



# Aukids®

Issue 45  
October/November 2019

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For Parents and Carers of Children with Autism Spectrum Conditions

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Four extra  
pages for  
Christmas!

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# Letter from the Editors



## Welcome to our bumper Christmas issue!

Grab yourself a huge mug of something hot and settle down with a cushion, because our extended Issue 45 is genuinely a belter.

We were in the presence of greatness when we interviewed our favourite autism children's author, clinical psychologist Dawn Huebner. Co-editor Debby has often used her books as her twins were growing up and so when readers started to ask about how to handle their children's anxiety, we knew just who to ask. She's also kindly donated three copies of her new book *Outsmarting Worry* to give away. Just flip to Page 12 to find out more.

Also this issue, Tim Tuff our volunteer has reflected on his own experiences in medical settings and given us some superb insights into difficulties that your child may have when attending these sorts of appointments. We've compiled his thoughts into a pull-out feature at the centre of this issue, that you can hand over to health centres, or photocopy if you feel it would be useful.

Pages 6 and 7 are home once more to our 'From the Archive' feature. The Search for the Holy Grail article was an early favourite of ours, inspired by our personal experiences and those of other families. Messages after diagnosis are often so muddled. We addressed that confusion and Jo worked her magic with the graphics.

Before we go, we'd like to thank everyone who came and supported our 80s Night in September, which was great fun, with lots of neon outfits and big hairstyles! Huge thanks to San Rocco restaurant in Ashton-under-Lyne for hosting this for us. A big thank you to our DJs James and Vicky, who did a great job on the decks. Plus a round of applause to Dave Seton for 'procuring' a great sound system for us.

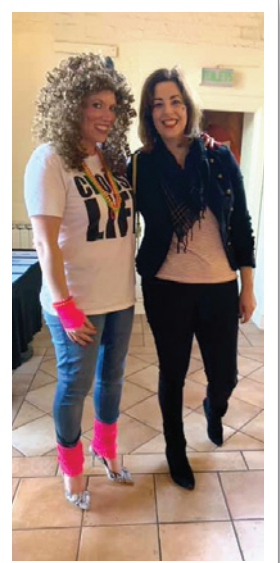
Generous raffle supporters included our own photographer David Laslett, Morrison's in Cheadle Heath, Sainsbury's in Cheadle, Eirene Mobile Beauty treatments, mobile hair stylist Lee Marsh, Barburrito, the Random Company, Lisa Tyrrell (donation of Younique make-up) and Room B beauty salon. A big mention must also go to Nicola Sweeney for supplying us with some fantastic runners-up prizes, too.

Exciting news to round off – our *Ice Cream Sundae Guide to Autism*, a board book for children ages 7-11, is now in production with Jessica Kingsley Publishers and due out during the summer of next year, just in time for a cornet or two! We'll keep you posted on its progress.

Enjoy your last issue of 2019, and don't miss our next issue out at the end of January 2020.



**PRIZE:** Debby shown here accepting a hamper from Janice at Customer Relations in Morrisons. The hamper was won by Stockports Postage team.



**GIRLS JUST WANNA HAVE FUN:** Tori and Debby get the 80s look for our fundraiser.

*Tori & Debby*



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Registered charity number 209782

COMM057

## Autism South West Parents and carers conference

**Our first conference specifically for parents, carers and professionals. An investment for anyone living with or caring for autistic children and young people.**



**Thursday 7 November 2019 9.30am - 2.30pm**  
Bristol Aerospace Welfare Association  
**Speakers: Debby Elley and Sarah-Jane Critchley**  
**Email: ststraining@southglos.gov.uk for more details**

Follow us on twitter @autismsouthwest #ASW19

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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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**RESEARCH AND ADVOCACY:** Tim Tuff  
**MAIN COVER IMAGE:** Caleb taken by David Laslett [www.manchesterphoto.com](http://www.manchesterphoto.com)

**PRINTING:** R and P Printers, Dukinfield  
**GRAPHIC DESIGN:**

**periscopestudios**  
[www.periscopestudios.co.uk](http://www.periscopestudios.co.uk)



# Be ready for the festive season!

Your top tips from..  
**Aukids**

An idea for relatives – a themed advent calendar to be given at the start of December. Advent calendars are superb countdown charts and they also orientate autistic kids at a time when they're out of routine.

If your child loves Thomas, why not wrap their Christmas presents in Thomas paper? Lots more fun than the usual stuff!

Don't forget outdoor, water, sand and bath toys, they're often a winner for autistic kids. Mini trampolines are also a great bet.

Get their wish list out early! Relatives are bound to be stuck but if you're organised and communicate over e-mail, they won't waste their efforts.

Tired of the hassle around Christmas dinner? Keep it small and simple, and if you really want to cut the hassle, do the meal in the evening after the kids have gone to bed!

If your relatives aren't sure what to get, compatible train pieces can be a winner. It also doesn't matter if they duplicate them.

Got an iPad? Get some Apps for them! They can break up journeys to relatives or be presents in themselves. Many of our parents on Facebook swear by them. Our current favourite is the Spingo bundle of apps from [www.speechandlanguagestore.com](http://www.speechandlanguagestore.com)

If you feel your child will be heart-broken if they don't get what they were expecting, don't worry about the surprise – tell them in advance what Father Christmas can and can't get. Maybe you can tell them that Christmas money or vouchers can be spent on these things in the New Year.

Did you know that you can create your child's wish list on Amazon, and also add ideas from other sites? A fab little tutorial on this can be found at [www.thelovelygeek.com/creating-your-christmas-wish-list-with-amazon-com](http://www.thelovelygeek.com/creating-your-christmas-wish-list-with-amazon-com)

Sometimes kids who can't communicate verbally will happily point to pictures in catalogues of things they fancy. You can make a wish list for a pre-verbal child in this way.

Don't bother getting a real tree. Honestly, you could do without the mess. Think about your decorations carefully and invest in shatter-proof baubles. Or not – in our experience, baubles are easily removed and the most edible-looking of decorations. If you have a nifty-fingered child, they're probably best avoided.

Avoid hanging ornaments from the lower tree branches your kids can reach. Hang the lights out of reach so they can't get tangled (or yank your whole tree down!).

If you're buying toys that come in boxes, invest some time beforehand removing the box, unravelling annoying wires and clipping the plastic clasps. You'll thank yourself over and over when the child doesn't have to wait on Christmas morning.

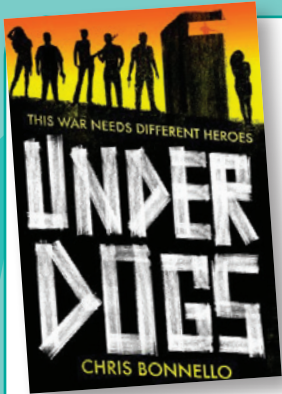
At Christmas, the awesome Poisson Rouge site (an interactive dream!) delights its users with a virtual advent calendar, with cause-effect games behind every door. [www.poissonrouge.com](http://www.poissonrouge.com)

Get batteries in before Christmas, for other people's presents as well as your own.

Worried they'll be overwhelmed? Open a present a day. Put some away and let them play with their favourites.



# Reviews & Prizes



## BOOK

### Underdogs

By Chris Bonello  
Published by Unbound  
Digital  
£9.99  
ISBN 9781789650358

Chris Bonello is a writer and speaker based in Nottingham and was diagnosed with Asperger Syndrome when he was 25. In 2015 he launched Autistic Not Weird ([autisticnotweird.com](http://autisticnotweird.com)) to share his insights on autism. He was formerly a primary school teacher and is now a speaker and also tutors students with autism and special educational needs. Underdogs is his first fiction novel.

His story is set in a dystopian Britain. It follows a small group of people, mainly teenagers from a special needs school, who have managed to avoid capture and incarceration with the rest of humankind and who now are the only hope in a war against an army of clone soldiers and those who created and control them.

Each character is unique and the author describes their differences freely and cleverly shows the different difficulties each character faces throughout their journey. As the story unfolds, you get to know each individual and their needs and see them struggle and confront their difficulties whilst also using their uniqueness as a strength when others may have only seen weakness.

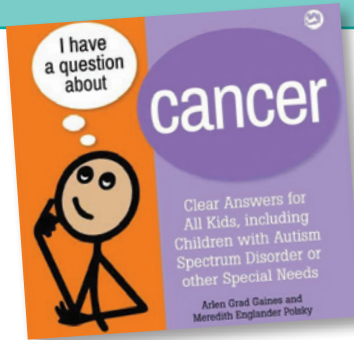
The storyline is gripping, you never know what is coming next and you genuinely feel for the characters. The story would appeal to fans of dystopian fiction novels and in my opinion is a must read for all teenagers (and adults), as it highlights diversity and helps readers to imagine how others may think and feel. The author does not shy away from the issue of special needs or what each person has to go through and gives an insight into the minds of those who have autism, ADHD, PDA and other conditions.

A gripping novel in its own right and a fantastic platform for educating everyone about how, no matter what our differences, everyone is important and valuable in society.

My 12 year-old daughter is now reading it and commented how great it is to see different kinds of characters portrayed in such a positive manner.

I understand that the sequel to Underdogs is on the way soon. I for one will be reading it to find out what happens next!

By Nicola Goodman, AuKids reader



## BOOK

### I Have a Question about Cancer: Clear Answers for All Kids, including Children with Autism Spectrum Disorder or other Special Needs

By Arlen Grad Gaines and Meredith Englander Polsky  
Published by Jessica Kingsley • £9.99 • ISBN 9781785926945

The authors of this book both have backgrounds in social work and supporting children with special educational needs and their families. One of the authors also has experience of supporting children with special needs in dealing with grief and loss.

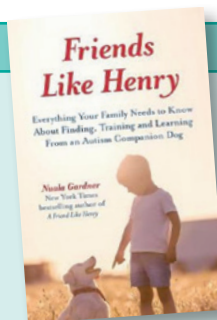
The book is designed with all children in mind including those with autism spectrum disorder and other special needs. The outline of the book is to answer questions children might have if someone they know has cancer.

The information included is based on real questions that children have asked about cancer and also the experiences that parents and carers have shared with the authors. It's split into three parts and the first two give different options of how the story can be explained. The first part - 'the complete story' - provides clear, straightforward information in text form and illustrations.

The second option - 'short picture story' - is designed for children who might understand better through the use of visual cues. Both these options are clear and concise but also informative and are explained in a way in which all children will understand.

The third section is aimed at parents and carers and provides information and suggestions on how to discuss the difficult topic of cancer with a child. Having read the book myself and also shared it with my son, who has autism, I would recommend this book. I have found it to be a really helpful tool in explaining the difficult topic of cancer and the changes it may bring to our lives. Sadly this is a topic which has recently affected our family and whilst I wish I could have read this book with my son sooner, it has still helped in explaining cancer and has answered everything he has needed to know about it.

By Laurie Davies, AuKids reader



## BOOK

### Friends Like Henry: Everything your family needs to know about finding, training and learning from an autism companion dog.

By Nuala Gardner  
Published by Jessica Kingsley Publishers • £10.99 • ISBN 9780340934029

I was keen to read this book. As a parent of a child with PDA and ASD who has a special bond with our dog, I wanted to see how we could facilitate this relationship further to support our son to access the community again and engage in activities. This book has helped us to do that by giving us the confidence in our knowledge.

Nuala is a mother to two children with autism with over 25 years' experience as a nurse. As the best-selling author of her true story, A Friend Like Henry, she talks very much from her personal experience, which helps draw you into applying her advice to your own experiences.

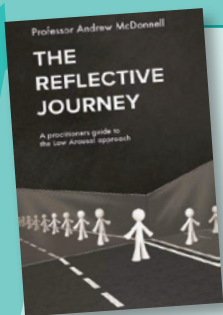
The book is mainly text. I was hoping it would have more pictures and diagrams

to help understand the techniques, however it's still an easy read with lots of examples. As we already had a dog, it was easier to understand the various stages of her programme and the importance of sticking to them. The book provides an excellent tool to help build on traditional obedience training so that you can use your dog to support your child's needs.

The book is one you can go to as an excellent reference depending on what part of the process you are at. It would appeal to both first-time dog owners but also to those wishing to specialise their dog's ability to support their young person.

By Tracy Weiner, AuKids reader





**BOOK**  
**The Reflective Journey**  
 By Professor Andrew McDonnell  
 Published by Studio 3  
 £17.99 available from  
 www.studio3.org  
 ISBN 9781916098107

Before I review this book I want to tell you a story about something that happened at my son's secondary school about a year ago.

Bobby was sitting at a computer during a PE theory lesson when his friend was told off for looking up something that was nothing to do with the lesson. Bobby 'went off on one' at this perceived injustice. There were many reasons why he exploded, not all of them obvious, but the point here is how the teacher reacted.

Instead of having a show-down during the lesson and making a bad situation worse, or punishing him for an outburst he had difficulty in controlling, the teacher found a remorseful Bobby on his own, squatted by him and said: 'I'll level with you. I wasn't expecting that at all. I didn't know quite what to do'.

This encouraged Bobby to reflect far more productively on his own reactions and their causes. After that, they worked together to prevent a similar situation.

This is an example of the Low Arousal Approach advocated in Professor Andrew McDonnell's new book, *The Reflective Journey*. The reason it's used at Priestnall, my son's mainstream secondary, is because the author is a close colleague of the school's Curriculum Support Director Gareth Morewood, also an advocate of it. In fact, Gareth is now on secondment to Professor McDonnell's company Studio 3, from which he is teaching this approach to education organisations internationally. I'll always remember a talk of Gareth's in which he said he was physically separating a fight between two autistic pupils and one of them spat at him. 'I could have said 'How dare you! Don't you know who I am?' Instead, I reflected on why we'd let this autistic pupil's arousal and anger get so high that he felt that was his only option'.

This book is not primarily written for parents but for care organisations, in particular residential settings where staff are face to face with potentially

threatening behaviour from adults on a daily basis. There's still a lot for parents to learn from it, even if you aren't 100% its target audience.

Its content is hinted at in the title 'The Reflective Journey'. Most books focus on the source of the 'difficult' behaviour, treating the recipient of it as more or less invisible. In this book, the author, a clinical psychologist and originator of the Low Arousal Approach, dedicates his first nine chapters to the reader, the way that they experience anger, fear, stress and empathy and their reactions to challenging situations. You'll be asked to do some real soul-searching, fill in questionnaires and to recognise the part you play in any interaction. As Andrew says: 'If we are part of the problem, then we are part of the solution'.

Some readers might get impatient that the author doesn't 'cut to the chase' and quickly issue some off the shelf advice on how to cope with someone hitting you. But in order to adopt the Low Arousal Approach, explained from Chapter 10, you firstly need to be self-aware. This doesn't come without a bit of homework.

One of the key principles guiding this approach is that everyone with special needs is entitled to dignity and control even (and sometimes particularly) when their behaviour appears to be threatening. In fact, it's the loss of both that often exacerbates a situation. Professor McDonnell guides readers through the reasons why punishment and restraint is both undesirable and ineffective, not as an 'ivory tower' professional but as one who has worked in the heart of care systems for most of his career.

When talking about giving consequences, he says: 'There is little doubt that success can be achieved to a certain degree by using external regulations, but the goal should be to help people regulate their own behaviour not to attempt to control it through external measures'. Numerous case studies provide illustrations of his point.

I hope this important guide will convince organisations and schools to rethink their entire approach, educate staff in better ways of understanding those in their care and prevent the kinds of hideous abuse that have come to light in recent years.

By Debby Elley,  
 AuKids co-editor

# WIN Your Own Tree Decorations!



Why do we love Jumping Clay? It's messy play without the mess! No need for an oven – this air drying clay makes a finished model within 24-48 hours. This jasmine-scented, soft, light and eco-friendly modelling clay is perfect for sensory play. It has a silky texture and can be easily blended together just like paint. Available in eight bright and intermixable colours. Your model will gently bond together without the need for any adhesives.



**We're giving away two Christmas decoration kits to one lucky AuKids reader.**

Create your own Santa and Friends Christmas tree decorations this festive season and add The Angel Trio kit, too. Comes with everything you need, including illustrated step-by-step instructions. Recommended for children aged 5+.

You can also watch how to make both of these kits using these tutorials:

- Guardian Angels: [youtu.be/E2cl8\\_zMUoI](https://youtu.be/E2cl8_zMUoI)
- Santa & Friends: [youtu.be/lmj5vXJXsRk](https://youtu.be/lmj5vXJXsRk)

For more modelling fun and to buy one of the kits yourself, head to [www.jumpingclay.co.uk](http://www.jumpingclay.co.uk)

To enter the competition, all you have to do is find one of our Jumping Clay Santa friends hidden in this issue. Send the answer to [aukidsmag@gmail.com](mailto:aukidsmag@gmail.com) with your name and address and 'santa' in the subject header, no later than the closing date of November 30<sup>th</sup> 2019.

By entering this competition you give permission for the winner's address details to be sent by AuKids directly to Jumping Clay purely so that you can receive your prize. No other third party will be informed.



Happy modelling!





# THE SEARCH FOR THE HOLY GRAIL

**W**hen you're told your child has autism, you might feel a bit stunned. After that, it may well seem as if it's all hands on deck. Not everyone else's hands, though, they don't seem in any hurry. No, it's you who are constantly reading, researching, ringing... trying to find some answers. So why isn't anything happening fast enough?

ONE parent we spoke to, whose son is now ten, remembers the early days: "You think that every second counts. It's understandable – the diagnosis of autism is a big deal and you feel such a responsibility. But when services aren't always quick to slot into place and you feel slightly helpless and lacking in knowledge, that wait can seem endless."

## **D**arn it, where have they hidden it?

There's also a sense that someone, somewhere, has all the answers, but they just aren't telling you.

## **W**ho has the answers?

There may be a tendency to see your paediatrician as the be-all and end-all at first. Well, they are the consultant in all things to do with childhood – they'll know what to do, right?

In fact, although your paediatrician may be initially responsible for diagnosing the autism, they are essentially a point of contact, a crossroads at which all your other professionals link up. They're also the source from which referrals are made, and the buck stops with them if professional services are not forthcoming. They aren't the person who has all the answers by any means, certainly not when it comes to practical daily strategies.

Part of finding some answers is gaining a proper understanding of

what all of the professionals connected with autism actually DO and also what you can do yourself. Professional job titles don't speak for themselves and can even be downright misleading.

Take the SLT (Speech and Language Therapist). The logical assumption is that a speech and language therapist can make your child speak. We've witnessed stutters being corrected in films like *The King's Speech* – why not the rest?

In fact, no-one can teach a child to speak when their brain isn't yet ready for it. There's plenty to be done, but verbalising itself is the icing on the cake when it comes to autism. The 'Holy Grail' in this case simply consists of a long and persistent journey.

A SLT will teach you ways to encourage the development of language in your child. Language, we need to be clear, refers not just to verbal skills but to those required to process and understand words (which can be really difficult for kids with autism) as well as to communicate with others – whether it's through signs, gestures, pictures, words or 'objects of reference' (showing them an object or part of an object to represent something else, eg. car keys to mean going out in the car).

These alternatives don't replace speech (a common misconception) but encourage it through understanding its purpose and

practice, so that when speech begins to emerge, kids are ready to use this appropriately.

When intentional sounds start to happen, then the speech and language therapist can focus on helping a child to practise, retain and perfect them.

## **W**hat's Occupational Therapy?

How on earth do you know if your child needs an O.T. – (Occupational Therapist) when no-one has told you what one does? If you didn't know, you'd probably assume that these professionals helped with 'life' skills. That might be last on your list when faced with behavioural challenges on a daily basis.

For a child with autism, occupational therapy means much more than that. Occupational therapy can help them to balance their sensory needs so that their nervous system can cope with processing all the input it gets.

Sensory processing difficulties are often the cause of unusual behaviour in autism. Kids who are hyper-sensitive to sensory input may find some sounds, smells or sights quite disturbing and overwhelming. Or, your child may be under-sensitive to sensory stimulation, and some of their behaviour may be a result of that.

Brains have clever ways of compensating for confusion, and so there's usually a reason for 'odd' behaviour. Occupational therapists can help you to decipher these reasons and, through a programme which is sometimes called a 'sensory diet', can help give you and your child strategies that will help 'balance' them out.

We all learn to balance our sensory needs through external input. After a long day, you might take a bath or have a hot drink (or something

## AuKids Tips For the Best Start to Your Journey:

**1 Acceptance:** To autistic children, people can be overwhelming. They need to learn to trust us. Acceptance is a big part of that. The more relaxed the child's environment, the more relaxed they'll be. Kids with autism are a bit like sponges when it comes to picking up on your 'vibes'.

**2 Look at what bothers them:** Try to understand what they don't like about their environment, even if it seems harmless to you. The less they battle with sensory issues, the more brain power is available for development and language.

**3 Have fun!** If an adult sits with you with a serious face and seems adamant that you do something 'just right', then pretty soon you will probably avoid that adult. So relax and enjoy whatever the child's doing, even if it doesn't seem that purposeful. For guidance, have a look at our DIY Communication Guide in our Starter's Special or look at the books at the end.

**4 Take it easy:** There is no deadline, despite what you may have heard. Individuals with autism are constantly blossoming. The notion that they have to speak by five to speak at all is a myth.

**5 Small steps lead to large ones.** Co-editor Debby says: 'Ten years ago Alec wasn't communicating at all. Several years on he carried bananas upstairs to tell me he wanted one. Now, he communicates using sounds, signs, gestures, pictures and an electronic talkboard. Progress only ever seems dramatic in hindsight.'





stronger!). If you're having trouble staying awake for a meeting, you may jog your feet or twiddle a pencil to keep yourself alert. We've all learned to control our level of alertness and our nervous system by doing these things automatically. An occupational therapist teaches our kids how to control their nervous systems on a grander scale using physical activity to calm or to alert them.

## But why does all this seem to take so long?

The word 'intervention' is also very misleading! It implies that some wise chemist somewhere is bottling up a giant concoction which once consumed will solve all your worries.

Intervention unfortunately can't make miracles happen. That doesn't mean to say it's not effective, though. These strategies lead to tiny but significant changes that will help your child's development. In the early stages a great deal of patience is required, because those changes may not immediately seem apparent to you.

Most of us are aware of the stages of ordinary development – we are used to sudden leaps. With autism, changes are far more subtle. As a parent, you learn to adjust your expectations and look at communication with a magnifying glass so that you are noticing key changes. If you're new to autism, it can take time to see things in this light and may at first feel a little dispiriting.

But keep the faith. Another mum tells us: "Day after day I'd wave to him as he left on the school bus. We'd also clap hands with him all the time. Nothing. This went on for years. Then when he was about eight, he started to wave and clap.

"It could well be that physical hobbies like cycling on a trike and swimming had improved his gross motor skills, which enabled his brain to focus on fine motor skills. Combine that with a lot of signing time at his special school and a growing awareness of social skills and their signals...it all went into one big melting pot. So much had to slot into place before it happened. You never know what your input now might achieve in several years' time, even if it doesn't seem that much is happening."

## What about those therapy programmes I've heard about?

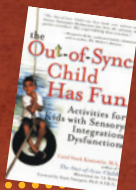
If there really was one programme that had fantastic results for all kids with autism, you'd be told about it. There are plenty of therapy programmes, and many have strategies in common. They may have great results for some, but not for all.

We do advise you to become familiar with the techniques that suit your child before honing in on any single approach. For more

information on weighing up the science, check out our Starter's Special issue (see below). Research Autism\* at [www.researchautism.net](http://www.researchautism.net) is also dedicated to sifting out the outlandish claims from the scientific reports worth looking at.

## GREAT BOOKS

**The Out-of-Sync Child Has Fun:** Activities for Kids with Sensory Integration Dysfunction by Carol Stock Kranowitz

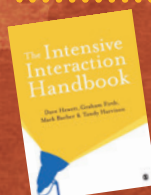


**RECENTLY UPDATED Ten Things Every Child with Autism Wishes You Knew** by Ellen Notbohm

**Choosing Autism Interventions: A Research-Based Guide** by Bernard Fleming, Catherine Ansell-Jones, and Elisabeth Hurley.

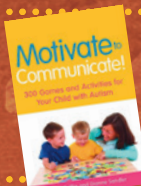
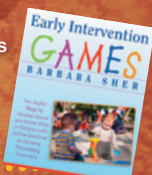


A definitive round-up to choosing autism-interventions, with the safety and success of each one evaluated through a summary of the available science.



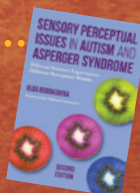
**The Intensive Interaction Handbook** by Dave Hewett, Mark Barber, Graham Firth and Tandy Harrison

**Early Intervention Games: Fun, Joyful Ways to Develop Social and Motor Skills in Children with Autism Spectrum...** by Barbara Sher



**Motivate to Communicate** by Simone Griffin and Dianne Sandler

**NEW EDITION Sensory Perceptual Issues in Autism and Asperger Syndrome** by Olga Bogdashina



**AuKids Starter's Special** can be purchased at [www.aukids.co.uk](http://www.aukids.co.uk). A guide to what's inside our Starter's Special can be found on our website.



New instructional short films aimed at parents and carers of disabled children have been created by disability charity Family Fund, to help their children use devices safely and to their full potential.

Lasting around two minutes each, the films cover the basics on setting up devices, managing parental controls and online safety. There are also three dedicated films for families with disabled children addressing how to customise accessibility features to meet touch, vision and hearing needs.

Family Fund, which is the largest grant-making charity for disabled children from low-income families, provided over 12,000 grants for computers or tablets last

year and offers free digital skills training to parents and carers.

Alison Davies, Head of Service Delivery at Family Fund said: "We know that tablets can be a fantastic support to disadvantaged or disabled children across communication, behaviour and engagement with education. But our families also told us that they need help and support to ensure they are used safely and to their full potential".

The films are available on Family Fund's You Tube Channel at [shorturl.at/kzX01](http://shorturl.at/kzX01) Read more about the Family Fund, where you can also apply for grants, at [www.familyfund.org.uk](http://www.familyfund.org.uk)

# EVERYONE CAN

We are a charity that specialise in technology for disabled people. Through training & assistive technology, we help disabled people speak, live independently, control their environment & have fun! We have a range of free services at our centre, get in touch to book an assessment, book onto our disabled gaming sessions or arrange a technology workshop!



Everyone Can Technology & Gaming Centre, 25 School Road, Sale, M33 7XX

[www.everyonecan.org.uk](http://www.everyonecan.org.uk) [contact@everyonecan.org.uk](mailto:contact@everyonecan.org.uk) 0808 800 0009

[@everyonecan.org.uk](https://www.facebook.com/everyonecan.org.uk) [@everyonecanuk](https://www.twitter.com/everyonecanuk) [@everyonecanuk](https://www.instagram.com/everyonecanuk)

\*The Research Autism information is now one of the services offered by the National Autistic Society (NAS)



## THE ANXIETY DEMON

My name is Jo Richardson and I am an autistic with a PDA profile. I have a four year-old son who is autistic with Global Development Delay and also an autistic husband!

I am a fierce autism advocate and co-run an autistic mothers' group on Facebook. My aim is to help others understand more about autism and the best way in which to help and support our children.



I have always been different, although I did not understand why until I was diagnosed last year as being autistic, as my son started his autism assessment.

Among other aspects of being autistic, one that has always affected me strongly is anxiety.

Anxiety is like having a voice in your head whispering all the things that can go wrong in any situation and not having the means to shut it out. For some of us, anxiety is part of daily life; there's a constant battle to overcome it, sometimes to do even the simplest of things.

People often believe that anxiety is situational or only happens during stressful periods. This isn't entirely the case. Like a lot of autistics, I overthink everything and replay conversations and events in my head on a constant loop while my anxiety demon is chastising my choices, actions or social interactions, making my anxiety peak.

My 'Anxiety Demon' convinces me that I have made a fool out of myself, that I've been misunderstood or that I've made a mistake. It makes me dread being in these situations again in case I repeat history.

When faced with new situations or social events, our 'Anxiety Demon's' voice grows louder, demanding our full attention, overwhelming all other thoughts that we are trying to process.

"What if it's too loud and there are too many people?"

"What if I get overwhelmed?"

"When will I be able to leave?"

"What if I say something stupid?"

"What will I be expected to do or act like?"

"What's going to happen and when?"

"Will people dislike or laugh at me, thinking that I'm weird?"

These are just some of the things that my Anxiety Demon says to me when I consider socialising or going somewhere new.

As an adult, I am able to manage my anxiety to an extent; I have worked out what situations I need to avoid, what I can do to prepare for new situations and how to self-regulate.

.....  
**"When I returned to the safety of my house, all of the anxiety and overwhelm from the day would explode out of me."**  
.....

Our children do not have this experience yet. Most young children do not understand what they are feeling or why, so they need us to be able to read their signals and understand when and why their anxiety is high and, most importantly, how to help them manage it.

At this time of year, our children are probably experiencing a high level of anxiety having either started school or advanced a year.

So many aspects are out of their control as well as having both educational and social demands put on them continuously, that it can trigger demand avoidance in a situation where they cannot easily avoid these demands.

The first year of school can be so daunting for any child, but more so for autistic children. It may be their first time away from being at home with a parent or carer full-time. Everything is new, they don't know the environment, they don't know what is expected of them, whether they'll get overwhelmed, what the other children will be like, whether they'll make friends or if they will fit in.

Consider for a moment that you are facing all of these things and your 'Anxiety Demon' is constantly whispering that it will all go wrong, that you won't cope, that no one will like you, that you'll fail.

When I was at school, diagnoses weren't commonplace and the schools weren't as quick to recognise the struggles that autistics experience as they are nowadays, so it was a case that I had to try to manage my anxiety myself.

This took the form of leaving classes as soon as they finished so that I could spend some time on my own in a quiet bathroom before rushing off to the next class as well as spending break times and lunchtimes alone and away from everyone else in the playground.

When I got home, I would spend all of my time alone in my bedroom immersed in video games that I could escape into; blocking out reality and all other stimuli for a while. This would quieten the Anxiety Demon, as I was focused so heavily on the game that I couldn't hear it as much.

Without doing this, I would often spiral into meltdown or would lash out at family members because I had, unknowingly, been 'masking' all day (hiding my anxiety and differences to my peers). So when I returned to the safety of my house, all of the anxiety and overwhelm from the day would explode out of me.

Nowadays there are many different tactics, equipment and toys that can help autistic children manage and cope with their anxiety, as well as different methods of signalling to others that their anxiety is high and that they're not coping. I would have found these invaluable when I was young.

Most of all, though, I'd like to pass this on: it's important to remember

that an anxious or overwhelmed child is incapable of learning effectively. They are not able to process all of the information they are being given. Therefore, it is imperative that measures are taken in order to help them to regulate their anxiety and overwhelm while at school.

*Editor's note: Jo refers to herself as 'autistic' and autistic people as 'autistics'. We recognize that different people prefer different terminology, and we've left this personal piece to her preferred style.*

### FURTHER INFORMATION

#### Links to Jo Richardson's work

- [www.oddlyautistic.com](http://www.oddlyautistic.com)
- [www.theaspergian.com](http://www.theaspergian.com)
- Jo Richardson's Facebook group is called The Sanctuary (A Safe Space for Autistic Mothers)

#### Books

Raelene Dundon's latest book, *A Parent's Guide to Managing Anxiety in Children with Autism*, on Page 4 is highly recommended by AuKids and has just been released.

Dawn Huebner, author of *Outsmarting Worry*, gives further guidance on managing anxiety on pages 12 and 13.





## Here Come The Girls!

On the cover of Issue 43, Christopher posed with his chicken Gloria. Unfortunately the following month, Gloria and the other hens were killed by a fox. AuKids stepped in and donated to the Hen Welfare Trust, where Christopher's mum Julie collected three new hens, which Christopher named after the AuKids team. Meanwhile Christopher's dad Shaun built a luxurious new hen coup which gives Fort Knox a run for its money.

Maybe these girls will work on their own publication, like the Tel-egg-graph? Groan...



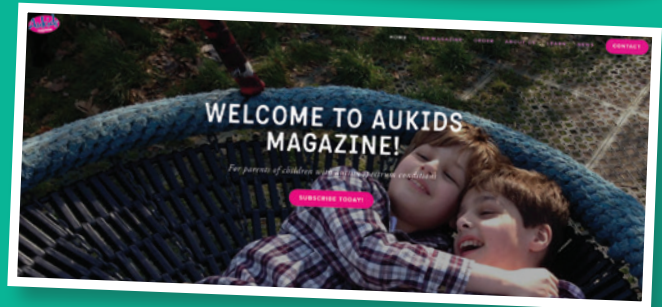
Jo, named after our graphics star, is curious about shape and colour, just like her namesake.

Tori, co-editor, likes a drink (no comment)...

...and co-editor Debby is just a big show off.

## NEW WEBSITE HAS LIFT OFF!

As we go to print, our new website at [www.aukids.co.uk](http://www.aukids.co.uk) is ready to launch. On it, you'll not only be able to download all past issues easily, you'll also be able to search them by topic. Plus, if we still have any left in print, you'll be able to buy them, too. For the first time our Starter Special is now available as a separate purchase for £5. Plus, you can easily renew online without the use of a username and password, they aren't required anymore. Don't worry – we'll know who you are!



The new site also has background to the AuKids team and all the experts who contribute to the magazine. There's some handy links too, to our books. Have a little shuffy around it, we are sure you'll be impressed.

 Any questions, please just write to us at [aukidsmag@gmail.com](mailto:aukidsmag@gmail.com)



Our Pass the Pearls feature from issue 6 was a great success

## We Need Your Gems!

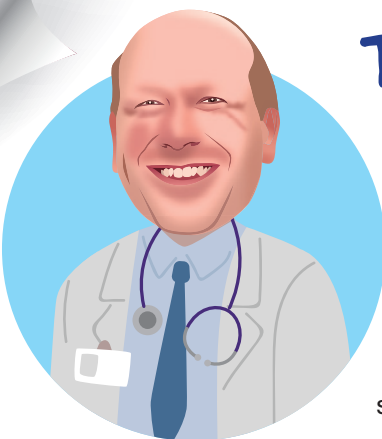
We want to hear little 'pearls of wisdom' from those parents whose children were diagnosed five or more years ago. Looking back, what single piece of advice would you give to parents of children who are newly diagnosed? We've done this before and it was a great success. Send your 'pearls' of 40 words or less to us at [aukidsmag@gmail.com](mailto:aukidsmag@gmail.com) no later than November 30<sup>th</sup>, with the name you'd like printed in the magazine to go alongside it. You can remain anonymous if you choose.

## Do You Home Educate Your Child?

AuKids is going to publish a feature starring parents who have decided to educate their children in this way. You'll need to complete an email interview and supply us with a photograph of yourself home educating your child/ren for use in the magazine. Interested? Contact [aukidsmag@gmail.com](mailto:aukidsmag@gmail.com)







# Time for Your Check-Up!

## Making medical appointments autism-friendly

Tim Tuff is an adult with autism who volunteers with AuKids magazine. Tim has sensory processing difficulties and plenty of experience in using hospitals and GP surgeries. We asked him what these places could do to make medical trips less stressful. Then we added a good dose of AuKids advice for parents. We hope you will pass this feature on to your hospital or surgery – let's help them all to be more autism-friendly!



## Environment

### Lighting

Hospital lighting is not usually helpful for autistic people, as it can be quite painful. With overhead bright lighting of the type used in hospitals, you may not be able to see that there is a slight flicker, but autistic people are generally very aware of this. It can give us a headache and increase our stress.

Sensory overload is a trigger for meltdowns or shutdowns.

#### AuKids tip:

*Be aware of temperature and lighting; if you think it may be a problem and you know how long you'll be waiting, walk around outside if possible ahead of your appointment, letting the receptionist know why. Quiet rooms are sometimes available.*

### Other visuals

Autistic people have very vivid visual imaginations – disturbing or distressing images on posters stick in our minds for a long time.

### Sounds

Something that never gets noticed in public places is hand dryers. It would be much easier if all hospitals had some paper towels as an alternative.

#### AuKids tip

*Bring a small towel with you and use the disabled toilet, they are larger and so it's easier to avoid the space around the hand*

*dryer and not accidentally set it off. Radar Keys for disabled loos are available cheaply from Amazon.*

### Smells

Cleaning smells can be strong enough to trigger distress. The feeling of hand gel is also sometimes disturbing to autistic people who are used to cleaning by washing their hands – the 'wrong' feeling of this can be upsetting.

#### AuKids tip

*If your child is anxious, now's not the time to try something new! Take your child to the toilet to wash their hands instead of using gel for the first time.*

### Waiting

At one of the hospitals I go to, there's a little flag on the computer that alerts the reception that I'm autistic and I can't wait too long. That would help a lot at GPs, too.

#### AuKids tip

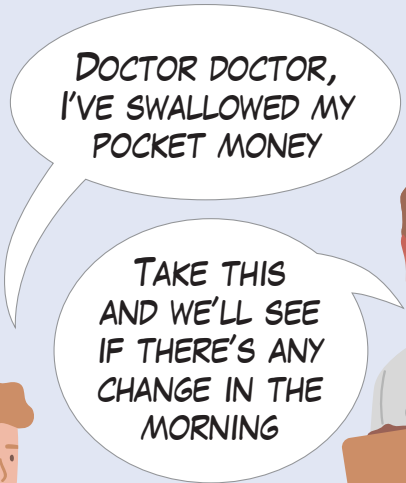
*Talk about waiting when you book the appointment to avoid it where necessary and remind the receptionist you have an autistic child when you arrive. Ask how long the waiting time is. It's far better to do this than to wait until you can't handle the situation any longer.*

### Rules

Some autistic people rely on electronic devices such as their phones or iPads to keep them distracted from a stressful situation. If all electronic equipment must be switched off, it's important to warn them before or to make exceptions where possible.

#### AuKids tip

*If electronic devices are allowed, we love Cognable's Sound and Light Show app; a mini sensory room on the go. It's always a good idea pack something small, exciting and new, like a sensory toy, especially for difficult trips where waiting may be involved. Or download something new on your child's iPad just beforehand.*



DOCTOR DOCTOR,  
I'VE SWALLOWED MY  
POCKET MONEY

TAKE THIS  
AND WE'LL SEE  
IF THERE'S ANY  
CHANGE IN THE  
MORNING





## People

### Crowds

If there are too many people in reception it makes me feel closed in and a little nervous.

#### **AuKids tip**

*Don't worry about other people's reactions to your child's noises or movements. If they want to move about the waiting room, let them. Restricting your child and keeping them totally quiet and still will not only be impossible, it will be draining for you and they'll pick up on your anxiety. So relax – as long as they're not hurting anyone, let them explore the space around them.*

### Announcements

When a member of staff shouts your name, it's quite intimidating – a lot of autistic people have that link with school and they feel they're in trouble!

Alternatives that I like are LED screens that display the next name (no adverts please – it's confusing!), or a deli-style number system so that a number is called out rather than a name.

The deli-style number system is also very good for autistic people as it gives them a good indication of where they are in the queue and how long they might have to wait.

When medics wear masks (such as at the dentist's) it's very intimidating – it would be good for them to introduce themselves without the mask on first so that we can see their full faces.

### Responses

We ask a lot of questions! Questions are just our need for reassurance – we aren't trying to test our doctors!

We can stare a lot if we're nervous. You should ask if we're okay or if we have anything we're worried about.



## Processes

### Preparation

Things hurt more if we're not calm! I'm more relaxed if the doctor knows what I'm interested in. For instance, my doctor says 'I've put you in this room because I know you like watching the trains going past'.

Ninety per cent of autistic anxiety can be taken away just by good preparation. Knowing what is about to happen and how long it will take is very important.

Preparation doesn't just mean showing you equipment, but how it's going to be used. So, photos should show someone using the equipment, or a video.

Also, it's important to include reassurance on whether something will hurt (if so for how long!) and how long it will take.

#### **AuKids tips**

*Prepare your child beforehand with small explanations and visuals. If possible, a photograph of the specialist you're seeing can help, too.*

*Before a regular trip to a paediatrician, your child will be weighed and measured. You can demonstrate it yourself if it makes them nervous. Sometimes the height-measuring board can seem restrictive and even scary as it lands on your head! Show them it doesn't hurt.*

### Equipment

We notice things more than other people. So, if you have a tray full of equipment, but not all of it is to be used, we need to know!

And we like to know what things are used for.

Or, just keep out of sight what you don't need! Otherwise we assume you have a tray of torture equipment!

### Slow down

Don't just 'do' to us! Autistic people need to see equipment, hear about it, have it demonstrated, maybe even handle it...then we are ready to get close to it!

For example, the tube that sucks water from your mouth in the dentist – I am given control of that.

#### **AuKids tip**

*Don't be shy of asking a dentist to put your child in more control of equipment. Speak to them before the appointment.*

### Restrictions

Before you ask someone to wear something, check they are okay with it. Bear in mind that restrictive equipment, such as in eye tests, where there is no escape, can make autistic people feel extremely panicky, so reassurance is very important.

### Questions

If you are asking for a quick response on whether something feels better or not, you may not get a quick answer! It's important to leave processing time. It's also important to say 'there is no right or wrong answer'. Eye tests for instance, can feel like an exam.

## Further Information

- Tim Tuff provides this information as a half hour talk. If you're interested, contact us at [aukidsmag@gmail.com](mailto:aukidsmag@gmail.com)
- Look up this advice from the National Autistic Society: [www.autism.org.uk/about/health/doctor.aspx](http://www.autism.org.uk/about/health/doctor.aspx)
- If your child is anxious, enquire at your usual dentist about being referred to a specialist one, where dentists are trained in examining children with autism.
- This YouTube video shows you what to expect from the dentist: [www.youtube.com/watch?v=HEIZWBDaxCU](http://www.youtube.com/watch?v=HEIZWBDaxCU)



Avoiding  
the

# WORRY Dance



A quick glance at AuKids over the last 10 years shows that Dawn Huebner's 'What to do When...' series of books have never been far from a mention. They are clear, fun and creative, cleverly helping autistic children to form helpful mindsets in approaching daily challenges.

We've had many readers write in asking for help about their child's anxiety. Who better to tackle this, then, than our favourite children's author? Dawn's latest guide for older children, *Outsmarting Worry*, is a fantastic resource for kids who can read by themselves (it's really visual, too!)



Dr. Dawn Huebner is a clinical psychologist specializing in the treatment of anxiety. Her nine skill-focused books have been translated into 23 languages, while her TEDx talk has been viewed over half a million times. Dr. Huebner delights in guiding young worriers and their parents toward happier lives.

## Q: What are the most common mistakes that parents make in dealing with their child's anxiety?

A: There's one particularly common mistake that parents of all children – autistic or non-autistic – make; they overly accommodate the anxiety.

This is done, of course, with the best of intentions. It's hard to see our children suffering, and nature has designed us to protect these young beings entrusted to our care. So, we comfort and reassure. We step in and take over. We foster avoidance and provide more support than is needed.

And then we get stuck in these ways of responding and start participating in a sort of dance, in which we immediately rush in to fix or relieve our child's distress.

This pattern comes from a place of love – coupled with a wish to avoid colossal meltdowns – but it is part of what sets anxiety in cement. We'll talk in a moment about what to do instead.

Another common mistake is to misinterpret anxiety as bad behaviour. Anxious children – both those on the spectrum and not – are notoriously resistant. They dig in their heels. Their behaviour gets wild. It would be easy if they just said, "I'm nervous," but often they don't. They act out their discomfort, instead.

Just as it is a mistake to accommodate anxiety, it is also a mistake to punish it. The goal is to find ways to support your child without supporting their anxiety. Keep reading. We'll get to how.

## Q: Why are autistic kids so susceptible to worry?

A: Studies estimate that up to 40% of children with Autism Spectrum Disorders also meet criteria for an anxiety disorder. That's huge. But while parents are often aware that their children are struggling, it can be difficult to tease out what is autism and what is anxiety. That's because many of the behaviours associated with anxiety are part-and-parcel of autism. Take repetitive behaviours. They are common among autistic children but can also be a sign of Obsessive-Compulsive Disorder (OCD).

Sensory sensitivity is another factor. Specific phobias – intense, irrational fears of something that isn't actually dangerous – sometimes grow out of over-responsiveness to sensory stimulation. A child sensitive to sounds, for example, might develop a phobia of automatic

toilets, or boats, or balloons, all of which make noises in unpredictable ways.

Social Anxiety might develop as a child with high-functioning autism becomes more aware of their own social difficulties, triggering a fear of judgement and rejection.

It is important to understand the interweaving of autism and anxiety, to tailor interventions to the needs of a particular child.

## Q: Is it important to develop early strategies to deal with anxiety?

A: Prevention is always key. And short of prevention, recognizing and treating anxiety in its earliest stages is best. When left un-addressed, anxiety snowballs and becomes an habitual way of responding. It gets wired into the brain. Yikes! So, what can parents do?

## Practical steps parents can take to help their anxious child:

**1. Label worry** Anxious children often have trouble with emotional literacy. They might not know that the jittery, agitated way they feel – complete with racing heart, shallow breathing and sweaty palms – means that they are scared.

**2. Externalize anxiety** This step can be tricky with autistic children who have trouble with abstract thinking, but you can talk about worry as if it's a little, personified being. A small gremlin or bug. Name it.

Tell your child that we all have a pretend creature like this, a creature that tries to protect us. But sometimes this worry-creature makes mistakes and alerts us to DANGER that doesn't exist. You and your child will be working together to spot this worry-creature and help it to become more accurate.







WIN

## Outsmarting Worry by Dawn Huebner

Published by Jessica Kingsley Publishers

We have copies of *Outsmarting Worry* to give away to three lucky readers before Christmas! To be in with a chance of winning, just answer this question. What plant is on the cover of *What to Do When you Worry Too Much?* You'll find the answer at [www.dawnhuebnerphd.com](http://www.dawnhuebnerphd.com) books-by-dawn Send your answer no later than November 30<sup>th</sup> by emailing [aukidsmag@gmail.com](mailto:aukidsmag@gmail.com), with DAWN in the subject header.



### 3. Explain false alarms

Teach your child that when the worry-creature pulls the DANGER alarm, his/her brain assumes that the danger is real and quickly springs into action, doing what it needs to do to keep him or her safe. That's why your heart speeds up and your muscles feel twitchy. It's why your stomach hurts and your breathing changes. Your body is preparing you to fight off or run away from the danger. But the danger alarm sometimes gets pulled by mistake. That's called a false alarm, which we'll talk about in Step 4.

But first, it is also important to know that when the internal danger alarm gets pulled, the thinking part of the brain shuts down. The best way to turn thinking back on is to do a breathing or other relaxation activity that has been *practised in advance* (the importance of practising in advance cannot be overstated).

### 4. Hunt for evidence

Once your child is calmer (see above), you can begin looking for evidence with them. Is there a real danger, or is this a false alarm? Teach your child to stick with facts (versus feelings). A simple question such as, "Do I feel this way because this situation is *new*, or do I feel this way because it is *dangerous*?" can really help. A related question, for kids with sensory sensitivities: "Am I nervous because I am uncomfortable or because I'm in danger?" Newness and discomfort are different from danger and can be managed in different ways.

### 5. Avoid avoidance!

This is one of the most important steps in helping children better manage anxiety. Most of us would prefer to avoid the things that make us nervous, but avoidance locks worry in place. Instead, children can be taught to approach the (safe) things that scare them, just a small step at a time.

The mechanism here is the same

as those that allow us to get used to the cold water in a swimming pool. We lower ourselves into the water, and stay in it, and eventually we stop feeling the cold. Work with your child to practise approaching feared situations. Make the approach gradual. Keep it playful. Project confidence in your child's ability to manage.

### 6. Support your child...

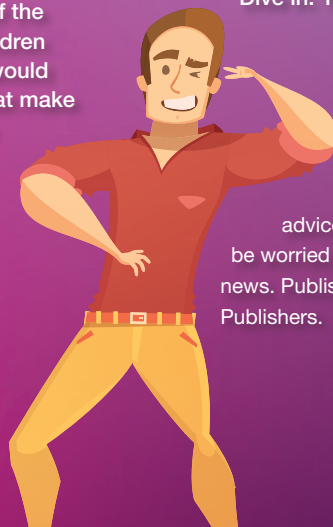
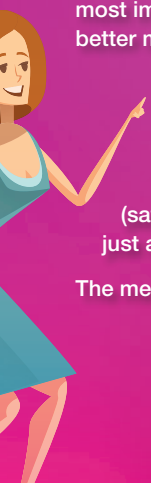
without accommodating worry. This is a skill and like all skills, there will be a learning curve. What you are trying to do is to separate your child from their worry. Understand that your child is genuinely nervous or scared – they aren't faking this, and they can't just snap out of it. But also know that when you give in to the fear, you are strengthening it.

Say things like, "I know your worry (that personified worry we talked about earlier) is making this seem dangerous, but let's remember what happened last time." Or "Let's not let worry be the boss of this!" Teach your child the skills they need, and then help them to use them. Be patient. Be kind. Maintain a sense of humour. Think in terms of incremental steps – see our side column for an example.

Anxiety is treatable. There are recent studies suggesting that children don't need to be directly involved in therapy to show marked improvements as long as parents understand the mechanisms surrounding anxiety and are working to help their children develop skills.

Dive in. You can do it!

.....  
Dawn's new book **Something Bad Happened** is full of advice for children who may be worried about events in the news. Published by Jessica Kingsley Publishers.



## Tackling Anxiety

### Small 'steps' to success

Imagine your child is afraid of bees. You might move them through the following progression:

- **Day 1:** Look at cartoon drawings of bees. Have your child repeat, "Bees are busy gathering nectar. They aren't interested in me!"
- **Day 2:** Look at realistic pictures of bees. Repeat the mantra.
- **Day 3:** Watch animated cartoons of bees. Repeat the mantra.
- **Day 4:** Watch realistic videos of bees. Repeat the mantra.
- **Day 5:** Go on a bee "photo safari", having your child try to capture pictures of bees from afar. Repeat the mantra.
- **Day 6:** Be detectives, checking out places where bees like to hang out. It's okay to do this from afar, but ham it up. Give your child detective shwag like a magnifying glass and notebook! Repeat the mantra.
- **Days 7 and 8:** Go on another photo safari and detective mission, getting closer to the bees.
- **Day 9 and onward:** Keep building on these activities, pairing them with the mantra, getting closer and closer to bees. You might have your child do an experiment to see which flavour of melted popsicle bees like best. You might have them study the differences between various stinging insects.
- **Do bee activities every day.** You might need to repeat an activity several times to help your child get more used to it before moving to the next step. Keep in mind that success is measured not by the absence of fear but by managing the fear and doing the activity anyway. Use the language your child is learning, "*Looks like worry pulled your danger alarm just now.*" "*Let's look for evidence so we know if the bee is interested in us, or if he's just searching for nectar.*"





“ Sometimes when I try to persuade my son to do something he doesn't want to (but has to), he kicks me. He seems to be okay until that point, so it comes from nowhere. He is always sorry afterwards. At home is one thing, but when we are in public it's pretty mortifying. What can I do? ”



**SILVER SERVICE:** Although it was unavailable at Debenhams and it made going to the toilet rather inconvenient, Denise felt she had found the perfect outfit for getting her son up in the mornings.

## Top Tips from Aukids

- 1 Pick your battles. Think of your child as having an 'anxiety bucket' which is constantly three-quarters full because of their autism. Every request that starts with a verb adds to that anxiety bucket. Alternatively, using phrases like 'Have you thought of...?' And 'What could we do here...?' is not necessarily the quickest route, but it's far better than tipping the bucket into overflow.
- 2 Note how you make a request and whether it sounds like an imperative. Save the imperatives for crucial demands and rephrase the rest to sound softer. 'Go to the bathroom and get your toothbrush' can be rephrased as 'Did you remember to clean your teeth? No? What do you need to do then?' Two advantages here. Firstly, the request isn't as anxiety-provoking. Secondly, rather than doing all their thinking for them, you're helping them to make their own judgements and decisions.
- 3 Warn them. If you are going to be in a situation which demands something from them, tell them in advance. 'We are going to have to leave at 3pm because that's when our session finishes and we have only paid for an hour. Do you have any questions about that?'
- 4 Warn them again five or 10 minutes before you make the actual request.
- 5 The words 'you have to' puts enormous pressure on autistic kids. What if I can't or don't? What if I mess up? Keep in neutral, stating the situation and why: 'It's important to stay here, because it's not safe if you go there without me'. If you have more time, ask them: 'Why do you think that might be important?'
- 6 Joking often diffuses a demand. 'Nag nag nag, I know! We don't like a nag do we - but do you know why I'm reminding you about this?'
- 7 'No' is always a difficult word - but sometimes the answer has to be 'No'. Check out our 'Say No Without the Volcano' feature - it's in Issue 17 which you can download online at [www.aukids.co.uk](http://www.aukids.co.uk)



**Luke Beardon**

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

Luke's Perspectives on Autism blog: [blogs.shu.ac.uk/autism](http://blogs.shu.ac.uk/autism)

OK - so I think it's worth just breaking this down (without wishing to get overly pedantic!). 'He seems OK' - I wonder what this is based on? Appearances can be (massively) deceptive when it comes to autistic children - often what you see is not what you get.

My advice in this instance would be to make as few assumptions as possible; in fact, I would go as far as to suggest that he is *not* OK - otherwise I doubt he would be stressed enough to behave in this way. Secondly - behaviour *always* has a reason - if there is no 'source' then the behaviour would not occur. We so often say "s/he did it for no reason" which, actually, is about as oxymoronic and nonsensical as can be - what we probably mean is "I haven't a clue why s/he did

it...". And, as he's sorry afterwards, it would strongly suggest that the behaviour is not within his control - but as a result of something so stressful or anxiety inducing that he needs a release of this kind to counter-balance it.

As is invariably the case in such circumstances, finding what the cause is and focusing on avoiding that is always the best way - prevention is the key! However, if it were that simple you would have done so already! So, perhaps in the meantime it's a case of providing a suitable alternative to releasing anxiety/stress/frustration that doesn't have such an impact. The crucial component here is recognising that he *does* need to have some form of release - but that it doesn't necessarily have to be kicking you!

If kicking is 'his thing' then you could start with introducing 'safe kicking' - identify what is OK to do - e.g. stamping on the pavement while out, may not be quite as effective as kicking you but might be a viable alternative. Turn it into a quiz: 'To kick or not to kick, that is the question!' Kicking a small child (or any child for that matter) - no! Kicking the dog - no! But kicking a toy dog at home - OK, go for it! BUT - this kind of teaching needs to be undertaken at times when he is calm, not when he is lashing out - at that stage I would suspect that his arousal levels are far too high to be learning new techniques, so always try to develop alternative actions when he is nice and chilled out.

Good luck!





**Heather MacKenzie**

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

[www.drheathermackenzie.com](http://www.drheathermackenzie.com)  
[spark-kids.ca](http://spark-kids.ca)

We need to help both people in this interaction. The parent needs simple, clear ways of helping her son. The boy needs a better understanding of what's being expected as well as some options for responding.

Try a problem-solving approach. In an approach such as this, you're teaching the young person to figure out what the problem is and then to work through alternatives rather than become upset.

So, firstly mum or dad sit down with their son and figure out what the problem is and how to deal with it. As a parent, you could say: "Sometimes, I notice you get upset when I ask you to do some things (stay neutral). What kinds of things do you think they are?"

If he can't think of anything, mention a recent event.

Then, define the problem. Ask him why he thinks he got upset. Keep in mind that his perspective can be very different from your own, so be open to anything. Don't impose your own beliefs.

If he can't come up with any ideas, suggest some. Ask him if he didn't want to interrupt what he was doing, was planning on doing something else, was too tired, or maybe the task was too difficult or would take too long... what? Listen carefully.

Also, he might not have understood what was expected and jumped to some 'scary' conclusions. Or, he might not have the motor skills needed to do the task as well as he wanted to. Then again, he might be overwhelmed by the number of things he's being asked to do.

There are so many possibilities.

Now, move on to looking at three

different ways of responding. Explain that the first step is always to stop, think, and take a breath before thinking of ways to respond. Explain that it helps his brain work more effectively. Practise it while saying: "I stop, I think, I take a breath," before thinking of ways to respond.

Then, prompt your son to suggest things he thinks he could do to help with the problem. Write them down exactly as he says them, regardless of whether you think they're good ideas.

This is also where you can teach your son about negotiating. I've taught very young children to use the phrase "How about...? This language gives them a sense of control and lets them introduce their own alternatives.

Help him to think about some possible negotiation points. For instance, where the task might be too overwhelming, you could help him to think through:

'How about I do one part now and the rest later?'

'How about I do it all 10 minutes from now?' (gives him time to warm up)

'How about I tell you the answers and you write them?' (if there are motor issues involved)

'How about I ask for clearer directions about what you want me to do?'

'How about I do it after I'm finished what I'm doing?'

Once you and your son have chosen the three alternatives, help him to figure out what might happen if he did each one.

Have him choose one plan. Then work out exactly what he needs to say and do in order to use it. Don't assume he'll know. Autistic people can struggle breaking down a problem this way.

Act out the scene together using the plan he's chosen. Switch roles to make it more fun and obvious to your son how his plan might/might not work in practice.

Then, ask him how his plan worked. Would one of the other plans work better or should you think of other ways to respond? Be sure to practise the plan he chooses a number of times before expecting him to use it in everyday life.



**Paul Burbage**

Trainer at Studio 3

Studio 3 works alongside professionals, families and individuals, providing crisis management coaching for those working and living with people who have autism and a range of other conditions.

For more information on referrals, go to [www.studio3.org/for-families](http://www.studio3.org/for-families)

This is probably one of the most common questions we get asked in training. Before we try to find some answers to this situation, it helps to look at the problem from two different perspectives – those of the parent's and those of the child's.

From the parent's perspective, it might be worth considering what we are asking of him and why. Some of the most common points of conflict revolve around compulsory demands – getting on the bus to go to school as the bus is here now; getting out of the pool as it's time to go home.

The problem is that whereas both the purpose and benefits of our demands are clear to us, they may not always be clear to an autistic child. So... does he really understand what is being asked and why in this instance? If there is a reason for the demand, has this been explained to him? And when explained, are we sure he understands? Also, the urgency - the "has to" part - may not be understood.

From our child's perspective, resistance is sometimes linked to aspects of autism that are hard to spot. For instance, sensory experiences. Maybe

they don't understand these themselves, or don't have the language to express what they're experiencing. Your demand may feel quite extreme because of the extra input it requires – not only to process the verbal request but also taking on all the other sensory input that your request may require, for example facing crowds, noise or lights. Also, take into account the many stress and anxiety issues related to autism – unfamiliar place, not sure what's next, routine change, or being tired and so possibly a bit fragile.... Our own responses may not be the most compliant and polite after a long stressful day!

Struggling to process extra demands whilst also regulating your emotional responses to the person making them can be extremely difficult if you have autism.

You may find that going over the same topic with encouragement or persuasion could also be contributing to stress rather than relieving it (continuous talking means even more processing is required). Think about those times when we are overwhelmed with demands on our mental/emotional reserves and how we react.

The explosive response leads to another common phrase we hear on training – "It comes from nowhere". Yet, that last request could be the proverbial "straw that broke the camel's back" – it pushed his ability to cope over the edge.

This isn't personal; it's purely an expression of anxiety, stress, or frustration. This is evident in that afterwards he is sorry – in other words, when his stress levels have come down and he can process again.

Returning to the original question, we can now consider that our perspective may be different from our child's. We can see why they may react, and we can consider alternatives to how we make these requests through communication and explanation methods – verbal instructions, Social Stories™, visual planners, etc. All of this reduces on the spot demands so they can understand what will happen and how, with less processing required at that critical time when it's a 'must'!

*We will be reviewing Heather's Teacher's Guide to Autistic Behaviour: What, why and how to help in our next issue of AuKids.*



# A Sweet Victory for Christmas



It's getting closer to Christmas and here they come...the sacks of goodies filled with sugar rushes! But if you have a child who responds to sugar by bouncing off the walls, or one whose behaviour takes a nosedive after sweets, the festive season isn't quite so easy. If you've received this magazine around Hallowe'en, you'll be only too aware.

Three years ago, Miguel Hayworth and his wife Amanda founded the online company Sweet Victory Products. The business, based in Cheadle, Cheshire, not only helps people find healthy alternatives, it also provides an education and future employment for their three autistic children Deborah, Joshua, cover star Caleb (...and maybe even brand new arrival Phoebe!) Debby Elley from AuKids chatted to Miguel (and tried to resist buying his entire stock).



## What inspired you to start Sweet Victory Products?

My three eldest children are autistic (*Ed's note: Phoebe was a month old at the time of going to press!*). We have found that high sugar was one of the reasons for certain triggers in our children's behaviour, as well as products that contain food colourings.

As parents, we're also very aware of the dangers of processed sugar and high sugar in our children's diets. As well as causing hyperactivity in our autistic children, sugar poses the risk of obesity and diabetes plus has detrimental effects on their teeth as well.

Also, for a long time we had already been searching for sugar-free products for other family members who are diabetic. Once we found some good products, we wanted to share them with others, so that's how we began.

As well as sweets, we now sell many types of natural products that are sugar free, with no added sugar and low carb. We also specialise in dietary food, with a range of low carb, ketogenic, gluten free, vegan and vegetarian products. We're expanding our ranges all the time.



## It's quite a leap to go from finding healthy snacks to starting up a business...

I was worried about my children's employment prospects when they reach 18, as the unemployment rate for autistics is still very high. I wanted to provide them with work. If this works out, there's the possibility that we could employ other autistic people, too.

As an autistic person myself, I also wanted to prove that autistic people can run businesses and manage them. I had no help when I started and people had said it would never work, but I was determined to prove them wrong.

Sure, I made lots of mistakes. But this was never a bad thing and my attitude has changed over time with failures; that we should never expect to fail but we should see our failures as a good thing and celebrate them.

The problem is autistic people like myself have always known people who focus on what we are incapable of doing rather than what we are capable of, and our gifts. For too long we have been held back by people constantly using negative narratives. I wanted to show that we can work within our limitations to achieve big things.



## What sort of difference do you hope the company will make to its customers?

Sugar-free does not have to be sweetness-free, and it is the company's aim to help as many people as possible to change their relationship with food from high sugar to sugar-free and healthier alternatives. This includes children, after an alarming increase in oral health issues and obesity. We are not on an 'anti-sugar' campaign, but we do want to help people make informed choices whilst educating them about low carb and sugar free products. We're also providing additive-free products that won't affect a child's behaviour and we get plenty of customers who are diabetic, too.



## Why aren't more people buying these sorts of things in your view?

In the past sweeteners have been frowned upon because of their laxative effect or potential links to cancer. This is now changing as the benefits are seen to outweigh the risks. There is still scepticism and so we often put it down to education. People need to know that the word 'sweetener' does not mean it is aspartame-based. Aspartame is just one of many sugar alternatives.

As the demand for sugar-free products has increased over the last five years, there are new sweeteners being developed and this is likely to expand in future.

People are not aware that there are thousands of sugar-free, no added sugar, gluten free, vegan, vegetarian and low carb products on the market. In our experience they struggle to find them and the general feedback is they think we are doing a good thing and that most people are becoming more aware about sweeteners.



## The big question: Are sweeteners safe?

A common concern has been around any long-term negative effects associated with the use of sweeteners. With the clinical trials done on sweeteners so far the results are very encouraging. According to the European Food Safety Authority (EFSA), sweeteners are considered safe and have no long-term effects on the human body. In 2011, EFSA stated there was sufficient scientific information to support the claims that sugar replacements caused a low rise in blood sugar levels after meals if consumed instead of sugars and maintained tooth mineralisation by decreasing tooth demineralisation if consumed instead of sugars.

Within my company we do place emphasis on the safety of sweeteners and so for this reason we can say with confidence that the use of sugar free confectionery, jams, whole foods and condiments have long-term lasting benefits within moderate amounts.





For anyone who is unsure, we are more than happy to send out information about how the sweeteners in our products are made and the safety of sweeteners for human consumption.



## What do your children think about what you do?

I had explained to my children why I had created a company in the area of sugar free - it was mainly for them, so that they could take joint ownership of the company when they reached 18. I was mainly a caretaker, should they choose to. They love getting involved and taking trips to the wholesalers. At first they were not used to it; they were overwhelmed when one warehouse had over 5,000 different sweets from all over the world!

The more they visited, the more they started to understand how trade works, from purchases to product information. Not many children have access to that type of learning. They see that we work with other wholesalers and distributors and it enables them to deal with other people and to learn about trade and industry as well as geography. It's helped them get used to different environments, which is a big thing for any autistic child to deal with.

We find our children to be the best product testers. As children with autism they can be brutally honest and this is a good thing! We include product testing and feedback as part of our children's educational development and encourage them to be entrepreneurial and passionate about the business.



## What's next for Sweet Victory Products?

Sweet Victory Products is in the process of developing new partnerships with Peter Bakare, an Olympic Athlete who is part of Team GB and the World Wide Olympics Association. Working together with a celebrity called Laura Church, who will be promoting Sweet Victory Products across schools UK-wide, they are going to look at the potential of improving children's eating habits and lifestyles through diet and exercise. We'll also be working alongside other organisations - Nutri-troops, Sports for Schools and Body Buddies.

### Know Your Sweeteners

There are three categories of sweetener: organic natural sweeteners, alcohol-based and synthetic.

#### Organic Natural Sweeteners

These are the natural sweeteners found in fruit and other plants. For instance, one of the jams we sell, made by St Dalfour, is sweetened only with fruit juice. (Ed's note - It's lovely!)

Erythritol, Xylitol and Stevia are natural sweeteners.

#### Alcohol-based sweeteners

These look and taste like sugar but have fewer calories and fewer negative health effects. As the name implies, they are like hybrids of sugar molecules and alcohol molecules.

Alcohol sweeteners are manufactured from alcohol sugar, a by-product of the fermentation process.

Unlike artificial and low-calorie sweeteners, sugar alcohols do contain calories, just fewer than plain sugar.

Alcohol sugar-based sweeteners are fine within moderation. You do have to exercise some portion control though, due to potential laxative effects.

Sweeteners that are alcohol-based include Maltitol, Isomalt, Erythritol and Lactitol. If the sweetener's name ends in 'ol' it is usually an alcohol-based sweetener.

#### Synthetic sweeteners

These are purely man-made. Examples include Aspartame, Acesulfame Potassium (Ace-K) and Saccharin. Sweet Victory Products likes to stick to the natural and alcohol-based sweeteners, but Miguel says that rigorous studies have so far failed to reveal any health risks associated with synthetic sweeteners such as Aspartame. He adds: "We don't choose it because it doesn't have any health benefits, whereas the sweetener Erythritol, for instance, is being promoted by some dentists as beneficial against gum disease".

#### Follow these links to find out more:

- [www.nhs.uk/live-well/eat-well/are-sweeteners-safe](http://www.nhs.uk/live-well/eat-well/are-sweeteners-safe)
- [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/470179/Sugar\\_reduction\\_The\\_evidence\\_for\\_action.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/470179/Sugar_reduction_The_evidence_for_action.pdf)
- [www.evidence.nhs.uk/search?ps=250&q=artificial+sweeteners](http://www.evidence.nhs.uk/search?ps=250&q=artificial+sweeteners)
- [www.bmj.com/content/364/bmj.k4718](http://www.bmj.com/content/364/bmj.k4718)

#### The European Union has a very clear guide to sweeteners:

- <https://ec.europa.eu/jrc/en/health-knowledge-gateway/promotion-prevention/nutrition/sugars-sweeteners>

## Sweet Victory's Top 5 Sugar-free Stocking Fillers

**Zollipops sugar free tooth kind lollies.** We also sell sugar free Chupa Chups lollies.

Zollipops are made with Xylitol, Stevia and Erythritol. These are also vegan and kosher.



**Sweet Switch No Added Sugar Chocolate Confetti**

Remind you of anything? These are egg and gluten free. Made with Maltitol, Sorbitol, and Stevia Glycerides.



**Free From Fellows - Midget Gems**

Made with Maltitol Syrup these are sugar and gluten free, suitable for vegans.



**Wizards Dairy Free No Added Sugar chocolate bars (In Original, Mint and Orange)**

Made with Isomalt, Inulin, natural flavouring, natural orange oil and sucralose. Dairy free, gluten free and vegan.



**Free'ist sugar free and gluten free marshmallows**

Uses Maltitol Syrup, Isomalt and Steviol Glycosides. Not vegetarian.



To buy any of these products, look up [www.sweetvictoryproducts.co.uk](http://www.sweetvictoryproducts.co.uk)



## WIN our Top 5 Stocking Fillers!

One lucky AuKids winner is in for a treat! Win Sweet Victory Product's Top 5 stocking fillers.

All you have to do is tell us where this sweet is hidden in the magazine. Send your answer along with your name and address to [auidsmag@gmail.com](mailto:auidsmag@gmail.com) no later than November 30<sup>th</sup>, typing **SWEETIES** in the subject header.

By entering this competition, you give permission for AuKids to send your address details, should you be a winner, to Sweet Victory Products so that they can send you your prize. No other third party will receive your details.





'Safe as houses' is a bit of a misleading phrase, isn't it? Every year more than 3.4 million children experience an unintentional household injury. When it comes to autism, parents know only too well how risky the home can be and it can be a constant worry even when you're supposed to be relaxing.

So, to save you having to install eyes in the back of your head, we wanted to publish some advice on good home safety features.

Colin and Elaine Pratt, the owners of Hartlands autism holiday centre on the Isle of Wight, have built four bespoke apartments for families like yours. Every detail has been carefully designed for safety and a stress-free holiday. Read on to find out about the equipment they wouldn't be without...

By Colin and Elaine Pratt



## About the Authors

Colin and Elaine Pratt own Hartlands Holiday Centre in Shanklin on the Isle of Wight. The centre is a converted hotel, including four modern, purpose-built apartments designed for autism families. Extensive facilities at the centre include a fully equipped sensory room and an indoor swimming pool, as well as a gym, games room, arts and crafts rooms and music room. There's a small cinema area alongside the sensory room and a computer room for gaming fans. AuKids reviewed Hartlands in Issue 40, which you can download at [www.aukids.co.uk](http://www.aukids.co.uk). The centre can be booked all year round, with schools and care centres welcome during term-time. To find out more, go to [www.spectrumbreaks.co.uk](http://www.spectrumbreaks.co.uk) or e-mail [support@spectrumbreaks.co.uk](mailto:support@spectrumbreaks.co.uk)

**Money off Your Hartlands Holiday With AuKids!**

If you book any dates at Hartlands between January and June 2020, you're entitled to a 5% discount if you quote the promo code **AUKIDS2020**.

Our youngest, Thomas, who is now 21, has autism and is non-verbal. As he was growing, we learnt ways to make his and ours lives safer and less stressful. When we built Hartlands autistic holiday centre, we were able to include these into the design and our guests say that our adaptations are part of what makes their holiday so special. We've selected our top 12 ideas – they're mostly inexpensive and will undoubtedly make your life easier.

### 1 A SAFETY KNIFE BLOCK

This Lock Block is made by JosephJoseph.com and is available from Amazon for around £65.

It holds knives securely in the block unless released from a hidden lever on the side. A useful kitchen item, it secures sharp knives from young children. Our guests love this simple yet effective safety item.



### 2 AN INDUCTION HOB

A type of cooker hob that works on magnetic induction, heating the pan not the hob, the induction hob only gets hot if a pan is on the hob; it's the pan that gets hot rather than the hob. The heat is quick to switch on and off, a bit like a gas hob, yet is much safer than any normal gas or electric hob.



### 3 AN OVEN DOOR LOCK

This prevents the oven door from being opened without first lifting the catch. It's now fitted to most new ovens, but can be purchased from Amazon and retro-fitted for around £25. A simple yet effective way to keep the door from being opened accidentally.



### 4 WATER SHUT-OFF VALVES

Installed in the plumbing to sinks or baths by a plumber, this allows you to switch off the water to sinks or baths very easily by simply turning the levers, preventing accidental floods. These are available from most plumbing merchants for around £6 each.



### 5 WINDOW SAFETY FILM

Available on the Internet or through your local glazier\*, this is an inexpensive and invisible plastic film placed on the glass that will keep glass in place if broken. This is an ideal and cost-effective way to make single glass windows safer and more secure. It has already proved its worth twice at the Hartlands when windows have been broken yet held together, preventing escape or injury.



\*AuKids found 100 Micron Safety & Security Window Film available from Active Window Films - [www.activewindowfilms.co.uk](http://www.activewindowfilms.co.uk) (or search Safety and Security Window films on ebay).





BUT JIM, NOW THAT WE'VE ADAPTED THE HOUSE FOR GEORGE, I HAVEN'T GOT ANYTHING TO WORRY ABOUT!



GREAT, MAYBE I CAN FINALLY GET AROUND TO BUYING A SMARTPHONE



## 6 STAR KEY DOOR LOCK

Available from most DIY stores for around £15, a door lock operated by a star key can be easily fitted to most wooden doors. This allows you to secure kitchens, lounges, front and back doors to restrict access to some areas of the home.



## 9 DOOR ALARMS

Available through Amazon, these Fortress door alarms are battery operated and can be fitted to most doors or windows for around £32. There can be multiple sensors to a single alarm and they can be set to sound a loud 'beep' when a door or window is opened, alerting you when someone has gone out or come in. These alarms are fitted to both the front doors to every apartment and also the doors to each of their patio areas. Our guests love the fact that their children have the freedom to come and go inside our centre, while letting the parents know when they do.



## 11 WINDOW LOCKS

These are available from most DIY stores for around £20 and can be fitted to most wooden windows. They prevent windows from being opened fully, helping to remove the risk of fall or escape. For many of our guests this is a must-have item so they know their children are safe at night, allowing the parents to relax.



## 7 L.E.D. LIGHT BULBS

These are available from most DIY stores. As well as saving energy, these bulbs don't generally get hot, helping prevent accidental burns. They also come in plastic to avoid the risk of broken glass.



## 10 ELECTRIC SAFETY SHOWERS

These Redring Selectronic safety showers are available from some plumbing merchants or on the internet for around £500 and can replace existing electrical showers or be used in new shower installations. They meet safety standards for care homes to prevent overheating and can be set to a safe temperature to prevent accidental burns. They also come with a remote on/off switch that allows you to control the shower from outside the shower cubical, which is very handy when our children don't want to come out!



## 12 OUTSIDE GATE MAGNETIC LOCK

Available from Amazon for around £45, this gate latch is made in Australia and designed to protect young children from swimming pools where preventing unsupervised access is critical. It works using a magnet and can be fitted to most wooden gates to help secure a garden or fenced area. It is the best gate latch we have found on the market to date that does not



jam open. It now also comes with an alarm version for extra safety and peace of mind. We use this to keep our garden areas secure and so it has proved very effective.



## 8 TOUCH LIGHTING DIMMER CONTROLS

Available from most DIY stores for around £15, these can replace most standard (not LED) light switches. You will need a competent person to fit these safely. With these touch switches there are no dials to pull off, lose or fiddle with. They are much safer than normal turn dimmer switches. Available at B&Q under the name 'Varilight'.







# The Last Word

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

## Speaking Without Words

Facebook likes to remind you every so often of the photographs you posted a while back, and recently this one popped up of Alec four years ago. He was 11 and he looks diddy compared to now. Believe me, the period of time between 'giddy junior school kid' and 'large bloke lolloping about the house' goes surprisingly quickly.



**Stereophonics:  
Alec's Sing-A-Me-Jigs**

The photograph also made me reflect on a facial expression that Alec used to adopt when he hit an emotional high that was beyond his usual levels of enthusiasm. You can't quite tell here, but his upper lip moved in such a way that suggested both awe and delight in immeasurable quantities. In this case, it was because he'd mastered how to get two Sing-A-Me-Jig cuddly toys performing in unison and therefore harmonising with each other. Sort of. It wasn't exactly Lennon and McCartney.

It struck me that Alec, who is non-verbal, has a number of facial expressions that seem to be unique to him and that speak a hundred words. They're part of what makes his warm spirit very visible – and they are utterly idiosyncratic.

To give just a few examples, there's the 'sad eye', when he pulls his lower eyelid down to indicate massive displeasure. Alec hardly ever cries, so this is how he shows the 'humph'. A lower jaw waggle is an indication that anger is mounting and you

should keep a two foot distance. He sometimes stops during a walk, squeals and moves his head side to side in a manner resembling Stevie Wonder performing something groovy like 'Superstition'. We call this his 'happy dance'.

He has many more examples, and his dictionary of facial expressions got me wondering...

Is Alec just someone with a naturally expressive face? Or, does he use more facial expressions than other people, to compensate for a lack of language?

Then again, is it just that we watch him so closely for clues about his inner state that we have started to notice movements that we would miss in other people, because we are focused on what their spoken language is telling us? To illustrate, Poldark fans can reflect on how George Warleggan's stirring conscience was only betrayed by a flicker of a glance from the actor Jack Farthing. We were watching closely because he didn't share his thoughts verbally. We may have missed it otherwise.

If you have a child who is non-verbal, this one bears thinking about. Rather than them lacking communication, it's quite possible that your interaction with them is far more honest and open than with others, whose verbal communication can be a smokescreen, obscuring their inner state. Parents of non-verbal children are primed to read the detail written in other people's faces and for me personally I can certainly say that it's made me a more sensitive observer. It's no doubt done the same for you.

I think Alec does have a more expressive face than many people. It's just another way of talking to himself. Whereas we would say 'Oh that's funny!' or 'I love that!' out loud to no one in particular, he has an alternative means. These expressions are not purely intended for an audience, they're yet another sign that his inner dialogue exists. You just have to tune into it. And, to quote the late great George Michael, listen without prejudice.

Living with autism isn't easy. But finding out all about it should be.

Everything you need to know in one place

[www.autismlinks.co.uk](http://www.autismlinks.co.uk)



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