ASD & PUBERTY By Dr. Kate Aubrey, Registered Psychologist

ASD IN THE TEEN YEARS

Adolescence and autism spectrum disorder (ASD) each on their own are difficult, together they can form a volatile mix. Most research in ASD is conducted with children and very little is known about the course of ASD through adolescence and into young adulthood. During puberty, parents can expect to see fewer non-functional and repetitive behaviours (e.g., lining things up, self-harm) and modest improvements in daily living skills. Socially, however, the gap between youth on and off the spectrum widens and parents will notice greater and greater social challenges during this time. Scaffolding and support from teachers, physicians, and interventionists also tends to reduce during adolescence as gold-standard treatments and supports for ASD are focused on children. **This brochure will give you some ideas of how to help your child during puberty and adolescence**.

PHYSICAL CHANGES & HYGIENE

TALKING TO YOUR CHILD ABOUT PHYSICAL CHANGES

For an adolescent with ASD, the physical changes that indicate increasing maturity can be quite out of place in comparison to other aspects of their development, such as social and self-care skills.

If your child has moderate to severe difficulties with language and abstract concepts, they will not need to know the reasons behind the developmental changes that occur during puberty. Preparation for these individuals is less about teaching the when and why, and more around teaching appropriate responses to the things that happen during, say menstruation and masturbation.

For higher functioning kids, some parents may delay discussions because they feel advance preparation may contribute to their child's anxiety; this is rarely the case. If you use straight-forward language and explain the "mechanics" behind puberty, your child will be less uncomfortable (even if you are!).

Physical changes should be discussed with your child between ages 10 and 11, before they occur. The absolute latest time to begin discussions about puberty is when the child first begins to show the early physical changes of puberty, such as breast buds in girls, or in boys, acceleration of growth.

Use social stories, visuals, books, and videos when you talk to your child about puberty. If you notice that your child frequently asks questions at inappropriate times, it may be helpful to establish a fixed response, which can be utilized by all family members. For example, a response may be "That's a great question, but let's talk about it when we are at home." Do not discourage them from asking questions.

MENSTRUATION

- Use red food dye in your daughter's underwear to mimic what the blood may look like when she begins her period.
- Describe a sanitary napkin as a very large bandage and create rules for maintenance (e.g., change your pad every 4 hours).

DR. KATE AUBREY



- Use a visual aid to describe the steps involved in changing a sanitary pad.
- Go to the pharmacy with your daughter and ask her to choose a variety of sanitary pads with you.
- Watch a video about menstruation online: <u>www.kidshealth.org/teen/sexual_health/girls/</u>

ERECTIONS

- Talk to your son about erections before they occur. Ensure that you let your son know erections can occur without warning and that they can cover their erection with a book or a shirt.
- Growing Up Book for Boys: What boys on the Autism Spectrum Need to Know" is a great resource!

MASTURBATION

A behavioural result of surging testosterone and estrogen levels in young males and females is masturbation. Don't be alarmed if your adolescent masturbates as it is a perfectly normal and expected behaviour. For younger children, you can call masturbation "self-soothing". Masturbation is also quite normal in pre-pubescent children, even before children know anything about sexuality.

It is best to assure him/ her that masturbation is normal and encourage him/her to masturbate in a private place. If you notice that your adolescent child is masturbating constantly you should seek help from your family doctor.

If your child has not yet reached puberty and has begun to masturbate many times a day, you should have your child's stool tested for yeast.

HYGIENE

Many children and teens with ASD dislike grooming and personal hygiene habits. Hygiene issues are part of an overall lack of social and self-care skills. Youth with ASD also seem to have difficulty establishing sound hygiene routines in the areas of bathing/showering, brushing hair, changing clothes, haircuts, cleaning teeth and washing hair. Here are some ideas to teach your child good hygiene habits:

- Provide a soft bristled electric or hand toothbrush and bland tasting toothpaste.
- > Set up regular bath times in the evening. Bathing the night before can help ease the morning rush.
- Using visual reminders/timetables to encourage the completion of daily grooming tasks can be helpful in establishing good routines.
- Whenever possible, give your child a choice of products, choice of textures, fragrances, etc.
- > Find out if sensitivities are causing an aversion to showering, brushing teeth, or grooming.
- Create specific rules for basic hygiene, such as: you must shower daily and wash your hair three times a week, you must brush your teeth twice a day, you must change underwear every day.
- Create a space in the bathroom for your teen's hygiene products. Give them their own basket to keep products all together. Give them their own towels in fun colours. Let them choose them!
- Have your teen play some favourite music while performing hygiene tasks. You can also get a "shower speaker" so they can listen to music in the shower.
- Use a visual timer, such as one from <u>www.timetimer.com</u>, to manage tasks like showers.



RELATIONSHIPS & SEXUALITY

ROMANTIC RELATIONSHIPS

Most adolescents begin to be interested romantically in the opposite sex (or same sex. Same sex romantic interest occurs with at least the same frequency in people with ASD as those without). A youth with ASD may act on such interest by becoming obsessed with another adolescent (as they may with any other topic of interest). Parents may initially think of this as a "crush", but should be on the look out for signs of obsession and stalking (see below).

Youth with ASD may not be able to 'read' the cues from another person as to whether the interest is reciprocal. In this case, the young person with ASD needs to have explicit instruction about indications that someone likes you as opposed to not being interested romantically.

INTERESTED

- Giving strong eye-contact
- Smiling
- Laughing at your jokes
- Texting/calling
- Starting
- conversations • Leaning in
- when talkingAsking you
- questions

NOT INTERESTED

- Looking away
- Talking over you
- Turning away
- Looking unhappy
- Having arms folded
- Not responding when talked to
- Not asking questions

Youth with ASD, due to social immaturity, may not show this interest in others romantically until much later than their peers, despite their sexual maturity. In this case the adolescent will need to be informed that attraction to another person may happen in the future. It will still be helpful to still educate your child on infatuation and attraction so that they can understand their peer's behaviour. This may also help them to understand that behaviours such as teasing, playful punching, etc. may be an indication that one classmate is flirting with the other, rather than being rude or offensive.

SEXUALITY

Parents often feel nervous and anxious about teaching their children about sexuality, especially children with autism. Many feel that it is less important to teach young adults with autism about this subject because they feel that they are less likely to be exposed to issues related to this topic. But sexuality education is actually more important for individuals with autism because they are less likely to learn about it from other sources such as peers, books, movies, etc. It is also crucial for them to understand the difference between appropriate and inappropriate behaviour, and to distinguish between the various types of relationships.

Though the idea may seem overwhelming, it is critical to start as EARLY as possible and to be as DIRECT as possible! For safety reasons, all children on the spectrum need to understand the differences between private and public body parts, private and public behaviours, private and public places, and private and public conversations. Developmental delays can affect all areas so just because your child reaches physical maturity doesn't mean he or she has the social maturity to know what to do. Therefore sexual activity, or ability to express the need or desire for it, may also be delayed.



PREVENTING SEXUAL ABUSE

A higher functioning youth may have good communication skills, but they are still at risk for sexual abuse. Unless they are taught, youth with ASD may not know what constitutes a sexual act, how to withhold consent etc. This happens because they may have few peers to learn from, are poor at predicting behaviours, they are gullible by nature, and they struggle with social cues and body language. A child with poor communication skills may be the perfect victim for sexual abuse because they can't say "no" to unwanted touch and they can't report abuse after it has happened.

Social Stories are effective at all ability levels for teaching who is allowed to touch a child and who is not. You can use the **"Relationship Circle"** like the one at the end of this brochure to help your child learn about different relationships and prevent sexual abuse or being taken advantage of.

Teach assertiveness, like saying "No". Teach negotiation and compromise versus compliance. You can also teach them to discriminate between reasonable and unreasonable requests and how to find an appropriate sexual partner. But don't forget, if you tell people that they cannot have sex, then you increase the risk that they will respond to their sexual feelings and not tell you.

STALKING BEHAVIOUR

If your child has trouble perceiving what others are thinking/feeling, it is possible that they may make poor judgement decisions such as touching someone who may not want to be touched, following someone when they may not want to be followed, or calling/texting someone continuously when they may not want to contacted. This can be misinterpreted by others as stalking. Personal boundaries are frequently a problem for children with an ASD, particularly during puberty.

Teach very clear rules about boundaries regarding how to let someone know when they like them. You can create a hierarchy with your child that includes varying degrees of social contact, such as: (1) walking beside someone; (2) asking for a phone number; (3) asking where someone lives; (4) following them on social media; (5) making comments on their social media; (6) texting; (7) phone calls; (8) visits to their work/ home, etc. Also set rules/guidelines regarding the frequency that these behaviours should occur.

If possible, try to reach out to the person who is being pursued and, if appropriate, their parent to help explain the situation and how to deal with it. It will be important to reinforce that there is likely no safety issue. Encourage the individual who is being pursued to send clear messages to your child, such as "Please stop texting me" or "I don't like it when you show up at my work." If you cannot be sure that the individual will be respectful or courteous, do not use this strategy.

ASEXUALITY

Some youth with ASD will describe themselves as asexual (do not experience sexual attraction). There is some evidence that asexuality is more common among individuals on the autism spectrum as opposed to typically developing individuals. Youth who are asexual may or may not experience romantic attractions. Some may be open to sexual behaviours and others may be repulsed by them. Your child may appear asexual during puberty due to late maturity of sexual attraction. Youth that report being asexual or appear asexual into adulthood may or may not experience sexual attraction later in life. Sexual and romantic behaviour should always be directed by the individual and not pressured by others, including family members.



MENTAL HEALTH

SOCIAL CHALLENGES & LONELINESS

Social challenges tend to worsen during adolescence due to higher stakes during social interactions and peer relationships. Adolescence is a time of increased self-consciousness and attention to small details in peers and peer interactions. Youth with ASD may be self-conscious but they will struggle to augment behaviour appropriately. Increased emphasis on physical attractiveness, fashion, and hygiene may further impede their ability to fit in and thrive. Many youth with ASD will report increased loneliness and dwindling friendships during this time.

SOCIAL ANXIETY & DEPRESSION

Tony Attwood, a leading authority on ASD, suggests that current research shows that around 65% of adolescents with ASD have a secondary mood or anxiety disorder. Social anxiety disorder is common in the teenage and adult years when those with ASD are more acutely aware of their confusion in social situations, of making social mistakes, and possibly suffering ridicule. Social anxiety can become debilitating in adolescence and depression may follow. Social skills training has been found to be marginally effective in treating social anxiety and youth with ASD respond relatively well to cognitive behavioural therapy for depression and anxiety.

INSIGHT

Research has indicated that the degree of one's insight into their social challenges is related to social anxiety and depression in youths with ASD. This is because the more aware someone is of their difficulties the more self-conscious they will become and inferior they will feel. Increasing insight into adolescent's social difficulties should be balanced with opportunities for youth to be in environments where they feel accepted, such as online, in autism clubs, special interest groups, with adults, with younger children etc.

READING LIST

- Taking Care of Myself: A Hygiene, Puberty and Personal Curriculum for Young People with Autism by Mary Wrobel.
- Life Skills Activities for Special Children by Darlene Mannix.
- Making Sense of Sex: A Forthright Guide to Puberty, Sex and Relationships for People with Asperger's Syndrome by Sarah Attwood.

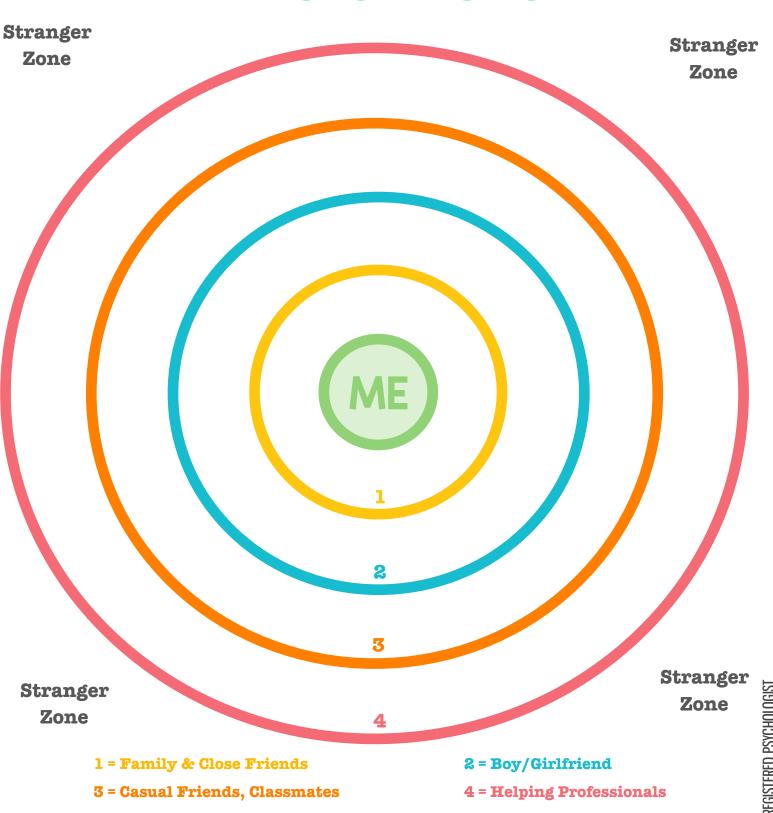
SOURCES

Dubie, M. (2015) Puberty and Children on the Autism Spectrum; Autism Victoria (2011) Puberty and Autism Spectrum Disorders; Autism Speaks (2014) Health and the Autism Spectrum; Fore, E. et al. (2015) Puberty: A guide for Teenagers With an Autism Spectrum Disorder and Their Parents.

This guide was prepared by Dr. Kate Aubrey for an invited presentation on Puberty & ASD hosted by the Autism Society of BC Community Support Group on May 2, 2016.

5

RELATIONSHIP CIRCLE



Questions to Ask: Who belongs in this circle? How do we act around people in this circle? How do you feel about those in this circle? How do you touch people in this circle? How do you let people in this circle touch you? How are people in this circle different from people in that circle? How do you know if someone is a stranger?