

# Puberty and autism spectrum disorders

*Kirsty Kerr, the Autism Victoria Family Counsellor, has taken up the challenge and prepared this article covering one of the most difficult developmental stages for parents of children with an autism spectrum disorder. It need not be a scary prospect, and all children (and parents) survive puberty! There is an increasing number of valuable resources to help families.*

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**W**hen a child reaches puberty, families can view this as a time of pride that their child is developing into an adult. Alternatively, families may view this period with trepidation, feeling unsure of how to explain the changes to their child.

For an adolescent with an autism spectrum disorder, the physical changes that indicate increasing maturity can be quite at odds with where the individual is at in other aspects of their development, such as academic and social skills. It can be a shock for parents to recognise that their child will have an adult's body, without all the adult capabilities to accompany this.

As with all children, the individual with autism spectrum disorder will need to be prepared for the changes that will take place. Many of these individuals already have difficulty coping with any type of change, and therefore there is even greater importance in adequate preparation for the physical and hormonal changes puberty brings. Society also expects more from those with an adult-like appearance, and individuals with autism spectrum disorder also need preparation for the new social expectations that accompany their body transformation.

## **What is my child able to understand about the changes during puberty?**

If your child has moderate to severe difficulty with intelligence, or language development as part of their autism, they may not be able to understand the abstract concepts related to puberty, such as mood changes, or the reason for menstruation. Preparation for these individuals is less about teaching when and why the changes will occur, and more around teaching appropriate responses to the things that happen during say menstruation and masturbation. Skills to be taught include hygiene during menstruation, and privacy during masturbation. These topics are covered later in this article. Also the book *'Talking Together About Growing Up'*<sup>1</sup> has a curriculum for teaching children about puberty which suggests different sets of exercises depending on the age and level of ability of the child.

## **When do I start to prepare?**

If your child shows an awareness of how older people are physically different to them, this is a great starting point for discussion. Noticing a beard, breasts or underarm hair is a very tangible visual sign for a person with autism spectrum disorder about difference to themselves. For young children (e.g. lower primary school) start to link these visual signs with 'having an adult body'. "The girl has those bumps on her chest because she is turning into an adult". "The woman has the bumps because she is already an adult". Showing the child pictures of yourself at different ages to see how you looked different can also be useful. As a more clear visual cue, line drawings of the body and how it looks at different ages can be used, such as those in *'Talking Together About Growing Up'*.<sup>\*1</sup>

The child's awareness of the differences can then be gradually added to. For example, the next level of information about 'the bumps on the woman's chest' could be discussing that these are called 'breasts', and the other alternative names for them. Next would be discussing that breasts develop for feeding babies when the woman is an adult. Finally the child should learn that breasts are a private area and are not able to be touched without permission.

For upper primary aged children, start to use the word 'puberty', such as in "puberty is when a child's body changes into an adult body", along with pointing out that as an adult, you have already been through this. Then, when the child notices physical differences in other people, this can be discussed in the context of 'puberty'. From an understanding of the differences in others, the individual can then begin to understand the transition from child to adult. They can be taught about the changes to expect in their own body, and the reasons behind these. Do this explicitly, as just because an individual with an autism spectrum disorder sees how things are for others, doesn't necessarily mean they will generalise this to their own situation. Therefore make clear statements like 'as you change into an adult, you will also have underarm hair'.

Other commonsense information that will need to be explained to the individual with autism spectrum disorder is the fact changes in themselves will only be those associated with the same sex (e.g. a boy will not begin to grow breasts). For a child who is anxious as part of their autism spectrum disorder diagnosis, covering misconceptions that the child may think, but not express is important so that the child does not worry in silence (e.g. the child may think the whole body eventually becomes progressively covered in hair like a werewolf. Therefore explain that extra hair just grows on the underarms and pubic area in women, and also on the chest and chin of a man).

Some parents may delay discussions because they feel advance preparation may contribute to their child's anxiety. Because it is never certain at what age puberty will begin, some parents don't want to confuse their child with information that may not be applicable for a while.

It is suggested that the child be given an approximate age range in which to expect the changes, in order to help reduce this uncertainty. The average age for girls to begin puberty is 11, with the possibility that it may begin as early as 8 years of age<sup>2</sup>. The average age for boys to begin puberty is 12–13 years, although it may begin as early as 9½ years of age<sup>3</sup>.

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 (the boy appears to have 'gangly' arms and legs). If children with an autism spectrum disorder are not prepared for the changes, they may become confused or frightened that they are very ill because things are changing with their body.

### ***How do I explain the changes to my child?***

Given the strength in visual skills for individuals with autism spectrum disorder, the information about body changes in puberty is best given in a visual way. A social story<sup>\*4</sup> is the ideal format for this. A social story can be personalised to the individual adolescent, and a separate social story can be written for each of the body changes the individual can expect. A title such as 'I am growing into a man/woman' can be used. Lots of descriptive sentences can be used to clearly state the facts. Here are some examples of topics that will need to be covered in the social stories.

#### ***Topics for puberty social stories for girls:***

- breast development and widening of the hips (could be titled 'the shape of my body will change')
- pubic and underarm hair development (title 'extra hair will grow')
- onset of menstruation (title 'I will begin to have my period')
- growth acceleration (title 'I will get taller')

### • **Topics for puberty social stories for boys:**

- growth acceleration (title 'I will get taller')
- pubic, underarm, and facial hair development (title 'extra hair will grow')
- testicular and penile enlargement (title 'my body will look different')
- spontaneous erections, sperm production, wet dreams (title 'my body will do new things', or use simplified versions of these terms as titles)
- voice deepening (title 'my voice will sound different')

The booklet *'Let's Talk About Puberty'*<sup>5</sup> gives the basis for information on all these topics, which can be adapted into a social story. The information will need to be personalised to your child. The book *'Talking Together About Growing Up'*<sup>1</sup> has a useful appendix with 'proper' terminology for body parts and occurrences during puberty, along with some commonly used slang your child may hear from peers. Given the tendency for literal interpretation of language by an adolescent with autism spectrum disorder, it is important to inform the child of such synonyms, so that they can understand that words like 'boobs' refer to breasts. Otherwise they may be confused by the conversations of their peers, and not think to ask for clarification. Misunderstanding often breeds anxiety! Incorporating a page in each social story with alternative terms related to the story topic can assist understanding.

### **Other resources to explain puberty**

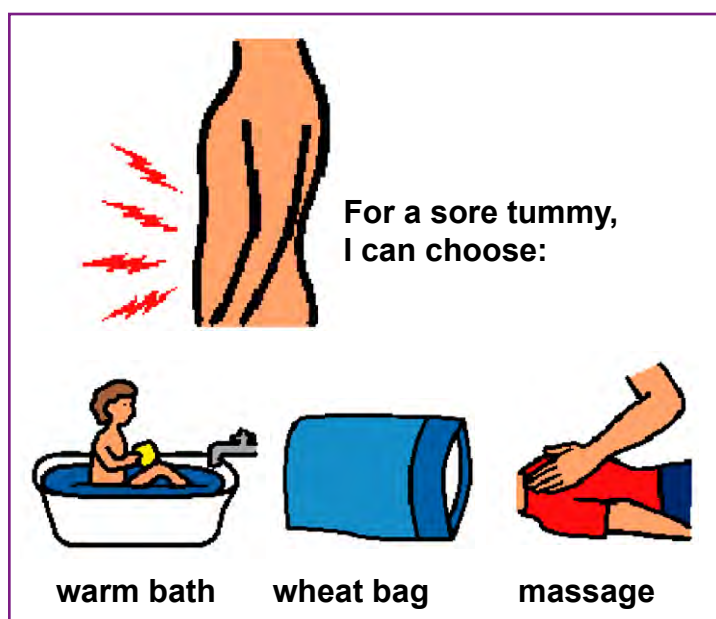
#### **Girls:**

The development of breasts, pubic hair, and menstruation management are all covered visually in the book *'Special Girls' Business'*<sup>6</sup>. Changes in mood are also discussed in this resource that is bright and colourful, and emphasises that the changes are a positive part of becoming a woman. The book is aimed at girls with special learning needs in general, not specifically girls with autism spectrum disorder, but it is still a very useful resource. Girls with Asperger syndrome may find the companion volume *'Secret Girls' Business'*<sup>7</sup> more suitable, as they would have the ability to understand the concept of ovulation, and the purpose of menstruation.

Having some ideas to help with menstrual discomfort is advisable, as is representing these visually\*.

The adolescent girl may not be able to self-regulate initially, but when you notice discomfort, consistently prompt using the visual cues, and choice making, until she is able to do this independently.

The video *'Kylie's Private World'*<sup>8</sup> is an animated short video in which the narrator, Kylie, takes adolescents step by step through the topics of hygiene, menstrual management, masturbation in private, sexual consent, the act of intercourse, and the importance of protected sex. The video is intended for adolescent girls with special learning needs. Although not autism specific, it is still highly useful, as it shows clearly and visually what all the concepts look like. It is strongly recommended that parents view the tape themselves before



letting their daughter watch it, so they can determine how much information to let her view. A young girl of 10 being prepared for menstruation management may not need or understand the information about contraceptive use and intercourse.

### **Boys:**

The video '*Jason's Private World*'<sup>9</sup> is an animated short video in which the narrator, Jason, takes adolescents step by step through the topics of hygiene, masturbation in private, gaining sexual consent, the act of intercourse, and the importance of protected sex. The video is intended for adolescent boys with special learning needs. Although not autism specific, it is still highly useful, as it shows clearly and visually what all the concepts look like. It is strongly recommended that parents view the tape themselves before letting their son watch it, so they can determine how much information to let him view.

For both adolescent boys and girls, it is then recommended that parents sit and view the videos with their child. Answer questions posed by the child as they arise, using the complexity of the question as a guide to how in-depth the answer should be.

The book '*Secret Boys' Business*'<sup>10</sup> is a great resource for adolescent boys with Asperger syndrome to explain puberty changes and some associated emotions.

### **Emotional changes**

The fluctuating hormones that are part of the physical changes of puberty can lead to changes in mood. It is important that the adolescent with an autism spectrum disorder understands that good and bad feelings will come as part of changing into an adult body. Girls who are interested in logic and facts may be interested in charting their own mood on a calendar to see if there is a cyclical pattern coinciding with their menstrual cycle. Having a collection of ideas to help adolescent boys and girls when their mood is low is recommended. Again it is recommended that these be represented visually\*.

Many adults assume that puberty is a time of inevitable low mood for the adolescent. Some even think that depression is an expected part of going through puberty. Depression is different from normal mood fluctuations as part of puberty. Depression is characterised by low self-esteem, a feeling of worthlessness, and withdrawal from previously enjoyed activities. In addition, depression may be expressed by an adolescent with autism spectrum disorder by disturbances in eating and sleeping that are markedly different to usual behaviour, increased agitation, or extreme lethargy which contrast with the individual's usual behaviour. Depression is not a 'normal' part of transitioning to adulthood, and the above symptoms should be discussed with the adolescent's GP as a starting point.



#### **When I feel upset or sad I can choose to:**

- \* Listen to music
- \* Have a nap
- \* Play the computer
- \* Have time on my own
- \* Read a book
- \* Look at my photo album

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 autism spectrum disorder as those without). An individual with autism spectrum disorder may act on such interest by becoming obsessed with another adolescent (as they may with any other topic of interest).

The difference between this scenario and any other adolescent 'crush' is that the person with autism spectrum disorder 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 an autism spectrum disorder needs to have explicit instruction about indications that someone likes you as opposed to not being interested romantically.

An adolescent with Asperger syndrome, 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. The adolescent can be taught that feeling tingly when being near another person, and thinking about that person a lot of the time shows that this is happening.

Talking to the adolescent with Asperger syndrome, even if they are not experiencing this themselves can help demystify for them the change in their classmates' behaviour from mainly same-sex interaction, to mixed interaction, with flirting, touching, and showing off for the benefit of potential girlfriends/boyfriends. This may help them make sense of what is going on around them. 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 an offence needing to be reported to the teacher, and punished!

Interested	Not interested
<ul style="list-style-type: none"> <li>• Giving strong eye contact</li> <li>• Leaning forward to hear what is said</li> <li>• Smiling</li> <li>• 'Flipping' or touching hair</li> <li>• Laughing at your jokes</li> <li>• Other person initiating conversation</li> </ul>	<ul style="list-style-type: none"> <li>• Looking away</li> <li>• Turning away</li> <li>• Moving away</li> <li>• Looking unhappy</li> <li>• Having arms folded</li> <li>• Not responding when talked to</li> </ul>

### **Social Expectations**

Puberty is usually a time of increased sex drive. Masturbation is a natural process of responding to urges that are not satisfied with a mate. Adolescents with autism spectrum disorder have the same needs in this respect as all other adolescents. A problem may arise when the individual does not understand that this is an act which people do in private.

Preparation about doing this in a private place can be assisted by the use of a social story, such as that found in '*Annette Joosten's Book of Cool Strategies*'<sup>\*11</sup>. A private place is where other people cannot see you. Given the difficulty of individuals with autism spectrum disorder with 'theory of mind'<sup>12</sup> (or perspective taking), the person may not be able to identify a private place, even when given the above definition. Therefore, making a list of public versus private places, in order to consolidate the concept is recommended.

Using this format, other behaviours that must be done in private can also be discussed (e.g. undressing, urinating, scratching private parts — specify all behaviours as generalisation often does not occur naturally).

The individual with autism spectrum disorder must also be told that it is not necessary to masturbate every time you are in a private place. Wendy Lawson<sup>13</sup> recounted in one of her entertaining presentations several years ago the story of a young gentleman who had been informed as part of his sex education that masturbation was to be done in private places, such as the toilet. The same young gentleman became very unhappy and sore when he interpreted that to mean that each and every time he went to the toilet, he should masturbate!



Although most adolescents notice their feelings of desire and 'stumble' upon the way to relieve such urges through masturbation, the individual with autism spectrum disorder may not come to this realisation, and may need assistance to understand how to respond to such urges. The article 'Sex education issues for the person with Autism'<sup>14</sup> suggests some guidelines for teaching masturbation to individuals with autism. Watching the appropriate parts of 'Kylie's Private World'<sup>8</sup> or 'Jason's Private World'<sup>9</sup> videos may also give a useful visual cue. Finally, the picture schedule above\* may be another visual means to complement the teaching of the desired behaviour or routine.

### **Increased manners and maturity**









A useful visual cue for individuals with high-functioning autism or Asperger syndrome is the step-by-step written procedure for appropriately responding to sexual urges described in 'Asperger syndrome and Sexuality'<sup>15</sup>.

Although inappropriate touching of self in public is of concern, parents will also need to help their child understand where it is inappropriate to touch others. Additionally individuals with autism spectrum

Private places	Public places
<ul style="list-style-type: none"> <li>• In my bedroom with the door and the curtains closed</li> <li>• In the toilet with the door closed</li> <li>• In the shower with the bathroom door closed</li> <li>• In the school toilet with the door closed</li> <li>• In the shopping centre toilet with the door closed</li> </ul>	<ul style="list-style-type: none"> <li>• All the other rooms in the house</li> <li>• School classrooms</li> <li>• In the shops</li> <li>• At other people's houses</li> <li>• In the car</li> <li>• At the park</li> <li>• etc.</li> </ul>

disorder will need to learn that others may not touch their private parts without consent. Such topics are covered in the book 'Taking care of myself'<sup>16</sup> which uses social stories, and other visual strategies to assist in learning these concepts\*.

Personal hygiene can be a concern for parents when their child is going through puberty. Pubertal development with extra hair and newly active sweat glands can lead to offensive odours, which the individual with autism spectrum disorder may not recognise are a cause for concern. The person may not recognise how they are perceived by others, understand what is socially acceptable, or might be avoidant of self-care tasks because of the sensory issues with brushing teeth, and brushing or washing hair.

	close my bedroom door		close the blinds
	have my private time		clean up using tissues
	throw messy tissues in bin		check my hands are clean
	open the blinds		go out of my room

The book *'Personal Hygiene — What does that have to do with me?'*<sup>17</sup> may assist, as it contains a curriculum for teaching children with autism spectrum disorder aged 8–14 years about the importance of hygiene for social acceptance and health.

None of us has a crystal ball to predict how an individual will respond to the challenges of puberty. An individual may require assistance with all or none of the issues outlined in this article. Being informed in advance may just mean as a parent or carer there is not the element of surprise and uncertainty as to how to approach such challenges if they do arise. A useful contact for further advice is the disability service at Family Planning Victoria — (03) 9257 0133.

\*All articles and visual cues marked with an asterisk throughout this article have been compiled into a 'puberty kit', available to borrow from the Autism Victoria library (#2761). This would be especially useful for members who require library items to be posted, as the relevant information from many books is presented in one compact folder.

### **Puberty Bibliography**

(The Autism Victoria library accession number is in brackets)

1. Scott, L., and Kerr-Edwards, L., *'Talking Together about Growing Up'* (#2381)
2. ACT Health Tipsheet, *'Precocious Puberty in Girls'*, <http://www.healthfirst.net.au/>
3. ACT Health Tipsheet, *'Precocious Puberty in Boys'*, <http://www.healthfirst.net.au/>
4. Gray, C., Social Story Kit (#2372)
5. Down's Syndrome Society of Scotland. *'Let's talk about Puberty'*, download from [www.dsscotland.org.uk/publications/learning-disability/talk-about-puberty.pdf](http://www.dsscotland.org.uk/publications/learning-disability/talk-about-puberty.pdf)
6. Angelo, F., Pritchard, H., and Stewart, R. *Special Girls' Business* (#2666)
7. Angelo, F., Pritchard, H., and Stewart, R., *Secret Girls' Business* (#2745)
8. Life Support Productions, *Kylie's Private World*, video and support notes (#2352)
9. Life Support Productions, *Jason's Private World*, video and support notes (#2353).
10. Angelo, F., Pritchard, H., and Stewart, R., *Secret Boys' Business* (#2746)
11. Joosten, A., *Annette Joosten's Book of Cool Strategies* (#2389). See the story — 'My Body'
12. Baron-Cohen, S., *Mindblindness: An essay on autism and theory of mind* (#1052)
13. Lawson, W., *Sex, Sexuality and the Autism Spectrum* (#2613)
14. Detmer, C., Dalrymple, N., and Sinex, L., *'Sex education issues for the person with Autism'* (#1216)
15. Henault, I., *Asperger syndrome and Sexuality* (#2642)
16. Wrobel, M., *Taking Care of Myself* (#2390)
17. Crissey, P., *Personal Hygiene — What does that have to do with me?* (# 2611)

Other puberty items in the Autism Victoria Library:

Fegan, L., *Sexuality and People with Intellectual Disability* (#2110)

Longhorn, F., *Sex Education and Sexuality for Very Special People* (#2615)

Mortlock, J., *The Socio-sexual Development of people with Autism and Related Learning Disabilities* (#1236)