

The Special Patient with Autism &/or Anxiety: How you can help.....

Karen A. Raposa, RDH, MBA

- Compared with a sample of 1,751 community children, Asperger Syndrome and children with Autism demonstrated a greater rate of anxiety and depression problems. These problems had a significant impact on their overall adaptation.
- Multitude of studies on the topic of “Autism and Anxiety Disorder”
- A recent review of scientific studies on autism and anxiety revealed that we have no clear gauge of how commonly anxiety disorders overlap with autism. A few small, relatively short-term studies have produced starkly different results: from 11 percent to 84 percent. (For comparison, the prevalence of anxiety disorders among the general population is about 18 percent.)
- A reliable estimate will require a study that tracks many more individuals with autism over longer periods of time and that considers the distinctive way that anxiety oftentimes expresses itself in those affected by ASD
- Anxiety disorder defined: An ambiguous awareness of danger that increases breathing, body temperature, and muscle tension. It prepares or alerts people to adapt to a “fight or flight” situation. For some, the anxiety becomes incapacitating and prevents the enjoyment of everyday life events.
- Anxiety disorder statistics:
 - 18% of American adults suffer from anxiety disorder.
 - At least 40 million American adults suffer from anxiety disorder in a given year.
 - 36.9% of people with anxiety disorder report having moderate to severe dental fear.
- Substance Abuse Behaviors:
 - Patients with substance abuse issues who may be seeking narcotics can present as an anxious patient
 - These patients most often seek care in pain on an emergency basis and may feel highly embarrassed by the neglect that lead to the appt
 - Important to recognize they will most likely not disclose their addiction and will proceed with severe anxiety that the addiction will be discovered by the dental professional.
- Female anxious patients:
 - These patients feel extremely vulnerable during the dental appt....this results in a sense of helplessness
 - -- 20% of all females seeking dental care are survivors of Childhood Sexual Abuse (CSA)
 - -- 34% experienced childhood molestation
 - -- 15% reported attempted rape
 - -- 13% reported rape or incest
 - *This means that during a typical day at the office, you are likely to treat a CSA survivor*
- Post-traumatic Stress Disorder defined: An anxiety disorder characterized by the development of symptoms following an exposure to an extreme traumatic stressor involving direct personal experience of an event that involves actual or threatened death

or serious injury, or other threat to one's physical integrity; or witnessing an event that involves the same, or learning about the same experienced by a family member or close associate.

- *Disclosure of PTSD may not be revealed in the health history as patient may not think it is relevant or simply may not realize they suffer from this.*
- Three levels of dental anxiety:
 - Dental fear – normal emotional reaction to a specific threatening external dental stimulus
 - Dental anxiety – when the patient experiences apprehension about the appointment and is prepared for something negative to happen
 - Dental phobia – severe type of dental anxiety that may result in avoidance or endurance of the dental experience with significant discomfort
- Behaviors consistent with Dental Fear due to an Anxiety Disorder:
 - Sudden tears or yelling out when minimal dental work is being performed
 - Acting aloof or angry once seated in the chair
 - Somatic symptoms such as shaking or sweating, tensing up, and/or having difficulty keeping mouth open
 - May move head abruptly and erratically during a procedure creating a dangerous situation
- Anxiety – Directly related to stress and can come from any event or thought that makes you feel frustrated, angry, or nervous. Anxiety is a feeling of fear, unease, and worry. The source of these symptoms is not always known.

- Autism spectrum disorders (ASDs) are a group of developmental disabilities that are caused by unusual brain development. People with ASDs tend to have problems with social and communication skills. Many people with ASDs also have unusual ways of learning, paying attention, or reacting to different sensations. ASDs begin during childhood and last throughout a person's life.
- As many as 1 in 68 children today have some form of an ASD
As compared with:
 - Cerebral palsy (1 in 357)
 - Juvenile diabetes (1 in 450)
 - Down's syndrome (1 in 800)
 - Hearing loss (1 in 909)
 - Vision impairment (1 in 1,111)
- More than 3 children per hour are being diagnosed with ASD
- The rate of ASD diagnoses is rising 10-17% annually
- Diagnosis has increased tenfold in the last decade
- More than 24,000 children are diagnosed with ASD every year
- 35 million individuals have autism in the US today
- The CDC and Prevention have called autism a national public health crisis whose cause and cure remain unknown
- Annual cost in US to care for individuals with autism \$35 Billion
- Impairment in Social Reciprocity
 - Reduced interest in and attention to social stimuli
 - May be more interested in equipment and instruments than in dental staff

- May not readily respond to name, verbal directions, questions, or compliments
 - May not face and observe speaking partners
- Impairment in Communication
 - Social usage and implied meaning of language
 - May be overly direct, blunt, curt, personal in questions/comments
 - May not respond to cordial greetings from others
 - May interpret idioms, metaphors, and sarcasm very literally and concretely
 - May react unexpectedly and inappropriately to social humor intended to put them at ease
 - Reduced social chat and reciprocal conversation
 - May not make small talk or chat socially
 - May not initiate or maintain conversation
 - May not respond to pleasant comments or questions posed by staff
 - May have significant difficulty with open-ended questions, especially those on social topics
- The Autism Spectrum
 - Broad range of developmental functioning
 - Cognitive/Intellectual Ability
 - Profound impairments to superior IQ
 - Speech and Language Functioning
 - Functionally mute to very sophisticated language
 - Adaptive Functioning
 - Totally dependent to relatively self sufficient
 - Temperament
 - Intense and highly reactive to calm and passive
- Autism Spectrum Disorders
 - Pervasive Developmental Delay – Autism
 - Pervasive Developmental Delay – Not Otherwise Specified
 - Rett Disorder
 - Asperger Disorder
 - Child Disintegrative Disorder
 - Diagnostic Tools
 - Autism Diagnostic Interview – Revised (ADI-R)
 - Autism Diagnostic Observation Scale (ADOS)
 - Early signs and symptoms
 - No big smiles or other warm, joyful expressions by six months or thereafter
 - No back-and-forth sharing of sounds, smiles, or other facial expressions by nine months or thereafter
 - No babbling by 12 months
 - No back-and-forth gestures, such as pointing, showing, reaching, or waving by 12 months
 - No words by 16 months
 - No two-word meaningful phrases (without imitating or repeating) by 24 months

- Any loss of speech or babbling or social skills at any age

Speculations are as follows:

- Psychiatric Disorder
- Cholosystokinin
- Oxytocin and Vasopressin
- Amino Acids
- Stress and Immunity
- Vaccinations
- Prenatal Aspartame Exposure
- Vitamin A Deficiency
- Orphanin Protein
- Smoke and Air Pollution

Theories are as follows:

- Opioid excess theories
- Gluten/Casein theories and relation to Celiac Disease
- Gamma Interferon Theory
- Free Sulphate Theory
- Methylation Theory
- Autoimmune Theory
- Viral Infection Theory
- Action of Secretin Theories
- Intestinal Permeability Theories

Treatment options are as follows:

- Educational / Behavioral interventions
 - ABA (Applied Behavioral Analysis) – Discrete Trials
 - Speech / Language Therapy
 - Occupational Therapy
 - Physical Therapy
 - Hippotherapy
 - Music therapy
 - Social skills training
- Medications
 - Antidepressants – treats symptoms of anxiety, depression, or obsessive-compulsive disorder
 - Anti-psychotics - used to treat severe behavioral problems
 - Anticonvulsants – for treatment of seizure disorders
 - Stimulants - used to help decrease impulsivity and hyperactivity
- Other therapies: There are a number of controversial therapies or interventions. Few, if any, are supported by scientific studies.
 - Diet
 - Hyperbaric Chambers
 - Chelation
 - Acupuncture
 - Stem cells

Minimal Clinical Training in Medicine on Intellectual Disabilities (ID)

- 81% of medical students will graduate without ever having ANY clinical training in how to care for a person with an ID
- 90% of primary care residency programs offer no formal training in ID
- 51% of graduating dentists have not treated a patient with an ID
- 75% admit feeling inadequately trained in this field

Recent California state survey of people with ID living in the community documented:

- Only 11% say that it is easy to find a physician
- Only 2.7% say that it is easy to find a dentist

○

For the practitioner

You will need:

- an open mind and open heart
- more emotional skills than intellectual or clinical skills
- to get close to your patient both physically and emotionally
- to leave behind your reasoning skills; most times they will not work

AGD advises: *While we encourage all dental professionals to treat these individuals, the law does not require professionals to accept patients with special needs into their practice.*

However, they should try to provide some guidance by knowing who does have the experience and education to treat patients with special needs in their community.

Start at the beginning:

- The VERY beginning in some cases means: Seek out these patients
 - Brochures available in the waiting area on treating a patient with special needs (American Academy of Pediatric Dentistry)
 - Provide parents that inquire with a form that asks questions about their child – this shows that you understand and care

What the Patient Information form should look like:

- Describe the nature of your child's disability
- Medical
- Dental experience
- Physical functioning
- Sensation
- Communication
- Vision
- Hearing
- Behavior / Emotions
- Oral habits (include eating, chewing, PICA)

- During the phone call:
 - Review patient information form in detail
 - Ask what is the best time of day for the appt.
 - Ask the parent to bring the child's favorite music, video, toy, comfort blanket, or other COPING DEVICES
 - Ask the parent to bring a friend who can sit with the child while the forms are reviewed

- Offer to send photos of office and a dental story home with patient for parent to review

Desensitizing/Trust-Building Appt.

- First scheduled appointment should be interview, orientation, and brief exam only (20 mins.)
- Primary goal is to establish trust
- Help parent and patient know that you care about them
- Ask parent to choose a location (waiting area, operatory, office, staff lunch room?)

Top 10: What caregivers need from dental office staff:

1. Dental office staff have an understanding of the disability and the anxiety that individuals may have about dental visits
2. Treat individuals and caregivers with the same respect and dignity as others receive and recognize unique family strengths
3. Have short wait times and a low stress, quiet environment, with special or separate waiting rooms
4. Speak directly to the individual
5. Allow extra time for the appointment
6. Listen to caregivers' and individuals' expressed needs (verbal and non-verbal)
7. Share complete and unbiased information with families
8. Allow caregivers to be present during visit and ask them questions when needed
9. See the individual as a person with unique needs, not as a "disabled person"
10. Make appropriate referrals and timely follow through with paperwork

Top 10: What caregivers said they should do for themselves:

1. Prepare the individual for dental visit through role-play, books, and pictures
2. Bring distractions for waiting and exam rooms (books, music, video, games, etc) and offer rewards (prizes, outings, etc)
3. Ask for a "get acquainted" visit
4. Schedule appointment at a time that is best for the individual (first or last appointment of the day)
5. Keep a dental journal of co-payments, medications, treatments, prior visits, referrals
6. Make sure the parking lot, building, and office are accessible
7. Talk to the dentist and staff before the visit, preparing staff ahead of time and reminding them of the individual's needs, mail or fax a summary letter (ie. patient information form)
8. Bring a support person to listen to the dentist/hygienist/assistant, write things down, and help with other children
9. Research dental issues in books, journals, and online, and ask lots of questions
10. Ask for the same staff each time

Oral Habits – Pica

- Comes from the Latin word for magpie, a bird known for its large and indiscriminate appetite

- Most common in people with developmental disabilities, including autism and mental retardation
- Commonly ingested foods include: dirt, clay, paint chips, plaster, chalk, cornstarch, laundry starch, baking soda, coffee grounds, cigarette ashes, burnt match heads, cigarette butts, feces, ice, glue, hair, buttons, paper, sand, toothpaste!, soap

Sensory modulation processing disorder

- *Sensory processing may be similar to infant* -
 - Olfactory – office, perfume, cologne
 - Auditory – sudden noises, music, high speed handpiece
 - Gustatory – tastes & textures
 - Visual – lights, peripheral dominance
 - Vestibular – chair height & tilt, being “still”
 - Proximity – people, water
 - Proprioception – jaw opening, gagging, body position, lead apron
 - Tactile (Touch/Temp/Texture) – room, gloves, air, cotton, metal
 - Taste – gloves, chemicals

Sensory Issues: Sensory modulation processing disorder

Manifests as one of the following:

- Over Responsivity – slight input causes extreme reaction
- Under Responsivity – requires stronger input to register sensation
- Sensory seeking – hypo and hyper sensitivities co-mingle within the same sense

Behavior / Emotions

Actions speak louder than words!! Questions to ask regarding possible dental pain....

- Any changes in behavior or prolonged episodes of behavioral abnormalities?
-

Behavior = Communication

- individuals with autism act out for a reason
- it is not about defiance, it is about coping with some type of anxiety
- they often can not communicate dental pain
 - More aggressive
 - Reduction in eating habits

Communication

- Hearing difficulties
- Receptive language skills
 - Following directions
 - Learning new things
- Expressive language skills
 - Make needs known
 - Ability to speak so others understand
 - Echolalia
 - Verbal and non-verbal cues

- Useful words and phrases
- Communication device(s)

“DESENSITIZATION / TRUST BUILDING APPOINTMENT”

- Ask parent to choose a location (waiting area, operatory, office, staff lunch room?)
- Orientation – Tell / Show / Do
- Brief exam (no instruments) – Let the patient decide where they would like to sit
- Reward, Reward, Reward

What did you learn?

The next scheduled appointment should be based entirely on what you learned about the patient at this appointment.

- How much time will you need?
- What do you plan to accomplish?
- What accommodations will be necessary?
- How will you measure success?

Focus on the patients abilities, not their disabilities, to determine what will work.

–

Basic Rules

- Keep the appt. short and sweet
- Perform treatment a little bit at a time
- A smile and sense of playfulness go a long way
- Speak the patient’s language
- Understand the patient’s developmental age
- Allow choices for the patient
- Establish a relaxed atmosphere
 - Keep instruments out of sight
 - Keep light out of eyes
- Exceptional memories
 - Good experience = more cooperation next visit
 - Poor experience = difficult future visits

Simple Tools - “*Sometimes the best tool for the job is the Simplest*”

- Positive reinforcement – Be sincere, consistent praise, high fives
- Extinction (ignore)
- Consistency (operator, personnel)
- Tell-Show-Do
- Distraction (counting, singing)
- Calm demeanor, using gentle tone of voice
- Easy requests first, build to more difficult requests
- Pre-appt preparation/Familiarization & Modeling

Low Tech Visual Cues

- Activity Schedule – could be added to “Tool Box”
- Basic Rules to Remember – “Hands on the Tummy” “Feet out Straight”
- Time cards – Linear sequence of visuals which are removed at set intervals
- Break card

- Visual negotiation – “First” you do this, “Then” you can do that
- Visual reward
- Positive visual Behavioral Support Strategies (Token board, star chart)
- Visual Timer

Familiarization Method – *“D-termined Program of Repetitive Tasking and Familiarization in Dentistry”Dr. David Tesini*

- One new step at each visit
- Parents/caregivers must practice routine at home
- Encourage caregivers to “play dentist” at home

Three Key Factors

1) *Eye Contact – “Look at me”*

2) *Educational Modeling (clear direction) – “Hands on your tummy”, “Feet out straight”*

3) *Counting Framework – “Let me do it for a count of 10”*

- Use analogy – Home care therapy is another goal for the IEP (Individualized Education Plan)
 - Individual must be conditioned to accept this routine (just like all other self care routines)
 - Use pictures (PECS) to show progress through the routine www.do2learn.com
 - Break down the routine
 - Put paste on the brush
 - Wet the brush
 - Brush 1 – 32 teeth
 - Rinse
 - Floss
 - Apply fluoride
 - Ideal therapy 2x/day

Overcoming Obstacles to Dental Health: 4th Edition *A Training Program for Caregivers of People with Special Needs* (includes training manual, workbook, and DVD)

University of the Pacific
 Arthur A. Dugoni School of Dentistry
 Pacific Center for Special Care
 2155 Webster Street
 San Francisco, CA 94115

415-749-3384

Caries Risk Reduction Regime

- Patients with disabilities that necessitate the help of a caregiver to provide daily oral home care will benefit tremendously
- If a hospital visit is the only way to accomplish restorative care for a patient with special needs, prevention takes on a whole new level of importance

ADDITIONAL READING:

- Textbook: “Treating the Dental Patient with a Developmental Disorder” Edited by Karen A. Raposa and Steven P. Perlman
- Textbook Chapter: “Clinical Practice of the Dental Hygienist” Esther M. Wilkins
Chapter 60: The Patient with a Developmental or Behavioral Disorder
Contributing author: Karen A. Raposa
- Publication: “Dental Clinics of North America: The Special Care Patient”
April 2009, Volume 53, Number 2
Chapter : “Behavioral Management for Patients with Intellectual and Developmental Disorders”
Contributing author: Karen A. Raposa

RESOURCES:

- www.autisminfo.com
- www.healing-arts.org
- www.do2learn.com
- www.cdc.gov
- www.arktherapeuticservices.com
- www.iancommunity.org
- www.mun-h-center.com
- www.ninds.nih.gov
- www.autismspot.com
- www.crosstex.com
- *Journal of Dental Education, Dec. 2005, Vol69, No12*
- www.especialneeds.com
- www.woodlaketechnologies.com
- *Folse, G., Glassman, P., Miller, C., “Serving the Patient with Special Needs” Access, January 2006*
- *Majeski, J CRA/CAMBRA and the Dental Hygiene Process of Care Access, Feb 2009.*
- *Science Daily, Feb 22, 2009*
- www.fightingautism.org
- www.specializedcare.com
- *Elliott-Smith, S., “Special Products for Patients with Special Needs” Access, January 2006*
- www.profitadvisors.com/word
- www.autismspeaks.org
- *“Special Care: Treating Patients with Special Needs Requires Both Training and Compassion” AGD Impact, October 2007*
- *Versloot, J., Hall-Scullin, E., Veerkamp, J., Freeman, R., “Dental discomfort Questionnaire: its use with children with a learning disability” Spec Care Dentist” 28(4): 140-144, 2008*
- www.eparent.com
- Kripke, Clarissa, “A Blind Spot in the System: Health Care for People with Developmental Disabilities
- www.snoezeleninfo.com

- www.thewingmensite.com
- “Standards for Clinical Dental Hygiene Practice” www.adha.org
- www.pedisedate.com
- http://dental.washington.edu/departments/omed/decod/special_needs_facts.php
- www.pwpde.com
- www.healthysmilesforautism.org
- www.gmc-uk.org
- www.cozycalm.com
- www.crescentproducts.com
- www.elevateoralcare.com
- Comer, R. J. (2010). *Abnormal psychology* (7 ed.). New York, NY: Worth Publishers.
- Gunn, R. L., Finn, P. R., Endres, M. J., Gerst, K. R., & Spinola, S. (2013). Dimensions of disinhibited personality and their relation with alcohol use and problems. *Addictive Behaviors*, 38, 2353-2360.
- Leeners, B., Stiller, R., Block, E., Gorres, G., Inthurn, B., & Rath, W. (2007). Consequences of childhood sexual abuse experiences on dental care (Abstract). *Journal of Psychosomatic Research*, 62, 581-588.
- US. Department of Health and Human Services (2009). *Anxiety disorders: national institute of Mental Health*.
- Willumsen, T. (2004). The impact of childhood sexual abuse on dental fear. *Community Dentistry and Oral Epidemiology*, 32, 73-79.

HELPFUL ORGANIZATIONS:

- The Special Care Dentistry Association (SCDA) www.scdonline.org
- *The National Foundation of Dentistry for the Handicapped (NFDH)* <http://nfdh.org>
- *The National Institute for Dental and Craniofacial Research (NIDCR)*
www.nidcr.nih.gov
- The American Academy of Developmental Medicine and Dentistry (AADMD)
www.aadmd.org
- National Survey of Children with Special Health Care Needs www.cshcndata.org
- National Oral Health Information Clearinghouse (NOHIC)
301-402-7364
www.nohic.nidcr.nih.gov
Order: Rolodex Card, Publication Order Form, and Practical Oral Care – Dental Provider’s Kit
Contains: Caregiver’s Guide to Dental Care Everyday, Continuing Education, and Booklets specific to a number of disabilities including Autism.
- American Academy of Pediatric Dentistry
211 East Chicago Ave, Ste. 700
Chicago, IL 60611

Brochure: “Dental Care For Your Special Child”

DR. PHILIP M. ROBITAILLE

PATIENT INFORMATION (Please Print)

Date: _____

PERSONAL INFORMATION:

Name: _____

Address: _____

City _____ State _____ Zip Code _____

Phone:
(home) _____ (work) _____

Email
Address: _____

Date of Birth: ____ / ____ / ____ Age: ____ Height: _____
Weight: _____

PERSON TO CONTACT IN CASE OF EMERGENCY:

Name: _____ Relationship: _____

Address: (if different from above)

Phone: home- _____

work- _____

Current Physician: _____

Phone: _____

MEDICAL INFORMATION:

Describe the nature of your disability:

Are you currently taking any medications? YES NO

If yes, what
medications: _____

Describe side effects of current
medications: _____

Have you ever had SEIZURES? YES NO

If YES, date of last seizure _____

Describe the type of seizure _____

Do you have any ALLERGIES? YES NO

If yes, please list _____

Do you have any FOOD SENSITIVITIES OR AVERSIONS? YES NO

If yes, please list _____

Do you have any BLADDER or BOWEL ADAPTATIONS? YES NO

Please list any adaptations:

Are there any precautions we should be aware of regarding bladder/bowel control?:

DENTAL EXPERIENCE:

Have you had any dental experiences? YES NO If yes, please
describe_____.

Do you have a dental experience at home on a daily basis? YES NO
If yes, please describe _____.

How would you describe your tolerance for dental experiences? Good Fair
Poor

Do you use a powered toothbrush or a manual toothbrush?_____

What are your dental health goals?_____

ORAL HABITS

How often are you snacking during the day?_____

Is food used as a reward during therapy?:_____

If yes, what types of food do you prefer?:_____

Do you need to chew for sensory stimulation?_____

If yes, how often per day?:_____

If yes, what materials do you chew on?:_____

Do you have a tendency to put non-edible items in your mouth?

If yes, please describe?:_____

PHYSICAL FUNCTIONING

Are you currently working or attending school?_____

If yes, how long is your average work or school day?:_____

Do you have difficulty breathing?_____

Do you have normal range of motion in the following?

Right arm: YES NO Left arm: YES NO

If NO. please

describe: _____

Describe your strength: (Circle all that apply)

Upper Body:	Weak	Average	Strong
Left Side:	Weak	Average	Strong
Right Side:	Weak	Average	Strong

SENSATION:

Is any part of your body paralyzed?	YES	NO
Can you feel hot and cold normally?	YES	NO

If YES to any of the above, please explain: _____

COMMUNICATION:

Receptive communication level	High	Medium	Low
Expressive communication level	High	Medium	Low
Can patient make needs known to dental team?	YES		NO
Do you have difficulty speaking or communicating?	YES		NO
Do others have difficulty understanding you?	YES		NO
Do you have difficulty remembering things?:	YES		NO
Do you have difficulty in learning new things?:	YES		NO
Do you have difficulty following directions?:	YES		NO
Do you have difficulty hearing?:	YES		NO

If you answered YES to any of these questions, PLEASE EXPLAIN: _____

Useful phrases or words that work best with patient?_____

Does student use non verbal communication? YES NO

If YES:

- Mayer Johnson Symbols
- Sign Language
- Picture Exchange Communication System (PECS)
- Sentence Board or Gestures

Will you be bringing a communication system with you? YES NO

Are there any symbols/signs that we can have available to assist with communication?_____

VISION:

Do you wear glasses?: YES NO

Do you wear contacts?: YES NO

Please mark any of the following that are true about your vision:

double vision_____

visual perceptual problems_____

can only see to one side_____ Which side, left_____

right_____

HEARING

Do you have a hearing impairment? YES NO

Do you wear a hearing aide? YES NO

If YES, please explain_____

BEHAVIOR/EMOTIONS:

Impulsive?	YES	NO
Do you become easily frustrated?	YES	NO
Do you become angry easily?	YES	NO
Do you every physically/verbally lose control?	YES	NO

PLEASE give details to any question that you answered yes to: _____

What are the best ways to help you gain control? _____

Behavior to be discouraged: _____

PLEASE GIVE ANY ADDITIONAL INFORMATION THAT MAY HELP US TO PREPARE FOR A SUCCESSFUL DENTAL EXPERIENCE: _____

Available now at Amazon.com

Karen can be reached at www.karenraposa.com or at
Karen@karenraposa.com

