this 'safety zone' that they can effectively experiment and look for connections to better understand the world. When things get confusing and stop making sense they can find comfort in something they know. For example, repeating speech is often a sign that your child has failed to understand what has been said to them. If you make the message clearer by using visual methods (e.g. Gestures, photos, written instructions, pictures) this will generally improve.

Usually the most successful approach is either to try and keep the behaviour within acceptable limits or to supplant it with some other activity. Given that any attempt to prevent one stereotyped behaviour will frequently provoke another". (Attwood, 1998:111)



Aut-Talk Buzz Page

Lethabo Le Khutso

Lethabo Le Khutso Residential and Vocational Therapy Centre for Adults with Autism will be hosting a Persian Carpet Auction on 12 August 2005. For more information on supporting this worthy cause, please contact the organizer, Diane Wonfor, at 0824601004. Alternatively you can contact the manager of Lethabo Le Khutso, Julian Benade, at 012 3293627.

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When negotiating with Government concerning services and facilities for people with autism, we are always asked as to the number of registered members on our records. Please help us to strengthen our case by becoming a member of Autism South Africa.

I _____
wish to become a member of Autism South Africa.

Please find enclosed my cheque/postal order for R 30 (tick)

OR I PREFER TO
directly deposit R30 and fax the deposit slip along with my
membership application to: 011-486-2619 (tick)

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Autism Spectrum Quarterly available in South Africa

Autism South Africa will be acting as a local distributor for a wonderful magazine from America called Autism Spectrum Quarterly. We need your urgent response should you wish to receive copies. Diane Twachtman-Cullen, Ph.D., Editor-in-Chief, Liane Holliday Willey, Ed.D., Senior Editor. *ASQ* is described as "THE AUTISM MAGAJOURNAL™" to underscore that it combines the readability and interest of a high-level magazine with the substance and depth of a professional journal. It is this combined focus that distinguishes ASQ from other publications of its type, and creates an important niche in the world of autism publications that has heretofore been lacking. Each issue features a line of research and commentary aimed at helping parents, teachers, and clinicians to translate this research into practice. Included in every issue of *Autism Spectrum Quarterly*

- Articles by, for, and about individuals with ASD
- A focus on families and family issues
- Book and product reviews and recommended resources
- Contributions by outstanding professionals in the ASD field
- Spotlight on Best Practices to highlight an educator, clinician, or paraprofessional support person whose work on behalf of those with ASD has been exemplary
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- and so much more!

Due to the financial implications, we will need potential South African subscribers to sign up, commit and pay up front for the period of a year.

We have been offered the wonderful price of R 33 per magazine (incl shipping from the USA). Therefore for a year's subscription, with local postage it will cost you only R 160 per year to receive 4 copies of this magazine with informative, practical and up-to-date information.

1. Deposit an amount of R 160 into our bank account Please ensure that you write your surname and initial in the reference block and fax us your proof of payment to (011) 486 2619.
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