

'IT IS EASY TO FIND YOURSELF WORKING OUTSIDE YOUR COMFORT ZONE WHEN WORKING WITH AUTISTIC CHILDREN'

Wendy Bellis is Assistant Clinical Director and Specialist Paediatric Senior Dental Officer for Camden and Islington Community Dental Service (Whittington Health). She is considered a world renowned voice on autism and paediatric dentistry, and news editor David Westgarth sat down with her to discuss some of the challenges presented by autistic patients.



Where did your interest in children on the autistic spectrum come from?

I have been treating children with special needs for many years and about 20 years ago began to notice that a growing number of autistic children were being referred to me. I also realised that these children required a completely different approach to the ones I usually use to manage their oral care and dental treatment. Over this time, I have come to the conclusion that autism is unique and in order to provide effective oral care, dentists need to have a better understanding of the problems facing those on the autistic spectrum. It has been reported that one in 100 people in the UK and one in 68 in the USA have autism spectrum disorder (ASD), and what you will find is their condition will affect them in different ways. This spectrum can present many and varied challenges to the dentist.

What are some of those challenges?

I have found that problems exist even before the patient arrives. There is evidence suggesting that parents are reluctant to take their child with ASD to the dentist and this can be for lots of reasons. The main obstacle seems to be that they are concerned about finding the right sort of dentist, one who understands their child's condition and special needs.

A dental surgery can present a huge challenge for an autistic child. Their behaviour may be unusual, disruptive and present a worry for some

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of the team, not to mention their parents. I have seen children self-harm, which is extremely distressing.

One of the factors linked to these behavioural challenges lies in the child's lack of the 'Theory of Mind'. This means they are unaware of the effect their behaviour has on other people, which can lead to confrontational behaviour in the waiting room. I have even had to examine (*not treat*) a child in the car park as they wouldn't get out of the car.

What about communication?

We know that autistic children have impaired communication with up to 40% being completely non-verbal and the language which you use and the way that you speak needs to be adapted.

Dentists and their staff also need to be aware of other forms of communication, eg pictures (PECS), social stories and Makaton.

The sensory challenges, unpredictability and anxiety caused by the nature of a dental examination and environment can contribute to a 'perfect storm' for autistic children. Research has identified that they process sensory information in a different way, and sensory overload can be the main trigger for their anxiety. Their ability to express pain and response to it may be also different, which is a worry for parents and dentists alike.

As if those problems aren't complex enough to navigate, NICE (2011) states that 70% of children with autism have one or more comorbid mental and behavioural

disorders, most likely ADHD, OCD or depression. More than half may have a learning disability. Epilepsy is a common comorbidity and this, in combination with their tendency to put objects in their mouth, can result in oral trauma.

What problems do these children have in the general dental settings?

Unfortunately, much of our child behaviour management training goes out of the window because most of the techniques you have been taught will not resonate with an autistic child. They may also be using communication aids you won't have encountered before. Any humour or jokes won't be understood, and what you do say may be taken literally. Asking them to hop on or jump on the chair – something you may have said 1,000 times in your career without really thinking about it – can have disastrous consequences. It has been found that current behaviour management techniques used in dentistry are not consistently effective for ASD patients. In addition, dental management of an autistic child requires in-depth understanding of the background of autism.

This means as dental professionals we should be able to be flexible in our approach and modify this to each individual patient. As a rule of thumb – but by no means something that is widespread – a busy general dental practice is not an ideal setting for treating an autistic child with learning difficulties, communication and sensory

problems. The more challenging autistic children should be seen in the community dental service (CDS) where staff should have the necessary training in the dental care of people with special needs and can offer the flexibility in approach and setting. The CDS is often the gateway to treatment under general anaesthetic and can link into other elements of community care.

It can't be easy for a general dentist, can it?

It is easy to find yourself working outside your comfort zone when working with autistic children.

Being prepared is important. Find out about the child and ask the right questions. The best way to ascertain these is by using a specific 'autism friendly' questionnaire. You can enquire about any sensory issues, past experiences, behavioural therapies, likes and dislikes. This is an opportunity to identify behavioural triggers for the child, both good and bad which are essential to know about as a dentist. Why? If you know what a child likes then you can use that to reinforce compliant behaviour. Knowing what they like can help you find shortcuts.

The questionnaire can also be used to 'set the scene' for the parent and help any unrealistic expectations about the first visit.

How do you engage with the family?

Autism is life-long and affects all facets of child and family functioning, and so it is important to consider the family unit and not just the child in isolation.

Lone parenting is not uncommon and I would advise dentists to be mindful of the pressures such parents are under. The effect of sleep disruption in families shouldn't be underestimated and interaction with the tired child and parent needs to be both sympathetic and measured.

Reports suggest that four in every five parents report that they are sometimes stretched beyond their limits and nearly half of these feel that way monthly or even weekly. For these reasons, safeguarding issues may need to be considered in some circumstances.

Parents can be under incredible stress. Compassion and empathy are essential when speaking to a parent who has missed 'yet another dental appointment'. As autism is largely a genetic condition, there may also be affected siblings.

So how can autistic children be managed in the surgery?

It really depends on where the child is on the spectrum and how early they manage to access appropriate dental care and prevention. Unfortunately, the average age of diagnosis is relatively late compared with other more obvious conditions such as Down syndrome. There is often a long waiting list for the definitive assessment which is a shame as any intervention works best when made early in life. Dental health and ASD have that in common. In the UK currently, treatment of autistic children under intravenous sedation is uncommon. Although inhalation sedation can be used, this tends to be confined to those autistic children who are able to communicate and are not excessively anxious. Although I do use it, I find that assessing the level of sedation can sometimes be quite difficult.

Unfortunately, if a child is autistic with a learning disability and has profound communication problems then treatment under general anaesthesia is probably the best option.

If this decision is made then the treatment should be planned appropriately in order to future proof the child's mouth and avoid further hospital admissions.

How do parents and child cope?

Treatment under general anaesthesia is stressful for all concerned. For example, trying to explain to such a child that they can't have their usual food before the operation can be extremely upsetting. Even the administration of premedication needs not only patience but sometimes a surreal imagination on the part of the staff.

There are some very good visual aids to help prepare children for this intervention but, although hospital play therapists do their very best to support families, it remains very stressful.

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How feasible is it to establish oral care practices for an autistic child?

In view of the challenges faced by dental staff in treating autistic children, early contact and intensive prevention is the best way forward.

Always bear in mind any sensory issues, for example, some of the things I have used to initially introduce a toothbrush into a child's mouth include peanut butter, Marmite and cream cheese. I'm sure jam and honey might work but obviously I couldn't recommend these!

What advice would you give?

Practical help and advice with brushing positions is a must. Safe holding and perhaps wrapping in a towel may need to be also demonstrated. The example I mentioned earlier about peanut butter applies here too. You may need to be creative when introducing toothpaste into their mouth, and/or low-foaming, mild flavour or even flavour free paste might be suggested.

Because the management of dental disease in autistic children can be difficult, prevention has to be of paramount importance. In accordance with the toolkit I would always recommend prescribing 2,800 ppm fluoride paste at age 10 and 5,000 ppm when they are 16. I still hear from some parents, unfortunately, that fluoride is a poison, which is nonsense and certainly not evidence based. Fluoride will help their child's teeth but this needs to be explained to them in a diplomatic and tactful way!

There is a plethora of material relating to therapies, causes and management of autism on the internet and much of that is not based on good science. Most parents don't know about Cochrane reviews and so dentists have a responsibility to steer parents towards evidence based resources and also accredited professionals.

I have been very fortunate to have learned from parents and therapists who have guided me through the minefields I have unexpectedly found myself in my practising life, but it is the children themselves who I have to thank for opening my eyes and allowing me to glimpse their fascinating world.

Interview by David Westgarth