



# Treating Autistic Patients in the Dental Office: A Common Sense Protocol

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## Introduction

The word protocol in any context conjures up a set of rules and regulations to which one must adhere. A proper medical treatment protocol will describe a definitive step-by-step set of procedural guides, while allowing for the patient's individuality and the doctor's professional judgment.

When developing a protocol for the dental treatment of children and adults afflicted with an autistic disorder, it's important for the dental team to establish a set of parameters to be applied to the behavioral management and clinical treatment of these special patients. However, any protocol must be more like a flexible framework within which we as dentists can provide the best service for our patients.

Sometimes it means thinking and operating "outside the box" in order to accomplish the task at hand in an efficient and timely fashion. You certainly wouldn't expect a severely affected autistic child or adult to simply stroll into your office, sit in the dental chair and say, "I'm ready!" Every nuance of people skills must come into play along with plenty of patience for the parent as well as the child. It could be said that my philosophy rests somewhere between well planned strategy and instinctive improvisation... "winging it." Whether the plan for any particular dental visit is to perform a prophylaxis or to restore teeth or simply do a well-baby exam, we may have to take 2 steps sideways in order to take one step forward.

The American Academy of Pediatric Dentistry is explicit in recognizing that "caring for persons with special health care needs is an integral part of our profession, that we value the unique qualities of each person and the need to maximize health attainment for all" [1].

This obligation to provide access to care for "special needs" patients, especially considering the marked increase in the incidence of autistic spectrum disorder (ASD), applies to general practitioners as well as specialists [2,3].

## Random Thoughts About: Sedation, Conscious Sedation and Hospitalization with General Anesthesia

As with all child patients it is my preference to eschew mind-altering drugs unless medical or physical limitations dictate otherwise. (An example would be a physically imposing 16-year-old boy with a severe form of ASD and rampant neglected caries).

It is incumbent upon the dentist and the other members of the dental team to focus not merely on the fixing of teeth but on the positive acclimation of the child and the child's parents to the dentist and dentistry. When children are subjected to sedative or tranquilizing drugs, the ability of the dentist and the child to communicate actively is considerably diminished. The intimacy of verbal and physical rapport—"showing, telling, and doing"—is compromised.

Premedication regimens are unpredictable, and conscious sedation is not a remedy for dental phobia. It may make the dental procedure easier for the dentist but does not eliminate the future apprehension, since no education has taken place. It would be comparable to getting drunk to forget our troubles and when sobriety returns we discover that our problems have not washed away. The fear of the unknown persists unless someone addresses it. Further, bear in mind that often the child with an autistic disorder is already under the influence of a combination of mind-altering medications.

## Parents In or Out of the Operatory

I strongly believe that it is in the best interest of everyone involved that children be separated from parents for treatment. It is essential that we establish a one-on-one relationship with the patient in an atmosphere of confidence and trust. Having a parent present in the operatory may confirm to the child that "mommy loves you" but does nothing to ingratiate the dentist to the child.

Certainly, parents may be invited into the operatory in instances where the dentist or a team member would like to demonstrate a procedure or point out a specific clinical situation. But in general, children are better behaved and more receptive when the parents are not with them. Ask any grandparent.

My philosophy notwithstanding, any policy you advocate should be clearly expressed in an individualized written office information booklet and discussed with the parent on the phone at the time the appointment is made. When the family arrives for the dental visit, the policy is reiterated and a parental informed consent form for treatment is signed. Comforting anxious parents may be important but treating the patient successfully is more important [4].

## Opening the Door... The Front Desk... Phone Conversation

All the amenities and courtesies that would normally be applied during the appointment-making conversation are even more relevant with parents of "special" patients. To promote the warmth and welcoming attitude, ask the name of the child and from that point forward always refer to the child by name, e.g., Ryan.

As the routine preliminary questions and answers play out, a parent may volunteer information about their child's special behavior. Sometimes the parent will ask outright, "Do you treat autistic children?" Or, "I have a child with a toothache, but we haven't been able to get him to sit in the chair at the dentist. He gets very agitated and screams and cries." At this point the office person at the front desk might ask, "Do you think that (Ryan) is just frightened or is there something special we should know about him?" You could also inquire whether the parent was in the operatory with the child and the dentist at the previous visit.

This might be the opportunity to mention the idea of how well the children do in the operatory without the parents and the high priority we place on promoting the “one-on-one” patient-doctor relationship. Elaborate on the strategies of engaging children, minimizing the need for active restraints, or mind-altering drugs. “Ryan may cry. But we’re very patient with children who cry.”

A reminder: It is important for everyone on the dental team, whether it be the office manager or the dental auxiliaries in the operatory, to be aware of the stress and the guilt parents may be feeling. This observation may apply to all parents but it is especially significant with parents of “special needs” children. They may be uptight, overprotective, and edgy. Smile! Patience!

Be sure to get the physician’s name along with a preliminary medical history (a more complete version can be obtained at the time of the first visit). Inquire as to any medications the child is taking. “Is Ryan in pain?” (If so, we’ll need more time for the first visit.) Be sure to ask how Ryan expresses his anxiety. “What does he do physically to show his displeasure? Would you call his behavior disruptive? Violent? Does Ryan speak? How does he let you know what he wants? Are you able to brush his teeth? Does he like it?” An obvious question to ask a parent if Ryan is a 16-year-old “special” child would be, “What does he like to do for fun? Music? Computers? Eat? Watch TV?”

Ask about school. Mainstreamed in classes? Special school? Perhaps the child is home schooled? Does he have a nickname he likes? These questions should not sound rehearsed or like they’re being read from a scripted page. This is not an interrogation. It’s about listening to the parent’s voice and having an intimate conversation.

Sometimes mothers and fathers are only too anxious to be able to talk about their child. Others are more private. Naturally, a lot of information will be revealed when you see the child and parent in action at the first visit, but asking these questions and getting some answers gives you a heads-up in knowing a little bit about the family, and reciprocally, the parent becomes aware that you’ve been down this road before Schedule the first appointment to allow sufficient time to properly meet the children and parents and complete all the necessary forms and computer entries, and most importantly to allow for doctor-parent child consultation time. Clarify that the first visit usually consists of an examination, prophylaxis and fluoride treatment, and radiographs, if practical and necessary. If emergency treatment is anticipated, explain that the parameters of time and the extent of treatment will depend on the nature of the clinical problem. We intentionally leave any discussions of finances, insurance coverages, and payment policies to the end. Although these issues should be clarified, they should not be the initial focus of attention [5]. Don’t forget to ask, “Do you have any questions?” “We’re looking forward to meeting Ryan.”

## The First Visit

When a new family arrives in the office, it’s always a good idea to try to address the children first. Say “Hello”...using names (Ryan)...upbeat and friendly, and then turn to the parent and say “Hi.” Acknowledge the appointment-making phone conversation, reminding the parent that we’ll be bringing Ryan into the operatory without them and ask the parent to fill out whatever information forms you require, including the medical history. In the meantime, let the child absorb the atmosphere of the waiting-reception area. The front desk personnel are instructed to unobtrusively observe the child and take mental notes...

talking or not, agitated and loud or calm and quiet, playing with toys, physicality, in wheelchair, size, parent-child interaction, etc.

When paperwork or computer registration is complete, ask the parent if there’s anything else that we should know about Ryan. Usually the parent will indicate details like “sings the ABC song” or “doesn’t like bright lights, hates toothpaste, can’t spit, likes to bite, may ask to go to bathroom often, Pac-man is his favourite, or we call him Woody because his favourite movie is *Toy Story*.” Make certain that this information is transmitted to the dental assistant and ultimately to the doctor. The clinical portion of the visit begins when the dental assistant comes out to the waiting area to escort Ryan into the operatory. First, it’s “Hi Ryan” to the child and then to the mother, “Hello Mrs. Wilson, I’m Judy. Dr. Berman is so excited to meet you. Wait here, Mom. Don’t go away! Ryan and I will be right back.” All of this talk offers reassurance that they won’t be separated for long. If it’s necessary to lift a child up and carry him or her into the operatory, then do so. The separation from the parent when the patient is being escorted or carried into the operatory should take place in the waiting room as previously arranged and discussed, and with parent’s consent [4]. Establishing the one-on-one rapport is not enhanced by the parent’s presence. Justifying the doctor-patient relationship is essential to the entire process. Developing trust and confidence with the child is at least as, and sometimes more important than, pacifying anxious parents. Explain the benefits of the communication process. There is no question that children across the board accept kind treatment more positively and graciously independent of their parents. Again, ask any grandparent.

## On the Subject of Crying

Crying...Screaming...Tantrums

Anyone working with or caring for children should be prepared for disruptive behavior at times. Crying can be provoked by fear or pain, or a child may just decide to cry. Most autistic children have difficulty in making their feelings known verbally so their negative behavior is more pronounced.

We should all be sensitive to and act in the best interest of our child patients, especially those afflicted with one of the many degrees of ASD. But crying and screaming should not automatically signal the end of the story...every effort should be made to utilize whatever skills we possess to turn the crying into laughter. It is impossible to prevent every child from crying, especially those children who because of their limitations cry and scream routinely, seemingly without reason. Often the physical acting out and verbal onslaught are their only means of communication. Very often we are able to work some magic and win the child over. There are situations where a child is so severely affected that you must continue to talk and work to finish the task as quickly and as effectively as possible. Assuming that you are not causing pain, screaming or crying should not be a deterrent to completing whatever treatment is necessary to assure the child’s ultimate comfort and health needs. Dental care is a vital part of the child’s well-being.

## Restraints

As with all patients, it is the responsibility of the dentist and the other members of the dental team to make certain the children are as happy and safe as possible. The severely affected child with ASD often presents a physical challenge, and therefore situations may demand some kind of passive or active restraining.

I am not an advocate of papoose boards, Velcro straps, or other means of tying down or immobilizing children. I am in favour of the human touch, as with 2- or 3-year-olds where a dental assistant will sit in the dental chair with the child in her lap and 2 other assistants are present to assist the doctor with the procedure. In the case of a larger, more reluctant patient, more than one dental assistant may be involved in controlling dangerous movements of the arms and legs.

In what I like to call the “battle stations position” (Figure), one dental assistant has an arm draped on the shoulder next to the head. Her free hand is lightly holding hands with the patient. If necessary, another dental assistant may be stabilizing the legs (See Dr. Berman videos *Oh No, Not the Shot* and *The Children Are Coming*) [6,7]. There is a demonstrable difference between using artificial restraints and utilizing the more human hand or leg holding approach.

### Some Strategic Tips

No sudden moves. Even touching or hugging can be sensory integration issues. Keep routine gestures small. The hearty “Hello” is sometimes good for getting a more verbal child’s attention but often the softer approach works better for a child who is nonverbal and wary.

Use the first name frequently when addressing the child. The repetition is rhythmically soothing and enhances focus. “Who’s the best boy? Billy’s the best boy. My best boy Billy!”

No sarcasm or irony. Speak directly and to the point. “So, what’s new?” won’t be as effective as “You just had a haircut. I like the way it looks.” Or “New shoes! They’re pink and grey, my favorite colors. Look, they match your shirt. Wow!” Over-compensate for the child’s lack of communication skills by reinforcing the words you say with relevant gestures.

Strive for eye contact whenever possible. “Look at me, Sarah. Look at Dr. Berman! Where is Sarah? There she is!” Many of the children focus on the hands or extraneous objects. They may be watching your lips and hands moving, especially those with hearing difficulties. Sometimes knowing sign language can be helpful. Eyes...hands...mouth...voice...all play a role in communication.

If the child is a talker and especially obsessive about a particular subject, get into it with him. Become engaged. Let him explain...let him elaborate and then find a convenient spot to say, “That’s so interesting. Okay, let’s brush your teeth. Then we’ll talk some more.” “Let’s sing a song while we brush!”

With wheelchair-bound patients, make a decision as to whether to work with them in the wheel chair or lift them into the dental chair. The size and physicality and attention span of the patient, the complexity of the treatment, and the need for passive restraints by the dental assistants may make it easier and more practical to utilize the dental chair. Patient safety and degree of accessibility in the mouth determine your decision.

Always show the “familiar” first, something they’ve seen before, ie, the toothbrush...water...etc. Don’t rush to put child in the dental chair or fasten the chain for the dental napkin or turn on the dental light. Nice and easy does it. Introduce everything one step at a time.

Position the patient more upright in the chair. Tilting the chair far back makes a child feel more vulnerable. This positioning also allows for the best eye contact and nonintrusive, passive restraint by the members of the dental team. No light in the eyes...no sunglasses.

Voice modulation can be very helpful. Variations between soft talk and a firmer tone can indicate your wishes. “Please put your hands down. Billy, hands down Billy! Hi Bill! Hands Down! Now! That’s better. Good boy, Billy!”

An open operatory is the best of all worlds when treating children. However, loud music playing, noise from TVs, and several people talking and moving around may combine to be unnerving for the ASD child. Keep the focus intimate and as one-on-one as possible. One voice of the dental assistant or the doctor. One subject at a time. Too many faces and voices can be a sensory overload.

Maintain a routine of “same chair, same dental assistant.” The need for adherence to a certain sequence of events and an orderly routine is characteristic of ASD. On the other hand, by exposing the patient to a variety of dental assistants and doctors over a period of time a reasonable comfort level can be reached.

The treatment plan should be thorough and complete...conservatively aggressive restoration of caries. Rampant caries, large interproximal lesions, hypoplasia, pulp exposures, and gross decalcifications call for full coverage (Unitek Stainless Steel Crowns [3M ESPE]). No waiting and watching...extend restorations into grooves and clear of embrasures. Do it once and do it right [8].

### Special tooth-brush instruction for parents and children

Show parents how to gain access and control their child during the daily oral hygiene regimen...how to make it more fun and less drudgery. Remember, routine brushing and flossing may be difficult for the child or the parent. Preventing recurrent caries is the goal [9-12].

Use an intermittent, light-footed pedal technique when using high-speed and low-speed handpieces. Introduce the handpieces...“my finger...your finger...my finger...your finger... listen to the sound... feel the buzz,” etc. This time spent pays dividends. Remember your role as a coach...as an educator for the child. If you wish to allow the parent to visit the room for a look, do so but without the child being aware. Don’t break the spell.

Use local anesthesia as you would for any other patient. Mepivacaine without epinephrine is ideal because of the quick onset and a relatively rapid reversal which cuts down on lip and tongue biting following the dental visit. For extractions and short procedures not requiring a mandibular block, Septocaine (Articaine) is very effective. Lidocaine with epinephrine is ideal for procedures of 30 minutes duration and where some postoperative analgesia is desirable.

### Bite Blocks

We prefer not to rely on bite blocks to keep a child’s mouth open. Teaching children to bite down on the block defeats the ultimate purpose of encouraging them to stay open and respect your fingers. Having said that, there are patients who are severely limited in their ability to respond to the “open” or “stay open” prompt, in which case we use a Logi block (Optident) which is flexible, kind to the soft tissues, and because of its open shape doesn’t restrict accessibility to the teeth.

### Check-ups! Check-ups!

The importance of frequent recall visits cannot be over-emphasized. Whereas the 6-month interval may be suitable for most patients, 3 or 4

check-up visits a year may be indicated for those children with special needs who might be more physically difficult to treat, who have a higher susceptibility to caries, and whose parents have difficulty maintaining recommended oral hygiene regimens.

Prevention of extensive, recurrent caries or soft-tissue disease is paramount. Detecting and treating a small carious lesion is certainly easier than contending with more serious treatment. Furthermore, the significance of the more frequent contact with the auxiliary personnel, the doctor, and the whole dental experience cannot be underestimated.

The issue of insurance coverage and fees for multiple check-ups must be addressed by petitioning the insurance company, or the additional expense must be assumed by the parent where possible. When all else fails, it may be time for a goodwill gesture extended to the family by the dentist.

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