

Puberty and Adolescence Resource



A Guide for
Parents of
Adolescents with
Autism Spectrum
Disorder



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AUTHORS' NOTE

This tool kit was developed in response to requests from parents for resources related to puberty for their child with ASD. Although there are excellent resources on puberty, we found gaps in the available resources related to autism. Our goal was to provide information that was limited or not available elsewhere. This Puberty and Adolescence Resource, also known as the [P.A.R.] Tool Kit, represents a joint effort of Parents and Professionals from the U.S. and Canada, to create what we hope is an intelligent, yet easy to read and share document for those who support an adolescent with an Autism Spectrum Disorder.

Some of the challenge in creating this tool kit involved the personal nature of puberty and sexuality. This is obviously a topic that requires sensitivity, and each family should address it within their own values and morals. We wanted to develop a tool kit that could provide general information, which is not easily found, but which is also specific enough to be as useful as possible for families.

We have tried to be respectful in the presentation of information. Still, we realize that some of the images and content in this tool kit could be overly personal for some parents. Of course, we encourage everyone to go through the material first, deciding what is most useful in his or her parenting style or in sharing with their child. You are also encouraged to seek guidance from your family's team of multidisciplinary specialists, social workers, family navigator, spiritual leader, etc. It was our goal to strike the best balance possible, knowing that some parents will prefer less information, and that others will want more!

We want to especially thank the parents and students who provided feedback on the development of this tool kit. Without their input, it simply could not have been completed.

For further info and resources visit: www.autismspeaks.org/atn or www.autismspeaks.org/family-services/tool-kits

Sincerely,

The ATN/AIR-P Puberty and Adolescence Resource Workgroup



(Pictured left-right top) Parent Partner Authors- Kameena Ballard-Dawkins, Amy Kelly, Charlene Prochnau, Alicia Curran, BS and Rich Hahn (bottom) Professional Authors Dr. Kristin Sohl, Lisa Voltolina M.S., CCRP, Dr. Shawn Reynolds, Dr. Lisa Nowinski, Martha Y. Porras and Yolana Parrott MSc OT, OT(C).

HOW TO USE THIS TOOL KIT

A “**Tool Kit**” is a set of print or electronic materials that are designed to support families and providers of children affected by autism in the management of their care. Tool kits may also be targeted directly to the children to educate them or support them in the management of their own care. Tool kits provide information on a focused topic with a specific goal such as supporting a family through the puberty and adolescent stage for their child with ASD. Below are suggestions on how this tool kit might be best used. Please visit our [ATN/AIR-P](#) Tool Kits page to learn more about all of the tool kits we have available for parents and professionals to date.

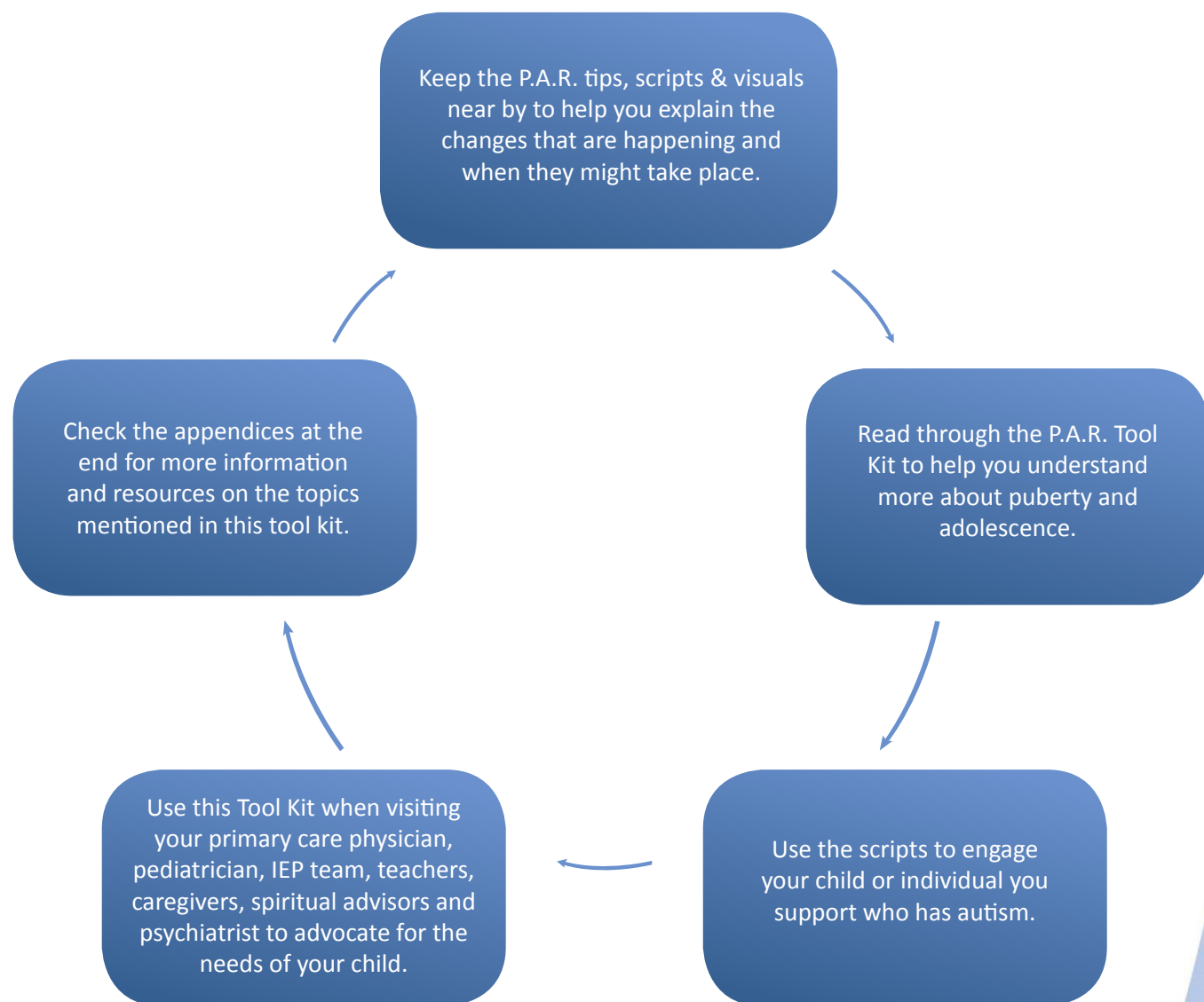


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INTRODUCTION

Puberty can be a time of mixed feelings for parents and pre-teens. It may be a time of pride and celebration as well as a time of worry and confusion. It is hard for pre-teens to understand the many changes that come along with puberty. Also, parents may feel unsure of how to explain these changes to their child.

Parents of pre-teens with ASD may find this time of transition especially difficult. The physical and emotional changes of puberty may seem out of sync with their child's social and academic development. Parents need the skills and confidence to talk about puberty and sexuality in order to confidently teach important life skills, including appropriate public and private behaviors, natural body changes and healthy social and romantic relationships.

A key to keep in mind is that while individuals with ASD often progress in ways that are different from other children, their bodies generally develop at a similar speed as their peers. Boys and girls experience changes in their bodies whether or not they have ASD. Children with ASD may have unique responses to what is happening to their bodies and may need additional guidance when navigating this time of transition.

All parents eventually face the challenge of teaching their children about the natural changes of puberty. However, parents of pre-teens with ASD may need the help of additional strategies to ease the transition. Our aim in developing this tool is to provide guidance on the subject of puberty that can be directly applied to pre-teens with ASD. In doing so, we hope to increase families' understanding of puberty and their ability to adapt to these changes with confidence.

This tool kit was a collaborative effort of parents of teens and pre-teens with ASD, physicians specializing in ASD, special educators and allied health professionals. It was designed to provide general information across a wide range of parents in hopes to provide a comprehensive perspective on puberty and adolescence. We recognize that many parents will deal with more significant challenges that we do not address in this tool kit, including but not limited to matters of sexual orientation and family planning. Therefore, this tool kit should not be seen as a substitute for personalized support when challenges are more specific and/or significant. It also does not take the place of any consultation with a physician, school or mental health provider, which is strongly recommended when needs are great.

Did You Know?

Several parents volunteered to collaborate on the development and writing of this tool kit. You will hear from them as a Parent Partner throughout this tool kit providing us with their personal tips and stories.

PUBERTY VS. ADOLESCENCE

Puberty and adolescence can be tricky concepts. Believe it or not, they do not mean the same thing and don't necessarily happen at the same time in development! Before we dive into more specific content, let's define these terms.

Puberty

- refers to the physical changes in the body that make a person able to sexually reproduce.

Adolescence

- is the period of emotional and social transition between childhood and adulthood.

This difference is important to keep in mind, especially when parenting pre-teens (sometimes referred to as tweens) with ASD. People with ASD often experience delayed development of social and emotional skills. They may not achieve the transition of adolescence until their late teens or early twenties. However, they will most likely undergo the physical changes of puberty within the typical time frame, which can be as early as 10 or 11 years of age.

What does all this mean? Simply put, many teens with ASD may experience the sensations of a physically mature body without the social, emotional or psychological maturity to understand these sensations.

Parent Partner's Tips: Body Changes

- **Start early with teaching privacy.** With siblings and therapists often around, privacy is difficult to find, but is absolutely appropriate at a certain point in life. Help your child learn when that is and how to safely obtain it.
- **Model appropriate hygiene behavior.** Let your child watch you when you shave, put on deodorant or any other activities that maintain good hygiene if you feel it's suitable.
- **Use the correct language for body parts and body functions.** Our children are all going to grow up to be adults one day and need to be taught proper terms for mature subject.
- **Start practicing early.** The sooner you and your child can develop a routine, the sooner he or she will get used to it. Teaching skills early makes it easier to incorporate them into everyday life.

Parent Partner's Personal Story:

I never imagined back in 2002 when my sweet little 6 pound 11 ounce baby Annie was born that 12 years later, I would be intensely teaching her, step by step, how to shower independently, apply deodorant and practice changing menstrual pads. That's right. This is all in anticipation of The Big P. PUBERTY.

Once again, I find myself in the never-ending abyss of autism, not knowing what to expect in Annie's next stage of life. Although somewhat intimidating, it is also very exciting to see her blossoming into a beautiful young lady, and I feel privileged to go through this journey with her. Annie, like many of our children with ASD, has defied expectations - she learned to start talking when she was ten, she can now read and write, she loves to cook and she is always talking about "Mama and Annie". It's wonderful.

I hope this resource will help to remind you of the silver linings your child gives to you and your families. (It helps to remember these when we want to pull our hair out during the inevitable frustrating times!) On the next page are some of the things I've done so far to prepare Annie for becoming a young woman:



-Amy K., Parent Partner, Philadelphia, PA

For girls who are beginning menses (menstruation or periods), it is helpful if the caregiver can see a doctor who specializes in adolescent care and birth control BEFORE the actual event occurs. I had seen a specialist at my Children's Hospital in our Adolescent Specialty Care division three months before my daughter began her period, and THANK GOODNESS! Once it started, I was able to call the doctor directly that day and move ahead with the plan we had already discussed would work best for my daughter (in our case it is birth control pills that regulate her period to come fewer times a year). This gave me immediate peace of mind that she is protected, and that we at least have a manageable schedule to deal with an unpredictable journey through puberty.

My daughter began her period when she was 12 ½ years old and is minimally verbal. It's hard for her to tell me when she is uncomfortable... but I was reminded to watch for other signs. She indicated to me she was in pain by rubbing her tummy and I knew that was her way of telling me she had cramps so I kept her on a mild pain reliever (Ibuprofen). I also, to my dismay, found that she had completely removed AND shredded her soiled pad the next morning when she woke up before she came to get me. That told me it felt really uncomfortable and I needed to consider having her use the bathroom in the middle of the night, or at least get up before she did, so I could wake her and get her changed and comfortable. It's all learning!

Did you know that they make underwear specifically designed to help keep menstrual pads in place and more comfortable? This is KEY when you are looking at young women who have sensory issues to begin with and who may not fully understand what is happening in their bodies during menstruation, or how to have appropriate hygiene. [Here's a link](#) to one type, but if you Google search, there are other types.

http://www.amazon.com/Anigan-StainFree-High-Rise-Menstrual-Underwear/dp/B008V1XNSG/ref=pd_sim_sbs_hpc_1?ie=UTF8&refRID=0TGW-C2RZPB212H6YW2VJ

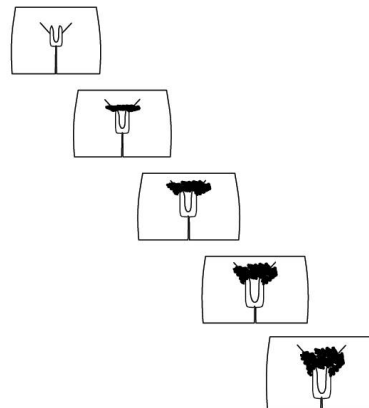
BODY CHANGES

It is important to give your child time to process the idea of his or her body changing before puberty actually starts. Boys will typically show signs of puberty around the age of 11 or 12. Girls usually experience changes in their bodies earlier, around the age of nine or 10.

It is natural for some parents to feel somewhat uncomfortable speaking to a young child about his or her body. To reduce discomfort, consider talking with your spouse, older children or trusted family or friends about your family's values, practices, and how to develop them in your child. Establishing family values (i.e. no pregnancies before marriage, etc.) can guide your interactions with your child and prepare you ahead of time for any questions that may come up.

Perhaps what may be just as important as establishing family values and practices is to gain a basic understanding of the body changes associated with puberty. One of the foundations for introducing the topic of puberty is to explain the changes that will happen to your child about his or her body parts. Make sure you can speak clearly, in a way your child can understand, so he or she will know what to expect as they grow.

Tanner Stages of Life



This chart can be used as a timeline, to show your child how hair will grow on male genitals.

<http://kc.vanderbilt.edu/healthybodies/>

Body Changes-Conversation Script

Get started by checking the picture resources we've provided. Then, add additional resources you discover through family, friends, and your community- that would be appropriate for your child based on their age, learning needs and abilities.

Starting a conversation about body changes is tough. Don't know where to begin? Here's a script to help you get started! (You can modify this depending on your child's maturity and verbal skills, of course.)

We're going to talk about some things that happen to everyone, even me. People's bodies change as they grow up, and I want to tell you about it so you know what's happening when your body starts changing too. It happens differently for everyone, and that's okay. The important thing is that we talk to each other, and that you know you can ask me questions whenever you want.

For the less verbal child with ASD, adjust language and information to the level of the child and add visual supports. Start saying something like..."the rule is that your body will change and I want to show you how. Everyone's body changes as we become a grown up. Your body is going to change like this (using pictures). You will start to look more like a grown up body like me (or another person)."

SELF-CARE AND HYGIENE

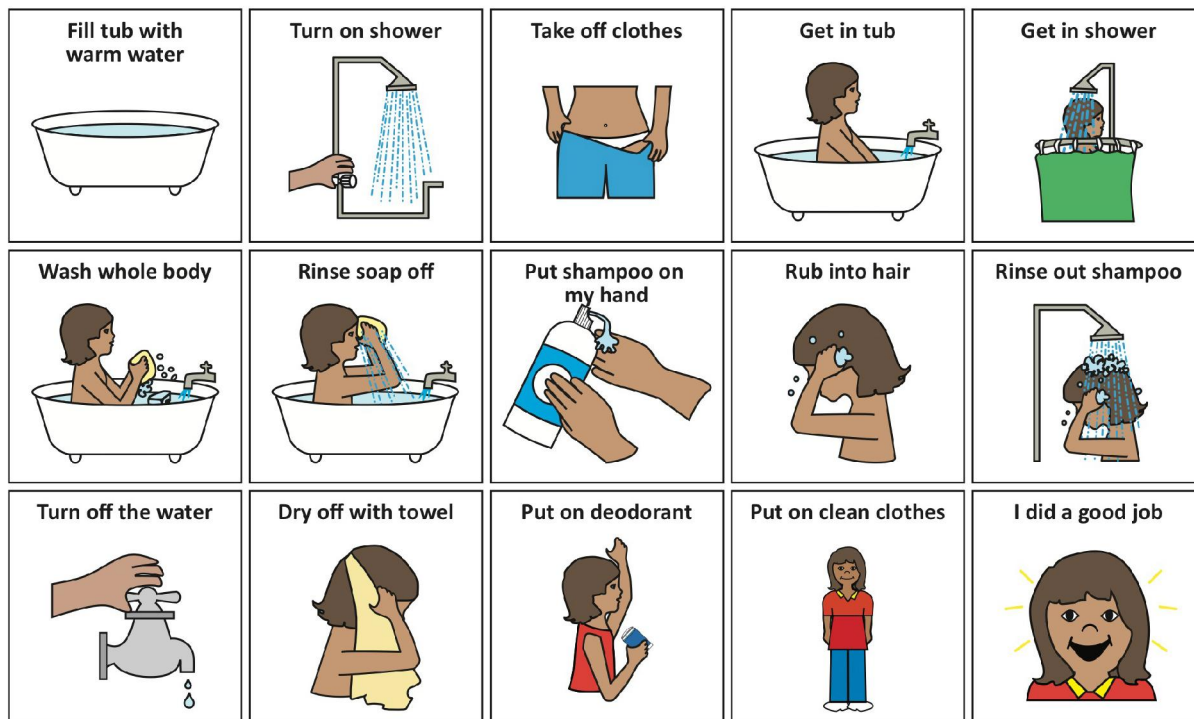
As puberty begins, there are many new challenges for kids to understand. Many children with ASD struggle with the changes in self-care and hygiene routines that is necessary for managing puberty. Here are some of the changes to expect and some ideas to help your child deal with them.

General hygiene

With puberty come sweat, oily skin, and pimples. Children will need to start bathing or showering daily to keep their bodies clean. Often, children with ASD are not aware of the social impacts poor hygiene may create. If it is appropriate, talk to your child (or set up a routine) about why he or she needs to bathe more frequently. Social Narratives can be a helpful way to teach children about why hygiene is important. If getting your child to become motivated to bathe is a struggle, you may need to introduce daily bathing as a “new house rule”, provide visual checklists and reminders to bathe, wash thoroughly, use soap and shampoo, etc. At this age, it may be increasingly hard for you to monitor how well your child is washing his or her body - another reason to teach independent bathing early.

This showering narrative can be used as a visual aide or as individual reminder cards to encourage good hygiene.

Appendix Encouraging Good Hygiene – Showering Schedule Visuals



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Shaving

This can be extremely tricky, especially if your child struggles with tactile sensations. You will need to teach your child how to shave safely, as pain or even a cut may lead to future avoidance. This may be an area where children require assistance until you feel confident that they can shave safely on their own. Try different razors and shaving creams to find one your child prefers and accepts. Often, an electric razor is a better option for teenagers just starting out. Keep in mind that some people with ASD may be sensitive to the sounds of electric razors. If your child is very averse to shaving, you may need to work on increasing his or her comfort level first. To do this, start gradually with single steps (i.e. put on shaving cream and rinse off), short periods of time (i.e. turn razor on for 5 seconds and then off), or small areas (i.e. put on shaving cream and shave a small area). At first, your child may only tolerate these small exposures. Gradually work your way up and be patient. If shaving is not an option, these same incremental steps could be used with depilatory creams, which may have less of a sensory impact and require less fine motor skills.

Parent Partner's Personal Story:

"I am the proud mother of a 14-year-old son with autism. There have been several times during my journey of raising a child with autism that I find myself in unknown territory. I find myself at one of those places now: PUBERTY!

I have so many questions and concerns. How will I handle him during times of moodiness, or even aggression, now that he is bigger than I am? Will I ever get his acne under control? Is he scrubbing all the right places when showering and using enough deodorant? What level of independence and accountability is appropriate for him? How will I handle the time when he starts experimenting with masturbation? My list of questions could go on forever.

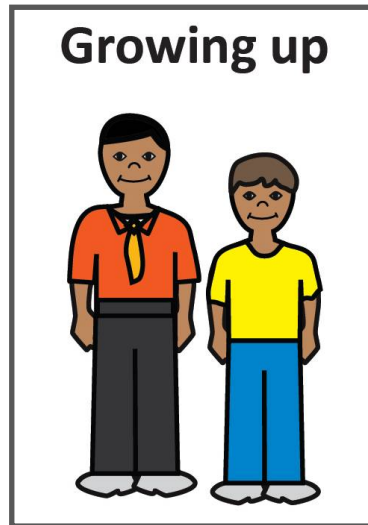
I do not have all the answers. However, I do know that across all the challenges we have faced during other transitions in his life, we have always figured it out. I have to keep focused on what is important: watching Samuel grow into a wonderful young man, who I am proud of, and being okay with not having all the answers today!"



-Alicia C., Parent Partner, Columbia, Missouri

Wearing deodorant

Adding a new step to the morning routine can be tough - your child may already have a well-established routine by this age. This can be a very crucial step when managing body changes. Try a variety of deodorants and antiperspirants (e.g., sticks, gels, sprays, etc.). Let your child pick which one he or she prefers - this may be helpful in motivating him or her to use it. Many teens do better when given a choice. Again, you may need a visual reminder for your child to put on the deodorant. You may also need to introduce it as a “new house rule” or provide rewards until your child integrates this step into his or her regular routine.



*Image courtesy of Vanderbilt Healthy Bodies Tool Kit for Boys:
www.vanderbilt.com/healthybody_boy*

Wearing a bra

Most girls will accept this change quite well. However, adding a new item to the dressing routine can sometimes be tricky. Try a few styles of bra with your daughter to find one that fits well and that she finds comfortable. You may need to start with a less supportive bra, or training bra, until she is tolerant of a more supportive bra. Explain that this is a part of becoming a woman and experiencing body changes. You may need to re-introduce a visual schedule or check list with steps for dressing to remind her to put on the bra while getting dressed.

Self-care and Occupational Therapy

Many children with ASD need support to be successful in coping and adapting to body changes. An occupational therapist is an excellent resource to address many of these changes. Occupational therapy (OT) focuses on self-care, productivity and leisure. For children transitioning into young adulthood, occupational therapy could include: establishing independence in hygiene, dressing, sleeping, sexual health, completing chores, volunteer or paid work and socializing with friends, peers, co-workers or family. Occupational therapists work collaboratively with children and their families to set goals and strategies tailored to meet your family's specific preferences. Below is a chart preview from the 'Autism Speaks Occupational Therapy Tool Kit' that can be used as a visual guide to see if OT could be a resource for your family.

How Can Occupational Therapy Help During Puberty?

Occupation	Examples of Occupational Goals	How can OT help?
Self-care	<ul style="list-style-type: none"> • Increase awareness or insight of proper hygiene • Tolerate sensations related to self-grooming and hygiene • Increase independence with dressing, bathing, grooming, shaving, and/or feminine care activities • Decrease dependence on caregivers for self-care activities • Increase independence with management of self-care materials, such as feminine care items, deodorant. 	<ul style="list-style-type: none"> • Facilitate awareness and motivation to become involved in self-care tasks • Help develop self-care skills to promote independence • Modify tasks to facilitate independence • Decrease sensitivity to the sensations related to self-care • Create visual supports to encourage independence in bathing, dressing, grooming, and feminine hygiene • Collaborate with parents to increase self-care expectations at home as skills improve • Create organizational strategies for daily responsibilities and to plan for more occasional responsibilities such as feminine care, haircuts, and replacing toiletries. • Help teach the adolescent to care for personal devices (e.g. glasses)
Social Participation	<ul style="list-style-type: none"> • Interact appropriately with romantic interests and on dates. • Understand what types of physical interactions are appropriate in different situations (i.e. hugging and kissing) 	<ul style="list-style-type: none"> • Teach rules for social interaction • Provide opportunities to practice social interactions • Increase understanding of social contexts and appropriate responses

Wheeland, A. & OT Practitioner Advisory Committee. (2014). Occupational Therapy Across the Lifespan: Autism Speaks® Family Services Tool Kit. Available at www.autismspeaks.org/family-services/tool-kits/occupational-therapy

MENSTRUATION (HAVING A PERIOD)

Your daughter with ASD will experience a lot of changes during puberty, just like other girls do. Getting her first period is likely to be one of her biggest milestones during this time. ASD does not affect when girls start their periods, so many girls with ASD will most likely have her first period between the age of 9 and 11 years old.

Since it is impossible to know exactly when your daughter will get her first period, it is important to take her personal preferences, personality and her level of understanding into consideration when deciding when to discuss this topic. Keep in mind that pre-teens with ASD often need extra time to adjust to changes and new information, and they sometimes can become fixated on events that are unpredictable and potentially frightening. Since the first period usually comes about 12 to 18 months after starting breast development, it is often a good time to start discussing it as she is getting used to wearing a bra.

It is crucial to prepare your daughter for her first period ahead of time. Make sure you pick the right moment to prepare her for this. Consider what point in time will minimize the stress and anxiety of anticipating her period, while also maximizing her ability to process this information. There is no right way to do this for every child, so use your best judgment!

Once you are ready to talk to your daughter, there are some key topics to address

What does “having your period” mean?

If girls don't know or understand what periods are, they may be frightened that they are sick or injured. Making sure your child understands that monthly bleeding is absolutely normal, natural and healthy is crucial to reducing anxiety. Consider whether a social narrative might be helpful for your daughter, both as an instructive tool and as a reminder of what to expect each month.

Stomach cramps and body aches are normal.

Try to prepare your daughter for the physical sensations associated with monthly periods. Abdominal cramping, feeling tired and experiencing breast, stomach or low back soreness are all normal sensations, even though they are not very comfortable! Teach your daughter appropriate strategies for relieving discomfort. For example, it may be fully appropriate for your daughter to use a hot water bottle to reduce cramps or body pain independently, but pain-relieving medications should only be used with permission and under parental supervision. Of course, if these symptoms appear to be severe or interfere with daily activities, you should speak to her medical provider for additional options.

Pre-menstrual syndrome (PMS) is normal, too.

Girls with ASD can experience the same range of PMS symptoms as typically developing girls. However, their symptoms may lead to challenging behavior if they have trouble regulating their emotions. Like most girls, your daughter may feel cranky, depressed, tired and find it difficult to concentrate. If she understands why she is feeling this way, your daughter may feel more in control of her changing body. A social story, specific to your child's symptoms, may help. As with physical symptoms, you should speak with your child's medical provider if symptoms of PMS are severe or interfering with daily life.

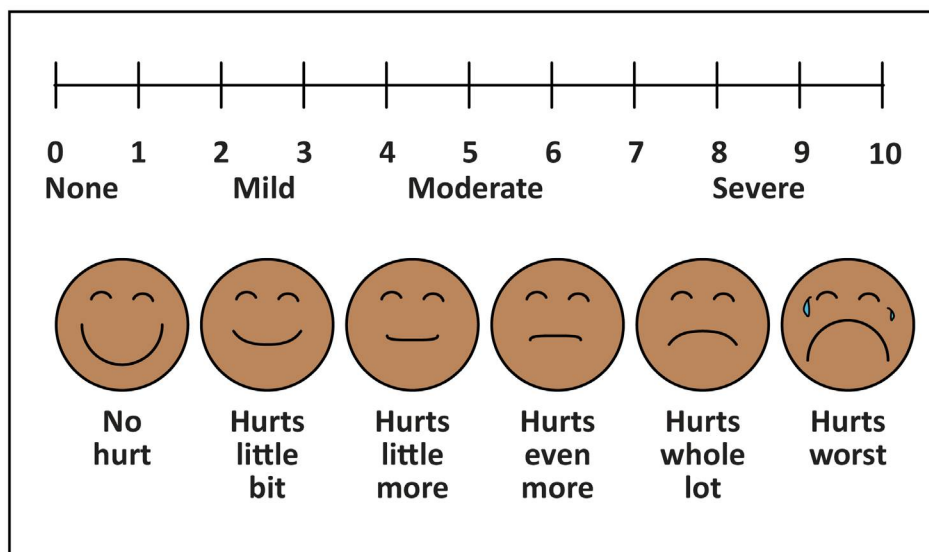
What are pads and tampons?

Once your child's periods have started, she will need to know what pads and tampons look like and how to use them. Consider going to the grocery store together to pick out different types to try. Girls of any age can use tampons, but they take practice and require regular changing to prevent any serious illness that could happen as a result of not changing your tampon frequently enough. It is often easier for girls who have newly started their period to use pads in the beginning, since they require less skill to replace and are, in and of themselves, a visual reminder to be changed. If your daughter uses visual supports, a visual schedule showing the steps involved in changing a pad, tampon or alternative sanitary product like a Diva Cup (a reusable menstrual cup that is a safe hygienic alternative) may be very useful.

Use this chart as a visual aide during menstruation, to help communicate during her puberty.

Teaching About Periods – Pain Scale

During her period, your daughter may feel tired and moody. Her stomach may swell or cramp. Using a pain scale like this can help her tell you how much she hurts or feels uncomfortable.



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<http://kc.vanderbilt.edu/healthybodies/>

It will be helpful to review this information with your child frequently, especially during the first several months after she starts her period. Reviewing the sensations, self-care and hygiene techniques each month will help turn these new skills into a habit. Experiencing a first period can be stressful and uncomfortable for your child. Natural hormonal changes may make it harder than usual for her to cope with unpleasant sensations or emotional states. Above all, remain calm and patient. This may be hard for you to talk about and for her to understand, so it may be stressful for both of you. Your continued support will ease the discomforts of this important life transition.

Parent Partner's Personal Tip: Menstruation

This is a worthwhile activity to do with your daughter after you've begun discussions about her first period.

Take your daughter with you to the grocery store the next time you need to purchase pads or tampons. Select other grocery items as usual and then head to the aisle for sanitary products. Show your daughter which products you are choosing and ask which one she thinks she would like. Let her choose an item and add it to your grocery cart to demonstrate that these products are a normal part of life, like milk and cereal. When you get home, let her help you take a closer look at the products you both chose in a casual, lighthearted way.

-Amy K., Parent Partner, Philadelphia, PA

PUBLIC OR PRIVATE?

Puberty and adolescence are times of body transformation and increased sex drive for individuals with and without ASD. Body exploration, sexual attraction and masturbation are all natural aspects of growing up and maturing. As we mentioned earlier, intellectual and social maturity do not necessarily go hand in hand with physical maturity: your child may experience real sexual impulses without fully understanding or knowing how to cope with the sensations. Conversations about sexuality are often uncomfortable for parents, but it is important to help guide your child toward appropriate behaviors and outlets.

One way to approach teaching appropriate social behaviors is to establish “Public and Private” rules. However, it is important to first make sure that the social concepts of “public” and “private” are well understood. In general terms:

Public

- means saying or doing something in front of strangers, siblings, relatives, friends, classmates, or teachers - even if they are familiar or well known.

Private

- means saying or doing something by yourself, with your parents or with a trusted doctor.

Consider creating a “Public or Private Places” list. Using this format, you can discuss behaviors that must be done in private (undressing, urinating, touching private parts).

For more info: <http://parents.teachingsexualhealth.ca/our-children/sexual-development>

Use these visual aides as individual cards to reinforce public and private behavior.

Public/Private Behaviors – Story

Private Parts

Public places are where other people can see me. **Private** means away from other people, like in my bedroom or bathroom with the door closed. Everyone has **private** parts of their body. I can tell what parts of my body are **private** because I cover them with my underwear. I don't touch my private parts in public where other people can see me. I don't ever put my hands inside my pants in public. I can help myself remember not to touch by putting my hands by my side, crossing my arms, or folding my hands. Sometimes I need to touch my private parts, like when I itch or my underwear is uncomfortable. I can ask to go to the bathroom. When I am alone in my bedroom or bathroom, I can touch my private parts.



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<http://kc.vanderbilt.edu/healthybodies/>

Addressing each topic specifically will help your child understand these broad concepts, which he or she may find difficult to generalize independently.

Depending on your child's needs and abilities, you may also create a similar list of "Public or Private People". Many children with ASD over-share personal information with people they trust. Over-sharing can lead to listener discomfort or to the spreading of rumors. In both cases, relationships can be damaged and people may feel hurt or uncomfortable.

Consider creating a list of names of people with whom your child can share private information - and make sure the individuals on the "Private People List" are comfortable with being your child's confidante beforehand. Then, explain that the things we do in our "Private Places" must only be shared with our "Private People".

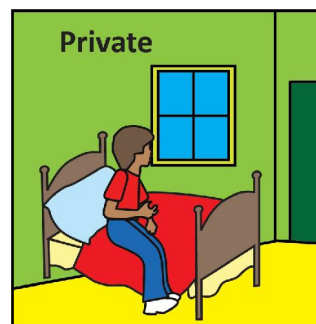
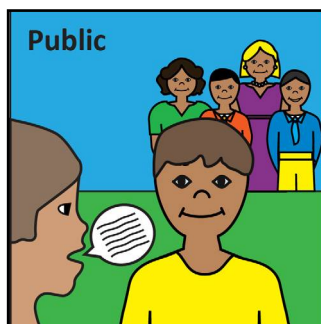
Perhaps foremost on parents' minds during this period of transition is the issue of masturbation. Of course, the guidance you provide your child should be aligned with your family's values. It is important, however, to teach your child about masturbation, even if you would prefer he or she not engage in the activity, as some children accidentally hurt themselves (e.g., rubbing too hard).

A Mother's Personal Story: Public or Private



At 13, our son has started puberty and does not have the verbal skills nor the awareness of social boundaries. It became evident when we were in church and something was bothering him. When I asked, he said “the carrot nose” was bugging him and pointed to his pants. (Carrot nose was how he described his erection in terms he could relate to.) Although he didn’t have any knowledge or direction in masturbation, he knows what feels good and has figured it out. We’ve been using redirection or distraction when necessary and simple instruction about how the activity he’s engaging in is okay in private (his bedroom) but not in other areas of the house or community (church, school, shopping centers, etc.). So far, he has accepted this well and we haven’t had a real problem - but, then again, we’re just beginning!

-Charlene P., Parent Partner, Edmonton, AB Canada



Images courtesy of Vanderbilt Healthy Bodies Tool Kit for Boys:
www.vanderbilt.com/healthybody_boys

A Father's Personal Story: Public or Private

As parents of children on the spectrum we face no shortage of challenges. Puberty, are you kidding?? Yep, it's here and it's our job to guide our children through this major life-changing event. My little Nic(holas) who used to fall asleep on my chest every night now is 12, almost looks me in the eyes and we wear the same shoe size. Although he has experienced a massive physical transformation, he's still very much a little boy. He has always been curious about his penis but we've not yet had to have a conversation about private time. When the time comes I will gladly educate him and would never shame my son for something that is perfectly normal.



-Rich H., Parent Partner, Des Moines, Iowa

STAYING SAFE: STRANGERS, SECRETS AND TOUCH

Parents always want their children to understand the rules of basic safety. This is especially hard for some pre-teens and teens with ASD because they may not know which adults are safe to trust. For years you have worked to build your child's ability to listen to others and comply with the requests and demands placed on him or her. However, as children get older, it is also important to help them identify what are safe and appropriate limits. Here are some key things to remember:

- **Be prepared to talk about and recognize sexual abuse in your child.** Remind him or her that his or her private parts are always private, so no one other than a person they trust, or a doctor or a nurse, is allowed to see, touch or talk about them. This goes both ways: remind your child that other people's private parts are not okay to see, touch, or talk about. It is also important to remind children and young adults that if someone touches their private parts in an unwanted way, they should tell a trusted adult immediately, even if that person is a relative, friend or caregiver.
- **Use visual supports to help your child learn concepts.** such as stranger awareness, good touch/bad touch and public or private behaviors. Explain the difference between appropriate and inappropriate touching. For example, consider parts of the body that are sometimes okay to touch (arms) and parts of the body that are never okay to touch (hips).

“ My doctor suggested that I look for any tearing or swelling in my son's private areas while changing him, to check for signs of sexual abuse since he is non-verbal.”

-Jezzrel T., Parent Partner, Los Angeles, CA

- **Use role-playing to help your child practice new skills in real world environments.** Ask your child what he or she would do if someone were to touch him or her in a way that he or she didn't like. Start with appropriate types of touch (like a tap on the arm) and gradually build up to inappropriate touch (like touching private parts). Make sure your child understands that he or she should talk to you, another parent or trusted adult if he or she ever feels uncomfortable.
- **Collaborate with your child's school team** to make sure that they are incorporating safety skills into your child's program. The safety curricula should incorporate real life scenarios into the lessons to help your child transfer classroom learning into daily life. Turning the lesson into a game - like choosing scenarios from a stack of cards - will make a serious topic less stressful.

“For individuals with ASD, ‘Self-Determination’ means more than choosing your own clothes or what to eat. It also means knowing that you have the right to say NO... I don't want you to touch me like that!”

-Kameena B.D., Parent Partner, Burbank, CA

For more information on this sensitive subject please visit: <http://www.autismspeaks.org/family-services/autism-safety-project/sexual-abuse>

Parent Partner's Personal Tip-Staying Safe: Strangers, Secrets and Touch

Tough conversations often feel easier when you've planned ahead. Here's a script to help get you started. Remember to speak clearly and adjust your language according to your child's verbal skills and level of understanding.

It is important that you know there are places on your body that no other person should touch in a sexual way until you are both mature adults. These body parts are called "private parts", and they include your [breasts, vagina, penis, etc.]. If anyone touches you on your private parts, you have to tell me - even if you don't want to, and even if the person who touches you is an adult or a friend from school that tells you not to tell. If someone makes you feel uncomfortable and gets into your personal space, tell them "NO"- to stop, and then tell me

For more information on this sensitive subject concerning behaviors to watch for – for those children with limited/non verbal please visit: <http://www.autismspeaks.org/family-services/autism-safety-project/sexual-abuse>

If you suspect child abuse has happened, make the call...

The National Child Traumatic Stress Network offers the following advice:


"If a child discloses abuse, it is critical to stay calm, listen carefully, and NEVER blame the child. Thank the child for telling you and reassure him or her of your support. Please remember to call for help immediately. If you know or suspect that a child is being or has been sexually abused, please call the Childhelp® National Child Abuse Hotline at 1.800.4.A.CHILD (1.800.422.4453) If you need immediate assistance, call 911.

SAFETY PLANNING FOR RUNNERS AND WANDERERS: ELOPEMENT

Many children with ASD have challenges with elopement; that is, running away from the family or the safe place. When children move into puberty though, this behavior can increase, both in terms of frequency, as well as risk. Children run or wander for many different reasons. Some may leave the watchful eye of their parents in search of something interesting or fun like a train, elevator or a different environment like a swimming pool. Others run in response to stress, anxiety or excitement.

As kids get bigger, they run faster, which can make it tough for people caring for older kids and pre-teens with ASD who are at risk of running away at school or in public. Older children like teens and pre-teens can become harder to keep in the safe place (especially if they become taller than their parents!). Regardless of the circumstance or reasons, it's important to know what you can do to keep your child safe. This section is designed for all parents who are concerned about this

If your child is prone to elopement or wandering, there are many things you can do to support his or her safety.



Security. First, consider securing your doors and windows from the inside or installing an alarm system that will ring when a door is opened. Many families find that they have to lock their doors and windows from the inside to ensure that their child is unable to leave without supervision. Make sure to have a key easily accessible to all adults in order to exit the house quickly, if needed.

Identification. Be sure that your child wears or carries some form of identification with him or her at all times. This is particularly important for individuals who are nonverbal, though even verbal teens can become overwhelmed in an unfamiliar situation and may not be able to give their name or phone number if they become separated from you. Shoe tags are a good option for children who cannot tolerate other wearable IDs, like bracelets. Temporary tattoos are appropriate for kids who only wander in unfamiliar settings. If your child is able to speak, help him or her practice telling people he or she has autism and needs help.

Technology. Technological devices can allow parents and caregivers to locate a child quickly in an emergency. Check out more resources at the end of this tool kit.

Preparation and Advocacy. Consider visiting your local Police and Fire Departments to introduce your child and alert them to your child's specific needs and behaviors. Encourage your public service agencies to learn about autism and how to help people with ASD in an emergency situation.

For more resources, visit: <http://www.autismspeaks.org/wandering-resources>

SAFETY PLANNING FOR INCREASED AGGRESSION

Kids experience lots of stress, as they become pre-teens and teenagers. This stress can sometimes be present itself as challenging behavior, and for some as aggression. Parents can be surprised at the changes their kids undergo. For example, younger kids are often motivated to spend time with their parents. But for some, this could stop being cool for them as they get a bit older. This may happen to families with children with and without autism!

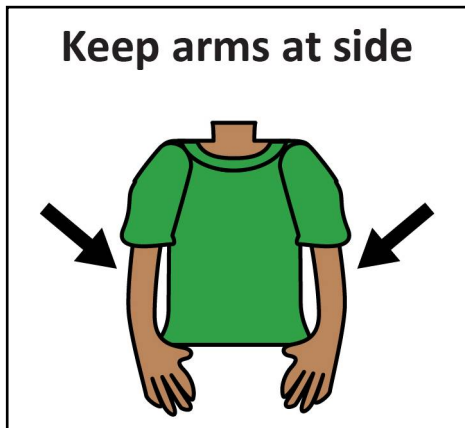


Image courtesy of Vanderbilt Healthy Bodies Tool Kit for Boys: www.vanderbilt.com/healthybody_boys

For pre-teens and adolescents with ASD who are developing, the challenges can be even greater. They may be experiencing new stress at school. They could also be experiencing hormonal changes to their body that happen as they are going through puberty. Many kids with autism have more social opportunities early in elementary school than they may have later on. This can create stress or sadness, too.

When we think about the ways that our kids with ASD express themselves, it's important to think about how this happens at different times. Most of us are better at expressing our feelings when we are calm and feeling well. When we get upset, we don't express ourselves as well, at all. (If you want proof of this, think about the last time you were in a big argument. Have you ever had the experience of thinking,

"What I should have said was _____!" It's hard to think of the right thing to say and the right way to say it when you are really upset.

When kids with ASD get upset, managing their own reactions and expressing themselves well can be a real struggle. Like all of us, they may react inappropriately and do things they regret afterwards.

For some of our children, this can become dangerous. Kids who can't communicate verbally may act out physically toward objects or other people. They may even begin to self-harm or hurt themselves. This problem could become even bigger as the child gets bigger, of course.

Many parents are willing to be the "safe" person for their child. While it's good to avoid aggression in public, reinforcing the wrong behavior creates great stress for the parent and can put the child at personal risk too.

For more information about challenging behavior and how to establish more positive communication visit: www.autismspeaks.org/family-services/tool-kits/challenging-behaviors-tool-kit or call **888-AUTISM2 (288-4762)**, or by email at: familyservices@autismspeaks.org

Parent Partner's Personal Story; Safety Planning for Increased Aggression

Nic's struggles with ASD and puberty have come with increases in aggression. He's bigger and stronger and his outbursts are more destructive, and to be honest dangerous. At the age of 12 he's already close to 150lbs and much larger than his older sister. School struggles at times with these changes- as do we at home. We are braving the rapids and looking forward to calmer waters as he adjusts to the hormone changes in his body.



-Rich H., Parent Partner, Des Moines, Iowa

Growing up can be stressful for anyone, and our Nic is no exception. He is afraid that as he grows older he will no longer be able to “be a kid” and enjoy the fun that comes with it. We just remind him that getting older is not a bad thing and he will always be our little boy.

In puberty, kids often experience different emotions in a more intense way than they used to. This means they may need more or perhaps different strategies to manage these feelings. So, what can parents do to help their children? Here are some ideas that might help:

The earlier you start, the better things may turn out. Even young children naturally find activities to help them when they are upset. Parents need to be aware of their child's go-to activities and how he or she can access them during tough times.

It's much easier to prevent a meltdown than to handle it when it's happening. This means adjusting your schedule to make sure the stress your child experiences is reasonable. It's important to expose kids to some stress, so that they can learn how to manage it - but this needs to be at a reasonable level.

Keep working with your child to find strategies to help avoid the meltdown. For verbal children, you can talk about things they can do to soothe themselves when they start to get upset. This might be a favorite stuffed toy, listening to music or taking time by themselves. They can give you some ideas. For nonverbal kids, parents need to develop a list of things that are soothing and to have these available on short notice.

Share strategies with your child's school. For example, if your child has a hard time in the grocery store, think about a job he or she could do (like pushing the cart), an enjoyable activity (like a video game) or a reward to look forward to (like a fun activity when you get home). When you think of these in advance, you can plan better than when your child having a meltdown in front of you.

Don't be shy to use positive reinforcement to prevent aggression. Don't be shy to use positive reinforcement to prevent aggression.

Make sure you have support. If your child becomes physically aggressive, make sure you have the supports you need to minimize the risk to yourself and to him or her. Special training in nonviolent communication and safety strategies may be very helpful to you and your teen to help keep everyone safe during an aggressive episode.

Parent Partner's Personal Story: Safety Planning for Aggression

Life has always been difficult for us with all of the tantrums and running in the street. But, in my opinion, my daughter really turned into a different person around nine years old. Originally, I thought it was because my ex and I had just separated. After that happened, her behavior became more aggressive toward me.

She's high functioning and speaks very well, but she would completely stop talking and do things like spit, scratch and bite during times when she was frustrated, nervous or anxious. The second I asked any other parent for help, all I got was somber looks of pity, pats on the back and a fist to the chin - telling me to hang in there. That's pretty much when I knew to shut down life, as we knew it, because I was in for a hell of a ride!

*I became determined to make life better for my family and me. I strongly requested to learn non-violent safety strategies from my Regional Center for her increased aggression, property destruction and elopement. I also worked with an outpatient program to get **Therapeutic Behavioral Services** in the home. I spoke to our **Psychiatrist** about adding **medication** that could help and held an IEP meeting to request an assessment from an **Occupational Therapist, Family Counseling**, social skills activities and elopement observation.*

*I was completely stressed out and not finding any relief when **residential placement** was suggested to me. At the time, the thought of "sending my daughter away" was heart wrenching. I did everything I could to cancel out the option.*

After many more upsets, I voluntarily placed her in a residential family environment. I'm so glad I did! My daughter absolutely needed all of this time to be able to process things for herself. As all of this has been going on, I've made sure to see my daughter often and also give her lots of breaks in her scheduling and lots of encouragement to let her know that she is beautiful! I also let her know that she is always in a safe place to be herself with me and that she can talk to me and safely touch me whenever she needs to.

Although we're not completely through puberty yet, my daughter is now becoming such a pleasure and joy to be around once again. She makes more grown up jokes and even talks about her future, which gives me hope that she'll be okay. Above all, I believe that she is a budding advocate for herself and for others with ASD, now that she is starting to be able to express her feelings more... and she's only 11!

I feel like I made the right decision for my own situation and what was right for my child during this pivotal time. My sacrifice still hurts, but I will do whatever it takes to make sure my daughter has a great quality of life - including asking for help to provide it

-Kameena B.D., Parent Partner, Burbank, CA

SAFETY PLANNING FOR RUNNERS AND WANDERERS: ELOPEMENT

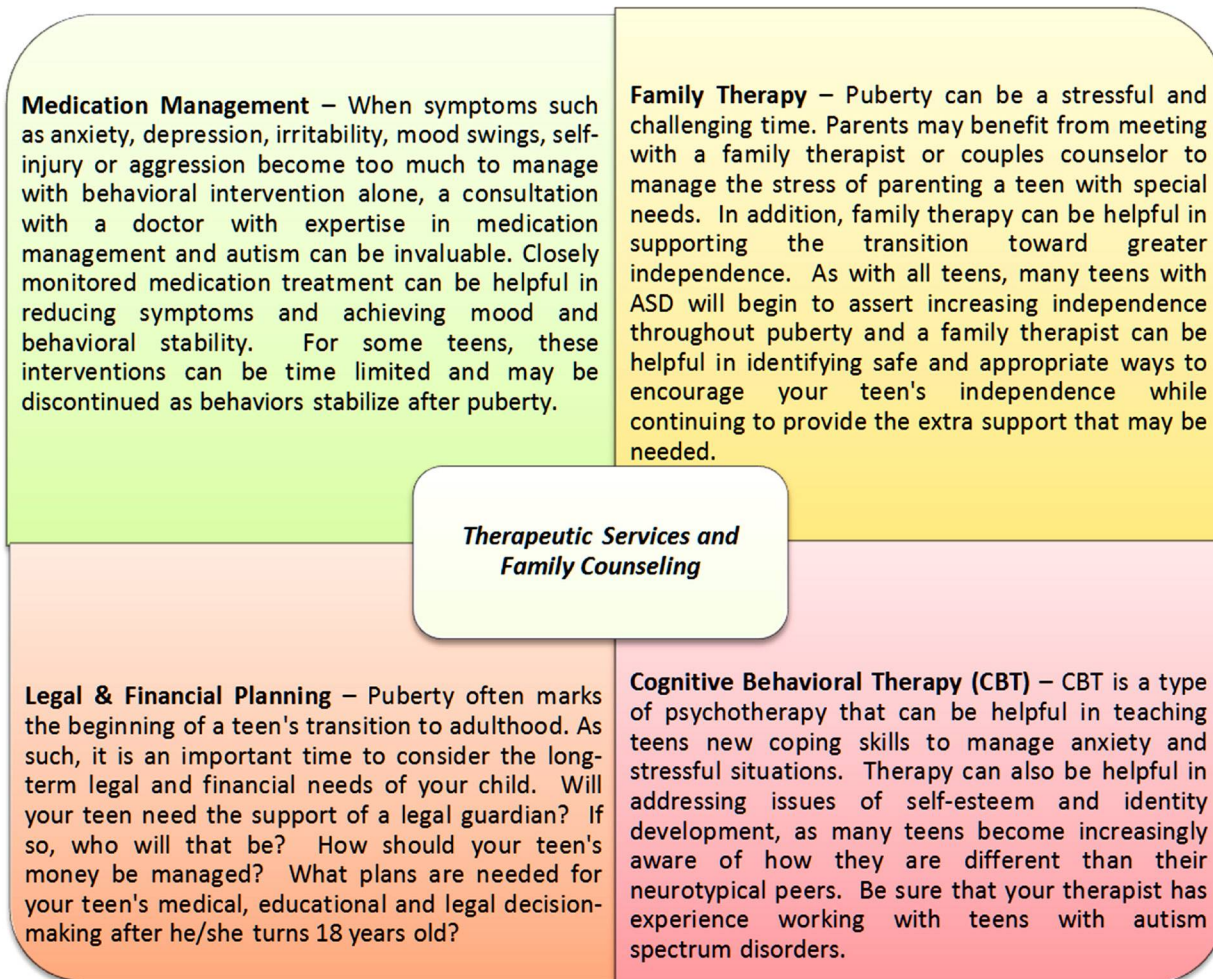
When problems with puberty or mental health become hard to manage, that's when a professional can help. Services can come from a lot of different places. Usually one or two of these can make a big difference.

The first step in finding the appropriate therapeutic services is to identify what is challenging for you and your child. Look to your trusted team of teachers, doctors and therapists to discuss any new challenges. Is your child anxious about the added responsibility of self-care in puberty? Are hormone changes contributing to increased irritability, aggression or moodiness? Are you and your partner finding it difficult to teach new skills? There are a number of helpful therapeutic services and supports that may be helpful.



The Autism Speaks- Autism Treatment Network Team at the Children's Hospital of Los Angeles-Boone Fetter Clinic, along with their Parent Partner- Kameena and her daughter Keena, who has ASD.

The chart below shows different types of services and counseling. Feel free to use it during a discussion with your child's doctor or another professional regarding your family's needs.



INTERNET SAFETY

Keep in mind that as children move into adolescence, they are becoming more and more computer savvy. Many of our children have already passed us by in their knowledge of the Internet! It is crucial that parents are very involved with their children when accessing information on the Internet. This can include inappropriate adult content, but can also include cyber bullying, which is hard, if not impossible, for an Internet filter to catch.

Safety Planning for Internet Users:

Individuals who use the Internet may be easy targets of cyber bullying, pornography, phishing or identity theft. Teach your child the signs of cyber bullying and other Internet threats, such as strangers who seem to know personal information about you, people who send aggressive or sexual messages, people who lie about you and any other people who make you feel uncomfortable.

There are filters that can be used to help limit access to dangerous and inappropriate material to pre-teens and adolescents, but perhaps the best filter is the parent's direct time with the child, to help him or her navigate web searches safely. Your child is much less likely to access something you don't want him or her to see if you are supervising him or her!

[Search these key words online for more info and details:](#)

- *Block Ads or Websites*
- *Web Filtering*
- *Internet Parental Controls*
- *Age Restricted Content*

There are also several social networking sites designed specifically for individuals with ASD. Two notable resources are [WeAreAutism.org](#) and [WrongPlanet.net](#). These are user-led web communities designed for individuals with neurological differences. Chat rooms, blogs and discussion forums provide users with opportunities to share their thoughts and establish, sustain and grow relationships.

Internet Safety Parent Tips:

*Make sure your child knows what to do if any of these problems occur while they are online. Before your child uses the Internet independently, establish the proper Internet etiquette or **Netiquette** ground rules:*

- **Never give out personal or private information, like your real name, account numbers, passwords, and address or phone number to others you do not know.**
- **Do not continue interactions with people that make you feel bad by saying mean things or calling you names.**
- **Do not send money or private banking information to others that may be nice to you but are untrustworthy, especially if they do not match their photo(s) and refuse to see you in person (or on video chat) for a long time.**
- **Tell a family member or trusted adult if people are making you feel bad or asking you to do, say or show things you don't want to do.**

AS ATN/AIR-P NETWORK FOR FAMILY-PATIENT CENTERED CARE

The Autism Speaks Autism Treatment Network (ATN) is a ground-breaking collaboration of hospitals, physicians, researchers and families at 14 specialty center locations or “sites,” across the United States and Canada. We are working together to develop the most effective approach to medical care by providing families with state of the art, multidisciplinary healthcare for children and teens affected by autism. The ATN was established to provide a place for families to go for high quality, coordinated medical care for children and adolescents with autism and associated conditions.

Family Centered Care.

At Autism Speaks ATN centers, parents experience a welcoming environment focused on family well-being. In addition to maintaining the highest standard of medical care, ATN experts carry out innovative research to develop more effective treatment standards for the wider community.

Our Care Model: Whole Care for the Whole Family.

The ATN Care Model represents a comprehensive, coordinated, multidisciplinary care approach for children with ASD. It promotes a high standard of coordinated care for the whole child and family. An ATN center is— a place that provides the highest level of direct care and clinical expertise and also serves as a resource for local families, community physicians, behavioral practitioners and educational advocates -- a cornerstone of the family’s care community.

See more and find an ATN in your community at: www.autismspeaks.org/atn

Contact us:

888-AUTISM 2 (288-4762)

En Español: 888-772-9050

Email: atn@autismspeaks.org

RESOURCES

The Autism Speaks Family Services Department offers resources, tool kits, and support to help manage the day-to-day challenges of living with autism <http://www.autismspeaks.org/family-services>

If you are interested in speaking with a member of the **Autism Speaks Family Services Team** contact the **Autism Response Team (ART) at 888-AUTISM2 (288-4762)**, or by email at: familyservices@autismspeaks.org.

ART En Español al 888-772-9050.

Books

Taking Care of Myself, A Healthy Hygiene, Puberty & Personal Curriculum for Young People with Autism. 2003, Future Horizons; Wrobel, Mary.

The Care & Keeping of You: The Body Book for Girls. 1998, Pleasant Company Publications; Valerie Schaefer.

The Care and Keeping of You 2: The Body Book for Older Girls. 2013, Turtleback Books; Cara Familian Natterson.

From diapers to dating: A parent's guide to raising sexually health children. 2008, William Morrow Paperbacks; Debra Haffner.

Sex Education for Parents of Children with Autism Spectrum Disorder. 2002, Steege Publications; Mark Steege and Shannon L. Peck.

Visual Aides

Visual Aides for Learning: Adolescent Girl Pack
www.visualaidsforlearning.com/adolescent-girl.html

Visual Aides for Learning: Adolescent Boy Pack
www.visualaidsforlearning.com/adolescent-boy.html

Websites

Autism Speaks Challenging Behaviors Tool Kit:
www.autismspeaks.org/family-services/tool-kits/challenging-behaviors-tool-kit

Autism Speaks Safety Project Tool Kit:
www.autismspeaks.org/family-services/autism-safety-project/sexual-abuse

Autism Speaks Transition Tool Kit:
www.autismspeaks.org/family-services/tool-kits/transition-tool-kit

Autism Speaks ATN Teen Sleep Tool Kit Quick tips:
www.autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use/sleep-tool-kit

Autism Speaks Occupational Therapy Tool Kit:
www.autismspeaks.org/family-services/tool-kits/occupational-therapy

Puberty in Kids with Developmental Disabilities-Acne Treatment:
www.acnetreatment.net/puberty-in-kids-with-developmental-disabilities

An online resource and community for Autism and Asperger's:
www.wrongplanet.net

Healthy Bodies for Boys/Girls:
Kc.vanderbilt.edu/healthybodies

Websites cont'd

Autism Speaks Challenging Dealing with big physical and emotional changes in your adolescent:
www.abilitypath.org/areas-of-development/delays--special-needs/autism/articles/puberty-and-your-child-with-autism.html

Menstruation Management and Disabilities:
autismbeacon.com/images/uploads/supporting-women-carer.pdf
<http://www.teachingsexualhealth.ca/>

DVDs & Videos

Be Safe- Movie & Workshop, Save a Life: Teach Students to Interact With Police.
Besafethemovie.com

Specialty OT Services for Transitioning Adolescents- Shaving video:
www.youtube.com/watch?v=SLG6AqkASaY

Managing Puberty, Social Challenges, and (Almost) Everything: A Video Guide for Girls
PREVIEW:
youtu.be/wQwNBIL4gY

A Boy's Puberty Video:
youtu.be/XdW_uU7sxMI

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Tessa Milman, OTD, OTR/L
Clinical Instructor OT 251: Across the Lifespan: Occupation, Health and Disability
Herman Ostrow School of Dentistry
Division of Occupational Science and Occupational Therapy
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