

# Sex education and children and young people with an ASD

Children learn about sex from a very young age even if we don't talk with them about it. Many of the things they learn are incorrect, confusing and frightening. In a world where sex is used to sell cars and ice creams, and celebrities' private lives become everybody's business, we cannot afford not to talk to our children about sex and relationships if we're going to help them make sense of it all.

**National Children's Bureau, Sex Education Forum 2003**

The quotation above is from a parent support guide that is not autism-specific. It describes how important it is to speak to any child about sex education so they do not become confused and anxious.

The unique difficulties of a child with an autism spectrum disorder (ASD) mean that ordinary, everyday conversation and social interaction can lead to many misunderstandings, confusion or upset. Consequently, parents - like you - spend a lot of time trying to explain this chaotic and scary world to your children. Your explanations and support are even more important when talking to your child about puberty, sex and relationships.

However this is not necessarily an easy discussion to have. Therefore we have written this information sheet to help guide you. It has been arranged over several sections to ease locating particular subjects of interest. But some areas may naturally overlap.

**Please NOTE: This information is aimed at the whole autistic spectrum, and a variety of ages, and therefore some adjustments may have to be made for your particular child.**

## When should I start talking to my child about puberty?

Most parents wonder when to begin discussing puberty with their child. Throughout a child's formal education, whether at a mainstream or specialist school/unit, issues of Personal, Social and Health Education (PSHE), which includes Sex and Relationships Education (SRE), are addressed in school classes. This starts with explaining family relationships in infant/primary school and progresses around nine years of age to addressing puberty, as many children seem to be reaching puberty earlier than in previous generations. We would therefore suggest that parents co-ordinate with their child's school to ensure consistency.

However it is important to realise that children with an ASD often need a longer period of time to adjust and understand any changes in their lives. Therefore you will need to decide how much preparation time your particular child needs. You may like to consider whether a particular behaviour or habit needs changing, for example; if your child removes their clothes at unexpected, inappropriate moments. It is helpful to adopt socially appropriate behaviour before puberty begins.

## How do I explain puberty to my child?

You can prepare your child from a young age by always being available to discuss any questions s/he might have about their body. This will help your child to learn that puberty is not something to be ashamed about and will help their self-confidence.

Try and be patient with the variety of awkward questions you might be asked. This is particularly important for children with an ASD who often ask more than the average 'why?' questions. You need to try to be honest with your child, while realising it is okay to say 'I don't really know - let's work it out or look it up together' (National Children's Bureau, UK, Sex Education Forum, 2003). It is better to say something like this than to try to reply to the question when you are unsure of the answer. You could make your child more confused if your answer is not clear.

Also, if your child wants to ask a question at an inappropriate moment, you may like to develop a standard response, which everyone in the family can use, such as 'That's a good question, but let's talk about it once we get home' (National Children's Bureau, Sex Education Forum, 2003). It is important to remember to deal with the question when you get home or your child may be reluctant to ask you questions again.

## Talk to the school

Before you begin any formal explanations at home, you may like to speak to your child's school about what will be covered in their PSHE/SRE classes at school. By working with the school, you will help to ensure consistency and fluency between school and home explanations.

During this discussion you might conclude that these lessons are paced inappropriately for your child, perhaps they progress too fast and assume too much prior knowledge. In addition, children with an ASD may need explanations of such things as 'why we must wash everyday', 'what friendship and being a friend means' and 'how our behaviour may be viewed by others'. Perhaps you and the school might be able to work together to ensure your child understands these concepts as well.

## Things to do at home

### Visual supports

Kerr-Edwards and Scott in their book *Talking together...about growing up* (2010) suggest that you start by demonstrating life cycles to your child, as these provide a basic context of development and ageing, in which puberty has a role. These can be demonstrated visually, through progressive photos of family members. Your child can then compare, for example, the differences in facial appearance, age and height of their younger and older cousins and siblings, with parents, aunts, uncles and grandparents. You could particularly focus on yourself, showing pictures of you when you were younger, and throughout your life. This activity may help your child to gain some

understanding of when puberty occurs in a person's life. This is important, as you are unable to give your child a precise date for when puberty might start for them.

You may like to produce a basic body outline and label all of the various body parts. In each area, you could highlight the various changes that will occur: from increases in height (which could be recorded on a piece of paper stuck to the wall) to growth of pubic hair. Encourage your children to be excited about these changes by perhaps talking about some of the advantages of being an adult, for example: you can make your own decisions about how to have your hair cut, you can vote etc, whatever will appeal to your particular child.

You could also encourage some healthy competition by comparing heights with other family members, especially if being taller will boost your child's self-esteem.

If your child has profound learning difficulties, you may like to employ a sensory game to enable body and self-awareness:

For example, the Shepherd School uses a range of sensory games to raise awareness of parts of the body using silk scarves and items that make a sound. When they move, each body part can make a different sound for example, feet on gravel, side on whoopee cushion', head on foil, arms in shells, bottom on bubble plastic. (National Children's Bureau, Sex Education Forum, 2004).

## **Books to use**

The fpa (formerly Family Planning Association - UK) produces a series of books that are not autism-specific but for people with learning difficulties. These are called: *Talking together...about growing up* by Kerr-Edwards and Scott (2010); *Talking together about sex and relationships* by Kerr-Edwards and Scott (2010b); *Talking together about contraception* by Kerr-Edwards and Scott (2010c). They describe puberty and sexual relationships in a clear, visual way, and include a number of ideas and activities to ease explanation (Kerr-Edwards and Scott, 2010). The figures in these books are of a realistic, though cartoon style.

## **Talking to the GP (Family Practitioner)**

Your GP may be able to help, particularly with any of those awkward questions about why these changes occur, and especially if your child will only be satisfied with an accurate, full and scientific answer.

You might also like to make an appointment with your GP when your child is older. This meeting could involve a routine medical examination and a discussion concerning sexual health or contraceptive needs. It might also be an opportunity for your child to feel comfortable about talking to their doctor about their bodies.

## **Use of language**

Regardless of what materials or methods you use, you may need to be careful that your child does not develop an unrealistic view of what their body or other people's bodies should look like. For example, some teenagers may look at the images represented through television or films and

believe that their body will be as muscular or as shapely as their favourite film star. This is important as such a disappointment could affect your child's self-esteem. It is common for a teenager's self-confidence to be in turmoil, but it can be a particular difficulty with individuals on the autistic spectrum.

You may also need to be careful about your use of language, particularly if your child is very literal, for example you may naturally describe your son's voice as "breaking", but this could be highly worrying for a child with an ASD. Instead you might say something simple, for example your voice is changing and likely to become deeper. You could then refer to their father's/uncle's/older brother's voices and explain that men's voices are usually deeper than women's.

You may also want to differentiate between the more medical terms for different parts of the body and those words that your child might hear in the playground. This may help to ease any confusion when they hear these words used, and prevent them from making any innocent mistakes that could lead to teasing. You might also want to refer to these body parts as being private, and suggest to your child that though they may hear these private areas being referred to at school, they should not feel they need to join in these conversations.

As well as the physical changes in shape that their body will go through, your child will also need to understand about such developments as menstruation or erections and wet dreams. Your child may need reassurance that these occurrences are normal processes within the body that everyone of their gender experiences, as these changes may be particularly confusing and upsetting.

Girls may believe that they are bleeding to death, while boys may think they have wet the bed and may be reluctant to talk to anyone about it. You may be able to reassure them that this is normal by being approachable, perhaps setting aside a particular time when you can listen and talk about their concerns with no disruptions. You could also compare them to other bodily fluids by using the body outlines and indicating what part of the body produces, for example, tears, sweat, urine and semen (Kerr-Edwards and Scott, *Talking together...about growing up*, 2010). This might help your child to gain a greater understanding of how their whole body works.

## Menstruation

When explaining menstruation to your daughter you will need to provide her with appropriate sanitary products. These can be placed in a particular drawer in her bedroom, or in the bathroom, so she can be reassured that they will always be there when she needs them. You may also need to tell her who to go to at school if her periods begin there, for example a designated school nurse.

As well as providing the products, you may also need to show your daughter how to use them, perhaps by opening one of the packages and demonstrating how they need to be placed, pointing out any particular features which might help her to remember how to place them correctly.

Wrobel (2003) has a whole section on menstruation in her book *Taking care of myself*, including an example of an activity which could be used to reinforce what has been taught.

The book *Periods a practical guide* by Mai Rees with Charlotte Carter and Lindsay Myers is a book with a CD-ROM that teaches girls and young women about menstruation. The same authors have also produced a pocket-size booklet called *I change my pad*.

If your child uses visual supports, you could use calendars to help her plan when her period is due. This may help her to feel less anxious. You might also like to encourage her to carry a small notebook around with her. It could provide particular information or reassurance for those instances when you will not be present. This will also encourage independence and could be used in various ways throughout her life.

## **Masturbation**

Masturbation is a natural activity for a child who is going through puberty. Be prepared to talk about masturbation with your child so that they do not develop any anxieties about what they are doing.

Wrobel (2003) in her book, *Taking care of myself*, includes a section on masturbation for both males and females. It encompasses rules about where and when you can masturbate. Kerr-Edwards and Scott (2010) in their book, *Talking together...about growing up*, uses pictures and stories to explain masturbation for both boys and girls and the importance of masturbating only in private areas.

The BBC website has a biological description for erections which might appeal to your son: [www.bbc.co.uk/science/humanbody/body/articles/lifecycle/teenagers/erections.shtml](http://www.bbc.co.uk/science/humanbody/body/articles/lifecycle/teenagers/erections.shtml). By reading through this explanation with your son, and perhaps looking at the interactive body video which shows male genitals developing, you may reassure your son that what happens to his body is something that happens to all boys and men. When talking to your son about erections, you will also need to explain to him about wet dreams.

It is important that your children know how to clean themselves afterwards, perhaps supplying tissues/wet wipes or an appropriate towel. In the instances of wet dreams, you may want your son to tell you what's happened so that you can change the bedclothes together. If your child would find this difficult, you could establish a symbol or sign that he could show you, perhaps either on a piece of card or a hand signal which could let you know what had occurred.

## **Private/public**

While you are talking to your children about puberty you may also need to provide some guidelines about who they can talk to about any concerns they have, for example mum, dad, the GP and school nurse. You may also need to tell them about 'private' and 'public' rooms and how they should restrict particular activities, such as masturbation, to private rooms only. To clarify this, you may like to put a 'private' sign on the door of their private place in the house, for example their bedroom. However, please ensure that your child understands that if a room says 'private' on it, it does not necessarily mean that this is a suitable place for any sort of sexual activity (National Children's Bureau, Sex Education Forum, 2004).

You may also want to establish a rule that people should knock on all bedroom doors before entering; you will need to make sure that everyone who visits your home is aware of these rules.

This subject of privacy could also extend to a conversation about how to keep safe. You may want to use a Social Story™ in order to describe a possible situation where another person may act inappropriately towards them, and if they are at all worried about someone else's behaviour towards them, they should tell their parent or teacher, for example. (Both Kerr-Edwards and Scott (2010), and Wrobel *Taking care of myself*(2003) cover privacy and keeping yourself safe.)

## Keeping your child safe

You may also be concerned about your child's safety while surfing the internet. There are various organisations that can provide advice on this, including details of filtering or blocking software, such as the NSPCC or ASPCC.

While the teenage years can be difficult for any child, they may be particularly stressful for a child who dislikes change and finds their own emotions confusing. For not only are their bodies changing at this time but their lives are probably in a state of flux too, as most children will be adjusting to a new school, new friends, teachers and routine. Hopefully by ensuring that your child understands and is prepared for these changes, any anxiety will be kept to a minimal level.

## Personal hygiene

We all know that as we go through puberty we need to pay better attention to our personal hygiene. Children with an ASD will need to be made aware of these changes and directed to the appropriate solution, for example using deodorants, showering and washing their hair more frequently.

Not only will the actual processes need to be explained, for example, how to shave, but the reasons behind them too. This is because people with an ASD have difficulties understanding the social rules behind these activities. For example, they may simply know a particular activity, such as a morning shower, as a part of their daily routine. Therefore if this changes in any way, they may not have a shower. This could make them unpopular with their friends or expose them to teasing from their classmates.

Maybe as your child approaches puberty they will already have an established routine for washing themselves, their clothes and their bed sheets, even if this only involves putting them in the laundry basket. You may already use a tick list that your child can work through to ensure they have completed each stage in their morning schedule. If this is the case, then perhaps it can be adjusted to include the use of deodorants, showering everyday, shaving every other day etc.

The fpa (Family Planning Association – UK) book *Talking together...about growing up*(2010) discusses using deodorants as part of their comic strip style stories on bodily changes. Wrobel's book (2003) is specifically aimed at individuals on the autistic spectrum and covers hygiene, health and puberty. It includes wearing a bra or shaving your face, as well as masturbation and how to keep yourself safe. Alternatively, if a more personal point of view might help, Luke Jackson, a

teenager with Asperger syndrome, has written a book called *Freaks, geeks and Asperger syndrome* which is aimed primarily at teenagers. It has good chapters on friends and dating, including the importance of hygiene to people you are attracted to!

## Sexual relationships and sexual health

As your child progresses through puberty you may feel that it is now appropriate to talk to them about sexual relationships. Your child may already have a biological context from studying science or PSHE at school. However you may also want to reinforce these teachings at home. You might like to liaise with the school to ensure consistency and lessen any chances of confusion.

You could use a variety of books, including the fpa publication *Talking together...about sex and relationships*. You will also need to discuss sexual health, such as smear tests and protection against pregnancy, as well as sexually transmitted infections. You may want to use a Social Story to explain the visits to the doctor or nurse. Alternatively, there is a series of books that uses pictures to explain their message called *Books beyond words*. These have titles such as *Susan's growing up*, about menstruation, and *Looking after my balls* which shows young men how to check their testicles.

There are others which provide information about what happens when a woman has a smear test; how and why we need to wash and keep clean; and when we can and cannot hug and touch new friends.

## Sensory issues

You may also have to consider any sensory issues your child may have.

For example, if they have difficulties hugging other individuals, it may impact on their future sexual relationships. You may like to try desensitising your child, by helping them to tolerate a hug from you. This might involve you sitting near to your child, whatever they will happily tolerate, and then increasing your physical contact with them by, for example, touching their arm for a small amount of time. You will then extend this process over a period of months or years to where they may tolerate a hug from you. However, please remember that they may never feel comfortable having a hug from you or anyone. Or they may tolerate a hug from you, but not from anyone else. They may also never fully understand the multitude of complex reasons for why or when we might need a hug. They may give hugs, but only as part of a routine that has been learnt, for example, mum likes a hug when she gets in from work.

A number of adults with an ASD describe their love or need for a particular object. Donna Williams, who has autism, writes how she "... fell in love with the things in people's homes far more than I fell for the people themselves." (Williams, 1999). Perhaps Donna felt this way because objects are predictable, solid and reliable, unlike her family members who appeared to change whom they were from one minute to the next. This is understandable when we appreciate the world from her point of view.

Please be assured that your teenager, though they have an autistic spectrum disorder, is still a teenager. Therefore there is a high probability that they will be interested in this part of life to a greater or lesser degree. They may have more complex questions, due to their difficulties in communication and social interaction, such as "how do I make friends?", "how do I get a girlfriend/boyfriend?", "how do you kiss someone?" but by answering these questions, and generally speaking to your child about sex and sexuality, you may help to prevent or reduce any instances of confusion or sexually inappropriate behaviour.

## Relationships

Alongside physical changes, individuals on the autistic spectrum may also require help to develop their social interaction skills in order to sustain a meaningful relationship. This is a very substantial subject and is mainly beyond the scope of this article. However there are various books which explain about forming relationships, for example the fpa book *Talking together...about sex and relationships* which describes how people make friends, become closer, become boyfriend and girlfriend, and eventually decide they would like to have sex with each other (Kerr-Edwards and Scott, 2010b).

Fitzgerald, Harpur and Lawlor describe making friends at university, dating and how to be considerate towards other people's relationships in their book *Succeeding in college with Asperger syndrome* (2003). Luke Jackson (2002) provides some dating tips in his book, *Freaks, geeks and Asperger syndrome*, which have been suggested by his teenage sisters. There are also social skills or social groups which individuals with an ASD might like to attend.

You may also need to discuss the role of marriage and long-term relationships: why do people get married or choose to live permanently with one person, what is the role of a husband/wife/father/mother/child within that marriage/relationship? Your child may already have an understanding of their role within the family, and perhaps that of their siblings. But they may need some guidance or support to understand those roles that they have not experienced yet.

You could explain these roles by discussing your relationship with your partner and those of other family members. This could be supported visually by drawing stick figures, or using photographs, of each significant person in this individual's life, including themselves, their family members, teachers and doctors, if appropriate. You may want to use a different piece of paper for each person. The pictures should be placed in the middle of the paper and connections should be made to a variety of drawings, words or photographs that surround this person. These other pictures or words should symbolise this person's role for the individual concerned and perhaps other members of the family. (You could change the person in the centre from the person with the ASD to mum, dad or sister/brother as this may help your child to understand how other people view the relationships within the family). It might involve a certain degree of work, but may help to clarify roles within the family. You may want to discuss another family that is different from your own, perhaps having a single parent or vice versa.

## 'Inappropriate' behaviour

The word 'inappropriate' has been highlighted because it is often non-autistic individuals who have decided this behaviour is inappropriate. It must be remembered that autism spectrum disorders are social communication difficulties which affect a person's ability to understand socially appropriate behaviour. Therefore individuals with the condition are not necessarily guided or constrained by the social rules which direct those who do not have an ASD. **This means that a behaviour might have a very significant and specific meaning for them which isn't 'just being rude' or sexually motivated.**

Much of the research or written material on this subject often has a negative tone. This has been highlighted by Heta Pukki, an adult with autism (Pukki, 2003), and focuses mainly on the action itself rather than the reasons behind it, such as an obsessive interest in masturbation.

However there are exceptions, Isabelle Hénault has written a chapter on *The sexuality of adolescents with Asperger syndrome* which is very pragmatic (Hénault, 2003). She has aimed her article at parents and is very practical in her outlook, including a number of suggestions. She also indicates that while parents and professionals might feel embarrassed about this subject, for the majority of teenagers 'sexual behaviours are perceived as any other behaviour, free of social rules and convention' (Hénault, 2003), and this concept should be considered when any inappropriate behaviour is displayed.

### Possible explanations

First consider that such behaviour could have a very different purpose from what might be assumed. You will want to determine the purpose of the behaviour for the individual with autism. For example, if an individual who has an ASD, touches or brushes against a specific woman's breasts every time they meet, they could be trying to determine the woman's mood by her reaction to this behaviour. If they are unable to read a person's facial expressions and body language, they may develop a routine action which they can perform each time they see that person in order to determine whether they are 'nice lady' or 'bad lady' today.

This example could also have other explanations: the individual on the autism spectrum may like the reaction they get, perhaps the shock on the person's face, or the verbal command which follows, gives them a nice feeling. Alternatively, they may have received some sort of sensory stimulation when they brushed against the lady's body the first time, and want to repeat this. They may be curious about what that part of a person's body feels like and are therefore acting on an impulse.

Unfortunately, each of these reasons could reinforce this particular behaviour, forming a self-perpetuating circle of inappropriate behaviour. It is therefore important to try and prevent this behaviour as soon as possible. **Social Stories™** or **comic strip conversations** could be used to discover how the autistic person viewed the situation and to describe what they should have done in that situation: "we greet people by shaking their hand". You could also try a Circles Concept

which can be used to visually demonstrate socially appropriate behaviour. This can be adapted to any situation.

People who have an ASD also have difficulties seeing situations from another person's point of view. This can mean that they are unable to consider another person's feelings, or they may think this person feels the same way as they do. For example, an individual with an ASD may have seen people kissing in the street; later they might approach someone they like, either someone known to them or a stranger, and kiss them. This might cause embarrassment or offence to the intended person, and their reaction may cause confusion and disappointment for the individual with autism. Perhaps they expected a more positive response: to be kissed or hugged back, as they saw happen with the couple on the street. Such examples demonstrate the complexities of socially appropriate behaviour. Individuals on the autism spectrum may need to be steered and supported by those around them to remember not to act on their impulses.

These behaviours can occur with all individuals on the autism spectrum, and may be aimed at another person or persons, or involve a deep fascination with a particular activity or object (see the 'sexual relationships' paragraph above). The reasons for the behaviour may vary greatly from one person, and situation, to another. Hopefully with the right support and explanations, these behaviours will be kept to a minimum. However, if difficulties do arise, try and gain professional support through your health authority. This might be a counsellor, psychiatrist or psychologist.

### **Possible strategies**

Complete a behaviour diary which records what is occurring before, during and after the displayed behaviour. This may help to gain a greater understanding of what purpose the behaviour has for the individual concerned. A diary may be completed over a couple of weeks or longer if appropriate. This may be difficult to do if the behaviour is particularly unpleasant for the individual or those around them but it is an important stage in understanding and trying to solve the behaviour. Please note that while it is understandable that the immediate reaction to a person's behaviours could be negative and comprise feelings of shock or alarm, a calm reaction and level tone should be maintained if at all possible.

If a person with an ASD is displaying inappropriate behaviour with someone they are attracted to they may need support to understand how to form socially appropriate relationships (see the 'Relationships' section above).

Clearly the many difficulties or incidences that could arise during puberty and the start of sexual relationships could not all be covered here, as they will be as unique as the individuals themselves, so please do not hesitate to contact your local [Autism Helpline](#) for any more advice or information.