



Sexuality Health and Hygiene



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Sexuality health and hygiene

“What will I teach my son with autism about puberty and sex?”

For parents of a child with ASD coping with the onset of puberty and their child's emerging sexuality can be challenging. Knowing what to teach, how to teach it and what to expect can be daunting. If young people with autism are misinformed it can have damaging and long lasting effects on their ability to deal with puberty, sex and having a relationship. Young people with Autism are often far behind their peers in their sexual knowledge and have less ability to stand up for themselves to avoid abuse and exploitation.

It is important for parents, teachers and service providers to know that

- People with ASD develop physically and sexually the same way as other people.
- People with Autism have the desire to express their sexuality.
- People with ASD have the choice and the right to do so.
- People with ASD can express their sexuality as an individual or as part of a relationship (either heterosexual or homosexual).
- With these rights come responsibilities and young people with ASD need to understand sexuality and relationships in the context of the law.

Puberty

Coping with change is extremely difficult for children with autism; the changes of puberty can be very frightening if the child does not understand what is happening to their body. It is very important to educate the child with autism about puberty in a very factual way. It is important to use factual information with anatomically correct diagrams so the child learns the correct names for body parts and their functions. It is important the child understands what will happen to them and how to deal with it.

For parents of children with autism the onset of puberty can be a very challenging time. Puberty will usually occur between the ages of 11- 17 and as young as 8 in girls, regardless of IQ or intellectual functioning.

Signs of puberty

Boys

- Rapid growth spurt
- Changes in mood
- Hair growth
- Increased erections
- Acne
- Increase in sweat and body odour
- Onset of 'wet dreams'
- Increase in aggression

Girls

- Onset of menstruation
- Breast growth
- Acne
- Mood changes
- Hair growth
- Body changing shape
- Increase in sweat and body odour
- Concerns about body image develop

What do I teach a child with autism?

- When discussing puberty and sex with a child with ASD it is important to teach to the child's level of understanding.
- Keep information factual using correct names and use pictures wherever possible.
- Talk to the child about the changes related to 'turning into an adult'
- Talk about the changes relating to boys and girls being different- children with autism may not realise that the changes are different for boys and girls.
- If the child has limited understanding and poor verbal skills, educating the child about key points such as privacy, appropriate touch, saying no and hygiene is essential.
- Use social stories to cover the different topics- "My body is changing" "I get my period"
- Find out what the child already knows and tailor your discussion to their needs.
- Consider the environment- a quiet private space free of distraction is important.
- Use realistic visual aides, books or diagrams if needed and keep language specific and factual.
- Check for understanding- the child or young person may be able to relate back to you word for word what you have told them but may have little understanding of what you have said.
- You may have to repeat your discussion or conversation a few times before the child or young person understands what they have learnt.
- Remind the child that they should come to you with any questions about puberty/sexuality.

Topics to cover

- Public and Private
- Body parts
- Knowing how babies are made (how egg and sperm meet to create an embryo) this is different to learning about how to have intercourse.
- Hygiene – how to keep clean, wearing deodorant etc
- Menstrual management for girls
- Self-protection /Assertion skills- how to say NO
- Rights and responsibilities
- Sexual awareness- what is sex/intercourse, what is appropriate behaviour and when.
- Masturbation
- Self esteem
- Appropriate expression of feelings.

Privacy

- It is important that children and young people with ASD learn about privacy to ensure appropriate behaviour is encouraged and to avoid unwanted behaviour such as public masturbation or nudity.
- It is important to ensure that the child is aware of the privacy needs of others in their family and community.
- Family members should respect each other's privacy and encourage closing doors and knocking on doors before entering private spaces.
- To help the child with autism remember to knock you can use some visual cues signs or sequences on doors such as STOP KNOCK WAIT in any format that is appropriate.

Public and Private

The discussion about public and private spaces covers topics listed below. Family Planning Victoria has some excellent resources that can assist with this discussion.

- Public and Private relates to places, body parts and the behaviours you do in those areas
- Private space- A private space is your bedroom with the door and curtains shut
- A bathroom or toilet is a private space
- A public space is anywhere other people can see you – this can be your lounge room, the kitchen, your classroom, the bus stop,
- In private space you can – do things which others should not see such as touching your private parts, taking your clothes off.
- In a public space you can eat, play, sit, talk etc.
- Public body parts- parts of you body that other people can see such as your face, hair arms, legs
- Private body parts – are those parts covered by underwear or swimwear
- You must respect others private spaces and private parts, no touching others
- Knock on the door
- Teach the child or young person they must ask before touching another person

- Teach the young person that no one is allowed to touch their private parts without permission.

Body Parts

- It is important that the child with autism learns the correct names for their body parts from an early age, so they can talk about what is happening to them and to avoid the use of inappropriate names for body parts when the child is older.
- Teach to the child's level of understanding using visual aides or models.
- Remember to keep names for body parts factual, but you may want to talk about slang words that other people use to refer to these body parts.
- Higher functioning children/young people with autism may enjoy learning about the human body and often find the functioning of the human body fascinating and very funny.
- Models and diagrams or science experiments may hold a lot of appeal.
- Whichever way the young person receives information about body parts is it very important they get a good understanding of their private parts and what they do.
- It is important the child understand the differences between boys and girls.

How babies are made

This is a basic concept that all children should learn, about how egg and sperm meet to make an embryo, how a baby develops in the womb and is born. Teach this concept in a factual way, using pictures, books or other resources. All children find this an interesting topic and may have many questions. Answer them honestly and factually.

There are many books and resources available for children of all levels to learn about where babies come from. Most children in mainstream Victorian schools cover the basics of puberty and where babies come from (with parent permission) in grades 5/6 Discuss with your child's school what they will be teaching and how they will teach it. You may need to work with the school to follow up on the information at home.

Hygiene

The child with autism will need to know about hygiene and why it is even more important during puberty.

They need to know that:

- Your body changes – you sweat and smell more
- It is important to wash properly every day and put on deodorant and clean clothes.
- They need to wash their hair and face – this can be extremely difficult due to sensory processing issues
- They need to clean their teeth at least twice a day
- They will need to learn to shave

Supporting hygiene

- Have the young person choose what kind of soap or body wash and deodorant they would like to use. Unscented or hypoallergenic soap/deodorant may be needed if sensitivity to perfumed soaps/deodorants is a problem.

- A special towel and washer with a favourite design or in their favourite colour can help.
- Plain toothpaste may be needed.
- For shaving, an electric shaver, used with supervision is safest. Note that many children with autism become obsessed about hair growth and may want to remove all pubic or body hair.
- Use charts or picture sequences in the bathroom to show the sequence of personal hygiene tasks and chart when they have completed the tasks each day – use a reward system if needed.
- Social stories or scripts can be really useful teaching tools during puberty. They can be found on line or written specifically to suit the needs of the young person. Some examples of social scripts can be found in the “hygiene issues’ file. There are many resources available on line to support hygiene tasks.

For girls learning about menstruation management is essential. See below for information regarding managing menstruation.

Menstrual management

Menstrual management for girls with autism can be particularly challenging, especially if the girl has an intellectual disability, which makes comprehension very difficult. A girl with autism will start to menstruate when puberty commences just like any other girl, regardless of IQ, intellectual or emotional development. There are many useful resources such as social stories, DVD’s, activity sequences available that can help.

When discussing menstrual management with a girl with ASD remember that

- The material needs to be age and developmentally appropriate.
 - Explain what will happen and how to manage it.
 - It is important that the child does not expect a lot of pain or fear of what will happen.
 - That it will happen to her each month. Mark dates on a calendar or in some other visually appropriate way.
 - Demonstrate with actual pads how to unwrap, place a pad in underwear and dispose of a pad.
 - A visual activity sequence for changing a pad may be useful
- Let the girl know she can talk or ask questions about menstruation
- In a private place and time
 - With her mum or other trusted female

- Ensure the child has clean pads and underwear in their school bag
- Ensure the carer/teacher/integration aide is aware and knows when to prompt changing a pad or to assist the girl in the bathroom if needed.
- Tampons are not appropriate for younger girls with autism. They may be too fiddly to place correctly and could present a hygiene or safety issue.

Note- some girls with autism and other disabilities are placed on the contraceptive pill /mini pill or receive a contraceptive injection which lasts 3 months and can help manage or stop menstruation.

This option needs to be discussed with the paediatrician or Doctor if the girl is not coping at all with menstruation, suffers a great deal of stress, anxiety or is exhibiting behaviours of concern.

- See further information for links and resources regarding menstruation.

Assertiveness and saying NO

Teaching a child with autism assertive skills and how to say NO is essential. The child must know when to say NO move away from someone who is being inappropriate with them and to seek help. As with bullying, a lack of ability to be assertive and say NO can leave a person with ASD vulnerable to becoming a victim of abuse.

Teach the child about what is appropriate touching, who can touch them and where and what to do if someone is too close and touching them.

- SAY NO
- Move away
- Tell someone

This lesson will need repetition

Social stories or scripts can also be really useful. There are social stories available about touching.

Rights and responsibilities in relationships –

It is particularly important to ensure young people with ASD are aware they have rights in a relationship to avoid being physically, emotionally or financially exploited and to ensure they are not put at risk from unsafe sexual practices. It is also important that young people with ASD understand they have responsibilities in a relationship so they do not put anyone else at risk through unsafe or inappropriate sexual behaviours.

Sex and the law

It is important that young people with ASD understand that there are rules and laws about sex –

- That no adults are allowed to have sex with anyone under 18
- That if they want to touch someone else or have sex with them it must be consensual- both people must agree
- That no one in their family is allowed to touch them in a sexual way
- That if someone says stop or no at any time during sex that the other person must stop
- That the rules are the same for straight people or gay people.

- That it is not ok to follow someone, go past their house all the time, call or text them repeatedly if the other person does not want them to.

Sexuality

Many people in the community assume people with disabilities/autism are not interested in sex or are not sexually active.

This is not true; many people with ASD become sexually active, but often do not understand the consequences.

- Young people with ASD have the same biological functioning as others but lack the maturity and social skills to deal with sexuality like others do.
- Young people with ASD have the same goals as others of their own age- they may seek a boyfriend/girlfriend/relationship but have more difficulty than the average teen in initiating contact with appropriate peers to build a relationship.
- Young people with ASD are often misinformed about sexuality – they have fewer friends to discuss issues with and may have had poorer quality or less sex education.
- They do not naturally acquire this knowledge from other sources and what they do know is likely to be fragmented and inaccurate.
- The young person with ASD may have many questions about sex and related topics, but not know who to ask.
- They are also more likely to engage in inappropriate sexual behaviour, have less knowledge of privacy and have poor sexual education.
- People with autism have the right to form relationships and have sexual experiences. It is important they receive adequate education and resources to be able to undertake this part of their life safely, legally and in an appropriate manner.
- Young people with ASD need the information to make **SAFE AND INFORMED CHOICES**.
- Many people with ASD desire long term relationships, intimacy and sexual contact but can be often easily rejected which can affect self-esteem and wellbeing.
- It is important families, schools and service providers treat issues of puberty, sexuality and relationships with the utmost respect and sensitivity as the attitudes passed on to the person with ASD can have a profound and lasting effect.
- People with ASD are more vulnerable to abuse due to difficulties in communication and social skills. They may not know what predatory sexual behaviour is, understand who may target them, how to protect themselves or recognise the signals when their body is telling them something is wrong.

Same sex attraction

- It is important that young people with autism learn that it is ok to be attracted to someone of the same sex, or to be gay.
- The young person with autism may be very confused about same sex attractions and what being gay means for themselves or others.
- The young person may be fascinated in the concept and want to ask a lot of questions.
- Young people with ASD may become sexually active with other people at a later age than peers and may take longer to find a boyfriend/girlfriend

•One of the obvious signs of a young person wanting to become sexually active is when they start noticing the bodies of others and begin engaging in masturbation. It can be a challenging and difficult issue for parents to deal with.

Masturbation

Masturbation can be a tricky subject for parents and carers to deal with, but if young people with ASD are not properly informed about masturbation it can become a problem.

- Boys will often masturbate at inappropriate times and places if they do not understand that this is an activity for private space only.
- Masturbation needs to be dealt with in a positive light free from stigma and myth.
- Masturbation is not often discussed with girls, but it can be a way for girls to express their sexuality in a private and healthy way.
- Discuss masturbation in the context that it is –private touching that should happen in a private place such as a bedroom or bathroom with the door shut.
- Discuss what the young person may feel like before they may need to masturbate.
- Visual cue cards may be needed depending on the person's level of functioning to remind the person to go to their room and close the door/curtains and to clean up afterwards.

Self esteem

It is important that a young person with ASD has good self-esteem and a positive self image. It is very easy for a young person with ASD to become lonely, isolated, have low self-esteem, develop depression and become a victim of bullying. Some people with poor self esteem may engage in behaviour that puts them at risk physically, emotionally, socially or sexually.

You can help build the young person's self-esteem by;

- Encouraging personal hygiene, grooming and appropriate dress
- Encouraging a healthy diet, plenty of exercise and sleep
- Encouraging the young person to have an interest, hobby or sport that they are good at and can feel proud of
- Give them plenty of compliments
- Provide opportunities to develop and master new skills
- Support transition into young adulthood by encouraging independence wherever possible.
- Encourage interactions with others.
- Reflect on achievements- keep a brag book of certificates and photos to remind them of their achievements and milestones.

Expressing feelings appropriately-

Puberty and sexuality can be confusing and raise many feelings that your average teenager will have difficulty dealing with – this confusion is worse for a young person with ASD.

It is important that the young person with ASD learns to express their feelings appropriately.

It is likely they will need some support to firstly

- Recognise what they are feeling
- Express what they are feeling and then
- Work out what to do about it.

There are many visual aides which can help in with recognising and expressing emotions such as an emotional thermometer or emotions volcano. See downloads

•It is important that the young person with ASD knows how to express their sexual feelings appropriately towards another person – i.e. what to do if they like someone, what to do if they are aroused etc. This can help avoid problems such as inappropriate touching, stalking behaviours (following someone around and watching them) or public masturbation.

•Model; appropriate expression of feelings at home and help the young person with ASD understand how you are feeling

Anger and frustration-

- During puberty the young person may exhibit more anger and frustration and be more argumentative (like most teens)
- It is important that you can try and reason with the young person once they are calm and talk about what they are experiencing.
- Do not engage in the argument with the young person as it will make the situation worse.
- If the young person is displaying a great deal of aggression and violence it is important to ensure your own safety and the safety of others. Move to a safe place until the aggressive behaviour is over and do not engage in the argument.

In Summary

- Children and young people with autism need factual information about their bodies, puberty, hygiene and sexuality.
- People with autism are sexual beings and will express their sexuality.
- Young people with autism need support to build their self-esteem and express their emotions appropriately during puberty through to young adulthood.
- People with autism need to know how to say NO and how to stay safe.

Further information

Family Planning Victoria on line resources-

<http://www.fpv.org.au/young-people>

<http://www.fpv.org.au/puberty-for-girls/>

<http://www.fpv.org.au/puberty-for-boys/>

<http://www.fpv.org.au/parents-carers/>

Books- Puberty and sexuality for young people with a disability- available from family planning Victoria

Secret girls Business

Secret Boys business

<http://www.fpv.org.au/bookshop>

The Centre for Developmental Disability and Health

<http://www.cddh.monash.org/sexuality-disability.html>

http://www.teachingsexualhealth.ca/media/pdf/Sexuality_Developmental_Disability.pdf

Living Safer Sexual Lives publication by Patsie Frawlie explores the sexual lives of young adults with various disabilities.

[http://www.latrobe.edu.au/arcshts/downloads/arcshts-research-](http://www.latrobe.edu.au/arcshts/downloads/arcshts-research-publications/people_with_intellectual_disabilities_living_safer_sexual_lives.pdf)

[publications/people_with_intellectual_disabilities_living_safer_sexual_lives.pdf](http://www.latrobe.edu.au/arcshts/downloads/arcshts-research-publications/people_with_intellectual_disabilities_living_safer_sexual_lives.pdf)

Menstruation

A booklet about menstruation for carers supporting someone going through menstruation

<http://www.cddh.monash.org/assets/supporting-women-carer.pdf>

Menstruation

<http://www.autism-help.org/family-puberty-autism.htm>