

Davida Hartman Illustrated by Kate Brangan

Sexuality and Relationship Education

for Children and Adolescents with
Autism Spectrum Disorders

A Professional's Guide to Understanding, Preventing Issues,
Supporting Sexuality and Responding to Inappropriate Behaviours



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Teach Puberty

Although teaching children about growing and changing will naturally include puberty concepts, this stage in a child's life needs to be particularly emphasized and prepared for due to the volume and significance of the changes that occur. Temple Grandin, in her book *Thinking in Pictures* (2006), describes the onset of puberty as like living in a constant state of stage fright, akin to how it feels before a big job interview or a speaking engagement. She describes her nervous system during puberty as being constantly under stress, like a frightened animal. While this may be extreme, and not everyone with ASD will experience puberty in this way, it highlights some of the emotional changes and challenges of this time and will resonate with many adults, with or without ASD, when remembering their teenage years.

In addition to the emotional changes of puberty (e.g. feeling scrutinized, an increase in sexual feelings and the desire for autonomy and independence), a teenager's body also begins to change, and with these changes comes a range of new self-care tasks that need to be included in their daily routines, for example, applying deodorant, shaving, wearing a bra, cleaning after masturbation or a wet dream, wearing make-up, looking after their skin, choosing clothes to suit their new body shape and changing sanitary pads or tampons. Old self-care tasks such as showering now need to be done every day, and washing now must include hair, underarms and private body parts. For children who may have taken some time to learn to complete self-care tasks independently, or who may not even be independent in most, these increased responsibilities and tasks are a challenge. See Chapter 11, 'Teach Appearance and Personal Hygiene' for more practical information and advice in this area.

Puberty in Girls

I didn't notice the underarm hair growth or my breasts enlarging. Getting my first period at the age of ten was a huge shock. I thought I was going to bleed to death! I didn't understand why the other girls at school giggled when the boys passed by or why they wanted to go around in groups. (Lawson 2005, p.130)

Puberty helped in some respects because I became sexy. I did everything to cultivate my looks. My peers' reaction began to change in the ninth grade. I was not ridiculed as much. However, puberty was hard because adults were having sex with my age. My 'popularity' was an illusion, and became one of the saddest parts of my life. (Mary Newport in Newport and Newport 2002, p.14)

For girls, the physical changes of puberty usually begin between the ages of 7 and 14 when they begin to experience growth spurts and weight gain. They begin to develop breasts and pubic, leg and underarm hair. Menstruation usually follows within a year or two of these changes. Menstruation typically lasts between four and five days each month, but can range from two to eight days. The time between menstruations varies, but is typically 28 days. It can take two years for menstruation to become regular, and some girls may never experience menstruation at regular intervals. The average girl will first menstruate between 12 and 13 years of age, but possibly as early as 9 or as late as 17 years.

At this stage girls will experience a range of new feelings, including sexual feelings, and may experience mood swings, all of which they may find hard to understand or control. They produce more sweat, and therefore smell of body odour quickly. Their feet may start to smell, their hair becomes greasier and they may develop spots on their face, chests and back. Girls start to grow taller faster than boys. Their nipple area will become larger and darker and will become more sensitive, including feeling itchy at times. Their nipples will also start to become hard when cold or sexually aroused. Their breasts will enlarge and may feel sore or tender. An issue which particularly affects girls at this time is a change in response towards them due to their changing bodies.

I'm not sure why I never learned to take the precautions I obviously needed during my periods, but I surely wish I had. I think the executive functioning skills were just too weak to plan ahead or have contingency plans beyond turning to a friend or the school nurse. (Holliday Willey 2012, p.108)

The onset of menstruation is one of the biggest challenges for girls to deal with at this time. In some cultures, the reaction to menstruation is positive. For example, in Hindu culture a girl's first menstrual cycle is celebrated with new clothes, feasting and ceremonial baths. In the west, however, menstruation is largely concealed and often has negative connotations. Although parents may dread its onset, anecdotally many girls with ASD have been known to accept it in a matter-of-fact manner. Where they may run into trouble, however, is in the self-care tasks that it entails and in dealing with PMT. Sanitary pads and tampons need to be changed regularly. However, difficulties with executive functioning, organization, sequencing, fine motor skills, sensory sensitivities and being either hypersensitive or under-responsive to the feeling of wetness can all lead to difficulties with self-care tasks.

Anecdotally, parents and teachers of girls with ASD have also reported an increase in behaviours (including self-injurious behaviours) prior to menstruation, as well as mood changes, including irritability and becoming withdrawn and less interested in previously enjoyed activities. These issues may be compounded by difficulties in locating, recognizing and reporting pain. PMT is a real occurrence, associated with fluid retention,

increased acne, pain in the abdomen, headaches, irritability, weepiness, anger and an increased appetite, although not all women experience PMT and it may be experienced on a continuum from mild to severe. If you are working with girls with ASD who have reached puberty, it is important to take menstruation and PMT into account when undertaking any behavioural investigations.

Another important change for a girl during puberty will be the development of her breasts, and with it the need to wear an extra (and often irritating) clothing item, a bra. Finding the right bra that does not irritate sensory sensitivities can be a challenge for many women on the spectrum and they may take some time to get used to it. Although some women choose not to wear one (and this is of course a valid and individual choice), not wearing a bra may bring increased and unwanted attention to an adolescent whose breasts have noticeably developed.

Puberty in Boys

This puberty thing has made me recognize the world around me a bit more, especially certain members of the world. Whilst the adolescent rituals are unattainable and unattractive to me, I am getting better at fitting in. Well actually I must admit that these feelings change from day to day. Sometimes I even question my diagnosis and wonder if it is wrong, but then on other days I really do feel like the world's biggest freak! In fact, I have gone from thinking about computers ninety-nine per cent of the time to only thinking about only ninety-seven per cent of the time. Can you guess what I am thinking of the rest of the time? (Jackson 2002, p.191)

Puberty usually begins for boys at 13 years of age, although some start at 12 and others may begin as late as 17 or 18. Boys typically lag behind girls developmentally by roughly two years at this stage. At this time they will experience growth spurts and increased muscle mass. They will also experience a range of new feelings, including sexual feelings, and may experience mood swings, all of which they may find hard to understand or control. Their voices will deepen, their hands and feet will get bigger and they will develop facial, pubic and underarm hair. They can develop smelly feet and their face, neck and back may become spotty. They will produce more sweat and therefore smell of body odour quickly. Their penises and testicles develop and they will begin to ejaculate semen (usually first while sleeping). This can be a frightening experience for some boys, especially those who initially struggled with toilet training. This has been known to lead to anxiety and emotional and behavioural issues in some boys with special needs, for example, refusing to go to sleep because they are afraid that they will 'wet' the bed. (To help adolescents with this, an instructional story about wet dreams is included at the end of this chapter.) Boys will also begin to have erections at odd or unplanned times. They need to learn that (despite any potential embarrassment) this is a normal part of puberty which should not cause alarm and will go away with time.

Puberty (General): Teaching Activities and Recommendations

1. Prepare in advance for the changes associated with puberty.

2. Emphasize the positive aspect of puberty. All changes need to be normalized and discussed and reacted to calmly and positively.
3. Many of the images already developed for use in Chapter 8, 'Teach Body Parts and Fluids' and Chapter 9, 'Teach Growing and Changing' can be used to teach about puberty. Relevant illustrations are also included in Appendix G.
4. First, concentrate on the more concrete aspects of puberty, such as observable physical changes. Introduce more abstract emotional changes later.
5. If possible, it is best if a female discusses puberty (including menstruation and wearing bras) with girls, and a male discusses puberty (including wet dreams and unexpected erections) with boys. It is also best if this information comes from a family member, at least for any initial teachings.
6. Start teaching the child about their own sex first, but remember to teach them also about the changes that the opposite sex will go through and experience. Emphasize the similarities as well as the differences between the two.
7. Use life-sized outlines of bodies. Either draw or add picture cards on the body where, for example, hair grows or spots can appear.
8. Teach the child about mood swings – for example, that they may feel a mixture of strong feelings all in one day. Link these feelings to hormones, which not only cause their bodies to change and grow but can cause them to feel a certain way. Support them in dealing with potential mood swings; for example, avoiding fights or taking a relaxing bath. See Chapter 17, 'Teach Emotional Understanding and Regulation' for more information in this area.
9. Create an 'I'm Growing Up' book, personal to each individual child.
10. Create instructional stories, e.g.:
 - What is Puberty?
 - Why is My Body Changing?
 - Getting Spots is Normal
 - My Breasts are Sore Sometimes
 - My Voice is Getting Deeper.
11. If the child likes reading, there are plenty of books available about puberty and the trials and tribulations of being a teenager. Nichols, Moravcik and Tetenbaum (2009) recommend adapting books that might not be wholly suitable by, for example:
 - using illustrations only
 - photocopying and enlarging specific pages
 - reading only specific pages or chapters
 - using certain pieces of information in the book as starting points, following which the child can look for more information on the internet

- reading a topic with the child before adding it to their 'I'm Growing Up' book
 - giving the child a part of the book to read independently, which they then discuss with their parents at a later stage.
12. There are more and more websites and magazines (both online and in hard copy) specifically for teens all about puberty. Again, these will need to be pre-checked for suitability.
 13. Use role play, social scripts and decisions worksheets to work through scenarios such as 'What if someone laughs at a spot on your face?'; 'Getting an erection in class'; 'What to do when you feel like everyone is looking at you?' and 'How to buy a bra'.
 14. Watch video clips (found online) of teenagers talking about puberty.

Puberty in Girls: Teaching Activities and Recommendations

Bras

1. Encourage female relatives to show the girl bras when out shopping, even before she has started to develop breasts.
2. Encourage female relatives to model putting on bras in front of the girl.
3. Teach the reasons *why* girls need to wear bras.
4. Consider starting the girl wearing a bra before she needs to.
5. Discussion forums for parents of children with ASD can often be a valuable source of information for appropriate brands of bras (i.e. the bras that are least likely to trigger sensory sensitivities). Older children could be supported in posting topics on discussion forums specifically for individuals with ASD, asking questions about bras, as well as other puberty topics. This would need to be highly supervised.
6. Start off with soft sports bras that can be worn over the head and that do not include hooks that need to be fastened.
7. Find bras with no tags, or cut tags off.

Menstruation

1. Start teaching about menstruation before it begins. Red food colouring (or fake blood from the toy shop) can be used to show what a period might look like on a sanitary pad or underwear. These materials can also be used for other teaching activities when the girl has started to menstruate.
2. Emphasize the positive aspects of menstruation. Encourage female family members to talk about it with the girl, using a calm, positive outlook and open communication style. Ask them to tell her about when they first got their period, how old they were, how they felt and what type of feminine products they use and why. Discuss with them whether they would be willing to model the appropriate use of sanitary

pads or tampons for the girl (an important learning tool). When she does start menstruating, encourage the girl's female relatives to do something fun on the day; celebrate it! Have a 'Red' or a 'Girls Only' party, or get her nails done. Of course, if a girl lives with only her father, he can do all of these activities with her. Even for girls with no verbal language, doing enjoyable activities on the days she menstruates will lead to positive associations with it.

3. It is important that everyone involved with a girl communicates with each other. It is also important that there is a plan in place for each step of the journey. Questions that everyone will need to know the answer to (prior to first menstruation) include:
 - What happens if she first menstruates in school?
 - Who can she talk to about it?
 - Will she need assistance in the toilet?
 - How will she ask if she needs to change her pad?
 - If she needs help in the toilet, give the girl choice in who accompanies her, if possible.
4. Teach slang terms (e.g. 'the curse', 'the time of the month' and 'Aunt Flo').
5. Ensure that menstruation is included in teachings about gender, body parts and fluids, and growing and changes. For example, when looking at pictures of different people in the child's family, say things like, 'That is your mammy as a child. She doesn't have her period'; 'That is your mammy when she is older. See, her breasts are bigger and her hips are wider. She has gone through puberty. She is a teenager. She now has her period every month' and 'That is your dad; he does not have periods. Men do not get periods.'
6. More able learners will benefit from having the connection between menstruation and reproduction explained in a simple way and linked to other changes during puberty (e.g. the growth of hair and breasts).
7. Some ideas to help prepare girls with poor language skills for menstruation each month:
 - Use 'calendar boxes' or 'anticipation shelves' (i.e. boxes for each day with the items that they will need in them).
 - Start using pads a few days before menstruation is anticipated. This will help communicate that it is about to begin.
 - Make changes to the environment, e.g. with music, candles and massage.
 - Show a 'Menstruation' symbol (e.g. a picture of a pad with blood on it, or a pad with red dye on it) when it starts.
 - Always show a 'Change pad' symbol before changing a sanitary pad.

- Show the full packet of pads before menstruation and continue to show the pack becoming emptier. On the last day show the empty packet. Have the girl throw it in the wastebasket.
- When menstruation is finished, show a 'Menstruation finished' symbol (e.g. a picture of a clean pad or a picture of a pad with blood on it with an X through it). This step may not be necessary if she understands that throwing the empty pad packet in the bin marks the end of menstruation.

A calendar will be a vital tool in teaching girls to self-manage their own menstruation. They should also be involved in their own charting, which will increase self-sufficiency and communication skills. More able girls can keep their own diary or personal calendar, recording changes throughout the month in their body, mood and menstrual cycle. Girls with poor language ability or who are less able can be supported to use adapted weekly or monthly calendars, which should be large and highly visual. Information can easily be recorded on them using stamps (e.g. happy or sad faces, different colours to indicate different moods, or red stamps to indicate menstruation). Visual pain scales can also be used to monitor PMT.

8. If appropriate (e.g. if the girl is experiencing behavioural difficulties), parents and professionals may also wish to keep their own record of the girl's monthly cycle. Relevant information to record could include mood, swollen abdomen, sore breasts, tiredness, blood flow, food changes, decreased language, cramps, irritability, as well as any potential positive changes.
9. Along with the child's parents, it will need to be decided whether changing her own sanitary pads is realistic (although independence should always be an ultimate goal). Questions to ask in making this decision should include:
 - What prompts would be needed?
 - How does she currently manage her underwear?
 - Is she independent in toileting?
 - Does she understand words, symbols, pictures or signs?

SANITARY PADS VS. TAMPONS

Before menstruation is due to start, teach the difference between pads and tampons and help the girl come to a decision as to which is more suitable or which she prefers. (There will of course be some situations where this decision may need to be made for her.)

1. In general, pads are easier for girls with ASD to use.
2. Tampons may be suitable if the girl has good fine motor and coordination skills, has no issues putting her finger inside her vagina and has an active lifestyle, e.g. she swims regularly. Some benefits of tampons are that they are small to carry and create no odour. However, they can be difficult to insert for lots of girls, and because they are easy to forget about after insertion they also carry the risk of toxic shock syndrome, relevant if someone is likely to forget to change them regularly.

3. Go to the shop together (or encourage a female family member to do so) to buy different menstruation products, including ones that are scented and unscented. (Scented products may need to be avoided to prevent potential issues such as itching and thrush.) Include different thicknesses, shapes and sizes.
4. Look at the packaging of different products with the girl. Which are easy to open? How many strips does each pad have? Will wings be too complicated to use? Will they fit in her bag?
5. Do experiments – e.g. How much liquid do certain pads take before they leak?
6. Let her take all of them apart. Discuss the purpose of each part.
7. Weigh up all of this information. Make lists of pros and cons. Then choose one product with the girl to start off with.
8. The girl can always decide to start with pads before moving on to tampons at a later stage.

Whether pads or tampons are decided on, teach how to wear, change and dispose of them appropriately. This may vary according to the setting. For example, in school she may need to dispose of a pad in a specific blue bin, whereas at home she needs to put them in a wicker bin under the washbasin. Therefore you will need to do task analyses specific to each of the child's settings. A picture-based instructional story is included at the end of this chapter to show some of the steps for changing a pad in certain situations. Photo sequence cards can also be useful. These, or other visual reminders, can be laminated and kept with the girl's other feminine products.

9. When teaching the use of pads or tampons, start with the final step of taking them off and putting them into the bin, as this is an easier task than putting them on.
10. Draw placement lines with a laundry pen on the girl's underwear if she is having difficulty with pad placement.
11. A desensitization programme may be needed if the girl does not like the feel of either pads or tampons. To do this, start with thinner and smaller pads or tampons before moving on to thicker and larger varieties. Also, only require the girl to wear them for short (and defined) periods of time which can be increased gradually. Pair these steps with positive reinforcement.
12. If tampons are chosen, a small amount of lubrication jelly may help with insertion initially. Decide between tampons with or without applicators. Practise opening and pushing out the tampon before teaching insertion into the vagina. Teach about relaxing vaginal muscles. The girl should understand that tampons are not meant to feel uncomfortable.
13. Being able to make a judgement as to how often a sanitary pad or tampon needs to be changed can be very difficult for girls with ASD, and guidance will need to be given appropriate to the circumstances. Rather than the girl needing to remember or judge when she needs to do it, it may be easier to have a hard and fast rule that she

should change them every four hours. Reminders will most likely be needed. Use whatever format works for the girl, e.g. a discreet alarm on her phone or a special buzzer. A visual reminder could also be used, e.g. a cue card placed discreetly on her desk. Alternatively, matching the changing times to the natural breaks at school may be more practical and less conspicuous for the girl, although reminders may still be needed.

14. Always keep menstruation products in the same place, e.g. a special drawer at home or a special bag in school. Wearing a bag with a long strap across the body will make it less likely to be forgotten or lost. Spare pairs of clean underwear should also be kept here.

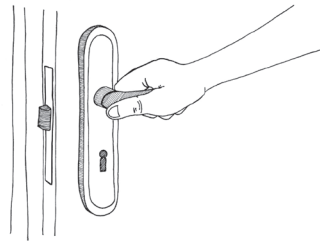
Premenstrual Tension

1. Teach the signs of PMT, preparing in advance through the use of a calendar. Encourage relaxation, exercise, light eating and lots of sleep during this time. Support the girl in finding ways to alleviate discomfort, e.g. a hot-water bottle, a microwavable 'wheat pillow', bubble bath or music. Note which of these tactics help her relax. Girls with less language can be given symbols or objects to represent these items so that they can request them independently (e.g. a bottle of massage oil to request a massage, a CD to request music, a piece of blanket to request a lie down, a piece of towel to request a bath). Make sure to have these items within the girl's reach when you anticipate that she will need them.
2. Recommend consultation with a doctor if she is experiencing severe pain (or behavioural concerns) alongside or prior to menstruation.
3. Taking pain killers may help alleviate PMT and, if a pattern emerges, could be taken as a preventative measure. Birth control can also help lessen PMT, as well as having the added benefit of making menstruation more predictable and therefore more manageable. Some women take a selective serotonin re-uptake inhibitor (SSRI) to manage emotional lows during menstruation. All of these would need to be discussed with the child's parents and family doctor before implementing.
4. Teach about appropriate clothing during menstruation, e.g. wearing dark clothes and underwear and avoiding white; wearing specific underwear to save all of her underwear from becoming stained; wearing clothes that are comfortable around the waist and breasts. Close-fitting clothes will help avoid odour. Clothes with pockets can also be useful to keep tampons, pads and spare underwear in. Also teach how to care for underwear by removing blood stains correctly.
5. Girls experience many unexpected difficult scenarios in relation to menstruation. Try to prepare for as many of these as possible, for example:
 - What if there is no wastebasket in the bathroom?
 - What if you get your period in a friend's house?

Changing My Pad



Go to bathroom.



Close door.



Pull down underwear.



Take off old pad.

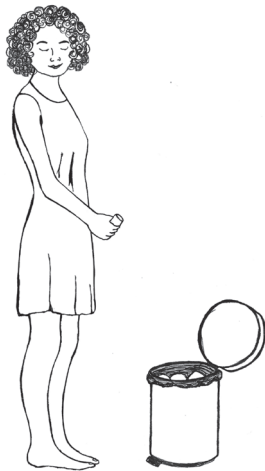




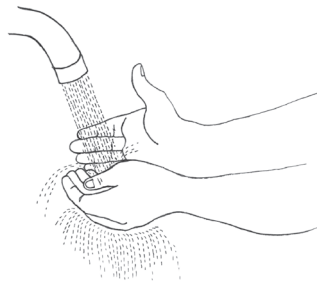
Put new pad on underwear.



Pull up underwear.



Put old pad in the wastebasket.



Wash hands.



Periods

Girls start their period at different ages.

'Having your period' means that blood comes from inside your body and flows out of your vagina.

Period blood is clean, not dirty. It does not mean that you are cut, hurt or sick.

It can come at any time of the day or night.

Having periods means that your body is working right. It means that you are becoming a woman.

You will usually bleed for a few days every month.

Over one period, only five or six tablespoons of blood will come out of your vagina.

Sometimes you will feel the blood coming out. Sometimes you won't.

Pads stop the blood from getting onto your clothes. Pads need to be changed regularly. If they are not, they will leak onto your clothes. Also, other people will be able to smell them.

Sometimes you might feel a bit cranky before your period. Sometimes your tummy and breasts might feel a bit sore. This is called PMT. Lots of girls get PMT. Things that might help you feel better if you have PMT are a hot-water bottle on your tummy or a bath.

Having your period is a private topic. It is OK to talk about it only with girls that you know well or your mum or dad.

