

Puberty and Autism: What to Expect

WEBINAR



*Families with autism
helping families with autism.*

Webinar Disclaimer

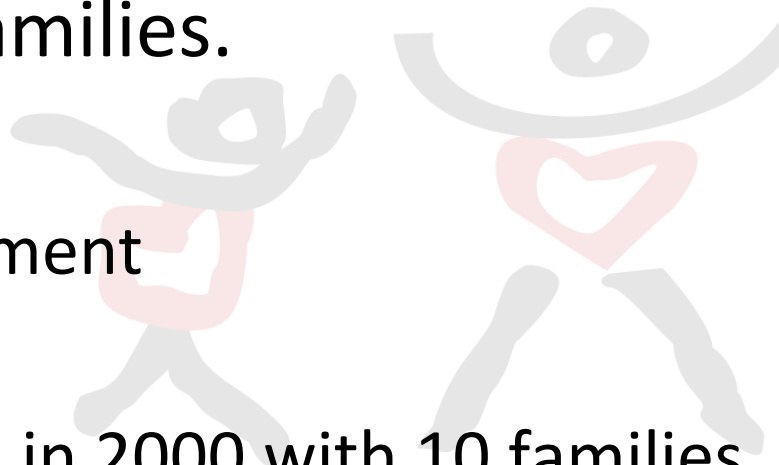
The information contained in this presentation applies to the USA only and is current as of the date of this live webinar, April 3, 2013.

Other countries have different laws, services and resources. To find information and help outside the USA, please go to <http://www.tacanow.org/family-resources/international-resources/>

Who is TACA?

A United States 501(c)(3) non profit organization

- TACA is Real Help Now for children with autism and their families.
 - ✓ Education
 - ✓ Empowerment
 - ✓ Support
- TACA started in 2000 with 10 families.
- We're now providing services to more than 31,000 families across the country.



TACA Programs

- TACA provides support and education for families affected by autism through the following efforts:
- Outreach & Support: Chapters in 19 states via meetings & Coffee Talks
- Social family events
- Autism Youth Ambassadors in high school and college campuses
- Support via Chapters, Parent Mentor Program, LiveChat, email and phone.
- Keep informed with our enews and social media
- Our extensive website, available free 24/7
- Conferences
- Journey Guides
- Scholarship Programs
- Spanish Outreach and more!

About the presenter

Holly Bortfeld is a single mother of 2 teenagers with ASD. A long time homeschooler living in PA, Holly has been doing biomedical treatments since 1998. Holly is the National Parent Support Manager and lead author for TACA.



Agenda

- Puberty
- Sexuality
- Seizures
- Anxiety
- For Girls Only

The future depends on what we do in the present. – Mahatma Gandhi

Puberty: The Great Equalizer

- I have always called puberty the “great equalizer” because I have seen so many kids drastically change, good or bad, during puberty. Some children, with no changes in therapies, regress terribly and some progress amazingly, without explanation. Although there is no published research on medically treated kids yet, in my experience the kids who entered puberty with a treated gut didn’t regress or begin seizures, so getting them in the best medical shape possible before puberty hits seems to be an important key.
- Parents ask me all the time what is puberty going to be like for my child? Honestly, we have no idea because like all things autism, it’s different for every child. There are certain things that will be happening for every child, but they are the same things that happen with or without autism – spontaneous erections, masturbating, facial hair and funky smells for boys; and for girls, periods, growing breasts, shaving and yes, more masturbating. The rest is truly child dependent so let’s talk about how a child with ASD might need a different approach to the most common issues.

Emotional outbursts

- Yep, you have these to look forward to. Hormone surges cause unreasonable mood swings, aggression, arguing, and the ever fun, defiance. For kids with ASD that may also include new or increased self-injurious behavior. Consider creating a safe place for them to go work out their outbursts, if they don't have one already. Their bedroom is the obvious place but if they share a room with a sibling, then they may need a private place. Teaching your child self-regulation will be critical in surviving the mood swings. Picking your battles will be the key to your sanity. Since the tiniest of things may set them off during the hormonal surges, if the topic isn't important, let it go. Remember the motto: "Let it go, let it flow." It may save what's left of your sanity.

Hygiene

- Hygiene crosses into both social skills and life skills. There is a great book called *Hygiene and Related Behaviors for Children and Adolescents with Autism Spectrum and Related Disorders: A Fun Curriculum with a Focus on Social Understanding* by Kelly J. Mahler (this comes with a CD with printable worksheets) that helped us fill in the gaps for my son's needs and I think your kids will enjoy the games and social stories they include.

Hair and Shaving

- Shaving is fun, right? Not so much. Boys are going to need to shave their facial hair even if full beards make a comeback, since facial hair also happens to be very itchy and our kids usually have sensory issues which lead us back to shaving.
- If your kid has sensory issues, you may have to take months or years desensitizing them to the buzzing and vibration of an electric shaver or brave the dreaded razor blade for shaving. You will likely have to shave your son's face for him many times before you can try a hand-over-hand approach. You can also start the independent trials with the cover still on the blade so he can learn the motions and procedures without the danger. Here is a nice tutorial http://www.ehow.com/how_2116_shave-face.html
- My son is 17 and I bought an inexpensive electric razor (on sale it was \$15). We just started by having him hold it (with the safety cover on) and just turn the motor on and feel and cope with the vibrations and noise. We then moved to getting it closer to his face, then touching his face (cover still on) and then actually using it on his face. All this before he ever had facial hair. Your OT and ABA therapists can also reinforce these skills to help with desensitization.

Hair and Shaving

- For girls, the only thing they really must shave is their armpits. Fortunately, this is a very small area and not nearly as tricky as the face for boys. You could have them waxed but it is painful and only lasts 2-3 weeks so shaving really is the best way.
- For girl's legs, if she/you choose to shave them, you can choose a traditional razor or an electric option. Since the calves are such a large area, an electric shaver may be a good bet. Panasonic makes a pretty good, pain-free shaver but if your daughter is very sensory defensive you will either have to work on sensitization (see previous slide for boy's facial shaving), or teach her how to safely use a regular razor.
- Organic waxes for both legs and female facial hair are available, such as Moom's brand and you can research them at www.cosmeticsdatabase.com and search for "hair removal". Hair removal creams like Nair work for legs, but are very toxic so they would not be recommended for a person with autism.
- Electrolysis is also a viable, painless option:
<http://www.webmd.com/beauty/hair-removal/cosmetic-procedures-electrolysis>

What's that smell?

- Ugh. My son was 15 when that smell started. I thought it was me but after sniffing around, I realized it was my son. He had just had a bath that morning so why did he smell like that? Puberty, that's why. In addition to being confusing, it's also stinky. Great.
- Daily baths or showers were now very important and deodorant just became critical. Because antiperspirants contain toxic aluminum, you should be avoiding them and using deodorants. This will create a little more work to find a good one to fit your child, since some are wet, some sticky and some just smell bad in their own right. We've tried them all and I will say that the powder gives both the best effects and causes the least problems. There is a brand called Pit Powder that makes both a men's and women's version that my kids (and I) love. Some people are allergic to corn (PitPowder uses cornstarch) so you can try other brands or even make your own. There is also a crystal that works great but you need water and some tactile kids may not do well with it but it's worth a trial.

What's that smell?

Recipes to make your own deodorants

- <http://1greengeneration.elementsintime.com/?p=596>
- <http://www.natural-homeremedies.org/homemaderecpiess/homemade-deodorant.htm>
- <http://recipemama.wordpress.com/2008/11/13/home-made-deodorant/>

Sexuality

- **Sexuality**
- I am not going to cover dating and actual sex in this article since there are great books available. And since each person is different, it's impossible to cover all of the possibilities of dating and consensual sex (plus I just don't feel like I have the expertise for it since my kids haven't gone there). The topics that I want to address are the parts that happen to all humans, no matter their functioning level or if they will ever be able to have a consensual sexual relationship or not. Please grab your sense of humor and read on.

Sexuality

When does sexuality start for kids with autism?

- Developmental delay can mean in all areas so just because your child reaches physical sexual age and things, um, blossom, doesn't mean they have the social maturity to know what to do with it. Therefore sexual activity, or ability to express the need or desire for it, may likely also be delayed.

Sexuality

Things we want all kids to know

- Ideally all children need to know a few things to keep them safe when it comes to sexuality. Some children may not fully understand what is happening to them or the urges they are having, and they also won't understand or know how to deal with advances made by others. As with all things autism, preteaching these skills and basics in advance is necessary.
- Knowing when and in what order these things will happen is necessary for preteaching and I have to admit, it's amazingly difficult to find non-pornographic information about ejaculation when surfing the internet. So here is a great, non-pornographic link to help at <http://www.bodyteen.com/dema.html> . You're welcome.
 - ✓ Anatomy – use real terms (not peepee or hoo-hoo)
 - ✓ Appropriate behavior – don't expose yourself, or do sexual things in public places
 - ✓ Safety – don't let people touch your privates or touch other people's privates; always tell mom/dad if it happens
 - ✓ Peer pressure to partake in anything sexual

Nocturnal Emissions

- One of the first fun things to happen with boys after achieving erections is ejaculation. This can happen involuntarily in the form of “wet dreams” when sleeping as well as during masturbation or sexual activity. It took us years to get my son NOT to pee in bed. We worked on the medical and behavioral aspects of it and tried everything, but we finally had success a few years before puberty. Puberty comes with a little delight called nocturnal emissions. Whee. Some children may fear they will be in trouble for “wetting” the bed due to involuntary wet dreams and depending on the functioning level of the boy, you may be able to explain the difference. Either way, check the sheets and bedding every morning and change them as appropriate. Social stories should help with this issue as well.
- One mom contacted me about her son who started to pee in his room after he discovered masturbation, something he hadn’t done in more than a decade. I surmised that it was likely that when he was finished and ejaculated and found it was wet, he assumed it was urine and just kept urinating. So be prepared to have to explain the difference.

Erections

Erections – Yeah, I said it.

- Spontaneous erections for boys are just that – spontaneous. Not much you can do about it happening but when they do, you can teach him to cover up the area with something like a book if he isn't home. Or if he is home, just sending him to his room usually works.

Masturbation

- Masturbating is different because it's a conscious activity and should ONLY be allowed in one place – their bedroom. Not the bathroom, because what if he decides to do it in a public bathroom – not only does that open him up to abuse but can also get him arrested. Nowhere that can be duplicated elsewhere, meaning HIS/HER OWN bedroom only.
- Reinforce that there is no other acceptable place except his or her own bedroom for masturbation. And before you decide to merely say NO to all masturbation, please remember that sexuality is part of the human condition and you cannot turn that off or stop it, no matter how much you don't like the idea. So give them one safe place where they can do what is natural and actually has been found to have many health benefits like calming, sleep aid, pain relief and more.

Masturbation

- **A note about masturbation and yeast**
- When parents ask why their child all of a sudden starts masturbation and does it A LOT, yeast is to be considered. Masturbation can be a form of stimming, or self-stimulation, rather than true sexual desire when it's caused by yeast overgrowth. The most common time we get this question is before the children have begun puberty and if the kids go from no masturbation to 20 or more times a day, you should have your child's stool tested for yeast. Please read this for more information on yeast overgrowth at <http://www.tacanow.org/family-resources/what-is-yeast-overgrowth/>

Paying for It

- I read a book a few years back where a mom was interviewed and she tells how she hired a prostitute for her son with autism. The danger I see with this is that he may assume all women will be with him for money and that may get him into trouble down the road, especially since this is still illegal (except in 8 counties in Nevada) in the US. This would present even more problems for lower functioning individuals who may not understand that “just any woman on the street” isn’t going to want to have sex with them without any relationship.
- As a parent of a child who may never function high enough to understand and participate in consensual sex with another, I don’t feel that I know enough about the topic to do it justice. Therefore, there is a list of books to explore the topic on our website, if you wish to do so.

Something Wicked This Way Comes

- One unfortunate thing that can happen with puberty-related hormone changes is the onset of seizures or conditions like anxiety. Even if you've never seen signs of anxiety or seizure disorder before puberty, you need to know these can start for some kids. Some are hormone-related so adjusting hormones, maybe even with meds, may be in order.

Seizures

- There has not been a lot of research done into older children with ASD to date unfortunately but there are data trends done by ARI and this article from ARI at: http://www.autism.com/index.php/symptoms_seizures_puberty
- **Puberty and Seizures** written by Stephen M. Edelson, Ph.D.
- About one in four autistic individuals begin to have seizures during puberty. The exact reason for the onset of seizures is not known, but it is likely that the seizure activity may be due to hormonal changes in the body. Sometimes these seizures are noticeable, (i.e., associated with convulsions); but for many, they are small, subclinical seizures, and are typically not detected by simple observation.

Seizures (continued)

- Some possible signs of subclinical seizure activity include:
- exhibiting behavior problems, such as aggression, self-injury, and severe tantrumming;
- making little or no academic gains after doing well during childhood and pre-teen years;
- and/or losing some behavioral and/or cognitive gains.
- Personally, I have known a few autistic individuals who were considered high-functioning prior to puberty. During puberty, they experienced seizures which were not treated. By their late teens, they were considered, however, as low functioning. Some parents have an EEG performed to see if their child shows any seizure activity. However, even if the EEG does not detect abnormal activity during the testing period, one cannot conclude that the person does not have seizures. To increase the likelihood of detection, some individuals are assessed with an EEG for 24 to 48 hours.

Seizures (continued)

- Interestingly, vitamin B6 with magnesium as well as dimethylglycine (DMG) are known to reduce or eliminate seizure activity in some individuals, even in cases where seizure drugs are ineffective.
- Note that the majority of autistic individuals do not have seizures during puberty. In fact, many parents have told me that their son/daughter actually experienced a dramatic developmental leap forward during this period.
- Parents of autistic children should be aware of the possible positive and negative changes that can occur with puberty. Of particular importance is the need for parents to be cognizant of the fact that about 25% of autistic individuals may experience clinical or subclinical seizures which, if left untreated, can lead to deleterious effects.

New Seizures Research

- A 2010 study says that not all seizures are purely neurological. Patients presenting with seizures who have no apparent epilepsy or other obvious cause may have an autoimmune condition, according to a study: ***Autoimmune Epilepsy: An Under-Recognized Cause of Epilepsy.***
- Before accepting seizure medications, running full immunological panels, and treating any issues, are **HIGHLY** recommended.
- Visit the TACA Seizures Page for more information
At <http://www.tacanow.org/family-resources/seizures/>

Anxiety

- Anxiety and stress can emerge or become more pronounced with puberty as well, so consider getting your child into activities that help them head off those issues. Yoga, Tai Chi and cardio exercise are very effective tools for kids with anxiety since they teach self-calming techniques and release endorphins which relieve stress and pain.

Common symptoms of anxiety

- Heart rate accelerations resulting in palpitations, sweating, dizziness, and difficulty breathing are common symptoms of anxiety. In fact, many people feel as if they are suffocating and cannot catch their breath. This can be enormously frightening and can only serve to exacerbate symptoms. Other physical symptoms may include diarrhea, vomiting, dry mouth, inability to swallow, headache, shaking, trembling, and frequent urination.
- But there are psychological anxiety symptoms that sufferers experience as well. Anxiety sufferers may feel ongoing heightened sensitivity or feelings of worry and unease, fatigue, difficulty concentrating, irritability, and insomnia. Many people feel as if they are “going crazy” and have difficulty separating reality from the imaginary.
- For a child who cannot express or explain these feelings or symptoms you may see increased OCD, self-injurious behaviors, sleep disturbances where there were none before, increased need for stimming, need for being alone, and aggression. Testing for PANDAS (Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections) in the presence of OCD should be your first step. Two good sites for info are **Latitudes Journal** and <http://www.savingsammy.net/>

Calming Techniques

- A sensory diet to include things like sensory breaks throughout the day with a quiet place to decompress; weighted vest, deep pressure massage, swinging, bouncing, and use of the Wilbarger Protocol.
- Using visual or written schedules to help them know what is going to happen during their day.
- Epsom salts baths
- Supplements like GABA, taurine, EFAs, B6, inositol, 5HTP, Magnesium, l-theanine and others that slow neurotransmitters.
- Removing the offenders like food colorings and preservatives, excitotoxins like MSG and aspartame and caffeine. (link to toxins in food page)
- If your child is able to participate in therapy, such as with a counselor or psychologist, it may help for them to talk it out and get advice on how to deal with the situations they are having problems coping with or understanding.
- Tai Chi or Yoga
- Cardio exercise
- “1-5 Scale of Frustration” by Buron and Curtis.

Why Tai Chi?

- Why Tai Chi? “In a world that assaults the senses, a common reaction to over-stimulation for a person on the autism spectrum is freezing up, or becoming tense, blocked, and withdrawn. With regular practice of Tai Chi, the mind learns how to let go, and the body responds by letting go of blocks and deeply held tension. As one practices, the body finds its own relaxation response.” Mary Christianson, Tai Chi for autism instructor.
www.taichiforkids.com sells a great set of DVDs that come with laminated picture (drawing, not photo) cards for \$25.

For Girl's Only

- For girls, breast changes and hair growth start usually between 7-14 with menses starting a few years after the physical changes. How you prepare your daughter will depend on her functioning level.
- Have her begin wearing a mini-pad a few months in advance to get used to the feeling of wearing a pad.
- When a girl starts menses, the first few periods are irregular but will normalize to approximately every 28 days. Use a calendar to show when her period SHOULD be coming by marking those days.
- Use a visual schedule to show times during the day that she needs to change her pad and bathe.
- Use a social story about blood coming out of their vagina and flowing between her legs, and what she should do about it (tell a teacher, use the “show period” PECS card, etc.) and how we change pads in the bathroom and bathe every day (or more often) during this 5-6 day time and that her tummy may hurt those days. It's important not to make the story sound too scary or painful, otherwise it may create OCD about it.
- Buy a dozen pair of light-colored underwear and mark on them with a sharpie where the pad should go and teach your child how to change the pad and dispose of the old (wrapped and in the trash).

Feminine Hygiene Products for girls

- Tampons should be the last resort for ASD girls since they are harder to use than pads but also because they can cause toxic shock syndrome if not changed often enough. Most commercially available tampons are treated with many chemicals which are not ideal to be used inside the body. Additionally, since sensory dysfunction is common, your child may not be able to feel when it needs to be changed. You can now buy organic, unbleached feminine hygiene products, tampons and pads at health food stores, online and even in your local grocery stores from brands like [Natracare](#), Maxim and Seventh Generation.
- **Anigan StainFree Seamless Menstrual Panties** can be bought on amazon.com

A special note about “controlling” periods

- Parents have asked us about using the new birth control products on the market that stop girls from having periods. However there are no long-term safety studies to tell us what effect that may have on our daughter’s health and is therefore not something that is considered a recommended practice for girls with ASD. We believe most girls, no matter their functioning level, can be taught the necessary skills needed. Birth control pills carry their own health risks even when they don’t suppress a period but the risk is even greater as there are more hormones given in the type that suppress periods. Though your gynecologist may recommend these pills, as parents you have to weigh the risks versus the benefits, since the risks are still unknown and as yet we have not yet seen long-term safety studies for these products.

Books for girls only

- *Girls Growing Up on the Autism Spectrum: What Parents and Professionals Should Know About the Pre-teen and Teenage Years* by Shana Nichols
- *The Care and Keeping of You* from the American Girl Library is one in a great series of helpful books for girls.
- *Sex, Puberty, and All That Stuff: A Guide to Growing Up* by Jacqui Bailey is a more detailed book about puberty, dating and sex.
- *Period.: A Girl's Guide* by JoAnn Loulan (2001 version)

Recommended Reading

There are many great books listed on our site on puberty and ASD at:
<http://www.tacanow.org/family-resources/teens-with-asd-puberty/#Reading>

Your Homework!

- TACA offers a lot for families. Be sure to:
 - ✓ Attend a meeting, Coffee Talk or conference
 - ✓ Come to a family event
 - ✓ Apply for a free Parent Mentor
 - ✓ There is so much we offer – be sure to plug into your community
- Don't have a chapter in your area? Learn how to develop your community to bring TACA to you. <http://www.tacanow.org/local-chapters/>
- Until then, you can access all of our programs, webinars, the immense TACA website, Live Chat and parent support via phone and email.
- Feedback: Tell us what you need if we don't already have it.

Questions?



Contact me

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- Follow me on Twitter: @TACANOW
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<http://www.facebook.com/talkaboutcuringautism>
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