

# Aukids®

Issue 28  
Summer 2015

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**Positive Parenting for Children with Autism Spectrum Conditions**



**Cut to the Chase**  
Olga Bogdashina on  
scissor sensitivities



**It's a Jungle Out There**  
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## WE DID IT!

**AuKids lands Specialist Magazine  
of the Year at media awards**

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# Letter from the Editors



## Welcome to issue 28

WEEEEEE are the champions, my frie-end...Yes, here at AuKids we're just a bit full of ourselves at the moment, after scooping a trophy at the Prolific North Awards - the largest media and creative gathering outside London.

AuKids magazine had been shortlisted for Magazine of the Year, but the category was so hotly contested that the judges created a new category - Specialist Magazine of the Year - especially for us. What they particularly liked about AuKids was its 'innovative style and its sense of humour'. They probably picked up on the fact that the entire editorial team is nuts.

This is the first award we've won, so we thought we'd tell you how we all feel about it, whether you like it or not. Before we do, a few tearful Oscar-like thank-yous: We'd like to thank our many expert contributors; our calm and forgiving graphic designer Jo Perry; fabulous printers (dahhling) R & P Printers in Ashton; endlessly patient website designers at Webguild Media in Gatley and Fins Design and Print in Bolton, who make our T-shirts. Without their price-busting generosity and belief in us, AuKids wouldn't have survived.

Finally thanks to you - our readers - for staying loyal to us and for convincing us time and time again that what we do is valued and enjoyed. It means the world to us. This award is for you as much as us for your faith in positive messages about autism. But we'll keep it, if it's all the same.

Enjoy this award-winning issue!

*Tori & Debby*

### Competition winners from issue 27:

- **Valuelights Competition:** Sarah Maughfling, Cheshire; Keri Kilbey, Greater Manchester; Tricia Lowther, Durham; Alexandra Gradwell-Spencer, Hyde, Cheshire.
- **Learners on the Spectrum Book:** Rebecca Bennett, Notts;
- **BObles Elephant:** Jessica Nash, East Sussex.



**DEBBY ELLEY:**  
AuKids' co-editor

"This award has brought my life full circle. Before having twins, I worked in quite a number of media environments - public relations, local radio, regional newspapers... After my twins were diagnosed with autism, I thought I'd have to leave that world behind. Instead, my love of writing took a new twist when Tori and I launched AuKids in 2008.

"It was such a small magazine - we just wanted to make a difference to the people we wrote for. Now eight years on, it is standing on its own two feet in the big wide world of magazine publishing, and we're getting recognised for it. What an amazing feeling! We're not in danger of getting too big for our boots, though. You're only as good as your last issue and without the loyalty of our readers, we wouldn't have got this far.

"The passion that goes into creating this magazine is what I think makes it special. Tori and Jo are both brilliant to work with, and Tim remembers nearly every subscriber by heart! Our team is small but perfectly formed!"



**TORI HOUGHTON:**  
AuKids' co-editor

"When our names were read out as the winners of the

award, I felt really overwhelmed. It feels amazing to receive this as recognition of the past few years of working on the magazine. I feel so lucky to work with such a fantastic, creative and supportive team. We work really well together. Myself and Debby never run out of ideas for features and Jo cleverly manages to interpret these into visual masterpieces! I'd like to especially thank all the autistic children I have been lucky enough to meet and work with who are the real inspiration behind AuKids, and most importantly Debby's boys Bobby and Alec who provide us with loads of stories and ideas to explore!

For me, this award is so significant as it's recognition outside of autism communities of the quality of work that we do, and this can only further raise the profile of autism awareness, which is incredibly important to me.



**JO PERRY:**  
AuKids' graphic designer

"I've been a graphic designer for the last 15 years, and

AuKids has been the most fun, fulfilling, and worth-while project that I've worked on.

"When they called our name out as the winners, it felt quite surreal - that our humble magazine was suddenly centre stage at a huge awards event. I was very proud of us all.

"Thanks to Debby and Tori for asking me to get involved with AuKids, and thanks to the readers who often say that they like the visual look of the magazine as well as the features themselves."



**TIM TUFF:**  
Tim helps AuKids with research and distribution.

Tim is an adult with autism and loves

reading AuKids; sometimes using his personal experiences to help us with the background to our features. He also has an avid interest in vintage home furnishings, old postcards and trains. He is well known within the autism community for being part of the AuKids team.

We asked Tim what the award feels like to him: "It feels like a piece of red plastic in the shape of an N". Let's rephrase that. What does this award mean to you? "It felt like the BAFTAs, when they've been given that. I am so happy to be part of an organisation that's helpful and kind and has done so much for us in the autistic community. I'm also thankful that my mum encouraged me to have the confidence to work somewhere like AuKids, where I've made such good friends. Thank you, mum!"

Whilst the products and services advertised in AuKids are recommended to us by readers, we are not an industry inspector or regulator. We advise readers to seek independent advice from regulatory bodies before signing up with a new service provider and to check that products and equipment meet with industry standards.

The opinions expressed in AuKids magazine are those of the contributor. Please seek medical advice before embarking on any therapy or behaviour intervention. All articles are copyright AuKids.

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## Sonny, Me and the Big City



Dear AuKids,

I used to work in a special needs school, as a one to one for a child called Sonny with ADHD and autism. When I left the school I asked his mother if I could stay in touch. I now see him most weekends and school holidays and I take him into London for the day. There have been many tears and tantrums (some from Sonny and some from me!) and we still have them now, and I am sure we will have some in the future. But to see his growth from where he was when we first met has made it all worth it.

When Sonny and I are out and about in London, we get a lot of stares. When he stims or has a meltdown we get even more attention. I actually quite enjoy the stares, because I think, 'Yes, look! This is autism! It isn't something to be scared of or feel sorry for! Get used to it!' It is just a part of who Sonny is, so if he wants to flap his hands or talk gibberish loudly, or say nothing at all, then all of that is fine. I will not allow him to conform to a society that does not accept autism.

But how do we achieve an inclusive society - one where we all accept difference and are not afraid of it?

My small way of attempting to achieve this is by not being shaken or deterred from taking Sonny out. That would only be of detriment to him, and actually of detriment to society. If I don't take him out for fear of what people may think or say or how they would judge, I am only contributing to the idea that autism is not accepted, and should not be. So despite any negative judgements we may

face, we go out. We use buses and the Tube, and visit museums and parks; cinemas and funfairs, you name it, we have been there - nowhere is safe from us! I can usually find a quiet spot if he gets overwhelmed, or a park nearby if he gets bored.

It is hard work. There have been many outings that have been chaotic and a bit stressful, but I think they are worth it for the ones where Sonny engages fully with the society he lives in. He will now say hello to the bus driver without being prompted. He also asks me for money when we go to a shop to buy a snack.

He points at birds and he says, 'Oh wow!' when he likes something.

Sometimes we just stand on the pavement and watch the cars drive past, which he loves. (I am not such a fan of this but if it gets him smiling we will stand there for 10 minutes or so!) Or go up and down the escalators in Selfridges for a while. London has joys in sometimes the most unexpected ways for Sonny!

London is one of the most diverse cities out there. It is all of ours to share. But even so, I feel that it has a long way, as much of the UK does, in accepting autism, and on a larger scale mental health. Sonny has shown me that stigma attached to autism need changing. So let's get out there and change them!

Mel Grand xx



I write a blog about Sonny's adventures, places we love and things we learn at [www.mysonnydays.wordpress.com](http://www.mysonnydays.wordpress.com)

My twitter is @MelantheGrand for autism news and info and my latest blog posts.

## Celebrity SPOTLIGHT

Age: 10 I live: in Manchester

Likes: Babies, emergency services, Lego™, planes, trains, trams, three-wheelers and cars, iPad, Crossy Road and Minecraft.

Doesn't like: Feeling rushed or being late.

Loves: Going out with his support worker Charlotte to visit the Lego™ store, and using their X-ray machine and going to the Runway Visitors Park at Manchester Airport.

Send your celebrity details to [editors@aukids.co.uk](mailto:editors@aukids.co.uk)



Mostafa Al-Tamini

## School's Autism March Gets Neighbourhood in the Know



HAIL TO THE FUNDRAISERS!  
And right on cue, it did hail. A lot.

To mark Autism Awareness month, Lisburne School in Offerton, Stockport, decided that the only way to get noticed was en masse. So the entire school braved the wind, rain and hail to raise money and awareness for autism.

Key Stage One pupils met at Stockport's Woodbank Park and hunted for clues, whilst ticking them off their worksheets. At the end of the walk, they met up to let off purple balloons to celebrate autism awareness. Interesting fact: they chose purple as it's the colour of their favourite magazine's logo - Lisburne School buys AuKids magazine for every family who has a pupil at the school with autism. How lovely is that?

In the afternoon, the weather was even less kind. The hail didn't stop the Key Stage Two pupils and staff walking at least a mile from school to the same park, chanting about their mission to increase autism awareness.

The school tells us that the pupils loved being outside on a wild day and raised £157.00 for the National Autistic Society.

Well done, Lisburne!

Dear AuKids

I received your magazine for the first time yesterday and read it last night in bed smiling to myself whilst reading the back page about Bobby's Blankies. I'm 25, I don't have autism, but I do have a stuffed toy rabbit (not very stuffed anymore...) that I sleep with every night.

It was the last bit of the article that really made me chuckle about Bobby being 25 and taking his Blankies on his honeymoon! Me and my boyfriend were discussing the other day if we thought I'd ever give my rabbit up (Ben hates him cause I'll wake up in the middle of the night searching for him, and God forbid he's ended up on Ben's side of the bed!).

I honestly cannot tell you why I have such a close attachment to him, but I decided to send you a message about it because even at 25 years old, I have just spent a panicked 10 minutes looking for my toy rabbit! (I found him in the washing basket).

Bobby will just have to find a girl who's happy to share a bed with Blankie 1 and 2. Ben often jokes about throwing my rabbit away without me knowing, but he knows his life wouldn't be worth living if he did!

Thank you for sharing about Bobby's Blankies and giving a good read!

Lauren Challener xxx





## Kids Fish for Fun With Poisson Rouge

The Poisson Rouge website is a creative, wild, surreal mixture of education and total fun. Co-founder Edith Furon explains that when it started back in 1999, the internet was not a pretty place.

"Patric and myself, its co-founders, wanted to make the Internet (and ultimately the world!) a better place. We set out to create fun interactives, without text, primarily for small children. As the site grew, parents started sending in their stories. One of the things that we learnt quite quickly was the appropriateness of the games and activities for a very special population of children (and young at heart adults) on the autism spectrum.

"This came as a total surprise as we hadn't thought of it and indeed didn't know anything about autism back then (now we are educating ourselves)".

There are so many games to play on the Poisson Rouge site – it's a bit like entering a fairground – the choice has made it into a one-stop shop at home for Debby's son Alec, who uses a touch screen computer to operate it. The cause and effect nature of all of the games means that there is an instant reward for every attempt to interact with the screen – whether or not you're matching or counting, which is hugely appealing.

Simple vocabulary in some of the games is available in different languages (just select the right flag for your country). Alec, who can't yet talk in English, nevertheless feels it's high time he learnt a bit of Chinese.

Edith agrees that the site isn't a traditional one: "It's educational but in an 'out of the box' sort of way. We drew on inspiration from all sorts of directions - theatre, arts, linguistics, the works of Piaget, Montessori, Vygotsky, and also real life toys! One of the aspects of our work that makes it accessible to all is that we made a point of not dumbing down anything. Ever. The world is complex, the only thing we make a point of simplifying is how one interacts with it".

You can enjoy a free ten-day trial at Poisson Rouge. The site doesn't take credit card details so you can have a go without that nasty feeling that it will 'automatically' sign you up after the trial. The site also has a free section that rotates: [www.poissonrouge.com/free](http://www.poissonrouge.com/free) and anyone can access the print and colour pages: [www.poissonrouge.com/print](http://www.poissonrouge.com/print)

Subscribers get full access to the site for £12 a year. Schools and groups can sign up from £36 (incl. VAT, for up to 30 computers). For more details go to: [www.poissonrouge.com/register/schools](http://www.poissonrouge.com/register/schools)

**Win a Year's Subscription to Poisson Rouge!** 

Where's that little red fish hiding, then? Find it and you can win one of two free individual subscriptions or one school subscription that our fishy friends have given us as prizes.

E-mail us at [competitions@aukids.co.uk](mailto:competitions@aukids.co.uk) with the answer, stating Poisson Rouge in the subject header plus 'school' or 'individual'. Include your name and address and contact us no later than August 31<sup>st</sup> 2015. Winners' e-mail addresses will be passed on to Poisson Rouge so that they can send you details of how to sign up.

Read more about Poisson Rouge's story and sign up at [www.poissonrouge.com](http://www.poissonrouge.com)

# Reviews & Prizes



## BOOK Tomas Loves... A rhyming book about fun, friendship - and autism

By Jude Welton

Published by JKP • £9.99 • ISBN 9781849055444

As a qualified child psychologist specialising in autism, Jude Welton was inspired to write the family-friendly resource 'Tomas Loves' by her young friend of the same name.

Tomas Loves... is a lovely book written in rhyme and aimed at a young audience of

two years plus. This enchanting children's story sets out to explain how Tomas - a special young boy with autism - lives and understands life, following him through his typical daily activities.

A simple yet insightful narrative gives us a unique and charming insight into Tomas' likes and dislikes (typical of an autistic child such as a dislike of loud noises and a need for routine) and the things his parents do to help him.

The beautiful illustrations and light-hearted, informative storyline cleverly combine to form a book which is enjoyable for both autistic and neurotypical children, whilst being endearing and informative for adults – especially parents of children with autism and learning disabilities.

Alison Walters,  
AuKids readers' panel



## The UK's Biggest Trampoline Park Has Landed!

Yep, you heard us right. The trampolining centre of the universe has opened in Essex. Jump Giants Indoor Trampoline Park in Thurrock is a 28,000 square foot cutting-edge entertainment, fitness and sports facility. The indoor trampoline park contains over 16,000 square feet of jumping surfaces, including a one of a kind 8-lane foam zone with 2 launch pads, a 7,000 square foot main jump arena with tumble runs, junior zone, dodgeball courts and basketball slam dunk lanes.



A day after its opening, we sent lucky local reader Katherine Gibbinson and her autistic son Edward for a private viewing (or should we say 'bouncing') session. Here's what she told us...

Jump Giants was like autism heaven for my four year-old son Edward. Unfortunately, I could not bounce myself as I currently have a broken foot. ☹️ But the lovely William from the centre joined in the jumping fun.

Jump Giants has a number of staff who have had experience in working with both children and adults with autism and I must say William was a superstar. Some members of staff are also trained trampoline coaches.

The park is constructed around different zones, each manned with a warden for health and safety and to ensure organised fun. There are two dodge ball courts, one for 3 to 10 years and another for teenagers and adults to use.

There's a trick jump pit filled with soft bricks, a general jumping fun area and my fave - a basketball ring with a fitted trampoline so that you can achieve slam dunks like Michael Jordan!

Around each zone is seating for spectators and also a small cafe with a twist - you can drink your coffee while watching your children on large CCTV screens. This means you can be secure in the knowledge that no meltdowns are in progress!

The experience Edward had was a bit different to how it will usually be as we had the place to ourselves (which I must say was super cool). Ordinarily, I would be wary that it might be too busy for autistic people, but the owners tell me that they are planning to set aside specific times for children and adults with disabilities – so watch this space!

Katherine Gibbinson,  
Essex



For more information on Jump Giants, look up [www.jumpgiants.com](http://www.jumpgiants.com) or call 08444 141 141.



**EVENT**  
**Autism Show**  
NEC, Birmingham,  
19<sup>th</sup>-20<sup>th</sup> June 2015

(Left) Geoff Evans of the Options Group

I have four children, three of whom have a collection of diagnoses, including autism. I live in Shropshire, so was excited to hear there would be an Autism Show held centrally at the NEC.

I attended the first day and was surprised at how busy it was. Numerous exhibitors offered a variety of services from the likes of the NAS, Autism West Midlands, Research Autism plus residential schools, lawyers and private therapists. I gathered a lot of useful information, but as a parent I found the exhibitors to be rather corporate, offering services to education settings rather than the home. I hope as the NEC show develops, more exhibitors will come on board as they have for the London and Manchester exhibitions to offer a wider variety of services and products.

The Hub Points 1 and 2 offered short talks throughout the day from a variety of perspectives, delivered through wireless headphones. Places were limited, so you had to arrive early. I managed to catch the inspirational Geoff Evans, Head of Autism Practice at Options Group, talking about holistic approaches to behaviour that challenges.

Early arrival was also imperative at the larger Autism Matters Theatre,

which hosted speakers including Dr Carole Buckley and Sarah Hendrickx. I was impressed with the opportunity to attend one-on-one clinics, but again you need to book early.

For me, it was lovely to meet people from the autism community who I interact with on social media. I would have preferred more exhibitors selling items for families – the handful that did were bombarded and it was difficult to get close.

It is well worth going to a show like this but plan your day if you want to hear a specific talk!

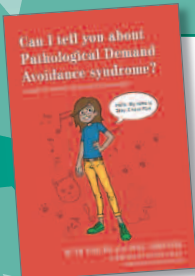
Reader Michelle Leonard

*P.S. AuKids was at the show; we were impressed with The Sensory Classroom installation hosted by [www.sensoryspectacle.co.uk](http://www.sensoryspectacle.co.uk) – it was a chance to try out what it might feel like to have a visual and auditory sensitivity in a classroom setting. Sensory Spectacle offers workshops around the country. P.P.S. Top tip from AuKids – arrive later in the day, exhibitions are much quieter during the last hour and a half.*



**SENSORY SPECTACLE:**

These visitors to the Sensory Classroom, hosted by Sensory Spectacle, are experiencing sound and visual distortion.



**BOOK Can I tell you about Pathological Demand Avoidance syndrome?**

By Ruth Fidler and Phil Christie

Published by JKP  
£8.99 • ISBN 9781849055120

Pathological Demand Avoidance (PDA) is a condition that is part of the autism spectrum, characterised by an anxiety driven need to be in control of situations. It has only 'existed' (in the sense of being recognised as a distinct condition) for a little over a decade, and the literature on the subject is still fairly limited (certainly when compared to autism as a whole).

The two authors of this book (Ruth Fidler and Phil Christie) are authorities in the field, and were two of the authors of a previous seminal book on the subject (also published by Jessica Kingsley in 2012).

The 'Can I tell you about...?' series offers simple introductions to a range of limiting conditions and other issues that affect our lives, and this book is aimed at anyone (aged 7 and upwards) living or working with someone with PDA.

It is split into two parts: the majority of the book is written from the

perspective of an 11 year-old girl, Issy, who has PDA (and features her friend who also has PDA). Issy is a very endearing character and one who lots of children will be able to relate to. There are countless clear, simple explanations throughout this section about autism in general, the specifics of PDA, as well as lots of examples of how it impacts Issy's daily life. The illustrations dotted throughout this section nicely bring the characters to life and elucidate many of the examples.

As someone who supports a child with this condition, I found it made me see things from a new, more compassionate perspective.

The second part of the book contains information and strategies that, in the authors' experience, can help support children with PDA. This is made up of a dozen suggestions that will be of great use to anyone who wants to know how they can help, as well as recommended resources for parents and professionals.

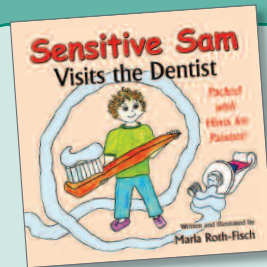
The book is short (50 pages) and very easy to read. If you have contact with someone with PDA, you really should get hold of it.

Mark Haworth, Time Specialist Support/AuKids' reader panel

**Link to the best help and support**

The website dedicated to making those helpful and sometimes vital links  
[www.autismlinks.co.uk](http://www.autismlinks.co.uk)

**autismlinks**



**BOOK Sensitive Sam Visits the Dentist**

By Marla Roth-Fisch

Published by Future Horizons  
£12.95 • ISBN 9780986067303

This is a great book aimed at older children and endorsed by renowned author Temple Grandin. It's written and illustrated by Marla Roth-Fisch, who has a son with Sensory Processing Disorder.

The book covers every aspect of a visit to the dentist; the journey there, the waiting room, the receptionist, the hygienist and finally the dentist. Its rhyming verses make it an easy read and it provides lots of ideas to help make the experience positive for your child.

The book is written well - Sam is sensitive and the story details the effects SPD would have on this experience. For example, the brightness

of the lights, the flavours of toothpaste and the feel of the protective glasses all have an impact on him. It demonstrates good practice, with the dentist always explaining what he is doing first, so parents can share these pointers with their own dentists to make visits successful. You could use just the pictures to discuss visiting the dentist with younger children.

At the back of the book, there are 15 further tips from dentists. On each story page, as the tale unfolds, a cartoon tooth indicates which tips would be beneficial at that part of the process.

Ali Palmer,  
AuKids readers' panel

**WIN**

**A Copy of Sensitive Sam Visits the Dentist!**

We have 5 copies of this book to give away to you lucky AuKids readers. All you have to do to enter is complete this sentence in under 30 words: 'I need this book in my life because...' Send your answers to [competitions@aukids.co.uk](mailto:competitions@aukids.co.uk) with 'Dentist' in the subject header no later than August 30<sup>th</sup>. The first 5 people we take pity on will win. If you'd rather use snail mail, send a lovely postcard to make us smile to AuKids, PO Box 259, Cheadle, Cheshire SK8 9BE.

**Good luck!**





“My son freaks out at the slightest demand. It’s got to the point where I avoid making demands altogether. Surely there’s a better way?”



**Heather MacKenzie**

Speech and Language Pathologist and Founder of the SPARK\* programme (Self Regulation Program of Awareness and Resilience in Kids)

Start with the **physical** first. Is he completely healthy and not suffering from some yet-unknown ache or pain (e.g. toothache, constipation)?

Next, how is his **mood**? Is he feeling anxious or stressed? Has anything changed at home or school? Could he be depressed? These things need to be considered seriously and carefully before working directly on his behaviour. If he’s feeling stressed or anxious, his ‘freaking out’ will have a hair-trigger.

Next, if both of the above seem ok, tell him that you’ve noticed that he gets upset when you ask him to do things and that you need help in understanding why. He needs to know that you need his help in getting things done. Sometimes, just stressing how important his contributions are can make a difference.

Then, think about the **situations** in which the ‘demands’ are being made. If he’s doing something he

enjoys when he’s asked, it’s going to be difficult for him to stop.

Timers can be helpful, but having a plan or schedule for the day, with his task(s) included can be very effective. This will give him forewarning, time allotments, and make the tasks part of his day.

To give him a sense of control, he could choose when to do the tasks. A task list with everyone’s responsibilities on it can be really helpful so he knows he’s not alone and the requests will seem less arbitrary to him. He can check them off, too, which should please him.

Sometimes, simply rephrasing a direction into a request or comment can make a big difference. Personally, I’m not fond of being ordered to do things but, if they’re stated differently, I’m on it! So make statements and use questions, like: “I really need some help with getting the table set for tea. How about you put the forks and knives out? I’m going to make the \_\_\_\_.” A lot of children like the possibility of helping younger people so perhaps he could be asked to help a younger sibling learn how.

It probably would be a nice surprise for him to be asked to do something that he’ll like. For example, if he’s fond of ice lollies, ask him to get them for everyone, including himself. Intermix tasks you know he’ll like with ones he may not enjoy so much.

All of this takes planning and organization but will likely be worth the effort.



**Luke Beardon**

Luke is a senior lecturer in autism at The Autism Centre, Sheffield Hallam University, as well as a speaker and author.

Some people’s initial reaction might be - well, this is an indication of Pathological Demand Avoidance (PDA)\*; however, without the label attached in this instance I will respond as best I can assuming the child’s diagnosis is of autism/autism spectrum...

I don’t think anyone should ever underestimate just how much can go on inside the brain of the autistic child. So often, I find myself in discussions with autistic individuals and the conclusion is that *just to come even close to being on a ‘level playing field’* with the predominant neurotype (i.e. non-autistic peers), the individual’s brain activity has to be that much higher.

Continually having to ‘work things out’ - verbal and non-verbal communication, the social side of things, what people actually mean (as opposed to what they are saying), the intentions of those around them; all of these are contributing factors to the whirlwind that can accumulate in the brain.

This might be on top of having to battle with all the sensory input of the environment, and having to figure out how long one has to respond in the most appropriate manner possible so as not to ‘get it wrong’. Perhaps, then, any additional demand is simply too much... rather akin to that poor old camel and the straw that did so much damage.

It might be worth identifying if there are patterns - for example, after a school day when the brain is possibly tired anyway is often not a good time to place extra demands on a child.

Is the child’s response different, dependent on the day? (e.g. weekends are okay but not schooldays; early in the week is more favourable than later) and/or time (e.g. are mornings different to evenings?).

Another thing to keep an eye on is what the child is doing when being asked to engage. If he is doing something that he really likes and in his head has set aside time to do, it’s unlikely that he will thank anyone for interrupting!

An alternative might be to engage in ‘activities’ rather than place ‘demands’. These can be planned well in advance so the child has plenty of opportunity to digest what is expected of him, they can be clear cut, achievable, and routine.

For example, if a parent knows that they will be expecting their child to tidy her room in the evening, this activity can be planned the evening before, or that morning.

Having a schedule can be really helpful - what’s in the *schedule* doesn’t seem like a demand from a parent.

Once in place, the schedule can become routine, which reduces what the child may perceive as unexpected, unreasonable, ‘out of the blue’ expectations.

Lastly, it’s sometimes a good idea when using the schedule to ensure that a favoured activity is clearly set subsequent to the less desirable one - this way there is always something to look forward to!

\*See review ‘Can I Tell You About Pathological Demand Avoidance Syndrome?’ - Page 4.



**Aukids Co-Editors**

Debby Elley and Tori Houghton

Even-handedness; reasonable adjustment in the face of sudden demands; the ability to stop, think and translate your mild annoyance at interruptions into socially-acceptable responses. These are all luxury items, socially-speaking. People who don't experience high levels of anxiety can deploy all of these without much thought.

The trouble is, tact and diplomacy are the first things to go out of the window when you're under stress. Think about your own responses and you'll know it's true!

People with autism are under a constant state of pressure. Even when they seem relaxed their brains are far busier than yours and mine.

Imagine your child is a small bottle of lemonade and you are a large bottle of water. You look the same, with one big difference. Lemonade is fizzy even when not agitated – and autistic people's minds are equally active! This is because they have difficulty processing new information; because of inflexibility of thought, dealing with uncertainty every day is difficult and even the possibility of uncertainty is ever-present.

Contrast that with you as the bottle of water and you'll notice

that when not under stress you're pretty inert, and it might take you a while to get agitated. In fact to get any reaction out of you, you'd need to be at boiling point!

Back to the lemonade and it only takes a small shake up before pressure starts to build to a dangerous level.

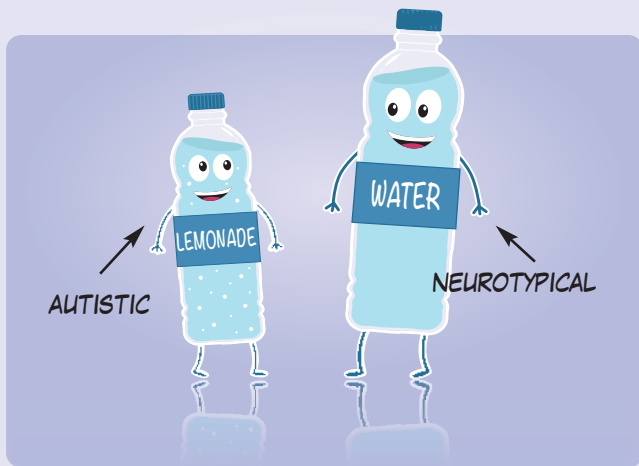
As the adult, you can recognise boiling point and calm yourself down. But autistic kids have difficulty in self-regulation – recognising their own emotions and responding appropriately to them.

Given the constant 'fizzy state' of an autistic person, home may be the only place where the lemonade has a chance to settle. Is it any wonder then, that when you shake things up in their most comfortable environment by placing an unexpected demand on them, they fly into a bit of a rage?

Don't avoid asking them to do things, though. Really, it's about not making a sudden, unexpected demand. Be mindful of when and how you're asking something of them – is it really a good time? Asking them for the best time is a positive start as anything that puts an autistic person back in control of their environment is always a winner.

With homework for instance, get them to choose the day and time – then make that a constant. Having tick-box charts for getting themselves and their things ready in the morning is also fab – and you can personalise the chart with their favourite characters.

A demand is like a sudden noise – but as the other experts have said, with warning and planning, it becomes far more easy to deal with.



**Do you have a question for Ask the Experts?**  
E-mail us at [editors@aukids.co.uk](mailto:editors@aukids.co.uk)



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# SPECTRUMITE MUM'S SURVIVAL KIT

by Debby Elley

My twins Bobby and Alec, both of whom have autism, are now 11. These things have become my autism armoury, the stuff I'd least want to chuck out of a hot air balloon. Having said that, a hot air balloon is in no way, shape or form a mode of transport that you'd find me taking with autistic twins. Let's just say that this is a hypothetical Top Ten and get on with it...

## 1 EAR DEFENDERS

When your child puts their hands up to their ears and squeals at sudden noises, it's not long before you are looking for a solution. How refreshing, then, that the answer was so cheap and effective. There are lots of colourful ones on the market but over the years I've found out two things. One, the more metal fiddly bits, the more you find yourself trying to fix them at the least convenient times. Two, don't waste too much money if you've got the sort of curious kid who likes to remove foam and chew it thoughtfully.



Edz Kidz defender ear muffs are available in a range of colours for £1.99 on Ebay, but these ones pictured without metal straps, may be a bit less fiddly in a hurry (for the less fashion conscious) and are about £6 on Ebay.

I found that they were most effective when used to block out overwhelming sound or crowd noise. Be warned, wearing them can become habit-forming and you don't want your child permanently in a quiet bubble. That's why I switched to having Bose Quiet Comfort 15 headphones recently, which are high-tech, battery-operated and noise cancelling. They block out background noise, but not voices. Very effective for school but also expensive – so we use the cheaper ones at home. You can get discount second hand Bose headphones at [www.cex.co.uk](http://www.cex.co.uk)

## 2 IPAD

Expensive, but engaging, appealing, educational, touch sensitive... and now with a gob-smackingly enticing array of autism specific games.



## 3 DR. BARMAN'S SUPERBRUSH TOOTHBRUSH

They say that two heads are better than one, but three are even better as I discovered after Alec's dental problems arose from too many biscuits and not enough brushing. His specialist dentist gave him one of these clever things – a three-headed toothbrush. When you finally manage to get the thing in, it does the job twice as effectively and he didn't seem to mind it one bit. Available for £4.96 from [www.dentaldirect.co.uk](http://www.dentaldirect.co.uk)



## 4 C.E.A. CARD

The joy of cinema! It's always there when it's raining, it's one big sensory experience and the only thing you have to worry about is whether they'll hack a full two hours of viewing.



Thank goodness then, for the CEA Card, which makes trips to the cinema far less expensive. If you are in receipt of Personal Independence Allowance or Disability Living Allowance, for just £6 a year you can get one of these cards for your child, which allows you as a carer to visit the cinema free of charge.

This means that you don't pay over the odds for having a child who finds flip-up seats more entertaining than the movie.

Go to [www.ceacard.co.uk](http://www.ceacard.co.uk) to apply online or print out an application form. Other carers can also use the card.

## 5 LAMINATOR

Photos, symbols, drawings – everything that needs to last gets laminated in our house. Once you've started, you can't stop and start trying to find random things to plasticize... They're inexpensive and very handy.



## 6 RADAR KEY

The Radar key is your personal passport to a world without hand dryers, since it allows you access to disabled toilets around the country. Some places give them away for free, but you can buy them for £2.39 on the Age UK website. You are completely justified in using disabled toilets with an autistic child, especially if they need extra help for their age or are an older boy with mum and too vulnerable to go to the men's toilets on their own.

This key has been invaluable... although there was that time when I closed the door behind me, leaving my Radar key, house and car keys inside the cubicle... In case you make a similar slip-up (my husband felt that no-one else was likely to), it's worth knowing that most libraries keep them.



## 7 HAND TOWEL

Take everywhere there's a hand dryer. Enough said.



## 8 COUNTDOWN CLOCK



When Bobby was little, his inclusive nursery very quickly taught us the countdown method of warning him before change was imminent. We used to give him warnings to stop what he was doing at half hour, ten minute and one minute intervals. This is the single most important behavioural tool we use at home and has become second nature.

Countdown clocks do visual warnings for you, by showing how much time is left. Buy an App that counts down from [www.timetimer.com](http://www.timetimer.com) Or, you can buy The Big Red Timer at [www.exploreoursenses.co.uk](http://www.exploreoursenses.co.uk). At about £35 they aren't cheap but you may be able to get a discount at certain exhibitions and shows the company attends.

N.B. Watch out for those little computer whizzes who give themselves more gaming time by adjusting the clock when you're not looking. I used to fall for this trick quite a bit.

## 9 WIND UP TOYS

Toys R Us sometimes have a dazzling display of cheap wind-up toys at their checkouts. Hawkins Bazaar at [www.hawkin.com](http://www.hawkin.com) is also good for them. When going to a restaurant, I always take wind-up toys with me. They're small, cheap if we lose them, and can keep kids happily entertained for ages. They're also a great communication tool as the child needs to request you to wind up the toy for them, 'do it again' and so on. If I can, I keep some new ones to hand for situations where we have to wait.



## 10 SHAVING FOAM

Spelling and drawing practise without the resistance associated with pen and paper. Use whilst in the bath for educational fun.







# Ten Exercises for STRETCHING the Comfort Zone!



## Are you inflexible? Yep, you!

We can all be inflexible when it comes to autism, even if technically autistic people are seen as the inflexible ones. We do it to try to keep a child in their comfort zone. But sometimes, our own inflexibility can make a person with autism more rigid than ever.

There's a big difference between accommodating a need for routine and security and being so inflexible that a child doesn't learn to get used to change.

The difficulty we're faced with is that autistic people often default to 'no'. Want to try something new? No. Absolutely not. No way, Jose.

This way, they protect themselves from anxiety and fear.

Sometimes we take that 'no' so literally that we enable a person to live a narrow existence, forcing those around them to do the same.

That 'no' actually means fear. As parents, we have to learn the difference between an absolute 'no' - change that would cause distress - and a 'not sure'. If we work to reduce fear, then gradually we can encourage an autistic person to step outside their comfort zone. The more they're out of it, the bigger the comfort zone becomes.

Tim, an adult with autism who

works in the AuKids office, tells us the fear of something new is sometimes overwhelming. "It's so big, it's really hard to get over it. But I know that if I don't do it, I'll end up sitting at home all day. So I make myself - and I always feel glad I've done it. In the last few years, I've done more and more things and it's made me a lot more confident. I know that I can, now - and that means that I've got that in my mind whenever I try something different."

When Tim's mobile phone started to fall apart, we knew he had to change it or he'd be left without one altogether. Oh, the anxiety! We bought Tim a new one and asked

him to carry it around with him without using it. We personalised its cover and we typed out all his phone numbers. It took a year from buying the new phone to Tim using it daily. Now he doesn't even think about the change. We've framed his old one!

The point is, if you never make a change, you'll never get used to adapting - and that makes you more rigid than ever.

Please don't think we're suggesting that you drag your child out of the house kicking and screaming. Here's some gentle ways to stretch that comfort zone. Try exercising it little and often!

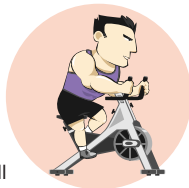
### 1. Warm Up: Prepare for Change

Social Stories™\* and photographs are always useful. Also prepare for the unexpected - what do you do if things go wrong?



### 2. Start Simple

Start small with an experience that you know they'll like, such as a new park at a very quiet time. Suggest that if they don't like it after ten minutes, you'll go home - and stick to it. Most people can tolerate anything if they know there's a definite end to it.



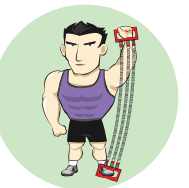
### 3. Look Back, Look Forward...and Rest

Think of a recent place they were reluctant to visit, or a food they were reluctant to try. If they can, ask them to rate what the fear was before the change on a scale of 1-10. Then ask them to rate how that feels now. This provides evidence that something is never as bad as they expect it to be. Use it as an example when you face new changes.



### 4. Don't Overstretch

We can ALL accommodate change if we have a certain amount of security, this is just more extreme for an autistic person. What should always stay the same no matter what? Story time? A familiar breakfast? Having Wi-fi? All of the above? Keeping the basic structure allows a person to explore smaller changes. So even if your home planet has suddenly been parked in a different galaxy, it still spins in the right direction!



### 5. Stick to the Beat

Some parents ask us if they should stick to routines at home or whether it's better to 'prepare' a child for the outside world by resisting them. Autistic people have to have somewhere where they can comfortably be autistic! We tend to find that rather than reinforce rigidity, a comfortable routine at home makes for greater flexibility in the big wide world. Coping with change comes from an inner sense of security that we develop through a structured home life.



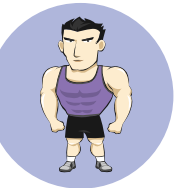
### 6. Let Them Twist And Shout

Your child may shout at the thought of change. This is often a knee-jerk reaction to change, but you mustn't assume that it means you shouldn't try. Stay calm. Reinforce the positives about the change and that they don't have to stick at it. If this becomes a full-on meltdown, maybe you need to think about smaller steps and more preparation before you try something new.



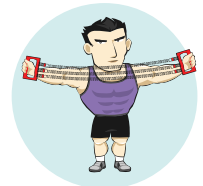
### 7. Relax Those Muscles

Autistic kids get so many signals from their parents. Unfortunately, when a child is looking worried, you become worried that they're worried...and the whole thing snowballs. Show that you're completely chilled and that there is nothing to worry about (even if inside you're thinking 'Arg, this is going to be a nightmare!').



### 8. Stretch Just a Little Ahead

Too much preparation too far in advance can increase anxiety. Some parents find it easier to tell their children about a change a few days beforehand. Pre-verbal children certainly get a clearer message about change if you show them pictures just a day beforehand.



### 9. Small Steps Forward

Small regular changes encourage children to become used to new environments, learning that they can be enjoyable.



### 10. Choose Your Move

Why not make the change the child's idea rather than something that's imposed on them by someone else? Give them options and information on three new places and ask them which they'd like to try. When would they like to go? The more the change is child-led, the easier it'll be! You don't have to do this just for visits, but for other things, too.



**Finally - Persevere! Even very rigid kids can adapt, but they need to learn how. Accept that it is difficult for them, use the word 'try' rather than 'must' and relaxed phrases such as 'Shall we give it a go?' Notice we use 'we' rather than 'you'. You're in this together and your child should learn that you're not quite sure what to expect either, but you're willing to give it a shot. Good luck!**

\*See Issue 15 on our online archive



# And Now It's Time for Play School

The Big Autism Play Day! is hosted by Hirstwood Training and aimed at both carers and professionals living and working with young children on the spectrum. Tori Houghton went along to the two-day course in Manchester earlier this year to find out about the different approaches on offer.



Richard Hirstwood



Chris Barson



Judy Denziloe



Issy Gammer



Greg Pasco



Steve Phillips



Jan Collins



Joanna Grace

If you're looking for innovative and motivating ideas for kids with autism, then this is the course for you. It's packed with creative ways of approaching play from every angle, with every day items taking on new identities as sensory surprises. There were plenty of higher-tech recommendations, too, with a specialist session on apps on Day Two.

At times, it was a great excuse to go back to my childhood, as the nature of the course was hands-on, practical, entertaining and fun.

The course leaders were **Richard Hirstwood** and **Chris Barson**. Richard has extensive experience in special education and Chris founded the training company Positive About Autism in 2009 and has a long involvement with autism and more recently with the SPARK programme. This Canadian approach to developing flexible thinking and problem-solving skills was featured in AuKids Issue 19. A session on SPARK features on Day Two of this course.

Both Chris and Richard are high energy presenters and the rest of the course trainers were full of enthusiasm, too.

## Here's a round-up of some of my favourite ideas:

**Judy Denziloe** is a specialist in sensory play. In her *It's A Material World* session, she gave delegates an enormous range of ideas for

simple, inexpensive, yet alluring toys. Try not to find this insulting, but I loved her idea of cheap, durable, highly tested and safe pet toys from Pets at Home for those autistic kids who enjoy mouthing. Just a quick look at [www.petsathome.com](http://www.petsathome.com) reveals plenty of squeaky toys with a lot of give. Cat wands can make equally fun fiddle toys.

I wouldn't be able to think about **Richard Hirstwood** without imagining an umbrella. In his amazing *Jolly Brolly Bonanza* session, he spoke about using umbrellas to engage and educate. You can hang things from them and create a story, use them as a safe space in the midst of chaos, project pictures onto them and well, you don't have to have autism to be captivated by spinning a rainbow coloured umbrella!

In *Hit The Floor and Start Having Fun!* **Issy Gammer**, a specialist in early intervention with children with autism, spoke about the approach popular in America known as Floortime ([www.stanleygreenspan.com](http://www.stanleygreenspan.com)). It's a play-based therapy programme in which children engage directly with their parents. Issy spoke about helping parents create more opportunities to play. One of her key messages, which I liked, was the idea of 'telling the story of what's happening'. This encourages parents to focus on

what the child is doing and give a commentary, providing language models\* for the child.

**"It was a great excuse to go back to my childhood, as the nature of the course was hands-on, practical, entertaining and fun."**

In *Small Talk Matters*, **Greg Pasco**, a speech and language therapist, focused on using the right language style during play. As a speech and language therapist myself, I was pleased that there

was a speaker focusing on this important aspect of play - the type of language to use and when to speak. We can't emphasise enough how important it is to reduce questions and directions and replace them with comments. This point was emphasised in a group activity where one person counted the types of language the others were using.

On Day Two, **Steve Phillips** and **Jan Collins** from Fountaindale School in Nottinghamshire hosted an impressive session titled *Developing a Curriculum for Play*. In this specialist SEN setting, an entire curriculum has been developed around the use of play for students with complex needs. This felt like a cross between a therapy session and an episode of *Blue Peter*, during which we made our own toys. These two showed how ANYTHING can be used in play - even a Brussel sprout!

Another highlight on Day Two was **Joanna Grace's** session *NOT the Same Old Story!* in which she

spoke about sensory stories and how easy they are to create cheaply. The different senses were discussed and the types of items that could be introduced to a story to help represent its meaning. During the session, we created our own sensory story with just a piece of paper. I was particularly proud of my attempt - a snowflake which ended up being blown through a tube in tiny pieces!



I couldn't fault the ideas on this course - they came fast and furious over the two days. In fact, this would make a good YouTube series as the ideas were a little overwhelming in one go. I would have liked to have listened to more theory interwoven between these sessions, to link the various aspects of the course and to enhance their meaning. For professionals who have an existing background in play development, this isn't perhaps as important as it would be for parents.

## FURTHER INFORMATION

**The Big Autism Play Day!**  
Takes place in 2016 at:

**Manchester** - 4<sup>th</sup> March  
**Nottingham** - 11<sup>th</sup> March  
**London** - 18<sup>th</sup> March

To find out more and to book, look up [www.hirstwood.com/courses-you-can-attend/big-autism-play-day](http://www.hirstwood.com/courses-you-can-attend/big-autism-play-day)



# BLOGDASHINA

A paper blog by autism expert Olga Bogdashina

Blog 2

## A PAINFUL TRUTH



**Olga Bogdashina** is an internationally renowned researcher and lecturer in autism and the author of books on sensory perception, the Theory of Mind, communication and spirituality in autism. Her autistic son Alyosha, 26, is the inspiration behind her career.

As he grew, I began to notice more and more Alyosha's very acute aversion to some things we would not think twice about. Seemingly mundane tasks such as getting dressed or getting his nails cut were surprisingly difficult.

When it came to having his nails cut, his distress was so severe that I had to start being creative to get it done. So when he was asleep, I would have to creep quietly into his room to accomplish the task. It probably wasn't the best option, but the only other one was for a friend (or two) to hold him down whilst I cut his nails, listening to his screaming protests.

Of course, anybody could see this was a highly uncomfortable situation for my son - but nobody could tell me why he was so distressed. Was it a fear of the scissors or was it the sensation of the scissors against the nail?

I needed to find out, because not understanding your own son and what puts him in such stress is hugely upsetting. Once I delved deeper, I found that for the majority of autistic people, the sense of touch

is highly acute. Plus, the duration of this sensation can last for hours, days and even weeks.

These sensations can be explained thanks to modern neurological research where comparative studies have been done with autistic and non-autistic individuals. Research found that in autistic individuals, transmitted sensory information was not contained in small units in the brain (called 'minicolumns'), but instead 'overflowed' to nearby units, creating an amplified effect.

Professor Manuel Casanova compares this with a shower curtain. When working properly and fully protecting the bathtub, the shower curtain prevents water from spilling to the floor. In autism, water is all over the bathroom. Sensory stimuli can be experienced very differently by autistic individuals. Just because we may not feel something, it does not mean that they don't.

It's something that is so simple to understand, yet not knowing anything about it makes you feel like you know nothing and you are unable to help your own child.

As my son grew up and got used to these sensations, he became able to express how they felt. He now says "My nails are sticky". Perhaps it's not that the feeling of nails being cut remains, but rather that the surface of the cut nail is broader and makes it feel like the air is pressing on the nails.

Because of this sensation being longer lasting and more intense for him than for others, it usually takes him a few days or sometimes up to a week to lose it.

Many parents of autistic children shared similar experiences with me. A common one is getting the child changed into different clothes. It is well known that autistic children insist on sameness and many prefer to wear the same clothes day in, day out.

Whilst others can forget the sensation of clothes on their skin after just a few seconds, (called 'habituation'), many autistic people do not. The habituation process does not work properly for them and that's why the sensation of something on their skin may last for hours or even days.

It's hard to imagine what it must be like to always feel clothes on your body. It's not only daily clothes that can cause problems - it can take weeks to get used to summer clothing and by the time they feel comfortable, it's autumn and time to start wearing trousers and long sleeved jumpers again!

My son has gradually got used to these experiences, from getting dressed in new clothes to having his hair or nails cut, and he now deals

with it much better than before. He now goes to a local hairdresser who knows him well and he is able to sit through it calmly and happily.

Not only have I learnt more about his experiences, but I have also learnt how to be able to communicate with him about them.

Now, when he asks me: "Mum, will my nails be sticky when you cut them?" I reply:

"Yes, your nails will be sticky, but this feeling will pass."

So with his language and my understanding, the process is now a lot more bearable for both of us.

Looking back, I've realised that over the years it wasn't only me learning how to cope with all of this. He was, too.

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### Brain Imaging In Babies (BIBS)

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**CONTACT**  
The BIBS team  
0207 848 0829 / 0207 848 5852  
bibs@kcl.ac.uk

NREC 12/LO/2017



# Our Holiday Heroes

An autism-friendly holiday is hard to come by, but some forward-thinking companies are doing their best to create a more blissful breather for families and their autistic youngsters. Here we salute a couple of chaps who started up their own specialist holiday company – plus some organizations that have gone that extra mile in the name of inclusion.

## Centre Algarve

**We wanted to make a difference!**

*By Malcolm Reeve, in his own words*

One of the many challenges that parents and carers of children with disabilities and/or special educational needs face is finding suitable places to take holidays. It can be very difficult even to plan a full family holiday due to concerns about safety and whether the needs of the person can be met, not to mention empathy by both the holiday venue and other guests.

That's even before all the potentially complicated travel arrangements are made. I became acutely aware of this in my previous role as CEO at Columbus School and College, a specialist setting in Chelmsford. Parents would regularly talk about the difficulties they faced and often it would just be impossible to have a full family holiday because suitable and affordable places could not be found or simply did not exist.

The real shame was that these families truly needed the opportunity for a break because of the daily pressures they faced and they desperately wanted to do this as a family unit.

Whilst at Columbus I met Andy Mahoney, who owned the company that provided transport for the children to and from school. In his discussions with families, he too had become aware of the challenges around family holidays and he had decided to do something about it.

Andy asked if I would lend my support to a project he was working on to open a dedicated holiday centre for people with special educational needs and their families. He had located a derelict hotel in the hills above Faro in the Algarve, Portugal, and thought it had the potential to be developed into a holiday centre. So we set about developing it.

Over the past five years it has turned from this:



Before...



...After!

We started thinking about all the adaptations and changes which would have to be incorporated into the building. Andy formed a charity - 24x7 Special Needs Holiday Trust - which was to provide the financial backing (and to ensure a secure legacy although in reality the bulk of the funds came from him!)

Andy also drew on his experience and business know-how along with some unconventional ideas about getting the project started (and finished!). He already had a house in Portugal and some very good friends there as well, two of whom were estate agents who had initially found the site, Tom and Belinda.

They gave up their own business interests to project manage the rebuild and their enthusiasm for the project was to set the tempo for the next four-and-a-half years.

When I say 'unconventional ideas', Andy was the inspiration behind involving volunteers from all over the world to support the project and lend their skills.



Volunteers having a well deserved break

We provided them with accommodation and food and they provided their expertise, knowledge and hard work. In total, just over 500 volunteers have helped to develop the centre. Some stayed for a week or so and some for many months. A number of volunteers returned again and again to help with the next stage of development.

In the beginning, a lot of the work was about ensuring utility supplies were in place and making sure everything was structurally sound. We brought in Haverstock Associates; acclaimed

architects from London with a dedication to supporting developments for people with SEN. Generously, they gave their time and services freely and also fundraised for us. They produced plans and sketches of the site and helped us to incorporate an education centre. Andy had many meetings with planners and officials to secure permission for the developments.



Specially equipped hygiene rooms

Later on in the project, we could think about décor and furnishings and of course I kept my mind focused on the necessary adaptations such as installing hoists and hygiene rooms and we installed a hoist into the pool. We also had to consider levels, steps, wheelchair access and a colleague of mine came out to help us with health and safety audits.

A lot of time was spent on landscaping and developing the unique plants and trees which make up the site. A raised garden was incorporated to ensure that every visitor could explore, enjoy and help in the gardens. Andy had a vision from the start that animals would be part of the experience for all who visited and I remember a trip to a zoo one day to collect two eagle owls, which were being donated to the centre! The most recent addition is a family of meerkats.

It's fair to say that Centre Algarve has been built on generosity, kindness and hard work...

So now we're ready!

The two-acre Centre Algarve now consists of 14 rooms, two of which have en suite hygiene rooms which are fully hoisted with hygiene beds, showers etc. It has a dining area, a lounge and sun area, education centre, American-themed diner, soft play/sensory room, swimming pool, paddling pool and of course the animals and the grounds.

It is located just a kilometre from the small town of Moncarapacho and around 20 minutes from Faro airport, to which the budget airlines fly. Centre Algarve provides bed and breakfast with the accommodation and has contacts with a reputable company based at the airport for collection from and transport back to the airport and any visiting families can be assured of a very warm welcome.

Anyone - family, school or organization, is welcome. We'd be happy to discuss the exact needs of any family or group visiting before they come so that we can ensure everything is set up and prepared.

We are just at the beginning...with your help, we can make it even better. If you are reading this as a parent, carer or friend who would benefit from the sort of service the centre offers, then please do get in touch.

**LOOK UP:** [www.centrealgarve.org](http://www.centrealgarve.org)

**WATCH:** [centrealgarve.org/the-reality](http://centrealgarve.org/the-reality)

# Six of the Best for an Autism-Friendly Summer

## 1 Airport Advice

Fubra Ltd produces a network of guides for major UK airports about disabled access and special needs at the airport. You can find links to each one at the AuKids links page – [www.aukids.co.uk](http://www.aukids.co.uk)

## 2 All Change at Airport

As part of recent upgrades quite a few UK airports have addressed the increasing need to offer a changing area for disabled passengers and their carers to use. Recently, Airport Parking Shop has compiled a list of the Changing Places facilities that are already installed at airports and available for access – [www.airport-parking-shop.co.uk/blog/changing-places-facilities-at-uk-airports](http://www.airport-parking-shop.co.uk/blog/changing-places-facilities-at-uk-airports). The blog post includes facilities at a number of UK airports including Heathrow, Gatwick and Manchester.

## 3 All Rise



Reader Sue Ahmad says her daughter's favourite place is the Science Museum in London when they have an Early Bird session. The huge museum opens early for SEN users and they put on special workshops for SEN kids and their families, too. [www.sciencemuseum.org.uk/visitmuseum/Plan\\_your\\_visit/events/other/early\\_birds\\_event](http://www.sciencemuseum.org.uk/visitmuseum/Plan_your_visit/events/other/early_birds_event)

## 4 Flying the Flag

Big 'up' to Manchester Airport for its Airport Awareness Scheme dedicated to autism friendliness. Here, you can get a wristband which allows a person with autism and their family to go through fast track security checks – one family told us it took them five minutes to get through security last year whilst others were taking hours. Staff look out for wristbands and help you throughout the airport. An airport awareness pack explains the whole travel process to reduce travel anxieties. See [www.manchesterairport.co.uk/about-us/media-centre/airport-awareness](http://www.manchesterairport.co.uk/about-us/media-centre/airport-awareness)

## 5 Taking the Mickey



**Special Mouse** is a helpful resource for families with SEN who are planning to visit the Disney theme parks or cruise with the Disney Cruise Line. Created by Kathy Kelly, a registered nurse and an autism mum, the website hosts a blog and a podcast that provides information, tips, guest interviews and trip reports. Kathy is currently working on the first in a series of special-needs Disney-related travel guides, *Walt Disney World with Autism: A Special Needs Guide*, which will be available at the end of the year. For more information please visit [specialmouse.com](http://specialmouse.com).

## 6 AuKids' Star Visitor Attraction!



For holiday days out, we can't fault Eureka, the National Children's Museum based in Halifax, West Yorkshire (near the train station). It's hands on, fun and interactive. It's brilliant for autistic kids because there are things to press, bang, feel, smell and play with. The staff are incredibly warm and welcoming and make payment easy and fast. They also do their best to include all their visitors in their special sensory story sessions. There are autism-friendly days and if you call in advance, you can book an 'extra pair of hands' for any visit to help you out for free – this is a service especially for families with special needs. Ear defenders are provided if you need them and there is a sensory room for 'quiet time'. [www.eureka.org.uk](http://www.eureka.org.uk)

## Supporting more active lives and accessing new experiences



Established in 1975, the Hesley Group provides specialist support through its schools, colleges and adult residential services with a highly experienced and expert multidisciplinary educational, care and therapeutic staff resource, in high quality purpose built settings. We're focused on positive outcomes and progress towards sustainable independence.

Referral enquiries freephone  
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[www.hesleygroup.co.uk](http://www.hesleygroup.co.uk)



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## Autism Friendly Screenings...

4 films, 4 cinemas,  
4 Sundays...every month!

Autism Friendly Screenings are now brought to you at over 200 cinemas, by Dimensions in partnership with Cineworld, ODEON, Showcase and Vue.

[www.dimensions-uk.org/autismfilms](http://www.dimensions-uk.org/autismfilms)



More Info!

You can find a mammoth amount of information in the NAS Information sheet – **Holidays: autism-friendly venues**. [www.autism.org.uk/living-with-autism/out-and-about/holidays-and-days-out/holidays-preparation-and-practicalities](http://www.autism.org.uk/living-with-autism/out-and-about/holidays-and-days-out/holidays-preparation-and-practicalities) Look up autism-friendly holidays at home and abroad as well as details of specialist travel operators and financial help.

# IT'S ALL RELATIVE

The tense, nervous headache that starts before you get in the car. Those gut-wrenching feelings as you draw to a halt and put the handbrake on. It's not your driving test, it's a trip to the relatives.

However well balanced your home life is, when you take your child out of that familiar environment, things start to get tougher.

Some families are very understanding of autism. For others, it's difficult to comprehend those social-communication difficulties. To them, those problems do a fantastic impersonation of bad manners. And whereas a friend might not say anything, families are not so hesitant in coming forward with their views.

This can make for really uncomfortable family visits. It's such a shame, when it doesn't take much to get a better relationship.

Here's our advice for families and for parents:

## THE FAMILY

### What You Should Know

The good news: you don't need to be clued up on autism to understand your young relative. You just need to know about *them*. If you also bear in mind that socialising is probably your autistic relative's least favourite occupation, you're onto a winner.

Relax the usual rules and the autistic child will relax around you. An autistic child is under constant pressure to conform socially, but family should be a safe haven from this (within reason – they should be able to get away with some social inappropriateness but not trashing your house).

Some autistic kids need space and time to process new surroundings especially when a lot of people are about. Don't see withdrawal as anti-social behaviour.

If you make the visit into a learning experience, you'll break the delicate trust of the youngster, so try not to jeopardise it. Instead accept that their social behaviour is a struggle and will be worked on in their own comfortable surroundings.

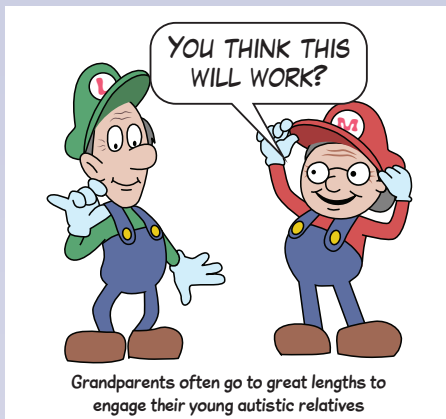
Change is hard for autistic children and new food represents change, so try not to be offended by what would be deemed 'fussiness' in other kids.

New environments aren't a good place for an autistic person to experiment with new foods, so stick to the tried and tested and yes, even it means a particular product or brand. We're sorry if this goes against the grain, but we'd only advocate trying new foods at home, since anxieties are often higher elsewhere.

Kids may point out differences between your home and theirs: that's just a way of observing discomfort through change, not deliberate rudeness.

Disciplining a grandchild may be something you're used to doing but be careful – autistic kids require different sorts of approaches and parents may be in the middle of learning them. They may appreciate it more if you ask them what you should do.

Bringing their own things will help an autistic child to feel more relaxed in a new environment and an autistic child will benefit more from becoming very familiar with a handful of places near to your home rather than visits to new places each time.



### Great Things to Do Before the Visit

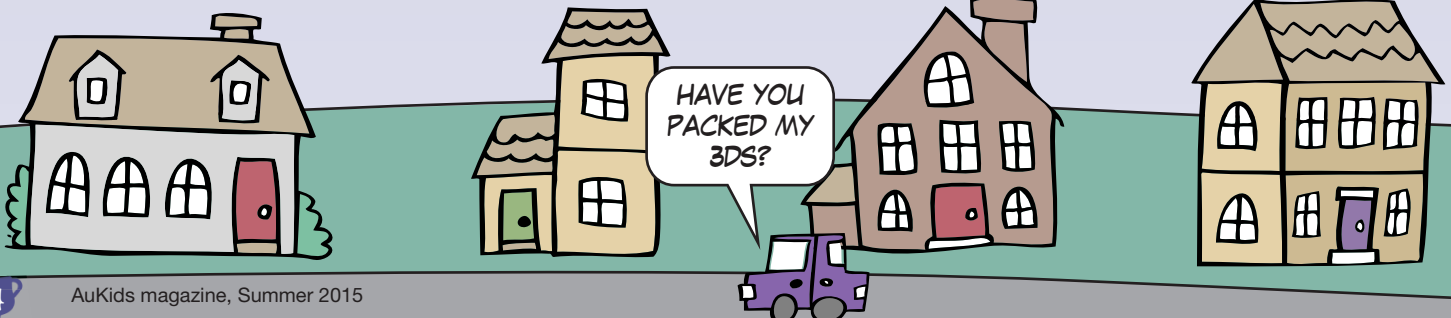
- Minimise tension by putting breakable objects out of harm's way!
- Ask the parents about what's needed for their child's comfort
- Have a plan about what to do
- Think of something that you can always do with the child as part of their visit that forms your

own little routine together. Maybe they have to guess what shape biscuits they'll have or what colour top you will be wearing? This provides you with an 'in-joke' and an immediate rapport.

- If the child writes and has an e-mail address, write to them. This sort of interaction is very undemanding and likely to build a great relationship. Don't make your e-mails too full of questions, though – that's yet more social demands!
- Using Skype or Facetime can help you to develop familiarity with a child you don't see that often.

### During the Visit

- Openly tell the parents that you want them to relax.
- Respect home routines with food times; flexibility in this area can be amazingly difficult for an autistic child.
- Have a chill out area – even a tent, where autistic kids can retreat to if the social demands get too much for them.
- By telling you about their special interest, your autistic relative is actually saying 'I want to connect with you but I'm not sure how!' so take the time to talk to them about it.
- If they take themselves off to the computer, don't leave them on their own (unless they've said it's what they want) - watch what they are doing and chat about it, if only for a very little while.
- If you are outdoors, offer to take turns in keeping junior safe. Parents of special needs kids rarely get an adult conversation at get-togethers because of their children's compromised sense of danger.
- If you can, create a regular routine for each visit.
- For autistic kids, even pleasant demands are pressure, so saying: 'When you're ready come and find me, I've got something to show you!' will produce a better response than saying 'Come and see this!'
- Leave cake off the table until sandwiches are finished! Autistic kids don't have the executive functioning or social skills to wait for the 'right' course.



# THE PARENT

## What You Should Know

- Don't forget your autism strategies at a relative's house. Apply the same understanding that you would do at another unfamiliar environment.
- We don't usually force our children to be 'social' but with family we may put more pressure on them. Try to relax!
- Put some faith in your family. If you always do everything for your child, it will knock your family's confidence in their ability to help.
- Don't cringe at your child's bluntness. Prepare relatives for it and just reinforce the correct way to say things gently e.g. 'Not for me thanks'.
- Remember that visits to relatives get easier the more you do them.
- No one expects perfect behaviour from a child all the time regardless of whether or not they have special needs.
- 'Normal' children may behave badly at home but know the rules about how to behave around others. Autistic children may not understand why they're required to make a special effort. Their tantrums may be on show more but 'normal' kids have them, too!
- Accept that your relatives have a separate relationship with your child to you and that this needs space and time to develop.

## BE PREPARED! Before a Visit...

- Seek opportunities to talk about being in someone else's house and respecting their things – don't just wait for right before a visit, when it may raise anxieties.
- Wait till after a visit to talk about any behaviour blips!
- If the child is staying overnight, show them where they are sleeping before doing anything else.
- Talk to your child (if verbal) about the interests of those closest to them and ask them if they can remember them from time to time.
- Write a Social Story™ to prepare them (see Issue 15 for how to).
- Hang a photograph of where you're going on the back of your car seat.
- Get photographs of family members and the inside of the house to prepare them.
- Tell your child how long the visit will last.
- Explain to your family what's difficult for your child in advance.



# The AUTISM FRIENDLY FAMILY TEST

Friends and family test: how autism friendly are you?  
Take our light-hearted test to find out!

## 1 Your autistic relative is coming round. What are you feeling?

- A) Great - can't wait to find out what quirky special interests he has to share with me this time!
- B) I'm wondering if he'll want to speak to me.
- C) Oh my god...hide the china.

## 2 The child arrives without making eye contact. Do you:

- A) Smile – he said 'hi' so has definitely noticed you!
- B) Not fuss, this is usual for him.
- C) Ask that he looks at you and greets you properly.

## 3 There's something you don't understand about the child's behaviour. Do you:

- A) Subscribe to AuKids, buy your entire extended family a subscription and spend your evenings trawling our free online archive? Ahem. 😊
- B) Ask the parent and listen without judgement?
- C) Put it down to bad parenting, but keep it zipped in case you get a mouthful?

## 4 All the adults are chatting but the child and his dad are nowhere to be seen, do you:

- A) Seek them out and ask if help is needed?
- B) Wait till they return and observe him for signs of stress and fatigue, then act accordingly?
- C) Carry on chatting? (He is used to running around).

## 5 The child is motoring a toy car across the floor. Do you:

- A) Get on the floor and join in with them.
- B) Leave them to it, they seem happy enough.
- C) Get a better toy out that will make them happier.

## 6 The child seems to be ignoring you when you ask him questions. What's your response?

- A) I wouldn't ask him lots of questions, I know it puts him under social pressure.
- B) Give up, he obviously doesn't want to talk.
- C) Keep repeating the question until he gives you an answer.

## 7 You've spent hours cooking and the little autistic relative has pushed your meal away. What do you do?

- A) This would never happen, I called ahead to check he liked it.
- B) I'd give him a cheese sandwich, it's not the end of the world.
- C) Say: 'Eat what's on your plate – in my day we were never given alternatives, we were too poor, etc. etc.'

## 8 Your autistic relative starts talking about their special interests. Do you:

- A) Join in because you already know all about their interests?
- B) Ask them questions but explain to them when you get a bit tired?
- C) Divert them to another family member who's more interested?

### MOSTLY 'A's

Autism Expert

WOW! You've obviously shown a great willingness to understand your little relative and go to tremendous efforts to know them well. Autism isn't going to stop you having a good relationship with them and you're doing everything to make them feel at home. Since your efforts are so great, you will be rewarded with a relaxed and comfortable relative. Well done!

### MOSTLY 'B's

Willing Amateur

Give it a go and let the parents parent, that's your motto. You don't claim to be an expert in autism and you adopt a relaxed 'live and let live' attitude. You might want to find out a little bit more about them if you want to develop a closer relationship, though.

### MOSTLY 'C's

Novice

Oh dear. These visits must be as stressful for you as they are for the child and parents. If you never make an attempt to understand autism, this 'strange' or 'rude' behaviour will continue to stress you out and confound attempts to bond with your relative. Read this article again for tips and relax your usual social demands. Well done on picking up this copy of AuKids, though, which shows a certain willingness to learn.



# The Last Word

By Debby Elley, journalist and mum of twins with autism.

## It's Never Too Early to Go Back to Bed



I only got up two and a half hours ago, but in that time I've managed to survive both a meltdown and backing into the neighbour's car (and yes, the two were related). Before I go back to bed and call the day a write-off (rather than the car – I merely caused a dent to the bumper and to the 21 year-old owner's pride), I'll recount the story. This is in the hope that we can all learn some valuable lessons from it. In the event of no valuable lessons being learnt, you have permission to snigger unsympathetically at my expense.

At 8.35am, I was ruminating over an unwise choice of lipstick, one that wasn't really appropriate for my age. Age-appropriate make-up is something that I'm only just coming to terms with now that I'm officially middle-aged. Hey, they should be grateful that I put any on at all, I thought, as there were more pressing things to attend to.

**"My own parental signature is required so often that I'm thinking of getting a rubber stamp made."**

Bobby now gets himself dressed, but like many boys of his age he doesn't really mind the sort of chaos he leaves in his wake. I've just about persuaded him to lean over the sink to clean his teeth by moving the mixer tap out of the way, when he forgets it's no longer over the sink and switches it on.

I can't really worry about the sink flood drama or the amount of toothpaste adorning his clean sweatshirt, since it's about now that a reluctant Alec rolls out of bed and takes himself for a wee roughly anywhere in the vicinity of the toilet but not necessarily in it.

We haven't even got to the good bit, which is whiling away precious minutes signing and dating a series of random consent forms. I can only remember my mum signing two things in my entire school career. One was the form for our annual trip to Drayton Manor Zoo. The other was my homework book at secondary school, which she didn't have to bother with

after two weeks because by then I had mastered the art of forgery.

In contrast, my own parental signature is required so often that I'm thinking of getting a rubber stamp made.

For Alec, in special school, it's endless. Yes, the dentist can have a look at him (good luck with that, I add); Yes, the speech and language therapist can use a tongue depressor on him (again, good luck with that); Yes, my doctor hasn't moved in a whole 12 months; Yes, my name and address is the same as it was last week...

That done, I regard the weight of Bobby's bag and wonder whether we'll make it through the school gates without an airport trolley. With autism, you need to carry your world around with you. That way lies comfort and security. That way also lies back problems for your parents.

Alec now heads carefully downstairs with an armful of singing teddies. Since this has obviously required some planning, who am I to get in his way?

Communication books have been filled, five cups of tea have been brewed for our new in-house builders. We finally make it out the front door and past three vans that currently decorate our cul de sac, pulling up at the school at 8.55am.

Bobby gets out the car and suddenly freezes: "Where is my Pikachu?"

This Pokemon soft toy now accompanies him everywhere. My brain races to assess whether it can get past autism rigidity with stealth tactics. "Oh, er...Pikachu's having a day off. He needed a rest after SATS." Good one.

"Nooooooooooooooooo, I need my Pikachu! I can't cope without it!!!!"

Not such a good one.

By this time Bobby is racing around the school foyer shouting.

I leave Bobby in good hands, dropping Alec off at his special school, where he ambles down the hall clutching the all-important singing teddies, then I race back home. I grab Pikachu from the lounge, curse at it, sit it in the front seat, do a three-point tur---THUNK.

So that's how it happened. I am still quizzing my car as to why it thought that this was a good moment to avoid deploying its parking sensors.

The lesson here is to never let a meltdown get in the way of health and safety. Plus to pack Pikachu the night before.

# Love Aukids?

**Get the T-shirt to go with it!**  
Plus the hoodie, beanie hat, cap, school bag, pump bag, apron and even teddy bear!

The Aukids clothing range carries a selection of slogans dreamt up by the magazine team and designed to inspire tolerance and positivity! Quality clothing at fantastic prices made by our friends at [www.finsdesignandprint.co.uk](http://www.finsdesignandprint.co.uk). Order online. Kids' t-shirts for £8 and kids' hoodies for £14. Adult sizes also available.

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